What's in the BIN: A Comprehensive Evaluation of Vermont's Birth Information Network

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The Birth Information Network (BIN) was established by Vermont legislation in 2003 and began collecting data in 2006 to conduct statewide, population-level surveillance of 47 National Birth Defects Prevention Network (NBDPN) structural and chromosomal birth defects, along with 28 metabolic and endocrine conditions, congenital hearing loss, and very low birth weight (a total of 77 BIN conditions). The BIN uses multiple data sources to identify potential cases and then conducts follow-up to confirm or rule out those cases. The program monitors trends, promotes prevention, and links families to resources. An evaluation of the birth cohorts 2006-2014 was conducted to assess the overall effectiveness of the BIN and provide recommendations for improvements.

Case information in the BIN was evaluated according to the 2001 Centers for Disease Control and Prevention's (CDC) *Updated Guidelines for Evaluating Public Health Surveillance Systems*, and in accordance with the National Birth Defects Prevention Network's (NBDPN) *Guidelines for Conducting Birth Defects Surveillance.* Evaluating a surveillance system is important to ensure that problems of public health importance are monitored effectively. This is the first evaluation of the BIN.

Attribute Analysis Methods
Birth cohorts 2006-2014
Representativeness: assessed by geographical hospital region for all NBDPN Conditions and for Cardiovascular Conditions
Acceptability: assessed by interviewing key stakeholders and by reviewing all conversation records from parents/guardians of children meeting criteria to be accepted into the BIN
Positive predictive value (PPV): diagnosis confirmation status was used
Data Quality: developed queries to assess 63 quality assurance checks for 26 Level 1 data elements recommended by the NBDPN
Simplicity: chart describing the flow of data from initial report to final case disposition
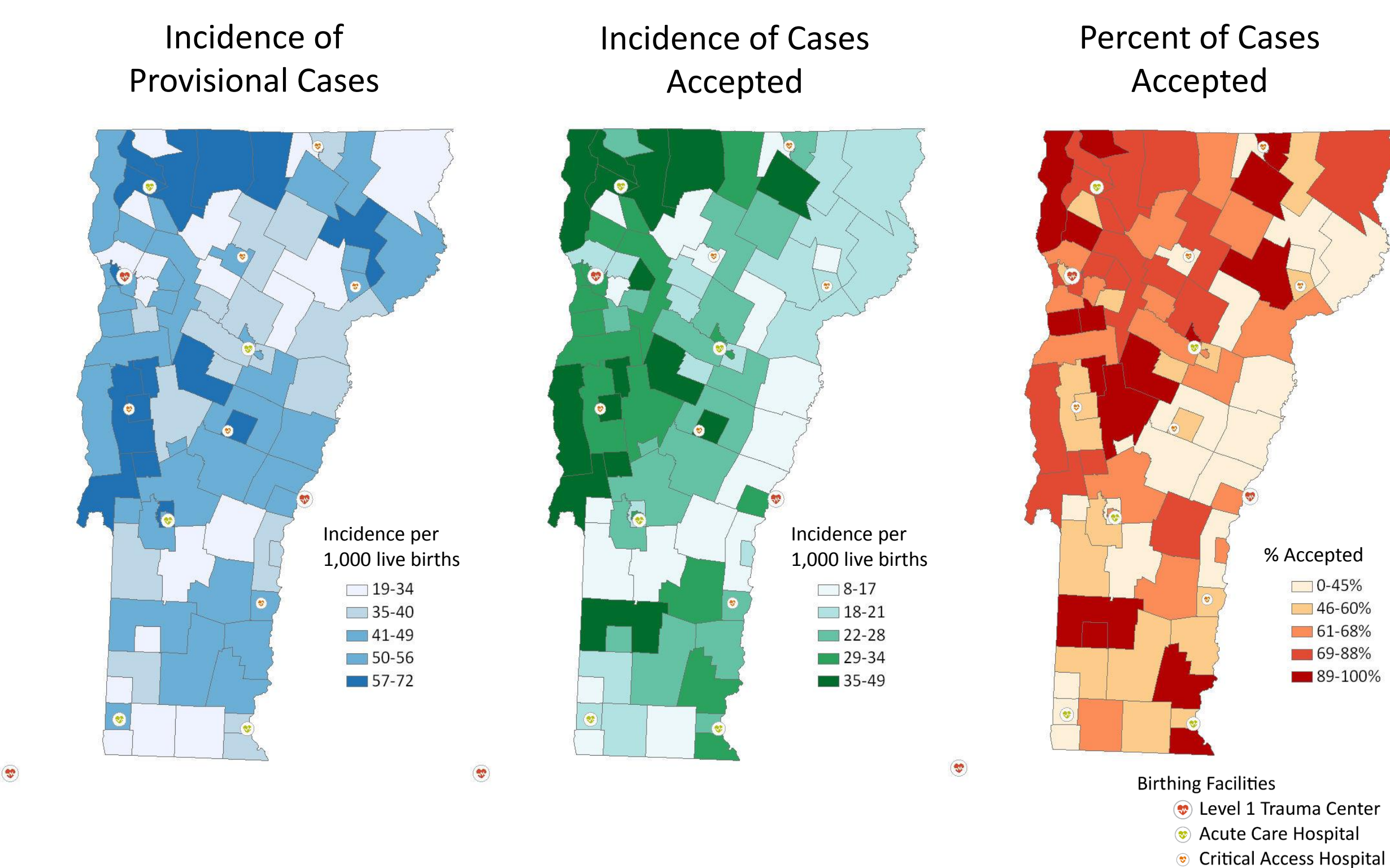**Stability**: considered number of reported system unscheduled outages
Timeliness: calculated average times between infant date of birth and investigation completion date and assessed percentage of investigation completion before two years of age
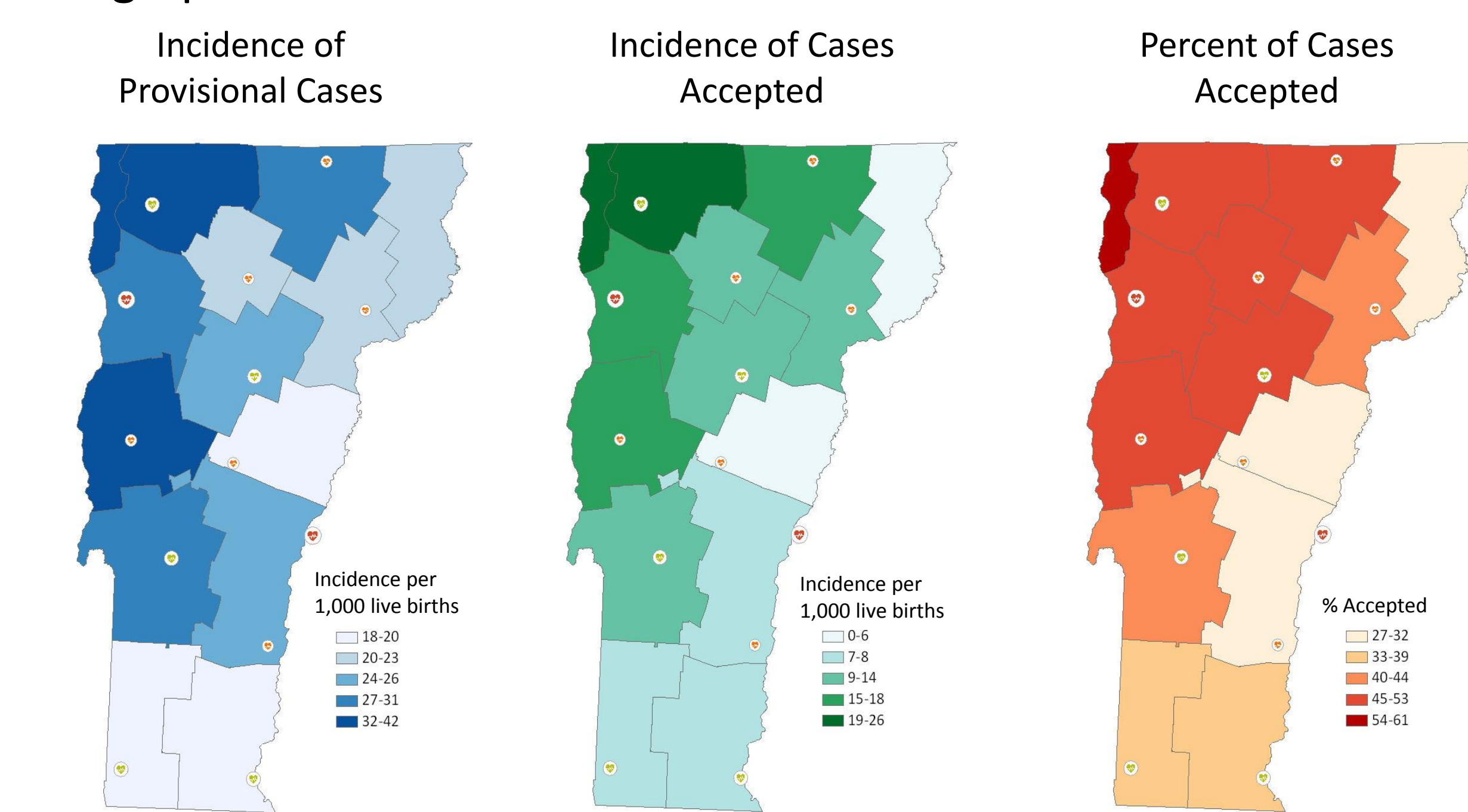**Flexibility**: reviewed the process for changes, both for individual cases and for database structural changes

