

# Patterns of HIV-Related Medical Care in New York City, 2001-2009

Applying surveillance data to measure case  
management need



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# SESSION GOALS

- (1) Present the usefulness of surveillance data to investigate gaps in care
- (2) Identify strategies to estimate the proportion of HIV-positive persons with gaps in HIV primary care
- (3) Describe how gaps in care analysis can be used to plan resource allocation and interventions.

# Presentation Content

Background

Methods

Results

Conclusions

# BACKGROUND

# The Challenge of HIV Service Planning in NYC

- Within \$100M of funded services under the RWHATMA are many (>20) service categories, often with overlapping descriptions
  - Defining in which ones case management (CM) was occurring was difficult
  - Service category allocations changed little from year to year
- The health literature has no consensus definition of HIV CM
- Our program data is drawn from mandatory reporting and not from client management
- Methods for estimating CM need are rough and non-standardized

# Review of the Literature

First author, Journal, Year	Data source and study sample (population)	Methodologic definition of care continuity or discontinuity	Primary focus	Key finding	% with gaps (period)
Lucas, AIM 1999	Johns Hopkins MR review – ARV naïve starting PIs 1996-8	Appointments missed among all missed and kept appointments (MVP)	Predictors of ARV success	Discontinuity predicts failure	n/a
Giordano, CID 2007	VA Immunology Case Registry – Case entries 1997/8 who started ARV	Number of quarters during the 1 year post enrollment in which an individual had at least 1 visit (continuous = 4/4)	Continuity as a predictor of disease control/progression and mortality	Discontinuity predicts disease progression and death	36% (1 yr)
Myerson, AJPH 2007	ADAP, RW STD MIS + others (MO) – Cases diagnosed prior to the end of the period	Whether or not an individual had any lab, visit, or prescription in each year of the period	Quantify care utilization and unmet need	Unmet need is high	40% - 57% (1 year x multiple iterations)
Tobias, AIDS Patient Care 2007	SPNS Outreach Initiative – Enrollees (chronically infected) from 10 sites	Whether or not an individual reported at least 1 episode of care in the 6 months prior to enrollment	Quantify care utilization and unmet need + consider predictors	Unmet need is moderate (12%) and the usual social culprits are to blame	12% (6 mo)
Mugavero, JAIDS 2009	UAB 1917 Cohort - Enrollees with at least 4 appointments August 2004 – January 2007	Appointments missed among all missed and kept appointments (MVP) for persons with at least 4 in 30 months	Continuity as a predictor of virologic failure	Discontinuity predicts failure	40%* (6 – 30 mo)
Olatosi, AIDS 2009	HARS (SC) – Prevalent HIV cases 12/2003	Regularity of lab reports across 12 month intervals for 3 years	Quantify care utilization and unmet need	Unmet need is very high	65% (3 yr)
Torian, In advance of publication	HARS (NYC) – New HIV diagnoses July – Sep 2005	Regularity of lab reports across 6 month intervals for 2.5 years	Quantify care utilization and unmet need	Unmet need is high	48% (27 – 30 mo)



\*Miss 25% of appointments or greater

# Goals of the Study

- Measure perturbations in care continuity
  - Gaps and irregularity
  - Discontinuity
  - Loss to follow-up
- Estimate the need for case management and health care services
  - Outreach and return to care
  - Navigation
    - Health promotion, coaching, advocacy, support
    - Accompaniment and logistics

# Analyses of HIV/AIDS Surveillance Data to Date

- Time since last care (2006)
- Gaps in care (2008)
- Regularity of care (2010)



# METHODS

- Data source
  - Routine NYC HIV/AIDS case surveillance for persons living with HIV/AIDS
  - Electronic laboratory reporting of VL and CD4 tests (began 2001) among persons with HIV, as proxy for care
- Analysis population: NYC-area residents living with HIV (more detail for each analysis)

# METHODS

- Definitions
  - Care – Either a CD4 count or a viral load
  - Gap in care – A predetermined interval (e.g. 12 months) without a laboratory record
  - Care irregularity – Pattern of care displaying one or more gaps (aka gappiness)
  - Care discontinuity – Laboratory records associated with more than one medical provider irrespective of continuity or gaps
  - Loss to follow up – Open ended interval where an expected observation of a laboratory event has not (yet) occurred

# FINDINGS

# Analysis 1: Time since last care, 2006

Year	Number (%) of patients with last care in year
2005	60,062 (61.8%)
2004	7,048 (7.3%)
2003	5,297 (5.4%)
2002	3,219 (3.3%)
2001	3,041 (3.1%)
No labs*	18,448 (19.0%)
<b>TOTAL</b>	<b>97,142</b>

34,738

\*Includes 2,342 records with HIV diagnosis 2001-2004 w/out subsequent lab values

