National Center on Birth Defects and Developmental Disabilities

DD19-1906 Capacity Building for Sickle Cell Disease Surveillance

Session 13: SCDC Data – Where are the Holes?

June 18, 2020

Data Holes and Gaps

California Sickle Cell Data Collection Program

TRACKING CALIFORNIA

INFORMING ACTION FOR HEALTHIER COMMUNITIES

Identified Gaps in California Data

- Don't assume the data has what you think it has
  - Ask and then
  - Trust but verify
- Why was the data set created?
  - Hospital discharge: Health planning and development
    - Lack of granularity
    - Errors in identifiers
  - Medicaid claims: billing/reimbursement
    - Dual eligible claims missing
    - Things that don't get billed
    - MCO bundled/capitated encounters
  - NBS: preventative care for newborns
    - No or limited follow up information
    - Limited genotyping

Identified Gaps in California Data

- How complete is the data set?
  - The variables are there, but not the data
- How linkable are the data?
  - Missing identifiers
  - Clinical data – no more SSNs
- How complicated?
  - Medicaid plan codes
- How consistent?
  - NDC coding

Dual Eligibility

CROSSOVER_STAT_CD	
Medicare_Ind	Frequency
1	29
3	5383
5	1752
6	5728
7	230060
Frequency Missing	1306922

	A	B
	Medicare status code	Medicare status code description
	1	Medicare Involvement Present
	B	Unknown
		No Medicare Involvement

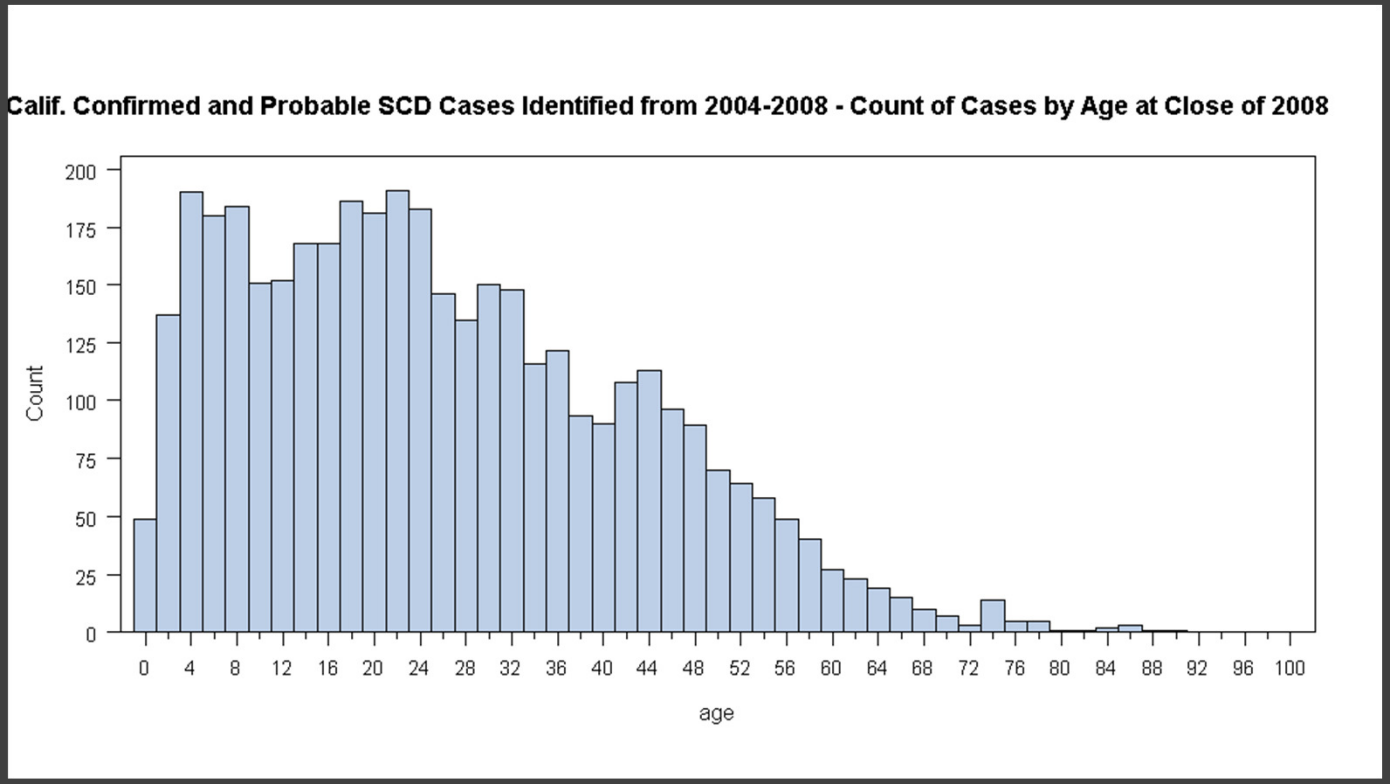
- 893 meeting case definition in 2018 with Medicare as payer, under age 65
  - Some may qualify for ESRD, but most likely dual eligible
- Data stewards/analysts often do not have program information

