



CSTE

COUNCIL OF STATE AND
TERRITORIAL EPIDEMIOLOGISTS

Review of Federal Access Policies for National Syndromic Surveillance Program Data

**Findings and Implementation
Strategies**

REVIEW OF FEDERAL ACCESS POLICIES FOR NATIONAL SYNDROMIC SURVEILLANCE PROGRAM DATA: FINDINGS AND IMPLEMENTATION STRATEGIES

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EXECUTIVE SUMMARY

BACKGROUND

Data are critical to the success of public health authorities. It is a component of the essential public health services that help to protect and promote the health of all people in all communities.[1] Data enables public health authorities to understand and protect against the specific health threats facing communities and individuals.¹ Public health agencies rely on various forms of surveillance to understand the health status within a community.

Public health surveillance rests on a social contract between governments and the populations that they serve.² In this social contract, individuals concede some privacy interests by permitting public health agencies to collect information on the condition that governments use collected information to broadly promote the public good.² In furtherance of this social contract, public health authorities systematically collect, analyze, and disseminate data to understand, detect, and respond to public health issues or evaluate public health programs or interventions.³

Syndromic surveillance emerged as a support surveillance method for state, tribal, local, and territorial health departments (STLT) to identify novel or emerging health threats in near real-time. The capacity to support public health situational awareness received considerable federal support and funding to promote the use of syndromic surveillance by health departments nationally.⁴⁻⁶ Since implementation, the National Syndromic Surveillance Program (NSSP, formerly BioSense and BioSense 2.0) has been used in detecting a wide range of public health events and issues.⁷⁻¹⁹

Even though many state and local health departments publish syndromic surveillance data and visualizations publicly, standard, nationwide visibility of syndromic trends is lacking.²⁰ Current data use agreements (DUAs) between the Centers for Disease Control and Prevention (CDC) and state or local sites submitting data to NSSP prohibit CDC from using submitted data to conduct surveillance at the state or local level. Default access to CDC NSSP staff for surveillance purposes¹ is limited to HHS region-level access.²¹ This limits CDC to a simplified national/regional database that does not

¹ Some CDC NSSP staff have additional access permissions for operational functions to ensure that the system is functioning as intended.

have the full suite of data variables available on the NSSP platform. Under these prohibitions, public health surveillance capacity is limited at the national level unless granted permission from each site.

These policy limitations raise questions about whether national syndromic systems, as they have been implemented and evolved, are capable of responding to the types of events—such as bioterrorism and epidemic disease—that they were created to address. These questions become increasingly salient as people become more transitory and public health becomes more global, as demonstrated by the COVID-19 pandemic.

The Council of State and Territorial Epidemiologists (CSTE), in collaboration with the CDC and Texas A&M University School of Public Health, Program in Health Law and Policy (referred to as the “Consultant Team” below), brought together STLT epidemiologists in leadership positions and/or with decision-making power (referred to as “CSTE NSSP Workgroup” or “Workgroup” below) to collaborate and provide input to develop a report on considerations and implementation strategies regarding revisions to permitted federal NSSP data access. The purpose of the report is to capture current perspectives and considerations regarding permitted federal data access and use of public health data, as well as to develop considerations and implementation strategies regarding revisions to permitted federal NSSP data access. Importantly, the implementation strategies of this report are limited to policies regarding federal access to state and local syndromic surveillance data collected from health care facilities, such as hospitals and urgent care centers. Policies pertaining to NSSP data from other sources (e.g., laboratories, federal health care facilities, environmental data, etc.) are not within the scope of this report.

LITERATURE REVIEW AND ENVIRONMENTAL SCAN

Several federal legal authorities were investigated to determine any impact on NSSP. These included the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule,²² the Health and Information Technology for Economic and Clinical Health (HITECH) Act,²³ the Coronavirus Aid, Relief, and Economic Security (CARES) Act,²⁴ and the Freedom of Information Act (FOIA), as well as several pending pieces of legislation.^{25–27} Generally, these federal legal authorities and pending bills provide support for pro-public health surveillance activities. For example, the public health

exception within the HIPAA Privacy Rule permits syndromic surveillance activities.²² HITECH incentives were important to boosting health care facilities' voluntary participation in syndromic surveillance in states without legal mandates. Lastly, FOIA contains an exemption for medical and similar files that has been broadly applied by courts and will likely apply to syndromic surveillance records.

There is also a growing body of literature assessing the ethics of public health surveillance and sharing data for public health purposes. A growing number of public health ethicists argue there is an ethical imperative to share public health surveillance data where there is a demonstrated public health need.^{2,28-31} The arguments for an ethical imperative to share public health surveillance data rest on critical assumptions that a public health justification exists, sharing surveillance data will produce a public benefit and that an acceptable policy framework exists to support good governance data practices. The factual bases for these assumptions have not been clearly communicated.

Nevertheless, the literature shows that public health officials and stakeholders still see several barriers with increased federal access to and use of NSSP data, such as political, motivational, economical, legal, and ethical concerns.^{20,30,32} In response, the literature shows three primary prior implementation strategies for NSSP, including improving data quality, developing policy to facilitate modernization of NSSP, and improving federal-state collaboration.

FINDINGS FROM THE COUNCIL OF STATE AND TERRITORIAL EPIDEMIOLOGISTS (CSTE) NATIONAL SYNDROMIC SURVEILLANCE PROGRAM (NSSP) WORKGROUP

The Consultant Team held two CSTE NSSP Workgroup calls to gather information from STLT epidemiologists in leadership positions and/or with decision-making power on federal NSSP access policies.

FIRST WORKGROUP CALL

In the first Workgroup call, participants were asked for input on three questions:

- (1) In what ways can increased federal access to state syndromic surveillance data (at the state or local level) benefit or support state public health activities?

- (2) What concerns you about increasing federal access to state syndromic surveillance data at the state or local level?
- (3) What rules, restrictions, guidelines, or codes of conduct could be implemented in the NSSP DUA or CDC policies that might address a concern addressed by you or a fellow Workgroup member?

Workgroup members identified ideas and then clustered the ideas into broader themes with assistance from the Consultant Team. Afterwards, Workgroup members scored and ranked each theme. Themes were scored via 5-point importance Likert scale, with 5 points for the highest importance score. For the ranking questions, an aggregate ranking score was calculated for each theme based on each Workgroup member's rankings (3 points for their most important theme, 2 points for their second most important theme, and 1 point for their third most important theme).

In response to question 1, participants identified five themes of benefits. In order of most important to least important, these benefits are: (1) improved cross-jurisdiction collaboration efforts (mean importance Likert =4.53), (2) improved syndromic surveillance practice (4.07), (3) enhanced state capacity (3.73), (4) technical assistance + expertise (3.53), (5) enhanced federal surveillance capacity (3.40). Participants were then asked to select their top-three from the five themes with the first one being the most important. The participants' top benefit was improved cross-jurisdiction collaboration efforts with an aggregate ranking score of 27.

In response to question 2, participants identified nine themes of concern. Of the nine concern themes, the concerns with the highest level of importance were the federal government independently sharing data or initiating public health action without notifying states (mean importance Likert = 4.60), followed closely by misinterpretation of data (4.53) and adequacy of and adherence to data sharing rules (4.53); privacy and confidentiality concerns (4.47); and Freedom of Information Act (FOIA) issues (4.40). Participants were then asked to select their top-three from the five themes, with the first one being the most important. The participants' top concern was the federal government independently sharing data or initiating public health action without notifying states with an aggregate ranking score of 24.

In response to question 3, participants identified twelve policy solution themes. Of those twelve, the policy themes with the highest importance scores were involving

state and local partners in data analysis (mean importance Likert=4.93), followed by making the DUA applicable to all federal recipients of NSSP data (4.53) and creating communication protocols between CDC and STLTs (4.53), establishing audit and documentation process for data access and analysis (4.33) and establishing restrictions on data publication (4.13). Participants were then asked to select their top-three from the five themes with the first one being the most important. The participants' top policy solution was involving state and local partners in data analysis (aggregate rank score of 22), followed by creating communication protocols between CDC and STLTs (aggregate rank score of 17).

SECOND WORKGROUP CALL

In the second Workgroup call, participants were asked to identify potential operational frameworks and other critical issues concerning three policy questions identified based on the feedback from the first Workgroup call and initial feedback from the key informants (see below):

- (1) What communication protocols should exist between federal and STLT agencies?
- (2) What should the framework for STLT and federal collaboration be?
- (3) What issues and questions exist for different federal use cases?

Participants of the second Workgroup call recorded their thoughts on these prompts on an online collaborative document (Google Doc). Following the second Workgroup call, the Consultant Team analyzed the provided ideas and identified different policy options related to Workgroup feedback. The Consultant Team then created an online assessment to evaluate and solicit feedback on these specific policy options. Questions in this online assessment fall within three general categories: communication protocols, collaboration protocols, and NSSP governance. Questions in this assessment were mostly either 5-point Likert questions on level of agreement or open-ended response formats. Eight randomly selected individuals on the list of STLT NSSP site administrators completed the online assessment.

Six questions pertained to communication protocols. Of those six, the top proposals were "all federal communications regarding syndromic surveillance data should be directed only to STLT syndromic surveillance contacts" (mean agreement=4.00) and

“no federal partner should contact participating facilities directly regarding syndromic surveillance findings or activities “(4.00). Moreover, participants generally supported a tiered approach to communication expectations.

Questions on federal-state collaborations focused on three issues: data access requests, routine federal activities using STLT NSSP data, and publication of state-level NSSP data. For proposals on access requests, the top proposals were that requests for granular access by federal partners should include a clear description of the group (mean agreement= 4.63), the purpose (4.63), the timeframe of the granular access (4.50), and the jurisdictions whose data will be accessed (4.50).

For questions on routine surveillance activities, the top-scoring options were “it would be helpful if CDC NSSP staff coordinated closely with my site to routinely provide an extra set of eyes on our data and provide either reports or informal communications about what they find in the data (expectations of type and frequency of communications can be agreed upon ahead of time)” (mean agreement =3.88) and “it would be helpful if CDC NSSP staff could generate regular visualizations based on agreed-upon queries of my state’s NSSP data for me” (3.88).

For proposals on federal publications of state-level NSSP data, the proposals with the highest level of agreement were permitting federal publication of state-level data only with express consent of the jurisdiction (mean agreement =4.38) and permitting federal publication of state-level data “so long as there is adequate and appropriate opportunity for a state to request that their data is removed from the analysis” (3.88). Overall, assessment participants indicated they were either substantially or slightly more concerned with *routine research uses* of state NSSP data than *routine surveillance uses*.

The assessment contained a question on two main governance issues: (1) the acceptability and role of a governance group, and (2) accountability and trust. For proposals on general governance the top proposals were “an NSSP governance group would be beneficial to state-federal collaborations” (mean agreement=4.00), “a governance group would be useful to ‘flag’ or alert states when a proposed federal use of NSSP data might require increased state attention or scrutiny” (3.88), and “to reduce the transaction burden of negotiating with all jurisdictions independently, an NSSP governance group should be empowered to restrict routine federal access to NSSP

data subject to reasonable limitations, including maintaining a right for jurisdictions to opt-out of governance board decisions” (3.88). Participants were then asked to rank the primary role (5=ranked most important, 1=ranked least important) the group should have. The highest-ranked primary roles were (1) providing pre-decisional input on federal uses of NSSP data (e.g., review of NSSP reports to the CDC director) (aggregate ranking score=28, i.e., sum of each participant #1-5 importance rankings) and (2) "flagging" or alerting states when a proposed federal use of NSSP data might require increased state attention or scrutiny (aggregate ranking score = 27).

For proposals on accountability and trust, the proposal with the highest level of agreement was that states should be provided access to audit findings related to their NSSP data (mean agreement=4.50), followed by the proposal of “an audit should be implemented for federal access to state NSSP data” (4.13).

FINDINGS FROM KEY INFORMANT INTERVIEWS

In addition to findings from the NSSP Workgroup, additional information was collected from eight key informants to further develop considerations and implementation strategies regarding revisions to permitted federal NSSP data access. The key informants were selected by CSTE based on their prominent roles within the public health informatics and surveillance community, and their expertise and extensive experience with syndromic surveillance, and included STLT, federal, and national public health perspectives.

After interviews were completed and transcribed, the Consultant Team conducted a deductive and inductive thematic analysis using NVivo. The Consultant Team held coding meetings to identify an initial list of themes to refine and standardize the thematic categories identified for this report. At least two members of the Consultant Team independently coded each interview.

The Consultant Team identified several themes from these key informant interviews. The most significant themes were:

- 1) Collaboration and Relationships
- 2) Communication
- 3) Data Stewardship and Ownership
- 4) Data Limitations and Pitfalls

- 5) Access Restrictions and Controls
- 6) Existing Policy Challenges
- 7) Relationships with Healthcare Facilities
- 8) Syndromic Surveillance Capabilities and Applications
- 9) Public Perceptions
- 10) Sustainability

While the interviews revealed different and diverse perspectives, there were significant and substantial areas of agreement. For example, all informants stressed the need for increased STLT collaboration in federal analyses, clear communication protocols, and access restrictions for syndromic surveillance data. However, there were some important areas of divergence, including syndromic data stewardship, ownership, and the perceived weight of anticipated benefits and risks associated with increased federal access to STLT syndromic data. Notably, there were numerous areas and issues where federal and non-federal informants shared similar concerns; these included access restrictions, syndromic data limitations, and unannounced publication of syndromic findings.

FINDINGS FROM CSTE, U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION(CDC), AND THE OFFICE OF THE NATIONAL COORDINATOR FOR HEALTH INFORMATION TECHNOLOGY (ONC) MEETINGS RELATED TO FEDERAL NSSP DATA ACCESS POLICIES

In addition to the findings from the Workgroup, the Consultant Team analyzed several meetings that included discussions on NSSP data access policies. These meetings include three CSTE executive or subcommittee meetings as well as two meetings with Workgroup members and the Office of the National Coordinator for Health Information Technology (ONC) and the Centers for Disease Control and Prevention (CDC).

CSTE EXECUTIVE AND SUBCOMMITTEE MEETINGS ON SYNDROMIC SURVEILLANCE POLICY

Two meetings of the CSTE Surveillance Practice & Implementation Subcommittee (August and October 2021) discussed federal NSSP data access. The discussion concentrated on access to new NSSP laboratory data sources. However, participants raised concerns regarding who was being granted access to the state-level data provided by these laboratories. There was also discussion on issues regarding privacy

and data identifiability, concerns about data shared outside of NSSP, and risks of misinterpretation. Participants identified certain policies that they would like clarified, such as defining what the CDC has access to and what and how the CDC is going to use the data.

Lastly, there were some expressed concerns regarding transparency in general. Some participants implied that there should be more transparency around the cooperation agreements, completeness of the data, and how trends are being tracked over time regionally and nationally. There were some suggestions that with more information shared, participants in various jurisdictions would have more trust in the process in terms of the utility of the data and in the appropriateness of the use.

Federal NSSP data access policy was also discussed during a CSTE Executive Board in October 2021. The broad question for discussion was determining CSTE's position on permitting broader federal access to state NSSP data. It was noted that certain groups and communities were frustrated with the lack of progress on data sharing policy issues. Participants noted the difficulty that CSTE has in stating an independent position while being representative of the diverse communities and perspectives of its constituent state and local public health membership. Several participants expressed that it was critical that someone have eyes on the national picture of syndromic surveillance trends. However, participant comments indicated the importance that federal use of NSSP must supplement—and not supplant—state syndromic surveillance activities. Public disclosure of syndromic surveillance data through a FOIA request appeared to be a critical concern and a factor in the support for increased federal NSSP access for several participants.

Participants also expressed the need for adequate policy guardrails to ensure that NSSP data are used appropriately by federal partners. Suggestions included procedures to remove access permissions from personnel that are using NSSP data inappropriately and NSSP governance.

CALLS WITH CDC AND ONC

The Consultant Team also analyzed two meetings with members of the CSTE NSSP Workgroup, ONC, and CDC. ONC and CDC were tasked with obtaining information relevant to the Executive Order on Ensuring a Data-Driven Response to COVID-19 and

Future High-Consequence Public Health Threats.³³ Two goals of this CDC and ONC engagement were particularly relevant to considerations of federal NSSP data access policy. First, CDC and ONC wanted to understand the technical and policy challenges and successes in capturing and sharing syndromic surveillance data across the public health and health care communities. Second, CDC and ONC sought to obtain information from public health officials and program leads on the ideal future state of syndromic surveillance.

Several participants noted that syndromic surveillance was very useful in the COVID-19 response, including for timely monitoring COVID-19 as well as related or synergistic events. However, several participants felt that syndromic surveillance data was underutilized nationally for the COVID-19 response. One participant suggested that the visibility of syndromic data on public facing sites was a transparency issue. Another comment suggested that syndromic surveillance could have been better utilized to inform policy and planning in response to COVID-19.

Concerns about the adequacy of and adherence to data use agreements were expressed during both calls. These concerns included applicability of the DUA to non-CDC federal partners and respecting DUAs between facilities and STLT agencies. There was some support for a standardized DUA between STLT partners and syndromic data providers, including its potential support for interjurisdictional data sharing and limiting the number and variety of DUAs that exist.

Participants noted both positive and negative impacts of federal incentive programs on syndromic surveillance messaging. Several participants noted that federal incentives were critical for health care facility participation. Nevertheless, several participants indicated that additional incentives could benefit future syndromic surveillance efforts, including health care facility onboarding and public health capacity.

IMPLEMENTATION STRATEGIES

The implementation strategies below are the result of the synthesis of the substantial data and findings described in this report. Public health ethical principles—such as common good, equity, respect for persons, and good governance—as well as considerations of reciprocity, trust, transparency, and accountability, were given

consideration and guided the implementation strategies below when evidence diverged, or perspectives on an issue differed.^{2,28-31,34-36}

This report's implementation strategies are:

- 1) Create communication protocols between CDC and STLT governments
 - a) Adopt a tiered classification system that indicates STLT response expectations for all federal NSSP communication.
 - b) All federal communications involving syndromic surveillance data should initially be directed only at STLT NSSP site administrators or designated contacts.
 - c) Establish standardized modes of communication regarding federal use of NSSP data
 - d) STLT NSSP site administrators should be notified if a federal data release, report, or other dissemination displays their jurisdiction's NSSP data below the HHS region level.
 - e) A jurisdiction's NSSP site administrator should be notified immediately if CDC receives public inquiries on that jurisdiction's syndromic surveillance data
 - f) CDC should refrain from making comments on a STLT jurisdiction's syndromic surveillance data to the press and should refer any inquiries to the appropriate STLT contact(s)
 - g) CDC should notify a STLT NSSP site administrator if they plan to share that jurisdiction's NSSP data or initiate a public health action based on that jurisdiction's NSSP data
 - h) Consider adding functionality to ESSENCE that enables NSSP site administrators to flag syndromic data that require additional interpretive caution.
- 2) Implement a framework for federal-STLT collaborations
 - a) Involve STLT partners in methodological development and data analysis
 - b) All federal and STLT collaborating partners should be appropriately acknowledged in disseminations
 - c) All new federal requests for STLT NSSP data should be standardized
 - d) STLT governments should have a right to have their jurisdiction's NSSP data excluded from any publicly available federal dissemination when the exclusion is based on legal, scientific, or public health grounds.
 - e) Federal users should not contact NSSP-contributing health care facilities without the express permission of the relevant STLT government

- f) Federal NSSP data users should provide STLT partners greater opportunities to collaborate when the objective is to publish NSSP findings for research, scientific, or academic purposes, as opposed to dissemination for public health activities.
- 3) Establish rules and restrictions for federal publication of NSSP data
- 4) Permit limited CDC NSSP staff to access state NSSP data to provide supplementary surveillance support subject to reasonable policy guardrails and limitations
 - a) All federal access to STLT NSSP data should be consistent with a documented public health need that is clearly communicated with state and local public health agencies
 - b) Generalized federal access to STLT NSSP data should be limited to core CDC NSSP staff
 - c) Routine federal use of STLT NSSP data should be limited to activities intended to detect or monitor interjurisdictional public health threats or to enable federal public health support activities.
 - d) The extent and substance of federal support for STLT NSSP activities should be at the sole discretion of STLT governments
- 5) The federal government should minimize additional burdens on STLT governments caused by increased federal access to STLT data and provide additional state and local funding as needed.
- 6) Create a STLT NSSP governance group guided by principles of public health ethics
- 7) Create processes for emergency federal NSSP access and use.
- 8) Establish audit and documentation process for NSSP data access and analysis
- 9) Require all federal NSSP users and regular recipients of NSSP data below the state level to sign the NSSP DUA
- 10) Federal and STLT NSSP partners should clarify breach responsibility
- 11) Create standards for removing access from federal users
- 12) Require training on NSSP rules, DUA obligations, and the code of conduct
- 13) Clarify and communicate DUA rights, duties, and restrictions
- 14) Clarify FOIA policy for syndromic surveillance data
- 15) Prohibit the use or release of STLT NSSP data to take enforcement action against NSSP-contributing facilities or data subjects
- 16) Investigate tribal issues related to increased federal access to STLT NSSP data and the potential impact on tribal communities

CONCLUSION

Consistently, trust and relationships are the most significant reported barriers and challenges to public health data sharing at all levels. This is consistent with our findings from the CSTE NSSP Workgroup discussions and key informant interviews.

Consequently, many of the implementation strategies in this report are provided with the intent of providing a constructive foundation for building trusting relationships between the federal government and state and local NSSP participants.

Notably, many of these implementation strategies are prudent even in the absence of enhanced federal access to STLT NSSP data. For example, the implementation strategies to improve communication and collaboration between federal and STLT partners will substantially improve national syndromic surveillance activities and the broader Community of Practice. Several of these implementation strategies are likely to facilitate stronger trusting relationships and more productive and efficient public health collaborations. Consequently, these implementation strategies should not be considered an all-or-nothing package.

Views expressed by Workgroup members and key informants support two important conclusions. First, public health practitioners in the U.S. syndromic surveillance system are strong and trustworthy stewards of public health data. Second, U.S. syndromic surveillance practitioners, at all levels, have a deep awareness of the sensitivity and confidentiality of syndromic surveillance data. These conclusions are required and foundational to public health data sharing.

Nevertheless, the zealous stewardship and staunch protection of confidence that exists within the U.S. syndromic surveillance community have likely contributed to an NSSP policy framework that creates substantial barriers to ethical public health data use. When a public health need exists, and adequate protections are in place, public health ethicists assert there is an obligation to share public health surveillance data. The implementation strategies above are intended to introduce appropriate guardrails and governance policies to support greater utilization of syndromic surveillance data to promote population health.

BACKGROUND

Data are critical to the success of public health authorities. It is a component of the essential public health services that help to protect and promote the health of all people in all communities.[1] Data enables public health authorities to understand and protect against the specific health threats facing communities and individuals.¹ Public health agencies rely on various forms of surveillance to understand the health status within a community. These include case reporting, routine surveying (e.g., Behavioral Risk Factor Surveillance System), sentinel surveillance, and more recently, syndromic surveillance. Laws, policies, and ethics provide support for public health surveillance practice.

Public health surveillance rests on a social contract between governments and the populations that they serve.² In this social contract, individuals concede some privacy interests by permitting public health agencies to collect information on the condition that governments use that information to broadly promote the public good.² In furtherance of this social contract, public health authorities systematically collect, analyze, and disseminate data to understand, detect, and respond to public health issues or evaluate public health programs or interventions.³

Syndromic surveillance emerged as a support surveillance method for state, tribal, local, and territorial (STLT) health departments to identify novel or emerging health threats in near real-time. The capacity to support public health situational awareness received considerable support after the terrorist attacks of 9/11/2001 and subsequent anthrax attacks, which led to considerable federal funding to promote the use of syndromic surveillance by health departments nationally.⁴ Since then, federal incentive programs have promoted the adoption of syndromic surveillance and participation by health care facilities.^{37,38}

Since its implementation, syndromic surveillance has been used in detecting various public health events, such as salmonella,⁹ tornado activity, wildfires, influenza-like illnesses, hurricanes, and hazardous material exposure or violations.^{7,8} It has also demonstrated potential to address new arising public health concerns, including: (1) sexual violence,¹⁰ (2) suicide and self-harm,¹¹ (3) heat-related illness,^{12,13} (4) Tick-borne illness,¹⁴ (5) adverse events associated with drugs (e.g., overdoses from opioids and

heroin),^{15,16} and (6) post-market surveillance of products (e.g., e-cigs, adverse reactions to COVID-19 vaccines).^{17,18}

The national syndromic surveillance platform, BioSense, has evolved since its introduction in 2002, including the BioSense redesign in 2010 and creation of the National Syndromic Surveillance Program (NSSP) in 2014.¹⁹ Forty-eight states currently collect and provide syndromic surveillance data to collect and provide data to NSSP.³⁹ In addition to the syndromic surveillance functions, NSSP includes a healthy community of practice to share knowledge and best practices between health departments.

Even though several STLT health departments publish syndromic surveillance data and visualizations publicly, standard, nationwide visibility of syndromic trends are lacking.²⁰ Current data use agreements (DUAs) between the Centers for Disease Control and Prevention ("CDC") and state or local sites submitting data to NSSP prohibit CDC from using submitted data to conduct surveillance at the state or local level. Default access to CDC NSSP staff for surveillance purposes² is limited to HHS region-level access.²¹ This limits CDC to a simplified national/regional database that does not have the full suite of data variables available on the NSSP platform. For example, an increase in a syndrome in HHS Region 10 could reflect either an isolated incidence increase in WA, unrelated incidence increases in WA and AK, or a related incidence increase in WA and OR. At the national level, the federal government has no capacity to differentiate between these scenarios without requesting additional data access from all states within HHS Region 10. Under these prohibitions, public health surveillance capacity is limited at the national level unless granted permission from each site.

While NSSP has the ability for STLT partners to grant unrestricted access to specified federal users, this fragmented data sharing approach inhibits nationwide monitoring of unidentified emerging health threats or health disparity trends. The federal government is particularly limited in its capacity to detect and respond to interjurisdictional events. Moreover, the transactional costs of separately negotiating differential access permissions with state and local governments only increase during public health crises when public health workers are preoccupied with response. These policy limitations raise questions about whether national syndromic systems, as they

² Some CDC NSSP staff have additional access permissions for operational functions to ensure that the system is functioning as intended.

have been implemented and evolved, are capable of responding to the types of events—such as bioterrorism and epidemic disease—that they were created to address. These questions become increasingly salient as people become more transitory and public health becomes more global, as demonstrated by the COVID-19 pandemic.

In 2021, the Biden administration issued an executive order calling for enhanced data collection and collaboration for high-consequence public health threats, the review of current public health data systems, and increased public health data modernization.⁴⁰ While not directly in response to the Executive Order, Congress has authored a number of bills implicating public health data-sharing and systems, which each incorporate funding for data modernization and public health surveillance efforts. Updates on these and other relevant bills will be available as the current 117th Congress continues its session. The order calls for the designation of officials who are charged with making data relevant to public health threats accessible to the public. In response, some public health stakeholders have called for further strengthening of syndromic surveillance systems. For example, a report by the Duke Margolis Center for Health Policy called for federal, state, and local public health officials to “agree on a consensus set of protocols governing which data from NSSP state ‘lockers’ can be used for Federal surveillance and how that data may be used at the Federal level.”²⁰ Revising federal access policies for state NSSP data is one proposed approach to public health data modernization. However, literature shows that public health officials and stakeholders still see several barriers with increased federal access to and use of NSSP data, such as political, motivational, economical, legal, and ethical concerns.^{20,30,32}

The Council of State and Territorial Epidemiologists (CSTE), in collaboration with the CDC and Texas A&M University School of Public Health, Program in Health Law and Policy (referred to as the “Consultant Team” below), brought together STLT epidemiologists in leadership positions and/or with decision-making power to collaborate and provide input to develop a report on considerations and implementation strategies regarding revisions to permitted federal NSSP data access. The purpose of the report is to capture current attitudes and considerations regarding permitted federal data access and use of public health data, as well as to develop considerations and implementation strategies regarding revisions to permitted federal NSSP data access. Importantly, the implementation strategies of this report are limited

to policies regarding federal access to state and local syndromic surveillance data collected from health care facilities, such as hospitals and urgent care centers. It does not address other types of syndromic surveillance data, including environmental data or data collected from laboratories or federally operated health care facilities.

Part I of this report explores the various information gathering activities commenced on behalf of this report. It contains a literature review of public health data use and ethical considerations, legal authorities governing NSSP, potential use cases and opportunities for NSSP, and barriers or concerns with increased access to NSSP. It also discusses the two Federal Use of NSSP Data Workgroup calls and their findings. It concludes with the information gathered from key informant interviews.

Part II discusses information from other CSTE meetings as well as discussions facilitated by the CDC and Office of the National Coordinator for Health Information Technology (ONC) pertaining to NSSP data access policies.

Part III provides policy implementation strategies to modernize the NSSP BioSense platform based on the results of this report and existent literature.

PART 1: FINDINGS FROM THE EXISTENT LITERATURE AND THE CSTE NSSP WORKGROUP

A. LITERATURE REVIEW AND ENVIRONMENTAL SCAN

This section summarizes the findings of the literature review and environmental scan. The full literature review can be found in **Appendix A**.

I. NSSP LEGAL AUTHORITIES AND MANDATES

In response to the 9/11/2001 terrorist attacks and the subsequent anthrax attacks, Congress passed the Public Health Security and Bioterrorism Preparedness and Response Act of 2002.⁴ The Act called for the improvement of public health surveillance and reporting activities, including establishing systems for public health communications and surveillance networks through the CDC. After promulgation of the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule regulations in 2003, public health departments and officials raised concerns about the Privacy Rule's effect on syndromic surveillance activities.²² But, it has been generally accepted that

the public health exception within the HIPAA Privacy Rule permits syndromic surveillance activities.²² By 2008, 83% of U.S. states and territories were implementing syndromic surveillance. Several states found their existing state laws granted broad authority for public health surveillance.⁴¹ Other states made explicit modifications to their existing law or regulations to allow for syndromic surveillance.⁴²⁻⁴⁴ Some states just request data pursuant to their general public health powers.^{45,46} Importantly, in some states, health care facilities voluntarily contribute syndromic surveillance data. However, other states mandate facilities to provide syndromic surveillance data.

In 2009, Congress passed the Health and Information Technology for Economic and Clinical Health (HITECH) Act, which awarded incentive payments to providers and hospitals for meeting certain "meaningful use" measures. One meaningful use measure was participating in syndromic surveillance.[29] The HITECH Act's incentives were important to boosting health care facilities' voluntary participation in syndromic surveillance in states without legal mandates.

More recently, the Coronavirus Aid, Relief, and Economic Security Act appropriated \$500 million to CDC to modernize "public health data surveillance and analytics."²⁴ In January 2021, the Biden administration issued an executive order calling for enhanced data collection and collaboration for high-consequence public health threats, the review of current public health data systems, and increased innovation of public health data and analytics.³³ Congress has also authored a number of bills implicating public health data sharing and systems. These include the Build Back Better Act and the Crush the Virus Act, which each incorporate funding for data modernization and public health surveillance efforts^{25,26} The Immunization Infrastructure Modernization Act directs CDC to develop a strategy to improve health data systems and to offer grants to state and local health departments to improve their systems.²⁷ These new authorities provide additional legal mechanisms for implementation and improvement of national syndromic surveillance practices. However, it is not yet clear how these new data modernization funds will impact syndromic surveillance.

