

Late Evidence, Delayed Action:

Late Presentation to Care and Its
Implications in the Continuing of Care in the
Prairies

Final Report
July 2010



Report prepared by
Paula Migliardi and Pumulo Roddy

Acknowledgments

As members of the organizing committee we would like to thank the presenters, Dr. Johnmark Opondo and Dr. Stuart Skinners, and participants of the event, our facilitator, Francisco Ibáñez-Carrasco (UWW), and the funders, GILEAD and the Canadian Institutes of Health Research (CIHR) through their HIV CBR Program.

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Introduction and Background

The *Late Evidence Delayed Action* session was a follow up to a meeting in April 2009. This meeting was concurrent to the Annual Canadian Association of HIV Research (CAHR) conference in Vancouver. The *Cocktails Scientifique* gathering was designed to address the gaps in communication about HIV research across the different disciplines, sectors and provinces.

The event was organized in partnership between the Manitoba HIV Program (Nine Circles Community Health Centre and Health Sciences Centre), the University of Manitoba and the Prairie HIV Community Based Research Program.

In April 2009, concurrent to the CAHR conference in Vancouver, a group of prairie-based researchers and HIV care providers from many disciplines gathered to: learn about the current state of HIV research in Manitoba, Saskatchewan and Alberta; discuss gaps and opportunities for future research and action; and to strengthen communication and build partnerships in the region. As result of the meetings' success, of the meeting, the participants agreed to reconvene at the next CAHR conference in 2010.

Members of the Committee engaged in regular follow up exchanges to organize the 2010 event. During that time, the group identified potential key participants, including a expanded list from those attending previous prairie focused meetings, speakers and an animator; sought and communicated with potential and actual funders; and developed materials and the agenda for the meeting. The animator of the event provided valuable suggestions in the development of the agenda and structure and flow of the meeting.

For 2010, we expanded the network of researchers and practitioners to further explore current research and turn knowledge to action in the prairies. An issue of major concern for practitioners in the prairies is that too many people get diagnosed with HIV or access health care services when an AIDS-defining opportunistic disease is apparent or when CD4+ T-cells are <200/microl. This late presentation raises a tremendous challenge for programs along the continuum of care. A multidisciplinary approach is required to address this challenge, including researchers from the social sciences, epidemiology, public health, basic sciences and clinical sciences as well as support from care providers across all sectors (i.e., research and practitioners along the spectrum of care from treatment, support and prevention).

Purpose of the Session

The session, an ancillary event to 2010 CAHR in Saskatoon, SK, brought together university, public health and community organizations for a discussion on HIV research in the Prairies. The objectives of the session were to:

- Present updated information on the HIV epidemic in the prairies
- Highlight knowledge specific to late presentation to care
- Identify 'best practices' at the prevention and detection stage (public health and non-for-profit community based organizations) and health care and treatment (public health) stages that effectively ameliorate late presentation to care
- Identify gaps in policy and services
- Formulate preliminary research ideas for a multi-sectoral and interdisciplinary research approach to fill this gap.

The Program

The *Late Evidence, Delayed Action* session was an ancillary session to the annual Canadian Association of HIV Research (CAHR) conference in Saskatoon, the three-hour event was designed to cover basic epidemiological information for the Prairie region, and a look at the issues around late presentation to care. Dr. Johnmark Opondo (Saskatchewan) and Dr. Stuart Skinner (Saskatchewan) presented on these two areas of knowledge respectively. Their presentations were followed by small group work around four areas in the continuum of care as relate to late presentation to care.

The Presentations

Dr. Opondo showed how the epidemic is faring in relation to other provinces demonstrating that Saskatchewan is increasingly becoming affected by it. With a focus on the HIV epidemic in Saskatoon, Dr. Opondo highlighted the need to focus on this city as HIV rates have risen dramatically to account for about half of the people testing positive in 2009 (about an even split between women and men testing positive). Among youth, female were more likely to test positive, while those aged 25 and above were more likely to be male, with an even split for ages 30 to 39. He also indicated that there is enough evidence to demonstrate that HIV affect those in low socio-economic status, from some key neighbourhoods, living with substance issues and experiencing physical and sexual abuse. Over three quarter of those testing positive in 2009 were of Aboriginal descent, mostly female. He highlighted the use of a syndemic theoretical approach and the need to understand the urban context to analyse the epidemic in the city of Saskatoon. Saskatoon Region used a social network approach to increase access to testing and investigate the local situation. This study rendered a number of learnings about social conditions, sexual and other behaviours that may put people at higher risk for HIV (e.g., having been in jail, homelessness, needle sharing, low of use of condom). A copy of the presentation is appended.

Dr. Skinner discussed the public health, clinical and health care cost implications of late presentation to care. He utilized a number of actual cases from his own practice as a teaching tool for increased awareness on the matter. He indicated that in spite of access to HIV medication, there is still significant mortality associated with those who present with advance disease. He highlighted diagnosis is different than presentation to care as presentation to care means access to the medical system for the purpose of monitoring the disease. He went further to indicate that presentation is also different than engagement in care, something that is required for increased quality of life, something that is challenging when it comes to people facing many challenging situations in life (e.g., homelessness, IDU, abuse, etc.). In Saskatchewan, those presenting late are: heterosexual, older people, immigrants and those coming from developing countries; in addition, those who inject drug may present late (and no necessarily diagnose late) be lost to follow-up. Dr. Skinner demonstrated the implications for HIV transmission (e.g., increased infectivity), for clinical management (e.g., increased mortality, risk of opportunistic infections, impact of HIV-related symptoms) and, the higher cost of medical care. Late presentation is a concern in the prairies with about 35% of patients in 2007 presenting late. He indicated that outreach and retention to care were main concerns. A copy of the presentation is appended.

Small Group Work

Participants were asked to join one of four groups. The groups were designed around the *Prevent-Find-Link-Retain* motto. This motto was chosen to indicate the different areas in the HIV continuum of care as they relate to late presentation. Each group was asked to discuss one of these aspects and respond to a series of questions. The questions were designed to assist each group to elicit a key research question and approaches to dealing with such question.

Four small groups of about 10 participants each was asked to focus on one specific area in the continuum of care. Most participants were pre-selected to participate in a specific group based on their professional background and assumed interest on the broad topical area. Each group was asked fulfill the following task:

- *Discuss a research topic and question on the aspect of the issue of Late Presentation assigned to your table.*
- *Tell us:*
 - *What will happen if we don't address this question?*
 - *Who is the target population?*
 - *How would you go about making this project happen?*
 - *Who are the partners or collaborators in the project?*
 - *What resources would you need? (include specific sources of funding if known)*
 - *How would you communicate with those that need to be at the table, including those already at the table.*

The groups developed a series of research questions or areas of research interest. These are as follows:

- **What is the most effective intervention post HIV diagnostic to prevent further transmission**
- **What are the perspectives of the clients/medical staff/ other stakeholders/etc. in regards to opt out point of care testing in ER's?**
- **What are the barriers that prevent persons from becoming linked/engaged to care?**
- **How do we keep people in care after they are diagnosed? What are the factors that increase engagement to care after diagnosis?**

The Participants

A cross section of researchers and practitioners from the three prairie provinces (i.e., Alberta, Saskatchewan and Manitoba) were invited to the event. Many indicated their interest in the event; however, were not able to attend. Excluding members of the organizing committee, about fifty participants attended the full event. Most of the participants had registered to the event

(n=35); however, as the event was advertised in the program for the CAHR conference, many more showed up. Most of them (registered and non-registered) attended the full event. Some of the participants only attended the first part of the event (i.e., presentations by Dr. Opondo and Dr. Skinner), while about 40 participants attended the full meeting. There was a larger representation from Saskatchewan and Manitoba, with a few participants from Alberta. This reflected the overall rate of participation from these provinces to the general CAHR conference.

