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 patterns of care

(2) Identify strategies to estimate the proportion of HIV-positive persons with gaps or discontinuity in HIV primary care

(3) Describe how gaps in care analysis can be used to plan resource allocation and interventions

Presentation Content

Background

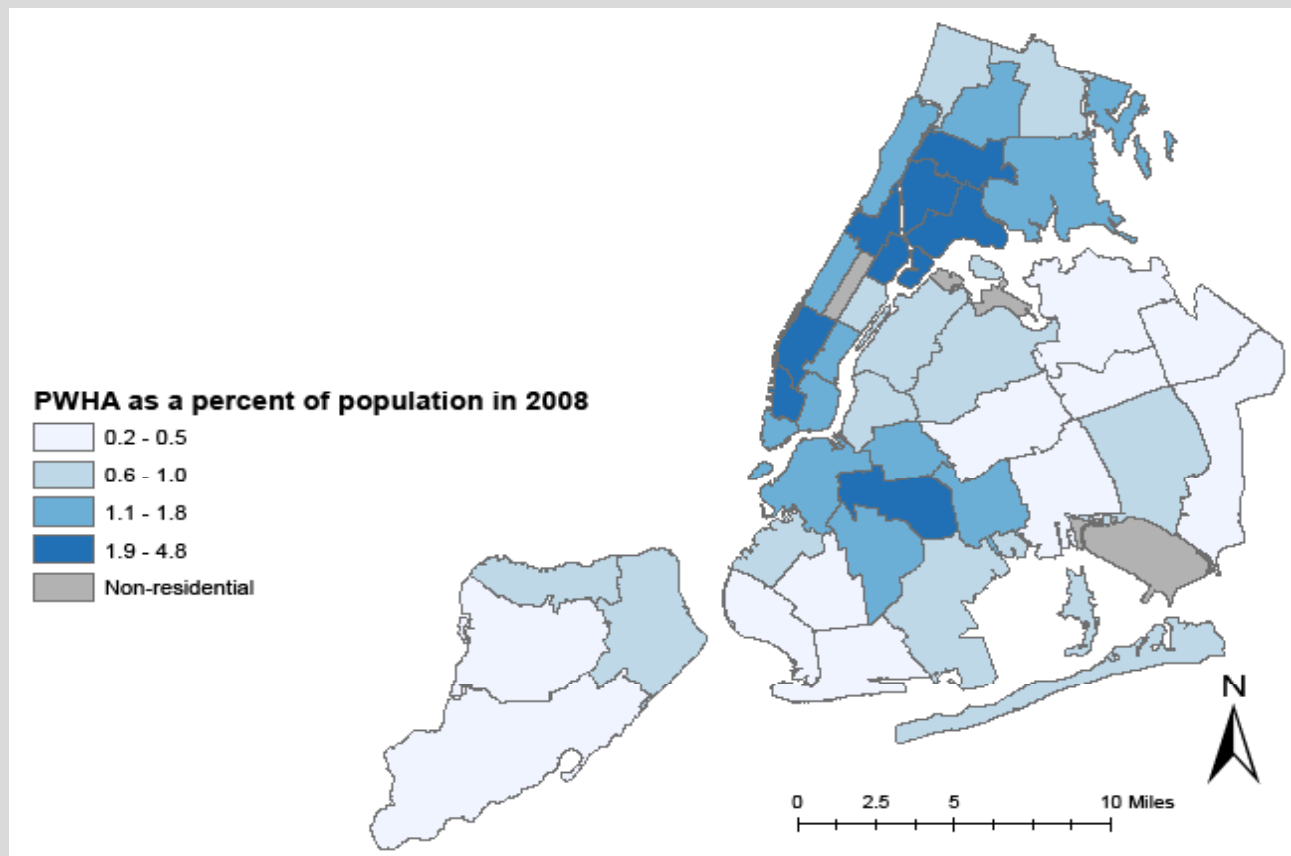## Methods

Results

Conclusions

BACKGROUND

New York, NY
Eligible Metropolitan Area (EMA)

