

↓ 50%
NEW HIV
DIAGNOSES

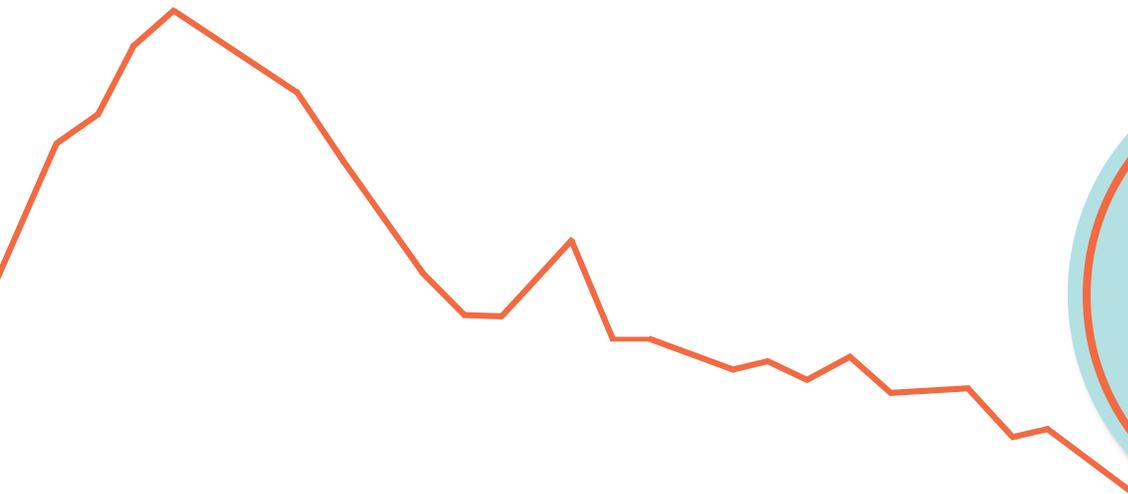
80%
SUPPRESSED
VIRAL LOAD

↓ 25%
HIV
MORTALITY

↓
HIV HEALTH
DISPARITIES

↑
QUALITY LIFE
WITH HIV

www.endaidswashington.org



**END
AIDS**
WASHINGTON
2020



People living with HIV and members of communities affected by HIV
Governor's Office | Washington State Legislature
Washington State Department of Health | Health care organizations and systems
Health Care Authority | Office of the Insurance Commissioner
Office of the Superintendent of Public Instruction | Local School Districts
Affordable housing sector | Local Health Jurisdictions
Local governments and service providers

DOH Pub 410-069 | August 2016

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End AIDS Washington

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By 2020...

1. Identify and reduce HIV stigma
2. Reduce HIV-related disparities
3. Implement routine HIV testing
4. Increase access to pre-exposure prophylaxis (PrEP)
5. Create health care that meets the needs of sexual minorities
6. Improve HIV prevention and care for substance users
7. Remove barriers to insurance and increase health care affordability
8. Increase access to safe, stable, and affordable housing
9. Deliver whole-person health care to PLWH
10. Launch *Healthier Washington for Youth*
11. Include meaningful community engagement and empowerment

↓ 50%
NEW HIV
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QUALITY LIFE
WITH HIV



EXECUTIVE SUMMARY

We are at a critical turning point in the HIV epidemic in Washington State. Rates of new HIV and AIDS diagnoses, as well as the mortality among people living with HIV (PLWH), have been gradually declining in Washington State over the last decade. This success is a product of scientific advances that have made HIV a treatable condition, and of the effectiveness of our state's prevention, care and treatment infrastructure. Public investments and collaborations among PLWH, HIV advocates, community-based organizations (CBOs), government, and health care and social service providers have put Washington at the forefront of HIV treatment and prevention efforts. These collaborations, investments and innovations have brought us to the threshold of ending the HIV epidemic and greatly improving health outcomes for PLWH in our state.

But this success is not guaranteed, particularly as racial and ethnic disparities in infection rates, access to care, and health outcomes remain. Continued progress will require us to do more than sustain existing services in their current forms. We need to intensify our efforts, break down silos, address the social determinants of health, and fully engage the communities most affected by HIV.

Governor Inslee's Proclamation to End AIDS in Washington

On *World AIDS Day* (December 1, 2014), Governor Inslee issued a *Proclamation to End AIDS in Washington*; set a goal of reducing new HIV diagnoses by 50%, by 2020, and reducing disparities in health outcomes for PLWH. The proclamation builds on the *National HIV/AIDS Strategy* (NHAS) and seeks to leverage opportunities within the *Healthier Washington* framework. While it is not possible to completely eradicate HIV in our state without a cure, a significant reduction in new diagnoses and in HIV-related disparities, along with an increase

in percentage of people diagnosed with HIV who have suppressed viral loads, will greatly reduce the impact of AIDS in Washington State, while improving the quality of life for those living with HIV. Governor Inslee's *Proclamation* is a bold commitment to expediting an end to the HIV epidemic, improving the health and quality of life for PLWH, reducing new diagnoses, and addressing disparities in health outcomes.

End AIDS Steering Team

The *Proclamation* tasked the HIV Planning Steering Group (HPSG), the statewide HIV treatment and prevention planning body, with overseeing a task force to put forward a set of recommendations on how the state can achieve its goals. The HPSG established the End AIDS Steering Team (Steering Team) to engage in a community input process and draft the initial set of recommendations. The Steering Team included PLWH, staff members of CBOs, an HIV medical provider, public health representatives, and members from Eastern and Western Washington.

Goals of End AIDS Washington

The Steering Team established five goals for the work of *End AIDS Washington*, which include the goals established in the Governor's *Proclamation*:

- Reduce by 50% the rate of new HIV diagnoses.
- Increase to 80% the percentage of people living with HIV who have a suppressed viral load.
- Reduce by 25% the age-adjusted mortality rates for PLWH.
- Reduce HIV-related health disparities among people living with HIV.
- Improve quality of life for people living with HIV.

HIV-Related Stigma and Health Disparities

Through the community input process it became clear that the intersecting issues of HIV-related stigma and health disparities are most commonly identified as significant barriers to accessing HIV screening, accessing culturally appropriate health care and support services, using HIV treatment or prevention regimens, and staying retained in care.

People living with and at risk for HIV often experience overlapping stigmas, including stigma associated with HIV, HIV testing and pre-exposure prophylaxis (PrEP); stigma related to sexual orientation or gender identity; stigma related to race or ethnicity; stigma related to poverty or homelessness; stigma related to mental health conditions and substance use disorders (SUD); stigma related to aging (especially for people over age 50 living with HIV) and others. Furthermore, persistent disparities—particularly by race and ethnicity—related to HIV risk, diagnosis rates, and health outcomes result in unacceptable health inequities.

End AIDS Washington Recommendations

The Steering Team prioritized recommendations that would advance one or more of the five stated goals of *End AIDS Washington*, and better ensure that systems and supports reach currently underserved communities.

The *End AIDS Washington* recommendations neither replace successful programs and interventions nor include the exhaustive list of all of the HIV work currently in progress.

Instead, as there are significant existing HIV treatment and prevention efforts underway in Washington's public and private sectors, the Steering Team focused on developing *End AIDS* recommendations that would complement, supplement, and/or expand upon these existing efforts. In addition, these recommendations specify leadership opportunities for ending AIDS for the Governor and the Legislature; and, in an effort to expand the scope

of work on ending AIDS, the recommendations identify other large systems—insurance, health care, behavioral health, housing, education—where public health, through creative and committed collaboration, can significantly improve outcomes for PLWH and those at risk for HIV.

This report makes 11 recommendations to achieve the goal of *End AIDS Washington*, and each recommendation includes specific action items. Stigma reduction and disparities reduction are their own recommendation areas, and these themes also run through the other nine recommendation areas. The *End AIDS* recommendations are:

- Identify, address, and reduce stigma experienced by PLWH and individuals at risk for HIV.
- Address and measurably reduce HIV-related disparities.
- Implement routine, standardized HIV screening for all Washington residents.
- Increase access to pre-exposure prophylaxis (PrEP), an important HIV prevention tool.
- Create a health care system that meets the needs of sexual minorities.
- Improve HIV prevention, care, and treatment among substance users, including persons who inject drugs (PWID).
- Remove barriers in insurance coverage and increase health care affordability for PLWH and individuals at risk for HIV.
- Increase access to safe, stable, and affordable housing for PLWH and people at risk for HIV.
- Deliver whole-person health care to PLWH and individuals at risk for HIV, and ensure continuity of integrated care across the lifespan.
- Launch *Healthier Washington for Youth*: Improve sexual health education, physical and behavioral health services, and social supports and interventions for Washington youth.

- Invigorate and strengthen meaningful community engagement and empowerment for people and communities disproportionately affected by HIV-related disparities and stigma.

Communities, Agencies and Sectors to Lead This Work

Successful implementation of *End AIDS Washington* will require collaboration across sectors and groups. The recommendations identify the following agencies and communities as leaders for the work:

- PLWH and members of communities affected by HIV
- Governor's Office
- Washington State Legislature
- Washington State Department of Health (DOH)
- Health care organizations and systems
- Health Care Authority (HCA)
- Office of the Insurance Commissioner (OIC)
- Office of the Superintendent of Public Instruction (OSPI)
- Local school districts
- Affordable housing sector
- Local Health Jurisdictions (LHJs)
- Local governments
- Service providers

Ending the HIV Epidemic in Washington—Looking Ahead

Washington State is in an exciting position to build on the strong foundation of public and private investment to keep PLWH healthy and prevent new HIV infections. We can address the social determinants of health and substantially reduce racial and ethnic disparities in health outcomes. By maintaining our state's efforts to deliver treatment and care to everyone living with HIV; by focusing our efforts on breaking down silos between systems and removing barriers to care; by prioritizing communities of color and other underserved populations; and by galvanizing communities to put these recommendations into action, Washington will cut the HIV diagnosis rate in half by 2020, reduce HIV-related disparities, and significantly improve the health and well-being of PLWH.

The end of AIDS is possible. Until there is a cure, Washington State is committed to innovative and collaborative public and private sector interventions to reach every person living with and at risk for HIV, to provide the tools and resources needed to protect their health and well-being, to measurably reduce HIV-related disparities, and to prevent new HIV diagnoses. Washington will be a model for other states and jurisdictions in tackling their HIV epidemics.

Successful implementation of these recommendations will rely on passionate and inspired leadership, a willingness and capacity for self-reflection, a commitment to honor those touched by HIV and all who are engaged in the effort to end this epidemic. The HPSG is confident that Washington State has these key ingredients in abundance, and looks forward to the day when we can all celebrate the end of AIDS.

The HPSG upholds the reality that words and names matter. The choice of language to identify individuals, groups, or behaviors is important and people may disagree about the most appropriate terminology. Different constituencies may use terms differently. An effort is made in this report to select and use descriptive language consistently, as one effort to provide clarity about the work that needs to be done to end AIDS.

The HPSG strongly supports the *Community Engagement* recommendation and processes in this report and envisions these community conversations as a way to hear more clearly from people what descriptive language is meaningful for them, recognizing that even within a group, there may be a variety of perspectives about the most appropriate and relevant language. Preferred language is likely to change and evolve over time, as language

is alive. [Appendix B](#) identifies a number of descriptive terms used in the report and the alternative wording that has been identified in this process. The HPSG looks forward to additional listening and dialogue about language and other aspects of the *End AIDS Report*.

The HPSG further emphasizes that ending AIDS is an active, ongoing effort. The work is iterative, meaning that as it begins and progresses, the voices of the communities most affected by HIV will be welcomed. Implementation will consider experience about what works and what doesn't, additional and new scientific or medical findings, and new information from others working to end AIDS. While the goals and recommendations of this report (the WHAT of *End AIDS*) stand themselves as a finished product, updates to the report will be developed, and implementation plans (the HOW of *End AIDS*) will reflect new information and learning.



"Of the 1.2 million people in the US living with HIV, 170,000 don't even know it. HIV is preventable, and we can help end the epidemic by getting tested. Know your status."

— *Paris*

INTRODUCTION

Washington's HIV Epidemic in 2015: Where We Stand and What We Can Do

While the HIV epidemic continues, Washington is in a position to dramatically advance our progress toward ending AIDS. Rates of new HIV and AIDS diagnoses, as well as the mortality PLWH, have been gradually declining in Washington State, over the past decade. This success is a product of scientific advances that have made HIV a treatable condition and of the effectiveness of our state's prevention and care infra-structure. This infrastructure represents a col-laboration among PLWH, public health, HIV advocates, CBOs, government, the health care system, and human service providers. It has allowed us to capitalize on scientific advances in a way that few other states can match. Indeed, Washington is at the forefront of prevention efforts, establishing the first state program to increase access to pre-exposure prophylaxis (PrEP), a medication that HIV-negative individuals can use to prevent HIV. Taken together, these collaborations, investments, and innovations have brought us to the threshold of ending the HIV epidemic and greatly improving health outcomes for PLWH in our state.

But this success is not guaranteed, particularly as disparities for some groups remain—in infection rates, access to care, and health out-

comes. Continued progress will require us to do more than sustain existing services in their current forms. We need to intensify our efforts, break down silos and fully engage the communities most affected by HIV. Our state already tests and treats the HIV-positive population that is easiest to reach and has ready access to the health care system. The people who are not reached by our current programs are the most vulnerable and often face multiple layers of stigma, discrimination, and other barriers. Some of the most vulnerable people are from communities of color and/or immigrant communities, facing poverty, and/or homelessness. Many vulnerable people struggle with mental illness or substance use disorders. Some become increasingly invisible as they age. We need a health care and support system equipped to reach and welcome everyone living with or at risk of HIV and meet each individual's needs.

Now is the time to build on our momentum. We must leverage the power of communities most affected by HIV; and work across sectors to improve the health and well-being of PLWH, to measurably reduce HIV-related disparities, and to dramatically reduce the rate of new HIV diagnoses. In doing so, we will move Washington State even closer to ending AIDS.

