



Kernow Positive Support

HIV Strategy for Social Care in Cornwall

Version 5 – September 2006

Executive Summary

HIV Strategy 2006-2009

To improve the quality of life for people infected or affected with HIV, living in Cornwall.

Kernow Positive Support (KPS), Cornwall Primary Care Trust(s), Cornwall County Council and Voluntary Organisations in Partnership.

Despite widespread education, HIV is still on the increase with 1 person being diagnosed every 3 hours. Locally we are no exception with a current registration of approx. 101 people infected with HIV and subsequently their families & carers who are also affected. Due to the stigma associated with HIV, isolation is common and those involved often don't benefit from standard community care services. KPS appreciates the diversity of the clients affected by HIV and look to develop services that are tailored to meet these needs but can also be integrated into mainstream provision.

In recent years there have been major advances in the treatment of HIV and with adherence to the drug regime, infected individuals can prolong their life expectancy. However in addition we need to consider an individual's emotional well being and the widespread misunderstanding and fear around HIV means an individual could face discrimination and prejudice from society. These individuals have a need and a right to live a normal life, and as much as possible we will empower them and enable them to do so. KPS' HIV Strategy aims to bring all stakeholders together to ensure people infected and affected by HIV are able to live their lives to their fullest.

The objectives of the HIV strategy are:

- To increase access to social care services for people living with HIV
- To increase access to appropriate housing for people with HIV
- To increase adherence to anti-retroviral therapy (ART)
- To reduce mother-to-child transmission
- To improve the emotional well being of people living with HIV and their families/carers
- To increase the employment rate of people living with HIV
- To increase access to education, leisure & social facilities for people living with HIV
- To increase the income of people living with HIV in need
- To improve coordination and collaboration between stakeholders

The strategy covers the following subject areas:

Technical Background

- Understanding the differences between HIV & AIDS
- Details of transmission, symptoms and treatments

Policies, Strategies & Guidance

- Detailing the various reference documents which influence and support this strategy

International Context

- Including global statistics, transmission risk areas & social care and delivery challenges

National Context

- UK transmission routes and statistics including age and ethnicity overview
- Areas of need in migrant communities, at diagnosis, from peers & at certain times

Cornwall Situation

- Local transmission routes and statistics including ethnicity overview
- Current provision by statutory & voluntary sectors and Cornwall & non-Cornwall provision
- Areas of need including practical, emotional, health and legal support
- Funding opportunities detailing public and private sector funds

Our Vision & Strategic Objectives

- Providing a breakdown of objectives, strategy strands and principles Challenges
- Including discrimination, confidentiality, immigration, inequality and KPS constraints

Moving towards our Vision

- Making the vision a reality with a breakdown of the objectives detailing current position and the way forward

Finance

- AIDS Support Grant detail and alternative areas of income

Performance Management

- The performance indicators that will monitor our progress

Issues Arising

- Issues arising from the development of the strategy that need addressing in the future

Implementation Plan

- Quarterly action plan spanning the next 3 years, incorporating monitoring tools

There is a role for all stakeholders to assist in the implementation of this strategy and subsequent action plan. Commitment to drive it forward and monitor the results in the proposed HIV Stakeholders Group meetings are essential to make this initiative a success and really make the difference. This strategy is the beginning in moulding our services for the next three years in conjunction with service user consultation, being mindful of their confidentiality

With our commitment to this strategy, Kernow Positive Support is proud to be at the forefront of improving the services for people affected by HIV in the county of Cornwall

Strategy preparation:

This strategy draws upon experiences and knowledge of the stakeholders who work with individuals and families infected and affected by HIV in Cornwall. Services users and their families contributed to the final draft.

Forward

This strategy sets out the way that Cornwall should plan to develop its services for those infected/affected with HIV over three years and beyond (2006-2009).

It is mainly concerned with social care services that the Cornwall statutory and voluntary sector currently provides directly or are provided by its partners, in particular the voluntary sector. This is important because people infected with HIV need help and support from different organisations, and services need to respond effectively, regardless of the organisational or professional boundaries.

This is KPS's first social care focused HIV strategy and builds on national strategies and information available on local needs. Research and publications from the Terence Higgins Trust and the National AIDS Trust provided overall direction. There was also substantial consultation with, and advice from, local stakeholders, including: CCC Department of Adult Social Care, Housing (*through details supplied in the Final Report from Cornwall Supporting People Team*), Genito-urinary Medicine Departments - RCH/DHP, and on behalf of HIV+ clients, KPS (*statistics and resources, and on behalf of HIV+ clients*).

Acronyms & Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Therapy
ARV	Antiretroviral
ASG	AIDS Support Grant
BME	Black and Minority Ethnic
CCC	Cornwall County Council - known as Cornwall Council (2009)
CDC	Cornwall District Council(s)
CSPT	Cornwall Supporting People Team
CWAC	Children with AIDS Charity
DH	Department of Health
DHP	Derriford Hospital Plymouth
GUM	Genito-urinary medicine Department
HIV	Human Immuno-deficiency Virus
HIV+	HIV-positive
HPA	Health Protection Agency
KHSG	Kernow HIV Stakeholders Group
KPS	Kernow Positive Support
IDU	Injecting Drug User
MCT	Mother to Child Transmission
MSM	Men who have Sex with Men
NASS	National Asylum Support Service
NHS	National Health Service
NIAS	National Institute for African Studies
NSF	National Service Framework
PCT	Primary Care Trust
PLWHA	People Living with HIV/AIDS
RCH	Royal Cornwall Hospital
STI	Sexually Transmitted Infection
TB	Tuberculosis
THT	Terence Higgins Trust
UNAIDS	Joint United Nations Programme on HIV/AIDS

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1. Introduction

HIV prevalence is increasing in the UK: every 3 hours, 1 person is diagnosed HIV-positive.

The majority of those recently infected will have acquired the virus through unprotected heterosexual intercourse, particularly through relationships in high HIV-prevalence countries. Unprotected sex between gay men also contributes to the increasing prevalence of HIV in the UK.

Although medical progress and the availability of drugs in the UK has drastically improved the health of people living with HIV, the virus impacts in other ways on people's lives. Living with a potentially life-threatening infection and knowing you could pass it on to someone else can be very stressful and difficult, combined with the desire, and the need, to live a 'normal' life. Misunderstanding and fears about HIV are still widespread, and people living with HIV may face hostility or rejection from society. Some people have lost jobs and homes, and children have been banned from schools due to their HIV status. Although these attitudes are improving in the UK - and discrimination at work or school is no longer legal - public understanding is still limited, and people living with HIV can still face prejudice from professionals, the general public, and even their own communities.

National policies focus predominantly on health care and treatment, with social care needs recognised as making an important contribution to someone's physical and emotional well-being. Working within the national policy context, this strategy draws upon the experiences and knowledge of stakeholders who work with individuals and families infected and affected by HIV in Cornwall. Service users and their families will also be involved in commenting on the final draft.¹

1.1 Terminology

This strategy is concerned with people both *infected* or *affected* by HIV. The former refers to an individual who is HIV-positive (HIV+) and carries the virus in their body. The latter refers to carers, families or children of someone living with an HIV diagnosis.

¹ Due to the confidentiality concerns of many people living with HIV, it was felt easier to use secondary information in the first draft of the strategy, and involve HIV-positive individuals in commenting on this draft through their links with voluntary organisations. In the future, when services have evolved further, it is hoped that service users could be brought in at an earlier stage.

2. Technical Background

2.1 What is HIV?

Human Immunodeficiency Virus (HIV) attacks the body's immune system, making it hard to fight off infections. HIV particularly attacks white blood (CD4) cells, which sets the immune system in motion when infections enter the body: the lower a person's CD4 count, the weaker their immune system.

2.2 What is AIDS?

When someone's immune system is damaged, they are particularly vulnerable to opportunistic infections (e.g. TB and pneumonia), which would not normally be a threat. Before effective treatments, if someone with HIV got one of these illnesses the person was said to have Acquired Immune Deficiency Syndrome (AIDS). However, it is no longer a widely-used term and doctors may instead call this 'late stage' or 'advanced HIV infection'.

2.3 How is HIV transmitted?

For someone to become infected, a sufficient amount of HIV must get into their blood, through the mixing of bodily fluids. Blood, semen, vaginal fluids including menstrual blood, and breast milk contain enough HIV to infect someone; saliva, sweat and urine do not contain sufficient virus.

2.4 What are the signs & symptoms of HIV?

Most people infected with HIV do not know that they have become infected, because no symptoms develop immediately after the initial infection.

