

# **Disturbing Symptoms 4**

**How Primary Care Trusts managed sexual health and HIV in 2005  
and how specialist clinicians viewed their progress**

February 2006

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## 1. Introduction

Despite national targets, a Sexual Health Strategy, an increasingly high public profile and the assumption by Ministers that it is a priority, sexual health across England continues to worsen. Diagnoses of HIV and almost all other sexually transmitted infections (STIs) continue to rise year on year. Why is this?

For the past three years, the British HIV Association, Providers of AIDS Care & Treatment and Terrence Higgins Trust have surveyed those responsible for the planning and delivery of NHS HIV and sexual health care in England. This year, they are joined by the British Association for Sexual Health & HIV, whose membership comprises the vast majority of sexual health clinicians in the country. Concern at the state of services, coupled with a desire to improve them, is universal amongst these major providers.

The 2004 survey *Clinical Trials?* gave indications for the first time that things were not universally worsening and that, with proper use of funding streams and careful modernisation, some services were coping better. This pattern is borne out by the 2005 findings, which again show a very mixed picture, with some services beginning to turn the tide while many more indicate that they are in danger of drowning.

In theory, conditions should be good for a reversal of the ill fortunes of sexual health services in recent years. Government has provided concrete targets and indicative funding, and has made it clear that sexual health is one of the seven key health priorities for the coming year. The patient choice agenda and Ministerial commitment to tackling health inequalities should both feed in to service redesign and renewal. And now, the whole future of sexual health services is very much in the laps of Primary Care Trusts. They can choose to use existing and newly available funding to tackle what should be easily addressed issues and to reverse the decline in England's sexual health through redesign, use of new technologies and service strategies, or they can continue to leave current problems untreated and festering, to cause long term health problems and spiralling expenditure on easily prevented conditions.

## 2. Executive Summary of Key Findings

- Previous service improvements appear to have slowed and, in some cases, stagnated in 2005 despite Government targeting and designated funding. There is a noticeable disconnect between Governmental strategic plans and local practical action.
- It is clear that money intended for the improvement of sexual health services is, in many cases, not reaching the intended target and if continued this will have long term consequences for the sexual health of the country
- Almost two thirds of clinics again reported that they sometimes or often have to turn patients away, mirroring the previous year, although the proportion doing so regularly had decreased. This is a key contributor to ongoing transmission.
- Some GUM clinics are reaching their 48 hour target for appointments by cosmetic changes to booking systems instead of practice improvements. This reduces access and may lead to more rather than less onward transmission and is stressful for staff and patients. There is an urgent need for the Government to make clear the inappropriate nature of such measures.
- The vast majority of clinicians (89%) report increased patient activity in 2005, but only 3% of them reported an increase in staffing; even with the staffing shortages and recruitment freezes reported by a number of respondents, only one in twenty said activity had decreased in their clinic.
- Around one in four clinics have discussed reducing treatment costs with their Trusts by introducing prescribing restrictions; there is some indication that others may have had such restrictions imposed without discussion
- Almost three quarters of clinicians believe that sexual health is not sufficiently prioritised locally despite clear Government targets
- HIV is the area of sexual health most neglected in Local Delivery Plans despite its being the fastest growing serious health condition in England
- Despite extra Government funding allocated to GUM and sexual health services, only half of PCTs reported a real increase in funding of their sexual health services and almost one in five reported a real-term decrease or were unable to answer at all
- Despite the National Strategy, Choosing Health, clear Government targets and designated extra funds, only one in six clinicians feel that access to sexual health services is improving. Twice as many report that it is getting worse.
- Almost three quarters of PCTs do not yet have a managed service network for sexual health. Where they do exist, voluntary organisations, local authority services and in particular primary care services are frequently excluded. At least one in twenty PCTs appear to have no planning mechanism for sexual health services at all.
- A quarter of PCT sexual health planning bodies fail to include a Director of Public Health, which may indicate a lack of prioritisation of prevention alongside treatment
- Almost a quarter of PCTs did not know if they had up to date needs assessment information, and this lack of a basic planning tool is ongoing over the past three years
- Less than 15% of clinician respondents felt in control of their drugs budget. As in 2004, the vast majority of clinics expect to be overspent on this and there is a further rise in those unable to predict their spend at all, now up to one in five.

