



Local Area Information Systems for Mental Health Services: General Principles and Guidelines

Developing Outcome Orientated Information Systems
for Mental Health Services: Discussion Paper 1

**national
mental
health
strategy**

**Local-Area Information Systems
for Mental Health Services:
General Principles and Guidelines**

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Foreword

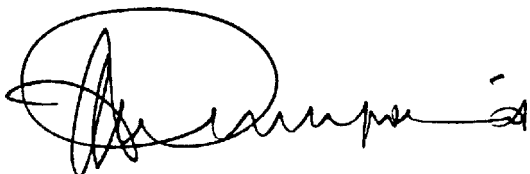
In 1992 when all Australian Health Ministers agreed to the National Mental Health Strategy, it was recognised that the lack of mental health data was a serious impediment to achieving the reform agenda. The Strategy is now approaching the completion of its first five years and with the Federal Government's recent Budget announcement of a further three years funding to the year 2001, it is timely to reflect on achievements in improving mental health data availability to date.

Activity has occurred at the State, Territory and Commonwealth Government levels to support the development of information systems, processes and business rules at the local level. The results of this activity can be seen in a number of ways; for example agreement has been reached on a mental health minimum data set for the institutional care setting and annual reporting on the Strategy has occurred through the National Mental Health Reports. Other areas where significant activity has occurred are: consumer outcomes where a national project is trialing measures of consumer outcome and facilitating information sharing regarding the benefits and challenges of different strategies of outcome measurement; funding models, where a national project aims to develop alternative models for funding mental health services including casemix classifications; and the endorsement and dissemination of National Standards for Mental Health Services for use by consumers and carers, and State and Territory mental health services.

Whilst much has been done since 1992 much remains to be done and, in most jurisdictions, little progress has been made in identifying who uses mental health services and why. This information will become available through minimum data set reporting for those who use inpatient services but information about consumers of non inpatient services still lags behind.

It is now time to build on what has been achieved and generate wider discussion on mental health information issues both for policy consideration and to inform developments in mental health service delivery information structures. In particular it is important to address the issue of how better quality mental health data can be made available to clinicians and administrators to improve the delivery of mental health services.

This paper will help to further such discussion by addressing issues surrounding the development of functional specifications for clinical information system design in mental health services and providing a statement of the minimum requirements needed to meet data needs of the National Mental Health Minimum Data Set. It also seeks to provide guidance to information system developers and mental health administrators who are developing or reviewing local-area clinical information systems. As such, I believe it will go a long way towards ensuring that new information systems will have the capacity to meet the requirements for national reporting.



Dr Harvey Whiteford
Commonwealth Director of Mental Health
September 1997

Contents

FOREWORD.....	ii
INTRODUCTION.....	1
Background.....	1
The Need For Information.....	2
The Key Stakeholders.....	4
WHAT INFORMATION IS REQUIRED?.....	5
Who Receives.....	5
What Services.....	6
From Whom.....	14
At What Cost.....	15
With What Effect?.....	15
General Functional Requirements.....	22
Specific Requirements Relating to Continuity of Care.....	25
INTEGRATING DATA COLLECTION INTO CLINICAL PRACTICE.....	30
Components of a Local-Area Information System.....	30
Identifying When Data Should Be Collected.....	34
Issues in the Use of Routinely Collected Data.....	39
THE DEVELOPMENT OF LOCAL-AREA INFORMATION SYSTEMS.....	41
Constraining Factors.....	42
General Requirements for Successful Implementation.....	46
Specific Functional Requirements.....	47
CONCLUSIONS.....	51
BIBLIOGRAPHY.....	53

Introduction

Background

The Information Strategy Committee of the AHMAC National Mental Health Working Group is developing the National Mental Health Minimum Data Set (MDS) within the framework of the National Mental Health Strategy and the National Health Information Agreement. The MDS comprises elements that will be able to be collected in in-patient as well as non-inpatient service settings.

Progress in developing the MDS has resulted in:

- two new items being added to the National Health Data Dictionary and the Institutional Health care National Minimum Data Set with a collection start date of 1st July 1996. These items were Mental Health Legal Status and Total Psychiatric Care Days; and
- endorsement under the National Health Information Agreement for a MDS comprising twenty six data elements to be collected from all psychiatric hospitals and all designated psychiatric units or services in acute care hospitals from 1 July 1997.

Further work is required in relation to implementation of the MDS (MDS) and using it in non-inpatient service settings.

Discussion surrounding the development of the MDS has identified that implementation procedure generally requires that State and Territory governments direct their specialised mental health organisations to collect information against specific indicators. This may be called a “top down” approach. Whilst this approach provides advantages, allowing for consistent data collection using a common vocabulary, there are also inherent disadvantages. Primarily this approach can impose an administrative burden without any immediate direct usefulness accruing to those collecting the information at the service organisation level.

Another approach is to provide a “roadmap” to information developments occurring at service level where higher level aggregate data become an administrative product of systems locally developed and designed around the information needs of service providers and consumers. This “bottom-up” mechanism can still meet the requirement of the MDS, but with better compliance in the collection of accurate data.

In the ongoing development of the MDS the AHMAC National Mental Health Working Group is combining elements of both the “top down” and “bottom up” approaches. This publication provides a statement of the minimum functional specifications for clinical information system design in mental health services to meet data needs of a MDS. It is an introduction and overview of the various issues that inform such functional specifications and which should be taken into consideration when designing systems for the acquisition and use of patient-related information by mental health service providers.

It should be noted that this paper is principally about issues relating to passive systems for the capture of data and its dissemination as useful information. Discussion of issues relating to the automation of clinical activities such as referral, order-entry and so on were not within the scope of the project.

The Need For Information

The fundamental aim of any publicly funded mental health service is to provide appropriate services to all those in need of those services. Clearly this task is challenging. Not only must effective interventions be identified and implemented, but ways must be found to package those interventions within efficient service delivery mechanisms that operate in an equitable manner. Implicit in all thinking about health service delivery are two very simple objectives. They are to use the best methods available and to keep improving the methods used. In the current technical language, these two objectives could be stated as: implement best-practice models for all aspects of the provision of mental health services;¹ and continuously improve the quality of the

services provided.^{2,3} However, our efforts in pursuing these two broad objectives are constrained by the simple social and economic fact that the need for services seems likely to always exceed the capacity of society to provide the resources required to meet all of those needs. As a consequence health care services must be rationed. Whether this rationing is based on explicit criteria of equity and efficiency (in all senses) depends on the degree to which the needs of people with mental illness, the costs of the services provided, and the health outcomes attributable to those services, are identified and clearly understood.⁴⁻⁶ The acquisition of information about the characteristics of the patient or client populations of mental health services and the health outcomes attributable to the actual mental health care services being provided is critical to the attainment of the two objectives identified above. It is the lack of reliable and timely information of this kind which is currently one of the greatest obstacles to the effective planning, delivery and improvement of the services provided.^{7,8}

In developing systems for the acquisition and use of information we should be guided by answers to the questions below.

- Who are the key stakeholders?
- What are their information needs? That is, what questions do they need the acquired information to answer?
- What data must be collected and when should it be collected?
- Who should collect that data and how can it be most effectively collected?
- Once collected, how can that data be transformed into useful, accessible information?
- Having acquired the information asked for, how can we ensure that it is effectively disseminated and used appropriately?

Answers to these questions enable us to specify and build effective local-area information systems. The information such systems can provide enable us to then evaluate the extent to which we are providing effective services in an efficient and equitable manner to those in need.

The Key Stakeholders

The principal stakeholders are the patients or clients of the service. Their main interests, in so far as they relate to information systems, include: that the processes through which they gain access to the mental health care services are efficient and that they operate in an equitable manner; that once initiated the quality of care they receive is of a high standard, and; that in moving between different service providers the continuity of their care is maintained.⁹⁻¹² Patients and their families and other caregivers are also particularly (and justifiably) concerned that any personally identified information be held securely and that only individuals directly involved in their care should have access to such identified information.¹³

Service administrators, clinical managers and clinicians needs and interests determine the form and operation of any local-area information system, and any proposed system must satisfy their requirements if it is to be acceptable and useful.

Clearly, these two major groups of stakeholders - consumers and service providers - have significant interests in what data is collected, how and when and by whom it is collected, and in how it is processed and disseminated. In the process of answering these remaining questions their requirements, interests and concerns must be considered if the implementation of local-area information systems for mental health services is to succeed.¹⁴

What Information Is Required?

In 1989 Walter Leginski and his colleagues in the U.S. Department of Health and Human Services argued that the questions asked by clinical managers and service administrators could be reduced to a set of five, very general questions, summarised succinctly as “Who receives what services from whom, at what cost, and with what effect?”.¹⁵ As these five questions are also asked, in a less abstract sense, by clinicians, the data collection and reporting needs identified through the consideration of those questions will define the core requirements of any local-area information system.

Who Receives

Who receives refers to the patients or clients who are the recipients of the health care services. The answer to this question is best given in terms of general indicators of the socio-demographic factors that determine risk of illness and equity of access to services and the clinical profiles, in terms of diagnosis and disability, of those who have contact with the service.

