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AFAO and NAPWA Submission

Submission to Human Rights and Equal Opportunity Commission Review of *Guidelines for providers of insurance and superannuation under the Disability Discrimination Act*

December 2003

About us

The Australian Federation of AIDS Organisations (AFAO) represents Australian HIV community based organisations at a national level. Our membership includes State and Territory AIDS Councils, the Australian Injecting and Illicit Drug Users League, the National Association of People Living with HIV/AIDS (NAPWA) and Scarlet Alliance, the national organisation representing sex workers. Amongst AFAO's activities is the provision of HIV policy advice to the Commonwealth government, advocating for our member organisations, developing and formulating policy on HIV/AIDS issues, and promotion of medical and social research into HIV/AIDS and its effects.

NAPWA is the peak national organisation representing state and territory organisations of people living with HIV in Australia, and conducts policy, advocacy and national health promotion programs on behalf of its members.

Significance of the Guidelines

Guidelines for insurance and superannuation providers can play an important role in educating both industry and consumers about the existence of obligations and rights under the DDA. We support the further development of the Guidelines to promote the achievement of the objects of the DDA in eliminating discrimination and promoting community acceptance of people with disabilities.

In the 1980s a range of drastic measures limiting the potential for exposure to HIV claims were taken by the insurance and superannuation industries. Insurers were clearly seeking to minimise the cost burden of an epidemic that was forecast to be of a far greater scale than ever eventuated in Australia.

Due to dramatic improvements in treatments for HIV/AIDS, HIV is now a chronic manageable illness and should not be treated differently by the industry from other chronic illnesses. However the experience of many people with HIV, and people considered to belong to a risk group for HIV (particularly gay men), is that HIV continues to be treated by the industry as a special case and that insurance is difficult to obtain on non-discriminatory terms, if at all. HREOC's Guidelines have an important role to play in ensuring that industry practice is informed by up to date information, particularly about the impact of treatments on life expectancy, and that differential treatment of HIV risks are justified by accurate and up to date data rather than generalisations and outdated assumptions.

The existence of Guidelines is significant in that they supplement the complaints process as a means for ensuring compliance with the law. It is particularly difficult for people with HIV to pursue individual complaints, due to concerns regarding confidentiality and the stress and costs associated with adversarial complaints processes against powerful and well resourced corporate respondents. It is therefore vital that other means of drawing DDA obligations to the attention of insurance providers are pursued by HREOC, such as through promotion of compliance with Guidelines and industry standards.

From the consumer perspective, there is too often an incorrect assumption made that insurance is completely exempt from the DDA. This leads to a situation where people with disabilities such as HIV are deterred from seeking insurance at all, as they perceive that they are unlikely to be eligible. Hence discrimination occurs by default, and consequently the disadvantage that people with HIV experience in their professional and personal lives is perpetuated. Development and promotion of Guidelines and Standards can address this by playing a positive educative role.

We understand that it is not possible under the current provisions of the DDA for legally binding Disability Standards to be developed for insurance and superannuation. Nonetheless, progress towards voluntary standards to supplement the Guidelines and which address industry practice in far more detail than the current HREOC Guidelines would be highly desirable. HREOC could play an important role in supporting consumers and industry to engage in development of voluntary standards. We note that the Productivity Commission Draft Report on *Review of the DDA* (Oct.2003, p 260) recommends that the Act be amended to allow for Disability Standards in insurance and superannuation. AFAO and NAPWA support this recommendation, with the caveat that amendments would also be required so that insurance and superannuation Standards are legally enforceable.

Scope of the Guidelines

We recommend that the Guidelines be extended to all forms of insurance, and in particular travel insurance, income protection insurance and mortgage insurance. Most travel and mortgage insurance products still have broad HIV/AIDS exclusions the continued justification of which is highly questionable.

Mortgage insurance exemptions are justified by insurers on the basis of alleged historical evidence of anti-selection. There is a danger that the industry will continue to discriminate in provision of mortgage insurance as a result of the decision in *Xiros*

v Fortis Life Insurance (2001) FMCA 15, in which the Federal Court found that there was evidence of anti-selection which provided a reasonable basis for exclusions in policies offered up until 1996. It would be particularly useful for the Guidelines to emphasise that the decision in *Xiros* should not be relied on by insurance providers to justify exclusions in mortgage insurance offered after 1996.

In respect of travel insurance, the Guidelines should stress the importance of not imposing blanket restrictions, and require insurers to assess people with HIV based on their current situation and how well HIV is being managed, rather than broad assumptions about HIV being a terminal condition. If an applicant for travel insurance has a pre-existing medical condition such as HIV, policies often withdraw certain medical and emergency benefits (whether or not related to treatment for HIV), or worse still, impose blanket restrictions. The practice of imposing blanket exclusions is applied particularly to those living with HIV, even if HIV is well managed. This is unreasonable, and the Guidelines should address the practice.

The case of *Bassanelli* (2003) FMCA 412 demonstrates the unreasonableness of excluding a person with cancer from all travel policy items (such as theft etc) rather than issuing a policy excluding only medical events. The HREOC Guidelines should highlight to industry the significance of the decision in *Bassanelli* to insurers' obligations to provide travel insurance to people with illnesses on reasonable terms.

