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HOUSE OF LORDS

**SELECT COMMITTEE ON HIV AND
AIDS IN THE UK**

Call for Evidence
18th February 2011



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BACKGROUND

HIV Scotland welcomes the initiative in establishing the 'Select Committee on HIV and AIDS in the United Kingdom'. We note that membership of the Select Committee includes individuals with a long-standing interest in HIV and sexual health. Whilst health and other responsibilities related to HIV are devolved matters, it is important to recognise the common interest across the United Kingdom as well as of those matters reserved to Westminster and with a direct relationship to the interests of people living with HIV throughout the United Kingdom.

HIV Scotland, established in 1994, is the national HIV policy charity for Scotland, and is the umbrella agency for Scotland's HIV voluntary sector. We want a society which is

- well-informed about HIV
- devoid of HIV-related stigma and discrimination
- dealing with the spread of HIV and providing excellent treatment services

We speak out for people with HIV. HIV Scotland provides knowledge and expertise to help inform and deliver strong policies and effective strategies.

To achieve this, we provide

- expert advice and a voice for HIV in Scotland
- information, training and resources
- signposting to evidence, expertise and community experience
- opportunities to engage with others in shaping policy and practice

HIV Scotland
Evidence to House of Lords Select Committee on HIV and AIDS in the UK

EXECUTIVE SUMMARY

Introduction - Rates of HIV infection in Scotland are increasing by, on average, 400 new diagnoses of HIV over each of the last six years. Successes in increased HIV testing, effective treatment by international standards, and pragmatic solutions to otherwise intractable problems, must not silence or distract from our obligation to respond to need. People living with HIV will not thank us if organisational survival and pride take precedence over the promotion of positive change. We must address need, build on evidence of effectiveness, challenge and address difficult issues. People with HIV must be at the heart of what we do.

Lessons learnt - It will assist if we consider lessons learnt in Scotland in the following areas:

1. Key drivers
 - a. Leadership at national and community levels
 - b. Integrated and combined approaches throughout and across all parts
 - c. Cutting across boundaries and acting outwith silos to influence generic structures
 - d. Multi-disciplinary and cross-sectoral working to the collective benefit
 - e. Evidence from a range of sources, including experience of people living with HIV
2. Policy at local and national levels
 - a. Pragmatism demonstrated in Scotland's harm reduction approach to drug use
 - b. Incremental and linked strategies for sexual health, HIV and blood-borne viruses
 - c. Bold adoption of latest approaches and making most of overarching public policy, eg 'Better Health, Better Care' and the 'Healthy Respect' demonstration project
3. Action not words
 - a. HIV testing in MSM increased 3-fold because clinics implemented policy
 - b. National social marketing campaigns in Scotland had Government support, not only financially, but also in taking risks and being genuinely accountable
 - c. Standards count for a lot, and Scotland has embarked on development of an integrated set of standards for prevention, recognition/detection, and treatment
 - d. Community action, often through voluntary agencies, to reach and support those most vulnerable on account of poverty, discrimination, and risk

What needs to improve – Constant improvement without unnecessary disruption through:

1. Coordination across and between boundaries to ensure best use of resources and shared learning and action – working within territorial limits is ineffective in addressing HIV
2. Greater consistency and equity of provision in all areas of HIV – no individual or community should be disadvantaged by geography, deprivation or identity
3. Maintenance and development of mechanisms to build evidence in surveillance and research – it is essential that established epidemiological information remain strong
4. The greater involvement of people living with HIV with a voice and a role
5. Contextualising HIV fundamentally as a human rights issue given its links and roots

How to achieve the above – Despite analysis of problems, solutions are thin, but include:

1. Scaling up, intensifying and reinvigorating HIV prevention, the key to success in HIV
2. Building a strong business and financial case to support cost effectiveness
3. Engagement of the right expertise from all disciplines to address a global epidemic
4. Development of a new paradigm in HIV prevention which is integrated to testing and treatment

OVERVIEW

Statistically Scotland has recorded on average 400 new HIV diagnoses every year for the last six years, with numbers exceeding the peaks in the mid-1980s. Injecting drug use accounted for 19 of the 360 new cases of HIV in 2010. Sexual transmission is now the most common infection route. Annually, those needing specialist care are likely to increase by between 5% and 13% (150 – 350).

Diagnosed HIV-infected persons living in Scotland	3803
Number of HIV-infected persons attending for specialist care and treatment	3254
Average number of new diagnoses per annum over last six years	400

Source: Health Protection Scotland

Policy – key strategic drivers

HIV Action Plan in Scotland December 2009 - March 2014 (Scottish Government, 2009)

Respect and Responsibility: A Strategy and Action Plan for Improving Sexual Health (Scottish Government, 2005)

Hepatitis C Action Plan for Scotland: Phase II: May 2008 - March 2011 (Scottish Government, 2008)

The **HIV Action Plan** is underpinned by the sexual health strategy and links to the Hepatitis C Action Plan, thus providing direction and impetus to HIV work in Scotland.

In addition to the strategic approach adopted in Scotland, **other key influences** on development are:

- consistent ministerial leadership since 1999;
- combination and integrated approaches to HIV prevention, testing and treatment;
- ability to make links to related issues eg education, rurality, service design;
- multi-disciplinary collaboration.

Structurally, devolved arrangements mean that national HIV policy is entirely the responsibility of the Scottish Government, and that delivery is through NHS Scotland, local authorities and Scottish HIV voluntary agencies. Divergence across the United Kingdom in HIV policy and practice already exists. Publication of 'Healthy Lives, Healthy People' and the associated creation of Public Health England is unique to England and Wales, and do not directly affect Scotland. The extent to which this change creates greater divergence in both HIV policy and outcomes within the UK remains to be seen.

Frameworks within which HIV prevention, testing, treatment and care are delivered within Scotland's NHS Boards tend to be through Managed Care Networks in Blood Borne Virus, with the West of Scotland's five NHS Boards operating under a single Sexual Health Network. This means that planning is variable across Scotland, and that, other than the West of Scotland, NHS Boards tend not to work across their own borders. HIV Scotland is of the view that this is a missed opportunity for improving services, reducing duplication, and ensuring the most effective implementation of the HIV Action Plan which was constructed around the creation of Regional Facilitation Teams, now dropped. HIV Scotland welcomes the opportunities in the consultation on development of a national Framework for Sexual Health and Blood-Borne Viruses (including HIV).

The proposed **National Framework** is a further advance in Scotland's strategic approach. Five overarching outcomes will be delivered on behalf of sexual and reproductive health, HIV, Hepatitis C and Hepatitis B. This strengthens integration and increasing evidence of the benefits of joined-up working. HIV Scotland will respond to the consultation and will work with key partners across sectors to deliver on a shared agenda.

MONITORING

a) How robust is the current system for monitoring the number of people with HIV in the United Kingdom?

Key points –

- i. Surveillance of HIV at national levels in Scotland has a good reputation for accuracy and detailed analysis, with good links to front-line services. Effective use is made of the surveillance information in planning at national levels
- ii. Local surveillance at clinic and laboratory level provides regular information which is used in local planning. Capacity at local levels to maintain data is more limited and depends largely upon clinic staff
- iii. There are increasing pressures on Health Protection Scotland staff to provide HIV data and also to contribute to the wider collection of data in Scotland in a fast-moving environment
- iv. It is essential that current capacity be maintained and that when specific projects emerge, that resource implications are considered and provision made to draw on the best from HPS
- v. It should be noted that the HIV Denominator Study is under review, and that care should be taken not to lose the undoubted benefits of this long standing resource in Scotland

SURVEILLANCE

Scotland benefits from a surveillance system at national level which produces comprehensive data on new diagnoses, attributable data through the HIV Denominator Study, and surveillance of CD4 and Viral Load.

Health Protection Scotland, a division of NHS National Services Scotland, has a dedicated team which provides advice, support and information at the heart of Scotland's health service and with excellent links and partnerships both within the NHS and with the range of agencies engaged in addressing HIV in Scotland.

Reports of new diagnoses of HIV/AIDS from England, Wales, Northern Ireland and Scotland, are pooled by the HPA Centre for Infection at the end of each quarter to produce the current UK data set of reported HIV/AIDS infections

<http://www.hpa.org.uk/web/HPAweb&Page&HPAwebAutoListName/Page/1201094588891>

Reports of newly diagnosed HIV antibody positive individuals and AIDS cases have been collated by Health Protection Scotland (formerly the Scottish Centre for Infection and Environmental Health) since the early 1980s.

