Annual health review for people living with HIV

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NATIONAL HIV NURSES ASSOCIATION
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A good practice guide

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Contents

Introduction

For people living with HIV (PLHIV), having a high-quality annual health review carried out by a healthcare professional is an essential part of managing their HIV infection. An annual health review can support PLHIV to lead healthy and fulfilling lives incorporating holistic needs and providing early detection and prevention of risk factors or comorbid illness. Defining what a high-quality annual health review is, and what standards healthcare professionals should aspire to and attain, has not been described.

This is the first good practice guide to describe a minimum set of standards for an annual health review.

The British HIV Association National audit (2015)[1] for adults living with HIV and the National HIV Nurses Association (NHIVNA) national nurse-led audit of the standards for psychological support[2] identified areas for improvement in the routine monitoring and assessment of adults with HIV. In response to the audit findings, NHIVNA in the UK—together with international colleagues—has developed this good practice guide to facilitate improvement in the quality of annual health reviews for PLHIV and it includes a set of nine measurable standards.

NHIVNA advocates that HIV-trained nurses are ideally placed to perform the annual health review due to their experience, expertise, knowledge, health promotion skills and holistic relationship with PLHIV. In practical terms, nurses contribute significantly to care responsibilities, are an integral part of the multi-disciplinary team and are less likely to be moved on a rotational basis.

As HIV nurse experts, we call upon the international HIV community of nursing to aspire to provide high-quality annual reviews for the people we care for, by adopting and implementing this good practice guide and, if necessary, adapting the content to suit different countries.

Aims of the annual health review good practice guide for people living with HIV

- Improve outcomes for people living with HIV (PLHIV)
- Ensure that best practice becomes a standard within HIV care settings to reduce variations in care
- Improve effectiveness and efficiency in healthcare systems
- Maintain appropriate prescribing and optimise adherence to antiretroviral therapy (ART)
- Increase appropriate prescribing of non-ART medicines across the pathway of care
- Provide recognised audit measures and tools for service monitoring and development

Limitations of this guide

The authors of this guide are clear that a person living with HIV has the right to a good standard of care at an annual health review no matter where they live in the world. It is acknowledged that HIV services (both provision and payer) differ not just from country to country, but region to region within a country and there are parts of the world where an annual health review does not happen or access to investigations are limited or not available. Furthermore, there are differences in guideline approaches to care (e.g. screening tools and screening frequency) and where care is delivered.

Rather than view these variations as a barrier to improving care, this good practice guide is the first step in creating a systematic approach for improving both care and practice. So, while there are obvious omissions to important issues (e.g. transgender, menopause, standards for pregnancy and childbirth etc.) this is not deliberate. This good practice guide is a flexible framework for nurses with expertise and experience in HIV care settings and can be easily adapted from country to country and therefore omissions can become inclusions where appropriate.

To aid the adaptability of this guide the example questions in each section are only prompts and are not a comprehensive or standardised way to deliver an annual health review. We are also keen to stress that the screening tools we have suggested are just suggestions and are not set in stone. Where there are validated screening tools available, we encourage their use.

Why do we need set standards for an annual health review?

Worldwide there are in excess of 36 million people living with HIV[3]. Whilst overall the number of newly infected people continues to decline[3], there are geographical changes in HIV infection data; Eastern Europe is reported to have the fastest growing rate of new HIV infection in the world[4]. There also remains a large number of undiagnosed PLHIV; in 2016, there were estimated to be 13,000 people who were unaware of their HIV positive status in the UK[5]. The personal and societal-level benefits of diagnosis, and for such a diagnosis to be early on after infection, point towards the need for continued inclusion of routine HIV testing as part of a wide range of healthcare interactions.

People with a diagnosis of HIV are living longer than ever before, largely due to effective ART[6]. As a result, challenges in relation to treatment and management are shifting. PLHIV are at increased risk of comorbidities and mortalities that can be physiological and/or psychological, e.g. CVD, mental health difficulties[7, 8] and PLHIV also continue to experience stigma[9]. An effective way to improve outcomes for PLHIV is to improve access and adherence to ongoing care regimes[10].

There are differences in health outcomes between those who access care and those who do not[11]. In one study, despite 80% of PLHIV being linked to care within three months of diagnosis, care was not sustained[12]. Furthermore, there are also certain social determinants that make it less likely for a person to access care: these factors include, age, poverty, mental health and health literacy[13].

Annual health reviews, therefore, provide an opportunity for bi-directional engagement for PLHIV and healthcare professionals.

Data from an annual health review will support prevention and early detection of changes to health status. Effective treatment can also help to prevent onward transmission of HIV[14]. Optimal prevention, management and treatment are cost-effective. Collectively, annual reviews generate empirical data sets that can lead to improvements in HIV health outcomes and enable benchmarking.

A study by Long *et al*.[15] compared outcomes between nurse-led and doctor-led primary care clinics and found favourable nurse led outcomes. This same study reported lower costs across all reported outcomes and estimated an 11% saving for people who stay in care and respond to treatment, as compared to costs at the treatment initiation site. A Cochrane review[16] explored the impact of 'task-shifting' in HIV programmes between doctors and non-doctors for people requiring ART and concluded that there was '… moderate quality evidence that shifting responsibility from doctors to adequately trained and supported nurses or community health workers for managing HIV patients probably does not decrease the quality of care and, in the case of nurse initiated care, may decrease the numbers of patients lost to follow-up.' A further study[17] highlighted evidence that adherence increased if the person was seen by the same care provider and the argument was made that nurses are well positioned to deliver and coordinate this type of care.

