

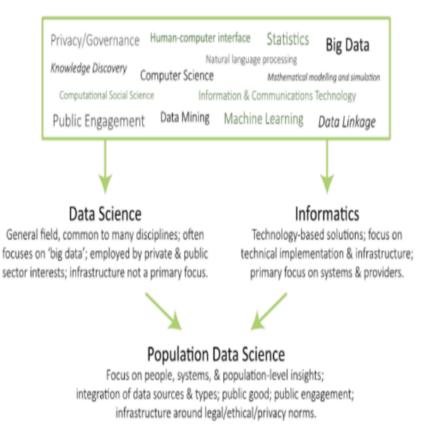
# Population-based epidemiology in the era of data science and routine health data:

# **Experiences from Brazil**

**Mauricio L Barreto** 



# **Population Data Science**



This multidisciplinary science aims to promote technological advancements, and discover new ways of analyzing data and methods of public engagement. • **Population Data Science** is characterized by four aspects:

i) It is valuable and in the public's interest, as it uses data in a positive manner to benefit citizens and society;

ii) Data from different sources are integrated and analyzed;

iii) Results are analyzed from a populational perspective;

iv) Technical infrastructure should be developed, and policies should be elaborated in conformity with regional ethical and legal standards to support scientific research, while preserving the privacy of data subjects.

McGrail et al., 2018. A Position Statement on Population Data Science: The Science of Data about People.



What challenges might an initiative using linked data to support research in Brazil face?

## **Brazil's Unified Health System - SUS**

- That largest Latin American country (8.5 million Km<sup>2</sup>)
- Population of ~215 million inhabitants

Universal access to health care services for the entire Brazilian population, and universal health coverage across Brazil is provided through the Brazilian Unified Health System (SUS).



## LGPD, Academic Research and Public Health Research

Presidência da República Secretaria-Geral Subchefia para Assuntos Jurídicos

LEI M<sup>4</sup> 13.709, DE 14 DE AGOSTO DE 2018.

<u>lección pi ado</u>

Mensagert de vero

El septe cobre a cretação de dados possoais e abare a Lain<sup>o</sup> 12,005 de 23 de cari de 2014 (Vanno Civil de Internet). Las Garal de Protecia: de Dacos Pesenes x1,04201 — (Pactacão casta de a Lain<sup>o</sup> 16,858, de 2019) - Voincia

<u>Vigên: a</u>

O PRESIDENTE DA REPÚBLICA Fago seber que o Congresso Nacional decreta e eu serciono a segunte Leo

#### CAPÍTULO DISPOSIÇÕES PRELIMINARES

Acl of Esaille logicle sobre o tratamento de dados pessoais, indus ve nos me de digitais con pessoai natural cu por pessoa jurídica de pretipiblico ou prvaco, com o objetivo de procegor os direitos hundamentais de libertíade e o inter desenvibilmento da persona dado ca pessoa natural.

- Parágrafo único. As normas gerais comides nesta Lei são de interesse nacional e devam ser observadas pela União. Estados, Distrito Federal e Municípios 🛛 (houido pela Lei nº 16.833), de 2018) 👘 🖉 gércia

Art 2ºA disciplina da proteção de pados pessoais tem como fundamentos:

- o respeito à privacidade)

l- a autoceleminação informativa;

II- a libercade de expressão, de irromação, de comunicação e de coin ão;

. V- a inviolacii dade da ntimidade, da horra e da imagent;

V - o desenvolvimento econôm co e tecnológico e a noveção

VI- a livre in ciatival a livre concorrência e a defesa do consumidor le

VI- os direitos humanos lo live ceservolvmento da parsonalidade la ólgo dade e o exercicio da o dadaria palas pessoas naturais

An 39 Esta Le laplica-se a cualque operação de tetemento realizada por cessoa natural ou por possoa julida de direito público ou civado independemente colmaió, do país de sua sede ou do país once estajam localizados de dealos, deade que

- a operação de Instamento seja realizada no tembrio nacional

 Scientific research and public health are considered specific contexts for processing personal data under the LGPD, provided that <u>recommendations</u> and safeguards established by the law are followed in conformity with specific regulations for each sector (Articles 4º, 7º, 11 e 13).



## **Brazil Data Ecosystem**

















# Many challenges to connecting these data "silos"

- Data heterogeneity (accuracy, format);
- ✓ Data fragmentation (multiple databases, multiple owners/ stakeholders);
- Data availability (protection for commercial or cultural reasons, or related to personal privacy);
- Data handling (data management, data access, data quality, data querying, data sharing);
- Data privacy and integrity (prevention of corruption and hacking);
- ✓ Data conceptualisation (ontologies).

## Why was CIDACS created?





CIDACS was created in December 2016 in the city of Salvador (Bahia-Brazil) with the objective of conducting interdisciplinary research on population health determinants using integrated Brazilian (national) datasets to generate scientific knowledge and provide evidence to support public policymaking.





# Unified Registry for Social Programmes (CadUnico)



## Individual level variables

- ✓ Age (at time of application)
- ✓ Sex
- ✓ Marital status
- Relationship to the person responsible for the household
- ✓ Race/Ethnicity
- ✓ Literacy status
- ✓ Level of education
- ✓ Employment status
- ✓ Household income (monthly)
- ✓ Individual income (monthly)
- ✓ Indigenous, *quilombola*, and other traditional population groups
- ✓ Experiencing homelessness?
- ✓ Place of birth





## Family level variables

- ✓ Municipality of family residence
- ✓ Region of family residence
- ✓ Location of family residence
- $\checkmark$  Housing and flooring material
- ✓ Household type
- Household water supply
- Sewage disposal system
- Electricity
- ✓ Waste collection
- ✓ Sidewalks around household
- Number of individuals in the household
- ✓ Number of rooms in the household

