#### UK guide to PrEP





### **10th edition**

February 2024



Easier access: anyone who can benefit from PrEP can access it.

Event-based PrEP for all: using either 2:1:1 or 2:7 dosing.

Quick-start PrEP: an option for everyone - starting with a doubledose protects within two hours.

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\*This guide is dedicated to our inspirational co-author Dr Mags Portman who was a leading advocate for PrEP in the UK. Mags died from mesothelioma in February 2019 aged 44 and we miss her deeply.

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### **Changes to this edition**

This updated edition includes new options that make PrEP easier to access and to take. The changes are based on new research about how PrEP works.

- Everyone who can benefit from PrEP should now be able to get it. You no longer have to be at high risk.
- Everyone now has the option to quick-start PrEP using a double first dose (two pills), working within two hours.
- Event-based dosing can also now be used by everyone. This uses either 2:1:1 or 2:7 dosing.
- New info covers starting and stopping PrEP and new versions of PrEP (TAF/FTC and injectables).
- UK guidelines in 2024 might include additional recommendations that could make PrEP even easier. This includes that people who currently need 6-7 daily doses a week might only need 4 or more.

## **Getting PrEP in the UK**

## **PrEP** is now available free from sexual health clinics across the UK. It can also still be bought online.

These sites have more information, including on how to find a sexual health clinic by postcode.

Scotland: www.prep.scot

Wales: www.shwales.online/wales-prep-project.html

Northern Ireland: www.rainbow-project.org/prep

**England:** www.nhs.uk/service-search/other-services/HIV-testing/LocationSearch/418

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### What is PrEP: first questions

#### What is PrEP?

#### **PrEP stands for Pre-Exposure Prophylaxis.**

PrEP is taken before sex, so it is pre-exposure. But it also needs to be taken afterwards too. Prophylaxis means to prevent infection. More than 86,000 people in the UK already use PrEP.

PrEP usually contains two HIV drugs in a single pill. This is usually TD (tenofovir disoproxil) plus FTC. A version using TAF (tenofovir alafenamide) instead of TD is used by the NHS if you have kidney or bone issues. Generic TAF/FTC can also be bought cheaply online, see p11.

During 2024, PrEP using a 2-monthly inection of cabotegravir is being assessed for approval in the UK. Studies are also ongoing using a 6-monthly injection of lenacapavir.

#### Who can take PrEP?

## Anyone who is HIV negative and who could benefit from PrEP should now be able to access it.

PrEP is especially important if you have used PEP, had a recent STI, have chemsex or have partners with these risks.

#### You do NOT need PrEP if you are HIV negative and...

- You are happy and able to always use condoms.
- You only have sex with HIV positive people who are on HIV treatment and who have an undetectable viral load.
- You don't use condoms but your partner is low risk.

#### How well does PrEP work?

## PrEP is more than 99% effective. There are very few infections when PrEP is taken as prescribed.

These rare cases are usually because HIV was missed in the pre-test. Recent HIV infections (six weeks before the HIV test) are not always detected. This is why it is good to have another HIV test six weeks after either the most recent risk or after starting PrEP.

A small number of cases are because the HIV that someone was exposed to was already resistant to the drugs in PrEP.

#### **PrEP and side effects**

#### Most people taking PrEP do not get side effects.

However, like all medicines, some people might get some side effects. Mild nausea, diarrhoea, bloating and headache are reported in the first month by less than 1 in 10 people. These side effects then usually stop.

Occasionally, PrEP can cause more serious side effects that reduce kidney function and/or bone health. This is why kidney tests are needed when using oral PrEP.

Changes in bone structure are usually small and reverse after stopping TD/FTC. This is similar to a commonly used oral contraceptive but might be important if you are younger than 18 when bones are still developing. Bone strength was not fully reversed after a year in one study in adolescents aged 15 to 19.

PrEP does not increase the risk of bone fractures.

#### **PrEP and drug resistance**

#### The chance of drug resistance to PrEP is very low.

Firstly, resistance relates to HIV and not the person. So an HIV negative person can't be drug resistant.

Drug resistance is only a risk if you become HIV positive but don't yet know this. This is especially likely with low adherence, even though the risk is still low.

Drug resistance affects PrEP in two different ways, both of which are very rare.