### 3. The Surveys

- 3.1 In 2002, three organisations representing the majority of provision of HIV services in England (THT, BHIVA and PACT) agreed to undertake a review of how health services were responding to recent organisational and policy changes. They conducted two short surveys: one with Primary Care Trusts (PCTs) and another with specialist sexual health and HIV clinicians. The findings from these surveys were published as *Disturbing Symptoms* in December 2002, and used extensively in evidence to the Department of Health and various Parliamentary committees.
- 3.2 Following the success of the first survey, further annual reviews were undertaken in subsequent years. While only representing a sample, they nevertheless gave a clear picture of services under great strain, struggling to manage greater need without matching levels of funding and often coping in inadequate buildings and with lower staffing levels than appropriate. The dedication of staff was clear, but so was the need for proper funding and a focus on modernisation of long-neglected services designed to cope with far fewer patients. The 2004 survey, following on an injection of Government funding, gave some indication that where used appropriately, funding and redesign could turn services around.
- 3.3 The purpose of the surveys was:
- To establish a snapshot of the current state of commissioning and planning of HIV and sexual health specialist services in England
  - To explore the extent to which NHS redesign, targets and funding had impacted upon these services in comparison with previous years
  - To map the involvement of non-NHS agencies in collaborative planning
  - To provide a conduit for comments on the current working of sexual health and HIV specialist clinical services in the light of structural reforms.
- 3.4 In 2005, the originators of the survey were joined by BASHH and the survey questions somewhat redesigned to reflect the wider range of STIs covered by both clinicians and THT. The twin surveys (reproduced as Appendix One) were tailored to PCTs and to sexual health clinicians and consisted of a small number of key questions, most of which were closed. A small number of questions enabled longer responses and all participants were invited to make further comments at the end of the survey. The surveys were designed to be easy to answer in a short amount of time, in deference to the pressure of work on respondents.
- 3.5 The geographical limit for the surveys was, as in the previous years, England, to reflect the boundary of the English National Strategy and the restricted ambit of the Department of Health (health being a devolved responsibility for the other countries of the UK).
- 3.6 The PCT survey was mailed to PCT Chief Executives, who were asked to delegate it to an appropriate officer.
- 3.7 The specialist clinician survey was mailed to England-based clinical members of BHIVA and e-mailed to members of BASHH.
- 3.8 Both surveys were intended to be used anonymously, although they identified which NHS region of England the respondent was from. Respondents were assured of individual anonymity for the purposes of the questionnaire, although a number actively chose to disclose their personal details within the responses.

- 3.9 Respondents were self-selecting and therefore there may be some bias. There was recruitment across most regions, although the variable number of clinician responses regionally reflects the distribution of HIV services to match differing prevalence. PCTs where there was no individual in post responsible for commissioning HIV services will have been least likely to respond, and clinicians with concerns about how things were changing, more likely.
- 3.10 Responses to the surveys were collated and analysed by the Policy & Public Affairs Team at THT.
- 3.11 The draft publication was read and commented on by officers from the collaborating groups before final publication.

#### 4. Primary Care Trust Findings

##### 4.1 Sample breakdown

A total of 66 responses were returned from separate PCTs, a substantial rise of 40% from the 47 in 2004. This represents around 22% of all PCTs in England. This was due in part at least to a return to the original practice of sending questionnaires via the Chief Executive's office rather than to a list of named sexual health leads. It appears that the former route is more likely to reach the most knowledgeable person, whatever their formal title or position. It is also possible that tasks delegated from the Chief Executive's office are given greater weight.

Regional breakdown was:

**Table 1:** Regional origin of PCT responses

South East	17%
Northern & Yorkshire	15%
North West	14%
Trent	14%
South West	12%
Eastern	12%
West Midlands	9%
London	7%

Once again, the highest level of response was from the South East followed by Northern & Yorkshire. London and West Midlands again provided the lowest level of responses, although in the case of London this is possibly the result of efficiently coordinated commissioning whereby a majority of the PCTs devolve at least HIV commissioning to a few key PCTs. The greatest improvement in response rate was from Trent.

##### 4.2 PCT key contacts for sexual health and HIV

**Table 2:** What post do you hold?

Sexual Health lead	53%
Sexual Health Commissioner (part of post)	18%
Director of Public Health	17%
Sexual Health Commissioner (full time)	6%
Other	5%
Not known	1%

Having a named lead for sexual health is a requirement of the National Strategy. However, in practice, the most knowledgeable person about sexual health planning in any PCT may vary (see 4.1 above). Only just over half of our respondents were the designated lead, with commissioning staff and Directors of Public Health also well represented. It was notable that commissioner respondents were three times more likely to hold responsibility for sexual health on a part time basis as to work on it full time.

Others filling in the survey included health promotion staff and a Director of Workforce Development & Nursing.

### 4.3 Local Delivery Plan priorities

A new question for 2005 asked PCTs which sexual health issues were in their Local Delivery Plans (LDPs). The LDP outlines the intended work to be undertaken by a PCT during the following three years.

**Table 3:** Which of these are explicitly mentioned in the PCT's LDP?

Sexually Transmitted Infections (STIs)	67%
General Sexual Health	65%
Contraception	50%
Abortion	42%
HIV	38%

General sexual health and STIs were unsurprisingly the most likely issues to be mentioned in LDPs, given that there are explicit Choosing Health targets to reduce waiting times for STI services and to reduce the rate of gonorrhoea. Equally unsurprisingly but of great concern when it is the fastest growing serious health condition in England, HIV (which is neither in the Choosing Health targets nor a factor in assessing star ratings) came in lowest. The results for LDP areas explicitly asked about are in line with the findings of a recent separate LDP survey by THT and other sexual health charities, which is encouraging in considering the robustness of the overall PCT results.

