

Wellesley Institute Urban Health Research Program Advanced Grant Final Report

**IMPROVING ACCESS TO MENTAL HEALTH SERVICES FOR IMMIGRANTS,
REFUGEES AND NON-STATUS PEOPLE LIVING WITH HIV/AIDS IN THE
GREATER TORONTO AREA**

**Project conducted by the Committee for Accessible AIDS Treatment (CAAT)
with funding from the Wellesley Institute and the Ontario HIV Treatment Network**

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Authored by:

Alan Li (Principal Investigator)
Yin-Yuan Chen (Project Coordinator)
Roy Cain
Jose Cedano
Kenneth Fung
Kwasi Kafele
Ronak Khan
Julie Maggi
Fanta Ongoiba
Lena Soje
Noulmook Sutdhibhasilp
Josephine Wong

The views and opinions expressed in this report do not necessarily reflect those of the Wellesley Institute.



Acknowledgement

The investigating team of this study consists of (in alphabetical order):

Roy Cain, *McMaster University*
Jose Cedano, *Centre for Spanish-Speaking Peoples*
Yin-Yuan Chen (Project Coordinator), *Committee for Accessible AIDS Treatment*
Kenneth Fung, *University Health Network*
Kwasi Kafele, *Centre for Addiction and Mental Health*
Ronak Khan, *Alliance for South Asian AIDS Prevention*
Alan Li (Principal Investigator), *Regent Park Community Health Centre*
Julie Maggi, *St. Michael's Hospital*
Fanta Ongoiba, *Africans in Partnership Against AIDS*
Lena Soje, *Black Coalition for AIDS Prevention*
Noulmook Sutdhibhasilp, *Asian Community AIDS Services*
Josephine Wong, *CIHR-Institute of Gender & Health Doctoral Fellowship, and CIHR - Health Care, Technology and Place Training Program*

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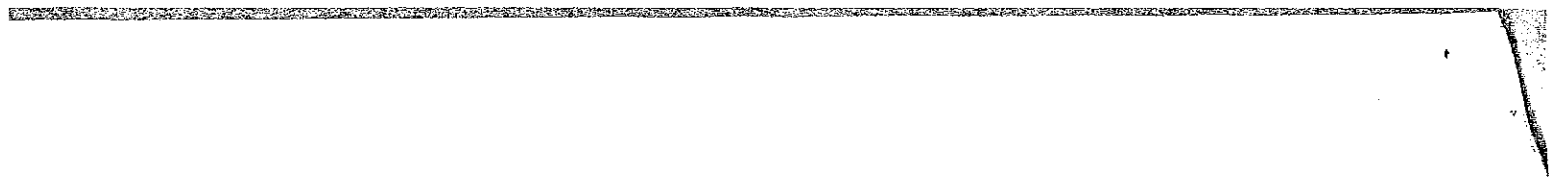


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Executive Summary

Backgrounds: Mental health care constitutes a critical component of the overall treatment and management of HIV. Immigrants, refugees and non-status people living with HIV/AIDS (I/R/N-PHAs), however, face complex barriers in accessing mental health services that take into consideration their culture, migration experiences, as well as HIV/AIDS conditions. In 2004, five ethnoracial AIDS service organizations (ASOs) in Toronto formed a partnership to develop a community-based action research that aimed to better understand the realities of and to subsequently improve mental health service access for I/R/N-PHAs. The investigating team was later broadened to include other university- and hospital-based academic researchers.

As per our funding agreement with the Wellesley Institute, this report will document the processes and results of Component 1 of this study, which explored I/R/N-PHAs' mental health needs, coping strategies, help-seeking behaviours, service utilization experiences, and ideas for improving existing services to better meet their needs.

Methods: The target population of this study was defined as PHAs that are first-generation immigrants, refugees, or people without legal status currently residing in the Greater Toronto Area who migrated from Africa, the Caribbean, South Asia, Southeast/East Asia, or Spanish-speaking countries in Central/South America. Through convenience sampling and snowballing, a total of 47 I/R/N-PHAs were recruited to participate in semi-structured interviews and/or focus groups. In accordance with the principle of "Greater Involvement of People living with HIV/AIDS", five research assistants from the target communities were hired to assist with recruitment, data collection, and analysis. Qualitative analysis was performed using N-Vivo 7.

Results: I/R/N-PHAs conceptualized mental health as a state of security insofar as their basic needs such as food, shelter, finances and employment were fulfilled. In situations where their stability was interrupted, I/R/N-PHAs identified having good mental health as their ability to successfully address these life challenges. The five main sources of stress affecting I/R/N-PHAs' included challenges related to the migration and settlement process, living with HIV/AIDS, stigma and discrimination, social isolation, and service utilization. These stressors often operated simultaneously and therefore amounted to compounding mental health impacts on I/R/N-PHAs. To cope with these stresses, I/R/N-PHAs relied on a mixture of informal strategies and formal services, including some organizations that did not traditionally have clear mandates in providing mental health care such as practical support programs, legal services and community centres. When accessing mental health services, I/R/N-PHAs reported having encountered a number of barriers, which included stigma and discrimination, lack of communications and follow-ups from service providers, linguistic difficulties, differences in understanding mental health, long wait time, and limited service availability.

Conclusions: Improving I/R/N-PHAs' mental health requires a comprehensive strategy that entails intersectoral collaborations. I/R/N-PHAs in this study outlined four recommendations: creating more opportunities for I/R/N-PHAs to enhance their capacity in dealing with challenges in life; developing more programs and services that reflect the diversity of I/R/N-PHAs; addressing issues of stigma and discrimination through education; and, enhancing I/R/N-PHAs' access to treatments and practices alternative to Western medicine. The full development of a best practice model to improve I/R/N-PHAs' mental wellbeing will take place in Component 3 of this study.

I. Introduction

A. Background of the Study

The Committee for Accessible AIDS Treatment (CAAT) is a coalition of service providers in AIDS-related health, legal, and social service fields as well as immigrants, refugees, and non-status people living with HIV/AIDS (I/R/N-PHAs). It operates as a voluntary collective. The coalition was formed in 1999 when a group of service providers began to meet regularly in response to the increasing observations in their practice that many I/R/N-PHAs suffer from multifaceted barriers in accessing essential services and HIV treatment. The primary objectives of CAAT are:

- To serve as a forum for information exchange, problem solving and skill building amongst service providers and affected populations; and,
- To identify and facilitate the implementation of creative solutions to these access barriers.

To this day, CAAT continues to address its objectives through PHA capacity building, research, knowledge transfer and exchange, coalition building, and advocacy.

In 2001, the Committee completed an action research that documented access barriers faced by I/R/N-PHAs when seeking HIV care as well as legal services. During this study, mental health needs of I/R/N-PHAs emerged as an important issue that requires follow-up investigation. In 2004, CAAT proceeded with a pilot study on the mental health issues faced by I/R/N-PHAs which included a literature review, a program scan, and two focus groups – one with I/R/N-PHAs and the other with relevant service providers. Results from this pilot project outlined the gaps in current literature around the lived experiences of I/R/N-PHAs in general, particularly their intersecting mental health stressors, and effective strategies for service providers to help address these mental health issues.

With funding from the Wellesley Institute and the Ontario HIV Treatment Network, in 2005 CAAT bridged a research partnership amongst five ethno-specific AIDS service organizations in Toronto – Africans in Partnership Against AIDS, Alliance for South Asian AIDS Prevention, Asian Community AIDS Services, Black Coalition for AIDS Prevention, and the Centre for Spanish-Speaking Peoples – to further explore and address the access barriers encountered by I/R/N-PHAs when seeking mental health support. The investigating team was soon expanded to include practitioners in the mental health field as well as other community- and institution-based researchers.

B. Literature Review and Research Rationale

Over the last few decades, the Canadian population has become increasingly diverse with immigrants coming from all over the world. Of the one million immigrants that arrived in Ontario between 1991 and 2001, 80% of them came from Asia, Americas, and Africa (Citizenship and Immigration Canada, 2005). Over three-quarters of these immigrants coming to Ontario have chosen to settle in the Greater Toronto Area (Ontario Ministry of Finance, 2003), making Toronto one of the most diverse metropolitans in the world.

As the Canadian society becomes more diverse than ever, the faces of those living with HIV and AIDS in this country have also changed. The proportion of reported AIDS cases attributed to Whites has decreased in the past 10 years while that attributed to other ethnoracial groups has been on the rise (Health Canada, 2004). There is also increasing amount of evidence suggesting that HIV/AIDS is becoming more prevalent amongst immigrants and refugees. For example,

newcomers born in endemic countries accounted for 2.9% of all HIV positive tests during the period between 1981 and 1995; in 1997 and 1998 alone, however, they accounted for 14% of the positive results (Remis and Whittingham, 1999).

In June 2002 a revision to the *Immigration and Refugee Protection Act* introduced mandatory HIV testing for all immigrant and refugee applicants. Until the end of 2005, approximately 2000 individuals had tested HIV positive during their application process (Public Health Agency of Canada, 2006). In 2005 alone 668 people were tested positive, the majority (67%) of whom were from Africa & the Middle East, 23% were from the Americas and 9% Asia. Demographic changes as such have significant implications for the HIV/AIDS sector. In order to facilitate evidence-based practice, it is vital for service providers to understand and appreciate the needs of the emerging I/R/N-PHA population through research. The current study therefore builds on the knowledge gathered previously around I/R/N-PHAs' access to health and legal services and seeks to shed light on I/R/N-PHAs' mental health needs.

In addition to the epidemiological changes, the nature of HIV/AIDS as an illness has also changed. Recent advances in medicine have led to improved prognosis, including prolonged lifespan, for people living with HIV/AIDS (PHAs). However, the evolution of HIV/AIDS from a terminal illness into a manageable chronic health condition has presented new challenges. All along, HIV/AIDS has been a disease with profound physical and mental health impact. The neurological effect of the virus, trauma related to facing the prospect of mortality, and the psychosocial impact of the stigma associated with HIV/AIDS can all be detrimental to the mental wellbeing of PHAs.

With the changing nature of HIV, PHAs now face additional burdens on their mental health due to the adverse side effects of antiretroviral medications, fluctuations in their health condition, and having to deal with AIDS-related discriminations on a long-term basis. Studies have found that reduced neurological functioning, depression, anxiety and other neuropsychiatric conditions are common among PHAs (Kalichman et al., 2000; Cook et al., 2004). At the same time, depression and other mental health conditions have been shown to negatively affect PHAs' adherence to medications, potentially causing the virus to develop treatment resistance (Murphy et al., 2004). Thus, within this new context mental health services have emerged as a critical component of the overall ongoing treatment and management of HIV/AIDS.

PHAs who are also immigrants, refugees, or without legal status face an additional layer of mental health stressors related to their experience of migration. It has been documented that immigrants and refugees in general experience a great deal of discrimination and social exclusion (Papillon, 2002). High level of settlement stress often results from under-/un-employment, financial strains, and social isolation (Nesdale, Rooney & Smith, 1997). As discrimination of various natures intersects, I/R/N-PHAs often find themselves caught between their ethno-cultural communities and the HIV/AIDS community. In some ethnic communities where AIDS-phobia is prevalent, PHAs are generally compelled to keep their HIV status in secrecy as disclosure often means being ostracized from the social networks. Meanwhile, the HIV/AIDS community has for a long time neglected the needs of PHAs from diverse ethnoracial backgrounds, leaving these PHAs feeling out-of-place. As a result, a growing amount of evidence shows that I/R/N-PHAs experience significant barriers in accessing needed services and support, potentially leading them to develop depression and other psychiatric conditions (Li et al., 2001; Lau, 1999; ASAAP, 1999; Baxter et al., 1993; Narcisco, 2001).

However, research on the mental health of I/R/N-PHAs is profoundly scarce (Wong et al, 2004). Current literature addressing the subject of mental health and HIV is mostly US-based and predominantly focuses on the experiences of gay white males. When issues of marginalized PHAs are examined, analyses often follow the ethnoracial lines. In so doing, factors such as country of origin and citizenship status that are important determinants of I/R/N-PHAs' health are often neglected. Also lost in existing literature is the analysis of how multiple marginalities like race, gender, socioeconomic status, sexual orientation, and citizenship intersect to affect PHAs' mental wellbeing. This study therefore aims to fulfill the gaps in scientific literature related to mental health of I/R/N-PHAs by approaching the lived experiences of I/R/N-PHAs in a holistic manner. It will also pay special attention to the Canadian social fabric so that findings are grounded in and relevant to local knowledge and practices. Furthermore, this study is unique insofar as it seeks to move beyond identification of challenges faced by I/R/N-PHAs towards synthesis of strategies to ensure their mental wellbeing.

