SIEMPRE POR TI
Anti-stigma Toolkit
¡BIENVENIDOS!
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ACKNOWLEDGEMENT

This toolkit was developed by Colectivo ALA in partnership with Santa Clara County’s Office of LGBTQ Affairs through the Getting To Zero initiative to help reduce HIV stigma in Santa Clara County and beyond.

This toolkit has been created as an effort to create awareness, develop empathy and understanding, and create strategies to reduce stigma to benefit those who have been impacted by HIV, homophobia, transfobia, and by the racial disparaties currently existing in our communities.
¡GRACIAS!

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OVERVIEW

The toolkit has the goal to provide the foundation for people to actively engage in conversations about stigma related to HIV/AIDS, its impact in our communities, and to develop strategies to reduce it.

The content in this toolkit has been gathered from a number of resources that are credited at the end. The main goal is to normalize the conversation about HIV related stigma by opening an honest dialogue among participants. In doing so, we will challenge attitudes, beliefs, and behaviors that continue to perpetuate stigma, prejudice, and discrimination.
HOW TO USE THIS TOOLKIT

This toolkit is intended to serve as a guide to begin a conversation about stigma related to HIV/AIDS.

The toolkit integrates “SiemPrE Por Ti”, a four-episode webseries that seeks to inform about PrEP and the importance of STD/HIV testing, to guide a discussion about HIV related stigma. In addition, there are suggested activities to help frame the discussions and promote participation.

It is intended to be facilitated in a group setting of any size. It is recommended to be delivered in two sessions of about 2 hour each, but each module can stand alone an be conducted separately.
MODULE 1

HIV/AIDS Timeline – The history of the HIV and AIDS epidemic began in illness, fear and death as the world faced a new and unknown virus. However, scientific advances, such as the development of antiretroviral drugs, have enabled people with access to treatment to live long and health lives with HIV.1

ACTIVITY – Divide the group in smaller groups (dyads, tryads, etc) and assigned a specific decade from the timeline in ATTACHMENT A. Ask participants to identify the events that could illustrate stigma. Allow small groups 5 minutes to discuss and come up with at least 2-3 examples they then could share with the larger group. Allow 10 minutes for sharing examples in the larger group and make comments. At the end, ask participants if they know of any other event, nationally or locally, that is not listed in the timeline.

1. https://www.avert.org/professionals/history-hiv-aids/overview
HIV Stigma and Discrimination

“There is a cyclical relationship between stigma and HIV; people who experience stigma and discrimination are marginalized and made more vulnerable to HIV, while those living with HIV are more vulnerable to experiencing stigma and discrimination.”

“Myths and misinformation increase the stigma and discrimination surrounding HIV and AIDS.”

The fear surrounding the emerging HIV epidemic in the 1980s largely persists today. At that time, very little was known about how HIV is transmitted, which made people scared of those infected due to fear of contagion.

This fear, coupled with many other reasons, means that lots of people falsely believe:

- HIV and AIDS are always associated with death
- HIV is associated with behaviors that some people disapprove of (such as homosexuality, drug use, sex work or infidelity)
- HIV is only transmitted through sex, which is a taboo subject in some cultures
- HIV infection is the result of personal irresponsibility or moral fault (such as infidelity) that deserves to be punished
- Inaccurate information about how HIV is transmitted, which creates irrational behavior and misperceptions of personal risk

“UNAIDS and the World Health Organization (WHO) cites fear of stigma and discrimination as the main reason why people are reluctant to get tested, disclose their HIV status and take antiretroviral drugs (ARVs).”

2-3. HIV Stigma and Discrimination avert.org

REFLECTION & DISCUSSION #1

**Telenovela SiemPrE Por Ti - Episode 1** – This first episode introduces the characters in the story and sets the tone by portraying each character’s own perception of risk. In contrast, we get to hear the experience of one of the characters from the moment of diagnosis, while thinking he was not at risk, to fully disclosing his HIV status to his family.

With this episode we will address how stigma influences how we perceive risk and how it can impact the way we cope when receiving a positive diagnosis.

**ACTIVITY** – Have the group watch the first episode of the telenovela and facilitate a reflection and discussion afterwards.
**Scenario 1** – General perception of risk

The group of friends are introduced to PrEP but there’s the initial idea that only individuals who have multiple partners should use it.

*How are certain ideas generalized?*

**Scenario 2** – Own perception of risk

The uncle does not feel he is at risk because he is feeling well.

