

i-Base

publications & information services for people living with HIV

2017

“All HIV positive people should have clear information to be able to make informed choices about our health care and treatment.”

For HIV positive people this needs to be easy to read and up to date.

We also need to know that our doctors and other health workers have the latest information...





Introduction

Since April 2000, i-Base has become a leading and trusted independent source of information about the latest HIV treatments.

During 2016 i-Base:

- Distributed more than 60,000 free leaflets and booklets to NHS clinics.
- Sent 5,000 technical bulletins every two months to doctors and health workers.
- Answered more than 5,800 direct Q&A treatment questions – by phone, email and online, on any aspect of treatment.
- Had more than 4,400,000 hits to the easy-to-access i-Base website, including from nearly every country in the world.
- Developed community involvement in research with the UK-CAB network of 850 advocates and treatment activist in the UK.

NEW

pocket ART



More than 50,000 of these new compact leaflets, will be distributed free to UK clinics in 2017.

- Bright and colourful pocket-size versions of key i-Base treatment guides.
- Free, including in bulk to UK clinics.
- Simple language.
- Short weblinks for more information.

First produced in 2015 for the Introduction to ART and the pregnancy guide, these small leaflets are easy to read introductions to HIV and treatment.

Each pocket guide summarises the most important points for each topic - with short URL weblinks for more information.

i-base.info/pocket-guides

i-Base treatment guides

i-Base guides use easy language to provide information on the most important treatment topics.

- Starting treatment
- Changing treatment
- Side effects & long-term health
- Having a baby
- HCV coinfection
- PrEP in the UK
- HIV testing and transmission

All publications are easy to read and use plain and direct English.

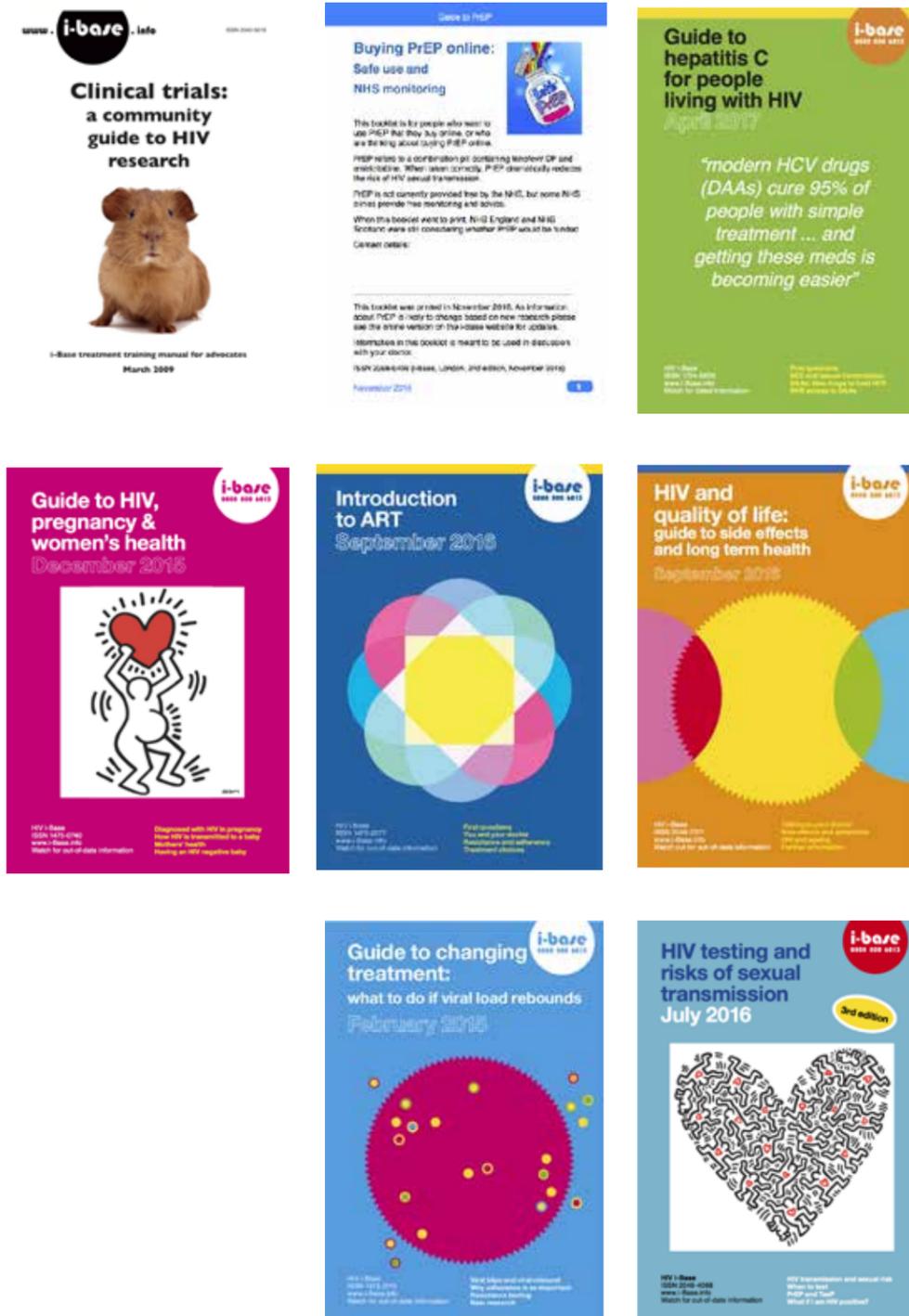
Guides are available in PDF and print format and are published online as html pages.

