Participatory machine learning & social justice in the development of neurological interventions

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Supported by NIMH BRAIN Initiative
Award 1RF1MH117813.

National Institute
of Mental Health

Machine Learning & Social Justice

Fairness in Machine Learning (ML)

Recent work in computer science has focused on addressing issues of bias and “fairness” in machine learning (ML) algorithms in response to mounting evidence that using algorithms to make decisions such as providing a loan or to assign healthcare resources can exacerbate and proliferate structural inequalities, further oppressing individuals from marginalized groups[1,2].

Much of this work has focused on developing measures of algorithm “fairness”, to capture the extent to which a model’s predictions are equivalent for individuals from marginalized and non-marginalized groups[3].

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Shifting Power

Jamelle Watson-Daniels from *Data for Black Lives*, demands for these efforts to go beyond the development of "fairness" metrics; where for marginalized communities to truly be empowered, **control over decisions made in the development of an algorithm must be shifted to individuals that are most impacted by their (mis)application**[4].

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Shifting Power

Marginalized communities must be engaged as active contributors, participating in decisions including what data is collected, what data is used for training, how models are interpreted and assessed, and how models are deployed for decision-making[2].

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Engaging marginalized communities in causal theory formation

Martin et al. (2020) argue that this engagement should include the process of causal theory formation used to motivate the structure of an ML model.

They use the example from Obermeyer et al. (2019) where an algorithm used to allocate health care resources to patients with a high risk of illness demonstrated significant racial bias because it used previous health care costs as a proxy for health. Unequal access to care results in less health care costs for Black patients, and thus less healthcare resources were allocated to Black individuals using this algorithm despite higher rates of illness and greater need[2].

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Engaging marginalized communities in causal theory formation

Martin et al. (2020) explain that the problematic choice of healthcare spending as a proxy for healthcare need was rooted in causal theory formation that failed to incorporate the perspectives of marginalized communities.

They proposed a participatory method, Community Based System Dynamics (CBSD), that **uses visual tools and simulation to include communities vulnerable to algorithmic bias as part of the process of developing causal theories to motivate the structure of ML models**[5].

Participation & adaptive neurostimulation

Adaptive neurostimulation

Deep brain stimulation (DBS) methods that alter brain activity are FDA-approved for epilepsy, Parkinson's Disease, and obsessive-compulsive disorder with several other diseases under investigation.

Closed-loop DBS delivers electrical stimulation to modulate neural circuits in response to recordings of an individual's brain activity in real-time.

These closed-loop systems are being developed to be "adaptive", or **algorithmically learn over time how to dynamically alter stimulation in order to predict and prevent hypothesized pathological brain states for a particular individual**[6,7].

There is a particular need for participatory methods in the research and development of ML algorithms for adaptive neurostimulation, with the foundational aim of social justice and the empowerment of marginalized communities.

Why participation in the development of ML for adaptive neurostimulation?

1. Poor representation in research for target diseases

A long-standing issue is a lack of representation of individuals from marginalized communities in clinical research, including research relevant to diseases targeted by neurostimulation treatments.

For example, Parkinson's Disease (PD) has no differential effect on individuals of a particular race or ethnicity, however these groups make up a very small percentage of patients participating in PD research[8].

Participatory processes are essential to developing ML algorithms that account for the true diversity of disease experiences, as well as prevent further disparities in care.

Why participation in the development of ML for adaptive neurostimulation?

2. Algorithms “learn”, or change over time

Because stimulation is automatically adjusted without conscious control of the patient, neuroethicists consider how this could impact patient agency: the ability to act deliberately, autonomously, and authentically[9-11].

As the algorithm learns, **participatory processes must be designed to continuously engage patients in order to understand when they would like to be able to provide input regarding how the intervention changes over time (e.g. be kept “in the loop”)**[12,13].

Why participation in the development of ML for adaptive neurostimulation?

3. Role of personalization

As neurostimulation interventions are being developed to better target disease symptoms, patients may experience undesired side effects.
For example, neurostimulation for a Parkinson's patient often helps with movement symptoms, but impairs speech.

In some cases these effects of stimulation impact a patient's personality, or other aspects of their daily lives where different patients may have different preferences in regards to the optimal trade off between how the intervention controls their disease symptoms versus affects other aspects of themselves and their behaviors.

