



Small Decisions

Big Consequences
Ethics Seminar 2014



Julie Schell
Sr. Educational Research Associate
Mazur Group, Harvard University

Brooklyn College
Brooklyn, NY
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Outline

1 Big Idea

Warmups in Human Subjects Research

Case Studies in the Ethical Conduct of Research

Quick start guide for making ethical decisions in research

Final evaluation



The Big Idea



Big Idea



**Ethical gray areas are everywhere
in life.**



Gert's Moral Rules

1. Do not kill.
2. Do not cause pain.
3. Do not disable.
4. Do not deprive of freedom.
5. Do not deprive of pleasure.
6. Do not deceive.
7. Keep your promises.
8. Do not cheat.
9. Obey the law.
10. Do your duty.

Heinz's wife was near death, and her only hope was a drug that had been discovered by a pharmacist who was selling it for an exorbitant price. The drug cost \$20,000 to make, and the pharmacist was selling it for \$200,000. Heinz could only raise \$50,000 and insurance wouldn't make up the difference. He offered what he had to the pharmacist, and when his offer was rejected, Heinz said he would pay the rest later. Still the pharmacist refused. In desperation, Heinz broke into the store and stole the drug.

Should Heinz have broken into the store to steal the drug for his wife?

A. Yes

B. No

Big Idea



**Ethical gray areas are everywhere
in **research.****

Big Idea



**Ethical gray areas are everywhere
in **research**.**

**3 cardinal principles to guide
research with human subjects.**



WarmUps: Principles of Human Subjects Research



Federal definition of a human subject

A human subject is: a **living** individual about whom an investigator conducting research obtains...

1. Data through intervention or interaction with the individual, or
2. Identifiable private information

Federal definition of death

“A person is dead when physicians determine, by applying prevailing clinical criteria, that cardiorespiratory or brain functions are absent and cannot be retrieved.” (p. 309, Neuroethics).

A person is brain dead “when ‘all functions of the entire brain, including the brain stem’ have irreversibly ceased.” (p. 309, Neuroethics).

Warmups

1. Whose brain did we study for today's session?

- A. Einstein
- B. Mozart
- C. Hitler
- D. Kennedy

Warmups

2. Which of the following is NOT a cardinal principle for guiding Human Subjects Research?

- A. Respect for persons
- B. Moral imperative
- C. Beneficence
- D. Justice

Warmups

3. A researcher's obligation to the principle of respect for persons is **primarily** carried out during which process:

- A. Subject recruitment
- B. Balancing of risks and benefits faced by subjects
- C. Informed consent
- D. All of the above

Warmups

4. Placing research participants at risk without the prospect of creating new, helpful knowledge or promoting the social good is a violation of which principle:

- A. Maleficence
- B. Respect for persons
- C. Justice
- D. Beneficence

Warmups

5. A researcher's obligation to adhere to the principle of justice is **primarily** carried out during which process:
- A. Subject recruitment
 - B. Balancing of risks and benefits faced by subjects
 - C. Informed consent
 - D. All of the above

A brain researcher is conducting fMRIs on student athletes and controls to evaluate differences in stress responses. She notices an incidental abnormality in the star quarterback's scans, in an area of the brain that was outside the bounds of the experiment. Use the three cardinal principles to justify what you think she should do and why.



Cases: Responsible Conduct of Research

Why is this dude smiling?



Who is he, anyway?



