

HIV Services and QIPP

Contents

1. Executive Summary
2. Background
 - 2.1 What is 'QIPP'?
 - 2.2 HIV Services – the current picture
 - 2.3 QIPP and HIV
3. Main Themes
 - 3.1 Outcomes – Developing measures that matter
 - 3.2 Treatment – Developing clinical and cost effective prescribing in the context of choice
 - 3.3 Care – Developing approaches to meet the needs of people living with HIV
 - 3.4 Secondary Prevention – Reducing late diagnosis and promoting earlier testing
4. Appendices
 - 4.1 Potential patient reported outcomes and experience measures for 2011/12 and beyond
 - 4.2 Possible CQUINs for 2011/12 and beyond
 - 4.3 London Clinical Outcomes
 - 4.4 Possible criteria for informing cost-effective prescribing choices
 - 4.5 BHIVA's 'four faces of HIV'

1. Executive Summary

This report is one in a series produced by the Specialised Healthcare Alliance looking at various services, including HIV, which have been prioritised by the National Specialised Commissioning Group in relation to QIPP (a policy which aims to deliver quality and productivity at a time of spending constraint). This report was particularly informed by a stakeholder workshop on HIV services organised by the Alliance and the London Specialised Commissioning Group on 10th September 2010. A wide range of stakeholders including patients, commissioners, clinicians and representatives from patient organisations attended the workshop.

The report sets out some background information on QIPP and HIV services before seeking to distil the major themes explored during the workshop in relation to outcomes, treatment, care and secondary prevention. For each theme, some context and background with regard to the key issues is given (including some salient issues which it was not possible to discuss at the workshop), as well as an overview of the discussion at the event.

Among the most important points to emerge, attention is drawn to:

- **The importance of involving individual patients in discussion at an early stage about potential efficiency savings, for example in relation to home delivery of drugs or the use of generic medicines;**
- **The need to look at clinical and patient outcomes in tandem and to use CQUIN as a means of securing delivery;**
- **The potential opportunity arising from GP commissioning to involve GPs more actively in non-specialised care for people with HIV and to normalise important aspects of prevention, notably testing;**
- **The continuing need for improved IT to support all aspects of care.**

2. Background

2.1 What is 'QIPP'?

Quality, Innovation, Productivity and Prevention (QIPP) is the flagship policy being used by the NHS to find the £15-20 billion of savings identified by Sir David Nicholson as necessary in 2011/14 as a result of rapidly rising demand for services and a challenging fiscal climate.¹

The overall aim of the scheme is to combine improvements in quality of care with efficiency savings which can be reinvested in front-line services. Ideally, quality and productivity will go hand-in-hand, providing a better service for the patient, as well as cost savings for the NHS as a whole.

The National Specialised Commissioning Group (NSCG) has prioritised ten services for taking forward the QIPP agenda, with each Specialised Commissioning Group (SCG) leading on one of the services. The London SCG is leading for HIV services.

The Specialised Healthcare Alliance is looking at nine out of the ten services in relation to QIPP. The Alliance's aim is to ensure a balanced discussion between the four strands of QIPP and to

¹ For background on QIPP: *The NHS Quality, Innovation, Productivity and Prevention Challenge: an Introduction for Clinicians* (March 2010), available [here](#).

identify any common themes which may be relevant to improving quality and efficiency in specialised commissioning across the board.

2.2 HIV Services – the current picture

The Health Protection Agency (HPA) reports that in 2009, 65,319 HIV-infected individuals (of all ages) were seen for HIV care in the UK, representing an increase of 7% on the number seen in 2008 (61,110) and a 250% increase on the number seen in 2001 (26,088).² At the end of 2008, the HPA estimates that there were 83,000 people infected with HIV, of whom over a quarter (27%) were unaware of their infection.³ Today, HIV is classified as a complex, chronic medical condition. At the same time, it retains several features which distinguish it from other long-term conditions.

