NYC DOHMH / TAG Workshop on PrEP Monitoring / Metrics in New York State / City

New York Academy of Medicine

19 February 2016

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Reports from Break-Out Sessions

I. PrEP Usage

Issue 1A: "Is the consumer using PrEP?"

Indicator: PrEP use at the time a consumer is encountered.

Data sources: Population-level data including HIV and STD case reports (via HIV report form and universal report form). By adding a question in the demographics section 'Is this person on PrEP?' we would be able to monitor newly diagnosed non-HIV STD cases among people on PrEP and provide PrEP referrals/linkages for those not on PrEP. For people who indicate that they were on PrEP, it would provide an opportunity to address challenges to use of PrEP.

Issue IB: "How will we measure who is eligible for PrEP?" Different guidelines exist. Potentially we could develop our own case definition based on city data to track PrEP use over time.

Data sources: The use of electronic medical records and a common set of ICD10 codes to indicate that the patient was a PrEP candidate would be helpful, even if that data were at the clinic-level. Primary Care Information Project (PCIP) data could also be a source.

Issue IC: "How do we measure PrEP coverage?"

Indicator: At any point in time, the number of people who should be on PrEP / are classified as high-risk / are candidates for PrEP / Have discussed PrEP with a healthcare provider – and the number of people on PrEP.

Data sources: Facility-level (EMR) and the NYC DOHMH Community Health Survey (CHS). The CHS is an annual survey of about 10,000 New Yorkers that captures elements of risk (indication for PrEP, for the denominator); now a binary PrEP use question, for the numerator and it is ongoing (repeated cross-section design), so we can get trends over time.

Data needs: More qualitative data are needed to better understand the reasons why people do not elect to use PrEP. In order to understand the complex interplay of factors and identify missed opportunities, we could draw from the experience of congenital syphilis cases assessment which involves looking at factors from multiple levels (i.e., systems-level, health facility-level, health department-level, patient-level). In addition, to better understand 'seasons of risk', we would need longitudinal data.

II. PrEP Prescribing + Measurement

Indicator: Denominator of all eligible PrEP candidates through modeling or predictive analysis, new, filled and refilled prescriptions, age, gender, zip, provider

Data sources: Regional Health Information Organizations [RHIOs]/Statewide Health Information Network of New York [SHIN-NY] and Medicaid if combined would provide a substantial prescription picture. Other possible data sets include proprietary databases, which are costly but probably include a broader set of prescriptions, including from private providers. However, prescription data with names may tell us more. Claims data on provider characteristics – e.g., where they are and where they are working – would be informative. EMR data though limited by patient characteristics and other claims info.

Data needs: PrEP-related care – e.g., HIV and STI tests, renal function markers – race/ethnicity, sexual/injection risks, insurance refusal of prescription coverage or decision not to take PrEP due to a high co-pay. These data are likely to be harder to collect as not routine.

III. PrEP Awareness + Literacy

Issue: There are multiple stigmas on several levels: provider and patient levels; community and individual levels; stigma around the intervention and/or the place where PrEP is acquired itself. In addition, there is difficulty in distinguishing between health literacy and PrEP literacy.

Indicator: Measuring health-care provider, client, and community PrEP shaming/stigma for people on PrEP/those considering PrEP, pressure people feel to take PrEP and how people perceive where they go to get PrEP

Data sources: Potential data sources at the health facility-level. No current statewide or citywide data source captures PrEP stigma. NYC DOHMH Sexual Health Survey (SHS) is conducted among men who have sex with men (MSM) and women of color and captures data about awareness of PrEP and what people would think if their partner disclosed their PrEP use.

Data needs: The need to better understand why people are not taking PrEP; self-assessment of risk. In addition, we would learn from existing knowledge from providers, consumers, community from ART and about the birth control, HBV, HCV, HPV, STD, needle exchange experiences to unpack stigma and literacy issues related to implementation and scale-up.

IV. Measuring the Whole Package

Issue: The whole package takes into consideration need, quality services, reaching the people we want to reach – e.g., people living in high HIV-burdened neighborhoods and those most likely to need services while lacking access, information, insurance, or social support.

