

# THE IOWA EXPERIENCE

## Re-assessing Timeliness Requirements for Time-Critical Conditions: No Time to Lose

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# SEAT BELTS and NBS

- 2009 was the 50-year anniversary of the conventional “three point” seat belt [invented by Volvo].
  - Cited as: “The most successful contribution to safety in the history of motoring.”
  - Purpose: Save lives and prevent harm
  
- 2013 was the 50-year anniversary of Newborn Screening [first begun by Dr. Robert Guthrie].
  - Cited as: “One of the most successful Public Health programs in the country.”
  - Purpose: Save lives and prevent harm

# SEAT BELTS and NBS

## Seat Belts

- No Previous Accident
- Drives very well
- If used could save lives and prevent harm

## Newborn Screening

- No Family History
- No Symptoms
- If used could save lives and prevent harm

Therefore, it is very important that every passenger in a motor vehicle put on a seat belt before traveling.

When seat belts are used there is a clear reduction in death and injuries.

# However...

Sporadic reports began to pop up indicating that seat belts were not working for all passengers in motor vehicles.

First questions: Were they using a seat belt? If they were using a seat belt were they using it correctly?

More reports of harm continued to surface with verified seat belt use.

# Then...

An investigative study<sup>1</sup>: A disproportionate amount of harm was observed among a certain subset of passengers using seat belts in motor vehicles.

Initial response: The reality is, seat belts can't protect everyone in every accident.

[Unspoken: Therefore nothing needs to be done.]

<sup>1</sup>Agran, P., Anderson, C., and Winn, D., "Restraint Use Among Children in Fatal Crashes," SAE Technical Paper 973300, 1997

# But...

Some recognized that this identified subpopulation of passengers was uniquely different.

- Encouraging more attention to the proper use of the existing structures (e.g., pull on the strap harder) was not going to help.
- Additional structures were needed to enable the seat belt to accomplish its stated purpose: Save lives and protect from harm

# NOW...

We all recognize the importance of the  
child car seat.

# SEAT BELTS and NBS

## Seat Belts

- Unique subset of small children
- Existing structures (i.e., the seat belt alone) are not enough
- Additional structures (i.e., the car seat) are necessary to allow the seat belt to succeed.

## Newborn Screening

- Unique subset of Time-Critical conditions
- Existing structures are not enough
- Additional structures are necessary to allow Newborn Screening to succeed for Time-Critical conditions.

# THE CHALLENGE: Timeliness

- Is there something that can be done for Time-Critical conditions?
- Are there additional structures that are needed that will allow NBS to better protect that subset of newborns with Time-Critical conditions?

[...in the same way the child car seat allows the seat belt to carry out its stated purpose of saving lives and protecting from harm.]
- What are the biggest contributors to time delays?

# REALITIES

- Babies are born with Time-Critical conditions that if not discovered in time and effective interventions initiated will suffer harm and may experience a metabolic crisis leading to coma and possibly death.
- Babies with these conditions can be born on any day of the week.

# In order to benefit these newborns...

- Specimens must be collected **everyday**
- Specimens must be transported **everyday**
- Specimens must be tested **everyday**
- Presumptive Positive results for Time-Critical conditions must be reported **everyday**
- Appropriate information must be able to be provided to the baby's PCP **everyday**
- So that a baby with a PP result for a Time-Critical condition can be evaluated on **any given day**.

Every baby should have the same opportunity for a healthy life regardless of which day they were born.

# But the Weekend

- The most significant contributor to delays in NBS is the weekend.
- Batching at hospitals exasperates delays; but
- The largest contributor is the current structures which include a weekly built-in “2-day batching” delay imposed by the weekend
- However, simply keeping the NBS laboratory open on weekends has little value if specimens are not able to get to the laboratory everyday.

