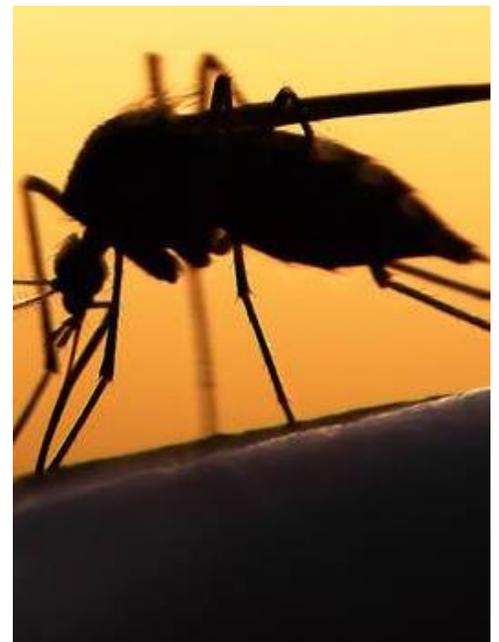




Beyond Zika:

Preparing Maternal and Child Health Programs for **Future Threats to the Health of Families and Communities**



In 2015, an outbreak of the Zika virus, which can be spread to people through mosquito bites, in Brazil, led to documented incidents of pregnant women giving birth to infants with birth defects and having poor pregnancy outcomes.¹ As the first documented mosquito-borne virus to cause birth defects, the Zika epidemic required a complex and coordinated response among federal, state, and local public health partners.

Infectious and noninfectious disease experts were involved, and many sub-systems were charged with protecting the nation's public health. From December 1, 2015 to October 2018, more than 7,400 pregnant women with evidence of confirmed or possible Zika virus infection were being monitored in the U.S. states and territories.²

From Dec. 2015 – Oct. 2018

7400+

pregnant women in the U.S.
with confirmed or possible
Zika virus infection

2017- 2019

Conversations brought light to
insights needed to strengthen health
and surveillance systems, and
prepare the workforce for future
emergency responses

The U.S. public health response to the Zika epidemic involved the following actions:

- Conducting rapid surveillance on Zika-affected pregnant women and using the findings to plan for services and update recommendations for treatment
- Developing and communicating clinical guidelines for health care providers caring for at-risk pregnant women and infants
- Providing coordinated care and services for pregnant women and infants and ongoing surveillance to refine clinical guidance and develop best practices for long-term monitoring and care³

Many lessons were learned from the 2016–2018 Zika response. In the realm of maternal and child health (MCH) programs, these were the most salient lessons learned:

- To effectively address Zika, MCH programs need to expand systems of care and networks to include non-traditional partners, such as local schools, border states and international communities, and airports, in addition to emergency preparedness and response and infectious disease professionals.
- Many Zika risk factors, which include living or traveling in countries that have experienced outbreaks or spending time in tropical areas where exposures may be higher, are beyond the locus of control of state and local public health departments. Thus, coordination with community partners and the general public is necessary.
- Health departments have a high degree of control over the level of their public health response efforts; public health professionals, in partnership with MCH providers, can address the level of response at a population-based level.
- State health departments can be most effective directing population-level Zika control efforts by coordinating with MCH professionals in the public and private sectors.

Key themes emerged regarding the types of strategies and activities initiated through the Zika response that can strengthen overall systems and infrastructure to respond to public health emergencies. This issue brief discusses the areas with the greatest potential to impact the ability of state public health programs to respond to future MCH public health threats. These areas of impact (or “impact points”) learned from the 2016–2018 national Zika response will be more fully explored through examples of implementation from Title V MCH programs that were actively engaged in the Zika response in their states. This information can inform local, state, and national leaders in MCH on how to respond to the current effects of Zika and future emerging issues for women of childbearing age, infants, children, and their families.

Future Impacts: Applying Lessons Learned from Zika to other MCH Public Health Threats

During the national Zika response, AMCHP, in partnership with the CDC, HRSA, and national organizations, convened MCH leaders (see Table 1) in several discussion groups and forums throughout 2017 to 2019 to reflect on lessons learned from Zika response efforts and implications for future MCH public health emergencies. These conversations contributed valuable insights that may strengthen efforts aimed at improving health and surveillance systems; they also served as a launchpad of ideas for preparing the workforce for future emergency responses.

