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GoTriple / Improving Discovery and Collaboration in Open Science 02.02.2023

Accessibility and Equity in Cross-Discipline Collaborations Tackling Global Change

Jessie Abbate, PhD

jessica.abbate@geomatys.com

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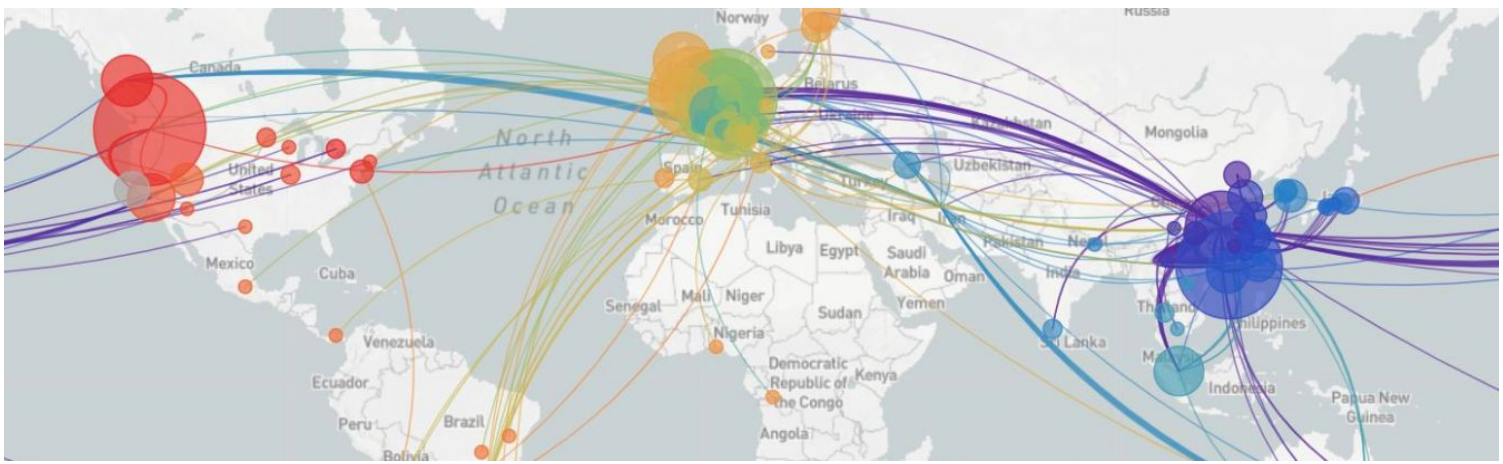
Summary

- Response to Global Change requires data sharing within and across fields
- Failure to address accessibility and equity creates barriers
- There are practical solutions!

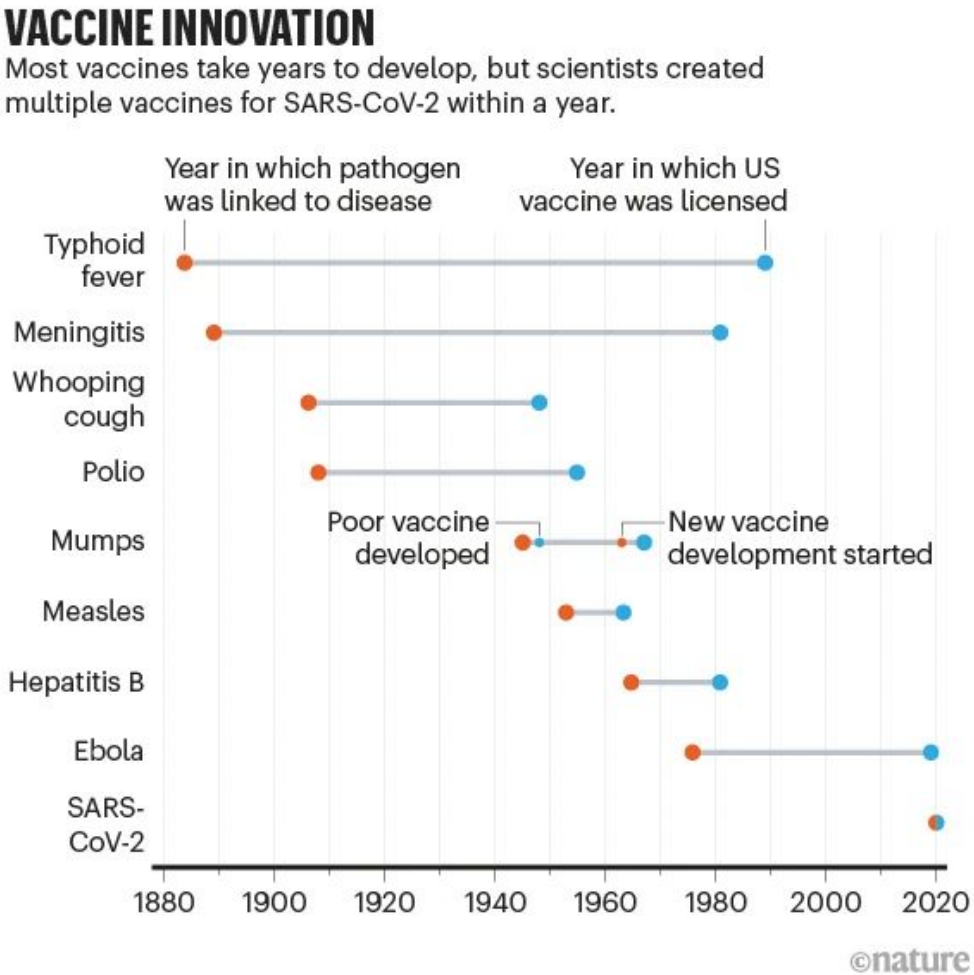
Data sharing is necessary for effective planning & response