C. Research Objectives and Framework

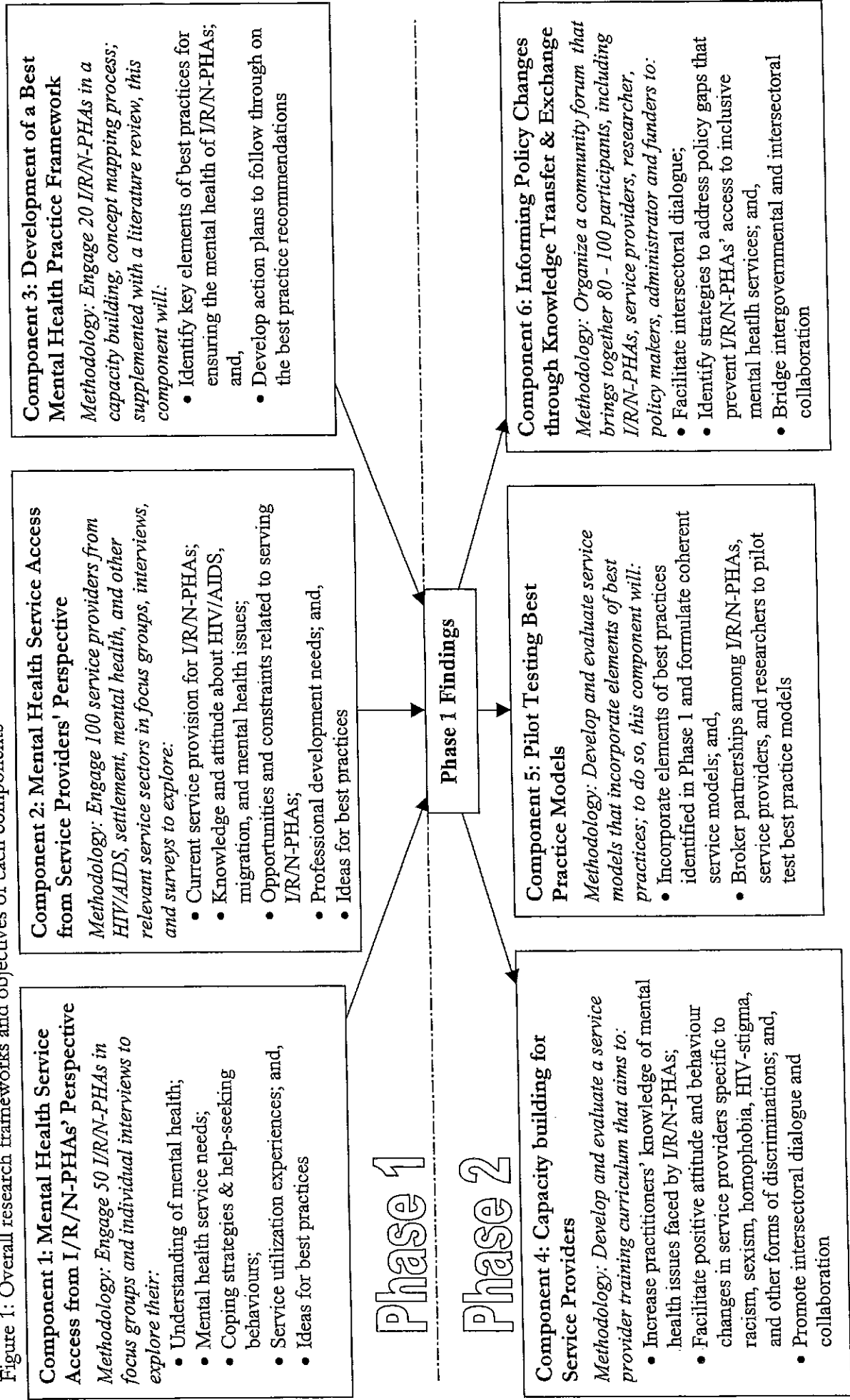
As an action research, the goal of this study is not only to address knowledge gaps but also to contribute towards improving mental health service access for I/R/N-PHAs, thus enhancing I/R/N-PHA's overall quality of life. In order to achieve this goal, a six-part research framework has been developed. These six interconnected research components, each with its respective objectives as summarized in *Figure 1*, are grouped into two phases. The first phase, consisting of Components 1 through 3, utilizes mixed methodologies to examine the following by incorporating perspectives from both I/R/N-PHAs and service providers:

- Intersecting effects of HIV/AIDS and migration on the mental health of I/R/N-PHAs;
- Mental health needs of I/R/N-PHAs;
- Capacity of existing service providers and organizations in meeting these needs; and,
- Solutions to improve mental health services and support for I/R/N-PHAs.

Building on these findings, Phase 2 of the study seeks to promote inclusive and accessible mental health services for I/R/N-PHAs by:

- Developing and evaluating a training curriculum for service providers;
- Pilot-testing the best practice model; and,
- Facilitating relevant policy changes.

Figure 1: Overall research frameworks and objectives of each component



D. Guiding Principles and Values

Traditionally, the PHA community has played a predominantly passive role in HIV/AIDS related research. Most aspects of conducting research are seen as the exclusive domain of academic researchers. PHAs, particularly those facing multiple marginalities, often face difficulties moving beyond the role of study subjects. Studies conducted without meaningful involvement of the PHA community run a high risk of being irrelevant to the experiences and needs of PHAs, and at times they can even cause harm to affected communities.

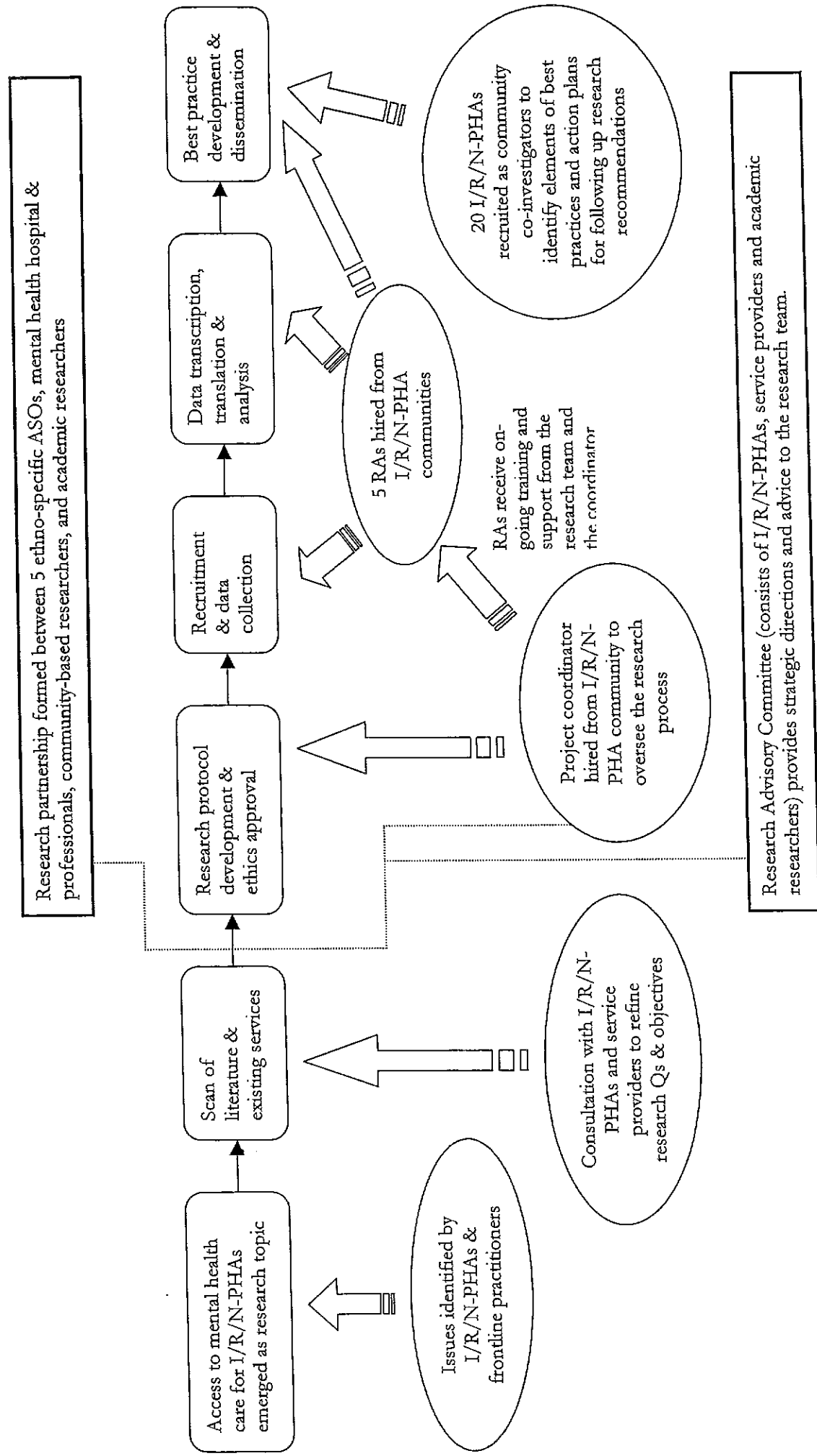
With aspirations to affect systemic changes and to improve the mental wellbeing of I/R/N-PHAs, this investigating team considers a positivist research approach which emphasizes objectivity and removedness of researchers to be inadequate. Instead, this study has sought guidance from the philosophy of community-based participatory action research (CBPAR). This research paradigm has been employed in social research since 1970s and is widely considered a valid methodology that puts research capabilities in the hands of the marginalized communities so that they can advance their lives through structural transformation (Hagey, 1997). Unlike traditional research, CBPAR offers PHAs an opportunity to move from the margin to the centre of the research discourse, and it seeks to meaningfully engage community members and their representatives in every aspect of the research process.

The CBPAR paradigm is also embraced by the research team as a commitment to the GIPA principle, which stands for Greater Involvement of People with HIV/AIDS. In the HIV/AIDS movement, the GIPA principle has been used to embody the ideal of community empowerment and capacity building (APN+, 2004). Whether it is prevention or treatment, service delivery or policy development, the GIPA principle emphasizes the importance of grounding all aspects of our responses to the HIV/AIDS epidemic in PHAs' first-hand knowledge and perspectives. To weave the GIPA principle throughout this study, multiple entry points for I/R/N-PHAs are built into the study design so that the community may become engaged in every stage of the research process.

Figure 2 depicts the strategies used by the investigating team to involve I/R/N-PHAs in this study. Some highlights include:

- **Facilitating equitable partnership in designing research protocol and instruments:** A Research Advisory Committee which consists of I/R/N-PHAs, service providers, and academic researchers is established at the start of the project to provide strategic directions.
- **Building research capacity of the I/R/N-PHA community through paid positions:** The investigating team makes a conscious effort to explicitly invite applications from I/R/N-PHAs on the postings for all paid and volunteer positions. As a result, this study employs a coordinator and a team of five peer research assistants (RAs) from targeted I/R/N-PHA communities to perform recruitment, data collection, and analysis. As part of our commitment to strengthening the community's research capacity, it is made clear when hiring the RAs that prior research experiences are not required. Rather, qualification is based on candidates' awareness of the issues faced by I/R/N-PHAs and a general interest in research. All qualified candidates for the position are invited to a one-day training that covers the basic principles of CBPAR and research ethics. I/R/N-PHAs who are hired as RAs receive further training on topics such as recruitment strategies, interview skills, and focus group facilitation skills. In addition, the investigating team offers the RAs ongoing support and mentorship throughout the research project.

Figure 2: Multiple entry points for I/R/N-PHAs to become involved in the research project



II. Research Methods

This study has received ethics approval from the University of Toronto HIV Research Ethics Board, McMaster University, and the University Health Network.

A. Recruitment

In this study, the target population is defined by the following criteria:

- Over the age of 16;
- Living with HIV/AIDS;
- First-generation immigrants, refugees, or individuals who have experienced the migration process but currently without legal status in Canada;
- Originally from Africa, the Caribbean, South Asia, Southeast/East Asia, or Spanish-speaking countries in Latin America; and,
- Currently residing in the Greater Toronto Area.

The decision to focus on the abovementioned ethnoracial communities is based on the nature of this study being a partnership initiative amongst five ethno-specific AIDS service organizations in Toronto; the five communities above represent the service populations of these agencies.

To recruit research participants, advertisements in the form of flyers and postcard-size leaflets were placed at various locations where I/R/N-PHAs frequent, including AIDS service organizations, sexual health clinics, community health centres, hospitals, immigration lawyers' offices and community centres. In addition, five peer research assistants (RAs) - one from each of the target ethnoracial communities - were hired to assist with recruitment. This arrangement is believed to have facilitated the recruitment process in two ways. Firstly, as people without full citizenship status may fear to access formal services and support, having RAs who are themselves I/R/N-PHAs allowed us to tap into and publicize the study through the informal peer network. Secondly, the RAs were able to empathize with their peers because of shared experiences. This was believed to have fostered a level of trust between the RAs and the potential participants, thus encouraging I/R/N-PHAs who may otherwise be suspicious of research to come forward.

