The UK Coalition of People Living with HIV and AIDS (UKC) is the national organisation of people with HIV infection, a registered charity and not for profit limited company.

The aims of the UKC are to enable the diverse voices of people living with HIV and AIDS to be heard with a view to influence change.

The UKC has a membership base geographically spread across the United Kingdom, and publishes the national HIV and Sexual Health magazine Positive Nation.

In preparing this response, we asked for individuals’ views via our website and internet discussion board, with partner agencies, our staff and volunteers, and through other contacts with plwha. Individuals’ responses were minimal which, perhaps, reflects a mixture of apathy and unwillingness of people living with HIV and AIDS (plwha) to take part in such consultations, particularly those on strategic issue of this nature. We also see this as evidence that very few plwha feel equipped to deal with issues at this level and that there is little in the way of meaningful involvement of plwha in the development of strategies and policies.

This response has been compiled by people living with HIV infection. It represents the views of those that contributed to it, but must not be cited as a definitive view of plwha – we respect people’s rights to differing views and, where these are made known to us, we will highlight this diversity of opinion.

We have also included some of the lessons learned in our position as the accountable body for London’s pioneering partnership “Positive Futures”, which built on the UKC’s pilot “Back to Work Project”, looking at the developmental and employment support needs of plwha in London.

We are very aware that the HIV epidemic in the UK and in London is a mirror of the situation in the rest of the world. Globalisation and migration mean that we cannot deal with London in isolation; we must as civil society acknowledge that whatever we do here will also impact elsewhere. Whilst we cannot expect the UK, or London, to solve the global crisis of lack of access to HIV treatments, certain of our activities in this country are effectively a denial of human rights to people who have arrived here in search of better lives, often in the face of persecution or war.

We subscribe to the “social model” of disability and are encouraged that the Government has promised steps to amend disability discrimination law to include HIV infection as a disability from the point of diagnosis, reflecting the potentially disabling effects of discrimination and stigma that accompany this disease, rather than any physical impairment that late stage HIV disease can bring.
Response to Questions

Section A: The Prevalence of HIV in London and Future Trends

We feel that this section is best addressed by epidemiologists and public health experts and have minimal contribution to make here.

Our understanding of the situation at present is that 25,203 people infected with HIV were seen for care in the UK in 2001\(^1\), to this we add a conservative 10% who knew they were diagnosed but didn’t present for care in that year, which is 27,723. The number of known diagnoses for 2002 was 5600, plus 2037 in 2003 so far\(^2\). That gives 35,360. Add to this around 7% of cases reported late, bringing the total to 37,835 which is the approximate total number of people diagnosed with HIV in the UK. Add to this one third more to reflect the people who are undiagnosed but are infected, which brings the total plwha in the UK to 50,447 although this total is probably an underestimate as around 50% of heterosexual infection is believed to be undiagnosed.

Around 60-65% of plwha live, work or are treated in London: **30,268 people**.

Of the UK’s estimated 1000 children and young people infected with HIV, around 750 are in London. HIV in children is different than in adults, more complex, affects the nervous system more and the children end up exposed to considerable drug therapy with the associated drug interactions and side effects.

Section B: Commissioning

We know that appropriate members of the NHS London Specialised Commissioning Group will make a significant contribution to this section. We shall confine our submission to what patients “see” of the process and what, if any involvement they have within it.

1. How are HIV treatment services and HIV prevention services currently commissioned?

The perception of the commissioning process overall is that “Shifting the Balance of Power” alongside mainstreaming of HIV Treatment and Care budgets made things more difficult. Much of the previous expertise in HIV commissioning has been diluted and, in many areas lost due to the devolution of functions from the former Health Authorities to a far larger number of Primary Care Trusts.

Some PCTs appear reluctant to invest time or resources in HIV services in the absence of a National Service Framework or government targets by which they are judged on performance. This is understandable given the immense challenges PCTs face, but is unacceptable where it means that patients suffer, either by being denied proper treatment for HIV infection or where prevention initiatives are curtailed through lack of investment. In

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1 PHLS, SOPHID 2001
2 PHLS Quarterly Surveillance Tables
areas of higher prevalence (noting that the UK is not a “high” prevalence country for HIV infection) more attention is being given to HIV as an issue.

The consortium commissioning arrangements have probably helped stabilise the position in London at a time when PCTs across the country have struggled to come to terms with their new responsibilities for sexual health and HIV. Strategically, the Government has placed HIV within the wider sexual health arena. It therefore becomes impossible to discuss HIV services without including other sexual health issues, including the rapid decline in the nation’s sexual health and sexual health services that currently “appear ill-equipped to deal with the crisis that confronts them”\(^3\).

The problem, particularly for African communities, of lumping HIV in with sexual health is that this reinforces cultural stigmatisation of sex per se, adding to the discrimination burden carried by otherwise “ordinary”, “normal”, “upright” members of London’s multicultural society.

What is clear is that there remains a “postcode lottery” with disparity in respect of some health care, and most certainly with social care provision for plwha in London. There are no standards of quality involved in the specialist commissioning process which has concentrated almost exclusively on financing service provision. There is also little or no linkage between specialist commissioning and social or primary care. HIV services allegedly have pan-London planning, but local procurement: instead of one lead PCT, there are five.

There is confusion and a lack of transparency over who commissions what and where. The process is a secret one and, until most recently, all but impervious to outside influence. There may be some commitment to involving stakeholders, including patients, but there has been little activity in this area at a strategic and ongoing level. The UKC suggested this more than five years ago, and under different commissioning arrangements, yet there has been little willingness to inform or engage with the diverse communities affected by the commissioning process.

For example, there is supposedly a split between purchasing arrangements for services either at pan-London or sectoral level. We understand that HIV is the only specialised condition which is commissioned in a “hybrid” manner: at London level, at sector level and at PCT level. In our view this only adds to the confusion and wastes resources on excessive bureaucracy and repetition. By failing to engage properly with plwha, these wasteful processes are not properly providing for the needs of the diverse communities affected by HIV.

In South London, some (predominantly support / social care) services are purchased across the board, which suggests that having two sectors in South London is actually one too many, whereas other services are purchased on a borough by borough basis, suggesting there is insufficient cooperation or trust between health and social care commissioning bodies to come up with a unified approach. This ramshackle approach makes it difficult to identify what or where the processes are, and effectively excludes people from having any input.

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\(^3\) Select Committee on Health, Third Report
In our submission to the original draft of the London HIV Strategy\(^4\), we put forward the view that the draft not gone far enough, that five sectors across London may well be three (even four) too many:

“The sectoral approach may lead to some reduction in overhead bureaucracy, but not if it continues to link in to a system of local authority service provision 33 times over. In fact, five sectors is probably three too many, but where is the radical approach to overhauling a system that, whilst it hasn’t really had time to bed in, is being threatened by the introduction of PCTs at a time when sustaining the sector system is probably beyond the budgets available?”\(^5\)

Services for children are commissioned on a “north and south” basis, whilst those for the parents on a mix of London-wide or five sector basis. There are difficulties for parents organising their own healthcare, plus that of their children, and potentially negotiating two different bureaucracies. Luckily, this is recognised by providers places like the Greenway Centre at Newham General Hospital where clinicians and staff strive to deliver holistic family services.

