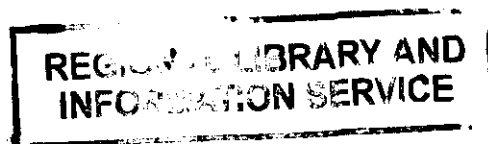




## **NATIONAL AIDS STRATEGY COMMITTEE**

**Reports and Recommendations of the Sub-  
Committees of the National Strategy Committee  
On:-**

- **Care and Management of Persons with HIV/AIDS**
- **Interim Report on HIV/AIDS Surveillance**
- **Education and Prevention Strategies**
- **Measures to avoid Discrimination against persons  
with HIV/AIDS**



**ADOPTED BY THE MAIN COMMITTEE ON THE 13TH APRIL, 1992**

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***ADOPTED BY THE MAIN COMMITTEE ON THE 13TH APRIL, 1992***

## **MEMBERSHIP OF NATIONAL AIDS STRATEGY COMMITTEE:**

Chairman - Dr John O'Connell, T.D.,  
Minister for Health

Dr Joe Barry, AIDS/Drugs Co-ordinator,  
Eastern Health Board

Mr Donal Devitt, Assistant Secretary,  
Department of Health

Dr Enda Dooley, Medical Director, Prisons

Mr Frank Dunne, Assistant Secretary,  
Department of Justice

Dr Cliodhna Foley-Nolan, AIDS Co-ordinator,  
Southern Health Board

Mr Tony Geoghegan, Project Director,  
Merchant's Quay Project

Mr Thomas Gillen, Assistant Secretary,  
Department of Education

Ms Helen Griffin, Counsellor, Body Positive

Mr Kieran Hickey, Chief Executive Officer,  
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Dr John O'Connor, Drug Treatment Centre,  
Trinity Court

Mr Tony O'Gorman, Chief Psychologist,  
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Dr Fergus O'Kelly, Irish College of General Practitioners

Mr John Rochford, Chairperson, The AIDS Fund

Ms Deirdre Seery, Education Officer,  
Cork AIDS Alliance

Dr James Walsh, National AIDS Co-ordinator,  
Department of Health

**REPORT OF THE SUB-COMMITTEE ON THE CARE AND  
MANAGEMENT OF PERSONS WITH HIV/AIDS TO THE NATIONAL  
AIDS STRATEGY COMMITTEE**

**REGIONAL LIBRARY AND  
INFORMATION SERVICE**

**9TH APRIL, 1992**

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1. INTRODUCTION

1.1 The National AIDS Strategy Committee at its first meeting on 20th December, 1991 decided to establish Sub-Committees to examine various aspects of its brief and to report back to the plenary meeting of the National Committee on 6th April 1992 (subsequently postponed to 13th April).

1.2 The "Sub-Committee on the Care and Management of persons with HIV/AIDS" (The Committee) was given the following terms of reference:

Care and Management of persons with HIV/AIDS

"To consider the development of appropriate arrangements for the care and management of persons with HIV/AIDS at primary care and hospital levels including the development of liaison arrangements between the prison, health and welfare systems. The development of policy recommendations should be carried out in co-ordination with the Committee on Infectious Diseases in Prisons established by the Minister for Justice".

1.3 In order to ensure that the Committee could examine its brief as comprehensively as possible it was decided to appoint as broadly representative a membership as practicable both from the statutory and voluntary services. The membership of the Committee is as follows:

Mr D. Devitt (Chairman) Assistant Secretary, Department of Health  
 Dr. J Barry, Drugs/AIDS Co-ordinator, Eastern Health Board  
 Dr E.Dooley, Medical Director, Prisons, Department of Justice  
 Dr C. Foley-Nolan, AIDS Co-ordinator, Southern Health Board  
 Ms M Foreman \*, Senior Medical Social Worker, St. James's Hospital  
 Mr T Geoghegan, Project Leader, Merchant's Quay Project  
 Ms A.M. Jones, Cairde  
 Dr J. Kiely, Medical Officer, Department of Health  
 Mr G. McCartney, Assistant Secretary, Department of Health

Dr. F. Mulcahy, Consultant in Genitourinary Medicine,  
St. James's Hospital

Dr J.O'Connor, Consultant Psychiatrist, Drug Treatment  
Centre, Trinity Court

Ms V.O'Dowd \*, Public Health Nurse, Eastern Health Board

Dr. F. O'Kelly, Irish College of General Practitioners

Ms D Seery, Cork AIDS Alliance

Dr J.H.Walsh, National AIDS Co-ordinator, Department of  
Health

Mr D. Ryan, (Secretary) Dept of Health

\* Ms Foreman and Ms O'Dowd were co-opted to the Committee to  
represent the Statutory Workers in this area.

1.4 The Committee met on nine occasions between 10th February and 6th  
April, 1992

1.5 The Committee gratefully acknowledges the submissions it received  
from individuals and agencies which greatly assisted the Committee  
in the preparation of this Report.

1.6 The Committee wishes to record its appreciation of the work  
undertaken in a most efficient manner by Mr Dermot Ryan, Higher  
Executive Officer, Department of Health who acted as Secretary to  
the Committee.

## 1. Statistics on HIV/AIDS

1.1 The following tables illustrate the statistics for AIDS cases and  
deaths to 31st December, 1991.

## AIDS CASES AND DEATHS TO 31ST DECEMBER 1991

## Cases of AIDS

	<u>1982</u>	<u>'83</u>	<u>'84</u>	<u>'85</u>	<u>'86</u>	<u>'87</u>	<u>'88</u>	<u>'89</u>	<u>'90</u>	<u>'91</u>	<u>Total</u>
Homo/Bisexual	2	0	1	1	1	6	21	17	22	23	94
I.V. Drug Users	0	0	0	1	1	9	10	21	27	31	100
Homo-Bisexual/ I.V. Drug Users	0	1	1	1	0	1	1	2	0	0	7
Haemophiliacs	0	0	1	0	3	3	3	6	1	3	20
Heterosexual	0	0	0	0	0	1	1	2	8	11	23
Babies born to I.V. Drug Users	0	0	0	1	1	0	2	1	2	1	8
Babies Born to Heterosexual Mothers	0	0	0	0	0	0	0	0	0	1	1
Undetermined	<u>0</u>	<u>0</u>	<u>0</u>	<u>1</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>2</u>	<u>1</u>	<u>1</u>	<u>5</u>
TOTAL	2	1	3	5	6	20	38	51	61	71	258

(In the period from 1st January to 5th April 1992. (inclusive) there have been 8 more cases of AIDS diagnosed: 2 Homo/Bisexual; 5 I.V. Drug users and 1 heterosexual bringing the total number of cases to 266).

## Deaths from AIDS

	<u>1982</u>	<u>'83</u>	<u>'84</u>	<u>'85</u>	<u>'86</u>	<u>'87</u>	<u>'88</u>	<u>'89</u>	<u>'90</u>	<u>'91</u>	<u>Total</u>
Homo/Bisexual	2	0	1	1	1	3	4	7	7	7	33
I.V. Drug Users	0	1	0	1	0	3	2	1	11	9	28
Homo-Bisexual/ I.V. Drug Users	0	0	1	1	0	2	0	1	1	0	6
Haemophiliacs	0	0	1	0	3	1	0	1	3	2	11
Heterosexual	0	0	0	0	0	0	1	2	2	2	7
Babies born to I.V. Drug Users	0	0	0	1	0	0	2	1	1	1	6
Undetermined	<u>0</u>	<u>0</u>	<u>0</u>	<u>1</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>2</u>	<u>1</u>	<u>0</u>	<u>4</u>
TOTALS	<u>2</u>	<u>1</u>	<u>3</u>	<u>5</u>	<u>4</u>	<u>9</u>	<u>9</u>	<u>15</u>	<u>26</u>	<u>21</u>	<u>95</u>

(In the period from 1st January to 5th April, 1992 (inclusive) there were eight deaths from AIDS; 2 Homo/Bisexual; 5 I.V. drug users; 1 heterosexual bringing the total number of deaths to 103).



2.2 The number of AIDS cases reported in any one year is of course a reflection of the level of HIV infection in previous years. The HIV virus has a long incubation-period, perhaps 4 to 10 years, but enough is not yet known to enable definitive parameters to be established for the onset of full AIDS.

CUMULATIVE TOTAL SAMPLES TESTED FOR HIV ANTIBODY - DECEMBER, 1991

CATEGORY TESTED	TOTAL SAMPLES	POSITIVE • (1) TESTS
INTRAVENOUS DRUG USERS		
Male	3467	461
Female	1483	150
Unknown	69	8
	5019	619
CHILDREN AT RISK	862	78
HOMOSEXUALS/BISEXUALS	2574	188
HAEMOPHILIACS	1038	112
HAEMOPHILIAC CONTACTS	67	0
HOSPITAL STAFF/OCCUPATIONAL		
HAZARD/NEEDLESTICK	790	0
TRANSFUSION	238	1 * (2)
BLOOD DONORS	1290	15
ORGAN TRANSPLANT	2602	0
VISA REQUESTS	4802	1
INSURANCE	13918	0
PRISONERS	385	13
HETERO/UNSPECIFIED	19233	129
TOTAL	52818	1156

\* (1) It should be noted that the figure given relates to tests and not necessarily to individuals as there may be some element of double-counting

\* (2) Transfused in U.S.A.

(In the period 1st January to 29th February, 1992 there were 2,326 tests resulting in 32 positives: the total figures therefore are; 55144 tests; 1188 positive tests).

2.3 To date the geographic distribution of HIV positive persons is unknown although it is understood that the sub-committee on AIDS/HIV Surveillance and Epidemiology is examining this issue at present. However it is estimated that of the known 1156 positive tests up to 90% are from the Greater Dublin area.

2.4 The Centres for Disease Control (CDC), Atlanta, Georgia, have identified four broad categories of progression along the path to full AIDS. These can be described as follows:

Category I From infection to appearance of anti-body - usually 6 weeks to 3 months - but can be as long as 2 years.

Category II From appearance of anti-bodies - HIV positive - to development of early symptoms. Patient is HIV positive but symptomless. Length of time in this stage of infection varies from 5 to 10 years plus, depending on age, co-factors and source of infection. At this stage treatment at primary care level is required.

Category III HIV positive plus initial symptoms - e.g. enlarged persistent lymph glands in a number of areas throughout the body and/or oral manifestations, ulcerations of mouth and gums etc. Again mainly manageable at a primary care level but may require hospitalisation.

Category IV The patient is clinically ill with a range of illnesses from general wasting to diarrhoea to candidiasis etc. Clear indications that the immune system is compromised. Patients in this category will require on average three to four admissions to an acute hospital bed each year for approximately 10 days per admission.

Note:

From Category IV the patient will probably go on to meet the CDC/WHO definition of a full AIDS case.

To date (5.4.92) 266 cases meeting the CDC/WHO definition have been recorded. Of these 103 have died.

### 3. Care and Treatment needs of HIV positive individuals at Primary Care Level

- 3.1 At the different Category levels there is a need for individuals to have access at different times to a range of appropriate medical and personal social services; such needs will vary depending on the individual's progress through the spectrum of the infection. As knowledge of the disease increases, it would appear that with proper management of the HIV positive patient with regard to diet, medication, counselling etc. the onset of full AIDS can be deferred and the quality of life for that patient improved accordingly. One of the difficulties for both patients and the services alike is that there is currently no way of predicting the course of the virus in any individual.
- 3.2 Because of the nature of the infection at Categories II and III it is accepted that the ideal method of delivery of services to the patient is by the general practitioner in a community-based setting. It is apparent that many people who are HIV positive, especially those who are also problem drug users, do not have general practitioners. It would also appear however that some GPs can have particular problems in the management of such patients. These problems include a reluctance to accept care of difficult or problematic drug users with HIV because of fear of personal safety; because of inadequacy of specific knowledge of the infection; because of dissatisfaction at the level of remuneration (many patients are in the 16-44 age group which attracts the minimal capitation fee under the General Medical Services Scheme) and also because of the lack of support services. A number of differing models of care or an amalgam of existing models and new structures have been suggested as a means of developing an integrated system of both medical care and psychosocial support. The Committee accepts that as a first step in encouraging GPs to undertake a comprehensive role in this area it is recommended that proper resource structures should be introduced to allow GPs to care for the HIV/AIDS patient in his own practice setting.
- 3.3 A significant number of people (500+) were diagnosed as HIV Positive in the mid 1980's. Many of this group are now having significant medical problems and there is therefore an urgent need to provide services. However, since some GPs encounter difficulties in treating such patients in their own practices a

mechanism must be found to allow for the delivery of the services as envisaged. This is particularly relevant in the case of HIV positive drug users as referred to in subsequent paragraphs. An approach would be to establish community-type services in clinics within the hospital setting where GPs, under the guidance of the relevant clinician would provide such services on a sessional basis. However the alternative favoured by the Committee in this context is that such clinics could be established as "satellite clinics" outside the hospital setting. These might be located in appropriate locations possibly within existing services, and should preferably be situated within or as close as possible to the areas of greatest need. THE COMMITTEE RECOMMENDS THAT THIS BE DONE INITIALLY ON A PILOT BASIS AND THAT A MINIMUM OF TWO SUCH CENTRES SHOULD BE ESTABLISHED IN THE DUBLIN AREA AND CONSIDERATION GIVEN TO THE ESTABLISHMENT OF A SIMILAR CLINIC IN CORK ON THE BASIS OF EVALUATION OF NEED AT LOCAL LEVEL. Consideration could also be given to appropriate remuneration for GPs who participate in these services.

- 3.4 All the indications are that the majority of people affected at present are from deprived urban areas and many have experienced social and economic disadvantage, unrelated to HIV and AIDS. For example, many women who are HIV positive are single parents, the majority are unemployed and live in local authority housing and many have had a history of drug misuse and consequently many members of the extended family network may be infected with HIV. Generic community services provided by the statutory authorities in deprived urban areas are under the greatest pressure. IT IS PROPOSED THEREFORE THAT A STRENGTHENING OF SUCH SERVICES PROVIDED BY THE HEALTH BOARDS IN THESE AREAS WOULD BE AN IMPORTANT INITIAL STEP IN DEVELOPING A RANGE OF ACCESSIBLE AND APPROPRIATE SERVICES. The Committee recommends that adequate services be provided at a local level in order to ensure that, having taken due consideration of medical needs, individuals can remain outside of hospital care as much as possible. It is also recognised that the Voluntary Agencies working in the area are providing a valuable service and they should be allocated additional resources to enable them to fulfill the role which they are currently endeavouring to undertake and to allow them to complement the expanded statutory services.

