

PrEP MEASUREMENT IN NYC

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PrEP Measurement in NYS and NYC

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Overview

- Background
 - Why Does Measurement Matter?
 - What (and How) to Measure?
- Overview of Sources of Data
- Introduction to Sources
- Closing Thoughts

If you can't measure it...

...you can't manage it.

Why Does Measurement Matter?

- Estimate impact
- Identify disparities
- Plan new and improve existing programs
- Remain alert to all possible outcomes, including unintended consequences
- Accountability

What (and How) to Measure?

WHAT

- Key outcomes: PrEP awareness, use, adherence, etc.

HOW

- Approach
 - Individual- vs. population-level
 - Consumers vs. prescribers
 - Cross-sectional vs. longitudinal
- Data collection
 - Surveys vs. charts/administrative data
 - Surveillance vs. program data

What (and How) to Measure?

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 - Surveys vs. charts/administrative data
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Overview of Current Data Sources

	Surveillance	Program
Consumer	<ul style="list-style-type: none">• Sexual Health Surveillance (SHS)• National HIV Behavioral Surveillance (NHBS)• Medical Monitoring Project (MMP)	<ul style="list-style-type: none">• NYC DOHMH Field Services Unit• Sexual and Behavioral Health Program (SBH)

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Provider	<ul style="list-style-type: none"> NYC DOHMH HIV/AIDS Surveillance Primary Care Information Project (PCIP) 	<ul style="list-style-type: none"> Public Health Detailing Program

Overview of Current Data Sources

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Data Source Description:

Sexual Health Survey (SHS)

- **Population included:** Sexually active NYC MSM
 - Eligible if NYC resident, assigned male gender at birth, 18-40 years old, who reports anal sex with a man in the past 6 months
- **Data collection methods:** Online and in-person (interviewer-administered)
- **Frequency of data collection:** Semiannual (online); annual (in-person)
- **Years for which PrEP data available:** Spring 2012 onward

Data Source Description:

SHS (2)

- **Key definitions of PrEP-related variables:**
 - **PrEP Awareness:** “Sometimes people who do not have HIV take HIV medications (Truvada) on a daily basis to keep from getting HIV. This is called pre-exposure prophylaxis, or PrEP. Have you ever heard of PrEP?”
 - **PrEP Use:** “In the past 6 months, have you used PrEP to prevent yourself from becoming infected with HIV?”
 - **Other PrEP related variables:** interest in PrEP, whether discussed PrEP with provider, perception of self as PrEP candidate, interest in injectable PrEP
- **Other relevant data collected:**
 - Basic sociodemographic data
 - Behavioral risks for HIV
 - HIV testing behaviors
 - Access to and use of prevention services
 - HIV testing results

Data Source Description:

SHS (3)

- **Opportunities**

- Ongoing monitoring of PrEP awareness/use among NYC MSM at risk, with consistent methods across survey rounds
- Ability to track PrEP awareness/use by sociodemographic factors and measure potential disparities in a timely manner
- Flexibility to add new questions that address emerging areas of public health importance and/or concern

