

Successful State-led Data Sharing Collaborations

2:15PM EST | November 17th, 2020 | 2020 SyS Symposium

Moderated by

Charlie Ishikawa, MSPH – Kahuina Consulting, LLC

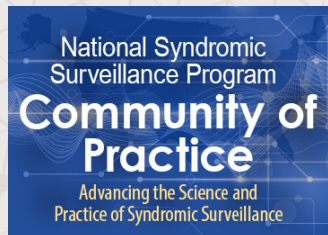
CAPT Loren Rodgers, PhD – CDC/NSSP

Dave Swenson, MEd, PMP – New Hampshire Department of Health and Human Services

Speakers:

Zach Faigen, MSPH, REHS + Mike Dolan Fliss, PhD, MPS, MSW – North Carolina Department of Health and Human Services

Veronica Fialkowski, MPH – Vermont Department of Health



Council of State and Territorial Epidemiologists



CAPT Loren Rodgers, PhD National Syndromic Surveillance Program



Charlie Ishikawa, MSPH
Kahuina Consulting, LLC





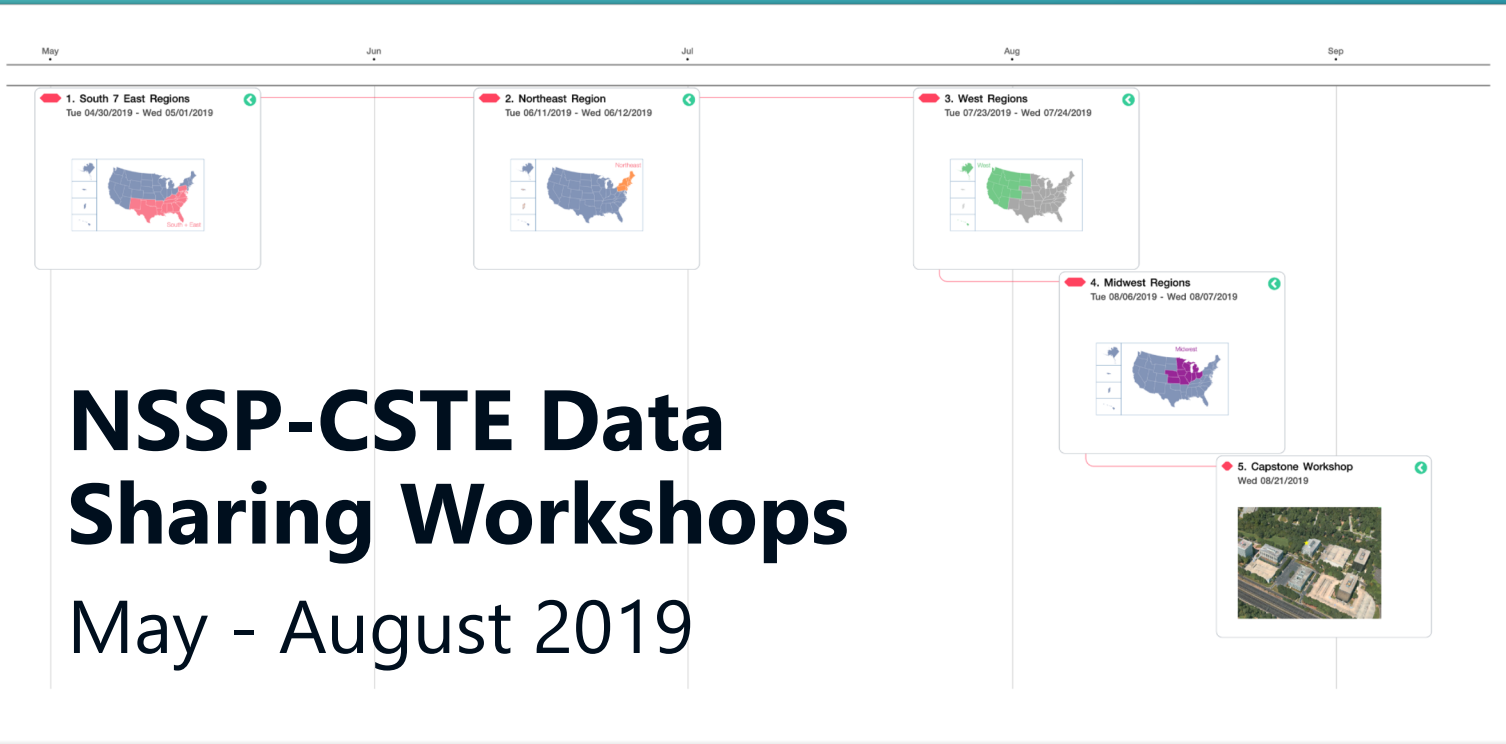
NSSP-CSTE Data Sharing Regional Workshop
Series

Findings and Impact

Tuesday, November 17, 2020 | 2:15 – 3:00 PM ET
2020 Syndromic Surveillance Symposium

NSSP-CSTE Data Sharing Workshops

May - August 2019



- Purpose and approach
- Results: Participation
- Findings: Mini-Projects
- Impact: Continuing work
- Extra: Lessons Learned



The Purpose

Strengthen public health agency capacity for syndromic surveillance (SyS) and enhance situational awareness using real-time electronic health data from emergency department (ED) settings through interjurisdictional data sharing and surveillance practice collaborations.

1

Enhance SyS skills to better support opioid crisis response.

2

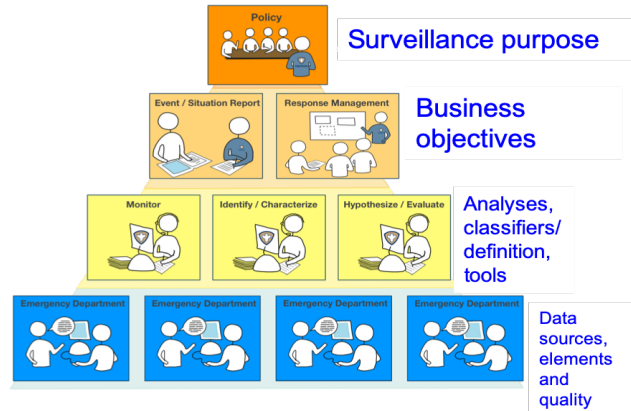
Examine and share SyS analytic methods and BioSense Platform tools.

3

Form and foster action-oriented collaborations to strengthen inter-jurisdictional data sharing.