Within the UK, Piercy *et al*.[18] report that nurse-led clinics are well established and accounted for two-thirds of the included sites. Nurses were also found to deliver a substantial proportion of the care for medically stable patients. Data from this qualitative study records clinicians who felt that nurse-led activities made the service more efficient and believed there to be an improvement in the patient experience. Piercy *et al*. go on to assert that '… developing the specialist nursing workforce to deliver an increasing proportion of HIV care has enabled some services to meet growing capacity demands and to improve access.' A further study found the primary benefits of the specialist nursing contribution to HIV care are: improvements in patient care due to better care alignment for medical and nursing staff; more effective use of staff resources and cost effectiveness of services[19].

So why do we need set standards for an annual review?

The global clinical picture, alongside the lived experience for PLHIV is changing and so too must policy and practice change in relation to HIV diagnosis, treatment and management. This guide supports the changing landscape and acts as a driver to improve health and wellbeing for PLHIV.

How to use this guide

This guide has been produced to enable HIV nurses and nursing bodies (e.g. NHIVNA) to facilitate the improvement of care with the flexibility to allow for adaptation in those countries that follow different guidelines and/or utilise different resources.

This guide is not about managing individual people living with HIV. This guide identifies the elements of good practice that a person with HIV should expect at an annual health review so that:

- PLHIV receive optimum evidence-based care relating to their health and wellbeing
- It sets a standard that PLHIV can expect from an annual health review
- It distinguishes what is different for a person living with HIV at an annual review (compared to other long-term condition reviews)
- Nurses can use it to hone their expertise, add value to their practice and set a benchmark for good care
- Providers understand what a good service should comprise in order to provide it
- Payers (Commissioners) know what a good service looks like

The good practice guide does not include every measure of care identified in national and international guidelines. This is not an omission, it is an attempt to focus on what is most important at this time for PLHIV.

This good practice guide should enable and enhance a quality annual health review to provide a holistic assessment of needs such as a discussion of the person's experiences of living with HIV, HIV-related tests, prescribing, examinations and addressing any other concerns.

Measuring these standards will enable care for PLHIV at an annual health review to become part of a continuous cycle of health and service improvement on an international level. It is essential that this guide is used within the context of holistic practice, education and an understanding of the needs of PLHIV.

Development of the standards

The good practice guidelines were developed following a consultation exercise with an expert panel from NHIVNA and in partnership with a number of different stakeholders both nationally and internationally. We reviewed guidance from the British HIV Association (BHIVA) Standards of care for people living with HIV[20], BHIVA guidelines for the routine investigation and monitoring of adult HIV-1-infected individuals 2016[21] and EACS (version 6) guidelines[22] that all advise on appropriate annual monitoring in order to maintain the health of PLHIV. These national and international guidelines are underpinned by strong medical evidence to support a wide range of routine investigations and monitoring required in HIV care.

The standards are designed to be person-centred and the working group included PLHIV to ensure that their voice is heard throughout the document.

The standards address:

1	Cardiovascular health
2	Bone health
3	Renal health
4	Sexual and reproductive health and psychosexual wellbeing
5	Mental health and psychosocial wellbeing
6	Antiretroviral therapy (ART) and non-ART management
7	Preventative medicine
8	Monitoring of comorbidities
9	Neurocognitive impairment

Structure, Process and Outcome is the format used to frame these standards. This approach is derived from the work of Donabedian[23]. This three-part approach to quality assessment is appropriate because good structure increases the likelihood of good process and good process increases the likelihood of a good outcome[24].

Structure

Settings, qualification of staff, administration structure, right institution providing care etc.

Process

What is known to be *good* care - and then applied (technical competence, how health and illness is managed, coordination and continuity of care, justification of diagnostic tests/therapy).

Outcomes

Outcomes should be measurable and may include elements such as therapeutic impact, health gain, social restoration etc.

The *Structure, Process and Outcome* format used to frame these standards is useful because it:

- is simple to understand
- is easy to replicate
- is straightforward to measure
- demonstrates quality of care
- provides a framework for audit
- can be used to build a business case or used in a commissioning context
- provides a platform to improve care by identifying need in either the structure or process part of your standard

Process and outcome measures

Process measures from national audits[1] have demonstrated that there is room for improvement in the process of care when assessing the needs of a person with HIV at an annual health review. However, in some settings, non-HIV care is delivered by non-HIV providers (e.g. blood pressure management by general practitioners/ family doctors). It is important, therefore, not to allocate an outcome measure to a HIV specialist who has little or no influence. Consequently, where appropriate, two sets of outcome measures, one for non-HIV direct care (e.g. a HIV unit managing blood pressure) and one for supporting the optimisation of health with another provider are provided.

NHIVNA encourages nurses and their colleagues to get involved in supporting the implementation of this good practice guide by collecting the suggested measures. We have not put a percentage figure on the process or outcome measures (as is traditionally practised) as we want nurses to understand the baseline practices at their individual units first. In the future, we can take these baseline measures and allocate more sophisticated indicators to the standards. Therefore, in time, we should all see a system-wide improvement in good practice, audit and organisational maturity. A random selection/ sample for audit is advised to reduce bias and to support clinics with very large caseloads.

Data collection

Attached to the process and outcome measures is the phrase 'Data source: Local data collection based on reviews of individual care records'. Currently there is no recognised national database that stores information from HIV annual health reviews. We have therefore developed a capability maturity model[25, 26] (see following text box) to support the delivery of a regional, national or international approach to data collection. We anticipate that this well-established model and framework can be used to articulate and measure HIV care, as well as providing an understanding of the maturity of an organisation's processes and the quality of care delivered at an annual health review.

