ScotPHN report

Scottish Public Health Network (ScotPHN)

Treatment and Care Needs Assessment: People Living with HIV

Dr Cathy Johnman
(November 2009)

Web version

Preface

The rising number of HIV cases in Scotland presents a challenge to those of us working in the public sector to ensure the effective delivery of care and treatment to those people living with HIV. With this in mind and following discussions with HIV clinicians in 2006, I asked the Scottish Public Health Network to undertake a needs assessment to inform future work in this area. I would like to thank the HIV Care and Treatment Needs Assessment group, led by Dr John Logan, for its work on this issue and the timely production of a report with recommendations that will shape how we move forward effectively in the future.

It is important however, that we look beyond the confines of clinical care to the wider social care requirements and ensure the integration of care and treatment with prevention activities to prevent the onward transmission of the virus. To drive and support this integration the Scottish Government has produced an HIV Action Plan that identifies strategic actions to be taken forward locally, regionally and nationally. These actions will increase our collective efforts and achieve effective co-ordination that will lead to improved outcomes for people at risk of or living with HIV in Scotland.

I encourage you to read this needs assessment report alongside the HIV Action Plan and support its delivery across Scotland.

Dr Harry Burns
Chief Medical Officer

Foreword

Following publication by the Scottish Government of the national sexual health strategy and action plan (*Respect & Responsibility*) the Chief Medical Officer commissioned the Scottish Public Health Network to carry out a needs assessment of treatment and care services for people living with HIV infection. (Whilst prevention of HIV infection is an important aspect of HIV treatment and care services, separate work has been carried out which focuses on HIV prevention.)

The provision of good HIV treatment and care services is complex due to the range of ways in which HIV infection can cause illness and the way in which illness may develop, and due to the variety of drugs that are required to treat patients. However, the clinical and drug treatment challenges must be seen within the context of the lives of people who have HIV infection which are influenced by factors such as cultural issues, ethnicity, communication needs, personal relationships, employment, income and wealth.

This needs assessment has followed the usual steps of study design, literature review, questionnaire design, field work and report write up – much of which has been undertaken by Dr Cathy Johnman, the lead author of this report. In addition, considerable time and effort has been invested in consulting on draft versions of the report with HIV treatment and care services stakeholders (including patients, voluntary sector organisations, local authority representatives, HIV professional groups and various parts of NHS Scotland), and by seeking the views of a patient scrutiny panel. Comments and suggestions received have been considered in detail and amendments made.

This report is part of an on going process. In Scotland, much has been achieved with regard to the development of HIV treatment and care services, however, there is much to be done to ensure the provision of quality assured, safe, culturally sensitive, easily accessible services which are readily available to all people living in Scotland who have been diagnosed with HIV infection. Services need to have the capacity to be able to develop to meet the changing needs of patients as the epidemiology of HIV infection in people living in Scotland changes. At a wider community level work is still required to further understand and address HIV related stigma and discrimination.

This report has helped to inform the development of the Scottish Government's HIV Action Plan. The publication of the Action Plan will lead to the development of improved structures and processes to monitor both the implementation of HIV policy and the way in which HIV funding is invested. NHS Boards, and other relevant organisations within NHS Scotland, now have a designated lead person for HIV work and a copy of this report will be sent to each HIV lead.

On the basis of needs assessment work carried out a proposal was submitted to NHS Quality Improvement Scotland for the development of clinical standards for HIV treatment and care standards. NHS QIS subsequently decided that the development of such standards would form part of its work programme. The quality of HIV treatment and care services is important across all ages, across all of Scotland, and across all ethnic groups, not only to people living with HIV infection but also to their carers, families, friends, and work colleagues.

Meeting the needs of people who have HIV infection is relevant to many Scottish Government action plans and areas of health policy including *Better Health, Better Care*; the health protection remit of NHS Boards; the Scottish Sexual Health Strategy and Action Plan – *Respect & Responsibility*; the national patient safety programme; *Equally Well*; *Towards A Mentally Flourishing Scotland*; *Getting It Right For Every Child*; equality, diversity and spirituality policies; and the management of long term conditions.

I would like to note the commitment that Dr Cathy Johnman has given to all aspects of the needs assessment and report writing and also to note the valuable contributions made to this work by members of the needs assessment project group.

In order to support the implementation of the recommendations made in this report I would ask that you disseminate the following web-link to it to relevant people within your networks
http://www.scotphn.net/projects/current_projects/hiv_aids_care_and_treatment_needs_assessment/

Dr John Logan
Chair, Treatment and Care Services for People Living with HIV Infection Needs Assessment Project Group
Consultant in Public Health Medicine, NHS Lanarkshire
9 November 2009

Acknowledgements

The project group wishes to thank the many people who contributed to the report. This included all those in HIV treatment and care units throughout Scotland who helped organise and participated in focus groups and provided service level data. All those who contributed to voluntary sector focus groups. In addition, all those who spoke to Cathy Johnman regarding their service and commented on the draft report. These included clinicians, representatives from the laboratory services, paediatric clinicians, members of the Blood Borne Virus Section of Health Protection Scotland, the BBV co-ordinators on NHS Orkney, Shetland and Western Isles, representatives from the Scottish Prison Service, dental services and dental public health, pharmaceutical public health, the Positive Forum and the UK Preconference Forum and the voluntary sector. Individuals are named in Appendix A.

Also those who attended the Stakeholder Event in September 2008 (Appendix A). All the people living with HIV who were members of the scrutiny panel and provided comment on the draft report. All those who contributed to the Stakeholder Review (Appendix A).

PROJECT GROUP

Dr John Logan *Chair of Project Group*	Consultant in Public Health Medicine, NHS Lanarkshire Chair of the Scottish Blood-borne Viruses & Sexually Transmitted Infections Prevention Network
Dr Cathy Johnman *Lead Author* *Health Care Needs Assessment: People living with HIV.*	Clinical Lecturer, Glasgow University Specialist Registrar in Public Health Medicine, NHS Greater Glasgow and Clyde
Dr Ray Fox	Consultant in Infectious Diseases, Brownlee Unit, NHS Greater Glasgow and Clyde
Prof David Goldberg	Consultant Head of BBV/STI Section, Health Protection Scotland Honorary Professor of Public Health, University of Glasgow
Dr Gwyneth Jones	Consultant in Infectious Diseases, NHS Dumfries and Galloway
Mr Roy Kilpatrick	Chief Executive, HIV Scotland
Mr Phil Mackie (From March 2008)	Lead Consultant, Scottish Public Health Network Senior Specialist in Public Health, NHS Lothian
Dr Gordon Scott	Consultant in Genito-urinary Medicine, NHS Lothian Chair of Scottish HIV and AIDS Group (SHIVAG)
Ms Ann Conacher	Co-ordinator, Scottish Public Health Network
Dr Rona Dougall (To May 2008)	Researcher, Scottish Public Health Network Public Health Resource Unit, NHS Greater Glasgow and Clyde
Dr Anne Maree Wallace (To December 2007)	ScotPHN Lead Consultant Consultant in Public Health Medicine, NHS Lothian

Glossary

AHP	Allied Health Professionals
AIDS	Acquired Immunodeficiency Syndrome
All cause mortality	Deaths from any cause (not just HIV/AIDS related)
ART	Anti Retroviral Therapy
BBV	Blood Borne Virus
BHIVA	British Human Immunodeficiency Virus Association - A UK professional association which acts as a national advisory body
Cardiovascular disease	Diseases affecting the heart and blood vessels of the body.
CD4	Cluster of Differentiation 4 (a glycoprotein expressed on the surface of T helper cells which is important in assessing the immune system of people with HIV)
CHIVA	Children's HIV Association - A UK professional association which acts as a national advisory body
GUM	Genitourinary medicine
HCNA	Health Care Needs Assessment
HIV	Human Immunodeficiency Virus
HPS	Health Protection Scotland
ID	Infectious diseases
Incidence	Number of new cases among subjects at risk over a given time
MTCT	Mother to child (vertical) transmission
NHS	National Health Service

Opportunistic infections	Infections which take advantage of a person's impaired immune system.
Prevalence	Total number of cases at any one time amongst subjects at risk
MedFASH	Medical Foundation for AIDS and Sexual Health-A charity which works with professionals and policy makers to promote excellence in prevention and HIV treatment and care
MCN	Managed Care Network
Morbidity	Disease, illness or disorder which affects normal function
Mortality	Death
MSM	Men who have sex with men
Palliative care	Approach which improves quality of life of people with life threatening-illness
ScotPHN	Scottish Public Health Network
SHIVAG	Scottish HIV and AIDS Group-A group of health professional and voluntary sector workers working in support of people living with HIV in Scotland
SIMD	Scottish Index of Multiple Deprivation—Identifies areas of multiple deprivation in Scotland
The Scene	The commercial side (bars, pubs, clubs, saunas, gyms and sex shops) of gay life in Scotland.
STI	Sexually transmitted infection
Viral Load	The amount of HIV virus found in blood and other bodily fluids

Executive Summary and Recommendations

An increase in new HIV reports and a dramatic reduction in HIV related deaths, mainly as a result of anti-retroviral therapy (ART), has led to a significant increase in the number of patients attending HIV treatment and care services in Scotland (2,674 in 2007 compared with 1,307 in 2000).

HIV treatment and care services in Scotland provide high quality, evidence based and BHIVA guideline appropriate ART therapy (as shown by the Key Clinical Indicators on page 44). However, it is important that services are responsive now and in the future, to the challenges of the complex social, psychological as well as physical needs of people living with HIV and their ability to benefit from such care.

People living with HIV require comprehensive care and services which are appropriate to the unique confidentiality and inequality issues raised by HIV and by the stigma and discrimination associated with a diagnosis of HIV (all of which can act as a barrier to accessing high quality care).

This health care needs assessment aims to assess the capacity of people living with HIV to benefit from services and to suggest service improvements to narrow the gap between service demands and need.

The epidemiology of HIV in Scotland has been changing recently, with an increase in new HIV reports (2007 had the highest ever recorded number since reporting began). This includes an increase in the proportion of people acquiring HIV through both heterosexual and MSM transmission.

The number of people attending treatment and care services has increased significantly since the turn of the century (it has more than doubled since 2000). Projections (using modelling techniques) suggest that this increase will continue. Potentially there could be between a 42% and 85% increase in numbers by 2012.

Services in Scotland have evolved to care for the growing number of people living with HIV. The context of existing clinical and financial structures has resulted in variations in models of treatment and care services being provided.

Issue

Despite the responsibility of NHS Boards to involve patients in the development of services, thus far, there have been few opportunities for direct patient involvement in the development of HIV treatment and care services.

This HCNA recommends that:

1. There should be wider patient and public involvement in planning future service development, as well as ongoing service provision, to ensure that services meet the needs of people living with HIV. (Page 47)
2. Creative national, local and community based approaches to patient and wider public involvement (e.g. on-line surveys and increased utilisation of the voluntary sector), are required to ensure that services meet the needs of people living with HIV. (Page 47)

Issue

Many HIV treatment and care services have existing clinic facilities which are of insufficient size and quality to meet current need and will require upgrading to meet projected demand.

This HCNA recommends that:

3. NHS services should provide adequate and confidential out-patient facilities which are fit for purpose. (Page 48)

Issue

Currently there are variations in the models of care, personnel and services provided by HIV treatment and care services.

This HCNA recommends that:

4. There should be access to a core set of appropriately skilled personnel provided by all HIV treatment and care units in Scotland. Further discussion is required to agree what these core personnel should be. (Page 54)
5. There should be access to a core set of services provided by all HIV treatment and care units in Scotland. Further discussion is required to agree what these core services should be. (Page 56)

Issue

Access to sexual healthcare services is important to ensure people living with HIV have support to prevent onward transmission of HIV as well as maintaining personal and sexual health.

This HCNA recommends that:

6. All HIV treatment and care services should provide comprehensive sexual healthcare integrated with HIV care in line with BHIVA guidelines[1]. (Page 57)
7. All NHS HIV services should have access to ongoing high quality counselling and support to ensure good sexual health and to maintain protective behaviours. (Page 57)

Issue

There is a lack of formal mechanisms in place to ensure equity of access to a range of other high quality HIV treatment and care services (some which may be provided in another location).

This HCNA recommends that:

8. All HIV treatment and care services should be part of, or affiliated to, an HIV Managed Care Network (following the Managed Clinical Network Quality Assurance Framework and working towards accreditation). These would support services to quality assure care, create smooth care pathways, facilitate communication between services, promote the use of shared resources and provide the opportunity to develop specialist skills. (Page 60)

Issue

Currently primary care has little or no involvement in HIV treatment and care although variations in practice occur throughout Scotland.

This HCNA recommends that:

9. HIV services should continue to strongly encourage and support patients to register with a GP and to inform their GP of their HIV diagnosis, allowing GPs to be updated regarding their patients' clinical status and medication. (Page 61)

1 British HIV Association (BHIVA) guidelines. Management of sexual and reproductive health (SRH) of people living with HIV infection. London 2008. http://www.bhiva.org/files/file1030950.pdf for (pre-press version accessed 2nd September 2008)

10. As for other conditions, GPs should continue to provide care for non-HIV-related conditions affecting people with HIV, including routine lipid management. They should continue to provide shared care in liaison with HIV services and with the patient's consent. (Page 61)
11. Consideration should be given (particularly in rural areas) to negotiating GP involvement in more specialist HIV care. With appropriate patient consent, this might include: taking bloods or prescribing prophylactic treatment. To facilitate this, shared care agreements, education and ongoing training would be necessary. (Page 61)

Issue

There is a lack of clear funding sources and strategic development for HIV treatment and care services.

This HCNA recommends that:

NHS Scotland should consider the development of:

12. Scottish Standards for HIV Treatment and Care. (Page 62)
13. A dedicated HIV policy which incorporates treatment and care. (Page 62)

Issue

HIV treatment and care services have limited access to patient management systems.

This HCNA recommends that:

14. A national HIV patient management system should be developed which is sensitive to patient confidentiality issues, whilst retaining the ability to link with generic records and provide audit facilities. (Page 64)
15. HIV treatment and care services should continue to maintain and support HIV surveillance programmes managed by HPS. (Page 64)
16. Key stakeholders should be consulted on the most efficient way of collecting and disseminating HIV surveillance data. (Page 64)

Issue

The treatment and care of people living with HIV is not only complex but is rapidly evolving making regular CPD particularly important. Staff involved in delivering this care need to develop and maintain up-to-date skills and knowledge appropriate to their roles.

This HCNA recommends that:

17. Support should be provided for members of staff providing HIV treatment and care services to enable them to develop and maintain up-to-date knowledge and skills appropriate to their roles. (Page 65)

Issue

There are opportunities for improvement in communication between laboratories which provide specialist HIV services and stakeholders. In addition, there are issues regarding laboratory space and other resources (particularly in the recruitment and retention of staff).

This HCNA recommends that:

18. Communication between policy makers, clinicians and laboratories should be improved along with increasing awareness of how changes in clinical practice impact on laboratory services. (Page 71)
19. Work should be undertaken to improve recruitment and retention of laboratory staff within the parameters set out in the Chief Scientific Officer's Modernising Scientific Careers. (Page 71)

Issue

The treatment and care of children living with HIV involves a whole family approach. Currently health education, support with adherence and HIV care is provided by consultant paediatricians. A multi-disciplinary approach to management is not possible as there is no pharmacy, dedicated social work, link/BBV nursing support available or even in some cases access to administrative or secretarial support. Ad hoc arrangements currently exist for transition to adult services.

This HCNA recommends that::

20. Paediatric services should have access to appropriately skilled personnel to provide a multidisciplinary service and appropriate support for children, young people and their families, affected by HIV. (Page 86)
21. Protocols should be developed to ensure smooth transition of children to adult services (in keeping with CHIVA guidelines). (Page 86)

Issue

Access to the support provided by the voluntary sector to people living with HIV varies throughout Scotland (with some notable gaps in provision). The level of collaboration which occurs between the voluntary sector and NHS services also varies.

This HCNA recommends that:

22. Support for voluntary and community sector provision, cross-sectoral collaboration and joint working with Local Authorities (including the use of service level agreements), should be part of the provision made at national and health board level to ensure that the social and psychological needs of people living with HIV are met. (Page 92)
23. There should be improved collaboration between NHS staff and the voluntary sector which incorporates capacity building through joint training. (Page 92)
24. All people living with HIV should have access, both directly and via HIV treatment and care services, to voluntary sector provision. (Page 92)

Section 1: Introduction

Background

The Scottish Public Health Network was commissioned by the Scottish Government to undertake this health care needs assessment (HCNA). It was requested by physicians managing people living with HIV in response to a number of issues highlighted regarding treatment and care services.

An increase in new HIV reports and a dramatic reduction in HIV related deaths, mainly as a result of the utilisation of anti-retroviral therapy (ART)[2], have led to a significant increase in the size of the cohort of patients attending treatment and care services in Scotland[3]. This cohort is not only living with, but also growing older with HIV infection (with the associated complications of ageing as well as those associated with HIV and its treatment). In addition, Scotland has a sizeable cohort of children with HIV who have acquired their infection through mother to child transmission (MTCT) either here or abroad.[3]

HIV patients have complex needs (physical, psychological and social) and require comprehensive clinical care[4]. Additionally, these patients are likely to present with a variety of chronic conditions unrelated to their HIV status.

Services have evolved to care for more and more people living with HIV within existing financial and clinic structures. Until now, no national or regional HCNA for people living with HIV has been undertaken. Currently there is variation across Scotland in the models of treatment and care for patients with HIV which is related to the evolution of HIV services, resources and geographical issues such as rurality.

Most areas have services which may be described by one of the following models:

2 The Antiretroviral Therapy Cohort Collaboration, Life expectancy of individuals on combination antiretroviral therapy in high-income countries: a collaborative analysis of 14 cohort studies, Lancet 372 (2008), pp. 293–299.
3 HPS. Focus HIV in Scotland 2007: review. HPS weekly report. 2008; 42: 0804. http://www.documents.hps.scot.nhs.uk/ewr/pdf2008/0804.pdf
4 British HIV Association. Standards for HIV Clinical Care. London, March 2007. http://www.bhiva.org/pdf/2007/StandardsHIVClinicalCare.pdf

1. A large unit with a combined infectious diseases (ID) and genito-urinary medicine (GUM) HIV service providing most aspects of treatment and care including in-patient services.
2. Separate infectious diseases and genitourinary medicine outpatient HIV services, but combined in-patient facilities which cover most aspects of treatment and care.
3. ID based units with a single-handed ID consultant who covers in-patient treatment but may not find sexual health easy to deliver unless close links exist with local GUM services (very close links in some Boards).
4. GUM based treatment and care services provided by a single-handed GUM consultant who can provide a comprehensive sexual health service, but requires to link with other clinicians to cover in-patient care.
5. NHS Boards which provide individualised care packages for those who require service provision but do not have HIV treatment and care services within their NHS Boards.

As morbidity and mortality from opportunistic infection become rarer (again as a result of ART), patients are likely to suffer ill-health from a number of chronic diseases, for example: cardiovascular disease[5] or cancers, both of which are being seen increasingly.

HIV is associated with significant stigma[6] as it asymmetrically affects already stigmatised minority groups, such as men who have sex with men, people from sub-Saharan Africa, asylum seekers/refugees and injecting drug users. As a result, people living with HIV often have complex needs (physical, psychological and social) and require holistic care which takes into account the unique confidential and inequality issues which HIV raises. HIV infection also carries significant stigma due to its association with sexual activity and, more historically, injecting drug use.

Consequently, the NHS faces a "challenge over the next 5 years in managing the care of people living with HIV".[7]

5 Friis-Moller N, Weber R, Reiss P et al. Cardiovascular disease risk factors in HIV patients – association with antiretroviral therapy. Results from the DAD Study. AIDS 2003; 17: 1179–1193.
6 Mahaja A, Sayles J, Pate ,V et al. , Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. AIDS. 2008; 2: S67-S79
7 MedFASH. Recommended standards for NHS services. MedFASH. 2004. London.

Scottish Policy Context

There are no consolidated Scottish national HIV treatment and care policies or standards. However, there are a number of UK professional bodies which have developed guidelines[6,8] and standards of care[3] and a number of Scottish policy documents which impact on HIV treatment and care services (i.e. Better Health, Better Care service delivery [9], drug use[10], BBVs[11]). There are also a number of policies which deal with prevention of HIV transmission (Sexual Health Strategy: Respect and Responsibility[12] and The Road to Recovery: A New Approach to Tackling Scotland's Drug Problem) which affect treatment and care services indirectly.