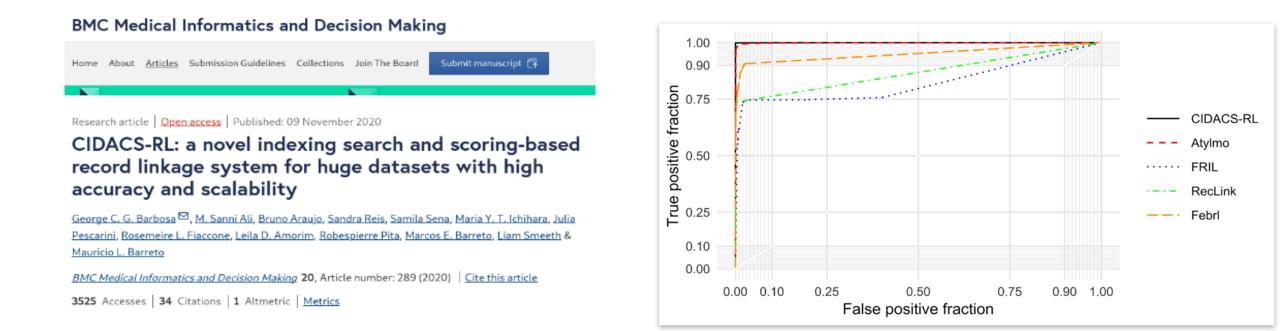


Ministério da Saúd

| Data source | Data type  | Approximate coverage   | Examples of relevant variables   |
|-------------|--|--|--|
| SINASC      | Live birth records in Brazil   | 97% of live births   | Newborn characteristics (sex, Apgar scores, birth weight, ICD-10 coded congenital malformation), maternal characteristics (name, age, marital status, education, race/ethnicity, place of residence), paternal characteristics (name, age), perinatal information (reproductive history: parity, abortions, stillbirths, gestational duration, delivery mode, number of fetuses, antenatal care attendance), location of birth       |
| CadUnico    | Social records from over 130<br>million individuals aged ≥16<br>years whose families applied<br>for social assistance in<br>Brazil | >50% of population   | Location of residence (municipality, region, urban or rural), living conditions (housing, water<br>sources, electricity, sewage, waste, household density), socioeconomic<br>characteristics (education, employment, income), demographics (age, sex, race/ethnicity), social<br>protection program participation and conditionalities   |
| SINAN       | Records of communicable<br>diseases of interest in the<br>country  | •  | It is disease specific. Onset of symptoms, date of birth, patient name, sex, address, laboratory confirmation, symptoms and treatment  |
| SIH-SUS     | -  | 75% of hospitalisations in the<br>Brazilian National Health System | Cause of hospitalisation (ICD-10 code), duration, costs, and date of hospitalisation, type of hospital   |
| SIM         | Death records in Brazil  | 75-95% of Brazilian deaths, with some geographic heterogeneity     | Cause of death (ICD-10 code), characteristics of the deceased (dates of birth and death, name, name of parents, sex, race/ethnicity, birth weight for infants), place of death, characteristics of mother of deceased children (maternal name, age, marital status, education, occupation, race/ethnicity, number of births, place of residence, length of gestation, number of previous stillbirths or abortions, type of delivery) |
| SISVAN      | consumption records  |  | Date of birth, age, sex, race/ethnicity, anthropometrics, breastfeeding, complementary feeding, consumption of healthy and unhealthy foods   |

# cidacsR

a novel iterative deterministic record linkage algorithm based on a combination of indexing search and scoring algorithms (provided by Elasticsearch) [...] for huge datasets, with higher accuracy, improved scalability, and substantially shorter execution time compared to other existing linkage tools.

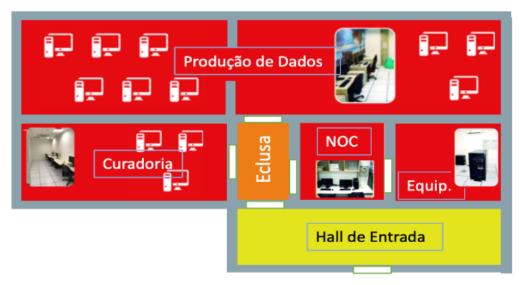


# cidacsR

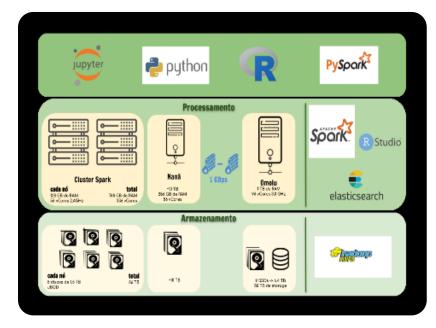
Computational **resources** on Data platform

<complex-block>

## Safety room for data integration



## **Datacenter Container**





# The centre employs a complex data management system incorporating information security, ethical principles, and privacy protection.

International Journal of Population Data Science (2019) 4:2:04

### International Journal of Population Data Science



Swansea University Prifysgol Abertawe

Journal Website: www.ijpds.org

## The Centre for Data and Knowledge Integration for Health (CIDACS): Linking Health and Social Data in Brazil

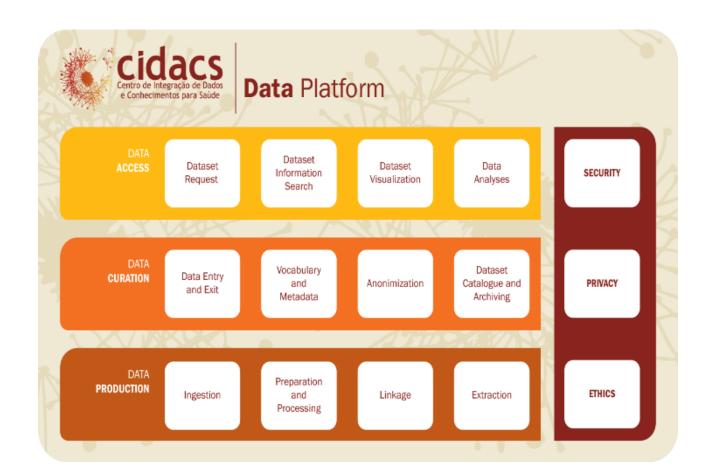
Barreto, ML<sup>1,2\*</sup>, Ichihara, MY<sup>1,2</sup>, Almeida, BA<sup>1</sup>, Barreto, ME<sup>1,3</sup>, Cabral, L<sup>1</sup>, Fiaccone, RL<sup>1,4</sup>, Carreiro, RP<sup>1</sup>, Teles, CAS<sup>1</sup>, Pitta, R<sup>1</sup>, Penna, GO<sup>1,5,6</sup>, Barral-Netto, M<sup>1</sup>, Ali, MS<sup>1,7,8</sup>, Barbosa, G<sup>1</sup>, Denaxas, S<sup>9</sup>, Rodrigues, LC<sup>1,8</sup>, and Smeeth, L<sup>1,8</sup>



