Partnering with a University Data Science Department to Develop Innovative Tools for the Analysis and Reporting of NBS Data

Rhonda West, NBS Informatics Scientist

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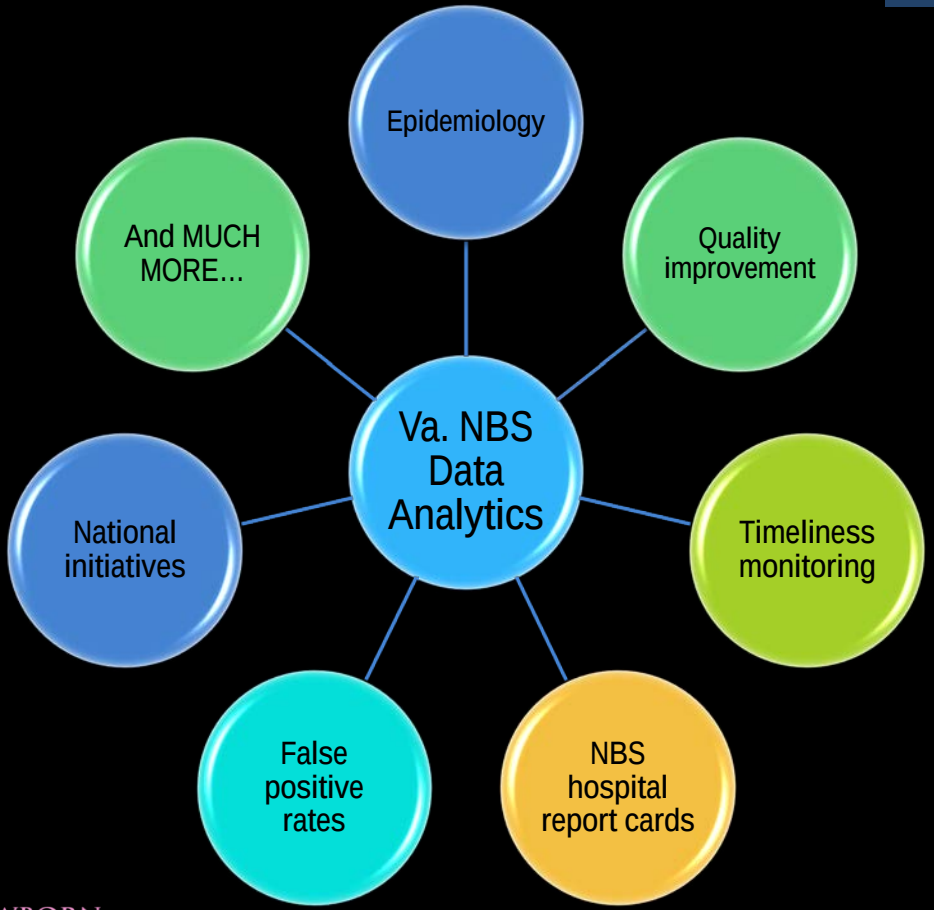
Background



Limited technical resources

=

Manual and time-intensive procedures

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September 2016: A Connection Is Made

- UVA M.S. Data Science – Capstone Project
  - 8-month assignment
  - Students apply knowledge base to help solve real-life data science problems
- Lab director learned of opportunity through an acquaintance at the UVA Data Science Institute
- Matched with 2 students

Hampton Leonard, M.S.

Christopher Patrick, M.S

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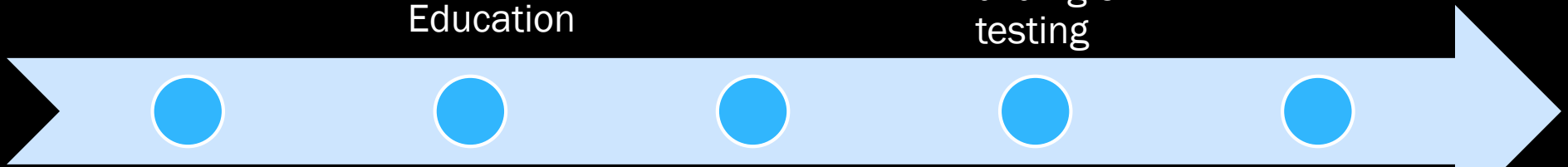
Project Timeline



