

A Framework for Coordination between Obstetric and Pediatric Providers in Public Health Emergencies: Lessons Learned from the Zika Outbreak in the United States, 2015 to 2017

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Abstract

Keywords

- maternal and infant health
- care coordination
- communication
- congenital threat
- public health

Emergency response to emerging threats with the potential for vertical transmission, such as the 2015 to 2017 response to Zika virus, presents unique clinical challenges that underscore the need for better communication and care coordination between obstetric and pediatric providers to promote optimal health for women and infants. Published guidelines for routine maternal-infant care during the perinatal period, and models for transitions of care in various health care settings are available, but no broad framework has addressed coordinated multidisciplinary care of the maternal-infant dyad during emergency response. We present a novel framework and strategies to improve care coordination and communication during an emergency response. The proposed framework includes (1) identification and collection of critical information to inform care, (2) key health care touchpoints for the maternal-infant dyad, and (3) primary pathways of communication and modes of transfer across touchpoints, as well

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as practical strategies. This framework and associated strategies can be modified to address the care coordination needs of pregnant women and their infants with possible exposure to other emerging infectious and noninfectious congenital threats that may require long-term, multidisciplinary management.

Key Points

- Emerging congenital threats present unique coordination challenges for obstetric and pediatric clinicians during emergency response.
- We present a framework to help coordinate care of pregnant women/infants exposed to congenital threats.
- The framework identifies critical information to inform care, health care touchpoints, and communication/information transfer pathways.

Emerging infectious diseases and other congenital threats present unique coordination and communication challenges for obstetric and pediatric clinicians that can result in gaps in critical care and follow-up such as delayed screening and laboratory testing, failures in transitions of care, lack of maternal and neonatal follow-up, and increases in morbidity and mortality.^{1,2} Potential for gaps in care escalates during emergency response when interdisciplinary coordination is critical but challenging.^{3–6} Rapidly evolving clinical recommendations and imperfect diagnostics may require shared decision-making models across obstetric and pediatric clinicians and shift decision making to clinical practice in the absence of jurisdiction-specific recommendations. Further, access to care including diagnostic testing and follow-up may be limited as jurisdictions scale-up response capacity.⁴ The public health emergency response during the 2015 to 2017 Zika virus outbreak in the United States and the identification of associated birth defects⁷ revealed missed opportunities for shared decision making in the clinical diagnosis, management, and follow-up of pregnant women and infants,^{3,4} highlighting the need to improve communications and coordination of care between obstetric and pediatric health care providers.^{3,4,8} For example, during the response to Zika virus, obstetric and pediatric care providers received targeted information for their specialty area. This approach may have inadvertently resulted in limiting opportunities for clinicians to build a shared framework of critical information and reduced communication with professionals outside their own specialization area. Although recommendations and models exist for care transition in various obstetric and pediatric settings,^{2,9} no broad framework has addressed multidisciplinary care of the maternal-infant dyad in the context of emergency response.

We describe a framework that can improve communication and transfer of critical clinical information across a multidisciplinary health care team overseeing the diagnosis, management, and follow-up of a complex congenital infection in the context of a public health emergency response. The children's interdisciplinary care coordination (ChICC) framework is informed by existing literature, individual expert opinions, and critical takeaways that emerged during the Zika virus response. This framework addresses specific challenges to shared decision making across clinical specialties including providing avenues and tools for information

transfer, positing roles, and responsibilities, and identifying critical contexts for shared decision making. The ChICC can be extrapolated to other emerging congenital threats that may require long-term, multidisciplinary management of maternal and child health.

