Clinical Registries Could Improve Influenza Like Illness and COVID-19 Surveillance

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Abstract

Capacity for tracking COVID-19 prevalence patterns is hampered by insufficient data, particularly from rural and small communities. The PRIME Registry holds data for 5.4 million patients in 47 states who made 638,983 Influenza-Like Illness (ILI) visits in 2019, mirroring CDC's ILINet temporal patterns but with higher volume and greater rural penetration. Clinical data registries are viable partners that could fill gaps for epidemic sentinel functions and have rich patient data which may identify factors predictive of COVID-19 morbidity and mortality.

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As COVID-19 case estimates and attributed mortality grow, so does national awareness of the

lack of reliable evidence on the number of people infected with SARS-CoV-2, especially outside

the emergency and inpatient sectors. Data from the largest platform of health care delivery,

primary care, is in short supply, particularly from rural and small practice environments.(1) The

PRIME Registry routinely pulls or accepts electronic health record (EHR) data for 5.4 million

patients who receive care in more than 800 practices located in 47 states. In 2019, 503,696 of

these patients collectively made 638,983 Influenza-Like Illness (ILI) visits as defined by CDC

protocol. The pattern of ILI prevalence in PRIME practices were temporally similar to those

reported by volunteer practices in CDC's ILINet but with higher volume. Nearly 40% of the

PRIME patients meeting ILI criteria lived in rural areas. In addition to rich health and treatment

data, the PRIME Registry has demographic and small-area social determinant data which could

inform COVID-19 morbidity and mortality disparity investigation. Clinical registries offer low-

burden epidemic sentinel capacity as well as depth data about patient populations that might

support CDC's mission, particularly in cases of national public emergencies.

The Centers for Disease Control and Prevention (CDC) Outpatient Illness ILINet accepts

volunteer reports of Influenza-like illness (ILI) from approximately 2600 physicians each week. It

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is currently being adapted for COVID-19 surveillance but is insufficient for monitoring regional differences in a pandemic. ILINet is also limited in detailed racial/ethnic and socioeconomic patient characteristics, important to addressing mounting concerns over COVID-19 outcome disparities. The PRIME Registry (www.primeregistry.org) is a Qualified Clinical Data Registry certified by CMS in 2016 to report clinical quality measures for federal and other reporting requirements.(2) It draws on electronic health record (EHR) data from around 3000 clinicians in 47 states. PRIME has race/ethnicity data for 87% of patients and access to census tract level Social Deprivation Index for 93% of patients.(3) Annually, more than five million patients make more than ten million visits to PRIME practices. We report here on a replication of the weekly ILI trends using PRIME data and describe its potential to supplement national sentinel surveillance during infectious disease epidemics, as well as in tracking more typical flu and respiratory disease outbreaks.

Methods

Using 2019 PRIME Registry data from 826 primary care practices, we identified ILI visits based on ICD9 and ICD10 codes used by the CDC for identifying ILI - a category of nonspecific respiratory illness defined by the presence of fever (temperature of 100 degrees F [37.8 degrees C] or greater) and a cough or a sore throat in the absence of a known cause other than influenza.(4) We compared 2019 CDC and PRIME ILI outputs across 52 weeks of reporting and across U.S. states.

Results

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We identified 638,983 ILI visits in 2019 by 503,696 patients out of a total of 5.4 million patients. Figure 1 presents the percent of visits from ILI comparing the PRIME Registry patient population with CDC National Outpatient Illness surveillance data.(5) For 2019, the PRIME practices had more ILI visits than did physicians' volunteer reporting to the CDC, but with similar week-to-week prevalence patterns. A high proportion (39%) of patients seen in PRIME ILI visits came from rural areas. Figure 2 shows the geographic differentiation of ILI activity by state in the PRIME registry compared to those reported by the CDC for the week ending November 23, 2019. Here, the spatial patterns differ substantially, which is most likely due to different composition of the samples.

