

Privacy and Security for Patient Data Collection (VO script)

(Music plays)

Today we're going to talk about data privacy. Privacy is something RARE-X takes seriously.

Managing issues of data privacy and security are a big task. Most rare disease patient organizations do not have the expertise, staff, and financial wherewithal to navigate the complex legal, technical, and policy landscape of privacy.

At RARE-X, we take several steps to ensure patient data privacy and security when handling patient information. Any RARE-X staffer who has access to any of the data entered, including those who verify data completeness and quality, must have training and certification in the federal rules that protect the privacy of people who participate in health research.

People who contribute data to RARE-X can choose who they want to share their data with including patient organizations, researchers, and biopharmaceutical companies. We are able to respect these patient choices through our partnership with the Broad Institute of MIT and Harvard, which supports RARE-X's data storage and sharing infrastructure. Access to RARE-X data is enabled by a cutting-edge, data access management service that governs use of data. This enables us to better protect patient privacy while granting access to data in a timely and effective manner.

When a researcher is granted access to RARE-X housed data, with the consent of the patient, that researcher must agree not to take any steps to try to re-identify patients and can only use the data for the specific purpose for which access was granted.

In addition to privacy, data security is important to RARE-X. We recognize the growing number of data breaches among providers and payers have patients concerned about the security of their health data. RARE-X uses data encryption that meets or exceeds the highest federal data security standards.

We're often asked whether RARE-X complies with the privacy and security rules under HIPAA, the Health Insurance Portability and Accountability Act which created national standards to protect patient health information. Although many people think that HIPAA protects all health information, it doesn't. HIPAA only covers health information that is held by a core group of organizations in the traditional healthcare environment, like hospitals, doctors, health insurers.

HIPAA does not regulate how a patient can share their OWN health information. Since data in RARE-X is directly from patient/patient families or with the patient's permission from a doctor, HIPAA does not apply to RARE-X. But we believe that RARE-X has put into place privacy protections that in many ways exceed those provided by HIPAA. For example, RARE-X only shares data for research with a patient's consent.

RARE-X is spending a lot of time, money, and effort to get this right so patient organizations don't have to worry about it. Instead, they can focus their precious resources on what matters most—finding the treatments and cures their communities need.

To learn more about RARE-X and how you can work with us, go to rare-x.org.