

**YOUR GUIDE TO**

# Standards of Care

*for People Living with HIV 2018*



HIV TREATMENT  
ADVOCATES NETWORK



# YOUR GUIDE TO

## British HIV Association

### *Standards of Care for People Living with HIV 2018*

All rights reserved. No part of this publication may be translated, reproduced, stored in a retrieval system or transmitted in any form by any means, electronic, mechanical, photocopying, recording, broadcasting or otherwise, without prior permission.

©British HIV Association 2020

*Published by*

**British HIV Association**

**ISBN: 978-1-5272-7954-4**

Photographs provided by kind permission of the photographers:  
Julie Proudfoot – Standard 5; David Morrison – Standard 7

---

## Endorsed by:

Association of Directors of Public Health (ADPH)  
British Association for Sexual Health and HIV (BASHH)  
British Dietetic Association (BDA)  
British Infection Association (BIA)  
British Psychological Society (BPS)  
Children's HIV Association (CHIVA)  
HIV Pharmacy Association (HIVPA)  
National HIV Nurses Association (NHIVNA)  
Public Health England (PHE)  
Rehabilitation in HIV Association (RHIVA)  
Royal College of General Practitioners (RCGP)  
Royal College of Physicians (RCP)  
Social Care Institute for Excellence (SCIE)  
UK Community Advisory Board (UK-CAB)



## Contents

Foreword	4	<b>5. Sexual and reproductive health</b>	<b>25</b>
<b>1. Testing, diagnosis and prevention</b>	<b>9</b>	5a. Sexual health	25
1a. Testing and diagnosis	9	5b. Reproductive health	26
1b. Prevention	10	<b>6. Psychological care</b>	<b>29</b>
<b>2. Person-centred care</b>	<b>13</b>	6a. Emotional wellbeing	29
2a. Stigma	13	6b. Mental health	31
2b. Self-management and peer support	13	6c. Cognitive function	32
2c. Participation of people living with HIV in their care	14	<b>7. HIV across the life course</b>	<b>33</b>
2d. Wellbeing	16	7a. Young adults and adolescents living with HIV	33
<b>3. HIV outpatient care and treatment</b>	<b>17</b>	7b. Early to middle adulthood	35
3a. Access to, and retention in, care	17	7c. Older age	36
3b. Outpatient care	19	7d. Palliative care	37
3c. Antiretroviral prescribing	19	<b>8. Developing and maintaining excellent care</b>	<b>39</b>
<b>4. Complex HIV care</b>	<b>21</b>	8a. Knowledge and training	39
4a. Inpatient care	21	8b. Monitoring and audit, research and commissioning	40
4b. Comorbidities, co-infections and cancers	22	8c. Public health surveillance, confidentiality and information governance	41
4c. Supporting people with higher levels of need	23	Glossary	42
		Further information	45
		Some thank you's	46

# Foreword

In 2018, the British HIV Association (BHIVA) published its third update of the Standards of Care for People Living with HIV (2018 Standards).

## What are the 2018 Standards?

The 2018 Standards cover the most important issues about care for people living with HIV. They are written for three groups of people:

- (1) Those responsible for providing care services (such as the NHS and local authorities)
- (2) Those giving care (such as doctors, nurses and other healthcare professionals)
- (3) Those receiving care (people living with HIV)

The 2018 Standards cover the range of care that can help people live well with HIV. They begin with HIV diagnosis and apply right through to end-of-life care. People living with HIV can expect to receive some or all of this whole range of care services at some point in their HIV journey. The 2018 Standards are very informative and detailed in over 100 pages, but sometimes the language used can be off-putting for people living with, or affected by, HIV. It makes it difficult to find what we should expect when accessing HIV care.

**This guide is specially designed to give you, the person living with HIV, the key information you need about what you could expect when you receive HIV care. This guide is available online. The online website also has the full 2018 Standards, so you can get more detail easily if you need it:**

[www.bhiva.org/standards-of-care-2018](http://www.bhiva.org/standards-of-care-2018)

Remember, though, as in other parts of the healthcare system, sometimes these standards may not be met. This gives you the chance to highlight any failings, with a view to improving care in the future. Some suggestions about who to speak to about this are given later.

## What's new in the 2018 Standards?

There are eight Standards that cover all aspects of HIV care, from HIV testing and diagnosis, to treatment, living well, and ageing with HIV. They also cover mental and emotional health, social care, support and wellbeing, as well as physical health.

Over the past few years, there have been three important developments in HIV;

## (1) U=U

U=U stands for: Undetectable equals Untransmittable.

Having an undetectable HIV **viral load** while on HIV treatment means HIV cannot be transmitted to your sexual partners, even without using condoms. Being undetectable means there's too little virus in your body for you to pass it on. Even though someone on antiretroviral treatment (ART) is still HIV positive, there is zero risk of HIV transmission sexually if you are undetectable. This protection, using ART, depends on you:

- Being on stable ART
- Having an undetectable **viral load**
- Continuing to take your HIV drugs – antiretrovirals (ARVs) – every day.

This works with all HIV drugs. It is true for all types of sex. U=U is something that is important in many areas of HIV care. It is referred to many times in this guide.

## (2) Starting ART and treatment as prevention (TasP)

There is clear evidence to show there are benefits to your health if you start ART as soon as possible after diagnosis. ART quickly reduces the amount of virus in your blood to a level where it cannot be detected – it is undetectable. This not only benefits your health, but also works well in HIV prevention. Once you have an undetectable **viral load**, there is zero risk of passing HIV to your sexual partners – it is untransmittable. You can't pass it on through sex. So, by starting ART as soon as possible, you are also helping with prevention. This is often referred to as treatment as prevention, or TasP.

## (3) PrEP

PrEP stands for pre-exposure prophylaxis. It is a way for HIV-negative people to use HIV drugs to protect themselves against HIV. PrEP currently consists of two HIV drugs (tenofovir disoproxil fumarate TDF and emtricitabine FTC) in one pill. You may know this medicine by its brand name, Truvada. There are also generic forms of the drug with the same active ingredients, which are just as effective. For the highest levels of protection, PrEP needs to be taken either daily or before and after sex as instructed. It is a very effective method of protection against HIV.

There has been a dramatic decline in the number of new cases of HIV in the UK over the past 2 years. This is a result of these three developments (U=U, TasP and PrEP), together with increased and regular HIV testing.

## How this guide to the 2018 Standards was developed

The 2018 Standards were developed and written with a lot of input from the community. The community representatives on the steering group of the 2018 Standards highlighted the need for a version aimed specifically at those receiving care. They subsequently led the project to develop this guide. The steering group for the guide was co-chaired and led by community members. Funding was applied for and obtained from the MAC AIDS Fund. The guide was also written by community members and carefully reviewed by the teams who wrote the 2018 Standards.

## How to use this guide

The guide follows the 2018 Standards, but it is written solely for those receiving care. It is not written for healthcare professionals or providers. It lets you know what you can expect in terms of your healthcare by focusing on quality of life and living well with HIV.

The guide uses the same section naming and numbering as the 2018 Standards, to make it easy to find the relevant section in the 2018 Standards if you are looking for more background or details about a particular section.

The guide can be found online at:

<https://standards.bhiva.org>

This also has links to the full 2018 Standards.

It is hoped that you find these Standards are being met in the care that you receive. But as all parts of the NHS and social care services are under strain, it may be that these Standards are not always being met. If that is the case, then you could:

- Talk to your HIV doctor or nurse or other healthcare professional about any issues you have – it might be that they can be easily fixed. You could use this guide or the 2018 Standards to help with such a discussion.
- Talk to your local HIV support organisation about your concerns. They may be able to raise issues on your behalf with those who set up services. In reality, some issues might take a long time to remedy. However, these Standards give us something to work towards. Their aim is for better ongoing provision of care for all people living with HIV in the UK.
- Please tell the [UK-CAB](#). Go to the homepage of the online guide where you will find a link in the Main Menu tab Additional Information to Surveys. There is a simple form to fill in. The [UK-CAB](#) is a network for people living with HIV who have a strong interest in HIV treatment and related issues, and who want to make sure people living with HIV are actively involved in all aspects of HIV treatment and care. This is called treatment advocacy. They would like to monitor and collate the experiences

of people using HIV services against these standards. Responses will be collected until the end of 2021. But neither [BHIVA](#) nor the [UK-CAB](#) will be able to help you directly with your specific issue. The form does not ask for your name or identifying details, nor which clinic you attend.

