ALL-PARTY PARLIAMENTARY GROUP ON AIDS

Response to the
Department of Health

NATIONAL STRATEGY FOR SEXUAL HEALTH AND HIV

FEBRUARY 2002

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Introduction

The All-Party Parliamentary Group on AIDS has had a close interest in the development of a national strategy to tackle HIV/AIDS, since first announced by Tessa Jowell MP, then Public Health Minister, to a meeting of the Group in December 1997.

We welcomed the announcement because we believed, and continue to believe, that a national strategy is necessary to co-ordinate this country's response to HIV/AIDS, to ensure it is accorded appropriate priority and to provide a framework for local responses around the country.

In 1998 we held a series of *Parliamentary Hearings*[1] and published a report with recommendations for the *Strategy*. This was warmly welcomed by HIV organisations and by Tessa Jowell who said: "This very good report…will form an important part of our thinking on the new strategy."[2]

On many occasions, Members of the All-Party Group have sought assurances and further information about both the process and content of the *Strategy*, through written and oral parliamentary questions, letters and meetings with Ministers and adjournment debates.[3]

The Group's regular meetings have discussed the *Strategy* many times. We have heard from people with HIV, HIV service organisations and affected communities about their hopes and fears for the *Strategy*. In 1999, the then Chair of its Steering Group, David Walden, reported on progress and in March 2000 the new Minister for Public Heath, Yvette Cooper MP, spoke to our Group about her intentions for the *Strategy*.

When the merger of the HIV/AIDS and Sexual Health Strategies was announced in 2000, we made a *Submission*[4] generally welcoming the merger but highlighting some concerns about the linked approach. When the *National Strategy for Sexual Health and HIV* was published in July 2001, we welcomed its arrival and have taken a keen interest in the many meetings and documents generated during the six months of the consultation period.

In November 2001, we invited a small number of people and organisations who had contributed to our 1998 Inquiry to a meeting to help us to consider how well the *Strategy* had responded to our recommendations.

We are very pleased that so many organisations have responded directly to the *Strategy*. An enormous amount of work has gone into these responses, demonstrating the faith that people concerned about HIV have in the *Strategy*, that it could be a meaningful tool improve the way we prevent HIV infections from occurring and care for people who are already infected.

The following is not a comprehensive response to the *Strategy*. Plenty have been produced by the various experts in these fields. Instead, we are highlighting a few areas which we believe the Government should take into account in its implementation and review of the *Strategy*.

Political support

HIV remains a highly-stigmatised condition that occurs primarily in stigmatised groups of people. The support of the general public or health staff for this subject cannot be assumed. Our 1998 report said "Evidence submitted to the Panel suggests that

there is a need for stronger political leadership on tackling the spread of HIV and discriminatory attitudes".

Specifically, our 1998 Report called for "A strong central lead from the [Department of Health] must ensure that key principles and objectives are implemented at local and national level" and recommended an "annual parliamentary statement" on progress to tackle HIV/AIDS.

HIV remains the most serious communicable disease that we face and the rapidly rising numbers of new diagnoses have serious implications for the health service. HIV contributes to the cycle of social exclusion experienced by communities vulnerable to it and is a significant health inequality. This calls for political commitment, something that is recognised worldwide as an essential prerequisite to tackling HIV.[5]

The *Strategy* does not have the power and status of a National Service Framework. It has not been co-ordinated across government. There has been no statement to Parliament and no government time allocated to debate its content. It is important that the Government does not appear ashamed of addressing HIV or of confronting prejudice, particularly in the media and in the Health Service. We would like to see the implementation of the *Strategy* achieve strong and visible political backing.

Whole government approach

Our 1998 Inquiry envisaged a cross-departmental *Strategy* and made recommendations for the Home Office, Department of Social Security, Department for Education and Employment[6] and the Lord Chancellor's Office. It specifically recommended that "An effective system of co-ordination is established within

central Government to ensure that any strategic approach to HIV is consistent across government departments". Our 2001 Inquiry, *The UK, HIV and Human Rights*[7] went even further and most of its recommendations are for departments other than Health.

We are very glad that the *National Strategy for Sexual Health and HIV* acknowledges the links between discrimination, social exclusion and HIV, but stress that it would only be able to address the underlying problems by joined-up cross departmental work.