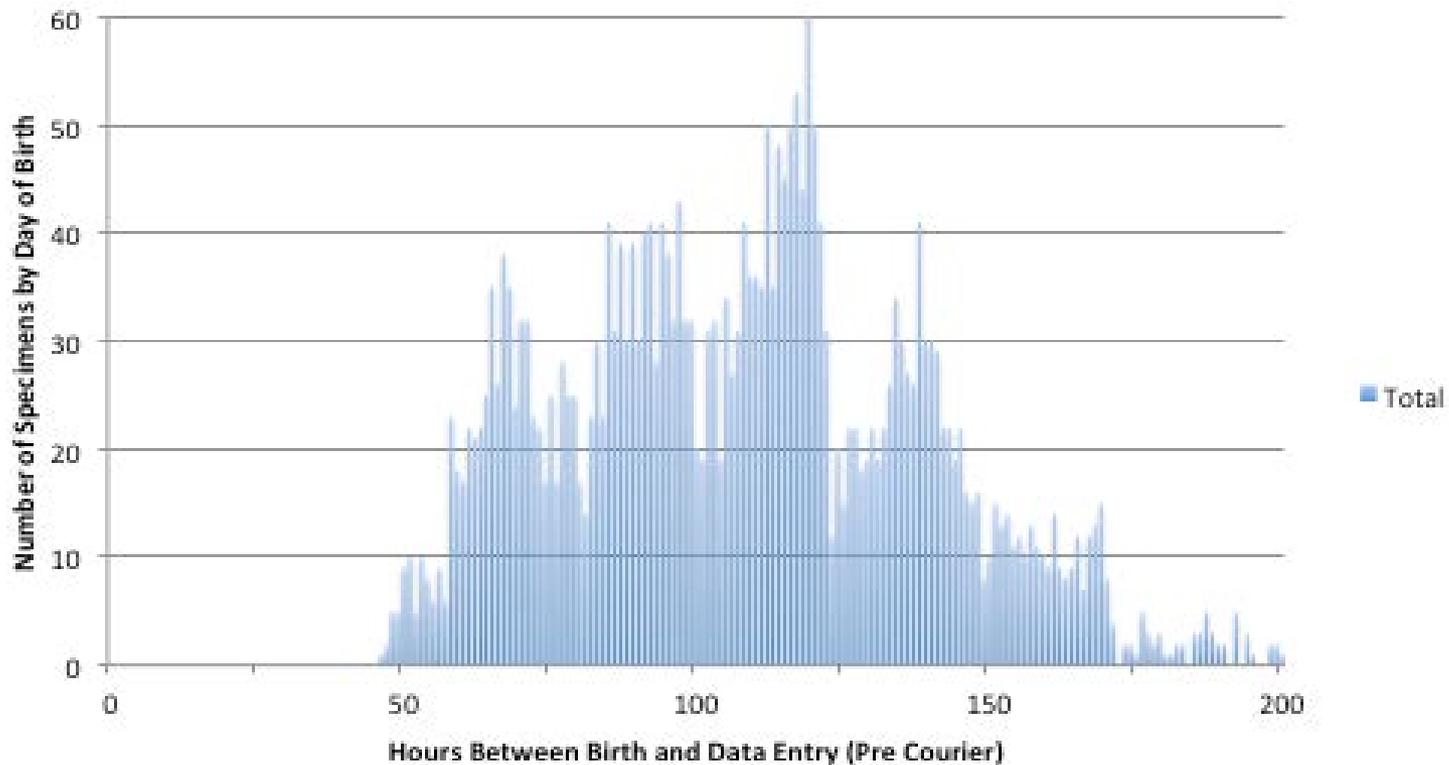
# But the Weekend

The most critical part of the structure is getting specimens picked up and delivered to the laboratory everyday.

