

# MORTAL OR MORBID?

A diagnosis of the  
morbidity factor

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THE REPORT OF A  
NUFFIELD PROVINCIAL HOSPITALS TRUST  
WORKING PARTY

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GORDON McLACHLAN*

THE NUFFIELD PROVINCIAL  
HOSPITALS TRUST

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## *EDITORIAL NOTE*

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The question of securing high quality data on morbidity has attracted many people seeking a strong base for the intelligence fundamental to planning health services, since the potential contribution of good data to policy formulation in health care is great and has a universal appeal. The methodological issues it raises however are highly complex. It is clear that better, more widespread and comprehensive data on various aspects of morbidity (as opposed merely to mortality which is often used as a surrogate) could substantially improve the effect of a number of centrally focused health service procedures ancillary to planning. Resource allocation, epidemiology, and the identification of priorities for services to answer real needs, are perhaps the most important areas for improvement. It would however be a mistake to dismiss the problems as intractable, and with the sophistication of choice necessary in a period of resource constraint, a systematic and careful approach to examine the problem in all its aspects would seem to be an urgent requirement for the production of the kind of intelligence necessary for good management.

This book reviews a number of the more significant of these aspects, and attempts to point the way to improved data collection. It also suggests policy directions and further research. While there are no easy answers as yet in this field, it is hoped that the issues raised in the various chapters will take the debate further, not least in analysing and grouping many of the key questions in moving from theory to practice.

This collection should be read in tandem with the Trust's contemporary Occasional Papers on resource allocation—*The Policy of Resource Allocation and its Ramifications*, information—*Data, Information, and Intelligence*, and Health Services Research—*A Fresh Look at Policies for Health Services Research*.

G.McL

# CHAPTER **1** BACKGROUND AND INTRODUCTION

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## ***Morbidity, need, and demand***

It has long been considered essential to be able to assess the impact of illness on populations by having information about the occurrence and distribution of disease in such populations, and sub-groups within them. From this information it is hoped that an appropriate level of health care provision can be determined and the scope for prevention identified. It is also essential that careful consideration be given to the information base for equitable methods of resource allocation, to the assessment of priorities for health care, and to the measurement of outcome of health policies and programmes.

Death rates have been traditionally used as crude, but often effective, surrogates for more comprehensive indicators of the pattern of disease. This is seen to be justifiable because the fact of death is unambiguous and its compulsory registration ensures completeness of the data. National mortality statistics are available over a considerable span of time. They are, of course, person based and routinely disaggregated by the important dimensions of cause and place of residence.

For the majority of diseases it is generally recognized that mortality only represents the readily quantifiable tip of a largely indefinite iceberg of morbidity. This can be illustrated by comparing the distribution of causes of death with that of disease as ascertained by the General Household Survey. For example if the 17 chapters of the *International Classification of Diseases*, (ICD) are ranked using both sources it can be shown that cancers, although the second most

common cause of death, come only as the sixteenth cause of prevalent morbidity. In contrast, musculo-skeletal disorders, such as arthritis and rheumatism, which rank low as causes of death head the list of causes of self-reported illness.

Morbidity, whilst an easily understandable concept, is not easy to define, as Buxton and Klein (1) have reminded us when they provided evidence for the Royal Commission on the National Health Service; and Palmer (2), in discussion of the conceptual complexities of relating need to morbidity, also drew attention to the incompatibility of definitions of morbidity used by different groups. The broad, long-standing and well known World Health Organisation (WHO) definition (3) of 'any departure, subjective or objective, from a state of physiological well-being', has the advantage of being comprehensive; but includes on the one hand subjective minor 'sickness' perhaps of a transient nature 'treated' by self-medication and, on the other, major pathology requiring extensive medical resources but about which the individual concerned may be unaware. Awareness by the individual is an axiomatic component of any definition used in a health interview survey, although this concept is frequently qualified by imposing a 'threshold of reaction' such as that of 'restricting activity' or resulting in the 'seeking of (medical) advice'.

Any serious consideration of morbidity, in its broadest sense, cannot fail to incorporate some discussion of the concepts of need and demand; and to take account of the various ways in which health services respond to the needs of populations. Definitions, explanations, refutations abound in this subject area and simple statements have been overtaken by exegeses and taxonomies. Until recently Government Reports and Commissions (4-9) have tended to suggest that 'needs' exist in some obvious and agreed way and that health and social services can simplistically 'meet' these 'needs' by the provision of appropriate services.

In 1975 Hogarth (10) in a glossary of WHO health care terminology gave definitions of health needs and demands, gleaned from WHO official records of 1973 as follows:

*Health needs* may be defined as scientifically (biologically, epidemiologically, etc.) determined deficiencies in health that call for preventive, curative and eventually (= where appropriate?) control or eradication measures.



*Health demands* are usually measured in terms of the actual utilization of health services. Consideration must be given to the fact that all felt needs by a population (most usually in curative medicine) cannot be translated into expressed need or demand for various reasons (absence of accessible health services, lack of information, lack of confidence, low income, etc.).

He also drew attention to a classification of need and demand proposed by a WHO expert committee on Health Statistics in 1971 (11). This committee suggested five categories:

(a) *Perceived need*: the need for health services experienced by the individual and which he is prepared to acknowledge. Under certain conditions it may exceed the professionally defined need.

(b) *Professionally defined need*: the need for health services recognized by a health professional from the point of view of the benefit obtainable from advice, preventive measures, management or specific therapy. Under certain conditions it may exceed the perceived need.

(c) *Scientifically confirmed need*: the need confirmed by objective measures of biological, anthropometric or psychological factors, expert opinion or the passage of time. It is generally considered to correspond to those conditions that can be classified in accordance with the *International Classification of Diseases*.

(d) *Potential demand*: the demand for health services corresponding to whichever is the greater of the perceived and professionally defined needs for each particular condition or for the conditions affecting a given population.

(e) *Expressed demand*: the demand actually made on the health services available to a population. It may be greater than the actual utilization because of the existence of waiting lists, limited resources or differences between patients' perceptions of their needs and professionals definition of those needs.

About this time Bradshaw (12) developed a taxonomy of social need with broadly similar concepts. He suggested a classification with four basic elements:

(a) *normative need*—as externally defined by social scientists or other 'experts';

- (b) *felt need*—as equated with perceived ‘wants’ in the population;
- (c) *expressed need*—felt need turned into action, as demand; and
- (d) *comparative need*—obtained by the identification of the characteristics of the population in receipt of a service—and subsequent definition of those with similar characteristics not in receipt as ‘in need’.

By combination of these four basic elements a dozen further categories could be constructed which, at the extremes, would represent universally agreed need—or its absence—but between which reflect varying degrees of conflict between internal and external opinions as to the presence of a particular need in any defined population. Thus the over-simple governmental uses of the term was replaced by what in many ways was an overly elaborate model. This analysis did however firmly establish the complex nature of the debate.

More recently, Acheson (13) defined the need-demand continuum from the view of the expert medical practitioner who might distinguish between appropriate and inappropriate treatment, in that for example, ‘ineffective treatment’ and ‘unnecessary investigations’ were seen as part of the range of met demand or utilization. Matthew (14) taking an ‘effective medical care’ perspective suggested that the ‘need for medical care exists when an individual has an illness or disability for which there is an effective and acceptable treatment or cure’.

Another group of professionals who have been concerned with definitions of need have been those economists who might be described as ‘needophobics’ in that they have been most critical of the early writing on these issues seeing much of it as an encouragement to sloppy thinking. Culyer (15) regarded the rigorous definition offered by Matthew as too limited in that it failed to acknowledge the existence of the need for health care in situations where no effective and acceptable treatment existed. The main early criticism of the use of the term ‘need’ offered by the economists is perhaps best summarized in the following quotation from Culyer, *et al.* (16) which sought to banish the word need because of its ambiguity and its frequent use in the arbitrary sense as ‘in many public discussions it is difficult to tell, when someone says that ‘society needs (something)’ whether he means that he needs it,

Professional/ Providers	Patient/Consumer		
		Individual	Group
	Individual	Doctor relationship a	Practice list Catchment population for speciality b
Group	Medical relationships c	d F.P.C., C.H.C., D.H.A., B.U.P.A. Royal Colleges B.M.A.	

FIG. 1. Patient and professional interrelationships.

whether he means society ought to get it in his opinion, whether a majority of the members of society want it, or all of them want it. Nor is it clear whether it is 'needed' regardless of the cost to society'. However, latterly Culyer (16) appears to have been converted to the 'need' concept, provided that appropriate qualification of the term is used.

It is clear that a major contribution of the economists has been to clarify the thinking on this subject, for example, they point out that in defining needs in health policy terms, not only do the providers and the consumers have a view but that also the third parties—such as the public, economists, administrators, the medical profession—have a major stake.

Figure 1 gives some indication of the complexity of relationships that can exist between patients and health care professionals in their various roles. These range from the well described individualistic doctor/patient relationship (a), through to the relationship between professional medical groups and major providers of health services (d). Area (b) in the diagram suggests that a given individual practitioner, while having a series of individual relationships with patients also has a relationship, for example, as a general practitioner with his practice list, or if the doctor is a hospital consultant he has a relationship with the catchment population that his hospital serves. Equally, individual patients (c) may have a series of relationships at any one time with the

medical and allied professions, and certainly over a life time will have such a series of interactions.

Given the complexity of roles and relationships that exist between individuals or groups of providers and patients, it is perhaps not surprising that definitions of need are varied and may often appear to be in conflict. It is therefore perhaps of value to consider further the concepts of need and demand for health services from the vantage points of, on one hand, the patient, and the other hand, the medical practitioner or health professional.

For the purpose of this discussion it is appropriate at this stage to consolidate some definitions for the terms used:

1. **Needs:** items of service, or resources, held to be required, either by consumers or providers.
2. **Demands:** items of service, or resources, held to be required, by either consumers or providers, and sought.
3. **Met demands:** demands that are sought and obtained.

Figure 2 shows, rather stylistically perhaps, how consumer and provider definitions of need and demand interact. The extent to which the consumer and provider definitions of need correspond will vary between different societies, points in history, and between individual providers and consumers. For example, in relatively primitive societies, with a small but highly trained medical profession, there may well be very little correspondence between consumer and provider definitions of need. Similarly, providers and consumers rarely present homogeneous statements of need, as illustrated by, say, the different religious and ideological views of obstetricians on the issue of providing abortion services. Similarly, a wide range of responses will be elicited from consumers on the necessity to provide contraceptive services through the Health Service.

The diagram also suggests that there are whole ranges of services which might be perceived by consumers to be 'health' services which would not be acknowledged by medical and nursing professions to be relevant provisions. This of course was the case in the early part of the century for almost all contraception provision, and more recently for many of the services provided for adolescents using drugs (17). Indeed many statutory services begin their life as informal services responding to a consumer's view of a health or health related need.

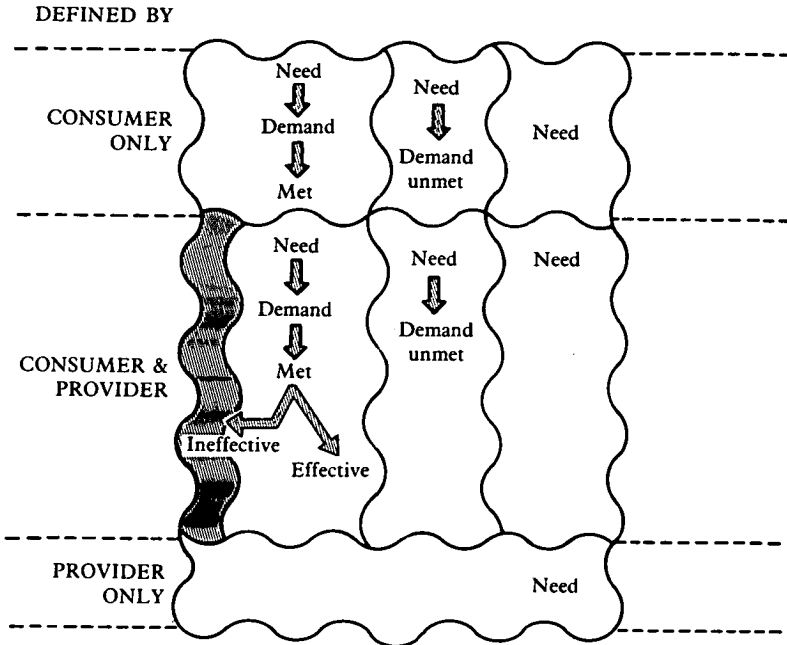


FIG. 2. Interaction of definitions of need and demand.

It is of interest to note that there is a section within Figure 2 that relates to provider definitions of need that have no corresponding sections in terms of demand. This relates to those needs that are at a stage of being defined by the medical profession, but have not yet been mobilized in terms of consumer activity. It makes the obvious point that a service cannot be provided unless the consumers are interested in using that service. This of course is of major relevance to preventive activities where it is often the case that prophylactic or other procedures are available, but that consumers are unaware of, or do not value, the provision, and the services are therefore not utilized.

Solutions to the difficult task of identifying medical and socio-medical needs of populations of people lie in, firstly defining geographical populations rather than groups of health service users and, secondly in measuring needs by a variety of definitions (both professional and lay). Once such needs have been identified and a

consensus has been reached, then—subject to satisfactory evaluation—it might be appropriate to attempt to provide for such needs.

Current routine information systems when based on utilization provide very little about unmet demand and nothing about unmet need. Indeed, unmet need is particularly difficult to assess and the extent of the problem has traditionally required specially designed community surveys (see chapter 6).

### **Need and resources**

Given the difficulty in defining and measuring need it is not surprising that it is difficult to quantify the resources required to meet need. There is ample evidence that national levels of expenditure on health continue to rise inexorably throughout the world. In the United States the proportion of the gross national product expended on health has doubled in twenty-five years (18), to 9.6 per cent in 1981. In the period 1960–80 in Great Britain the proportion of the gross national product spent on health has risen from 3.5 to 5.5 per cent. The supply of health care services is very unlikely to keep pace with the rising demands placed upon them (19), and although some feel that it is appropriate to spend ten per cent or more of a gross national product on health (20) it is clear that the current rate of increase cannot be continued indefinitely.

Yet, as the Royal Commission on the National Health Service (9) recalled, under the National Health Service Act, 1977:

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 assure the effective provision of services in accordance with this Act.

