

# Proof of Concept Project Using Electronic Birth Notification to Improve Surveillance and Quality of Newborn Screening Pre-Analytic Processes

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## Implementation of NANI in Select Indiana Hospitals: Final Report

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Milestones and Report Prepared by:

Victoria Buchanan, MS, MPH, Sarah Shaffstall, MPH, Steve Scroggins, and Sarah Wikoff, MS

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## **Introduction**

This proof-of-concept project tested the feasibility of establishing birth notification using *Integrating the Healthcare Enterprise's* (IHE) Newborn Admission Notification Information (NANI) technical framework for the Indiana State Department of Health's (ISDH) Genomics and Newborn Screening (NBS) program's pre-analytics. IHE NANI describes a mechanism that provides an accurate denominator of hospital births to state public health programs by using established HL7 messages. NANI improves data quality, reduces data entry errors, and decreases duplicate data entry burden on birthing facilities. Before this project began, the IHE NANI profile was already being implemented in a small number of hospitals in Indiana to send standards-based electronic messages from the hospital's Electronic Health Record (EHR) to ISDH's NBS program. This project helped to increase the number of birthing facilities involved. The NANI message notifies ISDH of newborn births and includes relevant information about the newborn. This typically includes the hospital or birthing facility; the baby's first and last name, medical record number, date and time of birth, gender, gestational age, and birth weight; and the mother's name and contact information.

Goals of this project were to evaluate 1) the use of a small financial incentive to facilitate a birthing facility participating in use of NANI, 2) whether specific data elements are more complete or correct on the filter paper card versus the NANI messages, and 3) the value of using NANI to help conduct surveillance on ISDH's newborn screening pre-analytic processes.

## **Partnering Agency and Birthing Facilities**

*Partnering Agency:* **OZ Systems** has developed standards-based tools to assist state public health programs to collect data electronically from hospitals and from medical devices and labs. The company has been a participant for public health and the CDC in the 2011, 2012,

2013, and 2014 IHE North American Connectathon, successfully testing multiple public health profiles and also participating in HIMSS Showcase for the CDC in 2012, 2013, and 2014. They have partnered with the Indiana State Department of Health's (ISDH) Genomics and Newborn Screening (NBS) program to provide a bridge for newborn admission notification data to go from the medical facility to ISDH. ISDH's NBS program currently has a contract in place with OZ Systems to establish and maintain individual connections between several of Indiana's birthing facilities and the ISDH data system. This connection is made so that data related to birth notification can be sent electronically from a birth facility to OZ Systems, and then on to ISDH. Before this project began, a small number of Indiana hospitals were already participating in submitting birth notification data through NANI. Funds from the project are being contracted out to OZ Systems in order to provide hospitals with small stipends to set up the necessary interface and messages to implement NANI. OZ Systems is an experienced public health vendor with the knowledge to implement NANI within a 90-day timeframe as this approach was recently used in Texas for a small NANI pilot there. OZ Systems' participation in the project has supported the successful implementation of NANI at several Indiana hospitals in a timeframe that has been conducive to the scope of this project. OZ Systems has received \$2,000 from the APHL funds through ISDH for an administrative fee for the project.

*Birthing Facilities:* Seven hospitals (called Hospitals A, B, D, E, F, G, and H throughout this report) are those that had already been submitting data through NANI before the start of this project and the availability of stipends. Two of these facilities were part of a larger hospital system and soon implemented NANI at an additional facility (Hospital C) for a total of eight individual hospitals submitting NANI data before the availability of stipends. As described in the "Detailed Description of Project Activities" section beginning on page 5, as well as the "Data

Analysis and Other Information Necessary for Developing Next Steps and Additional Projects” section beginning on page 19, NANI data from these hospitals was compared to data on the filter paper card to help assess NANI data quality. Because these hospitals had already been submitting NANI data, more data was available from these hospitals than those newly implementing NANI. Data quality from these facilities has helped determine the value of continuing efforts to implement NANI more broadly.

Two additional hospitals, Hospitals I and J, are the two hospitals that have been recruited with small stipends made available through APHL that had completed NANI implementation and that were submitting data by April 27, 2015. These two hospitals were examples of successful recruitment and implementation of NANI with the help of APHL funds used as small stipends. Each of these hospitals will receive a \$2,500 stipend for completing the project once ISDH is invoiced for the expense. Similarly to the eight original hospitals using NANI listed above, NANI and filter paper card data were analyzed for these hospitals as well, once available.

Two additional facilities, Hospitals K and L, had not yet completed the project as of April 27, 2015, but it is expected that they will reach the “Go Live” phase and start submitting data before the end of the grant cycle. These two facilities will likely each receive a \$2,500 stipend as well, contingent on completion of the project very soon. Because NANI implementation was not yet completed as of April 27, 2015, no NANI data was available for comparison to filter paper card data for these facilities.

### **Detailed Description of Project Activities**

Activities were based on the milestones established at the beginning of the project. These activities are described chronologically, based on the November 2014, February 2015, and May 2015 milestones described in the APHL SharePoint site.

