THE IOWA EXPERIENCE

Improving Timeliness in Newborn Screening

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Est. 1904
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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. [In the same way, NBS…]

However…

As the use of seat belts became more widespread and mandated, there were reports that seat belts were not protecting all passengers.

First response:

- 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[1]: A disproportionate amount of harm was observed among a certain subset of passengers using seat belts in motor vehicles.

[1]Agran, P., Anderson, C., and Winn, D., "Restraint Use Among Children in Fatal Crashes," SAE Technical Paper 973300, 1997

But…

For this identified unique subset of passengers:

- Attending to "proper use" of the existing structures was not going to help (e.g., pull on the strap harder) .
- It became apparent that ***additional structures*** were necessary 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.

The additional structures provided by the child's car seat allowed the seat belt to fully carry out it's purpose:

Save Lives and Protect from Harm

Is there something parallel in NBS?

Yes…

A subset of NBS conditions are “Time-Critical” meaning they can cause catastrophic damage within hours of birth.

SEAT BELTS and NBS

Seat Belts	Newborn Screening
▪Unique subset of small children	▪Unique subset of Time-Critical conditions
▪Existing structures (i.e., the seat belt alone) are not enough	▪Existing structures are not enough
▪Additional structures (i.e., the car seat) are necessary to allow the seat belt to succeed for children.	▪Additional structures are necessary to allow Newborn Screening to succeed for Time-Critical conditions.

REALITIES

- Babies are born with Time-Critical conditions who, 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.

THE CHALLENGE: Timeliness

- Is there something that can be done for Time-Critical conditions?
- Are there additional structures needed in NBS to better protect the 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?

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 (and exaggerated with Holidays): 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.

It is important to be clear about what we want as outcomes. Then we look to develop the structures and processes necessary to enable those outcomes.

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.