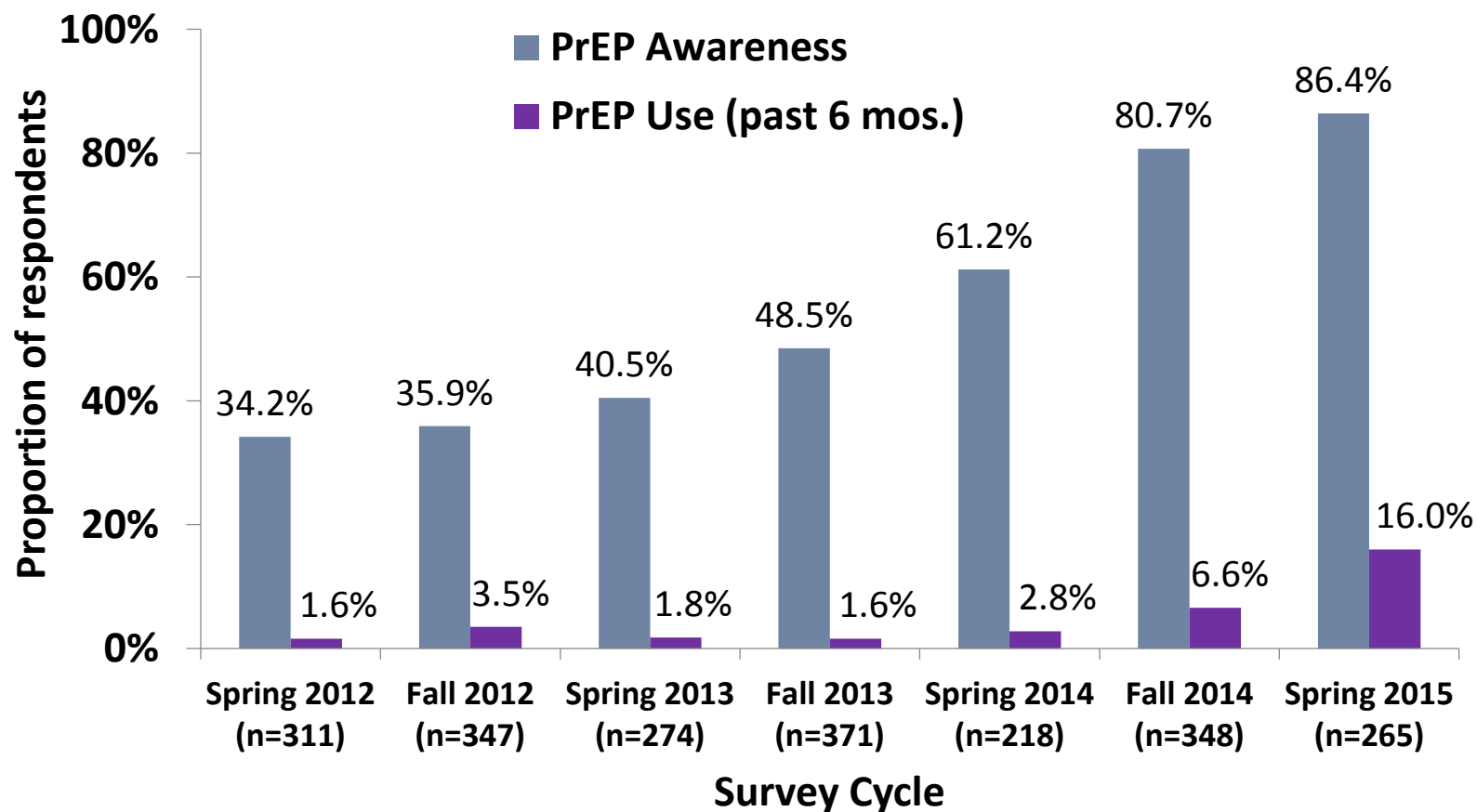
- **Limitations**

- Recall bias, social desirability bias
- Sample may be biased as a result of recruitment strategy (self-selection, convenience sample)
- Cross-sectional data
- Potential concerns with online survey data

Data Source Description:

SHS (4)

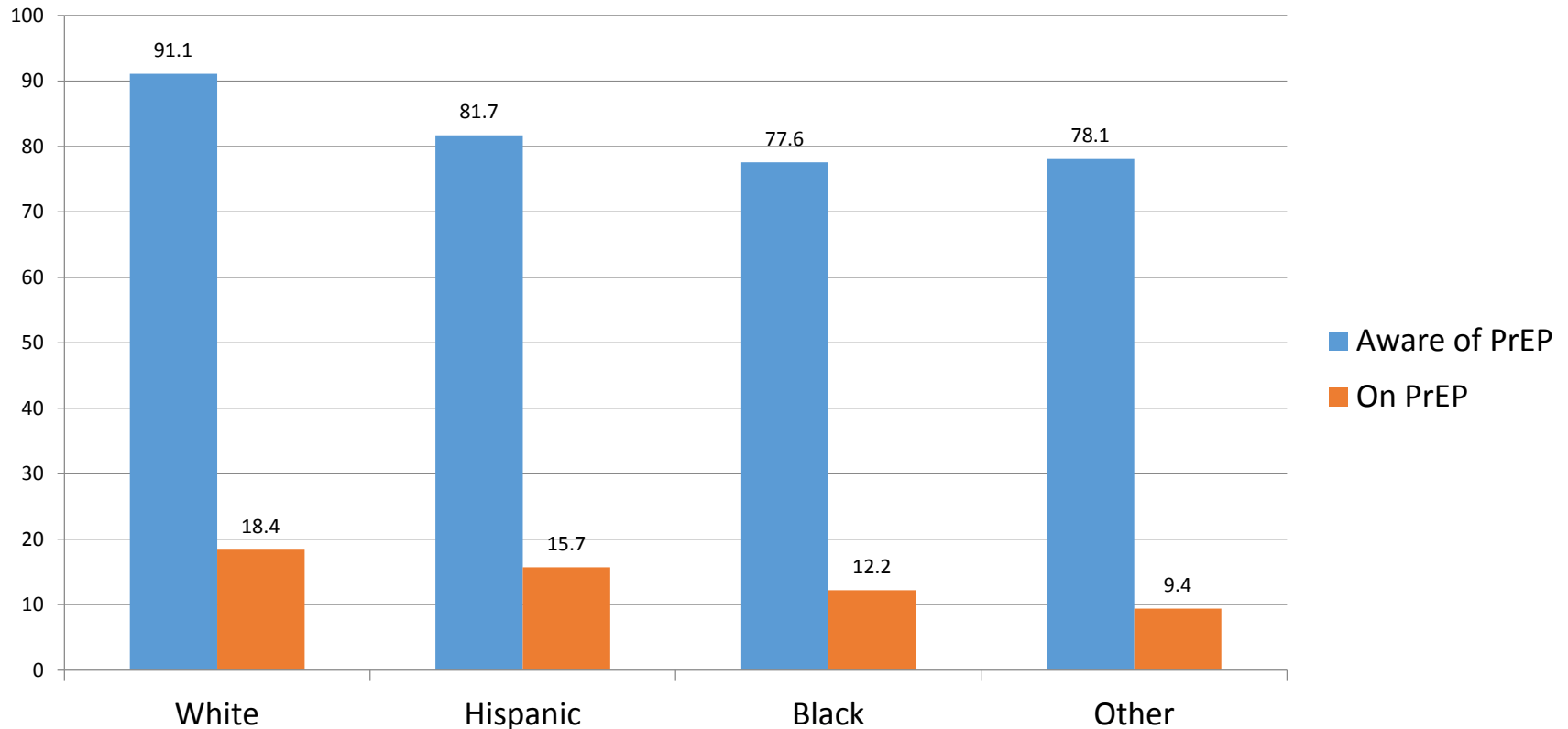
PrEP Awareness and Use among NYC MSM Internet Survey Respondents, 2012-2015; *Preliminary data*



