

An Integrated Information Agenda For Mental Health

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Purpose

With the release of the report of the President's New Freedom Commission on Mental Health (2003), it seems very timely to review and update our integrated information agenda for mental health. Approximately two years ago, we prepared a similar document (Manderscheid, 2001). The present document is intended to update and amplify some of the points presented there. We will discuss the vision, framework, current status, role of information technology; and future opportunities for mental health information.

What is the vision?

Stated simply, the vision for mental health information focuses upon common data standards for the entire field. Ideally, these common data standards would have three attributes:

- Consensual development;
- Universal adoption;
- Implementation through information technology.

All data standards work undertaken in the mental health field seeks to develop consensus on the standards and their implementation. Specific attention is paid to inclusion of both private and public systems of care, consumers and family members, as well as providers, academic researchers and managers.

Data standards are framed within the context of "decision support" rather than "information management" to denote that the user is given options in the questions that can be answered, that the feedback loop of information can be modified directly by the user, and that the goal of information is to improve decision-making (Turban, 1988).

The data standards are being developed for the purpose of recording information in a common way. They are for use by local mental health providers and organizations, and the larger entities that embed these local systems (e.g., states and corporations). They are also for use by consumers, families, advocates and other mental health stakeholders.

Data standards, per se, do not address reporting of outcome or performance information, although the types of performance measures selected by managers influence data standards, and the data standards circumscribe the range of performance measures that are possible at any time. Such decisions about performance measures are independent of data standard content and information technology; they are, however, one important potential "decision support" use of the standards by system managers at local, state, corporate and national levels.

What is the framework?

The framework for these common data standards is Decision Support 2000+ (Manderscheid and Henderson, 2003). When completed, DS2000+ will include data standards for each domain of the public health model. The public health model is a systematic way of defining problems, our response to these problems, and the effects of our response.

Figure 1 outlines the domains of DS2000+, each of which will have a set of data standards that can be shared in common across the field. In addition to these data standards for common usage, each domain may have one or more stakeholder-specific sets of data standards (e.g., for public mental health services, for providers, or for consumers/families). The common or core data standards are designed to apply throughout the mental health field; the stakeholder-specific standards to a specific group or service setting.*

The domains require additional comment. First, for each domain, data standards already exist or one or more projects are under way to develop them. Second, the domains from population through clinical outcomes are basic; the other two, performance and report cards, are derived (Figure 1). This means that all data elements in the latter domains are computed from or are combinations of the former.

Logically, this implies that work on the performance and report card domains takes place after work on the other domains has been completed. However, this is not actually the case--work is proceeding in parallel. Although this is unavoidable, these parallel activities have the potential to foster confusion.

Figure 1: DS 2000+ Domains and Current Projects

Domain	Projects
Basic Domains:	
Population	Common data set being developed
Person/Enrollment	Common data set completed**
Care Encounter	Common data set completed**
Organizations	Common data set completed**
Financing	Common data set completed**
Human Resources	Common data set completed**
Clinical and Systems Guidelines	Preliminary outline only
Clinical Outcomes	Abt/ACMHA project underway
Derived Domains:	
Performance Measures	Field summary, URS, Carter Center Forum
Report Cards	MHSIP Second Generation Quality Report

** Includes all relevant HIPAA requirements for the eight mandated transactions

What are the current projects?

The primary project to develop DS2000+ is a contract with Abt Associates designed to coordinate the development of common and stakeholder-specific data standards for each of the domains. Beyond this primary project, a series of other projects (Figure 1) is

currently under way to actually develop the common and stakeholder-specific datasets for each domain.

Several additional comments are required about the work on specific domains. The final set of common population data standards will link the characteristics of communities with population epidemiology. It will rely heavily on a developmental contract project completed for the Center for Mental Health Services (CMHS) by ROW Associates; on the work of the National Co-morbidity Survey to develop, test and implement the Composite International Diagnostic Interview (CIDI) and its abbreviated stems for community surveys; and on the Centers for Disease Control Behavioral Risk Factor Surveillance System (BRFSS). The goal is a set of data standards suitable for conducting community and state surveys.

It is also essential that work be done on data standards for clinical and system guidelines. The logic for initial work has been developed, and we expect the work to proceed later in the fall through an initial meeting of experts in these areas.

Work on the clinical outcomes domain has been initiated in a separate project with Abt Associates. The common data standards in this domain will focus on provision of information to consumers and providers to help them with decisions that need to be made to achieve particular clinical outcomes.

An oversight group representing all elements of the field has been formed under the leadership of representatives from the American College of Mental Health Administration (ACMHA). Stakeholder workgroups will recommend content for common data standards in this area, and a technical expert workgroup will recommend measurement tools already in use in the field (including relevant content from the MHSIP Second Generation Quality Report) and will advise on technological implementation issues. For the stakeholder-specific component of these standards, an effort will be made to incorporate successful work already under way in the field.

