5 2 a

OFFICE FOR NATIONAL STATISTICS

Census, Population and Health Group
Direct line: GRO-C
Fax:
e-mail: michel.coleman@ GRO-C

Ms Ceinwen Lloyd
Registration Division
Southport

MOR/7

12 July 1996

Dear Ceinwen,

Death certification and referral to the coroner

Further to my recent note enclosing the new guidance sent to doctors, I now attach the draft amendment to the registrars' handbook, revised after earlier discussions with (as I recall) Gwyn Hughes and Bill Jenkins. I would be most grateful if you will call me to suggest any changes you think are still necessary to the paragraph.

I have discussed implementation with John Fox. We feel it will be invaluable for the amendment to the registrars' guidance to receive the imprimatur of Tim Holt as Registrar General, in the form of a covering letter signed by him. The Exeter coroner has not renounced his views, and has asked to see our legal advice. Medical staff in the area tell me that at least some of the registrars are "in his pocket". It would be frustrating if the steps we have taken to prevent this coroner's bizarre behaviour - by publicly rejecting the arguments he has used to compel doctors to refer AIDS deaths to him - were to be outflanked by one or more registrars choosing not to reflect the spirit of the guidance. The consequences of any such action are predictable: doctors will continue to omit AIDS as a cause of death on the certificate, further undermining the quality and relevance of AIDS mortality statistics; bereaved relatives will continue to be humiliated at inquest, undermining the ONS goal to run a sensitive registration service; and the government will remain at risk both of further adverse publicity about its handling of AIDS and of a challenge it cannot win in the European Court of Human Rights.

All this as background to the attached draft letter to registrars, to come from Tim Holt. I would be very happy to discuss it with you. I have in mind that if we can agree its content, you would ask Isobel to put it to Tim Holt for his signature.

Will you please telephone me at your earliest convenience so we can discuss these points? Many thanks for your help. I attach a copy the press notice that will be issued on Monday 15 July.

Yours sincerely,

GRO-C

Professor Michel P Coleman
Deputy Chief Medical Statistician

cc: John Fox, Karen Dunnell

Dear <registrar>

DRAFT LETTER

Death certification and referral to the coroner

Doctors have been issued with new guidance on certification of death and referral to the coroner. A copy is attached. Since the national mortality statistics ~~for which I am responsible~~ depend critically on what doctors write on the certificate, I hope that the new guidance will lead to improvement in the quality of death certification.

I also hope that the quality and consistency of referral of relevant deaths to the coroner will improve. The legal basis of referral to the coroner by the doctor and the registrar is outlined in the new guidance, as are the categories of death that should be referred. It is essential for the coherence of national mortality statistics that the practice of referral to the coroner - whether by doctors or registrars - should be as uniform as possible.

~~My~~ legal advice on Regulation 41(1)(d) of the 1987 Regulations makes it clear that "... if the registrar reasonably believes that the death was not unnatural, [s/]he has no obligation to report [to the coroner]". ~~Equally,~~ Of course, registrars ~~have no power~~ should not to question informants about the sexual practices of the deceased, ~~and informants have no obligation to answer such questions.~~

~~In this context, I ask you~~ You should particularly ~~to~~ note the remarks addressed to doctors on deaths from AIDS or in HIV-positive individuals. These are echoed in the attached ~~new paragraph to be inserted in your Registrars'~~ a amendment to the Births and Deaths Handbook. A death for which the medical certificate of cause of death mentions AIDS or HIV-positivity should normally be considered as a death from natural causes, and unless there are other, separate, grounds for referral to the coroner, such deaths should not be referred to the coroner.

Yours sincerely,

~~Tim Holt~~ Isobel Macdonald Davies
~~Registrar~~ General Deputy Registrar General

OFFICE FOR NATIONAL STATISTICS

National Health Service Central Register
(England and Wales)

Direct Dial
Fax
GTN
GRO-C

FACSIMILE TRANSMISSION

TO: Paul Aylin

ADDRESS: St. Cats

No. of pages transmitted (incuding this cover sheet) 2

FROM: Ceinwen Lloyd

TIME: 4.45 DATE: 16/7/96

QUERIES - TEL: 0151 471 Ext:
FAX: 0151 471 Ext:
GRO-C

If you do not receive all the pages please call back as soon as possible.

Attached is the letter to registrars with suggested amendments as discussed. Circulars to registrars are regularly signed by the dep RG and anything else would look odd to registrars - Isobel wishes to sign.

OFFICE FOR NATIONAL STATISTICS

News Release

ONS (96) 96
15 July 1996

New guidance for doctors on death certification and referrals to the coroner

New guidance on how to certify a death has been issued to doctors in England and Wales today by the Office for National Statistics (ONS).