## Acknowledgements

We are grateful for the support and guidance of all members of the steering group for this guide to the 2018 Standards. Particular thanks go to those community members who gave their time, energy and expertise to the drafting and redrafting of this guide: Ben Cromarty, Rebecca Mbewe and Roy Trevelion. Without their enthusiasm, dedication and expertise, this publication would not have been realised. We also thank the many members of the 2018 Standards writing groups and steering committee for their oversight and comments, to ensure consistency with the 2018 Standards. And we thank those working ‘behind the scenes’ who supported us with the realities of turning our draft guide into print, and into a usable website.

We are very pleased that those professional bodies, whose members have a role in providing HIV treatment and care to people living with HIV, and who endorsed the 2018 Standards, also agreed to endorse this guide. The list of endorsements is shown at the front of this publication and on the website.

Also, a special thanks to those living with, or affected by, HIV who volunteered their photos to illustrate the 2018 Standards, and also this guide and website. We are extremely grateful to those who have contributed once more to the fight against the stigma associated with HIV. We are very grateful to Positively UK and [UK-CAB](#) for their help with organising this.

The entire project was made possible through grant funding from the MAC AIDS Fund, to whom we extend our particular thanks for their very generous support.

## Feedback on this guide

We hope you find this guide helpful. It would really help us to know if anything needs improving, though. We would welcome your feedback. There is a really quick survey that is easy to fill out, with space for your comments as well. Please go to the homepage of the online Guide where you will find a link in the Main Menu tab Additional Information to Surveys. There is a simple form to fill in. Let us know what you think about this guide!

## Glossary terms

Terms found in the glossary will be highlighted throughout this publication in [purple](#).





# 1. Testing, diagnosis and prevention

**It might seem odd to have a section on testing, diagnosis and prevention. After all, these are Standards for people living with HIV. So, for us, we've already been tested, diagnosed and are probably already being treated for HIV. But as people living with HIV, we might have some particular concerns about prevention. We might also have partners who are not living with HIV, so we need to be aware of, and involved in, prevention strategies.**

**HIV testing and diagnosis are crucial to stopping the HIV epidemic.**

## 1a. Testing and diagnosis

Routine HIV testing should be offered in a wide range of ways and should be encouraged. It is especially important in communities that have higher rates of HIV. Here, GPs should offer HIV tests. Testing should be offered when you're new to your GP, but also if you haven't had an HIV test in the past year. Routine HIV testing should also be offered in sexual health clinics, other hospital clinics or hospital departments such as A&E. HIV testing should also be offered more widely in the community. This might include [home testing](#) or [self-sampling](#). All these testing situations are listed in the 2018 Standards.

If you test HIV positive, you should be given clear information about what to do next, and where to get treatment and support. Information about what to do and where to go must be in easy-to-read language. As for any other infectious disease, testing should also be offered to your sexual partners, and your children, if there is the possibility that they might have been born with HIV.

## Key messages

- Routine offers of HIV testing should be made in a wide range of healthcare settings.
- Routine testing should also be available in the community, including [self-sampling](#) and [home-testing](#).
- In all cases, information about what to do if you test HIV positive should be readily available in a form that is clear and easy to understand.

## 1b. Prevention

Over the past few years, the number of new HIV diagnoses in England has been falling. This is the result of ‘combination prevention’. This is what this section is about. Combination prevention involves the use of HIV drugs, called antiretrovirals (ARVs), which is why they are discussed in the 2018 Standards. There are other prevention strategies, which the 2018 Standards do not cover, but these are still important, for example, condom use or needle exchange for injecting drug users.

Combination prevention relies on several factors:

### (1) Frequent testing

This includes testing at sexual health clinics, in the community, and testing at home. A quick diagnosis means fast access to treatment. Starting treatment sooner rather than later is better for your long-term health. Frequent repeat testing is recommended.

### (2) Treatment as prevention (TasP)

If you test HIV positive, some forms of HIV testing need to be confirmed. These tests might show a ‘reactive result’. This means that you are probably HIV positive, but another, different, test is needed to be sure. Between the time of the reactive test and the results of the second test, suitable professional and peer support should be available. Peer support means talking with someone else who lives with HIV. This can be very helpful and reassuring.

If you are HIV positive, then HIV treatment called antiretroviral treatment (ART) should be started as soon as you’re ready. Early ART is the best option for your long-term health. ART reduces the amount of virus in your blood. Once this level is undetectable, HIV cannot be transmitted to your sexual partners, even if you don’t use condoms. This is called ‘Undetectable equals Untransmittable’, or U=U. Starting treatment sooner rather than later reduces the chance of passing HIV to a sexual partner. This is referred to as ‘treatment as prevention’ (TasP).

### (3) PrEP (pre-exposure prophylaxis)

PrEP is ART that is used by people who are HIV negative to stop them getting HIV. At present, it usually involves taking drugs on a daily basis. PrEP is dramatically effective for HIV prevention. It's freely available in Scotland, Wales and Northern Ireland, and as of October 2020, also in England. PrEP users in England are being switched from an NHS trial to full access from the NHS. Advice on PrEP can be found on community websites such as HIV i-Base (<http://i-base.info>) or [iwantprepnov.co.uk](http://iwantprepnov.co.uk)

Together, these factors have helped to reduce the number of new cases of HIV. That's why it's called combination prevention.

Everyone having sex should be made aware of, and have access to, a complete package of HIV prevention options. This should include using condoms, access to free and repeat HIV testing, and sexual health screening. It could also include using HIV drugs called ARVs for PrEP or TasP, as required. Note that PrEP and TasP protect against HIV, but not other sexually transmitted infections. This is discussed more in Standard 5. (Sexual and reproductive health)

## Key messages

### For people who are HIV negative:

- You should have access to a wide range of testing opportunities. You should be helped to take part in a prevention strategy best suited to you. This may involve frequent testing for HIV, access to PrEP, and condom use.
- If you test HIV positive, you should get appropriate information and support. You should have access to HIV treatment as soon as you feel you are able to start. Starting HIV treatment as soon as possible is the best option for your health.
- You should know that U=U. Once someone's **viral load** is undetectable, they cannot pass on HIV to you through having sex.

### For people living with HIV:

- You should know that U=U. Once your **viral load** is undetectable you cannot pass on HIV through having sex.



## 2. Person-centred care

**‘Person-centred care’ is good-quality care that focuses on your needs as an individual. Your care should not only be about your healthcare needs, it should also be about everything that is important to you, including your family and social situation. You should be involved in making decisions about your care and not just receive healthcare services decided by your doctors. Healthcare professionals should talk with you about your life. You should feel able to talk about your health, your symptoms and your worries. You should feel able to ask questions about these things.**

**Healthcare professionals should help you manage all aspects of your quality of life. This could include, if needed, managing pain, emotional and mental health.**

### 2a. Stigma

Your care should be non-judgemental. You should be treated with dignity and respect. You should feel safe from discrimination. You shouldn't have to worry about being treated unfairly. Staff should support you if you face HIV stigma and discrimination. This support should extend outside the HIV clinic to include all aspects of health and social care.

#### ***Key messages***

- You should receive equal and fair services as an individual. If you are unhappy with your care, you should be able to raise it with your healthcare provider. This should not affect your care.



- All your medical records must be kept safe and confidential.
- You should feel safe, supported and be treated with dignity and respect. If you experience any stigma, you should be supported to bring an end to it, without this affecting the quality of your treatment.
- HIV-related stigma can have a big impact on mental health and wellbeing. Health and social care staff should be trained in identifying stigma, and there should be policies in place for dealing with it promptly, fairly and practically.

