



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 study¹: 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.]

¹Agran, 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.

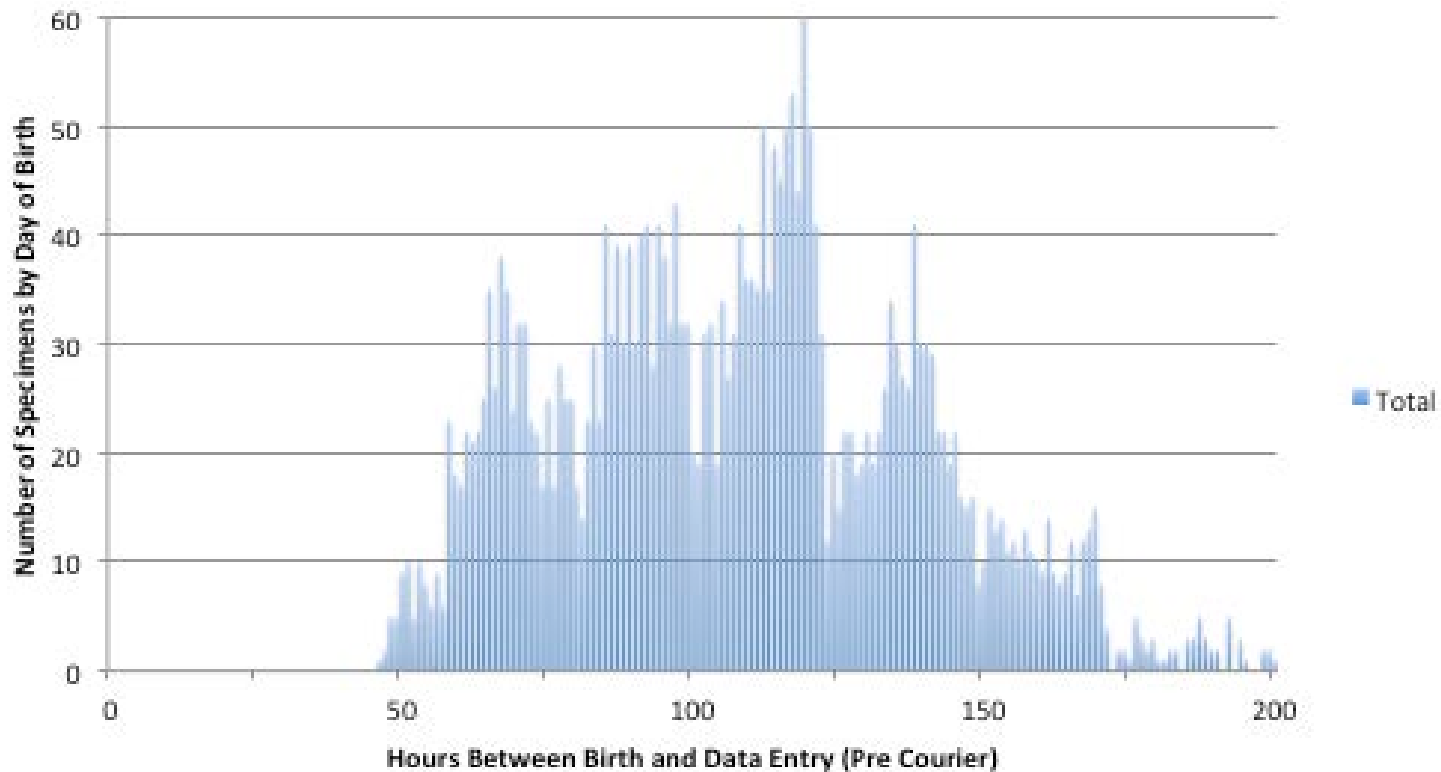
But the Weekend

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

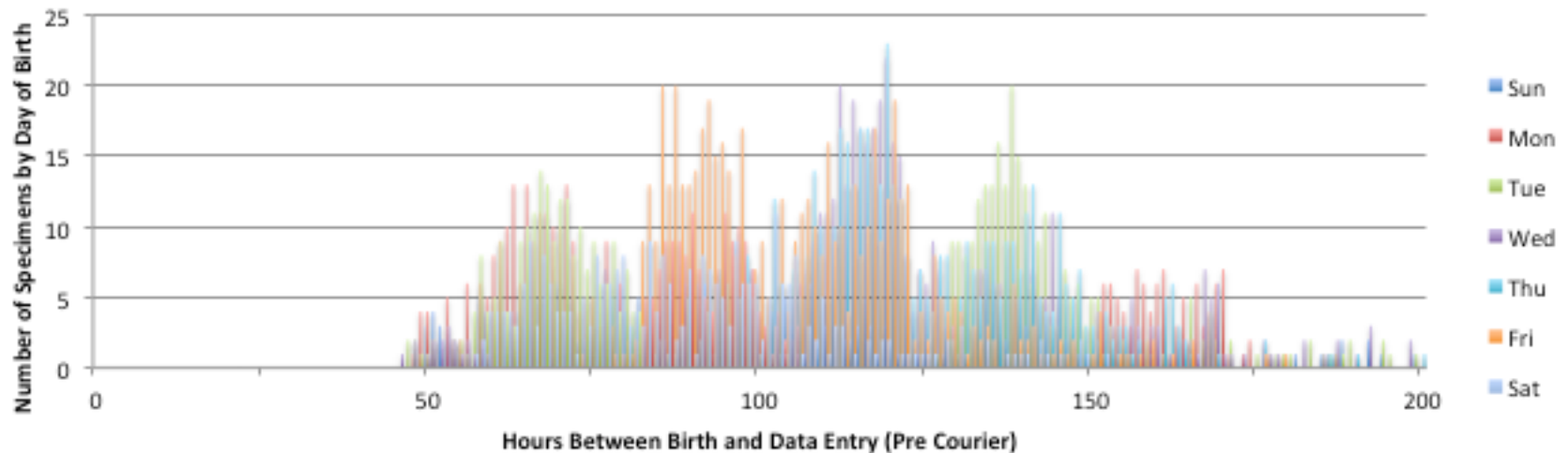