- 5 In order to ensure accessible and appropriate services a full range of support services will have to be provided. It is accepted that these services should be provided in a community-based setting and services which have been identified as desirable to complement primary medical services include the following:

#### Clinical Services

- Treatment of acute infections
- Infectious disease screening
- Medication supervision
- Dressings
- Drug related services
- Phlebotomy

#### Counselling/Social Work Service

The Committee recognises the need for non-hospital as well as hospital-based counselling/social-work services so that individuals can deal with a wide range of issues relating to HIV/AIDS. These issues would include pre- and post-test counselling; medical information; dealing with sexuality and safer sex practices; issues relating to the prevention of transmission of the virus and the sustaining of adapted safer sexual practices.

#### Community Welfare Allowances

- Diet allowance
- Heating allowance
- Household support

IN EXAMINING THE ISSUES OF WELFARE ENTITLEMENTS, THE COMMITTEE RECOMMENDS THAT WELFARE ENTITLEMENTS FOR THOSE WHO ARE HIV POSITIVE BE STANDARDISED. (It is understood that the Sub-Committee on Anti-discrimination is examining this issue at present).

#### Personal Services

- Home Help
- Home Care
- Terminal Domiciliary Care

Lack of Social Support: In many other illnesses, individuals can turn to a wide circle of community support, particularly to help them or family members experiencing illness. With HIV/AIDS, the social stigma that is experienced prevents families from asking neighbours and the wider community to get involved.

### Preventive Services

- Needles
- Condoms
- Information

### Child Care

- Creche
- Infant welfare

It is important that these services should be fully integrated to ensure that the best use is made of available resources and that the optimum level of care is provided in as accessible a manner as possible.

- 3.6 The Committee accepts that the services outlined in the previous paragraph based, as they will be, in or attached to the recommended satellite clinics require to be complemented by improvements in other areas. These include the following:

### Homelessness

Many individuals who are HIV positive or who are suffering from AIDS are discharged from institutional care (i.e. prison, hostel, or respite care) without adequate planning for suitable accommodation. THE COMMITTEE RECOMMENDS THE FOLLOWING:

- No individual who is HIV positive should be discharged from institutional care on Friday afternoons without clear prior arrangements being made for housing and medical care (if needed);
- that attention be paid to the special needs of individuals with HIV including the fact that ordinary hostel accomodation is often not sufficient;
- that existing discharge protocols for the homeless already in place in many hospitals should be examined to ensure that they provide for persons with HIV;
- that Hostels receiving public funding should not be entitled to continue their practices of refusing to take individuals who are HIV positive.

An example of good practice in the area of homelessness is the arrangement that has been made between the voluntary organisation, Body Positive, and the Eastern Health Board Homeless Unit, whereby Body Positive will facilitate an individual looking for a flat deposit by providing the money immediately in order that the individual can secure a flat. The money can then be refunded to Body Positive from the Eastern Health Board.

### Family support services

In a family where either or both parent(s) is infected with HIV, the type of support with the family that is needed during illness is currently not being provided. In particular, the need for someone to supplement the parenting role while the parent(s) is ill needs to be addressed. The Committee acknowledges that the statutory power exists to provide this service and that the service is at present being provided in certain areas for example health boards provide day nurseries and child care workers. The Committee considers that such services should be encouraged and developed in areas of particular need. These workers would provide full-time support within the home in particular in relation to:

- Home making (cleaning, shopping etc.)
- and
- care of the children.

The family support worker would provide support at times of illness and hospitalisation and would be available to move into the family home and take over should a single parent be hospitalised.

The Committee recognises the role of the voluntary organisations in providing support in the home and would encourage the good practice of co-operation and liaison which already exists - for example between Cairde's Home Support Project, St. James' Hospital and the Eastern Health Board.

The Committee recognises the gap in services in the lack of provision of night-sitting and night-nursing services which are essential in ensuring that individuals remain at home although this service need is not exclusive to HIV/AIDS patients.

### Child Care

The issue of planning for the care of children while parents are ill is obviously highly emotive and stressful for families. The Committee would support the streamlining of services so that continuity of care can be provided for children.

In the case of fostering, this would mean that the current system of separate short-term and long-term arrangements being made for children would be changed so that children would always go to the same foster family during any episode of illness. This would be regarded as an ideal situation but it is accepted that due to shortages of foster families from time to time, it is not always possible to arrange for such continuity.

In relation to adoption, the Committee recommends that provision be made so that the parent(s) can be involved in the selection of adoptive parents before their death and the inclusion of adoptive parents in the care of the children before their natural parent dies. It is understood that the parent can be involved under the Adoption Acts in choosing the prospective adopters. Ultimately however, it will be a matter for the Adoption Board to decide whether or not to make an Adoption Order.

### Preventive services- Condoms

The Committee recommends the availability of free condoms to those who are HIV positive, through health board and other service outlets.

### Retraining/Work Opportunities

The Committee recognises the need for people with HIV to have equal access to job opportunities and to retraining programmes in line with their changing physical abilities. The Committee recommends that open access to retraining opportunities should be given to individuals who are HIV positive through FAS, and where appropriate, the National Rehabilitation Board.

## 3.7 Research and evaluation

Because the care of HIV positive patients by community-based personnel is an emerging area where innovative service strategies will need to be developed, the Committee consider that on-going evaluation and research are necessary to ensure both the



widespread dissemination of information on good practice and the development of an integrated approach to the provision of primary care for the HIV/AIDS patient.

In this context the Committee welcomes the establishment of the HIV Primary Care Research Unit which has begun the work of establishing the optimum role for primary care in the management and prevention of HIV disease and the development of protocols and educational means of implementing this role. The Committee notes that the unit is to investigate the attitudes of GPs to treating HIV patients.

The First Interim Report of the Unit (March, 1992) is at Appendix I of this Report.

- 3.8 The development of the satellite clinics as recommended will require the training of medical, para-medical and community service personnel in order to ensure that the services which have been outlined previously may be provided in a prompt and appropriate manner. Accordingly the Committee would urge the health boards to urgently provide adequate training and support to personnel working in this area. An example of the type of training envisaged would be the need for public health nurses and other appropriate community care personnel to be trained in the care of the terminally-ill patient in the home.

#### 4. Care and Treatment of HIV positive drug users

- 4.1 The statistics previously quoted have shown that intravenous drug use is the main source of transmission of the virus. (Of the 1188 HIV positive tests almost 60% are drug related; of the full AIDS cases almost 40% are drug related; all figures quoted are as at 29/12/92). The problem has also been identified on a geographical basis highlighting the Dublin inner-city area as having particular problems in this respect.

This mode of transmission invariably leads to other problems such as paediatric AIDS, heterosexual spread and transmission of the virus within the prison population.

It is accepted, therefore, that any strategy to deal with the problem of HIV transmission must pay particular attention to the drug user as a prime source of infection. In order to do this services must be provided in a community - based, client-friendly, comprehensive and integrated manner.

The Committee has already outlined an approach in its recommendations in paragraph 3.3 (i.e. satellite clinics) for the delivery of services to HIV positive individuals, together with a full range of support services. It is considered that this approach, because of its emphasis on a community-based service, and because of its location in areas of greatest need, would provide an ideal mechanism for the care/treatment of the HIV positive drug user. The service as envisaged will therefore be available to all HIV positive individuals. In recognition of the particular problems presented by HIV positive drug-users the Committee has recommended the establishment of satellite clinics outside the Hospital setting. The Committee considers that such clinics should also provide primary, preventive care for all drug users. The Committee recognises the necessity for those clinics to have available to them the range of services outlined at Paragraph 3.5.

- 1.2 The "Government Strategy to Prevent Drug Misuse" (May, 1991) recognised that there was an overwhelming case to be made for decentralising services as far as practicable to ensure accessibility and continuity of treatment. In this context the Government Strategy proposed the establishment of Community Drugs Teams (CDTs) under the auspices of the Health Boards in specific targeted areas.

The role of the CDTs was set out as follows:-

- identifying the extent of the drug use problem in its area of operation;
- identifying and establishing contact with known drug users and persons at risk;
- establishing links with the appropriate statutory and voluntary treatment services and referring individual drug users for assessment and treatment as appropriate;
- ongoing monitoring of individual drug users on referral back following initial assessment and treatment;

- assisting in the development of appropriate primary prevention programmes;
- liaising with the prison service in the case of drug using prisoners from their area being released.

The individual local circumstances would dictate the composition of the CDTs but it was considered that the following membership might be appropriate:- GP; outreach worker; social worker; public health nurse, treatment agency representatives; juvenile liaison officer/probation officer.

- 4.3 In view of the proposals previously outlined concerning the development of services aimed at HIV positive drug users it is important to emphasise that the CDTs will work closely with and complement the proposed satellite clinic service in order to provide a comprehensive and integrated approach.
- 4.4 As previously stated it is accepted that the ideal method of delivery of services to the HIV infected patient is by the GP in a community-based setting. The "Government Strategy to Prevent Drug Misuse" recognised the validity of the model which exists for the treatment of acute medical and surgical conditions whereby the patient is referred to a consultant for specialist treatment/assessment and referred back to the GP for on-going treatment and monitoring. In the case of the HIV positive drug user this might involve the drug user being referred by the CDT to the Drug Treatment Centre (or by self-referral to the Drug Treatment Centre) for specialist assessment and treatment and then being referred back to the GP in the satellite clinic for on-going care.
- 4.5 In view of the recommendations made in respect of HIV infected drug users it is recognised that the role of the Drug Treatment Centre is essential in providing a national medical treatment and counselling service and in providing the relevant expertise to encourage an increased role for community-based treatment in this area.

4.6 The Committee considers that the prescribing of methadone for HIV positive drug users is an appropriate response to prevent the transmission of the virus. In view of this it will be necessary to allow methadone prescribing in the proposed satellite clinics. In these circumstances it is accepted that agreed protocols for the treatment of such individuals must be established to avoid unnecessary pressure to prescribe being placed on the GP and to avoid double prescribing and inappropriate prescribing. The Committee considers that the appropriate agencies to prepare such protocols are the Drug Treatment Centre, the Eastern Health Board, the Irish College of General Practitioners and the voluntary drug agencies through their representatives on this Committee, on behalf of, and under the aegis, of the Committee. The Committee recommends that this should be done as a matter of urgency so that the establishment of the proposed Satellite Clinics can proceed without delay.

4.7 Specific Issues pertinent to the Care and Management of HIV-Positive people in Prison.

- (i) HIV-positive prisoners should be able to avail of medical and para-medical services of an equivalent standard to those available to similarly infected people in the community.
- (ii) To facilitate continuity of care between the prison and the general community the overall integration of facilities between these two locations for this group should be encouraged. This may involve more formal linkage or liaison between care facilities in the community and those within the prison.
- (iii) Prison regimes should be structured, as far as possible, to facilitate the diagnosis, medical treatment, and on-going care of HIV-positive individuals.
- (iv) As far as practicable primary-care and consultant-based out-patient services should be provided within the prison. Where a prisoner requires specialist in-patient medical treatment this should be provided within the health service on the same basis as to any other citizen.

## 5. Acute General Hospital Care

5.1 As indicated previously in this Report patients up to and including Category III can generally be treated outside the hospital setting although Category III patients may require hospitalisation particularly as they reach the end of this stage of infection. However patients in Category IV will represent the largest burden in terms of hospital admissions: as outlined previously patients may require on average 3 -4 admissions to an acute hospital bed each year for approximately ten days per admission. Furthermore as initial contact with the statutory services for HIV infected patients is likely to be through the hospital setting this may be an important factor in the care and management of a patient's infection.

5.2 The Department of Health policy in the area of acute hospital care has been that each acute hospital would be responsible for the care and treatment of HIV/AIDS patients from its own catchment area requiring hospital treatment.

However as already indicated it would appear from the national statistics that the vast majority of individuals with HIV/AIDS either reside in Dublin and/or receive hospital treatment in Dublin and to a much lesser extent in Cork.

In practice therefore the vast majority of patients at present are either treated initially at or are referred to, St. James's Hospital, Dublin, by other hospitals, by general practitioners or they are self-referred. A relatively small number of patients have also been diagnosed and/or treated in Cork Regional Hospital, the Mater Hospital, Dublin, Beaumont Hospital, Dublin, Our Lady's Hospital, Crumlin, The Coombe Hospital, Dublin and the Rotunda Hospital, Dublin. It would appear that other acute hospitals throughout the country have dealt with very few or no HIV/AIDS patients.

It is expected however that the demands on the acute hospital sector will expand significantly over the next few years as many of the 500 + people, who were diagnosed as HIV positive in the mid - 1980's, develop full AIDS.

- 5.3 In its discussions on acute hospital care the Committee had available to it the recently completed report of the Comhairle na nOspideal Committee on the management of A.I.D.S. at Consultant Level. The terms of reference of the Comhairle na nOspideal Committee were as follows:

"Having regard to the policy of the Department of Health and following examination of the issues involved and consultation with appropriate interests, to make recommendations to the Comhairle on mechanisms to improve the management of A.I.D.S. patients at consultant level and to clarify the role of the different specialties in the services for persons who are H.I.V. positive and/or who have A.I.D.S."

The membership of the Comhairle Committee together with a copy of its conclusions and recommendations and final remarks are attached at Appendix II

- 5.4 The Committee supports the conclusions and recommendations of the Comhairle na nOspideal Committee, on the management of Aids at consultant level, and recommends their implementation at the earliest possible date. In particular the Committee consider that the following recommendations should be given priority attention:

- (a) the creation and appointment of an Infectious Diseases Consultant in North Dublin and a similar post in South Dublin (Paragraph 5.4, Comhairle na nOspideal Report)
- (b) the appointment of a Consultant in Genito-urinary medicine to North Dublin (Paragraph 5.9; Comhairle na nOspideal report)

- 5.5 In establishing a hospital-based HIV/AIDS service for the northside of Dublin the Committee considers that the necessary medical staff will require to be complemented by a range of staff including nursing, social workers, dietitian and occupational therapy personnel.

