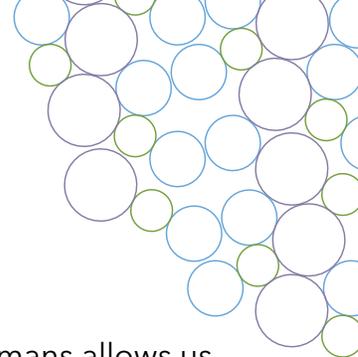


Lesson 1: Brain Donation and Bioethics

Learning Objectives:

- Students will be able to reflect on the importance of bioethics within biomedical research
- Students will be able to describe the process of both living and post-mortem brain donation, and how these types of donations provide different biological data
- Students will be able to appreciate and articulate why some people may choose to not donate their brain to science
- Students will be able to articulate the importance of neurodiversity within brain science
- Students will be able to reflect on the ethical implications of policies of expressed vs. presumed consent
- Students will be able to articulate the importance of consent within biomedical research





Part 1: Introduction

Biomedical research is integral to society. Learning more about the biology of humans allows us to uncover the mysteries of diseases that have large impacts on individuals and communities, from neurological diseases like Alzheimer’s disease to viral infections like COVID-19. Researching pathogens and diseases that impact our communities often requires the use of **human subjects** at some point in the research process.

Although these projects enroll humans as subjects to be studied, it is imperative that this research respects the autonomy and dignity of participants throughout the research process. While the field of modern biomedical research has numerous regulations in place to prevent ethical misconduct, the field has a long and storied history of exploiting communities of color for the purposes of biomedical research (Washington, 2006).

In this lesson, you will explore the role of bioethics within the context of anatomical donations. Recognizing that the field of neuroscience has a complex history of medical racism and exploitation, this lesson provides suggested readings and resources that explore the historical perspectives of biomedical research.

While biomedical research is a broad field, this lesson will specifically focus on biomedical research involving the human brain. By detailing the process of human brain donation and its role within biomedical research, this lesson aims to foster a critical reflection on why someone may or may not choose to donate their brain to science. After exploring the factors impacting a person’s decision to donate their brain, the lesson concludes by asking students to engage in a class debate on two distinct policies of consent that are used in various nations. This lesson is particularly reading heavy, though it is intended to provide you with a foundational understanding of the role brain donation plays within science. At the end of this lesson, we hope you gain an understanding of the importance of bioethics and how the field of modern biomedical sciences works to ensure that we do not repeat the injustices of the past. Human volunteers in science are integral to the field itself. Without the generous acts of individuals who choose to donate their brains to science, much of the research conducted on the human brain would not be possible.

Reference: Washington, H.A. (2006). Medical apartheid: the dark history of medical experimentation on Black Americans from colonial times to the present. New York: Doubleday.

Feeling Safe and Comfortable Participating in Research

The field of neuroscience has the unique yet challenging task of studying the most complex piece of organized matter in the known universe. Attempting to uncover the mysteries of the brain requires a deep ethical consideration of how to study something as personal and unique as the human brain.

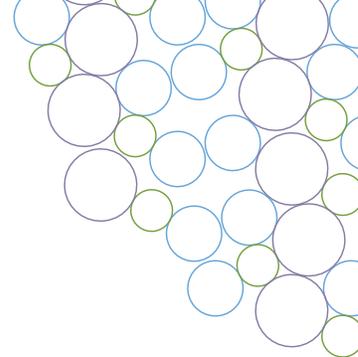
Unfortunately, the role of ethics and morals within scientific research has not always been respected. The field of science has a long and storied history of violating the rights and dignity of individuals who did not properly consent to participating in scientific research. Historically, the individuals who bore the majority of harm inflicted by science were more often than not from communities of color and/or individuals who identified as women. Despite this history of scientific harm, communities of color continue to be disproportionately impacted by issues involving bioethics.

