

Policy Considerations for Reducing Congenital Syphilis



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Executive Summary

Rates of congenital syphilis (CS)—when a pregnant person passes the infection to the infant during pregnancy or birth—are continuing to climb at an alarming rate in the United States. Although preventable, case rates more than tripled between 2016 and 2020, with more than 2,000 cases reported in 2020 alone. CS can cause stillbirth, infant death, or other serious and permanent complications including musculoskeletal defects (e.g., impairments in the muscles, bones, and joints leading to temporary or lifelong limitations in functioning), vision and hearing problems, and developmental delays.

The current high rates of CS <u>mirror syphilis rates</u> among people who can become pregnant. While the majority of CS cases were reported from only a few states, the number of jurisdictions reporting at least one CS case is widespread with 46 states, Washington, D.C., and two territories <u>reported at least one case</u> of CS in 2021, up from 31 states and one territory reporting at least one case in 2012.

Timely <u>diagnosis</u> and <u>treatment</u> of syphilis among pregnant people can prevent CS, and many state and territorial health agencies recommend CS screening up to three times during pregnancy. The two <u>most common</u> missed opportunities for preventing CS are a lack of adequate treatment for the pregnant person despite a timely diagnosis, followed by a lack of timely prenatal care and timely diagnosis. Public health leaders can help lower CS rates by supporting policy solutions that reduce structural barriers to syphilis diagnosis and treatment during pregnancy and encourage better access to regular prenatal care for all pregnant people.

Pregnant and postpartum persons can experience structural barriers to care, including the burdens of poverty, stigma of substance use in pregnancy, citizenship status, healthcare coverage, low sexual literacy, and pregnancy. Providers may also encounter hurdles to

providing CS care, including lack of adequate training and guidance on clinical management of syphilis in pregnancy, a diminished public health infrastructure, and inadequate support for managing patients' social comorbidities—all of which may delay timely syphilis diagnosis and treatment.

While no single policy solution will address the structural challenges to diagnosing and treating syphilis among people who are pregnant, public health leaders can leverage several policy options that may reduce barriers to care. Drawing on states participating in ASTHO's Congenital Syphilis Community of Practice, this report focuses on promising strategies in four different policy areas to address rising CS rates: (1) prenatal syphilis screening policies and requirements, (2) Fetal Infant Morbidity Review (FIMR) boards, (3) providing care for pregnant people experiencing substance use, and (4) Medicaid coverage. A summary of the policy considerations can be found in Appendix A.



State/Territorial Health Officials' Role in Policy Development

State and Territorial Health Officials (S/THOs) facilitate policies that reduce the incidence of diseases like CS. S/THOs can impact programmatic decisions, often by using their direct authority to hire more <u>disease intervention specialists</u> to connect with people at risk for contracting CS. As knowledgeable and authoritative voices on public health issues, S/THOs can engage with and educate policymakers to implement evidence-based policies shown to lower CS rates. Based on the laws specific to their jurisdiction, the policy option selected could necessitate S/THOs to use their direct authority or influence to facilitate policy change.

DIRECT AUTHORITY:

Areas where public health agency leaders are authorized to act. For example, public health has the authority to create and implement strategic plans and performance monitoring systems (e.g., budget authority, delegated rulemaking power).

INDIRECT AUTHORITY:

Areas where other agencies are required to collaborate with public health agency leaders in the development or implementation of their policies or actions. For example, state departments of education may be required to adopt rules governing student athlete physical exams subject to conference of the department of health (i.e., other agencies have authority but must consult health department).

INFLUENCE:

Areas where public health leaders can encourage action by another party. For example, public health has influence in recommending data to human services or transportation authorities to support community health improvements (e.g., working with cabinet, legislative education, engaging federal delegations).



Required Syphilis Screening for Pregnant Persons

The number of reported cases of CS has increased every year since 2012 in the United States. CDC recommends that all pregnant women in the United States be screened for syphilis at their first prenatal visit, even if they've been screened previously. For women who live in communities with high rates of syphilis, women with HIV infection, or those who are at increased risk for syphilis acquisition, additional screening in the third trimester and at delivery is also recommended.

