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Power of Data: Addressing Congenital Syphilis in DC

The Power of Data to Empower BIPOC Leadership and Drive Systemic Impact

Brittani Saafir-Callaway, PhD MPH| Senior Deputy Director
Center for Policy, Planning, and Evaluation
District of Columbia Department of Health

Agenda

- Background
- Local Epidemiology
- Local Response
- Next Steps

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Background

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Background

- Nationwide there has been a 10x increase in congenital syphilis between 2012 (n=335) and 2022 (n=3,761).
- Syphilis during pregnancy can cause miscarriage, stillbirth, or neonatal death
- Around 40% of the infants born to infected and untreated or undertreated mothers do not survive.
- Babies who survive can have life-long issues, including developmental delays, blindness or deafness unless treated within 3 months of birth.
- Of the 3,761 congenital syphilis cases in 2022, **<u>More than half</u>** were among people who tested positive for syphilis during pregnancy but did not receive adequate or timely treatment.

The Washington Post
Democracy Dies in Darkness

The tragic, preventable reasons syphilis is surging among U.S. infants

By Fenit Nirappil and Jenna Portnoy
Updated April 2, 2023 at 8:48 p.m. EDT | Published April 1, 2023 at 6:00 a.m. EDT

A decade ago, the United States stood on the brink of eliminating the scourge of babies born with syphilis. Now, cases are surging, a phenomenon that is underscoring deep inequities in the nation's health-care system and reviving concerns about a disease easily controlled with routine antibiotics.

HEALTH Health Disparities Add Topic

'Time to sound the alarm': Surge in babies born with syphilis draws attention to lack of care

Nada Hassanein
USA TODAY
Published 4:15 p.m. ET Feb. 13, 2023 | Updated 8:38 a.m. ET Feb. 15, 2023

A surge in babies born with congenital syphilis in Mississippi calls attention to rising cases throughout the nation, especially the South, experts say.

HEALTH

San Diego County public health officials alarmed by number of babies born with syphilis

A 3D illustration of a syphilis pathogen. (Getty Images)

County and pediatricians plan a deeper outreach to at-risk pregnant women. 'They are really a sentinel event.'

BY PAUL SISSON
MARCH 22, 2023 4:31 PM PT

Morbidity and Mortality Weekly Report

Vital Signs: Missed Opportunities for Preventing Congenital Syphilis — United States, 2022

Robert McDonald, MD[1]; Kevin O'Callaghan, MBBCh[1]; Elizabeth Torrone, PhD[1]; Lindley Barbee, MD[1]; Jeremy Grey, PhD[1]; David Jackson, MD[1]; Kate Woodworth, MD[2]; Emily Olsen, PhD[2]; Jennifer Ludovic, DrPH[1]; Nikki Mayes[1]; Sherry Chen, MPH[1]; Rachel Wingard[3]; Michelle Johnson Jones, MPH[1]; Fanta Drame, MPH[1]; Laura Bachmann, MD[1]; Raul Romaguera, DMD[1]; Leandro Mena, MD[1]

On November 7, 2023, this report was posted as an MMWR *Early Release on the* MMWR *website (https://www.cdc.gov/mmwr).*

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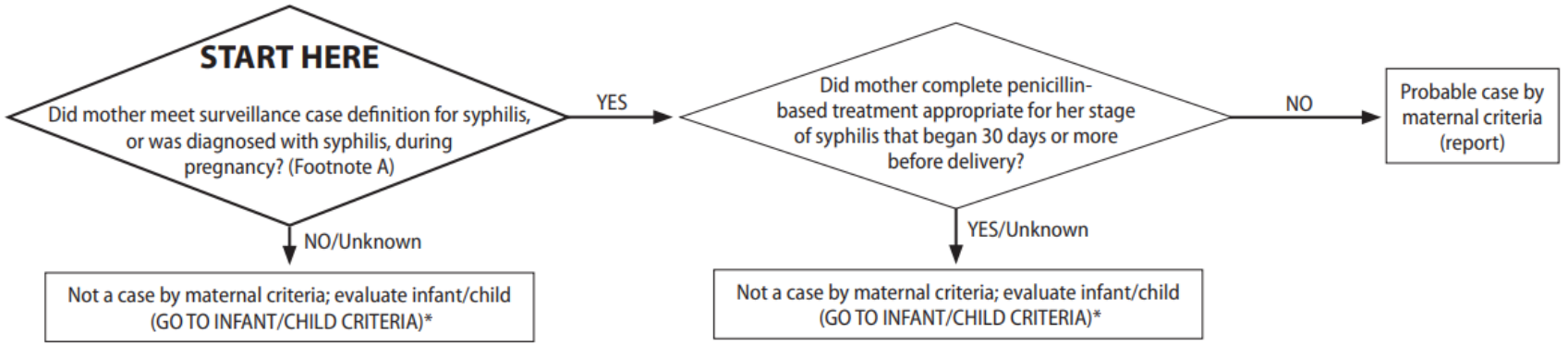
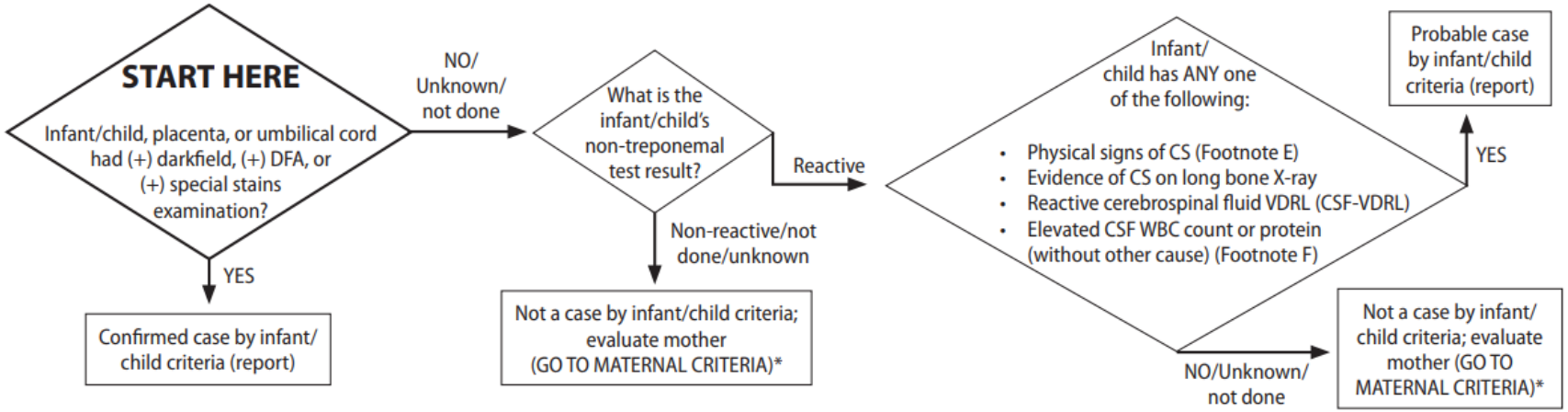
Surveillance Case Definition