# Analysis 1: Time since last care, 2006

Year	Number (%) of patients with last care in year
2005	60,062 (61.8%)
2004	7,048 (7.3%)
2003	5,294 (5.4%)
2002	3,249 (3.3%)
2001	3,041 (3.1%)
No labs*	18,448 (19%)
<b>TOTAL</b>	<b>97,142</b>

\*Includes 2,342 records with HIV diagnosis 2001-2004 w/out subsequent lab values

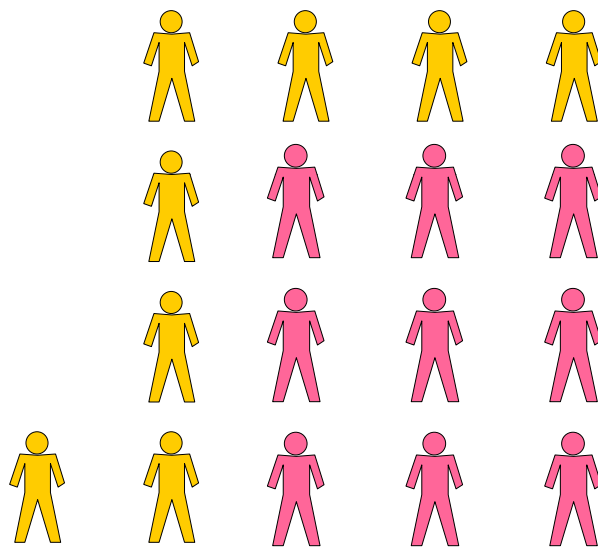
# Analysis 2: Gaps in care 2005/6/7

<b>Total</b>	<b>50,353</b>	<b>100.0%</b>
<b>Sex</b>		
Male	33,663	66.9%
Female	16,690	33.1%
<b>Race/ethnicity</b>		
Black	22,957	45.6%
Hispanic	16,609	33.0%
White	9,860	19.6%
Asian/Pacific Islander	635	1.3%
Native American	39	0.1%
Other/unknown	253	0.5%
<b>Transmission risk</b>		
Men who have sex with men	14,782	29.4%
Injecting drug use history	10,568	21.0%
Heterosexual	9,637	19.1%
Perinatal	1,449	2.9%
Other	159	0.3%
Unknown/under investigation	13,758	27.3%
<b>Place of birth</b>		
United States	28,316	56.2%
Puerto Rico + other dependencies	2,694	5.4%
Foreign country	7,203	14.3%
Unknown	12,140	24.1%
<b>Clinical status at end of 2004</b>		
HIV only (non-AIDS)	18,982	37.7%
AIDS	31,371	62.3%

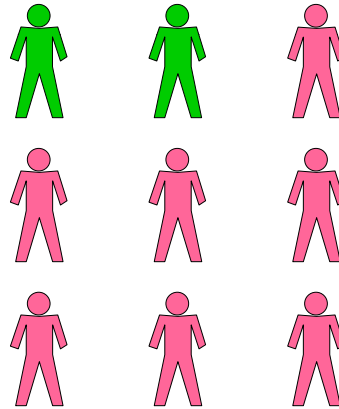
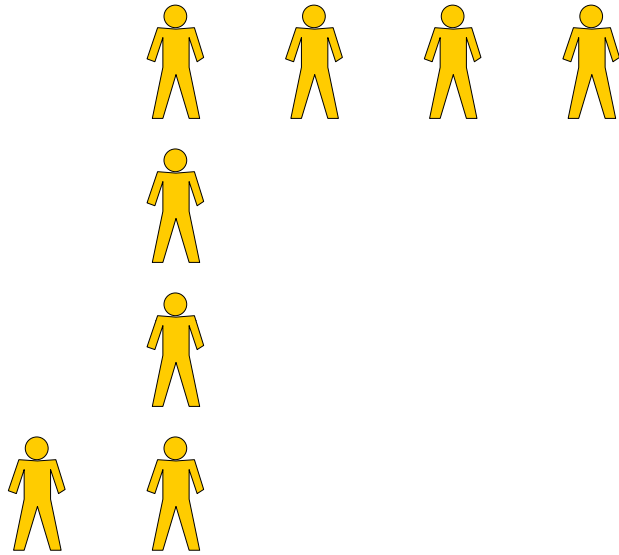
# Of 100 patients in a practice

