



# Putting the *demos* in democratic deliberation: *The search for public opinion about the ethical use of biospecimens*

[A meditation in three acts]

RG de Vries  
Center for Bioethics and Social Sciences in Medicine  
University of Michigan  
**@agoodbirth**



MEDICAL SCHOOL

CENTER FOR BIOETHICS & SOCIAL SCIENCES IN MEDICINE  
UNIVERSITY OF MICHIGAN

# To begin:

## Abstract

The creation of sustainable and ethical policies in health care and the life sciences requires soliciting and incorporating the attitudes and opinions of the “public,” a difficult task that is even more challenging in a political polarized society and when the policies in question are explicitly normative. Using research on public attitudes about the use of their biospecimens and health data, we will look at various methods used to solicit those attitudes and consider the strengths and limitations of those approaches. We will reflect on the value of empirical data for resolving normative questions (in other words, the age-old is/ought problem) and think together about better ways to incorporate the opinions of the *demos* in health policy.

# To begin:

In other words, we have a few problems:

1. Can empirical data be used to settle normative questions?
2. Should the demos have input into solving moral problems – like the collection and use of biospecimens – created by new technologies?
3. If yes, how can we collect trustworthy data?  
*Surveys? Interviews? Focus groups? Vignettes? Observation?*

# The three acts

Act I: Measuring public opinion about the use of biospecimens

Act II: We have a problem: reflections of a sociologist on  
empirical bioethics

*Scene 1: Sociology and bioethics*

*Scene 2: Why do we do what we do*

*Scene 3: How hard can it be?*

*Scene 4: “Ought” and “is”*

Act III: Is there a way forward?



The background features a repeating pattern of light gray icons on a white background. The icons include stylized trees, houses, horses, whales, a person in a wheelchair, an ambulance, and a pair of lungs, symbolizing the interconnectedness of the environment, human health, and society.

# Act I: Measuring public opinion about the use of biospecimens

# Using empirical data to inform policy in health care

**Research biobanks have great potential** for advancing knowledge of human health, disease, and treatment. **Recruitment of donors is vital to their success** and relies largely on broad consent – donors give one-time permission for any future research uses of their coded specimen. But **donors may have moral, religious, and cultural concerns** about the use to which their specimens are put, which may affect their willingness to give blanket consent.



# Information Ethics | Havasupai case example

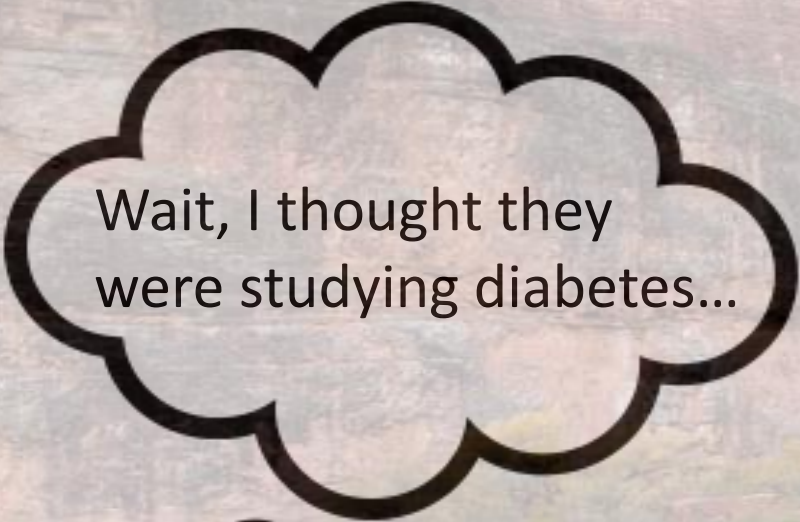
More than 200 of the 650-member Havasupai tribe signed a consent form stating that their blood could be used to “study the causes of behavioral/medical disorders.”

But many said they had believed they were donating it only for the study of **diabetes**, which tribal members suffer from at extraordinarily high rates.



Havasupai Falls





Wait, I thought they  
were studying diabetes...

But, in fact the data was  
used to:

1. Study schizophrenia
2. Study the geographic  
origin of tribe



# Information Ethics

Deidentified...

So no (*personal*)  
harm, no foul?

But what  
happens with  
their data matters  
to people.



# Moral concerns/Non-welfare interests

## **NOT:**

- Physical harm
- Breach of confidentiality

## **RATHER:**

- Stigma
- Threats to one's world view
- Exploitation
- Research goals contrary to one's beliefs



# No (personal) harm, no foul?

- We surveyed a cross section of Americans to find out what they thought





# Our question: The effect of Non-Welfare Interests (NWI)

At baseline: “I would donate tissue samples and medical information to the biobank, so that it can use them for any research study that it allows, without further consent from me.”

Under research scenario: “I would donate tissue samples and medical information to the biobank, so that the biobank can use them for any research study that it allows, without further consent from me even if researchers might use donations to...”

- **...develop more safe and effective abortion methods.**
- **...develop kidney stem cells.** They would then try to grow these cells in a pig embryo that would grow into an adult pig with human kidneys. The goal would be to grow kidneys or other organs that could be transplanted into people.
- **...develop patents and earn profits for commercial companies.** Most new drugs used to treat or prevent disease come from commercial companies.

# Our question: The effect of Non-Welfare Interests (NWI)

- **...develop stem cells that have the donor's genetic code.** These could be kept alive for many years. Scientists might use those stem cells to create many different kinds of tissues and organs for use in medical research.
- **...create vaccines against new biological weapons.** The government might need to develop biological weapons of its own when it does this research.
- **...understand the evolution of different ethnic groups, and where they come from.** What they learn might conflict with some religious or cultural beliefs.
- **...discover genes that make some people more violent.** This could lead to ways to reduce violent behavior. But if these genes are found to be more common among some racial and ethnic groups, this might increase prejudice.

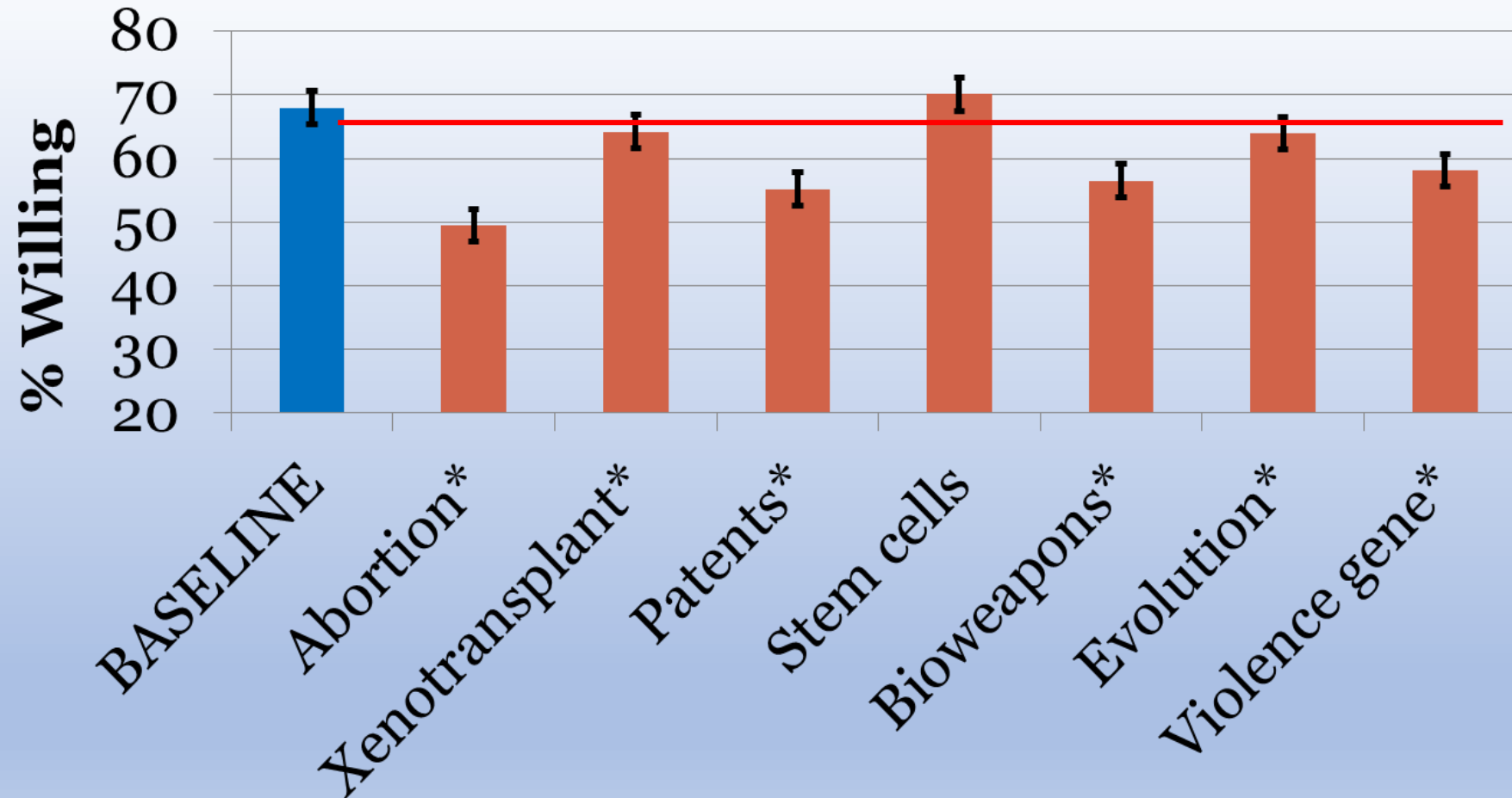
**Table 1. Willingness to Give Blanket Consent at Baseline and for 7 Potential Research Scenarios Raising Moral Concerns**