Maturity models

Maturity models enable recording of not just which standards or parts of standards are met, but how well they are being achieved. They provide three steps to reach compliance and then a further two to improve practice even further. We are providing an online maturity model tool to aid with completion of the standards. To access this resource please go to the NHIVNA website:
www.nhivna.org

Appendix 1 is an example of a template that can be adapted for use when undertaking an annual health review. The template has been linked to the good practice guide for ease of reference.

Standard 1 **Cardiovascular Health**

All people living with HIV should have a cardiovascular health check

Structure

Evidence of local arrangements to ensure that nurses working in the field of HIV care are competent and trained in cardiovascular risk assessment.

Process

Annual measurements of blood pressure, lipid profile, QRISK2 score or other validated tool (for people ≥40 years of age) plus advice on a healthy lifestyle.

Process measures		First measure	Second measure	Data source
a	Proportion of PLHIV ≥40 years of age who have a cardiovascular risk assessment	The number of PLHIV ≥40 years of age	The number of PLHIV ≥40 years of age who have a cardiovascular risk assessment using QRISK2 (or other validated tool)	Local data collection based on reviews of individual care records
b	Proportion of PLHIV with established CVD and those at increased risk of CVD (10 year CVD risk >10%) are screened annually based on BHIVA guidelines	The number of PLHIV with established CVD and those at increased risk of CVD (10 year CVD risk >10%)	The number of PLHIV with established CVD and those at increased risk of CVD (10 year CVD risk >10%) who have had an annual CVD screen based on BHIVA guidelines	
c	Proportion of PLHIV with established CVD and those at increased risk of CVD who have received healthy lifestyle advice	The number of PLHIV with established CVD and those at increased risk of CVD	The number of PLHIV with established CVD and those at increased risk of CVD who have received healthy lifestyle advice	

Outcomes (for those who manage blood pressure and lipids)

- Optimised management of hypertension
- Optimised management of dyslipidaemia
- Reduced modifiable cardiovascular disease risk

Outcomes (for those who *do not* manage blood pressure and lipids)

- Increased number of people with hypertension who are engaged with their provider for hypertension management and optimisation.
- Increased number of people with dyslipidaemia who are engaged with their provider for lipid management and optimisation.

Example questions

Have you experienced dizziness or headaches?

Do you get short of breath on exertion?

Has your diet changed in the last 12 months?

Do you undertake regular physical activity?

Would you like to be referred to smoking cessation? [if appropriate]

Supporting self-management for this standard

Diet and physical activity management

Check for non-ART medicines and side-effects

Smoking cessation [if appropriate]

Offer health education/promotion leaflets on blood pressure, suggest apps to monitor lifestyle management (e.g. diet, physical activity etc.)

Information for people living with HIV

How to reduce and/or manage hypertension

Beliefs and benefits of treatment

Setting goals for change and enabling PLHIV to make a plan about reducing risk

Make aware that heart disease can be prevented through effective action on modifiable risk factors: sedentary lifestyle; hypertension; smoking; stress; obesity; diabetes; dyslipidaemia, etc.

Standard 2 **Bone health**

All people living with HIV and 50+ years old should be monitored and assessed for osteoporosis and risk of fractures

Structure

Evidence of local arrangements that nurses working in the field of HIV care know when to refer for, and have access to, DEXA scanning and are competent and trained in the assessment of osteoporosis and fracture risk assessment.

Process

Annual measurement of FRAX score and recorded history of falls and low-level (impact) fractures in all PLHIV >50 years. PLHIV at increased risk of fracture should have their bone mineral density (BMD) measured, their vitamin D/parathyroid hormone status assessed and optimised, and ART and other medication reviewed. In addition, measure height (sign of vertebral collapse if decreasing).

Process measures		First measure	Second measure	Data source
a	Proportion of PLHIV who have had a FRAX score calculated and recorded	The number of PLHIV >50 years (or >40 years if major risk factors are present) on a caseload	The number of PLHIV >50 years (or >40 years if major risk factors are present) who have a FRAX score calculated and recorded	Local data collection based on reviews of individual care records
b	Proportion of PLHIV who have had a history of falls elicited and recorded	The number of PLHIV >50 years (or >40 years if major risk factors are present) on a caseload	The number of PLHIV >50 years (or >40 years if major risk factors are present) on a caseload who have had a history of falls elicited and recorded	
c	Proportion of PLHIV at increased risk of fracture who have their bone mineral density (BMD) measured	The number of PLHIV on a caseload who are at increased risk of a fracture (FRAX score>10%)	The number of PLHIV on a caseload at increased risk of fracture who have their bone mineral density (BMD) measured	
d	Proportion of PLHIV at increased risk of fracture who have their vitamin D/ parathyroid hormone status assessed and optimised	*For those who manage bone health*		
		The number of PLHIV on a caseload who are at increased risk of a fracture	The number of PLHIV at increased risk of fracture who have their vitamin D/ parathyroid hormone status assessed and optimised	
		For those who do not manage bone health		
		The number of PLHIV on a caseload who are at increased risk of a fracture	The number of PLHIV referred for vitamin D/parathyroid hormone status assessment and optimisation	

Outcomes

- Optimised bone mineral density in those people with osteopenia/osteoporosis or at risk of a fracture

Example questions

Follow the FRAX assessment form for specific questions

Supporting self-management for this standard

Regular physical activity, diet and medication optimisation

Offer health education regarding lifestyle management - e.g. increase weight-bearing exercise, avoid excess alcohol, smoking cessation, aim for 700mg/day calcium –refer to:

www.nos.org.uk/for-people-and-families/healthy-living-and-risk/healthy-eating/

so people can calculate their calcium intake for themselves.