Facts and Figures

The first case of AIDS in Washington State was diagnosed in 1981. Since then, more than 20,000 people in Washington have been diagnosed with HIV, and more than 6,500 have died. Washington State Department of Health (DOH) estimates there are over 14,000 people living

with HIV in Washington today. More than 70% of PLWH in Washington State are gay and bisexual men. Recent transmission rates have decreased slightly; Washington reports about 500 new cases per year, from 2010 to 2014.¹

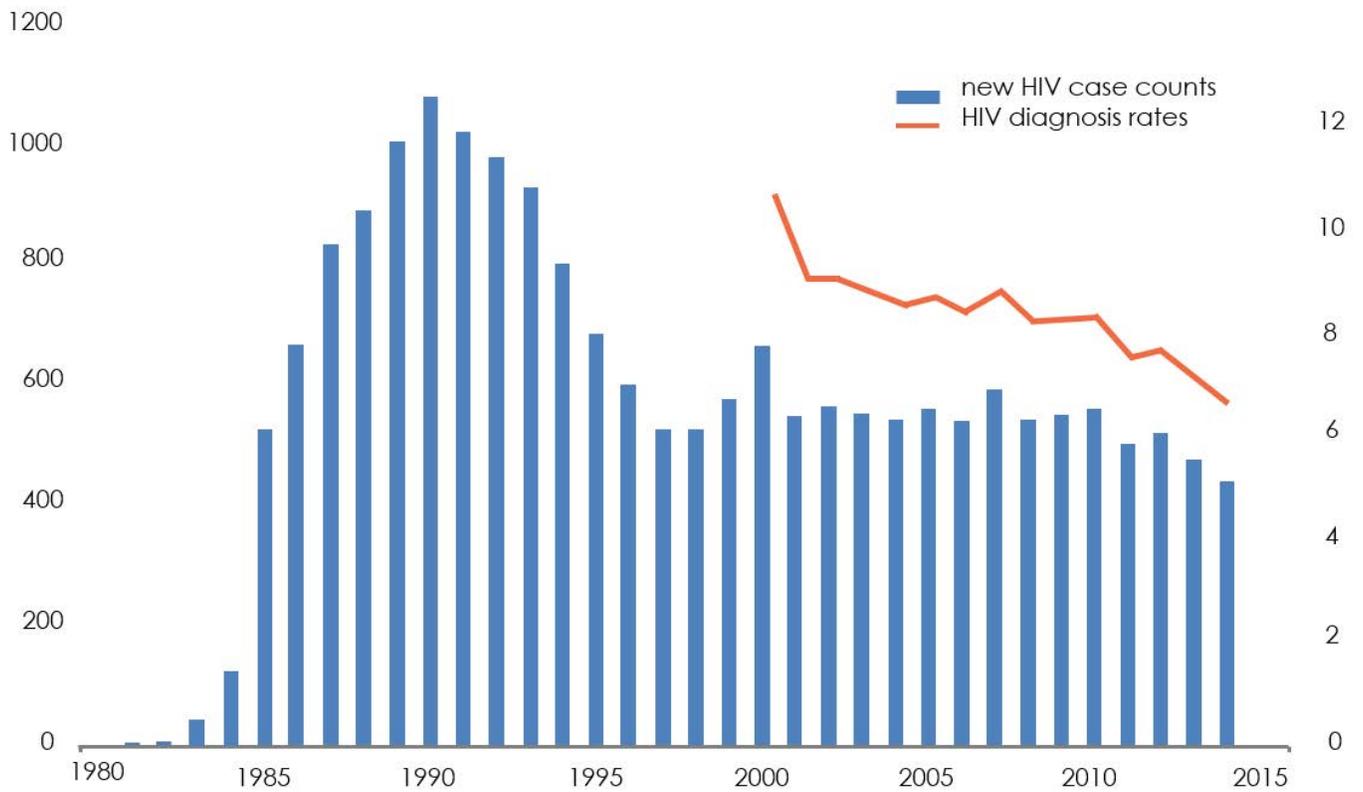


Figure 1. Counts and rates of new HIV diagnoses Washington State, 1981-2014

Based on case information reported to DOH as of March 31, 2015

HIV/AIDS Care Continuum

The care continuum is a useful way to look at how successfully the HIV system engages and retains PLWH in care, and at which points individuals fall out of care. The continuum starts at diagnosis and ends at viral suppression. The goal of the HIV care system is

to achieve 100% engagement at each step in the continuum, which would mean that all PLWH are diagnosed, retained in care, and virally suppressed, greatly improving individual health and well-being and vastly reducing the likelihood of transmission.

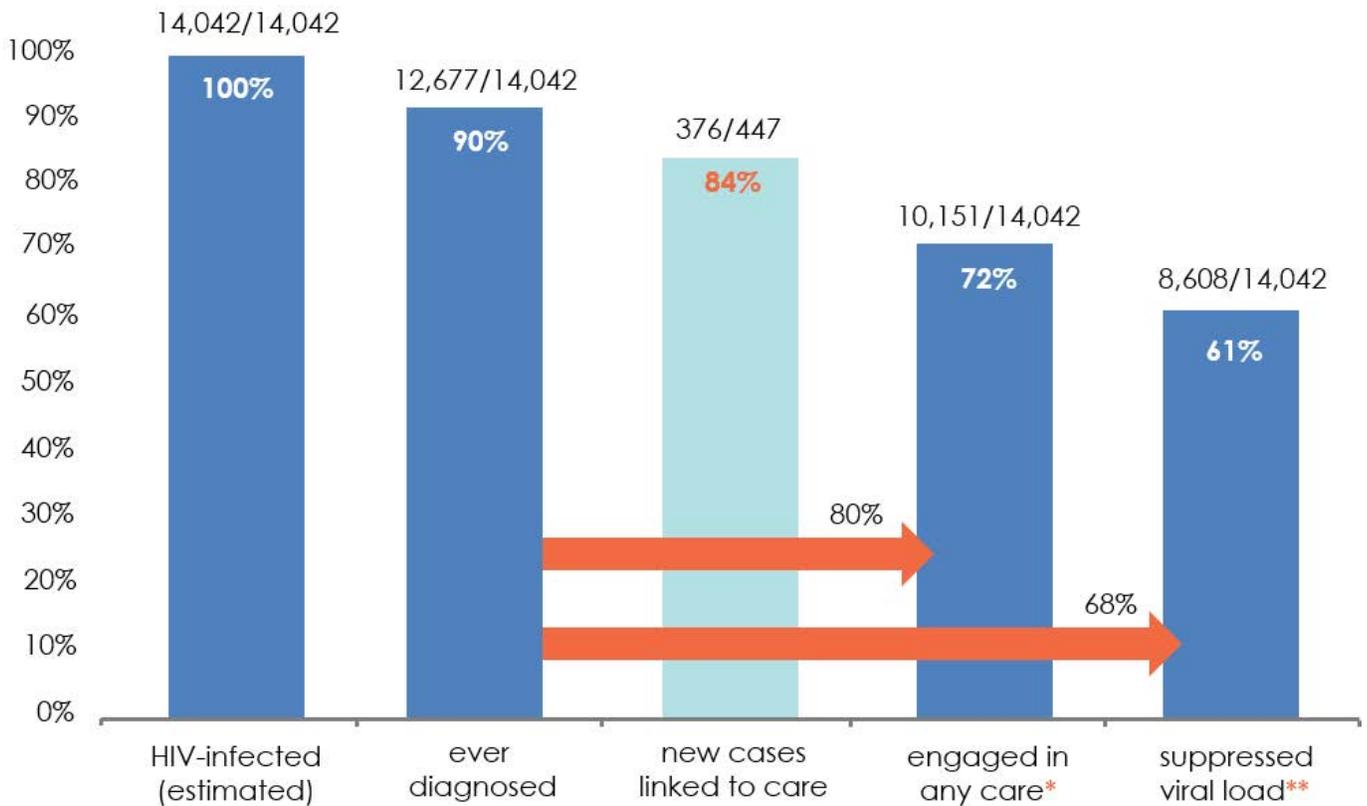


Figure 2. HIV care continuum
Washington State, 2014

Based on HIV surveillance data reported to DOH as of June 30, 2015

Limited to newly diagnosed HIV cases linked to care within one month (30 days) of HIV diagnosis

*Includes cases with laboratory evidence of at least one HIV care visit in 2014

**Suppression based on whether the last reported viral load test result in 2014 was ≤ 200 copies/mL

Washington State strives to achieve health equity. While the state has a greater percentage of PLWH engaged in each step of the care continuum than the U.S. overall, there is more work to be done, particularly in terms of reducing racial and ethnic disparities.

Gaps also exist between PLWH born inside vs. outside the U.S. The state must do what it can to assure all people have equal and sufficient access to HIV prevention, care, and treatment services.

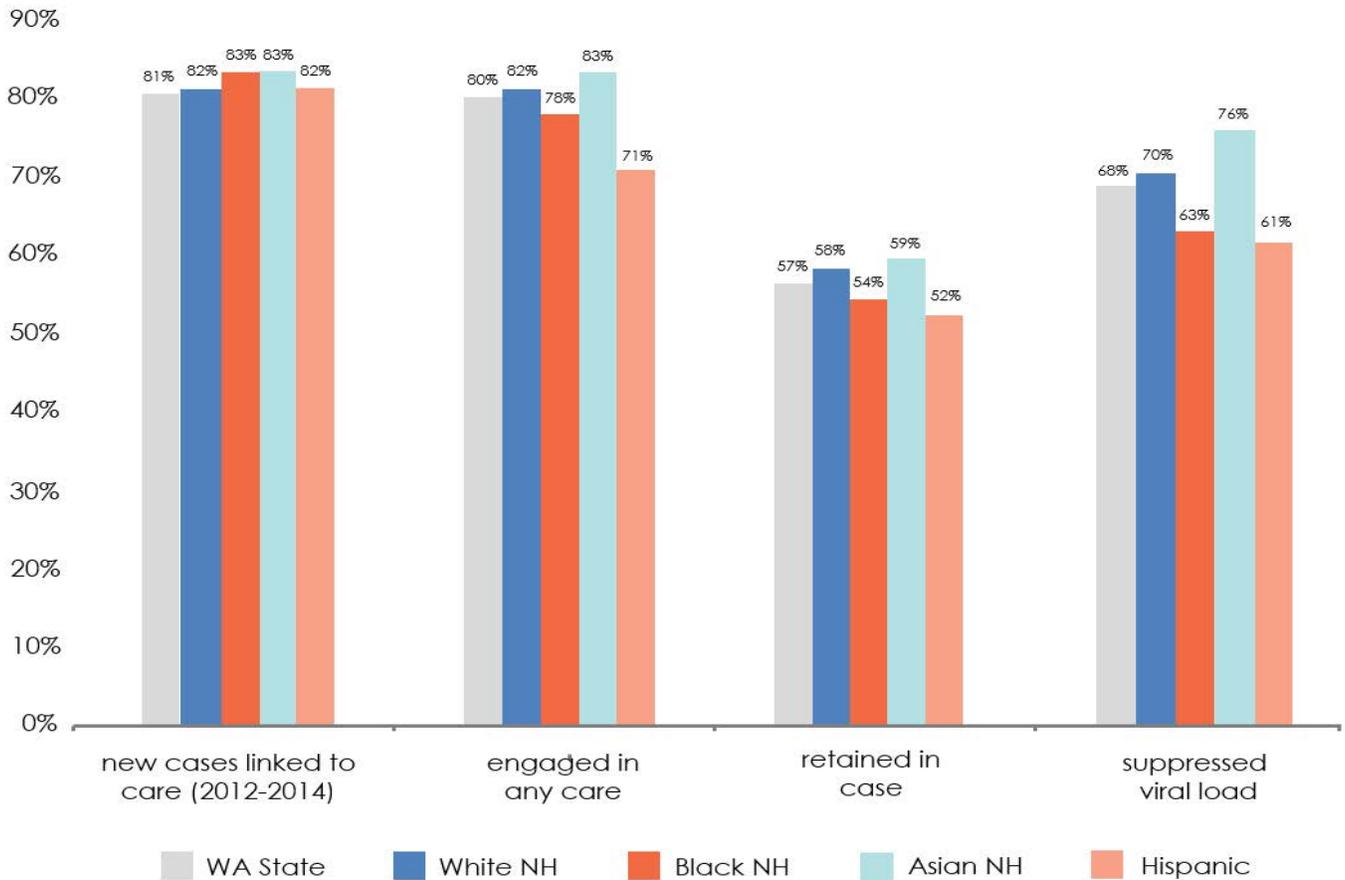


Figure 3. HIV care and virologic suppression among people living with HIV, by race/ethnicity Washington State, 2014

Exciting Advances in HIV Treatment and Prevention

The latest U. S. Department of Health and Human Services *HIV Treatment Guidelines* recommend starting anti-retroviral (ARV) therapy immediately upon HIV diagnosis.² When taken consistently, ARVs suppress HIV in the blood to the point that the HIV is undetectable. This not only improves the health and well-being of PLWH, it decreases the risk of transmitting HIV to a sex partner by 96%.³ Simply put, treatment is a powerful form of prevention.

HIV medication can also prevent people who are not infected with HIV from acquiring it. The U.S. Food and Drug Administration (FDA) has approved tenofovir/emtricitibine (commercial name *Truvada*[®])—ARV medication—for use by HIV-negative individuals as a prevention tool called pre-exposure prophylaxis (PrEP). When taken regularly, recent studies indicate PrEP is nearly 100% effective in preventing HIV transmission.⁴ PrEP, along with condom distribution and syringe exchange for people who inject drugs, is a critical prevention tool for HIV-negative individuals at risk for HIV.

Until there is a cure, it is imperative that our systems meet the needs of all people living with HIV, to assure the best possible health outcomes, and to reach all individuals at risk for HIV, providing access to the prevention tools and resources that best meet their needs. This is how we will move closer to the end of the epidemic in our state.

HIV Prevention, Care and Treatment in Washington State

Public and private investments and strategic initiatives already underway have made Washington a model of innovative HIV prevention, care and treatment programs. The Washington State Department of Health (DOH) and local health jurisdictions allocate funds from federal and state sources to support a wide array of services to diagnose and treat PLWH and prevent new diagnoses.

Working together, DOH, LHJs, and CBOs are on the front lines of our HIV work, from surveillance, to HIV testing, to linkage to care, to medical case management, to partner services. LHJs and CBOs have been and will continue to be an invaluable part of our state's HIV response.

The *Washington State Strategic HIV Prevention Framework (Framework)* guides DOH's investments in HIV prevention, care, and treatment. In 2013, DOH published the *Framework*, which was the outcome of a three-year planning process led by the HIV Prevention Planning Group (HPPG). It refocused HIV prevention goals, outcomes, and activities in Washington State. The Framework identified six outcomes:

1. Suppress viral load in all persons living with HIV in Washington State.
2. Decrease incidence of gonorrhea and syphilis among HIV positive persons and gay and bisexual men, in Seattle and secondary urban areas.*
3. Increase use of pre-exposure prophylaxis (PrEP) among gay and bisexual men, in Seattle and secondary urban areas.*
4. Increase use of non-occupational post-exposure prophylaxis (nPEP) among gay and bisexual men in Seattle and secondary urban areas.*
5. Increase use of condoms among gay and bisexual men, in Seattle and secondary urban areas.*
6. Increase the use of clean needles among intravenous drug users (IDU) in Seattle and secondary urban areas.*

Using the *Framework* as a guiding document, DOH, LHJs, CBOs, and others are implementing an array of programs and interventions, including:

*Secondary urban areas are: Everett, Kent, Renton, Shoreline, Spokane, Tacoma and Vancouver

Community engagement

Individuals and communities are central to Washington State's HIV response. DOH funds CBOs and LHJs to engage and mobilize communities to connect them to prevention, care and treatment services, including HIV/sexually transmitted disease screening, PrEP, and HIV treatment. Partners accomplish this through outreach, education, and services that help individuals enroll in health insurance and navigate the health care system. DOH also funds marketing campaigns targeted to communities most affected by HIV. One example is the *We Are One* campaign, which provides outreach and connection to services for gay and bisexual men and transgender/non-binary individuals who have sex with men in King, Pierce, and Snohomish counties.⁵

HIV and Sexually Transmitted Disease testing and linkage to care

DOH funds HIV and STD screening offered by LHJs and CBOs, for individuals who cannot or will not access these services through the health care system. For individuals testing positive for HIV and/or an STD, these programs facilitate connections to appropriate care and treatment. The goal of these programs is to find individuals currently living with HIV and/or an STD and connect them to the care they need to stay healthy and reduce the likelihood of transmission to others.

