Achieving an ethical health service: the need for information

HM Queen Elizabeth the Queen Mother Lecture

The National Health Service (NHS) has a series of objectives. To determine whether these objectives are being achieved, data need to be collected from which the necessary information can be derived. It is therefore important to define the accepted ethical principles and objectives of the NHS and assess whether the data and information we collect help us to judge the performance of the NHS.

An ethical health service

The concept of a national health service is relatively new. The 1946 Act [1] which created the NHS in England and Wales stated:

'It is the Secretary of State’s duty to continue the promotion in England and Wales of a comprehensive health service designed to secure improvement—
(a) in the physical and mental health of the people of those countries, and
(b) in the prevention, diagnosis and treatment of illness, and for that purpose to provide or secure the effective provision of services in accordance with this Act'.

The Commission accepted that some of these objectives were imprecise, and others controversial or even unattainable, but nonetheless believed they would serve to focus their discussions.

The Commission further considered that it was ‘legitimate and positively desirable to devote public resources to the maintenance and promotion of personal as well as public health’. However, they considered that it was ‘unrealistic to suppose that people in all parts of the United Kingdom can have equal ease of access to all services of an identical standard. Access to the highest standard of care will be limited by the numbers of those who can provide such care. There are parts of the country which are better or worse provided with services than others... Nonetheless, a fundamental purpose of a national service must be equality of provision so far as this can be achieved without an unacceptable sacrifice of standards’.

The Commission continued ‘the community will continually face the problem of a choice between one objective and another and between differing ways of achieving those objectives’.

The question of choices which was highlighted by the Commission has been tackled somewhat more explicitly by the Dutch [3]. They classified them as follows

‘— priority: what care must be available for everyone in a basic package?
— rationing: who gets priority in health care?
— innovation: is it necessary to do everything that can be done?
— appropriate use: effectiveness and efficiency of health care’.

They felt that choices needed to be consistent with the interests of public health and with society’s social goals—which they considered to be ‘to protect their lives and to give everyone a chance to participate fully in society’.

The Dunning Committee [3] had four starting points

‘— necessary care goes before less necessary care
— effective care goes before less effective care

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applicable care goes before less appropriate care
- care which cannot be left to individual responsibility goes before care which can'.

They considered it important to define health. After discussing the individual or professional approach they came down firmly on the side of a community-oriented approach. The interests of the community are dependent on its social values and norms. In the Netherlands they considered three major requirements

1. The fundamental equality of people
2. The fundamental need for protection of human life
3. The principle of solidarity'.

'Solidarity' means that the healthy pay for the ill, and good risks pay for bad risks.

Further fundamental points were made by Massie, the eminent Scottish writer [4], reviewing the proceedings of a Scottish seminar on the financing of health services. As he put it 'if one accepts that health is the primary duty of life' then it is important to acknowledge that the patient may be an 'involuntary, reluctant consumer'. He further elaborated that the 'moral philosophy of health services is a modern idea, so is the corresponding political philosophy' and there is no argument in the UK that 'it is the duty of the state to secure, and probably provide, a certain quantity of health care'. In continuing the argument he concludes that the NHS 'guarantee[s] the right of equal access to rich and poor'.

More recently the government enunciated certain principles in the Health Service reforms [5]. In her foreword, Mrs Margaret Thatcher, the Prime Minister, stated 'The NHS will continue to be available to all, regardless of income, and to be financed mainly out of general taxation'. She proposed 'to bring all parts of the NHS up to the very high standard of the best' and to 'aim to extend patient choice'. The key changes envisaged were

- to make the service more responsive
- to provide a better service
- to enable needs and wishes to be met
- to reduce waiting times and improve quality
- to improve effectiveness.

These principles and statements help to determine the information needs of an ethical health service. We can thus judge how far presently available information can be used to assess whether the service actually does what is intended.

There are always conflicts, and usually a balance has to be struck, for example, between the needs of an individual and the needs of a community, between the advantages of prevention of a condition by immunisation and the risk of brain damage to an individual. Herman put it plainly, 'we cannot apply the conclu-

sions of a sophisticated cost-benefit analysis with rigour to our practice without harming some individuals' [6].