Until 2009, 'HIV all ages' was included in the Specialised Services National Definitions Set and so was a commissioning responsibility of Specialised Commissioning Groups (SCGs). By that time over 50 treatment centres were providing outpatient care, implying a planning population of less than one million and thereby falling below the statutory definition of specialised. As a result, the third version of the National Definitions Set, which was published recently, no longer includes all types of HIV care. Only complex HIV care and paediatric services are included (these can be found in Definition 18 – Infectious Diseases⁴). While a number of SCGs continue to commission all HIV care and treatment, in some cases commissioning for outpatient care is being returned to Primary Care Trusts.

Under the government's proposals for England, set out in its White Paper *Equity and Excellence: Liberating the NHS*,⁵ the new NHS Commissioning Board will have responsibility for specialised services through national and regional commissioning, as defined by the National Definitions Set. PCT commissioning will be undertaken by GP consortia. The future commissioning arrangements for HIV are still unclear.

Inpatient HIV care is currently covered by Payment by Results (PbR), while outpatient care is not. Outpatient care is funded through local block or tariff arrangements. A project is underway – sponsored by the Department of Health – which aims to develop a national HIV adult outpatient PbR tariff for care. Progress to date has included the mapping of a standard care pathway for three categories of HIV patient (new, stable and complex) and a 'bottom up' costing approach to identify the elements of the pathway, in order to derive national average costs for each category.

2.3 QIPP and HIV

The relatively high cost of treating HIV means that HIV services are likely to come under particular pressure to produce efficiency savings. In addition, the year-on-year growth of the HIV patient population makes these savings, which would be reinvested, essential. At the same time, there are opportunities to drive up the quality of HIV services, for example through the agreement and delivery of various outcomes to measure quality of care.

² Link to web page: [here](#)

³ Link to document: [here](#)

⁴ Link to web page: [here](#)

⁵ Link to document: [here](#)

3. Main Themes

3.1 Outcomes – Developing measures that matter

The government's recent health White Paper places great emphasis on the importance of outcomes for the future of the NHS in England.

The purpose of this workshop session was to explore the outcomes which could be used to measure the quality of HIV services. Two types of outcome were examined at the workshop – patient-reported and clinical – as well as CQUIN goals, which are a way of incentivising outcomes. A focus on outcomes at the beginning of the workshop was designed to help set the scene concerning the standard of quality which could and should be achieved in HIV services.

The main conclusions from this session were:

- **There is a need to fine-tune proposed patient-reported outcome measures in order to ensure clarity and the recording of the most important and appropriate aspects of patients' condition and care;**
- **A key issue is the difficulty of data collection in relation to CQUIN goals, which could be solved through better IT systems;**
- **The three sets of outcome should not sit in isolation; rather there should be clear links between them.**

PETs to PROMs? Measuring the difference for patients

People living with HIV have a strong tradition of helping to shape the care they receive. This willingness on the part of patients to engage with their condition and care must be used to shape effective patient-reported outcomes for HIV.

At present, Patient Experience Trackers (PETs) and other validated tools are used in the NHS to measure the experiences of patients including people living with HIV. While PETs are useful in measuring patient experience, they do not capture the totality of outcomes that matter to patients.

Patient-Reported Outcome Measures (PROMs) are a carefully developed way of measuring the health gain to patients after a particular surgical procedure. The patient's health gain is typically measured using short, pre- and post- operative surveys which are filled out by the patient and which measure patients' health status or health-related quality of life at a single point in time.

While PROMs are currently being used only in relation to a small number of elective procedures, the government's health White Paper sets out plans to expand the use of PROMs 'across the NHS wherever practicable.' In addition, it must be noted that the approach used by PROMs questionnaires is not necessarily new. For example, mental health services and counselling services often use a framework to assess the impact of their intervention.

Participants at the workshop were asked to look at and critique a set of potential patient-reported outcome and experience measures for 2011/12 and beyond (see Appendix 4.1).

