Meeting Report

Event: SERC NBS Backup Planning Workshop

Date: July 17, 2014

Location: Florida NBS Laboratory, Jacksonville, FL

Summary: Five of the eight states and one of two territories of the southeast region engaged in a discussion on the issues related to sample submission/receiving and data reporting and emergency backup of their respective newborn screening (NBS) laboratory services assuming support offer from Florida NBS. Between discussions, a tour of the Florida NBS labs was accomplished during peak sample receiving times to offer participants a tangible understanding of how Florida NBS would undertake handling of a sample surge.

Participants:

Alabama: Danita Rollins  Danita.Rollin@adph.state.al.us  334-260-3475 invited, unable to attend
Florida: Ming Chan  Ming.Chan@flhealth.gov  904-791-1642 present
Patricia Parrish  Patricia.Parrish@fl.gov  904-451-5367 present
Marie-Claire Rowlinson  Marie-Claire.Rowlinson@flhealth.gov  904-791-1562 present
Georgia: Art Hagar  afgurar@dhr.state.ga.us  404-327-7900 present
Louisiana: Terry Crockett  Terry.Crockett@La.Gov  504-219-4696 invited, unable to attend
Mississippi: Ashlyn Booker  Ashlyn.Booker@msdh.state.ms.us  601-576-7743 invited, unable to attend
North Carolina: Shu Chaing  Shu.Chaing@dhhs.nc.gov  919-807-8880 present
Puerto Rico: Sherly Pardo  Sherly.Pardo@upr.edu  787-758-2525 x1623 present
South Carolina: Sandi Hall  hallss@dhec.sc.gov  803-896-0891 present
Tennessee: Nina Smith  Nina.Smith@tn.gov  615-262-6472 present
Virgin Islands: Arlene Lockridge  arlene.lockridge@usvi-doh.org  340-776-1239 invited, unable to attend
SERC: Hans Andersson  handers@tulane.edu  504-988-5101 present
Bill Perry  wrperry@eatel.net  225-337-4234 present
Tim Wood  tim@ggc.org  864-941-8177 present
Perkin Elmer: Jeanne Brunger  Jeanne.Brunger@perkinelmer.com  205-746-4113 present
APHL: Guisou Pineyro  Guiso.Pineyro@aphl.org  240-485-2736 present
Sikha Singh  Sikha/Singh@aphl.org  240-485-2726 present

Agenda:

Thursday, July 17, 2014:

07:30 – 08:00  Travel to Florida Lab

08:00  Meeting sign-in and breakfast (provided by Florida NBS)

08:30 – 10:30  Discussions:

- Introductions,
- Purpose/Goals,
- Sample Receiving Issues (review of how labs plan to approach loss of lab and reconstitution of sample receiving/shipping capacity, review of how Florida NBS plans to handle surge over days and weeks, review of various state NBS Forms),
- Completion of data collection tool,
- Sample Reporting Issues (review of Florida sample reports, identification of common data reject/resample causes, confirmation of how each state wishes to receive reports, where reports are to be sent and what are the critical data fields needing to be reported by Florida)
10:30 – 11:00 Tour of Florida NBS Lab:
- Walkthrough of Florida NBS Lab focusing on sample receiving and processing during daily peak activity,
- Review of methodology and equipment utilized by lab,
- Questions and answers.

11:00 – 12:00 Discussions:
- Review of how each state intends to proceed, what action items they feel exists for themselves, who is responsible and who is needed to accomplish, as well as their best guess on the timing of these activities and potential cost issues that exist for the actions,
- Completion of the participant evaluation forms and other forms used to document workshop data collection.

12:00 – 12:30 Return to SERC Conference site

Details: Data collection was accomplished including identification of primary and backup points of contact in participating programs. Potential submitting programs were also queried on price for services (both screening and follow-up), how they might break down disorders if they were to require partial support, how they accomplish accessioning and what their accession numbering scheme involves, whether their accessioning numbers are stamped or labels that are applied and where this information appears on their cards, and what their resampling rate was and their most common cause(s). This information was transcribed and is presented in the file: “2014_08_25_SERC-EP-NBS-Backup.xlsx”, under the tab labeled: “Work Products”.

Sample Receiving: Florida provided a detailed price breakdown for services based upon instrument employed in screening and for selected specific disorders. Pricing detail include Medicaid versus private insurance pricing, as Florida NBS charges based upon applicable payer sources. Requesting states were able to provide their respective total list charge rate but would have to work further to provide price breakdown by instrument employed. The ability to state what costs are by instrument is a necessary step for understanding how emergencies would impact requesting states. Total disorder pricing is a worst case scenario whereas per instrument pricing is a more likely scenario as total loss of capacity is less likely than loss of capacity relating to a single instrument or instruments of a certain type.

All participants were able to identify how they would approach sample receiving reconstitution and most requesting programs identify a desire to remain in the middle of their sample receiving process. All participants were able to identify how they approach labeling of their NBS cards for accessioning purposes. All participants were able to identify a primary and secondary point of contact.

Sample Reporting: All participants were able to identify those critical fields necessary for results reporting but of the fields listed some programs still have not limited fields listed to those that would appear on a sample report. No participants identified any issues for Florida reports. All participants but one desired to have reports flow directly from Florida to submitters. All programs wish to receive notification from Florida when elevated results are indicated.
Lessons Learned: Action planning is presented in the Excel attachment but apparently all requesting program identify development of understanding of how pricing breakdown by instrument and/or disorders is important. Also most apparently wish to develop standard operating procedures (SOP) as opposed for formal memorandum of understanding (MOU) as MOU development with its concurrence by legal departments is believed to be a slow process. SOP development is considered the a process that can be accomplished between laboratories, resulting in concrete steps that will reduce delays in activation and that MOUs can be developed at the last minute when pressure of turnaround will push MOU through legal review.

Action Items:
Perry: Complete meeting report.
SERC Lab Workgroup: Conference call in early October 2014.