

Data Privacy in Low Density Public Health Environments

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The Need for Actionable Public Health Data

A need for open public data standards and sharing in light of COVID-19

The disjointed public health response to the COVID-19 pandemic has demonstrated one clear truth: the value of timely, publicly available

timely open data, of spatial and temporal granularity, it is imperative that a reporting system for collecting high-quality infectious disease data in real-time should be established and temp

A need for open public data standards and sharing in light of COVID-19

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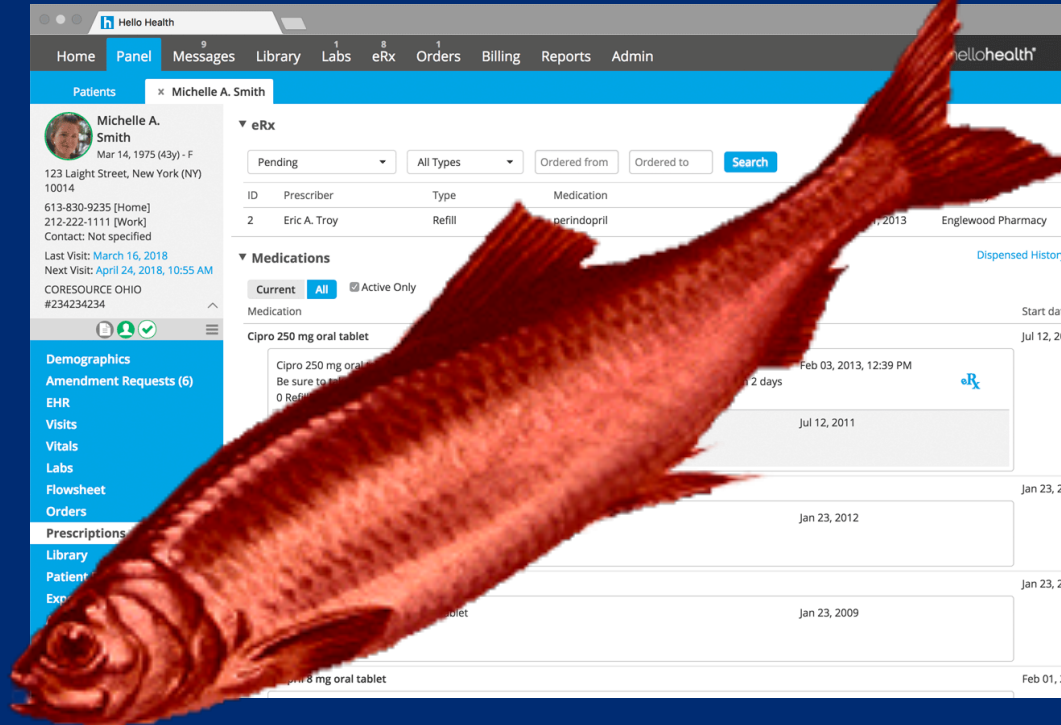
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“Moving forward, it is imperative that a **standardized reporting system** for systematically collecting, visualizing, and sharing high-quality data **on emerging infectious and notifiable diseases in real-time** is established. The data should be made available **at a spatial and temporal scale that is granular enough to prove useful** for planning and modelling purposes. Additionally, a critical component of the proposed system is the **democratization of data**; all collected information (observing necessary privacy standards) should be **made publicly available immediately upon release, in machine-readable formats, and based on open data standards.**”



What Data?



Electronic Health Records

| County | Case Status | Cases | Deaths |
|---------|-------------|-------|--------|
| Alcona | Confirmed | | 2 |
| Alcona | Probable | 8 | 0 |
| Alger | Confirmed | | 1 |
| Alger | Probable | | |
| Allegan | Confirmed | | |
| Allegan | Probable | | |
| Alpena | Confirmed | 15 | 14 |
| Alpena | Probable | 19 | 0 |
| Antrim | Confirmed | 111 | 0 |
| Antrim | Probable | 11 | |
| Arenac | Confirmed | 87 | |
| Arenac | Probable | 8 | |
| Baraga | Confirmed | 70 | |
| Baraga | Probable | 13 | |
| Barry | Confirmed | 609 | |
| Barry | Probable | 60 | |
| Bay | Confirmed | 1,275 | |
| Bay | Probable | 115 | |
| Benzie | Confirmed | 111 | |
| Benzie | Probable | 9 | |
| Berrien | Confirmed | 2,444 | |

Aggregate Data

What Issues?