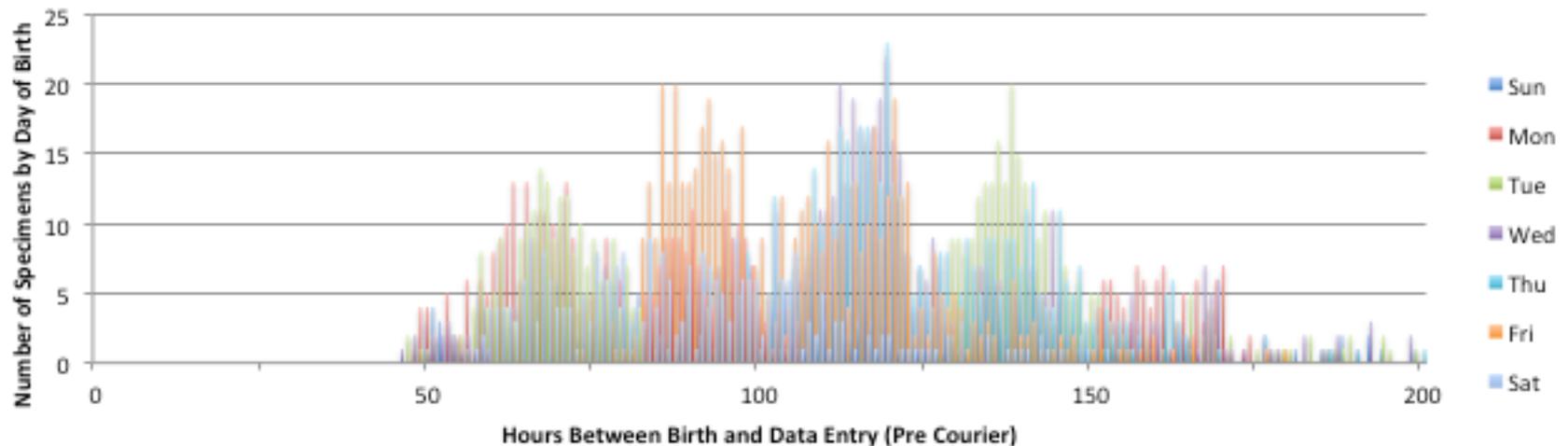
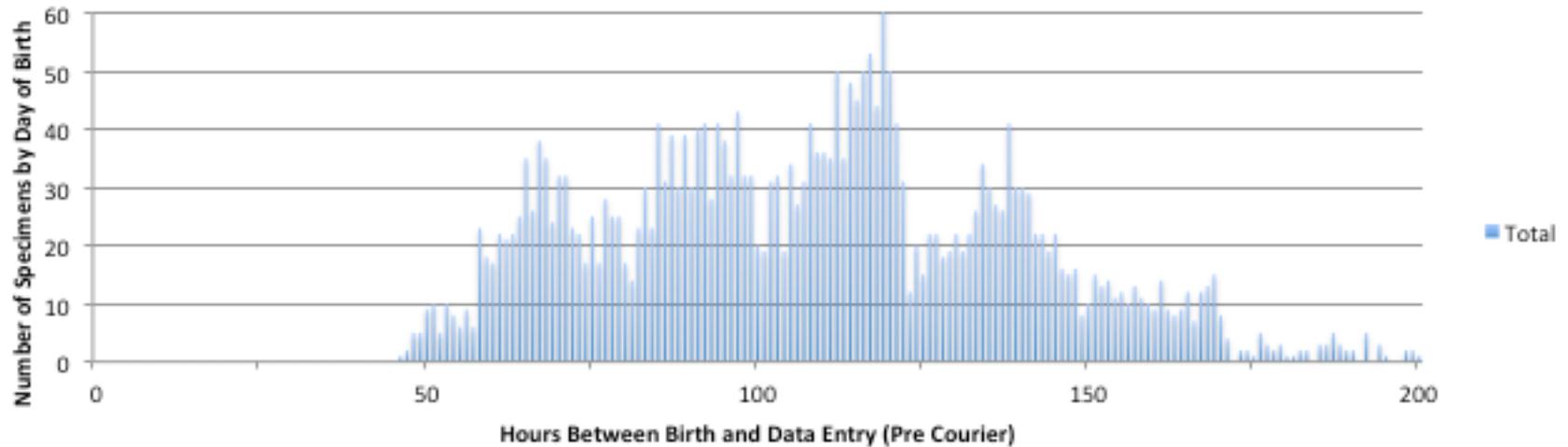
- Babies are born everyday
- Hospitals collect specimens everyday
- We need to get specimens to the laboratory everyday
- Once we have the structures in place to get specimens to the laboratory everyday we need to develop structures that enable testing, reporting and follow-up everyday.