There are also considerable overlaps with strategies in the wider sexual health and teenage unwanted pregnancy areas which are coordinated at PCT level. This probably introduces conflict and waste of resources, eg, promoting condom use is high profile within HIV prevention, yet evidence given to the Health Select Committee appears to point to a deprioritisation of contraception in respect of unwanted pregnancy.

PCTs have had trouble coming to terms with their ability to deal with sexual health issues: repeatedly PCTs ask to be told what to do at a time when the Department of Health has drastically reducing the amount of central dictat.

In the absence of centrally imposed targets, it is not surprising to hear that NHS managers pay less regard to HIV and sexual health services while concentrating on reducing waiting lists or trolley waits in Accident and Emergency Departments.

Review of HIV/AIDS Commissioning Arrangements

We are aware of the current review and are meeting with the London Specialised Commissioning Group to discuss how this can be publicised and how people can contribute to the debate. We are cautiously optimistic that the review will make changes for the better.

\(^4\) “Modernising HIV Services In London”, Camden & Islington Health Authority consultation paper, November 2001

2 Are the allocated resources adequate for the needs of HIV services across the capital?

In our view the answer is “no”, particularly when one takes into consideration the burden under which Genito Urinary Medicine clinics are working and around which most HIV clinical service provision is organised.

With sexual health services in crisis, increasing numbers of people diagnosed with HIV infection, the cost of treatment and care is a burden on NHS resources. However, as a proportion of the total cost of the NHS, HIV represents a small and cost effective percentage of health spending.

Treatment allows many people the opportunity to focus on living, working and contributing to society. Treatment is also a good HIV prevention tool, reduces infectiveness and thus contributes to future savings. Treatment is keeping alive some people with very complex support needs that may well not be directly related to their HIV infection, i.e., they would have had these needs anyway. Links between HIV and other generic services are not always in place to cater for complex situations, people with severe mental health problems, the homeless or people with chaotic lifestyles.

Whilst attempts to “mainstream” HIV are welcomed by plwha who are confident of their status, it has to be said that HIV is “special” and until society ceases to discriminate against people on the basis of HIV infection, it will remain that way. The challenge then is to provide services in HIV specific ways, but from within mainstream provision.

Pressures on providing treatment have put care and support services under threat. A number of approaches have been taken to rationalising the way that limited resources are used to provide community support services, predominantly using voluntary sector provider organisations. There has consistently been a lack of investment in contribution to organisational development which has left smaller organisations particularly at risk during rationalisation exercises and the emergence of one major service provider scooping up a raft of contracts and the demise of a number of the smaller providers which were widely regarded by plwha.

Whilst there is no doubting that there were too many HIV service organisations, there have been some spectacular collapses of organisations that would, anywhere else, have been central to designing a bottom up programme of peer support networks which, particularly in north London, are now missing from the equation.

- Body Positive London was one of the first of these to collapse under the financial strain of meeting the requirements of the then commissioning regime, being unable to cover the costs of a central London service base having been forced to move there after many years in more modest premises in west London. This was in 2000 just after the organisation qualified as a provider of “Millennium Products”; swiftly followed by the closed sign.

- A potential solution, identified by commissioners in South East London, was the proposal to merge neighbouring organisations in order to reduce management overhead costs and preserve service delivery in the area. However, the organisations involved were diametrically different in style and approach. On the one hand, the Landmark in Tulse Hill was a benevolent organisation offering services for
plwha, whilst on the other the Positive Place in Deptford was [then] an organisation of
people with HIV that provided services too. The differences in approach were
irreconcilable, thus enforced merger could not proceed. The Landmark was absorbed
by the Terrence Higgins Trust, while Positive Place has become the provider of peer
support services across South London.

• Most recently, the major service provider for Black communities, Blackliners, has also
closed in financial difficulties. This leaves a vacuum not only in social care provision,
but in prevention initiatives that target the African and, increasingly importantly the
Afro Caribbean communities.

This destabilisation has made it incredibly difficult to construct partnership approaches to
London-wide problems. A particularly successful example here would be Positive Futures, a
unique partnership of organisations that got together to take forward the pioneering work of
the UKC in the field of “Back to Work” options for plwha. Of the original partners, Body
Positive and the FACTS Centre (formerly in north London) both closed down, while the then
London Lighthouse merged with the Terrence Higgins Trust. All this was happening at the
same time as the original partner organisations (the UKC, Positively Women, and the Globe
Centre) were attempting (successfully) to achieve large amounts of mainstream funding to
invest in the future employability of plwha in London. (See also our comments in response
to Section D)

No doubt some of the organisational chaos during this period was caused through naivety,
but we contend that the commissioners of services played a big role by failing to provide
organisational development support over many years, by “wild card” inclusions within
competitive tendering arrangements⁶, introducing tendering processes that few
organisations had any experience of participating in, and by organisations following the
competitive lead and fiercely protecting their “turf” and failing to grasp the potential of
partnership working.

Competitors working in partnership has been a difficult, yet fruitful, arrangement for the
plwha that Positive Futures has provided services to. However, the downside has been that
organisations have had to choose whether to apply for funding as part of the partnership or
in their own right. For the lead agency, the UKC, this has meant that our apparent income
and expenditure has grown exponentially, yet at the same time we are constrained in where
we can obtain funds for other, non-PF, core and project funding.

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⁶ An example here would be the inclusion of Community Legal Service accreditation within tender arrangements for
advice and advocacy services when only one of the potential tender candidates already held that accreditation.
Is there a need for pan-London co-ordination and funding of HIV services?

In our view the majority of HIV health and social care services should be co-ordinated on a pan-London basis. Even if there were one regional specialist commissioning department for the NHS, there would be difficulties liaising with 33 local authorities on the provision of social care. It may be easier for the current sectors to form bonds with smaller numbers of local authorities, but even they cannot always agree on the best ways to provide HIV specific social care services.

All people with HIV have social care needs. It is the complexity of those needs that will decide the individual’s eligibility for care management.

In short we advocate—

- Integration of health and social care commissioning to an agreed set of pan-London standards regardless of authority of residence, and meaningful involvement of people with HIV within these processes
- Improved quality of local authority interventions through working to agreed standards
- Better integration of care management, or access to initial assessment, within clinical settings
- Improved co-operation between care management and other parts of local authorities
- Easy access to peer support services or networks for exchange of information, experiences, advice, on a whole range of issues faced by individuals (which may also feed into improving the involvement of pwHa in the design and delivery of services at least by having a readily available, if changing, group of people on hand to consult with). This would also assist in signposting individuals to other appropriate sources of support or information in a more holistic manner. This could also be considered a kind of “Expert Patient Programme” that pre-existed the Stamford University model.