Participants represented a wide range of sectors and disciplines from all three provinces. There were about an even participation of representatives from community and public health organizations, and academic researchers. Government researchers and representative of funding agencies (industry/private and public) were also in attendance. The community representatives were practitioners in the clinical and prevention areas. The academics represented all the discipline streams from the Public Health and Epidemiology, Social, Clinical and Basic Sciences, including researchers and students.

Over 50 percent of the participants to the full event returned the evaluation questionnaire (n=23).

Evaluation of the Meeting

Methodology

The evaluation is based on a half-day meeting on the issue of late presentation to care with people from the prairies. At the end of the meeting participants were asked to complete an evaluation form and a total of 23 forms were gathered. Participants were asked to respond to 15 questions, 11 of which required a rating (using a 4 point Likert Scale) and the remaining 4 were open ended questions. The data was coded and analysed using SPSS software.

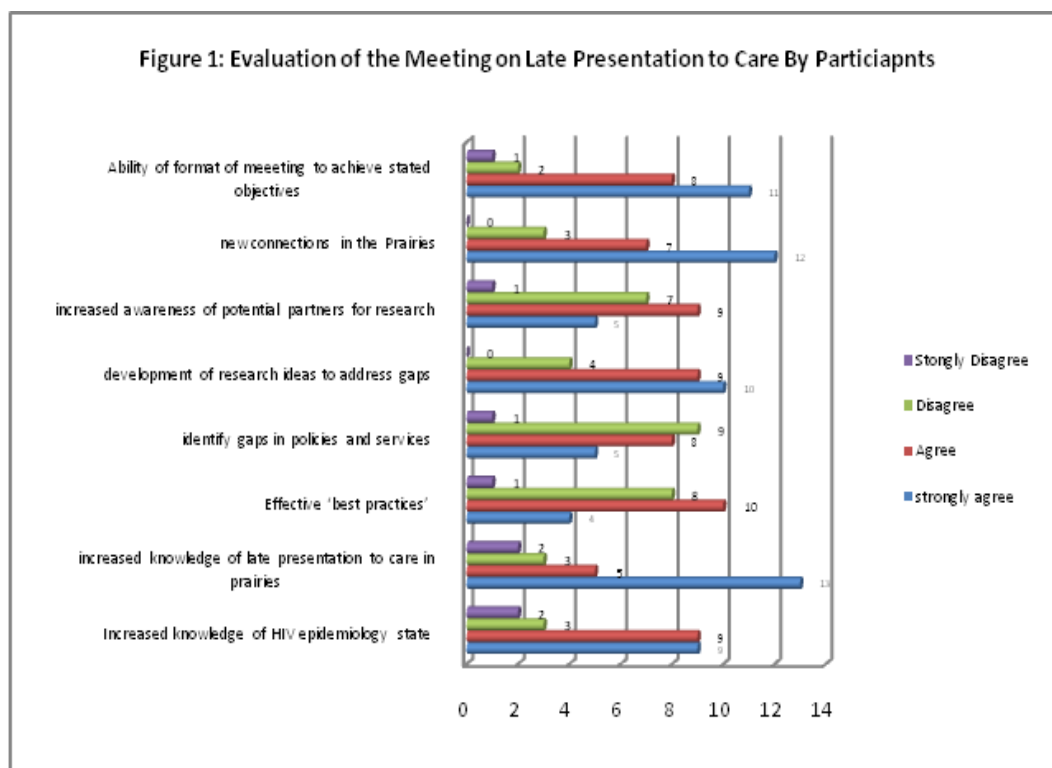
Outcomes

From Figure 1 below it is clear that the majority of the respondents (50 percent very strongly agreed and 36 percent agreed) believed that the **format of the meeting was adequate for achieving the objectives** set of the meeting. From figure 1 it is also clear that the meeting **increased participants' knowledge of late presentation to care** (57 percent agreed and 22 percent strongly agreed). Participants also strongly agreed (55%; N=12) and agreed (32% N=7) that the meeting **increased their interest in finding new connections** in the prairies which implies the need for more collaboration.

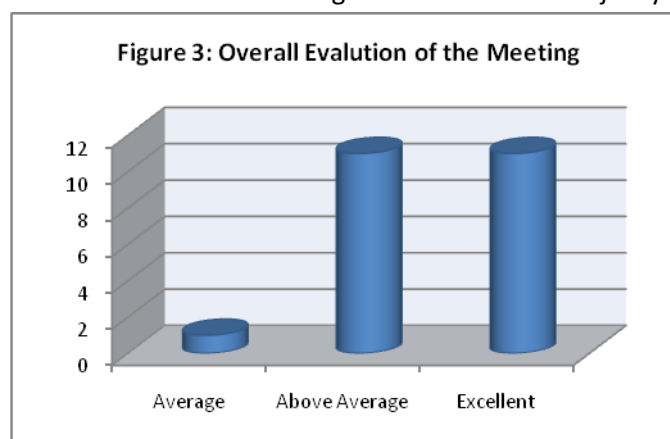
Furthermore, participants strongly agreed (43 percent) and agreed (39 percent) that the meeting also helped them to **develop preliminary research ideas** that would effectively address gaps in late presentation to care. Seventy-eight percent of the participants strongly agreed (39 percent) and agreed (39 percent) that their **knowledge about the state of the HIV epidemiology** in the prairies was increased by the meeting. Only 23 percent of participants strongly agreed that the meeting had **increased their awareness of potential partners for research** compared to 41 percent who agreed that this was the case. It is interesting to note however that only 22 percent of participants strongly agreed while 35 percent agreed that the meeting helped **identify gaps in late presentation to care policies and services**. Similarly, only 17 percent of participants strongly

agreed and 43 percent agreed that the meeting had helped them **identify ‘best practices’** that **effectively ameliorate late presentation to care.**

Ninety-five percent (N=20) of the participants indicated that the event was commercial free suggesting that the meeting was uninterrupted by industry influence. Only one person thought it was not commercial free (figure 2).

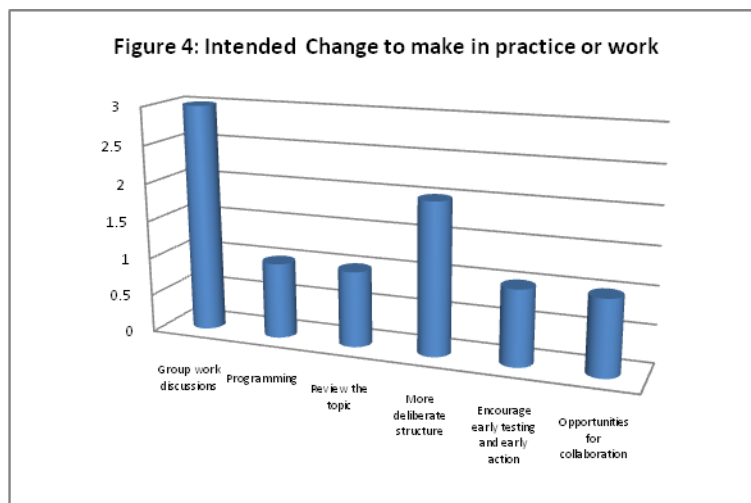


In terms of the overall rating of the meeting, the majority of responds believed that it was excellent (48 percent) and above average (48 percent) (Figure 3). Only one person thought that it was only average. This indicates that the meeting was useful to the majority of participants.



