CHIWOS

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

CHIWOS Peer Research Associate Training Manual

English
Quebec Version
March & July 2013

CHIWOS
Peer Research Associate (PRA) Training Manual

ACKNOWLEDGEMENT
CHIWOS would like to thank the CHIWOS PRA Training Working Group members for their invaluable role in conceiving, creating, translating, and facilitating the PRA training sessions.

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Une version française de ce document est aussi disponible en ligne à www.chiwos.ca.

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CHIWOS

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Canadian HIV Women's Sexual and Reproductive Health Cohort Study

Quebec

PRA Training Manual

SESSION ONE
Montreal, Quebec
March 26 & 27, 2013

SECTION ONE:
Training Objectives and Icebreaker Activities

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Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

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Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada
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AGENDA – CHIWOS- PRA Training session

Day 1- March 26, 2013

Time	Subject	Facilitator
9 :00 9 :15	**Welcome** • Coffee and Danish • Words of Welcome • Introduce the trainers	All
9:15 10:00	**Agenda & Training objectives** • Expectations and training objectives • Present the training agenda • Training functioning (bilingual) • Ice breaker activity- Treasure hunt	Mélina and Nadia
15min	**PAUSE**	
10 :15 11 :15	**What is CHIWOS & Epi of WLWHIV QC** • Overview of the CHIWOS project • Epidemiology of WLWHIV QC • Sum up key points retained	Nadia
11 :15 12 :00	**PRA Logistics for CHIWOS** • Expectations and support • Timelines • Payment procedures • Next Steps	Nadia
12 :00 13 :00	**Lunch**	
13 :00 15 :30	**Building Bridges Activity** • Poem : Turning to one another • Storytelling : Roadmaps activity • Pause 15min	Mélina and Nadia
15 :30 16 :30	**Closing** • Questions for clarification • Closing round : One idea I am leaving with • Introduce tomorrow's session	Nadia and Mélina

Day 2- March 27, 2013

Heure	Sujet	Facilitatrice
9 :00 9 :15	**Welcome** • Coffee and Danish	All
9 :15 9 :30	**Agenda & Objectives** • Objectives • Questions and Answer period	Nadia and Mélina
9 :30 10 :30	**Ethics and Community Based Research** • Ethics in research, institutions (MUHC) • Ethics of collaboration	Nadia Mélina
15min	**Pause**	
10 :45 11 :15	**Introduction to the Questionnaire** • Rational and reasoning of the questionnaire • Electronic format-coming soon	Dr. Alexandra de Pokomandy
11 :15 12 :00	**Basic principles of a good interview (part I)** • Example from a peer research associate	Mélina et a PRA
12 :00 13 :00	**Lunch**	
13 :00 13 :30	**Basic principles of a good interview (part II)** • Key aspect of a successful interview	Mélina
13 :30 15 :00	**Role Play Interviewing** • PRA *Checklist* • Practice interview and feedback • Introductions to closure	Nadia
15 :00 16 :00	**Closure** • Next Training • Key lessons learned • Questions for next training	Mélina and Nadia

CHIWOS
Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada
Canadian HIV Women's Sexual and Reproductive Health Cohort Study

STRENGTHS AND PASSIONS SCAVENGER HUNT

Instructions:

- Introduce yourself to someone in the group.
- Find out two things that they love to do on the list below.
- Write their name next to the things they love to do.
- Share two things with them that you love to do on this list.
- Go to another person and repeat until your worksheet is full.

I LOVE TO:

1) J'aime lire/ to read_____

2) J'aime faire du sport/ play sports_____

3) J'aime partager des idées/share idesa_____

4) J'aime contempler le soleil couchant/setting sun_____

5) J'aime vivre des aventures/have adventures_____

6) J'aime courir sous la pluie/run under the rain_____

7) J'aime me déguiser à l'Halloween/ dress up for Halloween_____

8) J'aime faire de la musique/ play music_____

9) J'aime aller à la cueillette des pommes/ pick apples_____

10) J'aime les animaux/ animals_____

11) J'aime passer du temps avec mes enfants / neveux / nièces/ play with kids_____

12) J'aime jouer dans les feuilles mortes à l'automne/play in leaves_____

13) J'aime cuisiner/ to cool_____

14) J'aime apprendre de nouvelles choses/ new things_____

SECTION TWO:
What is CHIWOS ?
Epidemiology of WLHIV in Quebec

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Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

Orientation for Peer Research Associates

CHIWOS

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

The Feminization of HIV

- Women now make up more than half of the world's HIV-positive population
  - In Canada, 23.3% of the PLWHIV are women (2011)
- Women are a group whose risk of HIV infection is rapidly increasing
  - 23.8% of new infections in Canada in 2011 were women
- Marginalized women are even more vulnerable to infection and less able to access care

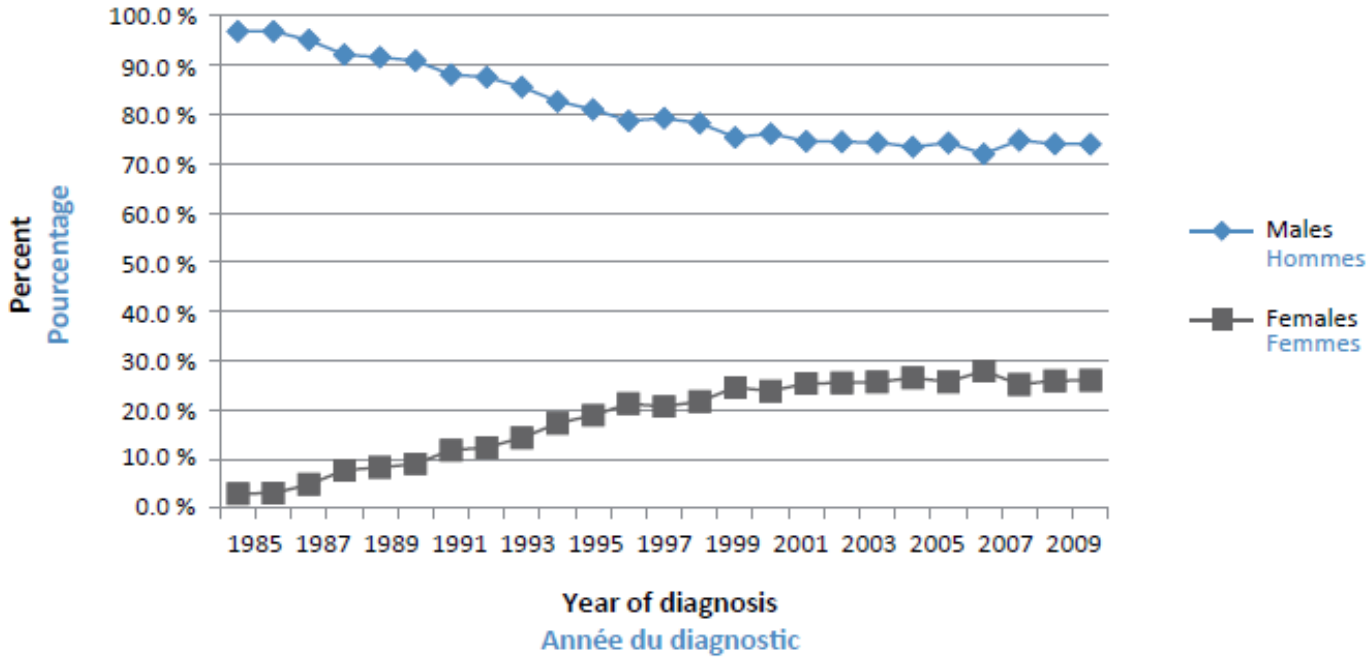
CHIWOS

Féminisation of HIV in Canada

FIGURE 3

Proportion of positive HIV test reports by sex, 1985-2009

Proportion de rapports de tests positifs pour le VIH, selon le sexe, 1985-2009



Diversity of WLWHIV in Québec (2002 - juin 2011)

Approx. 20-25% (~4500) of PLWHIV are women

Routes of transmissions

- Heterosexual endemic countries 46%
- Heterosexual non endemic countries 28%
- IDU 21%

Geography

- Montreal 61%, Quebec 9%, other areas 30%

Population

- Canadian 43%, African 29%, Caribbean 21%, Aboriginal 2%

Age

- ≤19= 4%, 20-29= 18%, 30-39= 33%, 40-49= 29%, ≥50= 16%

Comparison to Canada:

- In QC more women from African and Caribbean origins
- In QC less Aboriginal cases (could be under estimated, or under reported)

Programme de surveillance de l'infection par le virus de l'immunodéficience humaine au Québec: (2002-2011)

Féminisation of HIV

WHY are MORE WOMEN living with HIV now?

Women from these groups are at higher risk for HIV. Why do you think this is?

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Women have

unique

medical

needs

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Health and medical questions facing women living with HIV

- Does HIV disease progress the same as in men?
- Do antiretrovirals work as well?
- What is the best contraception?
- What are the issues related to planning pregnancies?
- What about menopause and aging?
- Are HIV-positive women at higher risk for cancers and other comorbidities?
- HPV & cervical disease; HPV vaccine?
- Mental health

Social Issues facing Women Living with HIV

- Sexual health – healthy sexuality
- Stigma and discrimination
- Issues related to HIV disclosure; criminalization
- Women more adversely affected by the social determinants of health

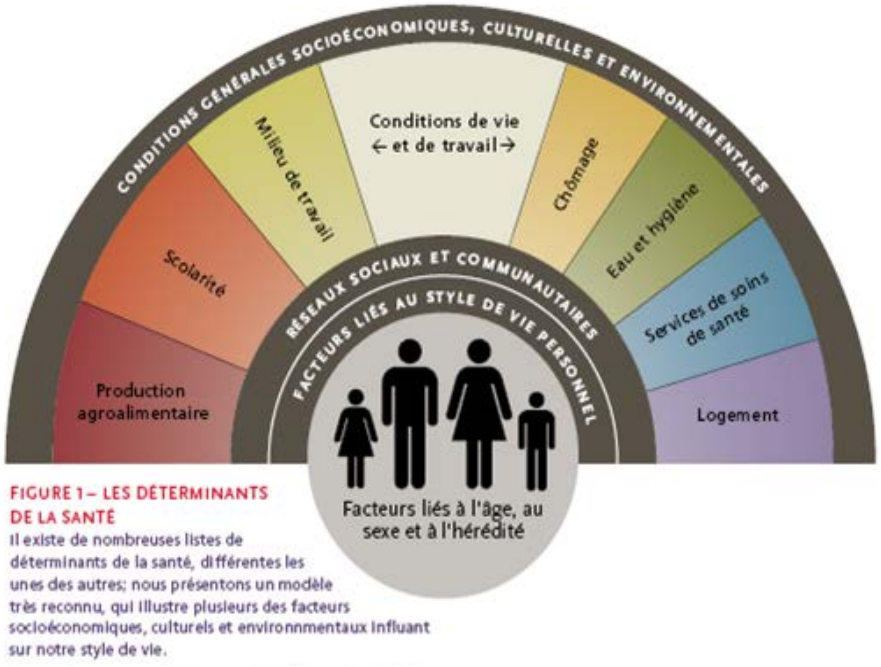
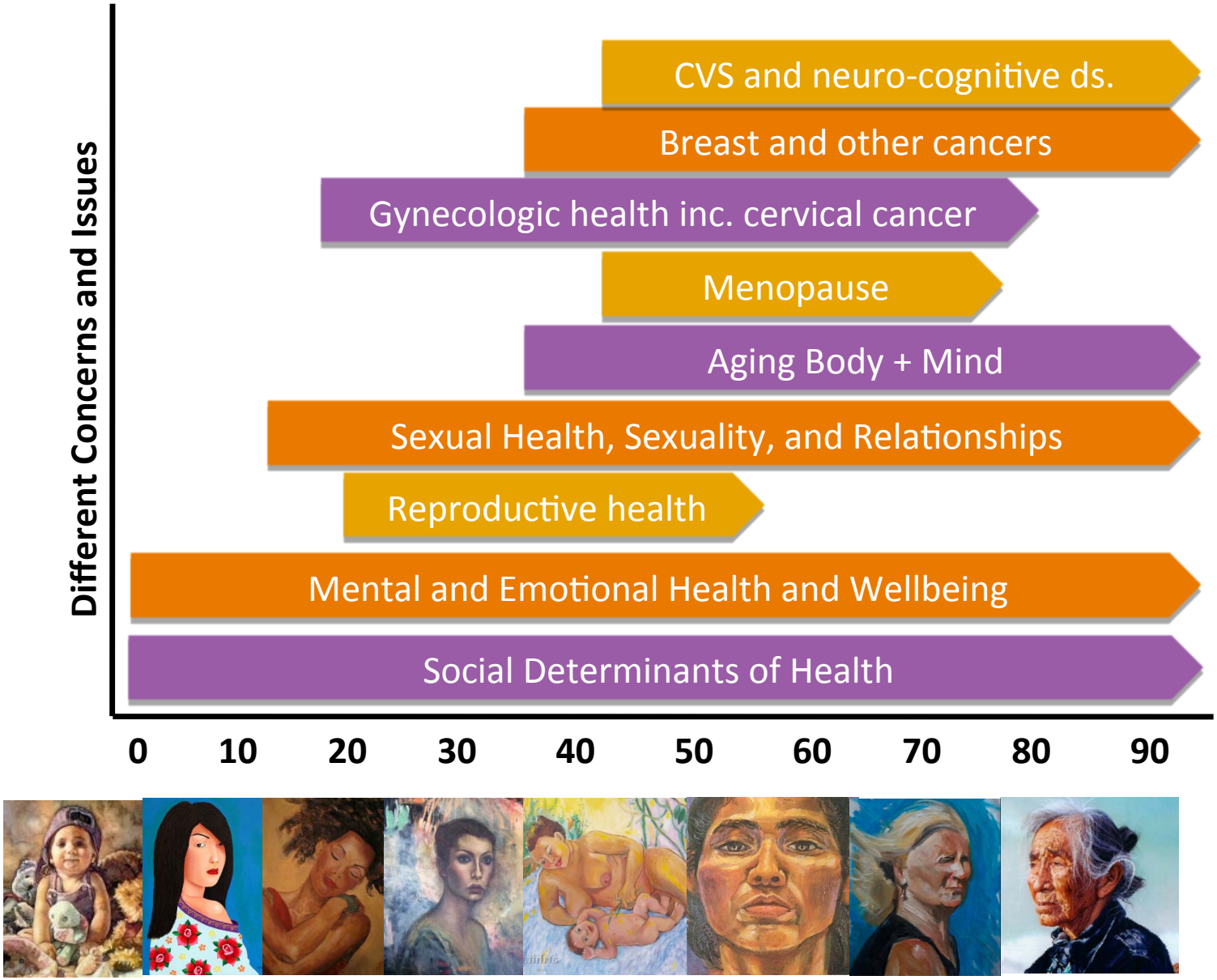


FIGURE 1 – LES DÉTERMINANTS DE LA SANTÉ
Il existe de nombreuses listes de déterminants de la santé, différentes les unes des autres; nous présentons un modèle très reconnu, qui illustre plusieurs des facteurs socioéconomiques, culturels et environnmentaux influant sur notre style de vie.

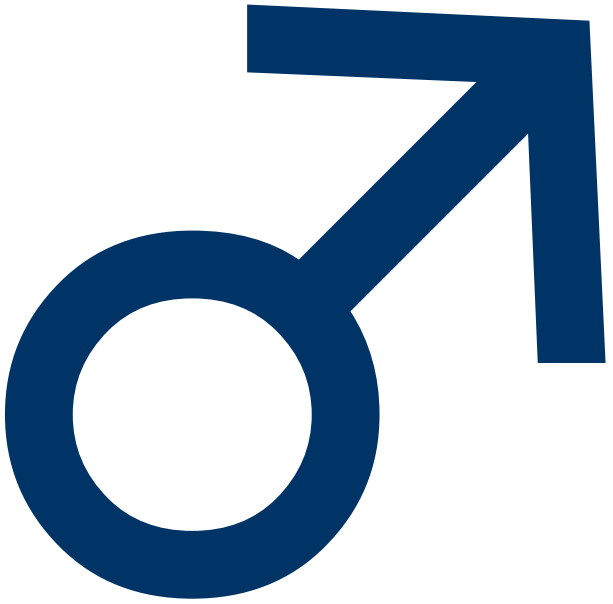
Main Social Determinants of Health

CHIWOS


Different Concerns and Issues
CVS and neuro-cognitive ds.
Breast and other cancers
Gynecologic health inc. cervical cancer
Menopause
Aging Body + Mind
Sexual Health, Sexuality, and Relationships
Reproductive health
Mental and Emotional Health and Wellbeing
Social Determinants of Health
0
10
20
30
40
50
60
70
80
90
Life span of a woman

Most HIV research studies have

focused on **men**



CHIWOS

CHIWOS

Canadian HIV WOmen's Sexual and reproductive health study

(pronounced "chee - wose")

CHIWOS

FUNDING AND SUPPORT

Funders

CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

the CTN
CIHR Canadian HIV Trials Network

le Réseau
Réseau canadien pour les essais VIH des IRSC

Ontario HIV Treatment Network

Affiliated studies

CANOC
CIHR TEAM IN HIV TREATMENT OUTCOMES: THE CANADIAN OBSERVATIONAL COHORT (CANOC) COLLABORATION
ÉQUIPE IRSC DE RECHERCHE SUR LES EFFETS DES TRAITEMENTS CONTRE LE VIH: COLLABORATION PANCANADIENNE DES COHORTES OBSERVATIONNELLES (CANOC)

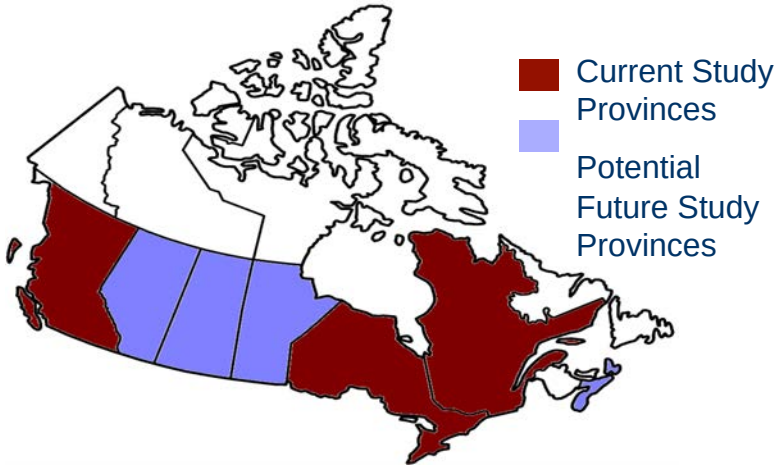
Research Evidence into Action for Community Health
REACH

OCS
OHTN Cohort Study

CHIWOS

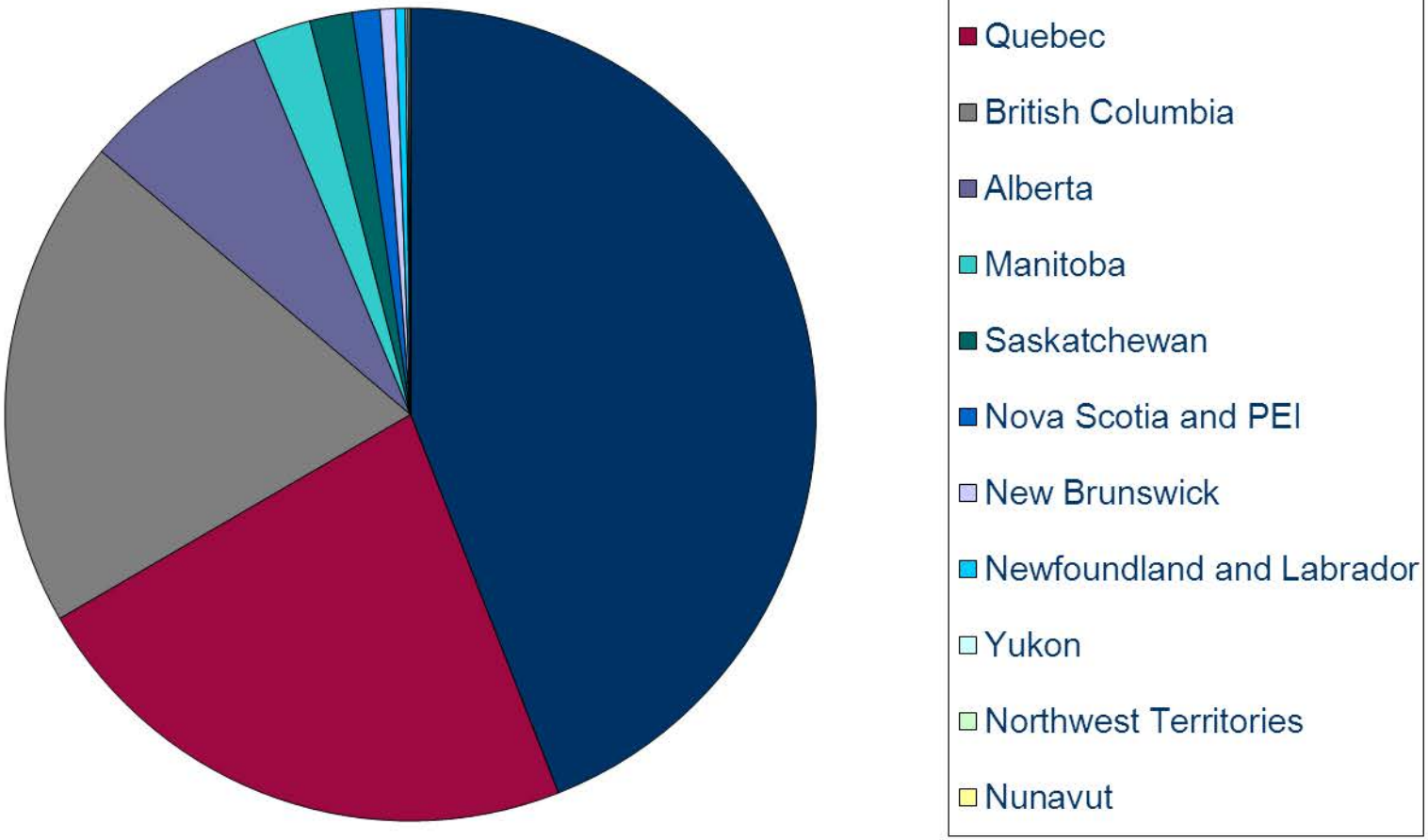
CHIWOS- Study Overview

- HIV-positive women's cohort ~1250n
- Study taking place in BC, Ontario and Quebec
- 5 year study- 2011-2016
- Anchored in community based research principles
- Formative phase - Focus Groups
- National Survey Phase - Quantitative Interviews



CHIWOS

HIV Prevalence by Province (2009)



CHIWOS

CHIWOS: Study Goals

Among HIV-positive women:

- To assess barriers to and facilitators of women-centered HIV care use
- To assess the impact of such patterns of use on sexual, reproductive, mental and women's health outcomes

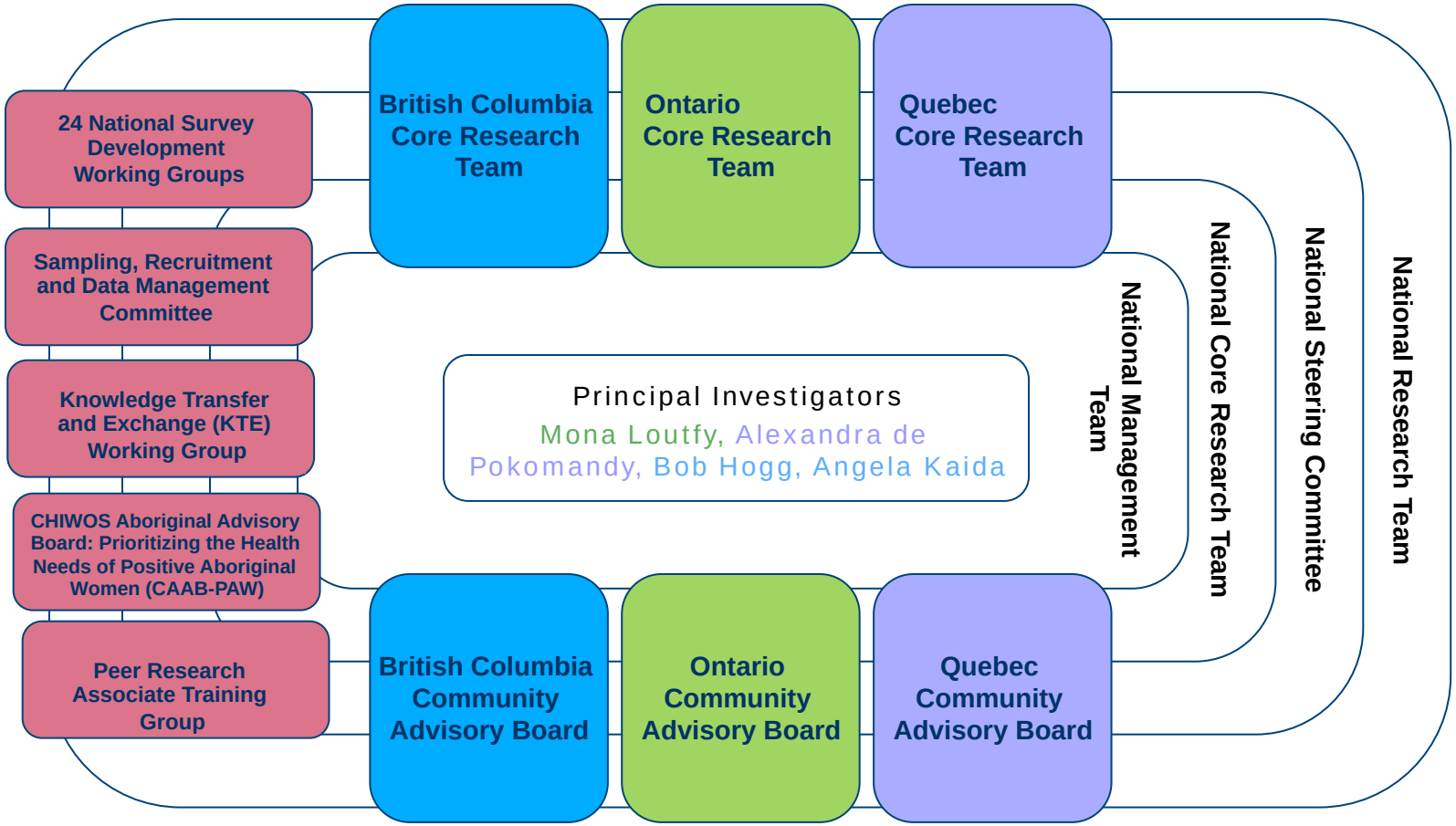
CHIWOS

Guiding Frameworks

- Critical Feminism
- Anti-Oppression & Social Justice
- Social Determinants of Health

CHIWOS

Study Team Structure



National Management Team

Principal Investigator

National Management Team PRA

Provincial Coordinator

CHIWOS

CHIWOS Québec research team

QC TEAM

Dr. Alexandra de Pokomandy - Principal Investigator

Nadia O'Brien – Coordinator

Mélina Bernier- COCQ-SIDA

Peer Research Associates (PRA)

Collaborators

COCQ SIDA

MIELS Québec

GAP VIES

ACCM

NWSM

And many more!!!

Co-Investigators

Dr. Marina Klein

Dr. Joanne Otis

Dr. Benoit Trottier

Dr. Cécile Tremblay

Dr. Danielle Rouleau

Dr. Jean-Guy Baril

Dr. Chris Tsoukas

CHIWOS

CHIWOS formative phase project update

CHIWOS

Project Update:
Québec Formative phase (2011-2012)

Implemented necessary project networks & infrastructure

- Quebec project launch at the MUHC (Sept 2011)
- Recruited three PRA (Oct 2011)
- Launch of the Community Advisory Board (Nov 2011)
- Focus group discussion (March-April 2012)
- **Survey finalization and programming- ongoing**

CHIWOS

Focus Group Objective

Recall the CHIWOS Study Goals:

- To assess barriers to and facilitators of **women-centered HIV/AIDS care** use.

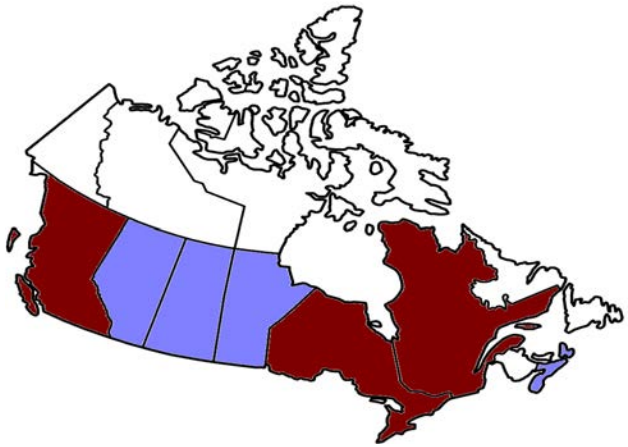
FGD objectives:

- Conduct focus groups with HIV-positive women to develop and refine a community based **definition of 'women centered HIV/AIDS care'**.
- Use this refined understanding of 'women centered care' to develop a scale to be used in the survey.

CHIWOS

National Focus Groupes

- In total, 11 focus groups were conducted
- In total, 77 women participated
- Focus groups were led by Peer Research Associates (PRA)
- Conducted in collaboration with diverse community organizations and medical clinics
- Were held between August 2011 and April 2012
- Quebec: GAP-VIES, MIELS-Québec, MUHC (24 women)



CHIWOS

Key Focus Group Themes

National Themes:

1. Social Determinants of Health
2. Stigmatization and Oppression
3. Women specific health care needs (pregnancy to menopause)

Provincial Themes :

1. Women meaningful involvement (ON-BC)
2. Family centred care (ON)
3. Importance of long term care services and long term relationships with health care providers (QC)
4. Importance of a “safe space” both physical and emotional (QC-BC)

Community Definition of Women Centred Care

It is defined as:

«“Women-centred care supports women living with HIV to achieve the best health and well-being as defined by women. This type of care recognizes, respects and addresses women’s unique health and social concerns, and recognizes that they are connected. Because this care is driven by women’s diverse experiences, women-centred care is flexible, and takes the different needs of women into consideration.”

What do YOU think?

- What do you think would be **possible** if there was women-centred HIV care?
- Do you see a **need** for women-centred HIV care? Why or why not?

Next Steps

National Survey Phase

Interview Logistics

National Survey Phase

- The survey will be approximately 2 hours and participants will receive a compensation of 50$
- 1250 participants overall, with 350 from Quebec
- Recruitment will be from clinics, ASOs and other non-HIV organizations (e.g. immigration, food banks)

350 participants

in Quebec and British Columbia.

550 participants

in Ontario.

CHIWOS

Quebec recrutement plan

Who can participate?

- Identify as a women
- Living with HIV
- Currently lives in Quebec
- Be 16 years old or older
- Able and willing to sign an informed consent form

- **We are aiming for a proportional representation**
  - Geographic distribution
  - Sub-Groups of women living with HIV

Embracing All Women

At CHIWOS, we include and embrace:

transgender & transsexual women, lesbian, bisexual and queer women, Aboriginal women, women of colour, women working in the sex trade, women who use drugs, women living in poverty…

ALL WOMEN

- **What will this experience of inclusion be like for you?**
- **What do you need to learn about in order to do this well?**

CHIWOS

Recruitment plan
Geographical distribution

Recrutement par region			
	Region	Quebec %	CHIWOS
1	Bas-Saint-Laurent	0.9	3
2	Saguenay-Lac Saint-Jean	0.7	2
3	Capital National	9.2	32
4	Mauricie et Centre du Quebec	2.6	9
5	Estrie	2.4	8
6	Montreal	61	214
7	Outaouais	3.5	12
8	Abitibi-Temiscamingue	0.8	3
9	Cote-Nord	0.5	2
10	Nord du Quebec	0	0
11	Gaspesie-Iles-de-la-Madeleine	0.2	1
12	Chaudiere-Appalaches	1	4
13	Laval	4.8	17
14	Lanaudiere	2.8	10
15	Laurentides	2.1	7
16	Monteregie	7.4	26
17	Nunavik	0.1	0
18	Terres Crie de la Baie James	0.2	1
		100	351

MTL vs. Outside/Hors Montreal	
Montreal	214
Outside/Hors Montreal	136
Large Urban Areas/ Milieu Urbain	
Montreal (214)+ Cap Nat (32)	246
Region/Rural	104

Programme de surveillance de l'infection par le virus de l'immunodeficience humaine (VIH) au Quebec: mise a jour des donnees au 30 juin 2010 (2002-2010)

Recruitment plan
Sub-Groups of women living with HIV

Mode de Transmission Transmission Routes	% Québec	CHIWOS
Hétérosexuel (de pays endémique) Heterosexual (from endemic countries)	45.5	159
Hétérosexuel (non-endémique) Heterosexual (non-endemic)	28.3	99
Utilisatrice de drogues par injections Injection drug user	22.2	78
Facteur de sang Blood product	1	4
Transmission verticale Vertical Transmission	2	8
	% 100	350

Distribution par origine ethnoculturelle	% Quebec	CHIWOS
Caucasienne/Canadienne	43.3	152
Autochtone	2.17	8
Caraibes	21.17	72
Europe	1.4	5
Asie	1.1	4
Africaine	28.5	100
Autres/Other	2.36	9
	100	350

Groupe d'age Age Group	% Quebec	CHIWOS	
<15 yrs	1.9	6.65	
15-19	1.8	6.3	Young
20-24	6.1	21.35	Women
25-29	12.4	43.4	78
30-34	15.8	55.3	
35-39	17.4	60.9	Middle
40-44	17.2	60.2	Age
45-49	11.9	41.65	218
50-54	7.4	25.9	
55-59	4.1	14.35	Older
60-64	2.5	8.75	Women
≥65	1.6	5.6	54
	100	350	

Programme de surveillance de l'infection par le virus de l'immunodeficience humaine (VIH) au Quebec: mise a jour des donnees au 30 juin 2010 (2002-2010)

Recruitment plan-to be confirmed!

