

# Evaluation of the congenital syphilis notification surveillance system in South Africa (2020)

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## Summary

Congenital syphilis (CS) is a public health problem in South Africa (SA) and is a category 2 notifiable medical condition (NMC). We conducted a cross-sectional evaluation of the CS notification system using qualitative and quantitative methods. The evaluation was guided by the United States Centers for Disease Control and Prevention (US-CDC) and the World Health Organization (WHO) surveillance guidelines for evaluating surveillance systems and their attributes. For the quantitative analysis, we used the CS line list, including all nine provinces in SA. For the qualitative analysis, we used data collected from a REDCap online questionnaire of healthcare workers (HCWs) who had notified a CS case using the NMC system and from CS surveillance officers of NMC and the Centre for HIV/STI (CHIVSTI) of the National Institute for Communicable Diseases (NICD) in the preceding year. This evaluation found that CS surveillance was done through the notifiable medical conditions surveillance system (NMCSS) platform, where all HCWs must report a case within seven days of diagnosis. Congenital syphilis cases are notified by completing and sending a paper-based case notification form (CNF) through the electronic NMC App and a paper-based case investigation form (CIF) emailed or faxed to the programme. The evaluation also showed that during 2020, there were 357 clinical CS cases in infants reported from 31 districts within the nine provinces in SA through the NMCSS. The mean age at diagnosis was 14 days (standard deviation = 49 days), with 184 (51.5%) males. 254 (71.15%) of the reported cases were notified within seven days or fewer from the date of diagnosis. KwaZulu-Natal Province reported more cases – 176 (49.30%) – than other provinces. Qualitatively, the HCW's response rate was 28.6% (14/50), with many (57%) using the paper-based reporting system to notify cases. Almost half of the HCWs 6/14 (43%) had good knowledge and understanding of the CS surveillance system. Data quality was compromised due to missing or incomplete data, and no CIF was attached to the CNF in many cases. All the key informants and HCWs accepted and were willing to report CS cases through the NMCSS. Most HCWs found the CS case definition challenging, although the NMC surveillance officers found the system simple to extract data from. It is therefore concluded that the CS surveillance system in SA is useful, acceptable, and timely. The notifying system is simple to understand and use, but the case definition is not easy to use. It is recommended that:

- The NMC/CHIVSTI and the National Department of Health (NDoH) educate HCWs on screening and diagnosing infants with CS.
- The government's sexual and reproductive programmes and maternal healthcare centres continue to implement comprehensive syphilis screening, testing, and treatment for pregnant women and their partners to reduce the recurrence of infection.
- The NDoH, policymakers, and the NMCSS continuously communicate the urgency of eliminating CS by 2030.
- HCWs be provided with better resources, such as electronic devices and internet connectivity, to enable use of the NMC App.



## Introduction

Congenital syphilis (CS) is a preventable cause of adverse birth outcomes such as low birth weight, stillbirth, premature birth, neonatal death, and other congenital deformities.<sup>1</sup> It results from mother-to-child transmission (MTCT) of syphilis during pregnancy.<sup>1</sup> Syphilis is a sexually transmitted infection caused by the spirochete *Treponema pallidum*.<sup>1</sup> The World Health Organization (WHO) estimated that an average of 3.2% (range 1.1%–10.9%) of women attending antenatal care tested positive for syphilis in 78 reporting countries in 2019.<sup>2</sup> Maternal syphilis in HIV-positive women increases the risk of MTCT of HIV.<sup>3</sup> In South Africa (SA), maternal syphilis is increasing among pregnant women, and failure to effectively diagnose and treat CS increases MTCT of HIV and syphilis.<sup>3</sup>

Since 2007, the WHO global plan to eliminate MTCT in syphilis targeted a reduction of the transmission rate to below 50 cases per 100,000 live births by 2030.<sup>4</sup> Establishing surveillance, monitoring, and evaluation systems is one of the pillars towards the elimination of MTCT in syphilis.<sup>4</sup> SA has established surveillance and programmes to measure progress towards preventing MTCT of HIV and CS.<sup>5,6</sup> The global target is that at least 95% of pregnant women in antenatal care (ANC) are tested for syphilis, and at least 95% of women who test positive for syphilis receive adequate treatment in addition to the targeted case rate.

Congenital syphilis is preventable through testing, diagnosis, and adequate benzathine penicillin treatment for syphilis-infected mothers.<sup>1</sup> SA's national guidelines recommend universal syphilis and HIV testing during pregnancy with immediate antiretroviral therapy or benzathine penicillin treatment for positive women.<sup>5</sup> The occurrence of CS depicts a failure to prevent MTCT of syphilis due to undetected, untreated, or inadequately treated maternal syphilis (<30 days before delivery).<sup>7</sup> Infants born to syphilis-infected mothers with little or no treatment also require treatment for congenital infection.

Monitoring CS burden and trends requires that the surveillance system identify CS cases on time. In SA, CS is a category 2 NMC that should be notified within seven days of diagnosis.<sup>8</sup> Surveillance also guides the health system's capacity to strengthen the prevention, detection, and treatment of maternal syphilis.

SA adopted the WHO case definition for CS surveillance in 2019 (Table 1).<sup>7</sup>



**Table 1.** South African case definition for congenital syphilis (CS).

A CS case is defined as a live birth or foetal death at >20 weeks of gestation or >500 g (including stillbirth) born to a woman with positive syphilis serology and without adequate syphilis treatment,

OR

a live birth, stillbirth, or child aged <2 years born to a woman with positive serology or unknown serostatus and with laboratory and/or radiographic and/or clinical evidence of syphilis infection (regardless of the timing or adequacy of maternal treatment).

