GEORGETOWN UNIVERSITY

UNIVERSITY of WASHINGTON

MAX PLANCK INSTITUTE
FOR SOFTWARE SYSTEMS

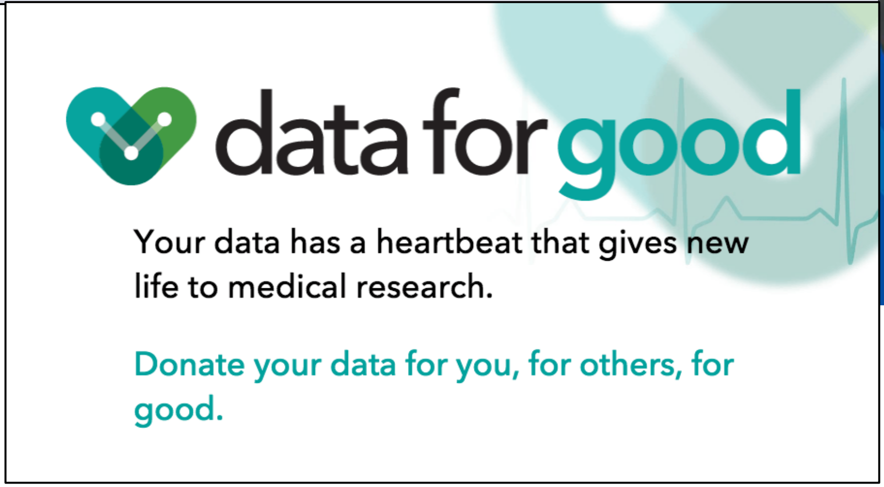
UNIVERSITY OF
WATERLOO

# The Role of Privacy Guarantees in Voluntary Donation of Private Health Data for Altruistic Goals

*Ruizhe Wang, Roberta De Viti, Aarushi Dubey, Elissa M. Redmiles*

*February 2026*

# Health Research & Data



Your data has a heartbeat that gives new life to medical research.

Donate your data for you, for others, for good.

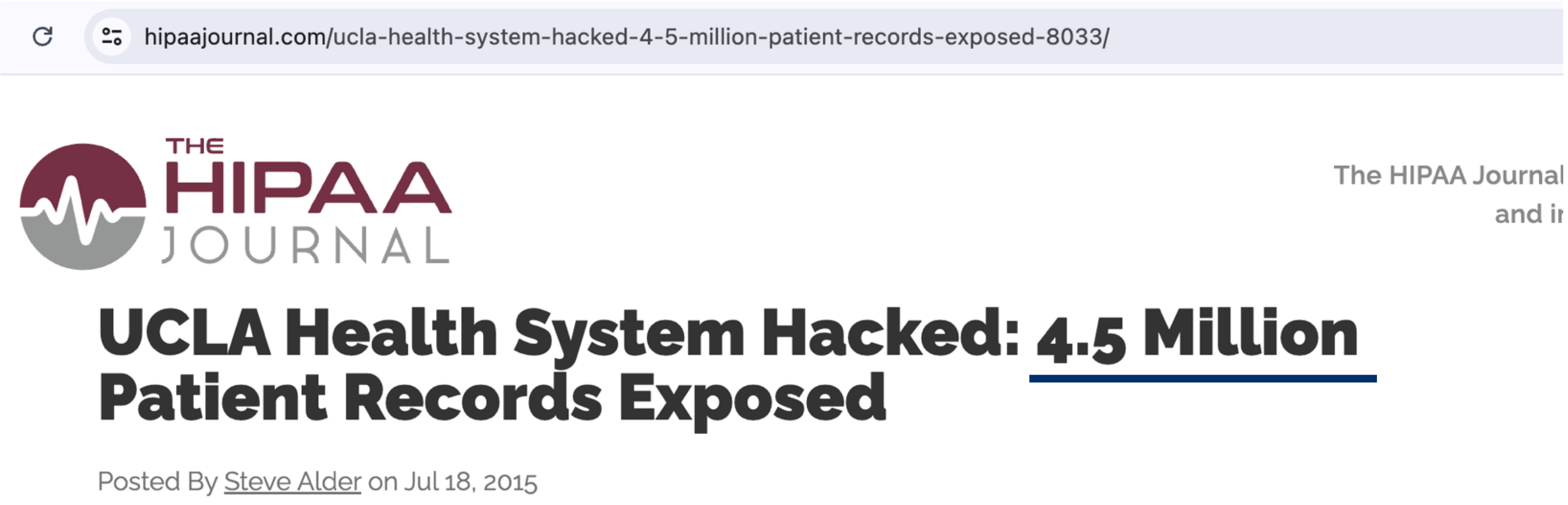
DONATING MEDICAL DATA CAN SAVE LIVES

LIGIA KORNOWSKA

Managing Director of the Polish Hospital Federation, leader of „AI Coalition in Healthcare" for Poland, Chair of the Board Donate your Data Foundation and Data Lake

https://penndonateyourdata.com/
https://d3.harvard.edu/platform-digit/submission/patientslikeme-crowdsourcing-patient-platform-for-healthcare/
https://eithealth.eu/news-article/innostars-talks-donating-medical-data-can-save-lives/

# Health Research & Data



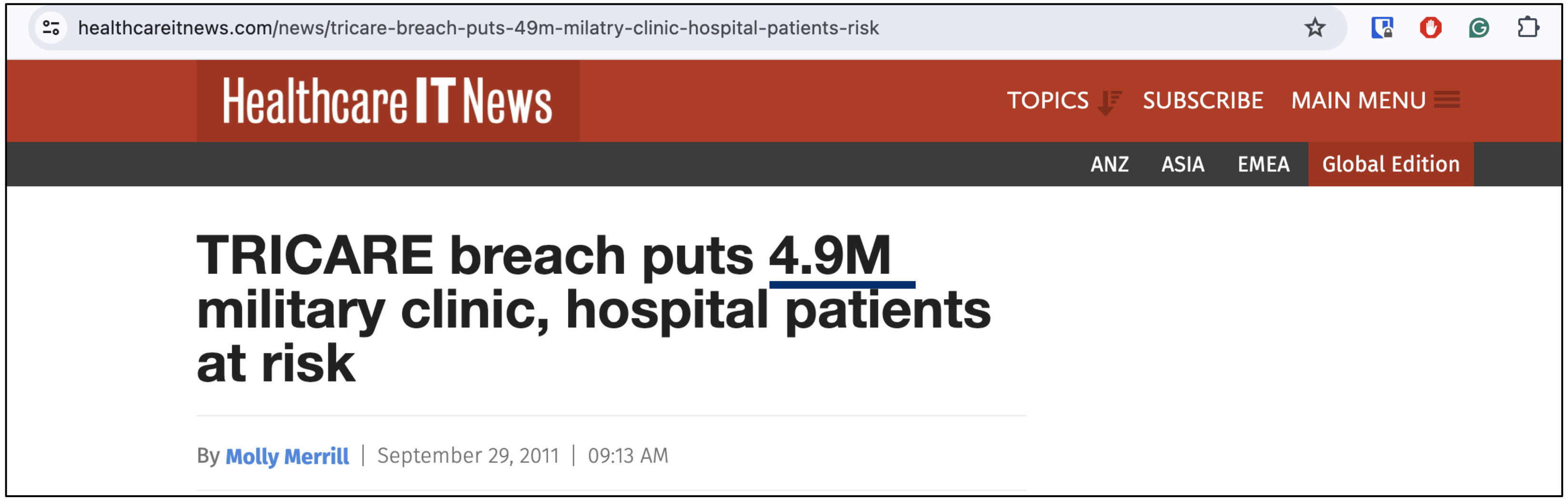
hipaajournal.com/ucla-health-system-hacked-4-5-million-patient-records-exposed-8033/

THE HIPAA JOURNAL

The HIPAA Journal
and ir

## UCLA Health System Hacked: 4.5 Million Patient Records Exposed

Posted By Steve Alder on Jul 18, 2015

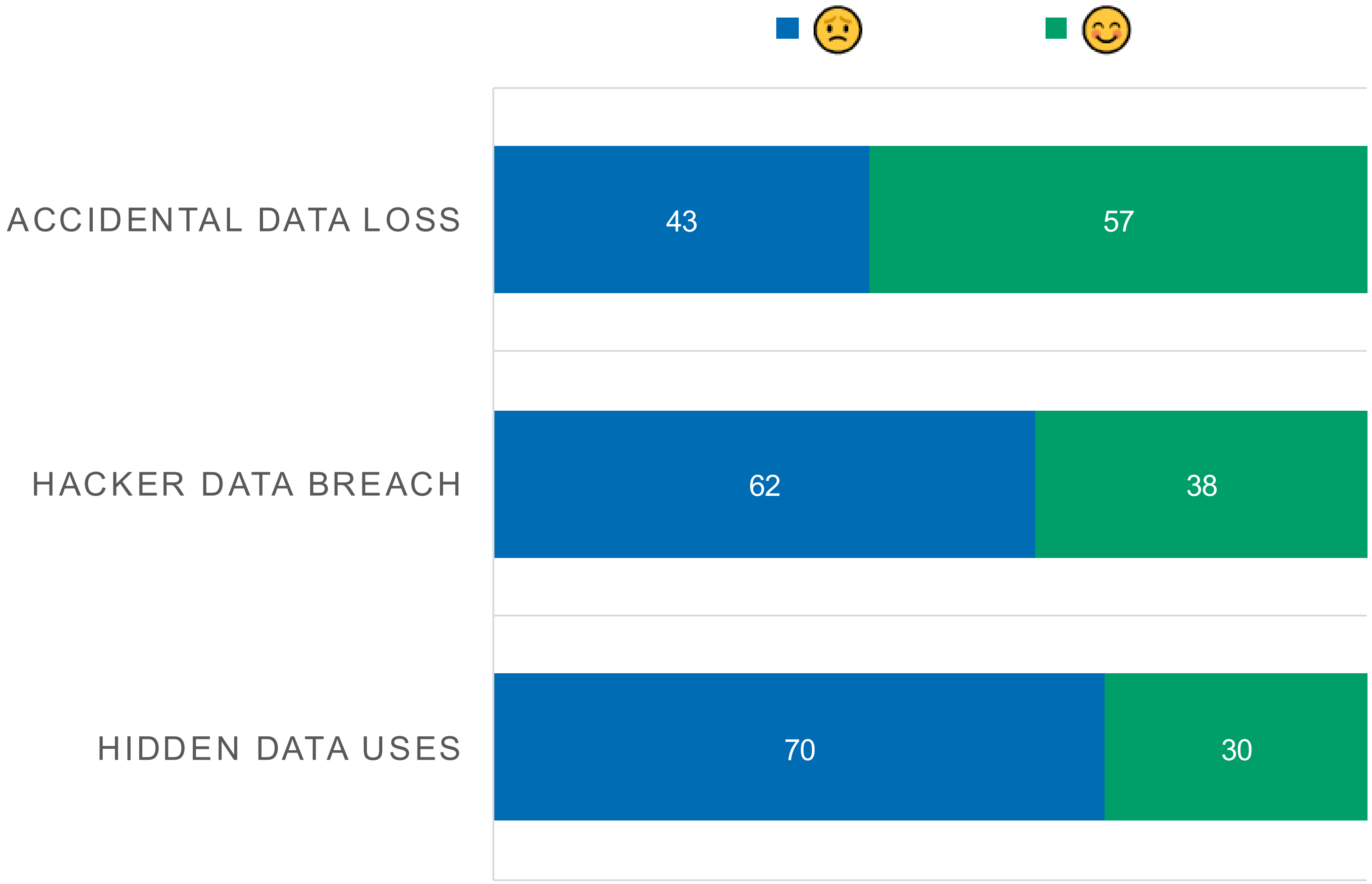


healthcareitnews.com/news/tricare-breach-puts-49m-milatry-clinic-hospital-patients-risk

