

# California NBS Process for NewSTEPs Data Repository Uploads

Jamie Matteson, MPH

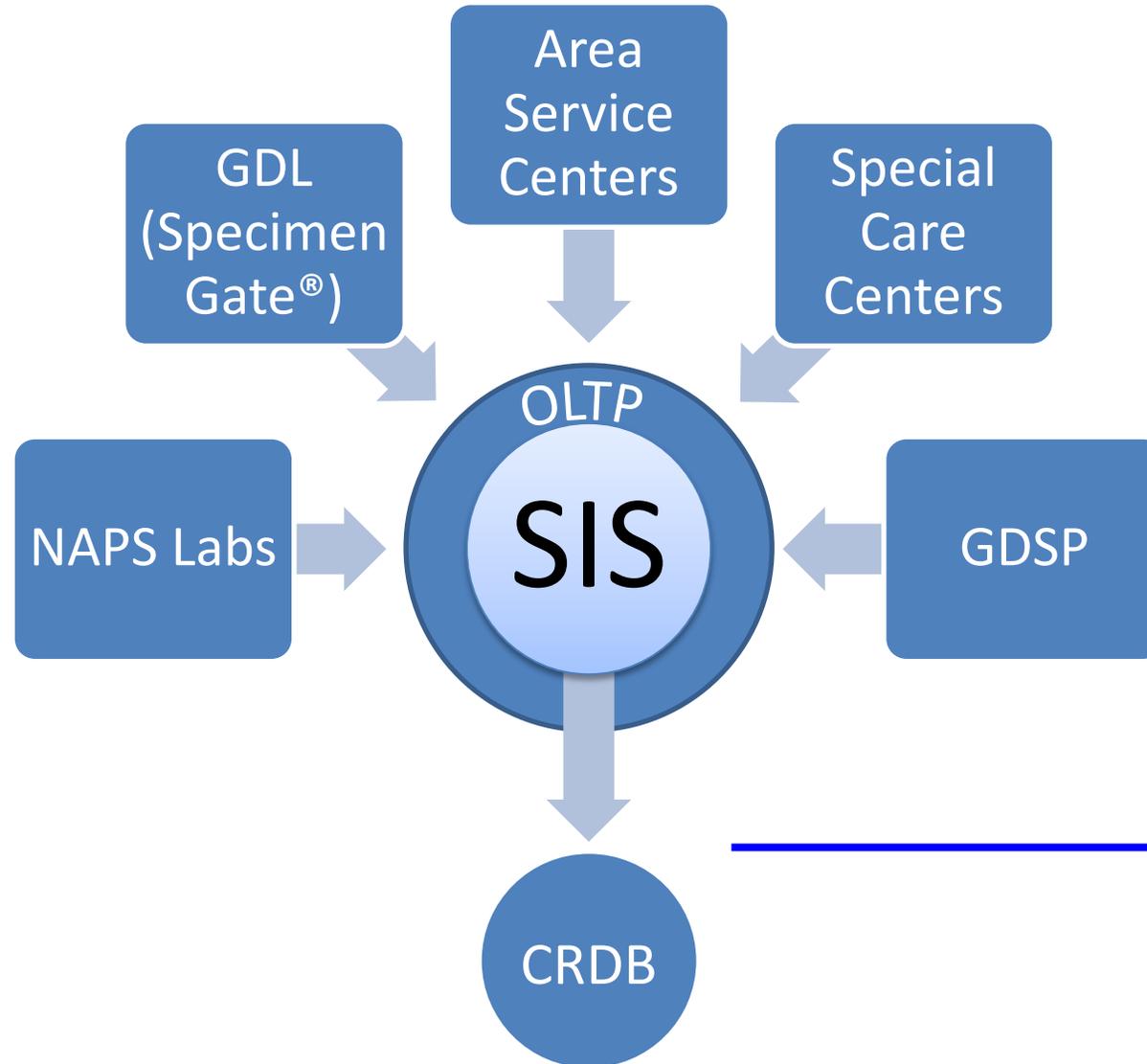
NewSTEPs Data Repository Office Hours  
March 24, 2021