- Grantee: NYC Department of Health and Mental Hygiene (DOHMH)
  - Bureau of HIV/AIDS Prevention and Control
    - Care, Treatment and Housing Program
      - Research and Evaluation
      - Health Care Services (includes program planning and technical assistance teams)
      - Housing Services (including HOPWA)
      - Ryan White Planning Council Support

- 2010 Part A Award is $121,088,606 (Base and MAI)
  - Support 182 Contracts (151 in New York City)

- New York, NY EMA includes:
  - Five Boroughs of NYC, and
  - Three Counties North and East of NYC (Tri-County)
    - Westchester, Rockland, and Putnam Counties

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HIV Prevalence in NYC, 2008
(N = 105,633)

PWHA as a percent of population in 2008

- 0.2 - 0.5
- 0.6 - 1.0
- 1.1 - 1.8
- 1.9 - 4.8
- Non-residential

The Challenge of Planning Medical Case Management

- 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

- Our program data is drawn from mandatory reporting and not from client management

- The health literature has no consensus definition of HIV CM

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)

Goals of the Study

- Measure disruptions in care continuity
  - Gaps and irregularity
  - Discontinuity
  - Loss to follow-up

- Estimate the need for medical 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 and population

- Data source
  - HIV/AIDS Reporting System (HARS) - Routine NYC case surveillance
  - AIDS cases first reported in 1981
  - Name based HIV reporting since 2000
  - Electronic laboratory reporting of VL and CD4 tests began in 2001*

- Analysis population: NYC residents living with HIV (more detail for each analysis)

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 regularity 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	5,294 (5.4%)
2002	3,249 (3.3%)
2001	3,041 (3.1%)
No labs*	18,448 (19.0%)
TOTAL	**97,142**

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

34,738

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Analysis 2: Gaps in care 2005-2007

Population characteristics and proportion with a care gap > 1 year (N=50,353)

	N	Gap %
Sex		
Male	33,663	8.6%
Female	16,690	8.5%
Race/ethnicity		
Black	22,957	9.2%
Hispanic	16,609	7.9%
White	9,860	8.2%
Other/unknown	927	10.2%
Transmission risk		
MSM	14,782	8.5%
Injecting drug use	10,568	7.3%
Heterosexual	9,637	9.0%
Perinatal + Other	1,608	4.4%

	N	Gap %
Place of birth		
United States	28,316	8.6%
US dependencies	2,694	7.2%
Foreign country	7,203	9.3%
Unknown	12,140	8.6%
Clinical status at end of 2004		
HIV (non-AIDS)	18,982	12.0%
AIDS	31,371	6.5%
Overall gap in care %		8.6%

Analysis 2: Rates of return to care over time

	N	Rate (% total / year)	Marginal rate (% eligible/year)
In care 2004	50,353	-	-
In care 2005	46,026	91.4	-
Continuous	42,052	83.5	91.4
Discontinuous	3974	7.9	8.6
Gap in care, 2005	4327	8.6	-
Returned 2006	948*	1.9	21.9
Returned 2007	195¶	0.4	7.0
Lost to follow up	2277	4.5	82.2

*An additional 610 people returned to care but to different providers than any of those they saw in 2004