Data are collected under three main categories -

1. New diagnosis of HIV and AIDS

The main sources of information on newly diagnosed HIV/AIDS infection come from voluntary case reporting of newly diagnosed HIV infections by laboratories (see Surveillance of Attributable HIV Antibody Tests in Scotland) and AIDS diagnoses by clinicians. The General Register Office for Scotland (GROS) reports all deaths that record AIDS or HIV among the causes of death to HPS. Records of HIV diagnosis, AIDS and death, which are regarded as relating to the same individual, are merged to create one record.

The objectives of the surveillance of new diagnoses of HIV and AIDS are:

- a) To monitor trends in diagnosed HIV infection and AIDS cases among the Scottish population;
- b) To provide timely and useful information for the targeting of health promotion, the evaluation of

- preventative measures, and the planning of medical and social services for those affected by HIV;
- c) To provide estimates of the national total of HIV infected persons and to assist in estimating future numbers of persons with severe HIV disease who will require care, in combination with other data.

2. Surveillance of attributable HIV antibody tests in Scotland (HIV Denominator Study)

The prevalence of HIV infection, among individuals having a voluntary attributable HIV test in Scotland, is monitored by a surveillance system established in 1988 by the Scottish Centre for Infection and Environmental Health (Health Protection Scotland's predecessor).

Information is derived from a standardised request form used by clinicians requesting an HIV test. In addition to routine information (referral source and specimen details), certain clinical and epidemiological, including risk behaviour, characteristics of the individual are recorded on the form and collated by HPS.

The objectives of the attributable HIV antibody test surveillance system are:

- a) To provide timely and useful information on the prevalence of HIV infection among the Scottish population
- b) To monitor the trends in prevalence and incidence of, and associated risks for, HIV infection among individuals having a voluntary attributable HIV test in Scotland
- c) To inform the targeting of health promotion, the evaluation of preventative measures, and the planning of medical and social services for those affected by HIV.

3. CD4 and Viral Load Surveillance System

Periodic monitoring of CD4 T-lymphocyte (CD4 cell) counts and HIV viral load are part of the routine clinical management of HIV seropositive patients in Scotland. CD4 cell counts and viral load data on all HIV infected individuals receiving specialised care in Scotland are collected and collated by HPS; information from the CD4 and viral load surveillance system is linked to records of HIV diagnosis (see New Diagnoses of HIV and AIDS).

CD4 cell counts give a measure of the degree to which an individual's immune system is 'compromised'. Measures of viral load indicate how actively HIV is replicating. CD4 cell counts and viral load measures, together, are used by clinicians to decide when to start an infected person on antiretroviral therapy and to help them monitor the effectiveness of particular therapeutic regimens.

The objectives of the CD4/viral load surveillance are:

- a) To monitor access of HIV infected individuals to specialist follow up services and treatment
- b) To monitor the proportion of treated HIV infected patients with undetectable viral load
- c) To monitor trends in immunosuppression associated with HIV infection
- d) To provide estimates of the future numbers of persons with severe HIV disease who will require care (in combination with other data)
- e) To provide timely and useful information for the planning of medical services for those affected by HIV.

Source: Health Protection Scotland

STRATEGIC CONTEXT

Surveillance and epidemiology are strongly supported at national levels in Scotland. This is evidenced particularly in the HIV Action Plan for Scotland (2009 – 2014). Actions relevant in this respect include -

Action 4 - *NHS Board plans to maintain and improve prevention, diagnosis and treatment and care services and initiatives will be developed and implemented, using the information gathered from the regional needs assessment.*

Action 6 - *An investigation into the reasons why some people living with HIV do not attend specialist clinical services will be undertaken.*

Action 7 - *Systems to monitor risk behaviours and new HIV infections among persons at highest risk of acquiring infection will be reviewed and, if appropriate, developed and implemented.*

a) Monitoring outwith formal surveillance

Knowledge of our epidemics is key to effective prevention, recognition/diagnosis, and treatment. Surveillance goes beyond the collection and interpretation of national data. It includes also information collected under the auspices of the Social Sciences.

Scotland's approach to HIV has been informed by a combination of the data and its interpretations from HPS with that drawn from institutions including the Medical Research Council, biomedical institutions, and Scotland's research community focussed around our Universities. Research in its widest sense has particular strengths.

Voluntary sector agencies play a crucial role in tackling HIV in Scotland. Support for monitoring of activity and trends has been inconsistent. Much of the local information and experience held by Scotland's voluntary agencies could be very beneficial in planning and learning if it were more comprehensively and consistently gathered. HIV Scotland is currently engaged with agencies to research the data collection and reporting needs of both HIV service providers and funders. This is with a view to improving the flow of information and to enable voluntary agencies to evidence their activity and outcomes.

b) Will the proposed public health reforms impact on this system?

The public health reforms apply only to England and Wales. Given the integral nature of the United Kingdom and in particular the flow of populations across our borders, this and other health reforms in England and Wales are likely, however, to have an effect upon Scotland. Already, the switch in responsibility from the Health Protection Agency to the Department of Health creates a divergent system between the four nations. Reduced capacity in England will affect the quality of reporting across the United Kingdom, particularly in those areas for which the HPA took primary responsibility. As an organisation, HIV Scotland makes requests for data from HPA and there needs to be confidence in the ability of the DoH to respond accurately and suitably. There is a risk that reporting will be affected, which in time could dilute Scotland's monitoring systems.

The split in public health responsibility between health and local authority, overlaying as it does upon the abolition of PCTs and Strategic Health Authorities is a further risk to the monitoring arrangements and to public health policy in general. Public health has recently been subject of legislative reform in England and Wales. Change will need to be carefully planned and resourced in order to minimise any adverse effects. Insofar as Local Authorities in England and Wales will have responsibility for public health, there is evidence of strength in their response at a population level in controlling infectious diseases. It is acknowledged that a role exists for Local Authorities in the HIV public health agenda. It is difficult, however, to transfer experience in infection control and risk at population levels to the complex contexts at individual and community of interest levels in which HIV is passed on. Great fragmentation of Public Health in England contrasts with and diverges from a policy of increasing integration and improved coordination in Scotland. It remains to be seen how the proposals will improve public health.

c) Could anything be done to improve monitoring?

In Scotland, implementation of the HIV Action Plan is in progress. As noted above, several actions have an impact upon the monitoring and surveillance of HIV in Scotland.

There is room for improvement even in a system as well developed as is that of the United Kingdom's Health Protection agencies. This is addressed directly and indirectly in actions under Scotland's HIV Action Plan. This is not to take away from the strengths of Scotland's epidemiological information, and of its links to the rest of the UK in this respect. It is clear, however, that a great volume of information is supported by Health Protection Scotland. HIV Scotland frequently draws upon the staff's expertise for the preparation of reports or for the understanding and interpretation of data. Their work in relation to Action 6 below is an excellent example of expertise, detailed analysis, responsiveness, relevance to the field, and collaboration within Scotland and with other UK colleagues. HIV Scotland is aware, however, that a significant volume of information could be extracted from the HPS data to support enquiries such as the factors, contexts of, and precursors to sero-conversion. Increased capacity is needed for this.

The key is in **Action 7** of the "HIV Action Plan" which has initiated the review, development and implementation of recommendations of risk behaviours and new HIV infections in Scotland. Other recommendations affect monitoring arrangements.

Already, under **Action 6** data has been thoroughly revised by a collaboration between HPS, NHS Health Scotland and HIV Scotland on those 'lost to follow-up in specialist services'. This has provided a ground-breaking information set at a statistical level and corrects some previous misperceptions, and in a new system to flag and act immediately to any loss of follow-up. Work is now underway to relate this to results of qualitative research which will frame recommendations to NHS Boards, Clinics and voluntary agencies.

Monitoring also takes place at regional or Health Board levels, and the recommendation of the HIV Action Plan **Action 4** is set against the background of a local needs assessment informed by the local epidemiology. In NHS Forth Valley, HIV Scotland has worked closely with partners to develop the "Needs Assessment Report: Integrated HIV Prevention in Forth Valley".

d) What groups in particular are at risk from HIV?