REPRESENTATIVENESS

Geographical Distribution of NBDPN Conditions in the BIN

Incidence of Provisional Cases — Incidence per 1,000 live births
Incidence of Cases Accepted — Incidence per 1,000 live births
Percent of Cases Accepted — % Accepted

Birthing Facilities
- Level 1 Trauma Center
- Acute Care Hospital
- Critical Access Hospital

Geographical Distribution of Cardiovascular Conditions in the BIN

Incidence of Provisional Cases — Incidence per 1,000 live births
Incidence of Cases Accepted — Incidence per 1,000 live births
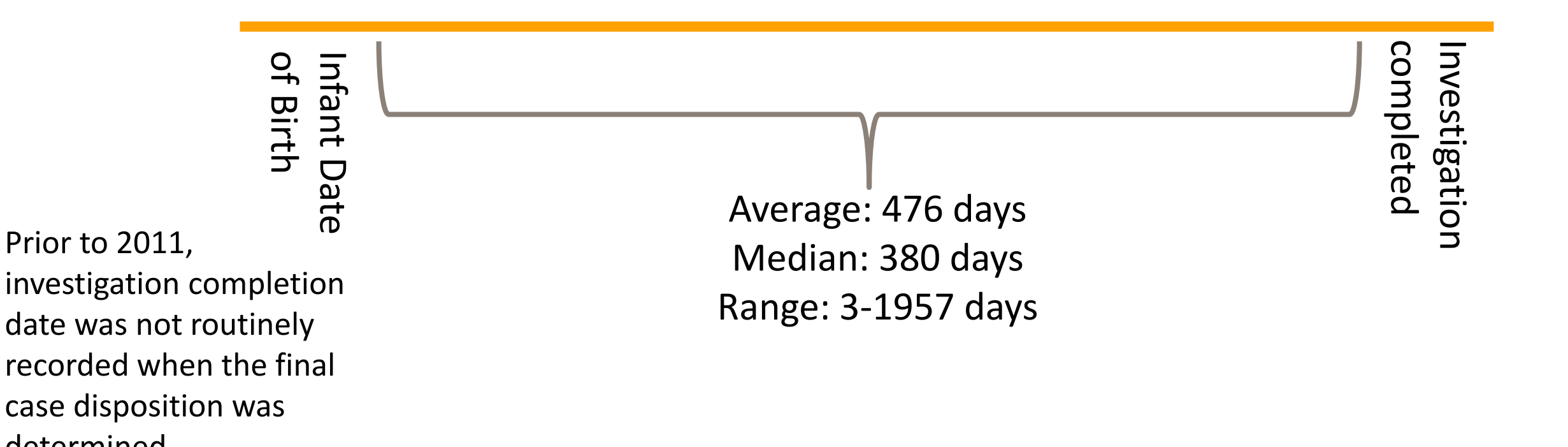Percent of Cases Accepted — % Accepted

STABILITY
The number of unscheduled outages reported is low. Due to unstable federal funding the BIN went through brief periods of inactivity. However, funding has been stable for the past 7 years.

TIMELINESS
Number of days to final case disposition for all conditions in the BIN for birth cohorts 2011 to 2014 for those with a disposition date indicated (N=2372):

Average: 476 days
Median: 380 days
Range: 3-1957 days

Prior to 2011, investigation completion date was not routinely recorded when the final case disposition was determined.