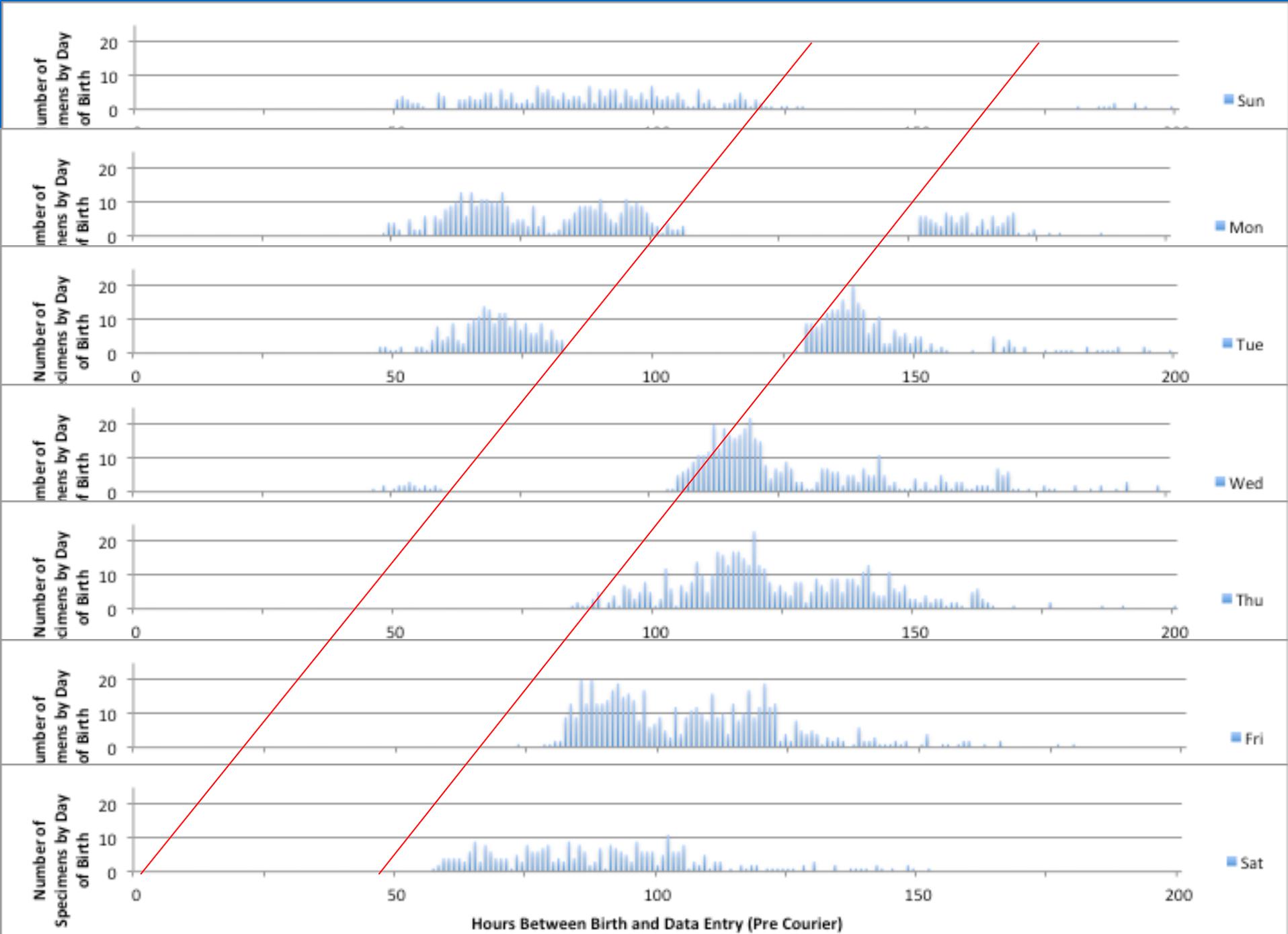
# Pre Courier

Pre Courier	Sun	Mon	Tue	Wed	Thu	Fri	Sat
Day of Birth	8%	15%	15%	15%	17%	19%	10%
Day of Collection	15%	10%	12%	14%	16%	16%	17%
Day Received	0%	9%	26%	23%	14%	15%	14%
Day of Data Entry	0%	23%	26%	23%	14%	15%	0%
med bir to entered	89	86	131	120	119	105	89