II. SYNDROMIC SURVEILLANCE USE CASES AND CAPACITY

The focus of syndromic surveillance has expanded beyond bioterrorism and epidemic detection to now include situational awareness, outbreak characterization, and resource allocation.⁴⁷ Syndromic surveillance has been used in detecting various public

health events, such as salmonella,⁴⁸ influenza-like illnesses, hazardous material exposure or violations,⁷ tornado activity, wildfires,⁴⁹ hurricanes, and other climate-related health impacts.⁵⁰ It can be further utilized to detect new arising public health concerns, including: (1) sexual violence,⁵¹ (2) suicide and self-harm,⁵² (3) heat-related illness,^{12,13,50} (4) cold-related illness,⁵³ (5) tick-borne illness,¹⁴ (6) adverse events associated with drugs (e.g., overdoses from opioids and heroin),^{15,16} and (7) post-market surveillance of dangerous and defective products (e.g., e-cigs, adverse reactions to COVID-19 vaccines).¹⁸ (See Table of Use Cases in **Appendix A**). Due to the regional nature of NSSP data in many of these studies, common limitations were the generalizability of the findings or trends and the representativeness of the data. However, several of these studies also suggested that access to state or local data and increased participation in NSSP could lessen the effect of these limitations.¹²⁻¹⁴

III. ETHICAL CONSIDERATIONS

A growing number of ethicists argue there is an ethical imperative to share public health surveillance data where there is a demonstrated public health need when applying a public health ethics approach.²⁸⁻³¹ The 2017 WHO Guidelines on Ethical Issues in Public Health Surveillance explicitly states this obligation with Guideline 14, saying, “[w]ith appropriate safeguards and justification, those responsible for public health surveillance have an obligation to share data with other national and international public health agencies.”²⁸ Similarly, in 2016 the International Association of National Public Health Institutes (IANPHI) called for sharing “public health surveillance data by default where a public health need is identified, in a timeframe necessary for public health decision-making and to the highest standards they can achieve.”²⁹ Additionally, the IANPHI called for sharing public health surveillance data “with as few restrictions as possible.”²⁹

Nevertheless, there are important reasons for limiting data sharing. Langat, et al., argue that these can be summarized in three categories, 1) data property and ownership, 2) just distribution of benefits and burdens, and 3) the contemporary ethos of science.³¹ However, they argue that each of these reasons is outweighed by considerations in favor of data sharing.³¹ For example, ownership of data is an important consideration, but Pisani and AbouZahr argue that data collected with public resources should be shared to maximize the public benefit from those resources.³⁴

Indeed, this theme is shared by other public health ethicists. For example, Lee, et al. argue that the justification burden falls on those *withholding* data from public health use, stating, “it remains our ethical obligation to use the data we collect for public health benefit; *not using the data for improving health must be justified*” (emphasis added).²

Others argue that an ethical imperative to share data is not enough. In a systematic review of ethical best practices in sharing individual-level data, Bull, Roberts, and Parker found that “support for data sharing is contingent on the development and implementation of ... policies and processes to support ethical best practices.”³⁵ Similarly, the Chatham House toolkit for Strengthening Data Sharing for Public Health emphasizes the importance of including guiding principles in data sharing agreements to help the parties cooperate and interact with each other.³⁶ The need for policies, processes, or principles is consistent with several descriptions of public health ethics as applied to the use of health data, which describe the importance of good governance,²⁸ stewardship,⁵⁴ accountability, and transparency.³⁵

Ethicists arguing that ethical imperatives to share public health surveillance data rest their arguments on critical assumptions that a public health justification exists, sharing surveillance data will produce a public benefit, and that an acceptable policy framework exists to support good governance data practices. Some of these assumptions could be tenuous given the current state of syndromic surveillance and NSSP. For example, some state and local syndromic surveillance partners do not have a good sense of the public health justification for sharing granular syndromic surveillance data with the federal government. Additionally, the risk for misinterpreting syndromic data can be significant without critical state or local knowledge. For example, a state or local health department is better equipped to determine whether a sudden spike in the data indicates an event of concern or a false positive caused by a facility submitting batched data. Finally, state and federal partners have acknowledged needs and challenges with the existing policy framework—particularly around protocols for communication and collaboration—that suggest additional improvements to syndromic surveillance governance may be needed prior to granting expanded federal access to granular syndromic surveillance data. This report and the implementation strategies below address these challenges. These issues are discussed in greater detail below.

IV. CDC & CSTE POSITIONS AND POLICIES ON DATA SHARING

In 2005, CDC, in coordination with the Agency of Toxic Substances and Disease Registry (ATSDR), published a policy on releasing and sharing data.⁵⁵ CDC recognized the need for high data quality standards, privacy procedures, and protection of highly sensitive information. The implementation of its policy aimed to balance these considerations with the need for data dissemination. In its policy, CDC set forth guiding principles and procedures for releasing data including accountability, privacy and confidentiality, stewardship, scientific practice, efficiency, and equity. Data could be released for public use without restrictions, but CDC recommended that, to the extent possible, data should be released to particular parties with restrictions using special data sharing agreements.

Following the publication of the data release and sharing policy, CDC, CSTE, and ATSDR published specific implementation guidelines regarding the re-release of state-provided data.⁵⁶ There were two guidelines pertaining to data agreements with state data providers and three categories of guidelines for procedures on protecting and releasing state-provided data. The guidelines encouraged the development of agreements with state data providers before receiving any data. The policy further suggests specific content that data providers should consider including in their agreements: (1) administrative requirements for all re-release of state-provided data, (2) re-release of state-provided data as public-use data, and (3) re-release of state-provided data as restricted-access data. CDC, CSTE, and ATSDR devised these guidelines in the hopes of complementing existing federal law, augmenting other CDC policies, and providing a more in-depth implementation guide pertaining specifically to the re-release of state-provided data.

CSTE adopted a policy to facilitate national public health data sharing of reportable conditions. In response to emerging public health conditions, CSTE implemented a policy allowing it to add “provisional” conditions to its Nationally Notifiable Conditions list at any time during the year.⁵⁷ As new conditions arise, CSTE may adopt “provisional” conditions to the list, and it becomes official CSTE policy until confirmed or disapproved at the annual meeting. This allows CSTE to promptly respond to emerging conditions by adding conditions to the NNC list without waiting for law to be established in each state making the condition reportable.

V. BARRIERS AND CONCERNS WITH INCREASED ACCESS

Since the Public Health Security and Bioterrorism Preparedness and Response Act of 2002, the use of syndromic surveillance has been accelerated by several incentive programs.¹⁹ However, there are still several barriers and concerns with syndromic surveillance data sharing. These include technical, political, motivational, economical, legal, and ethical barriers and concerns. Literature on these barriers and concerns is summarized below.

It is important to note that NSSP has evolved through several iterations, and a number of publications cited below raise issues that existed with prior versions of NSSP (i.e., BioSense, BioSense 2.0) that may not have the same relevance to NSSP as it existed in 2021.

TECHNICAL BARRIERS

Several technical barriers restricted the initial widespread and consistent use of syndromic surveillance including the limited availability and affordability of the technical software needed to participate at the time of its implementation, the initial quality of the data, and the lack of consistent types of variables, data formats, and metadata that each facility within each state reports.^{20,32,58} Nonetheless, technical barriers to syndromic surveillance have diminished since its introduction in 2002 and through the evolution of the BioSense platform and the creation of a Community of Practice that shares tools, methodology, and expertise.¹⁹ However, there are still states and territories that do not participate in NSSP, limiting the data's generalizability.

POLITICAL BARRIERS

Public health officials have also raised several political barriers and concerns. First, there is the predominant federalism issue as states have concerns with granting increased data access to the federal government.³² Second, without clear guidelines and trust, more protective policies on data sharing are likely to result, making it more difficult for federal-state collaboration.³² Third, there are concerns of bureaucratic hurdles and lack of political will and commitment to promoting data sharing.³⁰ However, these political barriers can be overcome by building trust, capacity building, and engaging politicians. Building trust through face-to-face meetings, workshops, and joint public health investigations are key elements to overcoming political barriers to

data sharing. In addition, political support is essential to the continued success of data-sharing networks.³⁰

The Mekong Basin Disease Surveillance network—an interjurisdictional surveillance operation established in 2001—is one example of a successful program that overcame general political barriers. The Mekong Basin Disease Surveillance network is built on bilateral agreements among six Southeast Asian governments (Cambodia, China, Laos, Myanmar, Thailand, and Vietnam). The bilateral agreements are intended to support trust-based data sharing. Cooperative, joint outbreak investigations have improved interjurisdictional disease surveillance and improved capacity building. Communication through regular meetings is used to continually build trusting relationships and address challenges and opportunities, with lessons learned shared to other networks around the world.³⁰

MOTIVATIONAL BARRIERS

Motivational barriers to data sharing include the lack of incentives, opportunity costs, the potential for criticism, and disagreement regarding data use.³² Transparency can be critical to overcome these motivational barriers. Recommended approaches include increasing transparency and being clear about the intended secondary use of the data as well as changing the publication.³⁰

ECONOMICAL BARRIERS

There are two primary economical barriers: (1) potential for economic damage and (2) lack of resources.³⁰ Increased public health data sharing could cause economic damage by reducing tourism and trade as it did during the SARS outbreak. The potential for such over-reactive market forces could reduce health agencies' willingness to release public health data.³⁰ In public sector agencies and low-income settings, human and technical resources are lacking to facilitate data sharing and may be financially unable to acquire the personnel and technology needed for data sharing.³² It is suggested that time and skills should be incorporated into the hiring and training process, as well as offering incentives and funding for data sharing could both help overcome these economic barriers.³⁰

LEGAL BARRIERS

There are reportedly several legal barriers to data sharing and participation in NSSP. The primary legal barrier appears to be the data use agreements between health departments and NSSP. Several public health officials and departments have reported concerns regarding the lack of clarity in the document concerning access to NSSP data and the role of Amazon as the vendor who houses the data⁴¹. Second, the lack of harmonization of legal requirements as public health laws between U.S. states slows down the ability to share data across jurisdictional boundaries.³⁰ Third, data protection laws are not uniform in the US.^{59,60} Fourth, perceived barriers exist when state freedom of information laws conflict with the federal FOIA statute. While FOIA preempts contradictory state laws that provide fewer privacy protections, states are free to mandate greater protections, including notice requirements.⁶¹ There is a lack of clarity on how data protected at the state level could be disclosed if it were shared with federal partners. Under FOIA, data will not be released if deidentification of the information “is not sufficient to safeguard privacy,” however, states and state laws determine sufficiency differently.⁶²

However, scholars have found that law and policy facilitate the use of syndromic data, and if there are legal barriers, they can be overcome.⁴¹ For example, HIPAA does not interfere with the sharing of syndromic data. Also, it is suggested that implementing a global governance framework, or alternatively, a framework implementing local, context-specific agreements, could assist in working with the patchwork of state public health laws. The framework or agreements should outline how and when data will be shared and with whom, as well as what specific types of data should be shared.³⁰

ETHICAL BARRIERS

There are several ethical barriers to data sharing, including lack of reciprocity, lack of proportionality of benefits and risks between providers and requestors of data, and protecting individual’s privacy.^{30,32} Public health ethicists have generally favored sharing public health data to promote public health. (See Ethical Considerations discussion above). Nevertheless, perceived ethical issues can become substantial barriers. Strategies to overcome these ethical barriers include anonymization of the data shared, prompt and clear communication about the intended use of the data, and the implementation of a responsible and transparent data collection process.³⁰ Communication about syndromic surveillance data to a wide audience will continue to be an ongoing challenge.¹

VI. APPLICABILITY OF THE FEDERAL FREEDOM OF INFORMATION ACT TO NSSP DATA

The Freedom of Information Act (FOIA) is a federal law that requires federal agencies to make government records available to any person upon request.⁶³ A FOIA request can compel the disclosure of records maintained by a federal agency or records that are "maintained for an agency by an entity under a Government contract."⁶⁴ Under this definition, syndromic surveillance records maintained by a federal agency, like CDC, are covered by FOIA. Similarly, syndromic surveillance data would be covered by FOIA if the federal government contracted with a non-governmental third party to maintain the syndromic surveillance records for a federal agency.⁶⁴

Nevertheless, FOIA exempts nine main categories of records from disclosure. Exemption 6 protects "medical files and similar files" when the disclosure of such information "would constitute a clearly unwarranted invasion of personal privacy."⁶⁵ The US Supreme Court held that FOIA's goal is providing information, so exemptions should be narrowly construed.⁶⁶ The court further clarified that redaction is not expected to eliminate all risks of identification, but must eliminate those that create "clearly unwarranted" invasions of privacy.⁶⁶ However, the US Supreme Court later clarified that Exception 6 (pertaining to medical or personnel records) is "intended to cover detailed Government records on an individual which can be identified as applying to that individual."⁶⁷ Lower courts applying this medical files exception have interpreted broadly. For example, in *Trotter v. Center for Medicare and Medicaid Services*, the US District Court in D.C. permitted the non-disclosure of email domain names (e.g., gmail.com) because that information conveys "information about a particular individual."⁶⁸ In a 2020 FOIA case, *Houser v. U.S Department of Health and Human Services*, a federal district court held that the government was justified in withholding information in survey records from disclosure, including individual medical information, identifying characteristics, location data, and facility names.⁶⁹ The court interpreted the FOIA exception broadly, saying "[p]rotection under Exemption 6 is not limited to 'a narrow case of files.'"⁶⁹ Importantly, the US Supreme Court has interpreted Exemption 6 to apply to natural persons, stating "'personal' does not ordinarily relate to artificial 'persons' such as corporations."⁷⁰

The literature search and environmental scan did not uncover any published court opinions interpreting the FOIA Exception 6 as applied to syndromic surveillance.

However, given recent broad interpretations of Exemption 6, it is reasonable that the exemption will apply to syndromic data. Syndromic surveillance data often lack names, but often contain substantial details about specific individuals that could enable some to be reidentified. Consequently, unredacted public release of syndromic surveillance data would certainly risk “clearly unwarranted” invasions of privacy for at least some individuals.⁶⁵ Cases interpreting Exemption 6 provide support that the federal government is entitled to protective redactions prior to disclosing any syndromic data pursuant to a FOIA request.⁶⁷⁻⁶⁹ However, one Supreme Court case suggests that Exemption 6 could not be used to specifically protect a health care facility (as opposed to the individuals seen at the health care facility).⁷⁰

VII. PRIOR IMPLEMENTATION STRATEGIES FOR NSSP

The overall aims of NSSP are to (1) improve technical capabilities for collecting and analyzing syndromic surveillance and (2) facilitate the opportunity for collaboration among local, state, and federal public health programs.⁷¹ Several prior implementation strategies to modernize the system have been suggested, such as improving data quality, establishing consistent research standards, and improving federal-state collaboration.

IMPROVE DATA QUALITY

Some existing implementation strategies pertain to improvements of syndromic surveillance data quality.^{1(p283)} For example, there are significant issues with working with unstructured free-text data as well as missing data linkages between de-identified data. Scholars have proposed both short-term and long-term solutions.^{1(p283)}

DEVELOP POLICY TO FACILITATE MODERNIZATION OF NSSP

A 2015 systematic review identified several priority areas for policy development to help modernize NSSP.³⁵ First, the authors argue that specific research standards should be developed, including how confidentiality will be maintained, specifically how and when data will be shared and with whom, as well as what specific types of data should be shared. Second, the authors argue that any future policy should establish ethical processes that minimize harm to individuals. Third, the authors recommend policy mechanisms that promote transparency and reasonableness standards for data access and use. Lastly, incentives (e.g., benefits or rewards) to share data should be outlined.³⁵

IMPROVE FEDERAL-STATE COLLABORATION

A 2020 report from the Duke Margolis Center for Health Policy recommends that federal-state collaboration be improved to realize the full potential of syndromic surveillance.²⁰ The report provided several specific implementation strategies, including recommending that protocols and permitted use specifications be updated and then articulated between public health officials, CDC, and other federal organizations in the data use agreement. Moreover, the report suggested that universal reporting by states and hospitals requires that the federal government should: (1) maintain engagement with state and local authorities, (2) provide guarantees that data will be used according to updated protocols, (3) exclude personally identifiable information from federal use, (4) provide real-time access to the data to state and local officials, and (5) provide federal support for data modernization and technical assistance. Finally, it is also suggested that CSTE and CDC should collaborate more with state epidemiologists and health officials about syndromic data on optimal practices in interpreting and using the information provided by syndromic surveillance.²⁰

B. WORKGROUP CALL 1

The purpose of the first Workgroup meeting was to gather information from STLT epidemiologists in leadership positions or with decision-making power on federal NSSP access policy revisions. The first meeting was intended to identify NSSP policy issues where a consensus currently exists, areas where there is an opportunity for future consensus or compromise, and group priorities.

The Consultant Team used a modified nominal group technique to solicit input and facilitate idea generation and prioritization. The nominal group technique method is one of the most used qualitative methods for group discussion making processes that have been shown to successfully help identify and clarify a problem. Three research questions were finalized for the nominal group technique Workgroup call: (1) In what ways can increased federal access to state syndromic surveillance data (at the state or local level) benefit or support state public health activities?; (2) What concerns you about increasing federal access to state syndromic surveillance data at the state or local level?; (3) What rules, restrictions, guidelines, or codes of conduct could be implemented in the NSSP DUA or CDC policies that might address a concern addressed by you or a fellow Workgroup member?

The Workgroup 1 call agenda was provided in advance and can be found in **Appendix B**. After some initial background information and the goals and purpose of the Workgroup, Workgroup members were given time to individually generate ideas on each question. Subsequently, members clarified, discussed, and grouped the ideas cluster into broader themes with assistance from the Consultant Team. After grouping ideas into broader themes, members were given the option to vote or prioritize the themes they believed were most important. Workgroup members scored and ranked each theme. Themes were scored via 5-point importance Likert scale, with 5 points for the highest importance score. For the ranking questions, an aggregate ranking score was calculated for each theme based on each Workgroup member’s rankings (3 points for their most important theme, 2 points for their second most important theme, and 1 point for their third most important theme).

The first Workgroup call had approximately 20 to 25 participants. Most participants were individuals who worked in STLT health departments, but other participants included individuals who worked for a national public health organization, such as the Association of State and Territorial Health Officials and CSTE. Three additional individuals who worked in state, tribal, local, or territorial health departments were permitted to provide feedback on the Workgroup’s findings after the call.

I. THEMES

The themes and representative quotes provided by Workgroup members during the first call can be found in Table 1. A full list of ideas for each theme can be found in **Appendix C**.

Table 1: Themes identified from Workgroup Call 1 participants and representative quotes

Question 1: In what ways can increased federal access to state syndromic surveillance data at the state or local level benefit or support state public health activities?
1.1 Technical assistance + expertise
<ul style="list-style-type: none"> - Even in states with dedicated staff there may not be appropriate resources to examine all potential issues on granular level - Support states without expertise in SyS with analysis/CDC can assist - Technical assistance in creating and standardizing syndromes for consistency across jurisdictions and support for less-resourced jurisdictions

1.2 -Enhanced federal surveillance capacity (e.g., providing national pictures, completing data request normally handled by states, increased cross-jurisdictional awareness)

- *“Easier to depict the national landscape of what’s happening and trends (especially geographically) - allocation of resources, early warning*
- *Timely identification of novel/emerging health issues that cross jurisdictional boundaries*
- *In states without the ability to monitor data routinely, NSSP might be able to point out issues for state follow up that would otherwise be missed.”*

1.3 -Improved cross-jurisdiction collaboration efforts

- *Collaborate on analysis and publications that impact more than one state, across jurisdictions, etc.*
- *Develop best practices and compare jurisdiction-jurisdiction collaboration/techniques*
- *Build powerful collaborations - tribal/local/state/federal that cross jurisdictional boundaries - border issues, tribal issues,*

1.4 - Enhanced state capacity

- *More ability to train and onboard new staff in lower resource states or others without dedicated staff*
- *During large emergencies there is a potential benefit to having additional eyes on data*

1.5 - Improved syndromic surveillance practice

- *Streamlining expectations from healthcare providers and the public and what info can be shared*
- *If the federal partner is using one system this allows for increased interoperability in a way since all data is flowing or being used and analyzed through that one platform vs. many at state/local levels and then can be shared back with the participating jurisdictions comprehensive visibility into the state of syndromic trends at the state or local level,*
- *More robust query and visualization options in NSSP ESSENCE based on the same level of access state/locals have.*

Question 2: What concerns you about increasing federal access to state syndromic surveillance data at the state or local level?

2.1 - Increasing the burden on jurisdictions

- *...High frequency of requests to states or locals to examine signals or other indicators of low importance or no value. (from a state perspective)*
- *CDC announcing something before state or locals know what is going to be made publicly available and being inundated with additional questions that you are not anticipating from the public.*
- *Situational awareness - double edge sword - too much info currently, can't stay on top of changing environment/situations*

2.2 - Misinterpretation of data

- *Inappropriate comparisons that are seemingly at a geographic level but in reality, are at a facility level because of data content, population characteristics, etc.*
- *CDC conducting analysis without understanding what caveats and limitations there are to the data and not talking to state/locals to be considered with analysis*

2.3 - Publishing the data can decrease jurisdictional credibility

- *Even beyond FOIA, CDC during COVID released large amounts of data to press, who ran analysis that then contradicted state analysis. Time spent clarifying the data and discrepancies. Costs time and credibility of state efforts. Pressure on states*

<p>to report publicly and accurately likely higher than pressure on CDC.</p> <ul style="list-style-type: none"> - CDC writing, publishing, presenting on state/local the pandemic, epidemic, event, outbreak, surveillance area of interest without approval, notification, or permission.
<p>2.4 - Inadequate, excessive, or inappropriate communication regarding data uses</p>
<p>-</p>
<p>2.5 - Negative effect on collaborations leading to presentations or publications</p>
<ul style="list-style-type: none"> - Publications of data or analysis using state, local, or facility-based data without state collaboration. - The emphasis on collaboration across CDC programs with the community dissolves for any use of the syndromic data.
<p>2.6 - Federal government independently sharing data or initiating public health action without notifying states</p>
<ul style="list-style-type: none"> - ... NSSP identifies issues and then passes it up the chain within CDC or HHS without early input from jurisdictions. - CDC contacting our hospitals/facilities and conducting an investigation without approval, notification, or permission. - Not knowing how CDC or any other federal partners that access to the data will use it
<p>2.7 - Privacy and confidentiality concerns, including data sensitivity, restriction of certain fields, and public perception of increased data sharing</p>
<ul style="list-style-type: none"> - ...Data details is extremely sensitive. That level without restrictions (individual users for short time period, limited fields accessed) would be a hard no. - How we account for sharing of rural locations and what protections are in place in terms of the analyses and display of that data or information - Risk of unlimited data mining
<p>2.8 - Freedom of Information Act (FOIA) Issues</p>
<ul style="list-style-type: none"> - Concern that data would have to be released due to FOIA - FOIA and info release w/o state, local, tribal knowledge/control
<p>2.9 - Adequacy of and adherence to data sharing rules (including agreements codes of conduct, etc.)</p>
<ul style="list-style-type: none"> - Concern that any DUA agreement that could be put into place with NSSP would not apply to the centers or program areas who are providing funding. - New CDC may not have full understanding on code of conduct (i.e., what they should and shouldn't post) - State vs Federal statute inconsistencies?
<p>Question 3: What rules, restrictions, guidelines, or codes of conduct could be implemented in the NSSP DUA or CDC policies that might address a concern addressed by you or a fellow Workgroup member?</p>
<p>3.1 - Restrict data access for specific purposes or events</p>
<ul style="list-style-type: none"> - Access to data should be at the specific individual user level, for defined time periods, for specific purposes. - Sharing should be for defined periods of time for specific users for specific purposes (Too open-ended)

3.2 - Establish audit and documentation process for data access and analysis

- Auditing and documentation of staff access and queries of state/local data.
- Audit trail of where, how, and to whom data was shared.
- Being clear on how the info is shared and notifying states receipts of disclosures; permission/collaborative discussion granted by the state prior to disclosures

3.3 - Restrict data access to specific users (as opposed to groups of users)

- Access to data should be at the specific individual user level, for defined time periods, for specific purposes.
- ... States need authority for removing state level data access based on a predefined set of criteria/issues- this would exist even after access was originally granted

3.4 - Make DUA applicable to all federal recipients of NSSP data

- DUA need to include specific provisions for data re-release (if any) and that includes to internal CDC staff outside of NSSP approved staff, other federal agencies, and contractors.
- ...DUA be for all of CDC and all data sources in the BioSense Platform.
- What are the limits of sharing data across federal agencies/programs/different administrations and who makes that determination

3.5 - Involving state and local partners in data analysis

- Right of first refusal by states/locals on analysis plans, protocols and publications- I am not sure exactly what I mean by this but more that states have the ability to say whether they want to complete a particular analysis or review of their own data rather than CDC just doing it and telling the state about it after- or something like that.
- Collaboration with Sites, NSSP, CDC, and the NSSP CoP, must be a part of the policy. Decisions on the data, system, access, use, cannot be done in a bubble.
- Being clear on how the info is shared and notifying states receipts of disclosures; permission/collaborative discussion granted by the state prior to disclosures

3.6- Require training on code of conduct

- ...HIPAA like training so that staff understand code of conduct
- In addition to the code of conduct which needs to be applied to all data sources in the platform, there needs to be training for specific sites. Not every Site is the same nor is its data contributing to the platform. Respecting and including those types of caveats. Limitations, considerations, need to be built into policy.

3.6 - Establish restrictions on data publication

- No publication of data below a national level without state/local participation offered (in the analytic stage specifically). If states prefer not to participate, they then need to at least sign off on the final publication. This should include national projects that use subsets of state data that then identify the facilities or states that subset came from.
- Different diseases and conditions have different policies surrounding use and publication. There is not necessarily a one size fits all definition. Something needs to be built into the larger DUA and policy to acknowledge this.
- No publishing of data publicly

3.8 - Create standards for removing access

- ... States need authority for removing state level data access based on a predefined set of criteria/issues- this would exist even after access was originally granted

3.9 - Create communication protocols between CDC and STLTs
<ul style="list-style-type: none"> - Perhaps some sort of decision matrix by state that includes things like geographies that are problematic, severe limitations on interpretations, etc. that CDC can refer to prior to reaching out to a state for examination of an issue - Defined communication protocols that include methods, timelines for reply, expectations of level of effort, etc. - In the event of a multi-state outbreak/event, how will CDC disclose info across different sites and considering the varying sites (decentralized vs centralized)
3.10 - Allow optional participation in greater federal access
<ul style="list-style-type: none"> - Formalize the process to request the data (opt in, not opt out) - ... Misuses of the data, where a local jurisdiction wants to opt out should be allowed. - Develop agreements with each jurisdiction to opt-in on varying levels; make it optional for jurisdictions to participate.
3.11 - Include procedure for DUA renewal
<ul style="list-style-type: none"> - There needs to be a renewal process for the DUAs. There are many changes that happen year to year, and some are huge shifts that need to be current in the DUAs used that align with current policies in place.
3.12 - Clarify breach responsibility
<ul style="list-style-type: none"> - Legal authorities to collect data, who is responsible in the event of a data breach

II. THEME PRIORITIZATION

QUESTION 1: BENEFITS

The Workgroup generated ideas that fit into five themes in response to the question: “In what ways can increased federal access to state syndromic surveillance data at the state or local level benefit or support state public health activities?” Scoring the Likert results, the most important benefit was improved cross-jurisdiction collaboration efforts (mean = 4.53), followed by improved syndromic surveillance practice (4.07); enhanced state capacity (3.73); technical assistance & expertise (3.53); and enhanced federal surveillance capacity (3.40) (Table 2).

Table 2: Frequency Distribution & Mean Calculation of Importance for Identified Benefits

Identified Benefit	Very Important (n)	Important (n)	Moderately Important (n)	Slightly Important (n)	Not Important (n)	Mean*
Improved cross-jurisdiction collaboration efforts	10	3	2	0	0	4.53

Improved syndromic surveillance practice	5	6	4	0	0	4.07
Enhanced state capacity	5	5	2	2	1	3.73
Technical assistance + expertise	3	6	3	2	1	3.53
Enhanced federal surveillance capacity (e.g. providing national pictures, completing data request normally handled by states, increased cross-jurisdictional awareness)	3	4	5	2	1	3.40

**In calculating the mean, Likert options were scored 1-5 with Very Important = 5, Important =4, Moderately Important = 3, Slightly Important = 2, Not Important = 1*

The results of the participants’ top-3 rankings show that participants’ top choice was improved cross-jurisdiction collaboration efforts with a total score of 27, followed by improved syndromic surveillance practice with a score of 23; technical assistance + expertise with a score of 17; enhanced state capacity with a score of 13; and enhance federal surveillance capacity with a score of 10 (Table 3).

Table 3: Frequency Distribution of Prioritization & Prioritization Score for Identified Benefit

Identified Benefits	Rank 1 (n)	Rank 2 (n)	Rank 3 (n)	Total Score
Improved cross-jurisdiction collaboration efforts	6	3	3	27
Improved syndromic surveillance practice	2	7	3	23
Technical assistance + expertise	4	2	1	17
Enhanced state capacity	2	1	5	13
Enhanced federal surveillance capacity (e.g., providing national pictures, completing data request normally handled by states, increased cross-jurisdictional awareness)	1	2	3	10

**In calculating the total score, items ranked 1,2, and 3 were assigned scores of 3, 2, and 1 respectively. The total score is the sum of all respondents’ ranking scores.*

Importantly, some participants were skeptical of the benefits relative to the perceived risks. For example, one participant stated, “potential benefits do not outweigh the risks.” Another participant felt that “[t]he benefits are very theoretical at this time and have huge downsides if not managed properly and with appropriate accountability at CDC for people who misuse the system.”

However, other participants saw opportunities in expanded federal access. For example, one participant stated, “I think federal access to the NSSP data will increase

awareness and better understanding of how to use the data, limitations and caveats, and furthermore collaboration for utilizing the tools in the BioSense Platform.”

QUESTION 2: CONCERNS

The Workgroup generated ideas that fit within nine themes in response to our second question: “What concerns you about increasing federal access to state syndromic surveillance data at the state or local level?” Of the nine themes, the concern with the highest Likert importance score was the federal government independently sharing data or initiating public health action without notifying states (mean = 4.60), followed closely by misinterpretation of data (4.53) and adequacy of and adherence to data sharing rules (4.53); privacy and confidentiality concerns (4.47); and Freedom of Information Act (FOIA) issues (4.40) (Table 4).