Data Source Description:
SHS (4)

PrEP Awareness and Use among NYC MSM Internet Survey Respondents, 2015; *Preliminary data*

PrEP Awareness and Use among MSM, Spring 2015



Data Source Description:

National HIV Behavioral Surveillance (NHBS)

- **Population included (every 3 years):**
 - Men who have sex with men (MSM)
 - Injection drug users (IDU)
 - Heterosexuals at increased risk for HIV infection (HET)
- **Recruitment:**
 - MSM – venue-based sampling
 - IDU/HET – respondent-driven sampling
- **Data collection methods:** Anonymous survey immediately followed by HIV testing
- **Frequency of data collection:** Every 3 years for each target population
- **Years for which PrEP data available:** 2008-2015, expected to continue in the future

Data Source Description:

NHBS (2)

- **Key definitions of PrEP-related variables:**

- MSM2, IDU2, HET2 (2008-2010):

- Question about use of HIV/AIDS medications to prevent HIV
- Question for HIV+ participants about giving HIV drugs to partners to prevent HIV transmission

- MSM3, IDU3, HET3, MSM4 (2011-2014):

- PrEP awareness, PrEP usage, PrEP prescribed by a provider, willingness to take PrEP

- IDU4 (2015):

- PrEP awareness, PrEP usage, PrEP discussed with a provider, PrEP prescribed by a provider

- **Other relevant data collected:**

- Demographics
- Behavioral risks for HIV
- HIV testing behaviors
- Access to and use of prevention services
- HIV testing results

Data Source Description:

NHBS (3)

- **Opportunities:**

- Sample, especially in MSM cycle, closely approximates population likely to benefit from PrEP
- Sophisticated sampling frame

- **Limitation:**

- Data collection every 3 years
- Sample may be biased as a result of recruitment strategy
- Recall bias, social desirability bias
- Questions have changed over the years, so comparability might be limited

Data Source Description:

NHBS (4)

PrEP Awareness Among HIV-Negative NHBS Study Participants by Meth Use in Previous 12 Months, 2011 and 2014

	2011		2014	
	No Meth Use Previous 12 Months	Meth Use Previous 12 Months	No Meth Use Previous 12 Months	Meth Use Previous 12 Months
Aware of PrEP	22.8% (98 out of 429)	38.9% (7 out of 18)	70.8% (269 out of 380)	75% (18 out of 24)
Have Taken PrEP*	0.5% (2 out of 429)	0% (0 out of 18)	4.8% (13 out of 269)	5.6% (1 out of 18)

NYC DOHMH National HIV Behavior Surveillance data

*PrEP use questions were asked of all participants in 2011 and only of participants aware of PrEP in 2014.

Data Source Description:

NHBS-YMSM

- **Population included:**

- Young men who have sex with men (YMSM)
 - Residents of the NYC metro area
 - Ages 13-17 (extended to 13-18 in August 2015)
 - Male-identified, male-assigned at birth
 - Ever had any sexual contact with another male OR self-identified as gay or bisexual OR reported same-sex sexual attraction

- **Recruitment:**

- 2 recruitment arms: venue-based sampling and respondent-driven sampling

- **Data collection methods:** Anonymous survey immediately followed by HIV testing

- **Frequency of data collection:** One-time pilot study

- **Years for which PrEP data available:** 2014-2015 with tentative plans for future cycles

Data Source Description:
NHBS-YMSM (2)

- **Key definitions of PrEP-related variables:**
 - PrEP awareness
 - Willingness to take PrEP
- **Other relevant data collected:**
 - Demographics
 - Behavioral risks for HIV
 - HIV testing behaviors
 - Access to and use of prevention services
 - HIV testing results

Data Source Description:
NHBS-YMSM (3)

- **Opportunities:**

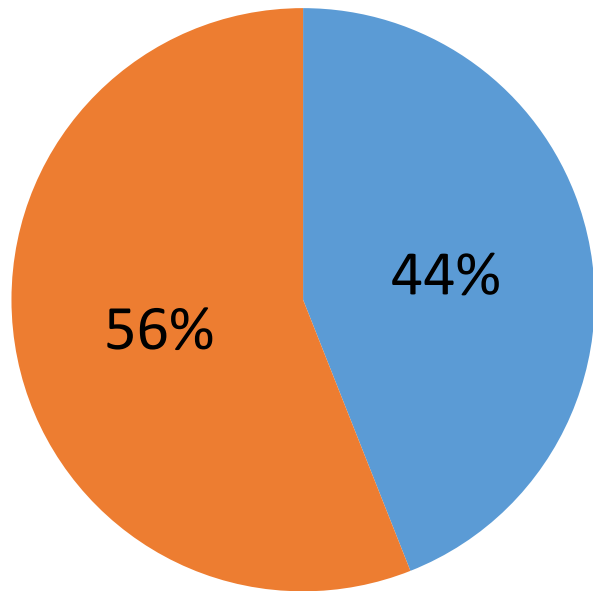
- Population is not well-studied
- Sample closely approximates population likely to benefit from PrEP
- Sophisticated sampling frame

- **Limitations:**

- Sample may be biased as a result of recruitment strategy
- Future cycles of NHBS-YMSM are uncertain