CS Report Algorithm: a case meeting *any* criteria (maternal, infant/child, or stillbirth) should be reported

MATERNAL CRITERIA TO REPORT CONGENITAL SYPHILIS

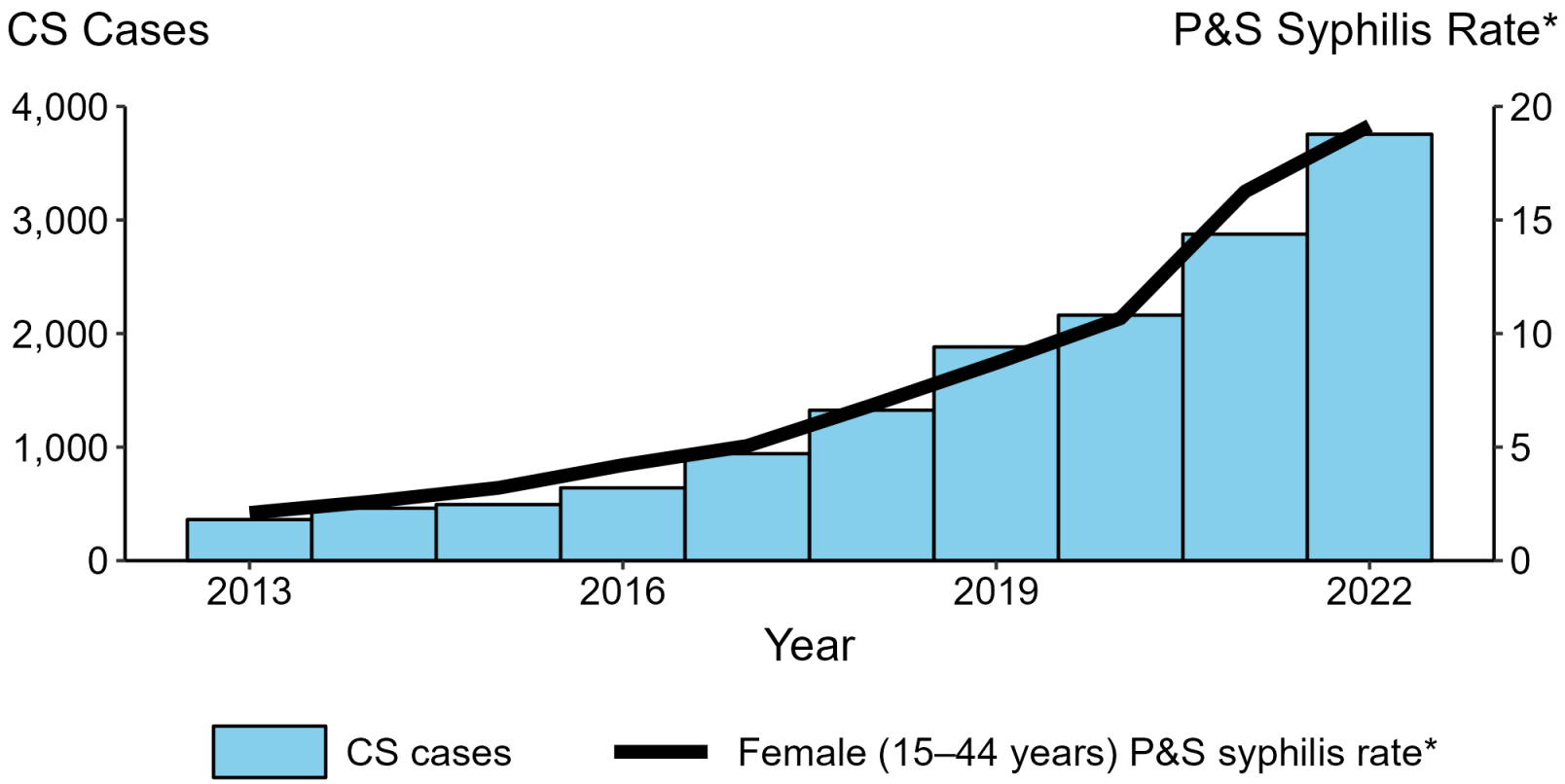


INFANT/CHILD CRITERIA TO REPORT CONGENITAL SYPHILIS



https://ndc.services.cdc.gov/case-definitions/syphilis-2018/

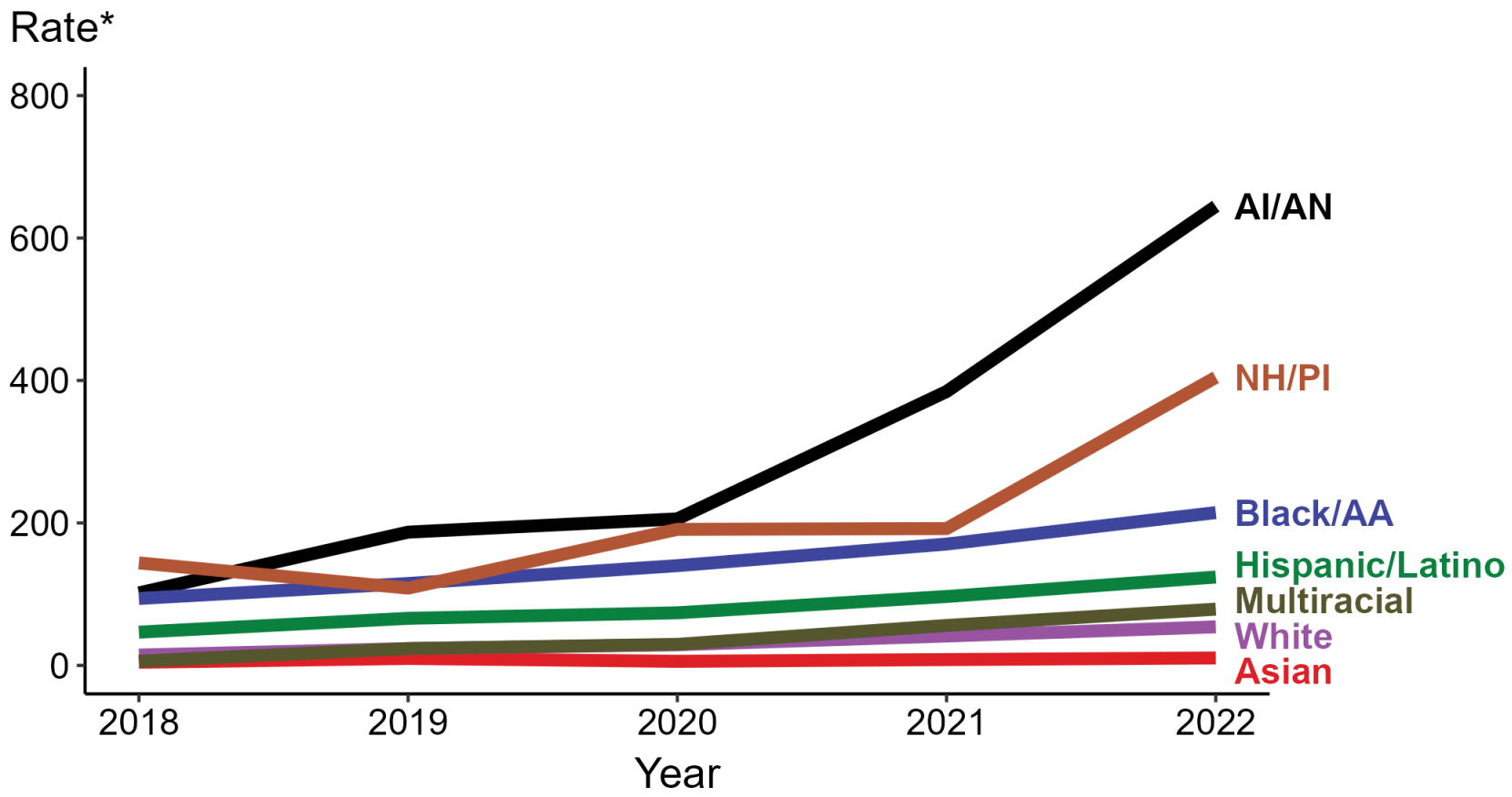
Congenital Syphilis — Reported Cases by Year of Birth and Rates of Reported Cases of Primary and Secondary Syphilis Among Women Aged 15–44 Years, United States, 2013–2022



* Per 100,000

ACRONYMS: CS = Congenital syphilis; P&S Syphilis = Primary and secondary syphilis

Congenital Syphilis — Rates of Reported Cases by Year of Birth, Race/Hispanic Ethnicity of Mother, United States, 2018–2022



* Per 100,000 live births

ACRONYMS: AI/AN = American Indian or Alaska Native; Black/AA = Black or African American; NH/PI = Native Hawaiian or other Pacific Islander

A rise in Syphilis Cases Regionally

Maryland
DEPARTMENT OF HEALTH

Larry Hogan, Governor · Boyd K. Rutherford, Lt. Governor · Robert R. Neall, Secretary

March 2, 2020

Dear Colleague:

The Maryland Department of Health (MDH) is providing you with the following alert in response to **ongoing significant increases in syphilis and congenital syphilis in Maryland** in 2018, the latest year for which data are final. Preliminary 2019 surveillance data indicate ongoing increases.

The ongoing syphilis outbreak in many parts of Maryland continues to disproportionately affect individuals who report exchanging sex for drugs and/or money, many of whom also report injection or other drug use. Of particular concern are increases among women of reproductive age, increasing the potential for **congenital syphilis** which can cause fetal or infant mortality, or devastating lifelong sequelae for infants.

A Commonwealth of Virginia Website
An official website Here's how you know

Find a Commonwealth Resource

VDH VIRGINIA DEPARTMENT OF HEALTH
To protect the health and promote the well-being of all people in Virginia

Virginia Department of Health > Blog > VDH > VDH Announces New Syphilis Webpage

VDH Announces New Syphilis Webpage

Posted on November 28, 2023

Today, the Virginia Department of Health (VDH) announces the unveiling of a new syphilis webpage, including a data dashboard tracking the number of reported syphilis cases, to help bring attention to the rising number of cases in Virginia.

