

Maternal and Early Congenital Syphilis in Ontario: 2020-2022

Findings from Retrospective Case Reviews



Surveillance Report
February 2024

Public Health Ontario

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Contents

Highlights.....	1
Introduction.....	3
Background.....	3
Maternal and Congenital Syphilis.....	3
Ontario Context.....	3
Public Health Reporting and Follow-up.....	3
Epidemiology of Infectious Syphilis.....	3
Epidemiology of Early Congenital Syphilis.....	4
Knowledge Gaps.....	6
Purpose and Scope.....	7
Methods.....	7
Findings.....	8
Early Congenital Syphilis Cases.....	9
Maternal Syphilis Cases.....	11
Syphilis Diagnosis and Treatment.....	11
Access to Prenatal Care and Screening.....	13
Access to Prenatal Care.....	13
Prenatal Syphilis Screening.....	14
Prenatal Screening for other STBBIs.....	15
Challenges Accessing Prenatal Care.....	16
Preventing Early Congenital Syphilis: Maternal Syphilis Care Access Cascade.....	17
Public Health Unit Experiences.....	18
Individual Level: Challenges.....	18
PHU/Health Systems Level: Challenges.....	18
PHU/Health Systems Level: Facilitators.....	19
Discussion.....	20
Early Congenital Syphilis.....	20
Access to Prenatal Syphilis Screening.....	20
Concurrent Conditions: STBBI Co-infections, Substance Use and Housing Instability.....	21
Access to Prenatal Care.....	22
Public Health Experiences.....	23

Limitations 24

Conclusion 24

References 25

Appendix A: Cumulative Number of Confirmed Cases of Early Congenital Syphilis 28

Technical Notes 30

 Data Sources 30

 Data Caveats 30

 Other Data Notes 31

Highlights

- Ontario has observed a substantial increase in the incidence of early congenital syphilis in the last four years. Between 2013 and 2018, a total of six cases of early congenital syphilis were reported provincially (i.e., an average of one case per year); however, from 2019 to 2022 a total of 41 cases were reported.
- A total of 36 cases of early congenital syphilis identified between January 1, 2020 and December 15, 2022, and their related maternal syphilis cases were included in the retrospective case reviews.
- Close to half (17/36; 47.2%) of early congenital syphilis cases presented with at least one clinical symptom. Almost two-thirds (22/36; 61.1%) of the early congenital syphilis cases experienced adverse outcomes related to their infection with the most commonly reported adverse event being born pre-term at <37 weeks gestation (13/36; 36.1%). Among those with a known duration of hospitalization (n=27), the average length of stay (LOS) was 20.9 days; those with an adverse outcome had a non-statistically significant longer LOS compared to those without an adverse outcome
- Nearly two-thirds (22/36; 61.1%) of maternal syphilis cases accessed any prenatal care, however, only 10/22 (45.4%) received care during their first trimester of pregnancy. A number of interdependent factors including unstable housing, substance use, transportation, communication challenges, and health systems issues were identified as barriers to accessing prenatal care and prenatal syphilis screening.
- Almost a third [11/36 (30.6%)] of maternal cases received syphilis screening at the time of delivery or in the post-partum period. Of the 24 maternal cases known to have been screened for syphilis during pregnancy, only 10/24 (41.7%) were screened in their first trimester, of which 7/10 (70.0%) were negative.
- Over half of the 36 associated maternal syphilis cases reported substance use (n=21, 58.3%) and/or being homeless/underhoused (n=19, 52.8%) as risk factors for acquiring syphilis during pregnancy.
- Co-infection with another sexually transmitted or bloodborne infection (STBBI) was identified in a number of maternal syphilis cases who were screened for other STBBIs at time of syphilis testing during pregnancy, including hepatitis C (5/17; 29.4%), chlamydia (6/23; 26.1%), and gonorrhea (3/23; 13.0%). None of the 24 maternal syphilis cases screened for human immunodeficiency virus were positive.

- Addressing the considerable increase in both maternal and early congenital syphilis cases in Ontario requires a multi-component approach including:
 - Updating provincial congenital syphilis surveillance case definitions to improve case detection for more accurate monitoring of epidemiological patterns in Ontario.
 - Improving access to prenatal syphilis screening early in pregnancy.
 - Designing approaches that enable equitable prenatal care access for those experiencing homelessness and who use substances.
 - Dedicating efforts to address the social determinants of health (e.g., housing) and supporting individual-level risk behaviours (e.g., substance use) among pregnant individuals to improve access and engagement in prenatal care.
 - Increasing public health resources to manage and support maternal syphilis cases.

Introduction

Background

Maternal and Congenital Syphilis

Syphilis is a sexually transmitted infection caused by the bacteria *Treponema pallidum*. Following exposure, the infection may progress through several clinical stages (i.e., primary, secondary, latent [early and late], and tertiary); however, it is only transmissible to others during the primary, secondary, and early latent stages.^{1,2} Maternal and congenital syphilis are significant public health problems. If a mother has syphilis of any stage (including late latent) during pregnancy, the bacteria can be transmitted to their fetus which can result in adverse fetal outcomes such as pre-term labour and stillbirth and/or severe infant outcomes secondary to congenital syphilis such as nerve damage, hearing loss and infant death.^{1,3,4} Early treatment of maternal syphilis infection is effective at treating fetal infection and preventing congenital syphilis, however, this requires access to adequate and timely maternal syphilis screening, diagnosis, and treatment.^{5,6}

Ontario Context

Public Health Reporting and Follow-up

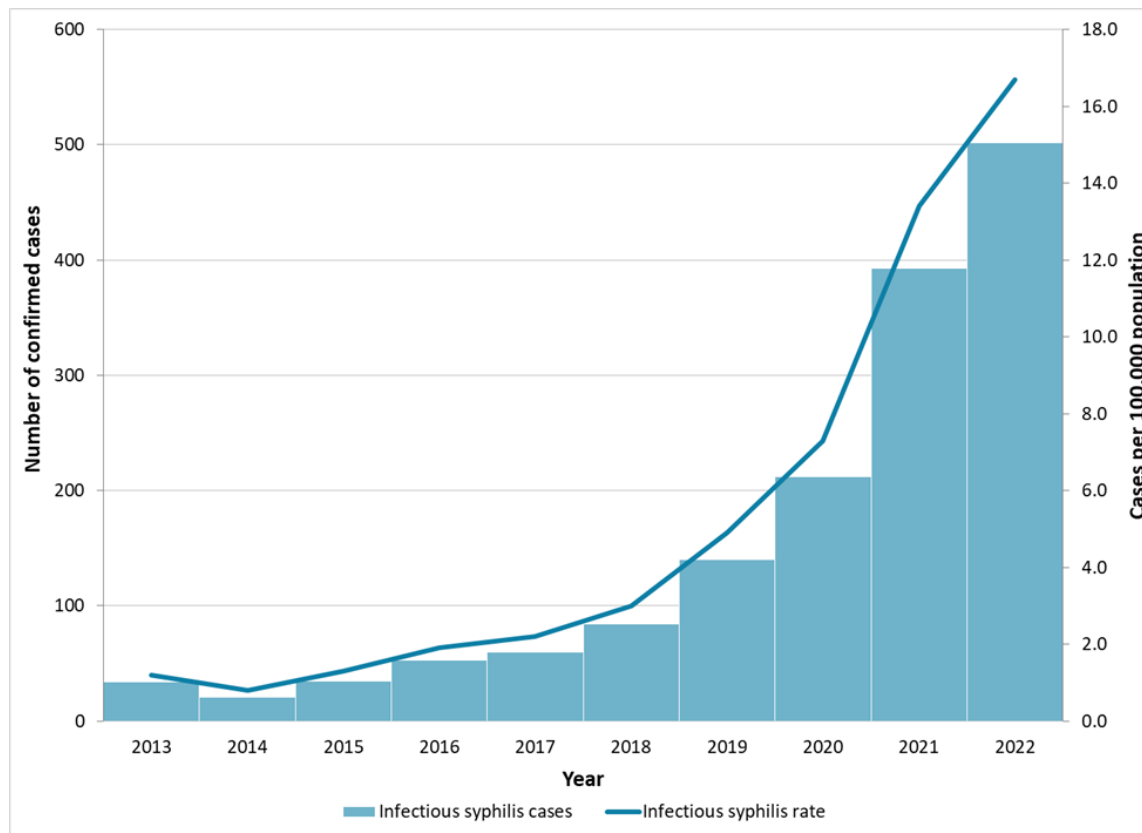
In Ontario, syphilis (including early congenital syphilis) is designated as a disease of public health significance under the *Health Protection and Promotion Act, R.S.O.1990*.⁷ As such, all confirmed cases meeting the [provincial case definition](#)⁴ must be reported to the public health unit (PHU) where the case resides.⁴ The PHU is responsible for completing appropriate public health follow-up in accordance with the [Infectious Diseases Protocol, 2023](#)⁸ and the [Sexual Health and Sexually Transmitted/Blood-Borne Infections Prevention and Control Protocol, 2019](#).⁹ Relevant case and contact details (e.g., demographics, symptoms, laboratory results) are also entered in the provincial public health surveillance database (the integrated Public Health Information System [iPHIS]).

