

# poslink

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## U=U: Our work is not done



At this month's Positive Women Victoria's International Women's Day event, Executive Officer, Kirsty Machon spoke about the continuing challenges of secrecy, silence and fear for women living with HIV.

Despite the liberating potential of the U=U message, not all of us have access to the education, support and treatment that would see an end to the HIV epidemic anytime soon. In this edition of *Poslink*, our contributors offer different perspectives on what living in the age of U=U means to them and the varying levels of impact that HIV still has on the community more broadly.

## AN ADVOCACY ISSUE FOR US ALL

By *Kirsty Machon, Executive Officer, Positive Women Victoria*

In 2017, the news broke that major health organisations and bodies had reached consensus on a crucial issue for all people living with HIV. They agreed that if HIV is successfully treated, and a person living with HIV retains an undetectable viral load for at least six months, the risk of that person transmitting HIV to sexual partners is negligible to non-existent. Over 450 organisations from more than 65 countries have endorsed this statement.

Communities breathed a collective sigh of relief, and the U=U slogan and movement was born, capturing this moment on T-shirts, websites and apps. U=U is, for people living with HIV, an increasingly recognised global brand.

Breathing out is one thing, but to an extent, it might be said that the enormity of that simple statement, its magnitude for individuals and communities emerging from three decades of huge trauma and massive turbulence, has yet to sink in.

For women, I think this statement is particularly accurate, and I set out some of the reasons why I think this is so, and why our work is as yet unfinished when it comes to women.

**For a monumental historical moment, the U=U message, with all its liberating potential, passed seemingly without a ripple in the mainstream media. This lesson tells us something important about the power of what have probably been the greatest enablers of HIV throughout the epidemic: stigma, fear, homophobia and sexism.**

Last week, we celebrated International Women's Day alongside the National Day of Women Living with HIV on March 9. The theme of that day was *Women are Stronger Together*. That is certainly true. But the point that might be added is that communities also are stronger together. It is time for us to bring the whole of Australia along with the simple and uncontroversial message that HIV is treatable, that treatment prevents

transmission, and that it is in fact stigma and fear that are the two things that most stubbornly stand between this moment and the goal of effectively ending HIV.

Rates of new diagnoses are declining at record numbers among gay identified men and many men who have sex with men, due to the combined impact of improved treatment and interventions like PrEP and rapid testing. This is a huge achievement, and we salute the men and women living with HIV and their allies who fought a huge fight to bring this about.

Yet the facts are that despite this, rates of new diagnoses for women remain stable at around 10%, while rates of new diagnoses in heterosexual men are beginning to rise. Women, along with heterosexual men, continue to be at increased risk of being diagnosed later in infection, of not getting access to testing when they need it (even when they request it), and therefore of not accessing testing when they need it.

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For women who are living with HIV, stigma and a lack of understanding about HIV within the community, patchy knowledge about or understanding of HIV from health care workers not closely linked to HIV communities of care, and the persistence of stereotypes and myths about women living with HIV and what their lives are like, mean many women continue to live with HIV in secrecy, silence and fear.

Our work, then, is for the over 3,000 women living with HIV, and their families and friends, to be able to share in the moment of change, with all its possibilities.

While there continues to be widespread ignorance of the fact that undetectable HIV means that women living with HIV can have full sexual lives without the fear of transmission, our work is not done.

While couples in serodiscordant relationships can still appear in the media under headlines suggesting that the negative partner is literally taking their life in their hands by having sex with a person living with HIV, our work is not done.

While women continue to be diagnosed late, fear the consequences of that diagnosis for their future lives, or for their families, or for their sexual life, or for their reproductive future, or for their safety and wellbeing, our work is not done.

While women living with HIV continue to be wary of using their names due to the concerns about repercussions for those they love, our work is not done.

While there remains gaps in our knowledge about important questions for women about the possibilities of the U=U moment for important health decisions like breast-feeding, and we do not support that decision with consistent and evidence based messages from health practitioners, our work is not done.

The community needs to know that women with HIV have relationships, sex, children, careers and lives. They need to see people thriving, showing everyone that HIV has changed, is changing, and moreover, that we are all still focused on finding a cure.