Sept 2016

DCLS joins UVA capstone project

Oct 2016

NBS Education

Nov 2016

Requirements & data use agreement

Dec 2016 – Apr 2017

Building & testing

May 2017

Final deliverables

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Objectives

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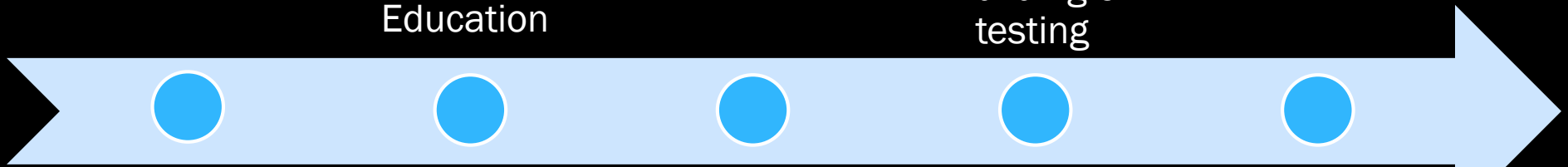
1. Automate the newborn screening hospital report card
2. Automate the NewSTEPs360 monthly reporting
3. Visualize disease distribution in Virginia
4. Explore false positive statistics

Project Timeline



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Methods

Methods

- R Programming
- What is R?
  - Statistical software and programming language
- How is R superior to Excel?
  - Automation and Reproducibility
  - Ability to handle BIG data
  - Superior visualizations
  - IT'S FREE!

Results

What Virginia Gained From One Academic Year Of A University Partnership

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Automated Hospital Report Card

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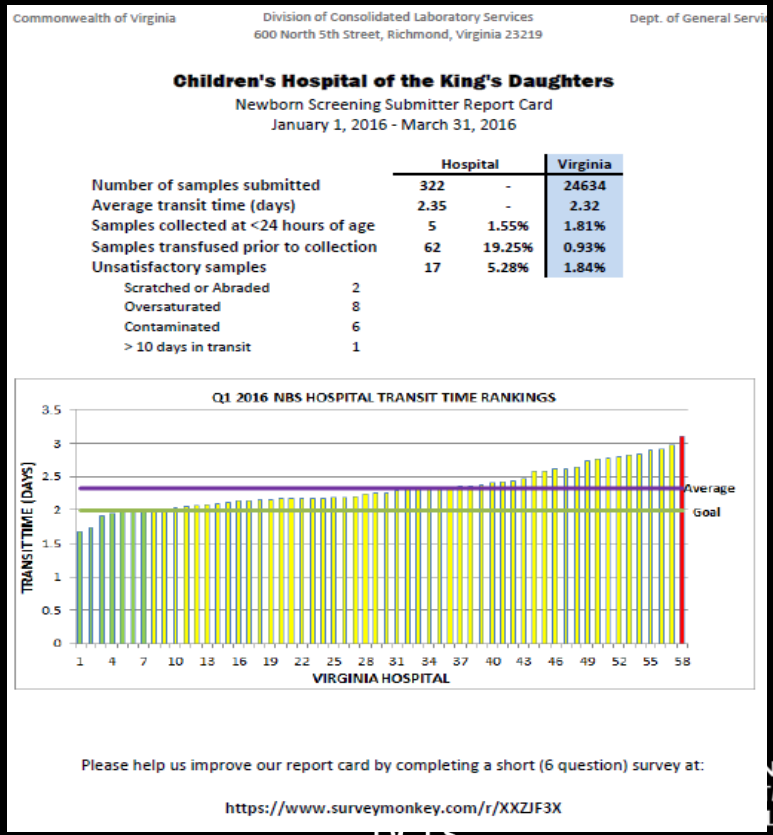
Hospital Report Card Process: Before

