Clinical information in the NHS—the why, what and how

A one day conference on this topic was organised jointly by the Royal College of Physicians (RCP), the National Health Service (NHS) Training Directorate and the Institute for Health Services Management in September 1993. The aim of the meeting was to make clinicians, senior nurses, clinical directors, managers and directors of public health aware of the importance of collection, communication and use of high quality information within the health services.

Overview

Dr L Loughridge (Senior Censor, Royal College of Physicians), opening the conference, said that many doctors still mistrust computers. However, collecting patient data for management and clinical audit can be done well in the clinical context. General practitioners (GPs) have been leading the way, but in hospitals computers are increasingly used in complex continuing situations such as in renal units.

Professor J van Bemmel (Medical Informatics, Rotterdam) showed how computers have infiltrated the health services internationally and have been increasingly accepted by health experts. The goals of information technology in health care are:

- support of patient care
- quality assurance
- management support
- research.

At present, systems are fragmented between those at patient level in a department or practice, and health care institutions, and at regional and national level. Integration is hampered by the lack of standards to promote exchange of information. Integrated systems will allow a better view of health care through care profiles which may be monitored by medical audit boards. GPs lead the way with the development of the computer-based patient record, while hospital specialists are still lagging 5–10 years behind. In future, electronic data exchange will ensure continuity of care. Systems for quality assurance of care and management will derive data automatically from computer-based patient records, and user support will come from graphical integrated workstations, in the hospital and outside. Success will come only if professional organi-

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Why do we need information?

Professor Dame M Turner-Warwick (past president of the RCP) described the clash of two forces, the entrenched central systems collecting potentially misinterpreted information for the management of the NHS, and the patient-centred clinical systems.

Dr J G Williams (consultant physician, West Glamorgan) started from the basis that clinical information, including the patient's history, circumstances, physical findings, investigations, treatment and progress with time, is the cornerstone of patient management. Complete patient-focused information is needed to take both patient management and clinical service decisions. Contrasting the data on gastroscopies held centrally in South Wales (12,789/year) with those recorded by the clinicians (21,576/year), Dr Williams emphasised the need for clinical validation of data. If clinically recorded information improves patient management, its aggregation will yield comprehensive and accurate information to manage a quality health service.

Miss R Roberts (senior nurse, Wales) said that the nursing record is vital for planned nursing care to ensure that each patient receives an appropriate professionally acceptable standard of care, and also to maintain continuity and act as a channel of communication between all disciplines involved in care. Nursing management at the ward level needs patient-focused information to enable staff with the right skills to be in the right place at the right time, at the right cost. She identified two key points for a clinical information system:

- data collection on a single occasion by the appropriate member of the team
- the definition of a common language for the process of care [1].

Mr R Jeavons (senior manager in an NHS trust, Sheffield) stated that provider units have to improve the quality of care at an affordable cost. Information is required on what is provided, its quality and cost; for example, is the organisation fit to operate in the short term (cash flow); what does it do well; what should be developed? Information is vital when negotiating with purchasers and other providers. Information technology has to compete for resources with staff and equipment, so evaluation of its use is vital. Clarity about the organisation and its objectives is needed before there is investment in information technology.

Dr M Dalziel (Chief Executive, Hillingdon Health Authority) remarked that the aim of a purchaser unit is to raise the level of health of its population. To buy health care, it requires information on the services provided both by itself and by its partnership agencies.
What data are needed to meet information needs?

Dr J Simpson (British Association of Medical Managers) introduced this subject by quoting two studies. One study showed an inaccuracy level of diagnostic coding of 35-45% in one area; the other indicated that 75% of clinical managers felt that the clinical and management data available were inadequate to manage their clinical service [4].

Mr D Carr (NHS Management Executive) explained that the NHS Management Executive needs information to bid for treasury funds, to ensure public accountability (eg to parliament), to formulate policy and research priorities, and to monitor performance. The information received is financial, on personnel and on activity. Knowledge of hospital clinical activity is derived from returns from health districts and trusts based on the consultant episode, giving details of patient, hospital stay, specialty involved, diagnosis and operational procedures. The chain of collection and aggregation of data (Fig 1), the base of which is clinical information, is long and only as strong as its weakest link. Information for national purposes must come from accurate operational data and for that, standards for aggregation, comparison and communication of data are central. The national thesaurus of clinical terms is a starting point [1].

