

# Creating a death register for general practice

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**SUMMARY.** *General practitioners complete approximately 26% of death certificates themselves but have considerable difficulty obtaining prompt and accurate information about their other patients who die. A random survey of district health authorities in England revealed that all were able to compile death lists but none included general practitioner details. This paper reviews the flow of information on patient deaths and describes a project to assess the feasibility of providing Newcastle general practitioners with comprehensive death registers. With the collaboration of the family health services authority and the district health authority, and with data from the regional perinatal mortality survey the creation each week of complete lists of patient deaths, broken down by general practitioner, is feasible. Death registers allow general practitioners to undertake audit of the quality of death certification and of the care of the recently deceased, and to improve the continuing care of the bereaved.*

**Keywords:** *death; registers; records management; information needs; information sources.*

## Introduction

THE registration of death became a statutory obligation in 1837 following the births and deaths registration act 1836. The original purposes were to provide legal proof of death and to produce accurate mortality statistics. Information on patient deaths remains essential for administrative purposes in the health service, social services and insurance and legal systems, and it is the keystone of much epidemiological research.

Medical audit of deaths in the hospital sector is well established.<sup>1,2</sup> Projects auditing deaths in general practice have looked at the quality of death certificates,<sup>3</sup> sought avoidable factors identifiable in records,<sup>4,5</sup> and have questioned doctors,<sup>6,7</sup> nurses<sup>8</sup> and relatives<sup>7,9</sup> about terminal care. Further audit of deaths has been advocated at the practice level, in particular the analysis of individual cases by the primary health care team.<sup>7,10,11</sup> At present, however, general practitioners are not given complete and accurate lists of patients' deaths including cause and place of death, yet this information is essential for the type of audit of mortality being advocated.

Currently, the flow of information about deaths in the United Kingdom is almost entirely one way. When someone dies, the death and its cause must be certified by a doctor, except where the circumstances dictate that the coroner must issue the certificate, for example any death which occurs outside a place of

residence or hospital, including the workplace, street or prison. The certificate is taken by the informant (usually the next of kin) to the local registrar who copies it into the register. The original certificate is sent to the Office of Population Censuses and Surveys to code the cause of death and compile mortality and vital statistics. A copy of the register entry is sent to the National Health Service central register in Southport who notify the Department of Social Security and, via a modem, notify the appropriate family health services authority to delete the patient from their list. The information is also used by the NHS central register to support a variety of research projects. A second copy of the register entry is sent to the district director of public health, and the information used to compile weekly death lists. At no point in this process is information fed back to those who had provided care during the patient's life.

Data produced by the Office of Population Censuses and Surveys are not useful to most general practitioners because they are not specific (by doctor or patient) and are based on geographical units which do not correspond with general practitioner lists. The data are published in documents that general practitioners do not routinely receive and there is at least a year's delay in their publication (McNay A, northern regional health authority, personal communication). The inaccuracy of the information is acknowledged.<sup>12</sup> Furthermore, general practitioners are not accustomed to looking at and interpreting these data.

In each district health authority, the weekly death lists compiled by the director of public health are more specific than the Office of Population Censuses and Surveys' data, in that they include the names and addresses of patients. The lists are prepared more quickly than the statistical outputs but contain variable amounts of information. For example, in Newcastle, only the general practitioner's name, where the general practitioner issued the death certificate, and the causes of death for people under 19 years old are included.

Nonetheless, general practitioners are interested in receiving information about patients who have died but for whom they did not issue the death certificate (about 74% of total).<sup>3</sup> General practitioners and primary health care teams are likely to have been involved in the patients' care, and will probably have referred them to the hospital or hospice where they died. However, in his study in Dundee, Neville found that general practitioners were not informed within a week of nearly 50% of deaths occurring in hospital, and in 15% of cases the practice received no official notification at all.<sup>13</sup> Information regarding sudden and violent deaths, usually coroners' cases, is the most difficult to obtain but may be of utmost interest to the primary health care team and the bereaved relatives. Most primary health care teams attempt to keep themselves informed through official channels, word of mouth and obituary columns in the local papers about patients that die.<sup>7,13</sup> However, complete and precise details regarding the certified cause of death can rarely be obtained in this way.

Few general practitioners maintain a death register or receive the existing death lists from the director of public health. A survey of general practices in Newcastle upon Tyne in 1989 found that 48 of the 51 practices were interested in receiving a confidential list of deaths for their practice 'which might provide a source of information for discussion and audit'.<sup>14</sup> Fifteen practices were endeavouring to maintain death registers but all faced problems as hospitals and other agencies sometimes delayed or failed to notify them of deaths.

