

# SIPPS 2021: Research Ethics



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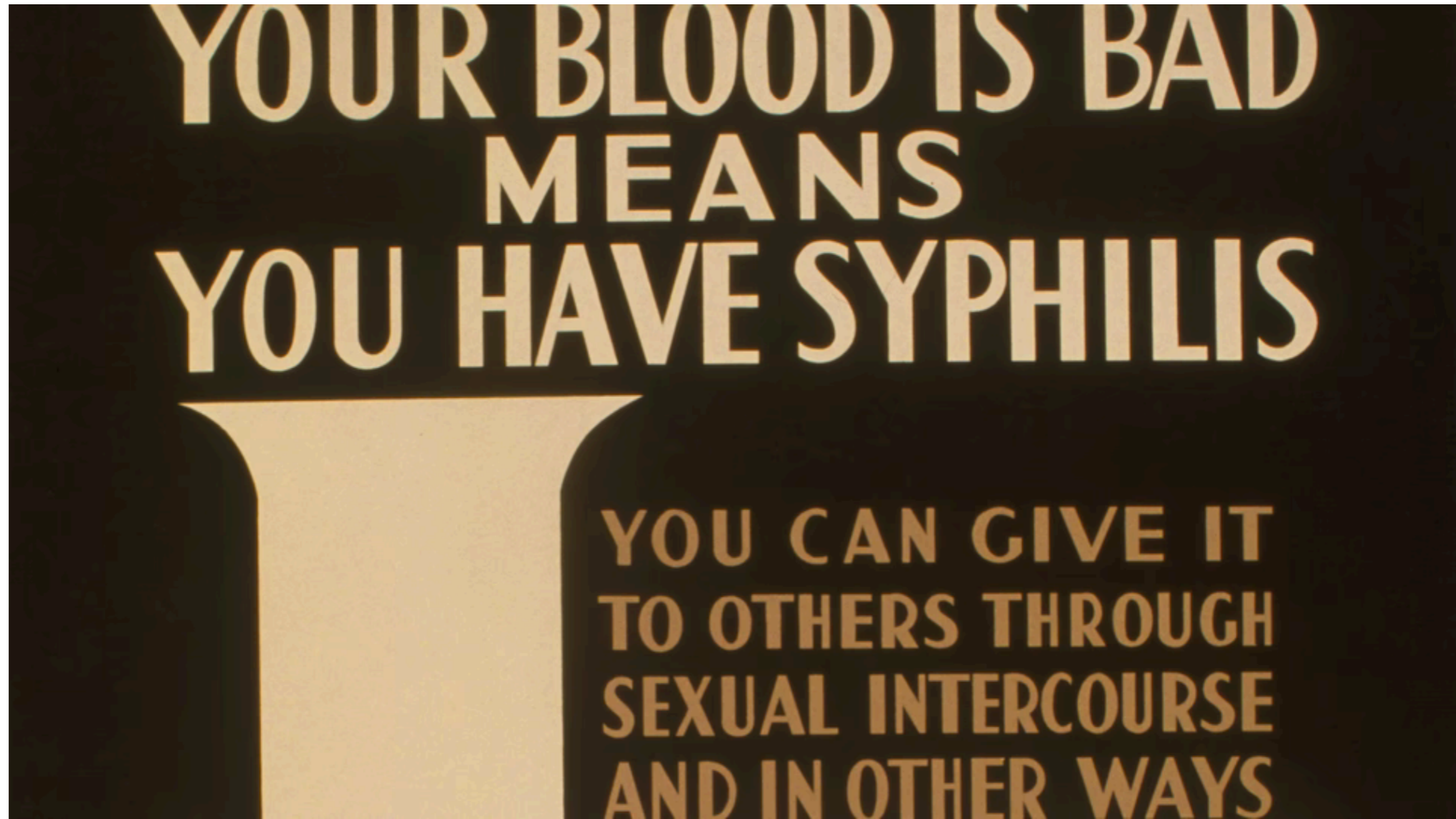
**What are research ethics?**

**Guidelines for conduct and behavior of researchers that maximize benefits and minimize harm.**

# Why do we need an ethical code?



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Tuskegee Experiment (1932-1972)

# Why do we need an ethical code?



Henrietta Lacks (1920-1951)

# Why do we need an ethical code?

## Henrietta Lacks' Family Hires Prominent Civil Rights Lawyer

August 4, 2021

BALTIMORE (AP) – The family of a Maryland woman who unwittingly spurred a research bonanza when her cancer cells were taken without her knowledge in 1951 has hired a prominent civil rights lawyer to seek compensation from pharmaceutical companies.