Materials and Methods

On August 30 to 31, 2017, the Centers for Disease Control and Prevention (CDC), in collaboration with the American Academy of Pediatrics (AAP) and the American College of Obstetricians and Gynecologists (ACOG), convened the Forum on the Diagnosis, Evaluation, and Management of Zika Virus Infection among Infants (Forum) with the goals of obtaining individual expert opinion to: (1) inform development of updated guidance for diagnosing, evaluating, and managing infants with possible congenital Zika virus infection; and (2) identify strategies to enhance communication and coordination of care of mothers and infants affected by Zika virus.⁸ Specifically, we focused on addressing challenges to communication and coordination of care identified by clinicians and public health professionals during the response and confirmed by participants prior to the Forum, including identification of existing strategies, models, and tools to facilitate consistent and clear communication and transfer of information from obstetric to newborn to pediatric clinical services; clear communication of laboratory results across clinical specialty areas; identification of essential information from the maternal medical file needed for early diagnosis and treatment of infants with congenital Zika exposure; and avenues for creating a health care team that includes clinicians, families, and patients in optimal management of Zika virus exposed infants. Experts from various medical specialties, professional organizations, public health sectors, and federal agencies participated in the Forum.^a

Prior to the Forum, we conducted a scan of the literature focusing on challenges to communication and coordination of care. The purpose of the scan was to provide a foundation for discussion with Forum participants. The scan focused on literature related to Zika virus, cytomegalovirus, HIV,

^a See Adabanjio et al⁸ for a complete list of specialty areas, organizations, and federal agencies represented at the Forum.

hepatitis C virus, and rubella. We searched PubMed, Scopus, and Embase databases for articles published between January 2005 and August 2017. Key articles were summarized orally for Forum participants (➔Supplementary Material, available in the online version).

Forum participants provided individual input based on clinical experience and expertise about addressing challenges to care coordination, lessons learned from the public health response to Zika, and practical strategies to improve

care coordination that could be implemented for other emerging threats. Individual input was recorded by a notetaker and the discussion was audiotaped. Written notes and the transcribed audiotape provided a record of proceedings that was used as a reference for participant input.

The development of the ChICC framework was iterative. A proposed care coordination framework was drafted during the Forum and refined based on review of the proceedings from the Forum. This framework was shared with

