Research Agenda to Reduce Zika and Improve Maternal Child Health
Title:
Research Agenda to Reduce Zika and Improve Maternal Child Health

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Preface

Impactivo, LLC. is a social-impact consulting firm that specializes in the fields of health and healthcare, child development and education, and philanthropy. Impactivo received funding by the Patient Centered Outcomes Research Institute (PCORI) to convene experts within and outside of the maternal child health field to discuss opportunities for improving Zika prevention, diagnosis, and quality of care to develop a research agenda using a patient centered oriented research and comparative effectiveness research methods (PCOR/CER).

We are proud to present the Research Agenda to Reduce Zika and Improve Maternal Child Health which was developed by patients, clinicians and health system stakeholders in Puerto Rico to lay a foundation for research responsive to patient and community needs that can result in valuable information for preventing and addressing the maternal-infant health care challenges that have emerged as a result of the Zika virus. A research agenda is a list of pending research investigations that are necessary to obtain sufficient information on an issue, in this case on how to reduce the impact of Zika in Puerto Rico, particularly on maternal-infant health. This agenda also encourages researchers to pursue studies in the spectrum of Zika disease based upon a model of patient and community engagement where findings can have more direct practical applications.

The Research Agenda to Reduce Zika and Improve Maternal Child Health is addressed to patients, researchers, health system stakeholders, government and non-governmental organizations in Puerto Rico and abroad. It is based on the understanding that multi-stakeholder dialogue is essential in ensuring that research that helps patients, policy makers and stakeholders in making better informed decisions about health care system choices.
Introduction

The emerging Research Agenda to Reduce Zika and Improve Maternal Child Health is the result of a unique initiative to address the spectrum of Zika disease. It is intended to contribute to the body of knowledge about Zika from a perspective of the people most impacted. The purpose of this effort is to outline the research questions and outcomes most important to the patients and stakeholders who live with Zika and help inform the way in which public health emergencies like Zika are prevented and addressed.

This research agenda summarizes the themes discussed by participants of the Blueprint for the future: Reducing Zika Conference that took place in San Juan on March 23-24, 2017. The conference brought together patients, researchers, clinicians, scientists, and community leaders, among others, to identify unmet needs regarding action and research on Zika virus and maternal-health care. Experts from Puerto Rico, Europe, United States, and Latin America, and patients and community leaders directly affected by the Zika virus participated in this conference. Fourteen patients, 13 researchers, and over 40 stakeholders from diverse fields attended the event. The supportive and respectful interaction among participants was in itself a great opportunity to co-produce and share knowledge. The conference also served to convene partners and establish collaborative relationships that enhance local research capacity. The proceedings of the Blueprint for the future: Reducing Zika Conference are available in PCORI the webpage:


The conference promoted full engagement of participants in a democratic dialogue that led to the identification research questions, which resulted in this research agenda. Panel presentations on impact of Zika in Puerto Rico, evidence-based practices, response of professional and community groups, and patient-centered and comparative effectiveness research models, were each followed by a discussion session with ample participation of the audience.

The Blueprint Conference allowed small groups of diverse stakeholders to work on five core areas based on participant interests. The core areas included:
1. Pregnant women
2. Sexual transmission of zika
3. Vector control
4. Community Engagement
5. Infants and children

The work carried out in each core area discussion group was co-facilitated by a lead researcher and a process facilitator to ensure equitable participation in the discussion. The process facilitator presented the issues/questions that emerged in each small group to the large group for discussion. The work was carried out with active patient participation and the facilitation team completed a preliminary list of research questions, which were then prioritized through a collective voting exercise. After the Conference, reports prepared by the process facilitators were sent to the lead researcher to assure that all critical research themes that emerged in each discussion group have been incorporated to the list of themes.

**Agenda Structure**

The *Research Agenda to Reduce Zika and Improve Maternal Child Health* consists of three sections: Core Areas, Critical Research Themes, and Top Priorities. The list of priorities is expected to help guide resource allocations towards the areas of research with the most applicability.

The critical research themes are linked to the five-core research areas used to organize the discussion and debate at the *Blueprint for the future: Reducing Zika Conference* (see Appendix A). Critical research themes are those identified by the small discussion groups as described above, as gathered in the groups’ report, and those identified through the reports’ analysis by the lead researchers. The top priorities, depicted in Table I, are those identified through a discussion and prioritization exercise where all conference attendees participated. These do not necessarily correspond to a specific core area, as many themes are cross-cutting. Top priorities are not presented in order of importance.
Summary of issues discussed

The following is a summary of the most salient issues discussed at the Blueprint for the future: Reducing Zika Conference. This summary contextualizes the research priorities and critical areas identified. It also includes recommendations on services and needs that go beyond the agenda.