Some of the discussion concerned particular aspects of the potential measures. For example, the importance of patients not only knowing their latest CD4 count and viral load but also understanding the significance of these numbers was highlighted. In addition, the difficulty of

capturing some of the measures was discussed, for instance that concerning the ability to improve adherence to treatment. It was also suggested that it is important to take into account and measure all aspects of a patient's condition and situation, including their social, housing and employment needs.

More generally, it was agreed that any patient-related measures should not unrealistically raise patients' expectations about the care they expect to receive. Similarly, measures should be based on what patients believe is important to them and must be presented in a way that is easy for all to understand. Finally, it was noted that it would be important to develop and agree patient-related measures (and clinical outcomes) relevant to children and young people, since adult measures are not always appropriate.

Commissioning for Quality and Innovation (CQUIN)

The Commissioning for Quality and Innovation (CQUIN) payment framework makes a proportion of providers' income conditional on outcomes which demonstrate improvements in quality and innovation in specified areas of care. The goals set by CQUINs may be described as 'stretch' goals since they aim to encourage improvements in the quality of care provided, over and above core requirements.

Participants at the workshop were asked to comment on a possible CQUIN scheme for 2011/12 and beyond which sets out several goals and related indicators (see Appendix 4.2).

Stakeholders across all groups emphasised the difficulty of data collection with regards to CQUIN goals. At present, the collection of data for many trusts involves case note review by clinicians which is extremely time-consuming. It was felt that proper IT systems with appropriate management would help to alleviate this issue.

Many stakeholders highlighted the importance of incentivising prevention to a greater extent through CQUINs. At the same time, it was warned that CQUIN goals must not deter trusts from treating more complicated patients.

London Clinical Outcomes

Stakeholders were provided with information on a set of clinical outcomes being used in London. Unfortunately, because of time pressures, it was not possible to discuss these outcomes in detail on the day. However, stakeholders were encouraged to record their comments on the outcomes during the workshop or to email their comments after the event, including their thoughts on whether it would be appropriate to roll out the London outcomes nationally.

The London clinical outcomes have been produced with clinicians and the HPA and were developed by combining surveillance data from a number of surveillance systems collated at the HPA.

The four clinical outcomes and the standards set by the London HIV Consortium can be found in Appendix 4.3.

3.2 Treatment – Developing clinical and cost effective prescribing in the context of choice

Since the mid-late 1990s, people living with HIV in the UK have been treated using a combination of antiretroviral drugs. This treatment approach is known as ‘highly active antiretroviral therapy’ or HAART and its aim is to reduce viral load to an undetectable level. HAART is not a cure, but has brought about a vast improvement in terms of life expectancy and quality of life for those living with HIV. It has also contributed to a reduction in onward transmission as a result of reduced infectivity. At the same time, the use of HAART can induce extreme side effects, some people can become resistant to certain treatment regimens and the long-term consequences of life-long treatment are, on the whole, still unknown.

HIV drugs are estimated to account for 65-70% of the total cost of treatment and care. At the same time, the HIV patient population is growing each year as a result of the longer life expectancy of people living with HIV since the introduction of HAART. A growing patient population puts pressure on resources, as more people require treatment. Clinicians and patients are already working together to come up with solutions to reduce costs such as home delivery of drugs (drugs delivered to a person’s home are not subject to VAT) and projects to reduce drug wastage.

The purpose of the workshop session on treatment was to explore ways to ensure affordability of effective treatments for the growing HIV patient population. Participants were asked to discuss a list of possible ways to make the best use of limited resources (see Appendix 4.4). Various issues needed to be taken into account, including current treatment guidelines and choice, which are discussed below.

