Blood Borne Virus Strategy: An Interagency Framework for Action

CONTENTS **PAGE**

EXECUTIVE SUMMARY			**3**
1	**INTRODUCTION**		**4**
	1.1	**The Process**	**5**
2	**STRATEGIC POLICY AND CONTEXT**		**6**
	2.1	**The National Context**	**6**
	2.2	**The Local Context**	**7**
	2.3	**Current Services for People with Blood Borne Viruses**	**7**
3	**UNDERSTANDING THE PUBLIC HEALTH CHALLENGE**		**8**
	3.1	**Hepatitis B Virus**	**8**
		3.1.1 Prevalence	8
		3.1.2 Risk Factors and Transmission	8
		3.1.3 Impact on Health	9
	3.2	**Hepatitis C Virus**	**9**
		3.2.1 Prevalence	9
		3.2.2 Risk Factors and Transmission	11
		3.2.3 Impact on Health	11
	3.3	**HIV**	**12**
		3.3.1 Prevalence	12
		3.3.2 Risk factors and Transmission	14
		3.3.3 Impact on Health	14
4	**PRIORITIES FOR ACTION**		**15**
	4.1 Leadership and Organisation		**15**
	4.2 Prevention		**17**
	4.3 Immunisation		**19**
	4.4 Testing for Blood Borne Viruses		**20**
		4.4.1 Who to Test?	21
		4.4.2 Where to Test?	21
		4.4.3 Testing for all 3 BBVs?	22
	4.5 Harm Reduction and Needle Exchange Services		**23**
	4.6 Care and Treatment		**28**
		4.6.1 Hepatitis B	28
		4.6.2 Hepatitis C	29
		4.6.3 HIV	30
		4.6.4 Service Redesign	30
	4.7 Social Care and Support		**31**
	4.8 Education, Training and Awareness-raising		**33**
5	**MEASURES FOR IMPROVEMENT**		**34**
6	**FINANCIAL PLAN**		**36**
7.	**BIBLIOGRAPHY**		**40**

EXECUTIVE SUMMARY

Blood Borne Viruses are a major health problem and present a major burden for affected individuals, families as well as the community at large. BBVs are life-threatening illnesses - and in the case of HIV, there is still no cure. BBVs affect some of the most excluded and disadvantaged groups in our communities.

Recent changes in funding arrangements to NHS Boards along with an increasing awareness of the impact of hepatitis C and the growing caseload of HIV facing both health and social services mean that we need to look again at how we best meet the changing needs of people and families affected by BBVs.

In Tayside, professionals from the health service, local authorities and the voluntary sector have worked together alongside local people to develop proposals that will tackle the growing public health challenge and improve the services provided to families and carers.

The Strategy sets out proposed priorities for action needed to *shift the balance of care* over the next three years. The key recommendations are highlighted below:

- **To improve strategic and clinical leadership and co-ordination through the development of a Managed Care Network.**
- **To realign health promotion activities from more broad-based generic interventions to those that focus primarily around BBV prevention.**
- **To increase testing for all three Blood Borne Viruses.**
- **To increase the uptake of immunisation for Hepatitis A and B.**
- **To redesign harm reduction and needle exchange services to improve access.**
- **To redesign the care pathway to increase the numbers of infected individuals in treatment and to improve integration across all services for people affected by BBVs.**
- **To increase awareness of hepatitis C amongst health professionals and 'at-risk' groups in the community.**

The proposals can be implemented through better use of use existing resources and retargeting of ring-fenced monies.

The proposals mean that services will be better targeted to meet the needs of those most in need, that more care and support will take place in communities and that we can maximise the potential of a wider range of professionals and organisations in delivering that care. The strategy represents a clear overall direction for the future and maps out the key actions that will deliver better care and improve the health and wellbeing of people affected by BBV.

1 INTRODUCTION

Blood Borne Viruses (BBVs) – HIV and hepatitis B and C – present a serious health problem across the world and in the UK. The incidence of HIV, whilst not reaching the epidemic levels in the UK predicted in the 1980s, has nonetheless steadily increased in Scotland over recent years and the number of cases occurring through heterosexual contact is not showing the same downward trend as for other risk groups. The incidence of hepatitis C amongst Scots is estimated at 1% of the population and there is a clear association between all three Blood Borne Viruses and poverty. Many infected people continue to face stigma and social exclusion.

The impact on the health and wellbeing for individuals with BBV and their carers is considerable. The long term consequences of hepatitis B and C are significant, with up to 85% of people exposed to the hepatitis C virus (HCV) going on to develop chronic disease, people with chronic hepatitis are at high risk of liver disease. HCV is responsible for between a half and three quarters of all liver cancer cases, and two thirds of all liver transplants in the developed world. There is no cure for HIV and no vaccine for either HIV or hepatitis C.

However, testing and treatment for BBVs has improved significantly in the last two decades. Effective testing is now available for all three BBVs providing the opportunity to target infection as well as referring positive individuals for prompt treatment. People with infected with HIV who have access to appropriate specialist treatment can now expect to live for 20 years or more and HCV infection can be effectively treated with drug therapy.

Prevention of Blood Borne Viruses is as important as care and treatment and awareness raising amongst the both the public and health professionals is a crucial element in tackling the spread of infection. In Scotland, a quarter of people infected with HIV are unaware of their infection and two thirds of individuals infected with hepatitis C are unaware of it.

A wide range of agencies from the statutory and voluntary sectors is involved in the prevention, care, treatment and support of individuals and their families living with HIV and/or hepatitis B and C. For individuals and families affected by BBV, access to support and social care is a vital part of coping with the ongoing physical and psychological effects of disease.

Locally the services for people with BBV have been developed in response to the needs of the specific conditions and population groups, which has resulted in poorly integrated services and gaps in provision. As in other parts of Scotland, only a small proportion of individuals with hepatitis C who could benefit from treatment actually receive it.

Changes in the pattern of demand and the desire to improve services along with the need to realign prevention activities in response to recent changes in the Scottish Executive's funding for BBV prevention have all acted as a catalyst for major service redesign.

This Strategy is the culmination of a process begun in 2006 by Community Planning Partners across Tayside through the Blood Borne Virus Strategic Planning Group (BBVSPG). It brings together key

recommendations for the further prevention of Blood Borne Viruses as well as for improving the care and treatment for people already infected with hepatitis B and C and HIV.

1.1 The Process

The multi-agency BBVSPG commissioned the development of a framework for tackling Blood Borne Viruses that would incorporate the redesign of prevention, care and treatment services. It set a series of key objectives, including:

- development of a coherent BBV care pathway that incorporates aspects of prevention and care and treatment
- improved integration of HIV and hepatitis C clinical services
- improved integration of health and social care services relating to BBV
- improved alignment of NHS BBV budgets to BBV activity with an action plan to deliver any associated changes in funding
- generation of plans to improve efficiency to deal with anticipated budgetary reductions following changes to the national funding allocation
- generation of plans to improve hepatitis C prevention in line with the Scottish Hepatitis C Action Plan

Two working groups were set up in 2006 under the auspices of the BBVSPG that brought together professionals from the statutory and voluntary sectors to consider the future recommendations for prevention of Blood Borne Viruses and the redesign of the care and treatment services. The groups carried out a detailed review of the health and care needs of the local population in light of national policy and guidelines, mapped out current provision and pathways to care and made recommendations to realign prevention activities, redesign harm reduction services, improve access to screening and testing, optimise care and enhance leadership and collaboration.

A series of events took place with service users in each of the Local Authority areas in Tayside during September 2006 to find out their views on the current services and how they could be developed in the future to better meet people's needs. The findings from the consultation events and the results of a separate user questionnaire have been used by both sub-groups to inform the final recommendations.

The emerging recommendations have also been discussed with a wide range of professionals and partner agencies through the Drug and Alcohol Action Teams (DAATs) in Angus, Dundee and Perth & Kinross and with the Sexual Health Strategy Group and the Health Advisory Forum.

2 STRATEGIC POLICY AND CONTEXT

2.1 The National Context

The Department of Health in England published the first National HIV and Sexual Health Strategy in 2001 that set out a programme for action to address poor sexual health and tackle the rise of Sexually Transmitted Infections (STIs), including HIV. In Scotland, the Scottish Executive responded to the continuing concerns over HIV by providing extra resources to tackle prevention and improve treatment services. This commitment was underlined more recently by the launch of the national sexual health strategy *'Respect and Responsibility'* in 2005, which made clear its commitment to improving the nation's poor sexual health and to tackle the rising incidence of STIs. Its recommendations for primary prevention complement those required for combating all three Blood Borne Viruses and underpin both national and local action being taken to reduce the rate of STIs. In addition to these broad-based prevention activities to combat the transmission of BBVs, action that concentrates on at-risk populations such as the reduction in injecting and sharing of injecting equipment remain UK and Scottish national priorities.

