



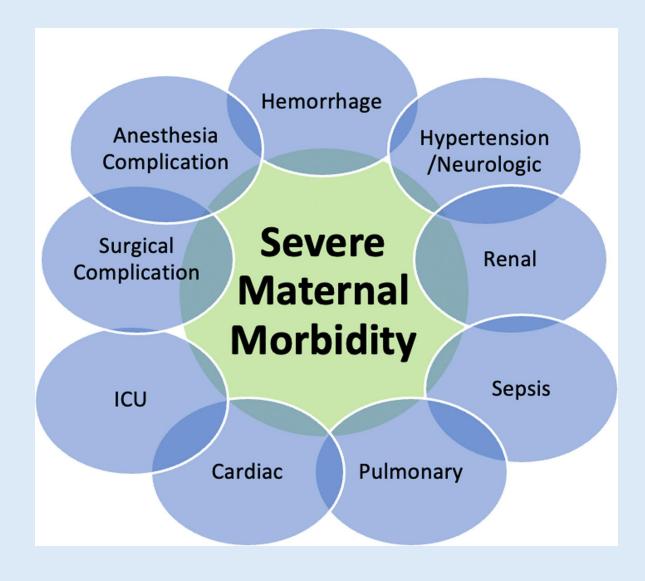
Estimating the risk of severe maternal morbidity among pregnant people with congenital heart disease

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OHDSI Community Call
13 May 2025



Background



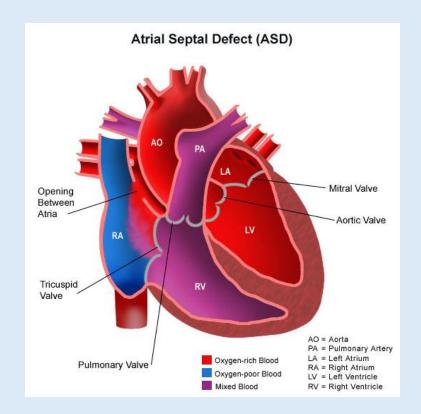


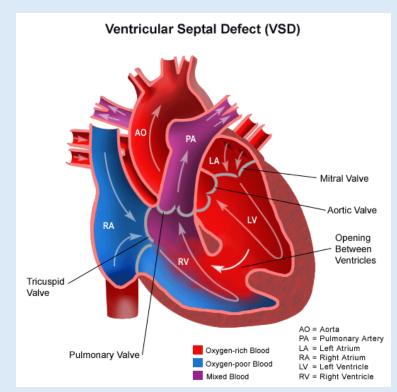
Source: Kern-Goldberger, AR, et al. 2023. AJOG MFM.

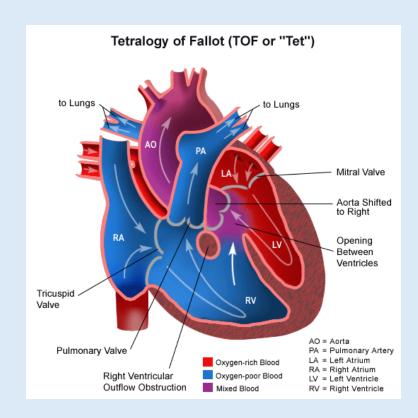


Background













Studies have shown that heart disease is associated with severe maternal morbidity (SMM)

Few studies separate out congenital heart disease (CHD) from acquired, and CHD is likely underreported in large databases

More people with CHD are surviving childhood to reach reproductive age





Describe the pregnant population with congenital heart disease (CHD)

Cohort Characterization





Describe the pregnant population with congenital heart disease (CHD)

Cohort Characterization

CHD Diagnoses

Demographics, comorbidities, SMM indicators





Do patients with CHD have an increased risk of SMM compared to those without CHD?

Population-Level Estimation





Do patients with CHD have an increased risk of SMM compared to those without CHD?

Population-Level Estimation

Target cohort: women with a diagnosis of CHD prior to delivery

Comparator cohort: women without a diagnosis of CHD prior to delivery





Do patients with CHD have an increased risk of SMM compared to those without CHD?