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Mr T Butler (directorate manager for psychiatry, Manchester Central Hospital and Community Care NHS Trust) believes that the only purpose of health management is to support clinicians. At a directorate level, data should be specific for specialties as well as for building a common data set for management purposes. His five priorities for information are:

1. A patient-based longitudinal record of care: the psychiatric case register including demographic, episodic and diagnostic data.
2. Performance data on contract compliance: number of patients seen, follow-up contracts, closed episodes, complaints and outcomes.
3. Individual care planning data, shared between key staff through a network, to log assessment of need, the services provided and unmet needs.
4. Standardised outcome measures, including quality of life indicators, to allow the charting of the impact of directorate care on individual patients.
5. Costing data for patients within each diagnostic area.

Concerns involve the cost of data collection on clinical time, the clinical usefulness of some data requested by the centre, and lack of data from the community for needs assessment.

Mr P Minshull (psychiatric directorate manager for nursing and quality assurance, Manchester Central Hospitals and Community Care NHS Trust) requires data to know:

1. How good is the current level of care by the nursing staff?
2. The staffing required for a given workload.
3. The 'what if' factor: for example, if a ward is closed at weekends, or activity, staff or care levels altered, what will be the effect on outcome?
4. What care/activity fails to occur when the workload exceeds the resources available to provide good care?
5. What are the consequences to patients of not receiving good care, for example, suicide attempts, violence, institutionalisation, absconding?

Mr Minshull quoted one disturbing study which showed that 80% of staff time was devoted to the 20% most difficult patients in a psychiatric ward. Only 3-4 minutes per nursing shift were given to the less difficult 80% of patients. The aim for nurses in his directorate is to be able to do the job well—otherwise staff sickness levels rise, starting a vicious cycle of poor care. Simple data, easy to collect, are necessary to monitor the situation.

Miss K Lowson (Bradford Community Health NHS Trust) as a member of a trust board is concerned with the business strategy of the organisation which drives
the information strategy. The objectives of a computer system to provide information to drive the trust’s decision making process are summarised in the glossary. The data must come from the patient through operational systems (those used for managing the patient or department). The questions which might be asked by a trust board include:

1. What is the cost by service directorate?
2. What is the cost by purchaser for each service directorate?
3. What is the performance in individual directorates?
4. Are individual directorates meeting their contract activity targets?
5. What are the staff absence levels by directorate?
6. What is the staff turnover?
7. What is the skill mix, for example, the proportion of skilled to unskilled, or the grade mix?
8. How are we using our facilities?

**Dr P Gentle** (public health physician, Exeter) stated that purchasers represent the views of the consumer and are concerned with equity in care. Data overload is worrying and selected long-term indicators are needed as follows:

1. The quality and completeness of data available to purchasers need to be improved. Quality control is important if data are to be used effectively, particularly for comparisons between providers or within a provider over time.
2. Wider information about the population’s need for care is required, including collaboration with GPs, to produce estimates of the prevalence of conditions, particular lifestyles and social factors. Additional facts are needed on why people seek or are referred for care.
3. More needs to be learnt about people with more than one condition, as they account for a significant proportion of medical care.
4. Comparative information is needed about the efficiency of services. Where there is true competition, this can be left to the market, but in many places it is certainly not the case.
5. Data on outcomes are essential. Methods of assessing the outcomes of care for key conditions need to be developed. In the short term (and probably also in the long term) proxies for this will have to be used. The ability to link records will contribute to this work.

**How can information technology be used to turn data into information?**

**Mr I Wickings** (Chairman, CASPE Consulting Ltd, London) set the scene for this important session by stating that whether data are the same as information depends on the user’s viewpoint.