## TRICARE breach puts 4.9M military clinic, hospital patients at risk

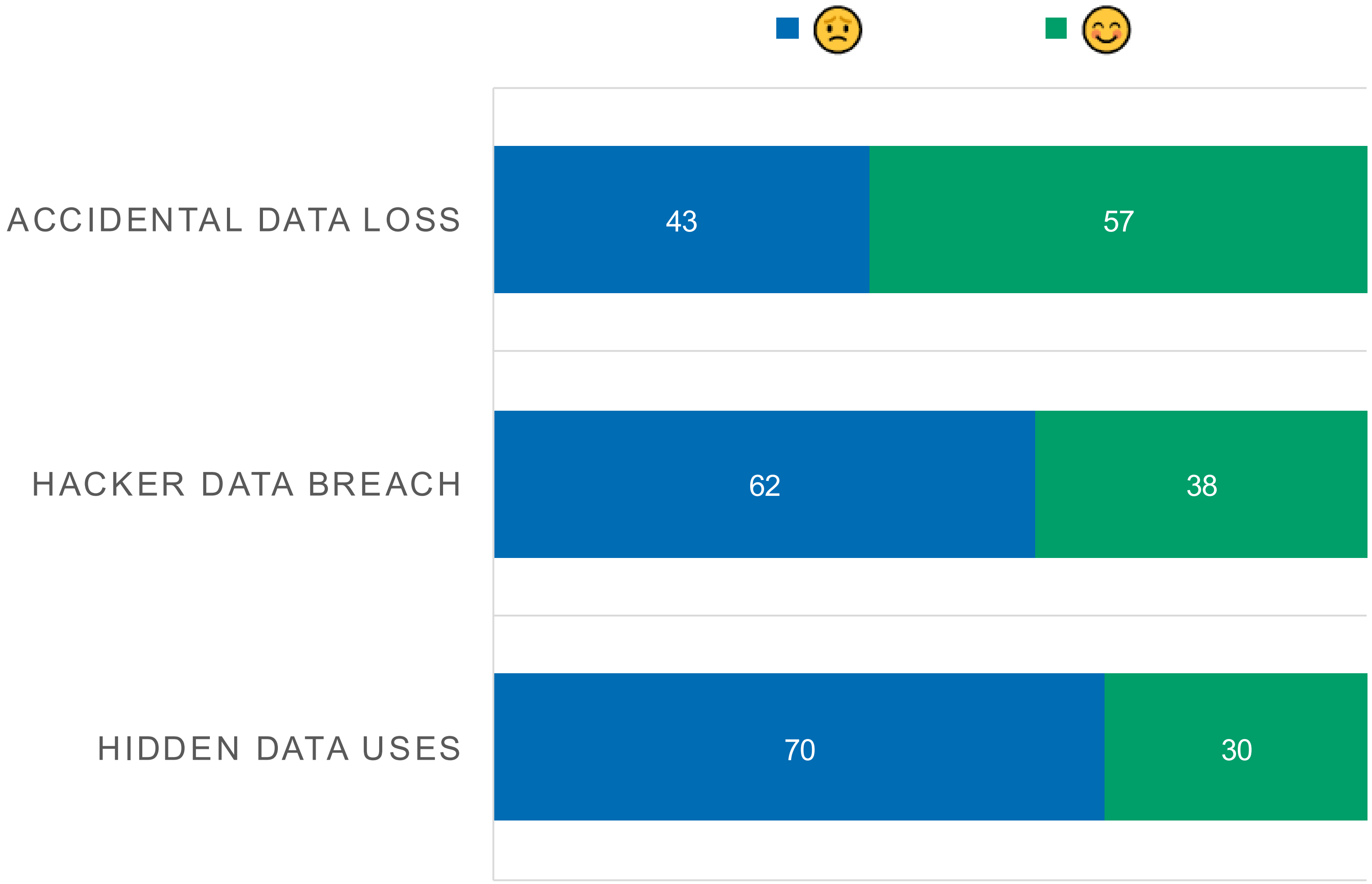
By Molly Merrill | September 29, 2011 | 09:13 AM

# Privacy Concerns in Data Donation



https://research.hscni.net/sites/default/files/G.Robinson_Report_9_June_17.pdf

# Privacy Concerns in Data Donation



Data Storage [14,15]

Data Processing [16-22]

ML Training [23,24]

https://research.hscni.net/sites/default/files/G.Robinson_Report_9_June_17.pdf

# From Technology to Donation

**More protection → More data donation ?**

# From Technology to Donation

**More protection → More data donation ?**

**RQ1** **Do users understand and expect the protections?**

# From Technology to Donation

More **protection** → More **data donation** ?

**RQ1** Do users understand and expect the protections?

**RQ2** Are protections make users more willing to donate?

# From Technology to Donation

**More protection → More data donation ?**

**We explore:**

# From Technology to Donation

More protection → More data donation ?

**We explore:**

PG1 **Anonymization:** [93-95]
data is not linkable to owner

# From Technology to Donation

**More protection → More data donation ?**

**We explore:**

**PG1** **Anonymization:** [93-95]
data is not linkable to owner

**PG2** **Access Control:** [4, 96-98]
data is accessible to authorized people

# From Technology to Donation

**More protection → More data donation ?**

**We explore:**

**PG1** **Anonymization:** [93-95]
data is not linkable to owner

**PG2** **Access Control:** [4, 96-98]
data is accessible to authorized people

**PG3** **Data Expiration:** [99-101]
data is discarded after a set time

# From Technology to Donation

More protection ⟶ More data donation ?

**We explore:**

**PG1** **Anonymization:** [93-95]
data is not linkable to owner

**PG2** **Access Control:** [4, 96-98]
data is accessible to authorized people

**PG3** **Data Expiration:** [99-101]
data is discarded after a set time

**PG4** **Purpose Restriction:** [24,102]
data is only used for stated purpose

# From Technology to Donation

**More protection → More data donation ?**

**We explore:**

PG1 **Anonymization:** [93-95]
data is not linkable to owner

PG2 **Access Control:** [4, 96-98]
data is accessible to authorized people

PG3 **Data Expiration:** [99-101]
data is discarded after a set time

PG4 **Purpose Restriction:** [24,102]
data is only used for stated purpose

AG1 **Expert Auditing:** [103-104]
have an external expert to verify

# From Technology to Donation

**More protection → More data donation ?**

**We explore:**

**PG1** **Anonymization:** [93-95]
data is not linkable to owner

**PG2** **Access Control:** [4, 96-98]
data is accessible to authorized people

**PG3** **Data Expiration:** [99-101]
data is discarded after a set time

**PG4** **Purpose Restriction:** [24,102]
data is only used for stated purpose

**AG1** **Expert Auditing:** [103-104]
have an external expert to verify

**AG2** **Self Auditing:** [105-106]
anyone can verify

# From Technology to Donation

**More protection → More data donation ?**

**We explore:**

PG1 **Anonymization:** [93-95]
data is not linkable to owner

PG2 **Access Control:** [4, 96-98]
data is accessible to authorized people

PG3 **Data Expiration:** [99-101]
data is discarded after a set time

PG4 **Purpose Restriction:** [24,102]
data is only used for stated purpose

AG1 **Expert Auditing:** [103-104]
have an external expert to verify

AG2 **Self Auditing:** [105-106]
anyone can verify

Collection Entity **For-Profit** or **Non-Profit:** [6, 45]

# From Technology to Donation

**More protection → More data donation ?**

**We explore:**

- **PG1** **Anonymization:** [93-95]
  data is not linkable to owner
- **PG2** **Access Control:** [4, 96-98]
  data is accessible to authorized people
- **PG3** **Data Expiration:** [99-101]
  data is discarded after a set time
- **PG4** **Purpose Restriction:** [24,102]
  data is only used for stated purpose

---

- **AG1** **Expert Auditing:** [103-104]
  have an external expert to verify
- **AG2** **Self Auditing:** [105-106]
  anyone can verify

---

- **Collection Entity** **For-Profit** or **Non-Profit:** [6, 45]
- **Egocentricity** **Whether respondents or their close relatives have the disease :** [6,46-47,110-111]

# Simulated Donation Scenario

Imagine that a Collection Entity wants to develop a new treatment for Disease (Egocentricity). They need medical data from people with and without Disease (Egocentricity) to develop the treatment. They ask you to donate your medical record to help develop the treatment.

# Simulated Donation Scenario

Imagine that a Collection Entity wants to develop a new treatment for Disease (Egocentricity). They need medical data from people with and without Disease (Egocentricity) to develop the treatment. They ask you to donate your medical record to help develop the treatment.

The Collection Entity uses a privacy-preserving technology to ensure that your data is

# Simulated Donation Scenario

Imagine that a **Collection Entity** wants to develop a new treatment for **Disease (Egocentricity).** They need medical data from people with and without **Disease (Egocentricity)** to develop the treatment. They ask you to donate your medical record to help develop the treatment.

The **Collection Entity** uses a privacy-preserving technology to ensure that your data is

**One or no PG**
deleted after a set period of time. You will be able to choose from a list of time period options how long your data will be stored.

# Simulated Donation Scenario

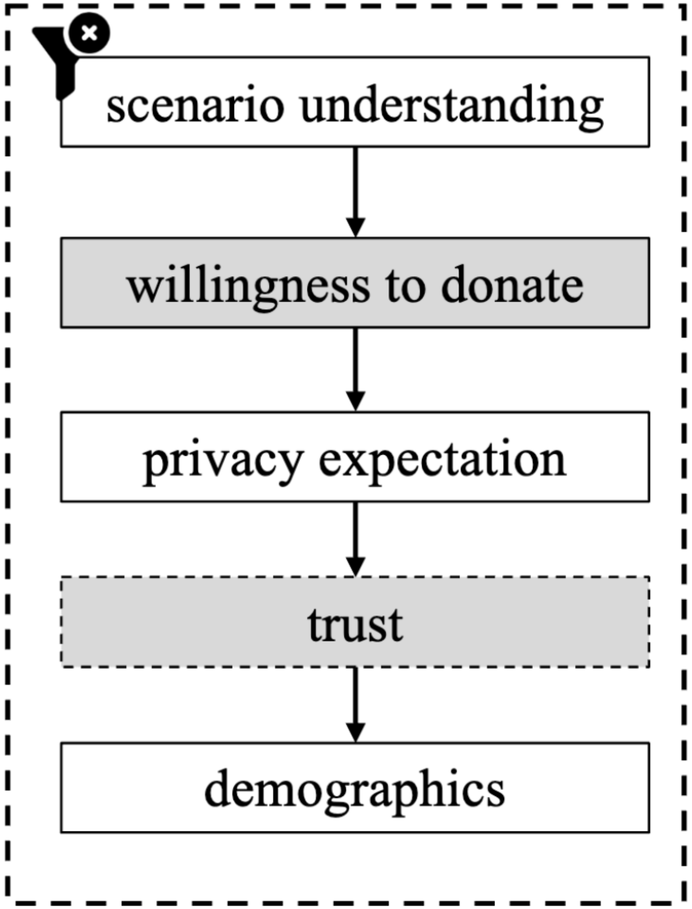
Imagine that a **Collection Entity** wants to develop a new treatment for **Disease (Egocentricity).** They need medical data from people with and without **Disease (Egocentricity)** to develop the treatment. They ask you to donate your medical record to help develop the treatment.

The **Collection Entity** uses a privacy-preserving technology to ensure that your data is

**One or no PG**
deleted after a set period of time. You will be able to choose from a list of time period options how long your data will be stored.

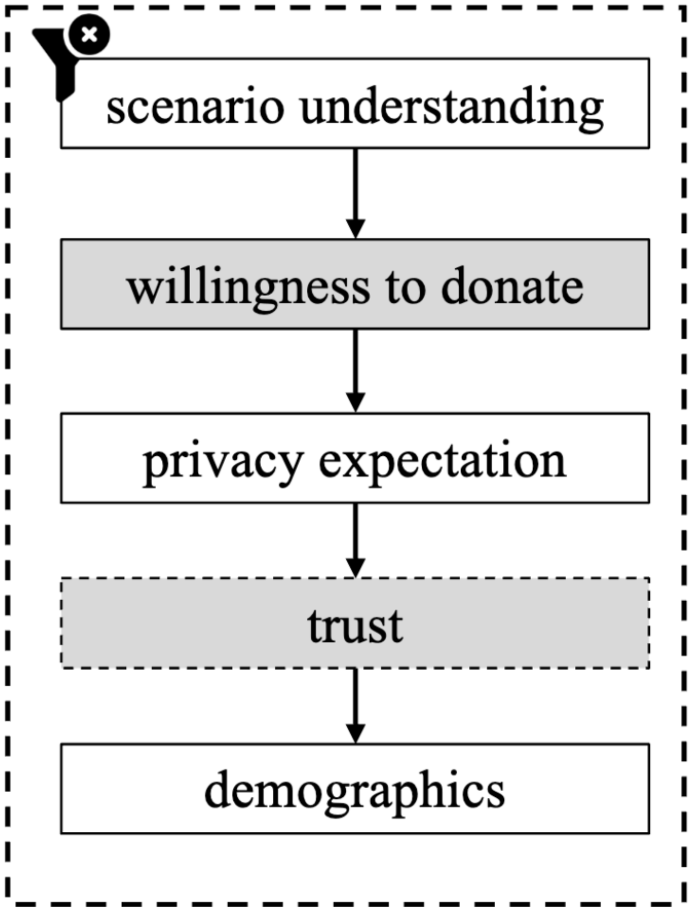
**One or no AG**
Anyone interested, including you and experts you trust, will be able to verify that the privacy-preserving technology is working as described. Anyone, including you and experts you trust, can post their verification results publicly.

