Advancing brain and mental health research via global data sharing and governance

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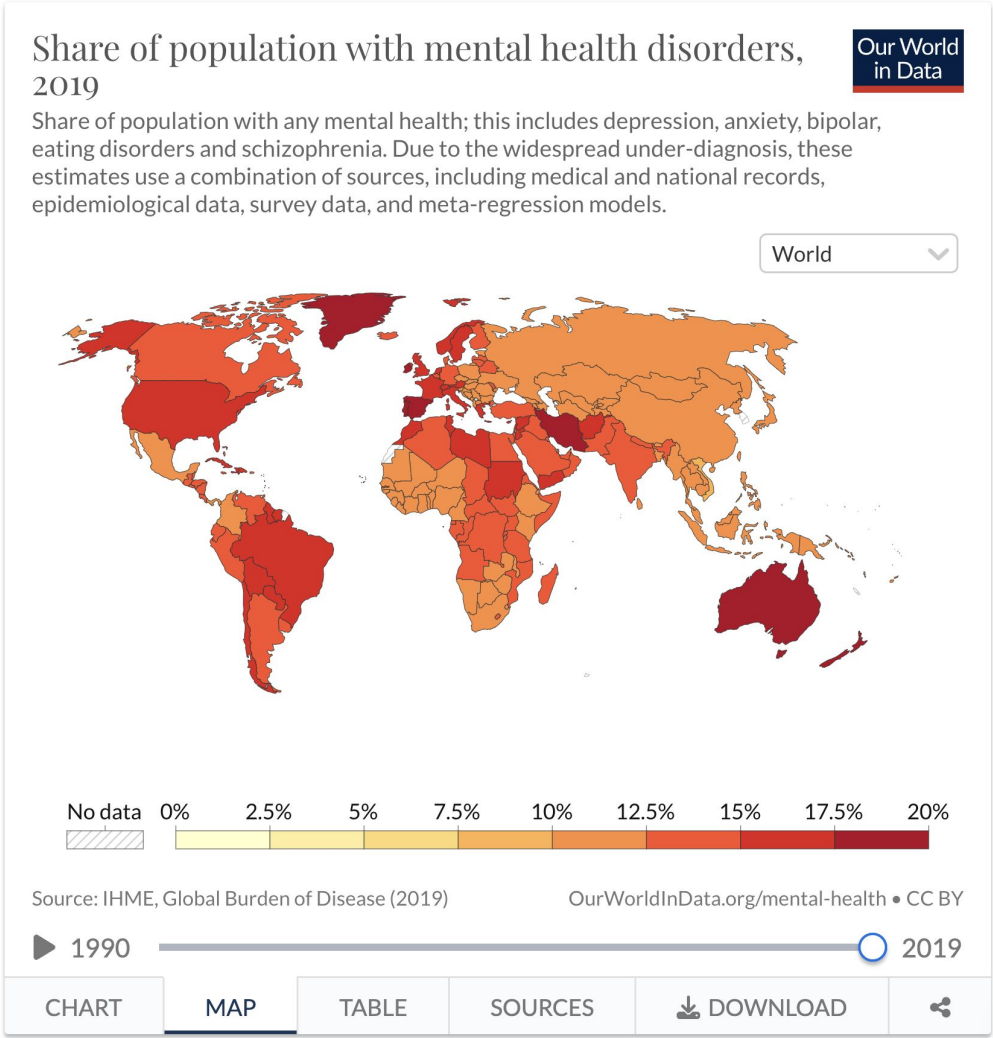
IBI INTERNATIONAL BRAIN INITIATIVE

It takes a village

Mental health is a global problem.

Brain and mental health research are global enterprises.

Their research requires sharing biological and behavioural measures across international cohorts to accelerate equitable development of treatments for all peoples.



The IBI Data Governance Task Force

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Neuron

Volume 110, Issue 4, 16 February 2022, Pages 600-612

Review

International data governance for neuroscience

Damian O. Eke [1, 2], Amy Bernard [3], Jan G. Bjaalie [4], Ricardo Chavarriaga [5], Takashi Hanakawa [6], Anthony J. Hannan [7], Sean L. Hill [8], Maryann E. Martone [9], Agnes McMahon [3], Oliver Ruebel [10], Sharon Crook [11], Edda Thiels [12], Franco Pestilli [13]

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https://doi.org/10.1016/j.neuron.2021.11.017

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Recommendations

- Make IDG a priority
- Develop principles for IDG
- Develop practical tools and guidance for streamlined IDG
- Increase awareness and education on IDG

