



Ministério da Saúde  
**FIOCRUZ**  
Fundação Oswaldo Cruz



Centro de Estudos  
Estratégicos da FioCruz  
Antonio Ivo de Carvalho



*NÚCLEO INTERDISCIPLINAR  
SOBRE EMERGÊNCIAS  
EM SAÚDE PÚBLICA*

# Community Engagement: Our experience on Zika

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NIESP/CEE/FIOCRUZ

CIDACS/IGM/FIOCRUZ

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Centro de Integração de Dados  
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**THE  
GLOBAL  
HEALTH  
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SOUTH AFRICA 2022



# Zika outbreak: Some initial statements

- **Collective Health** in Brazil

- Field of knowledge and practices based on the historical movement of sanitarian reform in Latin America
- It is an interdisciplinary field – Epidemiology, Policy and Planning, Humanities and Social Sciences – Ethically oriented by the **social determination of health** and the **democratization** of health.

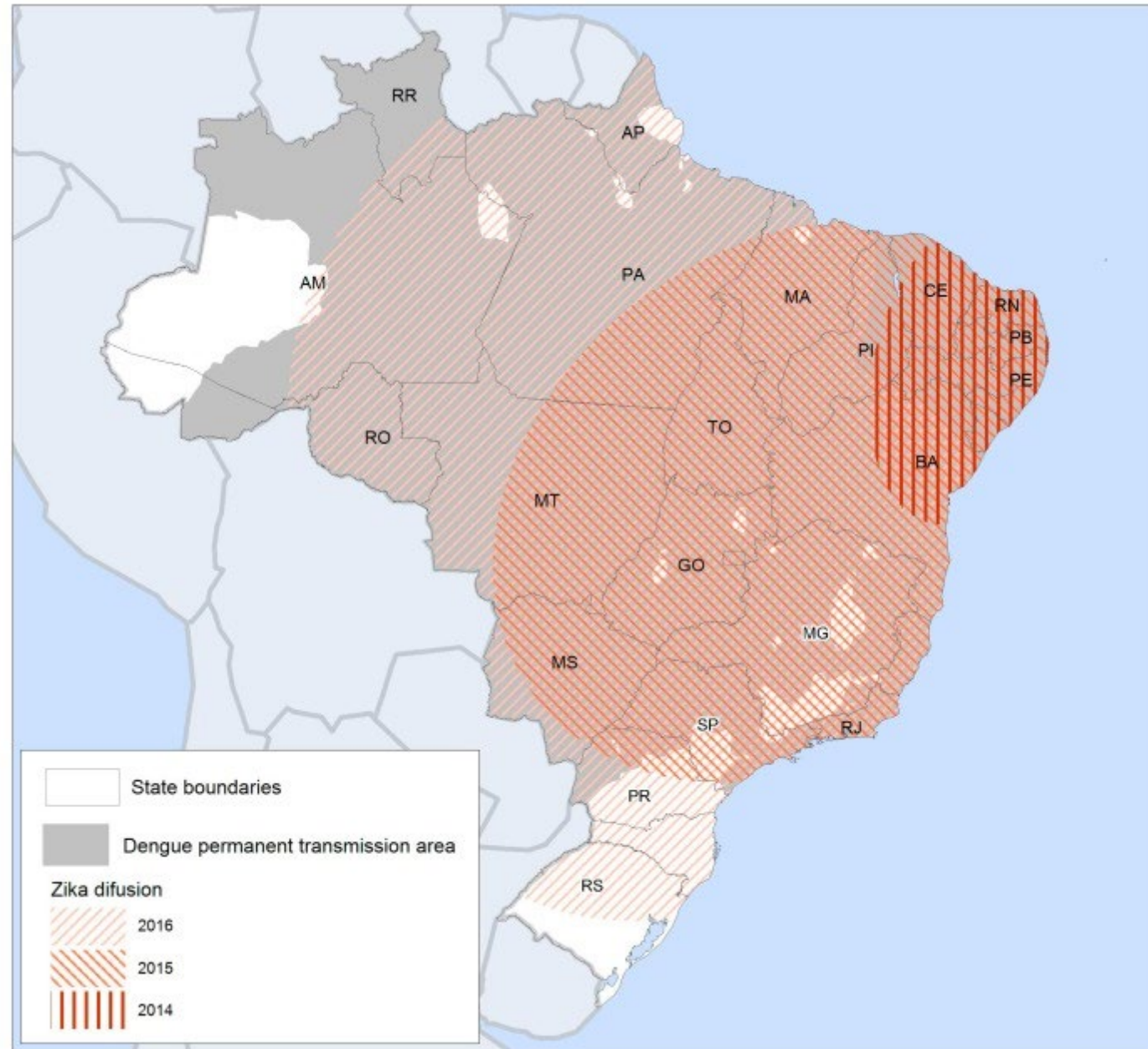
- Brazilian NHS (SUS) Principles

- The universal right to health;
- Decentralization – federal, state and municipal;
- **Social participation** – participation on policy planning and social control of the health policies implemented through federal, state and municipal health councils.

# Zika outbreak: Some initial statements

- Zika represented and still is an uncertain issue in public health;
- Science, health and society are intrinsically entangled in the Zika outbreak and its repercussions;
- Global, regional and local inequities characterized the Zika epidemic and responses;
- Zika as a political and social analyser of the invisibility of multi-disabled children and people in our world;
- **Controlling the mosquitoes itself as a biological entity without social, historical, and gendering entanglements.**