List of possible sites (wish list) for recruitment and/or interviews

Clinics

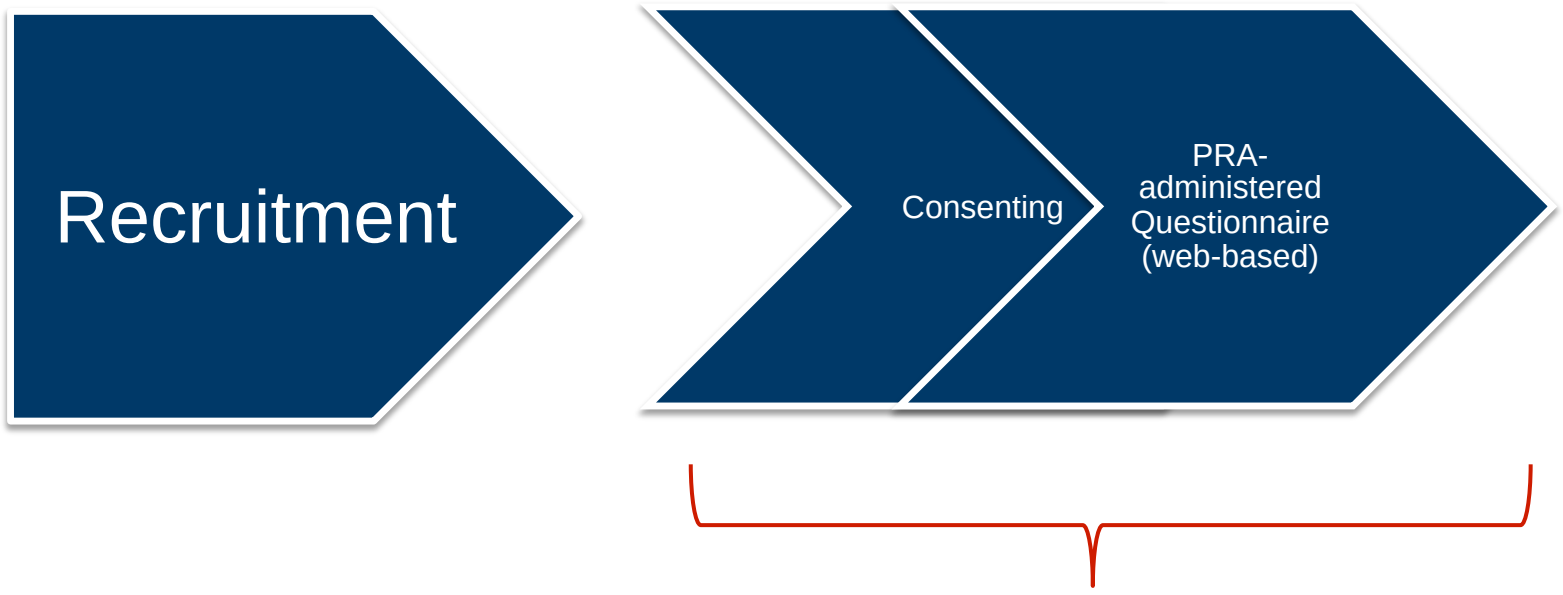
MUHC-Chest and the General
St-Luc
St-Justine
L'actuel clinic
Quartier Latin clinic
CHUL-Quebec

Community Based Sites

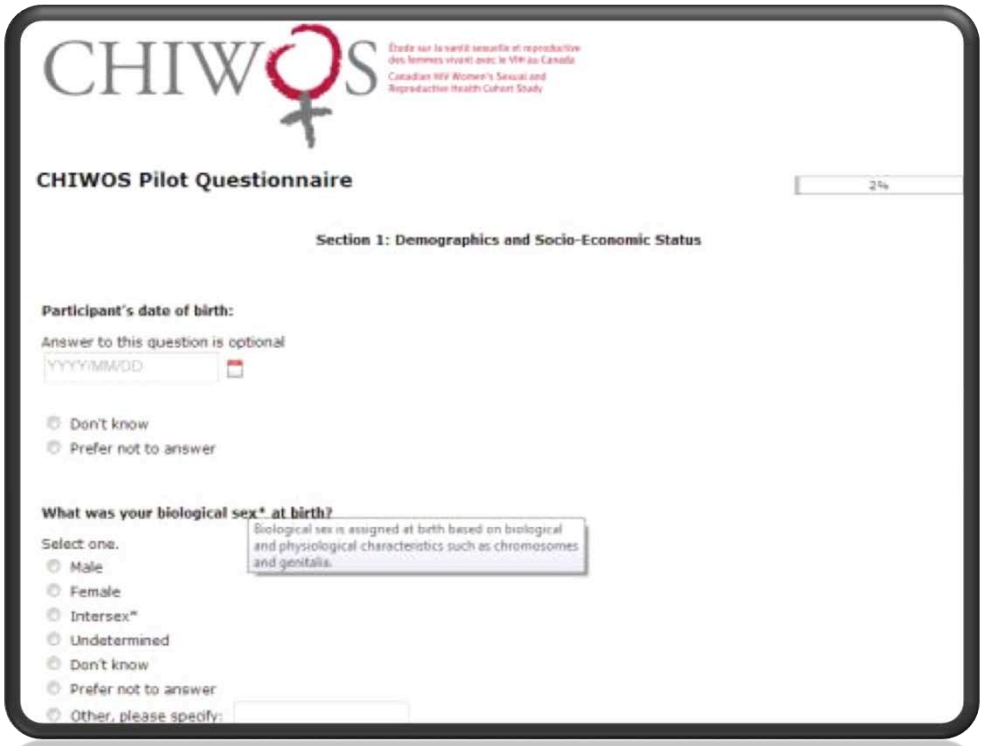
GAP-VIES
ACCM
CASM
MIELS-Quebec
Native Women's Shelter of Montreal
Maison Plein Coeur
Head and Hands
CACTUS
And more!

CHIWOS

PRA Research Duties



FluidSurveys



As you do the questionnaire, you will enter the information into an online program called FluidSurveys.

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Process and payments

- **Irregularity in work:** There may be months when you have a survey one week, no surveys the next 2 weeks, four surveys the next, etc. There might be days that you book interviews, but the participants don't show up. Then you don't get paid for that, so you should prepare yourself for this. Some months might be really slow. Other months might be busy.

- **Payment:** you will be paid based on how many surveys you complete (20-50 interviews). Every month, you will submit an invoice and then you'll get paid.

CHIWOS

Expectations and support

- **Delays:** There are often delays in these types of research projects while we wait for Research Ethics Board approval, finalize work with the other team members in other provinces, build partnerships—important to expect this and be patient

- **Support:** You can expect practical and emotional support in this job: here is who to go to for support

Everything is done as a team!!!

New Timeline

- **Spring and summer 2013**
  - Program "Fluid Based Survey" database
  - First Peer Research Associate Training (NOW ☺)
  - Confirm recruitment sites (clinics & ASOs)
  - Pilot electronic survey platform
  - Submit final questionnaire to ethics
  - Second Peer Research Associate Training- on the electronic platform
- **Summer 2013- START RECRUITING!**

CHIWOS

SUMMARY

- Take 1 minute to **write down 3 things** that seem **important** to you from this orientation to CHIWOS.

- Each person will share with the whole group.

EXPECTATIONS

What is expected of you:

When you are working in your new job as a Peer Research Associates, we expect you to:

- Steward and represent CHIWOS proficiently in the community
- Demonstrate familiarity with the project, background, context, and team
- Survey and assist research in confident, independent, professional manner
- Apply ethics, principles and teamwork in practice
- Communicate constructively with survey participants and with the CHIWOS team
- Practice self-care, communication, debriefing, and safety precautions
- Make informed decisions about the impact on yourself of doing the research
- Empower yourself and act in a community leadership role
- Build capacity and translate what is learned through CHIWOS to other contexts

What to expect while working for CHIWOS:

- **Timelines:** Additional training dates; survey start dates; survey end dates; meetings; phased roll-out; there may be a second survey with each participant but it pending funding
- **Delays:** There are often delays in these types of research projects while we wait for Research Ethics Board approval, finalize work with the other team members in other provinces, build partnerships—important to expect this and be patient
- **Irregularity in work:** There may be months when you have a survey one week, no surveys the next 2 weeks, four surveys the next, etc. There might be days that you book interviews, but the participants don't show up. Then you don't get paid for that, so you should prepare yourself for this. Some months might be really slow. Other months might be busy.
- **Payment:** you will be paid based on how many surveys you complete (20-50 interviews). Every month, you will submit an invoice and then you'll get paid. [Show example of the invoice.] You send it to (name and contact info): _____
- **Support:** You can expect practical and emotional support in this job: here is who to go to for support: _____

CHIWOS Guiding Frameworks

Critical Feminist Framework

A critical feminist framework looks at the overlapping and intersecting issues of gender, racism, homophobia, classism, sexuality, ableism, and HIV-related stigma, and how these issues intersect at individual and structural levels to create oppression; thus, there is an interdependent and mutually constitutive relationship between social identities and social inequities. These structural factors put women at increased risk of gender inequity, violence, poverty, and HIV transmission. A critical feminist approach examines how women are affected by patriarchal systems and structures that affect their social status in relation to men, and intersect with systemic inequality related to women's many other identities. This also involves looking at how the role of women in society is culturally limited and impacted by legal, financial, religious, and economic discrimination against women. This type of systemic and structural inequality has meant that women are not provided with opportunities to participate meaningfully in society or be involved in decisions that directly impact on their lives. Critical feminism draws on principles of social justice, anti-racism, and anti-oppression, which seek to challenge rather than perpetuate systems of oppression.

Anti-oppression, Intersectionality, and Social Justice

The integration of principles of anti-oppression into our critical feminist framework means that we recognize the systemic gendered oppression that women face without homogenizing the experiences of women. An anti-oppressive approach acknowledges that women throughout the world are situated differently, experience oppression in a multitude of ways, while other women experience privileges based on their social locations or identities. Through an understanding of anti-oppression, we are able to deepen our analysis in understanding the complexities of power relations, and how these power relations have an influence on the ways in which women experience their lives.

Intersectionality should be at the core of any conceptual framework that seeks to understand the multiple issues and concerns that face HIV-positive women in Canada. Intersectionality moves beyond the assumption that health outcomes may be caused by a number of contributing causes, by asserting that numerous factors are always at play and that “intersectionality examines gender, race, class and nation as systems that ‘mutually construct one another’” (Patricia Hill Collins,

1998:63). Intersectionality encourages a contextual analysis that probes beneath single identities, experiences and social locations to consider a range of axes of difference to better understand any situation of disadvantage (Yuval-Davis in Hankivsky, 2005). Researchers who are committed to social justice and working toward creating change in health and social care prevention policies can view intersectionality as more than merely a concept, but a term that can be enacted on to address social inequalities. “Intersectionality can inspire political action and policy development…by understanding how individual stories are politically embedded and have political consequences” (Pheonix and Pattynama, 2006, p.189).

The use of a social justice framework, particularly within research is connected to emancipatory resistance with the objectives of confronting oppression, and demanding – or creating – social justice. In order to achieve social justice, research must support communities through collaborative approaches that demand radical social change, and that incorporate, inform, and have community-members guiding the research; thus, community-based research approaches and practices are often used. Research that is working towards social change should have an impact on policies and practices in Canada in order to improve the lives and health of HIV-positive women in Canada.

Social Determinants of Health Framework

A social determinants of health (SDoH) framework, as established by the World Health Organization (WHO) in 2005, acknowledges that many interacting social factors have a large impact on health outcomes and service use. The premise for addressing the SDoH in a broad sense is that while good medical care is a vital component of good health, the underlying social causes that undermine people's ability to access these services must be addressed in order to have an opportunity for good health and well-being. Poverty and gender inequity are SDoH, given that these factors impact the lives of women and children on a global scale, affect access to secure housing, food security, health care, services, resources, and susceptibility to HIV.

However, this more traditional notion of SDoH does not go far enough in recognizing the unique and intersectional social positionings the women occupy in Canadian society. As such, we have recognized the need to understand the experiences of HIV-positive women within a ‘social determinants of women’s health’ framework. A ‘social determinants of women’s health’ framework recognizes the importance of differences between women, men and other gender groups, as well as differences between and within groups of women based on social factors, identity statuses, geographical locations and access to key material and ideological resources. It also recognizes that although women play multiple roles in our society, including mothering, they continue to have unequal access to

power suggesting that a social determinants of women's health framework is necessary when engaging in applied research aimed at developing more effective practice and policy based outcomes.

GIPA

The principle of GIPA (or Greater Involvement of People living with HIV/AIDS) demands the meaningful and emancipatory participation of people living with HIV (PHAs) in every stage of research and knowledge translation. GIPA recognizes the rights of PHAs to a voice in directing the decisions that impact their lives, and to self-determination and autonomy. The absence of meaningful participation of PHAs, as well as violating these rights, will render the research project, service-delivery or support program, or policy initiative significantly less effective. CHIWOS is striving to embody this principle in a genuinely transformative way, benefiting women living with HIV as well as researchers, and to avoid the pitfalls of tokenism and a shallow commitment to meaningful engagement.

Community-Based Research Approach

Community Based Research (or CBR) is an approach which seeks to genuinely democratize research, breaking down hierarchical power relations and problematic dichotomies between the researchers and the 'researched'. CBR moves beyond simple consultative relationships and instead tries to build collaborative ones: active co-research, by and for those to be helped. It involves *all* relevant parties – particularly, in this case, women living with HIV – in identifying problems, priorities and questions, shaping and implementing the research process, and actively working to change and improve conditions seen as problematic. CHIWOS seeks to bring together a radically different research community which includes PHAs, doctors, scientists, social scientists, AIDS Service Organization workers, service providers, activists, academics, and others. In and through this community, all members' contributions and diverse experiences will be valued and respected, critical self-reflection will be prioritized, and those to be helped will be able to determine the purposes and outcomes of their own inquiry.

Implications

It is essential to the success and integrity of the CHIWOS project that all members of the Core Research Team, the Steering Committee, the peer research assistants and the Community Boards understand these principles and work within these frameworks for all their CHIWOS-related activities**.**

What is CHIWOS?

Background and Motivation

Research has demonstrated that women face not only biological susceptibility to HIV, but also amplified vulnerability due to social factors such as poverty, marginalization, violence, and gender inequity. Women who are HIV-positive have unique care needs, but frequently face inattention to their specific social circumstances and health needs, particularly those of a sexual, reproductive and mental health nature, and may experience diverse challenges in accessing care. While there is limited literature and research about how women use HIV/AIDS health and social services, these factors indicate that many women could benefit from women-specific services that would more fully address their unique needs in a supportive, inclusive, and accessible manner.

Guiding Frameworks and Study Goals

The Canadian HIV Women's Sexual & Reproductive Health Cohort Study, or CHIWOS, was developed to address these issues, and will roll out in Ontario, Quebec, and British Columbia. Affiliated with CANOC, this prospective cohort study operates within community based research and GIPA (greater involvement of people with HIV/AIDS) approaches, prioritizing the leadership, and valuing the experiences, of the diverse women who are themselves living with HIV. CHIWOS is further guided by a Critical Feminist framework and a continuous analysis of the Social Determinants of Health over a woman's lifespan, and seeks to put its research into action in order to further social change and justice and to improve lives and care for women living with HIV in Canada. This research and approach aims to further social change for all women living with HIV around the world. The overall study aims to:

- Assess the proportion, distribution and patterns of use and uptake of women-specific HIV/AIDS services, and factors associated with service uptake among HIV-positive women living in Canada.
- Estimate the effect of women-specific HIV/AIDS services uptake on the sexual and reproductive and mental health outcomes and women's health outcomes and screening of women living with HIV in Canada.

The Study Team

CHIWOS has brought together a national, multi-disciplinary research team, drawing expertise and experience from various fields and areas of the country. Mona Loutfy, Alexandra de Pokomandy, Bob Hogg, and Angela Kaida, the principal investigators, are leading the Core Research Team. Advised by the National Steering Committee and by three provincial Community Advisory Boards (CABs), supported by administrative staff and provincial coordinators, and implemented by community Peer Research Assistants (PRAs), the study brings in a rich diversity of perspectives and specialities. CHIWOS is being run through and is supported by the Women's College Research Institute, Simon Fraser University, McGill University Health Centre, Women's Health in Women's Hands, the British Columbia Centre for Excellence in HIV/AIDS, the University of British Columbia, and Providence Health Care. The study is funded by the Canadian Institutes of Health Research and supported by CIHR Canadian HIV Trials Network (CTN 262).

Phases of Research

1) Formative Phase

Before the usage and impact of 'women-specific HIV/AIDS services' can be assessed, CHIWOS must determine how HIV-positive women define and envision these services. Two sets of focus groups will be conducted as part of this initial phase: 1) one to determine community definitions and perceptions of women-specific HIV/AIDS services, and 2) one to collect feedback and input on the preliminary survey instrument before it is employed on a larger scale.

2) National Survey Phase

The full cohort will recruit and enroll 1250 HIV-positive women living in the three study provinces. Participants will complete a PRA-administered survey at baseline and two years, with a phone call and brief survey at one year to ensure continuity of contact. This study will yield critical information which will help to fill knowledge gaps about women, HIV, and HIV/AIDS care, and will enable improvements in the health, care, and wellbeing of HIV positive women in Canada.

CHIWOS

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

For more information, please contact a study coordinator in your region: British Columbia: Allison Carter (allison_carter@sfu.ca); Ontario: Johanna Lewis (johanna.lewis@wchospital.ca); Quebec: Nadia O'Brien (obrien.nadia@gmail.com).

CHIWOS National Management Team Members

QUEBEC TEAM

Alexandra dePokomandy, Principal Investigator
McGill University Health Centre, QC
alexandra.depokomandy@muhc.mcgill.ca

Dr. Alexandra de Pokomandy MDCM MSc, is an assistant professor at the McGill University Health Center and a family physician specialized in HIV patient care since 2003, currently practicing at the Immunodeficiency Service of the Montreal Chest Institute. She completed a Post-Doctoral fellowship in HIV research with the CIHR Canadian HIV Trials Network in 2007 and a Master of Science degree in Epidemiology at McGill University in 2009. She is the recipient of a FRSQ Clinical Research Scholarship Junior 1 (Chercheur Boursier Clinicien Junior 1), for 2011–2015 and is a member of the scientific committee of the FRSQ network "AIDS and Infectious Disease" (Sida-Maladies Infectieuses). Her main interests of research are in cancer related to human papillomavirus (HPV) affecting people living with HIV (particularly regarding the potential prevention of anal cancer), HIV-positive women's health, and HIV integrated health care. Her work as a physician and researcher aims to recognize patient health concerns and make improvements to clinical practices that will benefit HIV-positive individuals.

Nadia O'Brien, Quebec Provincial Coordinator
McGill University Health Centre, QC
obrien.nadia@gmail.com

Nadia O'Brien is a graduate of the Masters of Public Health from Simon Frazer University and of Medical Anthropology (BA) from the University of Toronto. Originally from Montreal she is delighted to be back in Quebec. Her work in HIV has most recently included the joint-coordination of the LISA study housed at the BC Centre for Excellence in HIV/AIDS. Her work has also brought her to Namibia where she explored faith based responses to HIV/AIDS, and to India where she conducted two ethnographies with the Ashodaya Sex Workers Collective on mobilization processes (2008) and the shifting patterns of sex work in Mysore (2011). Her current work with CHIWOS brings together her interests in health interventions, sexual and reproductive health, marginalized communities and participatory research methods.

ONTARIO TEAM

Mona Loutfy, Principal Investigator
Women's College Research Institute, ON
mona.loutfy@wchospital.ca

Dr. Mona Loutfy MD, FRCPC, MPH is an Associate Professor and Clinician Scientist at Women's College Hospital and the University of Toronto where she focuses on clinical HIV research. Her clinical practice is at the Maple Leaf Medical Clinic which cares for over 2,500 HIV-positive patients; she is also the Research Director at the clinic. Her area of research is in women and HIV with a particular focus on pre-conception, pregnancy, parenthood, access to care, stigma, and women's and sexual and reproductive health . She launched the Woman and HIV Research Program at the Women's College Research Institute in 2006 to carry out these activities. Mona works from a community-based research model involving the people that her research will affect at all stages.

Johanna Lewis, Research Assistant
Women's College Research Institute, ON
johannamlewis@gmail.com

Johanna Lewis has been involved with the Women and HIV Research Program at Women's College Research Institute for two years, and has worked on CHIWOS in various capacities. She is now the Ontario Provincial Research Coordinator, and is finishing up her degree in Women and Gender Studies and Global Health at the University of Toronto. She has a particular interest in anti-oppressive approaches to conceptualizing and researching health, as well as in transnational feminism and queer, anti-capitalist, and anti-imperialist politics more broadly.

BRITISH COLUMBIA TEAM

Angela Kaida, Principal Investigator
Simon Fraser University, BC
angela_kaida@sfu.ca

Dr. Angela Kaida is a global health epidemiologist interested in the linkages between HIV and sexual and reproductive health. She received her Ph.D. in 2010 from the School of Population and Public Health at the University of British Columbia (UBC). She then completed a brief post-doctoral fellowship jointly at the Women's Health Research Institute at BC Women's Hospital and the Department of Obstetrics and Gynaecology at UBC. In September 2010, Dr. Kaida joined the Faculty of Health Sciences at Simon Fraser University as an Assistant Professor.Dr. Kaida's research interests pertain to understanding the impact of expanding access to HIV prevention, treatment, and care services on sexual and reproductive intentions, behaviours, and outcomes of HIV-positive women and men in Canada and high HIV prevalence settings around the world. Her research aims to contribute evidence towards the design of bio-behavioural interventions to reduce HIV transmission, minimize unintended pregnancy, support safer conception, and improve sexual and reproductive health among individuals and couples affected by HIV.

Valerie Nicholson, National Management Team and BC Research Associate, BC

Valerie Nicholson is known as Ma Bear in Vancouver's Downtown Eastside. She is a grandmother, a Peer Research Associate, a nutritional outreach worker, a volunteer with the SPCA Charlie's Foodbank, and a student at Simon Fraser University. She has a real passion for her community and representing them anywhere and everywhere she can. Her first experience in peer-based research was with the Food Security Study. Joining the CHIWOS research team has given her the opportunity to learn and develop her skills further. Not only is she a PRA on this project, she is also a member of several advisory boards, is involved in survey development, and is contributing on the core research team at the decision-making level. She is an integral part of an evolving research design that listens to our communities.

Allison Carter, BC Provincial Coordinator
Simon Fraser University, BC
ajc17@sfu.ca

Allison Carter is the British Columbia Research Coordinator for CHIWOS. She received her BSc in 2008 from the Faculty of Science at the University of British Columbia. Wanting a more holistic perspective of health, she then obtained her MPH and Graduate Certificate in Latin American Studies in 2010 at Simon Fraser University. Her graduate work examined the connections between social, political and economic processes and women's health outcomes, and she put that knowledge into action during her internship in Huancayo, Peru, where she helped implement a community-based mother-child health project. Through her work on CHIWOS, Allison has developed a strong passion for HIV and gendered issues. Her experience on this project has strengthened her resolve to study medicine one day to increase her versatility as a public health professional to advance the health of women and families affected by HIV.

CHIWOS

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

JOB DESCRIPTION *(February 4th 2013)*

JOB TITLE: Peer-Research Associate (PRA) (*6-8 Positions Available*)
JOB TYPE: Part-time (3-10 hours per week from March 2013-April 2015, with hours varying by week)
JOB LOCATION: Various cities across the province of Quebec.
REPORTS TO: Dr. Alexandra de Pokomandy, McGill University Health Centre
Deadline for applications: February 20, 2013

STUDY SUMMARY

The Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) is a 5-year, women-centred, community-based research project. It brings together researchers, clinical staff, community partners, and women living with HIV from across Canada. The CHIWOS study objectives are to understand if women are using women-centred care, and to learn about the impact of using these services on their sexual, reproductive, emotional, and women's health outcomes.

The study is currently in its second year. This first year, called the formative phase, was dedicated to building relationships within our study team and larger community and to understanding what 'women-centred care' means. We are now moving to the second phase of our study – the survey phase. As part of this survey phase, we will interview 350 women living with HIV from across Quebec, beginning in May 2013. The survey will be completed online and will include questions about use of women-centred care and sexual, reproductive, emotional, and women's health.

JOB SUMMARY

We are looking to hire 6-8 Peer-Research Associate (PRAs) to conduct the interviews in the province of Quebec. These positions are open to the three PRAs who have worked with the Quebec team during the formative phase, and to new peers interested in joining our team. We are seeking women from different geographical regions across the province Quebec.

All PRAs will be responsible for completing a multi-phase training session. This will include intensive training in research methods, privacy and confidentiality, facilitating interviews, the CHIWOS survey, computer literacy, supporting participants and self care. All PRAs will also be responsible for administering 20-75 surveys with women living with HIV, over a period of 12-18 months.

Women living with HIV from traditionally marginalized or silenced communities are encouraged to apply for these positions, including lesbian, bi, and transgendered women; racialized and Aboriginal women; women engaged in sex work; and other women from groups who have been historically under-represented in health research.

DESCRIPTION OF DUTIES AND RESPONSIBILITIES

1) Attend the 2 day provincial PRA training session in Montreal on March 26-27 2013.
2) Attend the 2½-day national PRA training session in Vancouver on April 7-9 2013.
3) Participate in refresher training in Montreal before study roll-out in your region.
4) Engage in self-learning before and after each training phase.
5) Review and be familiar with your training materials (especially the consent form, survey and protocol) before study roll-out in your region.
6) Assist with recruitment of potential participants by advertising the study in liaison with the Provincial Coordinator (Nadia O'Brien), PRAs, community organizations and peer networks.
7) Assist with screening potential participants to confirm that they are eligible to participate.
8) Assist with scheduling interviews for eligible participants.
9) Obtain voluntary, informed consent and administer the CHIWOS survey with women living with HIV. (Note: Number of surveys will vary by region and may include 20-75 surveys.)
10) Administer the CHIWOS survey instrument using an online platform (e.g., laptop, computer)
11) Complete administrative work associated with the interviews (e.g., payment of participants, completion of receipts, etc.)
12) Participate in bi-weekly Provincial Core Research Team Meetings to debrief interviews, discuss recruitment and data issues, and support fellow PRAs.
13) Liaise and debrief with the Provincial Coordinator as needed.
14) Return all completed materials to the Coordinator (e.g., informed consent form, receipts, etc.)
15) Act as a CHIWOS representative within your region

QUALIFICATIONS

1) Woman living with HIV;
2) Past experience/interest in research;
3) Past experience/interest in working with women living with HIV;
4) Compassion and understanding towards issues related to diversity, inequality, stigma and discrimination, and the needs of women living with HIV;
5) Passionate about learning;
6) Passionate about your community;
7) Ability to work as part of a diverse team of academics, community organizations, clinicians;
8) Effective communication skills (e.g., ability to actively listen, remain non-judgmental);
9) Average literacy skills (e.g., reading, comprehension, writing)
10) Time management skills
11) Basic computer skills (e.g., Microsoft Word, email, internet);
12) Flexibility in working hours;
13) Fluency in French and/or English.

COMPENSATION

1) Travel, accommodation, and food during training sessions will be covered.
2) Financial compensation for your time at the 2-day provincial PRA training session in Montreal on March 26-27 2013 and for the 2½ day national training in Vancouver on April 7-9 2013 will be provided.
3) Compensation for each completed survey will be provided at a rate of $75 per survey. This amount takes into account about 1.5-2 hours for completing the interview and 1-1.5 hours for other duties and responsibilities outlined above.

Please submit a short resume (1-2pg) with a brief cover letter outlining why you would like to work as a PRA with CHIWOS. Send via email to: obrien.nadia@gmail.com

c/o
Nadia O'Brien
CHIWOS Quebec Research Coordinator
Chronic Viral Illness Service, McGill University Health Centre
3650 St-Urbain, rm J8.24, Montreal, QC, H2V 1N8
T: 514-934-1934 x32146
Email: obrien.nadia@gmail.com

Deadline for applications: February 20, 2013

The hiring team will be composed of the Principal Investigator (Dr. Alexandra de Pokomandy), the Research Coordinator (Nadia O'Brien), and the Community Based Research facilitator from COCQ-SIDA (Mélina Bernier). The hiring team will consider every application carefully. All applicants will be notified of whether or not they have been selected for an interview.

SECTION THREE:
Building Bridges

CHIWOS

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

‘TURNING TO ONE ANOTHER’ POEM

By Margaret Wheatley (2002)

There is no power greater than a community discovering what it cares about

Ask: “What’s possible?” not “What’s wrong?” Keep asking.

Notice what you care about.
Assume that many others share your dreams.

Be brave enough to start a conversation that matters.
Talk to people you know.
Talk to people you don’t know.
Talk to people you never talk to.

Be intrigued by the differences you hear.
Expect to be surprised.
Treasure curiosity more than certainty.

Invite in everybody who cares to work on what’s possible.
Acknowledge that everyone is an expert about something.
Know that creative solutions come from new connections.

Remember, you don’t fear people whose story you know.
Real listening always brings people closer together.

Trust that meaningful conversations can change your world.

Rely on human goodness. Stay together.

CHIWOS
Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada
Canadian HIV Women's Sexual and Reproductive Health Cohort Study

ROADMAP ACTIVITY

Instructions for PRAs

- The point of this exercise is to create roadmaps for how to navigate five challenging human experiences based on the shared wisdom of this team.
- Both groups will respond to all five questions below. Both groups' answers will be on the same roadmap—you can build on each other's ideas.
- Each person in the group should briefly share a story based on the prompt.
- Based on your stories, ideas and experiences, write up notes on the big paper to try to create a "roadmap" that others could follow.
- As a group, you will spend 10 minutes on each roadmap.
- Then, you will move in the room to a new roadmap and work on that together for another 10 minutes, until you have worked on all five roadmaps.
- Afterwards, we will discuss as a whole group.

Roadmap Questions

Roadmap for Bridging Our Differences

- Tell a story about a time when you created a bridge between you and someone very different from you. What worked well?

Roadmap for Unlearning Prejudices

- Tell a story about a time when you judged someone at first. Then, you had to find a new way of seeing that person. What worked well?

Roadmap for Ethical Action

- Tell a story about a time when you witnessed someone in a position of power behaving ethically. What did they do that worked well?

Roadmap for Self-Care

- Tell a story about a time when you took good care of yourself in an emotionally difficult situation. What worked well?

Roadmap for Changing Roles

- Tell a story about a time when you had a new role or position in your family/community and how you navigated that change. What worked well?

SECTION FOUR:
Ethics and
Community Based Research

CHIWOS

Étude sur la santé sexuelle et reproductive
des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and
Reproductive Health Cohort Study

Institutional and historical aspects of ethical research

Objectives

- Review history of human protection in clinical research
  - Understanding of where research ethics came from and why it is so important
- Review guiding ethical principles of research
  - In Canada, we follows those of the Tri-council (CIHR, SSHRC NSERC – Federal funding bodies)

History of human protection in research

- The modern history of human protection in research
  - began post WWII with the discovery of the research wrong doing committed by Nazi physicians.
- In August 1947, in Nuremburg Germany
  - a group of judges investigated the war crimes committed
  - developed 10 principles which became known as the Nuremburg code = a set of research ethics principles for human experimentation

CHIWOS

Declaration of Helsinki

- Developed by the World Medical Assembly in June 1964 as a guide to the research community regarding human experimentation
  - Merged the Nuremberg Code with the Declaration of Geneva (1948, a statement on physicians' ethical duties)
  - Six revisions, 2000 version stands today
- Highlights the following ethical standards:
  - respect for persons,
  - protection of subject' health and rights,
  - submission to Research Ethics Board,
  - must have research protocol,
  - importance of informed consent

CHIWOS

Tri-Council Policy Statement:
Ethical Conduct for Research Involving Humans

Guiding Ethical Principles:

- ✓ **Respect for Human Dignity**
- ✓ **Respect for Free and Informed Consent**
- ✓ **Respect for Vulnerable Persons**
- ✓ **Respect for Privacy and Confidentiality**
- ✓ **Respect for Justice and Inclusiveness**
- ✓ **Balancing Harms and Benefits**
- ✓ **Minimizing Harm**
- ✓ **Maximizing Benefit**

CHIWOS

Last key point: Consenting & Ethics

- Consenting is likely most important aspect of research
  - **No study activity can start until the consent is signed**
  - **Key components in consent: full disclosure of project; benefits, harms; voluntary; free to withdraw; no influence on medical care; questions answered – see your IRB rules**
  - **To be done by objective individual in non-coercive manner**

CHIWOS

Ethics and CHIWOS

- McGill University Health Centre (MUCH) Research Ethics Board reviews the CHIWOS study
- All research protocols and documents (questionnaire, posters) must be approved by the MUCH Research Ethics Board
- Informed Consent procedures must be followed
- Exists mainly to protect participants
- Ethics approval can be timely and bring delays but it is an important and necessary step!

CHIWOS

Community Based Research: Ethical Conduct in the Context of Meaningful Involvement (GIPA)

CHIWOS

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

Objectives

- Introduce Community Based Research (CBR) and peer research associate (PRA) involvement
- Deepen our understanding of participatory research processes
- Prompt a critical reflection about ethical conduct within participatory research and Meaningful (Greater) Involvement of Peoples living with HIV/AIDS (MIPA or GIPA)

CHIWOS

Community Based Research

What do you think this means?

- Community?
- Research?
- Community Based?

CHIWOS

Community Based Research

- Collaborations- research benefits all; researchers, community organizations, and the people concerned
- Active peer involvement (GIPA-MIPA principles)
- Research needs and goals are established in collaboration (pertinence and solutions proposes)
- Knowledge transfer and capacity building (training)
- Knowledge transfer strategies must be adapted to various audience and stakeholders (creativity and leadership)
- Research must have multiple concrete impacts!!!

CHIWOS

Examples of research objectives

- Program and service evaluation
- To bring awareness to a lived reality, to debunk myths and challenge prejudices (eg: sex work)
- Study the social determinants of health to create appropriate interventions
- Document healthful practices and supports (treatment adherence, public testimonies), provide training for community health workers
- Etc…

Examples of research themes

Social Determinants of Health:

- Socio-economic status (income, age, sex, gender, citizenship, ect.)
- Education, employment
- Social supports: mental health
- Social environment (housing, safety)
- Health systems, access and accessibility
- *Ect…*
- AND…. Women Centred Care =CHIWOS!

What do you think?

In your opinion…

- What are the benefits of significant community participation in research?
  - For communities?
  - For researchers?
- What are some barriers to involvement for affected persons (ex: people living with HIV)?

Examples of potential barriers

- Health conditions
- Geographical barriers (rural or remote)
- Financial barriers
- Organizational barriers
- Lack of confidence or self esteem
- Lack of knowledge
- Stigma
- Fear of disclosure within ones community

Examples of potential benefits (1)

Community's active participation in research can:

- Allow for more relevant and pertinent research questions to be addressed
- Can validate and support research findings
- Allow for a better uptake of research findings
- Allow research to influence politics and policies

Flicker, S., Roche, B., Guta, A. *Peer Research in Action III: Ethical Issues*. The Wellesley Institute, 2010.

CHIWOS

Examples of potential benefits (2)

Community's active participation in research can:

- Facilitate access to populations who may be marginalised or under represented in research
- Allow for richer data that more closely represents lived realities
- Be an opportunity to enhance local advocacy and build capacity in the community

Flicker, S., Roche, B., Guta, A. *Peer Research in Action III: Ethical Issues*. The Wellesley Institute, 2010.

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Some challenges…

- Formal research ethics board evaluation
- Institutional and bureaucratic barriers
- Timely action vs. research timelines
- Communication and decision making
- Role of the Peer Research Associate (multiple identities)
- Potential conflicts of interests
- Confidentiality, privacy and respect
- Emotional triggers during research participation and the need to provide appropriate supports
- End of project transitions (funding challenges)

Flicker, S., Roche, B., Guta, A. *Peer Research in Action III: Ethical Issues*. The Wellesley Institute, 2010.

CHIWOS

What do you think?

In your opinion…

What are some ethical considerations of community based research that are not addressed by a traditional research ethics process?

How to do CBR? Key guidelines:

- Establish clear study rules and procedures
- Provide mechanism of support, between peers and with the team (Nadia, Alexandra, Mélina, etc.)
- Host training sessions (like today)
- Host knowledge transfer meetings and workshops
- Establish feedback mechanism (phone meetings, research log book)
- Other ideas?

CHIWOS

In summary - ethical conduct is:

- Respect the principles of Ethical Conduct for Research Involving Humans
- Establish informed consent, respect confidentiality and individual privacy
- Establish trust between partners and collaborators, mutual respect, clear communication, share power, and challenge systems of privilege
- Integrate additional precautions to prevent the exploitations of marginalised communities

CHIWOS

And for your two cents…

- Despite these obstacles and challenges, why are you interested in participating in the CHIWOS project? What do you wish to accomplish as a CHIWOS peer?
  - Goals and aspirations?
  - Empathy and compassion?
  - Meeting new people?
  - New skills and experiences?

- Mélina Bernier and the COCQ-SIDA contributed to the content of this presentation

WORLD MEDICAL ASSOCIATION DECLARATION OF HELSINKI
Ethical Principles for Medical Research Involving Human Subjects

Adopted by the 18th WMA General Assembly, Helsinki, Finland, June 1964, and amended by the:
29th WMA General Assembly, Tokyo, Japan, October 1975
35th WMA General Assembly, Venice, Italy, October 1983
41st WMA General Assembly, Hong Kong, September 1989
48th WMA General Assembly, Somerset West, Republic of South Africa, October 1996
52nd WMA General Assembly, Edinburgh, Scotland, October 2000
53rd WMA General Assembly, Washington 2002 (Note of Clarification on paragraph 29 added)
55th WMA General Assembly, Tokyo 2004 (Note of Clarification on Paragraph 30 added)
59th WMA General Assembly, Seoul, October 2008

A. INTRODUCTION

1. The World Medical Association (WMA) has developed the Declaration of Helsinki as a statement of ethical principles for medical research involving human subjects**,** including research on identifiable human material and data.