*How does stigma influence the way we perceive risk?*

**Scenario 3** – Social stigma and disclosure

The couple faces the issue of how social stigma affects individuals regardless of their HIV status.

*How does stigma influence the way we cope?*
STAGES OF ACCEPTANCE

The model was first introduced by Swiss psychiatrist Elisabeth Kübler-Ross in her 1969 book On Death and Dying, and was inspired by her work with terminally ill patients.

After a positive diagnosis the individual can through to different stages that will affect their behavior and interaction with others.

**Denial** – You tell yourself that it is not true

**Anger** – You will experience feelings of anger and hurt

**Bargaining** – This stage involves the hope that the individual can avoid a cause of grief.

**Depression** – The individual despairs at the recognition of their mortality.

**Acceptance** – The individual embraces mortality and the inevitable future.
BREAK TIME
Telenovela SiemPrE Por Ti - Episode 2 – In the second episode the main character decides to disclose the HIV status to his friends and faces different reactions.

With this episode we will address how the lack of knowledge can cause prejudice and how this can lead to stigma and discrimination.

**ACTIVITY** – Have the group watch the second episode of the telenovela and facilitate a reflection and discussion afterwards.
**Scenario 1 – Prejudice, stigma, and discrimination**

While having lunch, the main character disclose to his friends the HIV status of his boyfriend and faces different reactions from the group.

*What are some of the negative reactions that are displayed on this scene?*

*What kind of impact can these reactions have on him?*

*What are some of the positive reactions that are displayed on this scene?*

*What kind of impact can these reactions have on him?*

*How can these reactions positive or negative could impact the rest of the group.*
**Scenario 2** – Own perception of risk

The uncle decides to go get tested at a place that offers HIV testing.

*What kind of attitude we see on the uncle as he goes to get tested?*

*What might be causing the way he presents himself at the testing site?*

*Have you ever experienced something similar?*

*What role does family play in this situation?*

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**Scenario 3** – Social stigma and disclosure

The group of friends have a controversial conversation about the “boyfriend” at the gym.

*What are some prejudiced ideas we see in this scene?*
Prejudice – un unfavorable opinión formed beforehand without knowledge, thought, or reason.
Stigma – a mark of disgrace associated with a particular circumstance, quality, or person.
Discrimination – unjust treatment of a person or particular group of people based upon some characteristic.

FOUR DIMENSIONS OF SOCIAL STIGMAS RELEVANT TO HIV/AIDS

Origin – is often blamed on behaviors and choices.
~ Because the primary ways of transmitting HIV are sexual intercourse and sharing infected needles are perceived to be voluntary and immoral behaviors, people infected with HIV are regarded as responsible for their condition.
Course – the course of HIV infection is degenerative and not alterable.
~ Since the earliest days of the epidemic, HIV/AIDS has been widely perceived to be a fatal condition.
Contagious – whether the condition will physically, socially, or morally contaminate others.
~ HIV/AIDS is perceived as a way to place harm on others.
Apparent – it disrupts a social interaction or is perceived by others as repellent, ugly, or upsetting.
~ The advanced stages of AIDS often dramatically affect an individual’s physical appearance and stamina, ecoking distress and stigma from observers (e.g., Klitzman, 1997)

BREAK TIME
Telenovela SiemPrE Por Ti - Episode 3 – In the third episode the main character faces the reaction of his parents when they found out he is using PrEP to prevent HIV.

With this episode we will address stigma in the family when the values that are unique to a family contrast with the values of the society they belong.

**ACTIVITY** – Have the group watch the third episode of the telenovela and facilitate a reflection and discussion afterwards.
Scenario 1 – Family values
The main character is forced to disclose to his parents about his use of PrEP to prevent HIV.

What role does the family play in this situation?

How would you react if you were in a similar situation?

How cultural values might influence the way a family could react when a member discloses something similar?

“Family’s cultural values may dictate that the infected family member deserves the highest level of care and compassion from his relatives regardless of affliction simply because he is part of the family. However, if a family’s religious beliefs dictate that a lack of morality is the cause of HIV/AIDS, they may conflict with the notion of providing care and support and instead lead to stigmatization.”

Family Unique Values – specific customs within the family
Family Shared Cultural Values – set of shared values that are part of the culture of society

THE LATINO FAMILY AND HIV RELATED STIGMA

According to the 2010 Census, 308.7 million people resided in the United States on April 2010, of which 50.5 million (or 16 percent) were Hispanic or Latino origen. The Hispanic population increased from 35.5 million in 2000 when this group made up 13 percent of the total population. 14.0 million (28 percent) of the total Hispanic population lived in California were Hispanics accounted for 32.4 percent of the total population in the state.7

Source: U.S. Census Bureau, Population Division
Why are Hispanics/Latinos at higher risk?