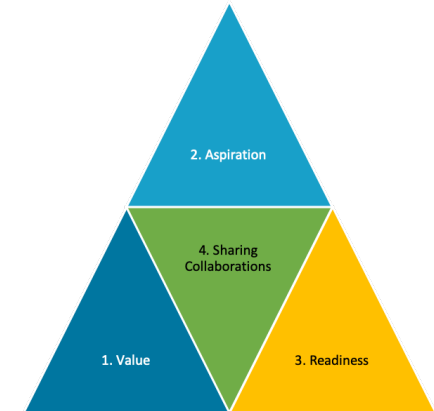


Approach | Foundational Concepts



Key Assumptions

1. Limit discussion to sharing...
...on the BioSense Platform
...for defined purposes and projects
2. Everyone wants to share data at the level useful for purpose
3. Sharing parties are...
...other BioSense Platform sites
...CDC programs



Syndromic Surveillance is ...

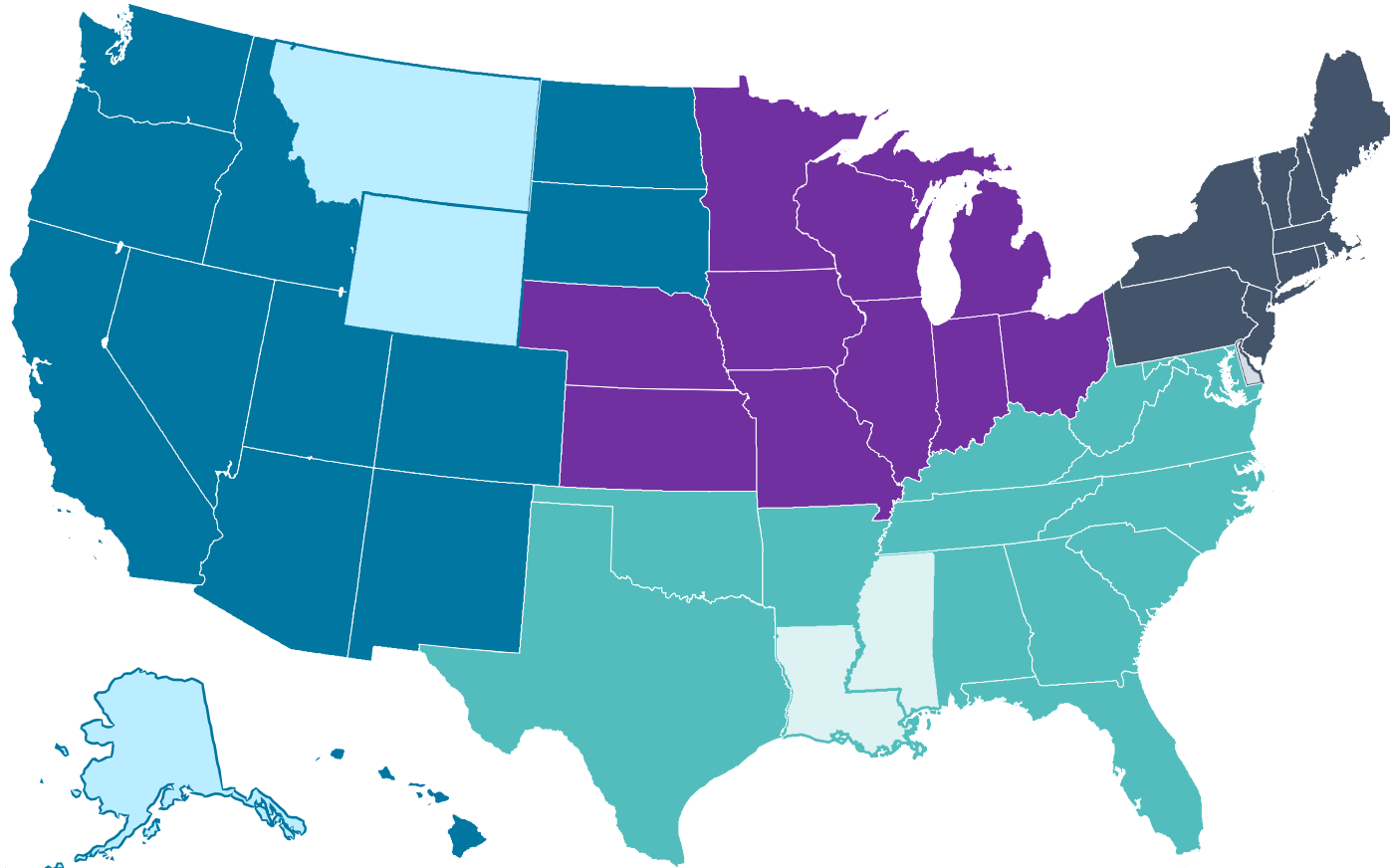
- Contextual
- Situation/question dependencies
- One tool among many
- All hazards



Appreciative Inquiry

1. Hands-on value discovery
2. Positive imagery of future state
3. Acknowledge what will make more ready
4. Initiate sharing collaborations

Participation | CSTE Regional NSSP Data Sharing Workshops & Capstone



States with no LHD or SHD: AL, DE, LA, MS, MT, WY

States with LHD participation only: TX, OK, IA

1. SOUTH + EAST

No. Participants	Avg. SyS years	Cum. SyS years
39	4.0	107.6

Professions/subject matter areas:

Biostatisticians, Directors, Epidemiologists (EPRP, Enhanced Surveillance, SyS), Informaticians

2. NORTHEAST

No. Participants	Avg. SyS years	Cum. SyS years
23	7.0	112.5

Professions/subject matter areas:

Coordinators (SyS), Data Analysts, Directors (Infectious Disease), Epidemiologists, Managers (ED, PH Surveillance), Researchers (Epidemiology)

3. WEST

No. Participants	Avg. SyS years	Cum. SyS years
43	2.8	82.5

Professions/subject matter areas:

Chiefs (Epidemiology), Coordinators (SyS), Epidemiologists (SyS, Respiratory Surveillance, Opioid Surveillance), Informaticians, Managers (Vital Statistics), Supervisors (Informatics, Preparedness and Response)

4. MIDWEST

No. Participants	Avg. SyS years	Cum. SyS years
30	4	68

Professions/subject matter areas: Coordinators (SyS), Directors (Vital Statistics), Epidemiologists (SyS, Infectious Disease), Site Administrators (SyS)

Mini-Projects

Use Case	Cross-border Sit. Awareness	Overdose Dashboard	Alert Network	Overdose Dashboard	Model Dashboard	Shared Suicide Data
Legal / Political	Data Sharing Parameters	Process for sharing	DUA Template	Common DUA		
Communication	HELP! (Resources for new users)	Leadership Comms	Comms. Guild			
Interpretation	Data Quality Reports	Data Quality	Data Quality			
Other	CA BioSense Participation					
	South and East	Northeast	West	Midwest		

Continuing the work

The data sharing workshops energized the community to organize around their needs to improve data sharing through the NSSP BioSense Platform.