In 2003, the charitable organisation, the Medical Foundation for AIDS and Sexual Health (MedFASH)[6] developed recommended standards for NHS HIV services in England. The standards aimed to ensure equity of access to the same quality of care wherever people lived throughout England. They emphasised the development of networks and highlighted the importance of partnerships between NHS, local authorities, the voluntary sector and service users in planning and implementation of services.

In the UK, the British HIV Association (BHIVA) regularly produces clinical guidelines, which are recognised and followed by HIV physicians throughout the UK. More recently (in 2007) they have also developed clinical care standards[3], which focus on where and by whom HIV care should be provided. These standards recognise that well-organised services are necessary but not in themselves sufficient to achieve high-quality care.

These standards state that the principles and approach which they set out are broadly applicable across the UK as a whole but recognise that "further work may be needed in adapting some recommendations to the particular circumstances and organisational arrangements applying in Scotland, Wales and Northern Ireland, and certain low prevalence areas in England".

8 British HIV association. Treatment of HIV-infected adults with antiretroviral therapy. 2008.
9 Scottish Executive. Better Health, Better Care. Scotland, Scottish Executive. 2007.
10 The Road to Recovery: A New Approach to Tackling Scotland's Drug Problem, Scottish Government, 2008.
11 Scottish Executive. Hepatitis C Action Plan for Scotland: Phase II: May 2008 - March 2011. Scotland, Scottish Government. 2008.
12 Scottish Executive. Respect and Responsibility. Scotland, Scottish Executive. 2005.

Factors influencing the provision of services for people living with HIV infection in England, and particularly in London, are significantly different from the factors that have influenced the development of services in Scotland. For example: epidemiological variability; population density; patient travel time and distance; availability of specialists in different disciplines; involvement of service users and carers in service developments and the way in which HIV and sexual health strategies have evolved. The Better Health, Better Care Action Plan[9] aims to "help people to sustain and improve their health especially in disadvantaged communities, ensuring better local and faster access to health care". The three main component areas are health improvement, tackling health inequality and improving the quality of health care; the plan is committed to local care whenever possible. These are particularly important for HIV treatment and care.

Partnership for Care: Scotland's Health White Paper (2003)[13] states that "NHS organisations must be aligned with the nature and scale of change required {redesign of services}. Healthcare improvement will best be delivered when the different parts of the health system work in partnership as teams of professionals and with patients".

Increasingly HIV is being recognised as a manageable chronic disease/long term condition (Defined as lasting longer than a year, limits what a person can do and may require ongoing medical care).

The strategy paper *Delivering for Health*[14] puts an emphasis on providing the majority of care in the community as locally as possible as it aims to reduce health inequalities, provide more integrated and targeted local care, reduce hospital admissions, provide systematic support for people with long-term conditions, and allow patients and carers more say in what services they receive.

The Hepatitis C Action Plan[10] has just entered its second phase. The £43 million which will be invested over the next three years, will be utilised to improve testing, treatment, care and support services for those infected, with a major emphasis being placed on increasing the number of people receiving treatment. The importance of prevention is addressed through several actions designed to reduce the sharing of needles/syringes and other injecting equipment by injecting drug users (which would also reduce the transmission of HIV).

13 Scottish Executive. Partnership for Care: Scotland's Health White Paper. 2003
14 Scottish Executive. Delivering for Health. 2005

Principles of Health Care Needs Assessment

The objective of Health Care Needs Assessment is to specify services and other activities which impinge on health care[15]. The principal activities involved in health care needs assessment are:

- an assessment of incidence and prevalence
- an analysis of the effectiveness and cost-effectiveness of services
- establishing the existing service baseline to help guide service development and redesign.

From these three components, health care planners and commissioners can determine the policy direction they wish to pursue. There can also be other objectives in health care needs assessment. These might include:

- improving access and the allocation of resources at local, regional and national levels
- targeting resources at area(s) of highest need
- securing the active participation of key stakeholders and players in understanding the need for change and how it can be achieved.

Undertaking such work usually requires a collaborative approach, bringing together people with the necessary knowledge base and those with the appropriate technical skills. Broadly speaking, this requires that there is an:

- *Epidemiological Needs Assessment:*
  - ◊ Incidence and prevalence;
  - ◊ Effectiveness and cost effectiveness; and
  - ◊ Description of baseline services.
- *Corporate Needs Assessment:*
  - ◊ Reporting the demands, wishes and alternative perspectives of interested parties and stakeholders including professional, political and public views.
- *Comparative Needs Assessment*
  - ◊ Comparing and contrasting the services in the population under the study with those provided elsewhere.

15 Stevens A, Raftery J, Mant J, Simpson S. Health Care Needs Assessment. First Series, Second Edition, Volume 1. Radcliffe Publishing Oxford. 2007.

The final assessment should describe the capacity or the ability of the population to benefit from a service or intervention, and to make suggestions as to how such benefits can be delivered. Health care need is not, however, the only important factor in planning and delivering health care. Decisions about health services should be derived from a combination of values which reflect the society in which they belong. Therefore, in Scotland, consideration may be given to political direction, health care costs, legislation, competing NHS priorities, professional opinion, scarcity of resources or expertise and the existing pattern of services. Given the NHS is a public-funded institution, it is essential to recognise and account for, the importance of population perceptions and the impacts of political processes.

Aim

To assess the capacity of people living with HIV to benefit from services and to make suggestions as to how such benefits may be delivered.

Methods

This needs assessment has been undertaken using the ScotPHN project methodology for health care needs assessments. The network recruited a lead author with previous relevant service experience who worked in conjunction with the project group.

The HIV treatment and care project group consisted of specialists in HIV management, surveillance, research, care and support from the NHS and the voluntary sector. Regular update meetings of the project group were held for the duration of the project.

The project group was able to:

- Undertake designated pieces of work including writing some sections of the report, sourcing information and identifying contacts in specific areas;
- Provide feedback to the lead author on work undertaken;
- Agree the final draft of report;
- Input to training events / regional workshops to disseminate findings of the project.

The ScotPHN was also able to allocate additional research support to the lead author to gather relevant data, national and local policies etc., and support the preparation of a questionnaire and focus group questions.

Epidemiological Needs Assessment

Health Protection Scotland (HPS) HIV database

HPS (previously known as the Scottish Centre for Infection and Environmental Health), in association with immunology laboratories and clinical departments across Scotland, developed a robust reporting system in response to the emergence of HIV in Scotland. (It has collected data since 1985 making it one of the longest running national HIV surveillance systems in the world.)

HPS coordinate and administer four HIV surveillance systems:

- Laboratory Surveillance of All Persons Having a Named HIV Antibody Test (The Denominator Study);
- Laboratory Surveillance of All Persons Having an HIV Positive Test Result;
- the AIDS Registration System; and
- Surveillance of Persons Undergoing CD4 Monitoring.

Data on those attending treatment and care services for monitoring or treatment were provided by HPS.

Projections

In the late 1990s, HPS developed a statistical model to predict the future number of people under CD4 count monitoring (and thus in specialist HIV care) and receiving ART in Scotland. The original model has since been modified to comply with a more formal Markov Model framework (where future states are reached through a probabilistic process).

HPS has provided projections based on three different modelling methods (data from 1996–2006, 2002–2006 and 2004–2006). In each case a linear regression model is fitted to the data; the only difference being how many years of data have been used.

The projections are based on data from the CD4 monitoring surveillance scheme coordinated at HPS. (As known to HPS at July 2007; due to the reporting delay, it is estimated to be complete to April 2007.)

Comparative Needs Assessment

A comprehensive literature search was carried out to compare and contrast services and health care needs assessments carried out in other areas of the UK.

Database Search

The following databases were searched (see Appendix E):

- Ovid MEDLINE(R): 1966 to February Week 6 2007
- EMBASE 1980 to 2008 Week 6
- The Cochrane Library 2005, Issue 4

Reference Checks

Those papers providing an insight into the area of study had their references examined for other relevant papers. These were selected initially using their titles and then using their abstracts according to the above criteria.

Web Search

A web search was carried out using Google and Google Scholar (see Appendix E).

Corporate Needs Assessment

Individual treatment and care units

A quantitative questionnaire (49 questions; 19 pages) was developed and piloted by the project group (see Appendix D). This was sent to all of the 14 adult and 2 children's HIV treatment and care units throughout Scotland. There was a 100% response rate. The questionnaire assessed levels of clinical activity, service provision, workforce, referral links and opportunity for continued professional development.

Information from key informants in NHS Boards without treatment and care units was sought either by teleconference or in person.

In-depth data on services was sourced using focus/discussion groups held at all of the HIV treatment and care units. These followed a discussion schedule (see Appendix C) based on qualitative focus group methods. The groups were recorded using an MP3 digital recorder and transcribed for future analysis. The analysis of the transcriptions followed the constant comparative method which is a form of grounded theory. Grounded theory was developed by the sociologists Strauss and Glaser as a way of formalising the operations needed to develop theory from empirical data.[16,17,18,19] It is an iterative methodological approach (entailing a cyclical process of induction, deduction, and verification) and a set of strategies for the analysis of qualitative data, designed to improve the reliability and theoretical depth of analysis. Particular attention is paid to the processes entailed in coding data. As each new theme is coded a continuous comparison is made with previous indicators to refine the fit to emergent conceptual theories.

Discussions included: the current and future challenges faced by the units; partner contact/notification processes; access to medications and services; patient involvement activities and thoughts about strategic development.

16 Ruston A, Clayton J, Calnan M. Commentary: Grounded theory and the constant comparative method. BMJ 1998; 316: 1065
17 Bradley E, Curry LA, Devers KJ. Qualitative data analysis for health services research. 2007;42:1758-1772.
18 Tavakol M, Torabi S and ZEIALOO AA. Making sense of grounded theory approach: implications for medical education research. Journal of medical education 2006;4:17-24
19 Starks H and Brown S. Choose your method: a comparison of phenomenological, discourse analysis and grounded theory. Qualitative health research. 2007;17:1372

Voluntary sector

Annual reports were provided by the main voluntary sector groups. Two focus/discussion groups were held with representatives of the voluntary sector to discuss baseline provision, links with NHS services and to gain an impression of the current challenges which face the sector and to assess future challenges in the face of an increasing number of people living with HIV. These focus groups were analysed using a constant comparative qualitative methodology.

Patient view

The patient view was sought using a number of different approaches and sources to allow triangulation. Existing focus group data were used from the UK Coalition of People Living with HIV and AIDS and Positive Forum.

The UK Coalition of People Living with HIV and AIDS (UKC) held a series of focus groups across the UK in 2007 to identify key HIV related concerns. This was followed up by a national conference "Positive Action" held in London on the 1 March 2008 and a smaller Scottish conference "Positive Forum" held on the 20 February 2008. HIV Scotland facilitated the Scottish focus groups held prior to the conference. The Scottish focus groups were held in Dundee, Edinburgh and Glasgow. The findings of the discussions pertaining to HIV treatment and care services are utilised in this report.

Patient satisfaction surveys have been undertaken in some of the HIV treatment and care units in Scotland. All NHS Boards (via the BBV leads) were requested to provide any patient satisfaction, health needs assessments or consultations with patients which may have been conducted and which could inform this health care needs assessment.

Laboratory view

Laboratory based data were provided by HPS and the laboratories themselves. A focus/discussion group was held with key informants. This followed a discussion schedule (see Appendix C) based on qualitative focus group methodology. The group was recorded using an MP3 digital recorded and transcribed for accuracy.

Consultation process

A consultation event was held in September 2008. This provided an opportunity to present an overview of the key issues from this health care needs assessment; to discuss the findings and to refine appropriate recommendations. The event was attended by 85 delegates with broad representation from NHS treatment and care staff, NHS managers, voluntary sector, laboratories and paediatric services. Recommendations were discussed in workshops and the workshop discussions were then corroborated by the wider group of attendees. The outcomes of the event have been incorporated into this report.

In keeping with ScotPHN methodology, the findings of this report were reviewed by an anonymous scrutiny panel of people living with HIV. The purpose of the scrutiny panel was to enable the ScotPHN to capture the views of service users, patients and carers, formally and comprehensively. The members of the scrutiny panel followed the ScotPHN protocol and the comments have been incorporated into this report.

Section 2: Epidemiology: HIV

HIV

Definition

HIV is a retrovirus discovered in the early 1980s[20]. Two types have been identified: type 1 [21] and type 2. Worldwide, the predominant virus is HIV-1. The relatively uncommon HIV-2 type is concentrated in West Africa and is rarely found elsewhere.[17]

Mode of Transmission

HIV can be transmitted from person to person through three different routes: sexual contact; blood and blood products (including contaminated needles and syringes) and mother to child transmission.

Incubation period

The window period for HIV is variable but generally antibodies are detectable between 1-3 months following infection. Without treatment about 75% of infected adults will develop symptoms and, within 10 years post infection, some 50% will develop AIDS (Acquired Immune Deficiency Syndrome)[22]. The median incubation period to developing AIDS is much shorter for infected infants and longer for infected young adults.

Testing

Screening for HIV is generally carried out by testing for both antibodies to HIV and viral proteins (antigens). An initial positive test is confirmed by repeat antibody/antigen testing (usually with an alternative assay) followed by Western Blotting, which is the standard confirmatory test for anti-HIV antibodies alone. A repeat sample is requested from a newly identified positive patient.

Newly diagnosed people with HIV have baseline HIV viral load (amount of circulating virus), subtyping and resistance testing carried out. Viral load, in conjunction with CD4 counts informs decisions on when to begin therapy and likely rate of clinical progression. Subtyping, which has an epidemiological role, is a by-product of resistance testing which guides best treatment options.

20 Adler M. W. "Development of the epidemic," in M. W. Adler (ed.), ABC of AIDS. London: BMJ Books. 2001
21 McCutchan FE. Global epidemiology of HIV. J Med Virol 2006;78:Suppl 1:S7-S12.
22 Williams IG. AIDS and genitourinary disease in Souhami RL and Moxham J. Textbook of medicine. London: Churchill and Livingston. 2002

Clinical features

Around 20–60% of people develop an acute seroconversion illness (caused by an increase in HIV virus in the blood and the body's immune response) of short duration, 1-6 weeks after initial infection. Commonly this presents as a glandular fever like illness with fever, malaise, myalgia, pharyngitis etc.

Asymptomatic infection may persist for many years with a gradual increase in the viral load and a decrease in the CD4 count. The progression of HIV has been dramatically altered by the use of ART causing prolongation of the asymptomatic phase.

Symptomatic HIV infection can present as persistent generalised lymphadenopathy, non-specific constitutional symptoms or AIDS.

AIDS is a severe disease syndrome which represents the late stage of infection with HIV. AIDS is made up of a number of opportunistic infections and cancers which develop due to the immunodeficiency caused by HIV infection.

Management

People with HIV infection, and often their families, need a great deal of psychosocial support (information, advice, counselling, peer support and social care and support with adherence) in addition to drug therapy.

Treatment and care for people with HIV infection is complex, rapidly evolving, involves specialised investigations and the use of potentially toxic medications. HIV clinicians may refer patients who are known to have HIV infection to other specialties such as oncology, psychiatry, dermatology, renal medicine and hepatology for assessment, investigation and treatment. Where available, input is provided to HIV services by pharmacists, dieticians and mental health services. Information about the availability of these services across Scotland is not currently available but has been collected as part of this health care needs assessment.

There are a number of chronic disease issues related to either the antiretroviral drugs, or long term exposure to HIV itself, which are important for people living with HIV (cardiovascular disease, renal disease, cancers etc).

Currently there is considerable concern about cardiovascular disease: not only are people living longer with HIV (and therefore at an increased risk of cardiovascular disease) but many of the antiretroviral drugs used in the treatment of HIV are associated with hyperlipidaemia[23]. Co-infection with Hepatitis C (HCV) is common in those HIV positive individuals who acquired HIV through injecting drug use and is increasingly found in men who have sex with men (MSM)[24,25]. HCV infection is more serious in HIV-infected persons as it leads to liver damage more quickly. Co-infection with HCV may also affect the management of HIV infection[26].

Prevention

Primary prevention focuses on health promotion activities which can bring about sustainable behavioural change to reduce the risks associated with transmission (unprotected oral, vaginal or anal sexual intercourse and sharing injecting equipment). Primary prevention (generally described as activities which focus on preventing an uninfected person from becoming infected), while not the focus of this health care needs assessment, is important as it has a direct impact on services.

Most HIV-infected patients in Scotland became infected through sexual contact. As more people remain symptom free on antiretroviral therapy, many will continue to have sexual relationships. There is evidence to suggest that there has been an increase in "at risk" sexual behaviour in people living with HIV with some notable outbreaks of sexually transmitted infections (STIs)[27]. There is also evidence showing that HIV is being transmitted from people who are already on antiretroviral therapies and therefore are aware of their HIV status and attending services[28 29 30]. It is well documented that HIV progression and transmission is increased and facilitated by STIs.

23 Triant VA, Lee H, Hadigan C, Grinspoon SK. Increased acute myocardial infarction rates and cardiovascular risk factors among patients with human immunodeficiency virus disease. J Clin Endocrinol Metab. 2007; 92: 2506-2512
24 Fox J et al. Increasing incidence of acute hepatitis C in idividuals diagnosed with primary HIV in the United Kingdom. AIDS 22:666-668, 2008.
25 Ghosn J et al. Sexually transmitted hepatitis C Virus superinfection in HIV/hepatitis C virus-coninfected men who have sex with men. AIDS 22:658-661, 2008.
26 Neilson M and Matthews G. BHIVA guidelines-HIV and chronic hepatitis: co-infection with HIV and hepatitis C virus infection. 2004.http://www.bhiva.org/files/file1001579.pdf
27 Fakoya A. BHIVA guidelines. Management of sexual and reproductive health (SRH) of people living with HIV infection (2007). http://www.bhiva.org/files/file1001318.pdf
28 UK collaborative group on monitoring the transmission of HIV drug resistance. Analysis of prevalence of HIV-1 drug resistance in primary infections in the UK. BMJ. 2001; 322: 1087-1088.
29 Pillay D. current patter4ns in the epidemiology of primary HIV drug resistance in north American and Europe. Antiviral therapy. 2004: 9: 695 – 702.
30 UK Collaborative group on HIV drug resistance. Evidence of a decline in transmitted HIV-1 drug resistance in the UK. AIDS. 2007; 21: 1035 – 1039.

The main aims of secondary prevention programmes include:

- Reduction of transmission acts (including the acquisition of HIV variants)
- Maintenance of an enhanced quality of life for someone living with HIV through improved self-care behaviours (eg injecting harm reduction and sex education to prevent STIs), and to improve treatment concordance.

Secondary prevention programmes also provide opportunities to address the wider determinants of health and wellbeing.

Tertiary HIV prevention aims to minimise the effects of ill–health experienced by someone who is symptomatic with HIV disease[31].

31 AIDS map: http://www.aidsmap.com/cms1009526.asp. Last accessed 2/2/09

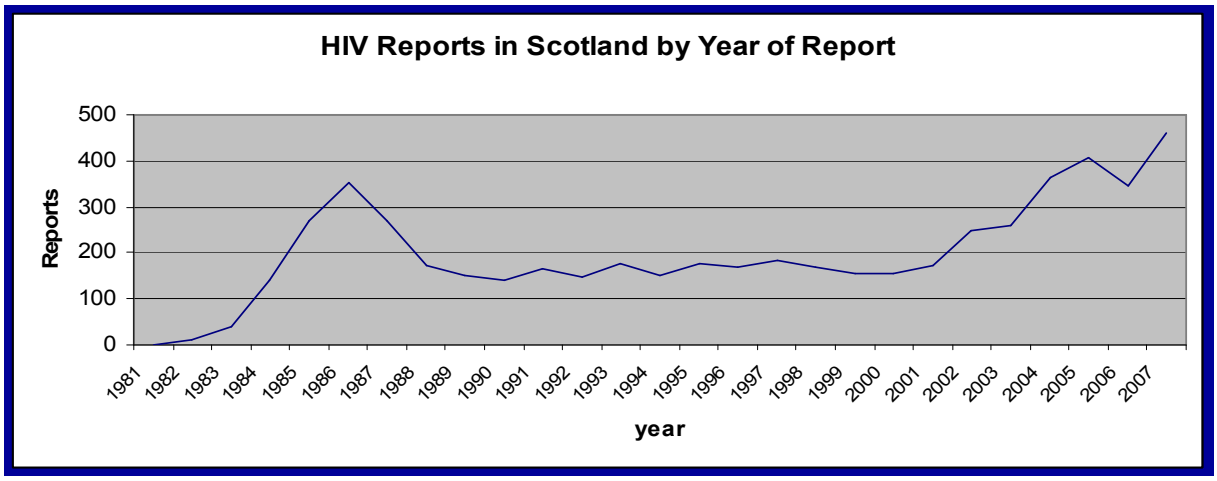
Epidemiology of HIV in Scotland

New HIV Reports

At the end of December 2007 there had been a cumulative total of 5,420 known HIV-positive individuals in Scotland. Some 3,950 (73%) were male and 1,470 (27%) were female. At least 1,560 (29%) were known to have died.