Most (42) states and Washington, D.C. have <u>laws that</u> require prenatal screening for syphilis, yet there is much variability among those requirements. Of the states that mandate prenatal screening, the majority require screening for syphilis at the first prenatal visit. There are not consistent requirements across states for screening during the third trimester and at delivery, with some states requiring it at both times, at one time but not the other, requiring this screening of all pregnant persons, or requiring it only among those at increased risk.

Requiring syphilis screening at three points of pregnancy care—for everyone at their first prenatal visit, for those at an increased risk at the beginning of the third trimester, and at delivery—is an evidence-based policy to reduce rates of CS. According to CDC, as of July 2021, eight states (Alabama, Florida, Georgia, Louisiana, Maryland, Michigan, Missouri, and Nevada) have codified a version of requiring screening at the three points of pregnancy care. These states require a screen for everyone at their first prenatal visit and require an additional screen be completed at the beginning of the third trimester or at delivery, making the other third point of care screening only required when the pregnant person is at increased risk for syphilis (e.g., live in communities with high rates of syphilis, are living with HIV, or engage in behaviors like sex with multiple partners). Three states' (Arizona, North Carolina, and Texas) laws require that screening be provided at all three of these opportunities.

Jurisdictions can encourage providers to increase testing during pregnancy through educational campaigns and statewide health alerts. Additionally, many states have mechanisms to enforce prenatal syphilis screening as a standard of care. For example, state professional licensure boards can offer education to providers and take disciplinary action should a provider not follow the standard of care for CS screening and treatment.

Each jurisdiction has laws and regulations that govern the practice of medicine and specify the responsibilities of the medical board in regulating that practice.

Jurisdictions can consider working with their state professional licensing board to increase awareness among providers about standards of timely screening and treatment of syphilis during pregnancy care.

Some states have "stand alone" enforcement mechanisms within their prenatal syphilis screening requirements. At least 14 states (Alaska, California, Colorado, Hawaii, Idaho, Missouri, Montana, Nevada, Rhode Island, South Carolina, Virginia, Washington, West Virginia, and Wyoming) have regulations to fine or penalize providers for neglecting to screen patients. In a majority of these states, healthcare providers can face criminal misdemeanor charges for not providing screening (Virginia provides a civil penalty and Virginia and Hawaii may revoke a provider's professional license). Jurisdictions with screening requirements without enforcement mechanisms can consider adding fines or penalties to ensure providers screen pregnant people.

Prenatal syphilis screening is not only important to the health of the pregnant person, but it is also the standard of care recommended by many national organizations such as CDC, the United States Preventive Services

Task Force (USPSTF), the American Academy of Family Physicians (AAFP), the American Academy of Pediatrics (AAP), the American College of Obstetricians and Gynecologists (ACOG), the American College of Physicians (ACP), the American Academy of Physician Assistants (AAPA), the American Public Health Association (APHA), and the American Nurses Association (ANA).

It is important that healthcare providers adhere to the professional standards of care put forth by their state as well as national recommendations to optimize the health of patients and the community and to avoid professional liability. Jurisdictions can consider working with state professional licensure boards or state healthcare professional associations to promote provider awareness of the standards of care recommended for prenatal screening and timely treatment of syphilis.

POLICY CONSIDERATIONS FOR REQUIRED SYPHILIS SCREENING:

- If a jurisdiction lacks prenatal screening requirements for syphilis, public health officials can consult their legal counsel to determine if they have the direct authority to require it through a health order, rulemaking process, or other mechanism. In some states health departments may have oversight of their state's medical licensing board and therefore may have direct authority. If the health official does not have the legal authority to require the screening, public health leaders can determine who has the authority and use their indirect authority by working with their state medical licensing board to develop education and provider awareness on the importance and benefit of syphilis screening during pregnancy care.
- Public health officials can review their jurisdiction's
 existing prenatal screening and disease reporting
 laws to determine whether syphilis screening is
 required. If screening or reporting is required, officials
 can consider the frequency and timing of required
 screening as well as the enforcement mechanisms to
 ensure provider compliance with the laws.
- Public health officials can provide educational outreach to state healthcare professional associations to ensure awareness of state requirements for prenatal syphilis screening and to learn of any difficulties or barriers practitioners may be facing.

Pregnant people who have sex with multiple partners, have transactional sex, use drugs, experience housing insecurity or homelessness, are incarcerated, or have late or no prenatal care are at increased risk for having a pregnancy outcome impacted by CS.