Epidemiology of Infectious Syphilis

Over the last 10 years, Ontario has observed a continuous increase in the annual incidence of infectious syphilis. Between 2013 and 2022, the overall number of confirmed cases increased from 755 to 3,554 and the annual incidence rate increased by over 300% from 5.6 to 23.5 cases per 100,000 population.

Although the majority of cases reported during this period occurred in males, the proportion of infectious syphilis cases occurring in females increased considerably, from 5.7% (43/755) in 2013 to 16.3% (579/3,554) in 2022. Furthermore, the vast majority of infectious syphilis cases reported among females between 2013 and 2022 occurred among those of childbearing age (defined as those aged 15 to 44 years for the purposes of this report) and the annual incidence for this age group increased approximately 1,300%, from 1.2 to 16.7 cases per 100,000 population ([Figure 1](#)).

Figure 1. Number of confirmed cases of infectious syphilis and rate per 100,000 population for females aged 15-44 years: Ontario, 2013-2022



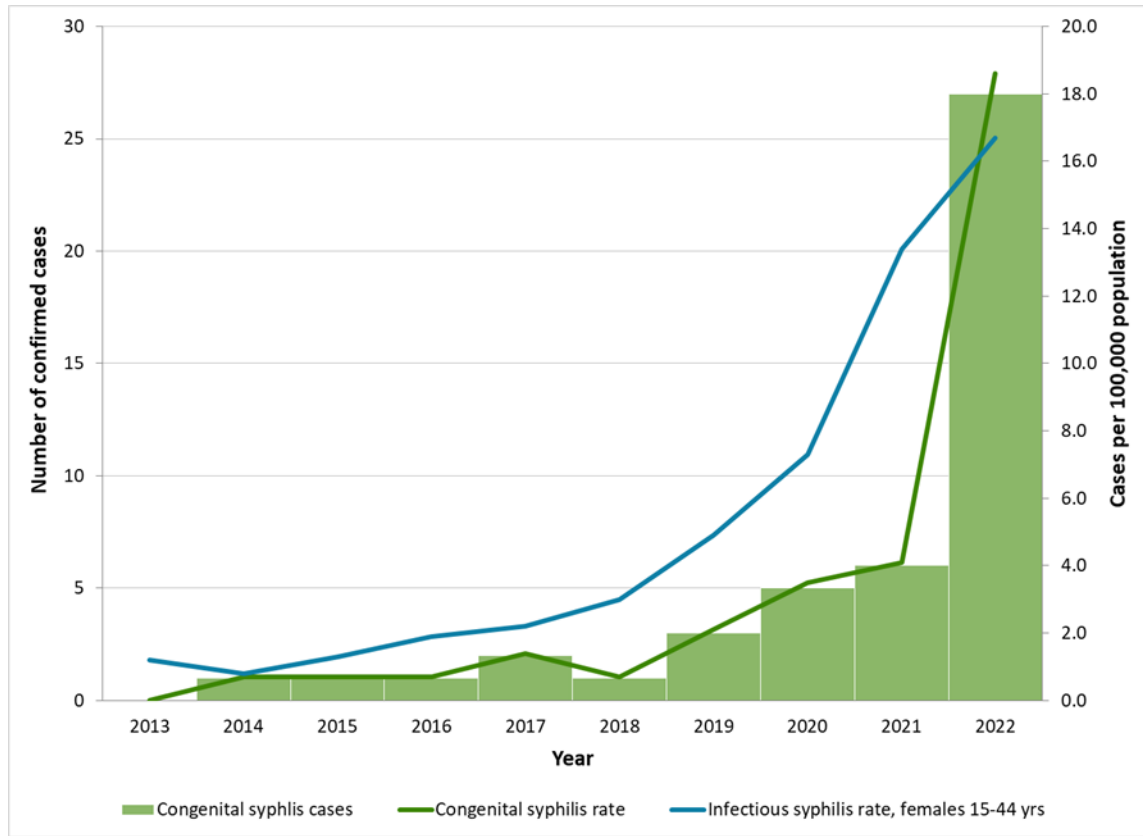
Data sources: Cases: Ontario. Ministry of Health. integrated Public Health Information System (iPHIS) [database]. Toronto, ON: King’s Printer for Ontario; 2023 [extracted 2023 Jul 31]. Population denominators for calculating rates: Statistics Canada. Population estimates 2001-2022. Ottawa, ON: Government of Canada; 2023 Mar 2 [extracted 2023 Mar 13].

Epidemiology of Early Congenital Syphilis

Since 2018, Ontario has observed a significant increase in the incidence of early congenital syphilis defined as laboratory confirmation of syphilis occurring within two years of birth.⁴ Between 2013 and 2018, a total of six cases of early congenital syphilis were reported provincially (i.e., an average of one case per year). From 2019 to 2022 there were 41 cases reported in Ontario (3 in 2019, 5 in 2020, 6 in 2021, and 27 in 2022).

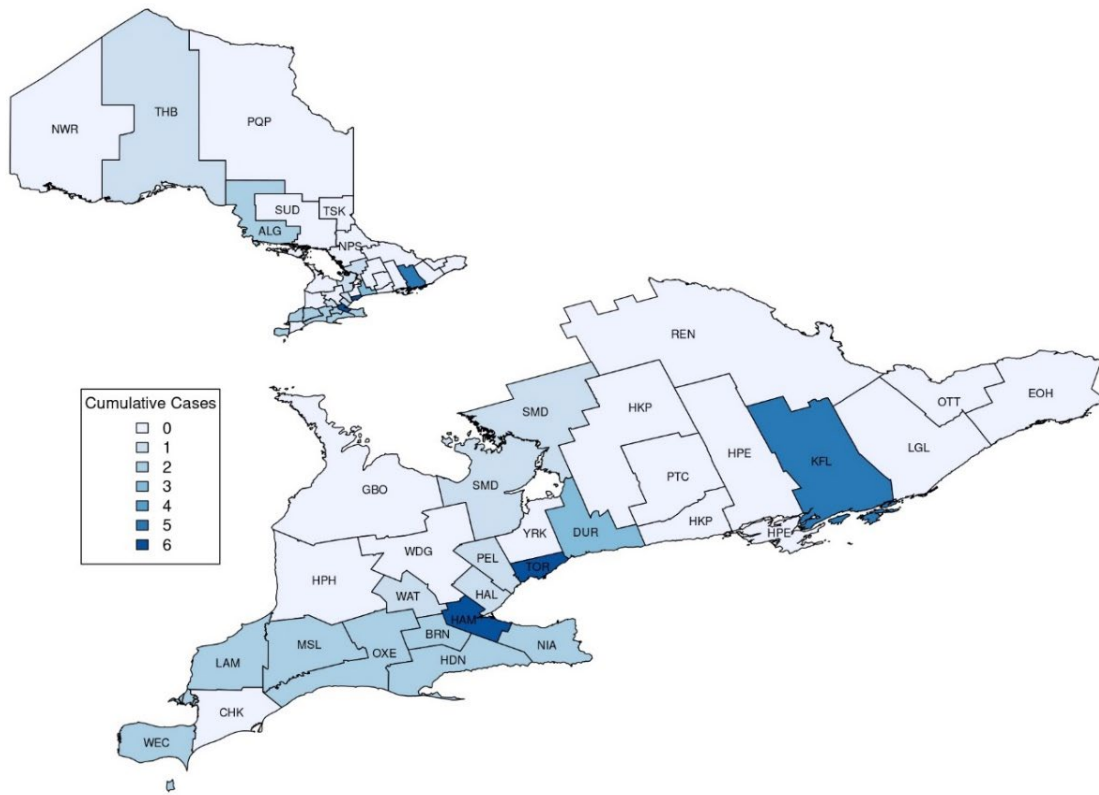
[Figure 2](#) illustrates the number and rate per 100,000 population of early congenital syphilis cases reported in Ontario between 2013 and 2022 along with the annual rate per 100,000 population of infectious syphilis among females 15-44 years of age. Of the 41 early congenital syphilis cases identified in Ontario between 2019-2022, 17 (41.5%) were reported by three public health units (PHUs): Toronto Public Health (6), City of Hamilton Public Health Services (6), and Kingston, Frontenac, Lennox & Addington Public Health (5). The remaining 24 cases were reported by 14 different PHUs ([Figure 3](#)).

