

Enhancing Ethical Review for Research Projects

AERDF

**We WANT
your input!**



SESSION PRESENTERS



Dr. Imani Goffney

Ast. Prof, Univ of
Maryland



Dr. Melina Uncapher

CEO, SETA-ED



Amelia Vance

President, Public
Interest Privacy
Center

Adj. Prof, William
& Mary Law

Agenda

- Research Ethics
- IRBs
- Where IRBs are not sufficient
- AERDF's Process

**We WANT
your input!**



- **Nuremberg Trials (World War II)**
 - During the Holocaust, German physicians conducted medical experiments on patients without their consent or regard for their suffering or survival.
- **Tuskegee Study of Untreated Syphilis (1932-1972)**
 - While there were no known treatments for syphilis at the start of the study, penicillin was discovered as a treatment in 1947. Researchers withheld treatment from participants without their consent, depriving them of a chance for recovery.

Research Ethics

IRBs

Benefits of Going Through an Approval Process

Additional insight into
proposed processes

Structured feedback
system

Evaluates risks &
concerns

Mapping out
plans in advance

Confidence moving
forward

Burdens of the Approval Process

Adds time to the
research process

May not get to do
everything you want

Additional
oversight

Extra hoops to
jump through

Can weigh risks
& ethics yourself

Where IRBs are not sufficient

Big Picture

Internal Ethical Review

AERDF developed an internal ethical review process to evaluate privacy concerns for **all research projects** & determine whether a project is UX/UI research or human subject research (which requires IRB approval).

IRB

IRBs are run by external organizations to evaluate research proposals for the ethical treatment of human subjects. IRB approval is mandatory for **all human subjects research projects**.

Why Do They Exist?

Internal Ethical Review

IRBs oftentimes do not adequately consider the wide variety of privacy risks involved in research, particularly when a project is not considered human subjects research. AERDF's internal ethical review process checks for privacy risks in all projects and can help determine if a project is human subject research (requiring IRB approval).

Example: AERDF's internal ethics review will look at how data is used (UX vs. improving learning outcomes).

IRB

IRBs were established primarily for the protection of human subjects. Because of this, their reviews prioritize evaluating the treatment of research participants and ensuring that participant rights are protected.

Example: An IRB will look for whether participants provide informed consent.

Risks of Not Completing DMPs, IRBs, and RDEC

Inadequate Privacy Protections	Allowing researchers to begin projects without undergoing intensive reviews of how privacy and data protection practices will be incorporated in the research process runs the risk that studies will be conducted without adequate protections in place.
Secretive Data Collection Practices	Not requiring IRB or Internal Ethical Review allows research to proceed without documentation of what methods will be used. This enables data collection without upfront disclosures and data collection plans to be changed without oversight throughout the research process.
Delaying or Calling Off Research	If researchers do not seek approval of research methods and privacy practices prior to beginning the research process, AERDF or other appropriate governing entities may require changes mid-way through the project that delays the research or even make it infeasible to continue.
Age-Inappropriate Research Design	Not requiring IRB approval prior to conducting research that involves children may result in utilizing research practices and consent methods that are not well-tailored to children's developmental stages.
Loss of Credibility	Failing to undergo review processes that are generally accepted by the scientific community may result in AERDF projects being perceived as non-credible.
Damaged Relationships	A data breach would be catastrophic to AERDF's community relationships, especially if privacy and security plans were not reviewed prior to a project beginning data collection and it turns out that participant data was vulnerable due to lack of protections.

AERDF's Process



The Challenge

Education research (and development) is prevalent but populated with very **poor practices and minimal oversight**. Federal and state legal policies fall WAY short of protecting students and their data. This puts our students at risk of being exploited, marginalized, and their data being mistreated.

We need a more ethical system and a more ethical infrastructure to support that system.

Meeting the challenge

Extant poor practices

Privacy:

Researchers, Educators, Developers don't know how to keep sensitive educational data private

Security:

Most educational data storage, sharing, analytics, and collaboration systems aren't secure

Ethics:

There are SO MANY gray areas not covered by federal and state legal compliance

Design features of a more ethical system/infrastructure

Privacy

- Data Governance Policies
- Human Subjects Approval process
- National Research Data Privacy Agreement (b/w districts and R&D teams)
- Dissemination Policies: Publication Review Process with data privacy audit
- Chief Privacy Officer and Ethics/Privacy Counsel

Security

- Built best-in-class (DoD level) secure MVP Data Environment for data sharing, storage, analytics, collaboration
- Independently certified for national accreditation (*SOC2 Type 2 cert*)
- Regular security audits of R&D and general IT
- Chief InfoSec Officer/team

Ethics

- Internal ethics review process for UX/UI
- Supplemental IRB review
- Ethical policies and procedures obligated in R&D contracts

Legal and Policy Infrastructure

A truly secure data environment is dependent on how users engage with the environment, and should be guided by ethical (not just legal) principles. To this end, we:

- Assembled a **team of experts** in student data security and privacy, district management, and data science
 - Determine ethical and legal principles
 - Translate to policies and practices
- Co-created a **wide library** of playbooks, guidelines, templates, contracts and agreements for R&D teams
- Onboarded an external **Institutional Review Board** (IRB) to approve in-house and outsourced R&D
- Created an internal **ethics review process** to approve R&D not covered by external IRB



◆
What could cause people to lose trust in your product?