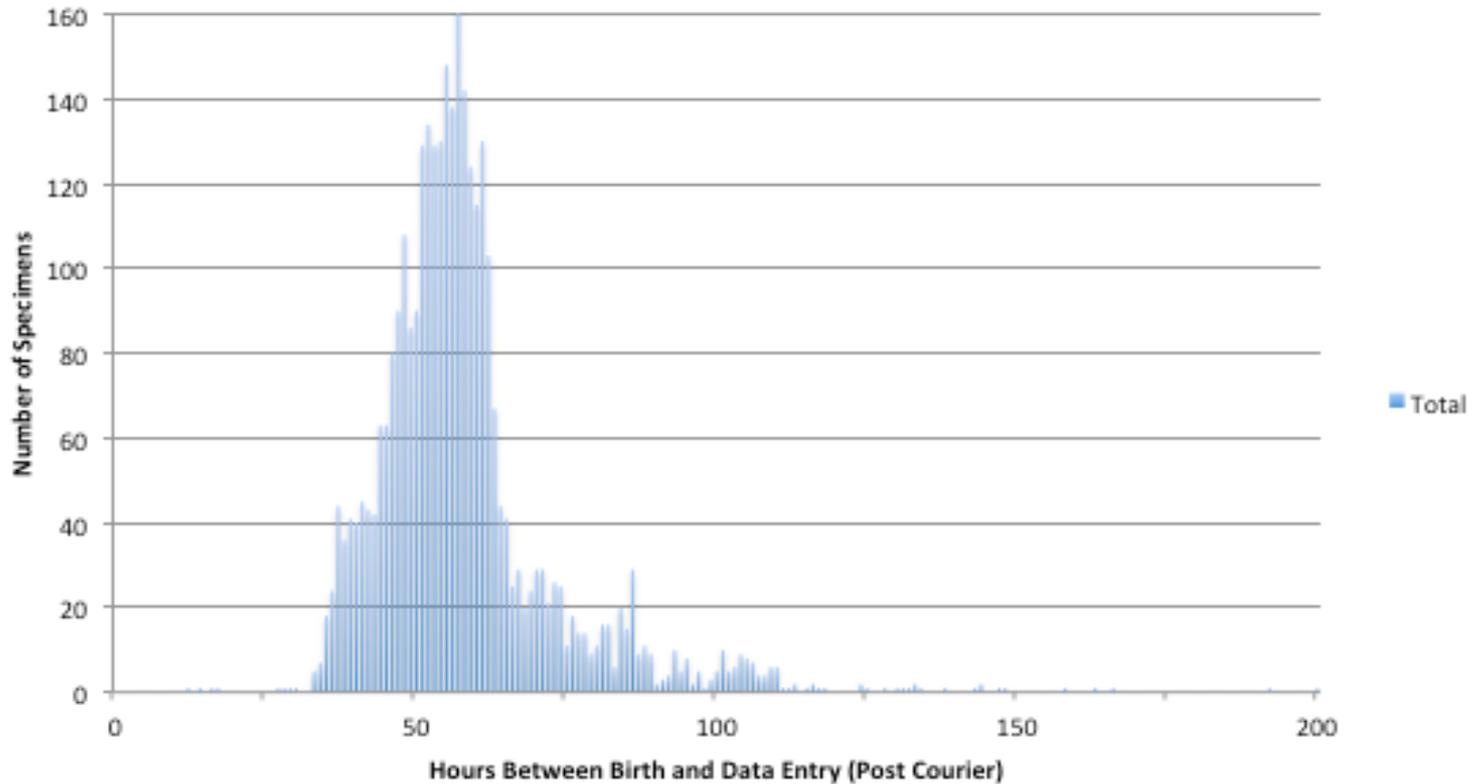
# Pre Courier