Advice on increasing vitamin D level - 20–30 minutes of sunlight on forearms daily throughout summer, oily fish/egg yolks/liver/wild mushrooms to increase vitamin D through diet

Advice on steroids increasing risk of osteoporosis

Information for people living with HIV

Advice/leaflets on how to optimise vitamin D exposure

Awareness of falls risk

Menopause and bone health

BHIVA and EACS recommend 3-yearly bone fracture risk assessment using the FRAX tool in women aged >50, postmenopausal women or with other risks, e.g. excess alcohol intake.

Note:
We have not included this measurement opposite as this is an annual review. However, we recommend that the 3-yearly assessment is highlighted at the annual review, and a date planned and recorded for the bone fracture risk assessment.

Standard 3 **Renal health**

All people living with HIV and chronic kidney disease (CKD) or post-kidney transplantation should have 6–12-monthly monitoring of their renal function

Structure

Evidence of local arrangements to ensure that nurses working in the field of HIV care are competent and trained in maintaining renal health and identifying possible chronic kidney disease.

Process

All PLHIV with chronic kidney disease have their renal function and blood pressure monitored. In addition, lipid profile, BMI, smoking status, antiretroviral therapy and other medications are reviewed annually. Kidney transplant recipients are reviewed at 6–12-monthly intervals with monitoring of renal function and CD4 cell count. All PLHIV to have a urine dipstick analysis to identify possible CKD.

Process measures		First measure	Second measure	Data source
a	Proportion of PLHIV who have had urine dipstick analysis	The number of PLHIV on a caseload	The number of PLHIV who have had urine dipstick analysis	Local data collection based on reviews of individual care records
b	Proportion of PLHIV with chronic kidney disease or post-kidney transplantation who have had their renal function assessed	The number of PLHIV on a caseload with chronic kidney disease or post-kidney transplantation	The number of PLHIV with chronic kidney disease or post-kidney transplantation who have had their renal function assessed	
c	Proportion of kidney transplant recipients who have their CD4 cell count measured every 6–12 months	The number of PLHIV post-kidney transplantation on a caseload	The number of kidney transplant recipients who have their CD4 cell count measured every 6–12 months	
d	Proportion of PLHIV with chronic kidney disease who have had lipid profile, BMI, smoking status, antiretroviral therapy and other medications reviewed annually	The number of PLHIV with chronic kidney disease on a caseload	The number of PLHIV with chronic kidney disease who have had lipid profile, BMI, smoking status, antiretroviral therapy and other medications reviewed in the past 12 months	

Outcomes

- Early identification of kidney disease
- Optimised clinical management (joint care or otherwise) of people with chronic kidney disease and people who have had a kidney transplantation including early referral to renal specialist

Example questions

Have you experienced any sustained changes in the colour of your urine in the last 12 months?

Are you finding you urinate more or less than usual?

Do you use painkillers regularly (e.g. anti-inflammatories)?

Do you take any other medicines that you can buy over the counter or gym supplements?

If appropriate, ask about alcohol withdrawal

Supporting self-management for this standard

To be aware of drugs that can affect kidney function (e.g. non-steroidal anti-inflammatory drugs)

Lifestyle management and preventative risk factors

Information for people living with HIV

Practical advice on diet, management of blood pressure, hydration etc.

Standard 4 **Sexual and reproductive health and psychosexual wellbeing**

All people living with HIV should be regularly screened for all sexually transmitted infections and have access to preventative interventions

All people living with HIV should be supported in establishing and maintaining health and enjoyable sexual lives for themselves and their partners should they want them

All people living with HIV should have access to safe, effective and acceptable methods of contraception

Structure

Evidence of local arrangements to ensure that nurses working in the field of HIV care are suitably educated and competent, trained in sexual health and are competent in partner/contact notification or have access to these services.

Process

Regular screening (depending on risk: 3–6-monthly or annually), recording and supporting people to protect themselves against sexually transmitted infections. Access and support for safe, effective and acceptable contraception.

Process measures		First measure	Second measure	Third measure	Data source
a	Proportion of PLHIV screened for all sexually transmitted infections	The number of PLHIV on a caseload	The number of PLHIV who have been offered screening for all sexually transmitted infections	The number of PLHIV who have been screened for all sexually transmitted infections	Local data collection based on reviews of individual care records
b	Proportion of PLHIV with an up-to-date sexual relationship history and sexual risk assessment identified and recorded	The number of people on a caseload diagnosed with HIV	The number of people with an up-to-date sexual relationship history and sexual risk assessment identified and recorded	—	
c	Proportion of PLHIV who need access and support for safe, effective and acceptable contraception	The number of PLHIV who need access to contraception	The number of PLHIV who access safe, effective and acceptable contraception	—	
d	Proportion of women living with HIV aged 25–65 years who have had cervical cytology (*see note page 15)	*For HIV-positive women*			
		The number of women with HIV aged 25–65 years on a caseload	The number of women living with HIV aged 25–65 years who have had cervical cytology	—	

Outcomes

- PLHIV have healthy fulfilling sexual relationships if they want them
- Increase in the identification and treatment of sexually transmitted diseases
- Improved safe and acceptable contraception
- Early identification of cervical pathology

Example questions

Are you having sex?

Are you having consensual sex?

Do you have pleasurable sex?

Is it a good relationship?

Do you feel safe at home?

[For men]

Are you able to sustain an erection?

[For women]

Was your last smear okay?

First day of your last period?

Do you have any pain/regular bleeding/ spotting?

Are you planning a pregnancy?

Any menopausal symptoms?

Sometimes it can be difficult talking about safer sex; are you comfortable/confident discussing safer sex with partners?

[For people using drugs during sex]: When was the last time that you had sex without drugs? (or use specific name for the drug(s) the person uses)

What contraception do you use?

Do you know your HIV status? (think U = U)

When relevant, how easy do you find it to talk about HIV with new sexual partners?