Acute hospital care

At present, acute hospital care is broadly co-ordinated on a pan-London basis. With “open access”, despite residence based funding, patient mobility and choice leave PCTs with little control over how, or where, any money is spent on treatment and care. In practice, this means that pooled resources are used to smooth the flow of funds across London at the end of the financial year. This is reactive and hardly “commissioning”, the lack of adequate resources across London leading to a constant catch up exercise which stifles new development or service improvement. The Consortium arrangement is broadly a risk management / sharing exercise.

There are challenges in recovering the costs borne by London PCTs in treating patients commuting into London hospitals for treatment from outside, from as far afield as Nottingham and Plymouth and all points in between. Patients from outside London make the deliberate choice to be treated in what they see as centres of excellence and to access
doctors and treatments that may not be available in their nearest HIV clinic. Confidentiality makes it difficult for NHS Trusts to recover the costs from the home PCT, but with the move to residence based funding, that is where the money is. Patients who understand parts of the funding scenario are concerned that the home PCT will be given information that could identify them in order to justify payment for their treatment. This is particularly concerning to people in rural communities where everybody knows everyone else’s business, ergo, a funding request could lead to the disclosure of status of a plwha who would rather not have members of their local community aware of their HIV status.

The hospital services we have currently are those that developed organically in response to the emerging epidemic since the early eighties. Many have continued to develop in line with the changing epidemic and to reflect the needs of patients. We applaud our clinicians and hospital staff for their work in creating services that fit patients even before the NHS Plan which attempts to put patients at the centre of everything the NHS does. HIV services in the NHS offer some of the best quality of care available, far better than many other disease areas. The challenge to the NHS is to bring some of these other services up to the standard of HIV care, rather than diminish HIV standards in line with other areas.

Treatments offered, in the absence of any National Service Framework or guidance from the National Institute for Clinical Excellence, remain as suggested by the British HIV Association Guidelines. However, funding pressures in some areas/hospitals/PCTs mean that changes to therapies are not always delivered on the basis of need, but on the availability of funding. One of the biggest challenges in this area is the introduction of a new class of treatment, “fusion inhibitors”, which appear to offer hope for patients for whom all other drug options and combinations have failed. The cost of this treatment is far more than any other HIV treatment currently available. We know that, even in the biggest HIV clinics, doctors are wary of even considering prescribing a regime including the fusion inhibitor available\(^7\), not due to concerns over efficacy or compliance, but to worries over pricing.

Prevention

Mobility in London means that prevention work has to be widespread as well as properly targeted at the communities most at risk. London as a tourist and commuter centre means that public health messages have to be delivered in far greater quantity than on a per capita basis to London’s resident population.

HIV also travels hand in hand with other infectious diseases that are prevalent in certain communities in parts of London. Therefore there is a need for a mix of London-wide targeted messages alongside appropriate local campaigns, for example where HIV and TB are prevalent.

We are aware that spending by the former health authorities on core HIV prevention activities varied dramatically. The Department of Health required that 50% of HIV prevention budgets were spent on target at risk groups, namely gay men and African communities. The authority spending the greatest percentage on core work was Lambeth, Southwark and

\(^7\) Enfuvirtide, manufactured by Hoffman La Roche
Lewisham at 28% (well short of 50%) with Redbridge and Waltham Forest spending only 0.28% on core prevention work. It remains to be seen whether the transfer to PCTs and the abolition of the ring fence on HIV prevention will have altered this position, particularly as some were incredibly slow to appoint sexual health leads within their new structures, therefore be in a position to report on activity within their area under the AIDS Control Act, 1987.

7 From the patient perspective, where within the NHS is the best place to provide HIV treatment services (i.e., the acute sector or primary care)

In partnership with the Terrence Higgins Trust, the UKC undertook a consultation exercise in late 2001 on behalf of the Department of Health.

430 questionnaires were completed. There was little support for GPs providing more sexual health and HIV services. 60% of people were opposed to this and would not use such a service.

Almost 80% of people with HIV had experienced some form of prejudice or discrimination since their diagnosis. Health service staff were common sources of this discrimination. In almost 45% of cases, people with HIV stated that the health services had discriminated against them and, where professionals were named, GPs and Dentists were the most common.

60% of people who took part in the consultation did not think it was a good idea to involve GPs in HIV testing and counselling. This figure was the same regardless of a person’s HIV status. Gay men were most likely to be against the idea.

14% of people said that they already used their GP for sexual health services and a further 16% said that they would be likely to do so in the future. 60% would not use such services and this figure rose to nearly 70% for gay men.

People were then asked what would need to improve to ensure that GPs could provide these services effectively.
• Almost 90% of people felt training around HIV was needed by GPs and their staff.
• Around 70% of people were concerned around issues of confidentiality.

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8 Data presented at the 5th annual CHAPS conference, February 2002
A similar number wanted to see protection from insurance and/or employment discrimination should their HIV status be recorded on their medical records and released by the GP.

There was no difference in the responses given due to HIV status, sexuality or ethnicity.

The question here is where to provide HIV treatment services; the informed answer has to be that HIV is a specialist and complex condition that has to be treated by specialists in specialist centres with access to all the required technical and diagnostic support, etc., that is available within HIV clinics and managed clinical networks.

That is not to say that GPs and primary care don’t have a role in general patient care and it isn’t saying that all plwha share the same lack of confidence in primary care. However, there is a challenge to GPs in recognising which conditions might be relevant to HIV or not, whether a presenting condition is better referred immediately to the HIV specialist, which general prescribed treatments might interact with HIV medications or not, and so forth. There may be fine lines, grey areas, and in cases where things go wrong, the patient will suffer. Without across the board improvement in GP knowledge of HIV issues, it is unlikely that if we asked the same question of plwha today, the level of confidence in primary care would be any higher than around the 40% discovered in the 2001 survey.

HIV is a relatively small illness group, is it realistic to expect all GPs to be made competent in delivering other than general medical care for anything that is probably not HIV related? Overall, the likelihood is that a GP without in depth knowledge of HIV will refer a patient with HIV to their HIV specialist for most anything the patient presents with. The reasoning may be a mix of lack of confidence to treat a patient with HIV and knowledge that the HIV clinic is perhaps better placed to either deal or refer on within the acute hospital setting.

We know that patients like – and want – “one stop” services for their health care. The acute sector has therefore struggled to try to deliver a general primary care style service for patients with HIV within HIV clinics. The challenge for HIV specialists is how to behave as general practitioners, mirroring the challenge for GPs in relation to training and development on HIV issues. From the patient perspective, it is NHS treatment no matter where or by whom it is delivered, quality is measured, in part, by how convenient it is to receive that treatment.

