Data Driven Strategies for Quality Improvement

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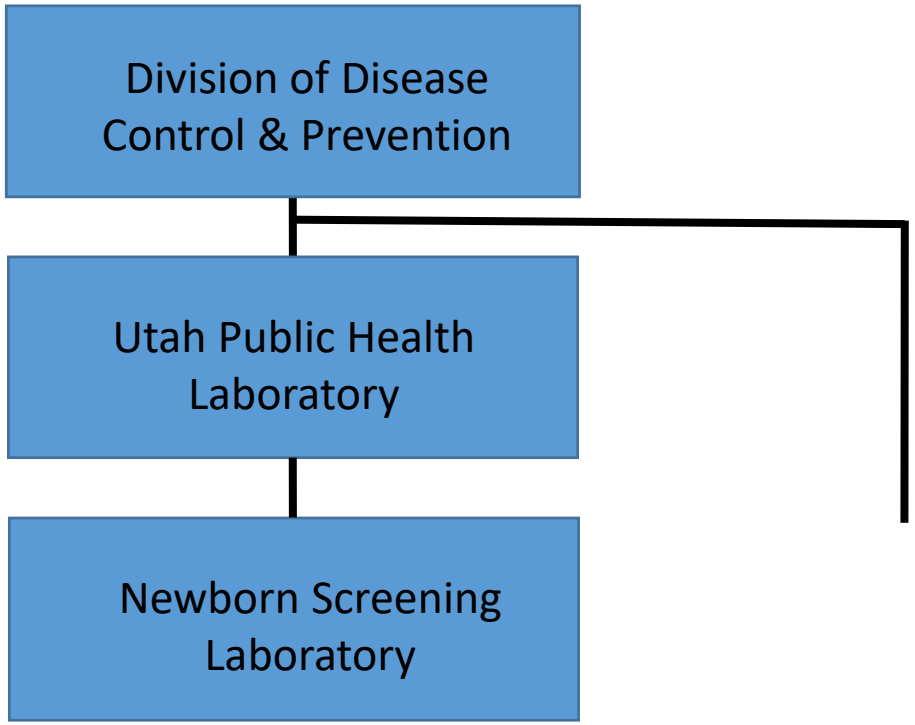
NEWBORN SCREENING

Utah Newborn Screening

- 50,000 births
- 2 screen state
  - 1st NBS collected at 24-48 hours of life
  - 2nd NBS 7-16 days of life
- $115 kit fee
- No additional funds or subsidies
- Fee includes diagnostic testing



