

Facility Barriers to Diagnosis and Reporting of Neonatal Abstinence Syndrome

**Bureau of
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Table of Contents	1
Introduction	2
Methods	2
Findings	3
Data Limitations	12
Discussion	13
Citations	18
Appendix	19

Introduction

On Jan. 10, 2018, Governor Wolf declared a 90-day disaster emergency for the opioid epidemic in Pennsylvania. With this declaration, neonatal abstinence syndrome (NAS) became a reportable condition to the Pennsylvania Department of Health (Department) per Chapter 27 of the Pennsylvania Health and Safety code. NAS is a withdrawal syndrome experienced by newborns due to prenatal substance exposure to opioids, benzodiazepines, or barbiturates, and infants with NAS are at increased risk for certain medical complications after birth.¹

NAS surveillance presented a unique challenge because, at the time of the emergency declaration, there was no nationally standardized case definition for NAS. NAS surveillance case criteria differed from state to state, and clinical diagnosis criteria varied across facilities within states and providers within facilities. Because of the case criteria challenges, the Department developed a NAS surveillance case definition for implementing rapid case ascertainment.

Approximately one year after NAS surveillance began, the Department teamed with the Pennsylvania Department of Human Services (DHS), the Multi-Disciplinary Workgroup on Infants with Substance Exposure (MDWISE), and the Centers for Disease Control and Prevention (CDC) to develop a survey aimed to assess the difficulties and barriers experienced by facilities for both clinical diagnosis of NAS and reporting of NAS to the Department. The Department intended to assess whether facilities had difficulties defining diagnostic criteria for cases versus non-cases within the facility, whether the state-provided case definition and reporting guidance were clear and effectively communicated, and whether any other barriers to reporting NAS cases existed.

This report summarizes facilities' responses regarding their experiences with internal NAS diagnosis and reporting of cases to the Department under the opioid emergency declaration in the first year of reporting.

Methods

Survey questions were developed with focus on internal diagnostic criteria, NAS-related protocols, and barriers to diagnosis and reporting. Questions related to protocols on screening mothers and infants for substance exposure, reporting infants to Child and Youth Services, and referral to treatment services were asked in a prior survey developed and distributed through collaboration of the Department, MDWISE, DHS, and the Hospital and Healthsystem Association of Pennsylvania (HAP).

A unique survey link was distributed to the Department's main contacts and reporters via email for each of the 95 NAS reporting facilities on Jan. 7, 2019. Facilities were asked to respond by Jan. 31, 2019. Reporters were instructed to submit only one completed survey per facility but were encouraged to submit for each facility within a health network, recognizing that different facilities within the network may experience different barriers.

Within the survey, questions about NAS diagnosis were asked with reference to the facility’s “NAS case definition or diagnosis criteria” to be inclusive of potential terminology used at facilities. To evaluate criteria related to positive toxicology results in infants or mothers, three survey response choices were provided for facilities to indicate whether specified drugs are included in their internal NAS case definitions. The response choices were: Yes, this criterion alone is sufficient to meet the case definition; Yes, but only in combination with other criteria; No, this criterion is never a part of the case definition. The “Yes...alone” versus “Yes...combination” choices were provided to better ascertain the scope of the facility’s case definition. For the purposes of summarizing data within this report, the two “Yes” responses are combined into a single value representing drug inclusion in the case definition. The “No” responses are displayed as a separate response.

Analyses were performed on the full dataset of all responses received using Base SAS 9.4. Some analyses were also stratified by rural versus urban or by the facility’s highest neonatal intensive care unit (NICU) level. Rural versus urban status was determined at the county level based upon 2010 census classification.² Stratified analyses were performed only when enough data existed to subgroup the data accordingly.

This report presents the survey findings of facilities’ experiences in diagnosing and reporting NAS during the first year of NAS being reportable to the state. Infant cases during this period were born between January 2018 to January 2019.

Findings

In total, 62 (65%) of 95 facilities submitted responses. In many cases, not all survey questions were answered by all responding facilities. Therefore, the total number of responses for each of the survey question varies.

Of 62 responding facilities, 40 were in urban counties, and 22 were in rural counties. Seventeen facilities (27%) had a level I NICU, 14 (23%) had a level II NICU, and 31 (50%) had a level III NICU.

Table 1 – Profile of Responding Facilities

	Location		NICU Level			Total
	Urban	Rural	Level I	Level II	Level III	
Number of responding facilities	40	22	17	14	31	62
Percent of total responding facilities (%)	65%	35%	27%	23%	50%	100%

SOURCE: NAS facility survey dataset, Bureau of Epidemiology, Pennsylvania Department of Health (2019)

NAS Diagnosis and Infant Evaluation

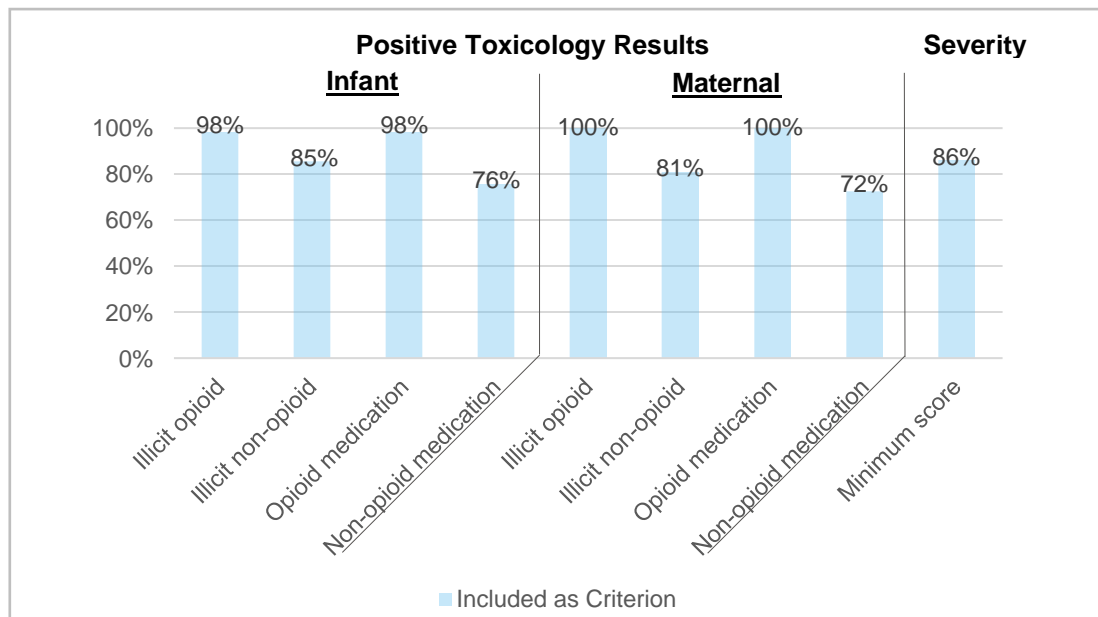
In total, 61 (98%) of 62 facilities reported that infant toxicology evidence of illicit opioids or opioid medications are included in the facility's case definition or diagnosis criteria. Eighty-five percent reported inclusion of infant toxicology evidence of non-opioid illicit drugs and 76% reported inclusion of non-opioid medications.

