

Charlotte-Mecklenburg Domestic Violence Research Collaborative

Guidelines for Data Collection and Data Sharing

Background: Why Data Collection and Data Sharing Matters

Data drives many decisions in today's world, and decisions about domestic violence-related services, policies, and funds are no exception. A multitude of agencies and institutions collect, store, and share data for various reasons. Domestic violence service providers collect data from clients to assess client needs, develop intervention plans, report program activities, and monitor outcomes. Service providers also collect data to monitor program utilization levels, community need trends, and service quality. Researchers collect data to investigate questions and hypotheses. Policy makers collect data to shape policy formation and implementation. And funders collect data to evaluate grantee performance and develop investment priorities.

Although domestic violence-related data is abundant, it is strictly protected. Victim service providers cannot share client data without explicit informed consent and release of information provided by the client. Even then, ethical guidelines require sharing the least amount of information possible to achieve the objective, such as helping a client apply for a community resource. Restrictions on sharing victims' data are governed by several laws. The Violence Against Women Act is the cornerstone of the victim services field, and it sets high standards for safeguarding victims' data.

At times, the lethal and ethical restrictions on sharing victim data conflict with data integration initiatives. When different agencies and institutions wish to share data sets across systems to identify overarching trends and patterns, including victims' data as one of the shared data sets is usually out of the question. In fact, this very scenario is what inspired the creation of the Charlotte-Mecklenburg Domestic Violence Research Collaborative (DVRC). The challenges around data sharing sparked the questions, "How do domestic violence survivors feel about the way their information is collected, stored, shared, and/or restricted? What do they think about the idea of sharing victims' data across systems?"

The DVRC is a group of self-identified domestic violence survivors, service providers, and researchers in the Charlotte-Mecklenburg area who have convened to examine issues related to domestic violence, data, and research. With respect to data collection and data sharing, the DVRC has developed guidelines to inform decisions about when and how survivor data is collected, restricted, and/or shared.

Proposed Guidelines for Data Collection and Data Sharing

- **Guideline #1: Consider timing**
 - Survivors may be less comfortable sharing a lot of personal information at a time of acute crisis. At this point, it is appropriate to collect only the data that is necessary.
 - Survivors may be more comfortable sharing personal information later on, when they have attained safety and stability. This timeframe will differ for every survivor.
 - The same points apply for sharing data across systems. Survivors may be more comfortable with this after some time has passed, but not at the point of crisis. Some

survivors may never be comfortable with their information being shared across systems, no matter how much time has passed.

- **Guideline #2: Consider safety**
 - Survivors are likely to be less comfortable sharing personal information when they are concerned about stigma, privacy, or security.
 - Survivors may be more comfortable sharing when their physical or psychological safety is not in jeopardy.
- **Guideline #3: Communicate the purpose of the data collection and data sharing**
 - The purpose of the data collection and data sharing makes a difference in whether survivors are open to it or not. The purpose should be clearly communicated to the survivor.
 - Survivors need to know if their data is being used to obtain services, to fulfill a reporting requirement, to conduct research, to raise awareness of an issue, to pursue criminal justice response, or for some other purpose.
- **Guideline #4: Communicate the risks of the data collection and data sharing**
 - Survivors have a right to gain a thorough understanding of risk before participating in data collection or data sharing, so they can make an informed decision.
 - Risks may include safety, privacy, data security, stigma, fear of retaliation, fear of injustice, legal ramifications.
- **Guideline #5: Communicate the benefits of the data collection and data sharing**
 - Survivors have a right to gain a thorough understanding of benefits before participating in data collection or data sharing, so they can make an informed decision.
 - Benefits may include obtaining services, advancing research, improving policy or legislation, advocating for funding, raising awareness, or supporting prevention efforts.
- **Guideline #6: Communicate how the data are stored and protected**
 - Survivors have a right to gain a thorough understanding of how their data is being stored and protected.
 - Information about data storage and protection may include what database is being used, who has access to it, what data does it contain, how long data is stored in the database, how the database is secured, how external data requests are handled, etc.
 - Survivors have a right to know how they can revoke their information from a data system, if they decide in the future that they no longer consent to the sharing and storing of their information
- **Guideline #7: Seek to understand the survivor's perspective**
 - Some survivors may be at a point when they find empowerment and strength in sharing their stories and their information for advocacy purposes.
 - Some survivors may not be comfortable with collection and sharing of their own data, but they may support collection and sharing data sets about offenders, if that data can help prevent future violence, raise awareness, promote safety, or increase accountability for domestic violence.
 - Other survivors may not be comfortable with either their own data being shared or collected, or offender data being shared or collected. This perspective could be influenced by distrust of institutions or fear of miscarriage of justice in the relatively rare event of false charges.