Reported total early syphilis (TES) cases in Virginia increased 14% from 2018 to 2022. To date in 2023, syphilis case reports are 21% higher than for the equivalent period in 2022. Most TES cases are diagnosed among men (84% in 2022); however, cases among women are on the rise (70% increase from 2018-2022). Syphilis diagnoses among persons who misuse substances (such as opioids, methamphetamine, and cocaine) are also increasing. Cases of congenital syphilis, which occurs when a mother with syphilis passes the infection on to her baby during pregnancy, have similarly increased dramatically in the last decade. National data show comparable trends.

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MURIEL BOWSER, MAYOR

HIV/AIDS, STD, Hepatitis and TB Administration

HEALTH NOTICE FOR DISTRICT OF COLUMBIA HEALTHCARE PROVIDERS

Syphilis Testing During Pregnancy

Summary:
Rates of congenital syphilis have dramatically increased nationally over the last decade. There has been a marked increase in early syphilis diagnoses among women of reproductive age in the District of Columbia in 2019. Current DC Municipal Regulations[1] **require syphilis testing twice during pregnancy**: at the first prenatal visit **and** in the third trimester. DC Department of Health (DC Health) recommends also testing at delivery, especially for high-risk patients, those without a documented test, or those without known prenatal care. Given the increase in syphilis among women of childbearing age, DC Health recommends pregnancy testing for all women of reproductive age diagnosed with syphilis. Pregnant females should be linked to prenatal care.

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Syphilis — District of Columbia

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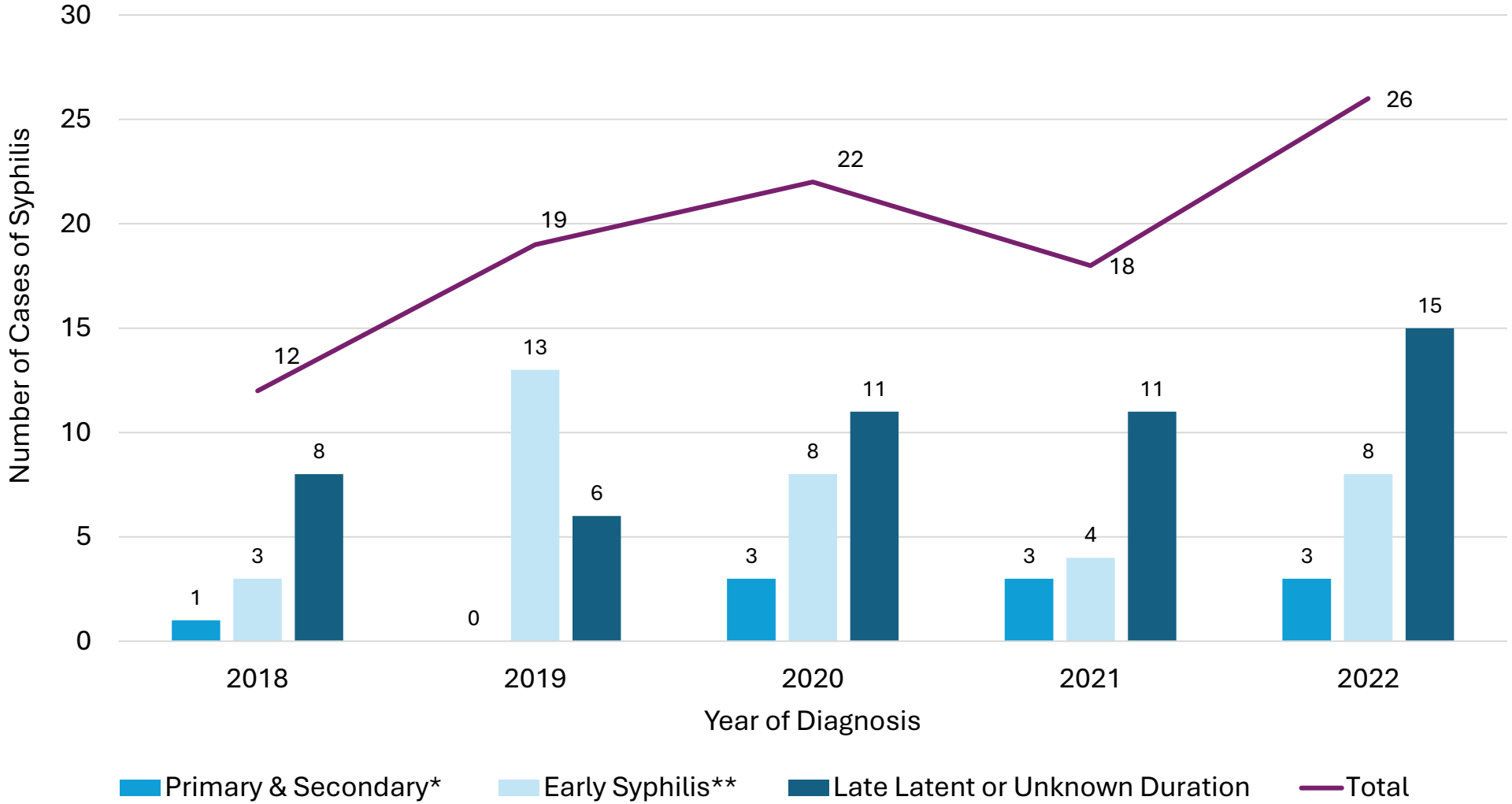
Stage at Syphilis Diagnosis Among Pregnant Persons District of Columbia, 2018-2022



*Primary and Secondary Syphilis Cases are combined due to the low frequency of primary syphilis.
** Early Syphilis refers to Early, Non-Primary, Non-Secondary Syphilis

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Characteristics of Pregnant Persons with Syphilis Reported in 2022