Objectives of an ethical health service

If an attempt is made to translate these broad concepts, one can state the following objectives for an ethical service which will govern the information needs; they omit such considerations as compassion, an essential component, but not, as yet, measurable.

1. To enable the individual or patient to attain an optimal level of health through knowledge of how to prevent illness, access to health care if necessary, and to know the quality of that care.
2. To enable those responsible for providing the service to judge whether it is as good as it can be.
3. To enable those responsible for planning and managing the service to judge whether there is equity of access.
4. To enable the population, individuals, patients, providers and planners to decide on priorities.
5. To enable research, development and innovation to improve the quantity and quality of health services.

How far does the presently available information embody these principles for all those involved, where are the gaps and how can they be filled? Part of such an analysis will be repetitive as the ethical objective of one principle is often similar to that of another.

The knowledge required by the population to attain and maintain health

Since we provide services for the population it is crucial to consider first what patients, individuals and communities need to know to attain an optimal level of health.

What to do

The individual or patient needs to know what to do [7]. Is it necessary to go to the doctor with a particular symptom, or is it something for which a visit to the chemist is all that is required, or should nothing be done at all? Most of this type of information is folklore, handed down from parent to child or passed on from friend or relative. Information leaflets, guides etc are available in practices, hospitals, libraries etc. Many voluntary agencies, such as the Stroke Association and Muscular Dystrophy Society, provide leaflets and information for patients and their relatives about particular disorders. Popular magazines, newspapers, television and radio provide nuggets of information, often accurate, but sometimes not. The growth of these sources of information has been phenomenal over the past 40 years and has contributed to greater knowledge, awareness, expectations and demand. Unfortunately,
doctors do not use this medium nearly enough to inform the public. Of greater concern, however, is that information is usually offered only after a health service contact has been made. We have not invested sufficiently in identifying the best way to provide such information; nor have we invested enough in looking at the best educational methods to promote and maintain health, or the best way to use available services effectively and efficiently.

Where to go

Although this may be included under the heading of what to do, there are issues such as: where a doctor's or dentist's surgery can be found, or where the nearest accident and emergency department is, or which chemist is open on a Sunday evening. Changes in society have meant that in some cases individuals are more likely to go to a general practitioner (GP) for help or advice than, more appropriately, to the social services or citizen's advice bureau.

Knowing what to expect

Health services should not be considered akin to a supermarket where consumers can choose between different brands or sizes at varying prices. Patients need to be aware of their entitlements and their rights and be aware of the quality of the care they receive. The Patients’ Charter [8] sets out a range of rights and standards which patients can expect, including waiting times.

However, while it is relatively easy to judge the process of care, e.g. the environment and the courtesy of staff, it is far more difficult to obtain information on the quality of care. The majority of patient-doctor contacts are in the GP’s surgery, about 10% lead to referral to a hospital [9]. There is a wide variation in referral patterns between different GPs for similar complaints. For some conditions, such as certain forms of cancer, there is good evidence that immediate referral to hospital is better than being seen by the GP on a second occasion to assess the progress of the complaint. For some conditions, GPs who have a particular expertise in a field are more likely to refer for a second opinion [10]. Although some studies have shown that restriction on hospital referrals may be detrimental to patient care [11], in general, neither the professionals nor the patients really know whether frequent use of hospital services by a GP leads to a better outcome. Clinicians vary in their expertise and skills, and hospitals in the performance of clinical procedures. How then do we enable patients to judge the care they will receive? Furthermore, there are many examples of individuals neglecting symptoms because of fear or ignorance, or because they sought help from the wrong agency. Finally, individuals do need to learn when clinical services are inappropriate and self-reliance may be better. It is thus clear that from the individual’s point of view there are many gaps in the information that ought to be provided.

What to demand and how to express an opinion

A problem for the NHS is the passivity of individuals and the conflict between individual and community values. Any society that guarantees the right of equal access for rich and poor on the principle that the healthy pay for the ill, and good risks pay for bad risks, has to make choices. ‘Community demand is not simply the sum of individual demands. Indeed, the unfettered satisfaction of individual demand is likely to conflict with the broader demands of the community’ [12]. The Dunning definition [3] puts forward health as ‘the possibility for every member of society to function normally’ and to participate in social life. Consequently, the need for care is ‘to enable an individual to share, maintain and if possible improve his or her life together with other members of the community’. Social or community demand is an expression of this need. This is much more limited than the total of individual demands, as it is defined by society or the community rather than by every individual separately; however, it is much more difficult to determine than individual demand. There will be conflict between doing all that can be done for a few patients and the ability to do something for many.