Supporting self-management for this standard

Access to sexual and reproductive health care and information, as well as autonomy in sexual and reproductive decision-making.

Information for people living with HIV

Health education for promoting a healthy and safe sexual experience and reducing incidence of STIs.

**** Note***

In the UK, BHIVA recommends that cervical screening should not be performed under the age of 25 or over the age of 65 unless women fulfil the criteria for ongoing surveillance or follow-up as indicated in national guidelines.

EACS recommends screening every 1–3 years for sexually active women aged 25–65 years.

Standard 4

Sexual and reproductive health and psychosexual wellbeing

Standard 5 Mental health and psychosocial wellbeing

All people living with HIV should have annual screening to identify psychological support needs

If required, all people living with HIV should be referred to appropriate services providing psychological support that deliver best practice using evidence-based guidelines

Structure

Evidence of local arrangements to ensure that nurses working in the field of HIV care are suitably trained and competent in screening and recognising mental health/psychological problems (including anxiety, depression, acute stress disorder, post-trauma distress), potentially unhelpful coping responses (e.g. substance misuse, self-harm) and have access to pathways for support and treatment. Evidence that services providing psychological support for PLHIV are using assessment and intervention methods developed, standardised and evaluated for use with HIV, other long-term medical conditions or relevant to the potentially presenting psychological presentations, as per the known evidence base pertaining to mental health issues in HIV.

Process

Screening and referral for mental health and psychosocial wellbeing needs at annual review by nurses using evidence-based practice tools.

Process measures		First measure	Second measure	Third measure	Data source
a	Proportion of PLHIV who have been screened for psychological support	The number of PLHIV on a caseload	The number of PLHIV who have been screened using a validated screening tool*	The number of PLHIV who have been referred and who require psychological support based on a validated screening tool	Local data collection based on reviews of individual care records

* These measures are not only important to identify the needs of PLHIV and the demands of a caseload but also to provide evidence to commissioners/payers of appropriate investment at the appropriate level.

Outcomes

- Increased number of people identified who are living with psychological and emotional issues

Note

In the UK, the PHQ-2 and the GAD-2 for screening for anxiety and depression are free and widely used. The use of the *wellness thermometer*[27] as an exploratory tool for psychosocial wellbeing issues is also available. Screening illustrates need, and outcomes will be dependent on identification of the relevant level of support.

Example questions

Use a validated anxiety and depression screening tool

EACS recommends screening for depression every 1–2 years and advises on two main questions:

- *Have you often felt depressed, sad or without hope in the last few months?*
- *Have you lost interest in activities that you usually enjoy?*

Other psychological/emotional distress indicators/ non-obvious signs of depression to look out for include: stress, burnout, angry outbursts, coping through work or alcohol.

Note 1

EACS also recommends ruling out an organic cause (such as hypothyroidism, hypogonadism, Addison's disease, non-HIV drugs, vitamin B12 deficiency).

Note 2

Referral to psychology services or a mental health team is a safe way to manage potential or actual mental health problems for PLHIV, especially for the inexperienced practitioner. Generic questions such as 'Have you been experiencing any issues like anxiety or low mood that are affecting the way you live your life?' may be related to the diagnosis and helpful to start a discussion.

Note 3

It might be helpful to explore the issues of stigma and living with a chronic condition (people often say that these are major issues even if not clinically depressed/ anxious). Questions such as: 'Have you experienced any stigma or discrimination because of your HIV in the last 12 months?' and 'Have you experienced any issues managing your HIV care over the past 12 months?' are useful to begin the discussion.

Supporting self-management for this standard

Offer health education regarding lifestyle management and effective coping strategies - this may include signposting for self-help, peer support groups or community support.

Referral to the many websites or apps that support mental wellbeing such as: (note: change for non-UK areas)

www.time-to-change.org.uk/mental-health-and-stigma/help-and-support

www.mindcharity.co.uk/advice-information/how-to-look-after-your-mental-health/apps-for-wellbeing-and-mental-health/

Information for people living with HIV

To have their psychological needs assessed regularly and held in mind with regard to holistic care

Social, peer support information

Beliefs and benefits of treatment/ support

Information about local services, e.g. psychological, wellbeing etc.

Risk

Health professionals delivering the annual health review should have accessed training regarding risk assessment and should use their local risk protocol to assess whatever risk is presented.

Standard 6 Antiretroviral therapy (ART) and non-ART management

All people living with HIV on ART should have proactive management of side-effects and assessment of the efficacy of the therapy and identification of drug–drug interactions

Structure

Evidence of local arrangements to ensure that nurses working in the field of HIV care are supported by the multi-disciplinary team and are educated in the management of ART and identification of drug-drug interactions.

Process

Annual assessment of drug-drug interactions, proactive side-effect management, appropriate monitoring of viral load to assess efficacy of therapy, support for self-management and drug regimen adherence.

Process measures		First measure	Second measure	Third measure	Data source
a	Proportion of PLHIV adhering to ART drug regimen	The number of PLHIV on a caseload on ART	The number of PLHIV who report optimal adherence (self-reporting of >95%)	—	Local data collection based on reviews of individual care records
b	Proportion of PLHIV with a reduction in unacceptable side-effects and/or concerns from ART	The number of PLHIV on ART	The number of PLHIV who have side-effects and/or concerns	The number of PLHIV who have unacceptable side-effects and/or concerns	
c	Proportion of PLHIV with comorbidities who have drug–drug interactions identified and rectified	The number of PLHIV and comorbidity on a caseload who have been identified as having a drug to drug interaction(s)	The number of PLHIV who have their drug to drug interaction(s) rectified	—	
d	Proportion of PLHIV who have an undetectable viral load	The number of PLHIV on ART	The number of PLHIV who have an undetectable viral load	—	
e	Proportion of PLHIV who have a CD4 cell count	The number of PLHIV on ART	The number of PLHIV who have a CD4 cell count	—	

Outcomes

- Improved control of HIV (as measured by viral load)
- Improved quality of life
- Improved self-management of medications
- Reduction in drug to drug interactions and polypharmacy

Example questions

Most people accidentally miss or double-dose their HIV medication at times, how often do you find yourself doing this?