As the new service develops the question of a dedicated ward will need to be addressed in the light of the experience gained to date at St. James's Hospital. The new unit must have clear admission criteria and therapeutic objectives. Furthermore the existence of the unit should not mean that patients with AIDS will not be cared for in other parts of the hospital, rather that there is a centre of expertise which may be used as a resource on a consultative basis.

- 5.6 The Committee are conscious that the new hospital - based services, as recommended, will take time to put in place. In the interim the Committee recommends that additional support be given to the present hospital-based services at St. James's which are under increasing pressure.

#### 6. Respite Care

As indicated previously many of the group of individuals, (500 +) who were diagnosed as HIV positive in the mid - 1980's are now experiencing significant medical problems particularly at late Category III or Category IV stages of infection. Whilst some may not require full acute general hospital facilities they cannot be discharged into the Community for a variety of reasons including on-going infections, inadequate family support or poor home conditions. A service was opened at Cherry Orchard Hospital in 1990 to address this need and the Committee recommends that the present services in Cherry Orchard Hospital should be expanded as required to cope with increasing demand.

## 7. Palliative Care

The Committee recognises that palliative care is an important element in the care of the terminally ill AIDS patient. The Committee supports the recommendation of the Comhairle na nOspideal Committee on the management of AIDS at consultant level that the existing services for palliative care of terminally ill patients, both home-care and in-patient care should be extended to include patients with advanced and terminal AIDS.

## 8. Concluding Remarks

The Committee is satisfied that the recommendations which it has made relating to primary, secondary and tertiary care will have an important impact on the care and treatment of those already infected by the virus and also in helping to prevent the further spread of the infection. The Committee has stressed the need for services to be integrated and community-based and also that the proposed satellite clinics and other complementary services should be as accessible as possible. It is accepted however, that the strengthening of existing services and the development of new services in the community is only addressing one area of the service requirements, albeit a crucial and essential element. Whilst the Committee considers that, where possible, the treatment of the HIV/AIDS infected patient should be in a community-based setting it fully recognises that at certain stages in the patient's progress through the spectrum of the infection hospital in-patient care will be required.

The Committee would emphasise however that there is a need to ensure that "separate" services do not develop but that the community-based and hospital-based services are integrated in a way that meets the needs of the HIV/AIDS patient in the most effective and appropriate manner. In this context the Committee recommends that all the agencies (both statutory and voluntary, community-based and hospital-based) providing services for HIV/AIDS should be represented on the local Aids Co-ordinating Committees.



9. Summary of Recommendations:

- (i) It is recommended that proper resource structures should be introduced to allow the general practitioner to care for the HIV/AIDS patient in his own practice setting. (paragraph 3.2)
- (ii) The Committee recommends the establishment of satellite clinics outside the hospital setting which would provide primary and preventive care for all HIV positive individuals and for all drug users. (paragraph 3.3)
- (iii) The Committee recommends that satellite clinics be established initially on a pilot basis and that a minimum of two such centres should be established in the Dublin area and consideration should be given to the establishment of a similar clinic in Cork. (paragraph 3.3)
- (iv) It is proposed that a strengthening of generic community services provided by the Health Boards in deprived urban areas would be an important initial step in developing a range of accessible and appropriate services. (paragraph 3.4)
- (v) The Committee recommends that adequate services be provided at a local level in order to ensure that, having taken due consideration of medical needs, individuals can remain outside of hospital care as much as possible. (paragraph 3.4)
- (vi) It is recommended that the voluntary agencies should be allocated additional resources to enable them to fulfil the role they are currently undertaking and to allow them to complement the expanded statutory service (paragraph 3.4)
- (vii) The Committee recommends that welfare entitlements for those who are HIV positive be standardised. (paragraph 3.5)

(viii) The Committee recommends the availability of free condoms to those who are HIV positive, through health board and other service outlets (paragraph 3.6)

(ix) The Committee recommends that open access to retraining opportunities should be given to individuals who are HIV positive through FAS, and where appropriate, the National Rehabilitation Board. (paragraph 3.6)

(x) The Committee recommends the following:

- No individual who is HIV positive should be discharged from institutional care on Friday afternoons without clear prior arrangements being made for housing and medical care (if needed);
- that attention be paid to the special needs of individuals with HIV including the fact that ordinary hostel accommodation is often not sufficient;
- that existing discharge protocols for the homeless already in place in many hospitals should be examined to ensure that they provide for persons with HIV;
- that Hostels receiving public funding should not be entitled to continue their practices of refusing to take individuals who are HIV positive. (paragraph 3.6)

(xi) The Committee considers that on-going evaluation and research are necessary to ensure both the widespread dissemination of information on good practice and the development of an integrated approach to the provision of primary care for the HIV/AIDS patient. (paragraph 3.7)

(xii) It is recommended that doctors operating from the satellite clinics should be permitted to prescribe methadone. (paragraph 4.6)

(xiii) It is recommended that protocols for the treatment of drug users be established by a sub-group of this Committee as a matter of urgency. (paragraph 4.6)

(xiv) The Committee supports the conclusions and recommendations of the Comhairle na nOspideal Committee, on the management of Aids at consultant level, and recommends their implementation at the earliest possible date and in particular

(a) the creation and appointment of an Infectious Disease Consultant in North Dublin and a similar post in South Dublin (Paragraph 5.4)

(b) the appointment of a Consultant in Genito-urinary medicine to North Dublin (Paragraph 5.4)

(xv) The Committee recommends that additional support be given to the present hospital-based services at St. James's which are under increasing pressure (Paragraph 5.6)

(xvi) The Committee recommends that the present services in Cherry Orchard Hospital should be expanded as required to cope with increasing demand. (paragraph 6)

(xvii) The Committee supports the recommendation of the Comhairle na nOspideal Committee on the management of AIDS at consultant level that the existing services for palliative care of terminally ill patients, both home-care and in-patient care should be extended to include patients with advanced and terminal AIDS. (paragraph 7)

HIV Primary Care Research Unit

First Interim Report - March 1992

Introduction

The availability of appropriate primary care services for patients with HIV and AIDS will be increasingly important in the future. Dublin's existing situation is that most of those with HIV infection attend the specialist centre at the Genito-Urinary Medicine Unit at St. James's Hospital. This centre cannot continue to provide both long term care and monitoring to all patients and specialist care to those who are seriously ill.

The HIV Primary Care Research Unit was set up in 1991 with funding from the Department of Health with the following aims:

- (1) To establish the optimum role for primary care in the management and prevention of HIV disease and
- (2) To develop the protocols and educational means of implementing this role in the setting of Irish general practice.

The setting for the initial work on these aims is that of two inner-city general practices which provide ongoing care for a large number of HIV seropositive patients.

This report is an outline of progress to date and a discussion of future phases of the project.

Structure of the Unit

The management group of the Unit includes:

Prof. B. Shannon (Chairman)  
Dr. F. D. O'Kelly  
Prof G. Bury

Initial funding from the Department of Health was received in August 1991. The key post of full-time Research Fellow was filled in December 1991 by Dr. F. Bradley and further part-time appointments of dietitian and clinical psychologist have also been made; further appointments are in train (see Appendix 1).

Patient care and data collection are principally provided at the general practices at Mercer's Health Centre and 478 South Circular Road. Exceptional co-operation and support has been provided by Dr. F. Mulcahy and her staff at the GUM Unit, St. James' Hospital.

## Research in Progress

### 1. Case-control study

A prospective case-control comparison has begun of patients attending the two general practices involved in the Unit and a matched sample who continue to attend the GUM Unit for most of their care. Approximately 80 HIV seropositive patients attend the combined general practices.

The hypothesis under study is that the patients attending the general practices for most of their routine care will maintain at least the same overall health status and quality of life as the matched sample attending the hospital clinic for care.

It is hoped that the study will show that at least the same care can be provided for patients through their GP as through the specialist hospital unit for most problems. The potential benefits include a reduction in hospital workload, continuity of care for individual patients and possible health economic effects.

Detailed records of attendance, prescribing, referrals, investigations, use of para-medical services and quality of life will be analysed, initially after a one-year period of care. The development of management protocols, epidemiologic data and preventive medicine approaches will also be derived from these data.

In order to provide patients with an appropriate level of care in general practice, a range of supplementary services has been provided; these include:

#### A. Anti-retroviral therapy.

Where patients have a clinical indication for antiretroviral therapy (usually AZT or DDI) and have been commenced on the drug by the GUM Unit, its dispensing and monitoring has been made available to patients through the general practices. Agreed protocols for this work are in use. Similarly, the prescription and supervision of prophylactic drugs such as pentamidine has been undertaken.

#### B. Monitoring of asymptomatic patients.

GPs involved in the project are undertaking the monitoring of asymptomatic patients. Guidelines for appropriate follow-up have been drawn up in conjunction with the GUM Unit (Appendix 2). Work has begun on the development of a combined-care card, similar to that used for combined antenatal care.

Conclusions of Comhairle na nOspideal Committee on the management of AIDS at consultant level.

SECTION 4 - CONCLUSIONS

- 4.1. The committee supports the need for co-ordination of the activities of the spectrum of statutory and voluntary agencies and professionals involved in the monitoring, education, prevention, treatment, care and research aspects of H.I.V. and A.I.D.S. It is understood that these elements of the services and their co-ordination are being dealt with by the National A.I.D.S. Strategy Committee. Most of these services are outside the remit of the committee. In accordance with its remit, the conclusions and recommendations set out in the following sections relate to the management of A.I.D.S. patients at consultant level and the role of the different hospital specialties in the services for persons who are H.I.V. positive and/or who have A.I.D.S.
- 4.2. As already mentioned, the committee visited two hospitals with major H.I.V./A.I.D.S. units in the United Kingdom - St. Mary's Hospital, Paddington, London and the City Hospital, Edinburgh. These visits were invaluable to the committee in acquiring a detached perspective on the most appropriate organisation and development of hospital services for people who are H.I.V. positive/have A.I.D.S.
- 4.3. The conclusions and recommendations are made in the context of current knowledge of the epidemiology of the disease. The committee envisages that its recommendations will meet the current and estimated needs for the next few years. Future needs will have to be addressed within a few years when the following recommendations have been implemented and when the future trends in relation to the disease will be, hopefully, more apparent than is currently the position.
- 4.4. Having considered all of the information and opinion expressed by hospital authorities and staff in Ireland and the U.K. and having taken into account the quite similar views contained in the submissions from the various professional bodies listed in paragraph 1.6., the committee has reached the following conclusions:-
  - (a) A.I.D.S. is a multi system disease/syndrome. At consultant-level, a multidisciplinary approach is essential to deal with the variety of complications which occur in H.I.V./A.I.D.S. patients.
  - (b) A.I.D.S. is an infectious disease.
  - (c) The two main ways of transmission of H.I.V. are sexual transmission and intravenous drug misuse.

- (d) There is no such entity as an A.I.D.S. Consultant per se.
- (e) The most appropriate consultant profile to manage H.I.V. and A.I.D.S. patients is a combination of infectious diseases consultants and consultants in genito-urinary medicine. Both specialties have complementary roles to play in the care of H.I.V. and A.I.D.S. patients.
- (f) As A.I.D.S. is a multi-system disease/syndrome and also an infectious disease, the primary responsibility for the care and management of H.I.V. and A.I.D.S. patients and the co-ordination of medical inputs they require at consultant level should be assigned to infectious diseases consultants. Consultants in this specialty are the most suitable because of their broad general medical training and experience including experience in the care of A.I.D.S. patients. The infectious diseases consultants should also play a major role in the co-ordination of A.I.D.S. services in the catchment areas of the hospitals in which they are based.
- (g) Consultants in genito-urinary medicine are also essential because of their traditional and continuing involvement in the care of patients with sexually transmitted diseases. They emphasise the importance of H.I.V. prevention to sexually active people attending for treatment of sexually transmitted diseases; they provide counselling and support; they supervise follow-up and treatment and contact tracing.
- (h) Acutely ill A.I.D.S. patients should be treated in large multidisciplinary general hospitals which have the full range of specialties necessary to cope with their serious illnesses.
- (i) The other consultant inputs which are on the campus of multidisciplinary teaching hospitals can be availed of by the infectious diseases consultant(s) as required e.g. respiratory physicians, gastroenterologists, neurologists, surgeons, psychiatrists etc. Sophisticated laboratory and radiological facilities and consultant expertise, particularly in microbiology would also be required.
- (j) The care and treatment of infants and children with H.I.V./A.I.D.S. can most appropriately be undertaken by a consultant paediatrician with a special interest in infectious diseases.

- (k) It is much more difficult to deal with H.I.V./A.I.D.S. patients who are drug misusers than any other group of H.I.V./A.I.D.S. patients. Their medical problems are different. They have serious behavioural problems. Many are involved in crime arising from their need for money to satisfy their drug dependency. They are usually poor. They are more likely to have poor quality housing or to be homeless. They are less likely to keep appointments at clinics. It is essential to simultaneously care for their drug dependency as well as their H.I.V./A.I.D.S. problems.
- (l) H.I.V./A.I.D.S. patients who are prisoners should be cared for in prison to a much greater extent than is currently the case. The consultants in infectious diseases with primary responsibility for dealing with H.I.V./A.I.D.S. should have a shared responsibility for H.I.V./A.I.D.S. prisoners.
- (m) Medical school support will be important in relation to educating medical students and doctors in respect of H.I.V./A.I.D.S. Medical school support is also likely to attract research funding into the disease. The teaching and research components of the proposed consultant posts are important and can best be facilitated by having the consultants based in large multidisciplinary teaching hospitals.
- (n) At this stage in the development of the disease, in-patient hospital services for H.I.V./A.I.D.S. patients should be concentrated in a small number of large multidisciplinary general hospitals. The hospitals chosen should be geographically accessible for the majority of H.I.V./A.I.D.S. patients, in particular drug misusers.
- (o) A small number of centres of special expertise being developed is preferable to a system whereby each hospital throughout the country would be entirely responsible for the care and management of people with H.I.V./A.I.D.S. from its own catchment area. In general, most consultants have neither the training or experience to deal with the spectrum of problems caused by a multi-system disease such as A.I.D.S. The experience in the U.K. is that most consultants refer H.I.V./A.I.D.S. patients to hospitals with A.I.D.S. units. In Ireland, a similar situation can be seen to exist to a significant degree in relation to referrals to St. James's Hospital.