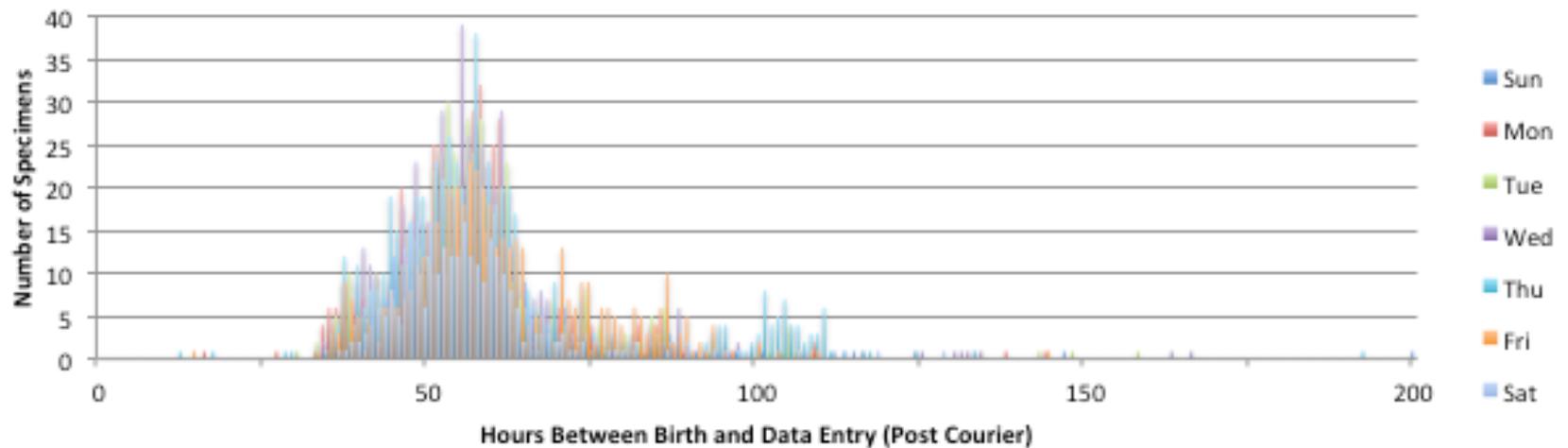
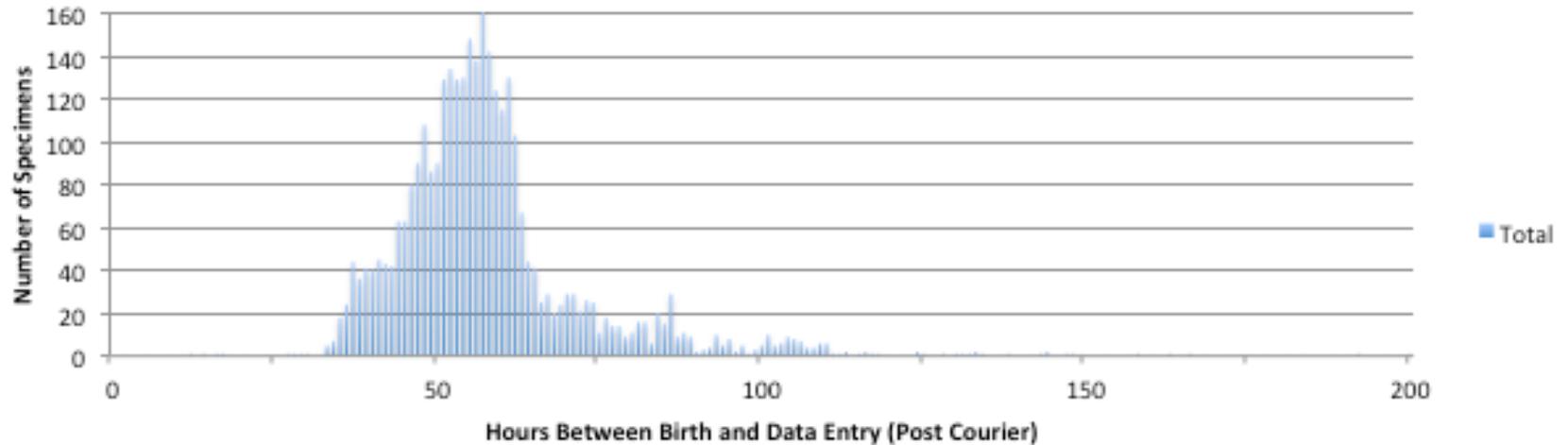