What could make people feel unsafe or exposed?

What mechanisms are in place for listening to your users?

How will you recognize larger patterns in feedback so that action can be taken?

◆
If your product was entirely dedicated to empowering the lives of an underserved population, what kind of impact could you make?

Who could your product most directly benefit outside of your targeted users?

How would your product change to better serve them?

Provocations from <https://www.artefactgroup.com>



Foundational Culture of Ethical Tx of Data

Any information worth
collecting is worth
protecting and respecting.

Design features culture building

- All staff CITI certification
- Contractual obligations
- Onboarding
- Auditing
- Technical Assistance
- Professional development
- Data Management Plans

AERDF's Goal

To appropriately **balance** the potential **benefits** of educational technology and data use by managing the privacy, security and safety **risks**, using AERDF's values to tip the scale one way or the other



Team R&D's core question: What are the ethical policies and practices that flow from these values?

- AERDF conducts and supports equity-centered inclusive research & development (R&D) projects
- AERDF will take proactive and continuous measures to use and design systems in an equitable way.
- AERDF R&D is centered in approaches that lift up the brilliance of Black and Latino students, and students of all races experiencing poverty.
- AERDF proactively protects Black and Latino students, and students of all races experiencing poverty from harms stemming from the unintended, yet foreseeable, uses or impacts of our R&D projects.
- AERDF R&D should not reinforce biases against, or rely on the profiling of, students based on race, color, national origin, sex, religion, disability, sexual orientation, gender identity, or other similar characteristics.
- AERDF is committed to ensuring the breakthroughs developed in its Inclusive R&D programs are made available to as many of our priority students as possible via Global Access and open science initiatives

What does it mean to center equity?

What does it mean to design systems in an equitable way?

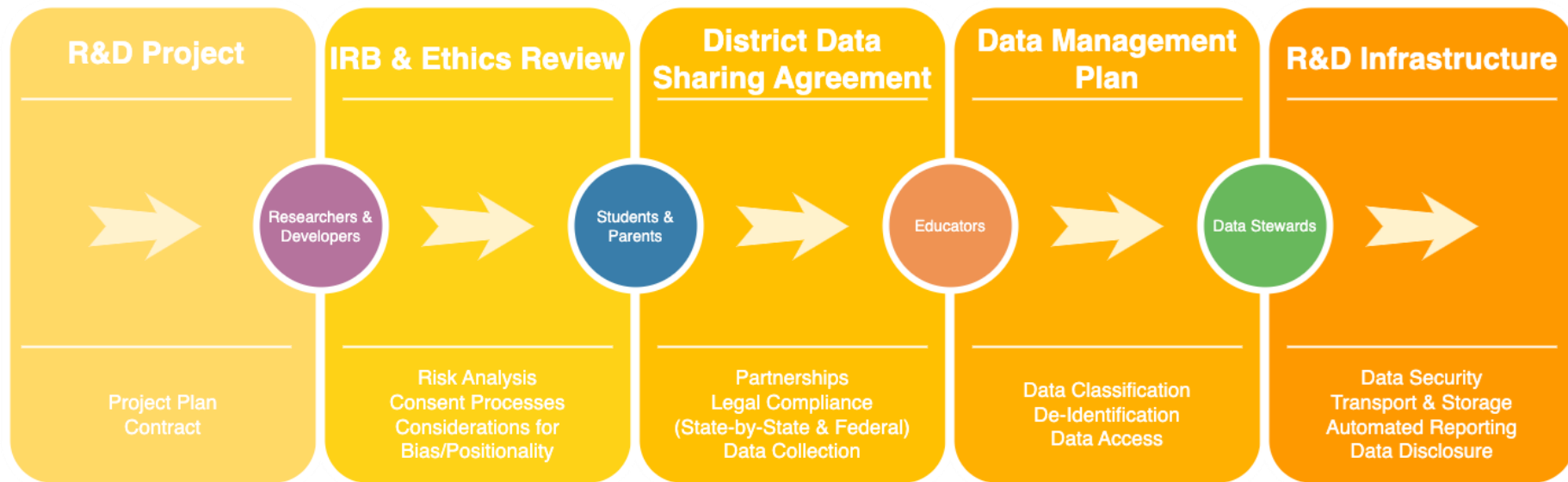
What does it mean to "lift up the brilliance"?

What are these potential harms? How will we detect them?

How can we avoid reinforcing biases?

What does it mean to make breakthroughs available?

AERDF's multi-dimensional approach to Privacy by Design



Questions?

Thank you for coming!

Contact information:

Dr. Melina Uncapher: melina@seta-ed.com

Amelia Vance: avance@publicinterestprivacy.com

Dr. Imani Masters Goffney: igoffney@umd.edu