The groups particularly at risk from HIV infection in Scotland are –

Group	% of all newly reported infections 2010
men who have sex with men (MSM)	36%
heterosexual	42%
injecting drug use	5%

Source: Health Protection Scotland

It should be noted that of all infections acquired in 2010, a total of 48% across all transmission groups were acquired abroad. This figure is expected to rise to about 60% (in line with previous years) after active follow-up has been completed on cases with little or no reported epidemiological information. The majority of newly reported infections acquired within Scotland are through the MSM route. In its report of 23rd February 2011, Health Protection Scotland indicates the following headline statistics-

Diagnosed HIV-infected persons living in Scotland 3803

Number of HIV-infected persons attending for specialist care and treatment 3254

Total deaths among HIV-infected persons 1783

Deaths among persons known to have been diagnosed with AIDS 1034

The following breakdown for the year shows that of the 360 cases reported during 2010, 130 (36%) are presumed to have contracted the infection by the MSM route, 151 (42%) through heterosexual contact, and 19 (5%) through injecting drug use. 174 (48%) are presumed to have been infected outwith Scotland. It is expected that all of these figures will rise in due course as the 53 cases (15%) for whom no epidemiological information has as yet been provided are subjected to active follow-up. (Volume 45 No. 2011/08)

Of the 360 cases reported during 2010, 174 (48%) and 2690 (41%) of the 6613 total reports are presumed to have acquired their infection outwith Scotland (Table 4).

It should be noted that of infections acquired within Scotland itself, the majority of cases is by the Men who have Sex with Men route (MSM), estimated at 67%. Of heterosexual transmissions, the majority are acquired abroad.

An increasing number of infections occurring within Scotland have no specific risk factor such as MSM or links to high prevalence areas such as sub-Saharan Africa. These cases often present late, and there are reports of serious complications and death.

Prevalence rates in the main groups indicates current levels of infection –

Prevalence by transmission route

HIV Prevalence Rate – All Scotland (population 5,450,914)	0.1146 %
Injecting Drug Users	0.5
Heterosexual (infected UK)	0.1
Heterosexual (infected Africa/abroad)	7.3
Pregnant women (Guthrie)	0.09
Men who have sex with men (MSM)	3.1

Source: Health Protection Scotland

Geographical spread of newly reported infections is indicated in the most recent figures from 2010, reported in Answer (Table 3) –

118	Greater Glasgow & Clyde
92	Lothian
37	Grampian
28	Lanarkshire
26	Tayside

Source: Health Protection Scotland

PREVENTION

a) Is Government policy sufficiently focused on HIV prevention?

Although there is a strong focus in Scotland upon HIV prevention, as outlined below, the critical questions for those with responsibility at national and regional levels relate to –

- Scope
- Intensity
- Effectiveness

- Evidence

Across all of four areas, we need a step change in order to address the growth of HIV, in the context not only of concerns within Scotland and the UK, but crucially at a global level. It is impossible to reduce the rates of new infection, costs of treatment and care, and related poor health without also addressing global imperatives. To this extent, Scotland as part of the UK and in its own right must respond to the clamant need of the young women, drug users and homosexual men who are discriminated against and outlawed by an increasing number of government legislatures, cultural practices and religious institutions.

Structural barriers internationally and within the UK need to be addressed. It is well established that HIV follows the track of poverty, inequality and discrimination, all of which fuel the epidemic. Human rights and public health are inextricably linked.

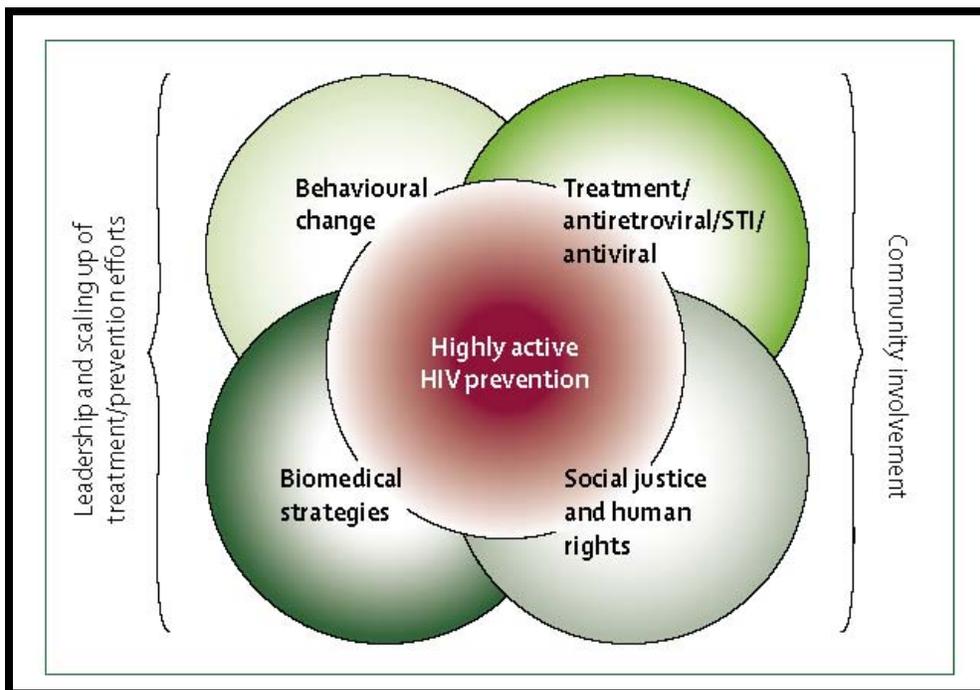
These considerations are not limited, however, to the international arena, and policy in all parts of the UK, reserved and devolved, must take account of the impact on people living with HIV and on those vulnerable to the infection, of welfare, economic, immigration, justice, education, and other powers. It is doubtful if the needs of people living with HIV feature large in the factors affecting many decisions, and agencies like HIV Scotland exist to keep HIV to the forefront of our collective social responsibility.

In its HIV Action Plan, the Scottish Government has adopted an integrated model of HIV prevention, diagnosis and treatment to underpin its strategy. This is set out explicitly in the plan's first summary point, which states that its overall aims are to be achieved through:

- Integrating HIV prevention, diagnosis and treatment and care
- Reducing HIV transmission and undiagnosed HIV through social marketing, education, service provision and guidance; and
- Improving performance management and accountability.

Illustrated thus –

Highly Active HIV Prevention



Coates, Richter et al., 2008

This strategic document is a practical plan highlighting what must happen and who must be involved if the overall aims are to be achieved. It builds on

- the draft proposals developed by the multi-agency HIV Action Plan Group
- the Treatment and Care Needs Assessment commissioned by the Scottish Government and produced by the Scottish Public Health Network (Scot PHN)
- extensive feedback received from key stakeholders and individuals, including those living with HIV.

Membership of the Group included a range of professionals and experts from across Scotland and represented leadership and expertise from treatment services, prevention, academia, policy, health promotion, and community.

Predating publication and implementation of the HIV Action Plan was the sexual health strategy, *“Respect and Responsibility”* (Scottish Government, 2005) produced by the Minister for Health as advised in the National Sexual Health and HIV Advisory Committee. This prepared the ground for the HIV Action Plan and already actions were underway at local levels as recommended by *“Respect and Responsibility”* to review their strategies and actions in light of the ‘Review of the HIV Strategy’ (Scottish Executive 2001). This committee also receive the report of its MSM sub-group, *“HIV Prevention, Report and Recommendations”* Clutterbuck, D (2008) MSM Subgroup NSHAC 11: <http://www.scotland.gov.uk/Topics/Health/health/sexualhealth/msmreport/Q/EditMode/on/ForceUpdate/on>

Actions 2, 8, 9 and 10 of the HIV Action Plan are specifically relevant to HIV prevention.

Useful links are made from HIV to other action plans and strategies, especially The Hepatitis C Action Plan and Scotland’s drugs strategy *“Road to Recovery”*.

It should be noted also that Standards in HIV prevention are being developed alongside recognition and diagnosis, and treatment and care. Undertaken by NHS Quality Improvement Scotland (soon to become NHS Healthcare Improvement Scotland) as an action under the HIV Action Plan, this will provide a

strong foundation and implementation plan to improve the quality, safety and effectiveness of our interventions under a set of key standards with exacting criteria against which services will be measured.