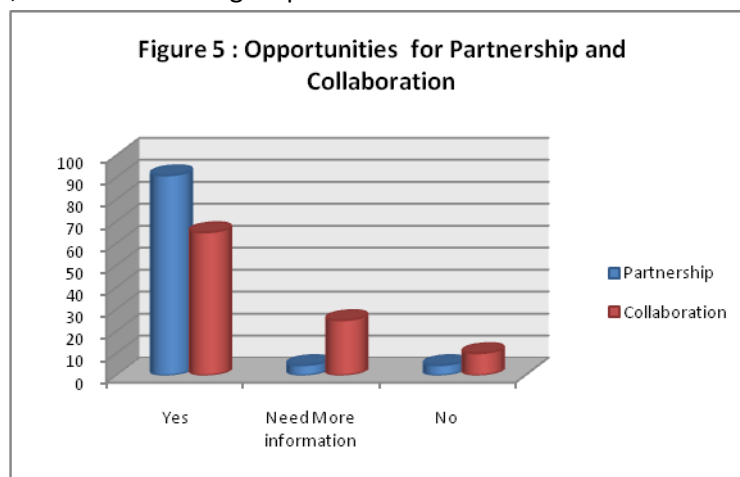
Practical Aspects

Out of the 23 participants only 9 of them identified a few changes they intended to make in their practice or work as result of the meeting (Figure 4). Of the 9 participants who answered this question 33 percent said they would organize group work discussions. Twenty-two percent said they would initiate more deliberate structures. The remaining respondents were divided equally with 11 percent each suggesting more programming; reviewing of the topic; encourage early testing and early action; and taking advantages of the collaboration with other researchers in the prairies.



Opportunities for Partnership & Collaboration

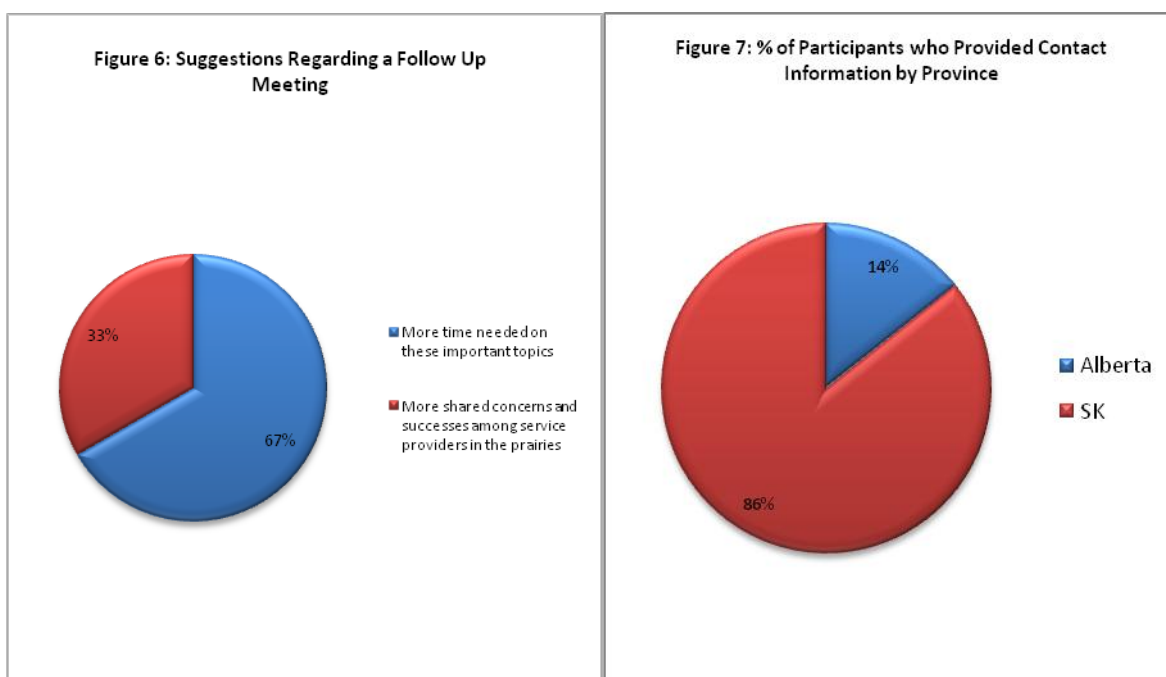
Ninety-one percent of the respondents expressed an interest in partnerships, i.e. in becoming part of the prairie focused network (Figure 5). About five percent wanted more information and the remaining five percent did not express any interest at all. In a similar vein, 65 percent were interested in collaborating with Prairie based researchers and community through participation in the organization of future events; twenty-five percent required more information on this before committing to this; and the remaining 10 percent were not interested.



Considerations for Future Meetings

Apart from being interested in making changes in their practice and work, participants also provided suggestions for a follow up meeting (see figure 6). To this end 67 percent suggested that there should be more **shared concerns and successes among service providers in the prairies**. The remaining 33 percent were concerned about the limited time allocated to the topics and therefore suggested that in the follow up meeting there should be **more time for the topics** that will be discussed.

Finally, in terms of contact information only a few participants provided some of the information requested. Saskatchewan accounted for 86 percent of those who responded while Alberta accounted for only 14 percent (Figure 7).



Concluding remarks

In summary, the late presentation to care meeting appeared to have significantly improved the participants' knowledge of various issues related to this topic of late presentation and late action. The objectives set of the meeting were adequately met. The meeting had quite a number of positive responses and benefits. The meeting increased participants' knowledge of late presentation to care; increased interest in networking and collaborating through the desire to search for new connections in the prairies; encouraged the need to develop preliminary research ideas that would effectively address gaps in late presentation to care; participants became more knowledgeable about the state of the HIV epidemiology in the prairies.

There were however not so strong responses. Participants felt that the meeting did not increase their awareness of potential partners for research as much as it did other issues touched in the meeting, possibly meaning that many of the participants were at least already in knowledge of each other. Also participants felt that the meeting did not strongly identify gaps in late

presentations care policies and services. Participants were also not strongly convinced that the meeting had helped them identify best practices for late presentation to care. Future meetings and networks need to take these issues into account if people are to be equipped with the right tools in their work and practice.

In order to strengthen the collaboration across provinces, the group decided to continue working together. A follow-up meeting was to be scheduled for the late spring to further discuss the research questions designed by the small teams and assess the interest to continue working together on a specific research idea.