*November:*

For the first milestone, the Indiana State Department of Health was to identify a list of 15 to 20 target sites for the project. Originally, it was anticipated that many hospitals would be interested in the opportunity to receive grant funds for implementing NANI at their facilities. Therefore, ISDH wanted to ensure strategic recruitment of hospitals for this project. Out of all birthing facilities in the state of Indiana, a list of 20 priority hospitals on which to focus on was developed. Priority of birthing facilities was based on 1) annual birth rates, 2) previous interest in NANI shown by the facility, and 3) whether a hospital was part of a larger hospital system that could bring on multiple facilities at once, rather than just a single facility. Once this list was created, ISDH and OZ Systems staff discussed the importance of hospital readiness for participation in the project. After much discussion, the decision was made to create a short, one page grant application notifying birthing facilities of the small stipend available to them for participating in the NANI project. This grant application was sent to *all* birthing facilities in the state, rather than only focusing on the list of priority hospitals. The grant application asked for information including but not limited to: whether a facility could implement NANI within a 6-week time frame, how many hours of technical support the birthing facility was willing to commit, and what percentage of the project lead's time would be devoted to the project. (The portion of the grant application with these questions is available in Appendix A on page 27.) Both the information from the original priority list of facilities and the grant application submissions were to be used to identify those birthing facilities that would be eligible to receive funds for NANI implementation. This milestone was completed without any significant barriers.

The next milestone was to contact each facility deemed eligible to participate in the project to determine interest levels in implementing NANI at their facilities. A total of two

hospital systems and three hospitals expressed interest in implementing NANI at their facilities. It was determined that each of these applicants were at a stage in which they were ready for implementation, and they were subsequently notified that upon successful implementation of NANI within the designated timeframe, they would be awarded a stipend. This stipend would be in the amount of \$2,500 for a single hospital implementing NANI, or \$3,500 for a hospital system implementing NANI at one or more of the system's facilities. As a next step, ISDH called each birthing facility in the state not currently using NANI or planning to implement NANI in order to discuss the NANI project by phone as well as the availability of funds. The original application deadline was extended in order to allow additional hospitals to apply. As a result of this additional communication and extended deadline, one additional facility submitted an application. Both OZ Systems and ISDH deemed this facility ready to implement NANI, so this facility was also notified that they would receive \$2,500 upon successful implementation of NANI within the designated timeframe. Several additional hospitals expressed interest in participating in the NANI project at that time, so ISDH and OZ Systems both began reaching back out to these hospitals to determine if they were interested in committing to participating in the project. There were no identifiable barriers during the completion of this milestone.

The next project milestone was that an Agreement to Participate would be signed by one hospital system and three individual hospitals. Hospitals and hospital systems that applied for funds for implementation of NANI and that were deemed ready for implementation were notified by email on December 5 and December 12, 2015 that they had been chosen to receive a small stipend contingent on successful implementation of NANI within the designated timeframe. As mentioned above, OZ Systems and ISDH considered the grant applications submitted by hospitals to be sufficient documentation of the hospital's intent to participate in the project and

therefore did not require a signed Agreement to Participate. Additionally, a document including a project plan specifying dates which each birthing facility should have specific milestones completed by has been developed by OZ Systems. (A sample of these NANI implementation milestones for the hospitals is available in Appendix B on page 28.) The project plan was sent out in subsequent weeks, along with a packet of information on the project. Facilities were asked to complete the project plan with anticipated dates of completion for each outlined milestone; these dates were then be reviewed by OZ Systems, ISDH, and the birthing facilities. Once all parties were in agreement, hospitals would then be asked to sign the document in order to indicate their agreement to complete each of their milestones by the designated date. At this point in time, two hospital systems (each with three facilities) had been selected to receive a small stipend for the successful implementation of NANI and were sent the project plan document. No barriers prevented completion of this milestone.

The final November milestone was that data from 50% of the 7 hospitals (Hospitals A, B, D, E, F, G, and H) currently submitting data via NANI would be analyzed in order to begin determining the consistency between the filter paper card (heelstick), lab-entered data and the NANI data by November 30, 2014. These were the seven hospitals that had already implemented NANI before the APHL grant. At this time, initial data analysis had begun for four of the seven hospitals submitting NANI data. Data for the months of September and October had been analyzed for three of the hospitals currently submitting NANI data; data for the month of September had been analyzed for one additional hospital. In total, a comparison of filter paper card data and NANI data for a total of 382 births was completed at this milestone time. Based on this initial analysis, it was found that the filter paper card and NANI record matched on the last name 71% of the time, on the first name 40% of the time, on the MRN 97% of the time, on the

date of birth 100% of the time, and on the time of birth 81% of the time. Analysis showed that first and last name data fields were incorrect or missing on filter paper card data more often than NANI data at three of the four hospitals analyzed, while the opposite was true for the one remaining hospital. The MRN was missing or incorrect about the same percentage of the time for both NANI and the filter paper card at all four hospitals analyzed. It was also found that while facilities are providing birth weight and an infant's primary care provider on the filter paper card, this information was not available through the NANI messages. For the contact's (or mother's) information, there was a match of 97% for the contact's last name, 57% for the contact's address, and 64% for the contact's city. Additionally, the match rate (or successful linkage) of filter paper cards to NANI records in Indiana's INSTEP system has been calculated for all seven of these facilities. For the final facility, there was only a match rate of 43%. The reason for the lower match rate for this single facility was likely due to NANI records currently being set up by this particular facility for individuals outside of the 48 hour birth range that is typically set for hospitals submitting NANI data. No barriers prevented completion of this milestone.