2.5 Can HIV be treated?

There is no vaccine or cure for HIV. However, taking a combination of anti-HIV drugs (combination or anti-retroviral therapy (ART)) can slow down the damaging effect of HIV on the immune system. When ART² is successful, it can improve the health of someone with HIV, making them less likely to develop opportunistic infections and hence prolong their life expectancy. However, drug regimes can be complicated (*requiring strict time-keeping or drug refrigeration*) and side-effects (*e.g. diarrhoea, nausea*) are relatively common. Other elements can also help maintain a high quality of life, such as: adequate nutrition, counselling, prevention and treatment of opportunistic infections, and generally staying healthy. Non-adherence to ART can increase the risk of the virus becoming drug-resistant.

² This is often referred to as HAART - Highly Active AntiRetroviral Therapy.

3. Policies, Strategies & Guidance

3.1 Overarching Social Care Policies

Social Services' legislative powers and responsibilities can be found in:

- National Assistance Act, 1948.
- Chronically Sick and Disabled Persons Act, 1970.
- Venereal Diseases Act, 1974.
- Mental Health Act, 1983.
- Children Act, 1989.
- NHS and Community Care Act, 1990.
- Disability Discrimination Act, 1995.
- Community Care Act Direct Payments, 1996.
- Carers Act, DH 1998.
- Human Rights Act, 1998.
- Health Act, 1999.
- Immigration and Asylum, 1999.
- Care Standards Act, 2000.
- Health Care Act and Health and Social Care Act, 2001.
- Fair Access to Care Services, 2002.
- Modern Social Services - A Commitment to Reform, 2002.
- Nationality, Immigration and Asylum Act, 2002.
- Disability Discrimination Act, 2005.

Of particular importance is the Disability Discrimination 2005, which defines persons deemed to have a disability to now include people who have cancer, HIV infection or multiple sclerosis.

3.2 Social Care Practice Guidance

Following the recent Green Paper³, the subsequent White Paper will show the direction of adult social care over the next 10-15 years.

However, the Government has already set a huge national agenda to modernise health and social care services. This is described in a wide range of documents, particularly *Modernising Social Services*⁴, which establishes a new framework for the provision of social services, and *The NHS Plan*⁵, which identifies a new approach to partnership working among health and social services. In addition, the focus of *Choosing Health: Making Healthy Choices*⁶ includes ensuring that the most marginalised and disadvantaged groups have the opportunity to see faster improvements in their health.

³ Department of Health (2005) Independence, Well-Being and Choice

⁴ Department of Health (1998)

⁵ Department of Health (2000)

⁶ White Paper, Department of Health (2004)

Within this change environment, the focus is on ‘whole system working’, whereby users experience seamless services and receive a continuum of care. The system places the service user at the centre of integrated care across all agencies.

Recurring themes are to:

- Better promote people’s independence.
- Ensure fair access to services and reduce inequalities.
- Deliver user focused, responsive services.
- Raise standards and ensure consistency and value for money.

There are a number of key overarching documents for people with a disability⁷ or long-term condition:

- *Improving the Life Chances of Disabled People*⁸ sets forward the vision: “By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society.” Four key areas are highlighted:
 - Help disabled people to achieve *independent living*.
 - Improve support for *families with young disabled children*.
 - Facilitate a *smooth transition into adulthood*.
 - Improve *support and incentives for getting and staying in employment*.
- *National Service Framework for Long-Term Conditions*⁹ provides overarching best practice guidance on planning service developments for people with long-term conditions¹⁰. Quality requirements include: a person-centred service; early recognition, prompt diagnosis and treatment; emergency and acute management; early and specialist rehabilitation; community rehabilitation and support; vocational rehabilitation; providing equipment and accommodation; providing personal care and support; palliative care; supporting family and carers; and caring for people with neurological conditions in hospital or other health and social care settings.

3.3 HIV Practice Guidance

3.3.1 National Strategy for Sexual Health and HIV - DH, 2001

The strategy is predominantly focused on clinical issues, however, it does consider social care in one of its aims, to: “*improve health and social care for people living with HIV.*”

⁷ As defined under the Disability Discrimination Act 2005.

⁸ Prime Minister’s Strategy Unit, Department of Work and Pensions, Department of Health, Department for Education and Skills, and the Office of the Deputy Prime Minister (2005)

⁹ Department of Health (2005)

¹⁰ Although the NSF focuses on people with neurological conditions, much of the guidance can apply to anyone living a long-term condition.

The key priorities related to social care are:

- 1) Helping patients adhere to drug regimes.
- 2) Helping access to education, employment and leisure facilities.
- 3) Ensuring people have their needs assessed and met for welfare, benefits, housing, advocacy, interpretation, peer support, and other practical support for life in the community.
- 4) Supporting carers and families.
- 5) Making sure that people living with HIV can benefit from wider initiatives that promote social inclusion.

The following principles for delivering services are highlighted:

- Involvement of people living with HIV.
- Effective partnerships between statutory and voluntary sectors.
- Ability to respond quickly to the changing health and social care needs of those living with HIV.
- Respect for individuals' rights, including the right to privacy.

There also needs to be:

- Better integration of social care and clinical treatment.
- Better knowledge among clients about the range of services available.
- Culturally appropriate services that are responsive to high need groups.

The strategy recognises the clear relationship between sexual ill health, poverty and social exclusion, and also that HIV has an unequal impact on gay men and certain minority ethnic groups.

3.3.2 Recommended standards for NHS HIV services - Medical Foundation for AIDS & Sexual Health, 2003

These standards, endorsed by the DH and British HIV Association, primarily focus on healthcare. However, social factors can be an important influence on the health of people living with HIV and their ability to use healthcare services effectively, as well as fulfilling their social needs in their own right:

Standard 6: Social care integrated with healthcare for people with HIV

People with HIV should have access to social care services that are responsive, culturally appropriate, tailored to individual need and integrated with healthcare.

Standard 9: Care of families with HIV

Children, their families and carers should have access to specialist adult and paediatric multidisciplinary care including community care and support.

It is recommended that HIV services should be:

- *Person-Centred*: empowering the individual to make healthy choices and to manage their own HIV infection, through education and support which recognises the importance of lifestyle, culture and religion, and which, where necessary, tackles the adverse impact of economic disadvantage, social exclusion and stigma.

- *Developed in Partnership*: so that overall goals and the responsibilities of the individual and the health and social care services are agreed and clearly set out in a regularly reviewed plan.
- *Equitable*: so that services meet the needs both of the overall population, including specific sub-groups, and the individual.
- *Integrated*: through the provision of a multidisciplinary HIV health and social care team.
- *Outcomes Oriented*: narrowing the inequalities between those groups whose outcomes are poorest and the rest of the population, and maximising the quality of life for services users by empowering staff to deliver, evaluate and measure care.

The recommended standards require staff in health, social care and community organisations to understand the experience of HIV and HIV care, and to recognise the expertise of people living with HIV. Service provision needs to empower people with HIV - through skills, knowledge and access to services - to manage their own HIV infection and fulfil their potential to live long lives free of the complications that can accompany HIV.

3.4 Cornwall County Council

Improving the quality of life for people living HIV should be considered under a strategic aim: *“To promote equality, social inclusion and a safe and healthy environment for all,”* and in two delivery themes of a Cornwall Local Strategic Partnership: *Healthy People* and *Inclusive Society*.

Considering the Council’s typical strategic priorities:

- *Equal Opportunities*: HIV can be a matter of unequal opportunities, as HIV-positive individuals and their families may be discriminated against, due to fear and ignorance over their status.
- *Target Groups*: HIV can be an issue for five of the Council’s target group: The majority of those known to be HIV-positive in Cornwall are White British; all people infected with HIV may be considered to have a disability, and are supported through the ‘physical disability and sensory need’ client group; Currently, there is a small percentage of HIV-positive individuals who are women, due to a number of biological, social, cultural and economic factors; HIV-positive individuals are more likely to be low paid and live in poverty; and a large percentage of HIV-positive women have children, who are affected through the virus’ impact on their family life (*a small percentage will also be infected*).
- *Sustainable Development*: Improved support, advice and guidance to people living with HIV - combined with the provision of anti-retroviral drugs - will increase the well-being of people infected with HIV and provide opportunities for them to increase their self-confidence, be (re)trained, and hence take-up paid or voluntary employment in the local community.
- *Health Implications*: Successfully addressing the many social care issues surrounding HIV is an important prerequisite for effectively meeting health care needs.

3.4.2 Community Care

In addition to the two DH publications which guide this strategy, there should be an HIV/AIDS policy considered for the Department of Adult Social Care which clarifies the principles that CCC staff follow when providing HIV/AIDS related services. These values should include: promoting independence, protecting the confidentiality of service users, responding promptly to referrals, non-discriminatory working, trained staff, integration into mainstream provision, involvement of all stakeholders and acknowledging the diversity of those infected or affected by HIV/AIDS.