## 2b. Self-management and peer support

Living with HIV may mean adjustments to some parts of your life. This includes things like starting HIV treatment. It can also mean things like starting, or going back to, school, college or work; entering into relationships; pregnancy; and many more. Each of these issues may need different ways of dealing with them. We all manage many complex situations in our lives, by developing an understanding of the issues and deciding how best to deal with them. This is called self-management. This is the case for living with HIV as well. Self-management can help you achieve a better quality of life. The NHS should offer you guidance and support in developing your self-management skills for living with HIV. Peer support organisations, where you can share experience with other people living with HIV, can also be very helpful. Both should help provide you with as much information, education and support about HIV treatment and care as you feel you need.

Your healthcare team can help you to understand your HIV treatment and care. They need to consider all aspects of your life that might affect your care. This might include immigration, housing or other social issues (such as addiction). Let your healthcare team know if there is anything you don't understand in the information you are given.

### **Key messages**

- You should have access to a wide range of services, including help to develop self-management skills, if desired. Services should provide support and information about HIV, its treatment and healthy living with HIV.
- You should be given access to information about your rights regarding HIV. This should include how to get financial, housing and employment support.
- You should be informed about peer support in your area. Peer support should follow National Standards for Peer Support in HIV ([www.hivpeersupport.com](http://www.hivpeersupport.com))

## 2c. Participation of people living with HIV in their care

You should be involved in all decisions about your own HIV care and treatment. You should have all the information you need in order to make decisions about your treatment and care. Your healthcare team should be able to provide you with the information you need to make these decisions. You can expect:

- To have your views respected
- To be involved in decisions about your diagnosis, health outlook, and treatment
- To be informed about making decisions for yourself
- To be given the information and support you need to make your own decisions
- To have your decisions respected. This includes the right to stop or refuse treatment.

There are information and support services that can help. Information is available in print form, online, by telephone and in peer support. These can help with HIV treatment, poor mental health, living with HIV, and social and financial difficulties (see the 2018 Standards for a full breakdown).

Being involved in your healthcare can benefit your long-term health (see Standard 2b – Self-management and peer support).

You may want to get involved in the design, delivery and performance of care services. If you do, then you should be offered information and training to help you. Information for getting involved should be provided by the NHS, councils and community support services.

### ***Key messages***

- You should be at the centre of any decisions about your health and care.
- You should be given information about your care. This should include all aspects of HIV and treatment. All information should be written in easy-to-understand language.
- You should be helped to develop your knowledge and skills in self-management. You can ask about any aspects of your care. Your doctors should direct you to any other services that can help, including social care and peer support.
- You should be offered the opportunity to get involved in the design, delivery or assessment of your health services, if you wish.

## 2d. Wellbeing

Wellbeing is about your quality of life. It is about being part of society, being treated with dignity, having better physical and mental health, and being able to cope with life's problems. Healthcare professionals can promote wellbeing by helping you access services for your individual needs. This might include things such as homelessness or housing issues, immigration problems, access to education or employment, intimate partner or gender-based violence, substance and alcohol misuse, stigma and social exclusion.

### ***Key messages***

---

- Your overall wellbeing, not just your HIV treatment, should be taken into account by everyone providing care for you.



## 3. HIV outpatient care and treatment

**If you are in the UK, and diagnosed relatively soon after you acquired HIV, then the care that you are most likely to receive is described in Standard 3 (HIV outpatient care and treatment). This describes how your HIV care should be assessed and delivered. It focuses on physical health. Emotional wellbeing and mental health are discussed in Standard 6 (Psychological care). There are still some circumstances where more complex care is needed. These are described in Standard 4 (Complex HIV care).**

### 3a. Access to, and retention in, care

You should be seen and assessed by a specialised HIV service within 2 weeks of testing HIV positive. At the same time, you should have access to psychological and peer support.

All options for HIV treatment, called antiretroviral treatment (ART), should be reviewed and discussed with you. Starting ART sooner rather than later has important benefits for your health. Modern ART drugs are safe and effective. They are easier to take than early HIV drugs and have fewer side effects. For most people, taking ART means you take only one or two tablets every day. ART does not cure HIV, but can control it for the rest of your life. But you will need to take tablets every day in the right way.

You and your doctor should make sure you're ready to start ART. Your doctor will support you in starting ART as soon as possible.

Support at the clinic should include access or referral to emotional and psychosocial services. You should also be referred to your local HIV peer support group, if there is one, so that you can talk to someone else who lives with HIV. Peer support can sometimes help you to access other advice, such as on finance and housing, if you need it.

When you start ART, the amount of virus in your blood (called the 'viral load') should come down very quickly. It will soon reach such low levels that it is called undetectable. It will only stay undetectable as long as you are taking your ART properly. Having an undetectable viral load on ART means you cannot pass on HIV sexually. You cannot transmit HIV if your viral load is undetectable on ART, even if you don't use condoms. So, Undetectable equals Untransmittable (U=U). U=U helps with prevention of HIV transmission.

ART will carry on working throughout your life. So you need to stay connected to care at the clinic. This is called retention-in-care.

HIV services need to keep in touch and see you regularly, to help you take ART and make sure it's working well. Sometimes people miss appointments and don't get seen regularly. The clinic should make sure you are contacted and brought back for treatment follow up. This helps you have a regular supply of drugs and regular blood tests.

If you transfer to another clinic, whether moving house or for another reason, your care summary should be sent to your new doctor and clinic, if you agree. You can ask to see your care summary.

If you are unhappy with your HIV doctor or clinic you should discuss this with them. If your concerns can't be overcome, you can ask for a second opinion. You can also transfer to another clinic if you wish. There is also a formal NHS complaints procedure.

## ***Key messages***

---

- If you are newly diagnosed, you should be offered an appointment with a specialist HIV service within two weeks and given access to psychological and peer support.
- It is best to start ART as soon as you are ready. If you are struggling with any aspects of your ART at any time, there should be support for you from both the HIV clinic and peer support groups.
- There should be systems in place, and support for you, to stay in care. If you need to change clinic for any reason, the transfer of your care should be done in a smooth and safe way.

## 3b. Outpatient care

The national guidelines for HIV care say you usually need to visit your clinic every 6 months once you're taking ART (although when you are just starting ART, you will need to see your care team more often). This is called 'outpatient care'. At clinic appointments, the care team will check to make sure your ART is working well. They will also check for any other issues that may be affected by HIV and ART, such as your liver or kidney function. If any problem develops, you might need to see other specialists.

GPs also have an important role to play in checking your general health. They will look for conditions such as high cholesterol, high blood pressure and diabetes. Your GP will look after other aspects of your general health and should know about your HIV treatment. You will need to tell your HIV doctor that it is OK for them to write to your GP, if that is what you want. They cannot do it without your explicit consent.

Other health and social healthcare workers will work together when there are complex healthcare needs. HIV care and wider health and social care need to be joined up smoothly.

### ***Key messages***

- ART needs to be taken throughout your life – retention in care is very important. HIV clinics will keep in touch with you and see you regularly. To keep your ART working well, you'll typically need to visit the clinic every 6 months.
- Your care should be provided in a welcoming and safe environment that protects your privacy and confidentiality.
- If you have complex care needs, you should have access to the full range of support services you need. Some of this may be provided by your GP.

## 3c. Antiretroviral prescribing

Modern ART uses several antiretroviral drugs (ARVs), often combined into a single tablet. These ARVs should be prescribed by a qualified HIV specialist. A wide range of ARVs is now available. Your HIV doctor will suggest the best individual treatment for you. This should be based on your physical, mental and social needs, and fit in with your daily schedule.

Your ART will be monitored to make sure it keeps working well. But if your treatment doesn't work well or if you need to switch for other reasons, you should be offered alternative ART options, using different ARVs.

You should be helped if you are struggling to take ART in the right way or if you have side effects. If you can't take it in the way that you should, such as with food, you should be

offered other ARVs that are easier to take. You can talk to your doctor about these issues at your regular appointment, or earlier if needed.