The critical socio-demographic variables to consider include sex, age, ethnicity (as indicated by aboriginality, country of birth, preferred language, etcetera.) area of usual residence, and employment status. The principal clinical variables to consider include indicators of the nature of the problem (usually but not always indicated by diagnosis) and a broad description of the type of care required. Definitions and classification schemes for many, but not all, of these variables can be found in recent editions of the National Health Data Dictionary.¹⁶

In the medical and surgical specialties it has been found that by combining the patient's age, sex and principal diagnosis with data on the procedures used in their care, it is possible to construct diagnosis-related groups that account for a large proportion of the variation in the costs of care.¹⁷ However, in psychiatry and especially in community-based psychiatric services, the classification of procedures is poorly developed so that classification of patients into diagnosis related groups is done solely on the basis of the

patient's principal diagnosis. It has been consistently shown that knowledge of a patient's principal psychiatric diagnosis often provides little insight into the severity and stage of their illness and the type of mental health care they may currently require.¹⁸⁻²⁰ In part, this reflects limitations in the diagnostic classification schemes used in psychiatry.²¹ However, a larger part of the difficulty stems from the fact that mental health services provide care to persons whose illnesses are often complex, with treatment being addressed to impairments or disabilities often, but not always, associated with their principal diagnosis.^{22,23} Therefore, in addition to the data items identified above, information on prognosis or phase of illness, comorbidity of substance use disorders and the level of psycho-social disability must also be included if clinically and administratively meaningful groups are to be defined.^{21,24-26}

What Services

What services refers to the actual services provided to patients. Answers to this question should describe the pattern and frequency of occurrence of various health service events. Several possible "classes" of health service event about which we might want information can be identified, including: service episodes; episodes of care; and occasions of service.

The unit of measure which captures the question "what services" is a complex one on which no uniform agreement has yet been reached.

Historically, service activity data for hospital inpatient services has been reported in terms of service episodes whilst for ambulatory care services it has been reported as counts of occasions of service. The principal reason for this appears to have been the difficulty of defining an episode in ambulatory care, with the major problem being that, unlike service episodes occurring in an inpatient setting, the duration of an ambulatory care service episode does not give a clear indication of the volume of services provided.

Despite the difficulties in obtaining an unambiguous and broadly applicable definition of an episode there are both clinical and administrative benefits in utilising the concept as the basis for thinking about what services have been or should be provided.

Clinically, the greatest benefit of having a notion of an episode is that it places a restricted time frame around the provision of services, during which the clinician expects to see some kind of health outcome occur. That health outcome may range from complete remission through to a slow but measurable improvement in quality of life. Whatever it is, the expectation is set up that there is some objective purpose to the interaction between the clinician and the patient. If that purpose is not attained within the expected time frame then the clinician can seek out reasons for that having happened and adjust their provision of care accordingly. In contrast, an open ended approach to the provision of services effectively means that today's emergency will always be more important. This can foster a band-aid approach to service delivery rather than a more collaborative, holistic and strategic approach to the planning of the care of patients. This is likely to be especially important for those people with chronic complex mental disorders.

Administratively, an unambiguous definition of an episode is critical if services are to be funded rationally. The funding model used by a health service agency is the critical instrument shaping the way services are delivered.^{8,27} Health service agencies want to be able to fund case-mix episodes, but without a definition of an episode that makes sense clinically and is related to the patients' actual health care needs, the definition of valid case-mix episodes is not possible. Without definition of valid case-mix episodes the provision of the kind of mental health care services believed to work best will be made even more difficult because service administrators will constantly have to fight the biases inherent in the funding arrangements.

From the service administrator's perspective the definition of episode also has importance because it defines the unit of service provision for which the expected

outcome(s) of the provision of that service may reasonably be defined, benchmarked, and assessed.

In the following sub-section the definition of episodes of care and of service episodes is discussed in some detail.

Service Episodes and Episodes of Care

A *service episode* can be defined as a period during which a person with some problem or illness requiring health care services receives such care from an identified service unit operating in a particular type of setting (such as a psychiatric inpatient unit in a general hospital, or a clinical team in a community-based mental health service). In contrast, an *episode of care* is an abstract concept referring to a period during which a patient receives a particular type of care for a given health problem or set of related health problems. During an episode of care the exact type and form of services provided are guided by a principal clinical intent (eg., relief of acute symptoms, rehabilitation of impairments, protection against relapse), the stated clinical intent being based on the nature and stage of the illness for which the provision of services is deemed necessary.^{16,p.2-1} Should a change in either the nature or stage of the patient's illness initiate a reformulation of the principal clinical intent and hence a change in the principal type of care to be provided, then by definition, the current episode of care will have terminated and if necessary a new episode will have been initiated.

The attributes characterising any given *service episode* include: the setting in which care is provided; the identity of the service unit responsible for the provision of care; the principal and additional types of care provided; the principal and additional interventions or procedures used in the treatment of the patient's identified health problem(s); and the dates on which the episode was initiated (admission or intake) and terminated (discharge or case closure).

The attributes characterising any given *episode of care* include: the type of care provided; the principal and additional interventions or procedures used in the treatment

of the patient's identified health problem(s); the setting(s) in which care was provided; the identity of the service unit(s) responsible for the provision of care; and the dates on which the provision of the identified type of care was initiated and terminated.

Clearly, the attributes characterising the two different kinds of episode are almost identical, with the important difference that the type of care provided during a service episode may change, whereas an episode of care is defined as a period during which a specific type of care is provided. Depending on the level of generality at which the attribute "type of care" is defined, several service episodes may be included within a given episode of care, or several distinct episodes of care may occur during a single service episode. Logically both alternatives are possible precisely because the episode of care is an abstract concept defined primarily by other abstract concepts like type of care, whereas the service episode is a (relatively) concrete fact defined primarily by the interaction of the patient with a service unit.

Although the most clinically natural and theoretically interesting questions about the provision of services relate to episodes of care, the basis for data collection should be the service episode and not the episode of care. There are a number of reasons why this should be the case. First, service episodes are concrete, easily identified periods, whereas episodes of care are abstractions whose definition depends very much on how the attribute "type of care" is defined. Second, for most practical purposes information is needed about the activities of service units and on the health outcomes attributable to those activities. Finally, by ensuring that data is collected whenever the principal type of care changes during a service episode, the characteristics and outcomes of episodes of care can be identified by looking within and across service episodes, depending on the level of generality at which type of care has been defined.

Interventions and Procedures

The attribute, type of care, when combined with information about the setting in which the care was provided - inpatient service, community-based residential, or ambulatory care - enables a general answer to the question "What services?" to be given. However,

this is clearly far too general for use by service administrators and clinical managers working at the local level, and for clinicians it is almost of no use at all. Hence, a means of identifying the actual interventions and procedures used in the provision of care is required.

The collection of data regarding interventions or procedures has a number of potential uses and is likely to facilitate the evaluation of patient care, the management of the systems of service delivery, the development of case-mix funding arrangements that reflect and encourage best clinical practice, and the assessment of the efficacy of specific interventions or procedures.²⁸ In order to remain consistent with the classification scheme for procedures being developed by the National Coding Centreⁱ we suggest that a general classification scheme for psychiatric interventions and procedures should have at least two axes, possibly three or four including:

1. the principal functional locus of action of the intervention or procedure.
2. the extent of modification of existing physiological, psychic or cognitive structures, personal routines, or interpersonal behaviours, or social relationships.
3. the degree of invasiveness, intensity, and/or duration of the intervention or procedure; and
4. the setting in which the intervention or procedure is carried out (indicating the degree of nursing care and behavioural or social support associated with the conduct of the intervention or procedure).

Once agreed definitions and classification schemes for the two data items *type of care* and *intervention or procedure* have been developed and validated, our capacity to describe what services patients receive will be greatly enhanced.

ⁱ In 1995 AHMAC gave the National Coding Centre (NCC) responsibility for the introduction of ICD-10 in Australia. Unlike ICD-9-CM, ICD-10 does not have an associated system for the classification of Procedures. As a consequence, the NCC found it necessary to embark on the production of an Australian procedure classification. This classification will initially be based on the existing Medicare Benefits Schedule (MBS), with extensions to cover a broader range of procedures. The NCC has begun the task by creating a multiaxial breakdown of the existing MBS procedure descriptions in terms of site, procedure, approach, device, qualifier, and so on.

Occasions of Service

The capture of data about occasions of service in the context of the ambulatory care service episodes within which care is being provided can serve useful and even critically important purposes. However, in their commentary on the definition of an occasion of service given in the National Health Data Dictionary,^{16,p.4-10} it is noted that the definition used takes no account of any of the attributes of an occasion of service that might relate to the level of resource utilisation which had occurred. In particular, it takes no account of the number of clinicians involved, the nature of the service provided, the duration of service, or the time of day when it occurred. At a very general level such a coarse indicator of service activity may have some use, but for service administrators and clinical managers, simple counts of occasions of service are of little use. What is needed is information that reflects the nature and extent of workload placed on the service by different patient groups. Clinical managers require this data at both an aggregate level for their service units and at the individual level for personally identified clinicians in the unit. The latter will enable clinical managers to more accurately judge individual clinician's workloads relative to their peers and so assist in the distribution and management of case-loads.

The collection of simple counts of occasions of service, in the absence of any other information about the nature of clinicians' workloads, also sends a very negative message about the health service agency's expectations of clinicians. By only collecting such data, the agencies are implying that they don't really care who the clinicians are providing services to, what services they are providing, or what effect the provision of those services has. The message is, just see as many patients as possible. Not surprisingly, clinicians have a low opinion of the collection of such data, with the result that many now view the collection of any data by health service agencies with suspicion. Thus, both the content of and the manner in which data collections are implemented may have significant implications for compliance by those providing the data, whether they be service providers or consumers.

A Minimum Data Set for Occasions of Service

Data items need to be developed which qualify each occasion of service with information that would enable the complexity and level of resource utilisation involved in each such service event to be identified. More comprehensive models for occasions of service have been defined by Leginski et al¹⁵ for the US Department of Health and Human Services and by the Victorian Department of Human Services²⁹ in its Community Services Information System. A number of common themes can be identified in the way in which occasions of service have been defined and characterised in the NHDD and by Leginski et al, the Victorian Department of Human Services, and others. They are summarised in the dot points below.