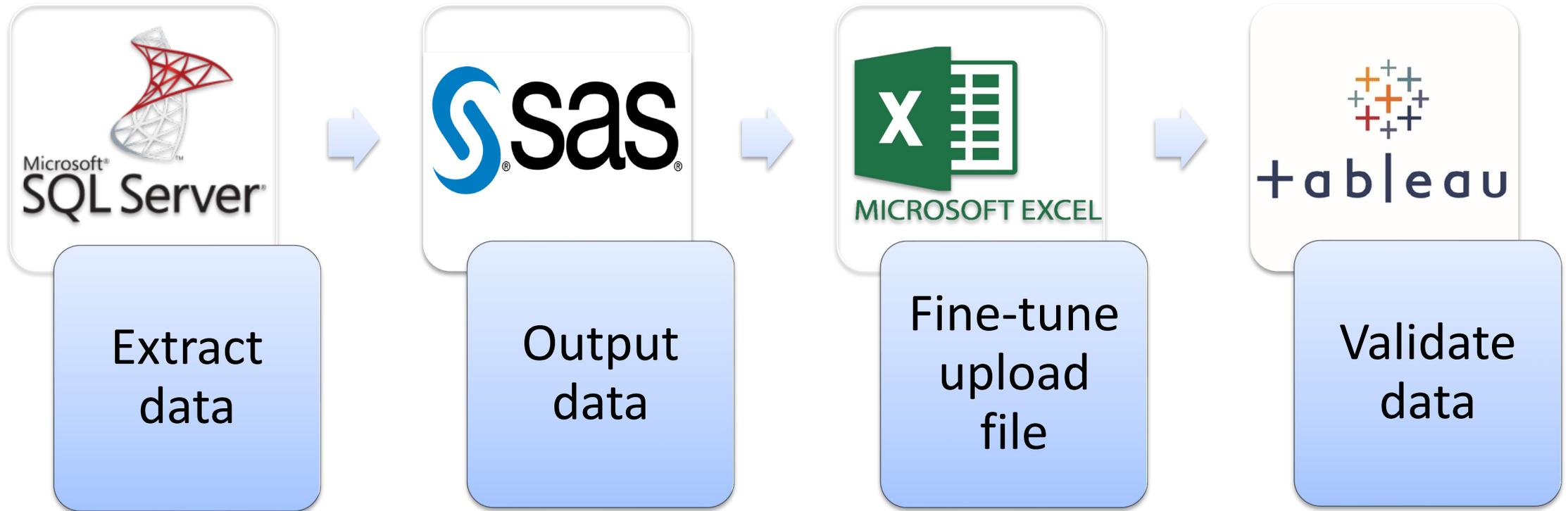
# Considerations for “Automated” Upload

- Manual data entry impractical for some states
  - Greater than 800 non-time critical confirmed cases in CA in 2018
- Big time investment for first year
- Big reward in subsequent years
  - Just a few hours to pull, validate, and upload data

