## Features of U=U and how to communicate and spread U=U



Simon Collins HIV i-Base

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U=U symposium, Tokyo, 2020



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### Overview

- Introduction and i-Base
- U=U evidence timeline
- Professional responses in the UK
- Community responses in the UK

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I would like to thank the Japanese Society for AIDS Research for the honour of invitation to speak at this important and timely meeting

Talk is from a perspective of a community advocate for the last 20+ years.

As an introduction I will say a little about my organization and recent work.

I will briefly outline the evidence that convinced me to support U=U.

And I will talk about the different community and professional ways that U=U has been adopted in the UK

### **HIV in the UK (2019)**

- 102,000 HIV+ (population: 66m)
- 92% dx, 98% on ART, 97% <50 c/mL.</li>
- Free testing, monitoring and treatment.

• Good surveillance data: Public Health England – annual 'HIV in the UK' reports.



• Late diagnosis still a problem (43% <350; 23% <200): linked to 50% of deaths. Black African, people who inject drugs, gay men 31%.

 Mental health, depression/anxiety (50% vs 25%) transgender, PWID and haemophilia), financial, loneliness, stigma.

Public Health England. https://www.gov.uk/government/publications/hiv-in-the-united-kingdom

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Approximately 102,000 people in the UK are HIV positive – out of a population of 66 million

94,000 are diagnosed (92%). Of these 98% are on ART and 97% are undetectable.

New diagnoses significantly fell over the last two years: combination of more frequent testing, early and universal ART, better ART and access to PrEP.

More clinics routinely start same-day ART – within a few days. Confirmatory HIV testing is not needed because false positive is so rare and viral load and resistance test results with be back within 1-2 weeks. Reduces loss to care.

Universal ART based on results from START study.

Late diagnosis is still a problem.

### **Combination prevention**

- 4,300 new diagnoses in 2018: significant drop for last two years.
- Regular testing, more often.

 'Same-day' ART (within few days) – becoming routine/expected for most people – but some still want more time.



· Confirmatory tests not needed (covered by VL, and resistance tests).

Universal ART including >500 CD4 based on evidence of clinical benefits shown in START study in 2015.

PrEP

Public Health England. https://www.gov.uk/government/publications/hiv-in-the-united-kingdom

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### i-Base.info

- Peer advocate/activist project.
- Latest treatment information.
- Q&A service: email, phone, online.
- Free booklets & leaflets.
- UK-CAB: link to research.
- Website: Google "evidence for U=U"

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ABT #

hiv

Although I have been a treatment activist for more that 20 years, I didn't have a formal medical training. Instead I was able to learn from support groups, community publications, writing and attending conferences - and also with the support of many earlier activists, doctors and researchers who have helped support community engagement.

i-Base produces HIV Treatment Bulletin - a review for doctors every 3-4 weeks.

We also produce patient booklets and leaflets that are distributed free to NHS clinics.

We run an open access Q&A service for any treatment related question – getting about 12,000 questions a year, 90% from outside the UK.

We also set up a community advisory board – the UK-CAB – to link community advocates to researchers and clinical guidelines etc

And a website – curently the first hit if you Google U=U...



These are examples of i-Base services and resources publications and a free information phoneline and Q&A service.

### **Historical caution...**

- Personal cautious approach until there was best evidence: no-one else should become positive.
- Many transmission factors: behaviour, viral load, genetics, luck, genital tract viral load, STIs etc.
- Rare transmissions might occur.
- Community representative on PARTNER study.
- Now fully endorse and support U=U and advocate for new evidence to be widely known.

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My own background to U=U has also been very cautious – as a community activist I don't want any one else to become HIV positive. It took me time to get to this position. I wasn't the first to sign U=U.

My advocacy training meant that I was worried that that in some rare circumstances might occur.

For example, if someone was genetically susceptible to HIV infection, AND their partner had detectable viral load in their genital compartment AND with high behavioural risk – long duration of sex without a condom – AND with an STI etc.

