
Mental health information systems: problems and opportunities

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Medical and nursing staff in acute specialities spend up to 25% of their working lives collecting, analysing, using and communicating information (Audit Commission, 1995). It is likely that staff delivering mental health care, which often involves services and staff based in a number of locations and inter-agency collaboration, spend just as much of their time on these activities.

Despite this enormous expenditure of time and effort, problems of poor recording of information, and failed communications, cause daily frustrations for clinicians and managers and are often cited by inquiries as having contributed to adverse clinical events. Too often the clinical record of a long-term psychiatric patient is dispersed in several jumbled sets of clinical notes. The presentation of the complete picture to individual workers caring for a patient might require the amalgamation of information contained in medical (in-patient and out-patient, psychiatric and acute hospital, primary and secondary care); nursing (hospital and community); psychology; social services' and depot clinic records, all of which might be stored at different locations. The value of these records is further reduced by its incompleteness and a lack of standardisation in the way in which information is recorded. Clinical audit of the quality of case-notes invariably demonstrates that important clinical data items are either incomplete or missing altogether (Cunningham, 1991; Butler & Greenberg, 1994).

These problems make it difficult to systematically monitor changes in the clinical condition of individual patients, in response to clinical decisions, let alone conduct routine monitoring of the effectiveness of a service using aggregated measures of patient outcome.

Data for service management are usually collected and processed through channels that run

in parallel to clinical data systems. These data too are incomplete, inaccurate and inadequate for purposes as diverse as the balancing of caseloads, monitoring of clinical quality and service contracts, and provision of returns for central planning.

The vision

If the huge amount of NHS time invested in clinical data collection was channelled using existing computer technology, through a rational system of information management, the NHS would benefit from more efficient, and perhaps more effective, patient care. The mass of clinical information, collected by the mental health care team about each individual under its care, could be captured and ordered into true personal healthcare records.

With proper controls to ensure security against unauthorised access, appropriate elements of this comprehensive personal healthcare record could be made available to all involved in care, and to the patient. They could also be made accessible whenever and wherever needed, whether that was to a community psychiatric nurse (CPN) in a mental health centre; a psychiatrist during an out-patient clinic; a GP in a primary care centre; a duty doctor in a casualty department in the early hours of the morning; a social worker making a care management assessment, or the home of the on-call consultant.

As well as improving completeness and accuracy, such records would minimise the wasteful duplication of information gathering that often characterises multi-disciplinary teamwork. Time saved in repeating clinical assessments, and collecting basic demographic information, could be used by clinical staff for patient care and by clerical staff to perform

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data quality checks on the accuracy and completeness of the record.

Agreement within clinical disciplines and between agencies on the use and definitions of common clinical terms concerning symptoms, signs, diagnoses, problems, needs, actions and outcomes could lead to standardisation of the way in which information is gathered and coded. This would open paths for better communication between those involved in mental health care and for comparisons between providers.

Such complete and standardised records would minimise the need for parallel systems for collection of data for service management which could instead be derived from clinical data through aggregation.

Box 1 lists some of the benefits that could accrue from such a system.

Box 1. Potential benefits from an integrated clinical information system

Routine measurement and monitoring of clinical outcome
 Electronic transmission of clinical messages to other workers in and beyond the NHS
 Clinical audit of outcomes of care
 Large scale epidemiological research
 Clinical administration, such as balancing caseloads
 Service planning
 Contract monitoring
 Comparisons between activity levels of providers
 Planning by the NHS Executive

The problems

There are considerable problems to be overcome before this vision can become reality. Clinicians must take some of the blame for the existing situation for not having attended adequately to issues of clinical data quality. It is difficult however for them to do this without changes to a central information policy, and a culture within the NHS, which have failed to evolve as rapidly as the environment from which mental health services are delivered.

Central monitoring

The information required by the NHS for central monitoring can be described briefly (Lelliott, 1995).