In addition to supporting screening efforts, some states have passed legislation that requires screening at three points of care and requires all pregnant people entering a medical facility as a new patient to be screened for syphilis. For example, in 2021 Nevada enacted AB 192, which requires syphilis testing during delivery for those at risk and expands the requirement to test pregnant people for syphilis. Nevada's SB 211 requires an emergency department in a hospital or other medical facility admitting a pregnant person to test for syphilis if the pregnant person indicates they have not had certain prenatal screenings and tests.

A 2018 statewide syphilis outbreak in Arizona saw the largest increase in cases among pregnant people and newborns. Following the outbreak, public health leaders reviewed 18 months of case data to determine if widespread third-trimester screening could have prevented infections. From that review, they discovered that nearly three-quarters of the more than 200 pregnant people diagnosed with syphilis got treatment; 57 babies were born with syphilis, nine of whom died. The analysis estimated that one third of the infections could have been prevented with screening in the third trimester. The state has since become one of the few that requires universal screening of all pregnant people at three points during pregnancy care.

Fetal Infant Morbidity Review and CS Morbidity Mortality Review Boards

Public health leaders can identify structural barriers pregnant people face in accessing prenatal care by implementing Fetal Infant Morbidity Review (FIMR) and/or CS Morbidity Mortality Review Boards. FIMR is a multidisciplinary, community-based, action-oriented process where teams meet to discuss case information to better understand fetal and infant deaths and missed opportunities for prevention. Members of these boards come from a variety of backgrounds (e.g., medical providers, WIC service providers, community-based organizations, county commissioners, community health workers, STI or infectious disease staff at state or local health departments) that conduct CS surveillance to identify opportunities for intervention at a systems level.

This form of CS epidemiology typically includes provider and pregnant parent follow-up and review of medical records to identify missed opportunities for disease intervention, barriers to seeking prenatal care, and provider-level barriers to completion of screening and treatment guidelines. Review boards are an important tool that localities use to identify specific missed opportunities for prevention and determine follow-up action aimed at system level changes.

As of 2020, there were 162 active FIMR teams in 27 states, Washington, D.C., Puerto Rico, and the Commonwealth of the Northern Mariana Islands; 80% are coordinated by state or local health departments and the others are led by hospitals, Federally Qualified Health Centers (FQHCs), and Healthy Start programs. More than 75% of FIMR teams are permitted or mandated by statute or administrative rules.

In areas with high CS rates, establishing a CS Morbidity Mortality Review Board or leveraging a FIMR board to review cases can help <u>identify missed opportunities</u> and prevention efforts unique to the jurisdiction. Review boards can also gather data and information on local systems and provide tailored solutions. For example, a <u>2017 study</u> showed that Louisiana congenital syphilis case review boards identified specific missed opportunities, including inadequate and delayed screening, treatment, or reporting. By sharing their findings, providers changed their practices to prevent future cases.



POLICY CONSIDERATIONS FOR FIMR AND CS MORBIDITY AND MORTALITY REVIEW BOARDS:

- Establish an FIMR or CS Morbidity Mortality Review Board through existing authority or work with policymakers to enact legislation to establish a review board. While many S/THOs have the direct authority to convene a review board, often legislation is required to provide that group clear authority to act or designate appropriate resources for the process. S/ THOs can influence the legislative process to ensure that the legislation aligns with the public health needs and to suggest the appropriate level of resources needed for success.
- States can enact legislation requiring the use of an FIMR in counties or areas with high rates of CS. In 2021, California passed <u>SB 65</u>, which-among other important prenatal efforts-requires counties that have five or more infant deaths in a single year and a higher infant death rate than the state average for two consecutive years to participate in the Fetal and Infant Mortality Review Process.

Case review boards equip communities to improve maternal and infant health outcomes. For example, in Texas an FIMR board reviewed a case where the birthing parent explained they were unable to attend prenatal care as they could not bring their other children with them in the Medicaid transport. The FIMR board report propelled the state into starting a pilot program to allow Medicaid patients the ability to use transportation with their children.



