

Comparing CCHD Surveillance Systems: Texas Birth Defects Registry and Texas Newborn Screening

Texas Birth Defects Epidemiology and Surveillance Branch
Newborn Screening Advisory Committee Meeting, July 2018

Topics

- Texas Birth Defects Registry (TBDR) and Newborn Screening (NBS) CCHD data
- BPA Codes used for this analysis

- Frequency of CCHDs by Birth Year, Texas, TBDR and NBS
- Identifying Underreporting

- Case fatality time trends, any CCHD, 1999-2015
- Case fatality time trends, HLHS, 1999-2015
- Discussion

Texas Birth Defects Registry (TBDR)

- The TBDR is a statewide, population-based, active surveillance registry.
- Trained TBDR program staff routinely visit medical facilities to review logs, hospital discharge lists, and other records to identify potential cases of birth defects.
- If any pregnancy outcome of any gestational age or an infant up through the **first year of life** has any of the **birth defects covered** by the registry and the **mother resides in Texas at delivery**, the medical record is abstracted.

British Pediatric Association (BPA) Codes

BPA codes used:

Straightforward:

745.000, 745.300, 747.215, 747.216, 747.217, 747.285, 746.200, 747.100, 747.110, 747.190, 747.420, 746.700

Problematic:

746.100, 746.000, 745.200, 747.310, 745.100, 745.110, 745.190, 745.130, 745.140, 745.150, 745.180

TVA

PVA

TOF

TGA

DORV

House Bill 740 (2013)

Elements of "point-of-care" newborn screening for CCHDs, by pulse oximetry

Exemptions from screening:

- Parent declines
- Infant transferred before screening performed
- Screen was previously completed
- Newborn discharged <10 hours post-delivery and referral made to another facility/provider
- Newborn previously diagnosed with CCHD
- Newborn has had a postnatal echo

Case reporting:

- Confirmed CCHD cases must be reported to DSHS NBS program by providers and facilities

Frequency of CCHDs by Birth Year, Texas, TBDR¹ and NBS²

Birth Year	TBDR ¹ (Active)	NBS ² (Passive)	Percent (%) NBS Reported to TBDR
1999	563	n/a ³	n/a ³
2000	569	n/a ³	n/a ³
2001	603	n/a ³	n/a ³
2002	634	n/a ³	n/a ³
2003	637	n/a ³	n/a ³
2004	640	n/a ³	n/a ³
2005	687	n/a ³	n/a ³
2006	746	n/a ³	n/a ³
2007	700	n/a ³	n/a ³
2008	806	n/a ³	n/a ³
2009	763	n/a ³	n/a ³
2010	721	n/a ³	n/a ³
2011	736	n/a ³	n/a ³
2012	739	n/a ³	n/a ³
2013	798	n/a ³	n/a ³
2014	846	70	100%
2015	715	174	91%
2016	n/a ³	120	80%
2017	n/a ³	97	45%
2018	n/a ³	25	12%
Missing	0	19	56%
Total	11,903	505	75%

How many CCHD cases are there?

What percent of NBS CCHD cases are captured by TBDR?

Does active surveillance identify additional cases not reported to NBS ?



!! The TBDR has not caught up to the NBS data !!

1: Texas Birth Defects Registry (TBDR) liveborn cases.

2: New Born Screening (NBS).

3: TBDR data not complete for delivery years >=2015; NBS CCHD data from 4th quarter of 2014, and through 6/1/2018.

Are the CCHDs the same in TBDR vs. NBS?

A sub-analysis of the 2014 NBS records that linked to a 2014 TBDR case found ~22% did not have a CCHD in the TBDR.

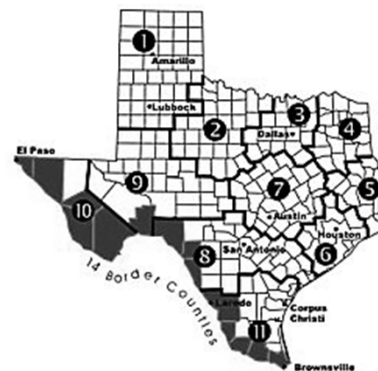
The majority of these non-CCHD cases did have heart defects e.g., ventral septal defect or atrial septal defect.