   The Declaration is intended to be read as a whole and each of its constituent paragraphs should not be applied without consideration of all other relevant paragraphs.

2. Although the Declaration is addressed primarily to physicians, the WMA encourages other participants in medical research involving human subjects to adopt these principles.

3. It is the duty of the physician to promote and safeguard the health of patients, including those who are involved in medical research. The physician's knowledge and conscience are dedicated to the fulfilment of this duty.

4. The Declaration of Geneva of the WMA binds the physician with the words, “The health of my patient will be my first consideration,” and the International Code of Medical Ethics declares that, “A physician shall act in the patient's best interest when providing medical care.”

5. Medical progress is based on research that ultimately must include studies involving human subjects. Populations that are underrepresented in medical research should be provided appropriate access to participation in research.

6. In medical research involving human subjects, the well-being of the individual research subject must take precedence over all other interests.

7. The primary purpose of medical research involving human subjects is to understand the causes, development and effects of diseases and improve preventive, diagnostic and therapeutic interventions (methods, procedures and treatments). Even the best current interventions must be evaluated continually through research for their safety, effectiveness, efficiency, accessibility and quality.

8. In medical practice and in medical research, most interventions involve risks and burdens.

9. Medical research is subject to ethical standards that promote respect for all human subjects and protect their health and rights. Some research populations are particularly vulnerable and need special protection. These include those who cannot give or refuse consent for themselves and those who may be vulnerable to coercion or undue influence.

10. Physicians should consider the ethical, legal and regulatory norms and standards for research involving human subjects in their own countries as well as applicable international norms and standards. No national or international ethical, legal or regulatory requirement should reduce or eliminate any of the protections for research subjects set forth in this Declaration.

B. PRINCIPLES FOR ALL MEDICAL RESEARCH

11. It is the duty of physicians who participate in medical research to protect the life, health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information of research subjects.

12. Medical research involving human subjects must conform to generally accepted scientific principles, be based on a thorough knowledge of the scientific literature, other relevant sources of information, and adequate laboratory and, as appropriate, animal experimentation. The welfare of animals used for research must be respected.

13. Appropriate caution must be exercised in the conduct of medical research that may harm the environment.

14. The design and performance of each research study involving human subjects must be clearly described in a research protocol. The protocol should contain a statement of the ethical considerations involved and should indicate how the principles in this Declaration have been addressed. The protocol should include information regarding funding, sponsors, institutional affiliations, other potential conflicts of interest, incentives for subjects and provisions for treating and/or compensating subjects who are harmed as a consequence of participation in the research study. The protocol should describe arrangements for post-study access by study subjects to interventions identified as beneficial in the study or access to other appropriate care or benefits.

15. The research protocol must be submitted for consideration, comment, guidance and approval to a research ethics committee before the study begins. This committee must be independent of the researcher, the sponsor and any other undue influence. It must take into consideration the laws and regulations of the country or countries in which the research is to be performed as well as applicable international norms and standards but these must not be allowed to reduce or eliminate any of the protections for research subjects set forth in this Declaration. The committee must have the right to monitor ongoing studies. The researcher must provide monitoring information to the committee, especially information about any serious adverse events. No change to the protocol may be made without consideration and approval by the committee.

16. Medical research involving human subjects must be conducted only by individuals with the appropriate scientific training and qualifications. Research on patients or healthy

volunteers requires the supervision of a competent and appropriately qualified physician or other health care professional. The responsibility for the protection of research subjects must always rest with the physician or other health care professional and never the research subjects, even though they have given consent.

17. Medical research involving a disadvantaged or vulnerable population or community is only justified if the research is responsive to the health needs and priorities of this population or community and if there is a reasonable likelihood that this population or community stands to benefit from the results of the research.

18. Every medical research study involving human subjects must be preceded by careful assessment of predictable risks and burdens to the individuals and communities involved in the research in comparison with foreseeable benefits to them and to other individuals or communities affected by the condition under investigation.

19. Every clinical trial must be registered in a publicly accessible database before recruitment of the first subject.

20. Physicians may not participate in a research study involving human subjects unless they are confident that the risks involved have been adequately assessed and can be satisfactorily managed. Physicians must immediately stop a study when the risks are found to outweigh the potential benefits or when there is conclusive proof of positive and beneficial results.

21. Medical research involving human subjects may only be conducted if the importance of the objective outweighs the inherent risks and burdens to the research subjects.

22. Participation by competent individuals as subjects in medical research must be voluntary. Although it may be appropriate to consult family members or community leaders, no competent individual may be enrolled in a research study unless he or she freely agrees.

23. Every precaution must be taken to protect the privacy of research subjects and the confidentiality of their personal information and to minimize the impact of the study on their physical, mental and social integrity.

24. In medical research involving competent human subjects, each potential subject must be adequately informed of the aims, methods, sources of funding, any possible conflicts of interest, institutional affiliations of the researcher, the anticipated benefits and potential risks of the study and the discomfort it may entail, and any other relevant aspects of the study. The potential subject must be informed of the right to refuse to participate in the study or to withdraw consent to participate at any time without reprisal. Special attention should be given to the specific information needs of individual potential subjects as well as to the methods used to deliver the information. After ensuring that the potential subject has understood the information, the physician or another appropriately qualified individual must then seek the potential subject's freely-given informed consent, preferably in writing. If the consent cannot be expressed in writing, the non-written consent must be formally documented and witnessed.

25. For medical research using identifiable human material or data, physicians must normally seek consent for the collection, analysis, storage and/or reuse. There may be situations where consent would be impossible or impractical to obtain for such research or would pose a threat to the validity of the research. In such situations the research may be done only after consideration and approval of a research ethics committee.

26. When seeking informed consent for participation in a research study the physician should be particularly cautious if the potential subject is in a dependent relationship with the physician or may consent under duress. In such situations the informed consent should be sought by an appropriately qualified individual who is completely independent of this relationship.

27. For a potential research subject who is incompetent, the physician must seek informed consent from the legally authorized representative. These individuals must not be included in a research study that has no likelihood of benefit for them unless it is intended to promote the health of the population represented by the potential subject, the research cannot instead be performed with competent persons, and the research entails only minimal risk and minimal burden.

28. When a potential research subject who is deemed incompetent is able to give assent to decisions about participation in research, the physician must seek that assent in addition to the consent of the legally authorized representative. The potential subject's dissent should be respected.

29. Research involving subjects who are physically or mentally incapable of giving consent, for example, unconscious patients, may be done only if the physical or mental condition that prevents giving informed consent is a necessary characteristic of the research population. In such circumstances the physician should seek informed consent from the legally authorized representative. If no such representative is available and if the research cannot be delayed, the study may proceed without informed consent provided that the specific reasons for involving subjects with a condition that renders them unable to give informed consent have been stated in the research protocol and the study has been approved by a research ethics committee. Consent to remain in the research should be obtained as soon as possible from the subject or a legally authorized representative.

30. Authors, editors and publishers all have ethical obligations with regard to the publication of the results of research. Authors have a duty to make publicly available the results of their research on human subjects and are accountable for the completeness and accuracy of their reports. They should adhere to accepted guidelines for ethical reporting. Negative and inconclusive as well as positive results should be published or otherwise made publicly available. Sources of funding, institutional affiliations and conflicts of interest should be declared in the publication. Reports of research not in accordance with the principles of this Declaration should not be accepted for publication.

C. ADDITIONAL PRINCIPLES FOR MEDICAL RESEARCH COMBINED WITH MEDICAL CARE

31. The physician may combine medical research with medical care only to the extent that the research is justified by its potential preventive, diagnostic or therapeutic value and if the physician has good reason to believe that participation in the research study will not adversely affect the health of the patients who serve as research subjects.

32. The benefits, risks, burdens and effectiveness of a new intervention must be tested against those of the best current proven intervention, except in the following circumstances:
    - The use of placebo, or no treatment, is acceptable in studies where no current proven intervention exists; or
    - Where for compelling and scientifically sound methodological reasons the use of placebo is necessary to determine the efficacy or safety of an intervention and the patients who receive placebo or no treatment will not be subject to any risk of serious or irreversible harm. Extreme care must be taken to avoid abuse of this option.

33. At the conclusion of the study, patients entered into the study are entitled to be informed about the outcome of the study and to share any benefits that result from it, for example, access to interventions identified as beneficial in the study or to other appropriate care or benefits.

34. The physician must fully inform the patient which aspects of the care are related to the research. The refusal of a patient to participate in a study or the patient's decision to withdraw from the study must never interfere with the patient-physician relationship.

35. In the treatment of a patient, where proven interventions do not exist or have been ineffective, the physician, after seeking expert advice, with informed consent from the patient or a legally authorized representative, may use an unproven intervention if in the physician's judgement it offers hope of saving life, re-establishing health or alleviating suffering. Where possible, this intervention should be made the object of research, designed to evaluate its safety and efficacy. In all cases, new information should be recorded and, where appropriate, made publicly available.

SECTION FIVE:
Interview Skills

CHIWOS

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

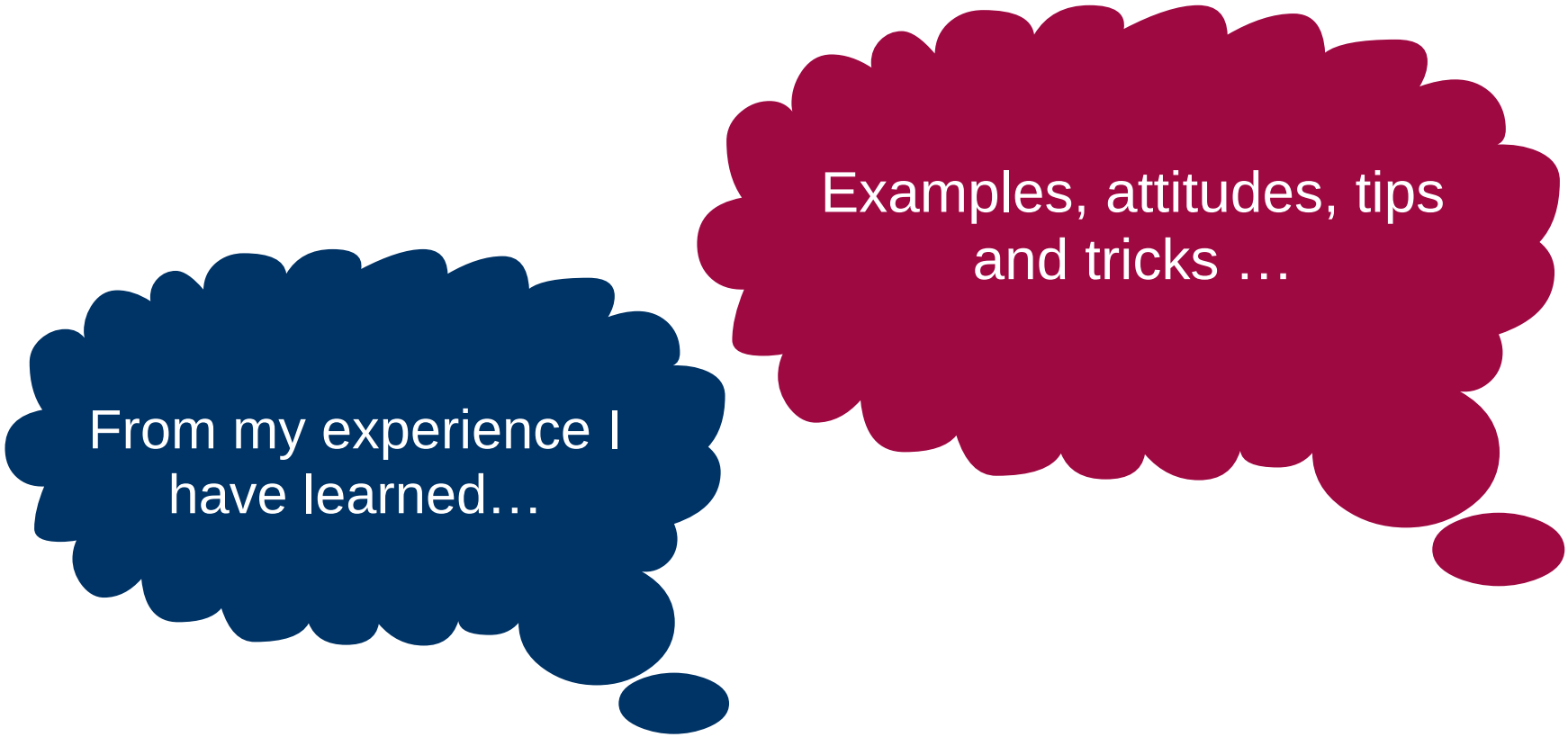
Canadian HIV Women's Sexual and Reproductive Health Cohort Study

An introduction to research interviews

What do you think?

In your opinion, what do you think are the key principles and attitudes essential to a successful interview?

PRA interview experience



A few tips and tricks…

- Plan sufficient time to welcome the participant
- Clearly communicate the study goals
- Describe the importance of their participation and the benefits of the research
- Take the time to answer the participants questions before starting the interview
- Take the time to familiarize yourself with the interview material (questionnaire, online platform, consent form, compensation procedures, checklist, ect)
- Locate the interview site and show up in advance of the scheduled interview time

CHIWOS

Principles of a good interview- (1)

- Don’t jump into the first question, chat informally to break the ice.
- Remember the interview goals, keep on task!
- Be relaxed, and comfortable (it’s contagious)
- Communicate with your body language (nod, face the participant, genuinely interested facial expression) in order to communicate your interest and the importance of the participants responses
- Pay attention to non-verbal cues

Principles of a good interview- (2)

- Make sure the interview site is comfortable
- Have an open attitude so the participant feels that her answers are valid and important
- Be aware of the participants fatigue and energy levels (be observant and considerate of others)
- At the end of the interviews thank each participant for their time and the quality of their participation

What do you think?

- In your opinion, why do you think some people do not like to do interviews?

Interview Challenges!

- Some questions are sensitive; it can be difficult to talk about sexuality or income, ect…
- Some people are skeptical about research, and researchers
- Participants can be very different from you (different age, community, social and economic backgrounds) and may be afraid of being judged
- Some participants may not like to talk about themselves
- Some participants may question the point of the study (will it change anything?)
- Some participants could be scared that their answers will not be kept confidential

CHIWOS

How can we address these challenges?

- Attitudes : create a sense of trust with the participant before the interview, put her at ease, be sensitive to the difficulties or hesitations she might experience
- Key Principles: reassure the confidentiality of the information (complete the Informed Consent Form)

Overall…

- Break the ice (put the participant at ease)
- Project a professional and reassuring attitude
- Introduce the study goals and their potential impact to the HIV community
- Seek the collaboration of each participant, seek honest and sincere answers
- Clearly present the interview process and procedures
- Reassure each participant that all information shared remains confidential (Informed Consent Form)
- Thank the participant for their presence, their participation, and validate the importance and value of their participation

CHIWOS

- Mélina Bernier et la COCQ-SIDA contributed to the creation the content of this presentation

CHIWOS
Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada
Canadian HIV Women's Sexual and Reproductive Health Cohort Study

SURVEY PROCESS CHECKLIST

Survey Steps	Done?	Suggestions	Strengths
Greet the participant			
Introduce yourself			
Carry out consenting process			
Respond to questions			
Obtain written consent			
Enter personal details into Oracle database			
Ask survey questions and enter responses into FluidSurveys			
Upload completed survey			
Inform participant about next steps			
Make referrals to further resources, as appropriate			
Administer participant's honoraria			
End session			

Comments:

CHIWOS

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

CHIWOS Pilot Questionnaire

2%

Section 1: Demographics and Socio-Economic Status

Participant's date of birth:

Answer to this question is optional

YYYY/MM/DD

- Don't know
- Prefer not to answer

What was your biological sex* at birth?

Biological sex is assigned at birth based on biological and physiological characteristics such as chromosomes and genitalia.

Select one.

- Male
- Female
- Intersex*
- Undetermined
- Don't know
- Prefer not to answer
- Other, please specify:

LISTE DES RESSOURCES

Impact de la sécurité alimentaire sur les résultats de santé des personnes vivant avec le VIH/SIDA à l'échelle du Canada

MONTRÉAL

Organismes communautaires / Local ASOs

AIDS Community Care Montréal, ACCM (Sida Bénévole Montréal) : 514-527-0928

CACTUS : 514-847-0067

COCQ-SIDA : 514-844-2477

Coalition sida des Sourds du Québec : 1-800-855-0511

Dopamine : 514-251-8872

G.A.P. - V.I.E.S. : 514-722-5655

GEIPSI : 514-523-0979

Ruban en route : 514 767 5656
Corporation Félix Hubert d'Hérelle : 514 844-4874

Spectre de Rue : 514-528-1700

Portail VIH/Sida du Québec : 514-523-4636

Services Communautaires CCS : 514-937-5351

Unité d'Intervention Mobile l'ANONYME : 514-842-1488

Plein Milieu : 514-524-3661

Accés-Soir team : 514-347-4207

RÉZO (Action Séro Zéro): 514-521-7778

TRAC : 514-798-1200

Sida-Vie Laval : 450-669-3099

BANQUES ET PROGRAMMES ALIMENTAIRES / Food Banks and Food Programs

Fondation d'aide directe sida Montréal (F.A.D.S.M) : 514-522-7744

AIDS Community Care Montréal, ACCM (Sida Bénévole Montréal) : 514-527-0928

Accueil Bonneau : 514-845-3906

Accordailles (les) – Ressources Alimentaires : 514 -282-1553

Accueil Bonneau – Ressources Alimentaires : 514 – 845- 3906

Armée du salut – services communautaire : 514 – 254- 1123 poste 234

Café sur la Rue : 514 – 525 – 5747

Centre Autochtone de Montréal – Ressources alimentaires (C.A.A.M.)

Chez Doris, la Fondation du refuge pour femmes- ressources alimentaires : 514 - 937 – 2341

Chic Resto-Pop (le) – ressources alimentaires : 514 – 521- 4089

Dîner Saint Louis : 514 – 521-8619, 514-521-8619 poste 306 (logement de transition)

Église Unitarienne de Montréal : 514- 485-9933, 514 – 934 – 4956 (dîner pour les aînés)

Hirondelle, services d'accueil et d'intégration des immigrants (L') – ressources alimentaires : 514 – 281-5696 (services)

Jeunesse au soleil – Ressources alimentaires : 514 – 842-1214

Maison Benoît – Labre (LA) – Ressources alimentaires : 514 – 937-5973

Maison des Amis du plateau Mont-Royal (LA) – ressources alimentaire : 514 – 527-1344

Mission Bon Accueil- ressources alimentaires : 514 - 937- 9317

Mission Catholique Espagnole : 514 – 271- 2483

Resto-plateau – ressources alimentaires : 514 – 527 – 5997

Roc, aide aux jeunes (LE)- Ressources alimentaires : 514- 284-9665

Service d'aide et de Liaison la Maisonnée-ressources alimentaires : 514 – 271- 3533

Services sociaux Helléniques du Québec – Ressources Alimentaires : 514 – 906 – 0784

SIDA Bénévoles Montréal – ressources alimentaires : 514 – 527 – 0928

Société de Saint – Vincent – de Paul – Santa – Cruz : 514 – 844 -1011

Y des femmes de Montréal – Point de services bonne boîte bonne bouffe : 514 – 866- 9941 poste 490

Œuvre des Samaritains (L') : 514 – 388 – 4095

Service de Nutrition et d'action communautaire (S.A.N.C.) : 514 – 386-6499

Société Saint – Vincent- de Paul – Saint – Antoine- marie- Claret : 514 – 321- 2002

Centre humanitaire d'organisation, de ressources et de ressources et de référence d'Anjou – ressources alimentaires (C.H.O.R.R.A) : 514 – 493-8278

Services d'aide communautaire Anjou – soupière (LA) (S.A.C. Anjou) : 514 – 354-4299

HÉBERGEMENT / Housing supports

Corporation Félix Hubert d'Hérelle : 514-844-4874

Maison Plein cœur : 514-597-0554

Sidalys: 514-842-4439

Maison Amaryllis : 514-526-2811

Centre Sida Secours : 514-842-4439

Hébergement de L'Envol : 514-523-0979

Maison du Parc : 514-523-6467

Habitations Jean-Pierre-Valiquette : 514 842 4439

Hébergement VIH/SIDA : 733-2589

RESSOURCES POUR FEMMES / Women's services

Centre d'Action Sida Montréal – Femmes : 514-495-0990

AMAL - Centre pour femmes : 514-855-0330

Carrefour des femmes d'Anjou : 514-351-7974

Carrefour des femmes de Saint – Léonard CFSL : 514-325-4910

Carrefour familial L'Intermède : 514-527-5188

Le Cartier Émilie : 514-685-3126

Casa C.A.F.I. (Centre d'Aide aux Familles Immigrantes) : 514-844-3340

Centre Berthiaume-du-Tremblay : 514-382-0310

Chez Doris : 514-937-2341

Le centre Booth : 514-932-221

Centre des femmes de Montréal CFM : 514-842-1066

Centre des femmes de Rivière-des-Prairies : 514-648-1030

Centre des femmes de Rosemont CFR : 514- 525-3138

Le Centre des femmes de Saint-Laurent : 514-744-3513

Le Centre des femmes de Verdun : 514-767- 0384

Centre des femmes d'ici et d'ailleurs CFIA : 514-495-7728

YWCA – Y des Femmes : 514-866-9941

APPUI SOCIAL ET DE SANTÉ MENTALE / Social and support services, Mental health services

Centre d'écoute et de référence Multi-Écoute : 514-737-3604

Le sac à dos (Action – réinsertion) : 514-393-8868

Les Accordailles : 514 282 1553

Accueil Chez Frédéric : 514 328-4982

Accueil liaison Pour Arrivants ALPA : 514-255-900

L'Accès – Soir : 514-347-207

Action Centre-Ville : 514-878-0847

Action Réfugiés Montréal ARM : 514-935-7799

Armée du Salut - Services communautaires et d'aide à la famille (SAF) : 514-722-8534

L'Arrêt – Source : 514 254 1123

Association IRIS : 514- 388-9233

Association Bénévole PAT\ ME Inc. : 514 -645-1264

Association Marie – Reine d'Anjou : 514 -352-9582

Association bénévole amitié : 514-931-5757

Centre d'intervention de crise du Sud-Ouest : 514 768-7225

Bureau de Consultation Jeunesse BCJ : 514-270-9760

Bureau des ressources des assistés sociaux Villeray : 514-495-8101

CALACS de l'Ouest-de-l'île : 514-620-4333

Carrefour d'aide aux nouveaux arrivants CANA : 514 -382-0735

Carrefour d'entraide de Lachine : 514-634-3686

Centre d'Entraide Le Pivot : 514 -251-1869

Centre local d'initiatives communautaires du nord-est CLIC : 514 -494-6457

Charité Soleil Levant : 514-279-1110

Chez Émilie, maison d'entraide populaire : 514-526-9652

Carrefour de liaison et d'Aide- multi-ethnique CLAM: 514 – 634-3686

I.R.I.S. (St-Michel-Ahuntsic-Cartierville-St. Laurent): 514) 388-9233

L'Autre Maison (Verdun, Émard, Côte St-Paul, Lasalle, Pte St-Charles) : (514) 768-7225 ou (514) 768-0098

Centre d'écoute et de référence Halte-Ami : 514 987-8509

Tracom (Centre Ouest-NDG-Côte des Neiges) : (514) 483-2516

Transit (Villeray-Plateau Mont Royal-Petite Patrie-St. Michel Sud-Faubourg : (514) 282-7553

Utilisez ces cases pour ajouter des ressources ou corriger une information.

QUÉBEC

ORGANISMES COMMUNAUTAIRES / Local ASOs

MIELS-Québec (Mouvement d'information et d'entraide dans la Lutte contre le SIDA à Québec) : 418-649-1720

BANQUE ALIMENTAIRE / Food banks

Le Pignon Bleu : 418-648-0598

HÉBERGEMENT / Housing supports

Action Habitation Québec : 418 648-1278

Archipel d'entraide (L') – Accroche-Toit : 418 649-9145

Armée du salut (L') : 418 641-0050

Maison Bonséjour inc. Québec métro : 418 527-4060

Maison de Lauberivière : 418 694-9316

Maison des femmes de Québec inc. : 418 522-0042

Maison d'hébergement Jeunesse Ste-Foy inc. : 659-1077

Maison Job 1 et 2 : 418 845-3072

Maison Marie-Frédéric inc. : 418 688-1582

Maison Painchaud inc. (La) : 418 661-0203

Mirépi maison d'hébergement inc. : 418 337-4811

Résidence La Colombière – Centre résidentiel d'intervention psychosociale, d'intégration, de formation région de Québec : 418 874-0222

RESSOURCES POUR FEMMES / Women's Services

Armée du Salut (L'), Maison Charlotte Booth : 418 692-2978

Association YWCA de Québec : 418 683-2155

Centre des femmes de la Basse-Ville : 418 648-9092

Centre Étape région : 418 529-4779

Centre Femmes aux 3A : 418 529-2066

Centre-femmes d'aujourd'hui : 418 651-4280

Expansion-femmes de Québec inc., Québec métro : 418 623-3801

Groupe les Relevailles Québec métro : 418 688-3301

Maison des femmes de Québec : 418 522-0042

Maison du cœur pour femmes région : 418 841-0011

Maison Hélène-Lacroix Ste-Foy et les environs : 418 527-4682

Maison Kinsmen-Marie-Rollet : 418 688-9024

Mères et Monde Québec : 418 522-5139

Mirépi maison d'hébergement inc. MRC Portneuf : 418 337-4811

Petit Répit (Le) Québec métro : 418 845-2580

Résidence La Colombière – Centre résidentiel d'intervention psychosociale, d'intégration, de formation région Québec : 418 874-0222

Résidence Le Portail : 418 878-2867

Violence info : 418 667-8770

Association YWCA de Québec : 418 683-2155

APPUI SOCIAL ET DE SANTÉ MENTALE / Social and support services, Mental health services

Autohommie : 648-6480 et 648-6464 (écoute)

Le pignon bleu : (418) 648-0598

Centre de crise de Québec : 418 688-4240

Archipel (L') d'entraide Quartiers st-Jean-Baptiste, Vieux-Québec et St-Roch, Limoilou, St-Sauveur : 418 649-9145

Centre communautaire l'Amitié inc. : 418 522-0737

Courtepointe (La) Ste-Foy et Sillery : 418 657-3836

Fraternité de l'Épi inc. Quartier St-Roch : 418 529-0007

Le Passage région de Québec : 418 527-0916

L'Équilibre Québec métro : 418 522-0551

Maison Lauberivière : 418 694-9316

Organisation anti-pauvreté Québec inc. : 418 529-7912

Projet intervention Prostitution de Québec (P.I.P.Q) : 418 641-0168

Réalité du Moment Présent (La) Québec métro : 418 628-9533

Relais d'Espérance : 418 522-3301

Relais la Chaumine inc. : 418 529-4064

Utilisez ces cases pour ajouter des ressources ou corriger une information.

ESTRIE

ORGANISMES COMMUNAUTAIRES / Local ASOs

ARCHE de l'Estrie : 819-348-2670

IRIS – Estrie : 819-823-6704

BANQUE ALIMENTAIRE / Food banks and programs

Cuisine collective le blé d'Or : 819-820-1231

La Chaudronnéee de l'Estrie inc. : 819-821-2311

HÉBERGEMENT / Housing support

Maison Wilfrid-Grégoire : 819-821-2233

Maison Oxygène Estrie : 819-791-4142

RESSOURCES POUR FEMMES / Women's services

La Parolière : 819-569-0140

La Bouée Régionale : 819-583-1233

L'Escale de Sherbrooke : 819-569-3611

La Méridienne : 819-877-3050

Séjour La Bonne Œuvre : 819-835-9272

Centre pour femmes immigrantes de Sherbrooke : 819-822-2259

APPUI SOCIAL ET SANTÉ MENTALE / Social and support services, Mental Health services

Info-Santé et Urgence-Détresse : 819 820-2822 ou le 1 877 822-2822

L'Autre Rive (anxiété, phobie) : (819) 879-4886

Virage Santé mentale :

La Cordée (Ressource alternative en santé mentale)
Organisme : (819) 564-0676

JEVI Centre de prévention du suicide – Estrie : 1-866-APPELLE (277-3553)

L'Autre Rive : 819-564-0676

Centre l'Élan : 819-843-8885

La Cordée, ressource alternative en santé mentale : 819-565-1225

La Croisée des sentiers : 819-879-4886

Pro-Def Estrie: 819-822-0363

Secours-Amitié Estrie : Tél : 819-564-2323

Virage Santé Mentale : Tél : 819-877-2674

Utilisez ces cases pour ajouter des ressources ou corriger une information.

OUTAOUAIS

CENTRES COMMUNAUTAIRES / LOCAL ASOs

BRAS – Outaouais (Bureau régional d'action Sida) : 819-776-2727

BANQUE ALIMENTAIRE / Food banks and programs

Banque Alimentaire La Manne De L'Ile : 819 770-5261

Soupe populaire de Hull inc. (La) : (819) 770-3789

HÉBERGEMENT / Housing supports

Le Gîte Ami : 819-777-5953

Logemen'Occupe : 819-246-6646

Mon Chez Nous : 819-669-6032

Les Habitations Nouveau Départ : 819 568-2442

Maison Réalité : 819 776-1214

Les Habitations Nouveau Départ : (819) 568-2442

Les Habitations partagées de l'Outaouais urbain : (819) 771-6576

Logement intégré de Hull inc. : (819) 776-2433

RESSOURCES POUR FEMMES / Women's services

Espoir Rosalie de Gatineau : 819-243-7663

Entraide familiale de l'Outaouais : 819-669-0686

Maisons d'aide et d'hébergement pour femmes victimes de violence conjugale : 819 568-4710

Halte-femmes de la Haute-Gatineau : 819.449.4545

Maison Libère-Elles : 819 827-4044

Maison de la famille de Gatineau (MESSF) : (819) 568-6830

Maison de l'Amitié de Hull (La) : (819) 772-6622

Maison d'hébergement pour Elles des Deux Vallées (La) : (819) 986-8286

Maison le Ricochet : (819) 456-4230

Maison Mathieu Froment-Savoie : (819) 682-3900

Maison Réalité : (819) 776-1214

Maison Unies-Vers-Femmes (La) : (819) 568-4710

Centre d'animation familiale de l'Outaouais inc. (MESSF) : (819) 561-5196

Clinique des femmes de l'Outaouais : (819) 778-2055

APPUI SOCIAL ET SANTÉ MENTALE / Social and support services, Mental health services

Le Centre d'aide 24/7 : 595-9999

La maison Alonzo Wright : (819) 246-7277

Centre d'intervention en abus sexuels pour la famille **:** (819) 595-1905

Centre social Kogaluk : 819 682-0198

Les Œuvres Isidore Ostiguy : 819 778-1325

Entraide familiale de l'Outaouais : 819 669 0686

Centre de rencontre Arc-en-Ciel ltée : (819) 243-2536

Centre de ressourcement pour la famille de l'Outaouais (MESSF) : (819) 457-4066

Centre d'entraide "La Destinée" (Le) : (819) 561-7474

Albatros-Maniwaki (Haute-Gatineau) : (819) 449-2513

Antre-Hulloise inc. : (819) 778-0997

Arche Agapè inc. : (819) 770-2000

Association Répit Communautaire : (819) 669-6352

Organisme d'aide et de support à l'intégration sociale (ODASIS) : (819) 426-2280

Portes ouvertes de l'Outaouais : 819 777 7776

Le Groupe Gai de l'Outaouais : (819) 770-7843

Prévention C.É.S.A.R. Petite Nation : 819 427-5511

Regroupement des organismes communautaires en santé mentale de l'Outaouais (ROCSMO) : (819) 771-2277

Ressources d'Aide et de Dépannage pour les Alcooliques et les Toxicomanes de Luskville : (819) 455-9161

S.O.S. Contact Al-To inc: (819) 281-0288

Utilisez ces cases pour ajouter des ressources ou corriger une information.

CHIWOS

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

Quebec PRA Training Manual

SESSION TWO
Montreal Quebec
July 24 & 25, 2013

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada
Canadian HIV Women's Sexual and Reproductive Health Cohort Study

AGENDA –PRA Training #2

Day Three – Wednesday, July 24th, 2013

Room 303 - Marguerite- Bourgeoys (NEW ROOM)
Centre Saint Pierre
1212, rue Panet, Montreal

Time	Topic	Facilitator
9:00 9:15	**Welcome** o Coffee and Muffins	**Nadia/Melina**
9:15 10:00	o Agenda o Respond to Muddiest Points o Project Details Scavenger Hunt	**Nadia/Melina**
10:00 11:00	**How To's** o The PRA job o Recruitment	**Nadia**
11:00 11:15	15 minute break	
11:15 12:00	o Appointment logistics o What to bring to the interview	**Nadia**
12:00 13:00	Lunch	
13:00 14:15	**Safety and Wellbeing** o Supports for Participants and PRAs o Emotional/Psychological precautions o Self-care plans	**Melina**
14:15 14:30	15 minute break	
14:30 16:00	**Problem-Solving Scenarios**	**Melina**
16:00 17:00	**Closing** o Evaluation: Muddiest Point	**Nadia/Melina**

Day Four, Thursday, July 25th, 2013

Hour	Topic	Facilitator
9:00 9:15	**Opening:** o Coffee and Muffins	
9:15 9:30	o Agenda o Elevator Speeches	**Nadia**
9:30 10:30	**Confidentiality and Data Linkage**	**Alexandra**
10:30 10:45	**15 minute break**	
10:30 12:00	**Review Informed Consent Process** o Read ICF o Questions and Practice **How to Close the Survey** o Resources for Participants o Payments o Next Steps	**Melina/Nadia**
12:00 13:00	Lunch	
13:00 14:30	**FluidSurvey/Database Training** o Laptops o Pratice on the databases	**Nadia**
14:30 14:45	**15 minute break**	
14:45 16:00	**Practice Surveying**	**Nadia**
16:00 17:00	**Closing** o Next steps	**Nadia/Alexandra/Melina**

Project Details Scavenger Hunt

Instructions:

- NOTE: This is not a test! You don't have to know all of these things. It is just a chance to playfully remember and learn from each other.
- Find someone in the room and ask them to tell you two things they remember.
- Write the answer.
- Help them fill out two questions on their sheet too.
- Make sure by the end of the session you've talked to everyone.

Question	Answer	Name
1) What does "CHIWOS" stand for?		
2) Who is the Principal Investigator in this province?		
3) What age and gender is required to participate in this study?		
4) What provinces are we starting in?		
5) What is a cohort study?		
6) How many women will be surveyed in this province?		

SECTION SIX:
PRA Job and Participant Recruitment

CHIWOS

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

Overview of the Job

CHIWOS

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

Key Questions

- What are my roles & responsibilities?
- What is expected of me?
- What can I expect from CHIWOS?
- What's the process for getting paid?