A lot of people take their medication late, how often do you find yourself doing this?

Generally, can you describe how well you take your medication?

Have you started on any treatment in the last 12 months including over-the-counter medicines - specifically multivitamins and mineral compounds such as iron and calcium, or gym supplements?

Note

Careful consideration, understanding and knowledge is needed on how to approach the topic of the use of illegal substances, recreational, party drugs, chemsex etc. The person may be relieved to discuss the subject and it may uncover issues which could be affecting adherence/drug-drug interaction. Exploring concerns about any alcohol or drug use your patient might engage in is helpful but, if in doubt, or outside your scope of practice, then please refer to an appropriate professional.

Supporting self-management for this standard

Adherence tools

Information on drug to drug interaction and adverse events of ART

Information on what to do if admitted to hospital or if run out of or lose ARTs

Information on drug resistance

Information for people living with HIV

Benefits of ART and improvement in quality of life

Standard 7 Preventative medicine

All people living with HIV should have access to preventative vaccines and interventions that reduce the incidence of illnesses

Structure

Evidence of local arrangements to ensure that nurses working in the field of HIV care are educated, trained and competent at identifying vaccine-preventable illnesses.

Process

Proactive assessment and risk-reduction strategies for PLHIV and vaccine-preventable illnesses.

Process measures		First measure	Second measure	Data source
a	Proportion of PLHIV susceptible to hepatitis B infection who have been vaccinated	The number of PLHIV on a caseload susceptible to hepatitis B infection	The number of PLHIV susceptible to hepatitis B infection who have been vaccinated	Local data collection based on reviews of individual care records
b	Proportion of PLHIV susceptible to hepatitis A infection who have been vaccinated	The number of PLHIV on a caseload susceptible to hepatitis A infection	The number of PLHIV susceptible to hepatitis A infection who have been vaccinated	
c	Proportion of PLHIV who have been vaccinated against influenza	The number of PLHIV on a caseload	The number of PLHIV who have been vaccinated against influenza	
d	Proportion of PLHIV susceptible to pneumonia who have been vaccinated	The number of PLHIV on a caseload susceptible to pneumonia	The number of PLHIV susceptible to pneumonia who have been vaccinated	
e	Proportion of PLHIV susceptible to human papilloma virus who have been vaccinated*	The number of PLHIV on a caseload susceptible to human papilloma virus infection	The number of PLHIV susceptible to human papilloma virus infection who have been vaccinated	

* HPV vaccine is not widely available and therefore this indicator may be irrelevant

Outcomes

- Reduced incidence of vaccine preventable illnesses

Example questions

Do you know why it is important to be vaccinated against different viruses?

If you are going abroad do you know where to get your travel vaccines?

Supporting self-management for this standard

Lifestyle management regarding health-seeking behaviour

Check whether the vaccination plan is updated

Information for people living with HIV

Update information of free vaccines for risk groups

Benefits of risk-reduction for preventable illnesses and risk factors

Standard 8 Monitoring of comorbidities

All people living with HIV and non-AIDS comorbidities should be on a clear pathway for appropriate, safe and effective management of care

Structure

Evidence of local arrangements to ensure that nurses working in the field of HIV care are coordinating care with the general practitioner or other healthcare provider to avoid duplication.

Process

Clear protocols and pathways between primary and secondary care are essential for accountability, safe clinical management and communication between health professionals.

Process measures		First measure	Second measure	Data source
a	Proportion of PLHIV who have established regular communication with another provider/GP regarding their comorbidity	The number of PLHIV and comorbidities on a caseload	The number of PLHIV who have established regular communication with another provider/GP regarding their comorbidity	Local data collection based on reviews of individual care records
b	Proportion of PLHIV at risk of diabetes who have been assessed and given risk-reduction strategies	The number of PLHIV on a caseload at risk of diabetes	The number of PLHIV at risk of diabetes who have been assessed and given risk-reduction strategies (e.g. healthy lifestyle advice)	

Outcomes

- Reduction in the progression of comorbid diseases
- Improved quality of life

Example questions

Have you seen another doctor or healthcare professional in the last 12 months?

Have you talked about your HIV status with your GP or other service provider?
Is there anyone specifically you do not want to know about your HIV status?

Who manages your comorbidity (e.g. diabetes, COPD etc.)?

Note

It is not expected or appropriate that all comorbidities are managed by the HIV specialist. Rather, we encourage a proactive approach to ensure that referral pathways are in place for specialisms, and integrated care pathways between primary and secondary care are effective. Allow communication [where appropriate] between HIV and specialties to provide holistic care. In addition, screen for infectious diseases such as hepatitis C if the person feels they have been at risk and do not wait for the annual health review.

Supporting self-management for this standard

People are encouraged to have a GP with whom to work and coordinate health management. People will feel actively involved in health planning when working with their GP, and with a person's consent a GP can work with the HIV providers to inform them of other specialists involved in the person's care

Lifestyle management to reduce preventable long-term conditions. Provide advice on risk factors such as smoking cessation, diet, exercise initiatives (gym referrals via primary care)

Encouraging people to search out strategies to manage co morbidity such as Telehealth or online websites (e.g. www.nhs.uk/Livewell/Diabetes/Pages/Avoiddiabetes.aspx)

Information for people living with HIV

Reassurance that referrals/communication with other specialities has/will take place

Awareness of family/ caregiver of signals to be alert to and know what to do

Standard 9 Neurocognitive impairment

All people living with HIV should have access to cognitive screening on an annual basis

Structure

Evidence of local arrangements to ensure that nurses working in the field of HIV care are trained and competent in screening for cognitive difficulties.*
Evidence of pathways in place for referral for further screening and in-depth cognitive assessment.

