



# The case of Costa Rica (and Latin America): high acceptance of genetic research and data sharing, but low representation

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# COSTA RICA

## General Facts

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51,000 Km<sup>2</sup> - 5,163 million (est.)

High literacy rate

Fertility rate: 1.8

Life expectancy: 78-83 (2018)

Infant mortality: 7.8 per 1000

GDP per capita \$11,700 (2019)



Genetic  
research in  
Costa Rica –

Advantages

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Large families

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Family members live close to one another

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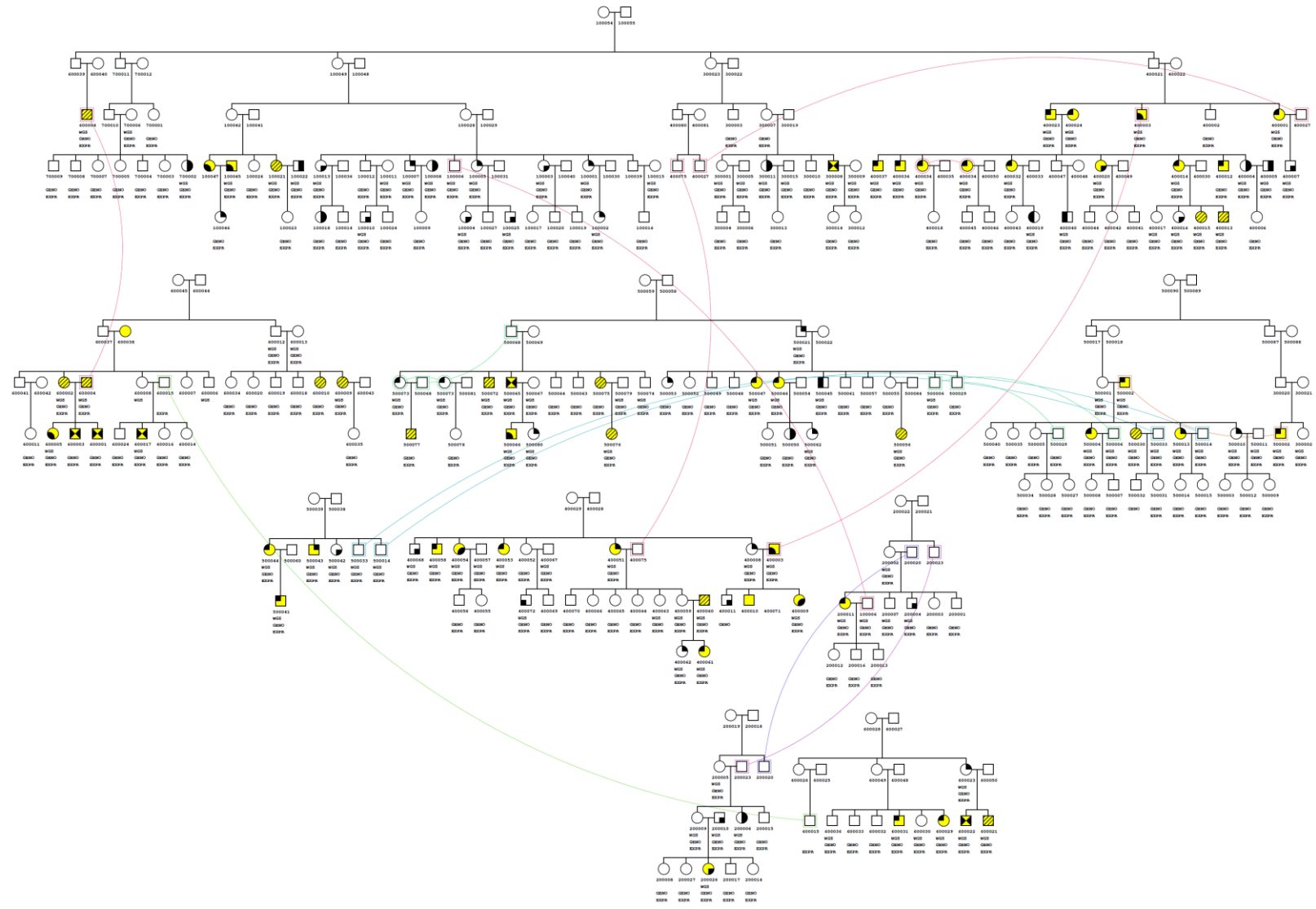
High willingness to participate in research