It is not only a waste of patient time when HIV clinics send patients to their GP’s, for example where the clinic will not dispense prophylactic drugs due to their own internal cost pressures, or where the GP refers back to the HIV clinic, it also costs the NHS more to have one patient presenting for treatment basically for the same condition, but in two places. Patients concerns over confidentiality also come into play – forcing a patient to use local GP and pharmacy services may well lead to unwitting disclosure of HIV status and is thus a potential barrier to service uptake for some people.
Section C: Prevention, Public Health Awareness and Reducing the Transmission of HIV

4 How does stigma affect the uptake of HIV services

Stigma, fear and self denial feature high in why people avoid HIV services, sometimes until too late. Whilst gay men may be better informed, therefore find it a little easier to access HIV support services, many find it difficult to do so, perhaps to take the step that acknowledges all their fears about their HIV infection.

Stigma, fear and self denial seriously affects the way that migrant communities present for health care or for HIV testing. This is dangerous as it often means that many migrants, particularly African men, are diagnosed with HIV when extremely ill. This limits the potential for immune system recovery when treatment for HIV is eventually started.

Fear of disclosure also affects the way that some plwha refuse to make use of local services in favour of those further away where their anonymity is less likely to be breached by being seen entering an AIDS service organisation. This creates difficulty in commissioning tailored services for people from specific communities as it may not be perceived by the individual as in their best interests to access these services too close to home.

Fear of disclosure within migrant communities that may be providing an HIV service is also known to be a deterrent, where, for example, a Ugandan woman may be more likely to approach a generic service and ask for help from a gay man rather than risk a member of her own community discovering her status and gossiping about it to others.

Machismo amongst many black or African men, alongside denial of HIV, means that many take no notice of HIV prevention programmes. Those with backgrounds where women are treated as second class citizens, or as property, are likely to practice unsafe sex even if they know their HIV status.

Whilst HIV prevention campaigns are being developed that target African communities, there is a distinct lack of work taking place that targets the Afro Caribbean community, both heterosexual and homosexual.

Section D: Living with HIV

1 What are some of the challenges faced by those living with the virus (including children and young people)?

Fear of disclosure and the stigma and discrimination still associated with HIV, are probably the major concerns for the majority of people with HIV. Whilst much of the stigma and discrimination are “real”, many plwha internalise the fear of discrimination. With HIV disproportionately affecting marginalised groups, many people are further marginalising themselves through fear.
Parents

Parents face challenges in dealing with disclosure to children, how their children engage with their peers in society, particularly in school or in finding school places if the child is also HIV positive. Many mothers, particularly migrants, have great difficulty negotiating fairly inflexible social care provision during periods of varying health: without access to an extended family to provide support, it is often difficult to achieve relatively minor, yet important tasks like taking children to school, keeping house or getting shopping. Rigid care management criteria fail to acknowledge urgent, often occasional and short-term needs like this.

Parenting is an important issue for many plwha, yet we know of cases where pregnant women have been encouraged to terminate pregnancy rather than face the risk of mother to child transmission. These are invariably cases in places where knowledge of the issues and risks is low, and fear and discrimination high, the result being an abuse of the individual’s human rights to found a family.

In sero-discordant heterosexual relationships there is also the potential for the partner with HIV to infect the negative partner in trying to start a family. There is insufficient support from the NHS in helping people deal with this challenge. Even in families where husband and wife are both HIV positive, there are difficulties that differing treatment regimes may pose for potential parents.

Whilst condom use is an important prevention tool, the emphasis within relationships, particularly heterosexual relationships, is different.

Adults facing a future

With the advent of combination therapies in 1996, many people have experienced either improvement in their health, and/or the possibility of maintaining their health for prolonged periods. Coping with the concept of future is not as simple as taking the pills and getting on with life. There are a number of psychological processes to go through to help cope with a shift in mind set from one of coping with death, or at least a life-threatening illness, to one of coping with life and the future.

Many are able to consider re-joining/entering the workforce. However the process of re-engaging with the employment market has proved to raise many issues for people with HIV. Migrants face particular additional issues here with validating qualifications from abroad on top of the difficulties faced by ethnic minorities in the employment market, yet many migrants are highly educated and well qualified for jobs that are available.

Others who are more recently diagnosed need to face the reality of a long-term future that the medications can offer most people. For these people the challenge is to remain in employment whilst coming to terms with their diagnosis. The impact of HIV diagnosis cannot be understated here, yet the lack of support, particularly peer support which appears to be most highly valued in this area and at the time of new diagnosis, means that many people end up in extreme distress and with relatively nowhere to turn to for help.
Employment issues faced by adults

Distance from the work force caused by
- a number of years retirement/ out of work force,
- unfamiliarity with the English labour market
- combination of both the above due to rearing children
can lead to de-skilling, existing skills becoming outdated, loss of confidence all causing
difficulty when attempting to re-enter the work force.

For those attempting to return to work after many years on state benefits there are many
issues to consider:
- Will working undermine my health?
- Will I be able to sustain the employment and if not what will happen to my
  benefit entitlements? Will I retain what I am getting now?
- Can I afford to take the risk of returning to work?
- What do I want to work for?
- What what do I really want to do with this second chance at life?
- Is ‘work’ the answer?
- What if I can’t do a whole job can I go part time?
- Who needs to know My HIV status?
- Who must I tell?
- What happens if colleagues find out?
- Will I be employed/promoted etc if my employer finds out?
- What if the employer finds out later and my status wasn’t declared earlier?
- How can I fit my medication regime around shift work hours?
- Will I still be able to get to the hospital for regular health checks?

These questions are relevant both to a person returning to work after many years and
are just as relevant everytime a person changes jobs/career etc.

2 What types of discrimination do people living with HIV experience?

Day-to-Day Living

People with HIV infection are shunned by their peers and often their families,
discriminated against in the workplace and even dismissed when their infection is
discovered, have difficulties with personal relationships, have difficult getting school
places for their children, and find very few places that offer non judgmental support to
help them live their lives.

By far the biggest issue is the FEAR of discrimination, not necessarily discrimination
itself, which causes many people to lead a double life, hiding their HIV from all but
trusted accomplices. Whilst this fear may well be based on actual experience, often it
stems from the general fear in society of infection with this life threatening disease, a
disease of poverty, filth, sexual deviance, low moral fibre. Describing it in this way may
help to understand how easy it becomes to internalise feelings of low worth and
compound a person’s marginalisation.
There is real discrimination taking place, in many cases HIV discrimination on top of other forms of racial or homophobic discrimination. Disclosure of status remains a big barrier to forming new relationships, hence the popularity of HIV positive dating services such as those provided through the contact advertisements in Positive Nation magazine either in print or on the internet.