Adult Social Care is no longer responsible for any 'Children in Need'¹¹ i.e. if an HIV+ child is referred for services, whether or not his mother/father is HIV+, access is currently in transition. However, the child may need to be seen by the Children and Families team for specific needs.

If a parent with living with HIV is owed a duty of care by the Local Authority, under section 21 of the National Assistance Act 1948, then under section 122 of the Immigration and Asylum Act 1999, NASS has to make and fund the arrangements to provide any necessary support to children as part of their parent's household. In this instance, the local authority has no duties to children under the Children Act 1989.

3.4.3 Housing

Housing's HIV/AIDS policy is currently being researched and a Final Report published by Leicester Business School is available from the Cornwall Supporting People Team (CSPT), to take into consideration latest thinking and 'modern' support needs of people living with HIV. Housing policy is the District Council's responsibility. However, the Department of Adult Social Care are involved in developing strategies with partnerships. It is the intention of KPS to implement signposting to specific (*named*) housing officer's who would be responsible for HIV issues (*Statutory/Voluntary agencies*) within each of the six councils operating with the county.

3.4.4 Children & Families

Children and Families do not have an overall HIV strategy or plan, although they should follow any HIV policy in place which focuses on testing, disclosure and ensuring that HIV+ children do not face discrimination in the provision of services. The department should also follow the advice in the 2004 DH publication, "Children in Need and Bloodborne Viruses: HIV and

¹¹ Under the Children Act 1989, a local authority has two general duties with respect to children in need: (i) to safeguard and promote their welfare, and (ii) to promote wherever possible their upbringing by their families. Under the act, a child in need is defined as: "he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority; or his health or development is likely to be significantly impaired; or further impaired, without the provision for him of such services; or he is disabled."

Hepatitis”, which focuses on prevention and testing, rather than children’s wider needs.

3.4.5 Supporting People

Within the Cornwall Supporting People Team’s Final Report, there are a number of HIV priorities of particular relevance to this strategy:

- Development of providers towards increasing the trust and confidence of communities to encourage and increase access to services.
- HIV awareness training for CSPT service providers.
- Working with KPS to fully utilise existing funding streams to improve existing services and support towards housing and social care.
- Joint commissioning of any new services for people living with HIV/AIDS.
- Improved access to Social Services for people living with HIV/AIDS needing social and personal care.
- Accommodation-based services for those with high support needs.
- Some existing accommodation-based services to have a more specialised focus, including staff with specialised training on HIV/AIDS (*see section 3.4.3 - Housing*)
- Increased Cross Authority working and commissioning.

4. International Context¹²

HIV/AIDS is a global epidemic. Nearly 14,000 people are infected with HIV each day. At the end of 2004, almost 40 million people were living with HIV. Sub-Saharan Africa still has the highest HIV prevalence rate of 7.4%, but infections appear to be advancing in other places, with Eastern Europe and Asia experiencing the fastest-growing epidemics. HIV infection in Western and Central Europe is estimated at 0.8%, i.e. 610,000 people: each year, there are 21,000 new infections and 6,500 AIDS-related deaths.

A substantial number of people living with HIV in the UK metropolitan areas will have acquired the virus overseas. It is therefore important to consider this context and the cultural issues which may impact on their social needs, and what this may mean for the county in the future, considering the increase of dispersals into the rural communities from these areas.

Considering the transmission of HIV:

- *Women are at particular risk:* Women in many countries are particularly susceptible to HIV infection, due to biological, social, cultural and economic factors - women in Africa have a traditionally low social and economic status, with often limited power over sexual decisions.
- *Young people:* 15-24 year olds account for nearly half of all new HIV infections worldwide.
- *Limited prevention programmes:* In high-income countries, treatment has been a much higher priority than prevention. As a result, there have been rises in HIV transmission for the first time in a decade.

Considering social care needs and delivery challenges:

- *Stigma and discrimination:* Stigma and discrimination can prevent people from testing for HIV, using condoms, or receiving the care and support they need. African women are more likely to be deserted by their partners,¹³ and the potential negative brutal reaction of male partners can severely reduce access to, and efficacy of, treatment and care.
- *Self-confidence:* Some HIV+ African men may have specific problems associated with, or exacerbated by, the stresses of migration, subsequent loss of status, unemployment and stigma within their communities.
- *Anti-Retroviral Therapy (ART):* ART is available in the UK without cost, if certain immigration criteria are met.
- *Carers:* Women bear the brunt of caring for HIV-infected family members.
- *Child-Care:* There is a high probability that HIV-positive women from sub-Saharan Africa will be caring for children, possibly as a single parent.
- *Faith & Attitudes:* Religious faith plays a significant role in the lives of many Africans. Attitudes and taboos may also differ from the 'UK norm.'

¹² UNAIDS (2004) 2004 Report on the Global AIDS Epidemic

¹³ If men are HIV-positive, women are much more likely to stay and care for them.

5. National Context^{14,15}

5.1 Transmission Route

5.1.1 *Heterosexual Relationships*

The number of heterosexually acquired HIV infections is increasing steadily and since 1999 has been greater than the number acquired through sex between men. In 2004, 57% of diagnosed infections were acquired through heterosexual sex, with 65% of these being women.

5.1.1.1 *Black and Minority Ethnic Communities*

Poor sexual health disproportionately affects the UK's black and minority ethnic (BME) communities. The groups affected and their experiences of HIV vary greatly, reflecting diversity of migration, socio-economic status, disadvantage and discrimination. The prevalence of heterosexually acquired HIV infections in the UK and the numbers of new HIV diagnoses reflect the focus of the pandemic in sub-Saharan countries with close links to the UK. In 2003, 70% of HIV-infected heterosexual patients seen for care¹⁶ were Black-Africans¹⁷. Over 40% of HIV-infected individuals seen for care reside outside London and are predominantly Black-African.

5.1.1.2 *Young People*

Sexually Transmitted Infections (STIs) are a major public health concern for people aged 16-24 years old, putting them at increased risk of HIV infection. In 2003, young people accounted for 14% of all new HIV diagnoses, of which 62% were probably acquired through heterosexual transmission in Africa.

5.1.2 *Men who have Sex with Men*

Men who have sex with men (MSM) remain the group at greatest risk of acquiring HIV infection within the UK. This is particularly due to increasing acute STIs and increasing high risk sexual behaviour. Evidence from GUM clinics suggests annual incidence rates of around 3%. Among MSM aged under 25 and outside London, HIV prevalence is around 1.6%.

¹⁴ Health Protection Agency (2004) Focus on Prevention: HIV and other Sexually Transmitted Infections in the United Kingdom in 2003

¹⁵ Health Protection Agency (2004) HIV and AIDS in the UK, Quarterly Update, Data to the end of December 2004

¹⁶ And for whom ethnicity was reported.

¹⁷ As opposed to Black British i.e. they are likely to have very strong links overseas, perhaps through being born in Africa, or having only recently arrived in the UK.

5.1.3 Pregnant Women/Mother to Child Transmission

Over 300 HIV+ women give birth in the UK every year. The transmission of HIV from mother to child has been greatly reduced since the introduction of the universal offer and recommendation of HIV testing in pregnancy. Among women giving birth in the UK, those born in countries with high levels of HIV prevalence continue to have high levels of HIV infection. For example, for mothers born in East and Central Africa, infection is around 3.2%, whilst for those born in the UK it is around 0.03%.

5.1.4 Injecting Drug Users

HIV infection remains relatively rare among injecting drug users (IDUs) in the UK, accounting for only 6.5% of all HIV infections by the end of 2003.

5.1.5 Blood Products

Since 1985, all blood products have been heat-treated to inactivate the virus and all blood donations have been screened for HIV antibodies. Since then, there have been no recorded transmissions of HIV through this route.

5.1.6 Statistics

UK diagnoses of HIV infection are shown below:

Route	Diagnoses			
	New, in 2004		Cumulative*	
Heterosexual sex	2,860	57%	25,521	38%
Sex between men	1,413	28%	33,037	49%
Mother to baby	80	2%	1,231	2%
Injecting drug use	81	2%	4,202	6%
Blood tissue/transfer or blood factor	13	0%	1,785	3%
Undetermined / other	8	0%	834	1%
Follow-up ongoing	560	11%	772	1%
TOTAL	5,015		67,382	

* The sum of all reported diagnoses since reporting began

New diagnoses of HIV infection include both long standing infections (which may be of many years duration) and those more recently acquired. Although the annual number of HIV diagnoses among heterosexuals has overtaken MSM, the latter remain most at risk of acquiring HIV within the UK.

