

## HUD's Responses on HMIS Data Sharing and Use Guidance

***RTFH's Question: Is HMIS data, funded by federal dollars, a matter of public record?"***

**HUD's Response:** No. CoCs are required to review, revise, and approve a privacy plan and security plan for HMIS, which governs the circumstances under which data may (and may not) be used and disclosed. The privacy and security standards, as described in the [2004 Data and Technical Standards Final Notice](#), seek to protect the confidentiality of personal information while allowing for reasonable, responsible, and limited uses and disclosures of data.

***RTFH's Question: Does this guidance apply as well to disclosing other HMIS data outside of the scope of CE, or is this guidance in the CE Management and Data Guide limited to CE-related disclosures? And if it is specific to CE, are there any limitations with regards to the type of data to be disclosed, and how data may be aggregated and/or de-identified and/or anonymized?***

**HUD's Response:** The [Coordinated Entry Management and Data Guide](#) does not supersede the 2004 Data and Technical Standards Final Notice, which is still in effect and outlines the basic requirements for HMIS. Rather, the Coordinated Entry Management and Data Guide provides guidance on the application of HUD regulations in the context of administering Coordinated Entry in a CoC. As described in the introduction and purpose of the document, the Guide “*expands on the policy and management responsibilities described in the U.S. Department of Housing and Urban Development's (HUD) Coordinated Entry Core Elements document and its Notice Establishing Additional Requirements for a Continuum of Care Centralized or Coordinated Assessment System (“Coordinated Entry Notice”). This guide discusses aspects of coordinated entry management and evaluation, data privacy and security, and use of data to guide system change efforts.*”

All data in HMIS, whether collected for purposes of Coordinated Entry or otherwise, must adhere to the basic standards outlined in the 2004 Data and Technical Standards Final Notice and the local privacy, security, and data quality plans of the CoC.

***RTFH's Question: In terms of disclosure, does HUD have any written guidance on what de-identified or anonymized or aggregated data means in practice? How much data must be removed to no longer make a dataset PPI on its own (with recognition of the idea that combining any data of any type may transform individual data to PPI with enough additional information)?***

**HUD's Response:** Protected Personal Information (PPI) is defined in the 2004 Data and Technical Standards as:

*“Any information maintained by or for a Covered Homeless Organization about a living homeless client or homeless individual that:*

1. *Identifies, either directly or indirectly, a specific individual;*
2. *can be manipulated by a reasonably foreseeable method to identify a specific individual; or*
3. *can be linked with other available information to identify a specific individual.”*

HUD does not provide guidance on de-identification of HMIS data. A CoC in collaboration with its HMIS Lead/system administrator must determine the extent to which a client's data would need to be masked or altered to prevent identification to a specific individual.

***RTFH's Question: we are seeking HUD's guidance to confirm our understanding or to identify examples where something beyond the posted guidance may affect disclosures of client-level data. It is our understanding that the 2004 HMIS Data and Technical Standards Final Notice, expanded by the Coordinated Entry Management and Data Guide in combination with a local CoC's privacy notice are the documents that govern disclosures, their purpose, and describe the limitations placed on disclosures.***

**HUD's Response:** Your understanding is correct; however the 2004 Data and Technical Standards Final Notice provides **baseline/minimum** standards that all CoCs must follow in management of HMIS data. Your community should conduct a legal review of state, local, and other federal privacy laws to determine if there are more restrictive or limiting requirements for data in your CoC's HMIS. If so, these laws will need to be considered when developing your local HMIS data sharing policies.

HUD does not recognize a distinction in any agency's public/private status in the ability to disclose data from HMIS, outside of local laws or policies that may be in effect.

***RTFH's Question: Is there any definition or clarification regarding what sort of research may be considered academic?***

**HUD's Response:** The determination of what sort of research is considered academic is a local decision made by each CoC or Covered Homeless Organization (CHO). Please note, as detailed in the 2004 Data and Technical Standards Final Notice, disclosure for academic research purposes may only be made under the following conditions (emphasis added):

*“A CHO may use or disclose PPI for academic research conducted by an individual or institution that has a formal relationship with the CHO if the research is conducted either:*

- *By an individual employed by or affiliated with the organization for use in a research project **conducted under a written research agreement approved in writing by a program administrator** (other than the individual conducting the research) designated by the CHO; or*

- *By an institution for use in a research project conducted under a written research agreement approved in writing by a program administrator designated by the CHO.*