Dr. Hwang Woo Suk



Successfully cloned a dog



Successfully cloned a dog



“Snuppy”



Most famous for making STEM cells from 11 cloned embryos



1 problem

REPORT

Patient-Specific Embryonic Stem Cells Derived from Human SCNT Blastocysts

Woo Suk Hwang^{1,2,*}, Sung Il Roh³, Byeong Chun Lee¹, Sung Keun Kang¹, Dae Kee Kwon¹, Sue Kim¹, Sun Jong Kim³, Sun Woo Park¹, Hee Sun Kwon¹, Chang Kyu Lee², Jung Bok Lee³, Jin Mee Kim³, Curie Ahn⁴, Sun Ha Paek⁴, Sang Sik Chang⁵, Jung Jin Koo⁵, Hyun Soo Yoon⁶, Jung Hye Hwang⁶, Youn Young Hwang⁶, Ye Soo Park⁶, Sun Kyung Oh⁴, Hee Sun Kim⁴, Jong Hyuk Park⁷, Shin Yong Moon⁴, Gerald Schatten^{7,*}

[±] Author Affiliations

[✉] * To whom correspondence should be addressed. E-mail: hwangws@snu.ac.kr (W.S.H.); gschatten@pdc.magee.edu (G.S.)

ABSTRACT

Patient-specific, immune-matched human embryonic stem cells (hESCs) are anticipated to be of great biomedical importance for studies of disease and development and to advance clinical deliberations regarding stem cell transplantation. Eleven hESC lines were established by somatic cell nuclear transfer (SCNT) of skin cells from patients with disease or injury into donated oocytes. These lines, nuclear transfer (NT)-hESCs, grown on human feeders from the same NT donor, were pluripotent, chromosomally normal, and matched at high rates, regardless of genetic unrelated individuals, which is important for clinical applications. NT-hESCs were genetically unrelated individuals, which is important for clinical applications. NT-hESCs were pluripotent, chromosomally normal, and matched at high rates, regardless of genetic unrelated individuals, which is important for clinical applications. NT-hESCs were pluripotent, chromosomally normal, and matched at high rates, regardless of genetic unrelated individuals, which is important for clinical applications.

At least 9 of 11 were fabricated.

Science 16 December 2005:
Vol. 310 no. 5755 pp. 1748–1749
DOI: 10.1126/science.310.5755.1748

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NEWS OF THE WEEK

STEM CELLS

Korean University Will Investigate Cloning Paper

Dennis Normile, Gretchen Vogel^{*}

With reporting by Sei Chong, Ji-soo Kim, and Richard Stone. Chong and Kim are freelance writers in Seoul.

SEOUL AND TOKYO-- Embattled Korean stem cell scientist **Woo Suk Hwang** and his university have bowed to pressure for an investigation into a growing list of questions about a landmark paper he and colleagues published online in *Science* on 19 May 2005. ([Read more.](#))

The editors suggest the following Related Resources on Science sites:

NEWS OF THE WEEK

STEM CELLS

Cloning Researcher Says Work Is Flawed but Claims Results Stand

Dennis Normile, Gretchen Vogel, and Constance Holden

At least 9 of 11 were fabricated.

Science 13 January 2006:
Vol. 311 no. 5758 pp. 156–157
DOI: 10.1126/science.311.5758.156

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NEWS OF THE WEEK

CLONING

South Korean Team's Remaining Human Stem Cell Claim Demolished

Dennis Normile, Gretchen Vogel, Jennifer Couzin*

With reporting by Sei Chong in Seoul.

In an announcement that researchers worldwide both expected and feared, **Woo Suk Hwang's** last remaining claim to have advanced the promising field of human embryonic stem cells has been declared fraudulent. ([Read more.](#))

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NY TIMES

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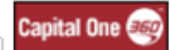
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Researcher Faked Evidence of Human Cloning, Koreans Report

Published: July 7, 2010

Dr. Hwang Woo Suk, the South Korean researcher who claimed to have cloned human cells, fabricated evidence for all of that research, according to a report released today by a Seoul National University panel investigating his work.

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The finding strips any possibility of legitimate achievement in human cell cloning from a researcher who had been propelled to international celebrity and whose promise to make paralyzed people walk had been engraved on a Korean postage stamp.

In his string of splashy papers, his one legitimate claim was to have cloned the dog he named Snuppy, the panel said.