Core area: Pregnant Women

This core area refers to issues related to the health of pregnant women at risk of Zika virus infection or to the health of pregnant women who have been diagnosed with the infection. It includes, but is not limited to:

- Coordination of care for pregnant women
- Quality of obstetrics and gynecology care
- Patient education and commitment
- Wellness, health promotion and healthy lifestyle
- Mental health and psychosocial services for pregnant women
- Diagnostic evaluations (e.g., sonograms, auditory assessments, vision tests, neurological tests)

The group discussing this area expressed concern about the lack of communication among health providers and the lack of information accessible to mothers and women who are planning to become pregnant about zika and its consequences which they indicated prevents them from making informed decisions. There was also concern on the lack of information that families have about existing services; the way medical plans are addressing the situation; and the low degree of mass media education about the prevention of Zika virus, among others. The group participants emphasized the urgency to disseminate information that already exists and of involving the research community in gathering and developing the information that is still missing. Recommendations were aimed at improving existing information services and platforms with the intention of making them increasingly effective.

Participants also discussed the need to create a surveillance system of pregnant women to be able to contact them and inform them pregnant women about Zika and other risks. Additionally, participants voiced the importance of strengthening the communication among health providers to improve
comprehensive treatment and follow-up; the need to engage more mass media, as well as other social networks to serve as information forums; and the importance of looking at previously existing intervention programs to address similar issues with the purpose of resuming strategies that have been successful. The group also identified the need to provide guidance and support programs for families, especially those with greater social and economic disadvantage, to offer tools to work not only on physical health but also on the emotional and mental health aspects for mother exposed to Zika.

**Core area: Sexual transmission of Zika**

This core area refers to issues related to the sexual transmission of the Zika virus and to the health of the parents before a fertilized egg is implanted in the woman's uterus. It includes, but is not limited to:

- Prevention of unplanned and adolescent pregnancies
- Prevention of sexually transmitted diseases
- Pre-conception health-related risk factors that include: not been vaccinated, infectious diseases, medical conditions, psychiatric conditions, exposure of parents to infected body fluids, genetic factors, nutrition, environmental exposures, psychosocial stressors, medications, special populations, reproductive history and health promotion
- Availability and sustainability of contraceptive methods

The group that met to discuss this area focused on education on methods to prevent Zika and other sexually transmitted diseases. It also discussed means that could be used or continue to be used to prevent sexual transmission of Zika. The modalities used to disseminate information about contraceptives and the current difficulty to provide education about these methods was also addressed. The group discussed different populations and generations perception on issues related to sexuality and importance of creating a sense of urgency to address the current tolerance toward mosquito transmitted diseases because the vector has always been in our environment. Participants agreed that education was fundamental, and discussed the responsibility of professionals and communities in addressing issues related to sexual transmission. Participants also concurred that the participation and inclusion of a diverse set of patients and stakeholders was essential in developing educational programs that can reach different segments of the population.
Core area: Vector control

This core area includes issues related to the control of Zika virus transmission through the bite of the mosquito Aedes Aegypti. It includes, but is not limited to:

- Vector control surveillance and prioritization, including laboratory capacity
- Chemical and behavioral resistance of the mosquito, including changes in its behavior
- Individual and community actions to prevent mosquito bites
- Efficient use of available resources to control vectors
- Strategies to attack the mosquito in all stages of development
- Ecologically appropriate control
- Communications in situations of urgency or risk and use of the media
- Integrated management for vector control

The group that discussed this area focused on the importance of individual, community and societal roles in vector control. Specific issues discussed included: logistics around the use of traps; educational and publicity campaigns; alternatives to improve access to information; transparency of information in an emergency; curricular changes or changes in public policy in relation to Zika education; and the need for a sustained dialogue to generate results. The recommendations made by the group focused on the importance of recognizing the extent to which information is being disseminated and where they will begin to take action on Zika.

Core area: Community engagement

This core area includes issues related to the active participation of the community on initiatives to improve the prevention of the Zika virus and care to patients. It includes, but is not limited to:

- Community self-management
- Preparing for outbreaks and disasters
- Community Outreach and program enrollment
- Education and health promotion
- Development of alliances and collaboration throughout health care and social services to meet needs of patients (specialized medical care, social service needs, etc.)
The group that discussed this area focused on the experiences of its members, most of which work in community contexts around the Island, and on challenges faced educating and promoting an active role of the population. One of the main challenges identified is the lack of recognition of the Zika virus as an important public health issue and the lack understanding of individual responsibility for control and prevention. The group reflected on the initiatives in which they are actively working and recognized that they need to measure their effectiveness in terms of changes in personal practices and behaviors. In order to meet these challenges, the panel recommended a national study on knowledge, attitudes and perceptions about Zika that would be the basis for the articulation of an integrated strategy among all sectors to educate citizens in reducing the impact of the virus. At the community level, it was recommended that this study be adapted and validated with the participation of community members using methodologies such as community based participatory research. Building on the findings, national strategies and intervention strategies at the community level would be designed.