- Hired informaticist
- Active engagement of clinical specialists

Analytics + engagement of clinical specialists

=

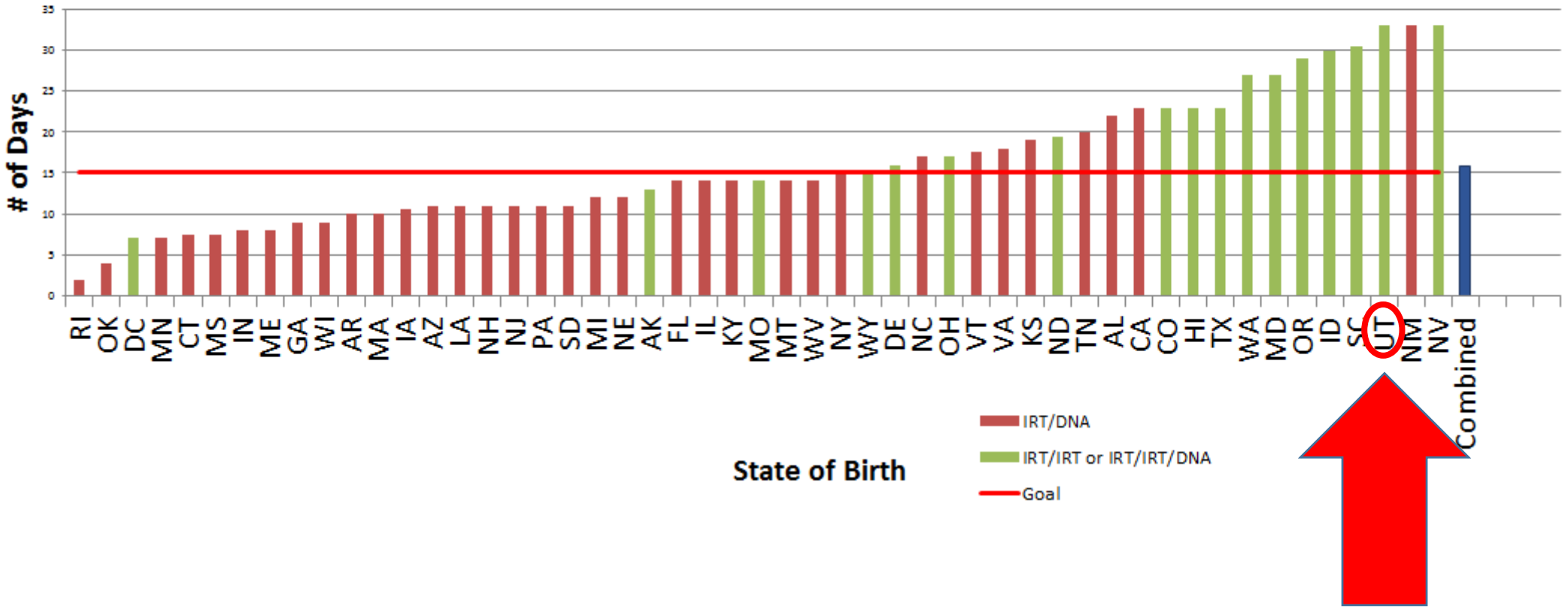
improved outcomes

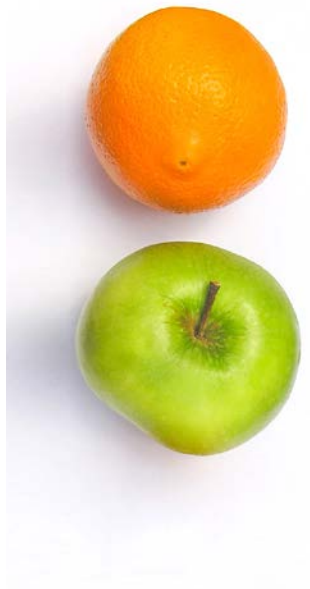
Cystic Fibrosis Screening

- Started 2009
- IRT/IRT/DNA
- 97.5% cutoff
- *CFTR* DNA outsourced

Median age at diagnosis, by state

CF Patients Born 2013-2016
Diagnosed after DOB
Median Age at Diagnosis, dx made one day or later after birth





So, we could just get rid of the second screen?

Two screens are beneficial

	2014	2015	2016	2017
Abnormal 1st IRT (n)	967	1002	1044	1014
Abnormal 2nd IRT (n)	84	86	81	116
Abnormal DNA (n)	21	27	23	26

- Reduced number reflexed to DNA; >$100,000 savings per year or $2/kit
- Reduced number of sweat chloride tests in comparison with an IRT/DNA algorithm
- Avoids resource saturation
- Reduced stress for patients/families