Across the various stakeholder discussions that reflected on the CDC 2016–2018 Zika emergency response, the following three impact points were consistently mentioned:

- **Coordination and collaboration among MCH, clinical providers, and emergency preparedness professionals**
- **Clear communications and messaging**
- **Innovative strategies for future emergency responses**

These three impact points are priority focus areas for future responses to MCH public health threats. The following summarizes lessons learned for each impact point including what went well, suggestions for improvement, and state implementation examples.

Coordination and collaboration among MCH, clinical providers, and emergency preparedness

What we know:

Coordination and collaboration is at the forefront of all MCH issues and should be enhanced across MCH, clinical providers, and emergency preparedness efforts.

What was done well:

Provider-focused successes included establishing partnerships with military hospitals in Zika-affected states, developing provider training materials, and providing continuing education unit (CEU) certificates. Other promising initiatives included the creation of Zika clinics; incorporating Zika screening into emergency department (ED) visits; including a variety of health care professionals and sub-specialists in Zika screening, such as community health clinicians and emergency departments; and disseminating health education and travel recommendations in clinical settings and public spaces, such as health departments and airports. Successful emergency preparedness activities include effectively communicating the importance of protecting mothers and infants; effectively using Pregnancy Risk Assessment Monitoring System (PRAMS) in scaling surveillance systems; and integrating MCH in emergency management.

Suggested Improvements:

Future opportunities for improvement include engaging non-pediatric providers (e.g., family practitioners, nurse practitioners) in education and screening to broaden community reach; coordinating clinical management, surveillance teams, and infectious disease programs; and improving outreach and engagement with providers beyond state/local chapters of the AAP and utilizing community connections, such as parent organizations and early intervention services. Additionally, there is a need for strengthening MCH involvement in Incident Command Systems (ICS)¹ for continuous communication; providing opportunities for continuous emergency response preparedness/recovery training; and providing ongoing situational awareness training to help plan and conceptualize MCH risk, in the event of a public health emergency.



Table 1: Partners Engaged in “Lessons Learned” Discussions

Note that this is not an exhaustive list, but shows the range of partners engaged in this process.

Local Partners

- City and county health department leadership and staff
- Emergency departments
- Hospital systems

State Partners

- Birth Defects Registry
- Children’s National Health System
- Developmental-Behavioral Pediatrics (DBP) programs
- Emergency Preparedness & Response
- Family Voices affiliate organizations (state/territory/tribal)
- Intellectual & Developmental Disabilities Research Centers (IDDRCs)
- Leadership Education in Neurodevelopmental & Related Disabilities (LEND) programs
- Title V MCH and Children & Youth with Special Health Care Needs directors and staff
- University Centers of Excellence in Developmental Disabilities (UCEDDs)

National and Federal Partners

- American Academy of Pediatrics (AAP)
- American College of Obstetricians & Gynecologists (ACOG)
- Association of Maternal & Child Health Programs (AMCHP)
- Association of Public Health Laboratories (APHL)
- Association of State and Territorial Health Officials (ASTHO)
- Association of University Centers on Disability (AUCD)
- Centers for Disease Control & Prevention (CDC)
- Centers for Medicare & Medicaid Services (CMS)
- CityMatCH
- U.S. Department of Education
- Family Voices
- U.S. Health Resources and Services Administration (HRSA)
- March of Dimes
- National Association of County and City Health Officials (NACCHO)

¹ Incident Command System (ICS) is a standardized approach to the command, control, and coordination of on-scene incident management that provides a common hierarchy within which personnel from multiple organizations can be effective. ICS specifies an organizational structure for incident management that integrates and coordinates a combination of procedures, personnel, equipment, facilities, and communications. Retrieved from:

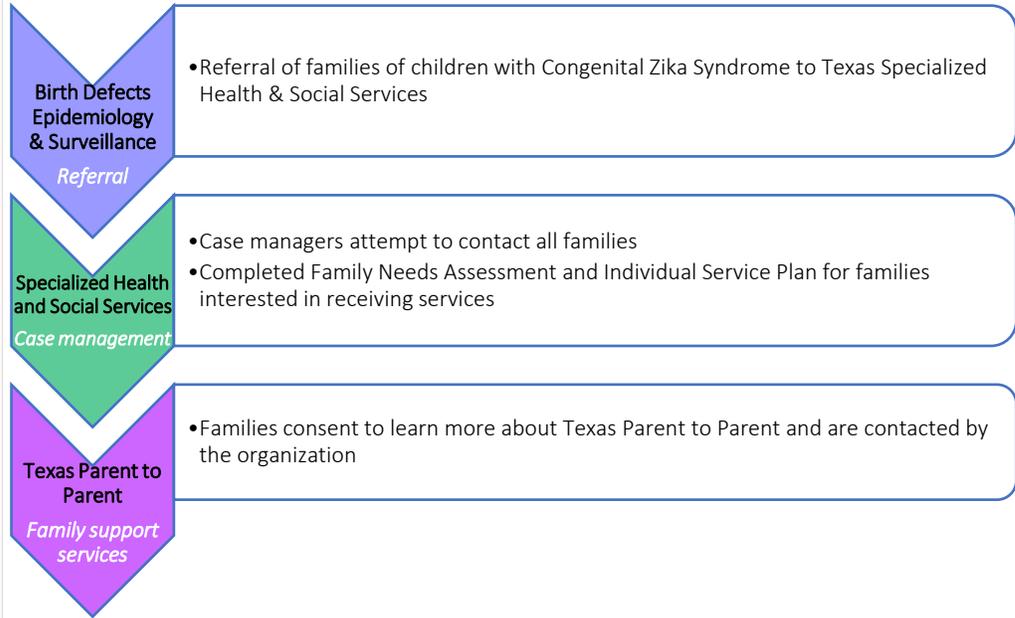
<https://training.fema.gov/emiweb/is/icsresource/assets/ics%20review%20document.pdf>

Strategy Used:

Case Management of Coordinated Referrals

Implementation Activities

- Developed the “[Texas Plan for System of Services](#)”: A cross-program workgroup focused on planning how systems of care would serve and identify children with congenital Zika syndrome.
- Developed collaborative partnerships between the Children with Special Health Care Needs (CSHCN) Systems Development Group, Texas Parent to Parent, Department of State Health Services (DSHS) Regional and Local Health Services, Texas Birth Defects Epidemiology and Surveillance (BDES) Branch, and Texas DSHS Specialized Health and Social Services (SHSS).
- Designated SHSS case managers as single point of referral, which helps reduce duplication of services. Most referred infants were eligible or already receiving services (i.e., Medicaid or Early Childhood Intervention Services, enabling case managers to review in the system.



Outcomes

- **Coordination of care:** The referral system developed through the Texas Birth Defects Epidemiology and Surveillance Branch is maintained and refers patients for structured regional case management.
- **Established relationships** between programs within DSHS and local health departments.
- **Identified sustainable funding** mechanism in DSHS.

Lessons Learned

- A more standardized definition of severe microcephaly diagnosis is needed. Factoring the newborn’s length and weight into the definition could result in more accurate diagnoses and avoid confusion for families.
- Communication is important and can facilitate understanding of already established capacity in other programs that can support the creation of a new, efficient system or process. This understanding will make it easier to create an efficient system for all programs involved.
- As a home rule state, where public health activities are primarily driven by local health departments, it is important to build strong relationships with city and county health departments.



