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# Getting the news....

OHTN Conference, November 13, 2012

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# How this study began...

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- ▶ Anecdotal evidence suggested that some IRN-PHAs who were diagnosed through the IME were not happy with that experience
- ▶ CAAT wanted a scientific investigation of the matter
- ▶ Key research question was:

**How is the diagnosis experience of people diagnosed with HIV through the Immigration Medical Exam *different* from people diagnosed through other ways?**

# Methods...

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- ▶ An advisory committee was created
  - ▶ consisted of PHAs, physicians, community partners
- ▶ Survey
  - ▶ PHBQ-based, anonymous, pilot-tested 23-item, 10-min long
  - ▶ Reviewed demographics, timing/setting of HIV diagnosis, CIPES domains of diagnosis experience (Likert Scales)
- ▶ Eligibility:
  - ▶ Only PHAs diagnosed after January 2009
  - ▶ Single site study – St. Michael's Positive Care Clinic
- ▶ Modest financial compensation (\$10)
- ▶ Target sample size = 50
- ▶ Approved by St. Michael's Research Ethics Board,

# More about the survey...the CIPES Domains

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Comforting

Informative

Private

Engaging

Satisfactory

The first person who told me that I was HIV positive...(3/4)

- Comforted and reassured me (20A)
- Expressed concern for my feelings and needs, not just my physical status (20B)
- Made uncaring remarks or did things I found offensive (20G)
- Was short-tempered or abrupt with me (20I)



# More about the survey...the CIPES Domains

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Comforting

Informative

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Satisfactory

The first person who told me that I was HIV positive also told me...(3/5)

- That public health was going to call me (19A)
- How to stay health and reduce my chances of getting sick (19B)
- How to reduce my chances of being infected with HIV again or infecting others (19C)
- About the legal consequences of NOT telling my sexual partner(s) my HIV status (19D)
- How to get in touch with a community agency (or support group) that could help (19E)



# More about the survey...the CIPES Domains

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Comforting

Informative

Private

Engaging

Satisfactory

The first person who told me that I was HIV positive...(1/1)

- Arranged for adequate privacy when talking to me (20H)



# More about the survey...the CIPES Domains

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Comforting

Informative

Private

Engaging

Satisfactory

The first person who told me that I was HIV positive...(3/5)

- Answered my questions (20C)
- Included me in decisions and choices about my care (20D)
- Didn't rush. Spent enough time with me (20E)
- Used words that I could understand (20F)
- Helped me contact an HIV physician or specialist (20J)



# More about the survey...the CIPES Domains

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Comforting

Informative

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Satisfactory

Overall, how satisfied are you with the way that you were told about your HIV diagnosis?

Agree/Strongly agree





## Demographic Profile of Participants

	Not IME n=36	IME n=12	Total N = 48
(* = 1 missing data in that section)			
<b>Gender</b>			
- Men	32 (89)	8 (67)	40
- Women	4 (11)	4 (33)	8
<b>Age(years)</b>			
		*	
- <20	0 (0)	0 (0)	0
- 21-30	9 (25)	3 (27)	12
- 31-40	8 (22)	4 (36)	12
- 41-50	13 (36)	3 (27)	16
- >50	6 (17)	1 (10)	7
<b>Sexual Orientation</b>			
	*		
- Bisexual	7 (20)	3 (25)	10
- Gay	17 (49)	4 (33)	21
- Straight	11 (31)	5 (42)	16
<b>Time since diagnosis (mths)</b>			
- <6	9 (25)	4 (33)	13
- 6-12	10 (28)	3 (25)	13
- 13-18	4 (11)	1 (8)	5
- 19-24	8 (22)	3 (25)	11
- 25-30	3 (8)	0 (0)	3
- 31-40	2 (6)	1 (8)	3

## Demographic Profile of Participants

	Not IME n=36	IME n=12	Total N = 48
(* = 1 missing data in that section)			
<b>Racial/Ethnic Background</b>			
- African/Black/Caribbean	7 (19)	11 (92)	18
- Caucasian	22 (61)	1 (8)	23
- Latin American	3 (8)	0 (0)	3
- South Asian	2 (6)	0 (0)	2
- South East Asian	2 (6)	0 (0)	2
<b>Country of Birth</b>			
- Canada	23 (64)	0 (0)	23
- Other	13 (36)	12 (100)	25
<b>Prior HIV Testing?</b>			
- Yes	26 (72)	10 (83)	36
- No	12 (28)	2 (17)	14
<b>Surprised by HIV Diagnosis?</b>			
- Yes	26 (72)	9 (75)	35
- No	10 (28)	3 (25)	13



## Demographic Profile of Participants

(* = 1 missing data in that section)	Not IME n=36	IME n=12	Total N = 48
<b>Diagnosis Setting</b>	*		
-Sexual Health Clinic	8 (23)	0 (0)	8
-Doctor's Office	16 (46)	12 (100)	28
-Walk-in Clinic	6 (17)	0 (0)	6
-Community Health Centre	2 (6)	0 (0)	2
-Hospital	2 (6)	0 (0)	2
-Public Health Clinic	1 (3)	0 (0)	1
<b>Diagnosed by</b>			
-Physician	25 (70)	12 (100)	37
-Nurse	7 (19)	0 (0)	7
-HIV Counselor	4 (11)	0 (0)	4



# Results...



	Comforting	Informative	Private	Engaging	Satisfactory
<b>Overall</b>	<b>50%</b>	<b>58%</b>	<b>73%</b>	<b>79%</b>	<b>69%</b>
IME	58%	58%	58%	58%	58%
No IME	61%	61%	78%	89%	72%
Fischer's Exact 2-tail	p = 0.008	p = 0.52	p = 0.12	p = 0.005	p = 0.48

Of the entire sample, what percentage of participants do you think found their diagnosis experience to be.....?

Of just the IME-diagnosed, what percentage do you think found their diagnosis experience to be.....?

Of just the No IME-diagnosed, what percentage do you think found their diagnosis experience to be.....?

Significant differences between IME and non-IME diagnosed PHAs



# So...what can we learn from these results?

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- ▶ Diagnosers are fairly good at making experience informative and private
  - ▶ The less interpersonal aspects of the diagnosis experience
- ▶ Diagnosers need to improve at making the experience more comforting and engaging
  - ▶ The more interpersonal aspects of the diagnosis experience
- ▶ How?
  - ▶ Touchy- feely?

**PATIENT-CENTRED APPROACH!**

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# So ...?

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## ▶ Limitations

- ▶ Small sample size
- ▶ Possible confounding factors
- ▶ Novel research instrument
- ▶ Recall bias
- ▶ Selection bias

## ▶ Conclusions

- ▶ Our results suggest that the HIV diagnosis experiences of adults diagnosed through the IME are less comforting and less engaging than that of people diagnosed through other means.



# Acknowledgements

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- ▶ Committee for Accessible AIDS Treatment
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- ▶ St. Michael's Positive Care Clinic Staff
- ▶ Pilot Study Participants
- ▶ Final Study Participants



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Thank you

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