This ethical conflict of how to judge between individuals or between services has always been present in our health service, but rarely openly addressed. It requires far more attention to what kind of information is needed, how it can become known and how it must be applied. Some call it rationing, others priority setting. Our political masters are remarkably agile in avoiding facing this issue which is bound to be present in all systems with finite resources. Health services are finite not only because we spend a fixed amount of money on them, but also because practitioners and their time are finite.

Most patients are satisfied with what is provided. Only recently have patients begun to express opinions about processes of care, the attitude and behaviour of staff, or the treatment received. Historically, such concerns have been professionally determined and staff have been reluctant to accept the validity of patients’ judgements. We must accept that opinions, qualitatively and quantitatively, can serve as reasonable measures of the quality and nature of the service provided. We need to learn how to use them constructively to make the service better. This implies developing a method for collecting and disseminating this information at all levels, as well as a method for monitoring any subsequent actions.

A contemporary source of confusion is the blurred boundary between health and social care provision and entitlement. Most of that is due to the ambiguous explanations [13] provided by central government,
management executive, health authorities and local authority social service departments. A good example of this problem has been given in a recent publication [14]. Since 1991 the Royal Association for Disability and Rehabilitation has noted an increase in complaints. During 1991 and 1992, 700 complaints were received from residents in England and Wales: after investigating them the researchers were convinced that they were the tip of a huge iceberg. Although special equipment, home adaptations, personal and domestic tasks such as cleaning, washing and preparing meals are considered crucial, 91% of complaints concerned those services. A clean home is apparently of little importance to elected members and officials as many authorities have excluded cleaning from the services they provide. ‘When information regarding criteria for eligibility for services is available, it is often unclear. When a senior member of a social services department was asked the definition of “essential needs”, a part of the authority’s criteria, he was unable to answer; yet that individual was supervising assessors. If he did not know the definition, how could he ensure that the team could undertake meaningful assessments?’

Staff are also to blame for misinterpreting guidelines, often trying to move patients from one type of care (and expenditure) to another. It exemplifies the obligation for authorities to give patients clear, unambiguous information about their entitlements, and how and to whom they can express their concerns. In view of the complexity of definitions in this area, valid measurement tools are also needed for assessing individual needs for different types of care; without them, it is difficult for patients or their relatives to comment on the treatment they receive. A recent case in Leeds, investigated by the ombudsman [15] highlighted the problems of definition and practice. The public, particularly the most vulnerable patients, are becoming increasingly alarmed.

The quality of service

Good quality in a health service implies not only that patients are seen promptly and dealt with courteously, and that the appropriate diagnostic procedures are performed (not too many and not too few), but also that the correct treatment and procedures are properly performed.

Audit

The appropriateness of diagnostic procedures and treatments is supposed to be monitored through audit procedures. These may take the form of case-conferences, examination of patient records, and even statistical analyses of procedures in a defined patient group. Only a few examples exist of examining the outcome of treatment or care.

To be able to judge whether the care given and received was appropriate, certain basic data need to be available.

- **Past history, family history, occupational history**—Although most medical students are taught the importance of past history, family history, occupation (and history of occupations), as well as social history (ie where patients live, and, for the elderly, what help they have, etc), it is surprising how often such details are missing from a patient’s record. In some places in the UK, and in some other countries, proformas have been developed which can be used by the patient sitting in front of a computer screen but, in spite of the taught importance of these facts for the management of the individual, they are often missing.

- **Physical signs, history, etc**—When a patient is seen, it is usual for the history and signs of the illness to be recorded by the health professional. Theoretically, in the computer age, this could be a pre-set questionnaire or proforma. Unfortunately no single form is applicable to all situations and no one would want to waste time completing an all-embracing form as this would take hours. Furthermore, it is difficult to know what aspects of a patient’s history might be relevant in the future; it has not always been seen as necessary to ask about a patient’s smoking habits. But things have improved, the standard, contents and completeness of clinical records is now much better than in the past [16]. Part of the reason for this has been the need to document events in case of challenge, such as medical negligence. The ability of most young health professionals to type and use computers has improved both the quantity and quality of the clinical record. Although various methods of summarising this material exists, eg Weed’s problem lists [17], Read’s diagnostic code [18], problems remain concerning the completeness of the data, their reliability, and the ability to retrieve them [19].