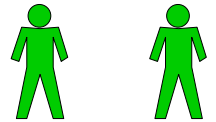
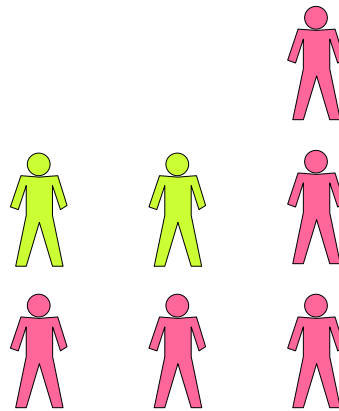
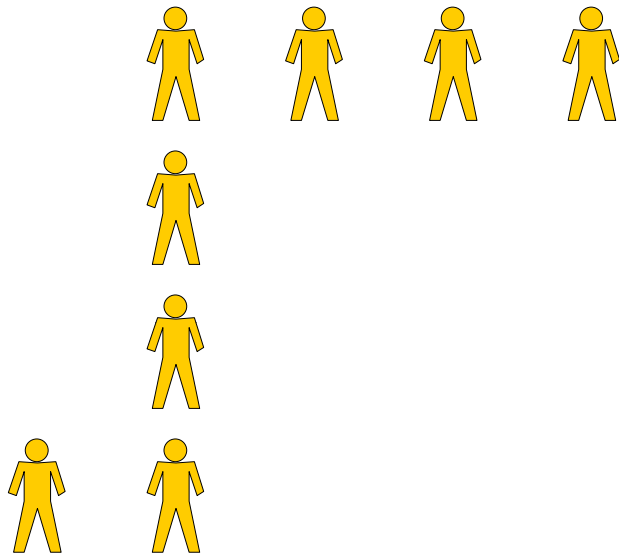


A provider can expect to lose sight of 17 each year

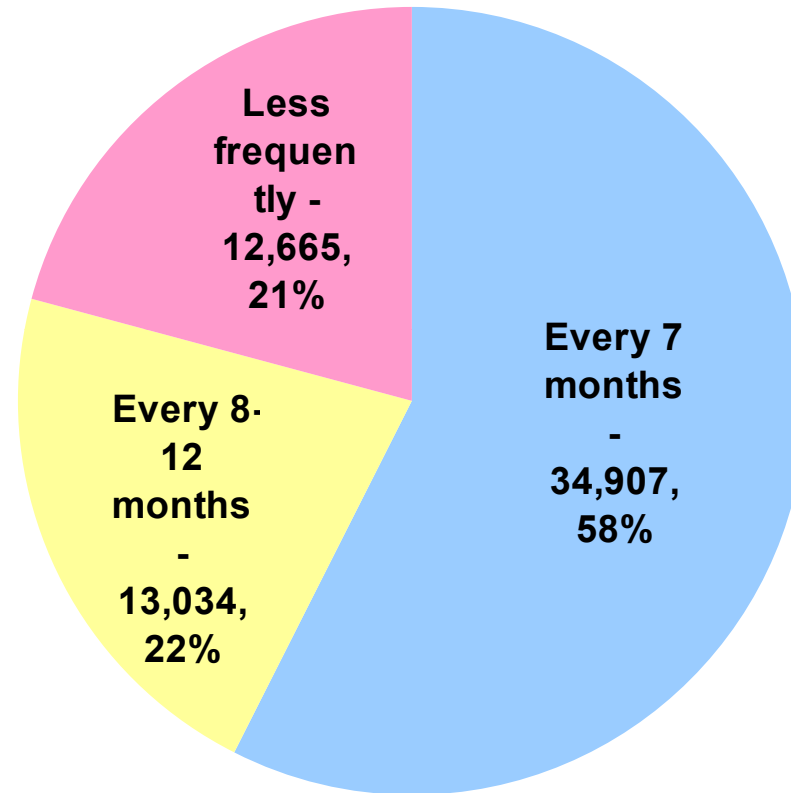








# Analysis 3: Regularity of care, 2007-2009



Of the 60,606 persons, 58% received care every 7 months and 79% every 12 months between September 1, 2006, and September 30, 2009, or death.

# Clinical Factors Associated with Regular Care

- First diagnosed with HIV or AIDS before 2001
- Ever having been diagnosed with AIDS
- CD4 < 350 during run-in period
- Proxies of clinical status
  - Hospital care in the run-in period
  - Frequency of care in the run-in period

40%+  
Problem



8% Switch  
doctors  
between 1 year  
and the next

22% in care  
every 12  
but  
not every 7  
months

10-11% With  
gaps of 1-3  
years

5% Out of care  
more than 3  
years



# CONCLUSIONS

# Limitations

- Laboratory reporting overestimates continuing care – some records represent acute care or blood tests without a clinician visit
- Generous definition of regular care: every 7 or 12 months, vs. guidelines which suggest every 3-6 months
- Neither our gaps nor our regularity analysis includes the more than 30,000 persons not in care during a given baseline period

# Summary

- Discontinuities in and irregularities of care patterns are common
  - At least 40% of persons in any care cohort can be expected to have difficulty maintaining continuous engagement in care for 3 years
- This is particularly true for the healthier or asymptomatic group
- Loss to follow up poses a great logistical challenge
  - It is exceedingly difficult for a provider to know which of his lost patients will respond to outreach efforts



# Next Steps

- Analytic
  - Measure discontinuity among persons with regular care over 3 years
  - Model time-varying return-to-care probabilities (e.g. the likelihood that a person lost to follow up will return in the next X years) for the entire prevalent cohort
- Programmatic
  - Support, monitor, and evaluate a \$25M care coordination initiative and seek additional resources as warranted

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