The Scottish Executive launched its ***"Hepatitis C Action Plan for Scotland"*** in September 2006 in response to the growing recognition of the serious health problem of hepatitis C and the consensus view of clinicians on the need to acknowledge the impact of the disease on public health and health services. The final statement published following the Consensus Conference on Hepatitis C held in 2004 highlighted that:

> *"Anti-viral treatment has so far had a relatively minor impact on the burden of disease and management of end-stage liver disease is expensive. Liver services are already over-stretched and the projected need for liver transplants will be impossible to meet. Prevention initiatives need to be expanded. Efficiency of the range of HCV services must be optimised, for example by reducing non-attendance, enhancing referral, improved data collection and crucially, service audit within the framework of a well designed MCN. What is certain is that, if we do not invest adequately now, we will not be able to afford the consequences of failing to tackle this epidemic".* [1]

The National Hepatitis C Action Plan aims to:

- put in place mechanisms to ensure better co-ordination, planning and accountability of hepatitis C-related services;
- build on existing activities and interventions to reduce the number of new cases of hepatitis C in Scotland;
- provide professionals and service users with the information and support they need; and
- gather robust data to inform the development and expansion of testing, treatment and care services beyond 2008.

[1] ©Royal College of Physicians Edinburgh, Consensus Conference on Hepatitis C, 2004

The Action Plan sets out a range of recommendations to be taken forwards over the next two years that cover prevention, testing, treatment, care and support, education and surveillance and monitoring. It represents the first phase of action that NHS Boards are expected to take to tackle the problem and lays the foundation for further long-term intervention. The Scottish Executive has allocated £4m over the two-year period to NHS Boards to support its implementation.

2.2 The Local Context

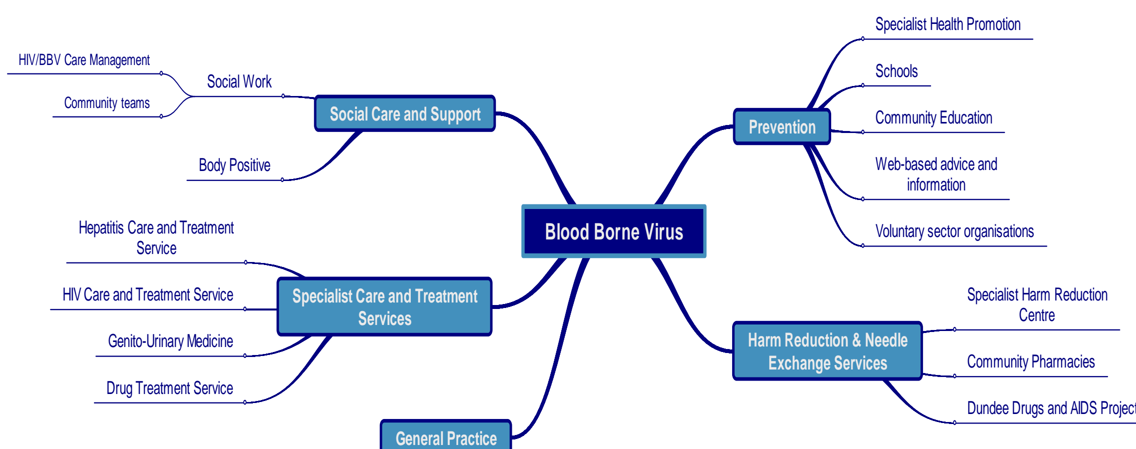
A number of reviews have been carried out in Tayside in recent years into aspects of BBV provision, most notably "The HIV Review Report" in 2000 and a "Review of Needle Exchange in Tayside" published in 2004. Both reports highlighted the need for change in the way that harm reduction and needle exchange services are provided.

As in many other parts of the country there has been a lack of overall cohesion and direction for services for people with Blood Borne Virus and insufficient leadership. The services are poorly integrated and there has been inadequate targeting of some 'at-risk' groups together with gaps in provision for both immunisation and testing. Hepatitis C is known as the 'silent killer' – up to 4,500 people in Tayside are estimated to be HCV positive, but almost three quarters are not currently diagnosed and up to 1,300 would benefit from treatment.

The recent change in the way the Scottish Executive Health Department allocates resources for BBV to NHS Boards means that Tayside will not receive an increase in the amount of the funding available for prevention activities and will need to meet the costs of both inflation and implementing Agenda for Change from existing resources. This, coupled with rising demand on clinical and social care services as a result of the rise in incidence of hepatitis C along with an increased caseload of people living with HIV for longer and experiencing more complex co-morbidities, created the impetus for carrying out a more fundamental review of the leadership, co-ordination, prevention and care for people with BBV.

2.3 Current Services for People with Blood Borne Viruses

There are a wide range of professionals and agencies involved in providing prevention advice, harm minimisation and care and treatment to individuals and families affected by BBV. The diagram below sets out the main agencies and the key services they provide.



3 UNDERSTANDING THE PUBLIC HEALTH CHALLENGE

Blood Borne Viruses (BBV) – hepatitis and HIV – present a major health problem.

People can be infected with only one of the three viruses or with any combination of two or three. The risk of contracting a blood borne virus infection varies with the individual virus. Hepatitis B carries a relatively high risk while hepatitis C and HIV infection carry a low risk except from those individuals considered at high risk of carrying the disease themselves, such as men who have sex with men (MSM)[2], intravenous drug users who share injecting equipment and individuals coming from an endemic high-risk area. The overall risk in the UK is low.

There is a strong association of BBV and social deprivation. There is also an unequal impact of sexually acquired HIV on MSM and certain minority ethnic groups. The incidence of both HIV and hepatitis C is significantly higher in Dundee City than in either Angus or Perth & Kinross.

3.1 Hepatitis B Virus

3.1.1 Prevalence

The World Health Organisation (WHO) estimates that in the UK the prevalence of chronic hepatitis B infection is 0.3%. Hepatitis B is more common in other parts of the world such as South East Asia, Africa and the Middle and Far East as well as Southern and Eastern Europe.

The overall number of new diagnoses of hepatitis B virus (HBV) in Scotland has declined between 2001 and 2004 from 357 to 341, but rose in 2005 to 372.

The rise in the most recent statistics is not reflected in the figures for new HBV infected Injecting Drug Users (IDUs), where the proportion of cases reporting injecting drug use as the main risk has declined from 30% in 1999 to 5% in 2005.

Nationally more than one in five injectors has been infected with hepatitis B. The number of newly diagnosed IDUs infected with HBV in Tayside is very small: from four in 1985 to one new case in 2004 and no new cases were reported in 2005.

The majority of cases of HBV identified in Tayside are now amongst MSM and people from high prevalence countries.

3.1.2 Risk Factors and Transmission

Hepatitis B may be transmitted by contact with infected blood or body fluids such as through household or sexual contact with an infected person. HBV is much more infectious than HIV. The virus can be spread by the following routes:

[2] For the purposes of this document the definition of MSM includes gay and bisexual men and other men who have sex with men but do not identify themselves as gay or bisexual.

- Sharing or use of contaminated equipment during injecting drug use
- Vertical transmission from an infected mother to her unborn child
- Sexual transmission
- Needle-stick or other sharps injuries (in particular by hospital personnel)
- Tattooing or body piercing

In the UK hepatitis B infection is usually acquired in adulthood with sexual activity or injecting drug use being the most commonly reported routes of infection in the UK.

3.3.3 Impact on Health

Hepatitis B is the most serious type of viral hepatitis. Infection with the hepatitis B virus typically causes an acute infection, with a smaller number of those infected going on to develop chronic disease. Those people who have been chronically infected are at high risk from cirrhosis of the liver and liver cancer. Chronic HBV in some patients is treated with drugs and people with cirrhosis are sometimes given liver transplants. For those who develop cancer of the liver, surgery and chemotherapy can prolong life up to a few years. However, it is preferable to prevent the disease with vaccination than to try and cure it.

3.2 Hepatitis C Virus

3.2.1 Prevalence

About 1% of Scots or 50,000 individuals are thought to be infected with the hepatitis C virus (HCV). Of these it is estimated that 37,500 (75%) are chronically infected. However, the prevalence of infection varies significantly between population groups and ranges between 50% in injecting and former drug users to less than 0.04% among the general population.

To the end of 2005, a total of 20,163 people had been diagnosed hepatitis C positive in Scotland. In 2005 there were 1,600 new cases of HCV reported in Scotland; with over half (55%) of the total diagnoses amongst IDUs.

The total number of IDUs known to be currently infected with HCV is 12,296, accounting for 90% of all HCV reports in Scotland for which the possible/probable route of transmission is known. The overwhelming majority (70%) of all cases of HCV among IDUs are in males. Half of IDUs are under 30 years of age when diagnosed, with 4% recorded as under 20 years old.

In the five years to 2005 there has been a small decline in the total number of HCV cases reported in Scotland, from 1,682 in 2001 to 1,600 in 2005. Proportionally there was a larger decrease in the number of injecting drug users infected with HCV reported over the same period, from 1,136 to 886. However, there was a corresponding increase in the number of cases where the possible route of transmission was unknown, some of which would be expected to be from IDUs.

In Tayside, there are currently 1,467 people diagnosed as being hepatitis C positive. However, prevalence studies suggest that the actual number of individuals with HCV is around 4,500.

There were 103 new cases of HCV reported in 2005, accounting for 6.4% of the total diagnoses in Scotland. The number of reported cases has fluctuated year on year in Tayside, but has shown a rise for the two most recent years. Figure 1 below shows new cases, by mode of transmission for Scotland and Tayside.

