

ABSTRACT

Title of Dissertation: AN EXPLORATION OF PUBLIC HEALTH
WORKER ENGAGEMENT WITH HEALTH-
RELATED SOCIAL MOVEMENTS
THROUGH AN ANALYSIS OF
#BLACKLIVESMATTER

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Social movements fight for social justice by protesting systemic social inequities. The field of public health aims to eliminate these same disparities as they relate to health. Many social movements are not currently viewed as health social movements despite these movements addressing health disparities by challenging existing inequities related to social determinants of health. One example is the Black Lives Matter movement which has gained considerable attention in its efforts to address systemic racism, a known determinant of health. While the Black Lives

Matter movement has evoked many academic and popular responses, there has been a lack of focus on this movement by the public health workforce. Therefore this work uses the Black Lives Matter movement as an example of a health-related social movement warranting engagement from the public health workforce.

This study utilizes a novel approach to the use of social media data in the public health field. The first part of this work examines tweets containing #BlackLivesMatter and compares the online discourse to the stated mission and principles outlined by the leaders of the Black Lives Matter organization. An analysis of the Twitter data was then presented in a Delphi study conducted with a panel of experts in public health. Delphi participants were tasked with developing ideas on how the public health workforce could best apply the information collected from #BlackLivesMatter Twitter data to aid in addressing the health-related issues highlighted by the Black Lives Matter movement. More broadly, participants also generated ideas about what can be done to encourage the public health workforce to systematically engage with health-related social movements. Finally, one-on-one interviews were conducted with self-identified social activists. These activists were asked about their participation in social movements, their use of social media regarding their advocacy work, and for ideas about how the public health workforce could engage with their causes. Findings from each study are discussed along with recommendations for future work aimed at developing relationships between public health workers and social movements.

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#BLACKLIVESMATTER

by

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Dedication

I dedicate this work to my former middle school students at Baltimore IT Academy. You opened my eyes to the impact of systemic racism on your lives and instilled in me a drive to fight for social justice.

I would also like to thank my family for supporting me throughout my time in graduate school. To the strong women in my family: you paved the way for me to get here. Thank you for making this long road easier to travel.

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Chapter 1: Purpose of Study

Background

Social movements can be defined as “loosely organized but sustained campaigns in support of a social goal” (Smelser, Turner, & Killian, 2018). Their goal is to enact social change, typically by protesting inequities to achieve social justice. Similarly, public health aims to eliminate health inequities and promote social justice (Institute of Medicine, 1988). While some work has focused on the relationship between social movements and public health, this branch of research concerning health social movements (HSMs) is often limited to social movements’ relation to a specific disease or illness (Brown et al., 2004).

This work forces an expansion of this definition to broaden social movements’ connection to public health by including movements which focus on social inequities, known in public health as social determinants of health. According to the Institute of Medicine, social determinants of health are conditions in the lives of people which impact a range of quality of life outcomes (Gornick & Swift, 2002). These include factors such as availability and access to resources such as quality education, healthcare, and safe housing, social support, transportation, and technologies in addition to socioeconomic conditions, culture, and social norms (ODPHP, 2018). In

this work these movements that fight inequities in these social determinants of health will be referred to as health-related social movements. To successfully combat health inequities, the public health workforce should collaborate with health-related social movements to further their shared social justice goals. This purpose of this work is to gain understanding of health-related social movements by examining the online presence of the Black Lives Matter movement and then consulting with experts in public health and social activists to identify effective methods by which public health workers can engage with social movements.

Social movements today readily use social media platforms to further their advocacy efforts (Obar, Zube, & Lampe, 2012). Social media have been well studied regarding their use in social movements and is considered largely responsible for the success of the Arab Spring protests (Eltantawy & Wiest, 2011; Howard et al., 2011), was heavily involved in the organization of the Occupy Wall Street movement (DeLuca et al., 2012; Gleason, 2013) and more recently the Women's March on Washington (Farhi, 2017). Many of these movements have health-related missions and yet none have been fully studied from a public health perspective. Twitter data has successfully been used in a variety of analyses on public health topics ranging from disaster relief to obesity to drug abuse (Gurman & Ellenberger, 2015; So, Prestin, Lee, Wang, Yen & Chou, 2016; Katsuki, 2015) but it is time to expand social media data use to include a public health analysis of online health-related social movements.

One example of a movement with a strong online presence is the Black Lives Matter movement. The Black Lives Matter (BLM) movement has gained

considerable attention since its creation in 2012 after the death of Trayvon Martin, a young Black man (Cullors, Tometi, & Garza, 2016), in its efforts to bring issues of anti-Black racism to light. Originally started as an online forum, the Black Lives Matter organization has grown into a social movement through an extensive social media presence under the hashtag #BlackLivesMatter. Leaders of the Black Lives Matter movement have outlined a mission and goals for the organization, which include rebuilding the Black liberation movement and striving to bring awareness to the many ways Black people face discrimination and oppression today (Cullors et al., 2016).

The BLM movement has evoked many academic and popular responses, but there has been a distinct lack of focus on this movement by the public health workforce (García & Sharif, 2015) despite strong connections to public health. BLM is drawing attention to current social justice issues, namely racial inequities, which clearly puts this issue at the center of public health given that social justice is a guiding philosophy in this field (Institute of Medicine, 1988; Beauchamp, 1976).

Issues addressed by BLM (including racism, discrimination, and social injustice) also tie into social determinants of health, a crucial component of public health. Racism is a known predictor of health disparities (Paradies, 2006); focusing on the BLM movement is one way to address racism, which in turn can impact health outcomes for this marginalized group. The movement also highlights violence that is unequally targeted towards Black people; systematic violence is also a public health issue. The goals of BLM are in line with the vision of *Healthy People 2020* as well as Goal 10 of the Sustainable Development Goals, which both aim to reduce health

inequalities and inequities (DHHS, 2017; United Nations, 2015). Therefore, the BLM movement should be viewed as a public health-related social movement and should be addressed through a public health perspective and seen by the public health community as an important part of their mission of eliminating racial inequities and improving health for all.

Strong ties between public health and the BLM movement, coupled with the lack of engagement with public health workers and this movement, makes the BLM movement an excellent case study example of a current health-related social movement. Yet the BLM movement is not alone in its connection to health-related topics. Many social movements today focus on systemic inequalities (Della Porta & Diani, 1999) and improving quality of life, thus entrenching them in the same social justice mission as public health. In order to gain a more detailed understanding of a health-related social movement the bulk of this work focuses on the BLM movement. Chapter 6 offers recommendations for future work which includes extrapolating knowledge from these studies to better understand health-related social movements more broadly.

The first goal of this study was to analyze tweets using #BlackLivesMatter to better understand the movement through the content of the messages and to compare the user-generated tweet content to the goals and mission outlined by the originators of the BLM movement. Given that much of this social movement is embedded in social media, this presents a unique opportunity to demonstrate the utility of Twitter data in confronting public health issues. This is an important step to understand if the

public mission and needs asserted by the leaders match with what advocates of the Black Lives Matter movement are promoting through their tweets.

For the second goal of this project, the acquired Twitter data was used as a case study example in a Delphi study of public health experts to assess how the public health community can best contribute to addressing the needs of the BLM movement and other social movements using this form of data analysis. The third goal of this study was to determine effective methods to directly involve the public health workforce with emerging and future health social movements. Responses from public health experts in the Delphi study were coupled with interviews of social activists. The interviews allowed activists to add their perspectives on how social media influences the social movements they are a part of, and also to gain insight on how the public health workforce could support activists, organizations, and social movements in achieving social justice by eliminating social inequities.

Statement of the Problem

The Black Lives Matter movement highlights social inequities caused by racism. In 2015, over 1,000 people were killed by police officers in the United States (Petrohilos, 2015). This number is skewed by race, with African-Americans comprising 13% of the population and 26% of victims of police shootings (Males, 2016). Last year, law enforcement killed African-Americans at 2.8 times the rate of white non-Latinos (Males, 2016), a statistic that supports a call to investigate racial inequities in the United States. These racially disproportionate statistics of police violence are just one example of how racism impacts health. Individual,

organizational, and structural racism all contribute to social inequities faced by Black people (Noonan, Velasco-Mondragon, & Wagner, 2016). Social movements such as the Black Lives Matter movement draw attention to these inequities and strive to eliminate them. The foundational public health goal of improved health for all groups of people will not be achieved without addressing health inequities due to factors such as racism (García & Sharif, 2015). Therefore, it is important for public health to join forces with other groups who are fighting for the same goals.

Additionally, it is important for the public health community to utilize available social media data as a resource to better understand health-related social movements. Internet use has been growing throughout the past decade, with 88% of adults in the U.S. now using the internet (Pew Research Center, 2017). Social media use has increased as well with more than two-thirds of U.S. adults (69%) using social networking sites (Pew Research Center, 2016). More than one in five U.S. adults are now specifically using the social media platform of Twitter and the use of social media, including Twitter continues to rise (Greenwood, Perrin, & Duggan, 2016). With social media use so prevalent in the lives of most Americans today, the use of Twitter as a source of data should be investigated further. Several studies have used Twitter data successfully to examine health topics at both individual and organizational levels (Katsuki, 2015; Wang & Zhou, 2015; So et al., 2016).

Social media is also an important area to examine when attempting to understand social movements. Social movements are made up of many smaller activist groups. These social activist organizations and groups use a variety of social media platforms to facilitate communication and advocate for their causes (Obar,

Zube, & Lampe, 2012). In fact, 96% of social activist groups in a recent study used Twitter to communicate with the general public (Obar, Zube, & Lampe, 2012). Social movements rely on online communication for a variety of reasons; two of the main purposes being recruiting additional members to join the collective movement and disseminating information about the movement (González-Bailón, Borge-Holthoefer, Rivero, & Moreno, 2011).

This study illuminates the importance of understanding a new social movement and its relation to public health. Examining Twitter data from a rising social movement for its potential usefulness in shaping public health practices is a novel endeavor. Twitter is the social media platform being used in this project for a variety of reasons. For one, the Black Lives Matter movement started online with the use of #BlackLivesMatter through Twitter. Today this social movement still exists largely through an online presence, including discussion of BLM topics and organizing events, protests, and demonstrations. Additionally, Twitter has been used to examine a variety of aspects of social movements from predicting uprisings (Hermida, Lewis, & Zamith, 2014) to categorizing riot sentiments (Burch, Frederick, & Pegoraro, 2015). Yet Twitter data have not been used to investigate these broader social movements as public health issues or to understand specifically how the public health workforce can best understand and address social justice issues highlighted by online social movements by using available online resources such as tweets. Using a Delphi study allowed for a unique opportunity to consult experts from a variety of public health areas and gave them a chance to see what kind of information can be extrapolated from Twitter aggregate data and to develop ideas about how public

health as a discipline can utilize this type of research in the future. This type of data analysis involving a social movement has not yet been well examined by a panel of experts to determine its full potential in the public health field.

Research Questions

Three primary research questions are addressed in this study:

1. How do the central themes and issues that emerge from #BlackLivesMatter tweets map onto the stated mission and goals of the Black Lives Matter movement and how do these themes relate to health?
2. How can the public health workforce apply information collected from #BlackLivesMatter Twitter data to aid in addressing the health-related issues highlighted by the Black Lives Matter movement?
3. What can be done to encourage the public health workforce to systematically engage with health-related social movements?

Significance

The Black Lives Matter movement highlights existing racial inequities and deserves to be investigated through a public health lens and supported by the public health community. The media has recently been focusing attention on violence against Black people. Phrases including “Hands up, don’t shoot” and “I can’t breathe” refer to two of a series of recently publicized cases where unarmed Black men, Eric Garner and Michael Brown, were killed by police officers (Rhodan, 2014). These individual cases of preventable deaths serve to highlight the many racial injustices

endemic in the United States and the existing racism that still affects Black individuals and communities today. The Black Lives Matter movement serves as an example of a health-related social movement. This movement points out inequities linked to social factors. These social determinants of health have been shown to have significant impacts on health (Bambra et al., 2010; Kondo et al., 2009; Wilkinson & Marmot, 2003).

Racism is a social determinant of health (Bailey et al., 2017; Williams & Mohammed, 2013; Paradies, 2006; Jones, 2002) addressed by the Black Lives Matter movement (Garcia & Sharif, 2015; Cullors et al., 2015). Racism is defined as “the set of institutional, cultural and interpersonal patterns and practices that create advantages for people legally defined and socially constructed as ‘white,’ and the corollary disadvantages for people defined as belonging to racial groups that were not considered whites by the dominant power structure in the United States” (Castañeda & Zúñiga, 2013, p. 58). It is the goal of public health to ensure the best conditions under which maximum health is possible for all people (DHHS, 2017). This goal is not possible when racism causes some groups to be more disadvantaged than others. Acts of violence targeted at a racial group is inconsistent with the vision of *Healthy People 2020*, which aims to “achieve health equity, eliminate disparities, and improve the health of all groups” (DHHS, 2017) and Goal 10 of the global Sustainable Development Goals which “aims to reduce inequality within and among countries” (United Nations, 2015). A social movement, Black Lives Matter, has successfully increased public and media focus on the issues of systemic violence against Black

people in the United States and deserves more focus from the public health discipline (García & Sharif, 2015).

The purpose of creating #BlackLivesMatter was to provide an online forum for discussion of extrajudicial killings of Black people and the racial inequities that lead to systemic violence against Black people in the United States (Cullors, Tometi, & Garza, 2016). Since then, the term “Black Lives Matter” has grown to represent a social movement which is largely organized through social media (Rickford, 2016). Social media is an important source of information transmission for many social movements (Obar, Zube, & Lampe, 2012), and by examining the Black Lives Matter movement through #BlackLivesMatter, insight can be gained into the content of messages delivered and received concerning this movement which is lacking in many studies of social media and social movements (Stokes & Atkins-Sayre, 2018).

Purpose

The purpose of this study is threefold. One aim is to better understand the Black Lives Matter movement as a social movement by analyzing #BlackLivesMatter aggregate Twitter data. Secondly, this research aims to determine how this type of social media data analysis can be beneficial in encouraging public health workers’ attention to online health-related social movements through a Delphi study. Finally, this study aims to understand additional methods that can be used by the public health workforce to engage with social movements by interviewing activists who work within these social movements.

This study uses publicly available Twitter data to study #BlackLivesMatter as a method to gain insight about the Black Lives Matter movement, which was created online and still holds a large online presence. This author contends the themes promoted by the Black Lives Matter movement address issues of violence and racism, which are serious public health concerns. Yet the public health community has not conducted significant research on online social movements, nor has it publicly acknowledged the Black Lives Matter movement as a health-related social movement. This work explores the themes present in the #BlackLivesMatter Twitter discourse and compares these findings to the overarching goals stated by the organizers of the Black Lives Matter movement. The main issues discussed in the collected tweets were also identified and categorized by significant topics related to public health.

Following the analysis of these data, a Delphi study was conducted with experts in public health. The Delphi study aimed to determine how the information obtained can best be utilized by the public health workforce to address the issue of health inequities, specifically violence and racism, highlighted by the tweets. The Delphi study also served as a source for the generation of ideas on how the public health community can become more involved in the work of online health-related social movements. The Delphi study expanded the conversation with public health experts to examine how to integrate social media data on health-related social movements into research in the public health field.

Individual interviews were then conducted with social activists to better understand the role that social media plays in their activist efforts and to learn how

the public health workforce can engage with activists and social movements to support their shared goal of social justice. These interviews revealed rich qualitative data that illuminated the relationship between activists and academia, and the role this may play in developing trust between public health workers and social movements.

Definition of Terms

Black Lives Matter movement: This term refers to the overall social movement. In this study, data on the Black Lives Matter movement was obtained via tweets using #BlackLivesMatter. It is recognized this sample of data from one online hashtag source does not represent the entirety of the BLM movement. It is understood that a movement consists of many organizations and groups, each comprised of individual social activists.

Black Lives Matter organization: The BLM organization was created by the founders of #BlackLivesMatter including Alicia Garza, Opal Tometi, and Patrisse Cullors. This term refers to official members of BLM (obtained by applying through a BLM chapter) and their events. The mission and goals outlined on the official webpage, blacklivesmatter.org, are considered the views of the BLM organization.

Social movements: “informal networks based on shared beliefs and solidarity which mobilize around conflictual issues and deploy frequent and varying forms of protest” (Della Porta & Diani, 1999).

Health social movements (HSMs): “collective challenges to medical policy and politics, belief systems, research and practice that include an array of formal and

informal organizations, supporters, networks of cooperation, and media” (Brown et al., 2004).

Public health workforce: a diverse group including “all those whose prime responsibility is the provision of core public health activities, irrespective of their organizational base” (Beaglehole & Dal Poz, 2003).

Social media: “a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of user-generated content” (Kaplan & Haenlein, 2010, pg. 60).

Additional terms used in the description of this study are defined in Appendix A.

Chapter 2: Review of the Literature

Introduction

This study includes a content analysis of #BlackLivesMatter tweets and uses the findings in a Delphi study to determine how social media data analysis of social movements, including the Black Lives Matter (BLM) movement, can best be used by the public health workforce. Activists were then interviewed to gain insight from key stakeholders about how the public health workforce can best engage with social movements. In the following literature review, context will be provided for the importance of the key components of this work. Background on the creation and development of the Black Lives Matter movement will be given, followed by a discussion of how this social movement and other current social movements relate to issues in public health.

The definition of public health will be discussed. The concept of health social movements (HSMs) will be described along with examples of these social movements. Theories underpinning social movements and their impact on different levels of society will then be discussed. Additionally, the growing use of social media within social movements will be discussed along with examples of how social media data, specifically Twitter data, has been used to analyze the online presence of social

movements. A framework for the data collection and analytical methods for Twitter data will also be provided with a description of the capabilities of several Twitter analytic tools which were employed in the work by this researcher.

Following this will be a description of Delphi studies and their importance and relevance in obtaining a consensus among experts on next steps to pursue regarding the issues presented in this proposed study. A discussion of the importance of qualitative data and conducting interviews with activists to get a fuller understanding of the complexities involved in the relationship between the public health workforce and social movements is also included.

The Black Lives Matter Movement

The Black Lives Matter (BLM) movement was chosen for analysis in this study as an example of a social movement that is related to health but has not been fully embraced by the public health community. BLM has grown over the past few years into a highly recognizable social movement in the United States and worldwide (Bassett, 2015; García & Sharif, 2015). The phrase “Black Lives Matter” was coined by three Black women: 1) Alicia Garza, 2) Patrisse Cullors, and 3) Opal Tometi. Garza & Kauffman wrote about the creation and organizing of #BlackLivesMatter (2015). It first appeared online in 2012 as a Twitter hashtag (#BlackLivesMatter) after the acquittal of George Zimmerman, a neighborhood watch member who was charged with killing Trayvon Martin, a 17 year old unarmed Black male visiting relatives in the neighborhood.

The BLM phrase developed into a movement as the three original creators continued to engage in social activism addressing concerns about the treatment of Black people and created Facebook, Tumblr, and Twitter pages where people could share stories and collaborate. A significant upsurge in the movement occurred in 2014 when organizers led a Freedom Ride to Ferguson, Missouri and participants chanted “Black Lives Matter” during protests against police brutality after the death of Michael Brown, an 18 year old Black man fatally shot by police. The BLM movement continued to grow both through the use of the hashtag, #BlackLivesMatter, and also through on-the-ground organizing.

Today, there are 38 chapters of the organization and myriad events, protests, and rallies that have been organized by local groups throughout the United States and Canada (Cullors et al., 2016; Garza & Kauffman, 2015). The organization has a specified mission and guiding principles for the Black Lives Matter movement (see Appendix B), but the focus of the organization is not limited to one form of violence; instead there is an emphasis on the variety of forms of state violence and specific mention of the oppression of different groups of Black people, including Black women and girls, the elderly and queer and trans folk (Cullors et al, 2016).

The three original BLM founders emphasize a feminist lens in the work of the BLM movement. Two of the creators also identify as queer, and there are Lesbian, Gay, Bisexual, Transgender, and Queer (LGBTQ+) issues in the Black community that are also emphasized (Cullors et al., 2016). Yet much of their vision and goals for the BLM movement, including affirming “the lives of Black queer and trans folks, disabled folks, Black-undocumented folks, folks with records, women and all Black

lives along the gender spectrum” (Cullors et al., 2016) seem to be overshadowed by the issue of police misconduct and violence which has become the central and galvanizing issue of the movement (Rickford, 2016) and has largely been the focus of news stories.

Black Lives Matter as a Health-Related Social Movement

The Black Lives Matter organization focuses on the issue of “state violence” against Black people, a term which encompasses issues of poverty, incarceration, violence, family structure, the role of women, the role of the community, immigrant status, disabilities, and sexual orientation and identity among Black people caused or perpetuated by government and society (Cullors et al., 2016). While all of these topics are frequently discussed within the public health discipline and are widely accepted as determinants of health, the word “health” does not appear a single time on any page of the BLM official website. Additionally, the public health community has not recognized the BLM movement as one bringing awareness to and combatting public health issues. Yet the BLM movement is fighting to improve all of these determinants of health and should be considered a Health-related Social Movement.

Health social movements (HSMs) have been defined as “collective challenges to medical policy, public health policy and politics, belief systems, research and practice which include an array of formal and informal organizations, supporters, networks of cooperation and media” (Brown & Zavestoski, 2004, pg. 679). In this study, the term “health-related social movement” is used. Although the BLM movement complies with the defined qualifiers for a health social movement, it is not

largely viewed as a social movement directly focused on addressing health by combatting a specific illness or disease.

The researcher is asking for an expansion of public health involvement into social movements that address health issues through social determinants of health. The BLM movement does meet the criteria to be an HSM; this study argues that the issues protested by the BLM movement are public health issues clearly influenced by institutional racism and current health policy and politics. Practices of the BLM movement also include formalized chapters and events created by a strong network of individuals as well as more informal use of #BlackLivesMatter by members of the public, including supporters and the media.

One question asked in this study is what is the role of the public health community in health-related social movements? In order to answer this, the term public health must be defined. Public health is described by the American Public Health Association (APHA) as a field which “promotes and protects the health of people and the communities where they live, learn, work, and play” (APHA, 2017). Public health is a very broad discipline which is inherently interdisciplinary (Gebbie, Merrill, & Tilson, 2002). The public health workforce is therefore also diverse and includes a variety of positions whose prime responsibility is related to the core public health activities (Beaglehole & Dal Poz, 2003).

These core public health activities have been quantified as ten essential public health services: anyone providing these services can be considered a public health worker, regardless of their place of employment (CDC, 2010). It is difficult to

measure or define specifically what jobs are involved in public health, as those providing essential public health services range from healthcare providers to philanthropic organizations and many more (CDC, 2010). By this definition, the very activists interviewed in this study are included as public health workers since they work to mobilize community partnerships and empower people about health issues, two of the essential public health services (CDC, 2010). In this work the term “public health workforce” is effectively used to refer to individuals who are in a more structured public health role and have a particular set of skills relevant to solving public health issues. A goal of this work is to determine how to best educate public health workers who do not current see the connections between public health and social movements (such as the BLM movement). Operationally, these are the public health workers discussed in this work.

Social justice is a foundational tenet of public health (Institute of Medicine, 1988). In order to accomplish this, individuals involved in the field of public health must actively engage in social justice work aimed at increasing health promotion and protection for all (Krieger & Birn, 1998). Unfortunately, health inequities exist and combatting these issues is often a political battle. This does not mean objective research cannot be conducted on these topics (Beland & Cox, 2010), but rather researchers, along with other professionals within the public health workforce must advocate for the health of disadvantaged people and communities. The BLM movement strives to combat issues associated with systemic racism, a known determinant of health and cause of health inequities, and clearly a public health concern (Bailey et al., 2017; Garcia & Sharif, 2015; Williams & Mohammed, 2013;

Paradies, 2006; Jones, 2002). To effectively promote and protect health, issues highlighted by the BLM movement must be acknowledged by the public health community and action must be taken to help combat these issues and improve health.

Police violence, including law enforcement-related deaths have largely been considered solely a criminal justice concern; however, these events affect not only the health (and sometimes life) of the individuals but also impact their families and communities, making police violence a public health issue (Krieger et al., 2015). Police violence specifically against Black people is not a new concern in public health either. In fact, APHA issued a statement about the inequity in rates of violence by police against people of color (APHA, 1998).

More recently, in 2016, APHA issued another policy statement reiterating how harassment and violence by police disproportionately impacts people of color and other marginalized groups and notes that officers are rarely held accountable for these inappropriate acts (APHA, 2016). The statement is titled “Law Enforcement Violence as a Public Health Issue” which highlights the importance of considering police violence as a public health issue. Additionally this statement lists action steps, including urging government “to address the root causes of instability and violence in communities (also known as the social and structural determinants of health)...to increase economic and racial equity...” (APHA, 2016), which aligns with the goals and mission of the BLM movement, further proving that the BLM movement deserves to be viewed as a Health-related Social Movement.

The need for the Black Lives Matter movement arises from the enduring racism that exists today. Racism should also be considered a public health issue, as it has been readily acknowledged as a social determinant of health (Jones, 2002; Ford & Airhihenbuwa, 2010). Ample research has been conducted showing the effects of social determinants on health (Bambra et al., 2010; Kondo et al., 2009; Wilkinson & Marmot, 2003). Garcia and Sharif declare that racism “perpetuates and exacerbates the very trends our field works to reverse” and “therefore, public health, at its core, is antiracist work” (2015, pg. e27). The goals of Healthy People 2020 are also in line with this thinking, as one of the overarching goals is to “achieve health equity, eliminate disparities, and improve the health of all groups” (ODPHP, 2018). Given that racism implicitly creates disparities, eliminating racism is beneficial for the health of all people. Jones suggests that it is the role of public health scientists to confront racism in part by developing measures of racism on individual and institutional levels and investigating and measuring the racial climate as part of the overall social environment (2002, pg. 11). Indeed, the public health community must confront racism in order to be successful in its mission to obtain social justice and health equity for all (Jones, 2002).

It should be noted that racism is a term distinct from the construct of race. Race has no biological base but is merely a social classification of people based on their phenotype or how they look (Ford & Airhihenbuwa, 2010). Racism references a system that assigns opportunities and value based on the way people look that unfairly disadvantages some individuals and communities (Jones, 2002). Therefore it is important to examine the health status of racial groups understanding the

differences in these terms (Cooper & David, 1986). While “race” is often examined in public health work, far fewer measures of “racism” are explored in the field (Jones, 2002). According to Critical Race Theory (CRT), race itself is not so much a risk factor but rather should be viewed as “a marker of risk for racism-related exposures” (Ford & Airhihenbuwa, 2010, pg. S33). Therefore the public health community should consider altering measures of race to focus more on the racism-related determinants of health rather than race-related ones (García & Sharif, 2015).

Other Health-related Social Movements

Historically, social movements have continually played a role in advancing the health of the population (Brown & Fee, 2014; Marmot, 2011). These movements have varied in their topics, but all hold a common thread: they aimed to improve the health of the public. While many social movements have played critical roles in altering health outcomes, they have not fully been studied by the field of public health; when public health experts have examined social movements, they rarely utilize existing social movement theory (Brown & Zavestoski, 2004; Brown et al., 2004).

Health social movements (HSMs) can be divided into three categories: 1) health access movements which address issues of access to healthcare services, 2) embodied health movements which challenge existing science regarding treatment and prevention of disease and disabilities, and 3) constituency-based health movements which focus on health inequalities and inequities (Brown et al., 2004). Many HSMs have achieved success in pushing a political agenda and changing policy

by creating relationships with health and other social sectors (Brown & Zavestoski, 2004).

Based on these descriptions, the BLM movement fits best within the description of a constituency-based health movement as it addresses health inequality and health inequity based on differences by race. Other examples of constituency-based health movements include the environmental justice movement and the women's health movement (Brown et al., 2004). Yet most HSMs, including constituency-based HSMs, have focused on improving access to and quality of health care. Currently this is not the framing used by the BLM movement. The BLM movement could also be considered an embodied health movement as it challenges current thinking about the impact of racism on health and joins individuals who are vulnerable to its effects. Examples of other embodied health movements include the children's health movement and the tobacco control movement. Embodied HSMs generally focus on the experience of illness in addition to improving healthcare, which again, does not fully align with the current stance of the BLM movement.

Regardless of their classification within HSMs, these social movements have been identified as HSMs mainly through their relation to a specific disease or illness. The women's movement has focused on breast cancer awareness (King, 2004; Klawiter, 1999) while the LGBTQ+ movement has lead the way in HIV/AIDS activism (Hutchison, 2015). The environmental movement is viewed as a HSM due to its efforts to bring attention to health effects of toxic waste and pollution (Stern, Dietz, Abel, Guagnano, & Kalof, 1999).