Reducing Barriers to Care for Pregnant People Experiencing Substance Use

Rates of substance use among pregnant people in the United States have increased over the last 10 years, with substance use becoming a behavioral risk factor for syphilis infection during pregnancy. Pregnant people experiencing substance use can face stigma and fear that may impede seeking or receiving care and treatment for their substance use and pregnancy. Among pregnant people who have a syphilis infection, those who use substances are less likely to receive adequate treatment than those who do not use substances. Various treatment options can successfully support recovery among pregnant populations but are underutilized in all substance use demographics. For example, only 12.2% of people who needed substance use treatment in 2019 received it at a specialized facility. More efforts are needed to address sustained engagement in treatment and recovery activities that support families and pregnant people.

Punitive policies that define substance use during pregnancy as a form of <u>child endangerment or abuse</u> can also prevent pregnant people from seeking care and treatment for substance use or engaging in prenatal care. Depending on the jurisdiction, if a patient screens positive for substance use, the healthcare provider may

be required to report their patient to child welfare services or the criminal justice system. This can result in the infant being separated from their parent after birth and/or the pregnant person facing criminal penalties.

One study recently looked at almost five million births in eight states and found that more infants were born with drug withdrawal symptoms in states with policies that penalize pregnant people compared to states that did not penalize pregnant people for substance use. This trend was observed both immediately after the policy was enacted and in the longer term. These types of policies can discourage pregnant people experiencing substance use from seeking prenatal care, making it more difficult to provide screening for syphilis.

Policies that overcome the effect of stigmatization, discrimination, and fear of punishment can resolve barriers to accessing prenatal care for many pregnant people. In 2016, Indiana passed a law prohibiting healthcare professionals from sharing drug screening information of a pregnant patient with law enforcement agencies without the patient's consent or a court order.

Additionally a number of states have prioritized making drug treatment more readily available to pregnant people by <u>creating targeted programs</u> and protection from discrimination for pregnant individuals. While access to services is an important component in addressing the health of the birthing parent, fear plays a large role in a person seeking care and their overall health.

The Indiana Pregnancy PROMISE (Promoting Recovery from Opioid use: Maternal Infant Support and Engagement) Program engages pregnant people experiencing opioid use and provides them enhanced case management during and up to 12 months postpartum at no cost for participants. The case managers ensure parents and infants are connected to resources to be healthy and well such as such as physical healthcare, behavioral healthcare, substance use disorder treatment, food security, safe housing, parenting education, and more. Indiana is one of eight states that received federal grant funding to support these efforts.

POLICY CONSIDERATIONS FOR PREGNANT PEOPLE EXPERIENCE SUBSTANCE USE DISORDER ACCESSING CS SCREENING AND TREATMENT:

- Public health leaders can support awareness and education about rising rates of CS and how stigma plays a key role in keeping pregnant people who use drugs from seeking healthcare services.
- Public health leaders can work with government partners, community organizations, and other groups to identify existing laws that disincentivize pregnant people experiencing substance use from accessing care and work to reduce penalties for accessing care. Public health leaders can leverage their influence to bolster care coordination and referral into treatment programs that will work with pregnant people and offer family-centered care, as well as increasing provider awareness and training. Family-centered care programs focus on parent-child relationships and provide support to families experiencing opioid use disorder. Treatment programs that provide childcare or offer some sort of assistance for families are particularly beneficial.
- Public health leaders can influence healthcare leaders to provide enhanced case management to support and connect pregnant people with healthcare, mental healthcare, and treatment as early as possible in efforts to reduce and prevent the negative impacts of substance use on both parent and child.





Medicaid Coverage

Medicaid is a health insurance program administered by states and territories according to federal requirements and is jointly funded by the states and federal government. In August 2022, 83.5 million people received healthcare coverage under Medicaid programs and Medicaid currently finances approximately 41% of all births in the United States.

Every state establishes and administers their own Medicaid program, so the populations and benefits covered vary across states. There are mandatory eligibility categories for Medicaid coverage, including qualified pregnant people and children, and also optional eligibility categories, including the adult expansion group available under the Affordable Care Act. States are also required by federal law to provide certain mandatory benefits, (such as laboratory and inpatient and outpatient hospital services) but can cover other optional benefits as well.

States deliver care in Medicaid in two main ways: directly paying providers ("fee-for-service") or through contracted arrangements with managed care organizations (MCOs) that oversee the delivery of services to the patient. State Medicaid benefits and care delivery approaches vary and public health leaders should consider these differences when comparing their program to others.