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### Background to study

To investigate mortality information available in the UK, a telephone survey of a 15% sample of district health authorities in England was conducted. Two authorities were selected randomly from each region; both small and large authorities were represented in the sample. The researcher (AB) asked to speak to the director of public health's secretary or to the person responsible for producing the list of deaths. All 25 of the 29 authorities that responded reported that they produced regular death lists, either weekly or fortnightly. All district health authorities knew the cause of death of patients but none included all causes for all patients on the lists. None included the name of the patient's general practitioner. The main reason given for producing a list was to update the district screening registers (for child health and cervical cytology) and to inform community nursing and social services. Less than half of the district health authorities (11) sent a copy to the family health services authority and only two used it to remove patients from the general practitioners' lists, so as not to pay capitation fees unnecessarily. Despite the availability of the information, no mechanism existed in any area to ensure general practitioners were informed of the deaths of their patients.

The aim of this study was to assess the feasibility of creating death registers for general practice. A process for compiling such registers in Newcastle is described and its applicability elsewhere is considered.

### Creation of a death register

Newcastle upon Tyne has about 290 000 residents and there were approximately 3500 deaths in 1990 (Newcastle family health services authority, unpublished data). There were 158 general practitioners working in 46 practices; thus there were approximately 22 patient deaths per doctor per year. The family health services authority area is coterminous with the district health authority area.

The study commenced in 1991. To provide an accurate and up to date death register the minimum data required were patient's name and date of birth, cause of death as it appeared on the death certificate and general practitioner's name. Additional desirable information included date and place of death, occupation, and autopsy report where applicable.

The three key information items — general practitioner's name, and name and cause of death of a registered patient — did not appear together on routine sources of information. Newcastle family health services authority could list deaths by patient's name alphabetically and by date but not by general practitioner. Although it routinely produced lists of patients to be removed from general practitioners' lists, it could not separate deaths from other reasons for deletion, such as transfer to another doctor or moving out of the area.

From 1988, the three data items were collected by family health services authority staff as a special project sponsored by Newcastle family health services authority. At this time the National Health Service central register informed the family health services authority of patients' deaths approximately three to four weeks after they had occurred by supplying them with a copy of the death certificate so that they could remove the patients from the general practitioners' lists. This process was established to prevent unnecessary payment of capitation fees. The general practitioner's name was found on the family health services authority register and added to the top of the death certificate, creating the basis of a death register by general practitioner. The information collected between 1988 and 1990 was used to compile a death list for only one Newcastle general practice in order to verify the accuracy of the information and as

the basis of another part of the project assessing case analysis as a method of audit.<sup>15</sup>

In March 1991, the National Health Service central register computerized the patient registration system. Since then, removal of the names of dead patients from family health services authorities registers take place via a modem link between the National Health Service central register and the family health services authority. Therefore, a new system of creating a death register needed to be established.

Apart from the National Health Service central register and the Office of Population Censuses and Surveys, the only individuals with a statutory right to receive death notification certificates from the local registrar are the district director of public health, the community charge registration officer and the director of education, although anyone can inspect the register with the registrar's permission. As the director of public health receives a copy directly from the registrar, details usually appear on the weekly death list within two weeks of the death, except when inquests are held.

The director of public health's copy of the certificate was previously stored in the basement of a local hospital. It is now sent to the family health services authority for the name of the general practitioner and the patient's postcode to be added. This copy is then sent on to the district health authority and a further copy given to the project team based at the university. The number of deaths of Newcastle residents each week averages 65 (Denley S and Berlin A, unpublished data), so the task of matching general practitioner with patient takes a family health services authority employee less than an hour a week. In this way the family health services authority can remove patients from general practitioners' lists and the district health authority has accurately postcoded data for local research. The district health authority still produces weekly death lists to inform hospitals and community services.

Since March 1992, the project team has taken the responsibility for producing computerized death lists with all causes of death recorded for each case. All deaths registered in Newcastle of people who were registered with the family health services authority's general practitioners are entered on to a database each week. Once a fortnight half the general practices (a randomly selected stratified sample) are sent a computer printout giving details of practice patients whose deaths were registered in the preceding fortnight. The control group does not receive printouts. Occasionally, small practices receive no list as they have had no deaths in the preceding fortnight. Thus, it is now possible to close the feedback loop and generate accurate, almost complete death registers for each practice, in a standard format, updated on a regular basis.