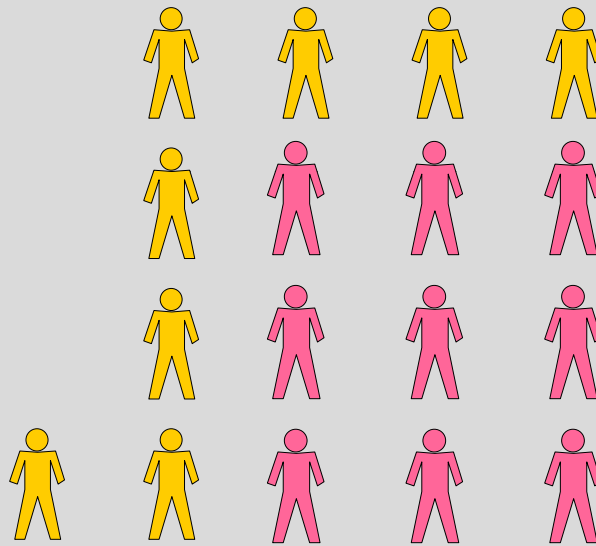¶An additional 297 people returned to care but to different providers than any of those they saw in 2004

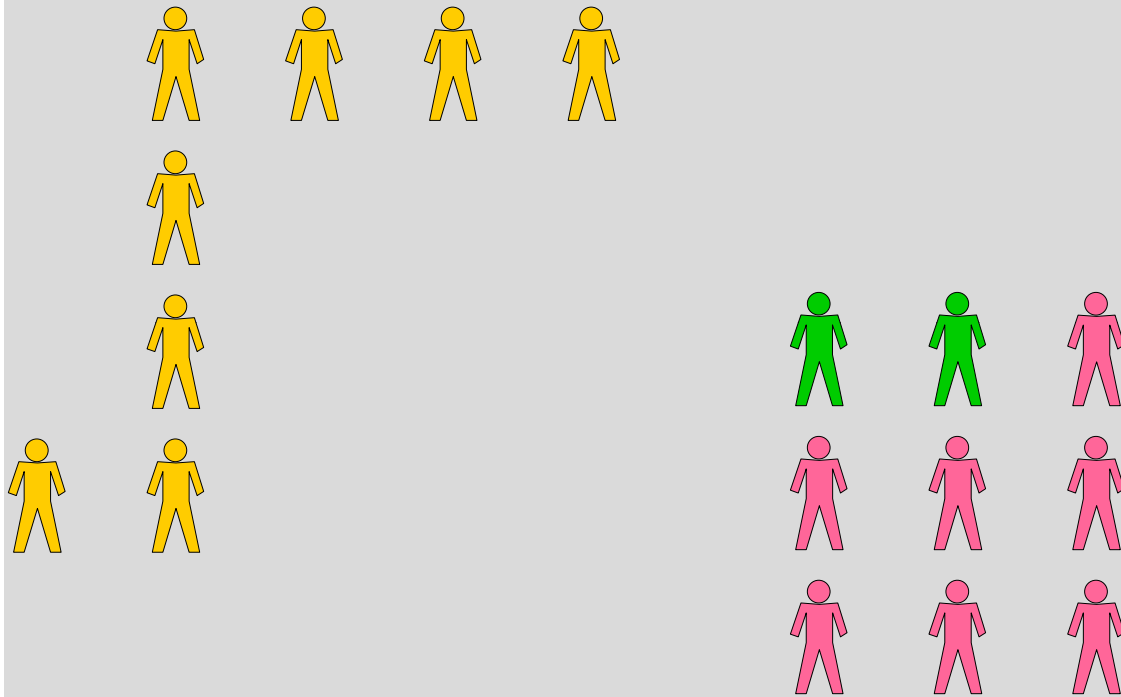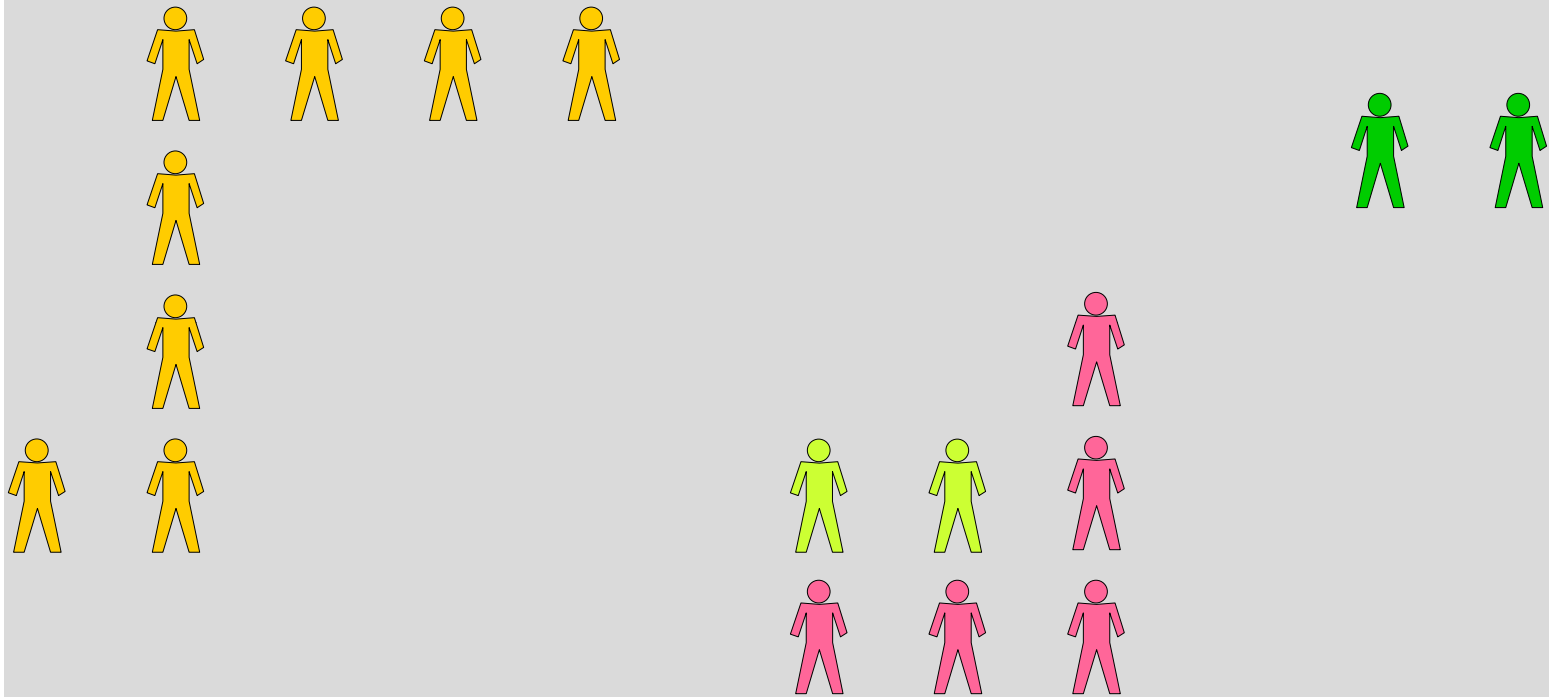# Analysis 2: Cohort loss to follow-up over time

