

Sexual Health IAG NEWSLETTER

Independent Advisory Group
on Sexual Health and HIV



The Newsletter of the Independent Advisory Group on Sexual Health and HIV
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Welcome to the latest newsletter from the Independent Advisory Group on Sexual Health and HIV.



HIV and AIDS has been a significant healthcare challenge for the last quarter of the century. We have seen enormous improvements in treatment which mean that HIV and AIDS - instead of being a death sentence - is managed as a chronic condition. This is an astonishing achievement.

Yet figures for sexually transmitted infections over the last 10 years show a worrying increase. Dr Evans, in his piece on STIs, points out that annual new diagnoses of HIV have risen from 2764 in 1997 to 7093 in 2006. This large increase was mainly made among people who were from, or who had acquired their infection in, Africa as well as ongoing high number of diagnoses among men who have sex with men (MSM). Studies around the re-emergence of syphilis and increase in LGV diagnosis show a correlation between an increase in STIs and HIV in certain groups which indicates risky behaviours. The number of people living with HIV and accessing care in England, Wales and N Ireland has risen from 13,947 in 1996 to 45,344 in 2005.

It is estimated that there are approximately 64,000 people with HIV infection in the UK and of these, 20,000 individuals are unaware of their infections, say Dr French and Professor Kinghorn. This is a compelling reason for improving testing and diagnosis of HIV and AIDS to help curb onward transmission.

To do that, our society must be better able to address issues relating to the normalisation of HIV, AIDS and sexually transmitted infections in general. This newsletter is a snapshot review of where we are in terms of HIV and AIDS

from the perspective of treatment, testing, prevention and promotion, care and social care and policy and legal issues.

Written by experts in the field of HIV and AIDS, the common theme of the newsletter is that there is a great deal of work to be done in clarifying the position of HIV and AIDS within health, social care and the legal system.

The IAG is holding a seminar this autumn to provide an opportunity for experts to debate and discuss the relative strengths and weaknesses of the current national strategy for sexual health and HIV and indicate areas where the strategy and related areas could be updated and improved for the benefit of people living with and vulnerable to HIV infection. Recommendations to Government will be produced from that seminar.

I would like to extend my most grateful thanks to all the contributors to this newsletter who have provided such authoritative and informative articles.

Baroness Joyce Gould

Chair

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Recent trends in sexually transmitted infections in the UK



Dr Barry Evans, consultant epidemiologist, Health Protection Agency

The 10 years from 1997 to 2006 saw an increase in STI diagnoses made in genitourinary medicine (GUM) clinics. New diagnoses rose by 63% (from 231 185 to 376 508), whereas other STI diagnoses increased by 84% (from 133 371 to 244 804).

Between 2005 and 2006 new STI diagnoses rose by 2% (from 368 341 to 376 508), and other STI diagnoses rose by 3% (from 238 204 to 244 804). Although new STI diagnoses made by GUM clinics have, in general, risen, rates vary substantially between conditions. Diagnoses of gonorrhoea and syphilis fell by 1%, whereas diagnoses of chlamydia, genital herpes and genital warts rose by 4%, 9% and 3% respectively.

Age specific rates in most of the major STIs were highest in 16-19 year old women and 20-24 year old men. In men who have sex with men, numbers of diagnoses have risen consistently in all the major diagnoses over the last 10 years; syphilis from 19 to 1417; gonorrhoea from 1954 to 4524; chlamydia from 387 to 3239, genital herpes (first attack) from 337 to 604, and genital warts (first attack) from 1639 to 2691.

Chlamydia trachomatis, with 113 585 diagnoses in 2006, remains the most commonly diagnosed bacterial sexually transmitted infection in UK genitourinary medicine clinics. The National Chlamydial Screening Programme (NCSP), which has detected a positivity of 10% amongst both men and women aged 16 to 25 years, has shown that there is a substantial reservoir of genital chlamydial infection in young people attending healthcare and non-healthcare settings outside GUM services.

