



Digital Frontier Alliance

Data Dignity: What the Words Mean

Understanding how your story is handled online.

Word	What it Means
Algorithm	A set of math or data rules a computer used to make a guess about you, like whether you might need a certain medicine or if you are at risk of experiencing a healthcare crisis.
Dark Web	The "hidden basement" of the internet. It is a place where stolen information is bought and sold by people who want to scam others.
Data Broker	A data broker is a company that collects, buys, and sells people's personal information, like where they live or what they buy, often without them knowing.
Data Scraping	It's when a computer program quickly sucks up information from a website, like a digital vacuum cleaner. This information can include what you are looking at on your computer or your current location.
Decentralized model	When many different people or places share the power to make decisions, instead of one person or place being in charge of everything.
De-identified Data	Removing your name from a report. But watch out: If the report still has your age, zip code, and other information, people might still be able to guess it's you.
Geofencing	Digital boundaries that are created around a physical location. The technology can be helpful for patient safety, alerting staff if a confused patient wanders away. Unfortunately, the technology can be used by advertisers to track a person's healthcare visits through smartphone apps. This includes physical and mental health appointments.
HIPAA	Health Insurance and Portability Accountability Act (HIPAA). The Federal law was enacted in 1996. It protects patient data and privacy; however, the law is outdated.



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Meaningful Consent	Clear and total understanding what you are agreeing to when responding “yes” to questions on what can be long and confusing forms. Your “yes” response should only be given when you feel safe and informed.
Opt-In	You agree to share your information with an organization.
Opt-Out	Your "stop button." It is your right to say, " <i>I don't want you to share my information,</i> " and still get the great care you deserve.
PHI	Protected Health Information (PHI). This is information in healthcare records, like your diagnosis, medications, the name of your doctor, and case notes from your therapist. PHI is protected by HIPAA, but it can be shared if it is de-identified (PII is removed).
PII	Personally Identifiable Information (PII). This is data that shows who you are, such as your name, address, birth date, and social security number.
Recipient Rights	Your "shield." In Michigan, these are special laws that protect your dignity and make sure you are treated with respect and privacy.
Shadow Profile	A "secret file." Even if you don't have an account with a company, they can use trackers to build a file about your health and habits without you knowing.
Tracker (or Pixel)	A "hidden spy." It is a tiny piece of code on a website that follows what you do and tells other companies (like Google or Facebook) about your visit.