Print versions have always been free. In 2016, 60,000 guides were distributed free to UK clinics.

All guides are regularly updated.

Since 2000, we have distributed more than 600,000 free booklets to NHS clinics.

These guides have been frequently commended or highly commended in the annual BMA patient information awards.



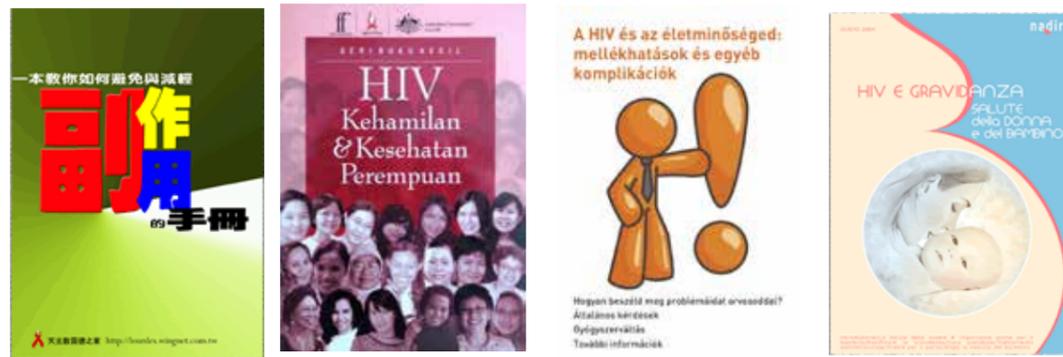
translations



More than 100 i-Base publications have been translated into over 35 languages.



These languages include Albanian, Arabic, Bosnian, Bulgarian, Chinese, Croatian, Czech, Estonian, French, Georgian, Greek, Hindi, Hungarian, Indonesian, Italian, Kosovan, Latvian, Macedonian, Montenegrin, Nepalese, Polish, Portuguese, Romanian, Russian, Serbian, Slovak, Slovenian, Spanish and Turkish.