### 4.4 Planning for sexual health services

**Table 4a:** Does your PCT have a planning body for sexual health services?

Yes	94%
No	5%
No response	1%

This was a new question for 2005 (replacing a more specific one on managed service networks) and while the overall response is a good one, it is of concern that one in twenty PCTs appears to have no clear mechanism for planning sexual health. However, it is important not only that such a body exists, but that it is appropriately populated. We therefore asked an additional question.

**Table 4b:** If so, who sits on the planning body?

GUM/HIV staff	100%
Family Planning staff	95%
Sexual health services Commissioner	89%
Director of Public Health	74%
Voluntary sector	73%
Local authority	56%
Patient/s	11%
Other	6%

(Other includes health promotion staff, school nurses and a Director of Primary Care)

It is encouraging to note that all the planning bodies included GUM or HIV-specific staff posts. However, it seems odd that some do not include the two people strategically most concerned with sexual health – the commissioner of these services and the Director of Public Health. Exclusion of the latter from one in four groups may indicate the increasingly lower priority being afforded to prevention rather than treatment of STIs and HIV.

Levels of involvement of the voluntary sector and local authorities are in line with previous years, but suggest a continuation of the slow trend towards greater involvement of the voluntary sector and lesser involvement of local authorities despite the need for joint working on prevention and care. The most startling response is the indication that only around one in ten of these planning bodies involves patients. Given Government commitments towards patient involvement in NHS decision making, this is a very low level indeed.

Some Trusts face particular challenges in how to organise such planning bodies. As one respondent observed:

"Joint PCT Steering Group – difficulty in engaging representatives from voluntary sector, Connexions, youth service, local authorities due to lack of coterminosity."

#### 4.5 PCT Needs Assessment

**Table 5:** Has your PCT undertaken a specific needs assessment for sexual health and HIV?

	Yes	No	Unknown
In the last year	50%	26%	24%
In last three years (a further)	29%	15%	(6% in all)

While it is encouraging that half of the sample respondents knew of a sexual health needs assessment in their PCT in the last year, it continues to be of great concern that such a large proportion of PCTs (around one in seven) continue to neglect the basic building blocks for good planning. A surprisingly large proportion of respondents – almost a quarter – were unclear about whether they had up to date needs assessment information. Given that this survey is likely to be filled in by one of the PCT staff with the greatest knowledge of local sexual health planning, this is problematic.

As we stated last year, *"This data has been consistent now over three years, and indicates a very serious lack of planning data – and very possibly of planning skills – which can only be attributed to an ongoing lack of local prioritisation of sexual health and HIV issues, and a disregard for the need for rational planning in this area of health services."* The situation is not improving, and we urge the Government to act to improve matters.

Some PCTs had found creative ways to undertake this work, including joint shared assessment county-wide and self-audit based on MedFASH guidance. However, it was also clear from comments made that some respondents had little idea where to access basic information available to every PCT, such as STI data from the Health Protection Agency.

#### 4.6 Managed Service Networks

**Table 6a:** Does your PCT have a Managed Service Network for HIV/STIs?

Yes	26%
No	38%
In development	33%
Don't know	3%

The responses to this question show a very different picture to 2004, when MSNs were first in development. The percentage of respondents with such a network in action is one in four and while this appears on the surface to be down on 2004's 35%, it is likely that the more concrete wording "do you have" (as opposed to "have you supported" in 2004) has promoted a more accurate response about the current reality. Those who have no network and no plans for one are also down significantly, from 53% to 38%. The greatest change is those with MSNs in current development – from around one in twenty (6%) to a third. Given that these networks are an important part of good service delivery, but are not a statutory requirement, the picture is a relatively encouraging one. Further encouragement needs to be given to the development of such networks in order to encourage the 38% who have yet to be persuaded of their benefits to both staff and patients.

One enterprising respondent indicated that they had created such a body across six PCTs as a modernisation group.

**Table 6b:** If so, is it (or will it be) supported by...

Recurrent funding	41%
Non-recurrent funding	2%
Organisational support (non-financial)	37%
No response	20%

These percentages are of the PCTs who responded that they currently had a MSN or that they had one in development. Being in development may explain the 20% of PCTs who could not tell us how the network would be supported, but it remains of concern that more than a third of PCTs with networks did not provide any level at all of financial support to their work. If nothing else, this is likely to severely restrict patient representation.

**Table 6c:** If so, which providers are involved?

GUM	80%
Primary care	71%
Voluntary & community sector	63%
Local authority	37%
Other acute services	34%

In terms of prioritising which groups plan services together, this correlates directly with relative levels of involvement in previous years and is therefore a strong indicator of the most common format of such service networks as they evolve.