Hospital

The core data set collected on people admitted to mental illness beds is the same as that for other hospital admissions and forms the Hospital Episode Statistics (HES). As well as basic patient identification and demographic data, HES identifies the health care provider, purchaser, the patient's GP and the responsible consultant, the date and method (emergency or elective) of admission and discharge, where the patient was admitted from, and discharged to, and one primary and up to five secondary diagnoses.

HES supports the concept of the hospital provider spell which "starts on admission to the

hospital provider and ends on discharge from it" (Data Manual).

HES for mental illness are supplemented by data gathered as part of the annual Psychiatric Census of patients in hospital at midnight on March 31st. This includes the length of stay of long-stay patients, the mental category (mental illness, mental impairment, severe mental impairment, psychopathic disorder or other) the patient's legal status (under the Mental Health Act) and if detained, the length of detention and the type of ward on which the patient is housed.

Aggregated data from HES and the Psychiatric Census about activity during a financial year are submitted to the Department of Health (DoH) via the Office for Population Censuses and Surveys. In addition the DoH requires Korner Aggregate Returns which provide some summary data on the use of hospital services by the mentally ill. These returns include: summary information about ward stays, finished consultant episodes, available beds, ward attenders, consultant out-patient clinic activity and accident and emergency activity, day care availability and use, legal status on admission, changes in legal status and health care supplied to a district's residents for mental illness.

Community

The majority of NHS care, outside hospital, for people with mental illness is provided by CPNs. The concepts of community episodes ("the time a patient spends in the continuous care of a nurse or nurses from one community nurse staff group") and face to face contacts underlie the data items collected.

In addition to patient identification and demographic data and the identity of healthcare provider and GP, community episode data record the source of referral (hospital staff or community staff/GP), the start and end dates of the community episode, the date of a planned review within the episode and the name of the responsible nurse. For each face to face contact occurring within a community episode the contact number, whether it is a first contact (during the episode and during the financial year), and the date and location need to be recorded.

The DoH recognises that community services' data collection systems are "in differing stages of implementation" and expects to receive aggregated data on community episodes and face to face contacts.

Paramedical

Occupational therapy and clinical psychology services also make summary returns of the number of face to face contacts broken down by location, source of referral, sex and age (in bands).

Local Authority data relevant to mental illness

Basic data are collected on residential accommodation and day centre provision; number of places by primary function, places in unstaffed accommodation, numbers, sex and ages (in bands) of residents in staffed homes and hostels and numbers of places and attendances at day centres.

Problems with central data returns

The information required by the NHS for central monitoring, which has influenced the thinking of local information and business managers, is inadequate in the following respects:

Completeness and accuracy: The quality of the data on which central returns are based is often poor. The principal reason for this is that the requirement to collect even the simple episode-based data on individual patients is beyond the capacity of existing information systems. This is most marked for data on the care of patients in the community.

Problems with linkage of data: Although some patients have single contacts (such as a single out-patient appointment for assessment by a consultant and advice to the patient and his/her GP) or a single episode (such as a single admission after which care reverts to the GP), the majority of the resources of mental health services are devoted to patients with long-term, severe mental illnesses

who require continuing care. This care is often provided in a variety of NHS settings and from a variety of NHS staff both consecutively (for example moving progressively from a hospital ward to a day hospital to out-patient care) and concurrently (a patient living at home may both be seeing a CPN and attending an out-patient clinic). Furthermore, care may be delivered consecutively or concurrently by a combination of different agencies (NHS, social services and independent agencies).

Episode-based data on individual patients cannot be linked to allow aggregated data to reflect the true patterns and volumes of care received by individuals or particular groups of patients. Patient data need to be linked between hospital, community and primary care and between the various agencies.

Inappropriateness of data items: Even if contacts and episodes could be linked in the manner described above the conclusions that could be drawn from aggregate data, about service provision and quality, would be limited. An adequate description of a service would require information on:

- (1) How many people are being looked after at any one time, where and by whom.
- (2) What problems these people have in terms of the nature and extent of their disability and requirements for services (psychiatric treatment, social care and sheltered accommodation).
- (3) At any one time, how many people are at serious risk of self-injury, violence or self-neglect.