Timeliness

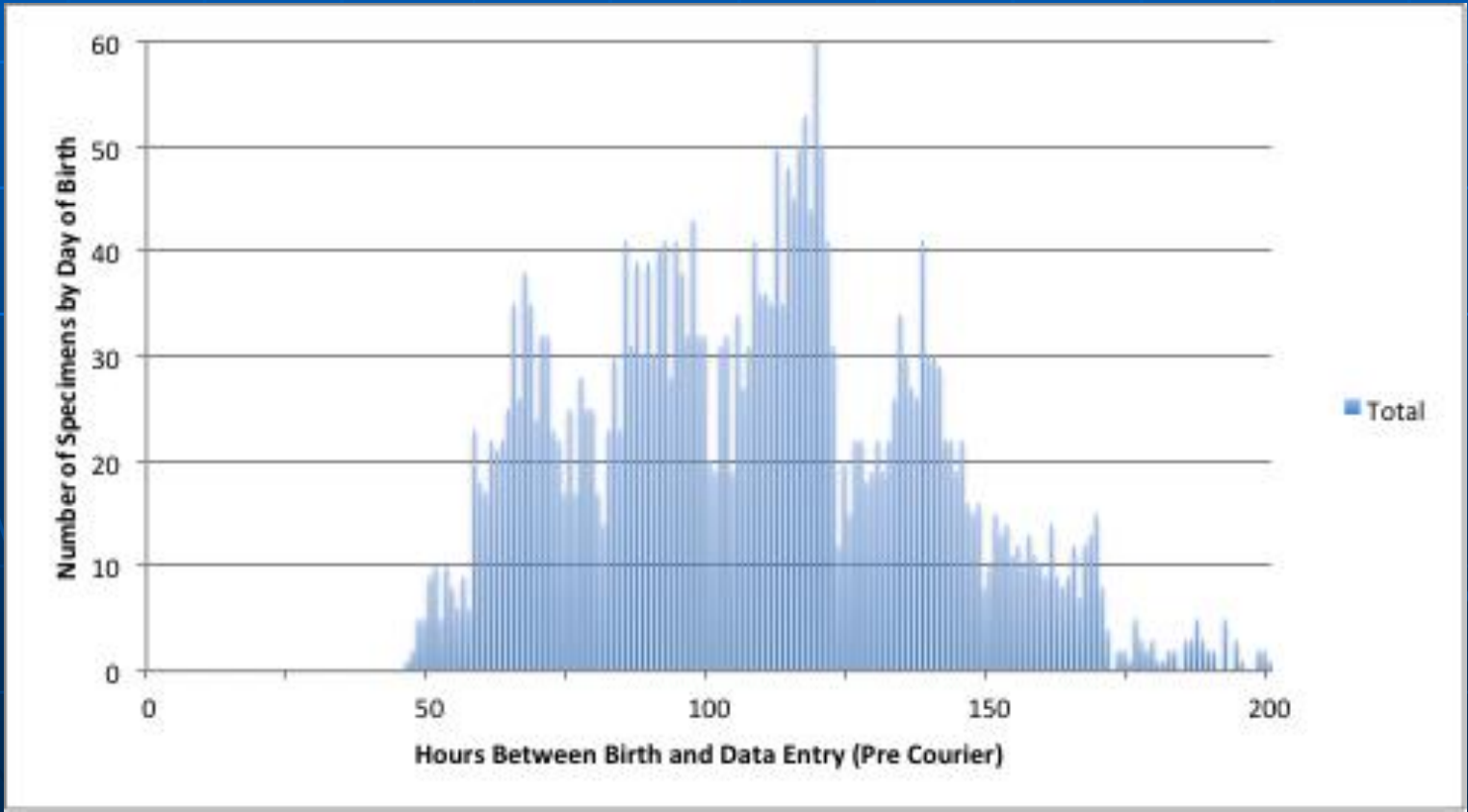
The Iowa Newborn Screening Program

- 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.

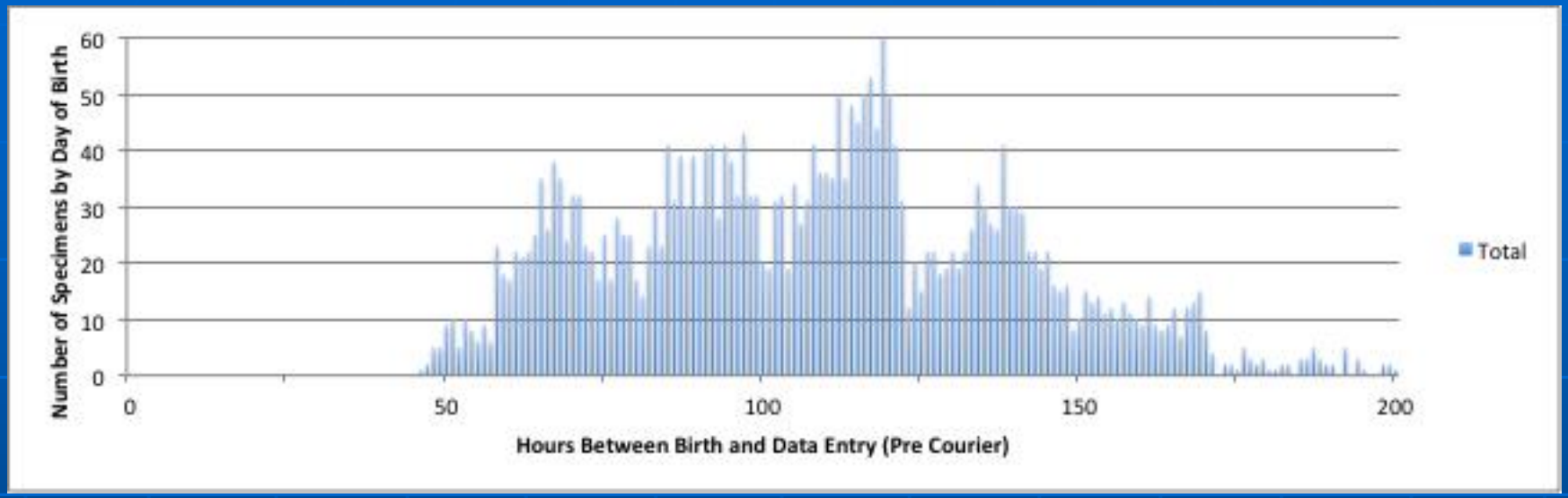
Does it make a difference?