- Every Health Emergency is a humanitarian crisis.

## Spatial diffusion of Zika virus (ZIKV) in Brazil from 2014 to 2016 (Lowe et al, 2018)















# UM MOSQUITO NÃO É MAIS FORTE QUE UM PAÍS INTEIRO.

Participação voluntária  
da atriz Camila Pitanga  
(Embaixadora Nacional da  
ONU Mulheres Brasil).



MOBILIZE SUA FAMÍLIA E ELIMINE A ÁGUA PARADA.



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# Uncertainties

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## Uncertainty in times of medical emergency: Knowledge gaps and structural ignorance during the Brazilian Zika crisis



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- Global Health Uncertainties
- Public Health Uncertainties
- Social and Political Uncertainties

# Gender, Race and Social Structural Inequalities

- The role and overwhelming of women as caregivers
- The sexual and Reproductive Rights
  - **Medicalization of women bodies and the failure of the abortion's debate.**
- The economic impact on families and women
- The political harassment on women rights
- The invisibility on race/social/gender intersectionality
- The role of women in Zika scientific leadership and social activism.



# Women in Science and Social Activism





# Community-led responses:

- Rapid organization of mothers' WhatsApp groups;
- Participation in the state's situations rooms;
- Access to confident information from scientists and health professionals;
- Resilient attitude to face Zika uncertainties;
- After scientific harassment, mother associations started to evaluate scientific protocols and participants rights;
- Zika turned visible disabled children and mothers created strategies to include other congenic mal-formations in the political agenda;
- Zika response produced experiences of engaged research among social movements, scientists and health authorities.