Table 4: Frequency Distribution & Mean Calculation of Importance for Identified Concerns

Identified Concern	Very Important (n)	Important (n)	Moderately Important (n)	Slightly Important (n)	Not Important (n)	Mean*
Federal government independently sharing data or initiating public health action without notifying states	12	2	0	0	1	4.60
Misinterpretation of data	11	2	1	1	0	4.53
Adequacy of and adherence to data sharing rules (including agreements, codes of conduct, etc)	9	5	1	0	0	4.53
Privacy and confidentiality concerns, including data sensitivity, restriction of certain fields, and public perception of increased data sharing	10	2	3	0	0	4.47
Freedom of Information Act (FOIA) issues	9	5	0	0	1	4.40
Inadequate, excessive, or inappropriate communication regarding data uses	9	3	2	1	0	4.33
Increasing the burden on jurisdictions	1	7	5	2	0	3.47

Negative effect on collaborations leading to presentations or publications	6	1	3	2	3	3.33
Publishing the data can decrease jurisdictional credibility	5	4	0	2	4	3.27

**In calculating the mean, Likert options were scored 1-5 with Very Important = 5, Important = 4, Moderately Important = 3, Slightly Important = 2, Not Important = 1*

When asked to prioritize their top concerns, the participants' top five concerns were the federal government independently sharing data or initiating public health action without notifying states, followed by misinterpretation of data, privacy and confidentiality concerns, Freedom of Information Act (FOIA) issues, and adequacy of and adherence to data sharing rules (Table 5).

Table 5: Frequency Distribution of Prioritization & Prioritization Score for Identified Concerns

Identified Concerns	Rank 1 (n)	Rank 2 (n)	Rank 3 (n)	Total Score
Federal government independently sharing data or initiating public health action without notifying states	5	4	1	24
Misinterpretation of data	5	3	0	21
Privacy and confidentiality concerns, including data sensitivity, restriction of certain fields, and public perception of increased data sharing	4	1	1	15
Freedom of Information Act (FOIA) issues	0	4	2	10
Adequacy of and adherence to data sharing rules (including agreements, codes of conduct, etc.)	0	1	5	7
Inadequate, excessive or inappropriate communication regarding data uses	1	0	2	5
Publishing the data can decrease jurisdictional credibility	0	1	2	4
Increasing burden on jurisdictions	0	0	2	2
Negative effect on collaborations leading to presentations or publications	0	1	0	2

**In calculating the total score, items ranked 1, 2, and 3 were assigned scores of 3, 2, and 1 respectively. The total score is the sum of all respondents' ranking scores.*

Acknowledging these important concerns around expanded access, one participant stated, “[f]or all users to have access to the data there are concerns, however, there needs to be a way to balance the benefits and concerns for every type of user that has access to NSSP data in the BioSense Platform.”

QUESTION 3: POLICY SOLUTIONS

The third question asked, “What rules, restrictions, guidelines, or codes of conduct could be implemented in the Nssp DUA or CDC policies that might address a concern addressed by you or a fellow Workgroup member?” In response, the Workgroup generated ideas that fit into twelve identified rules, restrictions, guidelines, or codes of conduct. The themes with Likert scores indicating the highest importance were: involving state and local partners in data analysis (mean=4.93), making the DUA applicable to all federal recipients of Nssp data (4.53), creating communication protocols between CDC and STLTs (4.53), establishing audit and documentation process for data access and analysis (4.33), and establishing restrictions on data publication (4.13) (Error! Reference source not found.).

Table 6: Frequency Distribution & Mean Calculation of Importance for Identified Rules, Restrictions, Guidelines, or Code of Conduct

Identified Rule, Restriction, Guideline or Code of Conduct	Very Important (n)	Important (n)	Moderately Important (n)	Slightly Important (n)	Not Important (n)	Mean*
Involving state and local partners in data analysis	14	1	0	0	0	4.93
Make DUA applicable to all federal recipients of Nssp data	12	0	2	1	0	4.53
Create communication protocols between CDC and STLTs	9	5	1	0	0	4.53
Establish audit and documentation process for data access and analysis	7	6	2	0	0	4.33
Establish restrictions on data publication	7	5	2	0	1	4.13
Include procedure for DUA renewal	6	6	1	2	0	4.07
Clarify breach responsibility	6	6	1	2	0	4.07
Create standards for removing access	3	10	2	0	0	4.07
Allow optional participation in greater federal access	5	7	1	2	0	4.00
Restrict data access for specific purposes or events	6	3	3	2	1	3.73
Require training on code of conduct	3	5	6	1	0	3.67

Restrict data access to specific users (as opposed to groups of users)	6	1	4	3	1	3.53
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**In calculating the mean, Likert options were scored 1-5 with Very Important = 5, Important = 4, Moderately Important = 3, Slightly Important = 2, Not Important = 1*

When asked to further prioritize the top-3 policy themes, participants' top choices were involving state and local partners in data analysis (rank score of 22), followed by create communication protocols between CDC and STLTs (17). These top-two were distantly followed by restricting data access for specific purposes or events (8), making DUA applicable to all federal recipients of NSSP data (8), establishing audit and documentation process for data access and analysis (7), and creating standards for removing access (7) (Table 7).

Table 7: Frequency Distribution of Prioritization & Prioritization Score for Identified Rules, Restrictions, Guidelines, or Codes

Identified Rule, Restrictions, Guidelines or Codes	Rank 1 (n)	Rank 2 (n)	Rank 3 (n)	Total Score
Involving state and local partners in data analysis	4	4	2	22
Create communication protocols between CDC and STLTs	4	2	1	17
Restrict data access for specific purposes or events	1	2	1	8
Make DUA applicable to all federal recipients of NSSP data	1	1	3	8
Establish audit and documentation process for data access and analysis	0	3	1	7
Create standards for removing access	2	0	1	7
Restrict data access to specific users (as opposed to groups of users)	1	1	1	6
Allow optional participation in greater federal access	1	1	0	5
Establish restrictions on data publication	1	1	0	5
Include procedure for DUA renewal	0	0	2	2
Require training on code of conduct	0	0	2	2
Clarify breach responsibility	0	0	1	1

**In calculating the total score, items ranked 1, 2, and 3 were assigned scores of 3, 2, and 1 respectively. The total score is the sum of all respondents' ranking scores.*

Several participants provided specific details they would like to see with user access. For example, one participant said:

"I would be amenable to having a small/core group of analysts who are named and whose role/purpose is clearly delineated that have constant

access to our detailed data. Other federal staff who would like access to detailed state data should require approval from sites after their purpose is clearly defined to improve collaboration with sites (similar to ED-SNSRO, FASTER, OD2A). I'm not in favor of NSSP granting other federal staff access to additional data for projects that come along without some sort of agreement or notification to sites."

Another participant recommended that "the federal request for access be specific in terms of geographic level of access, and purposes. If the request is unlimited access to all data for any topic or purpose, it will be harder to support/approve. This is especially true for line level requests or county-level access." On the other hand, a participant stated, "[t]here has to be a process for removing access for specific users, groups of users, and overall removal of state data from the sharing process. Without that ability, there are no teeth to the required codes of conduct, DUAs, etc."

Some participants highlighted specific issues with the DUA. For example, one participant stated:

"One DUA with only on[e] program or center like NSSP does not cover all other users. Giving direct access to data as a direct requirement of grant funding without coverage in larger DUA also does not cover all concerns because of the piecemeal approach to DUAs and access to the data. The more that can be covered under a larger agreement, reinforced by the code of conduct, protocols for maintaining access to the data, training for use of the data at multiple levels of users, the fewer the concerns can become."

Moreover, a few other policies were suggested by participants. One participant stated, "[i]t is important that any rules/policies/guidelines are emergency proof, so they don't just get thrown out the window in the event of an emergency." They would also like to see "some sort of policy that invites review/comment of analyses that uses a site's data prior to their release/submission and also some basic publication standards (e.g., suppression of small numbers)." Lastly, a participant recommended, "there needs to be a way to have some standardization across jurisdictions for direct access to the data and how it's used."

C. WORKGROUP CALL 2

The purpose of the second Workgroup meeting was to gather more information from STLT epidemiologists in leadership positions or with decision-making power on issues identified in the first call. Members of the Workgroup were asked to identify potential operational frameworks and other critical issues concerning three policy questions: (1) communication protocols between federal and STLT agencies, (2) framework for STLT and federal collaboration, and (3) identification of issues and questions for different federal use cases.

Thirty six state and local epidemiologists were invited to participate in the second workgroup. The Workgroup Call 2 agenda was provided in advance and can be found in **Appendix D**. The Workgroup reviewed the goals and purpose of the Workgroup and were provided the preliminary findings from the first Workgroup call. Then, Workgroup members were given time to develop ideas and questions regarding each policy question mentioned above. Workgroup member feedback was recorded on an online collaborative document that permitted all participants to simultaneously contribute comments, concerns, and suggestions. The discussion was intended to inform the consultants on potential operational frameworks concerning communication, collaboration, and governance.

Following the second Workgroup call, the Consultant Team analyzed the ideas discussed during the call and recorded them on the online collaborative document. Then the Consultant Team created an online assessment to evaluate and solicit feedback on specific policy options generated based on the feedback from the second Workgroup call. Following the second Workgroup call, the Consultant Team analyzed the provided ideas and identified different policy options related to Workgroup feedback. Questions in this assessment were mostly either 5-point Likert questions on level of agreement or open-ended response formats. Nine individuals on the list of NSSP site administrators who work in a STLT health department were randomly selected to participate in the online assessment. Participants were asked to confirm their participation within one day. Three of the original nine invitees declined to participate, so three additional participants were randomly selected. Eight participants completed the assessment within the deadline.

I. THOUGHTS ON COMMUNICATION PROTOCOL OPTIONS

Several assessment questions related to possible communication protocols between federal and STLT agencies. Based on the discussion in the Workgroup, the Consultant Team identified six communication protocol options. Of those six, the top-three were “all federal communications regarding syndromic surveillance data should be directed only to STLT syndromic surveillance contacts” (mean=4.00), “no federal partner should contact participating facilities directly regarding syndromic surveillance findings or activities” (4.00), and “I would be in favor of a classification system for federal NSSP communication to STLT syndromic surveillance contacts that indicates the expected response from STLT partners. For example, STLT contacts are not expected to respond to low-priority communications (i.e., for your information only), but a response is expected for high-priority communications” (3.75). (See Table 8).

Table 8: Frequency Distribution & Mean Calculation of Proposals on Communication

Proposals on communication	Strongly Agree (n)	Agree (n)	Neither Agree nor Disagree (n)	Disagree (n)	Strongly Disagree (n)	Mean*
All federal communications regarding syndromic surveillance data should be directed only to STLT syndromic surveillance contacts.	3	3	1	1	0	4.00
No federal partners should contact participating facilities directly regarding syndromic surveillance findings or activities.	3	3	1	1	0	4.00
I would be in favor of a classification system for federal NSSP communications to STLT syndromic surveillance contacts that indicates the expected response from STLT partners. For example, STLT contacts are not expected to respond to low-priority communications (i.e., for your information only), but a response is expected for high-priority communications.	2	4	0	2	0	3.75
All communications about the use of NSSP data by federal partners should only occur on a designated platform so that all communications can be easily located and monitored.	0	6	1	1	0	3.63

A communication portal should be implemented in the NSSP BioSense Dashboard.	0	7	0	0	1	3.63
If a communication portal is added to the NSSP BioSense Dashboard, users should have the ability to flag communications with different levels of importance.	0	4	4	0	0	3.50

**In calculating the mean, Likert options were scored 1-5 with Strongly Agree = 5, Agree = 4, Neither agree nor disagree = 3, Disagree = 2, Strongly Disagree = 1*

Participants were then asked if they had any suggestions about what the communication platform should be. One participant commented:

“Putting all communication onto a central location would be helpful, but communication shouldn't only be through access to a single location that users would have to seek out. Slack is a useful central tool, but emails should also be pushed out.”

An example of a tiered approach to communication was provided to participants to assess their opinion on this type of approach to communications (See image below). Participants generally agreed with the overall concept, but also provided additional details for consideration. For example, one participant noted that “no objections to the proposed tiers. Would be nice if the communication portal (login required) could tell you which communications were awaiting acknowledgment or receipt for your jurisdiction and kept track of your past responses.”

Tier	Public Health Threat	Expected Response from States
Tier 1	Low; or Moderate but only affecting targeted jurisdiction	None
Tier 2	Moderate but inter-jurisdictional in nature; or High but only affecting targeted jurisdiction	Acknowledge receipt
Tier 3	High and inter-jurisdictional in nature	Response is expected

However, one participant expressed that “regardless of the public health threat assessed by NSSP, [the state] wants to respond and approve of any use of data identified as [the state’s] data.”

II. THOUGHTS ON A COLLABORATION FRAMEWORK

The second question within the Workgroup concerned frameworks for STLT and federal collaboration. From the discussion by the participants, the Consultant Team identified three issues, including proposals regarding access requests, routine surveillance activities, and publication of state-level NSSP data. For proposals on access requests, the top-three were that requests for granular access by federal partners should include a clear description of **the group** (mean = 4.63), **the purpose** (4.63), **the timeframe** of the granular access (4.50). Moreover, participants indicated agreement that requests for granular access by federal partners should also state **the jurisdictions** whose data will be accessed (4.50). (See Table 9).

Table 9: Frequency Distribution & Mean Calculation of Proposals on Access Requests

Proposals on access requests	Strongly Agree (n)	Agree (n)	Neither Agree nor Disagree (n)	Disagree (n)	Strongly Disagree (n)	Mean*
Requests for granular access by federal partners should include a clear description of the group requesting access.	5	3	0	0	0	4.63
Requests for granular access by federal partners should include a clear description of the purpose of the granular access.	5	3	0	0	0	4.63
Requests for granular access by federal partners should include a clear description of the timeframe of the expanded access (i.e., the start and end dates of the data being queried).	4	4	0	0	0	4.50
Requests for granular access by federal partners should state the jurisdictions whose data will be accessed .	4	4	0	0	0	4.50
Requests for granular access by federal partners should state the stratification or level of granularity requested (e.g., state, county, facility, line).	4	3	0	1	0	4.25
Requests for granular access by federal partners should include an estimated timeline for data analysis .	3	3	1	1	0	4
Requests for granular access by federal partners should include	2	4	1	1	0	3.88

an estimated timeline for publication (e.g., submission to venue) or dissemination of findings.						
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**In calculating the mean, Likert options were scored 1-5 with Strongly Agree = 5, Agree = 4, Neither agree nor disagree = 3, Disagree = 2, Strongly Disagree = 1*

Some participants provided more specific details regarding access requests. For example, one participant said:

“Due to security restrictions in some jurisdictions regarding sharing data, acceptance is more likely if using de-identified data field, etc. Typically, lower granularity (town level, etc.) is suspect due to low numbers (Protected Health Information risk) and the possibility of constructive identification.”

In addition, another participant stated:

“We would like it to be routine practice to conduct a meeting between the state syndromic contacts and the federal partner requesting access to explain the project. Any state level or lower data request needs to be approved by [the state] before our data is used.”

For proposals on routine surveillance activities, the top-three were “it would be helpful if CDC NSSP staff coordinated closely with my site to routinely provide an extra set of eyes on our data and provide either reports or informal communications about what they find in the data (expectations of type and frequency of communications can be agreed upon ahead of time)” (mean=3.88), “it would be helpful if CDC NSSP staff could generate **regular visualizations** based on agreed-upon queries of my state’s NSSP data for me” (3.88), and “it would be helpful if CDC NSSP staff could generate **regular reports** based on agreed-upon queries of my state’s NSSP data for me” (3.75). In addition, participants seem to indicate that most agree with core CDC NSSP staff assisting in routine surveillance activities as a set of “extra set of eyes” on state-level data (mean=3.63); however, participants show more disagreement with these activities using county-level data (3.50), facility-level data (3.13), and line-level data (2.75). (See Table 10).

Table 10: Frequency Distribution & Mean Calculation of Proposals on Routine Surveillance Activities

Proposals on Routine Surveillance Activities	Strongly Agree (n)	Agree (n)	Neither Agree nor Disagree (n)	Disagree (n)	Strongly Disagree (n)	Mean*
It would be helpful if CDC NSSP staff coordinated closely with my site to routinely provide an extra set of eyes on our data and provide either reports or informal communications about what they find in the data (expectations of type and frequency of communications can be agreed upon ahead of time).	0	7	1	0	0	3.88
It would be helpful if CDC NSSP staff could generate regular visualizations based on agreed-upon queries of my state's NSSP data for me.	0	7	1	0	0	3.88
It would be helpful if CDC NSSP staff could generate regular reports based on agreed-upon queries of my state's NSSP data for me.	0	6	2	0	0	3.75
Assuming valid methods are used and a public health justification exists, I am fine with core CDC NSSP staff assisting our routine surveillance activities as an "extra set of eye" with state-level data subject to reasonable restrictions (e.g., dissemination).	0	6	1	1	0	3.63
Assuming valid methods are used and a public health justification exists, I am fine with core CDC NSSP staff assisting our routine surveillance activities as an "extra set of eye" with county-level data subject to reasonable restrictions (e.g., dissemination).	0	5	2	1	0	3.50

Assuming valid methods are used and a public health justification exists, I am fine with core CDC NSSP staff assisting our routine surveillance activities as an “extra set of eye” with facility-level data subject to reasonable restrictions (e.g., dissemination).	0	4	2	1	1	3.13
Assuming valid methods are used and a public health justification exists, I am fine with core CDC NSSP staff assisting our routine surveillance activities as an “extra set of eye” with line-level data subject to reasonable restrictions (e.g., dissemination).	0	3	2	1	2	2.75

**In calculating the mean, Likert options were scored 1-5 with Strongly Agree = 5, Agree = 4, Neither agree nor disagree = 3, Disagree = 2, Strongly Disagree = 1*

Participants were then asked if they had any additional thoughts about core NSSP staff conducting routine surveillance activities with state NSSP data. One participant responded that “I think activities should be clearly outlined and discussed prior to activities that might require a response or lead to a report/visualization or other use. Notification should be a minimum requirement.” Another said, “greater collaboration between NSSP Contractors and the NSSP Site administrators is welcomed but just want to limit by project (with a specific time frame, and limit PHI security concerns).”

For proposals on federal publications of state-level NSSP data, the proposals with the highest level of agreement among the participants were “assuming valid methods are used, I am fine with the federal government publishing state-level NSSP data **so long as all included jurisdictions provide express consent to have their data included in the analysis**” (mean=4.38). This was followed by “assuming valid methods are used, I am fine with the federal government publishing state-level NSSP data **so long as there is adequate and appropriate opportunity for a state to request that their data is removed from the analysis**” (3.88). (See Table 11).

Table 11: Frequency Distribution & Mean Calculation of Proposals on Federal Publications of State-Level NSSP data

Proposals on Federal Publications of State-Level Nssp Data	Strongly Agree (n)	Agree (n)	Neither Agree nor Disagree (n)	Disagree (n)	Strongly Disagree (n)	Mean*
Assuming valid methods are used, I am fine with the federal government publishing state-level Nssp data so long as all included jurisdictions provide express consent to have their data included in the analysis.	3	5	0	0	0	4.38
Assuming valid methods are used, I am fine with the federal government publishing state-level Nssp data so long as there is adequate and appropriate opportunity for a state to request that their data is removed from the analysis.	2	5	1	0	0	3.88
Assuming valid methods are used, I am fine with the federal government publishing state-level Nssp data with adequate and appropriate notice.	1	3	2	1	1	3.25

*In calculating the mean, Likert options were scored 1-5 with Strongly Agree = 5, Agree = 4, Neither agree nor disagree = 3, Disagree = 2, Strongly Disagree = 1

Overall, assessment participants were asked whether they were more concerned with routine federal use of state Nssp data for research or surveillance. More participants indicated they were either substantially or slightly more concerned with routine research uses of state Nssp data than routine surveillance uses. However, two participants were neutral on the issue. (See Table 12).

Table 12: Frequency Distribution & Mean Calculation of Concern with Federal Use of State-Level Nssp data for Research or Surveillance

Which routine federal use of state Nssp data are you most concerned with: research or surveillance?	Frequency
I am substantially more concerned with routine research uses of state Nssp data (1)	2
I am slightly more concerned with routine research uses of state Nssp data (2)	2
Neutral (3)	2
I am slightly more concerned with routine surveillance uses of state Nssp data (4)	0
I am substantially more concerned with routine surveillance uses of state Nssp data (5)	2
Mean	2.75

III. THOUGHTS ON NSSP GOVERNANCE

Several participant comments during the second Workgroup call related to a possible governance structure for NSSP. These Workgroup comments were closely related to input from key informants (discussed below). Consequently, the Consultant Team added a number of questions to the online assessment that solicited thoughts on issues of governance within increased federal access to NSSP data. These questions included questions on general governance, the role of a governance group, and accountability and trust.

Regarding general governance, the questions with the highest mean Likert scores were “an NSSP governance group would be beneficial to state-federal collaborations” (mean=4.00), “a governance group would be useful to ‘flag’ or alert states when a proposed federal use of NSSP data might require increased state attention or scrutiny” (3.88), and “to reduce the transaction burden of negotiating with all jurisdictions independently, an NSSP governance group should be **empowered to restrict routine federal access** to NSSP data subject to reasonable limitations, including maintaining a right for jurisdictions to opt-out of governance board decisions” (3.88). (See Table 13).

Table 13: Frequency Distribution & Mean Calculation of Proposals on Governance

Proposals on Governance	Strongly Agree (n)	Agree (n)	Neither Agree nor Disagree (n)	Disagree (n)	Strongly Disagree (n)	Mean*
An NSSP governance group would be beneficial to state-federal collaborations	1	6	1	0	0	4.00
A governance group would be useful to “flag” or alert states when a proposed federal use of NSSP data might require increased state attention or scrutiny	0	7	1	0	0	3.88
To reduce the transaction burden of negotiating with all jurisdictions independently, an NSSP governance group should be empowered to restrict routine federal access to NSSP data subject to reasonable limitations, including maintaining a right for	1	5	2	0	0	3.88

jurisdictions to opt-out of governance board decisions.						
An NSSP governance group would be useful to provide pre-decisional input on federal uses of NSSP data (e.g., review of NSSP reports to the CDC director)	0	6	2	0	0	3.75
To reduce the transaction burden of negotiating with all jurisdictions independently, an NSSP governance group should be empowered to recommend expanded or restricted routine federal access to NSSP data subject to reasonable limitations, including maintaining a right for jurisdictions to opt-out of governance board decisions.	0	5	1	0	1	3.50
An NSSP governance group should be comprised of elected CSTE members	0	3	2	3	0	3.00
To reduce the transaction burden on negotiating with all jurisdictions independently, an NSSP governance group should be empowered to expand routine federal access to NSSP data subject to reasonable limitations, including maintaining a right for jurisdictions to opt-out of governance board decisions.	0	2	2	3	1	2.63

**In calculating the mean, Likert options were scored 1-5 with Strongly Agree = 5, Agree = 4, Neither agree nor disagree = 3, Disagree = 2, Strongly Disagree = 1*

Participants were also asked to rank the most important role (1=most important) a future governance group should have. The three highest-ranked roles were “providing pre-decisional input on federal uses of NSSP data (e.g., review of NSSP reports to the CDC director)” (ranked score=28), “‘flagging’ or alerting states when a proposed federal use of NSSP data might require increased state attention or scrutiny” (27), and “expanding routine federal access to NSSP data subject to reasonable limitations, including maintaining a right for jurisdictions to opt-out of governance board decisions” (24). (See Table 14).

Table 14: Frequency Distribution of Prioritization & Prioritization Score for Primary Role of the Governance Group

Primary Role of the Governance Group	Rank 1	Rank 2	Rank 3	Rank 4	Rank 5	Total Score
Providing pre-decisional input on federal uses of NSSP data (e.g., review of NSSP reports to the CDC director)	3	3	0	0	1	28
“Flagging” or alerting states when a proposed federal use of NSSP data might require increased state attention or scrutiny	2	2	3	0	0	27
Expanding routine federal access to NSSP data subject to reasonable limitations, including maintaining a right for jurisdictions to opt-out of governance board decisions.	4	1	0	0	0	24
Restricting routine federal access to NSSP data subject to reasonable limitations, including maintaining a right for jurisdictions to opt-out of governance board decisions.	2	0	2	2	0	20
Recommending expanded or restricted routine federal access to NSSP data subject to reasonable limitations, including maintaining a right for jurisdictions to opt-out of governance board decisions.	0	2	2	2	0	18

**In calculating the total score, items ranked 1, 2, 3, 4, and 5 were assigned scores of 5, 4, 3, 2, and 1 respectively. The total score is the sum of all respondents’ ranking scores.*

There were five questions on processes that could promote accountability and trust. There was general support for implementing an audit process for “federal access to state NSSP data” (mean=4.13). Participants provided stronger support for sharing audit findings with states. (mean=4.50). (See Table 15).

Table 15: Frequency Distribution & Mean Calculation of Proposals on Accountability and Trust

Proposals on Accountability and Trust	Strongly Agree (n)	Agree (n)	Neither Agree nor Disagree (n)	Disagree (n)	Strongly Disagree (n)	Mean*
States should be provided access to audit findings related to their NSSP data.	4	4	0	0	0	4.50
An audit process should be implemented for federal access to state NSSP data.	2	5	1	0	0	4.13

**In calculating the mean, Likert options were scored 1-5 with Strongly Agree = 5, Agree = 4, Neither agree nor disagree = 3, Disagree = 2, Strongly Disagree = 1*

Participants were also asked what information should be recorded in an audit. Participants generally suggested who accessed the data and what data they accessed. Some participants were more specific, for example, one participant suggested “name of individual with access, CDC program affiliation, name of account who granted access, date access granted, date access removed” and another participant recommended “how often it was accessed, if there are specific areas that were accessed more often than others, if data was downloaded vs viewed.”

Participants were also asked about what processes or policies could be implemented to reinforce trust between state and federal partners regarding federal access to state NSSP data. Several participants mentioned processes related to transparency. For example, one participant said, “more transparency about where the requests are originating and the ultimate purpose of the research/goal for dissemination.” An audit or annual review was also mentioned by more than one participant. One participant suggested an “annual review of federal data access and use policies with ongoing opportunity for states to submit feedback, concerns, implementation strategies via the NSSP governance group. Always have an “opt-out” or “opt-in” policy.” Lastly, issues regarding the DUAs were raised. Specifically, a participant said:

“a standard Data Use Agreement with things that we support federal doing. Right now, it all seems to be project based and not overarching, but it would be great if it was a single standard for access that a state could agree to or opt out of.”

Participants were then asked about what processes or policies could be implemented to improve accountability regarding federal access to and use of state NSSP data. One participant recommended that federal workers get “acknowledgment from the state before publishing any data.” Continuing, the informant said,

“There have been times when we've gotten inquiries about data we didn't know was being made public, and so we were not ready to respond to those questions because we didn't know the context of how the data was presented (or have an opportunity to provide input).”

Another participant stated:

“Visibility to state about what federal users/groups have access to their data. Ability to set limit for how long a federal partner can have access to state's data before state is presenting will “renewal request” for continued data access. Routine audit process with results shared with states will also ensure there is accountability.”

D. FINDINGS FROM KEY INFORMANT INTERVIEWS

In addition to findings from the NSSP Workgroup, additional information was collected from eight key informants to further develop considerations and implementation strategies regarding revisions to permitted federal NSSP data access. The key informants were selected by CSTE based on their prominent roles within the public health informatics and surveillance community and their expertise and extensive experience with syndromic surveillance, and included STLT, federal, and national public health perspectives. These informants were invited to participate in a semi-structured interview (approximately 1 hour) on federal access to NSSP data. They were encouraged to talk openly about the things they believed were most important. An interview guide was developed in collaboration with CSTE and CDC project partners. See **Appendix F** for the semi-structured interview guide. It contained open-ended questions, and as needed, the interviewer used probing questions to solicit specific information.

After interviews were completed and transcribed, the Consultant Team conducted a deductive and inductive thematic analysis using NVivo. The deductive thematic analysis involves creating a list of pre-identified themes before commencing the in-depth analysis of the interviews.⁷² In this case, the initial themes were primarily based on the clusters identified from the three questions raised in the first Workgroup Call 1 discussed above. The inductive thematic analysis involved identifying themes that arose from the informants’ open-ended responses.⁷³ Each Consultant Team member began by independently reviewing one interview to identify an initial list of themes which were then discussed in a meeting with the entire Consultant Team to refine and standardize the thematic categories identified for this report. This refined list of themes was used for further inductive analysis of all informant interviews. At least two members of the Consultant Team independently coded each interview.

The Consultant Team identified several themes from these key informant interviews. The most significant themes were:

- 1) Collaboration and Relationships
- 2) Communication
- 3) Data Stewardship and Ownership
- 4) Data Limitations and Pitfalls
- 5) Access Restrictions and Controls
- 6) Existing Policy Challenges
- 7) Relationships with Healthcare Facilities
- 8) Syndromic Surveillance Capabilities and Applications
- 9) Public Perceptions
- 10) Sustainability

While the interviews revealed different and diverse perspectives, there were significant and substantial areas of agreement. For example, all informants stressed the need for increased STLT collaboration in federal analyses, clear communication protocols, and access restrictions for syndromic surveillance data. However, there were some important areas of divergence, including syndromic data stewardship, ownership, and the perceived weight of anticipated benefits and risks associated with increased federal access to STLT syndromic data. Notably, there were numerous areas and issues where federal and non-federal informants shared similar concerns, these included access restrictions, syndromic data limitations, and unannounced publication of syndromic findings. Conversely, there were also issues where informants in similar roles shared different positions. Representative quotes from the informants in each theme are highlighted below.

I. COLLABORATION AND RELATIONSHIPS

Informants saw increased federal access creating both opportunities and obstacles to federal and STLT collaborations and relationships.

Informants with both national and STLT roles suggested that increased federal access could provide a number of benefits, including backup review, visualization of the data, technical assistance, standardized syndrome definitions, surveillance support, and increased awareness of interjurisdictional public health issues. One informant in a

federal role suggested that “it would be beneficial for us to sort of serve the States as an extra set of eyes and collaborate with them for surveillance purposes.” Another federal informant suggested that one of the fundamental values to improved federal access to NSSP data is to leverage federal “time and resources and focus” to improve collaborative public health practice, saying:

“One of the things that we're able to do from a federal perspective is concentrate more resources on this activity than typical state or local jurisdiction who are tend to be pulled in many directions for many activities. And so [it allows us to] be able to represent best practices with the data. It's one thing for us to do data quality and speculate, but if we can ... actually conduct the surveillance and that helps us learn and be skilled and effective so that we can also share that knowledge with our partners. And I think that's an important piece that was kind of missing... it will bring us so much further and towards in advancing the analytic components of the system and really being in a support role to the jurisdiction as they respond to the data. And I think that's an important piece of it. And also, the -- being at the federal level gives us a cross jurisdictional focus that is unique and different, but unfortunately the nuance of that are often, it's challenging.”

Several STLT informants expressed openness to this type of assistance. One informant noted their inability to identify interjurisdictional trends, saying increased federal access could “help identify trends that may be, exist between states and not just a state or local level.” Continuing, the informant said:

“One thing that, you know, I know I do is look at trends for [my state], and [facilities within my state]. And so, if there's [an issue] that maybe crosses a border, I may not be as likely to see it, because I'm mostly looking at data from my state.”

Similarly, another STLT informant agreed, and added that jurisdictional comparisons are useful, and that increased federal access could improve STLT surveillance capacity, saying:

"[W]e use the public health preparedness grant to fund local jurisdictions to do syndromic surveillance. Their funding is pretty limited, and they do not have a lot of time to look at their data. There's no reports that are accessible to the public, so especially looking at a more local level, it's helpful, and especially if the public or certain stakeholders can access that data, I think that will be useful."