To change Medicaid eligibility, coverage, or other items states generally can either <u>amend their state plan</u> or seek <u>a waiver</u>—1915(b), 1915(c), or Section 1115. Public health leaders should work closely with their state Medicaid agency partners and experts. These partners can help to identify the best mechanism to adjust their state Medicaid coverage to support pregnant people and their partners at risk of contracting syphilis.

One way states have used the State Plan Amendment (SPA) process to ensure coverage for people who are or may become pregnant is by pursuing continuous eligibility and expanded coverage during the postpartum period. Continuous eligibility generally means that coverage continues even if the individual or family's circumstances change throughout the year.

Beginning in 2021 states were given a new option to expand postpartum coverage up to 12 months (instead of 60 days), even with changes in circumstances, by submitting an SPA. Under the Consolidated Appropriations Act of 2023, the 12-month extended Medicaid postpartum coverage option has been made permanent, whereas previously it was set to expire in 2027. Once states take up the option to extend the postpartum period from 60 days to 12 months, they will continue to receive federal matching funds. As of March 2023, 29 states and Washington, D.C. have extended this coverage, with eight states planning to implement the option.

States may also pursue broader initiatives to address related social needs through a Section 1115 waiver. The two most commonly missed opportunities for CS prevention are lack of timely prenatal care and lack of adequate treatment for the pregnant person despite a timely diagnosis. Section 1115 waivers can help address these intervention opportunities with Medicaid program and policy solutions that aim to enhance the quality of care enrollees receive and expand access to coverage, while also improving health outcomes and reducing disparities. For example, Arkansas' 1115 waiver grants beneficiaries participating in certain programs support to assist those with severe mental illness, substance use disorder, people with high-risk pregnancies and up to two years postpartum, and young adults at high-risk for long-term poverty assistance with housing support, nutrition support, education and case management support.

States can also leverage Medicaid in other ways to address both screening and treatment and to ensure coverage is not a barrier to accessing care. For example, in 2019 Alabama observed increasing rates of CS and, through a joint effort between the Alabama Department of Public Health (ADPH) and the Alabama Medicaid agency, Medicaid providers were informed both of ADPH screening and treatment recommendations and that Medicaid covered syphilis screening for pregnant patients outside of the global maternity code reimbursement structure.

Building upon and improving Medicaid policy to ensure support for adequate screening, treatment, and efforts to increase access to care for underserved populations is crucial in the efforts to reduce CS. States can work with their state Medicaid agency leadership, Medicaid subject matter experts, and legal counsel to explore the best mechanism to expand Medicaid eligibility and service coverage.

POLICY CONSIDERATIONS FOR MEDICAID:

- Optimize Medicaid eligibility and coverage for family planning and related services. This option may include expanding Medicaid eligibility for family planning services and maximizing Medicaid coverage for related services, including STI screening and treatment and other sexual health services. Medicaid and public health agency leadership can work together to explore options to maximize the reach of family planning services in their state.
- Public health leaders can work with their state Medicaid agency counterparts to explore additional ways they may be able to use their influence to pursue changes to Medicaid policy and provider manuals, agency administrative rules or policies, or managed care or administrative contracts that support the quality of prenatal care and services for pregnant people.
- State and territorial health agencies can build their relationship with Medicaid and be a valuable partner by sharing surveillance or other relevant data sources to shed light on disease trends and outbreaks as well as supporting education amongst Medicaid providers. Sharing this information promotes awareness of syphilis and other diseases and can highlight the importance of the issue and need for comprehensive coverage of syphilis screening and treatment.

The Colorado Department of Public Health and Environment started a partnership with their Medicaid partners to communicate with providers to sign up for Health Alert Network (HAN) to promote awareness of infection trends and to provide education and information through recommendations, such as screening in the third trimester. Colorado is also looking at building on these interagency communication efforts with data sharing agreements that are already in place and considering a newsletter to raise awareness with Medicaid partners.

Conclusion

Public health leaders can consider ways to promote the health and safety of pregnant people, neonates, and infants to reduce congenital syphilis rates. S/THOs can incorporate the promising policy considerations outlined above into states' plans, advocate for, and support to better provide access, treatment, and care for pregnant people.