Further to the efforts of the RAs, we relied on participants to refer their peers to our study, thus developing a snowball sample. A quota sampling method was utilized in conjunction to ensure equal representation from the five targeted ethnoracial groups. Towards the second-half of the recruitment process, a purposive sampling method was employed to make sure that I/R/N-PHAs facing further marginalities, such as youth, transgenders/transsexuals, and sex workers, are included in the study as well.

B. Data Collection

Both focus groups and individual interviews were used to collect qualitative information on I/R/N-PHAs' health beliefs, mental health needs, coping strategies and service utilization experiences. Using a mixed method enhanced participants' access to this study as they were able to choose the means of participation that better met their needs. While individual interviews provided participants with a sense of privacy, the focus groups proved to be an attractive option for participants who were seeking camaraderie and peer support. All together, 17 one-on-one interviews and 6 focus groups were conducted, reaching 47 I/R/N-PHAs in total. Three of the focus group participants were

invited back for individual interviews as their experiences were believed to warrant more in-depth exploration which was not feasible in a focus group setting.

The focus groups generally lasted between 90 and 120 minutes and their sizes ranged from 3 to 11 participants. Three of the six focus groups were conducted in English and open to participants from all targeted ethnoracial communities. By chance, one of these three groups turned out to have women only. Of the remaining focus groups, one was facilitated in Spanish, another in Cantonese and the other was specific to I/R/N-PHAs from the South Asian community. These language- or community-specific focus groups were organized in response to the needs arose during recruitment. All focus groups were moderated collaboratively by the research coordinator, an RA, and an additional seasoned facilitator. The facilitation guide used in focus groups is included in *Appendix A*. With constant interactions among participants, these focus groups helped generate a collective testimony of I/R/N-PHAs' needs and experiences.

The individual interviews, on the other hand, were between 60 and 90 minutes in length. All interviews were conducted by the RAs in person. Before an interview was arranged, participants were always given the option of requesting an interviewer based on gender or ethnoracial background. Most interviews were in English, six were in Spanish, one in Ugandan and one in Thai. Interviews in languages other than English were conducted either by an RA that speak the language or with the assistance of an interpreter. These interviews were semi-structured in nature (see *Appendix B* for the full interview guide), and they emphasized details in I/R/N-PHAs' personal experiences, thus complementing the collective data from focus groups.

Prior to each focus group or interview, participants were asked to complete an anonymous demographics form (see *Appendix C*). Information collected through this form helped the investigators to contextualize the qualitative data and to establish a general profile of the study sample.

C. Study Sample

A total of 47 I/R/N-PHAs participated in Component 1, of which 32 identified as male, 14 female and 1 male-to-female transgender. Nearly half of the study sample self-identified as heterosexual or straight, over one-third as gay or lesbian, 6 participants described their sexual orientation as bisexual and 1 as questioning/unsure. The age of the participants ranged from 17 to 53 years old, with the overall sample averaged at 36.4 years of age.

Of the five targeted ethnoracial communities, the African and the Spanish-speaking groups represented a slightly higher percentage than the others in the sample. Within the Caribbean group, 4 participants self-identified as Black while the other 4 described themselves as multiracial. Two participants from Trinidad described their ethnoracial background as East/Southeast Asian. As a result, despite their country of origin, these two participants were considered as a part of the East/Southeast Asian group for the purpose of this study. All together, 26 countries were represented in the sample. The length of time the participants have been in Canada ranged from as short as 3 months to as long as 38 years, with the median being 6 years. At the time of the interview, 34% of the participants had received their Canadian citizenship, 19% had permanent residence status, 41% had an active refugee application in the system, 2% held the Temporary Resident Permit, and 4% had no legal status in Canada.

A more detailed breakdown of participants' age, gender identity, sexual orientation, religious affiliation, years in Canada, and citizenship status by their ethnoracial identity is listed in *Table 1*.

Table 1: Basic demographics of the study sample

		Ethnoracial Identity					Total
		African	Caribbean	South Asian	Southeast/ East Asian	Spanish-speaking	
Age	Under 30 years	1	1	2	-	2	6 (12.8%)
	30 - 39 years	9	2	3	4	8	26 (55.3%)
	40 - 49 years	1	5	2	3	1	12 (25.5%)
	50 years or over	-	-	1	1	1	3 (6.4%)
Gender	Female	8	3	1	1	1	14 (29.8%)
	Male	3	5	7	7	10	32 (68.1%)
	Transgender/Transsexual	-	-	-	-	1	1 (2.1%)
Sexual Orientation	Heterosexual/Straight	11	3	5	2	2	23 (48.9%)
	Gay/Lesbian	-	4	3	2	8	17 (36.2%)
	Bisexual	-	1	-	3	2	6 (12.8%)
	Questioning/Unsure	-	-	-	1	-	1 (2.1%)
Religious Affiliation	Buddhism	-	-	-	3	1	4 (8.5%)
	Christianity/Catholicism	10	5	3	1	8	27 (57.4%)
	Islam	1	-	3	-	-	4 (8.5%)
	Hinduism	-	-	2	-	-	2 (4.3%)
	Other	-	1	-	-	1	2 (4.3%)
	No religious affiliation	-	2	-	4	2	8 (17.0%)
Years in Canada	Less than 1 year	3	-	-	-	1	4 (8.5%)
	1 - 4 years	6	2	2	-	5	15 (31.9%)
	5 - 9 years	1	-	3	4	4	12 (25.5%)
	10 years or over	1	5	3	4	2	15 (31.9%)
	No response	-	1	-	-	-	1 (2.1%)
Citizenship Status in Canada	Citizen	1	4	5	4	2	16 (34.0%)
	Permanent resident	-	1	2	2	4	9 (19.1%)
	Refugee claimant	10	2	1	-	6	19 (40.4%)
	Holder of TRP	-	-	-	1	-	1 (2.1%)
	Non-status	-	1	-	1	-	2 (4.3%)
Total		11 (23.4%)	8 (17.0%)	8 (17.0%)	8 (17.0%)	12 (25.5%)	47

Besides personal characteristics identified above, participants were asked on the demographics form questions related to their language ability, level of education, socioeconomic status, family relationship, and health status. Such information was gathered to help setting the context for interpreting narratives from focus groups and interviews as it might have some bearing on I/R/N-PHAs' service needs and help-seeking experiences.

Language Ability

Fifteen of the 47 participants (32%) had a first language other than English or French. In term of proficiency in English or French, 8 (17%) PHAs spoke only a little of either language, 6 (13%) could read only a little or not at all, and 10 (21%) could write only a little or not at all.

Level of Education

Of 43 participants that disclosed, 21 (49%) completed or at least received some post-secondary education, 17 (40%) finished high school or equivalent secondary education, and 5 (12%) attained less than high school education.

Socioeconomic Status

The employment status of the participants at the time of interview was as follows:

- 3 (7%) were employed full time;
- 7 (15%) had part-time employment;
- 15 (33%) were unemployed but actively looking for work;
- 6 (13%) were unemployed and not actively looking for work; and,
- 6 (13%) were students.

For the six-month period prior to their interviews, 38 (83%) participants indicated social assistance (e.g., Ontario Disability Support Program, Ontario Works, etc.) as their main source of income while 4 (9%) said it was their wages and salaries.

Of the 22 participants that ever held a paid position in Canada (either full-time or part-time), 14 (64%) worked in the service sector while 8 (36%) held blue-collar work (i.e. labourer, factory workers, etc.). In comparison, amongst the 30 participants who had work experiences before migrating to Canada, 25 (83%) were in the service industry, 2 (7%) were self-employed, 1 (3%) worked as a skilled labourer and 2 (7%) worked as general labourers. In addition, 6 of the 25 participants who held jobs in the service sector before coming to Canada indicated that they were in managerial positions.

Family Relationship

In terms of participants' marital status, of the 46 participants who answered this question, 6 (13%) were either married or in a common-law relationship, 3 (7%) were divorced, 5 (11%) were separated, and 32 (70%) were single. Seventeen (36%) participants had at least one child; the number of children ranged from 1 to 5.

Health Status

On average, participants in this study had been tested HIV positive for 5 years; the actual length of time since diagnosis ranged from 2 months to 22.5 years. A list of indicators for participants' health at the time of this study is listed in *Table 2*.

Table 2: Health status of the study sample

		Frequency ¹	Percentage
AIDS Diagnosis	Yes	14	31.1%
	No	29	64.4%
	Don't know	2	4.4%
Hospitalization due to HIV/AIDS-related Conditions	Yes	18	40.0%
	No	25	55.6%
	Don't remember	2	4.4%
CD4 Count	Less than 200	10	21.7%
	200 - 349	13	28.3%
	350 - 500	14	30.4%
	Over 500	6	13.0%
	Don't know	3	6.5%
Taking HIV medications currently or in the past?	Yes	38	82.6%
	No	8	17.4%

¹ Frequency does not always add up to 47 due to missing values.

In addition, participants were asked to self-evaluate their overall health and mental health at the time of interview using a 5-point scale; 5 being excellent, 4 very good, 3 good, 2 fair and 1 poor. In terms of overall health, 2 (4%) participants described themselves as in an excellent state, 14 (30%) as very good, 18 (40%) as good, 11 (24%) as fair and 1 (2%) as poor. The average value of this scale was 3.1. On the other hand, 4 (9%) participants described their mental health as excellent, 6 (13%) as very good, 15 (33%) as good, 15 (33%) as fair and 6 (13%) as poor. In comparison to their own assessment of overall health, there were fewer participants that described their mental health as excellent or very good and an increased number of PHAs thought their mental health state was fair or poor. The average of the mental health self-assessment scale was 2.7.

D. Data Analysis

All focus groups and interviews were audio-taped upon participants' consent. To protect I/R/N-PHAs' privacy, participants were given the option of using a pseudonym during their interviews. Furthermore, after the recordings were transcribed, identifying information such as names of the participants and the agencies from which they access services were removed from transcripts. Transcripts in another language were translated into English. All transcripts were then inputted into N-Vivo 7 for organization, thematic coding, and analysis. Open coding and axial coding were performed to identify both overarching themes and themes specific to subgroups.

III. Results

A. I/R/N-PHAs' Understanding of Mental Health

Traditionally, the understanding of mental health in Western society is through a medical lens that emphasizes discussions around mental disorders. Under this framework, mental health tends to describe a state of being that is internal to an individual. This concept is sometimes foreign to people from a different cultural background, including I/R/N-PHAs. In order to access the mental health system in Canada, I/R/N-PHAs often are required to consciously take up the medical lingo necessary so as to align their understanding of mental health with that of society in general. One participant said:

"For me, it was really important to know what a panic attack is, to know what depression is, to talk about it. I didn't know anything about those things. I had to learn, I had to include those words in my vocabulary, and I had to learn the meaning of those words in order to be able to express my feelings." (*Spanish-speaking man*)

When participants in both focus groups and individual interviews were asked to describe how good mental health is understood by them and their cultural community, most depicted a state of security where they are successfully integrated into the Canadian society insofar as they are able to attain stable housing, gainful employment, financial stability, and social support. That is, most participants described good mental health as an active response to external social determinants. A participant summarized the concept of security as follows:

"I think good mental health means security. By security I mean the security emanates from financial security, personal security, or housing. These are the basic kinds of necessities we all need." (*South Asian man*)

Others spoke of this idea of security in terms of stability and balance in life:

"I understand mental health as having stability, such as safe housing, where your next meal is going to come from, get to work, and also in the spiritual way." (*African woman*)

"Having good mental health is to have a regular lifestyle. I mean you are able to eat normally, sleep normally, and have certain degree of physical activities and normal sexual desire." (*Southeast/East Asian man*)

In other words, for some participants, having a balanced lifestyle where stability is achieved in bio-psycho-socio-spiritual aspects of life was reflective of good mental health. I/R/N-PHAs' understanding of mental health, however, went beyond the articulation of a secure and stable state. Participants described another facet of good mental health as having the ability to successfully respond when the desired state of balance is disrupted. A participant explained mental health as an active process of coping:

"Good mental health means being able to cope with day-to-day functions and whatever tricks life has in store for you, put in your path. It is the ability to get over life and to function in society without having a nervous breakdown." (*Caribbean man*)

Similar ways of understanding mental health has been identified in other studies with cultural-linguistic minorities in general (Community University Research Alliance, 2006). However, I/R/N-PHAs in our study went further to specify the skills they need to successfully cope with challenges in life, which included “positive thinking, having a good memory, good retention, good concentration, and being able to do math” according to a female participant. Whether they possess these abilities, therefore, was seen by a number of I/R/N-PHAs as an indication of their mental wellbeing.