Insurance and superannuation exemption

- Reliance on actuarial or statistical data and medical information

It would be useful to provide more detail for insurers on sources of up to date information to inform their decision making. For example, in the HIV field, the Australasian Society for HIV Medicine (the national professional association for HIV clinicians) and the National Centre on HIV Epidemiology and Clinical Research at the University of NSW could be listed as a contact points for insurers seeking to establish the impact on morbidity and mortality of treatment advances.

The findings from recent research in Switzerland published in the *Lancet* is an example of international data that the Guidelines might point to as an example of an overseas study that should inform Australian underwriting practices (C Jaggy et al Mortality in the Swiss HIV Cohort Study *Lancet* Vol 362, Sept 13 2003:p 877). The Swiss study measured mortality rates from 1997 to 2001 and found that people with HIV on treatments have a short term mortality as low or lower than people with cancer who have been successfully treated – a group that, unlike people with HIV, is able to obtain life insurance.

A report commissioned by the Commonwealth in 1993 *HIV/AIDS, Superannuation and Insurance* (Trowbridge Consulting 1993) examined the issue of whether there was any evidence of anti-selection by people with HIV in applications for group superannuation, in the form of claims arising from HIV soon after commencement of cover. The study found that the proportion of HIV related claims did not establish the existence of any more anti-selection than occurs in respect of claims due to other causes, and that the general use of exclusion clauses specifically for HIV/AIDS was not justified by evidence. It may be useful to refer to these findings in the Guidelines

so as to underline the importance of industry having robust and recent evidence of anti-selection if it is to be relied on as the basis of exclusions.

It is of concern to us that the one of the major superannuation providers in the Australian health and community sector, HESTA, excludes from automatic eligibility for insurance cover relating to HIV, any applicants who are employed by organisations with an affirmative action employment policy in relation to people with HIV. It would be useful if the Guidelines pointed to the importance of recent evidence of anti-selection in order to maintain such an exclusion, and that a practice of this sort may be considered unreasonable to the extent that it undermines the achievement of the objects of the DDA in terms of promoting equality and social inclusion.

- Reliance on other factors

It would be useful for further guidance to be provided on social factors relevant to the s46 defence, to emphasise that there are factors beyond those impacting on commercial risk taking which are relevant to an assessment of the reasonableness of discrimination. As indicated in *Xiros v Fortis Life Insurance*, the reasonableness defence requires taking into account all of the circumstances of the case: “the criterion is an objective one which requires the Court to weigh the nature and extent of the discriminatory effect on the one hand against the reasons advanced in favour of the requirement on the other” (relying on the High Court in *Waters*).

It would be useful for the Guidelines to provide examples of discriminatory effects that may be relevant, in terms of the negative impacts on people living with HIV of denial of insurance, for example associated with loss of income and difficulties accessing housing.

In the area of mortgage insurance, industry has sought to rely on maintaining exclusion clauses by alleging a history of anti-selection by consumers. The Guidelines should emphasise the unlikelihood that people with an illness would purchase a home simply for the purpose of obtaining insurance cover as a factor relevant to consideration of whether such an exclusion is “reasonable”.

Role of the Commission

We recommend that the Commission play a more proactive role in promoting compliance with the Guidelines. Where consumer groups consider that industry practice is falling short of the Guidelines, or that industry practices are undermining achievement of the objects of the DDA, HREOC should convene a process to explore and resolve concerns including development of Codes of Practice or industry Standards.

We thought it useful to draw attention to developments in Europe regarding agreements between industry and consumer bodies as examples of how insurance issues facing a range of disability and illness groups are being advanced in Europe. The annexures to this submission demonstrate progress in developing detailed standards in France and the UK. Although we do not fully endorse the detail of these standards, the development of these standards is important insofar as they indicate the acceptance by the industry in those countries of the need to engage constructively

with consumers and update their practices in the light of changes in the epidemic. We recommend that HREOC play a role in brokering similar processes in Australia, and that the Guidelines be drafted to support such processes.

In the HIV field, a Code of Practice on HIV/AIDS Underwriting was adopted by the industry in the 1980s but has not been updated subsequently despite dramatic changes in the epidemic since that time. Although it is possible for HIV organisations to negotiate directly with industry regarding development of standards, and indeed a dialogue between AFAO and the industry regarding key concerns has occurred intermittently over the last decade, it would be beneficial in terms of the power imbalance between industry and consumer organisations for HREOC to play a role in facilitating a more formal process.

Thank you for the opportunity to provide this submission.



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Annexure 1 French agreement between Insurers and Consumers

The Belorgey Agreement, signed in September 2001 by representatives of public authorities, insurers, bankers and a dozen patients' associations, makes access to credit loan insurance easier for people who are disadvantaged by their state of health. In France, credit loan insurance is often a prerequisite for obtaining a loan.

In 1991, the state and insurance federations signed an agreement on the insurability of HIV-positive people and on the confidentiality of medical data processed by insurance companies. This system offered HIV carriers death insurance for housing loans, later extended to loans for business premises and equipment. The maximum amount of cover was 150,000 euros for a term of 5-10 years. The agreement was the only one of its kind in the world and emphasised the importance of insurance in everyday life in France. The solutions it provided, and the use of an insurance pool mechanism to cover a complex risk that was little known at the time, are still highly innovative today.