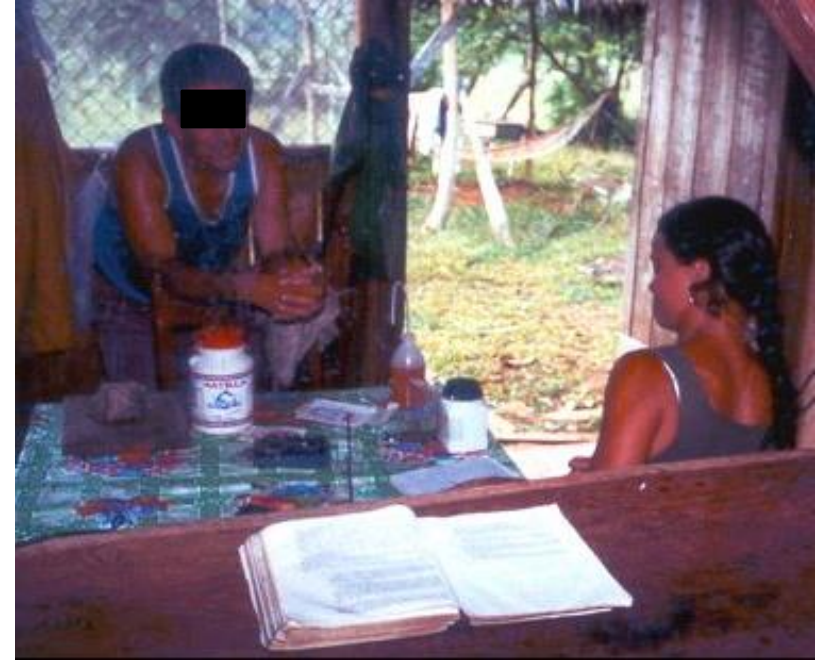
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Public health care system (1941)

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Unique ID number assigned at birth





Psychiatric  
genetics  
research group  
(1990-2021)

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Genetic risk variants for mental conditions: bipolar, schizophrenia, psychosis, Alzheimer/successful cognitive aging.

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Ancillary studies: Clinical assessment, diagnosis, sociodemographic characteristics, cultural differences, priorities for people with lived experiences.

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Impact of genomic medicine on causal explanations, practices and public policies for major mental disorders in Costa Rica

