

The Congenital Syphilis Morbidity & Mortality Review Toolkit

A PREVENTION TOOL FOR LOCAL HEALTH JURISDICTIONS

This toolkit is intended for use by local health jurisdictions to conduct in-depth multidisciplinary review of congenital syphilis cases to identify missed opportunities for prevention and potential upstream interventions to prevent future cases.

Contents

Contents	1
Background	2
Instructions	2
Resources	5
Appendices	6
Appendix I. CS M&M Review Face Sheet Template	6
Appendix II. CS M&M Review Notes Template1	2
Appendix III. Case Examples of Missed Opportunities Identified & Follow-up Actions Taken 1	3
Appendix IV. Sample Meeting Agenda1	4

Background

Congenital syphilis (CS), a preventable and potentially devastating disease, is increasing in California. From 2012 to 2019, female syphilis cases increased over 750% and CS cases increased over 1,200%, from 33 cases in 2012 to 446 cases in 2019. This is the highest number of reported CS cases since 1993. Local health jurisdictions (LHJ) should consider examining each CS case for missed opportunities and upstream interventions to prevent future cases. The California Department of Public Health (CDPH), Sexually Transmitted Diseases Control Branch (STDCB) has prepared this Congenital Syphilis Morbidity & Mortality (CS M&M) Review Toolkit to provide tools and strategies for local STD programs to conduct in-depth examination of CS cases, with consultation and technical assistance as needed from CDPH STDCB. The goal for conducting CS M&M Reviews is to review information outside of regular syphilis case reporting to identify patterns of missed opportunities among CS cases to inform structural changes in community provider practices and/or LHJ response that could prevent future cases.

Instructions

- Identify primary preparer of cases for discussion.
- Select cases. The goal is to review cases with missed opportunities for prevention.
 - Note: Consider prioritizing cases that meet the following criteria for review: syphilitic stillbirth, CS cases born to a Black/African American birthing parent, CS/perinatal HIV coinfected cases, and perinatal HIV cases regardless of CS coinfection.
- Identify case(s) for review. Review birthing parent/mother, infant, and partner/father records in the California Reportable Disease Information Exchange (CalREDIE). If either birthing parent or partner/father names additional partners, those incidents should also be reviewed.
- Compile information. Consider the following data sources: CalREDIE incident record, medical records, syphilis interview record, case investigation notes, and nursing case management notes, if applicable.
 - Note: if key data elements are not readily available in CalREDIE data fields, conduct a thorough review of available data in the electronic filing cabinet (EFC) within CalREDIE, such as medical records, supplemental questions for pregnant females with syphilis, and full investigative history.

- Input data on infant, birthing parent/mother, and partner/father into face sheet, as follows (see <u>Appendix I. CS M&M Review Face Sheet Template</u>):
 - Maternal information (section A in Appendix I. CS M&M Review Face Sheet Template), including demographics, stage of syphilis, risk factors, estimated date of delivery (EDD), gravidity (number of time a person is or has been pregnant)/parity (the number of times a person has carried the pregnancies to a viable gestational age) (G/P), prenatal care, syphilis testing/treatment, information from supplemental interview questions for pregnant females with syphilis, etc.
 - Maternal timeline (section B in Appendix I. CS M&M Review Face Sheet Template), which covers any documented health care encounter chronologically prior to or during pregnancy leading up to delivery. For each encounter, determine gestational age (GA), syphilis laboratory test results, syphilis signs/symptoms, syphilis treatment, HIV testing/treatment, chlamydia/gonorrhea testing/treatment, and other relevant information.
 - Infant information (section C in Appendix I. CS M&M Review Face Sheet Template), including newborn weight, vital status, other relevant diagnoses, and apgar scores (a test given to newborns that checks heart rate, muscle tone, and other signs that is usually administered at one minute and five minutes after birth and is scored between 0 and 10).
 - Infant timeline (section D in Appendix I. CS M&M Review Face Sheet Template), including syphilis laboratory test results at birth, clinical findings, treatment, HIV testing, etc.
 - Partner/Father information (section E in Appendix I. CS M&M Review Face Sheet Template), including demographics, stage of syphilis, syphilis treatment information, risk factors, etc.
 - Partner/Father timeline (section F in Appendix I. CS M&M Review Face Sheet Template), including any documented health care encounter chronologically prior to infant delivery. For each encounter, determine syphilis laboratory test results, syphilis signs/symptoms, syphilis treatment, HIV testing/treatment, chlamydia testing/treatment, and other relevant information.