Figure 2. Confirmed cases and rate per 100,000 population (≤ 2 years) of early congenital syphilis compared to the rate (per 100,000 population) of infectious syphilis among females 15-44 years of age: Ontario, 2013-2022



Data sources: Cases: Ontario. Ministry of Health. integrated Public Health Information System (iPHIS) [database]. Toronto, ON: King’s Printer for Ontario; 2023 [extracted 2023 Jul 31]. Population denominators for calculating rates: Statistics Canada. Population estimates 2001-2022. Ottawa, ON: Government of Canada; 2023 Mar 2 [extracted 2023 Mar 13].

Figure 3. Cumulative number of confirmed cases of early congenital syphilis by public health unit: Ontario, 2019-22



Data sources: Ontario. Ministry of Health. integrated Public Health Information System (iPHIS) [database]. Toronto, ON: King’s Printer for Ontario; 2023 [extracted 2023 Jul 31].

Note: The full name of each PHU that corresponds to their 3-letter abbreviation and map data can be found in [Appendix A](#).

Knowledge Gaps

To understand the factors contributing to the considerable increase in early congenital syphilis in Ontario, PHO conducted a preliminary analysis of case data captured in Ontario’s electronic public health surveillance system, iPHIS (integrated Public Health Information System). Significant gaps in the data for characterizing cases were identified, particularly for fields related to the clinical presentation and outcomes of early congenital cases, and the sociodemographic and risk factors for their maternal cases. These gaps could be attributed to differences in iPHIS data entry practices across the province, in addition to the lack of specific fields in iPHIS for entering relevant information if collected.

Due to these limitations in using iPHIS data alone to characterize emerging trends, and recognizing the depth and richness of information gathered by public health units (PHUs) during case management, PHO conducted a series of retrospective case reviews with all PHUs that reported early congenital syphilis cases between January 1, 2020 to December 15, 2022.

Purpose and Scope

The aim of this report is to provide a comprehensive description of early congenital and maternal syphilis cases in the province with the goal of enabling Ontario's Ministry of Health, PHUs and other key stakeholders to make evidence-informed decisions with respect to public health interventions, including policy and programming efforts to reduce the burden of maternal and congenital syphilis in Ontario.

The report presents the findings of the retrospective case reviews, describing the clinical characteristics of early congenital syphilis cases in Ontario from 2020-2022, as well as factors pertaining to their associated maternal syphilis cases (e.g., sociodemographics, risk factors, access to prenatal care and screening). In addition, potential barriers and/or facilitators PHUs experienced during the public health follow-up of these cases will be discussed.

Methods

Data on all infants entered in iPHIS as a confirmed case of early congenital syphilis⁴ with an 'Encounter Date' between January 1, 2020 and December 14, 2022 were extracted from iPHIS. Cases were anonymized (i.e., name and date of birth were not extracted) and only the case identification (ID) and the PHU where the infant resided at the time of diagnosis were included. An internal privacy impact assessment was conducted and approved prior to data collection.

PHUs that reported at least one case of early congenital syphilis during this time period were contacted by email to inform them of the retrospective case reviews and to invite staff involved in the management of these cases (e.g., public health nurses, managers, and associate/medical officers of health, as identified by the PHU) to participate in an interview. PHUs that consented were provided with a copy of the interview questions in advance, as well as the case IDs of the infant cases to be reviewed and from which they could also identify the maternal case in iPHIS.

Unrecorded interviews were conducted, via the online meeting platform Zoom, in January and February 2023. Two PHO staff members (one interviewer and one note-taker) conducted the interviews with PHU participants (e.g. public health nurses, managers) using a combination of open- and closed-ended questions. PHUs were asked to not disclose any potentially identifying personal health information during the discussion.

Information gathered during the interviews was reviewed and validated by both the interviewer and note-taker and entered into a pre-designed restricted access Microsoft Excel spreadsheet. A coding framework was developed by the project team to enable qualitative analyses of key themes that emerged during the interviews; any discrepancies in coding were resolved following a review of the interview notes by all members of the project team.

Findings

A total of 34 confirmed cases of early congenital syphilis with an episode date between January 1, 2020 and December 14, 2022 were extracted from iPHIS. Two of these cases were excluded from the case reviews as they resided in a federal jurisdiction (i.e., First Nations living on reserve). During the interview process, two PHUs identified a total of four additional cases of early congenital syphilis that had not previously been reported in iPHIS. Therefore, a total of 36 early congenital cases were included in the retrospective case reviews and interviews were completed with staff from the 14 PHUs where they were diagnosed and/or followed-up ([Table 1](#)).

Table 1. Public health units with early congenital syphilis cases included in the retrospective case reviews

PHU interviewed	Number (%) of early congenital syphilis included in retrospective case reviews
Algoma Public Health	2 (5.6)
City of Hamilton Public Health Services	5 (13.9)
Durham Region Health Department	4 (11.1)
Haldimand-Norfolk Health Unit	2 (5.6)
Halton Region Health Department	1 (2.8)
Kingston, Frontenac, Lennox & Addington Public Health	5 (13.9)
Middlesex-London Health Unit	2 (5.6)
Niagara Region Public Health	3 (8.3)
Peel Public Health	1 (2.8)
Southwestern Public Health	2 (5.6)
Thunder Bay District Health Unit	1 (2.8)
Toronto Public Health	4 (11.1)
Windsor-Essex County Health Unit	2 (5.6)
Wellington-Dufferin-Guelph Public Health	2 (5.6)
Total	36 (100.0)

Data source: Ontario. Ministry of Health. integrated Public Health Information System (iPHIS) [database] [extracted 2023 Jan 8]

Early Congenital Syphilis Cases

Of the 36 cases of early congenital syphilis cases included in the retrospective case reviews, close to half (17/36; 47.2%) presented with clinically apparent signs of infection (Table 2). Musculoskeletal abnormalities (including metatphysitis, periostitis, osteochondritis, periochondritis, dysplasia, and long-bone abnormalities [identified by x-ray]) and respiratory issues were the most commonly observed clinical signs of infection; however, the latter were likely associated with prematurity or neonatal abstinence syndrome. Close to half (16/36; 44.4%) of the early congenital syphilis cases did not present with any clinical signs of infection.

Almost two-thirds (22/36; 61.1%) of the early congenital syphilis cases experienced adverse outcomes related to their infection, including one infant that was stillborn. The most common adverse outcomes were pre-term birth (defined as <37 weeks gestation) (13/36, 36.1%), being small for gestational age (i.e., birth weight <10th percentile for gestational age) (7/36, 19.4%), and having a low birth weight (i.e., <,2500 gms) (5/36; 13.9%).

Excluding one infant that was stillborn, the duration of hospitalization was known for 27 of 35 (77.1%) early congenital syphilis cases. The average length of stay (LOS) was 20.9 days (range: 9 to 72 days). On average, cases that experienced adverse outcomes were hospitalized longer (23.3 days; 95% confidence interval [CI] 15.4 – 31.3 days) than those without adverse outcomes (16.8 days; 95% CI 12.3 – 21.3 days).