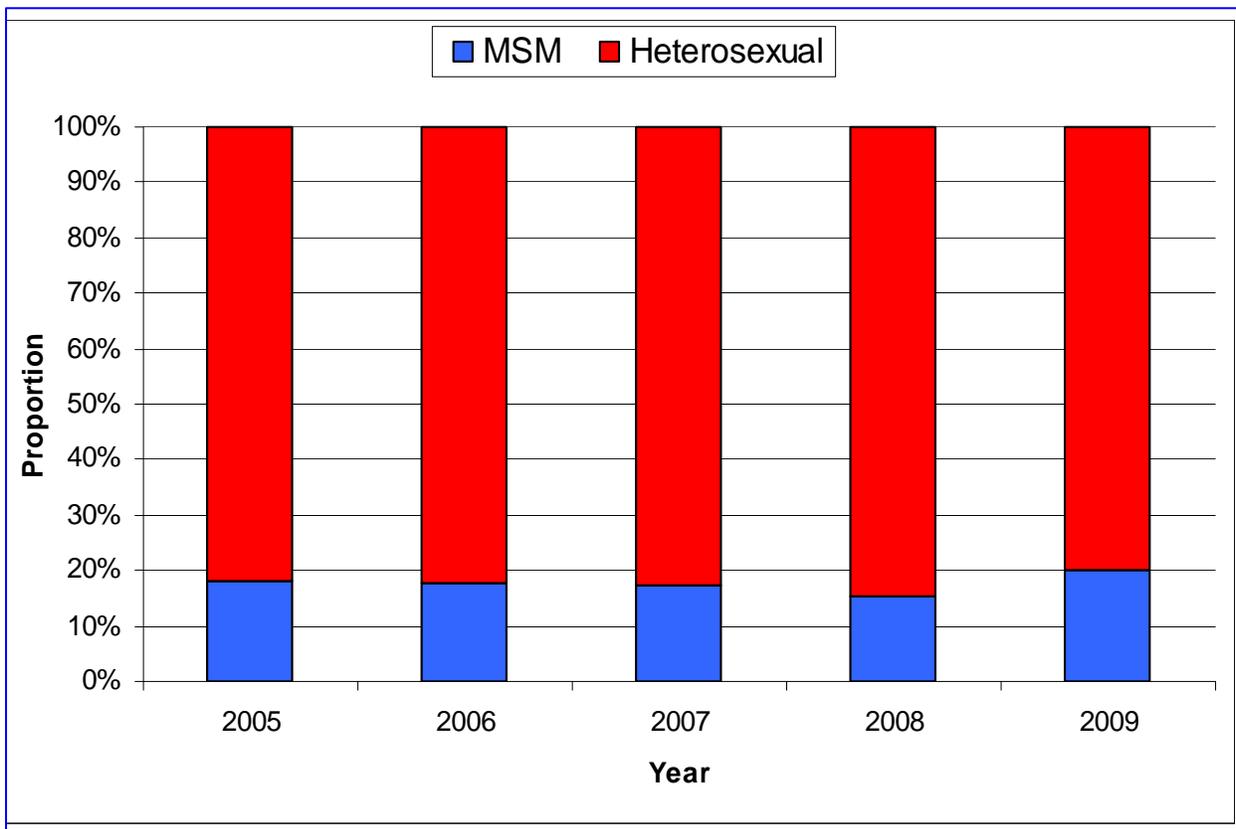
Planning structures in Scotland will not develop as foreseen in the HIV Action Plan. This is to be regretted as they would have improved accountability, provided a strong basis for equitable provision of prevention, testing and treatment services, and would have facilitated the practical sharing of expertise. Other more local structures are developing, however, with HIV integrated to sexual health and to a greater extent, blood-borne virus planning mechanisms such as Managed Care Networks. This allows HIV strategies and actions to draw upon the learning and capacity of Scotland's approach to Hepatitis C. At a national level, a National Framework for sexual health, HIV, Hepatitis B and Hepatitis C is to be consulted on with a view to an overarching approach.

b) Have the right groups been targeted in recent prevention campaigns?

The majority of HIV infections acquired within Scotland are through the MSM route. Effort must be focussed therefore on this particular group. Exposure outside the UK accounts in turn for the majority of heterosexual infections diagnosed in Scotland.

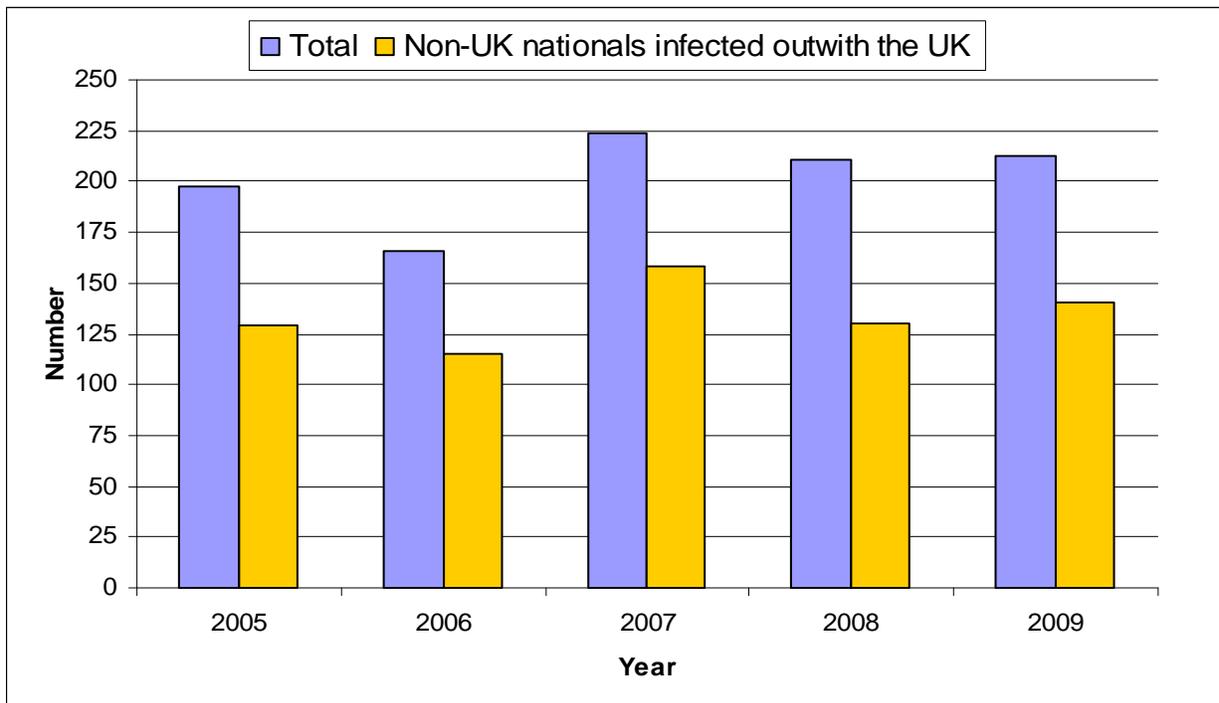
Reports of HIV infection: presumed location of exposure is outside UK, 2005-2009

(Health Protection Scotland) (This graph shows that the majority of infections acquired abroad are through the heterosexual route, but that a significant proportion is from MSM)



Reports of heterosexually acquired HIV infection, Scotland, 2005-2009

(Health Protection Scotland) (This graph illustrates that the majority of heterosexually acquired infections diagnosed in Scotland is in non-UK nationals infected outwith the UK)



Depending upon the group being targetted, prevention campaigns take a variety of forms and layers. The information below is intended to demonstrate the range and rationale for HIV prevention in Scotland targetted to specific purposes.

1. National sexual health campaign – developed collaboratively and with input from HIV Scotland, ‘Sexual Health Scotland’ was launched in June 2009. It is focussed upon relationships, is positive and encourages a healthy sex life. It was promoted on national radio and cinema adverts, with a strong, highly interactive and engaging website - <http://www.sexualhealthscotland.co.uk/>

This campaign has provided an excellent backdrop to sexual health and HIV and was designed in such a way as to appeal to younger age groups, and related to all sexualities and ethnicities.

