

# Exhibition ‘Zika Affecting Lives’: an experience report

## *Exposição ‘Zika Vidas que Afetam’: um relato de experiência*

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**ABSTRACT** The Zika virus epidemic in Brazil mainly affected women and children and mobilized responses from science, society, and governments between 2015 and 2018. The Zika Social Sciences Network promoted the exhibition ‘Zika Affecting Lives’, an unprecedented event for Fiocruz 120th anniversary. This narrative aims to report the experience of constructing the exhibition, emphasizing the contribution of women – mothers, managers, health professionals, and researchers. The exhibition is a scientific dissemination device built collectively from October 2018 to August 2020. The method involved the participation of various groups and institutions affected by the epidemic representatives – researchers, users, professionals, and health managers – through interviews, workshops, and meetings. Such participation included the design, production, finalization, validation, and readaptation of the exhibition to an online version format, in the context of the Covid-19 pandemic. The results show the potential and the challenges of collective construction – an experience that could affect other experiences. The exhibition’s narrative is made chiefly by women, from different viewpoints, based on the issues that affect them, and highlights their prominent role in mobilizing and responding to Zika in science, politics, and society.

**KEYWORDS** Women. Zika virus. Disaster emergencies. Social participation. Scientific and educational events.

**RESUMO** A epidemia do vírus Zika, que atingiu o Brasil entre 2015 e 2018, afetou, sobretudo, mulheres e crianças, mobilizando respostas da ciência, sociedade e governos. A Rede Zika Ciências Sociais promoveu a exposição ‘Zika Vidas que Afetam’, mostra inédita para os 120 anos da Fundação Oswaldo Cruz (Fiocruz). O objetivo desse relato foi trazer a experiência da construção da exposição, com destaque para a contribuição das mulheres – mães, gestoras, profissionais de saúde e pesquisadoras. A exposição é um dispositivo de divulgação científica construído coletivamente, entre outubro de 2018 e agosto de 2020. O método envolveu a participação, por meio de entrevistas, oficinas e reuniões, de representantes dos vários grupos e instituições afetados pela epidemia: cientistas, usuários, profissionais e gestores da saúde. Tal participação ocorreu desde a concepção, produção, finalização, validação e readaptação da exposição à versão on-line, no contexto da pandemia de Covid-19. Os resultados mostram as potencialidades e os desafios do modo de construção coletiva – uma experiência que pode afetar outras experiências. A narrativa da exposição é feita majoritariamente por mulheres, sob diferentes pontos de vista, a partir das questões que as afetam, e evidencia o seu papel destacado na mobilização e resposta à Zika, na ciência, na política e na sociedade.

**PALAVRAS-CHAVE** Mulheres. Zika vírus. Emergências em desastres. Participação social. Eventos científicos e de divulgação.

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## Introduction

The Zika virus epidemic (ZIKV) that hit Brazil between 2015 and 2017 affected, above all, women and children and mobilized various responses from science, society, and the State<sup>1</sup>. Several women eventually postponed the decision to become pregnant during the health emergency. Pregnant women had to protect themselves against the disease, given a situation of uncertainty regarding infection risks and consequences. Those who had their babies born with the Zika Virus Congenital Syndrome (ZVCS) searched relentlessly for information and answers to ensure their children's best treatment and living conditions. These women found themselves<sup>2</sup> in settings such as maternity hospitals and hospital waiting rooms.

Mothers of Zika-affected children soon organized associations in different regions of the country and contributed to the construction of knowledge about ZVCS and strategies for coping with it. These women underwent a shared experience of unpredictability and lack of control, which overwhelmed any individual project for the future and established stories of reconstruction, which were the basis for the mobilization of their union<sup>2</sup>. The narratives of collective actions, which followed their unique experiences, were soon perceived as causes of the different effects of their political organization. Families came to know along with several professionals the syndrome in the experience of building effective explanations for the multiple dimensions of illness and care.

The Unified Health System (SUS) was decisive in establishing responses to the epidemic. Managers and professionals had to reorganize and reprogram health systems and services given the new demands for care and care for children with a suspected and diagnosed syndrome<sup>3</sup>.

Investment in research and innovation was central to fighting the epidemic, with national and international resources, besides establishing a network and groups of specialists and institutions and involving researchers from

different scientific areas<sup>3</sup>. In this process, we highlight the action and leadership of women in the great revealing discoveries about the virus and its consequences.

