

A Person-centred Model of HIV Nursing Care



Eileen Nixon | Michelle Croston | Garry Brough | Liz Foote | Martin Jones | Linda Panton | Kirstie Salthouse Moses Shongwe | Katie Warburton | Sarah Rutter | David Munns | Sara Strodtbeck | Christina Antoniadi Jessica Colaco Osorio | Jonathan Roberts | Steve Callaghan The **National HIV Nurses Association** has developed the first model of nursing care specifically designed for registered nurses working in an HIV setting or whose role involves caring for people living with HIV.

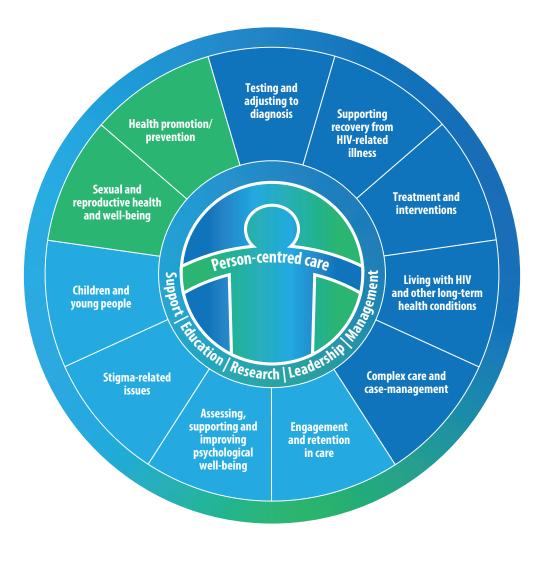


This was a collaborative effort involving PLHIV, clinical nurse specialists and academics from across the UK. While we recognise the invaluable contribution of other healthcare workers, it is not within the scope of this document to address the care delivered by non-registered nurses.

Each section of the model is linked to HIV Nursing competencies at different levels, training and quality.

We have also provided links to HIV-specific guidance and policies as well as broader NHS priorities to assist in demonstrating evidence for nursing roles at a local level.

We believe that this model will not only support nurses caring for people with HIV but also help to reduce any variation in care, improve the standard of care and provide a professional framework for NMC revalidation.



© National HIV Nurses Association (NHIVNA) 2024 www.nhivna.org

Contents

Being person-centred in the context of HIV Nursing Care	
The 'segments' of HIV Nursing Care	
Testing and adjusting to diagnosis	6
Supporting recovery from HIV-related illness	12
Treatment and interventions	18
Living with HIV and other long-term health conditions	24
Complex care and case-management	30
Engagement and retention in care	36
Assessing, supporting and improving psychological well-being	42
Stigma-related issues	48
Children and young people	54
Sexual and reproductive health and well-being	60
Health promotion/prevention	66

Being person-centred in the context of HIV Nursing Care

The overall aim of the HIV person-centred model of nursing care is to enable the delivery of high-quality nursing care that meets the evolving needs of people with HIV.

The model is designed to be used either as a whole or can be used as separate segments. However you choose to integrate this model of care into your practice, we believe that it will enhance care and improve quality of life for people living with HIV. This model has been developed to enable HIV nurses to facilitate and improve the delivery of care. The model was designed to be person-centred by a working group including people living with HIV, to ensure that their voices were heard and reflected within the model.

There are many definitions available as to what person-centred care means within the nursing literature. The most often cited is the person-centred framework by McCormack and McCance ¹, which is comprised of four constructs, which are: prerequisites, care

processes, person-centred outcomes and the care environment. Whilst McCormack and McCance's framework offers insight into how person-centred care can be developed within nursing, it does not take into consideration the nuances involved within HIV nursing, such as stigma and self-stigma and the impact this can have within the care setting.

NHIVNA felt it was important to define person-centred care in order to contextualise the model of care. Our definition is based on the HIV nursing philosophy² which articulates the significant role that empathy plays in care delivery and the development of therapeutic

relationships. It is through the empathic nurse/patient relationship that concerns are able to be raised, so that care can focus on the priorities of the patient. Empathic and open communication enables the delivery of person-centred care.

The well-being of people living with HIV requires strong self-management skills, education and engagement in peer support, an ability to deal with HIV stigma and active participation in decisions about all aspects of treatment and care, service design and delivery. This will be increasingly important as we support an ageing population in managing comorbidities and polypharmacy.

> Therefore, achieving personcentred care requires services to consciously prioritise the perspectives of individuals, families and communities in order to respond to their needs and preferences in humane and holistic ways. The person is a participant, not just a beneficiary of the health system ³.

NHIVNA recognises that stigma and self-stigma are fundamental issues within HIV care and what makes nursing in this context different. However, we feel strongly that stigma should not be placed within the definition, as we want to avoid automatically locating this concept within the individual. See stigma segment for further detail on the nurse's role in relation to stigma.

As the HIV care landscape continues to evolve, our understanding of what high quality care means in the context of HIV will alter ^{4, 5}. However, what will remain constant is our underpinning philosophy of ensuring that people living with HIV are at the centre of their care.

Competency levels

Throughout the model of care, NHIVNA will be recommending different levels of competencies within each section from intermediate to advanced levels being suggested in line with the NHIVNA competencies and consistent with NHIVA/STIF competencies. NHIVNA believe that person-centred care is the foundation of our nursing practice from which the rest of our nursing practices develops. As such, NHIVNA believe that the following competencies need to be met at all levels of practice.

- All people living with HIV should be provided with equitable and non-discriminatory care across all healthcare settings, including those outside sexual health and reproductive services.
- In keeping with other long-term health conditions, people living with HIV should be enabled to optimise self-management and access peer support opportunities to promote their physical and mental health, and overall well-being.
- People living with HIV should be **actively involved in decisions about their own health** and social care and may require support to facilitate this.
- People who use HIV clinical and support services should be actively involved in the design, planning delivery and review of these services.
- People living with HIV should receive **care that takes account of and enhances their well-being** beyond their physical health and life expectancy.

For more information of what it means to work in a person-centred way within HIV care please see BHIVA Standards of Care, chapters 2, 6 and 7.

References

- 1. McCormack B , McCance T V (2006) Development of a framework for person centred nursing , Nursing Theory and concept development or analysis, 472-479
- 2. Croston M, Jack K, Wibberley C (2022) How do we create therapeutic relationships with people living with HIV? : An exploration of the nurse patient relationship, British Journal of Nursing, 31,11, s16-22
- **3.** British HIV Association (BHIVA) (21018) Standard of care for people living with HIV, London.
- 4. Croston M, Rutter S (2020) Psychological perspectives in HIV care: An Interprofessional approach, Routledge
- 5. Croston M, Hodgson I (2021) Providing HIV care: lessons from the field for nurses and healthcare professionals, Springer.



Testing and adjusting to diagnosis

Introduction

This model of nursing care has been specifically designed for registered nurses working in an HIV setting or whose role involves caring for people living with HIV. While we recognise the invaluable contribution of other healthcare workers, it is not within the scope of this document to address the care delivered by non –registered nurses.

2 This section will cover HIV testing and support for those adjusting to a new diagnosis. This will include the nursing care required to support HIV testing, disclosure of a positive HIV test result and adjustment to diagnosis.

3 This links with treatment and interventions, living with HIV and other long-term conditions, sexual and reproductive health and well-being, engagement and retention in care, psychological well-being and stigma-related issues.

4 There are enclosed examples of competency documents that can be used by nurses looking after people living with HIV. Competencies will need to be assessed according to local protocols/ governance or as part of a formal qualification. Those who have undertaken NHIVNA/STIF competencies can use the related competencies for this segment.

5 In addition to the documents and competencies below, it is expected that HIV nurses will engage in relevant CPD for their role to ensure contemporary evidence based practice. It is also expected from HIV nurses to share best practice. The end of HIV transmission in the UK is now considered to be an achievable ambition¹. Increasing HIV testing and diagnosing the undiagnosed is a core component to reaching zero HIV transmission by 2030. The early initiation of ART, regardless of CD4 cell count, has clear benefit for the individual (with avoidance of morbidity and mortality), their sexual partners (avoidance of transmission) and public health (reduced community viral load and HIV transmissions)².

HIV testing is recommended in the following contexts³:

Individuals with increased risk of HIV for example; men who have sex with men (MSM) & their female sexual partners, Black Africans, injecting drug users, sex workers, prisoners, trans women and people from countries with high rates of HIV prevalence and their sexual partners, Individuals known to have/have had a mother living with HIV and who do not have documented HIV-negative status.

Individual attending the following healthcare settings: sexual health services, antenatal clinics, termination of pregnancy services, addiction and substance misuse services, health services for hepatitis B and C and TB and lymphoma.

All people presenting with symptoms and/or signs consistent with an HIV indicator conditions.

People accessing healthcare in geographical areas with high or extremely high HIV seroprevalence:

- High (>2/1000) if undergoing venepuncture and
- Extremely high (>5/1000) all attendees
- Sexual partners of an individual diagnosed with HIV

Opt out HIV/BBV screening programmes in Emergency Departments and in General Practice is being expanded across the UK⁴.

HIV Nurses are therefore key to promoting, supporting or undertaking HIV testing depending on their role and are pivotal in supporting a patient newly diagnosed with HIV.

References

- 1 Towards Zero: the HIV Action Plan for England 2022 to 2025 - GOV.UK (*www.gov.uk*)
- 2 NHS England 2016 Evidence review: Immediate initiation of Anti-Retroviral-Therapy
- 3 https://www.bhiva.org/HIV-testing-guidelines
- 4 Kirby T 2024. UK emergency department testing for HIV expanded. www.thelancet.com/hiv Published online January 19, 2024 https://doi.org/10.1016/ S2352-3018(24)00010-9

Competency levels

Competencies at **intermediate level** (1) as defined by NHIVNA/STIF: These are aimed at nursing posts working in an HIV setting or with HIV patients Band 5/6/7 and are equivalent to Level 3 of the NHIVNA competencies.

Competencies at **advanced level** (A) as defined by NHIVNA/STIF: These are aimed at nursing posts at band 7 and above who are working at an advanced practice level equivalent to Level 4 of the NHIVNA Competencies and with reference to the Advanced Nursing practice in HIV care (2016).

Nursing competencies

- Demonstrate competence in explaining HIV antigen and antibody tests & relevance of the window period
- Explain rationale for opt out HIV testing and impact of this
- Provide details for where to get an HIV test in local area
- Competent at explaining a reactive results depending on job role
- Has ability to order correct confirmatory HIV tests in line with to local and national guidelines 1
- Competent in giving an HIV diagnosis depending on job role
- Assessment of mental health, coping strategies and physical health at new diagnosis escalating concerns and referring on when required 1
- Signposting to peer support, befriending, and health condition specific support or local support programmes and facilities **I A**
- Arranges follow-up according to individual need and within local and national guidelines

- Assess suitability for starting treatment and initiate appointment when ready or undertake prescribing depending on job role **I A**
- Discuss rationale for and refer patient for partner notification
- Initiate partner notification depending on role
- Provide nurse led new patient clinics A
- Assess physical health, co-morbidities and concomitant medication at first appointment and discuss rational for PREP/PEP where relevant A
- Establish local pathways for newly diagnosed patients in accordance with national guidelines A
- Establish or support HIV testing in local area depending on job role/work setting A
- Transforming care through continuous improvement and sharing of best practice, teaching and educating others A

Recommended training

- HIV Awareness courses
- National HIV Nursing Competencies 2013 https://www.nhivna.org/competencies
- NHIVNA e-learning modules
- Intermediate NHIVNA/STIF competencies
- Advanced NHIVNA/STIF competencies

Case Study 1 HIV Testing

John is a Caucasian male; heterosexual, age 62 years old. He attended the sexual health clinic for a routine screen following receptive and insertive unprotected sex with a casual female and transgender partners in the last two weeks. He also reports paying for sex in the last 3-6 months.

HIs last HIV test was two years ago as part of a routine sexual health screen. He is needle phobic so struggles with venepuncture and has not had an HIV test since then. He reports being generally in good health other than being on treatment for hypertension and high cholesterol.

Please consider the following points in relation to your level of competency / clinical practice. These trigger questions are to enable you to reflect on your role as a nurse within regards to HIV testing. There is no expectation that everyone will know the definitive answer to these trigger questions. What is more important is that you recognise and address any gaps in your knowledge.

- What are the barriers to HIV testing for John and how can you help him to overcome these?
- What HIV tests would you recommend for John based on his risks?
- What considerations do you need to make for the window period based on the history above?
- How do you arrange for John to get his HIV test result?
- What advice would you give John to minimise his risks of acquiring HIV in the future ?

Case study 2: Adjusting to diagnosis

John's HIV test comes back as positive. He has a viral load of 700,000 copies/ml and a CD4 count of 320 cells/mm. He is very shocked and overwhelmed by the diagnosis and worried that people will find out. He cares for his disabled sister and is worried that he won't be able to attend appointments at the HIV clinic. Please consider the following points in relation to your level of competency / clinical practice. These trigger questions are to enable you to reflect on your role as a nurse with regards to newly diagnosed patients. There is no expectation that everyone will know the definitive answers to these trigger questions. What is more important is that you recognise and address any gaps in your knowledge.

- What may be the priorities for John given the information above?
- How can you facilitate peer support for John at the time of his diagnosis?
- What are the potential barriers for John to engage in care and what support can you offer to enable this?
- How do you approach discussing starting antiretroviral therapy with John?
- What strategies might you use to initiate partner notification?
- How do you support John to share his diagnosis with the people in his life that he wants to inform ?
- What information will you give John about PreP and PEP?

The dimensions of quality

The table opposite is for you to use in your practice. It is intended to be a quality framework for you to demonstrate HOW you are delivering this segment, of the HIV model of nursing care, in the context of quality and outcomes. It is based on The Institute of Medicine's six dimensions of healthcare quality.

This can be used in many different areas of your practice, for example, to reflect on your own practice, to engage your team in quality improvement projects, for your revalidation, teaching and other proactive elements of your role.

The righthand column is left blank for you to fill in as you explore the dimensions of quality and cross reference the information, guidance, standards and links on the following pages.

The dimensions of quality

Safe Avoiding harm to patients from care that is intended to help them
Effective Providing services based on evidence and which produce a clear benefit
Person-centred Establishing a partnership between practitioners and patients to ensure care respects patients' needs and preferences
Timely Reducing waits and sometimes harmful delays
Efficient Avoiding waste
Equitable Providing care that does not vary in quality because of a person's characteristics

Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. Washington DC: National Academy Press, 1990, p244

NMC code

Section 2 – Evidence, policy and

Commissioning

Why include NHS plans, policy and guidance alongside HIV specific guidance/policy? The documents below are not a reference list. They are there to help you to synthesise HIV, HSA and NHS plans, policies and guidance to ensure you are aware of, and can describe your role within a strategic context where required, secondly, for you to articulate and demonstrate the outcomes you are achieving in your role and finally, to support you to develop business cases or case for change narratives/documents.

HIV Specific guidance/policy/references

HIV-testing-guidelines-2020.pdf (bhiva.org)

Towards Zero: the HIV Action Plan for England - 2022 to 2025 - GOV.UK (*www.gov.uk*)

BHIVA Standards of care 2018

https://www.bhiva.org/HIV-partner-notification-foradults

UK emergency department testing for HIV expanded – The Lancet HIV

https://ssha.info/resources/manual-for-sexual-healthadvisers/

How this segment meets NHS Priorities

Embedding measures to improve health and reduce inequalities.

How this segment meets NHS Long-term Plan

This segment meets the long-term plan with regards to prevention of health inequalities and not only treating the underlying health condition bit preventing people from becoming unwell.

https://www.longtermplan.nhs.uk/areas-of-work/ prevention/

Relevant key performance indicators

- Relevant Specialised Services Quality Dashboard (SSDQ) indicators
- Public Health Outcomes Framework
- NHS Outcomes Framework:
 - Domain 1: Preventing people from dying prematurely
 - Domain2: Enhancing quality of life for people with long-term conditions
 - Domain 4: Ensuring that people have a positive experience of care

For further information on demonstrating the value of specialist nursing see Apollo Resource/Professor Alison Leary: *https://www.apollonursingresource.com/*



Supporting recovery from HIV-related illness

Introduction

This model of nursing care has been specifically designed for registered nurses working in an HIV setting or whose role involves caring for people living with HIV. While we recognise the invaluable contribution of other healthcare workers, it is not within the scope of this document to address the care delivered by non –registered nurses.

2 This section will cover HIV related illness and the support that is required. This requirement broadly comes under three categories. 1) Diagnosis, individuals who maybe unwell at the point of diagnosis, 2) Individuals that are off treatment and become unwell, 3) Individuals living with HIV and become unwell with long-term health conditions.

3 This will link with other sections including treatment and interventions, living with HIV and other long-term conditions, testing and adjusting to diagnosis and assessing, supporting and improving psychological well-being. As with other sections, this includes specialist HIV nursing practice at intermediate level and advanced level.

4 Competencies will need to be assessed according to local protocols/governance or as part of a formal qualification e.g. STIF/NHIVNA certificate in intermediate or advanced HIV nursing competencies. Nurses who have undertaken STIF/NHIVNA competencies can use the related competencies for this segment.

5 In addition to the documents and competencies below, it is expected that HIV nurses will engage in relevant CPD for their role to ensure contemporary evidence based practice. It is also expected from HIV nurses to share best practice.

Section 1 – Your Clinical practice

Supporting people recovering from HIV related illnesses is a key part of HIV specialist nursing. HIV related illnesses include opportunistic infections (see table below), HIV related malignancies including Kaposi sarcoma and non-Hodgkin lymphoma and HIV related co-infections including Viral Hepatitis B and C.