2. Targetting of men who have sex with men was a commitment under the HIV Action Plan. **Action 8** *The development and implementation of social marketing materials for MSM.* As a result, NHS Health Scotland in partnership with HIV Scotland launched the first national information HIV campaign since the 1980s. This has taken the form of
 - a. Website with strong imagery and clear messaging on prevention and HIV testing - <http://www.hiv-wakeup.org.uk/> Find out more about the website here - <http://www.hiv-wakeup.org.uk/about-the-hiv-wake-up-website/>
 - b. Literature disseminated through a variety of channels, particularly to areas outwith the main cities, and to generic services and venues. Samples available on request from HIV Scotland.
 - c. Professional briefings – informing on current epidemiology and factors to be considered in providing services to men who have sex with men.
 - d. Local support to the aims of the national campaign in specific geographical areas of Scotland, using a rolling programme to reinforce messages on the ground and to build on learning.
3. Development of targetted support for people from areas of high HIV prevalence, especially Africa. This has been slow as the approach has to be different to broader population approaches or to MSM who have a different social network. It also must avoid the risk of unintended stigmatisation of those living with HIV. Much of the prevention activity is directed therefore through support groups run by Waverley Care - <http://www.waverleycare.org/> HIV Scotland’s role in this respect has been to work

through the African Country Associations to build capacity within the community, and to reinforce the links between prevention and the broader socio-economic factors affecting Africans living in Scotland.

4. For injecting drug users who form now the lowest transmission group in Scotland, campaigns are directed through the Hepatitis C campaigns on the basis that if HepC is being adequately addressed, then prevention of HIV transmission through needle sharing will also be addressed. Issues remain, however, for the level of interaction of HIV positive drug users with mainstream services as well as with voluntary HIV services. **About 350 IVDUs are in specialist clinical care in Scotland, and the key need on their part is support in safer sex. It is doubtful if this need is being adequately addressed on their behalf.**

It is essential that we keep the eye on the ball and maintain vigilance.

c) To what extent have prevention initiatives targeted at injecting drug users been successful?

This has been highly successful. As noted above, the prevention of HIV through the harm reduction policies introduced in the 1980s established a strategy which has been maintained rigorously. Indeed, a 'defining moment' for HIV policy and practice was the opening in 1987 of the first needle exchange in Leith (Edinburgh), followed the year afterwards by an official heroin substitute prescribing scheme (Community Drug Problem Service), heralding the start to Scotland's harm reduction policy which has dramatically reduced HIV infections in Injecting Drug Users.

Arguably, it was prompted and supported by the influence of McLelland, D. 1986 – HIV in Scotland – Report of the Scottish Committee on HIV infection and intravenous drug use, in which he stated, "The prevention of HIV spread should take precedence over the perceived risk of increased drug use." This was echoed in the ACMD report of 1988.

In a recent personal communication, Professor David Goldberg of HPS wrote of Scotland's policy, *"In my view it was one of the great public health achievements of the 20th century and although it was successful elsewhere, the Scottish response in the context of very high prevalence was a model of excellent public health practice."*

There are risks, however, to this approach which emanates from unnecessarily polarised debates between methadone treatment and drug free treatment services.

HIV Scotland's **Holyrood 2007 manifesto** states that –

"Harm reduction is a major success in Scotland's proven achievements in reducing and maintaining remarkably low levels of drug related HIV infection. Harm reduction and comprehensive prevention are proven and effective approaches and must remain integral components of prevention strategies".

When the current strategy was being drafted, HIV Scotland coordinated representation from leading drug abuse experts from primary care, national policy, training, service delivery and prison services to advocate in support of current harm reduction approaches. Our argument was based on a number of considerations.

Most local, national and international drug treatment experts and clinicians have a **consensus view** that a range of evidence based treatment options should be available to meet the differing needs of a diverse population of drug users seeking help. In particular there is a basic need for services which fall under the general heading of harm minimisation and include maintenance treatment for those with enduring difficulties with addiction problems. This philosophy is enshrined in many documents not least the guidelines on the management of drug users in the UK (September 2007) which was endorsed by all four UK Departments of Health. This document provides a clear framework and a consensus opinion about the correct approach to contemporary drug problems in the United Kingdom. This evidence based guideline underpins the underlying principles of treatment services and refers extensively to the

evidence base on all aspects of treatment including methadone maintenance, other substitute treatments such as buprenorphine, detoxification in all its modalities and a wide range of support services. Further, recommendations from the NICE technical appraisals are integrated into the guidelines.

Observations in the guidelines and NICE appraisals on the relative values of different forms of treatment draw attention to the expensive and complicated nature of rehabilitation and detoxification and the strong evidence base for opiate substitute treatment such as methadone and buprenorphine in not only disengaging drug users from injecting but rehabilitating individuals over many years and supporting them as they grow into a more stable period in later life. It is widely acknowledged that methadone and such treatments are compatible with an otherwise normal lifestyle when delivered sympathetically and with support and that many individuals choose this option after years of attempting abstinence without success.

Strategic level review is needed to improve services and life opportunities for individuals with drug problems. Such changes, however, should recognise the value of existing services and listen to those who have benefited from them as well as those for whom other treatment modalities need to be developed. There is a real risk that a shift towards abstinence programmes will weaken the success of harm reduction measures which have kept levels of HIV, Hepatitis C and other health and social harms at their lowest level for many years.

It should be noted that access to **needle exchange in prisons** in Scotland and across the United Kingdom falls short of good practice in other European nations, contradicts recommendations from UNAIDS and WHO, and risks the health of prisoners who inject drugs. Policy is clearly stated in Scotland that needle exchange facilities are integral to drugs policy within prison. There are, however, understandable concerns which will require patience to resolve. Accommodation of concerns, however, ought not to be a permanent block. HIV Scotland urges inclusive UK-wide discussions on the way forward.

d) How could prevention initiatives be better delivered and evaluated?

Given the continuing high levels of incidence in Scotland and the UK, taken along with recent reports of increasing incidence in other European countries <http://www.aidsmap.com/HIV-incidence-increasing-among-gay-men-in-Amsterdam/page/1599246/> our prevention interventions need to improve. HIV Scotland has drawn attention to what we have called 'the failure of HIV prevention'. This is not to be taken as a generalised comment on all prevention work. NHS Boards and voluntary sector agencies have worked hard to improve the scope, cover, intensity and quality of HIV prevention. At national levels this has been supported by a number of initiatives. It is clear, however, that across the range of responsibilities both collective and individual, we are allowing HIV slowly to win the battle. We must halt this trend in increasing rates of HIV. The tone is set in the title of Scotland's most recent campaign, '**HIV – Wake Up**'.

One key area in which there must be better approaches is in the engagement of people living with HIV. The Greater Involvement of People Living with HIV (GIPA - http://data.unaids.org/pub/BriefingNote/2007/jc1299_policy_brief_gipa.pdf) is a principle endorsed at every level, but practised in few. HIV Scotland does not absolve itself from this charge. Action is needed to improve the collective advocacy for people living with HIV. Whilst some efforts have been made, these are generally sporadic and uncoordinated leading to disillusionment on the part of those who should be 'on the inside' and contributing the expertise of those with the experience. Lessons might be learned in this respect from general public engagement approaches as well as from those who have more successfully implemented the GIPA principle.

Other initiatives ought to address the onward transmission of HIV from 'HIV clusters' and in targeting much more specifically, groups and settings where HIV transmission is occurring. Links are needed also to other concerns such as mental health, and to training for generic staff.

There is no magic bullet; interventions work in combination and seldom quickly. That it can be achieved, however, is evident not only from the success in Scotland of harm reduction, but also from the experience of other countries. HIV Scotland is involved with partner agencies therefore in the following initiatives –

1. With NHS Health Protection Scotland and others to establish evidence based prevention guidance in MSM and in African populations.
2. With NHS Quality Improvement Scotland to draw up Standards in HIV prevention, testing and treatment, supported by an implementation plan.
3. Learning across the continents – collaborations with African Country Associations, voluntary agencies, Universities etc to draw on experience and learning to inform policy and practice – eg Africa in Scotland, Scotland in Africa conference - http://www.cas.ed.ac.uk/events/annual_conference , Policy Seminar in Feb 2011 - <http://www.ed.ac.uk/schools-departments/global-health/news-events/events/scotland> , and meetings facilitated between high level public figures from Africa and Scottish public (students, associations etc) – eg President Kenneth Kaunda, African High Commissions and late David Katu.
4. Building a policy and practice library within HIV Scotland's new website.

TESTING

a) Are current testing policies adequate across the country?