Understanding the history of biomedical ethics and the disproportionate impact nonconsensual research has had on communities of color is imperative in order to ensure that modern biomedical research does not repeat the harms of the past. These biomedical harms are relevant to both the field of neuroscience and other fields of science more broadly. We would need several lessons in order to adequately cover the history of injustices inflicted by science, as the history of science is an entire field in and of itself! Although we do not have time in this lesson to dive deeply into the history of biomedical research, there are several great resources you can reference to learn more about this subject:

Suggested readings:

- *The Immortal Life of Henrietta Lacks* by Rebecca Skloot
- *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* by Harriet A. Washington
- *The Mismeasure of Man* by Stephen Jay Gould
- *Superior* by Angela Saini
- *Inferior* by Angela Saini

Understanding the history of science is crucial to ensure that the field of modern biomedical research does not repeat the harms of the past. In this lesson, we will explore how consent and medical ethics both play crucial roles in how modern neuroscience ensures that its research is conducted in an ethical manner. Studying the human brain is an exciting yet challenging endeavor, and thus, bioethics plays a key role in guiding this crucial and important research.



How do we study the human brain?

Given that research on the human brain requires samples of human brain tissue and/or human brains to study, several ethical questions arise. **How** do we study the human brain, and **whose** brains do we study?

While some scientists use model organisms, such as mice, to study the brain, these models by themselves are not sufficient for fully understanding the human brain. Instead of relying solely on mice, neuroscientists seek out opportunities to ethically study the human brain. Often, these researchers rely on individuals who are willing to donate their brain to science following their death. In order to explore the process of brain donation from a bioethical and sociological perspective, we will use the Allen Institute for Brain Science as a case study.

The **Allen Institute for Brain Science** is a division of the Allen Institute, a nonprofit scientific research institute that was founded in 2003. The mission of the Allen Institute for Brain Science is to focus on defining and understanding cell types of the mammalian brain to ultimately better understand brain development, evolution, and disease. The Allen Institute for Brain Science is working towards creating a complete list of the different “parts” - cell types - in the brain. In addition to creating a list of the brain’s parts and cell types, the Allen Institute also aims to determine how these cell types connect and function in the brain and what changes happen in cells in the aging brain and in neurodegenerative diseases such as Alzheimer’s disease (AD). The Allen Institute for Brain Science conducts basic research on both healthy and diseased brains. This type of basic research means that scientists study healthy and diseased brains in order to gain a better understanding of the progression of Alzheimer’s disease. The Allen Institute does not conduct clinical trials on AD or other types of applied biomedical research. In order to carry out this research and achieve this mission, the Allen Institute relies heavily on the generous act of individuals in the community who donate their brains to science.

In order to explore the importance of brain donation, this lesson will address four main questions:

1. *What is brain donation and how does it differ from other types of biomedical donations, such as organ donation?*
2. *How do beliefs concerning brain donation differ on the basis of an individual’s cultural background?*
3. *Why is there no such thing as a “normal” brain?*
4. *What is the role of consent within brain donation?*

In many ways science helps individuals, whether that is through developing treatments for disease or providing insights into how the world works. However, equally important to how science helps people is to think about how people can help science. Brain donation is one small example of how science cannot be done without communal support and involvement. We will explore this concept in the activities that follow!

Part 2: What does it mean to donate your brain to science?

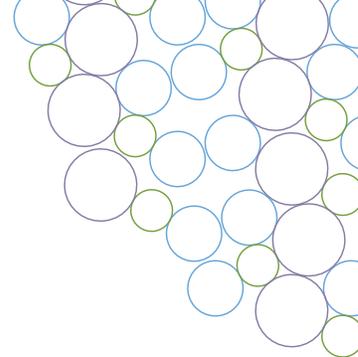
Brain donation is the process of granting permission for your brain and/or brain tissue to be used for the purposes of scientific research. Although the brain is indeed an organ, brain donation is a different process than **organ donation**. While being an organ donor means that your organs will be given to other people in need of transplants to keep them alive, being a brain donor means your brain will only be used for research purposes. The process of brain donation is also different than **whole-body donation** to science. Whole-body donation is a process where an individual consents to their body being used for biomedical research on their other organs or for their body to be given to a medical school for instructional purposes. Thus, there are three distinct processes for choosing to consent to brain donation, organ donation, or whole-body donation. These processes are also mutually exclusive, meaning that donors can only choose one type of donation. For example, if you elect to donate your brain to science, you are ineligible to be an organ donor.