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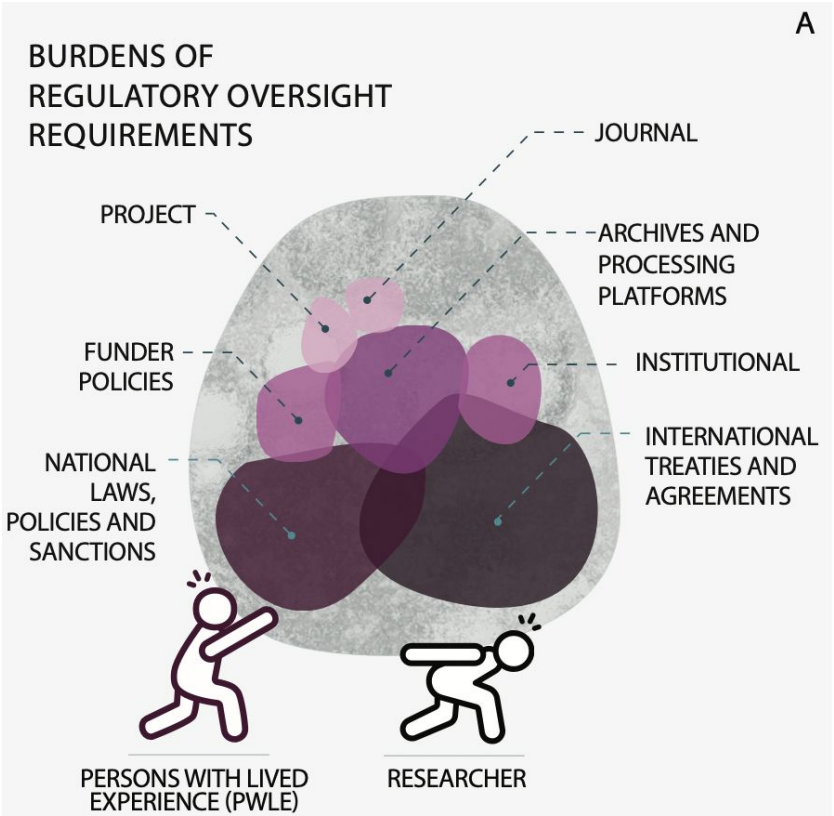


Lack of clarity on laws hinders data sharing

While brain and mental health research strives to become international, the lack of transparency and navigability of existing legal, ethical, and sociocultural guidance imposes barriers to data sharing.

Eke et al., 2021
10.1016/j.neuron.2021.11.017

If done right, data governance can facilitate research

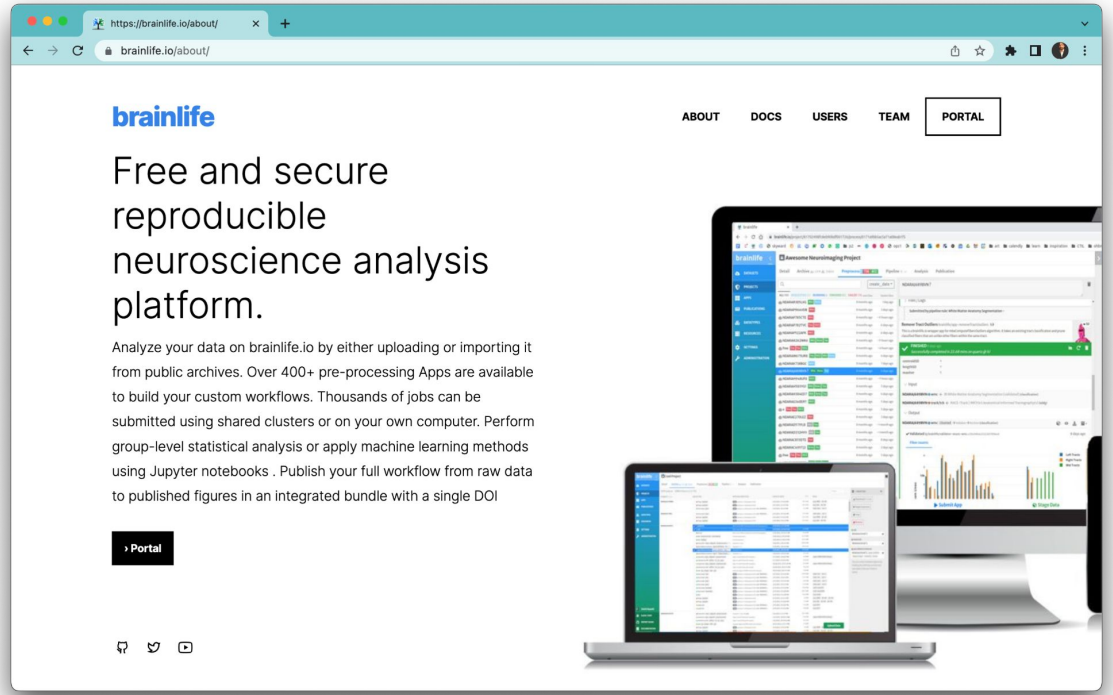
A robust brain and mental health International Data Governance Framework (IDGF) can turn heavy stones into stepping stones to accelerate research and discovery.