Facilities had similar drug inclusion criteria when using maternal toxicology results. All 58 facilities that responded to this question indicated that positive maternal results for illicit opioids and opioid medications were included in the facility's diagnosis criteria. Eighty-one percent of facilities included illicit non-opioids, and 72% included non-opioid medications.

Additionally, facilities were asked whether a minimum NAS severity score was a criterion for diagnosing an infant with NAS. Severity scoring is performed by assigning a numeric score for a series of known symptoms and totaling that score to assess the severity of withdrawal in an infant. This score may be used by facilities to track infant progress, determine if or when to use pharmacologic intervention, or diagnose an infant. In total, 50 (86%) of 58 responding facilities reported that a minimum severity score is a criterion for diagnosis, and eight said it is not.

Figure 1 below displays facility responses for infant and maternal toxicology results and withdrawal severity as they relate to their NAS case definitions or diagnosis criteria.

Figure 1 – Facility Responses on Inclusion of Toxicology Results in Their NAS Case Definition or Diagnosis Criteria



SOURCE: NAS facility survey dataset, Bureau of Epidemiology, Pennsylvania Department of Health (2019)

NAS symptoms typically appear within 1-5 days after birth. Timing of symptom appearance is dependent upon many factors including drug(s) of use, time of last use, dose, and infant metabolism (Kocherlakota, P., 2014). Related to this, facilities were asked whether they recommend infants suspected of NAS stay for a specified amount of time to be evaluated for symptoms prior to discharge. Excluding “unknown” response, 49 of 56 facilities (88%) reported keeping infants for an internally established number of days for observation. Urban facilities more often reported a recommended minimum length of stay for observation (95% of urban facilities, 74% rural, $p=0.03$). Table 2 shows the number of facilities advising a minimum length of stay for infant observation.

Of those that have an established amount of time for observation, most responding facilities (70%) keep infants for five days for observation, 10% of facilities reported holding infants for a shorter duration, 14% reported holding infants for a longer duration, and 6% did not specify a duration.

Table 2 – Number of Facilities Recommending a Specified Length of Stay to Observe Infants for Development of NAS Symptoms

	Facility		Total
	Rural	Urban	
Required	14	35	49
Not required	5	2	7
Total	19	37	56

SOURCE: NAS facility survey dataset, Bureau of Epidemiology, Pennsylvania Department of Health (2019)

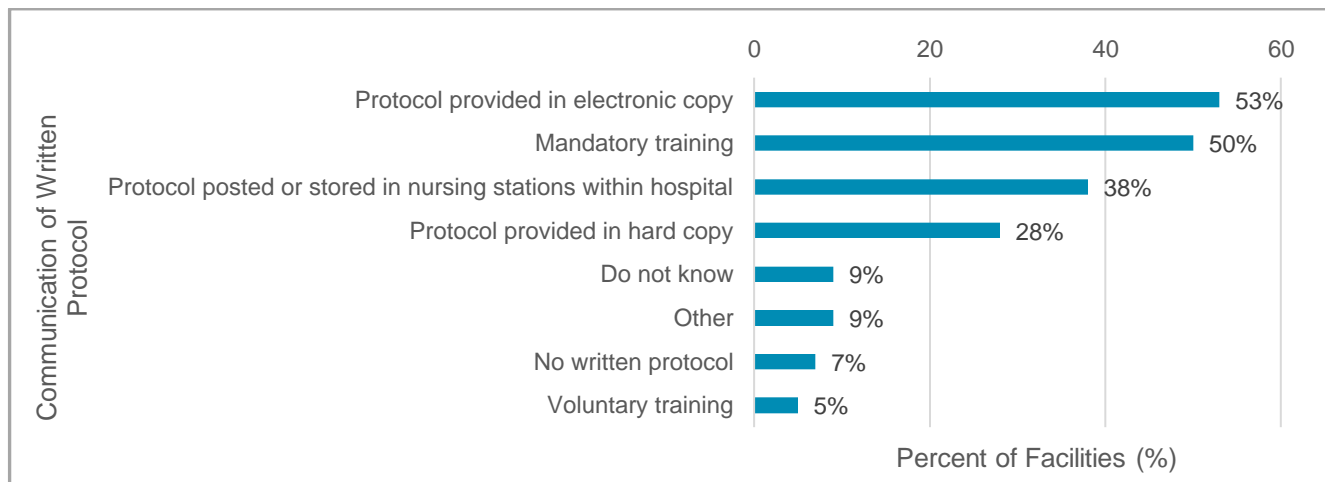
Documentation for NAS Diagnosis and Treatment

Facilities were asked to report their internal diagnosis criteria or case definitions if available. Thirty-three (53%) of 62 facilities provided a response to the question via either a written response or an uploaded document pertaining to their internal criteria. There were no differences between rural and urban facilities as to whether they provided a case definition.

Facilities were also asked whether they have an internal written protocol regarding NAS diagnosis or treatment, and if they do, how the protocol is communicated to staff. Out of 58 responding facilities, 49 (84%) reported having a written protocol, five (9%) were unsure whether they had a written protocol, and four (7%) reported they did not have a written protocol. Thirty-one facilities (53%) reported an electronic copy of a protocol is provided to staff, 29 (50%) reported having mandatory training on the protocol, 22 (38%) reported that the protocol was posted or stored in nursing stations within the hospital, 16 (28%) reported that they have a hard copy provided to staff, four (9%) reported “other,” and three (5%) reported voluntary training. For those facilities indicating “other,” three facilities indicated that the policy can be found on the facility’s intranet, one facility indicated that the policy can be found within a policy book, and two facilities outlined a written summary of how NAS is handled within the facility.

Urban facilities more often had a written protocol than rural facilities (27% and 5% in urban and rural facilities, respectively; $p=0.03$).