Territory: American Samoa (AS) Impact Point: Coordination and collaboration	
Strategy Used:	Coordination from Development to Implementation
Implementation Activities	<ul style="list-style-type: none"> • Structured process for referral: Tracked and monitored all pregnant women diagnosed with Zika and referred to Zika client navigators once infants were delivered. • Developed a Zika care map based on the Learn the Signs. Act Early. (LTSAE) developmental milestones, to distribute to each pregnant woman diagnosed with Zika and to integrate Zika resources into existing provider education materials. • Collaboration in development: The Zika care map emerged from the following Department of Health programs serving children and women taking a lead in addressing Zika: MCH Title V; Maternal, Infant, and Early Childhood Home Visiting; Part C Early Intervention; Helping Babies Hear; and Federally Qualified Health Centers. • Connected local stakeholders to initiate discussions on modifying health care systems to meet the needs of mothers and their infants affected by Zika. • Enlisted CDC and HRSA to maximize resources that were made available to address the Zika outbreak in American Samoa. Collaborating partners were identified based on their roles and services to women and children in the territory. • Incorporated cultural expectations and the contextual experiences of families, which were foundational to coordinating efforts and understanding how families access health care systems for services.
Outcomes	<ul style="list-style-type: none"> • The care map proved to be a tool-in-progress; numerous adjustments were made to align services provided and the needs of the population. • Increased awareness of Zika preventive practices across the community. • Increased understanding of need for adaptable monitoring: as the cohort of babies born to mothers with confirmed or possible Zika infections get older, updates will be made to ensure programs meet population needs and that systems of care are accessible. • Relationship-building for client navigators working with women diagnosed with Zika infection improved how receptive these women were to using health services and their compliance with appointments.
Lessons Learned	<ul style="list-style-type: none"> • LTSAE materials helped client navigators coordinate services for children and their families; however, more training is required for staff to fully optimize use of these materials with clients. • Systems change is never easy; however, change is vital to providing quality health care services. • Care coordination is most successful when it focuses on integrity and accountability and is evaluated frequently at all levels of care.

Clear communications and messaging

What we know:

Mothers and infants will have unique needs during public health emergencies and should be priority audiences of communications and messaging during public health emergencies. Due to the widespread impact of Zika, targeted messaging to priority audiences was found to be critical and should be prioritized in future emergency responses. Furthermore, coordination of priority messengers was identified as a key driver for ensuring shared messaging for future public health responses. These identified audiences include community members (e.g., pregnant women, mothers, fathers, caregivers, and families); MCH providers; public health practitioners/emergency responders; health systems; policymakers; and federal, state, local, and territorial health agencies.



What was done well:

Using consistent communication modalities, in this case, CDC messaging and infographics, and providing access to training information in multiple languages were identified as successes of the Zika response. Another strength was that multicultural work groups and advisory committees were established and valued, and that community health workers were included in those groups to strengthen community relations and address community needs.

Suggested Improvements:

When dealing with future public health threats, it will be imperative to have diverse partnerships, especially as it concerns improving risk communication and community perceptions, understanding, and awareness. In addition, provider collaboration needs to expand, and on-the-ground community health workers need to be integrated in response activities.

State: South Carolina Impact Point: Clear communications and messaging	
Strategy Used:	Integrated Zika messaging into Text4baby
Implementation Activities	<ul style="list-style-type: none">• Text4Baby for Zika: Created a partnership between the Text4baby national office and Department of Health and Environmental Control (DHEC) to create and distribute five state-specific messages for pregnant women and new mothers on the risks associated with the Zika virus.• Close surveillance of areas with active Zika infection by DHEC Division of Acute Disease Epidemiology enabled prompt provision of updates to women receiving text4baby services.• Designated DHEC Communications as centralized source for message approval and dissemination, with regular webpage updates by the South Carolina Hospital Association.• Designated centralized location for Zika response efforts: Through coalition building, DHEC Maternal and Child Health facilitated the creation of new partnerships, such as with providers via the South Carolina Birth Outcomes Initiative, needed to utilize text4baby as a dissemination strategy and ensure adaptability of messages as needed.
Outcomes	<ul style="list-style-type: none">• Women who do not frequent the DHEC/CDC website were able to receive updates on their growing baby and critical Zika messages via Text4baby.• Provider support and buy-in: The Text4baby platform reinforced clinical partners’ communication with pregnant women.• CDC recognition as a novel approach to communicating with pregnant women.
Lessons Learned	<ul style="list-style-type: none">• Gaining approvals from Text4baby and the DHEC proved to be challenging; it was also challenging to coordinate messaging between partners, establish appropriate relationships, and contract state-specific language.• The vision provided by leadership in decision-making with state epidemiology, CDC, and the state director of public health helped garner the clinical input needed to inform the most up-to-date messaging for a novel communication strategy.• The approval and support received from providers facilitated the uptake and utilization of Text4Baby for Zika messaging to mothers and families.

Innovative strategies for future emergency responses

What we know:

The coordination of and response to past public health emergencies have traditionally included all levels of leadership.⁴ Although experiencing one public health crisis can prepare systems for future crises, no one crisis is the same. As such, the emergency preparedness and response field can never be fully prepared. Thus, leaders must encourage their staff to continue to be innovative and think outside of the box. Innovation and forward thinking require leaders to integrate identified strengths, areas for improvement, and emerging threats to MCH to ensure the workforce is adequately responsive to public health emergencies. This impact point also encompasses forward thinking about how to leverage funding and capacity building efforts in an emergency to strengthen the overall system of care and public health infrastructure.