Figure 1 Persons reported to be hepatitis C antibody positive

		2001	2002	2003	2004	2005	Total[2]
Scotland	Total	1,682	1,791	1,629	1,626	1,600	20,163
	Injecting Drug User	1,136	1,142	1,000	907	886	12,296
	Other[1]	74	97	90	79	102	1,372
	Not Known	472	552	539	640	612	6,495
Tayside[3]	Total	92	107	84	95	103	1,411
	Injecting Drug User	49	54	38	30	45	816
	Other	5	10	12	4	3	142
	Not Known	38	43	34	61	55	453

Source: ISD 2006

1 Includes sexual contact, body piercing/tattoo, needlestick, bite, perinatal transmission and blood factor/blood transfusion risk.
2 Total includes data for years not featured.
3 Refers to the NHS Board of residence.

There is variation in the number of reported cases of hepatitis C between Council areas. Dundee City accounts for 40% of the total cumulative cases, whilst Angus and Perth & Kinross account for 12% and 13% respectively. However, this may be distorted by the large number of cases where the Council of residence is not known.

Figure 2 shows the numbers of reported cases by Local Authority area.

Figure 2 Hepatitis C reports by Council area of residence as at 30 June 2005

	Year of report					Cumulative reports to 31 Dec 2005
Council Area	**2001**	**2002**	**2003**	**2004**	**2005**	
Angus	14	11	16	17	10	166
Dundee City	44	58	44	50	20	544
Perth & Kinross	18	23	13	10	9	182
Outwith Tayside	0	0	1	0	0	9
Not Known	16	17	10	17	11	460
Total	**92**	**109**	**84**	**94**	**50**	**1361**

Source: Health Protection Scotland

3.2.2 Risk Factors and Transmission

The two main routes of transmission in the UK have been the sharing of drug injecting equipment by injecting drug users (IDUs) and transfusion of infected blood or blood products. Treatment of blood products to eradicate the risk of transmission started in 1987 and screening blood for HCV has been carried out since 1991, eliminating this as a source of infection. Whilst the association of hepatitis C infection and drug misuse is of most significance, there are other less common routes of transmission, including:

- From infected mother to baby, before or during birth
- From unprotected sex with someone who has the virus
- Through medical or dental treatment abroad where unsterile equipment has been used
- From tattooing or body piercing with unsterile equipment
- Through sharing razors or toothbrushes that may have been contaminated with infected blood
- Through needle-stick injuries

Up to two thirds of people infected with hepatitis C are unaware of it and many will show no symptoms over a long period of time. Those who are undiagnosed are not able to take the necessary steps to prevent onward transmission and to reduce the impact of the virus on their health.

3.2.3 Impact on Health

Since its initial identification in 1989, HCV has become a major health problem worldwide.

Hepatitis C is currently the most significant infectious disease affecting those who inject drugs. Of the people who have ever injected drugs living with chronic hepatitis C in Scotland, it is estimated that a quarter have moderate hepatitis C disease with over 5% having severe (cirrhosis) disease.

In the UK up to 80% of those infected with HCV become chronically infected. Most people will show evidence of chronic hepatitis or inflammation of the liver. The impact of HCV usually progresses over a period of many years. Between 5% to 15% of those with chronic disease may progress to develop liver cirrhosis over 20 years and of those with cirrhosis 4-9% will develop liver failure and a smaller number (2-5%) will develop primary cancer of the liver. HCV is responsible for 50–76% of all liver cancer cases, and two thirds of all liver transplants in the developed world.

Hepatitis C infection can also result in other health problems including fatigue and joint pain. It can be adversely affected by factors such as alcohol consumption, obesity, age and co-infection with HIV or hepatitis B.

3.3 Human Immunodeficiency Virus (HIV) and AIDS

3.3.1 Prevalence

At the end of 2003 an estimated 53,000 adults aged over 15 were living with HIV in the UK. By the end of 2005, 4623 HIV infections had been diagnosed in Scotland since the epidemic began in the early 1980s; at least 1450 (31%) are known to have died.

In 2005 405 new cases of HIV were identified in Scotland; most of these were new diagnoses although some had been previously diagnosed elsewhere in the UK or abroad. This is the highest annual number of newly identified cases on record and represents an 11% increase compared to 2004. The main reason for the increase in reported cases is thought to be the improved uptake of HIV testing. Two thirds of new cases were in men and 156 of these were in men who have sex with men (MSM). There were 184 new diagnoses among heterosexual men and women who were not injecting drug users (IDU); two thirds of these are considered to have probably acquired their infection outside the UK (mostly in African countries). The number of non-IDU heterosexual men and women who are thought to have acquired their infection within the UK remains low.

Recent years have seen a rise in the annual number of HIV diagnoses in Scotland. The major factor contributing to the rise has been the increase in the numbers of infected heterosexual males and females from high prevalence countries in sub-Saharan Africa coming to Scotland, coupled with increased testing of this population

The annual number of men who have sex with men (MSM) diagnosed with HIV has also seen a rise in recent years; this stems from a number of factors including increased HIV testing, particularly in the genitourinary medicine clinic setting, and continued transmission of HIV. The number of diagnoses among injecting drug users (IDUs) decreased following the introduction of harm reduction measures in the early 1990s and has remained relatively low. In Scotland, around one in 110 IDUs is probably infected with HIV.

The number of people living with diagnosed HIV is rising each year due to increased numbers of new diagnoses and decreasing deaths due to antiretroviral therapies. Consequently, the number of HIV-infected individuals in specialist care and receiving anti-retroviral therapy in Scotland is increasing.

In Tayside, there has been a total of 541 reports of HIV since 1981, 270 of which have died. There were 19 new cases reported in 2005. Figure 3 below shows the HIV reports by transmission category for Scotland and Tayside for the last five years.

Figure 3 HIV reports, transmission category and year of report

Scotland	2001	2002	2003	2004	2005	Total reports[1]
Sexual intercourse between men	66	89	96	127	143	1626
Sexual intercourse between men and women	76	128	133	194	178	1361
Injecting drug use	18	10	11	14	24	1285
Other	11	23	18	29	61	351
Total	**171**	**250**	**258**	**364**	**406**	**4623**
Tayside						
Sexual intercourse between men	3	4	3	3	6	76
Sexual intercourse between men and women	10	10	9	21	7	147
Injecting drug use	3	1	1	2	3	293
Other	0	3	1	3	3	25
Total	**16**	**18**	**14**	**29**	**19**	**541**

Source: Health Protection Scotland

1 Total includes data for years not featured.

There is considerable variation in the incidence of HIV between the different Community Planning areas in Tayside. The number of people with HIV is much higher in Dundee City, and accounts for 68% of the current HIV population (where the Local Authority area is recorded). The number of HIV cases recorded by Council area is set out in Figure 4

Figure 4 HIV reports by Council area of residence as at 31 December 2005

	Year of report					**Cumulative reports to 31 Dec 2005**	**Cases not known to be dead as at 31 Dec 2005**
Council Area	**2001**	**2002**	**2003**	**2004**	**2005**		
Angus	2	3	4	2	1	41	26
Dundee City	11	8	5	14	8	364	146
Perth & Kinross	3	3	2	5	3	50	37
Outwith Tayside	0	0	0	1	3	8	7
Not Known	0	4	3	7	4	78	55
Total	**16**	**18**	**14**	**29**	**19**	**541**	**271**

Source: Health Protection Scotland

There has been a change in the nature of the sex industry locally, which has until recently mainly involved women supporting their heroin habit through street prostitution. However, in the last 18 months there has been an increase in the number of women working in the sex industry who do not have addiction problems, who have moved from high prevalence countries, who are more likely to be infected with a BBV (particularly HIV) and who therefore present risks in relation to transmission.

3.3.2 Risk Factors and Transmission

The most widely recognised ways of acquiring HIV are:

- Having unprotected vaginal, anal or oral sex with someone who is infected
- Sharing needles, syringes or other drug injecting equipment with someone who is infected
- Receiving a transfusion of blood/blood products contaminated with HIV (in the UK blood and blood products have been screened for BBV since 1991)
- From an infected mother to her baby during pregnancy, at birth or through breast feeding

3.3.3 Impact on Health

People infected with HIV often have no symptoms for a prolonged period of time, while the virus slowly attacks and weakens the body's immune system. When this happens, a person will become vulnerable to opportunistic infections that a healthy immune system would usually be able to fight off. At this stage of infection, the person is often diagnosed as having AIDS. Progression from HIV to AIDS varies from person to person and can be affected by many factors including stage at diagnosis and treatment.

HIV therapies can be very demanding on patients and the human cost for people living with HIV is high. HIV accelerates the development of coronary heart disease and treatments for HIV can result in raised cholesterol, diabetes and ischaemic heart disease.

Many people with HIV cannot work and others still suffer from social isolation resulting from the stigma and discrimination still attached to the condition. HIV also impacts on families and carers, some of whom are children and young people and who may also require alternative care arrangements.

There is currently no vaccine or cure for HIV. Once a person contracts HIV, he/she will remain infected with the virus for life and will be able to transmit it to others. Combination anti-retroviral therapy suppresses HIV and can reverse damage to the immune system, and prolong the lives of those infected.

4 PRIORITIES FOR ACTION

4.1 Leadership and Organisation

The NHS, all three Local Authorities and many voluntary organisations locally play a significant role in caring for people and families affected by BBV. However, there has been a lack of overall co-ordination of services and agencies working in the field of BBV and no clear direction for improving care.

This Strategy is intended to provide the necessary framework to direct future service redesign and guide more robust joint commissioning.

The current Blood Borne Virus Strategic Planning Group brings together representatives from the various agencies. However, there is a need to strengthen the governance arrangements and all the stakeholders believe that there would be benefits in adopting more formal terms of engagement where members are empowered to take decisions on behalf of their respective services as well as share information with colleagues.