Why participation in the development of ML for adaptive neurostimulation?

3. Role of personalization

Because of these potential trade-offs, it is anticipated that there will be a need to personalize the intervention according to individual preferences for the different effects of neurostimulation[7].

Because there will likely not be one optimal treatment effect for all patients, **patient input will be necessary to determining what effects of neurostimulation should be considered a personal choice**.

There is a particular need for participatory methods in the research and development of ML algorithms for adaptive neurostimulation, with the foundational aim of social justice and the empowerment of marginalized communities.

These methods should include opportunities for patient input regarding:

1. When data collection is experienced as **surveillance or support.**
2. Whether the way a model uses data for prediction is a form of necessary **abstraction, or oppression**.

1. Support vs. Surveillance

Recording of passively sensed data

Recent developments in neurointerventions incorporate “passively” collected data about patients’ state in addition to self-report and clinical assessments, usually with the aim of decreasing burden and improving algorithm predictions.

This might include facial expressions of patients using video, continuous monitoring of movement and physiological measures using mobile sensors, or phone usage related to social communication.

Patient input should be used to identify issues of privacy and co-articulate justifications for recording this type of data, and how it is used to improve the intervention.

1. Support vs. Surveillance: Example

Algorithm for predicting SCD pain severity

SCD is a genetic disorder that results in the stiffening and distortion of red blood cells into a “sickled” shape that obstructs blood flow to different parts of the body, causing persistent chronic pain as well as intermittent acute pain crises that can occur quickly without warning and cause permanent organ damage or death[14].

There is significant variation with respect to mechanisms of pain, presentation of pain, and responses to different types of treatment both between patients and within a single patient across time[15,16].

1. Support vs. Surveillance: Example

Algorithm for predicting SCD pain severity

This creates difficulties for an SCD patient experiencing an acute pain crisis, where they often need high doses of opioids for adequate relief. When seeking emergency medical support, patients' self-reports of pain intensity are often met with disbelief and suspicion from healthcare providers, where they are perceived as potential substance abusers[17,18].

Communicating their pain and obtaining relief becomes a stressful interpersonal negotiation, where patients will dress up or "act out" their suffering in a more visible way in order elicit the treatment they need from medical staff[17] . Research has documented how medical stereotyping results in significant disparities in the prescription of pain medication[19,20].

1. Support vs. Surveillance: Example

Algorithm for predicting SCD pain severity

Evidence suggests that SCD pain might be predicted by heart rate, movement and even weather conditions. An adaptive intervention might be developed where mobile sensors are used to continuously monitor and record these bodily signals, so that it can be incorporated into a ML model for predicting acute pain in order provide support outside the clinical setting[21].

1. Support vs. Surveillance: Example

Algorithm for predicting SCD pain severity

Consider two different ways that this model could be developed:

1. **A model that predicts an SCD patient's pain, measured using self-report of pain severity,** from changes in the recorded movement and heart rate.
2. **A model that predicts an SCD patient's pain, measured by opioid consumption tracked using an electronic pill bottle,** from changes in the recorded movement and heart rate.

1. Support vs. Surveillance: Example

Algorithm for predicting SCD pain severity

In the first case, the model is taking as the ground truth of pain severity to be the self-reported pain experience of the patient.

In the second case, pain severity is measured based upon a deviation from expected consumption of opioids prescribed by a physician.

The latter case might seem to be preferable because it decreases the burden that might incur from the patient self-reporting their pain experience.

1. Support vs. Surveillance: Example

Algorithm for predicting SCD pain severity

However, important questions to ask include:

- ***To what extent is the recording of opioid consumption by an electronic pill bottle experienced as "surveillance" to the SCD patients?***
- ***How does the use of opioid consumption versus reported pain severity change the types of predictions a model makes regarding what support a patient might need?***