To gauge the appropriateness of service activity, data on these issues would need to be linked to information on service delivery and outcomes.

Cultural and NHS management issues

Underlying the problems described above are organisational and cultural issues that are hindering the development of better mental health data collection and management. These arise at all levels of the service.

Department of Health: The division of Health and Social Services, below ministerial level, with each having lead responsibility for different aspects of care delivery (hospital services and community care) is reflected in the lack of linkage between data on services provided by NHS and social services. The divide is most noticeable in the confusion that still exists about the relationship between the Care Programme Approach and Care Management.

Box 2. Key principles of the Information Management and Technology strategy (IMG, 1992).

Information will be person-based: systems will hold a healthcare record for each individual which can be referenced to that person's NHS number

Systems may be integrated: wherever practical, data will need to be entered on a computer only once. Subsequently, it may be available, in whole or in part, on other designated NHS systems.

Information will be derived from operational systems: data will be obtained from systems used by healthcare professionals in their day-to-day work. There should be little need for different systems to capture information specifically for management purposes.

Information will be secure and confidential: Great care will be taken to ensure that the information held on computer will be available only to those who need to know it and who are authorised to know it.

Information will be shared across the NHS: Common standards and NHS-wide networking will allow computers to communicate so that information can be shared, subject to security and confidentiality safeguards.

Certainly this division is a major hindrance to local services becoming 'client-centred' as opposed to 'facility-based'.

The NHS Management Executive (NHSE): The NHSE Information Management Group (IMG), based at Quarry House, Leeds, is responsible for ensuring that NHS-led developments in information systems support the business goal of the NHS "to create a better health service for the nation". The key principles of the IMG information management and technology (IM & T) strategy (Box 2; IMG, 1992) clearly indicate that clinical information systems should underpin the achievement of this goal. The cornerstone of any information strategy should be the personal healthcare record compiled by healthcare workers in the course of their daily clinical work, with data items being entered only once for all purposes. Information for service administration and management should be derived as a by-product of this process and not collected as a separate process.

Unfortunately, despite expenditure by the IMG of about £250 million over the past eight years, the

majority of clinicians, and doctors in particular, remain unenthusiastic about information systems currently in use within the health care system. A recent review by CASPE Consulting Limited found no computing initiative in the UK that had successfully married a hospital-wide range of clinical activity with electronic means of recording.

A major reason for this is that IMG initiatives to date have usually not followed the principles espoused by the IMG and have resulted in systems with an administrative bias which do little to support patient care directly. An example is the Hospital Information Support Systems Project (HISS) which led to the development of large, inflexible hospital-wide systems which capture little useful information to support clinical care.

This picture is mirrored in most local implementations of information systems, and is perpetuated by the fact that most procurement of systems is by directors of information and finance who give preference to systems that support hospital managers in the performance of their duties rather than clinicians in the performance of theirs.

Although there are a few small-scale, locally-driven hospital and community systems which have been developed by clinicians, the main exceptions to this gloomy picture are found in primary care. Many GP practices, which are in effect small businesses run by clinicians, have systems that integrate clinical and business functions successfully. The message appears simple: when clinical workers see a need for, and a benefit from, an information system, and are allowed to take a lead, useful clinical tools result. Furthermore these clinical tools can also fulfil a business role.

This is consistent with the attitude of clinical staff to other new technology. Far from being Luddites, doctors have incorporated an array of sophisticated imaging devices, surgical instruments, bio-medical techniques and new drugs, often tailored to target specific receptors, into their routine practice. Adoption of these technologies has followed demonstration of their effectiveness, through research and evaluation with doctors involved centrally in developments. When benefits are apparent, the limiting factor to adoption is usually cost rather than medical conservatism.