# CA NBS Database Structure



# Data Process

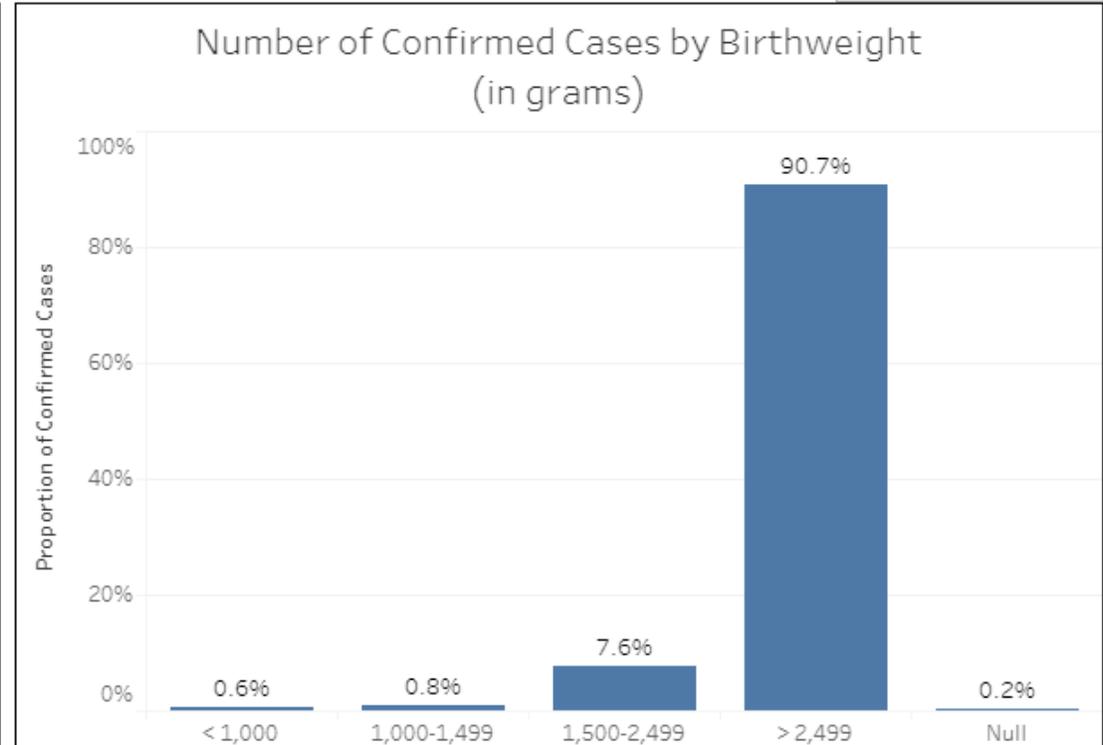
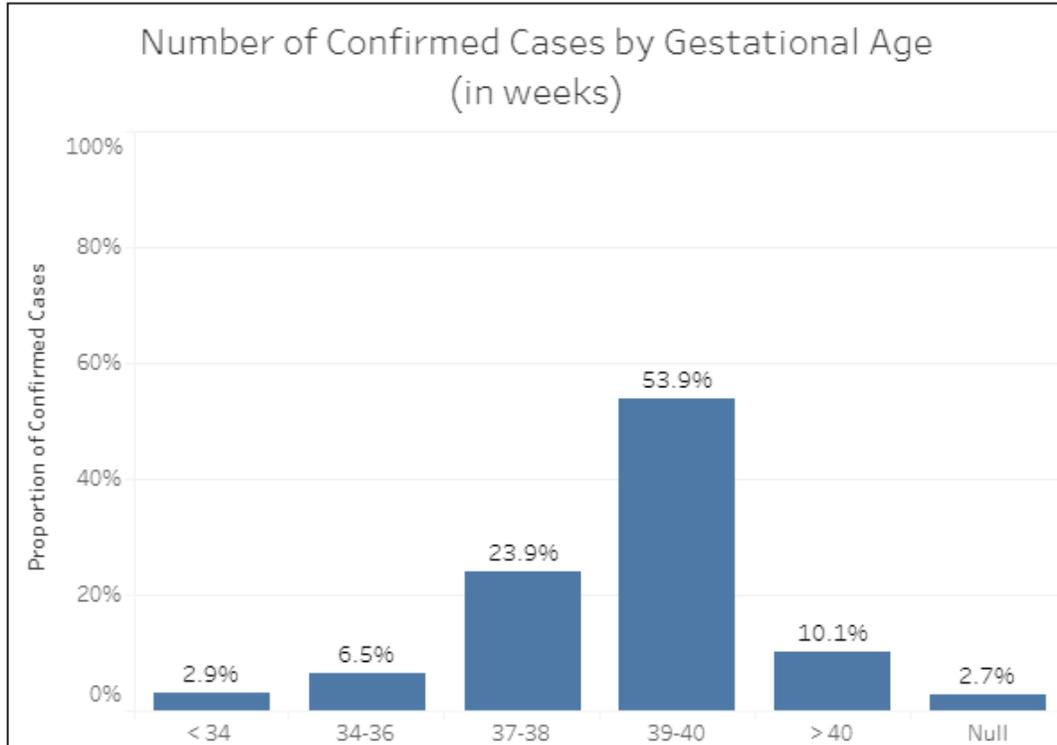


# Data Validation

Confirmed Case Counts | Sex + Birth Year | Ethnicity + Race | GA + BW | Prenatal Risk + Missed on NBS | Timely Specimen Collection | Timely Specimen Transit | Timely Results Re

## Non-time Critical Cases: Gestational Age and Birth Weighth

Birth Year  
(All)



Gestational Age	Client Id	Condition	Birth Year	Birth Weight
20		Short-chain acyl-CoA dehydrogenase def..	2018	3,430