Self-confidence was mentioned by some participants as another element that facilitated people’s coping. One such participant outlined a process of how having good mental health, and subsequently developing greater self-confidence, amounts to being capable of dealing with demands in life in a more effective manner:

“If you are mentally well, you have more self-confidence. And when you are more self-confident, you are able to take care of different aspects of life - such as housing, financial security, food, and clothing - much more productively.” (*Spanish-speaking man*)

This mechanism suggested a potentially self-fulfilling nature of I/R/N-PHAs’ mental health. That is, when I/R/N-PHAs have good mental health, it leads to them coping more effectively with day-to-day challenges, which in turn reaffirms I/R/N-PHAs’ mental wellbeing and the cycle continues.

In summary, I/R/N-PHAs in our study spoke of mental health as an external state where the challenges and responsibilities in life are successfully addressed. The fact that an individual is able to cope with migration-related stress, handle his or her HIV diagnosis, secure meaningful employment, obtain stable housing, maintain financial stability and fulfill family responsibilities may represent both a consequence and an enabler of good mental health.

B. Sources of Stressors Affecting I/R/N-PHAs’ Mental Health

This section examines in more detail challenges frequently faced by I/R/N-PHAs, including those related to the migration and settlement process, living with HIV, stigma and discrimination, social isolation, and service utilization. As discussed in the previous section, I/R/N-PHAs often consider their ability to successfully overcome these challenges as an indicator of having good mental health. By the same token, these challenges in life represent potential sources of strains to I/R/N-PHAs’ mental health. Although described here separately, it is important to recognize that these stressors often affect I/R/N-PHAs concurrently, thus causing compounding impacts on individuals’ mental health.

Migration and Settlement Process

The migration process for immigrants and refugees in general follows several distinct stages – namely pre-migration, departure, arrival in the host country, obtaining legal status, and settlement. I/R/N-PHAs in our study spoke of challenges and stresses they encountered in each of these stages.

A number of participants revealed experiences of war, abuse, and sexual assault in the country of origin or during the journey of migration. A Spanish-speaking participant, for example, described his childhood experience and how it has affected his mental health:

“My father would make me take my clothes off. Once I undressed, he would hit me with a belt and at the same time described to me the way he was going to beat me; those sessions

were around half-an-hour long. Nothing could stop him. So I had to leave home and I went to [another city]. There, I was raped as I was asking for directions... I was bleeding... the guy left me there bleeding. Now I have my father's ghosts inside my mind. The only thing I can do is using drugs to stop thinking. This is the only way I forget." (*Spanish-speaking man*)

Similarly, most other participants who disclosed such experiences to us never sought assistance for the resulted trauma, which continued to have lingering effects on their mental wellbeing. In some situations, I/R/N-PHAs faced multiple sources of pre-migration trauma which worked in conjunction to affect their self-image. The following quote briefly described the story of a woman from a war-torn African country where she experienced sexual assault, faced HIV diagnosis, and encountered discrimination as a single woman:

"In my country we went through genocide. We have two tribes and then we had a civil war. Because I don't belong to either tribal group, they got angry and I got HIV from this person who was seeking revenge. As a woman living with HIV, it is quite hard to get married. And, being single in my country, you don't have value. They just ignore you. You are nothing. I can't have a biological child and that makes me feel sad about life." (*African woman*)

During the actual journey of migration, I/R/N-PHAs spoke of mixed feelings. On one hand they were often elated by the prospect of a better life, but on the other hand they were also distressed by the uncertainty in the future. One female participant from Africa, for instance, talked about actually losing weight before coming to Canada as she stressed over not knowing when she would return home or what her future would hold.

For some participants, their journey to Canada actually included a few stopovers in other countries. Stresses often arose when these I/R/N-PHAs faced difficulties obtaining all the required travel documents, not to mention the demands of having to repeatedly adjust to new environments. One participant spoke of the stresses he encountered during his migration to Canada:

"It's extremely stressful leaving your family. The journey was also stressful and not easy to handle. After I left Africa, I went to [a country in Europe] where I spent almost a month before coming to Canada. I had to go to immigration three times to get the visa. It was a very gruesome experience going and not coming back with all the documents. Also, facing new people and new culture, it's been a challenging coping." (*African man*)

Upon their arrival in Canada, I/R/N-PHAs often face multiple setbacks and challenges when manoeuvring through the immigrant/refugee system. As the course from filing a claim to successfully receiving landed immigrant status in Canada can drag on for years, many participants spoke of feeling stressed and anxious during this process. A participant, for example, mentioned that she would wake up in the morning feeling tired and having no energy because she worried about what was going to happen with her immigration process. Another participant described her experience of applying for refugee status as follows:

"When I submitted my refugee claim, it was rejected. I had a bad lawyer who didn't know to provide much evidence and didn't tell me what was required ahead of the hearing. I went for a second hearing with another lawyer, but the decision was still negative. It increased my fears and later I applied to stay in Canada on humanitarian and compassionate grounds. During

that time, I had nightmares that kept occurring, constant headaches, and frustrations.”
(*Caribbean woman*)

In their attempt to find help with navigating through the immigration system, some I/R/N-PHAs unknowingly fell prey to some of the so-called immigration consultants. These immigration consultants often claimed to offer newcomers assistance with their immigrant/refugee applications while in reality they took advantage of unsuspecting people by charging them a large sum of money for extremely poor services. A participant shared with us his experience:

“I made my refugee claim with two immigration consultants. They asked me for my first welfare cheque. Those guys lied to me. They made me believe that the money was part of the cost of the immigration process. I didn’t speak any English and I didn’t know anything about the refugee process, so I believed them. They asked me not to talk to anybody. They wanted me to pay them \$2000.” (*Spanish-speaking man*)

Encounters like this added further stress to what has already been experienced by I/R/N-PHAs during the immigration process.

As I/R/N-PHAs tried to overcome the hurdles in the immigration system, they were simultaneously faced with the demands of settling down in a new country which usually included adjusting to the environment, learning a new language, securing suitable housing, and finding appropriate employment. However, as for immigrants and refugees in general, the settlement process could be quite challenging for I/R/N-PHAs. The issue of unemployment and under-employment was a case in point. Data collected from the demographics forms completed by participants showed that a significant number of I/R/N-PHAs in our study had trouble finding jobs that are equivalent to their employment in the country of origin. One participant said in an interview:

“Before coming to Canada, I worked in sales and in research and development. Since I have been here in Canada, I have been working in very low-end jobs, which I don’t like. I have been working in manufacturing companies as a labourer and I have also been working in coffee shops.” (*Southeast/East Asian man*)

In some cases, I/R/N-PHAs talked about feeling disillusioned because of the differences between their expectations prior to coming to Canada and what they actually experienced here. Part of this disillusionment came from not having full legal status in Canada and the consequent limitations on people’s ability to fully settle down and plan for the future. The effect of this uncertainty on mental health was particularly notable in non-status participants:

“When I sleep at night I have anxiety attacks. There are a lot of things on my mind such as my HIV status and my financial status. If you don’t have legal status you really have to pay everything out of your own pocket. I just go day by day. I don’t really think about what’s going to happen tomorrow.” (*Southeast/East Asian man*)

Diagnosed and Living with HIV/AIDS

According to I/R/N-PHAs in our study, living with HIV/AIDS represented another major source of stress in addition to dealing with the migration process. HIV as a stressor operates through several fronts, including the processes of coping with the diagnosis, dealing with uncertainty about the future, adjusting to HIV medications, negotiating around disclosure, and facing HIV-related stigma.

Almost all participants found testing HIV positive a traumatic event in itself. Some I/R/N-PHAs described their diagnosis as devastating and something that was very difficult to move pass in life. For a number of participants, such devastation came from their assumption that they were facing immanent death in the near future. For other participants, stresses surrounding their HIV diagnosis were mainly a result of worrying about their deteriorating physical health and not knowing how to deal with uncertainties. As a participant tried to explain:

“You don’t know what to do, so you get more stressed. If I get sick do I call the paramedics? Do I go to the hospital and tell them that I am positive? If I get thrown out of the place where I’m living, what do I do? How should I explain to people why I am not working although I am young? I get stressed just trying to figure these things out.” (*Caribbean woman*)

For I/R/N-PHAs with children, successful coping required both they and their children came to term with the HIV diagnosis. As a participant described here, this added burden could often be difficult to overcome and might have significant mental health impact on the entire family:

“My daughter tries to look like she is coping with my diagnosis, but I know she is not. It makes me feel guilty and then I burden myself with her problems. I find she becomes so depressed, so I have to give her assistance. I find that it frustrates me a lot. I am feeling very badly, very stressed. I find it very mentally challenging.” (*Caribbean woman*)

HIV diagnosis also affected some of the newer immigrants and refugees in a different manner. Due to a policy change, immigrants and refugees who file their claims after 2002 are required to undergo mandatory HIV testing as a part of their immigration medical exam. Complaints about immigration doctors who are in charge of conducting these medical exams were frequently brought forward by I/R/N-PHAs in our study. These complaints generally centred on how the HIV testing results were communicated, often without appropriate pre- and post-test counselling or proper referrals to support services. A participant described his dealing with an immigration doctor as follows:

“I received a phone call from the immigration doctor’s office saying: ‘Please come to the office. Did you know you are HIV positive? Please talk to the receptionist for the referral to the HIV specialist.’ Fortunately I had some information about HIV before that, but in other circumstances I would have jumped over a street car, or I might have been crying for weeks. I think these people should be sensitized about HIV issues.” (*Spanish-speaking man*)

Given the serious impact of HIV diagnosis on individual’s mental health, this lack of proper counseling is concerning. That is, not only was support not provided to I/R/N-PHAs, but the practices of immigration doctors may even cause more harm to I/R/N-PHAs’ mental health.

In addition to coping with HIV diagnosis, having to be on antiretroviral treatment was another aspect of living with HIV that generated lots of stress for the participants. For those not currently taking HIV medications, the seemingly immanent prospect of having to be on treatment in the near future was a significant source of stress. On the other hand, participants who were already on HIV treatment described the regimens’ detrimental effects on their mental health because of its complexity and side-effects. One participant spoke of the demand of having to take medications on a daily basis and the impact this has on his mental wellbeing:

“Sometimes in the morning I have to come back home from work because I have forgotten my pills. Sometimes that stresses me. Sometimes this stress makes me lose the balance in life. Sometimes it feels bad to be taking medication all the time. Although I know I have to do it, there are mixed feelings about it.” (*Spanish-speaking man*)

Participants who were on HIV medications talked about a number of side-effects they were experiencing, such as forgetfulness, fatigue, and lipodystrophy. As mentioned in the previous section, some I/R/N-PHAs saw their ability to retain information and to concentrate an important skill for coping with day-to-day challenges, thus a significant indicator of their mental health state. When these participants began to experience forgetfulness or difficulty concentrating because of their HIV medications, their mental health – insofar as they were able to feel secure – would likely be affected. One participant described his struggle with medication side-effects in the following way:

“I feel like the medications were all concentrated in my brain and stopping me from thinking clearly. I felt very insecure, very nervous. My thoughts were blocked and I couldn’t express myself. It was a very weird feeling.” (*Spanish-speaking man*)

Similarly, side-effects like fatigue have implications on I/R/N-PHAs’ ability to establish security in life, such as holding a job. The mental health of these participants suffered as a consequence. In terms of lipodystrophy, although another worrying side-effect for a number of participants, it seemed to be of a greater concern for women in particular. These female participants spoke of the negative impact of lipodystrophy on their body image and how it acted as a barrier to finding suitable partners. For some of the women who had not yet disclosed their HIV status to their children, changes in their body shape sometimes triggered unwanted questions from their children which in turn added more stress to their lives.

Another reason why I/R/N-PHAs in our study found living with HIV/AIDS stressful was due to their constant struggle with disclosure. Many participants, although having been diagnosed for years still found it challenging to tell others, including close friends and relatives, about their HIV status. I/R/N-PHAs often expressed fear of others in their ethnoracial communities finding out about their serostatus. This fear of being judged and outcast often led to I/R/N-PHAs keeping things to themselves, thus furthering their social isolation. One participant described her conscious effort to isolate herself as follows:

“I very much worried and feared about revealing my HIV status to anyone, and I felt this was leading to my mental health being unstable. I feared revealing to people my HIV status, so I didn’t have many people that I associated with.” (*Caribbean woman*)

Many participants also spoke of disclosure in terms of barriers to establishing intimate relationships. They were often afraid that disclosure of HIV status would make them less desirable as a potential partner. A youth participant explained the inner workings between not having a significant other in a peer environment and its effect on mental health like this:

“When I saw my friends all got girlfriends, I was really low. I was really negative because I realized it’s not outside, like the looks, but it is because of what I have. If a girl finds out about my HIV status, it’s gonna become a big problem.” (*South Asian man*)

The recent trend to criminalize HIV transmissions added extra pressure on I/R/N-PHAs to disclose their serostatus to potential sexual partners. Many participants in the study therefore expressed feeling distressed as they were forced to either not disclose and risk breaking the law or disclose but risk losing potential mates. For example, a Spanish-speaking participant described himself as “full of fears, fears of disclosing and fears of legal obligation to disclose.” One interview participant, in fact, revealed that she was in the midst of a legal proceeding where her ex-husband had accused her of infecting him with HIV. At one point during this process, the participant had to spend four days in jail until her family scrambled to gather \$20,000 required for bail. She described her legal ordeal and the uncertainty around how it might affect her immigration status as “a major stressor” for the past two years.