"Dr. Hwang's team cannot avoid taking grave responsibility for fabricating its papers and concealing data," said Chung

Myunghee, the head of the university's investigatory panel.

Last month the panel said there was no evidence to support Dr. Hwang's claim of June 2005 to have cloned cells from 11 patients with an efficient new technique using very few human eggs.

But that still left open the possibility that he had gotten the cloning technique to work to some degree, as he wrote in the report first announcing his success in an earlier article of March 2004. The panel has now found the 2004 article was also fabricated, according to wire service reports.

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**2 YEARS PRISON
EXPELLED FROM UNIVERSITY
BARRED FROM RESEARCH
PAPERS RETRACTED**



His poor judgement hurt many careers...



Big question....

How do you prevent this from happening to you?



The Newspaper Test

1. Imagine that what you are preparing to do (or someone you are working is doing) will be reported the next day on the front page of The New York Times.
2. Are you 100% comfortable having your advisor / employer, colleagues, friends, and family know **exactly** what you are involved in?

The Newspaper Test

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CASE A



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CASE STUDY A

CASE STUDY A

Since 2010, you have been an undergraduate student at Florida State University and you have done undergraduate research in Dr. Falk's lab there for 3 years, looking at what different brain structures can tell us about people.

In the summer of 2013, you do a summer REU in Dr. Schell's lab at Harvard on drugs that effect brain structure.

In the Fall of 2013, Dr. Schell asks you to prepare a research paper on a new drug you have tested. You write the paper and provide it to Dr. Schell's postdoc, Eric.

Eric states that he should be second author on the paper because:

1. he trained you in basic research methods that you used at Harvard
2. you wrote the paper under his supervision, while you were at Harvard, not at Florida

CASE STUDY A

Just before submitting the paper where you are first author, Dr. Schell calls you to let you know that she is submitting an invention disclosure and that a pharmaceutical company has already agreed to provide Harvard a 2M yearly listing fee for the new drug. You and *all* the paper's authors will share Harvard's "inventor share" of \$600K.

CASE STUDY A

The correct approach to issues of authorship:

- ✓determine if your lab or the journal has an authorship requirements, if not, use ours (next slide)
- ✓discuss the contents of the paper and authorship with all parties involved before beginning to write the paper, agree who will be responsible for each part
- ✓ensure every author satisfies all authorship requirements
- ✓include a paragraph at the end of the paper detailing author contributions AND acknowledgements for important non authors

CASE STUDY A

My lab's authorship requirements:

Each author must be willing to take full, public responsibility for the content of the paper and have made substantial contributions to:

- either the conception and design or the analysis and interpretation of the data
- drafting the article or revising it critically for important intellectual content
- final approval of the version to be published