Blanket Consent	Total <sup>a</sup>	Agreed <sup>b</sup>	% (95% CI) <sup>c</sup>	P Value <sup>d</sup>
At baseline: "I would donate tissue samples and medical information to the biobank, so that it can use them for any research study that it allows, without further consent from me."	1593	1122	68.0 (65.5-70.5)	
Under research scenario: "I would donate tissue samples and medical information to the biobank, so that the biobank can use them for any research study that it allows, without further consent from me even if researchers might use donations to..." <sup>e</sup>				
...develop more safe and effective abortion methods.	1588	790	49.5 (46.9-52.1)	<.001
...develop kidney stem cells. They would then try to grow these cells in a pig embryo that would grow into an adult pig with human kidneys. The goal would be to grow kidneys or other organs that could be transplanted into people.	1592	1066	64.2 (61.6-66.8)	.007
...develop patents and earn profits for commercial companies. Most new drugs used to treat or prevent disease come from commercial companies.	1591	912	55.2 (52.6-57.8)	<.001
...develop stem cells that have the donor's genetic code. These could be kept alive for many years. Scientists might use those stem cells to create many different kinds of tissues and organs for use in medical research.	1591	1151	70.1 (67.6-72.6)	.17
...create vaccines against new biological weapons. The government might need to develop biological weapons of its own when it does this research.	1590	918	56.6 (53.9-59.2)	<.001
...understand the evolution of different ethnic groups, and where they come from. What they learn might conflict with some religious or cultural beliefs.	1591	1042	64.0 (61.5-66.6)	.005
...discover genes that make some people more violent. This could lead to ways to reduce violent behavior. But if these genes are found to be more common among some racial and ethnic groups, this might increase prejudice.	1591	946	58.1 (55.5-60.7)	<.001



# NWI Scenario Results

## Willingness to Donate



# What did we find when we looked more closely at the data?

- ✓ **Characteristics of those with concerns**
- ✓ **Opinions about the best way to get consent**

ADJUSTED ODDS RATIOS	Abortion	Xeno-transplant	Patents	Stem cells	Bio-weapons	Evolution	Violence Gene
Age (in years)	<b>0.99*</b>	1.00	1.00	0.99	<b>0.99*</b>	<b>0.99*</b>	<b>0.99*</b>
Female	0.94	<b>0.68*</b>	0.84	0.77	0.94	0.86	0.84
Race							
White	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Black/AA	0.89	<b>0.43**</b>	1.17	0.63	1.01	0.80	<b>0.56*</b>
Other	1.41	0.78	0.78	1.02	1.00	0.68	0.79
Hispanic	0.65	<b>0.62*</b>	<b>0.51*</b>	0.91	0.69	0.87	0.82
Education	0.90	0.99	0.96	0.94	0.91	0.90	0.93
Income	1.00	1.02	1.02	1.00	1.03	1.02	1.01
Abortion view							
Always legal	1.00	1.00	1.00	1.00	1.00	1.00	1.00
In most circumstances	0.76	0.98	1.05	0.84	1.18	1.11	<b>0.64*</b>
In a few circumstances	<b>0.25**</b>	<b>0.61*</b>	1.11	0.84	1.06	0.91	<b>0.68*</b>
Always illegal	<b>0.09**</b>	<b>0.46*</b>	0.74	<b>0.60*</b>	0.90	<b>0.62*</b>	<b>0.51*</b>
Don't know	<b>0.26**</b>	0.59	1.05	<b>0.38*</b>	0.84	0.70	0.85
Religion							
Catholic	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Other Christian	0.79	1.08	<b>0.71*</b>	0.76	0.77	0.91	1.10
Non-Christian Religions	0.82	0.84	0.64	0.71	0.61	1.12	0.79
Unaffiliated	1.27	1.00	0.81	0.71	<b>0.61*</b>	1.02	0.86
Do not Know/ Refused	0.84	0.68	0.64	0.51	0.71	0.77	0.66
Political (lower=liberal)	<b>0.75**</b>	1.02	1.01	<b>0.86*</b>	1.02	<b>0.86*</b>	0.96
Privacy (higher=worried)	0.98	<b>0.81**</b>	0.91	<b>0.80**</b>	0.90	<b>0.88*</b>	1.00
RAQ (higher=more pos.)	<b>1.09**</b>	<b>1.12**</b>	<b>1.09**</b>	<b>1.13**</b>	<b>1.09**</b>	<b>1.09**</b>	<b>1.09**</b>

\* p < .05

\*\* p < .001



RESEARCH

Open Access

# The moral concerns of biobank donors: the effect of non-welfare interests on willingness to donate



Raymond G. De Vries<sup>1\*</sup>, Tom Tomlinson<sup>2</sup>, H. Myra Kim<sup>3</sup>, Chris D. Krenz<sup>1</sup>, Kerry A. Ryan<sup>1</sup>, Nicole Lehpamer<sup>4</sup> and Scott Y. H. Kim<sup>5,6</sup>

## Who is concerned?

1. Most people had non-welfare interests that significantly affected their willingness to donate to a biobank using blanket consent.
2. **Trust is critical in the decision to donate.** A positive attitude toward biomedical research was consistently associated with increased willingness to donate (regardless of NWI).
3. Concern with privacy was associated with decreased willingness to donate.
4. African Americans had concerns about donating that remained after controlling for attitudes toward research and concerns with privacy.

Act I: measuring public opinion about biospecimens

# What about policy options?

Policy Option	Description
<b>Blanket consent</b>	<b>This means that donors have control over whether to donate but not over how the samples are used in any future research. It gives the biobank and researchers a lot of freedom in deciding how to use samples.</b>
<b>Blanket consent combined with a caution</b>	Donors are alerted in advance with the following statement: “Some people may have moral, religious, or cultural concerns about some kinds of research.” Donors can then decide whether they are still willing to donate. Some donors may decide not to donate, resulting in fewer samples for research.
<b>Blanket consent combined with an option to withdraw</b>	Donors first give their blanket consent. The biobank then gives them easy access to information about current research projects being done with donated samples. If donors see research projects that worry them, they can decide to withdraw their tissues. If too many people withdraw their donation, researchers may have trouble finding enough samples to do their research.
<b>Blanket consent combined with limits</b>	Donors are given a short list of types of research projects that might worry some people. The donors then decide which types of research can’t use their donation. Research not on the list would still be covered by a blanket consent. This system may cost more, leaving less money for research.
<b>Real-time specific consent for each use of the donated samples</b>	<b>Donors don’t give blanket consent. Instead, the biobank contacts them and asks for their consent for each specific project. Donors are given maximum control, but some might get tired of being contacted repeatedly. The cost of recontacting every donor for consent will be high. If too many people refuse to give their consent, many research studies will not be possible.</b>

# Policy options

RESEARCH ARTICLE

## Understanding the Public's Reservations about Broad Consent and Study-By-Study Consent for Donations to a Biobank: Results of a National Survey

Raymond Gene De Vries<sup>1\*</sup>, Tom Tomlinson<sup>2</sup>, Hyungjin Myra Kim<sup>3</sup>, Chris Krenz<sup>1</sup>, Diana Haggerty<sup>4</sup>, Kerry A. Ryan<sup>1</sup>, Scott Y. H. Kim<sup>5,6</sup>

**Table 3. Percent finding societal consent policy “unacceptable” or “worst”.**

Policy Option	Unacceptable Option (n = 1,587) <sup>1</sup> %	Worst Option (n = 1,548) <sup>1,2</sup> %
Blanket consent	43.6	37.8
Blanket consent combined with a caution	28.1	4.2
Blanket consent combined with an option to withdraw	29.2	6.2
Blanket consent combined with limits	34.9	6.8
Real-time specific consent for each use of the donated samples	43.0	45.0

<sup>1</sup> Not all respondents answered the question.

<sup>2</sup> Data previously published in a JAMA research letter at <http://doi.org/10.1001/jama.2014.16363>.



