

40 Years: An HIV positive perspective



23 June 2021



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www.i-Base.info



The Worshipful
Society of
Apothecaries

Disclosure

No personal financial conflict of interest



Andrew, Andy B, Andy C, Chris M, Chris P, Richard, Chris W, Space,
Nick, Dolly, Wesley, Colvin, Jimi, Kevin, Mike, Paul, Mark, Steve.

Background

- Nothing about HIV was expected.
- The 80s were a lively time.
- Dynamic political and social times.
- No-one expected to become a patient: Expert or not.



Overview: positive history

- Expert patients and peer support...
- Denver principles - community engagement
- HIV+ representation: trials, guidelines and services.
- Treatment information for different people

Becoming active

- HIV+ people - we had the most to gain - and most to lose from our treatment.
- Actively engaging, sharing 'patient-led' decisions.
- CD4 count, acronyms (CMV, KS, MAC, PCP, PML), then viral load and drug resistance and adherence. Always a choice.

‘Active’ rather than ‘expert’

I made bad and good decisions:

- 3TC monotherapy on EAP - just wrong.
- Stopping nuke monotherapy - just luck.
- First person to stop CMV meds at CD4 100 (skill of Dr Suzanne Mitchell).

Being active means accepting responsibility for decisions for being right at the time.

Denver principles (1983)

- Document that put HIV+ at the centre of care - and responsibility.



- Supported by gay activists (Dr Joe Sonnabend and Dr Marcus Conant).

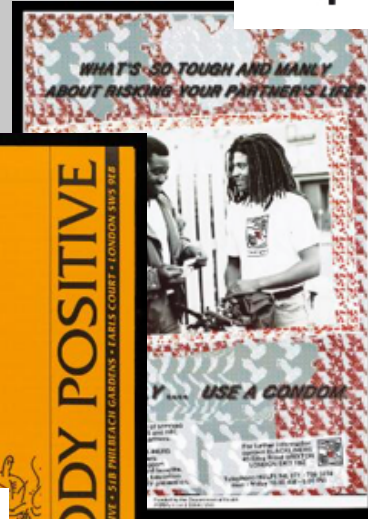
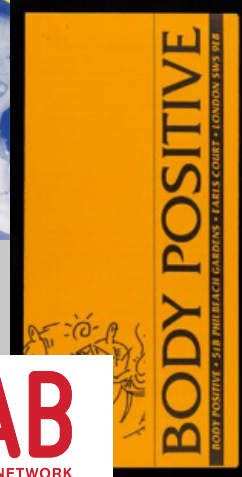
<https://i-base.info/qa/factsheets/the-denver-principles-1983>

Denver principles (1983)

- Self empowerment, rights, dignity, respect.
- Involvement in all decisions about care, including treatment (or not).
- Language: “People living with HIV/AIDS”.
- Also responsibilities.

<https://i-base.info/qa/factsheets/the-denver-principles-1983>

Peer-led community organisations



Community resources



Body Positive, Positive Times, DrFax, ATP, Positive Nation.

Peer support

- Early info about ART - does it work?
Are there side effects?
- Phone calls changed when
HIV status became clear.
- Benefits from working outside NHS.
- Early side effects (body changes), choice
of PIs, d4T, New-Fill.



AIDS Treatment
Project

ATP and DrFax

AIDS Treatment Project (ATP) 1996-2000.

Led by people with experience of ART.

DrFax, edited by Paul Blanchard – faxed critical research news to doctors every two weeks.

Most other HIV organisations in the UK were at best cautious and at worst were actively hostile to new drugs.



Community representation

BHIVA guidelines - Community now included at all levels of BHIVA and on all guidelines.

MRC and other research – first plans, on all committees, including DSMBs.

Commissioning services.

Meaningful involvement (MIPA)

UK-CAB

ukcab.net

Now >700 advocates.

70% HIV+

Founded in 2002.

Focus treatment issues.

Four training meetings a year (now over 70 are online).



Community goals

- Focus on better treatment.

Early access (EAP). Including price and choice.

- Five years wait after AZT for a second drug.

- 1997 - 20+ pills a day

2007 - Atripla - 3-in-1 (*note: Cipla 2003*)

2021 - 10 x single pill combinations

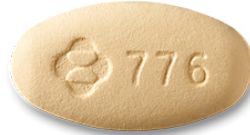
10 x single pill combinations



Atripla,



Biktarvy,



Delstrigo,



Dovato,



Eviplera,



Juluca,



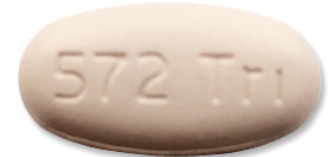
Odefsey,



Stribild,



Symtuza,



Triumeq

Early ART issues

- Triple > dual > monotherapy.
- Triple ART during pregnancy to reduce transmission.
- Goal of undetectable viral load to avoid resistance.
- Increased doses for children.
- Use more effective meds first.