**Dr J C Wyatt** (Biomedical Informatics Unit, Imperial Cancer Research Fund) developed the idea of information being data with a use (Table 1), namely, to take decisions. In the clinical area, data collected from the patient are combined with medical knowledge to take clinical decisions. Data need to be accurate, complete, timely, well structured, classified and coded, and sufficiently detailed to aid decision taking [5]. The incentive to collect accurate data is the immediate help users obtain to perform their role. Clinical knowledge comes from clinical trials or sometimes from routinely collected clinical data. The clinical workstation integrates the individual patient’s data with clinical knowledge to aid the clinician in taking appropriate decisions for that patient. Data entry needs to be painless, using all available technologies from keyboard to speech recognition. Dr Wyatt finally described the organisational changes in work patterns required to integrate information technology into routine clinical work.

**Dr P Howlett** (Director of Resource Management, Portsmouth Hospitals NHS Trust), starting from the basis that management information is ultimately derived from the patient (Fig 1), emphasised the building of data communications networks and integrated systems. The shared data need common methods of access and analysis. All users of data, from purchasers through providers to clinicians, must understand each other’s needs. Managers should invest in clinical systems, and clinicians should want their workstations to be part of a wider network of data sharing.

**Mr G Griffiths** (Director of Purchasing, Health Commission for Wiltshire and Bath) identified data which a purchaser needs to take decisions on identifying and satisfying the health needs of the population in his area. The list is large, ranging from public health data sets through patient and GP surveys to evaluation studies. He emphasised that a purchasing authority may in future ask for validated data from its providers.

**Mr I Smith** (NHS Management Executive) discussed the national information management and technology strategy. Its aim is to deliver a better quality and more responsive care for individuals, better targeted care for populations, and better use of resources. It lays down the principles of person-based, operational, integrated, secure systems that will share data across the NHS. There are four major initiatives:
- disseminating good practice
- a common infrastructure
- value for money
- training.

Projects include improving classification and coding through the clinical terms project [1], an NHS number for all patients, and technical standards.

However, he emphasised that we should not wait for standards but innovate now, especially on important clinical issues. How can clinicians be persuaded to want to use information to continue to improve the care they provide? Can we build on the common
Table 1. Different use of data in the National Health Service.

| Level in the National Health Service | Use of data                      |
|--------------------------------------|----------------------------------|
| Patient                             | Clinical decision                |
| Iso-resource groups                  | Audit                            |
| Clinical directorate                | Resource management              |
| Provider unit                       | Resource management, competition |
| Purchaser unit                      | Population health needs          |
| Department of Health                | Evidence for treasury, public accountability |

clinical terms [1] to create a generally understood structure for the clinical record, and is it possible, feasible or desirable to capture the patient record electronically?

The future of clinical and managerial information systems

Dr J Read (NHS Centre for Coding and Classification) emphasised the gap remaining between clinical data and the technology. The clinical culture needs to change, and the technology requires definitions: for example, what is diagnosis; what is an episode of care; how do we deal with uncertainty?

Dr M Severs (RCP Medical Information Technology Committee) challenged clinicians about the future requirements of the NHS. Themes developing amongst western cultures include:
- improving the quality of care
- decreasing the variability of clinical practice
- cost containment
- increasing consumer involvement
- a shift to a primary care focus for health care.

Some of these themes can harmonise differing interest groups, but others do not. Perhaps more interesting are the methods being developed to meet the objectives. Some, like the NHS reforms themselves, are enormous cultural and organisational changes; others may be smaller but nevertheless make an impact that is just as measurable. The new processes which will continue to need support in the clinical community include:
- audit (uniprofessional, clinical and service)
- guidelines
- patient satisfaction
- quality (from assurance to total quality management)
- contracting
- education
- outcomes and outcomes management
- research and development.

When the increasing pressure on clinicians with regard to communications (especially between primary and secondary care) is added to this, a position is reached which cannot be sustained in a paper-based information system. The discipline of computerisation and the nature of the agenda highlight the fact that the challenge to the clinical professions is not data processing but data ‘sharing and comparing’.

Dr Severs also discussed the complexity of the issues. Judging a clinician’s case mix requires knowledge of each patient’s diagnosis—not just primary diagnosis, but disease severity, functional ability and the patient’s well-being. How is outcome defined? How is a patient recorded who refuses to follow guidelines? The problem of variability in definition is shown by the lack of even a minimum structure for a discharge summary or definition of a complication.