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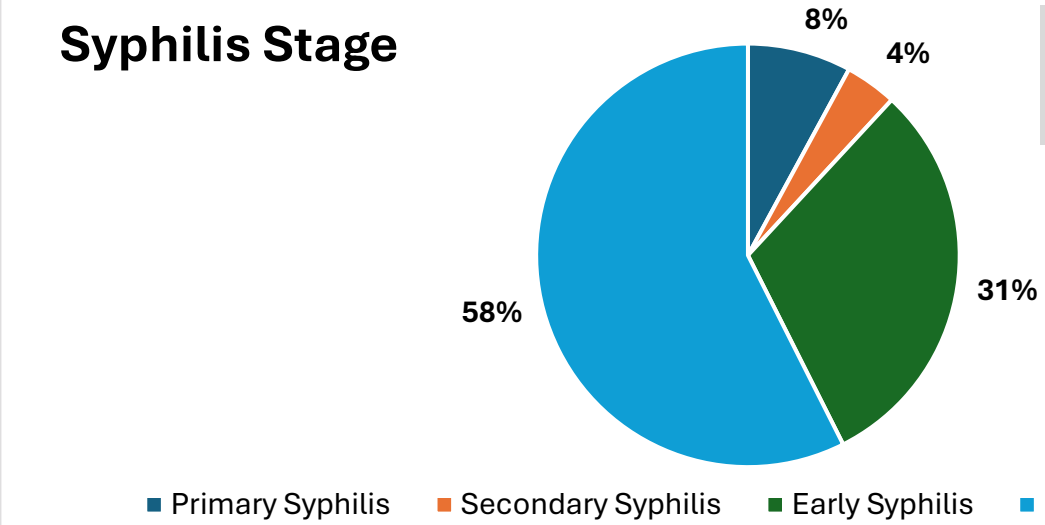
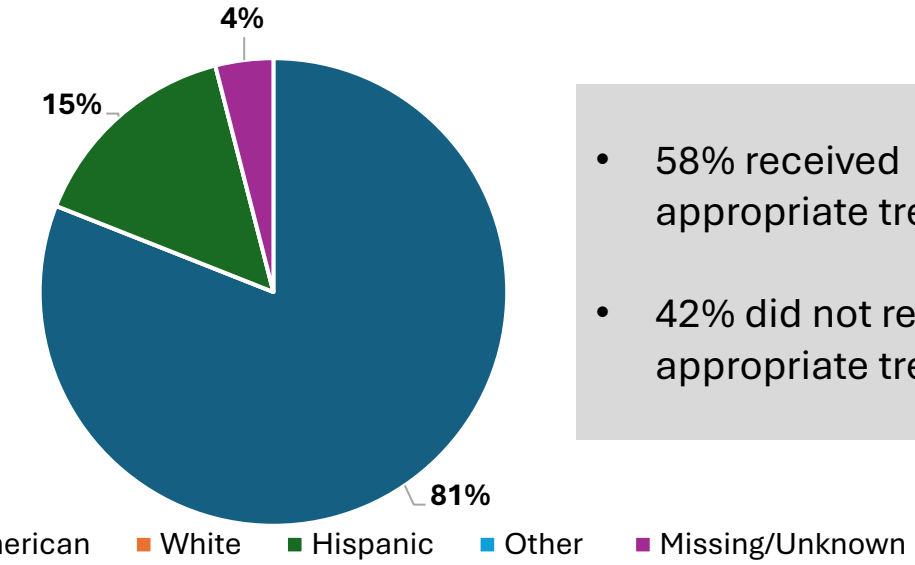
26 pregnant persons with syphilis were identified in 2022

Syphilis Stage



- 25 had a live birth in DC
- 1 relocated

Race/Ethnicity



- 58% received appropriate treatment
- 42% did not received appropriate treatment

Congenital Syphilis — District of Columbia

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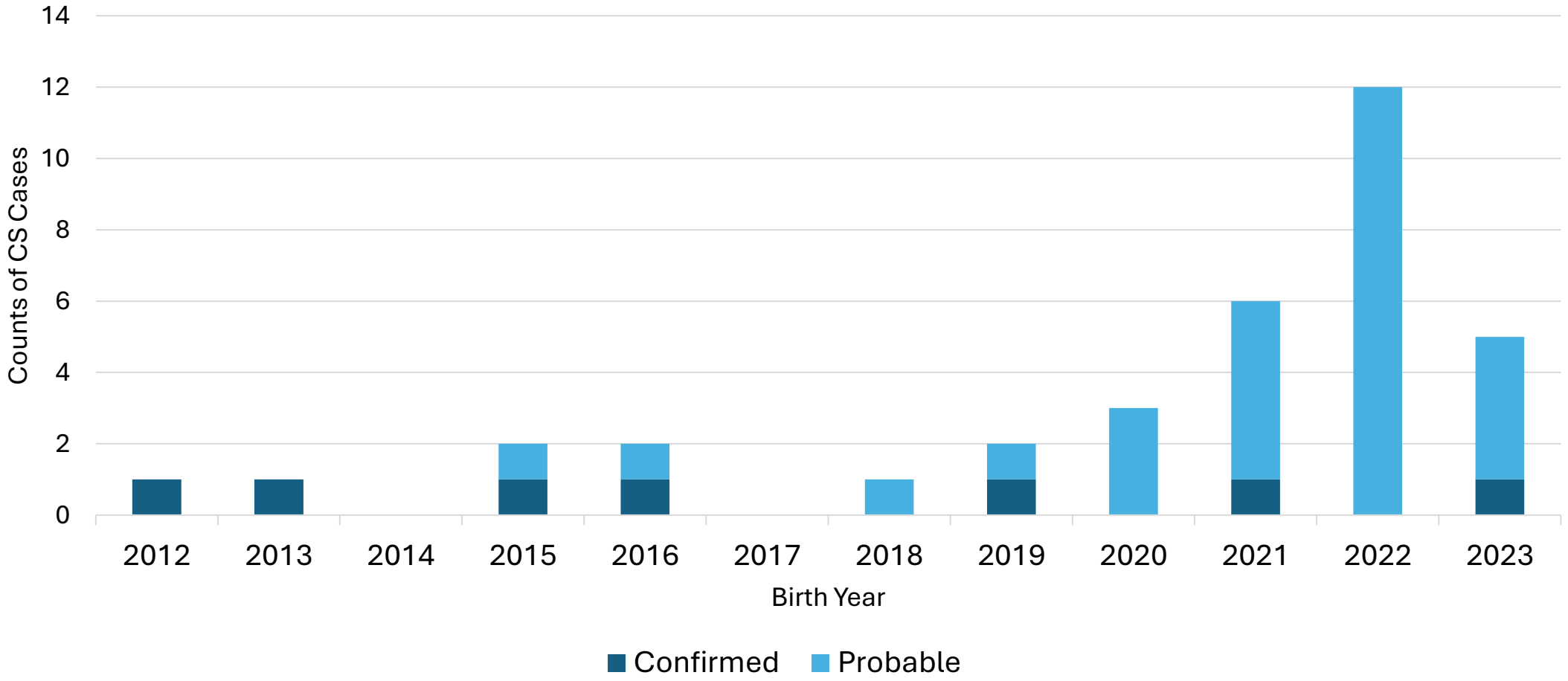
Congenital Syphilis (CS) cases by Year of Birth District of Columbia, 2012-2023