Core area: Infants and children

This core area includes issues related to the care and follow-up of babies at high risk of presenting or already presenting with developmental problems associated with the Zika virus in childhood. It includes, but is not limited to:

- Coordination of care for infants exposed to zika virus
- Understanding the implications of exposure to zika virus in vitro and for infants
- Preventive and developmental health exams
- Follow-up
- Maternal and child health
- Services to address special needs, for example: physical and speech therapy.

During the discussion of this small group several topics were tackled, mostly those related to the improvement of health care services. Some examples of identified needs include: to reduce the long time devoted by Zika diagnosed babies and caretakers to attend medical appointments; to improve communication among health care providers; to improve access to specialty and subspecialty care; and to eliminate duplication of efforts between government and health professionals.
Top Priorities

Priority 1: Communication systems/strategies to disseminate vital information to the public and healthcare providers in public health emergencies

This research priority is highly relevant where important questions have arisen on the need to effectively reach out the public as well as health care providers to keep them properly informed on how to prevent the transmission of Zika virus and to manage its short and long-term outcomes. The identification and use of communication methods and media attuned to specific needs and preferences of the public is critical to promote individual and collective active engagement. The effectiveness of communication strategies targeted to specific age groups such as adolescents, elders, young adults and people of reproductive age, as well as communication strategies used to efficiently convey information to health care providers, need further investigation. Research on behaviors, practices and attitudes could provide information from where to start developing communication strategies as mechanisms to achieve action and mobilization outcomes.

Priority 2: Education and orientation to patients, communities, and providers to promote specific actions to prevent Zika and to care for pregnant women and their offspring

The impact of specific prevention and care models on the prevention of Zika virus is largely unknown. A variety of health care approaches (i.e. individual vs group prenatal care; diverse management protocols) are used to address the needs of pregnant women and diagnosed infants, without taking advantage of the opportunity to perform comparative effectiveness research. Research on best practices of clinical care as well as best practices on education is of utmost importance to translate knowledge to actual individual and community action based on a well-informed decision-making process. Validation of diagnostic protocols and screening measures is critical to harmonize healthcare actions and thus to promote a better utilization of resources. Long term clinical follow-up and corresponding community education on the development of Zika-diagnosed infants requires longitudinal research on the virus impact along the process of child development. It also requires investigating the relationship between the impact of the disease in child development and the moment of virus infection.

1 Numbering of priorities is arbitrary and does not represent a particular order of preference.
Priority 3: Integration between surveillance and information to providers, coordination among institutions, and articulation among available community resources

This research priority is highly relevant, since serious questions have emerged in Puerto Rico about the fiscal sustainability of many government and non-government organizations that provide essential services to underserved population. It is critical to research mechanisms to properly articulate available services, including the promotion of partnerships between organizations, and the proper management and integration of surveillance and clinical data to improve information accuracy and access. Longitudinal research and long-term clinical follow-up also require a strong surveillance system, able to provide updated, accessible, and reliable information.

Priority 4: Lack of empathy toward and stigma carried by pregnant women diagnosed with Zika

The emotional burden that Zika imposes upon diagnosed women was identified as an important area in need of research. In addition to lack of empathy and stigma, the lack of supporting networks, imprecise information on the long-term impact of the disease, multiple and often repetitive follow-up appointments and interviews, and economic hardship, are some areas pointed out as potential determinants of emotional stress that Zika diagnosed pregnant women experience. There is a need to measure and monitor women response and adaptation processes and their effectiveness in preventing functional problems. The complex interactions of individual, cultural, social, and economic conditions as determinants of the wellbeing of the pregnant women diagnosed with Zika are an important area for research.

Priority 5: Engagement of groups and citizens into multisector work

Multisector has the capacity to address the issues posed by the Zika virus prevention and care. Health risks imposed by this infection are not limited to a specific part of the population, although the lack of proper housing, access to health care, information, and other, are acknowledged as elements that increase risk. This challenge points out the need of interconnectedness among sectors engaged in
action. As the community role is no longer expected to be passive one, there is a need to develop a knowledge base on the determinants that contribute to enrich community participation and activity, as well as the determinants of success in community-based partnerships. Factors that are likely to produce benefits when various stakeholders participate in a common effort also need to be studied. Research on this area should illuminate engagement of groups to address health risk situations related to other vector borne diseases.