Theory and evidence suggest that a significant difference both to the rates of HIV transmission and the lives of people affected by the virus could be made by addressing the following: lawful discrimination and social stigma directed towards people with HIV, social security rules, the education system, the social exclusion of gay men (particularly those with lower educational attainment), support systems for asylum seekers, the poverty and racism experienced by African people living in the UK, social factors which affect travel between the UK and high prevalence countries and the social exclusion of injecting drug users, among others.

We repeat our recommendation in *The UK, HIV and Human Rights* that the Social Exclusion Unit address HIV in a one-off investigation that considers the role of other government departments, with particular attention to Education and Skills, Work and Pensions and Home Office.

Funding

There is strong evidence that those responsible for local funding decisions have been reluctant to fund HIV-specific work,

particularly prevention with vulnerable communities. The special HIV/AIDS allocations were introduced in 1987 in order to ensure health authority spending. In 1991 it was found that this funding was entirely failing to be directed towards the group most at risk of infection.[8] The then government brought in strong central guidance and the "50% rule". Despite this, it is well known that, for many health authorities, prejudice and embarrassment have a greater influence on commissioning decisions than epidemiology and evidence. Our 1998 report recommended that "HIV prevention funds continue to be ring-fenced to Health Authorities". The Stocktake Group, set up by the Department of Health to look at the optimal mechanisms for funding HIV services also recommended this.

We have strongly urged the Government not to abolish the allocations on 1 April but to extend them for at least one year so that it is possible to track their transfer to Primary Care Trusts and to monitor what PCTs do in the first year for which they are fully responsible: 2003-2004.

Special allocations are clearly not the only system of control but are recognised as particularly effective in the Health Service. For that reason Teenage Pregnancy, Drugs and other comparable health topics, have them in order to allow central government to drive this work. We do not believe that there is any evidence that HIV no longer needs this central drive.

We are glad of recent reassurances that AIDS (Control) Act Reports will continue to monitor expenditure. If budgets are to be mainstreamed, it is vital that the Government maintains clear monitoring procedures - in order to be sure that large scale disinvestment from locally-commissioned HIV services does not happen unnoticed - and intervenes where significant disinvestment occurs.

Prevention

Our 1998 Inquiry recommended that a "framework for HIV health promotion is developed" so that HIV prevention strategies are developed on the basis of epidemiological data and evidence of what works". It said that a "firm central lead should be given to prioritising effective work with gay men and people with African countries with high HIV prevalence" with work with infecting drug users maintained and special attention for young people in the care system or in commercial sex work.

The *Strategy* is commendably clear in its prioritising of the main communities vulnerable to HIV. We hope that implementation of the *Strategy* will maintain this clarity and find ways to translate it into local and national action. The *Strategy* is clear that the CHAPS Strategy *Making It Count*, the African Health Promotion Framework, prevention work with people with HIV and links between prevention and treatment should be developed. However, it is likely to need greater direction from central government to translate this into locally-commissioned work than relying on the recommendations in the *Strategy*.

It is disappointing that the *Strategy* does not propose commissioning guidelines for HIV prevention alongside those for treatment and care and social care. The Group believes that HIV prevention cannot be left to PCT level commissioning. It requires targeted interventions with distinct non-geographic communities that would not be suitable for the whole population. For this reason, it should also be commissioned as a specialist service, i.e. that there should be central instruction, co-ordination across several PCT areas and a role for the Strategic Health Authority.

Our 1998 Inquiry also called for stronger links between HIV prevention and general sexual health promotion, alongside targeted work. We agree that HIV should be included in mainstream sexual health interventions, such as the planned media campaign.

Our 2001 *Human Rights* Inquiry explored the intrinsic link between HIV transmission among vulnerable communities and the other social factors which determine their well-being, their autonomy and their investment in their future. We would hope to see health promotion with these communities develop beyond the information-giving and antibody testing set out in the *Strategy*, making use of the large body of evidence supporting more sophisticated approaches.

Treatment and care

We welcome the clear focus in the *Strategy* on treatment services for people with HIV, backed by commitments to produce guidelines for services and commissioning. This is particularly thorough and endorses the importance of this key area of medicine as it is commissioned as a specialist service within the NHS. We hope that this will prove to safeguard against concerns that "mainstreaming" the Treatment & Care allocation will result in a decrease in services, particularly those which will be soft targets for cuts such as voluntary sector support, social care, positive groups, counselling and psychology.