Opportunistic Infections Subcategory	Examples
Central Nervous System	Cryptococcus, Toxoplasmosis, Progressive multifocal leukoencephalopathy (PML), Cytomegalovirus (CMV), Herpes Simplex Virus (HSV), Varicella Zoster Virus (VZV)
Pulmonary	Pneumocystis pneumonia (PCP), Bacterial Pneumonia, Cryptococcus, Aspergillosis, CMV, Influenza A,
Gastrointestinal	Oesophagitis, Diarrhoea (CMV, Cryptosporidium, Microsporidiosis), Candidiasis
Ocular	CMV Retinitis, Syphilis, Toxoplasmosis, VZV Retinitis

Advances in anti-retroviral treatment have dramatically reduced opportunistic infections and death^{1, 2, 3}.

However, there are still a significant number of individuals who become unwell with HIV-related illnesses.

There are many different situations where support is required, however it can be broadly categorised into:

- Individuals who are unwell at the point of diagnosis (late diagnosis)
- Individuals who are off treatment and become unwell
- Individuals who become unwell with long-term health conditions

It is important to recognise that the approach required may be different depending on the situation, however the fundamental skills will be the same. Therefore, HIV specialist nurses are required to have appropriate skills and training to enable this.

HIV specialist nurses are experts in HIV care. It is vital that specialist HIV nurses provide education and support for HIV related illnesses not only to people living with HIV but also within healthcare settings to ensure the highest standard of care can be delivered.

References

- 1. British HIV Association (BHIVA) (21018) Standard of care for people living with HIV, London.
- 2. Croston M, Rutter S (2020) Psychological perspectives in HIV care: An Interprofessional approach, Routledge
- 3. Croston M, Hodgson I (2021) Providing HIV care: lessons from the field for nurses and healthcare professionals, Springer

Competency levels

Competencies at **Intermediate level** (1) as defined by STIF/NHIVNA: These are aimed at nurses working in an HIV setting or with people living with HIV at Band 5/6/7 and are equivalent to Level 3 of the NHIVNA competencies.

Competencies at **Advanced level** (A) as defined by STIF/NHIVNA: These are aimed at Band 7 nurses and above who are working at an advanced practice level equivalent to Level 4 of the NHIVNA Competencies and with reference to the Advanced Nursing practice in HIV care (2016).

NB: For nurses working outside of England's Agenda for Change contracts, please use this as guidance for your level of practice in your area of work.

HIV Nursing Competencies

- Triage across physical health conditions and directing to appropriate place of care link that to NHIVNA/STIF triage competency, NHIVNA competency
- AHC competencies screening, assessment, prevention and signposting
- Knowledge and skills to manage complex care and provide case management
- Nurse-led clinics / Advanced practice roles
- Establishing and developing services
- Hepatitis A/B/C: diagnosis and management I
- Assessing and managing patients with complications of HIV and ARV meds (bone, renal, metabolic, cardiovascular, gastro/liver, dermatological, haematological, neuro/psych, IRIS, malignancies A
- Assessment and management of acutely unwell patient
- Assessment and management specific conditions A
- Assessment and management of patient with respiratory illness
- Assessment and management of patient with gastro/ liver complications
- Assessment and management of patient with CNS complications
- Assessment and management of patient with cardiovascular complications
- Assessment and management of patient with bone/ renal complications
- Assessment and management of patient with dermatological complications
- Assessment and management of patient with metabolic complications A
- Assessment and management of patient with haematological complications
- Assessment and management of patient with mental health/mood disorders
- Prophylaxis against opportunistic infections
 A
- Immune reconstitution inflammatory syndrome A
- Assessment and management of patients living with malignant disease
- Supporting patients with complex care needs (incl. end of life care)

Alongside the competencies for this section the skills required include:

- Triaging patients to provide alternative routes of care from emergency departments utilising advanced communication and assessment.
- Problem solving and decision making.
- Escalation of concerns and recognition of own limitations within sphere of competence/practice.
- Admission avoidance and prevention.
- Specialist care which allows for earlier discharge with appropriate specialist follow up.
- Highly skilled psychological support, including adherence support.
- Care co-ordination and liaison with third sector and other healthcare professionals.

Recommended training

- Non-medical prescribing
- National HIV Nursing Competencies 2013
 https://www.nhivna.org/competencies
- Physical assessment module (level 6 or 7)
- Advanced communication skills
- End-of-life care module (level 6 or 7)

Case Study: Fictitious case based on a number of real life experiences

Hasim is a 31-year-old male who has presented to Emergency department with shortness of breath, fever and weigh loss. National Early Warning Score (NEWS 2) is 9, indicating a high score which requires assessment by a critical care team. Due to the level of Hasim's oxygen levels a decision is made to admit Hasim to an acute medical ward for further investigations. Whilst speaking to one of the medical team Hasim informs the doctor that he is living with HIV, however he has not been taking his treatment for some time. The doctor informs Hasim that he will refer him to the HIV specialist team which includes both doctors and nurses for specialist input in his care.

The next day Hasim is seen by one of the HIV specialist nurses they talk to Hasim about how he is feeling and the investigations that are currently been undertaken, taking time for him to fully understand what is going on. This visit is used to start a therapeutic relationship with Hasim.

The HIV specialist nurse liaises with the nursing staff on the ward to ensure their educational needs are met.

Hasim is diagnosed with Pneumocystis Pneumonia (PCP), an infection caused by the fungus Pneumocystis Jirovecii, and started on appropriate treatment. Once Hasim's oxygen levels are satisfactory, he can be discharged. The HIV specialist nursing team ensure that an appropriate community plan is in place with follow up appointments prior to discharge. They have ensured that during the admission Hasim as met different members of the team and conversations regarding restarting anti-retroviral treatment have taken place whilst waiting for resistance testing profile. The HIV specialist nurses have utilised advanced communication skills to enable Hasim to talk about the reasons why he stopped taking his treatment and liaised with clinical psychologist colleagues to ensure that Hasim has the appropriate psychological support.

Hasim is seen a week later in clinic by a HIV specialist nurse who is able to undertake a physical examination of Hasim to ensure he is recovering from his PCP and determine whether he requires any further assessment by medical staff. Having access to this type of care has ensured that Hasim spent minimal time in hospital, reducing his hospital stay and likely to reduce chances of re-admission.

Please consider the following points in relation to your level of competency / clinical practice. These trigger questions are to enable you to reflect on your role as a nurse and to engage in professional discussions about people living with HIV who disengaged in care in your workplace. There is not an expectation that everyone will know the definitive answer to these trigger questions. What is more important is that you recognise and address any gaps in your knowledge and practice.

- What might the educational needs of the ward staff providing care for Hasim be?
- Outline how you will assess his support needs? And how will you decide on the priorities in this case?
- How would you start to plan Hasim's discharge? What factors may you need to take into consideration?
- Explore how you may work with Hasim and their GP, what factors will you need to consider and why?
- How will you continue to develop your therapeutic relationship with Hasim?
- Consider your own training needs with regard to managing people living with HIV who require inpatient support.

Demonstrating quality HIV care in this segment

Demonstrating quality in healthcare is more important than ever. We have created a quality framework based on The Institute of Medicine's six dimensions of healthcare quality for you to use in the context of your role. This quality framework is intended for you to demonstrate HOW you are delivering this segment of the HIV model of nursing care. It can help you:

- Define quality care for people living with HIV
- Link quality to the NMC code of conduct
- Communicate what HIV quality care means to all your stakeholders
- Develop continuous quality improvement projects in your area
- Link quality to the foundation of HIV care Person-Centred Care

This can also be used in many different areas of your practice, for example, to reflect on your own practice, to engage your team on quality improvement projects, for your revalidation, teaching and other proactive elements of your role. Feel free to print this page off and start to scope out quality for your area of practice under the six dimensions.

The middle column is left blank for you to fill in as you explore the dimensions of quality and cross reference the information, guidance, standards and links on the following pages. The righthand column helps you to cross reference your work to the NMC Code of Conduct – this will support your revalidation process as a focus for professional reflection.

NMC code

	Time coue
Safe Avoiding harm to patients from care that is intended to help them	
Effective Providing services based on evidence and which produce a clear benefit	
Person-centred Establishing a partnership between practitioners and patients to ensure care respects patients' needs and preferences	
Timely Reducing waits and sometimes harmful delays	
Efficient Avoiding waste	
Equitable Providing care that does not vary in quality because of a person's characteristics	

The dimensions of quality

Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. Washington DC: National Academy Press, 1990, p244

Section 2: Evidence, policy and

Commissioning

Why include NHS plans, policy and guidance alongside HIV specific guidance/policy? The documents below are not a reference list. They are there to help you to synthesise HIV, HSA and NHS plans, policies and guidance to ensure you are aware of, and can describe, your role within a strategic context where required, secondly, for you to articulate and demonstrate the outcomes you are achieving in your role and finally, to support you to develop business cases or case for change narratives/documents.

HIV Specific guidance/policy/references

Advanced Nursing practice in HIV care: Guidelines for nurses, doctors, service providers and commissioners 2016

BHIVA and BIA guidelines for he treatment of Opportunistic infection in HIV-seropositive Individuals 2011

BHIVA Standards of care 2018

HIVCommNursingModel.pdf (*nhivna.org*) Providing a model of HIV community nursing

HIV-Nursing-18-2-CPD-article.pdf (*nhivna.org*) HIV complex care and care coordination: the nurse's role

HIV-Nursing-19-4-CPD-article.pdf (*nhivna.org*) HIV and communication skills for practice

HIV_Nursing_19_3_BP5-BP8.pdf Barriers to adherence and intentional non-adherence: a guide for nurses

Service specification: adult specialised services for people living with HIV *https://www.england.nhs.uk/ publication/adult-specialised-services-for-people-livingwith-hiv/*

https://www.nhivna.org/file/5de4e62e8c7ad/HIV-Nursing-18-3-CPD-article.pdfn HIV co-infections: TB, HCV and HBV

https://www.nhivna.org/file/5e30401e69480/HIV-Nursing-19-1-CPD-article.pdf HIV and Cancer

https://www.nhivna.org/file/5f6201c20c35d/HIV-Nursing-20-3-CPD-article.pdf HIV, Disability and rehabilitation

NHSE Integrated Care Resources. *https://www.england. nhs.uk/integratedcare/what-is-integrated-care/*

How this segment meets NHS Priorities

Admission avoidance – Triage and nursing advice to ensure appropriate referral to Primary or specialist care settings and minimising use of A&E and inpatient stays (IA)

Reduction in Length of Stay – Support to allow earlier discharge from hospital with structured follow-up (] A)

How this segment meets NHS Long-term Plan

- Care closer to home
- Focus on support for people to manage their own health conditions (LTP)
- Continue to address health inequalities and deliver on the Core20PLUS5 approach (LTP)
- Promoting integrated care (A)
- NHS diagnose 75% cancers at stage 1 or 2 (LTP)

Relevant key performance indicators

- Relevant Specialised Services Quality Dashboard (SSDQ) indicators
- NHS Outcomes Framework
 - Domain 1: Preventing people from dying prematurely
 - Domain 3: Helping people to recover from episodes of ill health or following injury
 - Domain 4: Ensuring that people have a positive experience of care (evidence of patient satisfaction)
- Other Performance indicators
 - Documented care plans with patient involvement (BHIVA notes audit or NHIVNA care plan audit)
 - Documented adherence support and medicines review
 - Reduction in complications in complications of HIV disease including AIDS and non AIDS co-morbidities
 - Reduction in treatment associated complications and development of drug resistance
 - Effectiveness of networked arrangements and documented pathways.
 - Time to admission/ Transfer for inpatient care

For further information on demonstrating the value of specialist nursing see Apollo Resource / Professor Alison Leary *https://www.apollonursingresource.com*/



Treatment and interventions

Introduction

This model of nursing care has been specifically designed for registered nurses working in an HIV setting or whose role involves caring for people living with HIV. While we recognise the invaluable contribution of other healthcare workers, it is not within the scope of this document to address the care delivered by non-registered nurses.

2 This section will cover HIV treatments and interventions with particular reference to the nursing role in supporting or managing patients on antiretroviral therapy or associated treatments. This will include 1) preparing patients to start therapy [involving patients in treatment decisions and peer support], 2) supporting patients on therapy [ongoing monitoring, adherence, promoting selfmanagement, treatment failures] and 3) addressing other challenges to treatments that arise due to medical or psychosocial complexities.

3 This section will link with engagement and retention in care, living with HIV and other long-term health conditions, complex care management and psychological well-being and health promotion. As with other sections, this includes specialist HIV nursing practice at intermediate level and advanced level (NHIVNA/STIF)

4 Competencies will need to be assessed according to local protocols/governance or as part of a formal qualification e.g. NHIVNA/STIF certificate in intermediate or advanced HIV nursing competencies. Those have undertaken NHIVNA/STIF competencies can use the related competencies for this segment.

5 In addition to the documents and competencies below, it is expected that HIV nurses will engage in relevant CPD for their role to ensure contemporary evidence based practice. It is also expected from HIV nurses to share best practice.

Section 1 – Your Clinical Practice

Antiretroviral therapy increases both the physical and psychological well-being of people living with HIV. The primary objective of Highly Active Antiretroviral Therapy (HAART) is to achieve viral suppression therefore reducing mortality and morbidity. Earlier diagnosis and treatment results in less inpatient admissions and HIV associated co-morbidities due to better immune recovery¹. Patients diagnosed late tend to have lower CD4 counts and starting therapy can potentially be more challenging¹.

Starting HAART at diagnosis also decreases the risk of onward transmission. The U=U message highlights that a person with sustained undetectable levels of HIV virus in their blood cannot transmit HIV to their sexual partners². Maintaining an undetectable viral load during pregnancy prevents vertical transmission¹.

HAART needs to be tailored to each individual to optimise adherence and avoid potential drug interactions. Nowadays treatments have better tolerability and efficacy but it is important that they do not impact on a person's quality of life. Peer support plays a big part in preparing the person prior to commencing lifelong therapy³. People living with HIV should be involved in any treatment decisions and a trusting relationship between the person living with HIV and the nurse is associated with better adherence and treatment outcomes⁴.

Fortunately, the majority of people living with HIV in the UK maintain longterm viral control with good treatment outcomes, however there are often factors that can make adhering to daily medication challenging^{5, 6}. It is the role of the HIV nurse to deliver the highest quality of care by addressing any adherence issues and providing the best treatment options, enabling people to live healthy fulfilling lives.

References

- 1 https://www.bhiva.org/file/63513a1745ea9/BHIVAguidelines-on-antiretroviral-treatment-for-adultsliving-with-HIV-1-2022.pdf (accessed March 2024)
- 2 BHIVA 2018 U=U position statement *https://www. bhiva.org/BHIVA-encourages-universal-promotion-of-U-U* (accessed March 2024)
- 3 Berg RC, Page S, Øgård-Repål A. The effectiveness of peer-support for people living with HIV: A systematic review and meta-analysis. PLoS One. 2021 Jun 17;16(6):e0252623. doi: 10.1371/journal.pone.0252623.
- 4 Graham JL, Shahani L, Grimes RM, Hartman C, Giordano TP. The Influence of Trust in Physicians and Trust in the Healthcare System on Linkage, Retention, and Adherence to HIV Care. AIDS Patient Care STDS. 2015 Dec;29(12):661-7. doi: 10.1089/apc.2015.0156. PMID: 26669793; PMCID: PMC4684652.
- 5 Downes R, Foote E. Barriers to adherence and intentional non-adherence: a guide for nurses. HIV Nursing, 2019; 19 (3) BP 5-8.
- 6 Bolsewicz K, Debattista J, Vallely A, Whittaker A, Fitzgerald L. Factors associated with antiretroviral treatment uptake and adherence: a review. Perspectives from Australia, Canada, and the United Kingdom. AIDS Care. 2015;27(12):1429-38. doi: 10.1080/09540121.2015.1114992. Epub 2015 Dec 7. PMID: 26641139.

Competency levels

Competencies at **Intermediate level** (1) as defined by STIF/NHIVNA: These are aimed at nurses working in an HIV setting or with people living with HIV at Band 5/6/7 and are equivalent to Level 3 of the NHIVNA competencies.

Competencies at **Advanced level** (A) as defined by STIF/NHIVNA: These are aimed at Band 7 nurses and above who are working at an advanced practice level equivalent to Level 4 of the NHIVNA Competencies and with reference to the Advanced Nursing practice in HIV care (2016).

NB: For nurses working outside of England's Agenda for Change contracts, please use this as guidance for your level of practice in your area of work.

HIV Nursing Competencies

- Using Peer support prior to starting therapy
- Following European AIDS Clinical Society guidance on assessing readiness to start and maintain ART []
- Addressing physical and psychosocial barriers to adherence A
- Supporting patient decision making and patient choice I A
- Assessing adherence and potential barriers at every visit
- Following guidelines for appropriate monitoring to ensure efficacy and tolerability 1
- Understanding routine monitoring tests and blip management
- Treatment of any side-effects to maximise tolerability
 A
- Regular medicines check for drug interactions A
- Regular medication optimisation and prescribing management
- Promote patient empowerment and self-management
 A
- Partners of patients not wishing to take HAART should be signposted to interventions such as PrEP to avoid transmission A
- Manage virological failures by understanding resistance patterns and support patients during therapy switches A
- Nurse-led clinics/advanced practice roles

Relevant training

- HIV Awareness courses
- Local specialist courses
- NHIVNA e-learning modules
- National HIV Nursing Competencies 2013
 https://www.nhivna.org/competencies
- NHIVNA/STIF Competencies (Intermediate and Advanced)
- Non-medical prescribing (Advanced)
- Advanced Communication Skills

Case Study – fictitious case based on a number of real-life examples

Starting treatment: Jake was diagnosed in 2020 in a GU clinic. He was seen in the HIV clinic by a clinic nurse after a confirmatory HIV test. The clinic nurse does baseline new patient bloods and asks him if he would like to consider starting ARVs. Jake was feeling very overwhelmed by his diagnosis and struggling to take in information.