- Priority should be given to recording clinically significant activities directly related to the provision of services to patients or other persons.
- The immediate subject of an occasion of service may include: patients registered with the service and their family members and other caregivers; other persons not identified as patients of the service but to whom mental health services are provided; and service providers involved in the provision of services to an identified patient, including other providers of mental health services, other health service providers, and providers of other services such as welfare and education.
- The data model underlying a minimum data set for an occasion of service should be event focussed and should enable both the clinician(s) and the patient(s) involved in the event to be identified so that the participants in the event can be explicitly identified and its costs properly attributed.
- The principal clinical activity or purpose of the occasion of service should be identified. For example, occasions of service involving direct contact with the patient could be classified as: triage, assessment, or formal review; planned care in accordance with the interventions or procedures specified in the care plan; acute or emergency care; and other activities not elsewhere classified.

- Other attributes indicating the costs of the occasion of service should be recorded. Apart from the identity of the clinicians involved, the most important of these are likely to include the time of day at which the occasion of service began (eg. activities engaged in at 3 am are considerably more expensive than those at 3 pm), the place at which it occurred, and its duration. Where an occasion of service was identified as a response to psychiatric emergency, information about the actual nature of the emergency might also be captured.

These requirements imply the collection of a relatively small (6-10 data items) set of data for each occasion of service. The collection of such data is likely to be seen as a burden by clinicians and they will need to be convinced that, as service providers, they have a clear obligation to provide service administrators with information about the volume and nature of the services they provide. If such data is to be reliably collected by clinicians, not only will they have to accept their obligation to provide it, they will also need to see that the data is used effectively and appropriately by clinical managers and service administrators.

For service administrators, clinical managers and clinicians the collection of this data will provide a rich source of relevant information about the services provided to patients. Identifying efficient and informative schemes for the aggregation of such data within service episodes will present challenges not encountered when only simple activity counts were reported. Nevertheless, the combination of data about occasions of service with data about the service episodes within which they occur will throw new light on the very variable patterns of service utilisation exhibited by the diverse range of patients seen in ambulatory care mental health services. Comparison of these patterns of service utilisation across services using different models of service delivery are likely to be particularly informative and could be expected to be used, for example, in the development of quality of care indicators.

From Whom

From whom refers to the functional identity of the individuals or groups who provide patients with services. We say individuals or groups rather than clinicians because clinicians, clinical managers and service administrators may each have different individuals or groups in mind when they ask the question “From whom have these services been received?”. Clinicians generally want to know the personal identity of other clinicians or service units who are or have been involved in the patient’s care. Clinical managers may wish to know that, but they, like service administrators, will usually require answers to questions of a more general nature.

Typically clinical managers and service administrators need information about the establishments and associated service units for which they have responsibility. An establishment is defined in the National Health Data Dictionary (NHDD) as an independent unit separately administered in terms of financial, budgetary and activity statistics.^{16,p5-4} The concept of a service unit is not defined in the NHDD. Here a service unit is defined as a group of one or more clinicians who, for the purposes of clinical management, are treated as a single unit organised around the provision of a specific type or several related types of care. Such a group of clinicians will generally be located at or work from a single geographic location, but this is not a necessary attribute of a service unit. The prototypical example of a service unit might be a psychiatric ward located in a general hospital. As any one establishment is likely to encompass a number of different such service units, each of which may provide different types of care, it will be necessary for clinical managers and service administrators to have the capacity to identify services provided by each such service unit, as well as the capacity to aggregate that data up to the level of the establishment which is the administrative and financial unit responsible for its component service units.

At What Cost

At what cost refers to the quantity of resources used in the provision of services, where resources are taken to include both human and capital resources. Costs may be measured in financial terms, in terms of actual utilisation of resources such as staff type, numbers and time, inpatient bed days, etcetera, or in terms of the emotional burden experienced by clinicians when caring for certain kinds of patients under certain conditions.

The usual unit of measure of cost is the dollar value of the resources used. Whilst the financial cost of services is of particular interest to service administrators and those clinical managers who have financial responsibility for services, the other kinds of costs figure prominently in day-to-day management.

The costs of ambulatory service episodes will depend very much on the volume and costs of the occasions of service provided during the episode, with the cost of an occasion of service being principally determined by the time and the number and type of clinicians needed to provide the service. Collection of data regarding occasions of service, such as that identified under the section on “What Services”, will enable most of the costs associated with ambulatory care service episodes to be identified. It will also enable clinical managers to more effectively and equitably manage clinicians’ workloads.

The costs of service episodes occurring in inpatient and residential care settings will depend on the patient’s length of stay and the intensity of nursing care, supervision and assistance with activities of daily living required during their stay. The lack of any agreed system for identifying and classifying the type and intensity of psychiatric inpatient or residential nursing care means that at present this second major cost component can not be evaluated.

With What Effect?

With what effect refers to the outcome attributable to the services provided. This is the fundamental issue. Yet, clinical managers and service administrators have little if any

routine access to information about this aspect of the services for which they have responsibility.

The lack of routinely collected information about outcomes may at first seem surprising. As can be seen in Figure 1, the repeated assessment of a patient or client's clinical status is an integral component of the basic processes used in clinical practice. On referral to the service the person's needs and problems are assessed, then following any intervention their clinical status is reassessed. This whole process is both iterative and recursive, with many small cycles of assessment and intervention being encapsulated within any one episode of care.³⁰

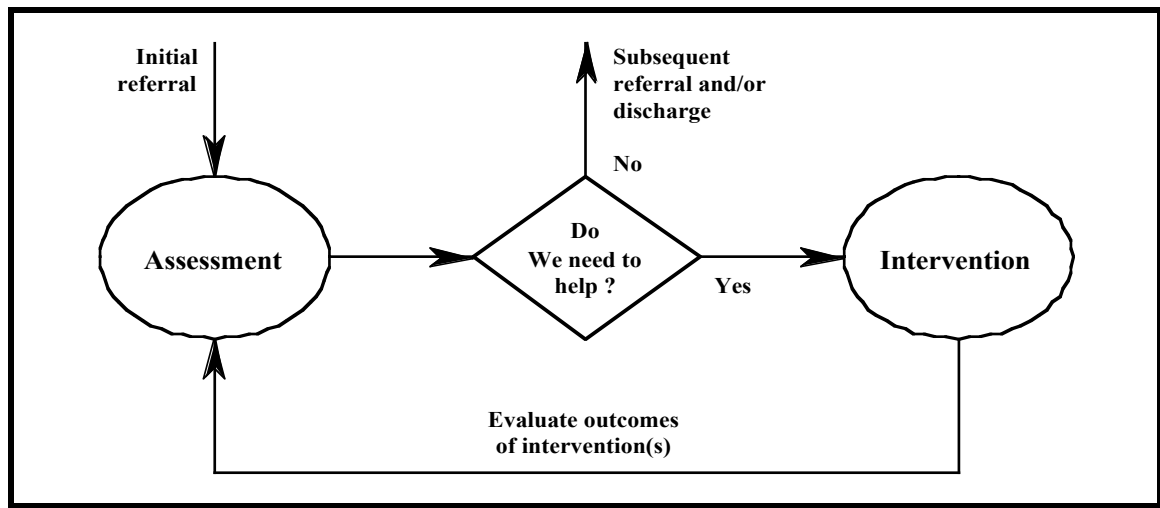


Figure 1: A flow chart depicting the recurring cycle of assessment and intervention used in clinical practice.

Although assessment is ubiquitous in clinical practice it is important to recognise that the assessment processes routinely used in clinical practice are usually related quite specifically to the client's current health problems and the interventions or procedures used in their treatment. As the costs of health care services began to rise at an increasing rate, health economists, health service agencies and service administrators became increasingly aware that they needed to broaden their focus to outcomes of a more general nature, particularly those relating to patients' quality of life and the degree of long-term interference to their life and activities associated with both their illness and its treatment.

The factors which brought about the need to broaden the outcomes focus included:

- The recognition that wide variations existed in the use of some interventions and procedures;
- Corresponding wide variations in the costs of services;
- A lack of any particularly rational justification for those variations in terms of known variations in the actual type of services needed; and
- An almost complete lack of information regarding how well different types of services worked, what differences existed in the outcomes of those services in terms that mattered to patients, and often no real information about whether many services actually met consumers' needs at all.

Initially, the pressing need to control costs by discouraging or preferably, eliminating, the use of ineffective practices led clinical epidemiologists and biostatisticians to call for the conduct of randomised controlled trials (RCTs) of all types of intervention. RCTs are the gold standard in evaluating the efficacy of any type of health related intervention.³¹⁻³³ There are however two significant problems with relying solely on the conduct of trials.

First, a controlled trial can only show that, when applied in a specific context with a specific group of patients or clients, a given intervention will have certain outcomes. Assuming that we have measured the outcomes that are of real importance to consumers,³⁴ the results of controlled trials can be used to identify which interventions

are likely to be efficacious and which are not. But by definition, they can't tell us anything about the services actually delivered to patients in general.

