

January 13, 2020

Submitted electronically to OIRA_submission@omb.eop.gov

Re: Agency Information Collection Activities: Submission to OMB for Review and Approval; Public Comment Request; Bureau of Primary Health Care Uniform Data System, OMB No. 0915-0193-Revision

The Fenway Institute at Fenway Health submits the following comment regarding the notice filed by the Health Resources and Services Administration (HRSA) titled “Agency Information Collection Activities: Submission to OMB for Review and Approval; Public Comment Request; Bureau of Primary Health Care Uniform Data System, OMB No. 0915-0193-Revision.” We previously commented on HRSA’s Information Collection Request related to the health center program’s Uniform Data System, OMB No. 0915-0913.

The Fenway Institute is the research, education and training, and policy arm of Fenway Health, a federally qualified health center in Boston, MA. We provide care to about 32,000 patients every year. Half of our patients are lesbian, gay, bisexual and transgender (LGBT). About 2,200 of our patients are people living with HIV. We are a Ryan White Part C clinic. Currently we have 3,200 patients receiving pre-exposure prophylaxis for HIV prevention, and have prescribed PrEP to 4,700 patients since it became available earlier this decade. We have been providing HIV care since the early 1980s, and conducting HIV prevention research since 1985.

We are pleased to see that following the public comment period last fall, HRSA made appropriate adjustments and updated the 2020 UDS data collection instruments in the following ways:

Adding CMS349v2 HIV Screening

The addition of this screening measure will contribute to concerted efforts to better identify priority geographies, assist high risk populations, and deploy interventions and resources in support of the Ending the HIV Epidemic Initiative. Fenway Health supports universal screening for HIV. Because health centers serve a broad and diverse swath of the U.S. population, it is especially important that all health center patients ages 15 to 65 be screened for HIV.

Revising the HIV linkage to care measure: The HIV linkage to care

Effective and timely linkage to care after HIV diagnosis is critical to the health of the newly diagnosed individual and to achieving the goals of the Ending the HIV Epidemic Initiative. According to the Centers for Disease Control and Prevention’s Diagnosis-Based HIV Care Continuum, 74% of people living with HIV are receiving care, 58% are retained in care, and 62% are virally suppressed.¹ Cohen et al. found that earlier treatment decreases HIV transmission, so connecting newly diagnosed individuals to care in a more timely manner will

¹ CDC, Understanding the HIV Continuum, July 2019, <https://www.cdc.gov/hiv/pdf/library/factsheets/cdc-hiv-care-continuum.pdf>

likely save costs by decreasing HIV incidence.² Connecting newly diagnosed individuals more quickly to HIV care will also help achieve Strategy 2 of the Ending the HIV Epidemic Initiative, “Treat HIV rapidly after diagnosis, and effectively, in all people with HIV to help them get and stay virally suppressed.” Fenway Health is confident that, with the help of high acuity case managers and an integrated approach to care that addresses behavioral health and the non-medical support service needs of the patient, that newly diagnosed individuals can be quickly linked to and retained in care and virally suppressed.

Adding Prescription for Pre-Exposure Prophylaxis (PrEP) International Classification of Diseases (ICD) 10 Codes and Current Procedural Terminology (CPT) codes

The addition of the PrEP measure will also support the Ending the HIV Epidemic Initiative by allowing for the collection of PrEP prescription data in health centers. The Fenway Institute at Fenway Health was involved in the first PrEP study to demonstrate efficacy—the iPrEx Study—and has been involved with a number of PrEP clinical trials since iPrEx, including studies of injectable PrEP and other modalities. We also conduct studies of microbicides and antibody infusion for HIV prevention. PrEP is an important prevention approach that will help our country achieve the goals of the Ending the HIV Epidemic Initiative and keep thousands of vulnerable individuals HIV-negative. We strongly support this addition, which will enable more efficient prescribing of PrEP for HIV prevention.

The ICD-10 diagnostic codes that are currently proposed can also be used for non-PrEP clinical assessments. Therefore, this may result in an over count of patients prescribed PrEP. We recommend instead that a measure would include patients who are HIV uninfected and have an ART prescription greater than 30 days. The greater than 30 days criteria would eliminate patients who were prescribe ART for nPEP (non-occupational Post-Exposure Prophylaxis), which is typically a 30-day prescription. We also recommend that the measure should report those who were prescribed PrEP—either new or ongoing—during the reporting period. Identifying patients who might be good candidates for PrEP requires more additional variables beyond ICD-10 codes.

Adding CMS125v8 Breast Cancer Screening

We support the addition of this CMS measure, which will help achieve higher screening rates, better treatment outcomes, and could help reduce disparities affecting sexual and gender minority patients and Black and Latina/o/x patients. Breast cancer is a major concern for lesbian and bisexual women. Transgender men are also at risk for breast cancer, even if they have had breast removal through top surgery. Because lesbian and bisexual women have higher rates of certain risk factors for breast cancer, such as nulliparity, they may be at elevated risk for breast cancer. Behavioral Risk Factor Surveillance System data³ and health center data⁴ indicate that

² Cohen S, Van Handel M, Branson B et al. Vital Signs: HIV Prevention Through Care and Treatment— United States. *Morbidity and Mortality Weekly Report*. December 2, 2011 / 60(47):1618-1623. <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6047a4.htm>. Accessed August 14, 2012.

³ Cochran SD, Mays VM, Bowen D, et al. Cancer related risk indicators and preventive screening behaviors among lesbians and bisexual women. *Am J Public Health*. Apr 2001;91(4):591-597.

⁴ Bazzi A, Whorms D, King D, Potter J. Adherence to mammography screening guidelines among transgender persons and sexual minority women. *Am J Public Health* Nov 2015;105(11):2356-8.

lesbians and bisexual women and transgender people are less likely to access breast cancer screening. There are also striking racial and ethnic disparities in breast cancer screening. It is important to note that while this addition is important, the CMS measure is not inclusive of all genders who may have breasts, such as transgender masculine people. In order for the breast screening measure to be effective, the inclusion criteria must be expanded to include all patients who currently have or have had breasts.

Adding ICD-10 Codes to Capture Human Trafficking and Intimate Partner Violence:

We support the addition of screening questions for these measures and many sexual and gender minority people experience high rates of intimate partner violence; however, there may be risk in adding ICD-10 codes to a patient's problem list. We recommend that a better measure is using positive screener than ICD-10 codes.

Thank you for the opportunity to comment on this Information Collection Request. Should you have any questions, please contact Sean Cahill, PhD, Director of Health Policy Research, at scahill@fenwayhealth.org or 617-927-6016.

Sincerely,

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