Please consider the following points in relation to your level of competency / clinical practice. These trigger questions are to enable you to reflect on your role as a nurse and to engage in professional discussions about people living with HIV who disengaged in care in your workplace. There is not an expectation that everyone will know the definitive answer to these trigger questions. What is more important is that you recognise and address any gaps in your knowledge and practice.

- How will the clinic nurse establish if Jake is ready to start antiretroviral therapy on the day of his confirmatory diagnosis?
- What support will Jake be offered to help him to decide about starting ARVs?

Two weeks later Jake attends to see the Nurse Specialist for his first new patient consultation.

- What factors need to be considered before discussing with Jake what ARV to start on?
- What are the possible barriers for Jake to starting ARVs?
- What are the advantages and disadvantages of waiting to start ARVs in a newly diagnosed patient?
- What strategies can the Nurse Specialist put in place to support long-term adherence and engagement in care?

How to demonstrate quality HIV care in this segment

Demonstrating quality in healthcare is more important than ever. We have created a quality framework based on The Institute of Medicine's six dimensions of healthcare quality for you to use in the context of your role.

This quality framework is intended for you to demonstrate HOW you are delivering this segment of the HIV model of nursing care. It can help you:

- Define quality care for people living with HIV
- Link quality to the NMC code of conduct
- Communicate what HIV quality care means to all your stakeholders
- Develop continuous quality improvement projects in your area
- Link quality to the foundation of HIV care Person-Centred Care

This can also be used in many different areas of your practice, for example, to reflect on your own practice, to engage your team on quality improvement projects, for your revalidation, teaching and other proactive elements of your role. Feel free to print the following page off and start to scope out quality for your area of practice under the six dimensions.

The middle column is left blank for you to fill in as you explore the dimensions of quality and cross reference the information, guidance, standards and links on the following pages. The righthand column helps you to cross reference your work to the NMC Code of Conduct; this will support your revalidation process as a focus for professional reflection.

The dimensions of quality

Safe Avoiding harm to patients from care that is intended to help them	
Effective Providing services based on evidence and which produce a clear benefit	
Person-centred Establishing a partnership between practitioners and patients to ensure care respects patients' needs and preferences	
Timely Reducing waits and sometimes harmful delays	
Efficient Avoiding waste	
Equitable Providing care that does not vary in quality because of a person's characteristics	

Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. Washington DC: National Academy Press, 1990, p244

NMC code

Section 2: Evidence, policy and Commissioning

Why include NHS plans, policy and guidance alongside HIV specific guidance/policy? The documents below are not a reference list. They are there to help you to synthesise HIV, HSA and NHS plans, policies and guidance to ensure you are aware of, and can describe, your role within a strategic context where required, secondly, for you to articulate and demonstrate the outcomes you are achieving in your role and finally, to support you to develop business cases or case for change narratives/documents.

HIV-specific guidance/policy/references

Advanced Nursing practice in HIV care: Guidelines for nurses, doctors, service providers and commissioners 2016

BHIVA guidelines for the routine investigation and monitoring of adult HIV-1 positive individuals 2016 (2019 interim update). Available at: *https://www.bhiva.org/ monitoringguidelines*

BHIVA-guidelines-on-antiretroviral-treatment-for-adultsliving-with-HIV-1-2022.pdf 2023 interim update

British HIV Association. British HIV Association standards of care for people living with HIV 2018. Available at: *https://www.bhiva.org/standards-of-care-2018*

British Psychological Society, British HIV Association, Medical Foundation for AIDS and Sexual Health (MedFASH). Standards for psychological support for adults living with HIV. 2011. Available at: *www.bhiva.org/ StandardsForPsychologicalSupport.aspx* (accessed July 2022).

European AIDS Clinical Society. EACS Readiness to Start/ Maintain ART. Available at: *https://eacs.sanfordguide.com/ art/readiness-to-start-maintain-art* (accessed July 2022)

Gilleece Y, Tariq S, Bamford A et al. British HIV Association guidelines for the management of HIV in pregnancy and postpartum 2018. HIV Med 2019; 20 Suppl 3: s2–s85.

Service specification: adult specialised services for people living with HIV *https://www.england.nhs.uk/ publication/adult-specialised-services-for-people-livingwith-hiv/*

National Institute for Health and Care Excellence. Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence. Clinical guideline 76 (CG76). 2009. Available at: *http://guidance. nice.org.uk/CG76* (accessed March 2022).

The electronic medicines compendium. Latest medicine updates. Available at: *www.medicines.org.uk/emc* (accessed September 2022).

University of Liverpool. HIV Drug Interactions. Available at: *https://www.hiv-druginteractions.org/* (accessed April 2022).

How this segment meets NHS priorities

Admission avoidance – Triage and nursing advice to ensure appropriate referral to primary or specialist care settings and minimising use of A&E

How this segment meets NHS Long-term Plan

https://www.longtermplan.nhs.uk/wp-content/ uploads/2019/01/the-nhs-long-term-plan-summary.pdf

- Promote testing, early diagnosis and treatment to avoid illness and hospital admissions
- Implementing integrated care systems where appropriate
- Preventing illness and tackling health inequalities

Relevant key performance indicators

- Relevant Specialised Services Quality Dashboard (SSDQ) indicators
- NHS Outcomes Framework
 - Domain 1: Preventing people from dying prematurely
 - Domain 3: Helping people to recover from episodes of ill-health

Other performance indicators

- Documented adherence support and medicines review
- Care and treatment to professional guidelines and commissioning policies.
- Improved treatment adherence. (caseload audit)
- Reductions in complications of HIV disease including AIDS and non AIDS co-morbidities
- Reduction in treatment associated complications and development of drug resistance
- Documented care plans with patient involvement (BHIVA notes audit or NHIVNA care plan audit)
- Improvement in the patient experience of individuals with HIV infection attending HIV outpatient service and improvement in reported understanding/selfmanagement of their condition

For further information on demonstrating the value of specialist nursing see Apollo Resource/Professor Alison Leary *https://www.apollonursingresource.com/*





Introduction

This model of nursing care has been specifically designed for registered nurses working in an HIV setting or whose role involves caring for people living with HIV. While we recognise the invaluable contribution of other healthcare workers, it is not within the scope of this document to address the care delivered by non-registered nurses.

2 This section will cover co-morbidities, coinfection, ageing, annual health checks, links with other services, nurse-led clinics for co-morbidities (TB, Hepatology, Ageing, Memory, renal, endocrine, cancer, cardiology)

3 This will link with complex care and case management, psychological well-being and health promotion. As with other sections, this includes specialist HIV nursing practice at intermediate level and advanced level.

4 Competencies will need to be assessed according to local protocols/governance or as part of a formal qualification e.g. NHIVNA/ STIF certificate in intermediate or advanced HIV nursing competencies. Those have undertaken NHIVNA/STIF competencies can use the related competencies for this segment.

5 In addition to the documents and competencies below, it is expected that HIV nurses will engage in relevant CPD for their role to ensure contemporary evidence based practice. It is also expected from HIV nurses to share best practice.

Section 1 – Your Clinical practice

As people are living for longer with HIV and have a normal life expectancy¹, there is increased prevalence of co-morbidities and many people with HIV have multi-morbidity at a much younger age than their HIV negative peers². The prevalence of cardiovascular disease³ and metabolic disorders is increased in people with HIV infection and there are additional risk factors for some in relation to bone health, renal function, liver disease and cognitive impairment. There is also an increased risk for some cancers⁴ such as cervical and anal cancers. As the population of people living with HIV in the UK are ageing, many are disproportionally affected by co-morbidities.

The prevalence of anxiety and depression⁵ is significantly higher in people living with HIV and this will be dealt with separately under the psychological well-being segment. The role of the nurse is to screen, triage and monitor for related co-morbidities at different levels of competency depending on training and job role.

References

- 1 Marcus JL et al. Comparison of Overall and Comorbidity-Free Life Expectancy Between Insured Adults With and Without HIV Infection, 2000-2016. JAMA Network Open, 3: e207954, June 2020.
- 2 Sukumaran et al (2023) Changes in multimorbidity burden over a 3–5 year period among people with HIV. Front. Syst. Biol., 27 February 2023 *https://www. frontiersin.org/people/u/2082341*
- 3 Shah ASV, Stelzle D, Lee KK et al. Global burden of atherosclerotic cardiovascular disease in people living with HIV: systematic review and meta-analysis. Circulation 2018; 138: 1100–1112.
- 4 Yuan et al. 2022. Incidence and mortality of non-AIDSdefining cancers among people living with HIV: A systematic review and meta-analysis eClinicalMedicine 2022;52: 101613. Published online 11 August 2022. https://doi.org/10.1016/j.eclinm.2022.101613
- 5 Chaponda M, Aldhouse N, Kroes M, Wild L, Robinson C, Smith A. 2018. Systematic review of the prevalence of psychiatric illness and sleep disturbance as comorbidities of HIV infection in the UK. International Journal of STD & AIDS. 2018;29(7):704-713. doi:10.1177/0956462417750708

Competency levels

Competencies at **Intermediate level** (**1**) as defined by STIF/NHIVNA: These are aimed at nurses working in an HIV setting or with people living with HIV at Band 5/6/7 and are equivalent to Level 3 of the NHIVNA competencies.

Competencies at **Advanced level** (A) as defined by STIF/NHIVNA: These are aimed at Band 7 nurses and above who are working at an advanced practice level equivalent to Level 4 of the NHIVNA Competencies and with reference to the Advanced Nursing practice in HIV care (2016).

NB: For nurses working outside of England's Agenda for Change contracts, please use this as guidance for your level of practice in your area of work.

HIV Nursing Competencies

Intermediate competencies 🛽

- Screening for co-morbidities at annual health check appointment in line with NHIVNA/STIF and NHIVNA Annual Health Check Competencies
- Able to undertake psychological and initial memory screening
- Competent in alcohol and recreational drug use screening
- Motivational interviewing training
- Competent in giving lifestyle advice to reduce risks of future co-morbidities while supporting patient choice and self-management
- Trained in HIV nurse triage assessing urgency of problem and directing to appropriate place of care

Advanced competencies A

- Promotion of self-management, patient education and empowerment
- Competent in undertaking nurse-led clinic for assessment and management of people living with HIV
- Undertakes clinic at advanced practice level
- Identifies potential side effects of antiretroviral therapy and recommends alternative regimens
- Identification of potential Drug-Drug interactions
- Liaison and co-ordination across multi-disciplinary team and with primary care
- Non-medical Prescribing / Physical Assessment Course
- Establishing and developing nurse-led services
- Linking with place based and ICB pathways where indicated

Recommended training

- NHIVNA e-learning modules
- National HIV Nursing Competencies 2013
 https://www.nhivna.org/competencies
- Intermediate NHIVNA/STIF competencies
- Advanced NHIVNA/STIF competencies
- Physical Assessment / Non-medical prescribing

Case Study – fictitious case based on merged real-life experiences

Joseph is a 54 year old man who has been HIV positive for 20 years. His HIV is well controlled.

He attends the HIV clinic for his HIV annual health check and sees a Band 5 clinic nurse. His blood pressure is 160/100 and the same when repeated in clinic. The clinic nurse looks at his previous blood pressure readings and sees they have been increasing over the last few years and refers him to his GP for further blood pressure monitoring. The clinic nurse also takes annual health check bloods, weight, a smoking history, recreational drug and alcohol history and undertakes psychological and memory screening. The clinic nurse gives some lifestyle advice in relation to blood pressure management.

Joseph then has a telephone follow-up with the HIV Specialist Nurse for his results one month later. The Nurse Specialist calculates Joseph's QRISK3 score¹ which is 25% and reviews his ARVs in relation to cardiovascular risks. Joseph tells his nurse that he has started on new hypertensive medication and further checks identify a potential drug to drug interaction. The Nurse Specialist links in with the patient's GP and discusses alternative anti-hypertensive medications and gives further advice and online resources to Joseph on self-managing his CVD risks.

Please consider the following points in relation to your level of competency / clinical practice. These trigger questions are to enable you to reflect on your role as a nurse and to engage in professional discussions about people living with HIV who disengaged in care in your workplace. There is not an expectation that everyone will know the definitive answer to these trigger questions. What is more important is that you recognise and address any gaps in your knowledge and practice.

What patient pathways do you have in place to address high blood pressure?

What lifestyle advice would you give to a patient with hypertension?

In what circumstances do you undertake a QRISK3?

What health preventative advice do you give to patients to reduce their CVD risks?

How to demonstrate quality HIV care in this segment

Demonstrating quality in healthcare is more important than ever. We have created a quality framework based on The Institute of Medicine's six dimensions of healthcare quality for you to use in the context of your role.

This quality framework is intended for you to demonstrate HOW you are delivering this segment of the HIV model of nursing care. It can help you:

- Define quality care for people living with HIV
- · Link quality to the NMC code of conduct
- Communicate what HIV quality care means to all your stakeholders
- Develop continuous quality improvement projects in your area
- Link quality to the foundation of HIV care Person-Centred Care

This can also be used in many different areas of your practice, for example, to reflect on your own practice, to engage your team on quality improvement projects, for your revalidation, teaching and other proactive elements of your role. Feel free to print this page off and start to scope out quality for your area of practice under the six dimensions.

The middle column is left blank for you to fill in as you explore the dimensions of quality and cross reference the information, guidance, standards and links on the following pages. The righthand column helps you to cross reference your work to the NMC Code of Conduct; this will support your revalidation process as a focus for professional reflection.

The dimensions of quality

Safe Avoiding harm to patients from care that is intended to help them
Effective Providing services based on evidence and which produce a clear benefit
Person-centred Establishing a partnership between practitioners and patients to ensure care respects patients' needs and preferences
Timely Reducing waits and sometimes harmful delays
Efficient Avoiding waste
Equitable Providing care that does not vary in quality because of a person's characteristics

Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. Washington DC: National Academy Press, 1990, p244

NMC code

Section 2 – Evidence, policy and

Commissioning

Why include NHS plans, policy and guidance alongside HIV specific guidance/policy? The documents below are not a reference list. They are there to help you to synthesise HIV, HSA and NHS plans, policies and guidance to ensure you are aware of, and can describe, your role within a strategic context where required, secondly, for you to articulate and demonstrate the outcomes you are achieving in your role and finally, to support you to develop business cases or case for change narratives/documents.

HIV-specific guidance/policy/references

Advanced Nursing practice in HIV care: Guidelines for nurses, doctors, service providers and commissioners 2016

Annual health review for people living with HIV: a good practice guide 2017

BHIVA guidelines for the routine investigation and monitoring of adult HIV-1-positive individuals

(2019 interim update) *https://www.bhiva.org/file/ DqZbRxfzlYtLg/Monitoring-Guidelines.pdf*

BHIVA Standards of Care 2018

EACS GUIDELINES Version 11.1. October 2022. https://www.eacsociety.org/media/guidelines-11.1_ final_09-10.pdf

HIV Commission *https://www.gov.uk/government/ publications/towards-zero-the-hiv-action-plan-forengland-2022-to-2025*

Service specification: adult specialised services for people living with HIV *https://www.england.nhs.uk/ publication/adult-specialised-services-for-people-livingwith-hiv/*

Hippisley-Cox J, Coupland C, Brindle P. Development and validation of QRISK3 risk prediction algorithms to estimate future risk of cardiovascular disease: prospective cohort study BMJ 2017; 357 :j2099 doi:10.1136/bmj.j2099

NHSE Integrated Care Resources. *https://www.england. nhs.uk/integratedcare/what-is-integrated-care/*

Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. Washington DC: National Academy Press, 1990, p244

How this segment meets NHS Priorities

Admission avoidance – Triage and nursing advice to ensure appropriate referral to primary or specialist care settings and minimising use of A&E

Recover the dementia diagnosis rate to 66.7% (LTP) and proactively screen for neurocognitive impairment Π

How this segment meets NHS Long-term Plan

- Increase percentage of patients with hypertension treated to NICE guidance to 77% by March 2024 (LTP)
- Increase the percentage of patients aged between 25 and 84 years with a CVD risk score greater than 20 percent on lipid lowering therapies to 60% (LTP)
- Continue to address health inequalities and deliver on the Core20PLUS5 approach (LTP)
- Promoting integrated care A

Relevant key performance indicators

- Relevant Specialised Services Quality Dashboard (SSDQ) indicators
- NHS Outcomes Framework:
 - Domain 1: Preventing people from dying prematurely (audit of Annual Health Check)
 - Domain 2: Enhancing quality of life for people with long-term conditions
 - Domain 4: Ensuring that people have a positive experience of care (evidence of patient satisfaction)
- Other performance indicators
 - Documented care plans with patient involvement (BHIVA notes audit or NHIVNA care plan audit)
 - Documented adherence support and medicines review (audit)
 - Improvement in the patient experience of individuals with HIV infection attending HIV outpatient service and improvement in reported understanding / self-management of their condition (patient satisfaction audits)
 - Care and treatment to professional guidelines and commissioning policies.
 - Effectiveness of networked arrangements and documented pathways.
 - Documented health screens e.g. 10-year cardiovascular disease (CVD) risk, smoking, psychological needs, and appropriate referral (AHC audit)

For further information on demonstrating the value of specialist nursing see Apollo Resource / Professor Alison Leary *https://www.apollonursingresource.com*/





Introduction

This model of nursing care has been specifically designed for registered nurses working in an HIV setting or whose role involves caring for people living with HIV. While we recognise the invaluable contribution of other healthcare workers, it is not within the scope of this document to address the care delivered by non –registered nurses.