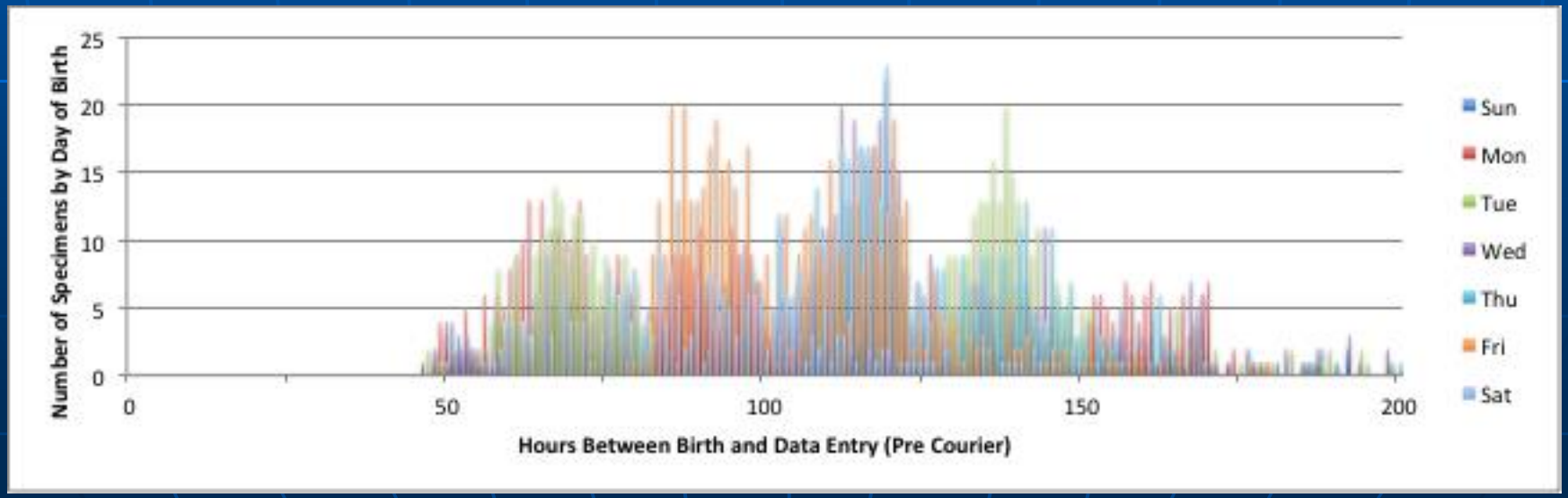
Pre Courier

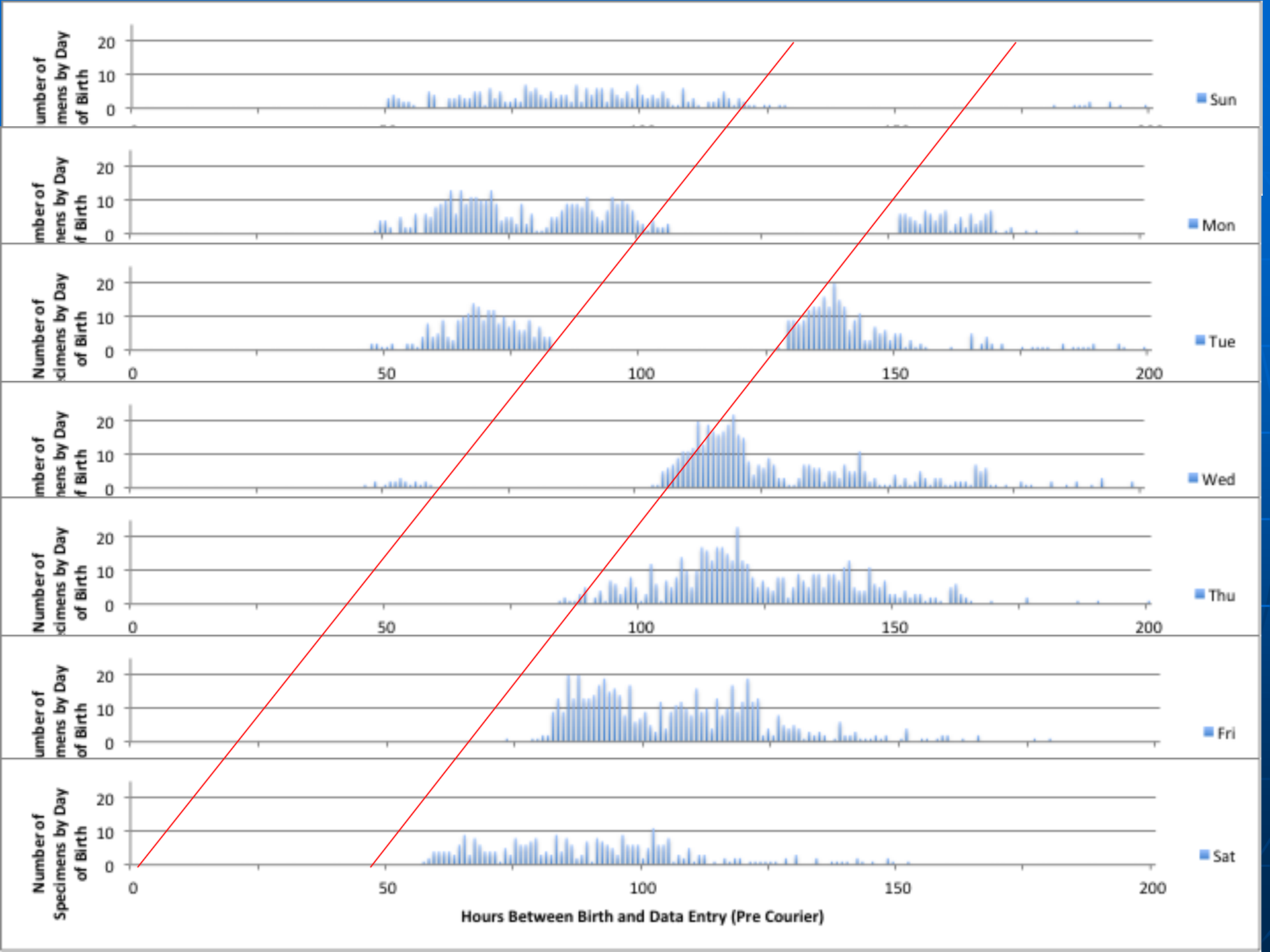
Pre Courier	Sun	Mon	Tue	Wed	Thu	Fri	Sat
Day of Birth	8%	15%	15%	15%	17%	19%	10%
Day of Collection	15%	10%	12%	14%	16%	16%	17%
Day Received	0%	9%	26%	23%	14%	15%	14%
Day of Data Entry	0%	23%	26%	23%	14%	15%	0%
med bir to entered	89	86	131	120	119	105	89



