AIDS IN ACTION:

A NEW MOVEMENT LED BY CANADIANS LIVING WITH HIV

& ITS IMPLICATIONS ON CRITICAL ANTI-OPPRESSIVE SOCIAL WORK PRACTICE

by

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ABSTRACT

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Master of Social Work, 2017
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Conducted by an HIV+ activist-researcher, the study reported upon in this MRP aimed to 1) explore the challenges and opportunities faced by a new movement led by Canadians living with HIV to place the affected community of people living with HIV/AIDS (PHAs) back to the forefront of the national HIV response; and 2) establish the key factors and conditions that may help strengthen this community-led effort. The qualitative study utilized the Positive People Centred Perspective as theoretical framework comprised of interviews with key Canadian HIV+ activists on their reflections of the recent efforts by the new Canadian Positive People Network (CPPN) to create a collective voice for Canadian PHAs and their views of the essential elements that are necessary for the network and movement to thrive. Results of the research will help strengthen the development of CPPN and inform critical, anti-oppressive social work practice and scholarship.

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LAND ACKNOWLEDGMENT

As a settler on Turtle Island and a Master of Social Work student at Ryerson University, I would like to first acknowledge the land I live on, as developed by the Ryerson Aboriginal Education Council:

> Toronto is in the 'Dish With One Spoon Territory'. The Dish With One Spoon is a treaty between the Anishinaabe, Mississaugas and Haudenosaunee that bound them to share the territory and protect the land. Subsequent Indigenous Nations and peoples, Europeans and all newcomers have been invited into this treaty in the spirit of peace, friendship and respect.

As HIV heavily impacts Indigenous Peoples and communities locally and worldwide due to the historical and social marginalization created by colonization, western imperialism, systemic discrimination, and genocide, I would like to preface by stating that I stand in solidarity with Indigenous and Decolonization movements locally and globally, and I commit to walking along with and supporting my Indigenous brothers and sisters as we find a solution to end AIDS.

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- Dr. Lynn Lavallée, from whom I have gained insights on critical approaches to research, and an understanding of how I as a settler immigrant can stand in solidarity and walk alongside with Indigenous Peoples and Communities respectfully.

DEDICATION

As a person living with HIV, a person who lived with and was cured from an HIV/Hepatitis C (HCV) co-infection, an Asian gay, cisgender, immigrant man living in the diaspora, a person who used/injected substances, a community mobilizer and activist, and a co-founder of the Canadian Positive People Network (CPPN), I would like acknowledgement in this major research paper to go to:

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CHAPTER 1. INTRODUCTION & THEORETICAL FRAMEWORK

At the end of 2015, over 36 million people lived with HIV/AIDS (PHAs) and more than 35 million lives were lost due to the illness globally (UNAIDS, 2016). In Canada, the Public Health Agency of Canada (2014) estimated about 71,300 Canadians lived with HIV/AIDS at the end of 2011. A historical look at the Canadian HIV response would reveal the Canadian Government did not start addressing the epidemic until 1998 due to activist pressure and anger for their inaction (Rayside & Linquist, 1992). In 2004, the Canadian Government updated its national HIV/AIDS strategy *the Federal Initiative to Address HIV/AIDS in Canada* for the last time (Public Health Agency of Canada , 2014). A year later, in 2005, the Canadian Public Health Association made a call for action to the government for a renewed effort to address HIV in *Leading Together: Canada takes action on HIV/AIDS (2005-2010*). This blueprint challenged governments, organizations, and individuals for a more strategic, coordinated approach to HIV, and made a particular recommendation on the participation and empowerment of people living with HIV/AIDS.

Despite PHAs having actively engaged and played an instrumental part of early AIDS response, neoliberalism gradually displaced PHAs from their roles as activists into the sidelines of the HIV discourse and the needs of PHAs are often not met by the present-day professionalized HIV industrial complex (Cain & Todd, 2009; Guta, Murray, & McClelland, 2011; Kerr, 2014; Namaste, 2015). Moving forward a decade later, PHAs in Canada have mobilized together and formed the Canadian Positive People Network (CPPN) in May 2015 as an independent, national network for and by Canadians living with HIV. A network which is the first of its kind in Canada, CPPN was formed to create a collective voice for the affected community of PHAs to counter the prevailing neoliberalist HIV and ever-increasing professionalized response to HIV (CPPN, n.d.; Leahy, 2015). This MRP explores the challenges

and opportunities, as well as the key factors and conditions that may help strengthen CPPN as a community-led effort by Canadians living with HIV and HIV co-infections.

Unlike many other countries in the world where networks of PHAs serve as an integral part of the local national HIV response, Canada is unique in a sense that an independent peer-led national network of PHAs like CPPN had never formed until two years ago. A critical historical review of HIV/AIDS serves as a testament of the extreme oppression and marginalization which people living the health condition had to---and continue to---endure. As people living with HIV/AIDS (PHAs) rallied to resist the systemic oppression and marginalization, they demanded for their rights to be included at every decision-making level within the HIV response (The Denver Principles, 1983). In 1994, member states of the United Nations ratified a principle to be known as the Greater Involvement of People Living with HIV/AIDS (GIPA) (UNAIDS, 1999), a key guiding value to promote and ensure PHAs are engaged throughout the HIV response ranging from service planning, formulation, implementation, and evaluation of HIV programs and policies (Paxton & Stephens, 2007).

Since there has not been a successful national PHA body formed in Canada since the advent of the AIDS epidemic more than three decades ago, the recent establishment of CPPN as Canada's only independent national PHA network, has been interpreted by Canadian PHAs as a much-cherished wish and much needed void to fill within the Canadian HIV movement and a new beginning to create tangible, people-centered, community-led changes within the HIV response. As a new grassroots and unfunded network, CPPN is in its formative years which can benefit greatly from collecting constructive feedback and rigorous research knowledge as it strengthens its presence in the movement.

History of a Canadian HIV Movement Without a PLHIV Network

Charles Roy (1998), the late Canadian HIV+ activist and former Executive Director of the AIDS Committee of Toronto, wrote in his dissertation "*Living and Serving: Persons with HIV in the Canadian AIDS Movement"* that within the Canadian HIV response, seven grassroots, local or provincial PWA (People With AIDS) organizations existed in 1992/1993 when he conducted his doctoral research. These PWA organizations were: the Toronto PWA Foundation located in Toronto (TPWAF), le Comité des personnes atteintes du VIH (CPAVIH) in Montreal, the Vancouver PWA Society (VPWAS) in Vancouver, the Body Positive Coalition of Manitoba in Winnipeg, the Edmonton Persons Living with AIDS Society (EPLWAS) in Edmonton, the PLWA (People Living with AIDS) Network of Saskatchewan in Saskatoon, and the Noa Scotia PWA Colaiton (NSPWAC) (Roy, 1988). Of these PWA organizations, only two organizations (the Vancouver PWA Society and Montrea's CPAVIH) had policies which guaranteed their board of directors were comprised exclusively of PWAs (Roy, 1998). The other PWA organizations, while initially having similar by-laws requiring their boards to be held only by PWAs, began to change its policies from an exclusive PWA board to a PWA-majority board due to "pragmatic realities" such as succession planning an ensuring the conitnuity of leadership of skills within organizations (Roy, 1988, p. 28).

Compared to the Canadian AIDS Society (CAS), which Roy (1988) had depicted as a "rapidly growing national coalition of community-based organizations involved in the fight against AIDS" (p. 1). With over 100 organizations CAS was "generally regarded worldwide as a successful model for community organizing" (p. 1), the peer-oriented National Organization for People Living with HIV, or referred by Roy as the "Network" (p. 29), was described as a "struggling, loosely defined collection of PWA organizations from different parts of the country" (p. 2). This group was documented by Rayside and Linquist (1992) as the "National Coalition of

People Living with HIV" (p. 61), with a slightly different name. The inconsistency in how these two respected Canadian HIV activists/scholars documented the name of this peer-focused coalition/network might be indicative of the limited presence or an inability of the group to effectively organize. The failure of the Network was attributed to a lack of effective leadership and the passing of its key founding and steering committee members Doug Wilson and Pei Lim; the increase in participation of PWAs within CAS as a national umbrella organization and a failure in engaing the interests of PWAs and funders in the Network; and the decision by the federal government not to fund the Network in 1993 (Roy, 1988). With an absence of a true PLHIV network since the first discovery of AIDS, the emergence of CPPN as an independent, peer-led network has created an opportunity for Canadians living with HIV to attain the "transformation that must put the needs and concerns of the people most affected by AIDS/HIV at the centre of social policy" within the Canadian HIV movement (Kinsman, 1997). As a co-founder of CPPN, in what follows I discuss my subject position as a researcher of the study.

Subject Positionality

As a Master of Social Work (MSW) student and a person living with HIV, I am truly honoured and privileged that I can conduct a graduate research for my major research paper (MRP) and lead a knowledge production process on a subject that is close to my heart. Since 2010, I have utilized my lived experience as a person living with HIV---in conjunction with returning to post-secondary education to study social work, working in the community---to become an activist within the HIV response. Within the past year and a half, I helped co-found and was elected as the chairperson (then one of the co-chairs after the change in governance structure) of CPPN. While Western research often emphasizes positivist epistemology, objectivity and a clear separation between the researcher and the researched, my graduate research is focused on real-time HIV activism in Canada through the community mobilization

efforts of CPPN, a topic and organization which I am intimately engaged in. As a critical social worker-researcher currently trained in anti-oppressive practice (AOP), my subject positionality is one where I have purposefully and intentionally situated myself in this study as a researcher, a knowledge co-creator and a vested community member living with HIV. As a person living with HIV, an HIV activist, and social work student, this research holds great meaning and significance to me and the community of which I am a part.

Problem Statement

The objective of the research is to help strengthen the Canadian PLHIV and HIV movement through CPPN and to inform the social work scholarship so practitioners can better support PHAs. This research will privilege the often-subjugated voices and lived experiences of PHAs as valid academic knowledge through utilizing research as an epistemic production tool to document, inform, and bolster the community mobilization efforts currently being led by Canadians living with HIV and HIV co-infections as a historically marginalized group.

In addition, I hope the research results can enhance and enrich the practice knowledge and scholarship of critical and anti-oppressive social workers in how they can better understand support peer-led movements. The community-led collective organized by Canadian PHAs through CPPN serves as an active resistance against the oppressive web of marginalization, social ostracization, discrimination and subjugation which PHAs face on a daily basis within the dominant society. The coming together of Canadians living with HIV and HIV co-infection as historically marginalized group and its current mobilization efforts to form our own network is an area of topic that has great relevance to the Canadian PLHIV and HIV communities. As opposed to conducting research just for the sake of research, the findings of this study will be shared with CPPN to help strengthen the young network in their efforts to create a stronger collective PHA voice within the AIDS industrial complex in a western, neo-liberal state. The

epistemic knowledge resulting from the study will be community-owned by Canadian PHAs and CPPN, and has the potential to help create positive, transformative changes in the Canadian PLHIV and HIV response through the strengthening CPPN.

Theoretical Framework: A Positive People Centred Theoretical Perspective

In his work as a Canadian AIDS activist and scholar, Kinsman (2006) proposed the process of conducting research is better served if it can be transformed from "a monological enterprise organized around the university-trained and 'connected' researchers to becoming a much more dialogical project with many centres and many voices weaving together an analysis of the social relations of struggle movements face" (p. 155). For my research, the study has been designed within a constructivist-interpretivist research paradigm and holds the following philosophical stance: an ontological assumption which states reality and truth are constructed in a relativist manner; an epistemological assumption that knowledge is socially constructed between the researcher and research participants; and an axiological assumption that the researcher's values, lived experiences and biases are not separated from---but can be acknowledged and bracketed in--- the empirical research process.

As such, my study not only privileges the often subjugated voices and lived experiences of PHAs; it also provides a platform for the HIV+ activists as interviewees and I as the researcher to co-create knowledge that can help benefit the Canadian PLHIV and HIV movements. For this research, I will utilize a "Positive People Centred Perspective," a theoretical framework I have conceptualized based on various established theories and praxis that is utilized and are relevant to the HIV response, CPPN, and the field of social work scholarship.

As a person living with HIV, an HIV activist who is actively engaged in the HIV movement, a community worker, and a MSW graduate student trained in anti-oppressive social work praxis, I have conceptualized the Positive People Relevant Perspective (Hui, 2017), which I

have later termed Positive People Centred Perspective, as an intentional act of resistance to disrupt dominant Western epistemology, academy, and approach to research. The Positive People Centred Perspective is drawn from the following elements: 1) the GIPA principle, a well-established praxis within the global HIV response (UNAIDS, 1999); 2) modern theorizing on citizenship and rights within a neoliberalist and globalized world (Ong, 2006; Kuisma, 2008); 3) critical, anti-oppressive social work theories which challenge power and privilege for transformative change (Baskin, 2003; Benjamin, 2011; Lavallée, 2014; Pon, 2009; Smith, 2011; Wehbi, 2007); and 4) movement-relevant theory, a counterpoint to traditional social movement theories which often place a greater emphasis on academic theorizing than relevance to social movements and community mobilization that are taking place real-time on the ground (Bevington & Dixon, 2005). Through integrating the above elements of theories and praxis, the resulting Positive People Centred Perspective is one that is people-centered and relevant to the mobilization efforts of PHAs, and aims to disrupt existing power structures to create transformative changes to further emancipate PHAs through action, research, knowledge production, and social work scholarship and practice.