Roles & Responsibilities

During Training

- Attend all training sessions
- Participate in refresher training
- Engage in self-directed learning before & after each training phase
- Review & be familiar with training materials

Roles & Responsibilities

During Recruitment

- Collaborate with your provincial coordinator, PRA team, community organizations, partners and peer networks to recruit participants
- Assist with screening potential participants to confirm study eligibility

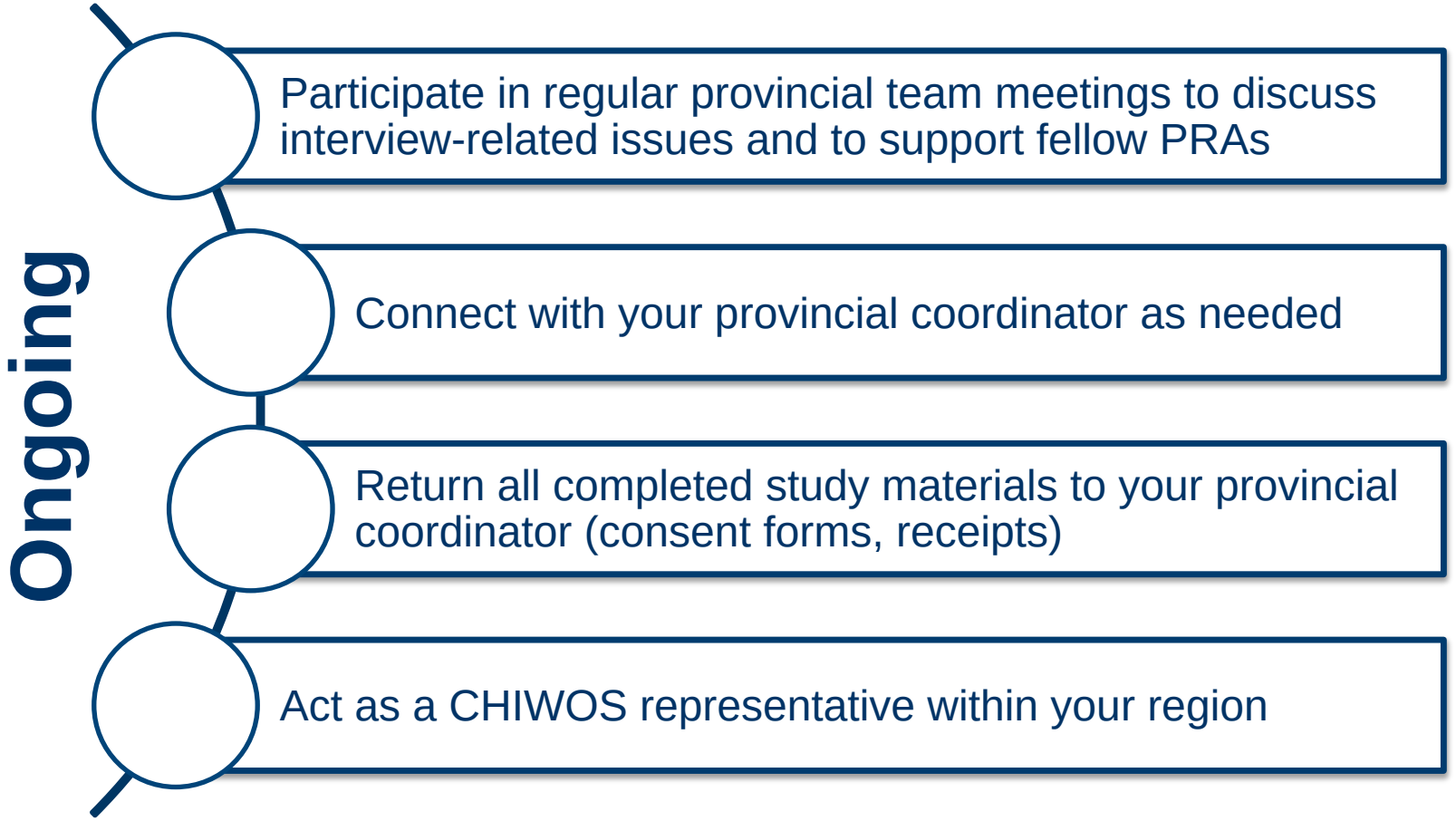
Roles & Responsibilities

During Surveys

- Assist with setting up interviews for participants
- Obtain voluntary informed consent and interview women living with HIV in your region
- Administer the CHIWOS survey using a computer (laptops will be provided)
- Administer the participant honorarium and complete necessary paperwork

CHIWOS

Roles & Responsibilities



What's Expected of You

When working in your new job as a PRA

CHIWOS

STEWARD & REPRESENT

CHIWOS

proficiently in the community

CHIWOS

Demonstrate **familiarity**

with the **project,**

background,

CONTEXT,

& team

CHIWOS

SURVEY & ASSIST

RESEARCH

in a

confident,

independent,

professional manner

CHIWOS

Apply Ethics, principles & **teamwork** in practice

Communicate

constructively

with survey participants

& the **CHIWOS** team

CHIWOS

PRACTICE SELF-CARE, COMMUNICATION, debriefing & **safety precautions**

CHIWOS

Make

INFORMED DECISIONS

about the

IMPACT on yourself of

doing the research

CHIWOS

What to Expect

When working for CHIWOS

PAYMENT

How much?

$75 per survey (you will do between 20-70 interviews total, depending on the region (20min)

How often?

Every month, you'll submit an invoice for the # of surveys completed

What does this include?

All time required to complete the interview and for other roles and responsibilities outlined previously

CHIWOS

PAYMENT

What about training?

You'll receive an honoraria for attendance at the PRA training sessions

What expenses are covered?

Travel, accommodation, and food during training

Please Note:

Laptops or access to secure desktop computers will be provided for use during your contract

YOUR OWN TIME

It is expected that you fulfill the roles and responsibilities outlined previously.

This includes reviewing and getting familiar with the survey materials, sometimes on your own time.

Please know that we welcome involvement in various study activities besides survey work (for example, the Community Advisory Board). However, due to limited funding, sometimes these extra activities might not be paid. These activities are voluntary.

TIMELINES

- Begin to roll out study in August or September
- Start in some regions first, then move to others
- Aim to enroll participants within 18 month period
- We are planning a 2nd survey with each participant (3years left)

Timelines may shift; be prepared to be flexible.

DELAYS

It’s important to expect delays and be patient.

There are often delays in these types of research projects, as we:

- Wait for Research Ethics Board approval
- Finalize work with team members in other provinces
- Build partnerships

IRREGULARITY IN WORK

THIS MEANS:

- Some months might be slow
- Other months might be busy
- Sometimes participants won't show up. You won't get paid when this happens.

Be prepared for varying numbers of surveys from one week to the next.

CHIWOS

SUPPORT

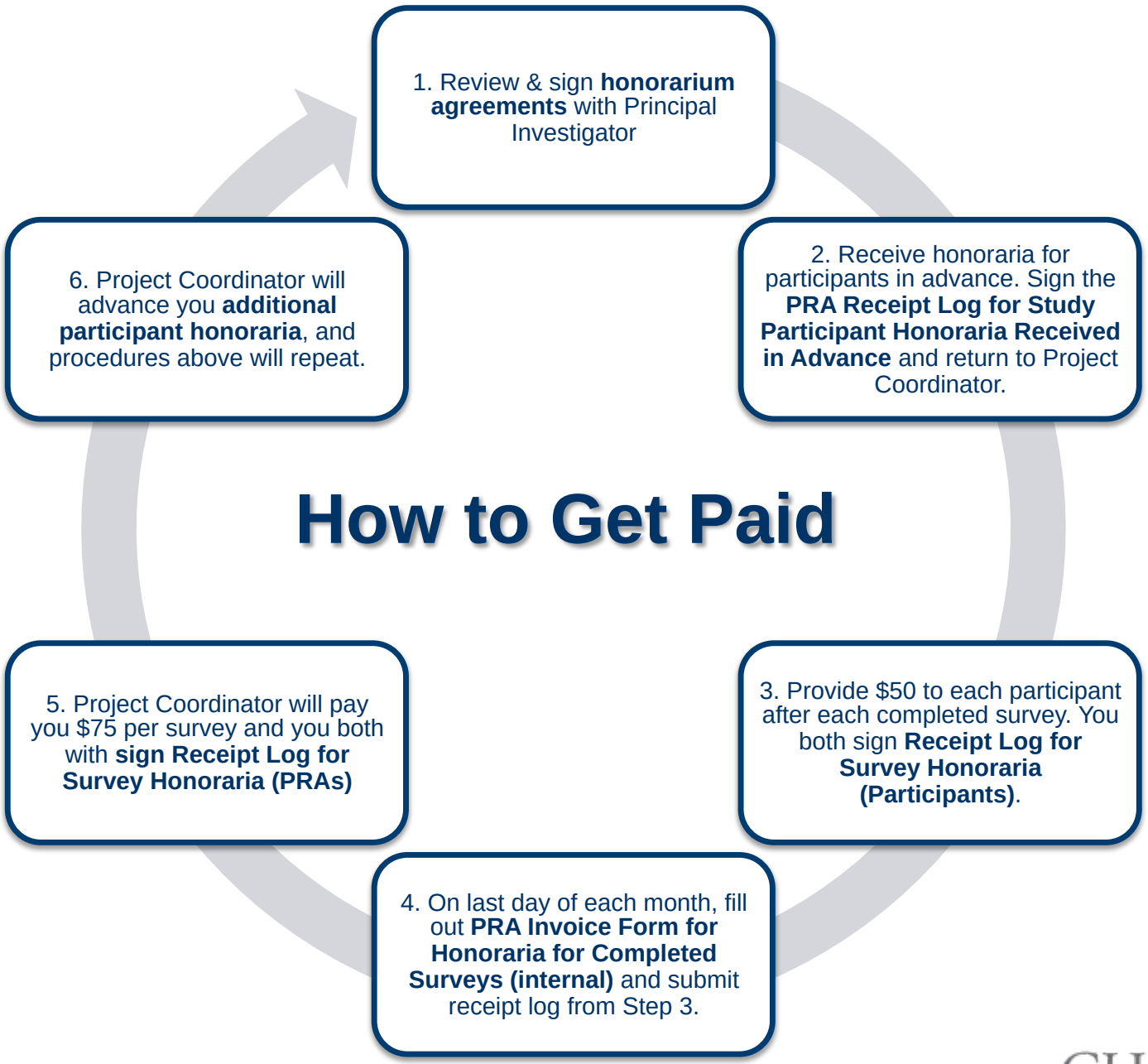
YOU CAN EXPECT:

- Practical support
- Emotional support
- You can go to any member of the team for support (see your provincial contact list)

How to Get Paid

When working for CHIWOS

How to Get Paid



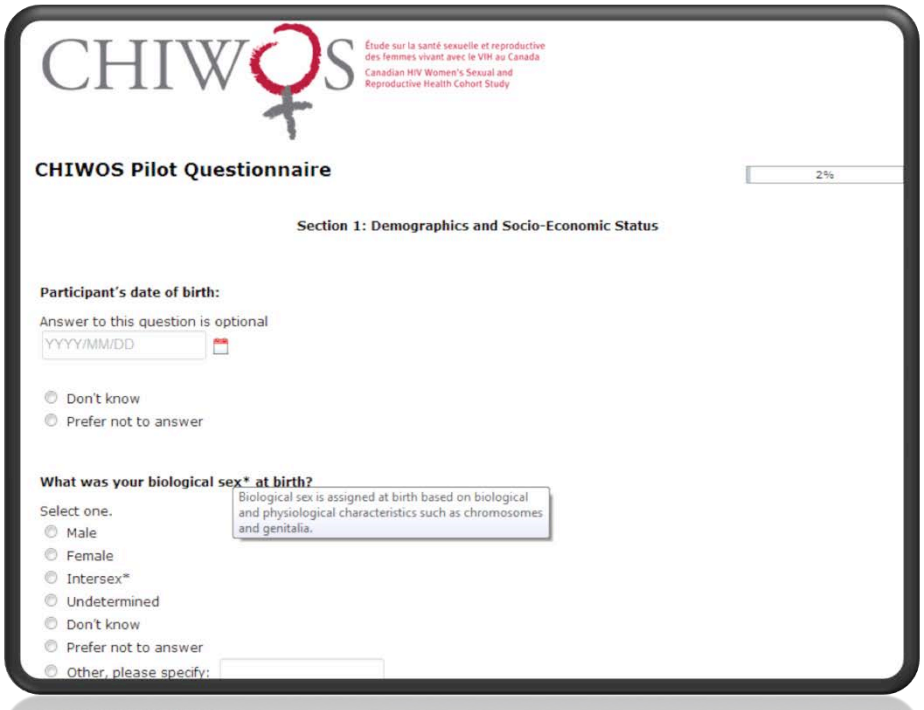
CHIWOS

QUESTIONS?

CHIWOS

Quebec Participant Recruitment

Summary of overall study design



- 350 HIV+ women (16 years or older) will be surveyed in Quebec
- Each participant will be surveyed at baseline, and 18 months later
- To be administered by a PRA (Peer Research Associate)
- Range of survey topics:
  - Women-centred care
  - Sexual health
  - Reproductive health
  - Emotional health
  - Women's health
- Survey will take ~ 2-3 hours
- Participants will receive $50 and PRAs $75 for each completed survey

Advertising Strategies

- Advertising will include:
  - (1) Placing r**ecruitment posters and postcards** at clinics, HIV service organizations (ASOs), and other community settings, as well as major events
  - (2) Peer-based **outreach** and networks
  - (3) **Word-of-mouth** between peers, providers, partners, etc.
  - (4) **Online methods**: CHIWOS Website, Facebook and Twitter
  - (5) Posting notices via **Listservs and Websites (i.e. PASF, COCQSIDA)**
- Push and pull strategies:
  - Provide clients at clinics/ASOs with flyers with study contact info (so clients can call us)
  - Provide clients at clinics/ASOs with flyers that asks "Can the CHIWOS coordinator contact you to provide more info & schedule an interview?" (so we can call them)

Example Posters (draft text only)

CHIWOS

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

Êtes-vous une femme vivant avec le VIH? Participez à une étude sur les besoins de soins de santé des femmes vivant avec le VIH au Canada

Quel est le but de l'étude?

L'étude vise à créer de nouvelles connaissances qui aideront les femmes vivant avec le VIH au Canada à atteindre un niveau optimal de santé et de bien-être.

Vous êtes admissible à participer si vous :

- vous identifiez comme femme
- êtes seropositive pour le VIH
- êtes âgée de 16 ans ou plus
- habitez en CB, ON, ou QC

En quoi consiste l'étude?

L'étude consiste à répondre à un questionnaire de 2 à 2½ heures avec une pair formée pour faire des entrevues, plus une entrevue de suivi 18 mois plus tard.
Vous recevrez une compensation financière pour couvrir vos dépenses liées à votre participation.
La confidentialité est assurée.

Pour plus de détails et pour participer, veuillez communiquer avec Allie au:

Nadia O'BRien, Coordinatrice de Recherche

514-934-1934, 32146

Toll-free # (XXX-XXX-XXXX)

chiwos.quebec@gmail.com

Joignez-nous à l'adresse : www.chiwos.ca
facebook.com/CHIWOS
twitter.com/CHIWOSresearch

19 June 2013

CHIWOS

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

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Vous recevrez une compensation financière pour couvrir vos dépenses liées à votre participation.
La confidentialité est assurée.

Si vous êtes intéressée à participer et que vous préférez que la coordinatrice Nadia O'Brien communique avec vous, veuillez cocher la case ci-dessous et inscrire vos coordonnées :

☐ Je suis intéressée à participer à cette étude et j'autorise la coordonnatrice de l'étude à me communiquer plus d'information.

Nom:_____

Téléphone:_____

Courriel: _____

Joignez-nous à l'adresse : www.chiwos.ca
facebook.com/CHIWOS
twitter.com/CHIWOSresearch

19 June 2013

Recruitment will vary by region

- Exact strategies will vary depending on the region

- **The epidemic is region-dependent** – the number and proportion of women who are positive is different, and the proportion of women of different backgrounds (e.g., ethnicities, drug use behaviours) is also different

Recruitment of WLWHIV in Québec

~Estimated 20000 PLWHIV in Québec.

Approx. 20-25% (~4500) of PLWHIV are women

Routes of transmission

- Heterosexual/endemic countries 46%, Heterosexual 28%, IDU 21%

Geography

- Montreal 61%, Quebec 9%, other areas 30%

Population

- Canadian 43%, African 29%, Caribbean 21%, Aboriginal 2%

Age

- ≤19= 4%, 20-29= 18%, 30-39= 33%, 40-49= 29%, ≥50= 16%

Language- In the general QC population, 80% are francophone

Programme de surveillance de l'infection par le virus de l'immunodéficience humaine au Québec: (2002-2011)

Recruitment Criteria in Quebec

1. Region
2. Ethnicity
3. Transmission Routes
4. Age
5. Language

Recruitment plan
Geographic distribution

Recrutement par region			
	Region	Quebec %	CHIWOS
1	Bas-Saint-Laurent	0.9	3
2	Saguenay-Lac Saint-Jean	0.7	2
3	Capital National	9.2	32
4	Mauricie et Centre du Quebec	2.6	9
5	Estrie	2.4	8
6	Montreal	61	214
7	Outaouais	3.5	12
8	Abitibi-Temiscamingue	0.8	3
9	Cote-Nord	0.5	2
10	Nord du Quebec	0	0
11	Gaspesie-Iles-de-la-Madeleine	0.2	1
12	Chaudiere-Appalaches	1	4
13	Laval	4.8	17
14	Lanaudiere	2.8	10
15	Laurentides	2.1	7
16	Monteregie	7.4	26
17	Nunavik	0.1	0
18	Terres Crie de la Baie James	0.2	1
		100	351

MTL vs. Outside/Hors Montreal	
Montreal	214
Outside/Hors Montreal	136
Large Urban Areas/ Milieu Urbain	
Montreal (214)+ Cap Nat (32)	246
Region/Rural	104

Programme de surveillance de l'infection par le virus de l'immunodeficience humaine (VIH) au Quebec: mise a jour des donnees au 30 juin 2010 (2002-2010)

Recruitment plan
Sub-Groups of women living with HIV

Mode de Transmission Transmission Routes	% Québec	CHIWOS
Hétérosexuel (de pays endémique) Heterosexual (from endemic countries)	45.5	159
Hétérosexuel (non-endémique) Heterosexual (non-endemic)	28.3	99
Utilisatrice de drogues par injections Injection drug user	22.2	78
Facteur de sang Blood product	1	4
Transmission verticale Vertical Transmission	2	8
	% 100	350

Groupe d'age Age Group	% Quebec	CHIWOS	
<15 yrs	1.9	6.65	
15-19	1.8	6.3	Young
20-24	6.1	21.35	Women
25-29	12.4	43.4	78
30-34	15.8	55.3	
35-39	17.4	60.9	Middle
40-44	17.2	60.2	Age
45-49	11.9	41.65	218
50-54	7.4	25.9	
55-59	4.1	14.35	Older
60-64	2.5	8.75	Women
≥65	1.6	5.6	54
	100	350	

Distribution par origine ethnoculturelle	% Quebec	CHIWOS
Caucasienne/Canadienne	43.3	152
Autochtone	2.17	8
Caraibes	21.17	72
Europe	1.4	5
Asie	1.1	4
Africaine	28.5	100
Autres/Other	2.36	9
	100	350

Programme de surveillance de l'infection par le virus de l'immunodeficience humaine (VIH) au Quebec: mise a jour des donnees au 30 juin 2010 (2002-2010)

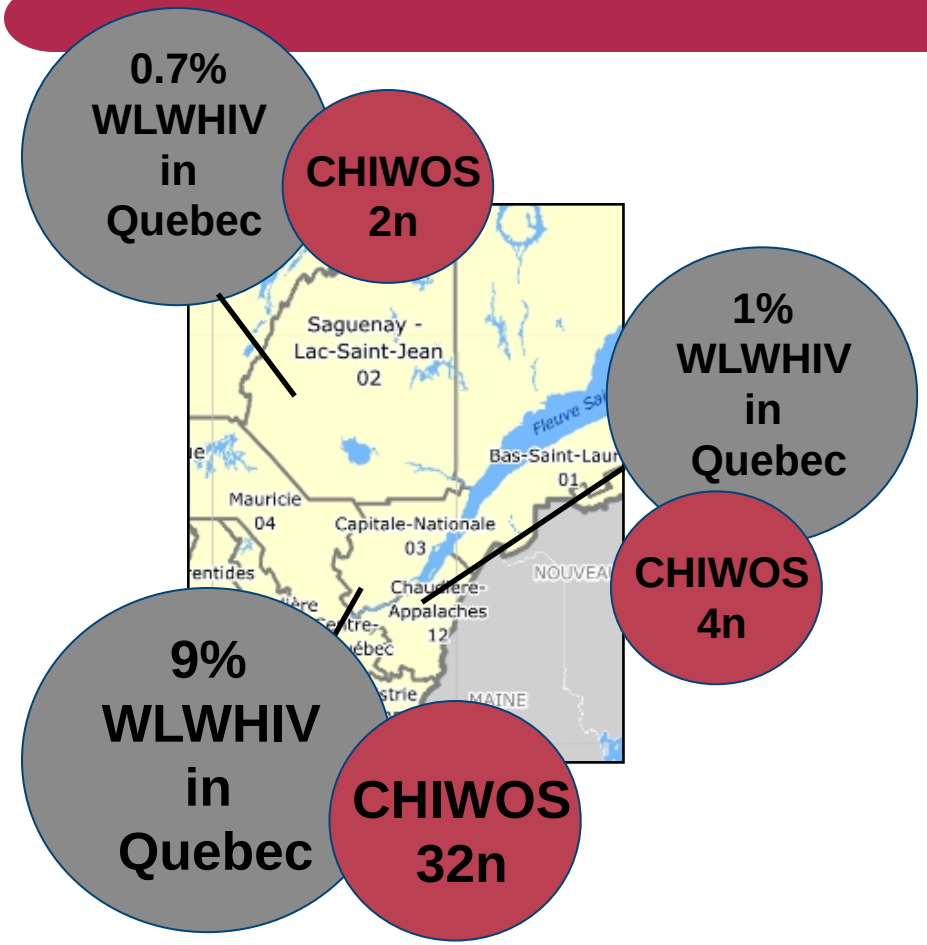
Region / PRA Specific Strategies

CHIWOS

Recruitment plan
PRA Interview plan

- Each PRA is expected to complete at least **20 interviews**
- We will work hard to set up 20 interviews for each PRA
- After 20 interviews we will readjust our plan for the remaining interviews
- With 9 PRA interviews could vary between **20-40 interviews**
- We will be flexible and request the same flexibility
- We cannot guarantee that each PRA will have the same number of interviews
- Recruitment and interviews are done as a team
- THE FOLLOWING INTERVIEW DIVISION IS A GUIDE ONLY!!!
- Variety of factors: The EPI numbers are not perfect, PRA can move one, participants move around the provinces ect….

Recruitment plan
Quebec/Saguenay/Chaudière Appalaches



Goal- 38/350

Community Based Sites

MIELS-Quebec

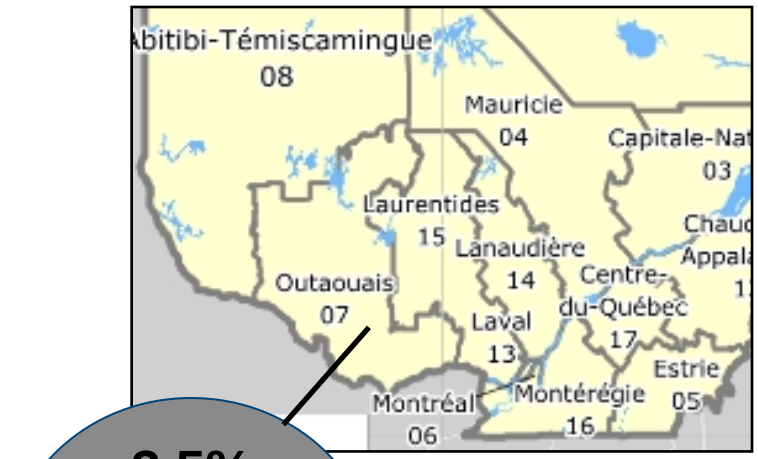
Clinics

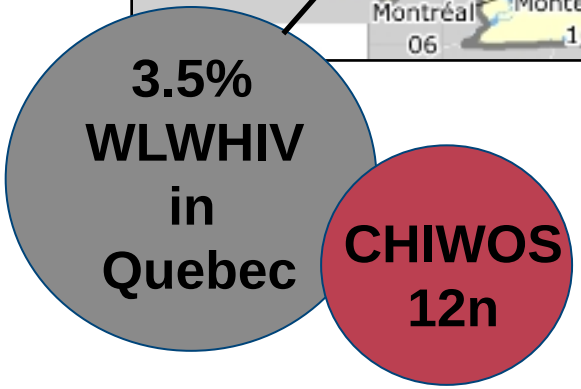
CHUL- Quebec

Other?

Cities: Quebec, Lac Saint Jean, Alma, Levis…

Recruitment plan-Outaouais/Ottawa





Goal- 12/350 (+Ottawa?)

Community Based Sites

B.R.A.S. – OUTAOUAIS

Clinics

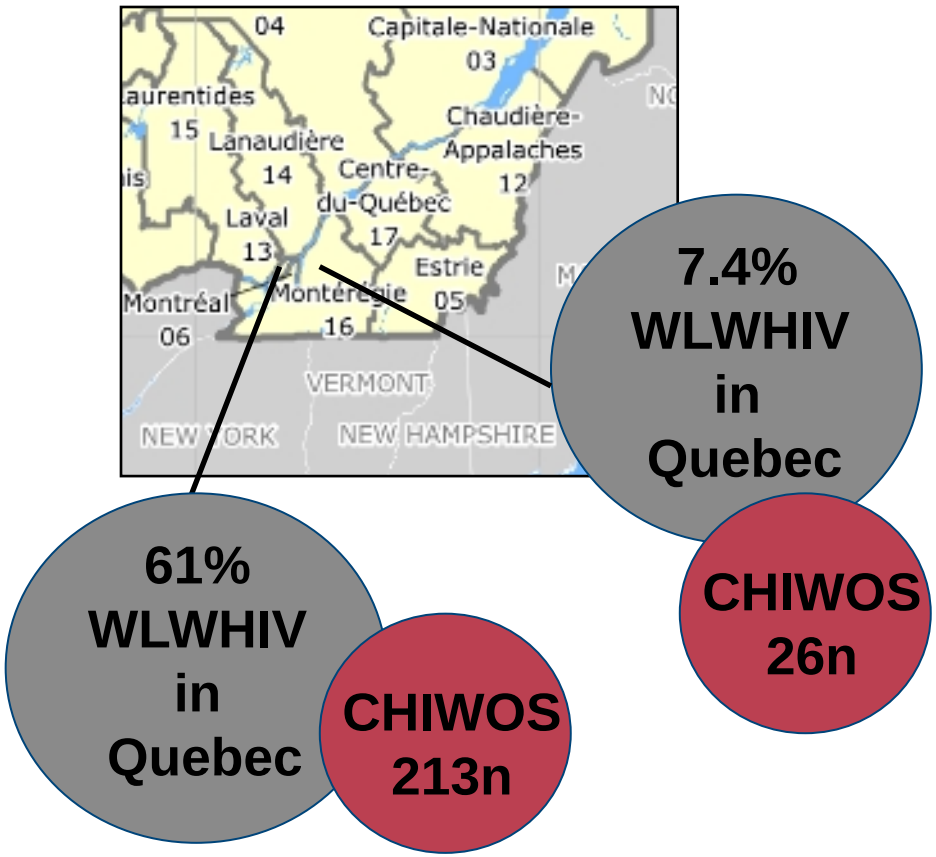
Hull/Gatineau

Ottawa?

Other?

Cities: Hull

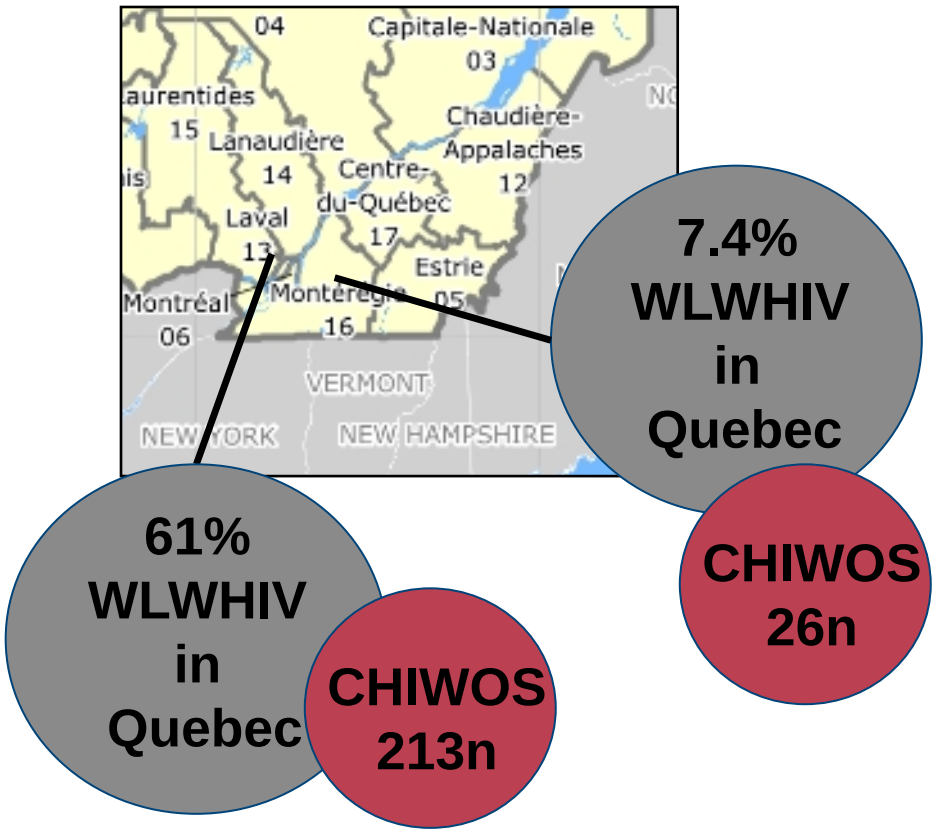
Recruitment plan-Montreal/Monteregie



Goal- 239/350

CHIWOS

Montreal/Monteregie (continued)



Goal- 239/350

Community Based Sites

GAP-VIES

ACCM

CASM

Native Women's Shelter of MTL

Maison Plein Coeur

Head and Hands

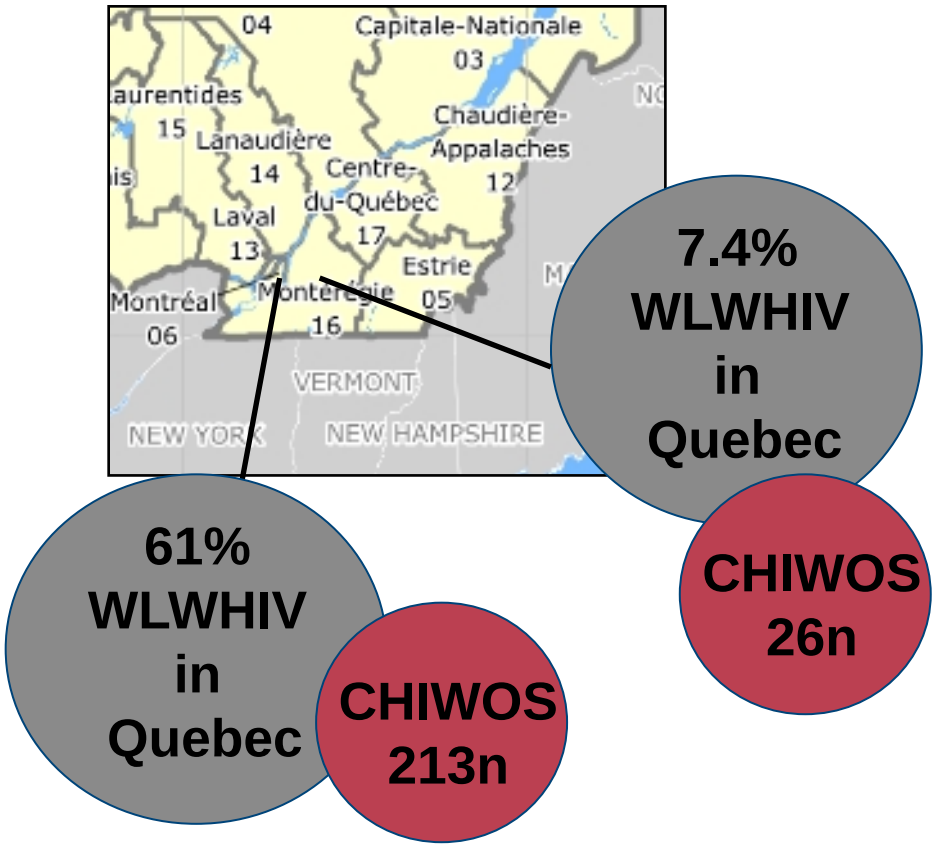
CACTUS

ACTION SIDA RICHELIEU

ÉMISS-ÈRE – MONTÉRÉGIE

And more…

Montreal/Monteregie (continued)



Goal- 239/350

Clinics

MUHC-Chest and the General

CHUM: Notre Dame, Hotel Dieu

OPUS

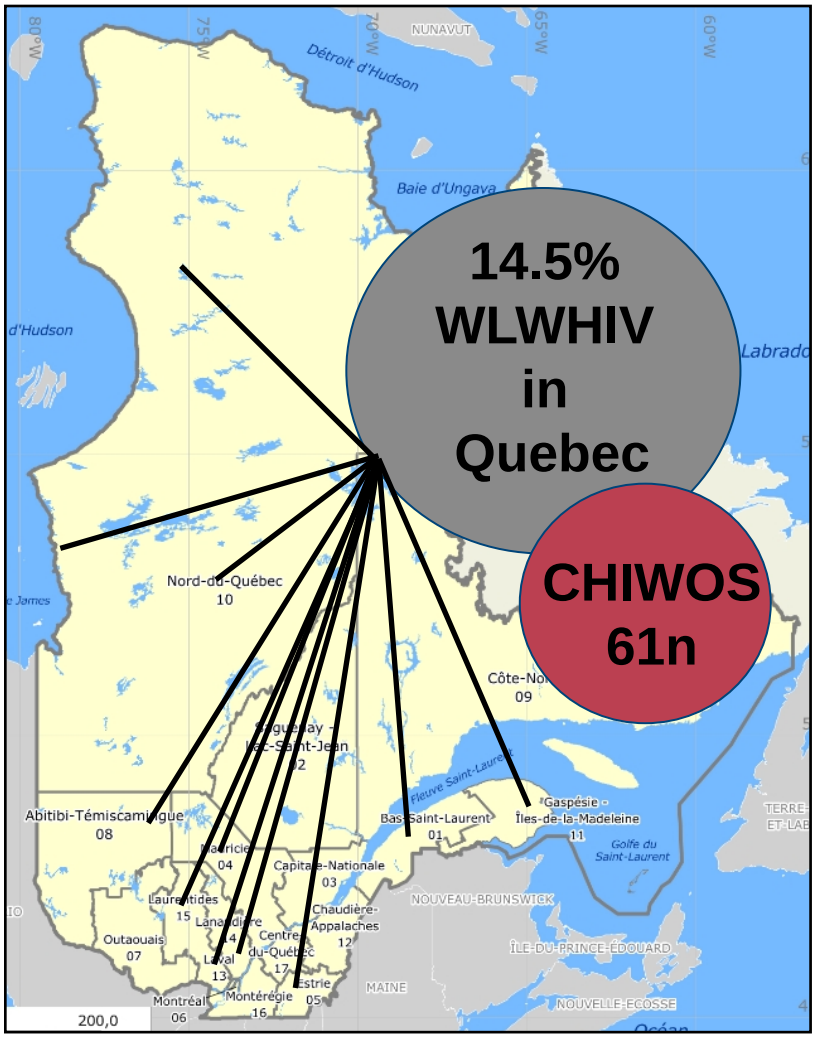
St-Justine

L'actuel clinic

Quartier Latin clinic

Cities: Montreal, Longueuil, Brossard,Granby, St-Hyacinte ect.