What was done well:

Some potentially successful strategies include expanding testing capabilities by developing relationships with commercial labs; providing skilled personnel in health departments using models like CDC's Local Health Department (LHD) Initiative, health brigades,ⁱⁱ or traveling nurses; cross-training of existing staff to support enhanced surveillance; and leveraging or updating existing surveillance systems to ensure a more rapid way to collect data and predict future needs. Additional strengths include strategizing to better engage providers, as they are an integral component of testing, screening, and data sharing as well as ensuring opportunities to equip them with readily available information and data.

Suggested Improvements:

Challenges and areas for improvement include improving overall readiness training and emergency preparedness across various sectors (private, clinical, LHD, educational). One aspect of this is to ensure that MCH partners are involved to aid in mitigation, response, and recovery. Another lesson learned in forward thinking is the importance of engaging MCH early and often in emergency response so the workforce is prepared in the event of unexpected implications for MCH populations, as was the case with Zika. Zika prevention and response efforts demonstrated that personnel needed to be knowledgeable and skilled specifically in working with MCH populations, as well as in other public health skill areas. This workforce demand can be achieved by cross-training current professionals and via models such as CDC's LHD Initiative, health brigades, or traveling nurses.



ⁱⁱ For example, the Virgin Islands Title V MCH Program partnered with their epidemiology unit, CDC, and local pediatricians in the territory to provide specialty pediatric services to ensure that 92 babies born to Zika positive mothers received the necessary screenings. For more information on this specific brigade, visit: <https://mchb.tvisdata.hrsa.gov/Narratives/AnnualReport5/164aea9a-d7e1-4889-9c12-9b95db15db12>

State: New Hampshire
Impact Point: Innovative strategies

Strategy used:

Flexible active case Zika surveillance system

Implementation Activities

- **Added new data fields to the New Hampshire birth certificate worksheets, both paper and electronic:** The newly added fields are head circumference, length, and microcephaly. This entailed modifying the print layout, re-printing the birth worksheets, and adding the corresponding items to the New Hampshire Vital Records Information Network. The MCH epidemiologist developed a program to extract these data to a report for the Birth Conditions Program.
- **Drafted business requirements for adding functionality to the existing secure online electronic birth registration system** to allow surveillance questions to be added quickly during a response effort. For example, at delivery, it is now possible to assess whether the mother had recently traveled to any of a specific list of Zika-endemic areas.
- **Implemented a new and flexible surveillance feature, *Situational Surveillance*,** through the Division of Vital Records Administration for future response. There were two objectives for pilot testing: (1) test the system and related processes (e.g., rollout, education) and (2) assess current/emerging issue [neonatal abstinence syndrome (NAS)].

Outcomes

- **Development of a population-based surveillance system** to identify cases of microcephaly, with the flexibility to identify other birth defects and emerging threats at the hospital level.
- **Piloted NAS questions** on paper with hospitals in different geographic locations with various birth volumes—the system was later updated to enable questions to be added at the hospital level, allowing for a much quicker pilot testing in the future.
- **Rapid, active surveillance enhanced by infrastructure improvements,** which allow delivery of situational surveillance data daily by the New Hampshire Department of Health & Human Services (DHHS). This allows near real-time monitoring of responses to any situational surveillance questions.
- **Pending new development:** a secure interactive dashboard, to allow ongoing monitoring by New Hampshire DHHS of situational surveillance questions.

Lessons Learned

- Flexibility is required for surveillance systems to be adaptable to other emerging threats that affect birth outcomes (e.g., NAS, opioid use).
- Real-time reporting and data collection are needed to monitor the impact of Zika virus and other emerging threats on pregnancy and infant outcomes as events unfold.
- Many processes had to be refined in order to use this system (e.g., paper worksheets and training for users, data access, etc.).