Greater Involvement of People Living with HIV/AIDS (GIPA)

As PHAs rallied to resist the systemic oppression and marginalization, they demanded for their rights to be included at every decision-making level within the HIV response (The Denver Principles, 1983). In 1994, member states of the United Nations ratified a principle to be known as the Greater Involvement of People Living with HIV/AIDS (GIPA) (UNAIDS, 1999), a praxis which my research is centred on. The principle emphasizes people living with HIV/AIDS should play a key role in the planning, formulation, implementation and evaluation of HIV programs and policies, and notes that there are various levels of involvement PHAs can become engaged in within the HIV response (Cain & Todd, 2009, Paxton & Stephens, 2007; Berg et al, 2015). GIPA

is not only a principle by concept; instead, GIPA is a praxis because it is a living principle which requires honouring and implementation. With this research centered on GIPA, it is especially important that I and other PHAs become actively and meaningfully engaged in the research and knowledge production process to strengthen a positive people network in Canada. As a living concept, GIPA has been further theorized from a critical stance by PHAs.

According to McClelland (2011), a peer and activist living with HIV, GIPA can be further categorized into two forms: instrumental GIPA and emancipatory GIPA. Instrumental GIPA is a form of GIPA which involves PHAs to serve particular functions---ones which require PHAs to become more "professional" within a neoliberal, professionalized work setting with the aim to enable HIV programming and policies to become 'more acceptable, relevant and effective'" without critically questioning or challenging the existing power structures (McClelland, 2011, p. 14). Emancipatory GIPA, on the other hand, challenges the "structural violence, systematic oppression, institutional racism, colonization, homophobia, cisgender normativity, sexism, classism and the many ways in which we are continually marginalized and exploited" and works towards the strengthening of PHAs through progressive social change by respecting the self-determination of the people (McClelland, 2011, p. 14-15). For my study, I will utilize emancipatory GIPA as part of the Positive People Centred Perespective theoretical framework.

Contemporary Citizenship and Rights

To facilitate the framing, exploration, and analysis of HIV activism, which are often grounded and justified by human rights and rights-based rationales, I have included critical contemporary theorizing of citizenship and rights in this research. The first theorizing of citizenship comes from the work of critical anthropologist Aihwa Ong (2006) and her concept of the "mutations in citizenship" that has taken place in a world of globalization and neoliberalism.

Ong describes the neoliberal world we live in as an "ever-shifting landscape shaped by the flows of markets, technologies, and populations" resulting in a mutated notion of citizenship which transgresses the traditional understanding of citizenship that is confined within geo-political borders. Instead, the conceptualization of citizenship and the elements of rights, entitlements, and human rights are re-defined within a normative neoliberalism frame (Ong, 2006, p. 499). In particular, Ong (2006) notes that territorialized citizenship and deterritorialized human rights have created a platform for newer rationales for claims of rights for resources, entitlements, and protection for the mutated citizens: "postnational" migrant citizens with partial and limited civil rights; "flexible" self-enterprising foreign citizens who exemplifies neoliberal market ideals, "technological" citizens who possess the right kind of knowledge in today's world; "cyber-based" citizenship where every citizens have formed strong linkages with cyber-based communities; and "biological" citizens based on the rights for mankind to health, healthy body, biological survivial and "biowelfare" (p. 504).

The second theorizing of citizenship and rights comes from international relations lecturer and political scientist Mikko Kuisma (2008). Kusima notes the concept of rights-based citizenship is defined as a contract between the existing power structures of the state and society where citizenship is a "membership which guarantees equality between citizens" (p. 622) despite newer challenges resulting from globalization in how citizens can claim and define equality or demand participation. He argues that as opposed to the traditional territorialized notion of citizenship that is tied to the nation-state, the core values of citizenship are equality and participation, where citizenship participation is a crucial element which defines citizenship rights, and such form of civic participation, "can be used as a way of challenging the prevailing inequalities" (Kuisma, 2008. P. 622). These modern theories on citizenship and rights fit well

with the efforts of activists in contemporary times, and will serve as one of the key theoretical lens for this study.

Critical, Anti-Oppressive Social Work

For the theorizing of critical, anti-oppressive social work, I have elected to employ the scholarship of social work scholars and Ryerson professors Cyndy Baskin, Akua Benjaim, Lynn Lavallée, Gordon Pon, Kristin Smith, and Samantha Wehbi. Critical, anti-oppressive social work theories are centred on examination the history and sources of social inequalities, and the active challenging of dominant power and privileges to end oppression and marginalization for transformative changes (Benjamin, 2011). The scholarship also focuses on uncovering the intersecting power and privileges and interconnectedness of the individual to the systemic and structural forces within a society, finding ways to disrupt the dominant discourse and knowledge production systems, and challenging the social work practitioner to utilize reflexivity to link social work theory to practice through a critical, anti-oppressive praxis (Baskin, 2003; Lavallée, 2014). Meanwhile, Smith (2011) calls for critical, anti-oppressive social work practitioners to challenge our neoliberalized profession and service delivery spaces by resisting discourse which focus on efficiency, numbers, evidence-based practice, and addressing the structural causes of social problems (p. 210-211).

Meanwhile, Lavallée (2014) describes anti-oppressive research as an approach to research that is reflective, reflexive, political---a research approach which actively resists oppressive power and privilege, ensures that the research findings are properly disseminated, and aims to create transformative change through building the capacities of marginalized communities from within. As for a critical, anti-oppressive social work approach to community organizing, Wehbi (2007) highlights the need for both the obstacles and facilitative conditions of community organizing and research be made available so activists and social work practitioners

alike can learn from the lessons to survive the "occasional failures and slowness of progress" in the efforts to effect change (p.77). To challenge oppression is to resist the dominant powers that maintain marginalization. Benjamin (2011) highlights resistance as an essential component in transformative and politicized social work, and notes that such praxis requires a thorough assessment of barriers, opportunities and potential supports as well as planning multiple strategies with allies to resist effectively. Through integrating theories with practice and the importance to create transformative change in action, I have integrated critical, anti-oppressive social work praxis in the Positive People Centred Perspective in my research.

Movement-Relevant Theory

In my process of researching academic theories to formulate the Positive People Centred Perspective, I encountered a critique of social movements and social research which states that social movement theories all tend to "construct social movements as objects of analysis and focus their attention on social movements themselves rather than on explicating the social relations of struggle in which these movements are engaged" (Frampton, Kinsman, Thompson, & Tilleczek, 2006, p. 11). Such a critique prompted me to gain awareness that much of the available theories on social movements had not focused on what is truly relevant to the social activists who are engaged in the movement, or that they are not truly relevant and applicable to the social movements themselves. Instead of utilizing a social movement theory that creates little significance to the community-mobilizations taking place on the ground, I have elected to utilize movement-relevant theory for this study. Movement-relevant theory is an activist-focused theory which emphasizes the importance of ensuring the work and theorizing of any social movements by academics and researchers must remain relevant to the activists engaged in the movements (Bevington & Dixon, 2005). As such, movement-relevant scholarship is a counterpoint to traditional social movement scholarship in that it does not focus on any or any particular life-

stage or variables of the social movement such as the movement's culture or structure (Bevington & Dixon, 2005). Instead, movement-relevant theorists recognize that activists and social movement participants produce theory as well, and the theorizing of social movement is thus produced through a dynamic and reciprocal engagement with the social movement and the actors of movements, where the focuses is placed on whether the theory holds *relevance* for the social movements being explored (Bevington & Dixon, 2005).

To ensure movement-relevant scholarship produces accurate theories, Bevington and Dixon (2005) note that movement-relevant research "cannot be uncritial reiteration of pre-existing ideas of a favored movement," and thus must consider exploring useful information and knowledge from both favored or opposing social movements (p. 191). Within a movement-relevant research framework, the researcher does not need to be detached from the movement; instead, the direct connection of the researcher to the social movement is considered as essential and value-added as the information produced through an engaged resarch process is considered to be more accurate and relevant (Bevington & Dixon, 2005). The theorizing of movement-relevant theories is not reserved only to uncovering immediate strategic tactical issues, but can include critical inspections on isues such as how power and exclusion operate within specific movements, or relevant issues that have not been brought forth by movement participants (Bevington & Dixon, 2005). Ultimately, the movement-relevant scholarship gages the success of theories or information produced through whether activists have incorporated the knowledge into the strategizing of the movement itself (Bevington & Dixon, 2005).

Researching with the Positive People Centred Perspective

The Positive People Centred Perspective attempts to fill a gap left by the Western academic of inquiry on the ontological realities as lived by PHAs and their engagement in activism as a result of marginalization and oppression they experience under neoliberalism. The

framework has been conceptualized through integrating existing theories and principles into a theoretical framework where the needs and well-being of PHAs, as well as HIV activist movements are centered as the theoretical approach (See Appendix F). My research focuses on the community mobilization efforts of CPPN within the Canadian HIV movement in relations to Canadians living with HIV, the academy, and the existing neoliberal power structure. This theoretical perspective will provide an integrated framework on how the research results be analyzed as related to the interconnected historical, contextual, individual, collective, institutional, systemic, political and structural factors that impact Canadians PHAs and how CPPN can be strengthened.

In what follows, I delve into the scholarship reviewed to examine this topic and then proceed to a discussion of my methodology. The latter part of the MRP presents the findings and implications for social work practice.

CHAPTER 2. LITERATURE REVIEW

A substantive literature review was conducted based on available empirical research studies on my research topic based on the following keywords: “HIV”, “Canada”, “self-organi*”, “GIPA”, “social movement”, “activism”, “community organi*”, “self advocacy”, and “national network formation”. Four major themes have emerged: 1) the history of HIV activism; 2) the GIPA Principle; 3) evolvement of the HIV response and the structural barriers facing PHAs in Canada; and 4) challenges to GIPA and facilitators to PHA peer engagement. I will conclude by highlighting the gaps in the literature and my research question.

The History of HIV Activism

One major theme from the substantive literature review described the historical and contextual factors that PHAs faced during the AIDS epidemic. In the early 1980s, LGBTQ groups in the US and the industrialized West often led grassroots HIV efforts as gay men encountered immense stigma from society and many of them died due to government inaction and a lack of available treatment and services (Hoffman, 2008; Parker, 2011; Smith & Whiteside, 2010). As more marginalized segments of society---women, children, racialized minorities, people who inject drugs, people who perform sex work, those who live in poverty---became increasingly affected by HIV with increased incidence and prevalence rates, the HIV activist movement faced a period of fragmentation (Lovell & Rosenberg, 2011; Parker, 2009). In the 1990s, economic disparity created tensions between those who had access to treatment in the global North and those who continue to die in the global South, thus transforming HIV activism into a global solidarity movement to fight against treatment access barriers and structural inequities (Parker, 2009; Smith & Whiteside, 2010).

By the early to mid 2000’s, the once popular concept of AIDS exceptionalism----a view that considers HIV as a unique health and social issue that deserves its own dedicated funding

and resources----became heavily contested, and HIV activism became less radical and more focused on the scaling up and monitoring of the HIV response (Parker, 2011; Smith & Whiteside, 2010). In his sociological and anthropological recount of the HIV response, Parker (2011) poignantly noted that it was the grassroots activists and the communities affected by HIV/AIDS that had played "a key role in shaping initial social and political responses to the epidemic around the world" (p. 22). He highlighted how grassroots activists have succeeded in building transnational coalitions which allowed for an unprecedented level of community mobilization in ways that no other global health issue has witnessed, a fact which gives hope for the future (Parker, 2011).

The GIPA Principle

As previously mentioned in the theoretical framework section, GIPA is a key guiding value which ensures PHAs are engaged throughout the HIV response, ranging from service utilization, service delivery, as well as the planning, formulation, implementation and evaluation of HIV programs and policies (Berg et al., 2015; Paxton & Stephens, 2007; UNAIDS, 1999). As a principle, GIPA is similar to peer-based approaches and user-driven philosophies that firmly believe the direct engagement of people with lived experiences will result in better quality of life and enhancement of the planning and delivery of programs and services for members of the affected community (Berg et al., 2015; Kerr et al., 2006). In the literature search, two frameworks of GIPA were described: 1) the UNAIDS (1999) six-tier pyramid model of user-involvement which places the target audience of HIV+ service users on the bottom and HIV+ decision-makers on the top; and 2) the Population Council/Horizons model which describes GIPA as ensuring PHAs have the abilities to make autonomous decisions and having PHAs highly visible throughout the HIV response (Paxton & Stephens, 2007). In sum, GIPA is an act of active resistance spearheaded by PHAs so their lived knowledge and experiences can become

a fundamental part of the HIV response.

Amongst the substantive literature found on GIPA, Paxton and Stephens (2007)'s study stood out as one which exemplifies GIPA as a praxis. The research examines how successful GIPA was implemented and its impact in three Asian countries. What I appreciated about this study was that Paxton and Stephens (2007) disclosed in the journal article of their HIV+ status, and noted that having HIV+ researchers involved in the knowledge production process is both significant and necssary. Meanwhile, the study conducted by Restall, Carnochan, Roger, Sullivan, Etcheverry, and Roddy (2016) utilized non-traditional and emancipatory group-work approaches such as the world café and dotmocracy methodologies to better engage PHAs in a research-focused community consultation process, an effort which I applaud as they were succcessful in effectively and meaningfully engaging PHAs without research knowledge in a forum that was focused on research.

Evolvement of the HIV Response and Structural Barriers Facing PHAs in Canada

One of the key themes from the literature review describes the changes and evolvement of the HIV response in Canada. In a study conducted with Ontario service providers serving PHAs, Cain and Todd (2009) noted the advancement of HIV medication created changes and tension within the HIV response between service providers and the target populations of PHAs whom they served. With PHAs now being able to live longer, their needs evolved and service providers struggled to fully meet the changing needs of their clientele. In a subsequent study conducted in Ontario conducted with AIDS service organizaiton staff, volunteers and service users, researchers learned the changes which took place within the HIV response included the improved health of PHAs, the changing demographics of HIV/AIDS, and the pressure and transformations needed by AIDS service organization to address these changes (Cain, Collins, Bereket, George, Jackson, Li, Prentice, and Travers, 2014). In another study, researchers found

that amongst PHAs who transition from service users to service providers in Toronto, such groups of PHAs often have less access to services and support, and being able to address mental health and self-care needs, and finding new support and coping mechanisms after their role transitions are emerging priorities (Li, Wales, Wong, Owino, Perreault, Miao, Maseko, Guiang, 2015).