The research done at the **Allen Institute for Brain Science** involves two different types of generous brain donations from individuals:

1. *Post-mortem brain donation*
2. *Living brain tissue donation*

Post-Mortem Brain Donation:

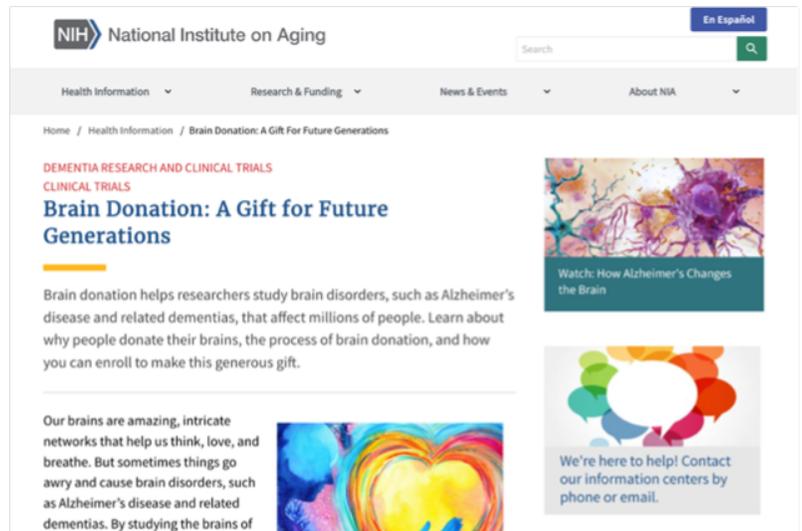
Post-mortem is a Latin phrase meaning “after death.” Post-mortem brain donation is the process whereby an individual chooses to sign up for their brain to be donated to science once they have passed away. Post-mortem donation allows scientists to gather crucial data about the brain’s activity after cell death, such as which genes it was expressing and in what quantities.



In order to gain a better sense of post-mortem brain donation and its importance to science and society at large, take 5 minutes to read the following article. After reading through the article, answer the reflective questions that follow.

Article: This article is linked [here](https://www.nia.nih.gov/health/brain-donation-gift-future-generations), or the full link is listed below.

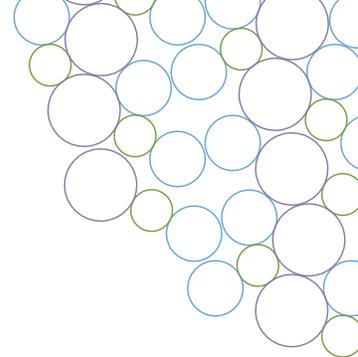
<https://www.nia.nih.gov/health/brain-donation-gift-future-generations>



Reflective Questions:

- Why do you think the National Institute on Aging refer to post-mortem brain donation as a "Gift for Future Generations?"

- Who does the National Institute on Aging consider to be "high priority" individuals for brain donation? Why are these individuals identified as especially important to add to the brain donor bank?



Living brain donation:

While post-mortem brain donation is available to everyone, everywhere, living brain donation is possible for a few individuals undergoing specific types of neurosurgical procedures in cities with living tissue donation programs. Living brain donation is a process where a small section of living brain tissue is taken from a living donor. How is this possible?

These donations only take place when individuals who are already scheduled for brain surgery opt in to provide a small piece of the brain tissue to researchers. This is only an option when the individual is already scheduled for a procedure where a portion of their brain tissue is being removed. For example, an individual who is having brain surgery for epilepsy to remove the site generating the seizures could choose to be a living brain donor. Because the surgery for epilepsy already requires removal of some healthy brain tissue that the surgeons must remove in order to reach the site generating the seizures, the individual undergoing the surgery could choose to donate this removed tissue to researchers. Individuals who are not already undergoing a surgery that requires removal of brain tissue are not eligible to be living brain donors.

Living brain tissue provides a unique opportunity for scientists to study the activity of brain cell's while the brain tissue is still alive. At the Allen Institute for Brain Science, researchers have been able to keep donated living brain tissue alive for up to 5 days.

10 minute activity:

In order to understand the process of living brain donation, read [this short article](#) written by the Allen Institute's Rachel Tompa, PhD, about the generous donation made by Casey Schorr. After reading the article, be sure to answer the reflective questions that follow.