Eke et al., 2021
10.1016/j.neuron.2021.11.017

The Kavli data governance pilot

Identify Bilateral Data Sharing Challenges (USA-AUS; EU-USA)

Develop Data Governance Documents around a specific technology.
Focus on EEG and MEG data



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Hayashi, Caron et al., *in preparation*

The Wellcome Trust project

How can brain and mental health data be shared across national borders in a way that maximizes benefits to society and affected individuals while upholding laws and ethical principles?

Develop a practical approach for exploring current challenges to responsible international data governance along four dimensions: *technical*, *legal*, *lived-experience* and *ethical*.

Credit: Sebastian Mar / Wellcome Photography Prize 2020
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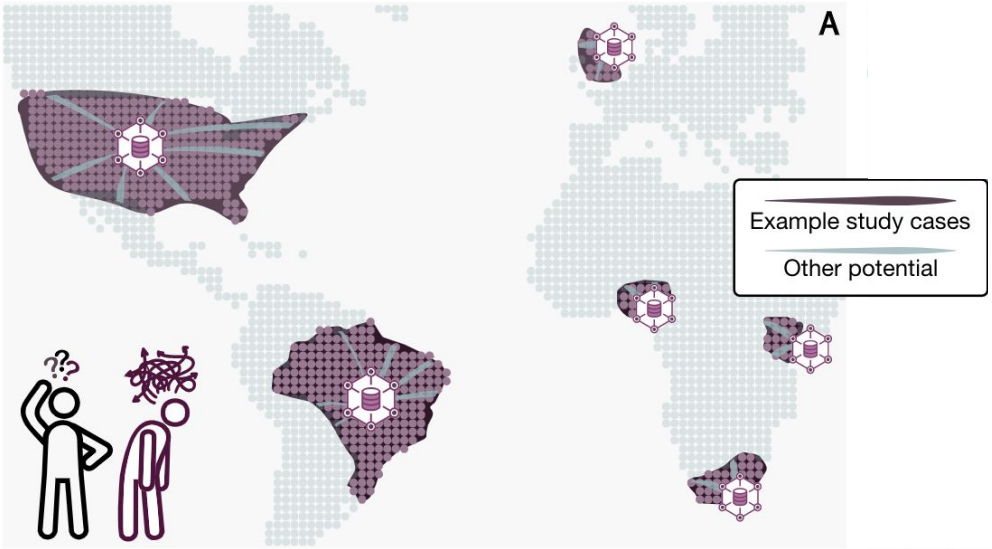
Data governance is defined nationally



Access to data at an international scale can advance brain research by increasing the opportunities for pooling data across cohorts, diversifying the existing cohorts within a nation and achieving the statistical power necessary for scientific rigor.