Underlining I/R/N-PHAs’ dilemma around disclosure is the stigma related to HIV in society, which may be even more prominent within some ethnoracial communities. In this study, participants shared with us a number of incidents where they experienced stigma and discrimination based on their HIV status. When faced with such stigma, I/R/N-PHAs often described feeling angry and powerless at the same time, suggesting a negative impact on their mental health. One participant talked about his experience with HIV-related stigma at a bathhouse:

“I met a man and I asked him, ‘what do you think about people living with HIV/AIDS?’ He said, ‘well, I don’t think they should have sex; they should stay by themselves.’ I was so upset that I couldn’t continue the conversation. I was so mad.” (*Caribbean man*)

Frequently, I/R/N-PHAs attributed the causes of stigma to the lack of accurate information on HIV/AIDS. A participant described to us in detail how the society’s lack of information on HIV/AIDS had affected his outlook on life, prohibited him from disclosing his status, and troubled his mental wellbeing:

“In my community, there is a huge lack of knowledge on HIV. I was not well informed when I tested positive. I didn’t know what types of treatment existed. That’s why when I received my diagnosis, I thought I was going to die really soon. But even now, it is still affecting me because now I am not able to disclose to my family. That has affected me a lot, socially and emotionally.” (*Spanish-speaking man*)

The relationship between HIV and I/R/N-PHAs’ mental health is not unidirectional, however. That is, although much was discussed by participants about how living with HIV/AIDS affected their mental wellbeing, a number of people also described the effects of their mental health on their management of HIV, potentially depicting a self-perpetuating cycle. One I/R/N-PHA articulated the relationship between his mental health and his coping with HIV as follows:

“If my mental health is not good, I abandon myself completely. When I am depressed, I tell myself I am not taking the HIV medications anymore. It would be better to die.” (*Spanish-speaking man*)

Stigma and Discrimination

As already mentioned, HIV-related stigma pose a significant threat to I/R/N-PHAs’ mental health. However, I/R/N-PHAs constantly battle against an array of additional discriminations including racism, sexism, homophobia and transphobia. These social oppressions frequently intersect to affect I/R/N-PHAs’ self-image and mental wellbeing as explained here by a South Asian participant:

“In Canada, I always knew that I was linguistically different, racially different, ethnically different, religiously different, and sexually different. It is like you just got banged against the wall. So, I experienced discrimination from different levels, from all these different perspectives and it took me to a point where I lacked self-confidence. I developed low self-image and that contributed to me having mental problems.” (*South Asian man*)

There was one participant in our study self-identified as a transgendered woman. Her experience helped shed light onto the issue of transphobia faced by transgendered/transsexual I/R/N-PHAs:

“I experienced a lot of humiliation and rejections from my own family and also from many men when they realized I am a transgendered woman. There were rejections after rejections, everywhere, and from everybody. It’s an endless nightmare. I am tired of this way of living. What is the meaning of all this suffering?” (*Spanish-speaking transgendered woman*)

Participants also reported facing a unique form of discrimination based on both their HIV status and their immigration status. Underlining such discrimination is an assumption that I/R/N-PHAs are bringing HIV/AIDS to and spreading it in Canada. Discrimination against I/R/N-PHAs can be quite overt at times as one participant reported hearing derogatory comments like “those fucking infected immigrants.” I/R/N-PHAs also spoke of this discrimination frequently taking a more covert form as a stereotype to equate HIV/AIDS with people from Africa.

Many of these encounters with stigma and discrimination described by I/R/N-PHAs involved dealings with service providers. Incidents as such not only directly affected I/R/N-PHAs’ mental health but also acted as barriers when I/R/N-PHAs attempted to access some much needed support. More details around this issue will be discussed in a later section of this report titled *Barriers to Service Access for I/R/N-PHAs*.

Social Isolation

Many I/R/N-PHAs in our study expressed the feeling of loneliness. The processes discussed to this point – namely migration and settlement, negotiation of HIV disclosure, and stigma and discrimination – all contribute towards I/R/N-PHAs’ social isolation, which in turn affects their mental health. On one hand, many I/R/N-PHAs were separated from their family and friends as a result of migrating to Canada. On the other hand, I/R/N-PHAs faced many challenges in Canada trying to establish a social network and to form intimate relationships because of stigma surrounding their HIV status. One participant talked about how being apart from his family affected his mental health in the following way:

“I consider my mental health right now to be quite poor because I am always depending on someone else to be okay. It is very hard to be far away from my family. Back home, I would have family support. It has been very hard without that closeness, that warmth.” (*Spanish-speaking man*)

For I/R/N-PHAs who were separated from their children in the home country, their sense of loneliness might be exacerbated by a layer of worry. A participant described her concern for her children who were still living back home as follows:

“I think for some of us whose children are still out of the country this becomes another stressful issue. I have two sons who are at home, and when you wait a long time applying to get them here, sometimes you can’t help but think what if something happens like if maybe tomorrow I get sick and die and I’m not going to see them again.” (*African woman*)

Challenges with Service Utilization

For some I/R/N-PHAs, the quality of service they received actually bore a significant impact on their mental health. When asked to describe his understanding of good mental health, a participant answered in the following manner:

“When I talk about good mental health, I am looking at a person who can actually cope with the stresses of life, implying adequate, effective and efficient service provision and that services being provided are acceptable to service consumers.” (*African man*)

That is, for these participants, having good mental health not only meant people needing to react to the external environment and accomplish a state of security, but also required the external institutions such as service agencies to satisfy people’s needs. However, depending on their legal status in Canada, I/R/N-PHAs in our study faced different sets of challenges when seeking support from organizations. For non-status PHAs, their main barrier to accessing services was precisely their lack of legal status. Besides the financial burden of having to pay out-of-pocket for some services, one participant also mentioned his fear of being reported to the authorities, which led him to avoid accessing services all together:

“I don’t contact any health services. I figure even if I contact them, one way or another they will find out about me, and then the cops will find out I don’t have legal status.”
(*Southeast/East Asian man*)

As for immigrant and refugee PHAs, many described the process of accessing services a stressful experience in itself. Participants frequently complained about not having access to information on services available. They also spoke of difficulties around finding support that met their personal needs in terms of the types of services, hours of operation, location of services, and the languages in which these services are delivered. Incidents of ill treatment from service providers were also reported by the participants. The section of this report on *Barriers to Service Access for I/R/N-PHAs* will discuss these challenges in further details.

In summary, I/R/N-PHAs described five main stressors in life – namely, the migration and settlement process, being diagnosed and living with HIV/AIDS, stigma and discrimination, social isolation, and challenges with service utilization. These sources of strains often intersect with one another and amount to compounding effects on I/R/N-PHAs’ mental health. The tall demand on I/R/N-PHAs to juggle amongst these stressors simultaneously was best summarized in the following quote:

“What makes life stressful for me is the loneliness, the uncertainty about my immigration process, the stress of not having people to talk to, and not having a job. The only job that I am able to get is in a factory but this is not a stable job; I have to wait for a phone call. Then, I don’t have enough money and then I am very stressed out. I can’t find a boyfriend. I had a very active sexual life back home but here it is non-existent. And then there is HIV and the fear of starting medication, fear of rejection, fear of not knowing what is going to happen to

me, the lab tests, my CD4 counts, to see people very sick and to recognize that I am a sick person for the rest of my life, the disclosure to my family, to my friends, who to tell and when..." (*Spanish-speaking man*)

C. Coping Strategies of I/R/N-PHAs

When faced with these stressors, I/R/N-PHAs described an array of informal strategies and formal services that they had utilized to cope and to improve their mental health. Informal strategies in this context refer to personal tactics that I/R/N-PHAs are able to adopt without having to seek support from professionals or organizations. Formal services, on the other hand, refer to structured programs and services by organizations that often require I/R/N-PHAs to undergo some form of intake before being able to access support.

Informal Strategies

Participants talked about a wide range of personal strategies they had used to cope with their stress. In most cases these strategies represent positive efforts from I/R/N-PHAs to restore their mental balance, including listening to music, reading, exercising, meditating, and gardening. Many participants also spoke of actively seeking support from family and friends as a way to combat their feeling of loneliness. This might involve phoning family members abroad, spending time with peers, or socializing with friends. One participant described her personal coping strategies as follows, which were in fact quite typical of those used by most I/R/N-PHAs in our study:

"I enjoy going out and dancing with my partner, renting movies, listening to music, spending some time with my friends, reading books, reading the Bible and believing in something."
(*Spanish-speaking woman*)

Spirituality constituted an important part of the coping strategies for many I/R/N-PHAs. Regardless of their religious affiliation, a significant number of participants spoke of seeking solace in faith-related activities, ranging from reading religious books, prayer, meditation, to actively going to church and temples, and joining Bible study groups. Some of these activities, such as attending faith-based functions, provided I/R/N-PHAs another outlet to break away from social isolation. A participant talked about the benefits of going to church on his mental health as follows:

"My heart relaxes when I go to church. Some of the people there know that I am HIV positive and they are very supportive. That gives me good feeling to know that there are people that care about me." (*South Asian man*)

In some rare cases, I/R/N-PHAs also talked about engaging in self-advocacy as a coping strategy against stigma and discrimination. Most of these participants, however, had been in Canada for a relatively longer period of time and had since acquired citizenship status, which provided them a greater sense of security to speak up. One I/R/N-PHA, for example, described having grown "a thicker skin" in the face of stigma and discrimination:

"I grew a thicker skin, because we do need it in Canada. You have to learn how to deal with people who are not treating you right. You can pick up the phone and you call their boss or you call your MPs. That's how I deal with a lot of my stuff." (*Caribbean woman*)

For I/R/N-PHAs whose legal status in Canada was more precarious, a few of them described a different set of coping strategies. Several participants who were having difficulties with their refugee applications mentioned plans of moving to another country, such as the U.S. and Australia, if their case was to be denied. The transgendered participant was one of these individuals and she explained her plans as such: "Somebody mentioned that Australia is very advanced regarding trans people's rights. So, if I can't solve my immigration situation here I would move there." In other words, for these I/R/N-PHAs the migration and settlement process is not a linear journey but a circular one. They actively sought alternatives when a window of opportunity to a better life was denied. On one hand, this continuous migration process implies potential hardship on these participants' mental health as they live in a state of long-lasting uncertainty. On the other hand, it signifies the resiliency of these I/R/N-PHAs and their utter determination to build a better life for themselves.

At times, however, I/R/N-PHAs also reported relying on negative coping strategies to achieve temporary escape, at the expense of creating more harm to their mental wellbeing in the long run. For instance, in dealing with their HIV diagnosis and its impact on their mental health, a few participants talked about going into a state of denial. One of these participants described how his mental health was further affected as a result:

"I just try to ignore it. I try not to think about my HIV status, but at the same time it keeps coming back like the anxiety attacks in the middle of the night. And sometimes when I am working, people who I work with tell me that I get very moody." (*Southeast/East Asian man*)

Another participant spoke of seeking sexual outlets, such as frequenting bathhouses and public parks, as his way of coping with frustration. Sometimes, I/R/N-PHAs became engaged in drug and alcohol use in order to deal with their stress. One participant actually developed a sophisticated line of reasoning that linked up gender norms and their impact on his mental health with his subsequent drug use as a source of mental health outlet. He explained:

"I grew up with all this ideas about masculinity – men don't get depressed, men have to be aggressive, men don't have nervous breakdowns, men don't suffer from anxiety. To be a man is to be invincible. I started using drugs and alcohol, cocaine to be exact, when I don't want to talk to people, when I am isolated, when I feel afraid of expressing my fears. Having to keep my feelings inside myself leads me to this self-destruction." (*Spanish-speaking man*)

Formal Support

In addition to personal coping strategies, most I/R/N-PHAs mentioned having also accessed formal services in order to deal with their mental health issues. A significant number of participants had sought support from psychiatrists and had been managing their mental health with the help of antidepressants and antipsychotics. One participant described how psychiatrists and medications had helped improving his mental health as follows:

"Right now, I'm very much stabilized. I am on anti-depressants, and I am also on antipsychotic drugs. I am currently seeing a psychiatrist, too. As a result, I am handling my situation much more effectively now." (*South Asian man*)

Besides Western medicine, complementary and alternative therapies were frequently mentioned by I/R/N-PHAs as another type of formal services they used to improve their mental health. One

participant, like many others, detailed a coping plan that involved a mixture of informal strategies and formal services, including accessing complementary and alternative treatments:

"I decided Tuesdays are the days for taking care of myself. Tuesday mornings I go to the counsellor, then to the naturopathic clinic, and in the afternoon I go to the support group. And after that, I do something that I like, usually going to a film. I strongly recommend the naturopathic clinic. I have gotten a lot of benefits from taking vitamins and acupuncture."
(*Spanish-speaking man*)

Counsellors based in either hospitals or AIDS service organizations (ASOs) were often mentioned by other I/R/N-PHAs as well. Many participants spoke of their appreciation for having someone to talk to about their stress. One participant, for example, talked about having seen a counsellor for four years and the experience had helped him greatly in "balancing [his] mind and emotions". Similarly, I/R/N-PHAs frequently brought up the mental health benefits they received from attending support groups. For example, a participant said:

"When I was first diagnosed with HIV, it was a shock because I didn't have much information. Obviously my mood was affected. My friend told me about this support group so I attended. Hearing other people's stories made me feel that I was not alone, and if other people had won the battle I would do it as well." (*Spanish-speaking man*)

In other words, support groups often helps I/R/N-PHAs' mental health as they foster peer support and role modeling. Although most participants spoke of support groups offered by ASOs, several people also mentioned the benefits from groups outside of the HIV/AIDS field, such as Alcoholics Anonymous meetings.