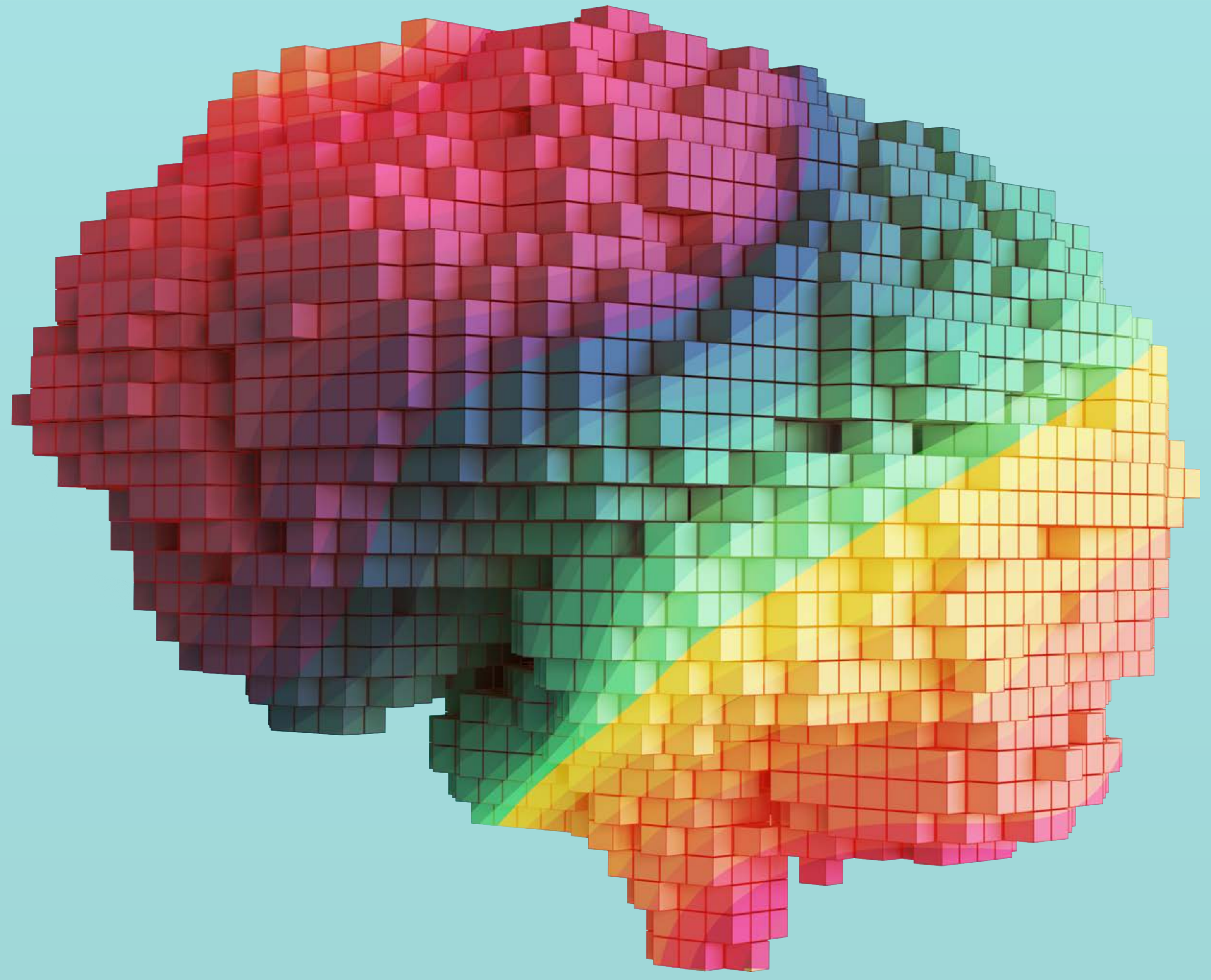
1. Support vs. Surveillance: Example

Algorithm for predicting SCD pain severity

In the case of SCD pain, researchers argue that because each SCD patient is a "unique human entity", interventions that support pain management **should promote patient empowerment and recognize patients as the authority on their experience of SCD pain**[15].

1. Support vs. Surveillance

Participatory methods for developing ML algorithms for neurostimulation should systematically include patient input regarding their experience of data collection, as well as tools for communicating and eliciting input for how this data is used to improve the intervention.



2. Abstraction versus Oppression

Ontological oppression

Timothy Brown (2021) calls for engagement and participation of marginalized individuals within neuroscience research, where they are recruited as active researchers in the process of collecting, storing, analyzing neurological data.