The main conclusions from this session were:

- **There is the potential to expand the use of home delivery of drugs, although caution is required;**
- **Reducing drug wastage should be explored further as a method for saving money;**
- **The importance of patient choice must not be overlooked when making prescribing decisions;**
- **When considering cost-effectiveness, it is important not to consider treatment costs in isolation, but to look at how the service is delivered as a whole.**

Treatment Guidelines

BHIVA (British HIV Association) guidelines for treatment with HAART (2008)⁶ recommend that treatment should begin in all patients with a CD4 count <350.

The guidelines also set out the Writing Group’s recommendations for treatment options with reference to both the stage in the patient pathway and any complications in the patient’s medical profile. For example, the guidelines recommend the non-nucleoside reverse transcriptase inhibitor (NNRTI) efavirenz as part of the first line treatment of all patients based upon the drug’s ‘efficacy, durability, toxicity profile, convenience and cost.’ However, in HIV there is a high level of individualised prescribing in the context of the guidelines, based on assessment by the clinician and patient in selecting the most effective treatment regimen. At present BHIVA guidelines are not equivalent to NICE technology appraisals and draw on expert opinion as well as randomised clinical trials.

⁶ Link to document: [here](#)

The BHIVA guidelines emphasise that HAART is extremely cost effective, but acknowledge that the price of newly introduced HIV treatments is high, while generic drugs are becoming available.

Participants at the workshop felt that it was important for BHIVA to continue to set treatment guidelines as a result of clinical evidence.

There was some discussion about the potential involvement of NICE, particularly with regards to expensive salvage therapies. While some participants felt that the involvement of NICE would be detrimental to patients, others suggested that those drugs which had been used as salvage therapies are now being used for wider purposes and are perhaps not as expensive as once thought.

It was acknowledged that the use of generic drugs could result in people taking more pills per day than usual. There was agreement that for some people with HIV, such as those who have problems with adherence or who suffer from dementia, this would not be a viable option.

Choice

The volume of information available on treatment options and development (for example NAM's monthly *hiv treatment update*) means that many people living with HIV have a very good understanding of their condition and their treatment options.

The decision to change a person's treatment regimen may be a result of one or more of the following: a) toxicity/side effects, b) resistance, c) difficulties with adherence, d) patient choice.

It is clear that various factors influence the decision to prescribe a particular treatment regimen, embodied by the differing viewpoints of the patient, the clinician and the commissioner, and that all factors cannot carry equal weight in every instance. The issue of choice is made more complex by the ever-growing number of treatment options, evolving attitudes concerning the clinical efficacy of existing and new treatments, as well as the emergence of previously unknown side effects or long-term consequences for a person's health of particular drugs – all of which must be considered in the context of limited resources.

The issue of choice was widely discussed at the workshop. Participants debated whether clinicians should be able to make decisions on behalf of their patients, for example regarding the number of pills which a person should take each day.

Choice was also discussed in the context of home delivery of medication. It was recognised that home delivery was not appropriate for all people with HIV. Examples of medication being sent to the wrong address were given and the potential difficulties of home delivery to shared housing were acknowledged.

Horizon Scanning

While it was not possible to discuss the issue of emerging HIV treatments in detail at the workshop, it is vital to point out that the development of new treatments has moved at an extremely rapid pace in the past and that this trend is set to continue.

In particular, as the number of older patients with prolonged exposure to established treatments grows, the need to develop new drugs for those who show resistance will increase. A limited number of treatment options which fall into new categories of drugs, such as fusion inhibitors, entry inhibitors and integrase inhibitors, have become available and others are in development.

3.3 Care – Developing approaches to meet the needs of people living with HIV

HIV services in the UK were first developed before the introduction of HAART and therefore needed to provide a lot of scope for inpatient care. By contrast, most people living with HIV today require very little inpatient care and are likely both to make greater use of outpatient services and to have a greater involvement in their own care.