Second, the delivery of effective health care involves a great deal more than just the identification and provision of interventions or procedures of known efficacy. The provision of services occurs in the context of a highly complex apparatus - a context in which many factors other than the probable efficacy of any one intervention determine the overall outcome experienced by patients. Conducting RCTs of such an apparatus is unlikely to be a practical proposition, especially in a world where even the conduct of appropriately sized trials of single interventions is becoming prohibitively expensive.³⁵

This fundamental, but often overlooked, difference between the theoretical question "What is the likely efficacy of this intervention?" and the pragmatic question "What has been the actual effect of the use of this intervention?" is the major reason why the assessment of health outcomes must become an integral component of the routine data collection practices of mental health services. Clinical managers and clinicians need strategies and assessment instruments that enable them to routinely assess and monitor both process indicators and health outcomes relevant to the services being implemented and to the patient as a consumer of those services. Without such data, Clinical Managers and Service Administrators cannot properly evaluate the consequences of any changes they may make in the provision of services and are inhibited in their efforts to continuously improve the quality of services provided.^{36,37}

The Measurement of Consumer Outcome

Assessing the health outcomes attributable to the services provided by a particular mental health service, establishment or service unit is a problem of much greater difficulty than the determination of the likely efficacy of a specific intervention or procedure. Historically, there are many good reasons for the lack of routinely available information on health outcomes, including:

- Confusion about what should be measured;
- A lack of valid, reliable and clinically acceptable outcome measures; and

- Few guidelines regarding how routine outcome assessment should be integrated into standard clinical care.

Now, in the mid 1990s, the issues surrounding what should be measured and difficulties finding suitable instruments have begun to be addressed.³⁷⁻³⁹ In their recent report on the measurement of consumer outcome in mental health services (written for the Information Strategy Committee of the AHMAC Mental health Policy Working Group), Andrews, Peters and Teesson argued that the ... *measurement of outcome should be multidimensional, covering symptoms and disability*, and that both clinician ratings and patient self-reports were required.^{40,p.29}

The report was principally concerned with the identification of the best instruments for general use. Six instruments of acceptable reliability, validity and sensitivity to change were identified as likely to be of practical use and acceptable for routine use in the assessment of consumer outcome. The instruments are listed below.

Health of the Nation Outcome Scales (HoNOS) - A clinician completed, 12 item, rating scale designed explicitly for use in community-based mental health services.^{41,42} The scales were designed for use in monitoring progress towards the UK National Health Service's target of ...*improving significantly the health and social functioning of mentally ill people*.⁴²

Role Functioning Scale (RFS) - A clinician completed, set of four 7-point ratings scales covering the domains of work, independent living and self-care, immediate social network, and extended social network.^{43,44} Like the HoNOS, it was explicitly designed for use on an area-wide basis.

Life Skills Profile (LSP) - A clinician completed, 39 item, rating scale designed to assess patients' abilities with respect to basic life skills over the preceding three months.^{45,46} The profile has five scales: self-care, non-turbulence, social contact, communication, and responsibility.

Behavior and Symptom Identification Scale (BASIS) - A self or interviewer administered, 32 item scale, explicitly designed to measure the outcome of mental

health care (particularly inpatient care), with a focus on the patients' perspective of their self and relations with others, depression and anxiety, impulsive and addictive behaviour, and psychosis.⁴⁷

Mental Health Inventory (MHI) - A self administered, 38 item, questionnaire assessing general psychological distress and well-being.^{48,49} Summary scores on subscales representing anxiety, depression, loss of behavioural or emotional control, general positive affect and emotional ties, as well as a global score representing general well-being can be derived.

Medical Outcomes Study Short Form 36 (SF-36) - A self or interviewer administered 36 item questionnaire designed to assess general symptoms of physical and mental health, functioning and quality of life.^{50,51} The SF-36 is now the most extensively used general measure of health outcomes.⁵²

The above list represents only some of the range of valid and reliable measures now available for general use in adult mental health services.⁵³ Quite a number of the recommended instruments are already in routine use. For example, the HoNOS is now in routine use in at least 14 health regions in the UK and the Life Skills Profile is in regular use in a number of regions in Australia.

Perhaps the most difficult aspect of the evaluation of the health outcomes is the need to attribute outcomes to services provided. Clearly, the health outcomes experienced by any individual person are determined by a whole range of factors, only some of which will be influenced by the care provided by the health service. Nevertheless, clinicians and service administrators need to know if the services they provide have an effect. The question of attribution can not be avoided. However, until we have well developed classification schemes for the different types of services provided and have collected sufficient benchmark data describing the outcomes experienced by a broad range of consumers following the provision of various types of care in a broad range of settings there are likely to be great difficulties in making such attributions.

In conclusion, a successful strategy for the routine assessment and monitoring of health outcomes by mental health services must meet several criteria. First, the strategy to be implemented should enable causal associations to be identified between the services provided and observed health outcomes. Second, the strategy must be capable of being implemented in mental health services in such a way as to provide the required information in a timely manner. Third, the strategy must be capable of being implemented routinely. This last requirement is important because, although there are a number of outcomes assessment strategies that could be used in one-off assessments of the outcome of a specific intervention, such strategies will not allow the outcomes of changes in either interventions or service delivery protocols to be monitored or their implementation to be continuously improved. More importantly, such one-off strategies are by their very nature not integrated into the delivery of care and hence return little information of immediate value to the Clinician asked to collect the data.ⁱ

We argue that because the assessment of health outcomes must serve a number of different purposes, there is unlikely to be just one model for its conduct. Instead, we suggest that a comprehensive strategy to achieve the twin aims of introducing best-practice into all aspects of service delivery and continuously improving the quality of the services provided requires both routine assessment of health outcomes associated with the actual mental health services provided and the conduct of methodologically rigorous trials of specific therapeutic interventions. The conduct of randomised controlled trials is an area that is now comparatively well understood and examples of successfully completed trials of such complex problems as the evaluation of case management have been published.⁵⁴ But, as Andrews, et. al have pointed out, much less is known about the conduct of routine outcomes assessment. In the preceding Section

ⁱ The distinction between data and information is an extremely important one in this context. The term data is generally used to refer to the essentially arbitrary and meaningless codes used to summarise some domain of reality in a way that can be effectively dealt with by computers and statistical tools. Information is the meaning drawn out of that data through interpretation and comparison with other data sets by informed users. It has generally been the case that clinicians have been asked to provide data but have not been given any information in return. This may be one of the reasons why clinicians show a considerable degree of scepticism about administrators' needs for more data.

we have outlined a strategy for integrating the routine collection of health outcomes data into the process of service delivery in a way that is likely to make sense and be useful to Clinicians and provide Clinical Managers and Service Administrators with valuable data about the effects of the services being provided.

Routinely collected data on outcomes will certainly not be free of the biases normally associated with case-control or prospective cohort designs used in epidemiological research. Despite such limitations, routinely collected, standardised data of this kind will allow Service Administrators to develop clinical profiles of their current Patient population; develop baselines against which modifications to existing services may be evaluated; conduct preliminary evaluations of the efficacy of new interventions and service delivery protocols, and; develop and validate case-mix classifications for mental health services. Similarly, regular collection of standardised data on outcomes for individual Patients may enable Clinicians or Clinical Managers to assess individual Patient change over time; assess the effect of specific interventions or service delivery protocols on groups of Patients, and; identify unusual variations in outcome which may be indicators of the need for closer attention to their practices.

General Functional Requirements

The answers to the five questions: Who receives what services from whom, at what cost, and with what effect; elaborated in appropriate ways according to the specific needs of service administrators, clinical managers, and clinicians, represent the core questions that a local-area clinical information system might be used to answer.

Therefore, stated in general terms, the minimal functional requirements of any such system are that it should facilitate the collection and transformation of data into information suitable for use in answering those five key questions.

Put in more specific terms, a local-area clinical information system for mental health services must be capable of efficiently capturing and reporting data regarding the socio-demographic and clinical profile of their patient population, the utilisation of services,

especially staff time and hospital beds, by those patients, and the effects of the provision of those services. In order to do this effectively and efficiently systems for routine outcomes audit and review should be implemented. Such systems must be capable of capturing the data items required by the MDS together with a small number of additional data items related to the type of care being provided. They must also be capable of recording a small number of data items describing each patient-related activity or occasion of service. Finally, they must be capable of capturing, processing and reporting data collected using standardised assessment instruments, such as those reviewed and recommended by the consultancy report on the measurement of consumer outcome in mental health services.⁴⁰

The Minimum Data Set

The Minimum Data Set (MDS) that has been approved by the National Health Information Management Group^{55,56} for collection from all psychiatric hospitals and all designated psychiatric units or services in acute care hospitals from 1 July 1997 comprises the following data items: establishment identifier; person identifier; sex; date of birth; country of birth; aboriginality; marital status; area of usual residence; type of usual accommodation; employment status; pension status; type of episode; problem status; admission date; discharge date; total leave days; mode of separation; source of referral; referral to further care; total psychiatric days in care; mental health legal status; principal diagnosis; additional diagnosis; diagnostic related group; major diagnostic category; intended length of stay. As indicated below in Table 1, definitions for all items are in the National Health Data Dictionary¹⁶ and the majority of the items are collected in the Institutional Health Care Minimum Data Set. Those items that are not included are: type of usual accommodation; employment status; pension status; problem status; and referral to further care.