Other timeline examples

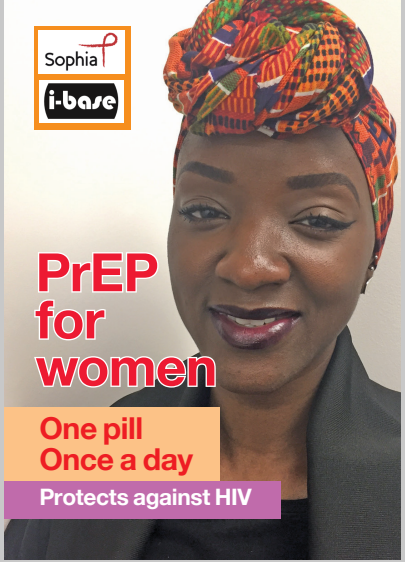
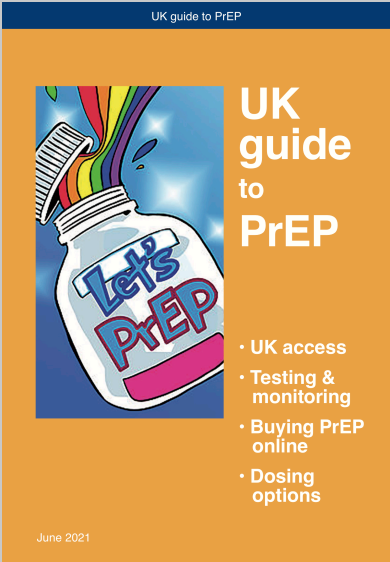
- 1981 - 1995+ viral load shows continuous viral replication - rather than 10 year period of latency.
- 1995 - PrEP with TDF pre/post infection protected macaques from HIV - PrEP approved 2012.
- 1998 - US DHHS guidelines include early ART to reduce HIV transmission. 2008 Swiss Statement. PARTNER 2014. U=U 2016/7.
- 2000 - "ART is not for Africa" - Cipla generics, 3x5 to 24 million...