In all communities, lack of awareness of HIV status contributes to HIV transmission. People who do not know they have HIV cannot take advantage of HIV care and treatment and may unknowingly pass HIV to others. A number of challenges contribute to the higher rates of HIV infection among Hispanics/Latinos:

~ More Hispanics/Latinos are living with HIV than some other races/ethnicities.
~ Hispanics/Latinos have higher rates of some STDs than some other races/ethnicities. Having another STD can increase a person’s chance of getting or transmitting HIV.
~ Though not unique to Hispanics/Latinos, stigma, fear, discrimination, and homophobia impact Hispanic/Latino lives. These issues may put many Hispanics/Latinos at higher risk for HIV infection.
~ Poverty, migration patterns, lower educational level, and language barriers may make it harder for Hispanics/Latinos to get HIV testing and care.
~ Undocumented Hispanics/Latinos may be less likely to use HIV prevention services, get an HIV test, or get treatment if HIV-positive because of concerns about being arrested and deported.

FAST FACTS

~ Hispanics/Latinos are disproportionately affected by HIV
~ About 7 in 10 new HIV diagnoses among Hispanics/Latinos occur in gay and bisexual men
~ About half of Hispanics/Latinos living with HIV have achieved viral suppression.

BREAK
MODULE 4

REFLECTION & DISCUSSION #4

Telenovela SiemPrE Por Ti - Episode 3 – In the fourth episode the group of friends reflect on their experience getting tested for HIV.

With this episode we will review how stigma affects our behavior and discuss the importance to address stigma at different levels.

ACTIVITY – Have the group watch the third episode of the telenovela and facilitate a reflection and discussion afterwards.
Scenario 1 – Review

The characters express their experience getting tested and their concern to disclose to their family their use of PrEP as a way to prevent HIV.

How do the characters reflect on their experience going to get tested for HIV?

What positive outcomes can we identify from that experience?

What worked for the group of friends to be able to have an open conversation about getting tested and considering PrEP?

What role did the family play in this situation?
HOW IS STIGMA HARMFUL?

Stigma and discrimination add barriers which weaken the ability of people and communities to protect themselves from HIV and to stay healthy if they are living with HIV.

HOW DO PEOPLE COPE WITH STIGMA?

Stigma and discrimination add barriers which weaken the ability of people and communities to protect themselves from HIV and to stay healthy if they are living with HIV.

HOW IS HIV STIGMA ADDRESSED?

Stigma exists, and should be targeted at multiple levels: individual, interpersonal (family, friends, social networks), organizational, community and public policy. Involving PLWH in the design, creation, implementation and evaluation of stigma reduction programs is critical to success.

The information contained in this page is an extract from “STIGMA (Fact Sheet) by the University of San Francisco. Full version available at: https://prevention.ucsf.edu/library/stigma/
## OVERVIEW ON PREVENTION

<table>
<thead>
<tr>
<th>SEXUALLY TRANSMITTED INFECTIONS - STIs</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Bacterial</td>
<td>Viral</td>
</tr>
<tr>
<td>~ Living organisms</td>
<td>~ Non-living organisms, need a host (our bodies are the host)</td>
</tr>
<tr>
<td>~ ANTIBIOTICS treated once infected</td>
<td>~ No CURE but vaccines for HPV and Hep A-B to prevent</td>
</tr>
<tr>
<td>EXAMPLES</td>
<td>EXAMPLES</td>
</tr>
<tr>
<td>~ Chlamydia</td>
<td>~ HPV</td>
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<tr>
<td>~ Gonorrhea</td>
<td>~ Herpes</td>
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<tr>
<td>~ Syphilis</td>
<td>~ Hepatitis A, B, C</td>
</tr>
<tr>
<td></td>
<td>~ HIV</td>
</tr>
</tbody>
</table>
WAYS TO PREVENT TRANSMISSION

GETTING TESTED

NEGATIVE

a. Window period
b. Pre Exposure Prophylaxis (PrEP) for HIV
c. Post Exposure Prophylaxis (PEP) for HIV if time of possible exposure occurred in less than 72 hours

