

## British HIV Association

### National Clinical Audit:

#### Deaths among adults with HIV infection Management of cardiovascular risk

To take part in the 2005-6 national audit, please complete and return the attached forms to arrive by **Friday 6 January 2006**. Please keep the patient summary sheets together with the main form. The forms should be returned to the following address:

British HIV Association (Audit)  
Mediscript Ltd  
1 Mountview Court  
310 Friern Barnet Lane  
London N20 0LD

In some areas there is an option to submit data for local/regional audit as well as inclusion in the national audit. If you are a member of a local/regional audit group, then release of your data to that group is on an opt-out basis.

#### **The forms are machine readable. Please follow these instructions carefully.**

- Please send your completed form by post. Because of problems with electronic reading, we are sorry we cannot accept faxed copies or photocopies.
- Please use black ink.
- Please only write in the spaces provided on the form.
- Please mark the box corresponding to your chosen answer with a tick:
  
- If you make a MISTAKE and wish to change your answer, completely fill in the box corresponding to the **WRONG** answer:
- If a question does not apply or you do not wish to answer it, please just leave it blank - do **NOT** cross it out.

This form is designed for confidential data processing, such that no one outside the BHIVA secretariat can link information which identifies participating centres to the audit data they have submitted. For further information, please see the confidentiality protocol at [www.bhiva-clinical-audit.org.uk](http://www.bhiva-clinical-audit.org.uk).

Please also COMPLETE and RETAIN the enclosed check-sheet to keep a record of which patients you have included in the audit. This may help you to interpret the audit results.

If you have any queries about how to complete the audit forms, please contact the BHIVA audit coordinator, Hilary Curtis, 020 7624 2148 (home) 07984 239556 (mobile), [hilary@regordane.net](mailto:hilary@regordane.net).

Thank you for your participation.

BHIVA acknowledges the contribution of the Department of Health towards the funding of the BHIVA National Clinical Audit programme.

**Section A: Identifying information**

Please complete this page either by hand or by using clinic address sticker or stamp.

Office use only	Centre code:
BHIVA secretariat: Retain this page, send other pages and Patient Summary Sheets to data entry bureau.	<b>600006</b>

Question:

- A1 Name of lead clinician for this audit: .....
- A2 Job title: .....
- A3 Department/unit: .....
- A4 Hospital or trust: .....
- A5 Address: .....
- .....
- A6 Town/city: .....
- A7 Postcode: .....
- A8 Telephone: ..... Fax: ..... Email: .....
- A9 Local primary care trust, health authority or board: .....
- A10 Does your department/unit offer adult HIV care?
  - Yes, we offer such care
  - No, we do not offer adult HIV care

If you answered YES to question A10, then please continue to complete the questionnaire. If NO, we apologise for taking up your time and will remove your unit from our list.

**Regardless of your answer, PLEASE RETURN THE QUESTIONNAIRE.**

- A11  Please tick this box if you are NOT willing for your centre to appear on a published list of centres taking part in this audit.
- A12  Please tick this box if you are NOT willing for your data to be released to your regional audit group for local analysis, identified by your centre code only.

Signature: .....

Office use only:
B <input type="checkbox"/> E <input type="checkbox"/> PF <input type="checkbox"/> <input type="checkbox"/>

Please give details of consultants whose patients have been included in audit data submitted with this form, and other clinical staff who have contributed significantly to the conduct of the audit (continue overleaf if necessary).

This is to enable BHIVA to provide individual certificates of audit participation.

1. Name: .....

Job title: .....

Address if different from that given on page 2:

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2. Name: .....

Job title: .....

Address if different from that given on page 2:

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3. Name: .....

Job title: .....

Address if different from that given on page 2:

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4. Name: .....

Job title: .....

Address if different from that given on page 2:

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Please use this page for additional details of participants, if necessary. Please do NOT use it for additional responses to any other questions.

5. Name: .....

Job title: .....

Address if different from that given on page 2:  
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6. Name: .....

Job title: .....

Address if different from that given on page 2:  
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\_\_\_\_\_

7. Name: .....

Job title: .....