Covid-19: How unprecedented data sharing has led to faster-than-ever outbreak research



Horizon
The EU Research & Innovation Magazine

Data sharing is necessary for effective planning & response



Ball 2021 *Nature*
https://doi.org/10.1038/d41586-020-03626-1

Data sharing can have unintended consequences

Ethics and governance challenges related to genomic data sharing in southern Africa: the case of SARS-CoV-2

Keymanthri Moodley, Nezerith Cengiz, Aneeka Domingo, Gonasagrie Nair, Adetayo Emmanuel Obasa, Richard John Lessells, Tulio de Oliveira

Data sharing in research is fraught with controversy. Academic success is premised on competitive advantage, with research teams protecting their research findings until publication. Research funders, by contrast, often require data sharing. Beyond traditional research and funding requirements, surveillance data have become contentious. Public health emergencies involving pathogens require intense genomic surveillance efforts and call for the rapid sharing of data on the basis of public interest. Under these circumstances, timely sharing of data becomes a matter of scientific integrity. During the COVID-19 pandemic, the transformative potential of genomic pathogen data sharing became obvious and advanced the debate on data sharing. However, when the genomic sequencing data of the omicron (B.1.1.529) variant was shared and announced by scientists in southern Africa, various challenges arose, including travel bans. The scientific, economic, and moral impact was catastrophic. Yet, travel restrictions failed to mitigate the spread of the variant already present in countries outside Africa. Public perceptions of the negative effect of data sharing are detrimental to the willingness of research participants to consent to sharing data in postpandemic research and future pandemics. Global health governance organisations have an important role in developing guidance on responsible sharing of genomic pathogen data in public health emergencies.

Lancet Glob Health 2022; 10: e1855-59
Published Online October 26, 2022
https://doi.org/10.1016/S2214-109X(22)00417-X
This online publication has been corrected. The corrected version first appeared at thelancet.com/lancetgh on November 17, 2022

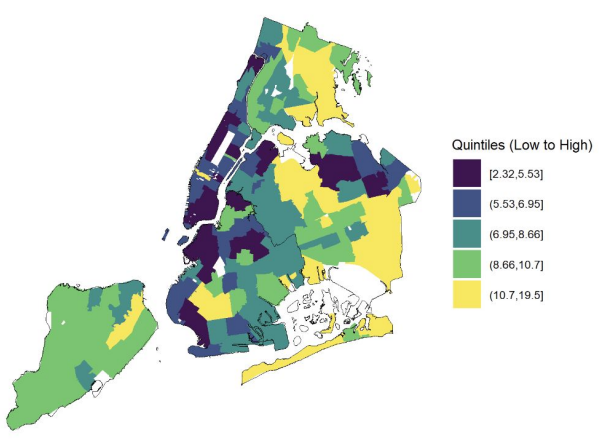
Centre for Medical Ethics and Law, Faculty of Medicine and Health Sciences Parow, Stellenbosch University, Cape Town, South Africa

Solution:

Take measures to avoid stigmatization and balance socio-economic implications

Moodley etal 2022 *Lancet* https://doi.org/10.1016/S2214-109X(22)00417-X

Data sharing can have unintended consequences



- In the US, COVID-19 data were not widely available at fine geographic scales, due in part to the potential socio-political backlash showing e.g., certain populations had higher death rates ("social determinants of health")

Your Zip Code Is More Important Than Your Genetic Code

By Emily Orminski / June 30, 2021 / Views

Where you live is one of the most significant components of overall health outcomes and life expectancy. Up to 60% of your health is determined solely by your zip code. This is largely due to the nature of the communities people reside in, such as whether it has wealth, whether or not there is strong community investment, and whether hospitals and health centers are present, among others. Your social and built environment determines your individual health and community health, above personal behavior and clinical care.

