Almost 220 million people globally use online dating services. In a world where more and more people meet partners virtually, how and when do you disclose your HIV status? This International Youth Day, three young people from three different countries share their personal experiences of living with HIV and navigating online dating.

Oguzhan Nuh, 25 years old, Turkey

My name is Oguzhan Nuh (Oz) and I am a 25-year-old university student from Turkey. I have been living with HIV for almost three years and I have been involved in the HIV response since I was diagnosed.

I was never into the dating scene that much, but I always enjoyed meeting new people. Just like my millennial peers, I mostly meet people online through dating apps. One common feature of the apps I use is the option to display your HIV status or the last time you had an STI test. In some of the apps, you can also say if your viral load is undetectable or if you are on PrEP, which I think is an amazing feature to promote biomedical interventions and reduce the stigma around HIV.

When I moved to Berlin last year for an exchange student programme, I started seeing many people who displayed their HIV status as “HIV positive and undetectable” on their profiles, which encouraged me to do the same. At first, I was nervous to do it, but I was in a different environment far from home. I thought that I didn’t have anything to lose, so I updated my profile. Surprisingly, it wasn’t much of a big deal. Yes, now and then, someone would write to me without reading my profile, and when I mentioned my status in the chat, they would stop talking or react with hostility. But it didn’t bother me that much simply because advocating was a part of my daily life and I would try to explain to them what undetectable means.

Some also said how brave I was to put my status out there so openly. Other people would just say, “Thank you for telling me and I am on PrEP”, and we would continue the conversation. This is how it should be, considering how far we have come with scientific developments. Someone’s HIV status should not affect the conversation you are having. But unfortunately, social stigma doesn’t always make this possible and some people basically run away when they hear you are living with HIV.
When I moved back to Turkey, I used a different app because the one I used in Europe is banned here. At first, I didn’t have my status on my profile, and as I had recently moved back and was new to the neighbourhood, people were messaging and trying to meet. One night, I saw someone whose status said “on PrEP”. I remembered mine was empty, so I made it “positive and undetectable”. I didn’t think much before I did that because I was quite open about my HIV status anyway. Then I realized no one’s status said positive. Those who displayed their positive status were rare and they were usually empty profiles. So I guess putting my status on my profile was brave in this context.

After this, some people I was talking to stopped responding. Some people messaged me, thinking I had made a mistake, trying to be helpful and asking me to correct my status. This happened for a couple of days. It started getting too much and all my conversations ended up discussing HIV, which I was doing enough of in my daily life, and so I removed it. Right now, even though I am open about my HIV status in my daily life and I give speeches on sexual health and HIV, I do not display my HIV status on my dating app profiles.

However, just because I don’t now display my status on my profile doesn’t mean I am not facing stigma on dating apps or not having any funny or weird moments with people I meet online. I usually get a good idea of their knowledge and awareness before I tell them about my status. If the conversation continues, we start talking about sexual health and HIV since it’s also the field I work in. Now and then, if the guy I am talking to makes a remark or says something that can be discriminatory, I correct them, and then it can get a bit awkward. They usually say something like, “Oh you are one of those LGBT+ activists, aren’t you?” And then I tell them I am actually an HIV activist, which in many cases is not the reaction they expect.

“I GUESS I CAN SAY THAT DATING APPS STARTED FEELING A BIT MORE TOXIC AFTER I WAS DIAGNOSED. GOING INTO AN APP WHERE PEOPLE COMMONLY USE HASHTAGS LIKE #DDF (DRUG AND DISEASE FREE) AND #CLEAN (MEANING HIV NEGATIVE), SOMETIMES FOLLOWED BY ‘U B 2’ (MEANING YOU SHOULD BE HIV NEGATIVE TOO), NOT ONLY ANGERS ME BUT IS ALSO UPSETTING. SEEING THOSE HIGHLY STIGMATIZING SIGNS AGAIN AND AGAIN CAN RUIN ONE’S SELF-ESTEEM. BUT THAT DOESN’T MEAN THAT YOU CAN’T MEET OR DATE PEOPLE ONLINE.”

I think that disclosing your HIV status is a very personal decision. There is no right time or way to do it and you don’t have to disclose either. I choose to disclose because I don’t think that it is something that needs to be kept a secret. But sometimes I don’t feel like having the same conversation again and again, and I don’t disclose. If you want to disclose your status, do it when it feels right to you and when you feel comfortable. Otherwise, it can happen in a moment that you least expect and make things awkward and uncomfortable for you. And yes, this comes from experience :)}
Anonymous IAS Member, 29 years old, Zimbabwe

Dating is part of our everyday life. As young people, we are all looking for love. In my work with young people living with HIV, I see that most of our concerns are around how we disclose and at what point we disclose. Coming from an African region, we have a different way of dating. We say that dating is the fun part, where we are not serious about getting married. Then we get into courtship and then we finally get married. It is difficult to disclose one’s HIV status in the dating phase because of worries that the relationship could go sour. Then the person you have been dating might start going behind your back and telling everyone that you are living with HIV.