Dual Eligible – LATE BREAKING

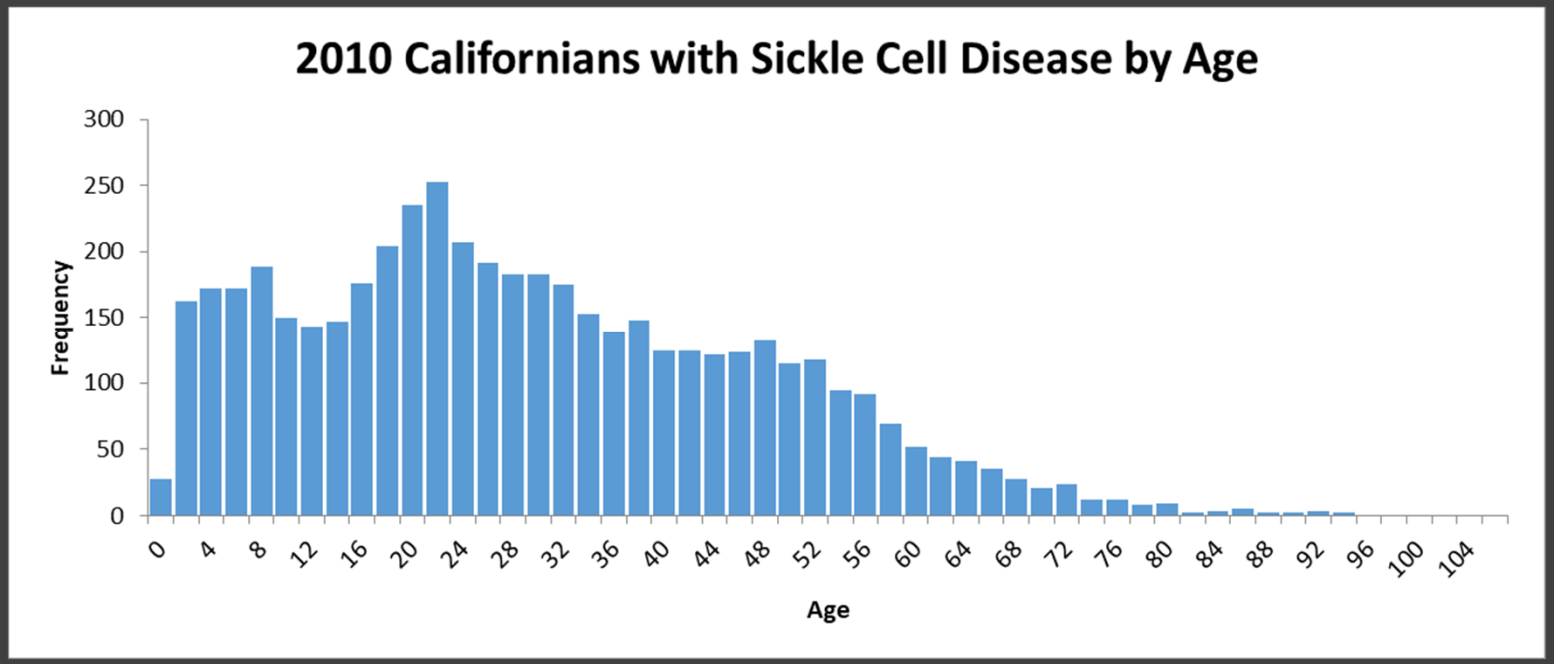
CROSSOVER_STAT_CD	
Medicare_Ind	Frequency
1	29
3	5383
5	1752
6	5728
7	230060
Frequency Missing 1306922	