Meanwhile, service providers who work with aging PHAs expressed concerns that the current housing and long-term care systems do not adequately meet the needs of this cohort of PHAs, and their primary concerns are having access to a well-coordinated waitlist for affordable housing and alternative therapies in long-term care facilities or retirement homes (Furlotte, Schwartz, Koornstra, & Naster, 2012). Of these studies, the Li et al. (2015) study stood out as an exemplar research where PHAs are meaningfully involved throughout the research process from conceptualizaiton to the data analysis and interpretation process.

While the HIV response has gradually evovlved through time, Canadians living with HIV continue to face many structural barriers. For sex-workers living with HIV in Vancouver, the structural barriers they faced as related to the uptake and adherence to HIV medication included factors such as incarceration, recent migration, substance use and younger age were correlated to gaps in the use of anti-retroviral medications (Goldenberg, Montaner, Duff, Nguyen, Dobrer, Guillemi, and Shannon, 2016). Meanwhile, researchers found Canadian PHAs who are food insecure tended to be younger, have unstable housing, would procure food in non-traditional means such as trading food for sex or drugs, or have poor mental health (Anema et al., 2016).

Challenges to GIPA and Facilitators to PHA peer engagement

Although the primary aim of GIPA is to ensure PHAs are involved within the HIV response, how GIPA is taken up and implemented by governments and the HIV sector and how PHAs are actually engaged on the ground in AIDS service organizations (ASOs) exemplifies

both the challenges and opportunities as related to the implementation of GIPA principle and the practice of PHA peer engagement. Tokenism and the exploitation of PHAs, along with social and structural barriers such as HIV-stigma, health challenges, access barriers to medical support and counselling, financial barrier, credentialism, and opportunities to build capacities for skills or research were identified by PHAs as barriers to GIPA and PHA engagement (Paxton & Stephens, 2007; Ti, Tzemis, & Buxton, 2012). On a structural level, Paxton and Stephens (2007) note governments often lack a pro-active commitment to engage PHAs in the development of policies. In addition, there is a lack of literature that examines the roles played by PHAs in policy development within the global HIV response, and what governments and organizations may need to provide PHAs to support their engagement in the movement (Paxton & Stephens, 2007; Ti et al., 2012). Given the varying levels of commitments given to GIPA within the movement and the challenges related to the implementation of GIPA**,** the formation of CPPN as a network is a direct attempt by Canadian PHAs to address the gap in GIPA and the structural challenges that PHAs face today an oppressed group.

One key challenge to GIPA is the tokenistic and exploitative engagement of PHAs by the sector (Cain et al., 2014; Maxwell, Aggleton, & Warwick, 2008; Paxton & Stephens, 2007). Cain et al. (2014) note that ongoing stigma and disclosure and limited opportunities for PHAs to become decision-makers are also key challenges as identified by PHAs. Other barriers to the engagement of PHAs and GIPA include individual-level considerations such as health, mental health, financial and income considerations, and need for self-care (Cain et al., 2014; Li et al., 2015; Paxton & Stephens, 2007). On the systemic and structural levels, challenges to GIPA and the engagement of PHAs include: HIV stigma and discrimination; the scarcity of accessible counselling and support services; complex social issues such as the misuse of substances, and food/income/employment insecurity; a lack of skills training or understanding on how to work

effectively with policy makers; a decrease in community activism and a growth of incohesion within communities; and insufficient will by governments to pro-actively engage PHAs in policy development (Cain et al., 2014; Li et al., 2015; Lovell & Rosenberg, 2011; Paxton & Stephens, 2007; Poindexter & Saunders Lane, 2003; Travers, et al., 2008).

Despite the noted challenges to PHA engagement, various studies have also identified facilitators for PHA engagement and GIPA implementation: possessing a sense of connection with others and being involved with a supportive agency or a coalition; having guidance and clarity on how one can express his/her concerns and achieve desired group outcomes; being presented with opportunities to network, learn about community resources, and build capacities to become better community advisors and representatives; building trust and creating mentorship opportunities with researchers; having timely and accessible feedback and the utilization of creative and emancipatory group consultation processes (Lovell & Rosenberg, 2011; Maxwell, Aggleton, & Warwick, 2008; Poindexter & Saunders Lane, 2003; Reed & Miller, 2013; Restall, et al., 2016; Travers, et al., 2008). Systematic and structural facilitators that facilitate PHA engagement and GIPA include: establishing user-driven or community advisory boards; having critical consutlations with agency staff and target community members to plan for appropriate services; and ensuring PHAs have opportunities to become experts and decision-makers in local, regional, national and international service and policy development (Berg et al., 2015; Cain, et al., 2014; Maxwell, Aggleton, & Warwick, 2008; Poindexter & Saunders Lane, 2003).

Critique of the Literature and Research Gaps

While an extensive social science scholarship exists on HIV/AIDS and GIPA, as a critical, AOP social worker-researcher living with HIV, I problematize that PHAs have often been excluded from opportunities to co-create knowledge in research as there is a lack of research capacity building opportunities for PHAs to move past the glass ceiling as peer research

associates (PRAs). The failure of researchers to engage PHAs in research meaninfully past their current roles as PRAs leads to a production of knowledge that is written *about* or speaks *on behalf of* PHAs but not co-created *with* PHAs. Lastly, despite of a large selection of literature on HIV, GIPA, and HIV activism, a research gap exists in terms of research on HIV activism in Canada or social movements led by PHAs within a Canadian context. Given this reality, my research serves as an active resistance by intentionally involving only PHAs in the study to inform the strengthening of CPPN. In addition, my research will contribute to the lack of literature on HIV activist movement and community mobilization efforts led by Canadian PHAs.

Research Questions

As my research is focused on strengthening the current, national organizing effort of CPPN by Canadian PHAs, my study will address the following two research questions:

1) *What are the challenges and opportunities faced by CPPN in its efforts to place PHAs and the affected communities back to the forefront of the country's HIV response?*, and
2) *What are the key factors and conditions that may help strengthen this community-led effort?*

CHAPTER 3. METHODOLOGY

For my research, I have chosen to conceptualize and utilize a methodology which can: 1) put GIPA in action, 2) is based on relevant contemporary critical theories, 3) allows me as a critical researcher to conduct a rigorous study while centering the lived experiences of PHAs as valid knowledge, and 4) help strengthen CPPN as a real-time, grassroots community-mobilization social movement. My research is qualitative in nature, and is based on a critical social constructivist-interpretivist research paradigm and a narrative approach so the personal narratives of key HIV+ activists in Canada can be documented and utilized to strengthen the organizing efforts of CPPN and further inform social work scholarship. A benefit of conducting research under the constructivist-interpretivist paradigm, is that I as the researcher have an opportunity and dialogical space to co-create knowledge with my interviewees (Ponterotto, 2005).

Moreover, the use of the narrative approach is because my study aims to capture the lived experiences of PHAs, turn these into sources of knowledge, and apply them to a social movement that is currently taking place by PHAs in Canada. As noted by Clandinin and Connelly (2000), "narrative is the best way of representaing and understanding experience" (p. 18). Meanwhile, Riessman (2008) notes that the power of stories and narratives have mobilized others into action for progressive social change---as it did in the twentith century major resistance movements such as the civil righs, feminists, and gay and lesbian movements where individuals from margainalized "sat together and told stories about small moments of discrimination….[which] created group belonging and set the stage for collective action" (p. 9). As such, the study's dissemination plan ensures that research knowledge is shared with CPPN where the board, community advisory group, and members of the network will have an

opportunity to learn about the findings of the study and engage in a critical dialogue of how the research knowledge can be best utilized.

Participants and recruitment

Careful consideration was paid to establishing the eligibility criteria for research participants to ensure suitable candidates can take part in the study. The eligibility criteria of the study's participants were:

- a person living with HIV over the age of 17 who resides in Canada;
- have experience in HIV activism (e.g. making positive change for PHAs, serving as an advocate, having taken on leadership positions at ASOs/networks, etc.); and
- someone who is *not* a current member of CPPN.

The rationale to recruit participants who are not directly involved with CPPN is based on the concept of the *critical friend*, an emancipatory approach to conducting research within the field of education research (Costa & Kallick, 1993; Stieha, 2014). Costa and Kallick (1993) define a critical friend as a trusted person who fully understands the context, work and the desired outcomes of the inquiry, asks useful and critical questions and offers an examination of a subject through an alternative lens, and one who actively promotes and advocates for the work. Meanwhile, Stieha (2014) echoes that a critical friend brings "his or her own lenses, which are formed from a unique set of experiences, histories and understanding, into the inquiry," (p. 207) and they are able to identify the blindspots and areas which the subjects themselves may miss. Such approach fits well with one of the key objectives of my research: To create critical insights based on the experiences and perpectives of Canadian PHA activists to strengthen the nascent nascent network of CPPN.

For my study, I opted to utilize purposive sampling as the recritument method. Emmel (2013) notes that purposive qualitative research and sampling sets "the very foundations through

which we purposefully choose information rich cases to be strategically compared in the research" (p. 106). Given that I am well-connected with other fellow activists living HIV across Canada, the use of purposive sampling is an approapriate choice as the potential participants I reached out to would recognize and entrust in me as a fellow peer and activist the HIV community. Such kinship we share as fellow HIV+ activists had enabled an honesty and open sharing by the interviewees during the interview process. To purposively recruit via my personal network, I contacted the potential interview participant once via personal email and allowed interested parties to contact me directly to avoid any sense of coercion for parties to participate in the study against their will (please see Appendix B for recruitment material). Interested study participants were verbally screened via the phone to confirm the eligibility requirement prior to the setting up of in-person or Skype interviews.

I recruited five HIV+ Canadian activists who are not directly involved with CPPN from a diverse intersection of activism experience and demographics in one-on-one interviews. These activists were all long-term HIV survivors and possess a long history of activism either within the HIV or other social justice movement prior to their engagement with HIV activism, with expereinces range from board member of AIDS service organizations, executive director, front-line worker, peer-staff and volunteer. The five interviewees represented a diverse intersection of socio-demographic characteristics, which helped provide a wide range of knowledge and lived experiences of PHA representative that is representative of the epidemic in Canada. Three interviewees resided in Ontario, while one lived in British Columbia and another in Quebec. The gender identities of the interview participants include 2-Spirit, genderqueer, transwoman, and cisgender man and woman, while sexual orientation span from 2-Spirit, queer, gay and heterosexual. Many of the interviewees identified as immigrants to Canada, settler immigrant, or has immigrant roots, and identified as Indigenous, Asian, Black, Latin, and white. The

interviewees represented the five major recognized key prioroty population groups most impacted by the global epidemic: gay, bi men and men who have sex with men; transgender persons; persons who use or inject substances; persons who are or have been incarcerated; and persons who perform sex work.

Data Collection

In-person or Skype one-on-one interviews were conducted utilizing an episodic interview method with a semi-structured interview guide (please see guide in Appendix C) (Flick, 1999; Flick, 2000; O'Toole, 2005). The interviews were conducted in-person at a private, mutually agreed upon location, and Skype interview for interviewees who live out of town. All the interviewees provided informed consent (see Appendix D for the research consent form) prior to the interview. The interviews were audio-recorded and each lasted approximately one and a half to two hours in length.

Episodic interview is a specific narrative interview method where the interviewer will ask specific questions to facilitate participants to tell a story on specific episodes or experiences from their lives (Flick, 2000). O'Toole (2005) adds that episodic interview "links between subjective definitions of topic concept and the concrete examples of situations for the participants" (p. 80). Flick (1999) notes within the interview method, the researcher can ask interviewees four main types of questions: 1) *episodes*, experiences from specific events or situation recalled by the interviewees; 2) *repisodes,* experiences from the accounts of repeated episodes; 3) historical situations, which interviewees makes references to and provides a contexts to the episodes or repisodes; and 4) the interviewees subjective definitions of specific topics or concepts.

For example, during the interview, I will ask the participants specific questions related to their subjective definitions of concepts, such as the term "HIV activism" *("What does HIV activism mean to you, and what are important elements of HIV activism?"*), and questions which

will elicit the interviewees to narrate concrete examples of situations (*"What are the most useful lessons you have learned around your HIV activism efforts [either in the past or what they feel would be helpful at the present time]?"*).

Data Analysis and Knowledge Translation

The audio-recorded interviews were transcribed with identifiable information anonymized to assure privacy and confidentiality of the interviewees. The data analysis was completed in NVivo utilizing an inductive thematic analysis approach. As noted by Franzosi (2011), thematic analysis is an ideal approach to derive dominant themes present in qualitative data in a structured manner through the categorization of code based on content from texts or transcripts. For the thematic analysis, I first read the transcripts and identified the various thematic codes expressed by the interviewees. Close attention was paid to the historical, contextual, individual, collective, institutional, political and structural factors impacingt PHAs in Canada. After the coding was completed, I reviewed the codes and consolidate them into major themes.

As the primary objective of this research is to create impactful recommendations to help strengthen CPPN, I will disseminate the findings through a knowledge translation exchange (KTE) activity to be held in conjunction with CPPN to interested members of network so they can learn about the findings and engage in a critical dialogue on how they would like to utilize the research knowledge to strengthen the network (Baskin, 2016; Lavallée, 2014). Outside of CPPN, the results will also be made available and shared with the interviewees, Canadian PHAs and other interested PHA networks, and the Ryerson Digital Repository. For ease of access, the study results will be made available on the CPPN website and my person web and/or social media platforms. To further the uptake and dissemination of the findings of the study and to concretize the lived experiences of PHAs as knowledge within the social work scholarship

literature, I intend to submit a paper based on the study to an open access, social work or other appropriate peer-reviewed academic journals.