Discussion

Public health officials require sentinel surveillance across multiple settings to understand and quantify the spread of COVID-19 but face a dearth of reliable data from primary care. We show higher rates of ILI from primary care physician practices and demonstrate the utility of PRIME Registry data for monitoring ILI across the U.S. It nationally replicates CDC ILI findings over time, while revealing different geographic patterns. The advantages of supplementing surveillance with PRIME, and potentially other registry data include increased sample size, a consistent panel of physicians across time, and greater coverage of rural areas. Registry data also contributes the additional richness of full EHR data to surveillance, including more detailed racial/ethnic and socioeconomic patient characteristics, diagnoses, medications, and biometrics. Clinical registries also offer ease of data extraction without additional physician burden (PRIME can provide weekly data feeds) and can be linked to claims data from other

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settings or even death indices to assess outcomes. The capacity to link to outcomes and richness of EHR data could enable the identification of factors predictive of hospitalization, need for intensive care, or death.

To mitigate the effects of COVID-19 and future epidemics, the U.S. must follow the lead of other nations and continue to grow multifaceted disease surveillance systems inclusive of all elements of the delivery system.(6) Clinical registries have their own limitations, for example, the PRIME Registry is a convenience sample of practices who largely joined to overcome reporting and quality measurement hurdles; however, clinical registries can contribute to this capacity and offer windows on sectors of care and communities currently missing from existing sentinel networks. The CDC should consider partnering with registries to supply a low-burden and regular source of clinical data to support national emergencies like COVID-19 but also to track other epidemics and health disparities, generally. The PRIME Registry has partnered with Stanford University to enable research and public health functions and other clinical registries may be willing to serve the same interests.

Figure 1. Percent of visits from Influenza Like Illness (ILI) from CDC ILI Net (orange) as compared to the PRIME Registry (blue), 2019.

Figure 2a and Figure 2b. PRIME Influenza Like Illness (ILI) Activity Map for the week

ending November 23, 2019, prior to the coronavirus disease epidemic based on CDCs

ILINet (2a) and the PRIME network of primary care clinics (2b).

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References

1. Green LA, Fryer GE, Yawn BP, Lanier D, Dovey SM. The Ecology of Medical Care Revisited. N Engl J Med. 2001 Jun 28;344(26):2021–5.

2. Phillips R. The PRIME Registry Helps Thousands of Primary Care Clinicians Liberate EHR Data and Prepare for MIPS. J Am Board Fam Med. 2017 Jul 1;30(4):559.

3. Butler DC, Petterson S, Phillips RL, Bazemore AW. Measures of social deprivation that predict health care access and need within a rational area of primary care service delivery. Health Serv Res. 2013;48(2pt1):539–59.

4. Armed Forces Health Surveillance Branch [Internet]. [cited 2020 Apr 4]. Available from: https://www.health.mil/Reference-Center/Publications/2015/10/01/Influenza-Like-Illness

5. FluView Interactive [Internet]. CDC Centers for Disease Control and Prevention; [cited 2020 Apr 4]. Available from: https://gis.cdc.gov/grasp/fluview/FluView8.html

6. Chuang J-H, Huang AS, Huang W-T, Liu M-T, Chou J-H, Chang F-Y, et al. Nationwide surveillance of influenza during the pandemic (2009–10) and post-pandemic (2010–11) periods in Taiwan. Plos One. 2012;7(4).

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Figure 1. Percent of visits from Influenza Like Illness (ILI) from CDC ILI Net (orange) as compared to the PRIME Registry (blue), 2019.