Managed Care Networks (MCN) – involving not only NHS clinical services, but also social work and voluntary sector services – can make a very important contribution to providing better, more integrated prevention, treatment and care services. An MCN for hepatitis C has been in operation in Tayside for a number of years and reports annually on developments to the Hepatitis C Action Plan Co-ordinating Group as well as to local governance committees.

There is now agreement to create a Managed Care Network for Blood Borne Viruses that would build on the existing hepatitis C MCN. It would be responsible for planning and delivering BBV services, as well as advising NHS Tayside and Local Authority partners on population need and how resources can be best allocated to meet clinical standards and patient/client's need.

The MCN would include representation from:

- Specialist services for HIV and hepatitis C
- Other related specialties including Drug Services and Sexual Health
- Public Health
- Pharmacy
- General Practice
- Strategic Lead for Blood Borne Viruses
- Each Local Authority
- Drug and Alcohol Action Teams
- All three Community Health Partnerships
- Voluntary sector organisations involved in delivering care and support for people with BBV
- Public/service user representatives

The MCN would operate in conjunction with the Tayside Centre for MCNs and make use of its considerable advice and expertise in the development stages.

Although there are considerable benefits from developing a Tayside MCN, there are a number of additional advantages from developing a regional MCN for BBV with neighbouring NHS Boards. This would mirror the arrangements that already work well for addiction services and would mean that the funding needed to support the MCN could be shared across up to three NHS Board areas, releasing further resources to deliver frontline care. The preferred option of the Strategic Planning Group is for a regional MCN to be developed from the outset. However, there is a pressing need to develop an MCN and it is likely that the regional network will take some time to establish. A Tayside MCN will therefore be designed in such a way as to allow it to evolve over time into a component part of a wider regional network.

The MCN will play an important governance role for all the services involved in BBV, through designing an overall performance and monitoring framework that would review activity and outcomes at regular intervals. The MCN would formally report to NHS Tayside through the Improvement and Quality Sub-Committee and submit an Annual Report detailing its activities and an assessment against agreed measures for improvement, as well as link to other structures in the three Community Planning Partnerships. The MCN would also submit the Annual Report to each of the Community Planning Partnerships.

The MCN would be led by a Lead Clinician and managed by a designated Co-ordinator who would have respective responsibility for providing clinical advice to the network and co-ordinating and facilitating the implementation of service redesign and improvement. The development of the Lead Clinician role and management support would be in line with the approach recommended by NHS Tayside's Centre for MCN and the forthcoming Heath Department Letter (HDL) on MCNs and the arrangements will also respond to the awaited national guidance from NHS QIS for external quality assurance and accreditation of standards for MCNs.

The MCN would consist of an MCN Board and an Executive Group with sub-groups to address specific topic areas, for example prevention.

In addition to the MCN there is a need for clearer and more robust strategic leadership for BBV services to ensure that services are developed in response to need, that standards are agreed and reflect best practice and that performance outcome indicators are developed and monitored through service specifications and agreements. In future, this role will be carried out by a designated senior officer in NHS Tayside Board who will also be a member of and report to the MCN.

Recommendations for leadership and organisation – what we need to do next

- Strengthen leadership and planning arrangements through the appointment of an Executive Lead who will take responsibility for co-ordinating, planning and overseeing all activity on Blood Borne Viruses, including strategic commissioning in partnership with Local Authority partners.
- Establish a Managed Care Network for Blood Borne Viruses to implement and monitor the Strategy and Action Plan, advise the NHS Board and Community Planning Partners on investment priorities and to provide overall co-ordination for audit and research activities.
- In developing an MCN detailed consideration should be given to strengthening the arrangements for governance, management and co-ordination.
- Appoint a Lead Clinician for BBV.
- Review the existing co-ordinator roles and put forward plans to maximise effectiveness and patient care.
- Appoint a co-ordinator to manage the MCN.
- Explore with neighbouring NHS Boards the potential to develop a regional BBV Managed Care Network with links to the existing regional Addictions MCN.
- Develop and agree in conjunction with national working groups a set of outcome indicators for measuring progress in respect of BBV prevention, testing, treatment, care and support.
- Seek greater user and carer involvement to influence future planning and improve service delivery.
- The MCN should commission an assessment of the specific needs of ethnic minority communities.

4.2 Prevention

The majority of people infected with hepatitis show no immediate symptoms and can remain unaware that they are infected for a number of years. Recent figures also show that 27% of those infected with HIV in the UK were also unaware of their infection. The prevention benefits of diagnosing the people unaware of their BBV status are not only important for the individual, but also counselling and testing of current and former sexual partners may prevent a whole chain of infection.

BBV prevention activities were redesigned in 2001 in response to the Scottish Executive *'Report of the HIV Health Promotion Strategy Review Group'*. In Tayside, health promotion and Blood Borne Virus prevention has concentrated activity and investment on interventions that minimise risk behaviour. For the general population this has meant raising awareness of BBV and how it is acquired through generic information campaigns. In young people the focus has been on providing accurate, consistent information and supporting the development of the necessary life skills to make informed choices about their behaviour as well as signposting to services. Services have also developed to support those who already have a BBV to minimise the risks they pose to others through programmes such as the condom initiative, which provides targeted access to free condoms for high-risk groups in the population.

However, several factors including recent changes to BBV prevention funding and changes in disease prevalence have meant that there was a need for a far-reaching review of current prevention activities. The increasing rate of HCV infection among injecting drug users and the launch of the Scottish

Executive's *'Hepatitis C Action Plan'* in 2006 means that there is a need to increase current prevention activity across Tayside, particularly targeted at IDUs.

A working group was set up during 2006 to carry out a review of the current prevention activities and interventions funded by BBV prevention monies in light of strategic guidance such as *'Shooting up'*, the National Treatment Agency for Substance Misuse (NTA) Commissioners Resource Pack on Needle Exchange/Harm Reduction, 'Respect *and Responsibility – Strategy and Action Plan for Improving Sexual Health'* and the recently published *'Hepatitis C Action Plan for Scotland'*. The group considered existing priority areas and perceived gaps in provision and used the recommendations of the HIV Health Promotion Strategy Review Group as a benchmark for local services.

The group concluded that all of the activity being carried out was largely evidence-based and in line with national guidance. Condom use and needle exchange continue to play a major part in greatly reducing the risks of transmission of all three BBV. There were no obvious gaps identified in provision except for the need to target health promotion and prevention at international workers and asylum seekers from high-risk areas of the world.

There was agreement that the principles and evidence for the prevention of all blood borne viruses are generic and much of the activity has to be broad-based – the prevention messages and measures for BBV are common to those required to combat poor sexual health and substance misuse. It is important that there is a balance between broad-based risk reduction programmes, particularly for young people, and interventions for those already identified as engaging in high-risk behaviour.

However, the group identified some areas where there was duplication or where better value could be secured, for example the production of leaflets and delivery of training.

The epidemiological evidence suggests that the priority groups for future BBV health promotion interventions should be:

- Injecting Drug Users – particularly to reduce the incidence of Hepatitis C infection
- Immigrants from Sub-Saharan Africa
- People travelling to high prevalence countries
- Men who have sex with men
- People who already have a BBV infection

Young people should remain a priority for broad-based risk reduction programmes, which include developing life skills to enable them to make informed choices. The needs of vulnerable groups such as the homeless and looked-after children should be met through tailored, interventions.

The working group considered a number of options for future health promotion and prevention activities. The option of realigning investment in primarily BBV focussed interventions was considered to provide the best solution. However, concerns over the impact on important broad-based primary prevention activities and the potential for this to compromise other strategic priorities, led the BBV Strategic Planning Group to recommend that this option is implemented in a phased way over a period of two to

three years that would allow time to identify alternative funding sources or different ways of achieving the outcome.

Recommendations for prevention – what we need to do next

- NHS Tayside should develop an action plan by summer 2007 to progressively realign investment on prevention activities that focus primarily on BBV risk factors rather than more generic health promotion.
- The funding released as a result of the realignment should be used to invest in effective targeted BBV prevention.
- NHS Tayside should review its health information to ensure that it provides clear, consistent and practical advice on safer injecting practices, how to avoid injecting site infections, prevent blood-borne virus transmission and the safe disposal of used equipment.
- The Specialist Health Promotion Service should take the lead in developing advice materials that would be signed off by the MCN for use across NHS Tayside and Community Planning Partnerships.
- NHS Tayside should strengthen the current arrangements for notifying professionals and the care group of 'risk alerts' about potential contamination of street drugs and their effects.
- NHS Tayside should ensure that all HCV patients are provided with effective harm reduction advice, including advice on reducing alcohol intake and immunisation against hepatitis A and B as well as receiving counselling on measures that they can take to decrease the transmission of HCV.
- NHS Tayside should make sure that good quality, consistent information is easily available for patients and staff about the nature of hepatitis C illness, treatment options and how to access local services.
- Primary care, drug treatment and specialist services should actively offer counselling, testing, sexual health advice and harm reduction interventions such as needle exchanges.

4.3 Immunisation

Infection with hepatitis B is preventable using a safe and effective vaccine. Studies have shown that the vaccine is 95% effective in preventing adults from developing chronic infection if they have not yet been infected.