The legal basis for the referral of certain deaths to a coroner - an independent judicial officer of the Crown - is explained. The coroner's duty is to investigate the circumstances of certain categories of death for the protection of the public. Examples are violent or unnatural deaths - such as accident, poisoning, suicide - sudden death from an unknown cause, or a death in prison or police custody.

The guidance lists the categories of death that need to be referred to the coroner by registrars of births and deaths but makes clear there is no statutory obligation under current legislation for a doctor to refer any death to the coroner. However, in practice, doctors voluntarily report 60 per cent of all deaths considered by a coroner. Other sources, mainly the police, also refer deaths. If a doctor has not referred a relevant death to the coroner the registrar has a statutory duty to do so.

There has been doubt about whether a death from AIDS should be reported to the coroner. Legal advice confirms that a death from AIDS should normally be considered as a death from natural causes. Therefore AIDS deaths should not usually be referred to the coroner, unless there are other separate grounds for doing so.

Prepared by the Government Statistical Service

Issued by
Office for National Statistics
Great George Street
London SW1P 3AQ

Telephone
Press Office 0171-270 5450
Public Inquiries 0171-396 2828

Contact
Professor Michel Coleman
Deputy Chief Medical Statistician
GRO-C

NATIONAL STATISTICS

Prompt and precise certification of death is essential. If the doctor's death certificate is vague or incomplete the registrar must refer the case to the coroner which causes delay in registration and distress to the relatives.

A copy of the guidance letter is attached.

BACKGROUND NOTES

1. Similar guidance is also being given to registrars of births and deaths.

2. Doctors are responsible for certifying three-quarters of the 580,000 deaths each year in England and Wales. The rest are certified by coroners.

3. Death certificates provide the raw data from which national mortality statistics are compiled. These are used by Government - for monitoring progress towards 'Health of the Nation' targets - by the NHS and by public health researchers.

4. ONS has statutory responsibility for registration of births and deaths and the production of mortality statistics, among a wide range of other statistics and has recently piloted a new model of the death certificate with the aim of introducing an improved certificate within two years. A training video - 'Death Counts' - has also recently been released to help newly-qualified doctors and general practitioners complete the death certificate more efficiently.

OFFICE FOR NATIONAL STATISTICS

Census, Population and Health Group
1 July 1996

Dear Doctor,

Death certification and referral to the coroner

There has been some confusion about who should refer a death to the coroner and under what circumstances, particularly for death from AIDS or in persons who are HIV-positive[1-3]. There is also recent evidence of continuing difficulty in medical certification of the cause of death[4,5].

This letter is intended to help resolve both difficulties. It updates guidance from 1990[6] on death certification and the referral of deaths to the coroner in England and Wales. Registrars of births and deaths will receive equivalent guidance.

I am sending this letter to all NHS and private hospital consultants, to all senior partners in group practices, and to all single-handed general practitioners. I would be most grateful if you would kindly make the letter available to all your colleagues and junior staff, as the case may be.

Death certification

Prompt and accurate certification of death is essential. It provides legal evidence of the fact and the cause(s) of death, thus enabling the death to be formally registered: the family can then make arrangements for disposal of the body. Death certification also provides the raw data from which all mortality statistics are derived. These are vital for public health surveillance, for resource allocation in the NHS, and for a wide range of research - and thus ultimately for improving the health of the population.

About three-quarters of the 580,000 deaths in England and Wales each year are certified by a doctor, and the remainder by a coroner[7].

The role of the doctor

If you are the attending doctor during the last illness of a person who dies, you have a statutory duty[8] to issue a medical certificate of the cause of death (death certificate). Conversely, if you did not attend the deceased during his or her last illness, you *must not* complete the death certificate.

You must state the cause(s) of death on the certificate to the best of your knowledge and belief. You have a duty to deliver the death certificate to the registrar of births and deaths: in practice, the certificate is often given to a relative of the deceased, then handed to the registrar by the relative (or other informant) who visits the register office to have the death registered.

The role of the registrar of births and deaths

The registrar has a statutory duty[9] to transcribe the cause(s) of death from the death certificate to the official register, nowadays usually a computer database, and to send this information to the Office for National Statistics (previously the Office of Population Censuses and Surveys). It is then coded automatically[10] and incorporated into national mortality statistics. The registrar must also obtain other information from the person who comes to register the death, such as the occupation and place of birth of the deceased. Finally, the registrar has a legal obligation to refer certain deaths to the coroner (see below).