It was evident from this study that both mainstream and ethno-specific ASOs represented an important setting of formal support to I/R/N-PHAs. In fact, for participants who had difficulties communicating in English or French, ethno-specific ASOs and a growing number of language-specific programs at mainstream ASOs were often identified as the single most essential sources of support. Besides counsellors and support groups, many I/R/N-PHAs described receiving mental health benefits from other services at ASOs as well. PHA support workers, for example, played an integral role in many I/R/N-PHAs' service access experience. On one hand, they helped to facilitate a smoother referral process for their clients and consequently reduce I/R/N-PHAs' stress and anxiety around service utilization. On the other hand, they often acted as motivators for I/R/N-PHAs by providing encouragement and emotional support. A participant spoke of his experience with a support worker as follows:

"Having my PHA support worker, who has compassion, who can walk me out of the HIV closet and give me that little extra push, really helps. It really uplifts you. It gives you a feeling that there are people who care." (*South Asian man*)

Attending social events, particularly retreats, organized by ASOs was another frequently mentioned coping strategy. Many participants saw the retreats as an opportunity to socialize with their peers, experience a change in scenery, and devote a significant amount of time towards self-reflection and self-care – or, "regenerate and refresh" as one participant described.

Interestingly, I/R/N-PHAs in our study also listed a number of organizations that do not have clear mandates in providing mental health support as formal services that they would access to cope with their stress. For instance, participants talked about accessing practical supports such as food banks, clothes banks, employment services, and training programs offered by ASOs. One participant mentioned calling her lawyer's office several times a day prior to her refugee hearing for reassurance and emotional support. Another participant spoke of the mental health benefits she received from attending an aquatic program at a local community centre which had helped her alleviate joint pains. The mentioning of these services and programs serves to reinforce how I/R/N-PHAs understood mental health. When I/R/N-PHAs placed their emphasis on obtaining security in basic necessities and having the ability to cope with challenges in life, it naturally follows that they would consider formal services beyond the conventional medical care and support to include other programs that may directly or indirectly resolve their basic needs and increase their capacity to deal with stressors.

In summary, I/R/N-PHAs in our study mentioned a mixture of informal and formal strategies that they had adopted to cope with stressors. Participants relied on a host of personal strategies to deal with their mental health issues. The positive coping strategies used by I/R/N-PHAs signified participants' resiliency and determination to establish a better life for themselves. However, a few participants also described the use of negative coping strategies that might result in more harm to their mental wellbeing in the long run; this matter therefore calls for the immediate attention from service providers. In terms of formal services, participants described medical establishments – both Western medicine and complementary therapy – and AIDS service organizations as two main sources of support. However, I/R/N-PHAs also reported accessing services from organizations without a clear mental health mandate as a form of mental health support so long as these agencies helped to fulfill their basic necessities and enhance their ability to cope with stress. Therefore, service providers may be required to reorient their understanding of the roles they play in supporting I/R/N-PHAs' mental wellbeing.

D. Barriers to Service Access for I/R/N-PHAs

This section of the report discusses in detail access barriers to mental health service as identified by I/R/N-PHA participants. As explained in the previous section, I/R/N-PHAs interpreted mental health services to include an array of programs and supports that go beyond the conventional understanding of mental health care. The service utilization experiences described in this section will therefore reflect this broader understanding of mental health services.

I/R/N-PHAs in our study identified both access barriers attributed mainly to service providers' attitudes and behaviours as well as those related to systemic issues. Regardless of the sources, these barriers either acted as gatekeepers that prohibited I/R/N-PHAs' service access or emerged amidst I/R/N-PHAs' service utilization to exclude them from the highest quality of services possible.

Barriers Attributed to Service Providers

Participants describe a number of access barriers that were related to the attitudes and practices of service providers – namely, stigma and discrimination, providers' lack of sensitivity towards PHAs, and poor communications and follow-ups from service providers. Stigma and discrimination, as aforementioned, are common experiences of I/R/N-PHAs. When these acts of discrimination were perpetrated by service providers – either consciously or unintentionally, they not only added to I/R/N-PHAs' stress but also tainted their service utilization experiences, hence deterring them from service access in the future.

HIV-related stigma was often brought up by participants in their dealings with service providers, particularly those outside of the HIV/AIDS field. At times, such stigma manifested itself as AIDS-phobia on the part of service providers. A number of participants described occasions where they felt the attitudes of service providers changed immediately after they had revealed their HIV status; sometimes it was a nurse decided to put on an extra pair of gloves, and some other times it was a dentist suddenly became more cautious to a point where the participants perceived to be excessive. One participant talked about his unpleasant interactions with a psychiatrist as follows:

“There should be more psychiatrists or mental health workers that understand HIV. I had a problem you know I had to explain to the psychiatrists every time I saw them about how I got HIV. It was like there was something in my body that they were afraid of.” (*African man*)

Sometimes, HIV-related stigma could also take the form of stereotypes. The most common stereotype encountered by I/R/N-PHAs was service providers equating HIV/AIDS to a disease of Blacks and gay men. For instance, one male participant although self-identified as straight spoke of psychiatrists instinctively assuming that he was gay based solely on their knowledge of his HIV status.

At times, stigma around HIV perpetrated by service providers went beyond creating an uncomfortable service utilization experience for I/R/N-PHAs. On occasions, participants reported being denied services because of their HIV status. In these instances, HIV-related stigma acted as a gate-keeping barrier that prohibited I/R/N-PHAs' access to services all together. For example, a participant detailed her failed attempt to access housing in the following quote:

“When I went to see this housing staff, she said to me, ‘No, I can’t give you a room here because it is shared accommodation and you are HIV positive. We don’t want people run out of this building because of you.’” (*African woman*)

Besides HIV-related stigma, participants also mentioned having encountered other forms of discrimination from service providers, including racism, sexism, homophobia, and transphobia. Unlike stigma around HIV which could be quite blatant at times, these other types of discrimination often took on a more covert form, thus more difficult for the perpetrator to be challenged and leaving I/R/N-PHAs feeling powerless. An African participant, for example, talked about feeling discriminated against by service providers because of her race:

“I feel trapped in my social situation. I find that a lot of places where you go to apply for help you don’t have the rights. And at some of the places, the way they treat you, they don’t treat you very well. Like the social worker that I first had, for two months we never met and each time we would communicate through phone instead of face-to-face. I realized that was because of race; that was why we were treated like that. We later found out that other black people were treated like that, too.” (*African woman*)

Similarly, the transgendered participant in our study described having great difficulties with accessing legal and social services in Canada due to service providers' transphobia. She said:

“When I went to the legal aid office to change my lawyer, they told me that was not convenient. They were very rude. I think they had issues at that moment to identify me as a transgendered woman.” (*Spanish-speaking transgendered woman*)

As mentioned in the previous section, because of the combination of their immigration status and HIV status, I/R/N-PHAs face a unique form of discrimination. Participants described several incidents where their merit to be in Canada was called into question by service providers because they were living with HIV. Underlining such discrimination was a prevailing assumption that immigrants and refugees were actively importing HIV/AIDS to Canada. This presumption was clearly depicted in a participant's exchange with her nurse:

"Every time I deal with my nurse, she is always negative. The first time I went there, the question she asked me was, 'I hope you are not sleeping around here. I hope you are not giving Canadian citizens HIV.'" (*African woman*)

In addition, the notion that I/R/N-PHAs were burdens rather than contributors to the Canadian society served to further the discrimination against them. One participant, for example, was told by a police officer: "You shouldn't be here. You got AIDS. You should go back to your country."

I/R/N-PHAs not only face stigma and discrimination when accessing services but also a lack of sensitivity on the part of service providers around their HIV status. A case in point was how immigration doctors performed the HIV testing and worked with individuals who tested positive. As mentioned in the previous section, participants frequently revealed situations where neither pre- and post-test counselling nor proper referrals to support services once they tested HIV positive was received from the immigration doctors. When immigration doctors failed to ensure an adequate referral process, they in essence acted as gatekeepers to I/R/N-PHAs by withholding information on services available.

On one occasion, a participant talked about having found out his HIV status by reading the test results that were displayed openly at the immigration doctor's office. In fact, having their privacy and confidentiality breached by service providers was a common experience reported by I/R/N-PHAs. At times participants were pressured to conceal their HIV status to service providers because an environment for safe disclosure was not created. For example, one participant described an encounter she had with the paramedics as follows:

"I called the emergency. When the paramedics came, they asked me if I am HIV positive. Because my housemate was near me and she didn't know my HIV status, I said, 'no I am not.'" (*African woman*)

Another access barrier to inclusive mental health services identified by I/R/N-PHAs was a lack of clear and regular communications from service providers, particularly during participants' hospital stay. Several participants talked about having unpleasant experiences staying at hospitals where they were not properly informed of their health conditions. Such a lack of communication not only increased I/R/N-PHAs' level of stress but also served to damage I/R/N-PHAs' trust in health care practitioners in general. One participant detailed her experience at a hospital like this:

"For the first two weeks in the hospital, I didn't know anything about my symptoms. Many doctors came and went but no one told me anything. I just prayed and prayed in order to survive." (*Southeast/East Asian woman*)

Sometimes the lack of communication between service providers and I/R/N-PHAs took the form of poor follow-ups. That is, on occasion service providers did not follow up on their clients despite

having promised to do so. In situations like this, participants often described feeling neglected by their service providers and as a result they decided not to return for support in the future. A participant described his reason for not accessing services as follows:

“When I went to the agency, the worker was not there. I left my contact information. They said they’d call me back but they never did. So, I didn’t insist.” (*Spanish-speaking man*)

Systemic Barriers

In addition, I/R/N-PHAs mentioned a host of barriers related to gaps in the existing services and misalignments between their needs and how services are currently structured. The service gap most frequently identified by participants centred on the issue of language. Not unlike many newcomers to Canada, participants who had difficulties with either English or French often found it challenging to locate services in their language. However, the inner workings of how language ability contributed to service access barriers were indeed far more complex as demonstrated here in a participant’s circumstance:

“I haven’t accessed many services. Most of the services are in English. I do speak English but not my partner, and he feels very isolated. So, I feel bad accessing help and leaving him behind, very depressed and lonely.” (*Spanish-speaking woman*)

In other words, sometimes it was not only I/R/N-PHAs’ lack of English or French skills but also that of their partners that prohibited I/R/N-PHAs from seeking formal support. What likely gave rise to such circumstances was the norm commonly observed in non-Western cultures to consider families rather than individuals as the unit of society. Therefore, in order to best meet the service needs of I/R/N-PHAs, service providers may be required to re-examine their structure of service delivery to consider occasionally conducting assessment and providing supports that centred on clients’ family as a whole.

Most often, in order to overcome the language barrier, I/R/N-PHAs had to rely on interpreters to communicate with their service providers. While participants were mostly very appreciative of the assistance they received, they also reported some challenges they had run into when working with interpreters. For example, when it came to translating medical terminologies, some participants talked about even having trouble understanding what the interpreters had translated. Furthermore, participants sometimes complained that interpreters lacked the basic understanding of HIV/AIDS and the cultural competency required to address the social aspect of the illness. For example, a male participant who self-identified as gay described the following interactions with the interpreters:

“Three times I heard the interpreters translating AIDS instead of HIV positive. I always had to clarify that I am HIV positive, not with AIDS. I think they are not doing their work properly just because of lack of education. Or, when I said ‘my boyfriend’ they translated by default to ‘girlfriend’. So, I had to clarify, ‘Yes, I said boyfriend.’ This kind of things could be very embarrassing.” (*Spanish-speaking man*)

Encounters like this revealed some important shortfalls in the current interpretation services and suggested that specific training might be required for interpreters who work with I/R/N-PHAs.