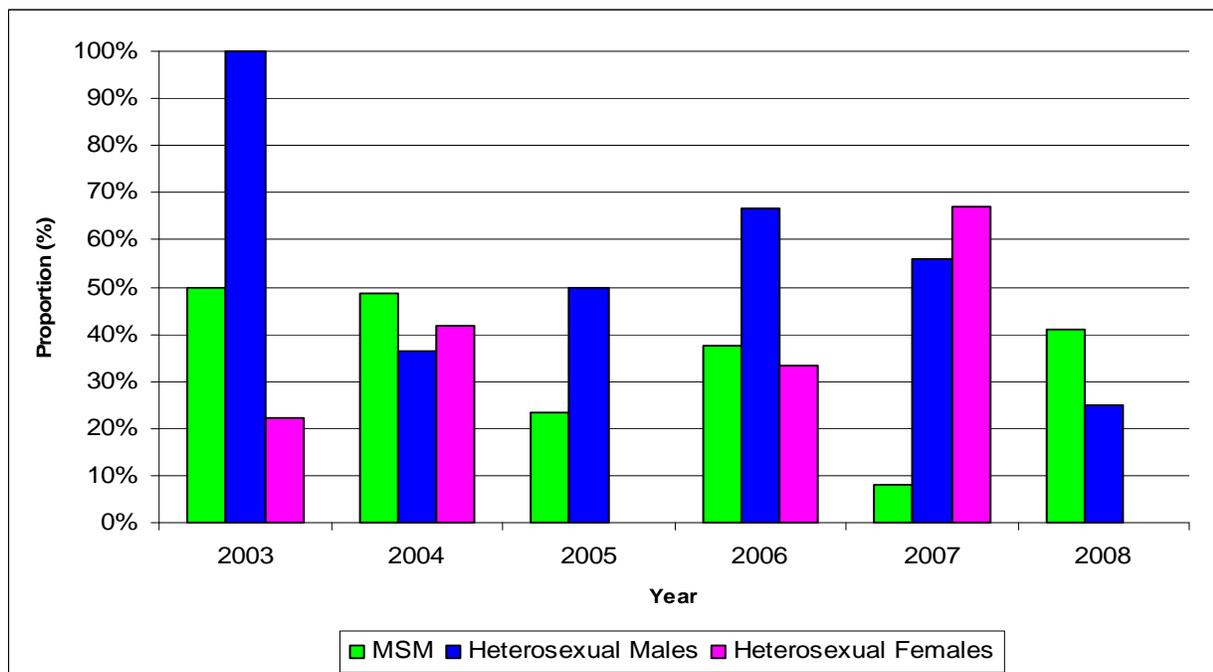
Improving the earlier detection of HIV is crucial to the success of prevention as well as of treatment.

HIV testing **almost doubled** in Scotland for the five years to 2008. Amongst MSM, for the same period, HIV testing saw a **three-fold increase** with 80% of all tests being undertaken in GUM settings, (Wallace, Gaycon 2010)

Policy switched within GUM clinics at the outset of this period of time, with testing for HIV becoming part of the usual set of checks undertaken as part of a sexual health check-up. In part, lessons were learned from the success of ante-natal testing, such as that most people would consent, uptake was largely dependent upon the commitment and skills of staff, and a culture of testing would emerge. This was backed by HIV Scotland in a national seminar, and in messages communicated through its Healthy Gay Scotland project and partner agencies. Results are evident in the graph below.

The following graph shows that combined policies such as ante-natal testing, opt-out testing in GUM clinics, and community awareness-raising with an emphasis on challenging stigma, have resulted in reductions in undiagnosed infections. It should be noted, however, that such policies may not necessarily address the need for improved testing among women who are not pregnant, or of gay men who may have additional risk factors in behaviour, psychology, or context.

Proportion of undiagnosed HIV infections in GUM clinic attendees remaining undiagnosed after their clinic visit, Scotland, 2003-2008 (Health Protection Scotland)



Late testing, defined as having a CD4 lower than 350 remains problematic, and morbidity and mortality which are otherwise preventable, result.

Of the 372 cases who entered monitoring and recorded a CD4 count for the first time between 1 October 2009 and 30 September 2010, 66 (18%) had a count <200, 66 (18%) a count between 201 and 350, 98 (26%) a count of between 351 and 500, and 121 (33%) a count of > 500. For 21 cases, the count was unrecorded or not known (data not shown). (Answer, HPS, Feb 2011).

The table below demonstrates late diagnosis –

HIV Detection

Description	Late
Detection Percentage ALL (2010) <350 ml	36%
Detection Percentage ALL (2010) <200 ml	18% (NB was 46% in 2000)
Detection Percentage MSM (2009) <200 ml	17% (NB was 35% in 2000)
Detection Percentage ALL MEN (2009)	13%
Detection Percentage ALL MEN (2006)	25%
Detection Percentage ALL MEN (2002)	34%
Detection Percentage ALL indigenous (2006)	25%
Detection Percentage ALL indigenous (2001)	33%

(collated from various sources – HPS)

Late diagnosis in heterosexuals and in those of African origin continues to be a particular problem.

More should be done therefore to –

1. promote testing in primary care and A&E settings
2. promote testing to younger gay men who are less likely to test than their heterosexual peers
3. provide testing opportunities outwith the usual clinic hours for those at work, possibly through group specific clinics, eg for gay men or young people
4. reduce the time from arrival in the UK to HIV testing for those with increased risk factors

5. provide information on availability of HIV testing and treatment to minority groups
6. integrate HIV testing to sexual health checks within sexual and reproductive health settings
7. improve sexual health and HIV components of medical and nurse training and education
8. include sexual health and HIV in the health 'MOT', provided to men and women
9. include an offer of HIV testing for all new registrations in GP practices
10. promote the benefits of HIV testing to counterbalance arguments 'not to test', including the benefits of HIV treatment, safer sex, ongoing mental and physical health
11. variability in testing practice and service quality needs to be equalised, eg in time from test to receiving results. Quality Improvement Scotland Standards in HIV should assist.

b) What can be done to increase take-up rates?

see above

Currently, NHS Quality Improvement Scotland is engaged in drawing up Standards which include standards in HIV recognition and diagnosis. A strong implementation plan will be needed. This significant development, unique within the UK, reinforces integrated approaches to HIV prevention, recognition/detection, and treatment and care

TREATMENT

a) How can the NHS best commission and deliver HIV treatment?

Delivery of HIV treatment in Scotland is through specialist infectious diseases units and GUM clinics. Currently, NHS Quality Improvement Scotland is engaged in drawing up Standards which include standards in HIV Treatment. A strong implementation plan will be developed. It is a model which ought to be emulated elsewhere. This aspect of work is based on Johnman, C. (2009) Treatment and Care Needs Assessment: People Living with HIV. Scottish Public Health Network (Scot PHN). This informative and influential document represents the outcome of the work of a small committee ably chaired and led by Dr John Logan, Consultant in Public Health Medicine, NHS Lanarkshire.

In 'Answer' Feb 2011, HPS reports –

During the period 1 October 2009 to 30 September 2010, 3254 HIV infected individuals attended specialist services for monitoring and treatment. This represents 86% of the estimated number of diagnosed cases currently living in Scotland. Of these, 3154 had a CD4 count recorded, while 3134 were measured for viral load. The majority of cases were from the Lothian (1061, 33%) and Greater Glasgow & Clyde (1036, 32%) areas.

Across Scotland, 80% of cases attending for monitoring are receiving triple therapy or higher (Table 6). Of the 3154 cases recording at least one CD4 count, 239 (8%) had a count <200 cells/mm³, 576 (18%) a count of between 201 and 350, 865 (27%) a count of between 351 and 500, and 1450 (46%) a count of >500. For 24 cases, the count was unrecorded or not known.

Of the 372 cases who entered monitoring and recorded a CD4 count for the first time between 1 October 2009 and 30 September 2010, 66 (18%) had a count <200, 66 (18%) a count between 201 and 350, 98 (26%) a count of between 351 and 500, and 121 (33%) a count of > 500. For 21 cases, the count was unrecorded or not known.

Of the 3254 attending between 1 October 2009 and 30 September 2010, 3134 persons had at least one viral load test performed. 2509 (80%) had evidence of reasonable viral control indicated by a viral load measure of <400 copies/ml. Of the 324 cases that entered monitoring for the first time in the same period, 158 (49%) had a viral load <400.

For 18 cases, the count was unrecorded or not known.

Time from diagnosis to entering specialist care is equal across all transmission groups, and generally within one month. Rates of uptake of ARVs are equal across all transmission groups.

b) What impact might the proposed new commissioning reforms have on HIV treatment?

N/A in Scotland

c) In what setting can treatment most effectively be delivered?