Table 1: The data items currently identified as constituting the recommended National Minimum Data Set for Mental Health Services, with their status as items in the Institutional Health Care Minimum Data Set (IHC MDS) and the proposed Community Mental Health Care Minimum Data Set (CMHC MDS)

Data Item	NHDD Item Code	Approved IHC MDS	Proposed CMHC MDS
Establishment identifier	P 1	✓	✓
Person identifier	P 2	✓	✓
Sex	P 4	✓	✓
Date of birth	P 5	✓	✓
Country of birth	P 6	✓	✓
Aboriginality	P 7	✓	✓
Marital status	P 8	✓	✓
Area of usual residence	P 9	✓	✓
Type of usual accommodation	P10	✓	✓
Employment status	P14	✓	✓
Pension status	P20	✓	✓
Type of episode of care	P21	✓	
First admission for psychiatric treatment	P23	✓	
Admission date	P24	✓	
Date of first contact	not defined		✓
Date of last contact	not defined		✓
Discharge date	P26	✓	
Total leave days	P27a	✓	
Mode of separation	P31	✓	
Source of referral	P29	✓	✓
Referral to further care	P32	✓	✓
Total psychiatric days in care	P114	✓	
Mental health legal status	P115	✓	✓
Principal diagnosis	P35	✓	✓
Additional diagnosis	P36	✓	
Diagnostic related group	P41	✓	
Major diagnostic category	P52	✓	
Intended length of stay	P53	✓	

Specific Requirements Relating to Continuity of Care

The discussion below is based on the fifth of the National Health Strategy Information Papers, in which continuity of care for people with chronic mental illness was discussed in detail.⁷

In general, health services are organised to meet the needs of people with episodes of illness which, although acute in intensity, are circumscribed and relatively brief in duration. Such acute episodes are usually handled very well. However, people with chronic mental illnesses, such as schizophrenia, bipolar disorder, major depression and the more severe anxiety disorders, have needs which are complex and which are likely to extend over a long period of time, often many years. Since the 1960s significant reforms in the way mental health services are delivered have been made. Unfortunately, the community-based health and other support services needed by people with chronic mental illness, are fragmented and inadequate. This fragmentation of services means that access to the services needed over extended periods and in accordance with one's changing needs is the critical real issue for persons with chronic mental illness. What is required is continuity of care - long-term access to the range of services needed, unrestricted by organisational or structural barriers.

The principal barriers to continuity of care appear to be structural, there having been ... *no fundamental alteration in the organisational or financing arrangements at Commonwealth, State, or Regional levels.*^{7, p.9} Despite the fact that the great majority of persons with chronic mental illness now live in the community, the bulk of financial resources are still directed towards hospital and institutional services. The effect of the existing funding arrangements is that ... *there are few financing incentives for the integration of public and private specialised mental health services to ensure wider access and continuity of care for people with chronic mental illness.*^{7, p.9} In practice this means that intersectoral links between general health, mental and disability and support services are still poorly developed.

A number of strategies for reform have been identified. For the most part these will involve changes to the organisation of State mental health services and their funding arrangements. The principal tool needed here is a case-mix classification system for mental health services which is relevant to Services operating on a model in which hospital and community based services are closely integrated. These service models have a number of common features:

- *the use of case management as the principal type of care;*
- *a multidisciplinary approach to service delivery;*
- *an assessment program which offers a single point of entry into an integrated service;*
and,
- *an information system to support the continuity and integration of service delivery.*^{7,p.10}

With regard to information systems, two principal requirements were identified in the Issues Paper. First, the information system should support the collection of standardised, comparable data about who is gaining access to what services. Therefore ... *a nationally consistent, co-ordinated system of collecting information on the provision of mental health services is essential. Mechanisms are also required to monitor the use of social and disability services.*^{7,p.13}

Second, the information system should support the organisational arrangements and procedures known to facilitate continuity of care. In practice, this means that ... *a single integrated information system across an area mental health service, tracking patients across treatment settings is essential to ensure that patients are not “lost in the system”.*^{7,p.94} Such a system should be able to support integrated management of the patient across hospital and community settings.

There are a number of aspects to the requirement that an information system support integrated care across different settings. All are related to what Clinicians working in one setting need to know about the patient and the care provided to the patient in other settings. This is likely to include:

- In what other settings has the patient received care?
- What care was provided in those settings and why was that care provided?
- Who was the clinician principally responsible for the management of the patient's care in each of those other settings?

The task for systems developers is to ensure that the information is made available to those with a need to know, without putting the patient's privacy and confidentiality at risk. There are a number of solutions to this problem.

The principal strategy relating to the implementation of information systems to facilitate continuity of care centres around mechanisms for ensuring that information collected in each establishment and service unit of an integrated service is available to all clinicians involved in the provision of care to the patient, wherever the patient may currently be located within the service as a whole. Mechanisms to facilitate the sharing of information include:

- Adoption of region-wide Personal identifiers (medical record number, unit record number, etc.) for patients.
- Implementation of computer-based local-area clinical information systems which enable access to summary information regarding:
 - the settings in which the patient has or is receiving care,
 - the type of care provided in each of those settings,
 - the reasons for the provision of that care, and
 - the identity of the clinician responsible for the management of the patients' care in each of those settings.
- Implementation of procedures and systems which ensure that, in making access to personally-identified patient information easy for clinicians with a legitimate need to know, patients' privacy and confidentiality is effectively protected. Failure to do so will result in the withholding of vital information by patients and clinicians frightened of the consequences of disclosure, and as a consequence the preceding strategies will also fail.

Essentially, the preceding requirements imply that each service unit in a region-wide integrated mental health service should have secure access to the same computer-based local-area clinical information system.

Where there are shared-care arrangements involving general practitioners or psychiatrists working in private practice outside the administrative structure of the health service agency, consideration should be given to mechanisms for facilitating those arrangements. At the very least this might involve the identification of the fact of the shared-care arrangement and the identity and contact details of the external clinician in the local-area clinical information system. Similar requirements may apply to other agencies actively involved in the provision of rehabilitation, accommodation and support services to patients. The possibility of actually giving those agencies some degree of restricted access to the computer-based local-area clinical information system should also be explored.

For each type of external arrangement, consideration needs to be given as to how much information should be recorded in the computer-based record and how much should be left in the paper-based medical record.

In some cases, it may be worth identifying the provision of services by an external service provider as a distinct, concurrent service episode. This would greatly facilitate the identification of the nature of the services provided (type of care or service, interventions and procedures) and the capture of information regarding health and other outcomes for that episode. The advantages of doing so need to be weighed against the questions of who would be responsible for the maintenance of such records and what the cost of that maintenance would be.

Where the services provided by an external service provider form a significant component of the mental health care services required by the consumer then it is likely that their involvement should be recorded. The information to be recorded could include: the identity and contact details for the service provider; the date on which the care provided by the service and that provided by the external service provider became linked

(formally or informally); the nature of the linkage between the service and the external service provider; the type of care or service provided by the external service provider; and the date on which the care provided by the service and the identified external service provider ceased to be linked.

Integrating Data Collection Into Clinical Practice

The determination of what data should be collected is relatively straightforward.^{37,40,57} However, in their report on the measurement of outcomes Andrews et al noted that *...we know of no service where routine measurement of consumer outcome occurs in all patients, and there is no model in the literature which lays down proven guidelines for implementation.*^{40,p.85} There are two significant issues remain to be solved before routine data collections which include outcomes assessment can be fully implemented in community-based mental health services. These are the questions regarding when the data should be collected and how the collection of that data should be integrated into clinical practice.

Components of a Local-Area Information System

The question of how routine data collection should be integrated into clinical practice is best answered by examining the components of a local-area clinical information system. Our aim is to identify the sequence of processes which might enable data collected in the course of clinical practice to be most easily transformed into information available to service administrators and funding agencies.

The data flow diagram shown in Figure 2 is a general representation of the processes which give rise to the major classes of information required by clinicians, clinical managers and service administrators. In the diagram, processes that create or transform data and information are identified by ellipses whilst the principal stores of data created by those processes are identified by open ended rectangles.⁵⁸

The flow of information is shown as first arising out of the actual assessment and review procedures used by clinicians. These procedures include both the instruments used and the protocols specifying when and how the assessments or reviews should be carried out.