Ethical Considerations

This study has undergone the review of the Ryerson Ethics Board, and the research was conducted in compliance of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (Government of Canada, 2015). To avoid any potential conflicts of interest that may arise from my dual roles as a researcher and a key personnel of the network, I assured the rights of the study's participants were upheld. To prevent situations where potential research participants may feel pressured to take part in the study, I only made one attempt of contact during the recruitment process. This process ensured the participants taking part in the study are doing so willingly, through self-selection, and without undue influence or coercion. Given that the interviewees are key activists living with HIV within the response, the transcript data were anonymized to privacy and confidentiality of the interviewees were protected.

Interview participants were informed of potential psychological risks as related to the recalling of their experience with HIV and their activism efforts. I informed the interviewees that if they chose to withdraw from the study, any data collected from the individual would be discarded immediately and not be included in the study. A list of community resources was provided to the interviewees at the beginning of the interview use in the event they feel distressed from the interview process and need to seek out appropriate services.

CHAPTER 4. FINDINGS AND DISCUSSION

Given my multiple identities as a PHA, activist, elected leader of a nascent network of Canadians living with HIV and HIV co-infections, and a social work graduate student researcher, I deeply treasure the opportunity to interview and engage in critical dialogues with five activists living with HIV who generously shared their activism experiences and views on CPPN and what could help strengthen this young network. While the AIDS epidemic continues to impact lives of many globally and locally in Canada, the HIV response has evolved from radical activism of the early days into a heavily professionalized sector and industry under an ever-increasing neoliberal environment. Such a shift has resulted in decreased opportunities for PHAs to be truly engaged in a meaningful manner within the response and their needs not being fully met by organizations and the state. The establishment of CPPN in 2015 serves as an indicator that Canadian PHAs are interested in creating a network that is for-and-by those living with the health condition, and to demand the rights and meaningful engagement opportunities for PHAs to once again be key decision-makers in shaping the policies and service delivery of a response which directly impacts our lives in Canada.

The aim of this graduate research is to provide key findings and recommendations based on the lived experiences of five key Canadian activists living with HIV to strengthen CPPN and the scholarship of critical anti-oppressive social work. While each interview of the study provided an immensely rich set of data, the thematic analysis yielded the following four major core themes: 1) key factors to consider in today's HIV activist movement; 2) creating resistance to oppression and marginalization within the HIV response; 3) rethinking and re-imagining GIPA; and 4) key recommendations and institutional considerations for CPPN. Based on the dominant themes resulting from the thematic analysis, I will utilize the Positive People Relevant Perspective as a theoretical lens to synthesize the thematic findings and engage in a critical

analysis and epistemological production process to produce answers for my research: To highlight the primary issues which intersect the present community-organizing efforts as faced by PHAs and the CPPN, and to produce key recommendations for the nascent network and the community. To protect the privacy and confidentiality of the study participants, all names used in this paper are pseudonyms.

Theme 1: Key Factors to Considers in Today's HIV Activist Movement

Since all activists who took part in this study live with HIV, the interviews provided an opportunity for them to reflect upon the health condition and what living with HIV meant for them. Drawing from their lived experiences as PHA activists within the Canadian HIV movement, four main topics emerged: 1) Changes in the HIV activist movement; 2) Enhancing the rights and well-being of PHAs; 3) Ensuring the response is community-led and has the right agendas; and 4) Factors for successful HIV organizing and activism efforts.

Changes in the HIV Movement

The activists spoke of the significant changes which the HIV epidemic and movement had experienced in Canada: From the early death tolls which heavily impacted the gay community to the grassroots activist response where HIV activists ensured PHAs had access to life-saving medications; from the professionalization of the sector and the push for GIPA by PHAs to demand for equitable representation in the HIV response; to the present where HIV not only impacts gay white men but heavily impacts marginalized key priority population groups and youth. Despite such changes, PHAs as a marginalized group continue to face immense systemic and structural stigma and discrimination, including: the criminalization of HIV; the lack of access of testing, treatment, and health infrastructures for Indigenous and migrant communities; and a lack of funding for services within the neoliberalist agenda which negatively impacts the health and well-being of PHAs.

Furthering the Rights and Well-being of PHAs

The interviewees described their primary motivations and drive behind their HIV activist work as their wish to further the rights and well-being of PHAs. Aside from the widespread HIV-stigma held by the public and the systemic and structural discrimination such as the employment barriers or the threat of being criminalized under laws which target PHAs, the interviewees also spoke of the wish to be treated with dignity and the hope that HIV will not be a reason that PHAs are *othered* in society. As noted by Eunice, a long-time HIV activist who now works outside of the sector as a school teacher: "It's a dream of mine so that all the kids [her students] and everybody can understand that, 'Okay, she's HIV-positive. She's not sick, we've been around her, and she's just a regular person'."

Ensuring the Response is Community-Led and Has the Right Agendas

Drawing from their experiences as HIV activists, the interviewees noted that it is critical that the HIV response be community-led. To ensure this happens, a broad spectrum of PHAs, along with key stakeholders involved in our community should become engaged in a process where they can participate in the decision-making and priority-setting process. Through engaging in consultations with the communities or constituents, the activists help ensure the issues taken up are acted upon in an accountable manner and that the community will become strengthened as a result. The interviewees noted that HIV activists should ensure the causes they engage in are the "right" ones. They also noted HIV activists should know the difference between activism and advocacy, both essential skills for HIV activists to have. Dino, a long-time HIV activist who had served on many board on the local, provincial, national and international levels, noted:

> Activism is about pushing, to make some action happen…An advocate is to give voice. The mistake that many of us make is we try to make change about something

> that we personally believe in, but we haven't taken the trouble to check to see if everybody else agrees with us.

Such a view was echoed by River, long-time Indigenous activist, who noted it is critical that for activists and organizations to verify with the community that they got the agendas right.

Factors of Successful HIV Organizing and Activism Efforts

Drawing from their activist experiences, the interviewees provided a number of factors and insights for successful HIV organizing and activist efforts. In addition to the tradition of radical mass demonstration tactics, these experienced activists spoke of various approaches, including learning how to work with funders yet also being cautious of the blunders which policy makers and funding bodies have made. Another strategy is for PHAs to infiltrate the dominant systems and structures to push for the PHA agendas from within. Some activists spoke of the utilization of scientific and research evidence and impact to gain support from politicians, policy makers and funding bodies. As well, the showcasing and documenting of successful efforts as evidence to the funders and public is noted as an important part of HIV organizing and activism efforts.

HIV/AIDS is arguably the most stigmatized health condition mankind has ever seen, and the marginalization, oppresson and injustice as experienced by PHAs have resulted in a social movement that is centered on countering the injustices and rights violations which PHAs have experienced since the advent of the epidemic (Parker, 2011; Smith & Whiteside, 2010). For PHA activists, understanding how the AIDS movement came about and how the HIV resoponse has changed through time help ensure that the activists involved in today's movement know the inconsolable historical context which their activism is based on (Smith, 2015). Through knowing the history (Smith, 2015), we gain a picture of why the movement has progressed a certain way,

why GIPA was created (Paxton & Stephens, 2007; UNAIDS, 1999), what success we have gained, and what challenges still exist and need to be addressed. As noted by Dino,

> HIV very slowly and surely became a disease of the marginalized. Just think of women, members of the ACB (African Carribbean, and Black) community, the Aboriginal community, drug-involved folks, sex trade workers, all the priority populations. And who's getting infected the most among gay men? Young men…

Since contemporary citizens can now utilize rights-based arguments that are not tied so much to the state but is centred on the notion of equality where participation in resistance to contemporary, neoliberal market pressures is encouraged (Ong, 2006; Kuisma, 2008), Canadian PHAs have gathered to form CPPN as a people-led movement to counter a highly professionalized sector where PHAs are often tokenized and to demand their rightful place so PHAs can once again drive the agenda of the HIV response (Kinsman 2005, Paxton & Stephens, 2007; Ti, Tzemis, & Buxton, 2012). Such mobilization efforts were engendered by positive people in a grassroots community-led movement to counter the problems and gaps which exist within the Candian HIV response, as illustrated by Dino:

> Now the syndemics of HIV have a lot to do with a lot of other broader trends that mitigate people's right to access their citizenship…We have a number of economic trends that are making the poor poorer… Because it's always about money…When we don't have the resources to support people who are drug involved. When we don't go out there and have extensive needle exchange programs and injection sites. We know what to do….

Through engaging in a reciprocal dialogue and drawing on the lived experiences of a diverse group of PHA activists, critical knowledge and key recommendations were produced to inform the work of the CPPN and social work scholarship (Lavallée, 2014). Such factors and

recommendations should be interpreted through the lens of the Positive People Centered Perspective, which centres on the dignity, rights, well-being, and meaningful engagement of PHAs as its core values, and considers a critical, anti-oppressive approach to activism, policy-setting, research, service delivery, and community-empowerment as essential to the strengthening of CPPN as a nascent network (Hui, 2017). Adding to his previous comments, Dino asked the following:

> We are having a systemic attack on our national ASO organizations. What we need to do is identify what all our risks are: one of them would be the lack of national organizations and support for them. We need to talk about the money that's spent in research that doesn't include us…All the determinants of health---we need to address those big issues. We need to talk about where is the PHA?

Theme 2: Resisting Oppression and Marginalization within the HIV response

As the study's interviewees belonged to diverse backgrounds and often spoke from an intersectional perspective, a key theme focused on the need to resist the various forms of oppression and marginalization which exist within the HIV response. Speaking with conviction, the interviewees spoke on the following four areas: 1) Systemic and structural drivers of oppression; 2) Whiteness; 3) Intersectionality; and 3) Creating resistance: Oppression and marginalization with HIV organizing and activism efforts.

Systemic and Structural Drivers of Oppression

The interviewees highlighted an array of systemic and structural drivers of oppression and marginalization. Neoliberalism and an ever-decreasing funding environment were noted as factors which undermine ASOs in their ability to deliver the services needed by PHAs. The media, on the other hand, have often acted as primary drivers of structural HIV stigma and discrimination through their production of sensationalized news stories on issues such as the

criminalization of HIV non-disclosure cases. PHAs from key population groups are often the target group most impacted by structural, systemic and institutional oppression, racism and violence. River notes a prime example is the systemic racism and structural violence which Indigenous Peoples of Turtle Island still must endure as a result of Canada's colonial history:

> [W]hen you talk about Indigenous People [on Turtle Island/in Canada], there are three groups [First Nations, Métis, and Inuit] and all three groups are still not being recognized at the same level… One of our battles with our funders on the provincial and federal level was making them understand our worldview.

Whiteness

Whiteness was noted as a significant form of power and privilege which drives oppression and marginalization within the HIV response. Given that HIV had first impacted the gay community and how power is distributed within society's social strata, whiteness within the Canadian HIV context is one which primarily benefits gay white men (GWM). Institutionalized racism and whiteness often lead to microaggressions and structural violence which are enacted by GWM PHAs as the dominant group holding power and privilege on non-white PHAs within institutional settings. Whiteness also limits the opportunities and freedom for non-white PHAs to access and also works as a covert force of oppression which attempts to control the narratives and agendas of non-white PHAs and activists within the response, as noted by Dana:

> [T]he white community, they're the ones invited to speak a lot at forums and conferences. Their words seem to hold more value. It's interesting because when they speak within these public spaces, they're speaking from a platform of strength, whereas racialized folks are pulled in to speak about their pain and their struggles…'So you you've gone through all of this, and we want to lift you up even

more. We'll put you here.' But here is wherever they're putting us; it's not something that we're forming or creating for ourselves…

Intersectionality

Given that all interviewees hold multiple identities, they had all described oppression and marginalization through an intersectional lens. The activists spoke of the double or multiple stigma, discrimination and oppression which many PHAs who also belong to other groups must face on daily basis. Maria spoke about what it was like to be a trans PHA activist: "Already trans people have a stigma on being trans, so imagine how it will be to be HIV-positive. It's like a double stigma, double heavy-weight, you got to shoulder." Meanwhile, Dana spoke of the intersectional oppression which PHAs often face on a daily basis and service providers like them should be aware of:

> [B]eing *othered* by white western supremacist culture, you still feel *othered*, and so that *othering* means that you're weird, there's something odd about you…[W]e can really start looking at people realistically from the experiences that they come from. Is racism dead? No. Is violence dead? No. And colonialism…settler colonialism, it's still there. Right?

Creating Resistance

While the interviewees spoke about the roots and dynamics of oppression which exist in the HIV response, they also offered concrete ways of how to resist oppression and marginalization in an anti-oppressive manner. Strategies provided include creating visibility and using the voices of PHAs for consciousness-raising and the exposure of injustices. The concept of infiltration of the existing dominant power structures and the utilization of the "master's tools" to dismantle the master's house was one of the recommended strategies. Taking the time and effort to build relationships based on trust has also been noted as an important strategy for

activists to engage in. In terms of allyship, the interviewees noted that it is important for activists to differentiate true allies from allies who benefit off PHAs or those who cause harm.

PHAs from non-mainstream communities also spoke of the importance of claiming spaces, establishing safe spaces, and creating agendas which are appropriate and meet the needs of one's specific community. An important lesson to learn is that working with people from an anti-oppressive approach is very different from working within the confines of an institutional framework. Dana shared their experience as a staff at an ASO serving racialized PHAs where taking a genuine interest in developing reciprocal and caring relationships with their peers is the primary objective, which differs from the way how mainstream agencies:

> [M]y agency is equated to a family unit, and that's how we approach our work. There will be times when we'll be hanging out with our peers: we might go see movies together; we might go and have a coffee together. It doesn't take on that sort of super clinical approach to support where like, 'After 5pm, I go home and I'm done.' It's never like that. They are part of me, just as much as I am part of them. And that care, regardless of whether I'm their worker or not, that care is a mutual exchange.