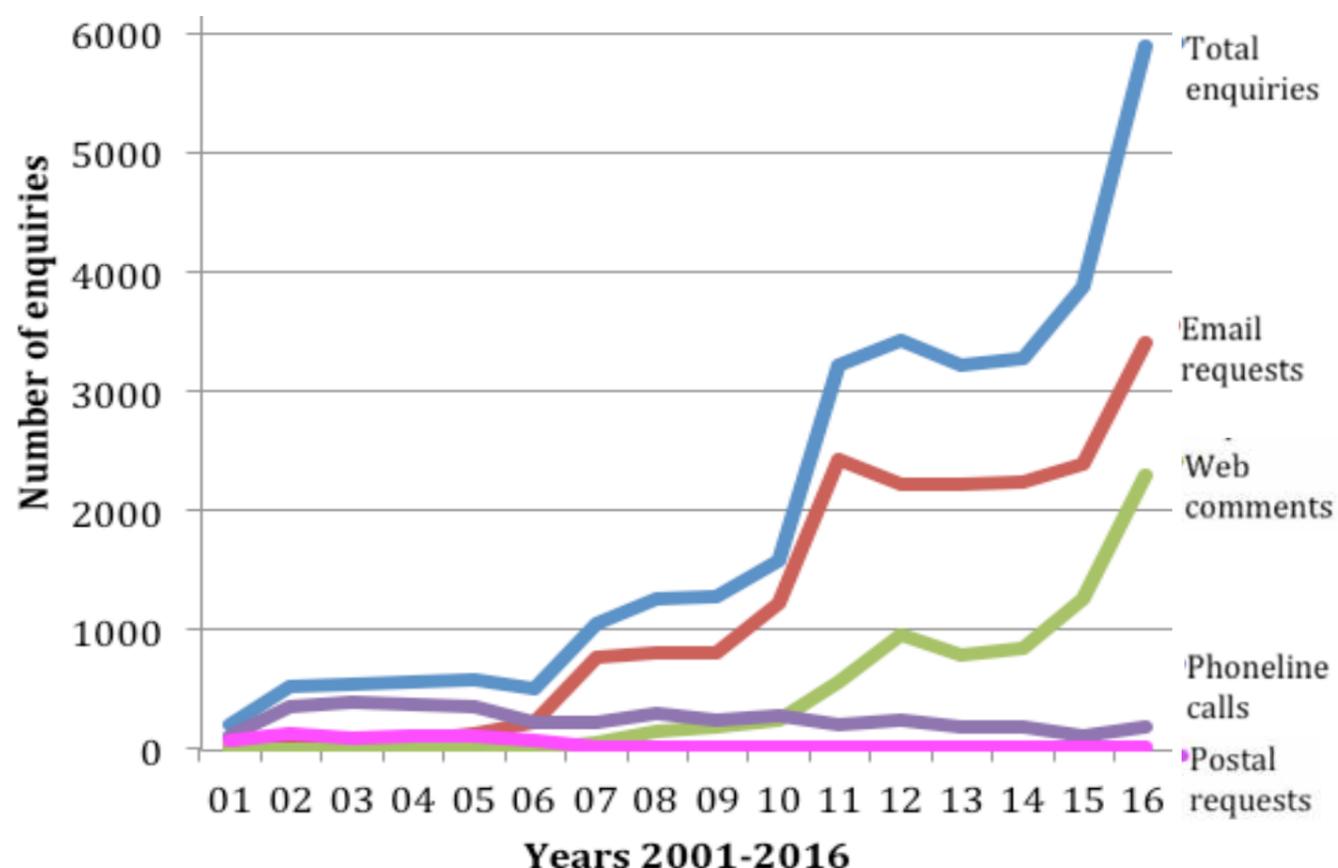


By making all resources copyright-free and working collaboratively with similar activist organisations internationally, i-Base resources have reached hundreds of thousands of HIV positive people globally.



A few covers from more than 100 translations of i-Base treatment guides.

