Privacy Matters.

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Today's Agenda

Privacy Matters.

Building the Ohio State Privacy Program

Privacy Impact Assessments

Privacy Perspectives

Privacy and Confidentiality – a Review
What is privacy?
Why does it matter?
Building the Ohio State Privacy Program
# Privacy Regulatory Framework

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Ohio State Privacy Principles

We value the privacy of everyone who visits, works, supports, and learns at Ohio State.

• We provide **notice** that explains how we **collect**, **use**, and **share** personal information. We don’t use it for other purposes.

• We provide **choices** when collecting personal information for a marketing purpose. We **honor** choices and never sell personal information.

• We make it easy for individuals to **access** and request **corrections** to their personal information.

• We implement new technologies using **privacy-by-design**.

• We **secure** personal information and **investigate** reports of unauthorized or inappropriate access to personal information.

• We **create**, **educate** and **lead** best practices and compliance across our communities.
PRIVACY IMPACT ASSESSMENT (PIA)

Ohio State uses PIAs to evaluate and assess the privacy implications of new or existing projects, systems, programs, products or services.

Let's try a few together.
Privacy Impact Assessment

1. Assess proposed use (6Ws) of personal info (PI) against the privacy principles.
2. Describe how privacy is managed.
3. Articulate benefit.
Privacy Perspectives
Privacy and Confidentiality
When appropriate, there are adequate protections to protect the privacy of subjects and to maintain the confidentiality of data.
Definitions

Privacy
• Person
• Free from intrusion, observation

Confidentiality
• Identifiable information
• Protection from unauthorized disclosure
Considerations

Privacy

Accessing identifiable information

• Original purpose
• Sensitivity/risk from disclosure
• Identifiable information required?
Considerations (cont.)

Confidentiality

- Identifiable information
- Informed consent description
  - Possible/planned sharing
  - Measures to protect information
Privacy of Participants

It is important to note the distinction between "privacy" and "confidentiality." In general, privacy concerns are about the people involved in the research (a person's desire to control the access of others to themselves), whereas confidentiality is associated with a participant's data collected for research purposes. This section should specifically address provisions to protect participants' privacy interests (e.g., limiting the number of people screening private records for recruitment, any interactions will be conducted in a way to avoid being witnessed or overheard, sensitive or medical information will be discussed in a private setting, etc.). For more information, please see the policy Privacy and Confidentiality.

All fields marked with an * are required.

Describe the provisions to protect the privacy interests of the participants.*

Consider the circumstances and nature of information to be obtained, taking into account factors (e.g., age, gender, ethnicity, education level, etc.) that may influence participants’ expectations of privacy.

You have entered 0 of 3000 characters.

Does the research require access to personally identifiable, private information?*

Yes  No

Describe the personally identifiable private information involved in the research. List the information source(s) (e.g., educational records, surveys, medical records, etc.).*


Privacy Provisions

- Clinical collaborators accessing information
- Clinical team introducing study
- Private setting
- Potential participants initiate contact
Privacy vs. Confidentiality

Explain how information is handled, including storage, security measures (as necessary), and who will have access to the information. Include both electronic and hard copy records.

You have entered 0 of 3000 characters.
Confidentiality Measures

- Physical security of hard copies
- Cyber security of electronic copies
  - Secure servers
  - Password protection
  - Encrypted portable devices
- Data storage/handling arrangements
Privacy vs. Confidentiality

TOP HAT
Certificates of Confidentiality
Regulatory Changes

• Policy effective October 1, 2017
• Certificate automatically issued
• Applies to:
  • NIH-funded research that was active on December 13, 2016 or subsequently approved
  • All previously issued Certificates of Confidentiality
Recipient Responsibilities

• No disclosure in proceedings
• No disclosure outside of research team
• Inform other recipients of restrictions
• Exceptions
  • Required by law
  • Consent of participant
  • Other scientific research
Ohio State Implementation

Accruing subjects

• Amend consent confidentiality section (screening at continuing review)
• Use standard text (revised 2/2019)
Certificates of Confidentiality (CoC) - Human Subjects

What is a Certificate of Confidentiality?

Certificates of Confidentiality (CoCs) protect the privacy of research subjects by prohibiting disclosure of identifiable, sensitive research information to anyone not connected to the research except when the subject consents or in a few other specific situations. Learn about the NIH Policy for Issuing CoCs, its purpose, scope and applicability, disclosure requirements, and responsibilities of CoC recipients.

Who Can Get a Certificate of Confidentiality?

CoCs are issued automatically for any NIH-funded projects using identifiable, sensitive information. Learn more about eligibility for receiving a CoC for research that is funded by other HHS-agencies, by non-HHS federal agencies, and for research supported by non-federal funders.
Ohio State Implementation

Study accrual complete

• May update ICF, if other changes
• Refer current subjects to NIH website for questions
Summary Overview

• Privacy Matters
• PIAs help balance privacy and use of information
• Privacy pertains to the person
• Confidentiality pertains to data
• Know CoC requirements
Questions