(p) The hospital resources required for the management of H.I.V./A.I.D.S. patients are both extensive and expensive.

Recommendations of Comhairle na nOspideal Committee on the management of AIDS at consultant level.

SECTION 5 - RECOMMENDATIONS

5.1. In the context of the conclusions in Section 4 and the current epidemiology of the disease, the committee makes the following recommendations on mechanisms to improve the management of H.I.V./A.I.D.S. patients at consultant level in Ireland in the immediate future.

5.2. The management of H.I.V./A.I.D.S. patients at consultant level in Ireland can only be comprehensively undertaken in the context of the availability of an infrastructure both in infectious diseases and in genito-urinary medicine.

Infectious Diseases.

5.3. A minimum level of consultant manpower in infectious diseases and genito-urinary medicine needs to be developed urgently in Ireland. In so doing, the most appropriate management of H.I.V./A.I.D.S. patients will also be achieved. The Comhairle in its Recommendations on Future Hospital Arrangements for Infectious Diseases (see Appendix C) noted the world-wide trend towards the management of most infectious diseases in appropriate accommodation in large general and childrens hospitals with the consequential closure (or change of use) of the existing separate infectious diseases hospitals. In view of the time-lapse and subsequent developments, especially the emergence of H.I.V./A.I.D.S., the 1978 recommendations need to be up-dated and modified to meet current needs.

5.4. For the foreseeable future, the committee recommends the appointment of four consultants in infectious diseases, two in North Dublin and two in South Dublin. Ideally, all four posts should be proceeded with immediately. At the very least, one North Dublin and one South Dublin post should be created and filled without delay with the remaining two following as soon as possible thereafter.

5.5. In order to clarify administrative responsibility for services at individual hospitals, the sessional commitments of the North Dublin posts should be shared on a mirror image basis (e.g. 7/4 or 8/3) between the Mater and Beaumont Hospitals. A small sessional commitment to Cherry Orchard Hospital should also be included. An initial post might be shared equally between the two major general hospitals with the proviso that it be restructured when the second post is created.

- 5.6. The sessional commitments of the South Dublin posts should be shared, on a mirror image basis, between St. James's Hospital and St. Vincent's Hospital including a small sessional commitment to Cherry Orchard Hospital. This will require the restructuring of the consultant post referred to in earlier paragraph 3.17. The position in relation to the Meath, Adelaide and the National Children's Hospitals (M.A.N.C.H.) should be kept under review in the light of developments in relation to the proposed new Tallaght Hospital.
- 5.7. Appropriate in-patient facilities in each of the four major general hospitals should be commensurate with demand. The sessional commitment to Cherry Orchard Hospital envisaged in each of the four consultant posts will be necessary as long as Cherry Orchard continues to admit adults with infectious diseases.

Genito-Urinary Medicine.

- 5.8. St. James's Hospital and the Mater Hospital were previously designated in a Comhairle recommendation to the Department of Health as the regional centres for sexually transmitted diseases in Dublin (see Appendix B). S.T.D. services in Dublin are currently concentrated at these two major general hospitals. The roles envisaged for these two hospitals in relation to sexually transmitted diseases should now be developed fully.
- 5.9. The committee recommends that St. James's Hospital and the Mater Hospital should be staffed by a minimum of one consultant each in genito-urinary medicine with each having a commitment to the Eastern Health Board for community care involvement. They should also have a sessional commitment to a nearby major maternity hospital. The approved vacant post in North Dublin referred to in paragraph 3.7 should be restructured as a joint appointment between the Mater Hospital and the Eastern Health Board with sessional commitments to the Rotunda Hospital and, possibly, Beaumont Hospital.
- 5.10. The committee recommends that the north Dublin post envisaged above be proceeded with as quickly as possible. Because the population of the south Dublin area (around 750,000) is 50% larger than north Dublin, a similarly structured second post of consultant in genito-urinary medicine based at St. James's Hospital may be required in the reasonably near future. St. James's Hospital should provide appropriate sessional inputs in genito-urinary medicine to the Coombe Hospital and the National Maternity Hospital, Holles Street.

### Mountjoy Prison.

- 5.11 The consultants in infectious diseases should have a shared responsibility for prisoners with H.I.V./A.I.D.S. in Mountjoy Prison. The responsibility and workload should be shared on the basis of the hospital catchment area of origin of the prisoners from Dublin. A protocol should be drawn up by the consultants in respect of allocating between them prisoners from outside Dublin. The committee envisages that the infectious diseases consultants would have a small sessional commitment to Mountjoy Prison whereby they would participate with the prison authorities and medical staff in establishing criteria for the management of H.I.V./A.I.D.S. prisoners in the prison and the movement of prisoners to hospital in appropriate circumstances. It is envisaged that the above recommendation, together with improved medical facilities being developed in Mountjoy Prison, will reduce the number and frequency of H.I.V./A.I.D.S. prisoners currently attending St. James's Hospital.

### Drug Misuse.

- 5.12. In view of the fact that over half of those currently infected with H.I.V. are drug misusers, there needs to be close co-ordination and shared consultant posts between the Drug Treatment Centre in Pearse Street/ Drug Detoxification Unit at Beaumont Hospital and the Mater, St. James's and St. Vincent's Hospitals. The latter three hospitals do not have this expertise. The committee recommends that there should be a second post of consultant psychiatrist with a special interest in drug addiction based on the Drug Treatment/Detoxification Centres. One post should have a significant sessional commitment to St. James's and St. Vincent's Hospitals and the other, a similar commitment to the Mater Hospital. It will be necessary, subject to the agreement of all parties, including the incumbent, to restructure the existing post to facilitate the implementation of the recommended arrangements.

### Infants and Children with H.I.V./A.I.D.S.

- 5.13. The committee recommends the creation of a post of consultant paediatrician with a special interest in infectious diseases to be based at Our Lady's Hospital for Sick Children, Crumlin with minor sessional commitments to the Children's Hospital, Temple Street and to Cherry Orchard Hospital. Close liaison with the maternity hospitals will be essential. The need for a second appointment shared between the children's hospitals should be determined in due course when the first appointment has been filled for a reasonable period. The sessional commitment to Cherry Orchard

Hospital will be necessary as long as Cherry Orchard Hospital continues to admit seriously ill children with infectious diseases.

#### Palliative Care.

- 5.14. The existing services for the palliative care of terminally ill patients, both home care and in-patient care, should be extended to include patients with advanced and terminal A.I.D.S. It is understood that the training of aspiring consultants in palliative medicine now includes training in the palliative care of A.I.D.S. patients. The committee recommends the creation of two new posts of consultant in palliative medicine. One of the proposed new posts should be based at Our Lady's Hospice, Harold's Cross with a sessional commitment to St. James's Hospital. This post is to augment the one existing post at Our Lady's Hospice which has a sessional commitment to St. Vincent's Hospital. The home care facility provided by Our Lady's Hospice should be extended to provide a service to patients with advanced and terminal A.I.D.S. It is envisaged that A.I.D.S. patients would be admitted to the Hospice as in-patients on the same basis as others requiring palliative care.
- .15. A new post of consultant in palliative medicine should be created in North Dublin for the recently established hospice service in Raheny with sessional commitments to the Mater and Beaumont Hospitals.

#### Respite Care

16. For social reasons, a number of drug misusers with A.I.D.S. who are homeless or have inadequate family support, require respite care at various stages of their illness which would be provided in more normal circumstances in the patient's home supported by the community care services. A respite care facility is required for such patients who might otherwise inappropriately occupy beds in an acute general hospital. If this cannot be provided by the hospice movement, then alternative facilities, such as that currently provided in Cherry Orchard Hospital, will continue to be necessary.

#### Munster Region

- .17. Munster comprises the administrative areas of the Southern and the Mid-Western Health Boards and parts of the South-Eastern Health Board i.e. Waterford and South-Tipperary. The committee recommends the appointment of an infectious diseases consultant to be based at Cork Regional Hospital including minor sessional commitments to the Mercy Hospital and the South Infirmary/Victoria Hospital. The appointee will

be responsible for infectious diseases including H.I.V./A.I.D.S. in the Munster region and will also be the A.I.D.S. Co-ordinator for the region. Depending on workload growth in relation to A.I.D.S. and infectious diseases generally, consideration may need to be given, in due course, to the appointment of a consultant in infectious diseases at Limerick Regional Hospital. The sexually transmitted diseases services based in Cork City will ultimately need a consultant in genito-urinary medicine.

#### Connacht Region

- 5.18. Connacht comprises the administrative area of the Western Health Board and the southern half of the North Western Health Board area. The committee recommends the appointment of a consultant in infectious diseases to be based at University College Hospital, Galway. The committee envisages that the appointee will be responsible for infectious diseases including H.I.V./A.I.D.S. in the Connacht region and will also be the A.I.D.S. Co-Ordinator for the region.

#### Rest of the Country

- 5.19. The number of H.I.V. and A.I.D.S. patients being identified and coming for treatment to hospitals in the rest of the country is to-date quite small. Such patients are looked after in the local hospitals by consultant physicians and/or are referred to Dublin. Some others are self referring to Dublin or to England. The committee is of the opinion that hospitals throughout the rest of Ireland are coping with the problem in so far as it has yet manifested itself. The committee recommends that H.I.V./A.I.D.S. patients requiring specialised expertise be referred to the most appropriate major centre where this is deemed necessary by the local consultants.

#### Academic Links

- 5.20. In the interests of research and teaching, the structuring of some of the recommended posts of consultant in infectious diseases should ideally include a formal sessional commitment to a medical school(s). The committee recommends that the hospital authorities concerned should enter into discussions with the appropriate medical schools to explore the possibilities in this respect. Ideally each medical school should be linked to a specific post. Such links would also make the posts more attractive to potential candidates.

### Other Hospital Services

- 5.21. As stated already, a multidisciplinary approach is necessary to deal with the myriad of complications which occur in H.I.V./A.I.D.S. patients. The multidisciplinary approach is having and will continue to have increased and significant implications for virtually all hospital specialties. The medical specialties most affected will be respiratory medicine, gastroenterology and neurology. There will be implications also for radiology, obstetrics/gynaecology, paediatrics and psychiatry. In surgery, the main workload increase will be in general surgery, ophthalmic surgery and neurosurgery. Theatre, anaesthetic, C.S.S.D. and I.C.U. resources will need to be developed to provide a safe environment for staff and patients and to reduce to a minimum the risk of contamination with H.I.V. infected body fluids. In pathology, there will be an increase in the overall number of specimens and in the complexity of the tests to be carried out on these specimens. H.I.V./A.I.D.S. patients will also have an impact on other support services.

### Virus Reference Laboratory

- 5.22. The national role of the Virus Reference Laboratory is vital. There are three elements to the role of the microbiology services on the St. Vincent's/U.C.D. campus (including the Virus Reference Laboratory), namely public health, academic and service. The committee recommends that these services should be jointly staffed by a minimum of three microbiologists each of whom would have a hospital commitment. The committee envisages that, while they would provide mutual support for each other, each consultant would concentrate on one major element of the services.

- 5.23. Specifically, the committee recommends -

- (i) The post currently occupied by the Director be replaced by a joint appointment of a Consultant Microbiologist with a special interest in virology by St. Vincent's Hospital and the Virus Reference Laboratory. The appointee would be responsible for the public health aspects of the laboratory and would liaise with the Department of Health.
- (ii) A joint appointment should be created between the Virus Reference Laboratory, University College Dublin and St. Vincent's Hospital, incorporating the academic element of the post formerly occupied by the retired

Professor of Microbiology referred to in paragraph 3.18.

- (iii) Subject to the agreement of the incumbent, the recently filled post of Consultant Microbiologist at St. Vincent's Hospital should be restructured to include a service commitment to the Virus Reference Laboratory.

The precise sessional split of the above posts would be a matter for consideration in the first instance by the authorities and individuals concerned. It is envisaged that these recommendations would not preclude links with other major Dublin hospitals.

#### Funding

- 5.24. Funding per se does not come within the remit of the committee. Nonetheless, there are special circumstances that prevail in relation to A.I.D.S. It is a new disease and the hospital resources required are extensive and expensive. It would be a serious omission for the committee not to make some comment on the issue of funding. During the consultation process, the major resource implications of caring for H.I.V./A.I.D.S. patients were raised by virtually all those consulted. The need for earmarked funding, allocated on an annual ongoing basis, was repeatedly stressed. During the course of the visits to London and Edinburgh, the hospitals' representatives were emphatic about the need for any hospital with a major commitment to A.I.D.S. patients to have a separate A.I.D.S. budget. Otherwise A.I.D.S. services will not be properly developed and other hospital services will suffer. St. James's Hospital has made a similarly strong argument to the committee. In England, the Department of Health has provided separate funding to hospitals for A.I.D.S. services, mainly by way of an annual grant of about £35,000 for each patient diagnosed by the hospital as having A.I.D.S. The annual grant continues as long as the patient lives. About 10% of St. Mary's Hospital budget is currently related to special A.I.D.S. funding which has facilitated a significant expansion in its consultant staff and hospital services in respect of A.I.D.S. patients. A special allocation of funding is also provided for H.I.V./A.I.D.S. services in Scotland - the A.I.D.S. unit in the City Hospital, Edinburgh, was established by this means. While not being prescriptive as to the method of doing so, the committee is convinced that ongoing earmarked funding to hospitals with a major commitment to A.I.D.S. patients is essential.



Final remarks of Comhairle na nOspideal Committee on the management of AIDS at consultant level.

SECTION 6 - FINAL REMARKS

- 6.1. In formulating the foregoing specific recommendations, the committee has attempted to be pragmatic. The committee feels strongly that the best interests of patients will be served by concentrating services in a number of large multidisciplinary teaching hospitals. The committee believes that implementation of its recommendations will result in the best service that modern hospital medicine currently has to offer to patients with H.I.V./A.I.D.S. Within the general hospital sector, the consultant requirements for the foreseeable future in respect of infectious diseases and sexually transmitted diseases have also, of necessity, been addressed.
- 6.2. The committee reiterates that its recommendations are in the context of the immediate needs for H.I.V./A.I.D.S. only and that an up-dated assessment of future needs will be required in a few years. In the meantime, the foregoing recommendations should be implemented without delay.

### C. Standard primary care

Patients are receiving care for all problems which they choose to present, including hospital referral where appropriate.