For clinical informatics to succeed, priority must be given to meeting the information needs of clinical workers. They must become the 'customers' of the information strategy and the success of the strategy judged by measures of the extent to which clinicians' needs are met. This approach would place the onus on clinicians to play an active role, as customers, equal partners and evaluators, in the development and implementation of information

strategies at all levels of the NHS. Only such partnerships can overcome the daunting obstacles to the development of successful clinical informatics.

Purchasers and providers: In local provider units, money to purchase information systems is controlled by service managers and directors of information and it is their perceptions of the need for information that have influenced system development and implementation. Where clinicians are poorly represented in management, the capture and use of data on crude volumes and costs will have priority over data on clinical process.

Commissioners of services will in future have greater influence in determining information priorities. Unless they too are convinced of the value of focusing on the clinical process, they will set their own agenda.

Clinical workers: Many clinicians do not consider the collection of data in a systematic way to be a priority. In part this is due to the 'top-down' nature of the current process. Data, other than for clinical notes, is gathered as an additional duty and not as a by-product of recording care activities. The data required by managers are not seen by clinicians to be relevant to their work in that they neither directly support nor assist them in their clinical activity nor even truly reflect the quality or purpose of their work. Once collected data disappear 'up the system' into a 'black hole'. It is often difficult to persuade local information managers to aggregate and report back data for local use, for example, for service planning, audit, etc. Unfortunately the training of doctors does not equip them to participate fully in local initiatives to develop better systems. Information management and technology are absent from medical education curricula at all levels.

The new opportunity

Recent national initiatives, and developments in computer technology, have created an opportunity to overcome many of the problems which make data capture and management a chore producing scant return to clinicians for effort made. It is possible that within a decade the IM & T strategy (see Box 2), allied to clinician-oriented information systems, will enable the capture of routine clinical data for the purposes described in Box 1.

Over the past few years clinicians have become increasingly involved in the work of the IMG (largely through the Centre for Coding and Classification at Loughborough (CCC) and the Conference of Colleges Information Group, chaired

by Dr Martin Severs). As a result the necessary elements for an integrated information structure built from the bottom up, starting from the capture of good quality information about clinical care, are already in various stages of development.

The Clinical Terms Project based at the CCC (Director, Dr James Read) has involved all medical specialities and clinical disciplines in a massive programme to develop an agreed nomenclature of terms used in clinical records, each with a unique alpha-numeric identifier (a Read Code) that can be recognised by computerised systems. The medical profession has recommended the Read Codes as the preferred coding system for clinical information systems, opening up the possibility of a 'common language' across the NHS. It is anticipated that the set of terms and codes for mental health will be released late in 1995 (Wing, 1993; Wing & Rix, 1994).

The Health of the Nation Outcome Scales (HoNOS) were commissioned by the DoH to provide 'brief standardised assessment measures' to express quantitatively the first Health of the Nation target for mental illness (to improve significantly the health and social functioning of mentally ill people) and so provide a means of measuring progress towards its achievement. HoNOS, which was developed by the Royal College of Psychiatrists' Research Unit (Wing *et al*, 1994) and will be launched in the summer of 1995, is intended for routine use by all clinical disciplines in services providing care for the severely mentally ill. The scales are an integral part of a new minimum mental health data set which is being piloted in nine mental health services and which, if found suitable, will be recommended to replace the unsatisfactory data sets currently required (see above). This, together with adoption of the NHS Number (a unique identifier for each NHS patient to enable linkage of records) would be of potential benefit to:

- (1) Patient care by improving the consistency of information recorded, enabling routine measurement of outcomes.
- (2) Clinical audit and research by facilitating the widespread use of outcome data.
- (3) Public health departments through the aggregation of data for use in epidemiological needs assessment and service planning.
- (4) The commissioning process by the provision, through aggregation, of measures of the benefits derived from care for use in comparisons between providers and with national data, and for contracting.

A version of the HoNOS Scales were incorporated into the data set used in the National Casemix Office's project to develop Healthcare Resource Groups for mental health (Anthony *et al*, 1992). It is hoped that this will lead to groupings that are both more meaningful to clinicians than diagnosis-related groups, and better predict resource use.

