

# Practical Guidance for Confidential Data Sharing on Domestic and Sexual Violence in Health Settings

February 2024

## *Introduction*

Health technology is rapidly evolving, including new data collection and sharing practices related to domestic violence and/or sexual violence (DSV). Data sharing between members of a health care team can be a crucial tool to coordinate important care for patients. Cross-sector data sharing can facilitate more effective responses to ensure that people can get the services they need and remain healthy and safe.

Yet, there exist important concerns related to data sharing unique to people who have experienced DSV. With potential impact to a patient's care utilization and engagement, this is not just an issue of privacy but also one of safety. Data sharing agreements must create an environment that prioritizes survivor autonomy, including respecting the confidentiality, integrity and authority of each survivor over their own health information. In addition, the delivery of health care services, and DSV services in particular, should never be contingent on consent to share data. In other words, a survivor should receive services from a DSV provider whether or not they sign a data sharing consent.

As the health care field continues to rely on data sharing for care coordination - including providing critical services for social needs (housing, food insecurity, transportation and increasingly DSV, it is vital that DSV providers partner with health providers and systems to consider the ways that data sharing could both increase care coordination, patient health and potentially decrease safety for survivors if not done carefully. They must take steps together to ensure that patients who are experiencing abusive relationships are in control of their own health information.

In 2021 and 2022, the California Health Care Foundation released two foundational documents on data sharing:

- [Breaking Down Silos](#): How to Share Data to Improve the Health of People Experiencing Homelessness (July 2021); and
- [How to Share Data](#): Practical Guide for Health and Homeless Systems of Care (May 2022).

In these papers, authors Erika Siao, Julie Silas, and Lauren Larin and their team provide research and case studies about how to build effective and sensitive data sharing arrangements across systems that serve individuals experiencing homelessness. They provide practical tips for approaching and *solving* common challenges in data sharing that can be used to start or enhance data sharing efforts between partners. Their thoughtful work provides an excellent roadmap for all sectors trying to coordinate care between health care systems and community based organizations working to address various needs, not only those that are addressing homelessness.

This paper explicitly builds on some of the recommendations in *How to Share Data: Practical Guide for Health and Homeless Systems of Care*. It is offered specifically to organizations that serve survivors of IPV, no matter the status of their health care partnership and data sharing, and for health care providers who are working with survivors. **Readers are strongly encouraged to read the full, underlying documents linked above.**

### ***Important Threshold Considerations for Advocates***

It is clear that care must be taken by health care and DSV providers in building appropriate data sharing systems. To inform these decisions, Health Partners on IPV + Exploitation and the National Health Resource Center on Domestic Violence, projects of Futures Without Violence, have developed [privacy principles](#) for protecting survivors and encourages health care providers<sup>1</sup> to consider the ways that electronic medical records and data sharing could impact DSV survivors. Health providers must take steps to ensure that patients who are surviving abusive relationships are in control of their health information to the greatest extent possible. Provider data privacy practices are even more critical as identification and documentation of DSV increases, patients receive expanded access to their own health information, and coordinated care is broadened to include services that address social determinants of health.

Federal legislation and state and local statutes are the backdrop when establishing a comprehensive baseline of regulations and protections for the use and disclosure of sensitive electronic information. Many DSV providers, operating under the scope of their federal grants, are required to get informed client consent before sharing any personally identifiable data. DSV services are delivered regardless of whether the patient signs the consent. These are important protections to safeguard survivors—and they must not supersede the survivor’s control of how and when their data is shared.

Community-based DSV advocates and service providers must consider how and when to engage in data sharing with health care providers. It is important to consider the context in your state and community and the potential benefits of partnering with the health care system (e.g., sustainable funding; better care coordination for survivors) as well as the capacity of your program to implement a plan that is safe and effective for survivors.

One challenge for DSV advocates is how to implement policies and practices for safe and confidential data sharing that center the experiences and needs of survivors while still supporting coordination between systems. Concrete tips and best practices can support DSV advocates in figuring out the necessary steps for engaging in data sharing.

