



## Voices from the Field

### Celebrating Successes while Continuing Our Fight for Rights U =U Campaign and more

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**Prelude** As a cis-, queer Asian settler immigrant originating in Hong Kong, a mental health consumer and a person who used and injected drugs, a poz (person living with HIV) HIV activist who now resides in the unceded Dish With One Spoon Territory on Turtle Island/Toronto Canada, and a co-founder of Ontario Positive Asians (OPA+), an independent network of East, Southeast, South and West Asians living with HIV the Greater Toronto Area and the province of Ontario to create a peer-led culturally-safe space for the diasporic community. It is with great honour that we were invited to pen an experiential commentary for Indian Journal of Health, Sexuality & Culture's special issue: 'Alternative Sexual Identities, Expressions, and Lives-A Global Dialogue'. The outcome of this process is a multi-national partnership between people living with HIV to document a genuinely global grassroots movement, Undetectable = Untransmittable (U=U), where the bravery and efforts of South Asian activists are acknowledged and celebrated.

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#### Celebrating Successes

Just in the recent month of May 2019, we witnessed several community-led victories which two-spirit, lesbian, gay, bisexual, transgender, queer, questioning,

inter sex, asexual and gender diverse or non-binary people (2SLGBTQQIA+) and people living with HIV should be proud of and celebrate widely. In Asia, people of alternative sexual identities, expressions and lives had their

human and political rights affirmed: The Karnataka High Court in southern India ruled that education institutes must allow a person to officially change their name and gender, while the country of Taiwan became the first nation in Asia to allow same-sex couples to apply for 'marriage registration' as part of 'exclusive permanent unions'. Internationally, the World Health Organization (WHO) removed being transgender from its list of mental illnesses in the latest edition of the International Classification of Diseases (ICD-11) guidelines, while the publication of the final results of the PARTNER 2 study in the Lancet (Rodger et al., 2019) upheld the message which global HIV activists of the Undetectable=Untransmittable (U=U) movement had so worked tirelessly to disseminate since 2016: that people living with HIV on effective treatment with suppressed viral loads cannot pass on HIV sexually.

### **Brief History of the U=U Campaign**

The roots of the U=U Campaign dated back to 2008, when Dr Pietro Vernazza and his team at the Swiss National AIDS Commission first noted in clinical observations that a person living with HIV on effective HIV anti-retroviral treatment (ART) could not transmit HIV through sexual contact (Vernazza, Hirschel, Bernasconi & Flepp, 2008). The Swiss Statement, as it came to be known as, was unilaterally criticized and disregarded by the scientific, research and medical community for concerns that the evidence was inaccurate as the data did not provide come from

randomized control trials and the was a fear that such information would lead people living with HIV to engage in sexual behaviours which scientists, researchers and medical professionals deemed as risky (Vernazza & Bernard, 2016). When evidence from the HPTN052 (Cohen et al., 2016) and PARTNER study (Rodger et al., 2014) surfaced in indicating that no linked HIV transmission occurred amongst serodiscordant couples when the poz partner was virally suppressed, very few people, and even fewer people living with HIV, learned of the news.

The lack of adequate knowledge translation to people living with HIV was a result of HIV colonialism, the intentional act of withholding vital information about HIV and sexual reproductive health from people living with HIV by scientists, researchers and medical professionals (Prevention Access Campaign, n.d.). Such injustice propelled Bruce Richman, Founding Executive Director of the Prevention Access Campaign, to jumpstart the grassroots U=U campaign. The spread and acceptance of the U=U message took considerable effort and time. At first, many, including people living with HIV, had questions and played suspect as the new science was too drastic of a



U=U Community Gathering IAS 2017, Paris, France



Manisha Dhakal IAS 2017 Paris, France  
change from what they had been known about HIV for decades.

Institutionally, some influential organisations failed to see the benefit of spreading the new evidence to communities whom they were supposed to serve and instead acted as gatekeepers. Then there were those who demanded proof of the impossible, the desire for an absolute probability of zero in statistics since ‘negligible risk’ was too risky for public health bodies to endorse the campaign. Supporting the campaign required excellent translation of science to communities and signing on the U=U Consensus Statement took courage. The tide eventually started to change at the International AIDS Society Conference 2017 (IAS 2017) in Paris. To express his gratitude to the delegates who showed bravery to support U=U at the conference, Richman proudly proclaimed, “#UequalsU activists from 16 countries were at our IAS meeting! Kenya, Singapore, Uganda, Pakistan, Nepal, Australia,

Malaysia, Turkey, England, France, Scotland, Zambia, Georgia, Tunisia, Canada and the USA! We're all working at the dirtroots, grassroots and toproots to change the definition of what it means to live with HIV in 44 countries!”