Furthermore, the original National Health Service Bill envisaged health services available to all regardless of financial means, age, sex, employment, or area of residence (21), and the Royal Commission on the NHS has construed that the NHS should:

1. encourage and assist individuals to remain healthy;
2. provide equality of entitlement to health services;
3. provide a broad range of services of a high standard;
4. provide equality of access to these services;
5. provide a service free at the time of use;
6. satisfy the reasonable expectations of its users; and finally, remain a national service responsive to local needs.

Concepts of equality and equity lead in 1975 to the appointment of the Resource Allocation Working Party (RAWP) (19) with the following terms of reference:

To review the arrangements for distributing NHS capital and revenue to RHAs and AHAs and Districts respectively with a view to establishing a method of securing, as soon as practicable, a pattern of distribution responsive objectively, equitably and efficiently to relative need and to make recommendations.'

From these terms of reference it was implicit that needs for health care should be the criterion for health service provision and hence its distribution of financial resources. As its criteria of need the Working Party took the size of the population to be served, the age and sex composition of the population, and mortality—the latter as a surrogate of morbidity. Mortality was incorporated on the grounds that there were no routine and reliable whole population measures of morbidity available that were independent of supply of resources. They argued that 'statistics of relative differences in regional morbidity, if they existed, would exhibit the same pattern as those for mortality.' However, subsequent work which will be reviewed in chapter 3 suggests that reported morbidity and use of services may have little relationship with mortality measures. The problem therefore remains as to how we might measure morbidity so as to better allocate resources to both preventive and curative services.

The survey in chapter 4 of the availability of routine information implies that the state of knowledge has at the moment a low rating. Much work has yet to be done, before it will be practicable to generate effective policies from existing sources of information. At the same time it would be necessary to have regard to the selection for improvement, of other types of information for improvement which can be correlated with morbidity for policy purposes. The

evidence for this assertion is illustrated in chapter 5 which shows that the most promising innovations in information systems are often highly local. It would be also a formidable task to formulate, from an analysis of local experience, a general policy for the future recording and collection of information related to the priorities perceived at government level, for planning purposes, and for medical practice. The pioneering studies referred to are hardly 'demonstration' projects, let alone raw materials from which national data can be constructed. In short it has to be recognized that the production of information on morbidity which can be used for strategic planning, for resource allocation, or for general operational purposes is still in its infancy; and equally that the frequent resort made to the more easily garnered statistics is at best a flawed substitute.

From all the evidence in the earlier chapters of this book—but especially chapter 6—it may be gleaned that there is increasing divergence between mortality rates and morbidity rates for similar disease classifications. Not the least of the causes may be the decline in mortality rates for illnesses for which the actual facts about morbidity might well present significant problems for care.

### **The complexity of objectives**

The question of the policies to be adopted in the future to develop knowledge about morbidity is extremely complex. There has hitherto been very little work carried out on how best to record and collect morbidity data and consequently to use it as a positive scientific base for both research and for operational requirements, including planning and monitoring health services. Yet the recent developments in data recording, collation and processing, have great potential and offer great opportunities in the search for improvements in the information base. This chapter has shown that the concepts already exists; in the next it will be demonstrated how these can be translated into data requirements and which should provide the benchmarks for policies.

It is also becoming evident that the use of mortality data as a bland surrogate for morbidity data may be becoming less appropriate as the complexity of the issues likely to stimulate health policies is revealed. Indeed the main arguments which have tended to underpin the use of mortality data in the past for planning purposes *viz* the claim that



mortality is in fact the best surrogate known, and that it is a guide of sorts which is better than nothing, have to be examined afresh. Considerations such as these, as well as the issues which will be raised for discussion of this matter in chapter 3 required increasing attention in the pursuit of making optimum use of provision.

The assertion that mortality data are better than nothing, should not be allowed to stand in the way of moves for improvement. Technological and methodological means for collecting information of various sorts for various purposes but with a bearing on resource allocation and planning are being continually developed. This is not to imply that mechanisms for producing improved formulae incorporating morbidity data will solve all problems concerned with the better use of resources, indeed it is doubtful if attempts to improve the RAWP formula by the inclusion of measures of morbidity instead of, or as well as, mortality would satisfy everyone. Hence the importance of the discussion in chapter 7 which will show the need for a range of better data to illuminate the search for more relevant indicators of health.

## CHAPTER 2 THE REQUIREMENTS FOR MORBIDITY INFORMATION

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Government interest in the provision of health services (22) includes an annual review of the strategy and planning of Regional Health Authorities (23). Recently, revenue cash limits have been imposed and manpower targets reduced (24). There are hopes that suitable 'performance indicators' can be devised (25), although the arguments for these and the measures chosen are far from clear cut (26).

These developments underline the critical importance of correct decision-making. This in turn emphasizes the need for appropriate information on which to base decisions, particularly in the context of resource allocation, the assessment of priorities, and the planning of services. Indeed it is important to consider these aspects together. Butts, Irving, and Whitt (27) when reviewing health service planning and resource allocation drew particular attention to the fact that 'the criteria upon which policies' (and hence priorities) 'for developing services are based should be consistent with the criteria used to allocate resources'. They further noted, however, that the present methods are fundamentally different and that 'the DHSS have made no attempt to reconcile the two approaches'.

### ***Resource allocation***

Geographical inequity in the distribution of resources, particularly of hospital beds, has been demonstrated on many occasions since the 'Domesday Book' studies of the Nuffield Provincial Hospitals Trust in 1946 (28). These and the subsequent related studies have been comprehensively reviewed (4,29) on several occasions and many

attempts have been made to identify the reasons that might lie behind the differences.

Feldstein (30), for example, demonstrated that these differences persisted after crude correction for case-mix and Griffiths (31) cited several reasons as to why this should be, namely: the lack of a concept of the correct level of provision; the late development of information systems in the NHS; and some inertia in a diffuse management structure. However, most observers agree that the most probable explanation is that of historical accident.

The allocation of resources in terms of revenue expenditure from the onset of the NHS to the 1960s simply provided the running costs for facilities which already existed; thus perpetuating inequalities in the NHS. In consequence initiatives were taken in 1970 (32) to redress this regional imbalance in revenue funding. A formula was introduced in 1971 with three elements:

1. *Population* weighted by national bed occupancy by age and sex.
2. Average daily occupied *beds* and outpatient *attendances*.
3. The number of in-patient, out-patient and day-patient *cases*.

A weight of 0.5 was given to the population element and weights of 0.25 each to the beds and cases components of the formula. The population element represented need for health care and favoured regions with a high proportion of elderly. The beds component favoured the high bedded regions with the case-flow element favouring high tempo regions (15).

The report of the Resource Allocation Working Party (RAWP) in 1976 had the objective of securing, through resource allocation, equal opportunity of access to health care for those at equal risk. Whilst the formula devised had to be achieved using statistical data which were *readily available* the concept of relative need was an essential ingredient (19). In essence, a region's notional revenue allocation for hospital and community health was, and still is, determined by its population weighted by national age/sex specific usage of services and by standardized mortality ratios (SMRs). In respect of acute non-psychiatric hospital inpatient services, condition-specific SMRs are used in the weighting procedure rather than all causes SMRs. Many refinements, not to be discussed here, are also incorporated in the formula, for example adjustments for cross boundary flow and the actual pace of change in a region's allocations

from one year to the next. A basic feature of the RAWP report is that mortality in the form of SMRs, rather than morbidity has been used as a proxy for health care need. A 'direct' indicator of morbidity which would adequately represent need for health care in a 'RAWP type' formula would have to meet criteria which would include:

1. An ability validly to identify the needs of Health Authorities for hospital and community health services separately from those of general practice (except FPC administration).

The NHS structure and RAWP procedures impose the drawing of a distinction between the need for care in Health Authority controlled services (e.g. hospitals, community health, etc.) and general practitioner services (excluding Family Practitioner Committee Administration) since the latter are funded separately and not through the RAWP mechanism.

2. Freedom from direct bias caused by availability of resources.

3. Accurate availability at regular intervals over time for health regions and districts.

4. The capability of disaggregation by age, sex, and diagnosis.

These requirements are perhaps more stringent than at first sight, but are necessary if any postulated morbidity indicators are to replace present mortality data which by and large fulfil requirements 2, 3, and 4; although their relevance to requirement 1 has been questioned.

However, the extant position in the present RAWP procedures is that the bulk of funds allocated from national level to region to district are not earmarked: with the spending of allocated funds from RAWP not necessarily directed towards the need elements in the formula which determined their magnitude. Moreover, there is no explicit requirement under the formula that the health care provided from allocated funds be effective and any indicators of success are ignored.

A state of health indicator measured at a single point in time or for a combined group of years may be interpreted either as indicating the need for health care or as the outcome resulting from a combination of inputs that affect health. Thus, the RAWP formula interprets mortality data solely in keeping with its objective of measuring the relative *need* for health care. Indeed, the RAWP report states 'we recognise that the prevalence of many of the

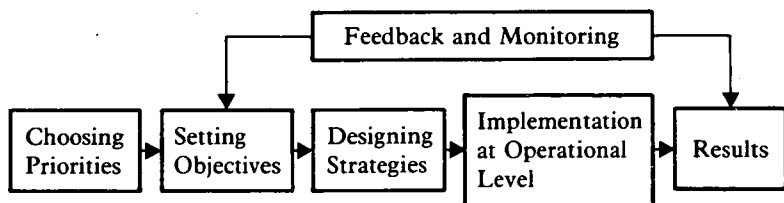
conditions which are among the main causes of mortality is probably not significantly influenced by the intervention of health care services and that the redistribution of resources may not therefore have a significant and early impact on morbidity characteristics' (19). In summary, the RAWP formula expresses no explicit requirements that the health care provided from allocated funds should be effective. This virtual rejection of a causal chain between a change in health resources and a change in morbidity is surprising, though a more sympathetic interpretation would be that RAWP was referring to the link between health care resources and *measurable* morbidity (using mortality as a proxy). The advisability of providing additional health care resources in response to increased allocation must rest on the notion of some benefit to the recipient population through effective use of those resources. Given presently available indicators, such benefits may be intangible but, with appropriate measures of the caring process such as patients' satisfaction with services, it may be possible to establish a more substantial causal link between services and outcome.

If a decision were taken to incorporate outcome indicators in a resource allocation formula, how could this be done? Firstly, the indicator or set of indicators must be measured for the relevant areas at two points in time. Secondly, change in the indicator in the intervening time period must be interpreted correctly. If there has been improvement or success with respect to the indicator, this may have been the result of (a) increased resource allocation, (b) better use of existing resources, (c) factors unrelated to direct health care activity, or (d) a combination of two or more of these factors. The weighting that improved outcome would carry in any resource allocation formula would partly depend upon the relative contribution of (a) to (c) towards success, measured by change in the indicator. If outcome were to be measured by change in mortality, it is known that the relationship between mortality and health inputs has not been favourably established (33). Moreover, it should be noted that the rank order of regions with respect to mortality has remained reasonably constant this century. The list of disease groups chosen by Charlton, *et al.* (34) in which mortality should be avoidable in the presence of timely and appropriate medical care, accounted for a very small proportion of all mortality. It seems likely, therefore, that on current evidence only minimal weighting, if any,

could be given to mortality outcome in a resource allocation formula. If progress is to be made in rewarding success, it must await the establishment of the strength of the causal link between input of health resources and sensitive morbidity indicators.

### **Planning and priorities**

It was noted earlier that, within current and inevitably future resource constraints, the choice of priorities is critical. In any simple planning model the choice of priorities is the primary task. For example, we might propose the following:



In determining the priority for specific services, it is necessary to distinguish between a set of options based on care groups, specialties, units or diagnostic groups. The following information, used in combination, would be helpful:

(i). **The trend in frequency in the disease category in question over time:** It would seem natural perhaps to consider diseases of reducing frequency to have a lesser priority, and all other things being equal, this may be the case. However, it may be that the frequency is reducing because of health service preventive activity. For example, in a situation in which there was a steady falling incidence of a disease due to immunization, it would clearly be a mistake to consider reduced frequency as the sole criterion for lowering the priority.

(ii). **Relative frequency compared to other areas and disease categories:** Common disease and diseases which have an excessively high frequency in a particular area may be candidates for priority, but in conjunction with;

(iii). **Severity:** Possibilities for inclusion here include:

- (a) risk of death
- (b) degree of disability and pain or distress
- (c) potential duration of disability and pain or distress.

(iv). **Effectiveness of prevention/treatment/care:** It might be argued that only those health care activities which have been shown to be effective should be put into practice. Certainly this would be an important factor in choosing priorities provided that effectiveness studies are able to evaluate the 'care' component of health care and not just the 'cure' aspects.

(v). **Efficiency of prevention/treatment/care:** This may be defined (after Drummond) (35) as providing the maximum health benefit to a community using potentially available resources. The techniques of cost-effectiveness analysis and cost-benefit analysis may be used to explore efficiency.

A question of interest is, given that priority for a service to aid a particular disease category has been established, can morbidity measures indicate the absolute and correct size of service required to meet this need? i.e. in our model what size of service should be implemented at operational level. If the frequency of the disease is known, the views on the size of service to be delivered are likely to depend on the choice of the threshold of severity at which intervention should occur, this may also include a consideration of screening. In practice, this choice may be constrained by a perceived lack of finance or more positively aided by evidence from cost-benefit analysis, i.e. out of a specific budget, the size of one type of health activity to combat a particular disease category can only be increased at the cost of reducing some other. In other words, the community will forego the benefits of the latter activity (35).

Two examples will be given of this difficulty of defining the absolute size of the service required. The admirable survey of Amelia Harris (36) divided the handicapped into the very severe category who it was felt needed special care and the severe category who needed considerable support. The former accounted for 5.3 per cent of the sample whereas the latter constituted 11.6 per cent.

On the assumption that both special care and support would bring benefits to all recipients, a considerable step-up in the level of services would be required to provide for the severely as well as the very severely handicapped. If we also include those defined as appreciably handicapped who were thought to need some support, then the population coverage required rises to 20 per cent. Where should the line be drawn? A second example is in the screening for

Down's Syndrome. Putting aside issues of the ethics and acceptability of amniocentesis and therapeutic abortion of foetuses screened as positive, it would be possible to consider the complete elimination of the incidence of Down's Syndrome by screening all pregnancies (37). In practice, however, the risks of detecting an abnormality only outweigh the risks of foetal loss and infant morbidity following amniocentesis in mothers aged 40 and over (38). Additionally, two cost-benefit analyses have shown that the economic benefits exceed the costs only when patients aged 40 and over are screened (39) (40). Given these criteria, less than 20 per cent of the incidence of Down's Syndrome would be detectable in the future as a maximum (41).