# Data Collection



survey questions

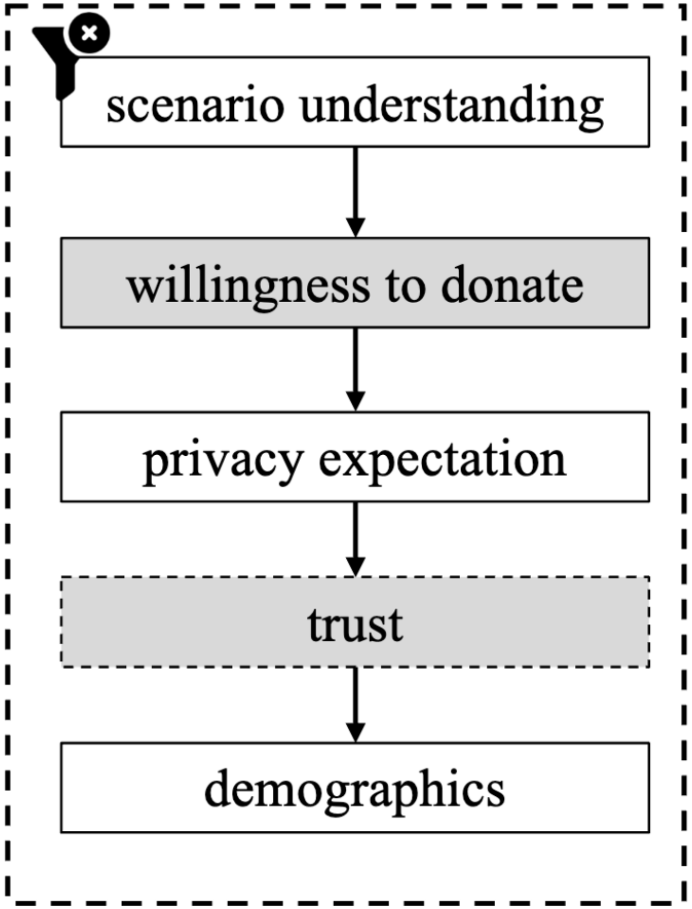
# Data Collection



survey questions

Filter out participants do not understand the text

# Data Collection



scenario understanding

willingness to donate

privacy expectation

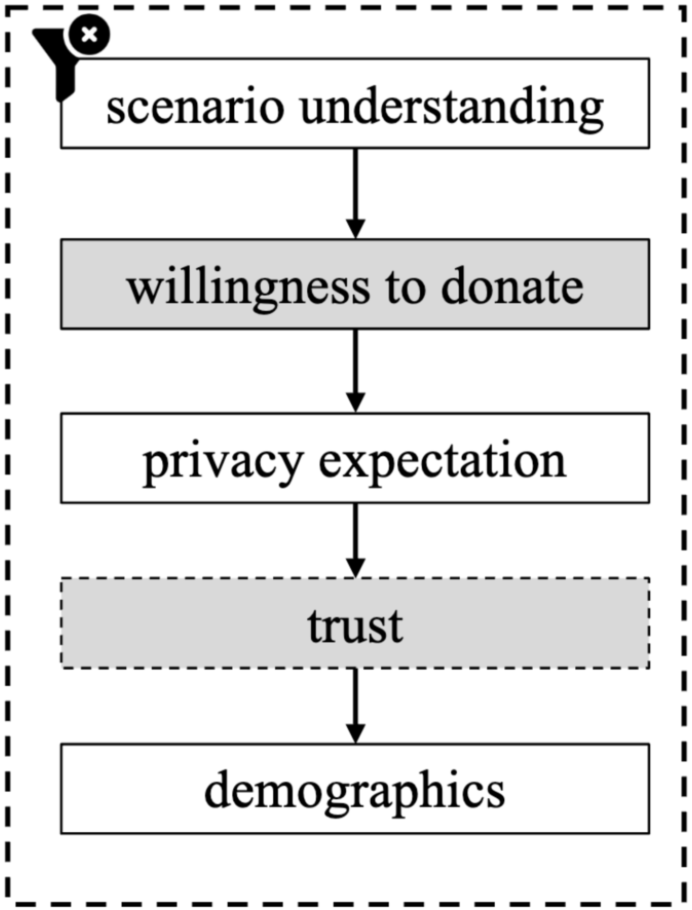
trust

demographics

survey questions

Filter out participants do not understand the text ← Cognitive Interviews ← Pilot Study

# Data Collection

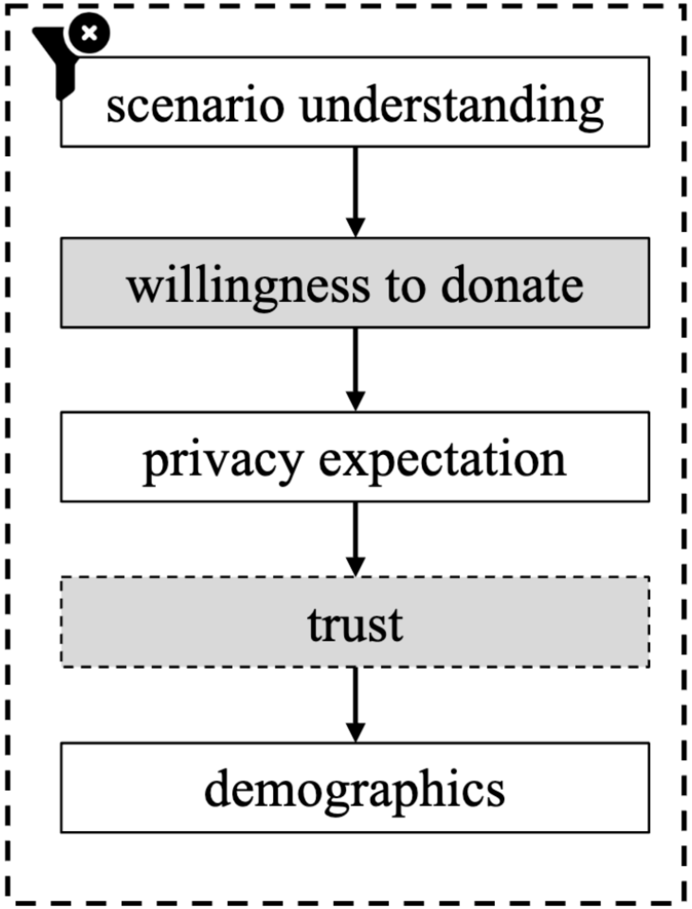


survey questions

Filter out participants do not understand the text ← Cognitive Interviews ← Pilot Study

**RQ2** Are protections make users more willing to donate?

# Data Collection



survey questions

Filter out participants do not understand the text

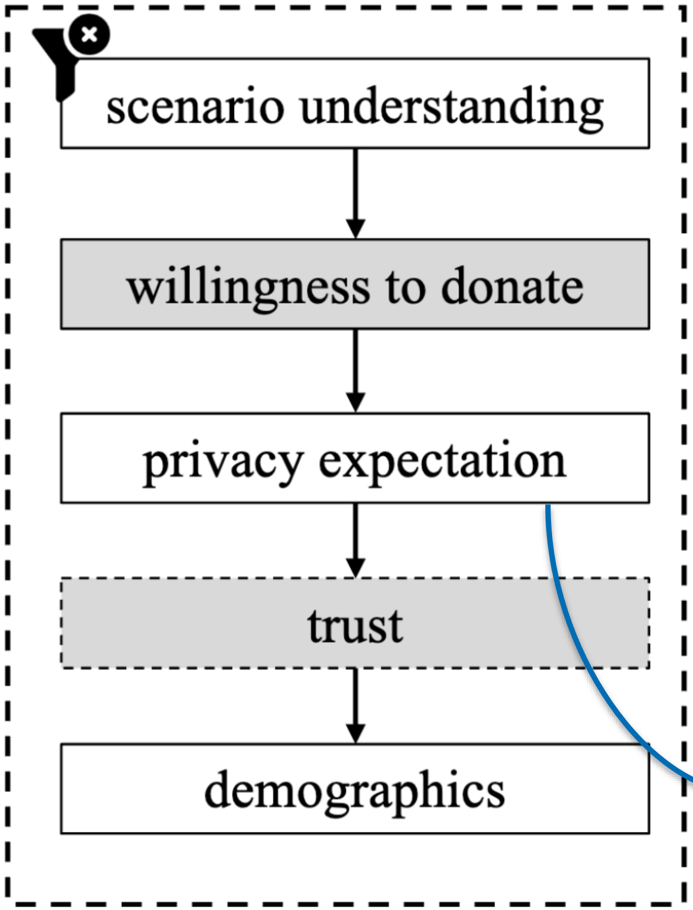
Cognitive Interviews

Pilot Study

**RQ2** Are protections make users more willing to donate?

**RQ1** Do users expect the protections?

# Data Collection



survey questions

Filter out participants do not understand the text ← Cognitive Interviews ← Pilot Study

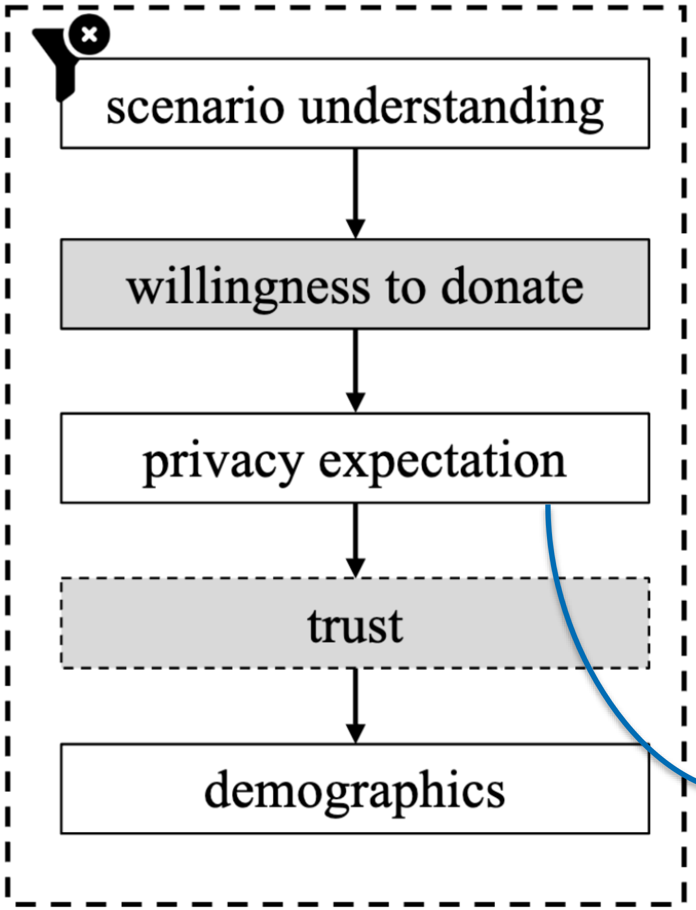
**RQ2** Are protections make users more willing to donate?

**RQ1** Do users expect the protections?

How likely do you think the following will occur?

The donated medical record will be deleted at a set point in time.

# Data Collection



scenario understanding

willingness to donate

privacy expectation

trust

demographics

survey questions

Filter out participants do not understand the text ← Cognitive Interviews ← Pilot Study

**RQ2** Are protections make users more willing to donate?

**RQ1** Do users expect the protections?

How likely do you think the following will occur?

The donated medical record will be deleted at a set point in time.

| | PG 1 | PG 2 | PG 3 | PG 4 | AG 1 | AG 2 |
|---|---|---|---|---|---|---|
| Q1 | 😊 | | | | | |
| Q2 | | 😊 | | | | |
| Q3 | | | 😊 | | | |
| Q4 | | | | 😊 | | |
| Q5 | | | | | 😊 | |
| Q6 | | | | | | 😊 |

# Sampling

# Sampling

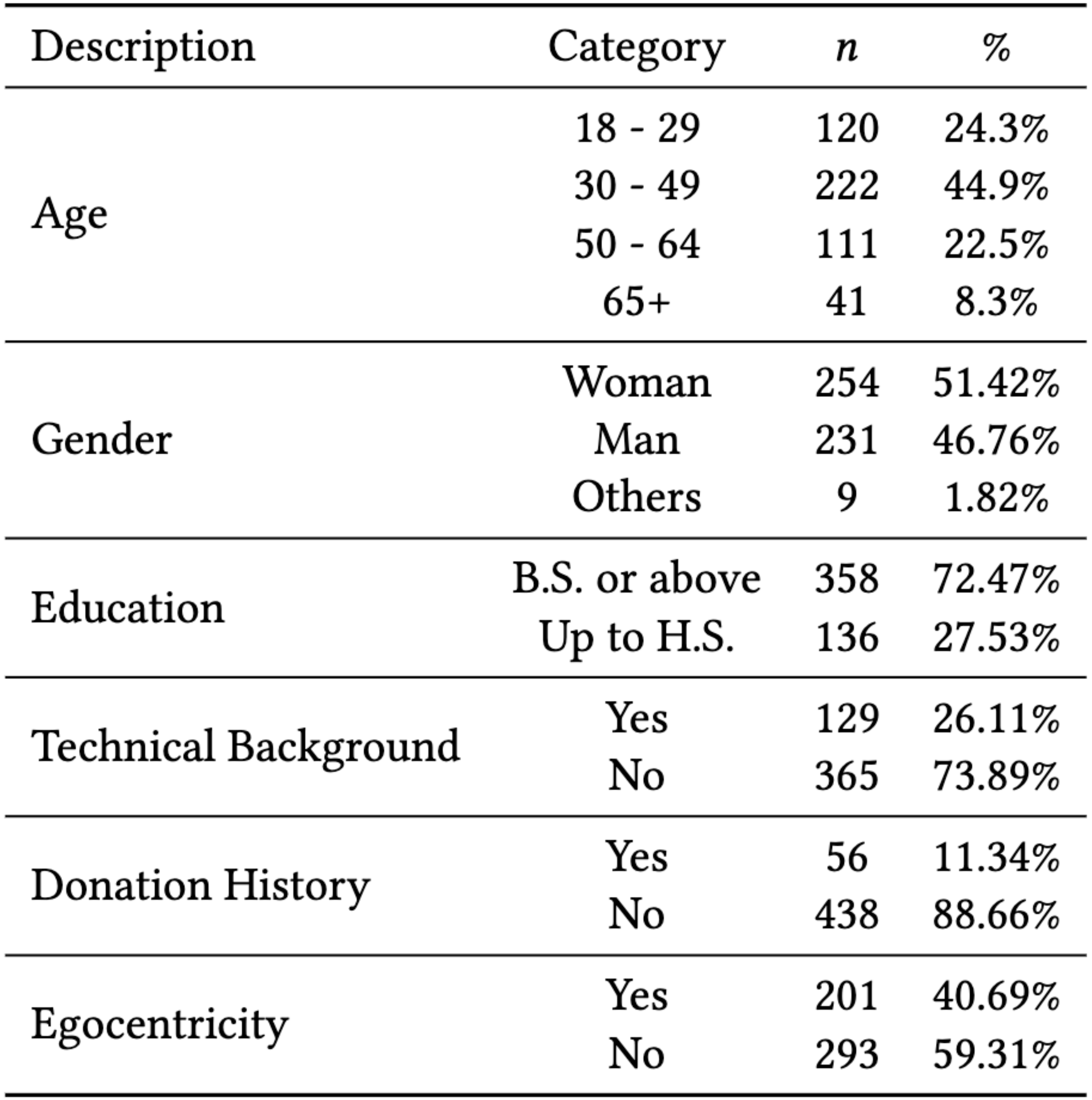
Participants recruited from Prolific

- gender-balance; US based
- $1.2 compensation
- 5:56 mins completion time
- 560 participants in total
- 494 respondents for analysis