<sup>1</sup>Centre for Data and Knowledge Integration for Health (CIDACS), Gonçalo Moniz Institute, Oswaldo Cruz Foundation (FIOCRUZ), Salvador, Brazil. Institute of Collective Health, Federal University of Bahia (UFBA), Salvador, Brazil. Computer Science Department, Federal University of Bahia (UFBA), Salvador, Brazil. Statistics Department, Federal University of Bahia (UFBA), Brazil \*Tropical Medicine Centre, University of Brasilia (UnB), Brazil. <sup>6</sup>Escola Fiocruz de Governo, FIOCRUZ Brasilia, Brazil. <sup>7</sup>Center for Statistics in Medicine, Nullield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences, University of Oxford, Oxford, UK. \*Faculty of Epidemiology and Population Health, London School of Hygiene and Tropical Medicine, United Kingdom, <sup>9</sup>Institute of Health Informatics, University College London, United Kingdom.

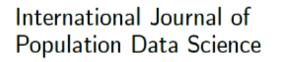
#### Abstract

The Centre for Data and Knowledge Integration for Health (CIDACS) was created in 2016 in Salvador, Bahia-Brazil with the objective of integrating data and knowledge aiming to answer scientific questions related to the health of the Brazilian population. This article details our experiences in the establishment and operations of CIDACS, as well as efforts made to obtain high-quality linked data while adhering to security, ethical use and privacy issues. Every effort has been made to conduct operations while implementing appropriate structures, procedures, processes and controls over the original and integrated databases in order to provide adequate datasets to answer relevant research questions. Looking forward, CIDACS is expected to be an important resource for researchers and policymakers interested in enhancing the evidence base pertaining to different aspects of health, in particular when investigating, from a nation-wide perspective, the role of social determinants of health and the effects of social and environmental policies on different health outcomes.



# Data management, data governance, data ethics

International Journal of Population Data Science (2024) 9:1:06





Journal Website: www.ijpds.org

CIDACS' efforts towards an inclusive and dialogic data governance in Brazil: a focused literature review

Bethânia de A. Almeida<sup>1,\*</sup>, Roberto P. Carreiro<sup>1</sup>, Maíra L. de Souza<sup>1</sup>, and Mauricio L. Barreto<sup>1</sup>

| Submission His | cory      |
|----------------|-----------|
| Submitted:     | 29/04/202 |
| Accepted:      | 20/02/202 |
| Published:     | 12/03/202 |

<sup>1</sup>Centre for Data and Knowledge Integration for Health (CIDACS), Gonçalo Moniz Institute, Oswaldo Cruz Foundation (FIOCRUZ), Salvador, Bahia

#### Abstract

The Centre for Data and Knowledge Integration for Health's (CIDACS) data governance efforts have primarily focused on legal, technical and operational procedures to provide high-quality linked administrative data for investigations on social determinants of health and the impact of social protection policies in low-income and vulnerable populations throughout Brazil. The Centre is moving towards an updated data governance model that incorporates the participation of, and consultation and dialogue with, data stakeholders, including groups covered by our linked data. To this end, this paper presents our procedures and challenges, outlining relevant considerations based on a focused literature review that aims to support the inclusion of societal participation in our revised data governance approach, which should be considered an ongoing process.

#### Keywords

data governance; administrative data linkage; data subjects rights as groups and communities

 Research analysis is focused on a population perspective; however, ethical and legal standards, as well as the preservation of privacy, target individuals.

• Our data governance approach has started to address questions related to data ethics, as well as the rights of groups as data subjects.



## **100 Million Brazilians Cohort**



Available at: <a href="https://doi.org/10.1093/ije/dyab213">https://doi.org/10.1093/ije/dyab213</a>

# CIDACS' Birth Cohort



#### DATA FOR RESEARCHING THE HEALTH OF THE MOST VULNERABLE POPULATION

The integrated data produced at CIDACS/Fiocruz Bahia as Cohorts allow investigating the most diverse health problems in vulnerable groups in the country.

Center with the largest data resource among all low- and middle-income countries in the world

> Data resources from a longitudinal perspective, that considers changes over time



With a large data volume, the Cidacs/Fiocruz Bahia samples allow visualizing issues that smaller samples cannot achieve.



Consulting in governance and curation of databases for institutions



# people, black people, and more

#5-c1

#### Comparing local levels of social, environmental, and health inequalities Region of the country, state, municipality, census tract,

health region, among other possibilities.

Check out the Guide for Accessing Integrated Data in Health Research, prepared by CIDACS/Fiocruz Bahia. prepared by Cidacs/Fiocruz Bahia.

Find out more about how CIDACS Inks large databases to generate search results. The 100 Million Brazilians cohort and CIDACS' Birth cohort support research initiatives in a variety of areas related to public health.

## Strategic research agenda

- Social and Environmental Determinants of Health and Health Inequalities
- Assessment of the Impact of Social Policies on Health
- Assessment of the Impact of Health Programs and Interventions
- Digital Surveillance and Public Health Emergencies
- Data Governance, Science and Society
- Knowledge Dissemination and Societal Engagement

## TO EVALUATE THE IMPACT OF POVERTY REDUCTION POLICIES ON HEALTH

### JAMA Network Open.

#### Original Investigation | Health Policy

## Participation in Conditional Cash Transfer Program During Pregnancy and Birth Weight-Related Outcomes

IIa R. Falcão, PhD; Rita de Cássia Ribeiro-Silva, PhD; Rosemeire L. Fiaccone, PhD; Flávia Jôse Oliveira Alves, PhD; Aline dos Santos Rocha, PhD; Naiá Ortelan, PhD; Natanael J. Silva, MSc; Poliana Rebouças, PhD; Elzo Pereira Pinto Júnior, PhD; Marcia Furquim de Almeida, PhD; Enny S. Paixao, PhD; Júlia M. Pescarini, PhD; Laura C. Rodrigues, PhD; Maria Yury Ichihara, PhD; Mauricio L. Barreto, PhD