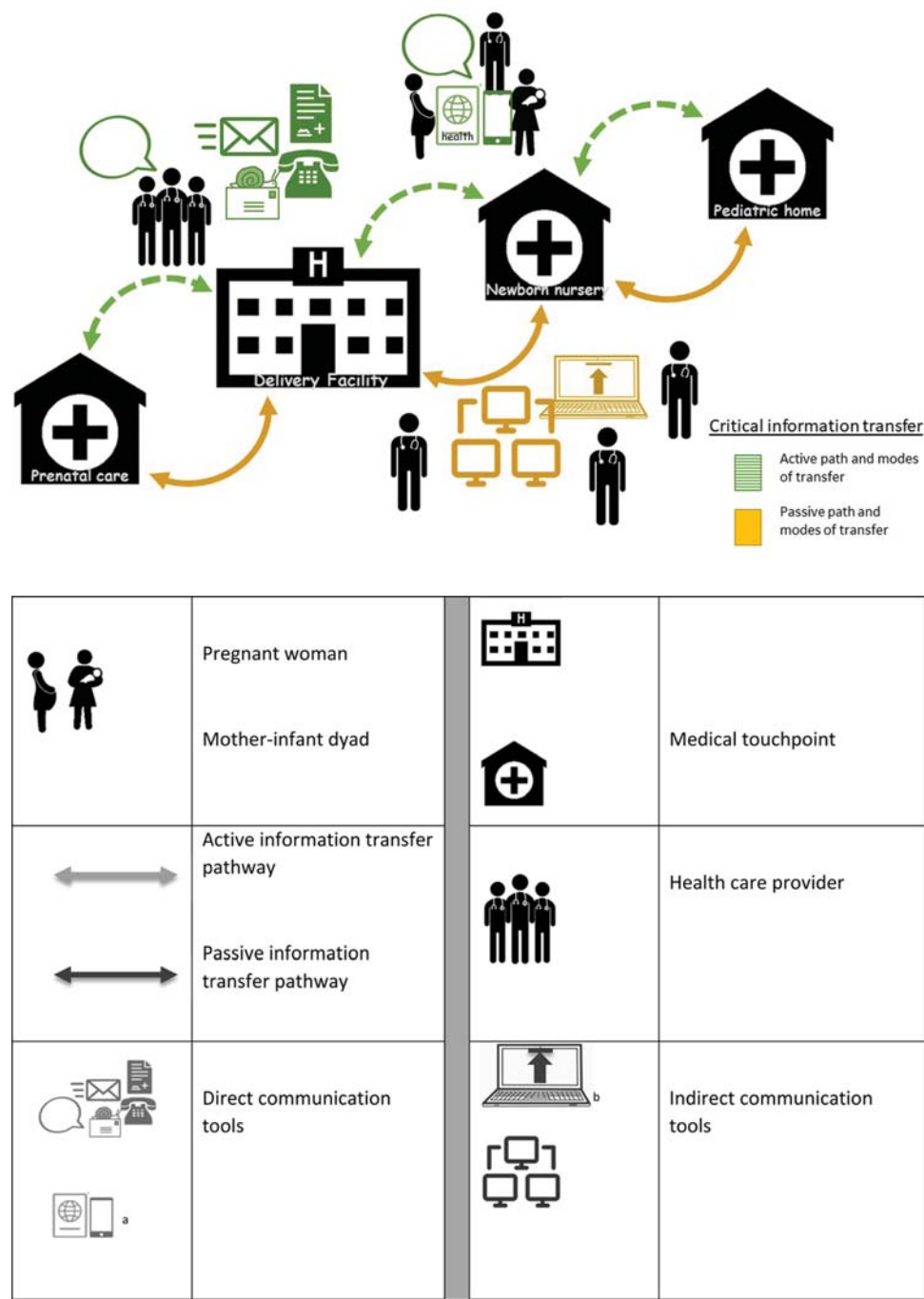


Fig. 1 Children’s interdisciplinary care coordination (ChICC) framework. ^aIcons clockwise from top right represent: letter, phone, smart phone applications, health passport, in-person exchange, email; center: postal service. ^bTop icon: electronic upload; bottom: electronic linkage.

participants and expanded and refined to reflect post-Forum input and peer-reviewed articles published through April 2019.

Discussion

Children's Interdisciplinary Care Coordination Framework

The ChICC framework (→Fig. 1) is based on the following three components: (1) identification and collection of critical information to inform care, (2) key health care touchpoints for the maternal-infant dyad, and (3) primary pathways of communication and modes of transfer that health care providers can use to transmit critical information between medical touchpoints, to other health care providers, and to the patient and family. Strategies are provided to facilitate implementation during public health crisis response.

1. Identification and collection of critical information: identifying the critical information to assess infant risk for congenital exposure and inform care facilitates multidisciplinary information exchange,^{10,11} promotes the accurate transfer of critical information across the continuum of care,¹² and reduces medical errors through targeted information exchange.^{6,9} Optimal treatment and follow-up is more likely when clinicians have common expectations about the specific information needed for successful care transitions.^{6,10}

Strategy 1.1: Identifying critical information: during emergency response to a novel agent, available information may be evolving rapidly but at varying paces across clinical specialty areas. A variety of sources can be used to inform the development of a list of critical information including available clinical guidance, standard data collection tools provided by the CDC, and existing clinical knowledge and experience with other congenital infections. For example, →Table 1 displays a broad list of critical clinical information about Zika virus, informed by clinical opinion and CDC guidance^{8,13} to be shared across clinical specialists using the ChICC framework. Although collection of all critical information is ideal, this list can be adjusted to accommodate available information, or adapted for other emerging or existing threats. Consensus between obstetric and pediatric teams about which information is essential to diagnosis and management is ideal. However, generating consensus can be difficult in the emergency response environment. In addition to using available guidance and tools, preparedness activities that bring together clinical teams that have few opportunities for day-to-day interaction can create a foundation that may facilitate smooth handoffs during emergency response.^{14,15}

Strategy 1.2: Adapt existing tools: adapting existing clinical tools enables more efficient collection of critical information compared with developing new tools. Clinical tools, such as those developed by CDC and partners to collect information about the maternal-infant dyad affected by Zika virus, provide a model for collecting and aligning critical information (→Table 1) across multiple tools.^b Clinical tools can help to organize, align, and structure critical information, guide

discussions with patients and providers about testing and treatment, and document communications.¹² The availability of multiple tools offers flexibility to providers.