Foster harmonization and continuation of mini-projects in CoP

- Interstate data-sharing projects are happening, encourage continuation and expansion for new use cases.
- Adopt standard methodology for new syndrome definitions with adequate documentation.
- Continue work to improve interpretation of shared data.



Improve National View

- Expand the utility of the national shared data to state level granularity (or 3-digit Zip).
- Standardize process and improve turn-around-time to engage in national queries.



Standard, shared Data Use Agreement

- Adopt a standard DUA that can be used across all states, allowing states to share at their level of comfort per their regulations and laws.

Acknowledgements | Facilitation Team



CDC NSSP

- Deborah Gould
- Mike Coletta
- NSSP and ICF Team



CSTE

- Hayleigh McCall
- Meredith Lichtenstein Cone
- Alexis Darden



Kahuina Consulting, LLC

- Charlie Ishikawa
- Marcus Rennick
- Heather Head
- Cat Tong

These workshops are sponsored by the Centers for Disease Control and Prevention (CDC) through Cooperative Agreement number 1 NU38OT000297-01-00 between the CDC and CSTE. Kahuina Consulting, LLC is an independent firm based in Boston, MA. Learn more about Kahuina at www.kahuina.com



Thank you



Contact

Hayleigh McCall at HMccall@cste.org

Workshops | Lessons Learned

Readiness to share SyS data via the BioSense Platform among sites and CDC programs

- **Value is clear** and compelling; motivation is not a barrier
- That classifiers should be standardized is indisputable
- Competency with the BioSense technology is building and can be stronger: i.e., technology is not a barrier, and technology adoption CBA would help
- Monitoring and sharing **data quality reports and site metadata** are critical for meaningful comparisons
- Value of in-person work, including with CDC personnel and contractors, is tremendous and key to trust
- Barriers to data sharing appear to be mainly **political in nature**: i.e., structural barriers inherent to systems of public health governance that are grounded in political or socio-cultural contexts

Keys to **advancing SyS data sharing** among sites and with CDC programs

- Sharing must be for a reason or centered on a use case
- The sharing agreement processes can be made more predictable, and then more effective and responsive
- Template agreements/projects such as model dashboards
- Stratified training for newly onboarded sites and analysts (including how to integrate with the CoP)
- Specialized courses for intermediate and advanced users (applied R)
- Continued BioSense system improvements to customize the “with whom” and “what” for granular data sharing
- Minimize representative ED coverage differences between BioSense and state/local systems



Zachary Faigen, MSPH, REHS & Mike Dolan Fliss, PhD, MPS, MSW
North Carolina Department of Health and Human Services



2020 Syndromic Surveillance Symposium

Successful State-led Data Sharing Collaborations

Zachary Faigen, MSPH, REHS. NC DHHS

Mike Dolan Fliss, PhD, MPS, MSW. NC DHHS

With thanks to partners in GA, SC, VA, TN,
and CDC NSSP!

Outline

- Introduction
- Example questions
 - Initial: Opioids
 - Current: COVID-19
 - Many, many examples
- Team & Questions
- Preliminary Results
- Ongoing Work
- Challenges
- Goals

Initial Drive: Opioids in 2019

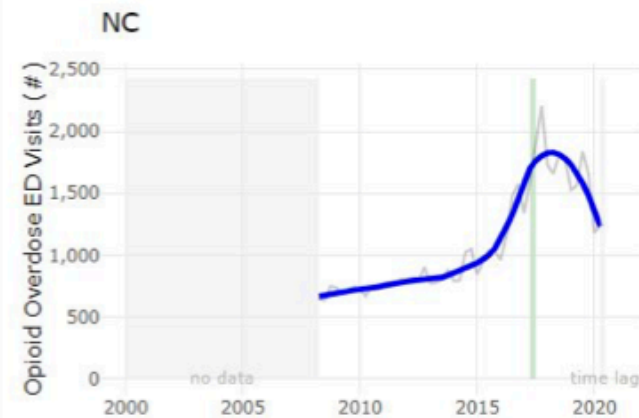


ED visits for opioid overdose are on the rise statewide

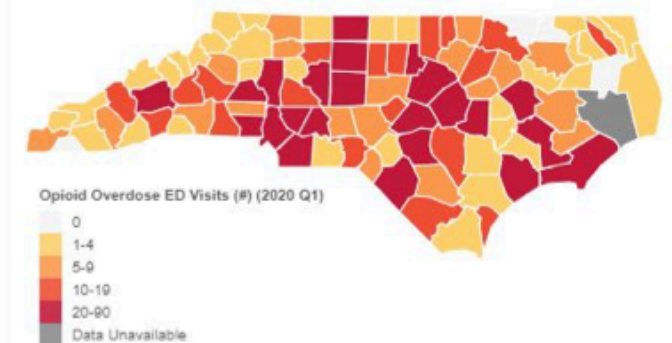
This metric tracks the number of opioid overdose visits to Emergency Departments (EDs) in North Carolina. These are visits of all intents: unintentional, intentional, and visits of unknown intent. If ED visits continue to increase as they did from 2013-2016, we expect there to be 1,326 opioid overdose ED visits in the fourth quarter (Q4) of 2021. Our goal is to reduce this expected number by 20%, which would result in 1,061 opioid overdose ED visits in Q4 of 2021.

ED visit data are updated quarterly. 2018 and 2019 ED data are provisional and subject to change. Please note that previous counts did not include the ICD-10-CM code for 'other and unspecified narcotics' (T40.6). The inclusion of this code may result in additional cases; historical data have also been updated to reflect this case definition change.

Opioid Overdose ED Visits



Most Recent Quarter's Opioid Overdose ED Visits by County



Data Source: North Carolina Division of Public Health, Epidemiology Section, North Carolina Disease Event Tracking and Epidemiologic Collection Tool (NC DETECT), 2008-present See Technical Notes.