Other Barriers to data sharing

Equitable access to tools developed from shared data

Barriers

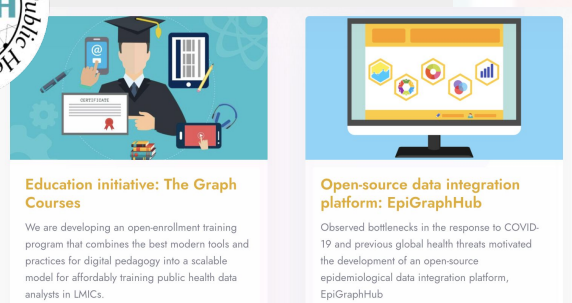
- Intermittent or slow internet access
- Limited knowledge for navigating platforms
- Communication barriers (e.g., language barriers, units, academic networks, travel restrictions)

➢ Failure to see the benefits of sharing

➢ Inability to access one's own data after sharing

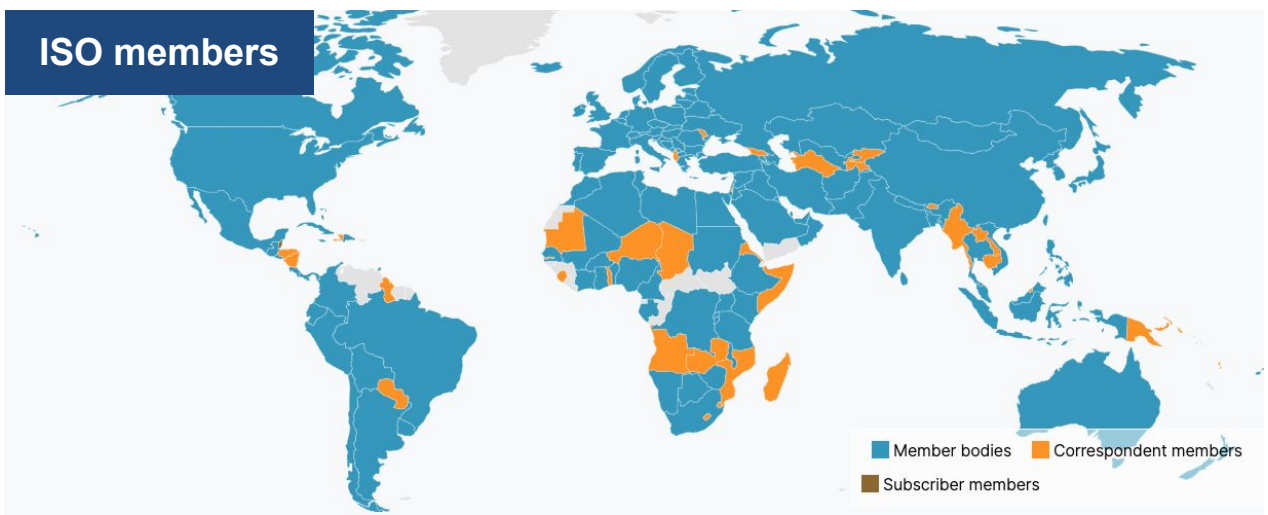
Solutions:

- Provide *accessible* access to tools
- Design systems that bring the tool to the data locally
- Incorporate training and outreach into budgets
- Hold meetings in more diverse locations



Other Barriers to data sharing

Tools and standards that consider diverse contexts



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Listed By Region

Africa (8)	Middle East (4)
Asia Pacific (116)	North America (200)
Europe (199)	South America (2)

HL7 - not a single affiliate member from Africa

Other Barriers to data sharing

Equitable career advancement and opportunities

Problems

- Parasitic (“colonial” or “parachute”) science
- Differences in target journals between fields

PLOS MEDICINE

EDITORIAL

Time to end parachute science

Beryne Odeny*, Raffaella Bosurgi

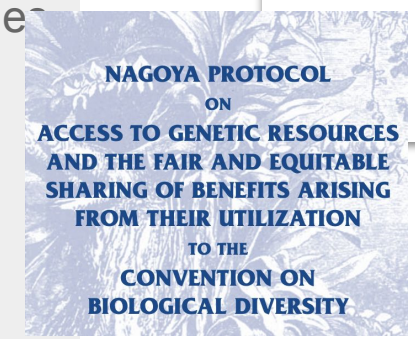
PLOS Medicine, San Francisco, California, United States of America