HIV/STD partner services

Partner services reduce future HIV/STD transmission through early diagnosis, treatment, partner notification, and testing. LHJs are trained to provide partner services for individuals who test positive for HIV and/or an STD. After providing support and linkage to care for newly diagnosed individuals, partner services professionals notify sexual and/or injection drug partners of possible HIV/STD exposure and connect them to testing services. Partner services programs also connect high-risk HIV-negative individuals to PrEP.

Health care engagement

Successful HIV prevention, care and treatment rely heavily on the health care system. To help ensure high-quality health care services are available, DOH works closely with health care providers, health care systems and health care payers. Efforts include scaling up the provision of clinical preventative services, building coverage capacity of HIV-related medical care, and working with health insurers and regulators to remove cost barriers to HIV services.

Clinical services

Ryan White-funded Part C Clinics provide HIV medical care in Seattle, Yakima, Spokane and Pierce counties. DOH funds Harborview Medical Center satellite clinics in Snohomish, King, Kitsap, and Thurston counties.

Early Intervention Program (EIP) and the AIDS Drug Assistance Program (ADAP)

Washington's Ryan White-funded ADAP is called the *Early Intervention Program* (EIP) and is administered by DOH. EIP pays for health insurance premiums and co-pays and co-insurance for HIV-related medications, office visits, and lab services for PLWH who qualify. (Current eligibility is all PLWH residing in Washington with incomes up to 400% of the federal poverty level, about \$47,000/year for a single individual).

Support services for persons living with HIV

Medical case management helps connect PLWH and other long-lasting conditions with health services and resources to help them be independent and achieve and maintain good health. Case managers play a critical role in connecting PLWH to support services, addressing barriers to treatment adherence, and promoting the overall well-being of PLWH. DOH and Public Health - Seattle & King County (PHSKC) fund medical case management. CBOs, medical providers, and LHJs provide this service. DOH and PHSKC also fund medical

nutrition therapy, oral health care, mental health services, substance use disorder outpatient treatment, non-medical case management, housing services, food and meals, treatment adherence counseling, psycho-social support services, outreach, early intervention services and medical transportation.

Reengagement in HIV medical care

For a variety of reasons, some PLWH disconnect from medical care at points in their lives. Because HIV treatment keeps PLWH healthy and reduces the likelihood they transmit HIV to others, DOH, in partnership with LHJs and CBOs, works diligently to identify and reconnect out-of-care PLWH to the health care system.

PrEP Drug Assistance Program (PrEP DAP)

Washington was the first state in the nation to start a PrEP DAP, which provides *Truvada*[®], the anti-retroviral medication approved for use as PrEP, to individuals at risk for HIV. When taken consistently, PrEP is highly effective at preventing HIV. There are more than 500 residents currently enrolled. DOH, which administers PrEP DAP, is working with LHJs and CBOs to train medical providers about PrEP.

Syringe services programs

DOH uses state general fund dollars to support syringe services programs. These programs, run by LHJs and CBOs, provide sterile syringes and other injection equipment, offer screenings or referrals for screenings for HIV and hepatitis C, and help connect people who inject drugs to harm reduction and other support services.

Condom distribution

DOH, LHJs and CBOs fund the distribution of condoms to help ensure these are available and accessible to individuals who need them.

In Context: National and State HIV/AIDS and Health Care Efforts

National HIV/AIDS strategy

In 2010, President Obama released the *National HIV/AIDS Strategy* (NHAS), our nation's first set of priorities, action steps, and measurable out-comes for addressing the domestic HIV epidemic. The White House updated the NHAS in July 2015.⁶ The NHAS established four strategic goals:

1. Reduce new infections.
2. Increase access to care and improve health outcomes for people living with HIV.
3. Reduce HIV-related health disparities and health inequities.
4. Achieve a more coordinated national response to the HIV epidemic.

Healthier Washington

Washington State is engaged in system-wide innovation, aimed at achieving better care for patients, better health outcomes, and lower health care costs. This endeavor, *Healthier Washington*, is working across the health care delivery system to better integrate physical and behavioral health and focus on whole-person care. Part of *Healthier Washington* is the establishment of nine *Accountable Communities of Health* (ACH), which are public-private partnerships that work regionally to engage their communities in priority-setting and decision-making around health care purchasing and delivery. ACHs are focused on the social determinants of health and linkages between clinical efforts and the community. Another component is the state's *Medicaid Global Transformation Waiver* application, which seeks to leverage savings in the state's Medicaid program for interventions aimed at whole-person health and reducing disparities in health outcomes. There are numerous ways for the HIV prevention care and treatment system to leverage opportunities within the developing ACHs, Medicaid waiver, and other initiatives of *Healthier Washington*.

Governor Inslee's Proclamation to End AIDS in Washington

On World AIDS Day (December 1, 2014), Governor Inslee issued a *Proclamation to End AIDS in Washington*, setting a goal of reducing new HIV diagnoses by 50% by 2020 and reducing disparities in health outcomes for PLWH. The *Proclamation* looks to NHAS and seeks to leverage opportunities within the *Healthier Washington* framework. While it is not possible to completely eradicate HIV in our state without a cure, a significant reduction in new diagnoses and in HIV-related disparities, along with an increase in percentage of people diagnosed with HIV who have suppressed viral loads, will greatly reduce the impact of AIDS in Washington State, and improve the quality of life for those living with HIV. Governor Inslee's *Proclamation* made Washington the second state in the country to declare an end to AIDS. His bold commitment has the potential to expedite an end to the HIV epidemic, by improving the health and quality of life for PLWH, reducing new diagnoses, and addressing disparities in health outcomes. Full text of the proclamation is in the [Appendix A](#).

End AIDS Steering Team

The *Proclamation* tasked the HIV Planning Steering Group (HPSG), the statewide HIV preven-

tion and care planning body, with overseeing a task force to put forward a set of recommendations on how the state can achieve its goals. The HPSG established the End AIDS Steering Team (Steering Team) to engage in a community input process and draft the initial set of recommendations. The Steering Team comprises PLWH, staff members of CBOs, an HIV medical provider, and public health representatives, from Eastern and Western Washington. The Steering Team identified five goals for their work.

Goals for End AIDS Washington

- Reduce by 50% the rate of new HIV diagnoses.
- Increase to 80% the percentage of people living with HIV who have a suppressed viral load.
- Reduce by 25% the age-adjusted mortality rates for people living with HIV.
- Reduce HIV-related health disparities among people living with HIV.
- Improve quality of life for people living with HIV.

Baselines and targets for each goal are found in the tables on the next pages.

END AIDS GOALS, BASELINES AND TARGETS

Goal	2014 Baseline	2020 Target
ONE Reduce by 50% the rate of new HIV diagnoses	6.3 new HIV diagnoses per 100,000	≤ 3.2 new HIV diagnoses per 100,000
TWO Increase to 80% the percentage of people living with HIV who have a suppressed viral load	68% suppressed	≥ 80% suppressed
THREE Reduce by 25% the age-adjusted mortality rates for people living with HIV	2.2 deaths per 100,000	≤ 1.7 deaths per 100,000
FOUR Reduce HIV-related health disparities among people living with HIV	See detail below	See detail below
a. Reduce by 50% the absolute difference between the HIV diagnosis rate among U.S. born Black residents and the statewide HIV diagnosis rate	Rate difference of 14.6 cases per 100,000	Rate difference of ≤ 7.3 cases per 100,000
b. Reduce by 50% the absolute difference between the HIV diagnosis rate among foreign-born Hispanic residents and the statewide HIV diagnosis rate	Rate difference of 8.9 cases per 100,000	Rate difference of ≤ 4.5 cases per 100,000
c. Reduce by 50% the absolute difference between the percentage diagnosed late among foreign-born black residents and the late HIV percentage among all new HIV diagnoses	2012-14: Difference in late HIV percentage of 4%	2018-20: Difference in late HIV percentage of ≤ 2%

Goal	2012-14 Baseline	2018-20 Target
<p>d. Reduce by 50% the absolute difference between the percentage diagnosed late among foreign-born Hispanic residents and the late HIV percentage among all new HIV diagnoses</p>	<p>Difference in late HIV percentage of 10%</p>	<p>Difference in late HIV percentage of $\leq 5\%$</p>
<p>e. Reduce by 50% the absolute difference between the percentage diagnosed late among people ages 45 and older and the late HIV percentage among all new HIV diagnoses</p>	<p>Difference in late HIV percentage of 10%</p>	<p>Difference in late HIV percentage of $\leq 5\%$</p>
<p>f. Reduce by 50% the absolute difference between the percentage who are linked to HIV medical care within 30 days of diagnosis among newly diagnosed U.S.-born Black residents and the percentage linked among all new HIV diagnoses</p>	<p>Difference in percentage linked of 4.1%</p>	<p>Difference in percentage linked of $\leq 2.0\%$</p>
<p>g. Reduce by 50% the absolute difference between the percentage engaged in HIV medical care among foreign-born Hispanic people living with HIV and the percentage engaged among all people living with HIV</p>	<p>2014: Difference in percentage engaged in care of 14.5%</p>	<p>2020: Difference in percentage engaged in care of $\leq 7.3\%$</p>
<p>h. Reduce by 50% the absolute difference between the percentage virologically suppressed among U.S.-born Black people living with HIV and the percentage suppressed among all people living with HIV</p>	<p>Difference in percentage suppressed of 8.1%</p>	<p>Difference in percentage suppressed $\leq 4.0\%$</p>

Goal	2014 Baseline	2020 Target
<p>i. Reduce by 50% the absolute difference between the percentage diagnosed late among virologically suppressed among foreign-born Hispanic people living with HIV and the percentage suppressed among all people living with HIV</p>	<p>Difference in percentage suppressed of 10.5%</p>	<p>Difference in percentage suppressed $\leq 5.2\%$</p>
<p>j. Reduce by 50% the absolute difference between the percentage virologically suppressed among persons living with HIV who inject drugs and the percentage suppressed among all people living with HIV</p>	<p>Difference in percentage suppressed of 20%</p>	<p>Difference in percentage suppressed $\leq 10\%$</p>
<p>FIVE Improve quality of life for people living with HIV</p>		
<p>a. General health indicator: Increase to 82% the percentage of people living with HIV who rate their overall health as good, very good, or excellent</p>	<p>81%</p>	<p>$\geq 82\%$</p>
<p>b. Health-related disability days: Decrease to 3.0 the mean number of days in which poor physical or mental health prevented normal activities among people living with HIV</p>	<p>3.6 days</p>	<p>≤ 3.0 days</p>
<p>c. Summary index of healthy days: Increase to 22.0 the mean number of healthy days reported over past 30-day period</p>	<p>19.8 days</p>	<p>≥ 22.0 days</p>

The Steering Team coordinated a community input process, which helped develop of these recommendations and action items. The Steering Team wrote the first draft of this report which was then discussed, revised, and approved by the HPSG for further public comment. Input from the public comment process has now been incorporated into the final report which will be submitted to Governor Inslee in 2016.

The *End AIDS Washington* initiative and the forthcoming implementation plan are not owned by any one government agency or CBO. *End AIDS Washington* is a community-owned effort, and will only be successful if all stakeholders—communities, government, the health care system, and people most affected by HIV—are fully engaged in its implementation and empowered to make decisions and set priorities. The need for community engagement and leadership is evident in the recommendations themselves.

Community Input Process

The *End AIDS* Steering Team worked to provide multiple opportunities to reach PLWH, individuals at risk for HIV, medical providers, support service providers, and other stakeholders, striving to hear from all parts of the state and all communities affected by HIV. Feedback methods included an open-ended survey, available in English online and in paper form, through which the Steering Team received a total of 137 responses. The Steering Team also held six community forums around the state: Seattle, Tacoma, Everett, Spokane, Yakima and Vancouver, as well as targeted community conversations. The Steering Team sought the input of subject matter experts as they refined the recommendations. Information about *End AIDS Washington* and ways in which community members can engage in the process are available at www.endaidswashingtong.org. Through all of these methods, approximately 350 people helped form the recommendations. These individuals also provided invaluable feedback into the process itself and how to ensure community

engagement and leadership in designing implementation plans for the recommendations.

The community input process then moved to a second stage, when the draft report was released for public comment, for the period December 1, 2015, through January 15, 2016. Topics proposed through public comment have been incorporated into this final version of the report, including an additional recommendation related to substance users and HIV prevention, care and treatment, and a number of *Future Work* and *Next Steps* items.

Barriers and Opportunities Identified Through the Community Input Process

Several themes were prevalent across surveys and in community forums and other conversations, and offered a powerful view of the barriers faced by PLWH to stay healthy and maintain a high quality of life, as well as the barriers faced by individuals at risk for HIV in staying negative. The surveys and community conversations also offered suggested solutions and interventions to eliminate these barriers, or at least mitigate their impact.

These ideas are listed in detail in the recommendations section of the report and are summarized briefly below.

Barriers identified by survey respondents

Stigma

Stigma was the barrier most commonly identified through surveys and in community forums. The multiple stigmas that affect many PLWH and communities affected by HIV cut across all aspects of the care continuum.

Social determinants of health, including poverty and its effects

PLWH and individuals at risk for HIV often live in poverty. Housing instability and homelessness, food insecurity, lack of transportation, and other issues related to poverty are significant barriers to accessing and staying in care.

Health care access and costs

Many survey respondents noted the high cost of HIV-related health care, as well as challenges accessing culturally responsive HIV medical care providers (including LGBT-sensitive providers), mental health, and other specialists, particularly in rural areas.

Substance use disorder and mental health care and treatment needs

Many PLWH and individuals at risk for HIV also face challenges with substance use and mental health conditions, as well as challenges with the availability and cultural appropriateness of the services.

Lack of knowledge about HIV

Survey respondents and participants in community forums report a lack of knowledge about and awareness of HIV among affected communities as well as the public at large. This lack of knowledge was seen as contributing both to HIV risk and HIV-related stigma.

Opportunities identified by survey respondents

Medical advancements, including more effective HIV treatments and PrEP

The survey and community response indicate a high level of excitement about the promise of PrEP as a prevention tool, as well as hope for the success of cure and vaccine research efforts.

Telehealth and telemedicine

The increasing use of telehealth and telemedicine to help individuals in rural areas or anyone unable to access in-office care offers a useful model for improving access to medical care, mental health and other services for PLWH and individuals at risk for HIV.

System-wide efforts to integrate physical and behavioral health

Healthier Washington's focus on whole-person health and the integration of physical and men-

tal health services is an exciting model to meet the complex needs of many PLWH and individuals at risk for HIV and to create more seamless ways to access services.