This is what it's like to donate your brain to science

Casey Schorr underwent invasive surgery to quell the epileptic seizures that were taking over his life. Now, a small piece of his brain tissue is helping scientists better understand the human brain.

August 6, 2019



Casey Schorr donated a piece of his living brain tissue to Allen Institute researchers to help them learn more about human cell types in the brain. On the right, a 3D reconstruction of a human neuron built thanks to tissue donations like Casey's, which allow the researchers the rare opportunity to study living human neurons.

If the embedded link above does not work, here is the full link to the article:

<https://alleninstitute.org/what-we-do/brain-science/news-press/articles/what-its-donate-your-brain-science>



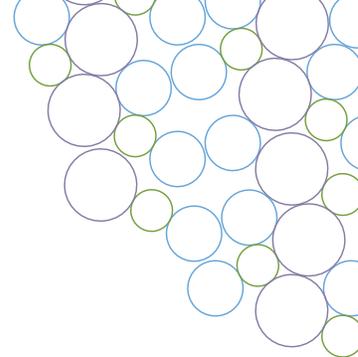
Reflective Questions:

- What can scientists study with living brain tissue that they cannot study with post-mortem brain tissue?

- Think about Casey's story and his experience with living brain donation. What reasons did he list for why he donated his living brain tissue to science?

- In addition to those listed by Casey, can you think of any other reasons as to why someone may opt to donate part of their living brain to science?

- Why do you think someone would opt not to donate part of their living brain tissue to scientists?

- 
- Spend 5 minutes and discuss your answers to the reflective questions above with a classmate, a friend, a family member, etc.

Optional: For more information about living brain donation, read this additional article by Rodrigo Pérez Ortega about research being conducted at the Allen Institute that uses living human brain tissue donations: <https://www.science.org/content/article/how-donate-piece-your-brain-science-while-you-re-still-alive>

Now that we understand the difference between living and post-mortem brain donation, let's discuss some factors that may influence a person's decision to donate their brain to science.

Reasons why someone may choose to not donate their brain to science:

While donating your brain to science as either a living or post-mortem donor is incredibly helpful to science and the advancement of biomedical research, it is important to note that some people may choose not to participate in brain donation.

Although there are a variety of reasons as to why someone may opt not to donate their brain to science, cultural and/or religious beliefs and practices are major factors that may dissuade someone from being a brain donor. Reasons as to why someone may object to donating their brain to science could include beliefs that one's body must remain intact for proper burial and/or travel to an afterlife or cultural norms that dissuade individuals from discussing death-related topics. Recalling what we learned at the start of this lesson, it is also important to recognize that historical injustices within the field of medicine against communities of color can also play a role in why an individual may not feel comfortable donating their brain to science. No matter what a person cites as a reason that they would opt not to be a brain donor, their decision should be respected. Scientists greatly appreciate the donations of those who choose to participate, but we do not want anyone to feel pressured to make a decision about donation unless they are comfortable doing so.

What types of brains does science “want” to study?

A common misconception about brain donation is that science only needs to study brains that have a specific characteristic. For example, some people tend to think that if scientists are studying dementia, then those scientists only want people who have dementia to donate their brains. This is not true! Science benefits when people with ALL types of brains sign up for brain donation.

But what does it mean to say that science benefits from the donation of *all types of brains*?

No such thing as a “normal brain:”

Word choice is incredibly important within science. For this reason, it is important to clarify what we mean when we discuss what a “healthy” brain is. A healthy brain refers strictly to disease pathology. This means a healthy brain is one that does not display symptoms or biological signs that are characteristic of known neurological diseases. There are many different types of neurological diseases, such as Alzheimer’s disease, Parkinson’s disease, and Huntington’s disease.