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**Laboratory evidence**

- a.** Demonstration by dark-field microscopy or detection by fluorescent antibody testing of *Treponema pallidum* in the umbilical cord, placenta, nasal discharge, skin lesion material, or autopsy material of a neonate or stillborn infant or from the placental PCR;
- b.** Analysis of cerebrospinal fluid (CSF) is reactive for a Venereal Disease Research Laboratory (VDRL) test or elevated CSF cell count or protein without other cause;
- c.** Infant with a reactive non-treponemal serology test with titre fourfold or more than that of the mother;
- d.** Infant with a reactive non-treponemal serology test with titre less than fourfold higher than that of the mother but that remains reactive  $\geq 6$  months after delivery;
- e.** Infant with a reactive non-treponemal serology test of any titre AND any of the clinical signs born to a mother with positive or unknown serology, independent of treatment.

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**Radiographic evidence**

- f.** Long bone radiographs suggestive of congenital syphilis (e.g., osteochondritis, diaphyseal osteomyelitis, and periostitis).

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**Clinical evidence**

- g.** Early clinical signs include non-immune hydrops, hepatosplenomegaly, rhinitis (snuffles), skin rash, pseudo-paralysis of an extremity, or failure to thrive or achieve developmental milestones. An older infant or child may develop additional signs or symptoms such as frontal bossing, notched and pegged teeth (Hutchinson teeth), clouding of the cornea, blindness, bone pain, decreased hearing or deafness, joint swelling, sabre shins and scarring of the skin around the mouth, genitals, and anus.
  - h.** For stillborn infants, maternal syphilis serostatus should be determined. Any stillbirth case from a woman with a reactive maternal syphilis antibody test should be considered a congenital syphilis case.
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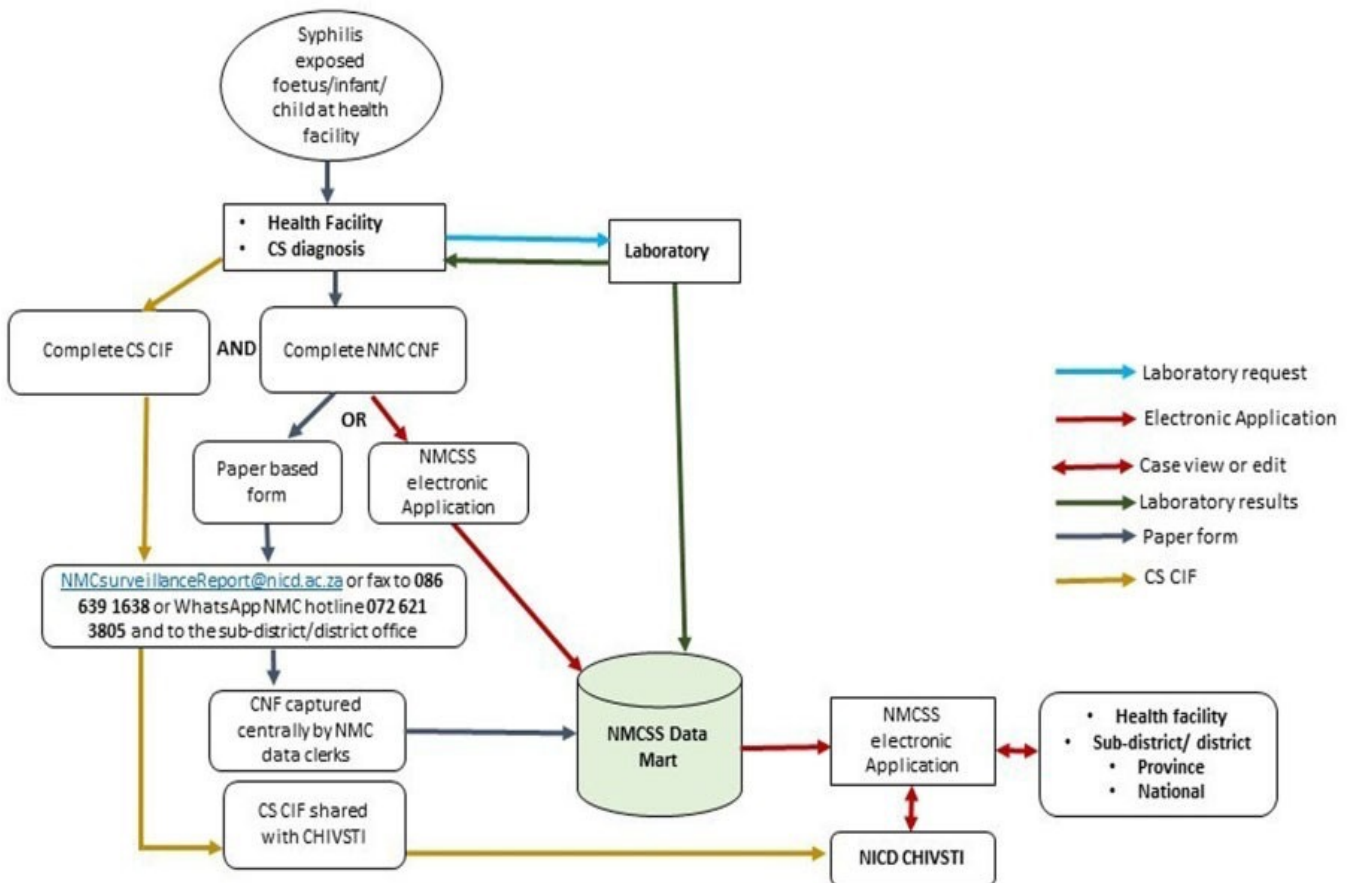
## The CS Surveillance System in South Africa, 2020