### Documenting the South Asian Leadership which Furthered the U=U Movement

At the International AIDS Society Conference in 2017 in Paris and the AIDS 2018 Conference in Amsterdam the following year, South Asian LGBTIQ+A2S+ and HIV activists from organisations played essential roles in helping to spread the message of U=U globally and in their home countries. For example, Muhammad Usman, Project Manager of Pakistan's Dareecha Health Society first learned about U=U at IAS 2017, brought home the news, and took steps to ensure his organisation would sign-on and support the U=U Consensus Statement. “In Pakistan, people living with HIV infection are often asked the questions 'What you have done and how you get that?' Or get bully and harassed by hospital staff. Such form of stigma and discrimination are the lead causes of loneliness amongst people living with HIV,” as Usman recalls, the reason that propelled him to bring the U=U message home to Pakistan. “Undetectable & Untranslatable is a message that helps end HIV Stigma and helps creates awareness of the benefits of anti-retroviral medications (ARV).”

At the same conference, a co-founding member of the Asia-Pacific

Transgender Network, ILGA Board Member and Executive Director of Nepal's Blue Diamond Society, Manisha Dhakal, invited Dr Tarun Paudel, who then served as the Director of the National Center for AIDS and STDs Control to discuss ways of how the Nepalese government could integrate the new science in their national strategy on HIV. Describing the strong public-civil society partnership, Dhakhal recalls, "We have worked closely with the government for a long time. We do not work just one day with them on one project; We continuously create good coordination the government. When I informed Dr Tarun about U=U, he was so excited about the news as it was something we did not know and learned at IAS 2017 in Paris. Since then, my responsibility is to continue to spread this important message".

At AIDS 2018, Simran Shaikh, former Asian representative of the NGO Delegation to the UNAIDS Programme Coordinating Board, Programme Officer at the India HIV/AIDS Alliance, and President of IMPULSE New Delhi chapter, helped spread and promote the message of U=U by taking part in a U=U Social Scholar Facebook Live session which was accessible to viewers who were unable to attend the conference. "In India, the trans community has the second highest HIV prevalence...It's time for innovations like U=U to be disseminated in India and globally," says Shaikh. "What we as activists do is we tell researchers and agencies that it is always best to develop innovations with the community...that key populations need to be included in innovation

science."

These are just a few examples of the vital work that were led by brave, courageous and visionary South Asian activists from the 2SLGBTQQIA+ and poz communities whom I admire and which I had the privilege to witness and be a part of. Last but not least, having Dr Maheswar Satpathy, Special issue Editor of the Indian Journal Of Health, Sexuality & Culture reach out to include a field-experience driven commentary on the subject in this special edition demonstrates the passion and commitment of South Asian activists and leaders to continue promoting this critical campaign.

### **Next Steps: Creating Equitable Universal Health Coverage**

As of May 29, 2019, 870 organisations from 98 countries have signed on to share the U=U message in ways that work for their communities. So what does this all mean, in particular when many of us are members of key priority population groups and are based in Asiatic countries? As there is no longer debate about the validity behind the science of U=U, we hope that the campaign can now focus more on addressing the "3<sup>rd</sup> U" of the U=U Campaign to rectify the



Simran Shaikh AIDS 2018 Amsterdam, The Netherlands

unequal access to HIV treatment and to effectively implement the knowledge through provisioning a differentiated care model. This is of critical importance in the light that HIV has slowly lost its visibility as a global threat and priority through the years, and Universal Health Coverage has now become the next global health buzz word. Eliminating the unequal through equity will be key to ascertain all people living with HIV to achieve and maintain viral suppression. "Our goal is to make the undeniable science of Undetectable = Untransmissible a foundational and common understanding of the HIV experience that will no longer be dismissed," notes Murray Penner, Executive Director of Prevention Access Campaign, North America. "U=U is life-changing and should be utilised strategically to catalyse improvements in our health care responses and increase the number of people living with HIV who benefit from HIV treatment. While this will vary from region to region and country to country, the campaign has tremendous momentum and the potential to normalise HIV care within universal access to health care framework".

While we have gained grounds as 2SLGBTQIA+ and POZ people, our fight for 'true equity' is far from over. As we celebrate our successes while continuing our fight for rights, from an anti-oppressive and intersectional lens, we must continue with our critical examination and reflection on how we as academics, researchers, scientists, students, service providers, policy makers, funders, donors, activists, people living with

HIV and allies must do to ensure that equitable universal health coverage can become a reality for people of all sero-status and alternative sexual identities, expressions and lives. We hope you will all enjoy this special issue of the Indian Journal of Health, Sexuality & Culture.

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