Persons remaining out of care in NYC from 2004 forward (N = 50,353)

8.6%

5.5%

4.5%

2004   2005   2006   2007

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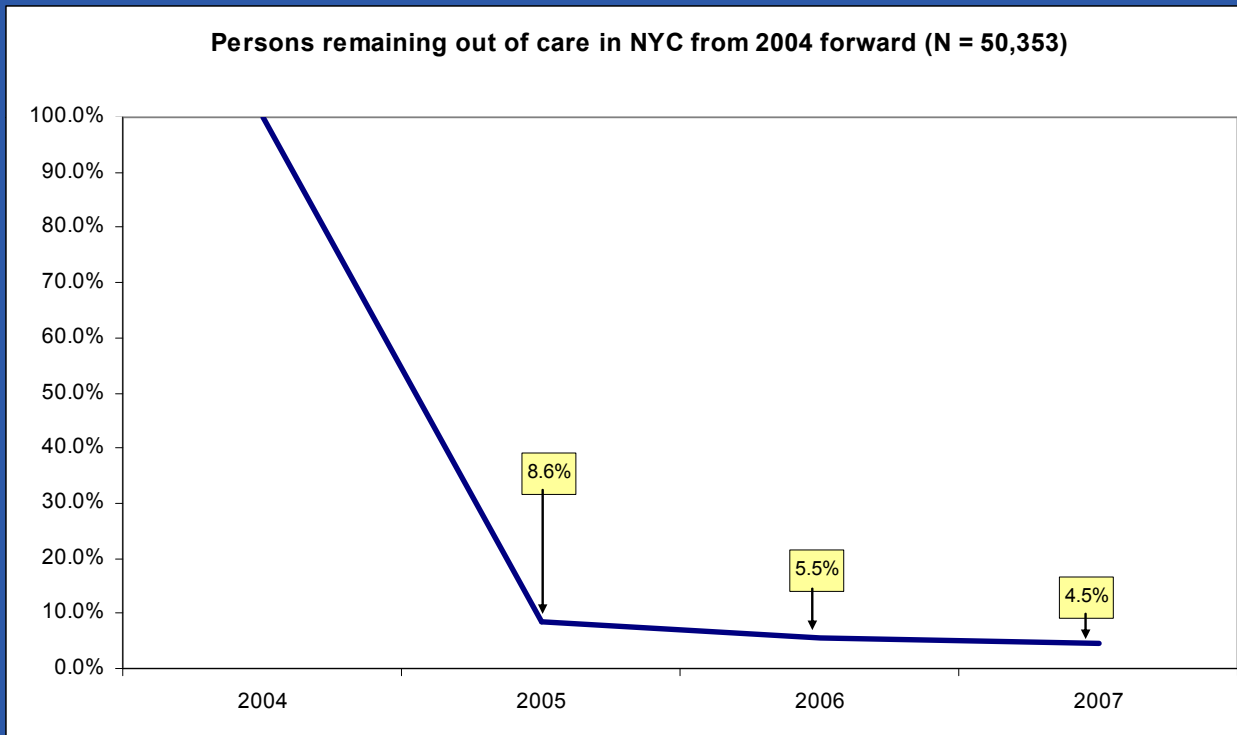