The AIDS epidemic had sparked a strong community-led movement which was centred on challenging the structural and systemic discrimination and oppression of PHAs (Parker, 2011). While the demographic of HIV has changed from one which primarily impacted gay white men to one which now affects key minoritized priority populations (Paxton & Stephens, 2007), mainstream service providers have lagged behind in fully addressing the needs of the now diverse PHA community (Cain & Todd, 2009). While CPPN has been created to serve as the network for all Canadians living with HIV and HIV co-infections, and efforts had been made to enhance its diversity, the network has nonetheless been perceived by the wider PHA community

as a mainstream organization which is dominated by GWM and an agenda that is not inclusive of the needs of women or other minoritized key priority population groups. Drawing from the Positive People Centred Perspective---in particular the critical, anti-oppressive social work scholarship and contemporary citizenship and rights theories which the framework is based upon---resistance to the oppression and marginalization within the current HIV response would require an active challenging of the systemic and structural drivers of oppression including racism, whiteness, neoliberalism, and colonialism through an intersectional approach (Benjamin 2011; Baskin, 2003; Pon, 2009; Smith, 2011).

Speaking from the point of view of a racialized minority and the elected ethno-cultural representative on the board of CPPN, I observed that the efforts to introduce the topics of diversity, inclusion, and equity within this mainstream space were often met by resistance from board members who were GWM. Recommendations made by a fellow racialized board member and I to state the network's commitment on key population issues were frequently countered by white colleagues utilizing white supremacist logics that such affirmative action efforts were unnecessary or create reverse discrimination (Pierce, 2014). Racialized genderqueer activist Dana spoke about utilizing mutual representation and solidarity as a strategy for minoritized activists to work with fellow peers to gain strength and to collectively challenge dominant, oppressive institutionalized power structures:

> If you're feeling alone within that space, it's really important to take that back to the community or communities that you identify with and talk to them about it. Leadership becomes strong when the support around that leadership facilitates that voice and represents it, like a mutual representation. When leadership represents the voices that are there---and the voices represent the leadership that's there----it is a collective voice, and it is solidarity in practice.

Since efforts aimed at challenging the normative dominant power structures at CPPN often resulted in the enactment of social and lateral violence by the dominant group of GWM board members on their minoritized peers (Pon, 2009; Thobani, 2007), all board members were asked to abide by upholding professional conduct and to adhere to the network's anti-oppression policies as a way to prevent future instances of microaggression and use of oppressive and violent communication amongst colleagues (Spencer, 2017). A noted by River, informing all members of the establishment and implementation of anti-oppression, non-discrimination and equity policies and making such policies publicly accessible can encourage the uptake of these values and principles within an organization or community:

> We undertook a development of our own non-discrimination policy. The reason that came about is that [group A] members were really being disrespectful to [group B]. We thought that was so inappropriate. So we developed a policy. When we developed a policy, we said 'Okay, now we need to enact it.' So we brought [Group A] in and we went, 'This is our policy' so everybody in the community was aware of the policy, and it became self-policing…

As CPPN establishes itself as a nascent network of all Canadians living with HIV and HIV co-infections, it should display its commitment to equity, diversity, and meaningful engagement of marginalized key priority populations within the HIV response publicly by proactively challenging structural oppression, racism, colonialism, neo-liberalism, whiteness, and violence with minoritized groups to create transformative change (Benjamin, 2011; Baskin, 2003; Barnoff, 2011; Pierce, 2014; Pon, 2009; Smith, 2011; Thobani, 2007).

Theme 3: Rethinking and Re-imagining GIPA

While GIPA has served as a core guiding principle to involve PHAs within the HIV response, interviewees revealed that the framework may not be working as well as the principle

had originally envisioned. The activists shared a number of important ideas on the topic of GIPA, including: 1) areas of concern and success as related to GIPA; 2) Examining the Peer Research Associate (PRA) role; 3) the Meaningful engagement of People Living with HIV/AIDS (MEPA); and 4) Re-thinking and re-imagining GIPA.

Areas of Concern and Success as Related to GIPA

Interviewees spoke of the professionalization which occurred within the HIV movement and within ASOs as both the original cause to create GIPA and as current barriers to fully achieve GIPA. One of the major issue noted by activists is the how tokenism is used as a way for the sector and response to check GIPA off the check-list without truly providing PHAs the opportunities to become involved or meaningfully engaged in the work of the movement. As aptly stated by Eunice on tokenism:

> [I]n many instances, folks would say, 'Oh, here's a lady who is outspoken, come join my group.' But they weren't interested---in many instances---in my opinion. They just wanted a person with HIV on their group. 'So here we are upholding GIPA, we've got a chick here, we've got a person here.' But, is that all there is?

Often, PHAs are given reasons by organizations that engaging PHAs in their work is challenging because PHAs lack the necessary skills or qualifications needed. As noted by Dana:

> [W]hat I'm hearing a lot from the institutions is that "You guys don't really know what you're doing…Right, because of the GIPA/MIPA thing, okay. But you guys are not trained in what you're doing.

The fact that PHAs who are involved and engaged in HIV need to be, and should be, remunerated also pose a complicating factor for service organizations. Other challenges which complicate GIPA include how the advances of medications and the improved health of PHAs

have rendered more and more PHAs not working within the HIV sector and fewer PHAs wanting to volunteer their time for the movement.

While the interviewees highlighted many areas of concerns for GIPA, there have been examples of cases where GIPA was successful or made positive changes to the lives of PHAs. As noted by Dana, one of her best experiences with GIPA came from a research coordinator who "looked at us as equals, valued our input and made sure the input was received by the rest of the research team. I felt my voice was valued, acknowledged, appreciated and put into action." Meanwhile, River noted that groups such as the Aboriginal Persons living with HIV/AIDS (APHA) Caucus is a successful case example of GIPA where it became "the driving force behind the work the national Indigenous HIV/AIDS organization."

Examining the Peer Research Associate (PRA) role

While the role of the peer research associate (PRA) in community-based research has often been interpreted as a primary example of GIPA within the HIV response, the interviewees offered both positive comments and critiques about such role. While Dana's positive experience as a PRA was linked by how their research coordinator had treated them as equals and made them feel that their voice was valued, heard, and put into action, other interviewees had shared quite varied views on the PRA roles. Dino offered an analogy about the PRA role:

> Don't get me started on peer researchers… I just think that's bullshit. Let me give you an analogy: Let's not make that poor little Black boy in Atlanta the president of the corporation. Let's just give him a job running the cotton mill. How nice. He gets to pick the cotton, and he gets to work in factory, but he doesn't own the factory.

Such reality is echoed by the experience of Eunice being a PRA: "I've also researched stuff. You're recruited and you're honed to be this PRA, and it stops there, right? There's no skills…no encouragement for it to go any further, right?"

The Meaningful Engagement of People Living with HIV/AIDS (MEPA)

Since GIPA as a framework has garnered various concerns by the interviewees, some have discussed the concept of the Meaningful Engagement of People Living with HIV/AIDS (MEPA) as an alternative. As PHAs had run into situations where they were prevented from being provided with opportunities to engage due to the lack of the necessary skills or qualifications, MEPA is an approach which attempts to address blatant attempts to marginalize PHAs. As described by Eunice, MEPA differs from GIPA in that:

> So it became meaningful involvement to say, 'Well, look. If you have me on your board, you need to listen to me. I don't want to feel intimidated. I have something to say, and I don't want to feel as if I don't know how.' So meaningful was, to me, was most important so that folk would understand that we're not just there as a token.

She continues to note that education or professionalism does not trump the lived experiences of PHAs:

> It's important for everyone, no matter what your level of professionalism or whatever, we all have a voice. Degrees and that means a lot in terms of when you want to make a dollars; also in terms of you maybe gleaned a lot of knowledge…but it's not the be all and end all. There are people who don't have that kind of education, who are very articulate and have valid and important points that need to be a part of the whole conversation.

Re-thinking and re-imagining GIPA

Despite the challenges and barriers as noted, interviewees also offered insights and recommendations on how the sector can re-think and re-imagine GIPA. River noted that the meaning of GIPA, to him, is endless:

> [B]ecause it has so many possibilities of helping people living with HIV. It's just not one thing… it's many, many possibilities for that individual, and it's up to that individual….People lift themselves up, right? So the work of GIPA is not only using them for their experience of living with HIV but also helping them along their life journey to whatever that might be."

Mentoring was noted as essential component of GIPA and a responsibility which must be provisioned so PHAs are given the advice and guidance needed for them to get the job done and to succeed. River added that it is critical that a re-conceptualized GIPA be able to: "[G]ive people the skills and abilities to contribute. It's whatever brings the new people to become informed so that they will be able to participate later." As noted by Dino and referring back to the example of the PRA, a re-conceptualized GIPA would ensure that person is given a real opportunity to access the types of education to gain the skills needed to become a researcher.

The study served as an opportunity for key Canadian PHA activists to offer their thoughts and feedback on GIPA. While the Positive People Relevant Perspective was conceptualized as an expanded theoretical framework based on GIPA (UNAIDS, 1999) and relevant theories on citizenship and rights (Ong, 2006; Kuisma, 2008), critical AOP social work (Baskin, 2003; Benjamin, 2011; Lavallée, 2014; Pon, 2009; Smith, 2011; Wehbi, 2007), and movement relevant theory (Bevington & Dixon, 2005), I will focus this discussion on GIPA based on the study's findings by offering concrete suggestions on how GIPA can be improved and help strengthen CPPN. Prior to the discussion, I would like to note that the term GIPA will be utilized as an umbrella term to include the Meaningful Engagement of People Living with HIV/AIDS (MEPA) and the Meaningful Involvement of Women Living with HIV/AIDS (MIWA).

As a universally recognized principle that has guided the work of the global AIDS response since 1996 (UNAIDS, 1999), GIPA is often recognized as a success of the PHA

movement for its call for PLHIVs to play a central role in the HIV response. As the principle is centred on PHAs and their active involvement in a social movement which directly impacts their lives (Maxwell, Aggleton, & Warwick, 2008; Paxton & Stephens, 2007), it would be much more fitting if a shift can enable GIPA to become focused on the people and expanding the capacities of PHAs as opposed to how PHAs can be fit into specific roles within the HIV response (Travers, et al., 2008). An improved GIPA should challenge the neoliberal professionalization of the HIV sector and create real, substantive opportunities for PHAs to gain the skills and capacities necessary for them to take on paid positions beyond becoming peer workers or peer research associates (Travers, et al., 2008). Given that many PHAs are living longer and healthier lives, a modern-day GIPA should also consider ways to maximize meaningful participation and engagement from PHAs who may be working full-time or those who may have returned to work or school given that their health has improved. Eunice noted her thoughts on an improved GIPA:

> Now, we're still talking about organizations and people with HIV not employed in most of these organizations yet still needing to be a part of the governing of these organizations…So you want me to join your meeting, why are you just assuming that I'm unemployed and I want to be on welfare…that people with HIV are not professionals? If this is a volunteer organization and you're calling meetings at 11 in the morning, are you kidding me?

Theme 4: Key Recommendations and Institutional Considerations for CPPN

Given the main objective of the study is to consider the issues and challenges faced by, and ways to strengthen, CPPN as a nascent network for and by Canadians living with HIV and HIV co-infections, the interviewees offered a number of useful insights drawn from their experiences in HIV activism as well as recommendations for the network. The major areas of

findings gathered from the interviewees include: 1) organizational goals and values; and 2) governance and operations.

Organizational Goals and Values

When the interviewees were asked what were their hopes for CPPN, they stated that the network should serve as a supportive space for all Canadians living with HIV and HIV co-infections to thrive. The network should host a national gathering for PHAs to create a much-needed dialogue space. To be accountable to the people and communities it serves, CPPN should ensure that its priorities are informed by PHAs on the ground. A primary objective of the network is to ensure the national HIV response is coordinated across provincial and territorial jurisdictions. Another recommended function for CPPN is to transform the often-disjointed work within the response through cross-issue collaborations. Besides raising public awareness of HIV, a key function of the network should focus on providing relevant education, information, and capacity building opportunities for PHAs. Operating from a resilience-based framework, CPPN should become a space where PHAs can provide support, care, and healing to one another.

The interviewees also spoke of key values which the CPPN should be centred on; one of which is the commitment to equity, inclusion, and non-discrimination. Given the diverse communities impacted by HIV, the interviewees noted it was critical for CPPN as a people's network to ensure it becomes an equitable and inclusive space for all Canadians living with HIV and HIV co-infections. In the words of Maria, it is important for CPPN to do the following:

> You have to put something there….non-discrimination for people. We accept everybody---trans, white, Black, Chinese…everybody who has HIV; 'Come to me, and I give you what you need'.

Creating equity and inclusion of diverse groups of PHAs requires the shift of agenda from one which privileges members of the dominant group, and the efforts of minoritized groups to create

and demand a different voice as they become engaged within mainstream spaces. Dana provided some important considerations for CPPN to enhance its commitment to diversity:

> [W]hen we're shifting from these marginalized spaces, what's really important is that when we move in there, we have a very clear idea of who we are, and what we want our role to be within the that larger and more powerful space. Because the idea is not for us to conform. The idea is for us to be a voice there that is different and that will engage the other community members to join.

Interviewees also noted standing and acting in solidarity with Indigenous Peoples and communities is an integral value for CPPN. To achieve solidarity, they recommended the following: The acknowledgement that non-Indigenous folks on Turtle Island are settlers and that we all live on Indigenous lands; to respect the self-determination and autonomy of Indigenous Peoples and communities; and to ensure that we check with Indigenous communities what we should say if we are to speak on issues related to them. Indigenous activist River noted that one of the most important key point for a non-Indigenous organization such as CPPN to understand is the nation to nation relationship Indigenous Peoples and communities have with the Canadian federal government:

> You need to be aware of the community that you're dealing with…Like where I worked, it was considered off-reserve. There was no way I could ever go to a First Nations community and say I am coming in to do an HIV workshop, right? I actually have to be invited.

As River himself is Indigenous, he shared an important lesson for on how to respectfully work with Indigenous nations and communities: that one must always seek free, prior, informed consent, permission and support from each community and respect the specific processes and protocols required.