The majority (27/36; 75.0%) of early congenital syphilis cases had a sample of cerebrospinal fluid (CSF) collected via lumbar puncture for syphilis testing. Of those who had CSF testing performed, only 6/27 (22.2%) were reactive for syphilis; the remaining 21/27 (77.8%) infant cases had non-reactive, indeterminate, or unknown CSF results.

Table 2. Clinical characteristics of early congenital syphilis cases

Clinical characteristics	Number of early congenital syphilis cases	
	n	(%)
Presented with signs of infection		
Yes	17	(47.2)
No	16	(44.4)
Unknown	3	(8.3)
Observed signs (n=17)*		
Musculoskeletal abnormalities	9	(52.9)
Respiratory issues	9	(52.9)
Rash	6	(35.3)
Hematological abnormalities [†]	4	(23.5)
Neurological manifestations	3	(17.6)
Hepatomegaly/splenomegaly	3	(17.6)

Clinical characteristics	Number of early congenital syphilis cases
	n (%)
Ocular symptoms	2 (11.8)
Jaundice	1 (5.9)
Fever	1 (5.9)

Adverse outcomes*

Pre-term birth (<37 weeks gestation)	13 (36.1)
Small for gestational age	7 (19.4)
Low-birth weight	5 (13.9)
Neurological injury	1 (2.8)
Stillbirth	1 (2.8)
None	14 (38.9)

Hospital length of stay (n=35)[‡]

≤7 days	0 (0.0)
8 – 14 days	12 (34.3)
15 - 21 days	6 (17.1)
22 – 28 days	4 (11.4)
≥29 days	5 (14.3)
Unknown	8 (22.9)

CSF testing

Reactive	6 (16.7)
Non-reactive	7 (19.4)
Inconclusive	13 (36.1)
Result unknown	1 (2.8)
Not performed	9 (25.0)

Data source: Retrospective case reviews with PHU staff.

*responses may add up to more than total as options are not mutually exclusive

[†]includes thrombocytopenia, anemia, and coagulopathy

[‡]excludes one case that was stillborn

Maternal Syphilis Cases

Syphilis Diagnosis and Treatment

Over half (21/36; 58.3%) of the associated maternal syphilis cases included in the retrospective case reviews underwent syphilis screening as part of prenatal screening, either pre-delivery (11/21; 52.4%) or at the time of delivery (10/21; 47.6%) ([Table 3](#)). Most (19/36; 52.8%) maternal syphilis cases were diagnosed with infectious syphilis (i.e., primary, secondary, early latent, and infectious neurosyphilis), however, 7/36 (19.4%) cases were either unstaged or staged as ‘unspecified’ at the time of their diagnosis.

The majority (22/36; 61.1%) of maternal syphilis cases were diagnosed with syphilis during pregnancy, of which only 3/22 (13.6%) were diagnosed during the first trimester. The remaining 14/36 (38.9%) cases were diagnosed either at the time of delivery or after delivery (range: 1 to 120 days). Less than half (17/36; 47.2%) of maternal syphilis cases received appropriate treatment (see [Other Data Notes](#) for definition); of these, 13/17; 76.5% were treated >4 weeks prior to delivery.

Substance use and being homeless/underhoused were the most common risk factors for acquiring syphilis during pregnancy as identified by 21/36 (58.3%) and 19/36 (52.8%) of maternal cases, respectively ([Figure 4](#)). Other identified risk factors included having previously been infected with a sexually transmitted or bloodborne infection (STBBI) (18/36; 50.0%) and being co-infected with another STBBI, in addition to syphilis, during pregnancy (12/36; 33.3%).

Table 3. Clinical characteristics of maternal syphilis cases

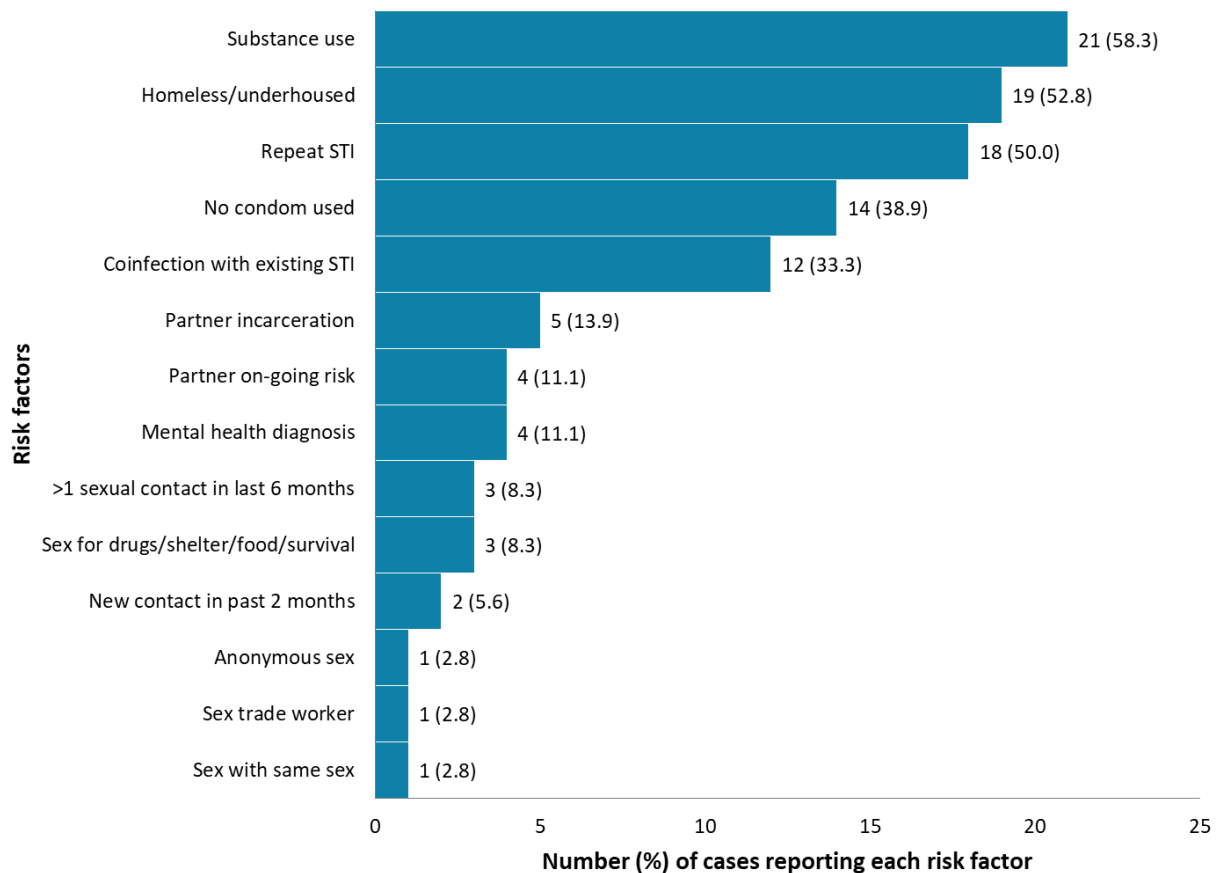
Clinical characteristics	Number of maternal syphilis cases n (%)
Reason for syphilis testing*	
Prenatal screening: pre-delivery	11 (30.6)
Prenatal screening: at time of delivery	10 (27.8)
Symptomatic	3 (8.3)
Contact of an infectious syphilis case	2 (5.6)
Infant diagnosed with early congenital syphilis	2 (5.6)
Unknown	9 (25.0)
Syphilis staging at time of diagnosis	
Primary	4 (11.1)
Secondary	8 (22.2)
Early latent	6 (16.7)
Infectious neurosyphilis	1 (2.8)
Late latent	9 (25.0)
Unspecified/unstaged [†]	7 (19.4)
Unknown	1 (2.8)
Timing of syphilis diagnosis	
First trimester	3 (8.3)
Second trimester	7 (19.4)
Third trimester	12 (33.3)
At time of delivery	11 (30.6)
After delivery	3 (8.3)
Received appropriate treatment	
Yes	17 (47.2)
No	19 (52.8)
Timing of treatment (n=17)	
Treatment completed >4 weeks prior to delivery	13 (76.5)
Treatment completed ≤4 weeks prior to delivery	4 (23.5)

Data source: Retrospective case reviews with PHU staff.