One common significant concern was the potential for increased burden on jurisdictions. Multiple informants expressed concern that increased federal access to NSSP data would mean more federal communications directed at STLT health departments that would burden thin public health workforces. This concern was pronounced where there was an expectation that STLT contacts would respond to federal communications. A key informant stated:

"[M]y worst-case scenario is that we get so many questions it just overwhelms our investigative staff. I will say in the past, we have sometimes received . . . communications from CDC that kind of say, hey, we see something in your data, we see four cases of carbon monoxide poisoning, maybe you should look into this and I don't know if we found a lot of value in that in the past, but I mean it could for example mean a lot more work, chasing down things that they see in our data."

However, one STLT informant reported a lessening of burdens with greater federal data sharing, saying:

"[Some] CDC projects . . . have direct access to the [state] data in the ESSENCE platform and I think that's been a great feature. It's simplified some of the data flows. In lieu of us you know sending datasets they can just pull the data themselves and then we verify the data that they've pulled. And so . . . in [our state] there's already federal access to the data in NSSP. As far as like what it would mean for states who aren't doing that, I mean, I think from our perspective it's eased some of the data sharing burdens."

Similarly, one non-federal informant with a national perspective described potential benefits, saying:

“Increased federal access could alleviate some burden on states too . . . A lot of states are very thinly staffed, and so it could actually help. [For example], if I can't look at these 20 things every day, there could be a data analytics and review model that would say, I want to sign up for the feds to notify me when they see something and I . . . want to have them as my backup”.

Several informants identified publications as a collaboration and relationship challenge. State-level informants expressed concerns about data being used and published without their input or knowledge. One state informant noted the lack of reciprocity in some federal publications saying:

“There have been several publications that have used the data on a national scale and junior states STLTs have not been involved in that work at all so there's clearly things that are being done without involvement of the people who are providing the data.”

However, some informants had different perspectives. For example, one informant said, “at the federal level, every time NSSP is moving forward with making data more available, they are -- they have been transparent.”

Some informants echoed a concern that CDC could publish a report that identifies particular states as contributors, but the state's themselves were not aware of their data being used.

Importantly, publication concerns were shared by informants in federal roles. One federal informant stated:

“I share the same concerns that our jurisdictional partners share as well. And that is, the worst thing to have happen is that we see something in the data, and we act unilaterally, or we act without the appropriate level of awareness on the part of our state and local partners, and we catch them by surprise. I think that's fundamentally, the thing that most are concerned about is to not be in the loop and [to] be unaware of activities...”

Notably, some informants suggested that there are benefits to STLT analytic involvement prior to federal publication. For example, one informant said:

"I think would be that state and local site administrators should be consulted before CDC distributes or publishes state or local level data analysis. There's the opportunity to provide details of methodology and how the data would be presented."

Another informant, shared a similar sentiment but argued that the collaboration should be supported by federal funds:

"I think if you're again if the unit of analysis is state or lower and you should involve those states in that analysis if you're planning to release information at that level and that work with the states and local shouldn't be unfunded work, so I don't know if that requires a cooperative agreement or some sort of you know overarching agreement that covers state and local time to provide feedback on those analyses."

Some key informant responses suggest that collaboration challenges may be associated with trust challenges as well. For example, CDC and STLT jurisdictions current positions seem to create an unintentional impasse, because per one informant, CDC "[is] reluctant to exercise reporting data at an HHS region level without really understanding what's going on in the states and at more detail." Meanwhile the STLT informants indicated a reluctance to share data without understanding how CDC plans to use and distribute it.

II. COMMUNICATION

Key informants unanimously supported the adoption of communication protocols between STLT and federal partners, with some calling them "necessary," "essential," or "valuable to reduce kind of the frustration and confusion."

In addition, many informant comments contain themes relating to communication. For some informants, communication issues have been a source of frustration. For example, one informant said, "obviously we've spent literally years asking for appropriate communications and they're not there"

Several communications suggestions stood out. For example, as noted above certain states fear that communication could increase the burden on jurisdictions, and several informants suggested a tiered communication approach to combat this. One informant described such an approach as:

"I think it would be useful to have some type of decision tree algorithm, as part of the policy. So, if we saw something at this level, we would definitely tell you. If we -- and expect a response, so I think it's the communication to [the STLT contact] and the expected communication back from [the STLT contact] that would be important to be included in the policy. If it's at this level, we're not going to expect a response."

Some informants discussed the need for clear communication "triggers" and standard communication content and structure. Another informant focused on *who* should be included in the communication chain, expressing a clear preference that initial federal NSSP communications should be directed at STLT syndromic contacts. The informant suggested that initial "syndromic to syndromic" communications could prevent unnecessary confusion, saying,

"I'm not saying that the syndromic people always have to be involved, but it might be useful to have them initially involved whenever the contact is made. Because I can obviously see a scenario... where the hepatitis program at CDC contacts, the group locally, and like here in [state], we have a hepatitis program, but hepatitis A is actually not in the hepatitis program. It's in the vaccine preventable diseases program. And so ... you contact hepatitis A to hepatitis A, then the hepatitis A program at the states like, well, we've never used syndromic surveillance data before, we have no idea what you're even talking about, then they have to backtrack to the syndromic person, the syndromic person has to get caught up on what's going on."

This concern was also shared by a federal respondent, saying that communications from different parts of CDC need "to be corralled, so that states don't feel like they're being bombarded from different parts of CDC about either related or related questions."

Other informant comments on communication related to notice of new federal projects or disseminations. For example, informant said:

“Especially we like to know if something is published in [state] that... I mean we don't want to be caught by surprise. You know the media follows everything especially now during COVID if there's something out there somebody will know and it's nice to know or expect it. I think it's important to know what's out there... I do think there should be a communication protocols if there's a new project that has started that will be displayed publicly or shared with stakeholders, we should be notified of that. I do think that we should have access to that and have an opportunity to look at up before going public I think that's important.”

Additionally, STLT informants expressed interest in better communication of surveillance objectives. Jurisdictions want to see specific examples of what would improve if federal partners had increased access to the data. “People haven't really sat down to be concrete enough or to say, this is a situation where if the feds had been involved, this would have been better.” Similarly, another STLT informant questioned the federal need for access to more granular STLT data, noting, “what is the rationale to call for additional access?”

Related, several key informants made comments related to transparency. Some informants indicated that STLT jurisdictions expect that they will be informed when data is shared that implicates their jurisdiction and want transparency around who is accessing the data and for what purpose. For example, one informant noted:

“I think the main one is the issue of confidentiality, and transparency, so that we're aware of, you know, upcoming changes and able to discuss those internally, or leadership. And I guess, other than, we -- making sure that we have ample time to react to it.”

Similarly, one informant asked in relation to FOIA disclosures, “How do we know as states or jurisdictions or even facilities that our data was disclosed as part of one of these requirements?” Other informants had similar concerns regardless of whether the data was shared through a FOIA request, or otherwise.

Some key informants were split on their views on the stewardship of the CDC NSSP team. Some STLT informants indicated CDC NSSP staff are “reasonable and responsible.” Another informant, expressed substantial confidence in CDC NSSP, but less trust in the rest of the CDC, saying:

“I think the NSSP program itself, in its current form, and I think it's probably important that this gets documented, has been an amazing steward of the data, but the system around it has become less trustworthy...[I]n today's world, CDC has become less and less willing to really talk to states in pre-decisional ways and help states understand [that] this data is driving this decision... [T]here's been a much larger tendency for CDC to make decisions and then just inform states about it in this response...”

However, another informant expressed a different perspective, saying “for some reason, [CDC NSSP] has historically not respected the autonomy of states, where other programs have.”

One informant suggested that NSSP might need to be moved outside of CDC to shield it from federal FOIA requests and used the AIMS Platform hosted by the Association of Public Health Laboratories as an example.

Several informants expressly or implicitly suggested that good stewardship of STLT syndromic surveillance data was necessary to ensure that health care facilities continue to voluntarily contribute data in jurisdictions without a reporting mandate.

Several informants identified data ownership as a significant issue. However, positions on data ownership were not consistent between informants. From one STLT informant perspective:

“I would say the hospitals own the data. And if not the hospitals, the patients own the data, I don't really see how states make the justification that they own data that they're not actually generating themselves.”

In contrast, other federal and STLT informants expressly or implicitly suggested that STLT agencies own the syndromic surveillance within their jurisdiction. For

example, an informant arguing stated, “the patients jurisdictionally belong to [the jurisdiction], and so it is [the jurisdiction’s] data.”

IV. DATA LIMITATIONS AND PITFALLS

Several informants expressed concerns about misinterpretations of data without appropriate controls. Some informants noted that syndromic surveillance data is substantively different from other data types in ways that warrant interpretive caution. For example, one federal informant stated:

“[S]yndromic data is a little bit different in terms of—well, it's true of any data, but we there's—there are certain things you need to know about it and understand about it, to use it effectively, ... the local context is important...”

Similar arguments—on the importance of local knowledge and perspectives—were made by several STLT key informants. One informant provided the following example:

“[O]ne of my main concerns about the use of syndromic surveillance data is, its use at very granular level... we work very closely with our facilities to make sure that they're sending the data in a consistent manner. But there are still unavoidable differences in how they submit the data on how they collect the data for their own clinical practice; we're secondary users of the data. So, there are underlying differences in the data by, for example, facility or health system, so that if you try to use the data at a very granular level and compare the data on county and another, you may not be making valid comparisons because people at one facility collect chief complaint as a very long free text narrative and another facility collect the chief complaint as a drop down, then you won't have equal ability to detect a given condition in those facilities, and you may accidentally say, well, the frequency of overdoses is five times higher in this county when it isn't. So, using data at a very granular level and especially making comparisons at a very granular level, I think is very often not valid.”

One STLT informant, acknowledging the risk of syndromic data misinterpretation through greater data sharing with the federal government, noted that STLT may nonetheless benefit:

"[D]epending on what the limitations are of how that data it's used I do think there's a little bit of risk of misinterpretation of that data but yes. I do think there's also a lot of opportunity like I said right now there's not enough capacity we need to look at local data."

Beyond misinterpretation, interpreting syndromic surveillance data without local knowledge or local cultural competence can also be an issue. One informant stated:

"I think that the [syndromic] data is just a little bit more fraught than other data, where issues with facility level disclosures, ... speaking poorly ... about a community without knowing that you are, and that ... cultural awareness ... that might not be apparent from a federal level... I think that states can bring a lot of value too."

Another limitation with national-level data arises when jurisdictions or health care facilities don't use the same standards, codes, or methodology. One informant noted this limitation of national standard queries, saying

"there's often a lot of difference between how syndromes are defined and seen as useful at a national level versus those that are seen as useful at a local level. I just don't think it's feasible for someone even at NSSP to have a working knowledge of all the syndromes for all their communities."

V. ACCESS RESTRICTIONS AND CONTROLS

Informants universally agreed on the need for access restrictions and controls for increased federal access to syndromic surveillance data. One informant noted, "Anything that's sensitive should always have specific purposes and roles associated with [it]." Another informant said, "There have to be user roles that allow different levels of visualization . . . I think [certain roles] would be very beneficial to be very granular, but that's not true for all the roles." Some informants saw clearly defined roles as a prerequisite to state assent to greater federal access. "I don't think that the majority of states are going to sign on for anything that doesn't have that defined." Suggestions included limitations both at the geographic level and by subject matter. "Limited in the sense of . . . they may only be able to see a handful of syndromes in the system or something like that."

Key informants in federal roles were also supportive of access restrictions based on specific use cases. For example, one federal respondent stated:

“I think [federal access] should never be unbridled. I think there should be as we think about whom we will work with and who we'll share data with, there should be a clear and defined use case for that engagement and the access that is permitted to those programs should be dictated by the use cases that they've laid out and planned for.”

Another informant in a federal role agreed, arguing:

“I don't think that we should be sending you know all of this data to homeland security or wherever else, right? I think that would shut the program [down]... I think states would probably stop sending data if we were to just really, really open the data that way. So, I think it has to be very careful and thoughtful. ... we can't give access to these data to the CDC at large; let's say there have to be very strict guardrails in place around the use of these data because you know these data are dirty messy data. ”

A common theme for implementation of these roles was ensuring the users understood how to interpret the data properly at each associated level of access. Large data sets like those for syndromic surveillance are messy and complicated, and lack of proper restrictions could lead to misinterpretation and misuse of the information. “It usually takes quite a bit of knowledge about the data to make interpretations so I do think some limitations around that are useful . . . when it's displayed there should be boundaries.” Some informants suggested that the further away an end user is from the data, the more restrictions should be in place.

Both state and federal users expressed concerns with the difficulty of tracking who has access to data and suggested an improved method for granting and tracking both which users accessed the data and how it was being used. Some informants indicated that it would be important to have standards for removing access from a user. For example, one STLT informant noted:

“I think that one of the critical things that came up in some previous conversations was the ability to remove access from staff who maybe

abused their privileges, whatever that is, what I think are going to end up being critical points for actually getting the majority of states to get on board with this."

VI. EXISTING POLICY CHALLENGES

Informant concerns related to existing policy range from political to technical. Current policy on data use and sharing agreements is a common concern at both the state and federal or national level. One informant described some policy barriers as a "turf war between homeland security and CDC," wherein the political and operational goals of the agencies create a barrier to effective data sharing and syndromic surveillance. "The technology is capable [of greater syndromic surveillance activities] but the policy is what's holding the system back." The majority of policy issues identified fall in two buckets: DUA issues and FOIA issues.

Informants expressed a range of issues and concerns with syndromic surveillance DUAs. One informant in a federal role noted that the biggest barrier to increased federal access to NSSP data is that the "DUA doesn't support it." One STLT informant noted that STLT governments often have separate DUAs with facilities that contribute syndromic surveillance data. Consequently, any revisions to the STLT-federal DUAs might necessitate creating new DUAs for those facilities.

Informants also expressed concerns about data sharing under FOIA, and how increased federal access could affect disclosure of sensitive information. One informant noted:

*"What is CDC's obligation for disclosing data under FOIA rules and laws?
... To me just means that there's additional disclosures that are possible.
... [the program] might not be sustainable if it continues in its current
setup of being subject to FOIA and under CDCs purview."*

Another informant noted that there can be problems when public information requests for syndromic surveillance data occur at both the STLT and federal level. The informant argued that if the syndromic data were redacted differently at the federal and state level it could be problematic even if both the federal and state governments appropriately disclosed data in isolation.

VII. RELATIONSHIPS WITH HEALTHCARE FACILITIES

Local jurisdictions often have more direct and responsive relationships with the hospitals or other facilities providing them with data. For example, one STLT informant said, “we have an understanding with the facilities that contribute data that we're not just going to release data from a single hospital to the public. So, sometimes it seems like federal users are not as sensitive to that.”

Several informants noted specific concerns about facilities in rural areas because identifying something from a jurisdiction with only one facility necessarily implicates more identification issues than data from a jurisdiction with more contributing facilities.

VIII. SYNDROMIC SURVEILLANCE CAPABILITIES AND APPLICATIONS

The key informants expressed positive views on the capabilities of syndromic surveillance, while noting important limitations. One key informant noted that syndromic surveillance was important as a supporting surveillance system to describe public health events:

“If you end up finding a case of Ebola when we're looking for in your syndromic system and you haven't heard about it yet, you're already screwed. You missed the boat. So, you got to develop what the focus [of syndromic surveillance] should be on and how you can use this, and I love syndromic, I mean, ... I've been working with syndromic, like -- I love it as a supporting surveillance system to help better describe public health events. That's what we use it for.”

Another STLT informant remarking on NSSP capabilities—as it has evolved at the federal and state levels—to respond to bioterrorism or epidemic disease noted that “we’ve really gotten away from those as the initial kind of impetus for setting up syndromic surveillance.” However, another STLT informant noted NSSP was “very useful” in detecting emerging public health issues like COVID-19 and vaping related injuries (i.e., e-cigarettes).

Informants expressed sentiments indicating that NSSP has untapped potential. One informant suggested that NSSP capabilities and usefulness were tied to its coverage of healthcare facilities within a jurisdiction:

"We actually fought for many years when we started onboarding facilities, we did not use the platform very much because we didn't have great coverage in [our state]. It's over the years we started onboarding more facilities and we have robust data. We feel more comfortable looking into this data and especially during the ... last two years, [and] we started taking a deeper dive into all the capabilities of the NSSP BioSense platform."

Another STLT informant suggested that facility delays in submitting data limit NSSP's capability to provide real time situational awareness:

"I would say when we look at it the first 24 hours are not always very complete, and it gets better especially between 24 and 48 hours it seems like we get most of the data in our system but sometimes we see updates like up to a month later before the initial trigger to record an event."

One non-federal informant with a national perspective argued that NSSP was not meeting the data needs of STLT health departments:

"There's a lot that's good about the [NSSP] platform. I think the problem is that it hasn't been able to fully meet the needs of the state and local health departments, in terms of all of the data that they would like to see incorporated and accessible at the state and local level."

Informants in federal roles noted that many limitations of NSSP are policy limitations not technical limitations. For example, one informant said, "The system is capable of doing it on any of the data as long as someone has given the ability to use the data."

Similarly, another informant in a federal role noted that current policy limitations cause NSSP to fall short of public expectations for public health surveillance capabilities, saying:

"I think ultimately where we're headed is there's an expectation among the general public that CDC has this capacity to do this work at a level that's far supersedes we're -- what we're actually able to do from a policy standpoint and so really, you know, thinking about the expanded use of this data, I think is essential if we're going to even begin to try and respond to the public at large around this question."

Several informants see syndromic surveillance improving through the influx of resources and support from the federal level (including increased data access). Many similar comments are addressed in the discussion of Collaboration and Relationships above. One informant in a federal role, noted the importance of building federal capacity and expertise to help the states, saying that being able to “practice with the surveillance side of it, it will bring us so much further and towards advancing the analytic components of the system and really being in a support role to the jurisdiction[s].”

IX. PUBLIC PERCEPTIONS

Informants were directly asked about their thoughts on the public’s perception of policy changes pertaining to NSSP. Several informants expressed that the public is unlikely to care one way or another. One informant said, “I don't know how well the general public understands the nuances of NSSP, versus national notifiable diseases, versus mortality surveillance.” Generally, informants did not express concern about this lack of understanding from the public. Generally, informants suggested that public perceptions of syndromic surveillance are currently a non-issue.

One informant recalled an instance where the lack of federal access to state NSSP data created some unnecessary confusion between media, and state and federal partners. In that instance, a media inquiry to a state related to a federal NSSP publication displaying data at only the HHS-region level, and the reporter wanted to know if the issue affected that state. Seeking clarification, the state contacted the CDC NSSP team, who could not provide the answer because the CDC NSSP team “couldn't access the data at a geographic granularity enough to determine,” which created some confusion and back and forth to get “it worked out.”

X. SUSTAINABILITY

When asked about the sustainability of NSSP, informants generally agreed that NSSP was sustainable, with one informant stating “in its current iteration it's the most sustainable it's ever been. It has the right balance of state and local participation, and it has appropriate federal support.” Another informant noted that technical advances have improved sustainability, saying: “Leveraging existing software like ESSENCE and then also building a platform where users can leverage tools like R and SAS, I think has greatly increased the usability and sustainability of NSSP.”

However, a number of informants noted sustainability challenges.

Several participants made comments suggesting uncertainty around the future of federal syndromic surveillance funding and political support. One informant noted, “The only thing that stays the same in public health is that funding comes and goes constantly.” Another informant remarked, “We have money today, but the next administration may not agree with spending this kind of money on public health.”

Making existing STLT funding conditional on assent to expanded federal access to STLT NSSP data was seen as a “nuclear option” by both state and national-level informants. While some expressed that this arrangement could help states by providing a written requirement to move needed policy forward, others saw it as a barrier to trust and meaningful collaboration.

One informant questioned the future of the program if there was not a national deal encompassing all of the states, wondering if it would be possible to move forward with some states buying in and other’s not.? This sentiment was echoed by both state and national-level informants, who share uncertainty about both the ability of CDC to get states to buy in as well as what the future of syndromic surveillance would be if that did not happen.

PART 2: ANALYSES OF MEETING DISCUSSIONS PERTAINING TO NSSP FEDERAL ACCESS POLICY

This part includes analyses of several meetings where syndromic surveillance and NSSP policy was discussed. These meetings include three CSTE executive or subcommittee meetings as well as two meetings with Workgroup members and the Office of the National Coordinator for Health Information Technology (ONC) and the Centers for Disease Control and Prevention (CDC).

A. CSTE EXECUTIVE AND SUBCOMMITTEE MEETINGS ON SYNDROMIC SURVEILLANCE POLICY

Excerpts from an CSTE Executive Board meeting and two meetings of the CSTE Surveillance Practice & Implementation Subcommittee were analyzed to provide a

more detailed understanding of CSTE perspectives on Nssp federal access policy revisions. CSTE determined that discussions in these meetings were relevant to this report and would be helpful to identifying implementation strategies regarding federal access policy.

I. CSTE SURVEILLANCE PRACTICE & IMPLEMENTATION SUBCOMMITTEE – AUGUST 2021

Federal Nssp data access was discussed during a CSTE Surveillance Practice and Implementation Subcommittee meeting in August 2021. The central focus of the discussion was introducing new laboratory data sources that were being added to Nssp. These new data include positive and negative test results, as well as test order data. However, participants raised concerns regarding who was being granted access to the state-level data provided by these laboratories.

It was reported that site administrators grant access to any site members for various purposes. At the site-level, users are able to see any test if the provider was in that state as well as any test at a location within that state. Moreover, users within CDC can be granted access after a direct application with Nssp. Potential users must provide a detailed project description so that Nssp knows how the data will be used. Federal requests for HHS regional granular access can be granted, but those that need granular access below the regional level can be granted given appropriate justification and if a compelling case is made. Access is granted through the ESSENCE system. One of the central goals of the discussion was to think through how granting access to Nssp data below the HHS-region level might work.

Participants raised broader concerns regarding Federal Nssp data access. They expressed issues regarding privacy of the data, and about how the data is being shared outside of Nssp. Concerns about the local context of the data, and concern with misinterpretation of the data were also raised. Several participant comments expressly or implicitly stressed their nervousness about CDC having access to this type of data. More specifically, they expressed concerns with the CDC having this information and not communicating the information back to the states. Overall, participants statements appeared to imply that states don't want to be surprised by the data Federal partners have access to. Several participants wanted Nssp to provide

specific use cases for this new data source. It was determined that a follow up conversation to address these concerns would be helpful.

II. CSTE EXECUTIVE BOARD MEETING – OCTOBER 2021

Federal NSSP data access policy was discussed during a CSTE Executive Board in October. The broad question for discussion was determining CSTE's position on permitting broader federal access to state NSSP data. It was noted that certain groups and communities were frustrated on the lack of progress on data sharing policy issues. Participants noted the difficulty that CSTE has in stating an independent position while being representative of the diverse communities and perspectives of its constituent state and local public health membership. In particular, the absence of progress on data sharing issues had created concerns that federal efforts to promote data sharing might target state health officials and governors, bypassing state epidemiologists.

Several participants expressed that it was critical that someone have eyes on the bigger (i.e., national) picture of syndromic surveillance trends. However, participants noted the importance of state and local public health involvement in interpreting NSSP data. For example, one participant noted that a local public health department might be able to easily interpret a sudden spike in syndromic data with local knowledge of a coinciding festival, whereas a state (or national) epidemiologist would not have that local knowledge when they interpret the same data. There was also discussion of the comparative knowledge and experience of federal and state health departments working with syndromic data, with some participants noting that currently federal NSSP personnel only receive syndromic data that have already been cleaned and are not as experienced working with raw syndromic data. Other participants noted that there is a "chicken and egg" dynamic, such that the lack of federal experience with syndromic data could be associated with the lack of access to these data, and that experience could improve if federal partners had more access. Regardless, several participant comments expressly or implicitly stressed the importance that federal access and use of NSSP must supplement—and not supplant—state syndromic surveillance activities. Others noted the imperative to identify a middle ground compromise that adequately protects syndromic data while achieving the benefits of increased national involvement in syndromic surveillance.

Participants expressed the need for adequate policy guardrails to ensure that NSSP data are used appropriately by federal partners. One suggestion included the addition of procedures to remove access permissions from personnel that are using NSSP data inappropriately. There was also considerable discussion on governance. On governance several key questions were identified, including defining reasonable uses of the data, mutually beneficial processes for collaborators to respond to each other, and ownership. Some participants noted that it was important for state partners to have a seat at the table in NSSP data governance.

There were numerous comments expressing concern regarding the applicability of the federal FOIA law to state NSSP data. Public disclosure of syndromic surveillance data through a FOIA request appeared to be critical concern and a factor to the support for increased federal NSSP access for several participants. Accordingly, there was discussion of how sensitive NSSP data shared with the federal government could be shielded from a FOIA request. This discussion included the option of moving control of NSSP to a trusted third party similar to how AIMS is operated by the Association of Public Health Laboratories as well as the history and evolution of BioSense/NSSP.

Finally, there was some discussion of change within syndromic surveillance, including current data modernization efforts and funding. Some participants speculated to whether the effect of data modernization funding would render these federal access policy questions moot in “three to five years.” One participant noted that despite federal insistence on immediate change, states needed time to work with data modernization funds to modernize state and local syndromic surveillance systems. Another participant questioned the “old model” of syndromic surveillance in the current evolution of the surveillance ecosystem and argued that data democracy is a reality that is inconsistent with older models.

III. CSTE SURVEILLANCE PRACTICE & IMPLEMENTATION SUBCOMMITTEE – OCTOBER 2021

The October meeting of the CSTE Surveillance Practice and Implementation Subcommittee included a follow up discussion on federal access to NSSP lab data (see initial discussion above). The discussion included a presentation on the laboratory data and potential use cases for the national laboratory data. Several of the example use cases included federal and STLT partnerships, including collaborations between:

- Arizona Department of Health Services and CDC's National Center for Birth Defects and Developmental Disabilities and CDC's National Center for Injury Prevention on issues associated with opioid use and abuse.
- Maryland Department of Public Health and CDC's Division of Vector-Borne Diseases to improve tickborne surveillance by integrating NSSP lab data.
- Georgia Department of Public Health, NYC Department of Health and Mental Hygiene and CDC's Division of HIV Prevention to investigate the impact of the pandemic on HIV testing and to understand area-specific prevalence and burden.

As with the prior call, several participants expressed concerns regarding the use of this new data being made available in NSSP. Participants expressed concerns with the level of identification of the data. CDC NSSP representatives discussed that there were no personal identifiers to cross connect the data and no identifier beyond the specimen ID. However, participants still believed that the level of identification in laboratory data is very identifiable and therefore is concerned with the level of access the CDC has.

Participants also raised issues with the laboratories being called A and B. It was explained that in the data use agreements with the laboratories, CDC NSSP agreed not to refer to the laboratories by their official name due to market share disclosure concerns. Market share concerns brought about a new discussion regarding generalizability and misinterpretation of the data. Participants were curious about the coverage across jurisdictions and how it may vary nationally. Moreover, participants were particularly concerned with the assumptions that might be made from this data with only two laboratories as sources and without CDC consulting with state or territorial experts on the ground.

Participants indicated issues with the pace at which this new data source has been integrated without first establishing certain guardrails or policies. Participants identified certain policies that they would like clarified, such as defining what the CDC has access to and what and how the CDC is going to use the data. For example, one participant contrasted access to COVID-19 pandemic data, where efficiency is paramount, with tickborne illness data, arguing that exigency does not exist with the latter and that time exists to discuss how the data will be used and what guidelines and restrictions should

be put in place. Moreover, it was suggested that CDC should consult with local partners on any findings or analysis that take place to prevent overstating the findings.

Lastly, participants raised concerns regarding transparency in general. Participants implied that there should be more transparency around the cooperation agreements, completeness of the data, and how trends are being tracked overtime regionally and nationally. Participants suggested that with more information shared, participants in various jurisdictions would have more trust in the process in terms of the utility of the data and in the appropriateness of the use.

B. CALLS WITH CDC AND THE NATIONAL COORDINATOR FOR HEALTH INFORMATION TECHNOLOGY (ONC)

In addition to the Workgroup activities described in Part 1 above, members of the CSTE Federal NSSP Access Policy Workgroup were invited to participate in two calls with ONC and CDC. ONC and CDC were tasked with obtaining information relevant to the Executive Order on Ensuring a Data-Driven Response to COVID-19 and Future High-Consequence Public Health Threats.³³ Specifically, ONC and CDC are required to characterize the “effectiveness, interoperability, and connectivity of public health data systems supporting the detection of and response to high-consequence public health threats, such as the COVID-19 pandemic,” and “review the collection of morbidity and mortality data by State, local, Tribal, and territorial governments during high-consequence public health threats, such as the COVID-19 Pandemic.”³³ Given the relevance of these executive order activities to state and national syndromic surveillance activities, limited summaries of these calls are presented below.

In two calls—occurring on October 8, 2021, and November 1, 2021—CDC and ONC engaged Workgroup members partners to gain an understanding of the priority data systems involved in an emergency public health response. Two goals of this CDC and ONC engagement were particularly relevant to considerations of federal NSSP data access policy. First, CDC and ONC wanted to understand the technical and policy challenges and successes in capturing and sharing syndromic surveillance data across the public health and health care communities. Second, CDC and ONC sought to obtain information from public health officials and program leads on the ideal future state of syndromic surveillance. The below analyses of these discussions are limited to these topics—specifically syndromic surveillance policy—and are not comprehensive

analyses of all topics discussed during these engagements (e.g., discussions of technical issues are omitted).

I. CALL WITH CDC AND ONC ON EXECUTIVE ORDER ON ENSURING A DATA-DRIVEN RESPONSE TO COVID-19 AND FUTURE HIGH-CONSEQUENCE PUBLIC HEALTH THREATS – OCTOBER 2021

During the first call with the CDC and ONC, discussion focused on the advantages of syndromic surveillance and existing challenges, including technical, implementation, and policy challenges. The summary below focuses primarily on syndromic surveillance policy and its use in the COVID-19 pandemic response.

Several participants noted that syndromic surveillance was very useful in the COVID-19 response, including for timely monitoring COVID-19 as well as related or synergistic events, such as mental health, and substance abuse. Participants also reported using syndromic surveillance data to inform specific public health responses and activities, such as implementation strategies on reopening, school closures, early warnings, case finding, and vaccine adverse event monitoring. Syndromic surveillance data was also used to inform heat warnings to prevent heat-related illness during times when hospitals were heavily burdened by COVID-19 patients. One participant noted that “NSSP support during the pandemic has been top notch,” and another appreciated “the ability to share state to state and with federal partners.”

Despite the usefulness of syndromic data, several participants felt that syndromic surveillance data was underutilized nationally for the COVID-19 response. One participant suggested that the visibility of syndromic data on public facing sites was a transparency issue. Another comment suggested that syndromic surveillance could have been better utilized to inform policy and planning in response to COVID-19.

There was some discussion on the challenges facing syndromic surveillance and a “future state.” Among the challenges mentioned were defining data ownership and appropriate data use, as well as a lack of “awareness of what NSSP can offer.” There was some discussion of benefits and concerns relating to a “national system.” Some participants thought a national syndromic surveillance system could facilitate developing and sharing syndrome definitions and standards. Other participants noted that national standards did not necessarily require a national syndromic surveillance system. One participant noted concerns about the need for “need better guard rails on

how the federal government uses the data and communicates that back to states,” and cited an example that the federal agreements with the states “were broken/not followed,” possibly indicating that the emergency federal access of state COVID-19 data negatively affected the trust relationship with some state and local partners.

