

JEDI on the BRAIN: a Justice Approach to Building Human Brain Cell Atlases

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BICAN: BRAIN Initiative Cell Atlas Network

BICAN is National Institutes of Health's (NIH) investment in multi-modal research: an effort to create reference "atlases" of brain cell types using multiomics data from whole brains.

HMBA: Human Mammalian Brain Atlas

- HMBA is a flagship center within BICAN whose goal is to **create a comprehensive whole-brain atlas across 4 species**: mouse, marmoset, macaque, and human.
- Collaboration between University of Washington's BRaiN Lab & the Paul Allen Center for Brain Science.
- Creating a brain atlas requires the collection of **high-quality, whole brain donations**.
- Specimens from human donors are collected through the **medical examiner's office** and a **palliative/hospice donor program**.
- A **consensus committee** meets once a month to review donors and vote on how to allocate brain tissue.



HMBA's JEDI Challenge

Creating brain atlases requires deep attention to issues of justice, equity, diversity and inclusion (JEDI) that arise from brain donation, biospecimen curation, genetic analysis, and dissemination of results.

Four Neuroethical Issues within HMBA

1. Underrepresentation of Minoritized Groups

- Legacies of betrayed trust make POC hesitant to contribute specimens to research.
- Many minoritized groups experience diseases and disorders that are strongly influenced by social determinants of health. **Excluding brain donors with such conditions will exclude minoritized groups more often.**

2. Recruitment & Relationships with Families

- Families that consent to their loved-one's brain donation could benefit from seeing its impact but might have their cultural & religious beliefs inadvertently violated.

3. Neurotypicality

- Some believe donors must be "neurotypical" to **ensure high tissue quality** or for our **results to serve as a control or reference**.
- These intuitions could **encode ableist biases** into the donor selection process.

4. Data Sharing, Analysis, Presentation

- Data must be **FAIR**: Findable, Accessible, Interoperable, Reproducible.
- The HMBA Neuroethics team suggests methods used adhere to **FATE** principles: Fairness, Accountability, Transparency, and Ethics.
- FAIR and FATE conflict when open data sharing practices come at the cost of communities' governance over data.

Ongoing Concerns

What does it mean to create a "representative sample" with such a small cohort?

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If we exclude for common life experiences - depression, trauma, drug use - then who do we recruit?

What are our responsibilities to communities who choose not to participate?

HMBA Neuroethics Goals

HMBA's goal is to produce a **reference** — or, a comprehensive taxonomy of cell types — rather than a **control**.

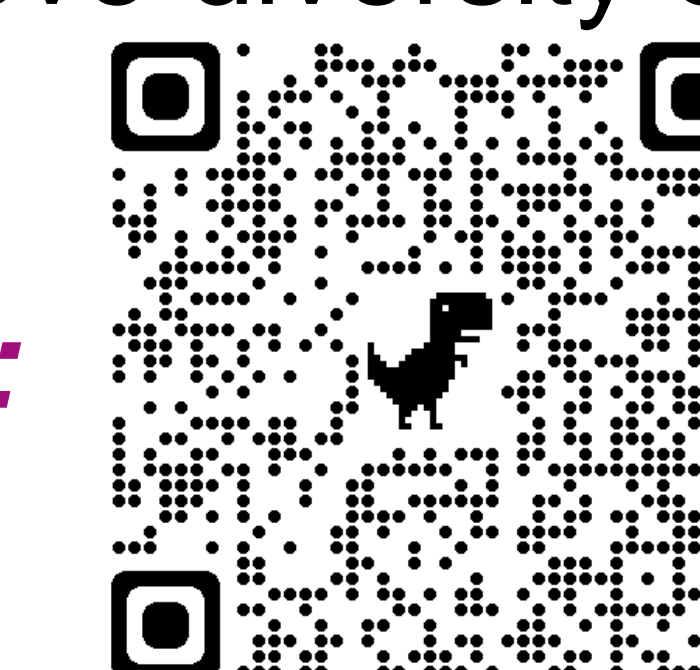
The HMBA Neuroethics team aims to achieve:

- Recognition, Representation and Reparation (through partnerships with historically marginalized individuals, groups and communities).

As such, the Neuroethics HMBA project will:

- influence how we move forward with exclusion criteria and the acceptance of brain donations currently available.
- start recommending community and patient engagement strategies to improve diversity of future brain donors.

Scan for references (and more):



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