Initial Drive: Opioids in 2019

- Local partners in certain border counties gave dashboard feedback at community meetings
- Partners did not (know to) differentiate syndromic surveillance data (which is not necessarily reported back to residence states) from death data, as an example
- Assumption is that “residential rates” are complete (and, implied, that “clusters” would include neighbor state counties)

*“I personally know more ED visits of our residents last month than you’re reporting the whole year. We can’t trust **state data**.”*

- Substance use coalition member in NC border county

Now: COVID-19

North Carolina residents traveling north to Virginia for COVID-related care... or SC traveling north to Charlotte

Under death certificate sharing practices, deaths will be reported back to the resident state (NC). Same with positive labs.

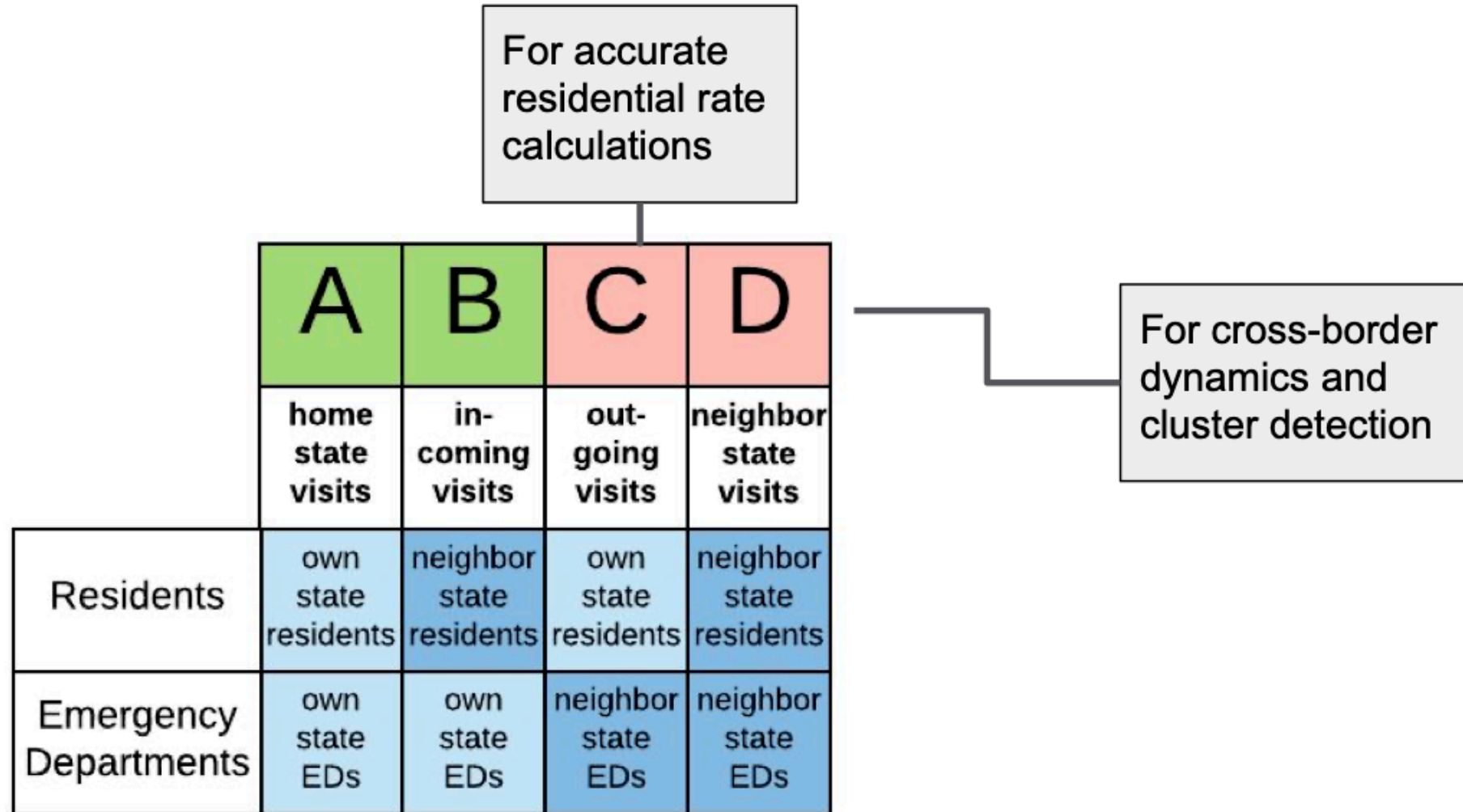
While infectious disease case-follow-up may include this case, lab and **syndromic surveillance ED visits** would not include this instance.

Syndromic surveillance rates based on resident populations miss it.

Pandemic, not epidemic - how do we collaborate for aggregate data sharing in a pandemic environment?



Matrix of in/out of state visits & residents



Investigation team

- **NC:** Zach Faigen & Mike Dolan Fliss
- **VA:** Erin Austin
- **TN:** Caleb Wiedeman
- **GA:** Jessica Pavlick & Amanda Dinwiddie
- **SC:** James Muncy
- **CDC NSSP:** Michael Sheppard

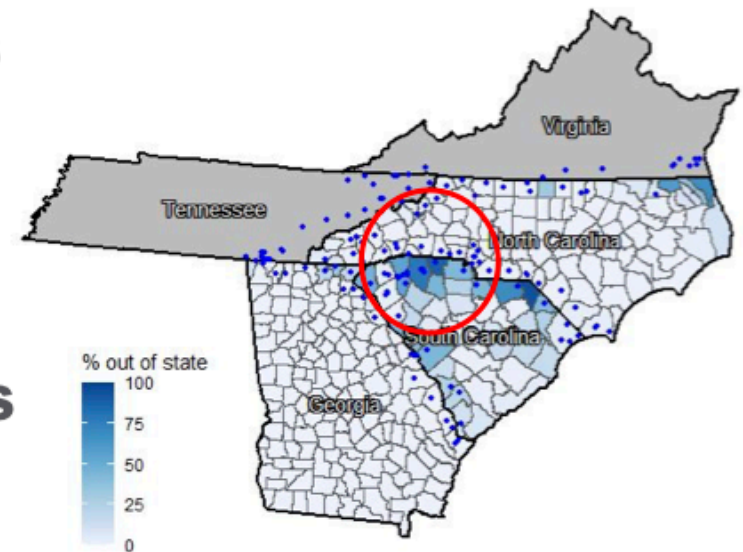
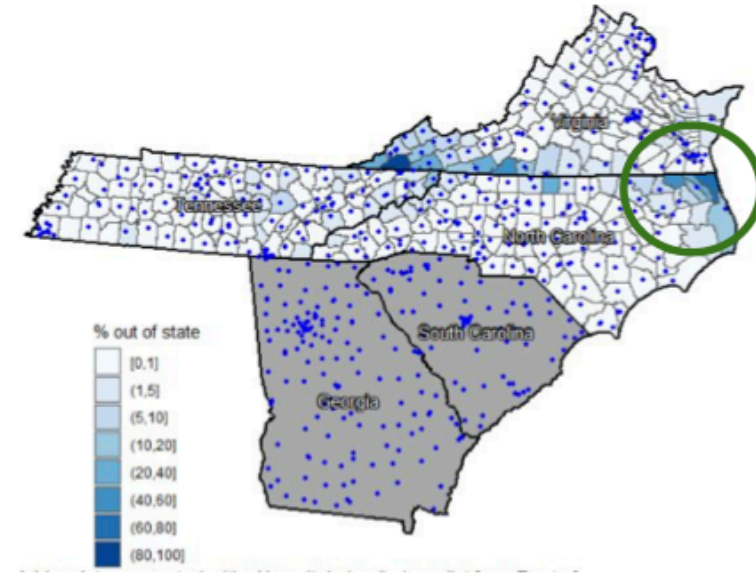