POSITIVE

a. Treatment
   i. Undetectable=Untransmittable

BARRIERS

CONDOMS

a. Latex or Polyurathene
b. Water or silicon base lubricant

DENTAL DAM
RESOURCES

HIV TESTING

- Primary care provider (If insured)
  The Crane Center - 976 Lenzen Ave, SJ 95126
  AACI - visit [hiv.aaci.org/get-tested/](http://hiv.aaci.org/get-tested/)
  Billy DeFrank
  The Watergarden
  Hope program at Story Rd
  Planned Parenthood - visit [plannedparenthood.org](http://plannedparenthood.org)
  Federally Qualified Health Center

STI Testing

- STI Clinic at Lenzen - 976 Lenzen Ave, SJ 95126
- Planned Parenthood - visit [plannedparenthood.org](http://plannedparenthood.org)
- Federally Qualified Health Center

PrEP/PEP

- Private provider (If insured)
  PleasePrEPme.org (provider locator)
  The Crane Center
  Planned Parenthood
  Federally Qualified Health Center
  NURX.com
  Pluscare.com

More information about STI/HIV Testing, PrEP, and PEP

- [PrEPisLiberating.org](http://PrEPisLiberating.org)
HIV/AIDS Timeline – The following is an extract of a longer document that reflects the history of the domestic epidemic from its origins in illness, fear, and death to our present, hope-filled years.

Full version available at https://www.hiv.gov/hiv-basics/overview/history/hiv-and-aids-timeline

1981 – The U.S. Centers for Disease Control and Prevention (CDC) publish a Morbidity and Mortality Weekly Report (MMWR), describing cases of a rare lung infection, Pneumocystis carinii pneumonia (PCP) in five young, previously healthy, gay men in Los Angeles. All the men have other unusual infections as well, indicating that their immune systems are not working; two have already died by the time the report is published. This edition of the MMWR marks the first official reporting of what will become known as the AIDS epidemic.

On June 5, the Associated Press and the Los Angeles Times report on the MMWR. On June 6, the San Francisco Chronicle covers the story. Within days, doctors from across the U.S. flood CDC with reports of similar cases.

On July 3, the New York Times reports on cases of Kaposi’s Sarcoma affecting 41 gay men in New York and California.

By year-end, there is a cumulative total of 270 reported cases of severe immune deficiency among gay men, and 121 of those individuals have died.

1982 – In June, a group of cases among gay men in Southern California suggested that the cause of the immune deficiency was sexual and the syndrome was initially called gay-related immune deficiency (or GRID)

On September 24 CDC uses the term “AIDS” (Acquired Immune Deficiency Syndrome) for the first time.

1983 – In September 9 CDC identifies all major routes of HIV transmission – and rules out transmission by casual contact, food, water, air, or environmental surfaces.

After a New York doctor is threatened with eviction from his building for treating AIDS patients, Gay Men’s Health Crisis (GMHC) and Lambda legal file the first AIDS discrimination lawsuit.

1984 – In October, San Francisco officials order bathhouses closed due to high-risk sexual activity occurring in these venues. New York and Los Angeles follow suit within a year.

1985 – The Pentagon announces that it will begin testing all new military recruits for HIV infection and will reject those who test positive for the virus.

Ryan White, an Indian teenager who contracted HIV (at that time called AIDS) through contaminated blood products used to treat his hemophilia, is refused entry to his middle school. He goes on to speak publicly against AIDS stigma and discrimination.

1986 – In May, the International Committee on the Taxonomy of Viruses declares that the virus that causes AIDS will officially be known as Human Immunodeficiency Virus (HIV).

1987 – On March 9, the Food and Drug Administration (FDA) approves the first antiretroviral drug, zidovudine (AZT).

On May 16, the U.S. Public Health Service adds HIV as a “dangerous contagious disease” to its immigration exclusion list and mandates testing for all visa applicants.

In July, the U.S. Congress adopts the Helms Amendment, which bans the use of Federal funds for AIDS education materials that “promote or encourage, directly or indirectly, homosexual activities.”

After Florida’s Desoto County School Board refuses to allow HIV-positive brothers, Ricky, Robert, and Randy Ray to attend school, a Federal judge orders the board to reinstate the three hemophiliacs, who contracted HIV through contaminated blood products. After the August 5 ruling, outraged town residents refuse to allow their children to attend school, and someone sets fire to the Ray house on August 28, destroying it.

1988 – The number of reported AIDS cases in the United States reaches 100,000

1990 – Ryan White dies at the age of 18

1991 – The Visual AIDS Artists Caucus launches the Red Ribbon Project to create a visual symbol to demonstrate compassion for people living with AIDS and their caregivers. The red ribbon becomes the international symbol of AIDS awareness.