In the Labour Market

Again the biggest issue is FEAR of discrimination. However, a few well-publicised cases of blatant discrimination caused by sheer ignorance serve to perpetuate this very real fear amongst individuals. There have been cases of supermarkets not wanting managers with HIV working for fear that this will scare customers away. Other workers have been forced to wear completely inappropriate protective clothing to prevent possible transmission to co-workers.

In many cases when working with employers it is often their supersensitivity which itself becomes discriminatory. Others panic at the thought of having someone with ‘AIDS’ on staff and fear the disruption this may cause amongst their workforce. Workers that disclose their HIV diagnosis face dismissal, or subtler forms of “redundancy” despite employment law. The reluctance of may people sacked in this way to take any action is often for fear of further disclosures of status and discrimination.

Therefore the discrimination that can occur is when a person declares on pre employment health forms that they are HIV positive leading to non appointment on that basis only. Others may be denial of promotion; denial of access to training and other assistance with internal advancement because it is considered wasted time investing in a person with HIV.

Discrimination can also take the form of more suble behaviour from colleagues such as snide comments, rumours and insinuations about sexuality/behaviour etc, exclusion from social outings.

For many the discrimination may be multiple HIV/sexuality, HIV gender, HIV race plus several other combinations of these types of and reasons discrimination.

For the ‘general public’ all too often there is direct association of the epidemic with sexuality and promiscuity and individual are treated according to these associations rather than taken as individuals.

This discrimination is often compounded when family and friends and communities reject people with HIV as BAD people and treat them accordingly. This of course has direct impact on the individual’s self worth, their health and therefore the ability to contribute fully and meaningfully in society.
3 What types of support is required by people living with HIV/AIDS?

Until and unless the public as a whole stop stigmatising HIV, based mainly on a mix of unfounded fears and Victorian attitudes to sex and sexuality, the major support need for plwha has to be for actions that seek to reduce stigma and discrimination, promote equality and diversity and thus reduce the amount of “excess baggage” carried by plwha.

Diversity within the communities affected by HIV means that services have to be provided in different and culturally appropriate ways. This is particularly important for migrant communities and refugees where there is great distrust and little understanding of the systems in operation in the UK.

HIV particularly affects people at the margins of society and at the lower end of the economic scale. Many people with HIV face particular difficulties with money, accessing the benefits system, and just making ends meet. Hand in hand with this, many people with HIV have difficulty with finding or retaining suitable housing. There is a need for many to be able to access holistic welfare benefits support and advocacy services, linked to appropriate legal assistance when necessary, and to peer support that helps people overcome their fears and distrust of organisations, the processes in which they may be embroiled, and society as a whole.

A needs assessment appropriate for today is not available.

People newly diagnosed with HIV

There is a need for increased support for people newly diagnosed, to help them normalise their feelings towards an abnormal situation. Much of this work has been best carried out by other plwha in peer settings, yet, as explained already, there is little in the way of resourcing for plwha groups.

People who are diagnosed with HIV today do not have the option of being fast tracked onto maximum rates of benefits as was appropriate pre 1996. Therefore it is important to provide support to people going through the crisis of diagnosis, or later, medication changes to assist them to keep their current employment, or negotiate appropriate changes to their employment such that they can physically continue in their job without having negative impacts on their health.

Peer Support is known to be appreciated by many plwha, however the old fashioned notion of “drop in” centres is no longer seen as appropriate and definitely contributed to creating dependence in a small number of plwha. However, the notion of being able to dip in and out of peer support is one that appeals to many, particularly when they feel that they need it, only to find that there is little provision. From our internet discussion board we see repeated examples of people either looking to gain from others’ experience or merely to share their own.

Counselling services are successfully used by many to attempt to deal with their situations. However, demand for professional counselling far outstrips supply with providers advising four to seven week waits for appointments. For some this results in referral to mental health services instead, on occasion because the individual's distress is so severe.
Parents

We asked a group of parents to identify their needs and they came up with the following:

- A “safe” place for families with children to meet to give peer support
- Make the voices of positive children heard and protect the welfare of young people with HIV
- Support for families with positive children
- Support to bridge the gap between families with children with HIV and their service providers.

Methods outlined by parents include workshops on child specific issues, particularly on treatments; specialised children’s counsellors; challenging discrimination in schools by educating about HIV and AIDS; support of asylum seekers with children who are HIV positive.

We see their use of the word “safe” as yet more indication of fear of discrimination that is particularly important when dealing with children and young people in education.

Young People

More work needs to be done with young people in general both to protect them from ignorance and possible infection but also to address discriminatory attitudes of future generations. This kind of work has to be highly creative and delivered by peers in appropriate settings. It ranges from educational work in schools, through to peer support in terms of sex and sexual health.

As the children of the HIV epidemic become old enough to understand what is happening to them, alternatively what is happening / has happened to their parents if as children they are thankfully HIV negative, they will develop support needs of their own. At present we may only be talking of 750 children with HIV, but this figure will grow and services will need to develop to help them manage their transition into adulthood. Alongside this the children of parents who are HIV positive may number many more and have a different set of support or educational needs.

Sexual health services provided for adults are not seen as appropriate by many young people. These services need to change to reflect the pressures on young people, like education, which make access to sexual health clinics during the normal working day difficult.

Young gay men particularly need support in dealing with sexuality issues which are not being dealt with properly by the education system.

Heterosexuals

Apart from culturally specific services operating in some areas, there is a lack of provision for heterosexuals, particularly single heterosexuals (of either sex). Heterosexual men are particularly marginalised and, particularly in African communities,
likely to be in denial about HIV issues. More work is needed to encourage and support appropriate peer group leaders who can give example to other members of minority groups.

Adults in general

The range of support services required depends on the circumstances of the individuals concerned, it is thus wide ranging. What is needed is the kind of support network that is available for whatever, and whenever, people need of it.

In order to mitigate the dependence on service providers to resolve issues, we have always concentrated on developing individuals to resolve their own problems. While we support efforts to roll out Living Well schemes that enable individuals to manage their long term condition, we also know that every so often there is a problem so big that expert assistance will be needed to help deal with it.

People don’t normally present with just one problem, yet most agencies are unable to deal with them in a holistic manner. For example, a person in need of housing may well be helped to obtain it, but not necessarily assisted in basic furnishing or equipping a new home.

Many plwha have problems with money, particularly those attempting to survive on state benefits. For some there will always be a need for access to hardship funds, such as that operated by Crusaid, which makes emergency contributions either to cover living expenses or to provide essential equipment or furnishings for the home.

Access to housing is important for some plwha as decent housing has a direct impact on their health. Those in difficulties with accessing housing need access to specialist housing advisors and, for some, there is a need for supported housing provision. However, there are difficulties with supported housing schemes when plwha find that they no longer need the support element but are faced with continuing to pay for it at risk of becoming homeless if they do not. Often plwha are placed in housing which doesn’t meet their medical needs assessment – placements in hostels with shared bathrooms and kitchens are not suitable for people on complex treatment regimens who need to eat healthily, may need the bathroom more frequently, etc.