Numeric Resolution

NSSP BioSense Platform - Virginia User Policy



In the event that Virginia users of the NSSP BioSense Platform wish to share the results of a [Permitted Data Use](#) outside their organization, they may request VDH permission to publish the results using the [Publication Request Form](#). The following criteria must be met in order for VDH to approve publication:

- All data with a count greater than zero and less than five are suppressed
- No medical record numbers, visit event identifiers, patient identifiers, insurance IDs, or any other person-specific identifiers are included
- No line-level data are included
- No names of reporting facilities are included (see section on [Individual and Entity Identification](#))

Publication permission shall be sought for finished projects only using the [Publication Request Form](#). The requestor will receive a response from VDH within one week regarding the status of their request. A request to publish is not a guarantee of approval. VDH will maintain the ability to deny or halt



COVID-19 CASES

| | | | |
|-----------------|----|------------------|-----|
| Barrington | 13 | New Shoreham | 0 |
| Bristol | 7 | Newport | 9 |
| Burrillville | 10 | North Kingstown | 10 |
| Central Falls | 11 | North Providence | 61 |
| Charlestown | <5 | North Smithfield | <5 |
| Coventry | 15 | Pawtucket | 91 |
| Cranston | 54 | Portsmouth | 7 |
| Cumberland | 21 | Providence | 102 |
| East Greenwich | <5 | Richmond | 0 |
| East Providence | 21 | Scituate | <5 |
| Exeter | <5 | Smithfield | 12 |
| Foster | <5 | South Kingstown | 12 |
| Glocester | <5 | Tiverton | 6 |
| Hopkinton | <5 | Warren | <5 |
| Jamestown | <5 | Warwick | 30 |
| Johnston | 11 | West Greenwich | <5 |
| Lincoln | 11 | West Warwick | 12 |
| Little Compton | <5 | Westerly | 8 |
| Middletown | 9 | Woonsocket | 9 |
| Narragansett | <5 | | |

Total 711

| Resident Cases | | |
|-----------------|--------------------------------------|--------------------------------|
| Resident (2020) | New Resident Cases (in past 14 days) | Cumulative Resident Fatalities |
| | | |
| | 0 | 0 |
| | 0 | 15 to 19 |
| | 0 | 35 to 39 |
| | 0 | 5 to 9 |
| | 0 | 10 to 14 |
| | 0 | 25 to 29 |
| | 0 | Fewer than five |
| | 0 | 5 to 9 |
| | Fewer than five | Fewer than five |
| | 0 | 10 to 14 |
| | 15 to 19 | 30 to 34 |
| | 5 to 9 | 5 to 9 |
| | 0 | 15 to 19 |
| | 0 | 10 to 14 |
| | Fewer than five | 25 to 29 |
| | 0 | 5 to 9 |
| | 0 | 20 to 24 |
| | 0 | 15 to 19 |
| | Fewer than five | 35 to 39 |
| | 0 | 0 |
| | 0 | Fewer than five |
| | 0 | 5 to 9 |
| | 0 | 20 to 24 |
| | 0 | 10 to 14 |
| | 0 | Fewer than five |
| | 0 | 0 |

| Number of COVID-19 Cases by School and School | | |
|--|--------------------------|--------------------------|
| Data last updated 10/21/2020 and include positive | | |
| School | Number of COVID-19 Cases | Number of COVID-19 Cases |
| In-Person and Hybrid Learning | | |
| Achievement First Illuminar Mayoral Academy | | |
| Achievement First Providence Mayoral Academy | | |
| Barrington High School | | |
| Barrington Middle School | | |
| Nayatt School | | |
| BEACON Charter School | | |
| Blackstone Academy Charter School | | |
| Blackstone Valley Prep Elementary 2 School (ES2) | | |
| Blackstone Valley Prep Elementary 3 School (ES3) | | |
| Blackstone Valley Prep High School (HS) | | |
| Gutierrez School | | |
| Kickemut Middle School | | |
| Stevens Farm Elementary School | | |
| Bishop Hendricken High School | | |
| Bishop McViney Regional School | | |
| Good Shepherd Catholic Regional School | | |
| Immaculate Conception Catholic Regional | | |
| La Salle Academy | | |
| Mercymount Country Day School | | |
| Mount St. Charles Academy | | |
| St. Augustine School | | |
| St. Mary Academy-Bay View | | |
| St. Paul School | | |
| St. Raphael Academy | | |
| St. Rose of Lima School | | |
| Central Falls Senior High School | | |
| Dr. Earl F. Calcutt Middle School | | |
| Eastgate Nursing & Rehab (East Providence) | 40 to 44 | |
| Elmhurst Healthcare Center (Providence) | 90 to 94 | Fewer than five |
| Elmwood Nursing and Rehab Center (Providence) | 45 to 49 | 0 |
| Evergreen House Health Center (East Providence) | 110 to 114 | 0 |
| Friendly Home (Woonsocket) | 60 to 64 | 0 |
| Golden Crest (North Providence) | 105 to 109 | Fewer than five |
| Grace Barker Nursing Home (Warren) | 2 to 4 | 0 |
| Grand Islander (Middletown) | 2 to 4 | 0 |
| Grandview Center (Cumberland) | 55 to 59 | 0 |
| Greenville Skilled Nursing & Rehabilitation (Greenville) | 75 to 79 | 0 |
| Greenwood Center (Warwick) | 5 to 9 | 0 |
| Hallworth House (Providence) | 25 to 29 | 0 |
| Harris Health Care Center North (Central Falls) | 20 to 24 | 0 |
| Heatherwood Rehab & Health Center (Newport) | 2 to 4 | Fewer than five |