- Relevant prenatal and postpartum disease investigation and enhanced case management notes (section G in Appendix I. CS M&M Review Face Sheet Template).
- Case discussion questions (section H in Appendix I. CS M&M Review Face Sheet Template) to stimulate brainstorming on missed opportunities, bright spots, and potential interventions to prevent future cases.
- HIV Testing/Treatment Information is included in Sections A, C, and E of Appendix I. CS M&M Review Face Sheet Template.
- Convene multidisciplinary group to examine case(s) for missed prevention opportunities and areas for follow-up. Group should include the primary preparer of the case(s) for discussion, disease intervention specialist (DIS), or other field investigator who worked the case, DIS supervisor, clinician, epidemiologist, and STD controller and/or additional LHJ leadership. LHJs are encouraged to include partners within their organization (e.g., Maternal, Child & Adolescent Health, Behavioral Health). LHJs may also want to consider including partners from outside their organization (e.g., community health care providers), which requires additional de-identification of cases presented to ensure anonymity. Representatives from CDPH STDCB are available to participate in these discussions, upon request. See Appendix IV. Sample Meeting Agenda.
- Capture missed opportunities for prevention, bright spots, and action items that were identified during the CS M&M review session (See <u>Appendix II. CS M&M Review Notes Template</u> and <u>Appendix III. Case Examples of Missed Opportunities Identified & Follow-up Actions Taken</u>).
- After the M&M session, finalize notes/action items and distribute to the attendees. Ensure follow-up on action items identified during reviews. It may be helpful to institutionalize checking on the status of action items from the last meeting at the start of each M&M review session.

Resources

- California Department of Public Health, Congenital Syphilis Webpage:
 (www.cdph.ca.gov/Programs/CID/DCDC/Pages/CongenitalSyphilis.aspx)
- Centers for Disease Control and Prevention's Syphilis 2018 Case Definitions:
 (ndc.services.cdc.gov/case-definitions/syphilis-2018/)
- Centers for Disease Control and Prevention's Congenital Syphilis Report Algorithm: (www.cdc.gov/std/program/Congenital-Syphilis-Form-2013.pdf)
- Centers for Disease Control and Prevention's MMWR Sexually Transmitted Infections
 Treatment Guidelines, 2021:

(www.cdc.gov/mmwr/volumes/70/rr/pdfs/rr7004a1-H.pdf)

For questions about the CS M&M Review Toolkit or for technical assistance with conducting CS M&M Reviews in your jurisdiction, please contact CDPH STDCB (<u>STDCB@cdph.ca.gov</u>).

Appendix I. CS M&M Review Face Sheet Template

Note: a customizable version of the <u>CS M&M Review Face Sheet Template</u> is available online.

Congenital Syphilis Morbidity & Mortality (CS M&M) Review Face Sheet Template [Enter Local Health Jurisdiction] | Review Date: [Enter Month DD, YYYY]

Acronyms: EDD: Estimated date of delivery; DOB: Date of birth; MOB = Mother of Baby; MSM = Men who have Sex with Men; EDD = Estimated date of delivery; PNC = Prenatal Care; ED = Emergency Department; UC = Urgent Care; WIC = [Special Supplemental Nutrition Program for] Women, Infants, and Children; SNAP = Supplemental Nutrition Assistance Program; RPR = Rapid Plasma Reagin; ART = antiretroviral therapy.