This was why we needed the best quality research to QUANTIFY any risk, however low.

In 2009 – I joined the PARTNER Study as a community representative.

I am now very happy to fully endorse and support U=U – and more strongly – work to actively ensure the new scientific evidence is widely

know.



NEJM 2011; 6. Rodgers A et al. CROI 2014 and JAMA 2016; 7. Rodgers A et al, IAS 2018 and The Lancet, 2019.

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A summary of the evidence is also probably useful as the plausibility of ART reduced the risk of transmission has been known for more than two decades.

The 1998 US DHHS treatment guidelines recommended early ART to reduce risks to partners back in 1998 – also Karen Beckerman's poster at IAS Conference in Geneva.

The Rakai cohort in Uganda in heterosexual couples before effective ART reported no transmissions between when viral load was < 400.

In 2008 the Swiss Statement suggested risk was zero based on evidence review of smaller studies - but also because they worked closely with the sperm-washing clinics and had samples from more than 600 serodifferent couples trying to conceive. The PARTNER study was planned to provide evidence to support the Swiss Statement.

HPTN-052 – again in serodifferent couples – reported only one transmission in the first weeks of ART when viral load would still have been high and detectable.

Then the large international PARTNER studies produced a large dataset showing the absence of transmission – in a study designed to actively look for such cases.

PARTNER 2 extended and expanded the number of gay male participants – where sexual risk form anal sex is highest – with zero transmissions after more than 77,000 sexual exposures.

The U=U campaign changed everything: from a scientific agenda to a mainstream public health campaign on an international stage. It is remarkable that within just a few years, it is now unthinkable to go back to pre-U=U time.



It is worth reporting the top line results from PARTNER again.

I was involved in this study – as one of the community representatives on the steering committee – the people in the poster were participants.

Everything was translated – leaflets, posters, website info into all languages.

The PARTNER studies produced the strongest real world dataset.

These observational studies included gay and straight couples, tracked real exposures/risk, included STIs and low level blips (is <200 c/mL) and still couldn't find a single linked transmission.

HIV positive people volunteered to be in the publicity.



I included this slide to show how much work was involved over 9 years of the PARTNER study.

The green line for the the target was always above the red line the actual enrolment – and this was a study that I thought would have enrolled overnight.

In some months only a few couples enrolled. For nine years we had monthly calls tracking enrollment – extending the study several times – first to get adequate power and then to balance data for gay to straight couples.

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These observational studies tracked tracked real exposures/risk, included STIs and low level blips (is <200 c/mL) and still couldn't find a single linked transmission.

### **Reverse challenge**

- Data now reverses the scientific challenge: Anyone suggesting transmission is possible should now provide evidence to support this hypothesis.
- No cases 11 years after the Swiss Statement.
- No cases in >100,000 events in PARTNER.

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The accumulated data supporting U=U now reverses the scientific challenge.

Anyone with a hypothesis that transmission might still occur with an undetectable viral load now faces a challenge to provide evidence to support this.

There is currently none – including the absence of case reports in the 11 years since the Swiss Statement.

The rest of my talk will look at was that we communicated this in the UK

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As confidence grew in U=U it was quickly clear that this was something that needed to be widely publicised.

Community groups provided an early lead.

But the lead taken by professional organisations was equally essential.

U=U needed to be a clearly communicatied by all doctors to all patients.



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In 2017, Professor Chloe Orkin, the chair of the British HIV Association – the largest professional organisation, largely of treating HIV doctors, pharmacists and researchers - made a clear and unequivocal statement.

This providing leadership for health workers.



### **BHIVA & community**

- Professional organization for doctors
- Community actively engaged.
  - 20+ UK-CAB on all guideline writing groups.
  - steering committee and all working groups.
  - programme conference sessions.
- Now close partnership.

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I also mentioned the importance of treatment guidelines and in April 2018 the BHIVA Standards of Care included U-U throughout.

These standards cover eight areas of essential aspects of HIV care.

It emphasised all doctors should talk to all patients – not just selected 'good' patients.