# Sampling

Participants recruited from Prolific

- gender-balance; US based
- $1.2 compensation
- 5:56 mins completion time
- 560 participants in total
- 494 respondents for analysis



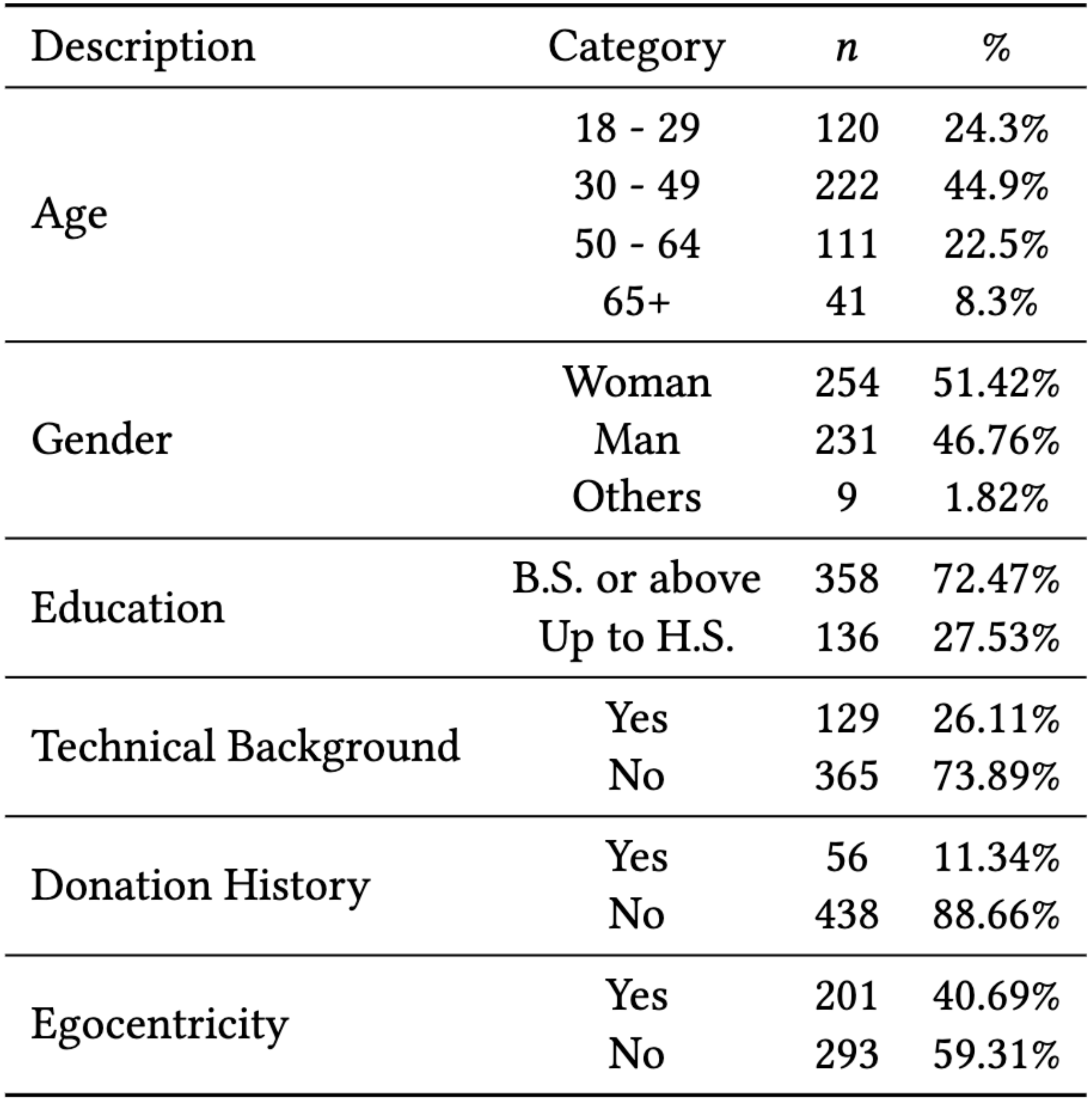
| Description | Category | *n* | % |
|---|---|---|---|
| Age | 18 - 29 | 120 | 24.3% |
| | 30 - 49 | 222 | 44.9% |
| | 50 - 64 | 111 | 22.5% |
| | 65+ | 41 | 8.3% |
| Gender | Woman | 254 | 51.42% |
| | Man | 231 | 46.76% |
| | Others | 9 | 1.82% |
| Education | B.S. or above | 358 | 72.47% |
| | Up to H.S. | 136 | 27.53% |
| Technical Background | Yes | 129 | 26.11% |
| | No | 365 | 73.89% |
| Donation History | Yes | 56 | 11.34% |
| | No | 438 | 88.66% |
| Egocentricity | Yes | 201 | 40.69% |
| | No | 293 | 59.31% |

# Sampling

Participants recruited from Prolific

- gender-balance; US based
- $1.2 compensation
- 5:56 mins completion time
- 560 participants in total
- 494 respondents for analysis

Is your work or degree relevant to CS?



| Description | Category | *n* | % |
|---|---|---|---|
| Age | 18 - 29 | 120 | 24.3% |
| | 30 - 49 | 222 | 44.9% |
| | 50 - 64 | 111 | 22.5% |
| | 65+ | 41 | 8.3% |
| Gender | Woman | 254 | 51.42% |
| | Man | 231 | 46.76% |
| | Others | 9 | 1.82% |
| Education | B.S. or above | 358 | 72.47% |
| | Up to H.S. | 136 | 27.53% |
| Technical Background | Yes | 129 | 26.11% |
| | No | 365 | 73.89% |
| Donation History | Yes | 56 | 11.34% |
| | No | 438 | 88.66% |
| Egocentricity | Yes | 201 | 40.69% |
| | No | 293 | 59.31% |

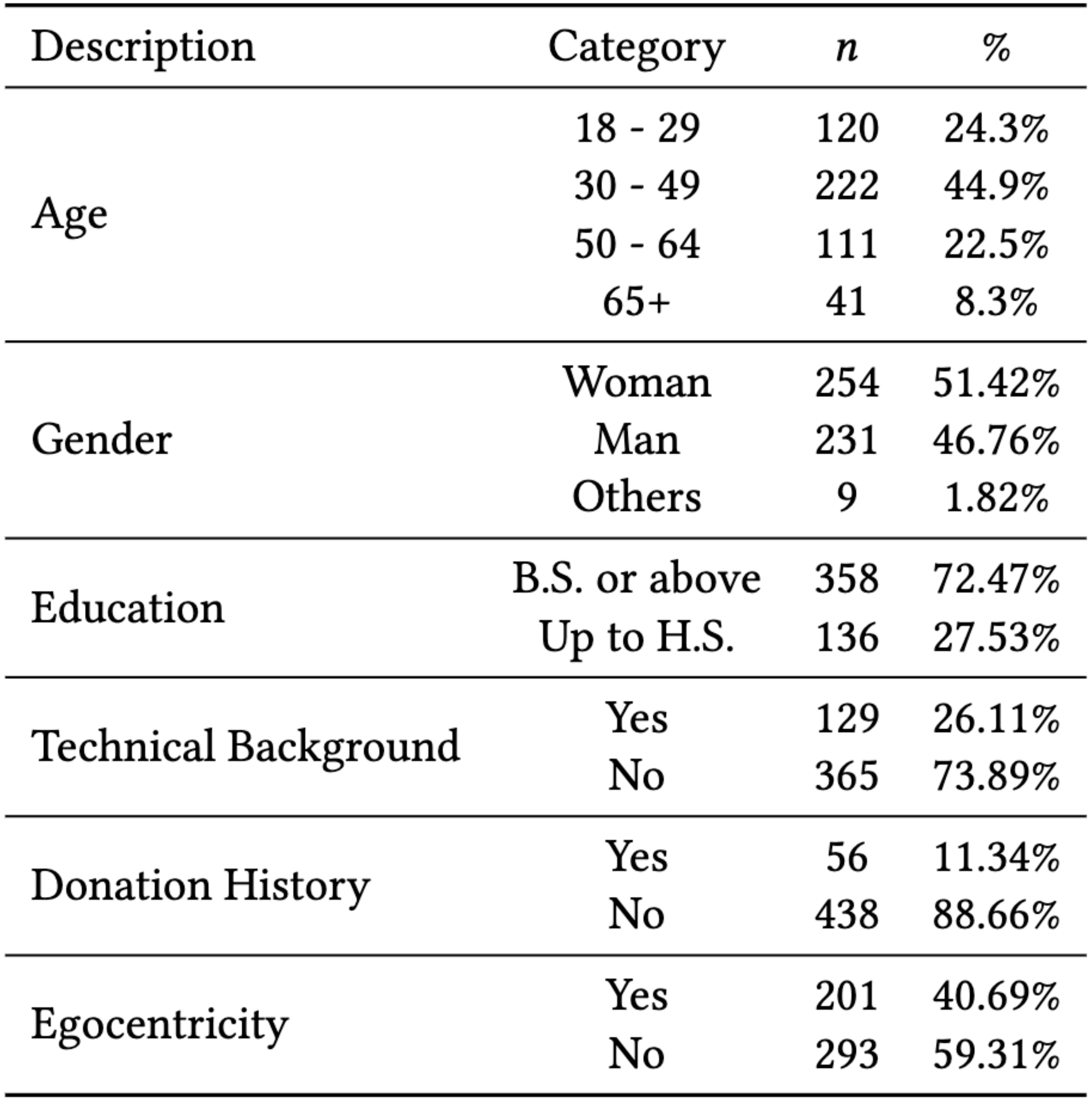
# Sampling

Participants recruited from Prolific

- gender-balance; US based
- $1.2 compensation
- 5:56 mins completion time
- 560 participants in total
- 494 respondents for analysis

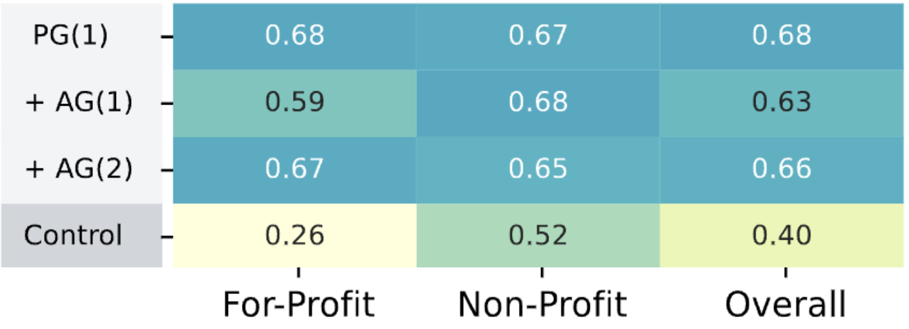
Is your work or degree relevant to CS?

We select a list of common chronical diseases to catch the positive rate.