Address if different from that given on page 2:  
.....  
\_\_\_\_\_

8. Name: .....

Job title: .....

Address if different from that given on page 2:  
.....  
\_\_\_\_\_

**Section B: Profile of participating centre**

Question:

- B1 Is the centre located:  
 In NHS London region     Outside NHS London region     Don't know
- B2 How many patients are currently receiving care for HIV at your centre?  
 1-50     51-100     101-200     201-500     501+     Don't know
- B3 How has the number of patients receiving HIV care at your centre changed over the past year?  
 Down/same     Up 0-5%     Up 5-10%     Up 10-15%     Up >15%
- B4 Please enter the actual number of HIV patients who have attended your centre for care at least once in the past six months. This is optional but enables us to estimate the proportion of the UK HIV population covered by the audit:
- |  |  |  |  |
|--|--|--|--|
|  |  |  |  |
|--|--|--|--|
- B5 Which of the following descriptions best fits the HIV care provided by your centre?  
 Out-patient HIV care only     Out and in-patient care for own patients  
 In-patient care for patients from other centres as well as own patients     Unclear

**Section C: Review of deaths in adult patients with HIV**

Question:

Please answer the following questions as they relate to your centre's current practice in relation to patients aged over 15 with HIV infection.

- C1 How many deaths among adults with HIV infection have there been at your centre during the past year? NB: Include all the following:  
 Patients known to have HIV who died at your centre.  
 Patients who died in the community after having been seen with HIV at your centre.  
 Patients whose HIV was diagnosed at your centre after death.  
 None     1     2-4     5-9     10-19     20 or more
- C2 Please comment on your information sources about deaths among people with HIV:  
 How do you find out when HIV patients under your care die in the community (tick all that apply)?  
 Grapevine/word of mouth     Routine follow up of non-attending patients  
 Community HIV team     Formal network meetings     Other

How do you find out about deaths among HIV patients whom you have referred to tertiary or specialist services (including non-HIV services such as oncology)?

- C3 What is your centre's policy on internal review of deaths among adult patients receiving HIV care?
- Formally review all such deaths       Review deaths in specific circumstances  
 Review deaths if clinicians have concerns       No clear policy       Not sure
- C4 Who is usually involved in reviews of HIV deaths?
- Hospital/community multidisciplinary team       Hospital multidisciplinary team  
 Medical team only       Other
- C5 How are reviews of HIV deaths done (tick all that apply)?
- A health professional reads the case notes       The case is discussed at a meeting  
 Varies       Not sure
- C6 What issues are usually considered in reviews of HIV deaths (tick all that apply)?
- Clinical care at your centre       Clinical care provided elsewhere, if relevant  
 Social circumstances       Pattern of attendance  
 Others, please describe: .....
- C7 How would you describe the usefulness of reviews of HIV deaths so far at your centre?
- Very valuable, have led to significant changes in policy or practice  
 Valuable, have led to modest changes in policy or practice  
 Useful for education only       Not useful       Not sure
- If you selected "Very valuable" or "valuable", please describe changes in practice that have followed death reviews:
- .....
- .....
- C8 What is your practice regarding certification of deaths attributable to HIV disease?
- Always write HIV or retroviral infection on the certificate (as direct or underlying cause)  
 Do not always write HIV on certificate, but if not doing so tick box to offer further information  
 Never write HIV on certificate, always tick box to offer further information  
 Sometimes neither tick box nor write on certificate  
 Not sure  
 Not applicable - have not certified deaths
- C9 Are deaths of HIV patients at your centre routinely reported to the Health Protection Agency Communicable Disease Surveillance Centre?
- Yes       No       Not sure       Not applicable - no deaths

**Section D: Management of lipid abnormalities**

Question:

Please answer the following questions as they relate to your centre's current practice in relation to patients with HIV and possible cardiovascular risk factors.

D1 What guidelines do you follow when managing cardiovascular risk in HIV patients (tick all that apply)?