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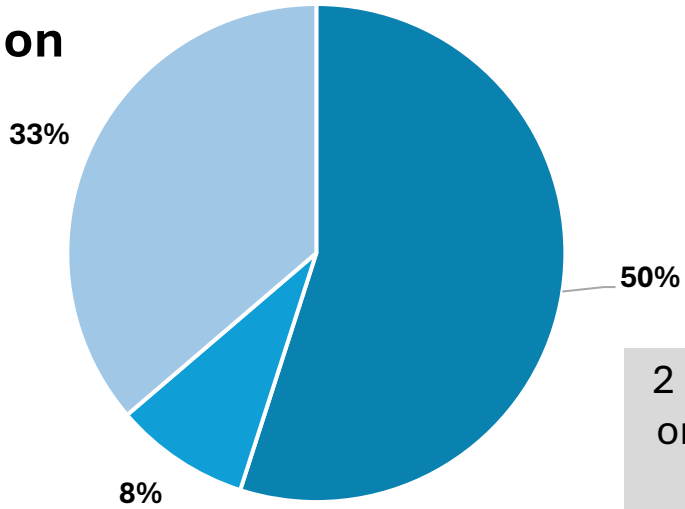
Characteristics of Congenital Syphilis Cases Reported in 2022

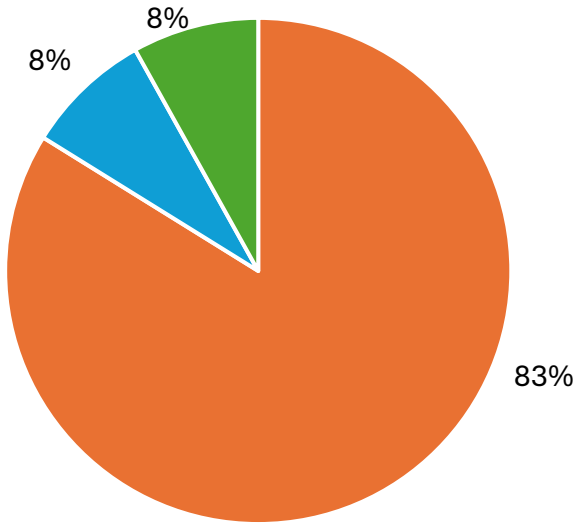
12 babies were born in 2022 with a diagnosis of Congenital Syphilis (CS)

Length of Gestation



2 had documented signs or symptoms consistent with CS

Birthing Person Race/Ethnicity



- Baby Median weight: 1945 grams
- Birthing Person Median Age: 28 years

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Local Response

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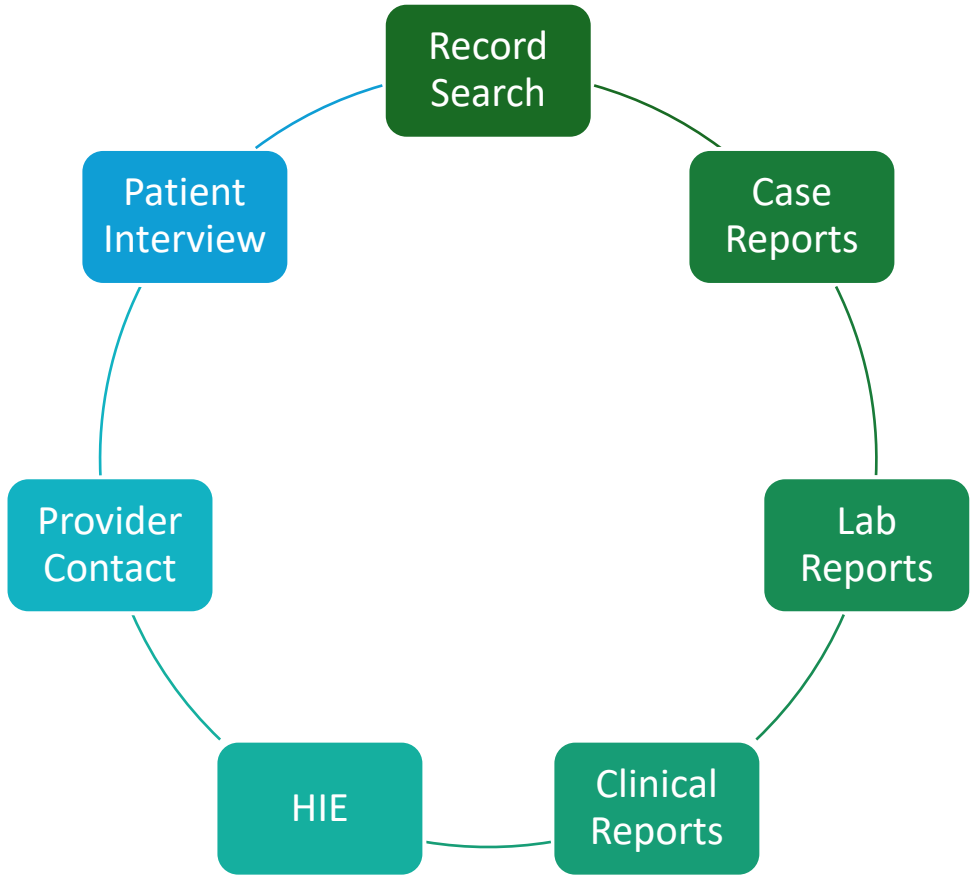
Identifying Gaps and Missed Opportunities