Of 100 patients in a practice
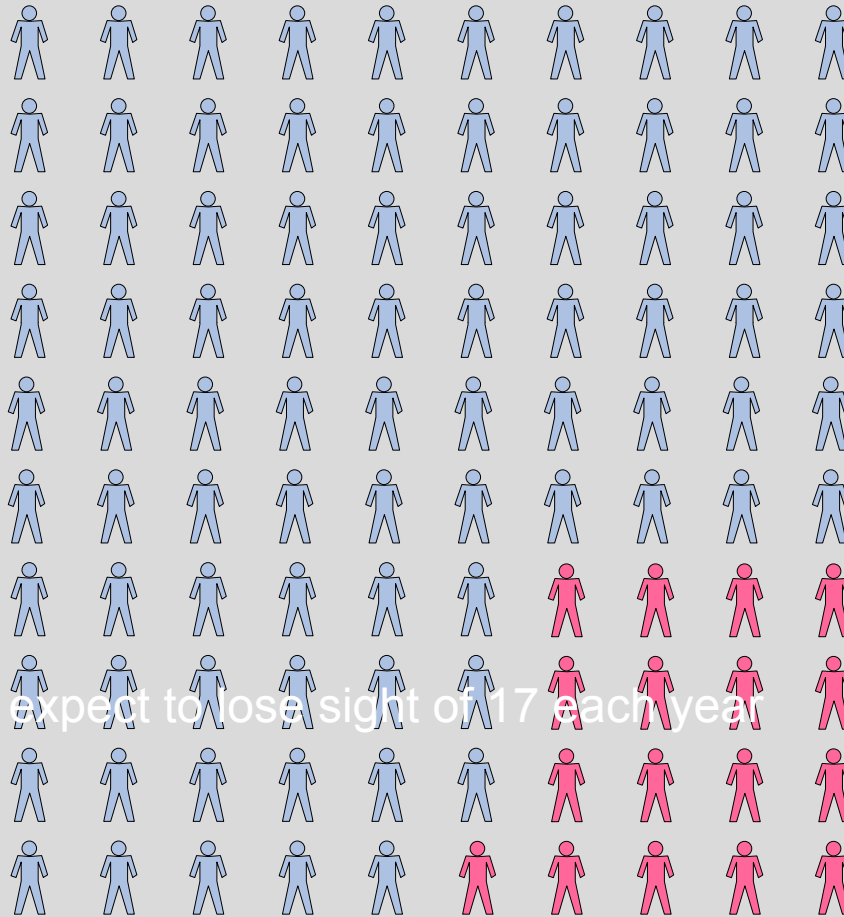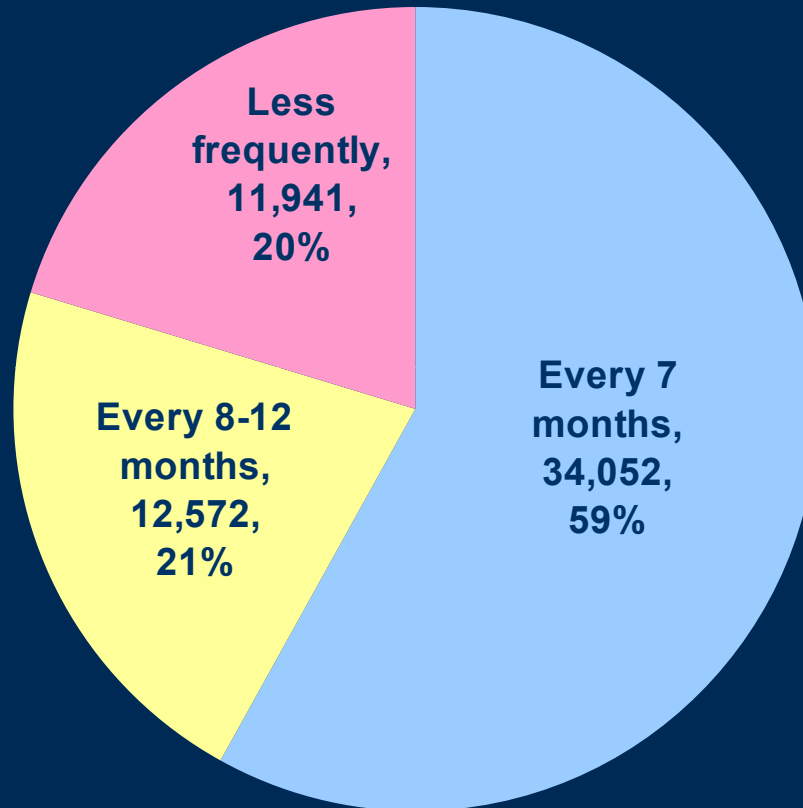
A provider can expect to lose sight of 17 each year

