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A model partnership for communication and dissemination of scientific recommendations for pregnant women during the emergency response to the Zika virus outbreak: MotherToBaby and the Centers for Disease Control and Prevention

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Abstract

Background: During the Zika virus (ZIKV) outbreak, an urgent need existed for strong partnerships to disseminate Zika-related information to pregnant women and women of child-bearing age.

Methods: The Centers for Disease Control and Prevention (CDC) partnered with MotherToBaby, a national organization experienced in providing information about exposures during pregnancy to healthcare providers and the public, to disseminate accurate information about ZIKV infection during pregnancy. Partnership activities included regular information sharing, crosslinking information for the public, and promoting common messaging. Following the ZIKV outbreak, we reviewed common inquiries received as well as key strategies and lessons learned from the partnership.

Results: Between June 2016 and June 2019, MotherToBaby received 5,387 Zika-related inquiries from the public and health care providers. The majority (90%) of inquiries came from preconception, pregnant, and breastfeeding women. Concerns about travel, pregnancy, sexual transmission, and preconception guidelines comprised the top information requests. Live chat was the preferred method of communication for Zika-related inquiries. Key strategies and lessons learned from this partnership included: capitalizing on existing nationwide infrastructure and expertise, prominently referring to partners as a resource, promoting shared messaging using

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online resources and social media, holding regular calls to share information, and collecting data to identify common questions and revise messaging.

Conclusions: This examination of strategies, lessons learned, and metrics from MotherToBaby and CDC's partnership during the ZIKV outbreak can be applied to future partnerships to address emerging public health threats.

Keywords

messaging; partnership; pregnant women; prevention; Zika virus

1 | INTRODUCTION

As the Zika virus (ZIKV) outbreak swept across the Western Hemisphere beginning in 2015 (Kindhauser et al., 2016), the Centers for Disease Control and Prevention (CDC) and other global partners quickly launched efforts to harness emerging data about the virus and translate those findings into viable prevention strategies to protect the public. As evidence emerged, CDC made recommendations related to travel, pregnancy planning, pregnancy, and testing, in order to help protect current and future pregnancies from exposure to the virus and to best manage those situations in which exposures had already occurred. CDC recognized the need to partner with existing national organizations with the capacity to disseminate this important information to the public-at-large—particularly pregnant women and women of child-bearing age.

MotherToBaby and CDC have a long-standing informal partnership on safer medication use in pregnancy, and CDC reached out to MotherToBaby about expanding this partnership to include dissemination of accurate information about ZIKV infection during pregnancy. With more than 30 years of experience providing teratogen information to healthcare providers and the public, MotherToBaby has expertise in communicating risk about exposures and their possible effects in pregnancy. As a service of the nonprofit Organization of Teratology Information Specialists, MotherToBaby offers individualized evidence-based information that is convenient, confidential, and available at no cost in English and Spanish to all U.S. states and territories.

The primary goal of this partnership was to disseminate information to pregnant women and couples in order to prevent the serious birth defects that can be caused by congenital ZIKV infection as well as the neurodevelopmental abnormalities that are increasingly linked to congenital ZIKV infection (Rasmussen et al., 2016; Rice et al., 2018; Shapiro-Mendoza, et al., 2017). The objective of this brief report is to summarize partnership activities, common inquiries, and lessons learned to improve partnerships and information dissemination during a future public health emergency.

2 | METHODS

Throughout the ZIKV response, MotherToBaby and CDC held monthly (and ad hoc) phone calls to share information. CDC shared updates on the epidemiology of the outbreak and any implications for CDC's guidance, and MotherToBaby shared common inquiries and

misconceptions they heard related to public-facing messaging. CDC prominently placed a link to MotherToBaby on its Zika and Pregnancy webpages to direct consumers to this service for individualized consultation. Together, CDC and MotherToBaby, along with other national partners, promoted ZIKV prevention messaging. MotherToBaby produces and maintains consumer-friendly online resources including fact sheets, Baby Blogs, and topic-specific web pages, as well as a social media presence. All ZIKV-specific resources contained embedded links to specific content on CDC's Zika and Pregnancy website. Similarly, through a separate collaboration with March of Dimes that was facilitated by CDC, MotherToBaby engaged in social media outreach such as Twitter chats.