II. CALL WITH CDC AND ONC ON EXECUTIVE ORDER ON ENSURING A DATA-DRIVEN RESPONSE TO COVID-19 AND FUTURE HIGH-CONSEQUENCE PUBLIC HEALTH THREATS – NOVEMBER 2021

The second call with CDC and ONC focused on syndromic surveillance data sharing practices and policies. Conversation prompts included thoughts on the impact of federal incentives, opportunities for future incentives, data sharing practices with healthcare facilities, policy challenges and opportunities, and DUA challenges.

Participants noted both positive (e.g., syndromic awareness) and negative (e.g., confusion on technical standards) impacts of federal incentive programs on syndromic surveillance messaging. Several participants noted that federal incentives were critical for health care facility participation, with one participant stating, “This is the only reason facilities are sending syndromic [data] in [state]. There is no other reason for our healthcare partners to report.” One participant, however, suggested that federal incentives were insufficient, saying that their state needed to adopt a legislative mandate for syndromic surveillance reporting.

Nevertheless, several participants indicated that additional incentives could benefit future syndromic surveillance efforts. Comments suggested that new federal incentives could be used to encourage urgent care centers to contribute syndromic surveillance data. One comment suggested that new incentives might be needed as HITECH funds are phased out. Several participants suggested that federal funds could support public health capacity to onboard health care facilities, quality assurance, and quality improvement efforts. One participant suggested that electronic health record vendors were charging health care providers too much for syndromic surveillance reporting functionality, arguing that excessive fees could constitute illegal information blocking under the 21st Century Cures Act.⁷⁴

There was some discussion on bi-directional data sharing between public health and healthcare facilities. These activities included offering facilities access to syndromic systems, sharing aggregated reports, participating in the Community of Practice,

sharing ESSENCE dashboards, and alerts relating to extremely drug-resistant organisms. One participant mentioned that they permitted facilities to use syndromic surveillance to meet mandatory opioid overdose reporting requirements in lieu of mandatory reporting (with periodic validation) and received positive facility feedback.

Several challenges and opportunities relating to sharing syndromic surveillance data were suggested in this conversation. One user expressed challenges ensuring that syndromic data sharing recipients understand the data and its limitations, efforts that can be substantial to health department syndromic units. One participant emphasized the view that syndromic data sharing should be situational when needed—as in the COVID-19 response—but sharing should not be “carte blanche.”

Participants discussed some DUA challenges and opportunities. One participant suggested that sharing syndromic data with other federal partners (e.g., Department of Defense) should be bound to the terms of the NSSP DUA. Another participant expressed that a challenge is to represent the shared data in a way that “protects the business model” of syndromic data contributors (e.g., health care facilities). Moreover, legal agreements with facilities contributing syndromic data can be jeopardized if syndromic data are not represented appropriately. There was some support for a standardized DUA agreement between STLT partners and syndromic data providers, including its potential support for interjurisdictional data sharing and limiting the number and variety of DUAs that exist. However, one participant noted that it would be difficult to identify standard DUA terms for facilities that permit the “re-release” of syndromic data.

PART 3: IMPLEMENTATION STRATEGIES

The implementation strategies below are the result of the synthesis of the substantial data and findings described in above in

Part and Public Perceptions

Informants were directly asked about their thoughts on the public’s perception of policy changes pertaining to NSSP. Several informants expressed that the public is unlikely to care one way or another. One informant said, “I don't know how well the general public understands the nuances of NSSP, versus national notifiable diseases, versus mortality surveillance.” Generally, informants did not express concern about this

lack of understanding from the public. Generally, informants suggested that public perceptions of syndromic surveillance are currently a non-issue.

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XI. SUSTAINABILITY

When asked about the sustainability of NSSP, informants generally agreed that NSSP was sustainable, with one informant stating “in its current iteration it's the most sustainable it's ever been. It has the right balance of state and local participation, and it has appropriate federal support.” Another informant noted that technical advances have improved sustainability, saying: “Leveraging existing software like ESSENCE and then also building a platform where users can leverage tools like R and SAS, I think has greatly increased the usability and sustainability of NSSP.”

However, a number of informants noted sustainability challenges.

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Making existing STLT funding conditional on assent to expanded federal access to STLT NSSP data was seen as a “nuclear option” by both state and national-level informants. While some expressed that this arrangement could help states by providing a written requirement to move needed policy forward, others saw it as a barrier to trust and meaningful collaboration.

One informant questioned the future of the program if there was not a national deal encompassing all of the states, wondering if it would be possible to move forward with some states buying in and other's not.? This sentiment was echoed by both state and national-level informants, who share uncertainty about both the ability of CDC to get states to buy in as well as what the future of syndromic surveillance would be if that did not happen.

Part 2: Analyses of Meeting Discussions Pertaining to Nssp federal Access Policy. Public health ethical principles—such as common good, equity, respect for persons, and good governance—as well as considerations of reciprocity, trust, transparency, and accountability were given consideration and guided the implementation strategies below when evidence or perspectives on an issue differed.^{2,28–31,34–36}.

IMPLEMENTATION STRATEGY 1: CREATE COMMUNICATION PROTOCOLS BETWEEN CDC AND STLTS

IMPLEMENTATION STRATEGY 1A: ADOPT A TIERED CLASSIFICATION SYSTEM THAT INDICATES STLT RESPONSE EXPECTATIONS FOR ALL FEDERAL Nssp COMMUNICATION.

Several Workgroup members and informants expressly or implicitly implied that federal communications involving Nssp data create additional burdens on state and local public health authorities by creating an expectation of response. This burden would be alleviated if communications that do not require a response (i.e., For-Your-Information communications) were clearly and consistently labeled.

State and local governments have the primary public health responsibility within their jurisdictions, and they are empowered with sweeping police powers (through the 10th Amendment of the US Constitution) to respond to public health issues. Moreover, state and local governments are better positioned to respond to public health issues within their jurisdictions.

Where a federal communication to state or local public health agencies relates to a low-priority public health threat or an isolated issue within a jurisdiction, it may be

inappropriate to expect state and local governments to respond to the communication. In these cases, the expectation that states respond to the communication forces sovereign state or local governments to triage the federal communication within existing priorities and spend resources in response. If a federal communication relates to a low public health risk or an isolated issue, an expectation of a response to creates an unjustifiable burden on the state or local governments.

However, the federal government has legitimate interests in acting in response to significant public health threats that are interjurisdictional in nature. Timely communications can be critical to determine how to allocate resources and support between multiple jurisdictions responding to an existing public health threat. For example, it may be necessary for the federal public health officials to determine whether NSSP data showing a sudden increase in incidence of a particular syndrome is an aberration (i.e., a hospital submitting an unexpected batch of syndromic data) or reflects that the jurisdiction is part of a multi-jurisdictional public health event (e.g., bioterrorism, epidemic disease). Where the public health risk is great and the threat is interjurisdictional in nature, the burden on state or local governments to respond to federal NSSP communications is outweighed by the public's need for an informed federal public health response.

In between these extremes, there are situations where a minimal response from state or local governments to federal NSSP communications is appropriate. For example, a state or local government acknowledging receipt of a federal communication about a potentially significant public health event indicates awareness of the event. It is the prerogative of the sovereign state or local government to decide how to respond to that event. Simply acknowledging receipt tells federal partners that they have appropriately satisfied their support role, and they can focus their attention on other issues. In these cases, a minimal response from a state or local government enables for the efficient use of federal public health resources.

Table 16 provides a recommended, tiered approach to response expectations for federal NSSP communications. Under this approach, the expected state or local governmental response to a federal NSSP communication depends on 1) the severity of a potential public health threat, and 2) whether the threat is isolated or inter-jurisdictional in nature. Under this approach, a response is expected from state or local

governments only when the public health threat is high and interjurisdictional in nature. If implemented, all federal communications should clearly indicate the expected response, if any.

Table 16: Recommended tiered approach to federal NSSP communication response expectations.

Tier	Public health threat	Expected response from states
Tier 3	Low; or Moderate but only affecting targeted jurisdiction	None
Tier 2	Moderate but interjurisdictional in nature; or High but only affecting targeted jurisdiction	Acknowledge receipt
Tier 1	High and interjurisdictional in nature	Response is expected

IMPLEMENTATION STRATEGY 1B: ALL FEDERAL COMMUNICATIONS INVOLVING SYNDROMIC SURVEILLANCE DATA SHOULD INITIALLY BE DIRECTED ONLY AT STLT NSSP SITE ADMINISTRATORS OR DESIGNATED CONTACTS.

Syndromic data cover a broad and diverse range of diseases and conditions. Consequently, a broad and diverse range public health professionals specializing in specific conditions have interest in syndromic data. Despite the broad relevance of syndromic data, typically only state and local syndromic units have the specialized knowledge to appropriately interpret syndromic results. Consequently, needless confusion can occur when communications about NSSP data bypass state and local syndromic surveillance contacts.

For example, it can be problematic when federal units, responsible for a specific condition, communicate with their equivalent state or local units about syndromic findings. Often the state or local units do not have the specialized knowledge to appropriately interpret the syndromic surveillance findings, and such communications can create needless confusion within state or local agencies. To avoid confusion, all federal communications should initially be directed at state or local syndromic surveillance contacts. Those syndromic surveillance contacts are better positioned to

efficiently facilitating communications with other state or local units or elevate concerns as necessary.

IMPLEMENTATION STRATEGY 1C: ESTABLISH STANDARDIZED MODES OF COMMUNICATION REGARDING FEDERAL USE OF NSSP DATA

Several Workgroup members and key informants indicated that they were sometimes caught off guard by an unexpected federal publication or federal use of their state's NSSP data. Workgroup members and informants stated that it was difficult to keep track of federal communications and notifications of these uses. For example, one informant stated:

"I think communication should be in writing. A lot of times it seems CDC says that, oh, we're sharing this information on the monthly webinar, which CSTE does record and make available later. That that type of communication is not easy to search. It's not easy to share. It's maybe not easy to attend, for example, in the middle of a pandemic."

To improve communication, CDC should establish standardized modes of communication that permit state and local site administrators to quickly find all federal NSSP communications. Some Workgroup members and NSSP site administrators support creating or incorporating a communication portal in NSSP ESSENCE. An ESSENCE communication portal has important advantages, including maintaining all NSSP communications on a single platform. However, certain high-priority communications—including but not limited to notification of federal publications, newly proposed federal NSSP use cases, and significant public health events—should also be sent via email to the designated contacts. This would permit appropriate notification if key state or local contacts are not logged in to the ESSENCE platform. In contrast, Tier 3 For-Your-Information communications, where no response is required (see Table 16), could be limited to communications on a portal implemented within ESSENCE.

Other third-party communication platforms were mentioned by informants (e.g., Slack). If acceptable to all state and local NSSP site administrators, these communication platforms could be adopted. However, uniformity should be promoted. Errors due to miscommunication are more likely if different modes of communication are adopted by various state and local governments.

IMPLEMENTATION STRATEGY 1D: STLT NSSP SITE ADMINISTRATORS SHOULD BE NOTIFIED IF A FEDERAL DATA RELEASE, REPORT, OR OTHER DISSEMINATION DISPLAYS THEIR JURISDICTION'S NSSP DATA BELOW THE HHS REGION LEVEL.

Workgroup members, key informants, NSSP site administrators, and CSTE committee members indicated that they were significantly concerned that they could be surprised by the release or publication of their jurisdiction's syndromic surveillance data. Surprise publications of NSSP data can become problematic for a several reasons, including but not limited to, misinterpretation of syndromic data, press-inquiries to units of STLT public health agencies that are unfamiliar with syndromic surveillance, and inconsistencies between federal and state data releases. STLT governments have a legitimate interest in ensuring that their data are validly interpreted and in efficiently responding to media inquiries on syndromic data.

Notifying STLT site administrators of federal NSSP data releases, reports, or other dissemination would have numerous benefits. Notice would give STLT site administrators the ability to alert federal users if there is a methodological or interpretive concern regarding local syndromic surveillance data, ensuring that federal decisions are grounded on sound analyses. Notice could alert STLT partners to potential confidentiality concerns (e.g., disseminated data potentially identifies an individual or facility) that could be remedied prior to publication. Notice of pending disseminations would permit STLT partners better prepare for related inquiries. Finally, notice significantly improves transparency between federal and state partners.

Critically, this implementation strategy that notice be provided to STLT site administrators should be considered a minimum requirement. Data from a small assessment of STLT NSSP site administrators suggested that concerns over federal use of NSSP data progressively increase as the granularity approaches line-level data. If the data that will be disseminated is below the state-level (e.g., county-, facility-, line-level), then additional processes could be warranted, including consent for the dissemination. Similarly, there is a meaningful difference between public-facing disseminations and internal disseminations (i.e., reports to federal agency leadership). The concerns identified above are heightened when federal disseminations are public facing, so additional protective processes beyond notice may be appropriate. In contrast, internal federal disseminations to agency leaders, containing only state-level data, could be unnecessarily burdened by protective processes beyond notice to STLT agencies. For

internal federal disseminations, if protective processes beyond notice are implemented, then they need balance the competing public health needs of mitigating legitimate STLT concerns and enabling federal public health decision making.

Additional considerations on NSSP publications are discussed in Implementation strategy 3 below.

IMPLEMENTATION STRATEGY 1E: A JURISDICTION'S NSSP SITE ADMINISTRATOR SHOULD BE NOTIFIED IMMEDIATELY IF CDC RECEIVES PUBLIC INQUIRIES ON THAT JURISDICTION'S SYNDROMIC SURVEILLANCE DATA

Being surprised by public inquiries was a consistently high concern of Workgroup members, key informants, and CSTE committee members. To mitigate this issue, CDC should immediately notify a jurisdiction via email whenever it receives a public inquiry on that jurisdiction's syndromic surveillance data.

IMPLEMENTATION STRATEGY 1F: CDC SHOULD REFRAIN FROM MAKING COMMENTS ON A STLT JURISDICTION'S SYNDROMIC SURVEILLANCE DATA TO THE PRESS AND SHOULD REFER ANY INQUIRIES TO THE APPROPRIATE STLT CONTACT(S)

STLT governments are best positioned to comment on their jurisdiction's syndromic surveillance data because the valid syndromic surveillance interpretation frequently requires knowledge of local context. Consequently, CDC should refrain from making comments on a jurisdiction's syndromic surveillance data to the press and should refer any inquiries to the appropriate STLT contact(s).

IMPLEMENTATION STRATEGY 1G: CDC SHOULD NOTIFY A STLT NSSP SITE ADMINISTRATOR IF THEY PLAN TO SHARE THAT JURISDICTION'S NSSP DATA OR INITIATE A PUBLIC HEALTH ACTION BASED ON THAT JURISDICTION'S NSSP DATA

One of the most significant concerns expressed by Workgroup members was if the federal government independently shared data or initiated public health action without notifying states. If the CDC notifies STLT governments that their NSSP data is being shared or used to inform public health actions, it empowers STLT governments to monitor the use of their data to ensure that it is being interpreted and used appropriately. Given the significant risk of misinterpreting syndromic surveillance data, STLT notification also benefits the federal government because STLT governments

would be able to inform federal decisionmakers when there is a risk that public health actions will be misinformed by inaccurate syndromic analyses.

Importantly, notification should be considered a *minimum* requirement for sharing a STLT jurisdiction's NSSP data. Often additional protective rules and processes should be employed (see Implementation strategy 2, Implementation strategy 3, Implementation strategy 9, and Implementation strategy 12 for examples). Notification, by itself, is insufficient for federal contact with a health care facility (see Implementation strategy 2). In contrast, notification might be sufficient where the federal government uses syndromic surveillance data to inform resource allocation decisions in a public health response.

IMPLEMENTATION STRATEGY 1H: CONSIDER ADDING FUNCTIONALITY TO ESSENCE THAT ENABLES NSSP SITE ADMINISTRATORS TO FLAG SYNDROMIC DATA THAT REQUIRE ADDITIONAL INTERPRETIVE CAUTION.

Syndromic surveillance data carry unique risks of misinterpretation. Benign events—such as a large festival or a facility submitting a large batch of syndromic data—can create false-positive anomalies within syndromic queries that might alarm data analysts that are not familiar with the local context. For this reason, local public health contacts are best positioned to interpret syndromic data.

However, it is not necessary that local context information remain secret. If ESSENCE users had the ability of flagging data (e.g., in a time range, or from a facility) where additional interpretive caution is warranted then the risk of misinterpretation of that data could be reduced. For example, if a county is hosting a festival that is expected to draw out-of-state visitors between June 10-16, syndromic data from that period can be flagged as requiring interpretive caution. If technically feasible, NSSP should implement a caution-flag function in ESSENCE to mitigate the risk of misinterpretation by non-local users of NSSP data.

IMPLEMENTATION STRATEGY 2: IMPLEMENT A FRAMEWORK FOR FEDERAL-STLT COLLABORATIONS

IMPLEMENTATION STRATEGY 2A: INVOLVE STLT PARTNERS IN METHODOLOGICAL DEVELOPMENT AND DATA ANALYSIS

Involving STLT partners in syndromic surveillance analysis was a highly prioritized opportunity by Workgroup members, received unanimous support from the key informants, and has previously been recommended by syndromic surveillance experts.²⁰

Involving STLT partners in data analyses has clear benefits. It can reduce the risk of misinterpreting syndromic data due to lack of local knowledge. The collaboration can enhance both federal and state syndromic expertise. It can support the development of transparent partnerships and trusting relationships. Additionally, Workgroup members and key informants suggested that federal and state collaboration in defining syndromes would be a substantial benefit to the Community of Practice.

Based on the input from Workgroup members and key informants, increasing state and local involvement in methodological development and federal syndromic analysis would contribute to a thriving Nssp community of practice.

One key informant stated that while many STLT partners would be interested in federal collaborations, other STLT partners might not be interested or might lack the capacity to collaborate. The federal government should make a good faith effort to involve interested STLT partners in analyses and methodological development. Where a STLT partner is interested in collaborating, but lacks capacity to contribute, federal support or funding to enable that collaboration may be appropriate. See Implementation strategy 5 below.

There are several options in how to involve STLT partners in data analysis and methodological development. One key informant suggested that a governance group could have a facilitating role by providing analytic expertise and guidance on report and visualization format and content, including clearly communicating syndromic limitations. Implementation strategies in the literature include face-to-face meetings, workshops, and joint public health investigations.³⁰ These types of events may have additional benefits of promoting trusting relationships and overcoming political barriers.³⁰

While STLT involvement in analysis or methodological development should not be mandatory, federal Nssp data users should make a good faith effort to engage and enable interested STLT partners. A good faith effort includes providing STLT partners

sufficient notice and opportunity to contribute and considering the merits and substance of each contribution prior to dissemination.

IMPLEMENTATION STRATEGY 2B: ALL FEDERAL AND STLT COLLABORATING PARTNERS SHOULD BE APPROPRIATELY ACKNOWLEDGED IN DISSEMINATIONS

Reciprocity is an important ethical consideration in any data sharing collaboration.^{30,32} Appropriate acknowledgement of contribution is an important step to ensure that benefits of collaboration to be shared between partners. Appropriate acknowledgement includes offering authorship on a dissemination when a STLT partner's contribution meets conventional standards for authorship.

IMPLEMENTATION STRATEGY 2C: ALL NEW FEDERAL REQUESTS FOR STLT NSSP DATA SHOULD BE STANDARDIZED

Workgroup members, key informants, and NSSP site administrators expressed support for including standard information in all new federal requests for NSSP access. Standardized federal NSSP access requests would substantially assist STLT governments efficiently evaluate these requests. Workgroup members and NSSP site administrators recommended that all federal requests for STLT NSSP data include the following information:

- The federal agency and unit requesting access
- The specific purpose of using NSSP data
- The requested start and end dates of the syndromic data to be queried
- The jurisdictions whose data will be accessed
- The requested level of stratification or level of granularity of syndromic data (i.e., state, county, facility, record)
- Estimated timeline for data analysis
- Any plans for dissemination of analyses
- Estimated dissemination timeline

IMPLEMENTATION STRATEGY 2D: STLT GOVERNMENTS SHOULD HAVE A RIGHT TO HAVE THEIR JURISDICTION'S NSSP DATA EXCLUDED FROM ANY PUBLICLY AVAILABLE FEDERAL DISSEMINATION WHEN THE EXCLUSION IS BASED ON LEGAL, SCIENTIFIC, OR PUBLIC HEALTH GROUNDS.

There are important and legitimate reasons to exclude a jurisdiction's data from a federal publicly available dissemination. Methodological issues with the data collection or analysis undermine any social benefit created by the publication by introducing a dangerous probability of interpretive error. A publication may present data that creates a substantial privacy risk for a syndromic surveillance data subject or contributing facility. A publicly available dissemination may be a restricted data use under a state's laws or applicable legal agreements. These are just a few examples of legitimate reasons for excluding a jurisdiction's data from a publicly available dissemination. Any justification based on legal, scientific, or public health grounds could be sufficient justification for excluding a jurisdiction's data from a publicly available dissemination.

However, there are some reasons for excluding surveillance data from a publicly available dissemination that cannot be justified under public health ethics. Public health surveillance rests on a social contract: the public concedes limited privacy interests to enable public health agencies to use that data to promote public health. Blocking the dissemination of surveillance data because the release of that data might increase public scrutiny or highlight a jurisdiction's population health status in unfavorable light is a violation of the public health surveillance social contract. Similarly, preventing dissemination of public health surveillance data from public health decisionmakers could also jeopardize the social contract and runs contrary to some definitions of public health surveillance.³

Nevertheless, there are many legitimate reasons for STLT governments to withhold syndromic surveillance data from publication. When a STLT government requests that their data be excluded from a publication based on a legitimate legal, scientific, and public health reason, the federal government should respect that. If an NSSP governance group is formed (i.e., under Implementation strategy 6), the governance group could serve an important role in evaluating exclusion requests.

IMPLEMENTATION STRATEGY 2E: FEDERAL USERS SHOULD NOT CONTACT NSSP-CONTRIBUTING HEALTH CARE FACILITIES WITHOUT EXPRESS PERMISSION OF THE RELEVANT STLT GOVERNMENT

STLT governments have the primary public health responsibility within their jurisdictions. The relationships between STLT public health authorities and health care

facilities are critically important to efficient public health activities, like outbreak investigation and response.⁷⁵ Moreover, facilities participation in syndromic surveillance is voluntary in many jurisdictions.

Direct federal communications with STLT health care facilities undermine or jeopardize all these considerations. Communications that bypass STLT public health authorities undermine the STLT government's position as the primary public health authority in the jurisdiction, jeopardize the relationship between the STLT public health authority and the facility, and increased administrative burdens from interacting with multiple public health authorities could discourage future voluntary syndromic surveillance participation.

IMPLEMENTATION STRATEGY 2F: FEDERAL NSSP DATA USERS SHOULD PROVIDE STLT PARTNERS GREATER OPPORTUNITIES TO COLLABORATE WHEN THE OBJECTIVE IS TO PUBLISH NSSP FINDINGS FOR RESEARCH, SCIENTIFIC, OR ACADEMIC PURPOSES, AS OPPOSED TO DISSEMINATION FOR PUBLIC HEALTH ACTIVITIES.

There is a meaningful distinction between using data for public health practice and using data for research activities.⁷⁶ When data is used for research, the purpose is to generate or contribute to generalizable knowledge. In contrast, when data is used for public health practice, the purpose is to understand the health status of a specific community or to evaluate a specific public health program or intervention. While this distinction has legal implications (e.g., applicability of the Common Rule protections for human subjects research), there are different concerns regarding NSSP data used for research or public health surveillance activities. Generally, NSSP site administrators indicated more concern with NSSP data used for research than if used for public health surveillance.

Federal research publications without STLT partner input raise several unique concerns. The risk of misinterpretation without local contextual knowledge from STLT partners means that the "generalizable knowledge" in the publication could have validity issues. Additionally, academic or scientific publications can advance an individual's career. Without reciprocity, STLT partners may be concerned that federal partners could take advantage of STLT data for personal gain. Moreover, unlike public health practice—where data might be needed for timely decision making—scientific publications have more flexible timelines, giving more time for STLT collaborations.

For these reasons and to promote reciprocity and trusting federal-STLT relationships, federal Nssp data users should provide STLT partners greater opportunities to collaborate when the objective is to publish Nssp findings for research, scientific, or academic purposes, as opposed to dissemination for public health activities.

IMPLEMENTATION STRATEGY 3: ESTABLISH RULES AND RESTRICTIONS FOR FEDERAL PUBLICATION OF Nssp DATA

Workgroup members, key informants, and Nssp site administrators expressed significant concerns about the publication of STLT Nssp data. For example, an Nssp site administrator stated, “[n]otification should be minimum requirement.” Several implementation strategies are intended to address some of these concerns. See Implementation strategy 1 and Implementation strategy 2 above. Nevertheless, additional restrictions should be considered. For example, imposing a minimum notice and comment period for STLT partners to review potential publications, and a policy requiring the suppression of small sample numbers to protect individuals and contributing facilities are reasonable publication rules and restrictions suggested by Workgroup members. However, other publication rules or restrictions may be appropriate. A governance group, such as one established under Implementation strategy 6, could be charged with identifying reasonable rules for federal publication of STLT Nssp data.

IMPLEMENTATION STRATEGY 4: PERMIT LIMITED CDC Nssp STAFF TO ACCESS STATE Nssp DATA TO PROVIDE SUPPLEMENTARY SURVEILLANCE SUPPORT SUBJECT TO REASONABLE POLICY GUARDRAILS AND LIMITATIONS

Workgroup members and key informants identified several benefits to permitting greater federal access to STLT Nssp data. For example, one CSTE representative noted several benefits including enhanced capacity for routine surveillance as well as supplemental assistance during emergency response or during staffing fluctuations, saying:

“[I]ncreased federal access could alleviate some burden on states too, it could actually help them do their job better. So, if I can't look at these 20 things every day, there could be a data analytics and review model that would say, I want to sign up for the feds to notify me when they see something and I really -- and I want to have them like my backup, so I

have a primary person in the state that's looking at it and my primary contact. But what happens when they're out on vacation or they're out on maternity leave? A lot of states are very thinly staffed, and so it could actually help them, I think, in particular, on the data visualization and analysis side, to have someone else, you know, be this like data visualization team that does some things for them, when they're out or during a response. Because I think part of the problem now is, during a response, the feds, they don't have that level of access, and so at the state level, trying to train them during a response is problematic. And so, I think the increased federal access could actually help in state responses if they were working in a really coordinated way, and there was some type of even memorandum of understanding to say, okay, during a response, like I'm going to check and produce a report once a day, but I want you to check and produce the afternoon report or something along those lines."

In addition to these specific benefits, Workgroup members identified improved cross-jurisdictional collaboration, improved syndromic surveillance practice, additional expertise and technical assistance, and enhanced state capacity as anticipated benefits of increasing federal NSSP access. (See the discussion of Workgroup Call 1 Theme Prioritization above). Moreover, several published studies indicate that increase federal access could lessen critical limitations of syndromic surveillance analysis.¹²⁻¹⁴ Critically, several CSTE executive board members noted the importance of having someone with the capacity to monitor the bigger (i.e., national) picture of syndromic surveillance. For these and other reasons, expanded federal access to STLT NSSP data has been recommended in the past.²⁰

Despite these benefits, a few Workgroup members were concerned that the "potential benefits do not outweigh the risks" of increasing federal access to syndromic surveillance data. Absent appropriate safeguards, policy guardrails, and mechanisms to promote transparency and accountability, the risks of sharing syndromic surveillance data can certainly outweigh potential benefits. Each of this report's implementation strategies are intended to address these needs and mitigate existing risks of greater federal access to STLT NSSP data.

Importantly, public health ethicists weighing the comparative risks and benefits of sharing public health surveillance data have firmly decided in favor greater data sharing for public health purposes.^{2,28-31,34} Ethicists describe sharing public health data as an ethical duty or obligation, with some placing a “burden of proof” on those that do not permit greater sharing of data for public health.^{2,28,29,31} While syndromic surveillance data carries additional risks (e.g., misinterpretation), these ethical arguments strongly support granting greater, but still limited, federal access to STLT NSSP data. The implementation strategies below describe the recommended scope of this expanded federal access.

IMPLEMENTATION STRATEGY 4A: ALL FEDERAL ACCESS TO STLT NSSP DATA SHOULD BE CONSISTENT WITH A DOCUMENTED PUBLIC HEALTH NEED THAT IS CLEARLY COMMUNICATED WITH STATE AND LOCAL PUBLIC HEALTH AGENCIES

There is an ethical obligation to share public health surveillance data where there is a public health need.²⁸ As a corollary, sharing public health surveillance data could be improper where there is no public health need. Although, there are numerous legitimate reasons to share public health surveillance data, it is not clear that CDC has communicated a specific public health need for general federal access to state NSSP data to state and local epidemiologists and NSSP site administrators. For example, only key informant stated:

“[W]hat is the rationale to call for additional access? That's the question [we] both had almost simultaneously, why do they want it? Why? Not just so you're sitting on [the data], that's not enough, not because some other pandemic might come along, and we want to have the data. We've already proved we can get you the data when the pandemic comes along.”

Critically, one of the core purposes of public health surveillance is to provide valid information to decision makers quickly and efficiently.^{3,77} The ethics of conducting public health surveillance while limiting this critical dissemination are questionable.⁷⁸ Beyond public health response, surveillance data can be legitimately disseminated to promote efficiency and effectiveness of public health activities and inform support functions.^{3,28,77} Unquestionably, state and local public health agencies have the primary responsibility to respond to public health threats within their jurisdictions. In this

capacity, state and local authorities should vigorously question federal requests for state and local public health surveillance data. However, the federal government bears an outsized role and responsibility in public health resource allocation, support, and interjurisdictional response and collaboration against public health threats. In this capacity, the federal government has legitimate interests in utilizing valid surveillance data to promote interjurisdictional public health activities and efficiently support state and local public health activities.

All federal uses of state and local NSSP data should be consistent with a documented public health need. The CDC should clearly communicate this need to state and local public health agencies. Prior to commencement, every new or proposed federal use should be similarly justified. Importantly, legal enforcement is not an acceptable or ethical public health need that can justify federal access to state and local NSSP data (see **Error! Reference source not found.** below).

IMPLEMENTATION STRATEGY 4B: GENERALIZED FEDERAL ACCESS TO STLT NSSP DATA SHOULD BE LIMITED TO CORE CDC NSSP STAFF

Developing the critical trust between federal, state and local partners to enable public health data sharing requires relationship building. Permitting unrestrained federal NSSP data use will be counterproductive to building trusting relationships. However, Workgroup members and key informants generally—but not uniformly—reported having trust in the CDC’s core NSSP staff. For example, one key informant stated:

“I think the NSSP program itself, in its current form, and I think it's probably important that this gets documented, has been an amazing steward of the data, but the system around it has become less trustworthy...[I]n today's world, CDC has become less and less willing to really talk to states in pre-decisional ways and help states understand [that] this data is driving this decision... [T]here's been a much larger tendency for CDC to make decisions and then just inform states about it in this response. And so, I think pre-Covid, it actually would have been easier—rather than harder—to implement some of these changes right now, in a way that the states felt good about...”