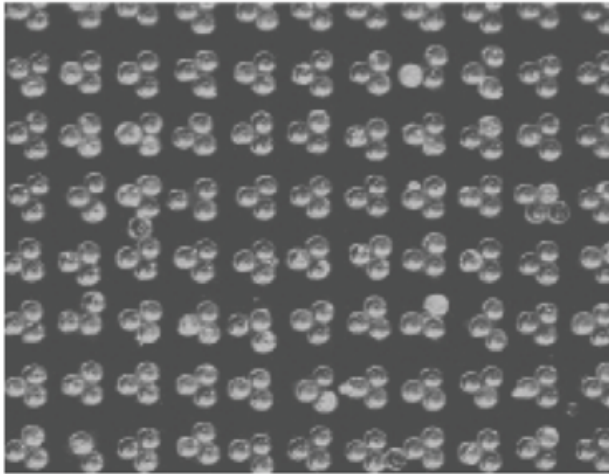
CASE STUDY B

CASE STUDY B

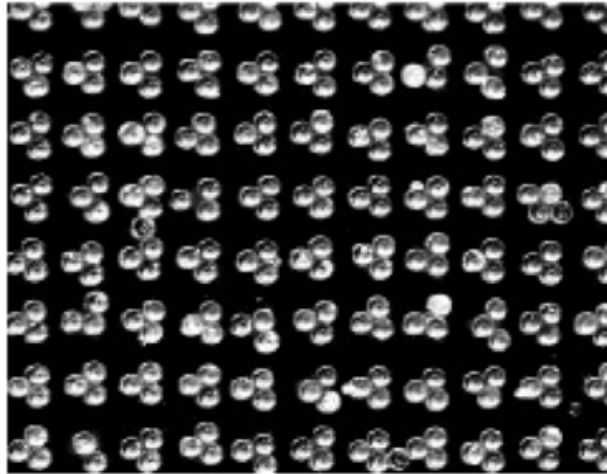
Dr. Schell asks you to take some images of cells in the brains of fish that have been effected by mercury. You find small mercury deposits in several of the fish and pull them out on a slide. You show them to Dr. Schell and she asks you to prepare an image to present to your group.