*February:*

The first milestone in February was to have an additional two hospital systems and one hospital sign an Agreement to Participate, bringing the total to three hospital systems plus four individual hospitals participating in the implementation of NANI no later than January 1, 2015. There were, however, barriers that prevented completion of this milestone at this time. At this point, all hospitals in Indiana had been contacted via email multiple times to inform them of the availability of funds for participation in the project and completion of NANI implementation. Additionally, all hospitals that did not specifically express that they were *not* interested in

participating were contacted by phone in an attempt to garner more interest. One hospital that was part of a system that had participated in the pilot of this project agreed to implement NANI in all additional hospitals with birthing facilities in their hospital system. In total, this hospital system planned to bring on seven facilities. (This hospital system, however, later determined that this project could not be completed at this time, but that they would be interested in implementing NANI at a later date.) One additional individual hospital expressed interest and agreed to participate; however, due to some unforeseen paperwork required by that hospital's security department, ISDH and OZ Systems were in the process of trying to get this required paperwork completed so that the hospital could begin building the interface for NANI. Finally, two additional large hospital systems in Indiana expressed interest in participating in the project, but neither had formally agreed to participate at this time. If both of these systems were to agree to participate, it would have brought on an additional eleven hospitals to the NANI feed. (Although it turned out that these facilities were unable to participate at this time, ISDH and OZ Systems staff continue to follow-up with these hospitals in hopes of bringing them onboard with this project in the future. At the time of this milestone, three hospital systems and four hospitals had agreed to participate. This milestone of convincing hospital staff to participate in the NANI project was more difficult than anticipated. Competing priorities within the hospitals, as well as significant cost and time required by the hospital to build the necessary interface for the NANI project likely contributed to their hesitation to commit to the project at this time. ISDH continued to follow-up with all hospitals showing any interest in the project.

The next milestone was to have NANI implemented at 100% of the recruited hospital systems and individual hospitals by February 28, 2015. A goal of the project was to have all hospitals that had agreed to participate in the project implement NANI as soon as possible to

ensure enough time was left for analysis of the data being received by the Indiana State Department of Health. The main barrier that ISDH faced in trying to meet this milestone has been competing priorities at the hospitals. Hospital IT staff were unable to begin efforts for implementation of NANI as quickly as expected. Although timelines had been drafted and agreed upon by the majority of hospitals, not all of the recruited hospital systems and hospitals were able to implement NANI during the agreed-upon time. Of the hospitals who had agreed to participate, only one hospital had actually “Gone Live” with NANI and was submitting data. An additional hospital was in the midst of setting up the NANI interface but ran into an unexpected problem; their electronic health record (EHR) would not allow them to send A03 messages, which NANI requires. This problem was later resolved and A03 messages were enabled. Barring any other unforeseen circumstances, this hospital was expected to be live on NANI in two weeks time. The third standalone hospital agreeing to participate discovered from their security department that they had to complete lengthy paperwork detailing the NANI requirements in order to obtain internal approval prior to beginning work on the project. ISDH worked with OZ Systems to see if they could complete this paperwork or come up with another solution so that NANI could be completed for this hospital. (OZ Systems and that hospital’s security department, however, were able to resolve most of their questions through a conference call, which they substituted for the paperwork.) The final standalone hospital agreeing to participate in the project had been set to begin work on February 16<sup>th</sup>. It was discovered that a VPN had already been established with this hospital, reducing the amount of time needed to complete the rest of the requirements for the NANI project. Unfortunately, ISDH and OZ Systems both had trouble contacting this hospital’s IT staff member to complete the remaining steps necessary to allow the hospital to “Go Live” with NANI. ISDH and OZ Systems continued

efforts to contact this hospital in order to finalize a timeframe for the remaining steps necessary in order to implement NANI. (Eventually, this hospital was contacted and agreed to participate, however it plans to complete this project later this summer, and is ineligible for the stipend available through APHL funds.) With regard to the hospital systems that had agreed to participate, one hospital system expressed concerns about not having enough time and resources to be able to implement the interface in the way OZ Systems needed it. OZ Systems met with the hospital system's IT and EHR staff to discuss the requirements in more detail. ISDH was expecting to have a response from that hospital by the end of the week during this milestone period regarding moving forward with the project. The second hospital system also expressed concerns with their ability to move forward with implementation at this time due to competing priorities. This second hospital system still plans to implement NANI and participate in the project despite timeframes not being established. OZ Systems continued to follow-up with that facility to determine when work on the project could begin. The final hospital system, which had two hospitals participate in the pilot of the NANI project, had already built the necessary interface for NANI. It was expected that this hospital could relatively easily add additional hospitals to the existing feed. Significant barriers prevented completion of this milestone. Competing priorities in the hospitals and unforeseen circumstances pushed back the implementation timeframe. Examples of these barriers include unexpected security forms that had to be completed, enabling of A03 messaging within the electronic health record, and simply not having enough hospital IT staff time to complete the project in a timely manner. ISDH and OZ Systems both continued regular contact with the hospitals and hospital systems to help manage any unexpected circumstances that came up and to encourage them to begin the project

as soon as possible. Hospitals were also reminded that they must complete implementation of NANI within a specified timeframe in order to be eligible for funds.