- Retrospective analysis to identify gaps and missed opportunities.
  - Uncovered significant data gaps in the surveillance documentation of testing and treatment for both mothers and babies.
  - Limited our ability to identify and address the maternal challenges leading to CS.
- **Action 1:** Procedural and systems enhancements to allow more accurate data collection
  - Developed internal training and accountability protocol
  - Updates to data system to improve collection
  - Dramatically improved our ability to accurately classify cases using the CDC criteria
  - Understand the demographic and social factors impacting these mothers
  - Findings- Maternal probable classifications due to either inadequate or untimely treatment.
- **Action 2:** Developed protocol to follow pregnant women diagnosed with syphilis at the initial reporting as well as 60 days prior to delivery
  - To ensure both the pregnant woman and their partners are tested and treated
  - Improved linkage to prenatal care.
- **Action 3:** Identify target providers and facilities to conduct presentations on CS in clinical grand rounds to provide education and raise awareness within the provider community.
  - Engaging providers with inadequate treatment
  - Engaging Emergency room/ urgent care facilities to establish connection to HWC

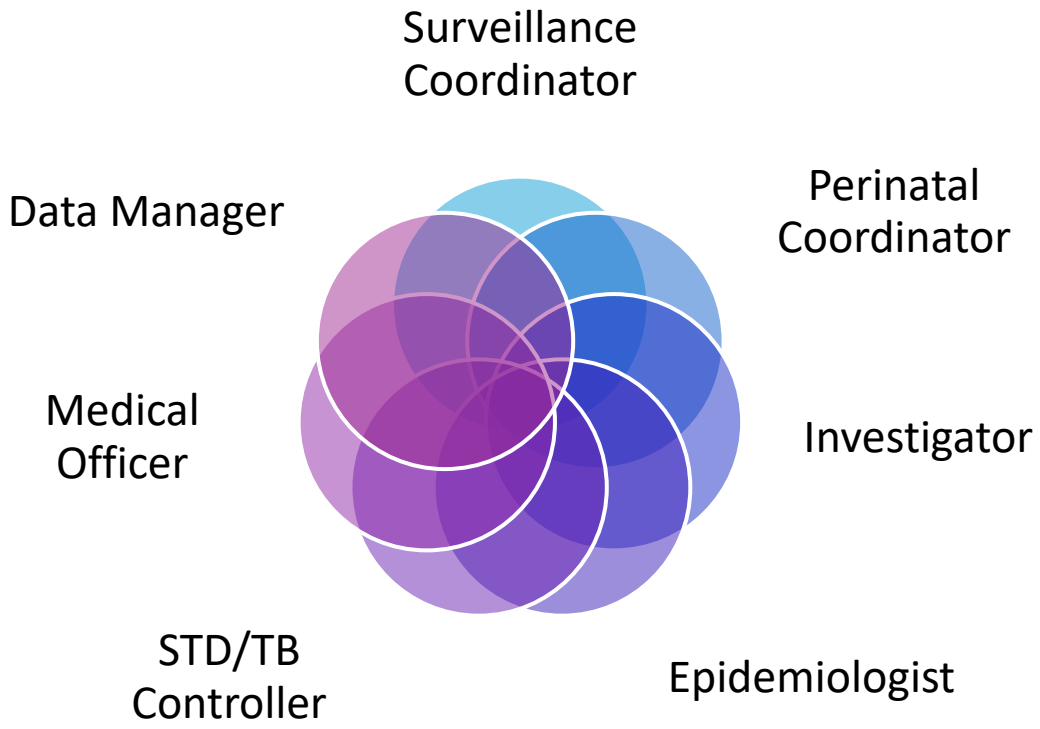
Expanding Data Collection Sources

- Leveraging multiple sources to complete information
- Increasing case completeness
- Understanding co-infections and syndemics
- Developing plans for individualized care
- Improving gap analysis
- Developing programmatic approaches



Pregnancy Review Committee

- Interdisciplinary Team
- Monthly case review for pregnancy and delivery
- Review of entire case
  - Pregnant Person
  - Partners
  - Baby
- Discussion of case classification
- Discussion of patient centric next steps
- Discuss of missed opportunities



Summary of Local Case Findings

Case 1: Pregnant person diagnosed with syphilis at delivery of congenital stillbirth. No evidence of prenatal care. Social barriers to care including substance abuse, homelessness, previous history of incarceration and transactional sex.

Case 2: Pregnant person with no history of prenatal care, diagnosed with syphilis one day prior to delivery. Baby was born preterm and diagnosed with probable congenital syphilis base on the infant criteria. Pregnant person had a history of syphilis and did not want to disclose due to stigma associated with belief of syphilis as a disease of men who have sex with men.