The BLM movement seeks to address the issues caused by systemic racism, which is not considered an illness in the same manner as breast cancer or HIV/AIDS, although there are clear health implications (Bailey et al., 2017; Williams & Mohammed, 2013; Paradies, 2006). It is important to understand that these social movements have more relevance to public health beyond their direct linkage to combatting illness and disease. Therefore the term “health-related social movement” is applied to the BLM movement and other social movements that protest inequities based on social determinants of health.

One of the most discussed social movements is the environmental movement. While concerns about the environment started in the late 19th century, the modern environmental movements began in the 1960s over concern about air and water pollution and quickly grew into a well-recognized social movement (Brulle, 1995). Public awareness of environmental issues heightened due to current events including the publication of Rachel Carson’s book *Silent Spring*, which focused on the damaging effects of pesticides on the environment (Carson, 2002).

The environmental movement was, and still is, rooted in both science and politics. The basis for the environmental movement issues are all related to health outcomes, making this a clear example of a HSM (Stern et al., 1999). Since many of these efforts were led by people protesting against unfair laws that would result in poor health for certain groups, this is considered a constituency-based health movement. The environmental justice movement stemmed from grassroots activism and has from its conception been intertwined with the field of public health (Bullard & Johnson, 2000).

The Black Lives Matter movement relates to the environmental justice movement in many ways. Both are movements led by people who have sensed a social injustice which is effecting the health of certain groups, both are political in nature, and both erupted through grassroots activism (Bullard & Johnson, 2000; Cullors et al., 2015). Yet different from the environmental justice movement, protests generally do not call explicitly for a change in health policies or describe the impacts inequities caused by racism have on health, which allows the environmental justice movement to be conceptualized more easily as a HSM.

Children's health reform was also a major mission in the 1960s. Much legislation has been created to assist in improving children's health outcomes. The Vaccination Assistance Act, which provided vaccines for children under 5, was passed in 1962 followed by the Comprehensive Community Mental Health Centers Act in 1963 which provided funds for mental health clinics (Grob, 1994). Head Start, a program that provides a variety of educational and nutritional services to preschool children from low socioeconomic backgrounds was started in 1964 under the Economic Opportunity Act. In 1973, the Children's Defense Fund was created to protect children from abuse, and aid them in receiving medical care and education (Edelman, 1980). In 1997, the State Children's Health Insurance Program (SCHIP, now CHIP) was created to cover the cost of medical care for children whose families could not afford it.

Despite all these efforts, low-income children in the United States today still have poorer health outcomes than those from families with higher income (Brown & Fee, 2014). Yet these changes in public policy undoubtedly improved many aspects

of children's health. This social movement was largely driven by policy which relied on scientific data to present the benefits of proposed mandates. To date the BLM movement has not affected change in nationwide policy, but more research into the effects of racism on health outcomes may lead to future policy solutions.

There have also been many social movements to improve public health which have focused on behavioral reform. One major category of behavioral reform movements involved use and abuse of substances, including alcohol, tobacco, and illegal drugs, and more recently have focused on diet and exercise as well. These movements have largely focused on changing individual behavior. In these movements individuals are often blamed or considered responsible for their behavior, be it lack of physical exercise or poor diet, rather than the movement focusing on exogenous circumstances leading to these undesirable behaviors (Brown & Fee, 2014).

One excellent example is the campaign against tobacco use. While smoking was considered a social norm, continued pressure by scientists and public health researchers alongside consumer groups helped fuel the movement to curb smoking habits, despite the power of the tobacco industry (Brown & Fee, 2014). This movement stretched over decades, winning multiple victories along the way; from the Federal Cigarette Labeling and Advertising Act in 1965 which required all cigarette packs to display a warning label, to today when smoking is banned from many public areas including schools, airplanes, and restaurants. It is clear that this social movement has contributed to the significant progress made in improving health from reductions in smoking and exposure to second-hand smoke.

The BLM movement is also fighting against strongly held societal norms, and again, it will take increased research to create a paradigm shift in how race and racism are viewed by society in relation to health. Given the importance of research in supporting positive changes in health advocated for by social movements, it is clear that the BLM movement would benefit from public health research to influence public opinion and develop policy changes to improve health outcomes for Black people. It is important that we look at these social movements not as separate from one another, but as connected. Each movement in history builds upon previous movements and works with other current movements to change the broader political and cultural atmosphere (Meyer & Whittier, 1994).

Social Movements and Social Media

Social movements are changing. The theories surrounding these movements have changed over time to fit new and emerging social movements (Rootes, 1990), and this is happening again with the shift towards online social movements. One important area of study is on the impact that a social movement has on society. Social movements can have effects on multiple levels including the individual, institution, and political systems (Amenta et al., 2010). Social Movement Impact Theory aims to understand the importance and efficacy of different organizational tactics. In the current research, the effects of an online social movement will be investigated by examining the similarities and differences between the goals and mission of a movement outlined by organizers of the movement and the online discourse about that movement (evaluated through Twitter data). According to Social Movement

Impact Theory, the four main ways social movements affect society are by creating: 1) individual change, 2) institutional change, 3) cultural change, and 4) political change (McAdam et al., 1996).

Social media, including Twitter, is a largely untapped source of data that can be a useful tool for public health workers, especially to examine social movements. As of 2016, nearly nine in ten U.S. adults were using the internet (Pew Research Center, 2017) and over two-thirds were using social media platforms (Pew Research Center, 2016). Social media has been defined as a group of internet-based applications that allow users to create and exchange self-generated content (Kaplan & Haenlein, 2010). Social media use has been on the rise in the past decade and is now used by people of all age groups (Archambault & Grudin, 2012). This research discusses the use of Twitter, which is a popular social media application that allows users to send text-based posts of 140 characters or less called “tweets” (Kaplan & Haenlein, 2010). In 2008, 75% of internet users had used social media (Kaplan & Haenlein, 2010). Twitter is a widely used form of social media with 320 million monthly active users worldwide, and one billion visits monthly to sites with embedded tweets (Twitter “Company: About”, 2016). Twitter is a particularly important social media platform to use in examining the BLM movement given that Blacks are overrepresented on Twitter (PEW Research Center “Social Media Use in 2018”, 2018).

The Black Lives Matter movement and many social movements today are increasingly relying on social media presence. In fact, the Black Lives Matter organization was first started through social media under the Twitter hashtag

#BlackLivesMatter, which is still a widely used channel of communication and messaging for those invested in the movement. Thousands of tweets are sent using #BlackLivesMatter every day from online participants throughout the world (TweetArchivist: #BlackLivesMatter, 2015). In recent years, researchers have started to examine the potential of using social media as a source of data collection. Social movements widely use social media (Obar, Zube, & Lampe, 2012). Social media has effectively been used by a variety of social movements, most commonly for increasing recruitment and disseminating information (González-Bailón et al., 2011). Using social media as a channel for activism has also shown to make contributions to broad societal change (Stokes & Atkins-Sayre, 2018).

Twitter data has been used across multiple fields for a variety of purposes (Bruns & Liang, 2012). Due to the popularity of social media as a method of communication and its ability to bring together people who have no personal affiliation, it is easy to understand why social media plays such a vital role in the creation and maintenance of social movements. Many studies of social movement use of social media have focused on the social networks developed or the type of platforms used (Vijaykumar et al., 2014; Bortree and Seltzer, 2009; Edwards and Hoefler, 2010; Greenberg and MacAulay, 2009) rather than the content of the messages (Stokes & Atkins-Sayre, 2018). Past studies have shown that individuals who are more involved in social media have a higher intent to participate in social movements (Hwang & Kim, 2015). Therefore examining social media is an important method of understanding the progression of composition of social movements.

Twitter aggregate data has previously been used to better understand certain social

movements and protests, such as predicting uprisings during the Arab Spring (Hermida, Lewis, & Zamith, 2014), understanding public and cultural perceptions of the Vancouver riots (Burch, Frederick, & Pegoraro, 2015) and determining the role of Twitter as a news source and form of social mobilization in the Spanish *indignados* protests (Ferré-Pavia & Perales García, 2015).

Social media creates new ways for people to interact with each other (Hwang & Kim, 2015). These online platforms allow individuals to share their thoughts and ideas with few barriers to social exchange (Marken, 2007). Thereby social media becomes an effective tool for people to become involved in current social issues (Hwang & Kim, 2015). This allows social media to attract large numbers of people who have similar thinking and engage and empower these people around a common cause (Hwang & Kim, 2015). Using these platforms, individuals are able to access information about social movements and participate in the movement itself by sending and receiving messages from others.

Social Media Data and Public Health

While the use of Twitter aggregate data is somewhat new in the field of public health, Twitter data has been successfully used in multiple public health studies and messaging campaigns. As more people are using social media as a regular form of communication, there has been increased study and use of social media to reach people from the public health workforce (Newbold & Campos, 2011).

Twitter data has been examined at the level of organizations – examining organization responses to natural disasters (Currie, 2009; Gurman & Ellenberger,

2015; Lachlan, Spence, Lin, Najarian, & Greco, 2014) as well as determining how sports organizations use social media to build relationships (Wang & Zhou, 2015).

Individual Twitter users have also been a focus of several public health studies, from content analyses on what users will share about obesity (So et al., 2016; Yoon, Elhadad, & Bakken., 2013), e-cigarette marketing and consumer conversations (Lazard et al., 2016), prescription drug abuse (Katsuki, 2015) to using aggregate data to predict flu trends (Achrekar, Gandhe, Lazarus, Yu, & Liu, 2011; Chew & Eysenbach, 2010) and using Twitter as a form of real-time Ebola outbreak surveillance to monitor the spread of information and early epidemic detection (Odlum & Yoon, 2015). Social media is also used in a variety of messaging campaigns aiming to change health behaviors (Freeman, Potente, Rock & McIver, 2015). The study of social media has successfully been used to better understand a variety of topics within public health and would be useful in further examining the Black Lives Matter movement.

Analyzing Twitter data from #BlackLivesMatter creates better understanding of the structure of the social movement and the importance the online public places on issues around racial health inequities, which could inform future public health initiatives to combat issues of health disparities. Social media allows the online public to participate in social movements, thereby making it an effective tool for allowing a social movement to gain and keep momentum (Hwang & Kim, 2015). Therefore, examining the online public Twitter dialogue surrounding the Black Lives Matter movement allows for a better understanding of the movement as a whole.

By understanding the views of the online public regarding the Black Lives Matter movement, we were then able to determine how well the online public discourse represents the views of the organization. The alignment between the online public's values and the constructed ideals and principles of the organization was examined to determine if the most frequently discussed issues in the movement are structured by the online public and popular media or the original leaders of the movement. This has implications for better understanding the progress and direction of the Black Lives Matter movement, as social media has been used to comprehend the public's view and participation in other social movements (Kavada, 2015; Chan & Lam, 2015; Egbunike & Olorunnisola, 2015; Kumar & Thapa, 2015; Smith, 2015).

Additionally, this information from this study is important for public health workers attempting to conduct interventions or create policy changes to combat racial health disparities, a relationship which has been lacking between members of the movement and the public health workforce (García & Sharif, 2015). The online public represents a large contingency of the Black Lives Matter movement (Rickford, 2016) and understanding the structure and importance that the online public places on specific issues and groups experiencing health inequities could better inform future initiatives for work in this field. Information learned from this study can also be applied to other health-related social movements. While each social movement is unique, they all share a drive to combat inequities relating to social determinants of health, and therefore public health workers should examine ways to engage with other health-related social movements as well.

Twitter Data Analytics and Available Tools

Social media allows access to large amounts of data on social interaction. In the case of online social movements, these data can be analyzed to learn about the structure and the organization of the movement. Various companies will now track and store information by social media users which is searchable by key terms and available for a small price (Bruns & Liang, 2012; TweetArchivist, 2014). This data tracking is in line with the privacy policies of the social media sites and allows researchers to collect large amount of aggregate data around specific topics (Fisher, DeLine, Czerwinski, & Drucker, 2012).

There are many tools available to help understand the properties of online social networks computationally (Zappavigna & Hyland, 2012). Quantitative measures can be used including: 1) number of tweets, 2) number of impressions, 3) location data, 4) top hashtags, 5) top images, and 6) top contributors (see Appendix A for glossary of terms). To learn more about the content of the social media messages, it was important to also conduct a qualitative analysis. A content analysis was conducted to group messages thematically and a sentiment analysis determined the level of positivity or negativity in the messages.

To thoroughly analyze the collected Twitter data, a variety of these approaches were employed. This involved the use of several existing social media analytic tools. The following list briefly describes each of the tools and programs used in this study.

Twitter: (located online at twitter.com) Twitter is a social media platform used by over 300 million monthly active users. Users create a profile, self-selecting demographic information and connect with other users by “following” them. Users create tweets which are generally composed of the @username, the tweet text, a timestamp, and in many cases a hashtag and media. In this study the tweets using #BlackLivesMatter on Twitter were collected and analyzed.

Tweet Archivist: (located online at tweetarchivist.com) Tweet Archivist is an online tool that allows users to track a hashtag campaign by collecting ~1% of all public tweets created with a certain hashtag. These tweets and accompanying information (@username, timestamp, location, etc.) are archived into an account and can be downloaded as a Microsoft Excel file in batches of 50,000 tweets. A monthly subscription was purchased to track #BlackLivesMatter tweets continuously from 9/16/2016 through 5/31/2017. Over two million tweets were collected during this time period.

NGram Analyzer: (located online at guidetodatamining.com/ngramAnalyzer/analyze.php) This is an online tool that identifies the most frequently used unigrams and bigrams in text. This will enable the identification of the top words and phrases within #BlackLivesMatter tweet sample and will give a numeric value for the number of times the word or phrase is found within the tweet text.

Linguistic Inquiry and Word Count (LIWC): (program must be purchased and downloaded, information and free trial located online at <https://liwc.wpengine.com/>)

This tool runs on Java programming language and analyzes text using a group of built-in dictionaries. LIWC reads text and compares each word to a user-defined dictionary. The percentage of total words matching each of the dictionary categories is computed along with counting parts of speech and positive/negative emotion. LIWC was used to analyze #BlackLivesMatter tweet text and to determine the percentage of words related to public health themes. Sentiment analysis was also conducted to examine the level of positivity and negativity of tweet content. Another variable, clout, examined the level of confidence expressed by the tweet text.

NVivo: NVivo is a computer software package useful for qualitative data analysis. This software is useful for sorting qualitative data and examining relationships between categories and themes, called nodes. Transcribed interviews were uploaded to NVivo and sorted into categories based on themes that emerge from the data. NVivo allows patterns to be detected and also aids in understanding the relationship between the nodes. Interviews were coded separately and nodes were created as themes developed. Text from all interviews was then analyzed for top words to uncover additional themes and patterns.

SPSS: Statistical Package for the Social Sciences (SPSS) is a statistical software program developed by IBM. The software contains built-in drop down menus to conduct statistical analysis, but is also open-source and uses a Python extension to run any statistical package from the free software R. In this study, Delphi survey quantitative data was analyzed in SPSS for frequencies and descriptive statistics, as well as for more complex statistical analysis such as the nonparametric Wilcoxon's Paired Rank Test.

Qualtrics: (information location online at qualtrics.com) All Delphi study questionnaires were developed using Qualtrics, a web-based application for survey development and completion. The survey was designed using Qualtrics and administered to Delphi study panel participants via a link sent through email. Participants completed the surveys online using their personalized link and their responses were recorded in Qualtrics. Data were downloaded from Qualtrics into Microsoft Excel and SPSS documents.

The Delphi Technique

The Delphi technique is a widely accepted method for gathering data from experts and working towards a consensus within the group (Hsu & Sandford, 2007; Hasson, Keeney, & McKenna, 2000; Rowe & Wright, 1999). Consensus refers to coming to agreement on the value of an item by the group. This convergence on a central value occurs through iterations of questionnaires where participants grow to accept the group rationale for assignment of a particular value to an item (Rowe & Wright, 1999). This flexible technique has been used in a variety of disciplines including business, industry, and public health (Powell, 2003). Within each of these areas, the Delphi technique has been used to achieve a variety of outcomes including: 1) determining a range of program alternatives, 2) exploring underlying assumptions in information, 3) seeking out information to create a group consensus, 4) correlating judgments on a wide range of topics, and 5) educating participants on a topic (Hsu & Sandford, 2007). It is a particularly useful method when addressing controversial subjects by obtaining a consensus (Fink, Kosecoff, Chassin, & Brook, 1984). In this

dissertation, Twitter data from #BlackLivesMatter was analyzed and the findings were presented to an expert panel consisting of individuals in the field of public health. Using the Delphi technique allowed for a better consensus about how the public health workforce can apply these and related social media data to further public health's goals of social justice and equity.

The Delphi technique works to gain group consensus through a process of iterations (Dalkey, 1972). Hsu and Sandford outline four rounds of the Delphi process routinely used (2007). The first round of the Delphi process usually starts with giving participants an open-ended questionnaire to obtain information about a specific topic area (Martino, 1983). This information is then analyzed by the investigators and reformatted as a structured questionnaire. In the second round, participants are given a second questionnaire and review the items, often rank-ordering them by priority. This allows areas of agreement and disagreement to be identified. The third round gives participants the questionnaire along with their responses and allows them a chance to adjust their responses and to clarify the rationale for their previous decisions. In the fourth round of the Delphi process, participants are given the questionnaire items and their ratings along with the ratings and opinions of the rest of the group. This study used a modified version of this Delphi process consisting of three rounds where the second and third round of the classic Delphi study were combined into a single round. Variations from the classic Delphi exist (Martino, 1983); often the number of rounds is variable with rarely more than one or two iterations (Rowe & Wright, 1999).

The use of the Delphi technique in this work created a unique opportunity to consult the experts from a variety of backgrounds to look into the issue of using aggregate Twitter data on social movements to enact social change in public health. This type of data analysis involving a social movement has never been examined by a panel of experts to determine its full potential in the public health field. The Twitter data collected and analyzed from #BlackLivesMatter served as a case study example of what can be learned from examining social media data through a public health lens.

Individual Interviews

In the initial proposal for this study, the Delphi technique was to be applied to two separate panel of experts, one including experts in public health (which occurred), and one including experts on the Black Lives Matter movement, focusing on activists personally involved with the social movement. The goal was to have each panel separately devise ideas for how the public health workforce should engage with social movements, including the Black Lives Matter movement. However, due to difficulty recruiting Black Lives Matter experts, the second arm of the panel was dropped. It was still necessary to capture the opinions of the on-the-ground activists who advocate within these social movements to better understand their views on how public health could best engage with their causes. Therefore, individual interviews were conducted with activists who were involved with a wide range of causes and organizations.

Individual interviews are an important tool to gather more in-depth qualitative information that may not be obtained through other quantitative methods of data collection, such as surveys or questionnaires (Dey, 2003; Lincoln & Guba, 1985). Contrary to quantitative work which often requires a structured response, qualitative interviews are often less structured (Brinkmann, 2014). Interview guides contain open-ended topics and questions the researchers believe could be pertinent to answering the research questions of the study (Ivey, 2012). Interviews and other qualitative methods provide information beyond answers to the questions asked, including participants' feelings and experiences surrounding the topics addressed. This adds context to the data which can be useful in developing a deeper understanding on a topic (Ivey, 2012; Dey, 2003; Lincoln & Guba, 1985).

Interviews in this study asked participating social activists about their involvement with social movements, their use of social media as a form of information transmission for social movements, their experience with academic research being conducted on or with social movements, and their knowledge of public health. The definition of public health was discussed and participants were asked how the social movements they are involved with relate to public health. Additionally, participants were asked how public health workers could be more engaged with social movements and gave examples for how public health workers could build relationships with social activists to further this type of work.

Guiding Theoretical Frameworks

Critical Race Theory and Public Health Critical Race Praxis

Critical Race Theory (CRT) is a race equity methodology that originated in legal studies but is applicable in many disciplines and offers public health a new lens with which to view the causes of health disparities (Ford & Airhihenbuwa, 2010).

CRT has been a dominant influence in racial studies since the 1980s (Ford & Airhihenbuwa, 2010) but more recently CRT has started to be utilized in public health studies (Graham et al., 2011), making important contributions to the framing of public health issues regarding race. For example, CRT has been used as a framework in a study on racial microaggressions and was important in understanding how they influence the racial climate on college campuses (Solorzano, Ceja, & Yosso, 2000). CRT has also been used to examine the intersectionality between historically oppressed populations, including women and minorities (Bowleg, 2012) and aided in understanding the impact of racism on HIV testing among African-Americans (Ford & Airhihenbuwa, 2009).

It is beneficial to examine how to use CRT as a framework for understanding the unique contribution of racial identity and racism to health research (Graham, Brown-Jeffy, Aronson, & Stephens, 2011). CRT differs from traditional behavior theories in that it is an iterative methodology rather than a concrete theory (Ford & Airhihenbuwa, 2010). CRT focuses on four main concepts: 1) race consciousness, 2) contemporary orientation, 3) centering in the margins, and 4) praxis (Ford & Airhihenbuwa, 2010). Public Health Critical Race praxis (PHCR) was developed to

make the elements of CRT more understandable and usable for public health researchers (Ford & Airhihenbuwa, 2010).

Each of the CRT components are actively used by the BLM movement to address issues of inequality and racism faced by Black people. The first component, race consciousness, simply refers to a direct acknowledgement of the influence of race and racism in society and in one's personal life. A tenet of BLM is to be "unapologetically Black" (Cullors et al., 2016) and all of their work is focused on the systemic consequences related to race and racism in society today.

Race consciousness was first used when conceptualizing this study. In order to apply race consciousness, researchers must self-reflect and become aware of their own relationship to race and the racial dynamics in their own personal realm as well as in the society they aim to study (Ford & Airhihenbuwa, 2010). The researcher constantly reflected on her own understanding of race and conscious and unconscious biases which may have influenced this work. When developing constructs, race was considered as a social construct (rather than biological). The differences between the terms race and racism were not ignored. Racism was considered as a separate determinant of health; this was expressly of concern to the Black Lives Matter organization and movement and tweets were analyzed with this in mind.

The second concept of CRT, contemporary orientation, makes the point that structural racism is always evolving over time and racism today is normalized and has been integrated into society. Acts of racism are so commonplace that people of color may become accustomed to it and ignore it or may become hypervigilant and

perceive any unfair treatment as a result of racism. The BLM movement is calling attention to “normalized” acts of racism and is aiming to disrupt this status quo.

Identified as “ordinariness of racism” in PHCR, this principle was at the foundation of the purpose of this work. This research assumed the normalcy of racism as an occurrence in everyday life. The idea of involving public health workers to support the Black Lives Matter movement stemmed from the desire to disrupt the ordinariness of racism as a way to enact social justice. Racism exists in multiple tiers, from the individual to structural level. Structural determinism, another principle of PHCR, relates to the multilevel factors that drive health inequities. For this reason, the Social Ecological Model is used in this study to capture the importance of factors at all levels, as well as understanding the relationship between each level.

The third CRT component, centering in the margins, refers to focusing on the perspectives of the individuals who are belonging to the marginalized group rather than the experiences and perspectives of the dominant race or culture. The BLM movement was created by and continues to be led by self-identifying Black women, two of whom identify as queer. It is a clear goal of the BLM movement to highlight the voices of marginalized groups focusing on Black people, and specifically Black women and members of the LGBTQ+ community. A study by the U.S. Department of Health and Human Services (DHHS) showed that among 30 health occupations in the U.S. workforce, Whites represent the majority in all health occupations, and are overrepresented in 76% of these positions (2017). It is important to acknowledge that public health is largely dominated by Whites and this influences the allocation of resources and research that is conducted. It is also important that when research

concerning populations of color is conducted by White researchers that care is taken to ensure the voices of the community are heard and represented in the work.

Interviews were conducted with social activists, the majority of who identified as people of color. While the racial identity of tweet contributors is unknown, this study provided a place for social media discourse surrounding the Black Lives Matter to be highlighted. Tweets focusing on race and racism were showcased rather than dismissed.

Praxis is an iterative process combining knowledge from theory and practice, including research and personal experience and understanding how these areas influence each other. The BLM organization references research on the discrepancies by race for law enforcement deaths, incarceration rates, and more (Cullors et al, 2016). These studies are coupled with accounts of individual incidents, such as the deaths of unarmed Black men including Eric Garner and Michael Brown, but it is unclear how the BLM movement is learning and growing from the combination of knowledge gained from these distinct sources. Praxis involves going beyond obtaining knowledge to engaging in action to disrupt existing inequities (Ford & Airhihenbuwa, 2010). This work echoes this call for action and provides a foundation for understanding engagement with social movements. Public health workers should continue to develop this understanding and implement ideas in conjunction with social advocacy organizations to combat health inequities.

Social Ecological Model

Health-related social movements often relate to public health through a shared interest in improving health equity via social determinants of health. In public health research it is important to consider social determinants of health affect all levels consistent with the social ecological model. The social ecological model includes: 1) intrapersonal, 2) interpersonal, 3) community, 4) institutional and 5) structural/policy levels. These levels all have an impact on specific behaviors, and influences on these behaviors interact within and across various levels (Glanz et al., 2008).

Social media has been applauded for connecting people and simultaneously criticized for isolating them (Benson & Morgan, 2015; Cook, 2013). Intrapersonal factors, such as one's self-concept, knowledge, and goals will clearly have a direct impact on an individual's behaviors. Social media users post messages via their personal platform accounts, and in turn receive information from these sites individually. Vijaykumar et al. (2014) revealed that individuals who perceived their own contributions to be effective in relation to a social movement's agenda were more likely to participate in the social movement online. This shows the importance of individual factors in participation at a community level.

Interpersonal factors are also relevant here, given that Twitter communication occurs between individuals on the internet. Tweets are often addressed to a specific user and are publicly viewable by others. They are a form of communication not just between individuals but also used by groups and organizations. Tweeting to a group or using a certain hashtag in some ways enables users to be part of an online community. Collective tweets using a particular hashtag, in this case

#BlackLivesMatter, build a community and shape the discourse on the social movement. It is the goal of social movements, which exist at the community organization level, to ultimately change political and cultural aspects of society, which requires a shift at a structural level.

The Black Lives Matter movement highlights racism as a major determinant of health. Jones describes three levels of racism including: 1) institutionalized, 2) personally-mediated, and 3) internalized (2002). Each of these levels impacts multiple levels of society. Institutional racism relates to the structures and policies resulting in differential access and opportunities by race. This is clearly a result of systemic racism but affects not only the outer structural level of the socioecological model, but also trickles down into the very center, influencing the mindset of individual. The Black Lives Matter organization focuses on the concept of state violence (Cullors et al., 2016), which refers to structural-level racism. Personally-mediated racism, also known as prejudice and discrimination, is usually committed by individuals but has implications for community and structural levels when this form of racism is perpetuated as a collective mindset among multiple individuals. Internalized racism results from individuals accepting messages about their self-worth based on their assigned race (Jones, 2002). This impacts individuals as well as whole communities and stems from interactions with personally-mediated racism, institutional racism, or both (Jones, 2002).

This work examines Twitter data to determine if the tweet content focuses on health-related issues at an individual, community, or structural level to help identify what is viewed as the necessary level for intervention. Additionally, current impacts

of racism as well as potential implications of the BLM movement agenda will be discussed at the various levels of the socioecological model. Actionable items generated by the Delphi study and individual interviews will be classified by their level on the socioecological model (see chapter 6).

New Social Movement Theory

New Social Movement Theory (NSMT) was developed to explain aspects of social movements that are not understood by traditional social movement models (Brown et al., 2004). Previous social movements often focused on class conflict, as evidenced by the labor movement and Marxism, while present-day movements focus on social and political conflict (Buechler, 1995; Walsh, 2012). NSMT includes a strong emphasis on the role of culture in development of social movements (Brown et al., 2004; Buechler, 1995) and also highlights the important role of social movements in the political sphere (Buechler, 1995). NSMT also stresses the importance of post-materialist values rather than material resources (Buechler, 1995). Instead of struggling to gain material resources, new social movements aim for collective control over socio-economic development (Melucci, 1980; Della Porta & Diani, 1999). New social movements are not limited to a single class, and focus more on personal and social identity of individuals (Melucci, 1980). This can be seen in many social movements today including the women's movement and LGBTQ+ movement which focus on gender and the immigrant movement which focuses on issues surrounding citizenship and ethnic identity. The BLM movement focuses on such post-materialist values as equality for all groups, emphasizes citizen input in

government decisions, and humanism while simultaneously focusing on material needs such as safety.