Another February milestone was to analyze data from 100% of the seven hospitals currently submitting NANI data (Hospitals A, B, D, E, F, G, and H). This analysis was to determine whether data between the filter paper card and NANI matched, if more accurate data was received from the filter paper card or NANI, and to determine if certain data elements were more often missing from the filter paper card or NANI. Because two of these seven hospitals were part of a larger system that was able to bring on an additional hospital (Hospital C), a total of eight hospitals were actually submitting NANI data at this time. Data from all eight facilities were analyzed. Filter paper card data and NANI data for over one thousand babies were compared. Based on this initial comparison, it was found that the baby's last name matched on the filter paper card and in NANI more than 95% of the time for babies analyzed at three of the eight hospitals. Typically, the reason for a baby's last name not to match was due to the baby being assigned the mother's maiden or last name in one source and the baby's correct, legal name in the other source. No hospitals submitting NANI data had more than a 95% match rate for first name in those babies analyzed. Typically, the reason for the low match rate was due to staff including generic words like "Baby Girl" or "Girl" in the electronic health record, which was pulled by NANI, instead of the baby's given first name that was included on the filter paper card. There was a 95% or above match rate for time of birth of babies analyzed for six of the hospitals. Of the hospitals analyzed, none of them included birth weight or the primary care physician in the NANI record; this data was received from the filter paper card. No barriers prevented completion of this milestone.

For the final February milestone, data was to be analyzed for 100% of the recruited hospitals submitting NANI data. Since only one recruited hospital was actually submitting data at this time, this hospital's data was analyzed (described above). Therefore, data was analyzed for 100% of recruited hospitals (one) submitting data via NANI. Barriers did not prevent completion of this milestone.

*May:*

The first May milestone was that 100% of recruited hospital systems and hospitals would implement NANI within ninety days from the date the Agreement to Participate was signed. As described above, the completed short grant application and timelines were used rather than having hospitals sign an Agreement to Participate. It was originally expected that each facility that agreed to participate would start and complete the project, and it was also expected that completion of the project would occur within ninety days of agreeing to participate.

Unfortunately, not all "recruited" facilities that had applied for the grant funding were able to begin the project during this grant cycle after all. Others who had applied for the grant funding and were able to complete the project took longer than ninety days from the time of application submission to project completion. Barriers to completing this milestone were similar to barriers for other milestones, including limited hospital IT staff time and competing priorities at the hospitals. Problems contacting the correct IT staff at hospitals also caused delays. Sometimes it was difficult to determine who the appropriate person to contact was even after the facility had applied for grant funding. Other times, individuals at those facilities were unresponsive to emails or phone calls. Although it is too late for additional hospitals to take advantage of the stipends available through APHL funding as incentives to participate, ISDH and OZ Systems will still continue to try to recruit additional hospitals to implement NANI by contacting those

that have expressed any interest in NANI as well as following up with those who had said they may be interested at a later time.

The next May milestone was to analyze data for 100% of hospitals submitting NANI data by April 27, 2015. Data were analyzed from submitting hospitals in order to determine whether data between the filter paper card and NANI matches, whether more accurate data is received from the filter paper card or NANI, and to determine if data is more often missing from the filter paper card or NANI (as described in earlier activities above). Data from all ten hospitals submitting NANI data by April 27, 2015 were analyzed, including the data from the eight hospitals originally submitting NANI data (Hospitals A, B, C, D, E, F, G, and H), and the two hospitals that fully implemented NANI after grant funds were offered (Hospitals I and J). (See “Data Analysis and Other Information Necessary for Developing Next Steps and Additional Projects” section beginning on page 19 for more details.) Barriers did not prevent completion of this milestone. The two hospitals that are expected to finish the project that had not yet “Gone Live” with NANI by April 27, 2015 (Hospitals K and L), were not included in the data analysis since there was not yet any data from these hospitals to analyze.

The final two milestones of the project were to complete a data report detailing the data analysis that has been performed for each hospital, including data element content, data completeness, accuracy, and differences in electronically generated NANI messages versus filter paper cards, and a report outlining whether there is sufficient benefit to move forward with enhanced electronic messaging in Indiana based on cost, time, data richness, and other factors. These are both part of this present final report. The data report is within the “Data Analysis and Other Information Necessary for Developing Next Steps and Additional Projects Section”

beginning on page 19. Figures 1 and 2 display this information and are in Appendix C of the report on pages 29 and 30. There were no barriers that prevented completion of this report.

## **Lessons Learned**

### *Lessons Learned by ISDH:*

The most challenging part of the project has been recruiting hospitals to use NANI. ISDH expected that the small stipends made available through the APHL grant would encourage many hospital systems to apply for the funds, but this was not the case. ISDH had wanted to help as many facilities as possible implement NANI while still providing a significant incentive, which was the rationale behind choosing small incentives that could be made available to several facilities. However, few facilities applied for funds and completed the project. In addition to the \$2,000 administrative fee for OZ Systems, two individual hospitals (Hospitals I and J) had completed NANI implementation and are being awarded \$2,500 each. (ISDH is expecting an invoice for these shortly.) The other two facilities (Hospitals K and L) are expected to complete NANI implementation very soon, and are expected to receive \$2,500 each as well. Based on this, ISDH has therefore only been able to use \$12,000 of the available \$22,500. One potential solution could be to award a larger stipend to fewer facilities, rather than these smaller stipends, which were not exhausted. By providing larger stipends that could better offset the cost (to hospitals) of implementing NANI, perhaps a greater number of facilities would be able to afford the IT staff time to implement NANI.

ISDH has also learned that periodically reaching out to those who have shown slight interest in the project but are unresponsive can still pay off. Sometimes it just takes politely reminding those facilities of the opportunities available as well as the deadlines to renew their interest in participation.