1992 – AIDS becomes the number one cause of death for U.S. men ages 25-44

Ricky Ray dies of AIDS-related illness on December 13.

1993 – The National Institutes of Health Revitalization Act codifies the U.S. HIV immigration exclusion policy into law; President Clinton signs it on June 10.

1994 – AIDS is the leading cause of death for all Americans ages 25-44
By October 31, 500,000 cases of AIDS have been reported in the U.S.
1997 – UNAIDS (the joint United Nations Programme on AIDS) estimates that 30 million adults and children worldwide have HIV, and that, each day, 16,000 people are newly infected with the virus.
1998 – CDC reports that African Americans account for 49% of U.S. AIDS related deaths. AIDS-related mortality for African Americans is almost 10 times that of Whites and three times that of Hispanics.
2000 – On May 10, President Clinton declares that HIV/AIDS is a threat to U.S. national security.
2002 – On November 7, the U.S. Food and Drug Administration (FDA) approves the first rapid HIV diagnostic test kit for use in the United States that provides results with 99.6 percent accuracy in as little as 20 minutes.
2007 – CDC reports over 565,000 people have died of AIDS in the U.S. since 1981.
2009 – In December, President Obama signs the Consolidated Appropriations Act, 2010 modifying the ban on the use of Federal funds for needle exchange programs.
2010 – On January 4, the U.S. Government officially lifts the HIV travel and immigration ban.
2011 - The National Institutes of Health (NIH) announce the results of the iPrEx study, showing that a daily dose of HIV drugs reduced the risk of HIV infection among HIV-negative men who have sex with men by 44%, supporting the concept of pre-exposure prophylaxis (PrEP) in a targeted population.
2012 - July 1: The Kaiser Family Foundation and the Washington Post release a joint survey of the American public’s attitudes, awareness, and experiences related to HIV and AIDS. The survey finds that roughly a quarter of Americans do not know that HIV cannot be transmitted by sharing a drinking glass—almost exactly the same share as in 1987.
On July 16, The FDA approves the use of Truvada® for pre-exposure prophylaxis (PrEP).
2013 – President Obama signs the HIV Organ Policy Equity (HOPE) Act, which will allow people living with HIV to receive organs from other infected donors. The HOPE Act has the potential to save the lives of about 1,000 HIV-infected patients with liver and kidney failure annually.
2014 – January 1: Major provisions of the Affordable Care Act (ACA) designed to protect consumers go into effect. Insurers are now barred from discriminating against customers with pre-existing conditions, and they can no longer impose annual limits on coverage—both key advances for people living with HIV/AIDS.
On March 4, European researchers announce the results of the first phase of the PARTNER Study. The study found that no HIV-positive partner who was undergoing antiretroviral therapy and had an undetectable viral load had transmitted HIV.
On November 25, CDC announces that only 30% of Americans with HIV had the virus under control in 2011, and approximately two-thirds of those whose virus was out of control had been diagnosed but were no longer in care.
On December 23, FDA announces it will recommend changing the blood donor deferral guidelines for men who have sex with men from permanent deferral to one year since the last sexual contact. In 1983, the agency imposed a lifetime ban on donating blood for all men who have ever had sex with another man.
2015 - February 23: CDC announces that more than 90% of new HIV infections in the United States could be prevented by diagnosing people living with HIV and ensuring they receive prompt, ongoing care and treatment.
On July 20, Researchers report that antiretroviral therapy is highly effective at preventing sexual transmission of HIV from a person living with HIV to an uninfected heterosexual partner, when the HIV-positive partner is virally suppressed.
On December 6, CDC announces that diagnoses in the U.S. fell by 19% from 2005 to 2014. Diagnoses among white gay/bisexual men decreased by 18%, but they continued to rise among Latino gay/bisexual men and were up to 24%. Diagnoses among black gay/bisexual men also increased up to 22%.
On December 19: Partly in response to the HIV outbreak in Indiana, which is linked to people injecting drugs, Congress lifts restrictions that prevented states and localities from spending Federal funds for needle exchange programs.
December 21: The U.S. Food and Drug Administration announces it will lift its 30-year-old ban on all blood donations by men who have sex with men and institute a policy that allows them to donate blood if they have not had sexual contact with another man in the previous 12 months.
2016 – January 19: CDC reports that only 1 in 5 sexually active high school students has been tested for HIV. An estimated 50% of young Americans who are living with HIV do not know they are infected.
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2018