Early in 1999, the government decided to review the issue and launched a fresh round of debate, based on the 1991 agreement, taking into account changes in the position of HIV-positive patients. Initiated by the Conseil National du Sida (National Aids Council), the task was entrusted to a committee headed by Councillor of State Jean-Michel Belorgey. Patient aid associations were included on the committee, which looked into the insurability of substandard risks within the framework of credit insurance.

The Belorgey Committee examined the current state of epidemiological and medical knowledge of HIV, rating methods, the collecting and processing of medical data and ways of ensuring confidentiality. The committee's initial findings suggested various measures concerning confidentiality, initial information provided by loan applicants, alternatives to insurance, simpler formalities for granting consumer loans.

With the insurers' consent, the committee suggested eliminating the health questionnaire for insurance of consumer loans not exceeding €10,000, with a term shorter than 4 years and for people under 45.

Furthermore, for insurance of housing or business loans not exceeding 200,000 euros, for a maximum term of 12 years and taken out before the age of 60, the committee recommended the following system:

If an application is refused at the "first level", made up of existing group credit loan insurance contracts, it will be examined at a second level. This "second level" is made up of "open group" credit loan contracts in the event of death. These contracts must be introduced by all lending institutions. If the application is refused or deferred at the second level, it will be forwarded to the "very substandard risks" pool, which is a co-reinsurance pool administered by the BCAC (Bureau Communes Assurances Collectives).

www.scor.fr/us/pdf/regards/Regards1_gb.pdf
The Insurability of Substandard Risks in France
SCOR Jan 2002 n° 1 January 2002

Association of British Insurers
Consultation Paper

Draft Statement of Best Practice
on
HIV and Insurance

September 2003

www.abi.org.uk

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1. Introduction

What is the purpose of this Statement?

- 1.1 HIV is an issue of major concern to public policymakers, the insurance industry and the general public. The Department of Health's 2001 Annual Report on the Prevalence of HIV and hepatitis infections in the UK draws attention to the continued high rate of HIV transmission among gay and bisexual men. It also highlights the increased impact of the global situation on heterosexuals in the UK.
- 1.2 Insurers' actions, and perceived attitudes, towards those who apply for insurance and are asked to take an HIV test continue to be an issue of public interest. From time to time, allegations are made about the conduct of individual companies.
- 1.3 This Statement is intended to help insurance companies selling long-term insurance products¹ to adopt best practice. It sets out requirements on, and guidance for, insurance industry professionals, for use when dealing with applications for insurance where HIV may be an issue.

Who should read the Statement?

- 1.4 This Statement is intended primarily for insurance underwriters. Some aspects of it will also be relevant to others working in insurance companies, including Chief Medical Officers, sales personnel and those working in customer services or complaints departments.
- 1.5 The Statement is also intended to explain to external stakeholders the way that the insurance industry deals with issues surrounding HIV. It may therefore be of interest to doctors, patient support groups, policymakers and interested individuals.
- 1.6 A user friendly Consumer Guide to HIV and Insurance will be produced for people applying for health protection insurance once this Statement has been implemented.

What status does the Statement have?

- 1.7 The Statement falls under the ABI Life Insurance (Non Investment Business) Selling Code of Practice.

How was the Statement developed?

- 1.8 This Statement has been drawn up by the Association of British Insurers (ABI) Medical Underwriting Committee. The ABI's HIV Working Party, the Terence Higgins Trust and Pinkfinance.com also made significant contributions to the Statement.
- 1.9 The Statement further develops the last ABI Statement of Practice on Underwriting Life Insurance for HIV/AIDS, first published in July 1994 and revised in 1997. That document is superseded by this one. The new Statement will be reviewed again in three years time.
- 1.10 The Statement also draws heavily on several previous ABI publications in related areas available from the ABI web-site. These are:
 - An Insurer's Guide to the Disability Discrimination Act 1995;

¹ The insurance products covered by this guide are income protection, critical illness, term life long term care and the life insurance element of whole life and endowments

- Statement of Best Practice for Critical Illness Cover; and
- Statement of Best Practice for Income Protection Insurance.

Responses to the Draft Statement and implementation

1.11 At various points in this Statement we have identified questions where views would be particularly welcome. **Please send your responses to them, and any other points you wish to make to Richard Walsh, Head of Health, Association of British Insurers, 51 Gresham Street, London EC2V 7HQ or e-mail Richard.walsh@abi.org.uk by 31 December 2003.** Once we have had an opportunity to consider the comments a final version will be issued for implementation. **Latest date for implementation by companies is will be six months following the issue of the final document.**

2. Key principles

2.1 There are a number of key principles which underpin this Statement of Best Practice. They are as follows:

- **Principle 1 – Underwriting approach** - take decisions on a case-by-case basis and assess premiums fairly
- **Principle 2 – Collection of information** - don't ask for excessive, speculative or irrelevant information
- **Principle 3 – Use of information** - take account of all relevant factors
- **Principle 4 – Accuracy of information** - stay up to date with developments and statistics.
- **Principle 5 – Company policy on HIV and underwriting** - have an agreed policy on dealing with HIV which is updated at least every three years

2.2 The following paragraphs in this section explain briefly what each principle is intended to cover. The other sections of the Statement then expand upon the principles in greater detail.