One of the leading scientific health institutions in the country, the Oswaldo Cruz Foundation (Fiocruz), was involved in several fronts of response to the Zika virus epidemic. It produced research, support for surveillance policies and systems, strengthening of health services, production of inputs and technologies, communication and information to society, and qualification of professionals<sup>4</sup>. In this context, the Zika Social Sciences Network (RZCS), which has funding and researchers from national and international institutions, was created and led by Nísia Trindade Lima and Gustavo Correa Matta. It mainly focuses on the implications of the Zika epidemic for science, health, and society<sup>5</sup>. One of its goals is

[...] to articulate education and research practices with the knowledge and strategies produced by social movements, health, social assistance professionals, managers, and users of the health system<sup>6(1)</sup>.

In celebration of its 120 years, Fiocruz presents the Exhibition 'Zika Affecting Lives' (<https://expozika.fiocruz.br/>). The result of a collective construction process and scientific research actions, the exhibition was conceived by the RZCS, held in partnership with the Museum of Life (House of Oswaldo Cruz/Fiocruz), and inaugurated in March 2021, date close to the 5th anniversary year of the Emergency Public Health Declaration of International Importance (ESPII). It aims to promote involvement with the problems arising from the epidemic and stir reflections on the lives of different people affected by the Congenital Syndrome, who cannot be made invisible or forgotten.

This account aims to show the experience of the community and participative construction of the exhibition, highlighting the relevant contribution of women – mothers, managers,

health professionals, and researchers. It covers the period from October 2018 to August 2020, in which the authors coordinated the participatory curation process, which involved the design, production, completion, validation, and readaptation of the exhibition to the online version in the context of the Covid-19 pandemic.

## Material and methods

The exhibition is a collectively constructed scientific dissemination device. The method involved the participation of representatives of the various groups and institutions affected by the epidemic through interviews, workshops, and meetings (scientists, users, professionals, and health managers), which occurred in all stages of the exhibition's development (design, production, completion, and validation), including its readaptation to the online version.

Much of the information and material used for the exhibition derived from research carried out within the RZCS. More than half of the people interviewed were women.

Another portion of the information used in the exhibition derived from the discussions held at the Workshop, also organized by the RZCS, at the XII Brazilian Congress on Collective Health in July 2018<sup>7</sup>. The 'Letter of Recommendations for Confronting the Consequences of Zika Virus Epidemic in Brazil'<sup>6</sup> was elaborated on that occasion. It was approved by the Deliberative Council of Fiocruz and generated a motion in support of the fight against Zika at the XVI National Health Conference in 2019<sup>8</sup>.

The event was attended mainly by women, who engaged in collective strategies to change uncertainty, inferring decisions and public policies in the name of care and better living conditions for children and their families. The engagement of different individual and institutional stakeholders blurred the boundaries between technical development and the social dimension of the epidemic, returning

the discussion to the production of responses to the public debate and political arena, establishing a true socio-technical network<sup>9</sup>.

These meetings were an opportunity to articulate the representations of science, health services, and families around a political commitment to public health and the lives of children, which expanded perspectives beyond issues related to the production of scientific knowledge. Experts and non-experts together managed to abstract their interests, place themselves from the viewpoint of common interest, ask different questions, and produce plausible recommendations.

The exhibition design and production processes were no different. They showed different types of collaboration between experts and non-experts in the research, both in situations in which specialists debate the issues and define methods for addressing them and when the results of the studies are widely disseminated to the general public<sup>9</sup>. In this sense, the exhibition results from a dialogue between scientists from different areas, health managers and professionals, civil society representatives, mothers, and relatives of children diagnosed with ZVCS. The public collection derives from families, health services, research institutions, and the RZCS.

Three meetings were held between October 2018 and August 2020 during the curation process, engaging representatives of science, health services, and families. On these occasions, the coordinators presented the roadmap project and the preliminary results regarding the content, organization, and layout of the exhibition. Everyone was assured the right to speak, without hierarchy, in a shared knowledge production process, which enriched the discussions. We emphasize that all construction stages were submitted to the group validation process.

The agreed objective was disseminating knowledge based on scientific research and collective construction and stirring emotions, empathy, and concern in the face of the consequences and coping with Zika. Thus, a simple

language was planned, with a narrative made through short texts, photos, videos, and games.