PRIME Registry ILI Visits vs. CDC ILI Net (2019)
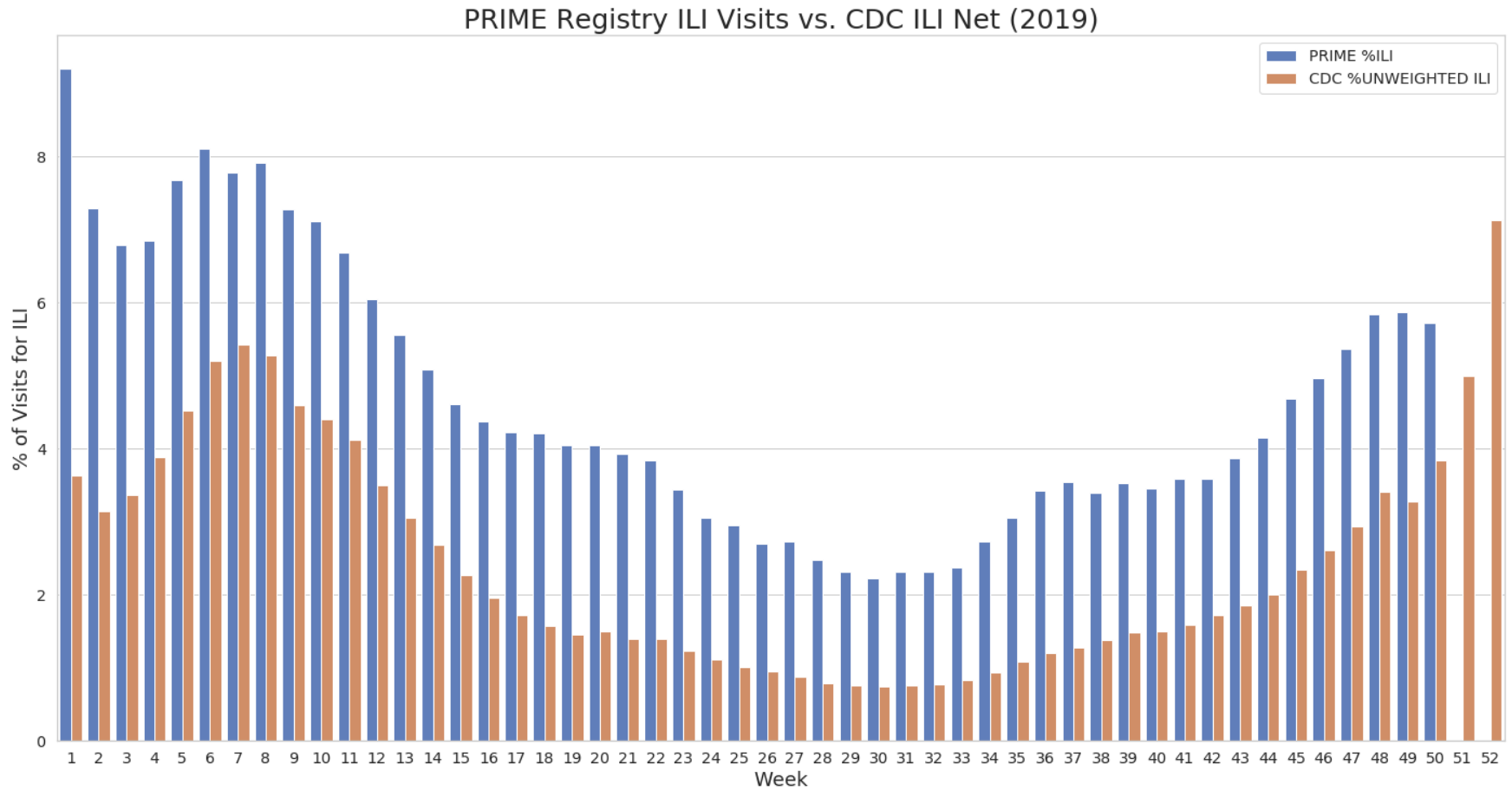
Figure 2a. PRIME Influenza Like Illness (ILI) Activity Map for the week ending November 23, 2019, prior to the coronavirus disease epidemic based on CDCs ILINet