Recruitment plan-Other Regions



Goal- 61/350

Laval (17n)

Lanaudiere(10n)

Laurentides(7n)

Mauricie et Centre du QC (9n)

Estrie (8n)

Bas-St-Laurent (3n)

Abitibi-Temiscamingue (3n)

Gaspesie (1n)

Cote-Nord/BaieJames/NduQ (3n)

QUESTIONS?
STRATEGY?

CHIWOS

Overview of Appointment Logistics

CHIWOS

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

Key Questions

- How will **contact** happen?
- How will I **keep track** of interviews?
- **Where** & **when** will interviews happen?
- How will I keep my personal info **private**?
- What should I **bring** to the interview?
- How should I **store** stuff?

CHIWOS

HOW CONTACT WILL HAPPEN

Email

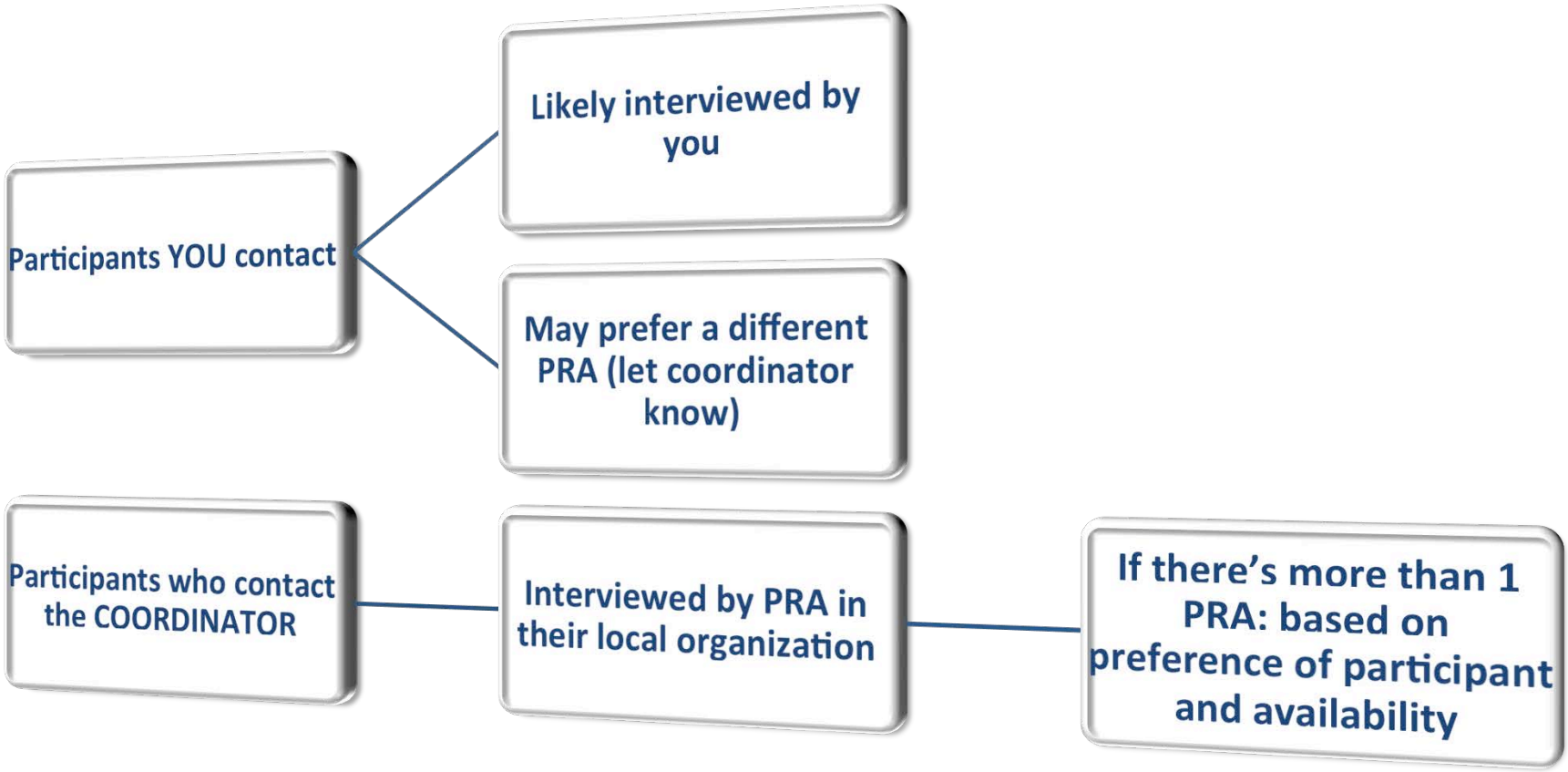
Phone

Drop-Ins

Provincial Coordinator

CHIWOS

Which PRAs get which appointments?



Keeping Track of Scheduled Interviews

Each time you schedule an interview, write down:

- Date
- Time
- Meeting location
- Participant's initials or first name only (non identifying)
- Participant's contact info

You can write this in your personal planner or calendar.

When you can, please log into the

PARTICIPANT DATABASE

and

enter the scheduling info
there as well

Where & When Interviews Should Happen

- During the **day** (not night)
- At your local HIV Service Organizations or **clinics**
- The study team will arrange the details (space, internet) and facilitate relationship-building
- Home interviews?

How to keep your personal contact info private

- **Create a work-related email**

  (like chiwos_nadia@gmail.com)

- **Block your number before making calls:**

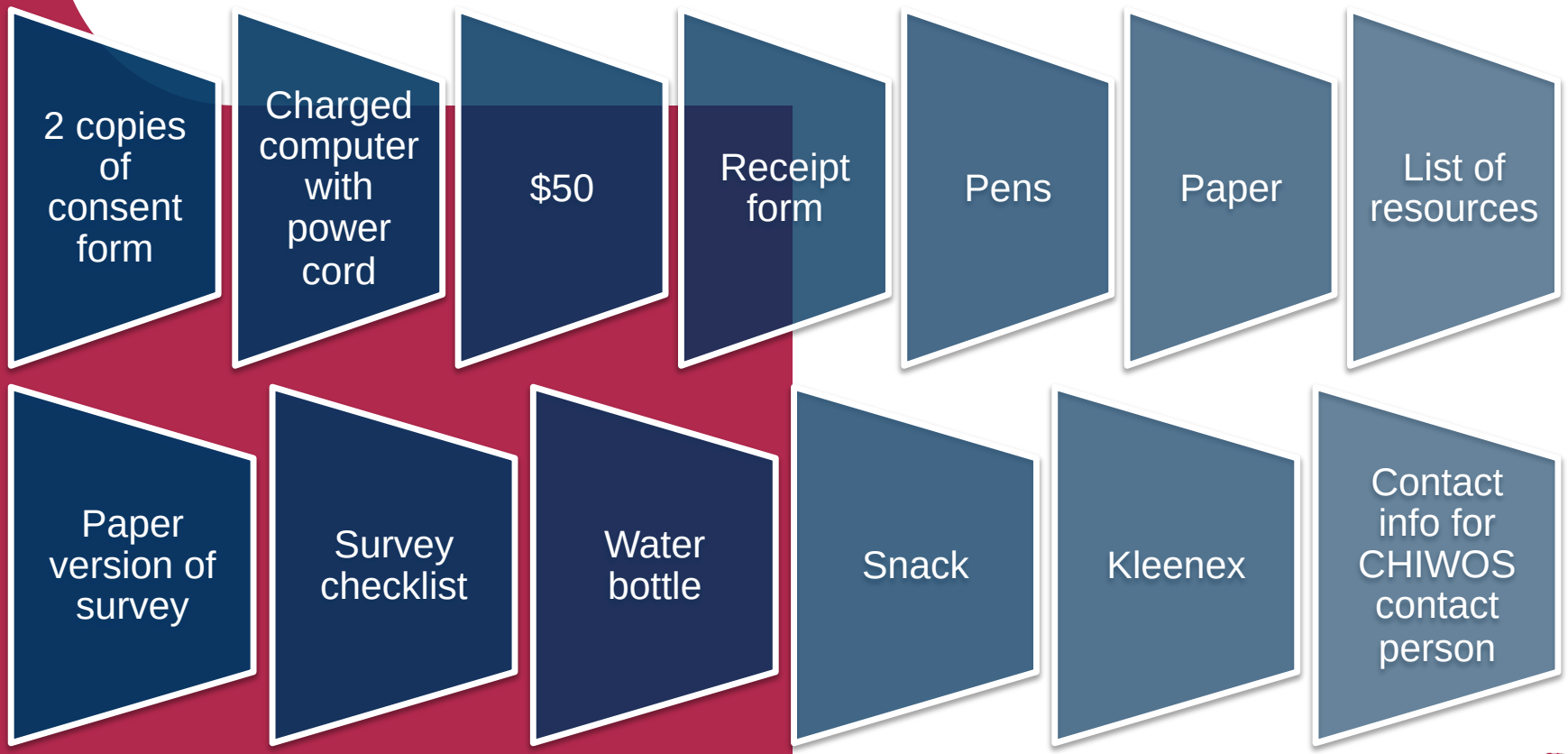
  (i) Dial *67 or #31# or *82 (try it first)

  (ii) Listen for 3 beeps, and

  (iii) Dial phone number. It's free!

CHIWOS

What to bring to the interview:

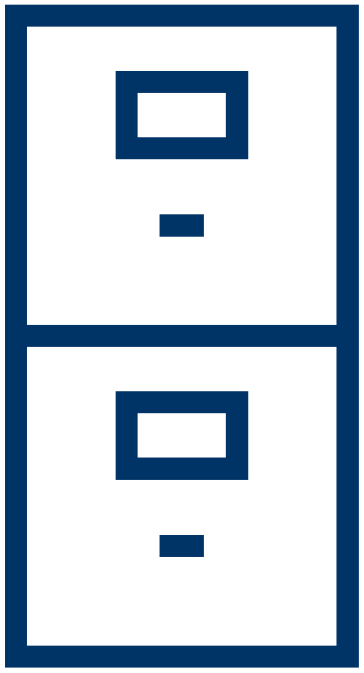


CHIWOS

STORING STUDY MATERIALS

- Computer
- Signed consent forms
- Compensation
- Receipt logs

must be stored in **locked storage space**



STORING STUDY MATERIALS

Each month…

- Signed consent forms &
- Receipt logs

must be **mailed back**
(or delivered in person)
in secure, sealed envelopes
to the coordinator's office

Handling Exceptions

CHIWOS

SURVEYING OVER THE PHONE OR SKYPE

Exception 1

We expect MOST surveys will happen in person in and around major population centres.

Participants may either live near these centres or be travelling into these centres to access care.

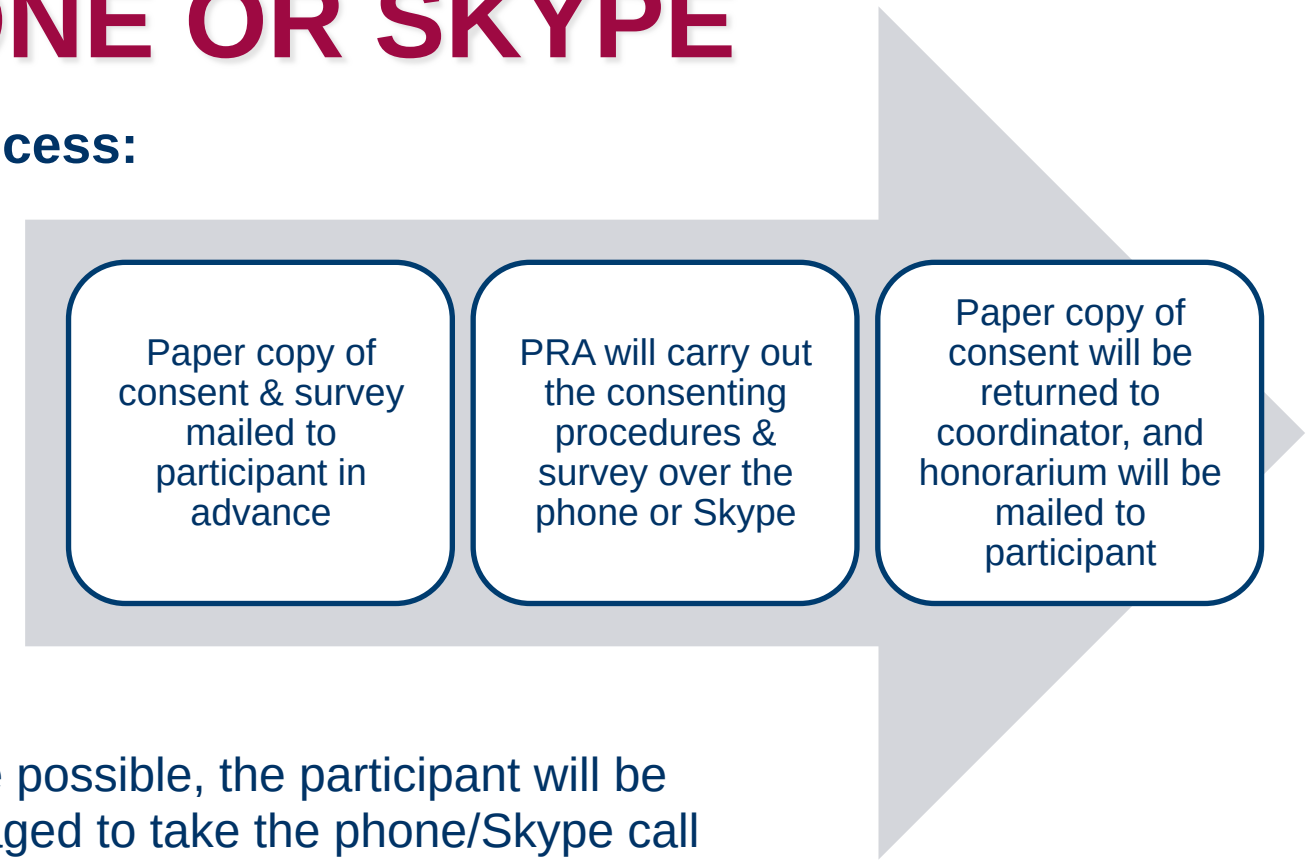
For women in more rural/ remote areas who are not travelling to major centres for care

PRAs may conduct telephone or Skype interviews WITH APPROVAL.

CHIWOS

SURVEYING OVER THE PHONE OR SKYPE

The process:



Where possible, the participant will be encouraged to take the phone/Skype call at their local ASO or clinic (in case in-person support is required).

CHIWOS

SURVEYING ON PAPER

Exception 2

We expect MOST surveys will happen with the online version.

If you are unable to connect to the Internet, try the OFFLINE mode.

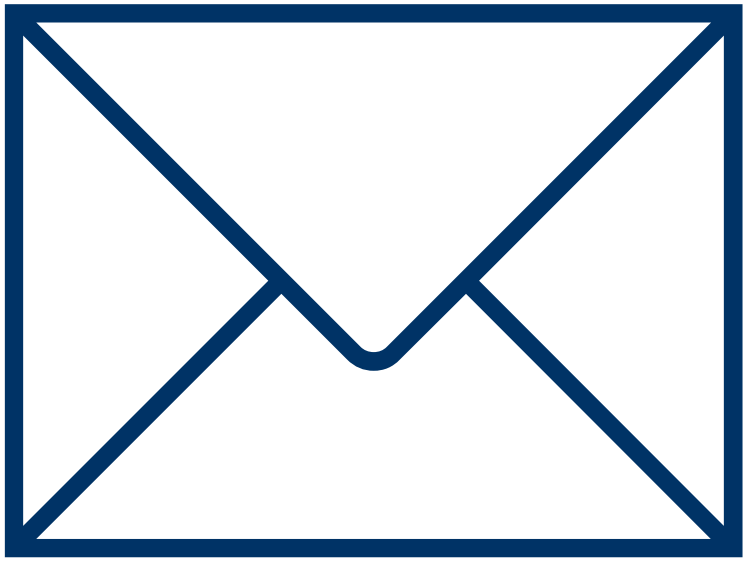
If offline mode doesn't work or participant refuses to use electronic version, complete survey on paper.

Store in 4 separate folders: Survey, Participant Info Form, Consent Form & Receipt Log.

CHIWOS

SURVEYING ON PAPER continued

Each month, all four items (surveys, participant info forms, consent forms, and receipt logs) must be mailed back (or delivered in person) in secure, sealed envelopes to the coordinator's office.



Note: You will be provided with pre-paid envelopes.

Also Note: These items must all be mailed back in separate envelopes.

QUESTIONS?

CHIWOS

SECTION SEVEN:
Safety and Wellbeing

CHIWOS

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

Safety & Wellbeing

CHIWOS aims to ensure that everyone involved with the study

feels safe

and has the

safest work environment

and

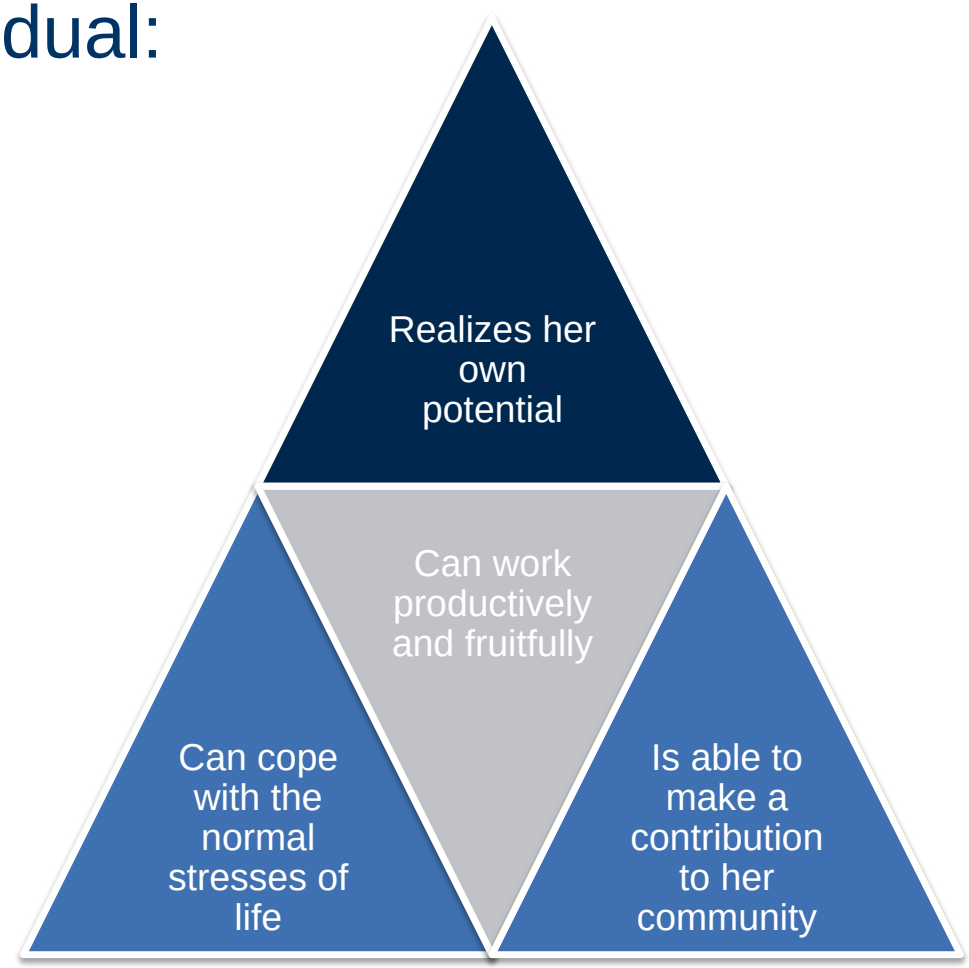
best psychological state possible

while engaged in CHIWOS research activities.

Safety means:

Wellbeing means:

Every individual:



CHIWOS

Safety & Wellbeing of Peer Research Associates

CHIWOS

Communication with RC

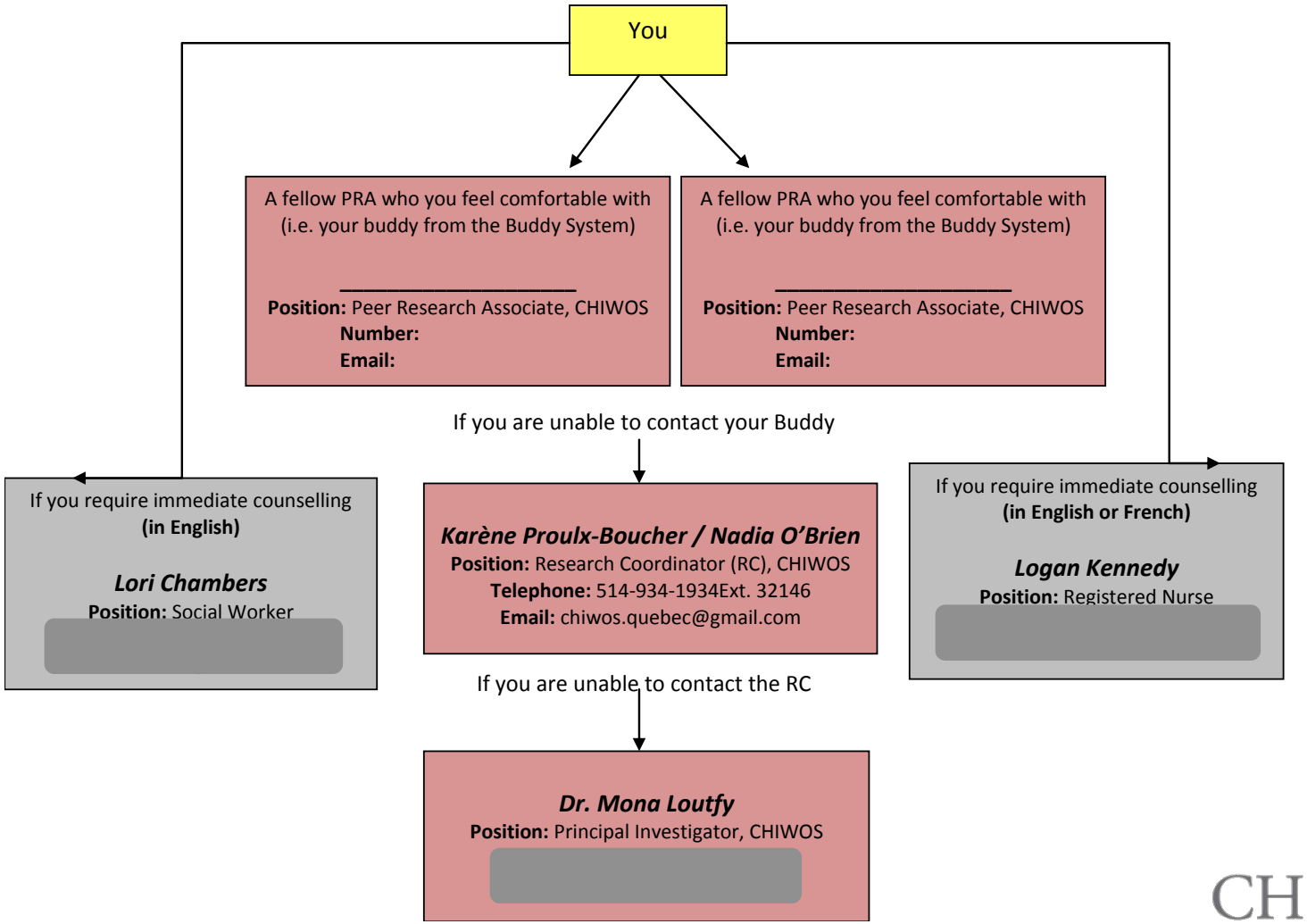
- Monthly check-ins with RC to help ensure PRAs are feeling supported in their work
- Regular team emails
- In-person/phone follow-up conversations as necessary
- All RCs have an open door policy and encourage PRAs to phone or email at any time during regular work hours
- If a more urgent matter occurs PRAs are instructed to contact their RC immediately.

CHIWOS

Buddy System and Phone Tree

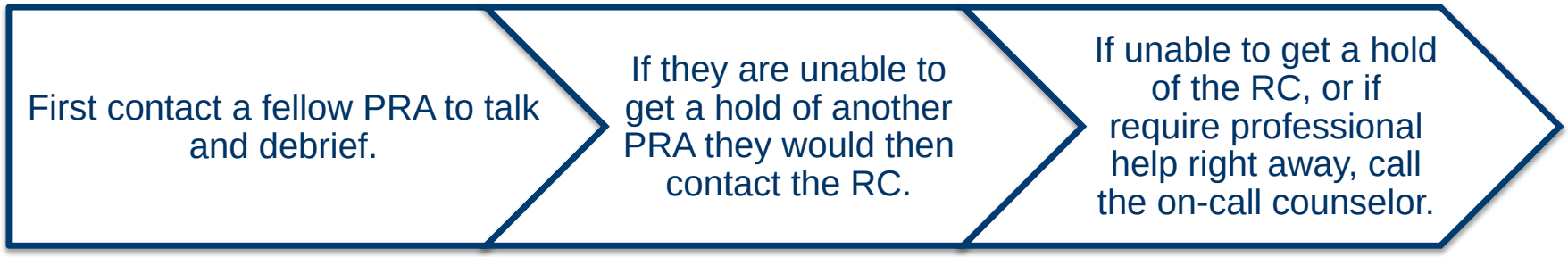
- PRAs will pair up as buddies, AKA peer-supports for one another other.
- A phone tree: a document which identifies a network of people that have been organized in a way to best facilitate rapid dissemination of information.
- Both will be used to ensure PRAs have the psychological support they need before and after conducting an interview.
- If the PRA has been triggered throughout the interview process, they can call a fellow PRA, the RC or the on-call counsellor.

PRA Phone Tree System



Phone Tree Example

If a PRA feels triggered by an interview, they should:



Mental Health Support & Resources

- PRAs will receive a list of counselors and support services in their province who have agreed to see/ speak with PRAs if there is a mental health concern after completing the survey.
- PRAs can contact the RC if they are negatively impacted or triggered by the survey process and need to see a counsellor.
- The RC will connect the PRA with a counsellor in their region or the on-call counsellor who they can speak with up to 7 days after the interview.

CHIWOS

Annual Provincial PRA Meetings

Having an annual in-person meeting with all the PRAs in your province will offer the opportunity for:

- capacity building workshops
- dialogue between PRAs and investigators
- team building
- brainstorming around the future direction of CHIWOS

Appreciation Events

CHIWOS is also planning to host appreciation events in order to support the PRAs and demonstrate appreciation for all of their hard work.

CHIWOS

Interview General Safety Guidelines

- Use the buddy system
- Feel free to cancel or reschedule an interview if you feel unsafe
- Position yourself between the door and the participant so you can have easy access to the exit if required
- Keep the door slightly ajar in order for others to hear if participant becomes loud and/or aggressive
- It is best not to do an interview in a space where you are completely alone with a participant unless you know the participant and feel very safe and comfortable
- Do not leave your belongings (laptop, phone, bag) unattended with the participant

CHIWOS

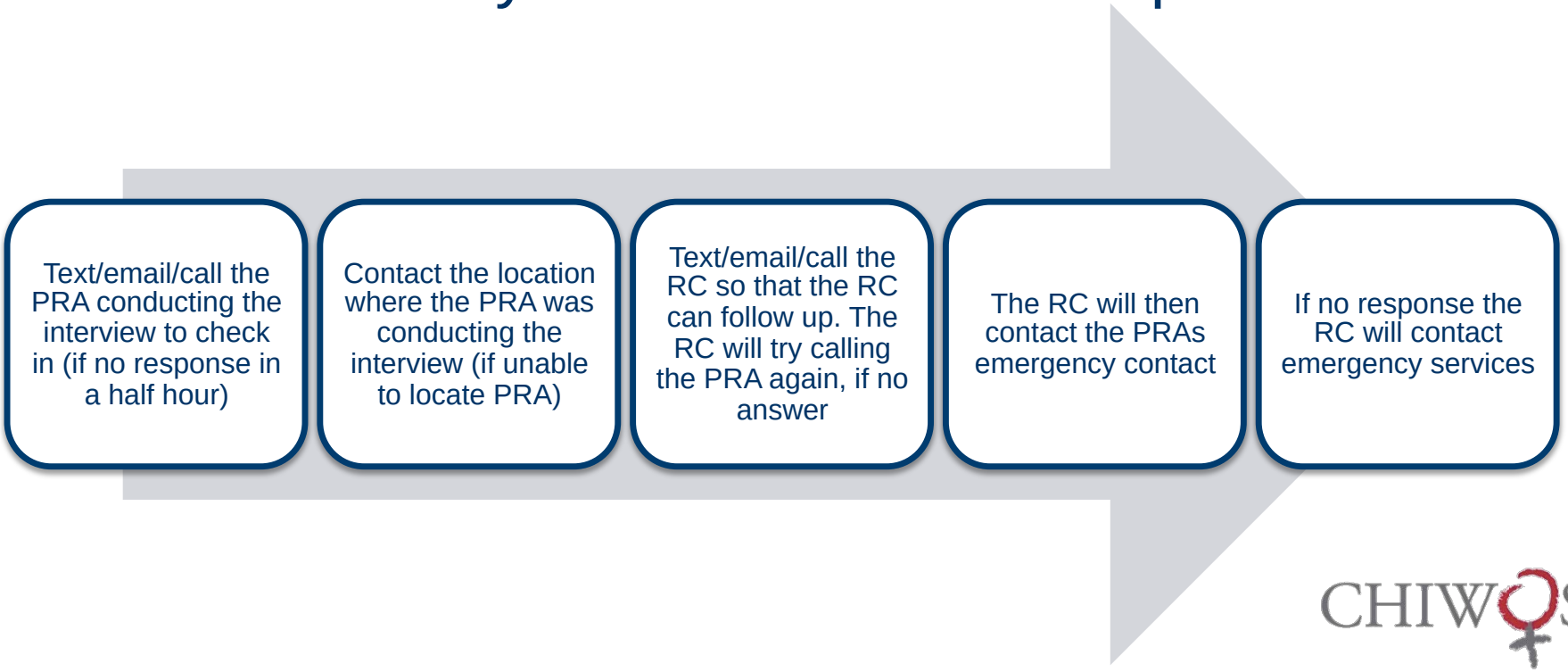
HOME INTERVIEWS

- ✓ At least 24 hours before a HOME interview, PRAs will notify the RC or their buddy to let them know the **date, time, and location's contact details** of their interview and also provide one **emergency contact person**.
- ✓ On the day of the HOME interview, before it begins, the PRA will contact their buddy to let them know they are beginning the interview.
- ✓ Once the HOME interview has been completed the PRA will contact their buddy to say the interview is over and how it went.

CHIWOS

HOME Interview Safety System

If the supporting PRA or RC does not hear back from the interviewing PRA 3 hours after the start of the interview they should follow the steps below:



CHIWOS

Safety & Wellbeing of Participants

CHIWOS

Ethics of Research (review)

- All policies, procedures, guidelines and operations are submitted for approval by REBs
- REBs ensure CHIWOS is being held to the highest ethical standards and that the greatest protection is provided to participants.
- Informed Consent Process
- Confidentiality- storage of data, participant ID
- Transparency- the nature of participation is clear

CHIWOS

Participation is Voluntary

It is important to recognize that participating in the CHIWOS Study is 100% voluntary.

At any time (even after a survey has been started) the participant can decline participation or withdraw from the study.

CHIWOS

Skip Sections or Questions

When completing the questionnaire, participants always have the option to skip sections or refuse to answer any question(s) that makes them feel uncomfortable.

Mental Health Support & Resources

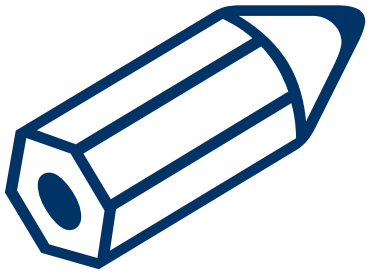
- Participants will receive a list of counsellors and support services in their province who have agreed to see participants if there is a mental health concern during or after completing the survey.
- PRAs can contact the RC immediately if a participant is negatively impacted or triggered by the questions in the survey and extra resources are needed.
- The RC can connect the participant with a counsellor in their region or the counsellor on-call.

CHIWOS

Stategies for Safety & Wellbeing

CHIWOS

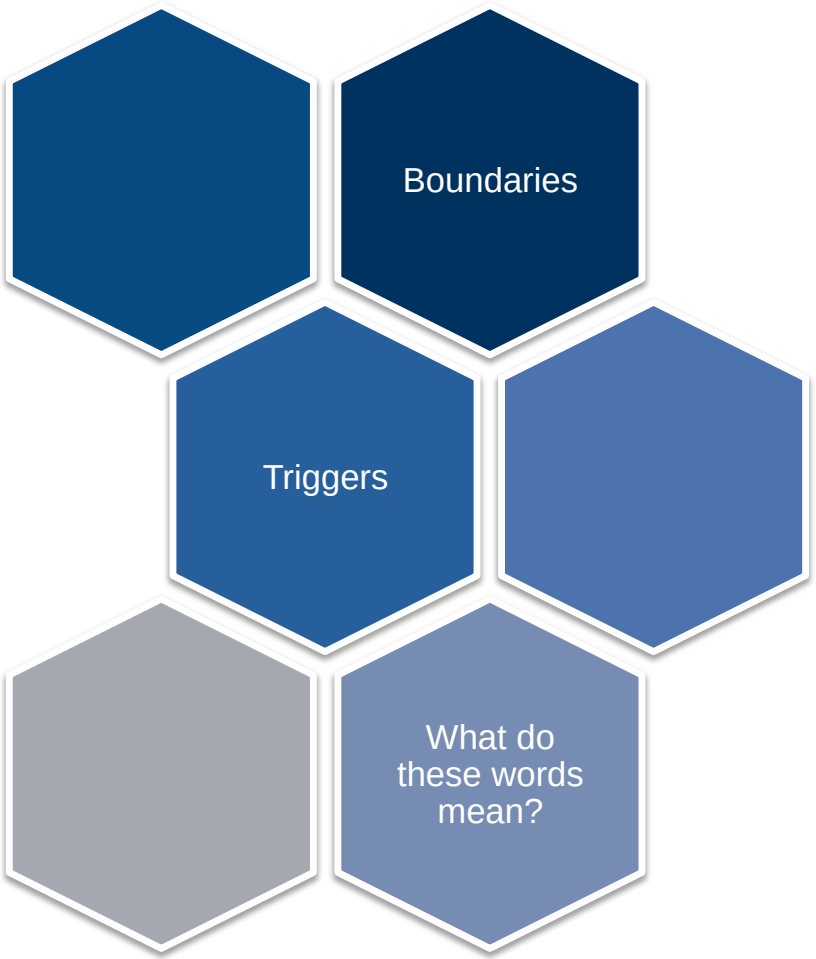
Have a List of Contacts Ready



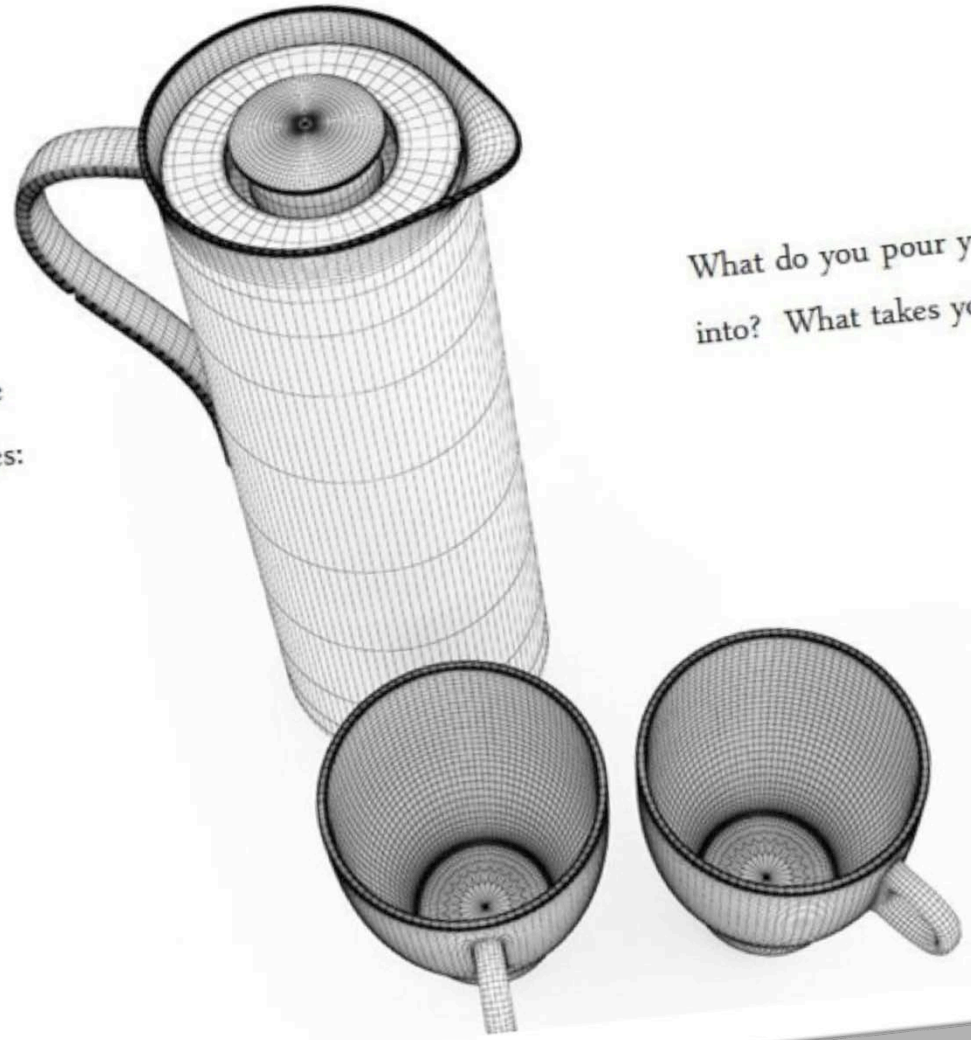
Contact List

- Coordinator:
- 24/7 Emergency Counseling:
- Counseling:
- PRA Buddy:
- Other Self-Care Resources:

Boundaries & Triggers



What fills you up with life and energy? What replinishes you?