2 This section will cover the nursing care and interventions to facilitate a HIV friendly healthcare environment to support complex care, case management and end of life care for people living with HIV.

3 This will link with engagement and retention in care, psychological well-being, health promotion, living with HIV and other long-term health conditions and treatment and interventions. As with other sections, this includes specialist HIV nursing practice at intermediate level and advanced level

4 Competencies will need to be assessed according to local protocols/governance or as part of a formal qualification e.g. STIF/NHIVNA certificate in intermediate or advanced HIV nursing competencies. Nurses who have undertaken STIF/NHIVNA competencies can use the related competencies for this segment.

5 In addition to the documents and competencies below, it is expected that HIV nurses will engage in relevant CPD for their role to ensure contemporary evidence based practice. It is also expected from HIV nurses to share best practice.

Section 1 – Your clinical practice

There is evidence that people living with HIV are more likely than the general population to have multiple long-term conditions, to have poorer mental health, poorer sexual health and to have problems with alcohol and substance use. These issues can lead to an individual having a collection of diagnoses that might be seen as a marker of complexity or increased need (1).

Complex care comes under four categories:

- Medical complexities such as adherence challenges, ageing and frailty, polypharmacy, comorbidities, pregnancy, cancer, drug use and alcohol misuse, disability, and end-of-life care.
- **Psychological complexities** such as stigma, anxiety, depression, and trauma.
- Socioeconomic complexities such as poverty, isolation, and housing issues
- Other complexities such as culture, faith, and past experiences. Dealing with complex patients requires effective case management.

End-of-life care is part of palliative care provided in the time leading up to a person's death, and this can be in hospital, care homes, hospice and or their home. There are four key stages of end-of-life: physical comfort, mental and emotional needs, spiritual needs, and practical tasks. End of life care plan sets out the priorities and preferences of care and treatment, decision about resuscitation, where they would like to be cared for, etc.

Case management is a way of integrating services around the complex needs of people with long-term conditions targeted at community such as:

- Case finding (high risk group and recent hospital discharge).
- Care Planning: make referrals, follow-up and monitor progress.
- Care Co-ordination: reduce duplication, improve access to services and improve disease management (2).

References

- 1 British HIV Association. Standards of care for people living with HIV-4C Supporting people with higher levels of need. BHIVA. 2018
- **2** National Institute of Clinical Excellence. End of life care for adults: service delivery. NICE guideline [NG142] Published: 16 October 2019

Why case management?

- Improve the experience of service users and their careers.
- Support better outcomes
- Reduce utilisation of hospital-based services.
- Cost effective approaches to care.
- · Be part of a wider programme of care
 - Access to primary care services
 - Support health promotion and primary interventions
 - Co-ordinating packages of rehabilitation, reenablement, medication management, self-care, advocacy, psychosocial support, monitoring, and review *
- * Ross S, Curry N and Goodwin N. Case Management: What it is and how it can be best implemented. The Kings Fund. 2011

Competency levels

Competencies at **Intermediate level** () as defined by STIF/NHIVNA: These are aimed at nurses working in an HIV setting or with people living with HIV at Band 5/6/7 and are equivalent to Level 3 of the NHIVNA competencies.

Competencies at **Advanced level** (A) as defined by STIF/NHIVNA: These are aimed at Band 7 nurses and above who are working at an advanced practice level equivalent to Level 4 of the NHIVNA Competencies and with reference to the Advanced Nursing practice in HIV care (2016).

NB: For nurses working outside of England's Agenda for Change contracts, please use this as guidance for your level of practice in your area of work.

HIV Nursing competencies

- Supporting patient decision making and patient choice [] A
- Identifying patient with highly complex needs and working alongside a nurse working in an advanced practice role
- Care co-ordination Prevention of DDI, polypharmacy, adherence, prevention of resistance A
- Promotion of self-management, patient education, and empowerment 1 A
- Interpersonal skills and building relationships
 A
- Problem solving skills
- Negotiation and brokerage skills A
- Prescribing qualification
- Training: mentoring and clinical supervision
- Understanding patient's individual characteristics, geographical areas and their circumstances I A
- Support plan on discharge I A
- Case closure: death, self-discharge, care optimised, and patient risks falls below certain levels of care.
- Continuity of care programme design
- Effective use of data and communication with wider healthcare provider A
- Stakeholder Engagement A
- Care provision in the community
 A
- Case load size factors: nature of conditions, proportion of patient at high risk and experience of working with patient with complex needs A

Recommended training

- Intermediate STIF/NHIVNA competencies
- Advanced STIF/NHIVNA competencies
- National HIV Nursing Competencies 2013
 https://www.nhivna.org/competencies
- Non-medical prescribing
- Physical assessment module (level 6 or 7)
- Advanced communication skills
- End-of-life care module (level 6 or 7)

Case study

Drew is a 33-year-old heterosexual diagnosed with HIV five years ago and disengaged from care for 3.5 years. He was subsequently admitted to hospital with progressive weakness and impaired vision and was diagnosed with progressive multifocal leukoencephalopathy. His symptoms worsened to the point where he was unable to mobilise and he was depending on the healthcare staff for activities of daily living. His girlfriend of 3 years was then also diagnosed with HIV following partner notification after his admission to hospital. His parents live abroad and came to stay in his flat visiting daily with his girlfriend.

During his stay, Drew needed support from Physiotherapists, Nurses, Occupational Therapist, Medical team, Nutritionist, Psychologists, Palliative Care Team, ITU (short stay), Continuing Care Team and HIV community nurse specialist. He was fed through a nasogastric tube and was administered medication via this route. Therefore, his antiretroviral therapy had to be selected accordingly to hopefully slow down disease progression, albeit his prognosis was poor. There were, at times, plans for him to go for rehabilitation and or to be discharged at home with his family. However, he spent 7 months in hospital with some improvement but finally he passed away in hospital.

Please consider the following points in relation to your level of competency / clinical practice. These trigger questions are to enable you to reflect on your role as a nurse and to engage in professional discussions about people living with HIV who disengaged in care in your workplace. There is not an expectation that everyone will know the definitive answer to these trigger questions. What is more important is that you recognise and address any gaps in your knowledge and practice.

- What strategies could have been implemented to potentially prevent Drew getting PML?
- What care would Drew have needed if he was able to be discharged home before he died?
- What were the end of life care concerns for Drew?
- Was ITU consideration appropriate with the condition of PML? If not why not?
- What options did Drew have for placement and how we could have made that possible?
- How can you improve care for Drew and his family?



How to demonstrate quality HIV care in this segment

Demonstrating quality in healthcare is more important than ever. We have created a quality framework based on The Institute of Medicine's six dimensions of healthcare quality for you to use in the context of your role.

This quality framework is intended for you to demonstrate HOW you are delivering this segment of the HIV model of nursing care. It can help you:

- Define quality care for people living with HIV.
- · Link quality to the NMC code of conduct
- Communicate what HIV quality care means to all your stakeholders.
- Develop continuous quality improvement projects in your area.
- Link quality to the foundation of HIV care Person-Centred Care

This can also be used in many different areas of your practice, for example, to reflect on your own practice, to engage your team on quality improvement projects, for your revalidation, teaching and other proactive elements of your role. Feel free to print this page off and start to scope out quality for your area of practice under the six dimensions.

The middle column is left blank for you to fill in as you explore the dimensions of quality and cross reference the information, guidance, standards and links on the following pages. The righthand column helps you to cross reference your work to the NMC Code of Conduct; this will support your revalidation process as a focus for professional reflection.

	Time coue
Safe Avoiding harm to patients from care that is intended to help them	
Effective Providing services based on evidence and which produce a clear benefit	
Person-centred Establishing a partnership between practitioners and patients to ensure care respects patients' needs and preferences	
Timely Reducing waits and sometimes harmful delays	
Efficient Avoiding waste	
Equitable Providing care that does not vary in quality because of a person's characteristics	

The dimensions of quality

Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. Washington DC: National Academy Press, 1990, p244

NMC code

Section 2 – Evidence, policy and

Commissioning

Why include NHS plans, policy, and guidance alongside HIV specific guidance/policy? The documents below are not a reference list. They are there to help you to synthesise HIV, HSA and NHS plans, policies, and guidance to ensure you are aware of, and can describe your role within a strategic context where required, secondly, for you to articulate and demonstrate the outcomes you are achieving in your role and finally, to support you to develop business cases or case for change narratives/documents.

HIV Specific guidance/policy/references

Advanced Nursing practice in HIV care: Guidelines for nurses, doctors, service providers and commissioners 2016

BHIVA Standards of care 2018

HIV Commission *https://www.gov.uk/government/ publications/towards-zero-the-hiv-action-plan-forengland-2022-to-2025*

HIVCommNursingModel.pdf (*nhivna.org*) Providing a model of HIV community nursing

HIV-Nursing-18-2-CPD-article.pdf (*nhivna.org*) HIV complex care and care coordination: the nurse's role

HIV-Nursing-19-4-CPD-article.pdf (*nhivna.org*) HIV and communication skills for practice

HIV_Nursing_19_3_BP5-BP8.pdf Barriers to adherence and intentional non-adherence: a guide for nurses

Service specification: adult specialised services for people living with HIV *https://www.england.nhs.uk/ publication/adult-specialised-services-for-people-livingwith-hiv/*

NHSE Integrated Care Resources. *https://www.england. nhs.uk/integratedcare/what-is-integrated-care/*

NICE Guidelines:

Overview | Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence | Guidance | NICE NICE guidance on adherence

Overview | End of life care for adults: service delivery | Guidance | NICE NICE guidance on end of life care

Preferred priorities of care documentation; beh-patient-4-a4-ppc.pdf (*scie.org.uk*)

How this segment meets NHS Priorities

Admission avoidance – Triage and nursing advice to ensure appropriate referral to Primary or specialist care settings and minimising use of A&E and inpatient stays A

How this segment meets NHS Long-term Plan

Care closer to home

Implementing Integrated care systems

Preventing illness and tackling health inequalities: https://www.england.nhs.uk/about/equality/equalityhub/national-healthcare-inequalities-improvementprogramme/core20plus5/

Relevant key performance indicators

- Relevant Specialised Services Quality Dashboard (SSDQ) indicators
- NHS Outcomes Framework
 - Domain 1: Preventing people from dying
 prematurely
 - Domain 4: Ensuring that people have a positive experience of care (evidence of patient satisfaction)

Other performance indicators

- Documented care plans with patient involvement (BHIVA notes audit or NHIVNA care plan audit)
- Improvement in the patient experience of individuals with HIV infection attending HIV outpatient service and improvement in reported understanding / self-management of their condition.
- Effectiveness of networked arrangements and documented pathways.

For further information on demonstrating the value of specialist nursing see Apollo Resource / Professor Alison Leary *https://www.apollonursingresource.com*/



Engagement and retention in care

Introduction

This model of nursing care has been specifically designed for registered nurses working in an HIV setting or whose role involves caring for people living with HIV. While we recognise the invaluable contribution of other healthcare workers, it is not within the scope of this document to address the care delivered by non –registered nurses.

2 This section will cover engagement and retention in care. This will include the nursing care and interventions to facilitate HIV friendly healthcare environments and to support patients who have or who are at risk of disengaging from care.

3 This will link with complex care and case management, psychological well-being, stigma, and health promotion. This includes specialist HIV nursing practice at intermediate level (I) and advanced level (A).

4 Competencies will need to be assessed according to local protocols/governance or as part of a formal qualification e.g. STIF/NHIVNA certificate in intermediate or advanced HIV nursing competencies. Nurses who have undertaken STIF/NHIVNA competencies can use the related competencies for this segment.

5 In addition to the documents and competencies below, it is expected that HIV nurses will engage in relevant CPD for their role to ensure contemporary evidence based practice. It is also expected from HIV nurses to share best practice.

Section 1 – Your Clinical Practice

Patient engagement, adherence and retention in care are primary determinants of viral suppression¹, risk of transmission, disease progression, resistance, health cost and death². This is a process and behaviour shaped by the relationship between the patient and provider and the environment in which the care is provided.

Key definitions

- Patient engagement the desire and capability to actively choose to participate in care that is uniquely appropriate to the individual, in cooperation with a healthcare provider or institution in order to maximise outcomes or improve experiences of care.
- Adherence is taking medication regularly, attend scheduled appointments and following a diet and change of lifestyle.
- Retention in care attends HIV care routinely in accordance to their health needs.

Attributes of patient engagement³

- Personalisation
- Access
- Commitment
- Therapeutic alliance

Measures to evaluate retention in care⁴

- Missed appointment visits
- Appointment adherence
- Visit constancy
- Gaps in care

Factors associated with engagement in care

- Heterosexual orientation
- Mental health illness
- Non-white race/ ethnicity
- Place of residence
- Stigma and fear
- Substance use disorder
- Transgender people
- Unmet needs
- Young person
- Language or communication

HIV Nurses are central to sustaining therapeutic relationships with people living with HIV and to creating a supportive environment that addresses barriers to engaging in care. Embedding care co-ordination within HIV nursing services will greatly assist in retaining people in care⁵.

References

- 1 Iqbal et al. 2022. Engagement in care promotes durable viral suppression among persons newly diagnosed with HIV infection. AIDS Care. Volume 34, 2022 - Issue 5
- 2 Ulloa et al. 2019. Retention in care and mortality trends among patients receiving comprehensive care for HIV infection: a retrospective cohort study. CMAJ Open 2019 Apr-Jun; 7(2): E236–E245.Published online 2019 Apr 9. doi: 10.9778/cmajo.20180136
- 3 Koester et al 2019 The influence of the 'good' patient ideal on engagement in HIV care. Plos One. 14(3): e0214636.
- 4 Howarth A, Apea V, Michie S, et al. 2017. Health Services and Delivery Research, No. 5.13. NIHR Journals Library; 2017 Mar.
- 5 Irvine et al. 2021. HIV Care Coordination promotes care re-engagement and viral suppression among people who have been out of HIV medical care: an observational effectiveness study using a surveillancebased contemporaneous comparison group. AIDS Research and Therapy 18, Article number: 70 (2021)

Competency levels

Competencies at **Intermediate level** (1) as defined by STIF/NHIVNA: These are aimed at nurses working in an HIV setting or with people living with HIV at Band 5/6/7 and are equivalent to Level 3 of the NHIVNA competencies.

Competencies at **Advanced level** (A) as defined by STIF/NHIVNA: These are aimed at Band 7 nurses and above who are working at an advanced practice level equivalent to Level 4 of the NHIVNA Competencies and with reference to the Advanced Nursing practice in HIV care (2016).

NB: For nurses working outside of England's Agenda for Change contracts, please use this as guidance for your level of practice in your area of work.

HIV Nursing Competencies

- Health equity and rapid access to care by appropriately trained staff A
- Peer mentoring and or support I A
- Medication optimisation and prescribing management: pharmacy, peer support, drug-drug interaction management, simplification of ART, adherence, and prevention of resistance A
- Patient empowerment, participation, and centeredness
 A
- Symptoms management of people living with HIV by referring as appropriate as they are more likely to have multiple long-term conditions, poor mental health, poor sexual health and have problems with alcohol and substance use A
- Care optimisation (co-ordination) with referrals to other services: coordination of hospital appointments, social services, district nurses, Peer mentors, social workers to avoid duplication and improve access to services
- Promotion of self-management, patient education, and empowerment 1 A
- Supporting patient decision making and patient choice 1 A
- Health and self-care promotion using tools such as PROM's and wellness thermometer to assist with monitoring of biological, psychological, social, and spiritual well-being of people living with HIV 1
- Management of co-morbidities through annual health reviews
 A
- Continuity of care: MDT members A
- HIV Community Clinical Nurse specialists' input: Assessment and linkage to appropriate healthcare worker 1 A
- Emotional support in relation to confidentiality, privacy and dignity issues through psychology, counselling and or psychiatry **1 A**
- Provision of out of hours service provision and weekend clinics
- Integration of care for those with conditions needing specialists' inputs such as lymphoma, Castleman's, neurology, Ageing, and other co-infection (TB, Hepatitis, cardiac and renal)
- Quality care arrangements of HIV inpatient units, maternity care, and young people services care (transitioning) and linking with HIV outpatient services
 A
- Good clinical leadership and management A

Relevant recommended training for specialist HIV nurses

- HIV Awareness courses
- National HIV Nursing Competencies 2013
 https://www.nhivna.org/competencies
- NHIVNA e-learning modules
- Intermediate STIF/NHIVNA competencies
- Advanced STIF/NHIVNA competencies
- Non-medical prescribing Physical assessment module (level 6 or 7)
- Advanced communication skills

Case Study

Marco is a 23year old MSM from Italy. He came to the UK 3 years ago and was diagnosed with HIV 2 years ago. This was his first HIV test here in the UK following STI screen with symptoms. Occasionally he uses chemsex drugs as part sex. He has no stable job and is living with friends who do not know of his diagnosis. He came from a religious family with strong beliefs. His sexuality is not acceptable to his family and the community. No one knows of his diagnosis, and they expect him to come home regularly. He is struggling to come to terms with living with HIV. He feels that this is a punishment for his deviation from his religion and therefore he should face the consequences of it. He reluctantly accepted to start HIV treatment. As no one knows of his diagnosis, he can only keep 3 months at a time of his treatment. Marco suffers from anxiety and possibly undiagnosed depression.

In the last 2 years he was seen only 4 times and on the 4th occasion, he came because he had gonorrhea after a visit in Italy. When he came to clinic, he was unkempt and reported being homeless on this visit and sleeping rough.