Identify and prioritize bottlenecks: CF DNA Testing

Outsourced

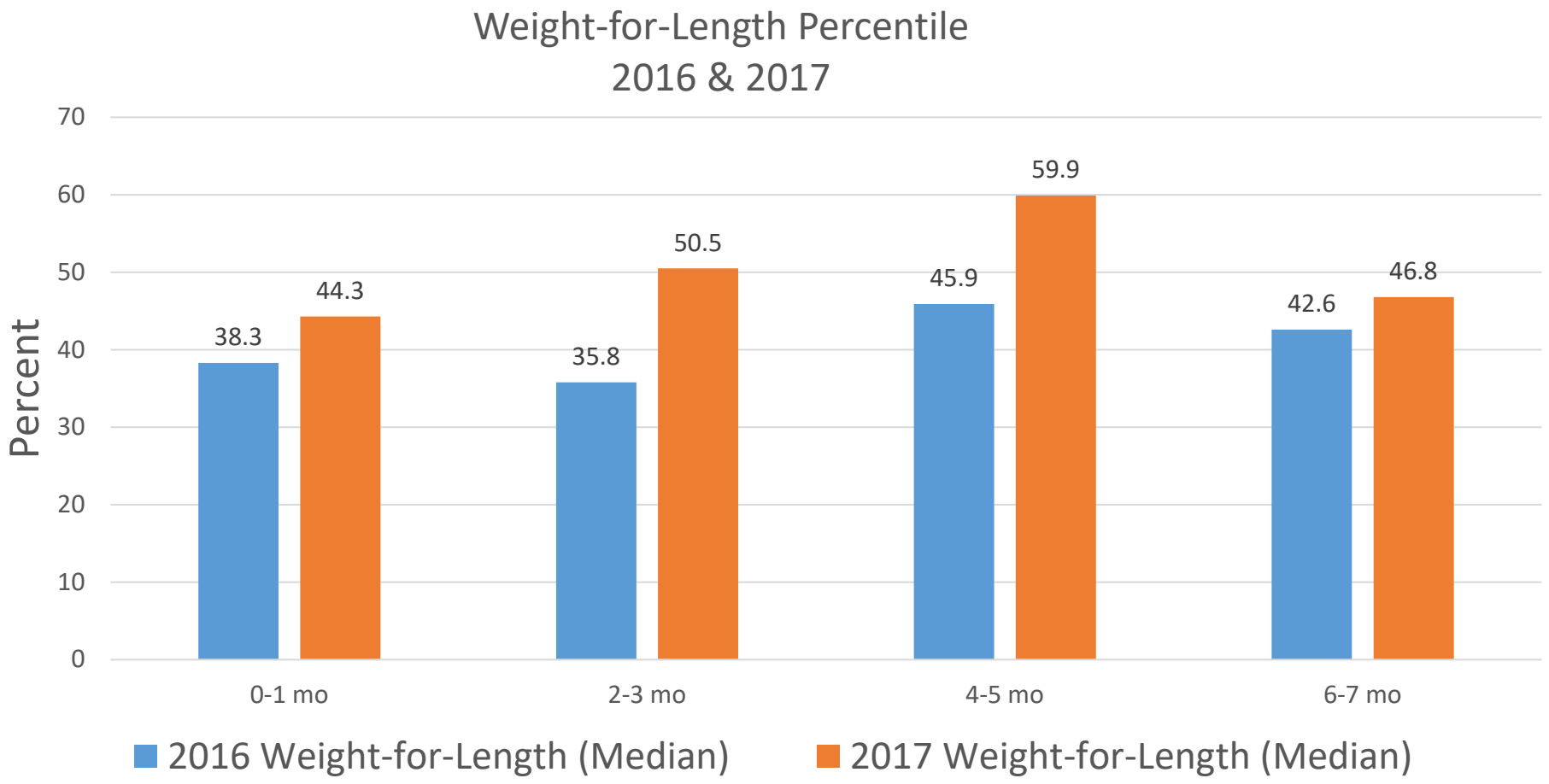
- Average age of infant at CF DNA result – **35 days**

In-house testing - 2017

- Average age of infant at CF DNA result **– 23 days**

Is there a significant clinical impact?

Benefits of earlier diagnosis: NBS improvement effect ?



Cutoff effects on process

- Retrospective comparisons
- Population analysis of IRT distributions for 1st and 2nd screens

Effect of cut-off changes on sample size

Card Type	Cut-Off (ng/mL)	Samples above 97.5% (2016)	Increase (+ n)
	97.5%	1213	
FIRST	51 (2-SD)	1769	556
SECOND	42 (3-SD)	13	5

Process Improvement: 2018 outcomes

- Average age of infant at CF DNA result **- 21 days**
- Average age of infant at CF diagnosis – **25 days**
  (***includes sweat chloride testing & genetic counseling***)

U.S News & World Report has ranked Primary Children's as a top hospital in the nation for pulmonary care.

CYSTIC FIBROSIS FOUNDATION®

The Annual Cystic Fibrosis Foundation's Quality Care Award:

Recognizing Outstanding QI Processes and Accomplishments, 2016 - 2017

Congenital Hypothyroidism Screening

- Utah incidence : 1 in 2,300 births
- TSH primary screen

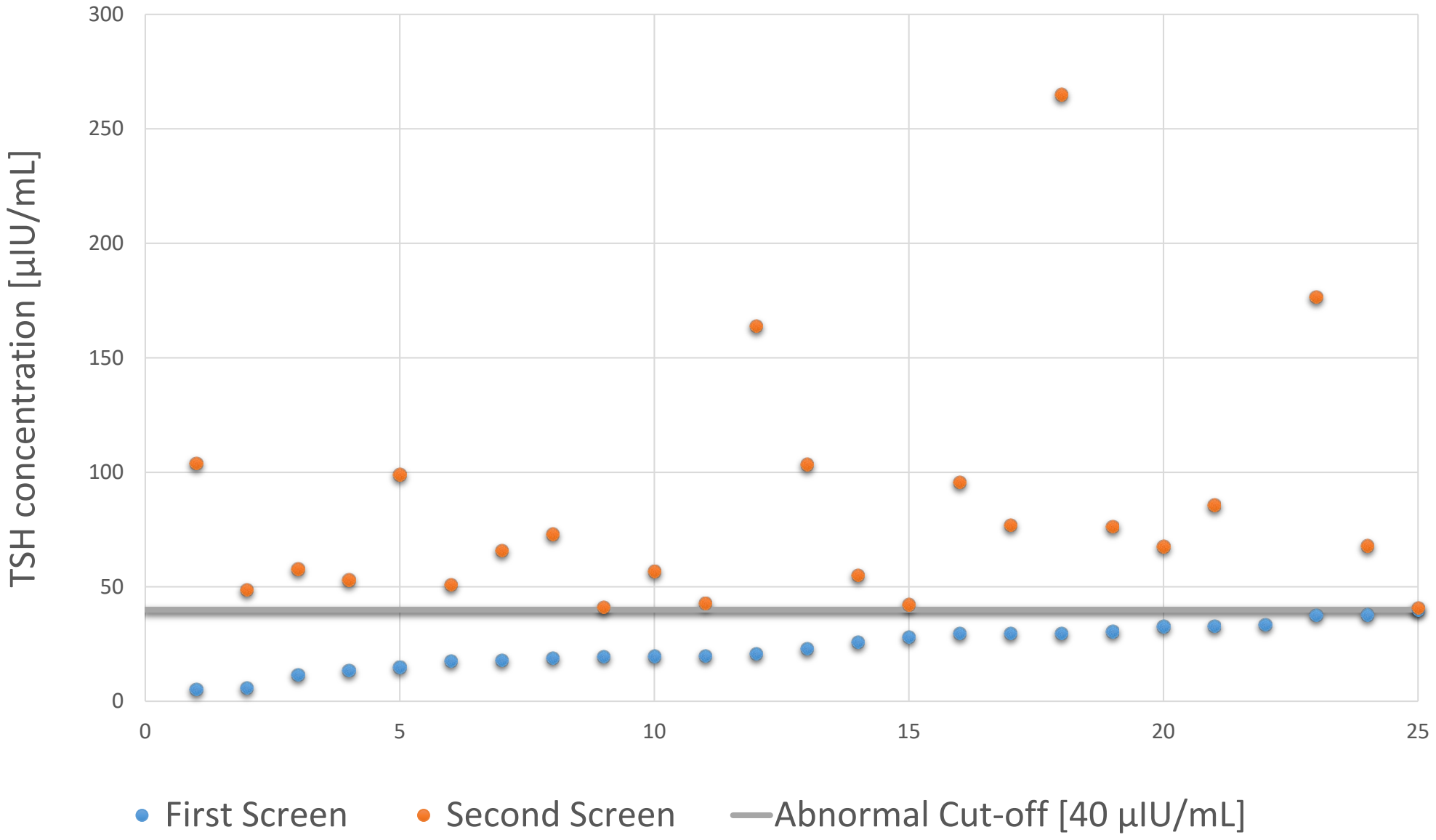
  routine on 1st and 2nd screens

Importance of the Second Screen

- 10 year data review
- TSH cutoff >40 µIU/mL (critical cut off >230 µIU/mL)
- 130 cases
- 20% identified on the 2nd Screen (1st screen normal)

Identification of Primary Congenital Hypothyroidism Based on Two Newborn Screens - Utah, 2010-2016. Jones DE, Hart K, Shapira SK, Murray M, Atkinson-Dunn R, Rohrwasser A. *MMWR Morb Mortal Wkly Rep.* 2018 Jul 20;67(28):782-785