*A written research agreement must:*

1. *Establish **rules and limitations for the processing and security of PPI** in the course of the research;*
2. *provide for the **return or proper disposal of all PPI at the conclusion of the research;***
3. ***restrict additional use or disclosure of PPI**, except where required by law; and*
4. *require that the **recipient of data formally agree to comply with all terms and conditions of the agreement.***

*A written research agreement is not a substitute for approval of a research project by an Institutional Review Board, Privacy Board or other applicable human subjects protection institution.”*

***RTFH’s Question: For research, are there limitations on the relevance or purpose of the research that is allowable by HUD guidance? For instance, does HUD guidance differentiate between market research for financially-driven purposes and programmatic research attempting to better understand service models?***

**HUD’s Response:** As above, the answers to these questions are local decisions.

***RTFH’s Question: Does the omission of “academic” in the newer document modify any guidance HUD has given around research disclosures?***

**HUD’s Response:** No. As stated above, the Coordinated Entry Management and Data Guide does not “modify” the 2004 Data and Technical Standards Final Notice, which is still in effect in full.

***RTFH’s Question: It is clear in the 2004 HMIS Data and Technical Standards Final Notice that an agreement is to be used to destroy or otherwise remove data once the research has been completed when disclosing data for academic research purposes. Do other types of data disclosures require such an agreement?***

**HUD’s Response:** No, unless otherwise stated in a CoC’s privacy policies or local, state, or federal privacy laws in effect for your CoC’s HMIS.

***RTFH’s Question: Are CHOs allowed to charge a reasonable fee for their services in analyzing and extracting data for the purposes of disclosure (outside of the responsibilities of federal, state, or contractually-based reporting)?***

**HUD's Response:** HUD does not provide guidance on decisions regarding local custom reporting and analysis. However, some CoCs charge a participation fee, which may be flat or based on tiered criteria, to cover some or all of the operating costs of the HMIS. HUD expects HMIS project staff and CoC leadership to assess any HMIS participation costs, document the allocation of those costs, and assess any participation fees in a fair and equitable manner.

***RTFH's Question: To what level are CHOs or HMIS administrative bodies required or encouraged to share data with non-covered homeless organizations, and to what level of de-identification or anonymization or aggregation is it appropriate to share this information?***

**HUD's Response:** Data sharing decisions are governed by a CoC's HMIS privacy policy and privacy notice. HUD encourages CoC's to develop HMIS privacy policies that allow for reasonable use and disclosure of data to assist in coordination of services while maintaining transparency in data collection by providing participants with a written copy of the CoC's Privacy Notice. Please note, the uses and disclosures described in the 2004 Data and Technical Standards Final Notice describe circumstances under which a CoC is either required or permitted to share PPI or personally identifiable information (PII) without needing to obtain client consent. Thus, these circumstances would not require de-identification. In some cases, CoCs may decide to impose more limiting restrictions on data sharing, but these would be local decisions. More detail on uses and disclosures can be found later in this response.

***RTFH's Question: Does HUD recognize in any formal way the terms de-identified, anonymized, or aggregated and if so, are definitions available for each?***

**HUD's Response:** HUD does not provide definitions for these terms.

***RTFH's Question: As the HMIS and CoC lead agency, we currently publish public dashboards using aggregate data from HMIS-participating programs to our website. Is this activity (aggregating and publicly sharing information from HMIS) in compliance with the 2004 standards as HUD understands it?***

**HUD's Response:** The uses and disclosures described in the 2004 Data and Technical Standards Final Notice cover circumstances under which client-level PII might be accessed or shared. Publication of non-identifiable data in aggregate does not violate HUD's standards.

**HUD's Additional Guidance:**

Below is additional guidance HUD provides CoCs and HMIS Leads regarding Privacy and HMIS:

The [CoC Program interim rule](#) gives CoCs authority over and responsibility for HMIS. These responsibilities include:

1. Designate a single Homeless Management Information System (HMIS) for the geographic area;
2. Designate an eligible applicant to manage the Continuum's HMIS, which will be known as the HMIS Lead;
3. Review, revise, and approve a privacy plan, security plan, and data quality plan for the HMIS
4. Ensure consistent participation of recipients and subrecipients in the HMIS; and
5. Ensure the HMIS is administered in compliance with [requirements prescribed](#) by HUD.

## **Privacy Policy**

The privacy and security standards, as described in the [2004 Data and Technical Standards Notice](#), seek to protect the confidentiality of personal information while allowing for reasonable, responsible, and limited uses and disclosures of data.