Appendices

List of Registered Participants in Attendance¹

Julia Bietz

Alberta Community Council on HIV

Faisal Shafiq

Alberta Community Council on HIV

Dr. John Gill

Southern Alberta HIV Clinic

Catherine Card

University of Manitoba

Dr. Ken Kasper

Manitoba HIV Program

Jennifer Juno

University of Manitoba

Yoav Keynan

University of Manitoba

Laurie Ireland

Nine Circles Community Health Centre

Shanna Chan

Manitoba HIV Program

MaryStella Anidi

Sexuality Education Resource Centre

Dr. Keleigh James

Nine Circles Community Health Centre

Kim Bresler

Health Sciences Centre/ HIV Clinic

Melissa Bendig

Planned Parenthood Regina

Shannon Stone

HIV & Hepatitis C Outpatient Clinic, SK

Kim McKay-McNabb

First Nations University of Canada

Dr. Stuart Skinner

University of Saskatchewan

Dr. Johnmark Opondo

Saskatoon Health Region

Neena Saxena

Public Health Agency of Canada

Michelle Bilan

Regina-Qu'Appelle Health Region

Yule, Angela

Saskatoon Health Region

Bosse, Monica

Saskatoon Health Region

Walters, Pamela

Saskatoon Health Region

Gibson, Sandy

Saskatoon Health Region

Cathy Johnson

AIDS Saskatoon

Susanne Nasewich

Regina-Qu'Appelle Health Region

Donna Bleakney

Saskatoon Health Region

Brenda McAllister

Saskatoon Health Region

Jessica Halverson

Public Health Agency of Canada

Neil Boutin

Gilead

Organizing Committe

Marissa Becker

University of Manitoba and Manitoba HIV Program

Paula Migliardi

Prairie HIV Community Based Research Program

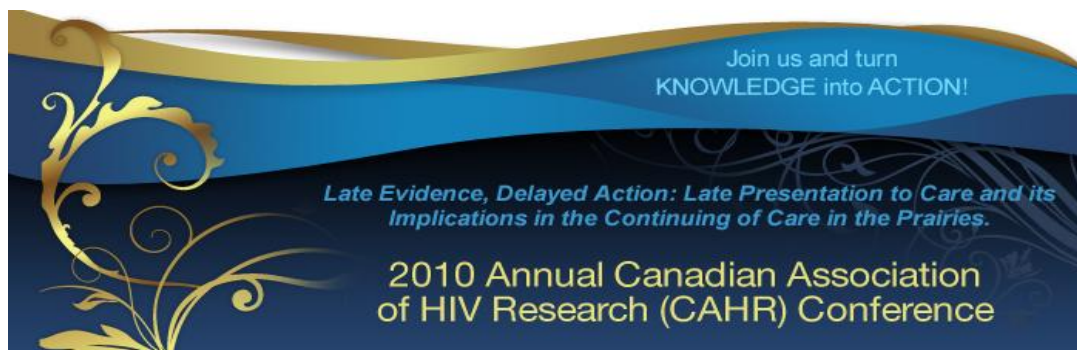
Carla Pindera

Nine Circles Community Health Centre

Francisco Ibáñez-Carrasco

University Without Walls (OHTN)

¹ A number of additional non-registered participants attended part or the full meeting.



Late Evidence, Delayed Action: Late Presentation to Care and Its Implications in the Continuing of Care in the Prairies
May 13th, 2010 – 2 to 5 pm
Prince Albert Room – Hilton Garden Inn, Saskatoon, SK

Objectives

The objectives of this meeting are to:

- Present updated information on the HIV epidemic in the prairies
- Highlight knowledge specific to late presentation to care
- Identify 'best practices' at the prevention and detection stage (public health and non-for profit community based organizations) and health care and treatment (public health) stages that effectively ameliorate late presentation to care
- Identify gaps in policy and services
- Formulate preliminary research ideas for a multi-sectoral and interdisciplinary research approach to fill this gap

Agenda

Welcome and Introductions (Ken Kasper)

Objectives and Meeting Procedures (Francisco Ibáñez-Carrasco)

Updated Information on the HIV Epidemic in the prairies (Dr. Johnmark Opondo)

Questions and Answers

Prairie-Based Knowledge on Late Presentation to Care (Dr. Stuart Skinner)

Questions and Answers

The presentations and questions will address the identification of 'best practices' and policies at the prevention and detection, and health care and treatment stages that effectively ameliorate late presentation to care, as well as the gaps in these areas.

BREAK

Agenda (continued)

Research Agenda Development (Small Groups)

Participants will join one of 4 groups in order to discuss the outcomes of the presentations and discussions and formulate preliminary research ideas for a multi-sectoral and interdisciplinary research approach to fill this gap (what kind of research is needed and possible in the Prairies, who can be and should be part of such partnership)

Report back and Discussion on Research Ideas and Opportunities

Strategy Moving Forward (Marissa Becker)

Close and Evaluation

Organizers

Manitoba HIV Program
Nine Circles Community Health Centre
Prairie HIV Community-Based Research Program
University Without Wall (OHTN)

Sponsors

GILEAD
CIHR

Saskatoon : Updated information on an HIV epidemic in the prairies

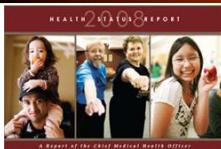


Dr. Johnmark Opondo
Deputy Medical Health Officer
CAHR Ancillary Event, Saskatoon
May 13, 2010

SHR is one of 12 RHAs in Saskatchewan



SHR's Vital Stats



Overall health status is great...
Population 300,638
Life Expectancy 79.8 in 2004
Infant Mortality Rate 5.9 per 1000 in 2006
HIV rates have risen dramatically from 5.6 per 100,000 to 31.3 per 100,000 in 2009
However...
Like most big urban centers in Canada significant disparities exist in health among residents of SHR

Health Profile SHR

Compelling evidence from SHR indicates that low socio-economic status in some Saskatoon neighbourhoods correlates with persistent:

- High Rates of HIV Infection
- High Rates of Substance Use and Abuse
- High Rates of Physical and Sexual Violence

Lemstra M, Neudorf C, Opondo J. Health disparity by neighborhood income. Can J Public Health 2006.

Prevention interventions in place SHR

- HIV Testing and counselling
- Education and Behaviour modification
- PEP
- Needle Exchange Programs
- Universal Precautions
- ARVs to prevent MTCT
- Non breastfeeding
- Blood supply screening
- Free condom distribution
- (Media campaigns on and off)

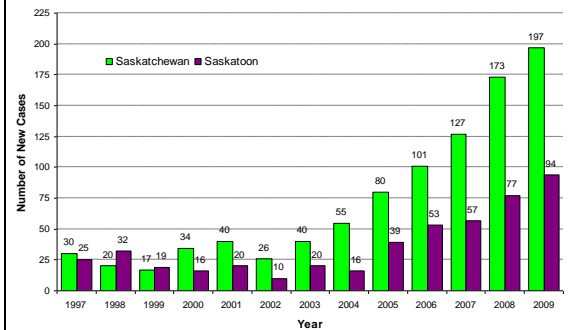
WHEN HIV TESTING IS OFFERED IN SHR

- As a part of a regular physical exam
- Prenatal care testing (opt out)
 - Newborn follow-up testing
- STI clinical exam
- HIV partner notification and contact tracing
 - HIV social network investigations
- Rapid POC HIV Testing (New)

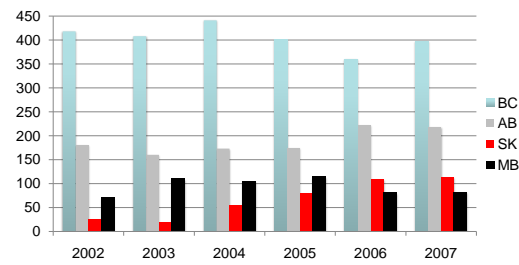
TESTING VOLUMES IN SHR

- Total number of tests in SK 2009
 - 48,983
 - Approx 1% positive
- This number includes
 - Prenatal care (Goal 100% coverage)
 - Occupational PEP
 - Clinical diagnosis