ARVs can interact with other drugs. As well as other drugs you may be prescribed, this also includes over-the-counter drugs, herbal remedies, supplements, vitamins and additives, and recreational drugs. It doesn't just apply to tablets you might take – it also applies for ointments, creams, sprays and inhalers, and injections. An interaction could mean that either your ARVs or the other medications don't work as well as they should. It's important to check for any possible interactions between your ARVs and any other drugs you might need for some other non-HIV condition. Your HIV healthcare team is well aware of this, as are GPs and pharmacists. They do need to know what drugs you are taking in order to check, so you need to tell them about the whole range of medicines you are taking. If there is an interaction with your ARVs, you could be offered adjusted or different medication. Sometimes, though, it may be necessary to review and change your ARVs.

## ***Key messages***

---

- Your ART should be prescribed by a qualified HIV specialist. A wide range of ART is available, using different ARVs. Your doctor should tailor your ARVs to your personal healthcare needs and situation.
- If for any reason you are prescribed drugs for some non-HIV conditions, the prescriber should check that these drugs don't interact with your HIV drugs. If you buy drugs over the counter, you should ask the pharmacist for advice about interactions.



## 4. Complex HIV care

**If you are in the UK, and diagnosed relatively soon after you acquired HIV, then it is most likely that you will NOT need complex HIV care as described in this section. You are more likely to get everything you need for your HIV care as described in Standard 3 (HIV outpatient care and treatment). There may still be some circumstances where more complex care will be needed. The three main areas of complex care need are described here in Standard 4. This, though, focuses on physical health. Emotional wellbeing and mental health are discussed in Standard 6 (Psychological care).**

### 4a. Inpatient care

Inpatient care is hospital care. Far fewer people diagnosed with, or living with, HIV now need to be in hospital for HIV.

The number of new HIV diagnoses in the UK has fallen in recent years. This is due to a combination of factors, including: people testing more frequently; earlier diagnosis; starting antiretroviral treatment (ART) sooner after diagnosis than in the past; and pre-exposure prophylaxis (PrEP). Even though the number is going down, some people are still being diagnosed late – that is, they have had HIV for a long time without knowing it. This can mean an increased risk of getting infections other than HIV or developing other complications. This is because your immune system is damaged by untreated HIV and a weak immune system can increase the risk of serious infections, such as tuberculosis (TB) and [pneumonia](#). If you have been diagnosed late with HIV, it could be that you may need to spend time in hospital to deal with some of these things. Most people respond well to this kind of treatment and then go on to outpatient care for HIV, as described in Standard 3b (Outpatient care).

Thanks to safe and effective ART, many people living with HIV are living well into old age. This means that like anyone else, you may need to go into hospital for non-HIV reasons.

If you do need to go into hospital, for whatever reason, you should receive the best care and treatment. If the reason is HIV-related, then an HIV specialist would normally lead your care. They will use the [BHIVA guidelines](#) for the treatment of HIV as a starting point, but all care is **individualised** to your specific needs. If you need support from other clinical specialties when the problem is not HIV-related, you may be treated by doctors and nurses who have limited experience in providing care for people living with HIV. Even so, you should be treated with dignity and respect, regardless of race, gender, sexuality or any other factors, and your wishes about confidentiality should be respected.

Not all hospitals have HIV specialist inpatient units. If that is the case, your hospital will work with another hospital that **does** have specialist HIV inpatient expertise. In some cases, you may need to be transferred to another hospital. This should take place within 24 hours of the request being made.

When you leave hospital, there should be a plan in place to make sure you get the full support you need to recover well.

## **Key messages**

- Fewer people living with HIV today need inpatient care. You should get the best care and treatment available in hospital. Your care may be led, or supported, by an HIV specialist, but other specialist doctors and nurses may also be involved in your care. You should be given privacy, dignity and respect, regardless of race, gender, sexuality or any other factors. Your wishes with regard to confidentiality should be respected.
- Not all hospitals have HIV specialist inpatient units. In some cases, you may be transferred to another hospital with these units. This should take place within 24 hours of the request for transfer.
- When you leave hospital, you should be supported by an appropriate rehabilitation or discharge plan, if needed.

## **4b. Comorbidities, co-infections and cancers**

Having another health condition as well as HIV is called a comorbidity. If this is an infection, then it is called a co-infection (with your HIV).

People who are diagnosed with HIV today, and taking modern ART as they should, are likely to have a life expectancy similar to someone who is HIV negative. This means that over our lifetimes, we may develop common conditions associated with getting older, such as those affecting the heart, kidneys or the liver. There should be regular age-appropriate screenings for these conditions. Some of these could be done by your GP.

People living with HIV can be at increased risk of other infections such as TB, [hepatitis B](#), and [hepatitis C](#). Everyone who is diagnosed as HIV positive should be assessed and monitored for TB, [hepatitis B](#) and [C](#) during ongoing HIV treatment.

People living with HIV may also be at slightly increased risk of some cancers.

Treatment for any of these conditions should be done by a team of specialists using a joined-up care plan. This team should involve your HIV specialist, together with doctors and nurses from other specialist areas, and may also include pharmacists and your GP. Good communication between the different areas is needed to make sure you get the best treatment. You should be offered the same standard of care as anyone else. All other treatments you receive should be checked to make sure that they don't interact with your HIV treatment. This is discussed in a bit more detail in Standard 3c (Antiretroviral prescribing).

### ***Key messages***

- You should be screened according to national standards for diseases associated with ageing, such as heart disease, liver or kidney disease, or cancers. This will usually be done at your HIV clinic. Your GP may also screen or test you for some conditions.
- You should be screened for co-infections such as TB and [hepatitis B](#) and [C](#) when you are first diagnosed with HIV.
- If you need treatment for any other conditions, it should usually be provided by a multidisciplinary team involving an HIV specialist. They must make sure that any other treatment given does not interact with your HIV treatment.

## **4c. Supporting people with higher levels of need**

People living with HIV still experience high levels of stigma and discrimination, and they are more likely to face social disadvantage, for example, poverty or being homeless. This can badly affect a person's quality of life.

People living with HIV are more likely to have multiple long-term conditions; poorer mental health; poorer sexual health; and higher levels of alcohol and substance misuse. They are more likely to face economic hardship, and [intimate partner violence](#).

If you face problems such as these, it can be harder to manage your healthcare well. It may be that you struggle to get to clinic, or that you find it difficult to take your ARVs as you should. This could result in your health getting worse. So, when you are diagnosed with HIV, you should get a complete assessment of all your healthcare needs. Wider social issues

such as housing, finances, employment and social support should also be considered, since these can have an impact on your health. You should feel safe and able to discuss any of these things with your healthcare team.

If you need increased support to deal with such issues, a **personalised care plan** should be developed for you. This could involve your GP, or another care coordinator, such as a specialist HIV nurse. Support could include local HIV services and peer groups. You might need to be referred to other support services, such as for help with alcohol or drug dependency, or poor mental health. Peer support, which lets you share your experiences with other people living with HIV, can also be of great help, both practically and emotionally.

Your needs can change over time, so a complete needs assessment should be repeated by your HIV healthcare team every year.

## ***Key messages***

---

- A thorough assessment of all your physical, mental and social needs should be made when you are diagnosed. This should be repeated annually. It should give you information about where to get the support you need.
- If you need increased support, an **individualised** care plan should be made for you.
- If needed, you might be referred to a wide range of other support services, including peer support.
- Services should have safe and confidential referral systems, especially to support people experiencing **intimate partner violence**.



## 5. Sexual and reproductive health

**This Standard looks at how you can have a healthy sex life. It also looks at the issues around contraception, pregnancy, breastfeeding and the menopause**

### 5a. Sexual health

Having a healthy sex life is important for everybody. It's important for you and your partners. Testing for sexually transmitted infections (STIs) may be available at your HIV clinic. If not, you should be told where you can access these services. A sexual health assessment should be offered at least annually.

You should be able to access [preventative vaccines](#) for [hepatitis A and B](#), and [HPV](#), according to national guidelines.