*Lessons Learned by OZ Systems:*

OZ Systems staff have expressed similar challenges in this particular project as well as others. They have learned that hospitals often have trouble obtaining the necessary IT resources and have difficulty in identifying the NANI implementation project as a priority. They have also found that gaining security clearance from hospitals can significantly delay a project, but has not completely stopped a project from happening in other states where NANI has been used. Finally, they have learned that “standards” are not always so. In other words, some data fields do not exactly adhere to the HL7 standard; common examples are race, relationship type, and nursery.

Additionally, one OZ Systems staff member recommends the following helpful advice in recruiting hospitals to implement NANI:

- *Unresponsiveness:* Unresponsiveness of hospital staff has been an obstacle throughout the project. A helpful tactic is to inform an unresponsive individual that a lack of a reply by a certain date will mean a certain truth.
- *Managing Outreach:* All outreach should be started with a phone call. If directed to voicemail, it helps to leave a voicemail message and then to email the recipient to inform them that a voicemail was left at the phone number as well as a summary of what was said in the message. If the individual answers the phone, it still helps to follow up afterwards with an email about what was discussed on the phone as well as thanking them for their time. Notes (such as in the form of emails) make it easier to remember what was discussed than simply trying to recall a conversation.
- *Deadlines:* If administering a program with a deadline, such as a grants program, deadlines should be declared approximately thirty days before the program ends. This

gives enough of a margin to manage candidates who have completed most of the work but have encountered a setback that causes some delay.

- *Documenting team progress:* When taking minutes for the project team meeting, it helps to read through the previous meeting's minutes in order to inform the agenda and look for incomplete or unresolved action items. Minutes should be completed as soon as possible after the meeting and reviewed by another attendee to make sure everything important has been included.
- *Mistakes:* When mistakes happen, rather than punishing oneself, that energy is better spent informing those affected that a mistake was made and how it will be corrected. People are usually understanding. When others make a mistake, it helps to ask for clarification (but not to copy others on the team if by email).
- *Planning:* Planners help to commit to milestones, especially if a national holiday occurs during one of the project weeks. If this is the case, hospitals should assure that the correct person will be working the other four days of that week. For weeks with larger holidays, however, such as July 4, Thanksgiving, Christmas, and New Year's Day, waiving the entire week should be considered since it is common for individuals to be out of the office during these times.

**Barriers, concerns, and other issues to be resolved prior to broader implementation:**

There are several issues that must be resolved before NANI may be implemented more broadly throughout Indiana. The first logistical issue in broad implementation of an electronic birth notification system is contacting all of the hospitals or other birthing facilities in the state where births occur and determining their eligibility for participation. In Indiana's experience, very few facilities were considered to be ineligible, including one hospital that no longer had an

OB/GYN department, two midwifery birthing centers that did not use electronic health records, and another midwifery birthing center that had closed.

It was at times difficult to determine who the appropriate individual to contact was at each of these facilities. Once this has been determined, it is often still difficult to get in touch with that particular person—some of these individuals do not even take calls outside of their facilities. Now, however, that these facilities and individuals have been identified and contacted relatively recently, it is likely that ISDH and OZ Systems will continue to contact these individuals periodically in order to gauge their interest level in implementing NANI in the future. An ongoing logistical consideration will be to keep updating this contact information as we learn of staff turnover or other changes at each respective facility.

It was very common to attempt to contact the same individual at a facility multiple times via email and phone calls to assess the hospital's ability and interest in implementing NANI at a particular time. Periodic attempts to reach the same individual at those facilities will likely continue, as this has led to some positive results.

Another logistical barrier is that the ISDH Genomics and Newborn Screening program is currently understaffed, so the staff are currently handling the responsibilities of the vacant positions along with their own duties. Because contacting hospitals and coordinating projects with their IT staff and OZ Systems requires a significant amount of time each week, once the program is fully staffed again, it will be much easier to complete the tasks required to implement NANI more broadly. It is likely that this will be resolved within the next few months.

**Data analysis and other information necessary for developing next steps and additional projects**

Aside from the information already discussed above, additional information about the project necessary for developing next steps includes the data analysis for each of the hospitals submitting NANI data. As described in the milestones above, specific data fields from NANI were compared to specific data fields from the filter paper heelstick card in order to help determine how well the NANI data matches up with the filter paper card data. This was done for all ten hospitals submitting data (Hospitals A, B, C, D, E, F, G, H, I, and J). Data were compared for approximately one hundred births at each of the original eight facilities submitting data that were not receiving stipends (Hospitals A, B, C, D, E, F, G, and H). Less data were available for the two facilities (Hospitals I and J) that went live more recently; data were compared for 48 births at one of these facilities and 25 births at the other. Each of the following data elements were included in these comparisons: last name of the child, first name of the child, medical record number (MRN) of the child, date of birth (DOB) of the child, time of birth (TOB) of the child, birth weight (BW) of the child, birth facility, mother's last name, address, city, and child's primary care physician (PCP).

In order to facilitate these comparisons, NANI data were pulled from OZ Systems' online application into separate Excel files for each facility. Each of the above data fields were compared to the respective data fields on the filter paper card used for the child's newborn heelstick screen to assess consistency between the two data sources. The filter paper card data is available from the Indiana University Newborn Screening Laboratory to ISDH staff through the Indiana Newborn Screening Tracking and Education Program (INSTEP), an online newborn screening application developed in-house. NANI records that could not be matched to filter paper records in INSTEP were not included in this part of the analysis. (See Figures 1 and 2 in

Appendix C, on pages 29 and 30. Birth weight and PCP are not displayed in these figures since they were 0% for all ten facilities submitting data.)

