Involving heterosexual men living with HIV in developing a research and advocacy agenda for their community
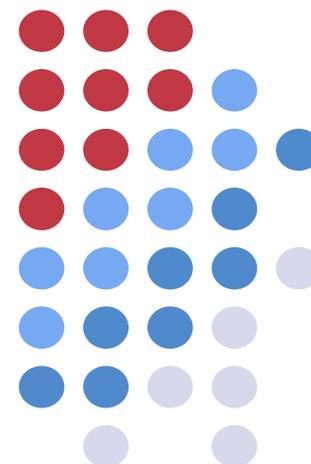
J Zuleuga, D Pineau, AM Tynan, C Strike, RH Glazier, M Loutfy, T Antoniou
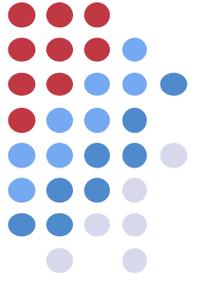
St. Michaels Hospital
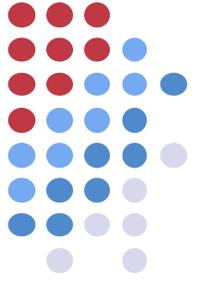
Ontario HIV Treatment Conference
November 19, 2013
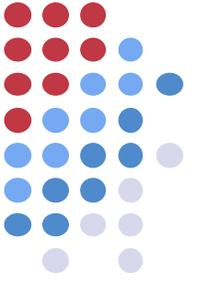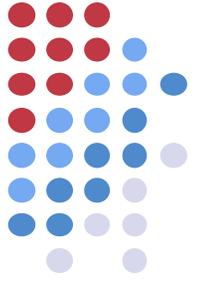
Conflict of Interest Disclosure

- None

Background

- Why is it important to hear from heterosexual men with HIV?
  - Heterosexual men are increasingly represented among the population of persons with HIV
    - Accounted for 13.8% of diagnoses among men in 2008
  - Improved outlook for all persons with HIV
    - Community engagement when funding for programs and services is allocated
  - Lack of engagement of researchers and policy makers with this community
    - Very little known about the priorities of heterosexual men with HIV

Objectives

- Host a summit for a diverse sample of heterosexual men with HIV

  - Provide opportunity for dialogue

  - Provide opportunity for community-building

  - Conduct roundtable discussions to identify research and advocacy priorities
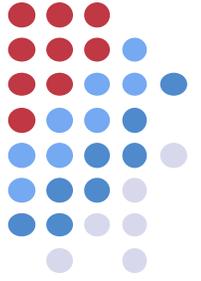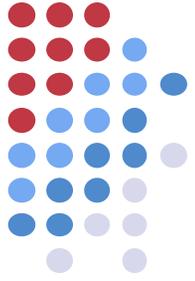
Methods – Participants

- Core group of community members involved in planning

- Work with ASOs across province to identify potential participants for summit

- Sampling was not random, but based on desire for representation according to geography, country of origin and mode of acquisition
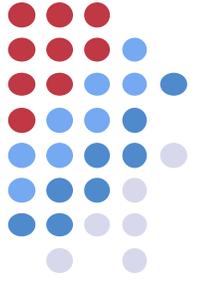
Methods – World Café Methodology

- Use World Café method to facilitate discussions
  - Multi-layered discussions
  - Participants rotate among the tables in the room so that each individual has opportunity to speak to each issue
  - Each table has a facilitator/note-taker – only individual who does not rotate
  - Discussion questions developed during several meetings preceding the event
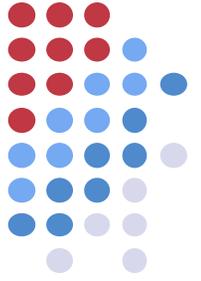
Methods – Process

- Four presentations to orient participants to topics for discussion
    - David Pineau, community member: reviewed history of project and World Café method
    - John Maxwell, Director Programs and Services at ACT: discussed how ASOs and community could better partner with one another
    - Winston Husbands, Director or Research at ACT: discussed advocacy and community mobilization
    - Tony Antoniou: reviewed principles of community-based research and state of research regarding heterosexual men with HIV
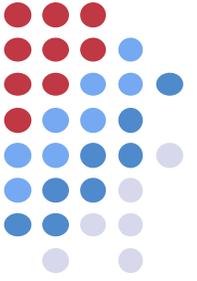- Two rounds of World Café discussions, followed by large group discussion

Methods – Discussion Questions

- Four domains/areas selected for discussion:
  - Advocacy and community-building
    - "What are some messages about heterosexual men with HIV that we need to get out there?"
  - Programming
    - "What are some ways to involve heterosexual men in providing input on programs and services?"
  - Priorities for research
    - "How can heterosexual men be meaningfully engaged in research?"
  - Health care and barriers to care
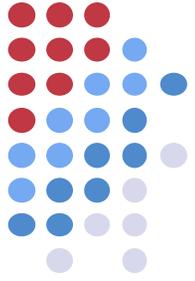   - "What gaps are there in social support services?"