Please consider the following points in relation to your level of competency / clinical practice. These trigger questions are to enable you to reflect on your role as a nurse and to engage in professional discussions about people living with HIV who disengaged in care in your workplace. There is not an expectation that everyone will know the definitive answer to these trigger questions. What is more important is that you recognise and address any gaps in your knowledge and practice.

- What are the barriers to retention in HIV care for this gentleman?
- What strategies can help reduce the risk of HIV transmission for this patient?
- What support can you offer Marco to help accept his HIV diagnosis?
- What actions could have been taken on his first visit to try and keep him engaged?
- Are there any RED flags in Marco's life that needs to be addressed urgently? And how?
- Why adherence is important in this case and what strategies can help Marco engage?



How to demonstrate quality HIV care in this segment

Demonstrating quality in healthcare is more important than ever. We have created a quality framework based on The Institute of Medicine's six dimensions of healthcare quality for you to use in the context of your role.

This quality framework is intended for you to demonstrate HOW you are delivering this segment of the HIV model of nursing care. It can help you:

- Define quality care for people living with HIV.
- Link quality to the NMC code of conduct
- Communicate what HIV quality care means to all your stakeholders.
- Develop continuous quality improvement projects in your area.
- Link quality to the foundation of HIV care Person-Centred Care

This can also be used in many different areas of your practice, for example, to reflect on your own practice, to engage your team on quality improvement projects, for your revalidation, teaching and other proactive elements of your role. Feel free to print this page off and start to scope out quality for your area of practice under the six dimensions.

The middle column is left blank for you to fill in as you explore the dimensions of quality and cross reference the information, guidance, standards and links on the following pages. The righthand column helps you to cross reference your work to the NMC Code of Conduct; this will support your revalidation process as a focus for professional reflection.

NMC code

	The uniteristons of quarty	Time coue
Safe Avoiding harm to patients from care that is intended to help them		
Effective Providing services based on evidence and which produce a clear benefit		
Person-centred Establishing a partnership between practitioners and patients to ensure care respects patients' needs and preferences		
Timely Reducing waits and sometimes harmful delays		
Efficient Avoiding waste		
Equitable Providing care that does not vary in quality because of a person's characteristics		

The dimensions of quality

Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. Washington DC: National Academy Press, 1990, p244

Section 2 – Evidence, policy and

Commissioning

Why include NHS plans, policy, and guidance alongside HIV specific guidance/policy? The documents below are not a reference list. They are there to help you to synthesise HIV, HSA and NHS plans, policies and guidance to ensure you are aware of, and can describe your role within a strategic context where required, secondly, for you to articulate and demonstrate the outcomes you are achieving in your role and finally, to support you to develop business cases or case for change narratives/documents.

HIV Specific guidance/policy/references

Advanced Nursing practice in HIV care: Guidelines for nurses, doctors, service providers and commissioners 2016

BHIVA Standards of care 2018

HIV Commission *https://www.gov.uk/government/ publications/towards-zero-the-hiv-action-plan-forengland-2022-to-2025*

HIV-Nursing-18-2-CPD-article.pdf (*nhivna.org*) HIV complex care and care coordination: the nurse's role

HIV-Nursing-19-4-CPD-article.pdf (*nhivna.org*) HIV and communication skills for practice

HIVCommNursingModel.pdf (*nhivna.org*) Providing a model of HIV community nursing.

HIV_Nursing_19_3_BP5-BP8.pdf Barriers to adherence and intentional non-adherence: a guide for nurses

Service specification: adult specialised services for people living with HIV *https://www.england.nhs.uk/publication/adult-specialised-services-for-people-living-with-hiv/*

Liverpool HIV Interactions (hiv-druginteractions.org)

NHSE Integrated Care Resources. *https://www.england. nhs.uk/integratedcare/what-is-integrated-care/*

NICE Guidance:

Overview | Alcohol-use disorders: diagnosis, assessment and management of harmful drinking (high-risk drinking) and alcohol dependence | Guidance | NICE

Overview | Drug misuse prevention: targeted interventions | Guidance | NICE

Overview | Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence | Guidance | NICE NICE guidance on adherence.

Preferred priorities of care document. *beh-patient-4-a4-ppc.pdf* (*scie.org.uk*)

How this segment meets NHS Priorities

Admission avoidance – triage and nursing advice to ensure appropriate referral to Primary or specialist care settings and minimising use of Accident & Emergency A

How this segment meets NHS Long-term Plan

https://www.longtermplan.nhs.uk/wp-content/ uploads/2019/01/the-nhs-long-term-plan-summary.pdf

- Do things differently
- Implementing Integrated care systems
- Preventing illness and tackling health inequalities: https://www.england.nhs.uk/about/equality/equalityhub/national-healthcare-inequalities-improvementprogramme/core20plus5/
- Backing our work force
- Making better use of data and digital technology

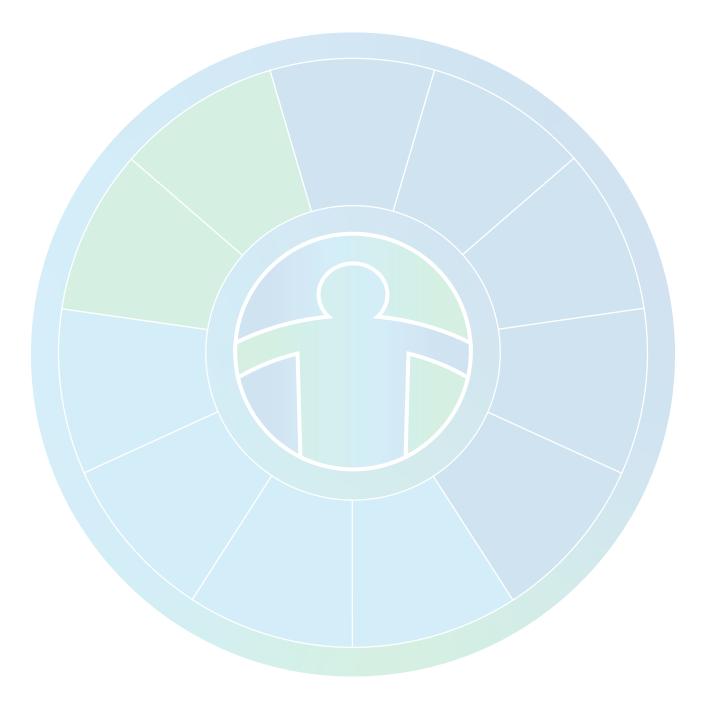
Relevant key performance indicators

- Relevant Specialised Services Quality Dashboard (SSDQ) indicators
- NHS Outcomes Framework:
 - Domain 1: Preventing people from dying prematurely
 - Domain 2: Enhancing quality of life for people with long term conditions
 - Domain 4: Ensuring that people have a positive experience of care (evidence of patient satisfaction)
 - Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm

Other performance indicators

- Documented care plans with patient involvement (BHIVA notes audit or NHIVNA care plan audit)
- Improvement in the patient experience of individuals with HIV infection attending HIV outpatient service and improvement in reported understanding / self-management of their condition.

For further information on demonstrating the value of specialist nursing see Apollo Resource / Professor Alison Leary *https://www.apollonursingresource.com/*



Assessing, supporting and improving psychological well-being

Introduction

1 This model of nursing care has been specifically designed for registered nurses working in an HIV setting or whose role involves caring for people living with HIV. While we recognise the invaluable contribution of other healthcare workers, it is not within the scope of this document to address the care delivered by non –registered nurses.

2 This section will cover the nursing assessment and interventions with regard to mental health and mental well-being.

3 This links with all other segments, as mental health and well-being are relevant throughout all aspects of person-centred care and indeed can be argued is central to human flourishing e.g. positive psychological and social functioning, and engagement with healthcare and treatment adherence. As with other sections, this includes specialist HIV nursing practice at intermediate level and advanced level (NHIVNA/STIF)

4 There are examples of competency documents that can be used by nurses looking after HIV patients. Competencies will need to be assessed according to local protocols/governance or as part of a formal qualification. Those have undertaken NHIVNA/STIF competencies can use the related competencies for this segment.

5 In addition to the documents and competencies below, it is expected that HIV nurses will engage in relevant CPD for their role to ensure contemporary evidence based practice. It is also expected from HIV nurses to share best practice.

Many people who access HIV care may present with mental health and well-being issues and where needs are complex they can be addressed by either psychological or psychiatric services. The term psychiatry and psychology are occasionally used interchangeably, however, the disciplines are distinct in many ways. In general, Psychiatry is a branch of medicine focused on diagnosing and treating mental health as a disorder, whereas Psychologists employ a variety of therapeutic techniques to help patients understand and heal from trauma to improve their mental health.

It is well documented that there is a higher prevalence of psychological distress, psychiatric issues and mental health needs in the HIV population, than in the general population¹. This can take the form of complex trauma, post-traumatic stress disorder, anxiety, and depression, sleep problems and increased suicide risk². Poor mental health and well-being has a significant impact on long-term engagement with HIV treatment and care. People living with HIV can often come from already marginalised populations, and therefore can carry preexisting distress in relation to historical experiences of stigma and discrimination before they are diagnosed with HIV. In addition, people with mental health issues are at increased risk of acquiring HIV due to higher risk sexual activity^{3,4}, inequity in social determinants of mental health⁵ and increased prevalence of injecting drug use⁶.

We also know that a diagnosis of HIV can be traumatising and, for those with complex histories, this can add to layers of powerlessness^{7,8}. For the population with vertically acquired HIV there a range of complicated issues. Prevalence rates for mental health issues for children and young people with vertical HIV acquisition are much higher than in the general population, and can often persist into adulthood⁹. Historical adversity/trauma generally underpin mental health issues and those from marginalized communities are more likely to have experienced trauma. People may cope with psychological distress in ways which make them more vulnerable to risk taking (e.g. seeking connection through multiple partners, using alcohol and substances). Low self-confidence/esteem may mean people are less confident/able to negotiate safe sex¹⁰.

Therefore, it is essential that nurses (and the wider MDT) who are involved in delivering HIV care do so in a psychologically informed manner, acknowledging and addressing mental health issues as part of assessment and treatment plans in line with the standards for psychological support for people living with HIV¹¹.

References

- 1 Chaponda M, Aldhouse N, Kroes M, Wild L, Robinson C, Smith A. Systematic review of the prevalence of psychiatric illness and sleep disturbance as comorbidities of HIV infection in the UK. International Journal of STD & AIDS. 2018;29(7):704-713. doi:10.1177/0956462417750708
- 2 LeGrand S, Reif S, Sullivan K, Murray K, Barlow ML, Whetten K. A Review of Recent Literature on Trauma Among Individuals Living with HIV. Curr HIV/AIDS Rep. 2015 Dec;12(4):397-405. doi: 10.1007/s11904-015-0288-2. PMID: 26419376; PMCID: PMC4837695.
- 3 Hughes E, Edmondson AJ, Onyekwe I, Quinn C, Nolan F. Identifying and addressing sexual health in serious mental illness: Views of mental health staff working in two National Health Service organizations in England. Int J Ment Health Nurs. 2018 Jun;27(3):966-974. doi: 10.1111/inm.12402. Epub 2017 Nov 18. PMID: 29150893.
- 4 Bonfils KA, Firmin RL, Salyers MP, Wright ER. Sexuality and intimacy among people living with serious mental illnesses: Factors contributing to sexual activity. Psychiatr Rehabil J. 2015;38(3):249-255. doi:10.1037/prj0000117
- 5 World Health Organization and Calouste Gulbenkian Foundation. Social determinants of mental health. Geneva, World Health Organization, 2014.
- 6 Stockman JK, Strathdee SA. HIV among people who use drugs: a global perspective of populations at risk. J Acquir Immune Defic Syndr. 2010;55 Suppl 1(Suppl 1):S17-S22. doi:10.1097/QAI.0b013e3181f9c04

- 7 Nightingale VR, Sher TG, Mattson M, Thilges S, Hansen NB. The effects of traumatic stressors and HIV-related trauma symptoms on health and health related quality of life. AIDS Behav. 2011 Nov;15(8):1870-8. doi: 10.1007/s10461-011-9980-4. PMID: 21667297; PMCID: PMC3629911.
- 8 Watkins-Hayes, C. (2013). The Micro Dynamics of Support Seeking: The Social and Economic Utility of Institutional Ties for HIV-Positive Women. The ANNALS of the American Academy of Political and Social Science, 647(1), 83–101. *https://doi. org/10.1177/0002716213475775*
- 9 Vranda MN, Mothi SN. Psychosocial Issues of Children Infected with HIV/AIDS. Indian J Psychol Med. 2013 Jan;35(1):19-22. doi: 10.4103/0253-7176.112195. PMID: 23833337; PMCID: PMC3701354.
- 10 Gibson, S., Vosper, J., Rutter, S & Irons, C. (2021). Bringing compassion to HIV care: Applying the compassion-focused therapy model to healthcare delivery. Switzerland: Springer
- 11 (BPS, BHIVA & MEDFASH, 2011) HIV Psych standards reference

Competency levels

Competencies at **Intermediate level** (1) as defined by STIF/NHIVNA: These are aimed at nurses working in an HIV setting or with people living with HIV at Band 5/6/7 and are equivalent to Level 3 of the NHIVNA competencies.

Competencies at **Advanced level** (A) as defined by STIF/NHIVNA: These are aimed at Band 7 nurses and above who are working at an advanced practice level equivalent to Level 4 of the NHIVNA Competencies and with reference to the Advanced Nursing practice in HIV care (2016).

Nursing competencies

- Awareness and understanding of the different approaches used by psychology and psychiatry in managing mental health 1 A
- Compassionate listening and supportive communication [] A
- A working knowledge of different screening tools used in assessing depression, anxiety and drug and alcohol use 1 A
- Risk assessment skills in identifying patients at risk of self-harm/suicidal thoughts etc. 1 A
- Conversant with local pathways for urgent mental health intervention
 A
- Utilises local referral pathways to different allied professions in mental health 1 A
- Identifies safeguarding issues and escalates according to local protocols
- Liaison/ care co-ordination with mental and psychological health services and other relevant agencies regarding ongoing management of mental health and well-being A
- Advanced communication skills
- Works with external agencies to develop and evaluate referral pathways
- Awareness of the different theories underpinning mental health and mental disorders A
- Leads on safeguarding interventions as required A

Recommended training

- NHIVNA e-learning modules
- National HIV Nursing Competencies 2013
 https://www.nhivna.org/competencies
- Intermediate NHIVNA/STIF competencies
- Advanced NHIVNA/STIF competencies
- Suicide awareness Local training or online training links:
- https://www.zerosuicidealliance.com/training
- https://www.every-life-matters.org.uk/training/
- https://www.mentalhealthatwork.org.uk/resource/ suicide-prevention-training-from-the-zero-suicidealliance/
- Psychological/Mental Health First Aid
- Trauma informed care Toolkit NHIVNA resource in development
- MIND Information on helping someone else with mental health problems – online resources

Case Study 1: Adherence and Trauma

Tee is a young woman accessing the adult HIV service who acquired HIV vertically. During her teenage years she began to experience adherence difficulties that remain an ongoing issue and have begun to pose a serious threat to her health. Tee was very well informed about HIV and the associated treatment needs, and was struggling to understand why she had problems taking medication. Being a mother herself now , she prioritised her children over everything and concerns relating to her health caused her distress and frustration with herself.

Tee had declined psychological therapy in the past due to prior experiences, however, the nursing team and her doctor continued to offer referral to the in-house specialist HIV psychology team. With their support and encouragement, Tee decided to give it another try and due to a naturally reflective nature, engaged incredibly well. Through the process she was able to understand how adherence issues linked directly to traumatic experiences and to issues relating to care in her early life.

On developing this insight, Tee was able to collaborate with the multidisciplinary team (MDT) to make a plan of ongoing care. She consented for MDT members to share information openly with each other so that there was a shared understanding of her issues. A care plan relating to adherence was then drawn together, based on a psychological understanding of her needs that took into account her history. Together, they created a nursing plan that involved regular, structured encounters, which reduced in frequency over time as Tee built confidence around taking treatment. This ran alongside a similar plan for therapy, which also spaced-out sessions as they came toward ending.

There were some unpredictable and stressful events along the way. However, knowing that the MDT understood her psychological needs, Tee was able to contact them and re-negotiate care plans as required. The shared understanding of the story and the associated psychological issues meant that the MDT could be responsive and support Tee to build her sense of agency over her treatment. She is now fully adherent and undetectable and living her best life as a working mother.

Please consider the following points in relation to your level of competency / clinical practice. These trigger questions are to enable you to reflect on your role as a nurse and to engage in professional discussions about mental health and well-being in your workplace. There is no expectation that everyone will know the definitive answer to these trigger questions. What is more important is that you recognise and address any gaps in your knowledge.

- How would you identify the need for psychological input in relation to adherence to antiretroviral therapy?
- In what ways could you support the psychological intervention outlined above?
- What other resources can you employ to psychologically support Tees' adherence if you don't have access to HIV psychology services locally?

Cast Study 2: Integrated mental health and HIV care

Michael is a 28-year-old male with a history of paranoid schizophrenia who is known to mental health services in the Borough where he resides. He travels about 20 miles to the clinic at his appointment times and attendance can be ad hoc due to travel costs secondary to low income. Michael is unemployed and on long-term social benefits. His adherence to ART has always been good during periods of mental well-being.