Additionally, the [Coordinated Entry Management and Data Guide](#) offers the most recent guidance on Privacy in Chapter 2.

A provider must collect Personally Identifying Information (PII) by lawful and fair means and, where appropriate, with the knowledge or consent of the individual. When a provider is required by law to collect information it must ask for the required information, although participants may refuse to provide the information and still receive services. In all circumstances, providers should make data collection transparent by providing participants with a written copy of the CoC's Privacy Notice, describing the notice in plain language, and posting a public statement like the following:

- We collect personal information directly from you for reasons that are discussed in our Privacy Notice. We may be required to collect some personal information by law or by organizations that give us money to operate this program. The personal information we collect is important to run our programs, to improve services for persons experiencing homelessness, and to better understand the needs of persons experiencing homelessness. We only collect information that we consider to be appropriate.

## **Amending the Privacy Notice**

Section 4.2.4 of the 2004 Notice discusses amendments to the privacy notice. A participating agency **must** state in its privacy notice that the policy may be amended at any time and that amendments may affect information obtained by the agency before the date of the change:

From the 2004 Notice: “An amendment to the privacy notice regarding use or disclosure will be effective with respect to information processed before the amendment, unless otherwise stated. All amendments to the privacy notice must be consistent with the requirements of these privacy standards. A Covered Homeless Organization (CHO) must maintain permanent documentation of all privacy notice amendments.”

## **Updated guidance regarding data disclosures not requiring client consent**

“Uses” are internal activities for which providers interact with participant PII. “Disclosures” of PII occur when providers share PII with an external entity.

Once collected, providers have obligations about how PII information may be used and disclosed. Uses and disclosures either are **required** by HUD (e.g., participants’ access to their own information, oversight of compliance with the HMIS data privacy and security standards) **or are permitted** by HUD (e.g., to provide services, reporting to funders). HUD’s required and permitted uses and disclosures must be stated in the CoC’s Privacy Notice.

HUD requires two mandatory disclosures regardless of their inclusion in the Privacy Notice:

- Client access to their information; and
- Disclosures for oversight of compliance with HMIS privacy and security standards.

HUD permits the following uses and disclosures of PII without participant consent, provided that the uses and disclosures are listed in the CoC’s Privacy Notice. If any of these uses and disclosures are not listed in the Privacy Notice, client consent is required:

- To provide or coordinate services to an individual;
- For functions related to payment or reimbursement for services;
- To carry out administrative functions, including but not limited to legal, audit, personnel, oversight and management functions; and
- For creating de-identified reporting from PII.

HUD also permits the following types of uses and disclosures of PII without participant consent, provided that these additional uses and disclosures are listed in the Privacy Notice. If any of these uses and disclosures are not listed in the Privacy Notice, client consent is required:

- Uses and disclosures to avert a serious threat to health or safety;
- Uses and disclosures about victims of abuse, neglect or domestic violence;
- Uses and disclosures for research purposes; and
- Uses and disclosures for law enforcement purposes.

## **Method of Consent**

Should consent need to be obtained from the client for uses and/or disclosures that are not listed on the Privacy Notice, the HMIS standards in effect at this time do not specify what method or terms of consent are appropriate in order obtain client consent, nor do the current HMIS standards indicate that consent to share information about the members of a household must be obtained from all adult members of the household.

Decisions about appropriate levels of consent may be made locally and in accordance with any local, state, or other federal privacy regulations applicable to the situation.

### **Authority to make changes in HMIS Policy and Data Ownership**

Remember that the [CoC Program interim rule](#) gives CoCs authority over and responsibility for HMIS. As a result, data ownership/access questions should be addressed by the CoCs through any HMIS governance, policies, and/or agreements in place between associated parties.

### **More Assistance Needed**

HUD understands that this updated guidance may change local policies and practices that have been implemented under older guidance.

If this updated guidance poses significant barriers to further HMIS implementation work, HUD recommends that you request HUD Technical Assistance (TA). If TA resources are available and your request is approved, a HUD TA provider can offer on-call or on-site TA depending on the complexity of the need. Submit your TA request through the [HUD Exchange TA Portal](#). Grantees should work in partnership with project sponsors to coordinate project sponsor TA requests.

You can find community examples of forms used for HMIS governance, privacy and consent purposes by visiting this website: <https://www.hudexchange.info/programs/coc/toolkit/responsibilities-and-duties/coordinated-entry-samples-toolkit/#data-management>

Reference: [AAQ Question ID 232585](#)