The sexual health in men who have sex with men and young people has not improved since the late 1990s. Investigation of the re-emergence of syphilis using detailed patient based surveillance has revealed a complex association between syphilis and HIV and high risk sexual behaviour. Enhanced surveillance undertaken as part of the outbreak of lymphogranuloma venereum provided further evidence that HIV, LGV and other STIs are linked, and that greatest risk of infection was associated with care groups reporting high risk lifestyles.

Annual new diagnoses of HIV have risen from 2764 in 1997 to 7093 such diagnoses made in 2006. This large increase was mainly due to the increase in people who were from or had acquired their infection in Africa as well as well as ongoing high number of diagnoses among men who have sex with men. Deaths in HIV infected people have fallen in the same 10 year period from 749 in 1997 to 497 in 2006. The number of people living with HIV and accessing care in England, Wales and N Ireland has risen from 13,947 in 1996 to 45,344 in 2005 (2006 prevalence data are not yet available so the 10 year period is for a year earlier than other data quoted).

Recent trends in the epidemiology of STIs and HIV will be presented in the 2007 HIV and STI Annual Report to be published by the Health Protection Agency in late November (www.hpa.org.uk). Detailed information by sex and age group and longer term historical trends are also posted on this website.

Diagnosing HIV on the Ground



Dr Patrick French, Consultant in GUM, Camden PCT

Professor George Kinghorn, Clinical Director for Communicable Diseases, Sheffield Teaching Hospital NHS Foundation Trust

The availability of highly active antiretroviral therapy (HAART) has transformed lives of people with HIV infection. Although not a cure, it has changed HIV from a progressive, often fatal, disease to a chronic medical condition.

Worldwide, WHO estimates that for each person currently starting HAART, another 6 people have acquired HIV¹. There are now compelling reasons in terms of accessing HIV treatment and reducing onward transmission for individuals to know their HIV status. This has led to a re-evaluation of HIV testing policy and practice in the UK.

It is estimated that there are approximately 64,000 people with HIV infection in the UK and of these, 20,000 individuals are unaware of their infections.² Most people with HIV are diagnosed in genitourinary (GUM) clinics where the uptake of testing among attendees has progressively increased over the last 10 years. Although over 80% of attendees accept testing, up to 30 % of heterosexuals with HIV and 40% of gay men with HIV remain undiagnosed after their visit. This has led to a rethink of HIV testing practice.

Whilst testing should not be done without patient consent, it is vital that the threshold at which testing is offered is lowered and that HIV testing is encouraged and normalised as routine care. This change is reflected in recent guidelines³.

Some individuals with HIV infection may not access GUM services. Guidelines now recommend increased HIV testing in both hospital in-patient and primary care

(general practice) settings^{4,5}

Finally, the role of HIV testing in non-medical settings is being explored and this has been facilitated by rapid point of care testing.

The effectiveness of these strategies is likely to be dependent on the prevalence of HIV in particular communities. It is essential that confirmatory testing and rapid referral into HIV treatment care services is available for all who have positive screening tests.

Undoubtedly HAART has changed the policy and practice related to HIV testing. It is hoped that these new testing strategies changes will significantly reduce the number of undiagnosed HIV positive people in the UK thereby helping to reduce premature deaths and prevent transmission.

1.WHO,2007. <http://www.who.int/mediacentre/news/releases/2007/pr24/en/index.html>

2.HPA,2006. <http://www.hpa.org.uk/publications/PublicationDisplay.asp?PublicationID=55>

3.BASHH,2006. http://www.bashh.org/guidelines/2006/hiv_testing_june06.pdf.

4.RCP,2005. <http://www.rcplondon.ac.uk/pubs/contents/62129e7d-97fb-496c-85de-038c4d9dcf47.pdf>

5.MedFASH,2005. http://www.medfash.org.uk/publications/documents/HIV_in_Primary_Care.pdf

HIV Prevention

– what works?



Professor Jonathan Elford, City University, London

A number of researchers have recently conducted systematic reviews to answer the question “HIV prevention, what works?” Systematic reviews synthesise the results of different studies and present an overall summary of their findings. Concerning the question “What works?” the most convincing evidence comes from randomised controlled trials, where one group of people receives an intervention and another group does not.