It seems clear, therefore, that morbidity information will be of critical importance in the choice of priorities. With the use of techniques such as cost-benefit analysis incorporating morbidity indicators, an optimum size of service may be proposed. This cannot be considered absolute, partly because of the constantly occurring scientific changes in health care, and partly because in the eyes of certain potential recipients of a service, the 'optimum' size of service planned was not the best as far as they were concerned (e.g. the 80 per cent of potential Down's Syndrome incidence not subjected to screening procedures). In addition, the 'optimum' size of service is frequently selected on the basis of value judgements without the benefit of objective aids like cost-benefit analysis.

### ***Monitoring and evaluation***

As part of the monitoring process of health care plans, the DHSS has recently introduced the concept of performance indicators. The indicators cover five topic areas, namely clinical work, manpower, finance, estate management, and the ambulance services. The measures relevant to this discussion are the clinical performance indicators and, to a lesser extent, those on finance. The clinical indicators (1981) published on a District basis for England referred to the specialties general medicine, general surgery, trauma and orthopaedics, gynaecology, and obstetrics (42). The clinical indicators are available for each of these specialties in the following format (with minor variations):

- (a). Immediate admission per cent.



- (b). Gross admission rate per 1000 population served.
- (c). Length of stay (days).
- (d). Annual throughput per bed.
- (e). Turnover interval (average length of time that a bed is empty between successive patients).
- (f). Day cases as a percentage of all cases.
- (g). New outpatient referral rate per 1000 population served.
- (h). Ratio of return to new-outpatients.
- (i). Waiting list per 1000 population served.
- (j). Estimated days to clear the waiting list at the present level of activity.

The principal epidemiological criticisms of the clinical performance indicators are that they fail to take account of differences in case mix and age distribution between the Districts. Moreover, they are not adjusted for the availability of resources (except for annual throughput per bed) such as bed supply per 1000 population served. The financial indicators are hospital based and include the cost per inpatient day and the cost per case. In the latter, actual and expected costs are calculated; having taken account of the mix of specialties in a hospital, length of stay, and additions for London and/or teaching hospitals.

The objective of performance indicators is to enable Districts' and Regions' efficiency to be assessed (23). Earlier, efficiency was defined as providing maximum health benefit to a community using potentially available resources. Although the performance indicators are on a population basis, it is clear that they cannot fulfil the definition of efficiency since the outcome of the hospital service (i.e. particularly in the form of morbidity) is not considered. In their present form the clinical performance indicators represent hospital activity and the financial indicators cost this activity. In short they are comparisons of utilization but take no account of the need for care or quality of care. It is better to consider them as screening devices in which the epidemiological concepts of specificity and sensitivity are of vital importance. If the specificity is low then the indicators will reveal a high proportion of false positives, which if handled badly may stigmatize and blight a district service such that morale is lowered and recruitment made more difficult. Moreover, much management and clinician time may be wasted in the further

exploration of false positive results. On the other hand, low sensitivity will produce a high proportion of false negatives. In this situation, screening with performance indicators gives a clean bill of health to a District service such that no further investigation takes place and the real problem continues undetected. In fact it may not come to light for many years. In the context of the routine indicators available for mental handicap hospitals, the evidence suggests that low specificity is the problem and that sensitivity is quite high. For example, Yates (43) using data from routinely available indicators for the years 1975 to 1978, successfully identified a hospital which became the subject of an enquiry. However, nine other hospitals which did not become the subject of enquiries during that period were also identified as positives.

Performance indicators should encompass epidemiological as well as administrative information. For example, the Table 1 shows discharge rates for trauma and orthopaedics in four Districts in the Oxford Region. The discharge rates for all traumatic and orthopaedic surgery apparently show District 4 in quite a favourable light; particularly as it also has short lengths of stay and a high throughput in the specialty. However this overall performance is largely in consequence of the greater number of short stay head injuries admitted to this specialty in this District compared with elsewhere. By contrast, rates for major cold orthopaedic surgery, and particularly for hip arthroplasty are strikingly low in District 4.

General conclusions would not be drawn from this example unless account was taken of the performance of each District for a wide

TABLE. 1

*Discharge rates per 10,000 people in four Districts in the Oxford Region for (a) trauma and orthopaedics as a whole,\* and (b) head injuries and hip arthroplasties discharged by T & O surgeons.†*

	<i>Discharge rates in Districts 1-4</i>			
	1	2	3	4
All T & O surgery	108.0	107.8	81.5	132.3
Head injuries	19.0	23.4	4.5	47.4
Hip arthroplasties	4.3	3.1	2.0	0.2

\*From performance indicators in the Oxford Region, DHSS.

†From Hospital Activity Analysis.

range of operations, as well as the two to which specific reference was made. Nevertheless, this example serves as a reminder that the use of 'tracer' conditions is advocated in the evaluation of performance; in this event great care should be taken to ensure that those conditions selected do indeed fulfil the intended role.

Interpretation of the information can also be difficult. In the example, the disparity between the hip arthroplasty rate in District 4 and elsewhere intuitively suggests that it is the low rate in District 4 that is out of line rather than, say, the highest rate in District 1. This intuition is not only based on the magnitude of the discrepancy; it also takes account of the innate knowledge that everywhere there is likely to be a need for such surgery which is in excess of the discharge rate achieved. Whilst this may be undoubtably true for this operation, such a premise by no means applies generally; and certainly in other circumstances, such as hysterectomy, particularly high rates would be subject to question. This identifies a need for adequate information about levels and trends of the incidence and prevalence of conditions in the community served. This would then allow those providing services to know if needs were being met, or whether the local 'pool of pathology' was becoming larger or smaller as a result of the level of provision of services.

## ***Epidemiology***

The perspective on morbidity taken in this volume is essentially that of physicians working within the community and using the skills of epidemiology. Unlike many other medical specialties epidemiology often fails to generate a sharp image as to the professional activities of the epidemiologist.

Present day epidemiology is a far cry from the definition offered by Wade Hampton Frost who defined it simply as the science of infectious disease and ignored the work of such men as James Lind, Percival Pott, and his own contemporary Joseph Goldberger. The change in emphasis over the fifty years since the infectious disease definition was offered, is explained by the major changes in the pattern of mortality and morbidity since that time, with the virtual disappearance of the, often fatal, infectious disease of the later nineteenth century, and the ascendance of the chronic degenerative diseases, such as ischaemic heart disease, cerebrovascular disease,

osteoarthritis, and so on. These changes in disease frequency and duration have forced parallel changes in the activities and interests of epidemiologists; in that a major component of epidemiological work is now concerned with the study of the causes and risk factors of chronic diseases.

Traditionally the epidemiologist's first action has been the scrutiny and analysis of mortality data relevant to the condition under investigation. The validity of using such data, or subsequently cases identified through mortality records, in aetiological studies rests on the assumption that there is no difference between fatal and non-fatal cases in respect of the risk factors under consideration. This is an assumption which often cannot safely be made. Furthermore the practicality of using mortality records depends on there being sufficient cases which resulted in death in the study population. This often rules out the study, by mortality records alone, of diseases which uncommonly result in death. Epidemiological studies which have used mortality data alone have made major contributions to identifying the causes of a number of fatal diseases. By contrast, relatively little is known about the causes of a wide range of common disabling diseases which uncommonly lead to death. Advances will depend on the existence of systematic ways of identifying non-fatal diseases in defined populations.

Access in recent years to the wide range of morbidity records described in chapter 4 and to the special studies in chapter 5 has added immeasurably to the epidemiologist's armamentarium in the pursuit of aetiological studies. It is considered, however, that further consideration of this topic is outside the scope of this volume. At the same time the relatively fast changing demographic and morbidity profile in many parts of the world, together with the explosive growth in the cost of health services, have encouraged the epidemiologist also to become actively involved in the process of planning and evaluating the complex chain of preventive and curative services; often placing particular emphasis on the assessment of the effectiveness of health-care strategies.

This latter activity can be illustrated by consideration of recent trends in mortality rates of myocardial infarction. After a long period of rising mortality in many industrialized countries, the coronary death rates began to fall in some (e.g. Australia and the USA) during the late 1960s and 1970s. There is also some evidence of a

more recent down-turn in Great Britain (44). The reasons for the decline are unclear. Two major contending possibilities are a reduction in the incidence of the disease, possibly related to changes in risk factors, an improvement in case-fatality rates, possibly related to advances in coronary treatment; or both. Credit for the decline has been claimed by the proponents of both preventive medicine and coronary care. The distinction between these two explanations has obvious implications for public health policy and for policies regarding patient care. It is distinction which cannot easily be made because routine incidence (as distinct from mortality) data have not been readily available. In the absence of information about strategy—for example, to assess the effectiveness of coronary care—it seems trivial to measure, say, whether some districts have more coronary care beds, or keep their patients in those beds one or two days longer, than others.

Another, equally important, aspect is that it is not only professional epidemiologists who need epidemiological information. The results of epidemiological studies of causes and risks are often, of course, of direct relevance to clinicians. They often form the scientific basis for personal advice about, for example, smoking, diet, exercise, the safety of contraceptive methods, and the use of medications during pregnancy. However, epidemiological information can also prove crucial to those concerned with health policy and health service management who need to be informed about patterns of disease, requirements for health care, the scope for prevention, the effectiveness of health care strategies, and the efficiency with which health care is provided.

## **Conclusion**

The Royal Commission on the NHS concluded that priorities at a national level were drawn up on the basis of subjective judgements. They supported the view that the discussion of priorities should be carried out in public and *illuminated by fact* (9). Decision-making within the fields of resource allocation, priorities, planning, and performance can be enhanced by the availability of appropriate morbidity information and subsequent objective analysis. This illumination of the issues by fact can only improve the public debate.

The advances in this field, however, are not uniform. For example,

resource allocation for general practitioner services does not appear in the RAWP formula. This is partly a reflection of the relative lack of morbidity information in general practice. The exclusion, to date, of a cornerstone of the NHS such as general practice from one of the more objectively guided aspects of decision-making illustrates the size and complexity of the task ahead.

# CHAPTER 3 MORTALITY AS A SURROGATE FOR MORBIDITY

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## ***Resource allocation***

A common response to RAWP's inclusion of mortality data as a proxy for morbidity was one of initial scepticism, on the grounds that 'surely there must be some more direct index available', followed by gradual acceptance that indeed no such alternative simple, readily available index exists. The use of mortality statistics in RAWP remains important for two reasons. Firstly, and obviously, it influences Health Authorities' financial targets and insofar as targets influence final allocations (45) it is important in the geographical distribution of health service finances.

Secondly, less obviously but understandably, acceptance of mortality as a surrogate for morbidity in the all-important area of resource allocation seems to have diminished interest (once the practical difficulties of seeking alternative measures had been acknowledged) in considering the conceptual basis of using mortality as a proxy for morbidity.

There is, however, no clear evidence of a simple linear relationship between mortality and needs for health care, as implied in the RAWP formula, even if there are broad geographical correlations between mortality and morbidity. It is possible that the current mortality weightings, used in RAWP exaggerate differences between Regions in 'true' needs; and it is also possible that they underestimate such differences between regions.

The main evidence presented by RAWP to justify the use of mortality statistics in geographical resource allocation was the fact of

significant positive geographical correlations between mortality statistics and morbidity data from sickness benefit statistics and the General Household Survey (19). RAWP's use of mortality statistics has been questioned in a number of ways. Forster analysed General Household Survey data and showed a significant positive correlation between standardized mortality ratios and chronic sickness but no significant correlation between standardized mortality and acute sickness, bed sickness, or sickness causing work or school absence (46). The relative importance which should be attached to the positive and negative findings is open to debate. The choice of standardized mortality ratios, rather than other numerical indices of mortality, has been discussed (47,48); and the effects of using mortality data based on small numbers of deaths, especially in sub-Regional resource allocation, have been aired (49,50). The point has been made that low mortality rates may even paradoxically increase the need for medical care, perhaps particularly among the elderly, because of residual morbidity which requires care (51,52); and, indeed, to SHARE in Scotland truncated age-standardized mortality rates are used which exclude deaths in people aged 65 years and over (53).

The relationship between mortality and concepts of morbidity and needs—needs for what?—requires consideration. It has been suggested that medical needs, to be useful, should be defined in terms of whether they can be met by appropriate medical intervention (14, 54). The question therefore arises of *which needs* for *which categories of medical service* may be measured by mortality statistics. This is an issue which is not explored in detail by RAWP. It provides us, however, with a conceptual puzzle which is worth recognizing. In reviewing possible measures of need for inpatient care RAWP sought, with justification, an indicator which is as independent as possible of the supply of services. This ruled out, specifically, the use of data from hospital statistics. A superficially attractive alternative would be data obtained from population-based morbidity surveys. But this presents another problem. In this context the requirement, by definition, is to enumerate not all those who are sick but those who need hospital care. Since at least a proportion of these people would be in hospital, the actual requirement for a direct measure of need for inpatient care is, firstly, a measure based on those people who were hospitalized and who (by some defined criterion) actually



required hospitalization plus, secondly, those people not in hospital who (by the same criteria) should have been. Thus population surveys of sickness *per se*—without the additional assessment of whether each individual required hospital care—would not necessarily in themselves be sufficient to quantify needs for hospital care.

Questions still remain as to which needs may be measured appropriately by mortality data and whether the relationship between such needs and mortality is approximately linear. RAWP itself recognized that 'many of the commonest condition—including some which lead to death—place relatively little demand on health care service' (19). Bennett and Holland (55) have written that 'deaths from particular conditions tell us little about other common conditions which seldom cause death. Deaths from stroke, lung cancer, and coronary heart disease say nothing about the prevalence of hernia, varicose veins, and prolapse. In reply it can be observed that there is little evidence of any striking variation in the incidence and prevalence of these and many other minor conditions'. The working of RAWP, however, includes conditions which seldom cause death and weights them by mortality ratios which are heavily influenced by deaths from other, unrelated causes. More recently Fenton Lewis, commenting on health indicators, wrote that 'the creation of indicators should start with extensive disaggregation by diagnosis and age-group so that poorly correlated factors are not merged into broad summarizing statistics' (56). These points need to be considered in detail. Whilst it may be impractical to obtain direct measures of need for (say) hospital care, in selecting proxy measures it is practical to state explicitly which specific conditions the chosen proxy indicators are considered to measure.