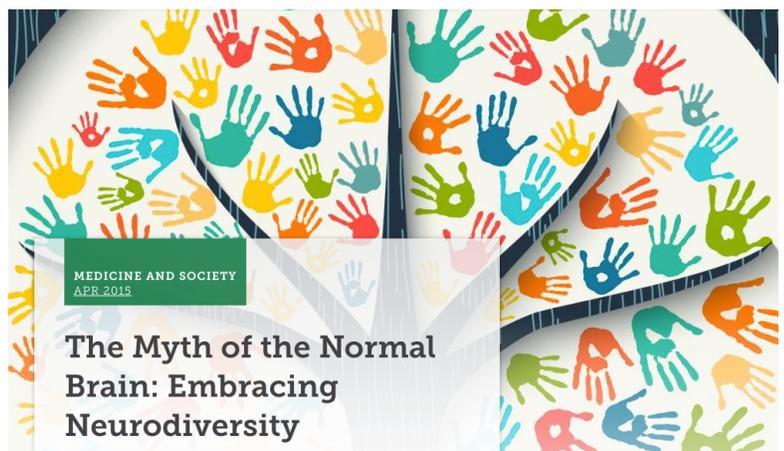
“Normal” is a word that should be avoided when referencing human brains and/or bodies. Specifically in terms of the brain, a “healthy” brain is not synonymous with a “normal” brain. In fact, many scientists support the theory that there is no such thing as a “normal” brain. Instead, many scientists have called for a widespread recognition of neurodiversity and its role within the field of neuroscience.

In order to explore the danger of using the word “normal” to reference brains, please take 5 minutes to read [this short article](https://journalofethics.ama-assn.org/article/myth-normal-brain-embracing-neurodiversity/2015-04) by Thomas Armstrong in the *AMA Journal of Ethics*.

If the embedded link does not work, the full link is listed here:

<https://journalofethics.ama-assn.org/article/myth-normal-brain-embracing-neurodiversity/2015-04>

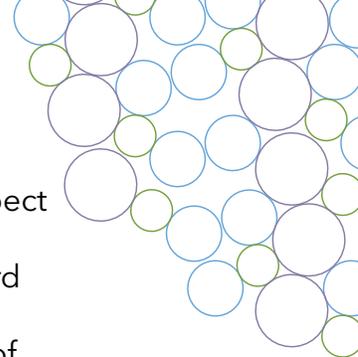
doi: 10.1001/
journalofethics.2015.17.4.msoc1-1504



Reflective Questions

- If someone asked you to define what a “normal” brain was, what would you say? Do you think it is possible for someone to have a normal brain?

- Why would it be beneficial to have someone who identifies as neurodivergent consent to donate their brain to science?



As explained by Armstrong, neurodiversity is a key part of neuroscience. One aspect of neurodiversity is the idea of neurodivergence. Neurodivergent is a term that was coined in the 1990s by Judy Singer. Nicole Baumer and Julia Frueh of Harvard Health Publishing define **neurodiversity** as “the idea that people experience and interact with the world around them in different ways; there is no one ‘right’ way of thinking, learning, and behaving, and differences are not viewed as deficits.” This understanding of neurodiversity highlights the importance of having a diverse range of individuals donate their brains. There is no such thing as a “normal” brain. Instead, scientists will often differentiate brains based on two distinct criteria:

- To explain whether or not a brain displays signs of known diseases, scientists will describe a brain as either healthy or diseased
- To explain an individual’s brain function and behavior, scientists will often use terms such as “**neurotypical**” or “**neurodivergent**”

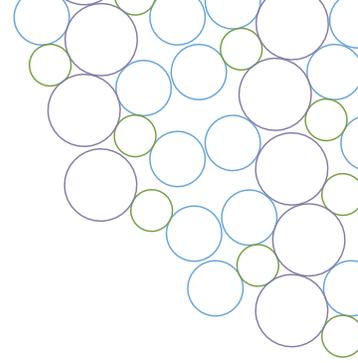
Any combination of these two criteria is possible. For example, it is possible for someone to have BOTH a healthy and neurodivergent brain. Given the vast amount of neurodiversity that exists among the population, science benefits when anyone and everyone decides to donate their brain!

Reference: <https://www.health.harvard.edu/blog/what-is-neurodiversity-202111232645>

Want to learn more about neurodiversity? Here are a list of other resources you can explore outside of this lesson:

- **Article:** *What is neurodiversity?* by Nicole Baumer and Julia Frueh <https://www.health.harvard.edu/blog/what-is-neurodiversity-202111232645>
- **Book:** *Out of My Mind* by Sharon Draper
- **Book:** *Furiously Happy* by Jenny Lawson
- **Podcast:** *Being Seen*

Part 3: Understanding the Role of Consent in Brain Donation



At the start of this lesson, you read about the importance of ethics within the context of biomedical research. Discussions of ethics within research also require a consideration of how **consent** will be obtained from study participants. Obtaining consent is essential to ensure that participants are aware of what their brain tissue will be used for, the purpose of the study to which they are donating their brain, and other details about the research itself. The ethical guidelines surrounding consent and brain donation differ based on what state and/or country you reside in. Comparing these policies to one another provides valuable insight into the field of bioethics.