In many cases, the reason for inconsistencies between NANI and filter paper card data was that the data element was missing from either one source or the other for a particular birth. It was observed that a reason for a lower consistency between NANI and filter paper card data for first names for one of the facilities was due to that facility's practice of entering a generic word or phrase such as "Baby," "Baby Boy," "Baby Girl," "Infant," etc., into the electronic health record rather than the child's given legal first name. Inconsistencies between NANI and filter paper card data for last names are frequently due to the mother's last or maiden name being entered into the electronic health record or written on the heelstick card, rather than the child's correct last name.

The medical record number (MRN), date of birth (DOB), and birth facility were highly consistent between the NANI and filter paper card data sources for all facilities (95% or higher for each facility). For the facilities that were able to successfully submitting time of birth (TOB) data via NANI, these were also highly consistent (95% or higher). Three facilities had a 0% consistency rate between NANI and filter paper card data for TOB, which was likely due to errors in being able to capture TOB correctly from the electronic health record for these facilities, which submitted 00:00:00 for all births (which is technically read as midnight for these births), rather than leaving the field blank. ISDH will work with OZ Systems and these facilities to attempt to build a possible solution in order to receive TOB data via NANI from the electronic health records at these facilities.

The mother's last name was fairly consistent between the NANI and filter paper card data, ranging from about 84% to over 99% consistency for the participating facilities.

Sometimes the mother's maiden name rather than her current last name is entered into either the filter paper card or the electronic health record, which is one reason for inconsistencies.

Consistency between the NANI and filter paper card data for the address and city varied among facilities. It was noted that some of the inconsistencies are due to different spellings of the same address or city, or addresses listed on the filter paper card not matching other more updated addresses in INSTEP that did match with NANI.

The consistency rate between NANI and filter paper card data for the birth weight and primary care physician (PCP) fields was 0% for all facilities. It seems that the main reason for birth weight inconsistency is that the units displayed in INSTEP (pounds) for the filter paper card data are different from the units captured by NANI from the electronic health record (grams). ISDH will work on remedying this issue by discussing the possibility of including an option to display birth weight in the desired units in INSTEP (i.e., to be able to switch the display from pounds to units and vice versa as desired by the user). NANI was unable to capture the PCP from the electronic health records for any of these facilities, which will be investigated further. It is possible that the electronic health records at these facilities do not include the child's PCP in the electronic health record or that the structure of the electronic health record at each of these facilities is incompatible with the way OZ Systems can pull that field. ISDH will work with OZ Systems to try to retrieve this data field for these facilities if that is possible.

In addition to comparing each of the data fields between NANI and the filter paper cards for these facilities, another way to determine the quality of NANI data was the ability to link NANI records to ISDH's filter paper card records. The original plan was to do this for all births at all facilities submitting NANI data. However, due to a transition in the way ISDH received this data (described below, in the "Gaps in the Overall Project" section beginning on page 24), it

was only possible to do this before that transition, which occurred in August 2014. This therefore only included the seven facilities (Hospitals A, B, D, E, F, G, and H) that were submitting data at the time, and included all births at those facilities occurring from the date they began submitting NANI data until August 6, 2014. The percentage of overall linking rate between NANI data and ISDH filter paper data for these records was 95.9%, which is considered by ISDH staff to be very high. A total of 7,060 NANI birth records were included in this estimate. (It is expected that once the code has been rewritten to compensate for the transition of data retrieval that this linkage rate for all facilities currently submitting NANI data will be similar.)

For this same time period (before August 2014), a list of NANI records was pulled where the NANI birth record could not be linked with the ISDH filter paper card record. This list contained 292 NANI records (out of 7,060) that were not matched to any heelstick data. This represents approximately 4.1% of births at these facilities that were not automatically linked to heelstick data. This could be due to a variety of factors, including discrepancies between DOB, MRN, last name, or other fields in either NANI or the filter paper card; if there were enough discrepancies between fields or too much missing data for a particular child in either the filter paper card or NANI data, this could prevent linkage. However, part of this number could mean that these children did not receive a newborn heelstick screen. Missed heelstick screens could be due to death in the newborn period or refusal due to religious reasons (allowed in Indiana if a religious refusal waiver is signed), but it is possible that a missed screen could also simply be due to a child being inadvertently discharged from the hospital prior to the screen. In the future, a list of NANI records without linked heelstick data may act as a safeguard by providing ISDH with a helpful starting point in short-term follow-up of any newborns that may have been

accidentally missed, helping to ensure that all newborns are receiving their mandatory newborn heelstick screens.

ISDH had also originally planned to evaluate the number of days between the child's date of birth as indicated by NANI and the number of days for receipt of the filter paper card by the Indiana University Newborn Screening Laboratory. However, due to the nature of the data and the transition in the way it was received (described below), ISDH staff were unable to pull this data for comparison. It had been anticipated that the NANI DOB would be more accurate than the filter paper card DOB and would be the most appropriate comparison; however, from the preliminary analysis of specific data fields for each facility, the DOB matched almost 100% of the time for all facilities. ISDH was, however, able to pull the average number of days between date of birth and date of heelstick screen for 8,511 individuals with NANI records using the DOB on the heelstick card. When including several large outliers that increased the value, this was an arithmetic average of approximately six days. It is expected that a more accurate time between DOB and time of screening will be available once the code has been rewritten to accommodate for the change in the way NANI data is received.