Case 3: Pregnant person delivered at preterm and was diagnosed with maternal and infant probable syphilis. The pregnant person is HIV co-infected, had history of polysubstance use, transactional sex and homelessness.

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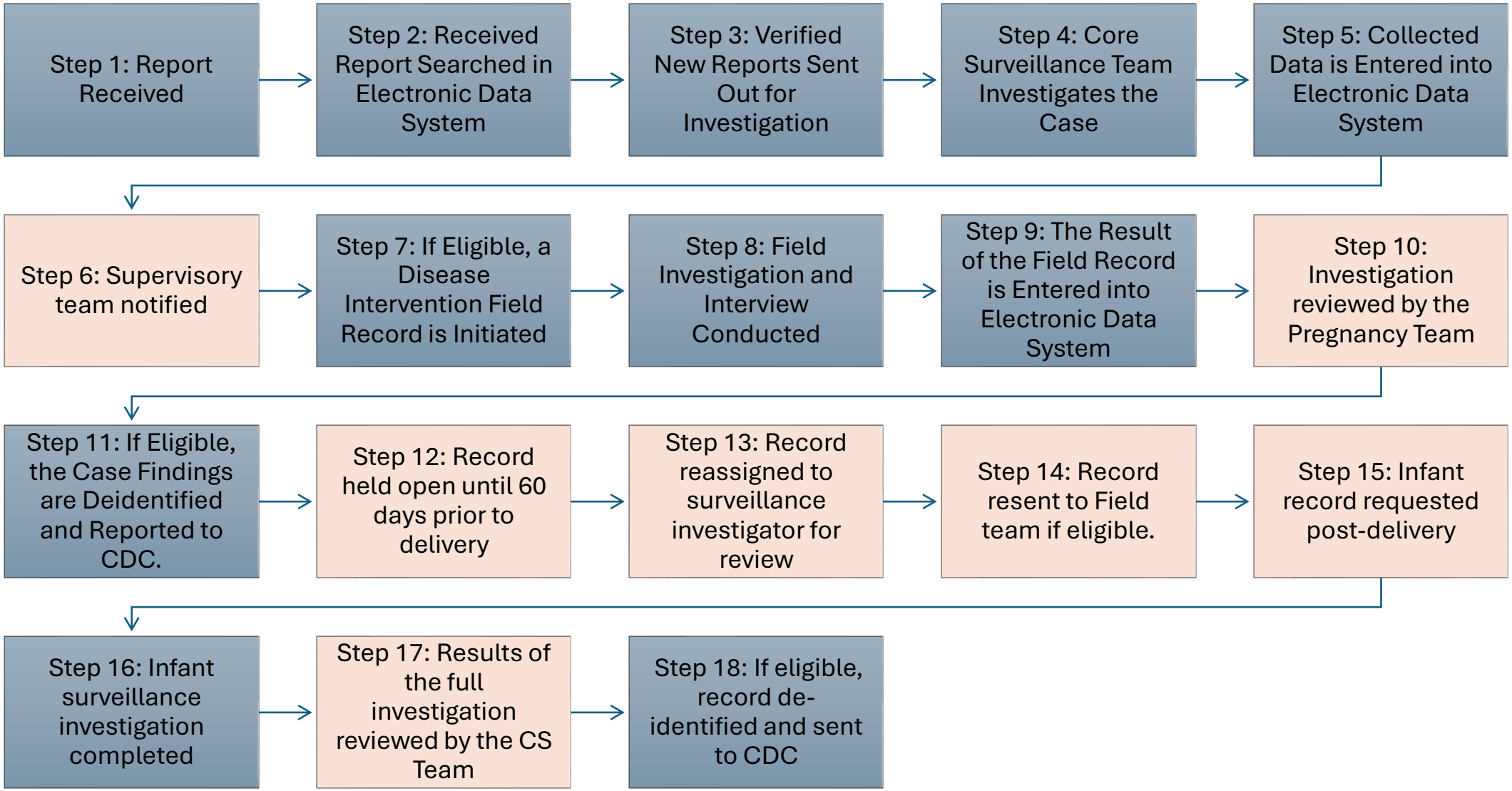
Surveillance Process



*Steps added to surveillance process to prevent CS cases

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Syphilis in Pregnant Persons Screening Recommendations

Overall Recommendations

- Screen ALL pregnant people when they first present for prenatal care (or at the time of delivery if no prenatal care).
- Rescreen if partner has been infected.
- Rescreen at 28 weeks and at delivery who live in communities with high syphilis incidence, high risk for new infection, no previously tested.

DC Municipal Regulations

- Requires screening minimum of TWO times
  - First Visit
  - Third Trimester
- Recommends testing at the time of delivery for high risk individuals or those without previous testing or prenatal care.

https://www.dcregs.dc.gov/Common/DCMR/SectionList.aspx?SectionNumber=22-B205

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Next Steps

Future Efforts

Successes

- Improved case classifications via data quality
- Improved coordination monthly pregnancy and CS coordination meetings
- Improved field services and linkage/treatment

Challenges

- Emergency room/ urgent care routine testing
- Human services- improve coordination and connection
  - substance use
  - mental health
  - unstable housing
- Medical/ governmental mistrust

- **Legislation:** mandatory testing at delivery to assist with capturing those not in pre-natal care
- **Regional Coordination:** monthly meetings with MD and VA to reduce jurisdictional barriers
- **Intergovernmental Coordination:** establishing and strengthening relationships with other agencies
- **Provider Outreach:** expanding our reach to include more providers, engaging midwives and doulas

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Reference

- CDC, Sexually Transmitted Infections Surveillance Report https://www.cdc.gov/std/statistics/2022/default.htm (retrieved Feb 1, 2024)

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https://www.cdc.gov/std/statistics/2022/default.htm

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899 North Capitol Street NE, 5th Fl, Washington, DC 20002

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