<https://seattlemedium.com/henrietta-lacks-family-hires-prominent-civil-rights-lawyer/>

**What are research ethics?**

**Scientific inquiry**

**Conduct and behavior of researchers**

**Ethical treatment of research participants**



# What are research ethics?

Scientific inquiry

Conduct and behavior  
of researcher

Ethical treatment of  
research participants

# Duty to Society



Research topics and practices must ultimately benefit society.

# Duty to Society

## What is universal pre-kindergarten?

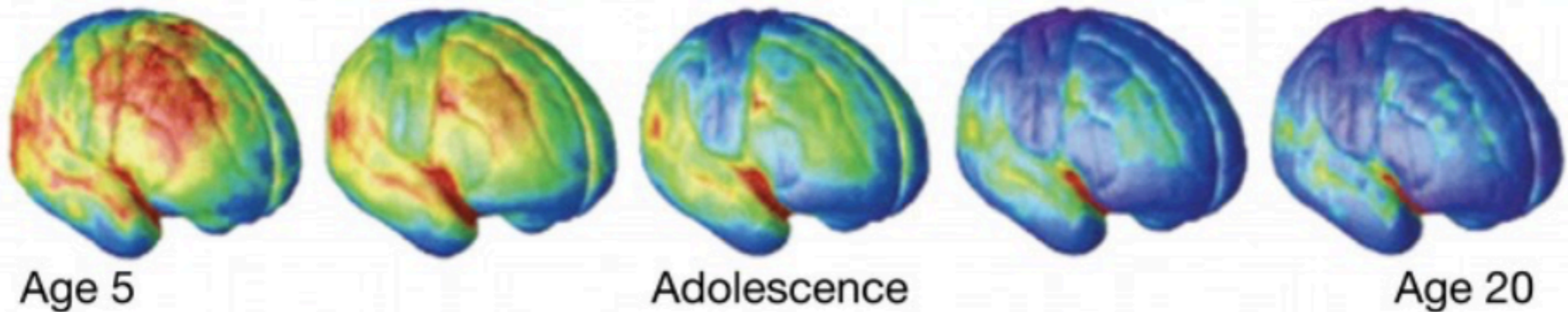
Pre-kindergarten refers to programs that provide a year of education prior to entry into kindergarten. Publicly funded pre-kindergarten (or Pre-K) is typically administered by states. The majority of these programs are based in public schools, although some states, like Tennessee, partner with a range of public and private agencies to provide pre-kindergarten services. States fund Pre-K in a variety of ways, including general funds, public-private partnerships, and special revenues like lotteries or taxes on tobacco.<sup>1,2</sup>

Universal programs are voluntary state programs that are open to all age-eligible children regardless of family income. So far, only a few states have universal eligibility for four-year-olds. Out of 51 state-funded Pre-K programs in 39 states, only eight are universal. The remaining 31 are targeted to at-risk children (usually based on low family income). Given the growing recognition that pre-kindergarten makes a tremendous difference in the lives of children, more and more states are working to expand the number of children served by their Pre-K programs.<sup>3</sup>

Research demonstrates that universal access to Pre-K is good policy. It reduces outreach costs, raises program quality, and increases public support for early education. Compared to targeted programs, universal programs have higher rates of enrollment among all socioeconomic groups.<sup>4</sup>

# Duty to Society

## Dynamic mapping of human cortical development



Source: "Dynamic mapping of human cortical development during childhood through early adulthood," Nitin Gogtay et al., Proceedings of the National Academy of Sciences, May 25, 2004; California Institute of Technology.

Scientists know that the adolescent brain is still developing, that it is highly subject to reward- and peer-influence, and that its rate of development varies widely across the population. They have developed basic tools that offer data with which to judge the potential for juvenile desistance, recidivism, and rehabilitation.