The role of the coroner

The coroner is an independent judicial officer of the Crown who has a statutory duty[11] to investigate the circumstances of certain categories of death for the protection of the public. Thus: *"Where a coroner is informed that the body of a person ('the deceased') is lying within his district and there is reasonable cause to suspect that the deceased (a) has died a violent or an unnatural death; (b) has died a sudden death of which the cause is unknown; (c) has died in prison or in*

St Catherine's House, 10 Kingsway, London, WC2B 6JP
Switchboard (0171) 396 2200

such a place or in such circumstances as to require an inquest under any other Act, then ... the coroner shall as soon as practicable hold an inquest into the death of the deceased ...".

In fact, the coroner only holds an inquest for some 12% of the deaths he certifies. Coroners often use their discretion[12] to decide that a post-mortem alone provides sufficient evidence of the cause of a sudden death: diseases of the circulatory system account for three-quarters of these deaths[13]. Deaths from accident, poisoning, violence or in prison or police custody are subject to inquest. When the coroner does hold an inquest, he will issue a verdict on the manner of death (e.g. accident, suicide) as well as certifying the cause(s) of death.

Referral to the coroner

Of the 180,000 or so deaths reported to a coroner each year, 60% are voluntarily referred by a doctor, 2% by a registrar, and the remaining 38% from other sources, mainly the police[7].

Legal aspects

As the law currently stands, there is no statutory obligation for a doctor to report any death to a coroner. The common law duty[14] that requires any person to inform the coroner of circumstances requiring an inquest cannot be enforced by legal sanction. Nevertheless, we encourage you to report all relevant deaths to the coroner. This letter is intended to help you decide whether any given death is reportable.

Referral by the registrar of births and deaths

First, it may help you to know that the registrar is legally obliged[15] to refer a death to the coroner (unless it has already been reported) if it falls, *or appears from the doctor's death certificate to fall*, into one of the following categories:

- the deceased was not attended during his or her last illness by a doctor;
- the registrar has been unable to obtain a duly completed death certificate, or else it appears that the deceased was not seen by the certifying doctor either after death or during the 14 days before death;
- the cause of death appears to be unknown;
- the registrar has reason to believe the death was unnatural, or caused by violence or neglect, or by abortion, or was in any way suspicious;
- the death appears to have occurred during an operation or before recovery from the effect of an anaesthetic;
- the death certificate suggests that death was due to industrial disease or industrial poisoning.

Referral by the doctor

We would like to encourage the prevailing practice of voluntary referral to a coroner by the certifying doctor. If you judge that the coroner will need to be involved (see box), you can reduce delay in registration of the death by prompt referral. This will also give you an opportunity to explain to the relatives in person the reasons for referral. If you are in doubt about whether to refer a death, contact the relevant coroner's office for advice. When referring a death to the coroner, you should still complete a death certificate unless the coroner advises you not to do so, and indicate on the certificate that you have referred the death.

You should complete the death certificate as accurately as possible. This will reduce the need for referral to the coroner by the registrar, and it will greatly improve the quality of mortality statistics. In particular, you should:

- *avoid* the use of abbreviations, question marks and vague terms such as 'probably';
- *avoid* giving 'old age' or 'senility' as a cause of death: do so *only* if you cannot give a more specific cause of death *and* the deceased was aged 70 or over;
- *avoid* giving a mode of dying such as 'heart failure', 'shock' or 'uraemia', especially as the *only* cause on the death certificate (modes of dying are listed in each book of certificates). These terms do not identify a cause of death.

Registrars will refer a death certified in such terms to the coroner. This will delay registration of the death and may well cause distress to the relatives.

AIDS-related death

There has been recent publicity[16] about one coroner's view that *"death from AIDS, as a direct consequence of anal intercourse, is - on the balance of probability - 'unnatural', according to the current values of our society, and is proper to put to a jury"*. The phrase 'unnatural death' is not defined by statute, but it has been the subject of a recent ruling by the Court of Appeal[17]. We have received legal advice, based in part on this ruling, that a death from AIDS should normally be viewed as a death from natural causes. **Therefore, unless there are other grounds for referral to the coroner, a death from AIDS or in an HIV-positive individual *should not* normally be referred to the coroner.**

Training video and pocket guidelines

The Office for National Statistics has recently issued *Death Counts*, a video designed to assist hospital doctors and general practitioners in completing the death certificate. The pack includes pocket guidelines on death certification and referral to the coroner, and test cases that are suitable for individual study or group teaching.

Improving the death certificate

A modified death certificate, designed to simplify completion of the cause of death, was piloted in five large hospitals and five general practices in late 1995. We hope to introduce an improved death certificate within the next two years.