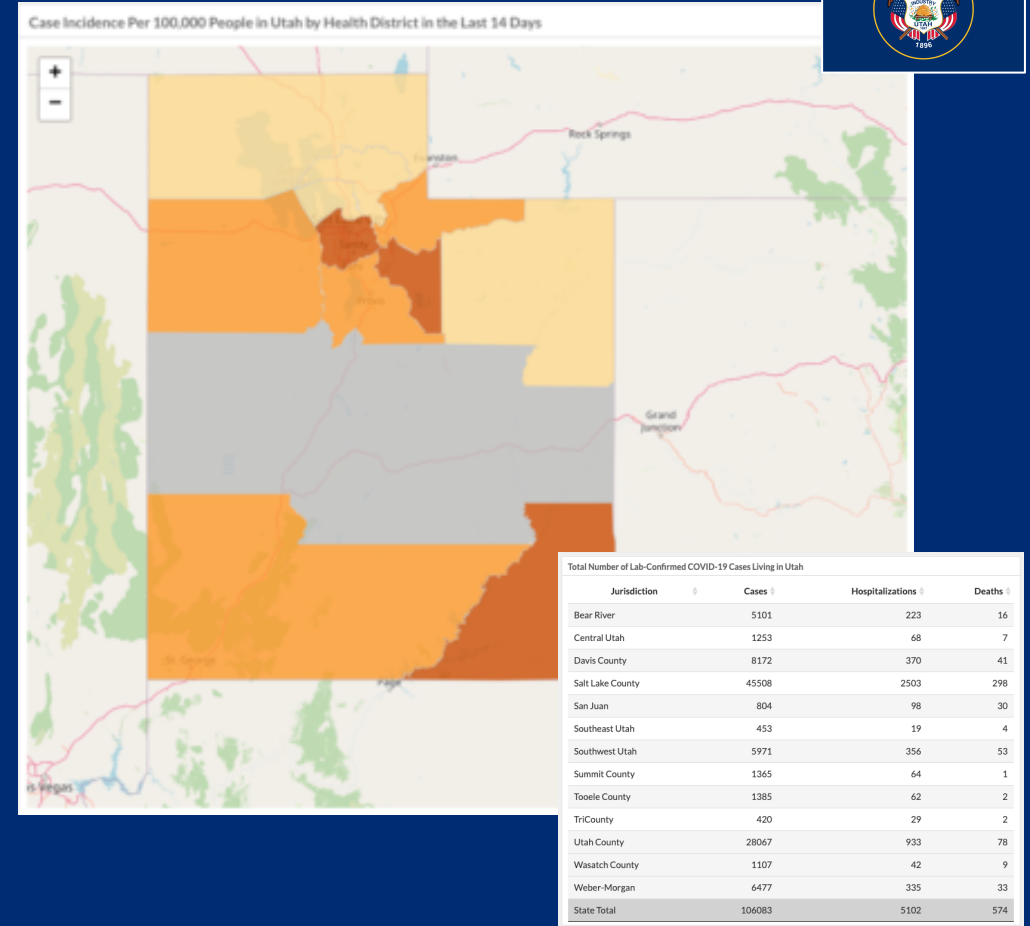
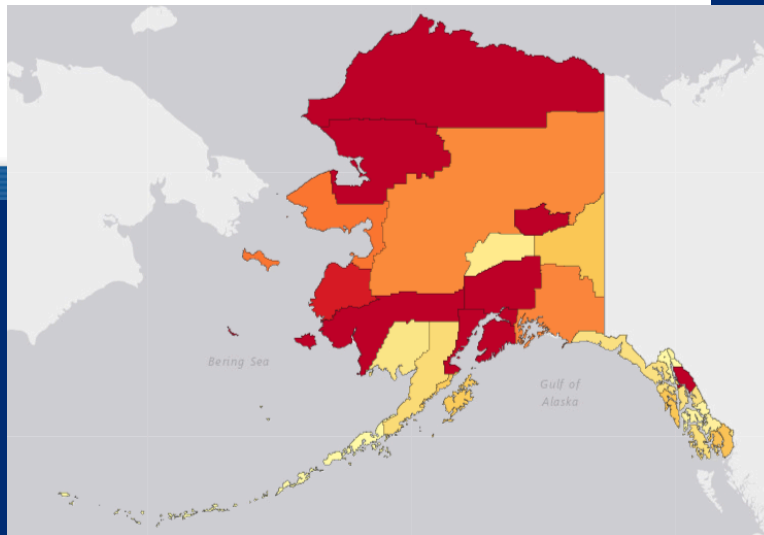
What Issues?

Spatial Resolution

How do these changes impact the numbers?

Implemented guidelines to protect privacy and misinterpretation of data means that we are **reporting case only for communities with > 1,000 residents**. As a result, a couple changes occurred:

2. If communities are <1,000 residents, they are now being reported at the Borough/Census Area level.
 - One case now is displayed in the Yukon-Koyukuk area instead of being combined in the Fairbanks counts.



My Questions

How do we balance legitimate privacy concerns against the need for open data to support response efforts in a public health crisis?

How do we do we strike this balance responsibly in low density environments (e.g. during the early phases of an outbreak, in remote and rural settings)?



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