NSMT is not an all-encompassing theory to describe current and emerging social movements (Melucci, 1980). For example, the BLM movement diverges from NSMT in some important aspects. NSMT de-emphasizes the importance of social class (Brown et al., 2004; Fitzgerald & Rodgers, 2000). The BLM movement does not follow this stance as its creation is upon inequalities in the existing social class structure. It is important to consider the history of race and racism in creating the inequalities that persist in the creation of social class, and consequently health outcomes, today.

Also, NSMT tends to consider collective identities as a product of group interests rather than assuming that group interests are structurally determined. While collective identities may be partially created from interpersonal factors, in this case, the BLM movement is predicated upon the presence of structural or systemic racism, therefore group interests are at least somewhat structurally determined. Therefore, while this work will draw on some aspects of NSMT, it will also rely on work specifically related to Health Social Movements as well as additional constructs such as collective identity, political opportunity, and framing which give a more comprehensive understanding of the BLM movement (Brown et al., 2004; McAdam, McCarthy, & Zald, 1996).

Community-Based Participatory Research (CBPR)

To effectively address issues highlighted by social movements, it is imperative to consider the voices of the individuals involved. Community-based participatory research (CBPR) is now often used to study and address social issues, including social movements (Minkler, Vasquez, Tajik, & Petersen, 2008). This framework, which involves community collaboration in the research process as well as enacting change as part of this process (Minkler et al., 2008) easily coincides with the efforts of community-university partnerships, built to assist in collaborative work aimed at eliminating health disparities and improving health policy (Brugge & Hynes, 2005).

Goodman et al. (1998) developed ten dimensions of community capacity including: 1) participation and leadership, 2) skills, 3) resources, 4) social and inter-organizational networks, 5) sense of community, 6) understanding of community history, 7) community power, 8) community values, and 9) critical reflection. All of these factors play a role in the Black Lives Matter movement, and are important areas to consider when conducting research.

For example, the first study (chapter 3) examines public participation in the online discourse surrounding the BLM movement, and determines if the organizational leadership goals are effectively transmitted through tweets containing #BlackLivesMatter. Considering a social movement to be a community, with it comes its own community understanding, history, sense of power, and values. This research aimed to better understand the community of the Black Lives Matter movement, and discover attributes that may be consistent within other social movement communities.

By understanding the needs and strengths of the social movement, areas for future research and engagement become clearer.

Another CBPR component, critical reflection, involves continual reflection on the community values to develop alternative possibilities from the current system, particularly in ways that promote and enhance social justice (Goodman et al., 1998). This critical reflection is similar to praxis discussed in Critical Race Theory (Ford & Airhihenbuwa, 2010). The ten dimensions of community partnership capacity have been altered to reflect other social movements, including the environmental justice movement (Freudenberg, 2004); this framework could also be adapted to the Black Lives Matter movement to examine factors that promote health equity within the context of this social movement and its community.

Chapter 3: STUDY 1: An Exploratory Study of #BlackLivesMatter Twitter Data: Determining Support for the Movement and Content Alignment with Black Lives Matter Organization Principles

Abstract

In this exploratory study, a content analysis of #BlackLivesMatter tweets was conducted to determine if these tweets reflect the mission and goals outlined by the official Black Lives Matter organization and how well tweet content reflected health-related themes. A sample of 236,354 tweets was examined for descriptive information including top users and top influencers. From here, a random sub sample of 11,000 tweets was examined more closely to determine level of support for the Black Lives Matter movement within the tweets, as well as to uncover how well tweet content matched the principles outlined by the BLM organization. Half of tweets (50%) were found to support the BLM movement, with nearly 20% of tweets showing opposition. Fifty-seven percent of tweets aligned with the principles of the BLM organization; other tweets not aligning with these principles were found to range in theme from news to politics to marketing. Tweets were also analyzed for health-related content, and it was determined that few tweets directly mention health, however, the issues

discussed in the tweets often relate to public health issues on a broader level. Hashtags cannot be exclusively used to generalize the motives of a social movement, however, by analyzing the online twitter discourse of a particular social movement hashtag, much can be learned about how the online public views the movement. Additionally, while this movement is significantly related to public health issues, this analysis found the Black Lives Matter movement does not seem to be viewed as combatting health disparities. More research should be conducted to better understand this and other social movements and to determine how the public health workforce could engage with the Black Lives Matter movement and reframe the issues discussed as public health issues to garner more support and resources from the public health community to address shared goals.

Introduction

Social Media and Social Movements

Social media creates new ways for people to interact with each other (Hwang & Kim, 2015). These online platforms allow individuals to share their thoughts and ideas with few barriers to social exchange (Marken, 2007). Thereby social media becomes an effective tool for people to become involved in current social issues (Hwang & Kim, 2015). This allows social media to attract large numbers of people who have similar thinking and engage and empower these people around a common cause (Hwang & Kim, 2015). Using these online platforms, individuals are able to access information about social movements and even participate in the movement itself by sending and receiving messages from others.

Due to the popularity of social media as a method of communication and its ability to bring together people who have no personal affiliation to work in collaboration (Kaplan & Haenlein, 2010), it is easy to understand why social media plays such a vital role in the creation and maintenance of social movements. Past studies have shown individuals who are more involved in social media have a higher intent to participate in social movements (Hwang & Kim, 2015). Therefore examining social media is an important method of understanding communication within social movements.

Twitter data has been used across multiple fields for a variety of purposes (Bruns & Liang, 2012). Twitter aggregate data has previously been used to better understand certain social movements and protests, such as predicting uprisings during the Arab Spring (Hermida, Lewis, & Zamith, 2014), understanding public and cultural perceptions of the Vancouver riots (Burch, Frederick, & Pegoraro, 2015) and determining the role of Twitter as a news source and form of social mobilization in the Spanish *indignados* protests (Ferré-Pavia & Perales García, 2015).

As of 2018, nearly nine in ten U.S. adults were using the internet (Pew Research Center, “Internet Fact Sheet”, 2018) and seven in ten Americans use at least one social media platform (Pew Research Center, “Social Media Use”, 2018). Social media has been defined as a group of internet-based applications that allow users to create and exchange self-generated content (Kaplan & Haenlein, 2010). Social media use has been on the rise in the past decade and is now used by people of all age groups (Archambault & Grudin, 2012). Twitter is a popular social media platform that allows users to send text-based posts of 140 characters or less called “tweets”

(Kaplan & Haenlein, 2010). In 2008, 75% of internet users had used social media (Kaplan & Haenlein, 2010) and these numbers continue to grow. Twitter is a widely used form of social media with 320 million monthly active users worldwide, and one billion visits monthly to sites with embedded tweets (Twitter “Company: About”, 2016). Roughly one-quarter of adults in the U.S. use Twitter, with nearly half (46%) of users frequenting Twitter on a daily basis (Pew Research Center “Social Media Use in 2018”, 2018). This shows that Twitter is a social media platform widely used for communication and it is important to better understand the impact of these online communications on today’s social movements.

The Black Lives Matter movement, and many social movements today, are increasingly relying on social media presence. In fact, the Black Lives Matter organization was first started through social media under the Twitter hashtag #BlackLivesMatter, which is still a widely used channel of communication and messaging for those invested in the movement. An average of 17,002 tweets are sent using #BlackLivesMatter every day, with nearly 20 million total tweets (PEW Research Center “Activism in the Social Media Age”, 2018). Researchers have now started to examine the potential of using social media as a source of data collection (Wang & Zhou, 2015; Burch, Frederick, & Pegoraro, 2015; Ferré-Pavia & Perales García, 2015; Gurman & Ellenberger, 2015). Twitter is a particularly important social media platform to examine discourse surrounding the BLM movement given that Blacks are overrepresented on Twitter (PEW Research Center “Social Media Use in 2018”, 2018).

Social Media Data and Public Health

While the use of Twitter aggregate data is fairly new in the field of public health, Twitter data has been successfully used in multiple public health studies and messaging campaigns (Chew & Eysenbach, 2010; Bonini & Sellas, 2014; Hambrick, Simmons, Greenhalgh, & Greenwell, 2010; So et al., 2016). As more people are using social media as a regular form of communication, there has been increased study and use of social media to reach people from the public health workforce (Newbold & Campos, 2011).

Twitter data has been examined at the level of organizations – examining organization responses to natural disasters (Currie, 2009; Gurman & Ellenberger, 2015; Lachlan, Spence, Lin, Najarian, & Greco, 2014) as well as determining how sports organizations use social media to build relationships (Wang & Zhou, 2015). Individual Twitter users have also been a focus of several public health studies, from content analyses on what users will share about obesity (So et al., 2016; Yoon, Elhadad, & Bakken., 2013), E-cigarette marketing and consumer conversations (Lazard et al., 2016), prescription drug abuse (Katsuki, 2015) to using aggregate data to predict flu trends (Achrekar, Gandhe, Lazarus, Yu, & Liu, 2011; Chew & Eysenbach, 2010) and using Twitter as a form of real-time Ebola outbreak surveillance to monitor the spread of information and early epidemic detection (Odlum & Yoon, 2015).

Social media is also used in a variety of messaging campaigns aiming to change health behaviors (Freeman, Potente, Rock & McIver, 2015). The study of social media has successfully been used to better understand a variety of topics within

public health and would be useful in further examining the Black Lives Matter movement.

Analyzing Twitter data from #BlackLivesMatter creates better understanding of the structure of the social movement and the importance the online public places on issues around racial health inequities, which could inform future public health initiatives to combat issues of health disparities. Social media allows the online public to participate in social movements, thereby making it an effective tool for allowing a social movement to gain and keep momentum (Hwang & Kim, 2015). Therefore, examining the online public Twitter dialogue surrounding the Black Lives Matter movement allows for a better understanding of the movement as a whole.

By understanding the views of the online public regarding the Black Lives Matter movement, we were then able to determine how well the online public discourse represents the views of the organization. The alignment between the online public's values and the constructed ideals and principles of the organization was examined to determine if the most frequently discussed issues in the movement are structured by the online public and popular media or the original leaders of the movement. This has implications for better understanding the progress and direction of the Black Lives Matter movement, as social media has been used to comprehend the public's view and participation in other social movements (Kavada, 2015; Chan & Lam, 2015; Egbunike & Olorunnisola, 2015; Kumar & Thapa, 2015; Smith, 2015).

Twitter Data Analytics and Available Tools

Social media analytic tools allow access to large amounts of data on social interaction. In the case of online social movements, these data can be analyzed to learn about the structure and organization of the movement. Various companies will now track and store information by social media users which is searchable by key terms and available for a small price (Bruns & Liang, 2012; TweetArchivist, 2014). This data tracking is in line with the privacy policies of the social media sites and allows researchers to collect large amount of aggregate data around specific topics (Fisher, DeLine, Czerwinski, & Drucker, 2012).

There are many tools available to help understand the properties of online social networks (Zappavigna & Hyland, 2012). Quantitative measures were used including examining number of tweets, top hashtags, and top contributors (see Appendix A for glossary of terms). To learn more about the content of the social media messages, it was important to also conduct a qualitative analysis. A content analysis was conducted to group messages thematically and a sentiment analysis determined the level of positivity or negativity in the messages. To thoroughly analyze the collected Twitter data, a variety of approaches were employed (see chapter 2 for social media analytic tool descriptions).

Methods

This study consisted of collecting and analyzing tweets using the hashtag #BlackLivesMatter to better understand the central themes and issues emerging from

#BlackLivesMatter tweets, and to determine if these are aligned with the stated mission and goals of the Black Lives Matter movement.

Data Collection: #BlackLivesMatter Tweet Sample

Tweets using #BlackLivesMatter were collected from TweetArchivist.com, an online repository of tweets. Tweets used were collected from January 1, 2017 through June 30, 2017. Over this six month timespan 917,999 tweets were collected. Information collected for each tweet included: 1) full text of the tweet, 2) language, 3) profile image, 4) source code, 5) location (self-reported), 6) time zone (if geotagged by user), 7) geotag (if geotagged by user), 8) hashtags, 9) URLs, 10) user mentions, 11) media links, 12) follower count, and 13) user name (see Appendix A for glossary of terms).

This study focuses on analyzing tweets which contain #BlackLivesMatter and also the users who created these tweets. In this sample, all tweets collected were made publicly available by the users. User data, such as profile image, user name, and location were all self-selected by the user. Other user information, including geotag and time zone must be enabled by the user and reflects a small percent of tweets collected (<1%) so it was not utilized in this study.

Of the 917,999 tweets collected, all non-English and incoherent tweets (such as tweets only including numbers and/or letters but no words) were excluded from the sample, leaving 771,272 remaining tweets. From here, 30% of these tweets were identified as unique (not duplicated), leaving 236,354 tweets for initial analysis. Top users were identified from this sample as well as number of impressions for each

user. Then, in order to conduct a more detailed analysis a random sub-sample of 11,000 tweets was examined further.

Since the majority of analysis was qualitative in nature, quantitative sample size calculations were not applicable. The 11,000 tweets analyzed for content reflect slightly more than 1.0% of the nearly one million tweets obtained, and nearly 5% of all unique tweets in the overall sample (n=236,354). This total number of tweets is larger than several comparable studies conducting tweet content analysis where between 1,000-6,000 tweets were analyzed (Jansen, Zhang, Sobel, & Chowdury, 2009; Golbeck, Grimes, & Rogers, 2010; Lachlan et al., 2014; Hambrick, Simmons, Greenhalgh, & Greenwell, 2010; So et al., 2016). This sample only includes tweets that were made publicly available and contain #BlackLivesMatter. Any tweets which used similar hashtags related to the Black Lives Matter movement including #blm, and any tweets where #BlackLivesMatter was misspelled, were excluded as they would not be detected by the TweetArchivist program as it detected and collected tweets.

Tweet Measures and Analysis Procedures

All data were reviewed and cleaned prior to analysis. Text was cleaned before linguistic analysis by spelling out common abbreviations and omitting certain special characters. This allowed for a more accurate analysis by ensuring consistency in spelling of words thereby allowing for a more valid reading of text sentiment (negative and positive words) and top words and phrases used. Retweets were kept in the sample, however duplicate tweets were filtered out. Retweets are tweets originally

sent by a user that are then re-sent in their original form by another user. These were included since the users in the sample felt the words they retweeted were important enough to share, even if those words were not their own. However, any duplicate tweets were not included so that popular repeated tweets, often sent out in mass by bots rather than people (Stringhini, Kruegel, & Vigna, 2010), do not skew the results with repetition.

Before analyzing the finalized tweet sample, a smaller random sample of 1000 tweets, none of which were included in the 11,000 tweet final sample, was examined and coded by the lead researcher based on categories relating to the described mission and goals outlined by the #BlackLivesMatter organization to determine if these tweet codes would be useful in categorizing the larger tweet sample (see Appendix B).

These categories describe multiple forms of violence and oppression against Black people, including a focus on Black women and girls, the elderly, and the LGBTQ+ community (Cullors et al., 2016). Looking at the guiding principles and mission of the Black Lives Matter organization, eight distinct categories were created (see Appendix B).

Tweets were assigned a code or codes for whichever categories were applicable. Using an open-coding approach similar to Golbeck, Grimes, & Rogers (2010), additional themes present in the tweet content not represented by the initial code categories were added to the codebook as they were uncovered. While the original categories were extrapolated from the mission and goals of the official Black Lives Matter organization, additional code categories were created using grounded theory strategies (i.e., original themes not based on a previous classification of Black

Lives Matter tweets or theoretical basis but derived from review of the source materials themselves). The percentage of tweets not included in the initial categories relating to the Black Lives Matter organization's mission and goals was calculated to determine how well the organization's mission and goals represented the issues discussed in online Twitter discourse.

All coders underwent training to ensure rating consistency prior to working on the data. Training included being given written instructions on how to code and watching a video of sample coding. Then student coders were provided practice time for coding sample tweets using Microsoft Excel. Tweets were coded by content based on the categories determined during the creation of the codebook. Coders were given a test set of 200 tweets to code and responses were then compared with the researcher's coded responses. Coding discrepancies were discussed with the coders in order to ensure high inter-rater-reliability in the final sample. Coders who struggled with consistency in the first set of 200 sample tweets were given a second 200-tweet sample to code before accessing tweets in the final sample. Tweets in the practice sets did not overlap with the final 11,000 tweet analytic sample. Individuals coding the sample were graduate students enrolled in a Social Media and Network Analysis course at the University of Maryland, College Park. Each student choosing to participate coded 1,000 tweets from the final sample (total of 22 graduate student coders). Each tweet was double coded and checked for inter-rater reliability.

Coders were asked to complete several tasks for each tweet. First, the tweet was categorized as either "for", "against", or "neutral" in regard to the opinion each tweet expressed concerning the Black Lives Matter movement. "For" tweets were in

support of the Black Lives Matter movement, “against” tweets were opposed, and “neutral” tweets expressed no opinion relating to the movement, expressed a neutral opinion, or an unclear opinion. The percentage of tweets in each category (“for”, “against”, and “neutral”) was calculated. Second, tweets were given at least one code from the developed codebook (eight possible categories, see Appendix B). If the tweet content did not fall into any of these categories the coders used the category “other.” If “other” was used then the coder described in a few words the new category. Tweets coded as “other” were reviewed by the principle investigator and new categories were developed. All “other” tweets were coded into one of ten sub-categories.

Inter-rater Reliability

When examining the sample of 11,000 tweets, each tweet was coded by two separate graduate students (22 graduate students coding 1,000 tweets each) and responses were checked for consistency by the lead researcher. Basic agreement was checked for each pair for their ratings of opinion of the social movement and ranged from 54-77% agreement. Overall, 68% of codes regarding opinion of the social movement were a match between raters. When examining these ratings as an ordinal scale and calculating intra-class correlations (ICC) for each pair using a 2-way random effects model (Shrout & Fleiss, 1979), the ICC ranged from 0.442-0.841, with an average of 0.708. For individual pairs these ratings rank from poor to very good inter-rater reliability (Koo & Li, 2016). Therefore, when there was a difference

between the coders' category identifications among any pair, a third rater made a decision about how to categorize the tweet.

Coders were also asked to label each tweet with one of eight codes relating to the Black Lives Matter movement's principles (obtained from Blacklivesmatter.com). Tweets that did not match any of the provided codes were labeled as "other" and were later classified into ten sub-categories. Fifty-nine percent of tweets had coders match on at least one of the assigned categories. Information on qualitative coding was stored and analyzed using Microsoft Excel.

Additional Analyses

To address the first research question concerning topics that emerge from #BlackLivesMatter tweets, several online tools were used. Microsoft Excel was used to examine quantitative measures such as most frequently used hashtags as well as identifying the top users and top influencers (see Appendix A). Microsoft Excel was also used to store information on qualitative coding conducted by human raters, and calculate inter-rater reliability. Twitter was used to learn more about the top users and top influencers, including identifying if the twitter accounts belong to an individual or an organization. This allowed for a better understanding of users employing #BlackLivesMatter and to discover what additional content is frequently associated with this hashtag. Looking specifically at the #BlackLivesMatter text content allowed for themes present in the text to be categorized. Ngram Analyzer (Zacharski, 2017) was used to identify the most frequently used single words (unigrams) and two-word phrases (bigrams) in the sample.

To gain a better understanding of the meaning behind the words used in the tweet text, Linguistic Inquiry and Word Count (LIWC) was used to count the percentage of words that reflected different emotions, thinking styles, social concerns, and parts of speech (Pennebaker Conglomerates, 2015). LIWC utilizes Java programming language and analyzes text using a group of built-in dictionaries. LIWC2015 has been reported to capture 83% of words used in tweets (Pennebaker, Boyd, Jordan, & Blackburn, 2015). LIWC helped discover health-related themes by finding related terms using the built-in dictionaries in the program. This data was used to group tweets by theme and to investigate the discussion of health-related topics. In LIWC2015, there are 79 categorical dictionaries. The health dictionary, a sub-category of the biological processes dictionary, contains 294 health-related words (e.g. “pill”, “clinic”, “flu”) (Pennebaker et al., 2015). This dictionary is limited by the terms it contains. The number of health-related terms used in the tweet sample (n=11,000) was counted.

Measurements of clout and emotional tone were also conducted using LIWC2015. Emotional tone measures the positivity and negativity of words to give a measure of emotion. How people express emotion and the emotions they express are a critical source of information on how people experience the world (Tausczik & Pennebaker, 2010). LIWC has been found to accurately identify positive and negative emotional words (Kahn, Tobin, Massey & Anderson, 2007) and provide ratings matching those of human raters on writing excerpts (Alpers et al., 2005). Clout is a term used to represent a variable measuring the level of confidence expressed in the

tweet text. Clout is a measure of authoritativeness and leadership, which was measured to discern if users posted tweets with conviction.

Both emotional tone and clout are expressed on a scale ranging from 0 to 100 from an analysis of all words in the text. Emotional tone is measured so that lower numbers represent a more negative tone with higher numbers indicating more positivity. Emotional tone scores below 50 are considered negative (Pennebaker et al., 2015). High clout scores indicate high levels of confidence and expertise while low numbers suggest more tentative or anxious expression (Pennebaker et al., 2015). Using natural language processing to decipher text is constantly improving and LIWC has shown reliability and validity in multiple studies (Alpers et al., 2005; McDonnell, 2015; Pennebaker et al., 2015); however, it still faces certain limitations. Therefore these results should be viewed as part of the overall analysis, which also includes human content analysis (Omondi Ochieng, Loki, & Sambuli, 2016).

Results

Descriptive Analysis

The analysis of the initial sample of 236,354 tweets yielded quantitative information about the source of tweets using #BlackLivesMatter. While some Twitter users were prolific in their tweets using #BlackLivesMatter, of the initial sample (n=236,354) only four users (of 114,613 users in the sample) had over 1000 tweets in the sample, and only 106 users had posted more than 100 tweets in the sample. The majority of tweeters (76%) had posted only one tweet in the sample. Twitter users who posted the most tweets are shown in Table 1 below.

Table 1. Top 20 tweet contributors to overall sample (n=236,354).

Rank	User Name	Number of tweets	Type of User
1	SanFranMediaPR	3343	organization
2	courtneyjahenry	1576	individual
3	CarlMatsx2	1378	individual
4	NoMoWarSite	1043	individual
5	Luluresearch	923	organization
6	trueblackresist	863	individual
7	ogkeyser	816	individual
8	GregLand33	671	individual
9	news_pence	659	suspended
10	LeBaronLordKing	656	individual
11	raider_truth	571	individual
12	hamm_lhamm1953	563	individual
13	berniewouldhav1	555	suspended
14	KNSRADIO	548	organization
15	ProtestWatch	520	organization
16	LynchedToday	447	organization
17	BlackLivesLies	423	suspended
18	TBTRrevolution	405	suspended
19	GOV847	378	organization
20	socialstartnews	353	suspended

*Suspended accounts were removed from Twitter and could not be accessed to determine if they belonged to an individual or organization

Only six of these top 20 users were organizations; the majority of top tweet posters were individuals. Further examination of their Twitter profiles revealed that many considered themselves activists, and many were bloggers. Not all of these users were pro-BLM. Several users were posting a significant number of tweets in opposition to the Black Lives Matter movement. Four accounts could not be classified, as they had been suspended by Twitter.

Another aspect of the tweets examined was follower count. This term refers to the number of users that follow, or pay attention to a certain account. Not surprisingly, nearly all of the top followed accounts were organizations (90%), all related to news, with only two exceptions (both famous individuals) (see Table 2).

Table 2. List of users with top follower counts (n=236,354).

Rank	User Name	Follower
		Count
1	CNN	33231294
2	BBCWorld	18910384
3	FoxNews	15148603
4	TIME	13549281
5	washingtonpost	9730732
6	HuffingtonPost	9725332
7	timesofindia	9636690
8	ndtv	9155222
9	mashable	8641591
10	NewYorker	7451486
11	XHNews	7040203
12	PerezHilton	6616280
13	guardian	6469151
14	cnni	6440552
15	ELLEmagazine	6332849
16	EW	6105743
17	CBSNews	5671308
18	htTweets	5380414
19	billboard	4904257
20	UncleRUSH	4819796

The top 68 accounts had over 1,000,000 followers, and of the top 1000 users, based on follower counts, all had over 50,000 followers indicating tweets posted by these users, including the tweets included in this sample, were seen by a vast audience.

Of the subsample of 11,000 tweets examined for further analysis, there were a total of 24,198 hashtags used in these tweets, including that each tweet contained #BlackLivesMatter. The sheer volume of hashtags suggests the important role they play in conveying information, as well as ensuring the message reaches as many other people as possible. Many of the top hashtags used in conjunction with #BlackLivesMatter refer to other current social movements and sub-movements, along with names of Black individuals who were killed by law enforcement, and for whom the Black Lives Matter movement is seeking justice for their death (see Table 3).

Table 3. List of top hashtags found in sample of tweets using #BlackLivesMatter (n=11,000).

Rank	Hashtag	Count (per 11,000)
1	#BLM	265
2	#AllLivesMatter	186
3	#WomensMarch	180
4	#BlackHistoryMonth	162
5	#PhilandoCastile	158
6	#BlackTwitter	152
7	#Resist	135
8	#MAGA	111
9	#SayHerName	110
10	#NFL	109
11	#HireBlackCoaches	99
12	#BlueLivesMatter	95
13	#PeoplesMonday	69
14	#TrayvonMartin	66
15	#NoDAPL	64
16	#Trump	64
17	#Racism	61
18	#CharleenaLyles	58
19	#Harley	54
20	#JordanEdwards	50

Human-coded Content Analysis

Based on human coder examination of tweet content (n=11,000) support for the movement, more than half of tweets in this sample were in favor of the BLM movement (57%), with about one-fifth of tweets opposed to BLM (see Table 4).

Table 4. Sentiment towards BLM determine by tweet content (n=11,000).

Sentiment towards BLM	Count (of 11,000)	Percent
Favorable	6275	57
Neutral/No opinion	2746	25
Opposed	1979	18

Additionally, when comparing tweet content to the principles outlined on the official BLM website, approximately half of the tweets aligned with the BLM organization's principles (52%) (see Table 5).

Table 5. Percent of tweet codes relating to BLM principles (n=11,000).

BLM Tweet Organization Principles	% of Total Tweets
Other	49.8
Loving Engagement	14.1
Genocide	11.9
Collective Value	11.0
Unapologetically Black	4.9
Black Women and Families	4.2
Restorative Justice	2.7
Incarceration Rates	1.0
Poverty	0.3

Combining code assignments from both coders, tweets had an average of 2.3 codes per tweet (total of 24053 codes for 11,000 tweets) with 11% of the tweets receiving more than one code. The BLM principles which received the most attention in the tweet sample were: 1) those describing protests (loving engagement), 2) the death of Black people by law enforcement (genocide), and 3) the value of diversity (collective value). These three categories comprised nearly 37% of all tweets. Other important topics which are listed as targeted issues by the BLM official organization’s website, such as poverty and incarceration rates, were rarely discussed in the tweets.

Not surprisingly, most of the tweets opposed to or neutral towards the BLM movement did not align with the principles of the BLM movement, as they were not

promoting the values of BLM. Looking specifically at the tweets that did not match with the designated codes, for neutral tweets, 76% of the codes were designated as “other” and with tweets in opposition to BLM, 81% of the codes were listed as “other.” This differs from tweets that were in favor of BLM, where only 31% of the codes were classified as “other.” Additional categories were created to summarize tweet themes not covered by the BLM principles. Themes most common in these tweets included news stories, politics, racist content, and marketing/promotional tweets (see Table 6).

Table 6. “Other” tweet subcategories (n=11,988).

Rank	"Other" Subcategories	Number	Percent of "Other" Tweets
1	News/media	1578	13.2
2	Politics	1114	9.3
3	General racism	606	5.1
4	Law enforcement	466	3.9
5	Marketing/promotional	424	3.5
6	Black crime	337	2.8
7	Education	299	2.5
8	Black history	228	1.9
9	Terrorism	224	1.9
10	Black leaders	220	1.8

Linguistic Inquiry and Word Count (LIWC) Analysis

Using the LIWC built-in health dictionary, 115 different health-related words were found in the tweets, which were narrowed down to 88 distinct stems (i.e., combining “wound” and “wounds”). Health-related words range from referencing physical harm (most common) and mental harm to overall health (see Figure 1). The word “lives” was present in all tweets within the hashtag #BlackLivesMatter, but was listed an additional 400 times. Aside from this, 19 other words were listed at least ten times (Table 7).

Table 7. Top 20 most frequently used health-related words found in tweets by LIWC health dictionary.