Treatment guides from 2000 - 2020

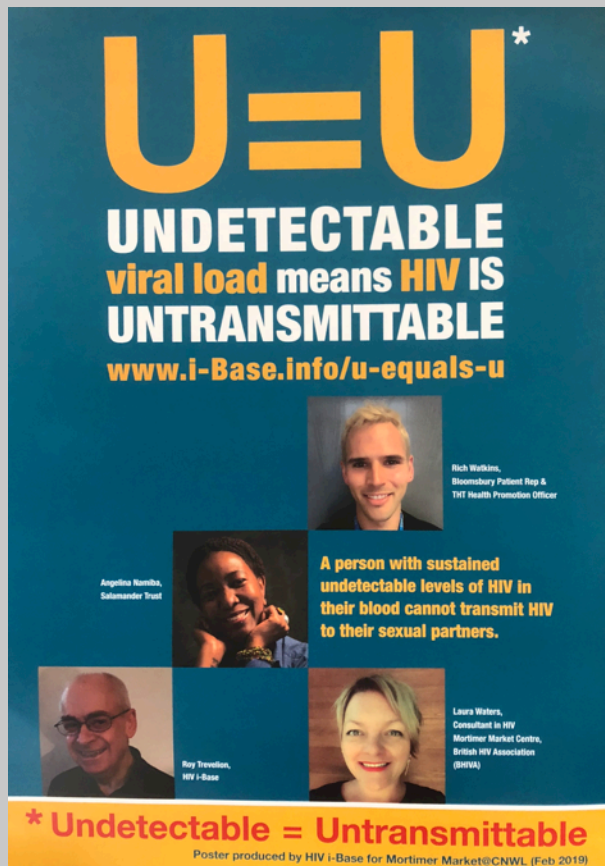




Recent resources on PreP



Posters
individualised
for different
clinics



U=U*

UNDETECTABLE
viral load means **HIV IS**
UNTRANSMITTABLE

www.i-Base.info/u-equals-u

Rich Watkins,
Bloomsbury Patient Rep &
THT Health Promotion Officer

Angeline Namiba,
Salamander Trust

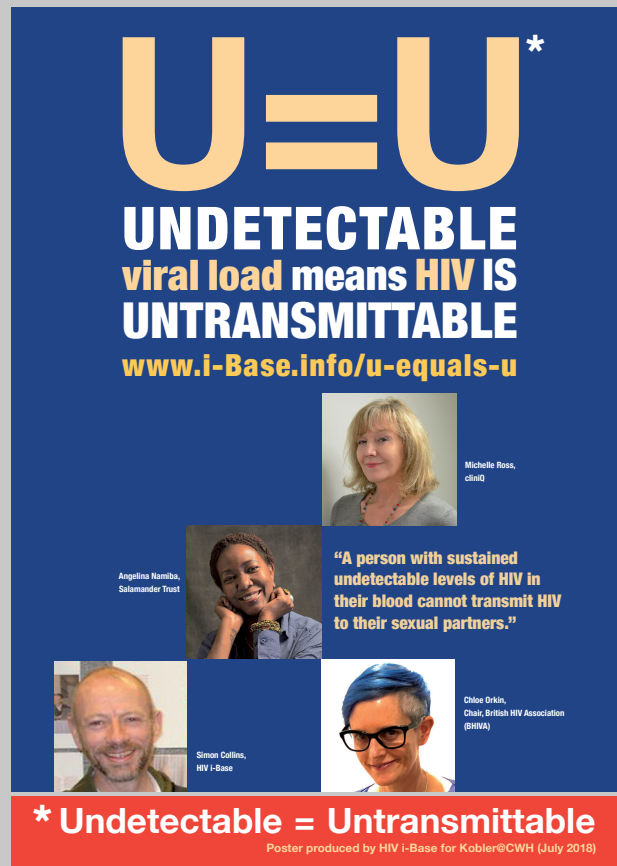
**A person with sustained
undetectable levels of HIV in
their blood cannot transmit HIV
to their sexual partners.**

Ray Trevillion,
HIV i-Base

Leana Walters,
Consultant in HIV
Mortimer Market Centre,
British HIV Association
(BHIVA)

*** Undetectable = Untransmittable**

Poster produced by HIV i-Base for Mortimer Market@CNWL (Feb 2019)



U=U*

UNDETECTABLE
viral load means **HIV IS**
UNTRANSMITTABLE

www.i-Base.info/u-equals-u

Michelle Ross,
cnn

Angeline Namiba,
Salamander Trust

**"A person with sustained
undetectable levels of HIV in
their blood cannot transmit HIV
to their sexual partners."**

Simon Collins,
HIV i-Base

Chloe Orkin,
Chair, British HIV Association
(BHIVA)

*** Undetectable = Untransmittable**

Poster produced by HIV i-Base for Kobler@CWH (July 2018)

Looking forward to zero

- Fast Track Cities in the UK works closely with many different HIV communities.
- They are optimistic targets and times.
- London at 95%, 98% and 97% was unthinkable a few years ago.
- The FTC campaign keeps HIV awareness.

For 2030, watch new PrEP for zero transmissions.

Zero preventable deaths and stigma are more difficult.

Thank you

Questions?

www.i-Base.info

A vertical poster for i-base. The background is light blue with a large white pill shape in the center. The pill has an orange band around its middle. The text 'i-base' is in white at the top left, with 'HIV treatment information service' below it. To the right of the pill, it says 'Calls are free from land lines and most mobile networks. All calls are confidential.' Below the pill, it says 'ASK A QUESTION by phone, email or online' followed by the phone number '0808 800 6013', the email 'questions@i-base.org.uk', and the website 'www.i-base.info'. At the bottom, a small blue bar contains a yellow circle icon and the text 'Information to be used in discussion with your doctor. Registered charity no: 1081905.' There are several small colored circles (yellow, green, pink) scattered around the pill shape.

i-base
HIV treatment
information
service

Calls are free from
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www.i-base.info

Information to be used in discussion with your doctor. Registered charity no: 1081905.

Summary and thanks

- Different 40-year histories will come from every country and groups of people affected by HIV.
- All community strength has been with dynamic support from nurses, doctors and researchers who were happy to teach us.
- Many medical professionals - doctors, researcher, chemists, drug companies - are all driven by similar activist goals to overcome HIV.