Assessing the Average Number of Days from Birth to Final Case Disposition by Year of Birth
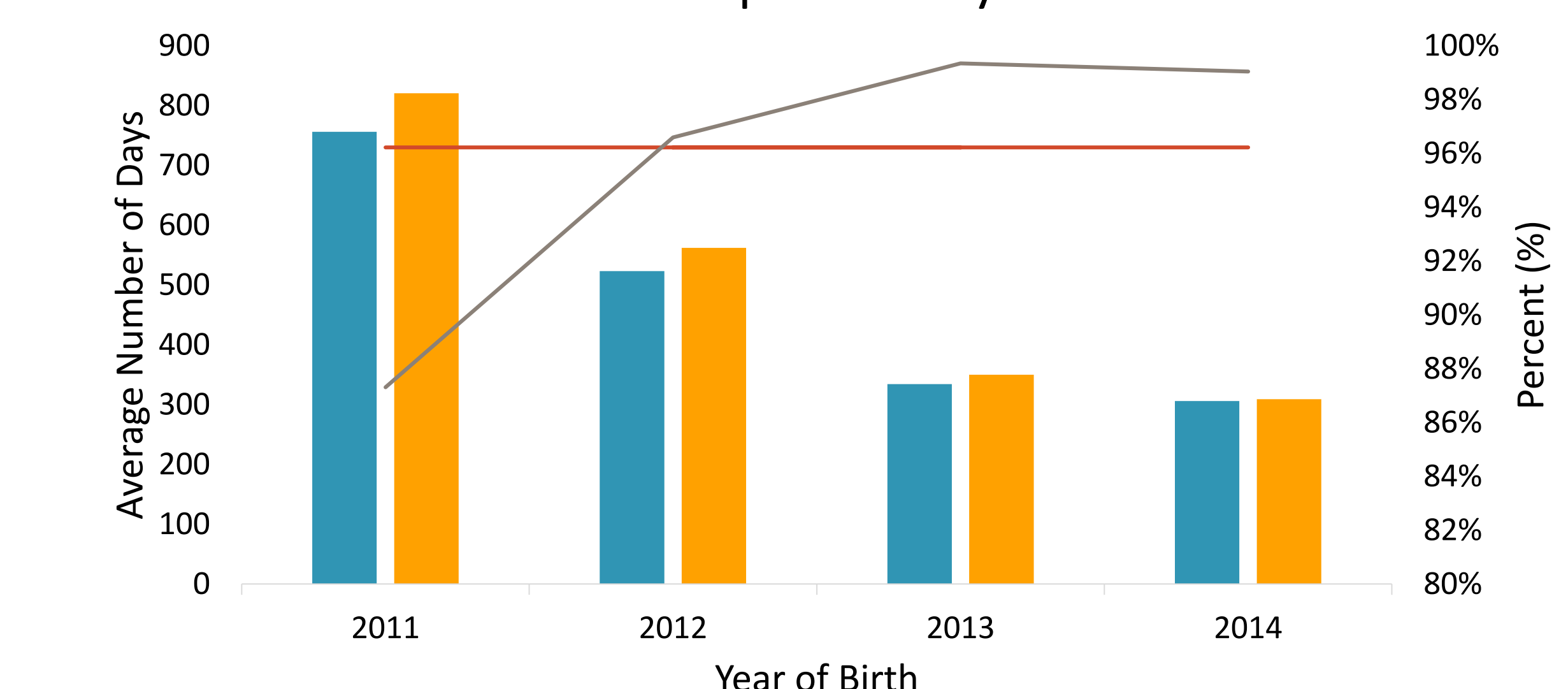
Non-NBDPN Conditions captured in the BIN include Very Low Birth Weight and some Metabolic Conditions that are quickly classified.

- Average Number of Days from Birth to Final Case Disposition for All BIN Conditions
- Average Number of Days from Birth to Final Case Disposition for NBDPN Conditions
- NBDPN Target of Two Years from Birth to Final Case Disposition
- Percent of Cases with Completed Date Field for Final Case Disposition

ACCEPTABILITY
Since 2006, 265 parents/guardians have responded to acceptance letters from the BIN. 114 (43.02%) of those requested referral to Children with Special Health Needs (CSHN) and 24 opted out (9.06%).

POSITIVE PREDICTED VALUE
All BIN Conditions: PPV = 50.99% (95% CI: 49.67%-52.31%)
NBDPN Conditions: PPV = 54.01% (95% CI: 52.22%-55.80%)

Proportion of correctly identified cases that meet the surveillance case definition compared to provisional cases ascertained for all BIN conditions and for the NBDPN Core and Recommended Conditions. PPV was also assessed by diagnosis.