During 2020, CS surveillance was done through the notifiable medical conditions surveillance system (NMCSS), a case-based reporting system for NMCs with two components: i) healthcare workers (HCW) reporting of clinical cases and ii) laboratory information system-generated alerts of infants who are rapid plasma reagin (RPR)-positive (Figure 1).<sup>8</sup> Two options are available to report a CS case to the NMCSS. The first option was to report an infant or child who meets the CS definition (clinical notification) to NMC through an electronic application (App) or paper-based case notification form (CNF).<sup>8</sup>



The HCW collects CS information on the App or uses the NMC webpage to fill in the NMC CNF form. The CNF contains the infant's demographics, symptoms at diagnosis, any specimen details, and the details of the health care provider, which were saved and automatically fed into the system (Figure 1). The second option was paper-based reporting, where the HCW worker completes the CNF and sends it to NMC through email, WhatsApp, or fax, and a scanned copy to the NMC personnel.<sup>8</sup> The NMC data clerks then enter the information into the NMC system.

The HCWs were also encouraged to complete a case investigation form (CIF), which collected supplementary maternal and infant clinical information.<sup>9</sup> The CIF was sent to the Centre for HIV and STIs (CHIVSTI) of the National Institute for Communicable Diseases (NICD). The second component was the laboratory-based alert of an infant or child under two years who tested positive for RPR and may have CS.<sup>9</sup> The NMC data mart receives RPR-positive results from tests done on infants or children under two years and sends out alerts of these results to HCWs so that they can exclude CS in these children who are likely syphilis exposed or suspected to have CS. Should HCWs make a diagnosis of CS among infants and children included in the alerts, they are required to still submit a case notification form.<sup>9</sup> Overall, the CHIVSTI is responsible for retrieving the CS case list and CNF for case management and following up on cases where the CIF was not submitted.



**Figure 1.** Notifiable medical conditions surveillance system (NMCCS) congenital syphilis (CS) case notification and surveillance data flow processes.<sup>8</sup>

CNF = case notification form; CIF = case investigation form; NICD = National Institute for Communicable Diseases; CHIVSTI = Centre for HIV and STIs, NICD.



## Aims and objectives of the evaluation

This evaluation aimed to assess the performance of the CS notification and surveillance system using the United States Centers for Disease Control and Prevention (US-CDC) guidelines.<sup>10</sup> The objectives of the evaluation were:

- To determine the performance of the CS notification system concerning the following attributes: knowledge, relevance/usefulness, representativeness, timeliness, completeness, flexibility, data quality, acceptability, representativeness, and stability of CS in the NMCSS in 2020;
- To make recommendations for the CS notification system and for CS surveillance, prevention, and management.

## Methods

### Design

The evaluation was cross-sectional, using both quantitative and qualitative methods. Quantitatively, a retrospective analysis of the NMC-CS line list included clinically notified CS cases in 2020. The qualitative component was a survey of healthcare providers and NICD key informants. Both evaluation components were designed using the US-CDC updated guidelines for evaluating public health surveillance systems.<sup>10</sup>

### Evaluation setting

In SA, the public healthcare system serves most of the population. The NDoH, provincial health departments, and municipal health departments work with the NICD for service delivery and effective monitoring of diseases.<sup>5</sup> The Centre for HIV and STIs within the NICD conducts CS surveillance through the NMCSS platform. Our evaluation includes all nine provinces in SA.

### Inclusion criteria and sampling

The quantitative analysis included all the notified CS cases on the 2020-line list. Data from clinical records of infants and children <2 years of age identified as syphilis cases through the NMC-CS notification system platform in 2020 were included. We excluded laboratory alerts for RPR-positive infants <2 years and cases discarded from the NMC 2020-line list due to missing data or not meeting the case definition.

For the survey, HCWs from facilities in the provinces responsible for notifying CS-exposed infants and cases to the NMCSS and surveillance officers from the NMC and CHIVSTI were included in the evaluation. Fifty HCWs were sampled among those who had reported CS-infected infants through the NMC system in the preceding 12 months. Five NMC surveillance staff and five CHIVSTI CS surveillance staff were sampled as key informants to provide information on the functionality of the surveillance system, data management, and CS report dissemination for public health action.

### Data collection and management

For the quantitative phase, data requests were submitted to the NMC team along with the ethics clearance certificate for the evaluation protocol. The CS NMC data from the surveillance records (CNFs and CIFs) and databases (NHLS laboratory data) with information on syphilis-exposed infants were received.

For the qualitative component, we collected data through the REDCap® online questionnaire from HCWs and surveillance officers. The online survey had a mixture of open and closed-ended questions.

### Data analysis

For the quantitative component, descriptive statistics were used to summarise data using Stata version 15 (StataCorp, College Station, TX, USA).



The qualitative information collected was summarised according to the surveillance attributes defined (Table 2). Discussion, lessons learned, and recommendations were provided to strengthen system attributes where applicable.

**Table 2.** Description and evaluation of the notifiable medical conditions surveillance system (NMCSS) attributes, South Africa 2020.