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Your DNA – Your Say

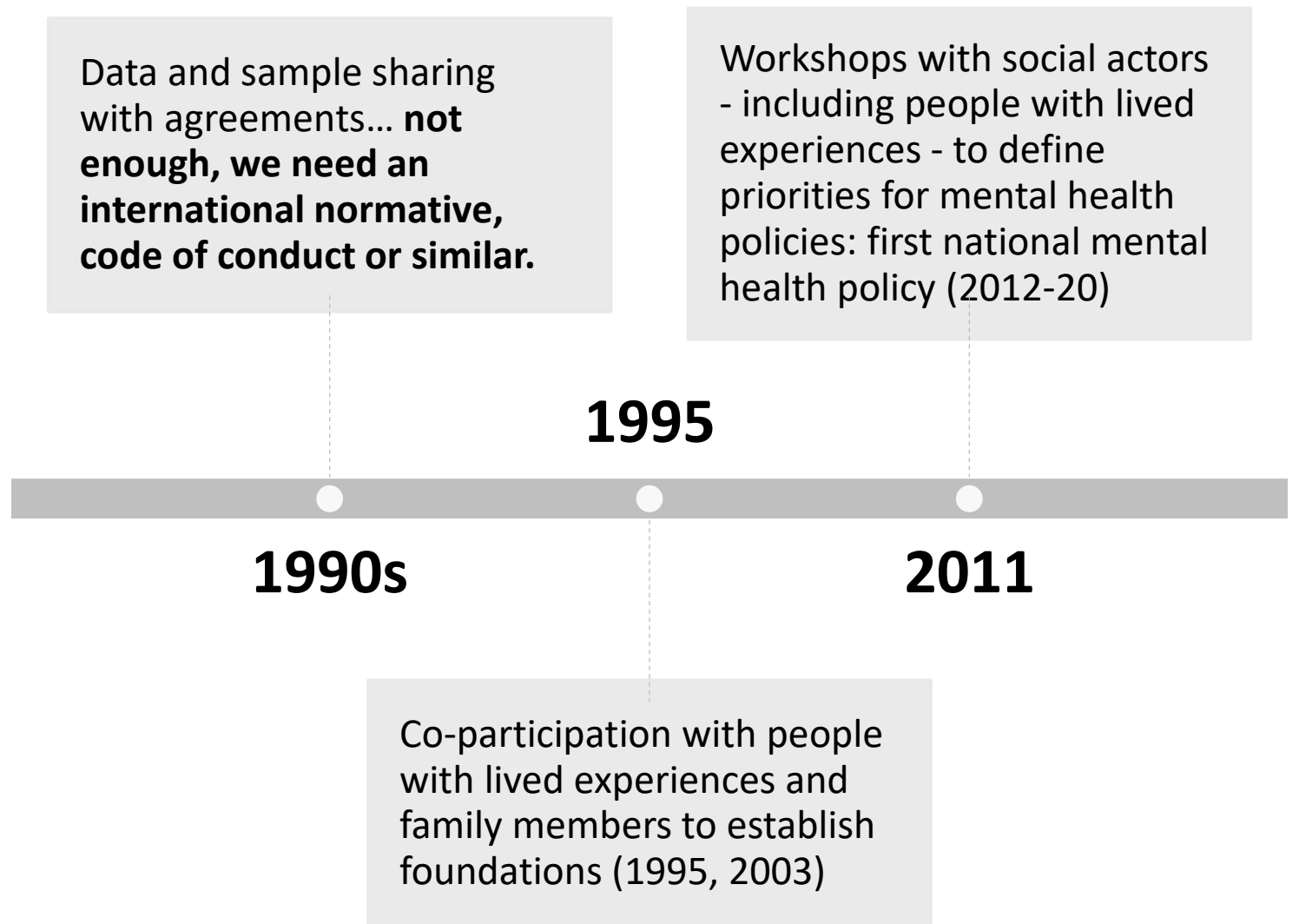
Collaborations -

Psychiatric Research Group



Autoras: Gloriana Brown y Paola Gómez  
Mapa: Freepik.com

# Public Engagement and Policy





# Survey “Your DNA / Your Say” for CR and other LA countries

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الحمض النووي الخاص بك	你的DNA, 你的话语权	Ihre DNA, Ihre Entscheidung	Your DNA, Your Say
العربية	中文	Deutsch	English
Tu DNA, Tu Decisión	Votre ADN, Votre AVIS	Wo dzadzomekaɔnu, Wo Susu	W'awoboasu ho asem ye w'asem
Español	Français	Ewe	Twi
Þitt erfðaeefni, þín ákvörðun	É il tuo DNA, Decidi Tu	あなたのDNA、あなたの意見	Twoje DNA, Twoje zdanie
Íslenska	Italiano	日本語	Polski
O seu ADN, a sua voz	Ваши гены - Вам решать	Ditt DNA, Ditt Val	آپ کا ڈی این اے، آپ کا کہنا
Português	Русский	Svenska	أردو

## Your DNA, Your SAY



films can be skipped, paused or watched again

### Welcome

This is a survey about your online health data and how it might be used by others.

It's really simple – watch the films and answer a few questions. The films tell you all you need to know. Hover your mouse over underlined words and you'll see a glossary.

The survey can be filled in by anyone and everyone, so please forward on. Your involvement is completely anonymous and we'll store all your answers securely at the Wellcome Genome Campus, Cambridge, UK.

