### **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:  $\overline{\mathbf{A}}$
- 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-clinicalaudit.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.

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

Question:

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.

600006

A1	Name of lead clinician for this audit:
A2	Job title:
А3	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 E PF

# Clinicians collaborating in the audit

Centre code:

600006

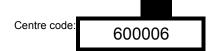
Please give details of consultants whose patients have been included in audit data submitted with this form, and other clinical staff who have contributed significantly to the conduct of the audit (continue overleaf if necessary).

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:
2.	Name:
	Job title:
	Address if different from that given on page 2:
3.	Name:
	Job title:
	Address if different from that given on page 2:
4.	Name:
	Job title:
	Address if different from that given on page 2:

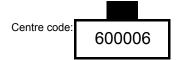
	Please use this page for additional details of participants, if necessary. Please do NOT use it for additional responses to any other questions.
5.	Name:
	Job title:
	Address if different from that given on page 2:
6.	Name:
	Job title:
	Address if different from that given on page 2:
7.	Name:
	Job title:
	Address if different from that given on page 2:
8.	Name:
	Job title:
	Address if different from that given on page 2:
	Page 4 Centre code: 600006

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# 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
В3	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 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  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:

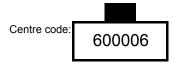
Please answer the following questions as they relate to your centre's current practice in relation to patients with HIV and possible cardiovascular risk factors. D1 What guidelines do you follow when managing cardiovascular risk in HIV patients (tick all that apply)? ☐ British HIV Association ☐ National 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 Limited Not sure access access No access Exercise classes Dietician Smoking cessation service Lipid specialist Diabetes specialist 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 Selected patient Not routinely patients groups done Not sure Smoking history Alcohol history Recreational drug history Family history Blood pressure Total cholesterol Triglycerides HDL cholesterol LDL cholesterol Random glucose Waist circumference Urinalysis Referral to dietician

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

	Smoking history Alcohol history Recreational drug history	patients	Selected patien groups	it N	done	Not sure
	Family history Blood pressure Total cholesterol					
	Triglycerides HDL cholesterol LDL cholesterol					
	Random glucose Waist circumference Urinalysis Referral to dietician					
D6	When starting patients on a individual patient's cardioval Major relevance - offer Some relevance - occurring Little relevance - rare Not relevant - usually patient factors	ascular risk profile en influences choid casionally influend ely influences choi	? ce of regimen ces choice of regin ce of regimen	nen		
D7	How frequently do you mea	asure the following		RT?	do not	
	Blood pressure Total cholesterol Random triglyceride	3 monthly 6	at least monthly yearly	varies	routinely monitor	not sure
	Fasting triglyceride HDL cholesterol Random glucose Waist circumference					
D8	Assuming you have alread what level of fasting triglycomes 2-4 4-6 No fixed threshold, de Refer to lipid/cardiova	eride would you st  6-8 epends on overall	art drug therapy (i	n mmol/l)? □ >12 k		hing, at



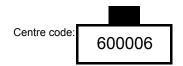
D9	Assuming you have already addressed modifiable risk factors and antiretroviral switching, at what level of fasting total cholesterol would you start drug therapy (in mmol/l)?
	□ >4.0 □ >5.0 □ >6.0 □ >7.0 □ >8.0
	No fixed threshold, base therapy on other lipid profile measurements (eg TC:HDL ratio)
	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/m2; 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:
	tenofovir/lamivudine/efavirenz:  Do nothing  Change ART regimen  Treat with statin
	tenofovir/lamivudine/efavirenz:  Do nothing Change ART regimen Treat with statin Treat with fibrate Treat with nicotinic acid (niacin) Treat with ezetimibe
	tenofovir/lamivudine/efavirenz:  Do nothing  Change ART regimen  Treat with statin
D11b	tenofovir/lamivudine/efavirenz:  Do nothing Change ART regimen Treat with statin Treat with fibrate Treat with nicotinic acid (niacin) Treat with ezetimibe
	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  Male Asian patient aged 50 with NIDDM and a positive family history of cardiovascular disease, on tenofovir/lamivudine/efavirenz:
	tenofovir/lamivudine/efavirenz:  Do nothing Change ART regimen Treat with statin Treat with fibrate Treat with nicotinic acid (niacin) Treat with ezetimibe Refer to lipid specialist clinic  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
	tenofovir/lamivudine/efavirenz:  Do nothing Change ART regimen Treat with statin Treat with fibrate Treat with nicotinic acid (niacin) Treat with ezetimibe Refer to lipid specialist clinic  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
	tenofovir/lamivudine/efavirenz:  Do nothing Change ART regimen Treat with statin Treat with fibrate Treat with nicotinic acid (niacin) Treat with ezetimibe Refer to lipid specialist clinic  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



600006

Question D11 continued..

	☐ 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 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 ☐ 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?
L4	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.	
	Page 11	

Page 12: this page is blank

# Case note review: Deaths among adults with HIV Patient summary sheet

Question

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.

P1	Please state the patient's sex and ethnic group:
	White Black-African Black-Caribbean Other Not known (NK)
P2	What was the patient's age at death?
P3	Where did death occur?
P4	Please give the month and year of the patient's death:    M M M
P5	What was the patient's last CD4 cell count in cells/µl during the six months before death?
P6	What was the patient's last HIV viral load in copies/ml during the six months before death?  0-50
P7	Did the patient inject non-prescribed drugs?  Yes, up to onset of 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 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
	Patient 0 1 Page P1 PI FASE DO NOT PHOTOCOPY THIS SHEET

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?
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?
	If no, was suitable pathology resource unavailable locally?
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).
	600040
	600019