Yours sincerely,

GRO-C

Professor Michel P Coleman
Deputy Chief Medical Statistician

Copy for information to:
Chief Medical Officers
Department of Health and NHS Executive
Directors of Public Health in NHS Regions
Directors of Public Health in NHS Health Authorities
NHS Trusts and private providers in England and Wales
University Departments of Public Health and of Pathology
Royal Colleges and Faculties; General Medical Council
Coroners' Society; Association of Police Surgeons

A death should be referred to the coroner if:

- the cause of death is unknown
- the deceased was not seen by the certifying doctor either after death or within the 14 days before death
- the death was violent or unnatural or suspicious
- the death may be due to an accident (whenever it occurred)
- the death may be due to self-neglect or neglect by others
- the death may be due to an industrial disease or related to the deceased's employment
- the death may be due to an abortion
- the death occurred during an operation or before recovery from the effects of an anaesthetic
- the death may be a suicide
- the death occurred during or shortly after detention in police or prison custody

References

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2068

D J Morgan Esq
Superintendent Registrar
The Register Office
Civic Centre
Newcastle upon Tyne
NE1 8PS

G 896/86B

DJM

14 November 1986

Dear Mr Morgan

ACQUIRED IMMUNE DEFICIENCY SYNDROME

Thank you for your letter of 5 November with which you enclosed the letter sent to you by Mr P A Cuff, H M Coroner for the Newcastle upon Tyne district concerning his request to be notified of certain deaths where AIDS is shown on the medical certificate of cause of death.

I would confirm that where it is apparent to a registrar of births and deaths from the information contained in the medical certificate of cause of death, information given by the informant or from information contained in the local press that the deceased had contracted AIDS from contaminated blood or blood products given to them as part of medical treatment, or from drug taking, the death should be reported to the Coroner as he has specifically requested.

Where AIDS is shown as the sole cause of death this is acceptable and should not be reported unless the above conditions apply. The informant should not be questioned about how the AIDS was contracted unless they volunteer information which suggests that the case falls into the category requested by the Coroner.

If, at a later date, the Coroner requests that AIDS cases, other than those mentioned above, be reported to him please notify me immediately.

Would you please ensure that each registrar is made aware of the contents of this letter.

Yours sincerely

GRO-C

City of Newcastle upon Tyne

D.J. Morgan, Superintendent Registrar.

The Register Office
Civic Centre
Newcastle upon Tyne NE1 8PS
Telephone Tyneside (091) 232 8520
Ext. GRO-C

Our Ref. DJM

Your Ref. M & G

5th November, 1986.

Dear Sir,

Further to my telephone conversation this morning, with Mr. Farrance, I enclose the letter from the Coroner.

The registrars have been advised that they should not question the informant as to how the disease was contracted, but they are concerned that as a result unnatural deaths may not be reported.

Your instructions in this matter would be much appreciated.

Yours faithfully,

GRO-C

Superintendent Registrar.

The Registrar General,
General Register Office,
St. Catherine's House,
10 Kingsway,
LONDON
WC2B 6BR.

GRO -C

PATRICK A.C. CUFF, LL.B.
Her Majesty's Coroner
Newcastle upon Tyne District
Tel. (0632) 612952
612845

Your Ref. DJM

Our Ref. PACC/PY

CITY OF
NEWCASTLE UPON TYNE

Coroner's Court,
Bolbec Hall,
Westgate Road,
Newcastle upon Tyne
NE1 1SE

30th October, 1986

D.J. Morgan, Esq.,
Superintendent Registrar,
The Register Office,
Civic Centre,
NEWCASTLE UPON TYNE NE1 8PS

Dear Sir,

Thank you for your letter of the 28th October. I have not, in fact, required all deaths resulting from Acquired Immune Deficiency Syndrome to be reported. I would, however, request that any such be reported where there is some evidence that that condition came about unnaturally, i.e. either through blood transfusion or drug taking. I have no doubt that such cases would be reported in any case by your Registrars.

Yours faithfully,

GRO-C

Patrick A.C. Cuff
H.M. CORONER.

To: All doctors
Dr Fox
MS Dunnell
Mr Jenkins GRO-
Dr Swinson (DH)

From: Anna McCormick

Date: 30 March 1995

Re: AIDS/HIV on death certificates.

Over the years I have been asked regularly whether doctors have to state AIDS or HIV on the death certificate or some other cause and initial Box B on the back.

My reply to the latest enquiry, agreed with Bill Jenkins, is attached. On the telephone Mr Burgess asked for some guidance about whether all or any AIDS/HIV deaths should be reported to the coroner. Bill tells me that
(a) there is no legistation requiring doctors to report deaths to the coroner, and
(b) registrars have to date been told by OPCS that they are not required to report any AIDS or HIV deaths to the coroner, as the death is not considered to be unnatural, although the circumstances may be. The conditions under which registrars should report to the coroner are covered by Regulations.

It appears that some coroners have reached agreement with local registrars for deaths to be reported to them under certain conditions which are not covered by the regulations, so there is no standard procedure throughout the country.