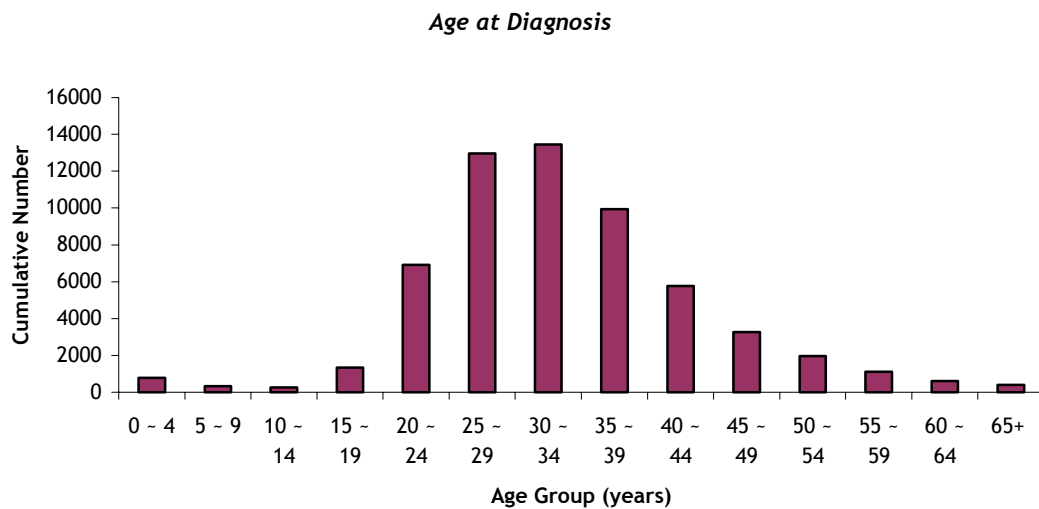
Considering heterosexual infections diagnosed in the UK: less than 1% of individuals diagnosed in 2004 were known to have had a 'high risk'¹⁸

¹⁸ E.g. a partner who had injected drugs.

partner; 11% of those infected without a high risk partner were probably infected in the UK; 76% of those without a high risk partner were probably infected abroad. Of the latter, 90% probably acquired the infection in Africa (predominantly East Africa, but increasingly Southern and the West).

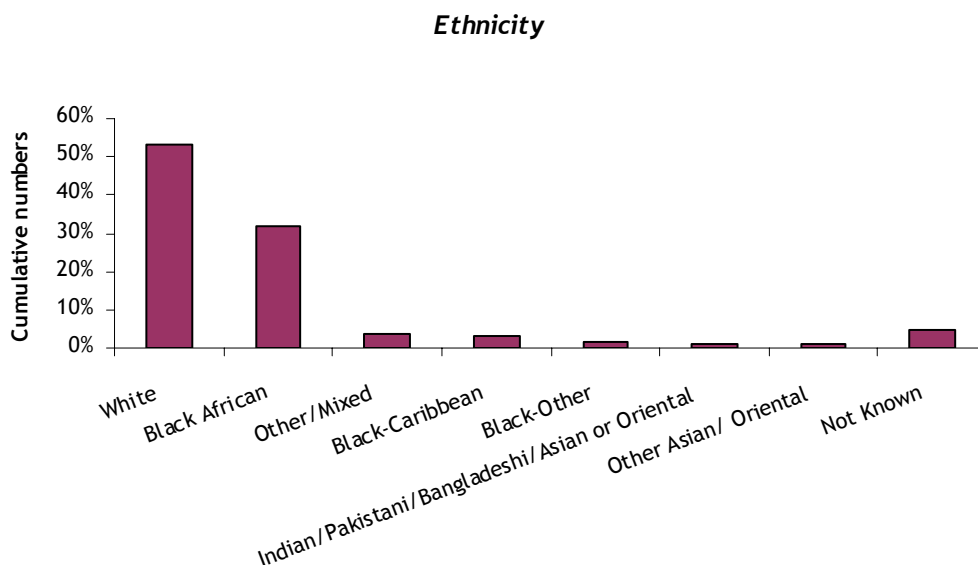
5.2 Age at Diagnosis

Considering the age of service users being diagnosed - and as shown below - most of those found to be infected in the UK are aged 25-39 years old, and to a lesser extent, aged 20-24 and 40-44 years old.



5.3 Ethnicity

As can be seen below, over 50% of UK-diagnosed HIV infections are amongst white communities and over 30% are amongst Black Africans. All other ethnic groups account for the remaining 15% of diagnoses.



5.4 Areas of Need

The Terence Higgins Trust (THT)¹⁹ has identified a number of HIV social care needs which have emerged in recent years:

5.4.1 For Migrant Communities

There has been a marked growth in social care need as a result of the increase in HIV infection amongst migrant communities. The areas of need reflect the level of social exclusion amongst these groups of people and include welfare, housing, immigration and childcare support. A principal underlying factor is the high levels of poverty and health inequality experienced. If not adequately addressed, these levels of need can become obstacles to an individual's management of their HIV infection.

5.4.2 At Diagnosis

There has been a marked growth in the volume of need for information and support at the point of HIV diagnosis. This need for support reflects the sharp increase in the numbers of people testing HIV positive.

5.4.3 From Peers

There is a continuing need for people living with HIV to be in contact with other people with HIV, especially in the period following diagnosis. This is in common with other client groups with long-term conditions, and is an important way of promoting self-management and empowerment, which in turn reduces demand on, and inappropriate use of, health and social care services.

5.4.4 At Certain Times

There is a move away from requiring ongoing social care support for the majority of people with HIV, to only requiring it at the times of greatest need. These times will usually be: at diagnosis, when starting HIV treatment, when changing treatment regimen and at times of ill health. This reflects the changing context of health amongst people with HIV and the increasing extent to which many people have begun to integrate their HIV infection with the rest of their life.

¹⁹ Terence Higgins Trust (2003) Meeting the Rising Challenge: The Growing HIV Epidemic and its Implications for Primary Care Trusts

Non-Government Support

For those in particular need, or who are not eligible for public support and hence have no recourse to public funds, there are a number of non-governmental hardship funds which currently provide small-scale grant schemes for those living within the county: KPS Peace of Mind Hardship Fund²⁷, Crusaid²⁸, PASW²⁹, Eddystone Trust³⁰ and CWAC (*Children with AIDS Charity*)³¹.

²⁷ www.kpsdirect.com

²⁸ www.crusaid.org.uk/whatwedo/hardship_fund.asp

²⁹ www.pasw.org.uk

³⁰ www.eddystonetrust.org.uk

³¹ www.cwac.org

6.5.3 Emotional Support

Peer Support

Emotional support, particularly from peers, can be vital, particularly at flashpoints of greatest need^{32,33}. This is important to those both infected or affected by HIV. Peer support can also assist with adherence to ARVs and making decisions over disclosure. It is recognised that in some situations, professional counselling may be beneficial.

Face-to-Face Support

Although some support services can be provided over the phone, face-to-face meetings are still needed (and appreciated) in many situations. At the moment, HIV+ Cornwall residents have limited opportunities for face-to-face support, particularly if they work full-time, cannot easily travel to the Peer Support meetings and/or the Knowledge Spa - KPS Drop-in Information Clinic held in Truro. Ideally, there should be somewhere within other areas that people can visit to receive support and advice and/or a more permanent arrangement, and meet with others in the same situation. Hiring rooms, even on a regular basis, raises issues of confidentiality and limits the support that can be provided: the possibility of finding a fixed location from which to provide support should be investigated.

Floating Support

There is also an emerging need for a floating support service, so that home-based emotional support can be provided at crisis-points.

6.5.4 Health Support

Health Needs

The health-related needs of people living with HIV include: treatment of opportunistic infections, self-management of their long-term condition, adherence to ARVs, and preventing transmission from mother-to-child and between sexual partners (*including re-infection*).

Role of Social Care

Cornwall PCT and the GUM (RCH) lead on all sexual health issues in the mid and west of the county, with Derriford (DHP) covering the north of the county, including health promotion, ARV adherence, and supporting the self-management of long-term conditions. However, given the multi-sectoral

³² Recommended by the Pan-London HIV Providers Consortium - Department of Health (2005) HIV and AIDS in African Communities: A Framework for Better Prevention and Care

³³ Terence Higgins Trust (2003) Meeting the Rising Challenge: The Growing HIV Epidemic and its Implications for Primary Care Trusts

nature of HIV/AIDS, the social care sector also has a role to address those areas which may become obstacles to a person's management of their HIV treatment e.g. poor housing, inadequate access to services, poverty, ability to manage their treatment, immigration and childcare support³⁴.

