

ABC of health informatics

Improving services with informatics tools

Frank Sullivan, Jeremy C Wyatt

This article describes how many sources of data can be linked, interpreted, and analysed before being presented to decision makers to improve care. It also discusses the legal issues surrounding data protection and freedom of information.

A huge volume of data flows across the desk of a director of public health (see box opposite). One of the director's problems is to know which signals to act upon and what "noise" to ignore. If the numbers being considered are small, as they probably will be in the case described here, a critical incident analysis may be all that is needed. An individual prescriber, or group, may have an erroneous belief or inadequate training. Critical incidents or other signals often indicate that more data (such as data on prescribing steroids for paediatric asthma in primary care and outpatients) are needed.

Sources of data

Health services are awash with data. Earlier articles in the series described the large and increasing numbers of sources of data available to consumers, patients, clinicians, and administrators. Clinicians, teams, divisions, and other groups collect the data they need to carry out their work, and they may do so using coding and terms that others can understand and share. The intensive care unit in this example integrated the data the team needs to manage patients during their stay with patients' pre-admission prescribing data. This local epidemiology may have been done as part of clinical governance activities, or as an ad hoc exercise when a patient's problem was investigated.

One difficulty with secondary uses of clinical data is that, having obtained the data indicating a problem exists, the issue must be dealt with effectively. It may be that the individual or group who identify the problem have the knowledge, skills, and resources to resolve it. In other cases, such as these potentially avoidable asthma admissions, those responsible are not those who have uncovered the issue, and those potentially responsible may be unaware of the problem.

Presentation of data

Ideally, the choice of measures, analysis, and presentation of data should be determined by the purpose of measurement and the use to which data are to be put. This poses another difficulty with the secondary use of clinical data. Studies have shown that interpretation of data is influenced by the method used to summarise the results. Health policy makers, like doctors, tend to prefer measurements that report relative risks (or benefits) to measurements providing estimates of absolute risks (or benefits). Once the decision has been taken to act on data, how best to present the information should be considered.

Feedback of performance data

Different approaches (using internal or external influences on decision makers) can be taken when using data to improve care. The interventions chosen should be tailored to the underlying problem. At least two, and preferably three, of the more effective approaches (see boxes on next page) should be taken.

This is the 10th in a series of 12 articles
A glossary of terms is available at <http://bmj.bmjournals.com/cgi/content/full/331/7516/566/DC1>

You are a director of public health. The local paediatric intensive care unit sends you a paper describing five potentially avoidable admissions in the past two years—for example, patients with severe asthma who were not being prescribed prophylactic drugs



UK clinical governance definition*

A framework through which NHS organisations are accountable for continually improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish

*From Scally G, Donaldson LJ. Clinical governance and the drive for quality improvement in the new NHS in England. *BMJ* 1998;317:61-5

Categories of improvement for health services*

- Safety
- Effectiveness
- Patient centredness
- Timeliness
- Efficiency
- Equity

*From Institute of Medicine Committee on Quality of Health Care in America. *Crossing the quality chasm: a new health system for the 21st century*. Washington, DC: National Academy Press, 2001

Analysis of approaches to changing clinical practice: internal processes

Approach	Theories	Focus	Interventions, strategy
Educational	Adult learning theories	Intrinsic motivation of professionals	Bottom up, local consensus development Small group interactive learning Problem based learning
Epidemiological	Cognitive theories	Rational information seeking and decision making	Evidence based guideline development Disseminating research findings through courses, mailing, journals
Marketing	Health promotion, innovation and social marketing theories	Attractive product adapted to needs of target audience	Needs assessment, adapting change proposals to local needs Stepwise approach Various channels for dissemination (mass media and personal)

Analysis of approaches to changing clinical practice: external processes

Approach	Theories	Focus	Interventions, strategy
Behavioural	Learning theory	Controlling performance by external stimuli	Audit and feedback Reminder systems, monitoring Economic incentives, sanctions
Social interaction	Social learning and innovation theories, social influence and power theories	Social influence of important peers or role models	Peer review in local networks Outreach visits, individual instruction Opinion leaders Influencing key people in social networks Patient mediated interventions
Organisational	Management theories, system theories	Creating structural and organisational conditions to improve care	Re-engineering care process Total quality management and continuous quality improvement approaches Team building Enhancing leadership Changing structures, tasks
Coercive	Economic, power, and learning theories	Control and pressure, external motivation	Regulations, laws Budgeting, contracting Licensing, accreditation Complaints and legal procedures

Today, it is less necessary to rely on individual clinicians or teams to produce routine reports because computerised data entry enables the routine extraction of data for many purposes. Data from multiple sources may be linked to records, and so provide additional intelligence beyond the purposes for which they were originally collected.