What do you pour your energy into? What takes your energy?

My Five Self-Care Strategies:

1)

2)

3)

4)

5)

CHIWOS

CHIWOS National Emergency Contact List

If you find yourself in an emergency situation and you require immediate counselling, use the phone tree below. Contact one of the CHIWOS on- call counsellors (who offer counselling in both English and French) from **8 a.m. to 2 a.m. EST/ 5 a.m. to 11 p.m. PST**. If you are unable to reach them, contact Dr. Mona Loutfy, the CHIWOS Principal Investigator who is **usually** reachable **24 hours a day, 7 days a week**. **If you are in a situation where you, or others are in immediate danger please call 911.**

You

English On-Call Counsellor

Lori Chambers
Position: Social Worker
Telephone: [redacted]
Email: [redacted]

French and English On-Call Counsellor

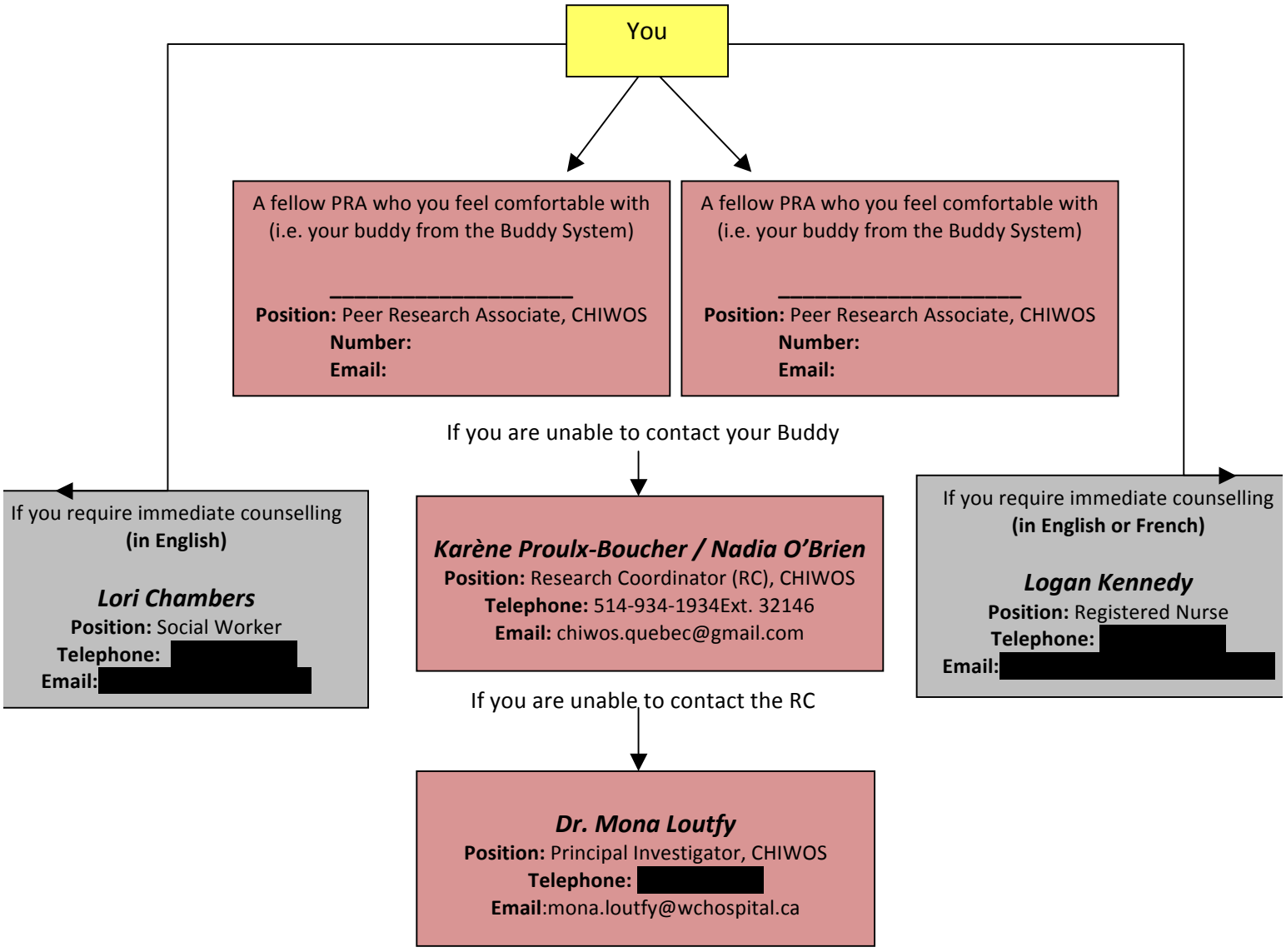
Logan Kennedy
Position: Registered Nurse
Telephone: [redacted]
Email: [redacted]

If you are unable to contact the on-call counsellors

French and English On-Call Physician
Dr. Mona Loutfy
Position: Principal Investigator, CHIWOS
Telephone: [redacted]
Email:mona.loutfy@wchospital.ca

CHIWOS Quebec
Phone Tree

This phone tree is meant to be used if an emergency situation occurs while conducting your duties as a Peer Research Associate. This tool is meant to help stream line information dissemination/collection, ensure the PRA is receiving the support they need, and the situation is being addressed in a timely manner. The primary instance when a phone tree would be useful is if a PRA feels triggered during an interview and needs to debrief. **If you are in a situation where you, or others are in immediate danger please call 911.**



SECTION EIGHT:
Problem solving difficult interviews

CHIWOS

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

CHIWOS

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

GUIDELINES FOR PROBLEM-SOLVING CHALLENGING INTERVIEW SCENARIOS

(Updated May 24th 2013)

INTRODUCTION

This document is intended to provide guidance around approaches for dealing with challenging interview scenarios that the Peer Research Associates (PRAs) and other interviewers may face while conducting interviews with study participants. Please see below for a list of possible scenarios and the CHIWOS policies for dealing with them.

SCENARIOS

SECTION 1: INTERVIEW / DATA-RELATED SCENARIOS

1.0: INTERVIEW/DATA-RELATED SCENARIOS

1.1: HOW TO CARRY OUT CONSENT

You may encounter a participant who would like to read or review the form alone. Or alternatively, you may sit down with a participant who wants you to explain and review it with them. Either scenario is fine. In general, if the participant has no preference, CHIWOS advises the following:

- Share the consent form with the participant and go through each section verbally explaining the details. It is okay to read the form word-for-word or you may prefer to ad-lib (improvise), but be sure to cover each heading: the purpose of the study, procedures, confidentiality, data storage and security, data linkage, the benefits and risks of participation, and contact information.
- Encourage the participant to ask questions throughout.
- After reviewing the entire consent form, give the participant the opportunity to read the consent form alone and encourage them to ask any remaining questions.
- If the participant consents to participate in the study, the participant and interviewer must sign, date, and complete any initial lines or checkboxes that appear on the form.
- Keep the signed copy of the form (it must be safely stored and returned to the Coordinator), and welcome participants to take a copy of the consent form home.

1.2: PARTICIPANT DOES NOT WANT TO READ/LISTEN TO THE FULL CONSENT FORM

You might encounter a participant who does not want to read or listen to the full consent form. Perhaps the participant is a friend and trusts you, or maybe the participant is in a hurry to complete the interview. Whatever the reason, it is important to explain to participants that informed consent is an important and necessary part of the interview process. It involves sharing information and addressing questions and concerns about the study, rather than simply obtaining a signature on a form. Therefore, the consent form must be explained to, or read by the participant prior to starting the survey. While shorter explanations may be provided if the participant wishes, we advise our interviewers to make sure all headings of the consent form have been covered and any questions answered before proceeding.

1.3: PARTICIPANT IS NOT ABLE TO GIVE INFORMED CONSENT

Impairments to reasoning and judgment may make it impossible for someone to give informed consent. A common scenario interviewers may encounter is a participant who is intoxicated (e.g., drunk or high). In these cases, interviewers are advised to not begin the interview. Explain to the participant that the survey questions are quite long and involve a lot of detail that require their full attention. We are also required to have informed consent before an interview starts and intoxication voids the ability to give informed consent. Ask the participant if they'd like to re-schedule the interview at a time when they're able to give informed consent. If the participant is persistent about completing the survey and argues that they are able to give informed consent, emphasize again that this is a legal document, they must understand the study and risks/benefits, and they cannot sign it while under the influence. If becoming

more aggressive and argumentative, move to safety protocols (e.g., Walk to and open door, saying something like: "I'm sorry. I'm going to have to end the interview. Thank you for coming.")

1.4: WHEN TO GIVE PARTICIPANTS THEIR HONORARIUM

The consent form states that participants will be reimbursed $50 upon completion of the survey. Therefore, it is CHIWOS policy to give participants their honorarium at the end of the interview process.

1.5: PARTICIPANT WANTS TO PAUSE OR END THE INTERVIEW

Participation is entirely voluntary and participants may skip questions or stop the interview at any time. If they want to simply pause the interview and complete it at another time, re-schedule the interview for another date and time and inform the participant that they will receive their honorarium upon completion of the survey at the end of the interview process at their next visit. If they want to end the interview altogether, thank them for coming; let me know that their consent form and survey data will be deleted; and encourage them to take the consent form and resource list home and call any of the numbers provided should they have any questions.

1.6: PARTICIPANT HAS CONCERNS/QUESTIONS ABOUT DATA LINKAGE

As part of this study, we plan to link data from the CHIWOS surveys to other provincial health database files. When explaining how data linkage works, it's important to mention the following:

Two different files are linked on the basis of common personal identifiers (e.g., provincial health card number and date of birth). If this information is unavailable, name and other available information may be used. This process is done by one authorized person following strict privacy and security guidelines and agreements. Once two different files that belong to same individual are identified / linked, the files are assigned an anonymous ID and any personal information is never accessed again.

As mentioned in the Voluntary Participation section of the consent form above, participants can choose not to provide their provincial health card number if they do not feel comfortable.

Also, participants may ask why the study wants to make these links, and interviewers should be prepared to explain why it is important. The reason we want to do this linking is because we cannot ask about everything in 2.5 hours. This linkage and data will provide us with extra information which will help us know a lot more and better understand positive women's health.

For more detailed information about data linkage and security, please see the document entitled: "Health Information Linkage and Security for CHIWOS."

1.7: WHAT TO DO IF A PARTICIPANT IS A NEIGHBOUR OR A FRIEND

Imagine you try to organize an interview with a participant who is one of your neighbours or friends. Before you schedule the interview, it is important to let them know that she may share highly personal information about her life during the interview. You may want to use examples here (e.g. number of sexual partner, mental health diagnosis, abortions and miscarriages) to illustrate how personal the

survey gets. It's important that she knows she has the option to complete the survey with you, or we can connect her with another interviewer. Ask her what she prefers. If she decides to complete the survey with you, then you may want to begin the interview a little differently than you normally would. For example, you might want to acknowledge your friendship with her and let her know that today you're wearing the hat of "interviewer". Everything that is said between the two of you will remain confidential and you will not discuss anything with her or others (e.g., mutual friends) outside this interview. Say, during the interview, she does share new highly sensitive information that you didn't know about before, how you react may depend on your relationship with this person, what / how information is being shared, and her response/mood. You'll have to be observant and use your judgment to decide how to respond. In general though, we'd encourage you to remember that you're wearing the hat of "interviewer" – this means remaining neutral and non-judgmental (e.g., not reacting with shock if you learn something new) and re-affirming confidentiality of any information that she shares. Also, please remember to never bring the topic up again with her – either during or outside the interview – unless your friend brings it up and wants to talk to you about it.

1.8: PARTICIPANT WANTS SOMEONE ELSE PRESENT DURING THEIR INTERVIEW

You might encounter a participant who wants someone else to be present while filling out the survey. Perhaps they have a young child and need to bring them to their visit, maybe English/French is not their first language and they'd like their friend present to help translate, or perhaps they want a partner or other family member present for support. However, given the nature of the survey and our commitment to confidentiality and safety of participants and PRAs, it is CHIWOS policy to strive to do the interview 1-on-1. In cases where a participant requests that someone else be present:

Before scheduling or beginning the interview, let the participant know about the nature of the survey. Inform them about its length (2 hours) and the personal and sensitive topics to be covered (e.g., demographics, sexual health, reproductive, mental health, violence). Because of this, we would prefer to do the interview 1-on-1. Then we suggest the following steps depending on the companion involved:

- If it's a child: Try rescheduling the interview for a better date/time.

- If it's a support person: Suggest that the person be close by but not in the interview room (e.g., in a chair outside the office).

- If it's a person there to help with translation: You can allow this person into the room, but care must be taken.

After this initial discussion, if you and the participant are both comfortable with their companion being present, then it's okay to proceed with the interview. However, for any person that you do allow to stay in the room, be sure to take the following precautions during the consent and throughout the survey:

- Remind participants that this companion will hear the stories shared.
- Tell them that unless you are told otherwise, you will assume that their companions may hear the discussion.
- Inform them that they do not have to answer any questions that may make them feel uncomfortable and they can pause or stop the interview (and res-schedule) at any time.

- Introduce each section in advance (e.g., "Now, we're moving onto to questions that deal with emotional health") so that they have an opportunity to proceed as normal or to ask their companion to leave the room.
- Take extra precaution with the information that you decide to self-disclose.
- If at any time, you feel uncomfortable or unsafe, stop the interview and re-schedule.

1.9: PARTICIPANT IS PROVIDING FALSE OR CONTRADICTORY RESPONSES TO THE SURVEY

Imagine, in an interview, a participant shares information that you know or highly suspect is untrue. Perhaps the participant says they haven't had a smoke in the last month, but you think you smell cigarettes on their breath. Your response may depend on whether the participant is a close friend or an acquaintance/stranger. However, in general, as an interviewer, it is important to remain neutral, maintain trust and rapport, and not question or confront people about their responses. All you should do is say things throughout the process to help them feel comfortable and confident in sharing accurate information (e.g., "everything you say will remain confidential", "you don't have to answer anything that makes you feel uncomfortable", "think carefully about the response options and choose the one that you think is most accurate", etc).

Imagine a participant provides responses to the survey that are contradictory. For example, when asked "do you use condoms?", they say "all the time", but when asked "if they used a condom the most recent time they engaged in sex", they said "no". What would you do? The first thing to know is that we have programmed the survey to detect *some* of these contradictory responses (mostly questions pertaining to dates) – so, if this happens, an error message might pop up indicating that their answer to these two questions must be similar. However, it was impossible to program all contradictory responses. So if you think two responses might contradict and no error message has popped up, it's okay to double-check with the participant that they have selected the right answer. For example, you could say: "I think you mentioned on the last question that you use condoms "all the time", and in your most recent sexual encounter you said "no". Do you want to take a moment to think about your responses to be sure you're selecting the response options that you think are most accurate?"

1.10: PARTICIPANT ASKS INTERVIEWER FOR THEIR OPINION

What if the participant asks you if their response is "right" or if they answered "correctly"? Or what if the participant asks you what their opinion is of one of their responses? What might you do? As an interviewer, your job is to capture the participant's stories/perspectives, not your own, and to remain neutral to what is being shared. Therefore, we'd advise you to NOT say whether their response is "right" and to NOT provide your opinion. Maybe you can say: "There is no right or wrong answer. My opinion doesn't matter. What matters is that you've thought carefully about the response options and chosen the one that you think is most accurately tells your story. Shall we read the question again?"

1.11: PARTICIPANT CHANGES MIND ABOUT SHARING INFO AFTER COMPLETING SURVEY

Imagine the participant consents to participate in the study. They provide you with their personal contact information and they complete the survey. Afterwards, they change their mind about participating and sharing all this information and they want to withdraw from the study. Also perhaps they told you this right away or maybe after they left the site. In either case, let them know that that is okay – they are free to withdraw from the study at anytime. Then, tell them that you will follow-up with

the coordinator to inform them of the situation and the coordinator will destroy (e.g., delete or shred) all study materials on file for this participant. If the participant did complete the survey (even if she doesn't want it to be shared), you should still give the participant her honorarium.

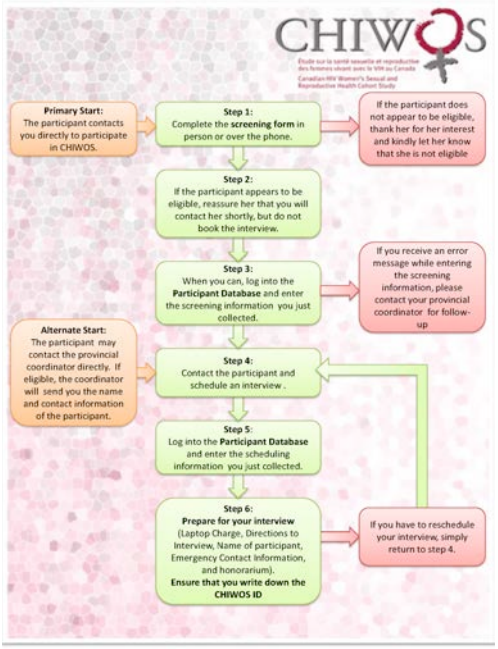
1.12: PARTICIPANT IS USING SLANG DRUG TERMS AND YOU DON'T KNOW THEIR MEANING

A participant may use slang drug terms during the "substance use" section of the survey. We anticipated that and included those slang terms in the survey. Below is the list of drugs that appears in the survey, with slang terms in brackets. If they use another term that's not listed, simply ask them: "Is there another name for that?" or "Do you see that drug on this list?".

Heroin (dust, horse, junk, down, or downtown)	Morphine
Heroin + Cocaine (speedballs)	Talwin & Ritalin ("T's & R's")
Cocaine alone (non-injected) (uptown, up)	T3s T4s (codeine)
Crack	Ecstasy (x-tasy, E, X)
Methamphetamine (crystal meth, ice, jib, gak)	MDA
Benzodiazepines	Speed (amphetamines, uppers)
Dilaudid (hydromorphone hydrochloride)	Acid (LSD, PCP, angel dust)
Oxycontin/Oxycodone	Mushrooms (magic mushrooms, mush)
Methadone	

1.13: YOU SUSPECT PARTICIPANT HAS ALREADY COMPLETED SURVEY

We have developed a series of steps that must be completed prior to scheduling an interview (see picture of flow-cart below). In step 3, you may discover that the participant is already in our database – in this case, contact the Coordinator who will follow-up with the participant. If they give a false name and thus do not appear to be in the database, but you still suspect they may have completed the survey, still do the interview. Afterwards, let the Coordinator know so that they can flag this interview for data-quality checks.



1.14: PARTICIPANT WANTS TO COMPLETE THE SURVEY BUT NOT WITH A PRA

Given our commitment to CBR and GIPA principles, we plan to prioritize having the PRA administer the survey. However, we recognize that this approach may not always be possible. For example, there may be women who do not want to be interviewed by a peer. In these cases, we can offer the participant an alternative (e.g., they can complete the survey with the Coordinator). However, the survey is NOT to be self-administered for data quality reasons.

1.15: PARTICIPANT HAS LANGUAGE / COMPREHENSION ISSUES

There may be cases where English/French is not the participant`s first language or they have reading / comprehension issues. CHIWOS is committed to including women who have diverse backgrounds and who may be marginalized from research. Thus, we welcome their inclusion and suggest the following strategies to support them in the interview process:

- Consider scheduling the interview when you have more time available (the survey may take longer if the participant has language/comprehension issues)
- Check to see if there is a translator at the clinic or organization where you are based who may be able to assist
- Ask the participant if they have a family member or friend who speaks both their native language and English or French and may be willing to attend the interview for translation support

1.16: PARTICIPANT IS DOING A LOT OF STORY-TELLING OR ASKING A LOT OF QUESTIONS

You'll find the interview process is more than just sitting down and asking survey questions. It can actually feel like a conversation between two people, where stories are told and information shared. While it is important to allow for this type of conversation to happen, it is also important to be aware of your own time and that of the participants. You'll have to use your discretion for when to stop and chat,

and when to move on. It'll be a bit of a balancing act or dance. If participant is sharing a lot of stories and you're concerned about time, you might say "I really want to hear this story. But I'm just conscious of time and that we have a few more questions to get through. How about we chat more at the end of the interview if there's still time?" Or alternatively, if the participant is asking a lot of questions or their seeking more information on one of the topics covered (e.g., pap tests), you might be able to answer some quick questions on the spot, but you can also remind the participant that you can discuss this at the end of the interview and provide the appropriate referrals for her questions.

SECTION 2: SAFETY-RELATED SCENARIOS

2.0: SAFETY-RELATED SCENARIOS

2.1: THE PARTICIPANT IS LOOKING AROUND FOR THINGS TO STEAL

It's best to do all that you can to prevent theft from happening in the first place. Here are some tips to help minimize the chances:

- **Leave valuables at home.** Keep expensive items—especially those with nostalgic value that you can't replace—at home. Also, keep a slim wallet, taking only the items you need and leaving items, such as your Social Security card, at home.
- **Take only what you need.** Refer to the checklist of what you need to bring with you (e.g., computer and power cord, pen and paper, etc). Only take those items that you need and leave everything else at home.
- **Keep the desk/office clean and clear:** Put or lock away everything you don't need. Store things in a desk drawer or put items in a locker, so that they are out-of-sight and hopefully out-of-mind.
- **Don't leave items unattended.** You might spend plenty of time at the interview office and might be tempted to leave your belongings unattended at times. Resist the urge. If you look away or leave your desk/office without locking the door, a participant or a stranger walking by might nab your purse, phone, cash honoraria study computer, or anything else of value. Keep things on you at all times. Maybe even keep the cash honorarium in your pocket.
- **Keep study materials and documents in a safe place.** Consent forms, cash honoraria, receipt logs, computers and any other study materials/documents should be stored in a safe place, such as a locked drawer.
- **Be careful about online information.** Make sure to create strong passwords for your computer and accounts, and do not share these passwords with anyone else. If you need to access personal accounts such as email on the study computer, you must log in to the 'Guest' account (do NOT use the CHIWOS account for personal use). Also, a participant may ask to use your computer for a minute to look something up – this is NOT allowed, as the computer contains confidential information.

If something is stolen, don't panic! The most important thing is your safety! If the theft is major (e.g., computer stolen): (1) stay calm, (2) inform on-site security and Executive Director of the organization (3) phone the police, and lastly (4) call the coordinator to let them know what happened.

2.2: PARTICIPANT IS DRUNK OR HIGH

There are several different signs/signals that may suggest that a participant is high and they vary depending on the type of drug used. In general, here are some signs / signals that someone may be drunk:

- Lower inhibitions/caution
- Lowered reasoning ability
- Staggering walk or inability to walk / Weakened balance
- Slurred speech; too-loud or too-fast speech
- Glossy appearance to eyes
- Slower reaction times
- Slower pupil response. After more drinks: pupils constricted.
- Nausea and vomiting
- Loss of consciousness
- Smell of alcohol on the person

There are several different signs/signals that may suggest that a participant is high and they vary depending on the type of drug used. In general, here are some signs / signals that someone may be high:

- Lowered ability to focus on the conversation/pay attention
- Picking on their skin (e.g., looking for bugs/worms)
- Nodding off (→ methadone or heroin)
- Pupils dilated
- Perfusely sweating (-> jib)
- Uncontrollable actions (all over the place)
- Wild look in their eyes / can't keep their eyes focused

Please note, sometimes these symptoms can be actually be sign of a health issue (week, fainting, on medication), so it is important not to judge. Ask the person if they are OK, or if they need help.

If you notice that a participant is drunk or high at the start of the interview during the consent process, do not begin the interview. Explain to the participant that the survey questions are quite sensitive / personal and may even be triggering, so it is important that the participant fully understands what they're signing up for. If they're drunk or high, their reasoning and judgment is likely impaired, making it impossible for them to give informed consent. Ask the participant if they'd like to re-schedule the interview at a time when they're able to give consent.

What if you consent the participant and start the survey, and only notice that they are drunk or high half way into the interview process? You will have to use your discretion. Every situation can be different. Sometimes it's okay – e.g., only mildly impaired so can keep going. But if it's a data quality issue, for whatever reason (including distracted or sleepy because of methadone), then it would be best to take a break, or end and re-schedule the interview. This is the preferred strategy but will depend on the situation (e.g., participant may resolutely deny being under the influence and insist that the interview be completed at the current sitting). Move to safety protocols (e.g., Walk to and open door, saying "I'm sorry. I'm going to have to end the interview.").

2.3: PARTICIPANT IS ANGRY AND YELLING AT YOU

If a participant is angry or yelling at you, your response may vary depending on the situation (e.g., is this a stranger or a friend? If they are the clearly aggressive and hostile or they are upset and unaware that they're yelling?). If this happens, here's some advice to help you navigate the situation:

- **Open door** – may diffuse situation because people will hear
- **Recognize their feelings and try to diffuse things**: For example, try saying: "I'm sorry, it seems like something has really triggered you hear. Do you want to take a break?
- **(If they persist….) Ask them to stop:** If someone is yelling they might be so upset they are unaware of what they're doing. Asking them to stop not only lets them know you wish them to stop, but it also alerts them to their own behavior.
- **(If they don't stop or calm down) Ask them to leave:** Walk to the door, open it, and speak loudly "I'm sorry. This is not a good time. We're going to have to end the interview. I'd like you to leave now" so that others in the office can hear.
- **Walk/run away:** If they refuse to leave, walk away yourself. In order to be able to do this, you should always try to position yourself closest to the door.
- Call 9-1-1
- Get help from someone in the clinic (e.g., security, support worker, Executive Director)
- Contact the Coordinator and your CHIWOS buddy ASAP to report the incident and debrief.
- Call the 24/7 CHIWOS counselor for further debriefing if necessary (# TBD).
- Remember: Your personal safety is ALWAYS more important than an interview, laptop, or $50.

2.4: PARTICIPANT IS GETTING PHYSICALLY AGGRESSIVE

If anger and yelling turns to physically aggressive behavior, here's what you can do about it:

- Respond quickly
- Walk/run away
- Scream for help
- Call 9-1-1
- Get help from someone in the clinic (e.g., security, support worker, Executive Director)
- Contact the Coordinator and your CHIWOS buddy ASAP to report the incident and debrief.
- Call the 24/7 CHIWOS counselor for further debriefing if necessary (# TBD).
- Remember: Your personal safety is ALWAYS more important than an interview, laptop, or $50.

2.5: PARTICIPANT IS TRIGGERED/UPSET AND STARTS CRYING

Imagine the following scenario. You are interviewing a participant who becomes emotionally triggered by one of the survey questions and begins to cry. How might you handle the situation? The answer is: it depends. Every participant may deal with sadness differently depending on their culture, values, self care practices, inner being, etc. Ask them what they need. Maybe they need a tissue, a hug, or a break. Perhaps they would like to cry it out with no interruptions, or maybe enjoy some laughter/jokes to take their mind off of it. Maybe they'd like to pause the interview and re-schedule it for another day, or maybe they want to try and plow through it. Try to be observant and tailor your response depending the person and situation. Also, be sure to spend some time at the end of the interview debriefing / checking

in, and provide them the resource list so they know who to call if they want to debrief further. Also remind them that they can call the on call counsellor at any point of time a week after the appointment if they need someone to talk to right away. Bring tissues with you to each interview.

Note: For women of Aboriginal ancestry: Valerie advises to not touch or hug them, unless they initiate it. Also, let them cry it out with no interruptions (this is a part of the recovery/healing process). When they have finished crying / talking, ask them if they need anything.

2.6: YOU, THE INTERVIEWER, ARE TRIGGERED/UPSET AND STARTS CRYING

Now, imagine you are interviewing a participant and you are the one who becomes emotionally triggered and begins to cry. How might you handle this situation? Again, it may depend on the situation and your own coping strategies. Feel free to ask if they don't mind if you take a break. If you feel like you need to re-schedule, that's okay too. Afterwards, be sure to follow-up with a peer, coordinator or other person for debriefing and support. You can also call the on call counsellor at any point in time if you need to talk.

2.7: YOU AND/OR THE PARTICIPANT ARE VERY TIRED

If you and/or the participant are feeling very tired, consider taking a break. A good stretch, fresh air, or a beverage (e.g., coffee, tea or water) might help. If the interview has been particularly long and draining, discuss re-scheduling for another day.

2.8: PARTICIPANT MAKES YOU FEEL UNCOMFORTABLE WITH ADVANCES/COMMENTS

If the participant hits on you or makes you feel uncomfortable with certain advances or comments, here's some suggestions about what you can do about it:

- Let them know that you feel uncomfortable
- Ask the them to stop
- End the interview and ask them to leave
- Get help from someone in the clinic (e.g., security, support worker, Executive Director)
- Contact the Coordinator and your CHIWOS buddy ASAP to report the incident and debrief.
- Call the 24/7 CHIWOS counselor for further debriefing if necessary (# TBD).
- Remember: Your personal safety is ALWAYS more important than an interview, laptop, or $50.

1. The participant is looking around for things to steal out of your meeting space.

2. The participant is drunk or high.

3. The participant is angry and yelling at you.

4. The participant starts crying.

5. You, the PRA, have a huge wave of emotion and you feel really upset during the survey.

6. The participant is using slang terms to talk about drug-use and you don't know what they mean.

7. The participant is getting physically aggressive.

8.The participant is very tired.

9.The participant is using language that is discriminatory.

10. The participant is rushing you and wants to speed up the process.

11. The participant is providing responses to the survey that are contradictory.

12. The participant has brought their child with them and is very distracted with caring for their kid.

SECTION NINE:
Confidentiality and data linkage

CHIWOS

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

UNDERSTANDING DATA LINKAGE

CHIWOS
Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada
Canadian HIV Women's Sexual and Reproductive Health Cohort Study

What is data linkage?

Linkage allows information on an individual from one data source (e.g., CHIWOS survey) to be linked to information on the same individual from another data source (e.g., cancer registries, mortality data, etc).

Why is it important?

Using the linked data makes it possible to gain a more comprehensive understanding the health of women living with HIV in Canada than could be obtained from either data source individually.

How does it work?

Personal information (such as name, date of birth and health care number) is used to link records belonging to the same individual across files, following strict guidelines and within a high-security environment .

How is my privacy and security protected?

Data linkage is done following strict guidelines and within a high-security environment. As personal information, such as name, dates of birth, and health care numbers may be used in linkages, a number of precautions are taken to maximize privacy and security:

- Personal information and survey data are stored in completely **separate** and **password-protected** databases
- All information is stored in a **highly secure space** accessible only to authorized personnel at the BC Centre for Excellence in HIV/AIDS
- Personal information is used **only** for (1) contacting you to arrange you next study visit and (2) making data linkages
- **Only one** authorized person (the Provincial Coordinator) has access to your personal info to arrange your next study visit
- **Only one** authorized person (the Data Analyst) has access to your personal info to make data linkages
- Data personnel work on terminals which have no direct connection to the outside world. This space is **separated and secured both physically and electronically**.
- All research and data personnel have undergone **privacy and information security training** and have signed **confidentiality agreements**.
- When data is released to researchers for approved research projects, investigators will only have access to **anonymous** survey data
- Survey data is summarized in publications and reports for groups ≥ 6 at all times to maximize security

Source: Population Data BC (PopData), http://www.popdata.bc.ca/datalinkage/overview

UNDERSTANDING DATA LINKAGE

Step One:

Data analyst finds a link (or a match) between <u>personal</u> data files, and assigns an anonymous linkage ID to this person

Step Two:

Data analyst applies linkage ID across all files, so anonymous <u>survey</u> data sets can be linked without ever accessing personal info again

Cancer ID	Last name	First name	DOB	Care #	Linkage ID
CANCER1	**Carter**	**Allison**	**12-03-85**	**561729102**	**LK123**
CANCER2	Bogue	Jessica	12-10-50	999871627	
etc					

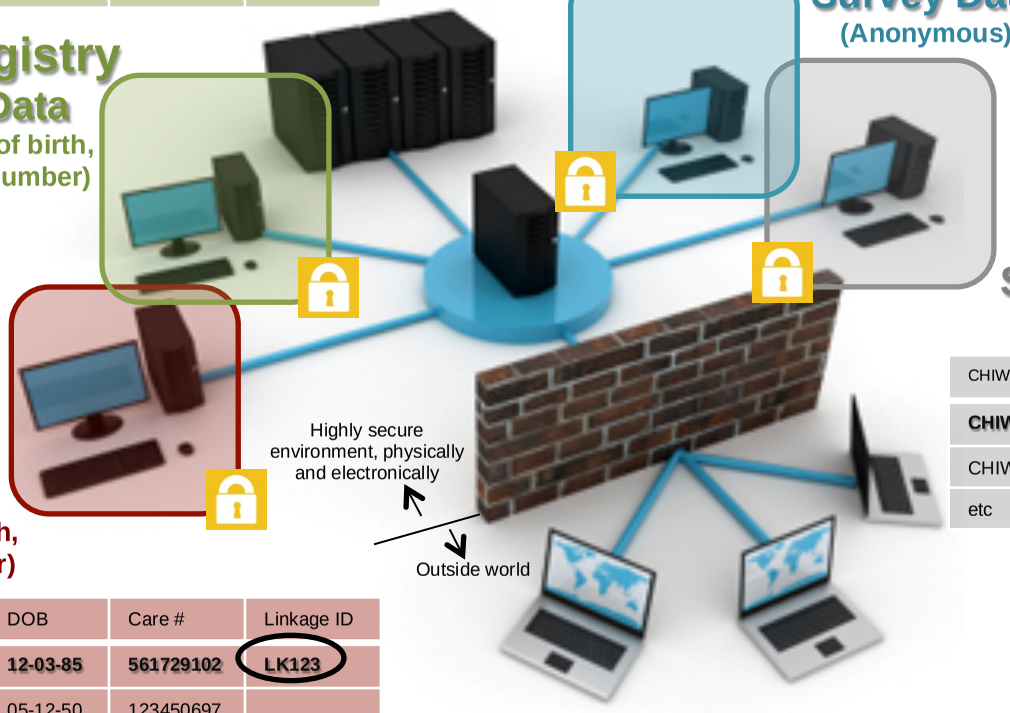
Cancer ID	Q1	Q2	Linkage ID
CANCER1	**Yes**	**No**	**LK123**
CANCER2	Yes	No	
etc			

Cancer Registry
Personal Data
(e.g., name, date of birth, and health care number)

Cancer Registry
Survey Data
(Anonymous)

Files linked!

