

*Mrs. Morris - for information.**MRS Holmes*

GRO-C

Dr Ashley

DRAFT PAPER FOR THE MAC - IMPROVING CAUSE OF DEATH INFORMATION

I would offer the following comments on your draft paper:-

1. In para. 2.1., the current regulations are embodied in a Statutory Instrument dated 1987 not 1968. These are the Births and Deaths Regulations 1987 (1987 No. 2088) which were made on 26 November 1987 and came into force on 1 January 1988.
2. Apart from stressing that the maiden surname is recorded only in respect of a woman who has been married, a significant omission from the content of the public record listed in para. 2.3. is the place of death of deceased.
3. The current Regulations for still-births (para. 3.5) are as for deaths, dating from 1987 and operative from 1/1/1988. The certifier of a still-birth is also asked to state, but not for the public record, whether the child died "before labour", "~~after~~ labour" or "not known".
during
4. The opening statement in para. 5.2. is not quite correct. If a coroner neither holds an inquest nor a post mortem, the cause of death is either certified by a medical practitioner who attended the deceased during the last illness or is registered as uncertified.
5. The opening sentence of para. 5.3. is incorrect. I enclose the OPCS guidance which is printed in every book of coroners' certificates after inquest and every book of coroners notifications (Pink Forms). Quite extensive guidance is given in both cases.
6. On a more general point, Professor Bernard Knight wrote to the Registrar General in February 1988 and among other things expressed concern about unsatisfactory causes of death being accepted by registrars. He went on to say, "I realise that registrars cannot be expected to have significant medical knowledge and I do not know what the answer may be to this problem without screening by a more senior or experienced doctor Junior house officers and even more senior hospital doctors, together with general practitioners, have a very poor appreciation of death certification and even when they are aware of the true disease process, the way in which they write the certificate is often unacceptable".

On taking up this matter with Andrew Bosi at the BMA, he wrote to Professor Knight in the following terms:-
"The problem which you raise can only really be resolved

by adequate training for junior house officers. We felt that there was no substitute for adequate certification by those who have the medical knowledge and training. I explained to Mr Jenkins that you were well aware of this need, and had been campaigning for many years for the return of the compulsory paper for undergraduates in legal medicine."

I hope this is helpful.

GRO-C

W Jenkins
29 June 1989

Mr. Takis

This is a draft file for the MAC

Has registration division any comments?

GRO-C

JJA ASHLEY

23.6.89

IMPROVING CAUSE OF DEATH INFORMATION

1 Accuracy of cause of death information

1.1 Is there a problem?

It is generally accepted that mortality statistics by cause of death must be interpreted with caution. For some conditions medical knowledge and facilities for diagnosis have altered markedly over time, or may vary from place to place. However most anxieties centre round the accuracy of certification particularly as a major part of the practical responsibility lies with very junior members of the profession. Whilst there is no hard evidence that there has been any recent deterioration in the situation, it has to be acknowledged that no major validation study has been conducted for some years (see para 8 below).

1.2 Content of this paper

This paper sets out the arrangements for the supply of cause of death information; identifies the guidance offered by OPCS as to the completion of the medical certificate; and reviews possible courses of action.

2 Registration of Death

2.1 Legislative background

In England and Wales the registration of deaths dates from the Births and Deaths Registration Act of 1836, although death registration was not made compulsory until a later Act of 1874. There were various subsequent modifying enactments which were eventually consolidated into the Births and Deaths Registration Act of 1953 and its companion legislation relating to the organisation of the registration service - the Registration Service Act, 1953. Current regulations are embodied in a Statutory Instrument (1968), but there has been a recent consultative Green Paper seeking views on some of current issues affecting Registration.

2.2 Registration procedure

Most information supplied by an informant of the death to the Registrar of Births and Deaths is put on the public record of the death (the register entry) (Table 1). Additionally, however, the Population (Statistics) Act 1938, and its revision in 1960 allow the confidential collection at registration of certain additional items of information regarding the marital status of the deceased, which are not entered in the public record, and may only be used by the Registrar General for statistical purposes.

2.3 The public record

The content of the public record is given in Table 1.