Besides the issue of language, participants identified another set of systemic barriers related to how mental health services are currently oriented in Canada. The differences between how mental health

is conceptualized traditionally in the Canadian society – which is to emphasize medical care – and how it is understood by I/R/N-PHAs – which focuses on concrete contributions to basic needs in life – posed a significant challenge for our participants when they sought to access mental health support. When they first encountered the Canadian mental health system, many participants spoke of their unfamiliarity with the types of services available or how to distinguish among different types of support, such as choosing a psychiatrist versus a psychologist or a counsellor. Subsequently, when participants attempted to learn more about mental health services, they often described feeling overwhelmed as they sifted through an array of scattered information:

“Initially it was like there was this mass of information and I didn’t even know where to start. The information doesn’t come in a package. It is all like here and there, like the internet. So it was difficult navigating through all that.” (*South Asian man*)

Even after I/R/N-PHAs managed to access mental health supports, the differences between service providers and I/R/N-PHAs around their conceptualization of mental health continued to be a potential service barrier. A significant number of participants reported feeling let-down because the mental health services they received did not match what they needed. For example, in several instances I/R/N-PHAs complained about their counsellors, contrary to their expectations, not offering them with concrete solutions to their problems. For some participants, such disconnection eventually led to them deciding not to return for further services as described here:

“I didn’t find psychiatrists helpful. I find it a waste of my time actually. I mean those couple hours in the session just brought back all the bad memories. It made me miserable and I had to cry. It was like they digging up dirt but offered no solutions. So, I just stopped going back.” (*Southeast/East Asian man*)

Similarly, many participants spoke of medications such as antidepressants not meeting their mental health needs:

“I tried antidepressants, but I was depressed on the pills! I was fine before I started the pills, but since I started taking them, I didn’t want to do anything and didn’t feel like coming out of the house. So, I said this is just ridiculous, and I stopped taking the pills myself. I didn’t speak to my doctor. I just stopped taking them.” (*Caribbean woman*)

I/R/N-PHAs who were already on HIV medications often speak of having to take antidepressants and antipsychotics in addition as a burden. One participant described feeling “overdrugged” as a result. In fact, a few participants mentioned that they would not seek help from psychiatrists at the first place because of their hesitation to take more medications.

Additional systemic barriers identified by I/R/N-PHAs in our study included long wait time and limited service availability, both are issue that have affected the health care system and the social service sector on the whole. One participant talked about his experience with long wait time in such a manner:

“Once you finally get the health services it is good, but it is the long wait, the long process of getting there that is tiring. That process can sometimes kill people in my opinion. I had to wait for two months before I finally got to see my counsellor.” (*South Asian man*)

Another participant described having difficulties accessing services due to limited availability:

“I did find some difficulties accessing mental health services especially when I had a problem on weekends; nobody was available. At the time a service agency referred me to a hospital because they thought there’s probably some emergency mental health specialist there. I did go but they didn’t have anyone to help me actually.” (*Southeast/East Asian*)

Like this participant, a number of I/R/N-PHAs talked about some services having limited hours of operation that were inconvenient for their schedules and unable to meet their needs in situations of crisis. The physical location of services posed another challenge for I/R/N-PHAs when accessing supports. Many participants talked about having to travel to the downtown core, despite living in the outskirts of the Greater Toronto Area often populated by newcomers, in order to access services that were perceived as more HIV-friendly. The amount of time and costs associated with traveling often hindered I/R/N-PHAs from accessing necessary services.

In summary, I/R/N-PHAs revealed having encountered multiple barriers when seeking formal mental health support. At times, these barriers were associated with negative attitudes and behaviours from service providers. At other times, our participants encountered barriers that were embedded in the overall healthcare and social service structure. These service barriers operated either as gatekeepers that hindered I/R/N-PHAs’ service access or as a deterrence that discouraged I/R/N-PHAs from returning for future services. Although some of these obstacles – such as the language barrier, long wait time and limited service availability – may be overcome by general, non-I/R/N-PHA-specific initiatives, others – such as stigma and discrimination as well as the disconnection between the dominant mental health framework in Canada and the concept of mental health understood by I/R/N-PHAs – call for service providers to re-examine their current service provision and develop a set of specific protocols for working with I/R/N-PHAs.

E. Recommendations from I/R/N-PHAs to Improve Mental Health Services

Upon their identification of service access barriers, I/R/N-PHAs were given an opportunity to put forward suggestions for improving mental health services. Four main recommendations were proposed:

- 1. *Creating more opportunities for I/R/N-PHAs to enhance their capacity in dealing with challenges in life:*** Participants identified a number of training programs through which they had acquired valuable skills around leadership, peer support, problem-solving, and employment-seeking. By building their capacity to address life challenges, these programs were considered by I/R/N-PHAs as very beneficial to their mental health. However, these training programs often run on limited resources and as a result are not always available to every I/R/N-PHAs who wish to participate. A recommendation was therefore put forward by our participants for service providers to devote more resources in these PHA capacity building programs.
- 2. *Developing more programs and services that reflect the diversity of I/R/N-PHAs:*** Some participants in our study felt outcast by existing services. For example, I/R/N-PHAs who had difficulty communicating in English or French described a host of challenges when accessing services not in their language. Male participants who self-identified as heterosexual sometimes described feeling unwelcome by AIDS service organizations that had traditionally

catered to gay and bisexual men. On occasion, I/R/N-PHAs also talked about not having enough services that worked with their family as a whole. Developing more programs and services that would meet the needs of these underserved populations was therefore suggested by participants as an area that required service providers' attention.

3. *Addressing issues of stigma and discrimination through education:* I/R/N-PHAs described stigma and discrimination as both a source of their stress as well as barriers to their service access. Participants in our study believed more education around HIV/AIDS would be necessary to combat ignorance and stigma. HIV training for service providers, including interpreters, was mentioned to be of particular importance.
4. *Enhancing I/R/N-PHAs' access to treatments and practices alternative to Western medicine:* Participants frequently described receiving direct and indirect mental health benefits from complementary and alternative therapies such as massage, yoga, meditation, tai-chi, and acupuncture. However, participants mentioned that some of these therapies required costs that were not always affordable to them. At times, some I/R/N-PHAs spoke of having interests in accessing these services but not knowing where to go. It was therefore recommended by I/R/N-PHAs that more complementary and alternative therapy programs should be offered free-of-charge by community-based agencies, such as ASOs where they had already been accessing services, in order to maximize the benefits they could attain from these therapies.

These proposals, although insightful, constituted only one of the sources of the final recommendations from this study. As per the research design, recommendations from Component 1 had subsequently been integrated with those from Component 2. In this second component, a total of 37 service providers – including both frontline practitioners and those in managerial positions – from HIV/AIDS, mental health, settlement, and other relevant fields participated in either focus groups or individual interviews and provided us insights into I/R/N-PHAs' mental health service access from their perspective. An online survey was also conducted with 66 service providers to collect quantitative information related to practitioners' attitudes, beliefs, and knowledge around issues of HIV/AIDS, mental health, and immigration. Triangulation of findings from both Components 1 and 2 allowed the investigating team to paint a holistic picture of the current mental health service landscape for I/R/N-PHAs.

Subsequently, in Component 3, a group of 22 I/R/N-PHAs worked in collaboration with the investigating team to analyze results from previous components. Through a concept mapping research process, they articulated a comprehensive best practice framework for improving I/R/N-PHAs' mental health which serves as the final recommendations from this study. Overall, seven program and policy directions have been identified under this framework:

- Intensifying social support and capacity building for I/R/N-PHAs;
- Promoting service providers' cultural competency;
- Enhancing service delivery and coordination;
- Reducing stigma and discrimination through public education;
- Addressing service inequities and improving accountabilities;
- Bridging gaps in healthcare coverage; and,
- Improving policies.

The Committee for Accessible AIDS Treatment has adopted these seven best practice domains as our strategic directions for the next several years, and we are committed to achieving the visions outlined within each of these focus areas in partnership with all relevant stakeholders. Towards this goal, in December 2006, the Committee underwent a strategic planning process to identify existing related services, pinpoint gaps, and strategize action steps. Committee members have identified and agreed upon the need to develop an Ontario-wide HIV/AIDS strategy for the immigrant, refugee and non-status population that will complement the efforts of existing provincial HIV/AIDS strategies for men who have sex with men, the African and Caribbean communities, and the Aboriginal people. We are currently seeking funding from various sources, including the AIDS Bureau at the Ontario Ministry of Health and Long-Term Care, to support the creation of this strategy. In addition, the Committee is channeling several recommendations from this research through existing intersectoral forums – such as the Toronto Community Planning Initiative and the Building Equitable Partnership Project spearheaded by the Centre for Addiction and Mental Health – to garner a broader-base support for systemic changes.

To date, the investigating team has presented findings and recommendations from this study in a number of academic and community forums. In the near future, we will continue to disseminate recommendations from this study to I/R/N-PHAs and other stakeholders through a holistic knowledge transfer and exchange strategy, including effective distributions of research reports, organization of community forums to facilitate intersectoral dialogue, and translation of research findings into culturally appropriate and user friendly tools such as fact sheets, PowerPoint slides and theatre skits.

IV. Discussion

A. Concluding Thoughts and Service Implications

I/R/N-PHAs in our study described their understanding of mental health as two-folds. Firstly, having good mental health was often associated with an external state where security in basic necessities was attained, including healthy diet, quality sleep, stable housing, gainful employment, and financial stability. Secondly, to maintain good mental health required I/R/N-PHAs to be capable of dealing with situations where their sense of security was threatened by stressors such as challenges related to the migration and settlement process, living with HIV, stigma and discrimination, social isolation, and service utilization. Such an understanding of mental health differs significantly from the dominant mental health discourse in Canada where emphasis is placed on medical-based assessment, diagnosis, and treatment of mental disorders (Health Canada, 2004).

When it comes to service utilization, this difference in understanding mental health has led to two challenges. First of all, when asked to identify formal services that they had accessed to improve their mental wellbeing, I/R/N-PHAs in our study listed both conventional mental health supports such as psychiatrists, counsellors, and support groups as well as a number of services that do not have clear mandates in providing mental health care, for example practical support programs within AIDS service organizations, legal services, community centres and religious venues. In order to adequately address I/R/N-PHAs' mental health needs, this latter group of service providers will be required to readjust their understanding of mental health and potentially become more proactive in defining their roles in I/R/N-PHAs' mental health care. Funders and policy makers will also need to re-examine their funding structures to ensure that resources are allocated to services that might traditionally be considered as outside of the mental health field but in reality providing essential mental health support to marginalized groups such as I/R/N-PHAs.

Secondly, the difference between how service providers and I/R/N-PHAs understand mental health was described by participants as a potential barrier to quality services. That is, I/R/N-PHAs did not always feel the assistance from psychiatrists or medications was effectively addressing their mental health concerns. Instead, I/R/N-PHAs described receiving mental health benefits from complementary and alternative therapies, spiritual practices, social gatherings, retreats, and capacity building opportunities. Mental health practitioners, therefore, might need to consider restructuring their care plans when working with I/R/N-PHAs by incorporating a mixture of therapies and practices that are more culturally appropriate in addition to providing Western medical support.

Additional mental health service barriers identified by I/R/N-PHAs included stigma and discrimination, poor communication and follow-ups from service providers, language barriers, long wait time, and limited service availability. Most of these barriers in fact are not exclusive to I/R/N-PHAs' service utilization experiences. Many marginalized groups in the Canadian society encounter similar issues when accessing healthcare and social services as well (Shahsiah and Yee, 2006; Access Alliance Multicultural Community Health Centre, 2005). Consequently, having these common experiences presents the I/R/N-PHAs and other marginalized populations an ideal opportunity to bridge their advocacy efforts and to develop a comprehensive mental health care strategy in collaboration.

B. Limitations, Challenges, and Lessons Learned

The investigating team faced several challenges during the research process. Firstly, we found that the existing research funding and ethics review processes were not always responsive to the needs of community-based initiatives like this study. Secondly, resources available for community-based research often were inadequate as they did not take into account the nuances associated with community-based work. Thirdly, it remained challenging for the investigating team to reach out to I/R/N-PHAs facing further marginalization despite our conscious efforts to do so.

Systemic Bias against Community-Based Researchers

When the investigating team first approached funders for support, we found ourselves disadvantaged during the funding selection process because of the fact that we consisted of and were led by mainly community-based researchers. The review panels, generally made up of academic researchers, called the team's research competency into question by highlighting our lack of credentials and publications in peer-reviewed journals. At the same time, the lived experiences and close connections to the affected communities possessed by the investigating team were largely ignored.

The community-based nature of our team faced another set of systemic challenges when undergoing the ethics review process. First of all, access to the ethics review boards required the principal investigator to be affiliated with either an academic institution or a hospital and was therefore a barrier for our investigating team. Secondly, as a partnership initiative, we were required to submit separate ethics review applications to all the institutions involved. The time and effort required in coordinating these applications proved to be a significant demand on projects like ours that had very limited amount of resources.