Governance and Operations

The activists noted that the network must be able to seek out persons who have the appropriate skillsets to help further the goals of the network. The leaders of CPPN should be passionate and tenacious, be able to inspire, and understand when to lead and follow. The policies and organizational priorities should come from PHAs, and the development of organizational policies should be GIPA-oriented. CPPN members should be given the skills so they can participate effectively in the organization's annual meeting where they can put forward resolutions as a way to guide the work of their organization. One important consideration for CPPN is to develop and establish a policy around anti-oppression and anti-discrimination and a way to enact such policy. The benefit of creating policies which addresses matters like anti-oppression, anti-racism, and anti-discrimination is that such policies can be shared with other organizations in the community to create systemic change. In certain instances, if organizations find themselves stalled by persons who may be impeding, blocking, obstructing the original goals or progress of the organization, they may then need to re-map or re-structure to ensure the organization can undergo transitions and engage a new group of members in its cause.

The interviewees also provided important insights related to organizational and human resource concerns. Citing lessons to be gained from other national organizations, the activists noted that the executive director of the organization must be able to listen and act appropriately to advice given by members and be able to develop and maintain relationships with board, staff, and key stakeholders. To ensure the sustainability and growth of the organization, CPPN should provide thorough orientations to its members so they know how to engage effectively at annual meetings and be able to offer appropriate resolutions to help shape the work and priorities of organization. In the same line of logic, the organizations should ensure it engages in sound succession planning so human resources changes will not impact the stability or sustainability of

the organization. Last but not least, the activists noted that it is critical that the network further improve the way it engages and communicate with its members, the PHA community and stakeholders, so that it can effectively galvanize the community around issues that further the vision, mission, values and goals of the network.

While the study had purposefully recruited Canadian PHA activists who were not members of CPPN to act as critical friends (Stieha, 2014) to provide feedback from an outsider view for the network, it was to my surprise that a few of the interviewees actually did not know a lot about the network or that it existed, and each of them held unique views about the grassroots organization. The findings provided valuable insights related to the network's goals, values, and purpose, as well as recommendations in the areas of governance and operations. A critical question related to these findings is, utilizing the lens of Positive People Centred Perspective, how can these key recommendations be applied to CPPN and the community of Canadians living with HIV and HIV co-infections?

The recommendations provided by the activists iterated the importance that as a people's network, the issues and priorities which CPPN takes on must be relevant and determined by the community so the voices of PHAs can once again lead and guide the movement (Maxwell, Aggleton, & Warwick, 2008). Since PHAs still face immense stigma and are marginalized and oppressed systemically as a group, the network must lead activist and advocacy efforts to enhance the rights of PHAs. The network should focus on developing caring and reciprocal relationships with its members and communities it serves (Baskin, 2016). As a nascent network, the CPPN must find ways to build trust and relationship with the Aboriginal PHA Caucus and become an ally network that won't cause more harm to Indigenous Peoples and communities (Baskin, 2016). All these recommendations center the people and community whom CPPN serves as the core of the organization.

From a critical anti-oppressive social work standpoint, the network must ensure it becomes a safer space for PHAs and one which upholds values of anti-oppression, anti-racism and gender equity (Baskin, 2003; Pierce, 2014). As HIV impacts a much more diverse community of PHAs, the network must undertake the responsibility to proactively engage and champion the issues facing key priority population groups while remaining a network for all Canadians living with HIV and HIV co-infections (Barnoff, 2011). With the various issues which exist with GIPA, CPPN needs to find ways to truly engage a wide intersection of PHAs, many of whom are living longer and healthier lives and may not be working within the ASO sector. A key way to ensure the network's sustainability and growth is that it provide its members with orientation, mentorship and capacity-building opportunities so they can meaningfully participate as members of the network (Paxton & Stephens, 2007). CPPN is people-led network in its formative years of growth (Barnoff, 2011). What the network represents, and has the potential to become, is noted by Dino:

> We all know enough how to build community, but that community is developed when we have common purpose that we're working towards something, when people can identify with each other. So, one of the things that we all must do, as people living with HIV and AIDS, is that we need to find ways of building community among ourselves. Joint programming, joint activity, joint advocacy.

It has been my hope that through completing this research, the nascent network of CPPN will gain useful information and insights from the experiences of Canadian PHA activists and further strengthen itself as an independent network created for and by Canadians living with HIV and HIV co-infections. As a Master of Social Work student living with HIV, it is my belief that the knowledge produced will also contribute to critical, anti-oppressive social work practice and scholarship.

CHAPTER 5: IMPLICATIONS & CONCLUSION

As a graduate research completed for the partial fulfillment of the requirements for the Master of Social Work (MSW) at Ryerson University, I have engaged in this knowledge creation process for a number of reasons: to further my activist work as a PLHIV and the community mobilization efforts led by Canadians living with HIV and HIV co-infections; to gain experience as a graduate student to engage in critical, anti-oppressive research; and to co-create and privilege the marginalized, subjugated voices of PLHIVs as rigorous and valid knowledge within the academy and the social work scholarship.

The implications and contributions of this research to critical, anti-oppressive social work practice, literature and scholarship have been demonstrated through the research process itself as well as through the impact and positive changes produced as a result of the study. As a generative epistemological process, this research study was grounded in an anti-oppressive praxis and served as an active resistance to the dominant traditional Western positivist research methodology (Lavallée, 2014). Throughout the entire research process, from the conceptualization of the research to its findings, lessons can be drawn and applied to further the critical, anti-oppressive approach of social work and scholarship on how social workers can better support PLHIVs and their engagement in HIV activism and community-organizing efforts.

The theoretical framework of the study, the Positive People Centred Perspective, was created by me, a PHA activist-researcher, through integrating existing theories that are most relevant to researching a real-time HIV activist movement. The perspective is grounded in an anti-oppressive approach to knowledge creation (Lavallée, 2014); movement relevant theory which argues that activists of any particular social movement should be the ones informing and shaping the social movement theory itself (Bevington & Dixon, 2005); the GIPA Principle which centers the engagement and lived experiences of PHAs as a core approach to action (UNAIDS,

1999); and contemporary theories on citizenship and rights which consider the impact of the neoliberal market system on equality and civic engagement of the citizen (Ong, 2006; Kuisma, 2008).

As a PLHIV, I have positioned myself not only as a researcher but also a co-creator of knowledge where I engaged in critical dialogues with my colleagues and peers as interviewees. The research recognizes the need to privilege the knowledge and lived experiences of Canadian PLHIV activists on a topic that involves and directly impact Canadians living with HIV and HIV co-infections. By drawing key themes emerging from the narratives of the interviewees (Flick, 2000; Franzosi, 2011), I have been able to synthesize the actual activist experiences and insights of five Canadian HIV+ activists to produce recommendations for a nascent positive-people network in Canada. The research findings will be disseminated and made available to members of CPPN and interested PLHIVs in Canada as a way to further strengthen the network and the PHA-led movement.

U=U: Undetectable Equals Untransmittable

Given that this research had engendered the Positive People Relevant Perspective as a new and more integrated, comprehensive approach to working with PLHIVs and advancing their rights and well-being in their activism, it is important that I as a PLHIV activist-researcher and social worker provide a case example of an emerging issue which has mobilized many PLHIVs including CPPN and its members: the Undetectable Equals Untranmisttable (U=U) Campaign, a PLHIV-led grassroots movement to champion the knowledge dissemination and uptake of the latest science on HIV transmission risk based on undetectably based on the U=U Consensus Statement. While the campaign was not an intended topic of this study, three of the Canadian HIV+ activists had mentioned the campaign during the interviews without any prompts referencing the subject, showing the importance and relevance of the U=U campaign to PLHIVs

and PHA-led movement in Canada. The inclusion of this case example on U=U here is to illustrate how critical, anti-oppressive social workers can utilize the Positive People Relevant Perspective in their work with PLHIVs and PLHIV-led movements.

A grassroots PLHIV campaign started in the US in 2016 to promote knowledge dissemination and uptake of the scientific evidence that people living with HIV who have been on effective treatment for at least six months and have an ongoing undetectable viral load cannot transmit HIV to their sexual partners (Prevention Access Campaign, 2017), the U=U Campaign has gained international momentum: Within a year, it has gained support of over 280 community organizations in over 33 countries in an effort to shift the discourse around HIV. While the campaign has brought forth great excitement amongst many PLHIVs on how the discourse on HIV is changing once more---an occurrence which has not happened since the discovery of the highly active anti-retroviral therapy (HAART) in 1996, it also has nonetheless ignited many passionate and heated discussions on issues that are often raised by fellow PLHIV activists related to the rights of PLHIVs---including concerns about the validity of the science; the lack of life-saving treatment access; the criminalization of PLHIVs in HIV non-disclosure cases; how treatment-as-prevention (TasP) approaches place the onus of HIV prevention being placed on PLHIV; what is the impact of U=U on HIV-stigma, etc.

Given the widespread mobilization the campaign has garnered by PLHIV activists, U=U is fitting to be considered a relevant topic within today's HIV response according to movement relevant theory. While the primary, sole objective of the U=U campaign is to promote the scientific evidence on the topic of undetectability and HIV transmission risk, specific PLHIV communities may hold different opinions on the campaign due to the realities and conditions they live in. Since these passionate and often heated debates require nuanced discussions and opportunities to dialogue, the utilization of the Positive People Centerd Perspective theoretical

framework to guide these important community-led deliberations would be highly beneficial within today's HIV response. Given that a majority of the interviewees spoke about U=U, CPPN as a people-led network is that the organization should explore the importance, relevance and value of the U=U Campaign, and more importantly consider the ways how this campaign can become a relevant topic for the diverse communities of Canadians living with HIV and HIV co-infections.

Conclusion

Conducting this graduate research has been a privilege of mine as a person living with HIV, a Master of Social Work student, a community mobilizer, and a community-minded knowledge co-creator. It has also been an act of activism and resistance against the oppression and marginalization faced by the 71,300 Canadians living with HIV, the 36.7 million people who live with the virus globally, and the lives that have been lost to the epidemic. As an activist, I have engaged in a research study which holds great personal meaning as well as much potential impact to my fellow peers of Canadians living with HIV, CPPN and the national HIV response.

Having completed this research and this major research paper has not meant the research process stops here. Instead, this present juncture only indicates the beginning of many exciting work and possibilities which this graduate research might have helped create. As noted by River,

> Somebody who had the degree would be able to put it in layman terms. Those terms that could be understood by a layperson, which was so important because when you are doing HIV activism, one of the key things is to not to put yourself on a pedestal with a degree, right? That is not going to work because you have to realize that you have to work with community. And between community and academia, there's big, big divide: knowledge and understanding.

My next step as a PLHIV activist-researcher is to disseminate and translate the knowledge gained through this research to the community which it will benefit from. It is my hope that this research has accurately reflected the experiences of the key Canadian activists living with HIV who engaged in this study, and that the findings and recommendations put forth will help strengthen the Canadian Positive People Network into a strong network led by Canadians living with HIV and HIV co-infections so the affected community members living with this chronic health condition can once again become the leaders of the national HIV response. As I end this paper, I would like to share the following quote provided by my dear fellow activist, Dana, as an inspiration for all HIV+ activists who are engaged in the work of fighting for the rights of PLHIVs and those who are engaged with CPPN as members: "HIV activism can be equated to a convergence of creativity, imagination, ideas, passion, commitment, collective supports, and solidarity".

APPENDICES

Appendix A – Recruitment Email

Dear _____ ,

As you may be aware, I am currently enrolled in the Masters of Social Work program at Ryerson University. I am contacting you to see if you may be interested in a research study.

This research is being done as part of my Master graduate research project and my supervisor's name is Dr. Samantha Wehbi, Professor, School of Social Work.

The study, ***AIDS IN ACTION: A NEW MOVEMENT LED BY CANADIANS LIVING WITH HIV & ITS IMPLICATIONS ON CRITICAL AOP SOCIAL WORK PRACTICE,*** aims to capture and analyze personal narratives of people living with HIV on their experiences around HIV activism, with a specific focus to explore the challenges and opportunities as faced by a nascent network formed by Canadians living with HIV in Canada, and to establish key factors and conditions that may help strengthen this community-led effort.

To participate in the study, you need to be:

1. A person living with HIV over the age of 17 who resides in Canada
2. Have experience in HIV activism

If you agree to volunteer for the study, you will be asked to participate in one session of a one-on-one interview which will last for approximately 1.5 hours either in person or via Skype.

In appreciation of your time, you will receive a $15 Apple Gift Card either in person or via email at the time of the interview, depending on whether the interview is held in-person or over Skype. Reimbursement of two TTC tokens may be provided to in-person interview participants upon the request of the research participant.

Your participation is completely voluntary and if you choose not to participate it will not impact our relationship, your relationship with the Canadian Positive People Network (CPPN) or Ryerson University.Privacy and confidentiality will be assured.

The research has been reviewed and approved by the Ryerson University Research Ethics Board.

If you are interested in more information about the study or would like to volunteer to take part in the study, please reply to this email at c6hui@ryerson.ca.

Thank you very much for your time and consideration.

Sincerely,
Christian Hui
Master of Social Work Candidate
School of Social Work
Ryerson University
c6hui@ryerson.ca

Appendix B – Recruitment Screening Tool

Screening Tool*: *"AIDS IN ACTION: A NEW MOVEMENT LED BY CANADIANS LIVING WITH HIV & ITS IMPLICATIONS ON CRITICAL ANTI-OPPRESSIVE SOCIAL WORK PRACTICE"*

**Due to the confidentiality and sensitivity of some of the screening questions, please note that this screening tool will only be performed orally with no written records kept*

1. **Are you a person living with HIV?**

   If yes, proceed to 2.

   If no, disqualify.

2. **Are you over the age of 17?**

   If yes, proceed to 3.

   If no, disqualify

3. **Do you reside in Canada?**

   If yes, proceed to 4.