### D. Counselling

A part-time counsellor (one day a week) is providing counselling for patients with HIV disease, and if time permits, for the key carers of these patients. It is planned to commence a support group for carers of people with HIV in the near future.

### E. Dietetics

A dietitian is attending the practice in South Circular Road on a fortnightly basis, providing dietetic advice, as well as access to dietary allowances and supplements.

## 2. Patients' quality of life

An evaluation of the quality of life of all patients involved in the case-control study is now being prepared jointly with the Department of Psychology, RCSI. This will be a prospective analysis of the quality of life of both groups, using both existing instruments and new ones devised for the special needs of the group under study. The hypothesis under study is that the quality of life of the two groups of patients, one group receiving care predominantly in general practice and the second predominantly from hospital sources, shows no measurable difference.

## 3. General Practitioners' attitudes to HIV and AIDS

The project is undertaking a survey of the attitudes of GPs in Ireland to people with HIV and AIDS. This will identify the current involvement of GPs in the care of patients with HIV, and point to areas of importance in considering GPs' future training needs.

## 4. Cohort analysis of HIV seroprevalence in IVDUs in the involved general practices.

Data on the seroprevalence of HIV infection in intravenous drug users (IVDUs) who have attended the two general practices has been collected and is currently being analysed. Cohort seroprevalence rates (the relative infection rates among those who first started to use drugs in different years) will shortly be available for publication.

## 5. IVDU use of GP services

A questionnaire study has been carried out jointly with the AIDS Resource Centre at Baggott Street on the use of GPs by drug users attending there. All attenders at the ARC for a three month period were questioned and analysis of the data has now been completed. This material will provide valuable insights into an area where virtually no data has previously been available; the study is now being prepared for publication.

## Future developments

The research projects outlined above will provide sufficient data to enable guidelines and educational materials for general practitioners to be produced. Discussions are being held with the Clinical Review and HIV/AIDS Committees of the ICGP about the implementation of this material.

At the end of Year 1 of the Unit (Jan. 1993), analysis and publication of research material will form the basis for these educational programs. The next interim report of the Unit will outline these plans.

Appendix 1. Staff of HIV Primary Care Research Unit

Prof B. Shannon (Chairman)  
Dr. F. D. O'Kelly (GP Liaison)  
Prof. G. Bury (Project Leader)

Salaried staff:

Dr. F. Bradley (Research Fellow)  
Mr. O. Hegarty (Clinical Psychologist)  
Ms. S. Dowling (Dietitian)

Further appointments to be made:

Secretary (part-time)	March 1992
Social Worker (part-time)	March 1992
Research psychologist (full-time)	April 1992
Liaison nurse (half-time)	Jan. 1993

## Appendix 2. Guidelines for patient monitoring

Group I:	Asymptomatic and T4 count >400
Group II:	Symptomatic or T4 count <400 but patient doesn't want AZT or referral.
Group III:	Patients on AZT

All patients who have not had a T4 count done in the last 3 months should have one carried out at the first opportunity after the start of the project (ie January 1 1992).

### Staging

It would be useful to include in the notes an assessment of staging of HIV disease at each consultation with patients. The current CDC classification (which will be used throughout the study) is summarised below:

- I. Acute Infection (seroconversion illness)
- II. Asymptomatic
- III. Persistent Generalised Lymphadenopathy  
(longer than 3 months)
- IV.
  - a. Constitutional Symptoms
  - b. Neurological Disease
  - c1. Infectious Diseases = AIDS
    - Pneumocystis Pneumonia
    - Cryptosporidiosis
    - Cytomegalovirus infection
    - Toxoplasma
  - c2. Other infectious Diseases
    - Candida
  - d. Secondary Cancers
    - Kaposi's
    - Lymphoma
  - e. Other conditions

GROUP 1 : Asymptomatic, T4 count >400

See every THREE MONTHS

Clinical exam

weight  
glands  
skin/mouth lesions  
other problems

Laboratory Monitoring

- T4 count
  - >400: repeat 3 monthly
  - 200-400: consider AZT; refer
  - <200: discuss with consultant/urgent referral

- FBC + platelets: 3 monthly

if \* Hb falls by 25% of baseline, or ) repeat in  
\* WCC falls by 50% of baseline ) two weeks

if fall in count is persistent, refer or discuss with consultant.

GROUP II : T4 count <400 but not yet on antiviral treatment

Clinical exam - six weekly if stable

weight  
glands  
skin/mouth lesions  
other problems

Laboratory monitoring

- T4 count - three monthly

- FBC + platelets:

six weekly if stable

if \* Hb falls by 25% of baseline, or ) repeat in  
\* WCC falls by 50% of baseline ) two weeks

if fall in count is persistent, refer or discuss with  
consultant.

Treatment .

- Strongly consider Cotrimoxazole prophylaxis,

960 mgs nocte.

- Antiviral treatment (AZT) should be considered.

Refer/discuss with consultant.

GROUP III : Those on AZT

Clinical exam - six weekly if stable

weight  
glands  
skin/mouth lesions  
other problems

Laboratory monitoring

- T4 count - three monthly

- FBC + platelets:

fortnightly for one month when AZT is commenced

six weekly if stable

if \* Hb falls by 25% of baseline, or ) repeat in  
\* WCC falls by 50% of baseline ) two weeks

if fall in count is persistent, refer or discuss with consultant.

Treatment

All patients in this group should be on Cotrimoxazole prophylaxis, 960 mgs nocte. If this is poorly tolerated consider changing to Pentamidine via nebuliser.

The definition of an appropriate role for the general practitioner in the management of HIV disease will be undertaken once analysis of data has been carried out. The implementation of educational, planning and other strategies will then be possible based on this information.



COMHAIRLE NA n-OSPIDEAL.

A.I.D.S. AT CONSULTANT LEVEL

REPORT OF THE COMHAIRLE COMMITTEE.

[Adopted by the Comhairle at its meeting on 20th March 1992]

SECTION 1 - INTRODUCTION

- 1.1 In January, 1991, following consultation with the Department of Health, the Comhairle established a committee with the following terms of reference:-

"Having regard to the policy of the Department of Health and following examination of the issues involved and consultation with appropriate interests, to make recommendations to the Comhairle on mechanisms to improve the management of A.I.D.S. patients at consultant level and to clarify the role of the different specialties in the services for persons who are H.I.V. positive and/or who have A.I.D.S."

- 1.2 The following members were appointed to serve on the committee:-

Dr. M. Darling (Chairman)  
Dr. J. Buttner  
Ms. C. Carney  
Professor D. Coakley  
Dr. K. Egan  
Professor M. Fitzgerald  
Mrs. A. Kelly  
Dr. S. Ryan  
Professor O.C. Ward  
Mr. G.P. Martin (Chief Officer)

- 1.3 In addition, the Comhairle, with the approval of the Minister for Health, invited Dr. J. Walsh, National A.I.D.S. Co-Ordinator, Department of Health, to become a member of the committee. The Comhairle gratefully acknowledges the significant contribution to the work of the committee made by Dr. Walsh.

- 1.4. Mr. T. Martin, Secretary to the committee, was mainly responsible for the drafting of the Report. He was assisted by Ms. C. Hickey, Executive Officer.

- 1.5 The committee held its initial meeting in March 1991. In pursuance of its task, the committee engaged in a wide-ranging information-gathering and consultation programme. In addition to seeking the views of all appropriate health agencies, the committee circulated a confidential questionnaire which was designed to get the maximum amount of relevant information on the current position in relation to H.I.V./A.I.D.S. patients and the services available for them. Most agencies completed the questionnaire, in particular, the section relating to hospital services.
- 1.6 The committee also sought and received written submissions from the Royal College of Physicians of Ireland; the Faculty of Paediatrics; the Faculty of Pathology; the Faculty of Public Health Medicine; the Royal College of Surgeons in Ireland; the Institute of Obstetricians and Gynaecologists; the Irish Thoracic Society; the Irish College of General Practitioners; the Irish Division of the Royal College of Psychiatrists; and the Society for the Study of S.T.D. in Ireland.
- 1.7 In order to get a clear view of the nature and extent of the H.I.V./A.I.D.S. problem; to familiarise each member with the range of medical services currently provided; and to get some idea of current and future needs, the committee also consulted with a variety of individual doctors directly involved in the provision of services to H.I.V./A.I.D.S. patients i.e. Dr. F. Mulcahy, Consultant in Genito-Urinary Medicine, St. James's Hospital; Dr. E. Griffin, Consultant Neonatologist, Coombe/Crumlin Hospitals; Dr. I. Hillery, Director, Virus Reference Laboratory; Dr. F. O'Kelly, General Practitioner, Dublin; Dr. E. Dooley, Director, Prison Medical Services; Dr. O. Carey, Medical Officer, Mountjoy Prison; Dr. C. Bredin, Consultant Respiratory Physician, Cork Regional Hospital; Dr. J. Barry, Co-Ordinator of A.I.D.S. and Drug Services, Eastern Health Board; Dr. E. O'Connor, Medical Superintendent, Cherry Orchard Hospital; Dr. L. Pomeroy, Director A.I.D.S. Resource Centre, Baggot Street and Dr. M. Kearney, Consultant in Palliative Medicine, Our Lady's Hospice, Harold's Cross. The committee visited St. James's Hospital, the Drug Treatment Centre and Mountjoy Prison and had discussions in each with the appropriate management and medical personnel.
- 1.8 Representatives of the committee visited and engaged in detailed discussions with medical and management representatives of St. Mary's Hospital, Paddington, London and Lothian Health Board/City Hospital, Edinburgh in November 1991.

- 1.9 The committee also visited and had detailed discussions with representatives of the Mater Hospital; Beaumont Hospital; the Children's Hospital, Temple Street; Our Lady's Hospital, Crumlin; Eastern Health Board/Cherry Orchard Hospital; the Virus Reference Laboratory, U.C.D.; and the Southern Health Board/Cork Regional Hospital. At the committee's request, Dr. E. McHale, A/Director of Community Care and Medical Officer of Health, made a written submission to the committee in relation to services for H.I.V./A.I.D.S. patients in the Western Health Board area.
- 1.10 A number of international reports on the organisation of A.I.D.S. services and data on the incidence of the disease were studied by the committee as well as the Government's A.I.D.S. Strategy dated November 1991 (see Appendix A). Policy documents prepared by Comhairle na n-Ospidéal in relation to sexually transmitted diseases (October 1977) and infectious diseases (October 1978) were also considered. These are set out in Appendices B and C respectively.
- 1.11 The programme of consultation and visitation, compilation of information and consideration of submissions described above had a significant influence on the committee's thinking. The volume of documentation considered by the committee was extensive and, for reasons of size, is not appended to this Report.
- 1.12 The committee wishes to record its sincere appreciation to the many people and agencies in Ireland, London and Edinburgh who assisted in its task by providing information/views either in writing or through discussion. A special word of thanks is extended to those who facilitated and participated in the discussions during the visits to St. Mary's Hospital, Paddington and the City Hospital, Edinburgh. The information and advice imparted and the impressions formed during the visits have been particularly helpful in reaching the conclusions set out in this Report.

National AIDS Strategy Committee

Interim Report of AIDS/HIV Surveillance/Epidemiology Sub-Committee

1. Introduction

AIDS was identified as a clinical entity in 1981. Diagnosed cases have been reported to the Department of Health since 1982. Serological surveillance of the disease became possible in 1985 and was initiated in Ireland on a voluntary linked basis in September 1985.

The epidemiological development of AIDS and HIV infection in Ireland is similar to that experienced in other Western European countries. From 1982 to 1985 cases were reported in homosexuals and haemophiliacs and the condition was seen as largely imported disease. When sero-prevalence monitoring became possible in 1985 it was apparent that the HIV virus was indigenous in the country and that a particular problem existed in relation to the spread of HIV infection in IV drug abusers.

To date we have 266 cases of AIDS reported which meet the CDC/WHO definition. Some 1,188 people have tested HIV positive. The percentage of IV drug related cases is now 39.5% of all cases as compared to 10.5% in 1986. This movement of the epidemic towards the drug abuser has been accompanied by a steady increase in the number of heterosexual cases. 9% of Irish cases are heterosexual. In 1986 we had no heterosexual case in Ireland.

Is AIDS/HIV slowly becoming a heterosexual disease? Can AIDS/HIV infection with its close direct relationship with the drug epidemic be controlled. Better surveillance of HIV infection is essential if these questions are to be answered. In the European context the problems of HIV surveillance and in particular unlinked anonymous blood seroprevalence monitoring over a number of years are being discussed. It is difficult to see given the 4 to 10 years incubation period of full AIDS how the future

surveillance of the spectrum of HIV infection can be carried out without improved seroprevalence monitoring.

AIDS/HIV Epidemiological/Surveillance Sub-Committee

The sub-committee was set up by the National AIDS Strategy Committee with the following terms of reference:-

"To consider the development of a sero-surveillance programme to determine as accurately as possible the spread of HIV by category of person and by region.

To consider the provision of information by the Virus Reference Laboratory, U.C.D. with a view to identifying the regional spread of the disease".

2. The sub-committee set itself the following targets:-

- a) to ensure that sero-surveillance programmes are appropriately designed,
- b) to ensure that such programmes provide information to identify the regional spread of infection, and
- c) as an initial step to amend existing AIDS notification forms and HIV test requests in order to capture information on an anonymous but regional basis. The existing notification documentation can be amended to provide information on Dublin Postal Code/County basis (proposed amended forms at Appendix A).

3 (i) The sub-committee recommends that AIDS cases should continue to be reported centrally as at present which has been the practice since 1982. However, that the reporting form should be amended to indicate the county, or in the case of Dublin the postal code, of the case and that this should be done

without prejudice to the confidentiality of the case. Confidentiality must remain the most important aspect of case reporting.

- (ii) The sub-committee recommends that HIV positive test requests to the National Reference Laboratory indicate the health board area, or in the case of Dublin the postal code, of the case and that the existing request form be amended appropriately. Existing confidentiality of these tests will be maintained.
- (iii) The sub-committee accepts that the provision of information to health boards regarding the numbers of HIV positive persons and AIDS cases in their area is necessary for the rational planning of services and programmes. We recommend, therefore, that information on the regional spread of infection, both AIDS notifications and HIV positive tests be made available to health boards on a monthly basis.
- 4. The sub-committee is examining the feasibility of establishing new surveillance programmes which would monitor the spread of HIV infection in the heterosexual population under the following headings:-
  - (a) Anonymous unlinked testing of Blood Specimens of Pregnant Women (already being tested for rubella).
  - (b) Anonymous unlinked testing on new-born infants (currently being tested for PKU using the Guthrie card).
  - (c) Anonymous unlinked testing of blood from out-patient's departments of General Hospitals.
  - (d) Anonymous unlinked testing of blood of hospital admissions.