RAWP itself recommended disaggregation of conditions, in considering utilization rates and standardized mortality ratios, for the purpose of calculating revenue allocation for inpatient care (though not for outpatient services, day care, or community services). For inpatient care it recommended the use of *ICD* chapters to disaggregate diseases (which it termed the use of 'condition-specific' data). This fairly coarse level of disaggregation is, however, open to criticism. Every *ICD* chapter contains a wide range of diseases. Palmer has compared standardized mortality ratios for cancers with standardized registration ratios from Cancer Registry data (2). He found that the geographical correlation was good

between site-specific mortality and site-specific registration ratios for cancers of lung and of stomach; but that, for other sites, the association was less obvious. He further suggested that the lack of association between mortality ratios and registration ratios for cancers of all sites may be explained by the inclusion of cancers of high fatality with those of low fatality; that it may be inappropriate to use overall mortality within chapter 2 of the *ICD* as a proxy for overall cancer incidence; and he also noted that those cancers which show the best correlation between incidence and mortality are the least amenable to medical intervention. West (57) has questioned the use of *ICD* chapter-specific SMR's to weight inpatient needs for diseases of the genitourinary system and for accidents. Goldacre and Harris (58) have shown that within most *ICD* chapters there are conditions which place heavy demands on the health service but which are uncommon causes of death. This emphasizes the the inappropriateness of using, as proxy measures of need, those chapters for which the mortality is from different conditions from those associated with morbidity.

RAWP recommended that geographical resource allocation for non-psychiatric outpatient services should be weighted by all-causes SMR's. The justification for using mortality as a proxy measure of needs for outpatient services is not stated by RAWP. A substantial part of the workload of outpatient departments is concerned with the management of conditions which uncommonly lead to death. For example, six specialties in which inpatient deaths are particularly uncommon—ophthalmology, consultant dentistry, ENT surgery, gynaecology, dermatology, and venereology—together account for nearly half of all new outpatient attendances nationally. There seems to be little or no *a priori* reason to suppose that needs for care in these specialties can be measured accurately by mortality statistics. Similar considerations apply to the use of SMR's as a weighting factor for needs for day care and community services.

The ways in which needs for services and mortality rates might be related requires more explicit consideration than it has hitherto received (59). One premise could be that morbidity and mortality are causally related such that a high morbidity rate leads to a high mortality rate. For some diseases (e.g. lung cancer and myocardial infarction) this may be so. It is, however, inconceivable that variation in the prevalence of uncommonly fatal conditions, such as,

say, hernia, varicose veins, or haemorrhoids, is causally related to variation in, say, all-causes SMR's. A second premise could be that morbidity and mortality have a non-causal, approximately linear association with one another—for example, that all-causes SMR's and the needs for treatment of non-fatal conditions are non-causally associated through their link with other factors common to both. Firm evidence, or in its absence a consensus of opinion, is needed to confirm or refute this possibility.

### ***Planning and priorities***

RAWP expressed the hope that the principles used in financial resource allocation would eventually be used in planning 'by providing a need-related base-line (19). The above reservations about the use of mortality data as a measure of need for resource allocation apply similarly to their use in planning. The reservations are, however, brought more sharply into focus in planning because of the requirement to consider specific services in planning. (Geographical allocation of resources by the RAWP mechanism is not directly concerned with individual services.) The question arises of whether SMR's should be used, and if so which SMR's (all-causes? chapter-specific SMR's?), in planning services for, general surgery, trauma and orthopaedics, geriatrics, ophthalmology, ENT surgery, gynaecology, plastic surgery, and so on.

Information about needs for services is important in making decisions between different demands for services within an Authority. Mortality data, though important in completing the picture, are very inadequate if taken in isolation. In order to predict priorities for services from mortality statistics alone the ratio of deaths to service needs would have to be similar for each disease. This is manifestly not so. For example, the ratio of hospital admissions to deaths in England and Wales in 1978 was 1.4:1 for lung cancer, 0.8:1 for myocardial infarction, and 228:1 for inguinal hernia. Mortality statistics, if taken alone, would suggest a far greater need for services for lung cancer than for inguinal hernia (34,348 deaths ascribed to the former compared with 270 for the latter in the year). In fact, the number of hospital admissions for inguinal hernia during the year was 26 per cent higher than that for lung cancer. The point that mortality statistics alone are a poor measure of relative needs for

services, comparing diseases, is an obvious one; but it is only obvious because, in this context, we can be guided by clinical experience and the availability of morbidity data from hospital statistics. Neither mortality statistics nor inpatient morbidity statistics can be used to predict the pattern of disease, or priorities for services, seen in general practice or ascertained by population surveys. The pattern of disease seen from the perspectives of mortality data, inpatient care, outpatient care, general practice, and population surveys are each very different from one another (60,61).

### ***Monitoring and evaluation***

The use of mortality statistics in resource allocation is open to the reservation that mortality rates may reflect both needs for, and the outcome of, services in ways which are usually hard to disentangle. In 1976 Rutstein, *et al.* (62) suggested an approach to measuring the quality of medical care which included the counting of unnecessary disease and disability, and unnecessary untimely deaths; using this as a warning that the quality of care may need to be improved. This is a similar philosophy to that which underlies confidential mortality enquiries of which there is a long history of development in England and Wales. The best known of these is that into Maternal Mortality described by Godber (63) as the only example of a national continuing outcome study mounted within the NHS. The latest report suggested that, of the deaths directly associated with pregnancy and delivery in 1976/78, 58.1 per cent should be classified as having 'avoidable' factors (64). However, as Alment (65) has suggested there is some doubt as to whether avoidable factors represent an 'idealistic objective' or some kind of 'balance of satisfactions'.

The use of this method of enquiry was also suggested by the 'Short' report (15) which recommended that local or Regional enquiries should be carried out on all perinatal deaths.

Perinatal enquiries have been the norm in many districts for a number of years, albeit often unit based, of non standard format and not related to population. The National Perinatal Epidemiology Unit recently listed thirty such surveys in England and Wales (61). Further examples are the recent surveys of the Medical Services Study Group (68) and of deaths associated with anaesthesia in five

NHS Regions (69). Response to this latter report acknowledged the need to continue this type of 'audit' on a local basis (70,71).

Recently Charlton, *et al.* have used routinely available information to explore the concept of avoidable deaths more widely (34). For a range of diseases where death was generally considered avoidable (a small minority of all diseases) they reported that substantial variation existed between Health Authorities in death rates. It may be that much of the local variation is due to the small number of deaths involved (72). Otherwise the question remains open at present as to whether such findings would reliably be attributed to geographically inequitable provision of resources in relation to needs, or whether they might reflect geographical variation in the quality of services provided within an equitable quantum of resources.

# CHAPTER 4 THE AVAILABILITY OF ROUTINE INFORMATION

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The arguments in the previous chapter suggest that suitable morbidity information would enhance decision-making in regard to the planning and distribution of health resources. Clearly it would be of great advantage if such information were readily and routinely available. Such information is not, and yet paradoxically a wide range of so called 'morbidity' statistics are collected regularly in England and Wales. It is thus important to review each of the major sources and to identify whether the statistics available are incapable of performing the task required, or whether they have been inadequately used hitherto. Subsequently it will be considered if relatively modest modifications could achieve more useful material.

## ***The needs for routine epidemiological data***

Much of what is needed has, by the very nature of the immediacy of the requirements for its use, to be readily accessible. Thus it falls to routine information systems to provide sources of appropriate epidemiological materials. The Steering Group on Health Services Information (73) has not yet made detailed recommendations about needs for epidemiological data, but without pre-empting their task, it may be apposite to suggest one possible framework. For the future consideration needs to be given to what epidemiological data should be available about each of the following:

- (i) Mortality;
- (ii) Disease as identified by hospital contact;
- (iii) Disease treated in general practice;

- (iv) Disease not resulting in health service contact;
- (v) Preventive programmes (e.g. coverage by immunization, screening, etc.);
- (vi) Personal characteristics (e.g. risk factors such as smoking and diet);
- (vii) Social and environmental factors (e.g. unemployment and atmospheric pollution).

This form of classification can be looked upon in several ways. Firstly it represents the spectrum of disease from predisposing factors, through hidden and overt morbidity to the stark reality of mortality. Secondly it provides a reminder that disease identified when contact is made with health services forms only a small, but nevertheless important, part of this spectrum. Thirdly it must be recognized that the identification of individuals at the 'risk' end of the spectrum can have several distinct modifying effects on their future use of health services. For some diseases screening or prophylaxis can prevent future use, whereas in others use will be enhanced through, for example, the need to monitor maintenance therapy.

### ***The use of routine information systems***

Those who regularly use routine health service data sets recognize that these can only have an indirect bearing on the measurement of anything other than utilization, and that no source provides a measure of unmet need. The majority of these surrogate measurements stem from the action of individuals suffering from perceived illness, and as such measures of the demand on various services. Sometimes they reflect unmet demand, such as waiting list data which are notoriously inaccurate (74), usually they are measures of fulfilled demand, and frequently episode-based (75).

Many of the existing statistics relate to substantial numbers of patients whose individual records are organized into large data bases designed to allow flexibility of access. Thus it might be thought that the underlying systems of collection of these data would have the potential to yield relevant information, even if the existing analyses are considered inappropriate as measures of morbidity. What then are the ideal criteria which would make these data bases usable for the measurement of health need? First, if geographical comparisons

are required the data set should be universally collected across the country so that relevant statistics can be made available in respect of any specific place, or series of places.

It may also be important to be able to derive detailed (small area) geographical disaggregates by place of usual residence to give accurate population based information. In many cases the data are initially associated with 'place of treatment' because they are collected where services are used and a suitable mechanism has to be available whereby each event can be appropriately re-assigned.

It is axiomatic that there should be the capability to produce statistics by diagnosis, or according to other classifications of medical conditions; and that these are available by at least the basic demographic characteristics of age and sex.

Systems based on records of contact with health services have an innate disadvantage in that the frequency of initial, and subsequent, utilization of such facilities is inevitably dependent on the level and distribution of available medical or other health resources. Use is further modified by the perceptions of patients regarding the severity of the condition for which help is sought. Thus it is difficult for the information systems concerned to meet the two further ideal criteria of being independent both of resource availability and disease severity.

Finally it is much more epidemiologically acceptable that a system is person rather than event based; although in some circumstances it may not be of vital importance to distinguish between, say, ten attendances of one person and ten persons with one attendance each. The current and relevant information systems for consideration can primarily be classified into those derived from notification or registration of disease, and those from the utilization of hospital or primary care services. In addition there are two other potential sources, the records of sickness absence and the national census of population. It is not considered necessary here to detail the methods of collection of the data in these systems, which are well documented in the published material derived from them. Additionally there are summaries available; for example those of Fenton Lewis (75) and Alderson (76). It is more pertinent to review how these major systems match up with the ideal criteria for yardsticks of morbidity. The situation is displayed in Table 2.



TABLE 2  
Suitability of principal data systems to measure morbidity.

NOTIFICATION OF	IDEAL CHARACTERISTICS							
	Nationally collected	Diagnosis or condition	Age and sex	Capability for SAS	Residence oriented	Independent of resources	Independent of severity	Person based
(Birth)	+	0	+	+	+	+	+	+
Abortion	+	+	+	+	+	(+)	+	0
Congenital malformation	+	+	+	+	+	+	0	+
Infectious disease	+	+	+	+	+	+	+	(+)
(Sexually transmitted Dis)	+	+	+	0	0	+	+	0
(Infections to CDSC)	0	+	(+)	0	0	?	?	(+)
REGISTRATION OF								
Cancer	+	+	+	+	+	+	+	(+)
HOSPITAL								
Discharge (HAA/HIPE)	+	+	+	+	+	0	0	0
(Statistics (SH3—IP/OP))	+	0	0	0	0	0	0	0
Mental Health Enquiry	+	+	+	+	+	0	0	+
Out Patients (Scotland)	0	+	+	+	+	0	0	0
PRIMARY CARE								
National Morbidity Study	0	+	+	0	0	0	0	0
Index Practices	0	+	?	0	0	0	0	0
OTHER								
Sickness Absence	+	?	?	?	?	0	0	0
Census of Population	+	0	+	+	+	+	+	+

## KEY TO SYMBOLS

+ Meets the criterion

(+) In some cases meets the criterion

? Questionably meets the criterion

0 Does not meet the criterion

## **Notification of disease**

### *Abortions, congenital malformations, and infectious diseases*

The data systems included in this section measure up well to the criteria, all having the advantage in being nationally collected over a number of years. The notification of infectious disease dates back to 1895, of congenital malformations to 1964, and that of termination of pregnancy to the introduction of the Abortion Act in April 1968. Each of these systems is designed to cover a limited number of conditions (or only one in the case of abortion), and is probably the most important source of information for these conditions; however there are deficiencies. The notification of congenital malformations is voluntary and although all Health Authorities participate, the yield varies from place to place.

Notifications of infectious disease, although prescribed by regulation, have traditionally been regarded as incomplete especially for the more common conditions. Indeed it has been shown possible to estimate the extent of such under reporting by making comparisons with admission rates to hospital for measles and whooping cough (79). There is every reason to expect that notification of abortions is complete in compliance with the regulations.

These notification systems collect demographic data and all include sufficient address material to allow assignment of events to district of residence. Furthermore, by definition, the systems are independent of resource provision because all cases have to be notified, wherever treated—subject to compliance. However, the notification of congenital malformations is known to be subject to a degree of variation in the reporting of minor abnormalities due, for example, to 'staff changes in individual hospitals' (78).

Notification of a congenital malformation is only carried out at a single point in time for each child—at birth—so that the data are effectively person-based, except to the extent to which analyses are presented in terms of mentions of individual abnormalities. Thus for babies with multiple malformations there is a minimal but finite amount of double counting.

Abortion notifications include reference to the occurrence of previous abortions, and thus analyses based solely on women not reporting a preceding event would meet the criterion of being

person-based; but such analyses would seem to have little relevance to the issues discussed in this volume.

As far as infectious diseases are concerned, the extent to which notifications represent persons, rather than events, strictly depends on the protective status that the particular infection confers. For the majority of conditions the system may be taken to be person-based. Nevertheless for many of these conditions immunization is not only practicable, but routinely offered, thus new cases of the disease reflect both morbidity and quantify the effectiveness of preventive programmes.