- British HIV Association       National Cholesterol Education Programme  
 Joint British Societies (as in BNF)       Framingham risk assessment  
 National Service Framework for Coronary Heart Disease       Other- please specify:

D2 What level of access do you have to the following services?

	Good access	Limited access	No access	Not sure
Exercise classes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dietician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Smoking cessation service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lipid specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

D3 When deciding about the need for intervention in an HIV patient with raised lipids, which of the following factors do you feel is most important (please tick ONE)?

- Overall risk of a cardiovascular event       Absence of other modifiable risk factors  
 Absolute total cholesterol or other lipid profile measurement       Not sure

D4 Which of the following form part of your baseline assessment when seeing a newly diagnosed HIV positive patient?

	Routine for all patients	Selected patient groups	Not routinely done	Not sure
Smoking history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alcohol history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Recreational drug history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Blood pressure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Total cholesterol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Triglycerides	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HDL cholesterol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LDL cholesterol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Random glucose	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Waist circumference	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Urinalysis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Referral to dietician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

D5 Which of the following form part of your routine assessment before starting a patient on antiretroviral therapy (ART)?

	Routine for all patients	Selected patient groups	Not routinely done	Not sure
Smoking history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alcohol history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Recreational drug history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Blood pressure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Total cholesterol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Triglycerides	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HDL cholesterol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LDL cholesterol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Random glucose	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Waist circumference	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Urinalysis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Referral to dietician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

D6 When starting patients on ART, to what extent is your choice of drugs affected by the individual patient's cardiovascular risk profile?

- Major relevance - often influences choice of regimen  
 Some relevance – occasionally influences choice of regimen  
 Little relevance – rarely influences choice of regimen  
 Not relevant – usually prescribe low cardiovascular risk regimen irrespective of individual patient factors

D7 How frequently do you measure the following in patients on ART?

	3 monthly	6 monthly	at least yearly	varies	do not routinely monitor	not sure
Blood pressure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Total cholesterol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Random triglyceride	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fasting triglyceride	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HDL cholesterol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Random glucose	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Waist circumference	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

D8 Assuming you have already addressed modifiable risk factors and antiretroviral switching, at what level of fasting triglyceride would you start drug therapy (in mmol/l)?

- 2-4       4-6       6-8       8-12       >12  
 No fixed threshold, depends on overall cardiovascular risk  
 Refer to lipid/cardiovascular risk clinic       Not sure



D9 Assuming you have already addressed modifiable risk factors and antiretroviral switching, at what level of fasting total cholesterol would you start drug therapy (in mmol/l)?

- >4.0       >5.0       >6.0       >7.0       >8.0  
 No fixed threshold, base therapy on other lipid profile measurements (eg TC:HDL ratio)  
 No fixed threshold, depends on overall cardiovascular risk  
 Refer to lipid/cardiovascular risk clinic       Not sure

The following two questions, D10 and D11, are optional, and designed to gauge opinion. They have no right or wrong answers. Please complete them to help us gain a picture of clinicians' views on management of cardiovascular risk.

An extended version of these optional questions is also available for completion online, to enable more clinicians to respond and as part of BHIVA's testing of an internet-based questionnaire system for possible future use. Please visit <http://www.bhiva-clinical-audit.org.uk> for more information on how to take part.

D10 Consider a 50 year old African male newly presented with HIV infection, with BMI 33 kg/m<sup>2</sup>; family history of hypertension and diabetes; long term heavy smoker; CD4 count 150; TC 8.0 mmol/l; TG 2.7 mmol/l; HDL 1.25 mol/l; fasting glucose 6.5 mmol/l.

What would be your preferred regimen for starting ART in this patient (tick all drugs in initial combination)?

- Abacavir       Atazanavir       Efavirenz       Emtricitabine or lamivudine  
 Fosamprenavir       Lopinavir/r       Nevirapine       Ritonavir (low dose)  
 Saquinavir       Tenofovir       Zidovudine       Other       Not sure

D11 Consider a patient with a TC of 8.5 mol/l and triglyceride of 6.0 mol/l where you have already addressed modifiable risk factors and where there are no concerns about CD4, VL, toxicity, intolerance or inconvenience.