Figure 2 – Facility Communication of Written Protocol for NAS Reporting



SOURCE: NAS facility survey dataset, Bureau of Epidemiology, Pennsylvania Department of Health (2019)

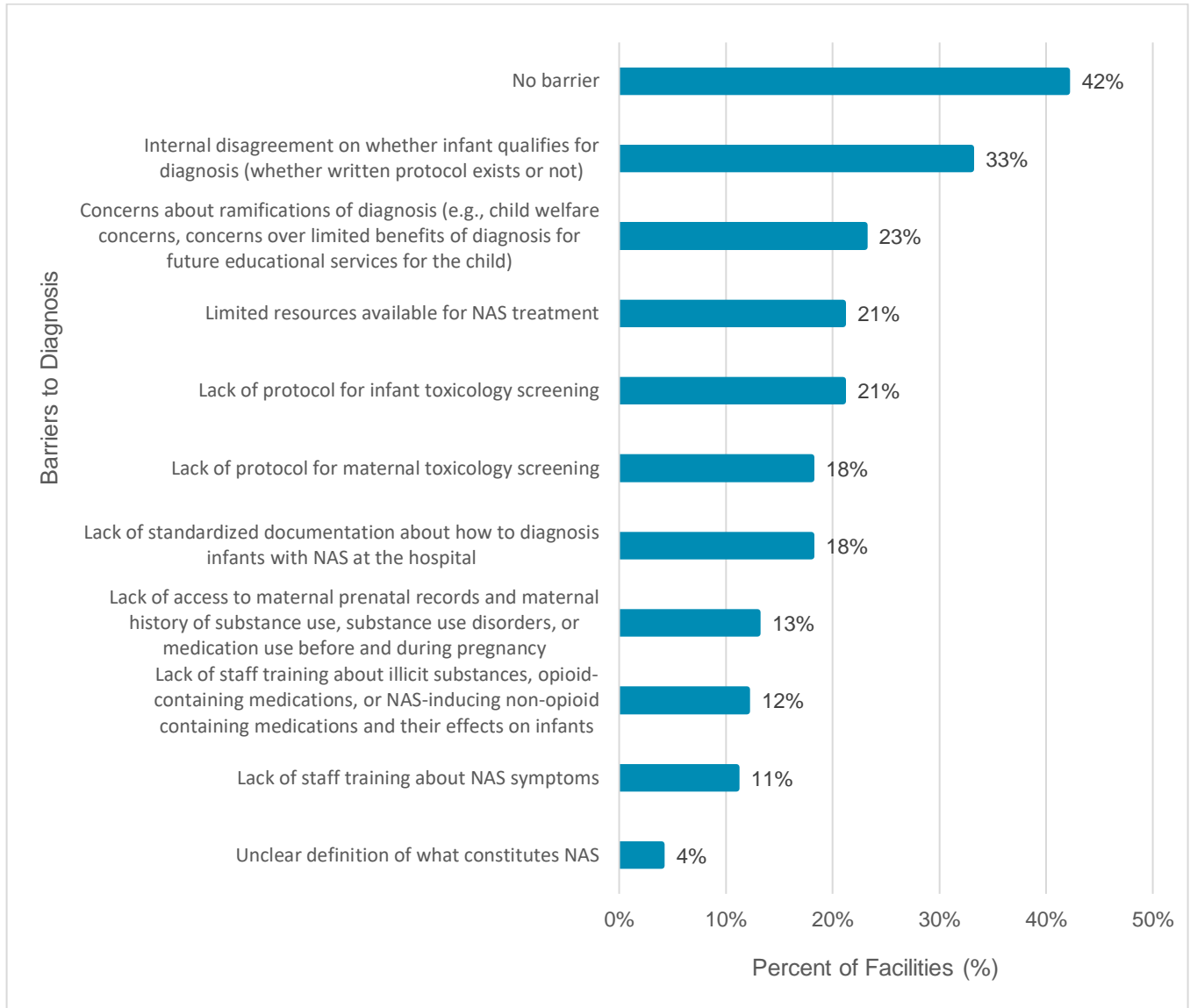
Barriers to Diagnosis

To assess barriers to diagnosing NAS in an infant, facilities were provided a list of potential barriers and asked to check all that apply. Of 57 responses, the four most commonly checked barriers included “Lack of access to maternal prenatal records and maternal history of substance use, substance use disorders, or medication use before and during pregnancy” (42%); followed by “Lack of protocol for maternal toxicology screening” (33%); “Lack of protocol for infant toxicology testing or other infant screening” (23%); “Internal disagreement on whether infant qualifies for diagnosis” (21%).

Twenty-two (39%) responding facilities reported having three or more barriers, and 13 (23%) reported having four or more barriers. Two facilities reported having seven barriers. Twenty-one percent of facilities reported that they had no barriers to diagnosing an infant with NAS.

Figure 3 shows the percent of facilities that reported experiencing the noted barriers. For display purposes, some responses have been abbreviated. The full text of the survey response choice is listed in the reference footnote. Response choices are not mutually exclusive.

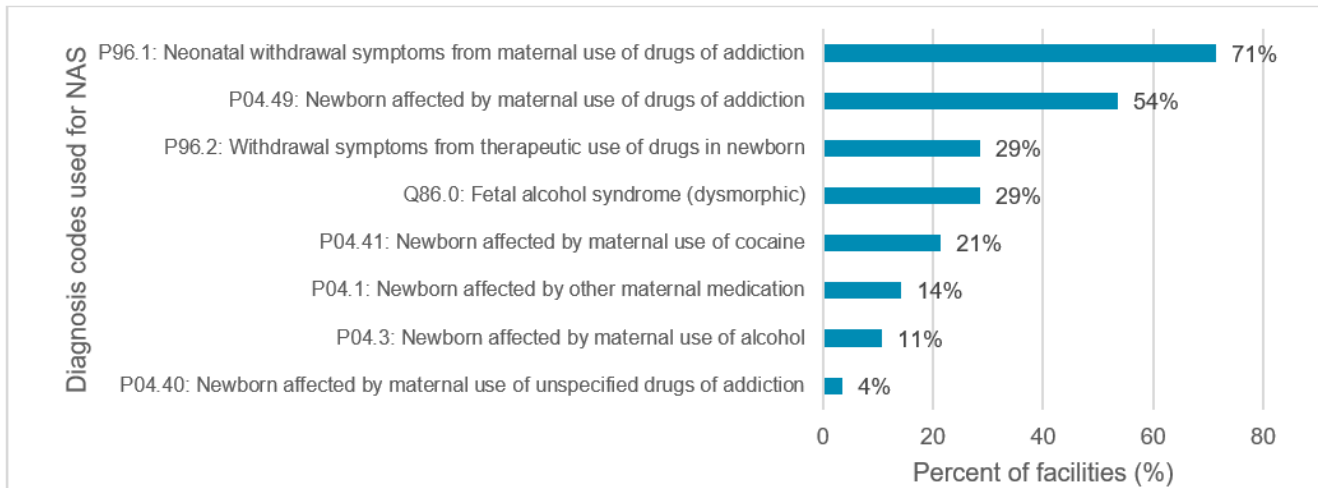
Figure 3 – Barriers to NAS Diagnosis as Reported by Facilities (Not Mutually Exclusive)



SOURCE: NAS facility survey dataset, Bureau of Epidemiology, Pennsylvania Department of Health (2019)

The survey also included a question to determine which ICD-10-CM diagnosis codes were assigned to infants with NAS. A total of 34 reporters of 56 responding indicated they did not know the diagnosis codes for infants with NAS. Of the remaining 28 that indicated codes they use for infants with NAS, the two most frequently reported diagnosis codes were P96.1 (71% of responding facilities) and P04.49 (54% of responding facilities). Code P96.1 represents “neonatal withdrawal symptoms from maternal use of drugs of addiction,” and P04.49 represents “newborn affected by maternal use of other drugs of addiction.” The full list of ICD-10-CM codes that facilities reported using for infants with NAS is listed in Figure 4.