Preliminary analysis: **#/% of out of state visits by county**

(1) Total ED visits, (2) COVID in 2020, (3) Opioids in 2019

Initial / Preliminary Results

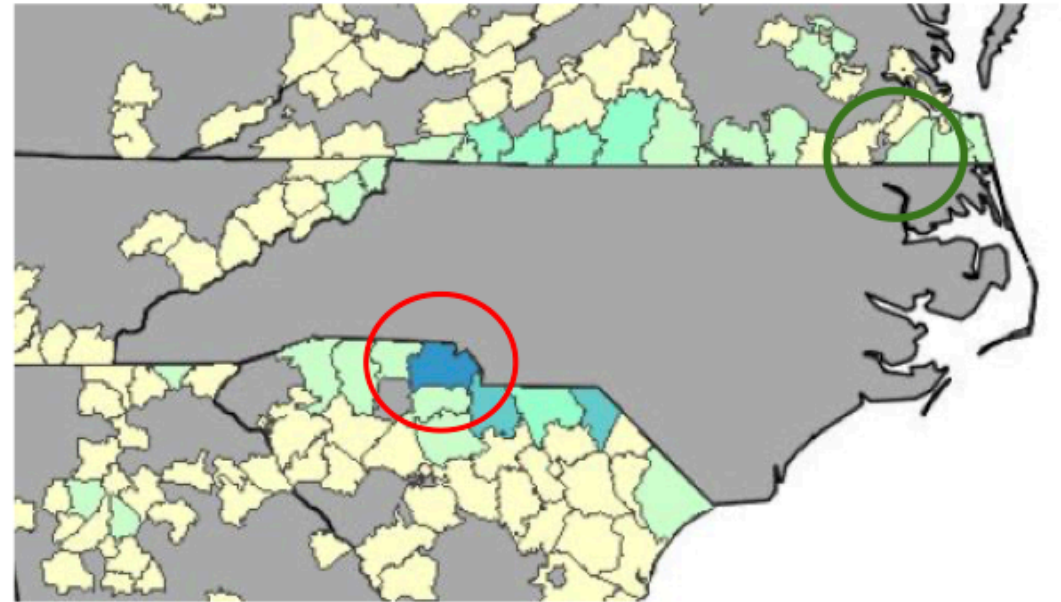
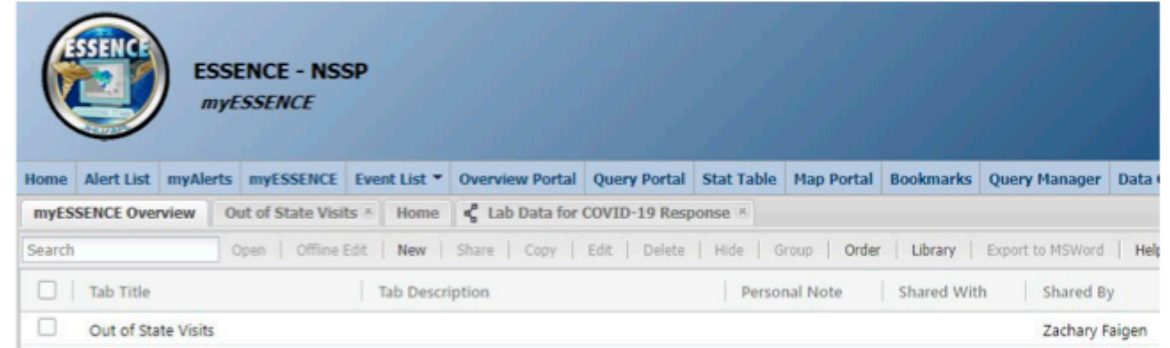
- While only 1% of 5 million NC visits were to out of state EDs...
- ...some **border counties** saw this number much higher (examples of 50%, 66%, or 80% out of state visits lost to residential-state surveillance, tens of thousands of visits)
- Concentrated where large cities are just across borders from more rural counties w/ few / no acute care hospitals (e.g. near **Norfolk VA**, **Charlotte NC**)
- Considering both directions, may be under-surveilling **hundreds of thousands of visits a year** as each state focuses on residential denominators. Nationally: **millions**



“One-sided” view from ESSENCE

Can see some of these dynamics
within a single state (e.g. gain of
visits into **Charlotte NC** from SC)

...But can't see all dynamics from
“one side,” e.g. loss of NC resident
visits to **Norfolk VA**



Ongoing Work & Recent Updates:

Total Out of State, 2019

- Total 2019 ED visits in NC: ~ 5 million (5,097,451)
 - 4,860,870 (95%) from NC
 - **109,015 from SC (2% of all NC visits / estimate 4-5% of SC visits are to NC hospitals)**
 - (~50,000 from one county, ~1% of all NC visits from a single out-of-state county)
 - **8,957 from GA**
 - **36,433 from VA**
 - **5,450 from TN**

68% of all out-of-state visits in 2019 were from neighbor states. Key border counties seem to drive these dynamics.