Table 1 CONTENT OF PUBLIC RECORD OF DEATH

Name of deceased ✓
Maiden Name if female ✓
Usual address ✓
Sex ✓
Date of birth ✓
Place of birth ✓
Occupation ✓
Date of Death ✓
Cause of death ✓
Details of informant ✓
Details of certifier ✓
Details of registrar ✓
Date of registration ✓

3 Cause of Death

3.1 History of cause of death information

The public record includes the certified cause of death from which the Registrar General has published mortality statistics by cause throughout the period since 1837. As originally tabled the 1836 Bill did not include Cause of Death as an item in the register entry. Its provision was added during the passage of the Bill through the House of Lords; and it is generally assumed that, in part at least, this was due to that the influence of Edwin Chadwick (Alderson, 1963).

3.2 The Medical certificate

Initially there was also no requirement that the cause should be supplied by a doctor, but apparently a medical opinion as to this was sought wherever possible. However, the 1874 Act which made death registration compulsory, also placed a specific duty on the medical practitioner who attended the deceased during the last illness, in that he or she had to provide the cause of death unless there was an inquest. Thus, for many years, cause of death data have been derived from a Medical Certificate supplied by a Doctor, and consistently about three-quarters of all deaths (76 per cent in 1986) are certified in this way; the remainder being certified by coroners (see para 4 below).

3.3 Format of Medical Certificate

In England and Wales, as in most other countries in the World, the format of the regulation medical certificate currently required in respect of deaths after the neonatal period is similar to that presently recommended by WHO (1977). The pre-printed medical certificate supplied by DPCS for completion requires the certifier to distinguish -

in parts I(a), I(b), & I(c)	diseases or conditions directly leading to death ; from
in part II.	other significant conditions contributing to death.

This format differs in only minor detail from that initiated by the then General Register Office in 1927 (Swerdlow 1987). Prior to that date certifying Medical Practitioners were merely required to issue a signed certificate of the cause of death, in any format. Although for most of this period the then General Register Office issued blank forms seeking primary and secondary causes of death.

Also, in line with WHO recommendations, provision is made for the supply of information as to the duration of each condition mentioned, but unlike the basic cause information this is not transcribed on to the public record.

3.4 The neonatal Death Certificate

For deaths occurring within the first 28 days of life a new neonatal death certificate was introduced in England and Wales in 1986. This also conforms with WHO recommendations and requires the certifier to distinguish fetal (in a & b), maternal (in c & d), and other cause contributions (in e) to the cause of death.

3.5 Stillbirths

For pregnancies that result in a stillbirth different documentation is used. Stillbirths were first registerable in 1927, under the provisions of the Births and Deaths Registration Act, 1926. A certifier, who may be the medical attendant or the midwife, completes a certificate where a child has been 'completely expelled or extracted from its mother after the 28th week of pregnancy and which did not at any time after such expulsion or extraction breathe or show any other evidence of life'.

The current regulations are as for deaths, dating from 1968, but the format of the certificate was revised from 1986 to be in line with the requirements for cause of death information for neonatal deaths. However, in addition to the cause particulars the certifier is also asked to give, not for the public record, the weight of the fetus and the estimated duration of pregnancy. It should also be indicated whether information has or will be obtained from post-mortem.

4 Education for completion of the medical certificate

4.1 WHO initiatives

At each revision of the ICD the World Health Organisation compiles a booklet of instruction (Medical certification of cause of death, WHO), as educational material to help doctors regarding the requirements for the completion of medical certificates. The latest issue, which is dated 1979, identifies the detail required and provides several examples to assist the understanding of the process.

Although this booklet does not exactly equate with OPCS requirements, for many years it was OPCS policy to supply annually about 3000 copies to Universities and Teaching Hospitals; with the intention that it should reach each graduating medical student. This practice was stopped from 1980, because of changes in HMSO charging policy, and Universities were encouraged to purchase their own copies. The booklet is still in print, and as relevant now as it was in 1980, but the annual sales by HMSO now run at about 3 or 4 copies in most years. It is not known whether the dramatic fall in Medical School interest reflects educational or financial reasons.

4.2 Other material

Some countries issue detailed educational material, for example the United States National Center for Health Statistics makes available a series of booklets and an audio tape for individual use. It also distributes a video tape for group instruction.