Pre Courier

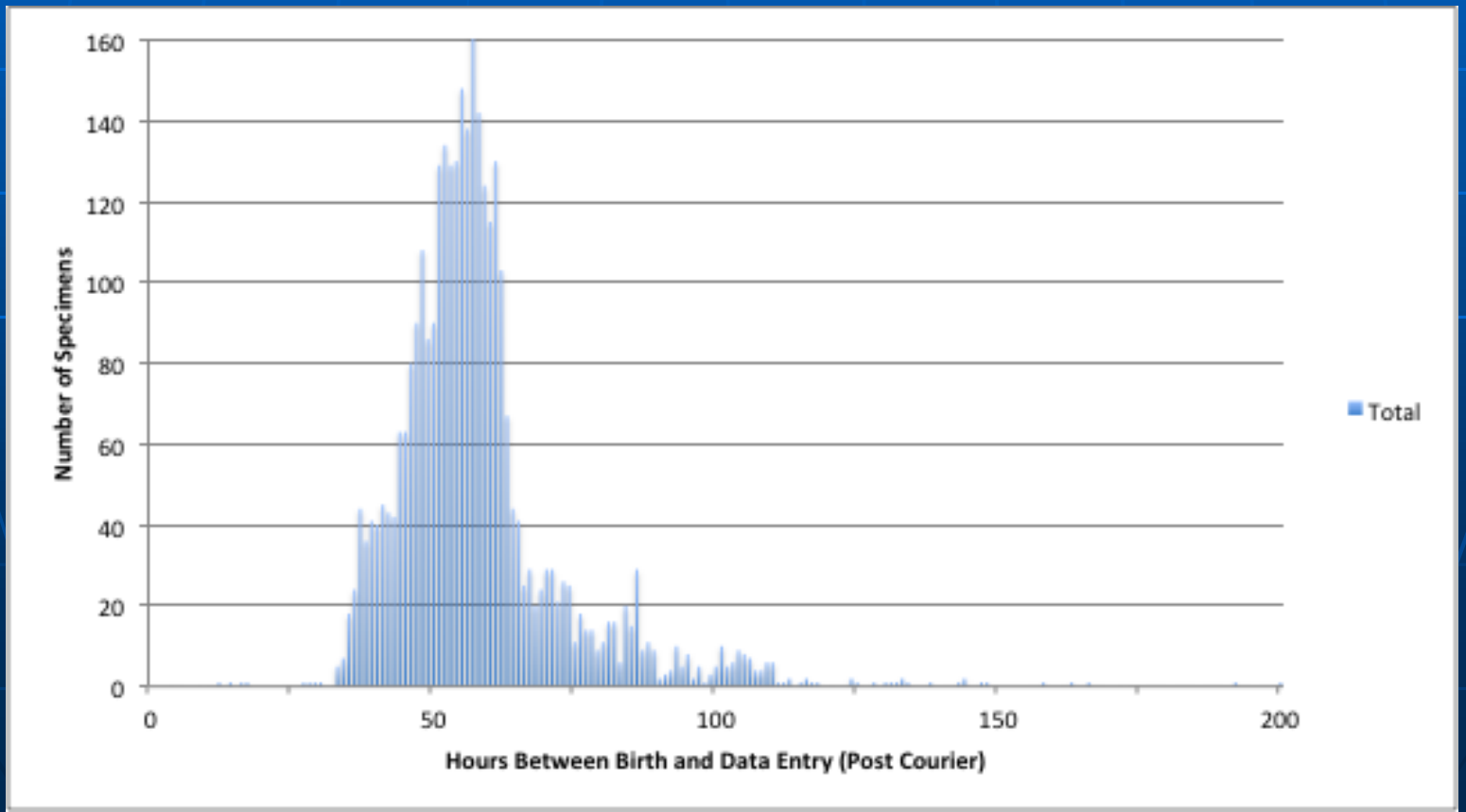

Number of Specimens by Day of Birth
60
50
40
30
20
10
0
0
50
100
150
200
Hours Between Birth and Data Entry (Pre Courier)
Total


Number of Specimens by Day of Birth
25
20
15
10
5
0
0
50
100
150
200
Hours Between Birth and Data Entry (Pre Courier)
Sun
Mon
Tue
Wed
Thu
Fri
Sat