As already stated, plwha prefer one-stop shops. We would prefer a situation where access to support services was much more closely aligned with their health care, with access or referral to social care and support agencies through HIV clinics. This is the kind of model being developed by the Terrence Higgins Trust at their Lighthouse Kings project where the service delivery point is all but part of the HIV clinic, offering a range of services and able to plug in to other services where needed.
Adults in Employment

Campaigns are needed to combat stigma and discrimination targeting:
- Employers
- Gay community
- African communities
- Afro Caribbean communities
- As well as more widely targeted campaigns.

Individual support to those who are considering entering/reentering the work force, specialized careers advice from advisors who are sensitive to the needs of people with long-term medical conditions and have understanding of HIV related issues.

Retraining some of which needs to be provided in a ‘safe’ environment with peer support an integral part of the training, through to fully accredited training affording people formal qualifications at completion.

Volunteering opportunities ranging from informal volunteering to allow people to begin to resocialise in a work environment through to highly structured goal orientated volunteer work experience placements.

A growing area is post employment/in employment support to ensure that people are assisted to obtain, retain and maintain meaningful employment. This is an emerging need and a growing one.

A future service may be to assist people to change career to more fulfilling jobs. Such changes and drive to make such changes come from a HIV diagnosis.

A number of forms of mentoring in employment are also a useful way forward. This mentoring may be provided either in peer format or from more senior employees within particular workplaces.

For Employers

Increased work with employers is needed to ensure that they are fully aware of the need to have comprehensive employment policies and practices that include HIV. This will ensure that there will be increasing numbers of workplaces that welcome people with HIV and are able to make any required reasonable accommodations should the individual worker need them.

It is also important to continue to ensure that employers are aware of the imminent changes to the disability discrimination act, as well as implications of European guidelines etc.

The main message to employers being – be prepared, act now, before you need it.
What types of support services are available?

Local Authority social service departments all provide a basic minimum of social care packages, the majority of these through generic social service departments. Families face problems with social care where the service for adults is provided (and assessed) by a different department to that dealing with their children; there is often a lack of communication and cooperation that leads to less holistic, poorer service provision. To our knowledge, the only borough with an HIV specific social work team still in place is Camden. Even here the service provided is prioritised towards acute care management packages.

Voluntary Service support services across London are patchy and have been particularly disrupted by the sectoral approach alongside a move towards competitive contracting in a sector that had never faced this kind of exercise prior to 2000. In the absence of both a needs assessment and any quality criteria, services are basically those that have developed over the years and survived to today.

Local Authorities all take different attitudes towards what, if any, support services should be provided or funded in their boroughs. In outer London boroughs, where there are less plwha, there is far less provision and less likelihood of there being a nearby voluntary sector service organisation.

Many plwha attempt open access to AIDS Service Organisations on the basis that they may not wish to access a local service for fear of discovery. The purchasing analogy of “local shops for local people” is not always viewed as appropriate by the plwha that the services are provided for. This creates difficulties for service providers in negotiating contracts with remote boroughs and can result in a postcode lottery of access to services. Some service providers are better than others at accepting out of area clients, but it has to be borne in mind that most, if not all, these voluntary sector providers are charities and it is sometimes difficult to work out where the charitable, as opposed to contractual, activity takes place.

The UKC has consistently argued against service provision by postcode and has tried it’s hardest as an organisation to avoid it, partly by disengaging from the NHS and local authority led contractual arrangements that brought it about in the first place. Mobility, personal choice and access to telephones and the internet mean that it is difficult to stop out of area clients attempting to access services. We also know that plwha resent the over emphasis on providing identifying data (postcode, date of birth, etc.) before even finding out that they may have to wait days or weeks for advice on an issue. This is unsatisfactory and happens even with the largest of service providers, the Terrence Higgins Trust, and is the cause of some resentment by people who perceive the service delivered through their THT Direct service as poor, citing as examples not being called back when agreed, or denied service on the basis of their borough of residence.

Some service providers are better than others, or perceived as such by their potential clients who therefore choose where to go for assistance. Whilst services for specific cultures are important, on occasions the insistence on providing them as stand alone units rather than part of an integrated support network of agencies, has led to over provision and lack of expertise in certain areas which have no bearing on culture at all.
move to more partnership working by organisations should bring benefits across the board, but is difficult to achieve in the existing competitive climate.

For migrants and asylum seekers

During 2002, the UKC conducted a six month experiment offering a legal telephone advice helpline which proved that there was a large need for immigration casework, often required urgently, for migrants who perhaps could, or should, have accessed legal advice at a much earlier stage. Reasons for late presentation were predominantly “fear” and lack of understanding of the legal processes in which they were involved.

A complicating issue for asylum seekers has been the dispersal programme operated by the National Asylum Support Service as, not only has it dispersed people away from their centres of health care, it has planted them in parts of the country least equipped to offer HIV specific support and assistance in immigration cases. We know of asylum claimants who are commuting to London from places like Middlesborough in order to maintain their health care provision; yet more example of the determination that asylum seekers display in trying to make the best out of a pretty shoddy situation in this country.

Additionally, the placing of plwha in detention centres for immigration purposes is proven to be undermining their health because it is not possible to provide suitable medical care for them.

The All Party Parliamentary Group on AIDS recently undertook a series of hearings to investigate the issues of migration and HIV. Their comprehensive report, “Migration and HIV: Improving Lives in Britain”\(^\text{10}\) was published in July 2003. The UKC was pleased to assist by encouraging personal testimony from migrants and asylum, or former asylum, seekers.

For children and young people

The range of service provision targeting children and young people is minimal. Additionally the major provider in this area, Body and Soul, are operating reduced services since they were forced to relocate from their former base at the Royal Homeopathic Hospital due to redevelopment.

For people in, or looking for, employment

The Positive Futures Partnership, comprising The Globe Centre, Oasis North London, Positively Women, Lighthouse West London & Terence Higgins Trust, and UKC, provides a range of services to people who are considering how to make the most of their future.

Over the last four years the partner organisations have collectively managed a large grant from Single Regeneration Budget via the London Development Agency. The partnership was successful in attracting the required match funding to ensure that the project went ahead in its entirety.

Services include:

- Welfare benefits advice with a specific focus on assisting people to manage the transition from benefit dependency into work.
- Individual support to those who are considering entering/re-entering the work force, specialized careers advice from advisors who are sensitive to the needs of people with long term medical conditions and have understanding of HIV related issues. These service were provided largely on an outreach basis ensuring that they were accessible across greater London.
- Retraining some of which needs to be provided in a ‘safe’ environment with peer support an integral part of the training, through to fully accredited training affording people formal qualifications at completion.
- Volunteering opportunities ranging from informal volunteering to allow people to begin to re-socialise in a work environment through to highly structured goal orientated volunteer work experience placements.
- Work with employers raising awareness of HIV as a business issue is currently expanding. This includes providing information, bespoke staff training, policy development advice and assistance.

