

How useful are official health statistics?

from David Jones.

Official health statistics are under scrutiny by Sir Derek Rayner, as part of his enquiry into the Government Statistical Service, and by the Department of Health and Social Security's Steering Group on Health Services Information.

The 'Unofficial Guide to Official Health Statistics' to be published at the end of August by the Radical Statistics Health Group raises important questions which appear to be absent from the agenda of either of these two enquiries: how useful are official health statistics for assessing the health of the population and for evaluating the effectiveness of the health services?

The reorganisation of the National Health Service (NHS) in 1974 led to the setting up of a planning system intended to formalise decision making within the health and social services. This ~~planning~~ system gives the appearance of relying heavily on the use of statistics. As a result, a series of reviews of the information available to the Department of Health and Social Security (DHSS) has been initiated and new statistical systems (such as the Standard Child Health System) planned.

Most public discussion about statistical systems has focussed on the issue of the confidentiality of the data. There are, however, other important issues which should be raised.

The original terms of reference of the DHSS Steering Group currently reviewing health service information were to consider the needs of health service administrators. Its scope may have been widened subsequently, and rightly so; it is futile to consider the needs of administrators in isolation from those of the health service workers and of patients. It is important to have data about the activities and staffing of the NHS. However, it is certainly equally important to know about the health of the population and, crucially, whether the activities of the health service have any impact on it.

Because most of what are somewhat misleadingly called health statistics are collected for administrative or legal purposes (as is the case with registration of births, marriages and deaths) they are not on the whole very well fitted to telling us about the health of the population.

For example. the Hospital In-Patient Enquiry contains much information about how many days patients spend in hospital but nothing about the outcome of their treatment, except whether they died in hospital or were discharged alive.

Similarly, from official health statistics we can find more about fashions in treatment than about the extent to which the population suffers from the conditions which the treatments are intended to remedy, except when death results and death certificate information is available. For example, opinions vary as to the advisability of removing children's tonsils. When the proportion of children who have their tonsils out varies from place to place, there is no way of knowing the extent to which the variations indicate that tonsillitis is more common in some places than others, rather than that doctors' views vary about removing tonsils.

In neither example are we told much about patterns of health in the population as a whole. We do not even learn much about the outcome of the medical intervention in those patients who are treated and so evaluation of the effectiveness of the treatment is difficult.

Thus one outstanding problem is the incompleteness of the data, while paradoxically in some areas there is considerable duplication of effort in the collection of those data which are obtained. This is well illustrated by the data collected on pregnancy and childbirth, although there are many other examples.

Data relating to pregnancy and childbirth are collected through a variety of different systems. For example, a doctor who terminates a woman's pregnancy, whether in the NHS or privately, is legally required to fill in an abortion notification and send it to the DHSS. After removing all identifying information, the DHSS sends the data to the Office of Population Censuses and Surveys (OPCS) for analysis and publication. In addition, a ten percent sample of abortions to NHS patients is also included in the Hospital In-Patient Enquiry (HIPE). When estimates from HIPE of the numbers of residents of each health region who have their pregnancies terminated in NHS hospitals in a given year are compared with the corresponding totals derived from abortion notifications, there are substantial differences for some regions, even when sampling errors are taken into account.

Ten percent of deliveries taking place in NHS hospitals are included in the Maternity Hospital In-Patient Enquiry. Although this duplicates some of the data collected on birth registrations and notifications, it is the source of data not found elsewhere, including some about the use of medical procedures (caesarean section, induction of labour and episiotomy) and of painkillers and anaesthetics. There is very limited information about the condition of the baby, although this does include birthweight and an

indication of the presence of congenital malformations, and whether the baby died in hospital under the age of 7 days, was discharged alive or was transferred to a Special Care Baby Unit. For over ten years these data have not been used very much as very little was actually published until 1979, although they had been collected and tabulated. Arrangements have now been made to publish these data with less delay.

Fortunately stillbirths and infant deaths are very rare events these days - only 8.3 out of every thousand births in England and Wales in 1978 were stillbirths and only 13.0 per thousand live born babies died before they attained the age of one year. But what about handicap? The Select Committee on Perinatal and Neonatal Mortality claimed that at least 5000 children survive each year with handicaps which could have been prevented. It has been claimed that Britain has more handicapped babies than France, Sweden or Japan, but no one knows whether this is true as there is no comprehensive national system for collecting data about handicapped children here - nor do any such systems exist in France or Japan. Indeed, as a Minister admitted in Parliament, there is no agreed definition of handicap. The only notification system is that for congenital malformations which is confined to malformations which are diagnosed within a week of birth. This means that those such as abnormalities of the heart, which are not usually diagnosed until later on, do not get included. As the system is voluntary the extent to which malformations are notified is dependent both on the gravity of the malformation and on the extent of local interest in notifying them.

For information about the numbers of beds available for maternity cases, and the numbers of staff involved, we have to go to separate returns made by hospitals to the Area Health Authority who then aggregate the data and in turn send it to the DHSS. Some of this data is duplicated in reports made to the Royal College of Obstetricians and Gynaecologists. The Royal College of Midwives also collects and publishes the numbers of its members who are practising in any given year.

All this duplication of effort is very wasteful, and because of discrepancies between the systems it is often difficult to use a data item collected in one system with a different one from another system. Even when data on the same subject are collected in two systems, the definitions used are often incompatible. Furthermore, other important data are not collected in any system; there is, for example, very little information collected about the health of a live born baby or the health of the mother.

These problems make it difficult to analyse and interpret perinatal statistics and use them to attempt to evaluate health care despite recent attempts to do so; as we have hinted, the Select Committee paid scant attention to many of these problems. It did, however, make some useful suggestions for improving the compatibility and completeness of the data.

The deficiencies of official health statistics which we have illustrated do not necessarily imply that statistics are useless and not worth collecting. Of course, official statistics cannot measure everything; their principal strength is evaluation. The message is that better statistics should be collected and more appropriate analyses should be made - more appropriate, that is, for the evaluation of the effectiveness and efficiency of the health services.

To return to our example again, perinatal mortality rates are strongly associated with the incidence of low birth-weights and of congenital malformations, neither of which can at the present state of knowledge be prevented by medical intervention, although the latter can be eliminated by abortion. So if we want to evaluate the work of the health services we need statistics which take birthweight and congenital malformations into account.

It is also essential to arrange feedback of the statistics to those who collect them if the quality of the statistics is to be improved. For example, in the community health services which, unlike hospitals, have no medical records departments, field workers are asked to provide the data. Many complain, however, that they never see the results of local or national analyses of these data.

Most of the improvements would of course cost more money at a time when less is apparently available. With £7500 million spent annually on the National Health Service this lack of data to provide the basis for evaluation of the service is surely a false economy.