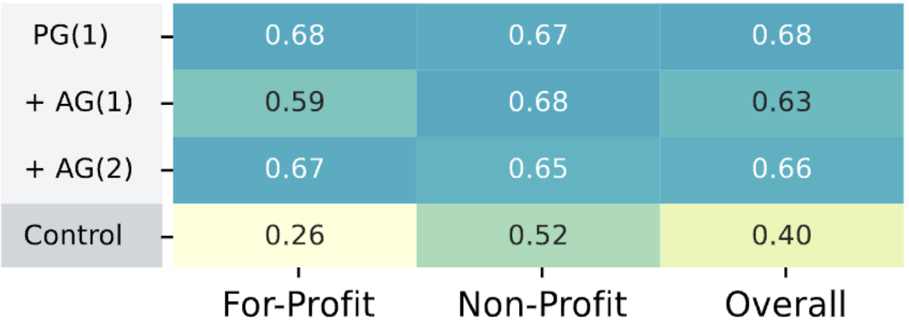
| Description | Category | *n* | % |
|---|---|---|---|
| Age | 18 - 29 | 120 | 24.3% |
| | 30 - 49 | 222 | 44.9% |
| | 50 - 64 | 111 | 22.5% |
| | 65+ | 41 | 8.3% |
| Gender | Woman | 254 | 51.42% |
| | Man | 231 | 46.76% |
| | Others | 9 | 1.82% |
| Education | B.S. or above | 358 | 72.47% |
| | Up to H.S. | 136 | 27.53% |
| Technical Background | Yes | 129 | 26.11% |
| | No | 365 | 73.89% |
| Donation History | Yes | 56 | 11.34% |
| | No | 438 | 88.66% |
| Egocentricity | Yes | 201 | 40.69% |
| | No | 293 | 59.31% |

# RQ1: Protection Expectation



| | For-Profit | Non-Profit | Overall |
|---|---|---|---|
| PG(1) | 0.68 | 0.67 | 0.68 |
| + AG(1) | 0.59 | 0.68 | 0.63 |
| + AG(2) | 0.67 | 0.65 | 0.66 |
| Control | 0.26 | 0.52 | 0.40 |

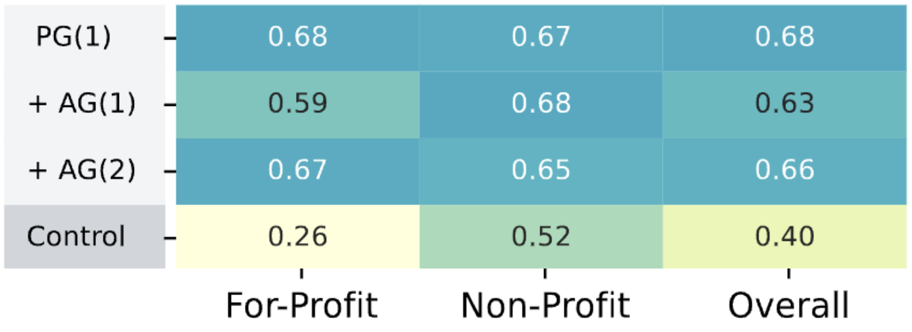
# RQ1: Protection Expectation



| | For-Profit | Non-Profit | Overall |
|---|---|---|---|
| PG(1) | 0.68 | 0.67 | 0.68 |
| + AG(1) | 0.59 | 0.68 | 0.63 |
| + AG(2) | 0.67 | 0.65 | 0.66 |
| Control | 0.26 | 0.52 | 0.40 |

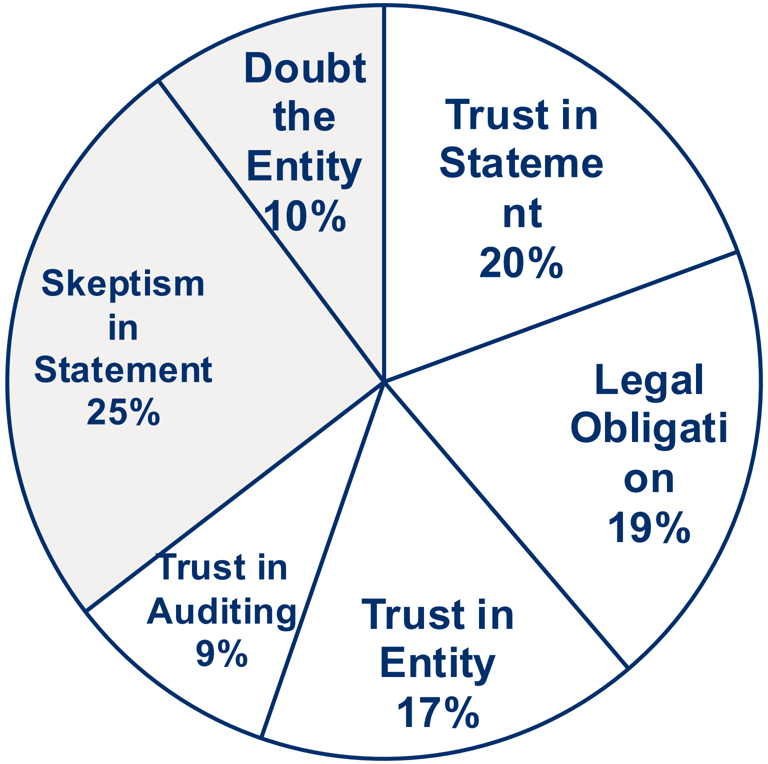
- AGs make no differences
- Both entities have almost the same expectation level with PG
- Higher expectation for non-profits

# RQ1: Protection Expectation



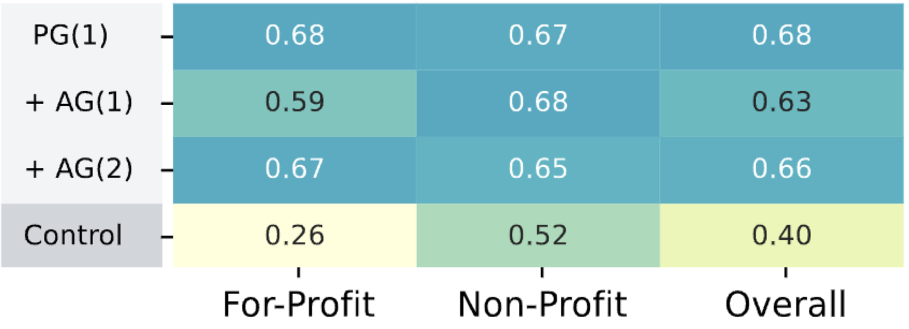
| | For-Profit | Non-Profit | Overall |
|---|---|---|---|
| PG(1) | 0.68 | 0.67 | 0.68 |
| + AG(1) | 0.59 | 0.68 | 0.63 |
| + AG(2) | 0.67 | 0.65 | 0.66 |
| Control | 0.26 | 0.52 | 0.40 |

- AGs make no differences
- Both entities have almost the same expectation level with PG
- Higher expectation for non-profits

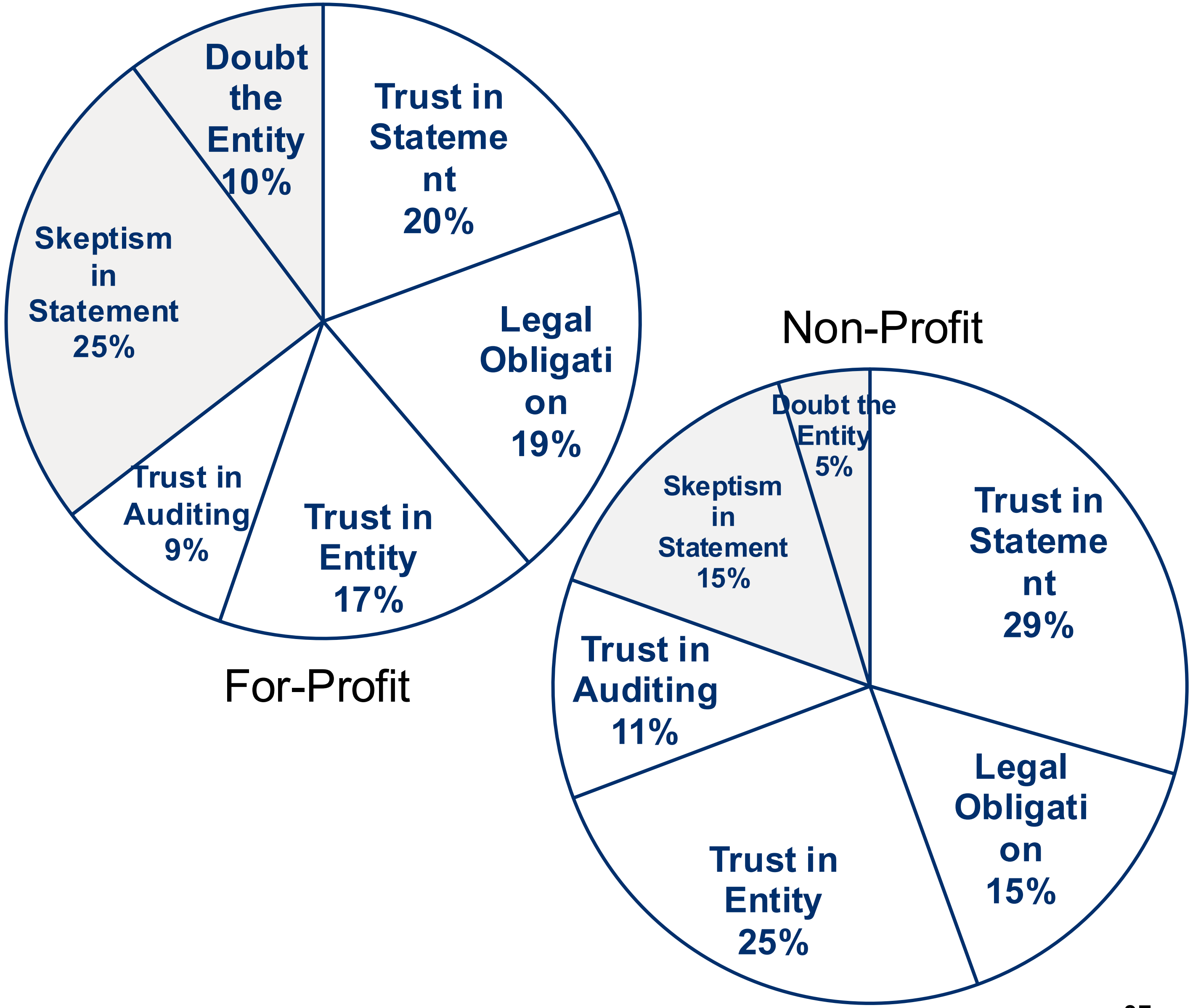


For-Profit

# RQ1: Protection Expectation



|  | For-Profit | Non-Profit | Overall |
|---|---|---|---|
| PG(1) | 0.68 | 0.67 | 0.68 |
| + AG(1) | 0.59 | 0.68 | 0.63 |
| + AG(2) | 0.67 | 0.65 | 0.66 |
| Control | 0.26 | 0.52 | 0.40 |



- AGs make no differences
- Both entities have almost the same expectation level with PG
- Higher expectation for non-profits

# RQ1: Protection Expectation

> “ …because it is a for-profit organization. I expect them to cut corners
>
> ”

---- P119, doubt the for-profit organization’s motivation

# RQ1: Protection Expectation

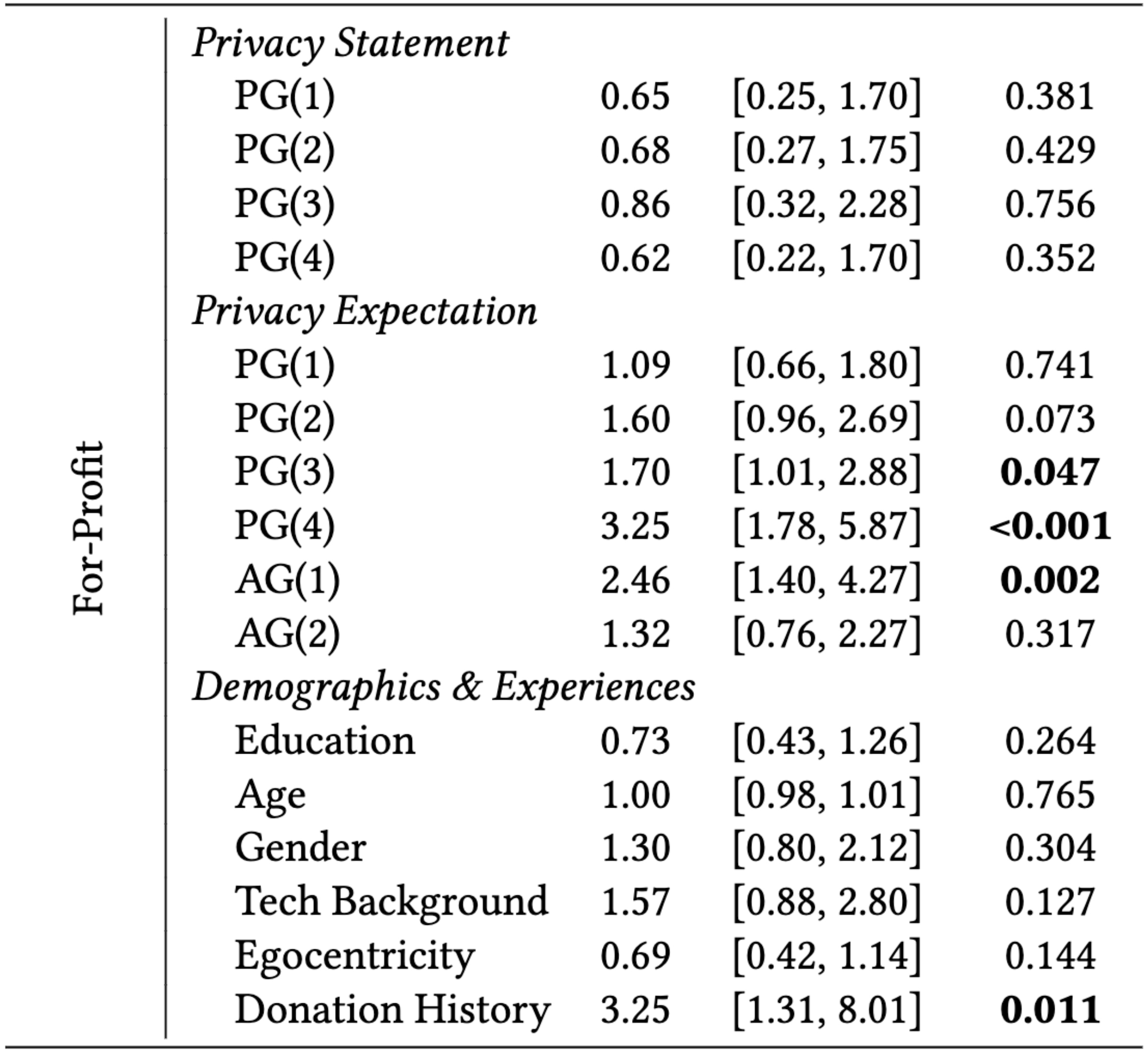
> “ …because it is a for-profit organization. I expect them to cut corners ”