* bodeny@plos.org

Colonial science, also known as parachute or parasitic science, is an extractive practice whereby researchers—typically from highly resourced countries—do research and extract data and samples from non-native regions or populations, typically low resource settings or countries, [1] without appropriately acknowledging the importance of the local infrastructure and expertise. In so doing, foreign researchers fail to establish long term, equitable collaborations with local partners [2].

Solutions:

- Actively involve experts from the populations affected by outcomes from start to finish.
- Nagoya Protocol-type rules for publication
- More journals?! or… Structural changes in how impact is evaluated



Other Barriers to data sharing

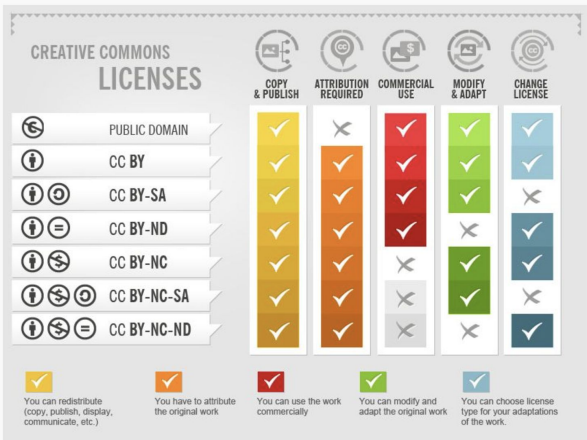
Sustainability and Rights

Problem

- Who pays to make tools, platforms and datasets open?
- How to capitalize on the value of data while encouraging sharing and open access?

Solutions:

- ???
- Public-Private Partnerships
- Choose the right license
- Budget for use review
- Prioritize getting buy-in



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CERN Open Hardware Licence Version 2 - Strongly	●	●	●	●	●	●	●		●	●	●	●	●

PREZODE

Preventing zoonotic disease emergence

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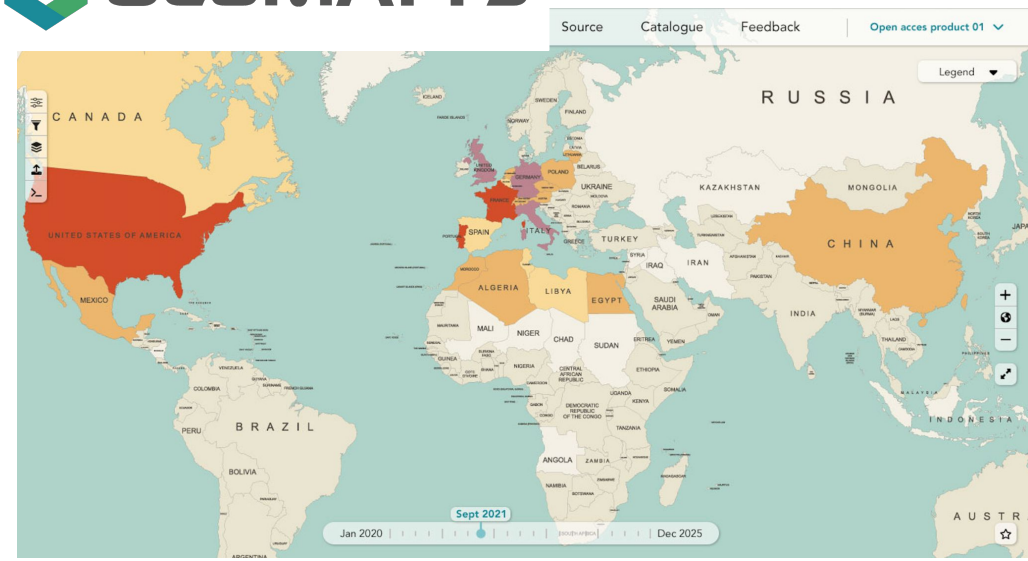

esa
European Space Agency
Agence spatiale européenne

https://www.geomatys.com/

Summary

Improving equity and accessibility can improve global data availability and collaboration

Really put “fair” in

Solutions:

- Take measures to balance socio-economic implications
- Design tools with a full range of access options
- Fully integrate the populations affected by the tools
- Include training and outreach in budgets for open data projects
- Think long-term