Work on the performance measure and report card domains needs to be discussed together. Conceptually, this work is linked in the following manner: Once finalized, results from the Carter Center Forum on Common Performance Measures (both administrative measures and modularized consumer survey measures) will be incorporated into the Mental Health Statistics Improvement Program (MHSIP) Second Generation Quality Report and will serve as a sub-set of the common performance measures for OS2000+. Other features of the Quality Report that are directly relevant for performance measurement will also be adopted as part of this common set.

The final Uniform Reporting System(URS) currently being developed for Block Grant reporting under Performance Partnership Grants will become a stakeholder-specific data standard for public systems in the area of performance measurement; other performance measurement systems may also be adopted as stakeholder-specific standards for other groups.

What is the role of information technology?

At present, an essential aspect of developing data standards is embedding them into modern information technology so that they can be implemented broadly in a

comparable way. This work focuses on the development of Internet-based software that is accessed over the Web in a distributed system environment.

We have made considerable progress in developing this aspect of DS2000+. A partnership has been formed with the Software and Technology Vendors' Association (SATYA), and SATYA has agreed to two major actions: (1) incorporation of the DS2000+ data standards into the "first order" software they offer to local providers and organizations, and (2) assistance in defining the basic functionalities and common DS2000+ data elements to be incorporated into less elaborate information systems for individual and small group providers.

We have also developed a "second order" DS2000+ information technology prototype that is currently testing a range of functions:

- Uploading data from public and private systems.
- Mapping user data elements against Health Insurance Portability and Accountability Act (HIPAA) requirements (HIPAA Mapper).
- User creation of queries and online analytical processing.
- Development of benchmarks based upon data uploaded to DS2000+.
- Direct surveying of consumers with feedback of results using the Version1 MHSIP Adult Consumer Survey.
- Accessing detailed use and cost information from Medicare, Medicaid and private insurance plans.
- Easy access to key documents on OS2000+ and other field activities.

The direct survey function is currently being tested in Idaho as part of URS data collection. Once completed, the common data standards from the Clinical Outcomes project will be programmed to be collected in a similar manner. It should also be noted that the survey software will be in the public domain and can be used directly online or can be downloaded to a SATYA vendor package, a local intranet, or even a local PC.

The HIPAA Mapper will be generalized so that any data system can be mapped onto any other data system (e.g., one state system to another state system, a state system to the DS2000+ common data standards, a local system to a new set of federal Medicaid requirements, etc.). This functionality will have considerable utility in the future.

Clearly, information technology is an important new tool for use in implementing data standards. Once included in software packages, data standards are much easier to implement on a broad-scale basis. Also, there is less deviation from the original definitions, computations, scoring protocols, etc. with implementation through information technology.

What are the future opportunities for mental health information?

There are three watch words with respect to the future of data standards:

- Customization of decision support tools.
- Incorporation of feed back loops to improve self-direction and decision-making.
- The combination of quantitative and qualitative data.

Each of these watchwords has tremendous implications for the directions in which the field will need to move in the future. Implicitly, the watchwords were recognized by the President's New Freedom Commission on Mental Health in Goal 6: "Technology is used to access mental health care and information." Further, this goal was defined with two sub-goals: "6.1. Use health technology and tele-health to improve access and coordination of mental health care, especially for Americans in remote areas or in underserved populations", and "6.2. Develop and implement integrated electronic health record and personal information systems."

In each of these sub-goals, the commission reflected the "Crossing the Quality Chasm" work of the Institute of Medicine (2001) on reinvention of the healthcare system, which called for the broad implementation of information technology as part of quality improvement endeavors.

Conclusion

The implications for us seem clear. We must design information systems so that those seeking to use data can customize the results they derive from decision support systems to be most useful for the question or problem at hand and, at the same time, use standardized data that permit comparison with benchmarks and other users.

Also, we must move rapidly to implement information technology; with a consumer-first orientation, in order to combine qualitative and quantitative information in a feedback loop that provides useful guidance to consumers, family members, providers, organizations, states and corporate entities.

Together, these actions can lead to dramatic quality improvements in mental healthcare in the near-term future.



*Throughout the text, we distinguish between data standards for use by every one and stakeholder-specific data standards for use by a subgroup or setting. The terms "core" and "common" have both been used for the former and connote both shared (common) use and foundation (core) element; the term "stakeholder-specific" is the functional equivalent of "important" to a sub-group or setting. The reader is cautioned that these terms are sometimes used interchangeably. This can lead to confusion because of the different meanings involved.

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