Increasing Numbers of New HIV Infections in SK and SHR



New HIV diagnoses, Western Canada – 2002-2007



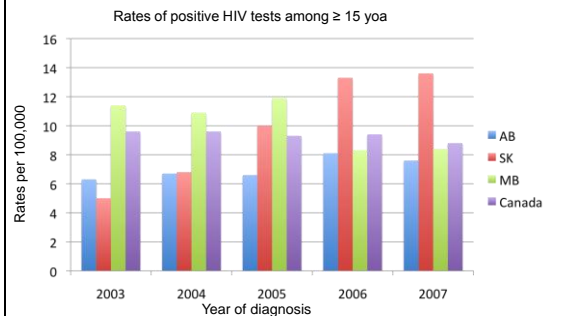
New HIV diagnoses, 2002-2007

- Canada: 2432-2559

- Saskatchewan proportionately: 1% → 4.3%

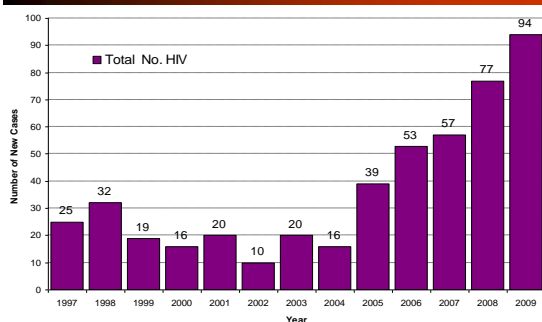
Public Health Agency of Canada, www.phac-aspc.gc.ca/aids-sida/publication/surveilport/pdf/surveilport1207.pdf

A comparison of rates across the prairies



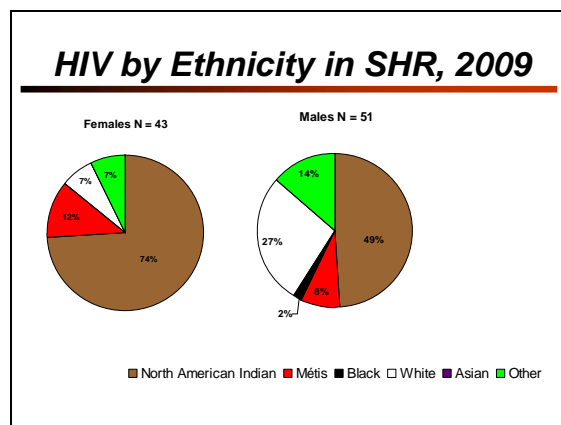
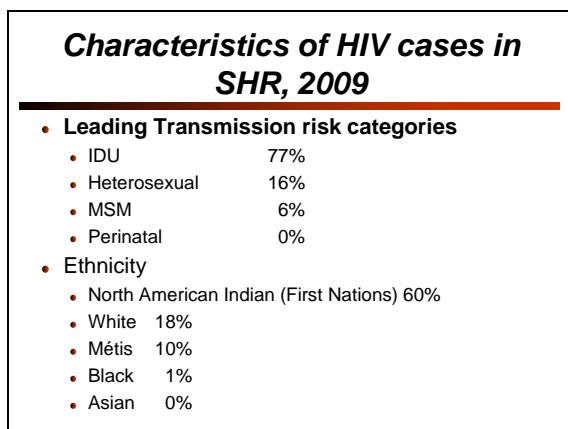
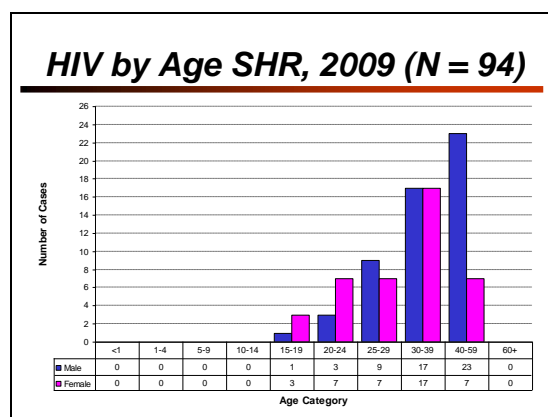
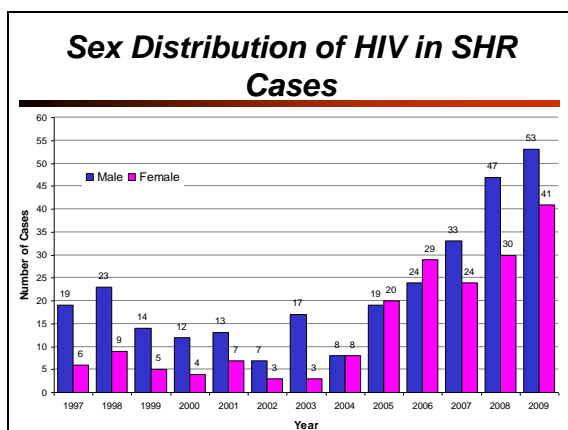
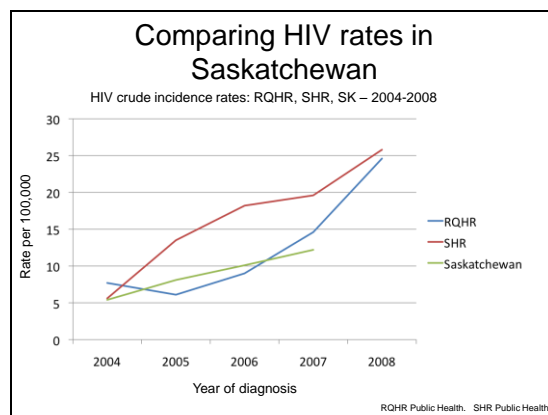
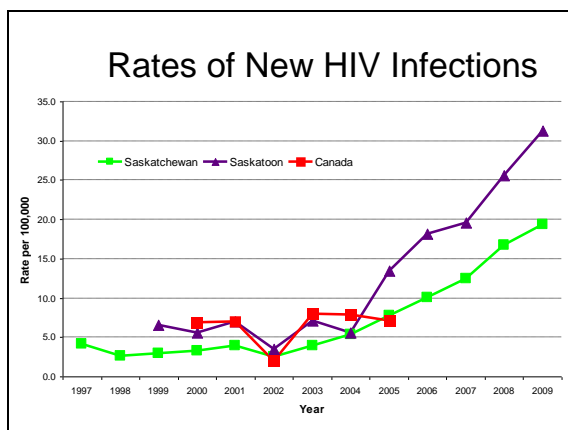
Public Health Agency of Canada, www.phac-aspc.gc.ca/aids-sida/publication/surveilport/pdf/surveilport1207.pdf

Reported Cases of HIV, SHR 1997 - 2009



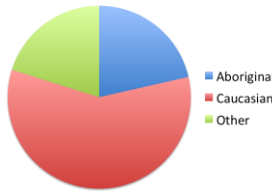
Basic Statistics of HIV in SHR, 2009

- 94 new HIV diagnosis
 - 53 Male
 - 41 Female
- Crude Rate
 - SHR 31.3 per 100,000 population
 - Saskatchewan 19.4 per 100,000 population
 - Canada 7.07 per 100,000 population (2005)

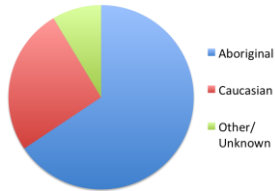


Ethnicity – Canada vs RQHR/SHR

Canada, new HIV diagnoses - 2007

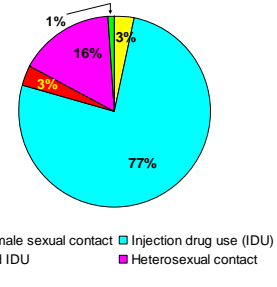


RQHR/SHR, new HIV diagnoses-2007



RQHR Public Health, SHR Public Health, Public Health Agency of Canada, www.phac-aspc.gc.ca/aids-sida/publication/surveilport/pdf/surveilport1207.pdf

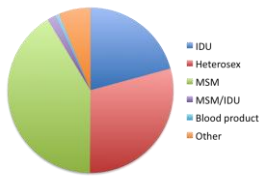
Percent of HIV/AIDS cases SHR by Transmission Risk Factor, 2009 (n = 93)