DATA QUALITY
Data Quality Assurance Standards Summary Report for NBDPN Level 1 Data Elements for Population Based Birth Defect Surveillance, Birth Cohorts 2006-2014, All BIN Conditions
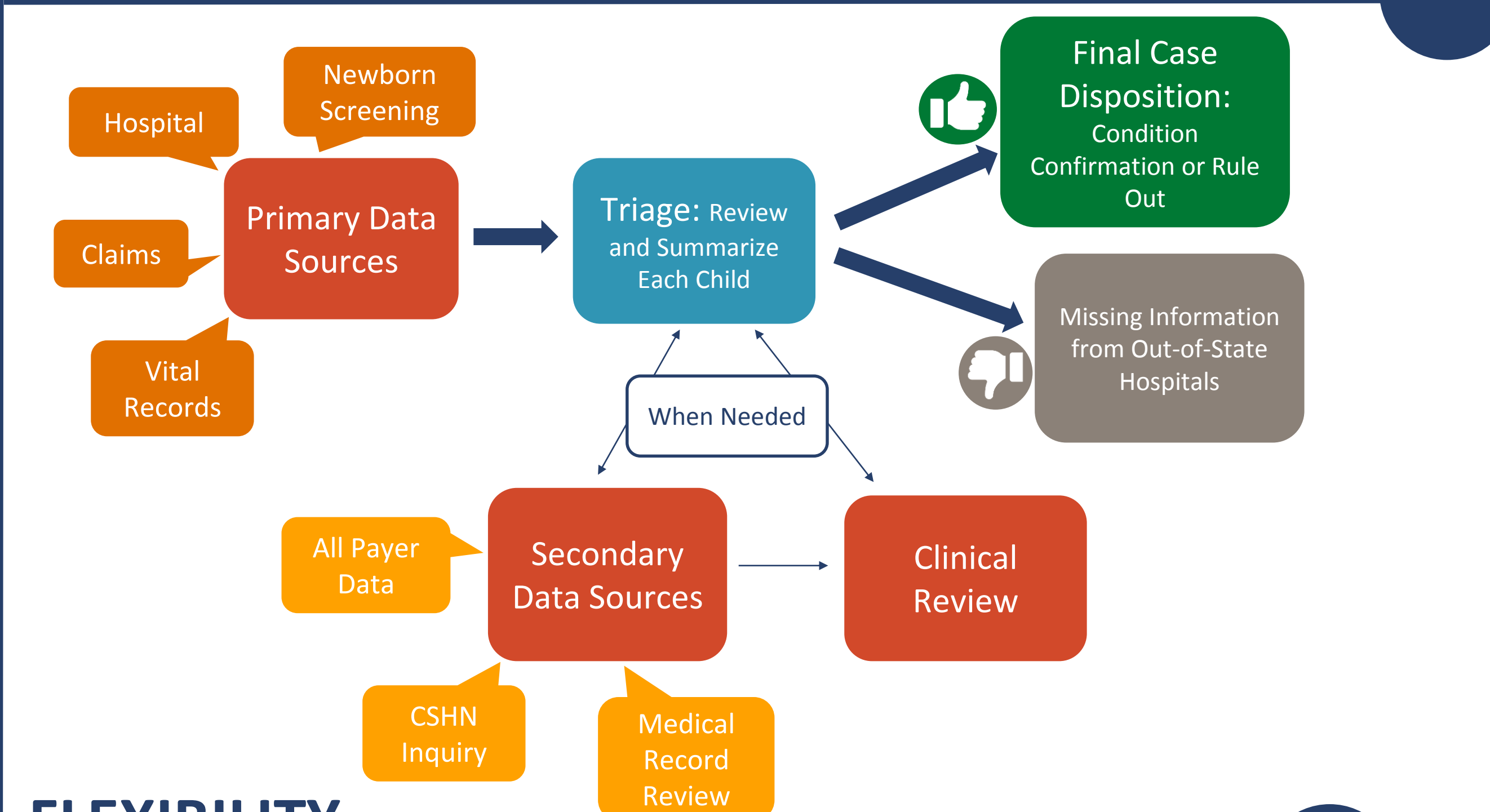
Denominator Type in BIN	NBDPN Level 1 Data Collection Element	Total Number of Quality Checks	Quality Checks Compliance Range			
			100%	99.00%-99.99%	90.00%-98.99%	<90.00%
Total number of Infants (n=4107)	Unique Case ID	2	2			
	Date of Delivery (for a live birth)	3	2	1		
	Gender (Sex)	1	1			
	Name	2	2			
	Medical Record Number(s) (Infant/Child)	2		1	1	
	Birth Certificate ID	2	1		1	
	Place of Pregnancy Outcome	2	1	1		
	Pregnancy Outcome	2	2			
	Birth Weight	2		2		
	Plurality	2	2			
	Birth Order	3	3			
	Gestational Age	3	1	2		
	Method of Determining Gestational Age	2	2			
	Was the infant transferred within 24 hours of delivery?	3	1	1	1	
	Infant living at time of report	3	2			1
	Mother's Date of Birth	3	1	2		
	Mother's Race	2	1	1		
	Mother's Ethnicity	2	1			1
	Mother's Name	3	2	1		
	Mother's Residence at Time of Pregnancy Outcome	3	1	1		1
Number of Infant Transfers (n=307)	Name of transferred facility	3	1	1	1	
Number of Infant Deaths (n=222)	Death Certificate ID	2	1	1		
	Underlying Cause of Death	2			2	
Total number of Diagnoses (n=6649)	Diagnosis Code	3	2		1	
	Date of Death for a live born infant	3	2	1		
Number of Reports (n=21663)	Source of Report	3	1	1		1