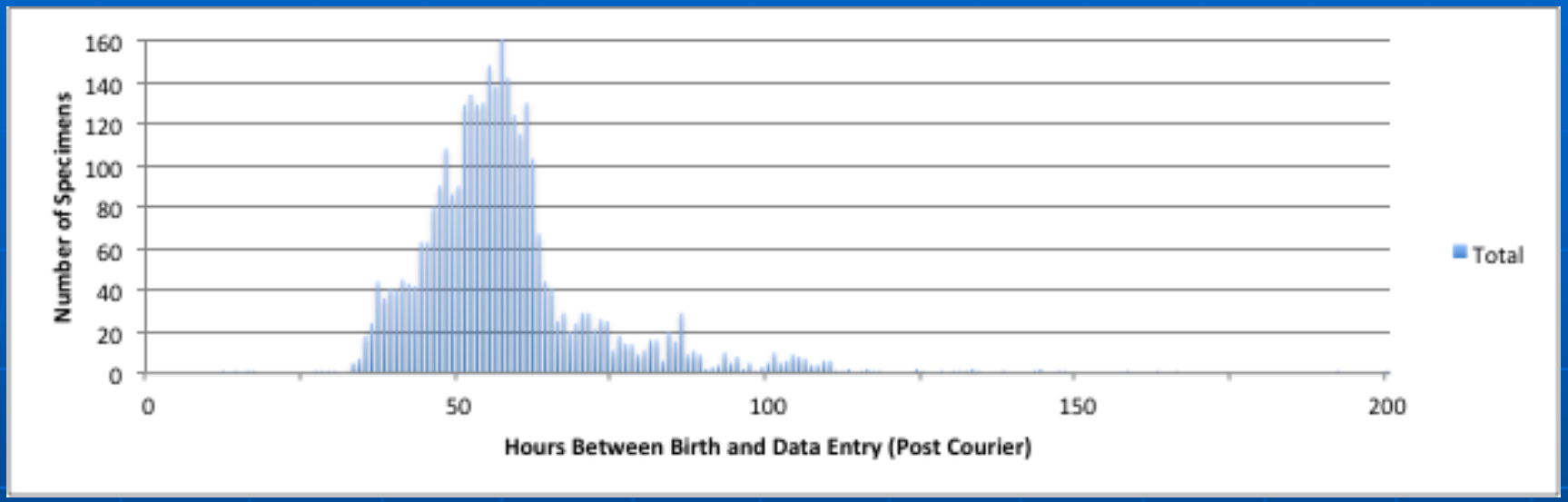

Number of Specimens by Day of Birth
20
10
0
Sun
Mon
Tue
Wed
Thu
Fri
Sat
0
50
100
150
200
Hours Between Birth and Data Entry (Pre Courier)