Abbreviations: Pos = Positive; Neg = Negative

Case [Enter Case Number] N Number]	laternal CalREDIE	ID: [Enter ID Number] I	nfant CalREDIE ID: [Enter ID			
A. Maternal Information						
1a. Age at delivery: Choose an 1b. Race/ethnicity: Choose an it 1c. Stage of syphilis: Choose an 1d. Insurance: Choose an item.	em.	2a. Gravida [X] Para [X] 2b. EDD: [MM/DD/YYYY] 2c. Infant DOB: [MM/DD/YYYY], [XwXd] GA				
3. Interview conducted: □Yes □	No If no rosson i		ated before delivery: □Yes □No 1			
Maternal risk factors within the second control of the second		merview nor conducted: [X	J			
☐ alcohol use		on drugs or intoxicated	☐ homelessness			
marijuana use	☐ had anonymo	-	☐ had a gang association			
methamphetamine use	•	person known to be MSM	given money/drugs for sex			
opioid use	maternal histor		☐ received money/drugs for sex			
other drug use; specify: [X]		bry of incarceration	other: [X]			
Li omer drug use, specify. [x]		•	Li olilei. [X]			
 □ partner history of incarceration 5. Supplemental Questions for Pregnant Females with Syphilis (CalREDIE Form): 5a. Which barriers to get prenatal care did the client report? [X] 5b. Which barriers to getting benzathine penicillin G (Bicillin L-A) treatment for syphilis did the client report? [X] 5c. Which health care services, other than prenatal care, did the client report accessing during pregnancy? [X] 5d. Which social/support services did the client report accessing during pregnancy? [X] 						
6a. Total partner(s) during preg		7a. Prenatal Care (PNC):				
6b . Initiable partner(s): [X] (com	plete partner	7b. Number of PNC visits				
table(s) below) 6c. Un-initiable partner(s): [X]; r	eason- [Y]	7c. Trimester of PNC initiation: Choose an item. 7d. First known PNC visit: [MM/DD/YYYY], [XwXd] GA				
8a. First syphilis test in pregnan			[MM/DD/TTT], [XWXG] GA			
8b. Tested for syphilis at/before	•					
8c. Result of first syphilis test in pregnancy: □Pos □Neg						
8d. If first syphilis test result positive, adequately treated: □Yes □No						
8e. If adequately treated after positive first syphilis test, reinfected during pregnancy: □Yes □No						
8f. If first syphilis test result neg						

9a. Tested for syphilis during third trimester (28-32 weeks): □Pos □Neg □No Test							
9b. If early third trimester test result positive, adequately treated: □Yes □No							
9c. If adequately treated after positive early third trimester test, reinfected during pregnancy: □Yes □No							
9d. If syphilis status unknown at delivery, tested at delivery: □Pos □Neg □No Test							
9e. If tested positive at delivery; adequately treated post-delivery: □Yes □No							
10a. Documented ED visit during pregnancy:	11a. Documented Urgent Care (UC) visit during pregnancy:						
□Yes □No	□Yes □No						
10b. Tested for syphilis at ED:	11b. Tested for syphilis at UC: □Pos □Neg □No Test						
□Pos □Neg □No Test	11c. If positive, empirically treated at UC: □Yes □No						
10c. If positive, empirically treated at ED:							
□Yes □No							
12a. Documented incarceration (e.g., jail) during p	- ·						
12b . Tested for syphilis during incarceration: □Po	s □Neg □No Test						
12c. If positive, confirmatory testing performed w	hile incarcerated: □Yes □No Test result: □Pos □Neg						
12d. If positive, treatment initiated in correctional	facility: Yes \square No \square Treatment completed in facility:						
□Yes □No							
13. Post-partum birth control plan: Choose an	14. Post-delivery RPR test: [MM/DD/YYYY]						
item.							
15. Chlamydia test during pregnancy: ☐Pos ☐Ne							
16. Gonorrhea test during pregnancy: □Pos □Ne							
17a. Documented HIV test during pregnancy: □Po	-						
17b. Date of first positive HIV test in pregnancy: [
17c. Trimester of first positive HIV test in pregnance	•						
18a. If negative during pregnancy, offered HIV P							
18b. If negative throughout pregnancy, tested 4-6							
19a. If positive during pregnancy, started on ART	· · · ·						
19b. If yes, viral load undetectable during third tr	<u> </u>						
20. Date of most recent HIV test: [MM/DD/YYYY]							
investigation or enhanced case management:	by health department staff <u>during</u> the course of disease						
Maternal, Child, & Adolescent Health (MCAH)	□Financial assistance/CalWORKS						
□Public Health Nursing/case mgmt. program	□Women, Infants, & Children Program (WIC)						
□Black Infant Health (BIH)	□CalFresh/Supplemental Nutrition Assistance Program						
□Adolescent Family Life Program (AFLP)	(SNAP)						
□Child Protective Services (CPS)	□HIV Care						
□California Children's Services (CCS)	☐Mental health services/treatment						
Social Work Services	□Domestic/interpersonal violence services						
□Housing	□Drug treatment/substance use disorder services						
□Transportation assistance □Syringe exchange/harm reduction services □Other; specify: [X]							

A. Maternal Timeline

Please include all healthcare encounters <u>chronologically</u> in the maternal timeline table that relate to this case, including preconception/interconception encounters – this may include healthcare encounters where syphilis testing or treatment were not conducted, syphilis lab results and treatment from prior surveillance incidents, and/or syphilis lab results and treatments after delivery. Please also include HIV testing results where available. Additional rows can be added to the table as needed for each healthcare encounter.