In Scotland, during the 1990s, the number of annual new HIV reports ranged between 150 and 180; since the turn of the 21st century (with the exception of the small decline (14%) observed between 2005 and 2006) the number of new reports has been rising steadily. In 2007 there were 453 new HIV reports: this includes 317 with no evidence of a previous diagnosis elsewhere in the UK or overseas. This is the highest annual number of new reports since HIV antibody testing became available in the 1980s (See Figure 1).

Figure 1: Time Trends in HIV Reporting in Adults



Some of the increase in new HIV reports can be attributed to an increasing trend in testing[32] following: opt-out testing in GUM clinics, antenatal testing and a recent CEL letter (Chief Executive Letter 15 2007[33]) requesting that clinicians "be alert to the circumstances in which it is appropriate to offer and recommend an HIV test".

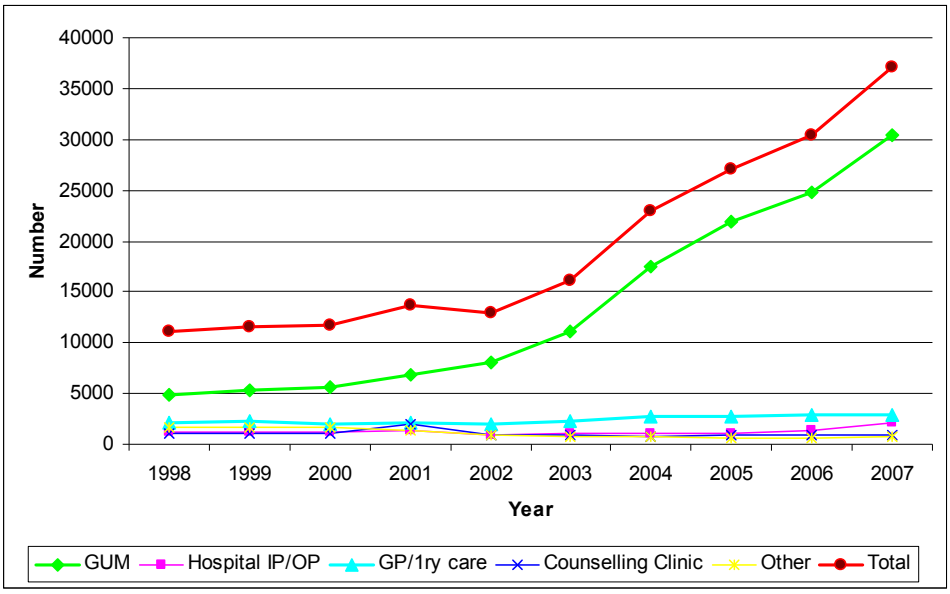
32 Dougan S, Elford J, Chadborn E et al. Does the recent increase in HIV diagnoses among men who have sex with men in the UK reflect a rise in HIV incidence or increased uptake of HIV testing? Sexually Transmitted Infections 2007;83:120-125

33 Dr Harry Burns, CMO and Mr Paul Martin, CNO (2007). Improving the detection and diagnosis of HIV in non-HIV specialties including primary care. CEL 15 (2007) 23 October 2007. Chief Medical Officer and Chief Nursing Officer Directorates, The Scottish Government. Available at http://www.sehd.scot.nhs.uk/mels/CEL2007_15.pdf

Between 2003 and 2007, there has been a greater than two-fold rise in persons undergoing a named (or attributable) HIV test (17,266 to 37,083). This is due principally to the dramatic increase in testing in GUM clinics since 2002/2003 when opt-out testing was introduced (see Figure 2).

There has also been an increase (albeit a much smaller one) in GP based testing but little change in other locations such as counselling clinics or hospital in-patient/out-patients.

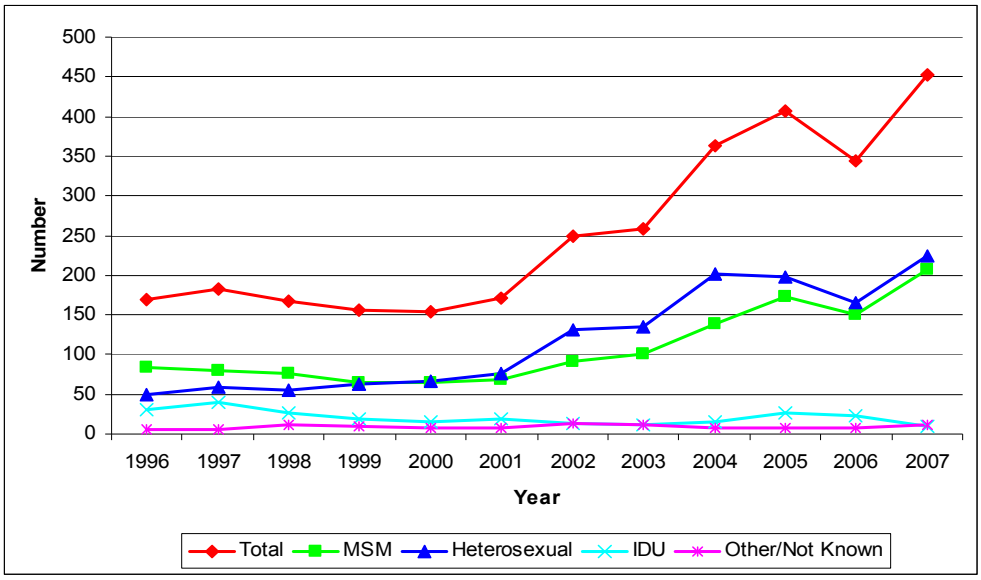
Figure 2: Trend in HIV Testing: Testing Location



Courtesy of HPS

At a risk group level, increases of 38% (150 to 207) and 35% (166 to 224) among MSM and non-IDU heterosexual men and women, respectively, were observed between 2006 and 2007 (See Figure 3). Less than 10 new cases were reported in the IDU population (one of the lowest annual figures ever recorded) suggesting that HIV transmission among IDUs in Scotland is now a rare event. In keeping with current trends, there were more new reports in the group who acquired their HIV heterosexually than in MSM group (224 and 207 respectively).

Figure 3: Trends in Risk Category of Exposure in HIV Infected Individuals, Scotland, 1998-2007



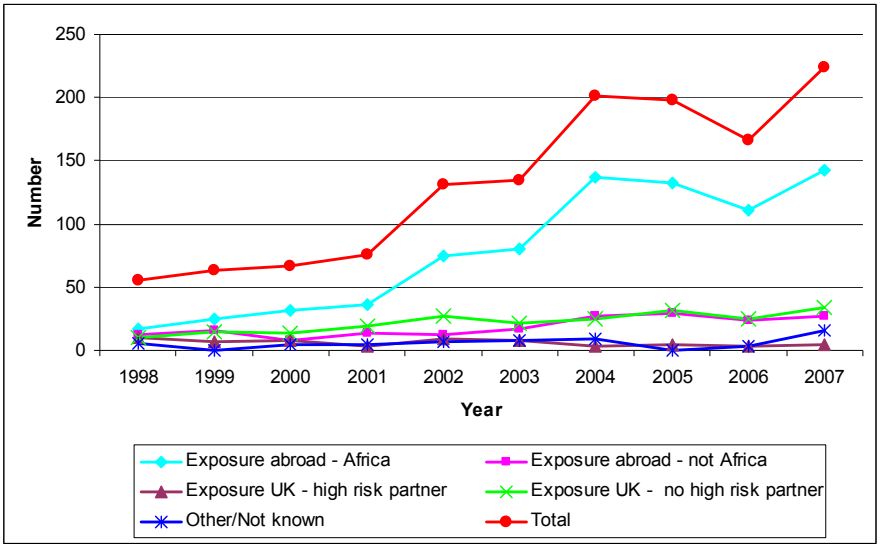
Courtesy of HPS

In 2007, reports of heterosexually acquired infection were highest in those whose region of exposure was described as sub-Saharan Africa. Of those who had acquired their HIV heterosexually, 16.5% (37/224) were known to have only had exposure to HIV in the UK.

Further analysis indicates that the majority of all newly reported cases (277) are presumed to have acquired their infection outside Scotland. Of the 154 presumed to have acquired their infection in Scotland, 79% (122/154) are MSM.

Overall, the recent increasing trend in new HIV reports appears to be the result of increasing new reports in MSM and among those who have acquired HIV infection as a result of sexual, blood product and MTCT exposure in African countries (see Figure 4).

Figure 4: Heterosexually Acquired



Courtesy of HPS

Recent surveillance data on sexually transmitted infections show increasing trends in cases of rectal gonorrhoea and syphilis among MSM in Scotland suggesting an increase in unprotected sex. Studies on sexual behaviour indicate an increase in unprotected anal intercourse among MSM suggesting the potential for resurgence in HIV infections among MSM.

Although some of the increase in new HIV reports can be attributed to an increase in testing seen since 2000, evidence from repeat testing (new diagnoses among those having repeat tests in a calendar year - a crude method of assessing seroconversion episodes) suggests that new transmissions are occurring. Prior to 2003 there were around 4 new transmissions shown from repeat testing within a calendar year. Since 2004, this figure has more than doubled.

Prevalence

Prevalence of HIV in the general population of the UK is very low. Using estimates based on unlinked anonymous data and antenatal screening, HIV prevalence in Scotland for the general heterosexual population is <0.1%.

Among the higher risk groups, current data, based on those undergoing named testing, indicate a prevalence of almost 4% among MSM, <1% among IDUs and 6% for those who have had unprotected sexual intercourse either in a high prevalence country or with someone from a geographical area of high HIV prevalence (most notably sub-Saharan Africa).

Figure 5: Prevalence of HIV in Named Settings

Group	Setting	Year of study	% Positive
IDU	All clinics	2007	0.3
Heterosexual (UK Exposure)	All clinics	2007	0.1
Heterosexual (African Exposure)	All clinics	2007	10.5
Pregnant women	via Guthrie Card	2007	0.08
Blood donors	All clinics	2005	0.002
MSM	All clinics	2007	4.3

Courtesy of HPS

HIV prevalence in MSM having named testing in Scotland has remained stable at between 3-4% for the past five years: this is similar to data across the rest of the UK except in London where prevalence is estimated to be 8.6% (range 7.1%-11%)[34].

A recent study undertaken to assess HIV prevalence among a community sample of gay men in Scotland showed a prevalence of 4.4% (95% confidence interval: 3.5% to 5.7%)[35].

Although the overall prevalence in IDUs remains at <1%, there are regional variations which reflect needle sharing and other behaviours associated with HIV transmission in this group across Scotland during the 1980s and early 1990s. Historically, prevalence in IDUs varies throughout Scotland with <1% in the West of Scotland and 17.7% in the East[36].

The Needle Exchange Surveillance Initiative carried out in 2007 showed that of 633 injecting drug using individuals only one respondent (from NHS Greater Glasgow and Clyde) tested positive for antibodies to HIV.

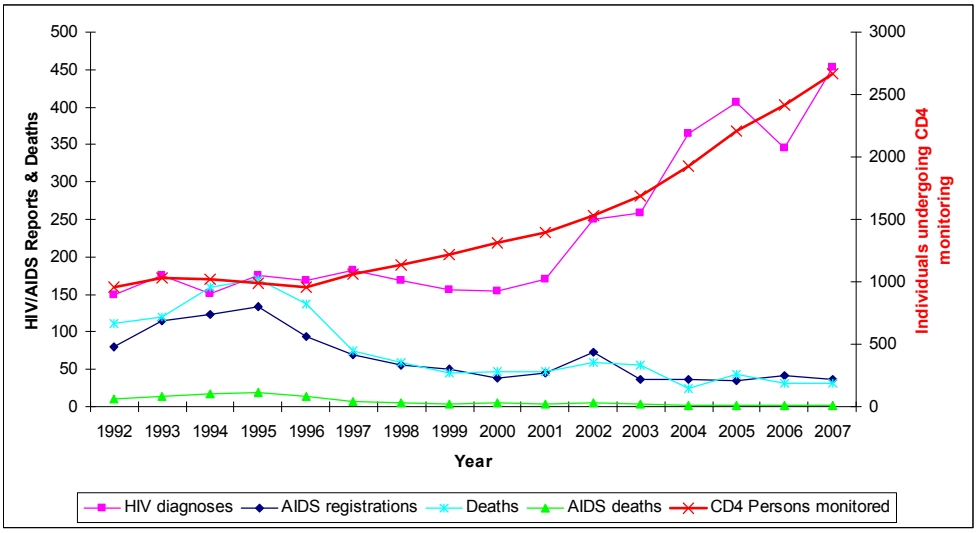
In 2007, there were 348 new reports in Scotland's four largest NHS Boards (NHS Grampian, NHS Greater Glasgow and Clyde, NHS Lothian and NHS Tayside) out of 37,083 tests (giving a 0.94% test positivity rate) compared with 11,690 tests undertaken in 2000, of which 154 were positive (1.3%).

34HPA. Testing times. HIV and other Sexually Transmitted Infections in the United Kingdom: 2007
35 Williamson L and Hart G. HIV Prevalence and Undiagnosed Infection among a Community Sample of Gay Men in Scotland. JAIDS Journal of Acquired Immune Deficiency Syndromes. 2007; 45(2):224-230.
36 Davies AG, Cormack RM and Richardson AM. Estimation of injecting drug users in the city of Edinburgh, Scotland and the number infected with HIV. International journal of epidemiology. 1999; 28: 117-121.

Numbers attending treatment and care services

As all patients attending HIV treatment and care services have CD4 monitoring carried out this can be used as a measure of the number of patients attending specialist services.

Figure 6: CD4 Monitoring and Treatment 2007



Courtesy of HPS

The number of HIV infected individuals in specialist care has more than doubled since 2000 (1,218 to 2,674). This shows how many more people living with HIV services are seeing. The 2,674 figure in 2007 represents an estimated 69% of the cohort of HIV infected persons living in Scotland. Approximately 71% of those in care were on ART at some time during 2007.

The majority of patients attend services within Scotland's central belt (matching Scotland's population distribution). Figure 7 shows the NHS Board breakdown of those who attended HIV services in 2007. The first three columns display cases attending by the patient's NHS Board of residence (based on their post code). The next three columns show the NHS Board where people attend for treatment and care. The third three columns detail the proportion of patients on therapy.

Figure 7: CD4 Monitoring and Treatment by NHS Board - 2007

	Cases attending for CD4/VL monitoring and treatment (presumed NHS Board of residence)			Cases attending for CD4/VL monitoring and treatment (presumed NHS Board of Treatment at most recent attendance)			% of cases on ART at triple therapy level or higher		
NHS Board	**Cases not known to be dead as at 31 Dec 07**	**Cases attending for CD4/VL monitoring and treatment [1]**	**Cases unaccounted for during 2007[2]**	**Total attendees**	**Attendees who have ever recorded a CD4 count of <200**	**Cases attending for the first time during 2007**	**% of all cases attending for monitoring**	**% of cases: ever recorded a CD4 <200**	**% of cases attending for monitoring for the first time**
				(A)	**(B)**	**(C)**	**(% of A)**	**(% of B)**	**(% of C)**
Ayrshire & Arran	85	63	22	31	19	2	71%	100%	0%
Borders	34	26	8	2	0	0	50%	-	-
Dumfries & Galloway	71	50	21	37	19	7	59%	74%	14%
Fife	153	107	46	69	46	8	80%	93%	50%
Forth Valley	96	66	30	43	15	3	58%	93%	33%
Grampian	295	202	93	202	109	45	68%	89%	33%
Greater Glasgow & Clyde	1134	793	341	891	451	160	71%	90%	43%
Highland	92	49	43	35	19	7	60%	74%	29%
Lanarkshire	183	136	47	103	57	21	62%	86%	43%
Lothian	1408	973	435	1066	655	120	75%	88%	44%
Orkney	0	0	0	0	0	0	-	-	-
Shetland	5	5	0	0	0	0	-	-	-
Tayside	303	201	102	195	122	25	69%	78%	48%
Western Isles	3	3	0	0	0	0	-	-	-
Scotland	**3862**	**2674**	**1188**	**2674**	**1512**	**398**	**71%**	**88%**	**41%**

1. Cases are allocated to a particular NHS Board based on their postcode of residence. If this is not known, the case is allocated based on the NHS Board from which they were referred for testing
2. "unaccounted for" includes cases who have not attended for monitoring during 2007, who have been diagnosed in Scotland but have since left the country (most likely to England) or have died but have not as yet been notified to HPS

There is evidence that patients travel across NHS Boards to receive HIV treatment and care. This is observed in the two NHS Boards where the greatest numbers of people living with HIV reside. In both NHS Greater Glasgow & Clyde and NHS Lothian, a greater number of patients attend for treatment and care than are resident in these areas.

To support the implementation of Respect and Responsibility, the National Sexual Health Advisory Committee (NSHAC) was formed. Action 12 relates to the development of a number of key clinical indicators (Key Clinical Indicators are part of the quality framework for sexual health in Scotland) to help monitor the progress of the strategy. The Key Clinical Indicator directly related to HIV treatment and care (in 2007) is:

"The proportion of HIV positive people in specialist care and eligible for antiretroviral therapy (ART) who have been treated and the proportion of those treated who have an undetectable viral load."

Scotland-wide, 97.1% of HIV positive people in specialist care who were eligible for ART were on ART and 79% of patients undergoing monitoring had an undetectable viral load[37].

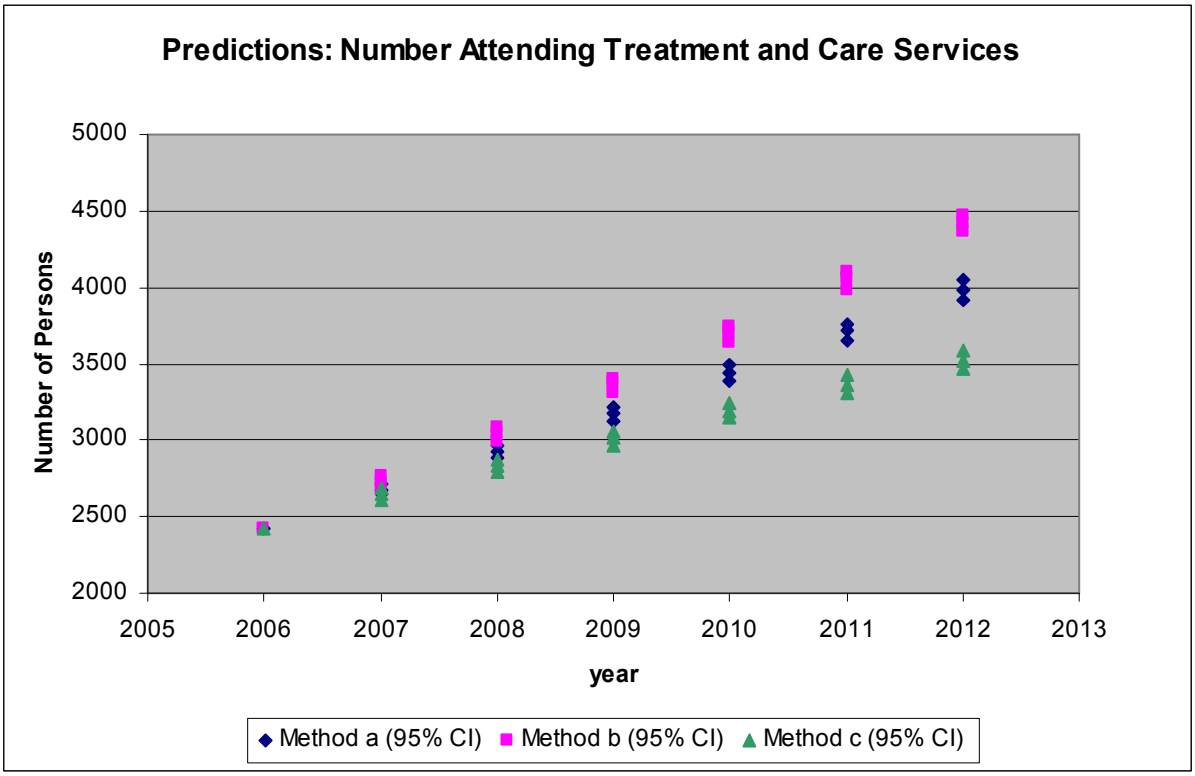
HIV treatment and care services in Scotland provide high quality, evidence based and BHIVA guideline appropriate ART therapy. However, it is important that services are responsive now and in the future, to the challenges of the complex social and psychological as well as physical needs of people living with HIV and their ability to benefit from such care.