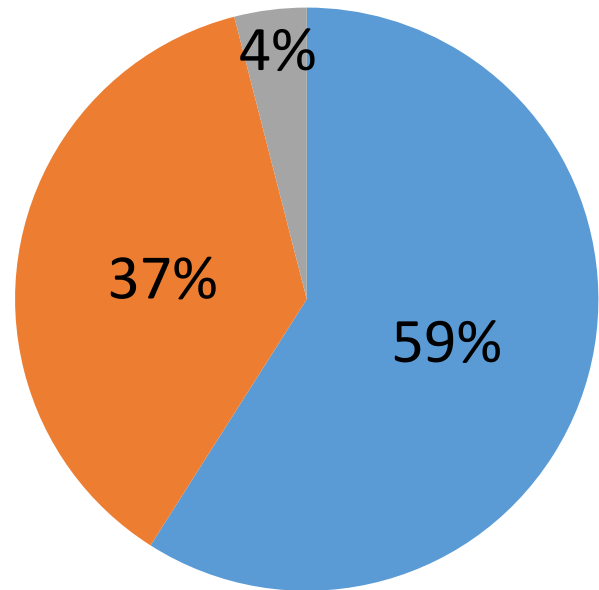
Data Source Description:
NHBS-YMSM (4)

Aware of PrEP



■ Yes ■ No

Willing to take PrEP



■ Yes ■ No ■ Don't Know

Data Source Description:

Medical Monitoring Project (MMP)

- **Population included:** PLWHA receiving medical care for HIV
- **Data collection methods:** Computer-based structured interview, administered face-to-face; medical record abstraction; 3-stage sample design: local areas, providers, patients
- **Frequency of data collection:** Annually
- **Years for which PrEP data are available:** 2013 (NYC local questions only), 2014, 2015 (currently being collected)

Data Source Description:

MMP (2)

- **Key definitions of PrEP-related variables:**
 - **PrEP awareness:** Have you ever heard of people who do not have HIV taking anti-HIV medicines to prevent themselves from getting infected with HIV?
 - **Partner PrEP use:** Do you know if any of your sex/drug injecting partners who do not have HIV have taken anti-HIV medicines as a way to prevent themselves from getting infected with HIV?
- **Other relevant data collected:**
 - Demographics
 - HIV treatment and adherence
 - Sexual and drug use behaviors
 - Prevention activities
 - From medical record abstraction, viral load and CD4 counts

Data Source Description:

MMP (3)

- **Opportunities**

- Useful for understanding PrEP awareness among positive partners in serodiscordant relationships
- Useful for understanding PrEP awareness among individuals with unsuppressed viral load
- Annual survey
- Sophisticated sampling method
- Dataset includes a large number of covariates

- **Limitations**

- Sample limited to PLWHA in care

Data Source Description:

MMP (4)

2013 New York City Local Interview Results

- Of 419 participants who completed the interview:
 - 120 (29%) reported ever hearing about PrEP
- Of 234 participants who reported having sex in the past 12 months:
 - 14 (6%) discussed PrEP with sex partners
 - 8 (3%) reported that a partner had used PrEP
- Of 9 participants who reported injecting drugs in the past 12 months
 - 1 (11%) discussed PrEP with drug injecting partners
 - None were aware of a partner using PrEP

Data Source Description:

MMP (5)

2014 New York City Standard Interview Results

- PrEP questions only asked of participants who reported having sex with at least one HIV-negative partner in the past 12 months
- Of 117 participants who met these criteria and answered questions about PrEP
 - 30 (26%) reported that their partner had used PrEP
 - 86 (74%) reported that their partner had not used PrEP
 - 1 (<1%) did not know if his/her partner had used PrEP

Overview of Current Data Sources

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Provider	<ul style="list-style-type: none"> NYC DOHMH HIV/AIDS Surveillance Primary Care Information Project (PCIP) 	<ul style="list-style-type: none"> Public Health Detailing Program

Data Source Description:

Field Services Unit

- **Population included:**
 - a) All newly diagnosed HIV-positive cases
 - b) All FSU-notified partners
- **Data collection methods:** In-person interviews using the Case Information Form (CIF) or Partner Information Form (PIF)
- **Frequency of data collection:** Ongoing
- **Years for which PrEP data available:** Late 2015-present

Data Source Description:

Field Services Unit (2)

- **Key definitions of PrEP-related variables**

- Newly diagnosed clients

- Ever used PrEP
 - When started PrEP
 - Pills per week (adherence)
 - When stopped PrEP and reason(s) for stopping PrEP
 - Likelihood of condom use with sexual partner on PrEP
 - Likelihood of disclosure of HIV status to sexual partner on PrEP

Data Source Description:

Field Services Unit (3)

- **Key definitions of PrEP-related variables, cont.**

- Partners

- Heard of PrEP
 - Discussed PrEP with provider (provider-initiated or self-initiated)
 - Ever used PrEP
 - Where obtained prescription and how PrEP was paid for (last PrEP use)
 - Pills per week (adherence) (last PrEP use)
 - If stopped, when and reason(s) (last PrEP use)
 - Risk behavior while on PrEP (condom use, number of sexual partners)
 - Willingness to use/resume PrEP
 - STD screening and diagnosis

Data Source Description:

Field Services Unit (4)

- **Opportunities**

- Population interviewed closely approximates population likely to benefit from PrEP
- Interview allows ascertainment of PrEP awareness and willingness to be evaluated for PrEP use
- Interview leads directly to FSU efforts to refer/link partners to PrEP providers for evaluation