# Policy options

## RESEARCH ARTICLE

### Understanding the Public's Reservations about Broad Consent and Study-By-Study Consent for Donations to a Biobank: Results of a National Survey

Raymond Gene De Vries<sup>1\*</sup>, Tom Tomlinson<sup>2</sup>, Hyungjin Myra Kim<sup>3</sup>, Chris Krenz<sup>1</sup>, Diana Haggerty<sup>4</sup>, Kerry A. Ryan<sup>1</sup>, Scott Y. H. Kim<sup>5,6</sup>

## What is the best way to get consent for use of biobank donations?

1. Substantial minorities found **both broad and study-by-study consent to be unacceptable** and identified those two options as the worst policies.
2. **The type of moral concern** (e.g., regarding abortion, the commercial use of donations, or stem cell research) **had no effect on policy preferences**, but an increase in the number of research scenarios generating moral concerns increased the likelihood of finding broad consent to be the worst policy.

Rejection of these ethically problematic and costly extremes is **good news for biobanks**. But the challenge remains: ***now to design a policy that combines consent with access to information in a way that assures potential donors that their interests and moral concerns are being respected.***

But are these the **informed** and **considered**  
opinions of the public?

The background image shows a large crowd of people gathered in front of the US Capitol building. Many people are holding American flags and banners that say 'TRUMP 2020'. The scene is crowded and appears to be a political rally or protest. The text 'The problem' is overlaid in the center of the image.

# The problem

The creation of sustainable and ethical policies in health care and the life sciences requires soliciting and incorporating the attitudes and opinions of the “public,” **a difficult task that is even more challenging in a political polarized society and when the policies in question are explicitly normative.**



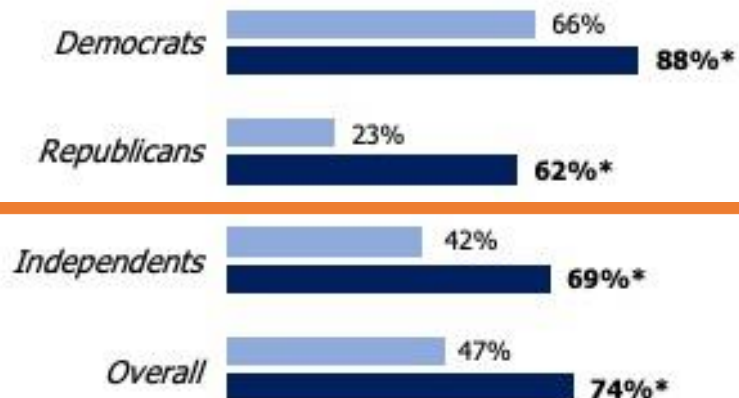
# One approach:



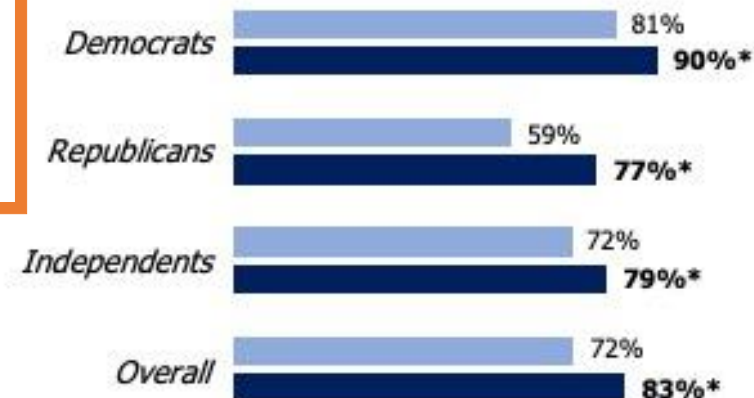
*In September of 2019, a total of 526 registered American voters were brought together to discuss important issues that impact all of us.*



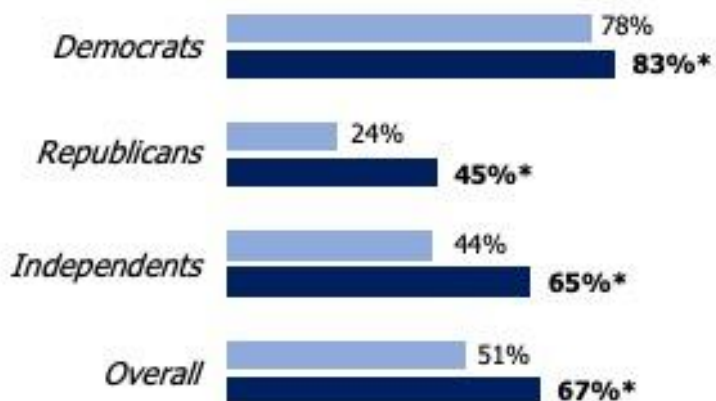
The US should rejoin the Trans-Pacific Partnership, a trading agreement between 12 countries excluding China.



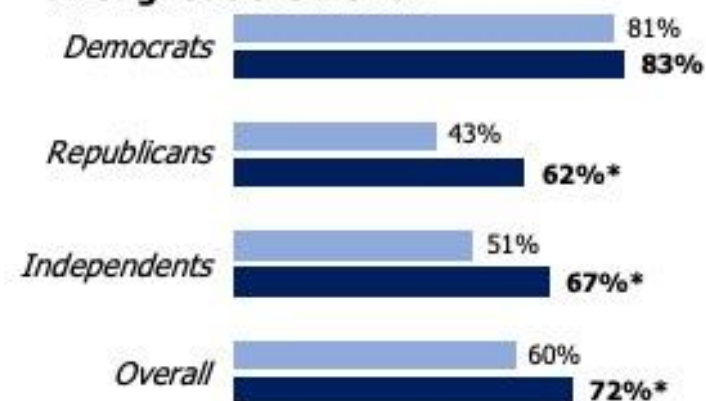
The US should reaffirm its commitment to defend any NATO ally attacked by a hostile force.



The US should recommit to the Iran Nuclear Agreement.



The US should use diplomacy and financial support to promote democracy and human rights throughout the world.



Can we, should we, use this approach  
to inform policy in health care?



# Beyond surveys: Looking for the **informed** and **considered** opinion of the public

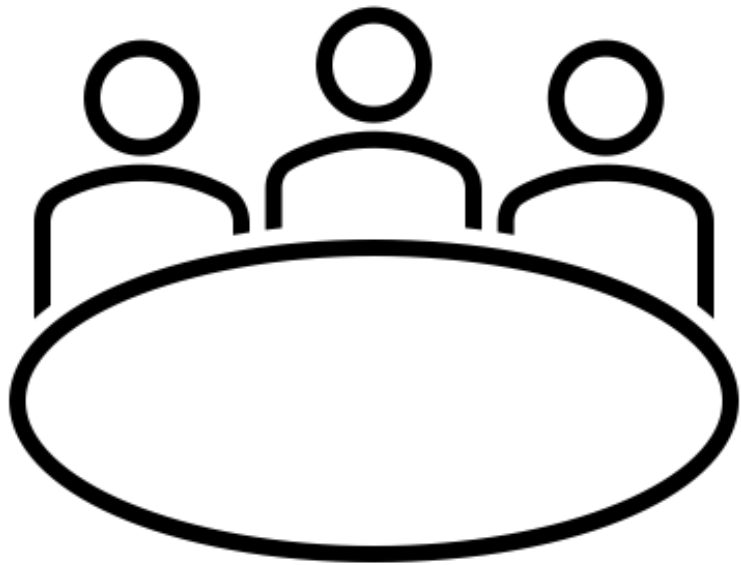
*Research Article*

---

## **Biobanks and the Moral Concerns of Donors: A Democratic Deliberation**

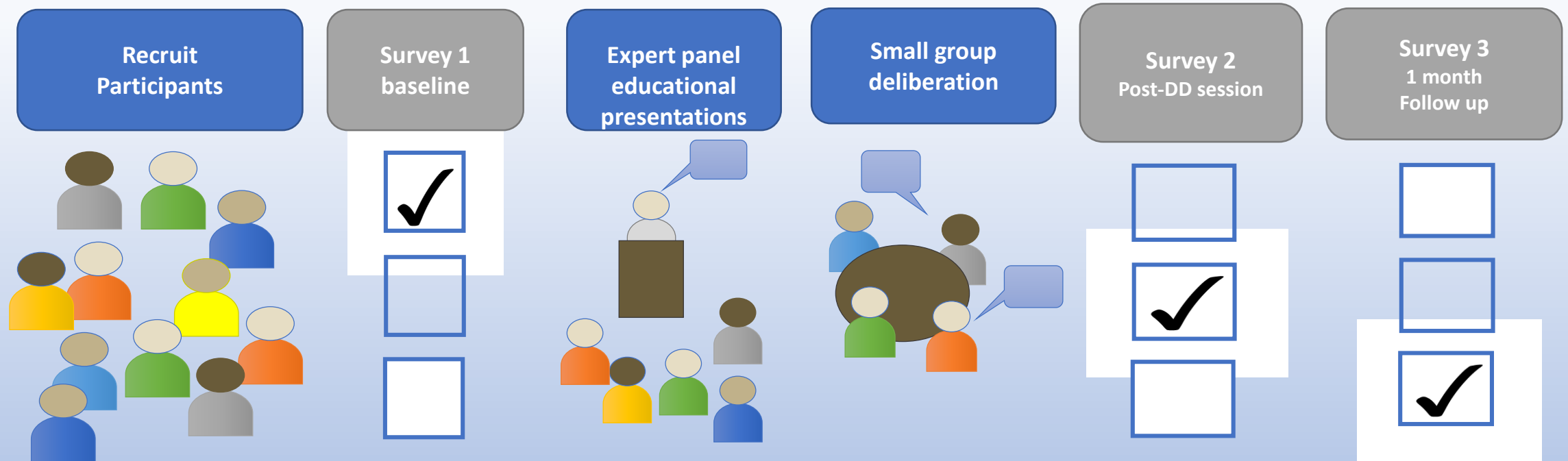
**Raymond G. De Vries<sup>1</sup>, Kerry A. Ryan<sup>1</sup>, Linda Gordon<sup>2</sup>,  
Chris D. Krenz<sup>1</sup> , Tom Tomlinson<sup>2</sup>, Scott Jewell<sup>3</sup>, and Scott Y. H. Kim<sup>4</sup>**