- **Options for diagnosis/treatment**—With the availability of computers in most practices and hospitals, it is surprising how few systems are used in the UK as aids for ordering appropriate diagnostic tests and/or treatments. Although programs and systems are readily available for identifying drug/treatment incompatibilities and the benefit or cost of different diagnostic procedures, eg one type of imaging versus another, it is surprising how many providers/institutions do not use such information aids but still rely only on their own knowledge [20].
• **Consequences of treatment**—All forms of intervention may have unintended consequences ranging from minor to major. Yet the record of a patient’s response to a form of intervention is often missing [16]. We still need to peruse temperature charts or the nurses’ record or day book for an accurate account of what really happened. Our inability adequately to record the side effects of treatment has important consequences for all involved; patients, providers etc. Our lack of concern and inability to impose discipline in this field has had dire consequences for patients, even if it has provided employment for many epidemiologists [21].

• **Costs**—It is surprising that those responsible for providing a service are not aware, or take little note, of the differences in cost of different diagnostic or therapeutic options in specific situations. Such information could easily be provided, particularly where computer systems are in routine use. At present the only imperative appears to be to reduce costs. With a proper, sophisticated computer system, other options could be presented and thus rational decisions made more easily. If appropriate information, which is already available in many cases, were presented to us we could avoid many of the problems we have to face [20].

**Outcome**

This is the current buzz word used by all and sundry. Florence Nightingale was one of the first to be concerned with case-fatality rates within hospitals. These have been available for many years but are a poor measure of the effectiveness of an intervention. Patients who are discharged home soon after an intervention and die within a day or two, are not counted in the hospital’s figures, whereas those who stay longer, are. The inability to link events has been responsible for inadequacies in assessing the effectiveness of many procedures [22,23]. Mortality is the simplest (and crudest) measure. For the patient, functional status, satisfaction, and return to work are important. A variety of tools now exists for measuring the outcome of individual procedures, both from the patient’s and the provider’s points of view [24-26]; they are, however, mostly complex research tools. Few simple measures, other than mortality, exist which could be used routinely for all patients, and not only as a research exercise. Compared with industry, little effort has gone into the development and application of such tools in medicine. Most effort seems to have been made with measures of satisfaction—important certainly, but, because of the general stoicism of our population, a poor guide to the effectiveness of treatment [27].

Wyatt [28] has elegantly described the data needs and concluded that a ‘true computerised clinical data system’ is the best solution. Weed [17], Körner [29-33] and others have discussed and described several health information systems intended to cope with the problems outlined. Unfortunately, experience over the past 30 years has not shown that any of the systems devised can be relied upon to deliver the information needs of audit or outcome. All depend on accurate, complete, consistent and reliable recording; unfortunately this does not occur. The Weed system, applied to the GP records of an individual patient, which is intended to follow the individual from birth to grave, would be ideal as it is meant to provide a synthesis of action and outcome in relation to a problem. But, while it may work in some practices, it is not uniformly applied and suffers from the gaps outlined. The use of a unique patient identifier (NHS number) will, at last, enable us to link records and thus health events and treatments, and so implement proposals first advanced in 1973 [22] as well as take advantage of the benefits demonstrated by the Oxford Record Linkage Study [23]. We may thus, eventually, be better able to assess the results of treatment and care.

It is unfortunate that we have not more thoroughly considered the principles of assessment of the quality of medical care so carefully set out by Donabedian [34]. Although much time, effort and money is spent on medical audit at this time [35], it is a pity that few have asked the fundamental questions which need to be answered if the results are to be relied on to improve the quality of care. The availability of affordable computer-based record systems, with appropriate safeguards, could enable us to tackle many of the problems. The Institute of Medicine [36] has put forward clear recommendations on what needs to be done and how. It is a shame that this is not yet a reality.