Strategy 1.3: Joint training promotes shared language: joint training for maternal and pediatric providers fosters shared language around critical information. Provider education can be facilitated by strategic and clear communication from agencies providing clinical guidance, for example, simplified clinical algorithms or decision trees for providers to determine whom to test and when. Professional organizations, such as AAP and ACOG, can provide training and education for providers, as well as promote the uptake, and improve the utility of clinical guidance, tools, and the use of new and existing systems.^{9,16} As emergency response evolves or wanes, continuing education for health care providers is critical to ensure sustained adherence to evolving clinical guidance. Ongoing collaboration between CDC, AAP, ACOG, and other maternal and pediatric partners to develop and promote clinical education can increase opportunities for clinicians to build a shared framework and promote communication across specialization areas.

Strategy 1.4: Use plain language: plain-language explanations of laboratory results coupled with actionable and defined next steps for both provider-to-provider and provider-to-patient communications facilitate the collection and improves interdisciplinary understanding of critical information. This strategy can increase the likelihood that patient care will be timely and appropriate, and empower patients to be proactive.¹⁷ Available tools can be helpful in constructing plain-language communication materials (e.g., <https://www.cdc.gov/other/plainwriting.html>).^b

2. Key health care touchpoints: the ChICC framework distinguishes the following four key touchpoints for coordinating information transfer: (1) the prenatal care setting, (2) the delivery facility, (3) the newborn nursery, and (4) the pediatric medical home (→Fig. 1). Each touchpoint provides a unique opportunity for collection and communication of health information. Timing of communication and information transfer will vary depending on maternal access to health care, as well as pathways, and modes of information transfer that are available. Although some women will not have access to, or contact with all touchpoints, most women will access at least one during the perinatal period.¹⁸ There are a variety of sources that can provide guidance and recommendations about timing, roles, and responsibilities for information transfer from preconception to postpartum, neonatal, and pediatric care that can be applied to the ChICC framework.^{19–21}

^b Clinical tools developed by CDC and partners include the following: maternal Zika screening tool: https://www.cdc.gov/pregnancy/zika/testing-follow-up/documents/ZikaPreg_ScreeningTool.pdf; pediatric provider screening tool: <https://www.cdc.gov/pregnancy/documents/zika-provider-screening-p.pdf>; clinical summary form: <https://www.cdc.gov/pregnancy/documents/zika-clinical-summary-p.pdf>; and patient summary card: <https://www.cdc.gov/pregnancy/zika/materials/documents/zika-clinical-summary-card-508.pdf>.

Table 1 Critical information about Zika virus exposure of the maternal-infant dyad to be communicated and touchpoints where this information can be queried to inform coordination of care