CASE STUDY B

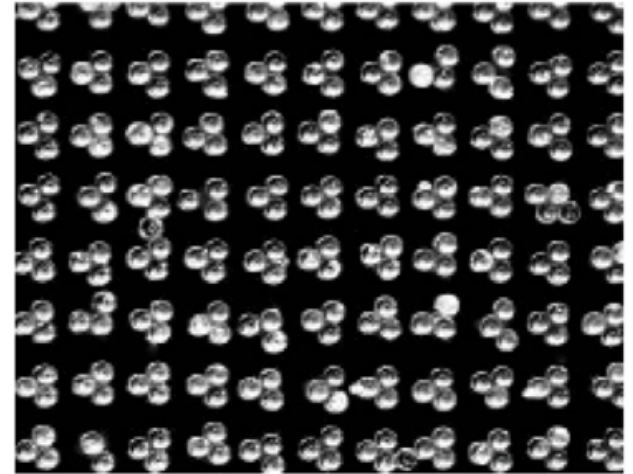
original



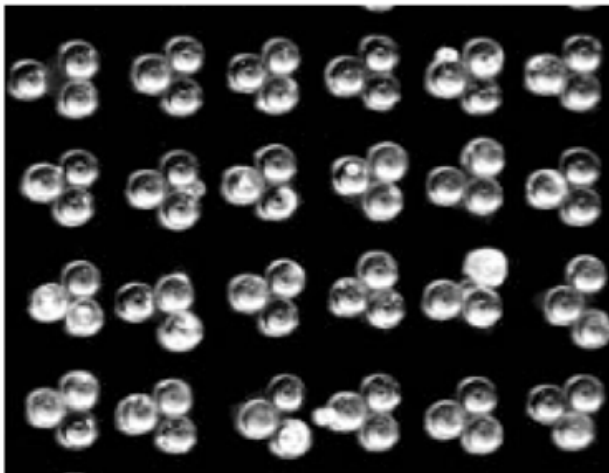
1. adjust contrast



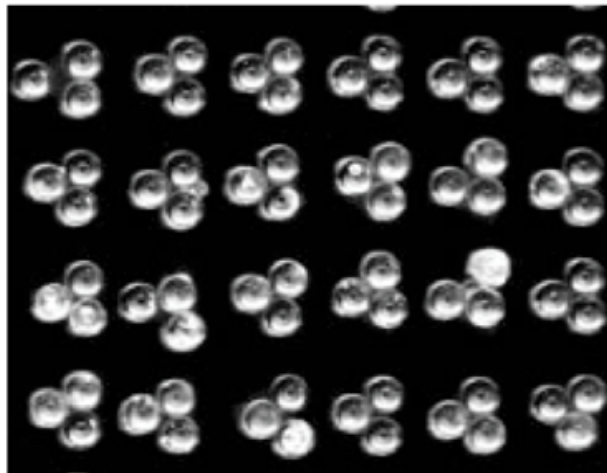
2. remove blemishes



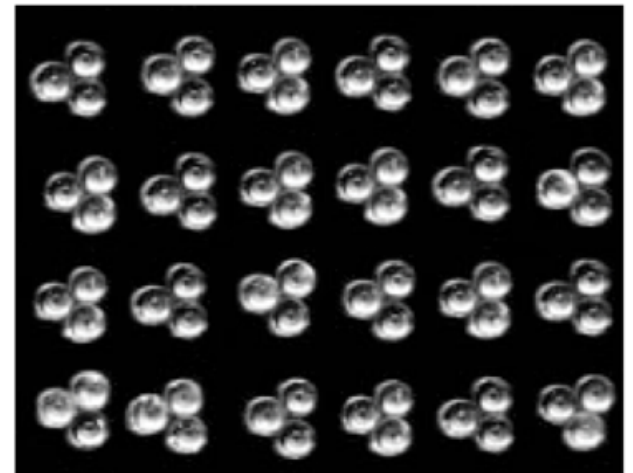
3. crop



4. remove outliers



5. reconstruct



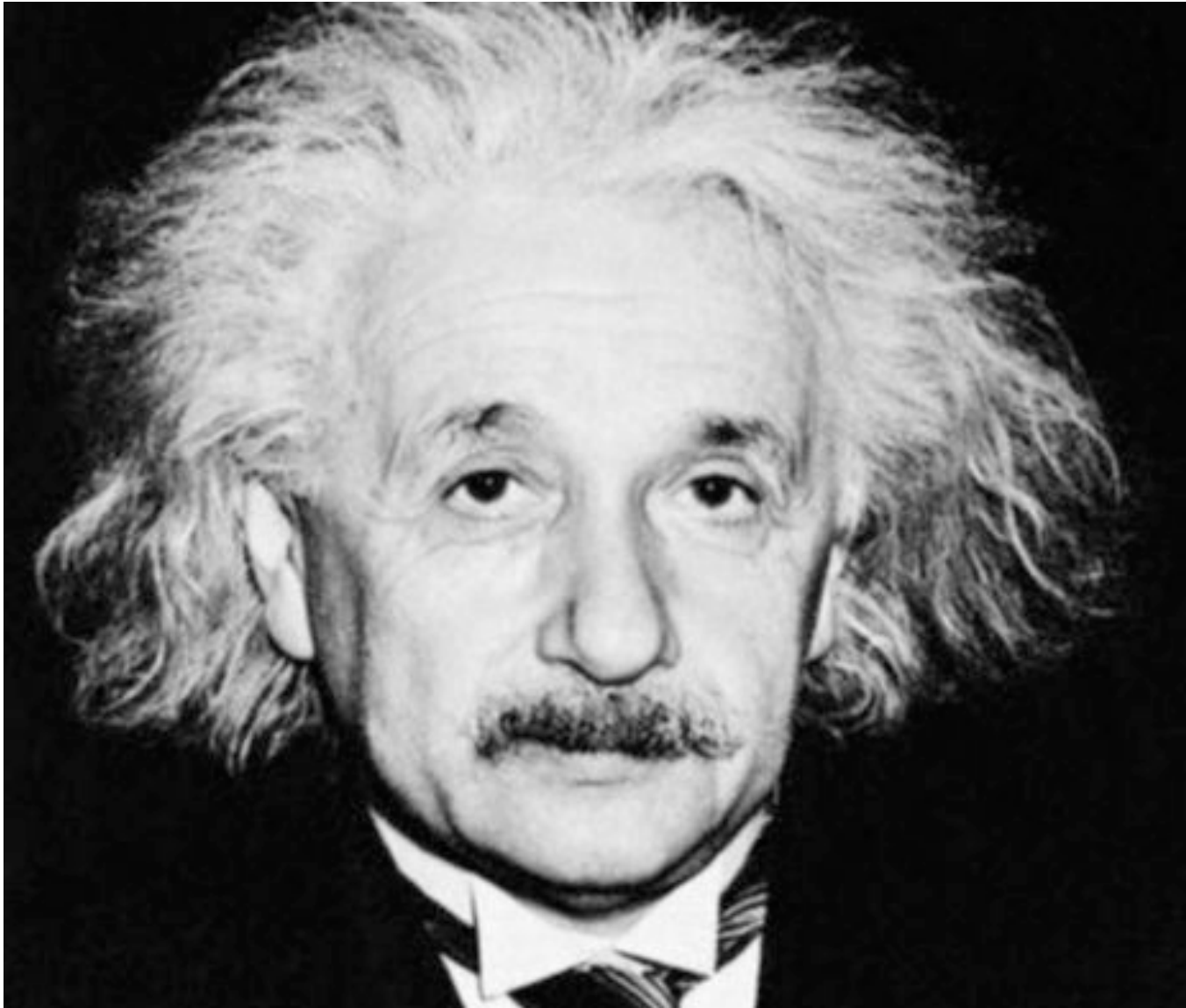
CASE STUDY B

The editor of Animal Brain calls Dr. Schell and asks for an original, unedited microscope image for posting on their website.

CASE STUDY C

CASE STUDY C

Einstein's Brain



CASE STUDY C

“We learn that Einstein’s son, Hans Albert, and his executor, Otto Nathan, gave Thomas Harvey permission to remove and preserve the brain for scientific study, but in “Einstein’s Brain Unlocks Some Mysteries of The Mind” we learn that the Einstein family has denied this claim. So which is it?”

CASE STUDY C

From: Dean Falk <dfalk@fsu.edu>

Subject: **Einstein's brain**

Date: February 23, 2013 at 1:24:26 AM EST

To: "Schell, Julie Anne" <schell@seas.harvard.edu>

Hi Julie,

My understanding is that Einstein's son, Hans Albert, gave permission for an autopsy to be performed but had not intended for the brain to be collected. He was upset when he learned from a newspaper article (shortly after Einstein died) that it had been, but was persuaded (by Harvey in a phone conversation) to give permission for Harvey to keep the brain for scientific study. My impression is that Harvey rationalized that harvesting the brain was a normal part of an autopsy, but had begun fixing it before he had Hans Albert's permission to collect it. Apparently, Otto Nathan attended the autopsy (at least according to Harvey), but it is not clear that he understood that Harvey intended to keep the brain and, reportedly, he was not happy when he learned that Hans Albert had given permission for Harvey to do so. Carolyn Abraham discusses the whole thing in her book, *Possessing Genius*, which I am just now reading. It's pretty riveting.

Your course sounds fascinating, and the collecting and subsequent "curating" of Einstein's brain (as detailed by Abraham) seems ripe for examination from an ethical point of view.

Good luck with it!

Dean

CASE STUDY C

“Would Einstein feel differently if he knew his brain would advance knowledge of science?”