All quality checks for the data element were 100% compliant with the NBDPN standards and recommendations

At least one data quality check for the data element was <90% compliant with the NBDPN standards and recommendations

The NBDPN *Guidelines for Conducting Birth Defects Surveillance* assigns Standard Level 1, 2, or 3 to a number of data collection elements and provides quality assurance checks, including minimum limits, ranges, or other criteria the element should meet.

SIMPLICITY

Primary Data Sources: Hospital, Newborn Screening, Claims, Vital Records
Triage: Review and Summarize Each Child
Final Case Disposition: Condition Confirmation or Rule Out
Missing Information from Out-of-State Hospitals
When Needed
Secondary Data Sources: All Payer Data, CSHN Inquiry, Medical Record Review
Clinical Review

FLEXIBILITY
The BIN is flexible, and changes to individual cases can be made easily; however, structural changes, such as altering variables to adapt to modified case definitions over time can be difficult. Time is required to change codes and to re-review cases for new status updates.

Conclusions
The BIN is not simple; it aggregates data from as many as 11 diverse primary sources, as well as a number of secondary sources, including medical records and clinical review. The BIN is flexible, and changes to individual cases can be made easily; however, structural changes, such as altering variables to adapt to modified case definitions over time can be difficult. The BIN is widely accepted by the community and by Vermont hospitals, but lacks support from out-of-state hospitals. Geographical distribution of cases, both provisional and accepted may reflect a lack of reporting from out-of-state hospitals. Per NBDPN standards, overall data quality is not meeting the expectation of 100% compliance for all Level 1 Data Collection Elements, however it is seemingly achievable in the near future. The Positive Predicted Value is low, indicating a over-ascertainment of provisional cases, which is time-consuming and tedious. Timeliness measures, however, are within NBDPN standards for all BIN conditions.

Recommendations to improve birth defects surveillance
A formal database quality assurance process should be implemented utilizing the NBDPN data collection element quality checks and queries produced during this evaluation. This will consistently measure data quality and inform focus areas for improvements. When Standard Level 1 compliance is achieved for all data collection elements, Levels 2 and 3 should be assessed. Expanding autofill fields in data tables will increase data completeness and reduce human error. Educating hospitals on Birth Certificate completion will help minimize missing variables. Building sustainable relationships with out-of-state hospitals will improve reporting and increase sensitivity. Ensuring goals in case completion times are met and decreasing over-reporting specifically for cardiovascular, central nervous system, and metabolic/endocrine conditions, without missing potential cases, will further improve overall timeliness measures.

References
1. Copeland G, Ethen M, Fornoff J, et al. NBDPN Guidelines for Conducting Birth Defects Surveillance. Appendix 4.1 Data Elements for Population-based Birth Defects Surveillance; 2015.
2. German RR, Lee LM, Horan JM, et al. Updated guidelines for evaluating public health surveillance systems: recommendations from the Guidelines Working Group. MMWR Recomm. Rep. 2001; 50 (RR-13):1-35.
3. WHO/CDC/ICBDSR. Birth defects surveillance: a manual for programme managers. Geneva: World Health Organization; 2014.

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