#### 1. Drug resistance developing while taking PrEP.

- Starting PrEP without knowing that you are already HIV positive. This is why the HIV test before PrEP is essential. It is also why some people need to re-test after six weeks.
- Becoming HIV positive during a break from PrEP and not retesting before starting again.
- Missing too many PrEP doses, so that drug levels are too low to prevent HIV infection.

#### 2. Coming into contact with drug-resistant HIV.

- In this case the drug resistance will stop PrEP from working.
- Very few cases have been reported of PrEP not working because of drug-resistant HIV.

#### PrEP and sexually transmitted infections (STIs)

PrEP does not protect against other STIs. Condoms can help prevent many of these though.

Although STIs are mostly easy to treat, symptoms can sometimes be unpleasant and sometimes serious. This is why regular STI testing is recommended.

The HPV vaccine reduces the risk of genital warts and cervical and anal cancers. Please ask your clinic or GP about this. Your clinic should also provide vaccines for hepatitis A and B if needed, and for mpox.

#### Does PrEP interact with other medicines?

#### PrEP only interacts with a few other medicines.

But if you routinely take other prescribed or over-the-counter meds, always tell your doctor (including your GP) that you are taking PrEP. Any pharmacist can also check for drug interactions.

Tenofovir (TD) should also be used with caution if you regularly take other drugs that affect the kidneys. These include some non-steroidal anti-inflammatory drugs (NSAIDs), especially diclofenac, ibuprofen and naproxen.

Routinely taking these drugs with PrEP can cause kidney problems. Avoid these meds when taking PrEP and please let your doctor know if you regularly need to take them.

TAF can interact with TB meds, anti-epileptics, St John's Wort and others. These interactions are not a problem with TD.

PrEP is very safe for trans and non-binary people taking hormone therapy (see p10).

See: www.hiv-druginteractions.org/checker

## **PrEP for women**

#### Why should women take PrEP?

#### PrEP can be used by anyone worried about the risk of HIV. PrEP is a very effective way to stay HIV negative.

The highest risk of getting HIV is if you don't always use condoms with partners who do not know that they might be HIV positive. Or if a partner is not yet on HIV treatment (ART) or is not always taking their meds.



People living with HIV cannot pass on HIV if they have an undetectable viral load on ART.

#### Other reasons to consider PrEP

- · If you are worried about HIV.
- If condom use is difficult or impossible to negotiate.
- If you have sex for money, or receive gifts for sex.
- If your partner or partners might be at risk of HIV. For example, if your partner has other partners. Or if you or your partner(s) inject drugs and share injecting equipment.

#### **Dosing for women**

#### Please see p15 to 20 for ways women take PrEP.

This includes a new option to start with a double dose for rapid protection, and new information on daily, 2:1:1 and 2:7 dosing.

#### Contraception

## It is very safe to use PrEP with all hormonal contraception (ring, patch, the pill, injectable or an implant).

PrEP will not affect your contraception. And contraception will not affect PrEP.

#### Pregnancy

## If planning a pregnancy and not using barrier protection or condoms, daily PrEP can protect you from HIV.

But if you know that your partner is HIV positive, it is better for them to be on HIV treatment. If their viral load is undetectable, this will also protect you from HIV.

If you become pregnant while taking PrEP, continuing PrEP is still recommended but please also talk to your doctor.

#### **Breastfeeding and chestfeeding**

#### Oral PrEP is very safe if you breastfeed or chestfeed.

Outside the UK, many people living with HIV use the same meds as HIV treatment during breast and chest feeding.

Only very small amounts of FTC and TD are present in breast milk. These low levels are not harmful to your baby.

#### UK community websites on women and PrEP

womenandprep.org.uk prepster.info/prep4women

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## PrEP for trans and non-binary people

## PrEP is just as safe and effective for people who are transgender or non-binary as it is for cisgender people.

Dosing choices depend on the type of sex, although daily dosing has generally been recommended.

Anyone having receptive vaginal/frontal sex can quick-start with a double dose (two pills). This works in two hours rather than the old advice to take daily PrEP for 7 days before sex.

After sex, take daily PrEP (one pill) for seven days. For daily PrEP, current guidelines recommend at least six daily doses a week. This might be reduced in the 2024 UK guidelines.

Anyone having insertive or receptive anal sex or insertive vaginal/frontal sex can use 2:1:1 event-based dosing. Event-based dosing using 2:7 dosing is recommended for receptive vaginal/frontal sex. Please see p15 to 20.