Given Government emphasis on increasing the involvement of primary care in sexual health, it is of interest that one in four do not include anyone from the primary care

area of the PCT. Almost as many – more than two thirds – involve their local voluntary sector. Given government commitments to encouraging plurality of service providers, the absence of voluntary organisations from more than a third of networks is of great concern. Furthermore, the low level of local authority involvement at 38% is a serious decrease from previous years. Given local authority responsibility for schools and youth services, this omission is more than unfortunate.

As with 6b, it is assumed that some respondents with networks in planning were unable to state definitively which providers would be included. This would be a logical explanation for the one in five who did not include their primary providers of sexual health services (GUM) in membership of the group; it is difficult to envisage a service network for sexual health without the GUM service. There is also therefore likely to be some under-reporting in the other categories.

**Table 6d:** What is the position of the lead officer?

Director of Public Health	24%
Sexual Health Services Manager	10%
Commissioner	7%
Consultant/GP	7%
Clinical Director	5%
Other	7%
No response	40%

It is of some concern that 40% of respondents could not name who the lead officer within their managed service network was, though again this may be partly due to incomplete information on networks still in planning. Where networks are established, it is vital that they are led by someone with the ability to influence investment in services e.g. a Service Director. It is disappointing, given the importance of good clinical leadership for networks, that only one in twenty was led by a Clinical Director, although it is good to see Directors of Public Health taking a lead role in one in four.

#### 4.7 PCT spending on HIV and sexual health

**Table 7:** Compared with last year, has your PCT's spending on HIV and STIs:

Increased	50%
Stayed the same (+ cost of living uplift)	32%
Stayed the same (no uplift)	5%
Decreased	3%
Don't know	10%

The major shift in responses to this question was that whereas last year every PCT responding knew whether their funding had increased or decreased, in 2005 one in ten was unable or unwilling to answer. However, the really disturbing figure is that in a year which saw an extra Government one-off allocation of £50 million towards improvement of sexual health services, distributed to every PCT in the country, only 50% of respondents were able to state that any uplift had reached this area of service. Even without this extra one-off funding, extrapolating treatment costs from the known increase in patient numbers suggests that the extra cost of HIV treatment alone last year must have been in the region of £35 million. For this cost to have been absorbed by the 50% of respondents who provided no uplift, there must have been a decrease in resources to other areas of sexual health.

#### 4.8 Help in improving sexual health

**Table 8:** What would enhance your ability to make greater progress locally in reducing the incidence of HIV and STIs?

This question was a variation on previous years, when respondents were asked what would help them achieve the goals of the National Strategy on Sexual Health. The new wording acknowledges the specific nature of this survey and also the greater local relevance of Choosing Health Targets over the Sexual Health Strategy. In all, 54 of the 66 respondents made comments in this open ended section.

More financial resources (of which, ringfenced)	50% (17%)
Greater capacity (of which, more staff)	26% (9%)
More health promotion	9%
Cross sector collaboration	9%
Better PHSE in schools	6%
Stability in the NHS	6%
Prioritisation by the PCT	4%
Service modernisation	4%
Reduction in stigma	4%
More meaningful national targets	2%

The different response to the variation in wording was instructive. Although capacity continues to be an issue for more than a quarter of respondents, from the PCT point of view it is lack of money that is seen as the greatest obstacle to reducing STIs and HIV. Given the existence of special allocations for sexual health, and the advent of Choosing Health funding on the horizon, this continuing and increasing worry about resources is an alarming finding. It is clear that money intended for the improvement of sexual health services is, in many cases, not reaching the intended target and this will have long term consequences for the sexual health of the country.

Specific comments made by some of the 54 respondents to this question included:

"Unless they're national/LDP targets, it's difficult to get funding."

"Remove the tendency to resist change locally and in the sector."

"NHS stability (versus reorganisation)."

"More time and involvement, balanced against other priorities. Sexual health prioritised by PCTs."

"Increased funding to allow development of one-stop shops and integrated services."

"More dedicated time to look at service modernisation. Greater working between GUM and family planning."

"Generic sexual health staff for integrated service provision."

"Commitment to using 'Choosing Health' monies on development/mainstreaming sexual health services."

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"We have the structures and willingness but funding is totally inadequate."

"Better use of GP contract, no charging of non-residents with HIV, national de-stigmatisation campaign."

"A more robust independent sector and more capacity in public health."

"We are keen to develop sexual health services according to BASHH guidelines. Sexual Health and HIV services have been Cinderella services for far too long – apart from a brief period when HIV was a) incurable and b) seen as a 'threat' so that money was available for prevention of HIV, which also helped with other STIs and SH in general (not to mention drug services). They got lost again in the organisational division of family planning, infectious disease, GUM, health promotion, gynaecology... multiple PCTs, confidentiality and the outpatient nature of GUM services meaning Trusts and PCTs don't take ownership... however, with 'Choosing Health' and PCTs getting bigger, we are finally getting to grips with it."