Word	Frequency
lives	11400
life	196
health	57
pain	41
nurses	33
sick	30
alive	23
tired	22
wash	21
living	19
abortion	18
drugs	15
pill	15
pregnant	13
blind	12
cancer	12
doctor	11
choke	10
wound	10
sore	9

Using LIWC analysis, clout is measured on a scale from 0 to 100 where low scores indicate less confidence in statements made and higher scores indicate greater confidence and expertise (Pannebaker et. al, 2015). The 11,000 tweet sample had a high clout score of 71 signifying that the tweets were said with significant confidence and authority in the statements. On a scale from 0 to 100 for emotional tone, where lower numbers indicate more negative emotion and higher numbers indicate more positive emotion (Pannebaker et. al, 2015) the tweet sample had a very low score of 18, showing that overall the tweet text conveyed a tone of sadness, anger, or hostility. Low emotional tone scores were present for both tweets in support of and against BLM.

Discussion

Quantitative tweet findings were consistent with previous studies on social media analysis. Olteanu, Weber, & Gatica-Perez (2016) examined the demographics of #BlackLivesMatter tweeters. Their research showed that the vast majority of tweeters posted only a few tweets (62% posting only one tweet), and only a few tweeters posted thousands of tweets. This is similar to findings in this study where over 76% of tweeters in the sample posted a single tweet. There were many different users who contributed tweets using #BlackLivesMatter; while there are some users who contribute frequently to the conversation surrounding this hashtag, the vast majority of users engage more sporadically. This could suggest the majority of tweeters using #BlackLivesMatter may not be highly engaged with the Black Lives Matter movement, at least not in the online discourse.

Being such a widely known and utilized hashtag, #BlackLivesMatter draws visibility from a wide array of people. This allows the hashtag discourse to have significant reach, but the messages posted may also be more diffuse. Since a wide array of individuals are posting tweets occasionally, this shows there is a large population of users who are somewhat aware of the Black Lives Matter movement and are open and willing to be part of the conversation, even if they are currently involved in a more limited capacity.

While a number of tweets were posted by organizations, the majority of the most frequent tweet posters were individuals. A number of organizations contribute to the Black Lives Matter movement, but their lack of tweet volume suggests it is individuals who dominate the online conversation surrounding the Black Lives Matter movement. Organizations, being more central to the social movement, may be more likely to contribute to on-the-ground aspects of this social movement such as organizing physical events and protests, and taking action beyond posting online, as opposed to individuals who are more peripheral members, who may be more likely to contribute to the movement online (Brunsting & Postmes, 2002). As for understanding the spread of the tweet messages, news organizations had the most followers and therefore reached the largest audiences. It is important to examine the messages coming from these news sources to know what content the majority of users are being exposed to as this could be significant in shaping public understanding of the Black Lives Matter movement. This data could also be used to determine the sociodemographics that these news media sources attract (Thurman & Fletcher, 2017; Messing & Westwood, 2012).

Five of the top ten hashtags used in these tweets referenced other current social movements with an online presence. This overlap points to the interconnectedness of activists and their causes. Some of these movements bear a direct connection to the Black Lives Matter movement, such as #SayHerName, which was started as a hashtag to recognize the Black female victims of police brutality and #AllLivesMatter which was started as a responses to #BlackLivesMatter. Other movements are distinctly separate from #BlackLivesMatter including #WomensMarch and #Resist, but have related goals. Several of the top used hashtags, including #MAGA, #AllLivesMatter, and #BlueLivesMatter are known for opposing #BlackLivesMatter. While some tweets use hashtags of multiple social movements to show their connectedness, others are used to show opposition to one movement while simultaneously supporting another.

Use of a hashtag does not mean that one supports it, but examining support of the Black Lives Matter movement within the tweet sample (n=11,000), the majority of tweets were favorable towards the movement. Freelon, McIlwain, & Clark (2016) used similar categories to understand tweet support for the Black Lives Matter movement by analyzing over 40 million tweets identified through various related keywords from June 1, 2014 through May 31, 2015. Freelon's study also found that supportive tweets outnumbered others by a substantial margin (Freelon, McIlwain, & Clark, 2016). In the present study, the majority of "neutral" tweets were news stories which did not express an opinion on the movement. Having a high number of tweets opposed to the movement can have positive and negative impacts for the Black Lives Matter movement. Tweets using the hashtag in opposition to the movement promote

hate, violence, and racism, and in large volume, dilute the messages promoted by the leaders of the Black Lives Matter movement. Contrarily, this use of the hashtag among multiple online social networks may also increase discussion of the movement among a diverse group of people and prevent it from growing stagnant by circulating within an echo chamber of supporters.

Overall, tweets were found to have very negative sentiment. This was true for both tweets in support of and opposed to the BLM movement. Social movements are known for propagating strong emotions (Jasper, 1998; Jasper, 2011). The negativity pervasive in supportive and opposing tweets may suggest that the tweet content is overwhelmingly sad and/or angry in tone. This significant emotion found in social movements however does not mean that they are irrational, and in fact, these emotions often serve an important purpose within the movement such as strengthening collective bonds and increasing impact (Jasper, 2011).

Considering the BLM movement is highlighting current inequities for Black people, this negative emotional tone makes sense and is often found in social movements (Jasper, 2011). While some tweets focus on positive aspects such as the value of diversity and the successes stemming from protests, these positive tweets are overshadowed by tweets discussing negative topics such as the death of Black people by law enforcement and racism encountered in daily life. Negative emotion can have a positive impact on creating a sense of solidarity within a movement by promoting feelings of a shared experience (Eyerman, 2005). Additionally, in order to have continual impact, accomplishments of social movements must be muted to remind the

public of the changes that still need to happen in order to achieve continued support (Jasper, 2011).

A main goal of this research was to determine how well the online tweet discourse of #BlackLivesMatter matches the goals and mission of the Black Lives Matter movement, as defined by the principles outlined from the Black Lives Matter organization, through Blacklivesmatter.com. It is important to note that many organizations contribute to the overall movement, and therefore the principles of this organization may not fully encompass the goals of the social movement in its entirety (Freelon et al., 2016). Yet this organization was founded by several of the women who also first coined the online hashtag. These women have been heavily involved with the on-the-ground movement as well (Cullors et. al, 2016) so it would be expected that there would be considerable overlap between tweets using #BlackLivesMatter and the BLM organization's principles, which is consistent with the results.

Tweets favoring the BLM movement were more likely to align with these principles than tweets labeled as "neutral" or "opposed." This is logical, given that individuals who are promoting the BLM principles are likely tweeting in favor of the BLM movement. Codes describing the tweet themes were used regardless of the support for the BLM movement. Neutral and opposed tweets did not often mention the BLM principles, not even to dispute them. Instead these tweets focused largely on other themes entirely, ranging from news and politics to history and even marketing.

Tweets opposing the BLM movement were not arguing against the principles of the BLM organization, but rather covered completely separate topics. This disconnect in topics between supporters and opponents of the BLM movement could suggest a lack of communication between these groups regarding the mission and goals of the BLM movement. This broad array of themes present in the tweets shows that online social movements can have difficulty controlling the messages that are sent, even within a hashtag dedicated to a specific cause. #BlackLivesMatter tweet users may be using the hashtag more for the purpose of expressing an opinion or garnering support for the movement (or countermovement) than discussing the issues of the movement with others coming from a different perspective. Many social movements thrive on this opposition, with dissent fueling solidarity through an “us” versus “them” mentality (Gerlach, 2001).

Another analysis examined the words in these tweets related to health. While over a hundred different words were found in tweets that related to health, few of these were used often. The vast majority of these words appeared only a few times in the tweets. Many of these terms discuss health abstractly such as “life” and “living,” while others focus on a specific health issue such as “cancer” or “drugs.” The word “health” was only mentioned 57 times in 11,000 tweets, indicating that this term is not closely related to issues discussed with #BlackLivesMatter in the eyes of these twitter users. Yet at its core, the issues highlighted in the principles of the BLM organization align with issues commonly addressed by public health workers, including violence, emphasis on race as a determinant of health, poverty, women and families, and more (Institute of Medicine, 1988; ODPHP, 2018).

The focus of the LIWC health dictionary used in this analysis is on medical terms related to biological processes. However, in addition to biology, there are many determinants of health including social, economic, educational, environmental, and health care factors (ODPHP, 2018). This limits the usefulness of the current LIWC health dictionary. Additionally, LIWC is limited to the denotative definitions of terms and cannot account for differing connotations including sarcasm, irony, and idioms (Tausczik & Pennebaker, 2010). In future work, a public health dictionary could be created to expand the current health lexicon by using words covering a broader range of social determinants of health. This would be useful in future work conducting textual analysis of public health documents, including social media data.

It is important to understand why this social movement and others that also have a health-related core, are not viewed as addressing public health issues. Research should be conducted to determine what the public health workforce can do to engage with the Black Lives Matter movement, through #BlackLivesMatter or other means, in order to support the goals of this movement shared by the discipline of public health.

There are several limitations to this study. Given this data, there are many additional analyses that could have been conducted. The results here are limited to some of the main analyses which were conducted to better understand what is being said online with this hashtag, who is using #BlackLivesMatter, and how well tweet content aligns with the principles of the BLM organization.

This study used a single sample from a fixed six-month time frame including the first half of 2017. Many events happened over this time span including the inauguration of President Trump, Black History Month, and protests in Tennessee following the shooting of Jocques Clemmons by police (Sawyer, 2017). Due to the capabilities of the data repository (TweetArchivist), this data set is unable to calculate the impact that these events held on the number of tweets using #BlackLivesMatter. Social movements are constantly changing and evolving, so to say these results represent the movement at this current time would be inaccurate. Additionally, #BlackLivesMatter is used prolifically, and a sample this size may not be representative of the millions of tweets that have been posted using this hashtag, even those posted during the same time period. The use of a single hashtag does not represent an entire movement, and while the majority of twitter discourse on this movement utilizes this hashtag, other peripheral hashtags (such as #blm) may offer valuable insight not detected in this study (Gonzales-Bailon, Wang, Rivero, Borge-Holthoefer & Moreno, 2014).

The goal of this study was to determine how well twitter discourse using #BlackLivesMatter matched with the principles of the BLM organization. This organization, while a major contributor to the BLM movement, is only one part of this expansive social movement. Future research should be conducted with twitter data from #BlackLivesMatter and other social movement hashtags to better understand how these movements evolve and interact with each other. More information is also needed to understand how this data can be useful for professionals

in other disciplines to engage with social movements and to support their mission and goals both online and offline.

In conclusion, exploratory analysis of #BlackLivesMatter Twitter data revealed that tweets align somewhat with the official BLM organization, however, there are many voices in the online discourse, and this dilutes the main messages but increases the number of people reached. While tweets did not often mention health-related terms, these terms were limited to those relating to biological processes. Tweet content corresponded more often with social determinants of health. Future research should involve analysis of tweet content relating to these social determinants of health and determine how public health can best utilize these types of data. Additionally, information from this study is important for public health workers attempting to conduct interventions or create policy changes to combat racial health disparities, a relationship which has been lacking between members of the movement and the public health workforce (García & Sharif, 2015). The online public represents a large contingency of the Black Lives Matter movement (Rickford, 2016) and understanding the structure and importance the online public places on specific issues and groups experiencing health inequities could better inform future initiatives for work in this field.

Chapter 4: STUDY 2: Use of a Delphi Study to Investigate Public Health Engagement with Social Movements

Abstract

Public health experts participated in three rounds of surveys using the Delphi technique and generated ideas about how to encourage the public health workforce to engage with social movements. Social movements and public health share common goals of social justice and both groups fight to eliminate inequities for disadvantaged populations (Institute of Medicine, 1988). Yet public health work does not often include collaboration with social movements, even though such partnerships could be beneficial (Garcia & Sharif, 2015). Today many social movements have a significant online presence (Obar, Zube, & Lampe, 2012). Delphi study participants, identified as public health experts (n=10) reviewed an analysis of Twitter data using #BlackLivesMatter tweets and determined what analytic techniques and information could be useful in public health work. Participants also developed ideas on how public health workers could engage with social movements to further their shared health-related goals both via online and on-the-ground interactions between these groups. Generated items were categorized and then participants were asked to rank and re-rank the importance and feasibility of each item on a 7-point Likert scale in

two additional survey rounds with knowledge of the mean ranking among other panel members. Participant consensus was formed on the importance and feasibility of a number of actionable steps.

Introduction

Social Movements, Social Media, and Role of Public Health

Historically, social movements have played a role in advancing population health (Brown & Fee, 2014; Marmot, 2011). For example, the women's movement has advanced breast cancer awareness (King, 2004; Klawiter, 1999) while the LGBTQ+ movement has lead the way in HIV/AIDS activism (Hutchison, 2015). The environmental movement has been very successful in its efforts to draw attention to health effects of toxic waste and pollution (Stern, Dietz, Abel, Guagnano, & Kalof, 1999). Another excellent example is the campaign against tobacco use. While smoking was considered a social norm, continued pressure by scientists and public health researchers alongside consumer groups helped fuel the movement to curb smoking habits, despite the power of the tobacco industry (Brown & Fee, 2014). This movement stretched over decades, winning multiple victories along the way; from the Federal Cigarette Labeling and Advertising Act in 1965 which required all cigarette packs to display a warning label, to today when smoking is banned from many public areas including schools, airplanes, and restaurants. These movements have varied in their causes, but all share a common goal: they have aimed to improve the health of the public. While many social movements have played critical roles in altering health

outcomes, they have rarely been studied directly in the field of public health (Brown & Zavestoski, 2004; Brown et al., 2004).

Today, social movements are changing, relying more heavily on social media as a form of communication (DeLuca, Lawson, & Sun, 2012). This is an effective channel for communication, as social media is widely used, with over two-thirds of U.S. adults using at least one social media platform (Pew Research Center, 2018). In recent years, social media data has been studied across multiple fields and found to be useful, among other things, in understanding public perceptions of protests (Burch, Frederick, & Pegoraro, 2015), predicting social uprisings (Hermida, Lewis, & Zamith, 2014), and determining the role of social media in the development and execution of social protests (Ferré-Pavia & Perales García, 2015).

Public health researchers have also discovered benefits of using social media data. Twitter has been used in several public health messaging campaigns (Freeman, Potente, Rock & McIver, 2015) and has been studied for a variety of public health uses from examining responses to natural disasters (Currie, 2009; Gurman & Ellenberger, 2015; Lachlan, Spence, Lin, Najarian, & Greco, 2014) to better understanding perceptions on obesity (So et al., 2016; Yoon, Elhadad, & Bakken., 2013) and E-cigarettes (Lazard et al., 2016). Twitter data has even been successfully analyzed to predict flu trends (Achrekar, Gandhe, Lazarus, Yu, & Liu, 2011; Chew & Eysenbach, 2010) and to track the spread of information concerning Ebola (Odlum & Yoon, 2015).

Social movements widely use social media, including Twitter (Obar, Zube, & Lampe, 2012). These movements rely on social media as a mechanism for recruitment and information dissemination (González-Bailón et al., 2011). Therefore, social media data analysis is a useful tool for better understanding social movements. Yet to date, analyses of social media data to understand social movements by the field of public health has been limited. Despite shared goals of social justice between public health and social movements (Institute of Medicine, 1988), these two groups often still lack collaboration (Garcia & Sharif, 2015). A goal of this study was to determine how social media data analytics on social movements could be useful to public health workers. Conversely, this study also examined how the public health workforce could become more involved with social movements. To answer these questions, the Delphi technique was used with a panel of experts in public health to generate and rank possible solutions.

The Delphi Technique

The Delphi technique is a widely accepted method for gathering data from experts and then working towards a convergence of opinions, or consensus, within the group (Hsu & Sandford, 2007; Hasson, Keeney, & McKenna, 2000). This flexible technique has been used in a variety of disciplines including business, industry, and public health (Powell, 2003). Within each of these domains, the Delphi technique has been used to achieve a variety of outcomes including: determining a range of program alternatives, exploring underlying assumptions in information, seeking out information to create a group consensus, correlating judgments on a wide range of

topics, and educating participants on a topic (Hsu & Sandford, 2007). It is a particularly useful method when addressing controversial subjects to obtain a consensus (Fink, Kosecoff, Chassin, & Brook, 1984; Rowe & Wright, 1999).

The Delphi technique works to gain group consensus through a process of iterations, or multiple survey rounds where participants rank and re-rank items until responses converge around the mean (Dalkey, 1972). Participants are given feedback after each round detailing a summary of each round, including how their responses compare to the responses of the group. This gives participants a chance to review their responses, gain insight from others, and clarify their responses. By offering multiple iterations, participants are given the opportunity to think more critically about their responses and reduce the effects of noise among respondents (Hsu & Sandford, 2007). The use of the Delphi technique in this study created a unique opportunity to consult with experts from a variety of public health backgrounds. The Delphi technique allowed for the development of consensus on how the public health workforce can apply social media data concerning social movements to further public health's goals. Additionally, it was useful in determining important and feasible ideas to get public health professionals to engage with social movements.

Methods

Experts in public health were recruited to participate in a Delphi study to develop practicable ideas for how to engage the public health workforce with social movements. These experts were presented with a data report based on part of a previous analysis of Twitter data using tweets containing #BlackLivesMatter

(n=10,000) (see Appendices C through E). The Black Lives Matter movement was chosen for its current notoriety as well as for the movements' goals, including curbing violence and improving quality of life for Black people (Cullors et al, 2016). These goals directly align with those of public health (Institute of Medicine, 1988).

The goal of the Delphi study was to formulate ideas and come to consensus on the importance and feasibility of the thoughts generated by the expert panel. Over three rounds of surveys, participants were asked to develop and rank ideas about how the public health workforce could apply information obtained from the presented analysis of #BlackLivesMatter Twitter data (see Appendices C through E and chapter 3 for further information). Delphi participants were also asked to expand beyond the given #BlackLivesMatter Twitter example to think more broadly about how to encourage the public health workforce to systematically focus on engaging with health-related social movements. Ideas generated in the first survey (Appendix F) were ranked and re-ranked in the second and third survey rounds based on their level of importance and feasibility. Importance was defined as the level of significant value an item had regarding its ability to improve health. Feasibility was defined as the achievability of enacting each item. Items deemed to be of high importance and feasibility should be considered as ideas that could be acted upon by public health workers as they are more likely to be both beneficial and attainable. Items with lower feasibility rankings should be examined further to determine what barriers may keep these ideas from being achieved.

Methods for Acquiring Delphi Study Participants

The Delphi process required participants to complete a series of surveys over a timespan of multiple months. The Delphi technique in this study consisted of three rounds of surveys administered from April through August 2018. In order to get individuals to participate, they need to be invested in the research topic (Goodman, 1987). If participants are more likely to be affected by the outcome of the study, they are more likely to be involved in the process (Hasson, Keeney, & McKenna, 2008). Experts may be more inclined to participate in a Delphi study compared to other studies for several reasons. The Delphi study incentivizes participation by providing experts with an opportunity to learn from consensus building within a diverse but selective group of individuals, and also gives them a chance to express their own opinions and beliefs about a topic that is of interest to them. These incentives should support attracting and retaining experts in this study (Okoli & Pawlowski, 2004).

Since a Delphi study involves selecting experts, non-probability sampling was used (Hasson, Keeney, & McKenna 2000). Response rate is also higher if there is a personal connection (Hasson, Keeney, & McKenna 2000), so this is a benefit of this type of sampling since all participants in this study are public health professionals and chose to participate in this study based on their personal interest in the topic. Representativeness is not assured since sampling is not random. Anonymity is a crucial aspect of a Delphi study, allowing participants to give unbiased answers since they are never face to face with other participants. While contacted individuals were initially asked to give the names and contact information for other individuals they

knew who meet the inclusion criteria and might be interested in participating in the Delphi study, participants were not informed of the identity of other participants.

Public Health Expert Panel Recruitment

Based on the guidelines of Delbecq et al. (1975), a multi-step iterative approach was used to identify experts for participation in the Delphi study. A protocol developed by Okoli & Pawlowski (2004) was adapted for this work which involved using a knowledge resource nomination worksheet (KRNW) for initial panel recruitment. A list of experts from a variety of public health roles was prepared by the researcher including: 1) academicians, 2) theorists, 3) researchers, 4) practitioners, and 5) policy-makers. These names initially came from personal contacts of the researchers involved with this study, all of whom are involved in academic research centering on behavioral and community health. This limited the number of experts who could be identified and introduced the potential for bias in the sampling frame. Each identified expert, before being asked to participate in the study, was also asked to identify others who fit the criteria of the study to broaden the recruitment pool.

In total, 29 individuals were contacted from the original list of names developed through the KRNW (n=18) and names of other potential participants obtained from the contacts on the KRNW (n=11). This method did not yield enough participants, so additionally an email was sent out through HEDIR, the health education directory listserv, which is targeted towards public health education and promotion experts. This listserv has an active community of over 2,000 members

(Kittleston, n.d.). This allowed for a broader range of expert identification and increased participation in this study.

A final list of experts was compiled from the KRNW list, associated contacts, and the HEDIR listserv. Potential participants were contacted via email to participate in this study. Interested individuals from the listserv were asked to reach out to the researcher directly; nine individuals agreed to participate from the listserv posting. Six additional public health expert participants were obtained from convenience sampling of personal contacts and subsequent snowball sampling. Potential experts were excluded if they met any of the following criteria: individual is under age 18, individual is opposed to the idea of health equality for all, individual is lacking basic computer skills (necessary since the surveys were given in an online format), or the individual could not commit to completing all rounds of the study. Exclusion criteria were explained prior to the start of the first survey.

A Delphi study relies not on statistical power but group dynamics, therefore a typical Delphi panel size ranges from 10 to 18 participants (Okoli & Pawlowski, 2004), which was the target for this study. The aim was to recruit more than 10 participants to guard against potential attrition, although participant drop-out rates are generally low in Delphi studies when respondents have verbally assured their participation (Okoli & Pawlowski, 2004). It is understood that with such a sample size results are not representative. Potential panelists were contacted and the study subject and Delphi study procedures were explained. The first questionnaire was sent to study participants on the day they confirmed their willingness to participate in this study (Delbecq et al., 1975). At the start of the study 15 public health experts had

agreed to participate, however only 10 of the 15 completed the first survey. Non-respondents were sent a follow up email. Eighty percent of these panelists completed the second and third surveys.

Conducting the Delphi Study

Round 1.

Once participation was confirmed, each expert received the first of three questionnaires (see Appendix F) via an emailed link to a Qualtrics survey. Qualtrics was used to create and administer all questionnaires in the Delphi study. The development of these questionnaires followed the protocols outlined by Schmidt, Lyytinen, Keil & Cule (2001). The initial questionnaire link was sent via email the day an expert agreed to participate in the study. This was primarily an open-ended questionnaire and served to solicit ideas and identify key issues. Participants were presented with an analyzed data report on a sample of 10,000 tweets using #BlackLivesMatter (see Appendices C through E). The Twitter data analysis report given to participants in the Delphi study included visual images referencing the main findings, an executive summary describing the methods and results of the Twitter data analysis, and a glossary of terms with specific social media and public health jargon explained. This served as an example of the information that can be gleaned from social media regarding the online presence of social movements.

Questions asked of the expert panel pertained to the main research questions of this study, specifically focusing on how the public health workforce can utilize information gleaned from #BlackLivesMatter tweets to aid in addressing the key

health issues emerging from these tweets (see Appendix F). Additionally, participants were asked to contribute suggestions the public health workforce could incorporate to increase engagement with online health-related social movements. Participants were not asked to limit the number of opinions they contributed in order to generate as many unique ideas as possible.

Participants in the Delphi study were asked to complete each questionnaire within two weeks of receiving it, as recommended by in the landmark work by Delbecq at al. (1975) and reiterated by Hsu & Sandford (2007). If a participant did not complete the questionnaire after the two weeks, a reminder email with the Qualtrics survey link was sent urging the participant to complete the questionnaire as soon as possible. A second reminder was sent if the questionnaire had not been completed by the end of the fourth week. If the questionnaire had not been completed within a week after the second reminder, then the response was not included in the analysis. Due to the nature of Delphi studies, if a participant did not complete a survey they were not eligible to complete any subsequent surveys and were removed from the study. The researcher then consolidated the responses from all the individuals. The responses from the first questionnaire were categorized, retaining the original wording of unique responses whenever possible. Some minor editing was done for the sake of clarity and when multiple participants had similar responses.

Round 2.

The second questionnaire included the consolidated list of factors developed from the first questionnaire (see Appendix G). Participants were provided with a list

of the factors created by all of the experts who participated in the first round of the study. A copy of the personal responses from the first questionnaire became part of the second survey. Experts were asked to verify that their original responses were appropriately summarized and were represented in the created categories and to add any additional suggestions for factors they felt were missing from the list. Then they were asked to rank each factor created by the panel in round 1 on 7-point Likert scales on both importance and feasibility (1=not at all important and 7=extremely important and 1=not at all feasible and 7=extremely feasible). The numeric rankings were analyzed to determine the top ranking factors for each criterion.

Round 3.

The items ranked as most important, most feasible and most important, and least feasible in round 2 were reviewed and compiled in the third round based on mean scores. For top importance, items with a mean greater than or equal to 6.0 (on a scale from 1 to 7) were retained. Within these items, those with feasibility means greater than 5.0 were included. Cutoff values were determined by the median values for all items in each scale. Additionally, items with the lowest feasibility scores ($\mu \leq 4.0$) were included regardless of importance ranking. Participants were given a copy of their rankings from round 2 and the central tendencies (mean, median, mode, and standard deviation) for the top factors with high importance, high importance and high feasibility, and low feasibility from the previous round. Participants were asked to re-rank this finalized list of factors again using a 7-point Likert scale ranking items based on their importance and feasibility. Participants were also asked to list first actionable steps (for items of high importance and high feasibility) or major barriers

to overcome (for items ranked with low feasibility). Participants were offered the opportunity to be given updates as the research progressed.

Analysis of Delphi Study Results

Each participant independently completed the surveys using Qualtrics. While surveys were taken individually, participants were able to view their responses as well as the central tendencies of all participant responses for each item included in the previous round. All qualitative Delphi study data was organized using Microsoft Excel to generate tables for participant responses. Data from the first round of the Delphi study was primarily qualitative and was analyzed using content analysis techniques congruent with previous Delphi studies (Hasson, Keeney, & McKenna, 2000; Kalaian & Kasim, 2012). Content was coded by item topic, and similar items were grouped together. While different terms may have been used by participants, if the items reflected the same sentiment the researcher grouped these items together (Hassan et al., 2008). The original wording used by participants was retained whenever possible. All generated items were retained in the analysis, even those that were mentioned infrequently.

It was considered the job of the Delphi study participants, not the researcher, to form consensus about the quality of each idea (Hassan et al., 2008). Longer participant narratives given in round one were structured and summarized into a one-sentence description for each item. During the second round all items generated in round 1 were ranked on 7-point Likert scales for importance and feasibility. Participants were also given the opportunity to comment on the newly worded items

and to make changes if they felt their original ideas were not accurately represented, or if they generated new ideas to add them.

In rounds 2 and 3, participants were asked to rate each of the items generated in round 1. The goal of the subsequent questionnaires was to determine respondents' views on the importance and feasibility of the items and to develop a convergence of ideas eventually leading to a consensus. Participants were asked to rank the ideas generated in the initial rounds based on their importance and feasibility using Likert scales. On the 7-point Likert scales response options ranged from 1=not at all important to 7=extremely important and 1=not at all feasible to 7=extremely feasible. Using two distinct criteria allowed for a more thorough understanding of the experts' views on each item; an item might be seen as important while simultaneously not very feasible, therefore it was worthwhile to have experts rank items using both of these measures.

Quantitative data was analyzed using Microsoft Excel and SPSS version 25. Statistical summaries for each of the rated items were calculated including central tendencies (mean, median, and mode) and the standard deviation and range for each round (Hasson, Keeney, & McKenna, 2000). In round 3, participants were provided with a table listing each item from the previous round with the central tendencies as well as their personal rankings. This allowed participants to more clearly understand their individual ratings in relation to the ratings from the rest of the group for each item.

A priority component in the Delphi technique is the requirement that participants must reach a consensus. The definition of consensus is open to interpretation (Hsu, Chia-Chien & Sandford, 2007) and a variety of analysis techniques have been used in previous Delphi studies (Van der Gracht, 2012; Kalaian & Kasim, 2012). While coefficient of variation or a paired t-test may be used to determine consensus (Shah & Kalaian, 2009; Yang, 2003), in this study there were fewer than 30 respondents, and additionally data were not normally distributed, therefore nonparametric tests were used to determine if consensus had been reached.