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# Guidelines for ethical researcher conduct

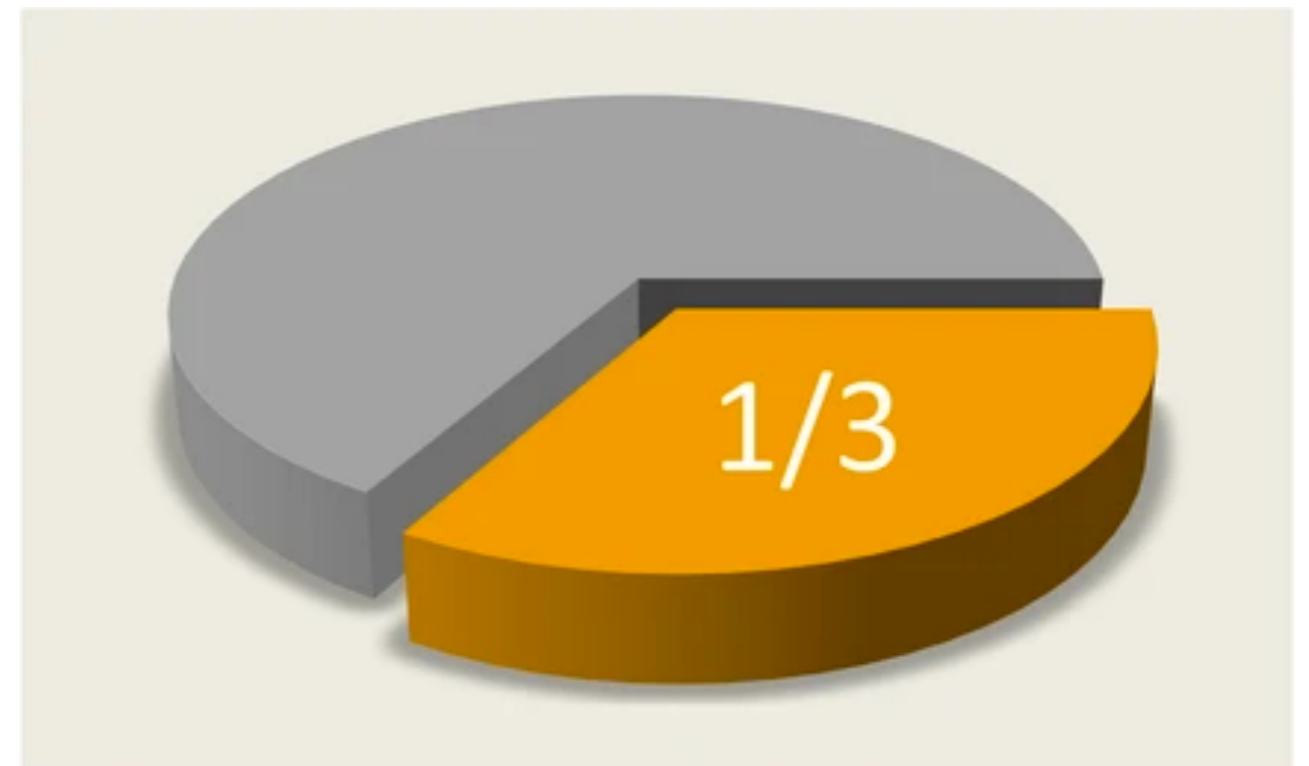
## Conflict of Interest

When a researcher's secondary interests (financial, personal) shape their research practices.

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## Safeguard

Journals require researchers to disclose any COI upon article submission.



# Guidelines for ethical researcher conduct

## Plagiarism

“Theft or misappropriation of someone else’s words, ideas, intellectual contribution.”

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## Safeguard

Peer-review process

# Guidelines for ethical researcher conduct

## Co-authorship

In papers with multiple authors, it's unclear who contributed what, and institutions/researchers are occasionally unduly credited.

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In papers with multiple authors, it's unclear who contributed what, and institutions/researchers are occasionally unduly credited.

## Safeguard

Journals require authors to submit a document outlining each authors' contribution along with their article.

# Guidelines for ethical researcher conduct

## Falsification/fabrication

Researchers exclude, alter, or intentionally misinterpret data to produce a significant result.