Process

Screening as a routine part of the annual review with established pathways for referral.

Process measures		First measure	Second measure	Data source
a	Proportion of PLHIV who are screened for cognitive impairment	The number of PLHIV on a caseload	The number of PLHIV who have been screened for cognitive difficulties using a validated tool (see note on page 25)	Local data collection based on reviews of individual care records
b	Proportion of PLHIV who have been referred for formal/in-depth cognitive assessment	The number of PLHIV identified (after screening) with self-reported cognitive difficulties	The number of PLHIV referred for formal/ in-depth cognitive assessment	

Outcomes

- Improved early detection of cognitive difficulties
- Improved early assessment and interventions for people with cognitive difficulties

Example questions

Use a validated screening tool

** Screening with three questions (as recommended by EACS) could be used as follows:*

1. Do you experience frequent memory loss (e.g. do you forget the occurrence of special events even the more recent ones, appointments etc.)?

2. Do you feel that you are slower when reasoning, planning activities, or solving problems?

3. Do you have difficulties paying attention (e.g. to a conversation, a book, or a movie)?

Note
When using a validated screening tool it should be administered by a suitably qualified practitioner or a healthcare professional who has received training and is accessing ongoing support to deliver screening assessments

Information for people living with HIV

Information relating to local services (e.g. access to neuropsychological assessment, neurorehabilitation, or peer support, e.g. charity organisations supporting people with cognitive problems)

Up to date information on HIV and possible cognitive impairment

Information on other preventable neurocognitive risk factors (e.g. alcohol, smoking, drug use, hepatitis C, neurosyphilis etc.)

A useful fact sheet regarding HIV and cognitive changes can be found here:

www.aidsmap.com/Cognitive-impairment-and-HIV/page/3135688/

Advise the use of a diary to help with any memory problems and seek advice from recognised support groups if there are any concerns about cognition

Supporting self-management for this standard

Lifestyle management for reduction of preventable neurocognitive risk factors

Encouraging people to search out strategies to manage cognitive difficulties perhaps from online websites (e.g. reputable sites for issues such as brain injury, dementia sites)

Consult with significant others to establish whether they have noticed any changes

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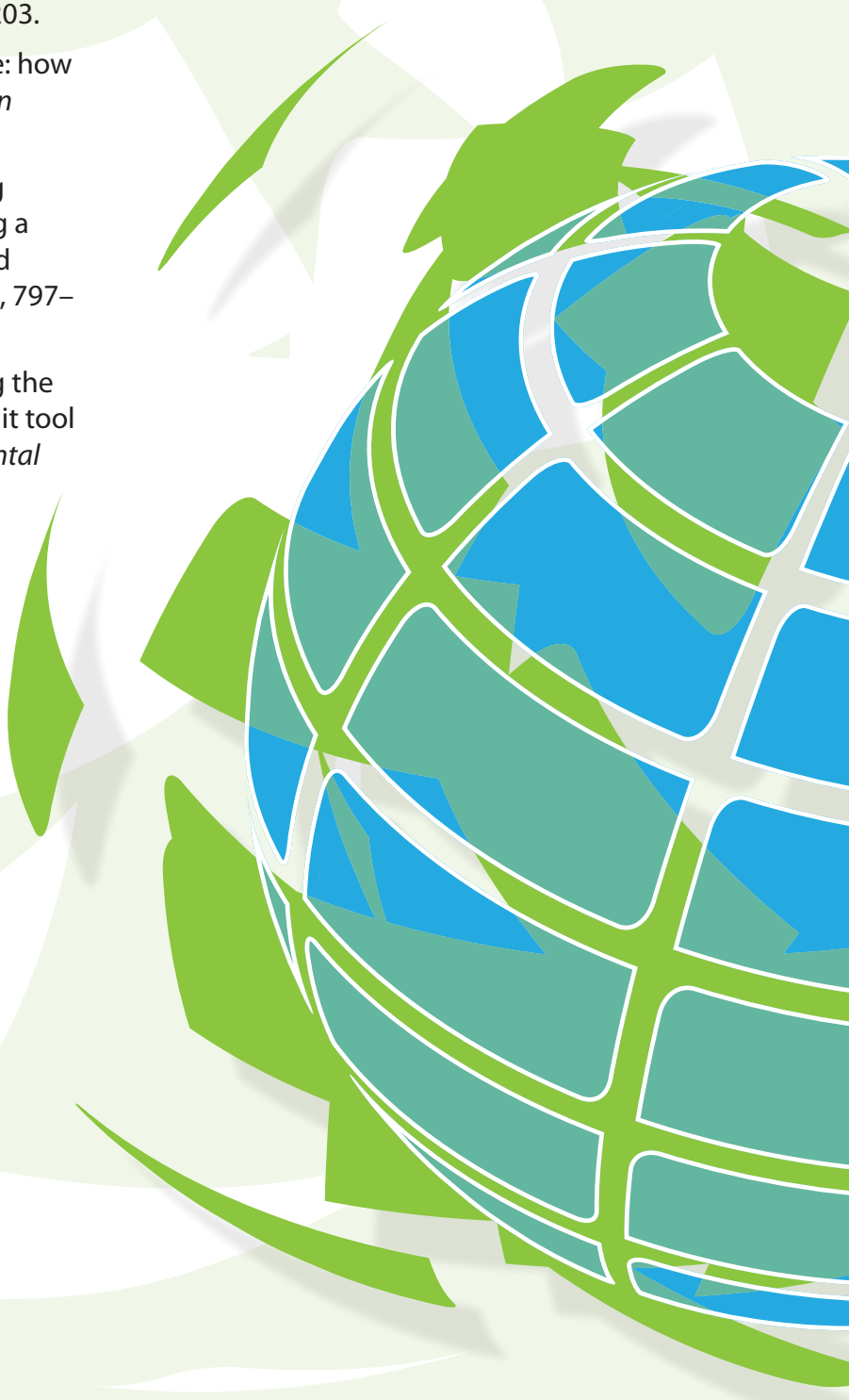

Generic pro-forma questionnaire

Reference numbers indicate the Standard to which the question is linked.