Two measures of consensus were used in this study. First, in order to determine if responses for each item had changed from round 2 to round 3, Wilcoxon's Paired Signed Rank Test was used in place of a paired t-test. This test shows if the item rankings from round 2 were significantly different from round 3. If items were not significantly different by round, it could be said the participants had reached consensus (Van der Gracht, 2012; Kalaian & Kasim, 2012). As in many other studies, consensus on a topic can also be decided if a certain percentage of the ratings fall within a predetermined range (Miller, 2006; Hsu & Sandford, 2007).

A commonly used measure of consensus was developed by Ulschak (1983) stating that consensus is reached when 80% of participants' votes fall within two categories on a 7-point Likert scale. For this study, the percent of participants' votes that fell within two categories on each 7-point Likert scale were calculated for each item at each round. Consensus was deemed to have been met when 75% of participants' votes fell within two categories on a 7-point Likert scale. Seventy-five percent was used instead of 80% due to a small sample size. For some items,

consensus was achieved after the second round. If these items were ranked as most important, most important and most feasible, or least feasible, these items were still included in the subsequent round in order to determine if there was a change in the stability of consensus between rounds.

Findings

Round 1

In round 1 of the study, 10 participants completed the survey. Eight of these participants completed rounds 2 and 3 (80% retention rate). While lower than desired, the number of participants is still adequate to obtain sufficient information (Okoli & Pawlowski, 2004). Round 1 had 7 female and 3 male participants. Participants were asked to indicate their ages in six separate categories: 18-25, 26-35, 36-45, 46-55, 56-65, and 65+. Participants ranged in age with 1 participant age 26-35, 4 participants age 36-45, 2 participants age 46-55, and 3 participants age 56-65. No participants were between ages 18-25 or above age 65. Public health educators were targeted for this study given this research was trying to understand how to motivate and engage public health workers. Educators are involved in the training of future public health workers and therefore are qualified to answer these questions. Eighty percent of participants were directly involved with public health education. The remaining 20% had extensive experience working in public health and while not currently involved in public health education, had previous experience with it through their own education or time spent teaching in academia.

While basic computer skills were required for participants to complete the surveys, participants did not need to have any expertise in social media use, personally or professionally. In the first round of this study participants were presented with an infographic of results from an analysis of 10,000 tweets using #BlackLivesMatter (see Appendix C) as well as an executive summary of that study (see Appendix D), an overview of a tweet and its components (see Appendix E) and a glossary of social media and twitter-related terms (see Appendix A).

Four participating public health experts were not Twitter users (40%), while 2 used Twitter less than once a month (20%), 2 several times per month (20%), and 2 were frequent users, on Twitter multiple times a day (20%). Of the six participants who used Twitter, 50% used it professionally and 50% used it personally. Three of the participants had previously read research utilizing Twitter data, and two of those three had found it useful in their own work. Those who found Twitter useful to their work used it in a variety of ways including helping them to understand others and their opinions, keeping up to date on current events, and gathering new ideas.

When asked about their knowledge of the Black Lives Matter movement, 100% of participants had heard of the movement. All had heard of BLM in the news, about 70% had also learned about it through social media. One participant had read about BLM through a professional paper or newsletter in public health. While only one panelist claimed to have expertise on the BLM movement, all participants shared what they knew about it during round 1. Most people thought of BLM as a movement against police brutality and the unjust death of Black people (60%) and believed those involved in the movement were campaigning against violence (50%). This is true, but

does not encompass all that the BLM movement is fighting for (Cullors et. al, 2016), however this is what is most commonly expressed by mainstream media (Hobson, 2016).

When asked about awareness of other social movements with an online presence, 80% of participants were able to name one or more additional movements. Collectively participants were able to identify 12 additional movements/sub-movements, including three associated hashtags (#metoo, #sayhername, and #resist). When asked if online social movements have any impact on public health or public health practitioners, 90% agreed they do. Participants listed five distinct ways public health is impacted, including: 1) raising awareness of social justice issues, 2) building research on evidence-based practice, 3) increasing thoughts of how to fight oppression in professional work, 4) helping stop potential health threats, and 5) creating future public health implications.

Sixty percent of participants believed they had already seen public health workers engage with online social movements in their official capacity, however when asked to detail the engagement, most responses were vague on the interactions between members of social movements and public health workers or did not necessarily involve any direct engagement with social movements at all (such as educating the public about vaccines or professional groups discussing the importance of issues also relevant to social movements).

When examining the executive summary of the tweet analysis using #BlackLivesMatter (see Appendices C through E), participants were asked what data

from this analysis they felt would be useful for examining social movements, including the Black Lives Matter movement, from a public health standpoint. Responses varied, but overall a large amount of the executive summary tweet analysis was deemed useful by multiple participants. Specifically, participants felt useful components included analyzing a large number of tweets, top themes, emotional tone, clout (confidence in the message wording), health-related terms, and hashtags. When asked how helpful the presented information could be to professionals in public health on a 7-point Likert scale (1=not helpful at all, 7= incredibly helpful), the mean was 5.3 (range 4-7, median=5, mode=5). Asking participants to identify how this information could be used by public health workers also generated a wide range of responses (see Table 8).

Table 8. How public health workers could use social media data from social movements, gathered from round 1 of Delphi study.

Improve understanding about ways to reach people with messages
Engage people in getting involved with social movements
Start conversations about sources of information and how perspectives can influence points of view about health and health disparities
Gain better understanding about the issues that are important to people, especially people who are working for social change
Understand the clout these messages hold to determine what messages are most influential
Examine the demographics of the population involved with the online presence of the social movements
Monitor emerging concerns in a group or area to pick up early warning signs and increase preparedness efforts for at-risk, vulnerable populations
Monitor the volume of discussion of different topics
Create awareness of public health issues
Direct research areas and resources
Examine health-related words to determine how the social movement relates to public health

Most of these ideas centered on starting conversations with community members, increasing awareness of topics related to public health and social movements, and monitoring and analyzing the online conversations of social movements to understand concerns related to public health. In general, participants felt that the Black Lives Matter movement would benefit from assistance by the public health workforce ($\mu=6$ on 7-point Likert scale where 1=would not benefit at all to 7=would greatly benefit; median=6.5, mode=7).

To better understand perceived acceptance of social media data analysis in public health work, participants were asked to rank the current level of acceptance of public health use of social media data regarding online social movements. The current acceptance level was rated a mean of 4.3 out of 7 (1=not at all accepting and 7=very accepting; median=4, mode=4, range 3:7). Participants were also asked to rate their perceived level of acceptance in the near future ($\mu= 4.8$, median=5, mode=5.)

When asked the best methods for engaging the public health workforce to utilize social media data for online social movements, a number of ideas were generated. These ideas ranged from educating and training public health workers and community members on its usefulness to conducting and publishing more research using social media data. Participants also developed suggestions for other ways (aside from social media) public health workers could engage with social movements. These ideas focused on increasing awareness and education within the public health workforce regarding the relevance of social movements to public health.

Rounds 2 & 3

The final two rounds of the Delphi study contained responses from 8 of the 10 participants in round 1. The majority of participants were between 36-45 years old, including 6 females and 2 males, and nearly all were involved in public health education (7 of 8), mostly through academia (5 of 8). From round 1 of the survey, ideas for each question were listed, and similar ideas were combined. Whenever possible, the original wording of the participants was maintained. Thirty-nine items generated in round 1 were included in round 2, and were divided into 7 questions based on theme. Additionally, participants were asked to add any additional ideas generated for any of the questions, or to clarify if they wished for any of the items to be revised.

Participants were asked to rank each item presented on 7-point Likert scales based on importance and feasibility (where 1=not at all important and 7=extremely important and 1=not at all feasible and 7=extremely feasible). Along with the survey, participants were given a copy of their personal responses to each of the seven questions from round 1.

From the rating results, the items with the highest average ratings for importance (>6.0), highest importance and highest feasibility (importance >6.0 and feasibility >5.0), and lowest feasibility (≤ 4.0) were selected for inclusion in round 3 of the survey. The items included in round 3 are shown in Table 9 with the mean ratings from round 2 and round 3. The Wilcoxon Paired Signed-Rank Test was used to compare the ratings for each item from round 2 and round 3 to determine if consensus had been reached between rounds (see Table 9). Additionally, within each

round consensus was determined if an item had 75% of responses within 2 points on the 7-point Likert scale that was used to rank each item.

Table 9. Rankings of items with highest importance, high importance and high feasibility, and lowest feasibility from round 2 and round 3.

	Round 2 Average	Round 3 Average	Round 2 Standard Deviation	Round 3 Standard Deviation
Items with highest importance rankings				
<u>Importance</u> of the potential long-term impacts of public health working with social movement to raise awareness of and attract attention to existing and underrepresented health-related issues**	6.00	6.13	1.20	0.99
<u>Importance</u> of the potential long-term impacts of public health working with social movement to increase research and evidence-based practice of neglected health-related issues	6.25	5.88	1.16	1.13
<u>Importance</u> of the potential long-term impacts of public health working with social movement to broaden the discipline of public health to include a wider definition of public health issues	6.00	5.50	1.20	1.60
<u>Importance</u> of addressing the lack of validated social media analytic tools for public health work	6.00	5.50	1.77	1.69
<u>Importance</u> of addressing the lack of measurable outcomes relating to health behaviors from use of social media data	6.00	4.88	1.41	1.73
<u>Importance</u> of addressing the barrier of peers in public health not viewing social media as a legitimate data source for in-depth analysis	6.00	5.25	1.41	1.39

	Round 2 Average	Round 3 Average	Round 2 Standard Deviation	Round 3 Standard Deviation
<u>Importance</u> of the following ideas to encourage the public health workforce to engage with social movements by increasing available funding for public health work with community members and social activists	6.38	5.75	0.74	1.39
Items with high importance and high feasibility rankings				
<u>Importance</u> of the potential long-term impacts of public health working with social movement by increasing the general public's understanding of public health's mission to achieve social justice*	6.00	5.38	1.69	1.60
<u>Feasibility</u> of the potential long-term impacts of public health working with social movement by increasing the general public's understanding of public health's mission to achieve social justice**	6.13	4.25	0.99	1.58
<u>Importance</u> of the following for public health workers to engage with online social movement by facilitating listening sessions with community members and social movement activists to address health concerns through community-based participatory research and interventions**	6.25	6.38	0.89	1.19
<u>Feasibility</u> of the following for public health workers to engage with online social movement by facilitating listening sessions with community members and social movement activists to address health concerns through community-based participatory research and interventions**	5.63	6.13	1.30	1.13

	Round 2 Average	Round 3 Average	Round 2 Standard Deviation	Round 3 Standard Deviation
<u>Importance</u> of public health workers using an analysis of twitter data from social movements to help frame the messages of social movements as public health issues in media campaigns, including social media	6.38	6.00	0.74	0.76
<u>Feasibility</u> of public health workers using an analysis of twitter data from social movements to help frame the messages of social movements as public health issues in media campaigns, including social media**	5.50	6.25	1.31	0.46
<u>Importance</u> of addressing the lack of a qualified public health workforce with necessary skill sets to use and analyze social media information appropriately**	6.13	5.88	0.64	0.99
<u>Feasibility</u> of addressing the lack of a qualified public health workforce with necessary skill sets to use and analyze social media information appropriately	5.13	5.88	1.36	0.99
Items with lowest feasibility rankings				
<u>Feasibility</u> of the potential long-term impacts of public health working with social movements to increase research and evidence-based practice of neglected health-related issues**	4.00	4.50	1.85	0.76
<u>Feasibility</u> of devoting research to follow up on the impact of social media data analysis, then promote the findings as a way to engage the public health workforce with social media data	4.00	3.88	1.85	1.64
<u>Feasibility</u> of addressing the lack of measurable outcomes relating to health behavior from use of social media data by the public health workforce	3.75	2.88	2.31	1.55

	Round 2 Average	Round 3 Average	Round 2 Standard Deviation	Round 3 Standard Deviation
<u>Feasibility</u> of addressing the bias in self-reported social media data; not knowing who sent the information and if the content is accurate	3.25	3.88	2.25	2.10
<u>Feasibility</u> of addressing the barrier of peers in public health not viewing social media as a legitimate data source for in-depth analysis	3.50	4.38	2.27	1.92
<u>Feasibility</u> of ensuring workers job security when advocating for social movements relating to health in their professional capacity, regardless of politics	3.88	3.13	2.10	1.96

*Note: Only item to have a significant difference between round 2 and round 3 based on Wilcoxon Signed Rank Test ($Z=-2.555$, $p=0.011$)

**Note: Consensus met with at least 75% of responses within 2 points on 7-point Likert scale in round 3 responses

Looking at consensus within round 3, one of the seven “most important” factors reached consensus (87.5%). This question asked about the importance of potential long-term impacts of public health working with social movements to raise awareness of and attract attention to existing and underrepresented health-related issues. This question also had the highest mean (6.125) of any question ranked for importance. Five of the eight items with high importance and high feasibility achieved 75% consensus or higher when ranked for feasibility. These 5 questions also had the highest means for feasibility of all questions. One of these questions “using an analysis of twitter data from social movements to help frame the messages of social movements as public health issues in media campaigns, including social

media” had 100% consensus. Six questions with the lowest feasibility scores in round 2 were re-ranked in round 3. In round 3, one of the six questions had a consensus of 87.5% (regarding potential long-term impacts of public health working with social movements to increase research and evidence-based practice of neglected health-related issues). This question also had the highest mean for feasibility in this category and the lowest standard deviation ($\sigma=0.76$). This question was also seen before as one where consensus was reached on its high importance.

In round 3, all items had lower standard deviations in ratings compared to round 2. The Wilcoxon paired test revealed that between round 2 and round 3, all items except one did not differ significantly in their ratings (see Table 9), suggesting that responses are unlikely to converge further and no further rounds should be conducted. Only one item, “importance of the potential long-term impacts of public health working with social movement by increasing the general public's understanding of public health's mission to achieve social justice” significantly differed between rounds 2 and 3 ($Z=-2.555$, $p=0.011$) but this alone did not warrant another Delphi round.

Discussion

This study used the Delphi technique to generate ideas from a panel of public health experts regarding how social media data could be useful to engage public health workers with social movements, including the Black Lives Matter movement. While social media data have been used in a variety of ways, the public health community has not used social media data to understand social movements. Today’s

social movements are often related to public health and both share similar goals of reducing inequalities and improving well-being for marginalized groups. In this study, multiple ideas were generated regarding the utilization of social media data in public health. Additionally, information was gleaned regarding the need for public health workers to become more involved with social movements using both online and on-the-ground practices.

In round 1 of the Delphi study, 90% of participants felt public health and public health workers were impacted by online social movements. One participant did not feel that there was any impact due to lack of involvement of public health practitioners with social media and with social movements. The vast majority of survey participants believe that online social movements do impact public health, yet it is unclear if their perceptions of the connection between these groups go much beyond helping to raise awareness of the existing inequities. One-third of those who said social movements impact public health listed awareness as their main impact on public health.

Sixty percent of participants believed that they had already seen public health workers engage with online social movements in their official capacity, noting the objectives of public health aligned with social movements and that public health workers were advocating for communities by providing education for health-related topics such as vaccines and emergency preparedness. Yet many struggled to provide specific examples. Of those who did, one participant noted the CDC Director posts tweets about public health issues, and another noted APHA and other public health professional groups have published statements and articles discussing the BLM

movement. While these responses show a commitment of public health workers to social justice, none of these show actual engagement with the social movements themselves or to connections with the activists who organize and maintain them. Future studies should emphasize direct methods of engagement for public health workers with social movements in addition to indirect methods, such as showing commitment to social movement issues through public health conferences and publications, which were more common responses here.

In general, participants knew about major aspects of the Black Lives Matter movement highlighted by mainstream media, but they did not know many specifics about how the movement was started or all that it encompasses. The majority (80%) of participants were able to name other recent social movements with an online presence such as Occupy Wallstreet, the Women's March, the March for Our Lives, and more, which shows these movements are reaching the general public through social media and other means. A limitation of this study is that not many participants used twitter regularly, and therefore results may not be representative of younger public health practitioners who may be more likely to be Twitter users. Yet lack of Twitter use is also beneficial to this study because we need to get people in public health on board with social media data analytics who aren't currently familiar with these techniques. Participants, even though not avid users themselves, still had valuable insight on how to reach the public health workforce that is not actively engaged with social media in a personal or professional manner.

Results from rounds 2 and 3 demonstrate there are significant barriers to this work (overall feasibility scores were lower than importance scores for all items).

Determining what these barriers are and how to overcome them should be the subject of future research. Despite the barriers, this work does have value, given that many items received high scores for importance. Participants were not likely to change their responses given another round based on Wilcoxon Paired Signed-Rank Test (see Table 9), yet there were wide ranges in responses within each round indicating there are a range of ideas on the importance and feasibility of the items in this survey.

Not all items were viewed as extremely important, but many were. Three items ranked over 6.0 for importance in both rounds 2 and 3. The first of these items involved the potential for long-term impacts of working with social movements to raise awareness about current under-represented public health issues. While this was considered important, it was also given a lower feasibility score. This lower feasibility could be due to higher perceived barriers by participants.

The other two items with importance rankings over 6.0 for rounds 2 and 3 (facilitating listening sessions with members of social movements to understand current health issues and using an analysis of twitter data from social movements to help frame the messages of social movements as public health issues in media campaigns, including social media) had high feasibility rankings as well. This may indicate these items are a good starting point for future work in this area.

Truly, all of the items that ranked highest for importance and feasibility should be examined further for their potential as actionable steps to improve the public health workforce's interactions with social movements and work with social media regarding these movements. While there are likely still barriers to adoption of

these items by the majority of the public health workforce, it is more likely that changes in these areas will be successful given that they are viewed as both important and feasible. Future work should consider examining the adoption of these practices by public health workers through the Diffusion of Innovation theory (Glanz, 2008). Therefore, these are the areas where future researchers may want to concentrate their efforts.

Limitations and Future Recommendations

This was a preliminary study. The size of this study was large enough to use the Delphi technique; however, future research should be conducted with a larger sample of experts to examine actionable steps more closely. Using convenience and snowball sampling creates sampling bias as the sample is not representative of the overall population.

Another limitation is the lack of diversity of participants. While the intent was for panelists to represent a more diverse sample of careers in public health, the sample was skewed towards those in academia due to utilizing an education-focused listserv for recruitment. The sample population may also be a reflection of who prioritizes completing multiple rounds of surveys—a time-consuming participant burden. Yet the vast majority of participants are involved with public health education, and this is the group that should be making recommendations on how to engage the public health workforce and develop training tools to educate current and future workers in public health. It was important to recruit individuals who were passionate about the topic of the Delphi study.

If participants are more likely to be affected by the outcome of the study, they are more likely to be involved in the process (Hasson, Keeney, & McKenna, 2008); however, this means the Delphi study process is subject to both researcher and subject bias. This is a noted limitation of this study. Additionally, this study is limited to the perspective of public health experts. In order to effectively engage with social movements, individuals who are involved with the functioning of these movements should be part of this research to ensure solutions developed will benefit from and be accepted by both parties rather than the implementation of interventions developed by public health professionals alone. Therefore future research should involve both public health experts and social activists to ensure the construction of collaborative partnerships.

Chapter 5: STUDY 3: Social Activist Experiences with Academic Research and Public Health: A Qualitative Study on How to Involve the Public Health Workforce in Social Movements

Abstract

Qualitative one-on-one interviews with social activists from a variety of social movements were conducted to determine activists' perceptions regarding public health engagement with social movements and to better understand the role of social media in activist communication. Many current social movements share similar goals with the field of public health, including improving the health and well-being of all people by eliminating health disparities prevalent in marginalized groups. It is therefore logical that public health workers should become more engaged with health-related social movements. In order to determine if this relationship would be beneficial or welcome, it was crucial to listen and learn from social activists themselves. Nine interviews were conducted and findings, while not generalizable to the overall activist population, indicate a lack of current involvement from public health professionals with certain social movements as well as willingness and desire for those involved with social movements to collaborate with public health workers.

on research. Barriers to such relationships, including distrust, were discussed along with solutions to generate positive connections between these groups. This study provides preliminary findings, which indicate a need for more research in this area.

Introduction

The field of public health at its core revolves around improving health for all. This is shown through the vision of *Healthy People 2020* as well as Goal 10 of the Sustainable Development Goals which both aim to eliminate health inequalities and inequities (DHHS, 2017; United Nations, 2015). Social justice and equity are main tenets of public health as well (Institute of Medicine, 1988). In 1978, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research issued the Belmont Report, written as guidelines for ethical research, which calls for researchers to ensure respect for persons, beneficence, and justice in their work.

Public health is described as a field which “promotes and protects the health of people and the communities where they live, learn, work, and play” (APHA, 2017). In order to accomplish this, individuals involved in the field of public health must actively engage in social justice work aimed at increasing health promotion and protection for all. Unfortunately, health inequities exist and combatting these issues is often a political battle. This does not mean objective research cannot be conducted on these topics (Beland & Cox, 2010), but rather researchers, along with other professionals within the public health workforce must advocate for the health of disadvantaged people and communities despite the political nature of these issues.

While some movements, such as the environmental justice movement and women's rights movement are considered as health social movements and receive research, funding, and attention from the field of public health (Brown & Zavestoski, 2004), there are numerous other health-related social movements, such as the Black Lives Matter movement, which still lack collaboration from public health (Garcia & Sharif, 2015). This study explores social activists' perceptions of academic research and public health practitioner involvement in social movements, as well as potential barriers and solutions to such a relationship.

It has been proposed that public health should become more involved with the issues addressed by current social movements (García & Sharif, 2015). This makes sense given one of the core tenets of public health is social justice (Institute of Medicine, 1988; Krieger & Birn, 1998). Today's social movements focus on eliminating inequalities and improving the well-being of marginalized groups (Smelser, Turner, & Killian, 2018). Similarly, public health aims to eliminate health inequities and promote social justice (Institute of Medicine, 1988). Yet in order to understand how public health practitioners should engage with these social movements to support their common missions and goals, it is crucial to discuss this with the social activists who are currently involved in these social movements.

Social movements today are different than those of the past in that they are now making full use of the internet to grow their membership, organize and plan events, advocate for policy and systemic change, and disseminate information (Walsh, 2012; Brown et al., 2004; Buechler, 1995). Social media provides online platforms for individuals and organizations to share information with few barriers to

social exchange (Marken, 2007). This makes social media a useful tool for social movements to attract large numbers of people to rally for their causes (Hwang & Kim, 2015). Higher rates of social media use have been associated with higher intention to participate in social movements (Hwang & Kim, 2015). Information was acquired from social activists regarding their use of social media, specifically for activism-related purposes.

Social movements are intrinsically related to social change (Killian et al., 2013). Historically, social movements have played a part in improving the health of the public (Brown & Fee, 2014). This form of collective organizing is responsible for advancing policy changes ranging from ensuring workers safety via the workers' rights movement in the early 1900s to improving environmental health such as clean air and water through the environmental movement starting in the 1960s (Brown & Zavestoski, 2004; Brown et al., 2004; Bulland & Johnson, 2000). While spanning a wide range of topics, all these movements have a commonality of aiming to improve the lives of people, thus directly relating to their health. Yet social movements have rarely been studied by public health professionals. There are several notable exceptions including the environmental justice movement, the women's rights movement, and the AIDS movement –all of which had direct and obvious links to health (Brown & Zavestoski, 2004; Brown et al., 2004). Other social movements, such as the Black Lives Matter movement and the March for Our Lives campaign, are also related to health but have seen less attention from public health in terms of research, funding, and engagement (Garcia & Sharif, 2015).

In recent decades there has been an increased focus on examining public health issues from a social-ecological perspective which involves examining behavior as a result of multiple levels of factors ranging from intrapersonal to community level (McLeroy, Bibeau, Steckler, & Glanz, 1988). Use of the social ecological model has increased due to a shift from focusing on the individual to collective behavior (Lewis et al., 2002); behavior is determined by multiple social determinants of health (McLeroy et al., 1988). Social, economic, cultural, and political factors influence individual behavior and therefore must be taken into account (Glanz et al., 2008). Organizations, especially those that promote social movements, are adept at raising awareness of social norms and values that can have significant effects on the health of their members (McLeroy et al., 1988).

The levels comprising the social ecological model all play a role in social movements; Social Movement Impact Theory; states the four main ways social movements affect society are by creating: 1) individual change, 2) institutional change, 3) cultural change, and 4) political change (McAdam et al., 1996). Social movements have been shown to effect change on multiple system levels (Amenta et al., 2010). Given that social movements operate on multiple levels, the public health community needs to construct active solutions to the persistent issues of health inequities at the individual, institutional, and societal levels as well.

Community-based participatory research (CBPR) as a framework centers on community participation in community-engaged research. Entwined with the social ecological model, CBPR improves the health of communities through multilevel action, including individual, group, community, policy, and social change (Rhodes,

Malow, & Jolly, 2010). CBPR is now often used to study and address social issues, including social movements (Minkler, Vasquez, Tajik, & Petersen, 2008). This framework aligns with the efforts of community-university partnerships, working collaboratively to end health disparities and improve healthy policies (Brugge & Hynes, 2005; CCPH, 2013; Belone et al., 2014). To effectively address issues highlighted by social movements, it is imperative to consider the voices of the individuals involved.

This conversation also needs to extend beyond simply recognizing the structural systems creating and enforcing these health inequities to also addressing ways to directly involve the public health workforce with emerging health-related social movements aiming to deconstruct these systems. By engaging more closely with social movements, public health practitioners can leverage these relationships to increase the efficiency and effectiveness of positive change at each of these levels. Questions posed in these activist interviews address the role that the individual activists hold, along with their role within the organization of the social movement. Areas for public health engagement are identified both at the individual and organizational levels.

While public health workers need to be trained to more effectively engage with social movements, it is important to understand how these public health workers could best be utilized in existing social movements. Similarly, a component of Critical Race Theory (CRT), “centering in the margins,” expresses the importance of focusing on the perspectives of the individuals belonging to marginalized groups rather than the experiences and perspectives of the dominant race or culture. Guided

by this component of CRT, it was imperative to talk with social activists who are part of social movement rather than solely relying on academic researchers and public health workers to determine how best to become involved with social movements.

Methods

Study Design

Social activists were interviewed to increase understanding of how appropriate relationships between social activists and public health professionals can be formed, in what capacity public health workers are needed in social movements, and what barriers might be faced in promoting this potential partnership. Further, activists were interviewed to add their perspectives on how social media influences the social movements they are a part of, and also to gain insight on how the public health workforce could support the activists, organizations, and social movements in their shared goal to achieve social justice. Individual interviews are an important tool to gather more in-depth qualitative information that may not be obtained through other quantitative methods of data collection, such as surveys or questionnaires (Dey, 2003; Lincoln & Guba, 1985). In order to understand the context and complexity of these topics and to preserve the richness of participant responses, this study required a different format than quantitative design could provide. A qualitative approach was used to gain in-depth knowledge from these social activists.

One-on-one interviews were conducted so that each participant would have the time needed to share their personal stories and involvement with activism, and this allowed the researcher to probe further into different aspects of their experience.

Interviews were conducted during August and September 2018. Due to participant preference and feasibility, some were conducted in person (n=2), while others were conducted by phone (n=7). Individual studies have shown conflicting results on the influence of in-person interviews versus phone interviews with no consensus on significant differences in results between these qualitative methods (Novick, 2008; Knox & Burkard, 2009). A total of nine social activists were interviewed. The University of Maryland Institutional Review Board approved all procedures prior to conducting these interviews. Written informed consent was obtained for in-person interviews and verbal consent was given for phone interviews; participants in phone interviews also received an electronic copy of the consent form via email or Facebook messenger that could be downloaded. Interview length ranged from 28 to 71 minutes.

During these interviews participants were asked a variety of questions broken down into four main sections: 1) experience with activism and social movements, 2) social media use in relation to activism, 3) experience with academia and the perceived value of academic research, and 4) knowledge of public health and the potential usefulness of this field within social movements (see Appendix I for a copy of the interview guide).

The first set of questions revolved around the topic of activism and allowed for an in-depth look at the participants' views on activism and the role they play in social movements. Then questions focused on social media, specifically participants' use of social media for information transmission purposes within their social justice causes. They were also asked if they viewed their advocacy causes as online social movements. Questions then led to participants' interactions with academicians and

researchers, focusing on their knowledge of any research, currently in process or completed, in conjunction with the social movements and organizations working for the social justice causes with which they are involved. Finally, participants were asked about their knowledge of public health, and when given APHA's definition of public health participants were asked if this definition seemed applicable to their respective social movements. Participants then gave examples of where and how they believed the public health workforce should become more involved in social movements and gave advice on how these interactions could be achieved.