Qualitative Health Research  
2019, Vol. 29(13) 1942–1953  
© The Author(s) 2018  
Article reuse guidelines:  
[sagepub.com/journals-permissions](https://sagepub.com/journals-permissions)  
DOI: 10.1177/1049732318791826  
[journals.sagepub.com/home/qhr](https://journals.sagepub.com/home/qhr)  

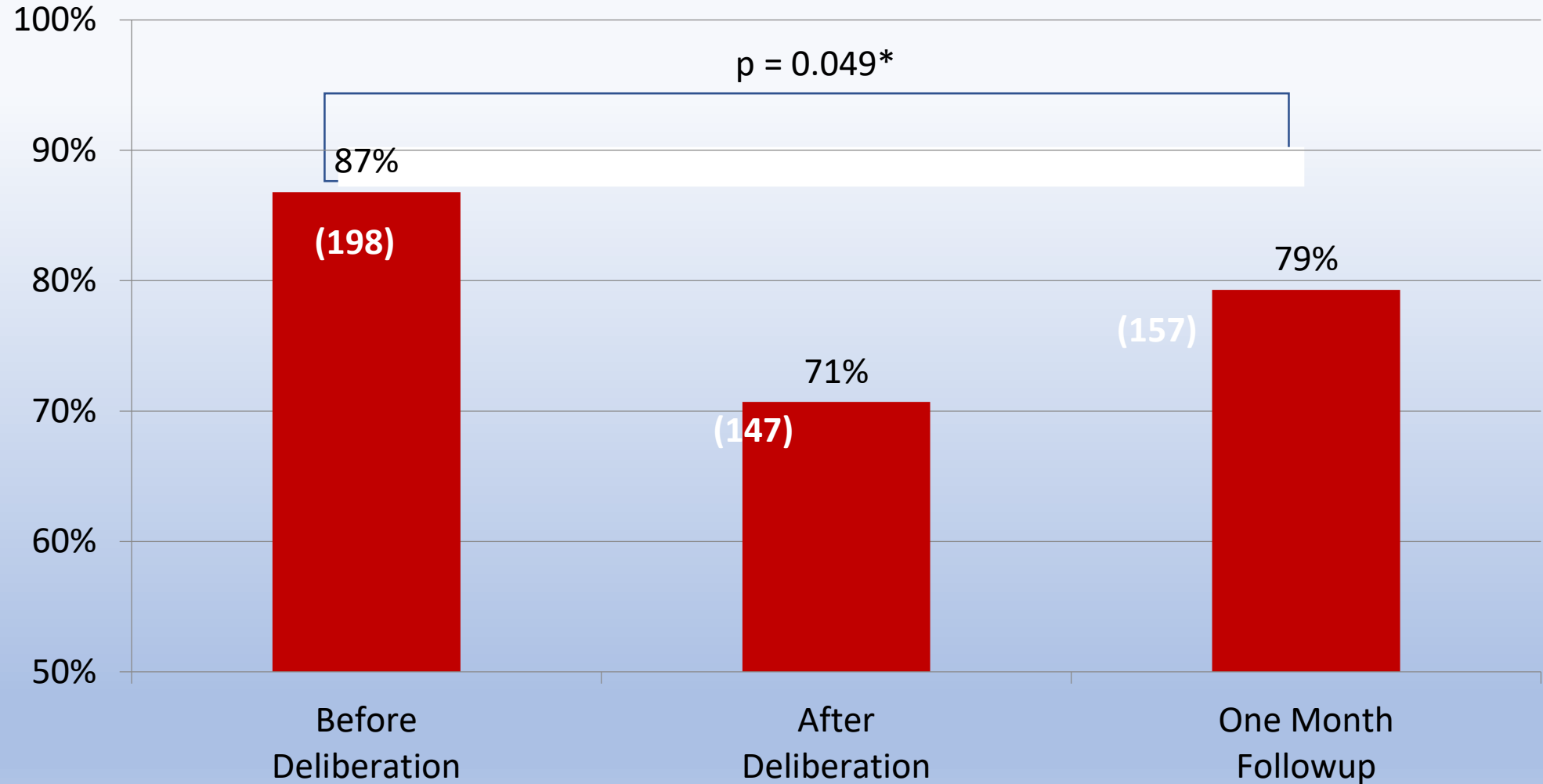
We organized **three democratic deliberations involving 180 participants**. The deliberative sessions involved **small group discussions informed by presentations given by experts** in both biobank research and ethics.