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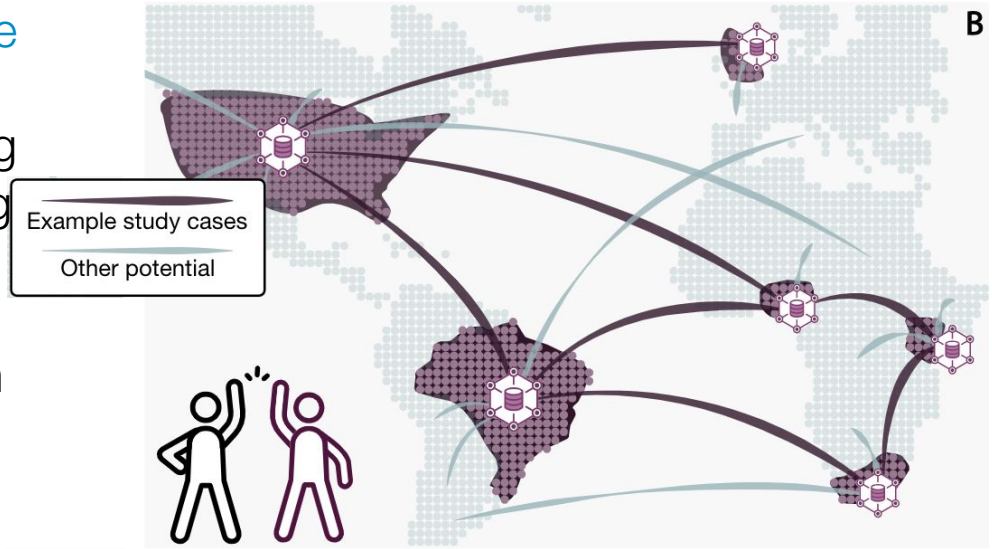
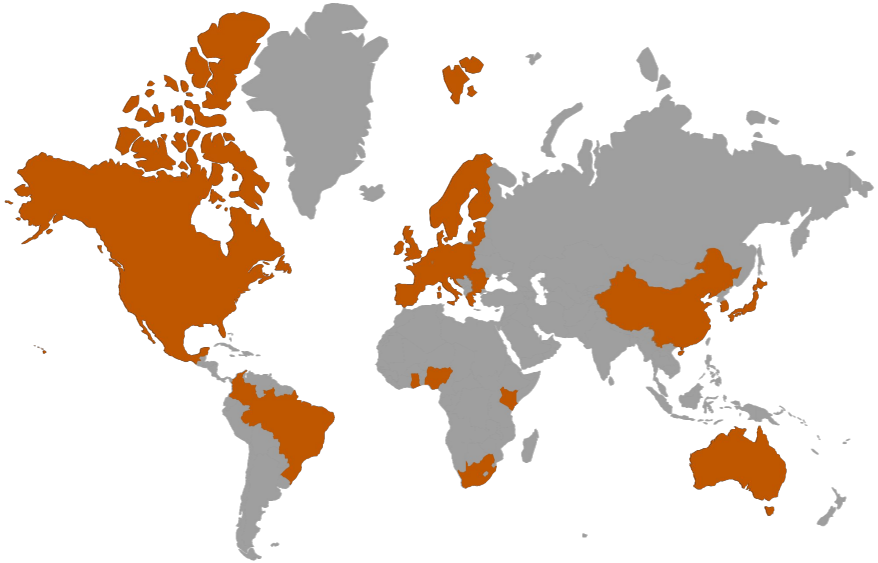
Facilitatory international data governance

The objective is to create responsible and sustainable governance frameworks for data sharing, building toward our long-term goal of forming a sustainable global consortium to develop, operate, update and disseminate a robust brain and brain and mental health IDGF.



The Wellcome Trust project – Team



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We need you!

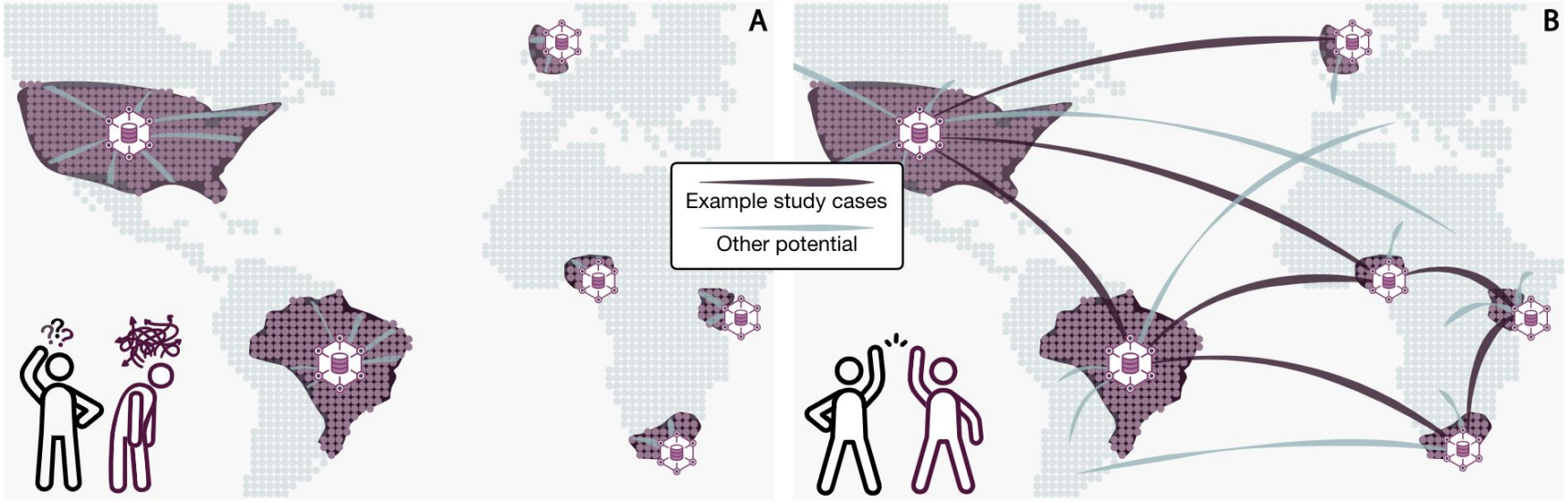
Ambassador program: Legal, Ethical, Technology, and Lived-Experience Ambassadors.