	A	B
1	Medicare participation code	Medicare participation code description
2	0	Unknown
3	1	Medicare Part A eligible
4	2	Medicare Part B eligible
5	3	Both Medicare Part A and B eligible
6	4	Medicare Part D Eligible
7	5	Medicare Part A & Part D Eligible
8	6	Medicare Part B & Part D Eligible
9	7	Medicare Part A, Part B, Part D Eligible
10		Not Medicare eligible

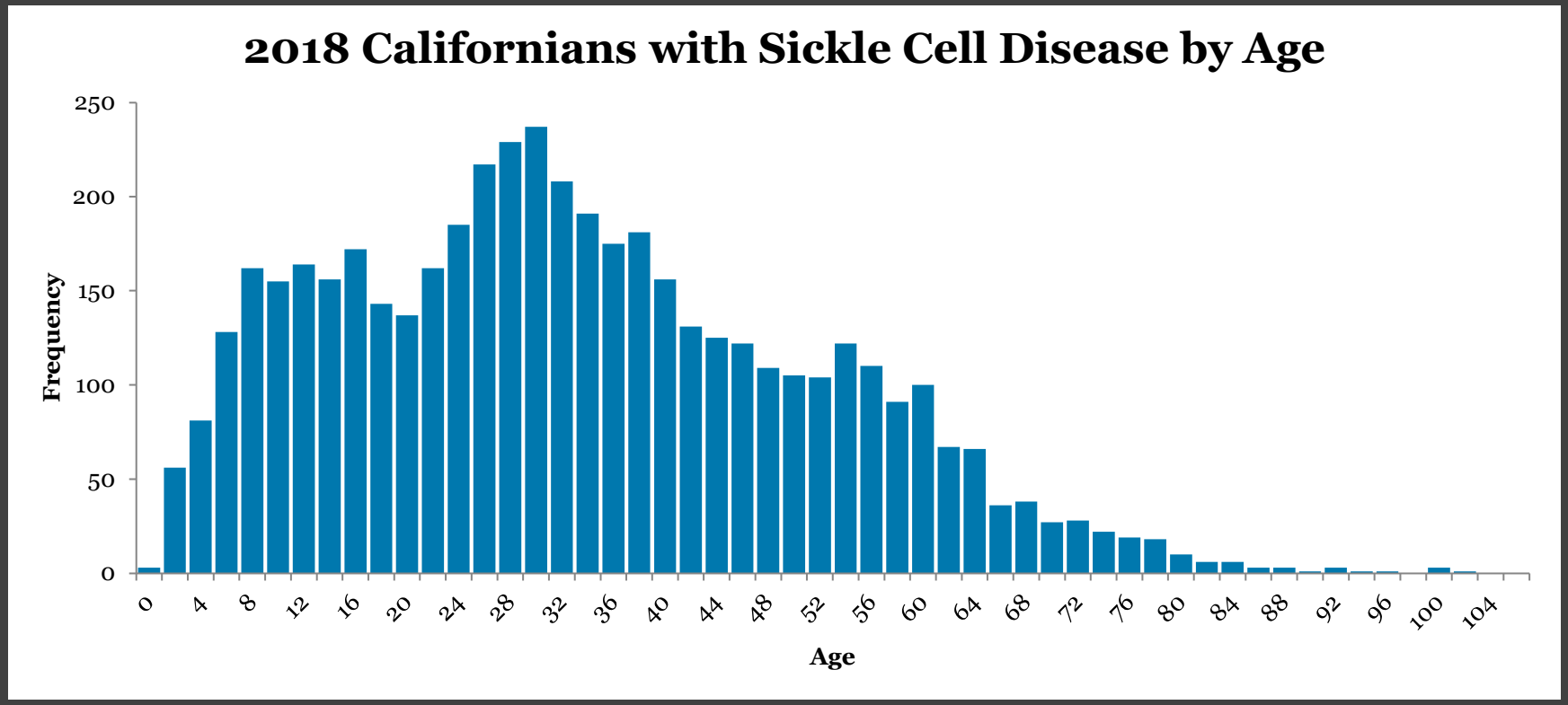
Data Gaps: Children and Older Adults



Data Gaps: Children and Older Adults



Data Gaps: Children and Older Adults



Medicaid Plan Codes (868 of them)

	A	B	C
1	Eligibility status	Eligibility status code	Eligibility status description
2	1	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Normal eligible / Regular eligible reported timely
3	3	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Normal eligible / 3 month retroactive eligible
4	4	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Normal eligible / Continuing eligible reported timely
5	6	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Normal eligible / Ramos/Pickle/IHSS/Other Extended eligible
6	7	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Normal eligible / Aid Paid Pending Ramos/Myers
7	8	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Normal eligible / Hold from LTC/SOC status
8	9	N	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Normal eligible / Ineligible or Regular hold
9	10	N	UNKNOWN
10	12	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported more than 1 month prior / Regular eligible reported retroactiv
11	13	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported more than 1 month prior / 3 month retroactive eligible
12	14	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported more than 1 month prior / Continuing eligible reported timely
13	15	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported more than 1 month prior / Continuing eligible reported retroac
14	16	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported more than 1 month prior / Ramos/Pickle/IHSS/Other Extended
15	17	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported more than 1 month prior / Aid Paid Pending Ramos/Myers
16	18	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported more than 1 month prior / Hold from LTC/SOC status
17	19	N	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported more than 1 month prior / Ineligible or Regular hold
18	21	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported 1 month prior / Regular eligible reported timely
19	22	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported 1 month prior / Regular eligible reported retroactively
20	23	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported 1 month prior / 3 month retroactive eligible
21	24	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported 1 month prior / Continuing eligible reported timely
22	25	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported 1 month prior / Continuing eligible reported retroactively
23	26	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported 1 month prior / Ramos/Pickle/IHSS/Other Extended eligible
24	27	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported 1 month prior / Aid Paid Pending Ramos/Myers
25	28	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported 1 month prior / Hold from LTC/SOC status
26	29	N	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported 1 month prior / Ineligible or Regular hold
27	31	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported in current month / Regular eligible reported timely
28	32	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported in current month / Regular eligible reported retroactively
	33	Y	Full Scope Medi-Cal Eligible (includes zero SOC) with no conditions / Unconfirmed Immediate Need eligible reported in current month / 3 month retroactive eligible

Missing SSNs in Administrative Data

Table 7. Count of SCD Related Hospitalizations without Social Security Number 2016-2018

	Hispanic Ethnicity		All Ethnicities	
	Pediatric	Adult	Pediatric	Adult
Total Admissions	181	187	1,740	1,212
Mean Admissions/Year	60.3	62.3	580	404
Total ED Encounters	244	228	1,978	1,966
Mean ED Encounters/Year	81.3	76	659.3	655.3

SCDC

SICKLE CELL DATA COLLECTION

Where are the Holes?

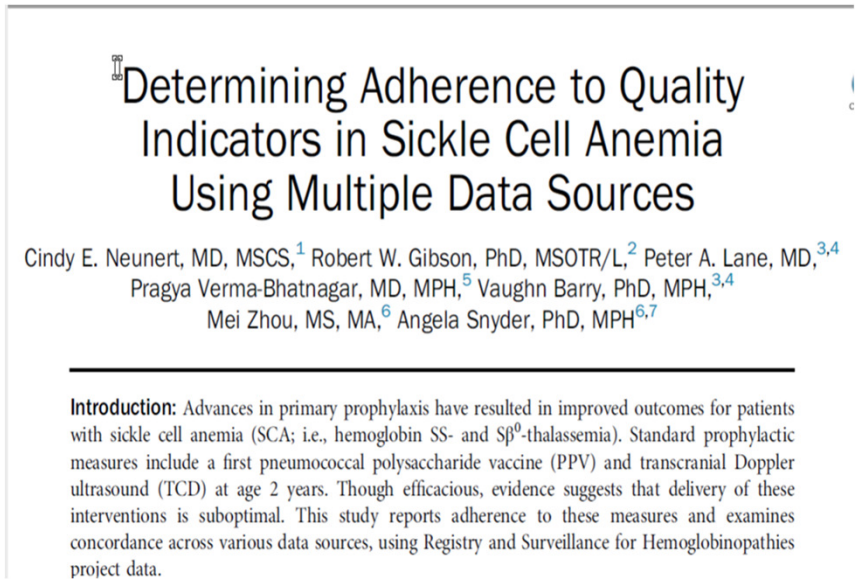
Angie Snyder, PhD

June 18, 2020

Georgia Health Policy Center

Georgia State University | Andrew Young School of Policy Studies

Measuring Preventive Care



Determining Adherence to Quality Indicators in Sickle Cell Anemia Using Multiple Data Sources

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Introduction: Advances in primary prophylaxis have resulted in improved outcomes for patients with sickle cell anemia (SCA; i.e., hemoglobin SS- and $S\beta^0$-thalassemia). Standard prophylactic measures include a first pneumococcal polysaccharide vaccine (PPV) and transcranial Doppler ultrasound (TCD) at age 2 years. Though efficacious, evidence suggests that delivery of these interventions is suboptimal. This study reports adherence to these measures and examines concordance across various data sources, using Registry and Surveillance for Hemoglobinopathies project data.

- Studied 125 children age 2 years
- Forty-five (36.0%) children had documentation of both interventions, whereas 19 (15.2%) had no documentation of either intervention.
- Sixty-one (48.8%) children obtained only one intervention. Of these, more were likely to have had PPV than TCD (77.0% vs 23.0%)

Validating TCD and PPV

Table 4. Measures of Agreement Between Data Sources for Documentation of PPV and TCD

Prophylactic measure	Data source comparisons	Overall agreement, %	Kappa
PPV	Medicaid and CHIP compared to clinical chart	77.6	0.552
	Medicaid and CHIP compared to GRITS	72.8	0.463
	Clinical chart compared to GRITS	63.2	0.263
TCD	Medicaid and CHIP compared to clinical chart	87.2	0.735

CHIP, Children's Health Insurance Program; GRITS, Georgia Registry of Immunization Transactions and Services; PPV, pneumococcal polysaccharide vaccine; TCD, transcranial Doppler ultrasonography.

- Agreement between claims data and medical record review was moderate for PPV (κ=0.55) and substantial for TCD (κ=0.74).
- Validation data from a TN study found procedure claims for TCD to be 90.5% sensitive with a positive predictive value of 100% compared to medical records.
- GRITS provided comprehensive information to document PPV.

