AIDS Vancouver opened its doors in 1983 as the first AIDS service organization in Canada in response to the growing need for community health organizations to support individuals vulnerable to this epidemic. Over the years, AIDS Vancouver has adapted and changed to meet the ever-changing needs of individuals living with HIV. AIDS Vancouver’s Peer Engagement Program champions the Guiding Principles in British Columbia’s Ministry of Health’s From Hope to Health: Towards an AIDS-free Generation, namely that “stigma surrounding HIV has been present since the start of the epidemic, and while it has lessened in many communities, it remains a barrier to testing and treatment.”¹

‘The New Face of HIV”, represents a community initiative to better reflect the realities of living with HIV today. In British Columbia, people living with HIV have access to the best treatments at the earliest stages of infection. Advancements in HIV treatment make treated HIV a manageable condition. Individuals with access to modern treatment interventions such as HAART can now expect to live normal lifespans with few, if any, HIV-related negative health outcomes. Furthermore, there is growing evidence that the likelihood of transmitting the HIV virus by someone who is undetectable is negligible.² Macintosh explains that “[m]any of those infected, affected, and at risk fear the stigma associated with HIV/AIDS, and thus avoid being identified....but the dissociation of persons from the realities of the disease is an epidemiological nightmare.”³ As such, this initiative argues that using the term “HIV-positive” to describe treated HIV is both inaccurate and unnecessarily stigmatizing.⁴ We need to create new language in order to differentiate between the health conditions of those who have treated HIV and those who have untreated HIV, in order to convey new realities, address stigma, and increase empowerment. As such, we propose a rebranding HIV Campaign using the terms “Undetectable”, “Treated HIV”, “HIV-Neutral” or “HIV in Remission” to describe this new category of HIV prognosis. Our goal is to begin a conversation using new language as an empowerment tool to prevent and treat HIV in our communities, thereby reducing fear and stigma, and decreasing barriers to testing and facilitating adherence to treatments.

We value your expert opinion and want to invite you to participate in this multi-faceted, multi-sectoral initiative. Please take a moment to review the attached materials, and contact Brent Sawlor with your feedback and recommendations. We would like to meet with you to discuss this initiative and explore ways to move forward. We believe that together, individuals, communities, and organizations can create change from within.

Warm regards,

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The New Face of HIV (in BC)
Undetectable, Treated HIV, HIV Neutral, HIV in Remission

Key Messages

○ Advancements in HIV treatment make treated HIV a manageable condition.

○ The terms “HIV-positive” and “AIDS” imply illness; they do not accurately reflect the healthy condition of a person living with treated HIV. Therefore, new language is needed to convey new realities, in order to combat stigma and enhance empowerment.

○ We propose a Rebranding of HIV Campaign using the terms “Undetectable”, “Treated HIV”, “HIV Neutral” and / or “HIV in Remission” to describe the new realities of HIV prognosis.

1. Treated HIV is not the same as Untreated HIV

The prognosis of people living with treated HIV and untreated HIV is dramatically different. The following table show clear distinctions between treated and untreated HIV:

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>TREATED HIV</th>
<th>UNTREATED HIV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily Life</td>
<td>Normal*</td>
<td>Often affects daily activities</td>
</tr>
<tr>
<td>Life Span</td>
<td>Normal (near normal) lifespan*</td>
<td>Often dramatically shortened</td>
</tr>
<tr>
<td>Immune System</td>
<td>Normal (non-compromised)*</td>
<td>Often Severely compromised</td>
</tr>
<tr>
<td>Infectiousness</td>
<td>Virtually non-transmissible**</td>
<td>Transmissible</td>
</tr>
<tr>
<td>Medication</td>
<td>1 to 3 pills per day*</td>
<td>Implies no medication</td>
</tr>
<tr>
<td>Treatment</td>
<td>Usually requires 4 visits to the lab per year for blood tests, to the doctor to review the results, and to the pharmacist to pick up the prescribed antiretroviral (ARV) therapy</td>
<td>Often no doctors' visits or Doctors’ visits may involve observing a declining immune system</td>
</tr>
<tr>
<td>Side Effects</td>
<td>“Like most medicines, antiretroviral drugs can cause side effects. These unwanted effects are often mild, but sometimes they are more serious and can have a major impact on health or quality of life. On rare occasions, side effects can be life threatening”</td>
<td>Untreated HIV may result in increased risk of acquiring airborne illnesses, such as the common cold, pneumonia etc. as well as increased risk of bacterial imbalances resulting in oral thrush or yeast infections.</td>
</tr>
<tr>
<td>HIV in the bloodstream</td>
<td>Undetectable levels (less than 40 copies of HIV per ml of blood)</td>
<td>As many as over a million copies per ml of blood</td>
</tr>
<tr>
<td>------------------------</td>
<td>---------------------------------------------------------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td>Mental Health &amp; Stigma</td>
<td>Depression and isolation for many because of the physical, social, verbal, and institutional stigma that impacts both individuals and communities living with HIV</td>
<td>Depression and isolation for many because of the physical, social, verbal, and institutional stigma that impacts both individuals and communities living with HIV, as well as issues dealing with a terminal illness</td>
</tr>
</tbody>
</table>