37 National services Scotland. Moving forward. STI and HIV in Scotland. 2005

5-Year Projections

Projections developed by HPS suggest that, for all Scotland, there could be an increase of between 42% and 85% in the numbers of people attending HIV treatment and care services for CD4 monitoring by 2012 (based on 2006 figures and using 3 different modelling methods). This is an increase of around 5-13% (some 150 – 350 persons) per year. The biggest increase is set to be in the NHS Greater Glasgow & Clyde and NHS Lothian board areas (see Appendix B).

Figure 8: Projections of persons under CD4 monitoring by year: 2007–2012



	Method a	Method b	Method c
Year			
2000	1307	1307	1307
2001	1392	1392	1392
2002	1521	1521	1521
2003	1680	1680	1680
2004	1925	1925	1925
2005	2203	2203	2203
2006	2417	2417	2417
2007	2677 (2644 , 2716)*	2730 (2689 , 2770)	2642 (2608 , 2682)
2008	2923 (2886 , 2967)	3042 (2987 , 3088)	2834 (2792 , 2875)
2009	3181 (3125 , 3221)	3368 (3305 , 3402)	3018 (2970 , 3063)
2010	3442 (3387 , 3488)	3710 (3635 , 3742)	3192 (3146 , 3246)
2011	3714 (3657 , 3757)	4062 (3977 , 4098)	3363 (3305 , 3429)
2012	3986 (3914 , 4051)	4413 (4364 , 4469)	3521 (3461 , 3584)

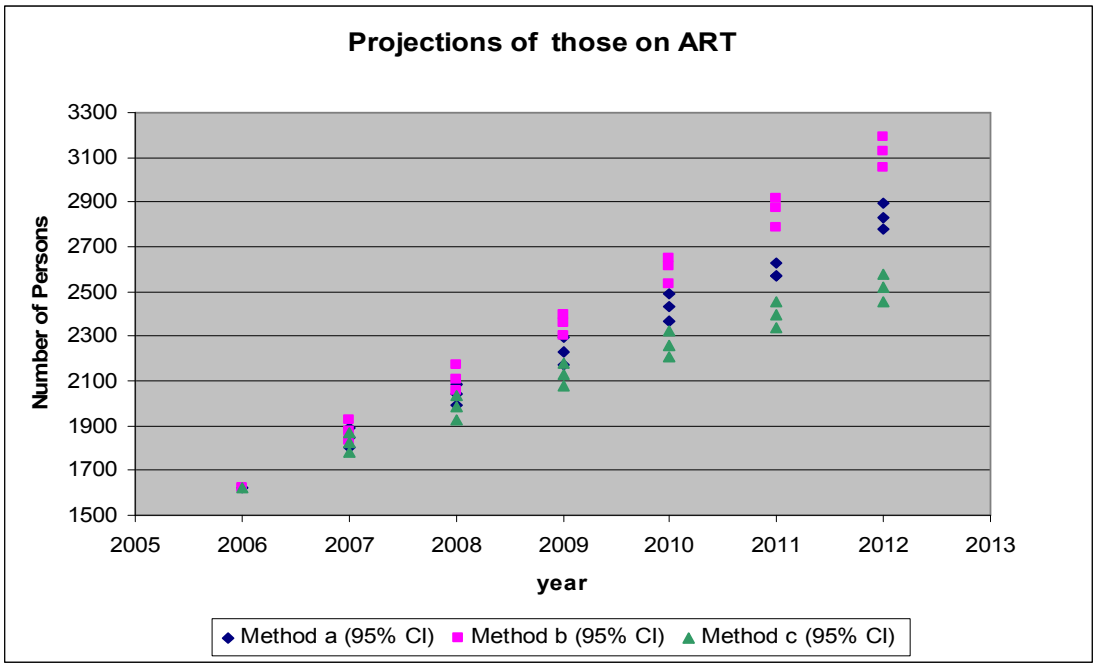
*95% Confidence interval

(Method a uses data from 1996 – 2006, b utilises 2002 – 2006 and c 2004 – 2006 data)

Method C predicts the least increase in numbers suggesting that by 2012 there will be 3,521 (95%CI: 3,461, 3,584). Method B projects the biggest increase in numbers 4,413 (95%CI: 4,364, 4,469). Overall, the projections have narrow confidence intervals suggesting a high level of precision with which we are able to assess the projections.

The number of people in Scotland who will be in receipt of ART is predicted to increase by 51–96% (based on the 2006 figures and using the three methods) by 2012. This is equivalent to a 5-16% increase (some 126 – 259 persons) per year. The biggest increase is set to be in the NHS Greater Glasgow & Clyde and NHS Lothian board areas (see Appendix B).

Figure 9: Projections of Persons on ART by Year, 2007–2012



95% Confidence interval

	Method a	Method b	Method c
Year			
2000	760	760	760
2001	859	859	859
2002	956	956	956
2003	1071	1071	1071
2004	1232	1232	1232
2005	1442	1442	1442
2006	1625	1625	1625
2007	1844 (1806 , 1889)	1879 (1835 , 1927)	1824 (1782 , 1872)
2008	2039 (1991 , 2088)	2109 (2054 , 2169)	1983 (1929 , 2032)
2009	2232 (2171 , 2293)	2358 (2303 , 2397)	2127 (2078 , 2178)
2010	2433 (2369 , 2488)	2613 (2535 , 2647)	2261 (2212 , 2325)
2011	2628 (2571 , 2688)	2872 (2787 , 2914)	2393 (2342 , 2453)
2012	2830 (2776 , 2896)	3123 (3057 , 3193)	2519 (2456 , 2580)

Method C predicts the lowest level of increase to 2,519 (95%CI: 2,456, 2,580) with method B suggesting that by 2012 there could be 3,123 (95%CI: 3,057, 3,193) in receipt of ART.

With the continuing increase in the numbers of persons in specialist care and on therapy in 2007, one of Scotland's most pressing HIV challenges is to ensure that all infected persons needing treatment and care receive it.

Section 3: Corporate: NHS HIV Treatment and Care Services

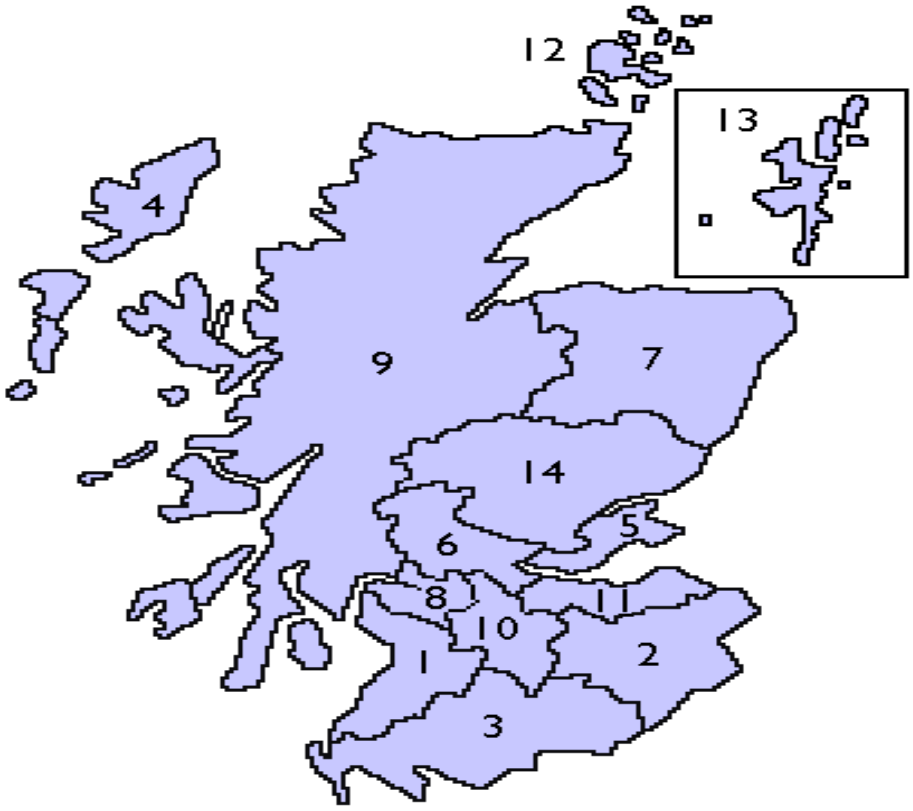
Adult NHS Treatment and Care Services

Evolution of services has resulted in variations in practice and the model of care provided throughout Scotland.

3.1: MODELS OF CARE

Scotland has 14 adult HIV treatment and care units in 11 different NHS Boards.

Figure 10: NHS Boards



NHS Greater Glasgow and Clyde (8) (see Figure 10) is the only board which provides a combined infectious disease and genito-urinary medicine HIV service which provides most aspects of treatment and care including in-patients.

NHS Fife (5), NHS Grampian (7) and NHS Lothian (11) all have separate ID and GUM out-patient HIV services, but combined in-patient services that cover most aspects of treatment and care.

NHS Tayside (14), NHS Ayrshire and Arran (1), NHS Lanarkshire (10) and NHS Dumfries and Galloway (3) have treatment services provided by a single handed ID consultant (single-handed or working in collaboration with colleagues) who covers in-patient treatment, but may not find sexual health easy to deliver. NHS Tayside and NHS Lanarkshire have GUM consultants who are actively involved in providing HIV treatment and care through sessions in the ID outpatient services and provide a link with sexual health services.

NHS Highland (9), NHS Forth Valley (6) and NHS Borders (2) have services which are provided by a single-handed GUM consultant who can provide a comprehensive sexual health service, but requires to link with other clinicians to cover in-patient care.

NHS Western Isles (4), NHS Orkney (12) and NHS Shetland (13) provide individualised care packages for those who require service provision but do not have HIV treatment and care services within their NHS Board. Some of the people living with HIV in these Boards attend services in Scotland - Highland, Grampian, Lothian and Edinburgh (generally through patient choice) or some attend services out with Scotland.

3.1.2: Service Level Data

Data collected from the units show that there were 2,768 patients attending HIV treatment and care services in 2007.

Figure 11: Service Level Activity Data

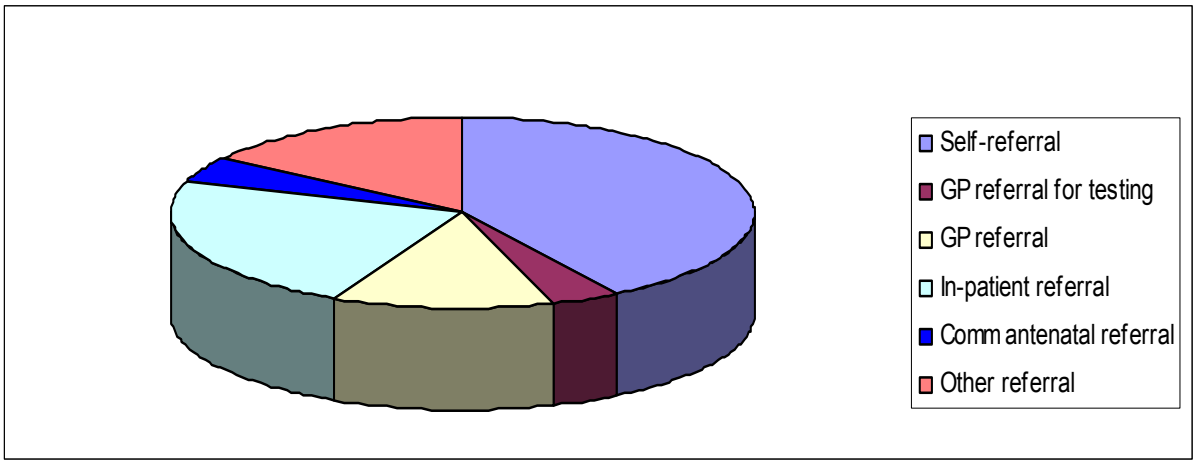
NHS Health Board	Total number of patients attending in 2007	Newly diagnosed patients attending in 2007	Patients transferred into the service (moved their care)
Ayrshire & Arran	42	2	2
Borders	14	1	1
Dumfries & Galloway	40	5	3
Fife GUM	13	3	1
Fife ID	62	9	3
Forth Valley	68	10	3
Grampian GUM	69	13	9
Grampian ID	140	30	5
Greater Glasgow & Clyde	923	113	58
Highland	44	5	5
Lanarkshire	97	12	20
Lothian GUM	470	37	43
Lothian ID	596	15	50
Tayside	190	16 – 24*	9 -12*
Scotland	**2768**	**271- 279**	**212- 215**

*based on estimates

Differences between HPS national data and service level data can occur for a number of different reasons. The HPS database is able to assess if a person attends two different units in the same year, via database linkage techniques and probability matching. Also, some units may have presented financial year rather than calendar year data.

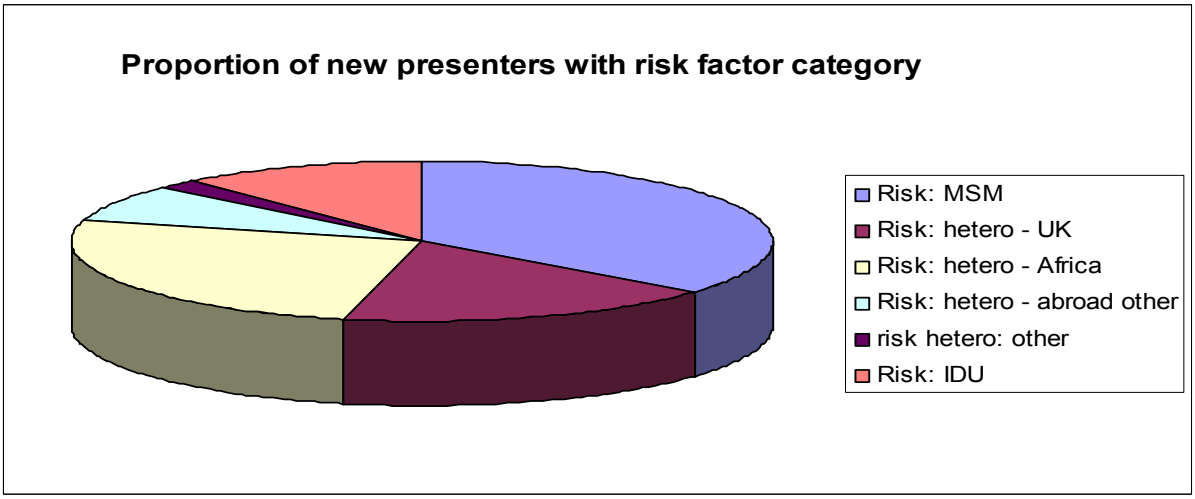
The majority of patients came into the service via self-referral mechanisms (33%) with in-patient referral being the next most common route (18%).

Figure 12: Method of Referral



Those who attended an ID based unit were much more likely to present as an in-patient referral than those who attended a GUM based or joint service (around 40% compared to 5%).

Figure 13: Proportion of new presenters with risk factor category



Key clinical indicators

Units reported that an average of 73% (56% – 90%) of those who attended services within the last year were on ART with an average of 11% of those starting the ART in 2007.

Of the units who responded an average of 91% of HIV positive patients, who have ever had a CD4 count <200, were on ART. This varied from 89–100%. The BHIVA standards of care emphasise the importance of ART for patients with low CD4 counts to reduce short and long term morbidity and mortality. This supports the finding that people living with HIV in Scotland receive excellent evidence based and guideline appropriate therapy.

3.1.3: Patient Involvement / Consultation

Despite the responsibility that NHS Boards have to involve patients in the development of services, thus far there have been few opportunities for direct patient involvement in the development of HIV treatment and care services.

Of 14 adult treatment and care units, 3 have carried out-patient satisfaction surveys in the past 2 years. Of these, none were specific to patients with HIV.

A small number of patient consultations have been carried out, although patient complaints have been useful in the process of changing clinic systems.

Of 14 adult treatment and care units, 3 have carried out-patient satisfaction surveys in the past 2 years. Of these, none were specific to patients with HIV. Patient satisfaction surveys can be a useful tool in assessing healthcare services. Their application may be enhanced with the use of technologies such as on-line and mobile surveys.

Patient groups have been consulted on the development of information resources in at least 3 NHS Boards. These resources have been well received by patient groups.

Clinic systems have evolved. There are a number of models:

- Dedicated ID/BBV clinics within a general out-patient setting
- GUM clinics with HIV patients being seen in any appropriate slot (not a dedicated HIV clinic)
- GUM clinics with set HIV clinics (although flexible arrangements where appropriate)
- Ward based out-patient services at dedicated times

It was suggested that there might not be any one clinic system which would suit all, given the diversity of background and needs of patients living with HIV.

Patient input and involvement in service development and ongoing service provision is extremely valuable and could help empower people living with HIV.

It is acknowledged that HIV related stigma and inequalities make it sometimes difficult to involve people living with HIV. Therefore, creative national, local and community based approaches need to be utilised to facilitate this process.

Recommendations

1. There should be wider patient and public involvement in planning future service development as well as ongoing service provision to ensure that services meet the needs of people living with HIV.

2. Creative national, local and community based approaches to patient and wider public involvement (eg on-line surveys and increased utilisation of the voluntary sector), are required to ensure that services meet the needs of people living with HIV.

3.1. 4: Facilities

Many services have existing clinic facilities which are of insufficient size and quality to meet current need and will require upgrading to meet projected demand.

Concerns regarding the lack of adequately resourced facilities were raised in the majority of units:
[There is a lack of] *"proper adequate confidential facilities for managing patients"**

Overall there was insufficient space and too few rooms. The lack of rooms often hampered the ability to provide a timeous and comprehensive service. For example, there is *"no space for pharmacists to provide direct patient services."*

Waiting rooms were highlighted as being of particular concern. In one case, there was no waiting area; another service had to use a corridor as a waiting area.

"I have a vision in my head of a cartoon when you see the walls bulging and pulsating because there are so many people inside" *

One unit described constant difficulties with temperature regulation.

Direct observation of these limitations within the relevant units was possible as part of the fieldwork for the report. However, formal assessment against current NHS building standards was not undertaken.

Of all the issues raised by staff, concerns regarding the quality of clinic facilities was discussed the most. Those few units who did not identify this as an area of concern were more likely to have moved into new premises or recently had their out-patient facilitates upgraded.

Recommendations

3. NHS HIV services should provide adequate and confidential outpatient facilities which are fit for purpose.

* HIV Treatment and Care Needs Assessment Focus Group quote

3.1.5: NHS Staffing

There are variations in the personnel providing care in NHS HIV treatment and care units.