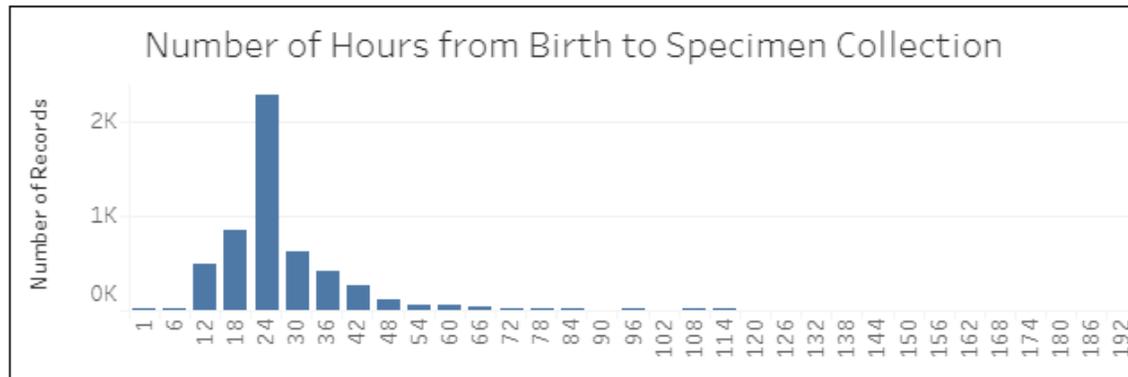
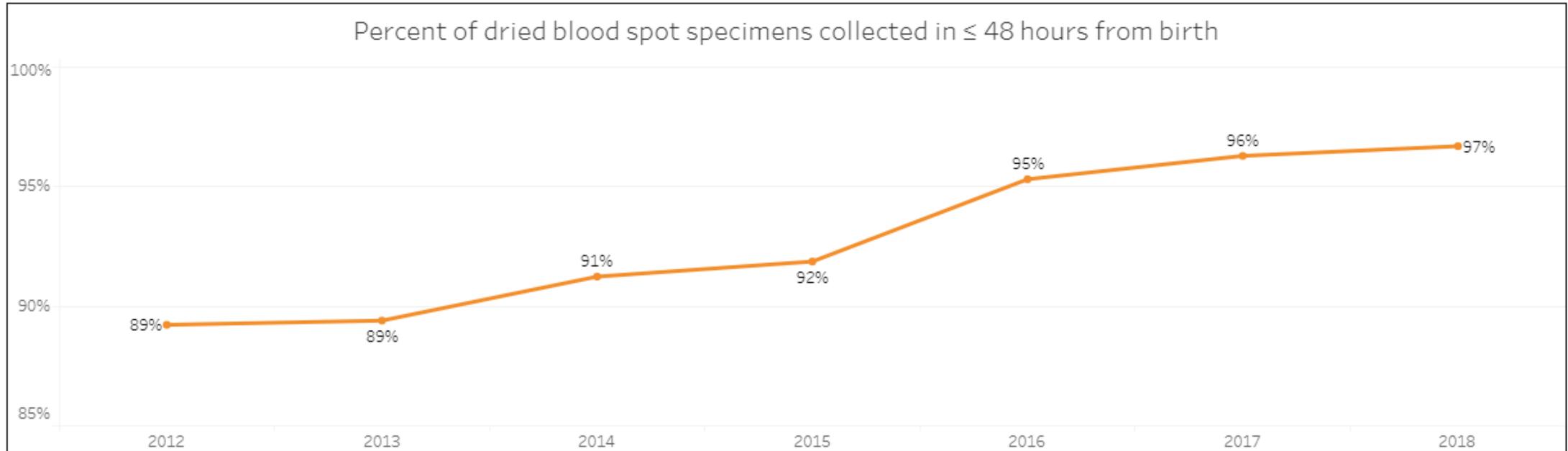
Birth Weight	Client Id	Condition	Birth Year	Gestational Age
311		X-linked Adrenoleukodystrophy	2018	39
5,020		Cystic fibrosis - CF	2013	41
5,093		Cystic fibrosis - CF	2014	39
5,220		Cystic fibrosis - CF	2016	39

# Data Validation

▼ < Confirmed Case Counts Sex + Birth Year Ethnicity + Race GA + BW Prenatal Risk + Missed on NBS Timely Specimen Collection Timely Specimen Transit Timely Results Re >