- **Limitations**

- Self-report limits recall of usage, specifically dates of PrEP initiation, discontinuation and adherence
- Incomplete data/refusals to answer questions due to circumstances of interview (i.e., during partner notification process)

Data Source Description:

Sexual and Behavioral Health (SBH)

- **Population included:** High-risk, HIV-negative uninsured/underinsured MSM and transgender women
- **Data collection methods:** eSHARE data (NYC DOHMH's program data system)
- **Frequency of data collection:** Ongoing, reports created quarterly
- **Years for which PrEP data are available:** September 2013 onward

Data Source Description:

SBH (2)

- **Key definitions of PrEP-related variables:**
 - PrEP awareness at intake/program enrollment
 - PrEP use
 - Measured at intake/program enrollment: PrEP use in the past 6 months
 - Measured as service provision: documented PrEP initiation at SBH
 - PrEP adherence: patient report of missed doses, barriers to adherence, and reasons for PrEP discontinuation
- **Other relevant data collected:**
 - Sociodemographic data
 - Behavioral risks for HIV
 - Access to and use of other prevention services
 - HIV testing behaviors and test results

Data Source Description:

SBH (3)

- **Opportunities**

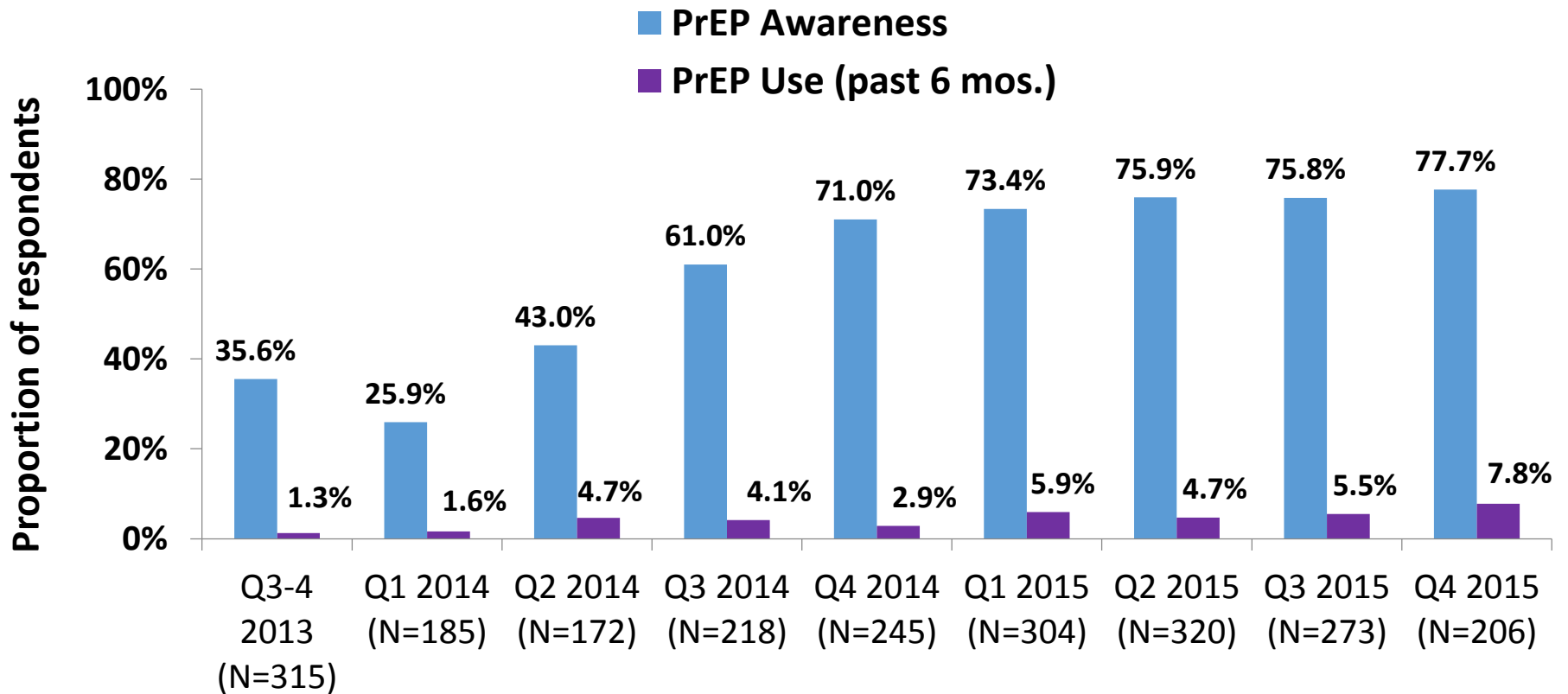
- Real-time data on uninsured individuals at risk
- Provides opportunity to collect information from clients at multiple time points

- **Limitations**

- Sample is not representative of all MSM and transgender women, particularly because they are already accessing services
- For data measured at intake: self-report, recall bias

Data Source Description: SBH (4)

PrEP Awareness and Use at Intake among SBH Clients, 2013-2015



Overview of Current Data Sources

	Surveillance	Program/One-time Survey
Consumer	<ul style="list-style-type: none"> Sexual Health Surveillance (SHS) National HIV Behavioral Surveillance (NHBS) Medical Monitoring Project (MMP) 	<ul style="list-style-type: none"> NYC DOHMH Field Services Unit Sexual and Behavioral Health Program (SBH)
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Data Source Description:

Public Health Detailing Program

- **Population included:** Providers practicing medicine at NYC facilities identified as diagnosing HIV and/or located in high needs neighborhoods
- **Data collection methods:** In-person survey among prescribing providers; administered at initial and follow-up visits (5-8 weeks later)
- **Frequency of data collection:** Currently, approximately biannual
- **Years for which PrEP data are available:** Fall 2014 onward

Data Source Description:

Public Health Detailing Program (2)

- **Key definitions of PrEP-related variables:**
 - **PrEP knowledge:** “If taken every day, approximately how efficacious is PrEP?”
 - **PrEP discussion:** “Have you discussed PrEP with any of your patients?”
 - **PrEP prescription/referral:** “Have you provided or referred a patient for PrEP?”
- **Other relevant data collected:**
 - Provider training, specialty
 - Practice type, location, neighborhood HIV diagnosis and poverty rates

Data Source Description:

Public Health Detailing Program (3)

- **Opportunities**

- Data directly reported from providers encountered by detailing representatives in the field
- Potential for long-term follow-up with providers

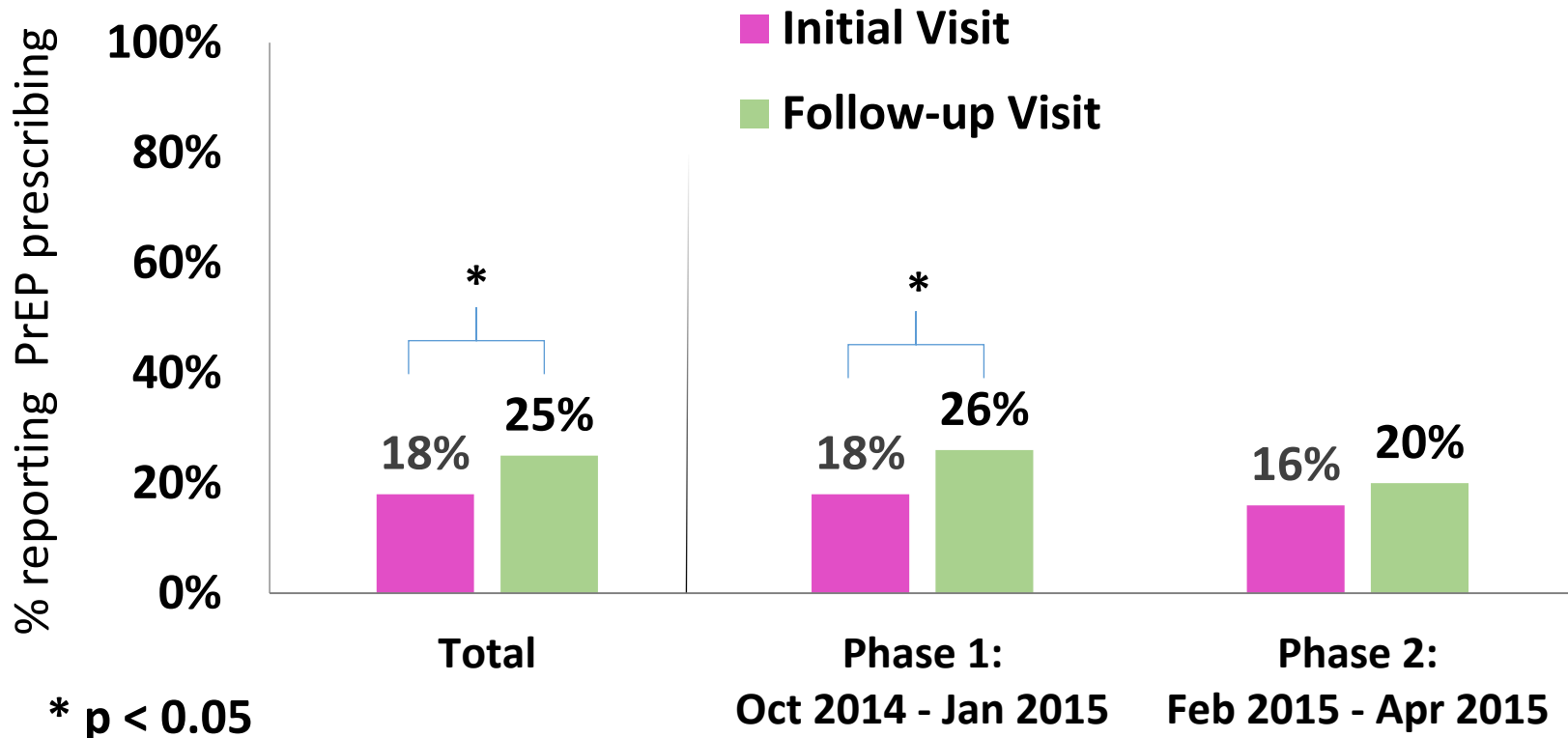
- **Limitations**

- Sample not representative of all NYC providers
- Recall bias, social desirability bias
- Brief nature of the detailing visit means limited covariate data collected

Data Source Description:

Public Health Detailing Program (4)

Report of PrEP Prescribing among Detailed Providers, Overall and by Phase (n=882), October 2014-April 2015



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Data Source Description:

HIV/AIDS Surveillance

- **Population included:** All persons newly diagnosed with HIV in NYC
- **Data collection methods:** Medical chart review
- **Frequency of data collection:** Ongoing
- **Years for which PrEP data available:** Mid-2015-present