Leveraging community expertise

Survey respondents and forum participants discussed the efficacy of using the expertise of PLWH and members of affected communities in all aspects of program planning, implementation, and evaluation.

An additional opportunity identified by DOH is the work being done by public health, CBOs, and the health care systems to increase the focus on addressing the social determinants of health that perpetuate health inequities. For example, the state's *Medicaid Global Transformation Waiver*, if successful, will allow the use of Medicaid resources to address the social determinants of health, which could greatly benefit low-income individuals living with and at risk for HIV.

Ideas Identified Through the Public Comment Process

Additional recommendation

Public comment identified HIV-related issues affecting substance users and the HPSG added new recommendation 6 in response to this input.

Need to address the unique circumstances of transgender people and people over the age of 50 living with HIV

Commenters raised concern that these two groups in particular have unique circumstances that require further engagement and listening before appropriate action steps or interventions can be identified. The HPSG agrees, and has added this work to the future work section of the report.

Implementation-related ideas

Public comment identified a number of suggestions that could affect implementation of the recommendations in the report. The HPSG has summarized these in the *Next Steps* section.

HIV-Related Disparities

Despite improvements in reducing the rate of new diagnoses, linking and retaining HIV-positive individuals in care, and achieving viral suppression among the overall population, persistent disparities remain for some groups in our state. Addressing and reducing these disparities is a moral imperative and is essential to the success of End AIDS Washington.

A special emphasis workgroup (SEW) for the HPSG released the HIV-Related Health Disparities Report in March 2015.⁷ This data is from the SEW report, based on data reported through year-end 2013, but some statistics have since changed based on newer, better data. The report identifies disparities experienced by specific populations across key indicators related to the care continuum:

HIV diagnosis rates

Gay and bisexual men are disproportionately at risk for HIV in Washington. HIV diagnosis rates among gay and bisexual men are 150 times higher compared to heterosexual men and women. U.S.-born blacks are four times as likely to be diagnosed with HIV compared to white residents, and foreign-born black residents are 16 times more likely than whites to have an HIV diagnosis. Foreign-born Hispanics are three times as likely to be HIV-positive than white residents.

Additionally, about half of all new HIV cases among adults ages 45 and older were late diagnoses.

Linkage to care

Linkage to care, meaning being successfully linked to HIV medical care within 90 days of an HIV diagnosis, is substantially lower for U.S.-born blacks (77%), compared to whites (90%) and foreign-born blacks (95%).

Engagement/retention in care

Foreign-born Hispanics and U.S.-born blacks are less likely to be retained in care (51% and 55%, respectively) than whites (60%). Younger adults living with HIV are significantly less likely to be engaged and retained in care than older adults living with HIV.

Viral suppression

Similar disparities can be seen in rates of viral suppression. While white residents living with HIV have a 70% viral suppression rate, only 58% of U.S.-born blacks, 64% of U.S.-born Hispanics and 55% of foreign-born Hispanics living with HIV are virally suppressed.

Disparities for groups vary across the care continuum, calling for carefully designed engagement strategies, depending on the group and the area where the disparity occurs. The HPSG acknowledges that the *End AIDS Washington*

***The HPSG gratefully acknowledges everyone
who took the time to provide thoughtful
and well-documented comments***

Late HIV diagnoses

Residents born outside of the U.S. are disproportionately likely to receive a late HIV diagnosis, meaning that an individual receives an AIDS diagnosis within a year of initial HIV diagnoses. While the late HIV diagnosis rate among whites is 33%, it is 40% among foreign-born blacks and 43% among foreign-born Hispanics.

recommendations prioritize specific communities for attention in reducing disparities and that there are other communities that also experience disparities, including Native Americans, and Pacific Islanders/Native Hawaiians. The HPSG prioritized specific populations in the initial *End AIDS Washington* implementation phase to maximize the impact on ending the epidemic by focusing on the largest numbers first.

Determining the Set of End AIDS Washington Recommendations

The Steering Team prioritized recommendations that would advance one or more of the five stated goals of *End AIDS Washington* and better ensure that systems and supports reach currently underserved communities.

The *End AIDS Washington* recommendations neither replace successful programs and interventions nor include the exhaustive list of all of the HIV work currently in progress.

Instead, as there are significant existing HIV pre-vention, care, and treatment efforts underway in Washington's public and private sectors, the Steering Team focused on developing *End AIDS* recommendations that would complement, supplement, and/or expand upon these existing efforts.

In addition, these recommendations specify leadership opportunities for ending AIDS for the Governor and the Legislature; and, in an effort to expand the scope of work on ending AIDS, the recommendations identify other large systems—insurance, health care, behavioral health, housing, education—where public health, through creative and committed collaboration, can significantly improve outcomes for PLWH and those at risk for HIV.

The Steering Team carefully considered all of the feedback received from the community, including all online and paper survey responses, in English and Spanish; all emails received at info@endaids.washington.org; all comments from community forums and other conversations convened for *End AIDS Washington*; and one-on-one conversations.

The Steering Team used both the community feedback and data and research from local, state, and national sources. Additionally, the Steering Team consulted with subject matter experts in developing a number of the action items detailed in this report. As noted above, the Steering Team prioritized recommendations that would advance one or more of the five stated goals of *End AIDS Washington* and

would better ensure that systems and supports reach currently underserved communities. The Steering Team also prioritized recommendations that leverage other resources, and that tie to the *HIV Strategic Framework*.

The Steering Team put the feedback from the community into recommendations that would need or benefit from the Governor's influence or direction, recommendations for consideration by DOH or other agencies, and recommendations for consideration by CBOs and others. Response to all of the feedback collected through the community input process is found in the [Appendix G](#).

The Steering Team submitted the draft report and recommendations to the HPSG on September 11, 2015, and the Steering Team presented the report and took questions and feedback from the HPSG at their September 17, 2015 meeting. The Steering Team then incorporated the requested revisions, and the HPSG received the report and took action on several proposed changes on November 19, 2015, prior to releasing an updated *Draft for Public Comment* version.

DOH released the *Draft for Public Comment* on December 1, 2015, for a 45-day public comment period. Following the close of the public comment period, DOH and the Steering Team reviewed all input and identified proposed changes for the HPSG to consider at its February 2016 meeting.

Based on public comment and the Steering Team's proposals, the HPSG made the following changes to the report:

- Added new recommendation 6: Improve HIV prevention, care, and treatment among substance users, including persons who inject drugs.
- Added to the *Future Work* section: The need to address the unique circumstances of transgender people and people over the age of 50 living with HIV. Commenters raised concern that these two groups in particular have unique circum-

stances that require further engagement and listening before appropriate actions or interventions can be identified for them.

- Added a number of implementation-related ideas to the *Future Work* section. Public comment identified a number of suggestions that could affect implementation of the recommendations in the report. The HPSG has summarized these in a table in the *Future Work* section.

The final *End AIDS Report* will be sent to the Governor and to DOH in the spring of 2016 to begin coordinating implementation of the recommendations. These are high-level recommendations and action steps to achieve the goals set in the Governor's proclamation. This document is not an implementation plan; implementation will need to be accomplished through a robust community engagement and leadership process. The *Next Steps/Future Work* sections of the recommendations document suggest some ways in which this work can be accomplished.

Looking Ahead: The End AIDS Washington Vision for 2020

The recommendations that follow have been carefully developed to address both short-term and longer-term opportunities to achieve

the goals for *End AIDS Washington*. There is a strong commitment to reducing stigma and HIV-related disparities, and investing in new forms of community engagement. While a number of the proposed action items build on the extensive work already being done by community-based organizations and public health, many of the action items reflect new or stronger partnerships between public health and other systems such as health care, insurance, housing, mental health, and education. While there is much yet to be done, there is great progress to be achieved toward ending AIDS in Washington State.

The HPSG further emphasizes that the effort to end AIDS is an active, ongoing, passionate effort. The work is iterative, meaning that as implementation begins and progresses, the voices of the communities most affected by HIV will be welcomed. Implementation will consider experience about what works and what doesn't, additional and new scientific or medical findings, and new information from others working to end AIDS. While the goals and recommendations of this report (the WHAT of *End AIDS*) stand themselves as a finished product, updates to the report will be developed, and implementation plans (the HOW of *End AIDS*) will reflect new information and learning.

The HPSG upholds the reality that words and names matter. The choice of language to identify individuals, groups, or behaviors is important and people may disagree about the most appropriate terminology. Different constituencies may use terms differently. An effort is made in this report to select and use descriptive language consistently, as one effort to provide clarity about the work that needs to be done to end AIDS. The HPSG strongly supports the *Community Engagement* recommendation and processes in this report and envisions these community conversations as

a way to hear more clearly from people what descriptive language is meaningful for them, recognizing that even within a group, there may be a variety of perspectives about the most appropriate and relevant language. Preferred language is likely to change and evolve over time, as language is alive. [Appendix B](#) identifies a number of descriptive terms used in the report and the alternative wording that has been identified in this process. The HPSG looks forward to additional listening and dialogue about language and other aspects of the *End AIDS Report*.



"Do not wait, get tested on a regular basis, because the sooner you know what your viral load is, the sooner you can get the medication to help knock that down."

— *Savannah*

RECOMMENDATIONS



Identify, Address and Reduce Stigma Experienced by PLWH and Individuals at Risk for HIV

Agencies and Sectors Impacted

The Legislature, Department of Health, health care organizations and systems, Local Health Jurisdictions and service providers, PLWH and members of communities affected by HIV.

Background

People living with HIV and individuals from communities affected by HIV often experience HIV-related stigma, as well as a number of other stigmas including those related to race, sexuality or gender identity, poverty, mental health status, or substance use. Stigma can be experienced in social and family settings, schools, health care systems, faith-based organizations and communities, social services agencies, the criminal justice system, and more. While HIV-related stigma may be declining, a significant number of *End AIDS* survey respondents reported that stigma in multiple forms remains a significant barrier to HIV testing, staying retained in care, disclosing HIV status, initiating and sustaining PrEP use, and overall quality of life.

"Addressing stigma [is the most important thing to consider in reaching the goals of *End AIDS Washington*] because stigma still keeps people from being tested, coming to our offices for help or engaging with medical care. Stigma continues to perpetuate myths and misinformation about HIV/AIDS and the communities most impacted. Multiple stigmas and levels of discrimination are responsible for the health disparities in marginalized communities. Addressing stigma through behavioral and social interventions within communities can greatly influence all four of these goals."

— *HIV Service Provider*

To achieve the goals of *End AIDS Washington*, government, health care providers, community-based organizations, faith communities and the broader society all need to address and reduce stigma experienced by PLWH and individuals at risk for HIV. We must do more to support LGBT individuals, people of color, and others affected by the various forms of stigma which foster HIV transmission, to embrace who they are, live their lives proudly, and enjoy good health. Work in this area should empower these groups that experience stigma, as well as increase the cultural awareness of professionals and others to provide services in a way that is welcoming and responsive.

National HIV/AIDS Strategy

"Stigma and discrimination must be eliminated in order to diminish barriers to HIV prevention, testing, and care. HIV-related stigma can be confounded by or complicated with stigma related to substance use, mental health, aging, sexual orientation, gender identity, race/ethnicity, or sex work. Stigma can lead to many negative consequences for people living with HIV. It is imperative that all levels of government recognize that these various biases exist and work to combat stigma and discrimination in order to reduce new infections and improve health outcomes for people living with HIV. In the legal arena, this requires ensuring that all federal and state criminal laws regarding HIV transmission and prevention are scientifically based, and that prosecutors and others in law enforcement have an accurate understanding of transmission risks."⁸ (emphasis in the original)

The sources of stigma can be diffuse, requiring a multi-sectoral community change effort that involves health care systems and providers, businesses, faith-based organizations and leaders, elected officials and government agencies, community-based organizations, community members, families, and others.

Leadership for Stigma Reduction Work

While recommending that the Department of Health be the 'entity in charge,' the HPSG also expressed that for this type of work (and for disparities and community engagement work) to be successful, it is critical that the leadership implement this work in new ways (specifically to include community member input and leadership of the design and implementation processes). The HPSG's recommendations about how to move forward with the implementation of this recommendation are found in the *Implementation and Next Steps* section of this report.

Action Items

Department of Health

1. Convene a Special Emphasis Workgroup (SEW) on HIV-related stigma.

Like the SEW that focused on HIV-related disparities, this Stigma SEW should bring together PLWH, members of affected communities, faith-based organizations, care providers, and others to analyze the drivers and effects of stigmas experienced by PLWH and individuals at risk for HIV in Washington State, and propose action steps to reduce these stigmas. HIV-related stigma is understood to be inclusive of stigma associated with HIV testing and stigma related to PrEP use. Members of the *Center For AIDS Research Community Advisory Board (CFAR CAB)* on HIV Stigma among MSM Working Group should be invited to assist in this effort.

2. Support the engagement and leadership of PLWH and members of affected communities in HIV planning and program evaluation.

Recommendations in this area are listed in full in the *Community Engagement* recommendation in this report.

Legislature

1. Modernize Washington State's HIV exposure and transmission laws to reflect current science and reduce HIV-related stigma.

Current state criminal law should be reformed to remove unfair discrimination based on HIV-positive status. Additionally, training on HIV risk and transmission is needed for prosecutors and other law enforcement officials in order to assure appropriate implementation of the criminal law.

Health care organizations and systems

- 1. When implementing action steps to reduce/eliminate HIV-related disparities (see next recommendation), address the impact of multiple forms of stigma on the groups experiencing disparities.**

HIV-related stigma and disparities are mutually reinforcing; addressing one barrier requires addressing the other.

- 2. Monitor access to health insurance to assure that PLWH and people at risk for HIV infection are not discriminated against in insurance coverage options, particularly in private employer health insurance plans, on the basis of perceived cost or medical condition.**

Several survey respondents report employers not wanting to provide health insurance coverage to HIV-positive employees due to cost. While this is anecdotal, monitoring access to insurance and other employment discrimination is needed.

How Stigma Is Addressed Across the End AIDS Recommendations

- 1. Overall:** Naming stigmas and how they are perpetuated, including unintentionally, throughout the recommendations and action steps.
- 2.** Routinizing and mainstreaming HIV screening for all Washington residents.

- 3.** Educating community members and providers about PrEP.
- 4.** Creating a health care system that meets the needs of sexual minorities.
- 5.** Addressing the stigma associated with HIV and substance use through a variety of action steps, including harm reduction based strategies for housing and health care.
- 6.** Having proactive support for increased access to HIV screening and PrEP from the Office of the Insurance Commissioner and the Legislature.
- 7.** Increasing the cultural responsiveness of housing and homelessness service providers in creating safe spaces for PLWH, LGBT individuals (including LGBT youth), people of color, immigrants and refugees, and people who inject drugs.
- 8.** Increasing the cultural responsiveness of providers across a newly integrated health care system to reduce stigma(s) experienced by PLWH, people at risk for HIV, and individuals seeking behavioral health services.
- 9.** Increasing culturally appropriate sexual health education, services and support for LGBT youth and youth of color in and out of school.
- 10.** Launching a comprehensive, meaningful community engagement and empowerment process to lead the implementation of all the *End AIDS Washington* recommendations.