“It’s time” for a national campaign that shines a light on life with HIV now, that presents risk realistically, but also shows that there is something you can do: test, treat, know, share that knowledge.

Such a campaign would banish once and for all that old enemy, the Grim Reaper, and show in its place the faces of real people living real lives, real women and men with real families. The message is: there is nothing to fear, pity, judge or blame, and there never in fact was. Everyone can play a part in putting an end to the last vestiges of a very old, very unwanted source of injustice, demystify HIV and put it into perspective.

# SHARE MY LOVE



Living Positive Victoria's Peer Navigators, Aashvin and Sarah take the message to the streets, sharing their love with attendees of the recent Sydney Road Festival. A presence at street festivals such as this are a key part of the way Living Positive Victoria reaches new and diverse audiences.

*By Brenton Geyer. Senior Communications Officer, Living Positive Victoria*

I am in a unique position to be able to guide the way Living Positive Victoria engages with our members, partners, stakeholders and the broader community around key issues affecting the health and wellbeing of people living with HIV. Through our current *Share My Love* campaign, I have been able to explore what U=U means to me and how this can shape the way Living Positive Victoria reaches out on the topic.

As far as HIV is concerned, it seems that wherever we turn the ever-present message is U=U. People living with HIV on effective treatment can't pass it on. It's a powerful life-changing and life-saving message. For many of us its significance is a foregone conclusion: we've been tested, we're on effective treatment and we can't pass on the virus. But let's consider unpacking this message to see what else it can mean and explore ways to convey its intent differently.

For me, a lot of the struggle in living with HIV is an emotional one, rather than physical. Although I've been HIV positive for more time than I care to recall, I'm as energetic and fit as I feel I need to be and I'm free of any debilitating or confining medical conditions that could stand in the way of living a long and healthy life.

**I'm on effective treatment. I can't pass the virus on. It's all looking pretty rosy. My mental outlook, however, could do with some nurturing and some stroking. This is where I can put the U=U message to its best work for me, and I suspect, a lot of us.**

We all know now that having an undetectable viral load means that we cannot pass the virus on. It means that a lot of the risks involved in having uninhibited, random and fantastical

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Living Positive Victoria's CEO Richard Keane and Health Promotion Officer Vic Perri share the message that if you're on effective HIV treatment you can't pass the virus on, as part of the *Share My Love* campaign.

sex are no longer such a risk to us. We can share our bodies more fully, more openly and more completely. These things can be very physically satisfying but how can U=U give us more emotional satisfaction and stability?

**U=U can be about much more than just sex. We can now learn to love again, to connect via the heart and the mind, to share so much more than our bodies. To share our love. To share our dreams and our fantasies.**

It is with this whole approach to U=U that we can build true resilience against the prevailing stigma that we as people living with HIV experience on so many levels. It's this stigma that can hold us back, build walls around us, and stop us from being the people we really want to be, hope to be, and certainly can be. It is with this aim that Living Positive Victoria developed a set of messages this summer to not only represent the intent behind

U=U, but interpret it in a way that invites us to explore how U=U can mean so much more than the science it stands for.

Creating a set of messages to align with a train of thought such as this is no simple matter. From a seed of an idea, the message needs to be formed into factual, meaningful and digestible bites of creative wordsmithing. This involved a whole team of people coming together to dissect the many ways an undetectable status can improve our lives.

We decided that U=U had benefits for the heart and soul, through our need to love ourselves and others, through our need to express and share our thoughts and our need for meaningful intimacy.

**It wasn't too long before the *Share My Love* campaign was born to convey the message that we can freely share our fantasies, share our touch and share our dreams, along with our bodies.**

It then has to reach the many and diverse individuals and communities that need to hear it. This can be achieved through the sharing of lived experiences; a catchy and memorable visual application; use of web and social media platforms; pounding the pavement with placards, banners and fliers; but most of all, it's about sharing. This summer, we attempted just that by presenting the campaign at a range of public and community events such as University O Weeks, the Sydney Road Festival, Lunar Festival and Daylesford's Chillout Festival.