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### BHIVA survey, Oct 2018

- Prompted by low patient awareness.
- Online doctors survey, n=270
- Also prompted by the impact the information had for people to reconnect socially, without fear of being a risk.

1. Gupta N et al. 25th BHIVA Conference 2019, U=U preconference meeting.

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However, throughout 2018 there was concern that many HIV positive people were still not aware of U=U, either rbecasue they hadn't heard about it, were uncertain if it was true, or hadn't been told about by their doctor.

Some doctors were also very moved when they realized the impact this information had on a person – enabling them to reconnect with society to to think about having relationships again.

This lead to a short internet survey of BHIVA members – with 270 people responding during 2018.

### BHIVA survey, 2018

" Are you sure? Is it really true?"

"Until now I haven't been able to date because of HIV... I can now go back to my life."

"My patient cried when I told her about this news."

1. Gupta N et al. 25th BHIVA Conference 2019, U=U preconference meeting.

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The doctor who developed the survey had been personally surprised at how the information affected her patients.





### When do you discuss U=U (tick all that apply)

	%	No.	Gupta N et al.
On diagnosis	69%	172	25th BHIVA Conference 2019, U=U preconference meeting.
After getting undetectable	47%	122	
When someone is adherent	38%	98	
Only when asked about it	2.7%	7	
I don't usually discuss U=U	2.3%	6	N=255
I routinely talk about U=U	71%	182	
When starting ART	55%	141	
When planning a baby	47%	122	
Other	11%	30	

Gupta N et al. 25th BHIVA Conference 2019, U=U preconference meeting.

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One question asked when doctors discussed U=U with their patients.

The range included on diagnosis, before treatment, and if wanting to conceive - but 5% of doctors never routinely discussed U=U

### Which words do you use?



Gupta N et al. 25th BHIVA Conference 2019, U=U preconference meeting.

**British HIV Association** 

вн

N=253

### Survey identified where additional support could be useful for doctors – adding confidence for direct language,

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Most importantly. asking which words were used though showed a larger difference of confidence from these doctors.

Back in 2018, only 37% were confident to say zero risk.

Without realsing it many doctors hadn't realised how the other terms worked mainly to emphasis doubt.



### BHIVA survey, Oct 2018

Important to talk about the evidence for U=U? Always 60%; sometimes 35%, never 5%.

### Important of information in the clinic? Always 35%, sometimes 25%, rarely 10%, never 30%

Gupta N et al. 25th BHIVA Conference 2019, U=U preconference meeting.

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Two other Q's from the survey are worth reporting

1. That discussing the actual evidence was as important for many doctors as just giving the final conclusion,

As a peer advocate – people always appreciate the final advice if they understand the evidence.

1. That only a minority of clinics had support materials, such as posters and leaflets.



### BHIVA U=U statement, 30 Nov 2018

- Universal promotion of U=U
- All doctors to all patients –throughout care diagnosis, ART, annual review etc.
- Clear, unambiguous, consistent language: <u>"no risk</u>" or "zero risk" NOT "negligible" or "minimal".
- Display posters, leaflets in clinics

https://www.bhiva.org/BHIVA-encourages-universal-promotion-of-U-U

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Results from the survey also contributed to an expanded BHIVA statement about U=U for World AIDS Day in 2018

### **UK community**

- Early support for U=U campaign.
- All media: print, social media, internet, Pride events, public transport, schools.
- Trainings advocates and health workers.
- Using real people not models.
- Also remember than not everyone is <50</li>

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The next few slides show some of the diversity of community responses are shown over the next few slides

Some campaigns were national and other local.

Many emphasised the importance of HIV positive visibility – with real people in the videos and photographs

Many used public events like gay pride

Others included examples of mainstream non-HIV forums – especially to tackle stigma and discrimination.





THT is the largest and best know HIV-based charity - now focused on sexual health.

The first THT "cant pass it on' campaign was launched in Summer 2017 for Pride in London and used on social media – and continued each year in 2018 and 2019



Later campaigns used more diverse images and included billboards with online videos.