# How does Deliberative Democracy work?



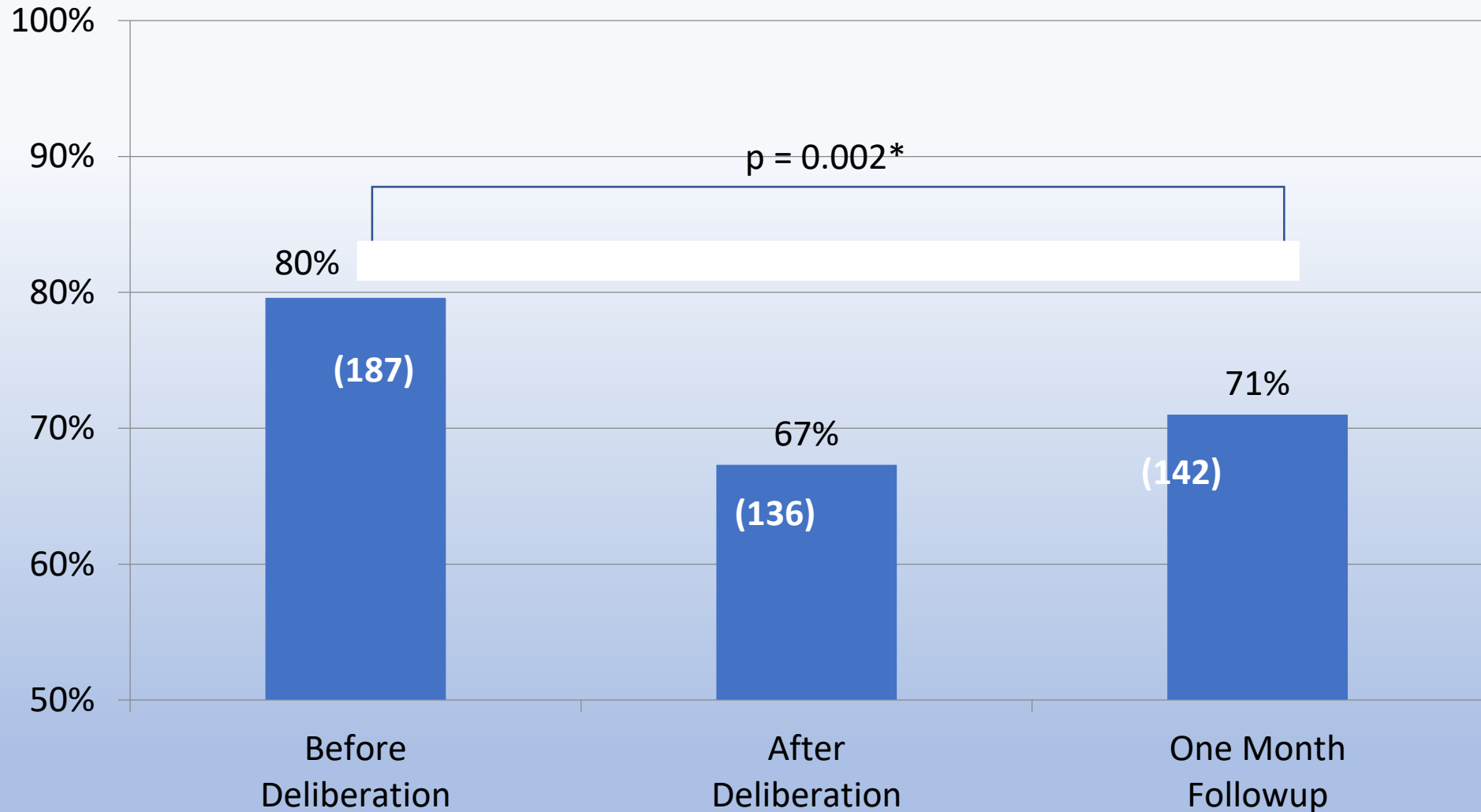


# Deliberation participants: % Willing to Give Blanket Consent



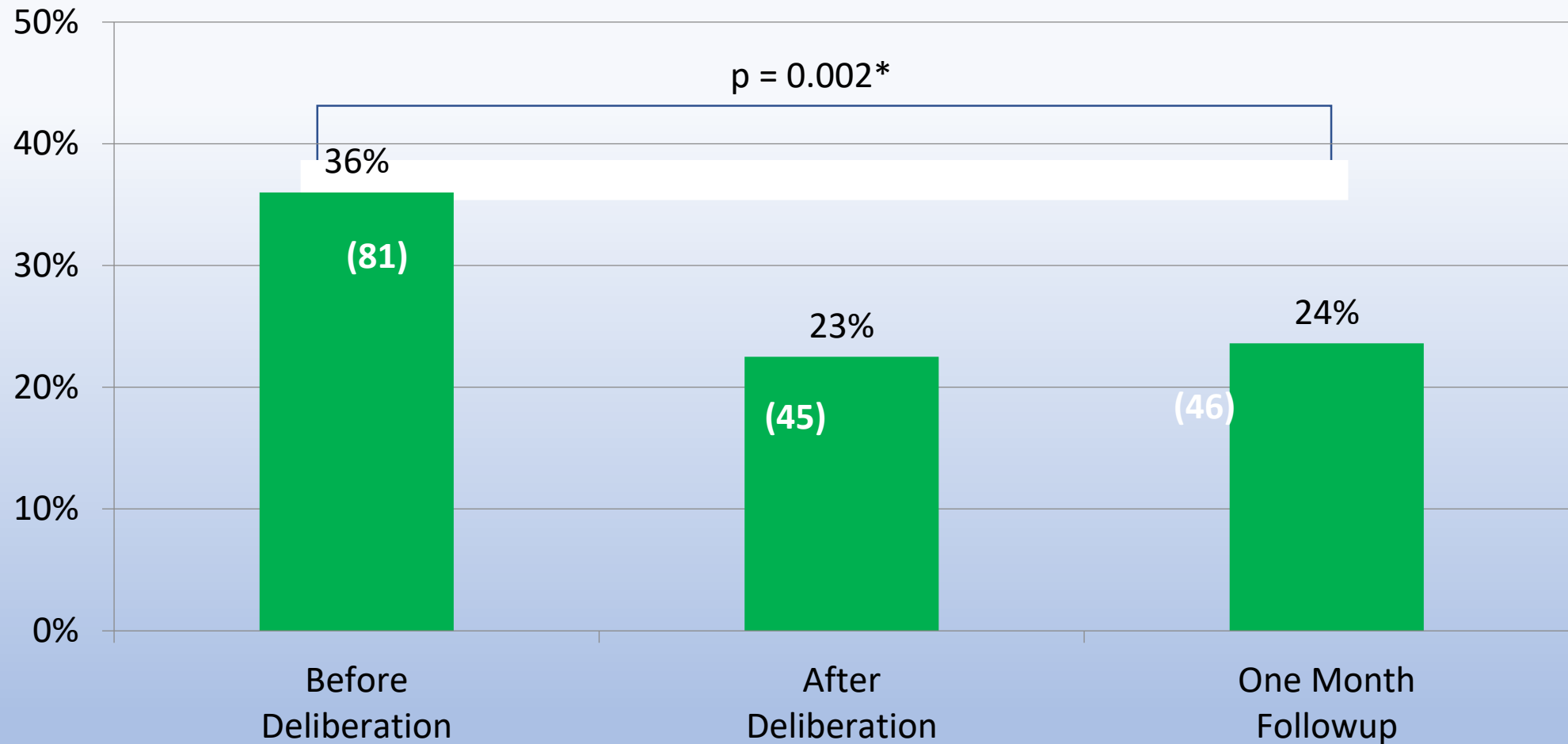
\*Based on McNemar's pairwise test.

# Deliberation participants : % Saying Blanket Consent is Acceptable



\*Based on McNemar's pairwise test.

# Deliberation participants : % Saying Study-by-Study Consent is Acceptable



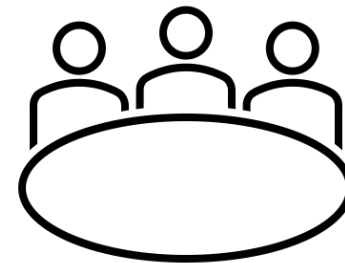
\*Based on McNemar's pairwise test.



**More important:** We found that participants had a **sophisticated understanding** of the ethical problems of biobank consent and **the complexity of balancing donor concerns while promoting research** important to the future of health care.

## **complexity of the problem**

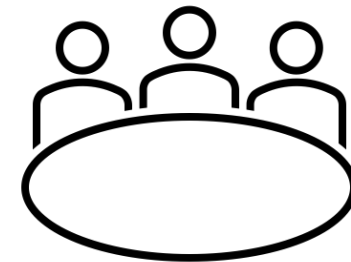
[ . . . ] everybody's got their own morals, their own values, their own ethics, and the challenge in this is how do you balance a steady flow of samples to preserve future research and future goals with being able to meet all those different values and all those different beliefs. How do you find that balance?



## concern about the conduct of science

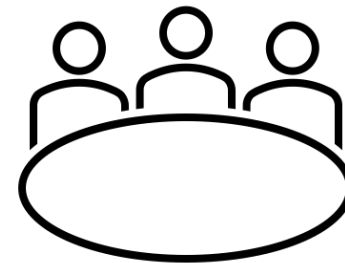
[. . . ] if you talk to a lot of people on the street, they will say, “Biobank.” That’s kind of like Dr. Frankenstein’s lab, you know, where they do all kind of weird things in there.

It’s not so much if we have a bunch of rogue scientists running around here that want to make 6-eared monsters and stuff like that. It’s just that we’re concerned. How could we put balances and checks to try to weed out the bad apples? That’s what I think our major concern is.



## **sensitivity to the need for trust in research and researchers**

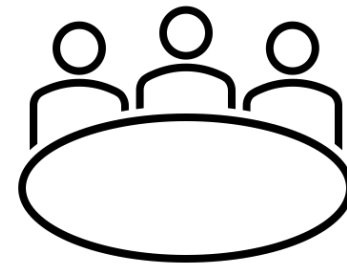
It's really important to have, in general, public trust, not just like say for instance one person, but if you, you know, damage the trust of your community, that definitely affects public opinion about other types of science and other types of research.





# Should biobanks care about the consent of donors? ?

- Biobanks should care
- Biobanks should not care
- It depends



## **“Should care”: Biobanks must take moral concerns into consideration (~ 50%)**

### **Pragmatic (utilitarian)**

[. . . ] **if they take those samples and they use it for things that are making people feel violated, they’re not going to donate anymore.** And eventually you’re not going to have a job. There will be no biobanks. You have to participate with peoples’ morals and beliefs, whether or not you feel strongly about them because they won’t participate.

### **Respect (Kantian)**

The best way is to actually treat people the way they want to be treated, and this biobank thing is exactly, I think, a case study on that. It’s not because . . . It’s easy for me to project and say, “Hey, I’d be okay with that. Once I donate something, I’m considering it gone.” This is me personally, right? [. . . ] But it’s not about me, right? **It’s about treating others the way they want to be treated.**

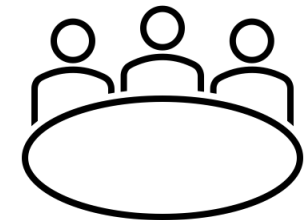


**“Should not care”: Biobanks should be free to use donation**

**(~ 30%)**

**It’s going to stop the research** and be very time-consuming for them to go back to you and get that permission.

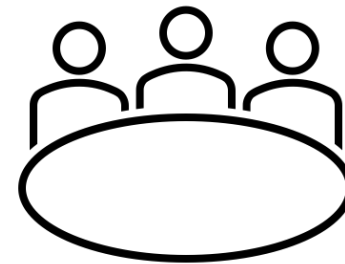
[. . . ] basically **every cure that we have today is done through . . . not biotech only but through study that’s taken from actual samples of bodies**. They cured polio [. . . ] Those are all done through studies. Look what they’ve done in our society today. We have people living into their eighties, nineties and even 100 is not unusual, all because of that.