ASTHO convened a Community of Practice from February- December 2022. The Community of Practice included ten jurisdictions with a large number of congenital syphilis cases and/or a large recent increase in cases.

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Appendix A. Summary of Policy Considerations.

Below is a summary of the policy options mentioned throughout this report that jurisdictions can consider. This list is neither exhaustive nor endorsed, only a summary of potential options jurisdictions can consider.

| Policy Area | Policy Considerations |
|---|---|
| Required Syphilis Screening for Pregnant Persons | • If a jurisdiction lacks prenatal screening requirements for syphilis, public health officials can consult their legal counsel to determine if they have the direct authority to require the disease screening through a health order, rulemaking process, or other mechanism. In some states health departments may have oversight of their states medical licensing board and therefore may have direct authority. If the health official does not have the legal authority to require the screening, public health leaders can determine who has the authority and use their indirect authority by working with their state medical licensing board to develop education and provider awareness on the importance and benefit of syphilis screening during pregnancy care. |
| | Public health officials can review their jurisdiction's existing prenatal screening and disease reporting laws to determine whether syphilis screening is required. If screening or reporting is required, officials can consider the frequency and timing of required screening as well as the enforcement mechanisms to ensure provider compliance with the laws. |
| | Public health officials can provide educational outreach to state healthcare professional associations to ensure awareness of state requirements for prenatal syphilis screening and to learn of any difficulties or barriers practitioners may be facing. |
| Fetal Infant Morbidity Review and CS Morbidity Mortality Review Boards | • Establish a FIMR or CS Morbidity Mortality Review Board through existing authority or work with policymakers to enact legislation to establish a review board. While many S/THOs have the direct authority to convene a review board, often legislation is required to provide that group clear authority to act or designate appropriate resources for the process. S/THOs can influence the legislative process to ensure that the legislation aligns with the public health needs and to suggest the appropriate level of resources needed for success. |
| | In efforts to be cost effective while also being responsive towards increasing rates of CS some states have worked to enact legislation that would require the use of a FIMR in counties or areas with consistently high rates of CS or when rates rise about a certain threshold. FIMR or CS Morbidity Mortality Review Board can provide public health leaders assistance on developing tailored interventions based on local analysis of missed prevention opportunities. |
| Reducing Barriers to Care for Pregnant People Experiencing Substance Use | Public health leaders can support awareness and educate about rising rates of CS and how stigma plays a key role in keeping pregnant people who use drugs from seeking healthcare services. |
| | Public health leaders can work with government partners, community organizations, and other groups to identify existing laws that disincentivize pregnant people experiencing substance use from accessing care and work to reduce penalties for accessing care. Public health leaders can leverage their influence to bolster care coordination and referral into treatment programs that will work with pregnant people and offer family-centered care, as well as increasing provider awareness and training. Family-centered care programs focus on parent-child relationships and provide support to families experiencing opioid use disorder. Treatment programs that provide childcare or offer some sort of assistance for families are particularly beneficial. |
| | Public health leaders can influence healthcare leaders to provide enhanced case management to support and connect pregnant people with healthcare, mental healthcare, and treatment as early as possible in efforts to reduce and prevent the negative impacts of substance use on both parent and child. |

| Policy Area | Policy Considerations |
|-------------------|---|
| Medicaid Coverage | Optimize Medicaid eligibility and coverage for family planning and related services. This option may include expanding Medicaid eligibility for family planning services and maximizing Medicaid coverage for related services, including STI screening and treatment and other sexual health services. Medicaid and Public Health Agency leadership can work together to explore options to maximize the reach of family planning services in their state. |
| | Public health leaders can work with their state Medicaid agency counterparts to explore additional ways they may be able to use their influence to pursue changes to Medicaid policy and provider manuals, agency administrative rules or policies, or managed care or administrative contracts that support the quality of prenatal care and services for pregnant people. |
| | State and territorial health agencies can build their relationship with Medicaid and be a valuable partner by sharing surveillance or other relevant data sources to shed light on disease trends and outbreaks as well as supporting education amongst Medicaid providers. Sharing this information promotes awareness of syphilis and other diseases and can highlight the importance of the issue and need for comprehensive coverage of syphilis screening and treatment. |

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