# Information

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Sociodemographic information

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Willingness to donate genetic data for research purposes

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Willingness to donate according to different uses of the data

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Concerns regarding data sharing

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Factors that influence the decision

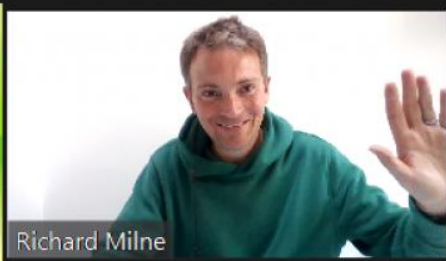
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Trust in different persons/institutions

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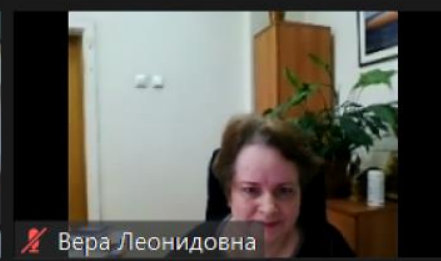
Anna Middleton



Richard Milne



Virginia Romano



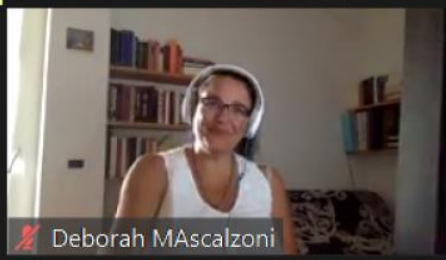
Вера Леонидовна



Jerome Atutornu



Jusaku Minari



Deborah MAscalzoni



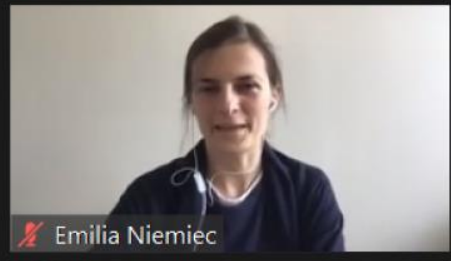
Christine Critchley



Alessia Costa



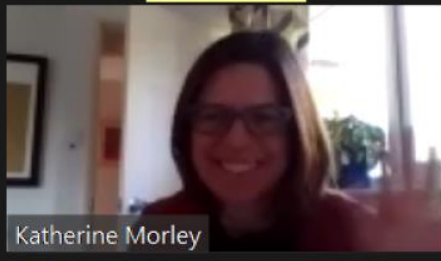
Dianne Nicol



Emilia Niemiec



Elena Baranova



Katherine Morley



Álvaro Mendes



If8



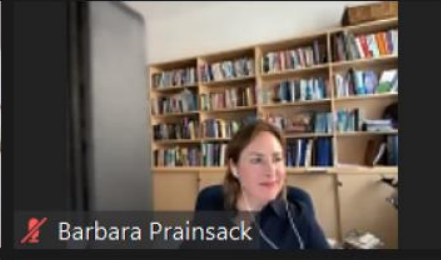
Q Annie Hasan



Jon Roberts



Yali Cong



Barbara Prainsack



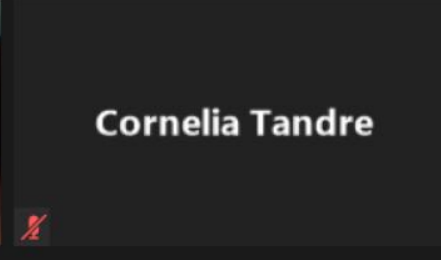
Chris Patch



Gabriela Chavarría



Peter Goodhand



Cornelia Tandre











# Personalized Medicine



Research Article

## Attitudes of Costa Rican individuals towards donation of personal genetic data for research

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Alejandro Ávila-Aguirre<sup>2</sup>, Maria Jose Castro-Gomez<sup>2</sup>, Lauren Robarts<sup>3</sup>, Anna  
Middleton<sup>3,4</sup> & Henriette Raventós<sup>1,2</sup>

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<sup>2</sup>Centro de Investigación en Biología Celular y Molecular/Universidad de Costa Rica/San José, Costa Rica

<sup>3</sup>Society & Ethics Research Group, Connecting Science, Wellcome Genome Campus, Cambridge, UK