Date	GΔ	EIA	Non-trep results (i.e., RPR, VDRL)	Trep results (i.e., TPPA, FTA-ABS)	Syphilis diagnosis & clinician observed signs &/or symptoms	Syphilis treatment	HIV info (i.e., test results, HIV PrEP offered if negative, HIV viral loads, ART initiation date + ART regimen)	Chlamydia/ gonorrhea testing + treatment	Notes
Preconception/ interconception healthcare encounters									
LMP: [MM/DD/YYYY]									
1st Syphilis Test in Pregnancy: [MM/DD/YYYY]									
Delivery: [MM/DD/YYYY]									
Post Delivery RPR: [MM/DD/YYYY]									

B. Infant Information								
1a. Infant DOB: [MM/DD/YYYY], [XwXd] GA 2a. Apgar scores: [X/X]			() 3a. Justification for CS case classification		for CS case classification:			
1b. Stillbirth: □Yes □No		2b. Weight: [enter wei	ght] g	Choose an item.				
				3b. Other relevo	ant diagnoses: [X]			
If infant is born to HIV-positive bi	If infant is born to HIV-positive birthing parent:							
4a. Infant begun on ART regimen a	t delivery: □\	′es □No	5. Infant bottle-fed and MOB advised NOT to breastfeed:					
4b. List medications: [X]			□Yes □No					
6. HIV viral loads performed:								
At delivery: □Yes □No 14-21 days: □Yes □No			1-2 months: □Yes [□No	4-6 months: □Yes □No			
Viral load: [X]	Viral load: [X]	Viral load: [X]		Viral load: [X]			

C. Infant Timeline

Please include syphilis lab results and treatments during and after delivery until the RPR becomes non-reactive. Please also include HIV testing results where available; info sources include: LDET, LISA, LEDI, CalREDIE HIV incident "Adult Case Report Form".

† Please include red blood cell count when reporting on CSF protein and white blood cell count or VDRL to facilitate clinical interpretation.

[‡] Please include information relevant to the <u>Diagnosis of HIV Infection in Infants and Children</u> to the notes column if applicable.

Date	Non-treponemal results (i.e., RPR, VDRL)	Treponemal results (i.e., TPPA, FTA-ABS)	Syphilis treatment	Other clinical findings (e.g., physical exam, CSF VDRL, CSF protein/white blood cell count [†] , x-ray, etc.) [†]	HIV testing & treatment	Notes (Syphilis treatment and evaluation appropriate? Concern for HIV vertical transmission?) ‡
DOB: [MM/DD/YYYY]						,
POST DELIVERY RPR: [MM/DD/YYYY]						

D. Partner Information (delete or duplicate tables E-F as needed)						
1a. Partner CalREDIE ID:	2a. Interview conducted? □	Yes □No	3a. Adequately treated? □Yes □No			
[ENTER ID NUMBER]	2b. If no, reason interview n	ot conducted: [X]	3b. Treatment notes/reason treatment not completed:			
1b . Age: [X]			[X]			
1c. Race/Ethnicity: Choose an item.						
1d. Stage of syphilis:						
Choose an item.						
4. Risk factors within the last 12 month	S:					
alcohol use	☐ had anonymous sex part	ners	☐ homelessness			
□ marijuana use	☐ [females only] had sex w	rith person known to be	☐ had a gang association			
☐ methamphetamine use	MSM		☐ given money/drugs for sex			
☐ opioid use	☐ [males only] had sex with	any pregnant partners	☐ received money/drugs for sex			
another drug use; specify: X	☐ history of syphilis		☐ other: [X]			
☐ had sex while on drugs or	☐ history of incarceration					
intoxicated	partner history of incarceration					
5a. HIV test: □Pos □Neg □No Test		6a. If positive, connected	I to HIV care? □Yes □No			
5b. Date: [MM/DD/YYYY]; viral load: [X]		6b . If negative, offered HIV PrEP? □Yes □No				

E. Partner #1 Timeline

Please include all healthcare encounters in the partner table that relate to this case – this may include healthcare encounters where syphilis testing or treatment were not conducted or syphilis lab results and treatment from prior surveillance incidents. Please also include HIV testing results where available. Please add additional rows to the table as needed for each healthcare encounter.