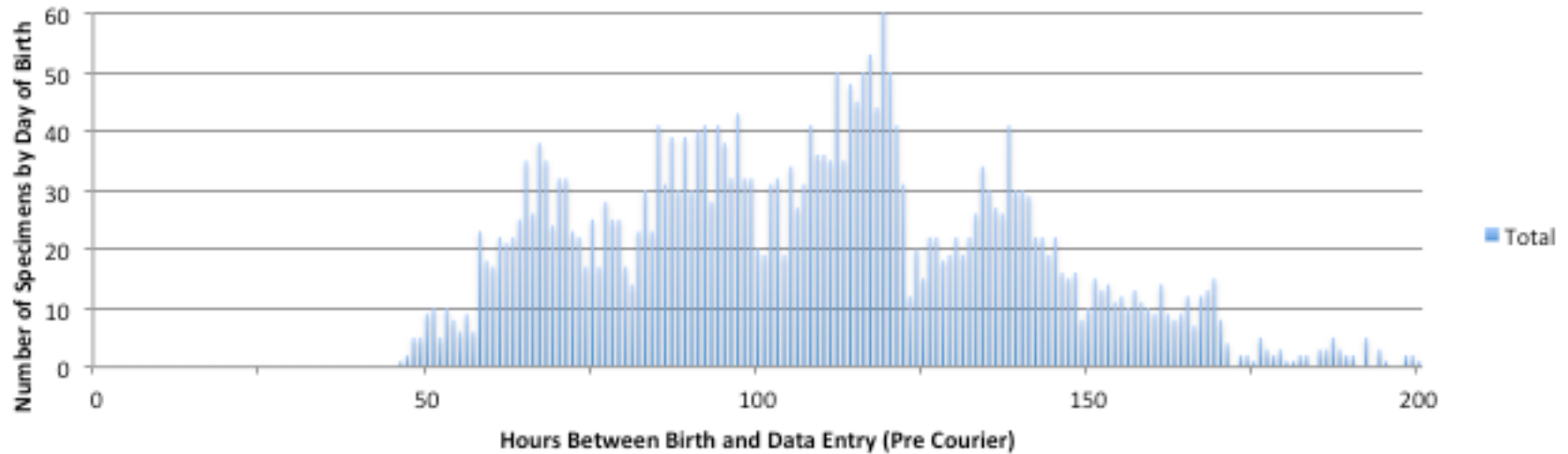
- Babies are born everyday
- Hospitals collect specimens everyday
- We need to get specimens to the laboratory everyday
- Once we have the structures in place to get specimens to the laboratory everyday we need to develop structures that enable testing, reporting and follow-up everyday.