Data Source Description:

HIV/AIDS Surveillance (2)

- **Key definitions of PrEP-related variables:** PrEP use history at time of HIV diagnosis
- **Other relevant data collected:**
 - Basic demographic data
 - Basic HIV-related clinical information (CD4, VL)
 - Genotype (if conducted)

Data Source Description:

HIV/AIDS Surveillance (3)

- **Opportunities:**

- Includes *all* persons newly diagnosed with HIV in NYC
- Data set links new positives, potentially PrEP failures, with phylogenetic data

- **Limitations:**

- Relies on successful medical record abstraction (possible to miss PrEP use)
- Relies on accurate provider documentation of patients' PrEP prescription/use
- Sample limited to HIV-positive persons

Data Source Description:

HIV/AIDS Surveillance (4)

- **Data:** Not yet available

Data Source Description:

Primary Care Information Project

- **Population included:**
 - Practices that are part of Hub*, located in NYC, with documented visits for ≥ 50 patients aged 13-100 in 2012, reported data for all quarters, 2012 – 2014
- **Data collection methods:** Electronic health record (EHR) abstraction collected through query
- **Frequency of data collection:** Ongoing, data queried semiannually
- **Years for which PrEP data are available:** 2012 onward

The Hub Population Health System (“the Hub”) of NYC’s DOHMH Primary Care Information Project (PCIP), which connects to over 700 practices using the eClinicalWorks EHR vendor

Data Source Description:

Primary Care Information Project (2)

- **Key definitions of PrEP-related variables:**
 - Current TDF/FTC prescription in patients aged 13-100 using a validated algorithm to eliminate non-PrEP prescriptions
- **Other relevant data collected:**
 - Practice type, location, and aggregate patient characteristics
 - Patient demographics: gender, race/ethnicity, age group

Data Source Description:

Primary Care Information Project (3)

- **Opportunities**

- Hub contains a large number of patients (2.1M in 2014)
- Hub reflects actual care under everyday conditions

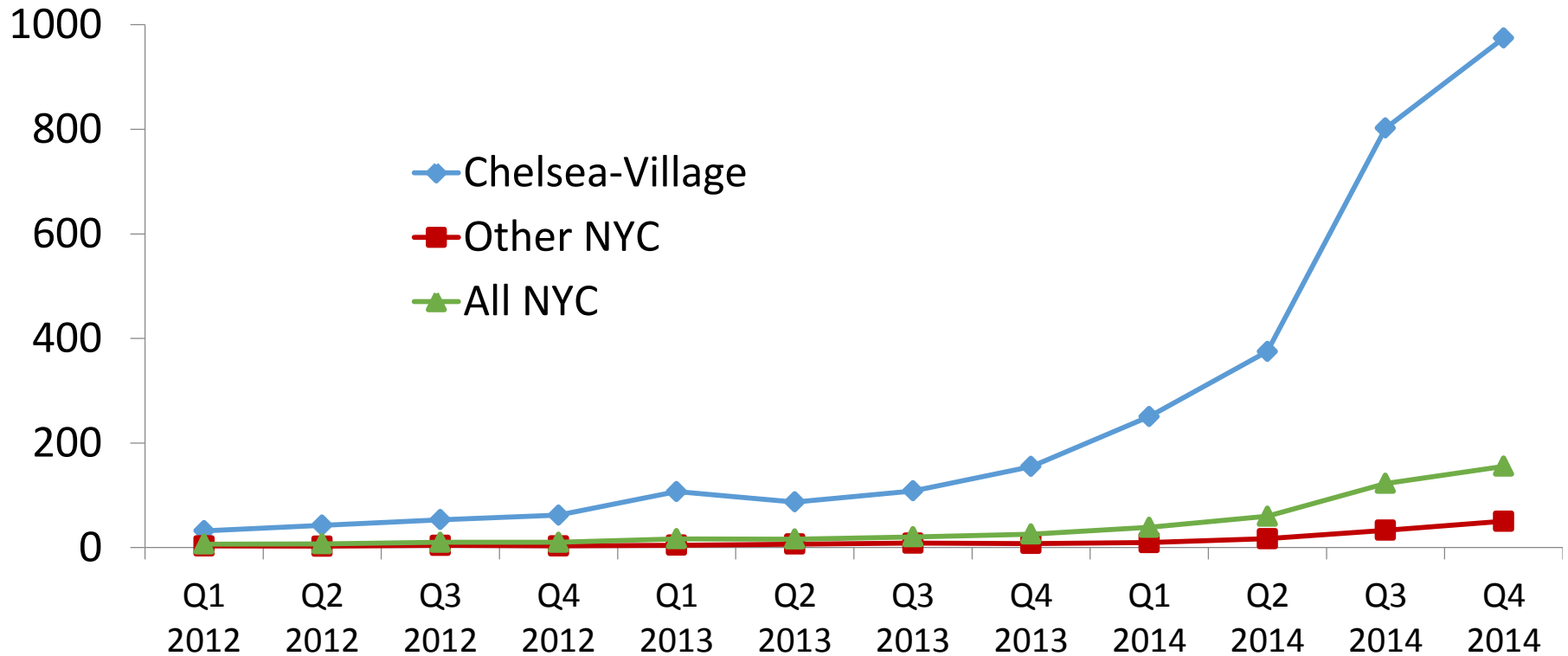
- **Limitations**

- Practices covered by the Hub may not be representative of all ambulatory care practices in NYC
- PrEP prescriptions identified based on EHR data elements, which could be incomplete or inaccurate
- Nature of query method limits number of covariates that can be analyzed simultaneously