Organize a workshop: Help organize Workshops in high, medium and low income countries.

Become a consortium member: Help us form a sustainable global consortium to develop, operate and disseminate IDGF similar to GA4GH.org for genetic data.

Contribute data or expertise to the pathfinder projects.

This is an opportunity to build a responsible and sustainable data infrastructure.



Wellcome's goal

To improve health by funding research, building global partnerships and running advocacy campaigns.

We work with people and organisations using science to solve the world's most **urgent health challenges.**

Long term vision: Neuroscience and mental health data can be shared across groups and geographies

Image: Ivan Bajic

istockphoto

Ethical, legal and technical transparency can build trust and increase impact of neuroscience and mental health data

Image: Riccardo Annandale

Unsplash

Help us build a global community to lay the foundations for sharing neuroscience and mental health data

Image: Gianmarco Unsplash

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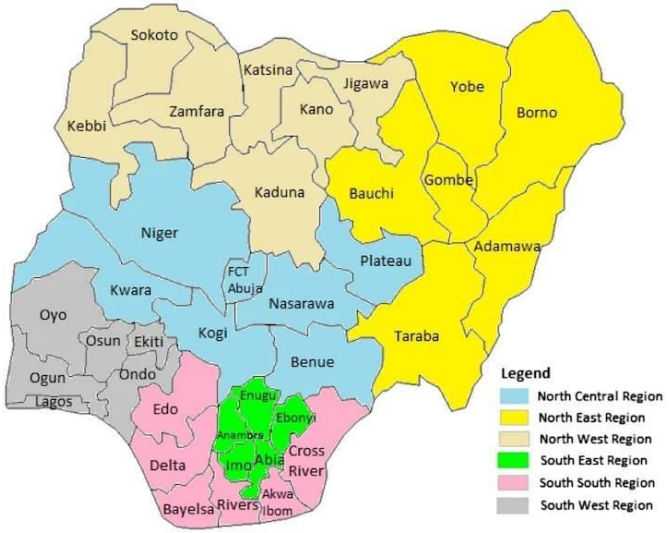
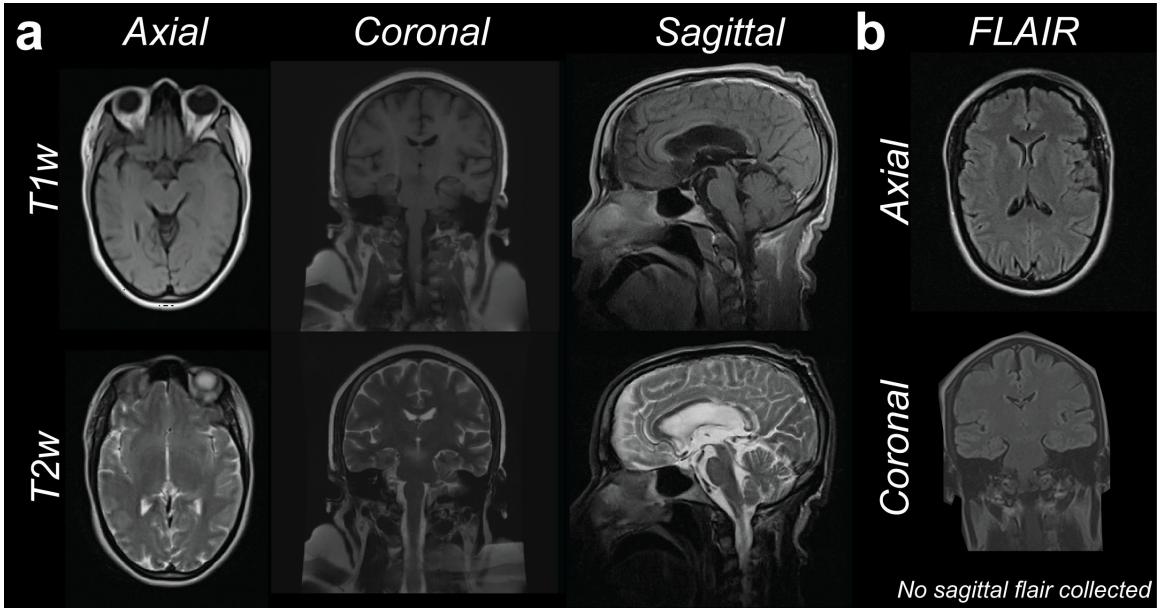
Example pathfinder study