*for most patients
**for vaginal intercourse. Similar results are expected but more research is needed for anal intercourse

2. **Rationale for New words to describe Treated HIV**

Given the differences between treated and untreated HIV, there is a strong need to update the language to accurately describe and distinguish between both conditions. The following section demonstrates the need for new language, new research and new approaches regarding prevention strategies as well as the need to separate our health care recommendations for people living with treated HIV from those living with untreated HIV:

**More accurate treatment**
Currently, people living with treated HIV are grouped into the broad category of HIV-positive. This results in health care professionals (doctors, nurses, pharmacists, naturopaths, etc.) recommending unnecessary treatments targeted at a compromised immune system, which many of these clients do not have. Many undetectable individuals are spoken to and treated in a way that is stigmatizing and disempowering implying they have problems associated with untreated HIV. We believe that new terminology such as “Undetectable”, “Treated HIV”, “HIV Neutral” and/or “HIV in Remission” would make it easier for health care professionals to speak with and treat undetectable patients in a way that more accurately affects their prognosis (see appendix A).

**Decreased stigma**
HIV is a disease with a stigmatized history involving discrimination, hatred and fear. Living with HIV no longer has to be the frightening death sentence that many people still think it is. Stigma may be described as a label that associates a person to a set of unwanted characteristics that form a stereotype. By using different and more descriptive terminology, the language we use can start to reflect the improved and near-normal health outcomes that a person associates with an HIV-positive diagnosis. While there is a need for “health care professionals [to] use diagnostic labels to classify individuals for both treatment and research purposes... [it is also important to acknowledge that] despite their clear benefits, diagnostic labels also serve as cues that activate stigma and stereotypes.”

The New Face of HIV
At an early consultation meeting of HIV positive individuals who identify as undetectable, which took place here in Vancouver during the initial planning stage for this project, group members spoke of the empowerment they experienced through their destigmatized undetectable identity. For many, identifying as Undetectable freed them to disclose their HIV status much more readily than ever before, when the inaccurate and stigmatized HIV positive label was their only option (see appendix C). This shows that by expanding the diagnostic labels currently used to include: “Undetectable”, “Treated HIV”, “HIV Neutral” and/or “HIV in Remission”, a new conversation will be encouraged which will more accurately describe the health outcomes of living with “Treated HIV” and thus reduce some of the stigmas associated with “HIV/AIDS.”

Reduce fear of testing

According to the Public Health Agency of Canada (PHAC), one of the barriers to HIV testing is “fear of stigma and discrimination associated with risk behaviours and/or testing HIV positive.”4 To reduce this stigma, PHAC recommends “emphasizing HIV as a chronic manageable condition and the benefits of treatment to reduce fear of HIV diagnosis.”5 Thus, by changing the terminology we use to describe HIV, we change our thinking and therefore decrease a significant aspect of the fears and thus barriers to testing. The term “HIV-positive” is a blanket term that fails to accurately describe the prognosis of treated HIV. New language and new terminology communicate the new reality that HIV is a manageable condition and that individuals can have a normal, healthy life and normal to near normal lifespan.

Encourage treated HIV research

Most of the current research on HIV/AIDS looks at the effects of living with HIV without distinguishing between treated and untreated individuals. Since people living with treated HIV have a much different prognosis and are much less infectious, new research is needed that specifically targets this group. This focused research would lead to more accurate treatment recommendations for patients with the prognosis “Undetectable”, as well as encourage more research on the risks of HIV transmission with an undetectable viral load. As it stands, gaps in research on treated HIV and transmission, particularly with MSM and anal sex, prevent the full integration of the science of antiretroviral therapy (ART) into contemporary HIV treatment and prevention strategies. Closing these gaps through targeted research will empower service providers to utilize the latest medical advances with confidence, with the potential to open up exciting and effective new avenues for education, prevention, and treatment.