The exhibition was planned to be inaugurated in person at the Post Office Cultural Centre in Rio de Janeiro, in April 2020 and for national and international itinerancy. However, the context of the Covid-19 pandemic led to the suspension of the in-person exhibition and readapt it to an online version. This format expanded access to its content.

In the virtual exhibition, the language incorporates digital elements that must provide dynamism to the content. The biggest challenge in the design stage was to get as close as possible to a visiting experience that was not simply accessing a website. The online model required a review of the videos produced for the in-person version to ensure light and agile content and visiting time. Thus, after a short general introduction, the visitor could ‘walk’ through the exhibition and view the contents of the four modules, in whatever order they prefer. As a result, a demand for greater integration between some vital video content elements was observed.

One of the fundamental issues was to ensure inclusion, interpreted here as an action by which groups of people’s distinct features are valued and recognized<sup>10</sup>. The issue of disability gained greater visibility precisely during the Zika epidemic because of the possible effects of ZVCS on children’s lives. In this sense, the exhibition project included accessibility features (color contrast, alternating font size, and audio description) to offer similar access conditions to all<sup>11</sup>. Digital tools were integrated to remove barriers to communication. The content was translated into the Brazilian Sign Language (Libras), English, and Spanish.

Considering that most of the Brazilian population accesses internet content exclusively via cell phones and smartphones and social networks have been necessary means of social mobilization since the beginning of the Zika epidemic, the online exhibition prioritized access through these devices. Above all, the method of collective construction and

the resources used to expand access to the exhibition respond to the need to produce

[...] environments and instruments that allow the Brazilian population to participate in a more democratic and citizen-oriented fashion in debates involving science and technology, particularly in the field of health<sup>12</sup>.

The research that originated this paper followed the Resolutions CNS/MS N° 510, of April 7, 2016, and CNS/MS N° 466, of December 12, 2012. It was approved by the Research Ethics Committee (CEP) of the Sergio Arouca National Public Health School under Opinion CAAE 67311617.8.0000.5240.

## Results and discussion

### Design and roadmap: narrative, symbols, and affection

The exhibition aims to tell the story of the current Zika epidemic in Brazil, further disseminating knowledge about how responses were constructed and their impact on people’s lives. It shows the global threat posed by the Zika virus and its current consequences from the Brazilian perspective. It also points out challenges and paths in the daily lives of affected children, their families, and caregivers. The exhibition is also the result of work that marks the 120-year history of Fiocruz and reflects the institutional commitment to science, life, public health, and its current challenges<sup>13</sup>.

The *Aedes aegypti* mosquito and images of the heads of babies with microcephaly were the primary visual representations during the Zika global epidemic<sup>14</sup>. The exhibition’s symbol is the intertwined adult and children’s hands. Hand in hand that refers to care, affection, love, and concern for the other. They symbolize a feeling of acceptance and protection, solidarity, partnership, and cooperation to overcome the Zika epidemic and

its consequences. They represent the broad social and political mobilization required on the various action fronts regarding issues that affect, above all, women and children.

The name 'Zika Affecting Lives' was chosen with female representatives of the families' associations. It arose from the understanding of the plural aspect of affection, which concerns the encounters that can mobilize the ability to act<sup>15</sup>. It denotes somehow that we were all affected by the Zika epidemic in Brazil, not just the families and children with ZVCS. The idea of 'affecting lives' refers mainly to sensitized, interested and mobilized people, whose action involved searching for answers and solutions to fight the epidemic. From this angle, this idea is related to the continued struggle for the rights of children and families and effective access to different sectors and necessary services. Likewise, it concerns support for scientific research on ZIKV in several fields of knowledge. Above all, affecting people means not allowing Zika and its consequences to fall by the wayside.

In this respect, the exhibition is a production that involves the return of collaborative research to the world. It is a scientific dissemination device with participative curation, whose construction promotes the interaction and legitimization of discourses between experts and non-experts. It is a setting for expressing different viewpoints and public authority on policies<sup>16</sup>, and the result can be seen as a dynamic between 'citizenship' and 'scientific literacy'<sup>16</sup>. The narrative line of the exhibition starts from the unexpected nature of the Zika event globally, traversing the uncertainties vis-à-vis the Brazilian microcephaly epidemic, the confrontation by different actors and institutions, and the need for answers and knowledge. The roadmap was designed to highlight the role of Brazilian science, families, and the SUS in fighting the epidemic. The exhibition is divided into four modules described below.