NHS Tayside already offers immunisation against hepatitis A and B for at-risk groups, including men who have sex with men (MSM), healthcare workers who are involved in a speciality that requires them to perform exposure prone procedures and post-exposure prophylaxis for babies born of infected mothers. However, there is no systematic 'contact tracing' programme in place to identify partners of people who have been diagnosed as hepatitis B positive.

Currently there is only limited vaccination provision for injecting drug users in Tayside. Other areas of Scotland have introduced HBV vaccination programmes for IDUs.

Recommendations for immunisation – what we need to do next

- NHS Tayside should increase the vaccination programme for hepatitis A and B to meet the needs of identified at-risk groups, especially injecting and former drug users, MSM and the homeless. A proactive immunisation programme for hepatitis A/B should be developed and implemented during 2007/08 to increase uptake by 400 additional people in the target at risk categories.
- NHS Tayside should introduce effective contact tracing arrangements, modelled on those already in place for sexually transmitted infections (STIs), for partners of people diagnosed as hepatitis B positive.
- Hepatitis A/B vaccination should be offered at selected Needle Exchange (NEX) sites which are likely to be the first point of contact with services for new injecting drug users.
- NHS Tayside should vaccinate children in high-risk settings, including children of families originating in high prevalence areas of the world and children in families where there is a known history of drug misuse.

4.4 Testing for Blood Borne Viruses

Testing is crucial in any attempt to control the spread of Blood Borne Viruses. People infected with any of the viruses need to be tested and diagnosed before they can be referred to the appropriate specialist team for treatment and support. Moreover testing can also play an important role in prevention – the process of testing and the pre and post-test discussion offers an opportunity to reinforce messages about how the virus is spread and what measures individuals can take to protect themselves and others.

The main reasons for testing are to:

- reduce transmission rates through immunisation and/or advice on minimising risk taking behaviours; and
- provide a route into treatment, which can offer a cure for hepatitis C or avoid life-threatening complications of this and other BBVs

NHS Tayside carries out routine antenatal screening for hepatitis B and for HIV and offers HCV testing for 'at-risk' groups.

Any individual, who feels that they may be, or have been at risk in the past, can request a free test from their GP. Confidential testing for hepatitis B and C and for HIV is also available through sexual health clinics and drug treatment services. Testing for HIV has already increased significantly as a result of the implementation of the local Sexual Health Strategy and accounts for the marked increase (52%) in the number of HIV tests carried out in genito-urinary medicine (GUM) during 2005. The HIV treatment service also offers 'accelerated' HIV testing with results being available within four hours or on the same day basis.

Both national and international guidelines recommend testing high-risk groups in the population. However, the recommendations vary according to the prevalence and risk factors for each of the Blood Borne Viruses. The current focus for BBV testing highlights the need to increase testing among former injecting drug users and the partners of former and current drug users.

There also is a particular need to increase testing for hepatitis C where there is evidence that there are significant numbers of individuals who are undiagnosed and unaware of their infection. In Tayside, estimates put this population at around 3,000 people. Those most at risk are current or previous injecting drug users, where prevalence rates are around one in two, and the prison population. However, despite the high prevalence amongst this population there is no HCV screening programme and clients are usually only given a test if they request it.

The working group considered several ways to improve the accessibility of testing services and to increase the uptake of testing by people most at risk of hepatitis C and BBV.

4.4.1 Who to Test?

Evidence suggests that testing should be targeted to identify groups, where there is a known undiagnosed, at-risk population and specifically at injecting and former injecting drug users, where prevalence rates for HCV are particularly high. Additional target populations should also include:

- people from high prevalence countries
- blood/tissue recipients before 1991
- prisoners
- men who have sex with men
- sex workers

4.4.2 Where to Test?

There is a need to extend the range of settings where testing takes place in Tayside and to recognise the role that community settings could have on increasing uptake amongst the target groups. Outreach needle exchange (NEX) services are often the first point of contact with services for injecting drug users and could play a much more significant role in delivering both vaccination and testing. As part of the proposed redesign of NEX services, sites offering ‘enhanced’ services, which could include community pharmacies and voluntary sector organisations, should provide testing. Equally drug treatment services and Sexual Health clinics are well placed to offer BBV testing.

Some areas have also begun to use the Enhanced Services funding under the new General Medical Services (GMS) contract to develop and improve services for current and former injecting drug users, including hepatitis C testing.

It will be important that the criteria and standards for testing are the same irrespective of where in the network people choose to access the service. Pre and post-test discussion must be available in all settings offering testing. Protocols, including arrangements to ensure that patients receive their results

and can be referred into appropriate services as well as for co-ordinating contact tracing should be developed and a training programme put in place to underpin the development of community-based services to ensure that all staff meet the required competencies.

Testing sites should be well publicised as part of health promotion materials.

4.4.3 Testing for all three BBVs?

There is no currently available national advice on screening for all three BBVs. However, we know that people testing positive for one Blood Borne Virus have an elevated risk of being co-infected with one or more virus. For example, individuals testing positive for hepatitis C have a higher risk of being co-infected with hepatitis B and/or HIV than the rest of the population. In addition, some people who are negative for hepatitis will still be infected with HIV. Moreover the prevalence rate for HCV amongst injecting or former injecting drug users is high and estimated at between 50-80%.

It is important to make the most of any contact with at-risk individuals, many of whom live chaotic lifestyles and may be difficult to contact or reluctant to return for subsequent tests. In the past selective testing for a single BBV has resulted in people not coming back for a follow-up test for one of the other viruses – often due to people mistakenly believing that they have been given the 'all clear' for all three viruses. Testing for all three viruses also has the advantage of ensuring that all cases of BBV are detected in the target populations.

The alternative approach of testing for HCV first and only offering a hepatitis B and HIV test for people who test positive for HCV would mean up to 80% of people being recalled, causing additional unnecessary anxiety and inconvenience for individuals and posing a significant risk that some infected individuals would not come forward for a subsequent test, and would continue to present a risk to their own and their partner's health. There would also be implications for staff time through the additional consultation time needed with patients for this two-stage approach to testing that would more than outweigh any possible saving on laboratory testing.

Testing should therefore be offered for all three BBVs for each of the target groups.

Recommendations for BBV testing – what we need to do next

- NHS Tayside should introduce a targeted BBV testing programme in the community for high prevalence groups, specifically injecting or former injecting drug users and the prison population. In year one of the programme the aim should be to screen 500 additional people.
- Testing for HIV, hepatitis B and C viruses should be offered as a choice for all people at all testing sites, but should be targeted at:
  - people from high prevalence countries,
  - blood/tissue recipients before 1991,
  - people with other BBV positive tests,
  - the prison population,
  - men who have sex with men,
  - sex workers.
- Testing for BBV should be blood based at present, but NHS Tayside should regularly review the potential for oral testing.
- Testing for Blood Borne Viruses should be offered at a range of sites and signposted at others.
- NHS Tayside should explore the feasibility of testing in community pharmacies and in the voluntary sector, where high-risk groups are already in contact with services, as part of the contract for enhanced NEX services.
- The MCN should explore the potential for extending the ante-natal screening programme to include targeted HCV testing.
- In the event of a national screening programme for BBVs, NHS Tayside should evaluate local practice in the light of national policy.

4.5 Harm reduction and Needle Exchange Services

Levels of needle and syringe (direct) sharing have increased since the late 1990s. Data from across the UK suggests that more than a quarter of IDUs reported direct sharing in 2005. The sharing of other injecting related equipment remains more common. Recent work in Scotland has demonstrated that the environment in which injecting takes place can also have an influence injecting practices. There is evidence that groin injection, which presents particular risks to health, is becoming more common. These findings highlight the need to reinforce harm reduction advice and intervention about injection hygiene, vein care and risk management.

Harm minimisation is a key element of the national approach to deal with drug problems and refers to the delivery of services, which aim to reduce the risk of a broad range of drug-related problems - physical, psychological, social, legal and financial – until a drug user is ready to move way from drug use. Reduction in injecting and sharing of injecting equipment remain UK and Scottish national priorities.

The provision of sterile injection equipment through Needle Exchanges (NEX) is central to reducing infection and maintaining good injection hygiene. Infections such as hepatitis C may be reduced by the provision of sterile injecting equipment other than needles and syringes, such as mixing containers, and

the correct use of sterile swabs before injection could help reduce bacterial infections at wound sites. Needle exchange is effective at reducing sharing of injecting equipment and reduces drug-related infection.

Initially NEX was developed in response to the HIV epidemic in the 1980s and there is strong evidence that it was effective. The incidence of hepatitis C infections in intravenous drug users (IDUs), even if using NEX services, suggest that it is essential to make available associated paraphernalia. National statements on good practice make clear that NEX should offer:

- Sterile syringe and needle distribution
- Safe syringe and needle disposal
- Advice on BBVs and drug problems
- Hepatitis B immunisation
- Overdose prevention advice and information
- Safer sex and sexual health advice and information
- Advice on a broad range of health and social issues
- Referral to other services
- Easy access
- Reduce the number of new injectors
- Collect data

One of the major considerations influencing effectiveness of NEX is accessibility. Delivery should be through a range of outlets or mechanisms and include:

- Community pharmacy outlets
- Drug treatment services
- Outreach or mobile exchanges
- Voluntary sector
- Police custody suites
- A&E or Minor Injury Units

A national survey of needle exchange facilities was carried out in 2005. The survey examined the extent, nature and commissioning of NEX provision across the UK. The Scottish Executive recently published the findings for Scotland. The majority of NEX sites are located in pharmacies (approximately 72% in Scotland), with the remainder being provided by specialist services, including outreach. Only a small number of NEX were located in Police custody suites or in A&E departments. The survey pointed to the clear benefits of having different types of service available.