Attribute	Description of the CS NMC surveillance system	Data collection method	Analysis
<b>Knowledge</b>	<ul style="list-style-type: none"> <li>• HCW knowledge of the surveillance system, including aims and objectives of the system.</li> </ul>	<ul style="list-style-type: none"> <li>• Survey of HCWs' knowledge of the NMC-CS surveillance system.</li> </ul>	<ul style="list-style-type: none"> <li>• Categorical data with subjective views on the knowledge of the CS surveillance system, categorised as "good", "partially know" and "did not know".</li> </ul>
<b>Usefulness/relevance</b>	<ul style="list-style-type: none"> <li>• A CS surveillance system is useful if it contributes to the prevention and control of CS adverse health-related events, as well as an improved understanding of the public health implications of CS.</li> </ul>	<ul style="list-style-type: none"> <li>• Survey. HCW/ surveillance officers were asked if the CS system is meeting its objectives, whether the system provides data or information on CS morbidity and mortality, whether it provides trends on occurrences of CS, identifies factors associated with CS, and leads to improved clinical practices.</li> </ul>	<ul style="list-style-type: none"> <li>• A qualitative measure of subjective views from the key informants using the CS surveillance system as to whether it leads to prevention and control or a better understanding of CS.</li> <li>• Quantitative measure in terms of the impact of CS surveillance data on estimating the burden of CS in SA, policies, and CS interventions.</li> </ul>
<b>Usefulness/relevance</b>	<ul style="list-style-type: none"> <li>• Evaluation based on how easy it is for clinicians to use the CS case definition, the number and type of reporting methods, the process of reporting the information, and;</li> <li>• How easy is it for the HCW to capture or send CS cases to the NMC system.</li> </ul>	<ul style="list-style-type: none"> <li>• Survey HCWs on how easily they can apply the case definition, compile reports, and complete CS notification forms.</li> <li>• Survey NMC surveillance officers and CHIVSTI epidemiologists on the functionality of the system, the data transmission process, and data analysis and information dissemination.</li> </ul>	<ul style="list-style-type: none"> <li>• Percentage of HCWs who reported that the system is easy to use.</li> <li>• Number of cases showing that the CS case definition is understood and applied.</li> <li>• Level of measurement on the functionality and flow of the system.</li> </ul>



<b>Flexibility</b>	<ul style="list-style-type: none"> <li>Refers to the ability of the system to adapt to changing needs or operations, such as a change in case definition, reporting case forms, and implementing new methods of operational procedures.<sup>10,11</sup></li> </ul>	<ul style="list-style-type: none"> <li>Check for any changes or enhancements to the CS surveillance system and how it is performing.</li> </ul>	<ul style="list-style-type: none"> <li>Percentage change in the number of cases reported.</li> <li>Feedback from HCWs and surveillance officers on whether the changes have improved the system.</li> </ul>
<b>Acceptability</b>	<ul style="list-style-type: none"> <li>Response and willingness of those using the system to provide accurate, consistent, complete, and timely data.<sup>11</sup></li> </ul>	<ul style="list-style-type: none"> <li>Survey HCWs and NMC officers' opinions on system acceptability and what they think should change in the notification system.</li> <li>Ease and cost of data reporting.</li> <li>Acknowledgement by the NMC system managers of the contributions made by HCWs.</li> </ul>	<ul style="list-style-type: none"> <li>Quantitative indicators summarising the number of CS cases reported within seven days of diagnosis (timeliness) and the completeness of report forms received at NMC.</li> <li>Subjective measures of the participation rate.</li> </ul>
<b>Timeliness</b>	<ul style="list-style-type: none"> <li>Rate at which the linking interval between steps in the surveillance system occurs.<sup>12</sup></li> </ul>	<ul style="list-style-type: none"> <li>Based on the interval of time between diagnosis of the case, reporting of the case, capturing of the case in the NMC surveillance system, laboratory confirmation of the case, prevention measures put in place, and follow-up of treatment on CS-positive infants.</li> </ul>	<ul style="list-style-type: none"> <li>CS line list used to determine if cases were identified on time to facilitate control and prevention measures.</li> <li>Percentage of CS cases notified through the NMC system within 7 days, as determined by the number of days between the date of notification and the date of diagnosis.</li> </ul>
<b>Data quality</b>	<ul style="list-style-type: none"> <li>Data quality evaluated based on the completeness and validity of CS data and information.</li> </ul>	<ul style="list-style-type: none"> <li>Calling clinicians who reported CS and comparing verbal information with medical records and/or laboratory records.</li> <li>Interview NMC data capturers.</li> </ul>	<ul style="list-style-type: none"> <li>Percentage of cases notified with complete data or information on the line list reflecting the actual number of cases.</li> </ul>





<b>Representativeness</b>	<ul style="list-style-type: none"> <li>A system that accurately represents and describes CS over time and its population distribution.</li> </ul>	<ul style="list-style-type: none"> <li>Use of the CS case line list and clinical variables by person, place, and time.</li> </ul>	<ul style="list-style-type: none"> <li>Analysis of population characteristics of CS cases and maternal background: age, socioeconomic status, access to healthcare, and geographical location.</li> </ul>
<b>Stability</b>	<ul style="list-style-type: none"> <li>Reliability and availability of the CS surveillance system.</li> </ul>	<ul style="list-style-type: none"> <li>Review consistency and methods used in the CS surveillance system and case definition.</li> <li>Survey information from HCWs and NMC officers on the availability of resources to notify: CIF forms, scanners, internet for email and App, ability to collect, manage, and provide data.</li> </ul>	<ul style="list-style-type: none"> <li>Stability in the operation, case definition, shortages of resources, and the time required for data management and reports.</li> </ul>

CS = congenital syphilis; HCWs = health care workers; CNF = case notification form; CIF = case investigation form; NMCSS = notifiable medical conditions surveillance system; CHIVSTI = Centre for HIV and STIs, NICD.

## Ethical considerations

Ethical approval was obtained from the Human Research Ethics (Medical) Committee, University of Witwatersrand (M210307). Permission to extract data from the NMC database was obtained after ethics approval. Survey participants consented before answering the online survey, and they were automatically de-identified by REDCap® for analysis.