A pilot scheme is currently being run to provide a mixture of work experience placements with integrated structured training through:

- Re-accreditation of qualifications, aimed mainly at people with overseas qualifications which require UK accreditation and who may require additional training.
- Vocational Training Scheme, which provides funding towards the cost of vocational course fees for those requiring advanced training for up to one year and unable to access mainstream funding.
- Supported Employment Programme which provides focused financial and other support to clients seeking to enter employment and with a specific job in mind.
- Employer Focused Training to provide vocational training in areas of recognised skills shortage.
How can services for people living with the virus be better provided?

The primary need would be consistency of funding which would allow continuity and assuredness of service over time, with sufficient consideration given to Core Funding needs of the organisations providing those services. Continued public unwillingness to support HIV as an issue means that most service providers rely too heavily on NHS and local authority contracts to survive. For many, this over-reliance results in financial instability due to the lack of diverse funding sources. Organisations are also faced with spending valuable time and resources chasing projects with funding streams attached, rather than producing new and innovative services that fit emerging needs, something which the voluntary sector has traditionally been excellent at doing.

A needs assessment for London would provide a better idea of what services are needed and how they could be provided.

Consistency of service from one part of London to another is another major consideration which could be addressed by having London-wide standards, if not pan London commissioning.

For example, the Positive Futures partnership made enormous advances over the last four years as a direct result of SRB funding allowing, indeed requiring, Pan London provision of service, thus breaking down the ‘health by post code’ approach to service provision. This service is currently challenged to continue this pan London approach at a time when health funding decisions have been decentralised to PCTs albeit within the London Commissioning Consortium. We expect a re-emergence of the health by post code ethos once again. This will unfortunately lead to inequalities in accessibility to services, unless sensible steps are taken to ensure that this does not occur and that ALL people with HIV across London can expect and access equal quality and quantity of services.

We know that plwha prefer a “one-stop” approach to service provision and that many are put off approaching AIDS service organisations outside of their HIV clinic setting. Whilst we would advocate more integration of social care and support service delivery within HIV clinics, we also respect the fact that some patients will choose not to follow that route, preferring to access other services elsewhere. Additionally, while patients have open access to HIV clinic services across London, the same does not apply to social services provision which may be more difficult to arrange by service providers unused to dealing with distant boroughs.

In line with steps being taken to increase the involvement of plwha within the NHS, similar processes need to be retained within AIDS service organisations in the community.
How are those living with HIV involved in:

(a) Development of health strategies and policies
(b) Health service planning and development
(c) Health service delivery and evaluation

As this is a London scrutiny, we have tried to confine our submission to London issues, but sometimes the national agenda has to play a part.

Is there a strategy for London?

The NHS Plan puts the patient at the centre of decision-making about their health. Patients are likely to be "experts" in their health care and have a great deal of experience and knowledge about their needs and local services.

“The involvement of the public in the NHS must be embedded in its structures: the perspectives of patients and the public must be heard and taken into account wherever decisions affecting the provision of healthcare are made.”

There remains no commitment to long term and meaningful involvement of plwha at many levels of health service policy development and service delivery.

In our response to the draft London HIV Strategy, we noted the then increased involvement of plwha in producing what we also saw as a consultation paper that was put together in a manner which implied to us that it had been done “with great haste, a lack of care, and scant regard for accuracy”.

Patient involvement in the process included input from the Greater Involvement of Positive People project of the Pan London HIV Providers Consortium, and the appointment of a community involvement worker who held a large number of outreach meetings trying to garner more understanding (although, perhaps not much in the way of meaningful input) to a draft strategy which remains unpublished in final form.

Patient involvement in most of the commissioning process today is minimal, patchy and mostly non-existent, despite the work started with the draft London HIV Strategy, from which the following is quoted:

5.3 Crucially, the work undertaken to secure positive people’s involvement will be maintained in the London HIV commissioning consortium, which will take forward implementation of the Strategy.

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12 “Modernising HIV Services In London”, Camden & Islington Health Authority consultation paper, November 2001
An evaluation of the involvement process was carried out by South Bank University\textsuperscript{14}. In short, the conclusion was that the entire process had little impact because, once it had finished, no one noticed. “The fact that the project seemed not to be missed suggests that the longer term route to involvement will move at a different pace from that envisaged by the project’s objectives and may well start from a different place altogether.”

We maintain that user involvement is a much more complex issue requiring a whole raft of approaches, but more importantly requiring consistency and sustained effort.

There is no evidence of any commitment to developing and sustaining ongoing and meaningful involvement in developing strategy or policy for London as a whole.

Examples of poor practice in NHS patient and public involvement

A patient led forum in South London was formed in late 2000 and foundered in 2001 due to lack of support and investment by the then health authorities.

A replacement user involvement project started in mid 2003 – a project developed in a process that involved and almost completely ignored the one service user involved who eventually withdrew from a process where he felt “fed up and disillusioned”. The process was commissioner and provider led, actually celebrated the retention of a “top down” approach and paid little regard throughout to the expressed views of plwha either within the previous South London Forum (while it was operational) or from the token victim on the project steering group.

The £2500 offered to the South London Forum of 2001 has now been replaced by a project of £80,000 per annum and which has taken over two years to put together.

In our view, the South London Project will not provide a sustained user involvement programme, it is designed as a fragmented project that will dip in and out of the services chosen for inspection by commissioning managers. It doesn’t appear that this will help to develop plwha in South London to contribute to the wider strategic debate, instead it seems to be a succession of user approbation exercises across a range of provider chosen services. We remain to be convinced that this contributes to the increased involvement of plwha in the development of public policy, in fact it looks more like the Community Involvement exercise mentioned above which, when formally evaluated, was proven to have been a waste of time, money and effort.

And pockets of good practice

There is more commitment from the Department of Health to encouraging patient involvement at national level, in the development of the national Sexual Health and HIV Strategy and finding innovative ways to take that work forward. However, at this level it is very easy for involvement to become no more than tokenistic – there was expressed

\textsuperscript{14} Bob Cant, Centre for Community Partnership Research, South Bank University Faculty of Health, a report of an evaluation exercise of the HIV Community Involvement Project and a mapping exercise on community involvement activities in the HIV communities in London.
concern about this as the national HIV Strategy progressed, eventually being absorbed into the Sexual Health and HIV Strategy with, perhaps, a slight improvement.