Because the implementation of NANI is still at a very preliminary stage in Indiana, and the way in which NANI data is received has changed (requiring ISDH IT developer staff to write new codes to accommodate this change), ISDH has not yet reached the stage in which it has been able to provide these NANI birth notifications to the Indiana University Newborn Screening Laboratory. It is expected that once ISDH is receiving NANI on a daily or more "real-time" basis, that the lab will receive these notifications as well and be better able to plan for the influx of expected heelstick cards it will receive shortly afterwards. Once this occurs, it will be possible to evaluate how timeliness in screening has changed if the lab can be better prepared.

The expectation is that the lab may be able to improve its efficiency if it is better able to predict how many heelstick cards it will receive based on birth notification. At this time, however, this information is not yet available.

### **Gaps in the overall project**

One of the unanticipated gaps in this project had to do with the way ISDH received NANI data from OZ Systems. Originally, OZ Systems had pushed the data to ISDH on a real-time basis, and ISDH was able to integrate this data daily at midnight to its own data system. During this time, ISDH was able to incorporate this data into its integrated data system and link the NANI records to the appropriate filter paper records based on medical record number, last name, DOB, and other fields. An unforeseen circumstance caused the ability to push the NANI data to ISDH to no longer be possible. At that point, in August 2014, the only way ISDH was able to retrieve NANI data was by pulling it from OZ Systems' database rather than having it pushed. Due to the way ISDH developers had written code to link NANI records to existing records, it became impossible to link NANI data to filter paper card data without re-writing the code. It is expected that once this code has been rewritten, ISDH will again be able to link NANI data to ISDH filter paper card data, and display the NANI data within INSTEP as well as provide the Newborn Screening Laboratory with these notifications. Because NANI has only been implemented at a small number of facilities, it has not been as high of a priority for ISDH IT developers to re-do this part of the code as other more urgent projects. However, it is expected that this will be fixed relatively soon, especially as more facilities begin implementing NANI.

### **Sustaining the Project in the Future**

The ISDH Genomics and Newborn Screening program has decided to continue to sustain the project. Despite the challenges and costs to ISDH, the Genomics and Newborn Screening program believes that the benefits of broader implementation of NANI at other facilities in Indiana outweigh these costs. ISDH plans to sustain this project by dedicating staff time towards continuing to communicate with OZ Systems and hospital facilities as well as paying for some of the basic licensing fees and technical support for NANI. Although ISDH will not be able to continue to provide the small incentives for the hospitals as made available through APHL funds to compensate for hospital IT staff time, the ISDH NBS program has budgeted for OZ Systems projects including licensing fees and technical support for several years and has included this in the budget for the upcoming fiscal year as well.

ISDH appreciates the participation of all hospitals that have or are in the process of implementing NANI, as it takes significant time and effort to build the NANI interface. ISDH recognizes that these participating facilities have gone above and beyond what is required of them for newborn screening. Considering that this project is in its preliminary phases, ISDH appreciates any electronic health record data it receives from these facilities through NANI as well as the opportunity to work with OZ Systems.

**Appendix A**

**NANI Implementation Grant Application**

*OZ Systems in conjunction with the Indiana State Department of Health*

To be considered for a grant offer, complete and return your application by email to:

Victoria Buchanan ([VBuchanan@isdh.IN.gov](mailto:VBuchanan@isdh.IN.gov)) AND Peter Ots ([POts@ozsystems.com](mailto:POts@ozsystems.com))