Dementia, Parkinson's Disease, Controls.

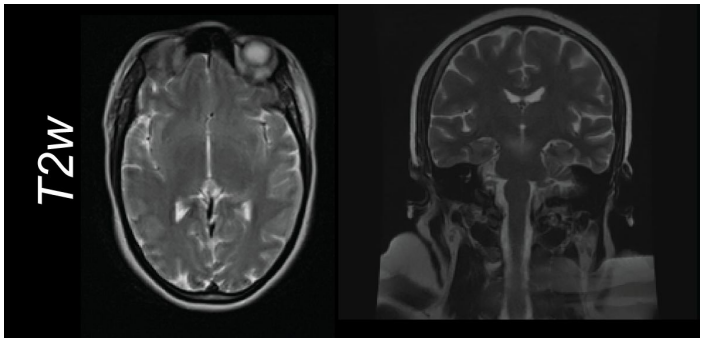




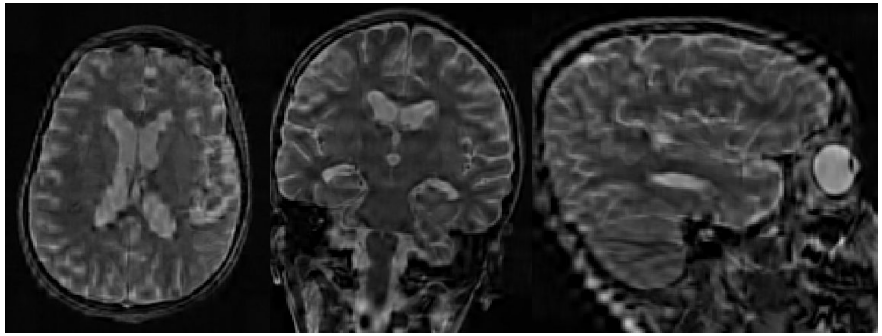
Wogu, Flim, Caron et al., *in preparation*

High-income country tool for MRI data processing

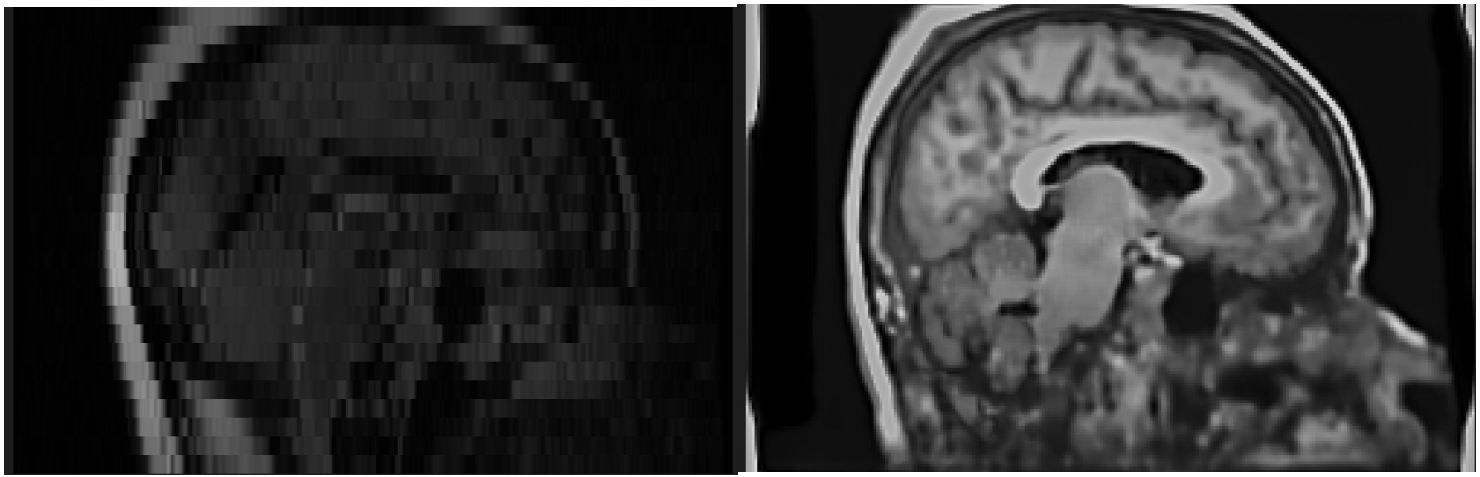
INPUT



OUTPUT



High-income country AI tool for MRI data synthesis



INPUT

Nigerian Clinical data

OUTPUT (MP-RAGE)