At his most recent bloods appointment, Michael was late and appeared slightly distressed, dishevelled, and voicing paranoid thoughts believing that the government was involved in conspiring against him and following him to the clinic. He was also experiencing auditory hallucinations, which he states were derogatory towards him. Michael admitted to having not been taking his ARVs over the past month or his antipsychotic medication. He refused to have his bloods done believing that the clinic was colluding with the government towards him. Michael said he did not have any thoughts of harming himself or others and he had good insight into his distress but stated that he was unable to get hold of his mental health team for support. He had run out of credit on his phone and believed the government was also tapping into his mobile phone.

The HIV CNS HIV contacted Michael's mental health team after speaking to Liaison Psychiatry and arranged for Michael to be seen by Liaison Psychiatry in the Emergency Department. Following an assessment by the psychiatry team, Michael was admitted informally to his local mental health unit. During Michael's stay in the psychiatric unit, the HIV CNS spoke to his mental health team and checked for any new medications that may interact with his ARVs. He was referred to a social worker for review of his benefits and support with travel costs to attend appointments. Michael restarted his antipsychotics and ARVs and consented to having his HIV bloods taken. Within a short period, Michael was discharged back home with more regular community follow up with his Community Psychiatric Nurse. There was an MDT prior to discharge that was attended by the HIV CNS, social worker and mental health team with an agreed care plan outlining roles and responsibilities of the MDT.

It was agreed that the HIV CNS and/or other staff at the clinic contact the mental health team if any concerns about Michael's mental health presentation. This ensured better communication and more cohesive management of Michael's care so that early intervention and early management of any relapse would limit any further adherence issues both to his ARVs and mental health medication.

Please consider the following points in relation to your level of competency / clinical practice. These trigger questions are to enable you to reflect on your role as a nurse and to engage in professional discussions about mental health in your workplace. There is no expectation that everyone will know the definitive answer to these trigger questions. What is more important is that you recognise and address any gaps in your knowledge.

- What questions would you ask to establish if Michael was at risk of harming himself or others?
- What are your local mental health pathways for acute mental health presentations?
- In these circumstances, why should restarting antipsychotics be a priority over restarting ARVs
- How would you monitor for drug-to-drug interactions while Michael is a mental health inpatient?
- What additional support could be offered to Michael to support him to remain well mentally and physically?

The table below is for you to use in your practice.

It is intended to be a quality framework for you to demonstrate HOW you are delivering this segment, of the HIV model of nursing care, in the context of quality and outcomes. It is based on The Institute of Medicine's six dimensions of healthcare quality.

This can be used in many different areas of your practice, for example, to reflect on your own practice, to engage your team, on quality improvement projects, for your revalidation, teaching and other proactive elements of you role.

The right hand column is left blank for you to fill in as you explore the dimensions of quality and cross reference the information, guidance, standards and links on the following pages.

The dimensions of quality NMC code Safe Avoiding harm to patients from care that is intended to help Effective Providing services based on evidence and which produce a clear benefit Person-centred Establishing a partnership patients to ensure care respects patients' needs and preferences Timelv Reducing waits and sometimes harmful delays Efficient Avoiding waste Equitable Providing care that does not vary in quality because of a person's characteristics

Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. Washington DC: National Academy Press, 1990, p244

Evidence, policy and commissioning

Why include NHS plans, policy and guidance alongside HIV specific guidance/policy? The documents below are not a reference list. They are there to help you to synthesise HIV, HSA and NHS plans, policies and guidance to ensure you are aware of, and can describe your role within a strategic context where required, secondly, for you to articulate and demonstrate the outcomes you are achieving in your role and finally, to support you to develop business cases or case for change narratives/documents.

HIV specific guidance/policy/Reports

The standards for psychological support for adults living with HIV (BPS BHIVA & MEDFASH, 2011) – in the process of being updated

BHIVA Standards of Care (2018)

Annual Health Review for People Living with HIV: A good practice guide (2017)

APPG Report – The Missing Link – HIV and Mental Health March 2020

HIV and Mental Health - NAT report Oct 2021

Integration of Mental Health and HIV interventions (WHO report) 2022

Mental Health and New Models of Care (The Kings Fund, RCPsyche) 2017

How this segment meets NHS priorities

- No Health without Mental Health 2011 (gov.uk)
- Delivering better mental health outcomes for people of all ages 2011 (*gov.uk*)
- Well-being and Mental health: Applying All Our Health (Guidance) Feb 2023
- Mental Health and New Models of Care (The Kings Fund, RCPsyche) 2017

How this segment meets NHS Long-term Plan

NHS Mental Health Implementation Plan 2019/20 – 2023/24

Relevant key performance indicators

- Relevant Specialised Services Quality Dashboard (SSDQ) indicators
- NHS Outcomes Framework:
 - Domain 1: Preventing people from dying prematurely
 - Domain 4: Ensuring that people have a positive experience of care
 - Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm

For further information on demonstrating the value of specialist nursing see Apollo Resource/Professor Alison Leary *https://www.apollonursingresource.com*

Stigma-related issues

Introduction

This model of nursing care has been specifically designed for registered nurses working in an HIV setting or whose role involves caring for people living with HIV. While we recognise the invaluable contribution of other healthcare workers, it is not within the scope of this document to address the care delivered by non – registered nurses.

2 This section will cover the nursing care and interventions to facilitate HIV friendly healthcare environments and to support patients who may previously or currently be experiencing HIV-related stigma.

3 This will link with the following segments; psychological well-being; engagement and retention in care and is integral to patient centred care and quality of life. As with other sections, this includes specialist HIV nursing practice at intermediate level and advanced level.

4 Competencies will need to be assessed according to local protocols/governance or as part of a formal qualification e.g. STIF/NHIVNA certificate in intermediate or advanced HIV nursing competencies. Nurses who have undertaken STIF/NHIVNA competencies can use the related competencies for this segment.

5 In addition to the documents and competencies below, it is expected that HIV nurses will engage in relevant CPD for their role to ensure contemporary evidence based practice. It is also expected from HIV nurses to share best practice.

Section 1 – Your clinical practice

Your clinical practice HIV stigma remains a significant issue for people living with HIV and impacts all levels of the care pathway including testing, accessing care, long-term engagement and mental/psychological wellbeing. People living with HIV may experience stigma and discriminating behaviours in their personal lives, workplaces and from the general public¹. People with HIV may also experience stigma and discrimination in relation to gender, sexuality, ethnicity and a range of other factors, which may potentially be compounded by an HIV diagnosis. Awareness of these potential intersecting layers of stigma will be key to providing sensitive and appropriate care to people living with HIV. HIV stigma and discrimination continues to be surprisingly high in healthcare settings². Nurses working in the field need to be proactive in enabling HIV stigma free environments and acting as role model for other healthcare professionals^{3, 4}.

HIV stigma manifests itself in 3 main ways:

- Self or internalised stigma: the acceptance of negative self-beliefs associated with having HIV
- Anticipated or perceived stigma: the expectation amongst people living with HIV that others will hold negative judgements about HIV and may discriminate against them
- Discrimination or enacted stigma: the negative and devaluing treatment of people due to their status. These may fall within the purview of the law.

Self or internalised stigma can lead to feelings of guilt and shame and compound anticipated stigma in many walks of life⁵. As healthcare professionals and primarily as nurses we need to be vigilant to the impact of stigma on engagement with healthcare, mental health and quality of life for people living with HIV.

NHIVNA also acknowledges that HIV peer support is a crucial component in addressing stigma⁶. As a professional body we value the contribution peer support makes in empowering patients to become active participants in their care. We fully support the implementation of the quality statements and auditable outcomes listed in the 2018 BHIVA Standards in relation to access to peer support⁷.

References

- 1 NAT 'Public knowledge and attitudes 2021': https:// www.nat.org.uk/sites/default/files/publications/ HIV%20Public%20Knowledge%20and%20Attitudes_0.pdf
- 2 Shongwe M et al. Measuring healthcare HIV knowledge within our NHS Trust. BHIVA conference, abstract 006, November 2020.
- 3 NAT 'Tackling HIV stigma what works?': https://www. nat.org.uk/sites/default/files/publications/Jun_16_ Tackling_HIV_Stigma.pdf
- 4 UNAIDS 'Evidence for eliminating HIV-related stigma and discrimination: *https://www.unaids.org/sites/ default/files/media_asset/eliminating-discrimination-guidance_en.pdf*
- 5 Fast-Track Cities London 'A framework for empowerment programmes to address internalised stigma': *https://fasttrackcities.london/wp-content/ uploads/2021/10/Empowerment-Programme-Framework.pdf*
- 6 Positively UK'National standards for peer support in HIV' https://positivelyuk.org/wp-content/uploads/2022/06/national_standards_final_web.pdf
- 7 BHIVA 'Standards of Care 2018': https://www.bhiva.org/file/KrfaFqLZRIBhg/BHIVA-Standards-of-Care-2018.pdf

Competency levels

Competencies at **Intermediate level** (**1**) as defined by STIF/NHIVNA: These are aimed at nurses working in an HIV setting or with people living with HIV at Band 5/6/7 and are equivalent to Level 3 of the NHIVNA competencies.

Competencies at **Advanced level** (A) as defined by STIF/NHIVNA: These are aimed at Band 7 nurses and above who are working at an advanced practice level equivalent to Level 4 of the NHIVNA Competencies and with reference to the Advanced Nursing practice in HIV care (2016).

NB: For nurses working outside of England's Agenda for Change contracts, please use this as guidance for your level of practice in your area of work.

HIV Nursing Competencies

- Assessment of mental and emotional health, including impact of internalised or anticipated stigma or actual discrimination [] A
- Referral for mental health support and/or peer support in relation to HIV stigma issues
 A
- Promotion of self-management, peer support, patient education and empowerment [] A
- Supporting patient decision making and patient choice 1 A
- Acting as a resource for people living with HIV in relation to HIV stigma 1 A
- Escalating any reports of HIV discrimination in healthcare
- Addressing complaints about HIV discrimination in healthcare settings and promoting a constructive learning environment to improve practice A
- Design, participate and deliver in education of other non-specialist areas in healthcare A
- Ensuring appropriate confidentiality in communicating with and about people living with HIV 1 A

Recommended training

- HIV Awareness courses
- NHIVNA e-learning modules
- National HIV Nursing Competencies 2013 https://www.nhivna.org/competencies
- Local HIV Stigma modules
- Intermediate STIF/NHIVNA competencies
- Advanced STIF/NHIVNA competencies

Case Study: fictitious case based on a number of real-life experiences

Beatrice is a 37 year old South African woman who was diagnosed with HIV while pregnant with her son who is now 12 years old. She has two older children. All the children are HIV negative. Beatrice finds it hard to attend appointments at the HIV clinic due to work and due to her concerns about meeting someone from her community. As a result, she has had intermittent antiretroviral therapy and her CD4 count is now 186 cells/mm. She has told only one friend about her diagnosis and is socially isolated.

Beatrice has high blood pressure and hyperlipidaemia but does not want to go to her GP because she had a bad experience at the surgery and feels the staff there judge her for being HIV positive.

Please consider the following points in relation to your level of competency / clinical practice. These trigger questions are to enable you to reflect on your role as a nurse and to engage in professional discussions about people living with HIV who disengaged in care in your workplace. There is not an expectation that everyone will know the definitive answer to these trigger questions. What is more important is that you recognise and address any gaps in your knowledge and practice.

- What are the potential stigmatising factors for Beatrice?
- Outline how you will assess her support needs? And how will you decide on the priorities in this case?
- What support can you offer Beatrice or who can you refer to in your local area? Or what national resources can you direct Beatrice to in order to support her to manage her concerns about HIV stigma in her life?
- How can you make it easier for Beatrice to receive her HIV care given her concerns about attending the clinic?
- How will you address the concerns Beatrice has about her GP practice and support her to get her primary healthcare needs met?

Demonstrating quality HIV care in this segment

Demonstrating quality in healthcare is more important than ever. We have created a quality framework based on The Institute of Medicine's six dimensions of healthcare quality for you to use in the context of your role. This quality framework is intended for you to demonstrate HOW you are delivering this segment of the HIV model of nursing care. It can help you:

- Define quality care for people living with HIV
- Link quality to the NMC code of conduct
- Communicate what HIV quality care means to all your stakeholders
- Develop continuous quality improvement projects in your area
- Link quality to the foundation of HIV care Person-Centred Care

This can also be used in many different areas of your practice, for example, to reflect on your own practice, to engage your team on quality improvement projects, for your revalidation, teaching and other proactive elements of your role. Feel free to print the following page off and start to scope out quality for your area of practice under the six dimensions.

The middle column is left blank for you to fill in as you explore the dimensions of quality and cross reference the information, guidance, standards and links on the following pages. The righthand column helps you to cross reference your work to the NMC Code of Conduct; this will support your revalidation process as a focus for professional reflection.

The dimensions of quality

Safe Avoiding harm to patients from care that is intended to help them
Effective Providing services based on evidence and which produce a clear benefit
Person-centred Establishing a partnership between practitioners and patients to ensure care respects patients' needs and preferences
Timely Reducing waits and sometimes harmful delays
Efficient Avoiding waste
Equitable Providing care that does not vary in quality because of a person's characteristics

Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. Washington DC: National Academy Press, 1990, p244

NMC code

Section 2 – Evidence, policy and Commissioning

Why include NHS plans, policy and guidance alongside HIV specific guidance/policy? The documents below are not a reference list. They are there to help you to synthesise HIV, HSA and NHS plans, policies and guidance to ensure you are aware of, and can describe, your role within a strategic context where required, secondly, for you to articulate and demonstrate the outcomes you are achieving in your role and finally, to support you to develop business cases or case for change narratives/documents.

HIV-Specific guidance/policy/references

Advanced Nursing practice in HIV care: Guidelines for nurses, doctors, service providers and commissioners 2016

BHIVA Standards of care 2018

HIV Commission *https://www.gov.uk/government/ publications/towards-zero-the-hiv-action-plan-forengland-2022-to-2025*

HIV: Public Knowledge and Attitudes, National AIDS Trust 2021

Service specification: adult specialised services for people living with HIV *https://www.england.nhs.uk/ publication/adult-specialised-services-for-people-livingwith-hiv/*

National Standards in HIV Peer Support 2017 (*https://hivpeersupport.com/*)

Peer Mentorship https://ukpublichealthnetwork.org. uk/wp-content/uploads/2021/02/A4-Best-Practice-Guidelines-for-Peer-Mentoring.pdf

People living with HIV Stigma Index 2015

Positive Voices Study 2017

Tackling HIV Stigma, NAT 2016 https://www.nat.org.uk/ sites/default/files/publications/Jun_16_Tackling_HIV_ Stigma.pdf

UNAIDS 'Evidence for eliminating HIV-related stigma and discrimination: *https://www.unaids.org/sites/ default/files/media_asset/eliminating-discriminationguidance_en.pdf*

NAT 'Tackling HIV stigma - what works?': *https://www.nat.org.uk/sites/default/files/publications/Jun_16_*

Tackling_HIV_Stigma.pdf

NAT 'Public knowledge and attitudes 2021': https:// www.nat.org.uk/sites/default/files/publications/HIV%20 Public%20Knowledge%20and%20Attitudes_0.pdf

Barts HIV knowledge survey: Shongwe M et al. Measuring healthcare HIV knowledge within our NHS Trust. BHIVA conference, abstract 006, November 2020.

BHIVA 'Standards of Care 2018': https://www.bhiva.org/ file/KrfaFqLZRIBhg/BHIVA-Standards-of-Care-2018.pdf

Fast-Track Cities London 'A framework for empowerment programmes to address internalised stigma': *https://fasttrackcities.london/wp-content/uploads/2021/10/Empowerment-Programme-Framework.pdf*

Positively UK'National standards for peer support in HIV' *https://positivelyuk.org/wp-content/uploads/2022/06/ national_standards_final_web.pdf*

How this segment meets NHS Priorities

Embedding measures to improve health and reduce inequalities A

How this segment meets NHS Long-term Plan

Supporting mental health and working alongside peer support services and peer navigators

https://www.longtermplan.nhs.uk/wp-content/ uploads/2019/07/nhs-mental-health-implementationplan-2019-20-2023-24.pdf

Relevant key performance indicators

- Relevant Specialised Services Quality Dashboard (SSDQ) indicators
- Public Health Outcomes Framework
- NHS Outcomes Framework
 - Domain 1: Preventing people from dying prematurely
 - Domain 2: Enhancing quality of life for people with long-term conditions
 - Domain 4: Ensuring that people have a positive experience of care



Introduction

This model of nursing care has been specifically designed for registered nurses working in an HIV setting or whose role involves caring for people living with HIV. While we recognise the invaluable contribution of other healthcare workers, it is not within the scope of this document to address the care delivered by non –registered nurses.

2 This segment will cover the specialist nursing care of children and young people with HIV and includes the relevant role of HIV nurses working in adult services.

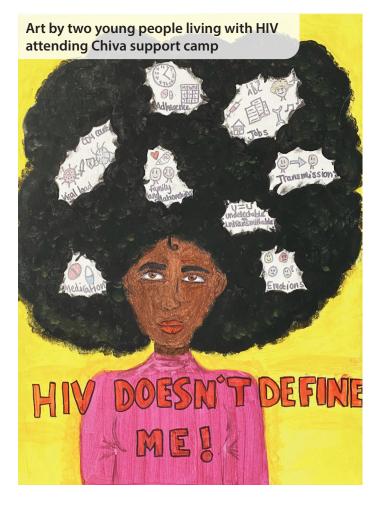
3 As the care of children and young people is family-centered this segment relates to all other segments in the model.

4 There are enclosed examples of competencies and/or documents that can be used by nurses looking after people living with HIV. Competencies will need to be assessed according to local protocols/governance or as part of a formal qualification e.g. STIF/NHIVNA certificate in intermediate or advanced HIV nursing competencies. Nurses who have undertaken STIF/NHIVNA competencies can use the related competencies for this segment.