Back-up slides

Evidence 2015

- START Study: benefits of ART at any CD4 count.
- Generated date for universal global access to treatment

Evidence 2014, 2016, 2018

<http://i-base.info/htb/32308>

PARTNER 1 ^[6] & PARTNER 2 ^[7]

ZERO after 53,000 times – gay
and straight - no condoms

ZERO after 77,000 times - gay
men only – no condoms

[undetectable below 200 c/mL]

6. Rodgers A et al. CROI 2014 and JAMA 2016; 7. Rodgers A et al, IAS 2018 and



The PARTNER 2 Study

Partners of people on ART: a New Evaluation of the Risks

HIV positive with a negative partner?
HIV negative with a positive partner?

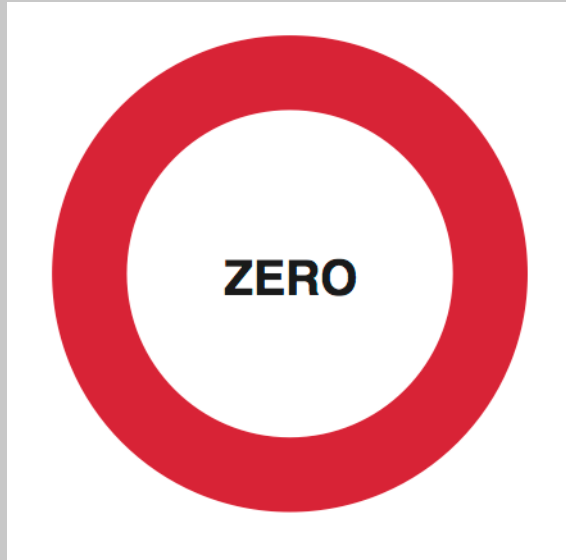
A study is looking at the impact HIV treatment has on reducing the risk of HIV transmission. While everyone wants to know these risks, there are hardly any accurate studies.

The PARTNER study is looking for couples where one partner is HIV negative and the other is HIV positive and on treatment. The study will also look at the different patterns of condom use. All information from the study will be anonymised and will be in confidence.

 PARTNER

www.chip.dk/partner

PARTNER studies



PARTNER 1: zero transmissions after gay and straight couples had sex more than 56,000 times ^[1]

PARTNER 2: zero transmissions after gay couples had sex more than 77,000 times ^[2]

1. Rodgers A et al. CROI 2014 and JAMA 2016; 2. Rodgers A et al, IAS 2018 and The Lancet, 2019.

Adapting resources

- Other histories from every country and groups of people affected by HIV.
- All community strength has been with dynamic support from doctors and researchers who were happy to teach us.
- Many medical professionals - doctors, researcher, chemists, drug companies - are all driven by similar activist goals to overcome HIV.

U=U

Undetectable = Untransmittable

Did you know that having an undetectable viral load on HIV treatment (ART) stops HIV transmission?

ART is not only good for your health – it also protects your partners if they are negative.

U=U means that you don't need to use condoms if you were only using them to stop HIV transmission.

Leading UK doctors and researchers strongly support the U=U statement.

"A person with sustained, undetectable levels of HIV in their blood cannot transmit HIV to their sexual partners."



Professor Chloe Orkin,
Chair, British HIV Association

UK guidelines state that HIV doctors should talk to all their patients about how ART stops transmission.

What is U=U?

U=U stands for:

Undetectable = Untransmittable

It means that someone with an undetectable HIV viral load on ART cannot transmit HIV, even without using condoms or PrEP.

What does U=U involve?

The protection from ART depends on:

- Taking ART to get an undetectable viral load. In the UK this means less than 50 copies/mL.
- Continuing to take your meds to keep your viral load undetectable.

How can U=U not be a risk?

This is because when viral load is undetectable in blood there is too little HIV in sexual fluids for transmission to occur.

May 2019

www.i-Base.info/u-equals-u

U=U *

**UNDETECTABLE
viral load means HIV IS
UNTRANSMITTABLE**

* Undetectable = Untransmittable

Free leaflets,
postcards, to
clinics and
online:
i-Base.info

www.i-Base.info

U=U
undetectable
viral load
=
untransmittable
HIV



Tsai C-C et al, Science 1995

Daily weight-based daily PMPA (tenofovir) SC for one month in 35 macaques inoculated IV with SIV (10 x 50% infectious dose): 5 arms, follow up 40-56 weeks.

Dose	Day started	n	% infected
20mg/kg	48 hrs pre	n=5	0
30mg/kg	48 hrs pre	n=10	0
30mg/kg	4 hrs post	n=5	0
30mg/kg	24 hrs post	n=5	0
Control	48 hrs pre	n=10	100

1. Tsai C-C et al, Prevention of SIV Infection in Macaques by (R)-9-(2-Phosphonylmethoxypropyl)adenine. Science 1995. (NIH funded).