Action:

I am circulating this note so that we may respond in a uniform and agreed manner should we be asked for guidence. I should be glad to discuss it further.

GRO-C

GRO-C

GRO-C

GRO-C

OPCS

Direct Dial GRO-C
Switchboard 071 396 2200
or 071 242 0262
GTN GRO-C
Fax

Mr M.J.C.Burgess.
Secretary,
Coroners' Society of England & Wales,
44 Ormond Avenue,
Hampton,
Middx TW12 2RX

30 March 1995

Dear Mr Burgess,

The Registrar General thanks you for your letter dated 20 February 1995 and has asked me to reply. I apologise for the delay.

As you are aware, the Births and Deaths Registration Act 1953, section 22, states that 'In the case of death of any person who has been attended during his last illness by a registered medical practitioner, that practitioner shall sign a certificate in the prescribed form stating to the best of his knowledge and belief the cause of death....'

From this it appears that the doctor is legally required to state AIDS or HIV in part I of the certificate if he believes this to be the cause or one of the causes of death, or if contributing to the death but not relating to the cause of it, in part II.

If the doctor anticipates that he may later have additional information as to the cause of death for the purpose of more precise statistical classification, he can initial Box B on the reverse of the certificate. This facility is intended for use, for example, when blood tests or histology results are awaited and there is no reason to delay disposal of the body by witholding a certificate. The public record is not altered as a result of this additional information, but it is used to update the record at OPCS. Some doctors do use this process to inform OPCS of a death due to AIDS or HIV where this is not stated as the cause on the death certificate. I am doubtful whether reminding doctors that they have an obligation to state AIDS or HIV as a cause when appropiate would induce them to change their ways. In fact it may lead some to cease initialling Box B, with the result that much valuable statistical information would be lost to OPCS.

As far as reporting a death to the coroner is concerned, again, this office can only quote the Coroners Act 1988. This states that 'where a coronor is informed that the body of a person is lying within his district and there is reasonable cause to suspect that the deceased-

(a) has died a violent or unnatural death;

(b) has died a sudden death of which the cause is unknown; or

(c) has died in prison ...

then ... the coroner shall as soon as practicable hold an inquest into the death ...'

I would suggest that the interpretation of definitions of terms used in the text of the Act are a matter for coroners and/or the Home Office.

I hope that this is helpful.

Yours sincerely,

Dr Anna McCormick MB,ChB, FFPHM

DM

16a

2068.

Hazel Smith
HIV/AIDS Prevention Co-ordinator
East Surrey Health Authority
District Headquarters
The East Surrey Hospital
Three Arch Road
REDHILL
Surrey
RH1 5RH

MG 90/3460B

4 October 1990

Dear Ms Smith

Your letter of 10 September to Susan Wilcox, Registrar of Births and Deaths at Redhill Hospital, has been passed to this Office.

May I first explain that S22(1) of the Births and Deaths Registration Act 1953 requires that a doctor who is in attendance on the deceased during his last illness should certify the cause of death to the best of his knowledge and belief. This certificate has to be on the prescribed form which requires doctors to include any underlying causes of death and any other significant conditions leading to death. However where a doctor believes he may be able to provide further information subsequent to certification, eg where the result of histological or microbiological tests become available later, he initials a box on his certificate indicating this to be the case. A follow up enquiry is issued and any further information that is returned subsequently is treated in confidence by OPCS and used for statistical purposes. This confidential procedure would be appropriate in suspected AIDS cases provided that at the time of certification there is some reason for doubt as to whether AIDS played a part in causing the death but it should <u>not</u> be used to evade full and proper certification. Indeed doctors who deliberately conceal information relating to a cause of death (including underlying causes), which it is evident to them at the time of certification should appear on the prescribed certificate, are acting unlawfully.

You also raise the question of registrars providing a certified extract from the death register entry which does not show the cause of death. In fact the Government has recently published the White Paper 'Registration: proposals for change' (Cm 939) in which it announced that provision will be made for the introduction of a short form of death certificate omitting the cause of death recorded in the death register. This measure will require legislation which the Government hopes to introduce when a suitable opportunity occurs.

I hope that the above comments prove helpful for your forthcoming meeting.

Yours sincerely

[redacted]

1 STA

Dear Jill

We spoke about this on the phone.

May I leave this in your capable hands.