American Journal of Epidemiology Vol. 00, No. 00 O The Author(s) 2020. Published by Oxford University Press on behalf of the Johns Hopkins Bloomberg School of Public Health. This is an Open Access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/4.0), which permits unrestricted reuse, distribution, and reproduction in any medium, provided the original work is properly cited. Vol. 00, No. 00 DOI: 10.1093/aje/kwaa127 Advance Access publication:

#### **Original Contribution**

Conditional Cash Transfer Program and Leprosy Incidence: Analysis of 12.9 Million Families From the 100 Million Brazilian Cohort

### PLOS MEDICINE

RESEARCH ARTICLE

Relationship between the Bolsa Família national cash transfer programme and suicide incidence in Brazil: A quasi-experimental study

Daiane Borges Machado<sup>1,2</sup>, Elizabeth Williamson<sup>3</sup>, Julia M. Pescarini<sup>1,3</sup>, Flavia J. O. Alves<sup>1</sup>, Luís F. S. Castro-de-Araujo<sup>1,4</sup>, Maria Yury Ichihara<sup>1</sup>, Laura C. Rodrigues<sup>1,3</sup>, Ricardo Araya<sup>5</sup>, Vikram Patel<sup>2,6</sup>, Maurício L. Barreto<sup>1,7</sup>

#### PLOS MEDICINE

#### RESEARCH ARTICLE

Conditional cash transfer program and child mortality: A cross-sectional analysis nested within the 100 Million Brazilian Cohort

Dandara Ramoso<sup>1,2</sup>\*\*, Nivea B. da Silva<sup>1,3</sup>\*, Maria Yury Ichiharao<sup>1,2</sup>, Rosemeire L. Fiaccone<sup>1,3</sup>, Daniela Almeidao<sup>1,4</sup>, Samila Sena<sup>1</sup>, Poliana Rebouçaso<sup>1,2</sup>, Elzo Pereira Pinto Júnioro<sup>1</sup>, Enny S. Paixãoo<sup>1,5</sup>, Sanni Allo<sup>1,5</sup>, Laura C. Rodrigues<sup>1,5</sup>, Maurício L. Barreto<sup>1,2</sup>

#### nature communications

Article

https://doi.org/10.1038/s41467-024-44975-z

9

h

# Income determines the impact of cash transfers on HIV/AIDS: cohort study of 22.7 million Brazilians

| Received: 4 September 2023         | Andréa F. Silva @ <sup>1,2</sup> , Inês Dourado <sup>1</sup> , Iracema Lua <sup>1,2</sup> , Gabriela S. Jesus <sup>1,3</sup> ,  |  |  |  |
|------------------------------------|---|--|--|--|
| Accepted: 10 January 2024          | Nathalia S. Guimarães <sup>1</sup> , Gabriel A. S. Morais <sup>(1)</sup> , Rodrigo V. R. Anderle <sup>1</sup> ,<br>Julia M. Pescarini <sup>2</sup> , Daiane B. Machado <sup>2,4</sup> , Carlos A. S. T. Santos <sup>2</sup> , |  |  |  |
| Published online: 12 February 2024 | Maria Y. Ichihara <sup>2</sup> , Mauricio L. Barreto <sup>1,2</sup> , Laio Magno O <sup>1,5</sup> , Luis E. Souza <sup>1</sup> ,<br>James Macinko O <sup>6</sup> & Davide Rasella O <sup>1,2,7</sup> ⊠                        |  |  |  |
| Check for updates                  | James Macinko @ & Davide Rasella @ 🖂  |  |  |  |



Vol. 00, No. 00

ccone.

stino Strina, O. Penna, and

#### Original Investigation | Public Health

Association of Conditional Cash Transfers With Maternal Mortality Using the 100 Million Brazilian Cohort

Flávia Jôse O. Alves, PhD; Dandara Ramos, PhD; Enny S. Paixão, PhD; Ila R. Falcão, PhD; Rita de Cássia Ribeiro-Silva, PhD; Rosemeire Fiaccone, PhD; Davide Rasella, PhD; Camila Teixeira, PhD; Daiane Borges Machado, PhD; Aline Rocha, PhD; Marcia F. de Almeida, PhD; Emanuelle F. Goes, PhD; Laura C. Rodrigues, PhD; Maria Yury Ichihara, PhD; Estela M. L. Aquino, PhD; Maurício L. Barreto, PhD

# Program (BFP) Impact on Child Mortality

### PLOS MEDICINE

RESEARCH ARTICLE

Conditional cash transfer program and child mortality: A cross-sectional analysis nested within the 100 Million Brazilian Cohort

Dandara Ramos<sup>1,2®</sup>\*, Nívea B. da Silva<sup>1,3®</sup>, Maria Yury Ichihara<sup>1,2</sup>, Rosemeire L. Fiaccone<sup>1,3</sup>, Daniela Almeida<sup>1,4</sup>, Samila Sena<sup>1</sup>, Poliana Rebouças<sup>1,2</sup>, Elzo Pereira Pinto Júnior<sup>1</sup>, Enny S. Paixão<sup>1,5</sup>, Sanni Ali<sup>1,5</sup>, Laura C. Rodrigues<sup>1,5</sup>, Maurício L. Barreto<sup>1,2</sup>

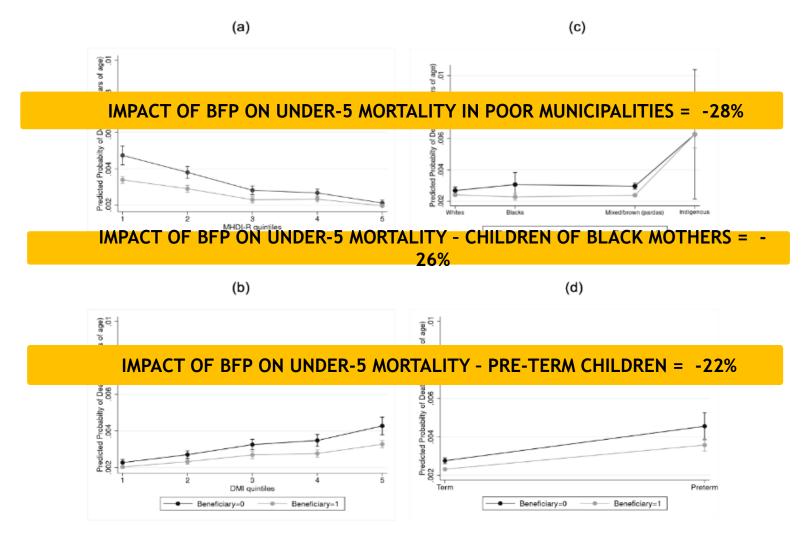
IMPACT OF BFP ON UNDER-5 MORTALITY OVERALL = -17% Participar de um programa de transferência condicionada de renda, como o Bolsa Família, **reduz em 17% a chance de mortes** 