Address and Measurably Reduce HIV-Related Disparities

Agencies and Sectors Impacted

Department of Health, health care organizations and systems, Local Health Jurisdictions and service providers, PLWH and members of communities affected by HIV.

Background

The HIV epidemic has affected some groups much more than others. To understand these disparities, the Department of Health convened a Special Emphasis Workgroup on HIV-related Disparities (SEW-D) to examine the statewide data in more detail. The SEW-D's report was published in February 2015.⁹

The SEW-D recognized the relationship of health disparities to the larger social context:

"HIV-related health disparities do not exist in isolation. They are part of a larger system of inequities that exists. They are compounded and exacerbated by one's daily experience of injustice. As the...Health Disparities SEW...convened as part of the Washington State HIV Planning System we recognize our role in identifying and proposing strategies directly related to the provision of HIV related services. However, it is our belief that achieving the vision described in the National HIV/AIDS Strategy will require a paradigm shift. It will require a social justice approach that looks not only at specific indicators of inequality but also attempts to address issues broadly associated with the social determinants of health."

National HIV/AIDS Strategy Vision

The United States will become a place where new HIV infections are rare and when they do occur, every person—regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socio-economic circumstance—will have unfettered access to high quality, life-extending care, free from stigma and discrimination.

"Social inequities that fuel the spread of HIV are only getting worse. We are not addressing the social determinants of HIV."

— HIV Service Provider

The SEW-D examined Washington's HIV-related data related to race and ethnicity, U.S.-born vs. foreign born, gay/bisexual men vs. heterosexual men and women, geography, age, and specified social determinants of health (income, education and poverty). The SEW-D identified the following specific disparities:

- 1. Overall:** Gay and bisexual men of all races/ethnicities, compared to heterosexual men, experience an actual disparity for HIV infection of more than 150:1. This disparity is being addressed in detail within the current HPSG framework.

2. U.S.-born black residents experience disparities in participation in prevention (PreP) and testing, in being linked to care, in retention in care and in viral load suppression (basically the entire care continuum, starting with prevention, needs to be improved for U.S.-born blacks). Disparities for U.S. blacks compared to whites are 4:1 for HIV infection. Seventy-seven percent of U.S.-born blacks, once diagnosed, are linked to care, compared to 90 percent of whites. The data show that U.S.-born blacks experience lower rates of retention in care and, as a result, are 10 percentage points less likely to be virally suppressed than other groups.
3. Foreign-born black residents experience disparities in the number of late diagnoses. Foreign-born blacks are 100 times more likely to be infected than whites and most likely to have been infected in their home countries, so testing as soon as possible after arriving in the U.S. would help address the disparity for HIV infection for foreign-born blacks.
4. Foreign-born Hispanics also experience higher numbers of late diagnoses, experience lower levels of retention in care, and lower levels of viral load suppression (much of the care continuum). Foreign-born Hispanics are three times more likely to be infected than whites and are at elevated risk for late HIV diagnosis (43% diagnosed with AIDS within 12 months of HIV diagnosis) and have a low level of viral suppression (55%) relative to non-Hispanic whites. These facts should prompt a new emphasis on HIV prevention, testing and retention in care for this disproportionately affected population. There is enough qualitative data to suggest that a number of these infections take place in the U.S. to warrant added emphasis on prevention. People whose status in the U.S. is undocumented have greater challenges in accessing health care in general, which must be addressed if undocumented people are to have access to prevention and stay retained in care.
5. Younger adults (ages 18-35) show lower lower rates of retention in care. Approx-

mately 51 percent of younger adults are retained in care, compared to 58 percent total.

6. In addition, specific geographic areas were identified as *hot spots* for HIV infection, related to residents' education and income levels. This geocoded information needs further analysis to verify *hot spots* for HIV-infection, for use in targeting prevention/existing efforts.

The SEW-D's focus included how to define disparities, which HIV disparities appear to matter most, what can be done to reduce disparities, and how disparities should be monitored over time. The disparity findings were then linked to socio-economic data by census tract, as a broader look at social determinants related to income and education. In the future, it would be useful to determine if racial-ethnic data can be linked to the income and education data in the geocoded areas. The SEW-D's findings are detailed in a report, which is included as an [Appendix E](#) here.

The HPSG acknowledges that the *End AIDS Washington* recommendations prioritize specific communities for reducing disparities and that there are other communities that also experience disparities, including Native Americans and Pacific Islanders/Native Hawai'ians. The HPSG prioritized specific populations in the initial *End AIDS Washington* implementation phase to maximize the impact on ending the epidemic by focusing on the largest numbers first.

Leadership for Disparity Reduction Work

While recommending that DOH play a major role, the HPSG also expressed that for this type of work (and for stigma reduction and community engagement work) to be successful, it is critical that the leadership implement this work in new ways (specifically to include community member input and leadership of the design and implementation processes). The HPSG's recommendations about HOW to move forward with the implementation of this recommendation are found in the *Implementation/Next Steps* section of this report.

Action Items

Department of Health - Special Emphasis Workgroup on HIV-Related Disparities

1. **Reconvene the SEW-D to define specific HIV-related disparities and set appropriate numerical goals for reducing disparities, as follows:**
 - a. **Overall:** Gay and bisexual men of all races, being addressed in the current HPSG framework.
 - b. U.S.-born black residents—prevention (PreP), testing, improve linkage to care, retention in care and viral load suppression (basically the entire care continuum, starting with prevention, needs to improve for U.S.- born blacks).
 - c. Foreign-born black residents—testing, to reduce the number of late diagnoses.
 - d. Foreign-born Hispanics—prevention (PreP) and testing to reduce the number of late diagnoses, improve retention in care, improve viral load suppression (much of the care continuum).
 - e. Younger adults (ages 18-35)—improve retention in care.
 - f. Analyze the geocoded data to verify *hot spots* for HIV infection, for use in targeting prevention/testing efforts.

Note that the SEW-D did further review of HIV-specific disparities. A number of baselines and targets have now been set for goal 4. See list in the *Introduction*, immediately following the list of goals.

Department of Health

1. **Ensure funding for HIV prevention, care and treatment, and prioritize addressing disparities in the black and Latino communities as reflected in the goals from action item #1 above.**

Members of these communities should have significant roles in planning, designing, and implementing programs and interventions for addressing disparities, in collaboration with funders, policy makers, and service providers.

2. **Coordinate a community engagement and empowerment process, led by members of affected communities, to design programs to address and reduce HIV-related disparities.**

Community engagement and empowerment efforts should include members of all communities experiencing HIV-related disparities, including the populations identified by the SEW-D (gay and bisexual men of all backgrounds, U.S.-born and foreign born blacks and Hispanics, and older and young PLWH) as well as other populations known to experience disparities, including transgender/non-binary individuals and people who inject drugs. These efforts should identify ways to diminish disparities across the care continuum, as well as in use of prevention tools like PrEP.

3. **Consider facilitating and funding partnerships between community-based organizations (CBOs) and the legal community to reduce gaps in access to legal advocacy services for PLWH and members of affected communities.**

Explore possible partnerships between the legal community and CBOs to offer legal support for PLWH and members of affected communities. Low-income PLWH and PLWH of color often lack access to these services.

4. **Develop and publish a disparities dashboard that tracks all of the End AIDS goals, baseline numbers, and annual progress, by county and statewide.**

Convene regular conversations about the amount and rate of progress in reducing disparities for the groups listed and be prepared to course-correct. The county-specific and statewide dashboards should be posted online so that stakeholders and community members can see the progress being made.

5. **Integrate the goals for diminishing HIV-related disparities across all End AIDS Washington recommendations and the entire HIV community services portfolio.**

To successfully address and diminish HIV-related disparities, a focus on disparities reduction must be applied to all HIV-related work. Across

this set of recommendations there are specific items on how the action steps will reduce disparities; DOH should apply this focus to the entire HIV community services portfolio. Additionally, these efforts should include naming and addressing institutionalized racism, anti-immigrant bias, and other intersecting factors affecting Black, Hispanic, and young people at increased risk for HIV.

6. Use research and other resources to foster a deeper understanding of HIV-related disparities and their effects on communities among decision-makers and other public health staff.

Resources such as the *Kaiser Foundation Survey of Americans* (2011) can help decision-makers more fully understand the concerns, interests and lived experiences of communities affected by HIV-related disparities.

How Disparities Are Addressed Across the End AIDS Washington Recommendations

1. Increasing testing support for gay and bisexual men and other groups disproportionately affected by HIV.
2. Reducing cost barriers for PrEP and increasing culturally relevant outreach and education about PrEP.
3. Creating a health care system to help reduce disparities experienced by gay and bisexual men and transgender/non-binary individuals.
4. People who use substances (especially People Who Inject Drugs (PWID)) often experience significant levels of socio-economic disadvantage and instability. Increasing access to health care, treatment

and housing to improve the health of substance users, with emphasis on harm reduction strategies, will contribute to a reduction in disparities in HIV.

5. Increasing access to specialty medications, including anti-retrovirals used for HIV treatment and prevention, by reducing barriers in insurance coverage, to address disparities experienced by low-income individuals, communities of color, and others who disproportionately lack access to affordable health care.
6. Reducing homelessness experienced by PLWH and people at risk for HIV, to address disparities in health outcomes that are exacerbated by homelessness and housing instability, and are disproportionately experienced by people of color, LGBT youth, and others.
7. Creating a comprehensive, integrated care care system that includes telehealth options, to address disparities experienced by PLWH, people at risk for HIV, and individuals seeking behavioral health services, including residents of rural areas.
8. Increasing access to comprehensive, inclusive sexual health education, health care services, condoms, and culturally appropriate youth services, within and outside of the school system, to address disparities experienced by LGBT youth and youth of color, including those experiencing homelessness.
9. Launching a comprehensive, meaningful community engagement and empowerment process to lead the implementation of all the *End AIDS Washington* recommendations.



3

Implement Routine, Standardized HIV Screening for All Washington Residents

Agencies and Sectors Impacted

Legislature, Department of Health, Health Care Authority, Office of the Insurance Commissioner, Local Health Jurisdictions and service providers, PLWH and members of communities affected by HIV

Background

HIV testing is a cornerstone for HIV prevention and care, and a critical component of both the *National HIV/AIDS Strategy* and Washington State's plan to end AIDS.¹⁰ Diagnosing people with HIV leads to long-term behavior change;¹¹ allows at-risk HIV-negative people the opportunity to consider PrEP, which can decrease the risk of transmitting HIV by 92 percent;¹² and allows infected people to initiate life-saving anti-retroviral therapy, which can decrease the risk of transmitting HIV by 96 percent.¹³

One in 10 Washingtonians living with HIV are undiagnosed

Too many PLWH are unaware of their infection. The Washington State Department of Health estimates that approximately one in 10 PLWH in the state are undiagnosed. These individuals face the adverse health effects of untreated HIV infection and have the potential to unknowingly transmit HIV to others. In many instances, undiagnosed people may not identify themselves as being at high risk for HIV, or may encounter stigma that inhibits them from testing or revealing risk behaviors to medical providers.

'HIV testing with all bloodwork [is how I would work to end AIDS in Washington].'

— Recipient of HIV Prevention and/or Care Services

Making HIV testing a part of routine health care is recommended by the U.S. Preventive Services Task Force (USPSTF) and the Centers for Disease Control and Prevention (CDC)

Normalizing HIV testing, making it a routine part of health care, can identify people unaware they are living with HIV, prompt them to receive life-saving treatment, and reduce HIV transmission. Making HIV testing routine is designed to identify infected people that traditional public health efforts can miss, thereby decreasing HIV transmission, the morbidity and mortality associated with the infection, and the racial and ethnic disparities that characterize the HIV epidemic.

In 2006, the CDC recommended that medical providers institute routine, opt-out HIV screening for patients ages 13-64 in all health care settings.¹⁴ The USPSTF subsequently made routine HIV testing a *Grade A* recommendation for people ages 15-64.¹⁵ This recommendation assures that all health insurance policies cover the full costs of HIV testing, without copays or deductibles. Despite these recommendations, HIV screening is not yet routine in Washington State. In part, this reflects residual concerns within health care organiza-

tions about the need to document patient consent prior to performing HIV tests. While the overall prevalence of HIV infection in the general population of Washington State is low, ending the HIV epidemic in Washington State will require new efforts to test people who do not voluntarily seek testing, those whom existing efforts miss. Routinizing HIV testing is a center-piece of efforts to identify infections in the populations we are currently reaching.

Additionally, HIV testing offers medical providers the opportunity to discuss and, if appropriate, prescribe PrEP to at-risk HIV-negative individuals. While PrEP use is increasing among at-risk populations, current population-level use remains low. In particular, people with risk factors, such as gay and bisexual men diagnosed with sexually transmitted diseases, have a greater chance of acquiring HIV than do low-risk individuals. Overall, HIV infection rates among gay and bisexual men are 150 times higher compared to heterosexual men and women.¹⁶ Through regular HIV testing, at-risk people are offered ongoing opportunities to access PrEP in order to reduce the likelihood of infection.

Action Items

Legislature

- 1. Pass legislation requiring medical providers in primary care, emergency departments, urgent care, and walk-in clinics in Seattle and the secondary urban areas* of the state to offer HIV testing to people without a prior documented HIV test.** This legislation should include simplification of consent for HIV screening to allow opt-out HIV testing without any documentation of consent beyond the general consent for care.**

*The secondary urban areas are: Everett, Kent, Renton, Shoreline, Spokane, Tacoma and Vancouver

**The HPSG notes that this recommendation is additionally a major opportunity to require routine Hepatitis C Virus (HCV) testing at the same time as routine HIV testing. It is very important to leverage this opportunity to accomplish both. See *Future Work* section of this report for additional recommendations about the importance of additional work on HCV. While the HPSG has chosen to focus this report on HIV, it is essential to address HCV in its own right.

Current Washington Administrative Code (WAC Chapter 246-100)¹⁷ allows for opt-out testing, but does not require health care providers to offer the test to their patients. Also, although recent changes in the law facilitate opt-out consent, many health care organizations have interpreted the law as continuing to require separate documentation of consent.

By streamlining the consent and testing process and placing the responsibility to implement opt-out HIV testing on the health care delivery system, our state will see a greater percentage of residents tested for HIV. Testing options should include screening via conventional serological testing or rapid testing where appropriate. Opt-out testing will enable more PLWH to be connected to care and will reduce HIV-related stigma. It should be noted that the recommendation for routine, opt-out testing does not preclude more frequent testing for people at higher risk for HIV.

Additionally, Washington should follow the CDC guidance that the general consent for care covers consent for HIV testing without separate documentation of consent,¹⁸ and support providers to implement this guidance. This will reduce barriers to HIV testing and reduce HIV-related stigma.

- 2. Continue and increase support for frequent, health department-supported HIV testing for populations at high risk for HIV infection, as outlined in the Public Health - Seattle & King County HIV testing and STD screening recommendations.¹⁹**

The HIV epidemic in Washington State is highly concentrated, with over 70 percent of cases occurring in gay and bisexual men. Although increased emphasis on testing in medical settings is an important part of a successful strategy to identify people with HIV infection, dedicated HIV testing programs, such as testing through community-based organizations (CBOs) and STD clinics, are a critical component to the state's plan to end the HIV epidemic and will require ongoing support.