A number of randomised controlled trials have been conducted among people living with HIV to examine the effect of behavioural interventions. Overall, they found that behavioural interventions among people living with HIV can reduce the likelihood of unprotected sex by up to 40%.

Several key features seemed to characterise successful behavioural interventions among people living with HIV. Successful interventions were based on behavioural theory and were designed to change specific risk behaviours. In addition they were delivered by health care providers or counsellors to individual patients in settings where they received routine treatment and care. They also addressed a range of issues related to mental health, adherence to medication and HIV risk behaviours.

Other randomised controlled trials have been conducted among people who are at risk of HIV but who are not necessarily infected, such as gay men. These trials found that behavioural interventions can reduce the proportion of gay men

engaging in unprotected anal intercourse by up to 23%. The most successful interventions among gay men promoted interpersonal skills and used a range of methods such as group discussion, lectures, role play and counselling.

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Most of the studies in the systematic reviews were conducted in the USA; relatively few behavioural interventions have been evaluated in randomised controlled trials in the UK. It is important to note that all these trials were able to examine efficacy (the effect of the intervention under ideal conditions) rather than effectiveness (the effect in the “real world” in large populations). Nonetheless, the systematic reviews provide persuasive evidence that HIV prevention can and does work.

References

Crepaz N, Lyles CM, Wolitski RJ et al. Do prevention interventions reduce HIV risk behaviors among people living with HIV? A meta-analytic review of controlled trials. *AIDS* 2006;20:143-157

Herbst JH, Sherba RT, Crepaz N, et al. A meta-analytic review of HIV behavioral interventions for reducing sexual risk behavior of men who have sex with men. *Journal of AIDS* 2005;39:228-241



HIV Treatment

in the Developed World – a Success Story

Professor Brian Gazzard, Chelsea and Westminster Hospital

One of the most important developments in medicine in the 20th century has been the successful treatment of HIV infection in the industrialised world.

The virus was first discovered in 1983 and this was followed by an explosion of scientific research, led by the pharmaceutical companies which provided a deep understanding of the viral life cycle. We now know more about this life cycle than that of any other animal or plant virus and this is led directly to the development of more than 20 drugs which interfere with viral replication and can be used to treat HIV infection.

When I started treating patients in the early 1980's there was no treatment and we would talk about quality of life issues and dying with dignity. Now with an HIV positive patient it is realistic to suggest that he/she will live a relatively normal life span providing that they take drugs when asked to do so.

The search for new HIV drugs continues and continues to be successful. Thus, in the last two or three years the prognosis for "salvage" patients has been revolutionised. This rather distasteful term was used to describe a group of patients in whom the virus had acquired mutations against all presently available



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new drugs. Most people arrived in this situation because to save their life they were given suboptimal therapy when this was all that was available. A smaller proportion also were unable to tolerate taking the drugs on a regular basis and developed resistance because of this. The ability to treat these people effectively has been based upon two sorts of drugs. Some drugs such as Darunavir were deliberately developed to be active against viruses which were resistant to other protease inhibitors. Other pharmaceutical companies tackled new drugs

attacking new targets within the viral life cycle. It is likely that the most successful of these will be an inhibitor of the integrase enzyme. While in its early days these drugs are now quite widely available and appear to be highly potent and free of the side effects that we normally associate with HIV treatment.

The precise way in which these new drugs will be used to treat HIV infection in the future remains determined, obviously the present sequence of treatment is a historical accident as drugs were used in the order in which they became available rather than in any more logical fashion. Large scale “strategic studies” will be required to know whether or not it would be better to give this range of drugs in different combinations and in different orders.

What is the future?

Many individuals with HIV infection would like to hope that their immune responses could be stimulated to control HIV replication more effectively without the use of antiretroviral compounds. While between 5-10% of people do have an immune system that appears to be able to do this my belief is that as this immunity is largely based upon the genetics of these individuals it is unlikely that we can simulate this in a wider range of individuals using immunomodulations, however the search continues.