Following the ZIKV response, MotherToBaby analyzed the inquiries received, documenting the number of inquiries, requestors, common themes, type of contact, geographic area, and language preference of requestors. They also reviewed and summarized key lessons learned to inform future partnerships during public health emergency responses.

3 | RESULTS

3.1 | Zika-related inquiries to MotherToBaby

MotherToBaby received 5,387 Zika-related inquiries from the public and health care providers between June 2016 and June 2019.

- By requestor (Table 1): The majority of contacts (90%) came from “consumers,” with preconception, pregnant, and breastfeeding women reaching out 4,847 times. Healthcare providers comprised 224 total contacts, many of whom requested help interpreting preconception and testing guidelines.
- By topic (Table 2): The top concerns were about travel (47%), pregnancy (36%), sexual transmission (22%), and preconception guidelines (19%). Inquiries about ZIKV testing comprised 18%, followed by concerns about local transmission (4%) and breastfeeding (2%). These categories are not mutually exclusive, as many encounters included discussion of multiple Zika-related topics.
- By method of communication (Table 3): Live chat was the preferred method of communication for Zika-related inquiries (51%). Other means of contact included phone calls (30%), e-mail (9%), and text (6%).
- By geographic area (Table 4): Residents in every U.S. state, the District of Columbia, and the U.S. territory of Puerto Rico utilized the MotherToBaby service for Zika inquiries. The highest number of contacts by state came from California (569), New York (485), and Florida (295). In addition to contacts from the U.S. and U.S. territories, MotherToBaby fielded a total of 625 international Zika-related inquiries during this time, effectively expanding the reach of ZIKV prevention messages globally.
- By language preference: Data on the language in which Zika inquiries were provided are lacking; however, MotherToBaby's online Zika resources were well utilized in both English and Spanish. The Zika fact sheet (MotherToBaby, 2019) was accessed over 69,000 times in English and nearly 6,400 times in Spanish.

The four Zika-related Baby Blogs (MotherToBaby, 2020) were accessed almost 5,300 times in English and over 1,500 times in Spanish.

3.2 | Key strategies and lessons learned

Key strategies to the success of this collaborative effort, and the resulting lessons learned, include:

- *Capitalizing on MotherToBaby's existing nationwide infrastructure and expertise.* MotherToBaby's service was already in place and well utilized by consumers and healthcare providers for pregnancy exposure inquiries other than ZIKV. MotherToBaby's Teratogen Information Specialists had expertise in communicating risk, even when data on the exposures in question were limited. Tapping into this existing service allowed CDC to provide an immediate resource for families with questions about their individual situations, without the inherent delays associated with creating an entirely new service and training staff to meet this urgent need.

Lesson learned: Making use of the expertise and infrastructure of existing organizations saves critical time in responding to public health threats.

- *Prominently listing MotherToBaby on the CDC website as a resource.* MotherToBaby observed an increase in the number of ZIKV inquiries to its telephone and live chat counseling services as a result of its prominent placement on CDC's Zika and Pregnancy webpages, providing evidence that MotherToBaby filled a need that might otherwise have gone unmet. For example, as ZIKV-related research emerged and recommendations evolved, MotherToBaby served as a direct conduit from the CDC to consumers to interpret technical information, answer questions about changes and updates (e.g., reduced preconception wait times for men with ZIKV exposure, interactive global map guidance), and help consumers apply the guidance to their own circumstances.

Lesson learned: Referring the public to expert groups that individuals can contact directly, expands the ways that consumers can access essential, individualized information.