5 In addition to the documents and competencies below, it is expected that HIV nurses will engage in relevant CPD for their role to ensure contemporary evidence based practice. It is also expected from HIV nurses to share best practice.

Introduction

Children and young people living with HIV are likely to have HIV transmitted from their mother in pregnancy, at birth or through breastfeeding. Nurses should provide support during pregnancy and/or be involved in pregnancy multi-disciplinary teams. The aim is to eliminate vertical transmission and provide support to parents and baby in pregnancy and during follow up care of the infant.



The World Health Organisation's triple elimination of HIV, Syphilis and Hepatitis B should be embedded in care. Nurses play a key role in ensuring children and young people growing up with HIV have the knowledge, understanding, treatment and care required to live well with HIV. Children and young people should be cared for in specialist paediatric HIV services until safely transitioned to adult HIV services. Paediatric services should remain involved in care or contact for one year post transition to support engagement in adult care. It is necessary to work in collaboration with, support and educate other organisations such as schools where required.

The role of Children and Young People's HIV specialist nurses is dynamic and evolving as medical knowledge and treatment options progress. They are at the forefront of providing compassionate, family-centered care, and they play a crucial role in improving the quality of life for Children and Young People living with HIV and their family.

Chiva Youth Committee Top Tips for Nurses

- 1. Make sure you know what you're talking about. Misinformation or misunderstanding can affect me.
- 2. Please talk to me and not just my parent or guardian. If you have a private conversation (which seems to be about me) with a colleague when I'm in the same room, it makes me feel anxious.
- **3.** Please take the time to explain my medicine and side effects.
- **4.** Please treat me my age. Think about the language you use.
- 5. Don't make assumptions.
- **6.** HIV doesn't define me; I'll always be me first and can still achieve my ambitions. Please acknowledge this and ask about my life.
- **7.** HIV affects my mental health just as much as my physical health; stigma hurts. Please consider this.
- 8. Confidentiality is really important to me, don't gossip about my life.

Competency levels

Competencies at **Intermediate level** (1) as defined by STIF/NHIVNA: These are aimed at nurses working in an HIV setting or with HIV patients at Band 5/6/7 and are equivalent to Level 3 of the NHIVNA competencies

Competencies at **Advanced level** (A) as defined by STIF/NHIVNA: These are aimed at Band 7 nurses and above who are working at an advanced practice level equivalent to Level 4 of the NHIVNA Competencies and with reference to the Advanced Nursing practice in HIV care (2016).

NB: For nurses working outside of England's Agenda for Change contracts, please use this as guidance for your level of practice in your area of work.

HIV Nursing Competencies

- Advocate for children and young people ensuring that the child's interests and needs are always of paramount importance **I A**
- Identify when a child or young person is at risk of harm and refer to, liaise with, and lead multi-agency working to ensure a child's safety and welfare are maintained.
 Work in partnership with others such as children's services, local authorities and school, prioritising the needs of children and families 1 A
- Support, advise and educate agencies and carers when a child is looked after, in the care of their local authority or in private or informal foster carer arrangements advocating for the child or young person at all times A
- Support and empower women who are pregnant to engage in care and make decisions in the best interests of the unborn child and then care of the infant. Support access to the provision of formula milk, feeding equipment and other necessities as required
- Assessment of infant exposed to HIV including clinical assessment, developmental assessment, and required investigations liaising with other professionals where appropriate A
- Arrange testing of children, including siblings regardless of age and support families with this process to ensure early detection, intervention and care can be provided A
- Assessment including clinical assessment of children and young people at planned and unplanned appointments. This includes reviewing medical histories, performing physical examinations if trained, and monitoring physical and mental health. Collaborate with other healthcare professionals to develop personalised care plans

- Provide advice and administration when required to ensure childhood immunisations are up to date and additional immunisations are provided where appropriate 1 A
- Deliver family-centred holistic care which considers physical, social, psychological, emotional and spiritual needs of children and their families taking in to account their concerns and ensuring they play a role in decision-making **I A**
- Support children, young people and their families between planned appointments remotely or in the community empowering families to live well 1 A
- Ensure age-appropriate communication and information is available and delivered and is inclusive of children and young people accessing services and support **I A**
- Positively promote, support and lead on early naming of HIV to children ensuring children know they are HIV positive by the age of nine in collaboration with parents or carers A
- Promote and support open communication about HIV within the family home and between children / parents or carers to reduce self-stigma and support positive family dynamics
- Support and promote adherence to medication acknowledging the challenges with taking HIV medication and support children, young people and families with strategies that may be helpful **I** A
- Liaise with clinical psychologists and ensure developmental assessments are carried out and support is arranged as necessary. This should be in line with chiva national guidelines to identify and support children who may have cognitive impairment and specific learning needs **I A**
- Act as a key worker and advocate for children and young people within multi-disciplinary teams liaising with others and making referrals to ensure children and young people can access required heath and social care A
- Recognise Adverse Childhood Experiences (ACES) and the role HIV may play assessing and making appropriate referrals for support 1 A
- Support engagement with local and national peer support groups and activities for children and families
 A

- Provide education and support to young people that explores sexual health, managing HIV as a sexually transmissible infection, pregnancy and healthy relationships A
- Support young people in developing self-care strategies and confidence that leads to independent management of appointments, medication, accessing support and health care contact by transition to adult services **I A**
- Work in collaboration with adult services to ensure a smooth transition to adult services and continue to have contact for at least 12 months post transition to support engagement in care **I A**
- Design, participate and deliver HIV education to other non-specialist areas, organisations and the community acting as a resource to such services A
- Design and participate in local and national audit to benchmark and develop services for children, young people and families living with HIV A
- Support research activities and contribute to the development of evidence-based HIV care guidelines to support improvements in care and outcomes 1 A

Recommended training

- PentaTr@ining Course previously Tr@inforPedHIV
- National HIV Nursing Competencies 2013
 https://www.nhivna.org/competencies
- HIV Awareness courses
- Chiva workshops
- NHIVNA e-learning modules

Case Study

This case study demonstrates the nursing role in supporting children, young people and families to live well with HIV.

Zanele is 10 years old and was diagnosed with HIV age 3. Zanele is her mother's only child and had lived with her in the UK after arriving here aged 5. Zanele's father died when she was four years old. They do not have any other family in the UK. Zanele struggles to take her HIV medicine and recent clinic bloods indicate her viral load is high. Zanele states that she feels fine and doesn't need medication for her asthma anymore. Mum also informs the team that there is a pending school residential and she feels she will have to miss this because it will be difficult to hide her medicines.

The Clinical Nurse Specialist (CNS) meets with Mum and arranges to visit Mum and Zanele at home to support knowledge and understanding of Zanele's HIV diagnosis. Mum reports that she is very worried about this so the CNS arranges some peer support for Mum with a mother of a child who is aware they are HIV positive. The CNS positively promotes naming HIV as the right approach in empowering, reducing self-stigma, reducing the impact of self-stigma and supporting adherence. The CNS leads HIV naming at home over a number of visits and Mum joins the conversations but doesn't want to lead naming in this scenario. After HIV naming Zanele has a better understanding of how her medicines work. Zanele, Mum and the CNS explore helpful ways to support medicine taking.

The CNS refers Zanele to a local peer support group and then to a national summer camp to meet other children and young people living with HIV. After careful consideration Mum, Zanele and the CNS have a meeting with the headteacher at school and share her diagnosis and appropriate support in school settings. School resources are also shared and the school arrange for the CNS to do an assembly sharing general information about HIV to educate children at the school. At the next appointment the CNS chats to Zanele and repeats blood tests. The results show an undetectable viral load. Mum and Zanele continue to have support from the CNS and are finding peer support very helpful in reducing isolation.

How to demonstrate quality HIV care in this segment

Demonstrating quality in healthcare is more important than ever. We have created a quality framework (overleaf) based on The Institute of Medicine's six dimensions of healthcare quality for you to use in the context of your role.

This quality framework is intended for you to demonstrate HOW you are delivering this segment of the HIV model of nursing care. It can help you:

- Define quality care for people living with HIV
- · Link quality to the NMC code of conduct
- Communicate what HIV quality care means to all your stakeholders
- Develop continuous quality improvement projects in your area
- Link quality to the foundation of HIV care Person-Centred Care

This can also be used in many different areas of your practice, for example, to reflect on your own practice, to engage your team on quality improvement projects, for your revalidation, teaching and other proactive elements of your role. Feel free to print this page off and start to scope out quality for your area of practice under the six dimensions.

The middle column is left blank for you to fill in as you explore the dimensions of quality and cross reference the information, guidance, standards and links on the following pages. The righthand column helps you to cross reference your work to the NMC Code of Conduct; this will support your revalidation process as a focus for professional reflection.

The dimensions of quality

NMC code

Safe Avoiding harm to patients from care that is intended to help them	
Effective Providing services based on evidence and which produce a clear benefit	
Person-centred Establishing a partnership between practitioners and patients to ensure care respects patients' needs and preferences	
Timely Reducing waits and sometimes harmful delays	
Efficient Avoiding waste	
Equitable Providing care that does not vary in quality because of a person's characteristics	

Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. Washington DC: National Academy Press, 1990, p244

Section 2 – Evidence, policy and Commissioning

Service Specification

NHS England (2023) NHS commissioning » HIV (*england. nhs.uk*)

Policy and Guidelines

Chiva Standards of Care

Chiva Developmental Assessment Guidelines

Chiva Standards and model for Psychological Care for Children and Young People Living with HIV

Chiva Guidance on transition for adolescents living with HIV

BHIVA Pregnancy guidelines

Children Act (1989) (2004)

Working together to Safeguard Children (2018)

BHIVA Standards of care 2018

Advanced Nursing practice in HIV care: Guidelines for nurses, doctors, service providers and commissioners 2016

World Health Organisation 2023 Triple elimination initiative

Relevant NICE Guidelines

Recommendations | Babies, children and young people's experience of healthcare | Guidance | NICE

Overview | Transition from children's to adults' services | Quality standards | NICE

How this segment meets NHS Priorities and NHS Long-term Plan

Preventing, recognising and supporting children, young people and parents or carers with mental health needs supporting appropriate referrals. Advocate for and prioritise the needs of children and young people. Act as a key contact to other services and provide resources and education. Work in collaboration with other professionals and services to provide the best possible care.

https://www.england.nhs.uk/wp-content/ uploads/2022/12/PRN00021-23-24-priorities-andoperational-planning-guidance-v1.1.pdf

https://www.longtermplan.nhs.uk/wp-content/ uploads/2019/07/nhs-mental-health-implementationplan-2019-20-2023-24.pdf



Sexual and reproductive health and wellbeing

Introduction

This model of nursing care has been specifically designed for registered nurses working in a HIV setting or whose role involves caring for people living with HIV. While we recognise the invaluable contribution of other healthcare workers, it is not within the scope of this document to address the care delivered by non –registered nurses.

2 This section will cover the sexual and reproductive health of people living with HIV.

3 This section also links with the following segments: living with HIV and other long-term conditions, health promotion and prevention, stigma and psychological well-being and mental health. As with other sections, this segment identifies specialist HIV nursing practice at intermediate level and advanced level.

4 There are examples of competency documents that can be used by nurses looking after children and young people who have HIV. Competencies will need to be assessed according to local protocols and governance or as part of a formal qualification.

5 In addition to the documents and competencies below, it is expected that HIV nurses will engage in relevant CPD for their role to ensure contemporary evidence based practice. It is also expected from HIV nurses to share best practice.

Section 1 – Your clinical practice

According to the National AIDS Trust, 92% of people accessing HIV care in 2021 acquired HIV through sexual transmission¹. Moral judgments and discrimination can lead to internalised stigma, shame and a negative impact on sexual and reproductive health and wellbeing.

Identifying and addressing sexual and reproductive health needs is a vital element in caring for people living with HIV. As the World Health Organisation stated: 'sexual health, when viewed affirmatively, requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences'². Prevention, screening, and treatment of sexually transmitted infections is just one aspect of promoting good sexual health. The wider determinants also encompass:

- Provision of good-quality sexual and reproductive health information that is accessible to all
- Identification and reduction in inequalities and barriers to accessing services
- Promotion of sexual well-being and importance of consent
- Assessment and management of sexual and reproductive healthcare needs through the lifecycle – including provision of pre-conceptual care, contraception and menopause care.

There are some particular considerations for the sexual and reproductive healthcare of people living with HIV. For example, the efficacy of some contraceptive methods may be affected by antiretroviral therapy³ and certain sexually transmitted infections may increase viral load⁴. People living with HIV may also need support around disclosing their status to sexual partners and managing any psychosexual problems relating to their diagnosis. Cervical screening is enhanced due to the increased risks associated with HIV with annual smear tests recommended for those with a cervix⁵. HIV has also been thought to lead to an early or premature menopause, and antiretroviral therapy may also be a risk factor in the development of osteoporosis⁶.

It is important to consider that having enjoyable and fulfilling sexual experiences can contribute to overall health and well-being and quality of life. As such, health care professionals involved in caring for people living with HIV need to be able to discuss sexual and reproductive health needs and develop an awareness of the factors that can positively, or negatively impact their sexual well-being. Provision of information and signposting, or referral within the multi-professional network will ensure that this is part of the holistic health care of people living with HIV.

References

- 1 National AIDS Trust, 2022. *https://www.nat.org.uk/about-hiv/hiv-statistics*
- 2 World Health Organisation, 2006. *https://www.cesas. lu/perch/resources/whodefiningsexualhealth.pdf*
- 3 Faculty of Sexual and Reproductive Healthcare, 2023. https://www.fsrh.org/documents/fsrh-ceu-guidancedrug-interactions/
- 4 i-base, 2023. https://i-base.info/ttfa/section-2/10impact-of-coinfections-on-viral-load/
- 5 GOV.UK, 2023. https://www.gov.uk/government/ publications/cervical-screening-programmeand-colposcopy-management/5-screening-andmanagement-of-immunosuppressed-individuals
- 6 Finnerty et al, 2017. https://doi.org/10.1016/j. maturitas.2016.10.015

Competency levels

Competencies at **Intermediate level** (1) as defined by STIF/NHIVNA: These are aimed at nurses working in an HIV setting or with people living with HIV at Band 5/6/7 and are equivalent to Level 3 of the NHIVNA competencies.

Competencies at **Advanced level** (A) as defined by STIF/NHIVNA: These are aimed at Band 7 nurses and above who are working at an advanced practice level equivalent to Level 4 of the NHIVNA Competencies and with reference to the Advanced Nursing practice in HIV care (2016).

NB: For nurses working outside of England's Agenda for Change contracts, please use this as guidance for your level of practice in your area of work.

HIV Nursing Competencies

- Provision of non-judgemental approach to sexual health
- Taking a detailed sexual history
- Undertakes correct screening tests for sexually transmitted infections
- Administers treatment for uncomplicated sexually transmitted infections under PGD
- Understands and addresses the specific sexual health needs of women living with HIV []
- Competent in providing sexual health promotion: safer sex, preventing STIs and unplanned pregnancy 1 A
- Utilises motivational interviewing skills when undertaking sexual risk reduction conversations
- Providing nurse-led clinics in an advanced practice role
- Interpersonal skills and building relationships [] A
- Supporting patient decision making and patient choice [] A

Recommended training

- Local competencies- see local Web based resources.
- NHIVNA Education: https://www.nhivna.org/ NHIVNAEducation
- National HIV Nursing Competencies 2013
 https://www.nhivna.org/competencies
- STIF/NHIVNA Intermediate Competencies
- STIF/NHIVNA Advanced Competencies
- Non-medical prescribing
- E-Learning: BASHH Sexually Transmitted Infections Foundation (STIF) courses: https://www.stif.org.uk
- E-learning: Sexual and Reproductive Healthcare programme: https://www.e-lfh.org.uk/programmes/ sexual-and-reproductive-healthcare
- E-learning: Faculty of Sexual and Reproductive Healthcare Contraceptive Counselling https://www. fsrh.org/education-and-training/fsrh-contraceptivecounselling-online-course/
- E-learning: Faculty of Sexual and Reproductive Healthcare Menopause Care: https://www.fsrh. org/education-and-training/menopause-care-ondemand/
- Advanced communication skills

Case Study 1

Marianne is a 45-year-old woman from Cameroon, who has been granted asylum in the UK. She was raped in prison prior to arriving in the UK 6 months ago and has been diagnosed as HIV positive. She has been established on anti-retroviral therapy and has good concordance and an undetectable viral load. She does not read or speak English and French is her first language. She is living in a hotel whilst awaiting longerterm accommodation. She has developed a relationship with Moussa, a 40-year-old male refugee also from Cameroon, who she met via a local support network for those seeking asylum.

Moussa and Marianne have not had sex, as Marianne does not think she is ready yet. She is worried about telling him her HIV status as she says she feels ashamed. She is not using any contraception and she thinks that she can no longer become pregnant as she is in the menopause. She has been experiencing less frequent but much heavier periods and has had some night sweats and hot flushes. Marianne has spoken to her GP about her menopausal symptoms but has been told she is too young to start on Hormone Replacement Therapy (HRT). She has come to you today to ask for some advice.

Please consider the following points in relation to your level of competency / clinical practice. These trigger questions are to enable you to reflect on your role as a nurse and to engage in professional discussions about people living with HIV with sexual and reproductive healthcare needs in your workplace. There is not an expectation that everyone will know the definitive answer to these trigger questions. What is more important is that you recognise and address any gaps in your knowledge and practice.