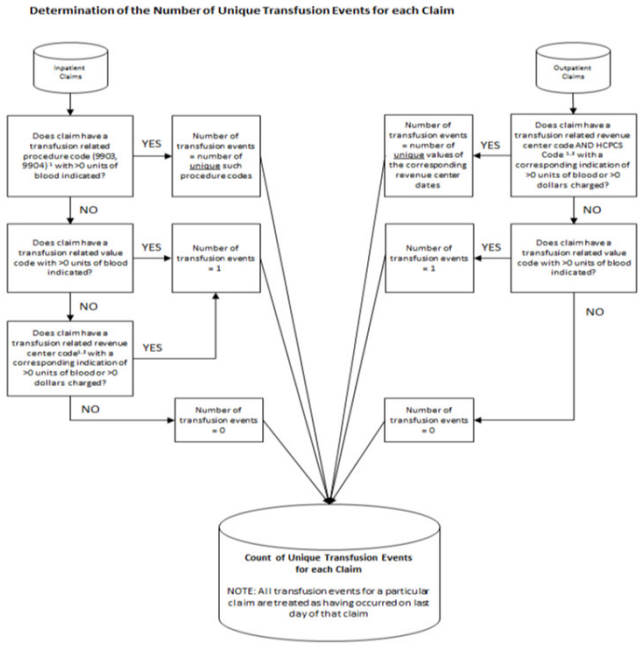
Sensitivity of Transfusion Codes

Study	Data	Gold standard comparison	Sample	Codes	Sensitivity (transfused patients billed)	Specificity (non-transfused patients not billed)
Segal (2001)	John Hopkins Hospital Discharge data	Electronic blood bank data	358 patients billed for RBC transfusions with 358 who were not matched on top 20 DRGs	Billed group contained code 9904; Not billed group did not contain codes 990-9909	83% (61 transfused patients were not billed)	100% (when revenue codes included; 9 patients had procedure code 9904 with no corresponding revenue code); 97.5% w/out revenue codes
Howard (2016)	Institute for Health Metrics, transfusions in 69 community hospitals (range of beds 25-400) from 2009-2013	Electronic health records including billing records, tissue bank, transfusion records and lab results	5214 patients receiving transfusions for hip fractures out of 12091 hip fractures.	9904; did not use revenue codes	71.6% 3733/5215 (60.4%-82.8%)	92.6% 6368/6876 (88.3%-97.0%)
Claster (2014)	CA Hospital Discharge data, 2009-2010—3 hospitals (2 peds, 1 adult)	Chart review- transfusions were identified from blood bank order sets, fluid input flow sheets, daily notes.	162 cases of ACS in SCD patients across 3 hospitals; reviewed to identify those transfused and to confirm ACS	99.0, 99.01, 99.03, and 99.04 for transfusion and exchange transfusion; not linked at the individual level to billing data, no revenue codes.	78%; 66/85 Range: 86% (57/66), 31% (4/13), 86% (5/6)	No specificity only PPV of ACS 75% (121/162); Range: 55% (12/22) to 86.7 (26/30) also 75% (83/110)
Romano (1994)	CA hospital discharge abstracts—July –December 1988	Full length and truncated versions of abstracted data compared to fully Re-abstracted non-financial data	87 transfusion events found out of 2,579 patient admissions for the top 10 Med-Surg DRGs and 9 related DRGs.	99.04; no revenue codes	25 field sensitivity 31%	Specificity 100%

From the Literature…

- Sensitivity of transfusion coding is variable--some don't get coded; however PPV are high (if billed for almost always received); if REV codes included sensitivities are higher.
- Hospitals with poor sensitivity also had lower claims-based transfusion rates
- Segal (2001): The 61 patients without a billing record who did receive a transfusion were older and less likely to have commercial insurance.
- Algorithm from CMS report on Standardized Transfusion Ratio

Report for the Standardized Transfusion Ratio Submitted to CMS by UM-KECC-June 13, 2014



[1] See Appendix III for the description of relevant revenue center codes, procedure codes, value codes and HCPCS codes.
[2] Transfusion related revenue center codes: 0380, 0381, 0382, 0389, 0390, 0391, 0392, 0399
Transfusion related HCPCS codes: P9010, P9011, P9016, P9021, P9022, P9038, P9039, P9040, P9051, P9054, P9056, P9057, P9058

Appendix III.