Nigerian clinical data

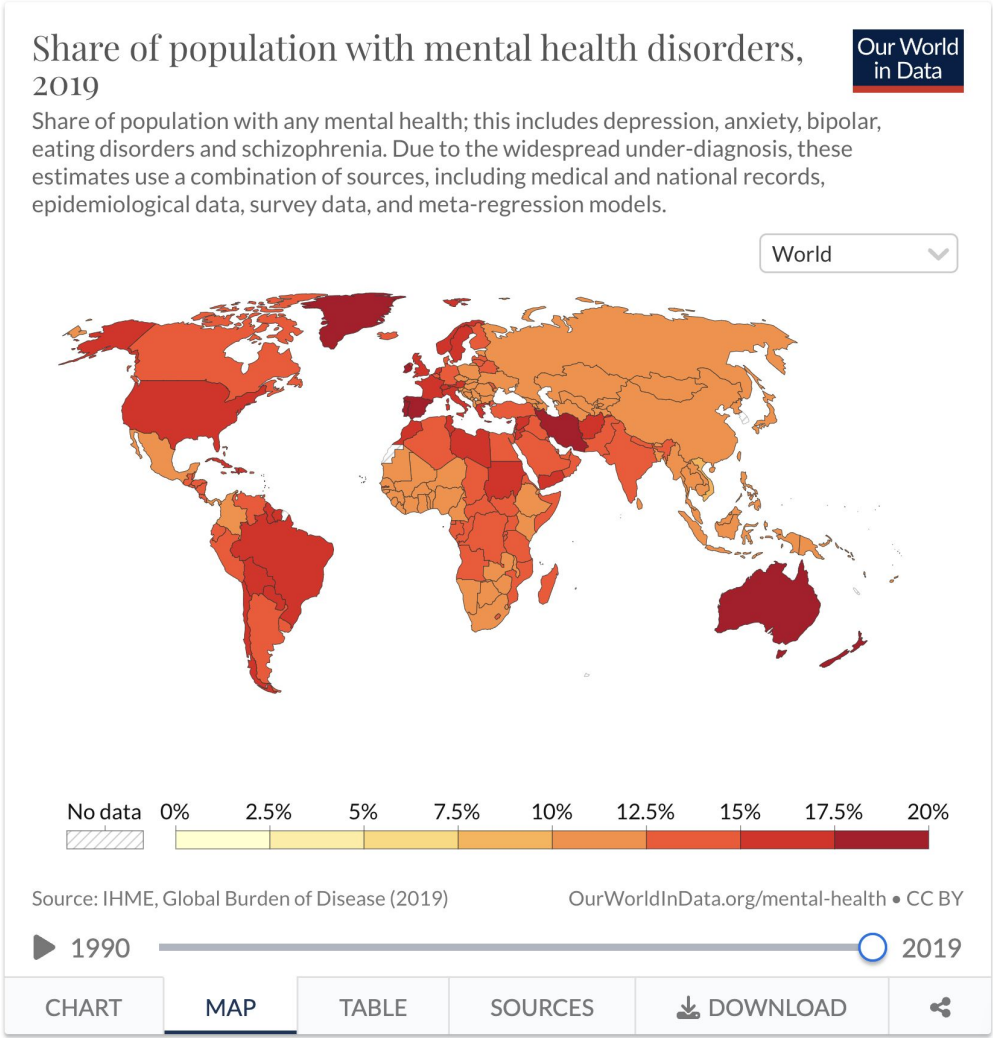
Understanding brain and mental health

Mental health is a global problem.

The WHO has developed a special initiative on mental health.

Mental health conditions contribute to poor health outcomes, premature death, human rights violations, and global and national economic loss.

World Health Organization. (2019). The WHO special initiative for mental health (2019-2023): universal health coverage for mental health. World Health Organization. https://apps.who.int/iris/handle/10665/310981.