## 5. Specialist Clinicians Findings

### 5.1 Clinician sample

**Table 9a:** Type of clinicians responding

GUM clinician (mainly GUM)	52%
GUM clinician (mainly HIV)	29%
ID (infectious diseases) clinician (mainly ID)	8%
ID clinician (mainly HIV)	2%
Other	9%

The sample size for the clinician survey was 88, a healthy rise from 2004's 69. The definitions offered varied from previous years in order to accommodate the wider range of sample clinicians, but essentially 60% of them defined as general STI clinicians (who may or may not be treating HIV patients) and 31% as mainly or entirely HIV specialists.

Other respondents included paediatricians, clinical nurse specialists and a GP/HIV physician.

**Table 9b:** Geographical distribution of responding clinicians

London	36%
South East	20%
Northern & Yorkshire	9%
South West	9%
Trent	8%
Eastern	8%
North West	7%
West Midlands	3%

The geographical distribution of respondents continues to show interesting patterns. As before, the highest levels of response come from London and the South East, reflecting the particularly high prevalence of HIV, and thus greater levels of HIV services, in these regions. Levels of response from other regions are, for the first time, all within two percentage points of each other except for the West Midlands, where the traditionally dire level of responses continues.

### 5.2 Changes in access to services

**Table 10:** What, if any, changes have there been to your open access (self-referral) GUM or HIV services in the past 12 months?

Got better	17%
Stayed the same	46%
Got worse	33%
Not answered/don't know	4%

This question changed in 2005 to enable us to identify positive and negative changes more easily. For the first time, it is clear that twice as many clinicians – a third of the entire sample – are reporting that access to services is worsening rather than improving, despite a clear Government target to ensure that by 2008 nobody waits

more than 48 hours for a GUM appointment. Despite the National Strategy, despite Choosing Health and despite clear Government targets and designated extra funds, only one in six clinicians feel that access to sexual health services is improving. This is a key finding of the 2005 survey.

This finding is to some degree contradictory to the results of the Health Protection Agency audit of access. However, the difference in findings can be easily attributed to the way in which the HPA results are linked to changes in their methodology which caused a false picture of improvement and the ways in which clinics have changed their systems to give good results to audit questions, but which in practice further restrict access (see below)

Open comments were invited in addition on this question, and elicited a wide (and sometimes contradictory) range of responses. One clinic had stopped walk-in services and instituted an appointments system to cope with increasing numbers, while another had instituted solely walk-in services alongside giving nurses greater responsibility and thus reduced their average waiting time to under one hour.

Two clinics had successfully reduced their DNA (did not attend) rate by instituting a system whereby patients could only book 24 hours or 2 hours respectively in advance, only to find that this in turn increased complaints and reduced access for those unable to ring repeatedly until they were early, or lucky, enough to get an appointment. This diminishes the patient experience and causes further stress to staff.

Others gave clear resource reasons for decreased access:

"Due to staffing problems we have not been able to see as many patients"

"Internal efficiency improvements have been offset by reductions in resources driven by hospital trust overspend"

"Recent cutbacks/freezing of staff posts have meant that the clinic has now had to close earlier two days in the week"

"PCT is trying to scale down Level III services and make referral only"

A number of responses in this section made it clear that some clinics are reaching the Government target of access within 48 hours to GUM services by simply instituting systems whereby it is impossible to make appointments any further ahead, and this issue will be dealt with at 5.5.

### 5.3 Turning people away

**Table 11:** Do you often have to turn people seeking initial diagnoses away without providing a service?

Yes, often	24%
Yes, occasionally	39%
No/not yet	37%

Responses to this question showed some improvement on 2004, although the overall level of clinics refusing services to at least some people was stable (and far too high). The proportion who were often unable to see people was reduced from 34% in 2004 to

less than one in four in 2005, but the proportion who were sometimes in these difficulties rose from 30% to 39% - almost two in every five clinics.

Given research which shows that around one in three people who suspect they have an STI will continue to be sexually active until diagnosed and treated, it is clear that clinic capacity is a key factor in the continuing rise in almost all major STIs in England. While almost two thirds of clinics sometimes or often have to turn away people who need a service, we are unlikely to bring about the needed reduction in STIs, and we continue to leave sexually active and untreated people with simple STIs more vulnerable to serious and incurable conditions such as HIV.

#### 5.4 Financial concerns

**Table 12:** Will your clinic drugs budget be overspent by the end of the year?

Yes	66%
No	14%
No response/don't know	20%

The vast majority of clinics responding continue to be overspent for the second year running. There is also steady growth in the number of clinicians unable to predict whether or not they will be overspent, rising over the past two years from 6% to 20%. This gives a picture of services which are increasingly nervous of continuing and unpredictable rises in STIs and HIV and of their associated costs and are increasingly not in control of their budget.