HIV Scotland had a similar campaign in Scotland to raise awareness in gay bars and at Gay Pride.

### Brighton: "Making stigma history"

- Martin Fisher
- Foundation.
- Brighton Pride.



- · Online video cartoons and interviews.
- U=U on local buses.
- Training with Sussex Beacon, and case worker

https://www.themartinfisherfoundation.org

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In 2018, the Martin Fisher Foundation launched the Making HIV Stigma History campaign based on U=U. It included a series of short online films.

Thsi included a high proflie at Brighton Pride in 2019.

In August 2019 in collaboration with the Brighton and Hove Bus company, had a double decker bus wrapped inside and out with images and information about HIV. On the rear of the bus is U=U which is also explained inside the bus. This bus will be travelling routes all over Brighton for as long as the bus lasts.

The Sussex Beacon runs courses at the Beacon and in business premises on HIV awareness and central to the educational course is the U=U message.

The Sussex Beacon

The Sussex Beacon has employed an HIV caseworker to work directly

with people in sussex living with HIV who are isolated. (its my job). I make a point of talking about U=U to every HIV positive person I encounter, to not only reinforce any knowledge they may have already heard, but not always taken in, but to explain to them that this message means that they have been unable to pass the virus on ever since they became undetectable. I feel really passionately about this as releases some guilt and shame that many of us have carried, unnecessarily for too long. I also push this message at clinicians and health care workers when ever I can. It is almost always, as one said, a "light bulb " moment. I think its important.



This is just because I like the photo and that U=U switching switch bus routes in Brighton

One side of the bus says :Towards zero HIV" and the other "HIV isn't scarey anymore".



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### **Positive Steps North West**

Campaign for gay men in the North West England including bars in Manchester and Liverpool, Pride events and local HIV STI clinics. Also lots of outreach discussions in residential training.

A4 + A3 posters beer mats, carrier bags, T-shirts, pens, stickers

http://www.positivestepsnw.info

www.i-base.info

<image>

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Positive Steps North West developed and delivered a U=U campaign during 2017/1 - funded from a National Lottery grant.

A key element of the campaign was to design and produce a range of promotional materials to inform and raise awareness of the U=U message including the evidence behind it. A number of

Positive steps NW members were involved in the design of range of materials for campaign for gay men in North West including bars in Manchester and Liverpool, Pride events and local HIV STI clinics. Also lots of outreach discussions.

A4 + A3 posters , beer mats, carrier bags, T-shirts, pens, stickers

We ran a residential weekend for members of our charity with workshops to explore their experience of HIV stigma and the impact it has on their lives. Included was a discussion around the importance of of disseminating the U=U message in order to change the outdated and stigmatising narrative about the risk from people with HIV. There was an opportunity to share ideas on how Positive Steps would use the campaign resources most effectively.

Successes:

- gay men living with HIV to share their experiences of HIV related stigma and the impact it has on their lives

- provide members of our charity with the latest U=U evidence.

- empowering for members of Positive Steps NW to be involved in the design and delivery of a campaign

-The campaign also provided us with an opportunity to discuss with clinicians and others working in GU the importance of disseminating the facts around U=U to their clients.

This was occasionally met with some resistance, but as Alan Spink says there was often a 'light bulb' moment after discussion and some have displayed our campaign posters in their clinics.

### **UK community: UK-CAB member**

• Positive Voice talks: U=U, PEP, PrEP to schools across the UK and Europe. Speaking publicly since my diagnosis in 1991. Sharing my story, including TED talks on stigma.

• In 2019 I spoke at 104 schools - approx 120 pupils per talk = 12,500-15,000 13-18 year olds in schools last year.



• I speak at 100-125 schools every year so in the last 5 years I would say approx 75,000 teenagers will have at least heard about U=U from my talk.

Emma Cole, Positive Voice for HIV Education https://www.positivevoice-emmacole.co.uk/media/

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Emma Cole is a heterosexual women who was diagnosed in 1991.