Population-Level Estimation

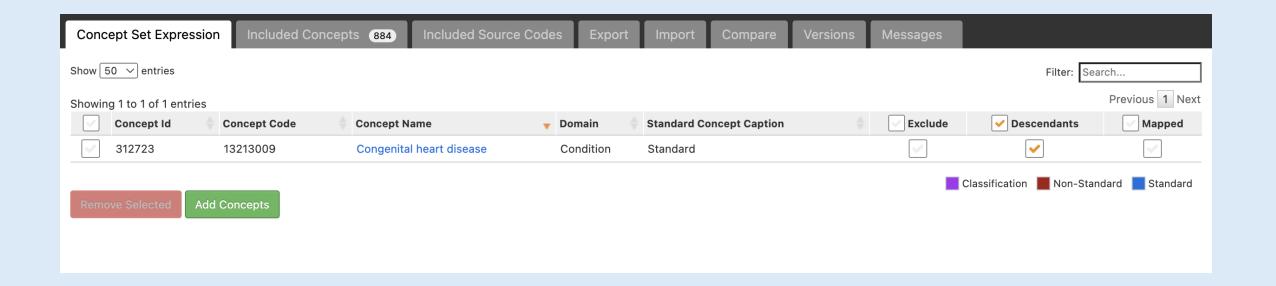
Target cohort: women with a diagnosis of CHD prior to delivery

Comparator cohort: women without a diagnosis of CHD prior to delivery

Outcome: SMM (One month before delivery to 6 weeks postpartum, and 6 months postpartum)







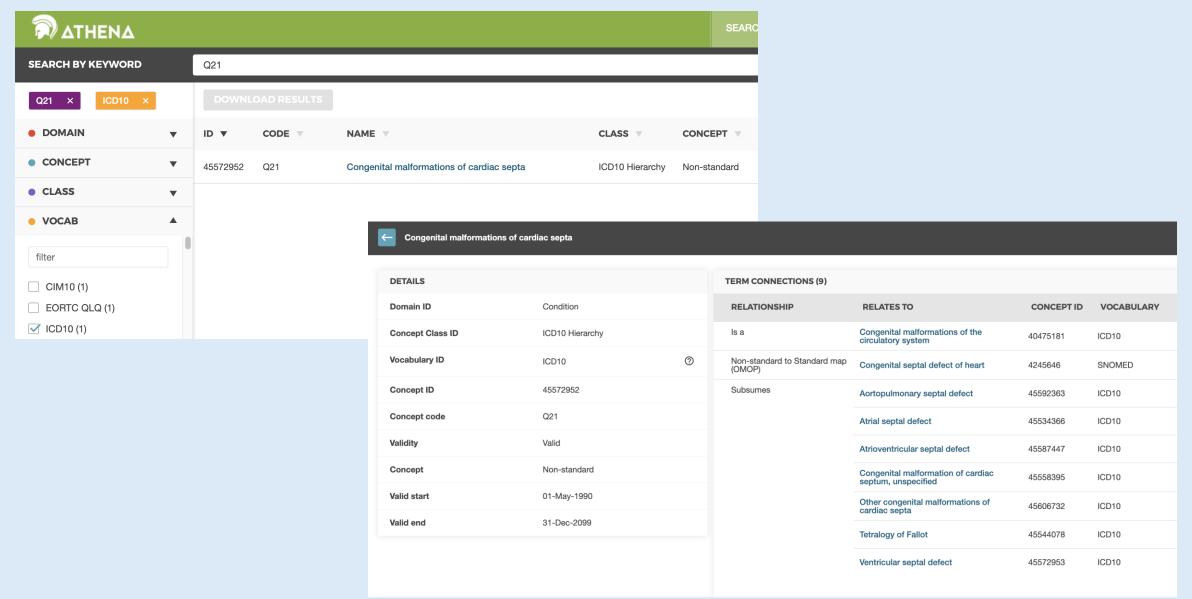




This was our starting list from other studies	
ICD10	
Q20 - Congenital malformations of cardiac chambers and connections	
Q21 - Congenital Malformations of cardiac septa	
Q22 - Congenital malformations of pulmonary and tricuspid valves	
Q23 - Congenital malformations of aortic and mitral valves	
Q24 - Other congenital malformations of heart	
Q25 - Congenital Malformations of great arteries	
Q26.0 - Congenital stenosis of vena cava	
Q26.1 - Persistent left superior vena cava	
Q26.2 Total anomalous pulmonary venous connection	
Q26.3 Partial anomalous pulmonary venous connection	
Q26.4 - Anomalous pulmonary venous connection, unspecified	
Q26.8 - Other congenital malformations of great veins	
Q26.9 - Congenital malformation of great vein, unspecified	







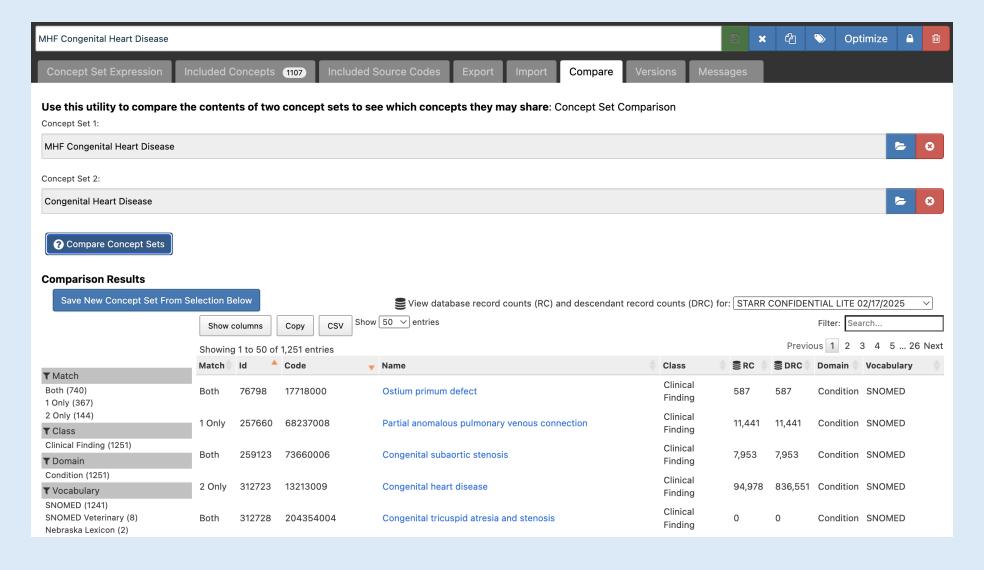




В	С	D	E	F	G	Н	1	J	K	L
Category from ICD10 Level 🔻 🤇	Category from ICD10 Level 2	ld	Code	Name	Class	Standard Con RC		DRC	Domain	Vocabulary
Q22 or Q23		4322316	70320004	Congenital anomaly of heart valve	Clinical Findir	Standard	7,832	439,379	Condition	SNOMED
Q20 - Congenital malformations	of cardiac chambers and conr	35615056	15964981000	Congenital anomaly of cardiac chamber	Clinical Findin	Standard	0	399,825	Condition	SNOMED
		42538528	762250009	Congenital anomaly of great vessel	Clinical Findin	Standard	0	383,909	Condition	SNOMED
		36676316	773139006	Congenital abnormality of cardiac ventricle	Clinical Findir	Standard	0	297,135	Condition	SNOMED
Q25 - Congenital Malformations	of great arteries	314463	59877000	Congenital anomaly of aorta	Clinical Findir	Standard	14,245	252,764	Condition	SNOMED
Q21 - Congenital Malformations	of cardiac septa	4245646	59494005	Congenital septal defect of heart	Clinical Findir	Standard	686	240,896	Condition	SNOMED
		4049296	123657001	Congenital stenosis of cardiac valve	Clinical Findin	Standard	0	218,514	Condition	SNOMED
		3656140	871668002	Congenital right ventricular anomaly	Clinical Findin	Standard	0	210,218	Condition	SNOMED
Q22 - Congenital malformations	of pulmonary and tricuspid val	319921	204339005	Congenital pulmonary valve abnormality	Clinical Findin	Standard	4,184	191,736	Condition	SNOMED
Q21 - Congenital Malformation: 0	Q21.0 - Ventricular Septal Defe	35625532	768552007	Congenital ventricular septal defect	Clinical Findir	Standard	0	189,469	Condition	SNOMED
Q22 - Congenital malformation (Q22.1 - Congenital pulmonary v	313005	67278007	Congenital stenosis of pulmonary valve	Clinical Findin	Standard	19,634	178,190	Condition	SNOMED
		4246554	93305002	Congenital malposition of aorta	Clinical Findin	Standard	0	170,840	Condition	SNOMED
		4103130	253511007	Congenital abnormality of ventricles and ventricular seg	Clinical Findir	Standard	0	160,395	Condition	SNOMED
Q21 - Congenital Malformation: 0	Q21.3 - Tetralogy of Fallot	320835	86299006	Tetralogy of Fallot	Clinical Findir	Standard	158,556	158,556	Condition	SNOMED
		4273708	63934006	Overriding aorta	Clinical Findin	Standard	0	158,556	Condition	SNOMED
		4244029	93078006	Congenital hypertrophy of cardiac ventricle	Clinical Findin	Standard	0	158,556	Condition	SNOMED
		4012483	1131009	Congenital valvular insufficiency	Clinical Findin	Standard	0	124,988	Condition	SNOMED
Q23 - Congenital malformations	of aortic and mitral valves	4030224	13689005	Congenital anomaly of aortic valve	Clinical Findin	Standard	0	124,061	Condition	SNOMED
Q23 - Congenital malformation (Q23.1 - Congenital insufficienc	321107	28656008	Congenital insufficiency of aortic valve	Clinical Findin	Standard	104,832	104,832	Condition	SNOMED
t Q25 - Congenital Malformation: 0	Q25.7 - Other congenital malfo	435646	36110001	Congenital anomaly of pulmonary artery	Clinical Findin	Standard	50,710	75,027	Condition	SNOMED
Q25 - Congenital Malformation: 0	Q25.0 - Patent ductus arteriosu	315922	83330001	Patent ductus arteriosus	Clinical Findin	Standard	74,079	74,079	Condition	SNOMED
		4182328	297218007	Congenital abnormality of arterial duct	Clinical Findin	Standard	0	74,079	Condition	SNOMED
		4246484	93262004	Congenital hypoplasia of heart	Clinical Findin	Standard	0	61,867	Condition	SNOMED
		37312323	788533006	Congenital abnormality of atrium	Clinical Findin	Standard	0	60,822	Condition	SNOMED
Q23 - Congenital malformation (Q23.4 - Hypoplastic left heart s	440207	62067003	Hypoplastic left heart syndrome	Clinical Findin	Standard	60,597	60,597	Condition	SNOMED
Q20 - Congenital malformation (Q20.5 - Discordant ventriculoa	432431	204296002	Discordant ventriculoarterial connection	Clinical Findin	Standard	43,746	53,727	Condition	SNOMED
Q20 - Congenital malformation (Q20.1 - Double outlet right vent	313867	7484005	Double outlet right ventricle	Clinical Findir	Standard	49,823	49,823	Condition	SNOMED
Q22 - Congenital malformations	of pulmonary and tricuspid val	4184499	4374004	Congenital anomaly of tricuspid valve	Clinical Findir	Standard	14,304	48,927	Condition	SNOMED
Q25 - Congenital Malformation: 0	Q25.1 - Coarctation of aorta	321119	7305005	Coarctation of aorta	Clinical Findir	Standard	43,814	43,814	Condition	SNOMED
Q21 - Congenital Malformation: 0	Q21.2 - Atrioventricular septal o	4100152	253414002	Atrioventricular septal defect and common atrioventric	Clinical Findir	Standard	41,509	41,509	Condition	SNOMED
Q20 - Congenital malformation (Q20.4 - Double inleft ventricle	4102833	253281003	Double inlet ventricle	Clinical Findir	Standard	30,913	30,913	Condition	SNOMED

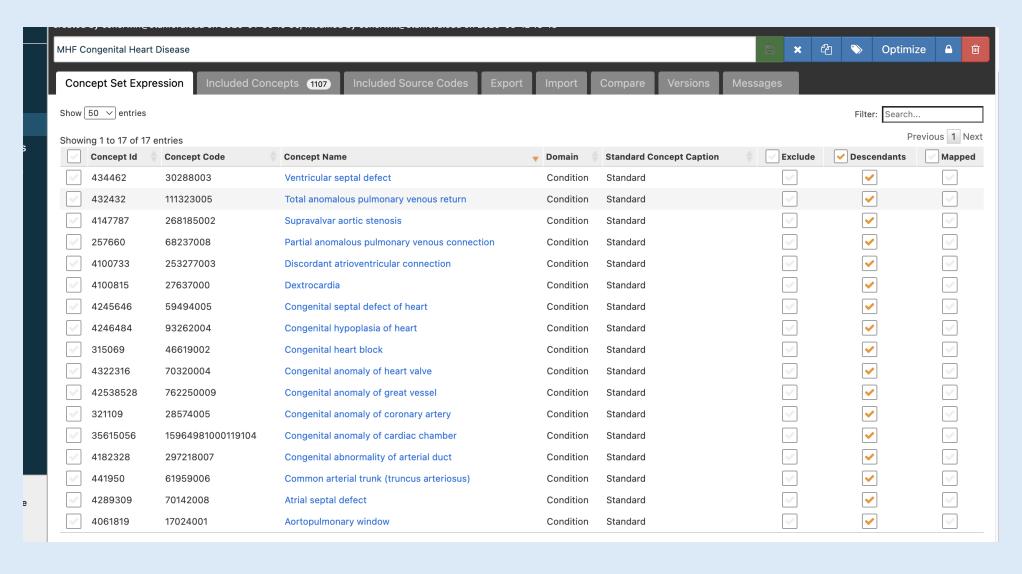








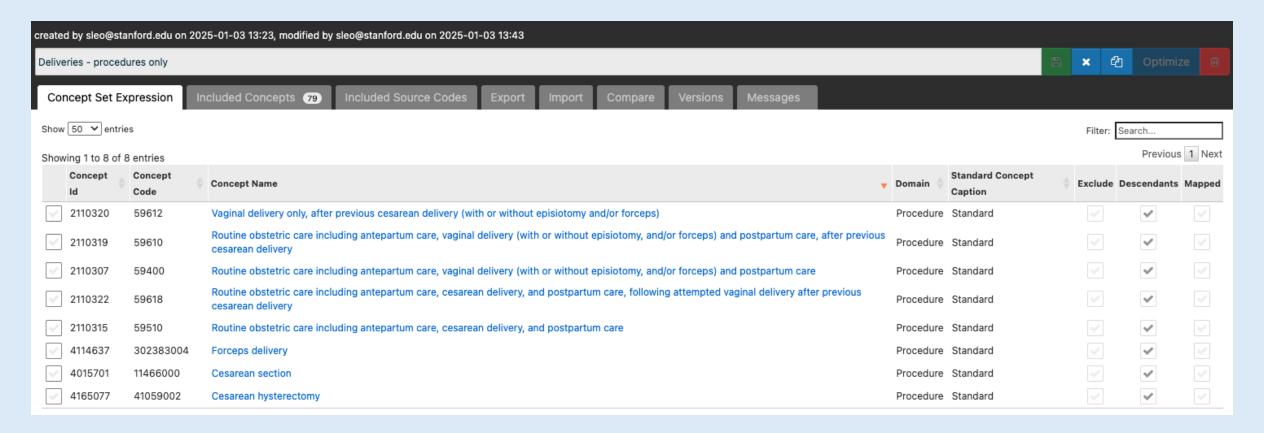






Creating a Concept Set for Deliveries in Atlas







Creating CHD Cohort Definition in Atlas



Cohort Entry Events			9
Events having any of the following crite	eria:	+ Ac	dd Initial Event 🕶
	es - procedures only 🔻	+ Add attribute →	Delete Criteria
× with age: Between			
	Add Import		
having all v of the following	g criteria:	+ Add criteria to group •	
with continuous observation of at least	60 ▼ days before and 0 ▼ days after event index date		
	per person.		
Restrict initial events			
Inclusion Criteria			9
New inclusion criteria	Congenital Heart Disease		Copy Delete
1. Congenital Heart Disease	enter an inclusion rule description		
	having any of the following criteria:	+ Add cr	iteria to group ▼
	with at least ✓ 1 ▼ using all occurrences of:		Delete Criteria
	a condition occurrence of MHF Congenital Heart Diseas	+ Add attribute →	
	where event starts between		
	All v days Before v and 0 v days After v index start date add additional constraint		
	The index date refers to the event from the Cohort Entry criteria.		
	allow events from outside observation period		





Cohort	Site A N deliveries	Site B N deliveries
Congenital Heart Disease	959	903
No Congenital Heart Disease	53,830	35,838





Demographics	Deliveries among	People with CHD	Deliveries among Pe	g People without CHD		
	SITE A	SITE B	SITE A	SITE B		
	N=959	N=903	N=53,830	N=35,838		
Race						
White	457 (47.65%)	546 (60.47%)	21,365 (39.69%)	16,769 (46.79%)		
Asian	238 (24.82%)	24 (2.66%)	18,528 (34.42%)	1,959 (5.47%)		
Black or African American	28 (2.92%)	221 (24.47%)	1,751 (3.25%)	10,305 (28.75%)		
Native Hawaiian or Other	16 (1.67%)	-	957 (1.78%)	-		
Pacific Islander or American						
Indian or Alaska Native						
Hispanic or Latino	275 (28.68%)	42 (4.65%)	11,184 (20.78%)	2,021 (5.64%)		
Age						
15-24	78 (8.13%)	82 (9.08%)	3,091 (5.74%)	4,061 (11.33%)		
25-29	157 (16.37%)	167 (18.49%)	8,163 (15.16%)	7,032 (19.62%)		
30-34	333 (34.72%)	299 (33.11%)	21,174 (39.33%)	12,903 (36.00%)		
35-39	279 (29.09%)	248 (27.46%)	16,701 (31.03%)	9,157 (25.55%)		
40-49	111 (11.57%)	107 (11.8%)	4,650 (8.64%)	2,647 (7.39%)		