## Results

### Overall CS clinical notifications on the NMCSS case line list in 2020

6,946 records were extracted from the NMCS system for children <2 years. We excluded from the analysis 6,256 (90.1%) laboratory-generated alerts and 333/690 (48.3%) cases labelled as discarded because they did not meet the case definition or were missing age information. We included 357/690 (51.7%) records in the analysis. Of the 357 infants notified as CS cases, the median age at diagnosis was six days (interquartile range, IQR 0–254 days) with 184 (51.5%) males, 161 (45.1%) females, and 12 (3.36%) unknown. A total of 254 (71.2%) of the reported cases were notified within seven days or less from the date of diagnosis. KwaZulu-Natal Province reported the largest number of cases, 176 (49.3%) followed by Gauteng with 86 cases (24.1%). Limpopo, Mpumalanga, and the Eastern Cape reported the fewest number of three cases each (0.84%) (Table 3).





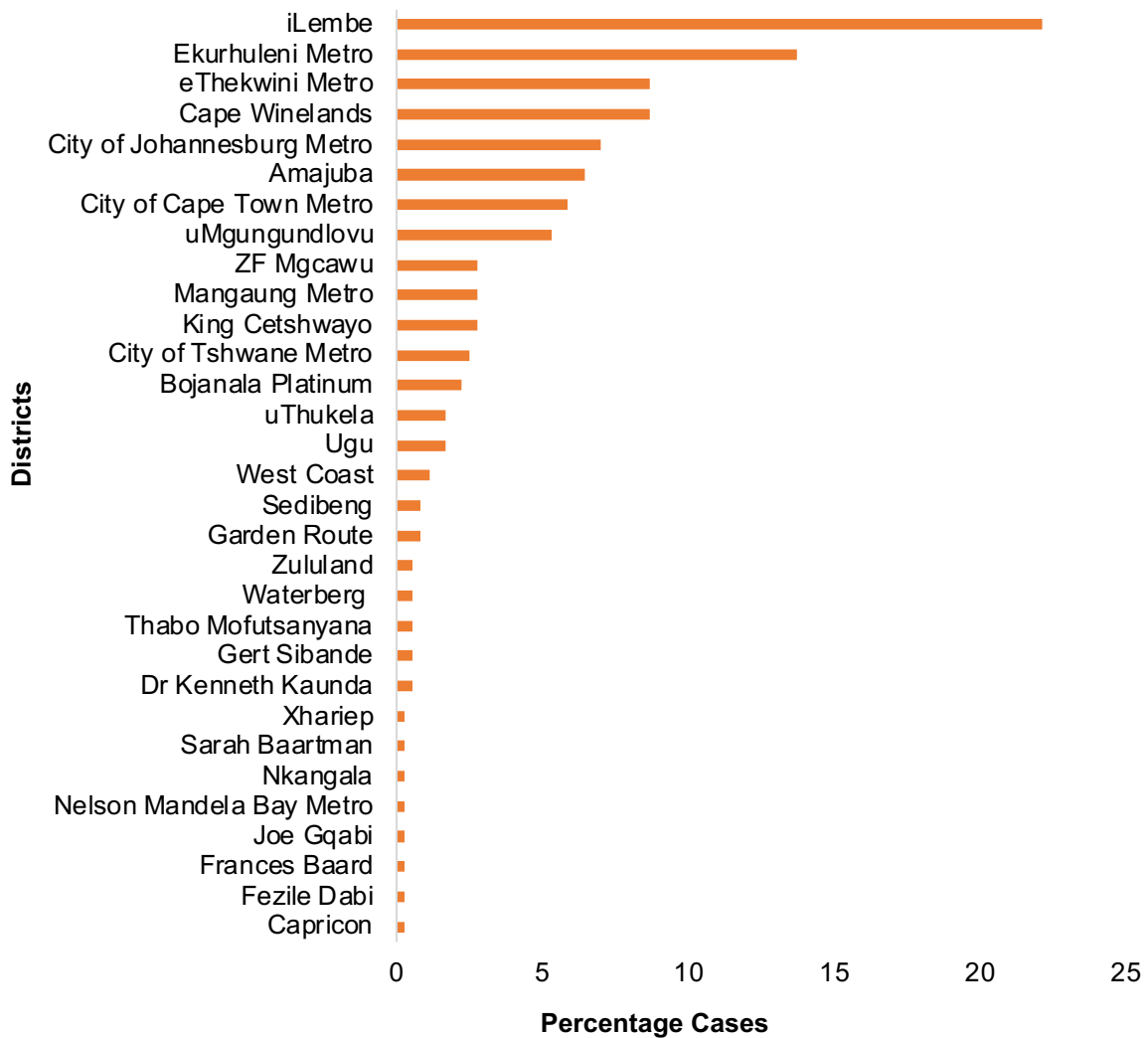
**Table 3.** Description of infants notified for congenital syphilis through the notifiable medical conditions surveillance system in South Africa 2020, N=357.

<b>Stability</b>	<b>N</b>	<b>%</b>
Age at diagnosis (median, IQR) in days		6 (0-254 days *)
Age of infants at notification (median, IQR) in days		22 (0-194 days *)
Days from diagnosis to notification (median, IQR in days)		3(3-194 days*)
Notified within 7 days from the date of diagnosis	254	71.15%
Notified within 7 days from the date of diagnosis	78	21.85%
Missing date of diagnosis	25	7 %
Female	161	45.10
Male	184	51.54
Unknown	12	3.36
<b>Province</b>		
Eastern Cape	3	0.84
Free State	6	1.68
Gauteng	86	24.09
KwaZulu-Natal	176	49.3
Limpopo	3	0.84
Mpumalanga	3	0.84
North West	10	2.8
Northern Cape	11	3.08
Western Cape	59	16.53

\*IQR-interquartile range



Most CS cases were reported from the iLembe district (22.3%) in KwaZulu-Natal Province. Ekurhuleni, a district in Gauteng Province, reported (13.73%) cases, which was the second highest number of cases, followed by eThekweni Metro in KwaZulu-Natal Province and Cape Winelands in the Western Cape Province (8.68%) (Figure 2).