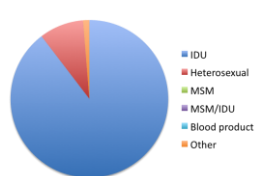
Male-to-male sexual contact Injection drug use (IDU)
MSM and IDU Heterosexual contact
Other

Risk factors – Canada vs Saskatchewan

Canada, New HIV diagnoses ≥ 15 yoa, 2007



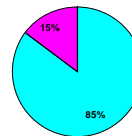
SK, New HIV diagnoses ≥ 15 yoa, 2007



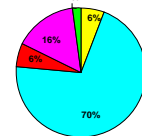
RQHR Public Health, SHR Public Health, Public Health Agency of Canada, www.phac-aspc.gc.ca/aids-sida/publication/surveilport/pdf/surveilport1207.pdf

HIV by Gender and Risk Behaviour, 2009 (n = 93)

Females N = 42



Males N = 51



Male-to-male sexual contact Injection drug use
MSM and IDU Heterosexual contact
Other / not identified

Key Observations

- Increase in number of + HIV test reports
- Increasing HIV infection among females
- Role of ethnicity and Hep C Co-infections as a risk marker

HOW DID WE GET HERE?

OLD ASSUMPTIONS

- The transmission of HIV and other blood-borne pathogens in SK is **mainly** an urban phenomenon
- That most community members understand the serious consequences of **needle sharing**
- That **chronic poverty** manifests only as an absence of material wealth.

Report of the Medical Health Officer, Saskatchewan Health Region, Public Health Services October 2008 The IDU Continuum of Care Report, Saskatoon, Saskatchewan

Syndemic theory...

- Is a framework for analysis which helps us to describe the tendency for multiple co-terminus and interacting epidemics to develop under conditions of health and social disparity, and maybe why.
- Individuals in these communities, employ a cultural logic of risk assessment which put them at high risk for infection.

Culture overlays behaviour

- This cultural logic is shaped by their experiences of growing up in the inner city which include:
 - coming of age in an impoverished family,
 - living in a broken home,
 - experiencing domestic violence,
 - limited expectations of the future,
 - limited exposure to positive role models,
 - lack of expectation of the dependency of others, and
 - fear of intimacy.

USING SOCIAL NETWORKS AS A TOOL IN HIV CASE INVESTIGATION

The Social Network Approach (SNA)

ENHANCED INVESTIGATION METHODS

ROUTINE

Obtain names of contacts exposed through:

- Sexual intercourse
- Injection drug needle sharing

With new case

SOCIAL NETWORK APPROACH

Obtain names of contacts exposed through:

- Sexual intercourse
- Injection drug needle sharing

With new case

PLUS

- Consider individuals in your social networks who you believe may be at high risk for HIV infection and would benefit from HIV CTR

A Strategy for Identifying Persons with Undiagnosed HIV infection

“Social Network investigation is all about breaking from the old model of just doing outreach. A main goal of social networking is to prevent HIV. What is put into the community in terms of knowledge and awareness is better than just random testing of people.”

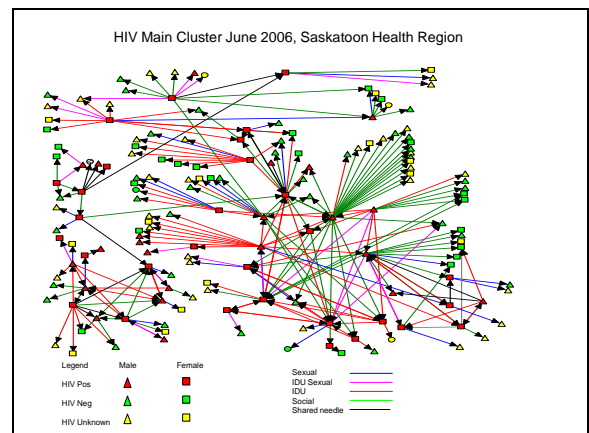


Table 1: Results of Enhanced Surveillance of the IDU Cluster Network Members (n = 187) 8 major clusters

	Male	Female	Total
Gender	107	80	187
Age (mean, range)	36 (20 – 68)	29.7 (9 – 66)	32.8 (9 – 68)
Newly diagnosed HIV*	19	27	46 (25%)
HIV positive (in total)	26	32	58 (31%)
HCV positive	43	42	84 (45%)
Survey Completed %	40	33	73 (39%)

*between May 1, 2005 - March 28, 2006

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Table 2: HIV Status and General Behavioural Characteristics (n=73)

	Male	Female	Total
Gender	40 (54%)	33 (45%)	73
Mean Age (range)	35.2 (20-67)	28.4 (17-48)	32(17-67)
HIV positive*	14 (35%)	23 (70%)	37 (51%)
Newly diagnosed HIV**	12	21	33
HCV positive*	32 (80%)	30 (90%)	62 (85%)
HIV/HCV positive	14(35%)	23(70%)	37(51%)
Ever in jail	35 (88%)	18 (55%)	53 (73%)
Homeless in last year	8(20%)	6 (18%)	14 (19%)
Used needle exchange in past 12 months	30 (75%)	29 (88%)	59 (81%)
Can always get as many needles as required	22 (55%)	19 (58%)	41 (56%)

* HIV confirmed ** Newly diagnosed between May 1, 2005 and March 28, 2006

Table 3: HIV Status and General Behavioural Characteristics (n=73)....

	Male	Female	Total
Currently using contraception or birth control	Not asked	10 (32%)	10
Sex partners HIV positive	7 (18%)	7 (21%)	14 (19.5%)
Uncertain of HIV status of sex partners	6 (15%)	7 (21%)	13 (18%)
Number of sexual partners in past 6 months	Mean = 2 Median = 2	Mean = 9.5 Median = 2	Mean = 5.25 Median = 1
Used a condom last intercourse	17(42%)	17(52%)	34 (47%)
Work in sex trade in past 6 months	0	14 (42%)	14
Current IDU#	32 (80%)	33 (100%)	65 (89%)

Table 4: Survey Respondents Injection Drug Use (n=73)

	Male	Female	Total
Ever been an IDU#	37(93%)	33 (100%)	70 (96%)
Average age of IDU initiation (range)	22 (12 -48)	19 (12-36)	20.5 (12-48)
Ever used other's needle/gear	27(68%)	28(84%)	55 (75%)
Others used your gear in past 6 months	14 (35%)	19 (58%)	33 (45%)

CONCLUSIONS

- HIV positive individuals associated with this cluster are current injection drug users and many are engaged in multiple high-risk activities:
 - Commercial sex work
 - Injection needle sharing
 - Low rates of condom use
 - Poor self care
- IDU use in this community takes place in private homes often in the company of close friends, sexual partners or family members
- A substantial proportion of these individuals are of First Nations heritage
- All the women surveyed are of reproductive age, need several special services. It is important that all pregnant are routinely tested for HIV.

OTHER ISSUES

- On-going support for HIV + individuals
- HIV stigma and discrimination
- Working with high needs clients who suffer serious social problems like:
 - Homelessness
 - Unemployment
 - Domestic violence
 - Addiction
- Need for integration of services along a continuum care
- Need a "new" model for case management?