	Prenatal care	Delivery facility	Newborn nursery	Pediatric home	Provides information about
Mother and Father					
Location of travel to/residence in area with possible Zika virus transmission	X ^a	○ ^b	○	○	Risk for fetal exposure
Date(s) of travel and/or time of residence	X	○	○	○	Timing of fetal exposure
Pregnancy trimester of possible exposure	X	○	○	○	Timing of fetal exposure
Was maternal Zika testing performed?	X	○	○	○	
Date(s) of testing: Zika IgM Zika virus NAT (serum and urine) ^c PRNT ^d Other (e.g., amniotic fluid, placenta)	X	○	○	○	Timing and type of maternal laboratory testing. Was maternal testing done according to available clinical guidance?
Laboratory result(s): Zika IgM Zika virus NAT (serum and urine) PRNT Other	X	○	○	○	Maternal Zika virus infection status
Was paternal Zika testing performed?	X	○	○	○	
Date(s) of testing: Zika IgM Zika virus NAT (serum and urine) PRNT	X	○	○	○	Timing and type of paternal laboratory testing. Was paternal testing done according to available clinical guidance?
Laboratory result(s): Zika IgM Zika virus NAT (serum and urine) PRNT	X	○	○	○	Paternal Zika virus infection status
Plain language interpretation of laboratory result(s)	X	○	○	○	Clear explanation of laboratory results
Actionable next steps based on laboratory finding(s)	X	○	○	○	Critical action steps for the next provider and patient
Fetus					
Was routine and/or prescribed fetal imaging (ultrasound or MRI) performed?	X	○	○	○	Possible atypical fetal development
Fetal imaging date(s), type(s) and result(s)	X	○	○	○	Was testing done according to available clinical guidance?
Interpretation of imaging result(s)	X	○	○	○	Is there evidence of atypical fetal development consistent with Zika virus exposure?
Actionable next steps based on imaging finding(s)	X	○	○	○	Critical action steps for the next provider and patient
Infant					
Date of birth		X	○	○	
Was routine TORCH screening performed?		X			Was testing done according to available clinical guidance?
Was testing for aneuploidy performed?		X			
Was Zika laboratory testing of infant performed?		X	○	○	
Date(s) of testing: Zika virus NAT (serum and urine) IgM (serum) Zika virus NAT (CSF) IgM (CSF)		X	○	○	Timing and type of infant testing
Laboratory result(s): Zika virus NAT (serum and urine) IgM (serum) Zika virus NAT (CSF) IgM (CSF)		X	○	○	Congenital Zika virus exposure status
Plain language interpretation of laboratory result(s)		X	○	○	Clear explanation of laboratory results
		X	○	○	

Table 1 (Continued)

	Prenatal care	Delivery facility	Newborn nursery	Pediatric home	Provides information about
Actionable next steps based on laboratory finding(s)					Critical action steps related to laboratory results for the next provider and patient
Follow-up testing recommended		X	○	○	Recommended clinical test(s) and specialist referral(s)
Was comprehensive physical exam conducted in accordance with published clinical guidance ^e ?		X	○	○	Was exam done according to available clinical guidance?
Date(s) of physical exam for: Head circumference Length Weight Head ultrasound and/or MRI		X	○	○	Timing and type of exam
Results of physical exam for: Head circumference (%) Length (%) Weight (%) Head ultrasound and/or MRI		X	○	○	Comparison to typical development
Date(s) of: Routine newborn hearing screen Hearing evaluation with ABR Ophthalmologic examination		X	○	○	Timing and type of exam
Results of: Routine newborn hearing screen (all infants) Hearing evaluation with ABR Ophthalmologic examination		X	○	○	Evidence of atypical results consistent with congenital Zika exposure
Interpretation physical evaluation including screening		X	○	○	Clear explanation typical and atypical results
Recommended follow-up evaluation(s)		X	○	○	Recommended follow-up and specialist referral
Developmental monitoring and screening ^f			X	X	Comparison to typical development
Date of appointment(s)			X	X	
Notable result(s)			X	X	
Interpretation of new information			X	X	Clear explanation typical and atypical results
Actionable follow-up steps			X	X	Recommended follow-up and specialist referral
Health care provider					
Point of contact for maternal primary obstetric healthcare provider	X	X	X	X	Point of contact for questions about maternal history
Point of contact for primary pediatric healthcare provider	X	X	X	X	Point of contact for pediatric medical home
Contact information for specialist referral(s)	X	X	X	X	Next steps for patient

Abbreviations: ABR, automated auditory brainstem response; CSF, cerebrospinal fluid; IgM, Immunoglobulin M; MRI, magnetic resonance imaging; NAT, nucleic acid test; PRNT, plaque reduction neutralization test; TORCH, screening for toxoplasmosis, other (HIV, hepatitis viruses, varicella, parvovirus), rubella, cytomegalovirus, herpes simplex, and syphilis.

^aX = primary touchpoint for collection of critical information.

^b○ = secondary touchpoint for collection of critical information.

^cMay also be "Zika polymerase chain reaction (PCR) (urine and blood)."