Mother-to-Child Transmission

Breastfeeding increases the risk of transmitting the virus from an HIV+ mother to her child, and so UK medical advice therefore recommends the use of infant formula milk in this situation. However, it should be noted that breastfeeding is a relatively common cultural norm (e.g. in Africa) and so thought must be given towards the potential consequences for a mother of not breastfeeding e.g. people may assume that she is HIV+, and she may then face prejudice or discrimination.

All mothers on low income - and who are eligible to receive benefits - can receive infant tokens (*instead of milk vouchers*), which can be exchanged for infant formula. However, there is evidence that a considerable number of HIV+ mothers, who don't have recourse to public funds, continue to breastfeed as they can't afford infant formula milk³⁵.

6.5.5 Legal Support

Immigration

Asylum seekers and other people who are seeking leave to remain (*e.g. students, people with UK ancestry, those who have been working in the UK, spouse of someone settled in the UK*) live with the basic uncertainty of an unresolved immigration status. Living with HIV obviously makes things even harder, as an individual's immigration status affects the services they are legally allowed to access, their opportunities for work, and their rights to benefits. For asylum seekers, there is the added potential complication that NASS can disperse individuals and families to different locations around the UK, as this may have a negative impact on someone's ability to access social or health care, as they have to 'start again' in their final location.

Accurate immigration advice and assistance is therefore an important issue for a large number of HIV+ clients, particularly Africans³⁶. There is also a role for social services if asylum seekers are being dispersed away from the larger metropolitan areas, in communicating with social and health care services in the receiving area, so that an HIV+ client finds it relatively easy to continue with their HIV treatment (if applicable) and link in with local support groups.

³⁴ Terence Higgins Trust (2003) Meeting the Rising Challenge: The Growing HIV Epidemic and its Implications for Primary Care Trusts

³⁵ Department of Health (2005) HIV and AIDS in African Communities: A Framework for Better Prevention and Care

³⁶ 55% of Africans living with HIV in the UK are coping with immigration or asylum problems - Weatherburn, P. et al. (2003) Project Nasah: An Investigation into the HIV Treatment Information and other Needs of African People with HIV resident in England.

Employment

Although, since December 2005 it is illegal to discriminate against an employee because of their HIV status, there are a number of ways that employers may try and skirt round the issue to encourage (or force) an HIV+ employee to leave. In such situations, advice and support may be needed to enable the client to maintain their employment or claim compensation.

6.6 Funding Opportunities

Statutory agencies receive an annual amount from the DH in the form of the AIDS Support Grant (ASG), which is based on the number of HIV+ individuals in the local authority and the number of HIV+ women and children. The value of this grant varies annually - figures aren't generally confirmed until after the financial year has begun - but the grant itself has been nationally ring-fenced until 2007/08 inclusive.

The ASG is currently used to fund the voluntary sector, HIV/AIDS training for statutory agency staff, a contribution towards HIV/AIDS-related staffing, and in-house support to HIV+ service users. However, outstanding costs related with the latter are covered by the general community care budget.

In 2005/06, the ASG provided £26,000.00 within Cornwall. This figure is increased to £29,000.00 for the 2006/07 financial year in relation to the increase of specific HIV service provision both in the statutory and voluntary sector.

7. Our Vision & Strategic Objectives

Considering the situation in Cornwall, discussed in chapter 6, the following vision and strategic objectives have been developed.

7.1 Vision

Our vision is a world where people infected and affected by HIV are able to live their lives to their fullest.

This can be achieved by:

- Empowering individuals to live as independently as possible, with control over the decisions which affect them.
- Providing and facilitating links with a holistic range of services.
- Reducing the stigma and discrimination often associated with HIV/AIDS.

7.2 Goal & Objectives

As part of this vision, the overall goal of the strategy is:

To improve the quality of life for people infected or affected with HIV, living in Cornwall and re-establish a cost-effective retreat and resources centre available to all those affected by HIV within the UK.

Which will be achieved by:

- 1) *Improving the health of people living with HIV, and their families and carers.*
- 2) *Increasing the income of people living with HIV.*
- 3) *Increasing the awareness for the needs of HIV-positive people and their care providers.*

In order to realise these, we will work towards specific objectives. If progress is made in each of these - assuming other things remain constant - then the purposes above will occur and progress towards our goal can be assumed.

The objectives of this strategy are:

- (a) To improve access to social care services for people living with HIV³⁷.*
- (b) To improve access to appropriate housing for people living with HIV³⁸.*
- (c) To improve adherence to anti-retroviral therapy (ART)³⁹.*
- (d) To reduce mother-to-child transmission of HIV⁴⁰.*
- (e) To improve the emotional well-being of people living with HIV⁴¹.*
- (f) To improve the emotional well-being of family members and carers of people living with HIV⁴².*
- (g) To increase the employment rate of people living with HIV⁴³.*
- (h) To increase access to education, leisure and social facilities for people living with HIV⁴⁴.*
- (i) To increase access to government benefits for people living with HIV⁴⁵.*
- (j) To increase income received from non-governmental hardship funds for people living with HIV⁴⁶. Plus a cross-cutting objective:*
- (k) To improve coordination and collaboration between stakeholders.*

³⁷ See 6.4.1

³⁸ See 6.4.1

³⁹ See 6.4.1, 6.4.3 and 6.4.4

⁴⁰ See 6.4.4

⁴¹ See 6.4.1 and 6.4.3

⁴² See 6.4.1 and 6.4.3

⁴³ See 6.4.1

⁴⁴ See 6.4.1

⁴⁵ See 6.4.2 and 6.4.5

⁴⁶ See 6.4.2

7.3 Strategy Strands

The overall strategy to deliver these objectives has three strands:

7.3.1 Increased Focus on HIV within Community Care

- Recognition that people infected or affected by HIV have specific needs that cannot be met by current service provision and procedures.
- Greater understanding of the needs of people living with HIV.
- Determination to improve the support available to people living with HIV in Cornwall.

7.3.2 More Sensitive, Person-Centred, Outcome-Focused Responses

- Respect and consideration for the confidential nature of someone's HIV status.
- Improved and more accessible information and advice, to increase people's choice, control and independence.
- Holistic approach to the support available.

7.3.3 Improved Coordination and Partnership Working

- A shared vision and strategy, agreed between partners, and focused on key objectives.
- More integrated working between KPS, CCC and PCT sexual health service and voluntary sector.
- Increased communication and openness between partners.

7.4 Principles

In line with the CCC Department of Adult Social Care HIV/AIDS Policy, Community Care will:

- Support an individual to be able to live as well as they possibly can with control over their own life, and with the knowledge and abilities to make decisions that are appropriate to them.
- Protect the confidentiality of service users and carers with provision that respects individual's rights including the right to privacy.
- Respond promptly to referrals.
- Require all workers to work in a positive and non-prejudicial way with people living with or affected by HIV.
- Ensure that all staff have access to the knowledge required through training and provision of reading material.

- Integrate HIV issues into mainstream provision for all client groups.
- Develop involvement of users and carers, statutory and voluntary agencies in planning and delivery of services.
- Be committed when formulating policy documents to include the diverse circumstances in relation to HIV/AIDS.

It is hoped that all HIV-stakeholders will also follow the above principles, as far as appropriate.

8. Challenges

The development of ARVs has transformed HIV infection (*in the developed world*) from being a death sentence, to a terminal illness which can, to a great extent, be monitored more effectively and controlled. Support needs have consequently changed and are now much more complex and focused on an individual's right, and desire, to be as independent as possible, for as long as possible. As HIV has a wide-ranging impact on an individual's life, a holistic approach is crucial: assessments need to be person-centred and outcome-focused, and support services should be coordinated to ensure seamless provision. It is also important to recognise that people living with HIV and their families and carers are a very diverse group, and are not a snapshot of the general population. As such, services should be particularly considerate of people's individual needs and the context in which they live.

People living with HIV may face stigma and discrimination in all areas of their lives. Many people experience discrimination and rejection from individuals and communities they would otherwise rely on, and can quickly find themselves isolated and marginalised. There is therefore a crucial need to build new networks of informal support, particularly amongst their peers in the same position.

Discrimination can also come from professionals or the general public, and so confidentiality is often of particular concern when someone living with HIV approaches a service for support, or decides to reveal their status. Whilst all stakeholders should work towards raising awareness of HIV and hence reducing stigma and discrimination, until it no longer exists, staff (*statutory and non-statutory*) must take particular care to maintain the confidentiality of service users, in line with their organisation's policy and government guidelines.