What would be your first choice of management for the above patient in each of the following scenarios:

D11a Female white patient aged 30 with negative family history of cardiovascular disease, on tenofovir/lamivudine/efavirenz:

- Do nothing       Change ART regimen       Treat with statin  
 Treat with fibrate       Treat with nicotinic acid (niacin)       Treat with ezetimibe  
 Treat with omega-3 fatty acids (maxepa/omacor)       Refer to lipid specialist clinic

D11b Male Asian patient aged 50 with NIDDM and a positive family history of cardiovascular disease, on tenofovir/lamivudine/efavirenz:

- Do nothing       Change ART regimen       Treat with statin  
 Treat with fibrate       Treat with nicotinic acid (niacin)       Treat with ezetimibe  
 Treat with omega-3 fatty acids (maxepa/omacor)       Refer to lipid specialist clinic

Question D11 continued..

- D11c Female white patient aged 30 with negative family history of cardiovascular disease, on tenofovir/lamivudine/lopinavir/r:  
 Do nothing       Change ART regimen       Treat with statin  
 Treat with fibrate       Treat with nicotinic acid (niacin)       Treat with ezetimibe  
 Treat with omega-3 fatty acids (maxepa/omacor)       Refer to lipid specialist clinic
- D11d Male Asian patient aged 50 with NIDDM and a positive family history of cardiovascular disease, on tenofovir/lamivudine/lopinavir/r:  
 Do nothing       Change ART regimen       Treat with statin  
 Treat with fibrate       Treat with nicotinic acid (niacin)       Treat with ezetimibe  
 Treat with omega-3 fatty acids (maxepa/omacor)       Refer to lipid specialist clinic
- D12 Are you contemplating a review of any aspect of your clinical practice as a result of completing this section of the questionnaire?  
 Yes       No       Not sure

**Section E: evaluation of audit**

Please complete all other sections before coming back to complete this section

Question:

- E1 In your opinion, is this questionnaire:  
 Too detailed or difficult to complete       About right  
 Too simple or superficial to give a fair picture       Don't know
- E2 Please estimate how much time it has taken to complete sections A, B, C and D of this questionnaire:  
 .....
- E3 Please comment on how easy or difficult it was to retrieve the information from patient records to complete the case note review sections of this questionnaire, and if possible estimate the time involved:  
 .....  
 .....
- E4 Which questions were most difficult to answer (give question number(s)), and why?  
 .....
- E5 Please enter any other comments about this audit project including suggestions for improvements for future audits  
 .....  
 .....

**Instructions for reviewing patient case notes**

**Review of deaths among adults with HIV**

Please complete one of the attached patient summary sheets for each of your patients aged 15 or over with HIV who died between 1 October 2004 and 30 September 2005, up to a maximum of 25. Include the following patients:

Patients who died at your centre/hospital

Patients who died in the community (including hospice) who had attended your centre and were NOT under the care of any other centre

Patients who died abroad after having been under your care up to the time of leaving the UK

Patients whose HIV was diagnosed at your centre after death

Note: if yours is an out-patient service and you do not have access to the data needed to complete these patient summary sheets, then please liaise with your designated in-patient HIV doctor to do so.

F1 Please enter the number of patients reviewed here:

--	--

**Please remember to complete section E after you have reviewed patient records.**



**Case note review: Deaths among adults with HIV****Patient summary sheet**Patient code for scanning: **600019**

Include adult HIV patients who DIED between 1 October 2004 and 30 September 2005, in accordance with the inclusion criteria on the main questionnaire (page 11). Please do NOT complete until you have read these criteria. If in doubt, contact Hilary Curtis, 020 7624 2148 hilary@regordane.net.