Brown advocates for the ability of marginalized communities to be able to **"interrogate what categories they (researchers) accept, propose or reject – to see if they exacerbate/create inequities"**[22].

2. Abstraction versus Oppression

Ontological oppression

Brown introduces Robin Dembroff’s term “**ontological oppression**” to describe the possible consequences of failing to engage marginalized communities in neuroscience research.

Ontological oppression is the result of structures and practices within social contexts that either fail to recognize, or construct social categories. Unwanted placement of an individual within a social category can unjustly constrain their behaviors, concepts or affect[23].

2. Abstraction versus Oppression

Abstractions in model development

There are several points in the development of an ML algorithm where categories are defined that serve as quantitative abstractions of patient attributes and their disease experiences.

This includes the process of causal theory formation, defining input variables and how they are measured, and defining the target outcome the model predicts. Furthermore, these categories may be continuously redefined as the algorithm is trained, evaluated and deployed over time.

2. Abstraction versus Oppression

Abstractions in model development

In the case of adaptive neurostimulation, an ML algorithm is often trained using data from a small sample of patients, or as part of an n-of-1 study.

Because there is significant heterogeneity with respect to individual neuroanatomy, neurophysiological instantiation of disease, and symptom experience, the algorithm will need to be developed over time to maintain predictive performance as it is exposed to data from new patients.

2. Abstraction versus Oppression

Abstractions in model governance

There are several different ways an algorithm might be changed over time as it is exposed to new data, including the addition or subtraction of features for predicting the outcome, changes in model architecture, sampling methods, or how it is optimized (i.e. the objective function used to adjust weights as the model learns from new data).

Therefore there is a need to develop strategies for **model governance,** or approaches to "auditing" and changing ML algorithms for neurostimulation as they are deployed over time, to ensure that they continue to embody ethical desirable values[24].

2. Abstraction versus Oppression

Model governance and "personalization"

When personalizing neurostimulation, **the categories used to change an ML algorithm in response to variability related to patients from marginalized identities needs to be thoughtfully "interrogated"**[22] **through the participation of individuals from these communities.**

2. Abstraction versus Oppression: Example

Genetics and race

Dorothy Roberts in *Fatal Invention: How Science, Politics, and Big Business Re-create Race in the Twenty-First Century*, investigates the way statistics is applied to describe race as a biological/genetic category, providing a detailed account of how each step of data analysis, from defining the data sample to deciding how the results apply to our every day lives– is dependent on and driven by preconceived notions of race.

She points out how: "**Science is the most effective tool for giving claims about human difference the stamp of legitimacy**"[20].

2. Abstraction versus Oppression: Example

Genetics and race

She interviews epidemiologists that explain **"…differences between racial groups are usually too small to warrant using this variable as a predictive tool or as a factor in clinical decision making. The practice risks 'stereotyping and the tendency to misapply quantitive differences between groups as though they were categorical differences'"**[20].

2. Abstraction versus Oppression: Example

Genetics and race: causal explanations

For example, Roberts gives an account of research focused on finding a genetic characteristic of black and Puerto Rican children that accounts for their higher rates and severity of asthma.

She also describes research studies focused on environmental allergens that trigger asthma, where elements in dust particles collected from inner-city homes were found to cause asthmatic symptoms in mice.

2. Abstraction versus Oppression: Example

Genetics and race: causal explanations

She points out that while it is widely accepted that genetic and environmental contributions to health cannot be separated, genes are frequently described as the “cause” of disease while environmental contributions are merely “triggers”. She asks:

Do black children have more severe asthma because they are genetically susceptible to triggers?

Or could it be because they are more likely to live in neighborhoods where these triggers are concentrated?