Table I. Top Priorities

Puerto Rico Research Agenda on Zika Maternal-Infant Care

1. Communication systems/strategies to disseminate vital information to the public and healthcare providers in health emergencies.
2. Education and orientation to patients, communities, and providers to promote specific actions to prevent Zika and to care for pregnant women and their offspring.
3. Integration between surveillance and information to providers, coordination among institutions, and articulation among available community resources.
4. Lack of empathy toward and stigma carried by pregnant women diagnosed with Zika.
5. Engagement of groups and citizens into multisector work.
Conclusion

This Research Agenda to Reduce Zika and Improve Maternal Child Health brings together the perspectives of patients, researchers and stakeholders living through the zika outbreak in Puerto Rico who were convened for two days of work at the Blueprint for the future: Reducing Zika Conference carried out in March 2017. Researchers and specialists from the United States, Latin America and Europe were also convened and participated fully in the activities to provide further context of the zika outbreak on an International level.

The purpose of this effort was to produce a patient centered research agenda to guide future efforts in this field. However, the value of the work carried out in this event cannot be fully captured in this document. For the first time on the Island, these diverse sectors worked together with ample patient participation that may be a model for future collaborations. A research community was born out of this effort which continues to meet to this day. The depth of the discussions was also significantly enhanced through the participation of patients and the communities directly affected by the outbreak. As a result, this research agenda is actionable and questions are highly relevant.

Answers to the research themes and question posed may better enable us to more effectively respond to Zika and future emergent epidemics. The lessons learned by working with a patient-centered approach has already impacted the capacity of participating groups in facing similar problems and has the potential to change the way we face public health emergencies and maternal child health efforts.
### Research Agenda to Reduce Zika and Improve Maternal Child Health

<table>
<thead>
<tr>
<th>Core Research Areas</th>
<th>Critical Research Themes by Core Area</th>
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| Pregnant women      | • Which are the best care models for care for zika positive pregnant women  
|                     | • Strategies for communicating information and providing education in an evolving environment to better meet the needs of pregnant women  
|                     | • Strategies to achieve an effective team work among health professionals across diverse settings  
|                     | • Best practices to address transmission of other vector and sexually transmitted diseases to pregnant women  
|                     | • Stress levels resulting from a zika positive diagnosis  
|                     | • Best practices to reduce stress levels and/or stigma in zika positive pregnant women  
|                     | • Explore experience of women who were Zika positive during their pregnancy to evaluate the services they received, their effectiveness and unattended areas  
|                     | • Cost effectiveness studies of funding necessary to cover the needs of zika positive pregnant women.  
|                     | • Strategies for managing the impact on the economy, tourism and health while responding to public health emergencies.  
|                     | • Effectiveness of prenatal care interventions to prevent Zika  
|                     | • Socioeconomic profile of Zika positive pregnant women |
| Sexual transmission  | • The impact of behaviors, practices and attitudes about human sexuality in different generational group on receptivity to information on sexual transmission of zika and other sexually transmitted diseases  
| of zika             | • Infant outcomes of zika infections transmitted through vector vs sexual transmission  
|                     | • Strategies to guide reproductive life planning  
|                     | • How Zika virus affects other sexually transmitted diseases  
|                     | • Provider-patient relationship and the flow of information between them  
|                     | • Impact of social networks on patient education about Zika  
<p>|                     | • Stigma related to Zika |</p>
<table>
<thead>
<tr>
<th>Vector control</th>
<th>Community Engagement</th>
<th>Infants and children</th>
</tr>
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</table>
| • How effective are biological vs. chemical measures to reduce the mosquito population  
• What factors influence behaviors that inhibit and/or promote individual and community action for vector control  
• Strategies to manage household waste  
• Factors that influence "the culture of doing nothing"  
• Possibility of virus transmission through mosquito eggs | • How can we collect what the population knows about the Zika and use it as a basis for educating about what is still unknown  
• Patient’s perception about the risks and actions they need to take to deal with the contagion  
• Effective use of media  
• Strategies for communicating information and providing education in an evolving environment on the Zika virus  
• Best indicators of effectiveness of educational interventions in a community. Identification of the indicators to assess educational interventions in the community  
• Communication strategies that facilitate community action and mobilization (not just increase in knowledge)  
• Most effective strategies in minimizing the transmission of vector-borne diseases; individual strategies vs. community strategies  
• Role of participatory research and collaborative partnerships in the promotion and prevention (or management) of public health emergencies as epidemics  
• Community’s perception of its role in controlling public health emergencies | • Identify all risk factors for infants associated with congenital Zika syndrome and/or zika during infancy  
• Benefits and risks of breastfeeding when the mother is Zika positive  
• Successful communication models for training of patients and providers  
• Analysis on health services from the perspective of the patient  
• Validation of available screening tests with our population of children  
• Length of time Zika virus stays in the body  
• Impact of the time of transmission on the Zika-diagnosed child, transmission during a specific pregnancy trimester vs early childhood  
• Barriers to better coordination of services for this population |
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