- Used Excel for analysis and template design
- Relied on snail mail
- Week-long process



Commonwealth of Virginia
Division of Consolidated Laboratory Services
600 North 5th Street, Richmond, Virginia 23219
Dept. of General Servi

Children's Hospital of the King's Daughters

Newborn Screening Submitter Report Card
January 1, 2016 - March 31, 2016

	Hospital		Virginia
Number of samples submitted	322	-	24634
Average transit time (days)	2.35	-	2.32
Samples collected at <24 hours of age	5	1.55%	1.81%
Samples transfused prior to collection	62	19.25%	0.93%
Unsatisfactory samples	17	5.28%	1.84%
Scratched or Abraded	2		
Oversaturated	8		
Contaminated	6		
> 10 days in transit	1		

Please help us improve our report card by completing a short (6 question) survey at:

https://www.surveymonkey.com/r/XXZJF3X

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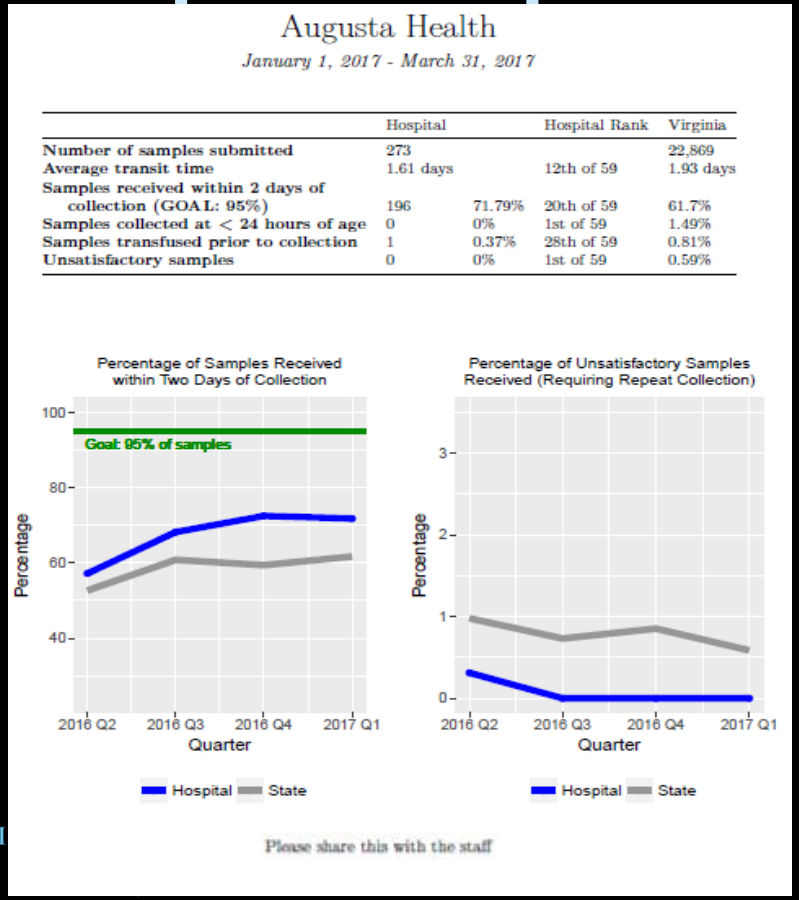
Hospital Report Card: After



Augusta Health

January 1, 2017 - March 31, 2017

	Hospital		Hospital Rank	Virginia
Number of samples submitted	273			22,869
Average transit time	1.61 days		12th of 59	1.93 days
Samples received within 2 days of collection (GOAL: 95%)	196	71.79%	20th of 59	61.7%
Samples collected at < 24 hours of age	0	0%	1st of 59	1.49%
Samples transfused prior to collection	1	0.37%	28th of 59	0.81%
Unsatisfactory samples	0	0%	1st of 59	0.59%