PrEP is very safe with hormone treatment. Even though you might worry about drug interactions, neither your hormone or PrEP levels will be affected. Liverpool University produce an excellent guide to drug interactions between hormone treatments and other HIV meds:

www.hiv-druginteractions.org/printable\_charts

Ongoing studies are looking at other aspects of PrEP in trans women and men.

**CliniQ** (cliniq.org.uk) is a London-based specialist clinic providing sexual health and well-being services for trans people. The **56T clinic** (dean.st/trans-non-binary) at 56 Dean Street in London also has PrEP services.

Other trans clinics include **Clinic T** in Brighton (https:// brightonsexualhealth.com/service/clinic-t) and **Indigo Gender Service** in Manchester (www.indigogenderservice.uk).

### **PrEP and sex work**

## PrEP can be used for any job in the sex industry including porn.

Many sex workers look after their sexual health but their clients might not. PrEP will protect against HIV if you are pressured to not use condoms. Use specialised services that are free from stigma and judgement. See: www.uglymugs.org

## **Buying PrEP in the UK**

It is perfectly legal to buy PrEP online, if this is for personal use. Personal use is defined as up to three months of daily PrEP.

Prices for online TD/FTC range from about  $\pounds 20$  to  $\pounds 40 + \text{post}$  for 30 tablets. TAF/FTC is similar or a little more expensive.

Generic PrEP contains the same meds as brand products but is made by different companies. For example, TD/FTC from NHS clinics will always be generic.

This FDA listing includes approved versions to check if you are buying PrEP online:

www.fda.gov/InternationalPrograms/PEPFAR/ucm119231.htm

Sometimes buying PrEP online means it might take a while for the drugs to arrive. It is best to order at least a month in advance.

You need a combined pill that contains both tenofovir (TD, TDF or TAF) and FTC (emtricitabine). For example, you need Tenvir-EM or Ricovir-EM rather than just Tenvir or Ricovir.

Several UK community websites have information about how and where to buy PrEP online.

iwantprepnow.co.uk

prepster.info

i-base.info/qa/category/prep

Some clinics will support you and provide advice and testing if you buy PrEP online. However, the NHS is only responsible for meds that it supplies.

## **Before you start PrEP**

First, please talk to a health adviser, nurse, doctor or community worker. These people can help you if you want to start PrEP, or are already taking it.

Then it is essential to have an HIV test before or as you start.

If you are already HIV positive and don't realise it, you could develop drug resistance.

Ask for a 4th generation HIV blood test. This is also called an antigen/antibody test. This will tell you if you have HIV so long as you haven't had other risks in the last six weeks.

Most finger prick tests are currently 3rd generation. This test needs 2-3 months to show a positive result. Don't rely on a finger prick test before PrEP if you have a more recent risk.

If you are just starting PrEP and had a risk in the last six weeks, have another 4th generation HIV test six weeks after starting. This is to be sure an early infection is not missed.

Be careful about starting PrEP if you have flu-like symptoms *and* had a recent HIV risk. This is in case these symptoms are related to a recent HIV infection.

If you are starting PrEP after PEP, it is best to start straight away if you need to. Ideally you should have a 4th generation HIV test after you finish PEP/start PrEP. Then have another test six weeks after starting PrEP.

#### **Check your kidneys**

A kidney test just involves a blood test for creatinine. This should ideally be done just before or on the day you start. Some clinics might still test for protein in a urine sample.

#### Check for other sexually transmitted infections (STIs)

Testing for HIV and STIs is a great idea for anyone with an active sex life. This is whether you use PrEP or not.

#### Hepatitis B (hep B, HBV)

## Testing for hep B is essential. This is because PrEP meds are active against both HIV and HBV.

This is a good time to have this vaccine, or to boost a previous vaccine. Please ask your clinic about this.

People with hep B need to take PrEP every day, with medical advice, especially if you want to stop.

Stopping PrEP can lead to rapid inflammation in the liver.

This can be very serious. It can lead to hospitalisation and in rare cases can be fatal.

## Care if you have already started PrEP

Once you have started PrEP, monitoring is just as important. If you are currently using PrEP and have not been monitored, talk to the clinic about doing this now.

#### **Every 3-4 months**

- Have a 4th generation HIV blood test. This is also called an antigen/antibody (Ag/Ab) HIV blood test.
- · Have a full screen for other STIs.
- An additional blood test for kidney function (creatinine) might be needed every six months. This is if you are older than 40 or are at risk of kidney problems. Abnormal kidney results might need monitoring more often.
- Some clinics are now happy for PrEP users to alternate quarterly monitoring between clinic visits and self-sampling postal kits.
- Some clinics might arrange for six-monthly prescriptions for PrEP.