# Post Courier

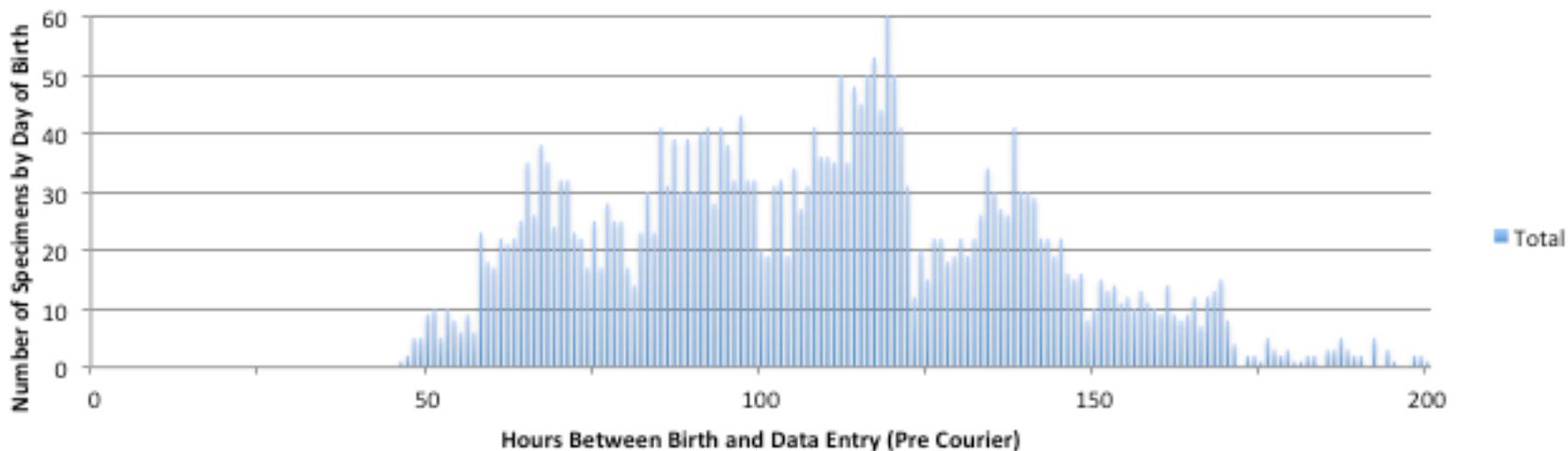
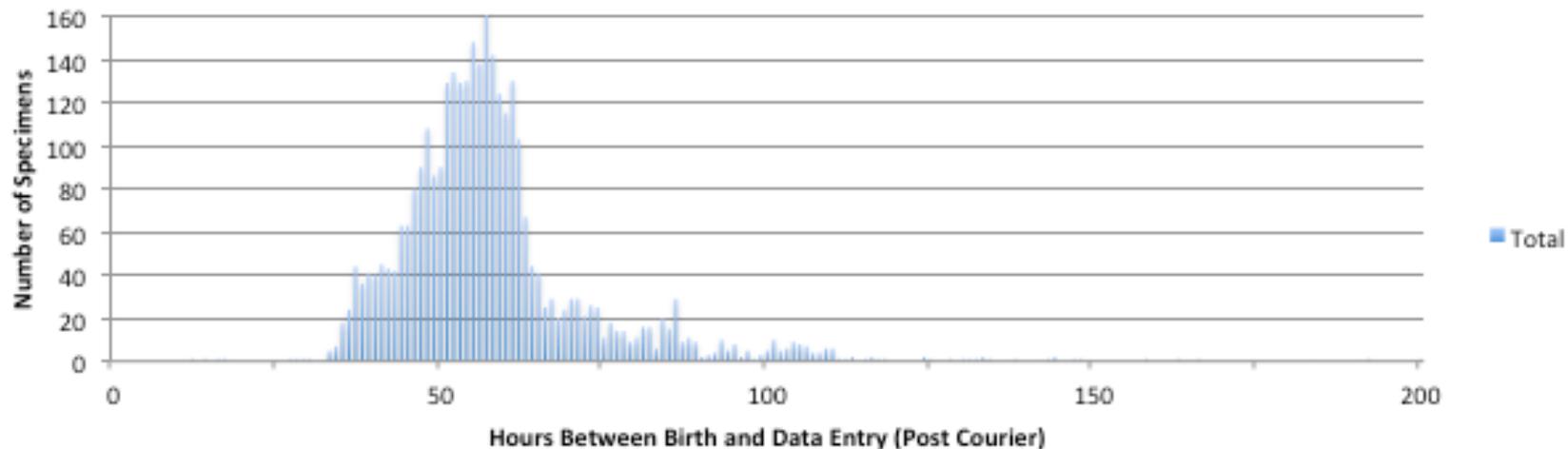
Post Courier	Sun	Mon	Tue	Wed	Thu	Fri	Sat
Day of Birth	8%	15%	16%	18%	19%	15%	9%
Day of Collection	13%	8%	13%	14%	18%	18%	16%
Day Received	13%	14%	9%	15%	16%	17%	16%
Day of Data Entry	12%	16%	9%	15%	16%	17%	15%
med bir to entered	55	55	56	55	56.5	58	54