HIV treatment as prevention (TasP) of HIV transmission should be explained to you. This includes information about U=U (Undetectable equals Untransmittable), as well as for PrEP (pre-exposure prophylaxis) for sexual partners. This is discussed in Standard 1b (Prevention). Although both U=U and PrEP protect against HIV, they do not protect against other STIs, or prevent pregnancy.

If you're at increased risk of other STIs or viral [hepatitis](#), you should be given advice and support to help manage this risk.

## Key messages

- You should have easy access to sexual and reproductive health services. A sexual health assessment should be offered at least annually.
- You should have access to vaccines for **hepatitis A and B**, and **HPV**, in line with national guidelines.
- You should be made aware of the wide range of interventions that reduce the risk of HIV transmission, including U=U (Undetectable equals Untransmittable), and PrEP for sexual partners.

## 5b. Reproductive health

You may wish to either plan pregnancies or avoid pregnancy.

If you wish to avoid pregnancy, you should be given advice on, and access to, the full range of contraceptive methods. Some types of contraceptive pill may interact with some HIV treatments. There are now many options for antiretroviral treatment (ART), so it should usually be possible to find one that works well with your preferred method of contraception.

If you are planning to have a baby, it is possible to conceive naturally. If the amount of virus in your blood is undetectable, then U=U, and there is zero risk of transmitting HIV to your partner, even when not using condoms. But, if you are not undetectable, then PrEP for your partner as protection against HIV may be considered.

Modern ART for pregnant women living with HIV has reduced the risk of HIV for newborn babies to almost zero. The most important things to consider for your baby to be healthy are your own health and your own HIV treatment. You should have full access to all the services and support you need during pregnancy, delivery, and after your baby is born, including peer support. Talking with other women who are living with HIV and who also have children can be very helpful.

You should be given information and support about options for feeding your baby. **Formula milk** has zero risk of transmitting HIV to your baby. Breastfeeding, even if you are undetectable on ART, means your baby may be at a very low risk of HIV. If you want to use **formula milk**, but can't afford it, it should be made available free of charge.

Pregnant women living with HIV can be more likely to experience poor emotional health. You can be at increased risk of postnatal depression. Assessing and treating poor mental health both during and after pregnancy should be part of your care.

There is some evidence that women living with HIV may experience the menopause earlier and more severely than women who are HIV negative. You should have access to

support and treatment for the menopause at whatever age this happens. This may include menopause hormone therapy (MHT), previously known as hormone replacement therapy (HRT). This has been shown to help reduce the symptoms of menopause. It should be made available to women living with HIV in the same way that it is for anyone else. It is usually provided through your GP, but expert advice from your HIV care team is needed to avoid any potential **drug interaction** with your ART.

## ***Key messages***

---

- You should have access to expert advice and services for all aspects of reproductive health. This includes contraception and pregnancy planning. It should also include information about breastfeeding .
- It's now possible to conceive naturally with no risk to your partner. Partners who are HIV negative are at zero risk because U=U (Undetectable equals Untransmittable). If you are not undetectable, PrEP may be available for a partner who is HIV negative.
- You should be given information and support during the menopause. This could include access to menopause hormone therapy (MHT), when appropriate.





## 6. Psychological care

The Standards for psychological care for people living with HIV use the following terms:

- **Emotional wellbeing:** this is how we feel and cope with the ups and downs of everyday life. It's also about how we feel about living with HIV. It can include feelings about HIV stigma or telling people about HIV. It's also about other things that HIV may or may not impact on. This could include things such as family and friends, relationships and sex, employment and society. In fact, it's about anything that's important to our confidence and self-esteem.
- **Mental health:** although we all have good and bad days, sometimes the way we feel, think and behave can seriously stop us from living life well. Poor mental health can include anxiety or depression. It can also include post-traumatic stress disorder, or poor sleep. Some people with mental health difficulties experience suicidal thoughts. They might also injure themselves, or use alcohol or drugs, to cope with stress.
- **Cognitive function:** this is about the health of our brain. It includes things like memory, concentration, using words and solving problems. If we have cognitive difficulties, we might forget things, be slower, or get confused easily. We might find it difficult to do the things we used to be able to do easily, like taking medication, or attending appointments.

### 6a. Emotional wellbeing

People living with HIV may sometimes experience stigma from society in general, and even from some healthcare workers and support staff. Sometimes these experiences can make people feel ashamed, guilty or bad about themselves. If this happens to you, let your healthcare team know and they can help you find professional support to help with this.

It might be difficult to talk about, but you can also ask for help if you experience bullying or violence from your partner, or people you work with.

Living with HIV means managing a chronic condition. For some people, this can lead to feeling down, anxiety or stress. This could affect your HIV if, for example, you miss clinic appointments or don't take your antiretroviral treatment (ART) in the right way. It could also affect your wider life too, for example in your relationships with family and friends. You can ask your healthcare team for advice and support to help with such issues, if needed.

Modern HIV treatment is much easier to take, with fewer side effects, than earlier HIV treatment. Some people are happy and able to take more control over their own HIV care. If this isn't the case for you and it is causing further stress, please let your healthcare team know. You can also ask for help from your partner, friends, family or others in your community. Peer support gives you the chance to share experiences with other people living with HIV. This can also help you manage your health better.

Peer support can be provided through face-to-face meetings, online, telephone or group support. Peer support provides HIV treatment awareness and understanding. It includes things like newly diagnosed courses, patient networks, social gatherings, charitable organisations and also NHS HIV services.

Getting the right support is important for everyone living with HIV. With good support, many people living with HIV manage their physical, mental and emotional wellbeing effectively, showing strength, growth and resilience. But if you are struggling, don't forget that you can ask for help and support – that is what the services are there for.

## ***Key messages***

---

You should be able to have:

- Regular monitoring for possible challenges of living with and managing HIV.
- Access to support for emotional wellbeing, including information about services and social support, that can help before problems start, or before they get worse.
- Access to peer support services.

## 6b. Mental health

There are many reasons why people living with HIV are more affected by mental health issues than those not living with HIV. These can include drug or alcohol dependence, stigma, long-term medical conditions, and treatment side-effects.

Some groups can be more affected than others, perhaps because of other wider experiences of stigma and discrimination. These include black African men who have sex with men, trans people, people in prison, people who inject drugs, sex workers and people with disabilities. Anyone can experience poor mental health at some point in their life.

Poor mental health can make it harder to cope well with treatment and clinic visits. It might affect your ability to take your ART regularly. If so, this can lead to detectable levels of virus. This can damage your own health and risk HIV transmission to partners. Regular mental health checks should be provided for everyone. Your HIV healthcare team should ask you about any changes that might affect your mental health. These could be things like changes to your HIV treatment, difficulty with relationships, loss of social support or benefits, and bereavement. But you should also feel able to raise any of these issues yourself, at any time, and ask for help and support, if needed.

Your medical team should provide referral to the most appropriate professionals. Mental health needs should be addressed quickly and professionally. Talk to your doctors and nurses if you have any concerns about your mental health. You should be referred to the right professional help at the right time.

You should have access to good healthcare that is culturally sensitive and respectful. You should be referred to other services if these are not available at your clinic.

### ***Key messages***

- You should have annual check-ups for your mental health. Changes in your life should be reviewed. You should be referred to other services quickly if you have symptoms of depression, anxiety, post-traumatic stress, sleep difficulties, addictions, self-harm and suicidal thoughts.
- When needed, you should be helped to access mental health services (including addiction services).
- All your mental healthcare professionals should have up-to-date HIV knowledge. Their skills should be culturally sensitive. They must take into account things that have happened in your life, demographics, side effects and treatment interactions. Training should be provided for them, if necessary.

## 6c. Cognitive function

Poor cognitive function usually means having difficulty remembering things, trouble concentrating, or getting confused with things. You might find tasks around the home or managing your health a bit more difficult than before. This usually happens for everyone as they get older. Sometimes health issues like stroke, dementia, and occasionally HIV, can cause big changes that mean you need help to look after yourself.