<sup>4</sup>Faculty of Education, University of Cambridge

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N=224,  
pilot sample

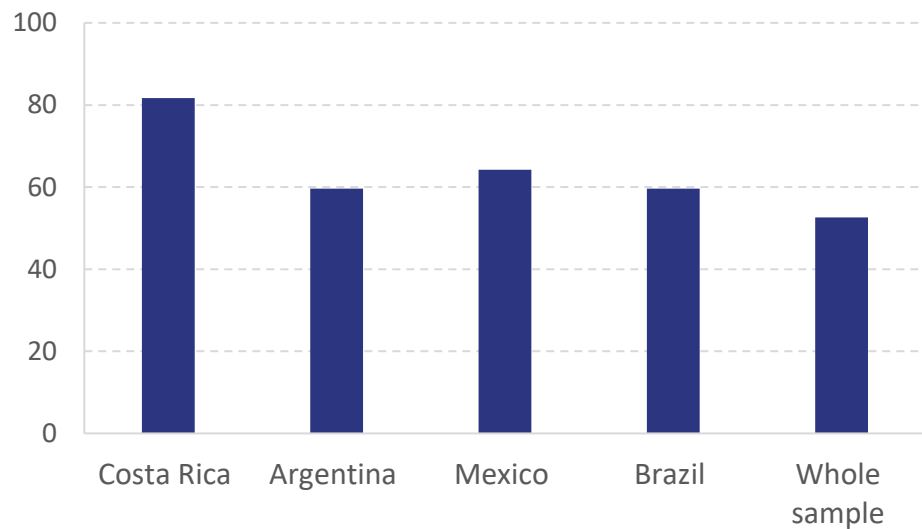
N=1347

N=919

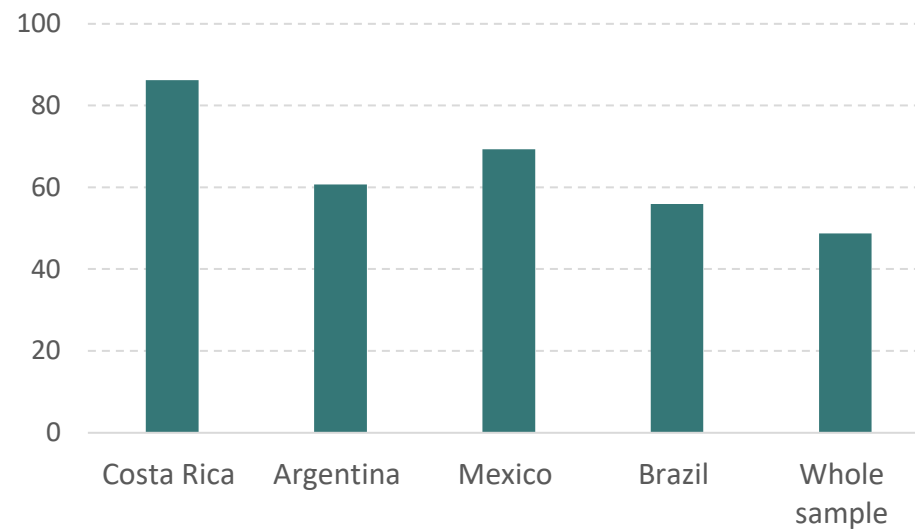
N=1349

# Willingness to donate medical or genetic data for research

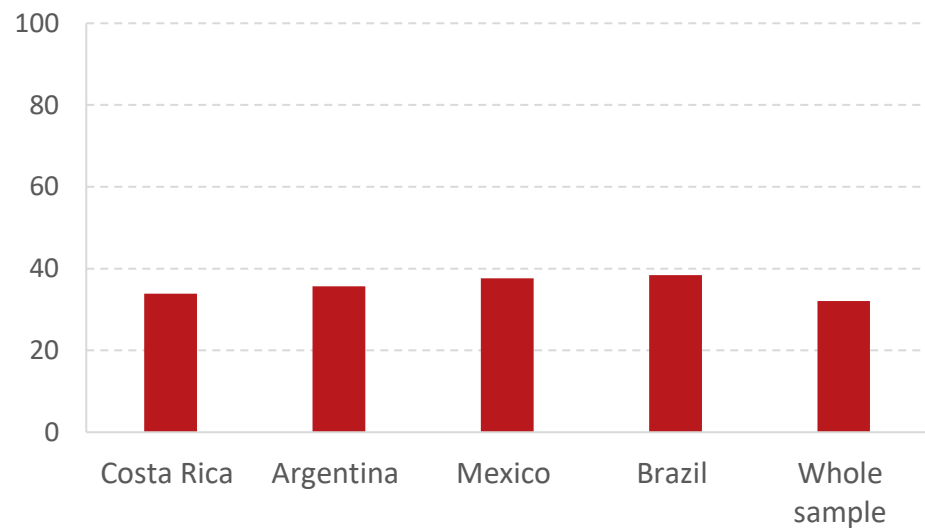
Medical doctors



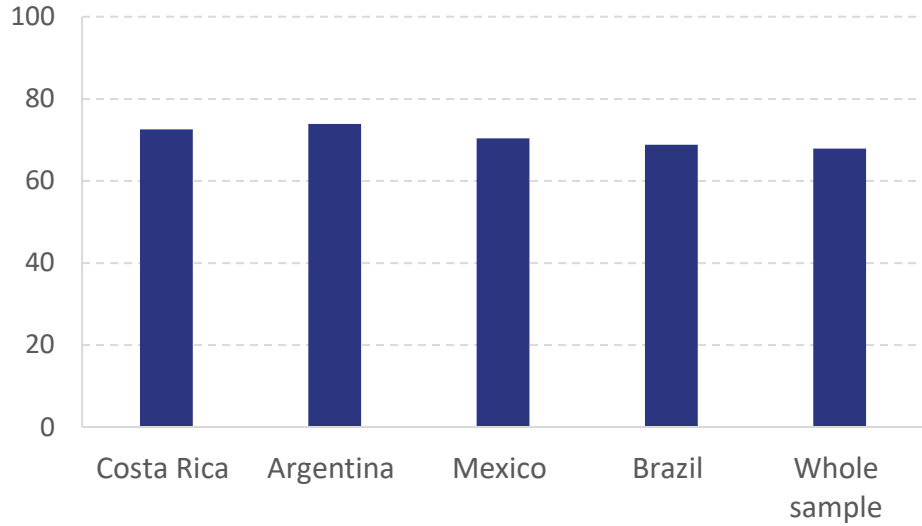
Non-profit researchers



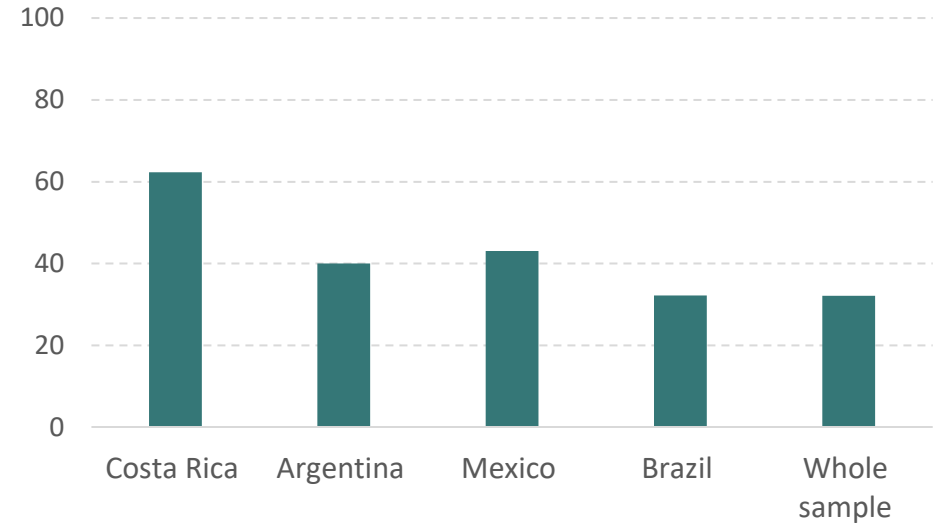