Figure 14: Overall Workforce (*WTE given in brackets where stated)

NH HIV treatment and care unit	Consult-ants (WTE)*	Other doctor grades (WTE)	Spe-cialist Nurs es (WTE)	SHA (WTE) Sexual Health Adviser	Phar-macists (WTE)	Social work (WTE)	AHP (WTE) Allied Health Profes-sionals	Mental Health Staff (WTE)
NHS Ayrshire & Arran	1	1	2	Dual role of BBV nurses	1 (part of ge-neric service)	Generic available		2
NHS Borders	1 (0.1)		1 (0.2)	1 (0.2)				
NHS Dumfries & Galloway	1 (0.5 for all ID work)		1 (0.8)		1			
NHS Fife GUM	1	1	2	2	1			
NHS Fife ID	1	1	1		1	2		
NHS Forth Valley	1		3 (1.02 +.5)	1	1		1	
NHS Grampian GUM	3 (2.2)	1 (1)	1 (0.6)	5 (4)	1 (1)			
NHS Grampian ID	3 (1.5)	2 (2)			1			
NHS Greater Glasgow & Clyde	5 (1.5)	8.6 (2.45)	6 (3.5)	1 (0.7)	3 (2) +2 techni-cians	5 (5) + 2 social care advisors	2 (1)	1 (0.8)
NHS Highland	1 (0.8)	1 (0.6)	2 (1.2)	1 (0.8)				
NHS Lanarkshire	4 (0.4)	1 (0.1)	4 (1.5)	1 (0.1)	1 (0.25)			
NHS Lothian GUM	6 (0.8)	5 (0.2 +?)	10 (2.6)	5 (1)	1 (0.5)		1 (0.1)	
NHS Lothian ID	5 + 1 GUM (0.6)	12 (5)	3 (3)	2 (2)	1 (1)	1 (1)	2 (0.5)	2 (1.5)
NHS Tayside	4 (0.6)	2 (0.3)	2 (1.5)		1	3	1 (0.1)	1 (0.5)

As of 20 July 2008 (based on returned questionnaires) there are 36 consultants providing treatment and care services throughout Scotland (2 of which undertake their clinical work in 2 NHS Boards). Of these, 19 were described as genito-urinary medicine specialists and 17 as infectious disease specialists.

There are no dedicated HIV consultants in Scotland (only London has a small number of HIV dedicated consultants in services with cohorts of >3, 000). In some of the smaller single handed ID units (NHS Dumfries and Galloway and NHS Ayrshire and Arran) consultants provide general medicine services for both out and in patients.

The proportion of consultant time which is dedicated to HIV care is often difficult to estimate. Those units which were able to provide an estimate of WTEs suggested that between 20% and 50% of their time is spent on HIV treatment and care.

This suggests that there is 1 consultant for every 69 people attending services or 1 WTE per 138–345 patients. This equates to 1 per 151,300 of the population (between 1 per 302,600 and 756,500 of the population WTE). The *Consultant Physicians Working for Patients*[38] recommends 3 WTE GUM consultants per 250,000 population and 2-3 WTE ID consultants per 300,000.

There are an additional 34 junior grade doctors (ranging from staff grades to doctors in their first year of training (FY1)) who have various levels of involvement in HIV treatment and care. Some 7 staff grades/associate specialists support HIV services (mainly in outpatients) and manage patients independently with consultant support.

38 Consultant Physicians Working for Patients. Royal College of Physicians, 2nd edition. www.rcplondon.ac.uk 2005

Nursing

There are 36 BBV nurse practitioners who have an important role in providing advice, support and education on all aspects of HIV treatment and care. There is additional nursing staff in a number of units (ward or outpatient department based) who assist with seeing outpatients but do not have an enhanced role in the management of HIV.

There are 19 Sexual Health Advisers (SHA) who provide advice, support and health education and who have a major role in sexual history taking, screening for sexually transmitted infections and contact tracing. Three of the 36 BBV nurse practitioners were described as having a dual role as SHAs. There are a number of units across Scotland which do not have access to SHAs while seeing HIV positive patients - although they do have the ability to refer to local GUM/reproductive health services if required.

In NHS Greater Glasgow and Clyde (the unit with highest number of patients) there is a dedicated SHA who manages and coordinates the sexual and reproductive health of the HIV cohort.

Pharmaceutical Support

The majority of units have access to pharmaceutical advice although only 12 of the 14 units have regular input to HIV treatment care and only 8 units have pharmacy time dedicated to HIV treatment. Even for those who have access to specialist pharmacy support, there is marked variation in the type of input provided.

In some areas the pharmacist has an active role in seeing patients and giving direct counselling regarding commencement of therapy, interactions and adherence. Others provide *"end of the phone"* advice and support to clinicians. All of the units had a mechanism in place to alert medical or pharmacy staff to medications not being picked up when expected, suggesting that there may be an adherence issue. This role was carried out by medical or nursing staff in 2 of the units.

Barriers to dedicated time from a pharmacist include resources, lack of specialist HIV knowledge and clinic space. The vast majority of HIV units without direct pharmacy input to patient care felt that this was an important area of unmet need.

Apart from a few incidences where concerns have been raised from senior management, units have full access to SMC accredited therapy as long as it is within current clinical guidelines. Senior clinicians did report that there were ongoing discussions with SMC regarding the assessment of new drugs which are to be used in combination with other HIV drugs. More generally, drug budgets are beginning to be questioned and some units have been asked to make savings where appropriate. Pharmacy departments are increasingly being asked to look at projections for drug budgets (not necessarily with financial provision associated with them).

An informal support network exists between many of the pharmacists, with the pharmacists in the larger central belt units providing advice to many of the other NHS board units.

Social workers

Social work input is important in ensuring people living with HIV have their social care needs (welfare benefits, housing, and support) assessed and met. These issues are of particular importance for many people living with HIV.

Only 4 units stated that they have dedicated social work input. Historically, these units have had a high number of IDUs with multiple social problems. Increasing social work input is required to help support asylum seekers and refugees.

The vast majority of HIV units without dedicated social work input felt that their patients "would benefit" from such a service.

Managed care (rather than clinical) networks would ensure issues such as safe housing, access to food, assistance with transport, and access to drug, alcohol and mental health treatment programmes are addressed.

Clinical Psychology / Mental Health

HIV infection affects all aspects of a person's life including mental and emotional well-being. Mental health issues are particularly important for people living with HIV. Not only do people present with issues related to their long term condition or treatment side effects (eg adjustment disorder, depressive disorders and organic brain syndromes) but also, the stigma and marginalisation associated with HIV (and its related at-risk behaviours) has an impact on mental health. Mental and emotional well-being may also be adversely affected by sexual dysfunction and the effects of substance misuse (opiates and recreational).

A high level of treatment adherence is necessary to ensure a good response and reduce the risk of developing drug resistance. Mental health issues have been shown to affect concordance with medication[39].

There has been a change in the pattern and severity of mental health issues since the introduction of ART[40]. Catalan *et al* showed there has been an increase in the proportion of referrals to mental health services for depressive and anxiety disorders compared to organic brain disorders or substance misuse.

Provision of mental and emotional support is important to all people living with HIV, not just after the initial HIV diagnosis when people are offered the services of a counsellor within HIV clinics. (Symptoms of anxiety, depression and social dysfunction are particularly common.)

Many services are generic in nature with only the large units having access to dedicated liaison psychiatry.

A need for increased mental health provision geared towards HIV as a chronic illness affecting vulnerable populations was highlighted by services, the voluntary sector and patients themselves.

Only 4 units had access to dedicated clinical psychology support and 1 to psychiatric support. (Data derived from both questionnaires and focus groups.)

Many of the voluntary sector organisations provide support and counselling services for people living with HIV. Managed care (rather than just clinical) networks, which include the voluntary sector, would ensure issues such as the mental and emotional well-being of people living with HIV are addressed.

39 Mehta S, Moore R and Graham N. Potential factors affecting adherence with HIV therapy. AIDS; 1997; 6: 1665 – 1670
40 Catalan J, Meadows J and Douzenis A. The changing pattern of mental health problems in HIV infection: the view from London, UK. Aids care. 2000; 12: 333-341

AHP (Allied Health Professionals)

Dietetics, occupational therapy and physiotherapy are important components in the care of long term conditions, particularly in HIV treatment and care. Only 3 units stated that they had access to dedicated time from dieticians and only two had access to occupational therapists (the two largest units).

Recommendations

4. There should be access to a core set of appropriately skilled personnel provided by all HIV treatment and care units in Scotland. Further discussion is required to agree what these core personnel would be.

A managed care network could provide the opportunity for those with generic skills to become highly skilled and allow "back-fill". An MCN could support staff to quality assure care, create smooth care pathways, facilitate communication between services, promote the use of shared resources and provide the opportunity to develop specialist skills.

3.1.6: Services

There are variations in services and personnel provided in HIV treatment and care units.

Services have evolved to become increasingly multidisciplinary and holistic in nature, with less focus on clinical treatment, while delivering complex HIV care. Smaller services were described as "bespoke" providing individualised care and larger services emphasised the multidisciplinary approach which aimed to meet as many of the needs of people living with HIV as possible in one visit. There is a general perception that there has been either a constant flow of late presenters or an increase in the numbers of patients attending late.

There was a strong acknowledgement that HIV is now a long term condition. It is no longer the *"Sword of Damocles"** it once was and issues of patient self-management are important.

Many units use teleconferencing to discuss complicated cases. Advice/discussion with other consultants occurred in an informal basis mainly involving the 4 larger services. The west and central Scotland areas (NHS Ayrshire and Arran, NHS Lanarkshire and NHS Forth Valley) would generally discuss cases with Glasgow, while the east and NHS Dumfries and Galloway would contact colleagues in Lothian.

* HIV Treatment and Care Needs Assessment Focus Group quote

NHS Highland had formal links with NHS Grampian (with the consultant undertaking clinics in NHS Grampian GUM) but also links with Chelsea and Westminster via the Associate Specialist who works in that hospital on a part-time basis.

Some links have developed through staff having been trained in larger units then taking up positions as consultant in other areas of Scotland (eg NHS Grampian GUM and Glasgow).

Where applicable (based in or near an acute hospital), services felt the benefit of being located within a hospital setting to facilitate referral to other services.

Additional services

Some areas have developed additional services, for example, NHS Fife has a transportation scheme which has reduced the failure to attend rate at out-patient clinics. NHS Greater Glasgow and Clyde has a peer support worker who is employed by the NHS but coordinates peer support volunteers. Several NHS Boards offer outreach services to prisoners in their area.

Links with other services

NHS Boards are able to provide the majority of clinical services required to manage patients with HIV. Notable exceptions include:

- Plastics – most of Scotland refer to St John's Hospital in Livingston *
- Oncology – this is provided by the large regional services
- Liver failure/transplant services in Edinburgh
- Preconception and fertility care – there are difficulties accessing these in some areas

Palliative Care

Although the introduction of ART has profoundly impacted on morbidity and mortality, the need for quality palliative and end of life care continues (as it currently remains an incurable and extremely stigmatising condition). Palliative care provides a holistic (physical, psychosocial and spiritual (where appropriate)) approach to improving the quality of life of patients and their families when affected by life-threatening illness.

* NHS Greater Glasgow and Clyde liaises with the local plastics unit in Canniesburn Hospital where nurse-led filler therapy is undertaken. (This therapy is used to reduce the appearance of sunken cheeks which can result from some of the ARTs.)

Palliative care in the UK will follow the DoH's *End of Life Care Strategy (2008)*[41] which emphasises the importance of care planning, co-ordination of care, rapid access to care and the delivery of high quality services in all locations. In Scotland, *Living and Dying Well* (2008)[42] uses "the concepts of planning and delivery of care, and of communication and information sharing as a framework to support a person centred approach to delivering consistent palliative and end of life care".

The vast majority of NHS HIV services have access to palliative care services when required for their patients. In this regard, links between an HIV MCN and the local palliative care MCN could support services to quality assure care, create smooth care pathways, facilitate communication between services, promote the use of shared resources and provide the opportunity to develop specialist skills.

Recommendations

5. There should be access to a core set of services provided by all HIV treatment and care units in Scotland. Further discussion is required to agree what these core services would be.

This may become an important issue in the future with people living with HIV growing older and requiring palliative care for HIV and non-HIV related conditions and therefore should be considered in future provision of care.

* quote taken from an HIV treatment and care unit focus group carried out for this HCNA

41 Department of Health. End of life care strategy. London. 2008.

42 Scottish Government. Living and Dying Well: A national action plan for palliative and end of life care in Scotland. Edinburgh. 2008

3.1.7: Access to Sexual and Reproductive Health Services

Access to sexual healthcare services is important to ensure people living with HIV have support to prevent onward transmission of HIV as well as maintaining their own sexual health.

Of the 14 treatment and care adult services:

- 13 units offer sexual and reproductive health services
- 7 units provide sexual and reproductive health services on-site
- 3 units have carried out audits of sexual history documentation
- 10 units have protocols in place for ensuring sexual infection screening of newly diagnosed patients (although one of these had very small numbers which allowed activity to be monitored on an individual basis)
- 11 units have Sexual Health Advisers available on-site to see patients with HIV

There is a degree of reluctance from some ID services to approach regular sexual history taking with patients, citing concerns regarding confidentiality, stigma and a feeling that patients attend ID services preferentially because they require or desire less sexual health service input.

Recommendations

6. All HIV treatment and care services should provide comprehensive sexual healthcare integrated with HIV care in line with BHIVA guidelines[43].

7. All NHS HIV services should have access to ongoing high quality counselling and support to ensure good sexual health and to maintain protective behaviours.

Obstetric and reproductive services

Obstetric care for women with HIV is very important as it can dramatically reduce the chances of a baby being born with HIV. Pre-conception advice and assistance can also be important in reducing MTCT and reducing the risk of transmission to an HIV sero-discordant partner.

Normal pregnancy and delivery in women with uncomplicated HIV infection is managed within generic midwifery/obstetric services.

43 British HIV Association (BHIVA) guidelines. Management of sexual and reproductive health (SRH) of people living with HIV infection. London 2008. http://www.bhiva.org/files/file1030950.pdf for (pre-press version accessed 2nd September 2008)

Most services in Scotland do not have access to a named consultant obstetrician or paediatrician. Only one service has an HIV liaison service which runs joint clinics with maternity and women's reproductive health units. One other has a named HIV consultant who facilitates linkage between the services.

In all areas, the provision of ART falls within the scope of the outpatient HIV unit and the pregnancy care within the obstetric unit. Communication between the two was highlighted as a significant issue in a number of HIV treatment and care units.

The BHIVA HIV Clinical care standards recommend that birth plans and plans for paediatric care should be developed in consultation with the HIV centre and regional paediatric HIV clinics.

There were difficulties in accessing reproductive health services (pre-pregnancy advice, pre-chemotherapy and assisted conception) throughout the majority of services.

Contraception

Community family planning services are available throughout Scotland. 10 units provided contraceptive services on site. The others reported that they were able to refer patients elsewhere. No particular concerns were raised from units regarding contraceptive services.

3.1.8: Harm Reduction

Units report that there are few people living with HIV who are currently injecting drugs. Harm reduction forms part of an overall risk assessment of care. Improvements in harm reduction and needle exchange services (training, access and quality) utilising Hepatitis C prevention funds were addressed as part of the Hepatitis C Action Plan.

3.1.9.: Organisation Framework

There is a lack of formal mechanisms in place to ensure equity of access to high quality HIV treatment and care.

Informal care links are already in existence. For example, NHS Dumfries and Galloway has mechanisms in place to provide HIV consultant support while the single handed practitioner is on leave.

Many focus groups discussed Managed Care Networks (MCNs):

Pros:

- Uniformly agreed referral triggers and pathways to deliver care safely and efficiently
- Provide clinical governance including quality assurance and audit
- Ensure patient input and involvement in service development and ongoing service provision
- Formalise existing informal links – public and voluntary sector
- Able to link with other related networks
- Ensure information is gathered efficiently, monitored appropriately and shared widely
- Able to carry out joint CPD programmes
- Able to argue the case more effectively for additional resources

Cons:

- Risk that issues of importance for larger boards will be given preference over issue of importance to smaller boards.
- Would require additional resource to collect data and "manage the network" – this was highlighted as a concern in a number of different units
- Informal links exist already – why do we need a MCN?

The Hepatitis C Action Plan sets the model through which Hepatitis C services (and likely BBV services) should be provided in Scotland.

Managed care networks exist in 2 NHS Boards as part of BBV MCNs which were set up in response to the Hepatitis C Action Plan.

Recommendations

8. All HIV treatment and care services should be part of, or affiliated to, an HIV Managed Care Network (following the Managed Clinical Network Quality Assurance Framework and working towards accreditation). These would support services to quality assure care, create smooth care pathways, facilitate communication between services, promote the use of shared resources and provide the opportunity to develop specialist skills.

3.1.10.: Primary Care Involvement in Treatment and Care

Currently primary care has little or no involvement in HIV treatment and care although variations in practice do occur throughout Scotland.

Over 80% (from completed questionnaires) of patients attending treatment and care services in Scotland are registered with a GP. The majority of patients who were registered with a GP agreed that there could be correspondence allowing GPs to be informed of clinical status and changes in medication. Data from NHS Lothian and NHS Greater Glasgow & Clyde show that approximately 25% of patients decline GP contact.

Currently primary care involvement in HIV treatment and care is very limited with just a handful of GPs undertaking shared HIV care (emergency ART prescriptions and blood monitoring). A larger number (although still limited) prescribe lipid lowering drugs and prophylaxis.

Some units report that GPs are reluctant to provide even non-HIV related care for people living with HIV (possibly relating to a lack of knowledge and/or confidence) resulting in many treatment and care units acting like primary care services.

An expanded role for primary care would encourage the normalisation of HIV (in line with the Scottish Government's approach to long term conditions) and would assist units to cope with increasing cohort numbers. This would require negotiated shared care, training and experience to achieve quality assured practice which is sensitive to the holistic needs of people living with HIV.

Recommendations

9. HIV services should continue to strongly encourage and support patients to register with a GP and to inform their GP of their HIV diagnosis allowing GPs to be updated regarding their patient's clinical status and medication.

10. GPs should coordinate care for non-HIV-related conditions affecting people with HIV including routine lipid management, as for other patients. They should continue to provide shared care in liaison with HIV services (with the patient's consent).

11. Consideration should be given (particularly in rural areas) to negotiating GP involvement in more specialist HIV care. With appropriate patient consent, this might include: taking bloods or prescribing prophylactic treatment. To facilitate this shared care agreements, education and ongoing training would be necessary.

3.1.11: Funding and Strategic Planning

There is a lack of clear funding sources and strategic development for HIV treatment and care services.

Services for people living with HIV have evolved within existing clinical and financial structures as funding has focused on prevention and the ever increasing drug budget.

Scotland's Sexual Health Strategy *Respect and Responsibility*[44] only briefly alludes to HIV treatment and care services. It recommends that lead clinicians should "ensure that local standards on agreed competencies, confidentiality, access to and provision of sexual health services are developed. This will include specialist sexual health services such as HIV testing and treatment".

Even though the funding of prevention for blood borne viruses is significantly larger than that allocated to Respect and Responsibility, there were concerns that a *"lumping all of HIV under the sexual health agenda*" had occurred. It was also felt by some that this may be to the detriment of funding, strategy or clinical care standards for HIV.

It has been suggested by treatment and care staff, patients and the voluntary sector that a Scottish national strategy and/or standards are required to ensure that HIV treatment and care is given appropriate consideration in planning or prioritisation exercises for service development. It is important that these standards are comprehensive and inclusive with patient involvement in their development.

Uncertainty surrounding the future location of services (due to restructuring in NHS Boards) is seen as a problem for HIV treatment and care services as it impacts on the ability to plan services. (For example, proposed relocation of services being cancelled.) HIV is not seen as a priority in such restructuring plans.

Recommendations

NHS Scotland should consider the development of:

12. Scottish Standards for HIV Treatment and Care.

13. Dedicated HIV policy which incorporates treatment and care.

44 Scottish Executive. Respect and responsibility. Strategy and action plan for improving sexual health. Edinburgh. 2005

3.1.12: Database / Surveillance

HIV treatment and care services have limited access to patient management systems.

Monitoring and surveillance in Scotland is fundamental to evaluate prevention strategies and to allow planning of services. Scotland has a robust HIV surveillance system (via HPS) which is recognised world-wide for its high standards.

7 units had access to an IT system or an HIV database (one of which was reported as not working very well). According to unit questionnaires, only 1 linked to generic records and only 1 linked to others systems by file uploads.

Many of the units struggled to provide data for the health care needs assessment questionnaires as there was no database available.

The Scottish HIV IT survey carried out in October 2007 concluded that:

"There is widespread support for a standardised HIV/IT solution for Scotland. The hardware infrastructure to support it is already in place. All patients are seen in a relatively small number of clinics so achieving national coverage is possible with the involvement of a relatively small number of clinicians. There are some dedicated A&C posts currently employed, and a number of knowledgeable amateurs who have developed current systems, but very limited current support from specifically trained IT professionals. HPS currently maintain a national database which contains limited anonymous data." [45]

45 SHIVAG. Scottish HIV IT Survey 2007

A national HIV patient management system could:

- Collect clinical data in real time during the course of consultation
- Present essential clinical data to clinicians and patients to facilitate decision making
- Facilitate exchange of data between clinical departments and laboratory services to inform decision making in the clinic and to enhance the quality of advice given by laboratory services
- Facilitate the collection of individual and aggregated data for transmission to national databases including the CD4/viral load monitoring scheme currently run by Health Protection Scotland
- Support the development of a national managed clinical care network for the delivery of HIV treatment and care
- Enhance clinical safety and support clinical staff by maintaining accurate records of antiviral therapy delivered, adverse events experienced, and by producing printed prescriptions for antiviral therapy which could be used locally or integrated into the national antiviral home delivery system.