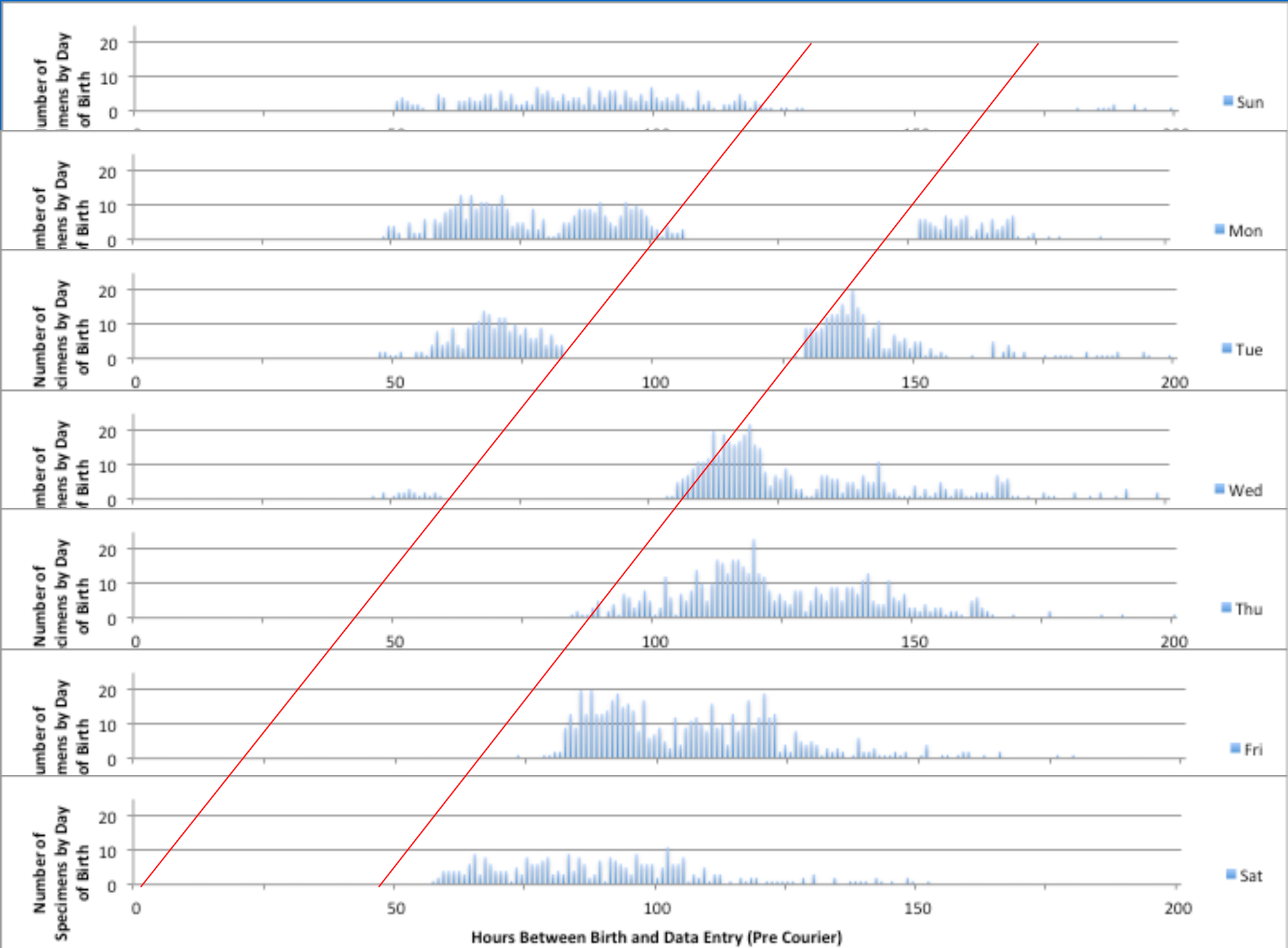
Pre Courier

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