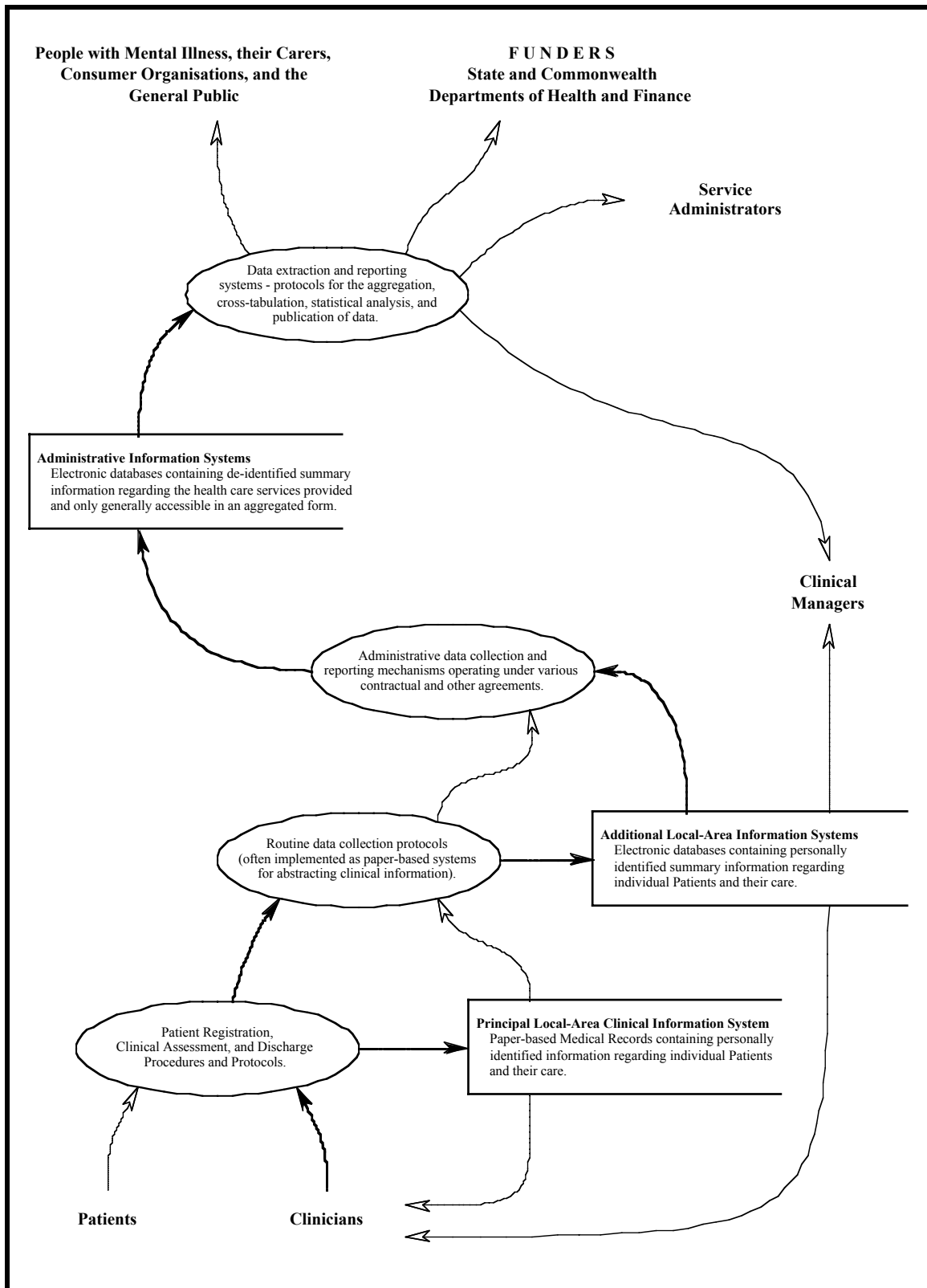


Figure 2: A data flow model depicting the information stores, processes, and the various sources and recipients of that information (the key stakeholders).

Some assessment procedures may be quite formally defined and may be based around the use of structured interviews and other standardised instruments. Others may be based entirely in the standard clinical interview or in simple discussion with and observation of the patient, with only the clinician's final conclusions being recorded.

Regardless of how they are obtained, the recorded results of such assessment procedures will be stored in the service's principal clinical information system, the paper-based medical record. This system is also used for recording formal statements and other notes regarding the provision of care, including such things as records of admissions, progress notes, discharge summaries and so on. In the data-flow diagram this information store is identified by the open ended rectangle in the lower third of the diagram. The medical record is the primary store of personally identified information about patients and their care. When clinicians or clinical managers need to refresh their memory or formally review a patient's recent clinical history it is also their primary source of such information.

Often a service will also have a secondary computer-based information system in which summary data regarding admissions, occasions of service and discharges are recorded. These systems may also be used as quick reference sources by clinicians. In the data-flow diagram this information store is identified by the open ended rectangle in the middle of the diagram.

The aggregated and summarised information needed by clinical managers and service administrators is derived from personally identified data about individual patients. These stores of de-identified and aggregated information are identified by the open ended rectangle in the upper third of the diagram. Such data may be collected using paper-based forms during the process of assessment, it may be extracted from the paper-based medical record, or it may be directly exported from the secondary computer-based information systems used to support the admission and discharge of patients. The systems which process this data must enable the production of routinely required reports regarding such things as the number of patients receiving care and so forth. They

should also enable clinical managers and service administrators to make ad-hoc queries in which one or other variable is cross-tabulated against others. The nature of these ad-hoc queries will change according to the immediate needs of the manager or administrator and can not generally be defined a priori.

Thus, a local-area clinical information system must make available several distinct classes of information. The first includes personally-identified information relating to individual patients, the second includes only personally-deidentified individual (unit record) data, and the third includes aggregated or group data and information. All three classes of data and information require systems for their collection and use, and, as a consequence, the major stakeholders must also have some interest in the systems used to collect data and turn it into useful information. From the stakeholders' perspectives, the information system as a whole may be divided into three primary components:

- The actual assessment and review procedures used by clinicians, including both the instruments used and the protocols specifying when and how the procedures should be carried out;
- The information systems, both paper-based and electronic, used to support the client registration, assessment, service provision, review, and discharge procedures, and;
- The data aggregation, statistical analysis, and reporting systems which convert information about individual identified patients into aggregate data and information suitable for use by clinical managers and service administrators.

The implication of the above is that the processes used in recording the results of assessments at admission or intake, review, discharge or case closure, and follow-up, together with the processes used in making a record of services as they are provided, are the primary sources of information for any computer-based local-area information system. Because the effective operation of those processes has a direct impact on patient care, very careful thought must be given to the procedures used for the assessment and review of patients' socio-demographic and clinical status, to the information systems used to collect and process the data collected, and to the statistical procedures used to aggregate and transform data into information.

Identifying When Data Should Be Collected

In routine clinical practice information is ascertained and recorded as needed. Usually, there will be some formal guidelines for how and when clinical assessments should be completed and their results recorded, what progress notes should contain and when they should be completed, and so on. In order to cope with the complexities of clinical practice, such guidelines do not define what must be collected or when it should be collected in very precise terms. Thus, clinicians generally only record what information they need when they see a need to. The paper-based medical records have a correspondingly loose structure, with their temporal structure being primarily imposed by the natural history of the person's illness and the rhythm of care being provided. This generally suits the needs of clinical practice quite well. But, because the reason for collecting the minimum data set is to develop and maintain a standardised source of information about the provision of services, the collection of data on outcomes or of the data constituting the minimum data sets can not be based on such an unstandardised framework.

Some examples relating to the questions "Who receives What services?" and "What services were provided with What effect?" may help illustrate why timing issues are so critical.

Answers to the question "Who receives services?" should be based on the Patient's socio-demographic and clinical status at the beginning of the service episode. However, it is often the case that a Patient's clinical status at the beginning of a service episode is not fully understood until some time part way through the episode. Therefore, the answer to such questions is often ascertained at the end of the episode. These considerations are reflected in the National Health Data Dictionary's definition of a number of socio-demographic and clinical data items. For example, the patient's "Type of usual accommodation" is defined as: *The type of accommodation the person lived in prior to admission.*^{16,p.3-24} Similarly, the patient's "Principal diagnosis" is defined as:

The diagnosis established after study to be chiefly responsible for occasioning the patient's episode of care in hospital.^{16,p.3-86}

Answers to the question “What services were provided with what effect?” should be based on information regarding the Type of care provided during the service episode and the patient’s clinical status following the episode. Again, these considerations are reflected in the NHDD’s definition of “Principal procedure”, which is defined as *...the most significant procedure that was performed for the treatment of the principal diagnosis.*^{16,p.3-93} As yet, the NHDD is silent regarding outcome indicators. However, on the basis of the discussion of health outcomes in the preceding section, it is likely that, at the very least, the assessment of the patient’s clinical status at the beginning and at the end of the service episode would be required.

Thus, in relation to service episodes provided in acute inpatient settings the situation is relatively straightforward. Information regarding the patient’s socio-demographic and initial clinical status should be collected at the beginning of the episode and information about the patient’s final clinical status and the services provided should be collected at the end of the episode.

The situation with respect to service episodes in ambulatory care mental health service settings is more complex, primarily because episodes of rehabilitation or extended care provided in such settings can often be considerably longer than that of the median inpatient admission of two to three weeks. This has significant consequences for the collection of those socio-demographic data items representing patient characteristics that are likely to change over periods of several months or more. For example, an episode of extended care may last for several years. Knowing what the patient’s type of usual accommodation was at the beginning of that episode may be of some interest, but it is not likely to be as useful as knowing what their current type of usual accommodation is. Similar comments apply to virtually all such socio-demographic data items and to all clinical data items.

In the discussion of outcomes assessment it was noted that many cycles of care may occur within a whole service episode. In such cases the assessment of the outcome of

any one episode of care during a longer service episode can be conceptualised as a review of the patient's clinical status. The question is, when should such reviews be conducted? One logical point at which a review could be expected to be conducted is immediately prior to a change in the principal type of care or the intervention or procedure used in the patient's treatment. However, for some patients' with a chronic but stable course of illness, the principal type of care and the interventions or procedures used in their treatment may not change over quite long periods. Also, as it is likely that the definition of a good outcome will vary quite markedly across different patient (casemix) groups, the choice of follow-up or review interval can not just depend on changes in the type of care provided. This issue lies at the core of the problems encountered in the routine assessment of outcomes. There are two ways of approaching this question.

We could ask, given a specific type of care (eg. General, Acute, Rehabilitation, or Extended) provided to a specific group of patients, at what time following either the initiation or the cessation of that care would the most important positive and negative effects of that type of care be likely to become apparent? This paradigm places specific emphasis on the evaluation of the care provided.

Alternatively, given that a person had a specific general type of illness (belonged to a specific diagnosis related group perhaps), what types of specialist care and interventions should be provided, and what positive and negative outcomes might be expected in the light of the expected course of that illness, both in the absence of any specialist care and when the expected types of care and intervention were provided? When would those outcomes become apparent?⁵⁹ In that it places less emphasis on attribution of outcomes to specific types of care and intervention, this second paradigm is more open and conducive to a whole system perspective.

In either case, the full specification of a data collection protocol requires considerably more information than is currently available. We should therefore resort to an interim, less fully specified solution.

The CHASP Standards⁶⁰ provides a way out of this difficulty. Under the heading Comprehensive Care, Standard 1.5 states that: *The Service will provide the range of care services needed to ensure people's health is comprehensively addressed.* Indicator 1.5.6 then asks: *Are care plans for long term users of the service reviewed at least every three months?*

Therefore, where a service episode exceeds three months in duration, a record of the review of the patient's socio-demographic and clinical status should be collected at three month intervals and whenever there has been a change in the principal intervention or procedure prescribed for their treatment. Where a review was prompted by a change in the patient's legal status, a record of that review should also be collected.