The first module addresses the increased number of Zika cases and microcephalic

babies in Brazil. The relationships established between researchers and research institutions in the debate on the health event and the causal nexus with cases of neurological alterations, mainly of congenital malformations in newborns, are evidenced. At this time, we outline the significant contribution of women such as Patrícia Brasil, Celina Turchi, Maria Elizabeth Lopes, Débora Diniz, and Cláudia dos Santos, researchers who have worked hard to resolve concerns, produce care, and unravel causes and effects on the living conditions of those affected.

The second module addresses the uncertainties about the consequences of the ZIKV epidemic for people's health, from the Health Emergency Declaration by Brazil and the World Health Organization (WHO), until confirmation of the existence of ZVCS. The conditions of congenital malformation cases, the difficulties faced by the affected families, and their impoverishment are narrated. The interactions between researchers, health professionals, and families are again presented, besides the support and funding of national and international networks, which allowed the unprecedented discovery of ZVCS by Brazilian science and the SUS. In international bodies, it is noteworthy that both the WHO and the Pan American Health Organization (Paho) were led by women then: Margaret Chan and Carissa Etienne, respectively. In Brazilian science, works by Adriana de Oliveira Melo, Ana Bispo, Vanessa van der Linden, Tereza Maciel Lyra, Consuelo Silva de Oliveira, and Thalia Velho Barreto Araújo stand out.

The third module presents the mobilization and responses generated in the context of the ZVCS epidemic. The joint action of Fiocruz, research institutes, and universities allowed the production of innovations, knowledge, and guidelines for policies. The role of the public and universal SUS and the organization of women in the struggle for rights are highlighted. In the associations of affected families, we underscore women who actively participated in the research carried out within

the RZCS, and they are: Germana Soares, Joana Passos, Amanda Mota, Vanessa Aguiar, and Vanessa Godoy Caldas.

The fourth module presents reflections and notes on what we still need to do concerning the occurrence and consequences of ZIKV in Brazil. Guidelines reiterate that the paths to ensure the rights of affected people must include protection and care for children and women. How the consequences of Zika portray Brazilian inequalities and the message that this and other diseases can be better answered when science, social movements, health, and public policies go hand in hand are highlighted. In this module, the visitor can access the Letter of Recommendations built by researchers, managers, and social movements, indicating what remains to be done.

### **The narrative of the exhibition from the perspective of different women**

The collective construction of the exhibition from different perspectives is its greatest asset and its most significant challenge. It is not simple to bring diversity, the clash of ideas and experiences, integrating them in the search for common meanings.

The meetings were settings of negotiations and tensions. On these occasions, representatives of the affected families' associations could express the threats to which they were submitted. The dilemmas derived from the affections, the willingness to continue the debate, and the need to give visibility to issues that are not on the State's agenda<sup>17</sup>.

The exhibition's narrative was primarily constructed by women, who showed everything from initial uncertainties and fears to current responses and needs. They were affected differently by the Zika epidemic, and brought in their experiences, interpretations, conceptions, and questions. They pointed out that the production of knowledge, proposals, and actions can be permeated by clashing ideas and contradictions in coping, even with common needs or fields of action, whether in

science, the management of health services, care, or the struggle for rights.

It is important to emphasize that it is impossible to achieve a unique definition<sup>18</sup> when reflecting on being a woman. Women who contributed to the production of knowledge and responses to the Zika epidemic bring different views and are affected by their experiences as scientists, mothers, managers, and health service professionals.

The two main topics that produced heated debates during the participatory curation process, construction, and validation of the exhibition roadmap were abortion and abandonment. Abortion is a controversial issue, mainly because of the moral issues it arouses. The latent discomfort in the discussion forums brought into play, on the one hand, the religiosity underlying the discourse of some family associations, especially their spokespersons; on the other, an entire enunciation of activists and experts on women's rights, which guides the collective health concerns. We emphasize that one group also argued that it was controversial to associate the discussion of abortion with issues about disability.

The controversies surrounding the abandonment strained the families' representatives. Parental abandonment, so publicized by the media and the narratives of some associations, was seen in an antagonistic way by others. For some representatives, emphasizing parental abandonment was to fail to recognize both the importance of male participation in child care issues and that abandonment did not occur in a generalized way.