Department of Health

1. Train primary care, emergency care, and urgent care practitioners to offer an HIV test as a part of the routine screening panel for patients.

A current barrier to implementing opt-out HIV testing is providers' varying degrees of familiarity and comfort with administering the test and delivering the result. Additionally, providers who do not regularly treat PLWH may be unaware of the services available to an HIV-positive person they have just diagnosed. Training for primary care, emergency care and urgent care providers in HIV testing, counseling, and linkage to treatment and services for those who test positive is essential.

Health Care Authority

1. Evaluate permitting non-clinical providers, such as CBOs, local health jurisdictions, chemical dependency treatment centers, and others, to bill Medicaid for HIV screening done in the field.

Patient access is a critical component of the successful implementation of opt-out HIV testing. Some individuals cannot or will not access HIV testing in a formal health care setting. For this reason, non-health care service providers, trained to administer HIV tests, should have the option to bill Medicaid for tests provided in the field. HIV screening training should include information on how to link newly diagnosed individuals to treatment and support services.

Action Steps to Address and Reduce HIV-Related Stigma

1. An intended outcome of routinizing and normalizing HIV screening (action item *Leg 1*) is to reduce stigma associated with HIV testing by offering testing to all patients.
2. An intended outcome of training providers to offer an HIV test and how to link patients who test positive to care (action item *Leg 2*) is to reduce HIV-related stigma patients may experience in clinical settings by increasing their providers' skill and confidence in providing HIV-related care.

Action Steps to Address and Reduce HIV-Related Disparities

1. An intended outcome of supporting frequent testing for individuals at high risk for HIV (action item *Leg 2*) is to address the disparate impact of HIV on gay and bisexual men.
2. An intended outcome of considering permitting non-clinical providers, such as CBOs, to bill Medicaid for HIV testing (action item *HCA 1*) is to reduce HIV-related disparities experienced by gay and bisexual men, communities of color, and young people, who in some cases are more likely to access HIV and STD-related services from these kinds of providers.

Increase Access to Pre-Exposure Prophylaxis (PrEP), an Important HIV Prevention Tool

Agencies and Sectors Impacted

Governor's Office, Legislature, Department of Health, Office of the Insurance Commissioner and health insurance carriers, Health Care Authority, Bree Collaborative, PLWH and members of communities affected by HIV

Background

Over the last three decades, individuals at highest risk for HIV infection have substantially changed their behaviors to protect themselves and their sex partners. In particular, the HIV epidemic led a significant increase in condom use, particularly in the communities most affected by HIV. However, as with other behaviors that adversely affect health, consistent and sustained behavior change is difficult. Despite safer sexual behaviors, HIV transmission has persisted. Pre-exposure prophylaxis (PrEP) offers at-risk individuals a new tool for keeping themselves HIV-negative. PrEP involves taking a single pill (*Truvada*[®] [emtricitibine/tenofovir]) every day to avoid HIV infection. When taken consistently, PrEP reduces the risk of HIV infection in people who are at high risk by up to 92 percent. Based on this high level of protection and in recognition of the need for additional effective interventions that protect people from HIV, the updated 2015 U.S. *National HIV/AIDS Strategy* (NHAS) includes PrEP as one of its four pillars of HIV prevention.²⁰ The CDC likewise recommends that PrEP be used as a prevention tool for people who are at substantial risk for HIV,²¹ including those in serodiscordant relationships, gay and bisexual men who have sexual partners of unknown HIV status, and persons who inject drugs. The 2015 DOH and PHSKC *PrEP Implementation Guidelines* likewise define characteristics of patients at high risk for HIV infection who are potential candidates for PrEP. In alignment with the NHAS and the CDC, *End AIDS Washington* emphasizes PrEP as a highly effective, scientifically proven intervention. Thus, the initiative seeks to make PrEP widely available to individuals at high risk for HIV infection, and to promote the use of PrEP among them.

Using PrEP provides people with the ability to take action to protect themselves from infection. It empowers HIV-negative people to be in greater control of their lives and health.

"Increase statewide PrEP efforts: require all medical providers to get training on PrEP (at the very least, to understand what it is; where they can refer patients to get it; and how they can assist patients to sign up for PrEP DAP)."

— Service Provider

There are several challenges for increasing PrEP use as a way to prevent HIV and end the epidemic. First, and perhaps most importantly, the high cost of *Truvada*[®] (approximately \$1,200/month) is a major potential barrier for some at-risk individuals to access the medication.

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Washington State has been a national leader in expanding PrEP access by starting the first statewide PrEP drug assistance program (PrEP DAP). This program currently provides access to *Truvada*[®] for more than 500 Washington residents at no charge. While PrEP DAP covers the cost of medications, it does not cover the costs of follow-up visits and required lab tests, which have been reported to be burdensome. Also, as this program expands, available funding will eventually be exhausted.

Second, the use of PrEP may not be reaching all of the communities and individuals that can benefit. In particular, PrEP use among black gay and bisexual men – a population that is disproportionately affected by HIV – may be inadequate. For example, of the 500 PrEP DAP enrollees, as of this writing only two percent are black, while black Washingtonians represent 18 percent of new HIV diagnoses.

In order to ensure that all who need PrEP can access it, the current prohibitive cost for PrEP medications must be reduced and PrEP should be included in insurance policies as a covered preventive service.

Action Items

Governor

- 1. Issue a statement about the importance of addressing the cost of PrEP for World AIDS Day or another opportune time.**

The Governor should also work with legislators and Washington's congressional delegation to issue similar statements to show broad support among elected officials for increasing PrEP access.

- 2. Collaborate with other governors, drug makers and insurance carriers to lower the cost of PrEP and other specialty medications.**

High-level, multi-state discussions could provide the momentum needed to address high prescription drug costs and help bring down prices for PrEP and other specialty medications. Additionally, engagement with insurance carriers should include education about PrEP to encourage PrEP coverage as a preventive service.

Legislature

- 1. Increase state funding for the PrEP DAP to meet the needs of Washington residents at high risk of HIV.**

Until other recommendations aimed at increasing insurance coverage and reducing the costs associated with PrEP are successfully implemented, the state should allocate funding to sustain PrEP DAP.

- 2. Establish out-of-pocket maximums for all specialty anti-retroviral medications, including those used as PrEP.**

California's recent implementation of co-pay and co-insurance caps for specialty medications covered by qualified health plans is a possible model.²² Out-of-pocket maximums will address part of the challenge of affordability.

Office of the Insurance Commissioner

- 1. Nominate PrEP clinical guidelines as a recommendation statement topic to the U.S. Preventive Services Task Force (USPSTF) for consideration to be covered as Grade A or B preventative services and therefore at no cost to patients.²³**

Clinical guidelines include reacted office visits and follow-up lab tests. With a USPSTF Grade A or B rating, all the services associated with PrEP would be covered with no out-of-pocket costs for patients.

- 2. Coordinate with other state Offices of Insurance to garner additional requests for consideration of changes to the USPSTF guidelines to include PrEP as Grade A or B preventative services.**

Collaboration among several states would demonstrate wide-ranging interest in considering this change to the USPSTF guidelines.

- 3. Monitor and review health plan formularies to ensure practices are not discriminatory with regard to HIV anti-retroviral medications.**

Discriminatory practices can include high co-pays, tiering, prior authorization, fail first policies, or low co-insurance, and can be barriers to accessing medications like PrEP, as well as other specialty medications.

Department of Health

- 1. Explore ways to provide PrEP DAP support, or work with the OIC to ensure insurance coverage for all services associated with PrEP, including office visits and lab tests as well as the medication itself.**

Recognizing that follow-up office visits and lab tests may require burdensome out-of-pocket costs for PrEP users, DOH should examine the best way to apply its finite funding to ensure that none of the costs associated with PrEP is a barrier to using this prevention tool.

- 2. Allocate funding for community-driven PrEP outreach and marketing and PrEP DAP enrollment initiatives to be designed and implemented by organizations that reach high-risk individuals, including black and Hispanic gay and bisexual men and transgender/non-binary people.**

Funding decisions should intentionally address disparities in knowledge about and access to PrEP, as the *Enhanced HIV Community Services* portfolio will do. Marketing efforts should be informed by research that identifies gaps in knowledge and misconceptions about PrEP and how to access it.

- 3. Create a support system that implements services to support successful PrEP use among high-risk populations.**

These interventions should include known preconditions of successful PrEP use, including health insurance and enrollment, health literacy, health care access, health care navigation, and ongoing health care coordination. Again, this is planned under the *Enhanced HIV Community Services* portfolio.

- 4. Work to expand the number of medical providers who prescribe PrEP, and foster the development of a pool of medical providers that people interested in PrEP can identify.**

This effort, some of which is already ongoing, should include making no-cost, online training available to general practice and specialty medical providers, and making lists of PrEP providers widely available to those

at high risk for HIV infection. Provider training should include PrEP, PEP (post-exposure prophylaxis) and nPEP (non-occupational post-exposure prophylaxis), as well as linking STD screening to PrEP, to maximize prevention efforts. Training programs should be informed by research that identifies gaps in provider knowledge and misconceptions about PrEP and who can benefit from it.

- 5. Promote PrEP use to the people at greatest risk for HIV infection.**

Maximizing the benefits of PrEP requires that those at highest risk for HIV use it. Working with local public health, general practice medical providers, and community-based providers, DOH should integrate PrEP referrals and promotion into services provided to populations at high risk for HIV, as they are defined in the 2015 DOH and PHSKC *PrEP Implementation Guidelines*.

- 6. Support access to PrEP in rural areas through telehealth.**

Through telehealth and training offered by the *AIDS Education and Training Centers* (AETC), people living in rural areas can have better access to providers knowledgeable about prescribing PrEP.

- 7. Support robust community engagement and empowerment to increase PrEP use.**

A community engagement process led by members of affected communities educate both PLWH and individuals at risk for HIV about PrEP as a prevention tool. Additionally, this process will help identify and develop leaders among communities most affected by HIV.

Health Care Authority

- 1. Request that the Bree Collaborative adopts PrEP treatment guidelines for review and analysis.**

Following analysis, the *Collaborative* would make recommendations for implementation to HCA.

Action Steps to Address and Reduce HIV-Related Stigma

1. An intended outcome of having Governor Inslee and other elected officials issue statements in favor of PrEP (action item Gov 1) is to reduce PrEP-related stigma by demonstrating public officials' support for PrEP as an important HIV prevention tool.
2. An intended outcome of increased, community-based PrEP outreach (action item DOH 2) and provider training on PrEP (action item DOH 4) is to reduce PrEP-related stigma by increasing knowledge and debunking misinformation among community members and medical providers.

Action Steps to Address and Reduce HIV-Related Disparities

1. An intended outcome of the action items addressing PrEP affordability and insurance coverage (action items Gov 2, Leg 1 and 2, OIC 1, 2 and 3) is to reduce disparities in access to PrEP by reducing the cost of PrEP medication and the associated office visits and labs.
2. An intended outcome of funding and supporting community-led outreach to promote PrEP to communities of color and transgender/non-binary individuals (action item DOH 2 and 7) is to reduce disparities in knowledge about and use of PrEP.
3. An intended outcome in supporting telehealth options for PrEP provider training and PrEP prescribing (action item DOH 6) is to reduce disparities in PrEP access that may be experienced in rural communities.

Create a Health Care System that Meets the Needs of Sexual Minorities

Agencies and Sectors Impacted

Department of Health, health care organizations and systems, Washington Health Benefit Exchange, PLWH and members of communities affected by HIV, including gay and bisexual men and transgender/non-binary individuals

Background

In 2013, 67 percent of all new HIV diagnoses in the U.S. occurred in gay and bisexual men and other men who have sex with men (MSM), a group that includes approximately 2 percent of the U.S. population.²⁴ In Washington State, over 70 percent of people living with HIV/AIDS are gay and bisexual men. However, the current health care system is ill equipped to adequately meet the needs of these men. A national survey conducted by the *Kaiser Family Foundation* in 2014 found that 47 percent of gay and bisexual men had never revealed their sexual orientation to a physician; 57 percent of gay and bisexual men reported that a medical provider had never suggested that they test for HIV.²⁵ Among 164 gay and bisexual men who responded to a Washington State internet-based survey, only 43 percent reported that they had a primary care medical provider who knew that they were a man who has sex with men.²⁶

Gay and bisexual men have specific health care needs, and ending the HIV epidemic requires a greater effort to meet those needs. While national guidelines recommend that all Americans test for HIV at least once in their lifetime, both CDC and local guidelines in Washington State recommend that most gay and bisexual men test at least annually, and that selected groups of gay and bisexual men test as often four times a year.^{27, 28} These guidelines also recommend that gay and bisexual men test frequently for other sexually transmitted infections.

Additionally, transgender/non-binary individuals have specific health care needs, and providers and systems need to be better trained to provide responsive care in a welcoming environment. Furthermore, transgender/non-binary individuals, particularly transgender women of color, are disproportionately likely to be at risk for HIV.²⁹ Integrating gender-affirming care and HIV prevention or treatment is essential to meeting the needs of the transgender/non-binary community.

"Having doctors/medical staff that are LGBTQA friendly, that ALL have a thorough understanding of HIV and treatment will really help. There is a SIGNIFICANT lack in LGBTQA friendly docs... I think talking with medical facilities and doctors to get medical staff trained to have thorough HIV/AIDS knowledge (how to tell someone they're positive, how to work with HIV+ clients) would be a good start. Also having medical staff and facilities trained on being LGBTQA culturally sensitive and to have certification that verifies training so LGBTQA patients can find respectful treatment."

— Medical Case Manager

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HIV pre-exposure prophylaxis (PrEP) is a promising intervention for decreasing HIV transmission and is a centerpiece of the U.S. strategy to prevent HIV, and of Washington State's *End AIDS* initiative. However, getting PrEP to those who need it requires a health care system that consistently identifies the people most at risk for HIV. At present, the health care system is often blind to transgender/non-binary individuals, as well as gay and bisexual men. Ending the epidemic in Washington State will require changing this. Ideally, all medical providers would be well prepared to care for gay and bisexual men and transgender/non-binary individuals, and efforts to end HIV should include an effort to educate all primary care medical providers on the subject of LGBT health. However, because gay and bisexual men and transgender/non-binary individuals are only 2-3 percent of the population, most providers have very few gay and bisexual male patients or transgender/non-binary patients, and ensuring that all providers have a high level of expertise and sensitivity in LGBT health care may not be feasible.

With that reality in mind, the Washington State *End AIDS* initiative seeks to promote the creation of a network of LGBT-responsive medical providers. This goal is consistent with the expressed desires of gay and bisexual men and transgender/non-binary people in our state. A University of Washington survey found that 52 percent of gay and bisexual men in Washington State would change primary care medical providers to receive care from an LGBT specialist, if one were available. Likewise, *End AIDS* surveys and community conversations identified a need among transgender/non-binary individuals to be able to see providers skilled and sensitive in transgender health care. The *End AIDS* initiative seeks to create a network for LGBT providers that ensures that all Washington residents can access a medical provider who is trained to understand and meet their needs. In some instances, this may be accomplished through telemedicine access to such providers in other communities.