*responses may add up to more than 36 as more than one option could be selected

[†]Ontario syphilis cases may be classified as unspecified when not enough information is available to assign a case classification (e.g., unavailable records for cases previously treated outside of Ontario).

Figure 4. Risk factors for acquiring syphilis during pregnancy among maternal syphilis cases (n=36)



Data source: Retrospective case reviews with PHU staff.

Note: Risk factors are not mutually exclusive and cases may have had multiple risk factors identified.

Access to Prenatal Care and Screening

Access to Prenatal Care

Close to two-thirds (22/36; 61.1%) of maternal syphilis cases were known to have accessed prenatal care during their pregnancy with 10/22 (45.4%) receiving care during their first trimester (Table 4). Among those receiving prenatal care during pregnancy, 7/22 (31.8%) had 4 or more visits and 5/22 (22.7%) had fewer than 4 visits; it is unknown how many prenatal visits were had by the remaining 10/22 (45.4%) cases. For 10/36 (27.8%) maternal syphilis cases, no prenatal or pregnancy-related care was received prior to delivery. It is unknown whether the remaining 4/36 (11.1%) of maternal syphilis cases received prenatal care.

Table 4. Prenatal care access characteristics of maternal syphilis cases in Ontario, 2020-2022

Prenatal care	Number of maternal syphilis cases n (%)	
Accessed prenatal care during pregnancy		
	Yes	22 (58.3)
	No	10 (27.8)
	Unknown	4 (13.9)
Timing of first prenatal visit (n=22)		
	First trimester	10 (45.5)
	Second trimester	5 (22.7)
	Third trimester	3 (13.6)
	Unknown	4 (18.1)
Number of prenatal visits (n=22)		
	≥4 visits	7 (31.8)
	<4 visits	5 (22.7)
	Unknown	10 (45.5)

Data source: Retrospective case reviews with PHU staff.

Prenatal Syphilis Screening

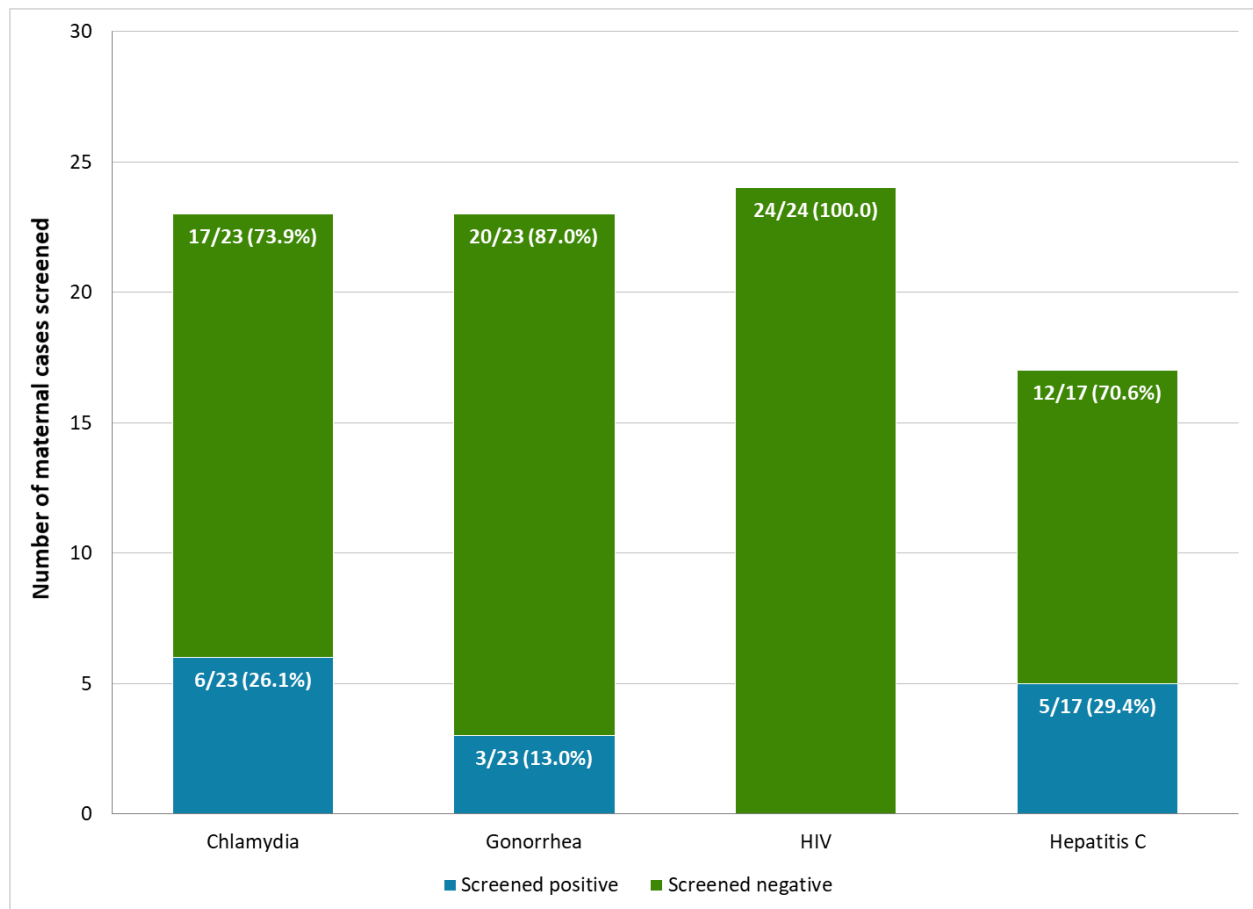
Two-thirds (24/36; 66.7%) of the maternal cases were screened for syphilis during pregnancy; including 20 of the 22 (90.9%) maternal cases who received prenatal care during their pregnancy and four of the 14 cases (28.6%) where no prenatal care was received or it was unknown if prenatal care was received. Almost one-third (11/36; 30.6%) of maternal cases received syphilis screening for the first time at the time of delivery or in the post-partum period. For one maternal case (1/36; 2.8%), it is unknown when their first screening test was completed.

Of the 24 maternal cases screened for syphilis during pregnancy, only 10/24 (41.7%) were screened in their first trimester and of these, three (30.0%) were positive. Of the remaining seven cases (70.0%) that screened negative in their first trimester, four screened positive later in pregnancy (e.g., after seeking additional testing in pregnancy due to symptoms, contact follow-up, or they were offered re-screening by a health care provider) and three screened positive after delivery either due to their infant's clinical presentation (i.e., suggestive of early congenital syphilis) or because they were identified as a contact of a syphilis case.

Prenatal Screening for other STBBIs

Details on prenatal screening for other STBBIs was not available for all 36 maternal syphilis cases included in the case reviews. Of 23 (63.9%) maternal cases known to have been screened for chlamydia and gonorrhea, 6/23 (26.1%) and 3/23 (13.0%) tested positive, respectively (Figure 5). None (0/24; 0.0%) of those screened for human immunodeficiency virus (HIV) tested positive. More than one-quarter (5/17; 29.4%) of those screened for hepatitis C (HCV) tested positive.

Figure 5: Number and percentage of maternal syphilis cases screened for chlamydia, gonorrhea, HIV, and hepatitis C during pregnancy



Data source: Retrospective case reviews with PHU staff.

Challenges Accessing Prenatal Care

To assess challenges in accessing prenatal care, PHO interviewers posed a variety of open-ended questions to PHU staff about the maternal syphilis cases they had reported. Overall, the challenges accessing prenatal care were inherently interdependent and overlapped with many of the maternal risk factors for infection reported. The most frequently reported factors PHU staff believed to impact prenatal care engagement were substance use and unstable and/or inadequate housing. While interviewees did not elaborate further on how substance use contributed to difficulties accessing prenatal care, challenges associated with unstable or inadequate housing included health care providers having difficulties reaching the client for scheduling appointments or follow-up care (e.g., phone number out of service, unable to reach at address provided) and loss of health card for demonstrating eligibility for provincially funded health services.