Figure 4 – Diagnosis Codes Used for Infants with NAS, as Reported by Facilities



SOURCE: NAS facility survey dataset, Bureau of Epidemiology, Pennsylvania Department of Health (2019)

To identify the most inhibitive barrier to diagnosis experienced by reporting facilities, facilities were asked to choose a single primary barrier to diagnosis from listed choices. The most commonly reported barrier, “lack of access to maternal prenatal records and maternal history,” was reported by 13 (33%) facilities of 40 responding facilities. Barriers were then assessed separately by rural and urban settings to evaluate whether differences existed. Rural facilities were more likely to report “lack of maternal prenatal records and maternal history” and “unclear definition of what constitutes NAS” as the two primary barriers. Urban facilities were more likely to report “lack of maternal prenatal records and maternal history” and “other” as the two primary barriers. Table 3 displays the frequency of primary barriers reported by rural and urban facilities.

Table 3 – Number of Facilities Reporting Primary Barrier to Diagnosis

Primary reason	Facility		Total
	Rural	Urban	
Unclear definition of what constitutes NAS	3	1	4
Lack of staff training about NAS symptoms	2	1	3
Lack of staff training about illicit substances and effects on infants	1	1	2
Lack of access to maternal prenatal records and maternal history	5	8	13
Lack of standardized documentation about how to diagnose NAS	1	0	1
Lack of protocol for maternal toxicology screening	1	3	4
Lack of protocol for infant toxicology screening	0	2	2
Limited resources available for NAS treatment	0	2	2
Concerns about ramifications of diagnosis	0	0	0
Internal disagreement on whether infant qualifies for diagnosis	0	2	2
Other	2	5	7
Total	15	25	40

^a Red text in each column represents the most commonly reported barriers.

SOURCE: NAS facility survey dataset, Bureau of Epidemiology, Pennsylvania Department of Health (2019)

Facility Reporting of NAS to the Pennsylvania Department of Health

The survey additionally aimed to determine whether facilities have written protocols for reporting NAS cases to the state. Of 57 responding facilities, 42 (74%) reported having a written protocol for reporting, 10 (18%) do not, and 5 (9%) facility reporters stated they do not know.

Urban facilities were more likely than rural facilities to report having a written protocol for state reporting (27% v 5%). However, the NICU level in a facility was not correlated with having a written protocol.

Table 4 below shows number of facilities that have a written protocol for reporting to the state by rural versus urban setting and by NICU level.

Table 4 – Number of Facilities with a Written Protocol for NAS Reporting to the State

Facility Type	Yes, protocol		No protocol		Total
	Count	Percent	Count	Percent	
Rural	1	5%	18	95%	19
Urban	9	27%	24	73%	33
Facility Type	Count	Percent	Count	Percent	Total
Level I	3	19%	13	81%	16
Level II	1	10%	9	90%	10
Level III	6	23%	20	77%	26
Total	10	19%	42	81%	52

SOURCE: NAS facility survey dataset, Bureau of Epidemiology, Pennsylvania Department of Health (2019)

Facilities were asked to identify barriers experienced in reporting NAS cases to the state health department. Fifteen facilities reported at least one barrier. It is unknown whether facilities with no indicated barrier had no barriers or did not respond. Four facilities reported “other.” The “other” category responses are not mutually exclusive, and they included: a provider may not have coded the infant properly; a social worker [reporter] may not have been made aware that an infant met the clinical diagnosis criteria; infants are typically transferred elsewhere for care and reported by the transfer facility; an infant was mistakenly not reported because the reporter was not aware that a reporting extension had been issued under a renewed emergency declaration; and reporter does not have a record of which patients were reported and therefore cannot determine patients that were not reported.^a Table 5 shows barrier choices and the number of facilities reporting the barrier.

^a Responses are summarized, not verbatim.

Table 5 – Facility Barriers for Reporting NAS Cases to the State

Barrier to Reporting	Number of Facilities
No infants diagnosed with NAS have been born in this hospital since Jan. 10, 2018	2
NAS cases have been identified, but they do not meet the state's diagnosis criteria	2
NAS cases have been identified, but we are unsure if they meet the state's diagnosis criteria	2
We do not have the time or staff capacity to report to the state	0
Volume of NAS cases is too high	0
Volume of NAS cases is too low	0
We are unsure of the importance of reporting to the state	0
NAS is not a current priority to the hospital	0
The hospital is concerned about the ramifications of reporting to the state regarding child welfare and confidentiality of reported NAS cases	1
The hospital does not have a process in place for collating NAS cases across the hospital	0
The hospital does not have a process in place for who is responsible for reporting or how frequently NAS cases are reported to the state	0
Inadequate communication from DOH - guidelines and updates are not sent to the correct contact person	0
Inadequate communication from DOH - reporting criteria are unclear	2
Our hospital prefers not to report these cases to the state	0
We were unaware that these cases should be reported	0
Other	4
Do not know	2

SOURCE: NAS facility survey dataset, Bureau of Epidemiology, Pennsylvania Department of Health (2019)

Facilities' NAS Population, Care Management, and Collaboratives

Multiple survey questions were created to assess NAS burden within the responding facilities. Facilities were first asked about the proportion of infants they transfer to a different facility for care, and 44 (71%) of 62 responding facilities indicated “few,” two (3%) responded “some,” two (3%) responded “most,” and one (2%) responded “all” (Table 6). Two (3%) facilities indicated they did not have any NAS cases but would transfer cases for care if they did; one (2%) facility reporter indicated they had no NAS patients, but the facility would not transfer a case for care; and 10 (16%) facilities responded with “do not know.”

In total, 51 facilities indicated they transfer “few,” “some,” “most,” or “all” infants, or they would transfer infants if they encountered NAS cases. These facilities were asked to identify all reasons for infant transfers from a list of response choices (Table 7). Most facilities (n=22,

43%) indicated they do not transfer infants, but they were captured in the analysis due to the response choice “few” which included zero transfers. Seventeen (33%) facilities stated they would transfer infants because they cannot provide the level of care required for NAS infants, six (12%) facilities indicated they have transferred infants at the family’s request, three (6%) facilities indicated they have transferred infants due to a lack of capacity to care for NAS infants, eight (16%) of facilities indicated “other” as a reason for transferring infants. Responses were not mutually exclusive, and percentages represent the percent of facilities reporting the individual transfer reason.

In describing “other” reasons for transferring an infant, six facilities indicated they have transferred or would transfer infants that need a higher level of medical care from NAS-related or non-NAS related complications, one facility indicated that a high census required them to transfer infants, and one facility indicated that they transfer infants for convalescent care before being discharged home.