Ongoing Work & Recent Updates:

Total COVID-19, 2020

- Total 2020 COVID-19 visits in NC: ~ 100,000 (99,587)
 - 95,469 CLI from NC
 - **2,451 CLI from SC (~45% from one county)**
 - **106 CLI from GA**
 - **613 from VA**
 - **72 from TN**

4 out of 5 (78.7%) out-of-state COVID-19 visits to NC came from neighboring states in 2020 - not included in those state's syndromic surveillance counts w/o data sharing agreements.

*Some counties may have **majority** of COVID-19 CLI visits to out of state hospitals.*

Punchline

No / little data sharing may mean:

- Millions of under-surveilled ED visits overall nationally, particularly impacting rural border counties with nearby cities / hospitals in neighbor sites
- Hundreds of thousands of COVID-19 and overdose syndromic surveillance ED visits nationally

Challenges

- **New Sharing:** Never had aggregate data shared at the same time, table by table, haven't built complete datasets yet. *As of last week we've got working code ready to run nationwide ...*
 - Generic NSSP reports still WIP.
- **Legal** conversations were / are slow
 - A dozen+ DUAs for NC? Hundreds for US?
- **Communication:** Individual case follow-up purposes (record-level data) are different than population-level surveillance needs (aggregate data)

Goals

- Continue the study in other regions / nationally - WIP!
- Eventually: aggregate-only data sharing **as standard** for as a matter of course for internal use only through NSSP?
- Data sharing agreements (galore, eek) or other options?
- An “**opt out**” process for aggregate national studies?
- Discuss these dynamics / data governance issues in brand new **data sharing workgroup (come join!)**

	A	B	C	D
	home state visits	in-coming visits	out-going visits	neighbor state visits
Residents	own state residents	neighbor state residents	own state residents	neighbor state residents
Emergency Departments	own state EDs	own state EDs	neighbor state EDs	neighbor state EDs

Questions & Discussion

- Updates from any of our neighbors? (VA, TN, GA, SC)
- Other similar, known border dynamics in other places?
- Other similar projects exploring the need for data sharing?
- How do we pursue national, aggregate studies like this?

Thanks!



Veronica Fialkowski, MPH, Vermont Department of Health
David Swenson, MEd, PMP, New Hampshire Department of Health & Human Services



Purpose

Define best practices in cross-jurisdictional data sharing for bordering states during acute events and routinely with states for residents seeking care in neighboring states