Best wishes

GRO-C

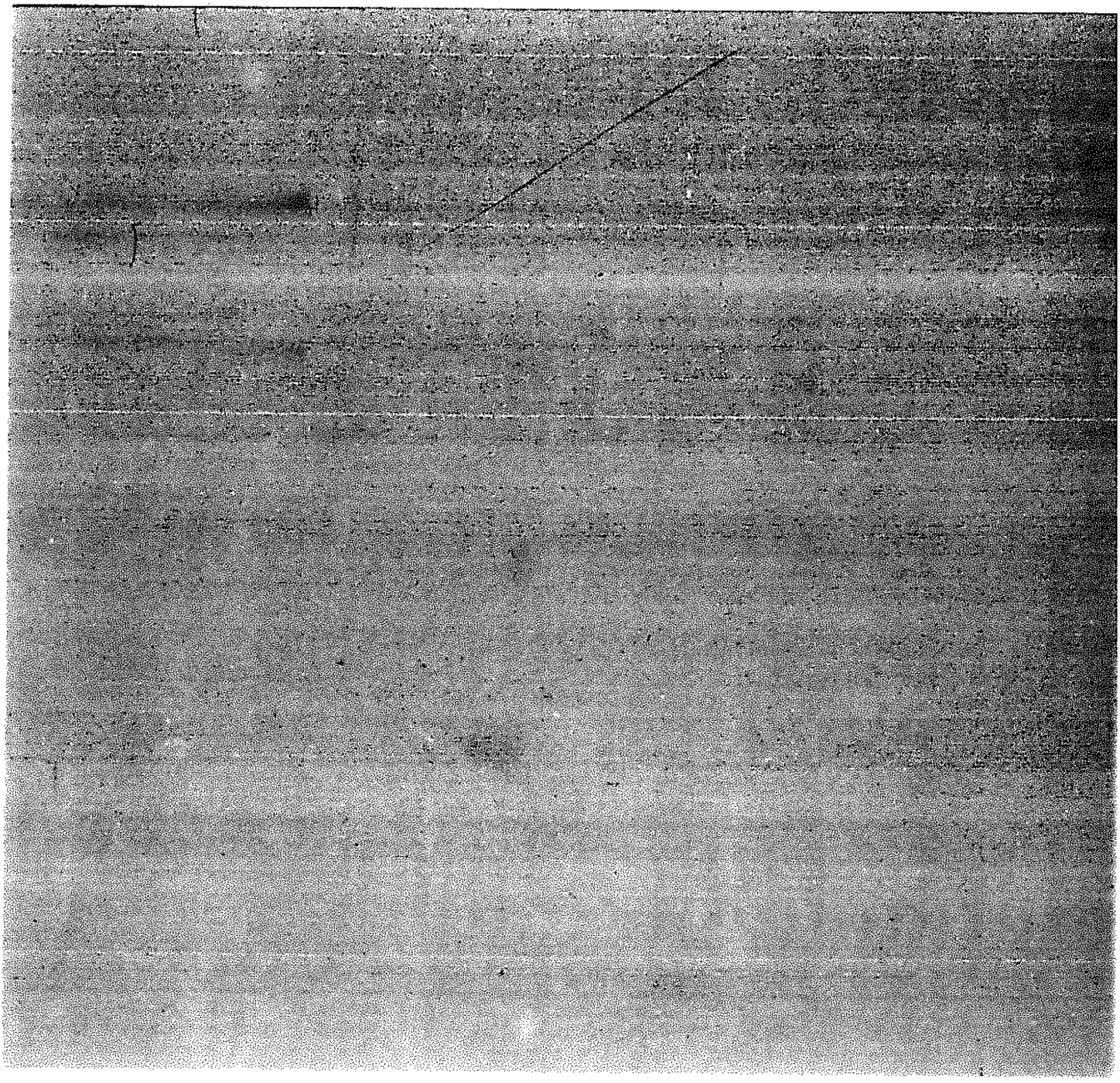
SURREY COUNTY COUNCIL

South Eastern Registration District
(Births, Deaths and Marriages)
Redhill Sub District
Redhill Hospital
Earlswood Common
Redhill
RH1 6LA

Miss S. M. Wilcox
Registrar of Births, Deaths & Marriages

Redhill 765030

with compliments



NHRO366

EAST SURREY HEALTH AUTHORITY

1 SP

Your ref.:

Our ref.:

Please reply to:

DISTRICT HEADQUARTERS
The East Surrey Hospital
Three Arch Road
Redhill, Surrey RH1 5RH

Tel.: 0737 768511 Ext: GRO-C
Fax.: 0737 772446

General Manager: D. B. LEGGETT AHSM

10.9.90.

Susan Wilcox
Registrar of Births & Deaths
Redhill Hospital
Redhill RH1 6LA

Dear Ms. Wilcox,

"AIDS" on Death Certificates"

At the last meeting of the E.S.H.A. AIDS Action Group, we discussed the problems of entering "acquired immunodeficiency syndrome" (AIDS) or "human immunodeficiency virus (HIV) infection" as the cause of death on a death certificate.The issue is basically the need to avoid breaching confidentiality after the patient's death and thereby causing distress to the family, conflicting with the need to provide the statistics for epidemiological surveillance at the C.D.S.C.