Obviously the holy grail of HIV research would be to eradicate the virus so that people could stop treatment after a few months or years. The reason that

treatment at present has to be lifelong is that the virus is irreversibly incorporated into long lived cells which only replicate very occasionally. As it is during the point of replication that antiviral agents are able to destroy the virus, the only way in which cure could occur is if we could persuade all these long lived cells to divide over quite a short period when the patient is taking drugs. The search for agents that might stimulate viral replication from these long lived cells continues.

It is essential that clinicians continue to be vigilant about unexpected side effects that may be related to the present drug regimens. As part of the world community we must also take on the responsibility for explaining that the prognosis of HIV infection can be revolutionised by treatment but less than 10% of those eligible for treatment across the world actually get it. This results in enormous social disruption in parts of Africa, the generation of millions of orphans and premature death for many. Feasible sums of money such as 10 billion dollars a year given to the global fund would transform the whole healthcare infrastructure of the poorest countries and will allow antiretroviral treatment to be widely applied.

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What happens to a woman with HIV needing Social Care?

Elisabeth Crafer, Chief Executive, Positively Women

The HIV sector has been shrinking for some years and HIV service commissioning has shifted from a specialist to a generic model, with emphasis on local services for local people. The voluntary sector organisations that have survived this change are beginning to restrict services to the residents of boroughs and PCTs that fund their services, and to refer people from non-funding boroughs to the local services.

So how do these services cope with the complex needs of the average Positively Women client, an asylum seeker who has experienced violence, torture, rape and in some cases has become pregnant as a result of rape? HIV is often low down on the priorities list.

Peer case workers at Positively Women support HIV positive women into the appropriate pathways to maximise their health and wellbeing while waiting for decisions on their applications to remain in the UK.

But all too often the social care system finds a woman without settled immigration status something of a puzzle and has little joined-up practice on which to draw to make a successful intervention.

The pathways to care are met by 'we don't deal with that,' or 'if you don't have the right to stay here we can't help,' as social care agencies struggle to apply complex directions on appropriate action for people who have applied for asylum, who are appealing against a decision on asylum or who have failed in their application.

The regulations often appear to lack a cohesive approach, and the level of social care response varies from borough to borough. In an overstretched system, there is

an understandable reluctance to allocate a social worker based on asylum and HIV status alone. The need for safeguarding children and identifying children at risk should change the level of service, but in our experience this is not the case.

Not acknowledging that HIV is an unpredictable illness in someone who presents late or starts treatment late, results in interventions that are crisis driven involving the physical or mental health of the asylum seeker, rather than a measured response to what may be the driving issues of domestic violence or child safety, housing or welfare. In these instances the Red Cross or Asylum Aid are asked to act as advocates to ensure rights are correctly upheld.

So how best do we care for the most vulnerable in our society and minimise the likelihood of onward transmission of HIV which is very expensive in social and financial terms?

To ensure accurate interventions and reduce crises we need to equip social care staff with a deeper understanding of HIV and asylum issues including clarity on welfare and treatment rights. Creating an agreed referral system among social care and voluntary agencies would maximise access to appropriate health and social care.

For those granted right to remain in the UK an 'entry' level model of support on how to access services would maximise health, wellbeing and ultimately, economic independence.



Policy & Legal Issues – update

Lisa Power, Corporate Head of Policy & Public Affairs, Terrence Higgins Trust

There are currently a range of policy matters of active concern in the HIV sector.

Chief amongst them are:

Public Health

The DH ‘Review of parts 2, 5 and 6 of the Public Health (Control of Disease) Act 1984’ which relates to powers and penalties for public health infringements and nuisances, from avian flu to badly kept food premises, and to which many responded is likely to be published in late September. Concerns focused on the vagueness of the drafting and the movement of important powers out of primary legislation, which could potentially lead to poor decisions in managing diagnosis and control of infectious diseases.

Charging for NHS services

An internal review by the DH and the Home Office about charging regulations in the NHS is expected to make recommendations shortly. There are a range of possible changes, from clarifying access to include categories of migrants who receive all other benefits, to extending charging to primary care. It is to be hoped that IAG and other interested parties in sexual health will also be consulted since the regulations have a profound and damaging effect upon a minority of people with HIV in the UK.