Treatment Information Service 2001-2016



Summary of individual annual requests 2011-2016

Year	Phone	Email	Web comment	Total
2016	175	3419	2300	5894
2015	112	2410	1263	3785
2014	174	2260	850	3284
2013	192	2237	800	3229
2012	231	2225	965	3421
2011	193	2448	577	3218
Total	1077	14,999	6755	22831

i-Base runs a unique Q&A service.

Anyone can ask any HIV-related treatment question, from anywhere in the world.

Individual answers from advocates are usually within two working days.

Demand for this service has increased each year but dramatically increased in the last two years.

The services have also moved to being largely electronically-based: online, by email and SMS.

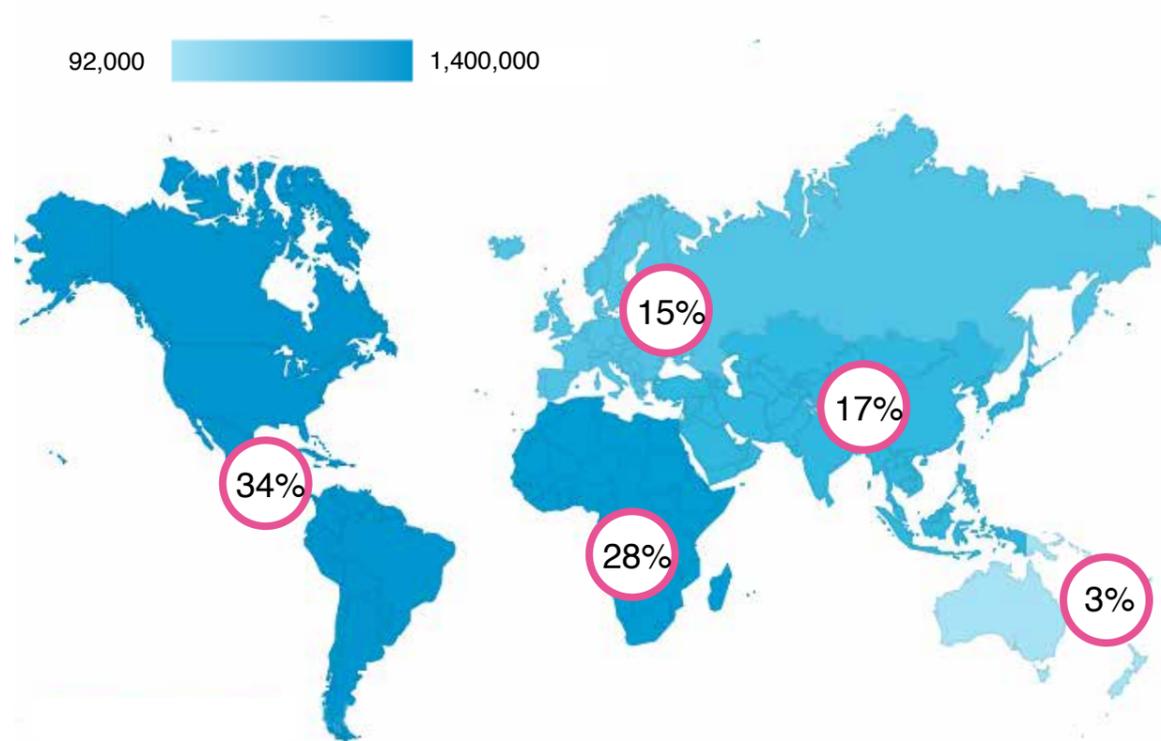
The online database now has more than 3000 Q&A answers which have generated a further 7000 comments, also all answered individually.

Over the last six years, i-Base have answered more than 22,000 questions.

During 2016, we answered 3,419 email questions, 2,300 website comments and 175 phone enquiries.