In Tayside, harm reduction measures have worked effectively to minimise the risk behaviour of current injecting drug users through the provision of needle exchange and paraphernalia. The services were developed to make sure that facilities are available in local communities through a combination of delivery by voluntary sector organisations, community pharmacies and the Specialist Harm Reduction team, which offers both static and outreach services.

However, the need to increase access to harm reduction services and NEX, and to reconsider the balance of provision between specialist and community based services and static and outreach services has been recognised for some time. A number of reviews of NEX have been undertaken locally, notably the *'Review of needle exchange in Tayside – October 2003 – February 2004'*. The review made 41 recommendations for improvement, specifically:

- Improved co-ordination, governance and evaluation of NEX services
- Explore further options for partnership working
- Establish outreach services in Dundee
- Carry out education campaigns assisted by Health Promotion
- Establish peer education programmes in relation to safer injecting
- Update information on service availability
- Improved communication and social marketing strategy
- Update the contact with community pharmacy
- Increase the number of pharmacy outlets in target areas and "hotspots"
- Increase the services available from pharmacies, including BBV testing
- Improved training for participating pharmacies
- The closure of the fixed NEX located at Constitution House in Dundee

Improvements in services are also required to support IDUs to improve their injection behaviour and hygiene and reduce the wide range of injecting related infections.

The recommendations made in 2004 are in line with national policy guidance. Whilst there is a longstanding and evidenced view of the changes required to better target and improve the efficiency of NEX, many of the recommendations have not been implemented in practice.

The current service model is delivered by three main providers:

- community pharmacies,
- voluntary sector static site (Dundee Drugs and Aids Project), and
- Harm Reduction Centre (a Dundee static site along with outreach in both Angus and Perth & Kinross).

The Specialist Harm Reduction team deliver an enhanced service to clients that includes wound care, counselling and training for other NEX providers. Historically, the team has been responsible for co-ordinating and distributing injecting equipment (paraphernalia) to community outlets. NEX services are provided through 11 community pharmacies and voluntary sector organisations, which together deliver the overwhelming volume of NEX activity. Services are not equitable across Tayside and do not match identified need. The table below sets out the needle exchange activity by provider for 2005-2006.

Needle Exchanges in 2005-2006		
Provider	**Issues**	**Returns**
Harm Reduction Team (Dundee)	42,152	14,464
Harm Reduction Team (Angus – outreach service)	29,813	29,640
Harm Reduction Team (Perth & Kinross – outreach service)	41,309	34,006
Community Pharmacy	143,984	24,813
Dundee Drugs & AIDS Project	52,900	26,147
TOTAL	**310,158**	**129,070**

Source: local data recording

The current contract between NHS Tayside and community pharmacies and the voluntary sector is based on a sliding scale that caps remuneration at a maximum annual payment of £1300 regardless of the level of activity being carried out. It does not adequately take account of the volume of activity or take advantage of the potential that pharmacies and voluntary sector offer to deliver a wider range of community-based, easily accessible, confidential services. In some instances it is clear that the cost of providing the NEX service exceeds the annual payment. This has resulted in the busiest needle exchange pharmacy withdrawing from providing NEX and considerable pressures on the voluntary sector provider.

Expenditure on harm reduction and NEX has increased above budgetary limits and has become routinely reliant on non-recurring resources.

We want to improve the way that services are delivered in future to improve access, better meet demand and make better use of resources. We have developed proposals for a new model of delivery that would be based on two tiers of service – standard and enhanced - that will allow the vast majority of NEX contacts to take place in community pharmacies and the voluntary sector.

The elements and characteristics of the tiers are set out below:

Standard NEX	Enhanced NEX
Broad based	Wound care
Health promotion advice	Immunisation
Signposting to other services	Testing
	Pre-test discussion
	General health checks
	Referral to specialist care & treatment
Wide coverage	**Targeted**
High volume provision	**Available in each Community Planning area**
	Matched to areas of high demand

A new NEX service would also be established in Dundee, where demand is highest, along side the newly commissioned Direct Access Service for Drug and Alcohol. Specialist nursing support would be

based alongside the Direct Access Service as well as being aligned to the enhanced NEX services to support outreach work.

Effective links would be established with the specialist services including drug treatment, the Direct Access Service, specialist hepatitis and HIV treatment services, sexual health and community based support to ensure that clients would be able to quickly access treatment and care.

In future, NEX services would be commissioned on the basis of a new contract that would reward both activity and quality, and be underpinned by robust outcome measures and regular monitoring. A revised training programme will also be developed to ensure that all staff providing NEX services base their practice according to recommended national guidelines and are part of the wider BBV network.

Best value considerations

It is difficult to compare harm reduction services on a like for like basis as they provide different levels of intervention. For example, the Specialist Harm Reduction, in addition to needle exchange provides a range of complementary services including clinical care such as wound management and counselling. There are also gaps in the data on effectiveness of interventions.

It is important that any redesign takes into account not just the cost per exchange, but also issues of access which can make some exchange activity appear less cost-effective e.g. outreach or less active pharmacy sites in more rural areas. However, there is merit in comparing the cost of delivering aspects of the service that are delivered by all providers, such as NEX, especially in light of the marked variation in the costs.

There are resources of £307,000 available to provide harm reduction and NEX services and there may be potential to release up to £100,000 over time through realigning the prevention monies. The proposed redesign of the service model for NEX would release the resources needed to address the current cost pressures facing the service and create increased efficiency and capacity to deliver improved access as well as the potential to deliver a wider range of community-based services.

Recommendations for harm reduction and NEX services – what we need to do next

- NHS Tayside should implement in full the recommendations of the 2004 Review of Needle Exchange services.
- NHS Tayside should develop a specification and commission specific services to deliver tiered services for harm reduction, including standard and enhanced NEX services, to ensure adequate coverage across Tayside so as provide sufficient needles and syringes to prevent sharing and that the provision is accessible and responsive to changing patterns of drug use and risk factors.
- NHS Tayside should give consideration to competitively tendering for harm reduction/NEX services that would be underpinned by incentivised, outcome-based contracts, develop clear roles for enhanced NEX delivered by the most cost effective routes and maximise accessibility that includes targeted outreach services for the most 'hard-to-reach' clients.
- The Commissioner for BBV should develop and negotiate a new funding structure and contract for pharmacy and voluntary sector NEX that would reward both activity and quality and be underpinned by robust outcome measures and regular monitoring.
- The MCN should support the development of pharmacy NEX and set targets for the number of pharmacies involved, the quality of care delivered and activity.
- The MCN should explore an item of service payment for NEX with an option for enhanced payments for specialist interventions.
- NHS Tayside should support the development of a balanced delivery of harm reduction services between static and outreach provision.
- Injecting Drug Users should be encouraged to make use of their entitlement to a greater number of sterile needles and syringes.
- NHS Tayside should monitor NEX provision to ensure an appropriate supply level of ampoules of sterile water, swabs, mixing containers, citric acid and filters.
- NHS Tayside should introduce pre-pack full needle exchange/paraphernalia kits and direct delivery from suppliers to all outlets.

4.6 Care and Treatment

Clinical services for people infected with HIV, hepatitis B and hepatitis C viruses have developed in a variety of settings and generally separately for each virus. This is despite clear overlaps in the client groupings and the risk factors. There are opportunities to reduce duplication of effort through the development of integrated care pathways and create capacity within the specialist teams.

4.6.1 Hepatitis B

Hepatitis B affects a smaller group of people. The main focus on activity relates to primary prevention and the treatment pathway is the same as for hepatitis C, which is described below.

There is currently no nominated clinician who has responsibility for the co-ordination of the management of babies and children with hepatitis B and C. This needs to be more effectively co-ordinated with

colleagues in obstetrics, midwifery and paediatrics, to make sure that mothers and newborn babies receive optimal care.

4.6.2 Hepatitis C

Up to 60-80% people with HCV will become chronically infected, the majority of whom will go on to develop liver inflammation, which may eventually lead to cirrhosis and liver cancer.

HCV infection can be effectively treated with a combination of drug therapy that results in sustained viral response rates in 50-80% of patients. Treatment is lengthy, complex and expensive to deliver. UK consensus guidelines recommend that antiviral treatment should be considered for patients who have at least moderate hepatitis C. In Tayside, at current estimated prevalence levels, around 1,300 patients should be receiving treatment.

A local audit carried out in 2003 revealed that only 400 (25%) of the known HCV population had been referred to the specialist clinic and only half of those referred actually attended for treatment.

Since then non-recurring funding was secured to appoint a Specialist Nurse and a number of steps have been taken to redesign the service, including the introduction of a referral pathway and new management guidelines, educational sessions and the development of outreach clinics in Drug Problems Centres and the Prison Service. The development of the nurse-led services and increased capacity had a significant impact on referral rates, which increased by 120%. Attendance rates also improved from 49% to 69%, waiting times came down from an average of 20 weeks to 4 weeks and uptake of treatment increased by 51%. However, the number of patients who have accessed specialist clinical care remains small and represents an estimated 12% of the actual incidence of the disease in the community.

One reason why uptake of testing and referral to specialist services has been low may be because health care professionals and clients believed that there was little prospect of follow up or effective treatment.