# **BFP** This study also observed heterogeneities in BFP effect among several subgroups

### Association was stronger for:

- (a) children living in municipalities in the lowest income quintile (1st quintile of municipal income: wOR= 0.72; 95% CI: 0.62 to 0.82)
- (b) municipalities with better BFP management (5th quintile of the Decentralized management index: wOR= 0.76; 95% CI: 0.66 to 0.88)
- (c) children of Black mothers (wOR =0.74; 95% CI: 0.57 to 0.97);
- (d) preterm children (wOR =0.78; 95% CI: 0.68 to 0.90);





## TO INVESTIGATE LOW-FREQUENCY BUT RELEVANT HEALTH EVENTS

#### THE NEW ENGLAND JOURNAL of MEDICINE

The Lancet Regional Health - Americas 3 (2021) 100045



Contents lists available at ScienceDirect The Lancet Regional Health - Americas

journal homepage: www.elsevier.com/locate/lana

Research paper

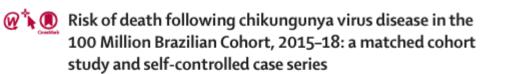
Risk of mortality for small newborns in Brazil, 2011-2018: A national birth cohort study of 17.6 million records from routine register-based linked data

Enny S. Paixao, Ph.D<sup>1,2,\*</sup>, Hannah Blencowe, MD, Ph. Eric O. Ohuma, Ph.D<sup>2</sup>, Aline dos Santos Rocha<sup>1,3</sup>, Flá Maria da Conceição N. Costa, MD, Ph.D<sup>1,4</sup>, Jorena St.

JAMA Dermatology | Original Investigation

### Incidence of and Factors Associated With L Among Household Contacts of Patients Wi

Camila Silveira Silva Teixeira, MsC; Julia Moreira Pescarini, PhD; Flávia Jôse Oliveira Alve: Joilda Silva Nery, PhD; Mauro Niskier Sanchez, PhD; Carlos Teles, PhD; Maria Yury Travat Anna Ramond, PhD; Liam Smeeth, PhD; Maria Lucia Fernandes Penna, PhD; Laura Cunh Elizabeth B. Brickley, PhD; Gerson Oliveira Penna, PhD; Maurício Lima Barreto, PhD;



Daa Thiago Cerqueira-Silva, Julia M Pescarini, Luciana L Cardim, Clémence Leyrat, Heather Whitaker, Carlos Alexandre Antunes de Brita, Elizabeth B Brickley, Manoel Barral-Netta, Mauricio L Barreto, Maria G Teixeira, Viviane S Boaventura, Enny S Paixão

#### Summary

WILEY

Losort Infect Dis 2024; 24:504-13 Nchihad Orline February 8, 2024 https://doi.org/10.1016/ 51/73-2039/(23)00739-9 Background Chikungunya virus outbreaks have been associated with excess deaths at the ecological level. Previous studies have assessed the risk factors for severe versus mild chikungunya virus disease. However, the risk of death following chikungunya virus disease compared with the risk of death in individuals without the disease remains intervention of the risk of death in the 2 years following chikungunya virus disease.

Figure 2. Cumulative Incidence of Subsequent Leprosy Cases Among Households of Patients With Leprosy

 Received: 31 August 2021
 Revised: 4 November 2021
 Accepted: 11 November 2021
 First published online: 13 December 2021

 DOI: 10.1002/ijgo.14053

#### CLINICAL ARTICLE

Obstetrics

## Recurrence of preterm births: A population-based linkage with 3.5 million live births from the CIDACS Birth Cohort

Aline S. Rocha<sup>1,2</sup> | Rita de Cássia Ribeiro-Silva<sup>1,2</sup> | Enny S. Paixao<sup>2,3</sup> | Ila R. Falcão<sup>1,2</sup> | Flavia Jôse. O. Alves<sup>2,4</sup> | Naiá Ortelan<sup>2</sup> | Marcia F. de Almeida<sup>5</sup> | Rosemeire L. Fiaccone<sup>2,6</sup> Laura C. Rodrigues<sup>3</sup> | Maria Yury Ichihara<sup>2</sup> | Mauricio L. Barreto<sup>2,4</sup>



ORIGINAL ARTICLE

#### Mortality from Congenital Zika Syndrome — Nationwide Cohort Study in Brazil

Enny S. Paixao, Ph. D., Luciana L. Cardim, Ph.D., Maria C.N. Costa, M.D., Ph.D., Elizabeth B. Brickley, Ph.D., Rita C.O. de Carvalho-Sauer, M.Sc., Eduardo H. Carmo, M.D., Ph.D., Roberto F.S. Andrade, Ph.D., Moreno S. Rodrigues, Ph.D., Rafael V. Veiga, Ph.D., Larissa C. Costa, Ph.D., Cynthia A. Moore, M.D., Ph.D., Glovanny V.A. França, Ph.D.,

## Incidence and risk factors of tuberculosis among 420 854 household contacts of patients with tuberculosis in the 100 Million Brazilian Cohort (2004–18): a cohort study

o S S Teixeira, Maria Yury Ichihara, Davide Rasella, Joilda S Nery, Samila O L Sena, Elizabeth B Brickley, ro N Sanchez\*, Julia M Pescarini\*

### LANCET tious Diseases

Causes of death in children with congenital Zika syndrome in Brazil, 2015 to 2018: A nationwide record linkage study