Date	GΑ	EIA	Non-trep results (i.e., RPR, VDRL)	Trep results (i.e., TPPA, FTA-ABS)	Syphilis diagnosis & clinician observed signs &/or symptoms	Syphilis treatment	HIV info (i.e., test results, HIV PrEP offered if negative, HIV viral loads, ART initiation date and ART regimen	Chlamydia/ gonorrhea testing + treatment	Notes

F. Relevant Disease Investigation and Enhanced Case Management Notes

Relevant DIS Investigation Notes

[X]

Relevant Enhanced Case Management Notes (e.g., STD public health nurse or MCAH referral for prenatal or infant case management beyond standard DIS work)

[X]

G. Discussion

Bright Spots: clinical, disease investigation, other

Missed Opportunities: clinical, disease investigation, other

Action Items (assign to individual): on this case and/or to prevent a similar case from happening

Appendix II. CS M&M Review Notes Template

Note: a customizable version of the CS M&M Review Notes Template is available online.

CONGENITAL SYPHILIS MORBIDITY & MORTALITY (CS M&M) REVIEW NOTES TEMPLATE [LOCAL HEALTH JURISDICTION] | REVIEW DATE: [Month Day, Year]

Attendance:

- Local Health Jurisdiction: [ENTER TEXT]
- California Department of Public Health (CDPH): [ENTER TEXT]
- Other partners (e.g. Maternal, Child & Adolescent Health (MCAH), behavioral health, local hospital or prenatal care providers, etc.): [ENTER TEXT]

Case

Mother CalREDIE ID: [ENTER ID NUMBER] Baby CalREDIE ID: [ENTER ID NUMBER]

- Missed opportunities
 - [ENTER TEXT]
 - o [ENTER TEXT]
 - O [ENTER TEXT]
- Bright spots
 - O [ENTER TEXT]
 - O [ENTER TEXT]
 - [ENTER TEXT]

Case # Action Items:

- [ENTER TEXT]
- [ENTER TEXT]
- [ENTER TEXT]

Meeting Action Items:

- Draft & send out meeting notes with action items assigned
 Due: [ENTER DATE], Assigned to: [ENTER NAME]
- Schedule next CS M&M review

Due: [ENTER DATE], Assigned to: [ENTER NAME]

Note: this template covers one case, but it can be replicated to capture review of multiple CS cases.

Appendix III. Case Examples of Missed Opportunities Identified & Follow-up Actions Taken

- Disease Intervention Opportunity: Pregnant person with syphilis was lost to follow-up after positive RPR results returned; no treatment administered.
 - Follow-up action: Offer provider assistance with locating pregnant people with syphilis who are lost to follow-up and bringing them to treatment.
- Clinical Missed Opportunity: Prenatal provider misdiagnosed syphilis during prenatal care visit.
 - Follow-up action: Provide prenatal provider with training on syphilis diagnosis and treatment, and/or encourage and participate in a M&M with that provider or facility detailing the specifics related to this sentinel-event CS case to consider documented missed opportunities, medical errors, or policies that need to be changed to prevent future cases.
- Other Opportunity: Mother had contact with the local jail during pregnancy and no screening was conducted.
 - Follow-up action: Meet with jail to explore the feasibility of implementing syphilis screening.

Appendix IV. Sample Meeting Agenda

- 1. Welcome & introductions: names, role/title, organization
- 2. Action item check-in: review action items from previous review meeting and provide/request updates on progress and/or completion from attendees
- 3. **Case presentation***: walkthrough face sheet for each case; display for all participants to see, e.g., via screenshare
- 4. Case discussion*: missed opportunities, bright spots, and action items
- 5. Action item review*: list all action items identified and confirm assignees
- 6. Closing: Share date of next meeting

^{*} Repeat steps #3-5 for each case.