Any system will need adequate security to ensure confidentiality of patient information in this sensitive area (being sensitive to the particular confidentiality and legal issues surrounding HIV as well as following data protection and Caldicott guidelines), and maintain an audit trail of user access.

It has been suggested that information requested for surveillance purposes could benefit from streamlining to improve efficiency.

Recommendations

14. A national HIV patient management system should be developed which is sensitive to patient confidentiality issues, whilst retaining the ability to link with generic records and provide audit facilities.

15. HIV treatment and care services should continue to maintain and support HIV surveillance programmes managed by HPS.

16. Key stakeholders should be consulted on the most effective and efficient methods of collecting and disseminating HIV surveillance data.

HPS disseminates data via its website, paper based weekly reports and other publications.

3.1.13: Training and CPD

As discussed, the treatment and care of people living with HIV is complex and rapidly evolving making regular CPD particularly important. Staff involved in delivering this care need to develop and maintain up-to-date skills and knowledge appropriate to their roles.

The BHIVA clinical care standards state that "all consultants providing HIV care must participate in CME directly related to HIV on at least an annual basis".

The NHS KSF (on which the development and review process for staff involved in Agenda for Change is based) is designed to identify the knowledge and skills that individuals need to apply in their post and to help guide their development.

CPD events occur throughout the year and are the main source of updating specialist knowledge.

Eight of the 14 adult HIV treatment and care units stated that members of their team had experienced difficulty in attending CPD events. The main reasons appear to be a lack of time, back fill, conflicting demands on study leave (HIV being just part of the overall workload) and funding issues.

HIV treatment and care staff are involved in running and participating in CPD events for other health and social care staff. Issues covered include ensuring quality assured practice and access to appropriate services throughout the NHS, includes staff training and CPD (not just in HIV treatment and care services) which are sensitive to the holistic needs of people living with HIV (including issues around equity and diversity).

Recommendations

17. Support should be provided for members of staff providing HIV treatment and care services to enable them to develop and maintain up-to-date knowledge and skills appropriate to their roles.

3.2. Laboratory Services

The Specialist HIV laboratory service is provided by the Blood-borne Virus Specialist Testing Laboratories in Glasgow and Edinburgh. The specialist laboratories are centrally funded to provide a number of different tests which are essential for the treatment and care of people living with HIV.

Specialist Testing Service comprises of:

Confirmation of all new diagnoses -

All patients who have had an HIV antibody reactive screening test on a 4th generation (antibody/p24 antigen) assay are retested using an alternative ELISA (enzyme linked immunosorbent assay) and a Western blot**.** These assays are in a different format to the screening assay and are used to confirm the initial result. The assays should also differentiate between HIV 1 and 2. This differentiation is critical for antiretroviral selection and monitoring. Confirmatory RNA detection by PCR (polymerase chain reaction) is also used to identify patients who are seroconverting. These patients have high levels of viral RNA but low levels in screening assays, are highly infectious, may be asymptomatic and must be differentiated from patients whose specimens are giving reactive, false positive results.

There is an increasing number of seroconverting patients being detected. This reflects the good practices in the laboratories and the clinics carrying out counselling and contact tracing. However, it is worrying because it means that there is an increasing amount of detectable, incident HIV infection.

HIV denominator database -

All patients confirmed as infected with HIV are entered onto the HIV database which is managed by HPS. The centralisation, on two sites, of the confirmation testing helps to ensure that all new HIV positives are captured onto the database. This data is reported on a regular basis.

HIV resistance testing -

Antiretroviral drug resistance is associated with poor virological and clinical outcomes. HIV resistance testing is technically demanding, requires specialist equipment and expertise in interpretation. Where interpreted genotypic resistance testing is available, patient outcomes are improved.

There are two reasons for testing (c.f. BHIVA guidelines):

- **Baseline resistance testing (introduced April 2005)**

  As transmission of virus with reduced drug sensitivity is well documented, testing for transmitted resistance is recommended in all newly diagnosed patients - close to the time of diagnosis. This will ensure that each patient receives the most potent first line antiretroviral regimen. All new HIV diagnoses in Scotland are tested for baseline resistance (where there is sufficient RNA). This process is helped by the fact that all new diagnoses are sent to the specialist laboratories and can be carried out on the diagnostic samples.

- **Viral failure resistance testing (introduced April 2002)**

  Resistance testing should be undertaken at each point of viral rebound on therapy (i.e treatment failure). This result informs the next line of antiretroviral (ART). The resistance tests available reflect the classes of antiretrovirals, currently and in the future. Consequently, there is an ongoing need to plan, budget and develop tests which sequence those new regions of the HIV genome to ensure that the patient is receiving the best advice on therapy efficacy.

HIV subtyping

HIV subtyping is carried out on all new diagnoses, at the same time as the baseline HIV resistance testing (same process and specimen). HIV subtyping has proved useful in monitoring the transmission routes of HIV in Scotland. Historically, subtype B infections are associated with MSM and IDU in developed countries. We now see an increase of non B subtypes which reflect the wider ethnic diversity in the population. Subtype C is the most common non-B subtype in Africa and is (hetero) sexually transmitted. So far, we have seen a small number of HIV subtype C patients who have not been outside Scotland. This service is also available for detection of transmission routes in outbreak situations.

Proviral DNA testing (Edinburgh only)

Follow-up testing of babies born to HIV positive women.

It should be noted that HIV antibody screening is carried out at a number of Microbiology or Virology testing laboratories in every NHS Board area in Scotland. The majority of these laboratories carry out a single screening ELISA and then refer the specimens to either Edinburgh or Glasgow for confirmation and further specialist testing as outlined above. Most NHS board areas send their specimens using courier or postal services and this works well. However, due to the availability of equipment and expertise, a range of further tests is carried out in the virology laboratories in Aberdeen (alternative ELISAs) and Dundee (alternative ELISA and WB). These are funded locally and prior to referral to the Specialist Service. This is standard practice throughout the UK if a laboratory has a critical mass of specimens and has a Consultant Virologist.

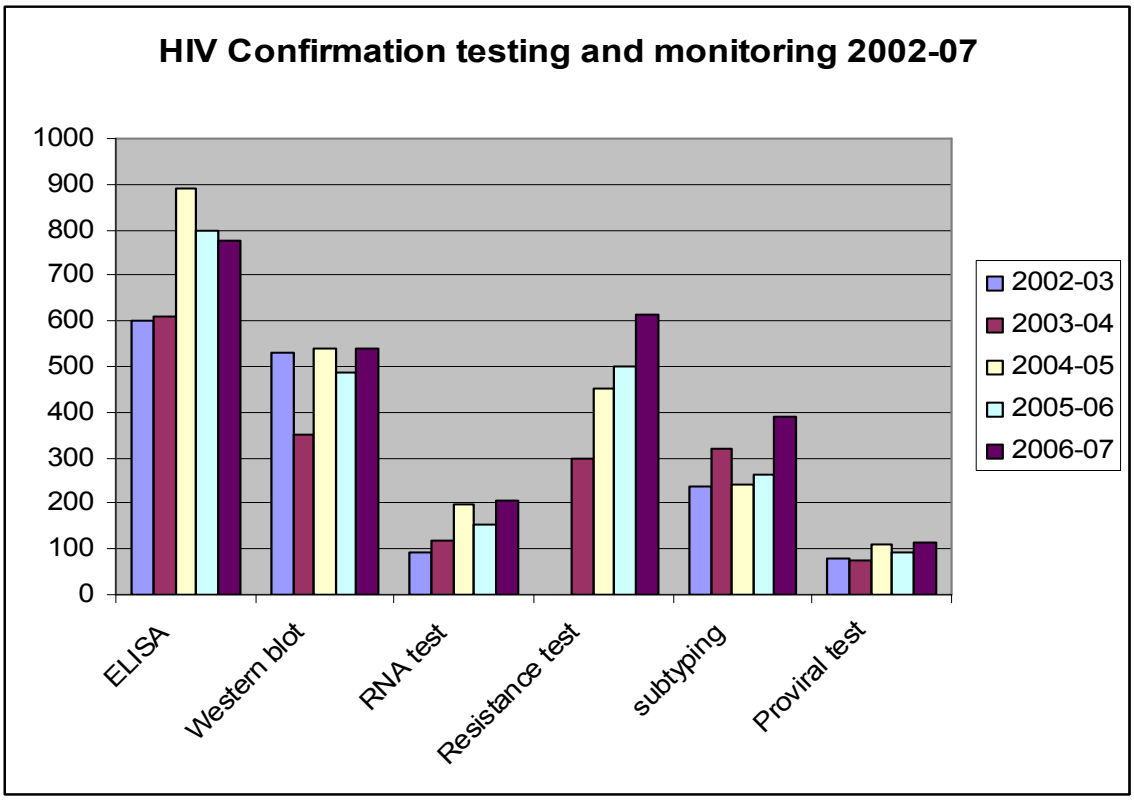
- **Viral load testing (Edinburgh, Glasgow and Dundee) –** used to assess the amount of virus in the blood. This is used to monitor the effectiveness of ART. Although less technically demanding than HIV resistance testing, HIV RNA (viral load) tests are expensive and require specific testing platforms (machines). This is why viral load testing is restricted to the laboratories which have sufficient workload to justify the use of this expensive equipment. This testing is not centrally funded and the cost is borne by the local NHS Boards. With the availability of resistance testing, HIV viral load monitoring has increased to allow clinicians to make more rapid treatment changes when current treatment appears to be failing.

It should also be noted that there is a significant amount of laboratory work involved with the management of HIV infected patients. For example:

- **Baseline viral antibody testing –** This is carried out on all newly diagnosed patients to assess if they have been exposed to viruses in the past which may reactivate when the immune system is compromised.

- **Symptomatic virological testing –** different types of tests carried out to assess if symptoms are caused by another viral infection/reactivation (eg herpes viruses, adenoviruses etc)

Figure 15: HIV confirmation testing and monitoring, 2002-07



Activity

As the number of new HIV reports in Scotland increases so does the number of baseline HIV tests which are carried out. With increasing cohort numbers, laboratory testing activity for the monitoring of patients has also increased. Notable increases have been seen in the number of HIV resistance testing and subtyping requests which is in keeping with recent changes in clinical practice.

Viral load testing is only carried out in Edinburgh, Dundee and Glasgow. Aberdeen is keen to take on viral load testing (particularly as rapid results for viral load are becoming more important in clinical care – allowing for faster changes to or introduction of therapies). This would involve input of resources and training. Some resource requirements could be met from that which is already being used to send Grampian samples to Glasgow and assistance with training would be forthcoming from the other laboratories in Scotland).

Most patients on treatment have viral loads checked every 3-4 months although more often if there has been a “blip” (transiently detectable viral load).

Data

HPS gathers comprehensive data on HIV testing and positive results. They use "the HIV denominator, which is an excellent monitor of people who are being tested for HIV"[46]. HPS also has a viral load and a CD4 database. There are some concerns that information from the databases at HPS is not always made available in the most useful or timeous manner to the public, contributors or stakeholders, although there is an awareness that "HPS are working very hard towards this".

Laboratory staff believe that an MCN could be a way of ensuring that information is gathered efficiently, monitored appropriately and shared widely. In some areas it would seem appropriate to have combined BBV or individual HIV MCNs depending on the numbers involved. A combined network would have the advantage of resulting in fewer meetings for laboratory and other staff to attend.

Testing Equipment

Few laboratories purchase their testing platforms. Instead they enter into an agreement whereby the company gives them a machine for as long as the lab is buying sufficient reagents to make it worth their while (reagent rental system). Some machines require a minimum number of samples to be carried out at the same time which results in either delay or wastage in the system if there are not enough samples for that particular test. Expense and wastage also come from the use of controls which have to be used each time the test is run. This means that for smaller sample numbers the individual cost of each test is higher.

Current challenges

Current challenges for laboratories include space, staffing and resources particularly if the number of people attending treatment and care services continue to rise at current levels and as new testing techniques are developed.

46 ANSWER (Supplement to the HPS Weekly report), 24 January 2006, volume 40. No 2006/03

Staffing

Staffing is a particular issue as there are problems recruiting biomedical scientists (BMS) even when posts are available. At present BMSs must have a Health Professional Council recognised degree in biomedical science. This has resulted in staff with degrees (even those with First Class Honours) from non-approved courses becoming medical laboratory assistants with less pay and less opportunity for career progression or development of skills. There is currently an ongoing review of scientific careers (Modernising Scientific Careers) which could have a significant impact on these and other staffing issues.

Communication

Communication between policy makers, clinicians and laboratories was highlighted as an area of concern. Consultation with laboratory staff is important particularly where there is a proposed change in policy or clinical practice which could have an effect on laboratory activity. For example:

- Communicating new HIV diagnoses (and how should that best be done)
- Provision of adequate ARV prescribing data from clinicians to laboratories when requesting HIV VL and/or resistance tests
- Communication of HIV diagnoses and subtypes to HPS and NHS Boards
- Setting up round-table events to discuss trends in HIV care to optimise clinical practice, maybe along the lines of HIV treatment and care services needs assessment
- Teleconferences to discuss clinical treatment of complex HIV patients

Recommendations

18. Communication between policy makers, clinicians and laboratories should be improved along with increasing awareness of how changes in clinical practice impacts on laboratory services.

19. Work should be undertaken to improve recruitment and retention of laboratory staff within the parameters set out in the Chief Scientific Officer's Modernising Scientific Careers.

3.3. Dental Health

Background

Despite considerable improvements over the last few decades, oral health in Scotland is still generally worse than in other areas of the UK[47] and has been described as being "poorer than in many European countries" [48]. Maintenance of oral health is important to: prevent pain and suffering, improve quality of life and maintain general health.

Studies which report on oral health and HIV tend to focus on the oral soft tissue and periodontal (tissues which surround and support the teeth) manifestations of HIV. There are limited data available on the need for routine dental care of people living with HIV in the UK[489]. However, evidence from the USA and South Australia suggests that those living with HIV have higher levels of dental caries[50,51]. It is also reported that they experience an increased social impact of oral disease. However, care should be taken before extrapolating these findings to the Scottish population.

There is well documented evidence that people living with HIV are susceptible to oral manifestations of the disease which can include: oropharyngeal candidiasis (thrush in the mouth and throat), oral hairy leukoplakia (white patches on the tongue), oral warts, herpes simplex (cold sores), gingival and periodontal disease (gum disease) and oral cancers[52].

These conditions may present as an early manifestation of HIV infection or at any stage in its progression, affecting some 30–80% of the HIV population[53]. However, the use of ART is changing the spectrum of oral disease associated with HIV infection with increases in salivary gland disease, oral warts and xerostomia (dry mouth) and declines in oropharyngeal candidiasis and oral hairy leukoplakia being reported[54].

47 Kelly M, Steele J, Nuttall N et al. Adult Dental Health Survey: Oral Health in the United Kingdom 1998. London: Stationary Office, 2000.
48 Scottish Executive. Modernising dental services in Scotland./ 2003.
49 Phelan, J.A., Mulligan, R., Nelson, E., Brunelle, J., Alves, M.E.A.F., Navazesh, M., Greenspan, D. Dental Caries in HIV-seropositive Women
J Dent Res 2004 83: 869-873
50 Glick M, Berthold P, Danik J (1998). Severe caries and the use of protease inhibitors (abstract). J Dent Res 77(Spec Iss):84
51 Phelan, J.A., Mulligan, R., Nelson, E., Brunelle, J., Alves, M.E.A.F., Navazesh, M., Greenspan, D.Dental Caries in HIV-seropositive Women
J Dent Res 2004 83: 869-873
52 Scoussi HY and Epstein JB. Changes in patterns of oral lesions associated with HIV infection: implications for dentists. Journal of the Canadian dental association. 2007; 73:
53 Patton LL, McKaig R, Straauss R, Rogers D, Enron JJ Jr. Changing prevalence of oral manifestations of human immunodeficiency virus in the era of protease inhibitor therapy. Oral Surg Oral Med Oral Pathol Oral Radiol Endod 2000;90:299-304
54 Scoussi HY and Epstein JB. Changes in patterns of oral lesions associated with HIV infection: implications for dentists. Journal of the Canadian dental association. 2007; 73:

Regular oral examinations are therefore essential for early recognition and treatment of both HIV associated oral lesions and other dental diseases. In addition, appropriate preventative dental treatment and oral health promotion will help improve oral health overall and reduce the severity of HIV associated oral conditions. Increases in life expectancy associated with the use of ART are likely to increase the demand for oral health services, but unfortunately the current literature would seem to suggest that barriers to obtaining dental care for people living with HIV exist.

In 2004, Crossly demonstrated that there was still a significant proportion of dentists who would be reluctant to take on patients with HIV, with older dentists being more likely to be hesitant compared to younger dentists[55].

Studies[56] suggest that patients with HIV faced two barriers to the receipt of dental care: patient perception (that they would be refused treatment, concerns regarding confidentiality and perceived risk to other patients) and the reported reluctance of dentists to provide treatment. Of the 33% of participants in Robinson et al's study, 50% reported that when they advised their dentist of their HIV status they had been refused or offered limited dental treatment.

In 2006, Elford *et al,* published a survey of 1,687 attendees at a London based HIV treatment and care service which showed that around 15% felt that they had been discriminated against by healthcare workers, of whom 26% reported that they felt that they had been discriminated against by dentists. (This may not necessarily be reflective of the Scottish population's experience.)

55 Crossley M L. An investigation of dentists' knowledge, attitudes and practice towards HIV+ and patients with other blood-borne viruses in South Cheshire, UK. Br Dent J 2004;196:749-754
56 Kinsler J, Wrong M and Sayles J– The effect of perceived stigma from health care provider on access to care. AIDS 2007; 21:584-589
57 General Dental Council. Maintaining standards. Guidance to dentists on professional or personal conduct. London: General dental Council.. November 1997, amended may 2001.

These reported findings are contrary to recommendations from both the regulatory body of the dental profession, the General Dental Council (GDC) and the professional body, the British Dental Association (BDA). The GDC has previously advised that it is "unethical for a dentist to refuse to treat a patient solely on the grounds that the person has a blood-borne virus or any transmittable disease or infection"[57] and the BDA advises that those infected with HIV may be treated routinely in primary care dentistry [58].

Access to dental services for people living with HIV in Scotland

There is a dearth of published research regarding access to dental services for people living with HIV in Scotland. However, a recent study conducted jointly by the Department of GUM at Edinburgh Royal Infirmary and the Lothian Salaried Primary Care Dental Service does provide us with some insight into the issues. The aim of the study was to assess attitudes towards the availability, accessibility and use of dental services in Lothian. In the study, out of 152 patients attending genitourinary services, 59 were known to be living with HIV and 93 were not known to have HIV[59]. Those who were known to be living with HIV were predominantly middle aged, white males who became infected through sexual transmission (only one declared past injecting drug use).

The study found that those living with HIV are less likely to be currently registered with a dentist (54%) compared to those not known to be HIV positive (80%). Also 8% of the HIV positive group had last accessed dental care as a result of an emergency compared with none of the control group.

Similar proportions of HIV infected persons and controls had been refused treatment in the past (11% and 10%). However, 5 out of 59 people living with HIV felt that they had been refused treatment by their dentist specifically because of their diagnosis. Worryingly, 18 of the individuals known to have HIV (31%) had chosen not to tell the dentist of their HIV positive status. Patients within this group who were regular attenders were more likely to tell the dentist of their diagnosis but among irregular attenders, 46% had not disclosed their status.

58 British Dental association. Advice sheet A12. Infection control in dentistry. London: British dental association. January 2000.
59 Steedman NM and Cunningham CJ (2009) *Is being HIV infected a barrier to accessing dental care?* 15th BHIVA conference. Poster P.11.
* All dentists in the UK follow universal infection control procedures but disclosure of a chronic medical condition would enable dentists to provide appropriate preventative dental treatment and health promotion.

Reasons given included:

"I didn't think it was relevant" * and *"I was worried that I would be treated differently"*

Others were concerned about confidentiality.