Indicators: Reasons for people starting, stopping, and/or turning down PrEP; Scale-up of PrEP services into primary care and not just in standalone places; Prevention of new HIV infections; Quality measures from the NYC DOHMH Prevention request for proposals (RFP; pp. 18, 55) should be considered; Allowing people to self-identify their risk; How to reach high-risk black women who do not consider themselves at risk.

Data sources: City contractors, surveillance, Symphony, IMS Health, or other proprietary prescription data – information de-identified by the vendor which precludes a match to surveillance data), Medicaid claims database, RHIOs.

V. Open Discussion

Opportunities for action

- ICD-10 codes and syncing NYS and NYC codes for consistency. Educate healthcare providers about the utility of using the designated ICD-10 codes to indicate PrEP eligibility.

- Follow-up on the costs of obtaining proprietary data sources

- This process may be highly variable. In the NYS experience, in general, managed Medicaid and Medicaid, and insurances in the NYS Exchange are relatively easier to work with than commercial insurance companies (partly due to the fact they do not meet regularly).

Considerations regarding data sources

- Measuring PrEP usage should not be siloed and should consider all pillars of the EtE Blueprint – HIV testing, care, and PrEP. EMR data are not perfect but can be used as data sources. Analyzing provider offering of PrEP would be good to measure but may be difficult.

- Keep in mind specific governance established in HIPAA as allowable use etc.

- Indicators are always contextualized by data sources and limitations; it is important to think about parsimonious indicators and what we really need in order to measure consistent trends over time. Be sensitive to excessive changing indicators given the need for consistency over time, but also be aware that as this is a new program paradigm, we will learn from doing and need to improve our metrics over time.

- New data from DOHMH-run PrEP programs will be received through eSHARE. There is always a lag in reporting but the data is shareable and we can mold what data we request of them. The city's STD EMR can tell us who is touched by PrEP. It's important to note the distinction between population data and data specific to a particular group (i.e., STD clinic patients).

- Minimize reporting burden for providers and consider conducting targeted studies. Integrating PrEP-related questions/data collection into existing systems would reduce reporting burden.

- RHIOS and Medicaid, Gilead, NYS PrEP Assistance Program (PrEP-AP) data can give relatively complete picture; CBOs that will be providing PrEP should use RHIOS in order to get a full view of a client's healthcare seeking behavior.

- Measuring disparities in PrEP use. We should consider whether that means closing the gap between certain races and ethnicities, reaching a certain level, etc.

VI. Next Steps

- NYC DOHMH to summarize notes and disseminate to all participants.

- NYC DOHMH to circulate and disseminate slides that can be shared

- Determine:
  – Action steps for NYS and NYC
  – Format and structure for in-person follow-up meeting
  – How community can incorporate today into advocacy efforts (e.g., buying data that is needed)

- NYC DOHMH will explore RHIO and SHIN-NY as ultimate data sources.

- NYS DOH/AIDS Institute, NYC DOHMH, and/or community organizations – e.g., TAG – will explore the cost, feasibility, scope, and usefulness of contracting for comprehensive prescription databases.

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AGENDA

8:30 am – 9:00 am	COFFEE & REGISTRATION
9:00 am – 9:10 am	Welcome/Intro
9:10 am – 9:30 am	Community Call to Action
9:30 am – 10:15 am	New York City presentation: Existing NYC-specific sources of data about PrEP implementation
10:15 am – 11:00 am	New York State presentation: Existing NYS-specific sources of data about PrEP implementation
11:00 am – 11:15 am	MORNING BREAK
11:15 am – 12:00 pm	NYC/NYS joint presentation: DOH-based municipal programming, Future activities, Data grid
12:00 pm – 1:00 pm	WORKING LUNCH – Unique Models of Implementation
1:00 pm – 2:00 pm	Panel discussion: • PrEP Usage • PrEP Prescribing Measurement • PrEP Awareness and Literacy • Measuring the "Whole PrEP Package"
2:00 pm – 3:30 pm	Breakout sessions: Pre-assigned small workshops addressing panel topics
3:30 pm – 4:00 pm	Breakout group report back
4:00 pm – 4:55 pm	Open forum / group discussion and Next Steps
4:55 pm – 5:00 pm	Closing remarks

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