



DD19-1906 Capacity Building for Sickle Cell Disease Surveillance

Session 9: What's Really in the Data??

April 16, 2020



Data Examples from California

California Sickle Cell Data Collection Program

TRACKING  CALIFORNIA

INFORMING ACTION FOR HEALTHIER COMMUNITIES

What's In the Data?

- Questions from States
 - What variables do we request?
 - How do we answer the analytic questions we have?
 - How can we see patients not in knowledgeable care settings?
 - What do we use to link _____ to _____?
- Real world data files
 - Variables and why
 - Where to find utilization and treatment information
 - Where to find care settings
 - Linkage

Simplest Cases

- Clinical case reports
 - Confirm or identify genotype or SCD variant
 - Confirm status as patient at that clinic (first/most recent date seen)
 - Possibly: EHR/clinical information
 - Whatever variables you request (CA: identifiers, zip code for linkage)
- Newborn screening
 - Identify genotype or SCD variant
 - Understand incidence, geography of births
 - In CA, linkage between clinical/NBS data based on names + DOB + sex + zip (if needed)

	DOB2	CLNT_LST_NAME	CLNT_FRST_NAME	GNDR_DSCR	DIS_TYPE_DSCR	HOSP_NAME	HOSP_COUNTY	RACE_ETHNCTY_DSCR1	RACE_ETHNCTY_DSCR2	ZIP_CODE
1	6/2000 S		C	Male	Hb S/S (Sickle S/S Disease)	SUMMIT MEDICAL CENTER - H	1	Black		94603
2	3/2000 W			Female	Hb FS confirmed but not differentiated	GOOD SAMARITAN HOSPITAL	19	Black		90043
3	9/2000 W		S	Male	Hb S/S (Sickle S/S Disease)	ALTA BATES MEDICAL CENTER	1	Black		94804
4	3/2000 T		M	Male	Hb C/C (Hb C Disease)	CITRUS VALLEY MEDICAL CEN	19	Black		91790
5	4/2000 J		D	Female	Hb S/S (Sickle S/S Disease)	ALTA BATES MEDICAL CENTER	1	Black		94801
6	4/2000 G		J	Male	Hb S/Beta+ (Sickle Beta+ Thalassemia)	MERCY HOSPITAL	15	Black		94621
7	4/2000 W		N	Male	Hb S/S (Sickle S/S Disease)	LONG BEACH MEMORIAL MEDI	19	Black		90805

Administrative Data: Patient Discharge

- In CA, linkage to SSN for clinical/NBS cases
- Healthcare utilization
- Patient identification for those not in clinical/NBS cases
- Time in cohort
- Treatments, procedures, comorbidities
- Payer
- Setting of care
- Geography
- ED and Ambulatory Surgery similar or in same file in CA and GA

Administrative Data: Patient Discharge

1

	6-digit Hospital ID	Type of Care	Age in Days at Admission	Age in Years at Admission	Patient Sex	Concatenated Ethnicity/Race Group	Ethnicity	Race	Patient Zip Code	Patient County of Residence	Length of Stay	Adjusted Length of Stay	Day of Week of Admission	Month of Admission	Year of Admission	Admission Source	Site of Admission	Licensure of Site	Route of Admission	Type of Admission	Disposition of Patient	Do Not Resuscitate (DNR)	Payer Category	Payer Type of Coverage	Payer Plan Code Number	Total Charges
1	010735	1	0	87 M	21	2	1	94	01		11	11 5	12	2017	5X1	5	X	1	2	03	N	01	3	0000	159604	
2	010735	1	0	66 M	24	2	4	94	01		11	11 5	12	2017	5X1	5	X	1	2	03	N	01	3	0000	184349	
3	010735	1	0	57 M	15	1	5	94	01		5	5 4	12	2017	1X1	1	X	1	2	01	N	03	2	0000	75524	
4	010735	1	0	83 M	25	2	5	94	01		4	4 5	12	2017	5X1	5	X	1	2	03	N	01	3	0000	52058	
5	010735	1	0	48 M	21	2	1	95	55		2	2 7	12	2017	1X1	1	X	1	2	07	N	03	2	0000	26727	

2

	Principal E-code	Present at Admission Principal E-code	Other E-code 1	Present at Admission Other E-code 1	Other E-code 2	Present at Admission Other E-code 2	Other E-code 3	Present at Admission Other E-code 3	Other E-code 4	Present at Admission Other E-code 4	Major Diagnostic Category	Medicare Severity Diagnosis Related Group (MS-DRG)	Principal Diagnosis	Principal Diagnosis Present at Admission	Principal Procedure	Days from Admission to Principal Procedure	Other Diagnosis 1	Other Dx1 Present at Admission	Other Diagnosis 2	Other Dx2 Present at Admission	Other Diagnosis 3	Other Dx3 Present at Admission
1											18	871	A419	Y	0W993ZX	1	I5043	Y	J9621	Y	J90	Y
2											08	480	M80052A	Y	0QS704Z	0	J690	N	E43	Y	R1310	N
3											06	354	K450	Y	0WQF0ZZ	0	K5090	Y	K279	Y	K219	Y
4											11	689	N390	Y			G8250	Y	L89152	Y	J111	Y
5											20	894	F10230	Y			N179	Y	E872	Y	E860	Y

3

	Other Procedure 1	Days from Admission to Proc 1	Other Procedure 2	Days from Admission to Proc 2	Other Procedure 3	Days from Admission to Proc 3	Other Procedure 4	Days from Admission to Proc 4
1	02HV33Z	1	B548ZZA	1	5A09457	0		-
2	0QS804Z	0	30233N1	6				-
3								-
4								-
5								-
6								-
7								-

Administrative Data: Patient Discharge

4

	Hospital Zip Code	Hospital County	Social Security Number	Age in Days at Discharge	Age in Years at Discharge	Quarter of Admission	Quarter of Discharge	Date of Birth - Raw	Age Range - 20 categories	Normalized Ethnicity/Race Group	Data Set Identification Number	Patient Identification Number	MS-DRG Severity Code	MS-DRG Category Code	Preferred Language Spoken ID	Preferred Language Spoken Write-in Value	Preferred Language Spoken Code	Date of Birth (DOB)	Admission Date	Discharge Date
1	94501	01	4	0	87.4	1	11	11/11/19	1	83406			1	M		1 English	ENG	11/11/19	12/01/2017	01/01/2018
2	94501	01	6	0	66.4	1	04	15/04/15	4	83406			1	S		1 English	ENG	04/15/15	12/01/2017	01/01/2018
3	94501	01	5	0	57.4	1	05	13/05/13	3	83406			2	S		1 English	ENG	05/13/13	12/01/2017	01/01/2018
4	94501	01	6	0	83.4	1	05	18/05/18	6	83406			1	M	56	Ukrainian	UKR	05/18/18	12/01/2017	01/01/2018
5	94501	01	5	0	48.4	1	12	11/12/11	1	83406			0	M		1 English	ENG	12/11/11	12/01/2017	01/01/2018
6	94501	01	4	0	93.3	1	05	19/05/19	1	83406			0	M		1 English	ENG	05/19/19	08/01/2012	01/01/2018
7	94501	01	5	0	67.4	1	01	15/01/15	1	83406			2	M		1 English	ENG	01/15/15	12/01/2017	01/01/2018

5

	Principal Procedure Date	Other Procedure Date 1	Other Procedure Date 2	Other Procedure Date 3	Other Procedure Date 4
1	12/01/2017	12/01/2017	12/01/2017	12/01/2017	.
2	12/01/2017	12/01/2017	12/01/2017	.	.
3	12/01/2017
4

6

MS-DRG Grouper Version Number
35.0
35.0
35.0
35.0
35.0
35.0

Administrative Data: Medicaid, SCHIP, Other State

- In CA, linkage to SSN for clinical/NBS cases
- Healthcare utilization
- Outpatient encounters (knowledgeable care setting)
- Patient identification for those not in clinical/NBS cases
- Time in cohort
- Treatments, procedures, comorbidities
- Provider type
- Setting of care
- Pharmacy claims (compliance/time on drug)
- Geography
- Program code
- Dual eligibility with Medicare

Administrative Data: Medicaid, SCHIP, Other State CLAIMS

1

	AKA_CIN	sc_ssn	SSN_OR_MEDS_ID	ADJ_IND	INPAT_ADMISSION_DT	ADMIT_FAC_NPI	AID_CD	AID_CAT_CD	BILLING_PROV_LOC_NBR	BILLING_PROV_OWNER_NBR	BILLING_PROV_TAXON	PLAN_CD	CAT_OF_SVC_CD	CCN
1	1111111	2222222	2222222		-		T3	T3			207L00000X	309		309M82531727
2	1111111	2222222	2222222		-		T3	T3			207L00000X	309		309M82531727
3	1111111	2222222	2222222		-		T3	T3			207L00000X	309		309M82531727
4	1111111	2222222	2222222		-		T3	T3			291U00000X	309		309M825316393
5	1111111	2222222	2222222		-		T3	T3			207L00000X	309		309M82531727
6	1111111	2222222	2222222		-		T3	T3			207L00000X	309		309M82531727
7	1111111	2222222	2222222		-		T3	T3			207L00000X	309		309M82531727
8	1111111	2222222	2222222		-		T3	T3			207L00000X	309		309M82531727
9	1111111	2222222	2222222		-		T3	T3			207L00000X	309		309M82531727
10	1111111	2222222	2222222	4	-		T3	T3	79			599		2018269190002
11	1111111	2222222	2222222		-		T3	T3	79			599		2018269190002
12	1111111	2222222	2222222		-		T3	T3	79			599		2018269190002

2

	EMERGENCY_IND	CROSSOVER_STAT_CD	CLAIM_TYPE_CD	COINSURANCE_AMT	INPAT_DISCHARGE_DT	INPAT_DISCHARGE_CD	FMLY_PLAN_IND	ADMIT_SRC	MEDI_CAL_REIMB_AMT	OTHER_CVG_AMT	MC_OTHER_CVG_AMT	MEDICARE_DED_AMT	NDC_UPC_HRI_CD
1	N		4	-	-				0.00	-	0.00	-	
2	N		4	-	-				0.00	-	0.00	-	
3	N		4	-	-				0.00	-	0.00	-	
4	N		4	-	-				0.00	-	0.00	-	
5	N		4	-	-				0.00	-	0.00	-	
6	N		4	-	-				0.00	-	0.00	-	
7	N		4	-	-				0.00	-	0.00	-	
8	N		4	-	-				0.00	-	0.00	-	
9	N		4	-	-				0.00	-	0.00	-	
10			5	0.00	-				12.00	0.00	-	0.00	
11			5	0.00	-				10.00	0.00	-	0.00	
12			5	0.00	-				3.00	0.00	-	0.00	

3

	PATIENT_LIAB_AMT	PRIMARY_DIAG_CD_ICD10	DIAG_CD_ICD10	DIAG_NBR_ICD10	PROC_CD	PROC_IND	PROV_SPEC_CD	FI_PROV_TYPE_CD	PROV_ZIP_CD	RLTD_CAUSE_CD_1	RLTD_CAUSE_CD_2	RLTD_CAUSE_CD_3	REVENUE_CD	SEC_DIAG_CD_ICD10
1		Z00129	Z7189		5 99393	4	05	026	950515173					Z0100
2		Z00129	J029		7 99393	4	05	026	950515173					Z0100
3		Z00129	Z6852		8 99393	4	05	026	950515173					Z0100
4		J029	J029		1 87651	4		009	947101703					
5		Z00129	Z713		4 99393	4	05	026	950515173					Z0100
6		Z00129	Z7182		3 99393	4	05	026	950515173					Z0100
7		Z00129	Z0100		2 99393	4	05	026	950515173					Z0100
8		Z00129	Z00129		1 99393	4	05	026	950515173					Z0100
9		Z00129	Z139		6 99393	4	05	026	950515173					Z0100
10	0.00								940871154					
11	0.00								940871154					
12	0.00								940871154					

Administrative Data: Medicaid, SCHIP, Other State, CLAIMS

	SVC_FROM_DT	SVC_TO_DT	REF_PRESC_NPI	REND_OPERATING_NPI	NPI	DRUG_SUPPLY_DAYS
1	30/01/2018	30/01/2018		1619090438	1073606299	.
2	30/01/2018	30/01/2018		1619090438	1073606299	.
3	30/01/2018	30/01/2018		1619090438	1073606299	.
4	30/01/2018	30/01/2018		1083777163	1083777163	.
5	30/01/2018	30/01/2018		1619090438	1073606299	.
6	30/01/2018	30/01/2018		1619090438	1073606299	.
7	30/01/2018	30/01/2018		1619090438	1073606299	.
8	30/01/2018	30/01/2018		1619090438	1073606299	.
9	30/01/2018	30/01/2018		1619090438	1073606299	.
10	24/01/2018	24/01/2018		1508099268	1114443686	.
11	24/01/2018	24/01/2018		1508099268	1114443686	.
12	24/01/2018	24/01/2018		1508099268	1114443686	.

Administrative Data: Medicaid, SCHIP, Other State ELIGIBILITY

	AKA_CIN	sc_ssn	BIRTH_DT	BENE_ADDR_CITY	CNTY_RES_CD	BENE_ADDR_ZIP	LANG_CD	ELIG_STAT_CD	ELIG_DT	ETHNIC_CD	GENDER_CD
1	90 [REDACTED] D 6 [REDACTED] 5	08 [REDACTED] 1998	LOS ANGELES	19	90 [REDACTED]	7		01JAN2018	9	F	
2	90 [REDACTED] D 6 [REDACTED] 5	08 [REDACTED] 1998	LOS ANGELES	19	90 [REDACTED]	7		01FEB2018	3	F	
3	90 [REDACTED] D 6 [REDACTED] 5	08 [REDACTED] 1998	LOS ANGELES	19	90 [REDACTED]	7		01MAR2018	3	F	
4	90 [REDACTED] D 6 [REDACTED] 5	08 [REDACTED] 1998	LOS ANGELES	19	90 [REDACTED]	7		01APR2018	3	F	
5	90 [REDACTED] D 6 [REDACTED] 5	08 [REDACTED] 1998	LOS ANGELES	19	90 [REDACTED]	7		01MAY2018	3	F	
6	90 [REDACTED] D 6 [REDACTED] 5	08 [REDACTED] 1998	LOS ANGELES	19	90 [REDACTED]	7		01JUN2018	3	F	
7	90 [REDACTED] D 6 [REDACTED] 5	08 [REDACTED] 1998	LOS ANGELES	37	90 [REDACTED]	7		01JUL2018	3	F	
8	90 [REDACTED] D 6 [REDACTED] 5	08 [REDACTED] 1998	ESCONDIDO	37	92 [REDACTED]	7		01AUG2018	3	F	
9	90 [REDACTED] D 6 [REDACTED] 5	08 [REDACTED] 1998	ESCONDIDO	37	92 [REDACTED]	7		01SEP2018	3	F	

Resources

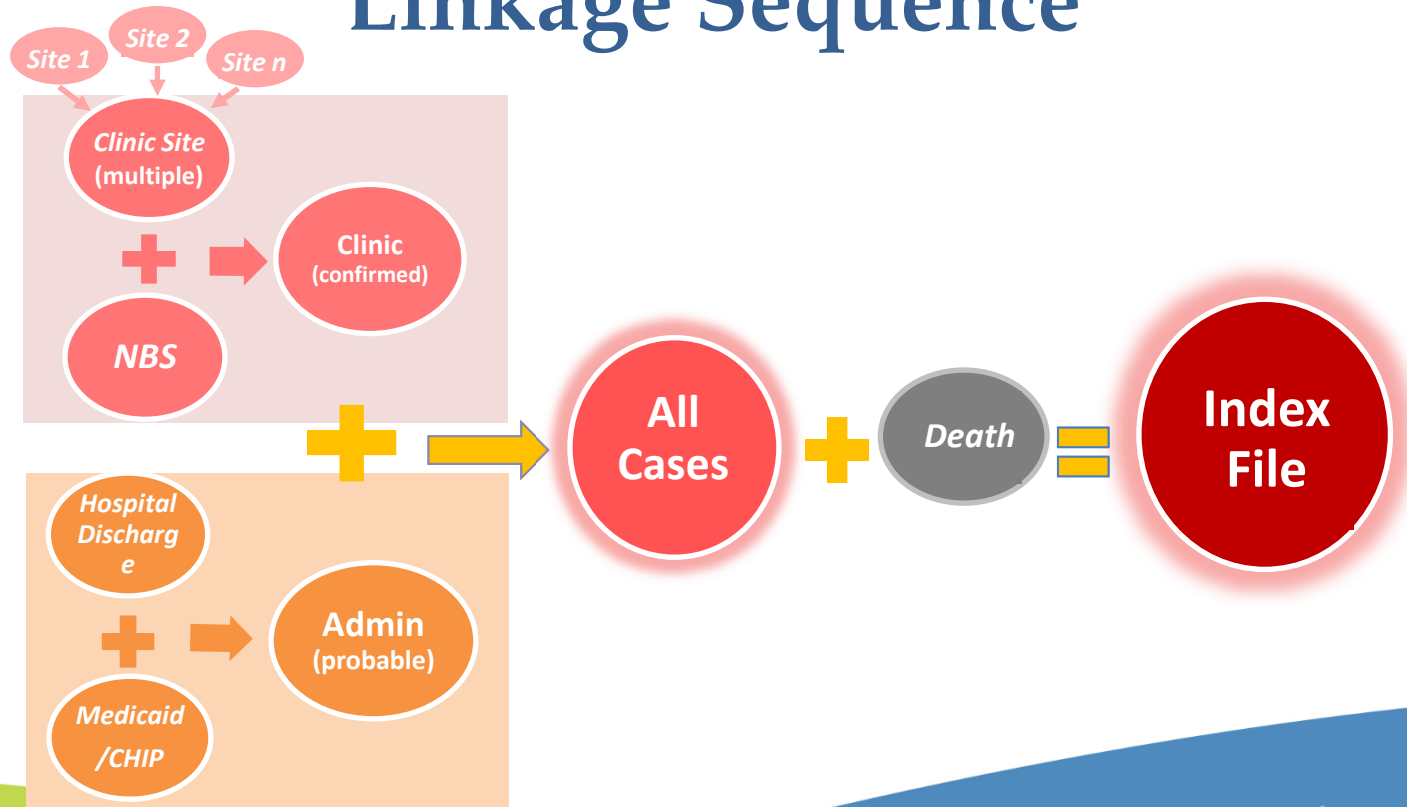
- California and Georgia Data Dictionaries
- CA and GA Data Requests (ask)
- Agency forms
- Agency data variable request tables
- Agency staff
- Key questions when deciding on variables
 - What does this contain?
 - How well is it populated?
 - How much change happens over time with coding/completeness?
 - Will it answer the question I think it will answer?



Data Request: Unaffiliated Patients

Angie Snyder, PhD
April 16, 2020

Linkage Sequence



Unaffiliated Patients

- Can we look at the SCDC data to examine patients seeing a hematologist versus those who do not?
 - By geography (demographics of where individuals live)
 - By acute care utilization
 - By receipt of hydroxyurea
 - By mortality
 - By # of eye doctor visits/year

Clinical Data/NBS point in time	Medicaid/Insurer Claims longitudinal	Hospital Claims longitudinal	Not Available but in the EHR/MR longitudinal
Demographics including geography	Demographics including geography	Demographics including geography	Demographics including geography
Genotype based on labs	Genotype based on ICD codes	Genotype based on ICD codes	Genotype on labs and ICD codes
	Complications	Complications	Complications
	Comorbidities	Comorbidities	Comorbidities
	Procedures	Procedures	Procedures
	Prescriptions filled		Meds prescribed/ administered
	All encounters inc. outpt & pharmacy	Hospital and ER encounters	Encounters at that clinic/hospital
	Provider information		Lab results
			Smoking status or self-reported hx
			Vital Signs

Contributions to Surveillance Data

Total cases identified (n=13,332)

Sickle Cell Cases in Georgia, 2004 – 2017*		
Data Set	Confirmed Cases	Probable Cases
Newborn Screening	1,912	107
Augusta University (clinical)	1,793	23
Grady (clinical)	2,660	2
CHOA (clinical)	3,217	98
Savannah Memorial (clinical)	275	-
Medicaid/CHIP	5,407	3,441
State Health Benefit Plan**	246	205
Hospital discharge	6,151	4,604
De-duplicated Total	7,457	5,875

*The ending time varies from 2016– 2018 depending on the data source.

**State Health Benefit Plan data was collected for 2004-2008 time period only.

Variable and Output Details

- Can we look at the SCDC data to examine patients seeing a hematologist versus those who do not?
Yes, for patients with insurance claims
- What time frame? Same time frame for visit to hematologist (1 visit within a year)? as other information or does one need to come first?
 - By geography (demographics of where individuals live); How to define? A county map, rural versus urban, or some distance calculation? Breakdown by Age?
 - By acute care utilization; How to define? Any ER visit, # of inpatient days?
 - By receipt of hydroxyurea; How to define? Any prescriptions filled? medication possession ratio?
 - By mortality; Link with mortality data, Cause of death? Age at death?
 - By # of eye doctor visits/year

Mary Hulihan (CDC): ibx5@cdc.gov
Susan Paulukonis (CA): Susan.Paulukonis@cdph.ca.gov
Angie Snyder (GA): angiesnyder@gsu.edu

For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348 www.cdc.gov

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