The Group is concerned that access to GUM clinics is becoming restricted throughout the country and that, alongside implications for general sexual health, this may slow down the access of people with HIV into treatments.

The greater involvement of Primary Care in the treatment of HIV is to be welcomed. However, it is important to recognise that primary care's limited involvement with HIV has come about for a number of reasons. General practice has clearly not shown itself free of the prejudice directed towards HIV. Long-standing problems with homophobia and insurance company questionnaires mean that gay men are less likely to be open with the GP about their sexuality. Being primarily transmitted through sex or injecting drug use has led to diagnosis usually taking place in GUM or drugs services. The specialist nature of HIV treatments has necessitated care at consultant level.

People with HIV will not use general practice unless there is a significant change in the approach to HIV seen in general practice and the communities affected by it.

Our 1998 Inquiry endorsed "service networks…which actively connect specialised regional medical, laboratory research and training services with high-quality locally accessible medical and social services". We welcome the commitment to service networks in the *Strategy* and believe they have the capacity to improve the treatment that people with HIV receive.

We also welcome the commitment to standards for social care and look forward to their development, particularly the intention to promote partnership with the voluntary sector. The review of the AIDS Support Grant must also take account similar issues to those identified above with Primary Care Trusts - i.e. the unlikelihood of HIV being prioritised against other more acceptable conditions. The Grant currently offers a mechanism to ensure some attention is paid to HIV even where its low numbers and the profile of the populations affected make prioritising unlikely.

Participation

Our 1998 Inquiry recommended that "people living with HIV and communities affected by the virus are enabled to participate meaningfully in the development and implementation of policies and services". There were clearly concerted efforts to do this with the *Strategy* but ultimately it seems that the HIV sector does not feel the process was as open as it could have been. We note the comments by the positive people involved in the *Strategy* development that they feel that their involvement was tokenistic and limited. Whilst African populations were specifically included in groups and supported to contribute, the other main affected communities, gay men and drug users were not. As far as we are aware, most of the participants had no opportunity to comment on a draft of the Strategy or its targets before publication.

The HIV sector was given the impression that the document published in July 2001 would be a draft for consultation, however this was not reflected in the printed document and the fact that there are no plans to publish a revised version after consultation has surprised many organisations which have contributed to the consultation.

We believe that the high level of interest, the importance of the subject matter and proposals and the large number of thoughtful and comprehensive responses, demand the publication of a revised version of the *Strategy*. Failing that, we note that the Cabinet Office *Code of Practice on Written Consultation* says that "responses should be carefully and open-mindedly analysed, and the results made widely available, with an account of the views expressed, and reasons for decisions finally taken". We

trust that this will be carried out with the *National Strategy for Sexual Health and HIV*.

We commend the *Strategy's* encouragement of local multi-agency partnerships to implement this work and to agree commissioning plans and local targets. Together with the Government's proposals in *Involving Patients and the Public in Healthcare,* these set particular challenges for people with HIV and the three communities most vulnerable to it in the UK: gay men, Africans living in the UK and injecting drug users. Significant efforts must be made to include these groups in these fora at local level. Unless this is done, these will continue to be invisible communities in most of the health service and their needs neglected by a health service that ought to be promoting their inclusion.

We commend the Department for commissioning specific consultation with positive people and trust that this will have significant influence over the review and implementation of the *Strategy*.

The new NHS

The All-Party Parliamentary Group on AIDS is concerned that the *Strategy* does not appear to have been synchronised with the changes in the NHS set out in *Shifting the Balance of Power*. Surprisingly, the *Strategy* refers to health authorities and does not grapple with the move to PCT commissioning.

The moves to primary care commissioning have clear benefits for many conditions. For HIV, however, there is concern that Primary Care staff will be less aware of local priorities and will accord HIV much less importance than other, more socially

acceptable conditions, which appear to affect more of their day-to-day patients. We note that, unlike health authorities currently, Primary Care Trusts will retain funds for their own use if not spent externally. A robust mechanism must be in place to ensure that Strategic Health Authorities have an overview of PCT decisions and intervene if inappropriate decisions are being made.

Furthermore, the move to mainstream HIV funding appears to be happening without any parallel moves to make sure that the health of people with HIV and vulnerable communities is embedded into other areas of NHS work, such as tackling health inequalities. We would feel more reassured about this move if there was evidence that other systems for performance managing local health commissioners were in place.