State: Puerto Rico
Impact Point: Innovative strategies

Strategy used:

Family Workforce Development

Implementation Activities

- **Developed, implemented, and mobilized a newly developed system of care:** Beginning in 2016, the Puerto Rico Title V Children with Special Health Care Needs (CSHCN) Program was mobilized among the first responders to the Zika virus and served as the lead program for services for families affected by the Zika virus.
- **Family-based innovation in workforce development by elevating mothers to MCH workforce as professionals:** Family engagement & support advocates (FESAs) were 12 mothers of CSHCN and two mothers possibly with Zika-positive pregnancies that were recruited and trained to offer family-to-family support, share their input with directors and administrators at Regional Pediatric Centers (RPC), support service coordinators, help review and implement family surveys, and organize educational and social activities for families and staff.

Outcomes

- **Staff development:** The majority of CSHCN staff completed an adaptation process to understand the roles of FESAs.
- **Leadership acknowledged that FESAs streamline CSHCN's programmatic processes.**
- **FESAs fill a family engagement gap within CSHCN:** Since inception, the principal role of FESAs has been to support families and staff, and they have become leaders and have gained empowerment.
- **FESAs have succeeded as part of the family-centered model for emergency response.** Their firsthand experience navigating the systems of care enables them to empower the families. The Zika response provided opportunities to create innovative and unique CSHCN systems that are strengthened by including families as part of the workforce.

Lessons Learned

- As a first public health work experience for some mothers, challenges came up in learning to work as part of the system, and in transitioning from "receiving" services to "providing" services. Challenges included learning to communicate effectively and adapting to schedules.
- Providing adequate and appropriate training for FESAs as they support families' navigation of the health care system and provide support to service coordinators is critical.
- It is important to offer trainings to all CSHCN staff about family engagement and family/professional partnerships at all levels.
- Recruitment of families should be done through community-based organizations for families of CSHCN and RPCs. However, finding mothers of CSHCN able to work, part-time or full-time, due to family obligations can be difficult.
- A commitment of investment in learning and capacity development is needed to sustain the enhanced workforce created by FESAs.
- Continued collaboration between FESAs and CSHCN staff will showcase the commitment to diversifying the CSHCN workforce.



Other Lessons Learned

Takeaways from stakeholder reflections also indicated that the Zika response was an opportunity to elevate birth defects issues and create partnerships with programs that traditionally had not worked together. The Zika epidemic highlighted the importance of having an MCH lens, and specifically a developmental disability lens, to address public

health emergency preparedness and response in general. It provided an opportunity to strengthen birth defects registry systems and linkages to family and health care services. This has led to stronger programs that are able to respond quickly to other MCH threats, such as the opioid crisis and NAS and will inform future responses to emerging MCH threats.

Conclusion

Reflections from the Zika response offered three areas to prioritize in the event of future public health threats to MCH populations: (1) having strong coordination and collaboration among MCH staff and programs, clinical providers, and emergency preparedness; (2) providing clear, consistent communications and messaging to the public, providers, and partners at all levels in the systems of care; and (3) implementing innovative and forward thinking strategies that not only address the emergency at hand, but also strengthen programs, systems, and services overall. In addition, it was critical to leverage existing systems during the response. For Zika, existing systems included systems

and programs for developmental screening and monitoring, engagement and partnership with families and programs that address comprehensive needs of children and families affected by Zika (e.g., community and support services, care coordination, educational, health care, long-term services, mental health). These lessons learned can be used by national, state, local, and community partners to continue to address the ongoing needs of children and families affected by Zika. By presenting the lessons learned here, March of Dimes and AMCHP, with support from the CDC, aim to provide a framework for responding to future public health emergencies and threats to MCH.

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Additional Resources

- **AMCHP Zika and Birth Defects Resources:** <http://www.amchp.org/programsandtopics/CYSHCN/projects/Pages/BirthDefectsDevelopmentalDisabilities.aspx>
- **March of Dimes - Zika Virus and Pregnancy:** <https://www.marchofdimes.org/complications/zika-virus-and-pregnancy.aspx> (Available in [Spanish](#))
- **March of Dimes – Congenital Zika Syndrome:** <https://www.marchofdimes.org/complications/congenital-zika-syndrome.aspx> (Available in [Spanish](#))
- **March of Dimes Zika Coalition:** <https://www.marchofdimes.org/advocacy/zika-coalition.aspx>
- **CDC Zika Virus Website:** <https://www.cdc.gov/zika/index.html>

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