Thank You

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Late Presentation to Care

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Objectives

- Review the public health, clinical and health care cost implications of late presentation
- Use clinical cases to illustrate the significance of late presentation
- Discuss some relevant Prairie and Saskatchewan data on late presentation and further research that is required

Case

- A 43 y.o. IDU presented to ER with fever and weakness
 - Subsequently diagnosed with bacterial endocarditis
- Found to be pancytopenic and an HIV test was positive
 - Never tested previously
 - CD4 = 9
 - Viral load = 2,000,000 copies/mL
- During further investigation, he was found to have disseminated MAC and disseminated CMV with CMV colitis
- He was started on the following medications:
 - Cloxacillin for IE
 - Dapsone prophylaxis
 - Fluconazole for thrush
 - Clarithromycin, ethambutol and rifabutin for MAC
 - Ganciclovir for CMV
 - G-CSF for neutropenia

Case

- After 2 weeks, continued cachexia and weight loss and diarrhea
 - Atripla was initiated
- Medication list:
 - Cloxacillin for IE
 - Tenofovir, emtricitabine and efavirenz for HIV
 - Dapsone prophylaxis
 - Clarithromycin, ethambutol for MAC
 - Valganciclovir for CMV
 - G-CSF for neutropenia
- Improved clinically and after 45 days discharged home
- At 2 months follow-up, continued cachexia and diarrhea
 - CD4 = 19
 - Viral load = 146 copies/mL
 - Still with MAC bacteremia
- Refused further investigation and felt medications were making him sick and stopped all meds and follow-up care

Late Presentation

- Current goals of managing patients with HIV are to prevent OI's and reduce mortality through ART
- Despite the advent of HAART, there is still significant mortality associated with patients presenting with advanced disease
- Late presentation has significant effects on individual health, public health and economic costs

What is Late Presentation?

- Typically, defined as:
 - CD4 count < 200 or AIDS-defining condition
 - Very late if CD4 count < 50
- May et al. AIDS 2007
- However, definition varies in the literature
 - Based on time (HIV diagnosis to AIDS diagnosis)
 - Based on CD4 counts
 - Based on clinical presentation

Is the Definition of Late Presentation Important?

- How we define it affects rates of late presentation
 - Specific rates reported may have implications for allocated resources
- Probably, best definition is presenting for treatment for HIV at a time after it may be beneficial to start treatment
 - Adler et al. AIDS Care 2009.

Is CD4<200 (or even <350) the right definition?

- Recent guidelines have recommended earlier treatment initiation
- Increasing evidence that starting between 350 and 500 may have better prognosis of HIV and non-HIV conditions
 - DHHS Guidelines

Late Presentation

- Diagnosis is different than presentation to care
 - Presentation to clinic that can monitor infection and prescribe ART if necessary
- There is a relevant difference between presentation to care and engagement in care
 - Given the high rates of IDU and irregular follow-up to care, should we use an alternative definition?

Who is likely to present late?

- Heterosexuals
- Older patients
- Immigrants
- Developing countries
- Intravenous drug users:
 - Less likely to be diagnosed late
 - More likely to experience a delay in presenting for clinical care once diagnosed
 - More likely to be lost to follow-up

How are people doing at picking up late presenters?

- 15-38% reported to present late
- Althoff et al, CID 2010
 - Assessed the immune status at initial presentation for HIV care from 1997 to 2007 in 13 Can/US centers
 - Mean CD4 increased from 256 to 317 over the study
 - Percentage with >350 increased from 38% to 46%

Prevalence of Late Presentation Among Various Centers

Country	Author, year	Definition	Prevalence
Australia	Hocking, 2004	<8 weeks from diagnosis to AIDS event	249/1021 (24%)
Spain	Castilla, 2002	HIV+ve test in same/preceding month as AIDS event	8499/30778 (28%)
US	Krawczyk, 2006	CD4 <200 cells/mm ³ /AIDS event	498/1209 (41%)
Canada	Krentz, 2004	CD4 <200 cells/mm ³	93/241 (39%)
US	Klein, 2003	CD4 <200 cells/mm ³	167/388 (43%)
Canada	Plitt, 2009	CD4 <200 cells/mm ³	205/526 (39%)

HIV Transmission and Late Presentation

Case

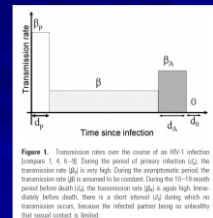
- A 19 y.o. sex-trade worker presented to ER with fever and difficulty swallowing
 - Found to have esophageal candidiasis and poly-microbial endocarditis
- Working up until the day before admissions - multiple partners
- HIV test positive
 - CD4 count = 1
 - Viral load > 10,000,000 copies/mL

HIV Transmission

- Estimated 21% don't know they are infected
- More than half of new infections from people unaware of infection
- Late presenters have a prolonged opportunity to transmit HIV
 - Early detection results in changes of risk behaviour
 - Brogly et al, AIDS Education and Prevention
 - ART can reduce viral load
 - Porco et al, AIDS 2004

Late Presentation and Transmission

- Late-stage infection estimated to be 7 times more infectious than asymptomatic infection
- Transmission concentrated between 19 and 10 months before death



Hollingsworth et al. JID 2008

Clinical Implications of Late Presentation

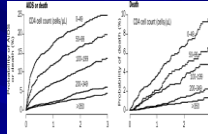
Late Presenters and Mortality

- Multiple studies have shown association with increased mortality
 - Short-term mortality reduced by 56% with earlier diagnosis
 - Chadborn, AIDS 2006
 - Up to 77% of AIDS-related deaths could be late-presenters
 - Ciancio IAS 2006
 - Late diagnosis affected as much as 35% of HIV-related deaths and 24% of total deaths
 - BHIVA 2006
 - Mortality after starting ARV could be reduced by 20% if patients presented with CD4 >400
 - Smit, PLoS One 2008

Prognosis from starting ART according to pre-therapy CD4 cell counts

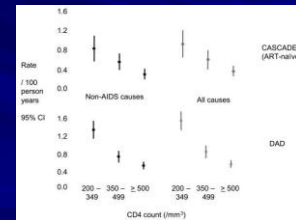
- Strongest risk factor for death after starting ART was CD4 counts <200

- Other risk factors included:
 - VL >100,000
 - Age > 50
 - Hx of AIDS
 - IDU



Egger et al, Lancet, 2002

Increased Mortality from Non-AIDS Causes in Patients with CD4 <350



Phillips et al., AIDS 2008

Additional Clinical Implications

- Increased risk of opportunistic infections
- Impact of HIV-associated symptoms
 - Diarrhea, weight loss, fatigue
- Increased difficulty in managing patients when starting ART
 - Immune reconstitution syndrome
 - OI prophylaxis and treatment
 - Drug related complications (e.g. TB)
 - Challenging assessment of symptomatology in these patients
 - Lack of available information when starting ART (e.g. resistance testing, HLA testing)

Late presentation associated with diminished reconstitution of CD4 cells

- 95% patients who started ART with CD4 >300 attained CD4 >500
 - Only 56% who started with CD4 <100
 - Only 75% who started with a CD4 of 100-200
 - The median follow-up period was 7.5 years

Kelley et al, CID 2009.

- Total, naïve and memory CD4 counts as well as naïve-memory ratios all lower for patients who start ART with baseline CD4 <350

Robbins et al, CID 2009.

HIV-infected adults with a CD4 cell count >500 on long-term ART reach same mortality rates as the general population

Lewden et al, JAIDS 2007

- 2435 adults with baseline median CD4 count = 270
- Median follow-up of 6.8 years
- Standardized Mortality Ratio = 7.0 (95% confidence interval [CI]: 6.2 to 7.8)
- Those with a CD4 count >500, the mortality reached the level of the general population after the sixth year after ART initiation (SMR = 0.5)

The Cost of Late Presentation

Case

- A 23 y.o., history of IDU, presented to ER with subacute SOB
- HIV test positive
 - CD4 = 11
 - Viral load 487,322 copies/mL



Case

- Admitted and treated for PJP and discharged 8 days later
- Returns in 72 hours with abdominal pain and diarrhea
 - Diagnosed with CMV ileitis and colitis and treatment initiated with ganciclovir
- Despite treatment, pain persists and unable to take anything orally
 - Requires TPN for nutritional support
 - ART unable to begin to absorption issues
- Required a 97 day admission to hospital for treatment of malnutrition due to CMV
- What is the total cost to the health care system due to the late presentation?