Your doctor should assess any reduction in cognitive function and arrange the appropriate tests to make the correct diagnosis. Regular mental health checks are needed for this. Any associated risks, such as alcohol or drug dependence, or depression, should be identified and managed.

You should be regularly asked about your cognitive function. Sometimes this involves puzzles and tests of memory, focus and problem-solving (called a 'neuropsychological assessment'), to see how quickly and well you can do things. If you do have cognitive difficulties, help can be given to cope with this. You might need your HIV treatment to be reviewed or changed if HIV or the medication is thought to be involved.

### ***Key messages***

---

- You should be asked about your memory or cognitive function every year.
- If memory or cognitive function symptoms are reported, you should be offered further screening. This may include a full neuropsychological assessment.
- If you are diagnosed with reduced mental or cognitive function, you should be offered a detailed review and appropriate treatment services.



## 7. HIV across the life course

**This Standard looks at the impact of HIV at different times in someone's life. Separate Standards exist for children living with HIV. These are produced by the Children's HIV Association (CHIVA) and are not included here.**

### 7a. Young adults and adolescents living with HIV

Adolescents are defined as aged from 10 to 19 years. Young adults are between 20 and 24 years.

The transition from child to adult HIV services happens at the same time as the huge change from being a child and adolescent to becoming an adult. All factors that can impact on a young person's sense of wellbeing should be taken into account by care services.

Your move from children's to adult services should be made easy. This is called your 'transition of care'. It needs to be planned and focused with your individual needs at the centre of your care. A slow transition can help you get to know your new doctors and nurses before they take over your HIV care.

As a young person, you'll learn about sex and relationships. When you are living with HIV, there can be extra challenges. Support should be given when you want to tell a new girlfriend or boyfriend about your HIV. Doctors, healthcare workers and specialist nurses should give you information and support when you start to think about beginning sexual relationships. Help can also be provided by other young people living with HIV. This is called peer support. Many young people find peer support easier around sex issues than talking to adult professionals.

Your clinic should discuss and advise you about sexual health. This should include information on contraception and prevention of sexually transmitted infections (STIs). You should be told about the use of condoms to prevent STIs. This should happen at least once a year, and more often if needed. Some HIV treatment and types of contraception can interact.

You can discuss your preferred contraception methods with your HIV doctor to make sure your contraception is effective and doesn't interact with your HIV treatment.

If you are having sex, you should have regular sexual health check-ups. These may be carried out at your HIV clinic, or you should be told where else to go for them if your clinic cannot do this. You should also be given the full facts about other ways to prevent passing on HIV. This includes Undetectable equals Untransmittable (U=U), treatment as prevention (TasP) and pre-exposure prophylaxis (PrEP). These are all explained in Standard 1b (Prevention). However, neither U=U nor PrEP protects against other STIs. Condom use is important to protect against both other STIs and pregnancy.

Adolescence makes many people anxious or confused. This is a normal part of being a teenager. During this time, it's important to keep taking your HIV treatment. This is not only best for your own health, but also for that of any sexual partners. If you have difficulty taking your treatment, you can talk to your doctor about it. You should be given advice and support to help you, and you may be able to switch to something that is easier to take.

## ***Key messages***

---

- Transition of care from children's to adult services should be gradual and planned. You should get support from both clinics and you should meet your doctors in the adult clinic before you transfer. A care summary of your individual medical and social healthcare needs should be included as part of your transition.
- Your HIV clinic should be friendly and helpful. Appointment times should try to fit around your education and work hours. You should feel able to give feedback to the clinic about your care. Access to mental health support and peer support should be available.
- You have the right to a full and healthy sex life. Information and advice about contraception should be provided. Regular sexual health check-ups should include advice about pregnancy and STIs. It should include information about U=U, TasP, and PrEP.
- If you find taking your HIV medication difficult, let your healthcare team know so that they can give advice and support. This may include peer support, and you should be shown how to access this if you want it. You can also ask whether there are other types of HIV medication that might be easier for you to take.

## 7b. Early to middle adulthood

If you are aged between 25 and 65 years you are in early to middle age.

People living with HIV in this age group can have very different lives.

Some may have been diagnosed as children and have grown up living with HIV and are now cared for in adult services. Your needs can be specific for both special physical and emotional healthcare. Services should be available for these specific needs at your clinic. These services should make sure you stay as healthy and well as possible.

Most people in this age group will have been diagnosed as adults.

If you have had an early diagnosis – that is, soon after you acquired HIV – and if you started HIV treatment soon after diagnosis, then it's likely that you've no or few HIV-related health issues. HIV care services should not interfere with your day-to-day schedule. This includes your education, training and employment.

Other people in this group may have been diagnosed a long time ago, or were diagnosed late – that is, a long time after they acquired HIV. People in this group may have complex care needs because of the harmful effects of early HIV treatments or they may have symptoms caused by previously untreated HIV. If so, they may need more support, both for physical health, and emotional and mental health. Support might need to come from other care services. Peer support organisations may also be useful. Here, people living with HIV can share experiences and get support from each other in a safe and caring environment.

Other factors should be considered for everyone, including drug and alcohol dependency, poverty, housing, immigration status and dealing with stigma. Peer support organisations can help in many of these areas, and you should be told about where to access peer support. Your doctors should also monitor your mental health and help you during this time.

People in this age group are usually sexually active. Everyone is entitled to healthy and fulfilling sex lives, including people living with HIV. Like everyone else, you should have access to sexual and reproductive health services. You should be informed about Undetectable equals Untransmittable (U=U), treatment as prevention (TasP), other sexually transmitted infections (STIs), and have access to regular and routine sexual health check-ups. This is discussed more in Standard 5 (Sexual and reproductive health).

Reproductive health services should be provided. If you plan to have a baby, you should be given access to information on HIV and pregnancy that is easy to understand. Thanks to U=U, it is now possible to have condomless sex without the risk of passing on HIV to your partner. It is possible to get pregnant naturally, even if you are HIV positive, but your partner is not. This is also discussed in Standard 5 (Sexual and reproductive health).

## Key messages

- You should have access to all information and support about living with HIV; starting and continuing HIV treatment; planning pregnancy; hospital care; education and employment; housing, benefits, immigration status; drug or alcohol dependency; poor mental health. Services should be **individualised** with access to peer and social support.
- Care and support services should not limit your daily routine. Clinic visits, simplified medication with home delivery, and access to test results should be made easy for you, with your agreement.
- You should get advice and support to maintain your health, such as stopping smoking, having a balanced diet, exercising, and support for alcohol or drug dependence.

## 7c. Older age

Your HIV treatment will carry on working well throughout your life. This means that like everyone else, you may experience some common health conditions as you get older. These could include things like high cholesterol, high blood pressure, diabetes, stroke and heart attack. So the care you may need in later life can be complex. This is discussed more in Standard 4 (Complex HIV care).

Some of us may have experienced long-term issues to do with stigma and bereavement and we may experience issues to do with mental or emotional health. Extra support might be needed at times. This is discussed more in Standard 6 (Psychological care).

Standard 2 is about person-centred care – good quality care that focuses on you as an individual. Your care should not be only about your healthcare needs. It should be about everything that is important to you, including your family and social situation. You might need care from several different health and social care professionals working as a team. This team must manage your HIV drugs and any other medications you're taking in case the drugs interact. If you find it difficult to manage all of these services on your own, you can ask your GP or another care coordinator, such as a specialist HIV nurse, to provide a personalised care plan for you. Peer support may also help.

Your HIV care should be tailored to your needs as you get older. You can expect all the standard screening tests for people of your age living with HIV.

## Key messages

- You should get support for coping with multiple illnesses from your healthcare team and from peer support. **Drug interactions** should be checked by all your doctors and healthcare workers.
- If needed, you should receive extra psychological and emotional support because of continuing stigma, discrimination and bereavement caused by HIV.
- You should receive standard health screenings for all people your age. Some of these may be provided by your GP.