Please share this with the staff

Extract Raw Data From LIMS

Run Scripts

- <10 minutes to generate
- Improved statistics
- Individualized comments

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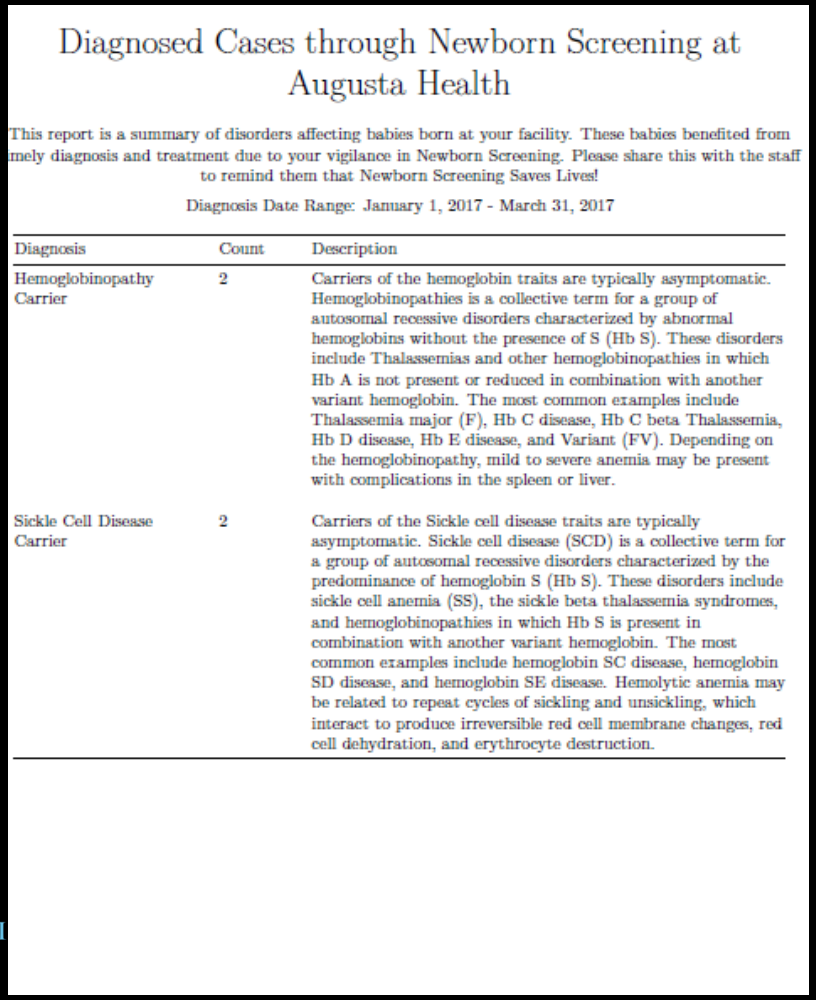

Diagnosed Cases through Newborn Screening at Augusta Health

This report is a summary of disorders affecting babies born at your facility. These babies benefited from mely diagnosis and treatment due to your vigilance in Newborn Screening. Please share this with the staff to remind them that Newborn Screening Saves Lives!

Diagnosis Date Range: January 1, 2017 - March 31, 2017

Diagnosis	Count	Description
Hemoglobinopathy Carrier	2	Carriers of the hemoglobin traits are typically asymptomatic. Hemoglobinopathies is a collective term for a group of autosomal recessive disorders characterized by abnormal hemoglobins without the presence of S (Hb S). These disorders include Thalassemias and other hemoglobinopathies in which Hb A is not present or reduced in combination with another variant hemoglobin. The most common examples include Thalassemia major (F), Hb C disease, Hb C beta Thalassemia, Hb D disease, Hb E disease, and Variant (FV). Depending on the hemoglobinopathy, mild to severe anemia may be present with complications in the spleen or liver.
Sickle Cell Disease Carrier	2	Carriers of the Sickle cell disease traits are typically asymptomatic. Sickle cell disease (SCD) is a collective term for a group of autosomal recessive disorders characterized by the predominance of hemoglobin S (Hb S). These disorders include sickle cell anemia (SS), the sickle beta thalassemia syndromes, and hemoglobinopathies in which Hb S is present in combination with another variant hemoglobin. The most common examples include hemoglobin SC disease, hemoglobin SD disease, and hemoglobin SE disease. Hemolytic anemia may be related to repeat cycles of sickling and unsickling, which interact to produce irreversible red cell membrane changes, red cell dehydration, and erythrocyte destruction.