CASE STUDY C

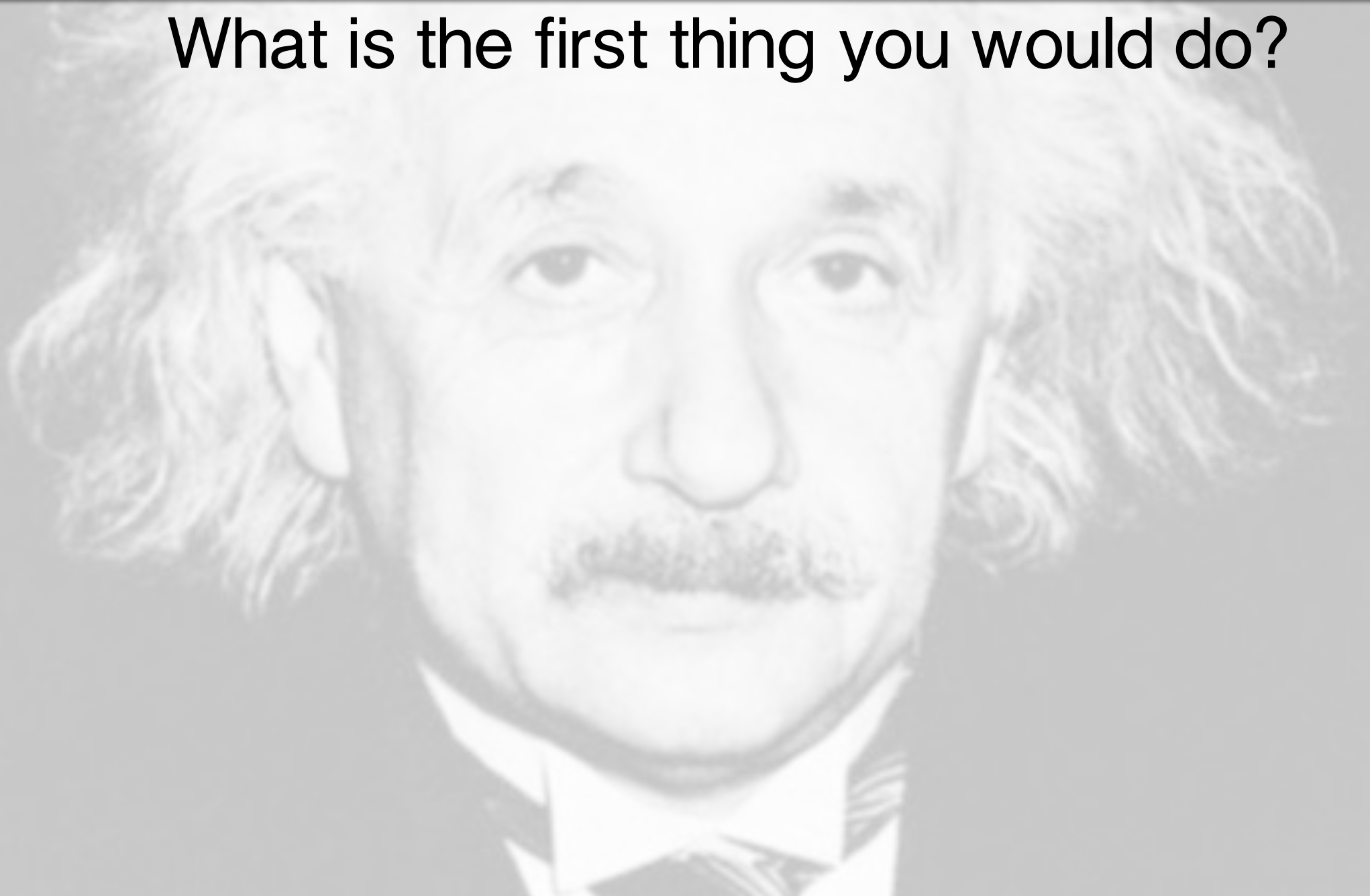
“It is amazing that people continue to study his brain, knowing that there was no consent. Especially after the family, from what it sounds like from the sources, was upset by it.”



QUICK START GUIDE FOR MAKING ETHICAL DECISIONS

Strategies for making decisions

What is the first thing you would do?