#### 5.5 Waiting times

**Table 13:** If you have an appointment system for routine patients, when is the next appointment currently available?

Waiting time	<48 hrs	<1 week	<1-2 weeks	<2-3 weeks	>3 weeks
HIV test	33%	28%	10%	3%	2%
Other STI test	15%	19%	17%	7%	9%

*(These figures do not add up to 100% because not all clinics have relevant systems and not all clinics provide both HIV and other STI services. There may also be a proportion who were unable to respond to one or both questions.)*

On the face of it, these responses appear to be reporting a remarkable improvement in the swiftness with which people are being seen in GUM clinics. Despite reports of cutbacks, lack of resources and high numbers being turned away without an appointment at all, apparently the proportion of clinics able to see people in less than a week for an HIV test has risen from 46% to 61%, and the proportion able to see someone for another STI in the same timespan from 24% to 34%. Similar improvements are reported all the way along the line, with those waiting for three or more weeks reduced the most.

Unfortunately, this picture is in direct contrast to the answers given at 5.2 as to whether clinic access has increased or decreased. Similarly, it contrasts with the recent "mystery shopper" exercise undertaken by BBC's Panorama programme, which found that only 7% of clinics could genuinely offer routine appointments within 48 hours, though 73% could see a client with symptoms within that timeframe. The Panorama

survey took into account not only those people who obtained an appointment, but also those who were turned away due to new booking systems which prevent longer waiting times by e.g. not opening the phones for booking until 48 hours or a week beforehand.

As a number of comments to both this and 5.2 make abundantly clear, in a number of clinics this apparent improvement has been achieved, not by modernisation but by simply altering the booking systems to prevent anyone booking more than a day, two days or a week in advance. Typical comments were:

"Appointments only released in 48 hours before clinic"

"Either walk in or appointments released 48 hours before clinic"

"Can only book one week ahead"

"48 hour booking system – not allowed to book more than 48 hours ahead"

These systems enable Trusts to claim with technical honesty that they are meeting Government targets, but in practice they lead to more restricted access for people unable to make persistent repeat phone calls and drop their work at short notice to attend. From some comments, it seems they can also lead to increased strain on clinic staff and complaints from patients. This is a clear example of subversion of a Government target, with unintended and inappropriate results and a major area for further NHS attention. False activity reports on this target will in fact undermine the ability to reach other sexual health targets such as the gonorrhoea reduction target.

## 5.6 Activity versus capacity

**Table 14a:** Has patient activity increased in the last year?

Yes	89%
No (of whom, levels remaining constant)	11% (6%)

This was a new question for 2005 and well worth asking. For the overwhelming majority of clinics, patient numbers and activity continue to rise. Only one in twenty clinics sampled has seen a decrease in patient activity in 2005 – and this includes respondents who stated elsewhere that decreased activity was directly due to understaffing. But patient activity levels may not be a problem where resources are increased in line with it, and thus we also asked:

**Table 14b:** If yes, has clinic staffing increased in line with it?

Yes	3%
No	97%

Of the 89% of respondents whose levels of patient activity had increased in the previous year, only 3% had received any concomitant increase in staffing. While there may undoubtedly be room, through service redesign, for some efficiency improvements in clinics, it seems unlikely that this was so universally the case in 2005 as to make this picture a reasonable one.

Again, comments in this section were very telling and paint an unacceptable and shameful picture:

"Staffing freeze – currently all bookings stopped and we wait until the day to see who we have available"

"4 vacant nurses posts presently two of which in the last week have been frozen. Overall GUM 2 posts frozen, HIV 2 posts frozen, SHOs 3 posts frozen."

"Minimal improvement as nurse led clinic introduced."

"Nurses doing nurse-led clinic during periods of poor staffing levels e.g. school holidays for doctors with children"

"Partly recruitment problems, partly lack of Trust support"

### 5.7 Overall impact of recent changes on clinical service provision

**Table 15a:** In the last year, has your ability to provide GUM (other than HIV) services:

Got better	11%
Stayed the same	42%
Got worse	39%
No answer	8%

**Table 15b:** In the last year, has your ability to provide HIV services:

Got better	10%
Stayed the same	62%
Got worse	28%

For the first time, this question separated out clinics' ability to provide different kinds of services. However, for both areas the answers are broadly the same; rates of improvement have slowed, with 10% or 11% reporting improvements as opposed to 15% in 2004, but with lower numbers also reporting an overall worsening (38% and 29% as opposed to 52% last year). For the majority of HIV services and for 42% of other STI services responding, overall they felt that things had stayed the same.

In other conditions, this would be a broadly hopeful picture. But in a situation where substantial designated funds have been provided nationally for improvements, standing still in the face of ever increasing service demand is not an appropriate response. The slowing in rates of clinicians reporting improved ability to provide services shows that something is going very badly wrong at local level with all the national funding, emphasis on service improvements and statements on prioritisation of sexual health by Government Ministers.