Birth Year  
 (All) ▼

## Non-time Critical Cases: Timely Specimen Collection



Birth to Specimen Collection Outliers

Birth To Ini..	Birth Year	Client Id	Condition
203	2013	[REDACTED]	Cystic fibrosis - CF
212	2017	[REDACTED]	T-cell related lymphocyte deficiencies
220	2018	[REDACTED]	Congenital hypothyroidism - CH
249	2013	[REDACTED]	Congenital hypothyroidism - CH
319	2017	[REDACTED]	Biotinidase deficiency - BIOT
387	2016	[REDACTED]	Severe Combined Immunodeficiencies - SCID
400	2014	[REDACTED]	Congenital hypothyroidism - CH

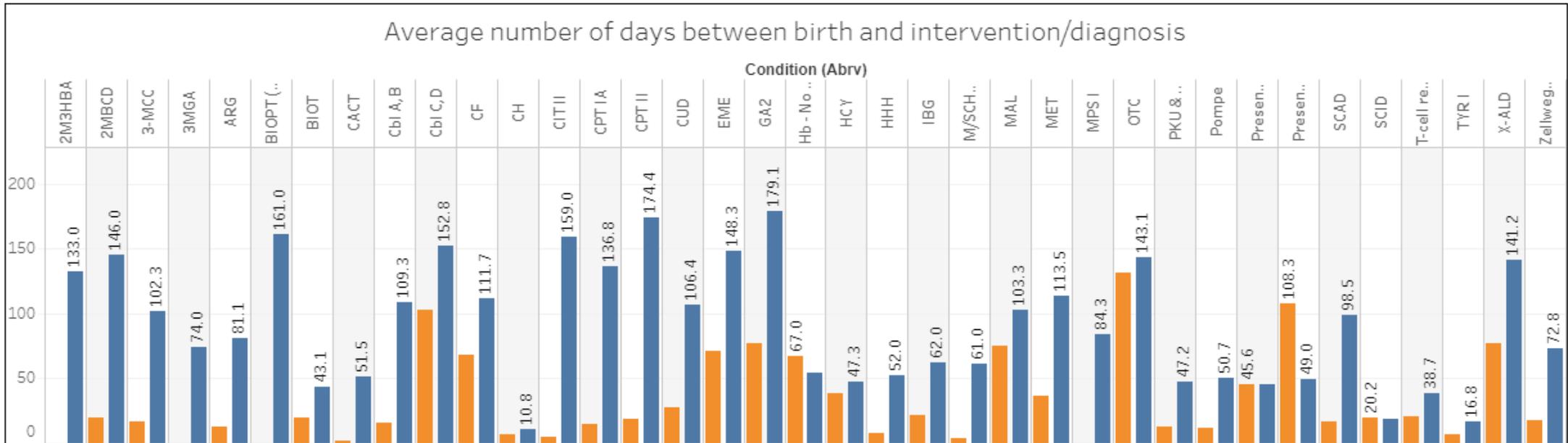
# Data Validation

[Birth Year](#)
[Ethnicity + Race](#)
[GA + BW](#)
[Prenatal Risk + Missed on NBS](#)
[Timely Specimen Collection](#)
[Timely Specimen Transit](#)
[Timely Results Reporting](#)
[Intervention + Diagnosis](#)

## Non-time Critical Cases: Intervention + Diagnosis

Birth Year  
(All)

■ Avg. Birth To Intervention
 ■ Avg. Birth To Diagnosis Confirmation



### Diagnosis Outliers

Birth To Diagnosis Confirmation	Client Id	Condition	Birth Year
402		Cystic fibrosis - CF	2015
403		Cystic fibrosis - CF	2016
407		Cystic fibrosis - CF	2016
		Cystic fibrosis - CF	2016
412		Cystic fibrosis - CF	2013
422		Cystic fibrosis - CF	2015

### Intervention Outliers

Birth To Intervention	Client Id	Condition	Birth Year
207		Cystic fibrosis - CF	2012
208		Presence of Other Hb Variant	2013
212		Cystic fibrosis - CF	2016
217		Cystic fibrosis - CF	2012
		Carnitine uptake defect/carnitine transport ..	2014
224		Cystic fibrosis - CF	2016

# Final Steps

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- Correct outliers
- Convert file to CSV
- Verify file structure with NewSTEPs (may not be necessary in subsequent years)
- Upload file to NewSTEPs Data Repository
- Correct errors/outliers (less frequent since implementing data validation)

# Questions?

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[Jamie.Matteson@cdph.ca.gov](mailto:Jamie.Matteson@cdph.ca.gov)