Files linked!



CHIWOS
Survey Data
(Anonymous)

CHIWOS ID	Q1	Q2	Linkage ID
CHIWOS1	**Yes**	**No**	**LK123**
CHIWOS2	Yes	No	
etc			

CHIWOS
Personal Data
(e.g., name, date of birth, and health care number)

CHIWOS ID	Last name	First name	DOB	Care #	Linkage ID
CHIWOS1	**Carter**	**Allison**	**12-03-85**	**561729102**	**LK123**
CHIWOS2	Jane	Mary	05-12-50	123450697	
etc					

CHIWOS
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Health Information Linkage and Security for CHIWOS

Why is linking to provincial and national health database files important?

As you have read in the consent form, as part of this study, we plan to link data from the CHIWOS surveys to provincial and national health database files. The reason this is important is because the CHIWOS survey data captures very good data on personal information, psychosocial issues and access to health care but does not capture any blood work data. The provincial and national health database files have accurate blood work data, visit information as well as information on hospitalizations and diagnoses. By merging these two types of databases, we can answer health research questions very accurately. For example, we can identify if women living with HIV have depression, have less children, immigration issues and/or have more hospitalizations.

Another reason we want to do this linking is because we cannot ask about everything in 2.5 hours. This linkage and data will provide us with extra information which will help us know a lot more and better understand positive women's health.

How does the linkage work?

At the beginning of the CHIWOS survey, we asked you for your provincial health card number. By using this number, we can identify you in the provincial and national health databases. If you do not want to provide your provincial health card number, or if you do not have one because you are a Federal Refugee, we can still find your information in the provincial and national health databases by using information such as your date of birth, first name, second name, last name, and postal code.

This kind of research is carried out by the provinces routinely to assess the quality of healthcare in each province. For this reason, excellent PRIVACY policies have been developed and are followed. For that reason, the linkage is done by only **ONE** authorized member of the study team (the Data Analyst) following strict guidelines and within a high-security environment.

The Data Analyst creates a non-identifying, unique LINKAGE ID that is assigned across all files so that data sets can be linked. Once this linkage is done, no one has access to your personal identifying information ever again. In fact, there will be no database with your personal information, CHIWOS study data and provincial and national health databases data in one. This is because, **ONLY** the CHIWOS provincial Research Coordinator will access to your personal information such as your name and contact information.

What does this linkage mean to your privacy and confidentiality?

Privacy and confidentiality are considered of utmost importance in healthcare and in research. Again, the provincial and national health databases are used routinely by the provinces to assess the quality of healthcare in each province. The provinces have developed excellent and detailed PRIVACY policies for the use of these databases.

For example, for the Institute for Clinical Evaluative Sciences (ICES) in Ontario, health card numbers are scrambled and converted into unique identifiers that make it impossible to identify a specific individual in provincial health care databases. Any identifying information is stripped away, leaving a number that is anonymous. This information is stored in a locked facility with tracked key access that is accessible to only one authorized person. In addition, access to offices with locked filing cabinets is restricted to certain staff room that only one authorized person has access to, and technological measures are in place to ensure that this data is not accessible to individuals outside of the ICES, where Ontario's provincial healthcare data is stored.

Additional measures to protect security include complex passwords, regular assessments of privacy protection software and measures both internally and by third party security review and local area and secured network audits. Only **ONE** authorized person at each provincial health database has the linkage information. Also, every single researcher and staff has to fill out and sign a privacy agreement every year, with immediate dismissal as a consequence of any breach of confidentiality.

In terms of linking the CHIWOS data, only one Data Analyst creates a non-identifying, unique LINKAGE ID that is assigned across all files so that data sets can be linked. Once this linkage is done, no one has access to your personal identifying information ever again.

Again, there will be no database with your personal information, CHIWOS study data and provincial and national health databases data in one. This is because ONLY the CHIWOS provincial Research Coordinator (and the Peer Research Associate that you are in contact with) will have access to your personal information such as your name and contact information.

Again, study investigators will not have access to any of your personal information they will only have access to anonymous data, stripped of personal identifying information. This is important as the investigators will be doing analysis but the analysis will only be presented in aggregate, or being summarized per group (i.e. average age of all 350 women living in BC, 350 women living in Quebec and 550 women living in Ontario). By summarizing data for an entire group, no data can be extracted for an individual. Another way this protection of privacy is guaranteed is by never summarizing data for a group < 6 in size.

SECTION TEN:
Interview practice: consent form, survey, and online platform

CHIWOS

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Canadian HIV Women's Sexual and Reproductive Health Cohort Study

CHIWOS

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

Primary Start:
The participant contacts you directly to participate in CHIWOS.

Step 1:
Complete the **screening form** in person or over the phone.

If the participant does not appear to be eligible, thank her for her interest and kindly let her know that she is not eligible

Step 2:
If the participant appears to be eligible, reassure her that you will contact her shortly, but do not book the interview.

Step 3:
When you can, log into the **Participant Database** and enter the screening information you just collected.

If you receive an error message while entering the screening information, please contact your provincial coordinator for follow-up

Alternate Start:
The participant may contact the provincial coordinator directly. If eligible, the coordinator will send you the name and contact information of the participant.

Step 4:
Contact the participant and schedule an interview .

Step 5:
Log into the **Participant Database** and enter the scheduling information you just collected.

Step 6:
Prepare for your interview
(Laptop Charge, Directions to Interview, Name of participant, Emergency Contact Information, and honorarium).
Ensure that you write down the CHIWOS ID

If you have to reschedule your interview, simply return to step 4.

CHIWOS

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

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Interview Start
You have arrived at to your interview

Step 1
Conduct pre-interview warm-up

Step 2
Initiate consent process, respond to questions, and obtain written consent

If the participant does not provide written consent, thank her for meeting with you and conclude the interview

Contact your provincial coordinator for further instructions

Step 3
Set-up your laptop and connect to the internet.

Step 4 (Internet)

a.After connecting to the internet, log into the **Participant Database** and verify the information from the screening form
b.Take note of the **Fluid Survey Passcode** and the **CHIWOS ID** provided by the **Participant Database**
c.Log into **Fluid Surveys** using the **Fluid Survey Passcode** and click 'next'
d.When prompted, carefully type the **CHIWOS ID** twice, enter the participant's Date of Birth, and click 'next'
e.Complete the survey
f.Conduct post-interview cool-down

Step 4 (No Internet)

a.Complete a paper copy of the participant database
b.Open the program called 'CHIWOS OFFLINE'
c.When prompted, carefully type the CHIWOS ID twice, enter the participant's Date of Birth, and click 'next'
d.Complete the survey
e.Conduct post-interview cool-down
f.Return home and log into the internet
g.Upload the survey

Laptop Problems?
You may have to conduct the interview using a paper copy

Pre-Interview Warm-up

- ❑ Check in with another CHIWOS staff
- ❑ Greet the participant
- ❑ Introduce yourself
- ❑ Honor and give thanks to the participant for coming
- ❑ Introduce the survey
- ❑ Talk about washroom and smoking breaks
- ❑ Comfort the participant, including security, confidentiality, and how it is normal for stuff to come up

Post-Interview Cool-down

- ❑ Honor and give thanks to the participant for completing the survey
- ❑ Provide honorarium
- ❑ Inform participant about next steps
- ❑ Address stresses, self-care, safe coping
- ❑ Provide resource list and make referrals to further resources, as appropriate
- ❑ End session
- ❑ Check out with another CHIWOS staff

Step 7:
Log into the **Participant Database**, verify the scheduling information, and mark this interview as complete

ADDITIONAL RESSOURCES

CHIWOS

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

Carter AJ et al. *Journal of the International AIDS Society* 2013, **16**:17433
http://www.jiasociety.org/index.php/jias/article/view/17433 | http://dx.doi.org/10.7448/IAS.16.1.17433

JIAS Journal of the International AIDS Society

Review article

Women-specific HIV/AIDS services: identifying and defining the components of holistic service delivery for women living with HIV/AIDS

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Abstract

Introduction: The increasing proportion of women living with HIV has evoked calls for tailored services that respond to women's specific needs. The objective of this investigation was to explore the concept of women-specific HIV/AIDS services to identify and define what key elements underlie this approach to care.

Methods: A comprehensive review was conducted using online databases (CSA Social Service Abstracts, OvidSP, Proquest, Psycinfo, PubMed, CINAHL), augmented with a search for grey literature. In total, 84 articles were retrieved and 30 were included for a full review. Of these 30, 15 were specific to HIV/AIDS, 11 for mental health and addictions and four stemmed from other disciplines.

Results and discussion: The review demonstrated the absence of a consensual definition of women-specific HIV/AIDS services in the literature. We distilled this concept into its defining features and 12 additional dimensions (1) creating an atmosphere of safety, respect and acceptance; (2) facilitating communication and interaction among peers; (3) involving women in the planning, delivery and evaluation of services; (4) providing self-determination opportunities; (5) providing tailored programming for women; (6) facilitating meaningful access to care through the provision of social and supportive services; (7) facilitating access to women-specific and culturally sensitive information; (8) considering family as the unit of intervention; (9) providing multidisciplinary integration and coordination of a comprehensive array of services; (10) meeting women ''where they are''; (11) providing gender-, culture- and HIV-sensitive training to health and social care providers; and (12) conducting gendered HIV/AIDS research.

Conclusions: This review highlights that the concept of women-specific HIV/AIDS services is a complex and multidimensional one that has been shaped by diverse theoretical perspectives. Further research is needed to better understand this emerging concept and ultimately assess the effectiveness of women-specific services on HIV-positive women's health outcomes.

Keywords: HIV; women; gender; women-specific services; women-centred care; HIV/AIDS programming; health services; CHIWOS.

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Introduction

The profile of the global HIV/AIDS epidemic has changed dramatically over the past three decades, from a disease that predominantly affected men to one that is affecting a growing number of women. Women now represent over 50% of the 33.3 million people living with HIV globally [1]. In regions of sub-Saharan Africa, women constitute a disproportionate 60% of HIV cases [1]. In Latin America and the Caribbean, the percentage is over 35 and 50%, respectively [1]. In Asia, the proportion of women living with HIV (WLWH) has grown even more rapidly. In China, for example, the male-to-female sex ratio among HIV-positive people has narrowed from 9:1 in the 1990s to 3:1 in 2007 [2,3]. In North America, men who have sex with men continue to account for the majority of people living with HIV, but the proportion of WLWH has steadily increased over the past decade. In Canada, 26% of newly diagnosed HIV infections in 2009 were among females aged 15 years and above, more than double the proportion observed in 1999 (12%) [4]. Figure 1 shows the increasing proportion of WLWH globally over time [5].

Differences in the biological and social realities of men and women are key drivers of the feminization of the HIV epidemic [6]. In the context of heterosexual vaginal intercourse, the efficiency of male-to-female HIV transmission is two times greater than female-to-male transmission, owing to a more receptive contact surface of the vagina, a higher

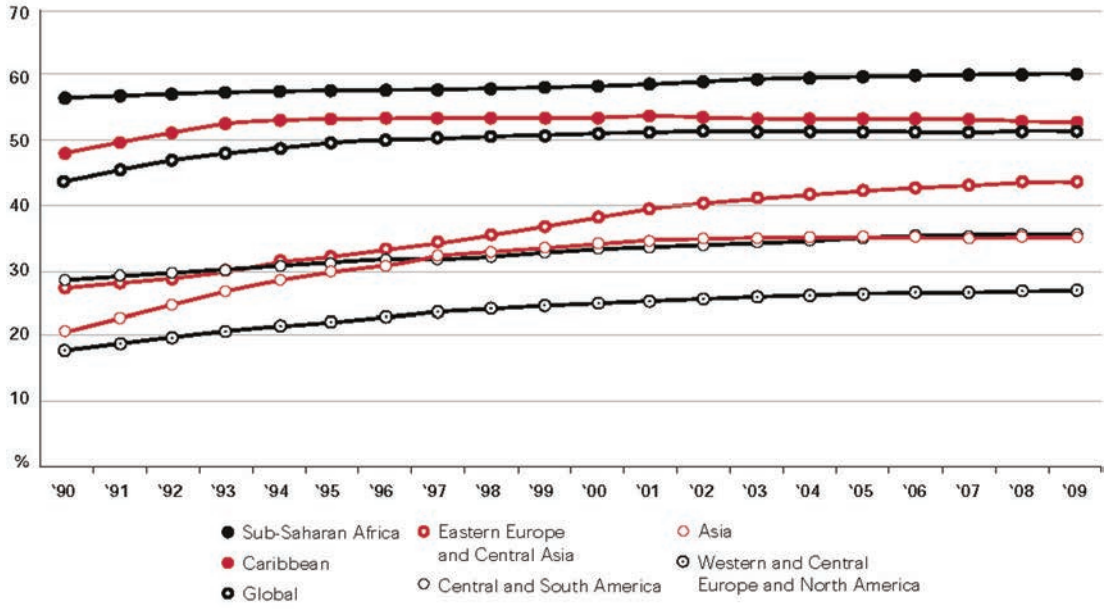

Figure 1. Proportion of people living with HIV (WLWH) who are women, 1990–2009. Reproduced with permission from UNAIDS [5].

concentration of HIV in semen compared to vaginal fluid and cervical ectopy [6,7]. Social factors can exacerbate this increased risk [8,9]. For instance, women who are economically disadvantaged [10–12] or who have experienced gender-based violence [13–15] are more likely to engage in unprotected sex, have multiple partners and resort to trading sex for money, drugs, food or housing. These women are also less likely to have the capacity to affirm one's self and to negotiate condom use, discuss fidelity with partners and leave risky relationships [10–15].

Access to and maintenance in treatment also varies by gender, both globally [16–19] and in Canada [20–22]. WLWH experience several barriers to care which are heavily shaped by gender, including stigma and discrimination (such as HIV-related stigma, sexism, racism and homo/transphobia) [23,24], violence [25], mental health and addiction issues [26], a lack of financial resources [27,28], lack of social support and feelings of isolation [26], inflexibilities in clinic hours [29–31], negative experiences with health care providers [32], a lack of services focusing on women [33], long travel distances to services from rural or remote areas [28,34,35] and competing responsibilities as mothers, partners, friends, homemakers, paid-workers and care-givers in which women prioritize the needs of others above their own [36,37].

Conflicting results have been published in terms of sex differences in outcomes after treatment initiation [38,39]. While some authors have reported improved virological suppression in males [40], others have showed advantages in females [41–44]. However, most evaluations have found no sex differences after adjustment for confounding variables [45–49]. Nevertheless, women are more likely to be non-adherent, have treatment interruptions and experience more adverse drug reactions [38,39]. Also, HIV infection increases the severity of menopause and menstrual disorders, osteoporosis, pelvic inflammatory disease and vulvo–vaginal and cervical diseases [38,50].

Women also have distinct reproductive health concerns, including contraception, fertility and pregnancy [38,50,51]. Provision of the full range of contraceptive options and access to safe abortion services are critical components of care to prevent unplanned pregnancies and improve women's overall health [52]. It is similarly critical to support women to safely achieve their future reproductive goals through pre-conception, pregnancy and post-partum services and support (including access to fertility treatment services as required), as an increasing number of HIV-positive women express the intention to have biological children [53]. In addition to reproductive concerns, sexual satisfaction, sexual functioning and sexual negotiation are increasingly important concerns to address as WLWH have been wrought with sexual stigma and a near absence of supportive services [54,55].

Women's experiences of HIV infection are unique and tailored services that respond to women's needs are critical for improving the overall health outcomes of WLWH [6]. In response, some regions have created women-specific HIV/AIDS programmes and services. For instance, in Canada, some of these include the Oak Tree Clinic, Positive Women's Network, the Maple Leaf Medical Clinic, Women's Health in Women's Hands Community Health Centre and the Centre for AIDS Services of Montreal Women; in the United States (US), the Johns Hopkins HIV Women's Health Program, the Women's Collective, SisterLove Inc. and US Positive Women's Network; and globally, Women Fighting AIDS in Kenya, Mama's Club in Uganda, Mujeres Positivas in Latin America and Women Organized to Respond to Life-threatening Diseases. Despite the emergence of this model of care, the concept of women-specific HIV/AIDS services remains largely undefined. These approaches are not well conceptualized and

little is known about the key characteristics of women-specific HIV/AIDS services.

Accordingly, the objective of this investigation is to explore the concept of women-specific HIV/AIDS services to identify and define what key elements underlie this approach to care. This literature review was undertaken as part of the formative phase of a new community-based, prospective cohort study entitled the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (study acronym: CHIWOS; study website: www.chiwos.ca). This study aims to enrol 1250 HIV-positive women from three Canadian provinces, including Ontario, Quebec and British Columbia, with plans to expand to Nova Scotia, Manitoba, Saskatchewan and Alberta. Understanding the concept of women-specific HIV/AIDS services is critical to our research, and more generally, to better addressing the unique needs of WLWH.

Methods

Theoretical framework

Our approach to understanding women-specific HIV/AIDS services emphasizes the relationship between many interacting social factors and women's health. While good medical care is vital, the underlying social and structural factors that undermine women's health must be addressed to have an opportunity for good health and wellbeing. Hence, the services that will be most effective in meeting the needs of WLWH will be those that reflect the intersectional social positions that women occupy in society. This understanding has resulted in our decision to ground our research in a Social Determinants of Women's Health (SDoWH) framework [56,57]. This gendered framework recognizes the high degree of variability between women, men and other gender groups, as well as between and within groups of women, based on intersections of identity and the lived social, economic and political realities, and the role that these intersections play on shaping individual health outcomes and experiences with health services [58,59]. In the context of HIV, this framework allowed us to recognize how multiple identity statuses and social factors are always at play in the lives of WLWH, and how this inter-sectionality affects their HIV/AIDS service needs and experiences in complex ways [60].

Search methods

This review was written using scoping review methodology [61]. A comprehensive literature search was conducted using online databases, including CSA Social Service Abstracts, OvidSP, Proquest, Psycinfo, PubMed and CINAHL. The first search included the following key words: ''women-specific'', ''services for women'', ''HIV-positive women''. After a review of the articles retrieved, our search strategy was expanded to include ''female-specific'', ''women-focused treatment'', ''women-only services'', ''programmes for women'', ''gender responsiveness'', ''women-centredness'', ''women's needs'' and ''gender awareness''. The terms were used both alone and in all possible combinations. After this initial retrieval of articles, additional articles were reviewed from the reference lists of articles eligible for inclusion. An Internet search was also conducted to locate grey literature, such as reports about women-specific models of service delivery from across Canada and elsewhere.

Inclusion criteria

All articles and reports identified were reviewed by two researchers (AJC, SB). These researchers were also responsible for discussing disagreements over eligibility until a consensus was reached. To be included for review, articles had to feature women-specific services as their central focus and make a contribution to the review aim of exploring the concept of women-specific HIV/AIDS services. Articles were restricted to English language publications with no limit set on the date or place of publication. Owing to limited literature on this topic as revealed in our preliminary search, we considered articles from various subject areas if they explored women-specific services in general and we discussed implications for the field of HIV/AIDS. While the rubric outlined by other disciplines may not perfectly translate to the context of HIV/AIDS, we believe this to be a reasonable approach since, from a SDoWH perspective, multiple issues and concerns besides HIV are always at play in the lives of WLWH. Thus, investigating a range of service models from several disciplines allowed us to better understand this concept for women in all of their diversity.

Results and discussion

The initial literature search generated 84 peer-reviewed articles. Of these, 22 met the inclusion criteria and were included for full review. After augmenting the search further, five articles were retrieved from article reference lists and three reports were obtained through a general internet search, for a total of 30 articles included in this review. Articles were published between 1995 and 2010. Most originated from Canada and the United States. Fifteen were specific to HIV/AIDS, eleven to mental health and/or addictions and the remaining four stemmed from other subject areas. Table 1 outlines the source of each article by country of origin and discipline.

Defining features of women-specific HIV/AIDS services

The review demonstrated the absence of a consistent, widely accepted definition for women-specific HIV/AIDS services. Within the literature, this approach to care was named and defined in multiple ways. In addition to ''women-'', ''sex-'' or ''gender-specific'' services, other terms commonly used included ''women-only'', ''(tailored or specialized) programming, programmes, services or treatment for women'', ''women-centred'', ''women-focused'', ''women-'' or ''gender-sensitive'', ''single-gender'' or ''single-sex'', ''women-'' or ''female-friendly'', ''family-focused'', ''family-friendly'', ''same-gender'' or ''same-sex'', ''women's health services'', ''transformative'', ''empowering'', ''women-exclusive'', ''gender-responsive'', ''gender-appropriate'' and gender-equitable'' approaches. Table 2 shows the frequency with which these terms were used in the literature reviewed.

A useful starting definition comes from Grella [62], who described women-specific services as those offered to women only or those in which there is a higher concentration of female clients. Examples of the former may include gynaecological, breast health or menopausal services, all of

Table 1. List of identified articles exploring women-specific services by region and subject area (total number of articles identified = 30)

	n (%)	References
Region		
United States	20 (67%)	[62–80]
Canada	6 (20%)	[81–86]
Others (United Kingdom, Australia)	4 (13%)	[87–90]
Subject area		
HIV	15 (50%)	[8,63,67,70–72,76–78,80,82,84–86,90]
Mental health and/or addictions	11 (37%)	[62,64–66,68,69,74,75,79,88,89]
Women's health in general	2 (7%)	[73,81]
Cardiovascular health	1 (3%)	[83]
Law and policy	1 (3%)	[87]

which are important issues for WLWH [51]. It may also include a range of other gender-neutral services, if offered in a women-only environment [62]. An example of the latter may be HIV-positive parent–baby groups that are attended by mostly women. Furthermore, while some women have expressed that having staff that are competent in and sensitive to HIV- and women-specific issues is more important than having female providers per se (Margarite Sanchez, Personal Communication, February 2012), others have emphasized that having one's identity reflected back at them is a crucial component to care for women [29,65]. Thus, the primary, defining and consistent feature of women-specific HIV/AIDS services is the gender of the clientele and/or staff. In addition, these services are either provided within larger single- or mixed-gender settings [62,65].

However, many authors [62,65,68,69,78,79,83,84] suggest that women-specific services ''must do more than segregate clients and employ only female staff'' [65]. Several studies have provided empirical support for this hypothesis. For example, in a retrospective, quasi-experimental cohort study of a drug treatment programme that segregated clients and staff but left the programme content unchanged, there were no significant differences in treatment outcomes between participants enrolled in single- or mixed-gender groups [65]. In contrast, Claus and colleagues [68] demonstrated that substance-using women treated in women-only settings with specialized programming for women (e.g. childcare services, education on women's health topics) had better outcomes after discharge compared to women treated in non-specialized, mixed-gender programmes.

Therefore, in addition to the provision of care and support in an all-female environment, many authors argue that, to be effective, women-specific services must also adopt approaches to care that are substantially different than the traditional care provided in mixed-gender settings [62,65,68,69,78,79,83,84]. This is based on recognizing that women are unique and therefore have health and social care needs that require specially designed programmes. It also is

Table 2. Comparison of terms used to describe women-specific services

Term	*n**	References
''women-'', ''female-'', ''sex-'' or ''gender-specific''	15	[62,63,65,68–70,72,73,76,77,82,85,87,89,91]
''women-only''	15	[62,64–66,68,69,74,78,79,81–83,85,88,89]
''(tailored or specialized) programming, programmes, services or treatment for women''	15	[62,64,66–71,74,75,77,84,87,89,91]
''women-centred''	9	[67,68,72,77,81,83,85,87,88]
''women-focused''	8	[62,64,67,68,73,74,78,83]
''women-'' or ''gender-sensitive''	8	[8,62,66,68,76,81,88,91]
''single-gender'', ''single-sex''	6	[62,64–66,88,89]
''women-'' or ''female-friendly''	4	[66,86–88]
''family-focused''	4	[68,70,72,80]
''family-friendly''	3	[70,80,84]
''same-gender'', ''same-sex''	2	[62,66]
''women's health services''	2	[73,91]
''transformative''	2	[8,76]
''empowering''	2	[8,76]
''women-exclusive''	1	[85]
''gender-responsive''	1	[62]
''gender-appropriate''	1	[77]
''gender-equitable''	1	[63]

*Many articles used more than one term to describe women-specific services. Hence, the accumulative numbers shown in this table (96) exceed the total articles reviewed (30).

based on an understanding of the close connection between women's health and their whole lives [58,59,73,81,92]:

> Women's health involves women's emotional, social, cultural, spiritual and physical well-being, and is determined by the social, political, and economic context of women's lives as well as by biology. This broad definition recognizes the validity of women's life experiences and women's own beliefs about and experiences of health. Every woman should be provided with the opportunity to achieve, sustain and maintain health, as defined by the woman herself, to her full potential. [92] (pp. 507–508)

Following from this, findings from the literature suggest that there are at least 12 additional components to women-specific HIV/AIDS services that are important for holistically addressing women's needs and promoting women's health. Drawing on the work done by the Vancouver/Richmond Health Board [81], which was informed by several women's health centres from across Canada and elsewhere, we distilled these elements into four different categories and now discuss each element to demonstrate how they may be applied in practice.

Importantly, these principles are presented with the understanding that some features of good HIV/AIDS service delivery may apply to women only and others may be universally relevant to both men and women. Hence, while we explore all the potential aspects of HIV/AIDS services for women, we appreciate that they are not necessarily exclusive to women-specific services and may be important in the care of men as well. In addition, we present these principles with the acknowledgement that they will evolve as additional research is conducted. It is also recognized that the degree to which these principles is achieved in practice may vary depending on the context, purpose and patients involved. Finally, although presented here as distinct items, it is important to recognize that many of the components overlap and are related to each other; women-specific HIV/AIDS services actually involve an integration of some or all of these items, which together impact the entirety of women's experience accessing care.

Additional dimensions of women-specific HIV/AIDS services

Strategies to successfully engage WLWH

Creating an atmosphere of safety, respect and acceptance

Some HIV-positive women have reported underutilizing health and supportive services because of negative experiences with providers where they have felt unsafe, unwelcome or discriminated against [29,30,32]. Other women, in the context of sex work, have reported avoiding care because of stigma, criminalization or fear of running into aggressors [29,93]. Thus, addressing the health of WLWH begins with safety, respect and acceptance [81,85,88]. This involves creating inclusive, welcoming and non-competitive women-only spaces where women feel comfortable sharing potentially sensitive and painful issues [64,66,68,83]. It also requires providers to recognize the different kinds of abuse experienced by WLWH [29,30] and to understand their subsequent coping strategies [81]. In such an approach, providers are encouraged to take stock of their language, training, and behaviour to minimize the possibilities for re-traumatization [81]. Providers are also encouraged to support women's choices based on their own unique circumstances and accept the validity of their concerns [83].

Facilitating communication and interaction among peers

Building connections with peers is an important source of support for women in general [68,74,81,83] and has been shown to be particularly important for WLWH [85,94]. Facilitating the development of a network of peers is an integral part of women-specific HIV/AIDS services which may not only serve as a source of support for women but may also help facilitate their access to information. Peers are women who are themselves living with HIV and may share similar life experiences. In-person peer-support groups are one way in which HIV-positive women can share, listen to and support one another [79]. Online peer networking groups are also common. An example of the latter is ViVA, an online community of WLWH in British Columbia, Canada, who share freely with each other about their personal experience, questions and opinions related to HIV/AIDS through a confidential listserv.

Involving women in the planning, delivery and evaluation of services

Many HIV-positive people want to participate meaningfully in decisions about the HIV/AIDS services that impact their lives. This was recognized at the international level through the principle of GIPA (Greater Involvement of People Living With HIV/AIDS) [95,96]. This point is particularly salient for WLWH, given their inadequate representation in interventions. Therefore, involving HIV-positive women in the planning, delivery and evaluation of services is an important element to women-specific HIV/AIDS care [81,83]. Policies that employ WLWH are key [78]. Policies that involve them in the planning and decision-making processes through, for example, representation on boards or steering committees [81,84] are also important [67]. Key informant surveys, exit interviews and follow-up evaluations also help ensure that women's perspectives are captured [81]. Applying this principle in practice may require the provision of childcare, transportation, honoraria, mentoring for skill-building or other services to support women's full and equal participation [81]. In addition, encouraging women's involvement also involves actually using their expert knowledge to bring about real change (Margarite Sanchez, Personal Communication, February 2012).

Providing self-determination opportunities

Providing self-determination opportunities that aim to help women transform gender norms and achieve equity in outcomes is important for WLWH to contain the epidemic and reduce its impact [8,81]. ''[I]mproving access to information, skills, services and technologies'' is essential to this approach [8]. Programmes that seek to help women empower themselves recognize the asymmetrical power dynamics between service providers and clients [81]. They seek to promote collaborative work environments that acknowledge

women's agency and encourage their equal participation in decision-making about their care [8,67,81,83,84,87]. This is practiced at the Oak Tree Clinic in Vancouver, Canada, where patients are offered a range of services to either select or decline and physicians ''stand by them whatever their decision is'' [84] (pp. 1408). Women-specific HIV/AIDS services may also have an empowering effect by emphasizing self-worth [64] or by using peer navigators (health advocates who are themselves WLWH) to assist women in building knowledge and skills to navigate the system and be vocal advocates in their own care [81]. They may also address women's oppression at a systemic level by advocating for women's rights [81,87].

Elements that account for women's unique patterns or preferences in maintaining health and seeking care

Providing tailored programming for women

Women-specific approaches to care often include services that are more relevant to women than those provided in mixed-gender settings [62,87]. The overall style of such programming is more supportive, nurturing and cooperative [62,64,68,84]. Programmes often focus on the multiple roles of women, self-worth, emotional safety, physical and sexual abuse, life skills training and strengths identification [64,68,79,89]. Other examples of such programming include women-only support groups, education on women's health topics and female condoms or microbicides along with negotiation skills training to avoid unsafe sex [8,67,76]. Other services typically associated with women's needs include childcare, housing assistance, employment counselling, transportation assistance, family counselling, mental health services and the full spectrum of women's sexual and reproductive health services, including access to safe abortion services [62,66,74,77,79,86]. Promoting women's health also involves efforts to promote healthy lifestyles and screening practices to enable women ''to increase control over, and to improve, their health'' (Ottawa Charter for Health Promotion).

Facilitating meaningful access to care through the provision of social and supportive services

Women-specific HIV/AIDS services understand and respond to the realities of women's lives by providing social and supportive services that facilitate women's access to care. For women with competing care-giving responsibilities, this involves allowing them to be accompanied by their children, providing on-site childcare or offering childcare subsidies [64,68,79]. For low-income women, the provision of travel and transportation support is an important facilitator to care [64,79,83]. Having flexible hours of operation that are ''client-driven [and] round the clock'' [83,97] (pp. 194) is also key. Other essential practices include being culturally sensitive and offering translation services [78,81,83], ensuring physical accessibility [83] and allowing self-referral to programmes [83]. Providing financially accessible alternative and complementary services is also key [81].

Facilitating access to women-specific and culturally sensitive information

In many countries, gender norms often restrict women's access to sexual health information [9,98]. Also, many available HIV resources have been designed for men, resulting in little support catering for women's needs [26,29]. Of the appropriate resources available, there is a lack of culturally- and linguistically appropriate information [30,99]. Limited HIV knowledge can greatly influence women's acquisition and management of the disease [9,98]. Thus, facilitating access to information that is women-specific and culturally sensitive is an important component of women-specific care [8,9,70,78,81]. This requires understanding women's unique learning styles. Women often acquire information through peers, exchanging stories and remembering personal testimonials [81]. Their uptake of information is also shaped by their literacy level, language training and their culture [81]. In response, women-specific services often entail the provision of information in accessible formats, peer-driven education, lunch seminars or women's resource centres [81].

Considering family as the unit of intervention

The social reality of HIV-positive women's lives is diverse. Some women are a part of a family unit and make decisions about their health in the context of their family life [81]. In many cases, women's decision-making about accessing and using services and treatments is affected by care-giving responsibilities [36,37] and male partners [8], owing to a power imbalance in gender relations. In other cases, women are either not part of a family unit at all or lack the support mechanisms from family that may be needed to cope with treatment-related issues [26]. Given this diversity, a women-centred approach to care is flexible and takes the different familial contexts of women's lives into consideration.

This type of care respects the role that family may play in a woman's life [62,68,81] and may encompass children, partners and other kin [70,80,84]. This concept of ''family-friendly care'' is practiced at Vancouver's Oak Tree Clinic, which provides health care to patients' family members (regardless of their blood relation and HIV status) and a supervised playroom for children [84]. Other examples of this approach to service delivery include HIV pre- and post-test counselling for partners, pregnancy planning with serodiscordant couples and family therapy to help families discuss beliefs about HIV/AIDS [8,80].

In contrast, this type of care may also recognize the harmful gender relations that may exist in families which adversely affect women's access to care and, thus, with a woman's assent, may involve efforts to more fully engage male partners to target these gender norms. For women without family as a social support, efforts to connect women with support mechanisms in their community are also key.

Philosophies or approaches to delivering women-specific HIV/AIDS services

Providing multidisciplinary integration and coordination of a comprehensive array of services

The intersectionality of women's health and social factors means that HIV-positive women face multiple challenges to having their needs met [60]. Managing their illness requires rigorous adherence to combination drug therapies and coordination of multiple specialists which may include primary care providers, psychiatrists, HIV specialists, hepatitis C specialists, social workers, outreach workers, pharmacists,

ophthalmologists, gynaecologists, fertility specialists, paediatricians and many others [63,71,90]. Acquiring stable housing, employment, nutritious food, reliable transportation, disability benefits, financial security, child care and other supportive services may also be critical to maintaining health [63,71,84]. Multidisciplinary integration and coordination of an array of services has been promoted as a means for managing the complexities of HIV/AIDS for women [63,64,68,69,72–75,77,80,81,83,84,91]. Achieving this principle in practice often involves one of two models. The first model of service delivery is known as ''one-stop shopping'' [63,74,81,84,91], in which several services by multiple specialists are offered on-site in one location. The second approach involves an integrated network of services that work in partnership to connect and refer women to the appropriate provider [74], such as case management [71,77,79,80]. This provides a unique opportunity for the coordination of various services where service fragmentation is common [63,71]. Both approaches require collaborative planning and delivery of care by an interdisciplinary team of providers [63,81,83].

Meeting women ''where they are''

A SDoWH framework highlights how WLWH have multiple overlapping needs and are at various stages in their lives and in their experiences of HIV. A women-specific approach to HIV service delivery acknowledges this by meeting ''women where they are'' [82,85]. This involves supporting each woman by adequately meeting her individual health and social needs and by being all of whom she wants to be without passing judgment [85]. It also involves a commitment to flexibility, adjusting care for different needs and stages in a woman's life [73,83,87]. In practice, this may mean not chastising women for a missed appointment but simply re-scheduling it. It may also mean delivering care directly to a woman's home if she has to care for a disabled child or parent at home. It also includes services that reflect the realities of WLWH, such as those with flexible hours of operation for women with daytime commitments or those with childcare provisions for women with young children and no access to childcare.