Hospital Report Card: After

- Diagnoses- number of cases and a narrative
- Shows impact of NBS on babies born in their hospitals

VI

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Hospital Report Card: Additional Features

- Automatically delivered to all individual hospital contacts in <10 seconds
  - Ability to customize the body of the email
- 4 additional ancillary reports for internal use
  - Hospital Summary
  - State Summary
  - Diagnosis Summary
  - Transit Time Outliers

Automated NewSTEPS360 Quality Indicator reporting

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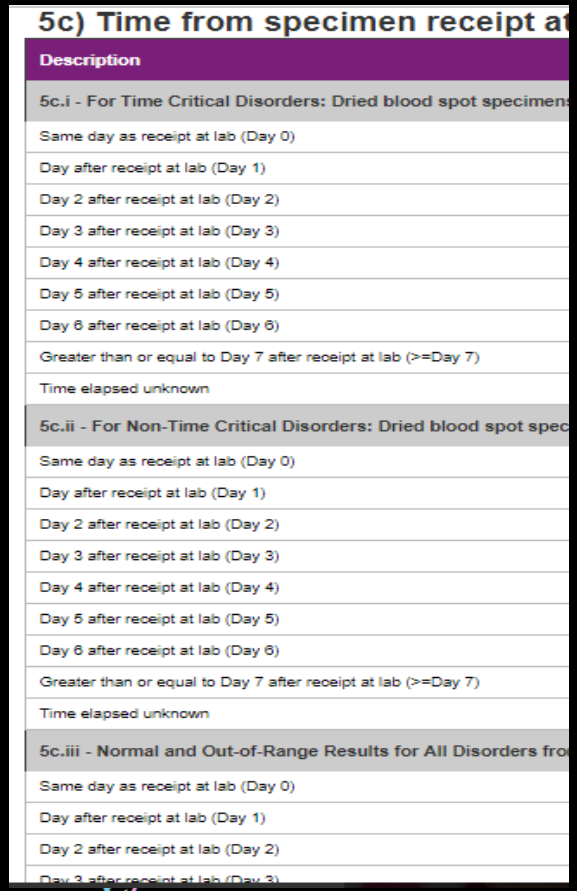
NewSTEPs Quality Indicator Reporting



5c) Time from specimen receipt at

Description
5c.i - For Time Critical Disorders: Dried blood spot specimens
Same day as receipt at lab (Day 0)
Day after receipt at lab (Day 1)
Day 2 after receipt at lab (Day 2)
Day 3 after receipt at lab (Day 3)
Day 4 after receipt at lab (Day 4)
Day 5 after receipt at lab (Day 5)
Day 6 after receipt at lab (Day 6)
Greater than or equal to Day 7 after receipt at lab (>=Day 7)
Time elapsed unknown
5c.ii - For Non-Time Critical Disorders: Dried blood spot spec
Same day as receipt at lab (Day 0)
Day after receipt at lab (Day 1)
Day 2 after receipt at lab (Day 2)
Day 3 after receipt at lab (Day 3)
Day 4 after receipt at lab (Day 4)
Day 5 after receipt at lab (Day 5)
Day 6 after receipt at lab (Day 6)
Greater than or equal to Day 7 after receipt at lab (>=Day 7)
Time elapsed unknown
5c.iii - Normal and Out-of-Range Results for All Disorders fro
Same day as receipt at lab (Day 0)
Day after receipt at lab (Day 1)
Day 2 after receipt at lab (Day 2)
Day 3 after receipt at lab (Day 3)