   If no, disqualify

4. **Do you have experience in HIV activism (e.g. making positive change for people living with HIV, serving as an advocate, having taken on leadership positions at AIDS service organizations/networks, etc.)**

5. **Are you a current member of the Canadian Positive People Network (CPPN)? [If answered yes, you are not eligible for the study]**

   If yes, disqualify

   If no, participant is qualified and meet the inclusion criteria to take part in the study

Appendix C – Consent Form

School of Social Work
Faculty of Community Services

Accredited by the Canadian Association of Schools of Social Work

Ryerson University
Consent Agreement

You are being invited to participate in a research study. Please read this consent form so that you understand what your participation will involve. Before you consent to participate, please ask any questions to be sure you understand what your participation will involve.

Project Title:
AIDS IN ACTION: A NEW MOVEMENT LED BY CANADIANS LIVING WITH HIV & ITS IMPLICATIONS ON CRITICAL ANTI-OPPRESSIVE SOCIAL WORK PRACTICE

INVESTIGATORS: This research study is being conducted by Christian Hui, Master of Social Work candidate, under the supervision by Dr. Samantha Wehbi, from the School of Social Work, Faculty of Community Services at Ryerson University.

DISCLOSURE OF POTENTIAL CONFLICT OF INTEREST OF THE RESEARCHER:
For this research project, I will interview research participants about a self-advocacy organization, the Canadian Positive People Network (CPPN), to highlight issues as related to activism, advocacy, empowerment, and community organizing. As I am both the study's researcher and a key personnel (co-founder and chair of the board) of an organization the research aims to investigate, I am taking the following measures to ensure that I am fully aware of: any potential conflicts of interest that may arise from my dual roles; my responsibilities as a researcher and the rights of the study's participants; and how I will manage potential conflicts.

While the research participants are recruited due to their HIV+ status, their experience in HIV activist work, and the fact that are not members of CPPN, in order to prevent situations where potential research participants may feel pressured to take part in the study, I will only make one attempt of contact during the recruitment process (flyers, telephone call, email, text message, Facebook message) related to the research study. I will then let interested participants contact me directly, and I will not make a second attempt to follow up with prospective participants whom I have already contacted. This process ensures the participants taking part in the study are doing so willingly, through self-selection, and without undue influence or coercion.

If you have any questions or concerns about the research, please feel free to contact:

- Participants can expect interview questions such as the following:
  - "Can you please describe yourself? Any markers of identity you are comfortable sharing?"
  - "What do you associate with the words HIV?"
  - "Please tell me about your experience with the Greater Involvement with People Living with HIV/AIDS Principle (GIPA) and HIV activism: How did you get involved with HIV activism and how did you feel when you first learned about GIPA?"
  - "Have you heard about the national organizing movement that is currently taking place by people living with HIV in Canada? What are your thoughts about such efforts?"
  - "What are the most useful lessons you have learned around your HIV activism efforts?"

- The interview will be digitally recorded. You have the right to ask the recording be stopped at any time. You may also review the transcripts of the interview for accuracy. The digital recording will be erased after the interview has been transcribed.

- Research findings will be made available to participants, which can either be emailed, mailed or picked up in person.

POTENTIAL BENEFITS: As a research participant, you may gain potential benefits through sharing your personal story and lived experience as HIV activist; engaging in a ~~critical dialogue~~ discussion on HIV activism within the Canadian context; and contributing insights which may help strengthen a current community organizing effort that is led by Canadians living with HIV. In addition, the study's findings may help inform and advance social work practice on how social workers can support people living with HIV with their social movement and community organizing efforts. As a researcher, however, I cannot guarantee that you will receive any benefits from participating in this study.

POTENTIAL RISKS: During this interview, you will be asked to recount your experience with HIV and your activism efforts. These questions may pose potential psychological risk or discomfort for you. Please note that your participation in the study is voluntary, and you are free to answer as few or as many questions as you are comfortable with, and you can request to take breaks, skip questions you do not wish to answer, or stop the interview process. If you choose to withdraw from the study, your data will be automatically and fully removed from the data set and destroyed. A list of community resources at the beginning of the interview will be made available should you feel distressed as a result of the interview process.

As the study intends to interview three to five key Canadian HIV+ activists for the study, their description of their involvement in HIV activism may potentially reveal their identity directly or inadvertently by those who are knowledgeable about the history of HIV activism in Canada. All identifying information of the interview participants will be removed and a pseudonym assigned to the person. To protect the identities of the research participants, I will remove identifying information of events and organizations as mentioned by the participants.

CONFIDENTIALITY:
To safeguard your privacy and confidentiality, the following steps will be taken: The interview

audio recording will be password protected and destroyed immediately upon completion of the transcript. Your name or any identifying information will be omitted from the transcript. To protect your privacy and confidentiality, only the researcher will have access to the interview data. In rare situations where the research supervisor needs to access and review the interview data, all identifying information will first be omitted prior to the sharing of the interview transcript; and only excerpts will be shared, not the entire interview. You will be provided with my preliminary findings through email in an password protected file for one week to verify the accuracy of the findings. If I do not receive feedback from you by the date stated in the email, it is assumed that the preliminary findings are accurately presented. The study's participant email list and all transcripts of the study will be kept on an encrypted, password protected USB kept in a locked file cabinet and destroyed at the end of August 2017. Scanned copies of signed consent forms will be stored in an encrypted, password protected USB in a locked file cabinet for one year after the completion of the research study, at which time they will be destroyed in August 2018.

INCENTIVES FOR PARTICIPATION: A $15 Apple Gift Card will be given in person or emailed to each research participant at the time of the interview as a token of appreciation.

COSTS TO PARTICIPATION: Reimbursement of two TTC tokens will be provided to in-person interview participants.

VOLUNTARY PARTICIPATION AND WITHDRAWAL: Participation in this study is completely voluntary. You may choose to take part in this study, and skip any question which you do not wish to answer or make you feel uncomfortable. You can choose to stop your participation in the study at any time and you will still be given the incentive and reimbursements ($15 Apple Gift Card and/or two TTC tokens) as described above. If you choose to withdraw from the study, your data will be automatically and fully removed from the data set and destroyed. Your choice of whether or not to participate in the study will not impact your future relations with Ryerson University, the Canadian Positive People Network (CPPN) or the study's investigator Christian Hui, or his supervisor.

QUESTIONS ABOUT THE STUDY: If you have any questions about the research now, please ask. If you have questions later about the research, you may contac

Christian Hui
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Ryerson University
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Dr. Samantha Wehbi, MSW, PhD, MFA
FCS Learning and Teaching Chair Professor
School of Social Work
Faculty of Community Services
Ryerson University
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This study has been reviewed by the Ryerson University Research Ethics Board. If you have questions regarding your rights as a participant in this study, please contact:
Research Ethics Board
c/o Office of the Vice President, Research and Innovation
Ryerson University
350 Victoria Street
Toronto, ON M5B 2K3
416-979-5042
rebchair@ryerson.ca

Project Title:

AIDS IN ACTION: A NEW MOVEMENT LED BY CANADIANS LIVING WITH HIV & ITS IMPLICATIONS ON CRITICAL ANTI-OPPRESSIVE SOCIAL WORK PRACTICE

CONFIRMATION OF AGREEMENT:

Your signature below indicates that you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your signature also indicates that you agree to participate in the study and have been told that you can change your mind and withdraw your consent to participate at any time. You have been given a copy of this agreement. You have been told that by signing this consent agreement you are not giving up any of your legal rights.

_____
Name of Participant (please print)

_____ _____
Signature of Participant Date

I agree to be audio-recorded for the purposes of this study. I understand how these recordings will be stored and destroyed.

_____ _____
Signature of Participant Date

I would like to receive a copy of the research findings sent to the following address or email address:

_____

Appendix D – Interview Guide

INTERVIEW GUIDE: *"AIDS IN ACTION: A NEW MOVEMENT LED BY CANADIANS LIVING WITH HIV & ITS IMPLICATIONS ON CRITICAL ANTI-OPPRESSIVE SOCIAL WORK PRACTICE"*

6. **Markers of Identity**
   - Can you please describe yourself? Any markers of identity you are comfortable sharing?

7. **Exploring subjective definitions of concepts [HIV, Citizenship & Rights, Activism, the Greater Involvement of People Living with HIV/AIDS Principle (GIPA)[1]]**
   - "What do you associate with the words **HIV**?"
   - "What comes to mind when you hear **citizenship and rights** as a person living with HIV?"
   - "What does **HIV activism** mean to you, and what are important elements of HIV activism?"
   - "What does **GIPA** mean to you? What are the challenges and opportunities associated with GIPA?'

8. **Questions about concrete situations**
   - **"Please tell me about your experience with GIPA and HIV activism: How did you get involved with HIV activism and how did you feel when you first learned about GIPA?"**
     - *Probe:* Can you describe **a best moment** when GIPA and HIV activism worked well?
     - *Probe:* **How** did you and/or people living with HIV create such success?
     - *Probe:* What are some **specific factors** that made this successful? Please describe in detail…
   - **"Have you heard about the national organizing movement that is currently taking place by people living with HIV in Canada? What are your thoughts about such efforts?"**
     - *Probe:* What is a national network of people living with HIV for you? (*Or, What is the Canadian Positive People Network (CPPN) for you [if the person has heard about the network])*
     - *Probe:* Are you or have you been involved with such network (CPPN) or a network/organization similar to this one? Please tell me about your experience?
     - *Probe*: What are some **challenges and opportunities** facing such network (CPPN) or a network/organization similar to this one? Can you please describe in detail?
   - **"What are the most useful lessons you have learned around your HIV activism efforts (either in the past or what they feel would be helpful at the present time)?"**
     - *Probe*: Are there any specific **relational, communal or cultural factors** which you feel are important to be considered in today's HIV activist organizing efforts?
     - *Probe*: Are there any specific **institutional, political, or structural factor**s you feel are important to be considered in today's HIV activist organizing efforts?
     - *Probe*: Any **specific recommendations or feedback** you may have for CPPN?[1]

[1] **GIPA**: The Greater Involvement of People Living with HIV/AIDS Principle states that people living with HIV/AIDS should play a key role in the planning, formulation, implementation and evaluation of HIV programs and policies

Appendix E – Ethics Approval

Ryerson University Research Ethics Board

To: Christian Hui
Social Work

Re: REB 2016-423: AIDS IN ACTION: A NEW MOVEMENT LED BY CANADIANS LIVING WITH HIV & ITS IMPLICATIONS ON CRITICAL ANTI-OPPRESSIVE SOCIAL WORK PRACTICE

Date: January 31, 2017

Dear Christian Hui,

The review of your protocol REB File REB 2016-423 is now complete. The project has been approved for a one year period. Please note that before proceeding with your project, compliance with other required University approvals/certifications, institutional requirements, or governmental authorizations may be required.

This approval may be extended after one year upon request. Please be advised that if the project is not renewed, approval will expire and no more research involving humans may take place. If this is a funded project, access to research funds may also be affected.

Please note that REB approval policies require that you adhere strictly to the protocol as last reviewed by the REB and that any modifications must be approved by the Board before they can be implemented. Adverse or unexpected events must be reported to the REB as soon as possible with an indication from the Principal Investigator as to how, in the view of the Principal Investigator, these events affect the continuation of the protocol.

Finally, if research subjects are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and approvals of those facilities or institutions are obtained and filed with the REB prior to the initiation of any research.

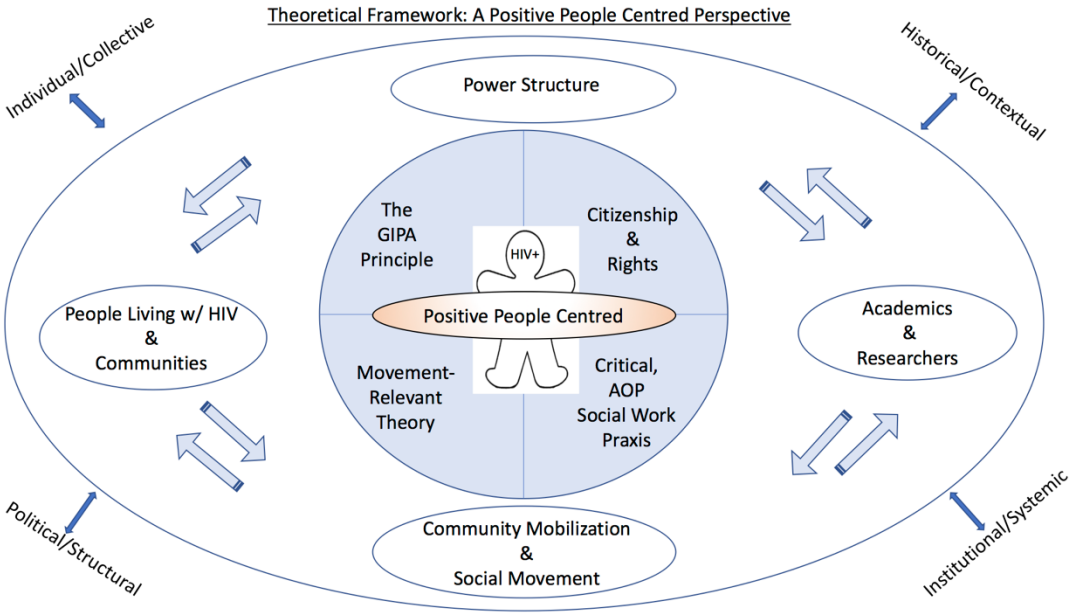
Please quote your REB file number (REB 2016-423) on future correspondence.

Congratulations and best of luck in conducting your research.