Methods that inform a women-specific approach to HIV/AIDS care

Providing gender-, culture- and HIV-sensitive training to health and social care providers

Many WLWH have reported negative experiences with service providers due to intersectional discrimination against being a woman, HIV-positive, Aboriginal, Black or being from an HIV-endemic country, being lesbian, bisexual or transgender [29–32]. Women have also reported a lack of knowledge among physicians regarding the impact of antiretroviral medications on women's bodies such as changes in menstrual cycles, weight and fat distribution [26]. In response, women-specific services often include gender-, culture- and HIV-sensitive training to help providers improve their understanding of WLWH and of different cultures, health practices and beliefs [70,81,84]. This begins with providers taking stock of their own assumptions and incorporating into practice only those values that support women-centred health [81]. It also involves continuing education on issues specific to women, culture and HIV. Facilitating this involves the provision of regular information updates, awareness workshops and comprehensive sensitivity training presented by diverse WLWH [70,81]. According to a SDoWH framework, attention to these intersecting social identities is necessary to understand their combined influence on health and to develop more effective health services [56,57,60].

Conducting gendered HIV/AIDS research

Historically, HIV-positive women have been inadequately represented in HIV/AIDS research [6,100]. Results from studies involving mainly men are not necessarily generalizable to women [101] and there is a critical need to address issues of gender in research to effectively respond to HIV in women in practice [6]. The importance of applying a gendered lens to interventions addressing the health of WLWH has been highlighted in the SDoWH literature [56,57,60]. In response, some women-specific care programmes have begun conducting their own gendered research initiatives [81]. This approach involves the participation of patients in onsite or offsite research studies. It also requires a breakdown by gender in all data and a consideration of gendered issues in all phases of the research process [101]. Use of multi-methods is also valuable as ''women's voices are an important part of evidence'' [81]. In this way, care programmes themselves can identify and address issues and gaps in service delivery [81].

Conceptual framework of holistic service delivery for WLWH

The previous sections provided a synthesis of the defining characteristics and other major elements of holistic service delivery for WLWH. After reviewing the literature, it emerged that recognizing and responding to women's unique health and social care needs is more at the core of HIV programming for women than being women-specific (or separate from men) *per se*. Thus, we propose the use of the term ''women-centred HIV/AIDS services'' in our conceptual framework and in future empirical research in this area since it better reflects the literature reviewed and our SDoWH theoretical approach. We now propose the following framework (adapted from Vancouver/Richmond Health Board) to illustrate this concept, positioning it within its broader context of the lives of HIV-positive women.

In Figure 2, WLWH have been placed in the middle of the framework to indicate the centrality of women to women-centred HIV/AIDS services. Women are then encircled by six dimensions of women's health: emotional, mental, social, cultural, spiritual and physical wellbeing [92]. This circle, designed as a wheel with spokes, represents women's overall well-being and illustrates the importance of maintaining balance between the six different aspects of one's health.

Women's health is determined by the context of their lives as well as by biology. As such, the next concentric circle shows 28 determinants of women's health. Of these, 14 were described by Raphael (Aboriginal status, gender, disability, housing, early life experiences, income and income distribution, education, race, employment and working conditions, social exclusion, food insecurity, social safety net, health services and unemployment and job security) [102], three

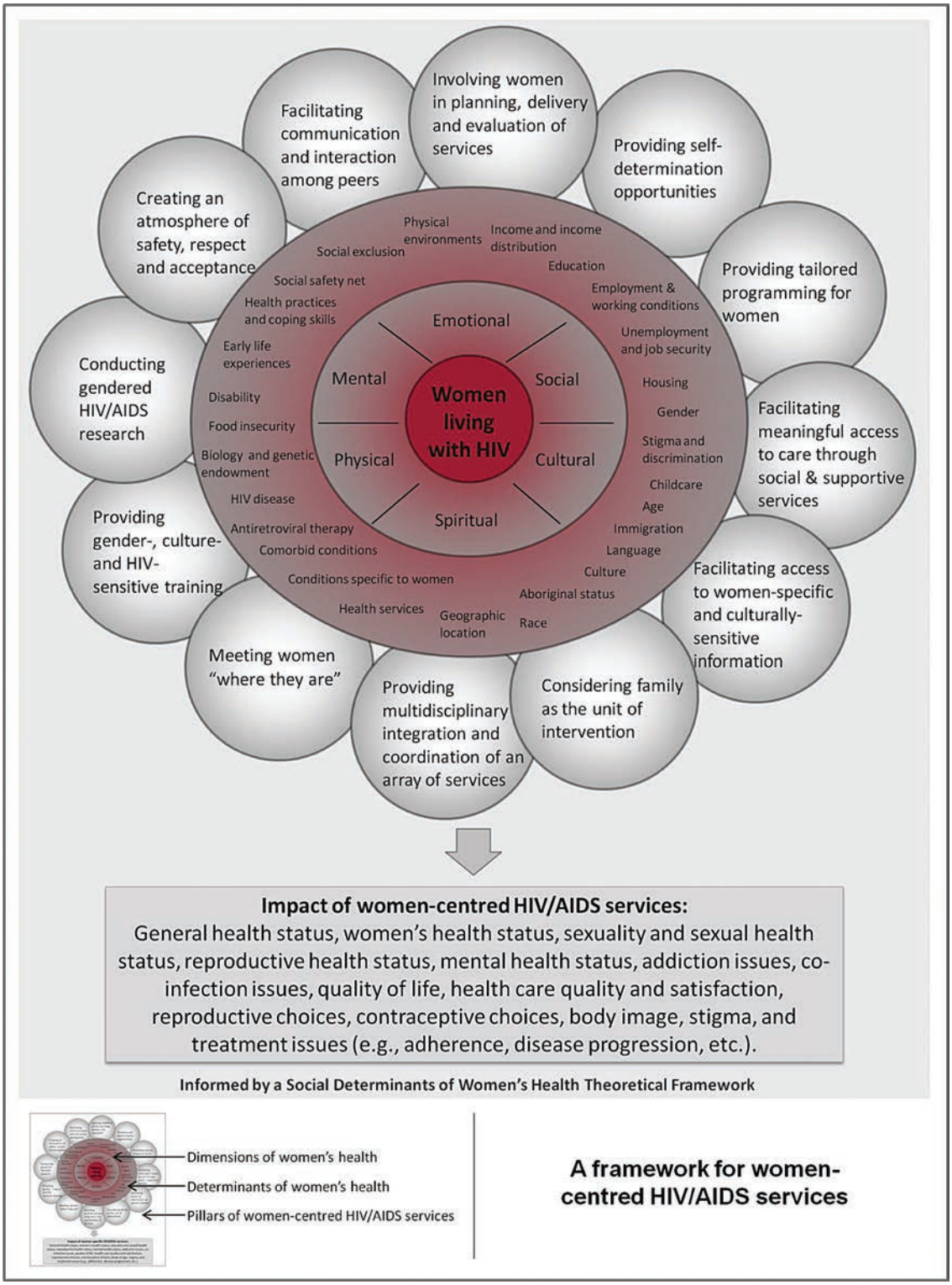

Figure 2. A conceptual framework of the concept of women-centred HIV/AIDS services, placed within the context of the lives of women living with HIV (WLWH). Adapted from Vancouver/Richmond Health Board [81]. WLWH are at the centre of the framework and are encircled, first, by six dimensions of women's health, and, second, by 28 determinants of women's health. Around this are 12 components, or pillars, of women-centred HIV/AIDS services. The box below summarizes the potential impact of these services on HIV-positive women's health outcomes. An SDoWH theoretical perspective overlays the entire framework as outlined in the final box enclosing the diagram.

were supported by Health Canada (biology and genetic endowment, physical environments (i.e., neighbourhood safety) and personal health practices and coping skills) [103] and seven were added from the literature on SDoWH [56,57,60] to better reflect the realities of WLWH (age, immigration, geographic location, childcare, culture, language and stigma and discrimination). This circle also includes four other elements relevant to the physical dimension of HIV-positive women's health, including HIV disease, antiretroviral therapy, comorbid conditions (e.g. Hepatitis C), and conditions specific to women (e.g. gynaecologic diseases).

In the outermost layer, the 12 components, or pillars, of women-centred HIV/AIDS services that we identified in this review are displayed. As shown, the components overlap and are not mutually exclusive; rather, in practice, they may operate either alone or in combination with other elements simultaneously depending on the context. The box at the bottom of the diagram provides a synthesis of the documented and hypothesized impacts of women-centred HIV/AIDS services on various health, social and treatment outcomes of WLWH.

The entire framework is informed by an SDoWH theoretical perspective as outlined by the final box enclosing the diagram. Grounded in social justice and human rights [104], this paradigm highlights how, with the exception of the work of peers, self-determination and GIPA, there have been few attempts in the literature to frame this issue beyond that of individualized interventions that are focused on the private sphere of one's life (e.g. decision-making, self-worth, family). This places emphasis on changing or controlling individual behaviours and deflects attention away from the broader socio-structural forces (e.g. poverty, patriarchy and other forms of structural violence) that systematically deny women's rights and well-being [104]. Therefore, the inclusion of this final box is meant to highlight the importance of understanding and addressing these social, economic and political structures to the promotion of women's health.

Limitations

The concept of women-specific HIV/AIDS services was shaped through a review of the perspectives of experts from many different disciplines. Thus, the data were fragmented across many subject areas and the information outlined by some theorists may not be perfectly relevant to the context of HIV/AIDS. In addition, the examples of how each of the 12 pillars to HIV care for women is applied in practice were not exhaustive and efforts should be made to expand on the breadth of the components. Furthermore, it was difficult to identify clear-cut components and, thus, there is overlap between some of the 12 pillars. Finally, most articles included in this review originated from the US, Canada, and Europe. Since models of HIV health care coverage and delivery differ worldwide, the recommendations in this article may not be generalizable beyond these settings.

Despite these limitations, there are also strengths stemming from the information gathered. The inclusion of articles from multiple fields helped to create a rich and textured understanding of women-specific HIV/AIDS services that holistically reflects women's lives. Also, while the framework is simplified, it nonetheless provides an overall picture of the various factors that make up a women-specific approach to HIV care. Thus, it is hoped that this framework can help guide future HIV care and research aimed at developing, measuring and evaluating women-specific HIV/AIDS services.

Conclusions: implications for practice and research

The evolving demographics of the epidemic and the underlying gender dynamics necessitate a tailored approach to service delivery worldwide that is responsive to the unique needs of WLWH and is guided by prevailing regional and local conditions. As demonstrated in this review, the concept of women-specific HIV/AIDS services is a complex and multidimensional one that has been shaped by diverse theoretical perspectives. The framework outlined in this article provides a useful tool that can assist health planners and providers to improve women-centred approaches to HIV care so that the system better meets the needs of WLWH. Further research is needed to better understand this emerging concept and ultimately assess the effectiveness of women-specific HIV/AIDS services in achieving optimal health outcomes for WLWH. This work will be undertaken in the next phase of CHIWOS and will have important implications for evidence-based holistic health services for HIV-positive women in Canada and worldwide.

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Competing interests
The authors have no competing interests to declare.

Authors' contributions
All authors contributed to the conceptualization and design of the review. SB carried out the initial literature search in online databases. SB and AJC reviewed the articles retrieved for eligibility, and AJC conducted the augmented search for literature in the reference lists of eligible articles and the grey literature. AJC analyzed the data, interpreted the results and wrote the first draft of the article. NO, KA, WT, SG, SM, AK, MS, AP, AC, AD and ML critically reviewed and revised the manuscript for intellectual content. The CHIWOS Research Team reviewed, edited and approved the final draft.

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PEER RESEARCH IN ACTION III: ETHICAL ISSUES

Flicker, S., Roche, B., Guta, A.

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Peer Research in Action III: Ethical Issues

Flicker, S., Roche, B., Guta, A.

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Executive Summary

ETHICAL ISSUES

This report is Part III of a series of working papers that provides an overview of research findings from our study related to the practice of peer research as a strategy in community-based research (CBR) in Toronto, Canada. In this section, we illuminate the particular ways in which participants discussed ethical challenges in their work when adopting a peer researcher approach.

Many participants articulated that the very decision to engage in more participatory processes was an ethical one. Nevertheless, new practices lay the foundation for different ethical dilemmas. When probed, many of our participants highlighted challenging ethical moments which emerged from their CBR practices. These included issues related to:

Formal ethics review: Those engaged in community based research sometimes have difficulty navigating the process. One strategy for dealing with this challenge is to start thinking about ethical review early in the proposal development process and as a group to identify potential red flags throughout the design.

Communication and power sharing: Many of the peer researchers we talked to felt like they had limited power and decision-making ability over the design or execution of project activities. Care should be taken to avoid research practices that benefit extensively from the labour and expertise of peer researchers, but offers little in return in the way of recognition, remuneration or a sense of ownership of the work.

Conflicts of interest: Many participants suggested that community members may be more inclined to participate in a study if approached by a known peer; however care needs to be taken to ensure that the likelihood of coercion is limited. It may be appropriate to have someone who is more at "arms length" walk through consent procedures and data collection.

Confidentiality: Confidentiality is always an issue in research. Peer researchers, like all staff with access to private information, need support and training to adopt careful protocols around privacy and confidentiality.

Emotional triggering and the need to provide special support: This phenomenon was experienced most acutely by peer researchers who had past experience with the topic under study (i.e. homelessness or drug use) rather than those currently being impacted by the issues. In these cases, peer researchers were sometimes asked to return to environments where they encountered peers, settings, and dynamics that were at times traumatic. The level of on-going support and supervision necessary to ensure that project needs are met should not be underestimated.

Considerations beyond the life of the project: Peer researchers may find it difficult to transition out of the project.

Conclusion: Ethical issues are by their very nature complex. There are rarely easy right and wrong answers to challenging ethical issues. Careful ethical reflection throughout the life of a research project can provide a team with the opportunity to come up with creative, attentive and just responses to these challenges.

WE ENCOURAGE COMMUNITY-BASED RESEARCH TEAMS TO:

- Use the formal ethics review process as an opportunity to reflect on broader ethical issues with the entire research team.
- Align their rhetoric of participation with commensurate power-sharing schemas and create transparent decision-making structures.
- Explore issues relating to conflicts of interest and confidentiality broadly and extensively in their training, and ongoing support work, with peer researchers.
- Consider the emotional impact of the work that they are asking of peer researchers and provide appropriate mechanisms for ongoing support and supervision.
- Think about how to develop appropriate wrap-up activities and a sense of closure.

Introduction

Community-based participatory research "emphasize[s] the participation, influence and control by non-academic researchers in the process of creating knowledge and change" (Israel, Schulz, Parker, & Becker, 1998, p. 184). The participation of community members in research is believed to enhance the validity of research findings and assist in ensuring that research results are used to inform and foster social change at the local level. The benefits of community involvement in research are well recognized; they include improved access to and greater representation of marginalized groups in research; data that are richer in quality and more authentic in their representation; and the creation of opportunities for local capacity building and empowerment (Minkler and Wallerstein 2008; Israel et al 1998; 2005). These benefits are often (although not always) realized through authentic partnership approaches that leverage the skills and assets of all team members.

Community members are thought to bring expertise that is informed by life experience to research projects, including perspectives on the issues at hand and insights about solutions. Actively engaging and involving members of the community in research has, however, not been without its challenges. Community-based research initiatives are often better at establishing partnerships among community representatives (i.e., agency staff) than among community members themselves (Flicker, Guta & Roche 2009). This finding raises critical questions about the assumptions that underscore community involvement in research (Dewar, 2005).

In an effort to achieve greater and more meaningful community participation in research, a rise has taken place in the number of projects that engage "peer researchers." Peer researchers (sometimes referred to as PRs) are members of a research project's target population who are trained to participate as co-researchers. In some cases, peer researchers partner in all facets of a research project. In others, they are instrumental in one or more aspects of a research project (e.g., participant recruitment and/or data collection). To date, there has been little critical discussion about the nature of peer researcher participation in community-based research.

The dearth of data on peer research in practice has meant that questions remain regarding the authenticity of community participation, how power differentials are addressed (if at all), and how participation may impact the lives of community members in social or economic ways that have not been fully appreciated (Roche 2008; Greene et al., 2009).

The Wellesley Institute has created a three-part series of papers examining the use of peer research as a model of Community-Based research in practice. In this series we consider Models of Practice; Management, Support and Supervision, and Ethical Issues as they surface in the context of Peer Research in Action.

Research Design and Methods

In 2007, we began to examine community-based research projects that adopted a peer research approach to better understand (1) the processes (recruiting, hiring, training, and managing) used with peer researchers in various aspects of community-based research; (2) the dynamics among peer researchers, their respective communities, and other members of the research team/hosting organization; and (3) the ethical, social, and practical issues that are particular to peer research models.

Our study began with a working definition of peer researchers as members of the target population who are trained to participate as co-researchers. This definition functioned as an important starting point and reflects our observations as researchers engaging in and supporting community-based research. In the course of our study, however, we learned that the definition of peer research and the role of peer researchers shift according to context, community, the nature of the project, the understanding of community-based research, and time.

Academic leads and community partners who had used peer research models in their community-based research in Toronto were invited to attend two focus groups to identify and discuss ethical, social, and practical issues related to using a peer research model.[1] Most of those who participated worked as research managers or staff at non-profit agencies in Toronto that were broadly engaged in addressing the social determinants of health.

Peer researchers were recruited for individual semi-structured interviews to discuss their experiences. The peer researchers who participated reflect a diverse group in terms of age, gender, sexual orientation, socio-economic status, culture, and ethno-racial identity. Sixteen individual interviews were conducted with peer researchers.

1 Projects were identified from among those that had been funded in full or in part by the Wellesley Institute.

Interviews and focus groups were audio-recorded and transcribed verbatim for coding and analysis. We conducted a thematic analysis using a coding scheme drawn from respondents' verbatim accounts of their experience. Coded data were analyzed and compared by theme, range, and type of peer research involvement, as well as the nature of the experience with peer research for both service providers and peer researchers.

Ethical Issues

In Part III of our three-part series on peer research, we provide an overview of the ethical challenges study participants noted in their work when adopting a peer research approach.

As described in Part I of this series, those engaged in community-based research often describe the approach in ideological terms. They are interested in democratizing the research process and finding mechanisms for those most affected by a problem to become part of imagining new solutions. Many study participants articulated that the very decision to engage in more participatory processes was an ethical one. They argued that conventional practices were often exclusionary and served to disenfranchise the very communities that health and social researchers were trying to reach. Moreover, historical abuses of power conducted in the name of research had left many communities angry and uninterested in research engagement (see Schnarch, 2004). By changing the rules of the game, and including peers in research planning and implementation, the practitioners in our study felt that they were challenging the status quo because it was "the right thing to do." Many invoked a moral argument, suggesting that community-based research was an inherently more ethical approach. This line of argument is echoed in the literature. Other researchers have also written about how adopting a community-based research approach may be one strategy to redress historical inequities (Malone et al., 2003).

Nevertheless, new practices lay the foundation for different ethical dilemmas (Flicker et al., 2007). When probed, many of our study participants highlighted challenging ethical issues that emerged in their community-based research when they adopted a peer research approach. These issues related to:

- formal ethics review
- communication and power sharing
- conflicts of interest
- confidentiality
- emotional triggering and the need to provide special support
- considerations beyond the life of the project

In addition, concerns around developing appropriate models of inclusion, hiring and compensation, covered in parts I and II of this series, were also seen as ethical issues.

Formal Ethics Review

Study participants identified a number of reasons for undertaking a formal ethics review of their research. A formal ethics review is often a requirement of funders. In addition, having arms-length reviewers examine policies and procedures from an ethical perspective can be very useful in illuminating unintentional potential harms. Finally, gaining ethics approval by a large institution can offer an air of legitimacy:

> [T]here was something about the University of Toronto's stamp on it, that I think actually had a fair amount of weight … it made a difference in terms of how we internally understood … how much we were bound to do certain kinds of things, or not. (Service Provider)[2]

Nevertheless, those engaged in community-based research sometimes have difficulty navigating the ethics review process (Flicker et al., 2006). One strategy for dealing with this challenge is to start thinking about the ethics review early in the proposal development process and to identify red flags throughout the design. Discussing these potential issues with the entire research team (including peer researchers) may help researchers see problems in new ways and develop creative solutions. The more documentation provided to review boards about how you came to your well-reasoned and thought-through approach, the less likely it is that you will be turned down. Another strategy might be to work with your university partners and contact the staff at the ethics review board to help you think through difficult issues prior to submitting your research protocol for review.

Very few of the peer researchers in our study were involved in the upfront work of thinking through the requirements of ethics review. Moreover, few of the service providers played a role in this process. Most told us

2 Many of our participantswere affiliated with academic and community based organizations. We have chosen to use the label "service provider" as a way to differentiate these researchers from "peer researchers."

Table 1

REFLECTION QUESTIONS THAT MAY NOT BE RAISED IN A TRADITIONAL ETHICS REVIEW

Background, purpose, objectives	• How was the community involved or consulted in defining the need for the study? • Who benefits from this research?
Decision making	• How will decisions be made? What role will community members or peer researchers have?
Research methodology	• How will the community be involved? At what levels? • What training or capacity-building opportunities will be built in?
Hiring staff	• What skills do the different staff members need to have? • What ongoing training and support do different team members need?
Participants	• Will the research process include or engage marginalized or disenfranchised community members? How? What kinds of support will be put in place?
Recruitment	• Who will approach people about the study and how? Who will seek consent? How can coercion (or the perception of it) be minimized? • How will (real or perceived) conflicts of interest be resolved?
Risks and benefits	• What are the potential risks associated with involvement for communities? For individuals? • Are there built-in mechanisms for how unflattering results will be dealt with?
Privacy and confidentiality	• How will the boundaries between multiple roles (e.g., researcher, counsellor, and peer) be maintained or broken-down? • What processes will be put in place to be inclusive about data analysis and yet maintain privacy of participants? • Where will data be stored? Who will have access to the data? How? • What rules will be put in place for working with transcripts or surveys that contain identifying information?
Compensation	• Who will be compensated for what? Who will be considered a volunteer? How will those decisions be made? • Who will have control over the budget?
Informed consent process	• What could "communal consent" look like? • Whose permission will be needed to talk to whom? • What mechanisms will be set up to ensure that everyone involved really understands all the risks and benefits?
Outcomes and results	• How will the research be disseminated? • What are the new ways that this research will be acted upon?

Expanded and adapted from Flicker, S., Travers, R., Guta, A., McDonald, S., & Meagher, A. (2007). Ethical dilemmas in community-based participatory research: Recommendations for institutional review boards. *Journal of Urban Health, 84*(4), 478–493.

that their academic partners had largely handled this "hurdle." Despite being uninvolved with the administration associated with an ethics review, several participants talked about how they had made important contributions to improving recruitment, data collection, analysis, and dissemination (many of which are arguably decisions about ethics).

All of the projects in our study underwent a formal ethics review, but there were some questions regarding the degree to which university review boards are equipped to deal with emerging new dilemmas in community-based research (Guta et al., 2010). Most conventional ethics reviews continue to focus their efforts on risks and benefits to individuals and do not take a community-level perspective. Review boards often see research as a short-term relationship that begins and ends after signing a consent form and filling out a survey. Community-based researchers may want to take a broader perspective when thinking about risks and benefits to the community as a whole. This is especially true for those that see research as a communal intervention that is part of a larger emancipatory agenda of community building and social development. Some questions that teams may want to consider that may not necessarily be covered in a traditional ethics review are outlined in Table 1.

Communication and Power Sharing

Invoking democratic ideals, many researchers write about the importance of sharing power and ownership with community members (Ross et al., 2010). Implementing this ideal, however, is persistently challenging (Flicker et al., 2008). Several participants in our study highlighted the importance of transparent decision-making and open communication regarding roles and responsibilities:

> People need to know where they stand and people also need to know that we all understand each other's roles in the same way. They are important conversations to have … just to feel out how people understood the roles in terms of hierarchy and power … I mean it's not power over in terms of you're a lesser of a person because you don't have letters behind your name or anything like that. (Service Provider)

Nevertheless, many of the peer researchers we talked to felt like they had limited power and decision-making ability over the design or execution of project activities. When peer researchers were asked whether they felt ownership or had an opportunity to participate in larger project decisions, one responded:

> I think I got a "don't worry about it" … I feel a little bit of a disconnect between what the coordinators know and what's filtered down to me. So, I feel a little bit of, like, they're withholding knowledge somehow … I feel a little bit on the outside. Like, that I'm part of the experiment, and that doesn't sit that well with me. Cause I want to be included in it … part of me thinks that … [at investigator meetings] there should be at least … a representative of the peer researchers. (Peer Researcher)

In some projects, peer researchers felt totally included in project decision-making, while in others, they felt excluded. In instances of the latter sort, peer researchers articulated that it did not feel right to hear project spokespeople using the rhetoric of participation when they felt like that was not the case.

The effective inclusion of peers relies on attention to power differentials and a commitment to shared, transparent decision-making processes. Failure to adopt these inclusionary practices runs the risk of making peer involvement instrumentalist rather than empowering. As Simon and Mosavel (2010) argue, used in isolation from many more comprehensive community-engagement approaches, peer research involvement can easily become tokenistic or exploitative. Care should be take to avoid research practices that benefit extensively from the labour and expertise of peer researchers but offer little in return in the way of recognition, remuneration, or a sense of ownership of the work (Elliot, Watson, & Harries, 2002; Simon & Mosavel, 2010).

Nevertheless, these dynamics are complex. One service provider noted:

> Can we comment on the decision-making process, and what peers are involved in? I mean, in some ways we try to involve the peers themselves in terms of what they'd like to … but that brings this very interesting ethical dilemma, conflict of interest kind of complexity as well, because we have peers involved in the advisory committee having shaped the research, right, and its these peers themselves, they often then get hired if there's actually data collection they can help with, whatever tasks, but in some ways we're sort of strug-

> gling about the conflict of interest, where we're in these decision making meetings, where we're saying, ok, we need to decide how many peers will be involved in data, ok, what peers will be involved in data collection, and analysis? … So, we're struggling with, maybe it's a better system that people on the advisory committee are notified beforehand that they can't be hired as actual research … surveyors. (Service Provider)

Although community members did not always use philosophical language to talk about ethics, they were more than able to describe when something simply did not "feel right." As well, community members often spoke from a lived experience of having been "researched" in the past, and could identify aspects of the research process that made them uncomfortable or that they would like to see used again:

> [A]ctually, every member around the table … has been part of a study … and they actually have some fairly strong ideas, that's one of the places we started, was actually to talk about what it was like to be interviewed, you know, what their experience was like with research … we had done some of that conversation about "how do you want," "how do you like to be treated?" (Service Provider)

Drawing on this rich experience can be beneficial in the planning stages. In one research project, peer researchers argued that it was wrong to survey youth about gaps and barriers to sexual health resources (including basic information about STIs and HIV) and leave without providing the needed information. In response, the research team decided to follow survey administration sessions with a sexual health education workshop. The youth advisory committee members also asked that the survey be administered in community rather than school settings, as they were worried about how other youth would feel filling out the survey sitting near their peers and teachers (for a full discussion of the ethical aspects of this study, see Flicker and Guta, 2008).

Conflicts of Interest

In research ethics, conflicts of interest are commonly understood to arise when a researcher has more than one role (e.g., a physician conducting research on his or her patients). The concern is that participants may become confused about the difference between these roles, and feel undue pressure to participate. For instance, patients may participate in a study out of a fear that their future care may be compromised.

In community based research, the benefits associated with leveraging these complex relationships are often promoted. For instance, peer researchers are often encouraged to use their personal contacts and stature to recruit their sometimes hidden networks into a study. Participants highlighted the benefits of "peer-to-peer" interactions:

> I think whenever you're doing a project that's looking at marginalized communities, you bring someone from that community into a leadership position, it really sends a strong message to the community you're actually interviewing, that you're important, you can play a bigger role. (Service Provider)

Indeed, peers highlighted the benefits of being a community member with a shared experience when doing outreach with participants:

> I think the fact that we were peer researchers … they were more comfortable … I think it actually improved the quality, the fact that they were very comfortable. So they started talking, and they were open, and they felt free with us. (Peer Researcher)

Many study participants suggested that community members may be more inclined to participate in a study if approached by a known peer rather than a researcher that they did not know. Furthermore, it was acknowledged that peers are often able to navigate hidden networks better than outsiders, especially when the community of interest has been traditionally difficult to engage through research. Peer recruiters could be a practical and benign way to overcome language barriers and cultural differences when recruiting potential subjects (Phillips, 2010). As a result, most of the studies we examined used peer researchers in their recruitment efforts.

In contrast to a physician-patient relationship (where a clear power differential exists), many participants in our study felt that peers were better able to level the playing field and help participants make informed decisions about participation. Nevertheless, a variety of more subtle power differentials surfaced. Several peers reported recruiting their close friends, intimate partners, and/or family members into studies. They spoke with pride about their ability to tap into these personal

networks and how the inclusion of their contacts contributed to the success of the research:

> It could not have been done without the peer researchers. Mainly, it could not have been done without the people we knew. (Peer Researcher)

Often, peer researchers not only recruited these participants but also were the ones to go through informed consent procedures and data collection with their close relations. This practice raises a number of ethical issues. First, it can sometimes be very difficult to say no to someone you know personally. Similar to the physician–patient example provided above, a close friend may agree to participate in a study to avoid jeopardizing a friendship (Bean & Silva, 2010; Phillips, 2010). On the other end of the equation, a peer researcher may feel uncomfortable about approaching those in his or her close circle. In one study, a peer researcher described how he stayed with an abusive partner in an effort to minimize study attrition because he had recruited his partner into the study. Another issue we heard about was how challenging it was for some peer researchers who felt confused by their dual role of researcher (who maintains confidentiality) and friend/family member who felt compelled to become an outspoken advocate. Others studies have also documented this challenge (Elliot et al., 2002; Simon & Mosavel, 2010).

While peer researchers are able to leverage their personal networks to recruit, it may be appropriate to have someone who is more at "arms length" walk through consent procedures and data collection (Bean & Silva, 2010). When that is not possible, it is doubly important for peer researchers to reiterate to study participants that they are participating in research (not just friendly conversations), and that they have the right to refuse to participate and not answer particular questions (Molyneux, Kamuya, & Marsh, 2010; Ross et al., 2010) . In fact, "refusals by community members are not only acceptable, but potentially indicative of an ability to make a choice" and should be seen as a good sign (Molyneux, Kamuya, & Marsh, 2010).

Confidentiality

> I don't think that … somebody who's not skilled in research wouldn't have the capacity to pick up the importance of the logic of confidentiality. It's just getting that match in terms of maturity and work ethic. (Peer Researchers)

Confidentiality is always an issue in research. Peer researchers, like all staff with access to private information, need support and training to adopt careful protocols around privacy and confidentiality. However, their training needs may be slightly different. They have likely never had professional training on clinical ethics that other members of the team may have undergone; moreover, the concept of confidentiality may be newer for them. Furthermore, because of the close relationships that peer researchers often have with research participants, and the community at large, they may feel increased pressure to share things that participants have disclosed. However, we should not necessarily assume that peer researchers will not honour the commitment to confidentiality. Many peer-researcher participants in our study felt that they had been adequately trained in this regard and were able to explain the value of maintaining strict policies around confidentiality. Nevertheless, in some cases additional training may be required to explore the challenges (and legal limits) of discretion in close-knit communities. In response to peers recruiting from their personal networks, one researcher told us about how confidentiality was discussed as an ongoing issue in the team:

> [P]art of the debriefing session was also to … re-highlight the importance of confidentiality, we had done that before, but again, after learning all that … and we wanted to double emphasize the importance of confidentiality. (Service Provider)

In this project, discussions of confidentiality were ongoing to make certain that all involved had a shared continuing understanding of their commitment. In another project, researchers only became aware of the complexities of confidentiality well into the project:

> [S]o in this one we involved them in actually, they helped in recruitment, they did the actual focus groups, and then we realised, wait a minute, there's lots of complex ethical issues about actually involving peer researchers, peers interviewing or conducting focus groups within their, among their own peers. (Service Provider)

Confidentiality of data may be more difficult to ensure when socially proximate individuals collect data from each other (Bastida et al., 2010). It can be hard to know how or why a secret becomes more widely known. Issues of confidentiality are not limited to data collection; they also need to be considered when analyzing

the data. Questions to consider include: Who will have access to the data? In what form? For what purpose? To what extent can the data by anonymous? How will data be shared among team members?

Emotional Triggering and the Need to Provide Special Support

Emotional triggering was another area of particular ethical concern that emerged in our interviews with study participants. This phenomenon was experienced most acutely by peer researchers who had past experience with the issue under study (such as homelessness or drug use) rather than those currently impacted by the issue. In these cases, peer researchers were sometimes asked to return to environments (e.g., shelters or needle exchanges) where they encountered peers, settings, and dynamics that were at times traumatizing. These difficult environments were often supportive of behaviours and lifestyles that peer researchers were struggling hard to "move on" from.

Service providers described how the strategy of hiring those with past experience of an issue was very useful because these peers were likely to be more stable and able to commit to project needs, and had an intimate cultural understanding of the community. Nevertheless, some projects underestimated the emotional toll that re-immersing peer researchers in spaces that they had worked hard to leave behind might take:

> Well, for me personally, um, it was a bit of an issue because I … wasn't really prepared for that aspect of it—for whatever reason … It had more of an impact than I thought it would … There [were] a couple people who got emotional and upset about certain issues. (Peer Researcher)

Some study participants described how they had tried to prepare peer researchers for this challenge during training. Others described how their teams instituted ongoing support meetings with peer researchers to debrief and assist peer researchers with the unanticipated emotional impact of the work. The level of ongoing support and supervision necessary to ensure that both project and peer researcher needs are met should not be underestimated (Elliot et al., 2002).

Considerations Beyond the Life of the Project

Whereas academics and service providers are often hurried along to the next project or pulled back to previous commitments following the completion of a project, peer researchers may find it difficult to transition out of the project. This may be especially true when a strong team has been developed, and peer researchers become accustomed to regular support. Coordinators should be wary of creating false expectations for individual peer researchers that exceed the limitations of any one community-based research project. As many peer researchers are drawn in from existing services and will continue to access those services, unmet expectations could create future problems in those relationships if the benefits of the project are not articulated clearly from the beginning.

Furthermore, it may be important to think through how to create closure and ensure that peer researchers find other mechanisms for support after the project ends. Many peer researchers talked about ongoing project meetings as a time when they could personally connect with others and get help with a variety of personal and work related matters. An abrupt end to these activities might leave many vulnerable peer researchers with a large void. Developing a thoughtful wind-down, with some additional follow-up mechanisms may be helpful for ensuring a smoother transition.

Conclusion

Ethical issues are by their very nature complex. There are rarely easy right and wrong answers to challenging ethical issues. While participants in our study were quick to argue that adopting a peer research approach was simply "the right thing to do," when probed they identified a number of new and emerging ethical issues that resulted from this approach. Careful ethical reflection throughout the life of a research project can provide a team with the opportunity to come up with creative, attentive, and just responses to these challenges. Failure to take the time to think them through could have devastating consequences.

Recommendations

WE ENCOURAGE COMMUNITY-BASED RESEARCH TEAMS TO:

- Use the formal ethics review process as an opportunity to reflect on broader ethical issues with the entire research team.
- Align their rhetoric of participation with commensurate power-sharing schemas and create transpar-

ent decision-making structures.

- Explore issues relating to conflicts of interest and confidentiality broadly and extensively in their training, and ongoing support work, with peer researchers.
- Consider the emotional impact of the work that they are asking of peer researchers and provide appropriate mechanisms for ongoing support and supervision.
- Think about how to develop appropriate wrap-up activities and a sense of closure.

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CENTRE FOR Urban Health INITIATIVES

Peer Research in Action III: Ethical Issues

Peer research has emerged as a popular form of community-based research (CBR) where research projects include members of the target population who are trained to participate as co-researchers. The inclusion of community members in CBR through peer research initiatives is thought to enhance the quality of the data collected, allow for the expertise of lived experience to be incorporated over time, while promoting capacity building at the local level.

In Part III, we consider the particular ways in which ethical challenges surfaced and were addressed when using a peer researcher approach. We consider issues related to formal ethics reviews, communication and power sharing on projects, conflicts of interest, confidentiality, and the emotional challenges that can accompany community based research projects in action.