Each DSV advocacy organization and each community has unique partnerships, infrastructure, policies, and procedures that need to be considered when developing data sharing efforts. Internal, ongoing training on how to implement data sharing is also critical to ensure that patients are informed about how their information is being collected and used and provided an opportunity to give consent. It is crucial that processes for informed patient consent do not pressure or coerce a patient into sharing their data.

There are also important lessons from communities that have already implemented data sharing that can guide others' efforts. We share some of those important lessons as well in this paper.

## ***What is data sharing and what are the implications for survivors?***

Data sharing is making a patient's data available to multiple providers for the purpose of coordinating patient care. It refers to the exchange of health information between patients, multiple health care providers and payers (e.g., health insurance plans). A data sharing feedback loop helps indicate that patient referrals from health care systems to community advocacy programs have been received, increasing our understanding of whether the patient is receiving the help they need. They also inform provider responses which can benefit survivors' health outcomes. On a population health based level, they also inform our understanding of prevalence, needs and resources accessed in our communities, as well as gaps we need to fill.

Increasingly, health systems are partnering with community-based services to address social needs. In order for health care systems to seek reimbursement for these supports

and services provided by advocates, the sharing of data and personally identifiable information may be required by the payor. Creating safe and effective data exchange strategies are a key element of accessing sustainable health care and advocacy reimbursement and financing.

Historically, health care systems and individual providers collect and confidentially maintain patient information. But the omnipresence of electronic health records (EHRs) and an increased focus on care coordination across the care team means that health care providers are increasingly collecting and sharing health information. There is now an expectation that all providers on a patient's care team including nonmedical providers participate in data collection and data exchange for the purposes of care coordination, reimbursement, and quality measurement.

Depending on the circumstances, some health information may be shared between DSV advocates/providers and health care systems/providers. For example, if a care team includes staff from a local health center and DSV advocacy organization, a patient's health information could be shared (with patient consent) to support the patient's direct care and identify if recommended services were accessed (e.g., did a referral for reproductive health services get completed or did the survivor receive access to emergency housing with the help of the advocate). Or a hospital system might want to refer patients who disclose exposure to violence to a local DSV program and will pay for those supportive services but they need to understand that the referral was accepted. Similarly, a DSV organization may refer a client to a primary care provider for health services and will want to coordinate with the health system to be sure the client is enrolled, has health coverage and is receiving appropriate care for themselves and/or their children.

There are also [statewide](#) efforts to bring social service providers, including DSV-service organizations, onto a shared platform with health care organizations, such as in the Healthy Opportunities Pilot in North Carolina. In this case, health information is shared with the goal of coordinating patient care.

In all of these examples, the goal is to share patient/client data across the care team to better serve that individual.

Data sharing can support a fundamental shift in patient care—and to engage individuals in their own care. Sharing key health information can improve care coordination, make sure needed services are actually received, and identify gaps in care—all important pieces of a holistic, survivor-centered treatment plan. Subject to federal and state policies, patients can direct how their information is shared, under what circumstances,

and direct their own care after receiving a thorough explanation of how their data will be used and who will have access to it. But these are complicated issues and DSV advocates can help support survivors to understand these policies and how to advocate for yourself as best as possible.

Fundamentally, discussing and establishing a meaningful consent process to share data is core to any data sharing consideration with survivors. By participating in a detailed informed data consent process with health providers, survivors are better informed about how their information is stored and shared in health settings. Survivors must have the opportunity to opt out of DSV-related data sharing between health providers and community partners when the data sharing or storage does not feel safe for the survivor.

Another benefit of data exchange for survivors and for IPV advocates is that providers can learn about a patient and their health history, including services already accessed to inform their care plan. This also means patients will not need to reshare this information or be retraumatized by being asked to reshare their history, including experiences related to DSV.