Mention should be made at this point of the other systems of notification included in Table 2. The reporting of relevant laboratory isolates to the Communicable Disease Surveillance Centre serves a valuable purpose, but the statistics therefrom do not represent all the cases of the appropriate infectious disease. Statistics of sexually transmitted diseases, collected and supplied by Departments of Genito-Urinary Medicine cannot be residence related for reasons of confidentiality, and any ambition to make them person rather than event based would be clearly unattainable.

The routine notification of birth includes no diagnostic material except when it also doubles as the initial reporting system for congenital malformations. However it has to be remembered that birth notification has the potential for the collection of a more extensive data set in respect of either mother or baby (79).

The mechanism of notification has great potential for estimation of the morbidity of the conditions currently included. Compliance seems to be assured only when backed by the force of law or when those involved in the reporting are convinced of the public health implications of the conditions concerned. Thus expansion of its scope may be limited. However, these convictions allowed the method to be used for the registration of cancer, which began in 1945.

### *Cancer registration*

Cancer registration forms one of the most widely available sets of locally collected data. Although it is often originally based on centres of treatment it is aggregated both regionally and nationally. The data

collected include the necessary nucleus of diagnostic and demographic information to meet the criteria under consideration, and also include treatment and occupational detail. Additionally, each cancer registration is linked by OPCS to death certification so that life expectancy and survival time can be calculated for individual types of tumour, and different methods of treatment.

Apart from minor double counting due to multiple tumour sites, cancer registration is person based and as few cases do not come to medical care it can be considered to be independent both of available resources and subjective severity.

Nearly a quarter (23 per cent) of deaths recorded in England and Wales are ascribed to cancer, and over 13,000 beds are used daily for investigation and treatment. Cancer registration include not only those known to be malignant tumours, but also carcinoma *in situ* and neoplasms of uncertain behaviour, together with certain benign tumours such as those of the bladder, pituitary, and brain. Completeness of the data varies from 90 per cent in the better registers to 60 per cent in the less efficient Regions (80), and timeliness in the promulgation of information is marred by slow returns from some places.

## ***Hospital utilization statistics***

### ***Inpatients***

Hospital Activity Analysis is the most extensive data set of abstracts of clinical records available to the NHS. It now covers almost 5m inpatient events annually, as well as an increasing number of day cases, and trends spanning a decade on a hundred per cent basis are accessible in many places. Through its ancestor the Hospital In-Patient Enquiry, which is now almost totally integrated with Hospital Activity Analysis, almost thirty years of national data in a ten per cent sample can be interrogated. Thus, with very few exceptions the information is universally collected.

Diagnostic data form an integral part of the system, from the first it being argued that hospital records provide the most accessible source of information containing reliable statements of diagnosis (81). This situation probably still holds, despite seemingly regular clinical anxieties as to the present validity of the data. Furthermore it has recently been suggested that there are now an increasing number

of clinicians who realise that the initial mistake is their own in that they take insufficient care in providing records suitable for easy abstraction (82).

The provision of appropriate demographic and residence data is not in question in a system in which each record includes date of birth, and is coded to small administrative areas or, in many cases, to postcodes.

The major difficulties lie in the obvious facts that Hospital Activity Analysis relates to discharges not individuals, and that the conditions treated have to be severe enough to warrant admission to hospital. This decision is usually made by a physician rather than the patient and although there are viable admission policies would indicate some degree of standardization of severity. For example, it is usually only complicated cases of the more common infectious diseases of childhood that are admitted to hospital. In contrast in many cases, particularly of the elderly, the threshold for admission may vary from place to place, or time to time according to provision of beds. It was for this reason that inpatient caseload used in the RAWP interim report (83) was subsequently discarded. As the final report put it—'caseloads fail both to distinguish between degrees of need and to assess the extent to which need is unmet through lack of facilities' (19). It is also still possibly the case as demonstrated in Liverpool in the 1960s (20), that relatively higher provision of beds leads to lowering of the threshold for admission, and consequently higher discharge rates.

As Hospital Activity Analysis is episode rather than person based, only in a few instances, characterized by a single obligatory admission—acute appendicitis, for example, can it be said that hospital in-patient statistics reflect true incidence. For most conditions it is still possible to explore trends and predict future patterns of use (84), but less easy to describe is the natural history of disease, including aetiological responses to treatment and prognosis. The distinction between an episodic and a person based system is somewhat easier in the field of mental health. The Mental Health Enquiry, which otherwise has the same general characteristics as Hospital Activity Analysis also includes reference as to whether a particular admission to hospital is the patient's 'first' with a mental disorder, thus simplifying the identification of the incidence of psychiatric disorder of such a severity as to require admission to hospital.

The deficiencies of the traditional hospital return (Form SH3) are obvious from Table 2, which shows it only has its obligatory collection and hence universality to commend it. It is not diagnostically orientated, although there have been some, perhaps misguided, attempts to use the specialty groupings therein as proxies for the types of condition treated by these specialties.

### *Outpatients*

The sheer volume of outpatient contacts makes analysis based on the characteristics of individual attendances a daunting prospect. Thus it is not surprising that there are no current attempts to measure outpatient morbidity in England and Wales. However, there has been a promising feasibility study in Scotland (85) based on two-stage sampling; first of clinics and then of patients attending. This yields age, sex, area of residence, diagnosis, and use of specified resources. However, the constraints of severity, resource provision, and the absence of person based information operate more acutely in respect of outpatients than even they do for inpatients.

### *Primary care and other sources*

Three national studies of 'morbidity' as seen in general practice have provided valuable information at national level. However, the relatively small number of practices included precludes the provision of information on a local or district basis. This constraint also applies to the forty or so index practices reporting communicable and respiratory disease to the Royal College of General Practitioners' research unit. Despite the much heralded distribution of micro-computers into primary care, this sector seems to be lagging far behind its obvious potential.

Information on social security claims is poor for epidemiological purposes but can be of considerable value in other circumstances, such as in the quantification of certified sick leave. Sickness benefit claims represent an index of cost to the community rather than morbidity, since they omit the non-employed and non-insured populations, who also suffer morbidity, and in fact account for a substantial part of it. The general omission, now, of short duration illness will even more lessen its effectiveness as a source of information; but in the past large sudden changes in the level of new

claims have mirrored influenza epidemics and served as a measure of their severity.

A final, and seemingly unlikely, potential source is the decennial Census of Population. By its very nature it is person based and includes all the appropriate demographic and residence information. It is universally completed but its apparently insuperable drawback is the absence of diagnostic information. However, general questions about present 'sickness' are included in relation to absence from work and the use of these should be evaluated, like others (86), using the mechanism of the one per cent National Longitudinal Study. It is perhaps a pity that more specific questions about illness are not included in the Census, with perhaps self-reported diagnosis, as was the case of the Census of Ireland in 1851 (89).

# CHAPTER 5 **LOCALLY AVAILABLE SOURCES OF DATA**

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In many Districts there are examples of locally collected information about specific morbidity which can add to and expand the previously described national sources. It is important not to overlook initiatives of this nature as tools to exploit, not only for the estimation of local morbidity, but also as yardsticks against which routine data, with all their deficiencies, can be measured. These data are frequently collected in schemes of notifications or registration which use similar mechanisms to those employed for the national programmes for the notification of infectious disease or the registration of cancer. Thus, although presently they have limited geographical coverage, they are often conceived as models for more general application. A further important source which should not be under-estimated is that of regular surveillance, even as is usually the case, when it is primarily carried out for operational purposes rather than to satisfy epidemiological objectives.

It would be impossible to comprehensively detail all such local schemes, but the most important or more generally available have been highlighted in order to illustrate their undoubted potential.

## ***Local registers of disease***

Coronary heart disease is responsible for a quarter of all deaths in this country, and patients with cerebrovascular disease occupy one hospital bed in ten. It is not therefore unexpected that there have been developments in the registration of both these major conditions. Indeed, it is perhaps surprising that a greater number of



registers for ischaemic heart disease, in particular, are not available. Pioneering efforts in this country were those of Kinlen (88) and Armstrong (89) in the early seventies and of Tunstall Pedoe in an inner London borough in the mid decade (90). In 1976 WHO published the results obtained from the establishment of a register in some seventeen countries (91).

Tunstall Pedoe (92) points out the difficulties which arise in the compilation and interpretation of the findings from such registers. In order for patients to be registered the condition must be diagnosed and meet a pre-determined definition. This will exclude, on the one hand, patients with sudden unexplained death and, on the other, those who have no contact with medical services. There are further difficulties in the interpretation of the data if the community is significantly mobile. In order to meet some of these difficulties the British Regional Heart Study (93) has sought to select from 'representative' general practices in 25 towns in Britain a group of men aged 40-59 years who will form a register of a susceptible population. The prospective nature of part of the study will allow examination of morbidity and attack rates among the study members. The study also aims to observe regional variations in greater detail and to examine the variations in risk factors and their effects.

Another ambitious prospective study is being carried out in Scotland, as part of the *MONICA* project (94) being conducted in thirty European centres under the auspices of WHO. It is a ten-year study of trends and determinants of cardiovascular diseases in two defined populations—one in Glasgow, and the other in Edinburgh. The study will aim to monitor the occurrence of non-fatal myocardial infarction, in both males and females between 25 and 65 years old in the selected populations. It will also monitor the incidence of strokes in the same population.

There have been numerous attempts over the past twenty five years to ascertain levels of stroke from registers, community, and general practice surveys. These have, however, been dogged with problems of inaccuracy. A recent report from the Oxford Community Stroke Project (95) suggests that very close liaison with general practice will achieve a high level of case finding even of transient ischaemic attacks. If this is supported by timely neurological, radiological, and pathological assessment to ensure accuracy and

confirmation of diagnosis then incidence rates can be calculated with confidence in a defined population.

Many other potentially useful registers exist—some kept by clinicians with a special interest in certain conditions, e.g. thalassaemia, and others by voluntary bodies, such as the Register of Diabetic Children maintained by the British Diabetic Association (96). This register was formed in 1972 and the notifications have now reached more than 12,000. The notifications concern children aged 0–15 years diagnosed after November 1972 and contain basic demographic data and timing of onset of the disease. This has allowed analysis of incidence, geographical clustering, seasonal variation, age and sex distribution, and familial influence. A detailed analysis of the ten year results is about to be published. A register such as this would be highly suitable as a starting point for detailed local analysis and further research. The recent change over to insulin 100 has resulted in the registration of all insulin dependent diabetics through pharmacists to a locally nominated physician. Place of treatment and demographic data only were collected, nevertheless valuable information could be obtained about prevalence of this type of diabetes in the community, since the registration is likely to be almost complete.

A very important field of development of registers has been in psychiatric illness. The impetus to develop these registers comes largely from the requirement to evaluate and plan services for the mentally ill (97). The patient registers are initiated by contact with psychiatric services whether on an inpatient, outpatient or domiciliary level. Whilst they are based on defined populations they have the disadvantage of all disease registers in that patients require to contact the service and hence the incidence or prevalence of the disorder—especially when mild—cannot be established. There are however alternative uses to which they can be put in terms of assessing need for services and measuring effectiveness. They also form a baseline for the observation of trends and can provide a suitable sampling frame for epidemiological and other research purposes.

There are well known and long established psychiatric registers at Aberdeen, Camberwell, Cardiff, Nottingham, Oxford, Salford, Sheffield, Southampton, and Worcester. These have recently been reviewed (98) to produce comparative statistics for the years

1976–81. The analyses are placed against a background of socio-economic indices and local policies in order to assist interpretation. The areas covered include admission rates, occupancy by short and long stay populations, and age specific point prevalence (defined as contact with specialist psychiatric services). This report is the first of a regular series which will add to the generally available data base on disablement levels.

The exigency of recall for screening procedures such as cervical cytology have resulted in the acquisition of registration data—albeit incomplete about the frequency of this condition. Registers primarily motivated by legal and statutory requirements also have come into being particularly in the realm of non-accidental injury to children, and drug abuse.

The scarcity of resources for treatment of certain conditions, for example end stage renal failure, have resulted in case registers such as that of European Transplant and Dialysis Association which provides not only figures on incidence of the condition regionally but also on aetiology, treatment and outcome of procedure. Annual reports are available about donor and cadaver kidney transplants (99). However, not all ‘registers’ are what they seem. The national cardiac surgery register, whilst assimilating individual cases locally, only provides statistics aggregated to national level (100).

### ***Registers of handicap***

The Chronically Sick and Disabled Person’s Act of 1970 enjoined each Local Authority to identify the disabled and to estimate their need for service and to provide it. Through this legislation Authorities developed registers of handicapped persons which separately identified the blind, the partially sighted, the deaf or hard of hearing, and the physically handicapped. These registers are voluntary in nature but are populations based including all who are resident in the Local Authority or who are ordinarily resident there in homes or hospital or workshops. There are considerable difficulties in comparing the handicap level between one local authority and another because registration is voluntary and also because there is no agreed definition of disability level. Thus, for instance, the interpretation of ‘hard of hearing’ may vary considerably from place to place, casting doubt on the validity of the statistics. Published statistics for

1978-79 which relate to the Boroughs of Greater London (103), for example, quote that in Bromley 6 per 1000 were registered deaf or hard of hearing compared with 0.3 per 1000 in Camden. It seems highly unlikely that such differences are a real reflection of the prevalence of substantive hearing defect in these two Boroughs. It is much more likely that they reflect differences in criteria and effectiveness of ascertainment. There is more uniformity in the registration of the blind, but again this does not seem to extend to the partially sighted. Brennan and Knox (104) showed marked differences in prevalence and incidence figures derived from the register, suggesting that poor employment opportunities and need for supplementary benefit encouraged registration. Cullinan (103) estimated in a community survey that the blind and partially sighted register in Canterbury under-estimated the problem by 30 per cent for the blind alone.

The Department of Employment is responsible for a central register whereby those registered (green card holders) are entitled to the training services of disablement resettlement officers. This register does not provide a very good estimate of population disability. Fear of stigmatization is a major barrier to self registration unless disability can no longer be concealed or handicap will become useful tools for measuring morbidity without substantial changes of attitude towards them; not only by the providers but also by the users.

Mental handicap registers have been in existence for some time. Amongst the longest established are Salford 1961—covering 250,000 population, Wessex 1963 covering 2,700,000, Camberwell 1967 covering 40,000, Sheffield 1975 covering 530,000, Lambeth 1977 covering 270,000. Prevalence data for severe handicap derived from these registers varies from 2.9 per 1000 to 3.4 per 1000 (104). The majority of these registers were designed to co-ordinate information about services for individual clients and to provide information for planning and monitoring. They also serve as data base for research and are funded by a variety of agencies such as the MRC, local authority and NHS. Problems of client definition exist in this field as in many others but in general the registers include persons receiving full time residential care, ESN (S) schooling, day care, and the designated severely subnormal. In addition the group includes behavioural problems, incontinence and difficulty with feeding,

washing, walking, and toileting. The client group may use a variety of services and therefore record linkage and personal identification is of particular importance. The advent of micro computers has made data handling much easier and has thus encouraged the setting up of further handicap registers (105).

### **Child surveillance**

The practice of child surveillance has been ongoing in this country for many years now and much of this activity takes place through the Community Health Service. Surveillance begins at birth and goes through school age.

All new-born infants are screened by heelprick for the presence of phenylketonuria. Those who are diagnosed as having the condition are registered on the MRC/DHSS Phenylketonuria Register. This is a national register which has been in existence since 1964 and has on its data file 1050 children registered between 1964 and 1978. These children have developmental assessments annually till age four years and then bi-annually until age 14. At the age of eight there is additionally a repeat IQ and a Rutter behavioural assessment with matched controls. A register is also held in respect of parental fertility dating back to the 1940s. This extensive data base is now computerized and a wide range of analyses will be possible to provide incidence, prevalence, morbidity, and outcome data on the condition for any locality in the UK (106).

The case registration is thought to be almost complete and the data recorded derive only from standardized tests. These criteria are rare amongst the data bases discussed to date. There is also a similarly designed MRC Register of children with congenital hypothyroidism. This began in January 1982 and is designed in much the same way. Yearly follow ups are planned until the first intellectual assessment at five years. There will be case-control examinations at this stage.

Within the Community Child Health Service systems have evolved using community medical staff, general practitioners, and health visitors to provide screening of all children from infancy through school age. Whilst there are different schemes from place to place, it is common practice to carry out periodic examinations around six weeks, seven months, eighteen months; and then

annually. These check for developmental or congenital abnormalities. Surveillance continues during school years at regular intervals. In conjunction with surveillance vaccination and immunization programmes are carried out. Traditionally details of findings have been manually recorded and maintained. The National Standard Child Health System has been introduced—and increasingly adopted—to develop computerized record keeping both for operational and epidemiological purposes. The birth file and vaccination and immunization modules are widely implemented, the pre-school module is being introduced, and the development of the school module has been completed. When all these modules are generally available they will provide easier access to a wealth of morbidity data about children in the population. A recent survey of OPCS (107) revealed 142 registers in England and Wales for pre-school children with impairments, disabilities, and handicaps. Only 18 of these were computerized. Almost all these registers used community health records as their main sources of information and many had ready access to hospital discharge information. Congenital abnormalities diagnosed after the first week of life were included as well as acquired impairments. The survey highlighted the difficulties posed in interpretation of incidence and prevalence data due to use of varying definitions and criteria of handicap. A follow up study (108) of handicap registers to investigate the implications of setting up standardized system using tracer congenital conditions demonstrated wide disparities in two superficially very similar systems. Discrepancies were particularly notable in the fields of visual and auditory handicap. This has important service as well as epidemiological implications and must raise serious doubts about the benefit of handicap registers.

Although data are available about other community health activities—for example surveillance by tuberculosis visitors and district nursing visits this can not be related to diagnostic details and is thus only a very tenuous proxy for morbidity.

In conclusion, many sources of locally available morbidity data exist but problems of completeness, definition and reliability hamper interpretation and comparability between Districts in most instances.

## CHAPTER 6 ESTABLISHING THE PROFILE OF DISEASE

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Initial consideration was given, in chapter 3, as to the possible extent of an association between morbidity and mortality, and it was acknowledged that for certain diseases there could be a direct causal relationship. What then are the characteristics of such diseases? Although diseases recognized as usually having a high mortality may be considered as obvious candidates, it is by no means axiomatic that statistics of deaths are the best available source of their incidence. Cancer registration, if properly implemented, can still include intractable cases which do not subsequently lead to death. Even for the more lethal infections, such as meningococcal meningitis, the amalgamation of mortality and notification information can give more accurate estimates of the disease than either source taken alone.

Nevertheless, in general terms, the higher the case-fatality rate the more appropriate it is to consider-specific mortality statistics as a measure of the incidence of any particular disease. In this context the statistics relating to carcinoma of the oesophagus were used for many years as a suitable index of the completeness of cancer registration. The extremely high fatality rate for this condition meant that registrations of the disease could be expected to virtually equate with the number of deaths. In consequence any numerical discrepancy between the two could be taken as the measure of the extent of under-reporting.

For only a limited range of diseases with high case-fatality rates can it be intuitively accepted that mortality rates might be suitable indicators of morbidity, which might be used for the purposes of achieving equity in the distribution of resources. It is suggested that

of the various causes of death, or admission to hospital, only cancer of the lung and acute myocardial infarction definitely seem to 'fit the bill' in this respect. The selection of these two conditions probably reflects not so much the high level of their case-fatality rates, but rather highlights the constancy of these rates and the relative inability of regimes of treatment to have much effect on them at the local level. Thus, for both conditions, the ratio of deaths between locations may be taken to equate with the ratio of their incidence.

Several other conditions may be worthy of further consideration. These include cancers of some other sites, namely the breast, cervix, and uterus, to which may be added leukaemia. All these diseases have substantially high case-fatality rates, but these may be varied to some extent by treatment, or more particularly by preventive strategies or early presentation. All these factors may in turn reflect the relative availability of local resources, and thus make the use of mortality data for these conditions less appropriate for the assessment of resource allocation. Although cerebrovascular disease and other forms and manifestations of ischaemic health disease are also distinct possibilities, it is by no means certain that the high case-fatality rates for these chronic conditions are constant. Furthermore, their selection by certifying doctors as a cause of death of elderly patients with multiple pathology may be somewhat arbitrary; so that there may be some degree of distortion of mortality statistics based as they are on the specific underlying cause of death.

Thus information about the impact of disease if needed for 'diagnosing' the needs of the community across the spectrum of services has to come from a variety of other perspectives as well as mortality; including hospitalization, general practice, and the community as a whole. One potential mechanism is to incorporate the record linkage of vital and other medical events. As is well known, such a system has been in use for many years in Oxford (109). In Scotland some routine data are organized in such a way as to make linkage possible but it is only carried out when required for particular studies (110). Further, it has been proposed as an important consideration by the Faculty of Community Medicine's response (111) to the proposals of the Steering Group on Health Information.

The desirability of medical record linkage in the present context is its ability to turn event-based hospital data into personal-based



information and, by amalgamation with that of vital events principally that of death, to enable such things as outcome and readmission rates to be more accurately determined. Medical record linkage is quite expensive to maintain and, more importantly, is particularly subject to the effects of migration by the population covered; thus it is not a procedure that can be carried out in every District. However, its potential as a means of extracting person-based morbidity information from otherwise unusable event-based data cannot be under-estimated.

There is also some 'mileage' at a local level in eliminating some of the more health service organizational reasons which contribute to the 'double counting' of admissions to hospital. These were proposed in the Körner Steering Group's First Report (81), and principally involve the use of a unique District number, although this has been questioned as a practicality (112).

Just as it may be misleading to base an impression of the pattern of illness solely on mortality information, so the experience of disease gained from clinical practice, and particularly from hospital practice, is often incomplete. For example, with a high proportion of the deaths from fatal coronaries occurring within hours of the onset of the attack, the overall outcome of heart attacks is considerably worse than would be apparent from a clinical impression based solely on hospital experience. More importantly, in the present context, such findings have implications for the organization and planning of coronary care services by emphasizing the need to relate medical events to an appropriately defined population base.

There is no doubt that a registration or notification procedure, being inevitably diagnostically and person based, has the most potential for the provision of accurate estimates of the local incidence of individual diseases. Its usefulness, of course, depends on its completeness and diagnostic accuracy which, in turn, is dependent on compliance in reporting. Whilst more simplistic systems could perhaps be built on patient self-reporting of illness, registration procedures frequently depend on medical reporting, and compliance by doctors tends to reflect the extent to which they perceive the process to be meaningful. They have to be convinced that registration or notification can contribute, for example, to the knowledge as to the aetiology or the better management of the disease in question. Even if these stringent conditions are met, so

that satisfactory levels of notification can be achieved for acceptable conditions, the effectiveness of registration is likely to decline if the same individual practitioners are required to notify a wide and complex range of conditions.

Furthermore, accuracy of reporting requires well specified and easily understood rules and standards for selection. This is essential if geographical differences are to be correctly interpreted, and do not, for example, merely represent biases generated by different interpretations of loosely defined diagnostic criteria. Finally, as with all registers, maintenance is of vital importance if a register is expected to yield ongoing estimates of the prevalence of the disease registered. However difficult it may prove to achieve completeness of compilation, there are potentially as many problems in keeping it up to date; in particular, in the ascertainment of deaths and migrations both in to and out of the area.

Nevertheless a limited extension of existing registers might form a nucleus of important conditions around which other methods of ascertainment could be constructed to form a comprehensive matrix. The existing national systems, described in chapter 4 form a solid, if restricted, base on which to build a more elaborate superstructure. These limited conditions if properly registered can potentially provide accurate incidence data relating to conditions which together generate over half-a-million admissions to hospital, use over 17 thousand beds and represent over 3 million general practitioner consultations; although these only constitute 10.9, 6.1, and 2.7 per cent respectively of these total workloads.

The more general application of the group of proven experimental schemes described in chapter 5 could broaden this base substantially to represent one-in-five admissions to hospital and one-in-seven general practitioner consultations. The actual or potential use of well over half of all non-maternity beds is also covered. This is largely attributable to the inclusion in this group of virtually all psychiatric beds, both for mental illness and for mental handicap, but it also encompasses about a quarter of non-psychiatric, non-maternity beds. Maternity beds and events are excluded from all these calculations as it seems to be generally accepted that the need for maternity provision is well expressed by actual or projected age-standardized fertility rates.

There is some scope for adding to the tally of registered morbidity

by the inclusion of data relating to well documented essential contacts with medical care. In this context there are a limited number of diseases for which immediate hospitalization is virtually obligatory, but for which only a single episode of inpatient care is the norm. Under these special circumstances use can be made of locally oriented Hospital Activity Analysis data. Acute appendicitis is the classical condition fulfilling these criteria; but even this is dependent on the current assignment to the diagnostic label of 'abdominal pain' of patients from whom a normal appendix is removed. As well as acute appendicitis there is also scope for the inclusion of a range of injuries, particularly fractures, provided that only 'immediate' admissions are included thus effectively restricting each person to one episode per injury.

At present, about 85 per cent of cases of injury treated as inpatients are admitted immediately. These can form the basis of a more detailed investigation to identify those individual diagnoses which meet the criteria; and for which the chance of inpatient, as distinct from ambulatory, care would be unlikely to be affected by the degree of severity of the condition. For example, virtually all fractures of the femur would be admitted to hospital, whereas those admitted for treatment of fractures at the wrist would have been selected on a variety of clinical, or perhaps social, grounds.

It may be reasonable to consider many injuries computed in this way to be 'person-equivalent', although of course, a small proportion of individuals may have multiple episodes of injury over a period of time. They may, for example, be in a hazardous occupation or be accident prone.

Whether or not they are supplemented from other sources, it would be foolish to under-estimate the task, or the cost, of simultaneously setting up and maintaining ischaemic heart disease, stroke, mental illness, and mental handicap registers. This course of action would, perhaps, have to be a minimum District objective if a strategy of directly measured disease incidence is envisaged. However, it is of some significance to note that, with the exception of the psychiatric specialties, those conditions for which registration appears the rational approach include most of those individual diseases for which it seems appropriate to use mortality information as a proxy.

Thus, however attractive a proposition the construction of even a

limited series of disease registers as a basis for directly measuring morbidity, any such proposals would have to be carefully evaluated, not only for scientific relevance, but also on practical and economic grounds. On present knowledge it is likely that on these grounds such a proposition might well fail.

### ***Alternative approaches***

If the use of routine mortality, or so called morbidity, data or even the establishment of disease registers does not provide a practical assessment of morbidity in a population, then what further avenues can be explored? One well-tried method is to carry out routine or *ad hoc* population surveys by questionnaire or physical examination. Fenton Lewis (75) pointed out, for example, that a prevalence study was necessary for an assessment to be made of the resource implications, as well as the cost-benefit, of screening for chronic glaucoma.

#### *Postal health surveys*

The postal health survey has obvious cost advantages over the face-to-face interview, and has been used, for example, in the London Borough of Lambeth to screen for disabled persons aged 16 and over (113). The overall point prevalence of disability was estimated at 15.4 per cent, and a long-linear modelling procedure identified the factors most strongly associated with disability. Identifying high-risk groups in a prevalence study by postal survey can be an important first step in the determination of unmet need; however its practicability is limited by the difficulties in attaining an adequate response rate.

#### *Health interview surveys*

Since 1971, a sample of approximately 15,000 private households has been surveyed every year in the General Household Survey (GHS). The information, obtained through personal interview, covers health issues ranging from self-reported illness, use of general practitioner services, and self-medication, to use of hospitals' inpatient and outpatient facilities. The GHS sample is stratified by standard Region and attempts have been made to use measures of self-reported illness (assumed to be independent of the level of service

provided) to estimate the relationships between the Regions in terms of their self-reported morbidity, and to determine the proportion of resources that would have to be allocated to each region in order to eliminate the differences found (114). However, resource allocation based upon Regional differences in morbidity would require, in addition to the necessary data, the determination of appropriate weighting factors to convert every aspect of morbidity into a common resource requirement (75). Furthermore, while the GHS may be representative at Regional level, a considerable increase in the size of the sample would be required to obtain sufficiently accurate data for use in resource allocation at District level, and changes in the sampling frame to accommodate health Regions. This appears optimistic at the present time, and in the current financial climate, though it should be noted that local health interview surveys have been carried out from time to time.

Household surveys, broadly based on the GHS, have only been carried out infrequently at a local level. One particularly comprehensive survey in the North East of England involved each of the five Metropolitan Districts of the county of Tyne and Wear in 1976 (115) and Newcastle City Council alone in 1975 (116) and 1978 (119). The 1976 survey aimed for a 5 per cent sample of all households and, in addition to the usual areas of interest such as accommodation, employment, education, and so on, asked health questions about the presence of long-standing disability and the uptake of sickness benefits. Similar surveys could be used as an aid to planning by mapping the distribution of morbidity within a health authority. Moreover, when linked to other sources of health information, the relationships between different measures of health may be investigated. For example, MacLean assembled health information for each of the 23 electoral wards in North Tyneside Health Authority and found a non-significant negative correlation ( $-0.17$ ) between mortality and long-standing disability (from the Tyne & Wear Household Survey) (118). Such findings serve to emphasize that mortality measurements should not be regarded as the sole measure of the need for health care.

Another survey was carried out by Curtis and Woods (119) in two East London boroughs, Redbridge and Tower Hamlets. Data on health status, service use, social and demographic characteristics, and perception of service quality were gathered by the interview of adults

in 300 randomly selected households in each of the two boroughs; in addition proxy information was gathered in respect of the children. This survey employed two main measures of morbidity by including the long-standing and recently restricting illness from the GHS (120) and a self-completed questionnaire—the Nottingham Health Profile (121)—on ‘problems people may have in their daily lives’—and which has now been used extensively.

Initial results from this study confirmed an expected differential morbidity between the two boroughs, thus suggesting that such a mechanism has considerable potential. The findings further suggest that General Household Survey questions are more susceptible to interviewer effects than the Nottingham Health Profile and thus it was concluded that the latter might be a more reliable, systematic and sensitive measure of morbidity.

Another extensive community survey was that among the elderly in Leicestershire (122) which attempted to estimate the extent to which there were, from a consumer and provider view, unmet health and social needs in a total population of people over the age of seventy-five years. In this population of approximately a thousand people, 59 per cent were in receipt of health or social services, or aids, and had no further needs, 27 per cent were in receipt of services or aids and wished for further services, 2 per cent were not in receipt of services or aids, but asked for some service or other, and 12 per cent were not in receipt of, and did not express a need for any service.

A more important question than the feasibility and expense of a health interview is whether it accurately measures health care need (123). This has been questioned since household surveys tend to pick up many minor conditions which may not be indicative of the need for health care, particularly hospital care. The expectations of patients may also be powerful conditioning factors, although this mechanism may be a very suitable one for identifying and quantifying patient satisfaction as an outcome measure.

It may be necessary, therefore, to augment health interview surveys in some way, apart from more rigorous and sophisticated questionnaires. One approach, superimposing professional norms on reported perceived needs, has been tried in an experimental Finnish project (124). In this study the morbidity recorded in a health interview survey was coded according to the *International Classification of Diseases*. Ten physicians (eight specialists and two general

practitioners) then estimated the medical care that should be recommended for the average patient in each diagnostic category. Thus, reported population morbidity was 'transformed' into normatively-determined need for health care in a population. Need for health care was estimated in terms of hospitalization, care by a doctor outside hospital, X-rays and laboratory examinations, treatment with medicines, and other types of care. Such methods are subject not only to the validity and expense of the health interview survey, but also to the 'transformation' process which would, not doubt, be highly sensitive to the attitudes of the adjudicating panel. Nevertheless, it suggests a possible procedure for estimating relative need for health care between populations.

In a series of population studies undertaken in 1966-8 in the London Borough of Lambeth (125), an attempt was made to supplement patient-reported symptoms with, albeit crude, objective measures, thus providing information acceptable to the medical profession and planners, about the prevalence of common conditions, such as duodenal ulceration (126). Utilization of medical services for these conditions was also measured in an attempt to relate met demand to medically-defined need for health care.

### *Health examination surveys*

A second method of more accurately representing the need for health care is to supplement health interview data by the examination of a sample of the respondents. In the United States, the health examination survey carried out by the National Center for Health Statistics (127) on chosen individuals lasts about two hours and focuses on certain cardiovascular diseases, arthritis, diabetes, visual and auditory acuity, and blood pressure, in addition to a detailed medical history. The survey is intended to provide data at national level and response rates, although often of the order of 85 per cent, may be a problem. The estimation of relative need for health care between Regions, let alone Districts, would require sample sizes that would be likely to be prohibitively expensive to examine. In addition, some arbitrary extraction of health care need from these data would be required, and for which standardized methods would have to be developed.

Other solutions might lie in identifying samples of consumers in defined populations and measuring needs by a variety of definitions.

A limited feasibility study, prompted by the RAWP proposals, was carried out on a random sample of households in two places in Wiltshire in 1976 (128). Systematic medical examinations were carried out by a general practitioner in the patient's practice. Although the co-operation rates were only moderate, the survey uncovered an appreciable amount of hitherto unknown morbidity in those examined. If such methods could be improved so that hitherto unmet needs could be identified in this way, then populations of this kind could form the basis of outcome studies. For example, the isolated elderly might be visited regularly by voluntary services and the health outcomes of the recipients assessed. The resources involved in such studies are considerable, but would contribute to a knowledge of local morbidity and also provide unique opportunities to detail information on the natural history of the conditions under investigation.

Health examination surveys would be inefficient if their sole purpose were to provide guidance on the distribution of funds, or even to assess or confirm priorities. As has been mentioned local initiatives for patient management and treatment must also surely flow from such studies. However the question must be raised as to whether a limited sample of conditions could be selected for detailed epidemiological surveys in each district and region on a regular basis, with the selection as far as possible representative of the need for health care. It is likely that a standard national definition of need for health care in the chosen conditions could be achieved. What is less likely is whether agreement could be reached about the choice of a small set of conditions which would validly represent health care need as a whole.



# CHAPTER 7 COMPOSITE HEALTH INDICATORS

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The previous chapters have examined the possibilities for morbidity indicators, especially in fields in which mortality is not thought to be an adequate proximate indicator for morbidity. Nevertheless in the assessment of health the expectation of life, and its quality should also merit inclusion. It is not surprising, therefore, that attention has turned to the design of composite or aggregate health indicators. Given appropriate, comprehensive formulation and calculation, a composite indicator has the attraction of reducing complicated concepts to a single indicator and hence should be easy to apply. In the affairs of health, the drive for the composite health indicator is an attempt at a final fulfilment of Charles Booth's dictum that 'in intensity of feeling, and not in statistics lies the power to move the world. But by statistics must this power be guided if it would move the world aright.' (129)

An aggregate health indicator has been defined as a measurement which summarizes the health status of a population at a point in time, and with repeated assessments on the same population will reflect changes over time in the health status of that population (130). Measurements and calculations to the same standards on different populations at the same point in time will obviously allow for a comparison of these populations, or groups. It is this comparison of groups, Districts or Regions which would be most promising for resource allocation. In terms of choosing priorities, this process would be greatly simplified if, for example, health care groups, health services for children, and health services for the elderly could be compared in terms of a common, simple index. A

note of warning should be sounded at this point, however, since conclusions depend upon the weighting given to the different components of the index, a point to which we shall return.

So far consideration has been given to health status indices as measures of relative need, i.e. that one population has greater need (in terms of the index) than another, or that priority might be given to one health care group rather than another because their need is greater in terms of the index. A further function of a health status index should be in the evaluation of clinical trials or of the output of health services. For example, Rosser and Watts have described the output of one hospital in terms of a health index and then expressed this as a proportion of the potential health index attainable if the system were perfect. Moreover, Rosser and Watts believe that the elements of an index used for assessing health outcome are essentially similar in concept and practice to those used in measuring health status as a need indicator (131).

Aggregate health indicators might also be of use in the day-to-day management of the health service. For example, Culyer and Cullis has proposed an admissions index by which persons would be admitted to hospital from the waiting list in a fair and efficient manner (132). The factors relevant here are that health status and expected rate of deterioration (for which some appropriate variant of an aggregate health indicator might be suitable) should form part of the index in determining urgency for admission, in addition to other components such as time already spent on the waiting list, the productivity of the patient and dependents, and other social factors.

One of the early approaches to the use of an aggregate health indicator was that of Sullivan (130). For the USA in the mid 1960s he calculated an index using current abridged life tables and age specific disability rates from a national health interview survey, such that the index represented for the population the average expectation of life free of disability. At that time the expectation of life at birth was 70.2 years, but life free of disability (hospitalization or restriction of usual activities) according to the health index was 64.9 years, a difference of 5.3 years of life with disability. Illness of the elderly was a major contributor to the years of expected life with disability. Culyer, Lavers, and Williams (133) have noted that in such indices, a year of disability is assumed to be equivalent to a year's loss of life (i.e. they are given equal weighting); and, current

and future disability is given equivalent weight subject to a discounting factor to reflect greater emphasis on the present. The disability component of the indices can of course be varied subject to the availability of appropriate data, for example Sullivan repeated his analyses using an alternative measure of disability namely bed disability (defined as hospitalization or confinement to bed due to illness for more than half the daylight hours). In this computation, the expected number of years of life with bed disability was two.

Other, mathematically sophisticated aggregate health indicators have been proposed such as that of Chiang and Cohen (134) in which they consider the health of an individual as varying on a continuum from optimum well-being to extreme illness. This continuum is divided into a set of ordered categories corresponding to different states of health. A stochastic statistical model is used to describe the change of an individual's health over time, taking into account the time factor and the chance mechanism. The values of the index may range from 0 to 1 and represent the distribution of individuals in the various health state categories during a given year. The longer the duration of occupancy of a person during the year in one of the lower states of health and the greater the proportion of individuals in these lower states, the lower the value of the index. Two main problems arise with the Chiang and Cohen index. Firstly, a sample of the population in question would have to be followed for a period of time to provide initial data for the model, and secondly, it is necessary to determine an appropriate set of weights to be applied to the different states of health in the model (135, 136). Chen (137) has proposed a health status index based on 'sentinel health events' by which he meant unnecessary death and disability caused by specific conditions on which medical agreement can be reached on avoiding negative outcomes (138). The author admits, however, that in the index the severity of disability is not taken into account and that although age at death is incorporated, there is no weighting for deaths from different conditions. Chen, Bush, and Patrick suggest a sophisticated two-part approach to a health index. The first approach is to construct a function status index which is classified in terms of mobility, physical activity, and social activity. These functions are then weighted in the index by reference to the preferences about function given by samples of the population. Data collection for the construction of the index would require a survey, but suitable

mechanisms for this were considered in the previous chapter, e.g. the National Health Survey in the USA and GHS in Britain. The authors recognize that the function status indicator is incomplete since it does not take into account the expected movement from one level to another in the future. A second indicator is then suggested which calculates the expected number of years of life free of dysfunction weighted by social preferences.

It could be argued that the ultimate in a democratic society should be to cater for, subject to resource constraints, the health conditions that the society would prefer. One of the major contributions of the work on composite health indicators has been the attention it has drawn to the topic of social preferences in health and the subsequent study thereof. Torrance (139) believes that the determination of the strength of preference of a community for various states of health is a crucial aspect of composite health indicators, the difficulties lying in the scientific method of assessment to be used. He compared three instruments for measuring health state preferences on criteria of feasibility, reliability, and validity. The three methods gave equivalent results for population means but not for individual values. The time trade-off method was the best measure of health state preferences; a method in which the subject is presented with two alternatives and asked to select the preferred one. One choice offers the subject a certain health outcome for a specific period of time, while the alternative offers a different outcome for a different length of time. However, the time trade-off technique is somewhat complicated to put into practice. Rosser and Kind (140) also acknowledge the difficulty of obtaining society's valuation of different health states. They also note that most methods, including that of Torrance, assume that death is the worst possible outcome. The authors introduce the use of a ratio scale in which subjects value combinations of states of disability and states of subjective distress and of death such that the valuations represent the relative degrees of undesirability as perceived by the subjects. The interview to obtain these valuations lasted from one and a half to four and a half hours. Importantly, the scale valuations obtained were independent of demographic variables but were related to current experience of illness.

Culyer, Lavers, and Williams (133) propose an indicator involving a ten point scale of intensity of ill-health (arbitrarily decided)

and duration. In their scale, death is the worst state of all but the incorporation of social preferences such as those from the work of Rosser and Kind (140) might place death at a level above certain extremely painful health states and also reduce the arbitrariness of all the rankings. Culyer, *et al.* are equally aware that a discounting factor could be introduced so that less emphasis (and hence weighting) is given to ill-health in the distant future than to ill-health in the present. They have also noted that the issue of externalities is not normally taken into account in aggregate health indicators. An example might be that equal weight is given to a specified level of morbidity caused by different diseases, yet one of these being an infectious disease, may affect adversely not only the individual in question, but others also.

What, therefore, are the advantages and disadvantages of aggregate health indicators. The advantages are principally theoretical since aggregate health indicators have been little used in practical situations; particularly those of a routine nature. This lack of practical application lies partly in the unavailability of the data for their construction and partly because of their inherent disadvantages.

The main attraction of aggregate health indicators rests on the fact that the state of health of a population (or group) or the assessment of the effectiveness of a variety of programmes are reduced to common unit. It is, however, this 'simplification' which leads to problems of lack of specificity, i.e. elucidating which individual variables are aetiological in a particular condition or which elements of a programme (preventive, curative or caring) have produced specific, identified improvements in health. Moreover, further work if required to establish the validity and reliability of aggregate health indicators.

The emphasis on social valuations of states of health in aggregate indicators has been important. Nevertheless, a number of fundamental questions remain. Doll (141), for example, believes that it is not possible to value death on a ratio scale with respect to other outcomes. As he succinctly states, 'being dead is not, and never will be, just ten times—or a hundred times—as bad as having some discomfort in the course of normal activity'. Moreover, can social preferences for states of health obtained from a national sample be used in assessing a regional need for health care? Although Rosser

and Kind (140) found preferences to be independent of demographic variables such as age, sex, and social class, a separate regional component has yet to be investigated. Moreover, it is unlikely that society's preferences would remain unchanged over time, thus requiring continuous monitoring. Additionally, in determining the need for health care, should we accept the preferences of a random sample of the population in question, or place greater weight on the views of those who are currently suffering (shown to be different by Rosser and Kind) (140) or on the views of groups of professionals (142). We should note that, if we accept that the preferences of a random sample of the community are appropriate, the scores for this sample can then legitimately represent the views of the population. However, the preferences of any one individual are unlikely to agree with the average view of this sample. This underlines one difficulty of using aggregate health indicators, namely the applicability to individual patients. This emphasizes the skill required of clinicians treating the individual patient since that patient's preferences for states of health may be quite different to that of the population as a whole, or indeed to that of a professional group such as doctors.

### ***Indicators in practice***

Composite health indicators do not necessarily have to be complex, mathematically sophisticated, or based on somewhat idealized value judgements of patients, consumers, or outside observers. Equally, indicators of morbidity do not have to be overtly illness, disease, or disability related. For example, the Resource Allocation Working Party was perfectly content to accept marital status of an appropriate measure of 'morbidity' for use in the determination of resources for psychiatry; and there may be similar scope in other directions.

### ***Social deprivation***

In 1978 a joint working group of the Department of Health and Social Security and the four Thames Regional Health Authorities was charged with devising a RAWP type methodology for the assessment of target allocations within the Thames Regions. The group recognized that standardized mortality ratios which were considered an essential component of the formula, in line with the general

RAWP philosophy, failed to take account of the element of what may be called 'social deprivation'.

Social deprivation is an easily understood concept which is considered by many to play a significant role in the need for health services, yet its definition is by no means universally agreed. In its report (143) in 1979 the group proposed the use of an additive score derived from three population characteristics enumerated in the 1971 Census of Population and which individually were found to be poorly correlated with standardized mortality ratios. These characteristics were:

the proportion of pensioners living alone;

the proportion of households lacking exclusive use of basic facilities; and

the proportion born in the New Commonwealth.

At the same time there were no specific data as to the quantitative effect that these selected variables had on the need for health services, or indeed on their use. Thus the basis of the computation of the score and the weight allocated to a particular value of it was the result of informed guesswork, rather than scientific evidence.

In order to provide information to quantify the effects of a range of social, economic, and environmental factors in the population on the utilization of hospital services, a census of hospital day and inpatients was undertaken by the North-East and North-West Thames Regions in 1981. The census was specifically designed to test the suitability of the three deprivation factors and their associated weightings identified by the working group and subsequently incorporated in the Thames sub-regional resource allocation formula, and to investigate whether other factors would be more appropriate for this purpose. It also sought to provide evidence as to whether there are differences in the severity mix of medical conditions of the patients in different hospitals and districts, and if so, further sought to quantify the extent to which social factors influence this severity mix.

The census enumerated the occupants of all the acute and regional specialty beds in both Regions, and in the North-East Thames Region also included geriatric beds, psychiatric, mental handicap and maternity beds were excluded, but the latter were later covered in a similar exercise. In all over 20,000 patients were included and for

each the information collected and brought together for analysis included that related to:

social deprivation, in similar form to that in the National Census, and acquired mainly by interview;

hospitalization, in the form of Hospital Activity Analysis, extracted from the routine regional system; and

(for North-East Thames only) patient dependency data, supplied by ward nurses in respect of the census day.

The principal method of analysis was to aggregate, from all sources, data related to hospitalized residents of each District Health Authority, wherever treated. This was then compared, characteristic by characteristic, with the total resident population of the District. This latter information was obtained from routine and specially obtained small area statistics from the 1981 Census of Population, the availability of which dictated the optimal timing of the 'bed' census.

The initial results of the study (144) confirmed the strong effect that age has on hospital bed use, showed that the factors used hitherto in the Thames sub-Regional Resource Allocation formula had a lower association; and identified a strong relationship between age-standardized use and socio-economic group (SEG). The regional utilization rate for the unskilled being almost three times that for the professional class and essentially the same relationship held in Inner London, Outer London, and in the surrounding counties. This is particularly important because the higher regional utilization rates for the unskilled might have been due to the known higher proportion of such persons in Inner London: where a greater provision of beds leads inevitably to a correspondingly higher overall utilization rate.

They have now replaced these deprivation indices in their formulae. Consideration is also being given as to how such information can also be included in the regional strategic planning guidelines.

The findings of these censuses in respect of bed use are broadly in line with those demonstrated for Glasgow by Carstairs (145) using the rather more simplistic approach of small area analysis; which she has described in detail elsewhere (146). This method may be used in a variety of circumstances but in the present context determined the



association between utilization of residents of small geographical areas and the proportion of suspected 'risk factors', e.g. of social class V, or overcrowding, in the population of these same areas. This method, which relies on the relative homogeneity of small areas, also employs composite social indicators of the type reviewed by Morgan (147) and which include the classification of residential neighbourhoods (ACORN) as developed by Webber and Craig (148).

The identification of socio-economic group as the most important variable may, of course, conceal a more fundamental parameter. Like social class, to which it is closely related, socio-economic group is a complex variable which is highly correlated with other census variables such as household tenure, car ownership, and the availability of amenities; although these individually are less correlated with bed use. Socio-economic group is also recognized as having a strong relationship with other variables such as education and income which are not presently measured in the National Census.

Whatever the value of social class in aetiological epidemiology (149), in the present context it should be accepted that a sub-group of the population has been identified which seems to be associated with differential utilization. The fact that such a group can be classified in terms of common occupational characteristics is incidental, but credible. If the subsequent process had been to identify aetiological factors then it would be used as a stimulus for further thought (150).

In the present situation it can still provide such a stimulus but it seemed perfectly legitimate for the Regions concerned to adjust the method of allocation of financial resources and plan services on the basis of the findings. Accordingly they have now replaced the deprivation indices in their formulae. Instead of the corporate one based on the three components advised by the Thames sub-General RAWP working party (143) the single—albeit complex indicator—of socio-economic group is now used. The appropriate weightings are derived from the results of the censuses. Consideration is also being given as to how such information can also be included in the regional strategic planning guidelines.

# CHAPTER 8 RETROSPECT AND PROSPECT

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The main challenges for action emerging from the issues raised in previous chapters can be briefly summarized.

## **1. Towards a better policy for analysis and uses of data and information**

### *(i). No single goal for actions to improve morbidity data*

It is evident that the case for improving morbidity data and its collection should not be based on a single goal, however important—for example, resource allocation—but rather to give a fuller identity to health service research for different purposes. In general the potential uses of accurately measured morbidity are many for basic, applied and strategic research.

### *(ii). Resource allocation: Morbidity in sub-Regional resource allocation*

Naturally mortality data have a contribution to make in sub-Regional resource allocation. However an improvement of significance in resource allocation poses the need for related or additional data to give an appropriate 'intelligence' for decision-takers. Merely one example of the use of morbidity information could be a contribution to an explanation of variations in mortality in diseases which are amenable to medical intervention. That is, mortality data on their own may be misleading. This is not to argue for ever more complex formulae for resource allocation at sub-Regional level, but for enlightened and pragmatic policy by Regions.

It is undoubtedly the case that high mortality ratios may sometimes be indicative of the relative *impotence of medical care* as well as the *need for care*. This is one of the key reasons which calls for the development of better morbidity measures to assist decision-taking by management. In this connection long-demonstrated but scarcely-implemented systems such as record-linkage may have a central contribution to make to practical measures of continuing health-care, and even outcome.

**Better quality data required.** There is thus a requirement for morbidity data of better quality to achieve a greater degree of justice in sub-regional resource allocations. The use of SMRs alone can produce disturbing statistical anomalies and fluctuations in target, at sub-Regional level.

What is more, even where mortality data appear to indicate similar or different results for two Districts, in fact each may require different or similar resources (depending on the purposes assumed). For example a District with twice another District's SMRs for every relevant disease classification might require more *or* less than twice the other's allocation, respectively if there are autonomous sources of treatable morbidity *or* if the SMRs overestimate the scope for effective health services in certain fields.

**Morbidity and social data.** It would also be important to seek further whether there is any significant correlation between morbidity data and measures of significant social characteristics.

### *(iii). Planning*

It is in principle desirable to use measures of need in planning. It is also the case that any such effective measurements will require morbidity data. However the interpretation of such data may often be contestable; indeed rival interpretations may point to opposite conclusions. For example, an apparent decline in morbidity might imply that the area in question had relatively less need of health resources; yet it is possible that more resources or better care had created the decline and that its continuation necessitated continuing additional resources. On the whole, however, further data on morbidity or sophistications of the preliminary data may help to point to the right answer.

Any such process of sophistication requires a commitment to morbidity data and their intelligent use by a carefully-structured management. Milestones beget yardsticks.

At present, planning at sub-Regional level may be subject to the rigidities of sub-Regional RAWP, although some Regions are moving away from a strict application of RAWP to sub-Regional levels. Yet movement away from the latter may leave general demographic factors or even almost arbitrary decisions as the guide to planning services and then allocating resources (as opposed to the reverse order under RAWP). Or alternatively existing demand may be the only real criterion used.

More balanced measures of needs in line with priorities may require morbidity data collected and analysed much more than at present.

#### *(iv). Priorities*

**Morbidity and needs in primary and secondary care: informed choice of priorities.** An exhaustive review of morbidity is needed to reconcile different perceptions of health service needs, *say by* general practitioners, as against hospital based specialists.

#### *(v). Aetiological epidemiology*

Investigation of the causes, progress, and prevalence of illness may well require morbidity data on a systematic basis, as argued above on pages 32 to 48. Such studies also have implications for clinicians, for clinicians in management, and for general managers as guardians of priorities. For example, prevention of disease, the incorporation of knowledge of aetiology into clinical practice, and allocation of resources all may be affected by aetiological epidemiology.

Epidemiology may also have a contribution to make in distinguishing diseases amenable to specific medical intervention or prevention from (say) diseases only or more amenable to changes in general environmental or social policy.

**Morbidity and prevention.** In this connection a careful examination would be desirable to review the morbidity data required for prevention policies. This could be part of a strategy designed to use

cost benefit data and information to compare the benefits of (say) prevention, cure and care for resource allocation, planning etc. The problems involved in this should not of course be under-estimated. For example, treating 'cure' as a 'residual' if prevention has failed or is impossible may be misleading and inaccurate.

(vi). *Evaluation of health services*

While management must have regard to all the issues, any studies of the use of morbidity data should particularly include the requirements of management in relation to the production and utilization of indicators of performance. This is specially relevant to the implementation of policies.

(vii). *Data collection and systems*

It would be important to select and assemble details of the most promising local initiatives in order to see how they can be used as indications of what will be required to improve the production of morbidity data with all that might follow. Undoubtedly such an exercise will be costly, but if related to the likely applications of improved data *viz.* exercises for epidemiological purposes, for resource allocation, for planning and for innovations in relation to existing services, the pay-off could well be worthwhile.

## **2. Conclusion: What action is called for?**

It is insufficient merely to explore the theoretical elements of the subject of morbidity. For use in the complexities surrounding health services, morbidity measures must be derived from clinical practice as well as health services provision. It is not the aim of this book to indicate a particular policy but rather to range over what is involved in securing a better intelligence for decision taking as well as in improving the epidemiological base for a national service, which in reality is made up of a wide variety of services for patients.

It is thus increasingly important that a special and co-ordinated attempt is made in the near future to spell out *priorities for action* towards the goal of improvement and in so doing *to pose some key questions*.

### *A. Recommendations for action*

The settlement of priorities in the management of resources is a central task for the new *NHS Management Board*. The objectives which require to be formulated pose the need for the *co-ordination* of the vital realms of information for the development and improvement of health services as well as for health services and epidemiological research. The Trust's work on *information policy more generally* expands on these themes [151]. Meanwhile, this morbidity study is a *specific* example of information needs for better management. As in the controversial (but also linked) field of the assessment of technology, the need to make rational choices about the provision of health-care in a context of constrained resources means that it will become evident that information on *outcomes* of health service procedures is vital. Without progress in the measurement of morbidity in many of the areas identified in this book, much of the present information available will be proved to be inadequate.

There are certain immediate principles for the Board to establish which will create styles and indicate what are necessary aims in the various authorities concerned with health care facilities and services.

- (a). **Roles of various Health Authorities.** A first task for policy-makers will be to explore *the respective roles of the centre, Regions, Districts, and non-NHS bodies in providing and analysing information on morbidity*. Improved information is clearly more vital in those fields where mortality figures are evidently less satisfactory as a measure of health-care need.
- (b). **Means for monitoring.** It will be important to establish a network of responsibilities for the production of good intelligence in *monitoring* existing sources of data.
- (c). **Costs and benefits.** Investment will be specially needed to accomplish the principal objectives of better intelligence for management. It is evident that major developments in this field will not come cheaply. Research and development in the NHS, including demonstration projects, are significantly underfunded by comparison with many if not most other large scale public- and private-sector

organizations. As always, the economic and allied *trade-offs between present cost and future savings, greater efficiency and greater effectiveness are dominant elements in intelligence* for decision-takers.

### B. Key issues

A settlement of priorities and functional roles should be followed by the application of *more resources* to the task of collecting information on morbidity—in the name of ultimate efficiency. It is evident that the key issues facing policymakers in the adoption of a practical strategy are as follows:

(i). The limits to the use of mortality should be more sharply focussed, especially for sub-Regional resource allocation. Better information systems are required to do this profitably; and the most immediately worthwhile purposes should be identified.

(ii). More than minor adjustments to existing routine data systems are required. It is important to assess which of the present developments and research projects hold out the most hope for results in this field. In this respect not only should specific examples of promising innovations, such as record linkage, be reviewed; but more generally the preoccupation of the (formerly) Körner Steering Group with *data collection* should be extended to cover *data organization* and the use of information for better management.

(iii). Local initiatives ought to be better co-ordinated and integrated. New advances and systems also should be developed.

(iv). Better performance indicators require better morbidity measures.

(v). Aggregate health indicators should be warily examined as to practicality and worth.

## POSTSCRIPT

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This book has been designed to sharpen the questions and to point the way ahead. It is of course a truism that it is difficult to define morbidity, but some suggestions have been made in the previous chapters to define and refine the concept for care. The most practical uses for morbidity information—epidemiology, management (specially for resource allocation and planning)—are likely to be prejudiced for lack of real accuracy if significant improvements are not forthcoming. To achieve this, ideas and methodology for collecting data based on the most profitable likely uses are necessary.

The prime message of this book is that morbidity is a subject requiring closer attention than heretofore, with a view to a better understanding and closer measurement of its effects if we are to improve the efficiency and effectiveness of health care practice and services.

The main tasks of management in health care are to ensure that *effective* services, of acceptable quality, are delivered *efficiently* to people in need of them.

It follows the NHS Management Board, and General Managers, will have to develop the tools to

- (i) assess the extent to which services meet needs for patient care;
- (ii) assess whatever services are deployed such that they are of demonstrable effectiveness and acceptable quality;
- (iii) assess whether resources are deployed for patient in ways which are both equitable and which secure value for money.



Systematic data and information on morbidity as argued in this study are a significant prerequisite of such efficient and responsive management. Information does not come cheap. But careful definition of needs, and *co-ordination of different uses profitable at different levels within the NHS*, can minimize unnecessary waste. Overall, value for money and quality in the long-run require investment in the short-run: in improved information and tools for management.

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