Of note, in this study 39 (66%) of those people living with HIV would prefer to use a dedicated dental service (note that NHS Lothian provided this service) despite there being no clinical reason why asymptomatic HIV positive individuals cannot be cared for by general dental practice.

In summary, this study would appear to suggest that the perception of stigma and concern over the reaction of dental staff is prevalent amongst this population, whereas actual discrimination is reported but appears less prevalent.

The topic of access to dental care was discussed as part of this health care needs assessment within the focus groups held in the HIV treatment and care units and as part of the voluntary sector group.

Analysis of the HIV treatment and care unit focus groups shows that there are many anecdotal reports from people living with HIV of both perceived and actual discrimination (eg being refused treatment or asked to attend at the end of a clinic) resulting in reluctance to disclose HIV status to dental staff. These reports result from information passed on by patients rather than being observed or scientifically observed, and therefore remain anecdotal.

Focus groups carried out for Positive Forum and the UKC Pre-Conference Forum show that patients themselves directly report discrimination and stigma:

"I've had surgeons say to me, 'there's no reason why this treatment can't be happening in any community dentist'" – from a person living with HIV.

HIV treatment and care units report that in many areas, HIV positive individuals are referred for routine dental care to specialist dental services such as Community Dental Services or hospital based maxillo-facial surgery and oral medicine.

Conclusion

Access to appropriate NHS dental services is viewed as a very important issue for people living with HIV. For the majority of people living with HIV this should normally be available through routine primary dental care services. However, there is some limited evidence to suggest that this is not always the case.

Future challenges:

- Further work is required to ensure people living with HIV in Scotland can access appropriate NHS dental care.
- Further work should be undertaken to establish if the findings of the NHS Lothian study are replicated in other NHS Board areas.
- NHS Boards should work with dental services, patients and support organisations to ensure that barriers, both perceived and experienced by people living with HIV are overcome to ensure appropriate access to NHS dental care. This will include training of dental staff which is sensitive to the needs of people living with HIV and incorporate issues around equality and diversity.

3.4. Scottish Prison Service (SPS)

Worldwide, HIV and TB are the two greatest contemporary prison health challenges, with co-infection occurring with increasing frequency.

At any one time, there are approximately 7,500 prisoners in prisons in Scotland (of whom, around 400 are women). In the course of a year, over 26,000 prisoners are admitted to prisons in Scotland. Over 43,000 prisoner receptions (new admissions) take place annually. There are currently some 7,609 people in prisons in Scotland.

Since the late 1990s the demography of Scotland's prison population has been changing. Whilst predominantly young males populate prisons, there has been an increase in overall numbers with a sharper increase in women and older men. This ageing population is likely to have an implication for long term condition management. Smoking (80%), drug addiction (c.70%) and mental health issues (>50%) are much more common than in the general population (with higher rates of co-infection with Hepatitis C)[60].

There are 15 prisons which house adult males (two of which are operated by a private company). One prison provides custodial facilities and services for remanded and convicted woman (including young offenders) and one for young men (under 21).

Currently, the overall model of health care in the prison service in Scotland is that of an enhanced primary care service, with enhanced care delivered in addictions, mental health and blood borne viruses. It is a nurse-led service, with nursing staff employed directly by SPS. The service is supplemented by contracted staff of general practitioners, pharmacists, specialist addiction staff and agency nurses. Nursing cover is extended in some prisons and doctors are on-call at all times. Out-patient and secondary care is provided by local NHS Boards and the State Hospital, sometimes with in-reach provision. There is no in-patient provision within SPS-run prisons.

On admission, every prisoner (remand or sentenced) undergoes a nurse assessment with a medical officer review at a later stage. Medical history and medications are confirmed as part of this assessment. At this stage, if HIV positive status is disclosed then arrangements are made with pharmacy to provide medication if required.

60 Graham L. Prison health in Scotland A Healthcare needs assessment. SPS 2007

There are currently 14 people known to be living with HIV in Scottish prisons.

Recently the Hepatitis C Action Plan has resulted in NHS Boards having allocation of funding which accounts for the size of its prison population. This has resulted in the development of BBV nurse practitioner posts for every prison. The piloting of in-prison needle exchange schemes has not been undertaken. Condoms are available to prisoners, and dental dams to women in prison though this provision is not universal. Sexual health services from voluntary and statutory sources are currently under development. Specialist care and resources are provided by the local NHS Board.

One central belt prison has a nurse-led BBV clinic. The nurse practitioner who provides this service is usually based within the NHS Lanarkshire ID unit.

Challenges faced by prisoner-patients are:

- Stigma (prisoners are more accepting of Hepatitis C status than of HIV status).
- Rapid transfer to other prisons means that there could be interruptions in care (including medication).
- Integration of care amongst primary care, specialists, addiction services, prisons and social services has been described.
- Release to the community, picking-up a complex series of services.

Future challenges:

- The Scottish Prison Service suggests that increasing numbers will put strains on the service.
- The transfer of responsibility for prison health services to the NHS will help to integrate services, patient and information flows.

3.5. Children Living with HIV in Scotland

Background

Worldwide, in 2007, more than 2.1 million children were living with HIV and more than 375,000 babies were born infected with HIV[61]. The vast majority of these are in the developing world; Western Europe and North America account for <1% of the world's burden of infection in children)[61].

Transmission

Prior to universal screening there were some children who acquired their infection from contaminated blood and blood products (particularly children living with haemophilia who received the blood product: Factor VIII[62]). Now almost all children with HIV under 15 years old, have acquired their infection through MTCT.

The successful identification of HIV infection among pregnant women (with the introduction of universal antenatal HIV testing in mid-2003) and a reduction in MTCT (through the use of ART, elective caesarean section and avoidance of breast feeding) has seen a dramatic reduction in the rates of MTCT[63].

In fact, studies have shown that with appropriate management (such as those available in the UK) vertical transmission can be virtually eliminated. Subsequently the overall UK MTCT rate has declined significantly from 18.5% (95% CI: 13.3–24.8%) in 1990-1993 to 1% (95% CI: 0.7–1.5) in 2004 – 2006[63].

61 WHO. Children and AIDS: Second Stocktaking Report. UNICEF - 2008 - Geneva, The United Nations Children's Fund.
62 Ramanarayanan J. factor VII. http://www.emedicine.com/med/topic3493.htm
63 Townsend CL, Cortina-Borja M, Peckham CS et al. Trends in management and outcome of pregnancies in HIV-infected women in the UK and Ireland, 1990–2006. BJOG. 2008; 1078 – 1086. 57 Graham L. Prison health in Scotland A Healthcare needs assessment. SPS 2007

Diagnosis

Clinical diagnosis of HIV infection is often difficult in children as many of the initial symptoms are non-specific and common in general paediatrics. Growth faltering is common (affecting height and weight) as is mucocutaneous candiasis (thrush in the skin, genitals, gut or mouth). There may be a poor response to childhood infections or persistent lymphadenopathy (swollen lymph glands), opportunistic infections are often more severe than in adults and encephalopathy (diffuse disease of the brain that alters brain function or structure) is seen earlier. Cancers are less common than in adults.

Testing

All children born to infected mothers have antibodies to HIV, which cross the placenta from the mother's blood and may persist for up to 18 months. This makes HIV antibody testing less useful than in adults. Tests which look for the virus (Proviral DNA testing) can be used instead which will pick up approximately 90% of infected children by 2 months and 95% by 3 months. However, all children with negative proviral DNA tests should have an antibody test at 18 months to confirm that they are not infected.

In children older than 18 months, testing follows the same process as in adults.

Progression

In the absence of ART, disease progression is generally faster than in adults. This means that approximately 30-40% of babies who have acquired HIV from MTCT will have some signs or symptoms by 12 months[64]. Without ART the median age to developing AIDS is approximately 6 years with 25 – 30% of children having died by this age[51]. However, some children do not present with symptoms until the second decade of life.

64 Evian C et al. 2000. *Primary AIDS Care*. Johannesburg: Jacana 3rd Edition

Treatment and care

The treatment and care of children living with HIV is extremely complex and needs to reflect the involvement of the whole family. According to Evian, the aim of treatment is to "maintain the best quality of life for as long as possible"[63] and maintain "*sustained ART benefits*" (quote from the paediatric service) which will continue on until the child has gone through transition to adult services. Since the introduction of ART, mortality, AIDS, and hospital admission rates have declined substantially in children living with HIV. There are challenges to the use of ART in children. There is limited evidence for the use of some of the ARTs in children. Regimes must take into consideration the ease of the regimen, possible dietary restrictions and the availability of therapies in easier to swallow preparations (not all ARTs are available in solution/syrup form).

Management of HIV in this age group may also be complicated by concurrent infection in family members including parents and siblings. As children survive longer planning transition to adult clinics is an important issue which will place new demands on services.

Transition of care

Transition of care from a paediatric to adult setting is not specific to HIV, but occurs in a number of paediatric specialties (eg cystic fibrosis, congenital heart disease, diabetes etc). However, there are important differences for young people with HIV which may make this process more difficult.

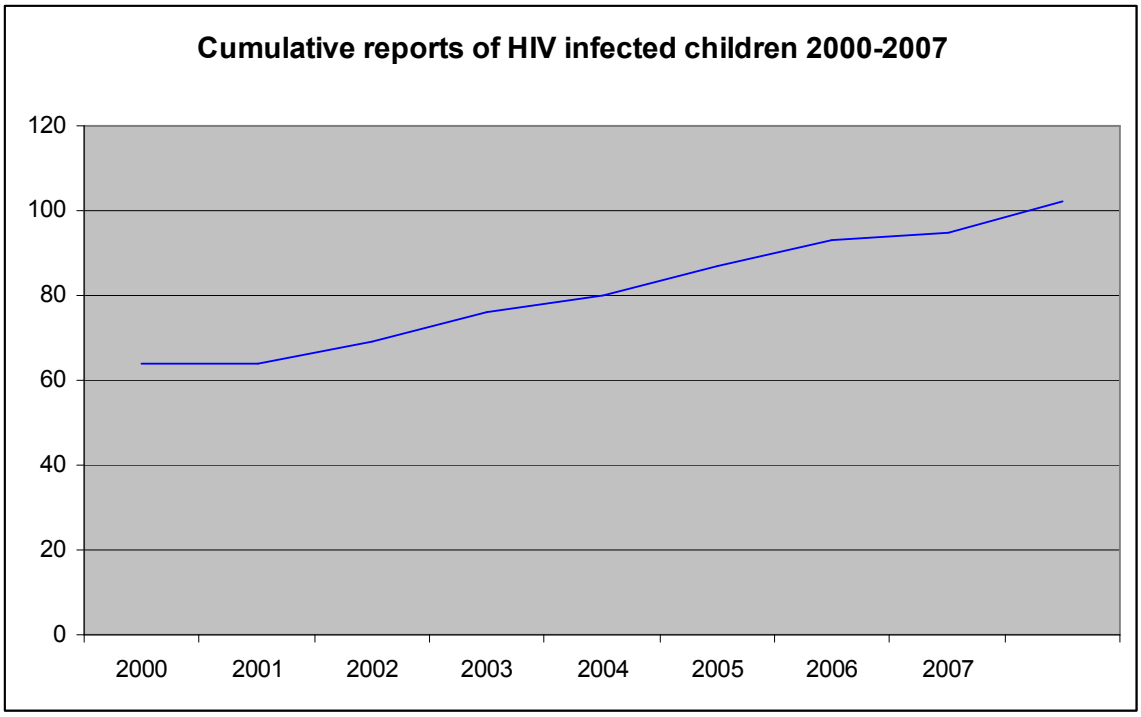
Other family members are also likely to be infected and one or other parent may even have died. HIV is a sexually transmissible infection, which is a complex burden for a young person developing their sexual identity to carry. HIV remains a stigmatised condition so it is very hard to share this diagnosis with peers. For these reasons it is especially important that young people are: 1) well educated about their condition and its treatment; 2) confident in their ability to talk about HIV with those who they want to know about their condition; 3) have a support system, so they know where to get help and advice when they need it.

Transitional links with adult services are important to deal with the medical, social and psychological needs of children entering adolescence and adult life.

HIV in Children in Scotland - Epidemiology

Since 2000 there has been an average of 5 (range 2-7) new reports of HIV in children per annum in Scotland. Cumulatively, there have been a total of 105 children reported to have had a positive HIV test in Scotland (aged 14 years or under at the time of HIV test).

Figure 16: Cumulative Reports of HIV in Children



Of these, some 66 (63%) were male and 39 (37%) were female. 68% of the children acquired HIV through MTCT and 29% through contaminated blood or blood products (prior to the introduction of universal blood and blood product screening).

Figure 17: HIV Infected Children In Scotland By Exposure Category (Cumulative)

Probable mode of acquisition	Male	Female	Total
MTCT	34	37	71
Blood factor (eg haemophiliac**)	25	0	25
Blood/tissue transfer (eg transfusion**)	3	2	5
Other/Undetermined	4	0	4
Total	66	39	105

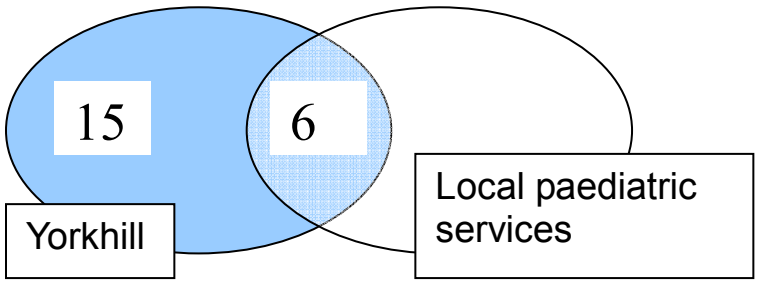
*Includes all children with AIDS, virus detection and HIV antibodies at aged 18 months or over.
** Includes persons infected in the UK prior to 1985 and persons who acquired their infection abroad

Paediatric treatment and care services provide a high level of clinical expertise and medical care following the Children's HIV Association (CHIVA) standards and clinical care guidelines. Services in Scotland have been involved in both audit and research. The Children's HIV National Network (CHINN) Review in 2005 proposed the development of regional network structures for paediatric and perinatal HIV treatment and care. Scotland was highlighted as an area where a lead network should be developed. Currently there are informal links with large London centres, chiefly St Mary's Hospital in London.

Paediatric services in Scotland follow two different models of care. Both models are coordinated by, and have their main base in, the two Royal Hospitals for Sick Children (RHSC) in NHS Greater Glasgow and Clyde (Yorkhill) and in NHS Lothian. In both areas, hospital based HIV services provide the vast majority of primary care to children living with HIV. However, 100% of children are registered with a GP and 70% allow correspondence with the GP to occur. The main barriers cited were difficulty of access, and GPs' unfamiliarity with HIV and concerns about managing HIV positive patients even for non-HIV related care.

NHS Greater Glasgow and Clyde - Yorkhill

NHS Greater Glasgow and Clyde provides care (both direct and as shared care) for a total of 26 children. Six of these children are resident in NHS Tayside and NHS Highland. Care of these 6 children is shared with their local generic paediatric services. One of the 2 consultants from Yorkhill travels to these Boards to undertake alternating shared care appointments (alternating with being seen by local services on their own) with the children.



The majority of children (estimated as 70%) were referred to Yorkhill services by their GPs and 30% were seen as in-patients. The service reports that 100% of children acquired their HIV infection via MTCT. 90% were reported as being from Africa or an African ethnic background. 52% of the children were currently receiving ART (following CHIVA guidelines) with some 64% of these starting therapy in 2007. Supporting anecdotal evidence suggests that the majority of children present with clinical symptoms/suspicion.

In 2007, there were a total of 18 in-patient episodes with 94 bed days (a much higher ratio than in adult services). 100% of children who fulfil the CHIVA criteria for commencing ART are currently receiving ART.

Royal Hospital for Sick Children, Edinburgh

NHS Lothian manages 22 children with HIV. The vast majority of children live in NHS Lothian although a number attend from other NHS Board areas. All children attend the RHSC in Edinburgh. A clinic questionnaire suggests that 100% of children acquired their HIV infection via MTCT. 41% were reported as being from Africa or an African ethnic background. 10% of children were originally from Eastern European countries. 64% of the children were currently receiving ART (following CHIVA guidelines) with none of them having started therapy in 2007. 100% of children who fulfil the CHIVA criteria for commencing ART are currently receiving ART. There were a total of 10-12 in-patient episodes in 2007.

Staffing

There are 4 paediatric ID consultants who provide HIV treatment and care services. (There is also shared care input from generic paediatrics in NHS Tayside and NHS Highland). There is also input from a consultant neonatologist at PRMH Glasgow, responsible for the care of infants born to infected mothers.

On average, 0.2 WTE of each consultant's time is spent on HIV related work per week. This includes:

1. Direct treatment and care of HIV positive children.
2. HIV testing of siblings.
3. HIV testing of babies born to HIV positive mothers (who require repeated testing over months).
4. HIV testing of children who have mothers who have had a positive HIV test.

Activities 3 and 4 take up a considerable amount of consultant time.

As discussed the treatment and care of children living with HIV is complex and involves a whole family approach. Ever since HIV in children first occurred in Scotland, all health education, support with concordance and HIV care is provided by the consultant paediatricians. Currently, a multi-disciplinary approach to management is not possible as there is no pharmacy, dedicated social work or even link/BBV nursing support available. At the time of this report, HIV services do not even have access to administrative or secretarial support.

A family care setting for paediatrics services would be ideal. However, this may be difficult due to the small numbers involved and local procedural issues in the adult services.

Transition of care

10 children in total have undergone transition (3 from Yorkhill services and 7 from RHSC in Edinburgh). Transition has been *ad hoc* as there have been such small numbers involved. Strong links exist with sexual and reproductive health services and their involvement in care has occurred when children become adolescents.

Late presenters

Clinical experience from paediatrics services in Scotland suggest that the majority of the children who test positive for HIV, present late with clinical symptoms or clinical suspicion rather than for “at risk” testing.

Strategic planning

HIV paediatric services do not appear to have featured strongly in the strategic planning of child services in Scotland.

Organisation framework

Paediatric services in Scotland are linked with St Mark's Hospital, London. Currently no Scotland wide MCN exists. A proposal for a network for children living with HIV is currently being drafted (where further work to collate and disseminate detailed evidence regarding treatment and core services for children (,) can be undertaken).

Voluntary sector

There is some voluntary sector activity to support children, young people and their families. Waverley Care has provided a service for infected children and young people since 1991 and a specific service, Poz Youth, since 2007.

Recommendations

20. Paediatric services should have access to appropriately skilled personnel to provide a multi-disciplinary service and appropriate support for children, young people and their families, affected by HIV.

21. Protocols should be developed to ensure smooth transition of children to adult services (in keeping with CHIVA guidelines).

Section 4: Corporate: Voluntary Sector

Access to the support provided by the voluntary sector to people living with HIV varies throughout Scotland. Variations in the levels of collaboration between NHS services and the voluntary sector exist throughout Scotland.

The voluntary sector is important in providing people living with HIV with information, advice, counselling, guidance on self-management and practical support (such as welfare advice). The voluntary sector provides services with less of a health focus in a non-clinical environment. It has an important role to play in reducing onward transmission through healthy sex promotion activities.

There are a number of different voluntary organisations providing information and advice, counselling and group support, guidance on self-management and practical support services for people living with HIV and their carers.

The voluntary sector provides many support services which are different to those in the NHS but more importantly they provide choice (flexibility of availability and locality); more of a general holistic approach to health and wellbeing *("working with the people and not around the condition"**); and a less threatening environment which may be more acceptable particularly if there are confidentiality issues. The voluntary sector can act as a patient advocate on NHS treatment and care issues and can provide continuity and confidentiality.

Organisations which are HIV specific or risk group targeted exist within Scotland. At the time of writing a number of organisations were identified as providing voluntary sector support for people living with HIV. These are described in Appendix F.

* Voluntary sector focus group quote

Referrals

Overall, the majority of referrals to HIV specific voluntary services come through the NHS services. The risk group based organisations get the majority of their referrals from self-referral, GUM services and the "scene". NHS services either provide information (contact details and leaflets) or have a member of the voluntary sector organisation available while the HIV treatment and care service is running. The former arrangement depends on the front line NHS staff providing the information and the person actively finding the service. The latter has the benefit of providing a point of contact that can see people while they are at the clinic. It also allows the voluntary service worker to become part of the multidisciplinary team. Barriers to this arrangement include: lack of space within the clinic setting; lack of comprehensive Scotland wide coverage (eg little provision in the north east and south of Scotland).