Maria da Conceição N. Costa<sup>1,2e</sup>, Luciana Lobato Cardim<sup>1e</sup>, Cynthia A. Moore<sup>3</sup>, Eliene dos Santos de Jesus<sup>2,4</sup>, Rita Carvalho-Sauer<sup>2,5</sup>, Mauricio L. Barreto<sup>1,2</sup>, Laura C. Rodrigues<sup>1,6</sup>, Liam Smeeth<sup>6</sup>, Lavínia Schuler-Faccini<sup>7</sup>, Elizabeth B. Brickley<sup>6</sup>, Wanderson K. Oliveira<sup>8</sup>, Eduardo Hage Carmo<sup>1,9</sup>, Julia Moreira Pescarini<sup>1,6</sup>, Roberto F. S. Andrade<sup>1,10</sup>, Moreno M. S. Rodrigues<sup>1</sup>, Rafael V. Veiga<sup>1</sup>, Larissa C. Costa<sup>1</sup>, Giovanny V. A. França<sup>9</sup>, Maria Gloria Teixeira<sup>1,2‡</sup>, Enny S. Paixão<sup>1,6‡</sup>\*

1 Center of Data and Knowledge Integration for Health (CIDACS), Gonçalo Moniz Institute, Oswaldo Cruz Foundation, Salvador, Babia, Brazil, 2 Collective Health Institute, Federal I Iniversity of Babia, Salvador

# DATA TO INVESTIGATE RARE **BUT RELEVANT HEALTH EVENTS**

Large sample sizes allow several analytical advantages, such as the analysis of rare events that are not possible in studies that rely on small sample size.



11.5 million live births, of which, 3,308 babies born with confirmed or probable CZS.



Babies born with CZS were at >11x greater risk of death during first three years of life than those born without.

#### ORIGINAL ARTICLE

### Mortality from Congenital Zika Syndrome - Nationwide Cohort Study in Brazil

Enny S. Paixao, Ph.D., Luciana L. Cardim, Ph.D., Maria C.N. Costa, M.D., Ph.D., Elizabeth B. Brickley, Ph.D., Rita C.O. de Carvalho-Sauer, M.Sc., Eduardo H. Canno, M.D., Ph.D., Roberta F.S. Andrade, Ph.D., Moreno S. Rodrigues, Ph.D., Rafael V. Veiga, Ph.D., Larissa C. Costa, Ph.D., Cynthia A. Moore, M.D., Ph.D., Glovanny V.A. França, Ph.D., Liam Smeeth, M.D., Ph.D., Laura C. Rodrigues, M.D., Ph.D., Mauricio L. Barreto, M.D., Ph.D., and Maria G. Teixeira, M.D., Ph.D.

#### ABSTRACT

#### BACKGROUND

Prenatal exposure to Zika virus has potential teratogenic effects, with a wide spectrum of clinical presentation referred to as congenital Zika syndrome. Data on survival among children with congenital Zika syndrome are limited.

#### HETHODS

In this population-based cohort study, we used linked, routinely collected data in Brazil, from January 2015 through December 2018, to estimate mortality among live-born children with congenital Zika syndrome as compared with those without the syndrome, Kaplan-Meier curves and survival models were assessed with adjustment for confounding and with stratification according to gestational age, birth weight, and status of being small for gestational age.

#### RESULTS

A total of 11,481,215 live-born children were followed to 36 months of age. The mortality rate was 52.6 deaths (95% confidence interval [CI], 47.6 to 58.0) per 1000 person-years among live-born children with congenital Zika syndrome, as compared with 5.6 deaths (95% CL 5.6 to 5.7) per 1000 person-years among those without the syndrome. The mortality rate ratio among live-born children with congenital Zika syndrome, as compared with those without the syndrome, was 11.3 (95% CL 10.2 to 12.4). Among infants born before 32 weeks of gestation or with a birth weight of less than 1500 g, the risks of death were similar regardless of congenital Zika syndrome status. Among infants born at term, those with congenital Zika syndrome were 14.3 times (95% CI, 12.4 to 16.4) as likely to die as https://www.unz.ukasi.neg those without the syndrome (mortality rate, 38.4 vs. 2.7 deaths per 1000 personyears). Among infants with a birth weight of 2500 g or greater, those with congenital Zika syndrome were 12.9 times (95% CI, 10.9 to 15.3) as likely to die as those without the syndrome (mortality rate, 32.6 vs. 2.5 deaths per 1000 personyears). The burden of congenital anomalies, diseases of the nervous system, and infectious diseases as recorded causes of deaths was higher among live-born children with congenital Zika syndrome than among those without the syndrome.

#### CONCLUSIONS

The risk of death was higher among live-born children with congenital Zika syndrome than among those without the syndrome and persisted throughout the first 3 years of life. (Funded by the Ministry of Health of Brazil and others.)

From the London School of Hygiese and Tropical Medicine, London (E.S.P., E.B.B. L.S., L.C.R.J; the Center of Data and Knowledge Integration for Health, Goncalo Moniz Institute, Oswaldo Cruz Foundation (ESP, LLC, M.C.N.C., EHC. RESA, MSR, RVV. LCC. LCR. M.L.B., M.G.T.), and Institute de Saude Coletiva Federal University of Bahia (M.C.N.C., M.L.B., M.G.T.), Salvador, the East Regional Health Center of the State Health Secretariat of Bahia; Santo Antonio de Jesus (R.C.O.C.-5.), and the Secretariat of Health Surveillance. Ministry of Health, Brasika (G.V.A.F.) - all in Brazil: and the Division of Birth Defects and Infant Disorders, National Center on Birth Defects and Developmental Disabilities. Centers for Disease Control and Prevention, Atlenta (C.A.M.). Dr. Paicao can be contacted at even ouz@ishtm.ac.uk or at the London School of Hugiene and Tropical Medicine, Repoel St., London WC1E 7HT, United Kingdom.

Drs. Palsao and Cardim and Drs. Barreto and Teaseira contributed equally to this article.