Washington State:

The Allen Institute is located in the state of Washington. In Washington, donating your brain to science falls under the Uniform Anatomical Gift Act: <https://app.leg.wa.gov/rcw/default.aspx?cite=68.64>. This act specifies who is authorized to provide consent for brain donation, which can vary depending on whether or not the donor is still alive or if the donor has passed away.

United States:

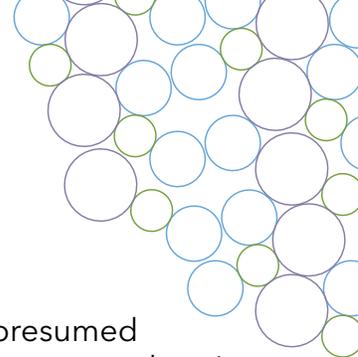
The United States operates from an “**expressed consent**” policy for organ and brain donations. This means that people are assumed to NOT be an organ or a brain donor until a person explicitly signs up and consents to be one. For organ donation, you can often sign up for this when getting a driver’s license in the United States. The policy of expressed consent is also practiced in countries such as Denmark, Brazil, Canada, and the United Kingdom. For brain donation, there are several different ways through the NIH NeuroBioBank to sign up to be a brain donor. The Allen Institute for Brain Science recommends <https://braindonorproject.org/> for inquiring about the process of donating your brain based on which state you reside in.

Globally:

Some countries, such as Spain, Belgium, France, Norway, and Singapore, operate from a “**presumed consent**” policy, also known as an “opt-out” policy. Instead of needing to sign up to donate your organs, you are assumed to consent to donating your organs unless you explicitly opt-out of doing so.

A policy of presumed consent requires individuals to remove themselves from the list of eligible donors, whereas a policy of expressed consent requires individuals to add themselves to the list of eligible donors.

Reference: <https://journalofethics.ama-assn.org/article/presumed-vs-expressed-consent-us-and-internationally/2005-09>



Activity: Bioethics Policy Evaluation

Now that you have heard about the different bioethical policies of expressed vs. presumed consent, it is now time for you to evaluate the benefits and drawbacks of these two approaches. In addition to the information provided in this lesson, feel free to find outside resources that further explain potential pros/cons of each of these policies.

After researching these two policies further, please fill out the following table:

	A policy of presumed consent	A policy of expressed consent
Pros		
Cons		



Post-Debate Reflection:

1. After learning about both expressed and presumed consent, which policy do you think is best practice from a bioethical perspective? Be sure to explain your answer in detail below.

2. List at least two reasons why consent is imperative within the context of biomedical research:

3. After what you have learned in today's lesson, do you think you would donate your brain to science? Why or why not?

Choosing to donate or not donate are both completely valid positions and there is no one "right" answer. Each individual has the right to decide whether or not brain donation is something that aligns with their beliefs.



Conclusion:

Understanding the role of consent within biomedical research is a crucial part of science. Given the history of injustices perpetuated by scientific research against individuals, particularly people of color and/or individuals who identify as women, it is imperative to reflect upon the importance of ethics within research. We hope you walk away from this lesson with an appreciation for the field of bioethics and the bioethical considerations that go into the work done at the Allen Institute for Brain Science.

If you continue on to complete the following three lessons in the Cell Types, Health, and Disease: An Interdisciplinary Exploration of Alzheimer's Disease lessons, you will have the chance to explore the open data from the Allen Institute that was obtained from 84 donors who consented to post-mortem brain donations. Some were healthy and some of them had Alzheimer's Disease. As you will see, the generous donation from these 84 individuals has allowed researchers at the Allen Institute to gather a large quantity of highly detailed data on the healthy human brain and pathological changes that may be associated with Alzheimer's disease. Without the 84 individuals who consented to donate their brain, none of this research would be possible.

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