Sharing of data helps facilitate referrals and warm handoffs between different agencies to meet the needs of the patient. It can also provide an important feedback loop to ensure services are delivered. Care coordinators can monitor the delivery of services and spot and fill gaps in treatment plans. This is particularly true as health care systems move to provide reimbursement for nonmedical supports and services (e.g., violence prevention, housing, access to food, transportation). Data sharing can help ensure survivors get the services they need.

When DSV advocates and other community partners participate in integrated health care teams and share data including required health information, they may be able to get paid (or reimbursed) for such services. Payment for services should be limited to environments where DSV advocates have training on voluntary consent processes, clear processes to discuss data sharing options and provide meaningful consent opportunities to survivors, including offering alternatives for service provision that do not involve survivors consenting to data sharing. Where these conditions are met, health care funding can be a sustainable source of funding to supplement existing streams and help DSV programs meet the needs of more survivors.

Challenges frequently arise around addressing privacy issues (discussed in more detail below), negotiating relationships and collaboration, overcoming technology, and improving data quality. Different legal, technological, historical, and cultural approaches

complicate how DSV advocates and health care providers collect and share data, resulting in safety implications for survivors. DSV advocates may also be frustrated by unidirectional data sharing where they share client data with health care providers but do not obtain feedback about their clients' experiences with the health care system in return.

However, it is possible to develop data sharing agreements that protect survivor privacy and confidentiality and value the participation and expertise of DSV advocates. It takes effort, dedication and willingness of all participants to address the key challenges (including privacy and bilateral collaboration). This investment of time and resources if done carefully can result in better coordination across the care team and improved supports for survivor health and other needs. With health systems increasingly connecting to and funding some of the needs some survivors desperately need (housing, food, transportation supports etc.) this can be a game changer for a survivor's health and ability to thrive.

## ***Survivor privacy and consent***

Obtaining robust, informed patient consent including health data is an underpinning value of all successful data sharing agreements. Consent puts the patient at the center of their own holistic care.

- The most successful and robust data sharing programs have developed data privacy policies that build trust between participating organizations and have detailed consent policies and systems that build trust with clients and talk through these policies. Patients should be given a clear choice about whether to share data (both in the health care setting and/or in the advocacy settings) and should never be pressured into sharing data to receive services. Principles include:
  - Survivors' privacy and confidentiality must be at the center of data sharing design;
  - Patients and clients must have the option to [consent](#) to share their personal information, when, how, and with whom they choose;
  - The informed consent process must clearly state that services will be delivered regardless of whether a patient consents to share information, and it be clear to the patient that receipt of DSV advocacy services is not contingent on giving consent to share information with health care providers;
  - Survivors must be provided a clear choice about whether to share data and should never be pressured into sharing data in order to receive DSV-related services;



- Patients and clients need to understand these choices through simple, clear and in-language materials and information, including access to interpretation services as required;
- The process by which a patient or client can revoke consent must be clearly and transparently identified; and consents must be time limited and renewed at least annually and when requested by the patient's;
- Data sharing agreements should spell out the right of clients, the need for client consent, and how clients can revoke permission;
- Develop consent and release of information forms so that they are clear, easy to read and include understandable instructions:
  - Ensure releases have been developed in partnership with survivors; and
  - Ensure releases are available in many languages; and
- Staff must be trained to be able to fully explain the benefits and risk of sharing data, and include sample scripts about the consent and release of information forms.

DSV advocates and other providers will have questions about the federal and state privacy rules governing the exchange of health information. New guidance from FVPSA on [reimbursement](#) and on the [provision of medical advocacy](#) makes clear that FVPSA-funded DSV advocacy organizations are permitted to participate in data sharing (with patient consent) for the purposes of health care reimbursement so long as consent is voluntary, informed, time-limited, and patients are aware that receipt of services is not contingent on providing consent.