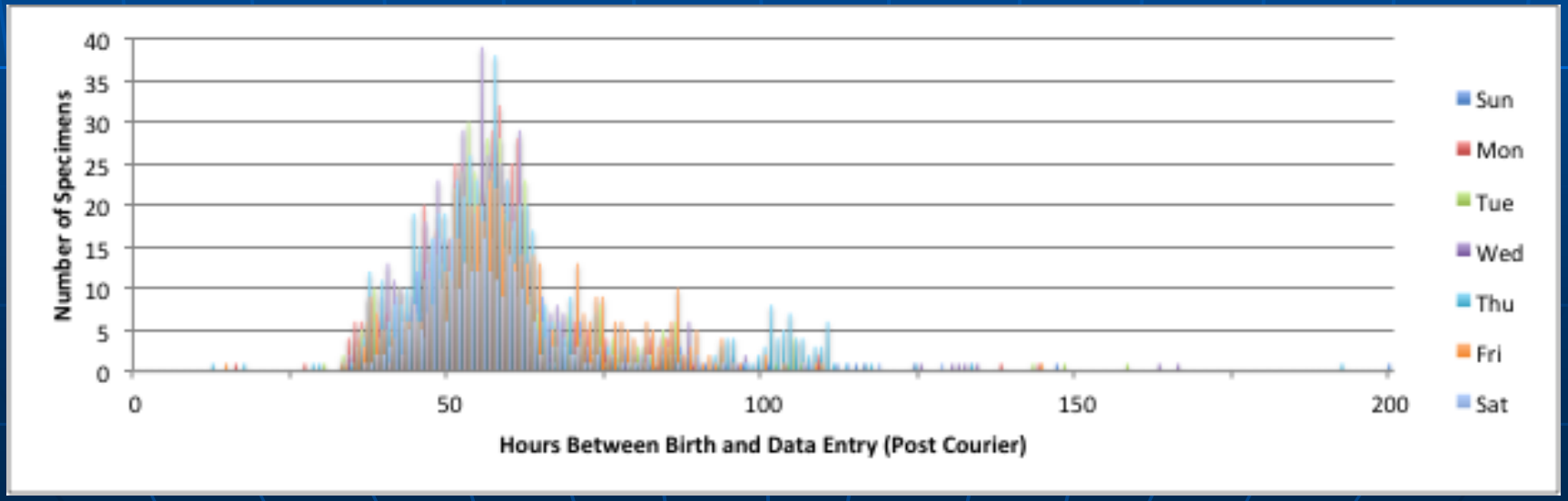
Post Courier

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

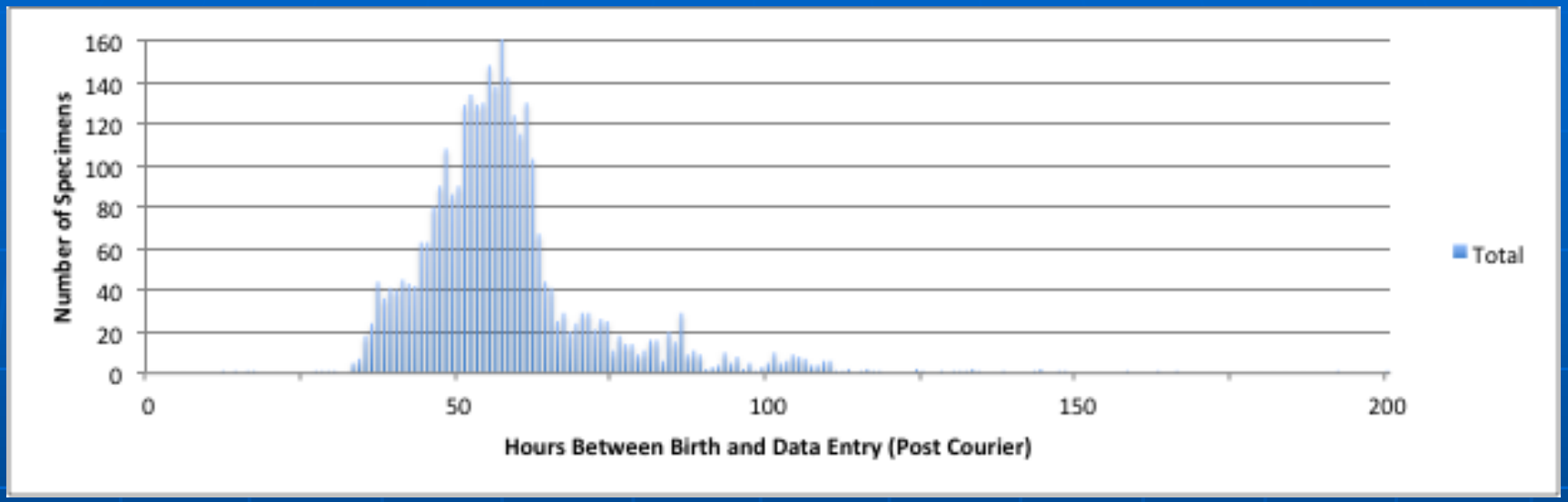