For-profit researchers



### My medical doctor

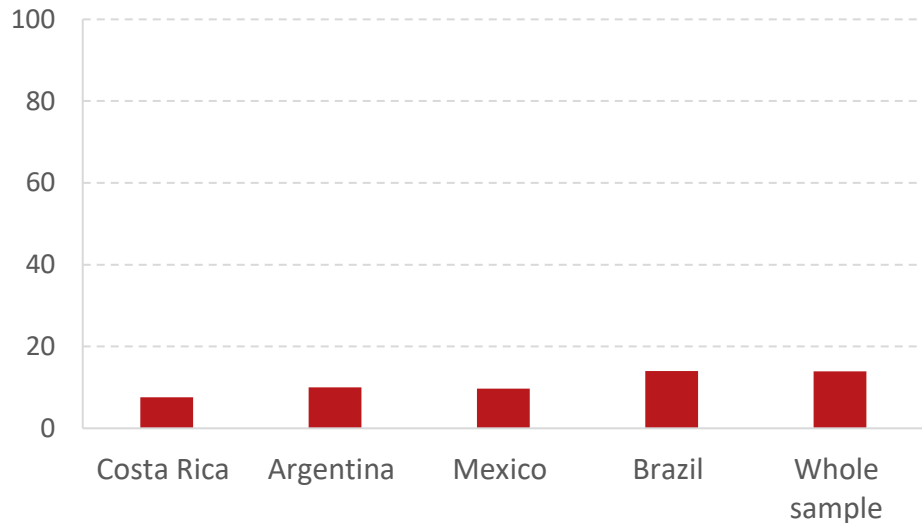


### Any researcher at a university in my country

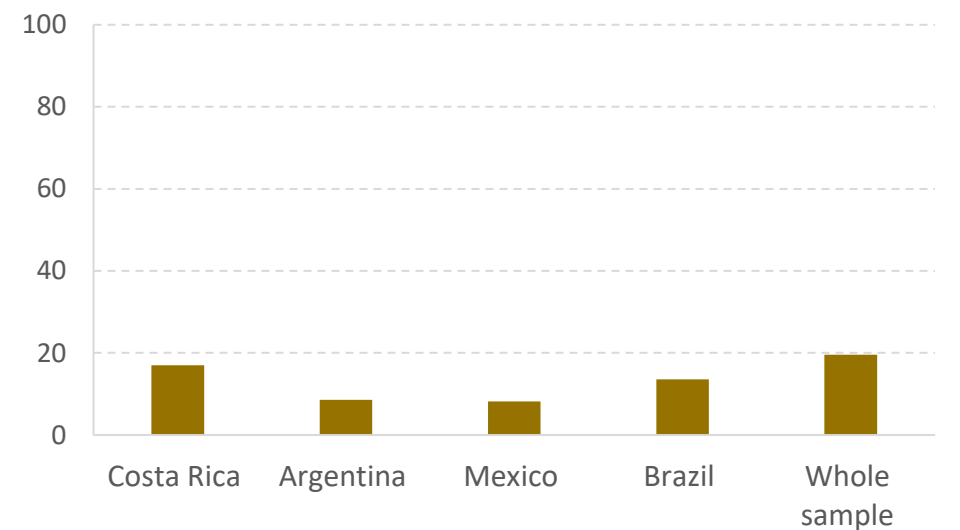


## Trust

### Any researcher at a company in my country



### The government of my country



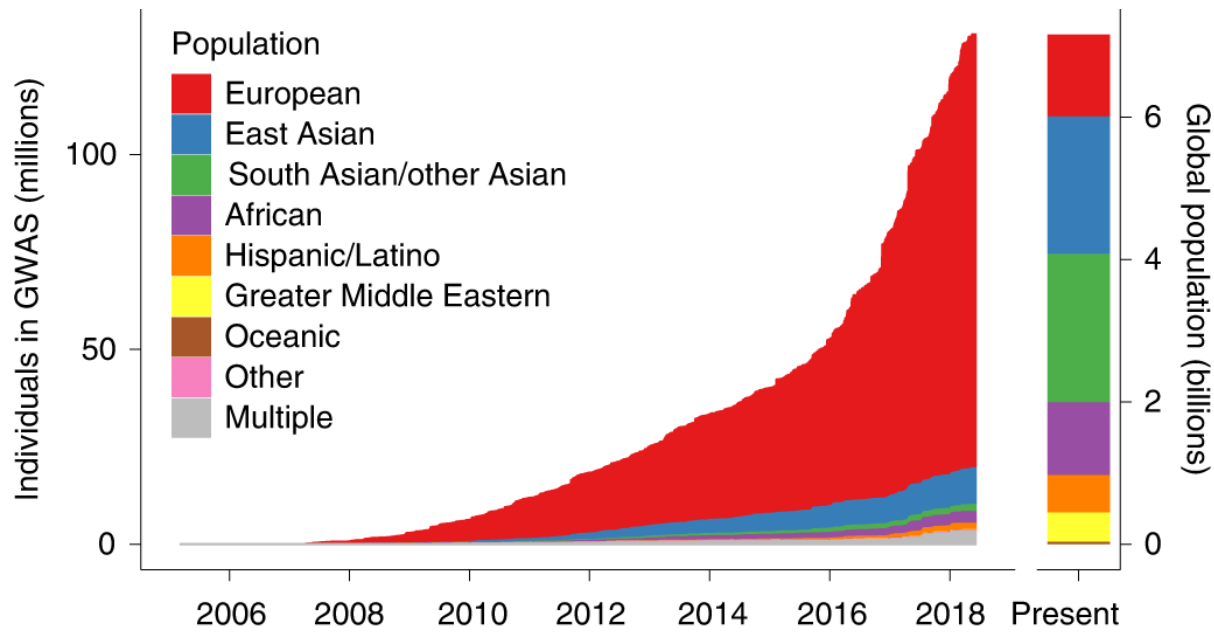


# Top three concerns regarding donation of genetic data

Concern	1	2	3
Costa Rica	Health or life insurance companies using the information to discriminate