Interview Participant Recruitment

Interview participants were recruited through a variety of means. Initially, this study aimed to recruit activists solely from the Black Lives Matter movement. All 38 current chapters of Black Lives Matter were contacted through email or Facebook. Due to recruitment issues, social activists involved with any nationally-recognized social movement were permitted to participate. This broadened recruitment methods; messages were also sent to five online activist-related Meetup groups through the Meetup application and Facebook posts were shared publicly to recruit any activists within the researcher's extended social network. In response to the Facebook posts, five activists contacted the researcher. Additional activists were recruited through the researcher's social network through convenience sampling.

After each interview, participants were asked if they knew of other activists who would be willing to participate. Many interviewees provided the researcher with additional sources, thus allowing for snowball sampling to occur. While these

recruitment methods are subject to bias, a wide array of voices and opinions were gathered for this qualitative work. It is difficult to reach the activist population without prior connections, therefore these were necessary recruitment methods (Shaghghi, Bhopal, & Sheikh, 2011). Participants who agreed to participate had to meet certain inclusion criteria; participants had to be at least 18 years of age, self-identify as a social activist, and be involved (currently or in the past) with at least one identifiable social movement.

The Data Producing Sample

Interviews were completed with nine social activists. Seven participants identified as female and two as male (see Table 10). Five participants (56%) described themselves as a person of color. All participants had at least some college education, with three holding advanced degrees. In this study participants will be referred to by an identification code, SA1 through SA9 (SA=social activist). All potentially identifying information has been removed to preserve confidentiality.

Table 10. Description of social activists interviewed.

Social Activist ID	Gender	Race/Ethnicity	Education Level	Age Range	Main Advocacy Causes
SA1	female	POC	college	18-25	immigrant rights, education
SA2	male	White	college	46-55	LGBTQ rights, education, voter's rights
SA3	male	White	advanced degree	56+	civil rights, worker's rights
SA4	female	White	some college	56+	women's rights, voter's rights, anti-war activism
SA5	female	POC	college	26-35	Black rights, women's rights, education
SA6	female	White	advanced degree	56+	women's rights, education
SA7	female	POC	some college	26-35	Black rights, drug and alcohol recovery, LGBTQ+ rights
SA8	female	POC/Hispanic	advanced degree	36-45	immigrant rights, Latino rights
SA9	female	POC	some college	36-45	Black rights, worker's rights

*POC=Person of color

Interview Analysis Procedures

Interviews were conducted in-person or over the phone based on participant location and preference between August and September 2018. Participants were given a copy of the consent form (hard copy for in-person interviews and downloadable electronic copy for phone interviews), which was reviewed prior to the start of the interview. All interviews were conducted by the researcher and were recorded with

participant permission. Interviews lasted between 28 and 71 minutes. The interviewer followed a semi-structured interview guide (see Appendix I). Interviews were then transcribed using Google voice technology and were corrected for inaccuracies by the researcher. Transcripts were then analyzed using NVivo software.

Data were analyzed using a grounded theory approach to explore the themes emerging from the interviews without predefined categories or assumptions. Queries were run to determine the most frequently used words in the interviews to assist with developing themes for the content. Then the researcher inductively coded each interview, and themes or “nodes” were created as they emerged. Interviews were then reviewed a second time and re-coded once all nodes had been created and adjusted using constant comparison by reviewing all the data and changing and re-categorizing nodes based on the emergence of additional patterns and categories. Peer debriefing (Lincoln & Guba, 1985) was conducted multiple times during the analysis of interview data with colleagues unfamiliar with the study to aid in conceptualizing logical themes.

Findings

Importance of Data and Facts

Many activists felt that research on topics concerning their social movements would be incredibly beneficial. All activists were decidedly strong proponents of spreading truth through facts and data. Several interviewees noted that while research and data are necessary to make changes, especially at the policy level, that may not be enough to change opinions.

You can't just have antidotes, you have to have numbers to back up what you're saying. So I think that's very important in social movements.” (SA2)

“I think that research and studies are really important because...it makes something more than just an opinion. I can say I feel like that or I feel like this, but when you have a study or a survey or research you can say okay through our research we found XYZ. And that makes it more valid. I think it is vital.”(SA9)

“It's obvious that more research needs to be done with everything that's happening.” (SA3)

“...they [social movements] need people pushing fact-based data” (SA4)

Additionally, activists were very adamant about ensuring the information they spread to others was factual.

“Sometimes I get very skeptical about what I see in articles and things like that so I definitely have to fact-check myself and others to make sure that I'm not spreading anything that isn't correct.” (SA5)

Education.

Along these same lines, education was clearly important to many of the activists. All nine activists had at least some college education, with several earning an advanced degree. Degrees aside, the value of education seemed to stem not from a formal classroom setting, but from learning about current events and the world around them.

“So formal education but also...just being intrigued by something and wanting to learn about it. And I'm always still learning.” (SA9)

All activists interviewed valued education quite highly, which aligns with their beliefs that research is crucial to the success of achieving the goals of social movements and the importance of conducting factual un-biased research. Many spent hours each day reading up on current events and policies to arm themselves with knowledge to better their causes.

Lack of Academic Research on Social Movements

While interviewees felt research about social movements would be valuable for the furthering of goals of the movements, very few activists knew of any research studies occurring, past or present, directly involving social movements or the people who comprise them. One activist named polls as a form of research being conducted at protests and rallies, and two others listed nearby universities that had some level of involvement with their social justice causes. None of the activists interviewed had ever been part of academic research themselves or could concretely say that they knew of any studies that had taken place with local activists.

It was noted that conducting traditional research might be especially difficult with social movements.

I'm not sure there's that much research going on because I think that a movement in process it's just like a flowing river and it's difficult to attach necessary assessment devices to a river. Of course I think the only way you could do any type of research is in the fashion that you are doing it, which

is talking to people. Because otherwise, I just can't imagine sending out surveys for example, or doing some sort of testing format or whatever. I just find it would be too hard to grab it. (SA3)

Yet activists made it clear that more research on social movements and also conducted with active participants in these social movements would be beneficial.

I think we've never really studied how they [social movements] work or don't work. We've studied how businesses work, how social services work, economics, but advocating for change has never really been studied. So there are no pathways, there are no methods. It's just 'okay let's get together and try to make change!' So I think that's fine, except if you have a science of something and models to replicate it then you have a better chance of success and you have less movements that are selling t-shirts and more of those who are actively trying to make change. So you need to make some models. Because it's not a business model, it's not an econ model, and it's not a social service model. There are no models to follow, you just get people together to talk and say 'how do we make this work?' Which is why so many of them fail. So many of them become nothing. (SA3)

Even though research on the study of social movements has been conducted for decades (Touraine, 1985; Zald, 2017), the results of those studies may not be reaching the populations studied; interviewed participants did not mention knowledge of existing research in this field.

Public Health in Social Movements

Interviewees were asked if they had heard the term “public health” and if so, in what context. Everyone had heard of public health, and it was most commonly associated with healthcare (mentioned by 5 participants). Multiple participants felt public health encompasses much more though, and discussed what they felt the term meant.

When I think of Public Health I think of comprehensive health for the people whether that be resources whether that be physical health whether it be mental health and just the healthiness and the safety of the areas of the public around the people. (SA9)

A common theme here was the collective nature of health. It was consistently discussed on a societal level, rather than the individual.

“I think public health is how we as a society take care of our own and it's immensely important.” (SA6)

One activist even shared how public health is integral to the social movement Black Lives Matter.

Anything that has to do with people has to do with public health. When I think of Black Lives Matter, literally racism is actually killing Black people. I know people may laugh when they hear that but there are studies, actual research on how Black people are dying because of racism. (SA5)

Importance of Trust Between Activists and Public Health Workers

Activists believed public health was significantly entwined with current social movements and that more engagement from public health workers would be beneficial for social movements. When asked what barriers they would foresee in developing these relationships, the main barrier discussed was trust. There are many possible reasons for why one group, in this case social activists, may not trust another group, including public health workers. A main reason for this lack of trust comes from history.

History.

Seventy-eight percent of activists mentioned history in their interviews. One activist stated:

“I think it is important to understand the lessons of the past in order to understand what is going on currently.” (SA9)

History plays a huge role in social movements, given that these movements are created to fight against history of oppression for certain groups. Looking specifically at the history of relationships between activists and public health workers, there are many examples to illustrate issues between these groups. It is clear activists are aware of these historical events and they shape how they view and interact with academia and public health workers today.

When you talk about Black women and their bodies you think of Henrietta Lacks and the Lacks cells and what they did to her and they how they used

her body without her permission. So when you're thinking of partnering with Johns Hopkins that's something you have to think about and have in the back of your mind. Because they have the money, they have the equipment, they have the resources to do what you need. But you also want to make sure that you are having integrity and that you are true to who you are as an institution or as a group. (SA5)

Along these same lines, another activist mentioned similar sentiment regarding the importance of history in creating the trust issues that exist today.

“I don't know if it's the history there that people have with each other for the past or hurts, but there is a lot of mistrust.” (SA8)

Other barriers to building trust.

In addition to history, another reason for lack of trust is due to the privilege maintained by academia. Public health workers, while not always from academia, are assumed to have formal training and education and oftentimes may be associated with an academic institution or university.

“I think there are some academic institutions that benefit from the things that these groups are trying to fight against. I think that would be the biggest barrier as to why groups would not want to partner.” (SA7)

“It kind of makes me think like maybe it's that hesitation of being labeled as elite, you know, that sort of liberal-bubble stereotype. That might give them [activists] hesitation of being associated with academia.” (SA1)

This can lead to resentment when working with activists who may know more about the population from first-hand experience but may not have the degree or title to earn them a formal job. This can lead to lower pay during a research study for activists than their public health worker counterparts.

“It's irritating as shit that...people are spending all this money to go to school to do these research studies or whatever so that they can get a job which the person who has not gone to school should get.” (SA7)

Another aspect of trust is looking at how decisions about who is allowed access to the group reflects on the group leaders by other members of the group.

One issue that I don't think would be thought of often is that they [activists] have the trust concerns of the people they are working with within the movement. Will they trust me if I submit to having this process assessed? Not only is there the concerns that would be the traditional trust issue of outsiders looking in and an evaluation process taking place, but is it from people that I can trust not to use the information, not to use the list in an inappropriate way, not to tell on others, not to tell on us? (SA3)

Importance of Being Physically Present at Events

Another theme emerged regarding the necessity of being physically present for the on-the-ground events led by social movements.

If you really want a movement, to me a movement means people. It doesn't mean I'm getting money online to advocate for my particular position...So

those that actually become a movement involve people, actual people doing things in communities. (SA3)

Online social media activities were considered important for showing support and making change, but were not listed by anyone as the sole method for involving oneself in a social movement as an activist. Being physically present was also the most commonly mentioned method for starting to build trust and start a relationship between activists and public health workers. For many of the activists, one of the best ways to earn trust was by being physically present at meetings, rallies, and other events over a period of time. This would allow activists to feel that the researcher or public health worker was devoted to the cause and had good intentions.

When asked how to reach out to people involved in social movements one interviewee responded.

“You better get to the rally honey, you better get to the rally!” (SA9)

Being present at events was viewed as crucial for the success of the social movement, but was also seen as important for activists. Events are integral for networking and meeting others involved in the movement. This aids in developing relationships and also boosting morale.

There's a certain boost to one's thought process and a boost to determination in social justice issues when you attend an event and there are a lot of other people who obviously share your concern for this particular issue. I think there's a lot to be said for that. And I've certainly gained from that. And it seems from the other people who are attending this event that they take that

away from this as well. It's really important that we are all in one place and we can feel that there's more than just us. (SA2)

The Role of Social Media in Activist Life

One aim of this study was to examine the role of social media in communication for social movements. Many of the activists used social media both personally and in their role as an activist. In fact, most even spend more time conducting activism work online than in-person, however the majority of online time was spent reading about current events to remain knowledgeable and up-to-date on relevant topics. When asked which activities were more important, online or in-person, the nearly all (seven of nine) activists felt their in-person actions were more valuable to supporting their causes with the other two believing the two were of equal value.

So I definitely think most movements these days start online but I think the key to actually making change happen is taking them from online to real life action. You know, senators and elected officials can ignore a thousand emails that come into their inbox but it's a lot harder to ignore a thousand people outside of their office. (SA1)

The role that social media played in information transmission was important, and many interviewees recognized that without it social movements would not be where they are today.

“Certainly if it wasn't for Facebook there never would have been the Women's March on DC. Certainly if it wasn't for Facebook there wouldn't have been the March for Our Lives rally.” (SA4)

Most activists agreed the causes they were part of could be considered online social movements. The term “online social movement” may be over used in their opinion, though. In order to be a social movement, most activists felt the movement must involve people at its core and could be organized through online means; however, several people mentioned that they felt not all online social movements were “real” social movements.

I think as anything you will find some of them are real, some of them want to be real, and some of them just aren't. So you will have an organization that may start there and they become real by having centers or small units of people that get together and do things but if all they are is basically a fundraising device for their own organization then I questioned their validity because all they're doing is acquiring funds of money in order to purchase the right to sell things or purchase the right to market their ideas. (SA3)

The Dire Importance of Time

Another emergent theme, is in regard to the timing of social movements and activism. Activists felt the causes they were advocating for were incredibly important. People work nearly non-stop for these social movements. One interviewee mentioned losing a family member and taking only a short 2-week break before rejoining

protests, showing serious commitment to their cause. Others mentioned feeling depressed when their movements experienced setbacks. No matter how much time the activists devoted to their causes, they felt the need to keep pressing and pursuing social justice.

“I need to do more. What I do is not nearly enough.” (SA8)

Others who concluded their interviews with the need for immediate action echoed this sentiment. These pleas were filled with threats of impending doom if warnings were not heeded and if people in the general public did not rise up and join these social movements. Numerous interviewees felt time is of the essence, and that a lack of increased action by social movements now would have dire consequences for the future.

“We are in peril and I think a lot of people don't understand that. I know a lot of people who think everything will be okay... but they don't know what's happening and that the nation is at peril.” (SA4)

The movements we have are not big enough and are not encompassing enough people and we are losing. As a society, as a community of middle class and poor people, even rich people, not up to the point where they are billionaires but even rich people with a million bucks, they're losing too. Doctors, lawyers they're all losing. We're not going to be able to have enough to make it. (SA3)

Engagement Opportunities for Public Health

While there are clearly significant trust issues that need to be overcome to create and maintain meaningful relationships between activists and public health workers, there are many opportunities for public health workers to become more involved with current social movements. Activists suggested several strategies that should be employed by public health workers when starting to build these relationships.

Recurring themes for building relationships included taking time to get to know the people and the communities you will be working with, recognizing your privilege, and making sure your work supports the community and the movement rather than taking control away from the people already involved.

“Visiting on a regular routine, going and doing whatever is important to the community, being present, being visible I think it's really important. Being transparent and being yourself I think really helps a lot.” (SA8)

“If you're not in that community it becomes about listening. Listening to the people and giving to them what they think they need, but also empowering the people so they can do it themselves.” (SA5)

Activists also listed ways in which they felt public health workers could get involved with their current causes. While many of these ideas were specific to certain social movements, several ideas traversed numerous interviews. The most discussed area of need was mental health. This included discussions of mental health services needed for activists themselves as well as for those whom the activists are advocating.

Mental health was mentioned in 6 of the 9 interviews, without any prompting by the interviewer. This was not an area that was even on the interview guide, but made its way into a number of conversations, indicating its importance and lack of current availability to those in need.

I think it's important too for people who are involved in these movements to be able to share with each other but also to be able on an individual level to share. Even if you're just at a rally handing out call cards and say hey if you need someone to give us a call. Saying are you struggling with whatever, just making yourself available or letting them know of resources that are available. (SA9)

[This community] needs a lot more education on mental health and what that really means and that it doesn't mean that you're crazy. Just like you would take care of part of your body that's sick you have to take care of your mind as well... going out and putting on workshops and having families be part of studies, educating the community on the different resources out there so they could help their children at home, on good practices, things that they could be doing that they don't realize are impacting their child or their health. (SA8)

The other area where interviewees wanted to see public health workers engage with social movements is in determining their long-term impacts. Several activists noted that in order to change policy they need research to show their actions have made meaningful change. Yet oftentimes, this evaluation is lacking.

“I consider activists as organizers and first responders for the movements. And there hasn't been much on the impact for these first responders.” (SA9)

Activists felt public health workers should focus academic research on the impacts of social movements on improving health outcomes for groups in these movements.

Discussion

These interviews revealed rich qualitative data that illuminated the relationship between activists and academia, and the role that this relationship may play in developing trust between public health workers and social movements. It should be noted that a sample of nine social activists cannot be generalizable to a population; however, these personal accounts give valuable insight into the current relationship between public health workers and social activists, as well as how to improve this relationship.

Activist Relationships with Public Health

While all activists had heard the term public health, fewer than half were able to give a description that included the comprehensiveness of the field. Public health is a very broad discipline which is inherently interdisciplinary (Gebbie, Merrill, & Tilson, 2002). The public health workforce is therefore also diverse and includes a variety of positions whose prime responsibility is related to the core public health activities (Beaglehole & Dal Poz, 2003). It would not be expected that these social activists would be aware of the breadth of public health and its workforce. The onus

for obtaining knowledge on the definition of public health should not be placed on these activists, rather spreading awareness of the various duties and roles of public health should occur via public health worker interactions with this population.

As a first step to engagement, public health workers should spread awareness of the field to social activists and explain the connections between the mission and goals of the health-related social movements and public health. Similarly, the definition of academic research, while discussed in the interviews, may not have been fully understood by the interviewees and should be examined further. This lack of academic research understanding by participants has been previously documented (Freimuth et al., 2001). Very few activists were able to recall any interaction between researchers and social activists. This lack of existing relationships illustrates the importance of this work. It is also possible that participants were not familiar with the CBPR concept and did not equate CBPR work with academic research.

The CBPR framework involves community collaboration in the research process as well as enacting change as part of this process (Minkler et al., 2008) and can be beneficial in developing community partnerships (Brugge & Hynes, 2005). It could be that CBPR research is taking place but due to its progressive format was not viewed as research by the interviewed activists. Indeed, CBPR should be used by public health workers involving themselves in social movements; this research framework who can offer collaborative methods for the development of researcher-community partnerships. Understanding the barriers to creating collaborations and working towards overcoming those issues will benefit both public health and social movements working towards social justice and health equity.

When developing a conceptual framework for CBPR, Belone et al. (2014) found four constructs prevalent across the dimensions addressed in the model including: 1) trust development, 2) power, 3) capacity, and 4) mutual learning. These constructs are mirrored by the necessary quality processes outlined by Community-Campus Partnerships for Health (CCPH) in building successful community-university partnerships (2013). All of these constructs were mentioned by activists interviewed in this study as well. Trust has been discussed; this was a major area of concern for activists in developing relationships with researchers. Trust relates to the concept of power –activists wanted to remain in control of their work within their social movements and also felt that power imbalances between researchers, who activists felt often have more formal education and receive higher pay in research work, may create a barrier for developing trust. Care must be taken to ensure that power dynamics are balanced and that researchers do not usurp social movement activities but provide a supportive or collaborate role (Muhammad, Wallerstein, Sussman, Avila, Belone, & Duran, 2014). Capacity, or the readiness and capability of researchers was called into question by activists discussing how public health could become engaged with social movements. Activists mentioned the need for researchers and public health workers to be physically present by attending meetings and rallies, as well as listening to the activist community members. Activists considered facts and data of utmost importance; while researchers are learning from the community this should be reciprocated and findings communicated with community members. Due to the overlap in CBPR constructs and the findings of this study, CBPR should be

considered as an important framework for future research involving social movements.

There are many potential barriers to developing a relationship between activists and public health workers. Interviewees cited historical examples where researchers have abused their power to the detriment of the people they claimed to be helping. These examples, while in the past, have created distrust between marginalized communities and academics. This lack of trust persists, and bolstered by past blights, continues to create a barrier between academics and these communities (Scharff et al., 2010). Social movements fight for those who are oppressed and social activists are often part of the communities for whom they are advocating. In many cases, these disadvantaged groups are minority communities. Researchers struggle to access and engage participants from these groups (Bonevski et al., 2014; George, Duran, & Norris, 2013), yet, studies have shown that minority communities are as willing to participate in health research as non-Hispanic whites (Wendler et al., 2006). This is in line with the findings of this study, showing eagerness among all activists to participate in health research that would benefit their social justice causes. Methods of recruiting and retaining participants need to be altered to increase participation from disadvantaged groups (Bonevski et al., 2014; George, Duran, & Norris, 2013).

Facts matter to these activists and research is not just considered important, but a priority. For a social movement to make lasting change, research is needed to back the mission of these movements. All of the interviewees had education beyond high school, with one-third obtaining advanced degrees. It is possible that this

particular sample of activists may have greater acceptance of academic interventions than the overall activist population. However these findings are in line with a nationally representative study on millennials (N =1,045) conducted by the Media Insight Project (2015), which found that nearly half of activists have a college degree (43%) with an additional 26% having at least some college or technical school training.

All interviewees believed the social movements they were a part of would benefit from academic research and public health worker engagement. Activists described anger and resentment at the idea of researchers coming in and taking information from them but not using it to benefit the community. To prevent this, a CBPR approach should be used when conducting research with social movements. In CBPR, research is not only conducted and owned by academic researchers, but also is developed by and belongs to the community (Rhodes, Malow, & Jolly, 2010). Sharing control over research and involving activists in the various stages of the research process could help develop healthy partnerships between these groups and lead to positive action (Rhodes, Malow, & Jolly, 2010). A lack of trust is certainly a barrier to building relationships, but by spending time with communities and listening to them, trust can be built. Past research has been successful in developing trusting and lasting relationships with communities of color (Brown et al., 2009; Thomas et al., 2018) and the same methods should be followed when creating relationships with social activists to conduct research with social movements.

Social Media's Role in Social Activism

This study asked social activists about their social media use to determine if public health workers should consider online engagement with social movements and analysis of health-related social movements via social media data. Social media was frequently used by the activists interviewed; however, it was primarily used as a source of information, typical of social movements (González-Bailón et al., 2011). Social media as a means of receiving and disseminating information was a far more common use of social media than developing relationships (such as swaying others to participate in the movement) or using social media as a method of maintaining relationships (such as organizing and uniting movement members around their cause). This may be a result of the type of social media interviewees used most often, as different social media platforms can play different roles in communication (Quan-Haase & Young, 2010).

Increased use of social media has been shown to positively predict intent and engagement of participation in social movements (Hwang & Kim, 2015; Valenzuela, 2013), and indeed all activists interviewed utilized social media in some capacity relating to their activism efforts. Given the association present in these previous studies (Hwang & Kim, 2015; Valenzuela, 2013), social media did not play as significant a role in furthering the activism of these interviewees as was expected. Some research suggests social media is an effective channel for activism leading to broad societal change (Stokes & Atkins-Sayre, 2018) while other work maintains that while social media may increase participation in social movements the quality of that participation is not sufficient to create significant change (Gladwell, 2010). The latter

appears to be the view shared by interviewees who felt that social movements that existed solely online were not real—that people needed to be involved to actual change to occur.

Valenzuela (2013) found that social media may not be creating a new form of activism so much as supporting existing more traditional activism, such as in-person protest. This matches with the work of the activists interviewed; none of these activists supported a cause through online means alone. Even interviewees who spent more time advocating for their causes through social media than in person felt that their “boots on the ground” efforts, such as organizing rallies and protests were the most influential of their activist efforts.

This coincides with activists’ feelings about how public health workers should become involved with social movements. Similar to their own feelings on what forms of activism are most impactful, interviewees believed that public health workers needed to immerse themselves in the social movements and that should start by attending meetings and meeting with movement leaders in person. Not one interviewee mentioned that public health workers should examine social media or the online presence of the social movements—it was clear that the value and the heart of the movements were viewed as coming through in-person activities.

This theme of the importance of physical presence persisted including public health workers building trusting relationships and later implementing interventions and providing support by engaging with activists at events. These findings suggest that future work should look at the supportive role of social media rather than

focusing on online activism as separate from activism organizing protests and in-person demonstrations (Valenzuela, 2013). Public health workers should expect to meet in person with social activists and develop trust by attending meetings, events, and rallies to show support and solidarity with these movements.

Mental Health and Activism: A Crucial Area for Future Study

When examining what this engagement would look like, many activists mentioned they would like to see more support for mental health. Specific examples were given including providing counseling services for social activists and developing interventions to combat the stigma of seeking mental health care. Studies have shown that by addressing social and economic inequalities, mental health and well-being can be improved (Royal College of Psychiatrists, 2010). Activists also reflected on the trauma experienced by others in the populations they were advocating for and first and second-hand trauma they experienced in their capacity as activists. Secondary, or vicarious trauma, occurs when a traumatic experience is shared with another person; secondary trauma can result in the same symptoms as primary trauma including nightmares, sense of hopelessness, PTSD, and depression among others (Bober & Regehr, 2005).

While a systematic review of formal volunteer work showed improved mental health for volunteers (Jenkinson et al., 2013), social activists are different from volunteers; strained political conditions coupled with trauma experienced by the disadvantaged populations with whom activists are working, would likely yield different results for social activists than those described in the study as volunteers.

Activists talked of being tired, depressed, and anxious when discussing their activism work. There is a lack of research on the impact of social activism on mental health (Satterthwaite, 2017). An online survey of human rights advocates globally (n=346) by Satterthwaite (2017) found rates of PTSD, burnout and depression comparable to first responders and combat veterans (Satterthwaite, 2017). These advocates had often been exposed to secondary and primary trauma, however the vast majority felt unprepared for the health impacts they faced (Satterthwaite, 2017). In this study, one interviewee pointed out how lacking mental health services for social activists were, and how it would be beneficial to have public health workers assist in providing those resources. This is clearly an area in need of additional research.

Public health workers could find that offering mental health services to individuals and communities may be an initial area of interest to engage with social movements. Mental health training and support should be supplied to individual activists, but should also be considered at the organizational and movement level (Satterthwaite, 2017). Additional support provided by public health workers to lessen health disparities would also provide a mechanism to improve mental health as well. Research should be conducted on the most beneficial methods of combatting mental health issues brought upon by trauma, including secondary trauma, for the activist population. Previous work found that recommendations for trauma therapists dealing with secondary trauma (n=259) were not helpful for improving mental health (Bober & Regehr, 2005), therefore additional suggestions should be made and tailored to the population to increase likelihood of intervention effectiveness.

Future research should also be conducted on the impact of social movement activities on the health and well-being of people in communities championed by these movements. People who have their basic needs met and feel like valued and equal members of society are more likely to have better mental health outcomes than those who don't (Lester, Hvezda, Sullivan, & Plourde, 1983). It would also be beneficial to have increased studies on the impact of social movements in forcing policy change, and to determine if those changes have long-term health benefits. These are only a few of the areas that could be studied, and further research should be conducted with specific social movements and organizations, developing relationships and understanding the needs and strengths of these individuals and groups before any intervention or study is attempted.

Strengths and Limitations

Personal views can bias results, especially in qualitative work. To combat this, a reflexive approach was adopted where inherent personal biases were acknowledged, recognized, and reflected upon by the researcher. There has always been debate over who should conduct research with disadvantaged communities, including communities of color (Milner, 2007). It is important to conduct culturally sensitive research and to acknowledge positionality (Tillman, 2002), which is an important component of CBPR (Wallerstein, Duran, Minkler, & Oetzel, 2018). A framework by Milner (2007) was used to guide the researcher in confronting and gaining awareness of racial and cultural biases in the research. This process involves researching the self and the relationship between the self and others as well as reflecting on that

relationship and understanding it in terms of the larger system (Milner, 2007). The researcher used questions posed by Milner (2007) to examine and reexamined positionality throughout the research process.

While not all the interviewees identified as persons of color, the majority did. Social movements are about enacting change and combatting systemic inequities. Those most involved in these movements often identify with the groups for whom they are seeking justice (Brown et al., 2004; Buechler, 1995). In this research, the oppressed groups advocated for by activists ranged from immigrants to the LGBTQ+ community to Blacks and women and beyond. Each group maintains its own culture and the researcher certainly did not identify with all of these groups. However, attempts were made to understand the perspectives of these groups by acknowledging the experiences of marginalization of these people faced as routine and by listening to their stories throughout the research.