Thus, the goal is to collect data at points in the process of care that make sense both clinically and administratively. This will generally mean conducting assessments at the beginning and end of an episode and at appropriate points during and possibly also following the episode. Where an episode extends over a long period, say greater than three months, then, as the CHASP Standards indicate (Standard 1.5, Indicator 1.5.6),⁶⁰ the patient's care plan should be reviewed and this is also likely to be an appropriate time to assess the outcomes of the care provided during the preceding period.

In brief then, it is proposed that data be collected at the following points during and after a service episode:

- At admission to hospital or intake into community-based care;
- At any time during a service episode when the Principal type of care being provided changes;
- Every 3 or 6 months (as appropriate) during a service episode in a community-based service during which the Principal type of care being provided does not change over a period of 3 months or more;
- At discharge from hospital or case closure in community based services; and,
- At an appropriate short-term follow-up point following a service episode.

These points all make good clinical sense. Collection of data in accordance with such a protocol would give rise to a well structured data set that was both clinically relevant and statistically tractable.

On the basis of the above discussion five occasions of assessment can be formally identified.

Intake Assessment

On this occasion of assessment only the patient's identity, contact details or physical location and presenting problems are likely to be ascertained. The information collected at this point is most likely to characterise why the patient obtained access to the service.

First Complete Assessment

On this occasion of assessment the patient's full socio-demographic and clinical status can be defined. At this point the type of care to be provided and the Principal and Additional interventions and procedures to be used in the provision of that care may be identified. Note that a record of a first complete assessment should only be collected after the responsible clinician has completed their first comprehensive clinical assessment. In community settings this stage may often be reached after several contacts between the patient and the clinician making the assessment - hence the need for the specification of both an Intake and a First Complete assessment occasion.

Review Assessment

Like the First Complete Assessment, on this occasion of assessment the patient's full socio-demographic and clinical status can be defined, including the type of care to be provided, the interventions and procedures to be used in the provision of that care, and any other indicators of health outcome relevant to that phase in the person's illness and its care. Note also that a record of the Review Assessment might be collected either during or after the actual conduct of the Review.

Discharge Assessment

A Discharge Assessment is virtually identical to a Review Assessment in its intention, with the additional collection of information regarding the termination of the episode.

Note that in order to be of any clinical or administrative use a record of a Discharge Assessment must be collected and entered into a computer-based local-area clinical information system immediately following the patient's actual discharge.

Acute Care Follow-Up Assessment

Patients should routinely be followed-up at approximately 28 days following discharge from any hospital admission. The 28 day delay to follow-up is specified because any significant positive or negative consequences of the hospital admission are likely to have become apparent at the time; the 28 day period corresponds with the period usually identified as the period within which readmission is said to represent evidence of premature discharge; and 28 days post discharge is likely to be an appropriate time for the clinician and patient to reconsider the care plan.

In services which are not fully integrated or where patients discharged from hospital are not routinely followed-up by community-based mental health services an Acute-care Follow-Up Assessment will be an important component of the assessment of the health and other outcomes attributable to Acute care. In practice this type of assessment should resemble a Review Assessment.

Issues in the Use of Routinely Collected Data

The routine collection of identified data on "Who receives what services from whom, at what cost and with what effect" based on individual episodes of care is likely to expose all service providers, whether they be health service agencies, regional health service administrations, individual establishments, service units or clinicians, to an intensity of inspection and comparison of their performance never before experienced. This is a very complex issue and very careful consideration must be given to identifying what are the appropriate uses of the information gathered and what are the appropriate means of

dissemination of such information. In particular, the comparison data regarding one region, establishment, service unit, or clinician with another must be handled with great care.

The use of information about what appear to be excessive negative variations away from a benchmark or median level of one or other indicator is particularly vulnerable to misuse. Service administrators and clinical managers must be trained in the proper methods for use of such data. This includes a thorough understanding of its limitations. In particular, all users of the data must understand that at the level of the individual clinician, such data can not, on its own, be used as a measure of performance. Every clinician, indeed every service unit, works within a complex system where the performance of any one individual is partially determined and constrained by the structure and limitations of that system. For example, an individual clinician's capacity to provide effective care to any one patient is determined to a large extent by factors outside their control. These factors include: the amount and quality of training they have received; the number of patients they are expected to care for; the number of other clinicians they are working with; the level of experience and training of those other clinicians; and the quality, experience and level of training of their clinical managers and service administrators.

The routine collection of data on health outcomes is of vital importance to the effective administration of mental health services. Careful selection of outcome measures and the development of information systems that return useful data to clinicians in real time can also make the collection of such data useful rather than burdensome to clinicians.

However, service administrators and clinical managers must be very careful in their use of this type of data.

The Development of Local-Area Information Systems

We began this paper with a discussion of the questions that needed to be asked in order to guide our development of systems for the acquisition and use of information. The first question was: Who are the key stakeholders? It is easy to understand that only the key stakeholders can really answer questions about what information should be collected, and because of the critical need for information regarding the delivery and outcomes of mental health services, most of our discussion so far has revolved around the specification of the information requirements of clinical managers and service administrators. But there is also a need to understand the context within which such systems are likely to be implemented and the various constraints arising out of both that context and the general nature of information systems development as an engineering discipline.

There are a number of constraining factors which must be taken into account when considering the design and implementation of local-area information systems. First, all publicly funded health services still rely on the paper-based medical record as their principal information system. This reliance is unlikely to change in the foreseeable future, no matter how alluring the prospect of the fully computer-based medical record may appear.⁶¹⁻⁶³ Second, the environment within which such information systems are required to function is constantly undergoing change. Often these changes are imposed on the health system by forces external to it, but in many other instances the changes are brought about by the continuing evolutionary developments in all aspects of the health care system itself. Furthermore, the process of information systems development is itself an evolutionary process. These issues are discussed in greater detail below.

Constraining Factors

The Primacy of the Paper-Based Medical Record

The principal information system in use in all publicly funded mental health services, whether they be hospital-based or community-based, is the paper-based medical record. Despite its many well-known limitations, the paper-based record is the legal document wherein the complete record of the patient's medical history is recorded. Given the significant difficulties, both theoretical and pragmatic that have been encountered in the development of fully computer-based medical records,^{61,62} it is unlikely that the paper-based record will cease being the principal store and source of information about patients' medical histories for some time.⁶³ The implications of this, seen in the light of the earlier discussion of the components of a local-area clinical information system, is that any attempt to add functionality to a computer-based system will necessarily result in some form of duplication or conflict with the role played by the paper-based record. Whilst the long-term goal is to develop and implement fully electronic and automated medical records systems, the immediate goal should be to add functionality to the existing paper-based systems, not compete for functions.

The potential for a fully automated electronic record associated with various decision support tools has long been recognised. Yet as early as 1968, Octo Barnett, a physician working in the laboratory of computer science at Massachusetts General Hospital, recognised many of the difficulties which still confront us some 30 years later.⁶⁴ His concluding comments regarding what he called hospital information systems were that: *The initial wave of optimism and enthusiasm generated by beguiling promises of an immediately available total hospital computer system has passed. Now, efforts are directed towards the painful, slow, evolutionary process of developing and implementing modules or building blocks for individual functions.*^{64,p.1326}

The startling point raised by this quote is that, so far as community-based mental health services are concerned, many States have no platform on which such building blocks could be placed.

Fully electronic medical records will become a reality,⁶⁵ but because the paper-based record is so intimately integrated within the process of care, the transition from completely paper-based systems must be incremental. At the present time the practical implications of implementing anything approaching an electronic medical record in mental health services are not well understood. There are simply too many details that will only become apparent as we build systems and learn from experience. Successful implementation of relatively simple systems based on the general principals and functional requirements outlined in this paper are likely to have considerable impact on clinical and administrative practice in their own right and will represent a very significant first or second step for most regional service administrators.

Evolutionary Development

The second constraint which should guide the development of local-area information systems derives from the recognition that the development of both health care services and information systems is continuing at a rapid rate. Any attempt to develop a complete and comprehensive information system in such an environment is likely to entail considerable risk of failure. Gilb⁶⁶ has discussed alternative development methodologies in detail and presents a convincing argument that an evolutionary approach is the only sane way to proceed. By this, Gilb means that we should identify key stakeholders core information requirements and the critical performance attributes of the system that, were they not to be met, could render the system unacceptable. A system which meets those requirements should be developed and implemented first and then used as the basis for further developments.

The development and implementation of information systems is an inherently iterative process. The initial specification of an information model and functional requirements is essentially an hypothesis about what might be required. The act of implementing a system based on that model and those requirements should therefore be formally treated as an experiment, with close attention being paid to users' experience with that new system. Expectations that a system can be built and implemented "once and for all"

must be abandoned for, once implemented, use of the system by the key stakeholders will change their understanding of their functional requirements.⁶⁶⁻⁶⁸

Costs and Benefits

Finally, it is a simple economic fact that the benefits we seek in terms of increased access to reliable, valid and timely information will have definite financial costs.