**Figure 2.** Proportional congenital syphilis cases by district, South Africa, 2020 (N=357).

## Interviewed Stakeholders using the CS NMCSS

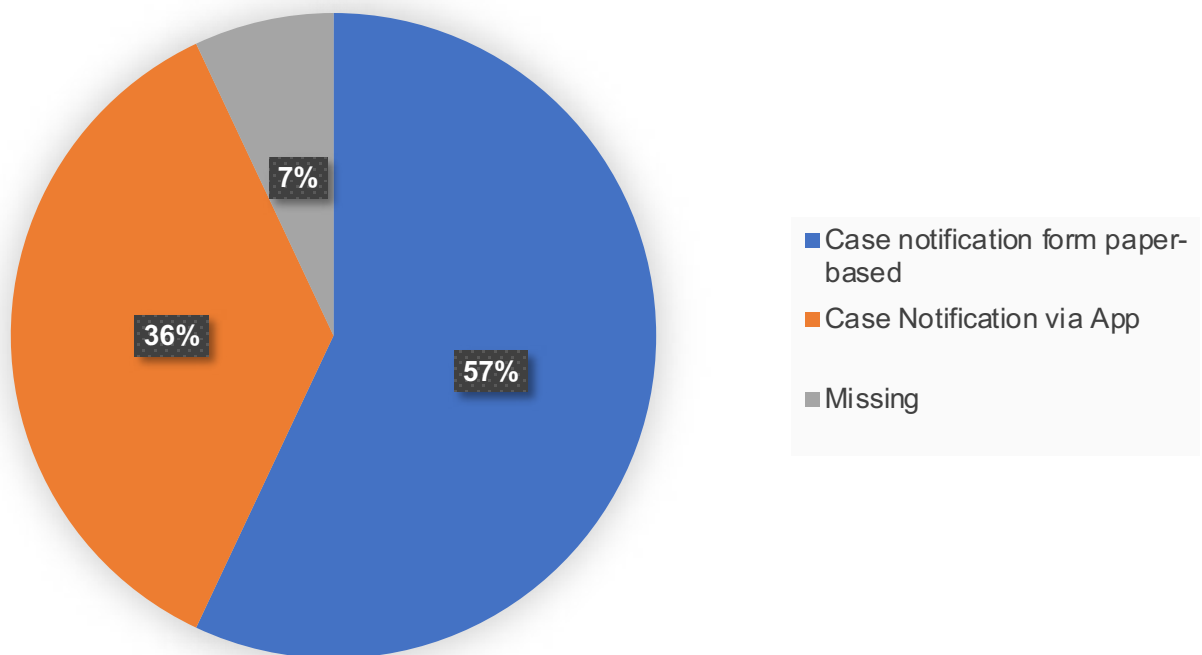
REDCap invitations were sent to 50 HCWs, and only 14 responded, giving a response rate of 28%. Northern Cape and Western Cape Provinces had a higher percentage of HCWs (28.6%) who participated in the survey than the Eastern Cape and Mpumalanga Provinces (7.1%). Approximately, a third of the HCWs had more than 5 years' work experience (35.7%) (Table 4). There were no responses from HCWs working in the Free State, Limpopo, and North West Provinces. Six key NMC surveillance officers from NMC and CHIVSTI responded to the survey.



**Table 4.** Characteristics of healthcare workers who participated in the congenital syphilis surveillance evaluation in South Africa, 2020 (N=14).

Characteristic	Characteristic	N	Percentage
Province	Eastern Cape	1	7.14
	Gauteng	2	14.29
	KwaZulu-Natal	2	14.29
	Mpumalanga	1	7.14
	Northern Cape	4	28.57
	Western Cape	4	28.57
Duration in position	<1 year	2	14.29
	>1 year ≤ 3years	4	28.57
	> 3years ≤ 5 years	2	14.29
	>5 years	5	35.71
	Missing	1	7.14

The paper-based case notification form was used by most HCWs (57%) and 36% used the App (Figure 3).



**Figure 3.** Notification methods used by healthcare workers to notify congenital syphilis using the notifiable medical conditions surveillance system (N=14).



## Attributes of the NMCSS for CS based on evaluation responses

### Design

Approximately half of the HCWs 6/14 (43%) demonstrated good knowledge and understanding of the aim and purpose of CS surveillance; 29% (4/14) partially knew and 14% (2/14) did not know (Table 5). On the other hand, all the key informants exhibited sufficient knowledge and understanding of the aim and purpose of CS surveillance.

**Table 5.** Attributes of the notifiable medical conditions surveillance system for congenital syphilis (CS) based on healthcare workers' responses, South Africa, (N=14).