Methods – Analysis

- Data were notes on flip-charts, note-pads and summaries of large-group discussions
- Summarized by content and thematic analysis
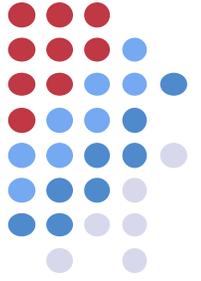
Results

- Three main themes generated:
    - Non-recognition: creating an identity for heterosexual men with HIV
    - Challenging negative stereotypes of heterosexual men with HIV
    - Research priorities and meaningful engagement
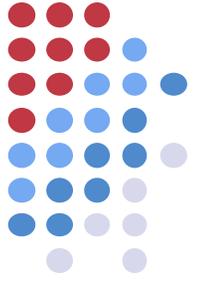
Results – Nonrecognition

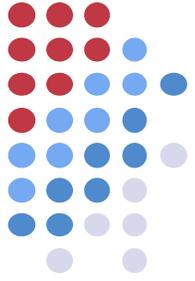| Consequence	Definition	Steps required
Lack of power	No input into decision-making	↑ visibility, name, logo, champions
Lack of programming	Lack peer support services	Meet with ASOs, positions within ASOs
Gaps in health care	Health care providers, mental health	↑ awareness among providers
Stigma and low self-esteem	Fear of disclosure, no community	↑ public awareness, opportunities for getting together, training in CBR

Challenges in forging group identity

- Early attempts unsuccessful
  - Lack of a 'champion' – considered key by group
  - Over-emphasis on social aspects
  - Lack of cohesion and cooperation among men
- Disclosure and stigma – hard to recruit others and sustain growth of group
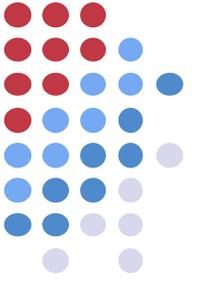
Challenging negative stereotypes

- Harmful stereotype that heterosexual men are a threat to community, dangerous
- Sources:
  - Media portrayals of men involved in criminal proceedings
  - Criminalization of HIV
  - Overlay of racial stereotypes, adding layer of stigma
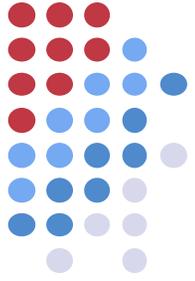- Requires collaboration with other communities

Results – Research Priorities

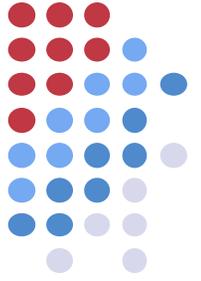| Research area	Definition	Subtopics/research questions
Treatment of HIV and complications	Health and treatment issues for heterosexual men	Access to treatment for hep C, differences in outcomes according to ethnicity/age, quality of care to care for heterosexual men
Health and social support service use	Access to and disparities in care among heterosexual men with HIV	Barriers, adequate cancer screening, mental health, variations in access according to ethnicity, residence, prisoners

Results – Research Priorities

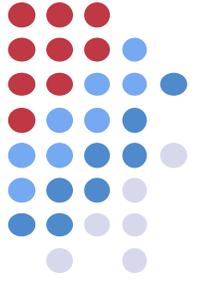| Research area	Definition	Subtopics/research questions
Social determinants of health (SDOH)	Impact of SDOH on health service use and outcomes	Effects of stigma, criminalization, housing and employment
Prevention	Primary and secondary prevention of heterosexual transmission	Knowledge of HIV-neg adolescent boys and men, interventions to ↑ testing, risk of transmission in discordant couples

Results – Research Priorities

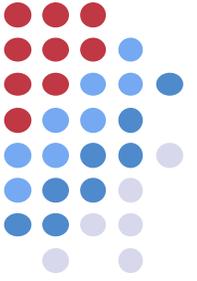| Research area	Definition	Subtopics/research questions
Family planning	Fatherhood and disclosure to children	Knowledge of family planning, importance of fatherhood, how and when to disclose to kids, attitudes of healthcare providers
Psychosocial research	Understand impact of HIV on heterosexual men	Coping with diagnosis, impact on social relationships, how common is depression

Limitations

- Absence of representation from important groups
  - Aboriginal men
  - Perinatally infected men transitioning to adult care
  - Men from transgendered community
- Absence of policy makers, decision makers, knowledge users
  - Summit was intended to hear from this community, offer rare opportunity for connecting
- Lack of 'solution focus'
  - Generating priorities and issues that could be taken forward

Next steps

- Create virtual community through email, website, among members of the summit
- Knowledge dissemination
  - Conferences (CAHR, OHTN)
  - Presentations to knowledge users (ASOs)
- Integrate community with policy makers and decision makers at follow-up summit to discuss solutions, proposals

Acknowledgments

- ASO partners: AIDS Thunder Bay, AIDS Niagara, AIDS Committee of Ottawa, Africans in Partnerships Against AIDS