## Should not care: trust in research and the motives of researchers

**I don't believe researchers are in their field to hurt people.** They are there to find answers and probably cures or maybe cures.

[I disagree with] trying to control a smart scientist for reasons . . . Well, some of it is religion. Some of it is just personal opinions. I think that's wrong. **Let them do their good work.**

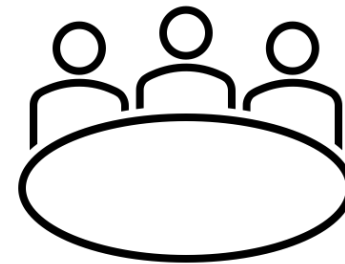




## Should not care: the morality of gift- giving

So you donate it, and they get to do what they want. I lost my right to object, I guess, I'd say at that point.

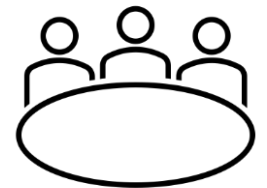
I kind of feel like once you donate it [. . . ] It would be more of a moral obligation of the people that are using it and hopefully they would do the right things with it . . .



# It depends...

I mean in the end, I'd like to think that ***most of us as humans want to contribute to society*** in a good way and help out our fellow ***man but, again, you can't leave behind those people who have really strong beliefs*** or opinions that were instilled on them probably since they were little.

there's got to be some freedom there or some way to approach it, you know, that when something that disastrous to the human community occurs, that ***we don't get in the way of the research***, but I'm ***not saying that we ignore everybody's moral beliefs*** either.



In sum

- NWIs matter
- Trust is important
- Consent policy should not be too broad or too narrow

The study was supported by grant  
R01 HG007172-01A1 from the  
National Human Genome Research  
Institute



# Thanks to colleagues

- Scott Y. H. Kim, MD, PhD
  - Department of Bioethics, NIH
- Tom Tomlinson, PhD
  - Michigan State University
- H. Myra Kim, ScD
  - Center for Statistical Consultation and Research, U of M
- Chris D. Krenz, BA
  - Center for Bioethics and Social Sciences in Medicine, U of M
- Kerry A. Ryan, MA
  - Center for Bioethics and Social Sciences in Medicine, U of M
- Nicole Lehpamer, MA
  - Department of Sociology, Michigan State University

The image features a black background densely populated with small, grey, stylized fish. These fish are simple in design, with a single dark line for a stripe and a small circle for an eye. In the lower right quadrant, a hand is visible, holding a yellow marker and drawing a much larger, yellow fish. This larger fish also has a dark stripe and a large eye, matching the style of the smaller fish. The text "So far so good?" is centered in the image in a white, sans-serif font.

So far so good?



# Act II: Why this is problematic

Reflections of a sociologist on empirical bioethics

# Scene I: Sociology and bioethics



# My Approach: *Sociology*

Berger



Mills



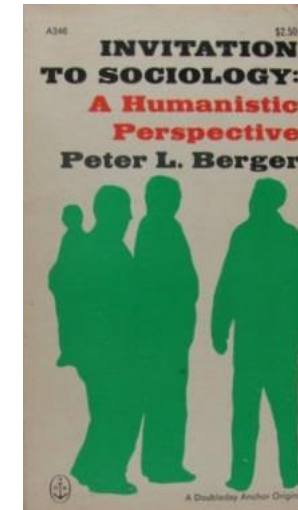
Becker

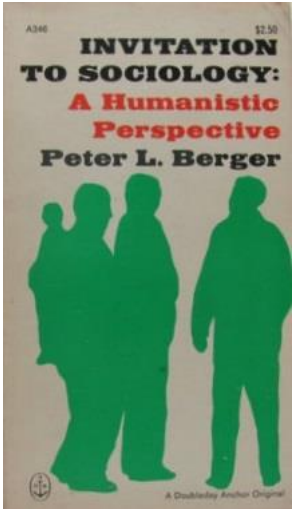


Act II: reflections of a sociologist of bioethics

# Why are there so few jokes about sociologists?

*“The dearth of jokes about sociologists indicates, of course, that they are not...part of the popular imagination...But it probably also indicates that there is a certain ambiguity in the images people have of them...”*

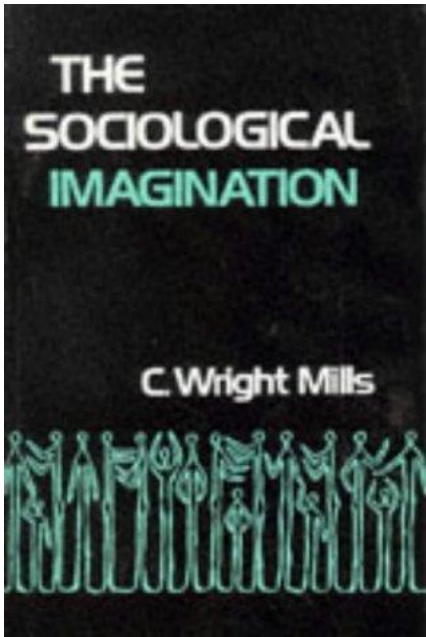




*“Sociology as a form of consciousness”*  
(RUDe)

- ❖ Relativizing
- ❖ Unrespectability
- ❖ Debunking





## A. Private troubles vs. public issues

An unemployed person v. unemployment rate

## B. Twin dangers of social research:

### 1. *Abstract empiricism*

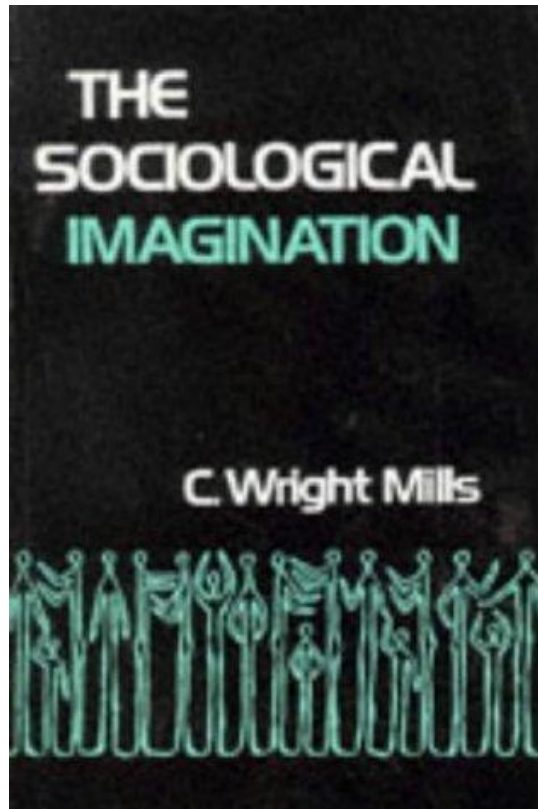
Description without understanding

### 2. *Grand theory*

‘Understanding’ without description



## The problem with 'abstract empiricism'



1959

The social scientist who spends his intellectual force on the details of power, class, and ideology is not transforming his work to outsidethe political conflicts and forces of his time. He is, at least indirectly, and in effect, distracting attention from issues of power and authority, they who distract attention from the structural realities of the society itself, accepts the full intellectual tasks of social science can merely of the powerful. The images and ideas produced by social scientists assume that structure. In fact, it is his job to make that structure may or may not be consistent with these prevailing images, but they explicit and to study it as a whole. (pp. 78-79)

By criticizing or debunking prevailing arrangements and rulers, they strip them of authority. (p. 80)

# The sociological approach to [bio]ethics

- Less than “grand theory” / but More than “abstracted empiricism”

***Otherwise***

# Otherwise

## Jane Kenyon



*I got out of bed  
on two strong legs.  
**It might have been  
otherwise.** I ate  
cereal, sweet  
milk, ripe, flawless  
peach. **It might  
have been otherwise.**  
I took the dog uphill  
to the birch wood.  
All morning I did  
the work I love.  
At noon I lay down  
with my mate. It might*

*At noon I lay down  
with my mate. **It might  
have been otherwise.**  
We ate dinner together  
at a table with silver  
candlesticks. **It might  
have been otherwise.**  
I slept in a bed  
in a room with paintings  
on the walls, and  
planned another day  
just like this day.  
But one day, I know,  
**it will be otherwise.***

# Therapeutic misconception: Moving beyond “abstract empiricism” in empirical bioethics

Appelbaum PS, Anatchkova M, Albert K, Dunn LB, Lidz CW. Therapeutic misconception in research subjects: development and validation of a measure. Clin Trials. 2012 Dec;9(6):748-61.

People in this study may not do as well as they would in usual treatment.

People in this study will do better than they would if they were just getting treatment as usual.<sup>a</sup>

Ordinary treatment could turn out to be better than the treatment people receive in this study.

My own treatment for (disorder) will almost certainly be better as a result of participating in this study.<sup>a</sup>

The reason I was asked to be in this study is that it will provide me with the best treatment available.<sup>a</sup>

The treatment I am getting by being in this study is the best treatment for me.<sup>a</sup>

There are other treatments I could get outside this study that might be just as good for me.