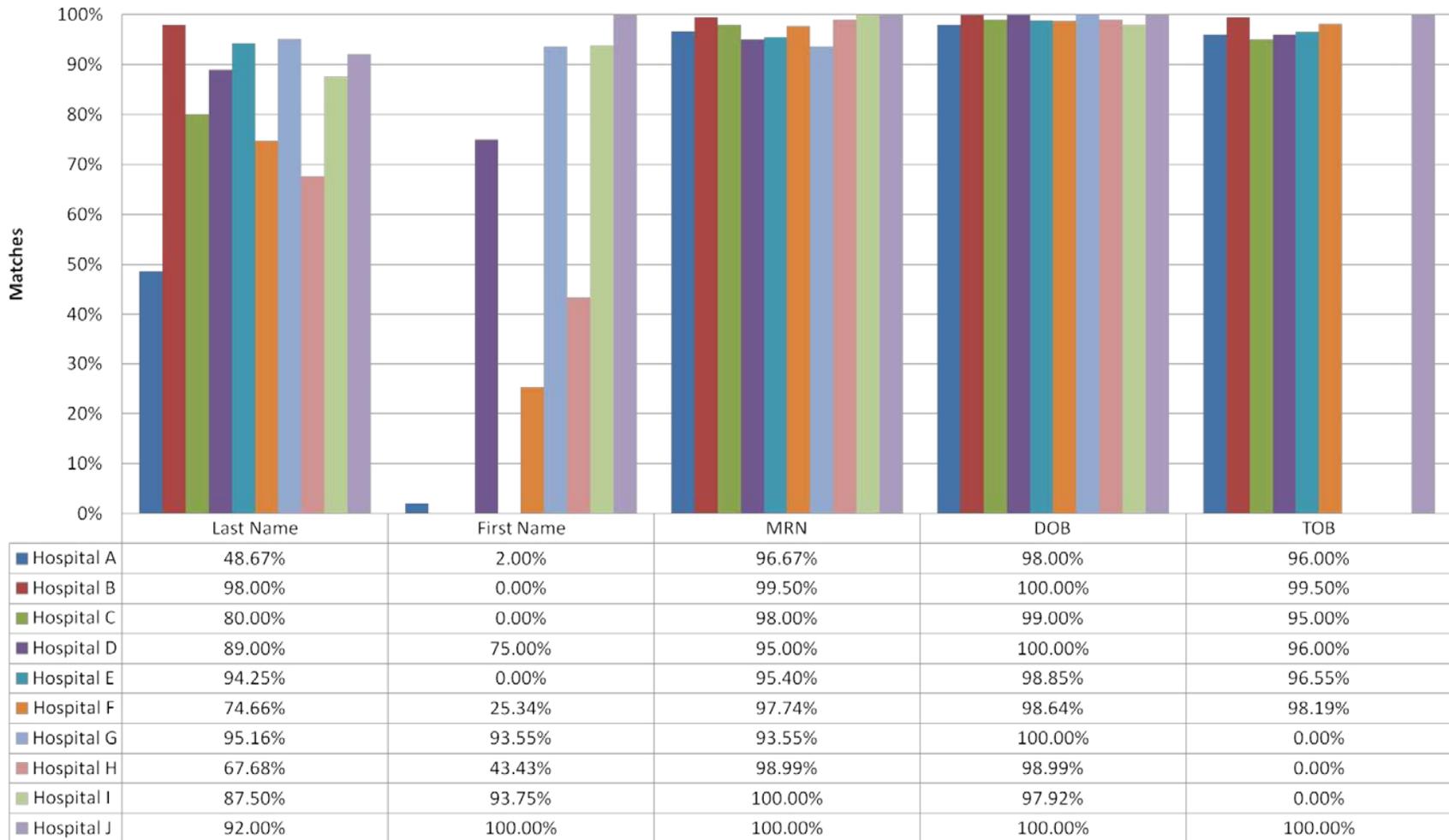
|                                                                                                                                                                                                                                 |  |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|
| Facility name                                                                                                                                                                                                                   |  |
| Grant applicant's (person) name                                                                                                                                                                                                 |  |
| Grant applicant's title                                                                                                                                                                                                         |  |
| Grant applicant's email(s)                                                                                                                                                                                                      |  |
| Grant applicant's phone number(s)                                                                                                                                                                                               |  |
| Does your facility have an EHR?<br>(Yes/No)                                                                                                                                                                                     |  |
| Name of the EHR system used for<br><i>newborn</i> admissions                                                                                                                                                                    |  |
| Can your facility complete the<br>implementation of NANI within a 6-<br>week timeline?                                                                                                                                          |  |
| How many hours of technical support<br>are you willing to commit to this<br>project?                                                                                                                                            |  |
| Project lead's (person) name<br>(if different from Grant applicant)                                                                                                                                                             |  |
| Project lead's title                                                                                                                                                                                                            |  |
| Project lead's email(s)                                                                                                                                                                                                         |  |
| Project lead's phone number(s)                                                                                                                                                                                                  |  |
| What percentage of the project lead's<br>time will be devoted to the<br>implementation?                                                                                                                                         |  |
| If you can implement for other<br>hospitals in your system, list their<br>names.                                                                                                                                                |  |
| If you can implement for other<br>hospitals in your system, and you seek<br>funds in excess of \$2,500, provide a<br>detailed description of the need for<br>additional funds and how you will<br>distribute the awarded funds. |  |

**Appendix B****Sample of NANI Implementation Milestones for Hospitals from OZ Systems**

| #  | Description                                                | At <Specific Hospital>           | At OZ Systems                     | Day |
|----|------------------------------------------------------------|----------------------------------|-----------------------------------|-----|
| 1  | Host project kickoff meeting with hospital                 | <Specific hospital staff member> | Project Liaison<br>NANI Team Lead | 1*  |
| 2  | Review IG                                                  | <Specific hospital staff member> |                                   | 3   |
| 3  | Determine OID & external IP addresses                      | <Specific hospital staff member> | Configuration Manager             | 3   |
| 4  | Determine security option (SSL or VPN)                     | <Specific hospital staff member> |                                   | 7*  |
| 5  | Create HL7 interfaces (A01, A08, A03)                      | <Specific hospital staff member> |                                   | 10  |
| 6  | Test HL7 interfaces (A01, A08, A03) in NANI Validator Tool | <Specific hospital staff member> |                                   | 15* |
| 7  | Connectivity for test environment enabled                  | <Specific hospital staff member> | Network Engineer                  | 15  |
| 8  | Complete interface and connectivity testing                | <Specific hospital staff member> | Support Personnel                 | 20* |
| 9  | Connectivity for production environment enabled            | <Specific hospital staff member> | Network Engineer                  | 23* |
| 10 | Determine the Go Live date                                 | <Specific hospital staff member> | NANI Team                         | 23  |
| 11 | Go Live                                                    | <Specific hospital staff member> |                                   | 31* |

Appendix C

**Figure 1. Percentage of NANI and filter paper card data matching for last name, first name, MRN, DOB, and TOB data fields for sample of births at each facility submitting NANI data.**



Appendix C

**Figure 2. Percentage of NANI and filter paper card data matching for birth facility, mother’s last name, address, and city for sample of births at each facility submitting NANI data.**