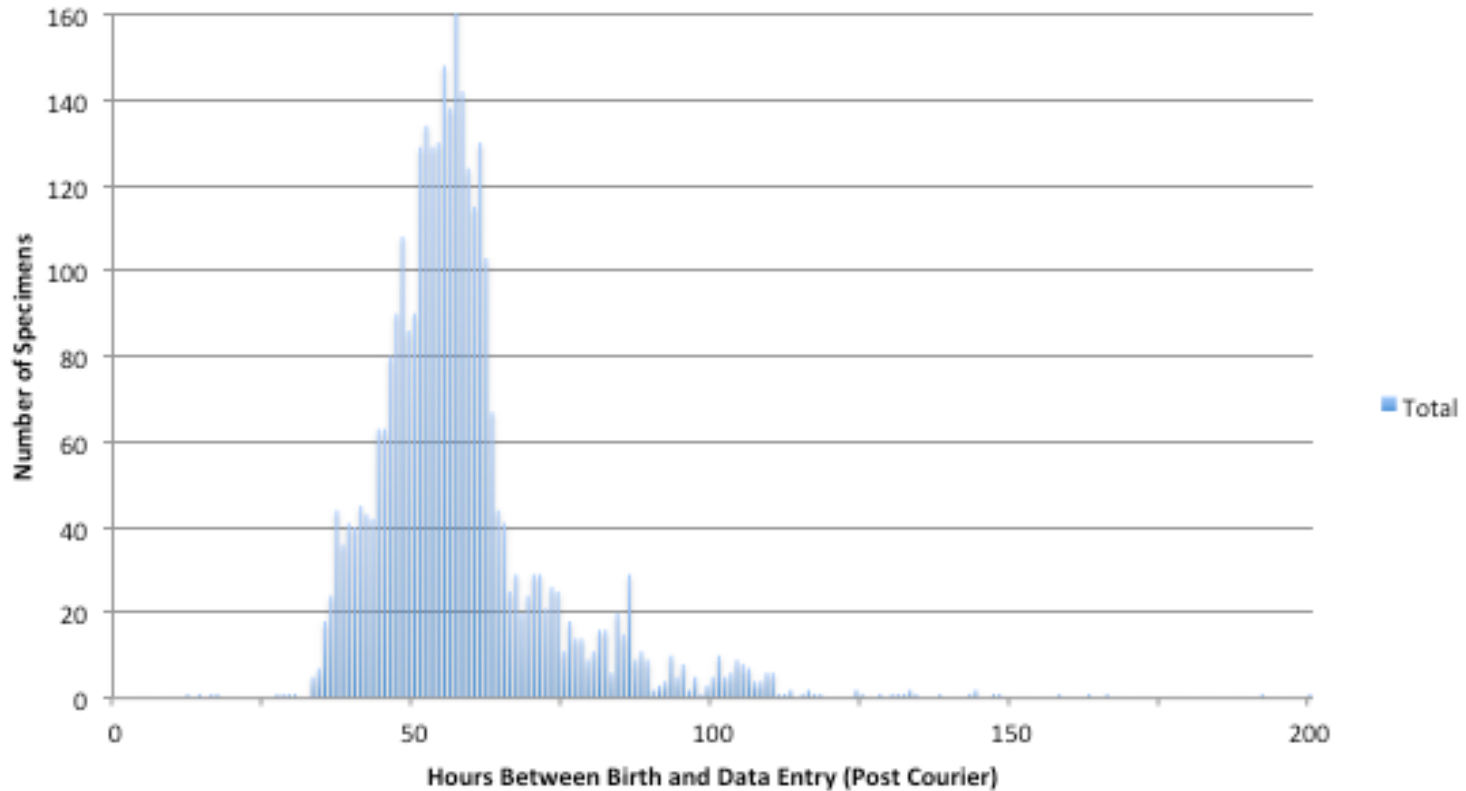
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