The high cost of medical care for patients who present late (CD4 <200 cells/microL) with HIV infection

Krentz et al. HIV Med 2004

- Compared costs of medical care in year following HIV diagnosis from 1996 to 2001 based on CD4 counts
- Estimated excess cost of late presentation (CD4 <200) after adjusting for patient characteristics: \$9,723
 - \$18,488 compared to \$8455
- Difference in total costs largely attributable to differences in HIV-related hospital care costs (15 times higher for late presenters)

Cost of Medical Care for HIV-infected Patients within a Regional Population

Krentz and Gill, HIV Med 2008

- Compared costs of medical care for HIV patients stratified by year from 1997 to 2006
- Overall, patient numbers increased by 74% and annual costs by 69%
 - i.e. proportionate increase in costs
- Mean CD4 increased from 388 to 433 while the numbers with CD4 <200 dropped from 32 to 13%
- Mean costs were stable, except for those with CD4 <75
 - Increased from \$1595/month to \$2687/month
 - Twice as many clinic, lab and physician visits
 - In-patient HIV and non-HIV related hospitalizations accounted for most of the increase
- Enhanced testing and early ART would reduce cost

Late Presentation in the Prairies

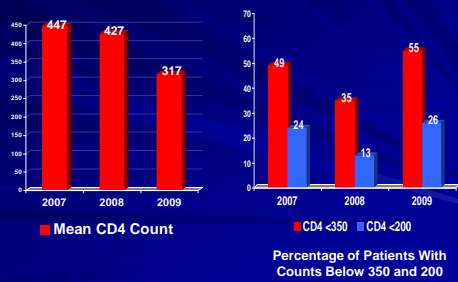
Characterizing the HIV epidemic in the Prairie provinces Becker et al. CAHR 2010.

Demographic analysis new patients to care, 2007

	Manitoba N (%)	Saskatchewan N (%)	S Alberta N (%)	Total N (%)
heterosexual	47 (71.2)	43 (53.1)	46 (62.2)	136 (61.2)
endemic	12 (18.1)	0 (0.0)	2 (2.7)	14 (6.3)
MSM	15 (22.7)	9 (11.1)	30 (40.5)	54 (24.3)
IDU	10 (15.2)	61 (75.3)	4 (5.4)	75 (33.8)
Aboriginal	17 (25.7)	58 (71.6)	5 (6.7)	80 (36.0)
Non-aboriginal	50 (75.8)	22 (27.2)	70 (94.6)	142 (64.0)
CD4 <200	33 (50.0)	24 (29.6)	21 (28.4)	78 (35.1)
Total	66	81	74	222

Slide Courtesy of Dr. Becker

CD4 Counts for New Patients at Positive Living Program-Saskatoon



Late Presentation of HIV-Infected Patients Admitted to Community Hospitals in Saskatoon 2008-2009 Hammond et al. CAHR 2010.

Figure 3. CD4 Count On Admission

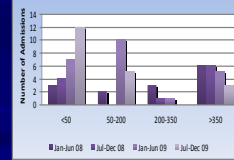
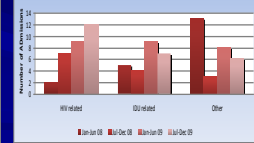


Figure 1. Primary Diagnosis for Admission of HIV Patients



Late Presentation of HIV-Infected Patients Admitted to Community Hospitals in Saskatoon 2008-2009 Hammond et al. CAHR 2010.

Figure 2. Length of Known HIV Infection Prior to Admission

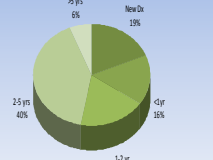
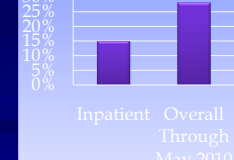


Figure 3. Taking HA vs. Not on HA



Late Presentation of HIV-Infected Patients Admitted to Community Hospitals in Saskatoon 2008-2009 Hammond et al. CAHR 2010

Figure 4. Mortality of HIV Patients In Hospital and Overall To May 2010



Total Inpatient Days	1761
Average Stay	20.7
Inpatient Days for HIV-Related Diagnoses	931
Average Stay for HIV-Related Diagnosis	31
Inpatient Days for IDU-Related Diagnoses	485
Average Stay for IDU-Related Diagnosis	22

Lack of Engagement in Care in Saskatoon

- In Saskatoon, minimal outreach available for patients
- For the period of April 2009 to March 2010 at West Side Community Clinic
 - 44% attendance rate
 - Involves population with lowest CD4 counts, >70% HCV co-infection rates, substance abuse and mental illness and high risk behaviors

Late presentation is common in our population and further research is required address the contributing factors

- HIV screening and awareness
- Engagement and access to care
- Rapid Progression

Late Evidence, Delayed Action: Late Presentation to Care and Its Implications in the Continuing of Care in the Prairies

Evaluation

For each of the following, please check off the best response:

- | | + | | | - |
|--------------------------------------------------------------------------------------------------------------------------|----------------------------------------|----------------------------------|----------------------------------------|-------------------------------|
| 1. The meeting increased my knowledge about the state of the HIV epidemiology in the Prairies. | 1 | 2 | 3 | 4 |
| 2. The meeting increased my knowledge about late presentation to care in the Prairies. | 1 | 2 | 3 | 4 |
| 3. The meeting helped to identify 'best practices' that effectively ameliorate late presentation to care. | 1 | 2 | 3 | 4 |
| 4. The meeting helped to identify gaps in policies and services regarding late presentation to care. | 1 | 2 | 3 | 4 |
| 5. The meeting assisted with the development of preliminary research ideas to address gaps in late presentation to care. | 1 | 2 | 3 | 4 |
| 6. The meeting increased my awareness of potential partners for research. | 1 | 2 | 3 | 4 |
| 7. The meeting increased my interest in seeking new connections in the Prairies. | 1 | 2 | 3 | 4 |
| 8. The format of the meeting was adequate to achieve the objectives set. | 1 | 2 | 3 | 4 |
| 9. Was this event free of commercial bias? | | | | |
| Yes <input type="checkbox"/> | | No <input type="checkbox"/> | | |
| 10. Overall, I would rate this event as (please check): | | | | |
| Excellent <input type="checkbox"/> | Above Average <input type="checkbox"/> | Average <input type="checkbox"/> | Below Average <input type="checkbox"/> | Poor <input type="checkbox"/> |
| 11. What changes, if any, do you intend to make in your practice or work as result of today's event? | | | | |

Opportunities for Partnership and Collaboration

- | | Yes | Need more
information | No |
|-------------------------------------------------------------------------------------------------------------------------------|-----|--------------------------|----|
| 10. I would like to become part of a Prairie research focused network. | | | |
| 11. I would be interested in participating in the organization of future events that bring together Prairie based researchers | | | |

and community?

12. Do you have any suggestions or comments regarding a follow up meeting? Please comment.

13. Please provide us with one primary contact from your province for the purpose of expanding the Network and knowledge sharing:

Name: _____

Position: _____

—

Province: _____

Thank you for you participation and collaboration.

Members of the organizing committee may be following up with the individuals who have attended this event in the next few months. We look forward to working with you to build successful ties regarding HIV research in the Prairies.