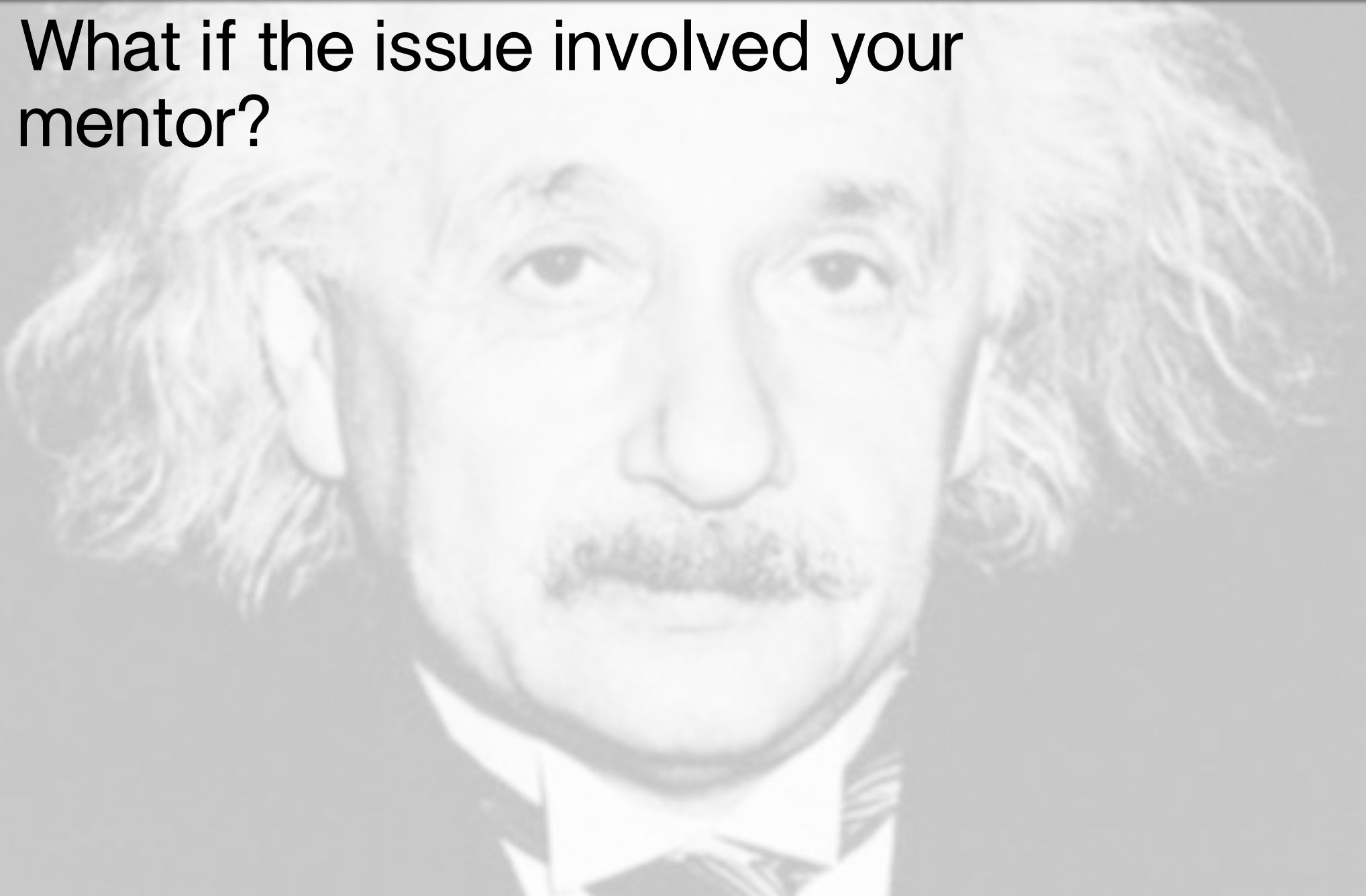
Strategies for making decisions

What is the first thing you would do?



Strategies for making decisions

What if the issue involved your mentor?



Quick Start Guide to GOOD Decisions in Gray Areas

G	Listen to your GUT , it is often the first to tell you something is wrong.
O	OUTLINE the possible consequences of all your decisions, when human subjects are involved consider the principles respect for persons, beneficence, and justice
O	seek the OPINION of a third party (your mentor OR REU supervisor OR the ombudsperson)
D	DO The Newspaper Test



POST-WORKSHOP ASSIGNMENT



<http://bit.ly/reupost>



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