In addition the sub-committee is considering the benefit of new surveillance programmes which would monitor the spread of HIV infection in 'high-risk' groups under the following headings:

- (i) Voluntary unlinked testing of blood from S.T.D. clinic attenders.
- (ii) Voluntary unlinked testing of blood from drug treatment attendee clinics.

5. Careful appraisal of the data currently available suggests that the AIDS virus HIV is largely confined to certain behavioural risk-groups and their immediate sexual contacts.

In this situation, which includes a steady rise in the rate of the spread to the heterosexual population, knowledge of the rate at which the virus is spreading will become increasingly important. This information will be crucial for targetting and sustaining strategies to prevent and care for AIDS.

Unlinked testing provides an exceptional opportunity to establish the level of infection both in high-risk groups and in the heterosexual population. Any future surveys which rely solely on named (linked) testing of volunteers may be flawed by changing attitudes of both subjects and professionals to allow the test. However, voluntary linked testing does provide opportunities for detailed follow-up of sentinel infected individuals.

6. The unlinked testing for HIV antibody in pregnant women is considered to represent the best option for obtaining data on the transmission of the virus amongst the heterosexually active population.

The Rotunda Hospital is at present carrying out a pilot scheme on ante-natal mothers.

7. The sub-committee is also considering the possibility of availing of the existing P.K.U. test on newborn infants to include an unlinked HIV test. The sub-committee is satisfied that unlinked anonymous testing of dried blood spots routinely collected on Guthrie cards for neo-natal screening is a feasible method for monitoring HIV prevalence in women at time of delivery.
8. To test the logistics and cost effectiveness of different sero-surveillance programmes the sub-committee is considering the establishment of pilot schemes dealing with the following groups:-
  - a) the testing of blood specimens of pregnant women (Rubella) one location outside of Dublin, (Rotunda pilot scheme to continue)
  - b) the Guthrie test on infants.

The feasibility, of a pilot scheme for unlinked testing of blood samples from the out-patients/in-patients department in one hospital is also being considered.

In addition the committee are examining the benefit of sero-prevalence studies of high-risk groups through STD clinics and drug treatment clinics.

The committee are conscious of the cost factor involved in implementing HIV linked surveillance surveys particularly as such surveys must be carefully designed, on a large scale, and sustained for at least 4 to 5 years. Final recommendations will take all these factors into account.



Patient code :   |   |   |   |   |   |   |

Patients Initials: \_\_\_\_\_

## - SEX M F - Age at time of diagnosis \_\_\_\_/\_\_\_\_

at onset of illness: \_\_\_\_\_

3 → Ireland / Dublin Postal Code  
Country .

DATE PATIENT FULFILLS CDC CASE DEFINITION         /    /    |    /    /   

- OPPORTUNISTIC INFECTION .....	YES	NO
- SPECIFY THE FIRST ONE _____		
- KAPOSI'S SARCOMA .....	YES	NO
- LYMPHOMA AND MALIGNANCIES .....	YES	NO
- HIV ENCEPHALOPATHY .....	YES	NO
- HIV WASTING SYNDROME .....	YES	NO
- LYMPHOID INTERSTITIAL PNEUMONIA ....	YES	NO
- PROGRESSIVE MULTIFOCAL LEUKOENCEPHALOPATHY	YES	NO
- EXTRAPULMONARY M. TUBERCULOSIS .....	YES	NO
- SALMONELLA SEPTICEMIA .....	YES	NO
- OTHER SPECIFY: _____		

*MODE OF TRANSMISSION:				HETEROSEXUAL	YES	NO
HOMOSEXUAL	YES	NO	UNK	IF YES, SPECIFY EXPOSURE:		
BISEXUAL	YES	NO	UNK	- HIV(+)	PARTNER	YES NO
IV DRUG ABUSER	YES	NO	UNK	- PARTNER RISK GROUP:		
HAEMOPHILIAC	YES	NO	UNK	. Haemophiliac	YES	NO
TRANSFUSED SINCE				. Bisexual	YES	NO
1978	YES	NO	UNK	. IVDA	YES	NO
DATE	__	__	__	. Transfusion	YES	NO
				. Unknown	YES	NO
MOTHER TO CHILD					YES	NO

Other, specify \_\_\_\_\_

\*STATUS Alive | | Dead | | Date of death. | | | | | | | |

NOTIFYING PHYSICIAN:  
HOSPITAL:

DEPARTMENT:  
TEL:

INSTRUCTIONS FOR FILLING IN THE QUESTIONNAIRE FOR AIDS SURVEILLANCE

## \*MODE OF TRANSMISSION

## HETEROSEXUAL TRANSMISSION:

PROVEN: HIV (+) PARTNER

PRESUMED: PARTNER AT RISK BUT FOR WHOM SEROLOGICAL STATUS IS  
UNKNOWN:

- haemophiliac
- IV drug abuser
- bisexual
- transfusion recipient
- originating from endemic areas

UNDETERMINED: subject for whom the mode of transmission is unknown.

OTHER: none of the above: please specify e.g. needlestick for  
health care workers.

**Request for HIV test.**

Surname initial \_\_\_\_\_

Forename initial \_\_\_\_\_

Sex M ☐

F ☐

Date of Birth

Residence: Dublin Postal code     
Rest of Ireland County \_\_\_\_\_

Requesting Doctor

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Previous test

Yes ☐ date

No ☐.

**Risk category.**

(tick most probable risk for this test.)

Homosexual sex ☐

Heterosexual sex "high risk" partner ☐

"low risk" partner ☐

Partner abroad ☐

Injecting drug use ☐

Blood haemophilia ☐

transfusion (Ireland) ☐

transfusion abroad ☐

Mother-child "low risk" parent ☐

"high risk" parent ☐

Occupational exposure

☐  
date

**MEMBERSHIP OF HIV/AIDS SURVEILLANCE EPIDEMIOLOGY SUB-COMMITTEE**

MR. KIERAN HICKEY EASTERN HEALTH BOARD, (CHAIRMAN)

DR. J.H. WALSH, DEPARTMENT OF HEALTH

DR. I. HILLARY, VIRUS REFERENCE LABORATORY

DR. M. SCULLY, EASTERN HEALTH BOARD

MR. M. LYONS, DEPARTMENT OF HEALTH

MR. H. MAGEE, DEPARTMENT OF HEALTH

MS. H. GRIFFEN, BODY POSITIVE

## NATIONAL AIDS STRATEGY

### SUB-COMMITTEE ON EDUCATION AND PREVENTION

#### Terms of Reference

To identify the education/information requirements (both formal and informal) needed to respond to the evolving epidemiology of the disease, with particular reference to the heterosexual community.

#### Sub-Committee Members

Mr Gerry McCartney (Chairperson),	Department of Health
Mr Tom Gillen,	Department of Education
Mr Tony O'Gorman,	Department of Education
Ms Anne Marie Jones,	Dublin AIDS Alliance
Ms Deirdre Seery,	Cork AIDS Alliance
Dr Joe Barry,	Eastern Health Board

The following people were co-opted onto the sub-committee

Dr Jim Kiely,	Department of Health
Mr Michael Lyons,	Department of Health
Mr Owen Metcalfe,	Department of Health
Ms Deirdre Foran,	AIDS Resource Centre
Ms Sheila Heffernan,	Community Care Area 5
Ms Joan Walshe,	Department of Education
Ms Maeve O'Brien (Secretary),	Department of Health

## NATIONAL AIDS STRATEGY

### SUB-COMMITTEE ON EDUCATION AND PREVENTION

#### RECOMMENDATIONS

This sub-committee's remit was to examine the primary role of prevention and education as an integral part of an overall strategy to prevent the transmission of HIV and AIDS, and to make recommendations on future strategies in this area.

The objective of preventive measures is to limit the spread of HIV infection through public awareness campaigns, community-based prevention initiatives and improved infection control procedures. All these initiatives should raise awareness about the disease, how the infection is spread and how the risk of infection can be eliminated and reduced. In the absence of a cure for the disease or a vaccine against infection, preventive measures must remain at the forefront of government policy.

The committee recognised that knowledge of and instruction in safer sex and the wider availability and proper use of condoms has a major role to play in preventing the spread of AIDS. In general, the committee feels that there should be no restrictions imposed on outlets who wish to sell condoms. In particular, it is recommended that the legislation be amended, one to allow for sale of condoms from vending machines and two, to allow for distribution of free condoms by statutory and voluntary agencies involved in HIV prevention.

It also considered that whilst HIV preventive services such as methadone maintenance and needle exchange were extremely important strategies these were more appropriate topics for consideration by the Care and Management Sub-Committee. It therefore confined its work to education and information.

The committee reviewed the initiatives and interventions which have been implemented by both the voluntary and statutory sectors since the AIDS problem emerged and considered that the combination of both voluntary and statutory input constitutes the most effective framework for delivering education and information on HIV and AIDS to particular target groups. The committee recommends that this should continue and that co-ordination between both sectors will lead to more effective service delivery. In order that this liaison can continue effectively, the committee recommends that funds to the voluntary sector should be increased.

In carrying out its work, the committee took cognisance of the preventive strategies already undertaken and has based its conclusions and recommendations on the experience gained through the implementation of various preventive programmes to date, together with the latest information regarding the evolving epidemiology of the disease. In this context, the committee is of the view that preventive strategies should be targeted to meet the needs of particular groups as well as giving due recognition to the fact that it is individual behaviour that puts a person at risk.

The strategies reviewed by the committee were:

- mass media initiatives;
- leaflet dissemination;
- targeted educational interventions;
- outreach initiatives;
- video manufacture and dissemination.

While all these approaches have a level of effectiveness, it is important that continuing research and evaluation are undertaken in order to assess the effectiveness of interventions.

The committee realises that the provision of information in and of itself will not prevent the spread of HIV, therefore it is important that dissemination of information is accompanied by a wide variety of other strategies which will help influence people's behaviour in such ways that the risk of further infection is greatly minimised.

In the light of this review and of the emerging epidemiology of the disease, the committee decided that the following groups should be targeted with specific interventions:

- (A) GENERAL PUBLIC
- (B) YOUNG PEOPLE
- (C) YOUNG EMIGRANTS
- (D) DRUG USERS
- (E) HOMOSEXUALS / MEN WHO HAVE SEX WITH MEN / BISEXUALS
- (F) PROSTITUTES
- (G) HEALTH STAFFS
- (H) PRISONERS AND EX-OFFENDERS

As a general principal, it was agreed that education and prevention work should not in any way contribute to prejudice and stigmatisation among those who are or may become HIV positive.



**(A) GENERAL PUBLIC**

It is recommended that the dissemination of the Health Promotion Unit's leaflet "AIDS - The Facts" should be continued.

It is also recommended that on-going, regular media campaigns be implemented on a national and local level emphasising different aspects of the problem from time to time as appropriate. It is recommended that a series of radio advertisements should be produced in time for Irish AIDS Day on the 16th of May and a bigger mass-media campaign be developed to coincide with World AIDS Day on December 1st.

Liaison should be built up between the regional health promotion officers, where they exist, and the local radio stations.

**(B) YOUNG PEOPLE**

To capitalise on the work already carried out with the Departments of Health and Education's AIDS resource materials for second-level schools (14-18 year olds), this committee recommends that the Department of Education in conjunction with the Department of Health should be responsible for developing appropriate materials accompanied by associated in-service which would target earlier years. It is recommended that early school leavers from post-primary schools should receive particular attention along with those from primary schools who are likely to drop out early. The committee recognises that the voluntary agencies have an important role to play as a resource in the formal and informal education sector.

**(C) YOUNG EMIGRANTS**

This committee recognises that the most effective means of reaching this group is through the production of an information leaflet which would be made available at travel agents, student welfare offices, student medical centres, voluntary agencies, youth information offices as well as at all points of exit from the country. It is recommended that the Health Promotion Unit should be responsible for developing this leaflet in conjunction with relevant agencies. There should be on-going links with emigrant groups abroad to monitor and evaluate the situation.

**(D) DRUG USERS**

This committee recognises that intervention of an outreach nature based on one-to-one communication is the most effective method of reaching this group. It is also recognised that there is merit in providing guidance through outlets such as the AIDS Resource Centre in Baggot Street, community drug teams, proposed

satellite HIV / drug clinics and the voluntary sector, in conjunction with the current needle exchange and methadone maintenance programmes. Members of this target group should be consulted in the development of future informational materials. This will necessitate increased expenditure for the voluntary sector.

**(E) HOMOSEXUALS / MEN WHO HAVE SEX WITH MEN / BISEXUALS**

It is recognised that the criminalisation of homosexuality inhibits promotional work in this field.

This committee recommends that information and education should be provided by developing an Outreach programme. The committee recognised the need to develop an Outreach programme particularly in the major population centres. Safer sex messages need to be part of an on-going Outreach programme. Recent studies have found that a high proportion of gay men continue to be involved in at-risk behaviour. This will necessitate increased expenditure for the voluntary sector.

It is also recommended that funding for appropriate literature should continue to be made available to the relevant agencies.

**(F) PROSTITUTES**

The committee recognises that the most effective method of reaching this group is through an Outreach programme and recommends the establishment of same. It is recommended that members of this group should be consulted in the development of educational materials. This will necessitate increased expenditure for the voluntary sector.

**(G) HEALTH STAFFS**

In-service and pre-service training initiatives are seen as being the most effective way of reaching Health Staffs. Core issues which need to be addressed include:

- The implementation of effective infection control procedures. To ensure this, hospitals and other health care providers need policy guidelines in this area e.g. in relation to needle stick injuries.
- The attitudes and behaviours to be adopted towards HIV positive people and people with AIDS.

### General Training:

The committee recognises that the establishment of a specific HIV/AIDS training unit would constitute the provision of a very important service to meet training needs of many groups working in the HIV/AIDS field. The proposal to establish such a training unit should be structured in conjunction with workers already in the field.