Principle 1 – Underwriting approach

2.3 The primary duty of insurers is to assess insurance applications fairly according to the degree of risk that the applicant brings to the insurance pool. Insurance companies should consider each application for insurance on a case-by-case basis, based solely on the best available relevant evidence, in accordance with the guidelines laid down in this Statement. An individual's general occupation is no guide to their HIV risk. Being, for example, a cabin crew member, ballet dancer or hairdresser cannot of itself justify an HIV rating.

Principle 2 – Collection of information

2.4 Only ask for information that is relevant. Insurers will not request information which is unnecessary or irrelevant to the risk being insured, such as speculative questions that rely on inference and assumption on the part of the underwriter, for example house co-purchasing arrangements.

Principle 3 – Use of information

2.5 In reaching a decision on a particular application, the underwriter will take account of all relevant information and will be able to explain the reason for the underwriting decision

Principle 4 – Accuracy of information

- 2.6 General information (for example, ratings manuals, public health data, actuarial studies – see **Annex A** on evidence) used by the underwriter to assist them in making underwriting decisions should be accurate and up to date and reviewed annually.

Principle 5 – Company policy on HIV and underwriting

- 2.7 Each member company of ABI should have a clear policy on how it deals with applications where HIV status may be an issue, and their practice on exclusions, to ensure that it reflects current knowledge as in **Annex A**. This policy should be updated by the company at least every three years.

Question 1 – are the five principles the right ones and do you have any comments on them?

3. Action at the application stage

Communicating with the applicant’s GP

- 3.1 Care should be exercised when communicating with an applicant’s GP. Prior explicit written permission **must be obtained** from the applicant before writing to the doctor with any information or questions that could directly or indirectly reveal the sexuality of the applicant to the GP. In particular, information arising from the applicant’s answers to questions about belonging to certain HIV risk groups **should not** be passed on to the GP.
- 3.2 Equally, insurers **must not** ask the applicant’s GP to **speculate** on whether the applicant is at higher than normal risk of infection from HIV, nor should they request an opinion **on a non-clinical issue**.
- 3.3 For more information on communication with GPs see the ABI/BMA joint Guidelines on Medical Information and Insurance published in December 2002.

Question 2 – do you agree passing information to an applicant’s GP should not be allowed unless the applicant has given explicit consent?

Medical Examiner’s Report or Health Screening Report

- 3.4 Some insurance companies ask applicants to have a medical examination (unrelated to HIV risk) and repeat some of the questions contained on the application form. Where this is done, the same principles about consent, and “speculative “ questions apply.

Asking about the applicant’s HIV status and risk

- 3.5 Since publication of the first version of the ABI Statement of Practice on Underwriting Life Insurance for HIV in July 1994, insurers have not asked whether an applicant had undergone counselling about HIV, or had taken an HIV test. Instead, insurers have been expected only to ask whether the applicant had tested positive for HIV, or was awaiting the results of an HIV test.
- 3.6 This continues to be the basic position. However, in the light of developments since that time, the recommended wording for use on application forms has been updated. ABI members **should** in future use the following form of words.

Have you ever:	
	(a) tested positive for HIV, Hepatitis B or C or are you awaiting the results of such a test?
	No / Yes

	(b) tested positive or been treated for any disease which was transmitted sexually during the last five years?
	No / Yes
	(c) visited, or been a resident of, a country which has a much high level of HIV infection compared with the UK?.
	If you have answered “Yes” to any of the above questions, please provide full details.

Question “c” assumes that the applicant knows which countries have a high level of HIV infection. In the case of Africa, for example, HIV prevalence rates vary hugely from country to country. An alternative question “c” could be:

“Have you lived in or visited for more than [X] weeks a country outside Western Europe, North America, Australia or New Zealand in the last [X] years? If so please list which countries

Given the increasing rates of HIV infection beyond those already identified as at higher risk there may be a case for asking all applicants the following question (see also Annex B7):

- o “Do you practice safe sexual behaviour?”

Question 3 – do you agree with the wording of the question that appears on the applications form to begin the process of establishing risk of HIV infection? If not please suggest alternatives and give your reasons. Which question “c” would be most appropriate – or please suggest alternatives. Should the question relating to safe sexual behaviour be asked of all applicants?

3.7 Companies that use “short” application forms (which have a minimum of medical questions) may choose to incorporate these questions in a separate questionnaire. The questions necessary to ascertain the risk of exposure to HIV from foreign travel or residence should also be asked on the application form unless a “short” application form is used.

4. Gathering further information

Supplementary questionnaire – guidance

4.1 Insurance companies should provide any applicants asked to complete a supplementary questionnaire with a leaflet or covering letter to explain their reasons. The guidance note at **Annex B** sets out the issues that should be covered.

General Practitioner’s Report

4.2 The ABI/BMA agreed GPR ensures that insurers will **not** ask the GP any speculative questions about HIV/AIDS. See also paragraph 3.1 above. The ABI/BMA Guidance on Medical Information and Insurance advises GPs that they should inform insurers if the applicant is HIV positive or is awaiting an HIV test result or if the patient has had one or more episodes of a sexually transmitted disease that have long term health implications.

