Appendix D

Reports

Request for Proposal Number 5710 Z1

FOLLOW-UP REPORTS

The following reports used for follow-up and monitoring can be run entering any date range. Descriptions of the type of data are provided. The date the report is run is also printed on each report. These reports are run daily and the capacity to close records is in the data system, such that once closed, the cases come off the report. All reports can be exported and saved in Excel® or PDF. All reports can be run using variably defined date ranges.

A desirable feature of a bidder's response will identify that a case can be closed on an infant for one reason yet remain open on other pending worklists as needed for other abnormalities or reasons for active follow-up to continue.

ABNORMAL HEMOGLOBINOPATHIES REPORT
Report lists every pending abnormal hemoglobinopathy screen, until closed by the State program (includes AF even though may be within normal limits for the age of the newborn/infant). Data fields include filter paper #, last name, first name, birth date/time, birth place, city of birth, test result abnormal, hemoglobin type and age in days.

INCONCLUSIVE CYSTIC FIBROSIS REPORT
Report lists every pending inconclusive CF screen, until closed by the State program. Data fields include last name, first name, birth date, filter paper #, birth place, city of birth, test result value, inconclusive result, and age in days.

MECONIUM ILEUS
Report lists every pending newborn with Meconium Ileus or other bowel obstructed identified, until closed by the State Program. Data fields include last name, first name, birth date, filter paper #, birth place, city of birth, test result inconclusive, result value, and age in days.

TESTS DRAWN TOO EARLY
Report lists every specimen collected at less than 24 hours of age, until closed by the State Program. Reports are listed in order by hospital. Data fields include city, place of birth, last name, first name, birth date filter paper # and which results were inconclusive.

UNSATISFACTORY SPECIMENS
Report lists every specimen determined to be unsatisfactory for testing, and which tests were unable to be completed, and the reason each specimen was determined to be unsatisfactory. Names come off list when the State Program closes the record. Fields include last name, first name, birth date and tie, filter paper #, disorders not screened, and reason unsatisfactory.

PRESUMPTIVE POSITIVE TESTS
Report lists every specimen presumptive positive on screening, and identifies for which condition it is positive. Names come off list when the State Program closes the record.
Fields include: Last name, First name, Birth Date and time, Filter Paper #, Birth Place, City of birth, which test result was abnormal, the result and age in days at the time report is run.

ABNORMAL MS/MS REPORT
Report lists every specimen deemed abnormal on screening, and identifies for which condition it is out of range. Names come off list when the State Program closes the record. Data fields include last name, first name birth date, filter paper # birth place, the test result that was abnormal, which profile and the age in days at the time the report is run.

ABNORMAL LSD'S REPORT (New in 2018) *(other relevant fields that would be useful?)*
Report lists every specimen determined to be out of range requiring repeat or confirmatory testing for GAA (Pompe) and IDUA (MPS-I). Data fields include last name, first name, birth date, filter paper #, birth place, abnormal analyte (GAA or IDUA), and result interpretation (INC or POS).

ABNORMAL X-ALD REPORT (New in2018) *(other relevant fields that would be useful?)*
Report lists every specimen determined to be out of range requiring repeat or confirmatory testing for C26:0. Data fields include last name, first name, birth date, filter paper #, birth place, C26:0 value and any relevant ratios, and result interpretation (INC or POS).

TSH VALUES >=20
Report lists all specimens with TSH's greater than or equal to 20. Names come off list when the State Program closes the record. Data fields include last name, first name, birth date, filter paper # birth place, city of birth the TSH value, and age in days at time the report is run.

INCONCLUSIVE 17-OHP REPORT
Report lists every specimen determined to be inconclusive - in need of repeat screen. Lists all babies with meconium ileus reported on the filter paper card or reported with meconimum ileus after submitting the filter paper card. Report is sorted by birth date and alpha last name. Date fields are last name, first name, birth date and time, filter paper #, IRT outcome (interpretation), and DNA results.

SCID INCONCLUSIVE TESTS REPORT
Report lists all babies with inconclusive SCID results requiring repeat screening. Data fields include last name, first name, birth date, filter paper number, birth place, city of birth, test result inconclusive, result and age in days when the report is run.

MONITORING, FOLLOW-UP and REPORTING

The following reports used for monitoring, follow-up and reporting are run routinely e.g. once a week, every two weeks, monthly or quarterly:

OUT OF HOSPITAL REPORT
This report includes specimens based on date of collection not date of birth. Report of all babies screened not born in hospitals (home, auto, etc.). The data fields are last name, first name, birth date, filter paper number, specimen collection date, submitter and the age at collection.

LOST TO FOLLOW-UP REPORT
List of all babies, the State program has designated/closed as "lost to follow-up." Data fields include city, birthplace, birth date/time, last name first name and lost to follow-up date.

