

A RESOURCE OF THE 2020 DATA EMPOWERMENT REPORT

Sample Privacy Policy

NOTE ABOUT THIS SAMPLE POLICY

This sample policy includes elements inspired by GDPR privacy policies, ethical data use guidelines, and other standards. We don't claim that it fully complies with the legal requirements your organization is subject to. Instead, it's a starting point for a policy that centers your community. This policy represents an ideal. It is more specific and more transparent than most nonprofits will be able to achieve.

Most nonprofits will involve a lawyer when drafting a privacy policy. A lawyer's job is to protect your organization, not your community. You will need to advocate for your community members as you work with your lawyer. Push for as much transparency as possible while still providing flexibility for the realities & unknowns of nonprofit work.

Also, carefully consider accessibility when creating your privacy policy. For example, you may need to translate this document, make changes to work with screen readers, adjust for different technology expertise, or account for specific cultural norms. Finally, be sure to work through this policy with members of your community before publishing (and pay them for their labor).

What information we collect

When you visit our website

We use Google Analytics which uses your IP address and information from your computer ("cookies") to track what you visit and how long you stay on our website. In addition, we may connect different "sessions" together (e.g., we can tell that the person who looked at our website last week also visited the website this week).

Google Analytics gives us some other basic information like your general location, device type, browser, and have you got to the website.

We don't connect your name or identity to your website activity. We still treat your IP address and browsing activity as sensitive since it could, in theory, be linked back to your identity

When you sign up for our newsletter

We'll keep your name and email address.

When you participate in our behavioral health services

We collect personally identifiable information like your name, social security number (if you have one), address, legal gender, gender identity, and more. We track sessions you participate in, and therapists record case notes about your participation in each session. We also record any diagnoses and may keep related information we receive from other providers.

We will not ask about your immigration status. Our therapists are trained to avoid including information about your immigration status in case notes or other medical records.

We know this is very intimate information, and we are very careful with it. You'll get a full HIPAA privacy notice with more details before you receive any services. You can also view our HIPAA policy at any time on our website.

When you participate in our community education services

We usually ask you to sign in when you come to an event, but it's OK if you choose not to. We may also ask for demographic information like your race, gender identity, age, etc.

When you volunteer with us	At a minimum, we'll ask for your name, emergency contact, and age. Because we work with kids, we might need additional information to run a background check (like a social security number, previous names, addresses, etc.). We don't store this information once we've received the results.
When you give us money	We store your name, email address, and any other information you give us in the donation form. We use a third-party tool to process credit card and bank transactions, so we don't store (and we can't see) your credit card number or similar financial information.

How we collect information

Fundraising, newsletter, and website information is collected either automatically or when you fill out forms on our website. Our forms have been built with accessibility in mind.

Clinical information is collected on the phone, on paper forms, in person during an intake, and then ongoing by your clinicians. We follow a trauma-informed approach to data collection. We try to explain why we ask for certain information and avoid asking sensitive questions over the phone or on paper forms.

If you feel uncomfortable when giving us information, please contact our privacy advocate (contact information is below) or our clinical director (contact information is on our website).

How we protect you from abusers, the government, and anyone else

We make every effort to only ask and record information needed for care. We take steps to protect people in abusive situations, people who are undocumented, and others who are worried about their safety. Unfortunately, we can't always provide services without asking for sensitive information. We want to talk things through with you about your particular situation. If you want help but are worried about giving us information, please reach out to our privacy contact below. You don't have to provide your name. We won't record anything unless explicitly required under mandatory reporting laws (typically just if we hear about possible neglect or abuse of or by you).

We do not voluntarily collaborate with law enforcement or ICE (unless you request it). We have lawyers we will work with if the government takes legal action to get any information about you without your consent.

We have a communication policy intended to keep you safe. We'll never email you, leave a message, or send you a text message without your consent. Our staff also are able to make calls with caller ID blocked. Talk to your clinician if there are steps we can take to keep you safe.

We have strong internal policies to keep your data safe. Staff receive regular training on the secure storage and sharing of data. We take steps to encrypt our devices so that data isn't lost if a device is stolen or lost. We pay a third-party expert to keep our systems updated and secure. Clinicians receive additional training about their obligations to HIPAA and other laws.

Your rights

We believe that information about you belongs to you. However, we are also required by the government and some funders to record and keep some information. We try to balance these as best we can.

We are required by law to store medical information for at least seven years after the last time we provide you with services. Some of our funders might require we keep information for even longer. You do not have the right to request the deletion of your medical information. However, you can request a copy and can also request that we update any incorrect information.

Unsubscribing from our newsletter will delete your contact information from our mailing list.

We are required to keep basic information about volunteers and donors. However, you can request a copy and also request that we update any information.

Who you can talk to

Our privacy advocate is Naomi Lee. You can reach them at naomi@ourorg.org or via phone or text at 215-555-1212. If you need to contact Naomi anonymously, we recommend signing up for a new email address ([we recommend ProtonMail](#)) and emailing Naomi from there.

If you feel that Naomi isn't addressing your needs, please contact our Executive Director or our Board Chair. Their contact information is available on our website.

Who sees your information (and how they use it)

We take steps to limit access to information only to people who need it.

Only the fundraising team can access detailed donor information, the website, and our mailing list. They may share summaries without identifiable information outside of their team. We do sometimes hire third-party organizations to help us understand data. We require that these companies delete the data when they are done. You may opt-in to sharing your name publicly on our donor rolls.

Your healthcare data is only accessible to your clinicians and their supervisors. People not working with you cannot see information about you unless your clinician specifically requests help. Your therapist might share some information about you during group or clinical supervision but not use your name.

We tightly control access to our medical records system. Our Outcomes & QA team has access to pre-approved reports. These reports do not include your name but may include a unique identifier and demographics information (including your postal code). The Outcomes & QA team only shares summarized information outside of their team (nothing identifiable). This summarized information may be shared publicly outside the organization.

Your healthcare data is also shared with your insurance company and our government fee-for-service providers. Typically we only provide your identity (name, social security number, etc.), any diagnostic codes, and the kind of service you received. However, these entities do have the right to audit and review our case notes.

We will share your healthcare information with you or other people if you ask. If you are a minor, your guardian has the right to request your healthcare record. We do not share detailed case notes with parents unless ordered by a court.

Note that our clinicians are mandatory reporters. If a clinician has reason to believe that you are the victim or perpetrator of abuse or neglect, we are required by law to notify law enforcement.

How long we keep your data

We try to delete data once it is no longer needed but are subject to several laws regarding data retention. Health information and most financial data are kept for at least seven years after your last interaction with us.

Ways we use automated decision-making

We do not make any clinical decisions using algorithms or machine learning. All decisions about your care are made by a person.

We do use machine learning and computer algorithms to determine who we follow up with for fundraising, what content we send you, and what we ask for.

How we update this policy

We may update this occasionally. We'll keep it up to date on our website and posted in our offices. When we change the policy, we'll give you a new copy when you have an appointment. If you have given us permission to email you and/or text you, then we may also use those to notify you of significant changes.