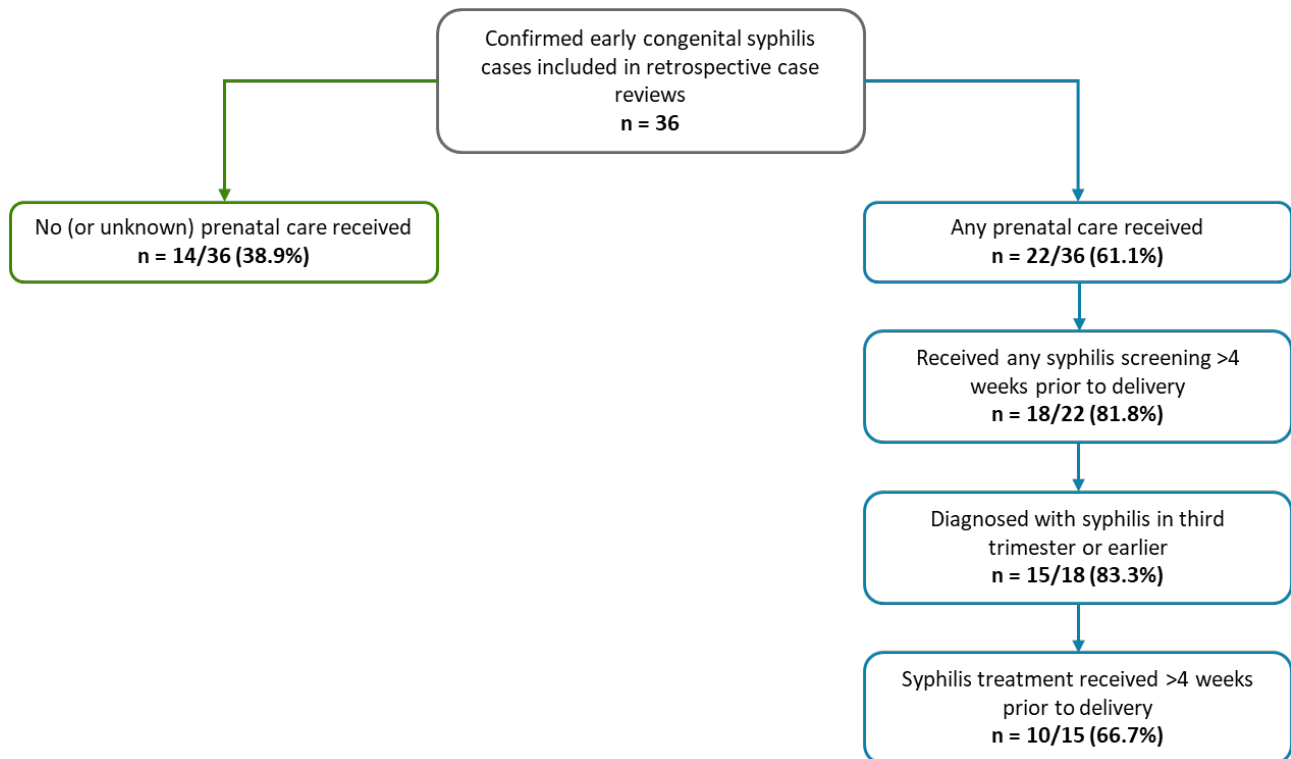
Additional themes identified by PHU staff included:

- **Transportation challenges:** This was shared as an issue in some non-rural settings (e.g., low income and challenges affording public transit to get to care); along with rural settings where transportation and distance to a clinic were identified as barriers to prenatal care. This can be a significant burden in terms of time needed to travel, cost and lost time from work.
- **Pregnancy awareness:** It was thought that some maternal cases may not have sought prenatal care due to either being unaware of their pregnancy or because they had planned to terminate the pregnancy
- **Health systems issues:** Some cases may have experienced challenges in accessing prenatal care due to a lack of primary care provider and disruption of care when moving between jurisdictions during pregnancy. Limited availability of both primary care providers and specialists in rural communities may have also served to restrict access to care.

Preventing Early Congenital Syphilis: Maternal Syphilis Care Access Cascade

Based on the 36 maternal syphilis cases included in the retrospective case reviews, a care access cascade was created (Figure 6) to illustrate when and how maternal syphilis cases were identified and treated to highlight the missed opportunities in the prevention of early congenital syphilis.

Figure 6: Maternal syphilis care access cascade



Of the 36 maternal syphilis cases, 14 (38.9%) either did not receive, or it is unknown if they received, any prenatal care. Of the 22/36 (61.1%) maternal syphilis cases that were known to have received any prenatal care, the majority (18/22, 81.8%) were offered syphilis screening at least 4 weeks prior to delivery and of these, 15/18 (83.3%) were subsequently diagnosed with syphilis in the third trimester or earlier. Two-thirds (10/15; 66.7%) of those diagnosed in the third trimester or earlier completed adequate treatment more than 4 weeks before their delivery.

Public Health Unit Experiences

During the interviews, PHUs were asked to describe any challenges and/or facilitators they experienced in managing their maternal and early congenital syphilis cases, particularly with respect to initiating and conducting case management and public health follow-up. These factors are grouped below into individual level (i.e., with regards to the client-PHU interaction) or PHU/health systems level factors.

Individual Level: Challenges

- **Unable to reach client:** This was the main challenge that PHUs identified. PHUs shared examples of when they made numerous unsuccessful attempts to reach clients, including situations where home visits were conducted, phone numbers were out of service, or no fixed address was provided.
- **Client engagement:** Some PHUs reported instances where the client received follow-up instructions but they were not completed. Examples include not attending booked appointments, including for specimen collection for repeat serology. The prenatal care access challenges described earlier in this report are also applicable, contributing adversely to client engagement. Other challenges reported to a lesser extent pertained to client interactions during follow-up (e.g., the client was uncomfortable with providing contact information for case follow-up, declined to speak to PHU or provide information during public health follow-up, or declined testing).

PHU/Health Systems Level: Challenges

- **Knowledge gaps and resources for PHU follow-up:** Challenges shared were related to knowledge gaps among community providers in case management functions such as identifying or staging syphilis infections, and being familiar with screening recommendations. In PHUs, challenges around a lack of available resources, limited experience with public health case management and follow-up, as well as lack of clarity or confusion around PHU expectations (e.g., length of public health follow-up, goal of public health follow-up of an infant case) were noted.
- **Access to information:** PHUs sometimes did not have access or timely access to health information and records for maternal syphilis cases who moved to their PHU during pregnancy. There were instances where the maternal case had been staged and treated within another PHU, moved during their pregnancy, and their current PHU was not able to access relevant clinical records. Other challenges obtaining case information included: a lack of access to clinical test records in Electronic Medical Records (EMR) or notes, or lack of communication between health care providers.
- **Workload for PHUs:** PHU staff noted the high workload for managing maternal syphilis cases given significant time and resources required to conduct follow-up of complex cases. After extensive efforts by PHU staff, 44% of maternal cases were deemed lost to follow-up. The emotional burden felt by PHU staff involved in case management was often heavy and took a toll on staff.

- **Public health reporting:** PHU staff reported challenges related to the interpretation and application of the provincial case definitions used for confirming and staging cases, as well as challenges entering cases correctly into iPHIS. .

PHU/Health Systems Level: Facilitators

PHUs shared two noteworthy facilitators of their management of congenital syphilis cases:

1. **Relationships with health care providers and other agencies:** PHUs reported that new and existing partnerships with internal and external agencies and health care providers were invaluable during follow-up. This includes relationships with outreach teams and community providers and establishing data sharing agreements and relationships with local hospitals (e.g., acquiring clinical information for case classification purposes, monitoring infant follow-up).
2. **Access to Electronic Medical Records (EMR):** While a lack of access to information came up often as a challenge in conducting public health congenital syphilis case follow-up, it was evident that appropriate access to EMRs facilitated successful case management through timely access to relevant clinical details, including symptom and treatment history.