- *Using online resources and social media to reinforce CDC recommendations.* Cross-referencing CDC links and information in MotherToBaby's communications materials allowed MotherToBaby to help consumers looking for particular information or guidance from the CDC to focus on specific information that was most relevant to them, and then continue exploring the CDC website for additional information. Collectively promoting common messages and by sharing, retweeting, and liking each other's content and resources, partners were able to reach even more women, couples, and health care providers.

Lesson learned: Cross-referencing official guidance across organizations and educational formats extends the reach of the content and reinforces messaging by

demonstrating a consensus from trusted public health organizations. Using social media allows the continuous introduction of fresh and up-to-date content as key messaging evolves throughout emergent public health situations.

- *Holding regular calls between CDC and MotherToBaby.* Calls with CDC staff helped keep MotherToBaby apprised of emerging technical data and any resulting changes to recommendations in a timely manner. This allowed MotherToBaby to communicate current, evidence-based information and rapidly respond to questions about new information. This was especially important at times of significant changes to pregnancy and preconception guidance, such as the implementation of differentiated testing guidelines for pregnant women based on their travel locations (March 2017), the addition and subsequent removal of preconception testing recommendations (September 2016 and July 2017, respectively), and the reduction of preconception wait times for men from 6 to 3 months following possible ZIKV exposure (August 2018). Timely communication from CDC allowed MotherToBaby to update its existing resources or generate new educational pieces in advance of the changes.

Conversely, MotherToBaby provided feedback to CDC on possible areas for improved messaging or website content, based on trends in public inquiries. For instance, MotherToBaby was able to pass along public and healthcare providers' questions related to the timeliness of updates to country-specific Zika information, inquiries about how areas of active transmission were defined, and clarifications regarding the interpretation of travel guidance.

Lesson learned: Holding regular calls between key partners allows all members of the team to be ready to communicate accurate information and reinforce key messages. Knowing about upcoming changes to any guidance in advance also allows prevention partners the opportunity to ask their own clarifying questions before fielding questions from the public. In addition, regular communication allows groups making recommendations to obtain feedback on how key messages are received by the public and to consider adapting the content of messaging or materials accordingly.

- *Collecting data:* To best understand consumer needs related to ZIKV information, MotherToBaby collected data on who was contacting the service and common themes of the inquiries (e.g., preconception guidance, exposure in pregnancy, breastfeeding, travel, sexual transmission, testing). In addition, MotherToBaby shared this information with its March of Dimes partners to plan how best to serve the public moving forward. For example, when the organizations noticed an uptick in travel-related concerns, they organized Twitter chats around the topics of keeping Zika "on the radar" for travelers and informing the public of travel precautions, through the #ZapZika hashtag.

Lesson learned: Establishing a means early on to collect detailed data on public inquiries allows organizations to measure their impact and adapt messaging in response to areas of public concern or confusion.

4 | DISCUSSION

The partnership between MotherToBaby and CDC provided a nationwide resource for answering specific ZIKV-related questions from the public when media reports, online resources, and advice from healthcare providers were not always adequate. While the CDC supplied the surveillance data and developed the official recommendations, MotherToBaby helped healthcare providers and the general public interpret that information and apply it to the circumstances of specific couples or individuals.

The descriptive summary of inquiries to MotherToBaby demonstrates the utility of partnering with an existing, direct-to-consumer service to disseminate information during an outbreak. Many of the encounters reflected opportunities to educate women and couples about the risk of ZIKV *before* potential exposure could occur. Online chat was the most common format for consumers to receive information, which could be due to a variety of reasons, including the ability to connect privately during work hours, to receive a transcript of the conversation at the conclusion of the chat, and to be linked to important webpages during the chat itself. The availability of various contact methods allowed both providers and consumers to reach out at their convenience and receive the specific information they needed via their preferred mode of communication. Given the local transmission of ZIKV in Florida in 2016, reaching residents of this state was particularly important. Providing Zika resources in Spanish was also especially important given that many Spanish speakers in the U.S. have family in Latin American countries, where travel could increase the chance of exposure to ZIKV.

