Data Privacy: Extra resources for ethical practice

Explore the resources below to learn more about the importance of protecting data in the era of digital health and guidance for developing safe and effective products.

Certificate of Confidentiality

A Certificate of Confidentiality (CoC) protects the privacy of research subjects by prohibiting the disclosure of identifiable, sensitive research information to anyone not connected to the project.

Ethical Legal and Societal Issues (ELSI) Framework

The ELSI Framework is an analytical framework for identifying ethical, legal and societal issues that could be associated with a given research project or the development of a technology.

Fast Facts: The Primer on Digital Medicine

This primer provides extensive information on how to accelerate the safe and effective advancement of the field of digital medicine.

GDPR Data Protection Impact Assessment

A Data Protection Impact Assessment (DPIA) is required under the GDPR when there is a "high risk" to people's personal data in new research or a project. This website includes a template for how to conduct a DPIA.

General Data Protection Regulation (GDPR) Checklist for Data Controllers

The GDPR checklist can help you secure your organization, protect your customers' data, and avoid costly fines for non-compliance.

ReCODE Digital Health checklist

This checklist was developed as guidance for digital health researchers, technology developers, ethics boards, clinical personnel, and anyone considering participation in a digital health study.

SageBionetworks Governance Toolkits

This toolkit provides a catalog of design tools and patterns that share best practices and information on an effective consenting process and data privacy and management.

The Light Collective

The mission of The Light Collective is to represent the collective rights, interests and voices of patient communities in health tech.

The Playbook: Digital Clinical Measures

The essential industry guide for successfully developing & deploying digital clinical measures and remote monitoring.

U.S. Digital Service Playbook

This playbook launched by the United States White House outlines specific strategies and best practices from the private sector for building effective digital services.

Source: https://www.dimesociety.org/courses/applied-digital-health-ethics/

Applied Digital
Health Ethics

DIGITAL MEDICINE ACADEMY

Use the checklist below to make sure you are taking all the steps necessary to protect your users' data privacy in your digital health solutions.

Data privacy & protection checklist

✓ **Disclose** what and how personal data is collected, accessed, and shared and when

✓ **Consider** potential risks and harms of privacy issues and data misuse or discrimination

✓ **Develop** systems with privacy by design

✓ **Comply** with regulatory requirements and become familiar with resources and communities around data privacy and protection

✓ **Revise** notice and consent to be fully transparent and comprehendible to broad audiences about their data