**Priorities and equity of access**

When thinking of how to ensure equity of access and identifying priorities, it is important to consider separately the two major groups involved, the professionals, such as managers and public health physicians, and the community or population.

**Professional requirements**

For professionals, the knowledge required can be subdivided into the following:

• **Health needs**—Information is available from demographic data, mortality statistics, utilisation data and general household surveys, which may help to provide a general picture. More appropriate assessments can be made using data from epidemiological studies [37]. Help may be forthcoming from national sources, eg the general household surveys, or the RCGP morbidity studies. It is important for public health physicians to be aware of the validity of such studies/information and to consider the range and incidence of a condition in their area, rather than rely on a single absolute number or point prevalence rate. Obtaining such information on a small area basis, crucial if we are to
be concerned with the population’s needs, may be difficult and costly. Furthermore, it is essential to appreciate that not only do populations change but so do diseases and needs. This is a dynamic process, and although a study done in one year may give guidance for the future, it should not be considered authoritative or everlasting [37].

- **Health gain/quality of life/outcome**—It is surprising that although most curative services are concerned with improving function or diminishing or curing a disease, we have remarkably few routine measures to assess whether any good is being done. In the field of caring or rehabilitation we have even less. Although many research studies have developed measures of quality of life, patient satisfaction, dependency, etc, few can be applied in routine practice. We still depend on measures such as cause-specific mortality to assess the performance of districts, hospitals, etc; measures of ‘avoidable’ death can be used for making broad assessments of the performance of a particular service, eg for surgery, or prevention [38,39]; cancer registries may be used to examine cancer services, and similar methods have been used in individual localities to examine the adequacy of services for the mentally handicapped, mentally ill and others. The advantage of these registries is that an individual is followed from diagnosis to death; but we are still without suitable routine tools to determine the outcome of, for example, hip or knee replacement therapy. We rely on the results of carefully undertaken research studies, usually randomised controlled trials, which are not necessarily representative of either the general population or the methods of treatment given. What is missing is in part, the inability to link events in the same individual, and in part, the lack of simple tools for measurement. As a result, politicians and others rely on waiting times, hospital league tables, etc, as a proxy measure, and we criticise these attempts unmercifully.

Thus the crucial need is to gather information that will enable us to track individuals both over time and through different areas of care, to look at continuity and consistency of care, as well as at outcome.

- **Evaluation/monitoring/surveillance**—To determine whether the services provided perform appropriately, it is essential to be clear of their objectives. There is, however, a problem of specificity. Most concerns are with lessening the burden of disease. But what does that imply? Many health professionals will couch their objectives in terms of reduction of mortality, but since the probability of dying is 100%, we should be more concerned with reducing impairment and distress, and improving the quality of life and ability to participate in society if we accept the definition of health put forward by this paper. The problem for the health professional is the paucity of valid, easily applied measurement tools.

The need to be precise in the formulation of objectives is illustrated by, for example, services for cancer of the lung. If one wished to reduce incidence, and thus mortality, the most important measure would be to prevent people from starting and continuing to smoke. The necessary action for this involves education, health promotion and fiscal measures. Improving the quality of life and reducing disability from cancer of the lung implies the development of oncological and supportive services. The information needed for the first objective is knowledge of smoking habits, both inception and prevalence; for the second objective one needs measures of quality of life and survival [40].

There are, however, many simpler aspects of evaluating services which are essential in any health service. It is important to be able to assess how many individuals have been treated or how many investigations, treatments, etc have been given. The latter is theoretically easy, the former, at present, impossible. Although much is made of the increase in number of treatments given (or number of discharges), little attempt is made to determine whether the number of individuals treated has changed. Multiple admissions of an individual, or transfer from one department to another which increases the number of completed consultant episodes, may give satisfaction to politicians but may be a reflection of poor or inadequate treatment or care rather than a sign of improving health.