MONTHLY MATCH REPORT (Text delimited data) (Run every 2 weeks)
List of all babies for whom a screening specimen has been received and tested. Data is exported by the NNSP in an Excel® format and merged with exported data from the birth certificate registry to identify any newborns that did not get a screen. Data is sorted by birth place, and city, and data fields includes newborn ID (number assigned by lab), last name, first name date and time of birth, mother's last name, mothers first name, and hospital code number identifier. This report export works with older data/older version of software.

TESTS DRAWN TOO EARLY WITH REPEATS
List of all babies for whom a screening specimen was collected at < 24 hours and if a repeat was collected identifies the repeat filter paper number. Sorted by place of birth. Data fields include city, place of birth, last name, first name, birth date and time, initial filter paper number, and repeat filter paper number.

DATA ARCHIVE MATCH REPORT
Report used to random check on a quarterly basis the completeness of specimen data in data archive. Data fields include filter paper number, PS_ID, accession number, collection date and lab received date.

INFANTS SCREENING RESULTS
Report used to ensure back-up paper copy of all results available for long term storage. (Variable date range). Includes all results for every baby by birth date during the date range of the report, includes actual result and interpretation (e.g. WNL= within normal limits, inc= inconclusive, pos= positive). Data fields include birth date and time, birth facility, submitter city, last name, first name, date/time collected 170OHP value, 17 OHP extracted value, AA result interpretation, AC result interpretation, BIO result interpretation and value, GAL result interpretation and value, Gal/BEU (GALT) result interpretation and value, Hemoglobin result, IRT result interpretation and value, T4 result interpretation and value, TSH result interpretation and value, TREC results interpretation.. The new report will need to include GAA, IDUA and C26:0 results interpretations and values when screening for MPS-I, Pompe, and X-ALD begins.

QUALITY ASSURANCE REPORTS

The following reports used for monitoring, follow-up and reporting are run routinely e.g. once a week, every two weeks, monthly or quarterly quality assurance reports

AVG. MIN. MAX. REPORT
Report is run on varying date ranges providing the average, minimum and maximum turnaround times from birth to specimen collection, collection to receipt in the laboratory, receipt to release of results from the laboratory, and total birth to release

times. Specific data lists the filter paper number birth date and time, collection date and time, receipt date and time, release date and time, and the associated time in days for each of the four measured parameters.

BATCHING TRACKING REPORT
This report is run weekly to provide monitoring feedback to hospitals, request investigation and develop plans to prevent recurrence of delayed or batched specimen handling in hospital and via shipping. It can be run on varying date ranges and is listed with facility data together identifying all specimens received on dates with any specimen equal to or greater than three days between collection and receipt at the laboratory. The information provided includes the baby's last name, filter paper serial number, medical record number, birth date and time, day of the week specimen was collected, date and time of collection, date and time of receipt and days/hours (in hundredths, e.g. 3.456 days) between collection and receipt times. This level of detail is provided to hospitals when a reasonable explanation for delays is not apparent to the program. Report can be exported to spreadsheet format so that individual facility information can be sent to them.

DRAWN EARLY STATS REPORT
Report used to periodically review the numbers and % of drawn early specimens received for various birth weight groupings and gestational ages. Broken down by hospital, provides the number and percent of drawn early specimens for < 2000 g babies, 2000g-<2500g, 2500g-<3000g, 3000g to < 3500 g, and ≥3500 g babies. Also for < 34 weeks gestation, 34-<36 weeks gestation, 36-< 40 weeks gestation, and ≥ 40 weeks gestation.

GREATER THAN 48 HOUR COLLECTION
Report run weekly to monitor late collection of initial specimens. Lists specimens collected at greater than 48 hours of age, in order by hospital (alphabetical). Data fields include baby's last name, filter paper number, medical record number, birth date and time, collection date and time, age in hours at time of collection, and name of submitter (facility). Specifics are reviewed to determine if other explanation such as out of hospital birth, data entry error or actually a repeat specimen not an initial specimen can rule out hospital error. Report can be exported to spreadsheet format so that individual facility information can be sent to them for investigation, correction or development of plan to prevent recurrence.

HOSPITAL QA REPORT
This report shows hospital or submitter performance by quarter over time of their average turnaround times for birth to report of results, birth to specimen collection, specimen collection to receipt at the laboratory, receipt to report out of results. Listed alphabetically by hospital.

INFANTS AGE COLLECTION REPORT
This report shows the total # of births and the number and percent of initial specimens collected between 6-12 hours of age, 12-24 hours of age, < 24 hours of age on day 1, day 2, day 3, day 4, day 5, day 6, day 7, greater than 7 days and those for whom time of collection was unknown.