Issues surrounding immigration status and having no recourse to public funds affect a large number of people living with HIV. NASS has particular responsibilities to provide support and accommodation while asylum applications are considered. However, if destitute asylum seekers have 'care needs', local authorities should both accommodate and provide services. The definition of 'care needs' needs to be considered, as although people living with HIV may not have care needs in the traditional sense (*e.g. homecare*), they may require professional support. The voluntary sector may also be able to assist the statutory agencies in this area.

The dispersal of asylum seekers with HIV, in line with government policy, brings challenges for the NHS, Department of Adult Social Care, the immigration service and the voluntary sector. All stakeholders need to ensure that dispersal does not have an adverse impact on an individual's health or interrupt treatment regimens. Social workers could have an important part to play in this regard, by communicating with the receiving

local authority regarding the health and social care needs of a dispersed service user.

The treatment and care of people living with HIV is fraught with inequalities, particularly along ethnic lines: poverty is more than ten times as common amongst HIV+ Africans than amongst White British; problems with treatment information occur eight times more often; housing problems are seven times more common; and discrimination is faced three times more often by Africans⁴⁷. This strategy cannot expect to change the world, but consideration and understanding of these inequalities needs to be forefront when supporting all people living with HIV, but particularly those from overseas.

At the moment, very few people living with HIV are assessed by CCC Department of Adult Social Care, and so information on their needs has to be collated from a range of sources. This is positive, in that triangulation occurs, but it also limits CCC's ability to quickly get a detailed understanding of the situation. There also appears to be limited HIV specialist knowledge within CCC, although this is improving, particularly within the Department of Adult Social Care and Housing (*through Cornwall Supporting People Team who are currently developing a strategy to address housing-related concerns for HIV+ clients*) and, increasingly, within Community Care. However, Children and Families' do not presently have any specific services to provide advice, support or signposting to HIV+ children or their carers.

⁴⁷ Weatherburn, P. et al. (2003) Project Nasah: An Investigation into the HIV Treatment Information and other Needs of African People with HIV resident in England.

9. Moving towards our Vision

Drawing together the context in which we're working (*chapters 3, 4, 5 and 6*) and the highlighted areas of need (*sections 5.4 and 6.4*), this chapter proposes the actions which will be taken to achieve the objectives described in chapter 7.

The activities proposed should be implemented by CCC Department of Adult Social Care and other HIV stakeholders in Cornwall, in particular the only voluntary sector provider (KPS) who is funded by CCC's ASG, Cornwall PCT and other independent trusts. Details of proposed implementation and those involved can be found in chapter 13.

9.1 To improve access to social care services

There should be improved availability of culturally appropriate information on the services available from the community care team at CCC Department of Adult Social Care - including access routes, eligibility criteria and confidentiality - as well as information on non-statutory service provision. The benefits for a person living with HIV to approach Statutory agencies for services should be publicised, in order to improve access to social care services, for example opening-up opportunities for respite care, communication with other local authorities if an asylum seeker is dispersed within the UK, home-care, and the provision of services available under the National Assistance Act 1948.

A named contact for all HIV+ service users requiring social care support is being developed with these social workers being responsible for all stages of assistance, from access through to assessment and provision of support. Further awareness training should be provided for CCC Department of Adult Social Care staff, and NHS staff on HIV issues and the named contact - possibly the newly recruited HIV-focused social worker - should receive additional training to support their role.

All HIV+ clients referred to CCC Department of Adult Social Care should be assessed for welfare, benefits, housing, advocacy, interpretation, peer support, and other practical support for life in the community. Services should then be provided, if appropriate, or users should be signposted to non-statutory provision. Community advocates could assist with this process.

9.2 To improve access to appropriate housing

Any new HIV strategy for housing will discuss many of the issues touched upon by this paper and will confirm the exact nature of the actions to be implemented by the various housing departments. However, any strategy should recommend that improved information is available on statutory housing provision and eligibility criteria, as well as clear advice and signposting for those living in the private sector. Community advocates

could assist in improving access to the housing team. It is proposed that a single point of access for all HIV+ service users requiring housing support is developed, regardless of their current housing status, to make it easier for people to receive assistance and prevent them from having to publicise their HIV status in the reception area at the housing office. Housing staff should also receive updated awareness training on HIV issues, as well as more detailed training for those working at the single point of access.

9.3 To improve adherence to anti-retroviral therapy

As discussed, peer support makes a valuable contribution to improving adherence to ART. Peer-led motivational and self-management programmes should be developed, as should more informal groups to provide peer support at flashpoints of greatest need. The KPS Peer Support and drop-in opportunities should be promoted and people living with HIV encouraged to attend and/or gain support and advice.

The provision of small grants to fund fridges (*to store ARVs - this is currently available from KPS's own unrestricted funding resources*) for those on limited income should be considered. These could potentially be funded from the ASG and distributed through the voluntary sector.

9.4 To reduce mother-to-child transmission of HIV

This strategy does not cover children's issues per se - as the skilled staff within the children's department should primarily address these - however overlap occurs when a mother is HIV+ and there is a danger of her passing on the virus through breastfeeding. As discussed, mothers on limited income and eligible for government benefits receive free vouchers for formula milk. Mothers who have no recourse to public funds, but who are in the country legally, should also be supported - under the Children Act 1989 - to receive free formula milk. This could potentially be funded from the ASG.

9.5 To improve the emotional well-being of people living with HIV

This objective covers a range of issues, connected with someone's knowledge and understanding of HIV-related issues, the attitude of front-line staff when they are accessing or enquiring about services, the emotional and practical support available (*both professional and informal*), and the confidence and self-esteem of people living with HIV (*which is often affected by their diagnosis*).

Culturally appropriate information on all HIV-related services in Cornwall should be more available. Front-line staff, of both statutory and voluntary organisations, should be non-discriminatory and have an understanding of the issues and concerns of people living with HIV. Staff should be aware of the range of services available in the area and signpost clients appropriately, according to need.

Professional counselling should be available and peer support groups should be developed to provide more informal support and advice. Any support to people living with HIV should be flexible, and the benefits of establishing a floating support service should be considered. A focal point for everyone infected or affected by HIV in Cornwall should be developed, to provide a range of services, support and advice to anyone infected or affected with HIV. Opening hours and services should consider the differing circumstances of individuals with regard to employment, childcare etc.

People living with HIV should be encouraged to become 'Positive Speakers' and receive training to provide them with the skills and confidence to be able to do so. Talks to local groups, schools, workplaces, and places of worship should be organised and facilitated, potentially in collaboration with the HIV and Sexual Health Promotion Team.

9.6 To improve the emotional well-being of carers and family members

The impacts of HIV stretch beyond the infected individual. Carers and family members are also affected, through the caring and support role they provide, the emotional strains of someone close having a terminal illness, and potentially being on the receiving end of discriminatory treatment.

Peer support groups should be developed for family members and carers, appropriate to their age, culture and particular needs. The development of a physical focal point within Cornwall - as described above - would assist with this, giving people the chance to meet others in a similar position. Information on statutory and voluntary services available to carers should be made more available, and individuals should be signposted to appropriate organisations and opportunities (*including flexible respite care*) by front-line staff.

9.7 To increase the employment rate

Many people living with HIV are physically able to return to (*or start*) work, but may lack the confidence to do so, be out-of-practice on the recruitment process, or may need retraining with particular skills. Practical advice on job-hunting, CVs, application forms and interview technique should be available, as should be one-to-one support in the early days of returning to (*or starting*) work - this could be assisted by the Government's 'Welfare to Work' initiative. There should also be signposting to skills-based training and motivational courses. For example, the 'Positive Futures Partnership'⁴⁸ supports the employment, education and skills prospects of people living with HIV, through advice, training and guidance. In Cornwall people living with HIV should be offered opportunities for voluntary working, and links with the Cornwall Voluntary Services should be explored.

⁴⁸ www.positive-futures.org - Unfortunately, funding restrictions mean that their services are currently only available to people living in the Greater London Area; however, they will signpost non-residents to alternative service providers.

9.8 To increase access to education, leisure and social facilities

This objective is again linked to the confidence of people living with HIV to access mainstream education, leisure and social facilities. Information on local opportunities should be made available and staff should signpost individuals to opportunities for motivational courses and programmes which promote skills development and option appraisal. On the education side, practical advice on application forms and interview technique should be available; on the leisure/social side, peer support groups should be encouraged (*perhaps with facilitation*) to organise local events. One-to-one mental support in accessing and attending education, leisure and social facilities should also be available.

9.9 To increase access to government benefits

A significant number of people living with HIV live on limited income. Information on the Government's welfare and benefit systems, eligibility criteria and application processes should be more available, and advice and support on completing and submitting appropriate claim forms should be provided. Community advocates could assist in ensuring that people receive the benefits to which they're entitled.