Our *Share My Love* campaign has become the driver of the U=U message - the message that if you are on effective HIV treatment, you can't pass the virus on, and equally as importantly, that being HIV positive should not be a barrier to sharing who you are and who you want to be.

# THE GOOD NEWS AND THE BAD

By Nicholas Medland. Sexual health physician, senior researcher at The Kirby Institute, UNSW and vice president of the Australasian Society of HIV, Viral Hepatitis and Sexual Health Medicine.

## **U=U has changed the world for people living with HIV, but does everyone enjoy the benefits?**

There's a saying in science that nothing is ever zero and that nothing is ever 100% but in this case researchers are adamant: the risk of transmission with undetectable viral load is zero. We've had more good news recently too. New HIV diagnoses fell across Australia in 2017 and have continued to fall in Victoria in 2018. These are the first sustained falls in 20 years. But have a closer look at the data. This good news is mainly restricted to Australian born gay and bisexual men living in cities. No change for women. No change for straight men. No change for indigenous people. No change for overseas born gay and bisexual men.

Is this because of PrEP? The timing of the reduction suggests that U=U probably gets equal credit. The U=U message, when applied to the whole community, means that if every person who might be at risk were to have an HIV test and every positive person could get on treatment and have an undetectable viral load, then there need be no new HIV transmissions in Australia ever again. And meanwhile, PrEP can protect those negative people who know that they are at risk.

**Except we know that this isn't so easy for everyone, and the inequalities emerging from the HIV notification data are a reflection of that. Late diagnosis is still common in heterosexuals in Australia (48% in 2017). How does U=U help if you don't know your HIV status or your partner doesn't know theirs? This is the experience of most women living with HIV who didn't realise they were at risk until their diagnosis.**

Gay and bisexual men on temporary visas and without Medicare cards are another group where U=U might be problematic. Overseas students are a big part of our economy, bringing in \$A34 billion per year, and make up a sizeable proportion of the population of our cities. They might arrive here with less in-depth knowledge of HIV as their local peers. Some may also avoid being tested if they fear a positive result will complicate their visas.

How do you get on treatment anyway if you don't have a Medicare card? One option, used by many, is to travel back and forward between your home country, getting bloods tests and medical care there and bringing your medication back here. Another is to attend a sexual health centre which doesn't require Medicare cards and buy your medication online from overseas. A third option is for your doctor to apply for free medication provided by the pharmaceutical giants. It sounds tricky to navigate and it's a big ask for people who are new to the country. We don't have good information on the effect of these obstacles for overseas-born gay and bisexual men, but it is safe to assume that if treatment is tricky to get, then less people will do it.

**U=U can mean freedom from anxiety about HIV transmission, freedom from what disclosure will do to a potential relationship. It should mean a normalisation of human intimate relationships. But for that to work, both partners in a relationship need to have a good understanding of HIV transmission. This level of literacy only really exists in certain parts of the gay communities in Australia. If you are not from that community, then your partner probably won't know what U=U means.**

For example, how does this work if you are a positive woman or a positive heterosexual man? Will a potential partner have a good understanding of HIV transmission and the benefits of antiretroviral therapy? "Oh, and by the way, I'm HIV positive" is going to remain incredibly daunting. The responsibility falls to the positive person to educate a potential partner, who might come to the relationship with knowledge around HIV that is 10 to 20 years out of date.

What about people who don't have an undetectable viral load? U=U has all sorts of positive connotations – it means you are looking after your own health, it means you are taking care of your partner. But a small proportion of individuals, for whatever reason, don't achieve this goal. U=U now potentially represents an expectation of disclosure of their personal medical information, complicated discussions about why you choose not to disclose your viral load or even more complicated discussions about why your viral load is not undetectable and what that means.

Australia should celebrate the good news. But don't forget that not everyone is benefitting to the same degree: if you or your partner don't know their status; if getting treatment involves navigation through a complicated health care system you don't know well; if there aren't good services in your community; or if you have an undetectable viral load but live in a community where that isn't well understood. We still have a long way to go to make sure these benefits are enjoyed by all and until we won't be free of HIV.