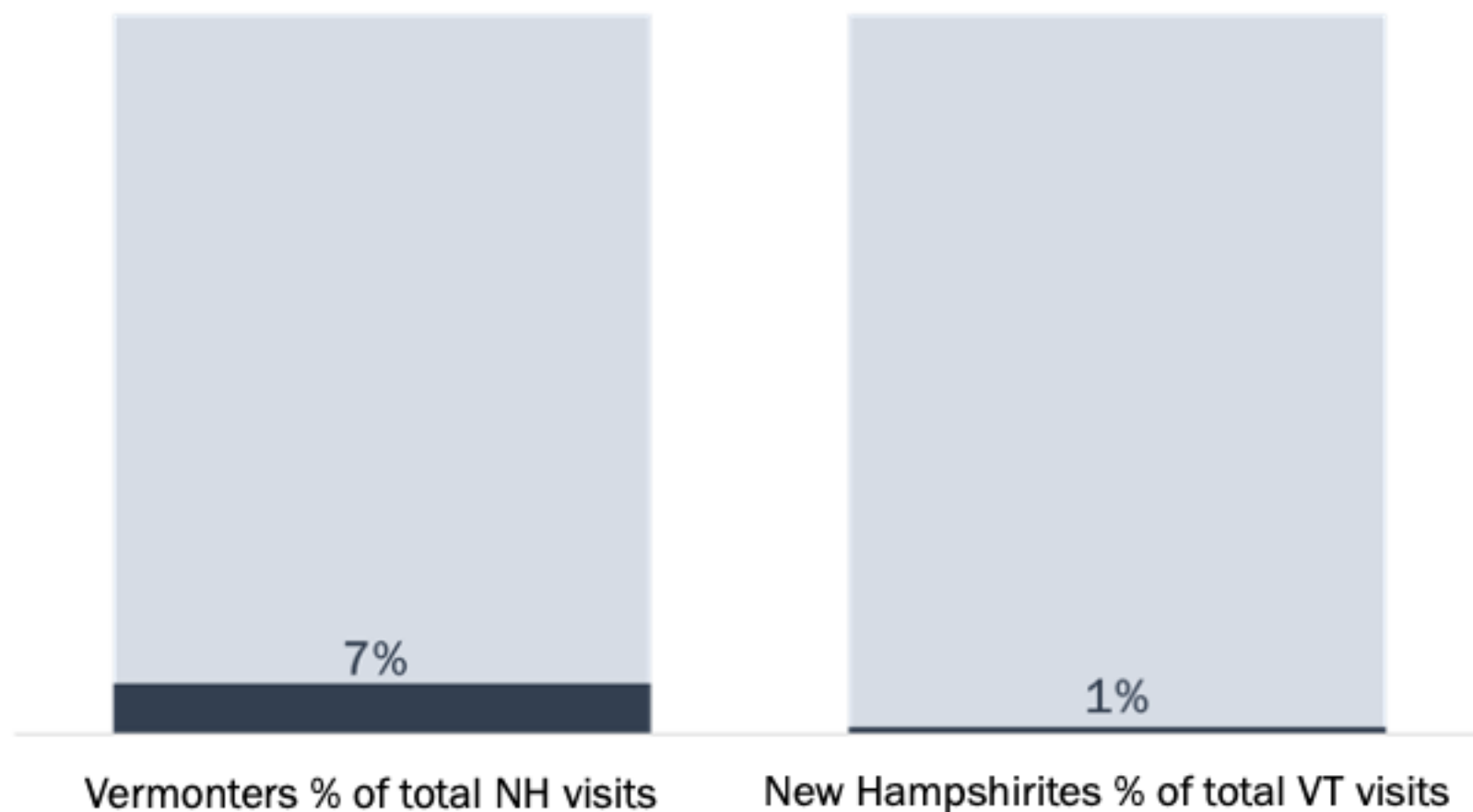
Routine sharing within ESSENCE

Data sharing with states for residents seeking care in neighboring states

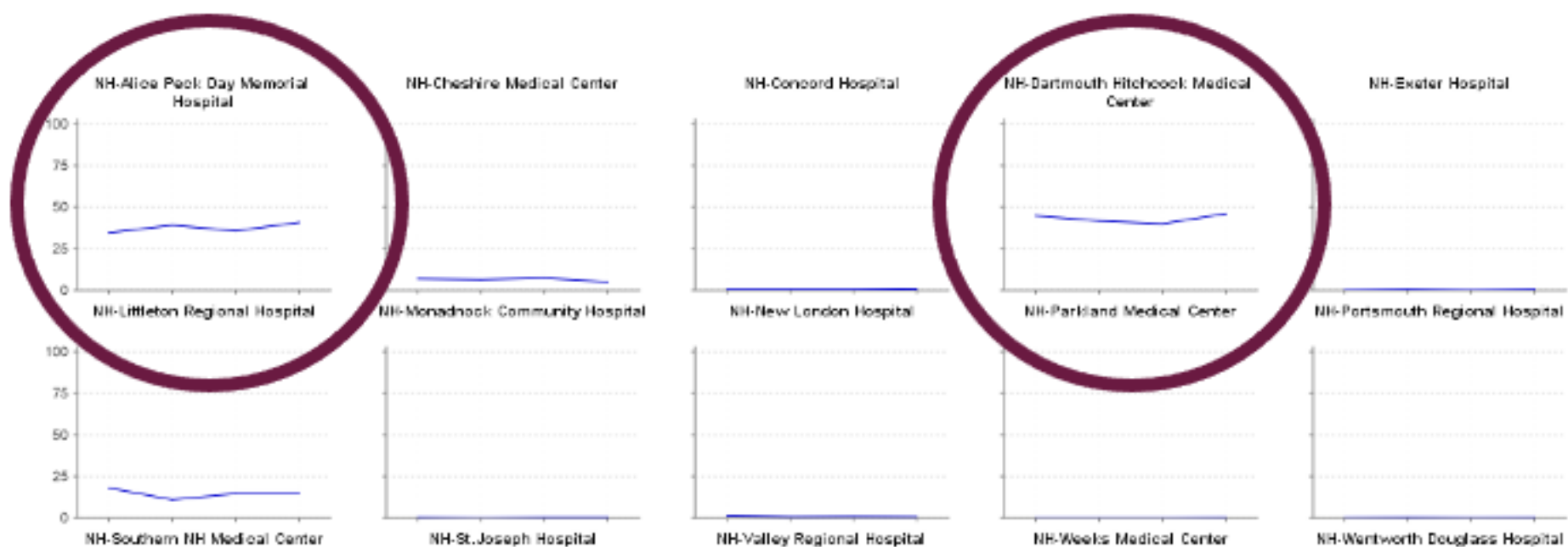
- Develop protocol for routine sharing on residents seeking care in neighboring states
- Routine sharing=giving access to data using AMC/ESSENCE
 - Patient location

NH and VT share data! What does it show?

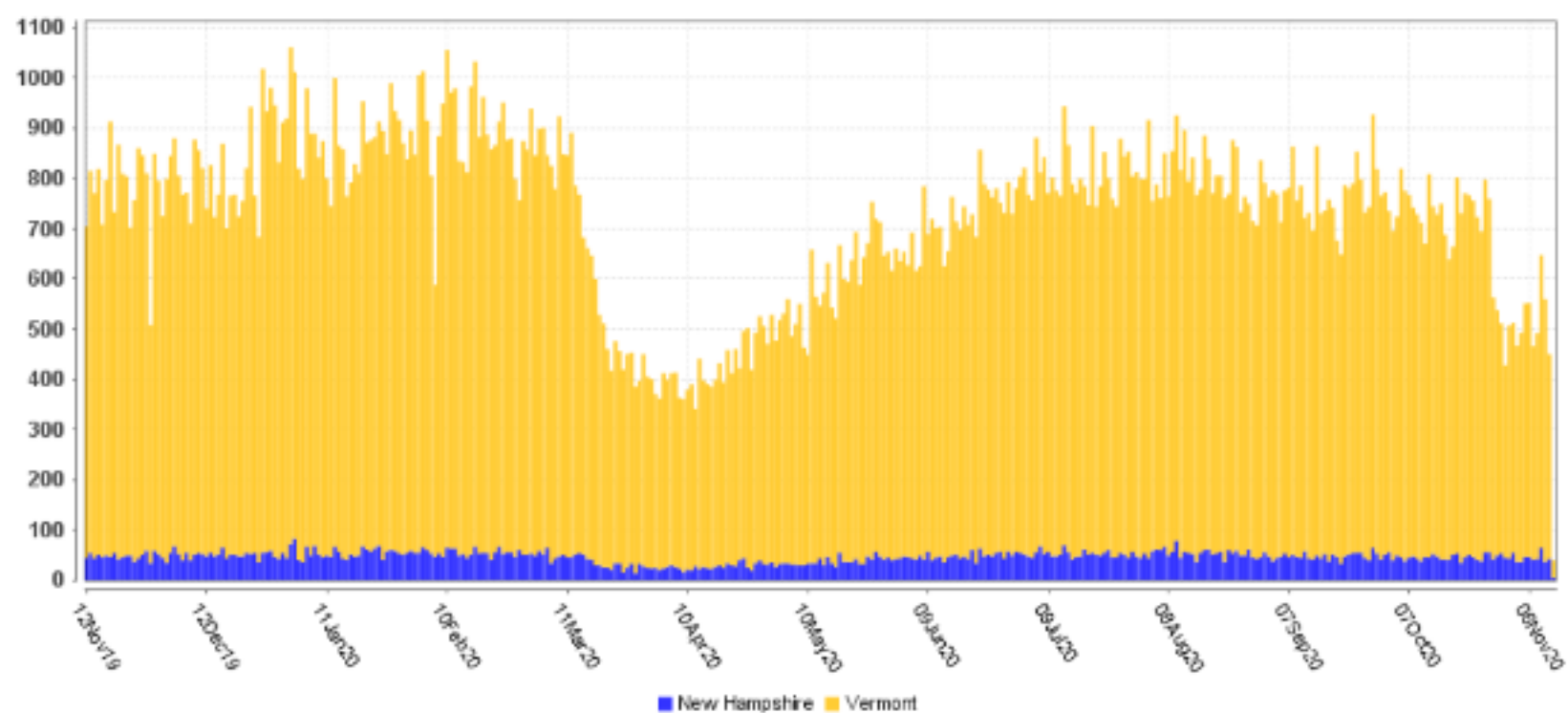
Problem: People seek care across state borders