### **(H) PRISONERS AND EX-OFFENDERS**

The committee acknowledges that certain difficulties arise in this particular area and many of these issues come under the remit of the Anti-Discrimination Sub-Committee. In recognition of the fact that high risk behaviour occurs in prison, it is acknowledged that the dissemination of information reinforced by counselling is absolutely essential to prevent the spread of the virus within this environment.

To do this the committee recommends:

- (a) The establishment of an organisational structure in the form of a centralised committee that would allow for the dissemination of HIV/AIDS information accompanied by a one-to-one counselling service within the prison context.
- (b) A process of desegregation should be initiated as soon as possible.
- (c) A policy of confidential testing should be adopted.

### CONCLUSION

Whilst the avoidance of at-risk behaviour is the surest way of minimising the possibility of infection, everyone involved in the implementation of preventive policies must recognise that large numbers of people will continue to behave in a way that exposes them to infection. It is therefore essential that much of the preventive effort is concentrated on making risk practices as safe as possible, as well as trying to change long-standing behaviour. By following these recommended interventions, all responsible agencies and individuals can build preventive programmes that can be adapted to meet changing needs. Only in this way can we be confident that the necessary steps are being taken to tackle what is a significant threat to public health both nationally and internationally.

It is recognised that a high level of priority attaches to all the recommendations made, but that variable periods of time will be required for the implementation of the recommendations. It would be useful therefore to divide the recommendations into those which can be addressed in the short term and those which require longer term planning and structural arrangements to be put in place.

In the short term it is recommended that the following be addressed:

1. A series of radio advertisements should be produced in time for Irish AIDS Day on May 16th and a bigger mass-media campaign be developed to coincide with World AIDS Day on December 1st.
2. Liaison should be built up between the regional health promotion officers, where they exist, and the local radio stations.
3. The legislation should be amended to allow for sale of condoms from vending machines and also to allow for free distribution of free condoms by statutory and voluntary agencies involved in HIV prevention.
4. In-service and pre-service initiatives should be used in order to target health staffs.
5. Intervention of an Outreach nature based on one-to-one communication is the most effective method of reaching the drug using community.
6. (a) An Outreach programme should be developed particularly in the major population centres in order to reach homosexuals / bisexuals / men who have sex with men.  
  
(b) Funding for appropriate literature should continue to be made available to the relevant agencies in contact with the above group.
7. Funds to the voluntary sector should be increased.
8. (a) In order to reach prostitutes an Outreach programme should be established.  
(b) Members of this group should be consulted in the development of educational materials.

In the longer term it is recommended that the following on-going initiatives should be undertaken:

1. Co-ordination of input from the voluntary and statutory sectors should be continued.
2. Preventive strategies should be targeted to meet the needs of particular groups as well as giving due recognition to the fact that it is individual behaviour that puts a person at risk.
3. Continuing research and evaluation should be undertaken in order to assess the effectiveness of interventions.
4. The dissemination of the Health Promotion Unit's leaflet "AIDS - The Facts" should be continued.
5. The Department of Education in conjunction with the Department of Health should be responsible for developing appropriate materials accompanied by associated in-service which would target earlier years.
6. Early school leavers from post-primary schools should receive particular attention along with those from primary schools who may be likely to drop out early.
7. An information leaflet should be developed by the Health Promotion Unit in conjunction with relevant agencies and should be made available at travel agents, student welfare offices, student medical centres, voluntary agencies, youth information offices, as well as at all points of exit from the country. There should be on-going links with emigrant groups abroad to monitor and evaluate the situation.
8. The establishment of a specific HIV/AIDS training unit would constitute the provision of a very important service to meet the training needs of many groups working in the HIV/AIDS field.
9. Dissemination of information reinforced by counselling is absolutely essential to prevent the spread of the AIDS virus within the prison system.

NATIONAL AIDS STRATEGY COMMITTEE  
REPORT OF SUB-COMMITTEE ON DISCRIMINATION

Introduction

1. The sub-committee was set up by the National Aids Strategy Committee with the following terms of reference:-

"To develop recommendations to avoid discrimination against persons with AIDS/HIV".

2. The original membership of the sub-committee was:-

Mr. Frank Dunne (Chairman).

Dr. Enda Dooley.

Mr. Tony Geoghegan.

Mr. Tony O'Gorman.

Mr. John Rochford.

Ms. Sandra Walsh (Secretary).

Ms. Helen Griffin.

The sub-committee decided to co-opt the following additional members to assist them in their work:

Mr. Christy Hill (for Helen Griffin)

Mr. Mick Quinlan.

Mr. Noel Usher.

3. The sub-committee set itself the target of producing a report by the end of March, 1992. It had its first meeting on 13 February, 1992 and held six meetings in all. A summary of our recommendations is in Appendix 1.

General

4. Persons with Aids or who are HIV positive are entitled as citizens to the fundamental rights which are accorded to all citizens in the Constitution. The Constitution, in particular, confers the following personal rights:

Art. 40.1 " All citizens shall, as human persons, be held equal before the law".

Art. 40. 3.1 "The State guarantees in its laws to respect and, as far as practicable, by its laws to defend and vindicate the personal rights of the citizen".

Art. 40. 3.2 "The State shall, in particular, by its laws protect as best it may from unjust attack and in the case of injustice done, vindicate the life, person, good name and property rights of every citizen"

The State, moreover, is party to a range of international agreements to promote human rights. Given this background, we would have been surprised to find evidence of institutionalised discrimination, that is, discrimination which was given the force of law. We received no evidence of such discrimination in relation to persons with Aids or who are HIV-positive.

5. It was represented to us, however, that the law which made

male homosexual acts a criminal offence discriminated against persons at high risk of infection. The law had driven homosexual activity underground. On that account it was less likely that gay men would readily identify themselves or volunteer for testing/treatment. This made the control of the spread of infection so much more difficult for public health authorities.

It was represented also that the stigma and feelings of guilt arising from the statutory prohibition were driving some gay men to other activities, such as IV drug abuse, which increased the risks of infection for them.

6. The sub-committee understands that the question of decriminalising homosexual activity among consenting adult males is already under review by the State. On 12 December, 1990, the then Minister for Justice said that he would be bringing proposals to the Government on the issue. In response to a Parliamentary Question on 4 February 1992 (Dail Debates, Vol. 415, No. 3 Col.811) he said that work was progressing on the preparation of legislation as quickly as other urgent legislative priorities and available resources allow. Apart from the fact of possible discrimination there is a serious public health issue



involved in relation to the criminalisation of homosexual acts. We recommend that consideration of decriminalisation of homosexual acts between male adults should be given priority.

Discrimination in practice

7. There is no evidence of direct institutionalised discrimination. Some indications were that persons with Aids or who were HIV-positive had either experienced discrimination or have the perception that they were being discriminated against in their daily lives. In order to get as full a picture as possible we decided to ask people themselves infected, and people working on a daily basis with persons infected, or at high risk of becoming so, to find out in what respect they perceived themselves as being discriminated against. Submissions were received from the list in Appendix 2. Based on the information which came to our notice we decided to proceed with our consideration under the following headings:-

- Segregation in prisons.
- Health care guidelines.
- General health services.
- Welfare benefits.
- Aids in the workplace.

- Insurance and other commercial transactions.
- Housing.
- Schools and colleges.

In the following paragraphs we will deal with each heading in turn.

#### Segregation in Prisons

8. The position paper on this topic submitted by Dr. Enda Dooley, Director, Prison Medical Service, to the Strategy Committee, is reproduced in Appendix 3 to this report. We understand that the Advisory Group on Communicable Diseases in Prisons which is referred to in the final section of that position paper and which is expected to deal with the topic of segregation, will submit its report shortly.
9. The following arguments for and against segregation in prisons were brought to our attention:

#### For

Health Care: Segregated prisoners have a higher standard of general health care, delivered by two part-time GPs assigned exclusively to the segregated prisoners; continuation of this high standard of health care might be difficult in a non-segregated environment;

Regime: It can be said that segregated prisoners have a more relaxed regime in that they are not compelled to do normal prison work or chores;

Protection: There is a risk that prisoners known to be infected could be ostracised, if not physically abused, by the general body of prisoners in a non-segregated situation;

Temporary Releases: Segregated prisoners generally are given more generous short-term temporary releases, and earlier final releases, than the general body of prisoners; it might be difficult to continue the concession in a non-segregated situation because other prisoners could then successfully claim to be discriminated against;

Supervision: Segregation makes supervision and control (for example, of drugs) easier.

Against

Regime: Many segregated prisoners would find it easier to "do time" with the wider range of activities available to the general body of prisoners;

Association: Segregated prisoners are denied normal social contacts with the main body of prisoners,

whether at work or recreation, which can ease the tedium of imprisonment;

Status: Segregated prisoners see themselves as social outcasts and the feeling of isolation so engendered makes it more difficult to cope with their lot;

Physical Conditions: The physical conditions in the segregated areas are poor and it is too much to expect them to cope with such conditions;

Supervision: Tight supervision and control, which is the inevitable consequence of segregation, can be oppressive.

10. The message coming from segregated prisoners is that they feel victimised and discriminated against by the practice of segregation. We recognise that there are many sides to the problem. It is clear, however, that there is no compelling medical justification for segregation. A decision to retain or abolish segregation must, therefore, have regard to the correct balance to be struck between management/supervisory needs and the need to provide conditions as humane as possible for such prisoners. We sympathise with the argument that, on the whole, segregation is unnecessarily discriminatory and favour ending it. We would not expect a final decision on the

matter to be taken, however, in advance of the report of the Advisory Committee referred to above which is expected to consider the subject in depth. We recommend, therefore, that segregation in prisons should cease and that our view be taken into account when the Advisory Committee's report is being considered by the Minister for Justice. We, furthermore, recommend that all prisoners receive the same standard of medical care as is presently afforded to known HIV positive prisoners.

#### Health Care Guidelines

11. Among the functions of the Medical Council is that

"It shall ... give guidance to the medical profession generally on all matters relating to ethical conduct and behaviour".

[Medical Practitioners Act 1978, Section 69 (2)]

To guide doctors in relation to these matters the Council publishes at intervals "A Guide to Ethical Conduct and Behaviour and to Fitness to Practise". The present edition (3rd) was published in 1989 and it is understood that a new edition is due to be issued during the coming year. Under the 1978 Act the Council can censure Doctors (to the extent of debarring them from practising) for serious proven breaches of this ethical code.

12. The 1989 edition of the Guidelines gave specific advice in

relation to the management (testing, confidentiality, etc.) of patients with HIV infection. Essentially they were to be treated medically as any other patient. As dental care workers are exposed to a wide variety of infectious agents in the blood or saliva of the patients they treat the Dental Council has issued guidelines on sterilization and cross infection control procedures to be followed in treating HIV-positive patients. We recommend that all patients presenting for medical or dental treatment, whether they are HIV-positive or not, should receive whatever medical or dental care and treatment is appropriate to their needs in a non-discriminatory manner and in accordance with the highest professional and ethical standards.

13. In the case of the Medical Council the Guidelines state that "Doctors do not have the right to refuse treatment on the ground of risk to themselves or of any moral disapproval but may properly refer a patient to a colleague if they have a continuous objection to a given line of treatment or feel that they do not have the personal skills or necessary facilities to undertake it". We subscribe to the obvious intent of this particular provision in the Medical Council's Guidelines. However, we recommend that medical practitioners should not use this provision to opt out of their responsibility to treat persons with HIV/AIDS.

14. During the early part of 1991 a number of prison doctors expressed their concern at the fact that certain departments in some outside hospitals were requesting the HIV status of prisoners be established (by the Prison Doctor) prior to placing them on the waiting list for surgery. This occurred even where the lifestyle of the patient did not contain any specific risk-factors. The doctors concerned considered this practice discriminatory against prisoners, purely on the grounds that they were in prison, rather than on the basis of any medical risk-factor. By requesting that the Prison Doctor establish the HIV status a further problem was raised due to the present policy of segregating known HIV-positive prisoners. Prisoners were unwilling to be tested in prison and consequently had to forego elective surgery. This poses a dilemma for the prisoner/patient and for the Prison Doctors involved. We recommend that the Medical Council should re-iterate that the same standards of care should be applied to known (or suspected) HIV-positive patients as to other patients. Furthermore, any specific investigation (including HIV testing) should be medically justifiable and only undertaken with the express informed consent of the patient following appropriate counselling.
15. In the light of the incidents cited above the advice of the Medical Council was sought in relation to apparent

discrimination against prisoners. In December 1991 a reply was received from the Medical Council indicating that - "where a patient refuses to give consent for HIV testing, the patient should be treated as HIV positive. The Council has also advised that the practise of medicine by registered medical practitioners should be the same inside prison as outside of prisons subject, of course, to the laws of the land". We recommend that the Medical Council in its guidance should emphasise that applying more stringent medical criteria (for instance in relation to placing someone on a surgical waiting list) in the absence of medical or social risk factors is inappropriate. It is perhaps worth noting that current advice in relation to dealing with blood spillages, etc., is that all patients should be treated as potentially HIV-positive and, therefore, the same precautions should be taken in these situations regardless of apparent risk.

16. Nothing in the Guidelines or in information from the medical defence bodies presently allows or justifies any lessening in the normal duty of a doctor in relation to Confidentiality or Consent when either Prisoner or HIV positive (or when both coincide) patients are involved. This is a further area where there is need for the Medical Council to provide more elaborate and precise guidance to the medical profession in this country. This is necessary because, notwithstanding the guidance to the profession



from the Council in relation to HIV-positive patients, there remains an ambivalence (in spite of developments in knowledge regarding risk of spread, etc.) among some members of the profession regarding their responsibility not to make distinctions between patients and to accept the risks which may be attached to treating patients with infectious diseases.

General Health Services

17. The sub-committee is aware that the Department of Health issued a circular to the health boards and voluntary hospitals in November 1990 in which it was stated

"where persons with AIDS/HIV require hospital treatment it should be provided in an appropriate acute hospital by the appropriate consultant depending on the nature of the clinical presentation. The Minister is concerned that each health board/your hospital should participate fully in the aspect of policy".

18. It has been represented to the sub-committee that certain hospitals are not prepared to participate in this aspect of policy. If this is true it is totally unacceptable and we recommend that the Department of Health issue a revised circular to health agencies pointing out that all hospitals must adhere to policy in this matter.