Discussion

Early Congenital Syphilis

This retrospective case series highlights the negative impact of early congenital syphilis on infant health and the significant health care resources required. In addition to long hospital stays requiring medical interventions (e.g., intubation and continuous positive airway pressure), many cases in this case series underwent intensive clinical investigations including medical imaging (abdominal, head, and skeletal), serological testing, and ophthalmology and audiology examinations. Numerous providers, including neonatologists, infectious disease specialists, pediatricians, ophthalmologists, and audiologists, were involved in the diagnosis, initial management, and clinical follow-up of the infants. The increasing incidence and the associated burden of early congenital syphilis on the health system highlight the need for early detection and treatment of maternal syphilis cases as a public health priority.

This case series also highlighted the challenges PHUs experienced with applying the existing provincial case definition for early congenital syphilis which at present only includes a ‘confirmed’ case classification. However, some infants at high risk for infection (i.e., those born to pregnant people with inadequately treated syphilis) may not always present with clinical, radiographic, and/or laboratory evidence at birth. As a result, these infants would not meet the criteria for a confirmed case of early congenital syphilis and subsequently would not be captured in provincial surveillance data. These ‘probable’ cases, however, could provide important additional insight into the burden of congenital syphilis in Ontario and thus updates to the provincial case definition to improve its sensitivity is warranted. Further, some PHUs noted examples of adverse fetal outcomes (e.g. still birth, late term abortion secondary to severe fetal abnormalities) in mothers with untreated syphilis. In these examples, as no serology was conducted on the fetus, they did not meet the definition for a confirmed case, resulting in an underreporting of adverse fetal outcomes for those with maternal syphilis. Updating the provincial case definitions to capture these scenarios would improve the detection of early congenital syphilis cases in Ontario.

Provincial congenital syphilis surveillance case definitions should be updated to improve case detection for more accurate monitoring of epidemiological patterns in Ontario.

Access to Prenatal Syphilis Screening

Delayed maternal syphilis screening is associated with negative fetal outcomes, with previous studies noting that maternal cases who receive screening late in pregnancy are eight times more likely to have an infant born with congenital syphilis compared to those screened in the first trimester.¹⁰ Canadian Guidelines currently recommend syphilis screening for all pregnant people in their first trimester or at first prenatal visit, with re-screening in the third trimester (i.e., at 28–32 weeks gestation) and at delivery for those living in areas with syphilis outbreaks and/or at ongoing risk of infection (e.g., sex with multiple partners, drug use, unstable housing or homelessness).^{2,11} Repeated syphilis screening during pregnancy

aims to identify syphilis infections that were acquired after, or were not detected on, screening done earlier in pregnancy. The vast majority of maternal syphilis cases included in this case review reported at least one risk factor for syphilis infection including substance use, being homeless/underhoused and/or having previously been infected with an STBBI. Despite these guidelines, the Ontario retrospective case review determined that two-thirds of the maternal syphilis cases (24/36; 66.7%) received syphilis screening at any point in their pregnancy and of these, less than half (10/24; 41.7%) were tested in the first trimester. Nearly one-third (11/36; 30.6%) of maternal cases received syphilis screening at the time of delivery or in the post-partum period.

A study in the United States estimated that 11.2% of maternal syphilis cases were identified late in pregnancy and following a negative first trimester screen, and this prevalence ranged from 6.5% in the west to 39.6% in the northeast.¹² In the Ontario retrospective case review, 7/36 (19.4%) maternal syphilis cases had a negative first trimester screen and their syphilis infection was identified later in pregnancy (n=4) or after delivery (n=3).

Improving access to prenatal syphilis screening early in pregnancy is a key component of congenital syphilis prevention efforts.

Concurrent Conditions: STBBI Co-infections, Substance Use and Housing Instability

Studies have shown that having a current or previous STBBI is a risk factor for acquiring a new STBBI, including syphilis.^{13,14} The CGSTI recommend universal screening during pregnancy for other STBBIs including gonorrhea, chlamydia and HIV, and risk-based screening for HCV. This retrospective case review found that nearly two-thirds of maternal syphilis cases were screened for chlamydia/gonorrhea (23/36; 63.9%) and HIV (24/36; 66.7%); however, less than half (17/36; 47.2% were screened for HCV. Of those who did receive additional screening, 11 individuals tested positive for chlamydia, gonorrhea, and/or HCV (14 total infections). Of the 17 individuals screened for HCV, five were positive (29.4%). A similarly high HCV and syphilis co-infection rate of 19.5% (n=87) was observed among pregnant people participating in a pilot program offering universal prenatal HCV screening in Alberta.¹⁵

Substance use and housing instability were concurrent issues faced by approximately half of the maternal syphilis cases in this series. It is notable that injection and non-injection drug use are also the most commonly reported risk factors among newly acquired HCV cases in Ontario.¹⁶ These concurrent conditions have also been reported among birthing parents of infants with congenital syphilis in Manitoba and the US, as well as more broadly among female cases with infectious syphilis in British Columbia.^{14, 17, 18} Characterizing the epidemic of increasing infectious syphilis among females and differentiating it from the epidemic among gay, bisexual and other men who have sex with men is an important public health surveillance activity relevant for congenital syphilis prevention.¹⁹

Given the prevalence of syphilis co-infection with other STBBIs, it is important that individuals diagnosed with syphilis in pregnancy receive screening for other STBBIs, particularly HCV. Ongoing surveillance of co-infections, specifically HCV and syphilis, and the overlapping social and behavioural factors among those impacted may help to inform public health action.

Access to Prenatal Care

It is important to contextualize timely prenatal syphilis screening and treatment with access to prenatal care. A California study found that a lack of prenatal care was the most significant predictor of congenital syphilis (odds ratio [OR] 18.5; 95% confidence interval [CI] 10.6-32.3).²⁰ As demonstrated in the Ontario cascade ([Figure 6](#)), 22/36 (61.1%) maternal syphilis cases were known to have had access to any prenatal care and were thus more likely to have received timely prenatal syphilis screening compared to those without any access to prenatal care. In total, 18/22 (81.8%) maternal syphilis cases who accessed any prenatal care completed a prenatal syphilis screening test >4 weeks prior to delivery. Despite having access to any prenatal care, a significant proportion received fewer than four visits with nearly one-third ([Table 4](#)) of all maternal cases receiving their first pregnancy related care at the time of delivery.

As stated above, the most common individual level factors contributing to prenatal care access challenges that were raised by PHU staff included unstable housing and substance use. These results are corroborated by studies reporting that individual level factors such as prioritization of food and shelter, mental health problems, lack of health literacy, and distrust of health care services all contribute to low engagement in prenatal care.²¹ The impact of system level policies (e.g., affordable housing, social assistance) that remove barriers to care for individuals as well as the impact of colonization and systemic racism on the social determinants of health, must be acknowledged and considered as a part of any integrated approach to congenital syphilis prevention.^{21,22} In the California study mentioned above, homelessness and methamphetamine use were also significant predictors of congenital syphilis; however, their impact was no longer statistically significant when controlled for prenatal care access.²⁰ Targeted solutions that make prenatal care more inclusive of those experiencing homelessness and/or use substances may reduce the burden of congenital syphilis.²³

Novel approaches that aim to enable equitable prenatal care access for those experiencing homelessness and/or use substances may mitigate the influence of these factors on congenital syphilis. Larger efforts to address the social determinants of health (e.g. housing) and support individual-level behaviours (e.g. substance use) amongst pregnant individuals may improve one's ability to access and engage in prenatal care.

Public Health Experiences

Although the impact of the COVID-19 pandemic did not emerge as a major theme related to public health follow-up or barriers to care during these interviews it would be remiss not to acknowledge that these cases were identified at a time when access to health services, including STBBI and reproductive health services, was disrupted and the Ontario public health workforce experienced immense challenges due to the reallocation of resources to the pandemic response.^{24,25}

Nearly half of the maternal syphilis cases in this case series were lost to follow-up by public health. A case that is lost to follow-up represents the use of substantial public health resources (e.g., numerous attempts to contact case) as well as a missed opportunity to educate and collect additional case details for characterizing the epidemiology of maternal syphilis in Ontario (e.g., syphilis stage, risk factors). Maternal syphilis cases who do not have contact with public health are associated with poorer fetal outcomes compared to those who do have contact. Gratrix et al., found that maternal syphilis cases in Alberta who did not have public health contact were 3.6 times more likely to give birth to an infant with congenital syphilis compared to those that did.¹⁰ Public health follow-up of maternal syphilis cases is important as it helps to ensure linkage to care and treatment, including monitoring of serological response to treatment.