Prosecutions

The Crown Prosecution Service consultation on guidelines for prosecutions for reckless transmission of sexually transmitted infections continues. The CPS, having consulted with a small group of clinicians through EAGA, has produced a “final draft” policy for comment by their Advisory Group members only by 25th September. This draft introduces a new concern by using language which greatly widens the range of people who might be subject to investigation because they “should have known” they had HIV or had been at risk of it. It also introduces the concept of expert doctors who will advise the prosecution on whether to pursue individual cases.

A reckless transmission case in Blackpool this February was dismissed by the judge in response to recent advances in understanding the use of scientific evidence. It is now clear that virus samples, while they can exclude a suspect, cannot be used alone as proof of source of infection.

In addition, both THT and NAT are working towards improving policing practice (THT) and policy (NAT) in this area through projects with ACPO. Information on past investigations which might provide evidence of either good or poor police practice is currently needed by THT.



The Profile of HIV

and the Fundraising Climate

Robin Brady, CEO Crusaid for the AIDS Funders' Forum

Over the past 20-odd years the face of HIV has changed and stayed the same. This might seem a contradiction, but the facts bear this out. Gay men were once the focus for both infections and services. The focus shifted to include the African communities. Yet new infections occurring in the UK continue to show that the gay community most affected. This tension between two very different user groups and their specific needs continues to drive the way HIV services are designed and commissioned in the UK.

When we review new diagnoses in the UK, there has been a decline in the number of infections happening abroad, but a steady annual increase in those occurring in the UK. Annual HIV-related deaths remain constant at about 7% of the annual infection rate. This disparity means that people living with HIV will continue to become a growing service user group with specific needs that must be met.

The complexities of living with HIV are likely to remain an area of debate and discussion until there is agreement UK-wide on where HIV is to be placed and how service users are supported.

This continuing lack of clarity makes funding HIV very difficult. Changing NHS priorities (that never include HIV) mean a constantly shifting landscape for service providing charities and organisations. The absence of HIV as a UK political priority

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(as opposed to HIV and AIDS in the developing world) also means that fundraising for HIV services remains a difficult, niche activity. The constraints on voluntary funding and disappearing public funds mean that HIV organisations have to develop successful entrepreneurial activities or diversify services in order to continue to support people living with HIV. This runs the risk of reducing further the focus on HIV in the UK.



The Needs of People Living with HIV

Christopher Woolls, Director, The Cara Trust and service user representative on the IAG

As we move into a period when HIV, for some, seems to be becoming a long-term manageable condition, it is interesting to reflect on the sheer diversity of needs that have arisen for people living with the virus.

For the lucky few, needs are mainly located around easy access to top-class clinical services, with visits to the clinician being moved out to 6 monthly or even once-a-year, depending on clinical need, and with medications available by home-delivery. Able to go to work and with little need for support services, these people represent the gold-standard 'long-term manageable condition' that many social care professionals now think is the common experience of people with HIV.

However, this is not the experience of the majority.

Growing old with HIV is a relatively new reality and is throwing up a wide range of needs, from lack of pensions, isolation, and dealing with the long-term effect of pretty toxic medications, to having to think all over again about disclosure issues in relation to care homes and social care staff. This at a time when specialist social care teams have virtually all been 'mainstreamed'.

Stigma and discrimination continue to have a huge impact – one that is getting worse due to the impact of lurid headlines about prosecutions, and which is also affecting how people choose to get treated for STIs, with the fear that

confidentiality no-longer applies to them. The sense of joint responsibility for safer sex now seems to be dissipating pretty fast as the law invades the bedroom.

Stigma and discrimination also impact on mothers that are unable to breast-feed which can be read as a 'sign' of HIV in some communities.

There continue to be a wide range of needs around housing, poverty and other social-exclusion issues. None of them have gone away, they have just slipped down, or off, the agenda as HIV is 'normalised or mainstreamed'.

Perhaps what people with HIV really need is recognition that they are as diverse as their needs, and that neither are going away.

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