The focus of this workshop session was the group of patients that may be described as 'stable' (according to BHIVA's 'four faces of HIV' – see Appendix 4.5) and the new models of care required to meet these patients' needs. Participants were asked to consider a model of care under development in North East London and elsewhere which involves the monitoring of stable patients led by specialist nurses, a greater emphasis on self-management and the use of technology and approaches such as e-clinics/t-clinics (blood test results are sent by email or given over the phone). Participants also considered what role GPs should play in the care of people with HIV. Key issues including the appropriate setting of care and patient support are discussed in detail below.

The main conclusions from this session were:

- **Appropriate IT systems would improve patient care – a single national database would be the ideal option;**
- **Patient choice and patient need must be taken into account when making decisions about a person's care;**
- **GP involvement in the care of people with HIV still creates debate, but is likely to become essential as the patient population continues to grow.**

Settings of Care

BHIVA *Standards for HIV Clinical Care* (March 2007)⁷ recommend that clinical care for diagnosed HIV infection in adult patients should be delivered through 'managed clinical networks'. The design of these networks, which involve one specialised HIV centre with associated outpatient units, reflects the reduced need for large numbers of inpatient beds and an associated increase in the volume of care provided in an outpatient setting.

In early 2009, BHIVA consulted on a briefing paper on primary and community based care for people living with HIV⁸ and a subsequent report on standards in primary and community care is planned for 2010/11. While the *BHIVA Standards* (2007) recommend that people living with HIV should be strongly advised to register with a GP, the briefing document highlights that GPs have traditionally not played a major role in the care of people with HIV in the UK. It therefore sets out the benefits of extending the role of primary and community care (for example, primary care and community clinics can be more convenient than hospitals and primary care has particular strengths in areas which have become important as people with HIV live longer, such as cardiovascular disease prevention, blood pressure and lipid management), as well as various ways in which this could be done. If primary and community healthcare providers become engaged to a greater extent in the primary care needs of people with HIV, greater involvement in other aspects of care could be introduced. For example, GPs could take responsibility for some aspects of monitoring of HIV infection for stable patients.

There was some acknowledgement at the workshop that there was a need to debate the skills mix required in caring for patients with HIV, as well as the frequency of monitoring of stable

⁷ Link to document: [here](#)

⁸ Link to document: [here](#)

patients, to ensure that consultant expertise is focused on the most complex patients. At the same time, it was recognised that it would be important for the lead clinician to retain clear accountability for their patients. There was broad agreement that patients who are seen most regularly by a specialist nurse should have an annual comprehensive assessment by their clinician, which would include a social and psychological review. It was felt that this would help to improve the quality of patient care, while ensuring that the consultant's time was used most effectively.

Some stakeholders believed that it was important for people with HIV, particularly those who are newly diagnosed, to be encouraged to see their GPs for various aspects of their care which are not directly related to the monitoring of their HIV infection, with some suggesting that GPs could eventually take on a more direct role in the monitoring of the infection. On the other hand, some participants felt that patients would receive better care if they were treated, even for routine health issues, in an HIV clinic. These people argued that specialised clinics know their patients and their needs and that referral for any complications can be done quickly and easily from this setting. In addition, it was argued that there is no clear evidence that providing care in the community is cheaper than in a hospital setting and that training up GPs to give appropriate care and support to people with HIV would itself cost money.

More generally, it was widely acknowledged that even within the 'stable' cohort, there would be variation in need. Patients should be aware that they are seen to be within this cohort and there should be clear mechanisms in place for deciding when a patient should be moved in or out of this group. In addition, it was recognised that patients should retain some choice over the care which they receive, including the setting of this care. Finally, it was noted that it is important to understand that an increased role for community and primary care works in some settings, but not others. In Brighton, for example, this model has proved successful principally because the gay community in the city has good links with GPs.

There was also general recognition that better IT systems would improve patient care, especially if care were to be provided in different settings by a number of healthcare professionals, as well as help to reduce duplication.