---- P119, doubt the for-profit organization’s motivation

> “ They can check their privacy technology all they want but when there is a breach it is done and info is stolen. After it fails then they say sorry and offer monitoring but the info is still stolen. ”

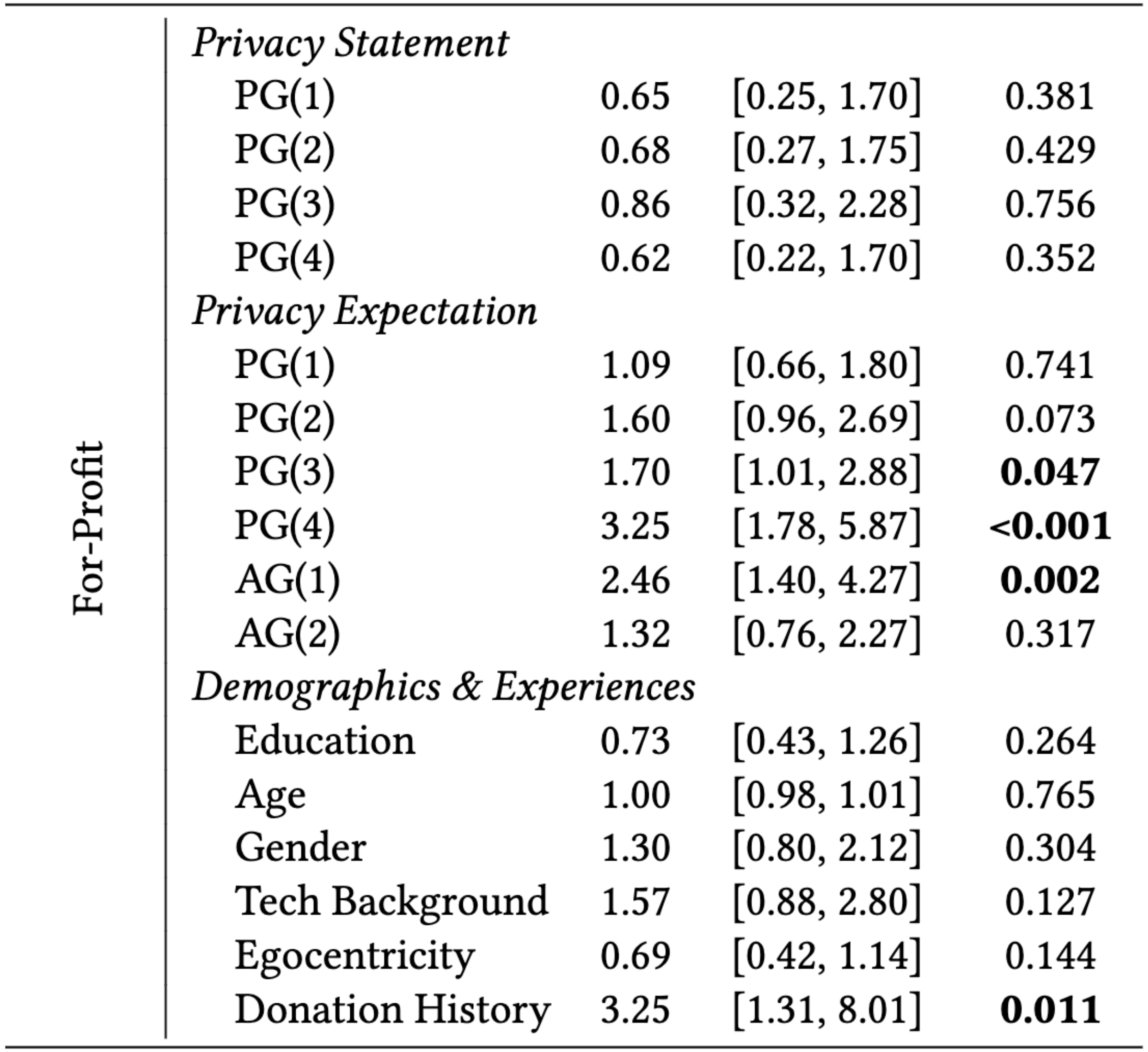
---- P474, limitation of protection techniques

# RQ2: Donation Willingness



| | | | | |
|---|---|---|---|---|
| For-Profit | *Privacy Statement* | | | |
| | PG(1) | 0.65 | [0.25, 1.70] | 0.381 |
| | PG(2) | 0.68 | [0.27, 1.75] | 0.429 |
| | PG(3) | 0.86 | [0.32, 2.28] | 0.756 |
| | PG(4) | 0.62 | [0.22, 1.70] | 0.352 |
| | *Privacy Expectation* | | | |
| | PG(1) | 1.09 | [0.66, 1.80] | 0.741 |
| | PG(2) | 1.60 | [0.96, 2.69] | 0.073 |
| | PG(3) | 1.70 | [1.01, 2.88] | **0.047** |
| | PG(4) | 3.25 | [1.78, 5.87] | **<0.001** |
| | AG(1) | 2.46 | [1.40, 4.27] | **0.002** |
| | AG(2) | 1.32 | [0.76, 2.27] | 0.317 |
| | *Demographics & Experiences* | | | |
| | Education | 0.73 | [0.43, 1.26] | 0.264 |
| | Age | 1.00 | [0.98, 1.01] | 0.765 |
| | Gender | 1.30 | [0.80, 2.12] | 0.304 |
| | Tech Background | 1.57 | [0.88, 2.80] | 0.127 |
| | Egocentricity | 0.69 | [0.42, 1.14] | 0.144 |
| | Donation History | 3.25 | [1.31, 8.01] | **0.011** |

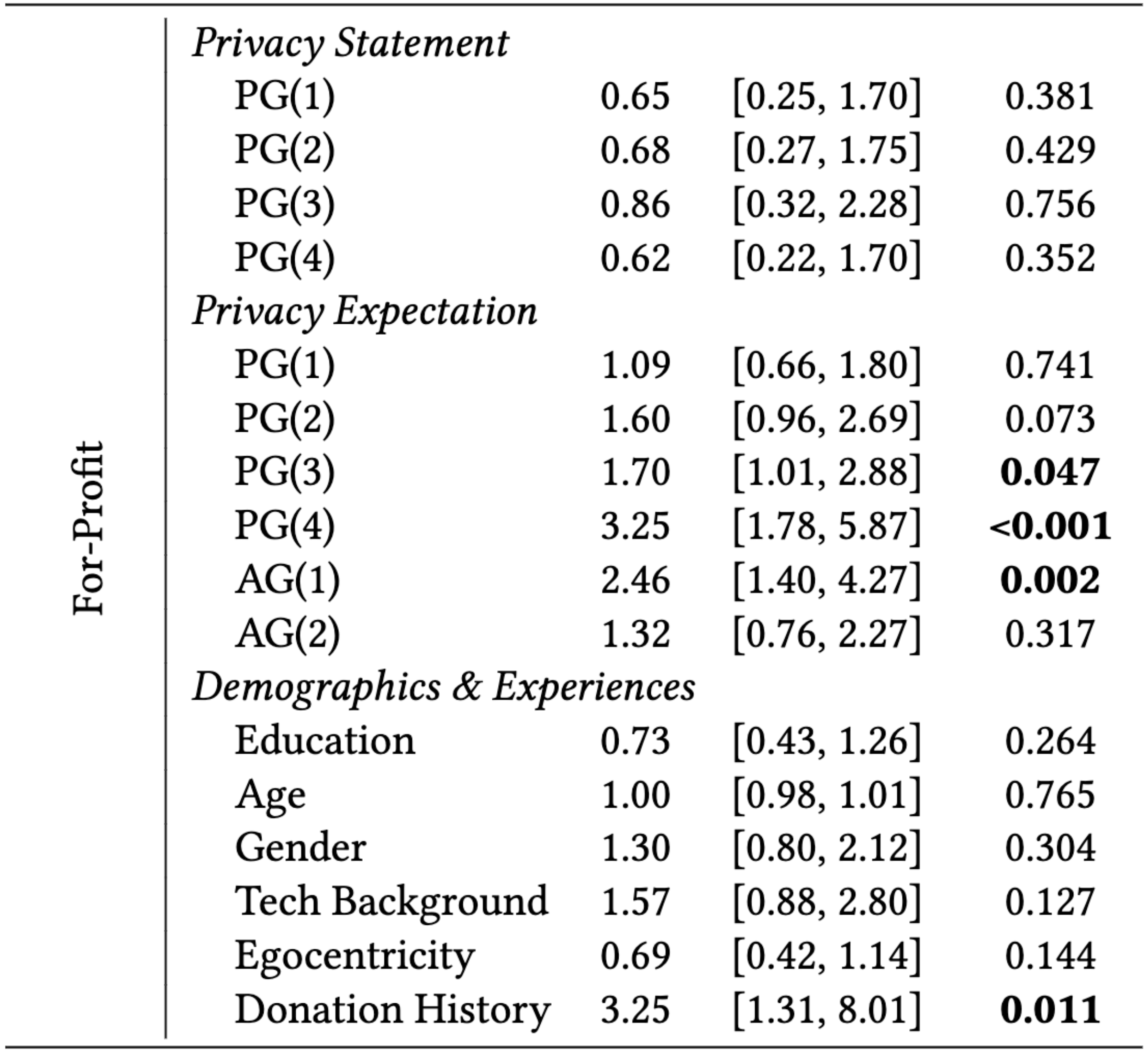
# RQ2: Donation Willingness



| | | | | |
|---|---|---|---|---|
| For-Profit | *Privacy Statement* | | | |
| | PG(1) | 0.65 | [0.25, 1.70] | 0.381 |
| | PG(2) | 0.68 | [0.27, 1.75] | 0.429 |
| | PG(3) | 0.86 | [0.32, 2.28] | 0.756 |
| | PG(4) | 0.62 | [0.22, 1.70] | 0.352 |
| | *Privacy Expectation* | | | |
| | PG(1) | 1.09 | [0.66, 1.80] | 0.741 |
| | PG(2) | 1.60 | [0.96, 2.69] | 0.073 |
| | PG(3) | 1.70 | [1.01, 2.88] | **0.047** |
| | PG(4) | 3.25 | [1.78, 5.87] | **<0.001** |
| | AG(1) | 2.46 | [1.40, 4.27] | **0.002** |
| | AG(2) | 1.32 | [0.76, 2.27] | 0.317 |
| | *Demographics & Experiences* | | | |
| | Education | 0.73 | [0.43, 1.26] | 0.264 |
| | Age | 1.00 | [0.98, 1.01] | 0.765 |
| | Gender | 1.30 | [0.80, 2.12] | 0.304 |
| | Tech Background | 1.57 | [0.88, 2.80] | 0.127 |
| | Egocentricity | 0.69 | [0.42, 1.14] | 0.144 |
| | Donation History | 3.25 | [1.31, 8.01] | **0.011** |