4.3 DPCS guidance

Since 1902 DPCS practice has also been to help Medical Practitioners by inserting guidance notes in the front of each book of blank forms. Whenever changes are made to the certificate these notes are revised, with their content discussed and agreed with the Medical Profession. Thus the notes accompanying the present general certificate date from 1985 when the neonatal and stillbirth certificates were first put into use.

The alternative types of certificate (see para 3 above) have different relevant versions of the notes which currently extend to four pages. In all cases they offer advice regarding the legal aspects of certification, such as the liability and entitlement to give a certificate and the reporting of deaths to coroners (see para 5 below); as well as the completion of the statement of the cause of death and other parts of the certificate.

4.4 Completion of the cause statement

The guidance provided in respect of the completion of the cause of death statement typically include notes on -

- the Medical uses of Mortality Statistics;

- the concept of the underlying cause of death, with particular reference to the avoidance of statements which only identify a mode of dying;

- handling multiple pathology, with emphasis on the differences between parts I and II of the certificate; and

- the need for maximum specificity when describing the cause.

However, over time varying emphasis has been placed on the different aspects. Thus, whereas the 1980 issue included a range of medical examples by way of illustration, the current issue for non-neonatal deaths (attached) was based on a policy of simplification and only a few examples are given. Rather more examples are provided in the notes accompanying the neonatal certificates, but there is some evidence that these are poorly understood.

5 Coroners

5.1 Reporting to coroners

A registrar when informed of a death for which legal requirements relating to certification are not met, or if there is unsatisfactory information as to cause of death, has to report it to the coroner. In the guidance notes Medical Practitioners are made aware of the list of categories of deaths into which the coroner may inquire, and may well refer the case to the Coroner without completing a medical certificate; although there is theoretically an obligation to do so.

5.2 Certification by coroners

For deaths referred to them, it is the duty of coroners to certify the cause whether or not they hold an inquest, or a post-mortem examination. Their decisions in these respects will depend on the results of their preliminary enquiries and whether death is from natural causes. When Coroners certify the cause of death they frequently constrain their statements within one of the internationally agreed formats, as used on the printed medical certificates issued to doctors; alternatively they may use a free format.

5.3 Guidance for completion of the coroners certificate

No specific guidance for completion of the cause statement is made available by OPCS to coroners. Furthermore when a post-mortem examination is ordered coroners are required to reproduce in exactitude the cause supplied by their pathologist, again to whom no specific advice is offered by OPCS. Again in the United States a relevant booklet is made available by the National Center for Health Statistics.

6 The underlying cause of death

Nearly all the national statistics published are based on the tabulation of a single cause for each individual death - the identified underlying cause of death. It has been pointed out a number of occasions (see for example, Farr 1854; Moriyama 1952; Guralnick 1966; Markush 1968; Cohen and Steinitz 1969; Abramson et al. 1971) that the conversion of the information on the death certificate to a single cause of death may fail to identify the combination of different diseases that are or are not related, but are thought by the certifier to contribute to death.

6.1 Identification of the underlying cause

Whilst some general advice is given to the certifier regarding completion of the medical certificate in a manner which will easily identify the underlying cause, its final selection is carried out at the stage when certificates are coded, using international rules set out by WHO, augmented by a series of standard national coding practices.

In most cases, however, the format of neonatal and stillbirth certificates preclude the assignment of a single underlying cause of death before the age of 28 days.

7 The provision of further information

Two mechanisms exist whereby the originally certified cause of death may be subsequently amended. Neither of these mechanisms leads to an updated cause of death on the public record; as this additional information (which perhaps includes causes considered sensitive) is supplied to the Registrar General on the understanding that it is only for statistical or other proper research purposes. Whilst the numbers assigned to a wide range of causes are changed by these procedures, some causes, particularly cancers, are differentially affected. (Swerdlow, 1989).

7.1 Statement B enquiries

The certifier may indicate (in statement B on the back of the certificate) that further information regarding the cause of death is likely to be available at a later date. If such an offer is made a standard enquiry form is then sent by the registrar at the same time of registration of the death. On receipt of a reply (there is a 85 per cent response rate) the cause of death details are amended in the statistical system where appropriate. Annually about 3 per cent of total deaths are affected in this way, and because these enquiries are effectively initiated by the certifier OPCS has little control on their quantity or content. The only possible changes to this system are either to cease to offer this option or to totally or partially ignore the response.