### ***Laying the groundwork for a data sharing agreement***

A data sharing agreement is the foundation on which safe and trusted health information exchange takes place between a health care provider and DSV service organization. It is the document that outlines when, what and how information can be exchanged. All parties must be part of the data sharing agreement and it must be built on a foundation of trust. It must also acknowledge the inherent imbalance of power that can exist in negotiations between a large, well-resourced health care organization and a small DSV service organization. It should ensure that the final product equitably reflects the needs and concerns of both sides.

Above all, the final data sharing agreement must keep the survivor in the center of the agreement and ensure that the informed patient consent process is embedded throughout and that there are no incentives or unintended financial policies that unduly burden survivors to consent to sharing information.

Keys to the success of a strong process include:

- Have the right people at the table, including decision makers from each organization, representatives from the technology company (for example, if there is already an EHR in place), legal counsel, and community members such as survivors of DSV.
- Identify the goals and the purpose of the data exchange. Why are partners coming to the table? Is it to improve outcomes for the person being served? Is it to ensure appropriate payment from health systems to CBOs for the services they provide? The data exchange policies should be in service to these goals.
- Have clear and transparent decision-making processes and communications mechanisms. All parties need trust in the system and to have a voice in the process that is reflected in the resulting document.
- Acknowledge that there are already data sharing efforts in place that can be built upon, such as a state-wide health information exchange, but that these may not meet the needs of all parties and will need to be adjusted appropriately.
- Clarify throughout the process that survivors must have ownership over their health information and that services must not be contingent on providing consent to share data.

## ***Ensuring survivors' needs are reflected in data sharing design***

Survivors have unique safety, privacy and confidentiality requirements and design must be centered with them in mind. Their perspective must be brought in from the beginning. In addition to including survivors themselves, advocates are in a position to represent survivors' perspectives and serve as a conduit between parties.

Including DSV advocates and survivors at the table can bring these perspectives to light and help identify problems and solutions that policymakers and systems designers can not. Advocates can help navigate various design solutions to increase the likelihood that survivors could be comfortable providing consent to share data, and help test tools, forms and resources with survivors. For example, including advocates and survivors in the data sharing design can help identify use cases that health care providers may not think of and they can identify language that can be triggering so that content can be framed differently.



Including survivors' perspectives in the design from the beginning is a different model that is traditionally used by data sharing designers. It must be approached intentionally and deliberately. While this will require time and dedication, and may add time to the design process, it is a necessary step in the process. Key factors to consider include:

- People must be financially compensated for their time and expertise;
- Meetings and events may need to take place at different times to accommodate people who work or have other daytime responsibilities;
- Take into account technology, transportation, translation and childcare needs when holding meetings in person or virtually;
- Create multiple opportunities for participation and leadership.

Investing the time that is needed—authentically including community members will take time and require a change in business-as-usual but will ultimately deepen the success of the project.

In North Carolina's Healthy Opportunities, the platform designers used feedback from survivors to incorporate safety-related information into their platform and designed and launched detailed fields for collecting and sharing client contact information, regardless of whether a patient is accessing DSV services. All clients must now be asked by care managers during intake about days of the week, times of day, methods of contact, and other details related to contact that would be safe or unsafe for them (ex. identify yourself as the vet's office when you call). This information is then shared with all partners so that no one is contacted outside of times/methods that are safe to them.

## *The actual data sharing*

Most health care providers, including those at health centers and hospitals, use an EHR for their clinical practice. These systems allow providers to capture data on patient visits and, increasingly, on social needs (e.g., housing instability; food insecurity). As awareness grows on the impact of exposure to violence on health outcomes and the intersection with other social needs, EHRs and other electronic health systems are integrating DSV screening and response into their tools. For example, the [PRAPARE](#) (Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences) screening tool includes screening for IPV and is included in many EHRs and [OCHIN EPIC](#) has developed tools to implement universal education and response to IPV.