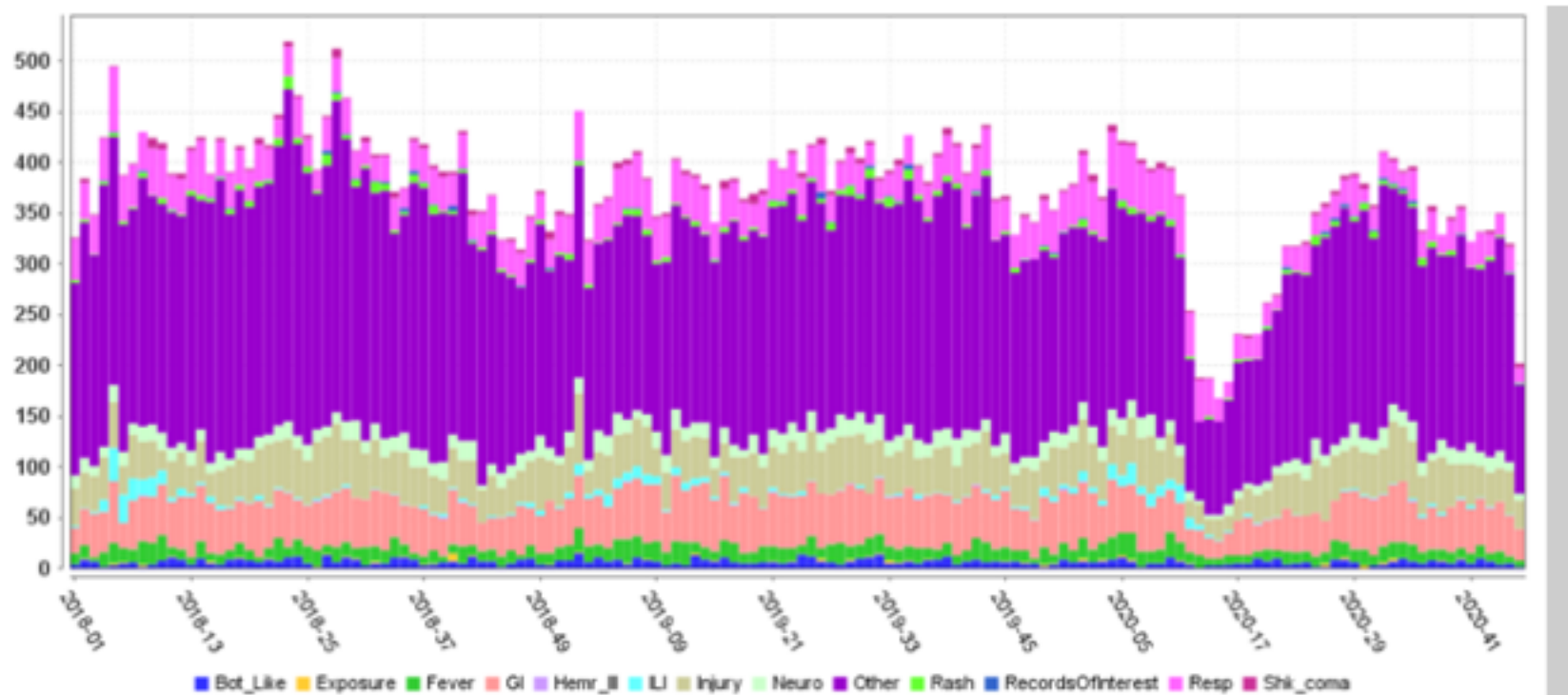
Almost 50% of ER visits at these NH hospitals are Vermonters



Vermont is now able to see NH hospital data for Vermont residents



Vermonters seek care in NH for a variety of syndromes



Special events, outbreaks, or disaster situations

Special events, outbreaks, or disaster situations

- Develop DUA for cross-jurisdictional data sharing for special events, outbreaks, or disaster situations
 - Develop use cases for cross-jurisdictional data sharing for special events, outbreaks, or disaster situations
- Develop protocol for cross-jurisdictional data sharing for special events, outbreaks, or disaster situations

Next Steps – Moving Forward

- Need National Collaboration for data sharing
 - Regarding development of standard protocols
 - What Data Sharing Agreements conditions are needed between jurisdictions?
 - What conditional use cases should be analyzed?
 - Who are the response partners and what are their needs?
 - What do we share, when, how, and for how long?
 - Regarding alerting
 - What should the alert strategy be?
 - What alert software is needed?
 - What are the conditional alert thresholds?
 - What are the alert response actions?

Next Steps – Mechanism for Standard Protocols

- A new NSSP CoP Data Sharing Workgroup is being lead by Zach Faigen from NC and Loren Rodgers from CDC to
 - Establish a protocol for evaluating requests for data submitted to NSSP
 - Evaluate individual data requests
 - Develop resources to assist in overcoming barriers to syndromic surveillance data sharing jurisdiction-to-jurisdiction or jurisdiction-to-federal
 - Share lessons learned and best practices from real-life experiences
 - Advance community discussions regarding CDC-managed public use datasets
 - **In future, may be able to help develop national data sharing and alert standard protocols**

Next Steps – Mechanism for Standard Protocols

- A new Overdose Spike Alert Advisory Group is developing a Landscape Analysis and an online Tool kit by summer 2021 to allow
 - Modification of the online tool kit to create an appropriate response partnership and an alert jurisdictional strategies to meet conditional spike response actions
 - This could lead to the development of conditional spike alerts using recommended software, algorithms, and thresholds

Thank you!



National Syndromic Surveillance Program

Community of Practice

Advancing the Science and Practice of Syndromic Surveillance



Council of State and Territorial Epidemiologists

Block Schedule

Training

Methods

Innovation

Data Sharing

1:30-2PM EST	Keynote Address			
	...BREAK...			
2:15 - 3PM EST	Training: NSSP ESSENCE 101	Breakout: Spike, Alert, GO!	Breakout: Data Access and Integration	Breakout: Successful State-led Data Sharing Collaborations
		...BREAK...		
3:15-4PM EST		Lightning: Significant Findings	Roundtable: Bringing New Partners to the Table	Breakout: Can I Do That? Ask a Lawyer.
	...BREAK...			
4:15-5PM EST	Training: Custom Syndrome Definition in NSSP ESSENCE	Breakout: Match Point - Data Matching Across Sources		Roundtable: Establishing a Public Use Shared Data Set
	...BREAK...			
5:15-6PM EST	Virtual Happy Hour			