5. Arranging an HIV test

Detailed Guidance

- 5.1 The guidance note at **Annex C** explains the points that insurance companies should consider when arranging for an applicant to be tested for HIV. It gives guidance on:
- The choice of test method and provider
 - Customer counselling and consent
 - Recommended clinical procedures
 - Model counselling and consent letters to the applicant
 - An example HIV protocol for health professionals

Test criteria

- 5.2 Companies should have a clear policy on the criteria they use as a trigger for a request that an applicant undergoes an HIV test, for example
- “staying in [country X] for more than [X weeks] in the last [X years]”, or
 - “undergoing an operation within [country Y]”
 - “applying for [X insurance] with a potential payout of [over £X]”
 - “being in a high risk group and applying for [X insurance] with a potential payout of [over £X]”

Question 4 – are these the right trigger questions for considering whether an applicant should be invited to take an HIV test? If not please suggest alternatives and amendments

Before the test – pre-testing leaflet and consent issues

- 5.3 It is particularly important that applicants are made fully aware of the purpose of the HIV test before they are asked to consent to being tested. To this end, a HIV pre-testing leaflet letter and a consent form **must** be issued directly to every applicant who is asked to have an HIV test. These must not be sent via the sales intermediary. The consent form **must** be issued to the applicant **before** papers are issued to a doctor, service provider or medical agency, to make arrangements for the HIV test. This is necessary to ensure that the applicant is aware of the situation prior to being contacted to arrange an appointment for the test.

Question 5 – have you any suggestions on alternative arrangements which would make it more certain that the applicant has been given the consent form before being invited to take an HIV test?

- 5.4 The pre-testing leaflet explains that the applicant should take the unsigned consent form with them to the test centre where, if they are willing to take the test, they should sign it and have their signature witnessed. They are also given the option on the consent form of nominating another person, for example a medical practitioner, that they wish to be contacted by the insurance company in the unlikely event of a positive HIV test result. The insurer **must** satisfy themselves that, should the applicant refuse to provide written consent, the health professional will not proceed with a test.

Question 6 – should the applicant be given the option of nominating another person to be contacted should the test prove positive or should this be a condition of proceeding with the test?

Question 7 – should the nominee be restricted to medical practitioners? If not should any restriction be applied?

Question 8 – where the applicant has a partner, what arrangements should be made to ensure the partner knows the result of an HIV test in the event of it being positive? (see also paragraph 5.11)

All test results

- 5.5 The insurer must ensure that the applicant is told the result (or nominee if that option is chosen) as quickly as possible, so that, in the rare cases of positive results, arrangements can be made for counselling and future care, and, in all other cases, so that the applicant's uncertainty is relieved as quickly as possible.
- 5.6 Wherever possible, the salesperson should not be aware that an HIV test has been requested. Whether they are or not, however, the salesperson **must not** be told the result of the test.

Negative test results

- 5.7 Negative test results should be communicated as soon as possible to relieve applicant uncertainty. The insurer should also explain that the negative test had no effect on the applicant's insurance rating. This is particularly important where premiums are rated or exclusions applied as applicants may be under the misimpression that negative tests have an impact on insurance.

Positive test results

- 5.8 In those rare cases where an HIV test returns a positive result, indicating that the individual has contracted HIV, the insurer **must** ensure that the applicant is told the result – by the person they have nominated on their consent form or directly if they have not nominated another person – as quickly as possible, so that arrangements for counselling and future care can be discussed.
- 5.9 If the Chief Underwriter or Underwriting Manager receives the test result, they should communicate it to their CMO immediately. Once the CMO is aware of a positive test result, they **must** contact the person nominated on the applicant's consent form, or directly, as quickly as possible.
- 5.10 When the applicant has a nominee they should be asked to advise the CMO when the counselling meeting has taken place. Only once this confirmation has been received should the insurer issue a letter, signed by the CMO or the Chief Underwriter, to the applicant giving the underwriting decision. Care must be taken to ensure that the decision letter is **not** issued until after the applicant has been counselled.
- 5.11 The applicant's HIV status **must not** be referred to in any oral or written communications with third parties, unless the applicant has given written consent. The only exception is where the insurer is aware that the applicant has a partner. In these circumstances the insurer must satisfy themselves that the partner has also been made aware of the result. If the insurer has reasonable grounds for believing that the partner has not been told they should put arrangements into place to make this happen.

Invalid test results

- 5.12 Occasionally, the test laboratory may not be able to obtain a clear result from the applicant's sample. This may be due to the sample being insufficient, contaminated, or being mislaid. In these circumstances the applicant should be told that the test was inconclusive and the reasons for this (if known). They should then be asked if they wish to pursue their application and it should be explained that, if they do, a further test will be required. It should also be explained that if they do **not** wish to proceed with their application this decision will not be held against them in future applications.

Question 9 – is it right to ask the applicant to take another test if the first one was invalid? Previous industry practice was to explain that the test was inconclusive and treat the result as negative for underwriting purposes. The change is proposed because an individual in such circumstances is likely to want to know their HIV status

and have a test independently. If the test were positive and the contract was not yet in force, they would have to declare it anyway under the continuing obligation to disclose. Is it also right that not pursuing an application in such circumstances should not be held against the applicant for future applications?