There can be no doubt that HIV treatment must be delivered within specialist HIV treatment centres. Outcomes are improved for patients in relation to a number of factors, including level of throughput of clinics. <http://www.ncbi.nlm.nih.gov/pubmed/12056114> and <http://www.namlife.org/cms1254921.aspx> and <http://www.nhstayside.scot.nhs.uk/BBVMCN/documents/ScotPHN%20report%20March%202009.pdf>

This must be through a multi-disciplinary team, with clearly identified lead contact for the patient. Links to other specialisms as well as to primary care improve the safety and efficacy of treatment. Management of the patient should be with full patient engagement.

NHS QIS is developing Standards in Treatment for people living with HIV.

COST

The HIV Action Plan states,

“By 2012, the number of people living with HIV and requiring specialist care is likely to increase by 5-13% (some 150-350 persons) per year and the average age of individuals living with HIV will increase over time as effective drug regimens sustain and improve their quality of life. Providing treatment and care for all those who require it is one of Scotland's most pressing HIV challenges”.

The annual cost of HIV treatment per individual is **£11,097**.

The estimated annual cost of ARV treatment alone for the 2487 individuals on ARVs (HPS) is therefore **£27,709,209**. Additional costs from inpatient care and HIV-related hospitalisations bring this total person per annum to **£13,164** and the total annual cost to **£32,820,508**.

On this basis alone, the annual **increasing cost** to Scotland of the treatment of people living with HIV is between **£1,660,550 and £3,880, 050**. The addition of inpatient and hospitalisation costs brings these figures to between **£1,974,600 and £4,607,400**.

This is likely to escalate as treatment guidelines return to the previously recommended level of CD4 count of 350 and higher.

None of these calculations takes account of the cost of other inpatient/outpatient costs, non-HIV related care, costs in work days lost, or cost in social care. Costs of onward transmission from people living with HIV are not included in this calculation. Costs to health and well-being and to relationships are considerable.

It is estimated that annual UK treatment and care costs could reach £750 million by 2013. Social care costs bring this figure to over £1,000 million. [Mandilia S et al. *Rising population cost of treating people living with HIV in the UK, 1997-2013*. PLoS One, 5, 12: e15677, 2010 <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3012705/?tool=pubmed>

a) Have cost considerations been satisfactorily balanced with public health imperatives in HIV?

HIV Scotland has undertaken a cost and benefit analysis of early detection and prevention for HIV in Scotland. Based on the 'Sunrise project' developed by Bristol-Myers Squibb, it is possible to calculate the cost savings in earlier detection of HIV and its prevention in set ratios of onward transmission.

Taking a CD4 count of <200, against a 20 percentage shift to earlier detection, it is estimated that over a five year period, Scotland could save £4,512,806 in treatment and hospitalisation costs alone.

(NB – this is work in progress, and follow-up required to update statistics for 2010. Report due Spring 2011)

It is concluded therefore that efforts to improve prevention, detection/diagnosis, and treatment are highly cost-effective. Greater financial investment at all levels is required.

b) Is research funding correctly prioritised?

Scotland has a strong track record in HIV related research, which is undertaken in a number of settings and with a number of collaborations. The Chief Scientists office has established a research Advisory Group in response to "Respect and Responsibility" and at the request of the National Sexual Health and HIV Advisory Committee. Priorities are advised from a body of experts from clinical, academic, planning, and HIV Scotland representing the HIV voluntary sector. HIV Scotland can provide a list of current research projects in Scotland.

STIGMA

It is important to try to understand the nature of HIV-related stigma.

Stigma has been defined as the 'systematic process of devaluation' (Aggleton et al). With its etymological root in the Greek **στίγμα** it refers to the mark which differentiated someone from the 'norm'. Its inextricable link to HIV and AIDS needs to be broken.

Its existence in internal thought processes, our language and actions need to be tackled at these points through the engagement of community, media, leadership and legislators.

Speaking of the People Living with HIV Stigma Index (Scotland) Report

<http://www.stigmaindex.org/50/analysis/uk.html> the Minister for Public Health Shona Robson said,

"I'm pleased to see the publication of the results of The People Living with HIV Stigma Index. One of the key aims of the HIV Action Plan in Scotland is to tackle the stigma and discrimination faced by people living with HIV. It is important to ensure that action taken to combat HIV be approached sensitively to avoid any increase in levels of stigma and the Index will provide us with the evidence needed to tackle this issue."

Undertaken by people living with HIV themselves, the above Report makes a valuable contribution to the evidence of the reality and impact of stigma on people living with HIV. This model of engagement of people living with HIV in tackling stigma within its own community was pioneered in Scotland in 1997 when, supported by HIV Scotland's Healthy Gay Scotland project, a group of gay men living with HIV developed a full publicity and web campaign focussed on HIV stigma among gay men themselves.

As is often the case with leprosy, mental health and cancer, it feeds on fear and ignorance, and often comes from family and community, and others close to its target.

Because of the associations of HIV with newly emerging trends over the past ten years, stigma persists well beyond the first wave of fear and ignorance in the 1980s. Increasingly it is perceived as an African (or Western) disease, associated with poverty (or wealth), and linked with gender. These add to the identification of HIV and AIDS with sexuality and drug use.

The multi-layered associations of HIV characterise the stigma and discrimination often experienced by people living with HIV. This makes it difficult to pin down or to deal with through legislation or education alone, essential as these are. These solutions must be combined with other measures such as human rights and the power of community.

a) What impact does stigmatisation of those with HIV have on those infected, and on addressing HIV as a public health problem?

There is probably no more powerful illustration of the impact of stigma than the experience of **children and young people** infected with the virus. In her most recent research publication in this area, Professor Vivienne Cree of Edinburgh University http://www.hivscotland.com/documents/HIV_Report.pdf summarises a key finding thus,

*“The infected children and young people were at pains to present themselves, their lives and HIV as ‘normal’. This was in spite of their very troubled backgrounds and current hardships. Being ‘normal’ is a major preoccupation in adolescence. It is also, however, an indication of **the wish to avoid stigma.**”*

From the mouth of one of the children interviewed,

*“**I want to be like the others.**”*

The impact on those affected by HIV includes shame, internal blaming, isolation, and secrecy. HIV Scotland is concerned by reports of domestic violence following disclosure of infection, often on the assumption on the part (usually) of the man that his wife or partner has been unfaithful and has infected him.

The **workplace** can also pose problems for some people living with HIV. Waverley Care, Scotland's largest HIV charity, has stated that

“At Waverley Care we hear numerous examples of people who have been discriminated against in the workplace because of their HIV but who do not feel strong enough, physically or emotionally to take out a grievance. In some cases it is simply easier to resign. A greater understanding of HIV and its transmission amongst the general population would go a long way to reducing workplace discrimination.”

In **healthcare settings**, inappropriate and irrelevant questions about a patient's HIV status, or use of procedures which single out people living with HIV unnecessarily, are also reported. For example, universal precautions ought to be taken to protect staff and patients when taking blood. Unfortunately, these procedures are not always followed, and when they are selectively used for people with HIV, it discriminates against the patient, fails to protect the healthcare worker in other situations, and may alert others who notice a difference in usual practice.

Culture and belief can and often are powerful supports to people living with HIV. At its General Assembly in 2006, the report of the Church of Scotland's HIV and AIDS Project stated that, “The Kirk recognises that HIV stigma and discrimination continue to act as barriers to effective prevention and

care within and furth of Scotland; confesses to people living with HIV that the Kirk has been involved in unwitting and unthinking stigmatisation of them; and calls on all Christians in Scotland to overcome ignorance and prejudice about people living with HIV wherever they may be.” Some measure of the success and impetus of the Kirk’s commitment is evident in the £1 million raised in its congregations for HIV and AIDS work in Scotland and internationally, its Scotland-wide ‘Souper Sunday’ awareness-raising on the first Sunday after World AIDS Day, and a programme of leadership training towards an ‘HIV-competent Church. This contrasts, however, with continuing reports of faith-based stigma and misunderstanding, particularly from some Christian bodies outwith the ‘mainstream’. Others, however, are exemplary in their solidarity with HIV positive people. It is worthy of note that individuals with stigmatising beliefs about HIV are less likely to test for the virus, regardless of personal risk.
<http://aidsmap.com/People-who-stigmatise-HIV-are-less-likely-to-take-an-HIV-test/page/1528949/>

b) Where are problems of stigmatisation most acute?

Based on the above, the problems of stigmatisation are most acute –

- In the home, family and community. HIV positive gay men, for example, often report stigma in the form of rejection, rumour, and isolation from their own peers.
- In the workplace, but also occasionally in schools and colleges.
- In healthcare settings, often through inconsiderate comments or actions
- In church and faith group.

c) What measures are currently taken to tackle HIV stigmatisation? What more should be done?