The concerns surrounding the themes of abortion and abandonment were aggravated by polarized discussions that signaled the specific concerns of some groups. The forums did not have a public with no direct link to those issues, who could distance themselves from them to mediate between singular and collective interests. Both topics were considered extremely sensitive as it was impossible to produce a general will from particular desires<sup>9</sup>. For this reason, it was agreed that they would

not be included in the exhibition's narrative. Quickly covering them was an unnecessary risk in the face of several other possible and indispensable statements to be put on stage. Although we upheld our opinions as public health professionals, our exercise in building the roadmap aimed to highlight certainties, uncertainties, controversies, assents, not to arouse irreconcilable interests on that occasion.

We observed a consonance that the government did not consider the different dimensions in which the lives of these families were affected. The insufficient public services and government measures that could meet the needs in different contexts and situations were generally classified as abandonment by the State, as were the difficulties of transport, income, school inclusion, information, basic sanitation, and access to health services. The theme was addressed cross-sectionally in the narrative.

The exhibition shows what was prioritized as a response, in scientific terms, in the agendas of social movements and public health policies. The construction of these responses demonstrates the experiences of different women in their fields of action. The final message is that Zika is not over and that there are still many things to be done together, articulated between society, science, and public authorities.

The exhibition invites us to reflect on the national health setting that refers to the phantasmagoric, new ZVCS epidemic, the evolving needs of families that continue to be affected, and the growing cuts in substantial budgets for operationalizing public policies.

## Final considerations

The exhibition takes place when many believe that Zika is water under the bridge due to the disappearance of news about the disease. Changing this belief is one of the main challenges highlighted in this work, as ZVCS continues to affect many people's lives, especially

women. The consequences have been less and less prioritized with the end of the epidemic and the Health Emergency Declarations. However, 178 and 55 new Congenital Syndrome cases were registered in 2018 and 2019, respectively<sup>19</sup>. Approximately 24% of the confirmed Zika case in 2019 were in pregnant women<sup>20</sup>. Furthermore, children with ZVCS are growing, and new demands continue to arise. Despite the declining number of cases of the disease, ZIKV continues to circulate, and some studies show the existence of more than one viral strain in the country<sup>21</sup>.

We are far from producing definitive and permanent solutions. Zika's plural and turbulent setting represents, to this day, impact and fear. On the other hand, we emphasized that it generated knowledge sharing and collective construction, creating coping efforts with great transforming potential in the relationships between society and research institutions: A story that has not ended, marked by uncertainties, union, and collective action. This story is told in the exhibition.

Public participation in the curation process occurred since the onset of the work. It is a perspective that has been valued as a methodology for building scientific dissemination devices. The challenges of this way of operating involve addressing different views, understandings, languages, experiences, and, above all, different expectations regarding results. This process requires the ability to incorporate issues traversed by disputes over narratives, interests, and contradictions arising from the experiences and demands of the diverse participants.

Another challenge refers to the approach to issues as delicate as disability and the repercussions of the epidemic for the affected families. Therefore, the fact that the exhibition's narrative was built mainly through women was relevant, as they were the most affected and the leading figures in the responses to the epidemic on various fronts.

The success of this construction shows that it is possible to collectively create a narrative

about a theme in a language that combines art and science. It also reinforces the countless potentialities of new forms of production and dissemination of knowledge based on a broad and systematic dialogue. The search for the creation of common senses, with the synergy of knowledge, narratives, and the most diverse experiences, enhances the establishment of other perspectives and ways of addressing contemporary issues, as was done in the exhibition. This way of operating favors better incorporation of the results by different people and groups interested in using the information to produce answers and advances in specific themes and sectors. This expands the forms, uses, and appropriations of scientific dissemination products.

In this sense, this experience could be reproduced in other contexts with due limitations. The numerous events and research materials that supported the exhibition transcend the results of the research itself, demanding a permanent dialogue with society, researchers, and governments, not without conflicts and contradictions. The practice has always been necessary and present in social, political, and scientific actions in public health and the defense of life.

Even with no prospect of generalizing the results in different contexts, we believe that this account can inspire those who understand the dialogic conception as an extraordinary meeting of people involved with the establishment of meanings of the common good.

This work highlights the prominent role of women in mobilizing and responding to Zika in science, politics, and society. The message must affect people so that the disease and its consequences are not forgotten, and children and families affected by ZVCS are not made invisible.

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