Patient Support

The AIDS Support Grant is paid to local councils to meet the additional costs of social care support for people living with HIV. However, in July 2010, the ring-fence protecting the Grant was removed, meaning that there is no obligation for councils to spend the Grant on HIV social care services. It has been argued that without provision of social care support in the community, there will be a greater pressure on healthcare professionals in clinical settings to provide this support.

The role of the voluntary and community sector is key in providing support to patients. There are many organisations providing different kinds of support across the country. The Positive Self-Management Programme, for example, is run by the Living Well scheme, while Terrence Higgins Trust provides a wide range of support services, which include emotional support, practical advice on employment, immigration, housing and finances and contact with support groups.

There was general recognition at the workshop of the importance of providing support to the full set of needs of people with HIV. The benefits of providing proper support to people with HIV are clear and include the likelihood of individuals showing greater adherence to treatment regimens as well as maintaining regular clinic attendance.

Transition and End of Life Care

Unfortunately, there was not time at the workshop to cover the issues of transition from children's to adults' services for people with HIV and care for older people with HIV. However, a brief overview of the current situation with regards to these key issues is given below.

Transition

Definition 18 of the National Definitions Set explains that the decline in mortality rates among children has led to new challenges for multidisciplinary teams as children grow up. The document explains that many centres are now developing combined adolescent clinics with adult HIV teams.

End of Life Care

The effects of long-term treatment of HIV are still unknown. As stable patients grow older, their condition is likely to become more complex. A greater number of problems is now recognised as being associated with the virus and/or its treatment, for example an increased risk of cardiovascular disease, liver disease, various cancers, kidney disease, osteoporosis and neurocognitive disorders. It is clear, however, that whilst end of life care for people with HIV has changed significantly with the reduction in mortality, future needs are likely to be complicated and, to some extent, the care requirements for such people are still unknown.

One of the benefits of an increased role of primary and community care in HIV services as set out in BHIVA's briefing paper is concerned with care of older people. The paper stresses that, unlike primary care providers, HIV specialists will be ill-equipped to cope as increasing numbers of people with HIV reach old age and develop a range of co-morbid conditions and social care needs.

3.4 Secondary Prevention – Reducing late diagnosis and promoting earlier testing

Primary prevention of HIV involves actions aimed at stopping people from becoming infected with the virus. Preventing the 3,550 HIV infections that were probably acquired in the UK and subsequently diagnosed in 2008, would have reduced future HIV-related costs by more than £1.1 billion (HPA).

Secondary prevention of HIV is vital since the early identification of HIV infection means that a person is more likely to respond well to treatment and to remain in a 'stable' condition (see above). Decreasing late diagnosis of HIV is therefore the central aim of secondary prevention of HIV (early diagnosis is also closely linked with primary prevention, since individuals with HIV who are aware of their status are less likely to engage in behaviour which could result in the onward transmission of the infection).

Late diagnosis is the most important factor associated with HIV-related morbidity and mortality in the UK and has been associated with impaired response to HAART, as well as increased cost to healthcare services. According to the HPA,⁹ in 2008 an estimated 32% of adults aged over 15 years had a CD4 cell count <200 within three months of diagnosis (a CD4 count <200 remains the definition for late diagnosis, although the recommended threshold to treat has been changed to <350 – in 2008, over half of patients were diagnosed with a CD4 cell count <350 within three months of diagnosis). In addition, national surveillance data show that over a quarter of all HIV infections in adults in the UK remain undiagnosed.

This session focused on the importance of secondary prevention and the potential methods for reducing late diagnosis. Various issues were taken into account, including the potential setting of testing and the normalising of testing. These are discussed in more detail below.