“NO MATTER HOW MUCH WE TALK ABOUT SAFE SEX AND USE OF CONDOMS, THIS MAY NOT BE AN OPTION FOR EVERYONE. FOR MANY YOUNG WOMEN, IT IS HARD TO NEGOTIATE THE USE OF CONDOMS BECAUSE THEIR PARTNER MAY SAY, ‘WHY DO YOU WANT TO USE A CONDOM? DO YOU HAVE HIV OR AN STI? OTHERWISE, SURELY WE CAN HAVE UNPROTECTED SEX.’”

Disclosure of HIV status is not easy, and unless our society changes, it will keep on being difficult. I was doing training for HIV focal points in Zimbabwe and I asked participants, “Is it okay for a person not living with HIV to date a person living with HIV?” Of course, they all said that it was okay. Then I brought it a bit closer to home and asked, “What if your teenager, who is not living with HIV, comes home and says, ‘Mummy, my partner is living with HIV?’” They all said, “No way.” And these are HIV professionals. So it is not just about two young people being together; it is also about what the family says, what colleagues say and what society says.

For young people living with HIV, general life is also more complex. Imagine going out with your partner with whom you have not yet disclosed your status and then you need to take your medication. You are sitting at the dinner table and you want to take your medication, but how could you do that without telling them what it is? You need to plan your life more: to always make sure that you have water so you can take your medication. And you cannot get drunk because then you may forget and you will miss a dose for a day.

Living with HIV is not easy, worse still not finding love when you need it. We need a world free of stigma and discrimination that can enable young people to enjoy and explore their sexuality regardless of HIV status. Young people are the leaders of today. We have the potential to be trailblazers when it comes to HIV prevention and ending stigma and discrimination – if you ignite the passion of just one young person, they can light up the whole forest. This can start with taking control of how we navigate our dating lives and choosing when and how we disclose our HIV status.
Diego Callisto, 28 years old, Brazil

I was diagnosed with HIV when I was 18. I started being an activist three months later, basically at the same time I started taking antiretrovirals. Since 2015, I have worked as a social mobilization advisor, focusing on youth at the Ministry of Health in Brazil.

I was 15 years old in 2006 when I had my first cell phone. At the time, technology was not being used to address issues related to sexuality. I come from a rural family. They did not know a lot about technology and there was strong resistance to embracing technology. In parallel to this, I was curious. I started using MSN for sexual networking – exchanging photos, making video calls and getting to know people.

In 2009, at the age of 18, I moved to São Paulo. I was dazzled by the city, its rhythm and its intensity. Soon, the parties started and, with them, the relationships. I was already completely in love with the world of technology and I used it to make new friends and to meet dates who circulated in the same tech universe. What I loved most about using technology was the speed at which everything happened.

My sweetheart at the time fell ill. My world froze. I was overwhelmed by doubts and uncertainties. He was hospitalized and his health deteriorated. He got worse day by day and then he passed away. During that period, I felt apathetic, tired and dull. I observed that my hair got thinner and that something was not right with my health. It was a matter of days before I was diagnosed with HIV. From there on, my life changed.

I realized that technology was used for various purposes and I wondered, why not use it to reach young people and promote attitudinal changes around HIV? Day by day, I found ways to do that by partnering with dating apps to promote the spread of sexual health information.

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“The stigma, prejudices and discrimination against people living with HIV in dating apps are very quiet. You feel it slowly, in small doses, when you realize that people do not send messages to you, that no one sends pictures or has any kind of interaction with you when you reveal your HIV positive status.”
Recently, this has changed. People are more open to discussing HIV in dating apps and they also seek information, especially on PrEP. Dating apps provide an excellent opportunity to reach out to young people and increase access to HIV information, making it available at any time through banners, messages, pop-ups and other resources. Enabling HIV and prevention information to be linked to a profile makes conversations on the subject lighter and more natural. This includes newer features, such as a field that allows you to show your HIV serology, whether or not you use PrEP and when you had your last STI test. These features are key to changing behaviour and attitudes surrounding HIV through apps.

I became an ambassador for an app and promoted prevention through the partnership. This was, in fact, the app that my husband approached me on. It was an important moment in our lives, not just because this is how we connected, but also because the app served to improve his knowledge about HIV and helped change his attitude.

We started dating in that period and we got married this year. I live with HIV and he does not and we are adept at U=U (Undetectable = Untransmittable) and combination prevention.