Information is needed not only on the resources available for the service, but also on the price of individual services and the cost of the service delivered. Although there has been some improvement in our financial information, we still cannot determine the true cost of treatment, diagnosis, etc, for an individual patient because we have no record links. Whether it is essential to be able to identify and cost precisely all items of service received by an individual is debatable. The cost of such an information system would be great and probably not worthwhile in the NHS. If, however, we changed to an individual charging system, eg insurance, it would be essential. We know staff costs, the costs of equipment, materials, buildings, etc, and can make rough estimates of the cost of providing particular services; if we know what service individual patients require, costs can be apportioned. If, however, we are to progress in the allocation of resources we need to develop better information to make it possible to choose between different aspects of treatment, or between prevention, cure, care and rehabilitation, and, in particular, compare the ‘avoidable’ costs of different treatments. The Health Care Programme of the Conference of Royal Medical Colleges [41] is an experiment in this direction which will enable choices to be made, for example between prevention and treatment. However, at present this project is tackling only three disease conditions; much more research and development will be necessary if we are to use such systems in a more generalised fashion.

Monitoring and reporting the health of a community or population is one of the most important tasks for demonstrating accountability, reporting
progress, and identifying problems or failures. Since the 19th century an essential part of this has been the Annual Report of the Director of Public Health. Such reports at both local and central level have been critically important in identifying problems and suggesting solutions. It is encouraging that such reports at local level were introduced in 1991 (after a 17 year gap) and are again beginning to fulfill their role. It is, however, worrying that their independence may be threatened by the increasing proclivity towards secrecy and gagging [42-44]. This must be resisted at all costs.

Reports such as those referred to depend on an adequate disease surveillance system: this means the continuing systematic collection, analysis and interpretation of outcome-specific data, closely integrated with their timely dissemination to those responsible for preventing and controlling disease or injury. Although some components of this process are available, e.g. vital statistical data, health information survey data, notification of infectious diseases or isolations, cancer registry data, disease specific registries, etc., other components, such as surveillance of industrial or toxicological hazards, are developed poorly or not at all. We need to bring them all together into a comprehensive information system that can be used at all levels of the NHS [45].

Population requirements

When we consider the health information required by the population to influence equity and priority, we face even greater difficulties. In the past, decisions on what services should be provided or where they should be sited, was largely left to those within the NHS, whether health professionals or serving on management committees or boards. Many of the lay people involved in such decisions were prominent, able and well-meaning individuals but were never considered to be representative; they merely provided a 'lay opinion'. National decisions are, of course, subject to parliament, but these can only be of a 'broad brush' nature, and the difficulties for 'local voices' to be heard are well known. Since 1974 there have been community health councils appointed by regional authorities on the nomination of voluntary bodies, community groups, local authorities and professional bodies. They comment on plans, transmit complaints and attempt to review local services. They cannot, however, be considered to represent the views of a community except in a very few instances. Between 1974 and 1991 district/area health authorities included four individuals (out of about 18) who represented the elected local authority; since 1991 all members of health authorities are there by appointment. All health authorities are enjoined to seek local views, and most make valiant attempts each year to canvas local people about important local plans concerning health. But we have almost no knowledge of what the majority really want to know nor how health authorities can obtain a view which is not dominated by a vocal, interested minority.

Furthermore, it is crucial to appreciate that information must flow in both directions. Although the population of the UK is reasonably homogeneous, nonetheless there are variations between different parts of the country; there are cultural, historical and other more subtle variations in the wishes of the population in different parts of the country, which are important for both the planning and delivery of services. The ability of health authorities to respond to the wishes of its population in a national service with national priorities is limited and we have not adequately tackled the antithesis—a national service responsive to local needs. Representation on health bodies of elected individuals makes them politically more accountable but does little to meet the above requirements. Consulting with and receiving responses from the population will be heavily biased towards the demands of the more vocal and is influenced by pressure groups or single interest concerns. Thus the data needs are clear, but how to obtain valid information which can be used in planning, is unclear. The voices of individuals or single groups cannot and should not be disregarded—the difficulty is to judge how much weight they should be given.

Thus, although we attempt to ensure an equitable health service and that its priorities are accepted by all those involved, whether they be the normal community, patients or professionals, we can see that we do not, in fact, meet these requirements. We have not been able adequately to define the data we require to help us in this task; we have not explored sufficiently what kind of information the population or patients require and can understand to obtain their contribution and agreement in defining priorities or assessing access and equity. We have not properly researched how to disseminate this information in the most effective way—to say nothing of implementing the necessary measures to ensure equity not only of access but also of outcome, and obtain agreement on priorities for the service.