Data Source Description:

Primary Care Information Project (4)

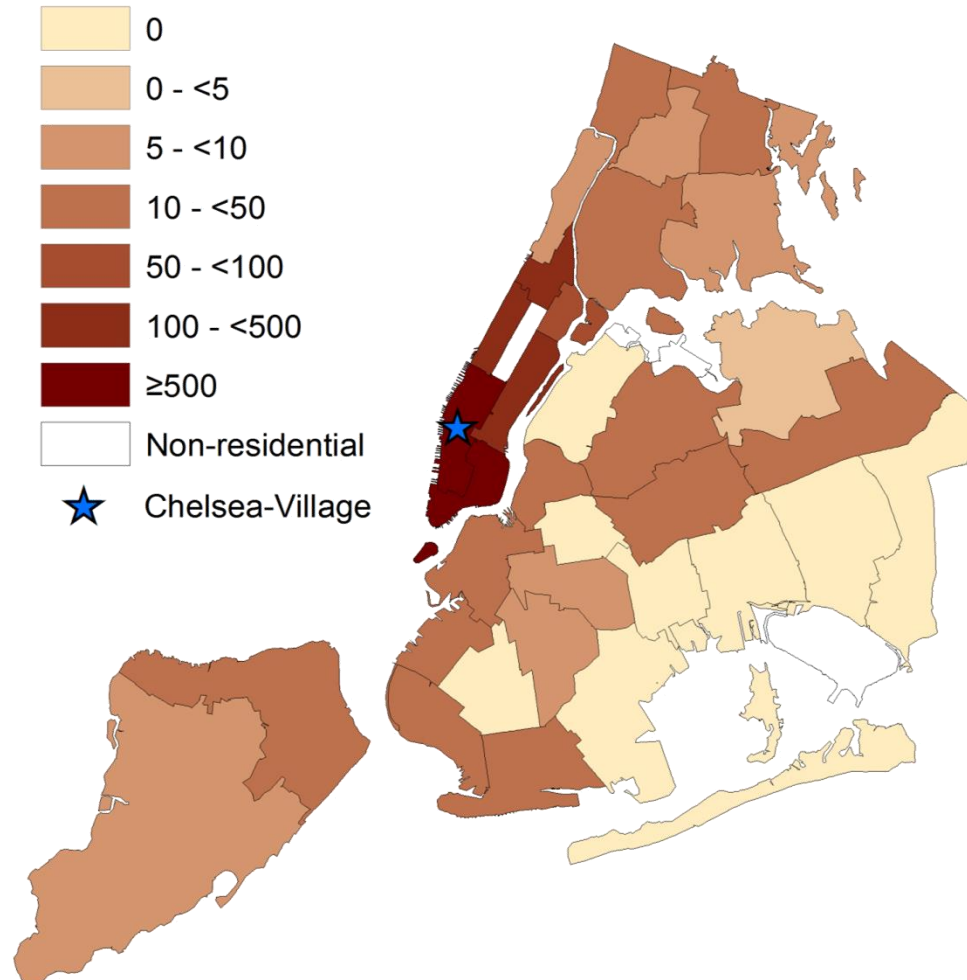
PrEP Prescription per 100,000 Patients Seen at Ambulatory Care Practices (n=538), NYC, 2012-2014



Data Source Description:

Primary Care Information Project (5)

PrEP prescriptions per 100,000 patients seen, Q4 2014



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Overview of Current Data Sources

	Surveillance	Program
Consumer	<ul style="list-style-type: none"> Sexual Health Surveillance (SHS) National HIV Behavioral Surveillance (NHBS) Medical Monitoring Project (MMP) Community Health Survey (CHS) (2016)* 	<ul style="list-style-type: none"> NYC DOHMH Field Services Unit Sexual and Behavioral Health Program (SBH)
Provider	<ul style="list-style-type: none"> NYC DOHMH HIV/AIDS Surveillance Primary Care Information Project (PCIP) ADARC survey (Spring 2016)* 	<ul style="list-style-type: none"> Public Health Detailing Program STD Clinic Programs (mid 2016) PrEP Network (mid 2016) Adolescent PrEP Program (mid 2016)

*Currently, only planned to be administered once.

Closing Thoughts

- Avoid classic data pitfalls
 - Focus on data collection/processing without sufficient time for analysis/interpretation
- Beware the unknown “denominator”
 - Difficult to know how program clients or certain survey samples compare to the overall population
- Carefully consider the “numerator”
 - Difficult to estimate PrEP “coverage” when the numerator and denominator have distinct sources
 - People may initiate PrEP without actually being considered PrEP candidates from the program planning perspective
- Caution with outcome selection
 - PrEP initiation/use is quite appealing but is likely overly simplistic
 - PrEP adherence is especially problematic (gold standard not yet established)
- Triangulation will be key
 - No one source is likely to be sufficient for all outcomes of interest

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- Emily Westheimer
- Rachel Lazar
- Paul Salcuni
- Other NYC DOHMH colleagues

THANK YOU!

Julie Myers

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EXTRA SLIDES

Data Source Description: Public Health Detailing Program (4)

Report of PrEP Prescribing among Detailed Providers,
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