Description of Relevant Revenue Center Codes, Procedure Codes, Value Codes and HCPCS Codes.

Field	Value	Meaning
Revenue Center Codes	0380	Blood - General Classification
	0381	Blood - Packed Red Cells
	0382	Blood - Whole Blood
	0389	Blood - Other Blood
	0390	Blood Storage and Processing - General Classification
	0391	Blood Storage and Processing - Administration
	0392	Blood Storage and Processing - Blood Processing and Storage
	0399	Blood Storage and Processing - Other Storage & Processing
Procedure Codes	9903	Other Transfusion Of Whole Blood
	9904	Transfusion Of Packed Cells
Value Code	37	Pints of blood furnished
HCPCS Codes	P9010	Whole blood for transfusion
	P9011	Blood split unit
	P9016	RBC leukocytes reduced
	P9021	Red blood cells unit
	P9022	Washed red blood cells unit
	P9038	RBC irradiated
	P9039	RBC deglycerolized
	P9040	RBC leukoreduced irradiated
	P9051	Blood, l/r, cmv-neg
	P9054	Blood, l/r, froz/degly/wash
	P9056	Blood, l/r, irradiated
	P9057	Red blood cells, frozen/deglycerolized/washed, leukocytes reduced, irradiated, each unit
	P9058	RBC, l/r, cmv-neg, irrad

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Transfusion Reactions

PHARMACOEPIDEMIOLOGY AND DRUG SAFETY 2012; **21**(S1): 230–235
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ORIGINAL REPORT

A systematic review of validated methods for identifying transfusion-related ABO incompatibility reactions using administrative and claims data

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ABSTRACT

Purpose This paper aimed to systematically review algorithms to identify transfusion-related ABO incompatibility reactions in administrative data, with a focus on studies that have examined the validity of the algorithms.
Methods A literature search was conducted using PubMed, Iowa Drug Information Service database, and Embase. A Google Scholar search was also conducted because of the difficulty identifying relevant studies. Reviews were conducted by two investigators to identify studies using data sources from the USA or Canada because these data sources were most likely to reflect the coding practices of Mini-Sentinel data sources.
Results One study was found that validated International Classification of Diseases (ICD-9-CM) codes representing transfusion reactions.

**Little research characterizing the utility of administrative data for conducting transfusion safety research

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Validating Transfusion Reactions

- Started with a set of known transfusion reaction cases in SCD from 3 blood banks and examined how they were coded in Medicaid billing data
- CHOA: 45 encounters matched; Augusta: 4 encounters matched; Grady: 24 encounters matched (10 peds/14 adults)—69/118 possible patients were found in Medicaid data
- 1 child at CHOA and 1 adult at Grady had a reported DHTR from Blood Bank data both were coded as Transfusion Reaction 999.8, child also had a CPT code 86078 for Investigation

Validating Transfusion Reactions cont.

- Other reactions included: allergic, FNHTR, ruled underlying disease/not transfusion related, and Infection
  - CHOA: 27 coded 999.8, 22 coded 86078 out of 44 additional events
  - Augusta: 1 coded 999.8, 2 coded 86078 out of 4 events
  - Grady: 3 coded 999.8, 0 coded 86078 out of 23 events
- Coding for transfusion reactions even in highly transfused SCD patients is not accurate enough to use in safety studies; unclear what events are preventable
- During the period 2004-2008 no reports of TRALI or TACO in these patients

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