### 5.8 Treatment restrictions

**Table 16:** Has your PCT or Trust discussed the use of less expensive combinations for HAART?

Discussion and significant pressure	7%
Discussion and minimal pressure	17%
No discussion	76%

This was asked for the first time in 2005 in response to complaints from some clinicians that their Trust management were considering restrictions on HIV combination therapy drugs. These drugs are often perceived as particularly expensive, although this perception is in part at least due to HIV stigma, given that many other long term condition treatments are both more expensive and less cost effective in terms of increased life expectancy. Without HAART, life expectancy for someone with HIV is considerably reduced and attendant costs for regular inpatient treatment vastly increased. In rough terms, a year of HAART is less expensive than one week in intensive care managing the impact of failure to treat, and anyone with late stage HIV will require regular inpatient and emergency attention.

In any situation of budgetary restraint it is inevitable and appropriate that drug costs will be considered alongside other possible areas for cost reduction, and thus responses were divided into those where routine discussion without resultant pressure to change clinical decisions had taken place, and those where significant pressure had been put upon the clinicians to reduce the cost of HAART. Although the resulting response of 7% who have experienced such pressure may seem small, it is likely to be the thin end of a very unacceptable wedge, and not cost effective in the long run. Unlike some other conditions, HIV combination therapy drugs can differ widely in their impact, side effects and appropriateness for a particular patient, and one size most definitely cannot fit all. Restrictions on HAART are particularly worrying because newer drugs are often more expensive but also more palatable and needed for those in whom resistance to existing treatments has become an issue.

The extent of drug restrictions may in fact be greater than these responses indicate, since one clinician commented that there had been no discussion in their Trust, but that nevertheless access to T20 and Truvada had been restricted.

### 5.9 Relative priority afforded to sexual health

**Table 17:** Are HIV and sexual health sufficiently prioritised within your local health services?

Yes	19%
No	73%
Don't know	8%

Less than one in five clinicians responding to the survey believe that HIV and sexual health are sufficiently prioritised locally, while almost three quarters actively believe they are not. Although sexual health is often mentioned as a priority at national level and sometimes at local level, it is clear that investment does not necessarily follow kind words.

These views, while negative, are entirely consistent with the other findings of this survey and of the recent Local Delivery Plans Survey by THT and other sexual health organisations. It highlights huge differences between NHS areas of genuine improvement, such as A&E and GP services, and GUM where modernisation has hitherto had much less impact.

### 5.10 How to improve ability to provide sexual health services

This year the final question to clinicians was slightly varied from that asked of PCT respondents, in recognition of their different roles. Whereas PCTs were asked what

could be done that would improve their ability to reduce sexual ill-health in their locality, clinicians were asked more specifically how *their* services to do so could be enhanced.

One thing that did not change was the tendency for clinician responses to this open ended question to be longer, more detailed, more diverse and occasionally more trenchant. Where possible, we have collated them into groups to show general trends. In all, 72 of the 88 clinicians gave extra comments in this section. Of those comments which were made by more than one respondent:

More staffing (all clinical posts)	54%
More/better administered funding	25%
Better/larger accommodation	19%
Modernised/reorganised services (esp. more use of nurses)	17%
Wider opening hours in clinic	13%
Community based services	7%
Better/more admin staff	7%
Better diagnostics	7%
Better support/management by Trust	7%
Better service targeting towards at-risk groups	6%
Better/more PHSE in schools	4%
More targets/linkage to star rating system	3%
Dropping entitlement restrictions for HIV and maternity services	3%

Other suggestions made by individuals included fast tracking asylum seekers with healthcare backgrounds into work, more specialist commissioners, abolishing PCT control over funding and employing nurses who did not take sick leave.

Individual comments included:

"More nurses for nurse-led clinic, NAAT (*urine based, using new technology*) chlamydia test... better clinic accommodation (in Portakabin presently)"

"Effective health promotion for Black Africans"

"More clinics in the community"

"Ability to use allocated budget as clinically appropriate. At present the Acute Trust has cut 5% of pay budget, to save money, without consultation. Why isn't the DH or Strategic Authority performance managing this better or do we all have to accept that the NHS is bankrupt."

"Clinic performance/access times affecting Trust star ratings (*would help*). Would lead to more support within organisation. GUM and HIV funding by specialist commissioners supported through managed local networks."

"1) Funds/Infrastructure. 2) Joined up government. 3) Free antenatal care for all. 4) Give an amnesty for all health workers in the asylum system and give them leave to train. 5) Ability to treat all HIV positive people in the UK regardless of visa/immigration status. 6) Government support for prevention policy..."

## Disturbing Symptoms 4

"Sadly all the third world human beings/citizens should be sent back to their countries if medication and support are possible\*. NHS is suffering by this unchecked and unnecessary expenditure..."

"More support from PCT – really have no insight into the needs of sexual health & HIV services but have all the power/money."

"Control over and access to 'Choosing Health' monies."

"More open access clinics throughout London – working as a network."