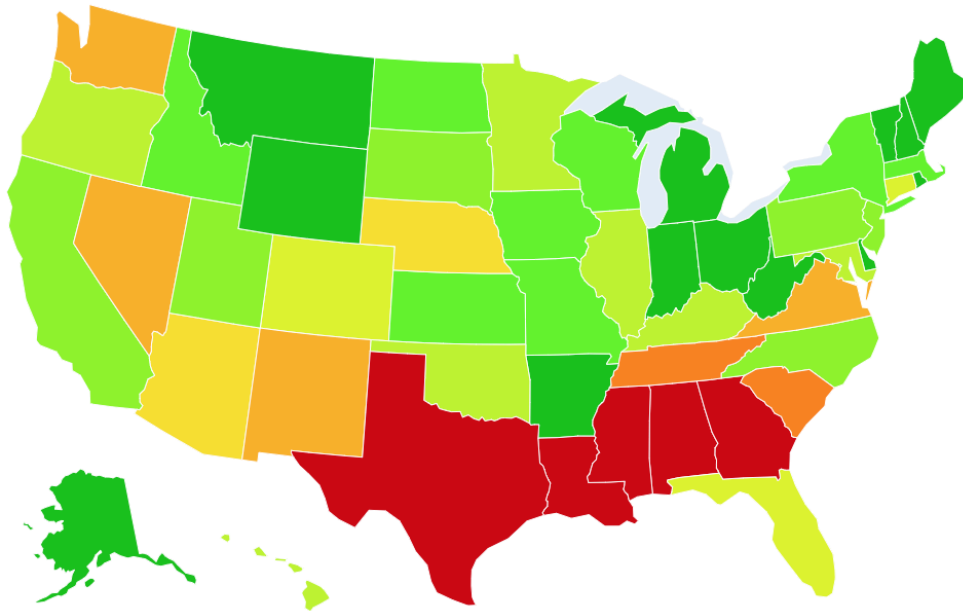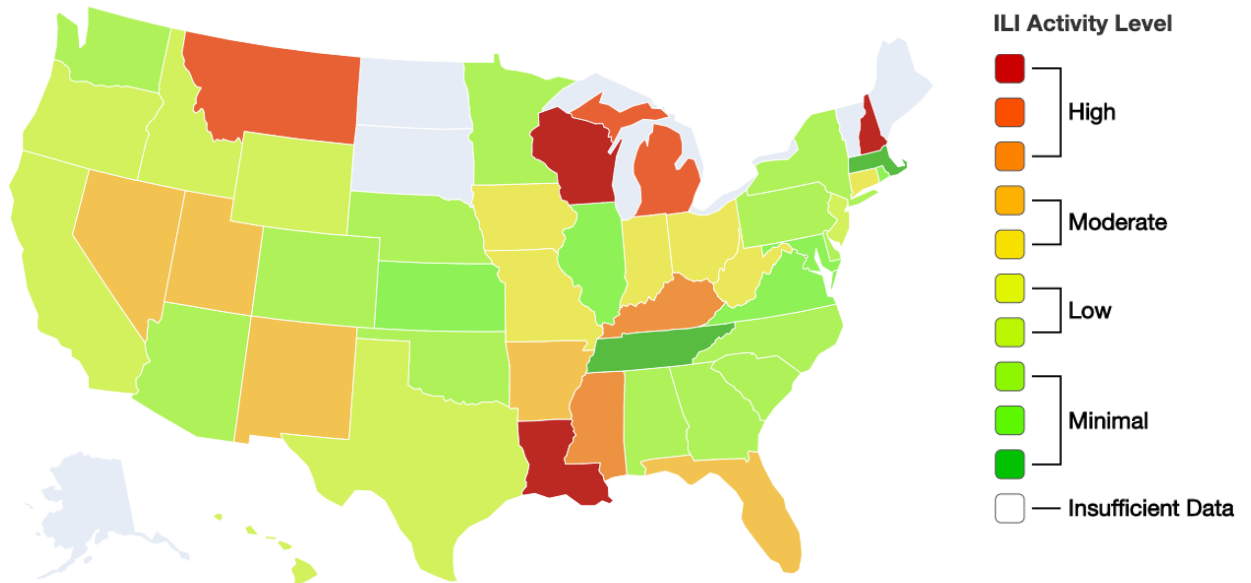2019-2020 CDC ILI Activity Map | Week 47 ending Nov 23, 2019

Figure 2b. PRIME Influenza Like Illness (ILI) Activity Map for the week ending November 23, 2019, prior to the coronavirus disease epidemic based on the PRIME network of primary care clinics.

2019-2020 PRIME ILI Activity Map | Week 47 ending Nov 23, 2019