Of those NBS cases with a CCHD, an overall agreement rate between the defects noted from the NBS system and the TBDR was 94%, with the lowest classification agreement for Coarctation of the Aorta (74%) and highest for Ebstein's Anomaly (100%).

Caveats: Difficulty in classifying heart defects + TBDR follows cases through the first year of life so the clinical diagnosis can change.

Identifying Underreporting Areas by Region, Texas, 2015

Region ¹	# of TBDR Cases Not Captured by NBS	# of Total TBDR Cases
1	19	22
2	16	16
3	184	187
4	33	38
5	7	8
6	138	143
7	74	79
8	42	82
9	15	17
10	20	24
11	79	99
Total	627	715



- Prenatal Diagnosis?
- Transfers?
- Parental Decline?
- Regional difference in outreach efforts in the state?

¹: Region is maternal region of residence at delivery

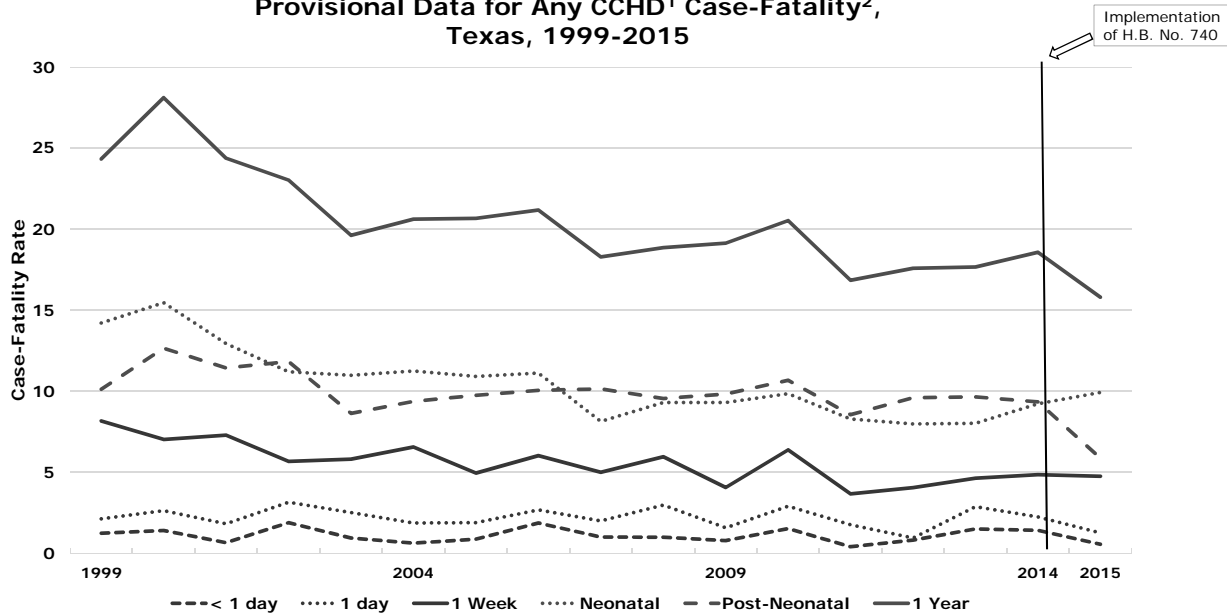
Identifying Underreporting Areas by Delivery City, Texas, 2015

Facility City	# in NBS	# in TBDR
San Antonio	79	74
Houston	58	141
Dallas	6	122
Edinburg	5	17
McAllen	5	7
Tyler	5	6
Victoria	3	2
El Paso	2	20
Galveston	2	7
Kyle	2	3
Laredo	2	8
Edinberg	2	17
Greenville	1	2
Mt. Pleasant	1	4
Pasadena	1	3
Ft. Worth	0	51
Austin	0	42
Corpus Christi	0	42
Lubbock	0	9
Mission	0	9
Harlingen	0	8
Amarillo	0	7
Plano	0	7
Arlington	0	6
Longview	0	5
Wichita Falls	0	5
Frisco	0	4
Grapevine	0	4
Odessa	0	4
Waco	0	4
Abilene	0	3
Athens	0	3
Bedford	0	3
Brownwood	0	3
Conroe	0	3
Kyle	0	3
Other	0	57
Total	174	715

Prenatal Diagnosis?
Transfers?
Parental Decline?