7.2 Medical enquiries

There is a further system (covering 2.5 per cent of deaths with a 90 per cent response rate) whereby queries are sent seeking clarification when there are difficulties in coding the cause of death; and a limited study has been set up to examine the characteristics of certifiers, whose certificates give rise to medical enquiries of this kind.

7.3 Philosophy of medical enquiries

There are theoretically two main objectives for carrying out medical enquiries:-

- a) to obtain further information needed to properly classify the cause of death; and
- b) to educate the certifier about the proper method of completing medical certificates.

Further information may be sought either

- i to enhance the description of the cause supplied with a view to the fuller utilisation of the facilities provided in the ICD, or
- ii to clarify the selection of the underlying cause of death (see para 5 below).

7.4 OPCS arrangements

The mechanism generally adopted by OPCS is to make an enquiry if, on the basis of the information available, the underlying cause of death would have to be assigned to one of a prescribed list of less specific ICD codes. Since 1986, in association with the implementation of the revised neonatal and stillbirth certificates it has also been policy to send a similar form of enquiry to certifiers, seeking confirmation that the causes previously supplied. This particular policy is currently being reviewed.

For deaths occurring outside hospital these enquiries are directed at the certifiers, but since 1986 enquiries in respect of hospital deaths have been made of the consultant in charge rather than of the junior doctor initially completing the certificate. This should provide a better standard of information than hitherto. However, a further recent instruction excludes from medical enquiry deaths where the deceased was aged 75 or over. This has the implication that OPCS may be inadvertently apparently condoning unsatisfactory practice by medical staff in some clinical specialties where high proportions of deaths certified are in the elderly.

7.5 The implications of OPCS practice

Whilst OPCS practice does to some extent address all the objectives, it is principally directed towards the provision of an enhanced description of the cause. Even so the prescribed list is about half the length of that considered desirable by the United States National Center for Health Statistics, which, unlike OPCS, also encourages enquiries directed at clarification of the

selection of the underlying cause of death.

8 Validity of cause information

Any routine data collection system is liable to inaccuracies, and in respect of death certification Alderson *et al.* (1983) identified many of the practical issues involved. This was in response to a report on the medical aspects of certification by a joint working party of the Royal College of Physicians and the Royal College of Pathologists (1982).

The several separate stages in the chain of events leading to the production of mortality statistics include -

- a) the allocation of a clinical diagnosis,
- b) the completion of a death certificate by a clinician,
- c) the transcription of this information on to the death notification,
- d) its classification and coding, and
- e) the processing, analysis and interpretation of the statistics produced.

Inaccuracies may occur at any of these stages and studies can, and have been designed the quality of each stage.

8.1 Accuracy of diagnosis

It is usual to examine the accuracy of the diagnostic information at the time of death by comparison of data derived from autopsy, as in a major study sponsored by the then General Register Office (GRO) (Heasman and Lipworth 1966). One cannot however assume the infallibility of the autopsy diagnosis nor that differences found for hospital deaths can be extrapolated to the certification of persons dying at home. Alderson (1981) reviewing the literature on this topic, pointed out that some studies indicate a worrying degree of variation between autopsy and clinical diagnoses. Other studies using this approach have been by Busuttill *et al.* (1981) and a number of interrelated ones in Scotland by Cameron and McGorogal (1981).

8.2 Certification practice

It is usual to investigate variation in certification practice by circulating 'dummy' case histories to clinicians requiring them to complete 'mock' death certificates. Reid and Rose (1964) used this technique with the collaboration of physicians from Norway, UK, and US. Similarly, in two related studies (Gau and Diehl 1982, Diehl and Gau 1982) a total of 25 fictitious case histories were circulated to samples of general practitioners and housemen in England and Wales for 'certification'. The number of different causes of death assigned varied widely, as did the proportion designated 'refer to coroner', but there was no marked regional variation in certification habits. McGoogan and Cameron (1978) obtained information from clinicians via questionnaires on their attitudes to the value of an autopsy in altering diagnoses.