6. Confidentiality – ongoing issues

Insurance company confidentiality – ABI guidelines

- 6.1 Insurance companies recognise the importance of ensuring the confidentiality and privacy of sensitive personal information of the kind disclosed on insurance application forms. They are also fully aware of their responsibilities under data protection and other legislation. To assist member companies in fulfilling their obligations, ABI has produced a set of confidentiality guidelines which were first published in 1997 in the ABI Code of Practice on Genetic Testing. The current version forms Part 7 of the August 1999 revision of that Code.

Group/corporate insurance policies

- 6.2 This Statement refers in general to the “applicant” for insurance. Normally, this will be the person whose HIV status is under consideration. However, in some circumstances (e.g. group insurance policies), the applicant, and the person whose personal sensitive information is being requested (“the life assured”), may not be one and the same. For group insurance policies for example, the applicant – who will subsequently be the policyholder – is the employer, not the employee.
- 6.3 When dealing with cases under this Statement of Best Practice, insurance companies **must** ensure that they communicate directly with the “life assured”, rather than the applicant (where they are different), on all personal, sensitive and medical issues. The applicant must not be informed of any enquiries the insurer makes about the life assured’s risk of HIV infection.

Question 10 – if the life assured in a company scheme is in an occupation where a positive HIV status could endanger others, for example a doctor, their professional occupational guidelines will have made them fully aware that they need to disclose the result to their employer. As such the insurer has no responsibility for notifying the employer. Is this correct?

Confidentiality and joint life applications

- 6.4 Where an applicant is asked to complete a supplementary questionnaire, it is important to recognise that the information disclosed is confidential to that person. In particular, when underwriting applications for joint life insurance, members **must** protect the confidentiality of such information. They must ensure that the “ignorant” party to a joint life application cannot infer any confidential information from the underwriting result. (But see also paragraph 5.11)

Security of electronic communications

- 6.5 Some doctors and laboratories fax or email HIV test results to insurers. In general they would only do this with negative results. There is a clear risk that such procedures could lead to test results being sent to an incorrect fax number or email address. Insurers are therefore encouraged not to accept test results – whether positive or negative – by such methods, and to make this clear to those who communicate HIV test results to them.

Question 11 – do you agree that fax and e-mail notifications of test results are inappropriate? Are there alternatives, for example a secure, designated e-mail or fax number?

7. Complaints

- 7.1 Insurance companies should ensure that their complaints procedure takes account of this Statement of Best Practice. Where a complaint is received that falls within the area covered by

this Statement, the complaint handler should consult the company's Chief Underwriter or Underwriting Manager and, if necessary, the Chief Medical Officer.

8. Further information

8.1 References:

Genetic Testing: ABI Code of Practice, August 1999

Medical Information and Insurance: Joint guidelines from the British Medical Association and the Association of British Insurers, December 2002

Prevalence of HIV and hepatitis infections in the United Kingdom 2001, December 2002

An Insurer's Guide to the Disability Discrimination Act, January 2003

ABI/BMA agreement on GPR and informed consent Aug/Sept 2003

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Guidance –underwriting – evidence and exclusions

Evidence

Insurers should review their underwriting practice and approach regularly to ensure that it is up to date. Annual reviews are recommended for evidence. Company policy should be reviewed at least every three years in the light of this evidence. Particular issues to consider in the reviews are:

- Statistics – companies should monitor regularly the data collected by the Public Health Laboratory Service (www.phls.co.uk) and their own death claims, and consider whether these suggest the need for changes in policy or practice;
- Higher risk countries – underwriters should have access to up to date information on the situation in those countries where the incidence of HIV infection is high (the “high-risk countries and territories”). Good sources of information on the European and global situations are the European Centre for the Epidemiological Monitoring of AIDS (www.ceses.org) and the Joint United Nations Programme on HIV/AIDS (www.unaids.org) ;

Question 12 – are there other sources of information that insurers should be aware of?

Excluding HIV/AIDS as a cause of claim

Life insurance policies do not normally exclude AIDS. However, HIV/AIDS exclusions are more common with other long-term health products such as critical illness (CI) and income protection (IP) insurance. The ABI’s Statements of Best Practice for CI and for IP insurance require that any general exclusions (for example, “drug abuse”) and any specific conditions, such as HIV/AIDS, that are not covered by the policy are shown prominently in the Key Features Document given to the customer as part of the sales process, so that the scope of the cover is clear.

Where an exclusion for HIV/AIDS is applied, the model wording which is recommended is:

- We will not pay a claim if it is caused directly or indirectly from infection with Human Immunodeficiency Virus (HIV) or from conditions due to any Acquired Immune Deficiency Syndrome (AIDS).

Question 13 – is the HIV/AIDS exclusion wording still correct?

Exclusions worded in this way ensure that, while HIV and AIDS are not included in the scope of cover, someone who has been diagnosed with HIV or AIDS is not prevented from claiming on their policy if they suffer an unrelated condition such as a heart attack.

The ABI document “An Insurer’s Guide to the Disability Discrimination Act 1995” makes clear (section 2.8.2) that insurers “must not use general exclusions that have the effect of preventing a person from claiming for a condition that is not related to the excluded condition. General exclusions that have this effect are not lawful as they would be regarded as both unfair contract terms ... and discriminatory”. The Guide then gives, as an example of an unlawful HIV/AIDS exclusion, the following: “we will not pay a claim if the insured person has HIV or AIDS”.