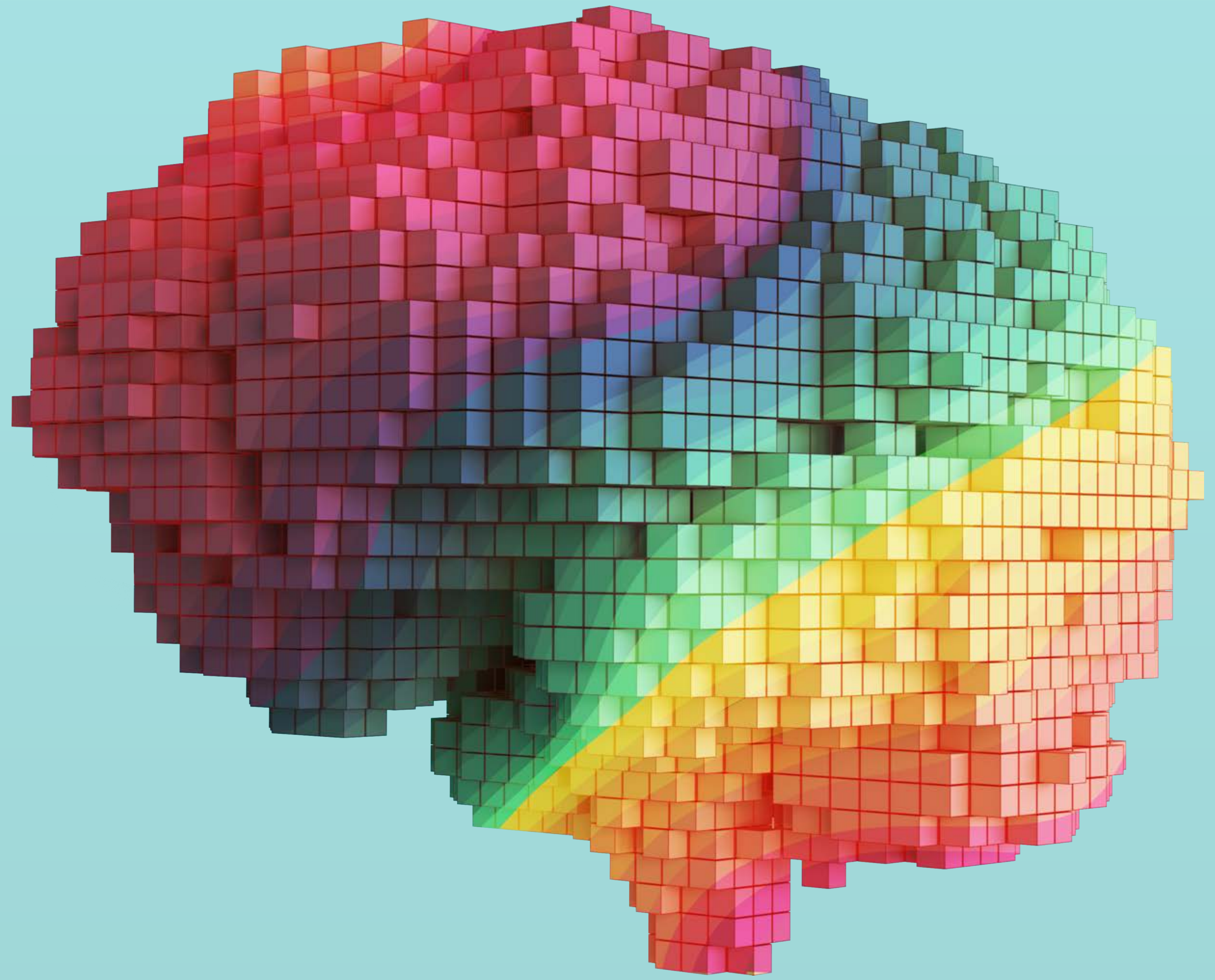
2. Abstraction versus Oppression: Example

Genetics and race: causal explanations

It is important to be mindful of the use of categories related to marginalized identities, particularly **how their use can imply causal relationships that neglect the role of environmental factors and the impact of structural inequalities that can lead to quantitative differences between groups**.

2. Abstraction versus Oppression

Participatory methods must engage marginalized individuals to determine when an ML algorithms is utilizing a necessary and acceptable abstraction to account for variability associated with social categories including race and gender.



Goals of participatory ML for adaptive neurointerventions should be:

1. **Long-term partnerships that recognize participation as labor,** and compensate individuals and communities for their contributions[25].

2. **Ongoing efforts to develop communication tools for sharing "technical" knowledge** in order to elicit meaningful input from patients.

3. **Integration of neuroscience research with concerns of population health** where understanding the impact of structural inequalities is essential to and inseparable from the successful generation of scientific knowledge to inform and direct neurotechnological progress.

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