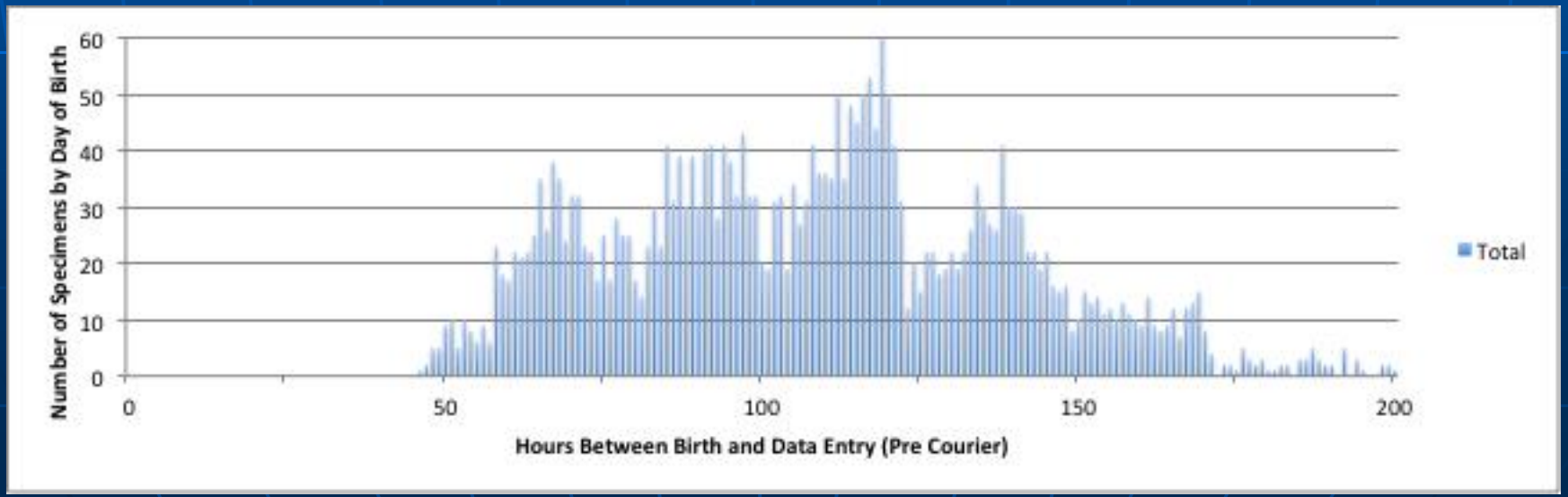
Post Courier





Post Courier





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!
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