Another Workgroup member noted support for granting greater access to a small group of federal users, saying:

“I would be amenable to having a small/core group of analysts who are named and whose role/purpose is clearly delineated that have constant access to our detailed data. Other federal staff who would like access to detailed state data should require approval from sites after their purpose is clearly defined to improve collaboration with sites...”

Keeping the number of federal users with regular access to STLT data allows for identified issues to be addressed quickly and minimizes additional correspondence directed at STLT governments. Importantly, fewer federal users with access permits states to form stronger trust relationships with individual federal users. For these reasons, generalized federal access to state and local NSSP data should be limited to core CDC NSSP staff.

IMPLEMENTATION STRATEGY 4C: ROUTINE FEDERAL USE OF STLT NSSP DATA SHOULD BE LIMITED TO ACTIVITIES INTENDED TO DETECT OR MONITOR INTERJURISDICTIONAL PUBLIC HEALTH THREATS OR TO ENABLE FEDERAL PUBLIC HEALTH SUPPORT ACTIVITIES.

Public health surveillance data should only be used pursuant legitimate governmental interests pertaining to public health. STLT governments have the primary responsibility for responding to public health events within their jurisdiction. However, the federal government has legitimate interests in detecting public health events that cross state and national jurisdictional boundaries. Moreover, the CDC is empowered by Congress to provide support to state and local public health responses. Using NSSP data to understand the public health burdens of state and local jurisdictions can inform federal support in allocation decisions and ensure that public funds and resources are deployed efficiently in public health crises. Consequently, the federal government has at least two legitimate interests in public health uses of NSSP data. Permitting CDC NSSP staff to access and use STLT NSSP data for these purposes greatly enhances national public health capacity. Moreover, enabling these federal functions is critical if NSSP/BioSense is to be useful to address the types of events—like bioterrorism and epidemic disease—that it was created and funded to address.⁴

IMPLEMENTATION STRATEGY 4D: THE EXTENT AND SUBSTANCE OF FEDERAL SUPPORT FOR STLT NSSP ACTIVITIES SHOULD BE AT THE SOLE DISCRETION OF STLT GOVERNMENTS

There was general support for having CDC NSSP staff providing STLT support as an “extra set of eyes” on STLT NSSP data. Several NSSP site administrators indicated that it would be helpful to have CDC NSSP staff generate regular visualizations or reports based on STLT NSSP data. However, STLT agencies have the primary public health responsibility for their constituent communities. Consequently, the extent and the substance of federal support of a STLT’s public health mission should be at the discretion of the STLT governments. If a STLT public health agency does not request CDC NSSP support for its STLT public health mission, federal access to STLT NSSP data should be limited to those uses that further legitimate federal public health interests. See Implementation strategy 4C above.

IMPLEMENTATION STRATEGY 5: THE FEDERAL GOVERNMENT SHOULD MINIMIZE ADDITIONAL BURDENS ON STLT GOVERNMENTS CAUSED BY INCREASED FEDERAL ACCESS TO STLT DATA AND PROVIDE ADDITIONAL STATE AND LOCAL FUNDING AS NEEDED.

Enhanced federal access has the potential to improve state syndromic surveillance capacity through enhanced assistance and support. For example, federal NSSP staff can run queries and generate reports or visualizations on behalf of STLT partners as needed to support a public health response, to cover a STLT syndromic surveillance personnel on leave, or to supplement regular public health activities. However, some federal uses of NSSP data will necessarily create burdens for STLT syndromic surveillance personnel. For example, syndromic data can be easily misinterpreted without local insights, so federal reports of state-level (or more granular) data may need to be reviewed for accuracy and awareness, and federal NSSP partners may reach out to state contacts for help interpreting anomalous data more frequently.

One key informant, arguing for the importance of involving STLT partners in federal data analyses, raised the importance of federal support for that additional burden, saying:

“I think if you're again if the unit of analysis is state or lower and you should involve those states in that analysis if you're planning to release information at that level and that work with the states and local shouldn't be unfunded work, so I don't know if that requires a cooperative agreement or some sort

of you know overarching agreement that covers state and local time to provide feedback on those analyses.”

As a general principle, the federal government should minimize additional burdens on STLT governments. STLT syndromic surveillance partners serve sovereign governments; their primary responsibility lies with their constituent populations and communities and not in fulfilling tasks for the federal government.

Nevertheless, public health threats often do not recognize jurisdictional borders. STLT partners that contribute to national public health efforts also protect their constituent populations and communities. National and interjurisdictional cooperation and collaboration is in the best interest of national public health efforts and justifies additional federal financial support.

Critically, STLT governments lacking capacity to evaluate the methodological validity of new federal uses of their jurisdiction’s data may legitimately withhold their jurisdiction’s data from federal disseminations. See Implementation strategy 2 above. Additional federal funding should be sufficient to support and incentivize future federal and STLT collaborations in syndromic surveillance innovation and practice.

Absent additional federal funding increased federal use of STLT syndromic data can create problematic risks. For example, if STLT public health authorities lack the capacity to collaborate in data analysis—such as providing local contextual knowledge—there is a risk that federal syndromic analyses could be flawed. Additionally, if STLT public health agencies provide unsupported or unfunded analytical assistance to federal syndromic surveillance data users, then the effect would limit STLT capacity to provide essential public health services to their constituent communities.

Moreover, increasing STLT epidemiologic capacity through additional federal funding is likely to have public health benefits beyond increased syndromic surveillance capacity.^{79,80} Consequently, the federal government should provide funding for additional STLT epidemiologic and informatic capacity to enable consistent and ongoing national and interjurisdictional collaborations and cooperation in leveraging syndromic surveillance data.³⁰

**IMPLEMENTATION STRATEGY 6: CREATE A STLT NSSP GOVERNANCE GROUP
GUIDED BY PRINCIPLES OF PUBLIC HEALTH ETHICS**

Several Workgroup members and key informants indicated support for an NSSP governance group with substantial STLT involvement. Among many potential benefits, a STLT governance group would be capable of recommending changes to the existing STLT-federal NNSP collaborative framework to ensure that it can evolve as syndromic surveillance practice changes. The STLT governance group's activities and implementation strategies should be grounded in public health ethics,²⁸ recognizing that laws may limit a jurisdiction's ability to adopt a implementation strategy in some cases.

The precise mission and authority of a future NSSP governance group should be considered in greater detail with input from the Community of Practice. However, several potential functions of a governance group warrant special consideration.

One key informant suggested that a governance group could be useful in monitoring and providing input on ongoing or proposed federal uses of NSSP data. This consultation role could enhance federal transparency and provide a foundation for improved trust. Operationally, consultation with a governance group could assist federal users identify methodological issues or interpret the data. One informant suggested that the governance group could provide useful input on the content and presentation of NSSP reports, visualization, analytic methodologies, and syndromic limitations. This type of input would benefit the federal government by ensuring that decisions are based on appropriate syndromic surveillance interpretation. This role would also enable greater STLT awareness of federal NNSP activities.

Several NNSP site administrators indicated that a governance group could benefit STLT health departments by 'flagging' potentially important issues for other STLT partners. A governance group could be well-positioned to identify issues that STLT governments should examine more closely. Having the capacity to elevate communications or "flag" messages would allow a governance group to reduce the risk that important issues are missed.

An NNSP governance group would also be well-positioned to collect information on perceived issues with federal access, use, communications, or collaborations regarding NNSP data (e.g., publication without notice, inappropriate data use). Inevitably, issues will arise that concern STLT governments. From a single jurisdiction's perspective, it might be unclear if the issue is isolated or systematic in nature. A STLT NNSP

governance group could be empowered to collect information and reports of these issues to objectively determine the scope and severity of the issue and to provide specific remedy implementation strategies.

A governance group should be empowered to recommend specific NSSP access restrictions for federal users. If the governance group determines that a public health rationale exists for restricting NSSP access to specific federal users or federal units, then it is appropriate to recommend restricting access to STLT NSSP data. The public health rationale for restricting NSSP access should be consistent with public health ethics.²⁸ Examples include, but are not limited to, malfeasance and non-adherence to the NSSP DUA.

Similarly, a STLT governance group should be empowered to recommend expanded federal access in response to an identified or suspected event of significant public health concern. Below, Implementation strategy 7: Create Processes for Emergency Federal NSSP Access and Use, describes the challenges of negotiating expanded federal access to NSSP data during an ongoing emergency. A STLT governance group empowered to recommend expanded access could make the process of justifying the public health need more efficient for the federal government. Although state sovereignty means that the governance group's implementation strategies would not be binding on other states, implementation strategies from a trusted governance group could be persuasive to STLT governments and significantly facilitate negotiations.

IMPLEMENTATION STRATEGY 7: CREATE PROCESSES FOR EMERGENCY FEDERAL NSSP ACCESS AND USE.

The legal authorities empowering public health agencies to respond in disasters or emergencies are expansive and include the legal authority to take and use property for the emergency response. These authorities enable governments to act expeditiously in response to imminent and existing threats.

During the COVID-19 response, federal NSSP staff were acquired emergency access to COVID-19 syndromic data. In this case, the restrictive NSSP DUA provisions (i.e., restricting any federal access to state, local, facility, and line-level data) limited the federal COVID-19 response by preventing CDC from surveilling the spread of COVID-19 within and between states. Federal authorities justified the expanded access to

STLT NSSP data as necessary for the federal response to the pandemic. However, this action caused significant harm in the trust relationship between the federal government and some states. For example, one participant stated, “[i]t is important that any rules/policies/guidelines are emergency proof, so they don't just get thrown out the window in the event of an emergency.” On this issue, another informant noted, “I think it would be helpful to have MOUs that really clearly laid out what the things that would be done differently during a response than during a non-response.”

The US Supreme Court has upheld the federal government’s ability to exercise the eminent domain power to seize state property for public use.⁸¹ In a public health emergency, the existent exigent circumstances would likely support a related exercise of eminent domain. Nonetheless, steps could be taken to make federal access more difficult. For example, moving NSSP to a third-party platform would enable states to vigorously resist a federal eminent domain claim in a court, but Supreme Court jurisprudence would make the success of such a legal challenge doubtful.⁸¹ Moreover, such steps would be antithetical to the impetus of US syndromic surveillance (e.g., bioterrorism, epidemics), handicap public health agencies, imperil population health, and would be contrary to ethical obligations to share public health data to promote population health. Consequently, these steps cannot be recommended.

Instead, emergency processes to expeditiously expand appropriate and temporary federal access should be developed in collaboration with state and local governments. These processes should enable appropriate access within an agreed upon guidelines and policy guardrails. There should be clear and objective triggering criteria for these emergency processes, and procedures to support transparency and accountability during the period of access. Importantly, these emergency processes should enable swift and efficient public health action. If the emergency processes are overly burdensome or bureaucratic, then it is possible that waiving restrictive provisions under an emergency or disaster declaration to respond to the public health crises may be required. For example, existing processes require individual state and local syndromic surveillance administrators to expressly approve expanded federal access. This places an extreme transactional burden on the federal government and all negotiating parties. In an emergency response—where key partners are preoccupied with public health activities—-independent negotiations over emergency access with dozens of syndromic surveillance sites are untenable given public health and ethical imperatives.

However, if policies are adopted that permit temporary emergency federal access, then access required for public health response can be accomplished within an agreed upon guidelines and guardrails.

IMPLEMENTATION STRATEGY 8: ESTABLISH AUDIT AND DOCUMENTATION PROCESS FOR NSSP DATA ACCESS AND ANALYSIS

CDC should establish an audit and documentation process to promote transparency, trust, and accountability between states and federal users of state NSSP data. Based on collected feedback from Workgroup members, key informants, and NSSP site administrators, the audits should collect and document information indicating answers to the following questions:

- What was the purpose of the access?
- Who accessed NSSP data below HSS region level (e.g., individual, federal unit name)?
- How was the access was authorized?
- Which jurisdiction's data was accessed?
- What level of granular data was accessed (e.g., state-, county-, facility-, line-level)?
- What were the dates of syndromic surveillance data that were queried?
- When was the data accessed?

Results from the audits should be regularly provided to NSSP site administrators and, if implemented, an NSSP governance group (see Implementation strategy 6).

IMPLEMENTATION STRATEGY 9: REQUIRE ALL FEDERAL NSSP USERS AND REGULAR RECIPIENTS OF NSSP DATA BELOW THE STATE LEVEL TO SIGN THE NSSP DUA

Workgroup members and key informants expressed concerns about the applicability of the NSSP DUA to federal recipients of NSSP data. To address these concerns, all federal employees and contractors that are given regular access to NSSP data (excluding aggregated reports or visualizations) should be required to sign and adhere to the NSSP DUA. Importantly, the DUA should be signed by individual users; a blanket DUA covering an entire federal unit is not sufficient to promote a trusting relationship between federal and STLT partners. For example, one key informant stated, "I would support permitting designated federal roles to access NSSP data so long as each

individual occupying that role individually signed a DUA and was subject to standards for removing access to NSSP data.”

IMPLEMENTATION STRATEGY 10: FEDERAL AND STLT NSSP PARTNERS SHOULD CLARIFY BREACH RESPONSIBILITY

Workgroup members suggested that breach responsibilities need to be clarified. Neither the 2018 nor 2021 NSSP DUAs include provisions describing party responsibilities in a breach. This uncertainty could lead to jurisdictions overestimating or underestimating the legal risk associated with increased federal access to NSSP. For example, it is unclear if the sovereign immunity legal doctrine would shield federal and STLT NSSP partners from liability in the case of a breach or if specific laws would create liability.^{82,83} Understanding the nature of risk involved will help facilitate discussions on NSSP data access provisions.

IMPLEMENTATION STRATEGY 11: CREATE STANDARDS FOR REMOVING ACCESS FROM FEDERAL USERS

Transparency and accountability are critical to promoting a trusting relationship between federal and STLT partners. Written standards for restricting or removing federal user access to STLT NSSP data published for the Community of Practice would promote transparency and accountability within NSSP. Workgroup members, key informants, and STLT site administrators indicated support for creating standards to restricting or removing access to STLT NSSP data. As one STLT partner put it, “[t]here has to be a process for removing access for specific users, groups of users, and overall removal of state data from the sharing process. Without that ability, there are no teeth to the required codes of conduct, DUAs, etc.”

Malfeasance, non-adherence to NSSP DUA provisions, and inappropriate access are examples of appropriate justifications for removing or restricting access to STLT NSSP data. However, the standards should consider the severity and frequency of a user’s actions when determining an appropriate sanction. In addition to creating standards for removing or restricting access to an individual user, there should be standards for removing or restricting NSSP access to a federal unit (e.g., a federal user is not adhering to the NSSP DUA under the direction of leadership). If a governance group is created under Implementation strategy 6, a role for the governance group in applying these standards should be considered.

IMPLEMENTATION STRATEGY 12: REQUIRE TRAINING ON NSSP RULES, DUA OBLIGATIONS, AND THE CODE OF CONDUCT

NSSP should require periodic trainings for federal employees and contractors with access to NSSP data as recommended by Workgroup members. This training should cover accepted communication and collaboration protocols, restrictions on data access, use and publication, as well as rights, obligations, and responsibilities provided in the NSSP DUAs.

IMPLEMENTATION STRATEGY 13: CLARIFY AND COMMUNICATE DUA RIGHTS, DUTIES, AND RESTRICTIONS

All but three of the policy opportunities identified and prioritized during the first Workgroup call are either fully or partially addressed in the NSSP DUAs. The Workgroup's inclusion of these suggestions may indicate an incomplete understanding of existing protections or provisions that are currently in place. Alternatively, Workgroup members could be concerned that existing DUA provisions may require revision if federal access policies are changed. Regardless, periodic communications reiterating or reenforcing commitment to existing NSSP DUA data protections, rights, and obligations may support trust-building between federal and STLT partners.

IMPLEMENTATION STRATEGY 14: CLARIFY FOIA POLICY FOR SYNDROMIC SURVEILLANCE DATA

The Literature Review and Environmental Scan did not identify any specific federal guidance on disclosing syndromic surveillance data (or public health surveillance data generally) pursuant to a federal FOIA request. Workgroup members, key informants, and CSTE representatives were highly concerned about the susceptibility of NSSP data under a federal FOIA request. However, it is important to note that all 50 states and the District of Columbia have some form of FOIA law (sometimes called a sunshine law, open records law, or public records law).⁸⁴ Consequently, even if STLT NSSP data were shielded from disclosure under a federal FOIA request, the same data could be subject to a state FOIA request.

The combination of federal and STLT FOIA laws can create additional problems, however. One key informant indicated that the lack of coordination between federal and STLT FOIA disclosures can create inadvertent privacy risks. For example, if the federal and STLT FOIA disclosures redact NSSP data differently, then linking the

separately disclosed datasets could provide sufficient information to enable re-identification of data subjects, where each disclosure by itself is sufficiently protective.

Coordinating FOIA disclosures between federal and STLT governments could potentially address this issue. Coordination could take several forms, including notification, cooperating with parallel FOIA requests, disclosing redacted NSSP datasets (i.e., state government sharing with federal government and vice versa), or sharing relevant details about FOIA requests with the Community of Practice for broader awareness. The simplest approach could be to develop a recommended standard FOIA redaction methodology that can be shared in the Community of Practice for all jurisdictions with a FOIA law.

Importantly, the literature review and environmental scan identified a FOIA exception that would likely protect NSSP from substantial disclosure. Exemption 6 restricts the disclosure "medical files and similar files" when the disclosure of such information "would constitute a clearly unwarranted invasion of personal privacy."⁶⁵ This exemption would likely apply to syndromic surveillance data derived from patient medical files, and at the very least, justify substantial redactions under recent court cases.^{68,69} Given the substantial FOIA concerns expressed by Workgroup members, key informants, and CSTE representatives, official federal guidance on the applicability of this exception to syndromic surveillance data (or public health surveillance data) could substantially support transparency and trust between STLT and federal NSSP partners.

IMPLEMENTATION STRATEGY 15: PROHIBIT THE USE OR RELEASE OF STLT NSSP DATA TO TAKE ENFORCEMENT ACTION AGAINST NSSP-CONTRIBUTING FACILITIES OR DATA SUBJECTS

Public health surveillance must rest on a foundation of trust. Individuals and organizations contributing data do so to contribute to the common good, recognizing that these data are used to identify and respond to public health threats. However, trust is fragile. Uses of NSSP data that are unrelated to public health or uses that put individuals or contributing organizations in risk of harm or legal peril can jeopardize the trust required for public health surveillance activities.

In recognizing this danger, the WHO Guidelines on Ethical Issues in Public Health Surveillance state "[p]ersonally identifiable surveillance data should not be shared with agencies that are likely to use them to take action against individuals or for uses

unrelated to public health.” Syndromic surveillance data typically do not include direct identifiers, but they are highly detailed and can include several indirect identifiers that might enable the re-identification of a data subject. Consequently, there is a real risk that individuals may be put at additional risk if adequate protections are not in place. Similarly, health care facilities—which voluntarily contribute syndromic surveillance data in many jurisdictions—are often readily identifiable in unaggregated syndromic data. Moreover, facilities in rural or health care shortage areas are especially identifiable in county-level data. Health care facilities are heavily regulated and enforcement penalties can be severe. Consequently, many health care facilities might decide against providing syndromic data if those data could be used against them in enforcement actions.

Consequently, it is recommended that specific policy safeguards are implemented to prohibit the federal use or release of NSSP data to take enforcement action against contributing facilities or data subjects. These policy safeguards, at minimum, should include provisions within the NSSP DUA and federal policies and procedures on NSSP access and use.

IMPLEMENTATION STRATEGY 16: INVESTIGATE TRIBAL ISSUES RELATED TO INCREASED FEDERAL ACCESS TO STLT NSSP DATA AND THE POTENTIAL IMPACT ON TRIBAL COMMUNITIES

Potential issues with tribal data and Tribal Epidemiology Centers were identified by Workgroup members. Tribal sovereignty and relationships between federal, state, and tribal governments were among the more prominent identified issues. Critically, there were no tribal representatives who participated in the CSTE NSSP Workgroup. Consequently, more information and engagement may be necessary to fully understand tribal issues and their implications.

CONCLUSION

Consistently, trust and relationships are the most significant reported barriers and challenges to public health data sharing at all levels. This is consistent with our findings from the CSTE NSSP Workgroup discussions and key informant interviews. Consequently, many of the implementation strategies in this report are provided with the intent of providing a constructive foundation for building trusting relationships between the federal government and state and local NSSP participants.

Notably, many of these implementation strategies are prudent even in the absence of enhanced federal access to STLT NSSP data. For example, the implementation strategies to improve communication and collaboration between federal and STLT partners will substantially improve national syndromic surveillance activities and the broader Community of Practice. Several of these implementation strategies are likely to facilitate stronger trusting relationships and more productive and efficient public health collaborations. Consequently, these implementation strategies should not be considered an all-or-nothing package.

Views expressed by Workgroup members and key informants support two important conclusions. First, public health practitioners in the U.S. syndromic surveillance system are strong and trustworthy stewards of public health data. Second, U.S. syndromic surveillance practitioners have a deep awareness of the sensitivity and confidentiality of syndromic surveillance data. These conclusions are required and foundational to public health data sharing.

Nevertheless, the zealous stewardship and staunch protection of confidence that exists within the U.S. syndromic surveillance community have likely contributed to an NSSP policy framework that creates substantial barriers to ethical public health data use. When a public health need exists and adequate protections are in place, public health ethicists assert there is an obligation to share public health surveillance data. The implementation strategies above are intended to introduce appropriate guardrails and governance policies to support greater utilization of syndromic surveillance data to promote population health.

ACRONYMS

ATSDR: Agency of Toxic Substances and Disease Registry

CDC: United States Centers for Disease Control and Prevention

CSTE: Counsel of State and Territorial Epidemiologists

DUA: Data Use Agreement

FOIA: Freedom of Information Act

HIPAA: Health Insurance Portability and Accountability Act

HITECH Act: Health and Information Technology for Economic and Clinical Health Act

NSSP: National Syndromic Surveillance Program

ONC: Office of the National Coordinator for Health Information Technology

STLT: State, Tribal, Local, or Territorial (i.e., governments)

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APPENDICES

Appendix A: Literature Review and Environmental Scan of Resources Relevant to Public Health Data Sharing Policy

I. National Syndromic Surveillance Program (NSSP) Legal Authorities and Mandates

1. Federal Level

In response to 9/11 and the anthrax attacks, Congress passed the Public Health Security and Bioterrorism Preparedness and Response Act of 2002.ⁱ The Act called for the improvement of public health surveillance and reporting activities, including establishing systems for public health communications and surveillance networks through the Center for Disease Control and Prevention ("CDC").ⁱⁱ However, with the implementation of the Health Insurance Portability and Accountability Act ("HIPAA") Privacy Rule in 2003, public health departments and officials raised concerns about its effect on syndromic surveillance activities.ⁱⁱⁱ But, it has been generally accepted that the public health exception within the HIPAA Privacy Rule permits syndromic surveillance activities.^{iv} Nonetheless, due to the slow adoption of syndromic surveillance technologies, Congress passed the Health and Information Technology for Economic and Clinical Health ("HITECH") Act in 2009.^v The HITECH Act provided funding to providers and hospitals for meeting certain "meaningful use requirements" for electronic health records, one of which includes participating in syndromic surveillance.^{vi} These were the primary legal authorities for the growth of syndromic surveillance from 2000-2019.

More recently, the Coronavirus Aid, Relief, and Economic Security ("CARES") Act appropriated \$500 million to CDC to modernization "public health data surveillance and analytics."^{vii} More recently, the Biden administration issued an executive order calling for enhanced data collection and collaboration for high-consequence public health threats, the review of current public health data systems, and increased innovation of public health data or analytics.^{viii} These new authorities provide new legal mechanisms for changes to national syndromic surveillance practices.

2. State Level

By 2008, 83% of U.S. states and territories were implementing syndromic surveillance.^{ix} Several states found their existing state laws granted broad authority for public health surveillance.^x Other states made explicit modifications to their existing law or regulations to allow for syndromic surveillance.^{xi} Some states just request data pursuant to their general public health powers.^{xii} Moreover, states may also have different reporting requirements regarding the data collected, such as which data to collect and if the data collected will or will not include personal identifiers.^{xiii}

II. Potential Use Cases and Opportunities for NSSP

A majority of states have implemented the use of syndromic surveillance. More specifically, they have participated in providing data to the National Syndromic Surveillance Program (“NSSP”).^{xiv} (See Figure 1).

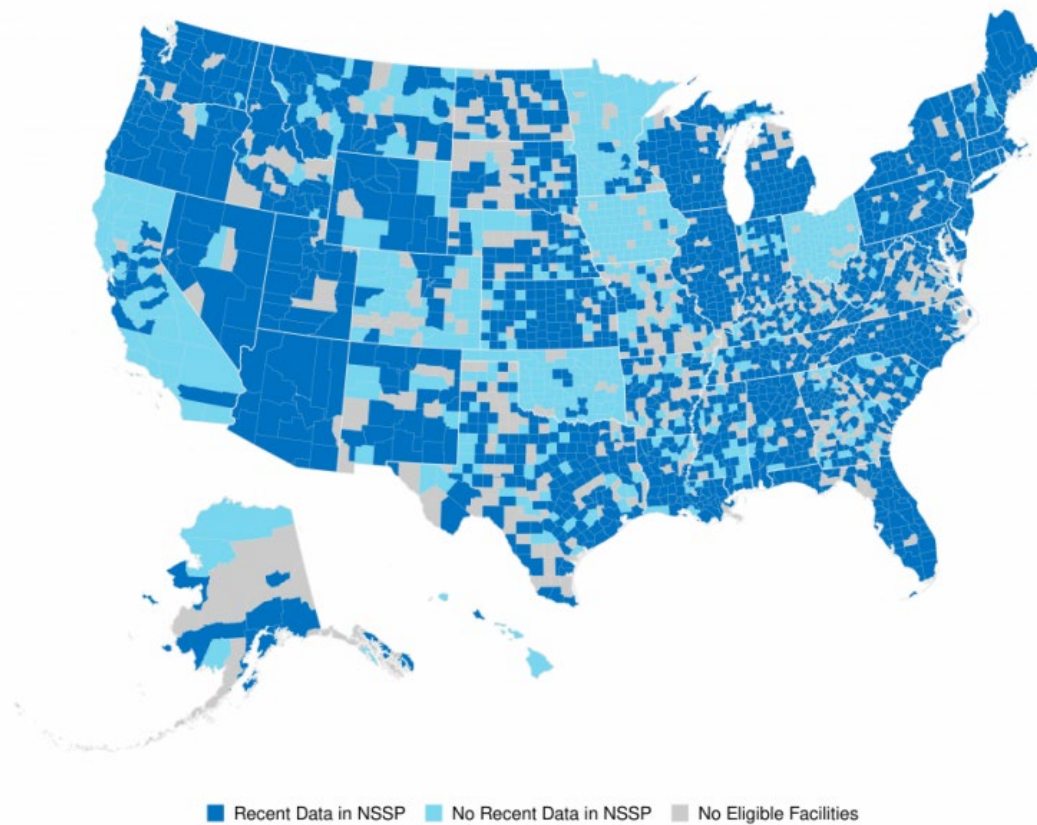


Figure 1: Non-Federal NSSP Emergency Facility Participation, May 12 – August 12, 2021; dark blue counties contain at least one eligible non-federal emergency care facility that

provided at least one patient visit record; light blue counties contain one or more eligible emergency care facilities that have not provided data to NSSP in the last three months; gray counties do not contain any eligible emergency care facilities.