The main conclusions from this session were:

- **Testing must take place in those settings recommended by the UK National Guidelines;**
- **Testing should take place in further settings, such as in A&E departments in areas of high prevalence;**
- **We should learn from the successes in introducing universal testing in antenatal settings;**
- **Testing should become normalised. A shift in attitudes towards HIV testing is required;**
- **When GPs take over responsibility for commissioning outpatient HIV services, this could facilitate a greater role for primary care in testing and early diagnosis.**

Testing

Testing guidelines and settings

The UK National Guidelines for HIV Testing 2008¹⁰ recommend that an opt-out approach to HIV testing should be implemented in GUM clinics, antenatal services, termination of pregnancy services, drug dependency programmes and healthcare services for those diagnosed with TB, hepatitis B, hepatitis C and lymphoma. Testing services are also increasingly being offered by voluntary sector organisations outside of clinical settings. The Department of Health has funded eight projects across the country which are piloting HIV testing in healthcare and community settings. A pilot in Brighton, for example, involves all new registrants aged 16-59 at 19 GP practices being routinely offered an HIV test.

Stakeholders at the workshop felt strongly that testing must take place in those settings

⁹ Link to document: [here](#)

¹⁰ Link to document: [here](#)

recommended by the *Guidelines*, particularly in TB clinics, where it was reported that testing is not happening as widely as it should.

It was also recognised that although BHIVA testing guidelines recommend that in areas where the prevalence of HIV is more than 2 in 1000 any person who registers with a GP should be offered an HIV test, testing take-up rates suggest that at present this is not happening. Stakeholders recognised that it is possible that GPs perceive HIV testing to be more time-consuming and complicated than it is in reality. However, there was wide agreement that pre-test counselling is no longer required and that in fact in most cases this is no longer the normal practice.

There was also broad agreement concerning the widening of settings of HIV testing. This could involve targeted testing to include, for example, gay saunas, as well as universal testing in A&E in areas of high prevalence. It was suggested that a CQUIN goal could be introduced on testing in A&E and the importance of setting outcomes on prevention more generally was highlighted.

'Normalising' HIV testing

One of the main aims of the 2008 testing guidelines is to reduce the stigma around HIV testing by 'normalising' the process, particularly within clinical settings.

Terrence Higgins Trust is campaigning for the introduction of a national screening programme which it argues would reduce the stigma of having an HIV test. The programme would distinguish between areas of high and low prevalence and would be targeted at particular populations which are at greater risk, but would also maximise opportunities to test within the NHS and would encourage the rolling out of community testing.

There was strong agreement at the workshop that a significant shift in attitudes towards HIV testing is required. It was felt that this was the responsibility not only of the voluntary sector, which has traditionally taken on this role, but also of healthcare professionals, particularly those working in primary care.

The issue of a national screening programme was raised, with some stakeholders suggesting it would be unfeasible, but with others highlighting that the possibility of such a programme would at least spark important debate.

4. Appendices

4.1 Potential patient reported outcomes and experience measures for 2011/12 and beyond

Type of goal	Description of goal	Possible measures
Patient Experience (measure of satisfaction and involvement)	To ensure services are planned and delivered with the involvement of patients	<p>Services undertake an annual survey of experience and publish the results</p> <p>Services have a patient forum or equivalent</p> <p>Services collect and respond to comments, compliments and complaints</p>
Patient Experience (measure of satisfaction and involvement)	To improve patient experience and support patients to self manage their HIV	<p>Patients involved in decisions about their care and supported to self manage as measured by responses to three questions in a survey:</p> <ul style="list-style-type: none"> • Were you involved in decisions about your care and treatment? • Were you given ready access to information about your condition? • Were you supported to manage your care?
Patient Experience (measure of satisfaction and involvement)	To ensure patients are involved in their care	<p>Patients know their latest CD4 count</p> <p>Patients know their latest viral load</p>
Patient reported outcomes (measure of health status)	To measure impact of HIV care and treatment on overall health and wellbeing	<p>Ability to participate in usual activities (work, housework, family, leisure)</p> <p>Experience of pain</p> <p>Experience of side effects</p> <p>Experience of anxiety/depression</p> <p>Ability to improve adherence to treatment</p> <p>Ability to make improved lifestyle choices eg giving up smoking, doing exercise etc.</p>

4.2 Possible CQUINs for 2011/12 and beyond

Please note that the patient experience goal on self-management, normally included as a CQUIN goal is omitted below since it was discussed as part of patient reported outcomes/experience measures (see Appendix 4.1).