Presentation of a PG makes no difference **even with AGs**

# RQ2: Donation Willingness

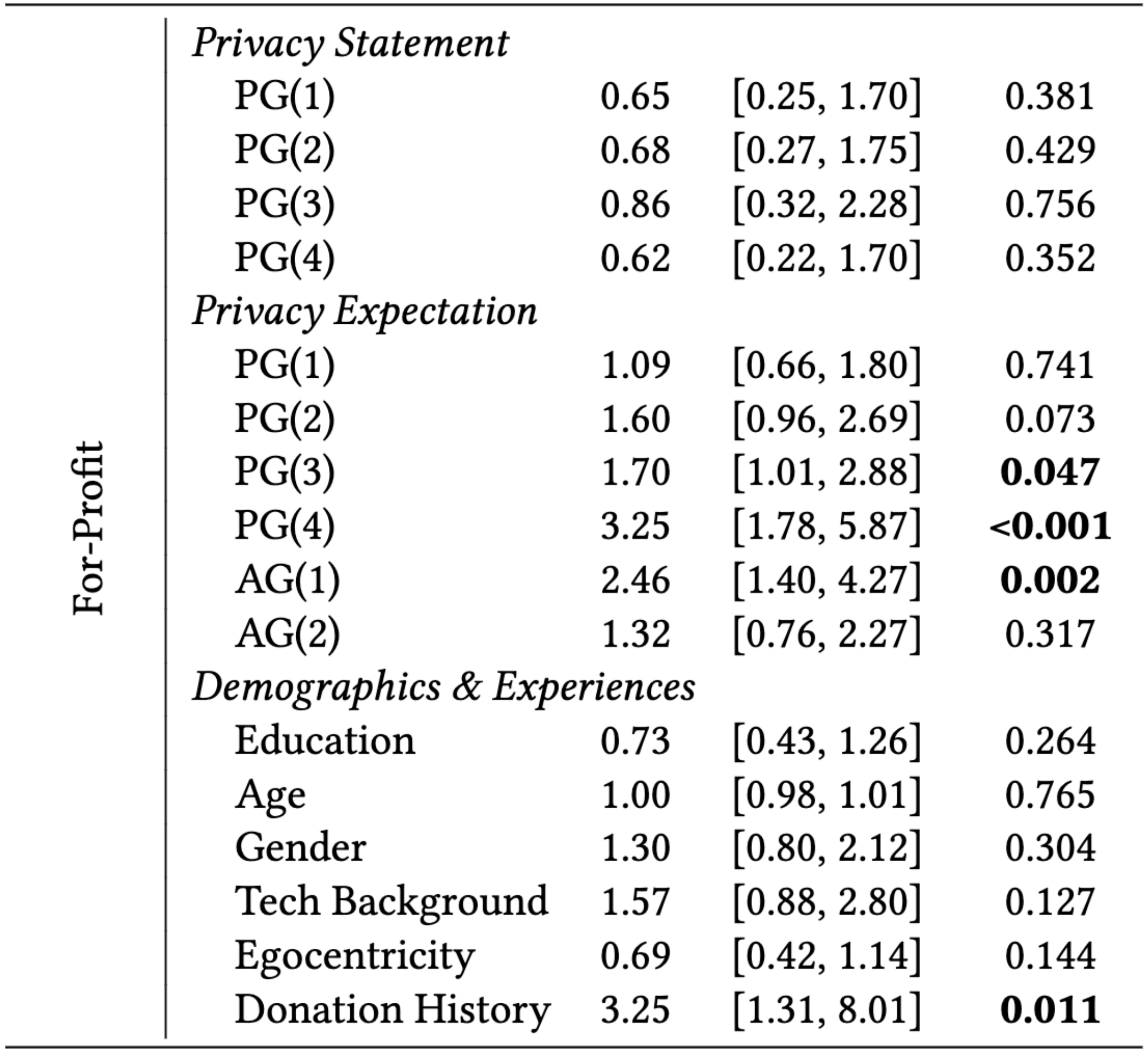


| | | | | |
|---|---|---|---|---|
| For-Profit | *Privacy Statement* | | | |
| | PG(1) | 0.65 | [0.25, 1.70] | 0.381 |
| | PG(2) | 0.68 | [0.27, 1.75] | 0.429 |
| | PG(3) | 0.86 | [0.32, 2.28] | 0.756 |
| | PG(4) | 0.62 | [0.22, 1.70] | 0.352 |
| | *Privacy Expectation* | | | |
| | PG(1) | 1.09 | [0.66, 1.80] | 0.741 |
| | PG(2) | 1.60 | [0.96, 2.69] | 0.073 |
| | PG(3) | 1.70 | [1.01, 2.88] | **0.047** |
| | PG(4) | 3.25 | [1.78, 5.87] | **<0.001** |
| | AG(1) | 2.46 | [1.40, 4.27] | **0.002** |
| | AG(2) | 1.32 | [0.76, 2.27] | 0.317 |
| | *Demographics & Experiences* | | | |
| | Education | 0.73 | [0.43, 1.26] | 0.264 |
| | Age | 1.00 | [0.98, 1.01] | 0.765 |
| | Gender | 1.30 | [0.80, 2.12] | 0.304 |
| | Tech Background | 1.57 | [0.88, 2.80] | 0.127 |
| | Egocentricity | 0.69 | [0.42, 1.14] | 0.144 |
| | Donation History | 3.25 | [1.31, 8.01] | **0.011** |

Presentation of a PG makes no difference **even with AGs**

Expecting the existence of PGs related to donation willingness

# RQ2: Donation Willingness



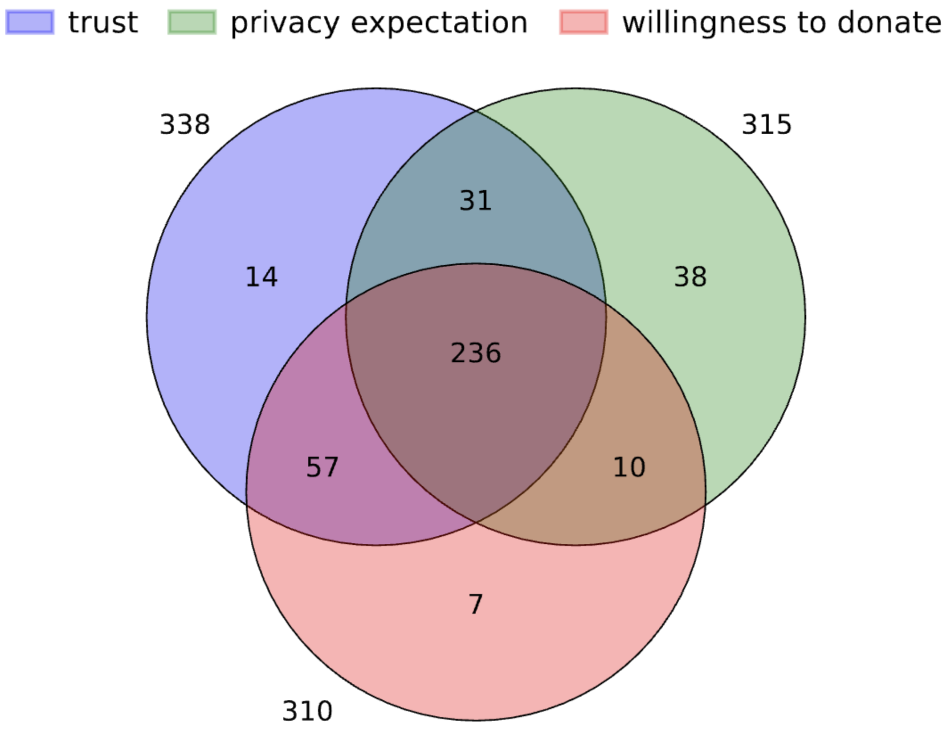
| | | | | |
|---|---|---|---|---|
| For-Profit | *Privacy Statement* | | | |
| | PG(1) | 0.65 | [0.25, 1.70] | 0.381 |
| | PG(2) | 0.68 | [0.27, 1.75] | 0.429 |
| | PG(3) | 0.86 | [0.32, 2.28] | 0.756 |
| | PG(4) | 0.62 | [0.22, 1.70] | 0.352 |
| | *Privacy Expectation* | | | |
| | PG(1) | 1.09 | [0.66, 1.80] | 0.741 |
| | PG(2) | 1.60 | [0.96, 2.69] | 0.073 |
| | PG(3) | 1.70 | [1.01, 2.88] | **0.047** |
| | PG(4) | 3.25 | [1.78, 5.87] | **<0.001** |
| | AG(1) | 2.46 | [1.40, 4.27] | **0.002** |
| | AG(2) | 1.32 | [0.76, 2.27] | 0.317 |
| | *Demographics & Experiences* | | | |
| | Education | 0.73 | [0.43, 1.26] | 0.264 |
| | Age | 1.00 | [0.98, 1.01] | 0.765 |
| | Gender | 1.30 | [0.80, 2.12] | 0.304 |
| | Tech Background | 1.57 | [0.88, 2.80] | 0.127 |
| | Egocentricity | 0.69 | [0.42, 1.14] | 0.144 |
| | Donation History | 3.25 | [1.31, 8.01] | **0.011** |

Presentation of a PG makes no difference **even with AGs**

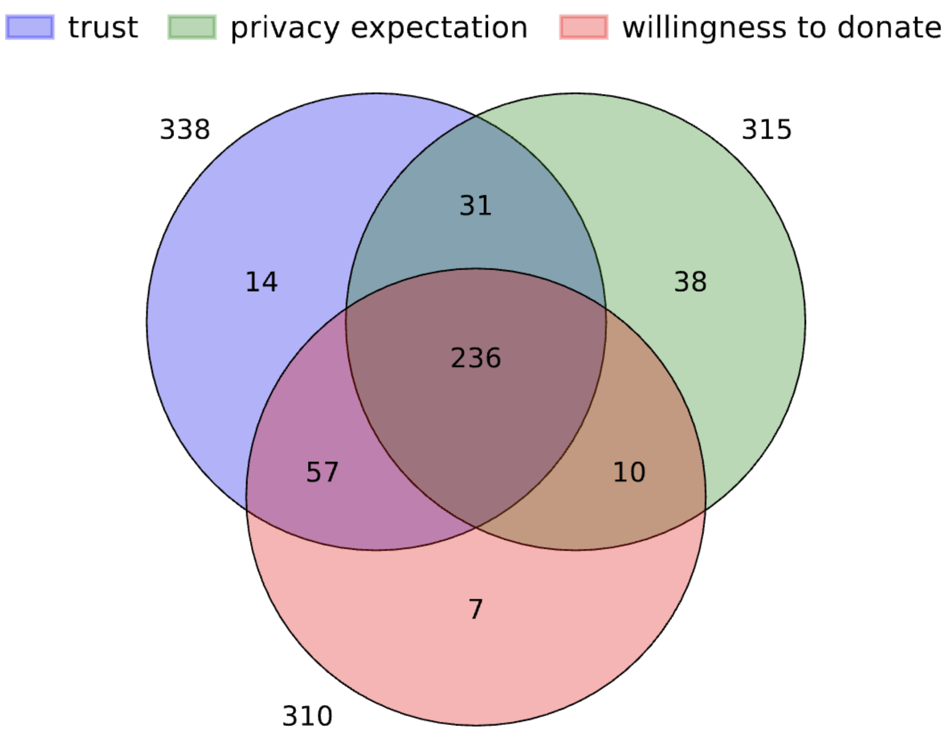
Expecting the existence of PGs related to donation willingness

Demographical factors matter

# From Presentation to Donation



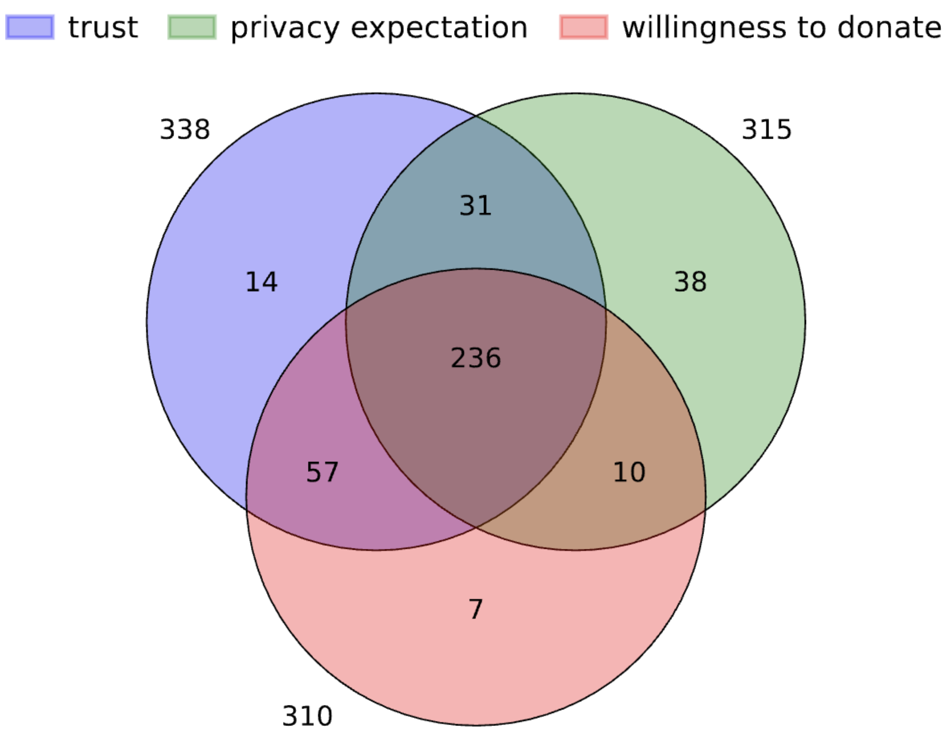
# From Presentation to Donation



**Halo Effect**

Participants hold overall persistent impressions.