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## Falsification/fabrication

Researchers exclude, alter, or intentionally misinterpret data to produce a significant result.

## Safeguard

Peer-review process, pre-registration, open data.

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# Protecting the rights of human participants

## IRB REVIEW PROCESS



IRB Decision is Required Prior to Contacting Participants or Collecting Data



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# Belmont Report (1974)

Beneficence

Respect for persons

Justice

Informed Consent

# Beneficence

Research practices should balance risks and benefits



**Belmont Report  
(1974)**

# Belmont Report (1974)

## Beneficence

Research practices should balance risks and benefits

## Confidentiality

Research participants are free to withhold any information they choose.

# Respect for persons

1. Respect for autonomy
2. Protect those with diminished autonomy (e.g. children)

**Belmont Report  
(1974)**



# Justice

Design recruitment, study procedures, and outcomes with participants in mind.



**Belmont Report  
(1974)**

# Informed Consent

## **Starts with:**

- 1) Disclosure
- 2) Comprehension

**Belmont Report  
(1974)**

# Belmont Report (1974)

## Informed Consent

### Starts with:

- 1) Disclosure
- 2) Comprehension

## Exception

Some studies require deception.



# Belmont Report (1974)

## Informed Consent

### Starts with:

- 1) Disclosure
- 2) Comprehension
- 3) Voluntariness
- 4) Competence
- 5) Proof of consent

# Informed Consent

**Coercion:** research participants are made to feel threatened unintentionally.

Belmont Report  
(1974)



# Ethical Scenarios

# Research Integrity

- A graduate student working on their first project finds that their study produces significant results and begins to write up their work for publication.

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# Research Integrity

- A graduate student working on their first project finds that their study produces significant results and begins to write up their work for publication.
- Upon running a few more participants, however, the results are no longer significant.
- The graduate student chooses to exclude those participants, claiming an error in data collection, and publishes their original result.

## Ethical Scenarios

## Research Integrity

- Why did the graduate student behave like that?
- Could this happen today?
- How does the scientific community weed out scenarios like this prior to publication?
- How does this action conflict with the ethical principle of scientific inquiry?

# Informed Consent

- During finals week, a college student is encouraged to complete professor evaluations.

## Ethical Scenarios



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### Informed Consent

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- The professor does not specify whether responses will be recorded anonymously, and the student becomes concerned that neglecting to complete the evaluation will affect their grade.

## Ethical Scenarios

### Informed Consent

- During finals week, a college student is encouraged to complete professor evaluations.
- The professor does not specify whether responses will be recorded anonymously, and the student becomes concerned that neglecting to complete the evaluation will affect their grade.
- The student completes the evaluation to avoid any penalty.

## Ethical Scenarios

# Informed Consent

- How does this scenario violate the pillars of informed consent?
- Could this happen today?
- How does the IRB protect against such scenarios in Human Subjects Research?
- Research within universities (like student evaluations) generally do not require IRB review. Should they?

# Questions for discussion

1. What ethical issues have come up in your study?
  1. What are the risks for participants? What are the benefits (direct vs. long term)?
2. Given what you've observed in academia, where does the temptation for plagiarism and falsification come from?
3. What are the potential benefits of varying ethical standards across universities and disciplines? What are the downsides?
4. Is our community doing enough to protect against ethical violations?
  1. If not, what else could we do?

# Resources I Used

1. Northeast Ethics Education Partnership at Brown University
  1. <https://www.brown.edu/research/research-ethics/teaching-materials-presentations/teaching-materialspresentations>
  2. In particular: Informed Consent Theory, Bioethical Principles for Research Ethics, Institutional Review Board (IRB) and Human Subjects Protections
2. Belmont Report
  1. <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/index.html>