In general, more should be done by –

- trying to understand stigma and the experiences of people living with HIV
- building a stronger Human Rights approach to HIV that respects dignity
- engaging and involves HIV positive people and draws on Community experience
- taking a multi-faceted and collective approach to tackling stigma
- recognising the difficulties that may arise within particular cultural contexts, including rurality

Services: Measures currently being undertaken specifically on HIV are usually very general. If we consider the areas of concern listed above, most HIV services are for adults and poorly suited to children infected with HIV or affected by the virus. There are notable exceptions, however, in for example NHS paediatric care in Glasgow, Edinburgh and Dundee, and Waverley Care’s long-standing dedicated children’s support services. The HIV Carers based in Glasgow take a distinctive whole family and whole person approach, work with all family members, and liaise where appropriate with social work services. Whilst services need to respond to the needs of the majority of those who ‘come through the door’, this neglect ignores the fact that those living with HIV have identities and lives other than their status or their risk factor, be it sexuality, drug use, country of origin or anything else. To the extent that even agencies at the front line ignore or are uninformed of the real lives of their service users, they fail to address the reality of stigma within home and community.

HIV services must address the needs of the whole person, social and otherwise.

Education in schools and colleges ought to address sexual health and HIV under the Curriculum for Excellence

Workplace: Good examples exist of efforts to inform employers and employees of their duties and responsibilities in relation to HIV and disability generally. Not only legislation but good practice needs to be well understood and implemented. The National AIDS Trust produces information and Guidance on Employment <http://www.nat.org.uk/Living-with-HIV/Useful-information/Employment-advice.aspx> Some agencies are able to provide employment support to people living with HIV, and the collaboration between Waverley Care and Terrence Higgins Trust (Scotland) in the Positive Scotland project (Big Lottery funded) is a good though too rare example

<http://www.waverleycare.org/content/employabilityandskills/207/> Local agencies such as Body Positive Tayside and Glasgow's HIV Carers provide excellent support to people living with HIV so that they are not isolated and on their own in trying to deal with some difficulties. This takes the form of support, eg one-to-one, group support, or advice and referral to welfare rights.

Healthy Working Lives has an excellent network, support and information for employers, and should promote more proactively sexual and HIV-related health

<http://www.healthyworkinglives.com/advice/workplace-health-promotion/sexual-health.aspx>

Healthcare settings: A number of approaches might help to reduce stigma and related discrimination in healthcare settings and in turn within the home and family.

Provide regular training and online guidance and updates on HIV for all staff.

Consider offering support on HIV testing for couples attending together.

Provide non-confrontational, confidential ways for people to flag up concerns.

Church and faith groups: Polarisation of views and alienation of people living with HIV or the communities to which they may belong can be avoided. There are numerous examples of excellent practice from faith-based organisations. Faith leaders must inform themselves about the facts related to HIV, and help to dispel the myths and prejudices. Equal treatment and consideration should be shown, and solidarity with people with HIV demonstrated. Links between HIV organisations and churches, mosques or faith groups can be encouraged. In addition to its General Assembly statement, the Church of Scotland has a dedicated HIV and AIDS Programme which aims to break the silence, offer practical support, work in solidarity with sister churches, speak for the voiceless and involve every member.

Specialist HIV agencies, churches and faith groups should work together to inform and support each other's work. See <http://www.e-alliance.ch/>

References

Aggleton, Parker and Maluwa (2003) *Stigma, Discrimination and HIV/AIDS in Latin America and the Caribbean*. Inter-American Development Bank, February 2003.

AIDS and Drug Misuse: ACMD Report. (1988) HL Deb 29 March 1988 vol 495 cc754-6WA

Clutterbuck, D et al (2008) *Report and Recommendations MSM Subgroup NSHAC 11: HIV Prevention Report*. Scottish Government, January 2008. Available from:

<http://www.scotland.gov.uk/topics/health/health/sexualhealth/msmreport>

Coates, Richter and Caceres. (2008) HIV Prevention 3. Behavioural strategies to reduce HIV transmission: how to make them work better. *Lancet* 2008. DOI:10.1016/S0140-6736(08)60886-7

Cree, V and Sidhva, D (2009) A cross sector needs assessment of children infected and affected by HIV in Scotland report. The University of Edinburgh. Available from:

http://www.hivscotland.com/documents/hiv_report.pdf

Health Protection Scotland (2009) *Health Protection Scotland: Protecting Scotland's Health* [online] (updated 8 December 2009). Available from: <http://www.hps.scot.nhs.uk/about/index.aspx>

Health Protection Scotland (2010) *Blood Borne viruses and Sexually Transmitted Infections* [online]. Available from: <http://www.hps.scot.nhs.uk/bbvsti/index.aspx>

Health Protection Scotland (2011) *Health Protection Scotland Weekly Report supplement ANSWER*. Volume 45 No. 2011/08, February 2011.

HIV Scotland and NHS Forth Valley (2009) Needs Assessment Report: Integrated HIV Prevention in Forth Valley. HIV Scotland, June 2009.

McClelland DBL. (1986) *HIV infection in Scotland. Report of the Scottish Committee on HIV infection and intravenous drug misuse*. Scottish Home and Health Department, September 1986.

NAT (2011) Employment advice [online] available from: <http://www.nat.org.uk/living-with-hiv/useful-information/employment-advice.aspx>

Scottish Executive (2005) *Respect and Responsibility – Strategy and Action Plan for improving Sexual Health*. Scottish Executive. January 2005.

Scottish Government (2007) *Better Health, Better Care. Action Plan*. Scottish Government, December 2007. Available from: <http://www.scotland.gov.uk/Publications/2007/12/11103453/0>

Scottish Government (2008a) *Hepatitis C Action Plan for Scotland Phase 2: May 2008 – March 2011*. Scottish Government. May 2008. Available from: <http://www.scotland.gov.uk/Publications/2008/05/13103055/0>

Scottish Government (2008b) *The Road to Recovery: A New Approach to Tackling Scotland's Drug Problem*. Scottish Government, May 2008. Available from: <http://www.scotland.gov.uk/Publications/2008/05/22161610/0>

Scottish Government (2009) *HIV Action Plan in Scotland – December 2009 to March 2014*. Scottish Government, November 2009. Available from: <http://www.scotland.gov.uk/Publications/2009/11/24105426/13>

Wallace, L (2010) *Epidemiology update (presentation), Gaycon 2010*, 20 October 2010.

Waverley Care (2011) *Employability and Skills*. [online] available from <http://www.waverleycare.org/content/employabilityandskills/207/>

Appendix

HIV voluntary agencies in partnership with HIV Scotland include:

Body Positive Tayside - offers a wide variety of services for people who are HIV positive and/or Hepatitis C positive, or directly personally affected

Gay Men's Health - involves and empowers gay and bisexual men to promote the health and well-being of all men who have sex with men. This includes men living with or affected by HIV

HIV-AIDS Carers & Family Service Provider Scotland - providing a range of practical and emotional services to carers, families, partners, friends and relatives who are affected or infected by HIV or AIDS

LGBT Youth Scotland - Scotland's largest youth and community-based lesbian, gay, bisexual and transgender (LGBT) organisation

Positive Help - offers volunteer led practical help to those affected by HIV/AIDS in Edinburgh and Lothian.

Terrence Higgins Trust - the leading and largest HIV and sexual health charity in the UK

Waverley Care - Scotland's leading charity providing care and support to people living with HIV and Hepatitis C, and to their partners, families and carers.

Glossary & Acronyms

ACMD – Advisory Committee on the Misuse of Drugs
AIDS - Acquired Immunodeficiency Syndrome
AMEHP - African and Minority Ethnic HIV Project
ARVs – antiretroviral drugs
BBV – Blood-borne virus
DoH – Department of Health
GIPA – Greater Involvement of People Living with HIV
GUM – Genito-urinary medicine
HIV – Human Immunodeficiency Virus
HPA – Health Protection Agency
HPS – Health Protection Scotland
IDU – injecting drug use
IVDU – intra-venous drug user
MCN – managed care network
MSM – Men who have sex with men
NAM – National AIDS Manual (aidsmap)
NICE – National Institute for Clinical Excellence
PCTs – Primary Care Trusts
QIS – NHS Quality Improvement Scotland
WHO – World Health Organisation