Speaking at more than 100 schools for each of the last five years means that more than 75,000 children have heard about U=U, PrEP and PEP.
#### UK community: UK-CAB member

by parents for parents

I try to target outside the HIV community.

Start threads to raise awareness: "U=U", "Getting back in the Saddle and HIV", "HIV testing" and "I'm HIVpos AMA" (ask me anything).

I'm 59, female hetero and diagnosed April 2017.

U=U awareness: Out of 508 responses, 62% did not know about U=U and 38% did.

https://www.mumsnet.com/Talk/am\_i\_being\_unreasonable/3631563-To-think-that-more-people-know-about-Undetectable-equals-Untransmittable-attempt-2

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Another UK-CAB member takes discussions out of the HIV sector to one of the largest online discussion - Mumsnet – advertised as "by parents for parents".

The survey with this post showed that most people had not heard about U=U and the discussions with hundreds of replies generated positive support.

#### **UK community: UK-CAB member**

Campaign in St Luke's Hospital, Bradford

- Not just posters, leaflets etc.
- Importance of good training.
- Talk to all staff and volunteers

   so there is high awareness
   throughout the hospital.



Damian Kelly, UK-CAB

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Positively UK run a peer mentoring training programme that has now trained more than 700 advocates.

U=U was included in all training sessions.

### UK – CAB member: Virginia Cucchi

Community gardens Planted U=U flower beds as part of 15 conferences or community workshops



"The participants were hugging each other at the end of the session. It was very, very emotional. U=U means a lot for all of us living with HIV even if we sometimes can't express it with words. Saying it with flowers works better." Virginia Cucchi, Seeds Project

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Another CAB member, Virginia Cucchi, runs the Seed Project and has planted U=U community gardens 0 with accompanying workshops on the theme of U=U for outreach discussions



Aidsmap – well known for conference news and other HIV news reports - signed U=U and produced a range of U=U graphics to use online linked to their online reports.

## **HIV Prevention England (HPE)**

 funded by Public Health England (PHE)

- All models HIV positive
- · Press and social media



https://hperesources.org.uk/

https://www.hivpreventionengland.org.uk/2019/04/16/new-i-cant-pass-on-hiv-resources/

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This campaign, funded by Public Health England also insisted on the importance or using real people not just models.



Finally, i-Base produced information online – search U=U for first hit – that were also printed as leaflets and postcards and available in bulk, free to all clinics

## i-base



What is U=U? How does U=U work? Will my doctor know about U=U? Do STIs affect U=U? What about blips? Translations: Arabic, French, German, Mandarin,

Polish, Portuguese, Romanian, Russian and Turkish – with community translators.

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These are a few of the questions in the leaflet – we used clear questions and clear answers.



i-Base also produced posters for clinics that cold be adapted to you doctors and advocates from each clinic.



GMFA is a long standing HIV prevention project

Recent campaigns include HIV positive men talking about treatment and U=U/  $\!\!\!$ 

This included a short (2 minute) video

# **Going forward**

- U=U impact on quality of life.
- It steadily reduces stigma.
- Both community and professional: diverse campaigns: social media, billboards, clinics, schools, bars and guidelines.
- Direct language, involve real people.
- Don't forget people with VL >50.

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In conclusion U=U can have a large positive impact on quality of life is for both HIV positive and HIV negative people.

It is nice to have a positive health message – and this is one of the best.

Diverse campaigns by and for different people.

Direct language - and involve people.

Finally – and important – is that not everyone will be undetectable. Some people will not be on treatment, some people for other reasons might be able to get and stay < 50.

Zero tolerance against any discrimination agains any HIV positive person.

### Thanks and questions

Hideta Nakamura.
Masazumi Yamaguchi.
Chlöe Orkin: BHIVA.
Yvonne Gileece: Brighton.
Tina Bruun, Jens Lundgren: PARTNER study.
Members of UK Community Advisory Board (UK-CAB).

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