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## TO INVESTIGATE HEALTH INEQUALITIES

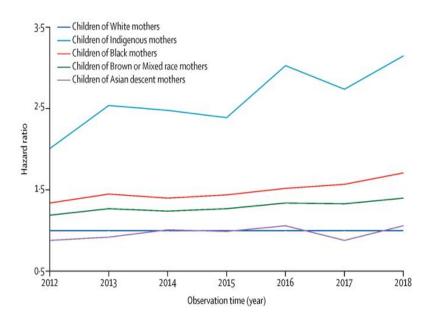
Ethno-racial inequalities on adverse birth and neonatal outcomes: a nationwide, retrospective cohort study of 21 million Brazilian newborns

Poliana Rebouças,<sup>a,\*</sup> Enny S. Paixão,<sup>a,b</sup> Dandara Ramos,<sup>a,d</sup> Julia Pescarini,<sup>a</sup> Elzo Pereira Pinto-Junior,<sup>a</sup> Ila R. Falcão,<sup>a</sup> Maria Yury Ichihara,<sup>a</sup> Samila Sena,<sup>a</sup> Rafael Veiga,<sup>a</sup> Rita Ribeiro,<sup>a,e</sup> Laura C. Rodrigues,<sup>c</sup> Maurício L. Barreto,<sup>a,d</sup> and Emanuelle F. Goes<sup>a,d</sup>

<sup>a</sup>Center for Data and Knowledge Integration for Health (CIDACS), Gonçalo Moniz Institute, Oswaldo Cruz Foundation, Salvador, Bahia, Brazil

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ETHNICITY & HEALTH 2024, VOL. 29, NO. 1, 46-61 https://doi.org/10.1080/13557858.2023.2245183

Profile 1: educational level < 4 years.

marital status = single

6 12 18 24 30 36 42 48 54 60

Age (months)

Profile 4: educational level = 4 to 7 years

marital status = single

6 12 18 24 30 36 42 48 54 60

Age (months)

Profile 7: educational level > 8 years,

marital status = single

18 24 30 36 42 48 54 60

Ann Imonths

-1.5

-0.5

-1.5

-0.5

1.5

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0.0

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marital status = married / stable union

0 6 12 18 24 30 36 42 48 54 6

Age (months

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The Lancet Regional

Health - Americas

2024;37: 100833

Published Online xxx

https://doi.org/10.

1016/j.lana.2024.

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LANGLH-D-23-00410R3 \$2214-109X(23)00405-9 Embargo: [add date when known] Doctopic: Primary Research

15 million births in Brazil

Summar

**BMC Pediatric** 

manifestations.

12 years of education as the baseline.

Maternal and congenital syphilis attributable to ethnoracial 🐴 🐧

inequalities: a national record-linkage longitudinal study of

Ennv S Paixao\*, Andréa J F Ferreira\*, Julia M Pescarini, Kerry L M Wong, Emanuelle Goes, Rosemeire Fiaccone, Guilherme Lopes de Oliveira,

Background This study estimated ethnoracial inequalities in maternal and congenital syphilis in Brazil, understanding

race as a relational category product of a sociopolitical construct that functions as an essential tool of racism and its

Methods We linked routinely collected data from Jan 1, 2012 to Dec 31, 2017 to conduct a population-based study in

intersection between two social markers (race and education) and compared it with White women with more than

Findings Of 15810488 birth records, 144564 had maternal syphilis and 79580 had congenital syphilis. If all women

had the same baseline risk as White women, 35% (95% CI 34-89-36-10) of all maternal syphilis and

41% (40 · 49-42 · 09) of all congenital syphilis would have been prevented. Compared with other ethnoracial categories,

percentages were higher among Parda/Brown women (46% [45,74-47,20] of maternal evolutie and

Brazil. We estimated the attributable fraction of race (skin colour) for the entire population and specific subgroups compared with White women using adjusted logistic regression. We also obtained the attributable fraction of the

Poliana Reboucas. Andrev Moreira Cardoso. Liam Smeeth. Mauricio L Barreto. Laura C Rodriaues†. Maria Yurv Ichihara

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International Health Lo

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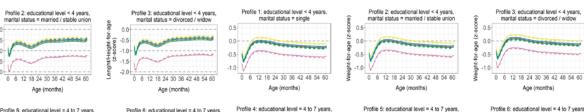
#### The intersection of race/ethnicity and socioeconomic status: inequalities in breast and cervical cancer mortality in 20.665.005 adult women from the 100 Million Brazilian Cohort

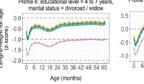
Emanuelle F. Góes<sup>a</sup>\*, Joanna M. N. Guimarães<sup>a</sup>\*, Maria da Conceição C. Almeida<sup>b</sup>, Ligia Gabrielli<sup>c,d</sup>, Srinivasa Vittal Katikireddi<sup>e</sup>, Ana Clara Campos<sup>a</sup>, Sheila M. Alvim Matos<sup>d</sup>, Ana Luísa Patrão<sup>f</sup>, Ana Cristina de Oliveira Costa<sup>g</sup>, Manuela Quaresma<sup>h</sup>, Alastair H. Leyland<sup>e</sup>, Mauricio L. Barreto<sup>a,d</sup> Isabel dos-Santos-Silva<sup>h</sup>\*\* and Estela M. L. Aguino<sup>d</sup>\*\*

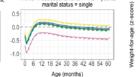
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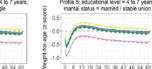
Ethnoracial disparities in childhood growth trajectories in Brazil: a longitudinal nationwide study of four million children

Helena Benes Matos da Silva<sup>124</sup>, Rita de Cássia Ribeiro-Silva<sup>1,2</sup>, Juliana Freitas de Mello e Silva<sup>21</sup>, Irina Chis Ster<sup>3</sup>, Poliana Rebouças<sup>2</sup>, Emanuelle Goes<sup>2</sup>, Maria Yury Ichihara<sup>2</sup>, Andréa Ferreira<sup>2,4</sup>, Julia M. Pescarin Ennu S. Paixão<sup>5</sup> and Maurício I. Barreto

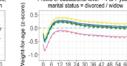




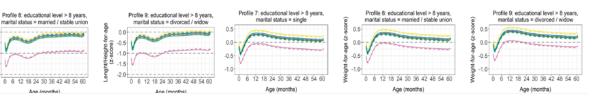




Age (months)



Age (months)