Research, development and innovation

Clinical databases are increasingly being used for research purposes—to identify suitable questions for greater in-depth research, and assess trends, efficacy of treatment, comparison between areas, etc. Most researchers are well aware of the variations in death certification both within and between countries. Most epidemiologists either take steps to assess (and control) these sources of variability or interpret their findings with suitable caution. Clinicians (and pathologists in particular) are acerbic in their assessment of such epidemiological studies. But both these groups often appear unaware of the sources of variation in reporting, recording and identifying physical signs, history, diagnoses or laboratory investigations. Most individu-
als believe in what is written in the case notes or recorded on the computer. This may become of greater significance in the future, with the increasing ability to access and interrogate large clinical databases for research and management. It is difficult to put forward a global solution for this apart from the need for caution in the interpretation of the data.

A more expensive, and laborious procedure would be to introduce the same methods of quality control in the clinical data collection that we now expect of our laboratories. This means the duplicate measurement or recording of data by both the same and different observers on the same patient or specimen. Obviously, this is not possible on every occasion—but such a system of ‘check’ recording on perhaps a one in ten random sample, would enable the future researcher to know the variability and thus the level of interpretation warranted by the recorded data. The cost of installing and maintaining large databases is considerable—the cost of such a system of random duplicate recording is likely to be small in comparison, even if complex to establish in the first instance.

The brevity of this discussion of the research, development and innovation aspects of an ethical health service does not imply that they are unimportant. This paper is intended to deal with health information requirements. As research depends on the questions it poses, I have not added to the large number of researchable but inadequately studied topics that have already been identified here.

Conclusion

The attempt to identify the information needed for an ethical health service has shown the importance of clarifying what this implies. Such a service has to inform the individual or patient on how to attain an optimal level of health, enable judgements to be made by the population, patients and professionals on the quality of the service, to make assessments of equity of access and on priorities, and make it possible to collect valid information and make it available for research and development.

We have always tried to develop and be concerned with better information. Computing technology now offers us a potential to approach a higher level of knowledge than in the past. If done well and carefully, it could improve the ability of our population to maintain their health, increase the quality, accessibility and appropriateness of services provided within the resources available and ensure greater reliability of our research and development.

This analysis of requirements and present status demonstrates deficiencies in the present situation. They may be listed as follows:

1 Patients/individuals have inadequate information on how to maintain health, what to do and where to go to seek advice and help, entitlements for services, how to judge the quality of service provided, and what to do if dissatisfied.

2 Populations/communities do not have enough information to comment on the services that are provided. They have little ability to influence the collection of data to help in deciding their own wishes. For both these aspects the mechanism for the interchange between those responsible for services and those for whom they are intended, is deficient.

3 The presently available information on ensuring quality and improving it, is profoundly flawed because of inadequacies of collected data, methods of assessment, and a deficient knowledge base. Concentration on the process data presently available can only lead to confusion.

4 Inadequate methods for the identification of procedures, services, or practices which are of no value lead to waste, inefficiency and frustration.

5 Methods for ensuring equity, assessing priorities and monitoring and evaluating services presently provided, lack crucial components and are threatened by current policies.

6 Reliance on currently collected health information for research and development in the future is deficient because of lack of concern with the validity and completeness of the data collected.

In this lecture I have attempted to identify the components of an adequate information system and to comment on the adequacy of what we have at this time. It should be obvious that we lack many of the essential items which are necessary to deliver a health service ethically. In particular, we spend large amounts on the provision of process data recording events, but have spent only trivial sums on the development of methods for measuring the outcome of procedures. We thus continue to provide ineffective services, eg some screening services in general practice.

It is surprising that the NHS still has so many crucial gaps in its information base when we have spent billions of pounds on information and the computers that go with it. It is even more surprising that although we decry waste in some authorities on unwise computer purchasing decisions, we still make little fuss over the scandal of having no data on which to make some of the most crucial decisions. It is even more surprising in view of the many governmental working parties, starting with RAWP [46] and Körner [29-33], and continuing current strategies [47-49], that these bodies have not heeded a number of past publications [50-52].

This analysis has highlighted the major objectives. It has attempted to define the deficiencies and suggest
what gaps need to be filled. As a result there is an opportunity for action—and a compulsion to act if one is to be ethical.

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