Characteristic	Level	Frequency	Percentage
Willing and actively involved in CS surveillance?	Yes	12	85.71
	No	1	7.14
	Missing	1	7.14
Know the aim and purpose of CS surveillance?	Yes	6	42.86
	Partially know	4	28.57
	No	2	14.29
Aware of notifying within 7 days?	Missing	2	14.29
	Yes	8	57.14
	No	5	35.71
Ever reported a case of CS?	Missing	1	7.14
	Yes	10	71.43
	No	3	21.43
Easy to understand the CS case definition?	Missing	1	7.14
	Strongly agree	2	14.29
	Agree	3	21.43
	Neutral	4	28.57
	Disagree	4	28.57
Easy to identify cases using the CS case definition?	Missing	1	7.14
	Yes	9	64.29
	No	4	28.57
Does the CS surveillance system help diagnose cases?	Missing	1	7.14
	Yes	11	78.57
	No	2	14.29
Do you have access to resources such as computers, CNFs, CIFs, and SOPs?	Missing	1	7.14
	I have access to resources	11	78.57
	I do not have access	2	14.29
Any training done?	Missing	1	7.14
	Yes	7	50
	No	6	42.86
Duration since last training?	Missing	1	7.14
	Less than 1 year	5	35.71
	1-2 years	1	7.14
	6-10 years	1	7.14
	More than 10 years	5	35.71
	Missing	2	14.29

CNF = case notification form; CIF = case investigation form; SOPs = standard operating procedures.



Most HCWs (8/14, 57%) were aware of the seven-day notification period for CS cases stipulated by the NMCSS, and 72% (10/14) had notified clinical CS cases in 2020 (Table 5).

### Acceptability

Most HCWs (85.71%) were willing to use the system's notification methods and accepted the use of the CIF and notification App (Figure 3). All the key informants accepted and were willing to use CS surveillance through the NMCSS.

### Usefulness

Qualitative responses indicated that 11/14 (78.57%) of the HCWs found the NMCSS very useful and assisted in diagnosing CS cases (Table 5). Reasons for their responses included the fact that the surveillance system helps to identify untreated infants during pregnancy, and to notify and treat even those that test positive after birth, even if the mother was treated for syphilis.

### Simplicity

Less than half of the HCWs (35.72%) agreed that the case definition is easy to understand, 4/14 (28.57%) were neutral or disagreed (4/14; 28.57%) with this statement, and 1/14 (7%) had a missing value (Table 5). All key informants acknowledged that the CS surveillance system is a simple and easy platform to extract CS cases.

### Data quality

The case line list had much information, with only about 7% (25/357) missing the date of diagnosis and date of notification (Table 3). Most key informants (5/6, 83.33%) specified that data are not complete since the CNF does not always come with the CIF, and half (50%) of them received incomplete forms.

### Timeliness

The median number of days it took for CS-infected infants to be notified from the day of diagnosis was 6 days (IQR: 0–254 days), with 254 (71.15%) cases notified within seven days from the date of diagnosis (Table 3).

Seventy-one percent of HCWs indicated that they reported a CS case within seven days of the date of diagnosis (Table 5). At least 50% (3/6) of the key informants agreed that the CS surveillance system helps record and report data on time.

### Flexibility

Half of the HCWs (7/14) highlighted that the surveillance system has not been structured or enhanced since they started using it. About 35% (5/14) of the HCWs agreed to a restructuring of the system that would not affect their work (Table 5). Most HCWs (57%) stated that they preferred the paper-based CIF and CNF to notify since the NMC App takes more time and needs data or a network connection (Figure 3). The HCWs also acknowledged that they have received pertinent training at least once in their working period but stated that they require refresher training when there are updated guidelines, SOPs, or enhancements to the surveillance system (Table 5).

The key informants had 2/6 (33.33%) strongly agreeing that the surveillance system allows them to update data on the system, with 3/6 (50%) not answering the question. They all stated that the system can be easily integrated with other laboratory systems. (Table 5).



## Stability

Only a third of HCWs had more than five years of work experience (35.71%) (Table 5). However, HCWs acknowledged availability and access to resources and supplies needed for their work, such as computers, CNFs, CIFs, and SOPs, and most (78.57%) highlighted that they have access to guidelines, case definition forms on CS, and access to the NMC App and CNF (Table 5).

## Representativeness

The case line list showed 357 clinical case notifications of CS in 2020. In the same year, there were 899,303 registered live births in SA<sup>13</sup>, and the national prevalence of syphilis was 2.6% (95% CI: 2.4%–2.9%) (793) in 2019 (Table 6).<sup>5</sup> The number of clinical notifications per province ranged from three cases (0.84%) in Mpumalanga, Limpopo, and the Eastern Cape Provinces to 176 (49.3%) cases in KwaZulu-Natal Province. Three provinces — Gauteng, KwaZulu-Natal, and the Western Cape — accounted for almost 90% of the notifications, 52% of live births, and 54% of syphilis-exposed infants in 2020 (Table 6). Interestingly, the antenatal survey 2020 showed low rates of maternal syphilis cases in these three provinces. The high number of CS cases in these provinces might suggest poor detection and reporting in other provinces.

**Table 6. Number of live births, and the prevalence of maternal syphilis and congenital syphilis notifications by province in South Africa, 2020.**

Province	<sup>a</sup> Estimated live births 2020 n (%)	<sup>b</sup> Maternal syphilis prevalence 2019 (%)	<sup>c</sup> Expected number of syphilis-exposed infants 2020 (%)	<sup>d</sup> Clinical CS notifications 2020 n (%)
Overall SA Estimates	899 303 (100%)	2.6% (95% CI: 2.4%–2.9%)	22829 (100)	357 (100)
Eastern Cape	104 319 (11.6)	3.8	3964 (17.4)	3 (0.84)
Free State	43 167 (4.8)	3.3	1425 (6.2)	6 (1.68)
Gauteng	194 249 (21.6)	2.3	4468 (19.6)	86 (24.09)
KwaZulu-Natal	181 659 (20.2)	3.2	5813 (25.5)	176 (49.3)
Limpopo	122 305 (13.6)	1.4	1712 (7.5)	3 (0.84)
Mpumalanga	87 232 (9.7)	2.0	1745 (7.6)	3 (0.84)
North West	53 958 (6.0)	1.7	914 (4.0)	10 (2.8)
Northern Cape	22 483 (2.5)	3.5	787 (3.4)	11 (3.08)
Western Cape	90 830 (10.1)	2.2	1998 (8.8)	59 (16.53)

<sup>a</sup> Estimated live births in 2020<sup>13</sup>

<sup>b</sup> Syphilis prevalence among antenatal women (National antenatal sentinel HIV and syphilis survey report, 2019) (assumed to have remained the same in 2020).