After consultation with the Terrence Higgins Trust and C.D.S.C. directly, it appears that there is a way around this problem. The certifying doctor states the cause of death as the opportunistic infection or cancer, etc (e.g.pneumonia or malignant melanoma); the underlying cause of death (part B) is left blank, and the box on the rear of the certificate, to say that further information will be forthcoming, is ticked and initialled. The Registrar then sends the doctor form SD17a, which can be completed with the medical information on AIDS/HIV. This form is then forwarded by the doctor directly to O.P.C.S., and from there to the C.D.S.C., without the medical details being entered into the public record.

An alternative approach would be for the Registrar to provide a certified and valid confirmation of the patient's death that does not show the cause of death, and that will satisfy the requirements of the DHSS, Bank Managers,etc. Would it be possible for you to enquire from colleagues in London how they have dealt with this problem.

If your own enquiries show that this second approach is impossible, then we should be prepared to advise the use of form SD17a by clinicians in order to avoid the under-reporting of AIDS deaths that will inevitably occur as a result of a doctor's primary obligations to his patient. We should then need to be prepared to circulate the forms to

doctors as needed.

I would appreciate your comments on the above, if possible before the AIDS Action Group meets again on 11th October. Many thanks.

Yours sincerely

GRO-C

Hazel Smith
HIV/AIDS PREVENTION CO-ORDINATOR

Mr A B Barton
AIDS Unit
Department of Health and Social Security
Richmond House
79 Whitehall
London
SW1A 2NS

8 August 1989

Thank you for your letter of 31 July. Terry Banks is currently away from the Office and I am replying in her absence.

A number of responses to the Green Paper proposals mention the problem you raise of embarrassment and distress being caused to families of bereaved persons by unnecessary disclosure of sensitive information. Indeed this has been a problem for a number of years in cases where, for example, a person has committed suicide or died of alcoholism or drug abuse. We recognise that the problems have become more acute with the increasing number of sufferers from HIV infection and AIDS. The other side of the coin, of course, is that information surrounding deaths has long been held to be of public interest with inquests being held in public and the cause of death being entered in the death register since civil registration began in 1837. I think there would be considerable disquiet if it were decided that this should no longer be the case.

A solution that we have considered in the past, and recently resurrected, is the provision of an abbreviated death certificate for issue to the public. Such a certificate would give details of the deceased person and the date and place of death but would not show the cause of death recorded in the death register; the registers themselves are not open to public browsing and this will remain so for recent records under the proposed legislation. To this end we have previously consulted interested organisations such as insurance associations, Probate and the National Savings Department to try to discover the extent to which the public would be able to use an abbreviated certificate and whether it would serve most of the purposes for which a death certificate is required. The insurance companies particularly have indicated that the usefulness of an abbreviated death certificate would be limited but nevertheless we have now taken the view that a short certificate would suffice for virtually all administrative purposes. We think such a certificate would generally be

welcomed by the families of the deceased and it might encourage better certification of death in those difficult cases where doctors are anxious to supply full information but also wish to avoid causing distress.

I have seen today that PS(H) has agreed the introduction of a short death certificate and we hope to take the opportunity to include this proposal with the other legislative changes towards registration reform.

J V RIBBINS

cc: Registrar General
Mr Ellis
Dr Fox
Miss McCall
Divisional Float

DRAFT REPLY FROM MR RIBBINS TO ALAN BARTON

Thank you for your letter of 31 July. Terry Banks is currently away from the Office and I am replying in her absence.

A number of responses to the Green Paper proposals mention the problem you raise of embarrassment and distress being caused to families of bereaved persons by unnecessary disclosure of sensitive information. Indeed this has been a problem for a number of years in cases where, for example, a person has committed suicide or died of alcoholism or drug abuse. We recognise that the problems ~~has~~ have become more acute with the increasing number of sufferers from HIV infection and AIDS. ~~But we need always to bear in mind that the cause of a death has, since the inception of civil registration, been a matter of public record. Similarly inquests are held in public. Therefore we must take particular care that there is no suggestion that the Government is seeking to conceal this kind of information from the public.~~

The other side of the coin of course is that information surrounding deaths has long been held to be of public interest with inquests being held in public as cause of death being entered into a register since civil registration began in 1837. This formed the considerable disquiet if it were decided that this should no longer be the case.