#### **Every 12 months**

- Have a blood test to check your kidney function.
- Test for hepatitis C if you are having sex with gay men. Some clinics do this more frequently depending on risk.

Testing might also be individualised if you are not having sex very often.

### How to start and stop oral PrEP

#### Starting

Everyone now has the option to start oral PrEP using a double dose (two pills) for the first dose BEFORE sex. This gives protection within two hours.

#### Continuing

Daily dosing then involves continuing with a single pill every day at roughly the same time.

For daily PrEP, current guidelines recommend at least six daily doses a week. Although studies suggest fewer weekly doses might be okay, it is not yet clear if this will be included in the 2024 guidelines update.

But if you stop PrEP for a week, please restart using a double dose and take seven daily post-sex doses that week.

#### Stopping

If you are using event-based dosing, continue daily dosing for either another two days (2:1:1 dosing) or seven days (2:7 dosing). See pages 17 to 20.

Before stopping daily dosing, please continue for either two or seven days after you last had sex. This depends on how you are dosing PrEP. See p16 and 17.

#### TAF and TD

TAF/FTC can be dosed the same way as TD/FTC. Although there is less data on vaginal and neovaginal sex this should still be okay.

### **Daily PrEP**

#### Most PrEP studies have used daily PrEP.

Taking PrEP every day makes sure that there are protective drug levels 24 hours a day, 7 days a week, even if you don't have sex. This means you can have sex anytime, without planning for PrEP.

If you generally have sex every week, daily PrEP might be an easier routine. After the first week, daily dosing needs at least 6-7 doses a week (unless you can use 2:1:1 dosing).

Guidelines later in 2024 might recommend less strict adherence. This could make PrEP easier for women and trans and non-binary people.

- Quick-start daily dosing using a double dose (two pills) for the first dose. This will protect you within two hours. The predose is important for the highest protection. But if you miss or are late with the pre-dose, start with a double dose as soon as possible.
- Once on PrEP, continue taking daily PrEP for at least six days each week. This might change when guidelines are updated.
- There is currently no data about neovaginal sex. Starting with a double dose and then using daily dosing is therefore a conservative recommendation.

### **Event-based PrEP**

## Event-based dosing involves only using PrEP when you want to have sex.

Start with a double dose (two pills) at least two hours before you are going to have sex. However, instead of continuing to take daily PrEP you only continue for either two or seven days – depending on the type of sex you have.

**Event-based dosing** is just as effective as daily PrEP. It is often used by people who have sex less often than once a week and who usually know when they might be likely to have sex.

Event-based dosing needs fewer pills, but it can't be used if you have hepatitis B.

**2:1:1 dosing** involves starting with a double dose and then taking daily PrEP for two days after sex. Each dose should be roughly 24 hours after the previous one.

2:1:1 dosing can be used by anyone for anal sex (if you are the insertive or receptive partner) or insertive vaginal/frontal sex. It can not be used for receptive vaginal/frontal sex.

**2:7 dosing** involves starting with a double dose and then taking daily PrEP for **seven** days after sex. Each dose should be roughly 24 hours after the previous one.

2:7 dosing needs to be used by cis women and trans and nonbinary people who are having receptive vaginal/frontal sex.

The pre-dose is important for the highest protection when using event-based dosing. But if you miss or are late with the pre-dose, start with a double dose as soon as you can.

### **Event-based 2:1:1 dosing: sex once**

2:1:1 dosing can be used by anyone having insertive sex or receptive anal sex.



## If you might have sex on Thursday take a double dose at least two hours before you have sex.

Then take a single pill for the next **two** days. This should be roughly 24 hours and 48 hours after the first double dose.

These times can be approximate. You still get good protection even if you have sex earlier or later than planned. **Even if the pre-dose is only just before or even after sex, some PrEP is always better than none.** 

If you have sex several times over a few days, keep taking a pill each day. Continue for two days after the last day that you have sex.

### Event-based 2:1:1 dosing: more sex!

If you have sex over a few days, keep taking a pill each day. Continue for two days after the last day you have sex.



If you have sex over several days continue to take a single pill every day you have sex at around the same time.

Then after you stop having sex, take daily PrEP for the next two days.