<sup>c</sup> The expected number of syphilis-exposed infants in 2020 was determined as the number of live births in 2020 multiplied by the proportion of women who were syphilis-positive in 2020.

<sup>d</sup> Clinical congenital syphilis cases notified through the NMC in 2020.



## Discussion

Quantitative data from 2020 case notifications and qualitative information from HCWs and surveillance officers were used to evaluate the attributes of the CS surveillance system. There were 357 CS infants under the age of 2 years reported. KwaZulu-Natal (49.3%), Gauteng (24.09%) and Western Cape (16.53%) Provinces had the highest clinical cases. However, maternal screening with syphilis prevalence was highest in the Eastern Cape (3.8%), Northern Cape (3.5%) and the Free State (3.3%) Provinces. The expected number of syphilis-exposed infants was highest in KwaZulu-Natal (25.5%), Gauteng (19.6%) and Eastern Cape (17.4%) Provinces. Notably, Gauteng, KwaZulu-Natal, and the Western Cape accounted for 52% of live births, 54% of syphilis-exposed babies, and 90% of notifications, suggesting poor detection and reporting of CS in other provinces.

Most of the HCW respondents reported clinical CS cases using the paper-based CNF (57.0%) with fewer electronic application (NMC App) notifications (36%). This means there was an over-representation of the paper-based notification system from HCWs who notify CS cases to the NMCSS. This may be due to training, availability, and ease of use of the CNF and CIF compared to the App. It could also be that HCWs are expected to report cases using their personal devices and data. The findings also showed that while HCWs had good knowledge of the surveillance system, the case definition was not easy to understand, and they did not always understand the procedures for reporting cases as it had been a long time since they had training. HCWs were not sure if the surveillance system met its objectives. The key informants acknowledged that most data had missing fields, and CNFs were not always submitted with their corresponding CIFs.

The evaluation of surveillance attributes showed that most of the reporting HCWs had a good knowledge of the CS reporting system, were willing to use it, and were aware of notification within seven days of diagnosis. However, most of the HCWs used paper-based notification, a laborious process involving printing, filling out, and scanning to the NMC database. It is likely that they still needed to adopt the electronic notification system because they are provided with CNFs and CIFs at health centres, and they may need internet access. NMC surveillance officers noted that CNFs were often not accompanied by their corresponding CIFs. This means that key informants had to follow up with the reporting HCWs or medical practitioners, prolonging the necessary data acquisition. Missing data may result in incomplete CS case reports, affecting the estimation of disease burden and hindering progress towards the elimination of CS by 2030.<sup>4</sup>

The CS case definition proved helpful to HCWs, who reiterated that it helps them to identify missed or untreated syphilis-exposed infants during pregnancy and helps them to diagnose infants that test positive after birth, even after maternal syphilis treatment. Although 36% of HCWs reported that it was easy to understand the case definition, more than half were either neutral or did not agree with this statement. This gap in their knowledge and understanding of the surveillance case definition means that HCWs may either miss CS cases or include patients who do not have CS. The evaluation also showed that HCWs needed more training, i.e., most had not had refresher training, and some had not had any training on CS surveillance. This corresponds with other studies showing that HCWs and medical practitioners lacked sufficient training on CS surveillance, including the use of the CS case definition, screening and testing of pregnant women, and notification processes.<sup>6,9</sup>

Limitations to this study include: missing information in the NMC line list, such as age data; missing information, such as maternal screening and treatment history in the clinical CS reports that prevented an evaluation of barriers to accessing prenatal care and receiving adequate treatment; use of a REDCap online survey of CS surveillance data that resulted in a low response rate; blank response fields or inappropriate response choices to close-ended questions; and no direct interviews or follow-ups on some of the questions.





## Conclusion & recommendations

Evaluation of the CS surveillance system in SA shows that the system is useful, acceptable, and timely. The notifying system is simple to understand and use, but the case definition is not easy to understand. Data quality is low due to missing data or CIF (which supplements the CNF by reporting maternal screening and treatment history). This indicates the need for closer collaboration between the CS surveillance system and healthcare sectors to avoid missed opportunities for CS prevention, provide training, and advance progress toward CS elimination.

It is recommended that:

- The NMC/CHIVSTI and the NDoH educate HCWs on screening and diagnosing infants with CS. This can be achieved by improving HCW's understanding of the surveillance case definition and how to notify cases on the NMC surveillance system. This will also help raise awareness of CS, thus improving the accuracy and timeliness of notification.
- The government's sexual and reproductive programmes and maternal healthcare centres continue to implement comprehensive syphilis screening, testing, and treatment for pregnant women and their partners to reduce the recurrence of infection. Maternal syphilis should be notifiable, which will help the CS surveillance system with maternal and broader clinical information.
- The NDoH, policymakers, and the NMCSS continuously communicate the urgency of eliminating CS by 2030. Training and frequent refresher training for HCWs on CS diagnosis, treatment, and follow-up of cases will improve case management and close the gaps in CS surveillance information.
- HCWs should be provided with better resources, such as electronic devices and internet connectivity, to enable the NMC App. This will alleviate under-reporting and improve data quality in the NMC case list.

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## Conflicts of interest

The authors declare no conflicts of interest.



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