When imposing exclusions on policies, insurers should pay particular attention to the following points:

- If the exclusion means that questions about a person’s **risk** of HIV infection are irrelevant those questions should NOT be asked. This is particularly likely to be the case for income protection and long term care insurance because it should usually be relatively simple to establish whether or not HIV/AIDS is the cause of the claim. Insurers may still ask for details of positive HIV tests as to do otherwise would be to offer an unfair contract to those already affected.
- Problems arising from, for example, the limitations of old computer systems should be solved, through manual administration if necessary. Individuals should

not be declined a policy simply because the system cannot impose a particular exclusion;

- The policy should state clearly whether the exclusion relates to the whole contract, to some part of it, or to one or more of the benefits;
- Where HIV/AIDS is excluded, name the occupations (if any) where the exclusion will be waived – for example, medical or emergency workers where HIV/AIDS is contracted through normal occupational duties;
- Documents should include the full names for HIV and AIDS:
 - HIV = Human Immunodeficiency Virus;
 - AIDS = Acquired Immune Deficiency Syndrome;
- Where definitions are required, suggested forms are:
 - HIV – a viral infection, caused by the human immunodeficiency virus, that gradually destroys the immune system;
 - AIDS – the most serious stage of HIV infection, characterised by symptoms of severe immune deficiency.

Question 14 – do you agree that where HIV/AIDs exclusions are applied to income protection or long term care insurance questions relating to the risk of HIV infection should not be asked?

Question 15 – should the principle in question 14 apply to other types of insurance for example critical illness insurance? If so which ones and how can insurers be confident that diagnoses will excludes HIV/AIDS and indirect, but related, claims?

Guidance – the supplementary questionnaire

- B.1 Insurance companies should provide any applicants asked to complete a supplementary questionnaire with a leaflet or covering letter to explain their reasons. Recommended text for such a document is provided below.
- B.2 Some insurers may prefer to include these supplementary questions within their application form. In such cases, a covering letter or leaflet should still be provided to the applicant, but the wordings in italics in the recommended text below should instead be used.

Covering letter or leaflet – recommended text

- B3. The following text is recommended for use in the covering letter or leaflet.

“We are currently considering your application for insurance. Before we reach a decision, we require some additional information. We are among a number of insurance companies which ask for more information from applicants, so that we can protect our overall risk profile. [We have chosen to ask you because, statistically, you fall within a recognised high risk grouping for contracting HIV. – delete if not appropriate]

“Any information given in your answers will be treated confidentially. We would be grateful if you would complete the questionnaire (*following questions*) and return it (*them*) in the envelope provided. If you prefer, you can answer the questionnaire (*following questions*) separately, and send your answers in a sealed envelope, marked for the attention of the Chief Medical Officer at our company.

“Answering ‘Yes’ to any of the questions may lead to you being charged a higher premium, or to your application being turned down (this will be in proportion to your perceived higher risk of HIV). We may also ask you for additional medical information before taking our decision.”

Question 16 – do you have any comments on the wording of the covering letter to the supplementary questionnaire?**Supplementary questionnaire – suggested wording**

- B.4 Whether companies choose to ask for additional information in their application forms, or in a supplementary form, to determine whether the applicant is at higher risk of HIV infection, the recommended wordings for the questions normally included are set out below. Companies need not, however, feel obliged to ask all of the questions below

Q1. Do you belong, or have you ever belonged, to any of the following groups?	
(a) gay men	No / Yes
(b) bisexual men (having partners of both sexes)	No / Yes
(c) intravenous drug users	No / Yes
Q2. Have you ever undergone any surgical procedure outside the UK, or been a recipient of blood products outside the UK?	
	No / Yes
If “Yes”, please provide us with the date(s), the country or countries and the reason(s) for each procedure and transfusion undergone.	
Q3. Have you ever stayed in any of the following countries [X] for more than [X] in the last [X] (companies may choose to use this more specific wording than the one in paragraph 3.6 “c” – see also the alternative wording consulted upon there)	

Question 17 – do you have any comments on the wording of the “standard” supplementary questions? Also – should these questions be asked of all applicants in the interests of even-handedness – even though for females some of them obviously cannot apply?

- B.5 The supplementary questionnaire should not be referred to as the “lifestyle” questionnaire, as this can cause offence. The term “supplementary questionnaire” should be used.

Additional supplementary questions

- B.6 Insurance companies should take care to ensure that any further questions they ask are relevant and verifiable, for example they should not ask supplementary questions relating to:
- Numbers of sexual partners
 - Length of relationships
 - Monogamy
 - Safe sex
 - HIV tests and sexually transmitted diseases beyond that set out in the main text

Question 18 – do you agree that insurers should not ask the supplementary questions listed in Annex B6?

- B.7 Insurers may wish, nevertheless, to offer different premiums to individuals within the same risk group. There are two options
- **Direct question related to the risk:** “Do you practice safe sexual behaviour?”
 - **Indirect questions – yet verifiable:**
 - “Are you in a civil partnership? If so please provide a copy of the registration document” (yet to be enacted in law however)
 - “Have you adopted or fostered children? If so please provide a copy of the adoption certificate or authority from your social services department” (applies to very few people however)

Question 19 – Which is the best approach to establishing risk – the direct or indirect approach? Also, given the level of risk in the whole population, should the direct question be asked of all applicants? The external contributors in paragraph 1.8 favour the direct approach being applied to all risk groups. Can you suggest any other questions and which at risk groups would they apply too?