**Source: Center for Disease Control and Prevention*

Since the implementation of syndromic surveillance, it has been used in detecting various public health events, such as salmonella,^{xv} influenza-like illnesses, hazardous material exposure or violations, tornado activity, wildfires, hurricanes,^{xvi} and other climate-related illnesses.^{xvii} It can be further utilized to detect new arising public health concerns, including: (1) sexual violence,^{xviii} (2) suicide and self-harm,^{xix} (3) heat-related illness,^{xx} (4) Tick-borne illness,^{xxi} (5) adverse events associated with drugs (e.g., overdoses from opioids and heroin),^{xxii} and (6) post-market surveillance of dangerous and defective products (e.g., e-cigs, adverse reactions to COVID-19 vaccines).^{xxiii}

Event	Short Description	Use	Version of BioSense
Salmonella ^{xxiv}	In 2018, a salmonella outbreak occurred in Georgia after a family reunion of 300 people. The Georgia Department of Public Health used data from its State Electronic Notifiable Disease Surveillance System (SendSS) Syndromic Surveillance (SS) module to successfully detect the salmonellosis outbreak early, help with actively searching for outbreak cases, track the peak of the outbreak, and ensure that no further spikes occurred.	Active Use	NSSP 2014-2016
Influenza-like	Epidemiologists found that monitoring of influenza-	Active Use	BioSense

Illness ^{xxv}	<p>like illness through syndromic surveillance detected the onset of flu season earlier. Specifically, during the 2006-2007 flu season in Georgia, epidemiologists in Georgia would supplement network data with its emergency department-based syndromic surveillance system. However, the syndromic data did not affect the health department's actions during flu season.</p>		2002-2009
Hazardous Material Exposure & Environment or Occupation Health Violations ^{xxvi}	<p>From 2005 to 2007 in San Diego County, epidemiologists had created a syndromic surveillance category for hazardous material exposure. The alerts generated by this category led public health officials to identify exposures not reported as required by law or a greater number of exposed individuals that went unrecognized initially. This included the detection of natural and intentional exposure. Syndromic surveillance was useful in supporting the local environment and occupation health programs, as long as there is a working relationship between the county and environment health officials.</p>	Active Use	BioSense 2002-2009
Tornado ^{xxvii}	<p>In 2007, a Georgia regional medical center was destroyed by a tornado. The 911 call data was the source of syndromic data, and the real-time nature of the data allowed local epidemiologists to update public health emergency managers on tornado-associated injuries. Moreover, it has been suggested that syndromic data can also help public officials track potential food or waterborne disease resulting from such a natural disaster.</p>	Active Use	BioSense 2002-2009

Wildfires ^{xxviii}	<p>In 2019, a substantial wildfire called the “Swan Lake Fire” burned between Anchorage and Soldotna, Alaska, impacting air quality on the Kenai Peninsula and Anchorage. Additionally, during August, there was wildfire activity in the Willow area north of Wasilla, Alaska, which also impacted the Anchorage area. To assess the impact of these fires, a year of syndromic data was reviewed. The most evident correlation was between a syndrome definition looking for smoke-related keywords and PM_{2.5}. The asthma syndrome definition illustrated a correlation with PM_{2.5} during the winter but remained within the expected range. During summer fires, asthma visits were observed at higher-than-expected levels (i.e., ESSENCE alerts and warnings). However, chronic obstructive pulmonary disease (COPD) and broad respiratory and cardiovascular visits did not appear correlated with fire-related increases.</p>	Active Use	BioSense 2014-2016
Hurricanes ^{xxix}	<p>Syndromic surveillance was used to analyze carbon monoxide poisoning during Hurricane Irma. NSSP data was used to compare pre-hurricane levels of Carbon Monoxide poisoning with the time frame of Hurricane Irma. The results showed that ten to nineteen-year-olds were more affected, which influenced response activity and community communication.</p>	Active Use	NSSP 2014-2016
Heat-related illness (HRI) ^{xxx}	<p>The New Jersey Department of Health examined HRI counts detected in syndromic surveillance data during May-September in 2009-2011 with patient billing data. The analysis found that heat</p>	Demonstrated by Case Study	NSSP 2002-2009 to 2014-

	<p>syndromic surveillance was relatively insensitive overall (16%) with a positive predictive value (PPV) of 40%, but the sensitivity (23%) and PPV (59%) improved during heat events, and identified all major episodes of HRI in billing data.</p> <p>NSSP BioSense data was used to detect heat-related illness in Maricopa County, Arizona in 2015. However, the unknown generalizability of the data and the query itself limits the application of this data. If this became a common query (HRI is now a national syndrome) among public health agencies, situational awareness could be improved nationally with data being shared across jurisdictions. Moreover, national data from other localities may speed understanding of generalizability for new and novel queries.</p> <p>In addition, CDC is using syndromic surveillance data to track extreme heat events and heat-related illness at a regional level in hopes of better preventing heat-related deaths.</p>		2016
Cold-related illness (CRI) ^{xxxi}	<p>Syndromic surveillance of CRIs can provide situational awareness and inform emergency response actions during extreme cold or other types of winter weather emergencies. For example, Michigan routinely monitors CRIs and releases a weekly cold-report during the winter season that includes the number of self-reported cold-related illness complaints analyzed in a time series compared with minimum temperatures from</p>	Demonstrated by Case Study	NSSP 2014-2016

	<p>across the state. The report also shows type of complaint, such as carbon monoxide exposure, cold exposure, hypothermia, etc. Trends in CRIs can be monitored to inform public health and its partners for messaging regarding possible situations including winter storm travel, outdoor safety, indoor safety, and power outages. Additionally, trends can guide the use of winter weather toolkits, such as those from Kansas and Wisconsin, that contain steps and strategies for public health partners and the public.</p>		
<p>Tick-borne illness^{xxxii}</p>	<p>CDC is currently using NSSP data to track tick bite-related emergency department visits in hopes of detecting trends in tick-borne illnesses. The data helps indicate when people in different geographical areas are at a higher risk for tick bites, increasing the chances of tick-borne illness. However, generalizability is an issue, and data at the local or state level may be more useful than the regional data in this case.</p>	<p>Demonstrated by Case Study</p>	<p>NSSP 2014-2016</p>
<p>Adverse events associated with drugs^{xxxiii}</p>	<p>In 2017, syndromic surveillance data from 166 health providers in Illinois was used to identify opioid overdose-related emergency department visits. It is suggested that this type of surveillance can aid drug abuse prevention, assist in allocating medication, and promote intervention.</p> <p>From 2016 to 2017, CDC used NSSP data to understand trends in heroin overdoses. Syndromic surveillance detected emergency department visits</p>	<p>Demonstrated by Case Study</p>	<p>NSSP 2014-2016</p>

	<p>associated with heroin overdose increased significantly over the year and successfully provided timely insight into regional and national heroin overdose trends. This information can further inform targeted prevention efforts and promote intervention.</p>		
<p>Post-market surveillance of dangerous and defective products^{xxxiv}</p>	<p>From 2018 to 2020, CDC used NSSP data to monitor vaccine-associated adverse events. The effort found that syndromic surveillance complements vaccine-associated adverse event reporting systems while not placing additional burden on resources.</p> <p>In 2019, cases involving e-cigarette or vaping product use-associated lung injury were reported. As a result, CDC and other health departments began to use NSSP data to assess trends and track the outbreak. Even though CDC stopped requesting case reports that didn't lead to hospitalization, it is suggested that syndromic surveillance can still offer insight into less severe cases.</p>	<p>Demonstrated by Case Study</p>	<p>NSSP 2014-2016</p>

Due to the regional nature of NSSP data, common limitations within the studies were the generalizability of the findings or trends and the representativeness of the data. However, several of these studies suggested that access to state or local data and increased participation in NSSP could lessen the potential effect of these limitations.^{xxxv}

III. General Public Health Data Use

Public health data has become critical to the success of public health organizations. The use of public health data in the U.S. is unique from other countries in that it tends to balance computer and informational science with social and behavioral science.^{xxxvi} The information is then used to inform decision-making regarding health policies and emergency responses, and prevention and intervention efforts.^{xxxvii} There are various benefits and risks associated with public health data use.

The wide range of benefits for the use of public health data includes improved public health, academic opportunities, capacity building, and insight into public health system performance.^{xxxviii} Collecting and sharing public health data can be used to improve public health by informing health care planning and regulatory review, improving patient care, allocation of healthcare resources, and clinical decision making.^{xxxix} Most importantly, it can improve disease detection, identify the source of an outbreak, and potentially reduce the impact of a global health crisis.^{xl} It also helps create academic opportunities for scientific publications by allowing the analysis of pooled surveillance data that can then be used to inform public health decisions.^{xli} Moreover, the use of public health data assists in capacity building within the public health sector as the knowledge gained from public health data can help "strengthen and maintain the infrastructure and resources necessary to sustain or improve system, organizational, community, or individual processes and competencies."^{xlii} Finally, the aggregation of public health data enables public health officials, stakeholders, and government agencies to review our public health system's overall performance.^{xliii}

Several risks are associated with public health data use, including inadequate security, ethical issues, and violation of public expectations of trust and privacy.^{xliv} When aggregating public health data in an online storage platform, there is the risk for the data to be compromised by cyberattacks or leaks.^{xlv} If there are no adequate safeguards to protect the data, people risk their personally identifiable information becoming known, thus violating the privacy of their medical data.^{xlvi} This risk will not only discourage patients from wanting to provide their data, but also healthcare facilities may be less willing to share data if they don't trust that adequate safeguards will protect their patients' information as such a story could result in reputational damage for the facility or organization.^{xlvii} There is also the risk that public health data will be misused, making data providers more reluctant to share data due to the possible reputational damages associated with occurrences of misuse.^{xlviii} Both of the risks described previously result in

the potential violation of the public's expectation of trust towards public health and their right to privacy.^{xlix} In addition, some scholars even suggest that public health data use may actually hinder health due to flawed analyses, invalid data sources, and the potential for second-guessing regulatory procedures and policies.^l

It is important to articulate the risks and benefits so that stakeholders can better understand the value and use of such data.^{li} Without public health data, public health organizations could not continue to successfully protect the health of individuals and communities.^{lii}

IV. Ethical considerations

Several publications argue that is an ethical imperative to share public health surveillance data where there is a demonstrated public health need when applying a public health ethics approach.^{liii} The 2017 WHO Guidelines on Ethical Issues in Public Health Surveillance explicitly states this obligation with Guideline 14, saying, “[w]ith appropriate safeguards and justification, those responsible for public health surveillance have an obligation to share data with other national and international public health agencies.”^{liv} Similarly, in 2016 the International Association of National Public Health Institutes (IANPHI) called for sharing “public health surveillance data by default where a public health need is identified, in a timeframe necessary for public health decision-making and to the highest standards they can achieve.”^{lv} Additionally, the IANPHI called for sharing public health surveillance data with as few restrictions as possible.”

Nevertheless, there are important reasons for limiting data sharing. Langat, et al., argue that these can be summarized in three categories, 1) data property and ownership, 2) just distribution of benefits and burdens, and 3) the contemporary ethos of science.^{lvi} However, they argue that each of these reasons is outweighed by considerations in favor of data sharing. For example, ownership of data is an important consideration, but Pisani and AbouZahr argue that data collected with public resources should be shared to maximize the public benefit from those resources.^{lvii}

However, others argue that an ethical imperative to share data is not enough. In a systematic review of ethical best practices in sharing individual-level data, Bull, Roberts,

and Parker found that “support for data sharing is contingent on the development and implementation of ... policies and processes to support ethical best practices.”^{lviii} Similarly, the Chantham House toolkit for Strengthening Data Sharing for Public Health emphasizes the importance of including guiding principles in data sharing agreements to help the parties cooperate and interact with each other.^{lix} The need for policies, processes, or principles is consistent with several descriptions of public health ethics as applied to the use of health data, which describe the importance of good governance,^{lx} stewardship,^{lxi} accountability, and transparency.^{lxii}

V. CDC & CSTE Prior Positions and Policies on Data Sharing

In 2005, CDC, in coordination with the Agency of Toxic Substances and Disease Registry (ATSDR), published a policy on releasing and sharing data.^{lxiii} CDC stated that it “believes that public health and scientific advancement are best served when data are released to, or shared with, other public health agencies, academic researchers, and appropriate private researchers in an open, timely, and appropriate way;” moreover, it states that “interests of the public . . . transcend[] whatever claim scientists may believe they have to ownership of data” CDC does recognize the need for high data quality standards, privacy procedures, and protection of highly sensitive information and aimed to balance these considerations with the need for data dissemination with the implementation of its policy. In its policy, CDC set forth guiding principles and procedures for releasing data. The guiding principles included, accountability, privacy and confidentiality, stewardship, scientific practice, efficiency, and equity. Data could be released for public use without restrictions, but CDC recommended that, to the extent possible, data be released to particular parties with restrictions using special data sharing agreements. The CIO’s duties included evaluating data quality, risk of disclosing private or confidential information, any outstanding memoranda of understanding (MOUs) are in compliance with the new policy and train their personnel in data release and sharing procedures.

Following the release of the data release and sharing policy, CDC, CSTE, and ATSDR published specific guidelines for implementing the policy regarding the re-release of state-provided data.^{lxiv} There were two guidelines pertaining to data agreements with

State data providers and three categories of guidelines for procedures on protecting and releasing state-provided data. In creating data agreements with state data providers, it is highly encouraged that data agreements are developed before receiving any data from data providers. The report further provides specific content that these data agreements should consider including. The three categories of procedure guidelines specifically for state-provide data include: (1) administrative requirements for all re-release of state-provided data, (2) re-release of state-provided data as public-use data , and (3) re-release of state-provided data as restricted-access data. CDC, CSTE, and ATSDR devised these guidelines in the hopes of complementing existing federal law, augmenting other CDC policies, and providing a more in-depth implementation guide pertaining specifically to the re-release of state-provided data.

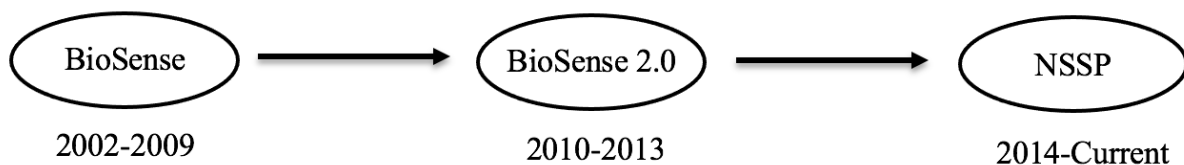
CSTE also adopted a new policy of its own. In response to emerging public health conditions, CSTE implemented a policy allowing it to add “provisional” conditions to its Nationally Notifiable Conditions list at any time during the year.^{lxv} As new conditions arise, CSTE may adopt “provisional” conditions to the list, and it becomes official CSTE policy until confirmed or disapproved at the annual meeting. This allows CSTE to promptly respond to emerging conditions by adding conditions to the NNC list without waiting for law to be established in each state making the condition reportable.

VI. Barriers or Concerns with Increased Access

The use of syndromic surveillance has increased since the Public Health Security and Bioterrorism Preparedness and Response Act of 2002,^{lxvi} accelerated by several incentive programs. However, there are still several barriers and concerns that public health officials and stakeholders have with syndromic surveillance and allowing increased access to their data. These include technical, political, motivational, economical, legal, and ethical barriers and concerns.

1. Technical Barriers (Current as of 2020)

Several technical barriers are facing the widespread and consistent use of syndromic surveillance. First, there are still states and territories that do not participate in NSSP, limiting the data's generalizability. One reason that may be affecting the adoption of syndromic surveillance is the availability and affordability of the technical software needed to participate.^{lxi} (2005, 2010, 2020). Congress has initiated a couple of incentive programs to try and bridge this gap.^{lxx} Another technical barrier is the quality of the data.^{lxi} The lack of data standards and procedures for this data makes secondary use of the data more difficult. Finally, due to public health being managed primarily by the states, there lacks consistency in the types of variables, data formats, and metadata that each facility within each state reports. (still a current issue 2001-2020). There have been several initiatives implemented to address this issue, such as the International Classification of Diseases (ICD), Data Documentation Initiative (DDI), and the Standard Data and Metadata eXchange (SDMX), Public Health Information Network (PHIN) Implementation Guide, and HL7-balloted Messaging Guide; however, it has been found that these standards are not always used efficiently. Nonetheless, technical barriers to syndromic surveillance have diminished since its introduction in 2002 and through the evolution of the BioSense platform and the creation of a community of practice that shares tools, methodology, and expertise.



2. Political Barriers (Current as of 2015)

Public health officials have also raised several political barriers and concerns. First, there is the predominant federalism issue as states' have concerns with granting increased data access to the federal government. This could stem from concerns regarding lack of trust and lack of guidelines.^{lxxv} (2009-2015). A lack of trust can cause providers to anticipate misinterpretation, misuse, or abuse of the data. In addition,

without clear guidelines and trust, more protective policies on data sharing are likely to result, making it more difficult for federal-state collaboration.^{lxxvi} (2009). Furthermore, there are concerns of bureaucratic hurdles and lack of political will and commitment to promoting data sharing.^{lxxvii} (2015).

However, these political barriers can be overcome by building trust, capacity building, and engaging politicians.^{lxxviii} Building trust through face-to-face meetings, workshops, and joint investigations are key elements to overcoming political barriers to data sharing. In addition, it is said that "you cannot have data sharing without political buy-in." Therefore, political support is essential to the continued success of data-sharing networks.

For example, the Mekong Basin Disease Surveillance (MBDS) network—an interjurisdictional surveillance operation established in 2001—succeeded by overcoming general political barriers. The MBDS network is built on bilateral agreements among six Southeast Asian governments (Cambodia, China, Laos, Myanmar, Thailand and Vietnam). The bilateral agreements are intended to support trust-based data sharing. Cooperative, joint outbreak investigations have improved interjurisdictional disease surveillance and improved capacity building. Communication through regular meetings is used to continually build trusting relationships and address challenges and opportunities, with lessons learned shared to other networks around the world.^{lxxix} (2015)

3. Motivational Barriers (Current as of NSSP 2014-2016)

There are motivational barriers to data sharing due to the lack of incentives (2005-2015), opportunity costs,^{lxxx} (2010-2015), the potential for criticism, and disagreement regarding data use (2010).^{lxxxi} Physicians and institutions are unlikely to prioritize data sharing without incentives due to the additional time and effort data sharing requires.^{lxxxii} In addition, in sharing data, an individual, institution, or state collecting data could lose the opportunity for publication if the data recipients gain most of the credit.^{lxxxiii} Sharing data also exposes data providers to criticisms concerning fabrication, manipulation, or errors being found during secondary use of the data.^{lxxxiv} Lastly, data providers, or states, could disagree about the intended use of the data and refuse to share.^{lxxxv} Transparency

can be critical to overcome the motivational barriers. Recommended approaches include increasing transparency and being clear about the intended secondary use of the data as well as changing the publication culture from one of "public or perish" to "publish data or perish" to allow researchers to share data immediately without fear of negative consequences to their careers.^{lxxxvi}

4. Economical Barriers (Current as of 2015)

There are two primary economical barriers: (1) potential for economic damage (2001-2015) and (2) lack of resources (2008-2015). Increased public health data sharing could cause economic damage by reducing tourism and trade as it did during the SARS outbreak.^{lxxxvii} The potential for such over-reactive market forces could reduce health agencies' willingness to release public health data. In public sector agencies and low-income settings, human and technical resources are lacking to facilitate data sharing.^{lxxxviii} Moreover, some facilities and institutions may be financially unable to acquire the personnel and technology needed for data sharing.^{lxxxix} It is suggested that time and skills should be incorporated into the hiring and training process to help alleviate some of these barriers.^{xc} In addition, offering incentives for data sharing at the personal and organizational level and mitigating the economic impact through funding initiatives could help overcome these economic barriers.^{xcii}

5. Legal Barriers (Current at of 2018)

There are reportedly several legal barriers to data sharing and participation in NSSP. One primary legal barrier appears to be the data use agreements between health departments and NSSP. Several public health officials and departments have reported concerns regarding the lack of clarity in the document concerning access to NSSP data and the role of Amazon as the vendor who houses the data.^{xcii} In addition, the lack of harmonization of legal requirements as public health laws in the U.S. vary from state to state slows down the ability to share data across jurisdictional boundaries.^{xciii} Lastly, institutions and state and federal agencies have to balance the need for access with

privacy concerns.^{xciv} This may restrict data sharing as states try to draw clear distinctions between what data should contain personal identifiers or be fully anonymous.^{xcv} This often leads to the promulgation of more restrictive policies on data sharing.^{xcvi}

Overall, scholars have found that law and policy facilitate the use of syndromic data, and if there are legal barriers, they can be overcome.^{xcvii} For example, HIPAA does not interfere with the sharing of syndromic data. Also, it is suggested that implementing a global governance framework, or alternatively a framework implementing local, context-specific agreements could assist in working with the patchwork of state public health laws.^{xcviii} The framework or agreements should outline how and when data will be shared and with whom, as well as what specific types of data should be shared.^{xcix}

6. Ethical Barriers (Current as of 2020)

There are several ethical barriers to data sharing, including lack of reciprocity, lack of proportionality of benefits and risks between providers and requestors of data, and protecting individuals' privacy.^c Concerning lack of proportionality, public health agencies may disagree about the risks and benefits of the secondary use of the data and its potential impact on public health. As previously mentioned, there are several risks associated with data sharing, such as that public health data will be misused only increases data providers' reluctance to share data.^{ci} The lack of reciprocity can slow data sharing as data providers often feel exploited by sharing their data and receiving little to no credit.^{cii} These ethical barriers may be overcome with the anonymization of the data shared, prompt and clear communication about the intended use of the data, and the implementation of a responsible and transparent data collection process.^{ciii} Communication about syndromic surveillance data to a wide audience will continue to be an ongoing challenge.^{civ}

VII. Recommendations for Modernizing NSSP

The overall aims of NSSP are to (1) improve technical capabilities for collecting

and analyzing syndromic surveillance and (2) facilitate the opportunity for collaboration among local, state, and federal public health programs.^{cv} Several recommendations to modernize the system have been suggested, such as improving data quality, establishing consistent research standards, and improving federal-state collaboration.

1. Improve Data Quality (Current as of Nssp 2014-2016)

It has been strongly recommended to improve the data quality of syndromic surveillance.^{cvi} There are significant issues with working with unstructured free-text data as well as missing data linkages between de-identified data.^{cvi} Proposed short-term solutions include (1) clarifying the current PHIN implementation guide on the CDC Nssp website and archive the outdated Guides and (2) update and address issues related to the inability of some systems to send certified messages through the NIST validation tool. Proposed long-term solutions to improve data quality include (1) conducting a review of the current flexibility in the PHIN Implementation Guide to find a balance between flexibility and data quality, (2) reviewing the HL7-balloted Messaging Guide for any changes or correction needed, and (3) implement a video orientation on using the PHIN Implementation Guide and HL7 Messaging Guide, (4) develop NIST tool tutorial, and (5) add the Nssp Data Quality Dashboard tools to onboarding.^{cviii}

2. Develop Policy to Facilitate Modernization of Nssp (Current for Nssp 2014-2016)

There are several suggested priority areas for policy development to help modernize Nssp.^{cix} First, specific research standards should be developed, including how confidentiality will be maintained. It should be determined how and when data will be shared and with whom, as well as what specific types of data should be shared.^{cx} Second, any future policy should outline how the process is ethical and how the use of the data will not harm individuals.^{cx} Third, there should be transparency and reasonableness about the need for access to the data and the uses of that data. Lastly, incentives (e.g., benefits or rewards) to share data should be outlined.^{cxii}

3. Improve Federal-State Collaboration (Current as of NSSP 2014-2016)

To realize the full potential of syndromic surveillance, it has been recommended that federal-state collaboration be improved.^{cxiii} To improve federal-state collaboration, it has been recommended that protocols and permitted used specifications be updated and then articulated between public health officials, CDC, and other federal organizations in the data use agreement.^{cxiv} In addition, it has been suggested that the data use agreement should clarify the role of Amazon as the vendor that houses the data and clarify the accessibility to NSSP data.^{cxv} Moreover, some suggest that universal reporting by states and hospitals requires that the federal government should: (1) maintain engagement with state and local authorities, (2) provide guarantees that data will be used according to updated protocols, (3) exclude personally identifiable information from federal use, (4) provide real-time access to the data to state and local officials, and (5) provide federal support for data modernization and technical assistance.^{cxvi} Finally, it is also suggested that CSTE and CDC collaborate more with state epidemiologists and health officials about syndromic data on optimal practices in interpreting and using the information provided by syndromic surveillance.^{cxvii}

¹ Public Health Security and Bioterrorism Preparedness and Response Act of 2002, Pub. L. 107-188, 116 Stat. 594 (2002).

¹ *Id.* at § 103.

¹ Centers for Disease Control and Prevention, *HIPAA Privacy Rule and Public Health: Guidance from CDC and the U.S. Department of Health and Human Services*, 52 MORBIDITY & MORTALITY WEEKLY REPORT 1 (2003), <http://www.cdc.gov/mmwr/preview/mmwrhtml/m2e411a1.htm>.

¹ *Id.*

¹ Health Information Technology for Economic and Clinical Health Act (HITECH Act), Pub. L. 111-5, 123 Stat. 226. (codified in 42 U.S.C. § 300).

¹ *Id.*; Public Health Information Network, *Meaningful Use Fact Sheet*, CENTER FOR DISEASE CONTROL AND PREVENTION, https://www.cdc.gov/datainteroperability/doc/historical/FS_MU_SS.pdf (last visited Aug. 29, 2021).

¹ Coronavirus Aid, Relief, and Economic Security Act (CARES Act), Pub. L. 116-136, 134 Stat. 281.

¹ *Executive Order on Ensuring a Data-Driven Response to COVID-19 and Future High-Consequence Public Health Threats*, WHITE HOUSE (Jan. 21, 2021), <https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/21/executive-order-ensuring-a-data-driven-response-to-covid-19-and-future-high-consequence-public-health-threats/>.

¹ James W. Buehler et al., *Syndromic surveillance practice in the United States: findings from a survey of state, territorial, and selected local health departments*, 6 ADVANCES IN DISEASE SURVEILLANCE 1, 1 (2008).

¹ Jonathan Purtle et al., *The Impact of Law on Syndromic Disease Surveillance Implementation*, 24 J. PUBLIC HEALTH MANAGEMENT & PRACTICE 9 (2018).

¹ 173 Neb. Admin. Code § 3-004 (2002); 10A N.C. Admin. Code 41A.0102, 41A.0103 (2021); *Legal Issues Related to Sharing of Clinical Health Data with Public Health Agencies*, APHA & ASTHO (Apr. 2016), <https://www.astho.org/Public-Policy/Public-Health-Law/Legal-Issues-Related-to-Sharing-Clinical-Health-Data-with-Public-Health-Agencies/>.

¹ *Public Health Collection, Use, Sharing, and Protection of Information*, ASTHO (2012), <https://www.astho.org/Programs/Preparedness/Public-Health-Emergency-Law/Public-Health-and-Information-Sharing-Toolkit/Collection-Use-Sharing-and-Protection-Issue-Brief/>; ORS 431.110, 433.004.

¹ *Id.*

- ¹ *Non-Federal NSSP Emergency Facility Participation*, Center for Disease Control and Prevention, <https://www.cdc.gov/nssp/participation-coverage-map.html> (Aug. 19, 2021).
- ¹ Renne Borroto et al., *Detection of Salmonellosis Outbreak Using Syndromic Surveillance in Georgia*, 11 ONLINE J. OF PUB. HEALTH INFORMATICS e379 (2019).
- ¹ James W. Buehler et al., *Situational Uses of Syndromic Surveillance*, 7 BIOSECURITY & BIOTERRORISM: BIODEFENSE STRATEGY, PRACTICE, AND SCIENCE 165 (2009); PUBLIC HEALTH INFORMATICS AND INFORMATION SYSTEMS, 3rd Edition (J.A. Magnuson & Brian E. Dixon, eds., 2020).
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Appendix B: Workgroup Call 1 Agenda

CSTE Workgroup on Federal Access Policy for NSSP

Meeting 1 Agenda, September 2, 2021

1. (3:00 – 3:14 PM ET) NSSP background

- a. History – legislative intent and public expectation for NSSP
- b. Current capacity and limitations
- c. COVID-19 and Executive Order as impetus for revisiting federal NSSP access policy
- d. Project goals and scope
 - i. Federal access to state health department syndromic surveillance data, including emergency department, urgent care, and vital records

2. (3:15 – 3:24 ET) Workgroup goals and objectives

- a. Purpose:
 - i. Identify key issues, including areas of consensus
 - ii. Identify potential opportunities and paths forward
- b. Today's workgroup meeting format: modified Nominal Group Technique
 - i. Individual idea generation
 - ii. Group clarification
 - iii. Prioritization
 - iv. Discussion

3. (3:25 – 3:39 ET) Individual idea generation

- a. Record your ideas to the following questions in a separate, *non-shared* document. Try not to be too critical of your ideas at this stage.
 - i. **Question 1:** In what ways can increased federal access to state syndromic surveillance data (at the state or local level) benefit or support state public health activities?
 - ii. **Question 2:** What concerns you about increasing federal access to state syndromic surveillance data at the state or local level?

4. (3:40 – 3:59 ET) Breakout rooms (4-7 persons per group)

- a. In a round-robin format, each member reads one of their ideas, starting with question 1. After all ideas are shared for question 1, begin sharing ideas for question 2 in the same round-robin format.
 - i. Paste all ideas in the Google document [here](#) (see Appendix A below)
 - ii. Members may ask clarifying questions during the round-robin, but the merits of specific ideas should not be debated at this time.
 1. Members may revise their ideas for clarification

2. Members may write new ideas, if they are inspired by others.
- iii. Similar ideas can be grouped or clustered at this time. See #7 below.
- 5. (4:00 – 4:09 ET) Individual idea generation**
 - a. Record your ideas to the following question in a separate, *non-shared* document. Try not to be too critical of your ideas at this stage.
 - i. **Question 3:** What rules, restrictions, guidelines, or codes of conduct could be implemented in the NSSP DUA or CDC policies that might address a concern addressed by you or a fellow workgroup member?
- 6. (4:10 – 4:19 ET) Breakout rooms**
 - a. In a round-robin format, each member reads one of their ideas, repeating as necessary until all ideas have been shared.
 - i. Paste all ideas in the Google document [here](#) (see *Appendix A below*)
 - ii. Members may ask clarifying questions during the round-robin, but the merits of specific ideas should not be debated at this time.
 - iii. Similar ideas can be grouped or clustered at this time. See #7 below.
- 7. (4:20 – 4:29 ET) Clustering**
 - a. Each group will be assigned a question to cluster.
 - b. In your group, *combine* identical and similar ideas in clusters for your assigned question.
 - c. *Label* each cluster as an overarching issue or theme
 - d. Some ideas might not fit with others in a group. It is ok to keep these separate.
 - e. Some groups may have started clustering already. You can take these clusters into consideration, but you are free to re-organize to include other group ideas.
- 8. (4:30 – 4:39 ET) Prioritization**
 - a. Each member will prioritize most significant ideas for each question
 - i. Voting link for Question 1 (*Please wait until asked before clicking*) 1. <https://forms.gle/Gw36SvT6jcw58x5p6>
 - ii. Voting link for Question 2 (*Please wait until asked before clicking*) 1. <https://forms.gle/iy95wW62vSYJUPf38>
 - iii. Voting link for Question 3 (*Please wait until asked before clicking*) 1. <https://forms.gle/1eevfhc7ceYdxtrE7>
- 9. (4:40 – 4:58 ET) Voting results and open discussion**
- 10. (4:59 – 5:00 ET) Next steps and closing remarks**
 - a. Informant interviews
 - b. Workgroup 2
 - c. Draft report

Appendix A: Google document format

<p><u>Idea Generation</u> In your round-robin discussions, list each idea here. It is ok to revise ideas if they need to be clarified.</p>	<p><u>Idea Clusters</u></p>
<p>EXAMPLE: List your favorite Muppets Round Robin list:</p> <ol style="list-style-type: none"> 1. Kermit 2. Ms. Piggy 3. Fozzie Bear 4. The one with the curved nose 5. Animal 	<p><u>Common Animal Muppets</u> Kermit Ms. Piggy Fozzie Bear <u>Monster Muppets</u> Gonzo Animal</p>
<p>Question 1: In what ways can increased federal access to state syndromic surveillance data at the state or local level benefit state public health activities? Round Robin list:</p> <ol style="list-style-type: none"> 1. ... 2. ... 3. 	
<p>Question 2: What concerns you about increasing federal access to state syndromic surveillance data at the state or local level? Round Robin list:</p> <ol style="list-style-type: none"> 1. ... 2. ... 3. 	

Question 3: What rules, restrictions, policies, or guidelines could be implemented in the NSSP DUA or CDC policies that might address a concern addressed by you or a fellow workgroup member?

Round Robin list:

1. ...

2. ...

Appendix C: Themes Participant Ideas from Workgroup 1

Table 1: Thematic analyses of *a//* ideas generated through NGT workgroup for each research question.

Question 1: In what ways can increased federal access to state syndromic surveillance data at the state or local level benefit or support state public health activities?
1.1 - Technical assistance + expertise
<ul style="list-style-type: none"> - "...Potentially better input on syndrome definitions from NSSP staff- more field access beyond cc and dd - In states without the ability to monitor data routinely, NSSP might be able to point out issues for state follow up that would otherwise be missed. - Even in states with dedicated staff there may not be appropriate resources to examine all potential issues on granular level - During large emergencies there is a potential benefit to having additional eyes on data - NSSP staff playing a role in discussing data artifacts, interpretation of data, and other issues with national level partners - If the federal partner is using one system this allows for increased interoperability in a way since all data is flowing or being used and analyzed through that one platform vs. many at state/local levels and then can be shared back with the participating jurisdictions comprehensive visibility into the state of syndromic trends at the state or local level, - Support states without expertise in SyS with analysis/CDC can assist - When you don't have the analytic capacity of expertise to develop dashboards for a new and emerging event, outbreak, or surveillance area of interest - More robust query and visualization options in NSSP ESSENCE based on the same level of access state/locals have. - Timely certification - Technical assistance in creating and standardizing syndromes for consistency across jurisdictions and support for less-resourced jurisdictions"
1.2- Enhanced federal surveillance capacity (e.g., providing national pictures, completing data request normally handled by states, increased cross-jurisdictional awareness)

- *“Easier to depict the national landscape of what’s happening and trends (especially geographically) - allocation of resources, early warning*
- *A beneficial example for increased access/use is the COVID dashboard, which was internal, county level, shared with all states and integrated.*
- *Increased understanding of what’s going on nationally (EVALI)*
- *Situational awareness - double edge sword - too much info currently, can't stay on top of changing environment/situations*
- *...Using syndromic data to inform other programs at CDC*
- *... Monitor issues that cross jurisdictional lines*
- *Data requests for state or local level data which are currently filled by state staff would no longer need to be filled-how would this then impact data releases that currently go through states or locals?*
- *If the federal partner is using one system this allows for increased interoperability in a way since all data is flowing or being used and analyzed through that one platform vs. many at state/local levels and then can be shared back with the participating jurisdictions comprehensive visibility into the state of syndromic trends at the state or local level,*
- *Timely identification of novel/emerging health issues that cross jurisdictional boundaries*
- *In states without the ability to monitor data routinely, NSSP might be able to point out issues for state follow up that would otherwise be missed.”*

1.3- Improved cross-jurisdiction collaboration efforts

- *Collaborate on analysis and publications that impact more than one state, across jurisdictions, etc.*
- *A beneficial example for increased access/use is the COVID dashboard, which was internal, county level, shared with all states and integrated.*
- *Improved Cross-state outbreak investigation (e.g., borders)*
- *Develop best practices and compare jurisdiction-jurisdiction collaboration/techniques*
- *Cross jurisdictional outbreak collaboration, possibly detection*
- *Timely identification of novel/emerging health issues that cross jurisdictional boundaries*
- *Build powerful collaborations - tribal/local/state/federal that cross jurisdictional boundaries - border issues, tribal issues,*

1.4- Enhanced state capacity

- *More ability to train and onboard new staff in lower resource states or others without dedicated staff*
- *During large emergencies there is a potential benefit to having additional eyes on data*

- Data requests for state or local level data which are currently filled by state staff would no longer need to be filled-how would this then impact data releases that currently go through states or locals?
- More eyes on the data - more likely to find/see things
- Develop best practices and compare jurisdiction-jurisdiction collaboration/techniques
- More eyes on the data, especially after ELC C1\$ decreased
- Timely identification of novel/emerging health issues
- Technical assistance in creating and standardizing syndromes for consistency across jurisdictions and support for less-resourced jurisdictions
- Feasible for federal access be given back (or allowed) to jurisdictions to look at local data/ analyses?