1. Are you taking antiretroviral therapy? [6]
Yes ○ No ○
If no, go to question 8

2. Do you suffer from any side-effects related to your medication? [6]
Yes ○ No ○ Maybe ○
If no, please go to question 4

3. Would you like to discuss these side-effects with your doctor/nurse/pharmacist? [6]
Yes ○ No ○

4. Do you have any problems remembering to take your medication? [6]
Yes ○ No ○

5. On average how many doses of medication have you missed in the last week? [6]
None ○ One ○ Two ○ More than two ○

6. On average how many doses of medication have you missed in the last month? [6]
None ○ One ○ Two ○ More than two ○

7. Do you take any of the following? [6]
○ Herbal/alternative remedies
○ Medications bought from chemist or elsewhere
○ Traditional remedies
○ Medication prescribed by your GP/another doctor
○ Gym supplements
○ Anabolic steroids
○ None of these

Any other medication/supplements/remedies can be discussed with the nurse/pharmacist.

8. Have you used recreational drugs in the last 12 months? [5, 6]
○ Yes
○ No
○ Would prefer to discuss with a nurse
If no, please go to question 10

9. If yes, which drugs have you used? [5, 6]
○ Cocaine ○ Heroin ○ Crystal meth
○ GBL/GHB ○ Ketamine ○ Mephadrone
○ Cannabis ○ Other

10. Do you smoke tobacco/cigarettes? [1, 7]
○ Yes
○ No
Number of cigarettes/day:

11. How many units of alcohol do you drink per week? [4, 5]
Units/week:

12. Do you have children? [4]
Yes ○ No ○
If no, please go to question 16
If yes, how many?

13. Has your child/children been tested for HIV? [4]
○ Yes/all
○ Yes/some
○ No

14. Is/are your children HIV positive? [4]
○ Yes/all
○ Yes/some
○ No
○ Don't know

15. Does your child/children live in the UK? [4]
○ Yes/all
○ Yes/some
○ No

16. Do you have a regular sexual partner/s? [4]
Yes ○ No ○
If no go to question 19

17. Have you had sexual contact with anyone other than your regular partner/s? [4]
Yes ○ No ○

18. Is/are your partner(s):
○ Male
○ Female
○ Both

19. When was your last sexual health screen?

20. Would you like to be referred for a sexual health screen?
(We recommend annual sexual health screens or more frequently if you have a new partner/s/)
Yes ○ No ○
○ Would prefer to discuss with a doctor/nurse

21. Are you/your partner using contraception? [4]

○ Not relevant ○ No
○ Condoms ○ IUD/Mirena coil
○ Depo-Provera injection ○ Implant
○ Pills

22. Have you been diagnosed with any of the following in the past year?

○ Heart disease ○ Bone disease
○ Fracture ○ Cancer
○ Depression ○ High blood pressure
○ Diabetes ○ Any other illness(es)
○ No

23. During the past month have you often been bothered by feeling down, depressed or hopeless? [5]

Yes ○ No ○

24. During the past month have you often been bothered by little interest or pleasure in doing things? [5]

Yes ○ No ○

25. Do you experience frequent memory loss? [9]
(e.g. forgetting special events or appointments)

Yes ○ No ○

26. Do you feel that you are slower when reasoning, planning activities or solving problems? [9]

Yes ○ No ○

27. Do you have difficulty paying attention? [9] (e.g. in conversation, reading or watching something)

Yes ○ No ○

28. Have you had a cervical smear test done in the past year? [1] [for women only]

Yes ○ No ○

Where was this done?

○ At the Hospital
○ GP surgery
○ Somewhere else

Checklist [1, 2, 3]**:**

- **Annual visit blood requests:**
- **Blood pressure:**
- **Height:**
- **Urinalysis:**
- **uPCR (if necessary):**
- **Weight:**
- **BMI:**
- **10 year CVD risk score:**
- **Adherence issues addressed** [5, 6]**:**
- **Hepatitis B** [7]

Vaccinated: Yes ○ No ○
Date of last vaccine:

sAb status:

- **Hepatitis A** [7]

Vaccinated: Yes ○ No ○
Date of last vaccine:

- **Hepatitis C screen** [7]

Yes ○ No ○
Date of last screen:

Result:

- **Referred for sexual health screen** [4]**:**

Yes ○ No ○ Declined ○

- **Cervical smear test** [4]**:**

Done ○ Not done ○ n/a ○

- **Up to date list of medication obtained** [6, 7, 8]**:**

Yes ○ No ○ n/a ○

- **Referral to pharmacy for further advice** [6, 7, 8]**:**

Yes ○ No ○ n/a ○

- **Contraception discussed** [7]**:**

Yes ○ No ○ n/a ○

- **Cognitive screen** [9]**:**

Yes ○ No ○ Declined ○

Name of healthcare professional:

Signature:

Date:

Notes

Produced in conjunction with