# Therapeutic misconception: Moving beyond “abstract empiricism” in empirical bioethics

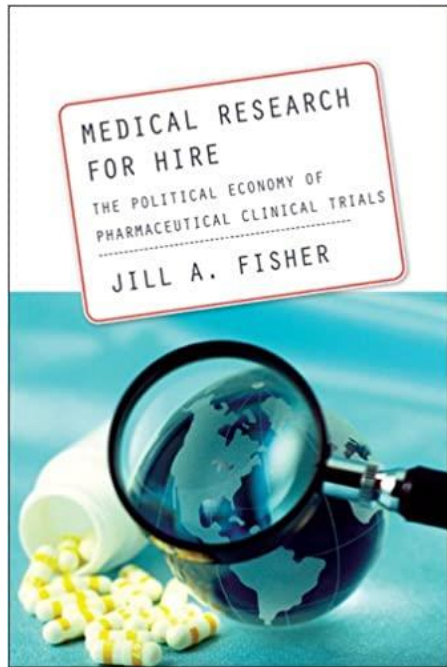
Henderson, G. E., et al. 2006. “Therapeutic Misconception in Early Phase Gene Transfer Trials.” *Soc Sci Med* 62: 239–53.

Three variables predict a subject’s TM score:

1. level of education,
2. disease type, and
3. communication by personnel about the likelihood of benefit.



# Therapeutic misconception: Moving beyond “abstract empiricism” in empirical bioethics



All those involved in clinical trials—pharmaceutical companies that must protect their data from the prying eyes of competitors, physicians who supplement their income by running drug trials out of their private practices, study coordinators who must find a way to balance their desire to care for their patient/subjects with market-based health-care goals, and research subjects who often see clinical trials as a way to get health care—are shaped by the historically situated organization of health care in 21st-century America.



# Scene II: Why do we do what we do?

## Why empirical ethics?

# A multiple choice question

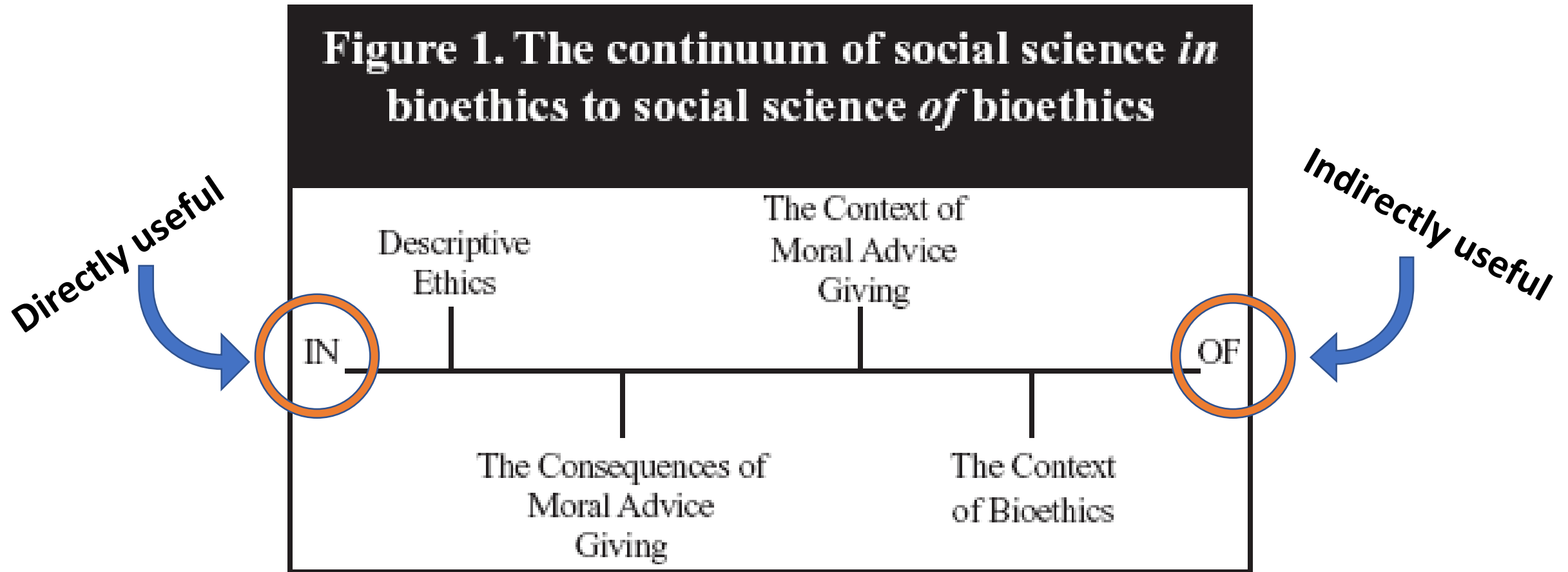
- a. To make the world a better place
- b. To hold normative bioethicists accountable
- c. Because we can get funding
- d. To build our CVs
- e. a. and b.
- f. c. and d.
- g. All of the above

# The import of prepositions

Robert Straus (1957): Sociology **of** and sociology **in** medicine

Raymond De Vries (2004): Sociology **of** and sociology **in** bioethics

With a bit more nuance:





# Conceptualizing the continuum: 'in' to 'of'

- ✓ *Descriptive*: Facts identify (determine?) values
- ✓ *Consequences*: Facts are useful in realizing values
- ✓ *Context*: Facts reveal how a society organizes values

...applied to the organization of bioethics:

perspective

THE HASTINGS CENTER  
**REPORT**

## The Prepositions of Bioethics

American Society **for** Bioethics and Humanities

President's Council **on** Bioethics

Kennedy Institute **of** Ethics

*American Journal of Bioethics*

International Association **of** Bioethics

The Program **in** Ethics in Science and Medicine

A plethora of centers **for** bioethics

The choice of **pre-position** reflects a certain disagreement—or perhaps confusion— among bioethicists about their place in medicine and science.

Act II: reflections of a sociologist of bioethics



# Scene III: How hard can it be?

How well do we do what we do?

# Four fallacies of empirical ethics

1: Anyone can do it

2: Quantitative research is not qualitative

3: Surveys can measure behavior

4: Qualitative research can (should?) be quantified

I'm a           \*\*           – *how hard can it be to do social research?*

\*\*Doctor

\*\*Philosopher

\*\*Nurse



# How hard can philosophy be?

A Critique of Pure Reason



# HOW HARD CAN IT BE TO **WRITE A SURVEY?**



- 1. Thou shalt avoid loaded questions or leading words
- 2. Thou shalt honor the ordering of questions
- 3. Thou shalt avoid non-specific questions
- 4. Thy question wording shall not be confusing or unfamiliar
- 5. Thou shalt not force respondents to answer
- 6. Thou shalt not adulterate your survey with non-exhaustive listings
- 7. Thou shalt use unbalanced listings skillfully
- 8. Thou shalt abolish double barreled questions
- 9. Honor thy dichotomous questions
- 10. Thou shalt use long questions wisely

# HOW HARD CAN IT BE TO DO SOME **INTERVIEWS/FOCUS GROUPS OR OBSERVATIONS?**



# Mistakes In Focus Groups

We need to do focus groups to get insights into why consumers dislike our product.

There is no budget, but James could be the moderator. We could do it in the lobby.

We need to hire an impartial moderator and be in a neutral space.

I don't have moderator experience. What if the group gets out of control?

I would handle it like I do in my family reunions. When it gets too loud, I blow a whistle and tell them to shut up.



Relevantinsights.com

<https://www.relevantinsights.com/articles/focus-group-mistakes/>



# Fallacy (2)

## Quantitative research is not qualitative

- There is no one here, just us *numbers* (odds ratios or p values!)

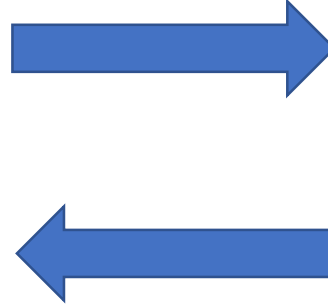


- But numbers need **interpretation**, and they are manipulated by people who *eliminate outliers, create indexes, create models*

# Fallacy (3)

## Surveys can measure behavior

We assume that survey questions are “actions in miniature:”



These questions are about experiences related to **who you are**. This includes both how you describe yourself and how others might describe you. For example, your skin color, ancestry, nationality, religion, gender, sexuality, age, weight, disability or mental health issue, and income.