Many of the people infected with HCV face challenging life circumstances and often have chaotic lifestyles associated with drug misuse, which can mean that conventional approaches to delivering care in hospital settings result in very high drop-out rates from treatment.

There is a need to build and sustain capacity in the specialist service and to work more closely with colleagues in related areas to share expertise and use specialist resources more effectively.

4.6.3 HIV

Treatment for HIV has changed significantly with the introduction of complex, expensive antiretroviral drug therapy in the 1990s, which means that patients can now expect to live with HIV for many years.

Over 500 HIV cases have been identified in Tayside since testing commenced. Over half (54%) of people diagnosed with HIV in Tayside have had a history of injecting drug use, which is a higher percentage than is found in the rest of Scotland. There are currently 175 patients who attend regular out-patient monitoring of their HIV infection – this represents 65% of the known local HIV population. Others have moved from the area or are out of touch with services, where they pose a higher risk of transmission and can be expected to be admitted acutely with an HIV-related illness. Of the 175 people in active treatment, 69% are receiving antiretroviral therapy.

The introduction of drug therapies has improved the lifespan of people infected with HIV, but this has presented new and difficult challenges for individuals and for those involved in their treatment, support and care. In addition, there are a number of factors that are increasing the demand on clinical services:

- increasing life expectancy of those on antiretroviral therapy
- rising incidence of cardiovascular disease in the existing patient population
- 'imported cases', including asylum seekers moving to Tayside from high-prevalence countries

HIV accelerates coronary heart disease (CHD) and treatments for HIV increase cholesterol. Other complications of treatment include diabetes related to drug toxicity, ischaemic heart disease and some patients on treatment also develop a disfiguring condition known as lipodystrophy, which results in body fat being redistributed away from the face and limbs to the chest and abdomen. The complications associated with treatment can have a significant psychological impact on individuals and act as a disincentive to treatment.

These factors have combined to increase overall patient numbers and the complications and intensity of outpatient and in-patient treatment.

The Chief Medical Officer has recently commissioned the Scottish Public Health Network to carry out a Health Needs Assessment on the care of long term survivors with HIV that go on to develop other co-morbidities.

4.6.4 Service Redesign

The Care and Treatment Sub-Group considered a range of issues in the light of national guidance, previous local strategic work and service user consultation The group has developed a revised care pathway for BBV that incorporates prevention and care and treatment aspects. There are opportunities to improve co-ordination, integration and effectiveness and address capacity issues by adopting a networked approach that would allow better use of all the skills and competencies of partner agencies.

Recommendations for care and treatment – what we need to do next

- The concept of a 'Care Co-ordinator' should be implemented for each service, who would be responsible for co-ordinating referrals and assessments and supporting the individual through the pathway of care.
- Partner agencies need to explore options to provide better support for people with complex needs and chaotic lifestyles, and to help retain contact with people who are not involved in active treatment.
- All new cases of BBV infection should have specialist assessment.
- NHS Tayside should introduce a BBV clinic at Perth Royal Infirmary.
- Appoint a full-time Specialist HCV Nurse and associated administrative support to deliver nurse-led outreach clinics.
- The specialist services should work with local support groups and voluntary organisations to develop more proactive approaches to encouraging 'hard-to-reach' clients to engage with services and to sustain treatment.
- Protocols should be developed when care is shared between Tayside Substance Misuse Services (TSMS) and BBV treatment services, to ensure that communication is adequate and patients are managed consistently and effectively and are not disadvantaged by their co-morbidity. Particular areas for action should include: TSMS increasing support during diagnosis or treatment initiation; BBV treatment services ensuring they liaise with TSMS regarding potential drug interactions or suggested alterations in substance misuse treatment.
- The management of hepatitis B and hepatitis C in antenatal care needs to be more effectively co-ordinated with colleagues in obstetrics, midwifery and paediatrics, using the joint management of HIV as a model, to ensure that mothers and newborn babies receive optimal care.
- The current clinical psychology and psychiatric support for patients with HIV should be realigned to offer a service to all BBV clients.
- NHS Tayside should identify how dietetic services can be provided for all BBV patients.
- The MCN should consider with colleagues in plastic surgery how the needs of HIV patients with lipodystrophy can be best met.
- The MCN should contribute to the work of the Scottish Public Health Network on the care needs of long-term survivors of HIV and consider the implications of any recommendations made.
- The MCN should carry out educational sessions for health and social care staff to raise awareness of best practice for the management, treatment and support of patients with BBV.
- The Commissioner for Blood Borne Viruses should carry out a review of the resources for BBV care and treatment to make sure that funding is directed to best support the needs of people with BBV.

4.7 Social Care and Support

Social care and support are a vital part of the care needed by many people with a Blood Borne Virus – many of the care needs of people with a BBV are social rather than medical. The types of support required will vary from individual to individual and will be influenced by the stage and progression of their illness, but will include:

- one-to-one support and counselling
- stress management and life skills
- signposting and referral to other services, including housing and health services
- benefits advice and income maximisation
- respite care
- care management
- family and carer support

Social care and support for people with BBVs includes a broad range of services: from high intensity one-to-one provision delivered by specialist statutory teams, to more generic community-based social care, through to advice and support from voluntary agencies and peer support groups.

An integrated approach to delivery makes sure that the needs of the most vulnerable people are met. Social workers provide support for people who are at times unable to access medical or clinical services and statutory agencies. The emphasis for intervention is on those people with clinical symptoms and/or at the time of diagnosis or during the terminal phase of the illness where increased support is often needed for individuals and their families. Enhanced care packages play an important part in enabling people to maintain their independence in the community. Services offered by the voluntary sector enhance the range of options for support open to people with BBV and their carers.

Funding for the Social Work aspects of care has historically been restricted to HIV and in some areas in Tayside this has meant that there is limited service provision for people living with the consequences of hepatitis B and hepatitis C.

Historically about one third of people with HIV have accessed some form of social work support. However, demand on social care services is expected to rise as a result of the identification of additional hepatitis C cases, the growing number of people infected with a BBV who are also injecting drug users who are more likely to experience difficult life circumstances, and can be expected to require access to social care and support, as well as an increase in the number of people at the terminal stage of their illness.

The model developed in Angus where a dedicated Care Manager and members of the Specialist Team work closely with generic community-based social workers and the Nurse Specialists from the hepatitis C and the HIV services to provide access to care and support for all BBV clients appears to offer a model of good practice.

A single shared assessment should be implemented across the pathway of care. This will consist of a core data set and a series of supplementary documents. The aim will be to store information electronically. With the patients permission stored, information will be shared between services on a 'need to know' basis. Robust governance arrangements can be put in place to assure confidentiality issues. The value of sharing appropriate information on a 'need to know' basis requires to be explored with individual patients.

Recommendations for social care and support – what we need to do next

- Community Planning Partners should consider the scope to re-organise existing social care resources to develop BBV specialist services in each of the Community Planning areas.
- A single shared assessment should be implemented across the pathway of care.
- Statutory agencies should explore with local voluntary sector organisations the potential to offer additional psychological support for people with BBV,

4.8 Education, Training and Awareness raising

Dialogue with local stakeholders has suggested that there is a lack of knowledge and awareness about hepatitis C among health and social care professionals and that this creates an additional barrier to access testing and appropriate treatment.

The Scottish Executive launched a website in February 2007 as part of its commitment to raise awareness of hepatitis C. It provides access to evidence-based information based on the SIGN Clinical Guideline on hepatitis C as well as more general guidance for patients and members of the public. The website can be accessed at www.hepcscotland.co.uk. Health Scotland is currently producing a hepatitis C resource pack, which will be available from April 2007. The aim of the resource pack is to educate, inform and raise awareness of hepatitis C among health, social care, criminal justice and voluntary sector professionals and it will include information on testing options and treatment, care and support as well as signposting other sources of information. NHS Education Scotland (NES) has now developed an on-line training package for community pharmacists that covers all aspects of substance misuse, Blood Borne Viruses and sexual health to support their public health role in these areas. The training programme includes an audit tool to record participation.

Recommendations – what we need to do next

- NHS Tayside should develop a sustainable educational programme for professionals working across agencies in relation BBV.
- The MCN should consider the role of E-health and web-based information as a means of raising awareness amongst professionals about best practice, local management guidelines and referral pathway.
- A training needs assessment should be carried out to identify training needs across all agencies.
- The Specialist Health promotion Service should take the lead role in developing and delivering multi-agency and multi-professional training in BBV.
- Education modules should be developed to provide different levels of training for professionals working across all agencies that range from awareness raising, on-line education to more tailored training responses. This should include a series of inter-active update sessions facilitated by the MCN.
- All staff providing standard NEX services should complete level 1 training, based on the programme developed by NES.

5 MEASURES FOR IMPROVEMENT

We have based the proposed action in the strategy on the evidence of what is required to prevent hepatitis and HIV and to improve the care, treatment and support for those affected by BBV. However, we need be able to measure what impact the action has on achieving the outcomes.