Table 6 – Approximate Number of Facility NAS Cases Transferred for Care

Infants Transferred for Care	Facilities	
	Count	Percent
Few (approximately 0-25%)	44	71%
Some (approximately 50%)	2	3%
Most (approximately 75%)	2	3%
All (approximately 100%)	1	2%
Did not have NAS, but will transfer	2	3%
Did not have NAS, but will not transfer	1	2%
Unknown	10	16%

SOURCE: NAS facility survey dataset, Bureau of Epidemiology, Pennsylvania Department of Health (2019)

Table 7 – Reason for NAS Infant Facility Transfer

Reasons for Transfer	Number of Facilities	% Facilities Reporting the Transfer Reason
Do not transfer	22	43%
Level	17	33%
Capacity	3	6%
Family request	6	12%
Other	8	16%

SOURCE: NAS facility survey dataset, Bureau of Epidemiology, Pennsylvania Department of Health (2019)

Facilities were also asked what proportion of their NAS infant population were out-of-state residents (Table 8). Of 62 responding facilities, most facilities (n=47, 76%) indicated “few,” two responded “some,” two responded “all (or nearly all),” and 11 responded “do not know.”

Table 8 – Approximate Number of Facility NAS Cases Having Out-of-state Resident Mothers

Out-of-state resident mothers	Facilities	
	Count	Percent
Few (approximately 0-25%)	47	76%
Some (approximately 25%)	2	3%
Most (approximately 75%)	0	0%
All (approximately 100%)	2	3%
Unknown	11	18%

SOURCE: NAS facility survey dataset, Bureau of Epidemiology, Pennsylvania Department of Health (2019)

Finally, facilities were asked whether they have any active projects or grants related to NAS, or whether they participate in any groups, collaboratives, or panels related to NAS issues. Twenty (36%) of responding facilities reported “yes,” 29 (53%) reported “no,” and 13 (24%) reported “do not know” (Table 9). Urban facilities were more likely to report “yes” than rural facilities (52% and 19% of urban and rural facilities, respectively; $p=0.03$), and NICU Level III facilities were more likely to report “yes” than Level II or Level I facilities (67%, 17%, and 15% in NICU Level III, Level II, and Level I facilities, respectively; $p=0.002$).

Table 9 – Facilities Participating in Projects, Grants, Collaboratives, or Similar Relating to NAS

Facility	Total	Participate		Do Not Participate	
		Count	Percent	Count	Percent
Rural	16	3	19%	13	81%
Urban	33	17	52%	16	48%
Level of Care	Total	Count	Percent	No	Percent
Level 1	13	2	15%	11	85%
Level 2	12	2	17%	10	83%
Level 3	24	16	67%	8	33%
Total	49	20		29	

SOURCE: NAS facility survey dataset, Bureau of Epidemiology, Pennsylvania Department of Health (2019)

Data Limitations

Not all reporting facilities responded to the survey, so the data in this report represents a subset of facilities. Facilities with fewer resources and greater barriers may have been less likely to respond, so survey data may underestimate the barriers experienced.

Further, we requested that facility reporters complete the survey, as they are most familiar with the NAS reporting process. However, depending upon a reporter's position within the facility, he or she may not have relevant experiences or access to information to effectively answer select survey questions, such as barriers to diagnosis. Additionally, some facilities have multiple reporters, and questions regarding barriers to reporting may be viewed subjectively and may therefore not accurately represent the experiences of all reporters if a single reporter completed the survey.

Discussion

NAS is mainly associated with prenatal exposure to opioids, and the Department's NAS case criteria at the time of this survey required all reported NAS cases to have opioid exposure. Accordingly, facilities were most likely to identify an opioid toxicology result as a criterion for NAS diagnosis compared to other substances of exposure. All facilities (100%) reported that a positive maternal toxicology result for illicit or prescribed opioid is a criterion included in their case definitions. All but one facility (98%) reported that a positive infant toxicology result for illicit or prescribed opioids is included in its case definitions. The facility that indicated exclusion of positive infants toxicology results for opioids in the case criteria is a large facility that regularly reports infants, so it is unclear whether the omission was due to mistake or a different interpretation of the question, or if the criterion is truly excluded from the facility's diagnosis criteria.

NAS can also be caused by barbiturates and benzodiazepines. Both substances may be used illegally, but they are also commonly prescribed for uses including, but not limited to, insomnia, anxiety, or seizures. Most benzodiazepines and barbiturates are classified by the Food and Drug Administration (FDA) as Pregnancy Category D, meaning there is "positive evidence of human fetal risk based on adverse reaction data from investigational or marketing experience in studies in humans, but potential benefits may warrant use of the drug in pregnant women despite potential risks." Although these substances have been identified as NAS-inducing, 24-28% of reporting facilities excluded non-opioid medications from their diagnosis criteria, depending on whether they were identified in a positive toxicology result for the infant or the mother. Since the time of this survey, the Department added benzodiazepine and barbiturate exposure to the case inclusion criteria beginning January 2020, in agreement with a national case definition published by the Council for State and Territorial Epidemiologists (CSTE) in June 2019. As a result, infants with exposure to these substances are now reported to the state regardless of their opioid exposure status.

Similar to the exclusion of prescribed non-opioid substance exposure from facilities' diagnosis criteria, illicit use of non-opioid substances was more often excluded from facility case definitions. Between 15-19% of facilities excluded illicit non-opioid substances depending upon whether the positive toxicology result was infant or maternal.

In assessment of infant care, rural and urban facilities differed in the recommended number of days of stay for infant observation for NAS symptoms. While approximately 95% of urban facilities reported having an established number of days for NAS evaluation, only 74% of rural facilities reported the same. Of the five rural facilities that reported having no specified number

of days for evaluation, four are lower-level care facilities that indicated they would transfer infants due to the inability to provide the level of care needed, and one indicated they would not transfer infants. Of urban facilities that do not have an established LOS for observation, one facility is a convalescent care facility that receives infant transfers, and one reported they do not transfer infants.

In total, two facilities without an established number of days for infant observation indicated transferring “few” infants to another facility for care, and two indicated infants are generally not transferred. With consideration that many facilities are providing NAS families with resources and education regarding expectations and care for infants with NAS, the evaluation period may be a missed opportunity for some families if infants are discharged prior to being symptomatic and diagnosed, especially for rural residents in which return to the facility may be more difficult, and for lower socio-economic status patients that may lack time or monetary resources to return. Further discussion may be useful in determining whether it may be beneficial and feasible for additional facilities to implement a recommended period of time for observation.

Case definitions provided by facilities were reviewed for content. While many facilities provided well-documented practices for identifying infants with NAS, managing care, documentation procedures, family education, and discharge practices, the clinical criteria used to diagnose NAS were only apparent in 14 (42%) of the 33 provided definitions. Responses with clear case definitions included specific criteria such as “Finnegan score greater than eight,” or one facility reported using the Department’s case definition for internal diagnosis. One reporter stated a lack of consistency within the facility, noting that an infant may not be diagnosed despite being scored on a NAS scale throughout the duration of his or her stay. It appears that a lack of diagnosis criteria may be under-recognized as a barrier, as over half of reporters that indicated having a case definition did not have one clearly outlined in the provided documentation, but more information would be needed to determine whether this is truly a barrier. It is possible that the documentation provided is more often intended for case management versus diagnosis.