# SIPPS post-workshop survey access (~1 minute survey)

## Post-workshop survey (anonymous)

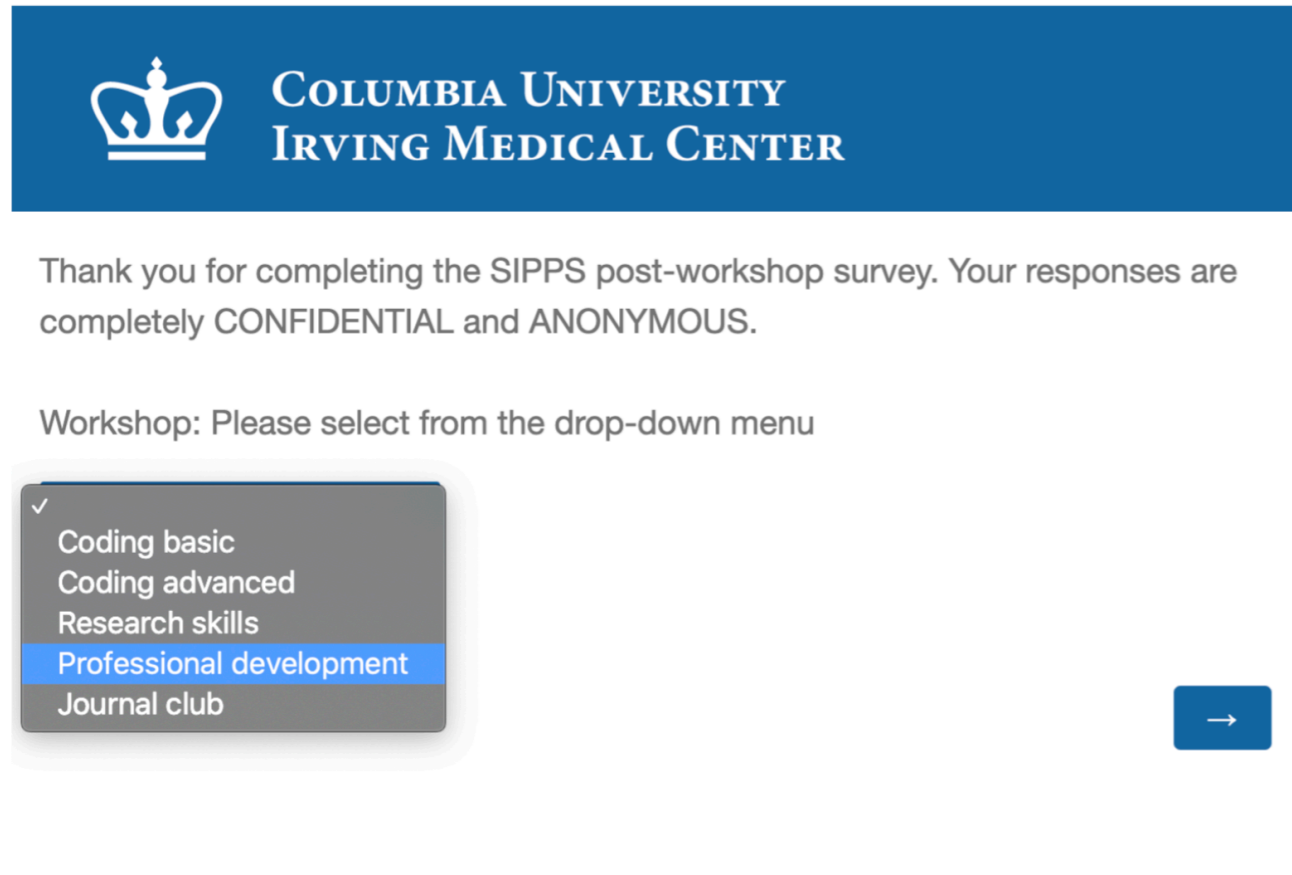
**link:** [https://cumc.co1.qualtrics.com/jfe/form/SV\\_9HVYLAL5iXvjEmq](https://cumc.co1.qualtrics.com/jfe/form/SV_9HVYLAL5iXvjEmq)