Some voluntary sector organisations are commissioned to provide services by some NHS Boards.

Focus Group Findings

The general findings from the focus groups are summarised below.

Collaboration

The general consensus was that collaboration between the voluntary sector and NHS services works very well (appearing to work best when it is integrated into the on going care of people living with HIV*).* Improved collaboration between frontline NHS and voluntary sector staff was seen as an important development (rather than at a managerial level) and units should develop a better understanding of the role and functioning of the voluntary sector.

Patient/User involvement

Patient (and carer – where appropriate) involvement in the development of services is important to ensure that services are responsive to patients' needs. Creative national, local and community based approaches to involvement are required.

MCNs

An MCN could support staff to ensure quality assurance and promote better use of shared resources

Primary care involvement

Concerns were raised about increased primary care involvement in HIV treatment and care as:

> *"GPs aren't skilled up perhaps to sexual health never mind HIV"*

Increased involvement may be a step towards normalising HIV care and improve access to care in a community setting.

> *"I'm wondering if there might be some scope for developing expertise amongst GP practices"*

Training, support and CPD along with shared care agreements would be necessary.

Additional services

Pharmacy services were seen as important in HIV treatment and care.

People living with HIV raised concerns regarding fears of unfair treatment or discrimination within non-specialist health care settings.

Section 5: Corporate: Patient View

Findings from Positive Forum and the UKC Pre-Conference Forum

(Provided by HIV Scotland)

The development of standards in HIV care and treatment would support people living with the virus, enhance their experience of the health service, improve their general health, and encourage self-management, which in turn is known to improve health outcomes.

Sexual health standards - The attendees recognised the benefits of NHS QIS standards in sexual health care generally and for people living with HIV in particular. There was discussion about the support needs of people living with HIV to enable them to enjoy a healthy and fulfilling sex life and relationships. 'Well-being' must be interpreted broadly and include social, psychological and relationships.

Support for individuals infected and affected, especially in relationships needs to be better, and information provided to a wider constituency to promote shared responsibility.

Access to sexual health clinics by people living with HIV can be difficult and at times inadequately provided. There needs to be more openness in provision of services, with, for example, sexual health services being located within HIV clinics.

Diagnosis and transitions – Wider discussion recognised that services are generally good and standards high. People can see, however, that numbers are increasing at clinics and health care workers are stretched. Some attendees referred to what they see as poor communication skills from staff, but also to threats or actual loss of some services, such as dentistry or social support which are crucial to the health of people living with HIV and not easily accessed elsewhere because of stigma or lack of knowledge.

NHS Services

NHS services are not necessarily arranged to suit the needs of people living with HIV (eg clinic times conflicting with non-disclosure at work) and suggest that alternative clinic times or advance prescribing could be considered. Enhanced primary care involvement is advantageous as it would provide choice and would promote the normalisation of HIV.

Attendees of NHS services recognised that there are various structures and systems through which services are delivered. In particular, they referred to co-infection with Hepatitis B and C and associated complications for services as well as for individuals. It was felt that improved information about delivery of care and what may be expected of HIV clinics and other departments would be helpful. At a very basic level, it was felt that even the way in which the unit's receptionist responded to people attending for care, could be quite daunting.

Ageing and associated health needs also arose as people are living longer and experiencing additional health complications. With growing knowledge of the long term effects of HIV and medications, care will have to adapt to take account of patient needs.

The rise in minority ethnic groups living with HIV means that counsellors and other staff should be more sensitive to cultural differences. Generally, all counsellors are white and middle class. For example, they may be unaware of the greater concerns about confidentiality amongst some of these minority ethnic groups.

There was a view that assistance is needed from NHS services to help people access specialist support in completing benefit forms and affordable housing. Such specialised help is needed as people tend to write about their best days, indicating little wrong with them, rather than their worst days which is more likely to get them entitlement to benefits.

Recommendations

22. Support for voluntary and community sector provision and cross-sectoral collaboration should be part of the provision made at national and NHS Board levels.

23. Improved collaboration between frontline NHS staff and the voluntary sector should be developed. Education on the role of the voluntary sector would help facilitate this.

24. All HIV treatment and care services and people living with HIV should have access to voluntary sector provision.

Section 6: Costings

Cost in health care can be a complex concept and is not merely the financial cost attributable to a service which is important. An important consideration is the opportunity cost of any change in the delivery of services. Opportunity cost refers to the benefits that must be foregone by not allocating resources to the next best activity. Opportunity cost is therefore fundamental to health economics and to needs assessment as it plays a crucial part in ensuring that scarce resources are used efficiently.

In the context of HIV treatment and care the opportunity cost of maintaining a more expensive service model than necessary will be that resources are not available for expenditure elsewhere in health care. These effects might be felt within BBV services or might be passed on elsewhere, but in a health system where resources are limited there are always opportunity costs related to any decision. It is also important to consider costs in the context of sustainability of services and affordability.

There is limited empirical evidence in the literature regarding the cost-effectiveness of setting up and managing MCNs or the subsequent opportunity costs. Draper *et al* in 2004 carried out a modelling exercise which suggested that "the costs associated with the introduction of managed clinical networks are not excessive".[65] MCNs have been shown to be associated with improved outcomes. However, they did require "considerable practitioner effort, funding and require energetic leadership".

There is limited scope for exploring cost-effectiveness and cost utility until the model of future services is known.

65 Draper ES, Manktelow BN, McCabe C, Field DJ. The potential impact on costs and staffing of introducing clinical networks and British Association of Perinatal Medicine standards to the delivery of neonatal care. Arch Dis Child Fetal Neonatal Ed 2004; 89(3):F236-F240.

Cost of HIV Treatment and Care Globally

Developing world

Financial resources for the HIV response have significantly increased in recent years. $10billion was made available for HIV programmes in 2007 from all sources (including domestic public funds and out-of-pocket spending)[66]. In low income and lower-middle income countries, per capita domestic spending on HIV more than doubled between 2005 and 2007 ($9.89 to $12.01). 10% of spending in developed countries is used to provide free treatment programmes for the two million people taking those treatments. The other 90% is used mainly in primary prevention.

Cost of HIV care in USA

Hutchison *et al*[67] found that the cost of new HIV infections in the United States in 2002 is estimated at $36.4billion, including $6.7billion in direct medical costs and $29.7billion in productivity losses. Direct medical costs per case were highest for whites ($180,900) and lowest for Blacks ($160,400). Productivity losses per case were lowest for Whites ($661,100) and highest for Hispanics ($838,000).

Though ART is costly, it has proven very effective at extending lives, and productivity. The researchers found that ART patients have direct medical costs averaging $230,044, with a projected life expectancy of 24.4 years. Patients not receiving ART have direct medical costs of approximately $114,938, with a projected life expectancy of 12.4 years.

Cost of HIV care in the UK

Mandalia et al suggest that the cost of providing both ART and NHS care to an individual living with HIV in the UK averages at just over £16,000 a year for someone on a first combination, and slightly more for second-line (£16,500) and third-line HAART (£16,666)[68].

The opportunity costs of providing HIV care in Scotland is extremely difficult to assess (a more detailed analysis would be required to assess opportunity costs). However, it is possible to assess the revenue costs (and therefore estimate any resource realisation implications) associated with providing care and how this is likely to change over time.

66 UNAIDS. Report on the global AIDS epidemic 08. Joint United Nations Programme on HIV/AIDS (UNAIDS) 2008.
67 Hutchinson A, Farnham P, Dean H et al. The economic burden of HIV in the United States in the era of highly active antiretroviral therapy. Epidemiology and social science. 2006; 43: 451 457.
68 Mandalia S, Brettle R, Fisher M et al. Cause and time to treatment failure of HAART and cost of care in UK NPMS-HHC clinics, 1996–2002. *HIV Med* 2006; **7**: 9 [Abstract No. O33].

HIV treatment in Scotland (ART therapy)

The average cost per patient per year on ART in 2007 (based on figures available from NHS Greater Glasgow and Clyde and NHS Lothian) in Scotland was £8,562.

Note that there are differences in the actual cost per patient based on:

- Complexity of the regimen.
- Combination of drugs used.
- Contract prices.
- VAT saving through the use of home care (a VAT free home delivery service) – some NHS Health Boards are currently able to provide this service. Coverage and administration cost are limiting factors.

The cost per patient has been estimated to increase by 4% per year (unless there is a dramatic advance in treatment which is associated with a significant increase in cost). This would suggest that the average cost per patient over the next 5 years would be:

- 2008 - £8,904
- 2009 - £9,260
- 2010 - £9,630
- 2011 - £10,015
- 2012 - £10,415

Using the projections of people receiving ART produced by HPS (see page 21 for methods) it is possible to predict the future costs of ART to the NHS.

By 2012 the overall annual cost to NHS Scotland can be estimated using HPS projections:

- Method a - £29.5 Million (95% CI: £28.9 Million; £30.2 Million)
- Method b - £32.5 Million (95% CI: £32.5 Million; £33.3 Million)
- Method c – £26.6 Million (95% CI: £26.2 Million; £26.9 Million)

HIV Care costs (excluding ART) in Scotland

It is not possible (within the scope of the health care needs assessment) to identify the precise costs for HIV care which is provided within the overall package of services in NHS Scotland. In particular, it is difficult to estimate what proportion of the costs of parallel and support services should be attributed to HIV care.

Approximate costs attributable to communicable diseases (but not specifically HIV) are published by ISD on an annual basis.

Out-patients

These suggest that the average cost per attendance at a communicable disease out-patients is £177 (£438 with drug costs added) for the year 2007. There is considerable variation in the cost per attendance at the different Boards (e.g according to ISD figure NHS Tayside costs £50 and NHS Lothian £270 – without drug costs. This is possibly a reflection of variations in local costs or in the proportion of communicable disease consultations which can be attributable to HIV.)

The average number of attendances for a new patient per annum is 5.3 (range 2.8 – 13.5). This would suggest an average cost of £938 per new patient (without drug costs) attending a communicable disease clinic. Return patients on average attend 3.5 times per year giving an average cost of £619.50.

If outpatient costs were applied to the projections provided by HPS for those undergoing CD4 monitoring then it would suggest that by 2012 there would be an additional outpatient cost of:

- Method a - £2.56 Million (95% CI: £2.5 Million; £2.6 million)
- Method b - £2.85 million (95% CI: £2.83 Million; £2.89 Million)
- Method c - £2.23 million (95% CI: £2.19 Million; £2.27 Million)

Assumptions made were that the average attendance for new and return patients will remain constant and that the average cost of an out-patient attendance will not rise over the next 5 years.

Changes in practice such as reducing the time between visits, greater primary care involvement, nurse led services or changes in when to introduce ART (such as proposed by BHIVA) may all have an impact on future costs.

In-patient costs

ISD data from 2007 suggest that, in 2007, the total in-patient cost per communicable disease episode was £3,863.

It was not possible to calculate the total number of bed days or cases from the clinic questionnaire as there were missing values.

Based on the episodes from NHS Greater Glasgow & Clyde and NHS Lothian and the number of persons attending HIV treatment and care services, it is possible to estimate the rate of episodes per 1,000 people attending services.

- Episodes = 549
- Persons attending services = 1995
- Episodes per 1,000 persons attending services = 275 per 1,000

If this rate continues then it is possible to estimate (using HPS predictions of those attending for CD4 monitoring) the number and total costs of episodes for 2012, assuming no change in in-patient costs or the number of in-patient episodes per persons attending HIV treatment and care services.

- Method a - £4.23 million (95% CI: £4.16 Million; £4.3 million)
- Method b - £4.68 million (95% CI: £4.63 Million; £4.75 million)
- Method c - £3.74 million (95% CI: £3.68 Million; £3.81 million)

Section 7: Comparative Needs Assessment

There is a dearth of literature regarding models of HIV care internationally. Intensive literature searching did not reveal any other national HCNA for people living with HIV.

The UK has a unique National Health Service and appears to be the only country which delivers HIV treatment and care through a mixture of ID and GUM services.

There is little research regarding the most effective or efficient mix, organisation or orientation of providers to effectively satisfy the needs of people living with HIV.

HIV Care in UK

BHIVA standards for HIV Clinical care for diagnosed HIV infection in adult patients state that care:

"*should be delivered through managed clinical networks each covering a defined geographical area and group of NHS organisations. These networks should comprise two types of clinical services: HIV units providing outpatient care for the majority of patients with uncomplicated HIV infection; and a single-site or virtual/cluster HIV centre within each network providing services for patients with more specialised needs, including complex outpatient care, in-patient care and referral/advice services*." [4]

Regional HCNA in the UK

There have been a small number of regional HCNAs carried out in the UK (Plymouth and Sheffield) or are currently underway (Newcastle).

Health and social care needs of people living with HIV.

There have been many studies and surveys carried out to assess need in people living with HIV[69] including some carried out in Scotland[70,71].

A literature review of the psychosocial and health care needs of HIV-positive people in the United Kingdom suggested that the most salient needs of many of the HIV-positive population in the UK are those related to "deprivation: safe housing, access to food, assistance with transport, and access to drug, alcohol and mental health treatment programmes. Integrated health and social care is therefore vital[72].

Weatherburn *et al* found that "Interest in gaining skills and retraining is now more common than problems with mobility or coping at home, but HIV still takes it toll on mental health, personal relationships and quality of life". This caused them to suggest that currently the "challenge for service providers is to respond sensitively, flexibly and creatively to the variety of needs of people with HIV" [69].

A Glasgow based needs assessment carried out in 2006 found that, for those individuals who reported that their needs were not being met, the top 3 most commonly reported unmet needs were in relation to housing, financial support and physical activity[71].

69 Weatherburn P, Anderson W, Reid D, Henderson L (2002) What do you need? Findings from a national survey of people living with HIV. London, Sigma Research.
70 West B. Treatment choices. A survey into the treatment and support needs of people who are HIV positive. Edinburgh. SOLAS 2001.
71 Carroll L and Craik J. An assessment of the support needs of individuals living in Greater Glasgow with HIV.
72 Green G and Smith R. The psychosocial and health care needs of HIV-positive people in the United Kingdom: a review. HIV medicine. HIV Medicine (2004), 5 (Suppl. 1), 5–46

Section 8: Conclusions

An increase in new HIV reports and a dramatic reduction in AIDS related deaths (and all-cause mortality of people living with HIV), mainly as a result of anti-retroviral therapy (ART), has led to a significant increase in the number of people living with HIV. The number of people attending treatment and care services has increased significantly since the turn of the century (it has more than doubled since 2000). Projections (using modelling techniques) suggest that this increase will continue. Potentially, there could be between a 42% and 85% increase in numbers by 2012.

People living with HIV have complex needs and require comprehensive treatment, care and services which are appropriate for the unique confidentiality, diversity and equality issues associated with HIV. Confidentiality is particularly important as there is considerable stigma associated with being HIV positive and subsequent discrimination.

Over the last 2 decades, NHS HIV treatment and care services in Scotland (,) have evolved to manage people living with HIV within the context of existing clinical and financial structures, resulting in variations in models of treatment and care. Five different models of care have been identified in the 14 adult HIV treatment and care units in Scotland's 11 mainland NHS Boards. In addition to different models, there are variations in access to appropriately skilled personnel and services. For example: social work or sexual and reproductive health services.

In 2008, the Global HIV Prevention Working Group (2008) recommended that governments should:

"develop and implement national AIDS strategies and operational plans that are tailored to the particular dynamics of national epidemics, integrate prevention and treatment services, and bring prevention interventions to a scale sufficient to have measurable impact"[73].

The development of such a national strategy is important to create an increased focus on HIV (including treatment and care services). It would enable HIV treatment and care services to be given appropriate consideration in planning or prioritisation exercises.

73 Global HIV Prevention Working Group. Behaviour Change and HIV Prevention:[Re]Considerations for the 21st Century. 2008

A structural framework for the organisation and development of HIV treatment and care services is important to improve quality, ensure smooth care pathways and promote the use of shared resources. This can be achieved through the development of Managed Networks: "Networks offer a way of making the best use of scarce specialist expertise, standardising care, improving access, and reducing any distance decay effects that can result from the concentration of specialist services in large centres" [74].

Managed Clinical Networks were defined in February 1999 by Management Executive Letter (MEL) (1999) 10, which stated that Managed Clinical Networks were "linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a coordinated manner, unconstrained by existing professional and health board boundaries, to ensure equitable provision of high quality clinically effective services throughout Scotland"[75].

The Scottish Executive HDL(2007)21[76] strengthened the role of Managed Clinical Networks. It emphasises that the development of Managed Clinical Networks cannot take place in isolation but should do so in the context of well-established joint working arrangements. It thus emphasises the integration of services across health and local authority sectors. This integration is a key aim of Delivering for Health[14] and is seen as a "vehicle for providing an integrated approach along the continuum of care from community to acute care settings, within which shifts in the balance of care would be possible". MCNs can also take account of wider partnership working across health and social care services, including housing, transport and the role of voluntary organisations.

The membership of Managed Clinical Networks should be broad and multi-disciplinary and extend into primary care and beyond the NHS, to include the voluntary sector and social care.

All HIV treatment and care services should be part of, or affiliated to, an HIV Managed Care Network (following the Managed Clinical Network Quality Assurance Framework and working towards accreditation). These would support services to: quality assure care, create smooth care pathways, promote the use of shared resources, facilitate communication between services and provide the opportunity to develop specialist skills.

74 Edwards N. Clinical networks. British Medical Journal. 2002; 324: 63.
75 NHSiS Management Executive. Introduction of managed clinical networks in Scotland. Edinburgh: NHSiS Management Executive, 1999 (MEL(1999)10).
76 Scottish Executive. HDL (2007) 21. Strengthening the role of managed clinical networks. Scottish Executive. 2007

The development of national auditable standards is also an important method to improve quality and standardise care. Standards are written statements describing the rules, actions, and conditions that direct patient care. Standards of care guide practice and may be used to evaluate performance. National Scottish Standards for the treatment and care of people living with HIV are also important to ensure that HIV treatment and care is given appropriate consideration from planners and NHS Boards.

Despite the responsibility NHS Boards have to involve patients in the development of services, this report highlights the dearth of current patient involvement in services. There is a need for initial and continued involvement in the delivery services. Creative national, local and community based approaches need to be utilised to facilitate this process.

Involving patients is seen as an integral part of the development of an MCN [69] and of national standards of care.

The issues raised by clinicians, voluntary sector and patients alike regarding the quality of outpatient facilities was particularly concerning and should be considered a priority.

Currently, there are only a small number of children and young people living with HIV in Scotland. Treatment and care for these children and young people is extremely complex and needs to reflect the involvement of the whole family. It is particularly important to maintain the benefits of treatment with ART into adulthood. Access to appropriately skilled personnel to provide a multidisciplinary service and appropriate support for children and young people (and their families) as well as having robust protocols to ensure the smooth transition of children to adult services is important.

Current Scottish Government approaches to long term conditions emphasises providing the majority of care in the community as locally as possible as it aims to reduce health inequalities, provide more integrated and targeted local care, reduce hospital admissions, provide systematic support for people with long-term conditions and allow patients and carers more involvement in the services they receive.

This report recommends that consideration should be given to increased primary care involvement in HIV treatment and care only with patient consent (given the confidentiality and stigma issues already discussed within this report). It acknowledges that GP/primary care involvement requires negotiated shared care, training and experience as well as patient consent. An MCN, shared care agreements and training would ensure quality assured practice, including staff training and CPD which is sensitive to the holistic needs of people living with HIV.

The voluntary sector is extremely important in providing support for people living with HIV and their carers. It can act as a patient advocate with NHS treatment and care issues and can provide continuity and confidentiality. Increased collaborative working with the voluntary sector is important to meet the comprehensive needs of people living with HIV. (For example, involvement in the development of national strategies and standards or locally by providing where possible on site referrals to volunteers). All HIV treatment and care services and people living with HIV should have access to voluntary sector provision.

HIV treatment and care services in Scotland provide high quality, evidence based and BHIVA guideline appropriate ART therapy (as shown by the Key Clinical Indicators). However, it is important that services are responsive now and in the future, to the challenges of the complex social, psychological as well as physical needs of people living with HIV and their ability to benefit from such care.

ScotPHN report

For further information contact:

ScotPHN
NHS Health Scotland
Elphinstone House
65 West Regent Street
Glasgow
G2 2AF

Email: scotphn@health.scot.nhs.uk
Web: www.scotphn/net