Many facilities reported that providers (physicians, physician assistants, or nurses) assign the ICD-10-CM codes. With many facilities reporting no internal case definition and lack of staff training, this can lead to internal discordance over diagnosis criteria and coding inconsistencies. Further, one facility noted that a billing department might update a diagnosis code depending upon whether the infant received pharmacologic care or did not. Although there may be utility and patient financial benefit in making this adjustment, it may inadvertently create disagreement between provider diagnosis and discharge codes. These uncertainties and discrepancies make the use of discharge data for the analysis of NAS more challenging.

With varying case definitions and methods for coding infants with NAS, the survey data confirms that use of discharge codes for NAS differs significantly across facilities. Further, as infant evaluation methods are modified over time, this will affect not only the raw numbers of cases but also the trends in discharge data. A newer NAS assessment method called “Eat, Sleep, Console” (ESC) has gained widespread use among facilities statewide and nationwide. It involves focusing on a core group of symptoms related to infant functioning to evaluate an infant for pharmacologic treatment needs. Studies have indicated that implementation of this method reduces the number of infants receiving pharmacologic treatment, shortens the

duration of hospital stay, and reduces cost of treatment.³ With some facilities including pharmacologic treatment as a criterion for NAS diagnosis, the number of infants diagnosed may drop. This will appear as a decrease in the number of infants presenting with withdrawal symptoms due to prenatal drug exposure, but the true reason may be that fewer infants are being pharmacologically treated and diagnosed, or it may be a combination of these factors. While these changes benefit infants and families in their disease management, it may comparatively underestimate the overall community burden of infants with NAS in the short term and, correspondingly, the resources needed for families and care after birth. It should be noted as a potential limitation in terms of data analysis.

Five facilities listed one or more “other” reasons as a barrier to diagnosis. Three of these facilities cited a lack of testing protocol as problematic (both infant and maternal testing); two noted that urine drug screens (UDS) do not test for all opioids and results can therefore be negative even with well-documented opioid exposure (e.g., medication-assisted treatment (MAT)); one facility cited a need for a level 2 NICU to care for infants; one noted a lack of community resources, including transportation for parents, drug rehabilitation, mental health resources for parents, resources for NAS families, and whole family care for NAS families; one facility noted a lack of consistency across county child welfare systems; and one noted that more “training is needed for nurses [and] facilities, especially small-volume facilities,” and stated that unclear terminology such as “affected by” is difficult to apply clinically.^b

A lack of testing protocol can lead to under-testing and therefore under-diagnosis, and drug screening that cannot accurately detect common types of opioids can also lead to under-diagnosis for those cases in which medical history is not well-documented, or if facility case definitions require a positive toxicology result to diagnose an infant. Similarly, a lack of staff training and unclear terminology may also lead to under-diagnosis or diagnosis inconsistencies. Other reasons listed, including low-level neonatal care, lack of family care resources, and inconsistent child welfare systems, highlight reporter concerns that diagnosing an infant with NAS does not provide sufficient downstream action. Select reporters appear to be indicating a hesitancy to diagnose an infant with NAS due to a perceived lack of infant and family support.

Looking at the difference in rural versus urban primary barriers to diagnosing NAS, rural facilities more often reported barriers pertaining to a lack of foundation for understanding or diagnosing NAS. These included unclear definitions of NAS, lack of staff training, and lack of knowledge regarding opioid-containing medications. Conversely, urban facilities tended to report barriers more closely related to a lack of formal process or documentation. These included barriers related to lack of protocols, limited resources, and internal disagreement on formal diagnosis criteria.

Since the time of conducting this survey, the case reporting process has changed in numerous ways. Most of the listed barriers for reporting to the state involved confusion over the Department’s case definition or reporting criteria. After this survey was conducted, a nationally standardized case definition was published by the Council for State and Territorial

^b “Affected by” terminology is used in select diagnosis codes that may be used for NAS diagnosis, including P04.49: “Newborn affected by maternal use of other drugs of addiction.”

Epidemiologists (CSTE) in June of 2019. Accordingly, the Department updated the state case definition to align more closely with the national case definition beginning on Jan. 1, 2020. Concurrently, data collection for facilities was moved from a NAS-only web-based reporting system to the newborn screening iCMS database that facilities were already using, and the Bureau of Family Health assumed management of data collection from the Bureau of Epidemiology. At the time of implementing these changes, the Bureau of Family Health conducted a webinar to train facility representatives on the new case definition and new reporting process, and they have allocated resources to conducting follow-up with facilities on reporting inconsistencies as needed. These changes may have increased reporter understanding of the Department's case definition.

To assess how the different parameters assessed in the survey can impact case reporting to the state and potential under-ascertainment, two high-volume reporting facilities were identified as being both consistent reporters and accurate in terms of infants meeting the Department case definition. The first facility identified is a transitional pediatric hospital. Infants transferred to this facility for care have already been diagnosed elsewhere, so this removes the burden of doing internal case classification. The reporter indicated there is no written protocol for reporting NAS cases to the state, but there is a single point person for reporting cases, and this person is in a Quality position. The reporter submits cases as identified, but only after all information has been collected. The reporter stated there are no barriers to reporting.

The second facility identified is a birthing facility. This facility reported multiple barriers to diagnosis and did not indicate whether they have an internal case definition. The reporter stated having a written protocol for reporting NAS cases to the state and indicated that the facility reports cases approximately every two weeks. There is a single point person for reporting cases, and this person is also in a Quality position. The facility's criteria for reporting includes all confirmed and suspected opioid exposure, whether illicit or prescribed. This facility is part of a health network, and the point person obtains cases from all in-network facilities to report cases to the state. The reporter stated having no barriers to reporting.

Overall, the survey data indicate that hospitals successfully developed various approaches to facilitate reporting in response to an emergency declaration. These differences include clinical diagnosis criteria, infant evaluation methods and recommended length of stay for observation, coding practices, and reporting practices. In total, approximately 79% of facilities reported experiencing an array of barriers to diagnosing infants with NAS. Some of these barriers could potentially be overcome by implementing an internal case definition and protocols to alleviate uncertainty. For NAS reporting, the mention of a clinical NAS diagnosis within the national case definition indicates that internal diagnosis criteria remains an important aspect for surveillance activities. Diagnostic consistency could therefore improve reporting consistency within facilities. However, internal facility protocols will not resolve all reporting uncertainties. Case determination for reporting will continue to vary substantially by facility if NAS diagnosis remains a critical component in reporting criteria. Although the Department indicated that no minimum scores or pharmacologic treatment were required for reporting cases, one facility indicated infants are not diagnosed unless they require pharmacologic treatment, and a second indicated infants are sometimes scored throughout an entire stay but are not diagnosed.