Analysis 3: Regularity of care, 2007-2009

Pie chart:
- Every 7 months, 34,052, 59%
- Every 8-12 months, 12,572, 21%
- Less frequently, 11,941, 20%

Of the 58,565 persons, 58.1% received care every 7 months and 79.5% every 12 months between September 1, 2006, and September 30, 2009, or death.

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Analysis 3: Population characteristics and proportion with irregular care

	N	Care < 1/7months	Care < 1/12 months
Sex			
Male	33,663	42.7%	21.5%
Female	16,690	40.1%	18.1%
Race/ethnicity			
Black	22,957	43.0%	21.0%
Hispanic	16,609	37.4%	17.6%
White	9,860	46.9%	23.9%
Transmission risk			
MSM	17,183	45.1%	22.8%
IDU	13,011	36.5%	17.1%
Heterosexual	11,732	42.0%	19.5%
Resides in a zip code where at least 20% of residents are below FPL			
Yes	35,020	40.4%	19.2%
No	21,360	43.8%	22.0%

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
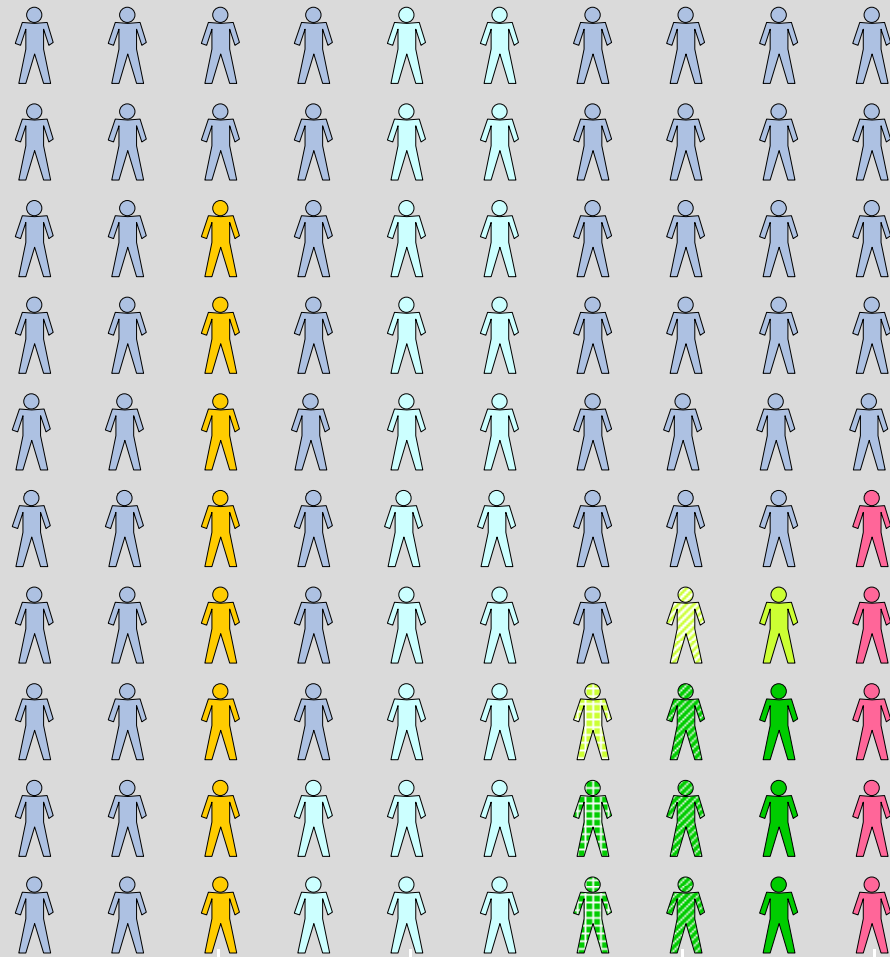
40%+

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

- We did not distinguish between good and bad care discontinuity

Summary

- Using a single existing population level dataset we were able to:

  - Follow a cohort of persons over time to measure care patterns as a time dependent phenomenon

    - Cross sectional measures will always *under-estimate* continuity

  - Account for out-migration and exclude most-likely cases from analysis

  - Derive a result – a proportion of persons with care disruption – that fits nicely in the mid range of reported values from other jurisdictions and an array of methods

Summary continued

- 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

    - Projected annual costs in excess of $140M

- 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

  - Measure regularity using a 1/4-month definition

  - 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

  - Emphasis on close monitoring and *prevention* of loss to follow up

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QUESTIONS?