We have developed a number of key objectives or outcomes for improvement that reflect the Scottish Executive Health Department's core HEAT (Health Improvement for Scots, Efficiency, Access more quickly to services and Treatment appropriate to individuals) objectives:

Core objective	Outcome	How it will be measured
Health improvement (Risk reduction)	▪ Reduced transmission rates through immunisation and advice on risk taking behaviours. ▪ Increased uptake of immunisation by 'at risk' groups. ▪ Reduced numbers of people injecting drugs. ▪ Reduction in sharing of injecting equipment. ▪ Reduction in wound infections and complications from injection sites. ▪ Safer communities through increased use of safe disposal of used needles and syringes.	Health Protection Scotland (HPS) statistics. Recorded numbers. ISD statistics and data local clinical data from Tayside Substance Misuse & NEX. Local clinical data. Numbers of incidents recorded by the police of needles found.
Efficiency (Capacity)	▪ Better integration of services for people and families affected by BBV. ▪ Better value.	User feedback. Numbers receiving care & treatment; improved outcomes and costs.
Access	▪ Enhanced access to NEX services. ▪ Increased testing for BBV among identified 'at risk' groups. ▪ Better routes into treatment. ▪ Increased numbers of infected people receiving treatment. ▪ Reduced drop-out rates from treatment.	Geographical spread, opening hours & user feedback. Increased uptake. Larger proportion of at risk population in treatment. Higher percentage of people engaged in or completing treatment.
Treatment appropriate to individuals	▪ Target prevention for those most 'at risk' of BBV. ▪ Increase in numbers of MSM immunised for HBV. ▪ Prisoners accessing BBV services.	Rolling audit of progress. The proportion of MSM attending GUM clinic eligible for hepatitis B vaccine who receive their first dose in this setting. Number of prisoners tested, immunised & in treatment.

We need to be able to measure the impact of the proposed changes. The MCN will develop a set of core performance targets and supporting outcome indicators to monitor the implementation of the strategic outcomes and to measure the impact of interventions.

Many of the outcomes are longer term and in order to check that the changes are having the desired effect we will adopt a series of 'proxy' indicators that will allow the MCN to evaluate the data on an ongoing basis, identify at an early stage if the action is not working as intended and make the necessary adjustments. The BBV MCN will regularly monitor and report on progress.

As part of the first Hepatitis C Action Plan the Scottish Executive has stated that it will develop a set of national outcome indicators for measuring progress in relation to hepatitis C prevention, testing, treatment, care and support as well as training and education.

The National Sexual Health Advisory Committee (NSHAC) has adopted a series of Key Clinical Indicators (KCIs) that include specific measures in relation to HIV therapy and hepatitis B vaccination for men who have sex with men. NHS Quality Improvement Scotland is currently developing clinical standards for sexual health services that will be published later in 2007.

These outcome indicators will be incorporated into the core performance targets.

6 FINANCIAL PLAN

The Scottish Executive has allocated ring-fenced monies since 2002 for HIV, and now BBV, to support prevention activities. NHS Tayside receives £861,000 each year from the Scottish Executive. The allocation is used to support all the primary prevention activities carried out by Public Health, to commission work in the voluntary sector and to fund the Specialist Harm Reduction and Needle Exchange Services as well as laboratory testing.

Some prevention activities are broad-based and are jointly funded by Drug and Alcohol Action Teams (DAAT), such as the Staff Tutor in Dundee or through the Sexual Health Strategy.

In 2005 the Scottish Executive announced its intention to alter the funding formula to NHS Boards to better reflect the local prevalence rates of hepatitis C. This has a significant impact on Tayside where, historically there has been a comparatively low rate of HCV identified through testing.

The change in the funding formula means that the resources will remain at current levels for the duration of the present Spending Review period, with no increase for inflation or the added costs of Agenda for Change. This means that there was an 8% or £69,000 shortfall in 2005/06 and a further 3% forecast reduction in both 2006/07 and 2007/08. In order to meet these cost pressures and to invest in additional activity in relation to hepatitis NHS Tayside needs to release around £100,000 from existing expenditure. Action has already been taken in 2006/7 to meet the immediate requirement and plans are being developed to make sure that a minimum of £100,000 is released for reinvestment.

In addition, to the changes in the BBV prevention allocation there are a number of significant cost pressures facing the services; notably rising clinical demand, the escalating cost of antiretroviral drugs, the needle exchange contract and the costs of paraphernalia. The cost of antiretroviral treatment for each HIV patient for one year is approximately £8,000 and accounts for around 80% of the total cost of clinical care.

A realignment of prevention activities along with major service redesign is needed in order to meet financial targets and to respond to changing patterns of demand and improve services.

The proposed redesign of the Specialist Harm Reduction and NEX services would allow NHS Tayside to meet the existing cost pressures associated with paraphernalia, renegotiate the NEX contract on a more sustainable basis, fund the recurring costs of the Managed Care Network and release extra investment to support additional immunisation, testing and support in the voluntary sector.

The redesign of the harm reduction and NEX services will also ensure that the costs associated with the Specialist hepatitis C Nurse funded on a two-year non-recurring basis can be funded on a recurring basis. Realigning the prevention activities is also expected to release resources that could be used to support an ongoing hepatitis B immunisation and BBV testing programmes.

The table below sets out the current and projected expenditure for the four-year period to 2009/10.

BBV Prevention budgets	**Note Ref**	**2006/07 £000s**	**2007/08 £000s**	**2008/09 £000s**	**2009/10 £000s**
Funding available					
Ring fenced SEHD funding		861	861	861	861
Employers superannuation increase		33	33	33	33
Brought Forward from previous year		30	36	20	61
Total		**924**	**930**	**914**	**955**
Expenditure					
Specialist Health Promotion		296	255	213	219
Grants to Voluntary Sector		152	172	162	167
Harm Reduction Centre		277	200	150	0
Specialist Nursing Harm Reduction			30	62	64
Hepatitis C Specialist Nurse		17	22	0	46
Paraphernalia		30	85	88	91
New Needle Exchange contract			30	62	64
HCV Treatment and care (MCN Co-ordination & support)	1				64
Audit and Training					15
GUM		90	93	96	99
School Nursing Service		10	6	2	2
HIV screening		16	17	18	19
Hepatitis B immunisation					23
Additional HCV testing					26
Total		**888**	**910**	**853**	**899**
Underspend carried forward to following year		**36**	**20**	**61**	**56**

Note

1 A proportion of this cost may be met by other NHS Boards

In addition to the ring-fenced allocation for BBV Prevention, funding is available within the Board's general allocation for HIV Care and Treatment. The following table provides information on the expenditure currently classified under this heading.

HIV Treatment & Care Expenditure	**2006/07 £000s**	**2007/08 £000s**	**2008/09 £000s**	**2009/10 £000s**
Staffing	306	315	324	334
Drugs	1,132	1,167	1,202	1,238
Supplies	5	5	5	5
Overheads	23	24	25	26
Laboratories - HIV review	14	14	14	14
Other acute services	247	254	262	270
General psychiatry (notional)	50	52	54	56
Total	**1,777**	**1,831**	**1,886**	**1,943**

Hepatitis C Action Plan

In 2006 the Scottish Executive announced an additional investment of £4m to NHS Boards over two years from 2006/07 to implement the recommendations contained in the Action Plan for Hepatitis C. In Tayside, this means an extra £129,000 each year from 2006/07.

NHS Boards were asked to consider how the additional funding should be used to develop community-based treatment, care and support services for people who have been diagnosed with hepatitis C. In Tayside, the immediate priorities for investment will focus on increased testing, immunisation and delivering enhanced capacity in the specialist service to sustain community-based nurse led services as well as support for a Managed Care Network (MCN).

The funding for Year 1 (2006/07) was allocated from 1 September 2006. There has been considerable slippage into the current financial year. However, to maximise the benefits of investment in frontline clinical services, the balance of funding will be accrued into 2007/08 and 2008/09 to ensure that immunisation, testing and the increased capacity in the specialist nursing service and support for the Managed Care Network (MCN) can be sustained for the two-year period.

The table below sets out the projected expenditure for the three-year period to 2008/09.

Hepatitis C funding	**2006/07 £000s**	**2007/08 £000s**	**2008/09 £000s**
Funding available			
SEHD non recurring allocation	129	129	0
Brought forward from previous year		109	131
Total	**129**	**238**	**131**
Expenditure			
Needle Exchange paraphernalia	20		
Specialist HCV Nurse		22	45
HCV Treatment and care (MCN)		38	39
Non recurring costs		2	
Hepatitis B immunisation		21	22
Additional HCV testing		24	25
Total	20	107	131
Underspend carried forward to following year	**109**	**131**	**0**

Future resources for Hepatitis C

The Scottish Executive has recognised in the *Hepatitis C Action Plan* that there is a need for substantial new funding to expand hepatitis C treatment, care and support services, but has also acknowledged that further details are required about the level of funding that is needed and how it is best targeted. To address this, the Scottish Executive is commissioning a needs assessment to identify the need for hepatitis C treatment-related funding in each NHS Board. It will involve:

- *"Identifying the locations of exiting hepatitis C testing, treatment, care and support services in Scotland,*

- *determining the existing capacity of those services (looking at referral practices, waiting times, numbers tested, numbers entering and completing treatment),*
- *identifying gaps in existing provision, and*
- *providing detailed, costed options for addressing the gaps."*

It will also take into account the impact on NHS Boards of providing care to large prison-based populations.

The results of this work, along with the statistical modelling being undertaken by Health Protection Scotland on the cost of current and projected burden of hepatitis C-related illness on the NHS and society as a whole, will inform a bid for phased new funding beyond September 2008.

In Tayside, the ongoing costs associated with specialist HCV nursing and the MCN as well as increased immunisation and testing would be met from the redesign of Harm Reduction and NEX services and the realignment of health promotion activities.

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