Dr. Nancy Walton, PhD
(A) Co-Chair
Ryerson Research Ethics Board
416-212-4952
nwalton@ryerson.ca

Dr. Chris Macdonald, PhD
(A) Co-Chair
Ryerson Research Ethics Board
416-979-5000 ext. 6903
chris.macdonald@ryerson.ca

Appendix F – Theoretical Framework: Positive People Centred Perspective



REFERENCES

Anema, A., Fielden, S. J., Shurgold, S., Ding, E., Messina, J., Jones, J. E., . . . Team, C. F. (2016). Association between food insecurity and procurement methods among people living with HIV in a high resource setting. *PLoS ONE, 11*(8), 1–21. http://doi.org/10.1371/journal.pone.0157630.

Barnoff, L. (2011). Business as usual: Doing anti-oppressive organizational change. In D. Baines (Ed.), *Doing anti-oppressive practice: Social justice social work* (2nd Edition ed., pp. 173-196). Black Point, NS, Canada: Fernwood Publishing.

Baskin, C (2016). *Strong Helper's Teachings: The Value of Indigenous Knowledges in the Helping Professions.* (2nd ed). Toronto, ON, Canada: Canadian Scholar's Press.

Baskin, C. (2003). Structural social work as seen from an Aboriginal perspective. In W. Shera (Ed.), *Emerging perspectives on anti-oppressive practice* (pp. 65-79). Toronto, ON, Canada: Canadian Scholars' Press.

Benjamin, A. (2011). Doing anti-oppressive social work: The importance of resistance, history, and strategy. In D. Baines (Ed.), *Doing anti-oppressive practice: Social justice social work* (2nd Edition ed., pp. 289-297). Black Point, NS, Canada: Fernwood Publishing.

Berg, R. C., Gamst, A., Said, M., Bardsen, K., Songe, S. H., Fangen, K., & Rysstad, O. (2015). True user involvement by people living with HIV is possible: Description of a user-driven HIV clinic in Norway. *Journal of the Association of Nurses in AIDS Care*, 26(6), 732-742.

Bevington, D., & Dixon, C. (2005, December). Movement-relevant theory: Rethinking social movement scholarship and activism. *Social Movement Studies*, 4(3), 185-208.

Cain, R., & Todd, S. (2009). HIV/AIDS Social Services and the Changing Treatment Context. *Qualitative Social Work*, 8(2), 249–265. http://doi.org/10.1177/1473325009103379.

Cain, R., Collins, E., Bereket, T., George, C., Jackson, R., Li, A., . . . Travers, R. (2014). Challenges to the involvement of people living with HIV in community-based HIV/AIDS organization in Ontario, Canada. *AIDS Care*, 26(2), 263-266. http://doi.org/10.1080/09540121.2013.803015.

Canadian Public Health Association. (2005). *Leading Together: Canada Takes Action on HIV/AIDS (2005-2010)*. Retrieved September 1, 2016, from http://www.leadingtogether.ca/pdf/Leading_Together.pdf

Clandinin, D. J., & Connelly, F. M. (2000). *Narrative Inquiry: Experience and Story in Qualitative Research*. New York, NY, Canada: Joseey-Bass Inc.

Costa, A., & Kallick, B. (1993). Through the lens of a critical friend. *Educational Leadership*, 5(2), 49–51.

CPPN/RCPS. (n.d.). Retrieved November 1, 2015, from *CANADIAN POSITIVE PEOPLE NETWORK (CPPN) / RESEAU CANADIEN DES PERSONNES SEROPOSITIVES (RCPS)*: http://cppnrcps.weebly.com/

Emmel, N. (2013). Purposive work in a realist sampling strategy. In N. Emmel, *Sampling and Choosing Cases in Qualitative Research: A Realist Approach*. London, UK: Sage.

Flick, U. (1999). Social constructions of change: Qualitative methods for analysing developmental processes. *Symposium: "Qualitative methods"*, 38(4), 631-658.

Flick, U. (2000). Episodic interviewing. In M. W. Bauer, & G. G (Eds.), *Qualitative researching with text, image, and sound*. Thousand Oaks, CA, USA: SAGE Publications.

Frampton, C., Kinsman, G., Thompson, A. K., & Tilleczek. (2006). Preface: Social movements/Social research: Towards political activist ethnography. In C. Frampton, G. Kinsman, A. K. Thompson, & Tilleczek, *Sociology For Changing The World*. Black Point, NS, Canada: Fernwood Publishing.

Franzosi, R. P. (2011). Content Analysis. In M. Hardy, & A. Bryman (Eds.), *SAGE Research Methods*. Thousand Oaks, CA, USA: SAGE Publications.

Goldenberg, S. M., Montaner, J., Duff, P., Nguyen, P., Dobrer, S., Guillemi, S., & & Shannon, K. (2016). Structural Barriers to Antiretroviral Therapy Among Sex Workers Living with HIV: Findings of a Longitudinal Study in Vancouver, Canada. *AIDS and Behavior*, 20(5), 977–986. http://doi.org/10.1007/s10461-015-1102-2.

Government of Canada. (2015, February 13). *TCPS 2 (2014)— The Latest Edition of Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. Retrieved March 10, 2017, from Panel on Research Ethics: http://www.ger.ethique.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/Default/

Guta, A., Murray, S. J., & McClelland, A. (2011). Global AIDS Governance, Biofascism, and the Difficult Freedom of Expression. *Aporia: The Nursing Journal*, 3(4), 15-29.

Hoffman, B. (2008). Healthcare reform and social movements in the United States. American *Journal of Public Health*, 98(9 Supplement), S69-S79.

Hui, C. (2017). *Positive People Relevant Perspective*. Toronto, ON, Canada.

ICASO. (2016). *CSO Letter on the Exclusion of CSOs at the UN HLM*. Retrieved December 12, 2016, from ICASO: http://www.icaso.org/wp/wp-content/uploads/2016/06/24067-CSOResponseMay6finalupdatedlist.pdf

Kerr, T. (2014). Who is HIV For? *WSQ: Women's Studies Quarterly*, 42(3 & 4), 333-338.

Kinsman, G. (1997). Managing AIDS Organizing: "Consultation," "Partnership," and "Responsibility" as Strategies of Regulation. In W. K. Carroll, *Organizing Dissent* (2nd ed.). Toronto, ON, Canada: Garamond Press.

Kinsman, G. (2006). Mapping social relations of struggle: Activism, ethnography, social organization. In C. Frampton, G. Kinsman, A. K. Thompson, & K. Tillezcek, *Sociology For Changing The World*. Black Point, NS, Canada: Fernwood Publishing.

Kuisma, M. (2008). Rights of privileges? The challenge of globalization to the values of citizenship. *Citizenship Studies*, 12(6), 613-617.

Lavallée, L. (. (2014). Anti-oppression research. In *The Sage Encyclopedia of Action Research*. Thousand Oaks, CA, USA: SAGE Publications.

Leahy, B. (2015, June 26). *Filling the void: Canada's national voice for people living with HIV takes flight*. Retrieved November 1, 2015, from Positivelite.com: http://positivelite.com/component/zoo/item/filling-the-void-canada-s-national-voice-for-people-living-with-hiv-takes-flight

Li, A., Wales, J., Wong, J. P.-H., Owino, M., Perreault, Y., Miao, A., . . . Guiang, C. (2015). Changing access to mental health care and social support when people living with HIV/AIDS become service providers. *AIDS Care*, 27(2), 176-181. http://doi.org/10.1080/09540121.2014.940269.

Lovell, S. A., & Rosenberg, M. W. (2011). Community capacity amongst people living with HIV/AIDS. *GeoJournal*, 76(2), 111–121. http://doi.org/10.1007/s10708-009-9289-2.

Maxwell, C., Aggleton, P., & Warwick, I. (2008). Involving HIV-positive people in policy and service development: Recent experiences in England. *AIDS Care*, 20(1), 72-79.

McClelland, A. (2011, September 15). *Social Change and HIV Response in Canada; Closing Keynote Presentation (Speaking Notes*). Retrieved March 1, 2017, from Pacific AIDS Network: http://pacificaidsnetwork.org/wp-content/uploads/2011/07/Alex-McLelland-speaking-notes.pdf

Namaste, V. (2015). *Oversight: Critical Reflections on Feminist Research and Politics*. (1st ed.). Toronto, ON, Canada: Women's Press.

Ong, A. (2006). Mutations in citizenship. *Theory, Culture and Society*, 23(2-3), 499-531. http://doi: 10.1177/0263276406064831.

O'Toole, S. (2005). Parents' past experiences as a mediational tool for understanding their child's current mathematical learning. *European Journal of Psychology Education*, 20(1), 75-89.

Parker, R. (2011). Grassroots activism, civil society mobilization, and the politics of the global HIV/AIDS epidemic. *The Brown Journal of World Affairs*, 17(2), 21-37.

Paxton, S., & Stephens, D. (2007). Challenges to the meaningful involvement of HIV-positive people in the response to HIV/AIDS in Cambodia, India and Indonesia. *Asia-Pacific Journal of Public Health*, 19(1), 8–13. http://doi.org/10.1177/10105395070190010301.

Pierce, J. (2014). *Racing for innocence: Whiteness, Gender, and the Backlash Against Affirmative Action*. Stanford University Press. Palo Alto, USA. Retrieved from http://ebookcentral.proquest.com/lib/ryerson/detail.action?docID=990658

Poindexter, C. C., & Saunders Lane, T. (2003). Choices and voices: Participation of people with HIV on Ryan White Title II Consumer Advisory Boards. *Health & Social Work*, 28(3), 196-205.

Pon, G. (2009). Cultural Competency as New Racism: An Ontology of Forgetting. *Journal of Progressive Human Services*. 20, 59–71. Retrieved from http://10.1080/10428230902871173.

Ponterotto, J. G. (2005). Qualitative Research in Counseling Psychology: A Primer on Research Paradigms and Philosophy of Science. *Journal of Counseling Psychology*, 52(2), 126-136.

Public Health Agency of Canada . (2014, November 28). *HIV/AIDS Epi Updates - October 2014*. Retrieved November 1, 2016, from Public Health Agency of Canada: http://www.phac-aspc.gc.ca/aids-sida/publication/epi/2010/1-eng.php

Rayside, D. M., & Linquist, E. A. (1992). AIDS Activism and the State in Canada. *Studies in Political Economy*, 39(Autumn), 37-76.

Reed, S. J. (2013). Connect to Protect and the creation of AIDS-competent communities. *AIDS Education and Prevention*, 25(3), 255–267. http://doi.org/10.1521/aeap.2013.25.3.255.

Restall, G. J., Carnochan, T. N., Roger, K. S., Sullivan, T. M., Etcheverry, E. J., & Roddy, P. (2016). Collaborative priority setting for human immunodeficiency virus rehabilitation research: A case report. *Canadian Journal of Occupational Therapy*, 83(1), 7-13. http://doi.org/10.1177/0008417415577423.

Riessman, C. K. (2008). *Narrative Methods for the Human Sciences*. Thousand Oaks, CA, USA: SAGE Publications.

Roy, C. M. (1998). *Living and Servicing: Persons with HIV in the Canadian AIDS Movement* (Unpublished dissertation). Hunter College, NY, USA.

Smith, J. H., & Whiteside, A. (2010). The history of AIDS exceptionalism. *Journal of the International AIDS Society*, 13(47), Retrieved from http://www.jiasociety.org/content/13/1/47.

Smith, K. (2011). Occupied spaces: Unmapping standardized assessments in health and social service organizations. In D. Baines (Ed.), *Doing anti-oppressive practice: Social justice social work* (2nd ed.). Black Point, NS, Canada: Fernwood.

Smith, K. (2015). Mourning the death of social welfare: Remaining inconsolable before history. In C. Janzen, D. Jeffery, & K. Smith (Eds.), *Unravelling Encounters: Ethics, Knowledge, and Resistance Under Neoliberalism*, pp. 21-45.

Spencer, M. S. (2017). Microaggressions and social work practice, education, and research. *Journal of Ethnic & Cultural Diversity in Social Work, 26*(1-2), 1-5. Retreived from http://dx.doi.org/10.1080/15313204.2016.1268989

Stieha, V. (2014). Critical Friend. In D. Coghlan, & M. Brydon-Miller (Eds.), *The SAGE Encyclopedia of Action Research*. Thousand Oaks, CA, Canada: SAGE Publications .

The Denver Principles. (1983). *The Denver Principles*. Retrieved December 1, 2016, from ACT UP: AIDS Coalition to Unleash Power: http://www.actupny.org/documents/Denver.html

Thobani, Sunera . (2007). *Exalted Subjects: Studies in the Making of Race and Nation in Canada*. Toronto, ON: University of Toronto Press.

Ti, L., Tzemis, D., & Buxton, J. A. (2012). Engaging people who use drugs in policy and program development: A review of the literature. *Substance Abuse Treatment, Prevention, and Policy*, 7(47), 3-9. Retrieved from http://www.substanceabusepolicy.com/content/7/1/47.

Travers, R., Wilson, M. G., Flicker, S., Guta, A., Bereket, T., McKay, C., . . . Rourke, S. B. (2008, July). The greater involvement of people living with AIDS principle: Theory versus practice in Ontario's HIV/AIDS community-based research sector. *AIDS Care*, 20(6), 615-624.

UNAIDS. (1999). *From principle to practice: The Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*. Retrieved November 12, 2016, from UNAIDS.org: http://data.unaids.org/Publications/IRC-pub01/JC252-GIPA-i_en.pdf

Wehbi, S. (2007). Obstacles and facilitative factors affecting community organizaing on disability rights: Case study of Lebanon. *International Social Work*, 50(1), 67-78.

GLOSSARY

ASO:	AIDS Service Organization(s)
GIPA:	Greater Involvement of People Living with HIV/AIDS (GIPA)
HAART	Highly Active Anti-retroviral Therapy
KTE:	Knowledge, Translation and Exchange
PHA:	People living with HIV/AIDS
PLHIV:	People living with HIV (a less common term in Canada but a more contemporary and widely used term internationally)
PRA:	Peer Research Associate(s)
PWA:	People living with AIDS (an older term used during the early movement. Now the common term used in Canada is PHA)
TasP	Treatment-as-prevention
U=U	Undetectable = Untransmittable