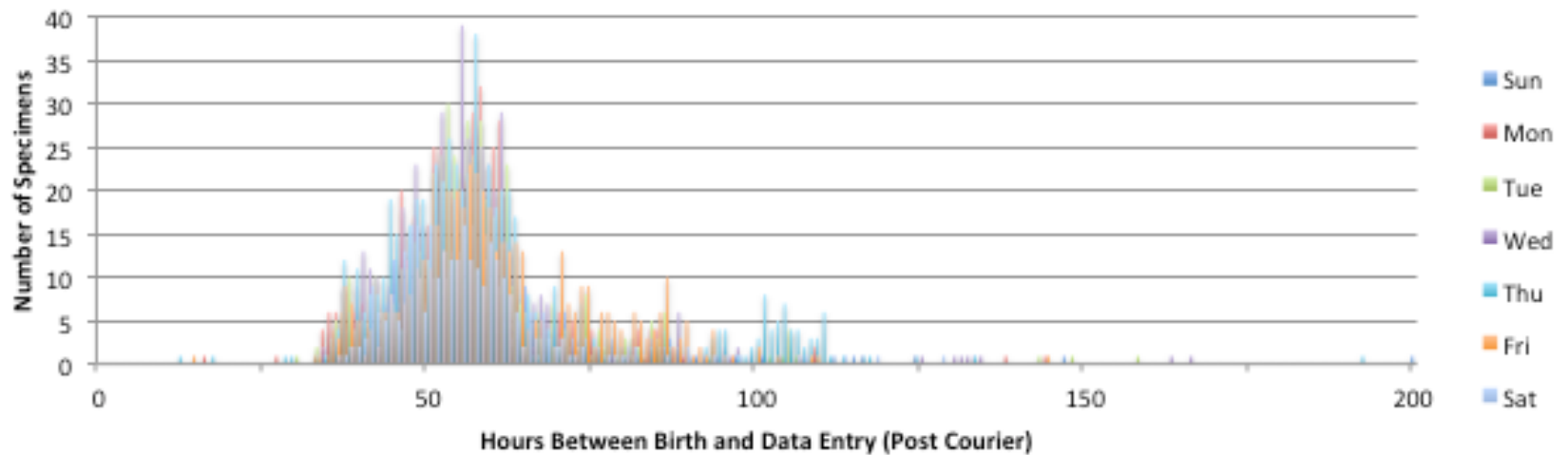
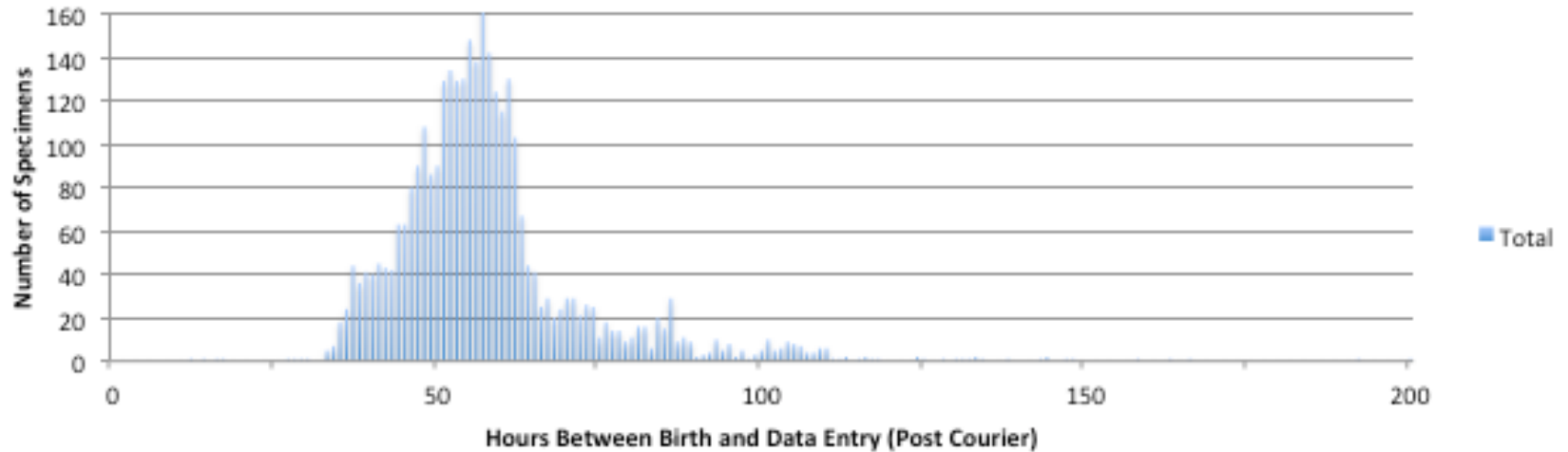