1.5 - Improved syndromic surveillance practice

- Streamlining expectations from healthcare providers and the public and what info can be shared
- If the federal partner is using one system this allows for increased interoperability in a way since all data is flowing or being used and analyzed through that one platform vs. many at state/local levels and then can be shared back with the participating jurisdictions comprehensive visibility into the state of syndromic trends at the state or local level,
- More robust syndrome definitions developed, validated and can be used with fields the state/locals collect that CDC cannot access like free text fields.
- More robust query and visualization options in NSSP ESSENCE based on the same level of access state/locals have.
- Technical assistance in creating and standardizing syndromes for consistency across jurisdictions and support for less-resourced jurisdictions

Question 2: What concerns you about increasing federal access to state syndromic surveillance data at the state or local level?

2.1 - Increasing the burden on jurisdictions

- ...High frequency of requests to states or locals to examine signals or other indicators of low importance or no value. (from a state perspective)
- Inadequate communication with local site administrators. The cadence and content of communications, method of communication.
- Concerns about the states responsibilities and need for on the ground
- CDC announcing something before state or locals know what is going to be made publicly available and being inundated with additional questions that you are not anticipating from the public.
- "Hot spot" PTSD

- *Situational awareness - double edge sword - too much info currently, can't stay on top of changing environment/situations*
- *As with past experiences during COVID, when CDC releases data at state level that states are also releasing and analyzing, any discrepancies can cause unnecessary public alarm and leads to extensive time at the state and local level evaluating and explaining*
- *It is a concern that there will be no benefit to the states, only negative impacts from overburdening states with data interpretation questions as well as fall out from sharing of analyses done by federal partners to stakeholders that act locally*

2.2- Misinterpretation of data

- *Inability to understand the local context of data*
- *Inappropriate types and levels of analysis given the limitations of the data, syndrome applicability, or relationship between facilities and jurisdiction.*
- *Inappropriate comparisons that are seemingly at a geographic level but in reality, are at a facility level because of data content, population characteristics, etc.*
- *Misinterpretation of state data (e.g., public dashboards)*
- *Misinterpretation of data that they don't understand and don't involve state/local in analysis*
- *Local context is critical and CDC does not have that expertise...*
- *CDC conducting analysis without understanding what caveats and limitations there are to the data and not talking to state/locals to be considered with analysis*
- *Lack of knowledge of local facilities, connections with local facilities and coders/hospital staff to help validate data/understand prescribing*
- *Emergency department visits may be impacted by changes in health-seeking behavior, as individuals with symptoms may avoid emergency department visits – so how do we leverage other data sources here?*

2.3 - Publishing the data can decrease jurisdictional credibility

- *...NSSP/CDC releasing or discussing local data (meaning below a state level) with policymakers from those jurisdictions without state or local input/awareness.*
- *Inappropriate public release of data, additionally an issue when it can be linked to a particular facility.*
- *Publications of data or analysis using state, local, or facility-based data without state collaboration.*
- *Even beyond FOIA, CDC during COVID released large amounts of data to press, who ran analysis that then contradicted state analysis. Time spent*

clarifying the data and discrepancies. Costs time and credibility of state efforts. Pressure on states to report publicly and accurately likely higher than pressure on CDC.

- New CDC may not have full understanding on code of conduct (i.e., what they should and shouldn't post)*
- Potential risk of data being released without states awareness and involvement.*
- CDC writing, publishing, presenting on state/local the pandemic, epidemic, event, outbreak, surveillance area of interest without approval, notification, or permission.*
- CDC announcing something before state or locals know what is going to be made publicly available and being inundated with additional questions that you are not anticipating from the public.*
- Publications/presentation surprises to the jurisdiction*
- FOIA and info release w/o state, local, tribal knowledge/control*

2.4 - Inadequate, excessive, or inappropriate communication regarding data uses

- ...NSSP/CDC releasing or discussing local data (meaning below a state level) with policymakers from those jurisdictions without state or local input/awareness.*
- ... NSSP identifies issues and then passes it up the chain within CDC or HHS without early input from jurisdictions.*
- Inadequate communication with local site administrators. The cadence and content of communications, method of communication.*
- Not knowing that our data is being used and how it was being used;*
- The access and results were not being communicated with states;*
- Communications with our LPHAs and hospitals if this data is going to be used wider than how we have done so far. Our data contains medical record numbers and hospital names and patient birthdates. I don't think that these fields are often needed to be used while federal agencies using the data for public health hazards, especially if they are looking at aggregate data.*

2.5- Negative effect on collaborations leading to presentations or publications

- Publications of data or analysis using state, local, or facility-based data without state collaboration.*
- Misinterpretation of data that they don't understand and don't involve state/local in analysis*
- The emphasis on collaboration across CDC programs with the community dissolves for any use of the syndromic data.*

2.6- Federal government independently sharing data or initiating public health action without notifying states

- ... NSSP identifies issues and then passes it up the chain within CDC or HHS without early input from jurisdictions.
- Not knowing that our data is being used and how it was being used;
- New CDC may not have full understanding on code of conduct (i.e., what they should and shouldn't post)
- Potential risk of data being released without states awareness and involvement.
- CDC contacting our hospitals/facilities and conducting an investigation without approval, notification, or permission.
- CDC writing, publishing, presenting on state/local the pandemic, epidemic, event, outbreak, surveillance area of interest without approval, notification, or permission.
- Not knowing how CDC or any other federal partners that access to the data will use it

2.7- Privacy and confidentiality concerns, including data sensitivity, restriction of certain fields, and public perception of increased data sharing

- Communications with our LPHAs and hospitals if this data is going to be used wider than how we have done so far. Our data contains medical record numbers and hospital names and patient birthdates. I don't think that these fields are often needed to be used while federal agencies using the data for public health hazards, especially if they are looking at aggregate data.
- ...Data details is extremely sensitive. That level without restrictions (individual users for short time period, limited fields accessed) would be a hard no.
- How we account for sharing of rural locations and what protections are in place in terms of the analyses and display of that data or information
- Public's concerns re: # of people accessing data and how it's being used
- Risk of unlimited data mining
- Often stricter parameters around privacy understood for infectious diseases than other conditions
- A limited (de-identified) data set can provide CDC with the necessary information and mitigate many of the concerns listed above
- Inappropriate public release of data, additionally an issue when it can be linked to a particular facility.
- Hospitals/Facilities/Jurisdictions Privacy Concerns
- Tribal data sovereignty a big concern in WA
- Privacy protection - line level data can identify without direct identifiers
- How will the data collected + used be utilized by CDC, other federal agencies

2.8- Freedom of Information Act (FOIA) Issues

- Concern that data would have to be released due to FOIA
- Public distrust with misinterpretation of the data/FOIA concerns

- FOIA
- FOIA and info release w/o state, local, tribal knowledge/control

2.9- Adequacy of and adherence to data sharing rules (including agreements, codes of conduct, etc.)

- Concern that any DUA agreement that could be put into place with NSSP would not apply to the centers or program areas who are providing funding.
- New CDC may not have full understanding on code of conduct (i.e., what they should and shouldn't post)
- Oversight of data linkage
- State vs Federal statute inconsistencies?
- Disregard for agreements in place due to pressures within federal government or emergency status

Question 3: What rules, restrictions, guidelines, or codes of conduct could be implemented in the NSSP DUA or CDC policies that might address a concern addressed by you or a fellow workgroup member?

3.1 - Restrict data access for specific purposes or events

- Requests for data per event/situation
- Access to data should be at the specific individual user level, for defined time periods, for specific purposes.
- There needs to be a specific rationale and stated purpose for broad line level access- no data mining. Parameters must be in place.
- Sharing should be for defined periods of time for specific users for specific purposes (Too open-ended)

3.2- Establish audit and documentation process for data access and analysis

- ...Code of conduct like Richard Hopkins' version-but with modifications. Needs to include process for removal of access.
- Auditing and documentation of staff access and queries of state/local data.
- Audit trail of where, how, and to whom data was shared.
- Robust and open communications about projects, staff roles, opportunities for state input.
- Being clear on how the info is shared and notifying states receipts of disclosures; permission/collaborative discussion granted by the state prior to disclosures

3.3- Restrict data access to specific users (as opposed to groups of users)

- Access to data should be at the specific individual user level, for defined time periods, for specific purposes.
- ... States need authority for removing state level data access based on a predefined set of criteria/issues- this would exist even after access was originally granted

- *Sharing should be for defined periods of time for specific users for specific purposes (Too open-ended)*

3.4- Make DUA applicable to all federal recipients of NSSP data

- *DUA need to include specific provisions for data re-release (if any) and that includes to internal CDC staff outside of NSSP approved staff, other federal agencies, and contractors.*
- *Not sure an agreement at the level of NSSP (or even CDC) will provide a guaranteed protection*
- *...DUA be for all of CDC and all data sources in the BioSense Platform.*
- *DUAs must apply to program areas/ centers that access the data, regardless of whether it is aggregated or line level.*
- *Concern that any DUA agreement that could be put into place with NSSP would not apply to the centers or program areas who are providing funding”*
- *What are the limits of sharing data across federal agencies/programs/different administrations and who makes that determination*

3.5- Involving state and local partners in data analysis

- *Robust and open communications about projects, staff roles, opportunities for state input.*
- *Right of first refusal by states/locals on analysis plans, protocols and publications- I am not sure exactly what I mean by this but more that states have the ability to say whether they want to complete a particular analysis or review of their own data rather than CDC just doing it and telling the state about it after- or something like that.*
- *Collaboration with Sites, NSSP, CDC, and the NSSP CoP, must be a part of the policy. Decisions on the data, system, access, use, cannot be done in a bubble.*
- *Being clear on how the info is shared and notifying states receipts of disclosures; permission/collaborative discussion granted by the state prior to disclosures*

3.6 - Require training on code of conduct

- *...HIPAA like training so that staff understand code of conduct*
- *In addition to the code of conduct which needs to be applied to all data sources in the platform, there needs to be training for specific sites. Not every Site is the same nor is its data contributing to the platform. Respecting and including those types of caveats. Limitations, considerations, need to be built into policy.*
- *...Code of conduct like Richard Hopkins' version-but with modifications.*

Needs to include process for removal of access.

- ... States need authority for removing state level data access based on a predefined set of criteria/issues- this would exist even after access was originally granted*
- In addition to the code of conduct which needs to be applied to all data sources in the platform, there needs to be training for specific sites. Not every Site is the same nor is its data contributing to the platform. Respecting and including those types of caveats. Limitations, considerations, need to be built into policy.*

3.1 - Establish restrictions on data publication

- No publication of data below a national level without state/local participation offered (in the analytic stage specifically). If states prefer not to participate, they then need to at least sign off on the final publication. This should include national projects that use subsets of state data that then identify the facilities or states that subset came from.*
- Different diseases and conditions have different policies surrounding use and publication. There is not necessarily a one size fits all definition. Something needs to be built into the larger DUA and policy to acknowledge this.*
- No publishing of data publicly*

3.8 - Create standards for removing access

- ... States need authority for removing state level data access based on a predefined set of criteria/issues- this would exist even after access was originally granted*
- ...Code of conduct like Richard Hopkins' version-but with modifications. Needs to include process for removal of access.*

3.9- Create communication protocols between CDC and STLTs

- Robust and open communications about projects, staff roles, opportunities for state input.*
- Perhaps some sort of decision matrix by state that includes things like geographies that are problematic, severe limitations on interpretations, etc. that CDC can refer to prior to reaching out to a state for examination of an issue*
- Defined communication protocols that include methods, timelines for reply, expectations of level of effort, etc.*
- Define communication strategy*
- Collaboration with Sites, NSSP, CDC, and the NSSP CoP, must be a part of the policy. Decisions on the data, system, access, use, cannot be done in a bubble.*
- In the event of a multi-state outbreak/event, how will CDC disclose info across*

- different sites and considering the varying sites (decentralized vs centralized)*
- *Clear written protocols are needed*

3.10 - Allow optional participation in greater federal access

- *Formalize the process to request the data (opt in, not opt out)*
- *... Misuses of the data, where a local jurisdiction wants to opt out should be allowed.*
- *Develop agreements with each jurisdiction to opt-in on varying levels; make it optional for jurisdictions to participate.*

3.11 - Include procedure for DUA renewal

- *There needs to be a renewal process for the DUAs. There are many changes that happen year to year, and some are huge shifts that need to be current in the DUAs used that align with current policies in place.*

3.12 - Clarify breach responsibility

- *Legal authorities to collect data, who is responsible in the event of a data breach*

Appendix D: Workgroup Call 2 Agenda

CSTE Federal Use of Nssp Data Workgroup Call #2 Meeting 2 Agenda, November 8, 2021, 3:00 PM CT

1. (3:00 – 3:39 PM) **NSSP Project Background and Initial Findings**
 - a. Project goals and scope
 - i. Federal access to state health department syndromic surveillance data, including emergency department, urgent care, and vital records
 - b. Preliminary findings
 - i. Workgroup Call #1 issue prioritization discussion
 - ii. Key informant interviews
 - iii. Literature review and environmental scan
 - c. Impetus
2. (3:40 – 3:44 PM) **Workgroup Meeting Objective**
 - a. Develop operational frameworks
 - b. Identify critical issues and potential sticking points
 - i. NOTE: These discussions are intended to inform the Consultants' recommendations. Nothing discussed or decided today will be construed as a negotiated or committed position of any federal or STLT agency.
 - c. Three policy questions:
 - i. Communication protocols
 - ii. Framework for STLT and federal collaborations (e.g., data analysis)
 - iii. Identification of issues and questions for different federal use cases (e.g., tiered use cases)
3. (3:45 – 4:04 PM) **Communication protocols between federal and STLT agencies**
 - a. https://docs.google.com/document/d/1Vn3O_MjC1uxxNjPJ3hk7KS6Mtg_vLWAx0tVrRsp6DYcs/edit?usp=sharing
 - b. Develop ideas and questions about appropriate communication protocols—discussion may include topics concerning:
 - i. Nature of communication
 - ii. Content of communication
 - iii. Communication triggers
 - iv. Communication response expectations
4. (4:05 – 4:29 PM) **Framework for STLT and federal collaboration (e.g., data analysis)**

- a. https://docs.google.com/document/d/1Vn3O_MjC1uxxNjPJ3hk7KS6Mtg_vLWAx0tVrRsp6DYcs/edit?usp=sharing
 - b. Develop ideas and questions about a collaborative framework—discussion may include topics concerning:
 - i. When to involve STLT HDs
 - ii. How should STLT HDs be involved
 - iii. How should STLT HDs be consulted
 - iv. How should CDC or other federal partners approach STLT HDs regarding new NSSP use cases
5. (4:30 – 4:54 PM) **Identification of issues and questions for different federal use cases (e.g., tiered use cases)**
- a. https://docs.google.com/document/d/1Vn3O_MjC1uxxNjPJ3hk7KS6Mtg_vLWAx0tVrRsp6DYcs/edit?usp=sharing
 - b. Issues and questions related to different use cases involving expanded access—discussion may include topics concerning access to:
 - i. NSSP core personnel
 - ii. Other CDC units (e.g., injury, infectious disease)
 - iii. Other HHS agencies
 - iv. Non-HHS federal agencies
 - v. Public-use NSSP data
6. (4:55 – 5:00 PM) **Follow Up Assessment**
- a. Consultants will send a follow-up assessment allowing participants to indicate support, identify concerning issues with generated ideas or policy frameworks, or offer alternative approaches.

Appendix E: Assessment of specific proposals on communication, collaboration, and governance

ANALYSIS FROM WORKGROUP 2 ONLINE ASSESSMENT OF SPECIFIC PROPOSALS ON COMMUNICATION, COLLABORATION, AND GOVERNANCE

Online Assessment Participant Characteristics:

Participants Primary Professional Role	Frequency
I work in a state, tribal, local, or territorial health department.	8
I work for a national public health organization, such as ASTHO or CSTE.	0
I work for the Federal Government	0
Other	0
	Total
	8

	Frequency		Total
	Yes	No	
Participants that attended the first CSTE Federal Use of NSSP Data Project Workgroup Call	1	7	8

I. PROPOSALS CONCERNING COMMUNICATION

Proposals on communication	Strongly Agree (n)	Agree (n)	Neither agree nor disagree (n)	Disagree (n)	Strongly Disagree (n)	Mean*
All federal communications regarding syndromic surveillance data should be directed only to STLT syndromic surveillance contacts.	3	3	1	1	0	4.00
No federal partner should contact participating facilities directly regarding syndromic surveillance findings or activities.	3	3	1	1	0	4.00
I would be in favor of a classification system for federal NSSP communications to STLT syndromic surveillance contacts that indicates the expected response from STLT partners. For example, STLT contacts are not expected to respond to low-priority communications (i.e., for your information only), but a response is expected for high-priority communications.	2	4	0	2	0	3.75
All communications about the use of NSSP data by federal partners should only occur on a designated platform so that all communications can be easily located and monitored.	0	6	1	1	0	3.63

A communication portal should be implemented in the NSSP Biosense Dashboard.	0	7	0	0	1	3.63
If a communication portal is added to the NSSP Biosense Dashboard, users should have the ability to flag communications with different levels of importance.	0	4	4	0	0	3.50

**In calculating the mean, Likert options were scored 1-5 with Strongly Agree= 5, Agree= 4, Neither agree nor disagree= 3, Disagree= 2, Strongly Disagree= 1*

II. PROPOSALS CONCERNING COLLABORATION

Proposals on access requests	Strongly Agree (n)	Agree (n)	Neither agree nor disagree (n)	Disagree (n)	Strongly Disagree (n)	Mean*
Requests for granular access by federal partners should include a clear description of the group requesting access.	5	3	0	0	0	4.63
Requests for granular access by federal partners should include a clear description of the purpose of the granular access.	5	3	0	0	0	4.63
Requests for granular access by federal partners should include a clear description of the timeframe of the expanded access (i.e., the	4	4	0	0	0	4.50

start and end dates of the data being queried).						
Requests for granular access by federal partners should state the jurisdictions whose data will be accessed .	4	4	0	0	0	4.50
Requests for granular access by federal partners should state the stratification or level of granularity requested (e.g., state, county, facility, line).	4	3	0	1	0	4.25
Requests for granular access by federal partners should include an estimated timeline for data analysis .	3	3	1	1	0	4
Requests for granular access by federal partners should include an estimated timeline for publication (e.g., submission to venue) or dissemination of findings.	2	4	1	1	0	3.88

**In calculating the mean, Likert options were scored 1-5 with Strongly Agree= 5, Agree= 4, Neither agree nor disagree= 3, Disagree= 2, Strongly Disagree= 1*

Proposals on routine surveillance activities	Strongly agree (n)	Agree (n)	Neither agree nor disagree (n)	Disagree (n)	Strongly disagree (n)	Mean*

It would be helpful if CDC NSSP staff coordinated closely with my site to routinely provide an extra set of eyes on our data and provide either reports or informal communications about what they find in the data (expectations of type and frequency of communications can be agreed upon ahead of time)	0	7	1	0	0	3.88
It would be helpful if CDC NSSP staff could generate regular visualizations based on agreed-upon queries of my state’s NSSP data for me	0	7	1	0	0	3.88
It would be helpful if CDC NSSP staff could generate regular reports based on agreed-upon queries of my state’s NSSP data for me	0	6	2	0	0	3.75
Assuming valid methods are used and a public health justification exists, I am fine with core CDC NSSP staff assisting our routine surveillance activities as an “extra set of eyes” with state-level data subject to reasonable restrictions (e.g., dissemination).	0	6	1	1	0	3.63
Assuming valid methods are used and a public health justification exists, I am fine with core CDC NSSP staff assisting our routine surveillance activities as an “extra set of eyes” with county-level data subject to	0	5	2	1	0	3.50

reasonable restrictions (e.g., dissemination).						
Assuming valid methods are used and a public health justification exists, I am fine with core CDC NSSP staff assisting our routine surveillance activities as an "extra set of eyes" with facility-level data subject to reasonable restrictions (e.g., dissemination).	0	4	2	1	1	3.13
Assuming valid methods are used and a public health justification exists, I am fine with core CDC NSSP staff assisting our routine surveillance activities as an "extra set of eyes" with line-level data subject to reasonable restrictions (e.g., dissemination).	0	3	2	1	2	2.75

**In calculating the mean, Likert options were scored 1-5 with Strongly Agree= 5, Agree= 4, Neither agree nor disagree= 3, Disagree= 2, Strongly Disagree= 1*

Which routine federal use of state NSSP data are you most concerned with: research or surveillance?	Frequency
I am substantially more concerned with routine research uses of state NSSP data (1)	2
I am slightly more concerned with routine research uses of state NSSP data (2)	2

Neutral (3)	2
I am slightly more concerned with routine research uses of state NSSP data (4)	0
I am substantially more concerned with routine surveillance uses of state NSSP data (5)	2
	Mean
	2.75

Proposals on federal publications of state-level NSSP data	Strongly Agree (n)	Agree (n)	Neither agree nor disagree (n)	Disagree (n)	Strongly Disagree (n)	Mean*
Assuming valid methods are used, I am fine with the federal government publishing state-level NSSP data so long as all included jurisdictions provide express consent to have their data included in the analysis.	3	5	0	0	0	4.38
Assuming valid methods are used, I am fine with the federal government publishing state-level NSSP data so long as there is adequate and appropriate opportunity for a state to request that their data is removed from the analysis.	2	5	1	0	0	3.88
Assuming valid methods are used, I am fine with the federal government publishing state-level NSSP data with adequate and appropriate notice.	1	3	2	1	1	3.25

*In calculating the mean, Likert options were scored 1-5 with Strongly Agree= 5, Agree= 4, Neither agree nor disagree= 3, Disagree= 2, Strongly Disagree= 1

III. PROPOSALS CONCERNING GOVERNANCE

Proposals on Governance	Strongly Agree (n)	Agree (n)	Neither agree nor disagree (n)	Disagree (n)	Strongly Disagree (n)	Mean*
An NSSP governance group would be beneficial to state-federal collaborations	1	6	1	0	0	4.00
A governance group would be useful to "flag" or alert states when a proposed federal use of NSSP data might require increased state attention or scrutiny	0	7	1	0	0	3.88
To reduce the transaction burden of negotiating with all jurisdictions independently, an NSSP governance group should be empowered to restrict routine federal access to NSSP data subject to reasonable limitations, including maintaining	1	5	2	0	0	3.88

a right for jurisdictions to opt-out of governance board decisions.						
An NSSP governance group would be useful to provide pre-decisional input on federal uses of NSSP data (e.g., review of NSSP reports to the CDC director)	0	6	2	0	0	3.75
To reduce the transaction burden of negotiating with all jurisdictions independently, an NSSP governance group should be empowered to recommend expanded or restricted routine federal access to NSSP data subject to reasonable limitations, including maintaining a right for jurisdictions to opt-out of governance board decisions.	0	5	1	0	1	3.50
An NSSP governance group should be comprised of elected CSTE members.	0	3	2	3	0	3.00
To reduce the transaction burden of negotiating with all jurisdictions independently, an NSSP governance group should be empowered to expand routine federal access to NSSP data subject to reasonable limitations, including maintaining a right for jurisdictions to opt-out of governance board decisions.	0	2	2	3	1	2.63

**In calculating the mean, Likert options were scored 1-5 with Strongly Agree= 5, Agree= 4, Neither agree nor disagree= 3, Disagree= 2, Strongly Disagree= 1*

Primary role of the governance group	Rank 1	Rank 2	Rank 3	Rank 4	Rank 5	Total Score
Providing pre-decisional input on federal uses of NSSP data (e.g., review of NSSP reports to the CDC director)	3	3	0	0	1	28
"Flagging" or alerting states when a proposed federal use of NSSP data might require increased state attention or scrutiny	2	2	3	0	0	27
Expanding routine federal access to NSSP data subject to reasonable limitations, including maintaining a right for jurisdictions to opt-out of governance board decisions.	4	1	0	0	0	24
Restricting routine federal access to NSSP data subject to reasonable limitations, including maintaining a right for jurisdictions to opt-out of governance board decisions.	2	0	2	2	0	20
Recommending expanded or restricted routine federal access to NSSP data subject to reasonable limitations, including maintaining a right for jurisdictions to opt-out of governance board decisions.	0	2	2	2	0	18

**In calculating the total score, items ranked 1, 2, 3, 4, and 5 were assigned scores of 5,4, 3, 2, and 1 respectively. The total score is the sum of all respondents' ranking scores.*

Proposals on accountability and trust	Strongly Agree (n)	Agree (n)	Neither agree nor disagree	Disagree (n)	Strongly Disagree (n)	Mean*

			(n)			
States should be provided access to audit findings related to their NSSP data.	4	4	0	0	0	4.50
An audit process should be implemented for federal access to state NSSP data.	2	5	1	0	0	4.13

**In calculating the mean, Likert options were scored 1-5 with Strongly Agree= 5, Agree= 4, Neither agree nor disagree= 3, Disagree= 2, Strongly Disagree= 1*

Appendix F: Key Informant Semi-Structured Interview Guide

Instructions:

The table below organizes the key areas of questioning for the key informant interviews. The “Area of Interest” column is for the interviewer’s use only. It contains descriptions of the general topics we wish to explore in the interview. The “Main Questions” column contains open ended questions for the areas of interest. As needed, the interviewer will use the questions in the “Probes” column to solicit specific information. At the interviewer’s discretion, additional clarifying questions may be asked in response to the interviewee’s responses.

Hello,

Thank you for joining me today. As you know, CSTE has convened a workgroup of STLT public health decision-makers and surveillance and informatics experts. The workgroup is providing input on current federal National Syndromic Surveillance Program (NSSP) BioSense Platform data access permissions and opportunities for revisions to federal NSSP data access.

My name is Cason Schmit, and I am an Assistant Professor at Texas A&M University. CSTE selected me as a third-party consultant to compile information from the workgroup and collect additional information from key informants to develop a report on considerations and implementation strategies regarding revisions to permitted federal NSSP data access.

You have been identified as a key informant in this process. During this interview, I will be asking you a number of questions about NSSP and specifically federal access to NSSP data. I want to encourage you to talk openly about the things that you believe are most important. It is ok if the conversation departs from my list of questions occasionally. Although this interview will be recorded, the recording will be held confidentially and will only be used by our team for analysis. Your name or other identifying features will not be shared in the final report or any other publication. Is that ok with you?

Thank you!

Could you please share your title and role?

Area of Interest (Interviewer use only)	Main Questions	Probes
Sustainability	The NSSP BioSense platform has evolved several times throughout its history. In your view, is the current form of the platform sustainable given current and anticipated needs for syndromic surveillance activities? Why or why not?	If not, how do you see it changing in the future?
		Assuming you could change anything about NSSP BioSense, what would that be?
		Do you believe that NSSP BioSense platform in its current form is capable of addressing the types of challenges--like bioterrorism and epidemic disease--it was created to address? If no, why not? If yes, can you elaborate?
	If the Federal government had greater access to state and local data, how would you like them to use that data?	Do you see any benefits to sharing NSSP data with other federal partners or units?
		Do you think that Federal data use should be limited to specific users' roles or purposes? If yes, what user

		roles or purposes?
		What would increased federal access to NSSP data mean for your practice?
	What are your biggest concerns relating to increased Federal access?	
Interests	Given that the CSTE Federal Use of NSSP Data Workgroup is exploring policy opportunities for expanded federal access to NSSP data, what interests or issues are important to you or your state/agency/program in these discussions?	What issues would you most like to see addressed in any agreement between the federal government and the states in relation to enabling greater federal access?
Challenges/B arriers	What do you see as being a significant barrier or challenge to enabling greater federal access to NSSP data?	How do you think this barrier should be addressed?
		Are there policies that could be implemented to address those challenges?
		What are the most significant data sharing barriers that you see?

<p>Policy Development</p>	<p>What do you see as a promising policy opportunity to address some of the concerns or risks associated with increased federal access to NSSP data?</p>	<p>[Ask for details on suggested policies]</p>
		<p>What are your thoughts on possibly implementing a policy that:</p> <ol style="list-style-type: none"> 1. Requires the federal government to involve state and local partners in data analysis? <ol style="list-style-type: none"> a. How should state and local partners be involved? 2. Establishes communication protocols between CDC and STLT HDs? <ol style="list-style-type: none"> a. What should those communication protocols be?
		<p>If you were to pick three policy changes that have the greatest promise to support federal data use of NSSP data while addressing relevant concerns, what three policy changes would you select?</p>
		<p>What are your thoughts on the feasibility of the proposed policy changes?</p>
<p>Best alternative to a negotiated</p>	<p>What do you think will happen if an agreement cannot be reached</p>	<p>What do you think is the federal government's best case scenario if no agreement can</p>

<p>agreement (BATNA)</p>	<p>between states and the federal government?</p>	<p>be reached?</p>
		<p>What do you think is the state governments' best case scenario if no agreement can be reached?</p>
<p>In the Other's Shoes</p>	<p>[Example 1: "If counties within your state stopped providing access to their syndromic surveillance data, how would you approach that situation?"]</p> <p>[Example 2: "How do you think the federal government should react to the increasing pressure to utilize and analyze data for the purpose of identifying national emerging health threats"]</p>	<p>For example, if counties are not providing data?</p>
<p>Private Individual</p>	<p>In your opinion, what would the public think about the NSSP Program having more access to data or any of the changes to the program that we've discussed?</p> <p>Do you have any concerns about what the public might think about syndromic data findings? How will</p>	

	the media or politicians respond to any changes?	
	Is there anything more that you would like to share regarding policies surrounding federal access to NSSP data?	