A solution that we have considered in the past and recently reconsidered is the provision ~~as an option~~ for issue to the public of an abbreviated ~~form of~~ death certificate. ~~Such a certificate~~ would give details of the deceased person and the date and place of death but would not show the cause of the death recorded in the death register; To this end we have ~~in the past~~ consulted interested organisations such as insurance associations, Probate and the National Savings Department to try to discover the extent to which the public would be able to use an abbreviated

The registers themselves are not open to public browsing and this would remain so for recent records under the proposed legislation

certificate and whether it would serve most of the purposes for which a death certificate is required. The ~~result of these enquiries~~ Insurance Companies particularly have indicated that the usefulness of an abbreviated death certificate would be limited ~~in certain circumstances, as insurance companies, for example, would wish to see the full details.~~ but we have now taken the views that a short certificate would suffice for virtually all administrative purposes. We think such a certificate would generally ~~Notwithstanding this response, our current view is that a short certificate could serve a number of useful purposes, and would~~ be welcomed by the families of the deceased. ~~Additionally~~ Both it might encourage better certification of death in those difficult cases where doctors are anxious to supply full information but also wish to avoid causing distress.

A submission on the introduction of a short death certificate is now with the Minister and we ~~We therefore~~ hope to take the opportunity to include this proposal with ~~our~~ the other legislative changes towards registration reform.

GRO-C

J S Morris

7 August 1989

DRAFT REPLY FROM MR RIBBINS TO ALAN BARTON

Thank you for your letter of 31 July. Terry Banks is currently away from the Office and I am replying in her absence.

A number of responses to the Green Paper proposals mention the problem you raise of embarrassment and distress being caused to families of bereaved persons by unnecessary disclosure of sensitive information. Indeed this has been a problem for a number of years in case where, for example, a person has committed suicide or died of alcoholism or drug abuse. We recognise that the problems has become more acute with the increasing number of sufferers from HIV infection and AIDS.

A solution that we have considered is the provision of an abbreviated form of death certificate. Such a certificate would give details of the deceased person and the date and place of death but would not show the cause of the death recorded in the death register. To this end we have in the past consulted interested organisations such as insurance associations, Probate and the National Savings Department to try to discover the extent to which the public would be able to use an abbreviated certificate and whether it would serve most of the purposes for which a death certificate is required. The result of these enquiries indicated that the usefulness of an abbreviated death certificate would be limited in certain circumstances; as insurance companies, for example, would wish to see the full details.

Notwithstanding this response, our current view is that a short certificate could serve a number of useful purposes, and would be welcomed by the families of the deceased. Additionally it might encourage better certification of death in those difficult cases where doctors are anxious to supply full information but also wish to avoid causing distress.

We therefore hope to take the opportunity to include this proposal with our other legislative changes towards registration reform.

J S Morris

4 August 1989

DEPARTMENT OF HEALTH AND SOCIAL SECURITY
RICHMOND HOUSE
79 WHITEHALL
LONDON SW1A 2NS

TELEPHONE 01 210 3000
210

03 AUG 1989

Mr Anson Dr Pollock
Mr Ribbins ✓ cc Dr Fox

To reply in RG's absence please, copy to Private Office

GRO-C

3.8.89.

Your reference:
Our reference:
GTB GRO-C

RECEIVED
- 3 AUG 1989
O.P.C.S.
PRIVATE OFFICE

Mrs G T Banks
Registrar General
OPCS
St Catherine's House
10 Kingsway
London WC2B 6JP

31 July 1989

Dear Terry

I have only recently become aware of the OPCS Green Paper on Registration which was published in December 1988. I should like to offer some comments on it in the hope that it is not too late to do so.

I have been dealing with the Department of Health's response to HIV infection and AIDS since late 1986. I have been struck by how badly our concerns about the confidentiality of people with HIV infection and AIDS when they are alive seem to match up with the arrangements which apply for certifying their death. Having gone to great lengths to protect confidentiality in life, the medical reasons for death are then supposed to be recorded on what is virtually a public document, which has to be sent round to all sorts of people such as the deceased's bank, employers, insurers etc, and of which copies can readily be obtained for payment of a small fee.

It does seem to me that this is an anachronism at the end of the 20th Century. I acknowledge the importance for epidemiological purposes of centrally recording causes of death, but wonder if the time has not arrived when very much more discretion should be looked for in making personal medical information about a deceased person so readily available. As it is, we know that many doctors do not reveal on the death certificate that a person has died of AIDS, so that much of the potential epidemiological value of the death certification system is not in fact achieved.

I realise that these may seem radical comments, but it seems to me that the unsatisfactory nature of the death certification system, as it applies to people with HIV/AIDS (and no doubt some other conditions) does call for consideration of radical changes.

Yours sincerely

GRO-C

A B BARTON
Assistant Secretary
AIDS Unit

REGISTRY
RECEIVED
4 AUG 1989
M. & C.