Facilities that have a single reporter and a clear indication of whom and at what time to report, whether this includes a written protocol or does not, seem better prepared to report cases more consistently and accurately. Having someone within a Quality department or similar with availability to report may prevent providers from having to maintain a dual perspective for classifying NAS cases. However, implementing this type of reporter would be dependent upon resource availability.

Because this survey was completed prior to implementation of the new NAS case definition and the new reporting system, facility experiences may have changed over time. However, the data serve as a reference for understanding barriers to diagnosis and reporting. The data may be particularly relevant for rapid process implementations in response to emergency declarations and emerging threats, for surveillance without a standardized case definition, and for surveillance of cases for which clinical diagnosis practices vary widely and multiple diagnosis codes may be applicable.

Citations

1. March of Dimes. Neonatal Abstinence Syndrome. March of Dimes. [https://www.marchofdimes.org/complications/neonatal-abstinence-syndrome-\(nas\).aspx](https://www.marchofdimes.org/complications/neonatal-abstinence-syndrome-(nas).aspx). Accessed April 14, 2021.
2. The Center for Rural Pennsylvania. Rural Pennsylvania Counties. Rural/Urban PA. https://www.rural.palegislature.us/rural_urban.html#maps. Accessed April 12, 2021.
3. Grisham LM, Stephen MM, Coykendall MR, Kane MF, Maurer JA, Bader MY. Eat, Sleep, Console Approach: A Family-Centered Model for the Treatment of Neonatal Abstinence Syndrome.

APPENDIX

Survey of Pennsylvania Birth Hospitals about Neonatal Abstinence Syndrome (NAS) Diagnosis and Reporting

NAS Diagnosis at your Hospital

1. Which of the following **infant** characteristics are part of your hospital's NAS case definition/diagnosis criteria (maternal characteristics are in the next question)? *Please check all that apply.*

	Check all that apply	Check if solely sufficient to meet case definition/diagnosis
Positive infant toxicology results for illicit opioids (e.g., heroin)		
Positive infant toxicology results for other illicit non-opioid substances (e.g., cocaine)		
Positive infant toxicology results for prescribed opioid-containing medications (e.g. oxycodone) or medications prescribed for opioid use disorders (e.g., methadone or buprenorphine)		
Positive infant screening or toxicology results for other prescribed, non-opioid NAS-inducing medications (e.g., SSRIs, benzodiazepines)		
Infant presents with symptoms consistent with NAS		
Medical provider diagnosis of NAS		
Finnegan score, modified Finnegan score, or other standardized tool of NAS severity above a specified cutoff value		
Infant receives pharmacologic treatment for NAS		
Infant receives non-pharmacologic treatment for NAS		
Minimal gestational age at birth → If yes, what gestational age: _____ weeks		
There are no infant criteria in our case definition/diagnosis criteria		
Other → Describe: _____		
Do not know		

2. Which of the following **maternal** characteristics are part of your hospital's NAS case definition/diagnosis criteria? Please check all that apply.

	Check all that apply	Check if solely sufficient to meet case definition/diagnosis
Positive maternal toxicology results at delivery or in the immediate postpartum for illicit opioids (e.g., heroin)		
Positive maternal toxicology results at delivery or in the immediate postpartum for other illicit non-opioid substances (e.g., cocaine)		
Positive maternal toxicology results at delivery or in the immediate postpartum for prescribed opioid-containing medications (e.g., oxycodone) or medications prescribed for opioid use disorders (e.g., methadone or buprenorphine)		
Medical history or self-report of <u>illicit non-opioid substance use</u> before pregnancy		
Medical history or self-report of <u>illicit non-opioid substance use</u> during pregnancy		
Medical history or self-report of <u>illicit opioid substance use</u> before pregnancy		
Medical history or self-report of <u>illicit opioid substance use</u> during pregnancy		
Medical history or self-report of <u>opioid prescription medication use</u> before pregnancy		
Medical history or self-report of <u>opioid prescription medication use</u> during pregnancy		
Medical history or self-report of <u>non-opioid NAS-inducing medication use</u> before pregnancy		
Medical history or self-report of <u>non-opioid NAS-inducing medication use</u> during pregnancy		
There are no maternal criteria in our case definition / diagnosis criteria		
Other → Describe		
Do not know		

3. Does your hospital require that infants stay a certain amount of time in the hospital to be evaluated and/or diagnosed for NAS?

Yes, evaluated → If yes, how long (in days):
 Yes, diagnosed → If yes, how long (in days):
 No time requirement for evaluation or diagnosis
 Do not know

4. Please provide your hospital's NAS case definition/diagnosis criteria below, or include an attachment of your facility's criteria if available.

Please include: Any scoring requirements; list of the symptoms your facility considers to be associated with NAS if symptoms are a criterion; etc.

Processes for NAS Diagnosis at your Hospital

5. Please assess barriers to **diagnosing** infants with NAS at your hospital. In column 1 please check all barriers that apply. In column 2 please select a single primary barrier.

	All barriers (check all that apply)	Key barrier (choose one)
Unclear definition of what constitutes NAS		
Lack of staff training about NAS symptoms		
Lack of staff training about illicit substances, opioid-containing medications, or NAS-inducing non-opioid containing medications and their effects on infants		
Lack of access to maternal prenatal records and maternal history of substance use, substance use disorders, or medication use before and during pregnancy		
Lack of standardized documentation about how to diagnosis infants with NAS at the hospital		
Lack of protocol for maternal toxicology screening		
Lack of protocol for infant toxicology screening		
Limited resources available for NAS treatment		
Concerns about ramifications of diagnosis (e.g., child welfare concerns, concerns over limited benefits of diagnosis for future educational services for the child)		
Internal disagreement on whether infant qualifies for diagnosis (whether written protocol exists or not)		
Other: Describe _____		
No barrier		
Do not know		

6. When an infant is diagnosed with NAS, in what section of the infant's medical record is the NAS diagnosis recorded (e.g. problem list, neurologic exam, NAS assessment section)? *Please describe briefly below.*

7. After a diagnosis of NAS is given, which type of staff members are responsible for assigning the ICD-10 codes (e.g., nurses, physicians, hospital administrators or billing staff), or ICD-9 codes if your facility has not transitioned to using ICD-10? *Please describe briefly below.*

8. After a diagnosis of NAS is given, what ICD-10 codes are typically assigned to infants with NAS? Identify ICD-9 codes used if your facility has not yet transitioned to ICD-10 codes.