# 12º Congresso Brasileiro de Saúde Coletiva

Fortalecer o SUS, os direitos e a democracia

Rio de Janeiro / RJ - 26 a 29 julho de 2018

## Zika Epidemic in Brazil: Lessons learned and Recommendations

24 e 25 de JULHO, 2018

# Recommendations

A - Child Care

B - Caring for women

C - Public policies, health communication and social participation

D - Health surveillance, prevention and control of Zika

E - Science, technology, information and ethics



Secretaria Municipal de Educação de Duque de Caxias.  
Photo: Maju Monteiro



SLIDE DOWN



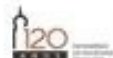
#### Realização



museu da vida



Secretaria de Saúde  
RIO DE JANEIRO  
Fundação Getúlio Vargas



#### Apoio



#### Parceria







## Zika Social Sciences Network

The **Zika Social Sciences Network** was created on the occasion of the Zika outbreak that affected Brazil in 2015/2016, understanding and managing the emergency demanded an interdisciplinary and comprehensive approach to give a proper response. It was convened by Fiocruz and gathers researchers and institutions to join combine efforts to address issues that arose from this experience from a social sciences and humanities perspective. The main focus is the repercussions of the Zika epidemic on science, health and society, and its ongoing legacy.

*A **Rede Zika Ciências Sociais** foi criada por ocasião da epidemia de Zika que afetou o Brasil em 2015/2016, entendendo a emergência exigia uma abordagem interdisciplinar e abrangente para dar uma resposta adequada. A Rede foi constituída pela Fiocruz e reúne pesquisadores e instituições para combinar esforços para abordar questões que surgiram dessa experiência do ponto de vista de ciências sociais e humanas. O foco principal está nas repercussões da epidemia do Zika na ciência, na saúde e na sociedade e suas consequências.*

### After 6 years, how social sciences have responded to the Zika epidemic?

Researchers from the four corners of the world who participated in one of the greatest Zika research consortiums gathered virtually (due to the current pandemic) to discuss its results and ways forward.

## ZIKAlliance

A Global Alliance for Zika Virus Control and Prevention




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# Collaborative Work

BMJ Global Health

## **The promise and pitfalls of social science research in an emergency: lessons from studying the Zika epidemic in Brazil, 2015–2016**

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Maria Joana Passos,<sup>1</sup> Gustavo Matta,<sup>2</sup> Tereza Maciel Lyra,<sup>3,4</sup>  
Maria Elisabeth Lopes Moreira,<sup>5</sup> Hannah Kuper <sup>6</sup>, Loveday Penn-Kekana,<sup>7</sup>  
Mila Mendonça<sup>1</sup>

- “Funders can also set in place mechanisms to help equalise the power dynamics between foreign and local researchers, researchers and participants, both to promote justice and to create best quality data.”

# Post-Zika repercussions

- Zika became invisible since 2018 in the national and global health agenda;
- Post-epidemic social and community consequences are usually missed by health and political authorities, as well as, funders.
- Mothers Associations are still fighting, acting to support and seek health assistance and social protection for their families and children.
- In 2020, the Brazilian parliament instituted a law which guarantees lifetime aid to children's family affected by Zika. It is a result of a community-led movement to recognition and human rights.

# Conclusions

- Children affected by the Zika virus have been framed and treated, to a large degree, as yet another segment of a neglected population group, inscribing further iniquities in Brazil and Global Health genealogy.
- Covid-19 difficulted health access and social protection among families.
- When WHO declared the end of PHEIC, Zika funding was over.
- Health access in the most Latin American countries still depends on research funding to support cohort studies and healthcare.
- Gender issues in Scientific production and social protection still are invisible to governments and funders.

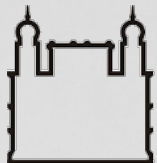


# The Scientific Colonialism Heritage

- Power imbalance between funders, scientists, health professionals and, last but... always least, communities.
- Unequal democratic settings.
- CE as a way to “legitimate” the scientific truth.
- Communities have to learn and scientists have to teach.
- Epistemicide of knowledge, practices and culture in the Global South.
- The scientific *ethos* – *What is it?*
- ***Which Science we want communities to be engaged?***

# A new ontology to Engage and research

- Three political and epistemological perspectives on CE:
- Democracy – Participative X Representative (CE as a political process)
- Decolonial Approach – Shifting power
- Research and Social Justice – What are main values to be addressed?



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Thank you !

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<https://fiocruz.tghn.org/zikanetwork/>  
<http://expozika.fiocruz.br/en/>