^dCDC clinical guidance states jurisdictions should make informed decisions about the utility of PRNT depending on the prevalence of dengue and Zika virus infection and observed performance of PRNT to confirm IgM test results. Available at: https://www.cdc.gov/pregnancy/zika/testing-follow-up/documents/Testing_Algorithm.pdf. Accessed: April 28, 2020.

^eSee "Interim Guidance for the Diagnosis, Evaluation, and Management of Infants with Possible Congenital Zika Virus Infection—United States," October 2017 for additional information on recommendations and timing. Available at: https://www.cdc.gov/mmwr/volumes/66/wr/mm6641a1.htm?s_cid=mm6641a1_w. Accessed: April 28, 2020.

^fCenters for Disease Control and Prevention and the American Academy of Pediatrics recommend that all infants receive developmental monitoring as part of routine care to ensure they are achieving appropriate developmental milestones. Available at: <https://www.cdc.gov/ncbddd/actearly/hcp/index.html> and <https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Screening/Pages/Screening-Recommendations.aspx> and <https://www.cdc.gov/pregnancy/zika/testing-follow-up/evaluation-testing.html>. Accessed: February 1, 2019.

3. Pathways and modes of information transfer: arrows in **Fig. 1** represent two primary pathways for critical information transfer. Arrows with broken lines represent an active transfer pathway in which one provider communicates directly with another. Arrows with solid lines denote a passive transfer pathway, in which critical information is recorded and stored in a format to be accessed by others, but it is not specifically directed to a particular recipient.

Modes of transfer can also be active or passive and encompass a range of technological sophistication. Icons above active transfer pathways (**Fig. 1**) depict direct or active interaction between communicating parties using verbal or written communication and tools (e.g., smart phone applications or health passports) that allow patients to be active in sharing and managing critical information. Advantages of direct modes include provider-to-provider and provider-to-patient engagement, empowerment of patients in the transfer of critical information, opportunities for real-time questions and clarifications to inform appropriate care, and increased likelihood that critical information is conveyed.^{9,12}

Passive modes of information transfer (icons below passive transfer pathways, **Fig. 1**) rely on technology (e.g., automated data uploads from electronic medical records or health care databases, and multisystem linkages) to convey information across touchpoints. Passive modes of transfer can be efficient for health care providers who have limited time.

Strategy 3.1: Anticipate information transfer pathways: identification of optimal pathways and modes of transfer before a crisis reduces the potential for gaps in capturing critical information during a crisis. Although we depict pathways of transfer as sequential across the touchpoints, these pathways may not be seamless from the prenatal care setting to the pediatric medical home, especially during a crisis response and among vulnerable populations who may have limited access to care. Transfer of critical information may bypass some touchpoints, creating gaps where information may be delayed or lost. Further, transfer may occur within and across health care systems with varying levels of interoperability.

Strategy 3.2: Standardize protocols and procedures: standardized protocols and procedures facilitate the movement of critical information across touchpoints and providers and reduce medical errors.^{5,21,22} The AAP and ACOG describe best practices for standardizing transitions of care^{9,12,19} that can be applied during emergency response. Handoffs that include both verbal and written components that capture the quantity and detail of shared information and clearly delineate the role of each health care provider are most effective.⁵

Strategy 3.3: Address challenges to linking medical records across systems and patients: technology to link electronic health care information is rapidly expanding and becoming more sophisticated. It is associated with improvements in maternal and neonatal care, and may make record linkage seamless in the future.^{23,24} During the response to a novel threat, adapting existing information collection systems,

such as the Zika Pregnancy and Infant Registry^c and Zika Birth Defects Surveillance system^d public health databases to facilitate record linkage may reduce time to implementation.