We are glad of recent reassurances that the reformed AIDS (Control) Act Report will apply to Primary Care trusts and will record levels of spending and activities, including specifically work with vulnerable communities. There have been long-standing concerns about the lack of attention paid to AIDS (Control) Act Reports or action to question inappropriate levels of spending. In 1998, we recommended that it be "reformed into a more meaningful tool of accountability and audit related to progress in implementing local strategies."

Medicalisation

The *Strategy's* sets a commendably ambitious target for a 25% reduction in newly-acquired HIV infections by 2007. We are unclear about the rationale for this target, as there appears to be no baseline data for newly-acquired infections. Data is available for newly-diagnosed infections. Recent epidemiology

and the other targets set by the *Strategy* - to increase uptake of HIV testing and reduce the percentage of undiagnosed infections - will, of course, increase rather than reduce the number of diagnoses.

As already pointed out, actions envisaged to reduce the number of people acquiring HIV are very limited. Even confining its focus to the NHS, this would need much greater targeted community development and health promotion with the vulnerable communities. The Strategy instead places great faith in information-giving and antibody testing. It appears to be focussed mainly on what clinical staff do in medical settings. At a time when health thinking has developed a long way from this approach, as evidenced in *Tackling Health Inequalities* and the SEU's *Teenage Pregnancy* report, this is particularly disappointing.

The non-medical care and support for people with HIV also need much greater attention, in particular addressing employment, benefits and discrimination issues. The role of Social Services and the voluntary sector are not as well-developed in the *Strategy* as those for clinical services.

The voluntary sector has led work to address HIV in the UK. A stigmatised condition affecting stigmatised people has had to find new and creative ways of working, usually outside the mainstream NHS. The development of the voices of people with HIV and affected communities should be a model for other health conditions to emulate. Yet the voluntary sector continues to exist on precarious one-year contracts with local health authorities. In 1999, Tessa Jowell MP told the House of Commons "The HIV strategy document will be issued for consultation next spring, and we are determined to deal with the problems faced by the voluntary sector by replacing annual contracts with

longer-term contracts to ensure that its work has the stability that is so important for the people it serves."[9] We are disappointed this is not reflected in the Strategy.

Conclusion

The Department of Health is to be congratulated on the production of a *National Strategy for Sexual Health and HIV*. It is a welcome development. We hope, however, that the Government will make use of the consultation during subsequent revision and implementation to make sure it becomes a meaningful strategy which can clearly translate its good intentions into real improvements in the lives of people living with HIV and communities which are particularly affected by it.

There is remarkable coherence in the views expressed by the numerous organisations which have contributed to the production and consultation on the *Strategy*. The experts seem to be unanimous that central instruction, cross-departmental work, addressing stigma and discrimination and political support are necessary to reduce the problems caused by this terrible virus.

We urge the Government to be guided by the clear advice it is receiving from those with expert knowledge about HIV, those who have devoted their lives to addressing it and those who live with the virus or have lost friends and loved ones to it. Doing so would ensure a partnership with real potential to address what remains the most serious but preventable communicable disease we face.

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[1] All-Party Parliamentary Group on AIDS, *Parliamentary Hearings for National HIV/AIDS Strategies*, October 1998.

[2] p.13, Department of Health, HIV/AIDS *Strategy* Conference Report, October 1998.

[3] Adjournment Debates held on 5 July 1999, 14 February 2001 and 30 October 2001. Written and oral parliamentary questions can be found in Hansard.

[4] This Submission can be seen alongside other publications on the Group's website: www.appg-aids.org.uk.

[5] Most importantly, this point was central to the Declaration of Commitment on HIV and AIDS issued from the United Nations General Assembly Special Session on HIV/AIDS in June 2001. The British Government was a signatory to this declaration and is therefore committed to implementing it through domestic policy.

[6] Since the 1998 Report, names changed to Department for Work and Pensions and Department for Education and Skills.

[7] All-Party Parliamentary Group on AIDS, *The UK, HIV and Human Rights: recommendations for the next five years*, July 2001.

[8] King, Rooney and Scott, *HIV Prevention for Gay Men: A Survey of Initiatives in the UK*, North-West Thames Regional Health Authority HIV Project, London, 1992.

[9] Hansard 6 July 1999, column 808.