While not directly quantifiable, the rapid dissemination of information about the risk of ZIKV infection during pregnancy likely prevented infections and subsequent serious birth defects of the brain and eye, primarily among individuals choosing not to travel to areas with risk of ZIKV if they were pregnant or planning to become pregnant. MotherToBaby's efforts in disseminating this emerging information were focused on the primary prevention of serious birth defects, by helping ensure that women who had exposure to ZIKV in pregnancy had up-to-date information about recommended testing and follow-up. It is recognized that prompt identification of birth defects and neurodevelopmental abnormalities and timely referral to appropriate services can improve outcomes for the affected children and their families (Council on Children With Disabilities, 2006; National Early Childhood Technical Assistance Center, 2011).

As ZIKV has evolved from epidemic to endemic Status in the Western Hemisphere, CDC and MotherToBaby have continued their strong partnership. While CDC remains the primary resource for technical information and guidance on ZIKV, MotherToBaby serves a critical role in reinforcing the CDC recommendations related to pregnancy or pregnancy planning, travel decisions, insect repellents, ZIKV testing, and prenatal and postnatal care guidelines—and helping individuals interpret this guidance for their unique circumstances. The shared goals of this partnership are to protect the public, enable informed consumer decision-making, and reduce preventable birth defects due to prenatal ZIKV exposure. Lessons learned from this effort can be applied to future public health threats, especially

those in which informed consumer decision-making is critical to the prevention of birth defects or other adverse health outcomes.

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DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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TABLE 1

MotherToBaby Zika contacts by requestor type, June 2016–June 2019

Requestor type	<i>n</i>	%
Consumer	4,847	90.0
Provider	224	4.2
Other	78	1.4
Unknown	238	4.4
Total	5,387	100

TABLE 2

MotherToBaby Zika contacts by topic, June 2016–June 2019

Topic	<i>n</i>	%
Travel	2,518	46
Pregnancy	1,944	36
Sexual transmission	1,200	22
Preconception	1,047	19
Testing	964	18
Local concerns	218	4
Breastfeeding	116	2
Total	5,387	n/a ^a

^aTotal exceeds 100%, as many contacts covered more than one topic.

TABLE 3

MotherToBaby Zika contacts by communication method, June 2016–June 2019

Communication method	<i>n</i>	%
Online chat	2,752	51
Telephone	1,587	29.5
Email	500	9.3
Text	337	6.3
In person	48	0.9
Unknown	163	3.0
Total	5,387	100

TABLE 4

MotherToBaby Zika contacts by geographic area, June 2016–June 2019

Geographic area^a	
Alabama	13
Alaska	5
Arizona	76
Arkansas	6
California	569
Colorado	73
Connecticut	266
Delaware	9
District of Columbia	33
Florida	295
Georgia	126
Hawaii	9
Idaho	8
Illinois	122
Indiana	36
Iowa	31
Kansas	19
Kentucky	22
Louisiana	24
Maine	12
Maryland	97
Massachusetts	138
Michigan	88
Minnesota	75
Mississippi	9
Missouri	57
Montana	6
Nebraska	59
Nevada	22
New Hampshire	20
New Jersey	173
New Mexico	9
New York	485
North Carolina	186
North Dakota	4
Ohio	104
Oklahoma	26
Oregon	34
Pennsylvania	149

Geographic area^a	
Rhode Island	9
South Carolina	38
South Dakota	4
Tennessee	45
Texas	212
Utah	172
Vermont	4
Virginia	104
Washington	60
West Virginia	9
Wisconsin	50
Wyoming	1
U.S. Territories	4
Outside United States	625

^aThese numbers reflect only those contacts who reported their state or territory.