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

GABRIELA CHAVARRÍA-SOLEY, HENRIETTE RAVENTÓS

Contact: gabriela.chavarriasoley@ucr.ac.cr/henriette.raventos@ucr.ac.cr
Twitter: gchavar/ hravento
COSTA RICA
General Facts

51,000 Km² - 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

- Large families
- Family members live close to one another
- High willingness to participate in research
- Public health care system (1941)
- Unique ID number assigned at birth
Genetic risk variants for mental conditions: bipolar, schizophrenia, psychosis, Alzheimer/successful cognitive aging.

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

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

Your DNA – Your Say
Collaborations - Psychiatric Research Group

Autoras: Gloriana Brown y Paola Gómez
Mapa: Freepik.com
Public Engagement and Policy

Data and sample sharing with agreements... not enough, we need an international normative, code of conduct or similar.

1995

Co-participation with people with lived experiences and family members to establish foundations (1995, 2003)

Workshops with social actors - including people with lived experiences - to define priorities for mental health policies: first national mental health policy (2012-20)
Survey “Your DNA / Your Say” for CR and other LA countries
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.
Sociodemographic information

Willingness to donate genetic data for research purposes

Willingness to donate according to different uses of the data

Concerns regarding data sharing

Factors that influence the decision

Trust in different persons/institutions
Attitudes of Costa Rican individuals towards donation of personal genetic data for research

Gabriela Chavarria-Soley*1,2, Fernanda Francis-Cartín1,2, Fabiola Jimenez-Gonzalez2, Alejandro Ávila-Aguirre2, Maria Jose Castro-Gomez2, Lauren Robarts3, Anna Middleton3,4 & Henriette Raventós1,2

1 Escuela de Biología/Universidad de Costa Rica/San José, Costa Rica
2 Centro de Investigación en Biología Celular y Molecular/Universidad de Costa Rica/San José, Costa Rica
3 Society & Ethics Research Group, Connecting Science, Wellcome Genome Campus, Cambridge, UK
4 Faculty of Education, University of Cambridge

*Author for correspondence: gabiela.chavarriasoley@ucr.ac.cr
$N=1347$

$N=224$, pilot sample

$N=919$

$N=1349$
Willingness to donate medical or genetic data for research

**Medical doctors**

- Costa Rica
- Argentina
- Mexico
- Brazil
- Whole sample

**Non-profit researchers**

- Costa Rica
- Argentina
- Mexico
- Brazil
- Whole sample

**For-profit researchers**

- Costa Rica
- Argentina
- Mexico
- Brazil
- Whole sample
## Top three concerns regarding donation of genetic data

<table>
<thead>
<tr>
<th>Concern</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Costa Rica</td>
<td>Health or life insurance companies using the information to discriminate against me</td>
<td>My DNA being copied and planted at the scene of a crime</td>
<td>Upsetting my genetic relatives</td>
</tr>
<tr>
<td>Argentina</td>
<td>My DNA being copied and planted at the scene of a crime</td>
<td>Upsetting my genetic relatives</td>
<td>Being cloned</td>
</tr>
<tr>
<td>Mexico</td>
<td>My DNA being copied and planted at the scene of a crime</td>
<td>Being cloned</td>
<td>Upsetting my genetic relatives</td>
</tr>
<tr>
<td>Brazil</td>
<td>My DNA being copied and planted at the scene of a crime</td>
<td>Being cloned</td>
<td>Upsetting my genetic relatives</td>
</tr>
<tr>
<td>Whole sample</td>
<td>My DNA being copied and planted at the scene of a crime</td>
<td>Marketing companies targeting me to sell products</td>
<td>Being cloned</td>
</tr>
</tbody>
</table>
Diversity in GWAS

GWAS Catalog


Psychiatric disorders

Acknowledgements