There are pockets of involvement of plwha within organisations and in some small parts of the health service, and in three or four local authorities. Suggestions made to us by plwha asked to contribute to this submission, by way of example, include

- organisations like the UKC, of which the governing body is and can only be made of people living with HIV, championing involvement and more open processes
- some of the recent work undertaken by the All Party Parliamentary Group on AIDS, in particular by encouraging the appearance of plwha to give evidence in person
- the “Taking Part” Project organised by Positively Women and aiming to skill up women and enable them to take up leadership positions
- service user forums within some, but not all, HIV voluntary sector organisations

The reality remains that there is little visibility of influential people living with the virus. There are a few people in positions of relative influence, but this is seen as an indirect influence as these are plwha (also predominantly white, gay men) at or near the top of organisations like the National AIDS Trust, The Terrence Higgins Trust, etc. Whilst organisations like the African HIV Policy Network have been encouraged to contribute to the wider debate, there are capacity and support issues, alongside cultural and discrimination which stand in the way of increasing the number of visible black and ethnic minority community leaders. Those that are in the limelight face increasing calls for their input, but in the absence of sufficient support to cope with the “after effects” of, say, appearing on national television.

The same has to be said for white gay men as leaders within a notional “community” of plwha – they also face the discrimination and stigma attached to the illness in deciding how public they are prepared to be about their contribution to the debate. Experience shows that there may be more white gay men who have traditionally been vocal participants, but as time goes by, the exasperation with sham consultations and lack of support means they contribute less and less. Alongside this, there are no apparent opportunities for “new” voices to jump onto an involvement process that, in itself, doesn’t exist.

There are other examples of unsustained involvement, but occasional “dip-stick” exercises are made more difficult in the absence of any sustained method of outreach to plwha who are equipped to take part in the debate. The impression given is that, by not supporting a continuous involvement debate, it is easier for the NHS to manage the occasional consultation or service quality exercises that do take place. By this we mean that vocal plwha are excluded (“the usual suspects”) and the respondents are cherry picked as those who have little or no idea what to contribute. It is not surprising that as an organisation of plwha, that the UKC would advocate a more user led approach rather than current processes that are more like users being led.

Examples include:
- The London Strategy consultations (as discussed above)
- Ad hoc research projects
- Focus Groups
- Service User Forums
- The South London User Involvement Project
Moving Involvement Forwards

Whilst the London Commissioning Consortium have held a number of “stakeholder” events, the number of patients involved has been small. There are also some patients involved who continue to hide behind organisational labels and “come out” as openly HIV positive, preferring to sit at a forum as an organisational representative. This has allowed some other organisational representatives to be perceived as plwha when they are not – a practice which, when exposed, has caused resentment from other plwha who are more confident in participating openly.

It appears that this openness is more difficult for women and for black and ethnic minorities. We are not just saying this because as an organisation we perceive it, it was one of the issues raised with us by plwha contributing to this debate.

At the UKC we know that plwha don’t always share the same views, and that often they will take an opposing view to any that are expressed by organisations on their behalf. We strive to include all the views in any submission we make, but it is sometimes difficult for other, benevolent organisations to avoid situations where they appear to be speaking on “our” behalf.

Some of the contributors to this submission have re-stated their complete and utter lack of faith in the NHS to involve people properly in the development of policy. They make these statements based on their past experiences and including statements like the following quote:

I think the one big thing that Ken Livingstone could do is to use his huge democratic mandate (the biggest in the country by far and totally eclipsing that of London local authorities with their dismal turnouts) to carry out some real consultation and participation with London people in relation to health. He could then speak authoritatively on their behalf with the health and social care organisations, whose own patient participation systems are in the main currently inadequate

We contend, that given the proper amount of support and development, plwha are quite capable of speaking for themselves. Obviously they cannot all be involved, nor would all of them want to be for a variety of reasons, but the current arrangements are totally inadequate.

People don’t become expert committee members overnight

There has been no investment in developing patient involvement at a strategic level and, we would suggest that this is the wrong place to start: patients do not become effective committee players without personal development and learning to equip them for this role. In the absence of that development, it becomes far easier to manage their limited contribution to the debate – this is tokenistic and of no real contribution to allowing patients to be at the centre of service development.

The London Consortium made very little effort, until now, to explain or publicise their role and their work to their patients, indeed some clinicians have also voiced concerns that the Consortium was a fairly impervious and anonymous group even to them. The UKC met with
David Stout, Chief Executive of Newham PCT and Chair of the London Consortium, in 2002 in an attempt to begin a dialogue.

The London Specialist Commissioning Group appear to be taking a more active approach to encouraging patient involvement, in part through dialogue and through a “Living Well” programme operated first in North East London, more recently in Hammersmith and Fulham. This is allied to the Expert Patient Programme where patients undergo a self-management course for living with an ongoing health condition. The assumption with the Expert Patient Programme is that, as a generic “one size fits all” programme, it meets the needs of plwha, and more importantly that plwha will have the confidence to come forward in the face of concerns about confidentiality, stigma and discrimination.

Some plwha have gained a great deal from Expert Patient and/or Living Well training and we cannot deny that it is an important and useful scheme. However, we know that there are large numbers who would never consider it for a variety of reasons, some of which we have already touched upon, or where there are other barriers to access and participation. We remain to be convinced that the rather strict regime of the Expert Patient Programme, which after all focuses on self management of long term medical conditions, is the right launch pad for long term involvement or activism.

Despite this concern, we have to acknowledge that the London SCG have access to a small number of patients and patient advocates at least six of whom are plwha and that a reference group is being set up (for the whole gamut of conditions which fall within the Specialist Commissioning remit). It remains the challenge is for the London SCG to accept what their reference group actually says – at present it is early days as the actual first meeting only took place on 5th August 2003.

What has to be applauded with London SCG’s Living Well programme is that there is an emerging third strand aiming at producing “expert staff”, that is front line staff who are developed to engage with patients on meaningful involvement. This also forms an ingredient of our work in encouraging the development of clinic user groups (see below) as it has to be recognised that the NHS is an organisation that has never been good at involving public and patients in its processes.

Start where everybody is

In order to equip patients to contribute at a higher level, UKC are promoting the introduction of clinic user groups from which people [that want to] can gain the skills and confidence to hopefully contribute at that and higher levels. This mirrors some of the activity with the Living Well programmes, but starts at the place where most patients are – their clinic – and accepts that, from work carried out so far with existing clinic user groups in London and Brighton, only around 1% of patients will actually get involved in this way.

The UKC are working towards a programme which will develop existing clinic user groups, facilitate the introduction of new groups, and create a network of groups to pool experience as part of a sustained programme to encourage and develop meaningful involvement from the bottom up, by starting where people are and engaging them there.
We are also taking into account the fact that HIV affects predominantly marginalised groups in society, that HIV compounds health inequalities, that stigma and discrimination are immense barriers to participation (and to accessing health care) and that there is no “one size fits all” solution. This fits neatly with our organisational mission statement which says that there will be “diverse voices” in any HIV debate and acknowledges the challenge for clinic user groups in taking all necessary steps to engage with people who are difficult to draw into the debate.

Conclusion

We would like to thank the people living with HIV who contributed their thoughts and experiences to the production of this submission. We hope that we have done them justice.