1: Facility City is based on location of facility at delivery

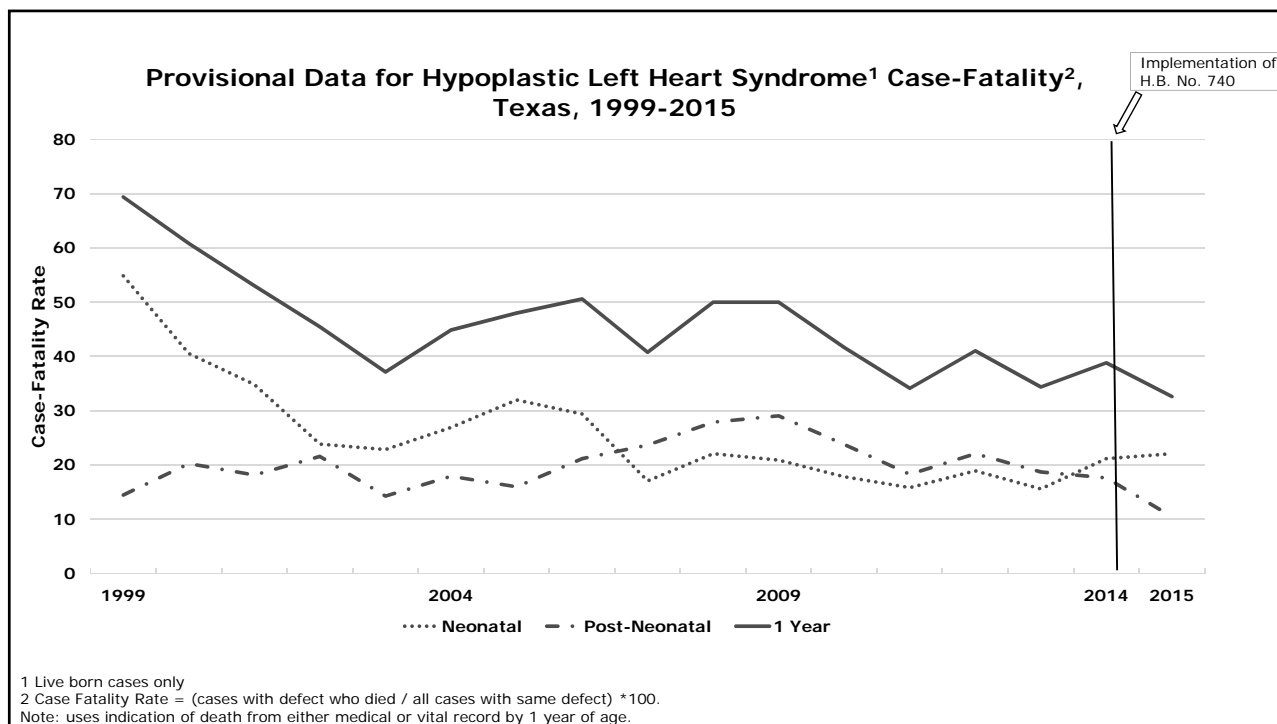
Provisional Data for Any CCHD¹ Case-Fatality², Texas, 1999-2015



1 Live born cases only

2 Case Fatality Rate = (cases with defect who died / all cases with same defect) * 100.

Note: uses indication of death from either medical or vital record by 1 year of age.



Discussion/Other Considerations

- 1/5th of CCHD cases would not be identified by Pulse-Ox before discharge
- These data are PROVISIONAL:
 - Please do not circulate
 - Abstraction of ~2015 deliveries not complete
 - Coding discrepancies; will resolve before finalizing these data
- Discussion
 - ✓ How many CCHD cases are there and what percent are being reported to NBS?
 - ✓ Is TBDR able to identify if there are specific regions/facilities that are underreporting?
 - ✓ Does active surveillance identify additional cases not reported to NBS?
 - ✓ Is there one specific defect that is not being reported, or has been missed by the Pulse-Ox screen?

Thank you

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