Type of goal	Description of goal	Description of indicator
Effectiveness	To ensure HIV therapy is optimised	<p>Patients with no resistance on NNRTI (non-nucleoside reverse transcriptase inhibitors) therapy</p> <p>Patients failing therapy re-suppressed within 6 months</p> <p>Patients with a CD4 <200 on therapy</p> <p>Adherence to ART documented</p>
Prevention	To support primary and secondary prevention	<p>HIV patients with positive STI results have health advice and support</p> <p>Patients notified for TB (or other indicator conditions) tested for HIV</p> <p>Enhance partner notification of newly diagnosed to promote testing</p> <p>Patients with 10-year cardiovascular disease risk calculated</p> <p>Annual assessment of weight, blood pressure, BMI etc</p>
Safety	To increase the role of primary care in the care of HIV patients	Annual correspondence with GP where patients have disclosed their HIV status

4.3 London Clinical Outcomes

Outcome	Aim	Standard	Patients included in the analyses
Outcome 1: Time interval between HIV diagnosis and date of first CD4 count at the same centre. This is used as a proxy for date of the first appointment with a clinician.	To ensure patients newly diagnosed with HIV are promptly integrated into HIV care.	100% of newly diagnosed patients receive a CD4 cell count within 28 days.	All newly diagnosed patients at the centre with an available CD4 count.
Outcome 2: Viral load <50 and still on therapy 1 year after therapy first started.	To monitor the effectiveness of HAART after one year treatment.	85% of patients who started treatment have a viral load <50 copies.	Patients with a VL count available after 9-15 months starting HAART.
Outcome 3: Patients to have CD4 ≥ 200 after 1 year or more at centre.	To monitor immune status of patients after one year or more of HIV clinical	90% of patients in care should have a CD4 ≥ 200.	Patients in clinical care at same centre for a year or more.

	care.		
Outcome 4: Proportion of patients still alive by 1, 2, 3 years from HIV diagnosis, stratified by CD4 count at diagnosis.	To identify early death among patients recently diagnosed and receiving HIV care.	No standard, death rate calculated.	Patients newly diagnosed at centre.

4.4 Possible criteria for informing cost-effective prescribing choices

- Switch patients to cheaper alternatives, including moving from one to more pills a day;
- Use of generic drugs;
- Home delivery as the norm;
- Programmes to reduce drug wastage;
- Standardised treatment guidelines to manage use of new/expensive drugs;
- Prior approval/peer review for use of the most expensive drugs;
- Threshold for treatment (eg not at CD4 > 350 unless AIDS diagnosis/Hep B/C co-infection or enrolled on clinical trial);
- Divert funding from 'care' to 'treatment'.

4.5 BHIVA's 'four faces of HIV.'

This model sets out four different patient profiles, including an outline of the care that each should receive:

- **Stable** – HIV treatment and care is relatively straightforward, no major social or medical issues complicating HIV care. Scope for increased self-management, as long as there are clear links and support from clinical services;
- **'Co-morbid'** – care is medically complex as a consequence of co-infection, ageing, effects of long-term treatment such as for osteoporosis, cardio-vascular disease, HIV or non-HIV malignancies and neurological conditions. Requires specialised care but needs are mostly predictable;
- **Complex social problems** – individuals with issues such as housing, drug or alcohol use, significant mental health issues or neuro-cognitive impairment. Characterised by erratic attendance, poor adherence, failure to achieve and maintain virological suppression. Needs cannot be met in a traditional, clinical setting as it is often difficult to retain them within services.
- **'Wild card'** – previously undiagnosed infection, presents as an emergency at a centre without HIV specialism with, for example, Pneumocystis Pneumonia (PCP), and is difficult to plan for.