Action Items

Department of Health, health care organizations and systems

- 1. Require that all health care organizations (HCOs) systematically ask patients about the gender of their sex partners and their gender identity.**

This might be done through the use of the electronic medical record (EMR) and be incorporated into efforts that collect other aspects of patients' social history, such as substance use, information about diet and exercise, etc. Consider adoption of a standard sexual history questionnaire, as was developed in New York State.

- 2. Direct HCOs to institute interventions, including the use of the EMR, to increase adherence with national and state HIV/STD testing and PrEP guidelines.**
- 3. Collaborate with the transgender/non-binary community to identify specific trainings and services to increase the number and availability of providers skilled and sensitive in gender-affirming care and other health care needs of transgender/non-binary individuals.**

Recognizing the lack of providers and health care systems skilled in transgender/non-binary health care, systems, and providers should work with the transgender/non-binary community to identify specific needs and increase access to appropriate and welcoming care for these individuals.

- 4. Direct state and local health departments to work with large HCOs to develop networks of LGBT-competent providers.**

HCOs should ensure that patients know about the availability of providers with expertise in the care of LGBT patients. The goal should be to ensure that all Washington State LGBT residents have access to a medical provider who can understand and meet their needs.

- 5. Ensure that all patients in the health care system who self-identify as a gay or bisexual man or as transgender/non-binary have access to culturally and medically appropriate care.**

All providers should be qualified to offer culturally and medically appropriate care for

gay and bisexual men and transgender/non-binary individuals. However, when that is not possible, it is essential to ensure this can be accomplished by referral to providers who have a high level of expertise and comfort with care for gay and bisexual men and/or transgender/non-binary individuals. In some parts of the state, particularly rural areas, use of telehealth and telemedicine models will support remote access to LGBT-competent providers and HIV specialists. Telehealth and telemedicine models are also an important option for anyone who perceives stigma or discrimination within their local community that may be exacerbated by a lack of confidentiality. Additionally, *AIDS Education and Training Center (AETC)* trainings can support provider training in LGBT-appropriate care outside of urban settings.

6. Create or adapt existing online curricula for medical providers, including nurses and lab technicians, and office staff, in LGBT health.

The Department of Health should have the resources to fund and help develop online curricula, or adopt existing curricula from another state or jurisdiction, to increase medical providers' and office staff's knowledge of and comfort with LGBT health care. This curriculum should include techniques for making the clinical setting a welcoming environment for LGBT patients.

7. Collaborate with state boards and medical associations to establish recommended LGBT-competency CME (Continuing Medical Education) standards for medical providers, including nurses and lab technicians.

Recommended CME standards will convey the importance of LGBT responsiveness and create a welcoming environment in clinical settings and will better ensure successful implementation of the trainings.

8. Require that all primary care residencies and medical schools in the state include a curriculum on the health of sexual minorities.

This curriculum could be delivered through lectures, readings, or online; all of the trainings referenced in action items *DOH/HCOs 6 through 8* can be based on the same curriculum.

9. Create and distribute informational videos for providers and office staff on creating a welcoming environment for LGBT patients.

A video series featuring real patient stories would provide ongoing education and address more subtle forms of stigma providers or their staff may unintentionally perpetuate.

Health Benefit Exchange, Department of Health, health care organizations and systems

1. Create and maintain a directory of providers who are LGBT-sensitive and culturally aware, and post the list on the Washington Healthplanfinder website.

This directory will help ensure that individuals seeking LGBT health care will be able to enroll in a qualified health plan or an *Apple Health* plan that includes providers who are LGBT-sensitive and culturally aware.

Action Steps to Address and Reduce HIV-Related Stigma

1. An intended outcome of action items *DOH/HCOs 1 through 8* is to increase the cultural awareness of health care providers and office staff about LGBT individuals' health needs and to increase access to culturally appropriate providers, in order to reduce stigma that gay and bisexual men and transgender/non-binary individuals may experience in health care settings, including when such stigma is unintentional.

Action Steps to Address and Reduce HIV-Related Disparities

1. An intended outcome of action items *DOH/HCOs 1 through 8* is to reduce disparities in access to appropriate care experienced by some gay and bisexual men and transgender/non-binary individuals.
2. An intended outcome of posting information about LGBT-skilled and sensitive providers on the *Washington Healthplanfinder* website (action item *HBE/DOH/HCOs 1*) is to reduce disparities in knowledge about and access to culturally skillful and sensitive health care for gay and bisexual men and transgender non-binary individuals.



Improve HIV Prevention, Care and Treatment Among Substance Users, Including People Who Inject Drugs

Agencies and Sectors Impacted

Not identified yet -- The HPSG added this recommendation in response to public comment about the HIV prevention, care, and treatment needs of substance users. There has not yet been opportunity to coordinate with likely key partners who could help move the *Action Steps* forward. This outreach will be a first step in the implementation of this recommendation. This implementation work is also reflected in the *Future Work* section of this report.

Background

Substance use in general continues to challenge HIV prevention, care, and treatment because it can impair decision-making around sexual safety, increase risk for HIV via syringe sharing, and interfere with the ability of PLWH to access and sustain HIV care and remain virologically suppressed. Drug use also compounds stigma and morbidity affecting PLWH and people at risk of HIV.

Cities in Washington State were among the first in the U.S. to institute syringe exchange programs (SEP). This successful effort has helped contain the HIV epidemic among those who inject drugs (PWID). HIV surveillance data provided by the DOH *Infectious Disease Assessment Unit* reported as of January 31, 2016, that roughly 18% of PLWH have a history of using injection drugs, and 16% of new HIV diagnoses between 2010-2014, occurred in PWID. Non-injection drug use is also a critical factor driving the HIV epidemic in Washington State. In particular, the use of methamphetamine by gay and bisexual men, including use through means other than injection, helps fuel the HIV transmission, as using methamphetamine is strongly associated with high-risk sexual behavior. Data collected through Seattle's participation in the 2014 *National HIV Behavioral Surveillance System* suggest that 15% of gay and bisexual men have used methamphetamine in the prior year, and approximately one-third of gay and bisexual men with newly diagnosed HIV in King County report using methamphetamine in the prior 6 months.³⁰ For King County, where the following data are tracked, HIV prevalence is nearly four times higher among gay and bisexual men who use methamphetamines (44%) versus gay and bisexual men who do not report methamphetamine use (12%), and local data suggest that using methamphetamine is the single strongest predictor of HIV acquisition.³¹ Indeed, PHSKC investigators estimate that 20% of all HIV infections gay and bisexual men are attributable to methamphetamine use.³² Statewide data related to HIV and methamphetamine use are not available at this time. NHBS data describe a high-risk sample and may not represent the entire population of gay and bisexual men in Washington State.

Substance use undermines the success of HIV treatment. In King County, over half of all people who are out of care use substances and approximately 25% identify substance use a reason for their inability to receive care or for discontinuing their HIV medication.³³ The failure to successfully treat substance users perpetuates the cycle of HIV transmission and undermines the state's efforts both to prevent HIV transmission and avert the morbidity and mortality associated with HIV/AIDS. In addition, substance users (especially PWID) often



experience significant levels of socio-economic disadvantage and instability. A recent survey of PWID in Washington State found that 34% were homeless, 39% had been incarcerated in the past 12 months, and at least 80% had incomes that met Medicaid eligibility.³⁴

Action Items

1. Sustain and increase the availability of sterile syringes for PWID.

Although some parts of Washington State have robust syringe exchange programs, sterile syringes are not consistently available throughout the state, and funding for syringe exchange remains a challenge. All Washington residents who inject drugs should have access to sterile syringes.

2. Increase availability and accessibility of opioid use disorder (OUD) medications.

Treating opioid use disorder with medications such as methadone and buprenorphine is proven to decrease injection drug use (and subsequent HIV risk) and morbidity associated with opioid use. There are currently long wait lists and multiple intake hurdles at methadone clinics, and there is a critical shortage of medical providers who prescribe buprenorphine. The need for and lack of these treatment resources is particularly acute in rural areas of the state. Barriers that limit availability and use of OUD medications should continue to be identified and policies developed to expand capacity. Efforts to increase the availability of buprenorphine/aloxone should include investigating mechanisms to simplify the credentialing process that allows medical providers to prescribe the medication. Other options to consider include piloting new models of community-based buprenorphine to induce and stabilize particularly vulnerable populations and building structural supports (such as case management capacity) to support medical providers to implement and sustain buprenorphine treatment.

3. Increase access to evidence-based, culturally appropriate, and effective substance abuse treatment.

Access to substance abuse treatment in Washington State is currently limited. Moreover, few effective options exist for treating methamphetamine abuse, the drug most consistently associated with HIV infection in the Seattle-King County area (statewide data is not available at this time). Access should be improved to high-quality, culturally appropriate and effective substance abuse treatment.

4. Expand supportive housing for substance users.

Homelessness is a serious problem among substance users and contributes to their difficulty in engaging in care. Supportive housing options, that take a harm reduction approach to substance use, should be expanded.

5. Develop models of clinical care that improve the success of HIV prevention, care and treatment substance users.

Many substance users struggle to remain engaged with care. In part, this reflects difficulty attending appointments and navigating the complexities of the medical care system. More flexible and comprehensive models of care for people who use drugs should be developed with the goal of increasing viral suppression among HIV-infected substance users, increasing PrEP use among HIV-uninfected substance users (particularly methamphetamine users), and broadly improving drug user health.

6. Integrate HIV-related efforts to improve the health of drug users with broader efforts to address the prevention, care, and treatment needs of people who use drugs, including treatment for hepatitis C infection and efforts to diminish overdose deaths.

Drug users face a wide range of health problems of personal and public health significance, including hepatitis C infection, overdose, bacterial infections, kidney disease

and mental illness. Efforts to improve HIV prevention and care should also address drug users' medical and psycho-social problems.

7. Improve the monitoring of morbidity and use of key prevention, care and treatment interventions among drug users.

Although public health has long monitored HIV diagnoses among PWID and, to a lesser extent, other substance use among PLWH, monitoring of access to key interventions has been limited. Part of an effort to improve HIV-related prevention, care and treatment among drug users should be more comprehensive ongoing assessment of drug users' access to and use of key prevention, care and treatment interventions, including syringe exchange, opiate substitution therapy and other types of drug treatment.

8. Explore opportunities to prevent methamphetamine use.

At present, there are not good evidence-based approaches to primary prevention related to methamphetamine use, particularly among gay and bisexual men. Ideally, efforts to prevent HIV would include primary prevention of methamphetamine use. Opportunities should be explored to identify and initiate effective targeted primary prevention programs designed to diminish methamphetamine use.

Action Steps to Address and Reduce HIV-Related Stigma

1. An intended outcome of sustaining and increasing access to HIV prevention interventions and services based on harm reduction principles (action items 1a, 1b, 1d, and 1f) is to reduce stigma associated with substance use and increase uptake and success of these interventions.

Action Steps to Address and Reduce HIV-Related Disparities

1. An intended outcome of sustaining and increasing access to sterile syringes for PWID (action item 1a) is to maintain the trend of lower HIV incidence among PWID as compared to the much higher infection rates observed earlier in the epidemic.
2. An intended outcome of increasing housing options, treatment for substance use disorders, and access to integrated health care among PWID (action items 1b, 1c, 1d, 1e, and 1f) is to reduce disparities in morbidity and mortality for both HIV and non-HIV-related outcomes.

7

Remove Barriers in Insurance Coverage and Increase Health Care Affordability for PLWH and Individuals at Risk for HIV

Agencies and Sectors Impacted

Legislature, Office of the Insurance Commissioner and health insurance carriers, Health Care Authority, PLWH and members of communities affected by HIV

Background

The *Affordable Care Act* (ACA) has fundamentally altered the health care delivery system and increased Washington State residents' access to medical care. As of 2014, an estimated 89 percent of the state's residents had health insurance. However, even with the advances in comprehensive access to health care, some aspects of the health care system still present impediments to the state's goals of ending the HIV epidemic in Washington.

Because sexual health is a highly private matter, some individuals at high risk for HIV transmission prefer to receive HIV/STD services from a confidential STD clinic. Receiving care at a provider other than their primary care provider often means that the preventive services are not covered by health insurance or are covered with a cost to consumers. These costs present barriers to accessing effective preventive care and patients lose access to specialized care, diagnostic tests, and services that may not be available through their primary care providers.

"A lot of people do not use insurance to get tested because of fears of loss of confidentiality or receiving a detailed explanation of benefits (or EOBs from insurance) at home that compromises confidentiality. I would like to see legislation that prevents insurance companies from sending detailed EOBs for STD/HIV testing and treatment."

— *Health Care Provider*

Additional issues around confidentiality are also complicated by the Explanation of Benefits (EOB) documents provided by health plans following visits. There is considerable consumer concern, particularly from young patients, that if they use their insurance for HIV/STD services, their insurance company will send an explanation of benefits statement to their homes, detailing the services, thus compromising their privacy.³⁵ This fear is an impediment to patients seeking medical care for HIV/STD testing and treatment as well as pre-exposure prophylaxis (PrEP).

Among people with HIV infection, loss or interruption of insurance coverage frequently causes patients to stop life-saving medications, treatments that also prevent HIV transmission.³⁶ Although no one needs to go without HIV care, in Washington State, because of lack of insurance, many patients don't know that. When patients lose their insurance or have outstanding balances due to cost-sharing expenses, some simply stop taking their medications and going to their medical provider. At present, medical providers and case workers who serve people with HIV infection have no way to know when their patients or clients lose their insurance, so they cannot help them find a way to continue

the treatment they need. Currently there is not a system-level mechanism to address this problem, so there is not an *Action Item* recommended here, but since this also affects people with other chronic medical conditions, it is raised here to draw attention to the need to solve it.

Finally, at present, many patients cannot access HIV PrEP because their insurance does not cover the full costs of receiving PrEP. Although the state's PrEP drug assistance program (PrEP-DAP) provides co-pay assistance to some people, allowing them to obtain medication, the program does not cover the costs of doctor visits or laboratory testing. Current funding for PrEP-DAP is insufficient to meet the needs of all who can benefit from PrEP. PrEP is a cornerstone of Washington State's *End AIDS* initiative. Ensuring that all Washington State residents at high risk for HIV infection have access to PrEP medications and medical services without co-pays or deductibles is consistent with how the ACA treats other preventive services, and will help bring about the end of the HIV epidemic in Washington State.

Action Items

Office of the Insurance Commissioner

- 1. Institute regulations requiring that explanation of benefits statements classify services related to sexually transmitted diseases (STD), HIV testing, PrEP, and HIV treatment as preventive health services, without additional explanation.**

Regulations should require that all health insurance companies use the same language to describe HIV and STD testing and treatment and PrEP as *preventive health services* so that medical providers can accurately inform patients about what explanation of benefits statements will reveal. This will protect the privacy of enrollees, including young people enrolled on their parents' plans, and remove a barrier in accessing care.