- 131 quality indicators
- Calculated and written to a .csv file in <5 seconds
- .csv allows for direct importing into the NewSTEPs data repository

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Visual Mapping of Diseases

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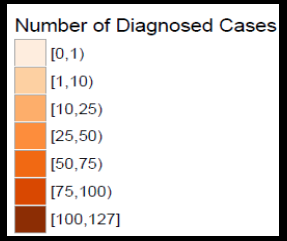
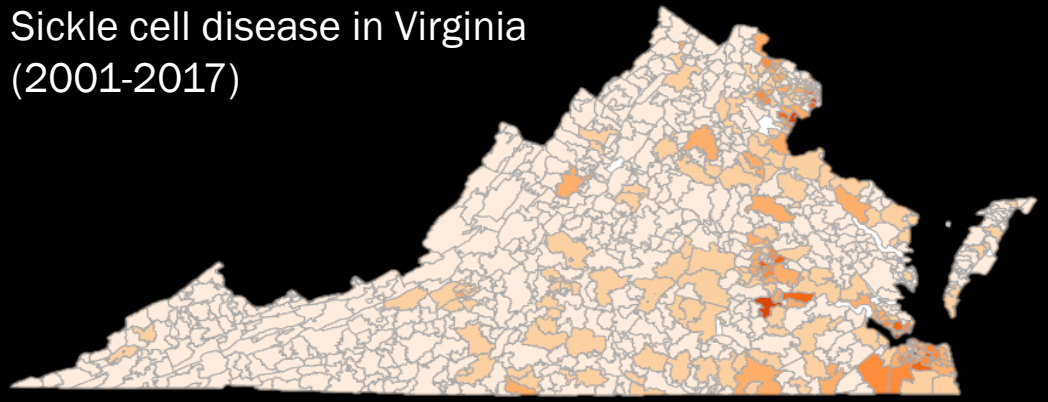
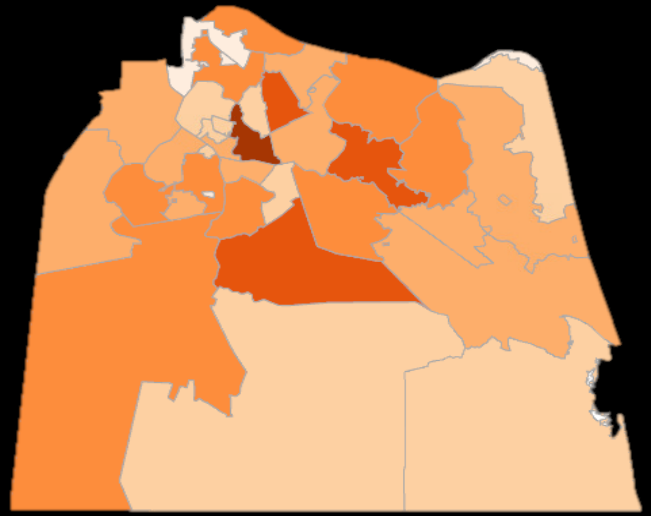


Sickle cell disease in Virginia (2001-2017)





- Ability to view disease distribution at the state and county level

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Automated False Positive Statistical Reports

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False Positive Statistics

IRT: Test Data	
# of Critical Samples Where No Disease Is Present	180
% of Critical Samples Where No Disease Is Present (Denominator: All Samples)	0.01
% of Critical of Samples Where No Disease Is Present (Denominator: All Abnormal Samples)	77.92

- Analyze positive sample results compared to disease state
- Ability to filter by date range and certain infant factors (such as low birth weight or TPN feeding)

So, why should you partner with a university?

- ✓FREE!
- ✓Skilled
- ✓Technologically equipped
- ✓They *want* to partner with you!

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Get out and make connections!

- 235 data science colleges across the country
- Be proactive!

> "Be willing to get creative and find ways to do things when you have limited resources" – Willie Andrews

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THANK YOU

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