As discussed above, a number of people living with HIV, particularly Black Africans, have undetermined, or non-residency, immigration status. Information on immigration issues should therefore be made more available, as should advice and support on completing application forms, appealing immigration decisions etc. Once someone is classed as a refugee or has been given exceptional leave to remain (*for example*), they may then be eligible for financial support through the UK's benefit system.

9.10 To increase income received from non-governmental hardship funds

For people living with HIV on limited income who have no recourse to public funds and are hence not eligible to receive government benefits, there are a number of hardship funds run by the voluntary sector. Information on these funds should be more available, with advice and support provided on completing successful application forms.

9.11 To improve coordination and collaboration between stakeholders

This strategy and an agreed implementation plan and monitoring arrangements are the first step towards improved coordination between the social care, housing, health and voluntary sectors in the field of HIV. An HIV Stakeholders Group should also be established - and meet regularly - to share information, monitor the implementation of this strategy, and coordinate service provision and delivery. Front-line staff in all sectors should have a better understanding of the system and procedures of the other organisations. Longer-term planning for all organisations should also be encouraged.

Voluntary sector organisations should also be supported to plan over a longer time period, through guaranteed funding from the statutory agencies within the county.

Given the mobility of clients, and issues of confidentiality and disclosure, KPS should be open to joint working or partnerships with neighbouring statutory and voluntary agencies (*locally and nationally*).

10. Finance

It is planned to implement the majority of this strategy with additional funding being needed. The ASG for 2005/06 (*and until 2008/09 inclusive*) should be sufficient for statutory agencies such as; CCC/PCT to provide funding for: the HIV-related work/services (*such as; respite/retreat and emergency payments*) of the HIV-focused social worker(s); Cornwall-focused HIV activities of KPS; providing improved and a more permanent solution to drop-in and peer support opportunities, small grants to assist in hardship issues faced by those living with HIV, providing fridges. The continuation and future development of KPS, and its service provision and resources.

Given the three-year life-span of this strategy, it is hoped that three-year agreements can be signed with KPS, so that KPS can plan for the future.

11. Performance Management

KPS propose within the ongoing development of the NHS Service User Group, a proposal for a new Kernow HIV Stakeholders Group (KHSG) could monitor implementation of this strategy, and its impact on the lives of those infected and affected with HIV. This would increase additional agency involvement within the statutory and voluntary sector.

Example:

Kernow Positive Support (KPS).
 NHS Service User Group.
 Cornwall County Council (Department of Adult Social Care).
 Cornwall District Council Representation (Housing)
 Genito-Urinary Medicine Department Representative(s).
 Primary Care Trust Representative(s).
 Health Promotion Representative(s).
 Cornwall Drug & Alcohol Team Representative(s).
 Other Voluntary Agencies i.e.
 (PASW/EddystoneTrust/Cornwall Voluntary Services).

Indicators will be agreed by all the stakeholders and relate to the strategic objectives. Output indicators will depend on the specific activities undertaken and should be reported to the KHSG on a quarterly and/or half-yearly basis. Impact indicators should ideally be measured now - so that baseline figures can be determined - and then reported annually. Proposed impact indicators are shown in the table below.

No.	Objective	Impact Indicators	Data Sources
1	To improve access to social care services for people living with HIV	↑ # of HIV+ clients who received assessments	CCC Community Care Records
2	To improve access to appropriate housing for people living with HIV	↑ # of HIV+ council tenants ↑ # of HIV+ users who received housing advice	CCC Housing Records
3	To improve adherence to ART	↑ % of HIV+ clients report full adherence to their ART	GUM Records
4	To improve the emotional well-being of people living with HIV	↑ % of HIV+ clients who appear confident with their HIV diagnosis	Voluntary Sector Reports
5	To improve the emotional well-being of carers and family members of people living with HIV	↑ % of families who appear comfortable with the HIV diagnosis of their family member	Voluntary Sector Reports
6	To increase the employment rate of people living with HIV	↑ % of HIV+ clients in work	Voluntary Sector Records
7	To increase access to education, leisure and social facilities for people living with HIV	↑ % of HIV+ clients taking a training course ↑ # of social events arranged by the peer support groups	Voluntary Sector Records
8	To increase access to government benefits for	↓ % of HIV+ clients who report difficulties accessing government	Voluntary Sector Records

	people living with HIV	benefits	
9	To increase income received from non-governmental hardship funds for people living with HIV	↑ total income received from non-governmental hardship funds ↑ # of annual recipients of hardship funds	Voluntary Sector Records
10	To improve coordination and collaboration between the social care, housing, health and voluntary sectors in the support of people living with HIV	↑ # of stakeholders who report improved coordination between stakeholders	Kernow HIV/AIDS Stakeholders Group Report

12. Issues Arising

In the course of developing this strategy, a number of statutory agency issues have arisen which are relevant to the provision of support for people living with HIV, but do not directly come under the remit of this strategy. These issues are highlighted here, as further work that needs to be done.

12.1 CCC HIV Policies

There currently appears to be only few HIV policies within CCC Department of Adult Social Care - those that do exist need to be updated with current thinking. The language in some policies also needs to be reviewed, as there is still reference to 'HIV disease'. There is also a staff policy statement on HIV infection, but it can only be obtained through contacting personnel. As this will be associated with disclosure.

12.2 Children's Strategy

Children's services have a number of (*old*) policies, however there appears to be no overall strategy or plan considering the support that children infected or affected by HIV need and hence how this can be provided by CCC (*and partners*).

13. Implementation Plan

13.1 Explanation Notes

The implementation plan below lays out the activities to be implemented, the time-frame (*for the 3 years from the beginning of this strategy and implementation*), the ‘main player’ and others involved, and also how it will be monitored that the activity has been completed. It will be finalised by the KHSG, along with agreement on the strategy as a whole.

Although, Kernow Positive Support (KPS) will have overall responsibility for implementation, the ‘main player’ indicates who will be primarily involved in taking on the activity in question.

In the plan, ‘front-line workers’ are those workers who deal directly with people infected or affected by HIV and offer support and advice. Examples are: the single contact point in community care (*i.e. the HIV-focused social workers*), the single contact point in housing within each of Cornwall’s District Councils and/or and specific link worker, who can represent all six District Councils with the county, the HIV/AIDS Community Nurses and staff at the GUM’s and the support workers/volunteers at KPS.

Abbreviations used:

CCC	Cornwall County Council.
GUM	Genito-urinary Medicine Departments - Truro/Derriford.
Hsg	Housing.
CVS	Cornwall Voluntary Services.
Vol	Voluntary Sector (KPS).
PCT	Cornwall Primary Care Trust.
TBC	To be confirmed.

13.2 The Implementation Plan

ACTIVITY	NOTES	TIMING (QUARTERS)												MAIN PLAYER	OTHERS INVOLVED	MONITORING	
		1	2	3	4	5	6	7	8	9	10	11	12				
1. TO IMPROVE ACCESS TO SOCIAL CARE SERVICES																	
1.1 Production and dissemination of social care information	<ul style="list-style-type: none"> • CCC produce • KHSG finalise 														CCC	All	- info produced - # of info disseminated
1.2 Development of a single contact point for all HIV+ service users, through recruitment of HIV-focused social workers	<ul style="list-style-type: none"> • Contact details to be shared with all stakeholders • Emphasis on confidentiality 														CCC	All	- Single contact point established - # of people accessing SCP
1.3 HIV-focused social worker trained/updated															Vol		- # of trainings attended
1.4 Assessment of needs of all HIV+ clients (plus carers & those affected by HIV) referred to CCC, by single contact point	<ul style="list-style-type: none"> • Care plan can focus on professional support if appropriate 														CCC	All	- # of HIV clients assessed
1.5 CCC social care staff trained on HIV issues	<ul style="list-style-type: none"> • Access officers to receive detailed training • Raise general awareness amongst staff 														Vol		- # of front-line workers trained - % of workers trained
1.6 Provision, and use of, community advocates	<ul style="list-style-type: none"> • Link with Mother Tongue? 														Vol	All	- # of advocates established - # of times advocates used
2. TO IMPROVE ACCESS TO APPROPRIATE HOUSING																	