QUARTERLY HOSPITAL REPORT
This report is run quarterly and provided to each submitter. It identifies the number of initial and repeat specimens submitted and provides the following measures with benchmarks, the statewide performance and the facility's performance:

a. Initial specimens collected at > 48 hours (%)
b. Unsatisfactory specimens (%)
c. Average time birth to collection (units of days, e.g. 1.23)
d. Percent non-NICU initial specimens collected @ 24-48 hours (%)
e. Average time collect to receipt (units of days, e.g. 1.34)
f. Percent received within 3 days from collection (%)
g. Percent received within 2 days from collection (%)
h. Percent received within 1 day of collection (%)
i. Average time receipt to result reported for all specimens (units of days e.g.1.45)
j. Average time collect to result reported for all specimens (units of days e.g. 4.22)
k. Percent of all specimens' results released 4 days from collection (%)
l. Percent of all specimens' results released 5 days from collection (%)
m. Percent of all specimens' results released 6 days from collection (%)
n. Percent of all specimens' results released > 6 days from collection (%)
o. Average age birth to result for all initial specimens (unit of days e.g. 4.57)
p. Percent of results released within 5 days of age (%)
q. Percent of results released within 7 days of age (%)
r. Percent of results released after 7 days of age (%)
s. Number of presumptive positive results for non-time critical conditions released by 7 days of age (#, e.g. 2 out of 4)
t. Number of presumptive positive results for time critical conditions released by 5 days of age (# e.g. 0 out of 2) *
u. Percent of presumptive positive results for time critical conditions released by 5 (%)*

*Time critical conditions as defined by the Advisory Committee on Heritable Diseases in Newborns and Children

The report also includes identification of the filter paper number, baby's last name, date of birth, collector's initials, date collected, reason unsatisfactory and tests unable to be completed for all unsatisfactory specimens during the period.

Graph's showing three years of data of the state benchmark, state performance and facilities performance are also included for these measures:

a. Unsatisfactory specimen rate
b. Average times birth to collection for initial specimens
c. Average times collection to receipt at the lab
d. Average times collection to results released for all specimens
e. Average times birth to results released for initial specimens
f. Percent of non-NICU initial specimens collected at 24-48 hours of age
g. Percent of specimens received < 3 days from collection
h. Percent of all results released by 7 days of age

INITIAL BIOTINIDASE DEFICIENCY AVERAGE VALUE REPORT
This report provides the number of initial screens for the enzyme measured, total of values, mean average value, variance, standard deviation, median, mode, minimum, maximum and 25^{th} and 75^{th} percentile values. It also lists any specimens during the reporting period reported to be positive identifying only the result and if applicable the DNA result.

INITIAL CAH AVERAGE VALUE REPORT
This report provides the number of initial screens for both the CAH and extracted CAH, total of values, mean average value, variance, standard deviation, median, mode, minimum, maximum and 25^{th} and 75^{th} percentile values. It also lists any specimens during the reporting period reported to be positive identifying only the result and if applicable the DNA result.

INITIAL CF AVERAGE VALUE REPORT
This report provides the number of initial screens for the IRT, total of values, mean average value, variance, standard deviation, median, mode, minimum, maximum and 25^{th} and 75^{th} percentile values.

INITIAL GALACTOSEMIA AVERAGE VALUE REPORT
This report provides the number of initial screen for galactose and GALT, total of values, mean average value, variance, standard deviation, median, mode, minimum, maximum and 25^{th} and 75^{th} percentile values. It also lists any specimens during the reporting period reported to be positive identifying only the result.

INITIAL T_4 AVERAGE VALUE REPORT
This report provides the number of initial screens for thyroxine (T_4), total of values, mean average value, variance, standard deviation, median, mode, minimum, maximum and 25^{th} and 75^{th} percentile values. It also lists any specimens during the reporting period reported to be positive identifying only the result for T_4 and thyroid stimulating hormone (TSH).

INITIAL TSH AVERAGE VALUE REPORT
This report provides the number of initial screens, total of values, mean average value, variance, standard deviation, median, mode, minimum, maximum and 25^{th} and 75^{th} percentile values. It also lists any specimens during the reporting period reported to be positive identifying only the TSH result.

PKU MONITORS REPORT
This report provides data for the Nebraska metabolic clinic dietician of all patients who submit their routine phenylalanine blood monitoring reports to the screening laboratory. (Testing of which is not covered under this contract, but reporting is),

NEWSTEPS 360 REPORTS
Multiple reports are available, and must be flexible to change with the expectations of the Newborn Screening Technical Assistance and Education Program (NewSTEPS) collecting state data for national dissemination to inform the federal Advisory Committee on Heritable Diseases in Newborns and Children. The number and percent of specimens are reported on 75 to 100 measures associated with timeliness for initial and subsequent specimens, categorized as time critical positives, critical/non-time sensitive positives, and all results. Data provides numbers and percent of specimens in monthly timeframes for birth to collection, collection to receipt, receipt to result and birth to result. The report requests the data for collection to receipt to be reported in days, but the Nebraska program also requires the data to reflect actual time from collection to receipt for enhanced accuracy. This data must be made available in comma delimited format in order for the NewSTEPS organization to upload the data. No individually identifying information is provided.