Record linkage

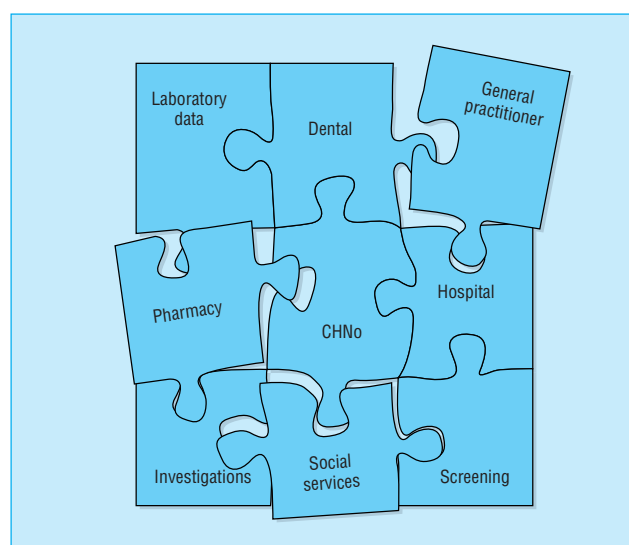
Deterministic or probabilistic methods can be used with similar success rates to link records. In the former case, a unique patient identifier, such as a 10 digit community health index number, is applied to all personal health data—for example, laboratory test requests and prescriptions. In the latter case, algorithms determine the likelihood that two items of data belong to the same person. The Soundex system converts a name to a code (for example, Michael becomes M240). The first letter is the first letter of the word, and the numbers represent phonetic parts of latter syllables. The algorithm determines that John Smyth and John Smythe is the same child with asthma if sufficient other characteristics (date of birth, street name) on the admission data and community prescriptions match. After linkage, each individual item of data may then be linked and anonymised for disease surveillance purposes.

Data protection

The main provisions of the 1998 Data Protection Act were implemented on 1 March 2000. This act builds on the earlier 1984 Data Protection Act. It is the means whereby the United Kingdom enforces the 1995 European directive on data

09 11 64	02	5	0
Date of birth	Sex	Sequence number	Checksum digit

The community health index number (CHNo) is a unique 10 digit number that includes the date of birth of individuals born, or moving to, Scotland so that their encounters with the health service can be linked



The community health index number (CHNo) allows the fragmented episodes of care experienced by individuals to be integrated into the completed jigsaw of an electronic health record

protection. It aims to ensure that the processing (obtaining, recording, holding, doing calculations on) of information using data is done in accordance with the rights of individuals. The European directive also extends the legislation to manual, as well as computerised, records containing personal information. Under the provisions of the act, data controllers (for example, general practitioners) are responsible for ensuring that access to patient data should be under strictly controlled conditions and, if necessary, with patients' consent.

Eight principles of good practice are in the act. Patients should be aware, at least in broad terms, of the purposes for which their personal data are used. However, it is the view of the data protection registrar that consent should normally be obtained when processing data about a patient's health. Many Caldicott guardians believe that the activities of the NHS are often in the public interest, and in most cases the consent of the patient can be inferred. Other bodies, such as the General Medical Council and the BMA, advise that explicit consent is still preferable in some cases, and examples include:

- Release of details of patients to diabetic and cancer registers
- Release of summaries of patient data to out of hours services.

The 2000 Freedom of Information Act came into force in January 2005. It is intended to "promote a culture of openness and accountability amongst public sector bodies by providing people with rights of access to the information held by them." It will probably conflict with data protection legislation because information about individuals is contextualised within families, communities, practices, and hospital units. It will be difficult to ensure that an individual's data are protected while giving freedom of information to others within that context.

Feedback of information

In many medical cultures it is difficult to provide feedback that will be taken in a constructive manner. Certain principles make it more likely that the feedback will be considered constructive by recipients, and changes that could improve care will probably be implemented.

Research governance

Confidentiality and security of data is probably a greater concern for researchers than clinicians, although clinical researchers need to live with concept of governance in both worlds. Data collected for patient care may only be used to produce research evidence with adequate safeguards for the patients. Legislation varies between countries, but the highest standards apply to use of personally identifiable data, where explicit signed, informed consent is often required. Some jurisdictions relax this standard if it is impossible, or extremely difficult, to obtain the consent. In other countries acceptable anonymisation and adherence to rules of good epidemiological practice allow the use of clinical data for research purposes.

Summary

A public health consultant faced with complex, difficult choices, such as the data on asthma prescribing, will prefer to discuss the reasons for apparent prescribing failures rather than taking pre-emptive action, which may do harm to the service overall. The factors that caused the presenting problem are often rooted in the culture of the health system, and so the solution often means changing the system. The consequences of failing to act when there is a problem need to be counterbalanced against the damage caused by incorrect interpretation of data collected for one purpose but used for another.

Principles of good practice in the 1998 Data Protection Act

Data are:

- Fairly and lawfully processed
 - Processed for limited purposes
 - Adequate, relevant, and not excessive
 - Accurate
 - Not kept longer than necessary
 - Processed in accordance with the rights of the subject of the data
 - Secure
 - Not transferred to countries without adequate protection
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Dame FIONA Caldicott's principles of data processing*

- Formal justification of purpose
 - Information transferred only when absolutely necessary
 - Only the minimum required
 - Need to know access controls
 - All to understand their responsibilities
 - Comply with and understand the law
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* <http://pmj.bmjournals.com/cgi/content/full/79/935/516>

Approaches identified by the Nuffield Trust to deal with the conflict between the the Freedom of Information Act and data protection legislation

- Use personal data with consent or other assent from the subjects of the data
 - Anonymise the data, then use them
 - Use personal data without explicit consent, under a public interest mandate
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Key issues in data feedback to improve quality*

- Data must be perceived by clinicians as valid to motivate change
 - It takes time to develop the credibility of data
 - The source and timeliness of data are critical to perceived validity
 - Benchmarking improves the meaningfulness of data feedback
 - Opinion leaders can enhance the effectiveness of data feedback
 - Data feedback that profiles an individual clinician's practices can be effective but may be perceived as punitive
 - Data feedback must persist to sustain improved performance
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*Bradley EH, Holmboe ES, Mattern JA, Roumanis SA, Radford MJ, Krumholz HM. Data feedback efforts in quality improvement: lessons learned from US hospitals. *Qual Safety Health Care* 2004;13:26-31

Further reading

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