A considerable volume of work is still outstanding. This will need support from a comprehensive educational strategy before real benefits from information technology will accrue, and to prevent a deterioration in the quality of patient care not only through clinical shortcomings but also through organisational mismanagement.

Professor D Ingrams (Medical Informatics, London) described both the promise and the dangers in technical development. The ability to store and rapidly analyse massive quantities of data leads to two situations:
- an efficient, largely invisible and secure information technology system integrated with clinical routine, enhancing the quality of health care
- a chaotic, socially and economically damaging information pollution with a poor ethical and legal framework, leading to a decline in professional (clinical and managerial) skills and over-reliance on inadequate and inaccurate systems.

The potential for wasting resources is spectacular. He also emphasised that innovation comes before standards.

Mr J McClenahan (fellow in management and planning, King’s Fund College, London) emphasised the gap between the visionary potential and the pedestrian reality. At present, small systems (clinical, departmental and administrative) have taken root when only small areas of the health care system are involved. Can the necessary changes occur, and the change equation [6] be activated (see Fig 2), to allow integration of the

Fig 2. The change equation.

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\text{Change takes place if:} \\
\text{Power of vision} \times \text{Pain of the present} \times \text{Feasibility of first steps} \\
\text{Greater than} \\
\text{Pain of change}
\]
many kinds of information required to improve patient care—attitudinal and organisational changes such as common clinical language [1], consistent data definitions, understanding of the clinical process, methods of implementation and money? The pain of these changes must be overcome across the NHS in embracing the points of view of other people, re-examining our beliefs, finding the time for information technology, investing financial and emotional capital, and supporting others through the stress of change. The pain of the present situation is high in contracting, quality measures, outcomes, audit and complaints. The power of the vision will increase when more success becomes evident, benefits realised, and bad experiences expurgated.

Discussion

There is a massive gap between the wish list of information needed by the health service to make sensible decisions at all levels, from clinician to the Department of Health, and the data that can be provided now. If some participants had hoped to find the solution at this conference, this was not—and could not—be provided. The following points were raised repeatedly:

1. Accurate and valid information is power.
2. The chain of information between patient and the Department of Health is long and fragile.
3. Data collecting systems must be integrated.
4. Data must be entered once by a user who gains an immediate return and thus has the incentive to enter accurate and valid data.
5. The basis of all information in the NHS is the patient and clinician interaction.
6. Standards are required for data definition, sharing, and communication.
7. Standards follow innovation, therefore we should not wait but build and evaluate the simple systems that work.

Much work is required and must be clinician led. The individual clinician needs to innovate, and clinicians as a group, possibly through the Royal Colleges, need to produce the following guidelines:

1. The data required from clinical systems: for example, outcome measures, the data required to manage a condition, and definitions of data items.
2. How should clinical work be organised to gather data? Who should collect them? What immediate return should they have for collecting them?
3. How to educate the clinicians into providing the data.

The information technology specialists must give clinicians the tools to gather, aggregate and communicate the data. The managers must realise that clinical systems come first and put money at that level. The case mix and other management information then follow.

The conference laid out the vision and showed the long path ahead. The clinician is central, and it was therefore worrying that fewer than 20 of the 175 participants were practising clinicians. Perhaps the next conference needs to address the problems of the clinician alone. But the day is bound to come when the statistics released by purchasers, providers and the Department of Health are not greeted by laughter and anger in the doctors’ dining room!

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Glossary

Quality: A measure of the contribution of community services to the quality of care and the highlighting of areas for improvement of quality through clinical audit.

Support: Support for the management processes through which improvements in quality, activity and cost will be made (primarily clinical audit, contract and budget).

Health gains: An understanding and measuring of the contribution of community services in terms of inputs and outcomes on the health of the population served.

Costs: An understanding and measuring of the cost of community care in terms of individual patients/clients and their outcomes.

Flexibility: The response to changes in community care within other agencies.

Patient record: A longitudinal patient record, incorporating events of other agencies as appropriate, to support an understanding of the use of resources and cost of community care.

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