Avoiding Deadly Delays in Newborn Screening

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Problem Statement

- Newborn Bloodspot Screen (NBS) tests for over 50 serious congenital disorders for which early treatment is critical.
- The MA DPH mandates a NBS on all newborns between 24 and 72 hours of life.
- In-hospital steps for obtaining NBS include sample ordering, collection and transportation to the State Lab (NENSP) for testing.
- Delayed diagnosis and treatment in a newborn with a time-sensitive disorder tested in the mandated Massachusetts (NBS) may lead to significant lifelong morbidity or death.
- In response to deaths from such delays, Congress passed the "Newborn Screening Saves Lives" legislation that requires timeliness in obtaining, testing and reporting samples.
- Key stakeholders: newborns, parents, nurses, physicians, laboratory personnel, NENSP and the MA DPH, all of whom desire optimization of this system towards the goal of protecting our newborns from avoidable devastating outcomes.





Cause & Effect Diagram





Diagnostic Data

- REDCap database output
 - Number of samples
 - Number of Unsatisfactory samples (rejected by NENSP)
 - Number of too early (drawn at <24 hours)
 - Time of birth
 - Time sample drawn
 - Time sample received in lab control
 - Time courier picks up sample



- We propose to minimize delays in sending NBS samples to the State Lab.
- All samples should be shipped to the testing laboratory on the "Appropriate Day" (AD) in order for fastest transit time.
- AD = NBS sample is drawn between 24 and 48 hours of life and reaches lab control for the next possible 11 AM courier pickup.
- Our first SMART goal will be to reduce the % NBS samples NOT sent on the AD by 50% from 6% to 3% by June 16, 2016.



Measures

	Process Measure	Outcome Measure	Balance Measure
What is your measure?	% samples that left lab control on time	% of samples not sent on the "Appropriate Day" (AD)	Increase in % of missed samples that could lead to delay in critical diagnoses
Patient population (exclusions if any)	Newborns	Newborns	Newborns
Calculation methodology	(# samples that didn't reach lab control by 11 AM)/ (total # daily samples)	(# samples not sent on AD)/ (total # daily samples)	(# missed samples)/(total # of daily samples)
Data source	Birth Certifiate Registry (EPIC) + SunQuest	Birth Certifiate Registry (EPIC) + SunQuest	Birth Certifiate Registry (EPIC) + SunQuest
Data collection frequency	Daily (compiled weekly)	Daily (compiled weekly)	Daily (compiled weekly)
Data Quality	Excellent quality	Excellent quality	Unknown



Prioritized List of Changes (Priority/Pay-Off Matrix)

	High	Nursing + phlebotomy Education re: 24h+1 min	Restructure EPIC orders from timed to list for nursing with hour of age
Impact		Rapid login in of samples at Lab Control	Increase number of courier runs
	Low	Time stamp on Sunquest labels to confirm draw time with written information	More frequent phlebotomy draws
		Confirm and advertise shortest filter paper drying time	Nurses draw their own samples in Well Baby Nursery
		Easy	Difficult

Ease of Implementation



Date	Description of Intervention	Results	Action Steps	
2/8/2015	• Change nursing policy from drawing sample by 72h to draw sample at 24h+1 min and no later than 48h.	 Improvement from 45% – 12% (% not AD) 	• Continuing education	
3/1/2016	 Change EPIC order by MD from admission template to EPIC list for nursing with baby age (to maintain parameters 24 – 48h) for those without sample in lab 	 Improvement from 6 - 3% (% not AD) 		
Planned	• Create EPIC list which crosses Birth Certificate and Lab Control lists to check for missing samples			



Conclusions

• With thorough process evaluation, in-hospital NBS sample collection can be optimized to lower the number of samples transported outside of the Appropriate Day window, thus minimizing time to results, diagnosis and initiation of therapy.



Next Steps/Plan for Sustainability

	Things to consider
Additional tests of change	 Missed sample safety net – EPIC list Decrease "too early" through education
System based changes	 Getting newborn screening results into the lab system Disseminate evaluation to other hospitals through NeoQIC Change EPIC pop-ups to remind repeat samples in NICU
Measurement & reporting	 Missed samples, unsatisfactory sample rate
People	 Parad/Murphy