Post Courier

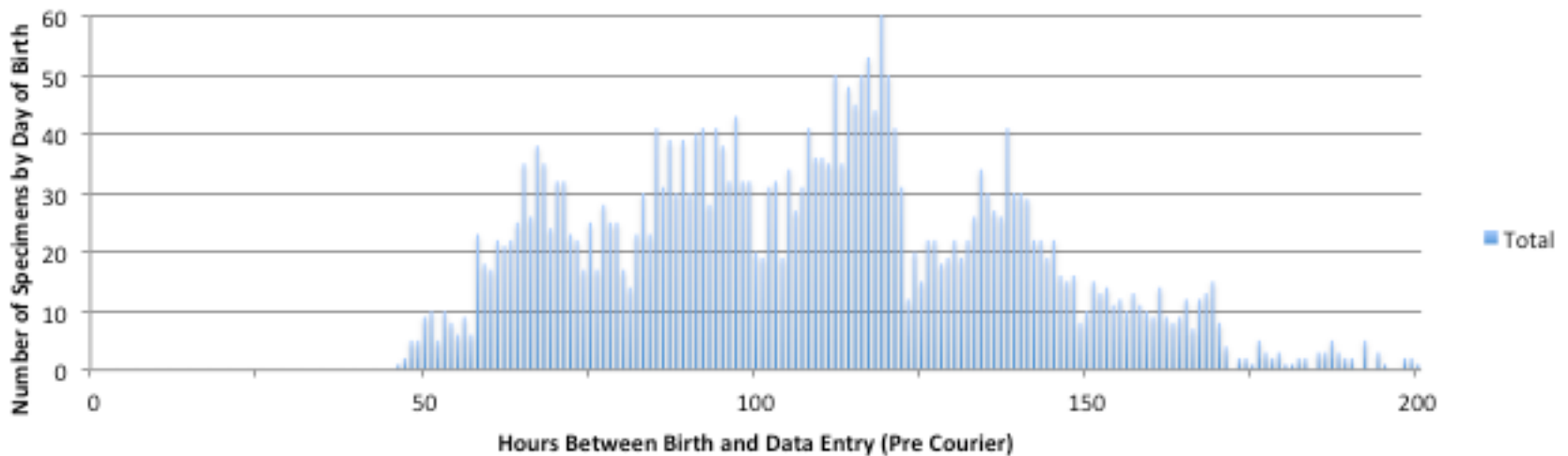
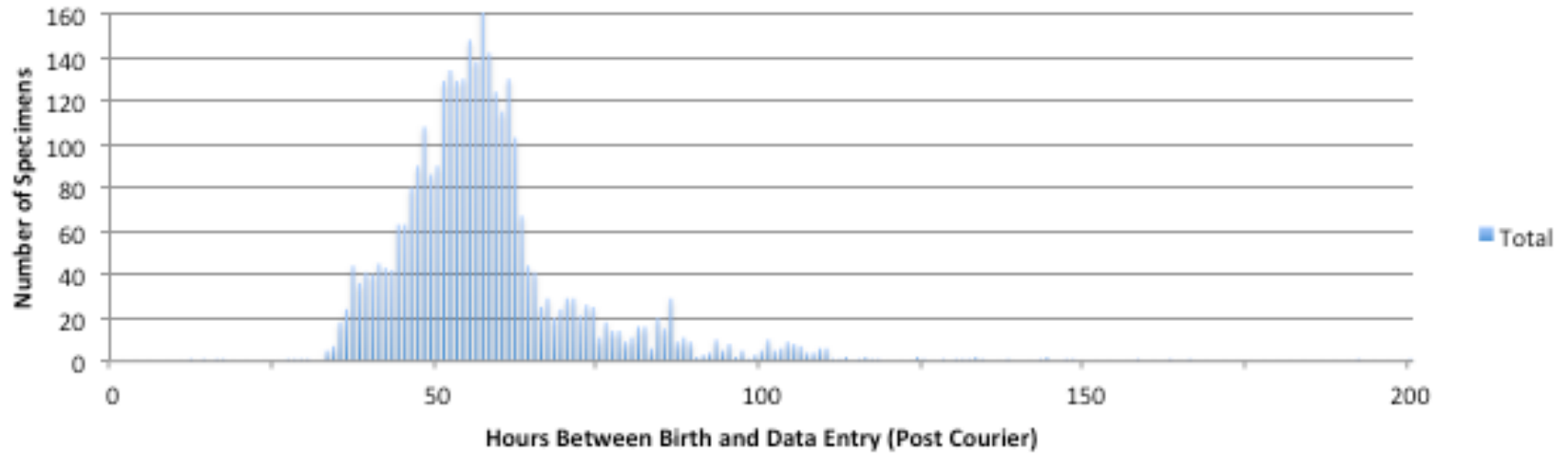
Post Courier	Sun	Mon	Tue	Wed	Thu	Fri	Sat
Day of Birth	8%	15%	16%	18%	19%	15%	9%
Day of Collection	13%	8%	13%	14%	18%	18%	16%
Day Received	13%	14%	9%	15%	16%	17%	16%
Day of Data Entry	12%	16%	9%	15%	16%	17%	15%
med bir to entered	55	55	56	55	56.5	58	54



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
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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

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

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

Thank you!