Most DSV providers and other community-based providers will have limited experience using an EHR. They may track client services on paper or they may use a “closed” system or different database that allows them to track client services with internal colleagues but that doesn’t share information with other providers. In order to realize the benefits of data sharing, some health care providers are devising interoperable referral platforms to allow for the sharing of information. Embedded in EHRs or connected to them – these referral systems are increasingly interoperable and capable of sharing information across systems if desired. Alternatively, DSV programs can work with the health partner to devise what data will be shared and develop their own approach to sending that information to a key health contact, focusing on the least amount of data possible to share in order to facilitate care coordination and connection to services.

All participating parties will need a data sharing agreement. This will dictate how, when, and under what conditions health information can be shared. As a reminder, national and state laws govern data exchange and DSV programs should consult a lawyer to confirm the national, state and territorial laws that govern data exchange before entering the agreement.

Health care providers may have a standard or uniform data sharing agreement that they ask all partners to sign when engaging in a partnership. It may or may not reflect the privacy and confidentiality expectations of DSV providers, and it may not be drafted in a way that is easy for readers to understand. Co-developing the DSV portion of that agreement with a DSV provider is important.

When constructing the data sharing agreement, it is important to clearly define what data elements will be shared, under what circumstances, how often and why. It is equally important to examine the scenarios under which data can NOT be shared, and account for survivors who do not want to share data after reviewing and discussing consent options with DSV advocates. It is important to continually acknowledge this reality so that consent processes are developed with survivor autonomy, especially around their data, in mind. Some arrangements will begin with extremely limited data exchange to start with and will be reexamined over time.

Questions to consider include:

- What data elements can be shared between all parties?
- What data elements will need to be restricted and in what circumstances?
- Will all users have access to the data, or will there be differential access depending on the user role?
- Will sensitive data be segmented from data exchange? How will that be identified?

DSV advocates should be specific when developing a use case for sharing survivor information and avoid sharing more than what is required.

## **What's next**

This advice adapted from Communities in Action offers important takeaways that providers and DSV service organizations should consider.

- Get started. Don't wait to have everything perfect and in place. Even small steps can have a meaningful impact in improving health care and other outcomes such as housing outcomes for people and can set the foundation for more support. Start out small if you need to. But do something.
- Be patient. Don't lose patience before you have a chance to see successes. It might be three steps forward and two steps back.
- Don't be afraid to make people uncomfortable. For a long time, the perception has been that it is not okay to share data. As communities have learned over the years, that is not true. Provide details, develop use cases, help explain the intentions and values of data sharing, and share the strong protections you can put in place. Engage with organizations who support the efforts, and ultimately others will come along.
- Remember how complex the systems are. It might not be easy to do cross-sector data sharing. Be willing to adjust or even pull back goals and expectations rather than stop the project because of seemingly insurmountable barriers. Downsize expectations or take on a small piece. One staff person said that it's all about "relentless incrementalism." But if you have the will and capacity to go big, go for it. There are a wide range of models for cross-sector data sharing. There is not one cookie cutter solution to cross-sector data sharing.
- There are a range of models — county-led, nonprofit-led, funded by state or large local grants, etc. Develop the model that works best for your community, your location, and the people willing to be at the table and engage.

## Conclusion

This advice adapted from Communities in Action offers important takeaways that providers and DSV service organizations should consider.

At the forefront of sharing information related to health care for survivors are understandable concerns about survivor consent, privacy, and health. Data sharing agreements, including the informed consent process, must create an environment that prioritizes the survivor's autonomy, including respecting the confidentiality, integrity and authority of each survivor over their own health information.

### Key Resources

- [ipvhealth.org](http://ipvhealth.org) – *A toolkit on cultivating partnerships between healthcare providers and domestic violence advocates to promote survivor's health and safety.*
- [National Health Initiative on Violence and Abuse](#) – *Find resources and information to advance quality and equitable health care and supportive services for survivors of domestic and sexual violence and human trafficking and exploitation.*

Have more questions about addressing survivor health needs? Contact the National Health Resource Center on Domestic Violence for tailored training and technical assistance. Email: [health@futureswithoutviolence.org](mailto:health@futureswithoutviolence.org)