The interview guide was reviewed and revised prior to use to minimize leading questions and word bias and questions were ordered from general to specific and more positive before negative questions in order to minimize question-order bias. As in any qualitative study, researcher bias exists. For example, it is noted that only activists from progressive social movements were interviewed in this study. While this may limit the generalizability of the findings, all of the social movements and groups participants were involved with social movements that would qualify as health-related social movements as they are working to lessen health disparities and improve health and well-being for all, concentrating on achieving social justice for marginalized groups. This study could have benefited from triangulation; however,

this is an exploratory study and future work should incorporate multiple sources of data to increase confidence in the data obtained (Patton, 1999).

Since this study consisted of solely qualitative work, the issues of reliability and validity differ from quantitative work (Golafshani, 2003). The general meaning of these words still apply; validity refers to the integrity and precision of the methods used to accurately assess the data while reliability refers to the consistency and replicability of findings. In this study, interviewees were diverse in many respects including age, race/ethnicity, education level, geographic location, and social justice causes of interest. This diversity shows the data are robust and encompass a wide range of viewpoints from activists participating in a multitude of different social movements, thus increasing confidence that the themes that emerged are may be found among activists from a variety of causes.

During data analysis, discussing emerging patterns and proposed theories in an analytical manner with peers can be beneficial in helping researchers discover their own biases in perceptions and to determine if their hypotheses are plausible (Lincoln & Guba, 1985, p. 308). Peer debriefing was conducted multiple times during the analysis of interview data and aided in conceptualizing the data into themes and deepening exploration of several nodes, thus improving the credibility of the analysis. Confirmability of the analysis was increased by keeping detailed records throughout the data collection, transcription, and data analysis process to understand how codes were developed to categorize the interview material (Lincoln & Guba, 1985).

Sample size in this study was small, with only nine individual interviews. Saturation, if defined as the point where no additional themes are discovered upon additional interviews (Gerrish & Lacey, 2010), may not have been reached with such a small sample size (Mason, 2010). This potential premature closure was due to time constraints, however the vast majority of salient themes (>80%) were recounted by multiple interviewees and is considered saturation in some studies (Trotter, 2012).

While there are several limitations to this study, its value lies in the novel conceptualization of social movements as public health issues and the findings which can inform the pursuit of new relationships between social activists and public health workers. Many social movements today are relevant to public health and the field of public health should become more engaged with these health-related social movements. These groups have a shared goal of social justice and are both pursuing ways to improve the health and well-being of disadvantaged communities. This work adds to the limited body of literature on the relationship between public health and social movements. Talking with social activists invited a deeper understanding of the experiences of these people. Findings suggest that public health engagement would be welcome and useful for social movements, and a deeper understanding of issues that could impede the relationship between these groups was gained.

Conclusion

This study provides evidence that academic and health-related research is not often pursued within social movements but that it would be beneficial in advancing the causes of social movements. Relationships between social activists and public

health workers may face challenges, including distrust stemming from negative historical interactions between academia and minority communities, but these issues can likely be overcome as long as researchers take care to cultivate trusting relationships. It is imperative for public health workers to be intentional and cognizant of the need to develop relationships with activists. To do this effectively, they must be physically present, transparent about their intentions, and listen actively to activists with whom they hope to work. Researchers aiming to work with activists will need to dedicate significant time to constructing these relationships and prove to the communities they aim to work with that their intentions are positive. Several potential areas of interest for public health worker research were determined, and further research should be conducted with social activists to continue to understand the most effective ways public health workers can engage with social movements in a constructive and supportive way in order to improve the health of all people.

Chapter 6: Summary and Conclusions

Chapter Overview

This chapter begins with a summary of key study findings, followed by a discussion of common themes reflected across all three study components. Next, limitations, including issues faced in conducting this research, are discussed along with the strengths of this work. Finally, implications of this study and recommendations for future research are provided.

Recapitulation of Study Purpose and Findings

The overall goals of this study were to learn more about the relationship of social media data to social movements, and to determine how public health workers could use social media data from online social movements and other methods to engage with social movements. The need for this project stems from the idea that social movements are often centered on the desire to address health disparities and improve the well-being of disadvantaged groups. From this view, social movements are related to public health and efforts should be made to develop mutually beneficial relationships between public health and social movements.

This study aimed to address three research questions. The first question aimed to understand how well the central themes that emerge from tweets about social

movements map onto the stated mission and goals of the official organizations representing those social movements and how the tweet content relates to health. To answer this question, the Black Lives Matter movement was chosen as a case study example. Eleven thousand tweets using #BlackLivesMatter were analyzed revealing approximately half of the tweets directly related to the mission and goals of the Black Lives Matter organization. Health was rarely mentioned in these tweets directly, yet the main issues discussed included themes of racism and violence, which are known social determinants of health. These issues are not being discussed as health issues by the Black Lives Matter organization or people conversing online about the Black Lives Matter movement, indicating a need for research such as this.

The second aim of this study was to determine how the public health workforce could apply information collected from an analysis of social media data originating with social movements to aid in addressing the health-related issues highlighted by these movements. A Delphi study was conducted with 10 experts in public health to generate ideas related to this aim. Ideas were then ranked and re-ranked on importance and feasibility until the group came to consensus and the most effective ideas for implementation emerged. Delphi study participants overall felt it was important to engage with social movements, and while the concept of social media data analytics was new to many participants, they found value in this type of analytic work. To increase effective use of social media data analytics regarding social movements among public health workers, more work needs to be done to promote the value of this type of data analysis among public health practitioners. Additionally, Delphi participants noted more engagement with social movements,

such as through community-based participatory research (CBPR), would be beneficial.

The third aim of this study was to determine more specifically what could be done to encourage public health workers to systematically engage with health-related social movements, from the perspective of social activists. Individual interviews were conducted with nine social activists to learn about their views on activism, academic research, and public health. Activists were also asked about how they use social media. It was initially thought, given the large online presence of social movements that public health workers might do best to engage with social movements online. Yet in talking with activists, it became clear that in order to develop relationships they felt a need for public health workers to be physically present in the on-the-ground aspects of the social movements such as attending meetings and events planned by activists in these social movements. These activists in general downplayed the online role of social movements; indicating more research needs to be conducted to determine if that thought is consistent and generalizable to larger activist populations. Interviewed activists confirmed results of the Delphi study, suggesting public health workers engaging with social movements could be beneficial to improving the health and lives of people.

Major Themes Present Across Studies

The Social Ecological Model as a Theoretical Framework

The analysis of tweets using #BlackLivesMatter (n=11,000; see chapter 3) demonstrated tweets were contributed by both individuals and organizations.

Organizations had higher follower counts indicating greater reach (see Table 2) while more individuals contributed tweets. Looking at the top 20 tweet contributors, of those identified more were individuals, while one organization generated more tweets than any other user in the sample (see Table 1). This goes to show that both individuals and organizations are heavily involved with the Black Lives Matter movement. It seems likely this trend would be reflected in other social movements as well. This information could be useful to public health workers aiming to examine health-related social movements through social media data analytics. Effective interventions supporting social movements could reach individuals via an online media platform. Alternatively, organizations already involved in the online component of the social movement could be examined for potential partnership opportunities. Groups with exceptionally large follower counts could be targeted as effective channels for health promotion messages, as they have already-established connections with large numbers of people who are invested in what they have to say online.

Many user mentions (n=10,512) were found in the tweet sample (n=11,000). This indicates the majority of tweets sent are not just people talking into a void, rather people are talking to each other. The interpersonal relationships within these online social media platforms are strong. While an individual may be reading and writing tweets, they are sharing their thoughts with other individuals and groups. By using hashtags specific to a social movement, they are also sharing their views with a larger community. In this way tweeters are capable of involving themselves in multiple levels of the social ecological model with a single tweet. Each level demonstrates its

own barriers and benefits as a potential area for health promotion. Additionally, by further examining these levels, public health workers can determine the most effective strategies for moving to the policy level and creating positive change in this arena to benefit the joint mission of social movements and public health of increasing social justice.

The Social Ecological Model is noticeable in other components of this work as well. In the Delphi study (see chapter 4), public health experts formed consensus on the importance and feasibility of obtaining public health engagement with health-related social movements. These discussions centered on the interactions between groups, be it within public health organizations, or between groups, such as between public health workers and social activists. These public health experts sensed the value of working at an organizational and community level --both online and in-person-- to support social movements in their mission for social justice.

Interviews with social activists echoed this sentiment as well. During one-on-one interviews, activists consistently mentioned how in order to engage the collective group or social movement, interpersonal relationships with key leaders in the movement would need to be established first. These different social ecological levels work together and public health workers must be willing to dedicate the time and effort needed to build trust at the interpersonal level before aiming to conduct research beneficial for the social movement as a whole. Similarly, research and data must be collected at the organization and community levels in order to advance to policy and institutional change.

This requires long-term investment and will undoubtedly be challenging, yet there are significant potential benefits of establishing a relationship between public health professionals and social movements. Academia can provide resources in the form of both financial and personnel support, as well as health expertise and a position of power that could be beneficial in supporting social movements in developing interventions and advocating for the rights of disadvantaged groups. Public health workers could find an area to utilize their skills while working with an established group of people who are passionate about improving the well-being of certain disadvantaged groups and can access hard to reach populations. A relationship between these groups could be mutually beneficial, but developing these bonds will not come without challenges, including combatting distrust.

Interconnectedness of Social Movements

During interviews, every social activist was asked about the social movement(s) they participate in, and what causes they are especially passionate about. Interestingly, every activist interviewed listed off multiple causes and groups for which they advocate. These groups were often tied to their personal identities, such as Black women being more likely to advocate for Black rights and women's rights than white males. This is indicative of social movement makeup, as described by New Social Movement Theory (Brown et al., 2004; Buechler, 1995).

While interviewees' primary social movements of interest may have related to their personal characteristics, it was also clear there was a feeling of connectedness to other groups and organizations. For instance, interviewees mentioned that at rallies

and protests calling to end gun violence, women's rights and Black rights activists were present alongside youth advocates and those working to reform the criminal justice system. These groups are able to work together and membership within these social movements often overlaps. This phenomenon was described by Meyer & Whittier (1994) as social movement spillover. This "spill over" of engagement goes beyond activists themselves being involved with multiple movements. Since social movements desire to make change at structural and institutional levels, the impacts of these movements resonates to other social movements, both current and future (Meyer & Whittier, 1994). This social movement spillover was also seen in the analysis of tweets. In the tweets the majority of the top 20 hashtags referenced other social movements or sub-movements (see Table 3).

There is clearly interconnectedness between social movements. One aspect they have in common and may bond over is a shared mission to improve life for unfairly disadvantaged groups. Be it direct or indirect, all of these social movements are based around improving health for all. The social activists interviewed are involved in a wide range of social movement topics including race, gender, sexuality, and more.

For all the activists interviewed, their causes of interest related to them personally. Identity is not singular –one can identify as both Black and as a woman, as a White man and a gay man. Critical Race Theory discusses the interrelatedness of race and racism with other identifiers, such as gender and sexual orientation, which can compound oppression (Yosso, 2005). Solely focusing on identity from one aspect, such as race, limits the understandings of how people respond to systemic

inequities and rally against them (Yosso, 2005). Therefore it is a positive finding of this work that social activists are expressing their whole identity in the causes they are championing rather than focusing on one component of their identity. After discussing the many areas of public health, regardless of the movements these activists were involved with, they all agreed public health was important within these social movements although most had not previously viewed it that way.

The environmental justice movement stemmed from grassroots activism and has from its conception been intertwined with the field of public health (Bullard & Johnson, 2000). The Black Lives Matter movement relates to the environmental movement in many ways. It is also a movement led by people who have sensed a social injustice which is effecting the health of certain groups. It is also a movement that has been deemed highly political in nature, although there are scientific data to support the claims made by advocates of the BLM movement on the presence and effects of systemic racism.

Yet different from the environmental justice movement, BLM movement protests generally do not call explicitly for a change in health policies or describe the impacts inequities caused by racism have on health. The connections between the BLM movement and health are present, just as they are in the environmental justice movement, however, what is perceived as relating to health differs. In both movements, social factors are at play and those lacking the necessary capital are too often people of color. For environmental justice, this could mean that those of lower socioeconomic status end up living in an area with greater levels of pollution, which in turn increases their likelihood of developing a disease caused by exposure to these

toxicants. In the BLM movement, the pollution is racism – less tangible but just as pervasive. The health effects are not as easily linked to the cause, making it more difficult to conceptualize BLM as a health social movement. Recent studies on the effects of racism demonstrate that it is a determinant of health (Bailey et al., 2017; Garcia & Sharif, 2015; Paradies, 2006); hopefully, this type of research will help make the connections between the BLM movement and public health more vivid.

Additionally, public health workers aiming to engage with social movements currently removed from public health intervention should consult those public health practitioners who currently work within social movements. For example, public health workers involved in the environmental justice movement, the women’s rights movement, and individuals who are involved with communities in other capacities through CBPR, could add further insight on working with a social activist population. Future efforts should use existing successful community-university relationships between public health and social movements as a guide.

Strengths and Limitations

Problems Arising During Research

Several issues were encountered throughout this research process that impacted this study. First, when conducting the tweet content analysis using graduate students to code the tweets into different categories, there was low inter-rater reliability. This could be due to lack of clear instructions, or a result of the highly subjective nature of tweet content. Instructions were given in written and video format with multiple examples. Coders were also given a test set of tweets to practice

coding which was reviewed prior to analysis of the final sample. Regarding subjectivity, it can be difficult to determine tone, such as sarcasm, with the mere 140 characters comprising each tweet. This was complicated further by not using attached URLs (Universal Resource Locators) - web links addressed to secondary sites) to aid in determining the intended message. Many URLs were no longer working at the time of data analysis and were therefore disregarded in analyzing the content of tweet messages. Future studies should consider the usefulness examining URLs in tweet content analyses to increase validity of the content analysis and perhaps to increase inter-rater reliability as well.

A second issue emerged during recruitment of the Delphi study. It was difficult to recruit public health experts willing to participate in a series of surveys over several months without providing any incentives. Previous work with Delphi studies suggested this type of work is prone to high retention rates since the participants are generally interested in the subject of the study and therefore excited to participate (Okoli & Pawlowski, 2004). While this may be true, participant burden is rather high when using the Delphi technique. I believe this thwarted recruitment and thus the sample size was smaller than anticipated. Another factor at play was the timing of survey dissemination to participants. Initial surveys were sent to participants the same day they agreed to be part of the Delphi study. However, due to slow recruitment, this meant several participants were forced to wait multiple months to receive the second survey, as this time was needed to recruit a sufficient sample size to the study. This may have dampened enthusiasm from participants and led to high rates of attrition throughout the study.

The final portion of this study, individual interviews, had issues with recruitment as well. While over 50 social movement groups and organizations and over two-dozen individual social activists were contacted online via email and Facebook, this resulted in only two interviews. It became clear this method of recruitment was not effective and I was forced to shift strategies by relying on social networking to contact activists instead. This technique, coupled with snowball sampling, proved much more fruitful in obtaining interviews.

Additionally, understanding researcher positionality proved important to understand issues with recruitment. Positionality is crucial when conducting culturally-sensitive research (Tillman, 2002). In order to gain trust with potential participants, I was forced outside my comfort zone as a researcher to interact with people and share information not only about the purpose of the research study, but information about my personal self. These questions from potential participants led to considerable self-reflection which benefited recruitment and the study overall (Milner, 2007).

Other techniques previously used successfully for building trust between health researchers and minority communities were utilized as well, such as including increased transparency about the nature of the overall project, spending time learning about the person prior to asking for something (in this case interview participation), and again, sharing more about myself personally outside my capacity as a researcher (Thomas et al., 2018). In cases where relationships were built more successfully, interviewees were more likely to share contact information of other activists or to share my contact information with them.

Additional Limitations

Exploratory in nature, this research was limited by lack of ability to use previous studies for validation. The analyzed tweets were limited to a six-month period of time from January 1 through June 30, 2017. Social movements change rapidly and #BlackLivesMatter has been used millions of times since 2014. While a sample of 11,000 tweets is larger than many studies which conduct content analysis of social media data (Jansen, Zhang, Sobel, & Chowdury, 2009; Golbeck, Grimes, & Rogers, 2010; Lachlan et al., 2014; Hambrick, Simmons, Greenhalgh, & Greenwell, 2010; So et al., 2016), these tweets still represent a small snapshot of all the tweets using #BlackLivesMatter and therefore cannot claim to represent the opinions of the overall use of the hashtag.

Additionally, content of tweets using #BlackLivesMatter were compared to the mission of the Black Lives Matter organization. The Black Lives Matter organization was founded and is still run by the founders of the Black Lives Matter movement and creators of #BlackLivesMatter (Cullors et al., 2016). However, a social movement is much broader than a single organization; the Black Lives Matter organization's mission and goals were used to approximate those of the movement as a whole, however there are related yet independent entities.

In the second study, participants were responsible for generating ideas relating to how social media data could be useful to public health and how public health workers could engage with social movements. Experts were selected to participate in this study based on their expertise in public health, specifically with a focus on public health education so that they would be able to offer insight on training the future

public health workforce. Results were limited by the ideas generated by this group. It is possible that a different panel may have produced different ideas with different rankings concerning the importance and feasibility of these ideas (Okoli & Pawlowski, 2004; Powell, 2003; Rowe & Wright, 1999). The same limitations apply to the third part of this research: activist interviews. Nine social activists who participate in a variety of social movements were interviewed and information was learned about how public health workers might best engage with social activists, however the results of these interviews cannot be generalized to the social activist population at large. Both Delphi study participants and social activist interview participants involved snowball sampling which may have introduced sampling bias but was necessary to obtain a large enough sample size.

Study Strengths

One strength of this study is that it involved a novel conceptualization of social movements as groups advocating for public health. While the term health social movement has been used in some previous research, this term is limited in its scope and usually applied only to social movements which are directly linked to a specific disease or health problem such as HIV/AIDS and breast cancer awareness (Brown et al., 2004; Brown and Zavestoski, 2004). By expanding the view of what qualifies as a public health issue to include social movements that combat disparities focused on the social determinants of health such as racism, safety, income, and employment opportunities, we are able to include groups fighting for the same goals as public health in this new definition of health-related social movements.

Public health has a wealth of knowledge and resources that could benefit these health-related social movements. By encouraging public health workers to engage with social movements this opens up numerous possibilities for collaboration. Strengthening the positions held by both groups by bolstering large numbers of motivated people with research-driven data could eventually lead to policy changes that would improve health and aid both groups in reaching their shared goals of eliminating health disparities.

Another strength of this study is the use of multiple sources of data to discover more about this topic. By analyzing Twitter data, a great deal was learned about the online public discourse surrounding social movements and how this is similar to and different from the messages put forth by leading social movement organizations. To then take this further to probe into how public health professionals could become more engaged with social movements, two additional sources of data were used.

A Delphi study with public health experts provided a starting point where many ideas were generated and the group was able to form consensus on the importance and feasibility of several actionable steps to involve the public health workforce with social movements. This view alone was not sufficient as developing relationships requires both parties to agree. Therefore conducting interviews with social activists themselves was a crucial strength of this work. This allowed the researcher to understand barriers that may be present when attempting to enact the ideas produced by the public health experts, as well as provided solutions to effectively develop productive relationships between social activists and public health workers.

Implications of Findings

Much was learned about the content of tweets using #BlackLivesMatter and the relation (or lack thereof) of tweet content to the Black Lives Matter organization. This work shows the complicated nature of leadership and messaging in social movements of today where social media is a major channel in communication but one that cannot be controlled by a single group or individual. More work should be done in the area of social media data analysis. Public health experts in the Delphi study agreed the public health discipline should increase awareness and training of public health workers in this fast-growing field and noted several possibly beneficial uses of this type of data analysis pertaining to social movements.

There are many uses for social media data surrounding social movements for public health. Yet social media is not a silver bullet. “On the ground,” or in-person work still needs to be conducted. Public health workers still need to meet with activists in person to build relationships and gain trust. This task is made more difficult given history cannot be ignored. Academia has unfortunately developed a negative reputation among minority and disadvantaged communities with past atrocities committed against minority groups such as in the Tuskegee Syphilis Study (Alsan & Wannamaker, 2016; Scharff et al., 2010; Freimuth et al., 2001), the Havasupi Tribe in Arizona (Sterling, 2011), and many more. Even if researchers have the needs of a community at heart, they must be aware of the historical connotations of their work. (Thomas et al., 2018)

Overall this research implies public health workers and organizations should think of social movements as health-related and that the two share a common goal of obtaining social justice for all by reducing health disparities. Both the public health experts participating in the Delphi study and the social activists interviewed believed public health engagement would be beneficial for advancing causes of social movements.

Recommendations for Future Work

There is a dearth of knowledge on the relationship between public health workers and social movements. While there has been some research on health social movements, this term needs to be broadened to include social movements which link to public health through their desire to better social determinants of health such as education, income, and safety. More research should be conducted to examine social movements through a public health lens and to strengthen the evidence on the connectedness between these groups.

Social media data has proven to be a useful source of data regarding social movements given their large online presence. Additional research should be conducted using #BlackLivesMatter tweets and other hashtags relating to this social movement (including #blm and #sayhername among others) to gain a more complete picture of the current movement and how it has changed over time. Freelon et al. (2016) conducted an intensive study on tweets relating to the Black Lives Matter movement, but the movement continues to evolve and therefore must be continually analyzed. Additionally, previous studies of Black Lives Matter social media have not

related their findings to health. Increased social media data analysis should be conducted to examine other health-related social movements. When examining these movements, health-related themes and words present in larger samples of tweets could identify areas of public health most salient to these social movements for future intervention or health promotion efforts.

The Delphi study elicited some important first impressions from public health experts on the usefulness of social media data when engaging with social movements. Future research should further examine the importance and feasibility of implementing the ideas proposed in the Delphi study. Social activists agreed the public health field should become more involved with social movements and noted this relationship must start with a trusting relationship. Public health workers should take this message to heart. Those interested in working with social movements should engage in community-based participatory research and conduct an ethnographic study of the culture of social movements (Diani & McAdam, 2003). Additionally, social activists should be educated on the broad scope of public health work and how to access support from public health professionals.

In order for progress to be made in cultivating these relationships, public health practitioners must first be receptive to the idea that social movements are relevant to public health practice. More than that, a call to action must be made as it is the duty of public health workers to fight for social justice through improving health for all people. Social movements are struggling with this same fight and by forging strong relationships and leveraging the resources available through public health, these groups could increase their chances of successfully improving health. Health

disparities are vast and not able to be solved by any one method. A major takeaway from this research is that we have a long way to go to get the field of public health as a whole to recognize the dire importance of social movement involvement. Social activists have lit a fire forcing the public to recognize systemic inequities. Public health must act now to support these movements to ensure those flames continue to burn and snuff out systemic health disparities.

Appendices

Appendix A: Glossary of social media and Twitter-related terms given to participants in round 1 of Delphi study.

Bigram: (noun) A pair of consecutive written words.

Classifier: (noun) A classifier is a method for determining the likely class of an unknown object or event based on a number of instances of each of the classes

Code: (noun) Code, or source code, is any collection of computer instructions written using a human-readable programming language, usually as ordinary text.

Follow: (verb) Subscribing to a Twitter account is called “following.” Anyone on Twitter can follow or unfollow anyone else at any time, with the exception of blocked accounts.

Follower count: (noun) This count reflects the number people that follow a Twitter account.

Geotag: (noun) Adding a location to your tweet (a geolocation or geotag). This tells those who see your tweet where you were when you posted that Tweet.

Hashtag: (noun) A word or phrase preceded by a hash sign (#) to identify messages on a specific topic.

Impressions: (noun) Exposure is the total number of times tweets about the search term were delivered to Twitter streams, or the number of overall potential impressions generated.

Influencer: (noun) A social media influencer has access to a large audience (high follower count).

Profile: (noun) The profile displays information the user chooses to share publicly, as well as all of the Tweets they've posted.

Profile image: (noun) A personal image chosen by the user that appears next to each tweet.

Python: (noun) A high-level general-purpose computer programming language.

Timestamp: (noun) The date and time a tweet was posted to Twitter. A tweet's timestamp can be found in grey text in the detail view of any tweet.

Trigram: (noun) A group of three consecutive written words.

Twitter: (noun) An information network made up of 140-character messages (including photos, videos and links) from all over the world.

Tweet: (noun) A post made on the social media application Twitter. A tweet may contain photos, videos, links and up to 140 characters of text.

Tweet: (verb) The act of sending a tweet. Tweets get shown in Twitter timelines or are embedded in websites and blogs.

Retweet: (noun) A previously published tweet that was forwarded by another user. Retweets always retain original attribution.

Retweet: (verb) The act of sharing another account's tweet to all of your followers.

Script: (noun) A script is a list of commands written in source code using a programming language that can be executed without user interaction.

URLs: (noun) A URL (Uniform Resource Locator) is a web address that points to a unique page on the internet.

User mention: (noun) Mentioning other accounts in your tweet by including the @ sign followed directly by their username is called a “mention.”

User name (@username): (noun) A username unique to each Twitter account and is how an account is identified on Twitter. It is always preceded immediately by the @ symbol.

Appendix B: List of initial codebook categories based on the mission and principles of the Black Lives Matter organization

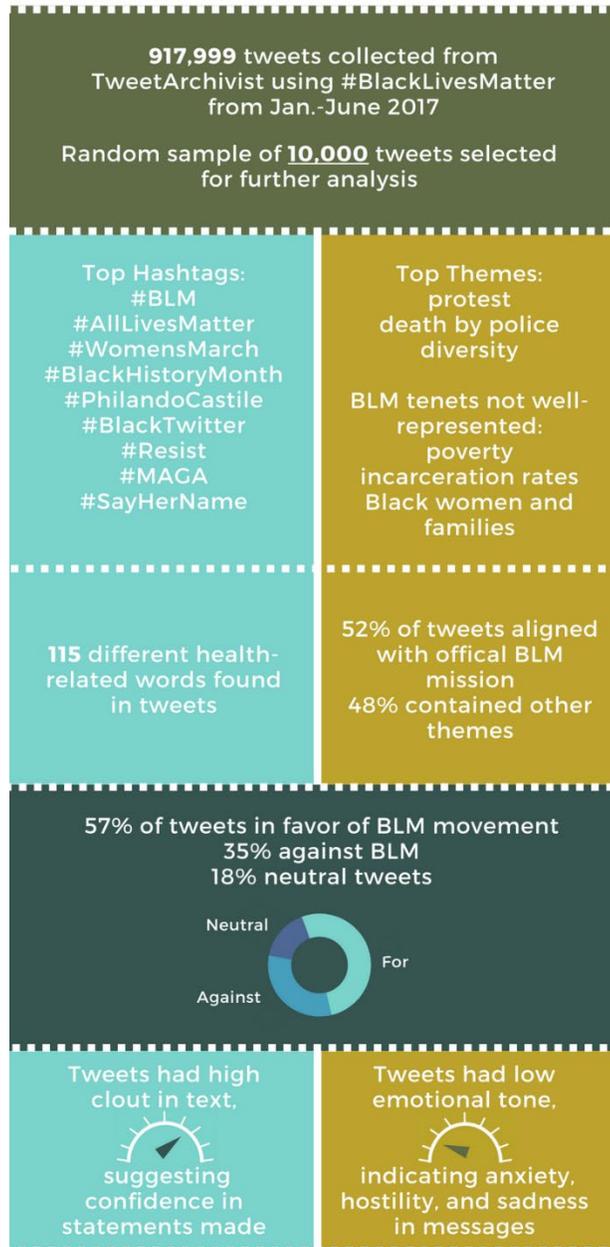
- Loving engagement/empathy (peaceful pursuit of justice)
- Restorative justice (focus on offender rehabilitation and reconciliation with victims)
- Unapologetically Black (taking pride in being Black)
- Poverty
- Genocide (death of Black people by law enforcement/state entities)
- Incarceration rates
- Black women and families
- Diversity/Collective value (includes differences such as sexual identity, gender identity, ability/disability, religion, immigration status, etc.)

Note: Original terms developed by the Black Lives Matter organization are used here, followed by a brief description of these terms written by the researcher based on consolidation of some of the BLM principles after examining 1000 tweets using #BlackLivesMatter to refine this codebook. In some cases terms were combined due to similarities (e.g. diversity and collective value, loving engagement and empathy.)

Appendix C. Infographic given to participants in round 1 of Delphi study as case study example of social media data analytics, based on study of #BlackLivesMatter tweets.