**Because of who you are, have you...**

	Never	Yes, but not in the past year	Yes, once or twice in the past year	Yes, many times in the past year
1. Heard, saw, or read others joking or laughing about you (or people like you)				
2. Been treated as if you are unfriendly, unhelpful, or rude				
3. Been called names or heard/saw your identity used as an insult				
4. Been treated as if others are afraid of you				
5. Been stared or pointed at in public				
6. Been told that you should think, act, or look more like others				
7. Heard that you or people like you don't belong				
8. Asked inappropriate, offensive, or overly personal questions				
9. Been treated as if you are less smart or capable than others				

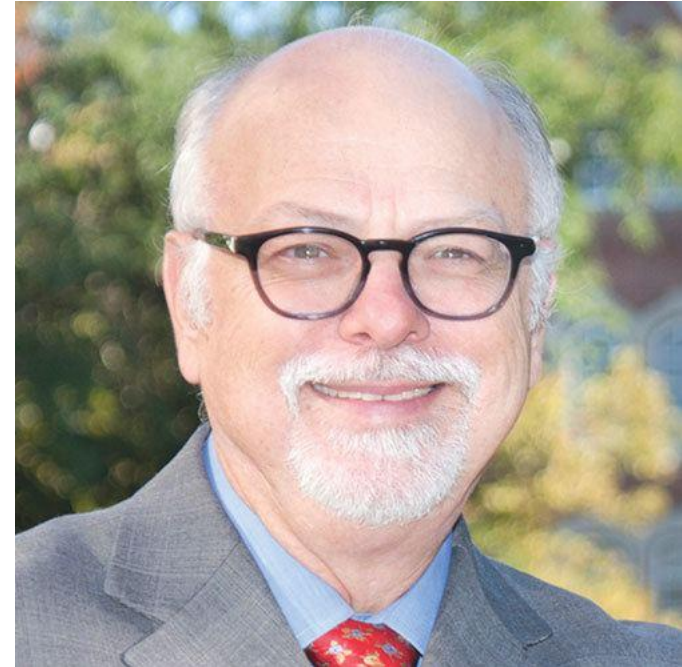
Irwin Deutscher, *What We Say/What We Do*. Scott Foresman & Co., 1973

## Attitudes vs. Actions

Author(s): Richard T. LaPiere

Source: *Social Forces*, Vol. 13, No. 2 (Dec., 1934), pp. 230-237

Published by: Oxford University Press



Beginning in 1930 and continuing for two years thereafter, I had the good fortune to travel rather extensively with a young Chinese student and his wife...In something like ten thousand miles of motor travel, twice across the United States, up and down the Pacific Coast, we met definite rejection from those asked to serve us just once. **We were received at 66 hotels, auto camps, and "Tourist Homes," refused at one. We were served in 184 restaurants and cafes scattered throughout the country and treated with what I judged to be more than ordinary consideration in 72 of them.**

What I am trying to say is **that in only one out of 251 instances in which we purchased goods or services necessitating intimate human relationships did the fact that my companions were Chinese adversely affect us.**

Yet the existence of this prejudice [against Asians], very intense, is proven by a conventional "'attitude" study. To provide a comparison of symbolic reaction to symbolic social situations with actual reaction to real social situations, I "questionnaired" the establishments which we patronized during the two-year period.





**Six months were permitted to lapse between the time I obtained the overt reaction and the symbolic.** It was hoped that the effects of the actual experience with Chinese guests, adverse or otherwise, would have faded during the intervening time. To the hotel or restaurant a questionnaire was mailed with an accompanying letter purporting to be a special and personal plea for response. The questionnaires all asked the same question, **“will you accept members of the Chinese race as guests in your establishment?”**

With persistence, completed **replies were obtained from 128 of the establishments** we had visited; **81 restaurants and cafes and 47 hotels...** **In response to the relevant question 92 per cent of the former and 91 per cent of the latter replied "No."** The remainder replied "Uncertain; depend upon circumstances."

*From the woman proprietor of a small auto-camp I received the only "Yes," accompanied by a chatty letter describing the nice visit she had had with a Chinese gentleman and his sweet wife during the previous summer.*



La Piere: "Sitting at my desk in California I can predict with a high degree of certainty what an "average" businessman in an average Midwestern city will reply to the question, "Would you engage in intercourse with a prostitute in a Paris brothel?" Yet no one, least of all the man himself, can predict what he would actually do should he by some misfortune, find himself face to face with the situation in question.

# Also true for *vignettes* and “*design bioethics*”

THE AMERICAN JOURNAL OF BIOETHICS  
2021, VOL. 21, NO. 6, 37–50  
<https://doi.org/10.1080/15265161.2020.1863508>



TARGET ARTICLE

OPEN ACCESS Check for updates

## Design Bioethics: A Theoretical Framework and Argument for Innovation in Bioethics Research

Gabriela Pavarini<sup>a</sup> , Robyn McMillan<sup>a,b</sup>, Abigail Robinson<sup>a</sup>, and Ilina Singh<sup>a</sup>

<sup>a</sup>University of Oxford; <sup>b</sup>Abertay University

### ABSTRACT

Empirical research in bioethics has developed rapidly over the past decade, but has largely eschewed the use of technology-driven methodologies. We propose “design bioethics” as an area of conjoined theoretical and methodological innovation in the field, working across bioethics, health sciences and human-centred technological design. We demonstrate the potential of digital tools, particularly purpose-built digital games, to align with theoretical frameworks in bioethics for empirical research, integrating context, narrative and embodiment in moral decision-making. Purpose-built digital tools can engender situated engagement with bioethical questions; can achieve such engagement at scale; and can access groups traditionally under-represented in bioethics research and theory. If developed and used with appropriate rigor, tools motivated by “design bioethics” could offer unique insights into new and familiar normative and empirical issues in the field.

### KEYWORDS

Design bioethics; empirical bioethics; epistemology; games; videogames; young people

## Fallacy (4)

We should quantify qualitative research

### The quantification of qualitative research

- Interrater reliability
- Counting responses v. looking for meaning
- Counting v. analyzing

## Fallacy (4)

Qualitative research can (should?) be quantified





# Scene IV: Ought's and is's

Can empirical data be used to determine what is right?

Can there be an 'ought' without an 'is'?



Can you get an ought from an is?

You cannot get an *ought* from an *ought*

You cannot get an *is* from an *is*

C. Leget et al., 'Nobody Tosses A Dwarf!' The Relation Between the empirical and the Normative Reexamined, *Bioethics*, 2009.

# You cannot get an ought from an ought

*Norms do not come from nowhere. Norms are embedded in culture and in social structures and in language. The idea that an ought is some free-floating, non-empirical, detached value that has no connection to the empirical world is wrong.*

# You cannot get an is from an is

*Facts are embedded in normative ideas. When social scientists initiate an explorative study, they choose a topic based in their ideas about what is important and what is not important. They analyze their data based on their (often unacknowledged) values.*

C. Leget et al., 'Nobody Tosses A Dwarf!' The Relation Between the Empirical and the Normative Reexamined, *Bioethics*, 2009.



Act III: *Is there a way forward?*

## Back to where we began:

- Can empirical data be used to settle normative questions?
- Should the demos have input into solving moral problems – like the collection and use of biospecimens – created by new technologies?
- If yes, how can we collect trustworthy data?  
*Surveys? Interviews? Focus groups?*  
*Scenarios? Observation?*

Back to where  
we began:

The creation of sustainable and ethical policies  
in health care and the life sciences...

*....is not easy:*

Surveys and interviews:

are **difficult to do well** and get  
**uniformed and unconsidered** opinion,

**BUT**

***Does deliberation put the demos in democratic  
debate and policy making?***

# Is deliberation the answer?

The problems with deliberation:

- Who is asking?

*Funders/Investigators*

- Who is talking?

*The problem of representation*

- Who is listening?

*The uses of deliberation*





If we want to put the demos in ethics policy

- Reflection/sociological vision
- Multiple methods (frenemies)

## Pandemic preparedness and COVID-19: an exploratory analysis of infection and fatality rates, and contextual factors associated with preparedness in 177 countries, from Jan 1, 2020, to Sept 30, 2021

COVID-19 National Preparedness Collaborators



Measures of trust in the government and interpersonal trust, as well as less government corruption, had larger, statistically significant associations with lower standardised infection rates... **If these modelled associations were to be causal, an increase in trust** of governments such that all countries had societies that attained at least the amount of trust in government or interpersonal trust measured in Denmark, which is in the 75th percentile across these spectrums, might have **reduced global infections** by 12·9% (5·7–17·8) for government trust and 40·3% (24·3–51·4) for interpersonal trust.



## **Jean Rhys, *Paris Review* interview (1979)**

*All of writing is a huge lake. There are great rivers that feed the lake, like Tolstoy or Dostoyevsky. And then there are mere trickles, like Jean Rhys. All that matters is feeding the lake. I don't matter. The lake matters. You must keep feeding the lake.*

summary



RG de Vries  
Center for Bioethics and Social Sciences in Medicine  
University of Michigan  
rdevries@umich.edu  
**@agoodbirth**



MEDICAL SCHOOL

CENTER FOR BIOETHICS & SOCIAL SCIENCES IN MEDICINE

UNIVERSITY OF MICHIGAN