

UK National Guidelines for HIV Testing 2008

prepared jointly by

British HIV Association

British Association of Sexual Health and HIV

British Infection Society



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Executive summary

- HIV is now a treatable medical condition and the majority of those living with the virus remain fit and well on treatment.
- Despite this a significant number of people in the United Kingdom are unaware of their HIV infection and remain at risk to their own health and of passing their virus unwittingly on to others.
- Late diagnosis is the most important factor associated with HIV-related morbidity and mortality in the UK.
- Patients should therefore be offered and encouraged to accept HIV testing in a wider range of settings than is currently the case.
- Patients with specific indicator conditions should be routinely recommended to have an HIV test.
- All doctors, nurses and midwives should be able to obtain informed consent for an HIV test in the same way that they currently do for any other medical investigation.

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Contents

1	Introduction	1
2	Background	2
3	Confidentiality and HIV testing	4
4	Recommendations for testing	5
	4.1 Who can test?	5
	4.2 Who should be offered a test?	5
	4.3 How often to test?	6
	4.4 Which test to use?	8
5	Pre-test discussion	10
6	Post-test discussion	11
7	Suspected primary HIV infection	13
	Appendix 1: <i>Providing written confirmation of results</i>	14
	Appendix 2: <i>Detailed post-test discussion and partner notification</i>	14
	Appendix 3: <i>Community-based HIV testing</i>	14
	Appendix 4: <i>Testing where the patient lacks capacity to consent</i>	15
	Appendix 5: <i>Testing infants, children and young people</i>	16
	Appendix 6: <i>The source patient in a needlestick injury or other HIV risk exposure</i>	18
	Appendix 7: <i>HIV testing and insurance</i>	18
	Appendix 8: <i>HIV testing and criminal prosecution for HIV transmission</i> ...	18
	Appendix 9: <i>Auditable standards</i>	19
	Acknowledgements	20
	References	21

1

Introduction

These guidelines are intended to facilitate an increase in HIV testing in all healthcare settings as recommended by the UK's Chief Medical Officers and Chief Nursing Officers [1–4] in order to reduce the proportion of individuals with undiagnosed HIV infection, with the aim of benefiting both individual and public health. Misconceptions remain regarding HIV testing that hinder increased testing. In particular, many clinicians believe that lengthy pre-test counselling is required prior to testing. These guidelines provide the information needed to enable any clinician to perform an HIV test within good clinical practice and encourage 'normalisation' of HIV testing.

For this change in approach to be beneficial and ethically acceptable, it is imperative that following a positive HIV diagnosis, a newly diagnosed individual is immediately linked into appropriate HIV treatment and care.

This guidance refers to both diagnostic testing of individuals presenting with 'clinical indicator diseases' (i.e. where HIV infection enters the differential diagnosis) and opportunistic screening of populations where this is indicated on the basis of prevalence data. We also include an appendix on the provision of community-based HIV testing (Appendix 3).

It must be emphasised that in the UK, HIV testing remains voluntary and confidential. This is entirely possible within any healthcare setting if these guidelines are followed.

2

Background

Whilst the availability of highly active antiretroviral therapy (HAART) has transformed the outcome for individuals with HIV infection, there continues to be significant and avoidable morbidity and mortality relating to HIV infection in the UK. A national audit by the British HIV Association (BHIVA) showed that of deaths occurring amongst HIV-positive adults in the UK in 2006, 24 per cent were directly attributable to the diagnosis of HIV being made too late for effective treatment [5]. Furthermore, it has been shown that many of these 'late presenters' have been seen in the recent past by healthcare professionals without the diagnosis having been made [6]. National surveillance data shows that approximately one-third of all HIV infections in adults in the UK remain undiagnosed [7] and that approximately 25 per cent of newly diagnosed individuals have a CD4 cell count of less than 200 (an accepted marker of 'late' diagnosis).

Late diagnosis of HIV infection has been associated with increased mortality and morbidity [7], impaired response to HAART [8] and increased cost to healthcare services [9]. Furthermore, from a public health perspective, knowledge of HIV status is associated with a reduction in risk behaviour [10] and therefore it is anticipated that earlier diagnosis will result in reduced onward transmission [11]. Modelling has suggested that over 50 per cent of new infections in the US occur through transmission from individuals in whom HIV has not been diagnosed. Furthermore, modelling in the US has also suggested that routine screening for HIV infection is cost effective and comparable to costs of other routinely offered screening where the prevalence of HIV exceeds 0.05 per cent [12].

All the published literature suggests that uptake of testing is increased where universal routine ('opt-out') strategies have been adopted [13–15].

Universal HIV ('opt-out') testing means that all individuals attending specified settings are offered and recommended an HIV test as part of routine care but an individual has the option to refuse a test.

Prior to 2001, HIV testing was largely confined to individuals presenting and requesting HIV testing in GUM clinics. The uptake of testing was low and a significant proportion of HIV-positive individuals were known to remain undiagnosed. The National Strategy for Sexual Health and HIV (2001) [16] recommended that all attendees at GUM clinics should be offered an HIV test with clear targets for the proportion offered testing and test uptake. Since this policy was introduced the proportion of infections which remain undiagnosed has reduced but still remains significant [25% in heterosexuals, 47% in men who have sex with men (MSM)] [7]. The majority of GUM clinics now utilise a universal 'opt-out' approach to testing with high acceptability and success although the reasons why some high-risk individuals still refuse testing require further study.

In the antenatal setting, prior to 2000, uptake of HIV testing was highly variable and dependent upon healthcare worker factors rather than clinical need.

The only randomised controlled trial published to date [13] on testing methods showed that a universal 'opt-out' approach to HIV testing in antenatal patients was acceptable, did not cause anxiety and had a higher uptake than other methods. Assessing patients for risk merely reduced the number of patients tested and it is recognised that women who refuse antenatal testing are more likely to be HIV positive.

The adoption of universal opt-out testing [17] has resulted in a dramatic improvement in antenatal testing rates and a significant reduction in the proportion of HIV infections that remain undiagnosed prior to delivery, from 18 per cent in 2000 to fewer than 10 per cent in 2006 [7]. Furthermore the median CD4 cell count at HIV diagnosis of women detected through antenatal screening has been consistently higher than among other women (even after adjusting for age) and heterosexual men diagnosed with HIV. This indicates that efforts to detect HIV infection in asymptomatic individuals are likely to result in earlier diagnosis, hence reducing morbidity and mortality in diagnosed individuals as well as reducing onward transmission [7].

In the USA in 2006 the Centers for Disease Control and Prevention (CDC) recommended opt-out testing for all individuals aged 13 to 64 presenting to any healthcare facility (mainly Emergency Rooms) for any reason [18]. Initial reports suggest that this has been successful in increasing the number of new HIV diagnoses but barriers continue to exist including legal requirements in some states regarding testing, a requirement for written consent, and lack of access for some patients to ongoing HIV treatment and care [19].

In the UK, where the vast majority of patients have access to healthcare free at the point of delivery, all patients have access to a general practitioner, and where there are pressures upon Emergency Departments to achieve four-hour waiting targets, we believe universal opt-out testing in all settings may not be the most feasible approach but support the use of opt-out testing in certain situations.

3

Confidentiality and HIV testing

HIV testing has historically been exceptionalised and treated differently to testing for other serious medical conditions. The outlook for individuals testing positive for HIV is now better than for many other serious illnesses for which clinicians routinely test. Whilst there remains stigma associated with HIV infection, this can be minimised by following the general principles of confidentiality for any medical condition as laid down by the GMC in its guidance *Confidentiality: protecting and providing information* [20].

'Patients have a right to expect that information about them will be held in confidence by their doctors. Confidentiality is central to trust between doctors and patients. Without assurances about confidentiality, patients may be reluctant to give doctors the information they need in order to provide good care.'

The result of an HIV test (if positive) should be given directly by the testing clinician (or team) to the patient and not via any third party, including relatives or other clinical teams unless the patient has specifically agreed to this (see section on post-test discussion).

4

Recommendations for testing

4.1

Who can test?

It should be within the competence of any doctor, midwife, nurse or trained healthcare worker to obtain consent for and conduct an HIV test.

4.2

Who should be offered a test?

A. Universal HIV testing is recommended in all of the following settings:

1. GUM or sexual health clinics
2. antenatal services
3. termination of pregnancy services
4. drug dependency programmes
5. healthcare services for those diagnosed with tuberculosis, hepatitis B, hepatitis C and lymphoma.

B. An HIV test should be considered in the following settings where diagnosed HIV prevalence in the local population (PCT/LA) exceeds 2 in 1000 population (see local PCT data[†]):

1. all men and women registering in general practice
2. all general medical admissions.

The introduction of universal HIV testing in these settings should be thoroughly evaluated for acceptability and feasibility and the resultant data made available to better inform the ongoing implementation of these guidelines.

C. HIV testing should be also routinely offered and recommended to the following patients:

1. all patients presenting for healthcare where HIV, including primary HIV infection, enters the differential diagnosis (see table of indicator diseases and section on primary HIV infection)
2. all patients diagnosed with a sexually transmitted infection
3. all sexual partners of men and women known to be HIV positive
4. all men who have disclosed sexual contact with other men
5. all female sexual contacts of men who have sex with men
6. all patients reporting a history of injecting drug use
7. all men and women known to be from a country of high HIV prevalence (>1%*)
8. all men and women who report sexual contact abroad or in the UK with individuals from countries of high HIV prevalence.*

* for an up to date list see

<http://www.unaids.org/en/KnowledgeCentre/HIVData/Epidemiology/latestEpiData.asp>

[†] Diagnosed prevalence is a good indicator of the undiagnosed prevalence in a population (ratio 2:1). All PCTs are routinely informed of the diagnosed prevalence rate by the Health Protection Agency (HPA) Survey of Prevalent HIV Diagnoses (SOPHID) data on an annual basis (further information on SOPHID data and its dissemination is available at http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1201767906579). A diagnosed prevalence exceeding 2 in 1000, in those aged between 15 and 59, is a proxy for an undiagnosed prevalence exceeding 1 in 1000, the threshold at which routine testing is assumed to be cost effective based on the US data [18].

D. HIV testing should also be routinely performed in the following groups in accordance with existing Department of Health guidance:

1. blood donors
2. dialysis patients
3. organ transplant donors and recipients.

4.3. How often to test?

Repeat testing should be provided for the following groups:

1. all individuals who have tested HIV negative but where a possible exposure has occurred within the window period
2. men who have sex with men (MSM) – annually or more frequently if clinical symptoms are suggestive of seroconversion or ongoing high risk exposure
3. injecting drug users – annually or more frequently if clinical symptoms are suggestive of seroconversion (see section on primary HIV infection)
4. antenatal care – women who refuse an HIV test at booking should be re-offered a test, and should they decline again a third offer of a test should be made at 36 weeks. Women presenting to services for the first time in labour should be offered a point of care test (POCT).

A POCT test may also be considered for the infant of a woman who refuses testing antenatally.

In areas of higher seroprevalence, or where there are other risk factors, women who are HIV negative at booking may be offered a routine second test at 34–36 weeks' gestation as recommended in the BHIVA pregnancy guidelines [21].

Table 1: Clinical indicator diseases for adult HIV infection

	AIDS-defining conditions	Other conditions where HIV testing should be offered
Respiratory	Tuberculosis Pneumocystis	Bacterial pneumonia Aspergillosis
Neurology	Cerebral toxoplasmosis Primary cerebral lymphoma Cryptococcal meningitis Progressive multifocal leucoencephalopathy	Aseptic meningitis/encephalitis Cerebral abscess Space occupying lesion of unknown cause Guillain–Barré syndrome Transverse myelitis Peripheral neuropathy Dementia Leucoencephalopathy
Dermatology	Kaposi's sarcoma	Severe or recalcitrant seborrhoeic dermatitis Severe or recalcitrant psoriasis Multidermatomal or recurrent herpes zoster
Gastroenterology	Persistent cryptosporidiosis	Oral candidiasis Oral hairy leukoplakia Chronic diarrhoea of unknown cause Weight loss of unknown cause Salmonella, shigella or campylobacter Hepatitis B infection Hepatitis C infection
Oncology	Non-Hodgkin's lymphoma	Anal cancer or anal intraepithelial dysplasia Lung cancer Seminoma Head and neck cancer Hodgkin's lymphoma Castleman's disease
Gynaecology	Cervical cancer	Vaginal intraepithelial neoplasia Cervical intraepithelial neoplasia Grade 2 or above
Haematology		Any unexplained blood dyscrasia including: <ul style="list-style-type: none"> • thrombocytopenia • neutropenia • lymphopenia
Ophthalmology	Cytomegalovirus retinitis	Infective retinal diseases including herpesviruses and toxoplasma Any unexplained retinopathy
ENT		Lymphadenopathy of unknown cause Chronic parotitis Lymphoepithelial parotid cysts
Other		Mononucleosis-like syndrome (primary HIV infection) Pyrexia of unknown origin Any lymphadenopathy of unknown cause Any sexually transmitted infection

Table 2: Clinical indicator diseases for paediatric HIV infection

	AIDS-defining conditions	Other conditions where HIV testing should be considered
ENT		Chronic parotitis Recurrent and/or troublesome ear infections
Oral		Recurrent oral candidiasis Poor dental hygiene
Respiratory	Pneumocystis CMV pneumonitis Tuberculosis	Recurrent bacterial pneumonia Lymphoid interstitial pneumonitis Bronchiectasis
Neurology	HIV encephalopathy meningitis/encephalitis	Developmental delay Childhood stroke
Dermatology	Kaposi's sarcoma	Severe or recalcitrant dermatitis Multidermatomal or recurrent herpes zoster Recurrent fungal infections Extensive warts or molluscum contagiosum
Gastroenterology	Wasting syndrome Persistent cryptosporidiosis	Unexplained persistent hepatosplenomegaly Hepatitis B infection Hepatitis C infection
Oncology	Lymphoma Kaposi's sarcoma	
Haematology		Any unexplained blood dyscrasia including: <ul style="list-style-type: none"> • thrombocytopenia • neutropenia • lymphopenia
Ophthalmology	Cytomegalovirus retinitis	Any unexplained retinopathy
Other	Recurrent bacterial infections (e.g. meningitis, sepsis, osteomyelitis, pneumonia etc.) Pyrexia of unknown origin	

4.4

Which test to use?

There are two methods in routine practice for testing for HIV involving either venepuncture and a screening assay where blood is sent to a laboratory for testing or a rapid point of care test (POCT).

Blood tests

The recommended first-line assay is one which tests for HIV antibody AND p24 antigen simultaneously. These are termed fourth generation assays, and have the advantage of reducing the time between infection and testing HIV positive to one month which is one to two weeks earlier than with sensitive third generation (antibody only detection) assays [22]. It is reasonable to expect universal provision of these assays, although they are not offered by all primary screening laboratories.

HIV RNA quantitative assays (viral load tests) are not recommended as screening assays because of the possibility of false positive results, and also only marginal advantage over fourth generation assays for detecting primary infection.

Confirmatory assays

Laboratories undertaking screening tests should be able to confirm antibody and antigen/RNA. There is a requirement for three independent assays, able to distinguish HIV-1 from HIV-2. These tests could be provided within the primary testing laboratory, or by a referral laboratory. All new HIV diagnoses should be made following appropriate confirmatory assays and testing a second sample.

Testing including confirmation should follow the standards laid out by the Health Protection Agency [23].

Point of care testing (POCT)

Point of care tests offer the advantage of a result from either a fingerprick or mouth swab sample within minutes. They have advantages of ease of use when venepuncture is not possible, e.g. outside conventional healthcare settings and where a delay in obtaining a result is a disadvantage, but these must be weighed against the disadvantages of a test which has reduced specificity and reduced sensitivity versus current fourth generation laboratory tests. Due to the low specificity of POCT and therefore the resulting poor positive predictive value all positive results must be confirmed by serological tests as there will be false positives, particularly in lower prevalence environments. Only CE-marked POCT kits should be used and a nominated accredited pathology laboratory should assist with governance issues and quality assurance of the testing process.

POCT is therefore recommended in the following contexts (see BASHH Point of Care Testing Guidance) [24]:

1. clinical settings where a rapid turnaround of testing results is desirable
2. community testing sites
3. urgent source testing in cases of exposure incidents
4. circumstances in which venepuncture is refused.

General laboratory issues

All laboratories undertaking any diagnostic HIV services should be able to demonstrate satisfactory external quality control data for the tests undertaken, and should have full accreditation status [23] [such as clinical pathology accreditation (CPA)].

All laboratories must have satisfactory HIV diagnosis confirmatory assay systems available to allow timely definitive diagnoses. This may involve referring samples to specialist virology laboratories, if appropriate, or even national reference laboratories.

All acute healthcare settings should expect to have access to an urgent HIV screening assay result ideally within eight hours, and definitely within 24 hours, to provide optimal support for exposure incidents.

Routine opt-out test results should be expected to be available within 72 hours.

5

Pre-test discussion

The primary purpose of pre-test discussion is to establish informed consent for HIV testing. Lengthy pre-test HIV counselling is not a requirement, unless a patient requests or needs this [1–4].

The essential elements that the pre-test discussion should cover are:

- the benefits of testing to the individual
- details of how the result will be given.

This approach has been successful in GU and antenatal clinics and is generally acceptable.

For some patients raising the issue of HIV testing in other scenarios might require more explanation as to why the doctor or nurse is recommending this, for example when a patient presents with a condition which is more common in HIV infection.

As with any other medical investigation the discussion should address any other issues which may be raised by the patient as it is important that patients are given the opportunity to make a decision with adequate information about the test and the virus.

If a patient refuses a test the reasons why they have made that choice should be explored to ensure that these are not due to incorrect beliefs about the virus or the consequences of testing. If implications for either insurance or criminal prosecution for transmission are raised by the individual as reasons for not testing these should be further explored and any factual inaccuracies corrected (see Appendices 6 and 7).

Some patients may need additional help to make a decision, for example, because English is not their first language. It is essential to ensure that these patients have understood what is proposed, and why. It is also important to establish that the patient understands what a positive and a negative result mean in terms of infection with HIV as some patients could interpret 'positive' as good news.

Children and young people, and those with learning difficulties or mental health problems, may need additional support and time to understand what is proposed and to make a decision (see Appendices 3 and 4).

As with any other investigation the offer of an HIV test should be documented in the patient's case record together with any relevant discussion. If the patient refuses a test the reasons for this should be documented. Usually, written consent is unnecessary and may discourage HIV testing by exceptionalising it.

This advice is consistent with the GMC Guidance *Consent: patients and doctors making decisions together* [25].

6

Post-test discussion

As with any medical investigation it is essential that clear procedures are established as to how the patient will receive the result, with particular attention paid to the means by which a positive result will be delivered.

Arrangements for communicating the results should always be discussed and agreed with the patient at the time of testing, particularly if the test is being performed in an outpatient or emergency care setting.

Face-to-face provision of HIV test results is strongly encouraged for:

- ward-based patients
- patients more likely to have an HIV-positive result
- those with mental health issues or risk of suicide
- those for whom English is a second language
- young people under 16 years
- those who may be highly anxious or vulnerable.

Post-test discussion for individuals who test HIV negative

It is considered good practice to offer health promotion screening for sexually transmitted infections and advice around risk reduction or behaviour change including discussion relating to post-exposure prophylaxis (PEP) to those individuals at higher risk of repeat exposure to HIV infection. This is best achieved by onward referral to GUM or HIV services or voluntary sector agencies.

The need for a repeat HIV test if still within the window period after a specific exposure should be discussed. Although fourth generation tests shorten the time from exposure to seroconversion a repeat test at three months is still recommended to definitively exclude HIV infection.

Occasionally HIV results are reported as reactive or equivocal. These patients may be seroconverting (see section on primary HIV infection) and management of re-testing may be complex and so such individuals should be promptly referred to specialist care.

Post-test discussion for individuals who test HIV positive

As is good clinical practice for any situation where bad news is being conveyed, the result should be given face to face in a confidential environment and in a clear and direct manner. If a patient's first language is not English, consideration should be given to utilisation of an appropriate confidential translation service.

If a positive result is being given by a non-GUM/HIV specialist, it is essential, prior to giving the result, to have clarified knowledge of local specialist services and have established a clear pathway for onward referral.

It is recommended that any individual testing HIV positive for the first time is seen by a specialist (HIV clinician, specialist nurse or sexual health advisor or voluntary sector counsellor) at the earliest possible opportunity, preferably within 48 hours and certainly within two weeks of receiving the result [26].

More detailed post-test discussion (including assessment of disease stage, consideration of treatment, and partner notification) will be performed by the GUM/HIV specialist team.

Non-attendance for positive results

It is recommended to have an agreed recall process following failure of a patient to return for a positive result as with any other medical condition.

As with all other medical investigations it is the responsibility of the healthcare professional requesting the test to ensure that all results of investigations requested are received and acted upon where necessary.

If there is no means of contacting the patient or if attempts are unsuccessful, it is recommended that advice be sought from the local GUM/HIV team who are likely to have experience and resources to deal with this issue.

7

Suspected primary HIV infection

Primary HIV infection (PHI) or seroconversion illness occurs in approximately 80 per cent of individuals, typically two-to-four weeks after infection. It is well recognised that this represents a unique opportunity to prevent onward transmission as an individual is considerably more infectious at this stage. Furthermore this may be the only clinical opportunity to detect HIV before advanced immunosuppression many years later.

It is known that the features of PHI are non-specific, that individuals usually do present to medical services (primary or emergency care) but frequently the diagnosis is missed or not suspected.

The typical symptoms include a combination of any of:

- fever
- rash (maculopapular)
- myalgia
- pharyngitis
- headache/aseptic meningitis.

These resolve spontaneously within two-to-three weeks and therefore if PHI is suspected, this needs to be investigated at the time of presentation and not deferred.

It is recommended that consideration be given to HIV testing in any person with these symptoms perceived to be at risk of infection. It is acknowledged that in some non-GUM settings details of an individual's sexual risk may be difficult to ascertain, but a low threshold for offering a test should remain.

Although with fourth generation tests infection can be detected much earlier than previously (see section on primary screening assays), in very recent infection – when patients may be most symptomatic – the test may be negative. In this scenario, if PHI is suspected, either urgent referral to specialist services (GU clinic or HIV service) or a repeat test in seven days is recommended. HIV viral load testing can be used in this clinical setting, but it is recommended that this is only performed with specialist input.

Appendices

Appendix 1: Providing written confirmation of results

There may be occasions when patients request or require written confirmation of their results.

A written protocol is recommended to set out criteria for those who receive results in this way and how this is done.

Clinicians who are not personally acquainted with the patient requesting such a letter should consider referring the patient back to their general practitioner.

If the patient requests a letter confirming their HIV status then ensure that they are correctly identified both at the time blood is taken and when the result is given, by documenting the method of identification such as photographic ID (e.g. passport, driving licence) in both the notes and the correspondence.

It is preferable to have a written letter signed by the doctor (or another appropriate healthcare professional), rather than a copy of the actual result, and this should be addressed to a specific individual, not 'To whom it may concern'.

Appendix 2: Detailed post-test discussion and partner notification

The following issues would normally be dealt with when the patient is seen at the HIV clinic.

Post-test discussion for individuals who test HIV positive provides an opportunity to address any immediate concerns and to look at the individual's support and information needs.

It is good practice to check if the patient has any immediate medical problems. In case of any symptoms an immediate link with a doctor or nurse may be indicated.

It is again good practice to offer follow-up appointments (including testing where relevant) and ongoing support for the patient, partner or family where appropriate, although this may be done by specialist GUM/HIV services.

Consideration should be given to discussion of partner notification. This will be dependent on the individual but services should have clear guidelines on partner notification in HIV, how it is offered, including offering clients the option of provider referral.

Issues such as preventing the onward transmission of HIV and the medico-legal issues surrounding this, as well as post-exposure prophylaxis for current or future partners who may be at risk, should also be discussed.

Appendix 3: Community-based HIV testing

Historically, HIV testing has been performed almost exclusively in medical settings. More recently, programmes have been explored to evaluate testing in community settings. Such programmes acknowledge that many individuals may prefer to test in non-medical settings, may not be registered with primary care, may feel stigmatised by attending medical settings and being targeted for HIV testing, and may not be prepared to disclose risk behaviour, including sexual orientation, to healthcare professionals. The ability to perform community-based testing has been largely enabled by the development of newer technologies for HIV testing, particularly POCT (see section on point of care testing).

Pilot studies have shown that community-based testing is acceptable and feasible and may encourage potentially high-risk individuals who would not otherwise have accessed HIV testing through conventional services [27]. The development of such services, complementary to expansion of existing healthcare-based services, should therefore be encouraged and evaluated, particularly in areas where there is a high prevalence of undiagnosed infection. It is vital to ensure that community testing services are linked to the local HIV clinic to ensure that patients will promptly and appropriately access care with clear referral pathways.

Potential disadvantages to community testing include the limitations of the current POCT technologies, such that very recent infection may be missed, and the higher rates of 'false positive' results compared to conventional laboratory-based testing. It is essential that anyone performing HIV testing in a non-healthcare setting has adequate governance arrangements including quality assurance.

The false positive rate will particularly affect individuals whose risk of HIV infection is low, and therefore it is recommended that such programmes are targeted toward communities where undiagnosed HIV prevalence is high, particularly MSM and immigrant communities.

If individuals report high-risk activity within the 'window period' of POCTs (currently 12 weeks), either repeat testing in 12 weeks or attendance at a local healthcare HIV testing site should be encouraged.

Individuals who test negative for HIV but who are at risk of other sexually transmitted infections (particularly MSM) should be encouraged to attend local GUM services for testing for other infection and to ensure adequate immunisation against hepatitis viruses.

Appendix 4: Testing where the patient lacks capacity to consent (including the unconscious patient)

Legislation in England, Wales and Scotland provides a framework for decision-making on behalf of adults aged 16 and over who lack capacity to make decisions on their own behalf. The Mental Capacity Act 2005 applies to England and Wales. In Scotland the Adults with Incapacity (Scotland) Act 2000 applies, for which there is a separate BMA guidance note. In Northern Ireland common law applies.

A person lacks capacity if, at the time the decision needs to be made, he or she is unable to make a decision because of a mental disorder, or is unable to communicate their decision. Key points to consider when assessing capacity:

1. The assessment of capacity relates to the specific issue in question – in this case consent to HIV testing.
2. Start from the presumption that the patient has capacity to make this decision.
3. Consider whether the patient understands what decision they are being asked to make and can weigh up the information relevant to the decision; do they understand the consequences of making a choice?
4. Take all possible steps to help patients make a decision for themselves (e.g. provide information in a more accessible form – drawings, tapes etc.). If you judge that a patient lacks capacity to consent to an HIV test you should consider whether this is temporary or permanent. If temporary, you should defer testing until the patient regains capacity, unless testing is immediately necessary to save the patient's life or prevent a serious deterioration of their condition.

If the lack of capacity is, or is likely to be, permanent you should seek a decision from any person with relevant powers of attorney or follow the requirements of any valid advance statements. If the patient has not appointed an attorney nor left a valid advance statement, HIV testing may be undertaken where this is in the best interests of the patient (England and Wales) or is necessary and of benefit to the patient (Scotland).

Guidance on assessing capacity is published by the BMA [28–30]. Advice on how to assess appropriate treatment of patients who lack capacity is available in the relevant statutory codes of practice for England [31] and Scotland [32].

If consciousness is regained the patient should be told of the test result as soon as practicable.

If they die, a decision should be made on disclosure according to the circumstances, e.g. others at risk and previously disclosed wishes.

Appendix 5: Testing infants, children and young people

Any infant/child/young person thought to be at significant risk of HIV infection, including all those with parents or siblings who are HIV-infected, should be tested. It is in the best interest of the infant/child/young person to be tested in these circumstances although this only needs to be undertaken urgently in infants who are at risk of rapid disease progression.

Who to consider for HIV testing

- infants and children whatever their age where the mother has HIV, or may have died of an HIV-associated condition
- infants born to mothers known to have HIV in pregnancy
- infants born to mothers who have refused an HIV test in pregnancy
- infants and children who are presented for fostering/adoption where there is any risk of blood-borne infections [33]
- infants and children newly arrived in the UK from high-prevalence areas (they may be unaccompanied minors)
- infants and children with signs and symptoms consistent with an HIV diagnosis
- infants and children being screened for a congenital immunodeficiency
- infants and children in circumstances of post-exposure prophylaxis [34]
- infants and children in cases where there has been sexual abuse (see below).

Obtaining consent for HIV testing from children

In England and Wales, children are defined as those under 18 years old (Children Act 1989) and in Scotland as under 16 [Children (Scotland) Act 1995].

Under English law young people aged 16 years or over are assumed to have the capacity to consent to medical treatment and should be treated in the same way as adults.

Young people under 16 years accessing sexual healthcare (which would include HIV testing as part of a sexual health screen) without a parent or guardian should be assessed for competency to consent [35].

Testing in a non-competent child

If a child lacks the capacity to consent, then the consent of one parent or carer with parental responsibility is sufficient. If you are aware of parental disagreement, refer to GMC guidance [36].

Refusal of testing by a competent young person

This is a difficult area and varies according to country in the UK.

In Scotland, parents cannot override a refusal to test by a competent young person.

In England, Wales and Northern Ireland, the law on parents overriding a competent young person's refusal to testing is complex. Legal advice should be sought about whether to apply to the court if testing is thought to be in the best interests of a competent child who refuses.

Refusal of testing by parents of a non-competent child or young person

If parents refuse testing that is clearly in the best interests of a non-competent child or young person then you should consider involving other members of the multidisciplinary team, an independent advocate or named/designated doctor for child protection before seeking legal advice. This also applies if both a young person with capacity and their parents refuse testing.

Testing victims of child sexual abuse

Testing of victims of child sexual abuse should be considered in every case according to risk factors [36]. Testing should always be performed if post-exposure prophylaxis is to be given. Where parental consent is refused, refer to consent section of RCPCH guidelines on physical signs of child sexual abuse [37].

Testing of children of known HIV-positive parents

Testing should be offered in all cases at risk of vertical transmission. Increasing evidence shows that children infected vertically can survive into teenage years without being diagnosed. Therefore, it can not be assumed that older children of mothers with HIV do not require testing. This raises difficult issues of informed consent for these young people, particularly if they are unaware of the mother's diagnosis.

Testing of neonates, children and young people where the mother refuses consent and/or disclosure of her HIV status is a complex area. The overriding consideration must be the best interests of the child, and multidisciplinary decision-making and expert advice should be sought, including legal advice where appropriate. It is not acceptable to simply accept a mother's refusal. Referral to a paediatric centre with experience of management of HIV-infected children is strongly recommended.

Parents may need to be supported in making the decision to go ahead to test their children; paediatric HIV support is available nationally through the Children's HIV National Network (CHINN), details of which can be found on the Children's HIV Association (CHIVA) website, www.chiva.org.uk.

What do children need to know about having an HIV test?

One of the main reasons that parents do not want to test their children for HIV is because they are afraid to share the diagnosis with them. It should be explained to parents that a developmentally and age-appropriate explanation of the test should be given to children and that this does not necessarily mean using the term HIV.

- 1) Older children (usually those older than 11) should be asked to give consent for an HIV test.
- 2) Younger children (usually five to ten years of age) can be told they are being tested for a 'bug' in the blood.
- 3) Pre-school children and infants do not need any formal explanation of why they are having a blood test.

Appropriate HIV tests for infants and children

Children older than 18 months of age: HIV antibody test, as for adults.

Infants younger than 18 months of age: infants born to mothers with HIV receive transplacental maternal HIV antibodies which can usually be detected in the infant blood until about 18 months of age. Infants are therefore tested for genomic evidence of HIV by PCR. For details see BHIVA guidelines on the management of HIV in pregnancy [21].

Appendix 6: The source patient in a needlestick injury or other HIV risk exposure

The Human Tissue Act (2004) which governs the obtaining of source patient consent supersedes previous GMC guidance.

The source patient's consent to testing must always be gained. Consent from the patient should be obtained from a healthcare worker other than that who sustained the injury. If the rationale for testing is explained, it is unusual for consent to be refused. If the patient does not wish to know the result the option of testing without any documentation should be considered.

For guidance on testing a source patient from a needlestick injury who is unconscious or unable to give consent seek expert advice as the law on this is being reviewed. Guidance on post-exposure prophylaxis for occupational exposure to HIV is published by the UK CMOs' Expert Advisory Group on AIDS (EAGA) [38].

Appendix 7: HIV testing and insurance

The ABI code of practice 1994 states that questions regarding whether an individual has ever had an HIV test or a negative result should not be asked. Applicants should however declare any positive results if asked as would be the case with any other medical condition [39,40].

Appendix 8: HIV testing and criminal prosecution for HIV transmission

Concern about this issue should not be a barrier to testing. There have been a number of prosecutions of individuals under the Offences Against the Person Act 1861 for reckless HIV transmission. This has included a prosecution of an individual who had not been HIV tested. There is detailed guidance on the legal implications of this available from the voluntary sector as well as advice on safer sexual practices designed to minimise risk of transmission of HIV to others [41,42].

Appendix 9: Auditable standards

Standard	Audited by what data and by whom?	How often?	Comments
Offer and uptake of HIV test in GUM	GUMCAD; HPA	Annually	National report; local feedback
Offer and uptake in of HIV test in antenatal care	National Antenatal Infections Screening Monitoring programme (NAISM); HPA	Annually	National report; local feedback
Offer and uptake of HIV test in drug misuse services	Sentinel unlinked anonymous seroprevalence data, HPA	Annually	National report
Offer and uptake of HIV test in TOP services	Local clinic data sources	Annually	National report; local team discussion
Proportion of HIV undiagnosed (by risk group)	Sentinel unlinked anonymous seroprevalence data, HPA	Annually	National report
Proportion of newly diagnosed HIV positive with CD4 < 200	New diagnoses/SOPHID/CD4 surveillance; HPA	Annually	National report; local feedback
Proportion of newly diagnosed HIV positive with CD4 < 350	New diagnoses/SOPHID/CD4 surveillance; HPA	Annually	National report; local feedback
Number of HIV tests performed in primary care	Local lab with GUM/HIV/ID input	Annually	Local meeting with PCT if no increase
Number of HIV tests performed in secondary care	Local lab with GUM/HIV/ID input	Annually	Local meeting with relevant teams if no increase
Proportion of individuals with indicator disease being tested for HIV	Local data sources (using IT or case note audits)	Annually	Local team discussion
Offer and uptake of HIV test among TB patients	Chest/ID clinic (using IT or case note audits)	Annually	Joint meeting to discuss
Offer and uptake of HIV test among lymphoma patients	Oncology (using IT or case note audits)	Annually	Joint meeting to discuss
Offer and uptake of HIV test among hepatitis B and C patients	Hepatology/ID/gastroenterology (using IT or case note audits)	Annually	Joint meeting to discuss

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