



September 19, 2003

Michael Roanhouse
Office of Special Needs Assistance Programs
Community Planning & Development, Room 7262
US Department of Housing & Urban Development
451 Seventh St. SW
Washington, DC 20410-7000

RE: Docket No. FR 4848-N-01
Homeless Management Information Systems (HMIS) Data and Technical Standards
Notice

Dear Mr. Roanhouse:

Please accept these comments of the National Health Care for the Homeless Council in response to the proposed HMIS data standards. The National Health Care for the Homeless (HCH) Council is a membership organization representing grantees of the federal HCH program.

We recognize the importance of good data for the design of effective services; indeed, HCH projects have been pioneers in developing a scientific understanding of the needs and service utilization patterns of homeless people. We also recognize the Congressional mandate to seek an unduplicated count of homeless people. HUD and the researchers it has consulted have obviously taken these concerns quite seriously in developing the HMIS proposal. The distinction between “universal” (required) and “program-level” (optional) data elements is particularly important for the local communities that would implement HMIS.

However, we question the necessity of imposing a detailed, standardized data collection protocol on a huge and multi-faceted national body of service providers, when excellent longitudinal information describing demographic characteristics, conditions and service utilization patterns of homeless people already exists and is being used to re-design service delivery (cf. the emergence of housing first and permanent supportive housing models). Given the complexity of the decentralized HMIS design, the great variety of providers who are expected to participate, the widely varying capacities and sophistication of those providers, and many homeless persons’ protectiveness of their privacy, we believe that credible data will not be generated. Far less intrusive and burdensome statistical methods can be used to establish a reliable “unduplicated count of clients served.” Moreover, the proposed rule contains serious threats to the confidentiality of health care information and no provision for federal oversight of local HMIS. Finally, we believe that seeking data in the prescribed manner from homeless clients would

become a barrier to services despite the best intents of the researchers who designed the questions and the service providers who would be required ask them.

Participation Requirements

Section 1.5 of the notice, referring to conditions attached to certain HUD grant awards, indicates that agencies that receive those funds will be *required* to participate in local HMIS. Numerous HCH grantees participate in the relevant HUD funding streams, particularly as providers of services in the various Supportive Housing programs. However, in the chart “Priority Participation in HMIS by Program Type” on page 43437, the cell where HCH programs and “Permanent Supportive Housing” intersect is marked “NA.” The ambiguity of the proposed rule on this point would create confusion and inconsistent participation from community to community.

The “Priority Participation” chart also targets HCH and various other non-HUD funded programs that provide “Outreach to Street” as number 1 priorities for HMIS participation. In most instances, HUD is not funding these outreach services and has no authority to compel participation. The rule consequently sets expectations that “local communities” will obtain participation of non-HUD funded programs. The proposed rule does not address possible repercussions for “local communities” that do not obtain such participation, and should clearly state that no reduction of a community’s pro-rata share from HUD would result from its failure to include non-HUD funded agencies in HMIS. Otherwise, implementation of the rule would create great disruptive pressures within communities’ systems of services. (It is interesting that number 1 priority status obtains to “Outreach to Street,” in that street outreach is the setting where collection of accurate universal data elements is least likely.)

In Section 1.5, HOPWA and ESG recipients are “*expected*” to participate in HMIS. Is there a *requirement* that recipients of this funding participate in HMIS? Will they be sanctioned by HUD if they do not?

The proposed Rule does not involve the mainstream programs that are viewed by the Administration as the future major providers of services to homeless people. A successful HMIS would embrace the services provided by such programs as Medicaid, the Substance Abuse and Mental Health block grants, and public housing authorities. The proposed Rule could be an important vehicle for encouraging mainstream programs to track their interaction with and impact on homelessness, but it misses this opportunity.

At a time when HUD has begun to diminish its support for provision of services, HUD seeks to use local communities to secure the participation of homeless service providers. The proposed Rule refers repeatedly to the local Continuum of Care (CoC) as the operator of the HMIS and defers to local decisions made by the CoC. However, the proposed Rule nowhere establishes a clear definition of what constitutes a CoC or establishes legal authority for CoC’s. This murkiness is particularly troublesome when CoC’s are given significant latitude regarding the collection, use and management of protected personal information. The Rule should include a discussion of the status of CoC’s, including their potential liability for improper disclosure of protected personal information.

Cost and Administrative Burden

Implementation of HMIS by local service providers will impose costs that will reduce resources for actual delivery of services. A recent survey of HCH grantees indicates that local HMIS are often not consistent with existing HCH data systems, and that participation in HMIS would require, at a minimum, double entry into parallel data systems. HUD is not providing resources to offset these agency costs, but HUD's provision of resources to CoC's – in addition to siphoning off resources from housing and services – will provide greater local imperative for service providers to make the expenditures necessary to participate in HMIS. The cost of this data collection effort should be paid by HUD, using HUD administrative funds that will not reduce services to the homeless poor.

Privacy Concerns

In Section 2.0 and elsewhere, the proposed Rule identifies data elements that are to be treated – properly – as protected personal information, i.e., “any information that can be used to identify a particular individual.”

The “notice neither requires nor prohibits the sharing of client [i.e., protected personal] information among programs in the CoC, but does require that local policy regarding information sharing be established and that either client notification or written consent be provided for in the event that information is shared.” (Section 4.3) Elsewhere “Sharing of HMIS Data Among Providers Is *Encouraged* But Not Required.” (Section 1.4, emphasis added)

Sharing of client information among various programs would by definition allow access to protected personal information by HMIS users. “An HMIS user . . . is defined as program staff (*or trained volunteers*) and CoC system administrators who use the HMIS.” (Section 4.1, emphasis added)

In light of long-standing standards of health care confidentiality – as well as the requirements of HIPAA – we believe that health information that would be linked to “protected personal information” in HMIS databases must in no circumstances be accessible to HMIS users at other programs within the HMIS. We do not believe that HMIS users generally need to know health care information, or that health care consumers can reasonably give informed consent for their personal health care information to be made readily available to “trained volunteers” or staff in various agencies throughout a jurisdiction. The final rule should prohibit the entry of personal health care information into shared HMIS databases.