Note: totals do not add up due to missing demographic data



Results



Congenital Heart Disease Condition	Number of Deliveries	Number of Deliveries
Congenitat Heart Disease Condition	(Percent of total with CHD, n=959)	(Percent of total with CHD, n=903)
	SITE A	SITE B
Ventricular septal defect	235 (24.50%)	244 (27.02%)
Atrial septal defect	159 (16.58%)	185 (20.49%)
Tetralogy of Fallot	122 (12.72%)	80 (8.86%)
Congenital insufficiency of aortic valve	71 (7.40%)	67 (7.42%)
Coarctation of aorta	66 (6.88%)	56 (6.20%)
Double outlet right ventricle	54 (5.63%)	47 (5.20%)
Discordant ventriculoarterial connection	46 (4.80%)	31 (3.43%)
Hypoplastic left heart syndrome	45 (4.69%)	26 (2.88%)
Persistent left superior vena cava	36 (3.75%)	18 (1.99%)
Congenital anomaly of aorta	35 (3.65%)	19 (2.10%)
Congenital anomaly of coronary artery	34 (3.54%)	15 (1.66%)
Congenital stenosis of aortic valve	33 (3.44%)	17 (1.88%)
Congenital stenosis of pulmonary valve	33 (3.44%)	29 (3.21%)
Congenital anomaly of pulmonary artery	23 (2.40%)	17 (1.88%)
Patent foramen ovale	21 (2.19%)	54 (5.98%)
Atrioventricular septal defect and common atrioventricular junction	19 (1.98%)	38 (4.21%)



Creating SMM Concept Set in Atlas



[PRH	eG] Severe ma	aternal morbidity						
Show	25 V entries					Filter:	Search	
Showi	ng 1 to 25 of 3	32 entries					Previous 1	2 Next
	Concept Id 🌲	Concept Code 🔷	Concept Name	Domain 🍦	Standard Concept Caption 🍦	Exclude	Descendants	Mapped
	437894	71908006	Ventricular fibrillation	Condition	Standard	~	✓	~
	4195473	43988005	Temporary tracheostomy	Procedure	Standard	~	✓	~
*	432923	21454007	Subarachnoid hemorrhage	Condition	Standard	~	~	~
*	198307	16217003	Shock due to anesthesia	Condition	Standard	~	✓	~
	201965	27942005	Shock	Condition	Standard	~	✓	~
*	196236	76571007	Septic shock	Condition	Standard	~	✓	~
*	132797	91302008	Sepsis	Condition	Standard	~	✓	~
	2788036	5A1935Z	Respiratory Ventilation, Less than 24 Consecutive Hours	Procedure	Standard	~	✓	~
~	440417	59282003	Pulmonary embolism	Condition	Standard	~	✓	~
*	4078925	19242006	Pulmonary edema	Condition	Standard	~	✓	~
*	4051932	233154000	Procedure for arrhythmia	Procedure	Standard	~	✓	~
~	4020879	213026003	Malignant hyperpyrexia due to anesthetic	Condition	Standard	~	✓	~
	4127886	236886002	Hysterectomy	Procedure	Standard		✓	~
~	26942	417425009	Hemoglobin SS disease with crisis	Condition	Standard	•	✓	~
~	2805869	5A	Extracorporeal or Systemic Assistance and Performance @ Physiological Systems (Procedure)	Procedure	Standard		✓	~
	443700	15938005	Eclampsia	Condition	Standard	~	✓	~
~	436093	67406007	Disseminated intravascular coagulation	Condition	Standard	~	~	~
~	441874	71444005	Cerebral thrombosis	Condition	Standard	~	~	~
*	443454	432504007	Cerebral infarction	Condition	Standard	~	~	~
~	376713	274100004	Cerebral hemorrhage	Condition	Standard	~	~	Y





		nong People CHD	Deliveries among Peop without CHD			
	SITE A N=959	SITE B N=903	SITE A N=53,830	SITE B N=35,838		
SMM within 6 months postpartum	62 (6.47%)	34 (3.77%)	948 (1.83%)	844 (2.36%)		







- Set up Analysis
 - Strategus pipeline
- Invite other sites to participate





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