- What would be important to explore with Marianne prior to giving her any advice?
- How can you support Marianne to discuss her HIV status with Moussa if this is what she wants?
- Think about what advice you would give to Marianne if she decided to have sex with Moussa:
 - a) Does she need contraception?
 - *b)* What interactions are there between contraceptive methods and ART?
 - c) What precautions can she take to reduce her risk of acquiring sexually transmitted infections?
- Does Marianne need any further investigation of her menopausal symptoms?
- What aspect of Marianne's health will need to be monitored if she is menopausal?

Case Study 2

Pablo is 35-year-old Spanish man has stable HIV infection and an undetectable viral load at this last appointment 6 months ago. He has had a previous history of syphilis infection and is Hepatitis B and C Ab negative. He attends the HIV clinic for routine HIV Annual Health Check. At the nurse appointment he is asked about his recent sexual history. He reports having regular unprotected receptive and insertive anal sex with his RMP whose HIV status is unknown and with multiple partners at two chem-sex parties in the last month.

Please consider the following points in relation to your level of competency/clinical practice. These trigger questions are to enable you to reflect on your role as a nurse and to engage in professional discussions about the sexual health needs of people living with HIV. There is not an expectation that everyone will know the definitive answer to these trigger questions. What is more important is that you recognise and address any gaps in your knowledge and practice.

- What sexual health screening tests do you undertake for Pablo?
- What questions do you ask to gain a more detailed sexual history?

Two weeks later, Pablo phoned the nursing team for his results as he was not able to attend his scheduled follow-up appointment. His LFTs are newly raised with ALT at 80 U/L and Bilirubin at 28µmol/L. His Hep C RNA is 15.000.000 copies/ml and he is Syphilis EIA positive with an VDRL/RPR 1:8.

- What are your immediate concerns about these results and what assessment, investigations, referrals and follow-up do you do/arrange next for Pablo?
- How do you interpret Pablo's Syphilis result and what actions do you take in relation to these results?
- How will you approach partner notification in light of his results?

How to demonstrate quality HIV care in this segment

Demonstrating quality in healthcare is more important than ever. We have created a quality framework based on The Institute of Medicine's six dimensions of healthcare quality¹ for you to use in the context of your role.

This quality framework is intended for you to demonstrate HOW you are delivering this segment of the HIV model of nursing care. It can help you:

- Define quality care for people living with HIV
- Link quality to the NMC code of conduct
- Communicate what HIV quality care means to all your stakeholders
- Develop continuous quality improvement projects in your area
- Link quality to the foundation of HIV care Person-Centred Care

This can also be used in many different areas of your practice, for example, to reflect on your own practice, to engage your team on quality improvement projects, for your revalidation, teaching and other proactive elements of your role. Feel free to print this page off and start to scope out quality for your area of practice under the six dimensions.

The middle column is left blank for you to fill in as you explore the dimensions of quality and cross reference the information, guidance, standards and links on the following pages. The righthand column helps you to cross reference your work to the NMC Code of Conduct – this will support your revalidation process as a focus for professional reflection.

See table overleaf.



The dimensions of quality

NMC code

Safe Avoiding harm to patients from care that is intended to help them	
Effective Providing services based on evidence and which produce a clear benefit	
Person-centred Establishing a partnership between practitioners and patients to ensure care respects patients' needs and preferences	
Timely Reducing waits and sometimes harmful delays	
Efficient Avoiding waste	
Equitable Providing care that does not vary in quality because of a person's characteristics	

Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. Washington DC: National Academy Press, 1990, p244

Section 2 – Evidence, policy and

Commissioning

Why include NHS plans, policy and guidance alongside HIV specific guidance/policy? The documents below are not a reference list. They are there to help you to synthesise HIV, HSA and NHS plans, policies and guidance to ensure you are aware of, and can describe your role within a strategic context where required, secondly, for you to articulate and demonstrate the outcomes you are achieving in your role and finally, to support you to develop business cases or case for change narratives/documents.

HIV Specific guidance/policy/references

A Framework for Sexual Health Improvement in England (*publishing.service.gov.uk*)

BHIVA Standards of Care *https://www.bhiva.org/standards-of-care-2018*

British Association for Sexual Health and HIV: UK national guideline on safer sex advice

British HIV Association: BHIVA guidelines for the routine investigation and monitoring of adult HIV-1-positive individuals (2019 interim update) Monitoring-Guidelines.pdf (*bhiva.org*)

British Menopause Society: HIV and the Menopause

Faculty of Sexual and Reproductive Healthcare Clinical Effectiveness Unit: Drug Interactions Between HIV Antiretroviral Therapy (ART) and Contraception (February 2023) *https://www.fsrh.org/documents/fsrhceu-guidance-drug-interactions/*

https://www.bashhguidelines.org/media/1299/safersex-2012.pdf

https://thebms.org.uk/wp-content/uploads/2018/10/ BMS-TfC-HIV-and-the-menopause-01B.pdf

Making_it_work_revised_March_2015.pdf (*publishing. service.gov.uk*)

NHIVNA Advance practice guidelines *https://www.nhivna.org/Advanced-Nursing-practice-in-HIV-care*

NHIVNA Annual Health Review *https://www.nhivna.org/ annual-health-review-for-people-living-with-HIV*

Sexual health (nice.org.uk)

Towards Zero: the HIV Action Plan for England - 2022 to 2025 - GOV.UK (*www.gov.uk*)

Health promotion for sexual and reproductive health and HIV Strategic action plan, 2016 to 2019

How this segment meets Health Promotion Priorities

- Reduce onward HIV transmission, acquisition and avoidable deaths
- Reduce rates of sexually transmitted infections
- Reduce unplanned pregnancies
- Reduce rate of under 16 and under 18 conceptions

How this segment meets NHS Long-term Plan

Preventing illness and tackling health inequalities:

https://www.england.nhs.uk/about/equality/equalityhub/national-healthcare-inequalities-improvementprogramme/core20plus5/

https://www.longtermplan.nhs.uk/areas-of-work/ prevention/

Relevant key performance indicators

- Relevant Specialised Services Quality Dashboard
 (SSDQ) indicators
- NHS Outcomes Framework:
 - Domain 1: Preventing people from dying
 prematurely
 - Domain2: Enhancing quality of life for people with long-term conditions
 - Domain 4: Ensuring that people have a positive experience of care
 - Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm

For further information on demonstrating the value of specialist nursing see Apollo Resource/Professor Alison Leary *https://www.apollonursingresource.com/*

Health promotion/ prevention

Introduction

This model of nursing care has been specifically designed for registered nurses working in an HIV setting or whose role involves caring for people living with HIV. While we recognise the invaluable contribution of other healthcare workers, it is not within the scope of this document to address the care delivered by non –registered nurses.

2 This section will cover health promotion and prevention for people living with HIV. Health promotion has been defined as the process of enabling people to increase control over, and to improve their health. Health prevention includes nursing interventions that identify and mitigate the risks of potential morbidities.

3 This section will also link with; HIV testing & adjusting to diagnosis, living with HIV and other long-term health conditions, engagement and retention in care and assessing supporting & improving psychological well-being. As with other sections, this includes specialist HIV nursing practice at intermediate level and advanced level.

4 Competencies will need to be assessed according to local protocols/governance or as part of a formal qualification e.g. STIF/NHIVNA certificate in intermediate or advanced HIV nursing competencies. Nurses who have undertaken STIF/NHIVNA competencies can use the related competencies for this segment.

5 In addition to the documents and competencies below, it is expected that HIV nurses will engage in relevant CPD for their role to ensure contemporary evidence based practice. It is also expected from HIV nurses to share best practice.

Section 1 – Your clinical practice

To aid understanding of this section, NHIVNA felt that it was important to define the following concepts, health promotion and health prevention. Within the academic literature health promotion has been defined in a number of different ways. The definition that NHIVNA believes best reflects what we understand health promotion to mean comes from the World Health Organisation (WHO) and, whilst we acknowledge that this is almost 30 years old, we believe that it captures what health promotion means in the context of HIV care. WHO stated that 'Health promotion is the process of enabling people to increase control over, and to improve their health¹.

Therefore, the role of the HIV nurse is to enable people living with HIV to increase control over, and to improve their HIV health.

When considering what prevention means in the context of HIV care we have also selected a definition that is provided by the World Health Organisation who state 'Disease prevention covers measures not only to prevent the occurrence of disease, such as risk factor reduction, but also to arrest its progress and reduce its consequences once established².

When exploring the concept of health promotion, the following terms are used, primary, secondary, and tertiary prevention and disease prevention.

Primary prevention is directed towards preventing the initial occurrence of a condition. Secondary and tertiary prevention seeks to supress or stop existing disease and its effects through early detection and appropriate treatment. Alternatively secondary and tertiary prevention aims to reduce the occurrence of relapses and the establishment of chronic conditions, for example, through effective rehabilitation. Disease prevention is sometimes used as a complementary term alongside health promotion. Although there is frequent overlap between the content and strategies, disease prevention is defined separately. Disease prevention in this context is considered to be action which usually emanates from the health sector, dealing with individuals and populations identified as exhibiting identifiable risk factors, often associated with different risk behaviours³.

Prevention in HIV nursing falls into all three categories. In this context primary prevention is nursing activity that aims to prevent new HIV infections and providing care to people living with HIV with the intention of preventing HIV disease progression. Secondary and tertiary prevention involves working with people living with HIV to maximise their overall health. This will be discussed further in relation to Living with HIV and other long-term conditions. This section will primarily deal with living well with HIV infection.

References

- 1 Ottawa Charter for Health Promotion. WHO, Geneva, 1986
- 2 Health for All series. WHO, Geneva, 1984
- 3 Health Promotion Glossary. WHO, Geneva, 1998

Competency levels

Competencies at **Intermediate level** (1) as defined by STIF/NHIVNA: These are aimed at nurses working in an HIV setting or with people living with HIV at Band 5/6/7 and are equivalent to Level 3 of the NHIVNA competencies

Competencies at **Advanced level** (A) as defined by STIF/NHIVNA: These are aimed at Band 7 nurses and above who are working at an advanced practice level equivalent to Level 4 of the NHIVNA Competencies and with reference to the Advanced Nursing practice in HIV care (2016).

NB: For nurses working outside of England's Agenda for Change contracts, please use this as guidance for your level of practice in your area of work.

HIV Nursing Competencies

- Regular review: adherence to antiretroviral therapy, concomitant medicines and substances, sexual and reproductive health 1
- Annual review including medicines review, mental health, memory, sexual and reproductive health; risk of cardiovascular disease, type 2 diabetes, osteoporosis, etc.
- For People Living with HIV with viral load >200, including those newly diagnosed: promoting safer sex, safer injecting, partner notification, etc.
- Activities that aim to retain People Living with HIV in treatment & care, and to re-engage those who have disengaged from HIV treatment and care A
- Links with primary care and other specialties, e.g. mental health and social care services, drugs services, housing, etc.
- Nurse-led clinics and advanced practice roles
- Establishing and developing services

Recommended training

- Local competencies see local web-based resources
- NHIVNA Education: https://www.nhivna.org/ NHIVNAEducation
- National HIV Nursing Competencies 2013 https://www.nhivna.org/competencies
- STIF/NHIVNA Intermediate Competencies
- STIF/NHIVNA Advanced Competencies
- Non-medical prescribing
- Health promotion/public health module (level 6 or 7)
- E-Learning: BASHH Sexually Transmitted Infections Foundation (STIF) courses: https://www.stif.org.uk
- E-learning: Sexual and Reproductive Healthcare programme: https://www.e-lfh.org.uk/programmes/ sexual-and-reproductive-healthcare
- Advanced communication skills

Case Study: fictitious case based on a number of real life experiences.

Michael is not surprised when he is diagnosed HIV positive. He had enrolled in the PrEP Impact Trial and had decided not to continue to its conclusion. His last HIV test was when he enrolled in the trial; he was HIV negative two years ago. Michael informs you that he is currently living in temporary accommodation, provided by the local authority and is at risk of losing his accommodation and worries that he will either be forced to sofa surf or become street homeless.

In this case when considering primary prevention as HIV specialist nurses we would be involved in partner notification; advice on strategies that are designed to avoid onward transmission of HIV including:

- Promoting adherence to antiretroviral therapy (ART)
- Promoting the U=U message which means that, if you are living HIV, taking ART and your viral load is undetectable, you cannot pass HIV to a sexual partner
- Encouraging and supporting Michael to engage in care. NB. Michael has previously disengaged from services and as such the role of the nurse will be key to ensuring that he remains engaged in HIV treatment and care.

This is not exhaustive and HIV nurses my engage in other primary prevention strategies either working independently or as part of a wider multidisciplinary team.

Secondary prevention in the context of HIV, involves:

- Providing information about HIV
- Baseline assessment & monitoring
- Promoting HIV peer support
- Facilitating access to mental health services
- Adherence to ART

Other health promotion activities may include exploring the use of tobacco, alcohol and recreational drugs use.

With regards to tertiary prevention, HIV nurses will see Michael at regular intervals to promote:

- Lifelong adherence to ART
- Regular medicines review and checking for drug-drug interactions
- Regular sexual health assessment with the offer of screening
- Appropriate vaccinations including hepatitis A, hepatitis B, HPV, etc.
- Assessing the risk of cardiovascular disease, type 2 diabetes, osteoporosis, etc.
- Working with outside agencies, e.g. peer mentoring service, local HIV voluntary services (where these exist), Michael's GP, housing officer, etc.

Please consider the following points in relation to your level of competency / clinical practice. These trigger questions are to enable you to reflect on your role as a nurse and to engage in professional discussions about people living with HIV who disengaged in care in your workplace. There is not an expectation that everyone will know the definitive answer to these trigger questions. What is more important is that you recognise and address any gaps in your knowledge and practice.

- What information do you think Michael will need about his care at this stage?
- Outline how you will assess what health prevention / promotion that you think Michael will need? What will be your main priorities and why?
- What resources could support health promotion and prevention for Michael?
- What further information do you feel that you need to build your knowledge around HIV health prevention and health promotion? Make a list of where you might be able to obtain this information.



How to demonstrate quality HIV care in this segment

Demonstrating quality in healthcare is more important than ever. We have created a quality framework based on The Institute of Medicine's six dimensions of healthcare quality for you to use in the context of your role.

This quality framework is intended for you to demonstrate HOW you are delivering this segment of the HIV model of nursing care. It can help you:

- Define quality care for people living with HIV
- Link quality to the NMC code of conduct
- Communicate what HIV quality care means to all your stakeholders
- Develop continuous quality improvement projects in your area
- Link quality to the foundation of HIV care Person-Centred Care

This can also be used in many different areas of your practice, for example, to reflect on your own practice, to engage your team on quality improvement projects, for your revalidation, teaching and other proactive elements of your role. Feel free to print this page off and start to scope out quality for your area of practice under the six dimensions.

The middle column is left blank for you to fill in as you explore the dimensions of quality and cross reference the information, guidance, standards and links on the following pages. The righthand column helps you to cross reference your work to the NMC Code of Conduct; this will support your revalidation process as a focus for professional reflection.

NMC code

	The unrensions of quarty	Time coue
Safe Avoiding harm to patients from care that is intended to help them		
Effective Providing services based on evidence and which produce a clear benefit		
Person-centred Establishing a partnership between practitioners and patients to ensure care respects patients' needs and preferences		
Timely Reducing waits and sometimes harmful delays		
Efficient Avoiding waste		
Equitable Providing care that does not vary in quality because of a person's characteristics		

The dimensions of quality

Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. Washington DC: National Academy Press, 1990, p244

Section 2 – Evidence, policy and

Commissioning

Why include NHS plans, policy and guidance alongside HIV specific guidance/policy? The documents below are not a reference list. They are there to help you to synthesise HIV, HSA and NHS plans, policies and guidance to ensure you are aware of, and can describe your role within a strategic context where required, secondly, for you to articulate and demonstrate the outcomes you are achieving in your role and finally, to support you to develop business cases or case for change narratives/documents.

HIV Specific guidance/policy/references

BHIVA Standards of care 2018

BHIVA 2018 U=U position statement *https://www.bhiva. org/BHIVA-encourages-universal-promotion-of-U-U*

BHIVA/BASHH guidelines on the use of HIV pre-exposure prophylaxis (PrEP) 2018 *https://www.bashhguidelines. org/media/1189/prep-2018.pdf*

UK Guideline for the use of HIV Post-Exposure Prophylaxis 2021 *https://www.bhiva.org/ file/6183b6aa93a4e/PEP-guidelines.pdf*

BHIVA position statement on HIV criminalisation

https://journals.sagepub.com/doi/ pdf/10.1177/09564624221132407

NHIVNA Advance practice guidelines

https://www.nhivna.org/Advanced-Nursing-practice-in-HIV-care

NHIVNA Annual Health Review

https://www.nhivna.org/annual-health-review-forpeople-living-with-HIV

How this segment meets Health Promotion Priorities

- Reduce onward HIV transmission, acquisition and avoidable deaths
- Reduce rates of sexually transmitted infections

How this segment meets NHS Long-term Plan

This segment meets the long-term plan with regards to prevention of health inequalities and not only treating the underlying health condition but preventing people from becoming unwell.

https://www.longtermplan.nhs.uk/areas-of-work/ prevention/

Relevant key performance indicators

- Relevant Specialised Services Quality Dashboard (SSDQ) indicators
- Public Health Outcomes Framework
- NHS Outcomes Framework
 - Domain 1: Preventing people from dying prematurely
 - Domain 4: Ensuring that people have a positive experience of care (evidence of patient satisfaction)
- Other performance indicators
 - Documented care plans with patient involvement (BHIVA notes audit or NHIVNA care plan audit)

For further information on demonstrating the value of specialist nursing see Apollo Resource / Professor Alison Leary *https://www.apollonursingresource.com*/