A summary of the service was presented as an oral presentation at the BHIVA 2016 conference.

i-Base website data (Google analytics)



Website use by region (2016)

Region	Sessions	% of total
Americas (North, South & Central, including the Caribbean)	1,408,888	34%
Africa	1,291,885	28%
South Asia and East Asia	827,809	17%
UK, Europe and Central Asia	659,401	15%
Australia/NZ	92,022	3%
Location not set	102,910	3%
Total	4,382,915	100%

Top 12 countries: Jan to March 2017

Country	Sessions	~ % of overall total
United States	326,641	25%
South Africa	269,472	21%
India	133,936	11%
UK	118,874	10%
Kenya	35,370	3%
Nigeria	34,432	3%
Canada	30,116	3%
Philippines	27,890	2%
Australia	23,103	2%
Malaysia	14,310	1%
Singapore	11,907	1%
Zimbabwe	10,298	1%
Total (from 10 countries)	1,036,349	84%
Total	1,271,108	100%

Every month, more than 400,000 people use the i-Base website, from more than 230 countries.

The site is designed to be fast to access and easy to navigate.

- In the first three months of 2017, more than 1.2 million people accessed the i-Base website.
- During 2016, the website was used more than 4,380,000 times.
- All publications are published online, as html web pages and in PDF format.
- Approximately 90% of use is from outside the UK. But the UK is the fourth highest user, showing we are both a national and international resource.
- Data from 2016 showed wide global use: 34% from the Americas, 28% from Africa, 17% from South and East Asia and 15% from Europe and Central Asia.
- The top 12 countries account for 84% of web traffic, with highest use from the US, South Africa, India and the UK.
- Demand has increased dramatically - by more than 300% between 2014 to 2016.
- The site has been accessed by people from 233 of the world's 241 countries and territories.

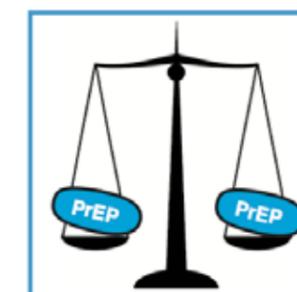
Annual increases in website use

2016	4,382,915
2015	2,785,757
2014	1,323,629
2013	700,993
2012	621,000

i-Base has been working for years to make PrEP available in the UK.

This has included collaborating with community groups, researchers and doctors to increase awareness and access.

- * Last year, i-Base produced the first PrEP booklets for NHS clinics - produced with doctors, researchers and community advocates.
- During 2016-17 we will have distributed more than 20,000 free PrEP booklets and 14,000 free PrEP leaflets.
- We worked closely with the UK PROUD study to ensure the best evidence would support NHS approval. This included collaborating on participant leaflets and working with the study investigators.
- i-Base provided pill boxes for the PROUD study, to help improve adherence, when several workshops showed this was a problem.
- We are actively involved in raising the profile of PrEP in community demonstrations for access.
- We reported all early PrEP studies, including those that led to approval of PrEP in the US and continue to report research into better drugs.



Guide to PrEP

**Buying PrEP online:
Safe use and
NHS monitoring**



This booklet is for people who use PrEP that they buy online, or are thinking about buying PrEP. PrEP refers to a combination pill of emtricitabine. When taken correctly, it reduces the risk of HIV sexual transmission. PrEP is not currently provided in NHS clinics provide free monitoring and support. When this booklet went to print, Scotland were still considering whether to provide PrEP. Contact details:

This booklet was printed in November 2016. Information about PrEP is likely to change but you can see the online version on the i-Base website.

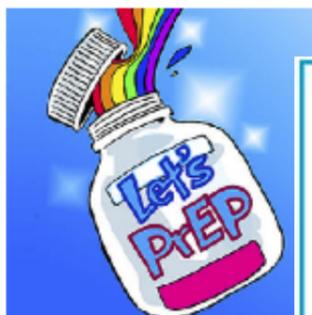
Information in this booklet is meant to be used with your doctor.