Others have compared death certificates with a review of detailed case histories (see for example, Moriyama *et al* 1958; Alderson 1965; Puffer and Griffith 1967; Alderson and Meade 1967; Pole *et al* 1977; Clarke and Whitfield 1978). Edouard (1982) compared the clinical case notes with the certified cause of death for 200 stillbirths in 1973-77. Using 14 categories of cause of death, there was concordance for 69 per cent of the stillbirths; the discrepancies were most frequently omission of particulars known at the time of death.

More recently Cole (1989) has compared the causes recorded on certificates of neonatal deaths with those assigned in the Scottish neonatal survey and found general agreement in the functional, if not the precise, cause of death. A more extensive validation study of deaths due to ischaemic heart disease was carried out in Belfast by McIlwaine *et al* (1985). Relevant death certificates over a one year period were verified not only from hospital sources and post mortem, but also the coroners office, general practitioners and ambulance service records. The study found that, the number of deaths recorded as being due to this cause was numerically accurate, but that most of the inaccurate certification occurred in hospital. It was thus suggested that accuracy might improve if consultants issued death certificates in hospital, or countersigned those completed by junior doctors.

Another source, a confidential reporting system to the Communicable Disease Surveillance Centre, was used by McCormick (1988) in the assessment of the validity of mortality statistics for AIDS. That AIDS and HIV infection were noted to be considerably understated as a cause of death may, however, be due to a variety of reasons - not least the particular sensitivity of this condition.

8.3 Coding practices

The influence of coding was studied by Wingrave *et al*. (1981) using death data from the Royal College of General Practitioners (RCGP) study of oral contraception. The authors compared the coding by the RCGP with that of OPCS/GRO Scotland of 205 death certificates using B codes. There was considerable agreement for non-violent deaths, but some discrepancies occurred from using different sources of information and there were 10 codes not in accordance with ICD rules.

Because of the importance of coding and classification, the WHO Regional Office in Europe (1966) investigated coding consistency by circulating standard certificates amongst coders in different European vital statistics offices. It was suggested that there was considerable disagreement, both between coders in different countries, and between these countries, coders and the WHO Centre for Classification, in the selection and coding of the underlying cause of death. There was relatively less variation between coders working within the office in each of the participating countries.

9 Possible OPCS action

OPCS could pursue this issue in a number of ways

a Carry out, or encourage, studies designed to measure the present quality of the information.

b Get more involved in the primary education of medical students and newly qualified doctors in this topic, perhaps by the provision of a wider range of educational material more geared to present day methods.

c Revise the processes of Medical Enquiries to emphasise their educational function.

9.1 Investigatory studies

There are no current plans to conduct any major studies of this nature, for the most part because of their resource intensive nature, but it would be possible to consider whether the maximum potential has been derived from linkage possibilities with say hospital records. However, a more limited initiative is being considered in relation to the coding of one condition. OPCS has expressed an interest in participation in that part of a European study on Diabetes which will ascertain and compare national coding practices for deaths mentioning this condition. This study also includes a protocol for the investigation of certification practice in diabetes, but OPCS find it too difficult to conform with the proposed methodology.

9.2 Provision of educational material

Despite the fact that the production of mortality information by cause is part of its core responsibility, it may be considered that OPCS pays insufficient attention to safeguarding the quality of the cause of death information it receives. Should the office update and expand the educational material available perhaps to the extent that it is produced in the United States? Is the time ripe for such an initiative bearing in mind that any legislation stemming from the recent green paper on registration is likely to be associated with amendment of the medical certificate and a consequent requirement to revise the accompanying notes.

9.3 Revision of the strategy for medical enquiries

Should QPCS reorientate its strategy for medical enquiries more towards their educational value? There are several matters for consideration with respect to this. Medical enquiries involve a heavy use of clerical time so that the process is under continuous pressure if there is a need to reduce resources. Secondly any change in enquiry practice, even if it yields improved information, can easily lead to systematic changes in secular trends so that its adoption should be treated with discretion. As for timing the probable implementation of the tenth revision of the ICD in 1993 could lead to inevitable changes at that time.

10 The Medical Advisory Committee

The MAC is invited to comment on the suggestions in Para 9.