CH cases identified only through second screen



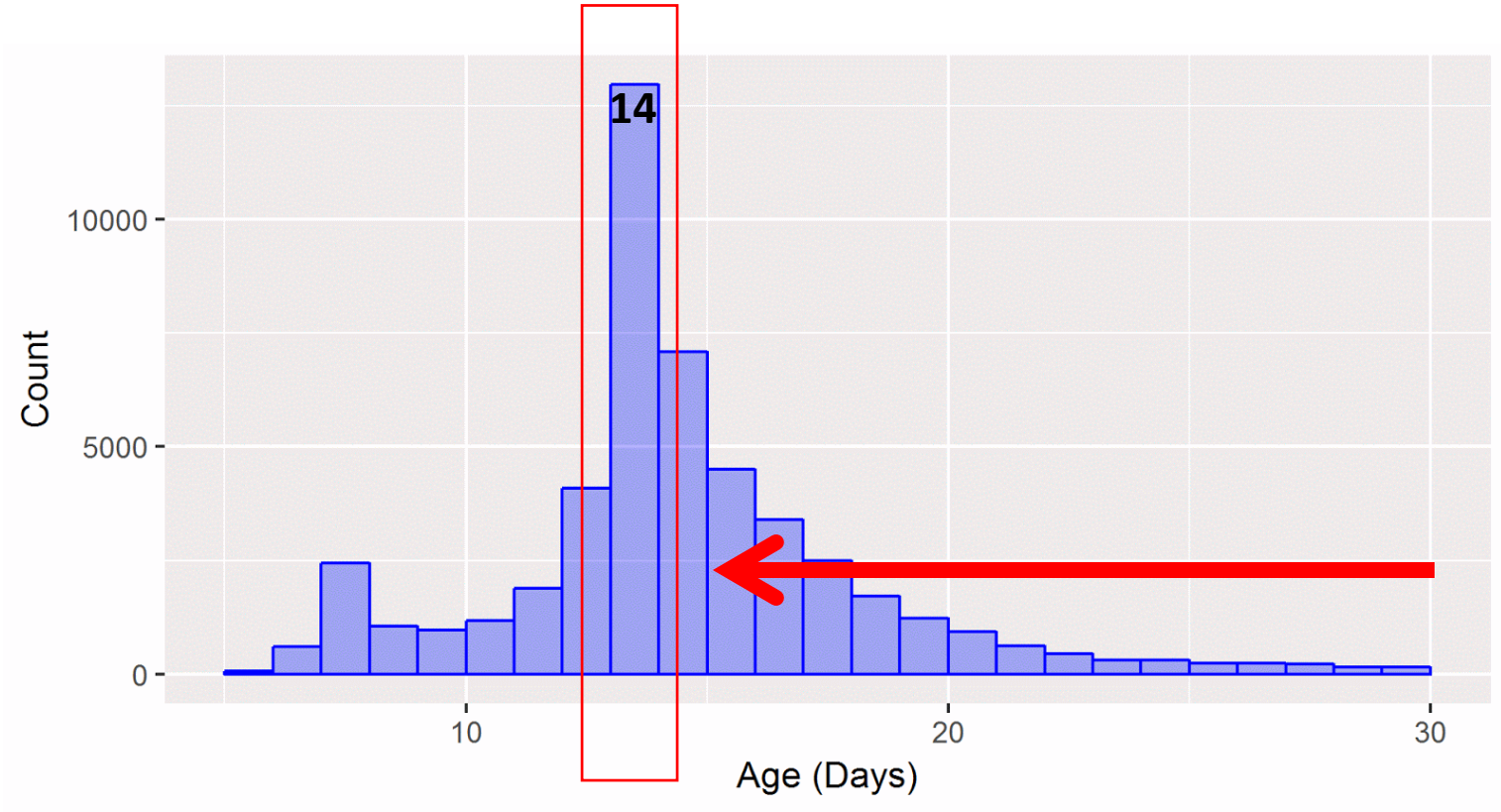
Effect of cut-off changes on sample size

Card Type	Cut-Off (µIU/mL)	Total Sample Size	Increase (+ n)
FIRST (n)	40	773	
SECOND (n)	20	67	41

Universal Issue: Timing of the Second Screen

	Goal	Delayed cases in 10yr period (n)
Congenital Hypothyroidism	21 days	10
Cystic Fibrosis	< 4 weeks	39

Utah Age Distribution: 2nd NBS



Utah Rule Change

- July 1, 2018 - 2nd NBS collection required between 7-16 days of life
- Previously 7-28 days

Delayed CF Diagnoses

	<2017	2018	Since July 2018
Total	39	2	0
Estimated annual average	5.4	2	0

Summary

- Engage clinical specialists in regular assessment of cut-off values and follow-up logic
- Benefits of 2nd screen
  - Clinical
  - Prevent saturation of resources
  - Financial
  - Less stress/anxiety for patients and families
- Timely 2nd screen important

Acknowledgments

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