ICD-10

- P96.1: Neonatal withdrawal symptoms from maternal use of drugs of addiction
 P96.2: Withdrawal symptoms from therapeutic use of drugs in newborn
 P04.49: Newborn (suspected to be) affected by maternal use of drugs of addiction
 P04.41: Newborn affected by maternal use of cocaine
 P04.3: Newborn affected by maternal use of alcohol
 Q86.0: Fetal alcohol syndrome (dysmorphic)
 P04.1: Newborn (suspected to be) affected by other maternal medication

ICD-9

- 779.5: Drug withdrawal syndrome in newborn
 760.72: Narcotics affecting fetus or newborn via placenta or breast milk
 760.71: Alcohol affecting fetus or newborn via placenta or breast milk
 760.75: Cocaine affecting fetus or newborn via placenta or breast milk
 760.79: Medicinal agent or other noxious influences affecting fetus or newborn via placenta or breast milk
 Other: If other, please list _____
 Do not know

9. If your facility has a standard written protocol about **diagnosing or treating** NAS how has this plan been communicated to relevant staff? *Please check all that apply.*

- No written protocol
 Mandatory training
 Voluntary training
 Protocol provided in hard copy to individual staff
 Protocol provided in electronic copy to individual staff
 Protocol posted or stored in nursing stations within the hospital
 Other → If other, describe: _____
 Do not know

Processes for Reporting Cases of Infants with NAS to the PADOH State Surveillance System

10. How frequently does the hospital send NAS cases to the state surveillance system? *If the hospital has not had any diagnosed NAS cases, indicate what the protocol would be for reporting.*

- As each case is identified
 Cases are compiled across the hospital and are typically sent at least 2 times per week.
 Cases are compiled across the hospital, and sent approximately weekly

- Cases are compiled across the hospital, and are sent approximately monthly
- There is not a systematic frequency for sending NAS cases to the state surveillance system
- Our facility has not had any cases to report
- Our facility has had cases but has not yet reported any to the PADOH
- Do not know whether cases have been reported
- Do not know how often cases are reported
- Other → If other, describe: _____

11. Is there are a written protocol in place to facilitate obtaining the records of all NAS cases from across the hospital or hospital system to report to the PADOH NAS surveillance system?

- Yes
- No
- Do not know

12. How does the hospital identify which NAS cases to report to the Pennsylvania Department of Health? Check all that apply

Suspected exposure (Mother has documented or admitted use *prior to pregnancy*, or appears intoxicated during delivery, etc.):

- Illicit opioid
- Prescription opioid
- Other NAS-inducing non-medically prescribed substance or illicit drug (e.g., alcohol, cocaine, non-medically prescribed methadone)
- Other NAS-inducing prescription medication

Confirmed exposure (documented use during current pregnancy in maternal medical record, positive maternal/infant testing, maternal self-report, etc.):

- Illicit opioid
- Prescription opioid
- Other NAS-inducing non-medically prescribed substance or illicit drug (e.g., alcohol, cocaine, non-medically prescribed methadone)
- Other NAS-inducing prescription medication

Symptoms:

- One of the above Suspected or Confirmed Exposure criteria and has symptoms of withdrawal
- One of the above Suspected or Confirmed Exposure criteria, even if the infant does NOT show symptoms of withdrawal
- Has symptoms of withdrawal but does NOT have at least one of the above Suspected or Confirmed exposure criteria
- Report based on discharge ICD codes or diagnoses
- Do not know, we have not reported cases
- Do not know, I report all cases that are provided to me for reporting
- Other → Describe _____

13. Which type of staff members in your hospital are responsible for reporting NAS cases to the Department of Health via REDCap (e.g., neonatologist, nurse manager, social worker)?

14. Is there a single point person for reporting NAS cases to the Department of Health via REDCap?
- Yes
 - No, multiple people are responsible for reporting
 - Do not know
 - We do not have cases to report
15. If none or not all NAS cases have been reported, why have they not been reported to the PADOH? Please check all that apply
- No infants diagnosed with NAS have been born in this hospital since January 10, 2018
 - NAS cases have been identified but they do not meet the state's diagnosis criteria
 - NAS cases have been identified but we are unsure if they meet the state's diagnosis criteria
 - We do not have the time or staff capacity to report to the state
 - Volume of NAS cases is too high
 - Volume of NAS cases is too low
 - We are unsure of the importance of reporting to the state
 - NAS is not a current priority to the hospital
 - The hospital is concerned about the ramifications of reporting to the state regarding child welfare and confidentiality of reported NAS cases
 - The hospital does not have a process in place for collating NAS cases across the hospital
 - The hospital does not have a process in place for who is responsible for reporting or how frequently NAS cases are reported to the state
 - Inadequate communication from DOH – guidelines and updates are not sent to the correct contact person
 - Inadequate communication from DOH – reporting criteria are unclear
 - Our hospital prefers not to report these cases to the state
 - We were unaware that these cases should be reported
 - Other → If other, describe: _____
 - Do not know

NAS Burden at your Hospital

16. In 2018, what proportion of infants born at your hospital and diagnosed with NAS do you estimate were transferred to another hospital to receive care?
- Few (0-1 out of 4, or approximately 0-25%)
 - Some (Approximately 2 out of 4, or 50%)
 - Most (Approximately 3 out of 4, or 75%)
 - All (Approximately 4 out of 4, or 100%)
 - We have not had any infants with NAS, but our protocol indicates that we would transfer them
 - We have not had any infants with NAS, but our protocol indicates that we would NOT transfer them
 - Do not know

17. What proportion of infants born at your hospital and diagnosed with NAS do you estimate are NOT Pennsylvania residents?

- Few (0-1 out of 4, or approximately 0-25%)
- Some (Approximately 2 out of 4, or 50%)
- Most (Approximately 3 out of 4, or 75%)
- All (or nearly all) NAS cases that we've seen (Approximately 4 out of 4, or 100%)

18. What are reasons infants diagnosed with NAS may be transferred to a different hospital for care? (check all that apply)

- We cannot provide the level of care that these infants require
- We do not have the capacity to care for all of these infants within our facility (e.g., infant beds, or room-in rooms where infant can stay with mother, etc.)
- We have the level of care needed but do not have expertise in caring for infants with NAS

- Family requests a transfer (proximity to home, etc.)
- Insurance reasons
- Not applicable. We do not transfer infants for care
- Other reasons

Please list other reasons:

19. Does your facility have any active projects or grants related to NAS, or participate in any groups, collaboratives, or panels related to NAS issues?

a.

- Yes → Please list: _____
- No
- Do not know

b. If yes, who is the primary representative (e.g. neonatologist, nurse manager, social worker) for each group?

Final Comments and Contact Information

20. Please provide any additional comments (suggestions to improve communications or reporting process, etc.):

21. Please provide your name and contact information and your institution's name and location below. We will use this information to follow-up on any confusing responses and so that we can ensure that we only received one response per facility. No hospital will be individually-identified with their responses. Data from this survey will only be presented in aggregate summary, with potential stratification by the number of live births (categorized), level of care provided, geographic region,

or status of NAS reporting. In addition, a subset of hospitals that complete this survey will be contacted by an epidemiologist working on this project to request additional data collection to better understand NAS diagnosis and reporting.

Name: _____

Phone: _____

Position: _____

Email: _____

Hospital name: _____

Hospital address: _____

This is the end of the survey, and thank you for answering our questions.