To address these systemic biases requires institutions such as funders and ethics review boards to review their policy and procedures so that they are more responsive to the needs of community-based initiatives. In terms of the funding process, a different set of selection criteria that emphasize community representation and participation should be adopted when reviewing community-based research proposals. As for the ethics review process, review boards need to work collaboratively to explore options that will facilitate smoother access for community-based researchers and to potentially streamline their application and review process.

Inadequate Resources for Community-Based Research

Despite the intention to enhance community capacity, existing funding for community-based research, in our opinion, often did not take into account the time and resources needed for community members on the research team to be adequately trained and continually supported. In this study, limited resources meant that we were only able to hire the peer research assistants on a very part-time basis. This presented a challenge for the research team to devote an adequate amount of time to provide the RAs with ongoing mentorship.

Furthermore, we found that the existing funding for community-based research was often not adequate to address the needs of participants from marginalized communities. For example, due to lack of resources, we were not able to hire professional interpreters and translators to address the language needs of participants who had difficulties with English. We often had to rely on the generosity of volunteers to perform interpretation and translation, which was not the most ideal. In addition, it turned out that a greater than expected number of I/R/N-PHAs opted to participate in one-on-one interviews rather than focus groups due to concerns around privacy and confidentiality. As a result, more resources needed to be allocated to cover for the interviewers as well as for

additional transcription. This meant that the investigating team was left with insufficient amount of resources to conduct knowledge transfer and exchange activities after the completion of the study.

We therefore urge funders to re-examine their funding structure to better reflect the reality and demands of the community. Adequate resources need to be devoted to community-based research so that it may achieve the intended objectives of partnership development and community capacity building.

Challenges with Recruiting Marginalized I/R/N-PHAs

Ideally, the investigating team would have like to speak with more non-status individuals as well as I/R/N-PHAs facing further marginalities such as women in some of the targeted ethnoracial communities, transgenders/transsexuals, sex workers, and injection drug users. Greater inclusion of these groups in the study might have generated further insights into how intersecting oppressions affect I/R/N-PHAs' coping strategies and service utilization experiences. Findings from this study therefore need to be reviewed with this limitation in mind. Nevertheless, the sheer difficulties encountered by our research team in recruiting these participants despite our conscious efforts spoke volumes about the access barriers faced by these individuals. It might be useful to researchers and service providers alike for future studies to explore more about effective methods in identifying and reaching out to these marginalized I/R/N-PHAs.

C. Future Research Directions

Component 1, as aforementioned, represents the first of many steps of the investigating team to identify and implement a comprehensive mental health framework for improving I/R/N-PHAs' mental wellbeing. Findings from this component will need to be juxtaposed to those representing service providers' prospective in order to create a holistic understanding of the current mental health service landscape for I/R/N-PHAs. Only then, a comprehensive best practice framework may be developed and its effectiveness pilot-tested.

The investigating team is currently seeking funding support to further develop the second phase of this study and to expand our existing research partnership. In Phase 2, we seek to build on Phase 1 findings to promote inclusive mental health services for I/R/N-PHAs by:

- Developing and evaluating a training program for service providers;
- Pilot-testing best practice models; and,
- Facilitating policy development and changes.

Additional follow-up research is also in discussion, including a study that aims to examine I/R/N-PHAs' resiliency in the face of stigma and discrimination.

It is the hope and commitment of the investigating team that this research study will mark a pivotal shift in the practices of service providers, funders, and policy makers when working with I/R/N-PHAs and eventually lead to an overall advancement of I/R/N-PHAs' quality of life.

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Appendix A: I/R/N-PHA Focus Group Facilitation Guide

Mental Health Issues

Q1. In this study, we are interested in hearing from immigrants, refugees and non-status people living with HIV/AIDS about their experiences with mental health. We know that “mental health” may have different meanings in different cultures. It may also include different things for different people. Can you tell us what it means to have good mental health for you or for people you know?

- Probes:
- To you or people you know, what does “mental health” include?
 - What other words or phrases would you use to describe “mental health”?
 - In your opinion, how is mental health related to a person’s overall health?

Q2. What kinds of things have an impact on your mental health?

- Probes:
- How has the experience of coming to Canada affected you?
 - How has living with HIV affected you?
 - How would you describe these effects? Are they positive or negative? Are they short term or long term?

Access to Mental Health Services

Q3. How do you deal with your mental health needs? How do people you know deal with their mental health needs? Where do you or people you know go for help? What kind of help do you or people you know seek?

- Probes:
- Do you go to family or friends for help? What kind of help do you get from them?
 - Do you go to organizations or professionals for help? What kind of help do you get from them?

Q4. When you or people you know try to get help, what kind of problems do you run into?

- Probes:
- Could you tell people your HIV status and/or immigration status? Did you run into any problems if you tell people your HIV status and/or immigration status?
 - Were you put on a waiting list? If yes, how long did you have to wait?
 - Did you have trouble explaining to people the kind of help you needed?
 - Did you get all the help you needed?

Q5. What kind of services or help would be most useful to address your mental health needs?

Closing

Q6. Is there anything else about your mental health or your experience with mental health services that you would like to tell us? Are there any questions?

Appendix B: I/R/N-PHA Individual Interview Guide

Experiences with Immigration and HIV

Q1. I am interested in hearing about your experience as someone who moved to Canada and is currently living with HIV/AIDS. To start, could you tell me a little bit about your experience of coming to Canada? How has this experience affected you?

- Probes:
- How long ago did you leave your home country?
 - What were your reasons for leaving?
 - Did you experience any challenges while moving to Canada?
 - Did you experience any challenges after arriving in Canada?
 - Do you still have families that live there? If so, what is it like to live in a different country from the rest of your family?
 - How would you describe the effects of moving to Canada on your life? Are they positive or negative? Are they short term or long term?

Q2. What was the experience like when you first learned that you have HIV? How has living with HIV affected you?

- Probes:
- How long ago did you first learn that you have HIV?
 - How did you react to this news?
 - Did you tell anyone that you have HIV? If yes, to whom did you tell and how did they react to the news? If no, why not?
 - Did you know anyone else in your family or community that also have HIV?
 - How would you describe the effects of living with HIV on your life? Are they positive or negative? Are they short term or long term?

Mental Health Issues

Q3. In this study, we also want to learn about your experiences with mental health. We know that “mental health” may have different meanings in different cultures. It may also include different things for different people. Can you tell us what it means to you to have good mental health?

- Probes:
- To you, what does “mental health” include?
 - What other words or phrases would you use to describe “mental health”?
 - In your opinion, how is mental health related to a person’s overall health?

Q4. In general, how would you describe your mental health right now?

- Probes:
- Has a doctor ever diagnosed you with a mental illness? If so, what is your diagnosis? Was the diagnosis made in Canada or in your home country?
 - Are you taking any medications for mental illness now? Have you taken any medications for mental illness in the past?
 - Have you ever been hospitalized because of a mental illness?

Q5. What kinds of things have an impact on your mental health?

- Probes:
- How would you describe these impacts? Are they positive or negative? Are they short term or long term?

Access to Mental Health Services

Q6. How do you deal with your mental health needs? Where do you go for help? What kind of help do you seek?

- Probes:
- Do you go to family or friends for help? What kind of help do you get from them?
 - Do you go to organizations or professionals for help? Which organizations or services in Canada have you tried to get help from?
 - Do you do anything differently to deal with your mental health needs before and after coming to Canada? If so, what are the things you do differently, and why?

[Scenario A: If the participant has tried to access formal services...]

Q7A. What was your experience of using these services like?

- Probes:
- How did you first hear about these organizations / services?
 - What made you decide to get help from these organizations / services?
 - What kind of support did you receive? How often do you receive this support?
 - Do you think the services that you received were helpful? Why or why not?
 - Did you experience any challenges when using or trying to use these services?

[Scenario B: If the participant has not tried to access formal services...]

Q7B. Why have you not tried to get help from organizations or services to deal with your mental health needs?

Closing

Q8. Is there anything else about your immigration experience, HIV, or your mental health that you would like to add? Are there any questions that you would like to ask before we end our interview?

Appendix C: I/R/N-PHA Demographics Form

You are asked to fill out this form because the researchers would like to get an idea of who has participated in the study and how diverse they are. None of this information will be shared with any government officials or anyone outside of the research team. You will not be asked to give us your name. This way, your identity will be protected. In addition, any identifying information about you will not be used in any of the research reports. If you do not wish to answer certain questions, it is okay for you to leave them blank.

1. How old are you?

_____ years old

2. What is your gender?

- ☐ Female
- ☐ Male
- ☐ Transsexual / Transgendered
- ☐ Intersexed
- ☐ Other (specify: _____)

3. Which of the following best describe your ethnoracial identity? (Please check all that apply.)

- ☐ Black / African
- ☐ Black / Caribbean
- ☐ East and Southeast Asian (e.g., Korean, Chinese, Japanese, Filipino, Thai, Vietnamese, Indonesian, etc.)
- ☐ South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)
- ☐ West Asian (e.g., Afghan, Iranian, Arab, etc.)
- ☐ Latin American / Hispanic
- ☐ White / Caucasian
- ☐ Multiracial (specify: _____)
- ☐ Other (specify: _____)

4. Which country were you originally from?

5. How many years have you lived in Canada?

_____ years

6. What is your immigrant/refugee status in Canada now?

- ☐ Canadian citizen
- ☐ Landed immigrant/Permanent resident
- ☐ Refugee applicant
- ☐ Holder of Temporary Resident Permit
- ☐ No official status
- ☐ Other (specify: _____)

7. Which of the following best describe your religion / faith / spirituality? (Please check all that apply.)

- ☐ Buddhist
- ☐ Christian
- ☐ Hindu
- ☐ Jewish
- ☐ Muslim
- ☐ Sikh
- ☐ No religious affiliation
- ☐ Other (specify: _____)

8. What is your first language?

9. The next few questions will ask you about your language skills. (Please answer the questions by circling a number between 1-4.)

	Not at all	A little	Good	Well
a. How well can you speak English?	1	2	3	4
b. How well can you read English?	1	2	3	4
c. How well can you write English?	1	2	3	4
d. How well can you speak French?	1	2	3	4
e. How well can you read French?	1	2	3	4
f. How well can you write French?	1	2	3	4
<i>If your first language is NOT English or French, please answer g – i.</i>				
g. How well can you speak your first language?	1	2	3	4
h. How well can you read your first language?	1	2	3	4
i. How well can you write your first language?	1	2	3	4

10. How would you describe your sexual orientation?

- ☐ Heterosexual / Straight
- ☐ Gay / Lesbian
- ☐ Bisexual
- ☐ Questioning / Unsure
- ☐ Other (specify: _____)

11. What is your marital status right now?

- ☐ Single
- ☐ Married
- ☐ Separated
- ☐ Divorced
- ☐ Widowed
- ☐ In common-law relationship

12. Do you have any children?

- ☐ Yes (if yes, how many? _____)
- ☐ No

13. Who are you currently living with in Canada? (Please list all persons by their relationship with you. For example, aunts, brothers, roommates, etc.)

- ☐ I live alone
- ☐ I live with: _____
- _____
- _____
- _____
- _____
- _____

14. Where have you been living in the past 6 months?

- ☐ A home that I own
- ☐ A home that I rent
- ☐ Staying with family or friends
- ☐ No stable housing / homeless / living on the street
- ☐ Other (specify: _____)

15. What is the highest level of education you have completed? (You may refer to education that you have received anywhere in the world. For example, grade 6, high school, university, Doctoral degree, etc.)

- ☐ I did not receive any formal schooling
- ☐ Highest level of education that I have completed is:

16. For the past 6 months, are you: (Please check all that apply.)

- ☐ Employed full time
- ☐ Employed part time
- ☐ Unemployed but actively looking for work
- ☐ Unemployed and not looking for work
- ☐ A student
- ☐ A volunteer
- ☐ Other (specify: _____)

17. What was your job before coming to Canada, if any?

18. What is/was your job after arriving in Canada, if any?

19. What was your main source of income for the past 6 months?

- ☐ Wages or salaries
- ☐ Self-employment
- ☐ Investments
- ☐ Old Age Securities / Canadian Pension Plan
- ☐ Social assistance (e.g., Employment Insurance, Ontario Works, ODSP, etc.)
- ☐ Other (specify: _____)

20. How many years has it been since you first learned you have HIV?

_____ years

21. Have you been diagnosed with AIDS?

- ☐ Yes
- ☐ No
- ☐ I do not know

22. Have you ever been hospitalized because of HIV/AIDS-related conditions?

- ☐ Yes
- ☐ No
- ☐ I do not remember

23. What was your last CD4 count?

- ☐ I do not know
- ☐ Less than 200
- ☐ 200 to 349
- ☐ 350 to 500
- ☐ over 500

24. Are you taking any HIV medications now?

- ☐ Yes
- ☐ No.....have you ever taken HIV medications in the past?
 - ☐ Yes
 - ☐ No
 - ☐ I am not sure

25. In general, how would you rate your overall health right now?

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

26. In general, how would you rate your mental health right now?

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor