Changing disease incidence: the consulting room perspective

‘Reliable information on deaths by cause is an essential input for planning, managing and evaluating the performance of the health sector in all countries.’

With these words Murray and Lopez introduced their chapter on the causes of death in the book *The Global Burden of Disease*. The statement is equally true when considering diseases that do not usually cause death. They went on to consider what was meant by the words ‘reliable’ and ‘cause’ and examined protocols for assigning cause, disease classification, age standardisation and other factors important to the recognition of difference, be that between countries and regions, groups of individuals within a country, or differences over time. Although the performance of the health sector was an important element of their deliberations, when evaluating change we must never lose sight of the persons who die or experience disease but do not consult. Changes in sickness certification for example have knock on effects on consulting patterns.

The initial priority in any comparison is to establish the fact of change and this should precede efforts to interpret the reasons for change. Routine healthcare data are collected for a particular purpose and they are not always appropriate to describing change. The introduction of the Quality and Outcomes...
Framework in the British NHS has had fundamental effects on the ways doctors record information. Differences between the before and after situation do not necessarily indicate fundamental changes in the health problems of the subjects monitored or the way in which they have been managed: sometimes the main change is in the way the information is recorded. Mathematical techniques such as age standardisation and statistical estimation of confidence intervals enhance our ability to make comparisons but are only appropriate if monitored samples are truly representative of the population. When interventions are considered, the representativeness of the doctors undertaking the intervention is also relevant.

The quotation commenced with the word ‘reliable’: components of reliability include consistency and accuracy. In the use of general practice derived patient electronic records for epidemiological research, consistency is a major challenge. With the introduction of electronic records there have been changes in recording discipline and changing attitudes towards the content of the record. Some GPs focus their records on systematic recording of the patients presented symptoms, others on their assessment and interpretation and record their assessment opinion as a diagnosis, which is stored as a Read code (as in the Weekly Returns Service [WRS] of the Royal College of General Practitioners). A haphazard mixing of the way records are generated by different doctors, and perhaps at different times by the same doctor, is not conducive to their use for epidemiological research. The most serious limitations are found when the record is incomplete, as for example a consultation without a recorded reason, or the issue of a prescription for no apparent illness. This happens when essential morbidity items are entered in free text rather than in accessible Read codes, or when handwritten prescriptions are issued and the electronic record is not updated. If the use of electronic records for epidemiological research is to be encouraged, a reliable and consistent recording discipline is essential.

The routine weekly reporting of new episodes of illness in sentinel practices in the WRS since 1967 provides a unique opportunity to examine trends. During that period, there have been changes in several diseases particularly infections. Until 1994, the WRS was chiefly a paper-based recording system collecting new episode data on a range of conditions mostly due to infection; but since then, data have been collected covering all consultations and all conditions. Since 2000 the annual prevalence of disease has also been reported using the same methodology as that in the National Morbidity Surveys. As examples to illustrate change over the last 30 years (1976–2005), age standardised (to the 1991 census population) annual episode incidence rates are given for selected diseases (Figure 1).

For comparative purposes, the age standardised annual incidence in 1976 is used as the reference point: diabetes, age standardised incidence rate 15 per 10 000; hypothyroidism = 7; acute myocardial infarction = 19; acute cerebrovascular disease (CVD) = 30; duodenal ulcer = 15; chickenpox = 34; shingles = 33; glandular fever = 10; scabies = 26; hepatitis = 3; infectious intestinal disease (IID) = 381; appendicitis = 10; acute bronchitis = 416; asthma = 51; hay fever = 128 (1981 age standardised incidence rate). Change is indicated as the percentage difference in each year since 1976. Illnesses have been grouped to highlight interesting comparisons. Trend data covering other conditions are available as an electronic appendix, and contained within the regular annual reports of the WRS on incidence and prevalence (www.rcgp.org.uk/bru).

For some illnesses there is good evidence of continuous change. The increase and prevalence of diabetes are increasing and this has been shown in independent studies. The increase is reflected in the routine annual reports of prevalence produced by the WRS. Some of the increase is likely (but not certainly) explained by greater diligence of doctors in investigating at-risk patients, some is possibly due to changes in lifestyle and increasing obesity, but it is equally possible that the improved management of diabetes, which has occurred gradually since the introduction of insulin, has strengthened the pool of genetically susceptible subjects. Hypothyroidism, as seen in patients presenting to GPs, has increased to a similar extent but that is not attributed to lifestyle changes. Certainly, the ready availability of simple diagnostic tests is likely to be part of the explanation but in both these examples it is far easier to establish change than to explain why it has occurred.

For some conditions, advances in treatment are likely to be the direct cause of change. Continuous decreasing change as seen in the data for CVD and acute myocardial infarction probably reflects reduced tobacco smoking and improved management, especially of hypertension. Exacerbations of duodenal ulcer have also decreased especially during the last 10 years, likely, but not exclusively, as a result of treatment for Helicobacter infection. Total consultation rates (available in the WRS since 1994) and the annual prevalence (available since 2000) for CVD and ischaemic heart disease have increased. These two statistics together reflect the increased care given to sufferers and increased survival after acute infarction. The paradox of increased prevalence and consultation rates set against a background of decreased episode incidence cautions the use of consultation-based comparisons. Changes in consultation patterns for a particular disorder may have little to do with real changes in the extent of the problem in the community: changes in annual prevalence cannot be interpreted without an appreciation of the natural history of the condition and the life expectancy of the sufferers. Changes in the proportions of consultations in which interventions occur are even more difficult to interpret because they are dependent on the completeness of the dataset.

The incidence of shingles has remained almost constant for 30 years. Some small apparent ‘increases’ that have occurred in recent years are likely due to the increasing elderly population. The data presented here are standardised crudely by age in a single group of males and females age 65 years and over because prior to 1994 data were not available in the
WRS in greater age-specific detail. In the case of shingles, for which incidence is maximum in elderly people and greater in females, more detailed age and sex standardisation is desirable. In contrast, the incidence of chickenpox varies from year to year. A distinct change in the age-specific incidence of chickenpox reported in the WRS occurred in 1983 introducing a period in which maximum incidence appeared in pre-school children which has been sustained since. It will be interesting to see if that has repercussions on the age specific incidence of shingles.

In more detailed data available since 1994 there have been other conditions which have been reported with similar consistency: they include for example, episodes of gout, molluscum contagiosum, eczema and skin infections. The consistency of reporting for these conditions provides a degree of reassurance in the quality of reporting and help to give context to information on conditions in which the incidence is changing.

Changes in the incidence of scabies illustrate the benefits of continuous recording to describe trends. There was a small reducing incidence between 1986 and 1992 followed by a sharp increase to 2000 and a subsequent reduction. A two-point comparison between 1991 and 2001 would not show any change. Periods of increased incidence of scabies have been reported previously but never explained. The incidence of pediculosis reported in the WRS showed a similar rise and fall during the 1990s which slightly preceded that for scabies. Both these increases occurred at a later time than changes in the incidence of respiratory infections and occurred at a time when the incidence of eczema and of skin infections was relatively constant. The incidence of glandular fever has also fallen over the same period, an observation unlikely to be due to changing diagnostic behaviour since this condition has for so long been diagnosed on the basis of laboratory data. These reductions are surprising in illnesses which are spread by close contact. Since 1994 the WRS has also reported a reduction in persons presenting with sexually-related infections.

The incidence of intestinal infectious diseases fell slightly between 1976 and 1990 and much more sharply since. The reduction is evident in all age groups but particularly among children. The incidence of viral hepatitis fluctuated prior to 1990 and then decreased gradually to 2000, but since then it has been recorded more frequently: this increase is due to increased diagnoses of hepatitis B and C rather than A. There has been a gradual decreasing incidence of acute appendicitis over the 30-year period. WRS data are based on assessment diagnoses in patients who consult and in recent years may have been reduced as a result of the decreased involvement of GPs in out-of-hours work. However, this factor is not relevant to reduction seen over the period 1976–1996. Improvements in hygiene are a contributory explanation for these reductions although other factors may be equally important. The spread of disease is a particularly interesting subject and demographic factors, such as family size and overcrowding, and environmental conditions, such as humidity, ambient temperature and air pollution, may influence the spread of a disease as well as be directly causative of some conditions.

The incidence of asthma episodes has provided some of the most interesting changes seen in recent years and further illustrate the benefits of continuous recording over long periods. New episodes
of asthma tend to occur at the same time as new episodes of respiratory infection and these exceed the increases seen during the pollen season. The episode incidence of hay fever (data available since 1981) has not shown the general decline as seen for asthma although there was a small increase in the early 1990s peaking contemporaneously with asthma. For both asthma and acute bronchitis episodes (Figure 1) the WRS reported large increases of incidence in the late 1980s and early 1990s that peaked in 1994 and were followed by equivalent reductions over the last 10 years, which are now levelling off. The increase for asthma episodes was particularly strong and in all-age data appeared to peak slightly before acute bronchitis: however more detailed analysis by age group shows the peaks were simultaneous.

The incidence in all age groups of both upper and lower respiratory illnesses reported to GPs has shown the same trends as asthma episodes (increase in late 80s, peak in 1994, decrease since), which has been matched by contemporaneous reductions in antibiotic prescribing. These changes have been shown in an independent UK data source and in the Netherlands. Although the facts of change are well established, the explanation for them is elusive. The three studies concluded that the main reason stemmed from reductions in the numbers of people consulting because of respiratory infection: Ashworth and colleagues thought there was a significant additional factor from reduced likelihood of the GP to prescribe antibiotics; the Dutch study found the opposite and expressed concern about a relative increase in the use of second-line antibiotics; the WRS study did not have access to individual patient-linked prescription data but it was based on national data on dispensed as opposed to issued prescriptions. The latter study had the further advantage of being based on an information system that has consistently entailed the GP in describing the morbid problem in directly accessible codes at every consultation, a protocol which has resulted in generally higher levels of consultation reporting for common respiratory infections in the WRS as compared with other information systems. The interpretation of research findings must always consider the impact of missed or inaccessible consultation or prescribing data, especially where recording discipline may have improved over time. None of these studies can address the question ‘do patterns of acute respiratory illness presented to GPs truly reflect the burden of illness in the community?’, although we can make inferences from comparisons based on different age groups, different respiratory syndromes and other illnesses for which antibiotics might be prescribed. Timing is also of the essence; the downturn in antibiotic prescribing appeared well before the publication of the Standing Medical Advisory Committee report in 1998 and subsequent pressures to reduce prescribing. These facts, together with the lack of evidence of consultation bias to explain the increase in the period 1986–1994 support the opinion that these are true changes in the incidence of disease, which have not been explained. This review of some recent changes in the incidence of disease episodes reported in general practice prompts a number of conclusions highly relevant to the use of practice databases for monitoring change.

- It is of utmost importance to record morbidity consistently and without omissions. The WRS data have been derived from reports of the assessment of the GPs in a logical manner focused on the diagnosis. Although some ‘diagnoses’ are no more than symptom descriptions they nevertheless express the opinion of the doctor consulted and not simply the complaint of the person consulting.
- Consultations, whether counted as a numerator or used to provide a denominator are not a secure basis for describing change. For epidemiological purposes new episodes of illness need to be separated from ongoing consultations.
- The interpretation of change must explain all changes whether increases or decreases, but usually will depend on complementary data from hypothesis driven research. However, hypotheses generated because change has occurred, sometimes limit opportunities for truly scientific research.
- The expansion of sentinel practice networks in European countries provides opportunities to examine hypotheses generated in one network in data collected in another.
- There are many changes occurring continuously and they provide an enormous challenge for epidemiological research. General practice is in a very strong position to describe change provided data capture is reliable and consistent. The establishment of high quality recording on electronic records is a target to which all doctors should subscribe as part of their contribution to knowledge improvement; a target for which we should not look to for payment beyond the basic cost of recording time. Maintaining accurate consultation records with particular reference to their epidemiological value must take precedence over accountancy and quality assurance purposes.

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Supplementary information
Additional information accompanies this article at http://www.rcgp.org.uk/bjgp-supp-info

REFERENCES