The use of these developments as the building blocks of an integrated information strategy depends on the availability and adoption of clinical information systems that are so accessible and easy to use that they are employed widely as clinical tools. The IMG Electronic Patient Record (EPR) and Integrated Clinical Workstation (ICWS) projects are addressing these issues.

A patient record on paper contains a variety of information including patient identifiers and demographics, past history, test results and care plans. An electronic patient record would therefore need to bring together information held in a variety of information systems operating in a hospital or community service, including the Master Patient Index, clinical notes, pathology, radiology and

pharmacy. The benefits of an EPR over a paper record are that it would be accessible wherever there was a terminal and could be linked to decision support systems (such as local clinical guidelines, formularies and research data-bases).

An integrated clinical workstation is the interface between clinicians and the EPR and, through the EPR, other hospital and community systems. The ICWS project is focusing on the development of interfaces that are acceptable to clinicians because they are intuitive to use and save time over pencil and paper approaches. Only when such interfaces exist will clinicians use information systems widely.

Although the EPR project demonstrators are all in acute hospital sites, one of the ICWS demonstrator sites is a mental health service and another a learning disability service. One by-product of the ICWS project has been the development of user requirements for doctors in acute hospitals, nurses, and professions allied to medicine. For perhaps the first time the IMG has started to define the information requirements of clinical staff thus creating the potential for dialogue between information managers and clinicians.

Developing or buying a local system

Clinicians must play a central and leading role when a local provider service introduces a mental health information system. The system is only likely to be successful in meeting the full information needs of service management if it first meets the needs of clinicians. To this end much attention must be paid to developing a user requirement and, for this, clinicians must be considered as important 'customers'. The clinical requirement must be specified in clear and non-technical terms. An example of what might be considered in a clinical operational requirement is given in a review of seven leading mental health information systems conducted in 1992 (Lelliott *et al*, 1993); and is summarised in Box 3.

Box 3. Points to consider when developing a functional operational requirement for a mental health information system (adapted from Lelliott *et al*, 1993)

Data

- variables
- structure
- linkage
- entry storage

Security

- Ease of use
- screen layout
- response times

User aids

- diary, flagging, reminder and messaging facilities
- cross-checking
- word processing and statistics
- spare data fields

Applications

- clinical
- clinical audit and research
- clinical administration
- contracting

Supplier

- number of users of system
- number of employees
- training
- support

Cost

Summary

The recent history of mental health information illustrates the dangers of a top-down implementation of an information strategy. The new NHSE information and management strategy is now the right one, and if applied to recent developments in coding systems, outcome measures, data sets and information technology, could lead to information systems that do support patient

care. To achieve this vision, clinicians must become involved as both active participants and customers in information management.

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Multiple choice questions

- Current national data relating to mental health:
 - are likely to be accurate and complete
 - do not allow data on in-patient and community care to be linked for individual patients
 - tell the NHS how many patients are being treated
 - help to monitor patient outcomes
 - have an administrative rather than clinical focus
- The Health of the Nation Outcome Scales:
 - are intended for use in routine clinical practice

- are intended to monitor the second Health of the Nation target, relating to suicide
- are included in the draft new mental health minimum data set
- are not intended to be used during the process of commissioning
- are designed to be applied by psychiatrists only

- The development of successful, integrated mental health information systems is hampered by:
 - a lack of education and training for doctors in information technology
 - a general tendency for clinicians to resist any new technology
 - the lack of involvement of clinicians in management
 - the top-down nature of the implementation of the information strategy
 - the fragmentation of health and social services
- Local mental health information system:
 - should prioritise the information needs of managers
 - should be developed with a view that clinicians are customers
 - should meet a functional operational requirement agreed by the clinicians
 - should have screen layouts and response times that are acceptable to clinical users
 - should conform to the key principles of NHSE Information management and technology strategy

MCQ answers

1	2	3	4
a F	a T	a T	a F
b T	b F	b F	b T
c F	c T	c T	c T
d F	d F	d T	d T
e T	e F	e T	e T