"More nurses who don't leave or get genuinely ill!"

"Sexual health targets need to be embedded in quality frameworks for GPs, action plans for PCTs and assessments for Acute Trusts."

"Just use urine (*testing*) to crack through the asymptomatics."

"Funding for staff and (*new, simpler tests*) would increase number of patients we could see and increase ability to do outreach. Support (not necessarily financial) to develop IT/web/texting to enable phone triage/booking, texting appointment reminders etc., help to improve target access for minority groups."

"Decisions about service configuration to be made by informed people not by financial directors or others with no or little knowledge of services."

"GU allocation to PCT actually being delivered."

"Correct use of indicative allocations of 'Choosing Health' monies."

"Better relationships/access to ethnic minority and refugee groups."

"We have an increase of 20% per years without increase in doctor provision. Personally, I cannot physically have more patients..."

*\*NB: people with HIV who are refused asylum or otherwise subject to deportation are in practice currently returned to countries with no HIV treatment access. Having HIV is not a deciding factor for asylum applications.*

## Appendix One: The Survey Questions

### Primary Care Trust Questionnaire

1. Who is your lead officer for commissioning HIV/STI services? *(Please give name and title)*
2. Are you involved in a consortium arrangement for commissioning these services? *(If so, please state with which other PCTs and which PCT is the lead)*
3. Are HIV and STIs explicitly mentioned in your PCT's Local Delivery Plan? Yes/No
4. Has your PCT undertaken a specific needs assessment for this area of work?  
 Within the past year? Yes/No  
 Within the past three years? Yes/No
5. Have you supported the development of a Managed Service Network for HIV/STIs? Yes/No  
 If so, was it by:  
 Recurrent funding    Non-recurrent funding    Organisational support (non-financial)  
 If so, which service providers are involved?  
 GUM    other acute services    primary care    local authority    voluntary & community
6. Compared to last year, has your PCT's spending on HIV and STIs:  
 Increased/stayed same with cost of living increase/stayed same without cost of living increase/decreased
7. What would enhance your ability to make greater progress locally in reducing the incidence of HIV and STIs?
8. My PCT is based in:    Northern & Yorks    Trent    North West    Eastern  
 West Midlands    London    South East    South West

### BHIVA/PACT/THT HIV/GUM Clinician Questionnaire

1. Who is the lead officer for commissioning HIV and STI services in your area? *(Please give name and title)*
2. Has your ability to provide an open access/walk in service changed?  
 Within the last year? Yes/No  
 Within the last three years? Yes/No  
 If so, please state how and why:
3. Do you have to turn people away without providing a service?  
 Yes – often    Yes – occasionally    No
4. Will your clinic drugs budget be overspent by the end of the year? Yes/No

## Disturbing Symptoms 4

5. How long is the current average waiting time for an appointment in your clinic?

For HIV tests?

For other STI tests?

For first appointment for new HIV patient?

6. In the last year, has your ability to provide services:

Got better/Stayed the same/Got worse

7. Do you believe HIV and sexual health are sufficiently prioritised within your local health services?

Yes/No/Don't know

8. What would enhance your ability to make greater progress locally in reducing the incidence of HIV and STIs?

9. I am a: GUM clinician HIV specialist clinician Other clinician

10. Based in: Northern & Yorks North West Trent South West  
West Midlands Eastern London South East

## Appendix Two: Recommended Reading List

The National Strategy for Sexual Health and HIV (Department of Health, 2001)

Disturbing Symptoms series (1, 2 & 3) (Terrence Higgins Trust/BHIVA/PACT December 2002 etc.)

Blueprint for the Future: Developing sexual health & HIV services (Terrence Higgins Trust, April 2004)

Review of Primary Care Trust Local Delivery Plans 2005-2008 (Brook, fpa, Medical Foundation for AIDS & Sexual Health, National AIDS Trust, Terrence Higgins Trust January 2006)

Sexual Health and HIV: An urgent economic and public health challenge (Brook, fpa, Medical Foundation for AIDS & Sexual Health, National AIDS Trust, Terrence Higgins Trust, June 2004)

Meeting the rising challenge: The growing HIV epidemic and its implications for Primary Care Trusts (THT, June 2003)

Practice Guidance on involving people with HIV and other long term conditions in planning and developing services (THT, November 2002)

Practice Guidance for Primary Care Trusts on meeting the prevention needs of local communities at risk of HIV transmission (THT, November 2002)

Recommended standards for NHS HIV services (Medical Foundation for AIDS & Sexual Health, 2002)

British HIV Association website (includes library of HIV Treatment and other clinical Guidelines) [www.bhiva.org](http://www.bhiva.org)

British Association for Sexual Health & HIV website (includes clinic directory and primary care testing guidelines) [www.bashh.org](http://www.bashh.org)

Terrence Higgins Trust website (includes many policy and practice publications including those above) [www.tht.org.uk](http://www.tht.org.uk)