Better understand risks of HIV transmission

Studies of heterosexual couples living with HIV who are on ARVs and who have undetectable viral levels in their blood are much less likely to pass HIV to others.6,7 According to a report tabled at the 3rd International Workshop on HIV & Women held in January, 2013, a multi-study review of HIV-discordant heterosexual couples concluded that “if 100 discordant heterosexual couples whose positive partner had an undetectable viral load
had sex for 1 year, the HIV transmission rate would be 0, or at most vanishingly small.\textsuperscript{98}

Additionally, according to British HIV Association Guidelines, “The observed reduction in HIV transmission in a clinical trial setting demonstrates that successful [antiretroviral treatment] use by the person who is HIV positive is as effective as consistent condom use in limiting viral transmission”\textsuperscript{99} in heterosexual couples. There is mounting evidence that risk of transmission is reduced to negligible levels, therefore, new terminology is needed to enable more accurate education regarding risk of HIV transmission in the era of HAART.\textsuperscript{10 11}(see appendix B)

Such education is critical across multiple contexts. For example, accurate information about HIV transmission risks can relieve individuals living with treated HIV from the stigmatizing specter of infectiousness that characterized HIV in the pre-HAART era but no longer applies today. The great gains in longevity associated with ARV treatments have yet to be matched with similar gains in quality of life; too many individuals living with HIV continue to be stigmatized based on outdated fears of transmission that prevents them from forming intimate relationships and leaves them vulnerable to the adverse impacts of isolation.

For the estimated 42\% of HIV negative individuals who choose not to use condoms consistently,\textsuperscript{12} we believe that knowledge of the reduced risks of transmission from partners with treated HIV can empower these individuals to make informed safer sex choices within the context of unprotected sexual activity.

While continuing to emphasize that consistent and proper condom use is one of the most effective means of preventing HIV transmission, prevention strategies also need to target those individuals who choose not to use condoms. A recent Vancouver study demonstrated that “while close to 70\% of HIV-negative men reported always using condoms as a method of preventing HIV acquisition, when asked specifically about condom use the last time they had anal sex, this number fell to 58\%.”\textsuperscript{13} Furthermore, the study found that “3\% of men who self-reported as HIV-negative were, in fact, HIV-infected.”\textsuperscript{14} Given the fact that 42\% of HIV negative men engaged in anal sex without a condom and 3\% of men who identify as negative have untreated HIV\textsuperscript{15} and thus could be highly infectious, the need to expand HIV education and prevention strategies is evident. The terminology proposed allows for more accurate and larger conversations that reflect the realities of HIV infection today. Currently, there is a tendency to assume those that identify as negative are indeed negative, and those that identify as positive are infectious. However, neither of these assumptions are accurate. New terminology encourages new understanding of the grey areas and allow people who choose not to use condoms to make more informed choices. New terminology makes it possible to create more accurate safer sex messaging (See appendix B)
3. Conclusions

The term “HIV-positive” is currently an umbrella term used to describe anyone living with HIV, regardless of their viral load, prognosis, and infectiousness. Due to medical advances in treating HIV, this is no longer accurate. By rebranding HIV and using new terminology such as “Undetectable”, “Treated HIV”, “HIV Neutral” and/or “HIV in Remission” we can encourage education about HIV and move away from the negative health associations and outcomes of the term HIV-positive. New language is necessary to reduce stigma and promote empowerment, as has been found in attitudes toward addiction recovery. Referring to recovery, Dr. John F. Kelly said, “There’s an old proverb that states, if you want something to survive and flourish, call it a flower; if you want to kill it, call it a weed.”

Some individuals in the Undetectable community have already started to use these new terms to describe themselves. Using more accurate language to describe their health condition has helped them feel more empowered and freed them to disclose their HIV status. With this project, we hope to make these terms common terminology that can help undetectable individuals feel more confident talking about their status, while also facilitating adherence to treatment, decreasing barriers to testing and expanding safer sex messaging.

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APPENDICES:

APPENDIX A: Stigmatizing and incorrect medical care and advice because of Inaccurate label

Some health care professionals offer undetectable patients unnecessary treatments because they group these patients into the category of HIV+ and make the assumption that these people have a compromised immune system. Speaking to an Undetectable patient as if they have a similar prognosis as someone with untreated HIV is disempowering and stigmatizing. To illustrate how undetectable patients are affected by these misconceptions, undetectable individuals were asked to share real personal stories about their experience with health care professionals:

- An Undetectable male saw a nurse at a clinic that specializes in HIV care in Vancouver in 2013. During the course of their conversation, the nurse told this patient that he was immune compromised. Knowing that he was undetectable and had a normal CD4 count, the patient challenged the nurse on this statement and was told that he was not in fact immune compromised, but that “That’s just what we are used to saying.” The patient mentioned this incident to his doctor, an HIV specialist, and was told that he was correct in asserting that his immune system was not compromised. “The virus replication is shut down in your body and you have a normal immune system.”

- An Undetectable male saw a naturopath in Vancouver in 2013 who regularly treats HIV-positive patients as part of his practice. Knowing only that this client was HIV-positive, the naturopath suggested that he try acupuncture as it has been found to be an effective treatment for lung conditions “and people living with HIV have lung problems”. The client stated that he was undetectable with a normal CD4 count, and asked the naturopath if he was sure that he was still likely to be more prone to lung problems. “I hadn’t thought of it that way, I don’t know?” was the naturopath’s reply.