		TIMING (QUARTERS)															
2.1 Production and dissemination of housing information	<ul style="list-style-type: none"> • CCC produce • KHSG finalise 														Hsg	All	<ul style="list-style-type: none"> - info produced - # of info disseminated
2.2 Development of single contact point for all HIV+ service users	<ul style="list-style-type: none"> • Contact details to be shared with all stakeholders • Emphasis on confidentiality 														Vol	All	<ul style="list-style-type: none"> - Single contact point established - # of people accessing SCP
2.3 Single contact point trained/updated														CCC/Vol		<ul style="list-style-type: none"> - # of trainings attended 	
2.4 All HIV+ clients referred to CCC supported by single contact point														CCC/Vol		<ul style="list-style-type: none"> - # of HIV clients support 	
2.5 CCC housing staff trained on HIV issues	<ul style="list-style-type: none"> • Access officers to receive detailed training • Raise general awareness amongst staff 													Vol		<ul style="list-style-type: none"> - # of front-line workers trained - % of workers trained 	
2.6 Provision, and use of, community advocates	<ul style="list-style-type: none"> • Link with Mother Tongue? 													CCC	All	<ul style="list-style-type: none"> - # of advocates established - # of times advocates used 	
3. TO IMPROVE ADHERENCE TO ANTI-RETROVIRAL THERAPY																	
3.1 Development & pilot of peer-led motivational and self-management programmes	<ul style="list-style-type: none"> • Contribution from ASG 													Vol	GUM	<ul style="list-style-type: none"> - programme established 	
3.2 Provision of self-management/peer-led motivational programmes														Vol		<ul style="list-style-type: none"> - # of users attending programmes 	

		TIMING (QUARTERS)														
3.3 Promotion of KPS's Peer Support opportunities	<ul style="list-style-type: none"> • Contribution from ASG 	■		■		■		■		■		■		Vol	All	- # of HIV clients attending programmes
3.4 Development & pilot of system to provide peer support at flashpoints of greatest need	<ul style="list-style-type: none"> • Contribution from ASG 	■	■	■										Vol	All	- system established
3.5 Provision of peer support at flashpoints of greatest need						■	■	■	■	■	■	■	■	Vol	All	- # of incidences supported
3.6 Dissemination of information on ART		■												GUM/ Vol	All	- # of info disseminated
3.7 Development of criteria and procedures for small fridge grants	<ul style="list-style-type: none"> • Funded from ASG 	■	■											CCC	All	- procedure developed
3.8 Provision of small grants fund	<ul style="list-style-type: none"> • Funded from ASG 			■	■	■	■	■	■	■	■	■	■	Vol		- # of grants given - value of grants given
4. TO REDUCE MOTHER-TO-CHILD TRANSMISSION OF HIV																
4.1 Provision of free formula milk to mothers on low income (& with no recourse to public funds)	<ul style="list-style-type: none"> • Funded from ASG • Cash or in-kind 	■	■	■	■	■	■	■	■	■	■	■	■	CCC		- # of mothers receiving milk
5. TO IMPROVE THE EMOTIONAL WELL-BEING OF PEOPLE LIVING WITH HIV																
5.1 Production and dissemination of Cornwall information on HIV-related services	<ul style="list-style-type: none"> • CCC produce • KHSF finalise • Update every 18 months 	■	■					■						Vol	All	- info produced - # of info disseminated

		TIMING (QUARTERS)															
5.2 Awareness raised amongst front-line staff of other available services and hence appropriate signposting of opportunities															All		- % of front-line staff attending awareness-raising sessions
5.3 Development of peer support groups for those infected with HIV	• Contribution from ASG														Vol		- # of groups established
5.4 Support & facilitation of peer groups															Vol		- # of clients attending groups
5.5 Development & pilot of system to provide flexible support e.g. floating support service															Vol	All	- system for floating service developed
5.6 Provision of flexible support															TBC		- # of clients supported
5.7 Development & pilot of system to provide professional counselling	• Service to be contracted out if necessary														Vol	All	- system for professional counselling developed
5.8 Provision of professional counselling															Vol/ CCC/ PCT	All	- # of clients supported
5.9 Development through funding of a Cornwall focal point for everyone infected or affected by HIV/AIDS	• Could external funding be found? - see 6.3														CCC/ PCT	All	- focal point established
5.10 Provision of training to encourage and enable PLWHA to become 'Positive Speakers'	• Contribution from ASG														Vol		- # of clients attending training

		TIMING (QUARTERS)															
5.11 Facilitation of Positive Speakers to give talks to local groups, schools, and places of work and worship	<ul style="list-style-type: none"> Establish links with HIV & Sexual Health Promotion Team 														Vol		<ul style="list-style-type: none"> # of clients giving talks # of talks given
6. TO IMPROVE THE EMOTIONAL WELL-BEING OF CARERS AND FAMILY MEMBERS																	
6.1 Development of peer support groups for those affected by HIV	<ul style="list-style-type: none"> Contribution from ASG 														Vol		- # of groups established
6.2 Support & facilitation of peer groups															Vol		- # of carers attending groups
6.3 Development through funding of a Cornwall focal point for everyone infected or affected by HIV/AIDS	<ul style="list-style-type: none"> Could external funding be found? - see 5.6 														CCC/PCT	All	- focal point established
6.4 Dissemination of information on services (<i>both statutory and voluntary</i>) available to carers, and the opportunities for flexible respite care															CCC/Vol	All	- # of info disseminated
7. TO INCREASE THE EMPLOYMENT RATE																	
7.1 Provision of practical advice on CVs, application forms and interviews															Vol		- # of clients receiving advice
7.2 Research into skills-based training and motivational courses															CCC	Vol	- information collected

		TIMING (QUARTERS)														
7.3 Provision of information & signposting to opportunities for skills-based training and motivational courses														Vol		- # of info disseminated - # of users signposted
7.4 Research into, and establishment of links with, voluntary working opportunities	• Link with CVS?													Vol		- information collected - link with CVS established
7.5 Provision of information & signposting to opportunities for voluntary working														Vol		- # of info disseminated - # of users signposted
7.6 Recruitment of worker to support clients in accessing and retaining employment	• Contribution from ASG													CCC		- worker recruited - # of users supported
8. TO INCREASE ACCESS TO EDUCATION, LEISURE AND SOCIAL FACILITIES																
8.1 Dissemination of information on education, leisure and social facilities														CCC		- # of info disseminated
8.2 Facilitation and encouragement of social and leisure events for peer support groups	• Contribution from ASG													Vol		- # of events occurring - # of users involved
8.3 Research into motivational courses and programmes which promote option appraisal & skills development														CCC	Vol	- information collected

		TIMING (QUARTERS)															
8.4 Provision of information & signposting to opportunities for motivational courses and programmes which promote option appraisal & skills development															Vol		- # of info disseminated - # of users signposted
8.5 Provision of practical advice on course application forms and interviews															Vol		- # of clients receiving advice
8.6 Recruitment of worker to support clients in accessing and attending education, leisure and social facilities	<ul style="list-style-type: none"> • Contribution from ASG 														CCC		- worker recruited - # of users supported
9. TO INCREASE ACCESS TO GOVERNMENT BENEFITS																	
9.1 Dissemination of information on the Government's welfare and benefit systems, eligibility criteria and application methods	<ul style="list-style-type: none"> • Including Welfare Food Scheme 														Vol	CCC	- # of info disseminated
9.2 Provision of advice / support in completing relevant claim forms															Vol		- # of clients receiving advice
9.3 Provision, and use of, community advocates	<ul style="list-style-type: none"> • Link with Mother Tongue? 														Vol	All	- # of advocates established - # of times advocates used

		TIMING (QUARTERS)															
9.4 Front-line workers trained on immigration issues	<ul style="list-style-type: none"> • IAS 2-day training 														CCC	All	- # of front-line workers trained
9.5 Provision of advice and support on immigration issues															Vol	All	- # of clients receiving advice
10. TO INCREASE INCOME RECEIVED FROM NON-GOVERNMENTAL HARDSHIP FUNDS																	
10.1 Investigation of alternative funding sources for hardship grants	<ul style="list-style-type: none"> • Consider submitting funding bid 														Vol		- information collected - bid submitted?
10.2 Dissemination of information on known hardship funds															Vol	All	- # of info disseminated
10.3 Provision of advice / support in completing application forms															Vol		- # of clients receiving advice
11. TO IMPROVE COORDINATION AND COLLABORATION BETWEEN STAKEHOLDERS																	
11.1 Establishment of HIV/AIDS Kernow Stakeholders Group, to share information, monitor strategy implementation and coordinate services															Vol	All	- KHSG meeting quarterly
11.2 Strategy, implementation plan and monitoring arrangements agreed by all stakeholders															All		- implementation plan followed

		TIMING (QUARTERS)														
11.3 Front-line workers spend at least 0.5 day work shadowing and learning about each other's organisation	<ul style="list-style-type: none"> New front-line staff to also visit organisations 													All		- % of visits undertaken
11.4 3-year Service Level Agreements developed between CCC/PCT and the voluntary sector, detailing activities agreed in this strategy														CCC/ PCT	Vol	- SLAs developed

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