# From Presentation to Donation



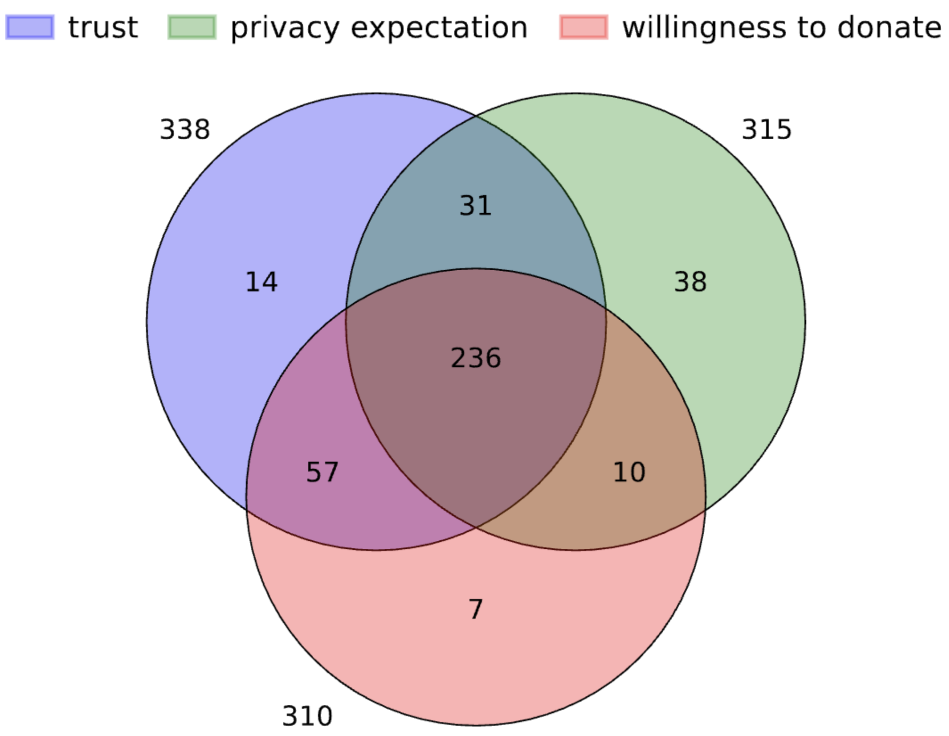
**Halo Effect**

Participants hold overall persistent impressions.

**Horn Effect**

A single negative impression causes an overall feeling.

# From Presentation to Donation



**Halo Effect**

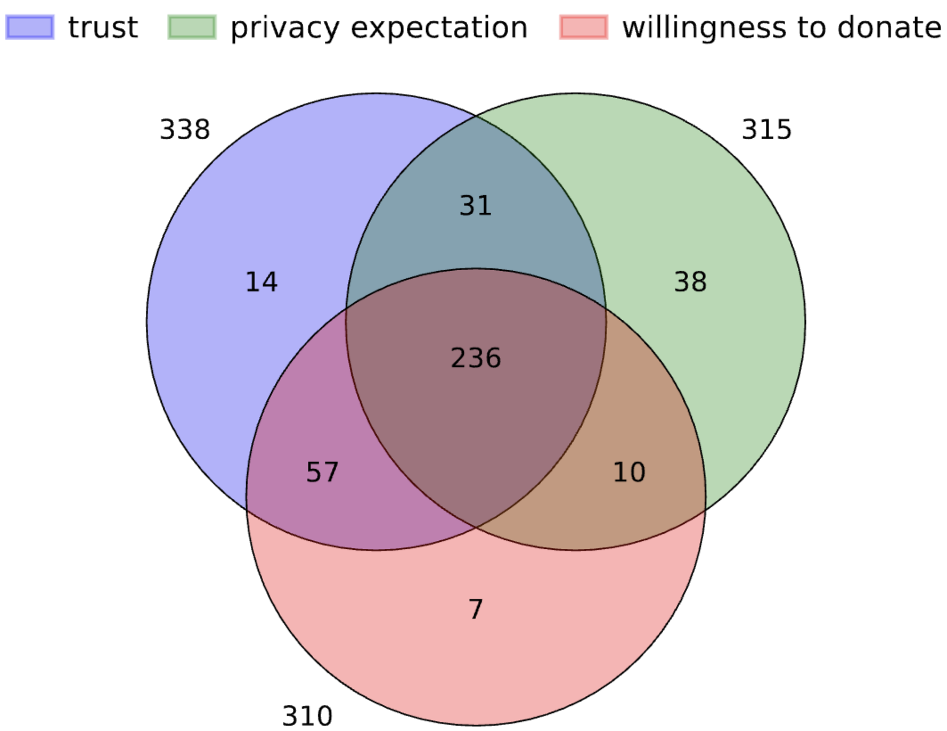
Participants hold overall persistent impressions.

**Horn Effect**

A single negative impression causes an overall feeling.

**Non-Privacy-Related Factors Matter**

# From Presentation to Donation



**Halo Effect**

Participants hold overall persistent impressions.

**Horn Effect**

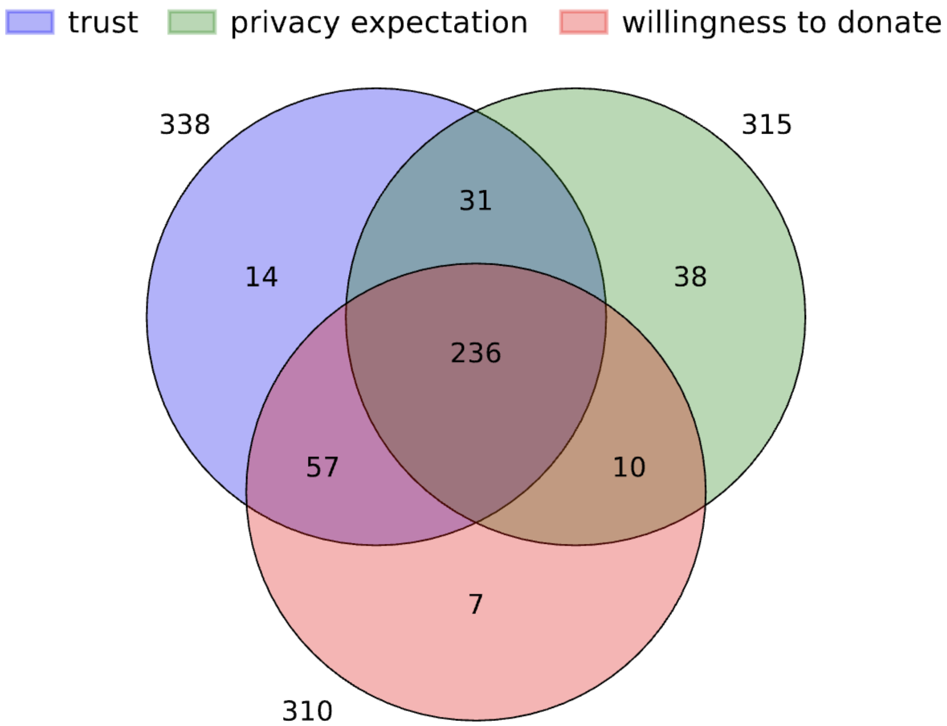
A single negative impression causes an overall feeling.

**Non-Privacy-Related Factors Matter**

**PGs/AGs**

Participants can understand the guarantees they provide.

# From Presentation to Donation



**Halo Effect**

Participants hold overall persistent impressions.

**Horn Effect**

A single negative impression causes an overall feeling.

**Non-Privacy-Related Factors Matter**

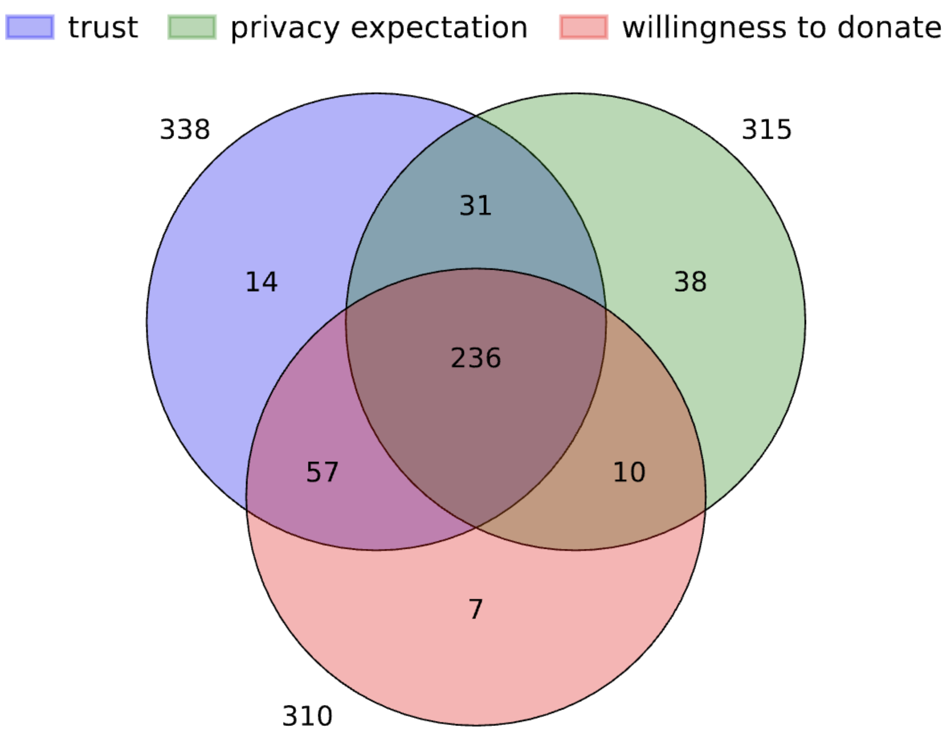
**PGs/AGs**

Participants can understand the guarantees they provide.

**PGs + AGs**

Participants cannot reason the strong guarantees AGs provide.

# From Presentation to Donation



**Halo Effect**

Participants hold overall persistent impressions.

**Horn Effect**

A single negative impression causes an overall feeling.

**Non-Privacy-Related Factors Matter**

**PGs/AGs**

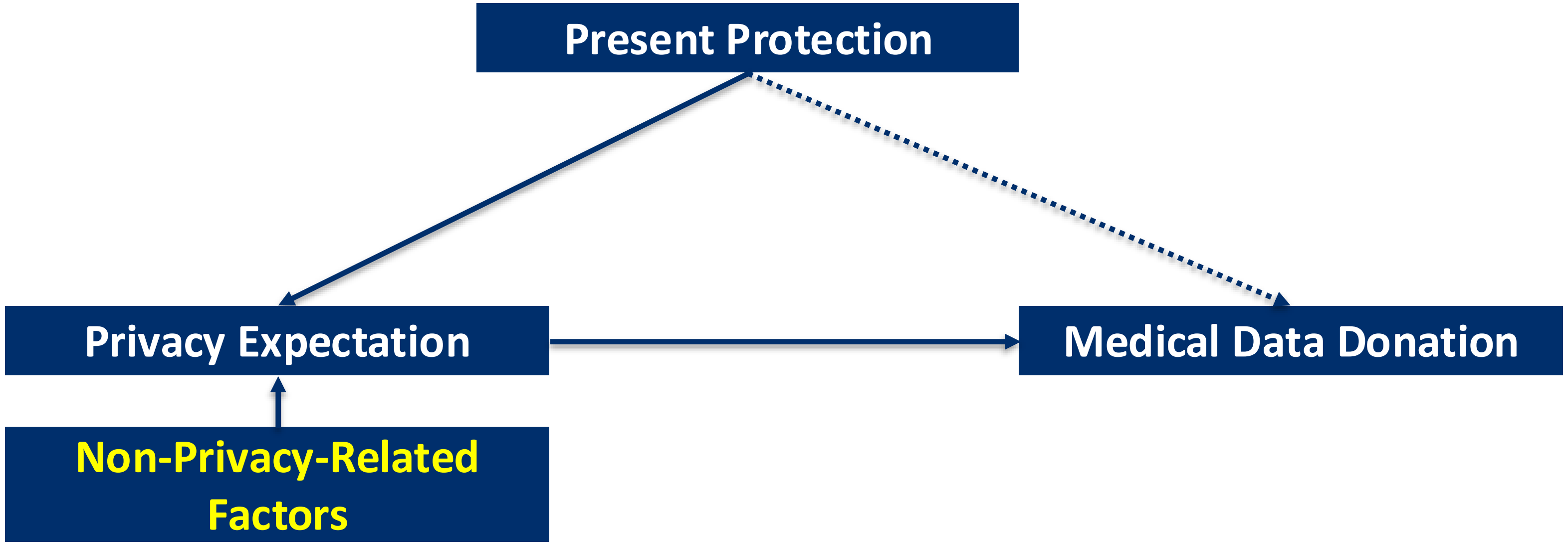
Participants can understand the guarantees they provide.

**PGs + AGs**

Participants cannot reason the strong guarantees AGs provide.

**Efficient Express AGs is Pivotal**

# Summary



- Presenting protections alone is not sufficient to make people donate
- Non-privacy-related factors stop people from trusting the protections
- Auditing guarantees seem promising
- More work is needed to let people understand auditing guarantees