However, available medical and public health databases have limited utility for health care provider tracking of individual mother-infant pairs, can be geographically exclusive, and incompatible with systems outside a particular catchment area, and may have limited accessibility.^{16,24} Further, electronic storage of information may be structured with few limitations to size or scope of inclusion, and excessive details may obscure critical information.⁵ Access to linked records is also a substantial challenge for clinicians, particularly those working with complex emerging congenital threats,²⁴ as well as those working across medical systems. Interoperability of electronic record keeping platforms across health care systems may be limited. Current technologies can be resource intensive and may require extensive staff training and incentives to promote uptake.^{16,24,25}

Strategy 3.4: Align incentives to support care coordination: children and youth with special health care needs are best served through a coordinated approach across the myriad programs and agencies that touch them (e.g., Medicaid, public health, and social/human services).^{26,27} Care coordination services that address interrelated patient and family needs within a framework of the family-centered medical home promote optimal health and wellness, benefit children with complex health care needs, and meet the standard of care outlined by AAP.^{20,27} However, high-quality care coordination services require seamless transfer of critical information across medical touchpoints, particularly for women at risk for pregnancy complications who may have limited access to care.^{20,27} Alignment of Medicaid and private insurance reimbursement incentives to support care coordination, as well as linking care coordination to quality improvements, promote and expand its use.^{20,26}

Strategy 3.5: Intentional redundancy reduces gaps: programmed redundancy can reduce the potential for communication gaps, support timely transfer of critical information, increase the likelihood that critical information is received, and enhance preparedness for other threats to public health. The ChICC framework incorporates multiple pathways and modes of transfer offering flexibility and allowing providers' options for selecting appropriate methods to convey information. During the Zika outbreak, natural disasters (e.g., Hurricane Maria, 2017) prevented transfer of information through existing provider-to-provider channels, which increased the need for programmed redundancy.

As health information technology is refined and the ease of record linkage increases, programmed redundancy may become less essential for routine care but will remain a useful strategy in response to novel threats. Ultimately, health care systems and facilities must determine the most effective combination of methods to ensure that critical

^c Zika Pregnancy and Infant Registry: <https://www.cdc.gov/pregnancy/zika/research/registry.html>.

^d Zika Birth Defects Surveillance system: <https://www.cdc.gov/pregnancy/zika/research/birth-defects.html>.

information for the mother and infant is transferred cohesively in a clear, feasible, and cost-effective manner.

Implications and Remaining Gaps

The challenges encountered during 2015 to 2017 with congenital Zika infection identification, treatment, and management pointed to the need for strategies to promote communication of critical information in a fluid and rapidly changing outbreak environment and coordinated multidisciplinary care of the maternal-infant dyad in the context of emergency response. The ChICC framework may promote a better understanding and reinforcement of communication strategies among pre-, peri-, and postnatal health care professionals to provide optimal care in both routine and emergency response settings, as well as inform and improve preparedness efforts, for novel and emerging congenital infections. In combination with lessons learned from existing models for transferring critical information between obstetric and pediatric health care teams,^{23,28–31} the ChICC framework may facilitate clinicians' ability to leverage methods used for addressing other congenital infections.

With the emergence of coronavirus disease 2019, there is a continuing and pressing need to improve the collection of relevant health information about emerging congenital threats and enhance the interoperability of data systems. Additionally, training and education for clinicians and medical personnel concerning the diagnosis, evaluation, and management of Zika virus and other emerging infectious diseases continues to be a significant gap directly impacting clinical practice. Improving communication and care coordination between obstetric and pediatric providers through the ChICC framework may increase awareness of the needs of the maternal-infant dyad affected by emerging pathogens with potential for congenital transmission. Training options for health care providers are available (e.g., <https://www.cdc.gov/zika/hc-providers/index.html>) but barriers remain and require a multifaceted approach to remediate.³

Conclusion

With increased global travel, infectious diseases can spread faster and more widely than in the past. The Zika virus outbreak in the Americas and the associated birth defects underscore the need to improve communication and care coordination between obstetric and pediatric health care providers to promote optimal birth outcomes and infant development. The ChICC framework provides a model and strategies to improve care coordination and communication in the face of novel and emerging congenital threats.

Note

The findings and conclusions in this article are those of the authors and do not necessarily represent the official position of Centers for Disease Control and Prevention.

Conflict of Interest

None declared.

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