The processing of the register works quickly. The certificate for a death which occurred on a Thursday can be registered on the Friday, copied to the family health services authority the following Wednesday then on to the university by Thursday and go out to practices in the register on the Friday. Compiling and mailing the registers takes the project secretary approximately three hours per week.

Data on stillbirths and deaths of neonates not yet registered with a general practitioner cannot automatically be assigned to the appropriate general practitioner register (the general practitioner with whom the mother was registered). Clearly, general practitioners need to know about such deaths, both to review antenatal and family care and for educational reasons. In the northern region, however, the death and the mother's general practitioner can be identified from the regional perinatal mortality survey and then entered into the appropriate general practitioner register.

Problems also arise for practices with patients living in an

adjoining family health services authority area where it will continue to be necessary to supplement information from other sources at the practice level. Although deaths of Newcastle residents registered outside of the city (less than 5% of the total, Cooper A, Newcastle family health services authority, unpublished data) are notified to the director of public health via the Office of Population Censuses and Surveys, the delay in notification may be over three months.

### Autopsy reports

To paint a more complete picture of the cause of death, details from the autopsy report would be desirable. In principle, pathologists in Newcastle will supply autopsy reports to general practitioners on request, but state that they have neither the staff nor the information systems to do so routinely. Whitty and colleagues<sup>16</sup> reported that less than a fifth of pathologists' autopsy reports are seen by general practitioners.

Similarly, the coroner's officer will supply reports on an occasional basis, but is reluctant to do so regularly without a fee. This is in spite of the recommendations of the Brodrick report on the role of coroners in certification which stated 'We consider that the deceased person's general practitioner has a moral right to know the findings of an autopsy . . . that a coroner should be obliged to supply a copy . . . and that no charge should be made'.<sup>17</sup>

### Discussion

The potential benefits of providing general practitioners and their teams with accurate, up to date information about patient deaths fall into four groups: to achieve better administration; to permit care of the bereaved in good time; to act as a stimulus to improve the accuracy of certification; and to form the basis for clinical audit and self education.

Recently deceased patients, particularly those who had suffered from chronic disorders, may have been awaiting domiciliary, outpatient or inpatient care. The early cancellation of such arrangements is necessary, not only for reasons of economy, but also to avoid the unnecessary distress caused to relatives when, for example, an ambulance calls for someone who has died.<sup>18</sup> The primary health care team is ideally placed to make arrangements to prevent this happening.

The awareness of a recent bereavement is important when providing continuing care for family members and carers. In Newcastle and Sunderland, 52% of general practitioners have a policy of offering to visit the bereaved (Wagstaff R, Berlin A, Bhopal R and Spencer J, unpublished data). Some patients may need counselling or extra support while others may need screening and advice regarding familial conditions.

If doctors were supplied with complete, accurate and prompt information about the death of their patients, this might stimulate more careful completion of death certificates. For maximum benefit, the information should include deaths which occur outside the health district, those of the newborn not yet registered with a general practitioner, the stillborn and those who are referred to the coroner.

It is difficult to assert with confidence that in future the coroner will routinely provide reports to Newcastle general practitioners, without exacting a fee. As the recommendations of Brodrick<sup>17</sup> and the report on autopsy and audit,<sup>19</sup> calling for autopsy reports to be sent to the clinicians, have gone unheeded it is proposed that specific funding be identified for the family health services authority to purchase such reports on behalf of general practitioners.

Primary health care teams are being encouraged to undertake audit of deaths.<sup>5,10</sup> Death is a potentially useful outcome measure for, although health care may have a relatively small effect on the length of life, there is evidence that it can deeply

influence the quality of life, the quality of death,<sup>9</sup> and for the bereaved, their quality of life after a patient's death.<sup>20</sup> Furthermore, as both the family health services authority and district health authority have an increasing interest in improving the quality of health care through medical audit, their collaboration in creating death registers may help them achieve this common goal.

This project has shown that it is possible to set up a system which keeps general practitioners informed of the deaths of their patients. In a few places problems may arise because districts coincide with more than one family health services authority or registration district, or deaths occur in hospitals in adjacent districts. With collaboration, specific local solutions may be possible and all parties stand to gain. Whether simply providing teams with an accurate register of deaths is sufficient to produce better care, without further support or education, is being evaluated.

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