# Post Courier



# Post Courier



# But the Weekend

The most critical part of the structure is getting specimens picked up and delivered everyday.

- Babies are born everyday
- Hospitals collect specimens everyday
- We need to get specimens to the laboratory everyday
- Once we have the structures in place to get specimens to the laboratory everyday we need to develop structures that enable testing, reporting and follow-up everyday.

# Timeliness

## The Iowa Newborn Screening Program

- Dedicated courier picks up NBS specimens 365 days a year.
- The specimens are picked up **every day** in the early evening and delivered by about 9:30pm that same day.
- The laboratory night shift staff is present **every day** to receive the specimens and begin testing right away and through the night.
- The laboratory day shift staff is present **every day** to continue the testing and report results to Program Follow-up staff **every day**.
- The Program Follow-up staff are available **every day** to ensure that a baby at risk for a time-critical condition is tracked down and can be assessed that day to determine the need for appropriate interventions.

# Timeliness

<b>ALL SPECIMENS</b>		<b>Median</b>	<b>Average</b>	<b>sd</b>
<b>Birth to Collection</b>	<b>Pre</b>	35	38.6	23.3
	<b>Post</b>	29	32.8	14.3
<b>Birth to Data Entry</b>	<b>Pre</b>	109	110.5	39.1
	<b>Post</b>	56	58.7	19.4
<b>Birth to Report</b>	<b>Pre</b>	151	155.1	41.7
	<b>Post</b>	97	101.9	21.9

<b>Time Critical</b>		<b>Median</b>	<b>Average</b>	<b>sd</b>
<b>Data Entry to Test Result</b>	<b>Post</b>	13	14.8	8.2
<b>Birth to Test Result</b>	<b>Post</b>	70	74.0	21.0

Thank you!