## Question

- P1 Please state the patient's sex and ethnic group:  Male  Female  
 White  Black-African  Black-Caribbean  Other  Not known (NK)
- P2 What was the patient's age at death?  <30 years  30-50 years  > 50 years  NK
- P3 Where did death occur?  In UK hospital  In community in UK  Outside UK  NK
- P4 Please give the month and year of the patient's death: 

m	m

y	y	y	y
2	0	0	
- P5 What was the patient's last CD4 cell count in cells/ $\mu$ l during the six months before death?  
 0-50  51-100  101-200  201-350  >350  
 Measured, but result not available  Not measured  Not known whether measured
- P6 What was the patient's last HIV viral load in copies/ml during the six months before death?  
 0-50  51-400  401-1000  1001-10,000  10,001-100,000  >100,000  
 Measured, but result not available  Not measured  Not known whether measured
- P7 Did the patient inject non-prescribed drugs?  Yes, up to onset of final illness  
 Previously, but stopped prior to final illness  No known history of injecting  NK
- P8 What was the immediate cause of death, ie the condition directly leading to death (tick ONE)?  
 Tuberculosis  Pneumocystis pneumonia  Bacterial sepsis anywhere  
 Other opportunistic infection  Lymphoma  Kaposi's sarcoma  Other malignancy  
 Cardiovascular disease  Chronic liver disease due to alcohol and/or viral hepatitis  
 Renal failure  HIV dementia  Other disease probably related to HIV  
 Multi-organ end stage HIV disease excluding above single categories  
 Other disease NOT related to HIV  Overdose of drugs of misuse  Accident/injury  
 Suicide or self-harm  NK
- P9 Was this immediate cause of death attributable to an adverse effect of therapy?  
 Definitely  Probably  Possibly  No, not attributable  NK
- P10 What other conditions were present and may have contributed to the death (tick all that apply)?  
 Tuberculosis  Pneumocystis pneumonia  Bacterial sepsis anywhere  
 Other opportunistic infection  Lymphoma  Kaposi's sarcoma  Other malignancy  
 Cardiovascular disease  Chronic liver disease due to alcohol and/or viral hepatitis  
 Renal failure  HIV dementia  Other disease probably related to HIV  
 Multi-organ end stage HIV disease excluding above single categories  
 Other disease NOT related to HIV  No other conditions  NK

P11 Which of the following scenarios best accounts for the death of this patient (tick ONE)?

- Patient with multiple drug resistant HIV had run out of treatment options
- Patient being successfully treated for HIV suffered a catastrophic event (eg adverse reaction)
- Patient was under care for HIV but had an untreatable HIV-related complication
- Patient was under care for HIV but had chosen not to receive treatment
- Patient was under care for HIV but treatment was ineffective due to poor adherence
- Patient was under care for HIV but was unable to take treatment because of toxicity/intolerance
- Patient who was not treated or had treatment delayed because of ineligibility for NHS care
- Patient known to have HIV but not under regular care, re-presented too late to treat effectively
- Patient not diagnosed with HIV until too late for effective treatment
- Patient died in the community without seeking care
- Patient whose death was not directly related to HIV
- None of the above
- NK

P12 When did the patient arrive in the UK in relation to the time of death?

- <3 months before death
- 3-6 months before death
- >6 months or UK resident
- NK

P13 When was the patient diagnosed with HIV infection in relation to his or her death?

- After death
- Within last week of life
- A week to a month before death
- 1-3 months before death
- More than 3 months before death
- NK

P14 Please describe the circumstances of this patient's death briefly in narrative terms:

.....

.....

.....

P15 Was a post-mortem performed:  Yes, please summarise results if available:  No  NK

.....

If yes, was the post-mortem:  Coronial  Consented  NK

If no, did relatives refuse consent?  Yes  No  NK

If no, was suitable pathology resource unavailable locally?  Yes  No  NK

P16 How was death certified?

- HIV written on certificate
- Further information box ticked
- Both
- Neither
- NK

P17 Was this death formally reviewed at your centre?  Yes  No  Review is planned  NK

If "yes", please summarise any conclusions or lessons learned from the review

.....

P18  Please put a tick in this box if you wish to comment further about this patient, and then do so below (NB COMMENTS MAY NOT BE READ UNLESS BOX IS TICKED).

.....

.....

600019