- An Undetectable male saw a pharmacist at Infectious Disease Control in a hospital in Vancouver in 2013 to get his HAART medications refilled. The pharmacist indicated that this individual should take Vitamin D supplements as a result of being positive. “I am undetectable with a normal CD4 count,” stated the client. “Are you sure I need more vitamin D than someone who does not have HIV?” The pharmacist indicated that the bulk of scientific studies do not distinguish between someone with HIV and someone who is undetectable, and that much of the science have been conducted on people with untreated HIV.

- An Undetectable young woman was told by her doctor during the course of her checkup that if she is to receive oral sex, she would need to use a dental dam. Unfortunately she did not have the knowledge to challenge this assertion and was left thinking that her sex life was over. Thankfully, this woman received more accurate information regarding risk of transmission at AIDS Vancouver and expressed great relief that she was able to have a normal sex life. Sadly, this doctors visit occurred in 2013 in Vancouver.
APPENDIX B: Update the Current Safe Sex Messaging using the science of Treatment as Prevention (TasP):

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>RISK LEVEL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vaginal Intercourse With a Condom</td>
<td>Low Risk</td>
</tr>
<tr>
<td>Vaginal Intercourse Without a Condom</td>
<td>High Risk</td>
</tr>
<tr>
<td>Vaginal Intercourse Without a Condom* with Undetectable partner</td>
<td>Low Risk</td>
</tr>
<tr>
<td>Anal Intercourse With a Condom</td>
<td>Low Risk</td>
</tr>
<tr>
<td>Anal Intercourse Without a Condom</td>
<td>High Risk</td>
</tr>
<tr>
<td>Anal Intercourse Without a Condom* with Undetectable partner</td>
<td>Low Risk</td>
</tr>
</tbody>
</table>

* Moore et al. (2012) reported that “while close to 70% of HIV-negative men reported always using condoms as a method of preventing HIV acquisition, when asked specifically about condom use the last time they had anal sex, this number fell to 58%.”

Appendix C: Comments from a meeting for People Who Identify as Undetectable when asked what Undetectable means to them:

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>COMMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disclosure</td>
<td>On some web sites, the drop down menu allow you to choose 1. Negative 2. Positive 3. I don’t know. Some guys choose Poz. I ask them if they are undetectable and often they respond - Yes. I ask them why they don’t disclose as undetectable and they often respond that they didn’t think of it</td>
</tr>
<tr>
<td>Disclosure</td>
<td>Being undetectable has allowed me to take more responsibility. It allows me to disclose</td>
</tr>
<tr>
<td>Disclosure</td>
<td>Undetectable makes it easier to disclose.</td>
</tr>
<tr>
<td>Education</td>
<td>Newly diagnosed guys often only know that they are not going to die. They don’t know any of the other ‘good’ news about what it means to be undetectable</td>
</tr>
<tr>
<td>Education</td>
<td>It takes longer to take care of my teeth than HIV</td>
</tr>
<tr>
<td>Education</td>
<td>Its all about education and knowledge</td>
</tr>
<tr>
<td>Education</td>
<td>I find myself educating people. (disclosing as undetectable often generates a conversation about what it means)</td>
</tr>
<tr>
<td>Education</td>
<td>The word undetectable doesn’t confuse the message. It cuts to the chase. (it clearly communicates one’s health status to someone else)</td>
</tr>
<tr>
<td>Stigma</td>
<td>I need to know that I am not putting other people at risk.</td>
</tr>
<tr>
<td>Stigma</td>
<td>Undetectable allows me to be accepted</td>
</tr>
<tr>
<td>Stigma</td>
<td>Undetectable is less in your face than POZ or HIV-positive. There is less stigma</td>
</tr>
<tr>
<td>--------</td>
<td>--------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Stigma</td>
<td>I would say that I am undetectable so that I didn’t sound diseased. Even though I do not fully know what it means to be undetectable</td>
</tr>
<tr>
<td>Stigma</td>
<td>I was rejected less when I disclosed as undetectable, rather than POZ</td>
</tr>
<tr>
<td>Well Being</td>
<td>Before I went on meds, conversations with my doctor were always about my falling CD4 counts and high HIV viral load. Now that I am on meds and am undetectable, conversations with my doctor are easy and positive. The news is always good</td>
</tr>
<tr>
<td>Well Being</td>
<td>Before I went on meds, when I ejaculated I had a visualization that my cum was like 'daggers of death'</td>
</tr>
<tr>
<td>Well Being</td>
<td>I wear the label Undetectable as a badge of honour</td>
</tr>
</tbody>
</table>
References