## 7d. Palliative care

Palliative care helps to relieve distress to the patient and their family and friends. It ensures that the patient and their family are supported and do not experience unnecessary suffering. Access to palliative care is a human right. Palliative care deals with you as a whole person and respects every aspect of your life and health. It includes symptom and pain management. It also should include emotional and spiritual support, together with practical and social support.

Your healthcare team should draw up a care plan with, and for you, that reflects your wishes. This should be person-centred, and culturally and socially sensitive. You can change things at any time, and your wishes should be reviewed often. This plan should include unexpected or emergency events. You might also want to name somebody to take decisions on your behalf in case there comes a time when you are no longer able to do so yourself.

Thinking about the end of life may not be easy, but it can help you and your family. You should be given the information you need to help make suitable decisions about how you and your family would like to care for each other at the end of life. This should be at a time that suits you, and not cause unnecessary distress.

You will need to let your clinical team know about any confidentiality issues that need to be respected. This may include issues around telling people about your HIV status. Your team is obliged to keep this confidential if you wish it. The exception to this is that HIV may need to be disclosed on your death certificate, but only if your death is related to your HIV.

## ***Key messages***

---

- A care plan should be made to reflect your wishes. You will be asked if you've changed your mind about any aspects of your care. Plans should include unexpected or emergency events too.
- Your healthcare team will help you manage symptoms like pain, and also take into account your psychological, emotional and spiritual wishes.
- Making decisions about your end-of-life care is an ongoing process based on your specific needs and preferences. You should be given the information you need to make suitable decisions about how you and your family would like to care for each other at the end of life.
- Your team is obliged to respect issues around confidentiality. If your death is related to your HIV, this must be disclosed on your death certificate.



## 8. Developing and maintaining excellent care

**This Standard is really aimed at doctors and healthcare managers, but you should know about it too.**

### 8a. Knowledge and training

Treatment and care for people living with HIV is complex. It should usually be managed by an expert doctor who has specialist knowledge and skills in HIV medicine. If you have other health conditions as well as HIV, your care could be provided by a team of healthcare professionals, including nurses, dietitians and pharmacists, all of whom are required to demonstrate they have achieved a high level of competency to specialise in HIV care. This team is called a multidisciplinary team (MDT). You should also have a GP for common healthcare needs. Your GP and your HIV clinic team should work together to benefit your overall health, but they will need your consent to do this.

As well as clinical care, you may need access to other services. This could include social care, which focuses on giving help with activities of daily living, maintaining independence and encouraging social interaction. Unfortunately, HIV stigma still exists, even in the health and social care services. Non-HIV specialist health and social care workers should be trained in up-to-date general knowledge about HIV. This should help overcome any ignorance and stigma.

Peer support, where you can share experiences with other people living with HIV, can also be very helpful. Peer support can be given in many different ways – for example, face-to-face, online or over the phone. Organisations providing peer support should have appropriate structures and training in place for peer supporters.

## Key messages

---

- Caring for people living with HIV is complex. It can involve a wide range of people from different areas. In all cases, plans need to be in place to provide good, joined-up care.
- HIV care should be provided by a wide range of healthcare professionals, including nurses, dietitians and pharmacists, all of whom are required to demonstrate they have achieved a high level of competency to specialise in HIV care.

## 8b. Monitoring and audit, research and commissioning

An **audit** is the process where the quality and safety of the HIV services you receive are monitored and reviewed. This should improve the quality of care given and enable best practice to be shared with other care providers. Serious incidents such as late diagnoses of HIV, serious injuries or avoidable deaths in care should be recorded and reviewed. This is to learn from, and avoid, similar events in the future, where possible.

Research trials and studies can improve the knowledge and understanding of HIV. This can then lead to improved treatments and better rates of recovery. You should be informed of any studies and trials that are suitable for you, and you may be invited to take part. You should be given full information about any such study or trial. This must be in easy-to-understand language. It's always your choice whether to take part – you don't have to join. It will not affect your standard of care if you choose not to join.

The organisations and people that define and pay for your care are called commissioners. They make an assessment of what the HIV needs are, and allocate services accordingly. So it is important to get the best information about what is needed. There should be active involvement and representation of people living with HIV in defining these needs.

## Key messages

---

- Systems to monitor, **audit** and improve the care you receive should be in place and used effectively.
- Research can help to improve HIV treatment and health outcomes. You may be invited to join trials or studies. If you are, you should be given all the information you need to decide whether to join.
- Commissioners should have structures in place that include involvement of people living with HIV.

## 8c. Public health surveillance, confidentiality and information governance

It's important to keep records, or data, about how many people are newly diagnosed with HIV. A record must also be kept of the number of people who are living with HIV and accessing care and treatment. This is called public health surveillance. They are used to measure how well the ways to prevent HIV are working. They can also show how well HIV treatment is working overall, and this information can be used to plan and commission services for people living with HIV. Data are used to make sure that everyone in the UK is treated fairly and equally. The way these data are collected means that someone cannot identify you personally from it. All data are kept confidential.

Your personal medical information can only be used if you agree to it – you give consent. Sometimes, consent is 'implied', for example, when information has to be shared with other doctors who are looking after any complex health needs. However, that information should be shared only within that team. Consent for public health surveillance data is also implied consent.

There may be other circumstances where your clinical team may wish to share your data with someone else, for example, for research purposes. If this is the case, you should always be told what your data might be used for, and you can decide whether to agree. This is 'explicit' consent.

All your data should be held securely. You have the right to access your records and to have any factual inaccuracies corrected.

### ***Key messages***

- Your healthcare team actively participates in public health surveillance. Information about you is submitted electronically to Public Health England. You cannot be identified from these data, and they are used in confidence.
- If your doctor wants to share information about you with someone else (other than for public health surveillance), for example, for research purposes, then they must tell you clearly what it will be used for and ask your permission to use it.
- You have the right to access your records and to have any factual inaccuracies corrected.

## Glossary of terms and abbreviations

Here is a list of common terms and abbreviations used in these Standards. The 2018 Standards has a more complete list in Appendix 3.

### **Advocate:**

a person who helps guide a patient through the health or social care systems and makes sure their rights are being upheld.

### **Audit:**

a process used to find out if healthcare is being provided in line with agreed standards. It lets patients and providers know where their service is doing well, and where there could be improvements.

### **BHIVA:**

British HIV Association ([www.bhiva.org](http://www.bhiva.org)). BHIVA is a UK association representing professionals in HIV care. It publishes a range of clinical guidelines, covering the treatment and management of HIV and associated illnesses.

### **BHIVA guidelines:**

these are produced for use by healthcare professionals and others for the management of all aspects of HIV care in the UK. They are the starting point for individualised care. They are evidence-based, developed by independent committees with membership that includes knowledgeable professionals, and people living with HIV. All BHIVA guidelines are NICE accredited. Some are available in non-technical form.

### **CHIVA:**

Children's HIV Association (<https://www.chiva.org.uk>). CHIVA works to ensure young people living with HIV have the treatment and care, knowledge, understanding, skills and wider support needed to live well and achieve their greatest potential.

### **Drug interaction (sometimes drug–drug interaction, or DDI)**

You might not get the correct dose when drugs interact with each other. ARVs may interact with other drugs you might be taking. These other drugs might be prescribed from your GP, or other specialists, to treat other conditions. They could also be other drugs you might buy from a pharmacy or chemist. And they include supplements or recreational drugs. You might get an increased or reduced dose of any of the drugs involved. This means you might not get the correct dose of your ARV, which could lead to increased levels of virus in your blood. Or you might not get the right treatment for your other condition. So this can be very serious. You should check with your HIV doctor and GP if you're planning to take any drug as well as your ARVs.

### **Formula milk:**

formula milk, also known as baby formula or infant formula, is usually made from cows' milk that has been treated to make it more suitable for babies. There's a wide range of brands and types of formula available in pharmacies and shops. It comes in two different forms: a dry powder you make up with water, or a ready-to-feed liquid formula. Formula milk has zero risk of transmitting HIV to your baby.

**HIV:**

human immunodeficiency virus.