against me	My DNA being copied and planted at the scene of a crime	Upsetting my genetic relatives
Argentina	My DNA being copied and planted at the scene of a crime	Upsetting my genetic relatives	Being cloned
Mexico	My DNA being copied and planted at the scene of a crime	Being cloned	Upsetting my genetic relatives
Brazil	My DNA being copied and planted at the scene of a crime	Being cloned	Upsetting my genetic relatives
Whole sample	My DNA being copied and planted at the scene of a crime	Marketing companies targeting me to sell products	Being cloned

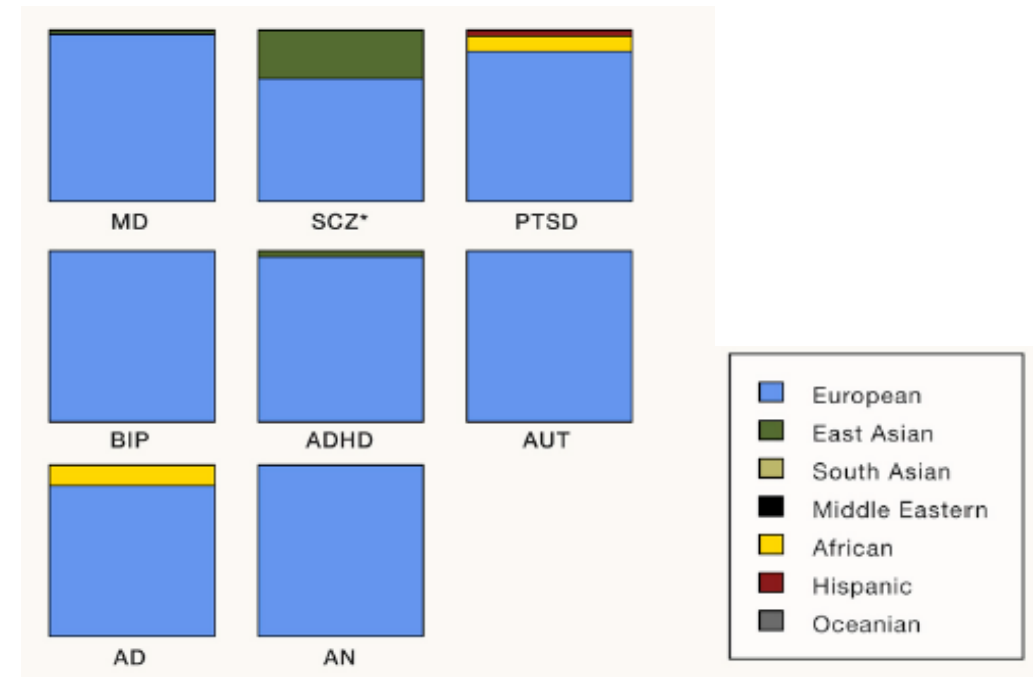
# Diversity in GWAS

## GWAS Catalog



Martin et al. 2019. Nature Genetics 51.

## Psychiatric disorders



Peterson et al. 2019. Cell 179.

# Acknowledgements

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**WELLCOME  
GENOME  
CAMPUS**



**ESCUELA DE  
BIOLOGÍA**



**Global Alliance**  
for Genomics & Health  
Collaborate. Innovate. Accelerate.