GP Report

- B.8 The supplementary report is entirely separate from any report that is issued to the GP since it is addressed solely to the applicant. Communications with GPs are covered in the main text

Guidance – arranging an HIV test

- C.1 This guidance note details the points that insurance companies should consider when arranging for an applicant to be tested for HIV.

Choice of test method and provider

- C.2 When deciding whether to employ blood or saliva tests, and when deciding which laboratory to use, insurance companies may wish to consider:
- The robustness of individual laboratories' protocols;
 - The testing kits used – in particular their reliability and whether they are customer-friendly;
 - The service standards of each laboratory;
 - The cost of the testing procedure;
 - Any customer requirements.
- C.3 Companies will want to undertake regular reviews to ensure that the chosen laboratory continues to be a reliable and effective provider of test services.

Question 20 – are the criteria in Annex C the right ones for insurers to apply in choosing their test method and provider? Should blood or saliva tests be standard practice and if so why?

Customer pre-testing leaflet and consent

- C.4 A pre-testing leaflet and a consent form **must** be issued directly to every applicant who is asked to have an HIV test. They should be sent by first class post, and the name and address should be carefully checked prior to posting.
- C.5 Recommended text for the pre-testing leaflet and the consent form are reproduced at the end of this annex.

Recommended procedures for the insurer

- C.6 If an HIV test is to be requested, it will need to be carried out by a clinician. The insurer should inform the applicant that a test is being requested (see paragraph 5.3 – 5.4 of the main text), establish whether the applicant would prefer the test to be carried out by their own doctor or by an independent doctor or nurse, and explain to the applicant whether the test will require a sample of blood or saliva.
- C.7 If an independent provider is to be used, they should be asked to provide the insurer with a copy of the protocol used by their health professionals. The insurer will want to satisfy themselves that the professional who will carry out the test has clear instructions covering:
- The content of the counselling to be given prior to obtaining consent for the test;
 - The need to obtain the applicant's written consent to a tissue sample being taken, and to obtain the contact details of an individual (either the applicant or the applicant's nominee) who the insurer will contact if the test result is positive;
 - The need to refuse to proceed further if the applicant does not provide consent.

Question 21 – are the procedures for insurers' arrangements with health professionals in Annex C 6 and 7 and the HIV protocol correct?

<u>HIV Pre-testing leaflet</u>

As you are probably aware, the Acquired Immunodeficiency Syndrome is caused by infection with a micro-organism known as Human Immunodeficiency Virus (HIV).

In the United Kingdom, the majority of those infected with the virus to date are thought to belong to so called *high risk groups* such as homosexual or bisexual males, intravenous drug abusers, and people who are frequent visitors or resident in countries with high HIV prevalence, but there remains a concern that the virus could spread into the general population. This has caused the life assurance industry to introduce measures designed to protect the funds held for both existing and future policyholders. Your insurance company therefore requires a routine HIV antibody test for applications over a certain sum assured, which is why you have been asked to undergo such a test.

Our trained nurse will take a sample of saliva on a swab. The test will form a routine part of your medical examination and the sample will be sent to a specialist central laboratory. Your test will be protected by a strict code of confidentiality and will not be disclosed to anyone else, not even your general practitioner, unless it is your wish and we have written authority to do so. It is, however, in your best interest to be advised regarding future treatment should your test prove positive and we suggest you name a doctor or clinic to whom we may refer you in the extremely unlikely event that the situation should occur.

A positive test would mean that you have been exposed to HIV and have developed antibodies. A positive result could have social and medical consequences and you may decide that you do not wish to have the test performed. If this is the case, please sign the appropriate section of the enclosed section of the enclosed declaration and ask the nurse to return it to the Insurance Company. You will, of course, understand that this will mean we cannot proceed further with your application for life assurance.

If you have no objections to this test being performed, please sign the declaration and consent in the nurse's presence.

Full Name:

Insurance Company:

Reference Number:

Refusal to be tested form

REFUSAL TO BE TESTED

I am unwilling to undergo testing for HIV antibodies. I understand that, as a result, my application for life assurance will be cancelled.

Signature:

Date:

Witnessed by Nurse:

Question 22 – do you have any comments on the wording of the pre-testing leaflet?

Example text for HIV protocol

To: The health professional providing HIV counselling and test services

We would be grateful if you could please follow the procedures below when dealing with individuals who have applied for insurance with us, and whom we have asked to take an HIV test. This will help to ensure that a consistent and thorough approach is maintained.

1. Ensure that the person to be tested has read and understood the HIV counselling letter ([give a reference where possible]) that has been sent to them;
2. Carry out the pre-test counselling;
3. Ask the applicant if they are willing to take the HIV test;
4. If they are, ensure they complete the written consent form for the HIV test, including, if they wish, nominating another individual apart from themselves (normally their GP) who the insurer will contact if the test result is positive;
5. Witness their signature on the consent form;
6. Take a sample of blood or saliva, as directed by the insurer;
7. Send the sample to the analysing laboratory on the same day;
8. Return the completed consent form to the insurer with the medical examiner's report.

[Insurance company sign off.]

See question 21