**HPV:**

human papilloma virus. These are viruses that cause warts and there are lots of different types. They are also responsible for cervical cancer, anal cancer and some other cancers. The virus that causes HPV infection is transmitted through skin-to-skin contact. It can be contracted during unprotected anal, vaginal or, rarely, oral sex. It's so common that most sexually active people will get some variety of it at some point, even if they have few sexual partners. Many people have HPV and don't even know it. It's possible to have multiple types of HPV.

**HRT:**

hormone replacement therapy (HRT) is a treatment to relieve symptoms of the menopause. It replaces hormones that are at a lower level as you approach the menopause. HRT is now referred to as menopause hormone therapy (MHT). It should be made available to women living with HIV in the same way that it is for anyone else. It is usually provided through your GP, but expert advice from your HIV care team is needed to avoid any potential drug interaction with your ART.

**Hepatitis:**

this is the term used to describe inflammation of the liver. It's usually the result of a viral infection or liver damage caused by drinking alcohol. There are several different types of viral hepatitis. Some types will pass without any serious problems, while others can be long-lasting (chronic) and cause serious health problems.

**Hepatitis A (or hep A):**

this is caused by the hepatitis A virus. It's easy to pass on during sex or get from contaminated food and water. Nearly everyone makes a full recovery. A vaccine is available.

**Hepatitis B (or hep B, or HBV):**

this is caused by a virus that infects the liver. It's easy to pass on during sex or by sharing injecting equipment. Most people who get it make a full recovery, but for some, it can be more serious. A vaccine is available.

**Hepatitis C (or hep C, or HCV):**

this is the most common type of viral hepatitis. It's caused by a blood-borne virus that attacks the liver and is easily spread by sharing drug injecting equipment. It can also be spread through sex. Without treatment, the virus can cause liver disease that, over a long period, can be fatal. Most people will be offered a 12-week course of tablets with few side effects and a high cure rate. There is no vaccine against hepatitis C.

**Home sampling:**

this is where you collect a sample of blood, or moisture from your mouth, but then send it away for testing. You will then usually receive the results of the test some days later. If the result is reactive (positive), then this will need to be confirmed by a further test in an HIV clinic.

**Home testing:**

this is where you collect a sample of blood, or of moisture from your mouth, and test it. You perform the whole test yourself. After a few minutes, you read and interpret your own test result. If the result is reactive (positive), then this will need to be confirmed by a further test in an HIV clinic.

**IPV:**

intimate partner violence. This is sometimes called domestic violence and is usually violence from a current or former spouse or partner.

**Individualised (or personalised) care:**

this involves a whole-system approach, integrating services around the person by involving health, social care, public health and other issues. It is based on 'what matters' to the individual, and their individual strengths and needs.

**NICE:**

the National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care. They provide guidance, advice, quality standards and information services for health, public health and social care. They also have resources to help maximise use of evidence and guidance.

**Pneumonia:**

pneumonia is swelling (inflammation) of the tissue in one or both lungs. It's usually caused by a bacterial infection.

**Preventative vaccine:**

this is given to someone who is free of the targeted infection. By introducing a part of the virus (or bacterium) or an inactive virus (which acts like a decoy) into the body, the immune system reacts by producing antibodies. If, years later, you are exposed to this virus, these antibodies will recognise and destroy it, preventing infection. There are many preventative vaccines, for example, for hepatitis A, hepatitis B, HPV and many more. There is no preventative vaccine for HIV.

**Self-sampling:**

this is where you collect a small blood sample yourself and send it off for analysis. You should get a result in a few days.

**UK-CAB:**

this is a network for people living with HIV who have a strong interest in HIV treatment and related issues, and who want to make sure people living with HIV are actively involved in all aspects of HIV treatment and care. This is called treatment advocacy.

**Viral load:**

this is the term used to describe the amount of HIV in your blood. The more HIV there is in your blood (and therefore the higher your viral load), the greater your risk of becoming ill because of HIV. All viral load tests have a cut-off point below which they cannot reliably detect HIV. If your viral load is below 50, it is usually said to be undetectable. Although there are more sensitive tests that can measure viral load to even lower levels, anything less than 50 is still called 'undetectable'.

## Further information

There is a lot of information on the web, but not all of it is accurate! It is best to rely on trusted sources of reliable information. Here are some sites that we know are trustworthy and up-to-date:

**1. HIV i-Base** – <https://i-base.info>

HIV i-Base is a treatment activist group that provides timely and up to date information about HIV and its treatment. This includes technical and non-technical publications (all available online, many in other languages) on a wide range of HIV-related topics, and a Q&A service (by phone, email and online). All resources are produced by and with the involvement of people living with HIV and are reviewed by a medical advisory group.

**2. NAM** – <https://www.aidsmap.com>

NAM also provides independent, accurate, accessible and comprehensive information about HIV. As well as detailed news items, NAM has a range of easy-to-read items on all aspects of HIV and its treatment, and related issues.

**3. National AIDS Trust (NAT)** – <https://www.nat.org.uk>

NAT focuses on HIV policy in the UK, and champions the rights of people living with HIV. They consider issues such as employment rights; immigration and asylum issues; discrimination; social care; and many more.

**4. Terence Higgins Trust (THT)** – <https://www.tht.org.uk>

THT is the UK's best-known HIV and sexual health charity. They support people living with HIV in a number of ways - by providing local services in some areas, as well as nationally online. They also run a phone helpline, THT Direct.

**5. Positively UK** – <https://positivelyuk.org>

Positively UK provides peer-led support, advocacy and information to everyone living with HIV to effectively manage any aspect of their diagnosis, care and life with HIV. They are strong advocates of peer support. Peer support is a relationship in which people see each other as equal partners and where the focus is on mutual learning and growth.

**6. NHS** – <https://www.nhs.uk>

The NHS encourages people to engage with their health, care and wellbeing so they can stay healthy and help manage any long-term health conditions. They provide thousands of clinically validated articles, videos and tools to improve people's experience of the NHS and help people make the best choices about their health, care and wellbeing.

**7. The UK Community Advisory Board (UK-CAB)** – <http://www.ukcab.net>

The UK-CAB is a network for people who are interested in, and **advocates** for, HIV treatment and care in the UK. It has over 900 members, from over 120 HIV support organisations in the UK. As well as running HIV training and holding regular meetings with HIV clinicians, researchers and pharmaceutical companies, the UK-CAB also has a Members Online Forum, where issues can be shared and discussed. The UK-CAB is free to join and open to individuals, whether or not you are linked to an HIV organisation.

## Some thank you's...

It has been a pleasure and a privilege for Ann and me to co-chair this project, ably assisted by our Project Facilitator, Memory. We have already expressed our thanks to all those involved in the Acknowledgements, without listing names. But there are some who deserve a special thank you...



**Ben Cromarty**  
UK-CAB  
Co-chair



**Ann Sullivan**  
Chelsea and Westminster  
Co-chair



**Memory Sachikonye**  
UK-CAB  
Project Facilitator

We are extremely grateful for the time and energy generously given by the Steering Group for this project:

**Members;** Fiona Burns – University College London. David Chadwick – James Cook Hospital. Paul Clift – UK-CAB. Cheryl Gower – NAT. Alison Howarth – University College London. Rebecca Mbewe – UK-CAB. Sheila Morris – NHS Lothian. Angelina Namiba – UK-CAB. Laura Waters – Central and NW London Foundation Trust.

**Secretariat;** Medivents.

We also extend our thanks to all those on the 2018 Standards writing groups who reviewed all the material, and to all the others “behind the scenes” who helped us make this project come together.

There is more information about the need for this Guide, and how it was produced, on two posters (in pdf form). They can be found in the Downloads section of the Guide website <https://standards.bhiva.org>

But perhaps the biggest thanks go to the writer group, all from the community, who really made this guide possible!

*Thank you!*



**Ben Cromarty**  
UK-CAB



**Roy Trevelion**  
UK-CAB



**Rebecca Mbewe**  
UK-CAB



Supported by