If you start PrEP but then don't have sex – and you have no plans to have sex – there is no need to keep taking PrEP.

### **Event-based 2:7 dosing (first week)**

2:7 dosing is sometimes needed by cis women and trans and non-binary people having receptive vaginal/frontal sex.



If you are a cisgender woman, or are transgender or nonbinary, having receptive vaginal or frontal sex might need daily PrEP to continue for seven days.

## This is for situations when you didn't take at least four doses of PrEP the previous week.

Start with a double dose before sex and then take daily PrEP for **seven** days after sex, at roughly the same time each day.

### Other tips on how to take PrEP

#### What to do if you miss a pill on daily PrEP

## If you are taking daily PrEP, then do not worry if you sometimes miss one or two pills.

Everyone taking daily PrEP will get good protection so long as you take at least four pills every week.

#### What to do if you miss a pill on event-based PrEP

Event-based dosing really needs all the recommended doses.

If you are late or miss a pill, just take it as soon as you remember and then continue as recommended.

Drug levels will still be high enough to protect against HIV. If you often miss doses perhaps it would be better for you to use daily dosing.

Everyone should now start PrEP with a double dose.

- A pill box makes it easy to see if you missed a dose.
- Aim for the same time each day. Link it to a routine task like brushing your teeth.
- If you have risks during a break from PrEP, remember to also have another HIV test.
- With event-based dosing, if you miss the BEFORE dose, still take a double dose asap AFTER sex, and continue single daily doses. Contact your clinic in case PEP is recommended (see p22).

#### Can I switch between daily and event-based dosing?

#### PrEP dosing is very easy to change.

PrEP can adapt to your needs at different times. You can stop and restart PrEP, or change the way you take it.

Talk to your clinic about ways of taking PrEP and about how to stop or restart when you need to.

See pages 15 to 20 about daily and event-based dosing.

#### Having active hepatitis B needs daily PrEP, every day.

Stopping PrEP can lead to rapid inflammation in the liver.

This can be very serious. It can lead to hospitalisation and in rare cases can be fatal.

#### Is PEP recommended if I am on PrEP?

PEP stands for post-exposure prophylaxis and involves taking a combination of three HIV meds for one month.

PEP is now used less often. But if you need PEP, the earlier you start, the more likely it is to work.

#### Ideally, PEP should be started within 24 hours.

In the UK PEP can be started up to 72 hours after sex.

There is no benefit from starting PEP after more than 72 hours.

 If you have a risk when you haven't been taking PrEP, or enough PrEP, contact a doctor to discuss whether you might need PEP.

- Take a double dose of PrEP asap (if you still have some). This will cover you while you are trying to access PEP.
- You can get PEP from your clinic or from A&E when your clinic is closed. A&E departments are open 24 hours a day, 7 days a week.

#### Can I stop PrEP completely?

## As with the flexibility for dosing, you might decide that you want to stop PrEP altogether.

Please discuss this with your clinic.

You might want to discuss this with your partner(s) and get tested for HIV and other STIs together. Use a 4th generation HIV test six weeks after the last time you had sex.

How you stop PrEP depends on how you were taking PrEP.

#### If you were taking daily PrEP, then continue for seven days.

# If you were using event-based dosing then stop after your last planned dose. This will be after two days with 2:1:1 dosing or seven days with 2:7 dosing.

It is always easy to restart PrEP in the future if your circumstances change again.

If you stop PrEP and have a risk afterwards, please contact your clinic. This is in case you need post-exposure prophylaxis (PEP). Outside of clinic hours, please contact A&E.

PEP needs to be started as soon as possible (see p22).

### **Credits and further information**

This leaflet was produced by doctors and community advocates from the following organisations.

BASHH (SIG MSM)	www.bashh.org
HIV i-Base	i-base.info/prep
iwantprepnow.co.uk	iwantprepnow.co.uk
PrEPster.info	PrEPster.info
56 Dean Street	www.dean.st
Mortimer Market Centre	tinyurl.com/3s4th3cc
cliniQ: sexual health for trans people cliniq.org.uk	
Sophia Forum	sophiaforum.net

Further information:

PrEP in Scotland PrEP in Wales PrEP in N. Ireland IMPACT trial Drug interactions PrEP guidelines HPV vaccine for gay men

www.prep.scot tinyurl.com/v4d5796z rainbow-project.org/prep prepimpacttrial.org.uk hiv-druginteractions.org bashh.org and bhiva.org i-base.info/htb/31151