Most systems or organisations become more cost effective as they get larger because adding a unit only incurs a marginal cost that is directly related to the costs of the addition. Information systems are different - costs bear a logarithmic relation to the number of data items.⁶⁹ To many this seems nonsense, after all what computers do well is handle vast quantities of data effortlessly. That is true, they are excellent at handling vast quantities of the same data item, but by adding new data items and relating those data items to other already existing data items, we add not just the new field but a whole set of new relationships, potentially the number of new relationships is proportional to the number of data items already in the system. To take a very simple example: with three items there are three potential relationships, with six items there are 15 and with twelve items 66 potential relationships. Now, not all data items need to be linked to all others, and some data items like date of birth need only to be recorded once, and other data items like date of admission have a very restricted use. Nevertheless the exponential rise in cost with the increasing size of the data set is real and can be attributed to a number of things.

It is obvious that the more complicated a data set the greater the programming and debugging time required, and the greater the cost of software maintenance and support. Maintenance costs especially rise with complexity. More complex applications obviously require larger machines on which to run and, once there are cases loaded into the database, are more likely to have their performance degraded as the application deals with the complexity of the relationships between the data items. But the real cost is not to do with the programming and the hardware, it is related to the costs of training staff

to understand and be competent to enter the larger data set and the staff time required to capture all the items accurately.

Where the collection of a data item or data set conveys a clinical benefit then the cost can justifiably be discounted to some extent. Often however, the benefit of data required by one group of stakeholders is not immediately apparent to others. Moreover, in order to retain its utility any data collected must reach or exceed acceptable levels of validity and reliability. In some cases the costs of obtaining valid and reliable data of the exact type needed may be unacceptable, so less valid or reliable data must be accepted.

A small system capable of meeting the data collection requirements of the National Minimum Data Set would be likely to capture 30 to 40 data items by the time treatment and outcome variables are included. It is sobering to realise that while a 20 item system might cost \$50,000 per year per site in maintenance, staff training and data entry costs; a 40 item system could cost five times this. Managers might well decide that the additional 20 items are just not worth the expense. Small is beautiful, at least until one knows precisely why each item is being collected and the extent to which the additional items will contribute to the efficient running of the service and the better treatment of the patients.

The Need for Parsimony

Taking into consideration the relevant needs and interests of the key stakeholders, the primacy of the paper-based medical record, the range of costs likely to be incurred as system size is increased, and the advantages of an explicitly experimental and evolutionary model of systems development, we conclude that the principle of parsimony must guide the design and development of any computer-based local-area information system. Systems should be kept as small and simple as possible. Unless clinicians can be given a clear and acceptable rationale for the collection of a data item it should not be included in a routine collection. And if service administrators, clinical managers, and clinicians are subsequently found not to actually make use of a data item, report, or other system component it should be excluded or deleted.

General Requirements for Successful Implementation

Based on consideration of the likely interests of the above mentioned stakeholders, practical experience in introducing new information systems in mental health services, and the theoretical rationale and context for the changes being introduced, five related components required in the successful introduction into mental health services of local-area clinical information systems which include routine outcomes assessment and review procedures can be identified. These are:

1. The identification of data items and outcome measures or indicators that are both clinically relevant and relevant to the overall health outcome goals of the service.
2. The development of protocols that enable standardised data collection and outcomes assessment procedures to be smoothly and effectively integrated into clinical practice.
3. The development of effective local-area clinical information systems capable of quickly processing assessment information and generating reports for use by clinicians and clinical managers.
4. The development of associated systems which enable service administrators to query the data held in clinical information systems and quickly obtain answers to the diverse range of questions they may wish to ask about the services they administer, without violating the privacy and confidentiality of patients or clinicians.
5. The development of training materials and programmes to instruct:
 - a) clinicians in the ascertainment of individual data items and in the conduct of the assessment and review protocols;
 - b) clerical and other staff in the use of the information systems; and,
 - c) clinical managers and service administrators in the appropriate use of the information.

Each of these five components is critical to the successful implementation of local-area clinical information systems. In any one region, initial failure to successfully develop

and implement any one component may not cause the whole endeavour to fail, so long as there are dedicated staff willing to plug the gaps. There are numerous examples of local-area information systems which limp along despite their many obvious disabilities and handicaps. However, since part of our goal is to introduce the collection of the MDS and procedures for outcomes assessment and review in such a way that they become a routine component of the service, we believe that the implementation of systems that are reliant on unusually intense levels of support would be inappropriate. Service administrators should not be expected to put in place systems that will require the same attention to detail as a controlled trial. Such a result would defeat the object of the exercise.

Specific Functional Requirements

The minimal functional requirements for local-area information systems are quite straightforward. The critical point to remember is that the paper-based medical record is the principal local-area clinical information system. The aim is to add functionality, not compete for functions.

Data Collection

The system should enable the collection of the data items included in the proposed MDS, together with a small number of additional data items characterising the initiation of a service episode, the type of care provided during the episode and the current status and outcome of the episode. This local-area minimum data set should be collected at the First Complete Assessment of the patient, at any formal Review Assessment, and at Discharge. Standardised data on health outcomes, including information on both symptoms and disability should also be collected at the above occasions of assessment.

The key issue in successfully integrating this data collection regimen into clinical practice is to develop clinically meaningful definitions and classification schemes for the principal attributes of both service episodes and episodes of care, type of care and intervention or procedure. The point in time at which a decision to change the principal

type of care provided should then be the trigger for the formal Review of the patient's clinical status discussed above.

The system should also enable data on occasions of service to be collected. A minimum data set characterising an occasion of service should consist of no more than ten data items.

All data entering the system should be captured on paper-based forms. clinicians may, but should not be required to enter any data.

Reports

A small number of reports are likely to be of routine use, principally lists for use by clinicians and their clinical managers. Several, more flexibly defined reports can be defined for use by clinical managers and service administrators. However, most of their information requirements centre around ad-hoc investigations of unusual variances or trends in data. Therefore, an effective local-area clinical information system should enable personally de-identified unit record data to be exported into other systems for ad-hoc queries and statistical analyses. These facilities should not be built into the clinical information system itself. The following list identifies the key reports likely to be routinely required.

Reports regarding the clinical status of individual patients

- Current Episode Summary (similar in form to a discharge summary)
- Current or Other Episode History (tabulation of clinical profile and outcomes at each assessment occasion)
- Summary History (tabulation of all episodes characterised by start and finish dates, class or service provided, summary clinical profile, etc.)

Lists of patients currently receiving care or requiring attention

- Current Case List by Responsible Clinician (identity, location, principal diagnosis and type of care)

- Current Case List by Service Unit (a brief summary including patients' identity, principal diagnosis and type of care, and their responsible clinician)
- Cases Due For Review
- Cases Requiring Follow-Up or Closure (no recent record of an occasion of service)

Reports for clinical managers and local service administrators

- Occasions of Service (number, etc.) by Responsible Clinician
- Clinician's Workload (casemix in terms of diagnosis, type of care, occasions of service)
- Service Unit's Workload (as above)
- Outcomes by Patient Group (aggregated by casemix classification, type of care, etc.)
- Data Quality (proportion of missing data, clinically unusual data combinations)

Service administrators and clinical managers are likely to need training in the use of the very rich information source that even a minimum data set will provide them with. In particular, they will need training in how and why not to draw hasty conclusions!

Provision of Summary Data

The content of summary data records exported to administrative data collections requires careful consideration. In particular, the level of detail at which data on outcomes and occasions of service should be made available to State and Commonwealth Health Departments will require negotiation. Discussion of these issues is beyond the scope of this paper.

Privacy and Security

All access to personally identified data should be strictly controlled in accordance with the Commonwealth's Information Privacy Principles, the Australian Standard AS 4400-1995 Personal Privacy Protection in Healthcare Information Systems,¹³ and each State Department of Health's Guidelines.

System users must be identified by personally identified logon procedures and an audit trail of all access to personally identified data should be kept and reviewed. Automated mechanisms for identifying possible inappropriate accesses should be developed to ensure that the audit trail is effectively utilised.

Administrative guidelines regarding privacy and security need to be developed, staff need to be educated in their content and application, and those guidelines must be rigorously enforced.

Conclusions

Modern healthcare services and their information needs are constantly evolving. No information system built now can meet all the requirements system users will come to identify. System development should therefore follow an evolutionary model. The initial cycle of design and implementation should be completed as soon as possible, with the goal being to produce the smallest possible system, at the least expense, with the largest immediate utility for the key stakeholders.

Few if any ambulatory care mental health services have any experience in the routine collection and use of the wealth of data identified above. As a consequence, system design and implementation must be approached in an explicitly experimental and scientific manner, with very careful attention being paid to feedback from users of the systems. Pilot testing must be taken very seriously by all involved, with the explicit intention being to reconfigure initial prototypes in the light of such feedback. Any attempt to identify all functional requirements and solve all design issues before a system is implemented is likely to result in excessive time lags to implementation with the very real risk that the users' requirements will have moved beyond the proposed final solution by the time it appears.

Nevertheless, local-area information systems developed in accordance with the principles and minimal functional requirements specified in this paper could be built and implemented immediately, without great difficulty or cost, and with considerable benefit.

Assuming that staff see the benefits in the implementation of such a system and that the system development and pilot testing processes are handled properly, the only major issues for services will be training clinicians to reliably collect the information required and ensuring that service administrators, clinical managers and clinicians use the information appropriately.

The implementation of local-area clinical information systems capable of supporting routine outcomes audit and review has many potential benefits for all the identified

stakeholders, it has a few costs, and for clinicians and patients it has some dangers. And although we believe that the benefits far outweigh the costs, we also believe that failure to address the dangers would result in the ultimate failure of the implementation. It is therefore critical to effectively address the issues relating to the security and confidentiality of identified patient data, and the appropriate use of routinely collected outcomes data in continuous quality improvement rather than in the identification of possibly incompetent individual clinicians. Failure to address these two issues could well result in both passive and active subversion of the system by service providers and consumers.

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