# SIPPS post-workshop survey instructions

## Outreach (Aug 4)

1. Select “Professional Development”



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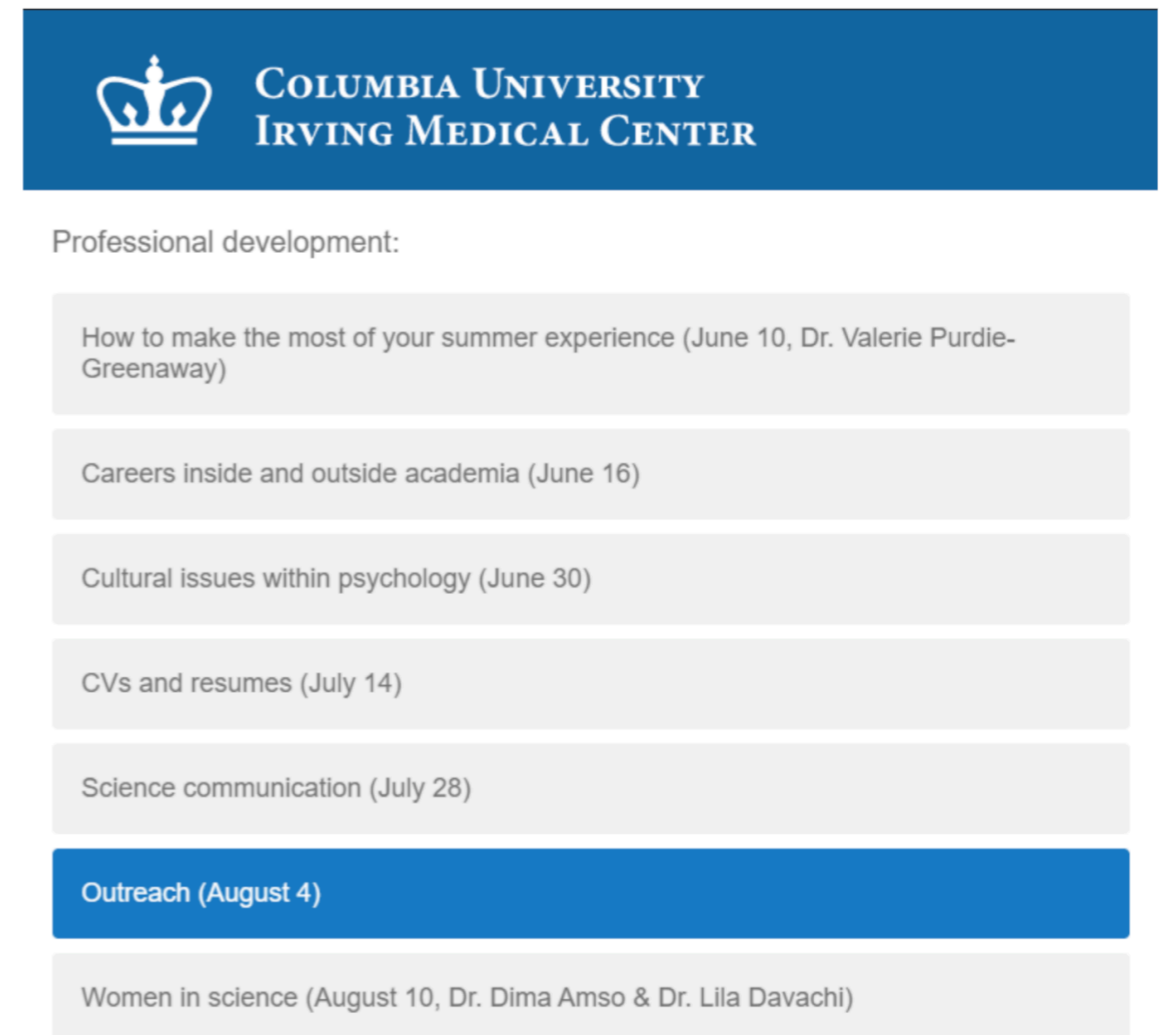
Thank you for completing the SIPPS post-workshop survey. Your responses are completely CONFIDENTIAL and ANONYMOUS.


Workshop: Please select from the drop-down menu

- ✓ Coding basic
- Coding advanced
- Research skills
- Professional development**
- Journal club

→

2. Select “Outreach (Aug 4)”



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IRVING MEDICAL CENTER

Professional development:

- How to make the most of your summer experience (June 10, Dr. Valerie Purdie-Greenaway)
- Careers inside and outside academia (June 16)
- Cultural issues within psychology (June 30)
- CVs and resumes (July 14)
- Science communication (July 28)
- Outreach (August 4)**
- Women in science (August 10, Dr. Dima Amso & Dr. Lila Davachi)