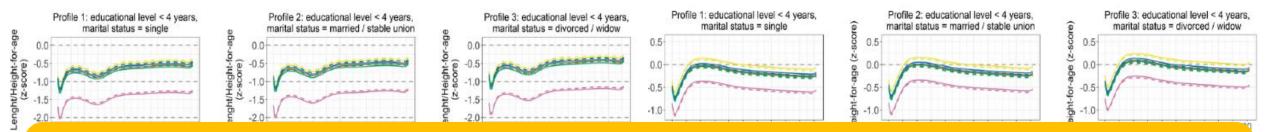


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#### RESEARCH

#### Ethnoracial disparities in childhood growth trajectories in Brazil: a longitudinal nationwide study of four million children

Helena Benes Matos da Silva<sup>1,2+†</sup>, Rita de Cássia Ribeiro-Silva<sup>1,2</sup>, Juliana Freitas de Mello e Silva<sup>2†</sup>, Trina Chis Ster<sup>3</sup>, Poliana Rebouças<sup>2</sup>, Emanuelle Goes<sup>2</sup>, Maria Yury Ichihara<sup>2</sup>, Andréa Ferreira<sup>2,4</sup>, Julia M. Pescarini<sup>5</sup>, Rosemeire Leovigildo Flaccone<sup>6</sup>, Enny S. Paixão<sup>5</sup> and Maurício L. Barreto<sup>2</sup>



Children born to indigenous mothers were on average 3.3 cm (95% CI: -3.36, -3.27) shorter than their white counterparts.

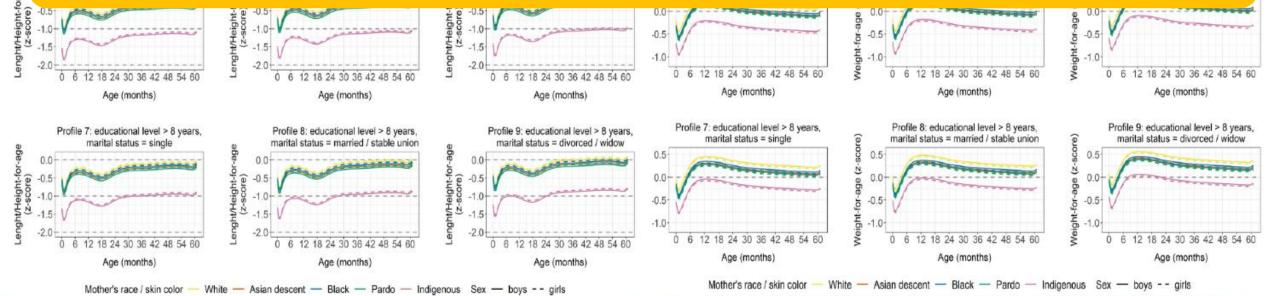


Fig. 5 Estimated mean curves for length/height-for-age z-scores, according to mother's age, educational level, and marital status. Brazil, 2008–2017

4 Estimated mean curves for weight-for-age z-scores model, according to mother's age, educational level, and marital status. Brazil, 2008–2017

# Platform to study environmental and climate effects on health



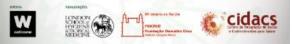
Objective 3. Expand and update the 100 Million Brazilian and CIDACS Birth Cohorts and develop the CIDACS Climate and Environmental Platform

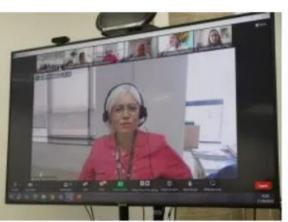
- Extend and expand the geocoding of data in the 100 Million Brazilian and CIDACS Birth Cohorts
- Update the the 100 Million Brazilian and CIDACS Birth Cohorts to include new data up to 2023.
- Develop a fully functional CIDACS Climate and Environmental Platform
   Hydrometeorological, reanalysis, and satellite imagery data



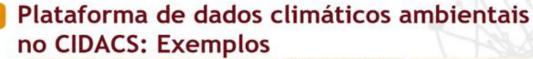
Mário Moreira (Presidente da Fiocruz), Agnes Soares (Diretora de Saúde Ambiental e do Trabalhador-MS), Liam Smeeth (Diretor da London School of Hygiene and Tropical Medicine), Ronaldo Oliveira (Pró-reitor PRPPG-UFBA), Maurício Barreto (Cidacs/Fiocruz - Ba) e multo mais

PALESTRA QUAIS OS DESAFIOS DA QUESTÃO CLIMÁTICA GLOBAL NO BRASIL? Bit.ly/CidacsPlataformaClima





Agnes Soares, coordenadora geral de Vigilância em Saúde Ambiental do Ministério da Saúde



| Dados medidos in<br>situ pelo INMET  | Modelo de Reanálise<br>ERA 5 LAND  | Modelo de Reanálise<br>VAN DONKELLAR   | MAPBIOMAS   |
|--|--|--|---|
| Período: 2000-presente<br>(diário).<br>Download: municipio e UF.<br>Variáveis:<br>• Temperatura: max - min-<br>média - ponto orvalho<br>• Precipitação Total<br>• Vel e direção do vento<br>• Pressão à Superfície<br>• Umidade Relativa | Periodo: 2000-presente<br>(diário).<br>Download: municipio e UF.<br>Variáveis:<br>• Temperatura: max - min-<br>média - ponto orvalho<br>• Precipitação Total<br>• Comp do vento: u e v<br>• Pressão à Superficie<br>• Umidade Relativa | Periodo: 2000-presente<br>(mensal).<br>Download: municipio e UF.<br>Modelo: V5GL01.HybridPM25<br>Variàvel:<br>• PM2.5<br>• NO2 | Período: 2000-presente<br>(mensal/anual).<br>Download: município e UF.<br>Variáveis:<br>Uso e ocupação do solo<br>Cicatriz de fogo<br>Cobertura de água |
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# Final considerations

- CIDACS' central mission entails generating scientific knowledge and providing evidence to support public policymaking to tackle health inequalities and other major challenges the Brazilian population faces.
- CIDACS has faced and overcome many challenges in producing scientific knowledge and evidence using integrated data.
- Overcoming these challenges requires the collective efforts of an interdisciplinary team and the development of in-house solutions, including customized data infrastructure, linkage algorithms, data acquisition processes, and analytical strategies.







# Obrigado! Thank you!





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