#BLACKLIVESMATTER TWEET ANALYSIS

AN EXAMPLE OF INFORMATION LEARNED FROM SOCIAL
MEDIA ANALYSIS OF AN ONLINE HEALTH-RELATED
SOCIAL MOVEMENT



Appendix D. Executive summary given to participants in round 1 of Delphi study as case study example of social media data analytics.

Executive Summary

The Black Lives Matter (BLM) movement has gained considerable attention in its efforts to bring issues of systemic racism to light and has grown into a social movement through an extensive social media presence using #BlackLivesMatter. While the Black Lives Matter movement has evoked many academic and popular responses, there has been a distinct lack of focus on this movement by the public health workforce. The Black Lives Matter movement is drawing attention to issues of social justice by focusing on racial inequities that exist today. Social justice and health equity are core tenets of public health, putting the mission of the Black Lives Matter movement in line with the mission of public health and deserving of being called a health-related social movement.

This study proposes a novel approach to the use of social media data in the public health field. 10,000 tweets using #BlackLivesMatter were analyzed to better understand the online discourse surrounding the Black Lives Matter movement. Some of the main findings of the analyzed twitter data is presented below. The Delphi study which you are participating in is being conducted with panels of experts in public health and leaders of the Black Lives Matter movement. As a Delphi study participant, you are tasked with reviewing this twitter analysis and developing ideas on how the public health workforce can best apply the information collected from #BlackLivesMatter twitter data to aid in addressing the health-related issues highlighted by the Black Lives Matter movement. More broadly, you will also be asked to generate ideas about what can be done to encourage the public health workforce to systematically engage with online health-related social movements.

Below you will find several sample tweets with key information labeled. This served to show what type of information is collected from Twitter users that can be analyzed. In addition to what is shown, location data and a unique ID are also attached to each tweet. A glossary of terms is also attached.

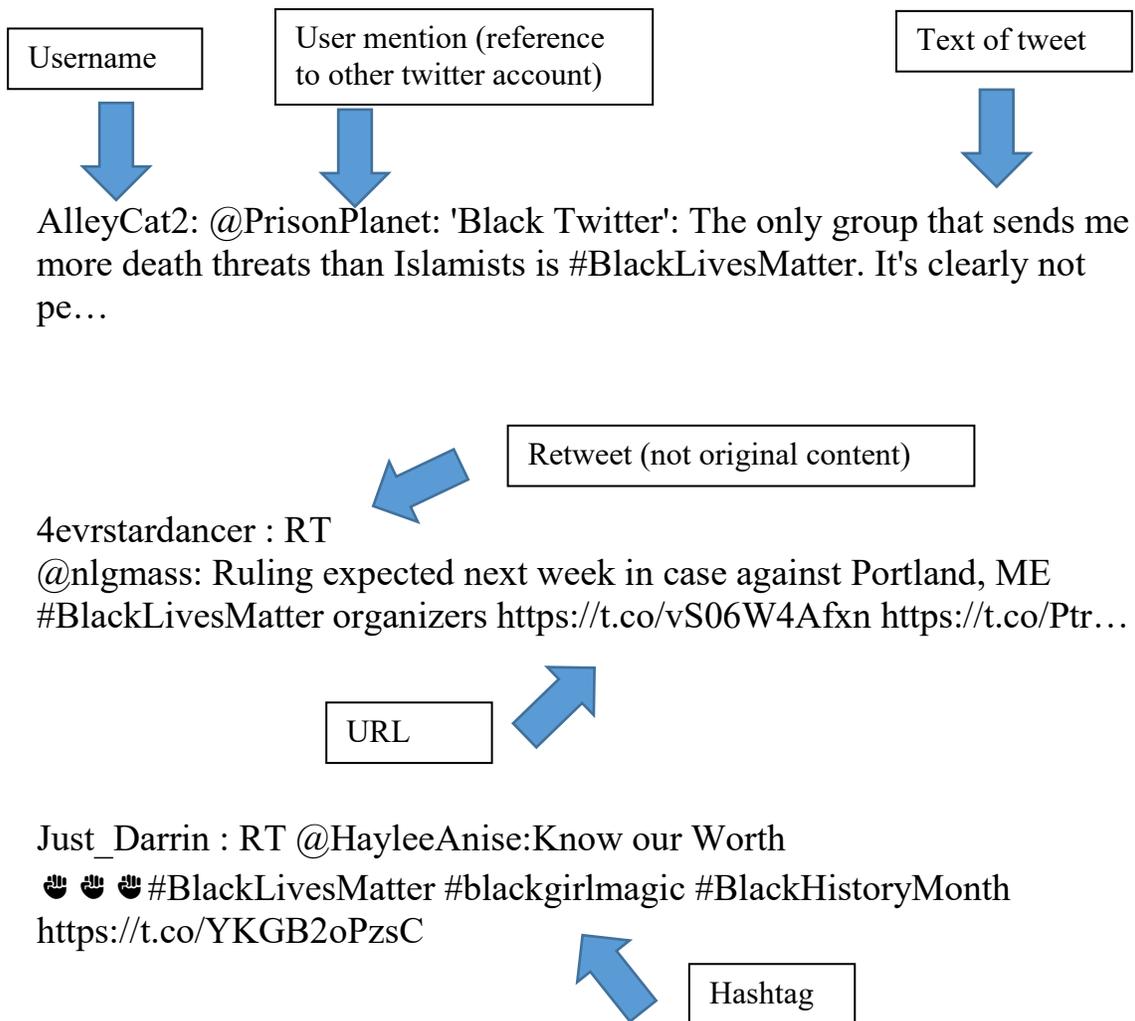
Conclusions

The analysis of tweets yielded a lot of information about the content of tweets using #BlackLivesMatter. More than half of tweets in this sample were in favor of the BLM movement (57%) while 35% were opposed. Additionally, when comparing tweet content to the principles outlined on the official BLM website, approximately half of the tweets aligned with the BLM organization's principles (52%). The BLM principles which received the most attention in the tweet sample were those describing protests, the death of Black people by law enforcement, and the value of diversity. These three categories comprised nearly 37% of all tweets. Other important topics which are listed as targeted issues by the BLM official organization's website, such as poverty and incarceration rates, were rarely discussed in the tweets. Not surprisingly,

most of the tweets that were opposed to or neutral towards the BLM movement did not align with the principles of the BLM movement, as they were not promoting the values of BLM. Additional categories were created to summarize tweet themes not covered by the BLM principles. Themes most common in these tweets included news stories, politics, racist content, and marketing/promotional tweets. It is interesting to note that the majority of top hashtags used in these tweets referenced other social movements with an online presence. This seems to indicate the interconnectedness of activists and their causes. Using Linguistic Inquiry and Word Count (LIWC), 115 health-related different words were found in the tweets, referencing physical harm (most common) and mental harm to health. On a clout scale from 0 to 100 where low scores indicate less confidence in statements made and higher scores indicate greater confidence and expertise, the 10,000 tweet sample had a high clout score of 71 signifying that the tweets were said with significant confidence in the statements. On a scale from 0 to 100 for emotional tone, where lower numbers indicate more negative emotion and higher numbers indicate more positive emotion, the tweet sample had a low score of 18, showing that many tweets conveyed a tone of sadness, anger, or hostility.

Appendix E. Tweet component chart with sample tweets given to participants in round 1 of Delphi study.

Sample tweets:



Appendix F. Survey administered to participants in round 1 of Delphi study

11/13/2018

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Default Question Block



Institutional Review Board

1204 Marie Mount Hall • 7814 Regents Drive • College Park, MD 20742 • 301-405-4212 • irb@umtd.edu

CONSENT TO PARTICIPATE

Project Title	<i>An Exploration of #BlackLivesMatter: Using the Delphi Technique to Determine How the Public Health Workforce Can Engage with Online Health-related Social Movements</i>
Purpose of the Study	<i>This research is being conducted by Abigail Bickford at the University of Maryland, College Park. We are inviting you to participate in this research project because you have been identified as an expert who may be interested in this study. The purpose of this research project is to form a consensus with a panel of experts on how Twitter data can be used by the public health workforce and to determine how to engage the public health workforce with online health-related social movements.</i>
Procedures	<i>The procedures involve participating in 5 rounds of an online Delphi study. You will be able to complete the initial survey once completing this consent form. Once you complete the survey, responses from all panel members will be compiled and a second survey will be administered within 2-3 weeks. The results of each survey will inform the creation of the next, with the goal of reaching consensus on the survey items by collecting ideas and ranking them. Each survey should take approximately 30 minutes to complete with a total of 5 surveys over the next 3-4 months. The initial survey will ask questions about your familiarity with social media and the Black Lives Matter movement such as "Have you ever used Twitter?" and "What online social movements are you aware of?" You will also be asked to describe how you see social media data being useful in public health work.</i>
Potential Risks and Discomforts	<i>There is no more than minimal risk from participating in this research study. This risk includes the potential for the loss of confidentiality, however, all responses will have identifying information removed before analysis and no one outside the research team will be aware of your participation. Additionally, identifying information will be saved in a password protected file.</i>
Potential Benefits	<i>The benefits to you include gaining an opportunity to learn from consensus building within a diverse but selective group of individuals and getting a chance to share your opinions about this topic. We hope that, in the future, other people might benefit from this study through improved understanding of how public health can engage with online health-related social movements by utilizing social media data.</i>

<https://umdsurvey.umd.edu/ControlPanel/Ajax.php?action=GetSurveyPrintPreview>

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Confidentiality	<p>Any potential loss of confidentiality will be minimized by storing identifiable information in a password protected excel document only accessible by two members of the research team. All information will be de-identified before analysis is conducted and only members of the research team will have access to the data. If we write a report or article about this research project, your identity will be protected to the maximum extent possible. Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else is in danger or if we are required to do so by law.</p>
Right to Withdraw and Questions	<p>Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.</p> <p>If you decide to stop taking part in the study, if you have questions, concerns, or complaints, or if you need to report an injury related to the research, please contact the investigator:</p> <p style="text-align: center;">Abigail Bickford 1213 Centerville Hall, University of Maryland, College Park, 20742 Abbic001@umd.edu 717-781-3712</p>
Participant Rights	<p>If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:</p> <p style="text-align: center;">University of Maryland College Park Institutional Review Board Office 1204 Marie Mount Hall College Park, Maryland, 20742 E-mail: irb@umd.edu Telephone: 301-405-0678</p> <p><i>This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.</i></p>
Statement of Consent	<p>Your signature indicates that you are at least 18 years of age; you have read this consent form or have had it read to you; your questions have been answered to your satisfaction and you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form via email.</p>

Signature:

Date:

Email address you would like this consent form to be sent to:

You were selected for this study based on your area of expertise. Which of the following best describes you?

-
- expert in public health or a related field
- Black Lives Matter activist
- Both

Please select your gender.

-
- Male
- Female
- other
- prefer not to answer

Please select your age.

-
- 18-25
- 26-35
- 36-45
- 46-55
- 56-65
- 65+

What is your job title?

Have you heard of the social media platform Twitter?

- Yes
 No

How frequently do you use Twitter (either reading or posting tweets)?

- I do not use Twitter
 less than once a month
 a few times a month
 a few times a week
 daily
 multiple times per day

For what purpose do you use Twitter?

- Personal
 Professional
 Both

Please describe the nature of your professional tweets.

Have you read any published or unpublished research that uses Twitter data?

- Yes
 No

Have you found the research useful in your own work?

- Yes
- No

Please describe the top three ways you have used Twitter data in your work.

Which of the following best describes the reason why you have NOT found the research useful?

- Haven't seen any studies using Twitter data
- Didn't find the twitter data relevant to my work
- Other (if so, please describe)

Have you heard of the Black Lives Matter movement?

- Yes
- No

Where have you heard about the Black Lives Matter movement?

- Social media
- News
- Family/ Friends
- Radio
- Newspaper
- Other (If yes, please specify)

What do you know about this social movement?

How are you involved with the Black Lives Matter movement?

What other online social movements have you heard of? Please list them below.

The American Public Health Association says that public health "promotes and protects the health of people and the communities where they live, learn, work and play."

Public health aims to improve the health and wellness of all individuals and public health professionals engage in social justice work in an effort to achieve health equity.

After reading this definition, **Do you believe the Black Lives Matter movement relates to public health?**

Yes (if so, how?)

No (if no, why not?)

Do you feel that these online social movements have any impact on public health or public health practitioners?

Yes (if so, how?)

No (if not, why?)

Have you seen public health practitioners engage (in any way) with these online social movements in their official capacity?

Yes (if so, how?)

No

Not sure

Are there any methods that you typically use to engage a group of professionals from a specific discipline with the Black Lives Matter movement?

What do you feel are the greatest barriers to engaging professionals in a strategic way with the Black Lives Matter movement?

Have you ever engaged in systematic efforts to include public health practitioners in issues of the Black Lives Matter movement?

Yes (if so, how?)

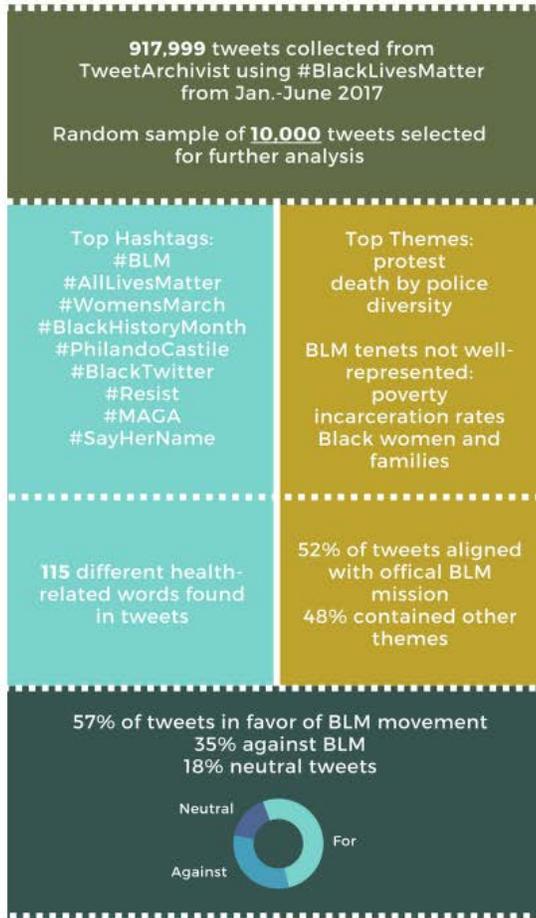
No (if so, why not?)

How do you think the public health workforce could become more involved in the Black Lives Matter movement?

Below is an infographic with some of the key findings from an analysis of tweets using #BlackLivesMatter along with an [Executive Summary](#). Please review these items before answering the following questions.

#BLACKLIVESMATTER TWEET ANALYSIS

AN EXAMPLE OF INFORMATION LEARNED FROM SOCIAL
MEDIA ANALYSIS OF AN ONLINE HEALTH-RELATED
SOCIAL MOVEMENT



<https://umdsurvey.umd.edu/ControlPanel/Ajax.php?action=GetSurveyPrintPreview>

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Do you believe the Black Lives Matter movement would benefit from the assistance of the public health workforce?

Please rate on a scale of 1-7, (1 being not helpful at all, 7 being incredibly helpful)

	1=not helpful at all				7=incredibly helpful		
	1	2	3	4	5	6	7
Benefit of public health assistance to BLM movement							

How could activists and leaders in the Black Lives Matter movement use the presented information?

Do you believe the public health workforce is currently accepting of using social media data collection and analysis to better understand online social movements and their relationship to public health?

Please rate on a scale of 1-7 (1=not at all accepting, 7=very accepting)

	1= not at all accepting				7=very accepting		
	1	2	3	4	5	6	7
Level of perceived current public health acceptance for this type of analysis							

Do you believe the public health workforce WILL be accepting of using social media data collection and analysis to better understand online social movements and their relationship to public health in the near future?

Please rate on a scale of 1-7 (1=not at all accepting anytime soon, 7=very accepting in the near future)

	1=not at all accepting anytime soon				7=very accepting in the near future		
	1	2	3	4	5	6	7

1=not at all accepting anytime soon 7=very accepting in the near future
1 2 3 4 5 6 7

Level of perceived public health acceptance of this type of analysis

What do you believe would be the best methods for engaging the public health workforce to utilize social media data for online social movements?

What do you believe are the major barriers to use of this type of data collection and analysis technique?

What can be done to encourage the public health workforce to engage with online social movements in a manner relevant to improving health?

Appendix G: Survey administered to participants in round 2 of Delphi study

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Please rank the value of these potential long-term impacts of public health working with social movements

	Importance							Feasibility										
	low	1	2	3	4	5	6	7	high	low	1	2	3	4	5	6	7	high
Raise awareness of and attract attention to existing and underrepresented health-related issues	<input type="radio"/>																	
Broaden the discipline of public health to include a wider definition of public health issues	<input type="radio"/>																	
Increase research and evidence-based practice of neglected health-related issues	<input type="radio"/>																	
Encourage public health worker participation in social movement activism/advocacy in their professional capacity	<input type="radio"/>																	
Improve public health worker interactions with community members	<input type="radio"/>																	
Increase the general public's understanding of public health's mission to achieve social justice	<input type="radio"/>																	

Please rank the value of the following methods for public health workers to engage with online social movements in their official capacity

	Importance							Feasibility										
	low	1	2	3	4	5	6	7	high	low	1	2	3	4	5	6	7	high
Align public health research objectives with the values of people working within these organizations/social movements	<input type="radio"/>																	

<https://umdsurvey.umd.edu/ControlPanel/Ajax.php?action=GetSurveyPrintPreview>

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	Importance							Feasibility										
	low	1	2	3	4	5	6	7	high	low	1	2	3	4	5	6	7	high
Educate the public with research-based knowledge on solutions to health-related issues discussed by these social movements	<input type="radio"/>																	
Facilitate listening sessions with communities members and social movements activists to address health concerns through community-based participatory research and interventions	<input type="radio"/>																	
Publish papers discussing these social movements as based around health issues	<input type="radio"/>																	
Utilize social media to get professional public health groups involved in these issues online	<input type="radio"/>																	

Please rank the value of analyzing the following aspects of twitter data regarding social movements as they relate to public health

	Importance							Feasibility										
	low	1	2	3	4	5	6	7	high	low	1	2	3	4	5	6	7	high
Sentiment analysis (positive and negative emotions shown by text in tweets)	<input type="radio"/>																	
Examining central themes present in tweets	<input type="radio"/>																	
Obtaining descriptive information on people involved in posting tweets	<input type="radio"/>																	
Examining hashtags and URLs referred to in tweets	<input type="radio"/>																	
Analyzing health-related words obtained from tweets	<input type="radio"/>																	
Analyzing the degree to which tweet content aligns with the mission and values of the social movement	<input type="radio"/>																	

Please rank the value of public health workers using an analysis of twitter data from social movements for public health in the following ways

	Importance							Feasibility										
	low	1	2	3	4	5	6	7	high	low	1	2	3	4	5	6	7	high
Present data to communities to spark conversation about the impact of these health-related issues	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											
Use data to frame the messages of social movements as public health issues in published papers	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											
Use data to help frame the messages of social movements as public health issues in media campaigns, including social media	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											
To direct research areas and resources towards the health issues discussed in tweets	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											
To discuss among public health colleagues the relationships between these social movements and public health work	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											

Please rank the value of using the following methods to engage the public health workforce to utilize social media data

	Importance							Feasibility										
	low	1	2	3	4	5	6	7	high	low	1	2	3	4	5	6	7	high
Demonstrate the value through research and publication in respected journals	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											
Get trusted public health professionals to advocate for use of social media data analysis	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											

	Importance							Feasibility										
	low	1	2	3	4	5	6	7	high	low	1	2	3	4	5	6	7	high
Educate public health workers in how to effectively utilize social media data and other new technology to help them achieve their research goals	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											
Devote research to follow up on the impact of social media data analysis, then promote the findings	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											
Train public health workers to teach community-based organizations to utilize social media data and other new technology to help them achieve their organization's goals	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											
Showcase the use of social media data through conference exhibits, online resources and how-to guides, research papers and trainings	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											

Please rank the value of addressing the following barriers to the public health workforce using social media data analysis

	Importance							Feasibility										
	low	1	2	3	4	5	6	7	high	low	1	2	3	4	5	6	7	high
Lack of a qualified workforce with necessary skill sets to use this type of information appropriately	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											
Constant changes in social media; the need to constantly stay up-to-date with emerging trends and current events	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											
Lack of validated analytics for this purpose	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											
Lack of measurable outcomes relating to health behavior from use of social media data	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											

	Importance							Feasibility										
	low	1	2	3	4	5	6	7	high	low	1	2	3	4	5	6	7	high
Bias in self-reported data; not knowing who sent the information and if the content is accurate	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											
Peers in public health not viewing social media as a legitimate data source for in-depth analysis	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											

Please rank the value of the following ideas to encourage the public health workforce to engage with online social movements in a manner relevant to improving health

	Importance							Feasibility										
	low	1	2	3	4	5	6	7	high	low	1	2	3	4	5	6	7	high
Educating the public health workforce on the possibilities of social media data use in research	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											
Educating the public health workforce on how to interact with activists and social movement advocates	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											
Ensuring workers job security when advocating for social movements relating to health in their professional capacity, regardless of politics	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											
Using publications to show other public health professionals how these social movements relate to health	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											
Increasing available funding for public health work with community members and social activists	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>		<input type="radio"/>											

Are there any other suggestions you have for engaging the public health workforce with online health-related social movements that were missing from this survey?

	Importance							Additional comments: If you do not believe the item is of high importance (rate <5), please state why
	low 1	2	3	4	5	6	7 high	
Addressing the lack of measurable outcomes relating to health behaviors from use of social media data	<input type="radio"/>							
Addressing the barrier of peers in public health not viewing social media as a legitimate data source for in-depth analysis	<input type="radio"/>							
Encouraging the public health workforce to engage with social movements by increasing available funding for public health work with community members and social activists	<input type="radio"/>							

The following items were ranked as very important action items that ALSO had a high feasibility level. Please rank the following items on a scale from 1 to 7 (7= very high importance/very high feasibility and 1=very low importance/very low feasibility). If you do not believe these items are both important and feasible, please state why. If you do believe these items are both important and feasible, please list any first steps required to make these ideas actionable.

	Importance							Feasibility							Additional comment If you do not believe these items are both important and feasible, please state why. If you do believe these items are both important and feasible, please list any first steps required to make these ideas actionable.
	low 1	2	3	4	5	6	7 high	low 1	2	3	4	5	6	7 high	

Appendix H: Survey administered to participants in round 3 of Delphi study

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	Importance							Feasibility							Additional comment If you do not believe these items are both important and feasible, please list any first steps required to make these ideas actionable
	low 1	2	3	4	5	6	7 high	low 1	2	3	4	5	6	7 high	
Potential long-term impacts of public health working with social movements by increasing the general public's understanding of public health's mission to achieve social justice	<input type="radio"/>														
Facilitating listening sessions with community members and social movement activists to address health concerns through community-based participatory research and interventions	<input type="radio"/>														
Using an analysis of twitter data from social movements to help frame the messages of social movements as public health issues in media campaigns, including social media	<input type="radio"/>														
Supplying the public health workforce with skill sets to use and analyze social media information appropriately through educational training and workshops	<input type="radio"/>														

The following items were ranked the lowest for feasibility. Please rank these from 1-7 (7= very high feasibility and 1=very low feasibility) for their feasibility. Additionally, please list what you believe are the major barriers to achieving the following items.

	Feasibility							Barriers Please list any major barriers to achieving these items
	low 1	2	3	4	5	6	7 high	
Potential long-term impacts of public health working with social movements to increase research and evidence-based practice of neglected health-related issues	<input type="radio"/>	<input type="text"/>						
Devoting research to follow up on the impact of social media data analysis, then promote the findings as a way to engage the public health workforce with social media data	<input type="radio"/>	<input type="text"/>						
Addressing the lack of measurable outcomes and data validity relating to health behaviors from use of social media data by the public health workforce	<input type="radio"/>	<input type="text"/>						
Addressing the bias in self-reported social media data; not knowing who sent the information and if the content is accurate	<input type="radio"/>	<input type="text"/>						
Addressing the barrier of peers in public health not viewing social media as a legitimate data source for in-depth analysis	<input type="radio"/>	<input type="text"/>						
Ensuring job security for public health workers when advocating for social movements relating to health in their professional capacity, regardless of politics	<input type="radio"/>	<input type="text"/>						

Do you have any additional comments, questions, or concerns regarding this survey or the previous surveys in this Delphi study?

A large, empty rectangular box with a thin grey border, likely intended for a user to enter a name or email address.

Would you like to be kept updated on future developments of this research project?

- Yes, please keep me updated
- No, I do not want to receive any research updates

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Appendix I: Social activist interview guide

General Questions:

- Do you consider yourself a social activist? Do you prefer another term to “social activist”?
- How would you define an “activist”? (If other term preferred, how does that differ from an “activist”?)
- What cause(s) do you or have you supported as an activist (or other similar term)? How many years have you spent advocating (in general and for this specific cause)?
- How active are you in supporting this cause? What is your role as an activist?

Social Media:

- How do you prefer to get information about your cause(s)?
- Do you use social media? Do you post on social media or read message from others? Both?
- Do you use social media to advocate for your cause(s)? What type of social media? How frequently do you use it? In what way do you use it? What type of messages do you send?
- Do you consider your cause an online social movement?
- Do you participate in your cause more in person or online? How much time would you say you spend each week on each?

Academia

- As an activist, have you ever worked with an academic researcher on a project? (Researcher defined as someone who works at a college or university—someone who wants to collect data or information from you to better understand a particular problem/issue)
- Do you believe working with academic researchers would benefit your cause?
 - How so or why not?
- Have you ever been a participant in a research study in your activist capacity?
 - If so, what role did you play? (Participant only, involved in design of study, etc.)
 - If so, how were you contacted about the study? Did you have a previous relationship with the researchers?
 - If not, have you ever been approached by a researcher asking you to be part of a research study based on your experience as an activist?
 - If not, would you be interested in participating in a research study to further the goals of a cause you are passionate about?
 - If yes, what would be an effective strategy for an academic researcher to reach out to you about this project?

- What would the researchers need to say to get you on board, and how should they contact you ---email, social media, etc.?
 - If no, why not?
- What would hold you back from participating in such a study?
- What barriers do you think would hold other activists in your cause back from participating in a research study?
 - How could these barriers be overcome?
- What is your experience with formal education?
- How important is trust between activists and researchers? How could issues of trust be addressed by researchers? What could be done to gain your trust?

Public Health

- Have you ever heard of public health? What do you know about it?
(Give APHA definition of public health to participant; APHA definition of Public Health: Public health promotes and protects the health of people and the communities where they live, learn, work and play.)
- Do you believe your cause/social movement relates to public health?
 - How so or why not?
- Would it be a good thing for public health workers to engage more with your cause/social movement?
- How would you like to see them do that?
- Is there a way that public health workers should definitely not try to engage with your cause? Why not?
- Is there anything else you want me to know about your work or about how academic researchers or public health professionals should interact with activists?
- Do you know any other activists who would be interested in participating in an interview? If so, are you willing to share their contact information with me?

Appendix J: IRB Approval for New Project



1204 Marie Mount Hall College Park, MD 20742-5125 TEL 301.405.4212
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INSTITUTIONAL REVIEW BOARD

DATE: March 1, 2018

TO: Abigail Bickford, M.S.
FROM: University of Maryland College Park (UMCP) IRB

PROJECT TITLE: [1159787-1] An Exploration of #BlackLivesMatter: Using the Delphi Technique to Determine How the Public Health Workforce Can Engage with Online Health-related Social Movements

REFERENCE #:
SUBMISSION TYPE: New Project

ACTION: APPROVED
APPROVAL DATE:
March 1, 2018
EXPIRATION DATE:
February 28, 2019
REVIEW TYPE: Expedited Review

REVIEW CATEGORY: Expedited review category # 7

Thank you for your submission of New Project materials for this project. The University of Maryland College Park (UMCP) IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

Prior to submission to the IRB Office, this project received scientific review from the departmental IRB Liaison.

This submission has received Expedited Review based on the applicable federal regulations.

This project has been determined to be a Minimal Risk project. Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval before the expiration date of February 28, 2019.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Unless a consent waiver or alteration has been approved, Federal regulations require that each participant receives a copy of the consent document.

Please note that any revision to previously approved materials must be approved by this committee prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others (UPIRSOs) and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office. Please note that all research records must be retained for a minimum of seven years after the completion of the project.

If you have any questions, please contact the IRB Office at 301-405-4212 or irb@umd.edu. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Maryland College Park (UMCP) IRB's records.

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