In addition to the challenges faced with case engagement during public health follow-up, PHUs identified a need to improve communication with health care providers to enable information sharing across different databases. Together, these two challenges hindered the ability to appropriately stage syphilis infections. In our case review a greater proportion of the 36 maternal syphilis cases associated with congenital syphilis could not be staged compared to syphilis cases among women aged 15-44 years over the same period (19.4% versus 7.9%). One impact of this is the possible underestimation of the burden of infectious syphilis among this population.

PHUs also identified the need for additional training and resources related to congenital syphilis case classification and public health follow-up. There is also an opportunity for public health to engage with community providers to ensure they have adequate knowledge and skills related to syphilis diagnosis and awareness of existing screening guidelines, particularly who may benefit from ongoing screening throughout pregnancy.

Increased public health resources, including financial and human resources, to manage maternal syphilis cases and educate local health care providers may result in improved congenital syphilis detection and outcomes.

Limitations

Data for this report on risk factors, testing, and other relevant clinical information (e.g. history of prenatal screening/care) were collected through interviews with the PHUs and was not reconciled with other data sources (e.g. iPHIS, Health Care Connect, the Ontario Laboratory Information System, or other electronic medical databases). Data were obtained from the PHUs; PHO interviewers did not speak directly to cases. In some circumstances the original case managers were not available for the interview (e.g. had left the program area) and substitute case managers had to rely on available documentation to complete the interview. Socio-demographic information (e.g. race, income, education status) for maternal cases is not routinely collected during public health follow-up in Ontario and so was not included as part of the case interviews. Regional analyses for maternal and infant case characteristics were not conducted due to small numbers. It was out of scope for this project to validate the appropriate application of the case definition so it is possible that some included cases from iPHIS were inaccurately reported as meeting the confirmed case definition.

Conclusion

Given the increased burden of early congenital syphilis and maternal syphilis, early detection and treatment of maternal syphilis and addressing underlying factors such as prenatal care access, social determinants of health, and limited public health resources is paramount. Public health and health systems interventions to address this issue must acknowledge the impact of colonization, structural racism and social policies (e.g., drug-related legislation) on the social determinants of health, trust in health care and vulnerability to STBBI, including syphilis.^{20,23} Steps must be taken to achieve equitable collaboration, that focuses on local priorities and ensure leadership, resources and services are inclusive.

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Appendix A: Cumulative Number of Confirmed Cases of Early Congenital Syphilis

Public Health Unit 3-letter abbreviation	Public Health Unit full name	Cumulative Number of Cases in Ontario (2019-2022)
ALG	Algoma Public Health	2
BRN	Brant County Health Unit	2
CHK	Chatham-Kent Public Health	0
DUR	Durham Region Health Department	3
EOH	Eastern Ontario Health Unit	0
GBO	Grey Bruce Health Unit	0
HAL	Halton Region Health Department	1
HAM	City of Hamilton Public Health Services	6
HDN	Haldimand-Norfolk Health Unit	2
HKP	Haliburton, Kawartha, Pine Ridge District Health Unit	0
HPE	Hastings Prince Edward Public Health	0
HPH	Huron Perth Health Unit	0
KFL	Kingston, Frontenac, Lennox & Addington Public Health	5
LAM	Lambton Public Health	2
LGL	Leeds, Grenville and Lanark District Health Unit	0
MSL	Middlesex-London Health Unit	2

Public Health Unit 3-letter abbreviation	Public Health Unit full name	Cumulative Number of Cases in Ontario (2019-2022)
NIA	Niagara Region Public Health	2
NPS	North Bay Parry Sound District Health Unit	0
NWR	Northwestern Health Unit	0
OTT	Ottawa Public Health	0
OXE	Southwestern Public Health	2
PEL	Peel Public Health	1
PQP	Porcupine Health Unit	0
PTC	Peterborough Public Health	0
REN	Renfrew County & District Health Unit	0
SMD	Simcoe Muskoka District Health Unit	1
SUD	Sudbury & District Health Unit	0
THB	Thunder Bay District Health Unit	1
TOR	Toronto Public Health	6
TSK	Timiskaming Health Unit	0
WAT	Region of Waterloo Public Health and Emergency Services	1
WDG	Wellington-Dufferin-Guelph Public Health	0
WEC	Windsor-Essex County Health Unit	2
YRK	York Region Public Health Services	0

Data sources: Ontario. Ministry of Health. integrated Public Health Information System (iPHIS) [database]. Toronto, ON: King's Printer for Ontario; 2023 [extracted 2023 Jul 31].

Technical Notes

Data Sources

- The data for this report were based on information entered in the Ontario Ministry of Health (MOH) integrated Public Health Information System (iPHIS) database as of **January 8, 2023**.
- iPHIS is a dynamic disease reporting system that allows ongoing updates to previously entered data. As a result, data extracted from iPHIS represent a snapshot at the time of extraction and may differ from previous or subsequent reports.

Data Caveats

- These data only represent confirmed cases of early congenital syphilis reported to public health and recorded in iPHIS. As a result, all case counts are subject to varying degrees of underreporting due to a variety of factors, such as disease awareness and medical care seeking behaviours that may depend on severity of illness, clinical practices, and changes in laboratory testing and reporting behaviours.
- Only early congenital syphilis cases meeting the confirmed case classification as listed in the [Ontario MOH surveillance case definitions](#) were included in the retrospective case reviews.
- Case counts by geography are based on the diagnosing health unit (DHU). DHU refers to the case's public health unit of residence at the time of illness onset or report to public health and not necessarily the location of exposure.
 - Cases for which the DHU was reported as MOHLTC (to signify a case that is not a resident of Ontario) or MUSKOKA-PARRY SOUND (a public health unit that no longer exists) were excluded from this analysis.
- Cases for which the Disposition Status was reported as ENTERED IN ERROR, DOES NOT MEET DEFINITION, DUPLICATE-DO NOT USE, or any variation on these values, were excluded from this analysis.
- The potential for duplicates exists because duplicate sets were not identified and excluded unless they were already resolved at either the local or provincial level prior to data extraction from iPHIS.

Other Data Notes

- Infant signs and symptoms
 - Narrative text for symptoms was analyzed for themes and grouped together.
- Maternal case classification
 - Case classifications are based on the surveillance case definitions as per the [Ontario Public Health Standards, Infectious Diseases Protocol Appendix 1](#) at the time of the interviews.
- Maternal risk factors
 - Data for risk factors was obtained by combining findings from narrative text with reported iPHIS risk factors checklist for infectious syphilis.
- Timing of diagnosis
 - Timing of diagnosis of maternal case was based on the iPHIS encounter date of the maternal infectious syphilis infection associated with the congenital syphilis case.
 - “At delivery” defined as at time of presenting for delivery or within 24 hours of delivering infant.
 - “After delivery” defined as diagnosis greater than 24 hours since delivery and less than 2 years post-delivery.
- Timing of treatment
 - Appropriate treatment was defined as completed treatment with Benzathine penicillin G-LA 2.4 million units IM (one to three doses as per recommended guidelines for the appropriate stage) during pregnancy.
 - In some circumstances, re-treatment with a single dose or with three doses of Benzathine penicillin G-LA 2.4 million units IM was recommended (e.g., inadequate serological response to first treatment). If the individual did not complete recommended re-treatment (i.e., all doses) less than four weeks prior to delivery, then their timing of treatment was coded as less than 4 weeks prior to delivery.
- Prenatal care
 - The use of at least four prenatal care visits was used to align with the [WHO antenatal care coverage indicator](#).

- Maternal syphilis care access cascade
 - Frequencies of persons at each cascade step were calculated. Conditional proportions for each step were calculated using the number of persons identified who met the definition for being at a particular step divided by the number that met the definition from the previous step.

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