The Kavli data governance pilot

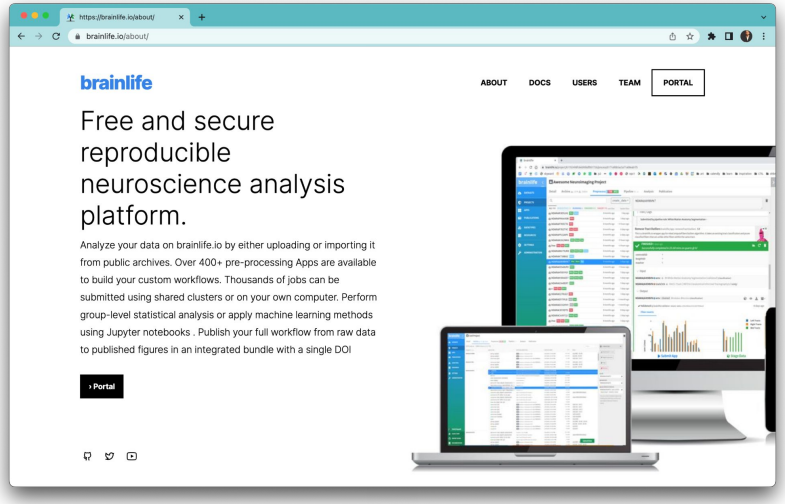
Analysis of laws and legislation that regulate the sharing of human data between the USA and France and the USA and Australia.

Interim results

- Data User Agreements that apply to USA-Australia
- Data Processing Agreement
- Data Deposition Consent Form
- Draft IDG Framework Proposal
- Modified brainlife.io use of cookies

What is next

- Analyze legislation between USA-EU-France
- Develop documents specific to USA-France
- Develop interface brainlife.io / France



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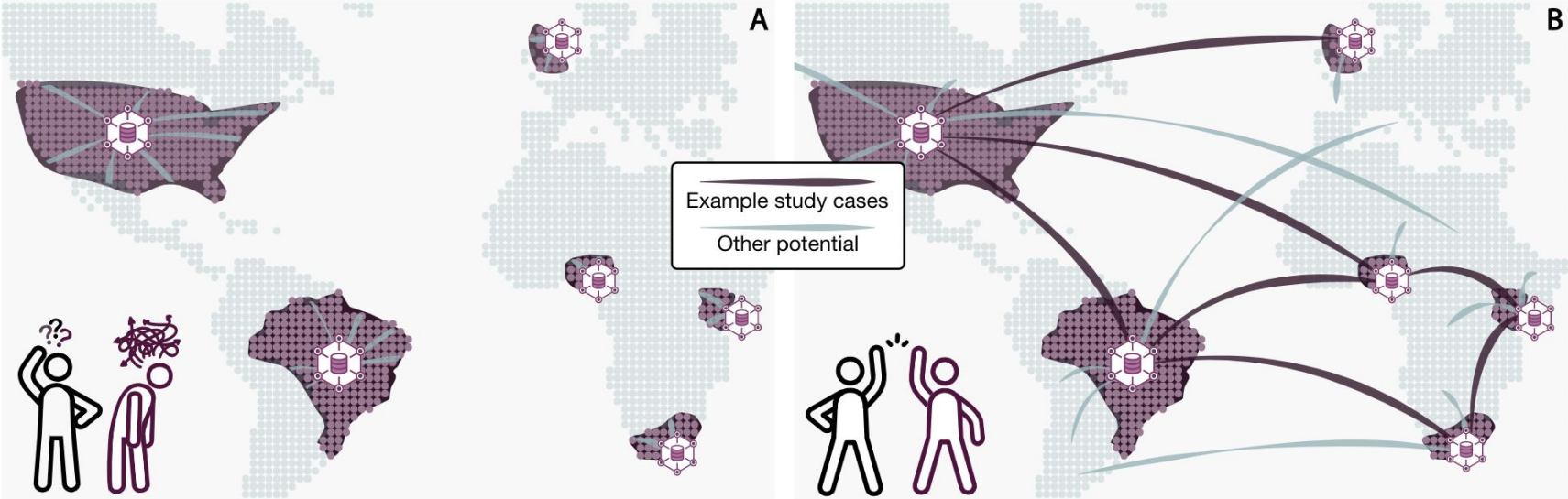
Data-driven research approach

Regional and global workshops to collect laws, ethical needs and cultural challenges.

Pathfinder case studies to test international data exchange using validation datasets.



Increased data diversity of neuroscience and mental health studies is a critical component of robust findings

Image: NASA Unsplash