Three areas of the proposed Rule are of particular note in this regard:

- In Section 2.7, the required response categories for the question regarding residence prior to program entry, a universal-level data element, include “psychiatric facility,” “substance abuse treatment facility” and “hospital.” A positive response to any of these categories clearly reveals program-level data, defined in the proposed Rule as including “private or

sensitive information on topics such as . . . behavioral health status.” Asking for this level of specificity (as a universal data element) constitutes an invasion of an individual’s health care privacy. If this line of questioning is retained as a universal data element in the final rule, HUD should collapse these three response categories into one: “health care treatment facility.”

- In Section 3.13, the program-level data element “Services Received” requires use of the Taxonomy of Human Services. We note that this is a proprietary product not in the public domain, and we object to the requirement that agencies purchase the product in order to comply with the rule. The taxonomy’s 4,300 terms for services reach a level of specificity that will inevitably and clearly identify the health conditions of individuals served. Such information should not be available to HMIS users, and we believe that health care providers are ethically and legally prohibited from entering it into HMIS.
- A number of the prescribed program-level questions likewise reveal personal health information that should not be available to HMIS users. These include physical disability, developmental disability, general health status, pregnancy status, HIV/AIDS status, behavioral health status, and domestic violence. We note that the value of this data, collected by self-report usually at the time an individual is seeking services needed for survival, may be compromised by individual calculations regarding what is the most productive answer. Far better data on these conditions is available from data already collected by HCH providers and other health care professionals serving homeless people.

The proposed Rule does not require service providers who are gathering the information to clearly inform each client that the client’s refusal to answer any of the HMIS questions will not result in a denial of services. Without this protection, informed consent to *any* sharing of personal information is meaningless.

Additional Comments on Universal Data Elements

It is inappropriate to use Social Security Numbers, issued for a different purpose, as a personal identifier. Moreover, in the early stages of engaging homeless clients, requests for their Social Security Numbers have proven to become a barrier to their receiving services. Unique client identification numbers, useful for seeking an unduplicated count, can be readily generated without resort to collection of Social Security Numbers.

Poor memories, poor cognition and chaotic living arrangements may result in highly unreliable responses to questions 2.8 “Zip Code of Last Permanent Address” and 2.9 “Month and Year Left Last Permanent Address.”

Additional Comments on Program-Level Data Elements

We concur with the comment of our colleague Janna Wilson, Program Manager of the Health Care for the Homeless Network of Seattle-King County, that the difficulties posed by the

proposed collection of program-level data are so great that this part of the effort should be abandoned altogether.

For the record, we find the following specific items particularly troublesome:

3.7 HIV/AIDS Status. In some jurisdictions, it may be unlawful to ask this question to someone seeking services. We believe that the question should not be asked unless the program requires the information for its own diagnostic and treatment purposes, that is, only “if the program is prepared to help persons.” The question should not be asked only “for programmatic reporting purposes” such as HMIS data collection.

3.8 Behavioral Health Status. As above, these issues (e.g., “current . . . thoughts of suicide”) should be introduced only by an agency that is prepared to respond professionally to them.

3.9 Domestic Violence. We appreciate the recognition here that “it is only appropriate to ask these questions if the program is prepared to help the person.” However, we note that the prescribed line of questioning may be counter-therapeutic, and that the Rule should provide explicit permission to approach this area of inquiry in accordance with the interviewer’s sensitive professional judgement and agency policy.

The caution that “these questions should only be asked and recorded when a program has adequate data confidentiality protections to ensure that this person or location cannot be learned by anyone whom they themselves do not voluntarily provide or give permission to have this information” is absurd, though well-intentioned. Asking and recording the question does not place the individual at greater risk; the availability of the individual’s location on the HMIS system puts the individual at greater risk of being found by an abuser who already knows the answer to those questions. We know that very many homeless women and children and some homeless men are victims of domestic violence. To protect vulnerable persons from domestic violence, data confidentiality standards throughout the HMIS should be such that the location of any individual cannot be ascertained by an HMIS user.

Oversight

Nowhere does the proposed Rule describe a federal role in overseeing implementation of HMIS by CoC’s. The improved policies and safeguards that the final Rule will expect CoC’s to implement will be complex and critical for the protection of homeless individuals and for the generation of useful data. We do not believe that poorly-defined local CoC’s should be left to their own devices in implementing HMIS; HUD should implement a strong oversight role.

Aggregation of data

While the proposed Rule makes it clear that HUD does not intend to establish a national-level database, it remains unclear what aggregated, de-identified data will be shared by CoC’s with

HUD nationally. HUD's intentions regarding its collection and use of universal, program-level and elective data elements should be clearly stated as part of the rationale for HMIS.

Housing First

Finally, the record should note that with respect to ameliorating homelessness, the importance of determining the precise number of people seeking or receiving homeless services, their demographic characteristics and service utilization patterns pales in relation to the implementation of public policies producing adequate supplies of affordable and appropriate housing, adequate incomes, and effective and accessible health services. America has a low-income housing gap of at least five million units. Filling this gap must be HUD's first priority in the effort to address homelessness. The proposed collection of data on those who have been left behind by the housing market and their government is far less important.

Sincerely,

John N. Lozier, MSSW
Executive Director