ISSN 2398-6409 (i-Base, London, UK)

November 2016

Pocket size

**PrEP:
a UK guide**



March 2017

<p>World Health Organization</p> <p>PrEP Reduces HIV risk by close to 100% if taken daily.</p>	<p>No PrEP 6000 new HIV diagnoses every year for 10 years.</p>
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UK-CAB is a network of HIV treatment advocates. UK-CAB works to ensure that people living with HIV in the UK have a meaningful role in shaping treatment research, policy and practice.

**UK-
CAB**

The UK-CAB now has more than 850 members who represent the diverse communities affected by HIV.

The educational programme is developed to strengthen treatment literacy across the UK.

The UK-CAB network enables a democratic process for community representation on research groups and national guidelines committees.

- An online forum connects all members.
- Quarterly CAB meetings provide a formal space for the community to meet with drug research companies and independent investigators. All materials and reports are posted online as an open community resource.
- The CAB works with BHIVA to enable greater community involvement in national treatment guidelines and for the programme of national conferences.
- The third residential training course will be held later in 2017, supported by lottery funding.

Advocates from i-Base are currently or recently involved with the following research studies.

ASTRA large cross-sectional questionnaire study about HIV treatment, lifestyle and transmission in HIV positive people in the UK.

AURAH large cross sectional questionnaire study similar to ASTRA but in HIV negative people attending sexual health clinics in the UK.

CHERUB UK collaboration of researchers working on aspects of HIV cure research that includes the REACH and RIVER studies.

CIPHER an ASTRA sub-study on cognitive function and brain-related disorders.

COBRA collaborative EU research on HIV and ageing.

D:A:D the largest prospective international database study looking at side effects of HIV drugs and impact of other complications.

PENTA European network of paediatric HIV trials.

HALL social science research looking at issues of HIV in later life.

HIPvac randomised study comparing approaches including a vaccine to treating genital warts, predominantly in HIV negative adults.

HIV Drug Resistance Database - Ongoing database that now has more than 125,000 resistance test sequences collected in the UK since 2001. This research resource answers important questions on drug resistance.

INSIGHT group including the START study - see below.

PANTHEON programme of research into cost-effectiveness of strategies including self-testing to reduce HIV transmission (SELPHI study).

LEAP - Long-Acting Extended Release ARV Resource Programme

PARTNER and PARTNER2 risk of HIV transmission in sero-different couples where the HIV positive partner is taking HIV meds and has an undetectable viral load – and who do not always use condoms. PARTNER reported zero HIV transmissions after couples in the study had sex more than 58,000 times without condoms. PARTNER2 continues in gay men.

POPPY UK study on HIV and ageing.

PROUD UK PrEP study using daily oral tenofovir/FTC to prevent HIV infection in HIV negative gay men and transgender women.

RIVER trying to reduce the latently infected viral reservoir in people who were recently infected. This study related to cure research involves a treatment interruption.

START a large international randomised study looking at when to start HIV treatment based on CD4 counts above 500 or waiting to 350. Results showed that ART can reduce serious HIV-related illnesses even at high CD4 counts and led to changes in treatment guidelines to routinely recommended ART for all.

SUPA interventional option to help adherence.

TAILoR randomised study looking at use of telmisartan and insulin resistance in HIV positive people.

UK-CHIC prospective database that includes anonymised medical history from over 45,000 HIV positive people in the UK.

UK Seroconverters Register prospective UK cohort of people diagnosed within a year of infection.

In addition to the UK-CAB, individual advocates at i-Base work with more than 20 current research groups.

Many of the related studies are based both in the UK and internationally.

- In addition to the study groups opposite, individual advocates from i-Base are on the writing groups for UK (BHIVA) and European (EACS and PENTA) guideline writing groups.
- We are included in advisory meetings for WHO guidelines and developed a leading role in research into treatment optimisation for low- and middle-income countries (LMIC).
- i-Base advocates are involved as community representatives in UK regional and national commissioning.
- The majority of this work is based on volunteer positions.



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