19. It has also been represented to the Sub-Committee that, within hospitals, health care staff are occasionally rude and abusive to HIV patients, sometimes carry out tests on patients for the HIV antibodies without any pre or post test counselling and without obtaining informed consent, and practise other forms of discrimination against HIV patients e.g. segregation. We recommend that all patients, regardless of their illness, receive whatever care and treatment is appropriate to their needs from health care staff in a courteous, ethical and professional manner. Any health care staff found not to be complying with this provision should be subject to the usual disciplinary procedures.

#### Funeral Arrangements

20. We understand that the use of body-bags and other practices for persons who die of Aids is highly traumatic for the next-of-kin. The prospect of this happening when they die causes particular anguish for those with Aids. Some undertakers, at least, take extraordinary steps in dealing with the bodies of people who have died from Aids. We presume that they feel it necessary to do so in order to protect their staff from the risk of infection. They may also feel that they must take such steps to avoid being sued successfully for negligence should a member of the staff become infected.

21. The basic question to be addressed is whether there is adequate medical reason for these practices. If there is a real danger of the infection being passed on from the body then there is clearly justification from a public health point of view for precautionary measures to prevent that happening. If there is no real health risk then the practices should cease. Even if there are health risks, the measures taken in laying out the deceased should be proportionate to the risks.
22. We understand that there is no known case of the infection being passed on from the body of a person who has died of Aids. This suggests that the practices we referred to are altogether disproportionate. We recommend, therefore, that the Dept. of Health examine the matter with a view to developing realistic guidelines for the handling of bodies of persons who have died from Aids.

#### Welfare Benefits

23. Many persons with HIV/AIDS are, because of their medical and financial circumstances, in receipt of the Supplementary Welfare Allowance. This Allowance is administered by the health boards' Community Welfare Officers (CWO's) on behalf of the Department of Social Welfare. The CWO's have discretion in determining eligibility for the Allowance and it has been represented to the Sub-Committee that there is a lack of uniformity of

approach in determining such eligibility not only between health boards but also between individual Community Welfare Officers.

24. The sub-committee accepts that CWO's must have some discretion in granting this Allowance. We are conscious, however, that persons with HIV/AIDS have significant outgoings in terms of exceptional expenses on travel, heating, healthy food,.etc. over and above those of many other applicants for the Supplementary Welfare Allowance. We recommend, therefore, that the Department of Social Welfare ask the health boards to bear in mind the very special needs of persons with HIV/AIDS when assessing eligibility for this Allowance. This recommendation should also apply to health boards when they are assessing the eligibility of persons with HIV/AIDS for the Disabled Persons Maintenance Allowance.
25. The Sub-Committee also believes that people with HIV/AIDS are not aware of their possible entitlement to these benefits and we recommend that the availability of such benefits be publicised in such a way as to ensure that all those who may need such benefits, and be entitled to them, are aware of their availability.
26. It has been represented to the Sub-Committee that when health boards are assessing a persons eligibility for the

DPMA a number of different people deal with the application from the time it is received until a final decision is made on eligibility. In the case of an applicant who has HIV/AIDS all of these people would, therefore, be made aware of that persons HIV status and the question of confidentiality arises. The Sub-Committee recommends that, in order to safeguard confidentiality health boards should introduce procedures to reduce the number of people dealing with such cases and ensure that such cases receive the utmost confidentiality.

27. Aids in the work-place

We made enquiries to establish if there was evidence of discrimination in the work place. The statutory bodies (Employment Equality Agency and Employment Appeals Tribunal) could not point to any particular cases although there were indications to them of possible discrimination against, for example, gay persons. We suspect from other information given to us that some discrimination exists even though it is difficult to elicit positive proof.

28. There is, clearly, potential for discrimination in the work-place either by colleagues/work-mates or employers. Discrimination by the former would be best forestalled by education/information to promote a better understanding of the condition. Educational projects which are ongoing in the Dept. of Health should, we feel, meet this need. As to

employers we took note that the Department of Finance has already taken steps to prevent discrimination in the Civil Service by the issue of "Circular 12/88 - Civil Service Policy on Aids" which is reproduced at Appendix 3. We recommend that, so far as it has not been done already, semi-State and other employer organisations should issue similar guidelines and take steps to ensure that the guidelines are followed.

Insurance and other commercial transactions

29. It was represented to the sub-committee that persons with Aids or who are HIV-positive are discriminated against in securing life and other insurances, and possibly in other commercial transactions, because of their medical status. We enquired of professional bodies in this field as to their practices. It is clear that their decisions are taken on a purely commercial basis taking into account, for example, actuarial predictions of life expectancy. This applies to a range of persons with life-threatening medical conditions and not just those with AIDS/HIV. They must do so in the interests of all policy-holders and for the protection of reserve funds.
30. We take the view that this is not discrimination in the ordinary sense in which that term is understood. Clearly, however, persons with Aids or who are HIV-positive are

placed at a disadvantage in not having access to, for example, life insurance or other death benefit cover. We can only recommend that this factor be taken into account in the application by public authorities of discretionary welfare funds.

Housing:

31. It was represented to the sub-committee that persons with Aids or who are HIV-positive were continually facing accommodation problems. There were suggestions that when they left accommodation temporarily (for example, for hospital in-patient treatment) they found themselves locked out on returning. Moreover, where they had short term accommodation difficulties (e.g. on leaving prison, home, or hospital) some voluntary hostels were refusing to accept them because of their medical condition or because of their high-risk status.
32. Where ordinary commercial accommodation is involved (e.g. private sector flats) we cannot see that the State can usefully take action to force landlords/landladies to be more considerate. Private property rights are involved and at the end of the day the right to a reserved tenancy must depend on the nature of any legally enforceable contract.
33. So far as public housing is concerned we asked Dublin and Dun Laoghaire Corporations and Dublin County Council for

information on their policy. We are satisfied from the information given to us that, far from discriminating against persons with Aids or who are HIV-positive, they take active steps to discriminate in their favour. They do not seek information on the health status of applicants but make judgements on the basis of need. If, however, the application discloses a medical condition they take it into account on a strictly confidential basis by allocating additional qualification points under guidelines approved by the Dublin Chief Medical Officer. They state that it is not correct to suggest that persons admitted to hospital are denied access to their houses on discharge.

34. We are impressed with the forward looking policy of these local authorities and it was confirmed to the sub-committee from independent sources that the policy does, in fact, work in practice. We need merely recommend that insofar as these policies may not have countrywide application, steps be taken to ensure that they are applied by all local authorities.

35. In relation to hostels two points were made i.e. that there is insufficient hostel accommodation and that even with existing accommodation persons with Aids or who are HIV-positive are often denied access because of their medical status. We recognise that there is a shortage of hostel accommodation for a multitude of disadvantaged groups of



which our target group is but one. The need is for more accommodation for all groups. However, irrespective of the the volume of available accommodation there is no justification, given the present state of knowledge about the condition, for discriminating against persons with Aids or who are HIV-positive. These hostels operate with public funding and we, therefore, recommend that it should be a condition of continued public funding that discrimination by hostels against persons with Aids or who are HIV-positive must cease.

Schools and colleges

36. We did not receive any evidence of discrimination in schools. There is potential for discrimination in schools and colleges against students who either themselves have Aids or who are HIV-positive, or who have members of their families so diagnosed. It would be prudent to take such practicable steps as are necessary to avoid such discrimination.
37. It is the view of the Department of Education that children and young persons who are infected by HIV should be able to attend school in the normal way and that principals and staffs should be aware of this view. Furthermore, there is an understanding between the Departments of Education and Health that the relevant medical staff of Regional Health

Boards are available, on request, to advise and support school staffs on issues relating to HIV.

38. We also understand that seminars and courses have been organised for post-primary teachers on HIV and Aids. We recommend that information on HIV should be available to all teachers and these seminars/courses should be open, therefore, to primary teachers as well. We recommend, also, that guidelines on first-aid and hygiene routines should be issued to all schools. It is not necessary that these guidelines should be in respect of HIV solely. Principals and staffs of schools may be expected to be alerted to the possibility that children who are infected by HIV or who have family members so infected could be isolated or even stigmatised, and also alerted to the needs of a growing number of bereaved children who have lost close relatives from Aids.

## APPENDIX 1

1. We recommend that consideration of decriminalisation of homosexual acts between adults should be given priority.
2. We recommend that segregation in prisons should cease and that our view be taken into account when the report of the Advisory Committee on Communicable Diseases in Prison is being considered by the Minister for Justice. We, furthermore, recommend that all prisoners receive the same standard of medical care as is presently afforded to known HIV positive prisoners.
3. We recommend that all patients presenting for medical or dental treatment, whether they are HIV-positive or not, should receive whatever medical or dental care and treatment is appropriate to their needs in a non-discriminatory manner and in accordance with the highest professional and ethical standards.
4. We recommend that medical practitioners should not use any provision of the Medical Council's Guidelines to opt out of their responsibility to treat persons with HIV/AIDS.
5. We recommend that the Medical Council should reiterate that the same standards of care should be applied to known (or suspected) HIV-positive patients as to other

patients. Furthermore, any specific investigation (including HIV testing) should be medically justifiable and only undertaken with the express informed consent of the patient following appropriate counselling.

6. We recommend that the Medical Council in its guidance should emphasise that applying more stringent medical criteria (for instance in relation to placing someone on a surgical waiting list) in the absence of medical or social risk factors is inappropriate.
7. We recommend that the Department of Health issue a revised circular to health agencies pointing out that all hospitals must adhere to official policy on the provision of hospital treatment for persons with AIDS/HIV.
8. We recommend that all patients, regardless of their illness, receive whatever care and treatment is appropriate to their needs from health care staff in a courteous, ethical and professional manner. Any health care staff found not to be complying with this provision should be subject to the usual disciplinary procedures.
9. We recommend that the Department of Health examine the

use of body bags and other practices for persons who have died of AIDS with a view to developing realistic guidelines for the handling of bodies of persons who have died from Aids.

10. We recommend that the Department of Social Welfare ask the health boards to bear in mind the very special needs of persons with HIV/AIDS when assessing eligibility for the Supplementary Welfare Allowance. This recommendation should also apply to health boards when they are assessing the eligibility of persons with HIV/AIDS for the Disabled Persons Maintenance Allowance.
11. We recommend that the availability of such welfare benefits be publicised in such a way as to ensure that all those who may need such benefits, and be entitled to them, are aware of their availability.
12. The Sub-Committee recommends that, in order to safeguard confidentiality health boards should introduce procedures to reduce the number of people dealing with applications for the Disabled Persons Maintenance Allowance and ensure that such cases receive the utmost confidentiality.

13. We recommend that, so far as it has not been done already, semi-State and other employer organisations should issue similar guidelines to those issued by the Civil Service to prevent discrimination in the workplace and take steps to ensure that the guidelines are followed.
14. We recommend that account be taken in the application by public authorities of discretionary welfare funds of the fact that persons with AIDS/HIV are placed at a disadvantage in not having access to, for example, life insurance or other death benefit cover.
15. We need merely recommend that insofar as the policies of the local authorities in Dublin in relation to housing for persons with serious illnesses such as AIDS/HIV may not have countrywide application, steps be taken to ensure that they are applied by all local authorities.
16. We, therefore, recommend that it should be a condition of continued public funding that discrimination by hostels against persons with Aids or who are HIV-positive must cease.
17. Information on HIV should be available to all teachers

and these seminars/courses should be open, therefore,  
to primary teachers as well. We recommend, also, that  
guidelines on first-aid and hygiene routines should  
be issued to all schools.

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## APPENDIX 2

Written submissions were received from the following:

The Irish Haemophilia Society.

Dublin Corporation.

Dun Laoghaire Corporation.

Dublin County Council.

The Gay & Lesbian Equality Network (GLEN).

Lifetime Assurance Company Ltd.

The Employment Appeals Tribunal.

The Ana Liffey Project were invited to make a submission to the Sub-Group. They declined to do so, however, at this stage.



### APPENDIX 3.

#### THE MANAGEMENT OF HIV-POSITIVE PERSONS WITHIN THE PRISON SYSTEM.

The Irish Prison system has an average daily population of approx. 2,150 spread through 12 establishments. During the course of a year approx. 8,000 people are committed to prison. All identified HIV-positive prisoners are dealt with in Mountjoy. The problem of HIV disease in relation to prisoners first became an issue during the latter part of 1985. At that time (based on the best advice then available) a policy of segregation of HIV-positive individuals was established. Currently, known HIV-positive male prisoners are segregated in two separate locations in Mountjoy Prison. Female HIV-positive prisoners are not segregated but they have separate sleeping accommodation.

Since the first HIV cases came to light in prisons a total of 182 different individuals known to be positive for the virus have been dealt with in Mountjoy (150 male and 32 female). Currently at any one time there would be up to 42 male and 4 female known HIV-positive prisoners in Mountjoy. It is assumed that there is a further unknown number (estimated to be at least the same number again as the known group) among the general body of the prisoners who have not disclosed their HIV status or have avoided testing to establish their status. To date identified HIV-positive prisoners have come, almost exclusively, from a background of heavy IV drug use, often going back a number of years.

#### Medical issues -

Following the introduction of segregation in early 1986 a doctor was specifically allocated (part-time) to supervise the medical care of the known HIV-positive male prisoners. Due to the increasing work load related to the gradually increasing medical needs of this group as their disease progressed a second (part-time) doctor was obtained in mid-1991 to share this workload. Apart from the part-time medical, psychiatric, and psychological input there are currently no other professionally trained staff working with this group. Para-medical services are supplied by Prison Officer Medical Orderlies who have undergone a short training course. We rely a great deal on the services provided by Dr. Mulcahy's clinic in St. James' Hosp. for other specialist assessment and support.

For some considerable time the medical staff have been increasingly concerned at the fact that potentially infected prisoners have declined to seek clarification of their HIV status while in prison, or have avoided treatment on the grounds 1) that this information would not remain confidential, and, 2) that it would result in their being segregated within the prison system.

Cont./

We hope to follow this up with an education/information programme which will involve small group seminars, question and answer sessions, etc.

A new Health Care Unit is being built in Mountjoy and it is proposed that this, when completed in mid-1992, will facilitate the medical care of various groups of prisoners, including HIV-positive prisoners whose illness has progressed to the later stages.

Dr. Enda Dooley,  
Director of Prison Medical Services

22/1/1992.