- 2. Increase health care plan network adequacy standard to include a minimum**

number of qualified HIV/STD, family planning or PrEP providers in a plan's network. Require that network adequacy incorporate geographically diverse options.

By increasing the number of providers actively treating high-risk populations for HIV, STDs or prescribing PrEP, the plan's network will increase access to HIV and STD screening and treatment outside of a primary care setting.

- 3. Diligently respond to consumer complaints when STD screenings (syphilis, gonorrhea and chlamydia) are not correctly coded as preventive services, with no out of pocket costs, even if disease is detected and subsequent treatment provided.**

Screenings that uncover STDs disease are being considered by payers as treatment rather than prevention. In response to consumer complaints, the OIC should clarify for health care plans this designation and determine the extent to which payers must cover any STD screenings as preventative even if disease is detected and subsequent treatment provided.

- 4. Submit a nomination for PrEP clinical guidelines as a recommendation statement topic to USPSTF for consideration to be covered as Grade A or B preventative services and therefore at no cost to patients.³⁷**

A Grade A or B rating from USPSTF would ensure coverage of PrEP with no out-of-pocket costs for all insured residents at risk for HIV. Additionally, the OIC should coordinate with other state *Offices of Insurance* including the *National Association of Insurance Commissioners* to generate multiple requests for the USPSTF to consider this change to the guidelines.

- 5. Monitor and review health plan formularies to ensure practices are not discriminatory with regard to HIV anti-retroviral medications or medication-assisted therapies for substance use treatment.**

Discriminatory practices can include high co-pays, tiering, prior authorization, fail first policies, or low co-insurance, and are a barrier to accessing anti-retroviral medications

and medication-assisted therapies. Additionally, the OIC should monitor and evaluate coverage of single-tablet regimens for HIV treatment, which can reduce out-of-pocket costs and improve adherence.

- 6. Issue guidance to health plans on HIV testing coverage requirements applicable to qualified health plans (QHPs) marketed on the health benefit exchange.**
- 7. Monitor and review life insurance and disability insurance policies to determine if there is discrimination against current or potential enrollees who are prescribed PrEP.**

There are reports³⁸ that life insurance and disability insurance plans may be refusing coverage for individuals using PrEP. The OIC should investigate this potentially discriminatory practice.

Health care plans

- 1. Ensure that claims are covered as preventative care for STD screenings (syphilis, gonorrhea and chlamydia), with no out-of-pocket costs, even if disease is detected and subsequent treatment provided.**

Screenings that uncover STDs are being classified by payers as treatment rather than prevention. Health care plans should ensure that benefit coverage clearly includes these services as preventative with no out of pocket costs. Health care plans should provide additional details to provider networks outlining these details for accurate coding and billing of claims. STD preventative services must be provided at no cost even if disease is detected and subsequent treatment provided.

- 2. Include at least one performance measure prioritizing HIV viral load suppression among people with HIV infection as part of the Quality Rating System (QRS).³⁹**
- 3. Include full coverage for anti-retrovirals being used for PrEP.**
- 4. Work internally to use utilization and claims data to identify high-risk individuals who could benefit from referral to PrEP.**

This risk assessment data could include claims data on recurring or recent STD diagnosis, substance use history, and/or mental health diagnosis related to substance use or behavior risk.

Legislature

- 1. Make STD clinics essential health care providers in Washington State.**

These clinics are ideally poised to provide HIV and STD-related services to people at risk for HIV. Making them essential health care providers will allow them to provide HIV testing and related services (including PrEP) to people regardless of their source of health insurance. Many people report that they prefer to receive HIV and STD-related services from a medical provider who is not their primary care provider, for confidentiality and/or cultural sensitivity reasons.

- 2. Pass legislation that reduces discrimination through exorbitant cost sharing by capping cost sharing at a maximum dollar amount per prescription for 'specialty' medications, including those used for HIV prevention and treatment.**

A growing number of states have passed legislation that limits cost sharing for specialty medications at (for example) \$100 or \$150 per prescription or \$1,000 annually. This action is urgently needed now to protect against cost-sharing discrimination. Cost sharing, particularly for expensive prescription drugs, can be a barrier to care. A possible model is *Covered California's* recent implementation of co-pay and co-insurance caps for specialty medications covered by qualified health plans.⁴⁰

- 3. Pass legislation eliminating tiers in insurance plans' prescription drug formularies for specialty medications.**

Prescription drug tiering leads to high out-of-pocket costs for anti-retroviral and specialty medications used to treat a number of chronic and acute health conditions. Covering all specialty prescription medications at the same level will increase access and affordability for patients and eliminate a barrier to care.

Action Steps to Address and Reduce HIV-Related Stigma

1. An intended outcome of having the OIC (action items *OIC 1* through *7*) and the Legislature (action items *Leg 1* and *2*) work to increase access to HIV testing and to PrEP is to reduce stigma associated with HIV, HIV testing, and PrEP use.

Action Steps to Address and Reduce HIV-Related Disparities

1. An intended outcome of addressing insurance coverage and out-of-pocket costs for specialty medications, STD screening and all costs associated with PrEP (action items *OIC 3, 4, 5, HCP 1, 3, Leg 1* and *2*) and network adequacy for HIV/STD services (action item *OIC 2*) is to reduce disparities in access to HIV prevention, care, and treatment services that may be experienced by low-income individuals, communities of color and others who disproportionately lack access to affordable, comprehensive health care.

8

Increase Access to Safe, Stable and Affordable Housing for People Living with and At Risk for HIV

Agencies and Sectors Impacted

Legislature, Health Care Authority, affordable housing sector, health care organizations and systems, Washington State Human Rights Commission, local jurisdictions and service providers, PLWH and members of communities affected by HIV

Background

Housing is an essential component of health, particularly for PLWH

Research has shown that housing assistance for PLWH is cost-effective⁴¹ and improves health outcomes at each stage of the HIV care continuum;⁴² conversely, homelessness and housing instability are linked to inadequate HIV health care, high viral loads, poor general health, avoidable hospitalizations, and increased mortality.⁴³ Stable housing improves health outcomes for PLWH and reduces the likelihood of HIV transmission. Yet the demand for temporary and long-term housing for PLWH far exceeds the supply. Nationally, more than 40 percent of PLWH will experience homelessness or housing instability over the course of their illness.⁴⁴ Vouchers provided through the *Housing Opportunities for People with AIDS* (HOPWA) program meet only one-third of the demand for housing assistance.⁴⁵ There are waitlists for housing support for PLWH throughout Washington State. Some areas lack any transitional housing services.

Homelessness is a significant barrier to wellness for PLWH. When a person's primary focus is finding food to eat and a safe place to sleep, treating one's HIV becomes a lower priority. The lack of housing stability can lead to consequences, including missed medical appointments, lost or stolen medications, higher viral loads, worse health outcomes, and increased risk of transmission to others.⁴⁶

'One of the biggest barriers is housing. Without housing the whole medical care piece becomes very tricky to manage your illness.'

— HIV Service Provider

Homelessness also increases the risk for acquiring HIV

Homelessness can increase pressure on people to engage in risk behaviors, such as transactional sex, in order to secure housing⁴⁷. Individuals experiencing homelessness are more likely to engage in substance use and to have mental health conditions. Housing support is critical to successful health care and prevention.

The needs of PLWH experiencing or at risk for homelessness vary. Some individuals are in need of rental or mortgage assistance to get through a brief crisis, while others require long-term permanent supportive housing. Housing models should respond to this diversity of need to ensure that all PLWH and at-risk people can be healthy and reduce the risk of HIV transmission.

Finally, substandard housing is an additional barrier for PLWH and other individuals in need of affordable housing options. Housing that is not well maintained, infested with vermin, or has environmental toxins, such as black mold, not only endangers residents' physical health, but evidence suggests it can also exacerbate mental health conditions.⁴⁸

To get closer to ending HIV in Washington, the strategy must include safe, affordable housing options and homelessness prevention for people living with and at risk for HIV.

Action Items

Health Care Authority, health care organizations and systems, and affordable housing sector

- 1. Ensure that PLWH with an AIDS-defining illness or other serious health condition are always discharged from the hospital or other institution to a safe, secure place to stay.**

When PLWH with a health status that jeopardizes their ability to care for themselves or their safety are discharged from the hospital to the street or shelter, the result is poor health outcomes and likely hospital re-admittance. HIV programs and care providers should establish mechanisms to assure that all medically vulnerable PLWH have a place to live. This will require expanding the supply of temporary and permanent housing for medically vulnerable PLWH. More temporary and permanent housing units, including units sized for families, are needed across the state to address the health needs of PLWH who are experiencing homelessness or are unstably housed. Additionally, the stay in medical motels or other temporary housing should be long enough to help ensure successful transition to permanent housing.

- 2. Expand and fund a permanent supportive housing model for people living with HIV and other at-risk people with chronic physical and/or behavioral health diagnoses.**

Using innovative models, such as those described in Washington State's *Medicaid*

Global Transformation Waiver, PLWH and others with chronic physical and/or behavioral health conditions who face chronic homelessness should be expeditiously placed in permanent supportive housing. Washington State should adopt a housing first model of HIV care, ensuring that all HIV-infected people with significant chronic and disabling physical and/or behavioral conditions have rapid access to permanent housing with appropriate levels of supportive services without having to first meet requirements, such as sobriety. This housing model should be paired with social supports to enable tenants to remain successfully housed and connected to physical and behavioral health services. Clients of HIV-specific housing programs have higher rates of viral suppression.⁴⁹

Affordable housing sector

- 1. Institute cultural awareness training for service providers in homeless shelters, transitional housing and permanent supportive housing to increase the number of safe spaces for PLWH, LGBT individuals (including youth), people of color, immigrants and refugees, and people who inject drugs (PWID) experiencing homelessness.**

Services must be truly accessible for everyone in need. LGBT individuals and others report not feeling safe in shelters or that the services available in the community do not meet their needs. To help close this gap, measures to increase the cultural awareness of housing providers is recommended.

Legislature, Local Health Jurisdictions and service providers, Washington State Human Rights Commission, and affordable housing sector

- 1. Implement measures to help PLWH stay housed and avoid potential homelessness.**

Interventions to prevent homelessness help maintain stability and health for individuals and families at risk for homelessness. Short-term rental and mortgage assistance, utility assistance, landlord/tenant relations to mediate disputes, and other skill building for te-

nants are options to help people through brief periods of crisis and maintain safe and stable housing. Public resources for housing assistance should be used for these kinds of homelessness prevention measures. Additionally, the permanent supportive housing model described above should include behavioral supports for tenants to help them be successful in housing.

2. Implement policies to remove barriers to accessing rental housing.

PLWH and others who have experienced poverty or homelessness are disproportionately likely to have evictions on their records, adverse credit histories, and prior or current involvement with the criminal justice system, all of which are barriers to passing tenant screenings and securing housing. The Legislature and local jurisdictions should work with housing providers and landlords to reduce these barriers to housing in state and local laws. Additionally, PLWH, LGBT individuals, and people of color can face discrimination in the housing market, as was recently documented by the *Seattle Office for Civil Rights*.⁵⁰ Policies are needed to reduce barriers to housing through the tenant screening process, and anti-discrimination laws must be strictly enforced by local jurisdictions as well as by the *Washington Human Rights Commission*.

3. Remove barriers to accessing housing services.

Current policies require that individuals seeking housing and homelessness services first satisfy a minimum number of days unsheltered; essentially, that they have to be *homeless enough* to access services. These policies exacerbate the negative effects of homelessness by requiring an individual to stay homeless longer. Additionally, immigrants without documents are often prohibited from accessing housing and homelessness services. These policies should

be changed to get individuals experiencing homelessness, regardless of immigration status, housed more quickly.

Local jurisdictions and service providers

1. All housing should meet safety and sanitation standards. Substandard housing is not an acceptable option for housing assistance.

Housing that is in poor repair, has mold, lacks insulation, lacks working appliances, heat, adequate hot water, safe electrical and plumbing systems, and/or has other deficits is not an appropriate placement for any homeless person, much less medically vulnerable people such as those living with HIV. Therefore, any intervention to assist this population must have a housing inspection component to insure safe, decent and sanitary conditions.

Action Steps to Address and Reduce HIV-Related Stigma

1. An intended outcome of increasing the cultural awareness of housing providers (action item *AHS1*) is to reduce the stigma(s) that may be experienced by PLWH, LGBT individuals (including youth), people of color, immigrants, refugees, and PWID experiencing homelessness and seeking services.

Action Steps to Address and Reduce HIV-Related Disparities

1. An intended outcome of reducing homelessness experienced by PLWH and people at risk for HIV (action items *HCA/HCOs/AHS 1, 2; Leg/LHJs/WSHRC/AHS 1, 2, 3, and LJ 1*) is to reduce disparities in health outcomes that are exacerbated by homelessness and housing instability, and are disproportionately experienced by people of color, LGBT youth and others.



9

Deliver Whole-Person Health Care to PLWH and Ensure Continuity of Integrated Care Across the Life Span

Agencies and Sectors Impacted

Department of Health, Health Care Authority, Department of Social and Health Services, Legislature, health care organizations and systems, Corrections, Office of the Insurance Commissioner, Local Health Jurisdictions and service providers, business community, PLWH and members of communities affected by HIV

Background

Twenty-five years ago, the federal government enacted legislation to provide services exclusively to PLWH – the *Ryan White Comprehensive AIDS Resources Emergency (CARE) Act*, now known as the *Ryan White Program*. This program was established with the recognition that people with HIV, especially those with limited resources, needed a coordinated and comprehensive system of care and treatment. At the time the program was established, its main goal was to provide people with the services and support they needed over the relatively limited time that they would survive.

Since that time, tremendous advances in treatment have allowed people to live longer, healthier lives with HIV, as long as they stay engaged with care and adherent to medication. Multiple studies have shown that access to interdisciplinary care improves engagement and retention in care and adherence to medications.^{51, 52, 53} A study of nine clinical sites funded by the *Ryan White Program* suggests that successful delivery of interdisciplinary care includes:

- Patient-centered, one-stop-shop approaches with integrated or co-located services.
- Diverse teams of clinical and non-clinical providers
- A site culture that promotes a stigma-reducing environment for clients.
- The availability of a comprehensive array of medical, behavioral health, and psychosocial services.
- Effective communications strategies, including electronic medical records.
- A focus on quality.⁵⁴

While the characteristics of a coordinated system of care for people with HIV have been described and some clinics in the state have established systems that integrate diverse services, other providers continue to experience challenges in creating this type of system and some clients continue to experience barriers to getting the care they need. The fragmented system sometimes leads to delays in seeking medical care, reduced adherence to HIV treatment, and increased HIV transmission through risk behaviors.

The need for an integrated system of HIV care that provides truly comprehensive services is now more important than ever. The PLWH who remain out of

care and unsuppressed often confront tremendously difficult social circumstances exacerbated by complex medical conditions. Mental illness and substance use disorders are common among those living with HIV; of those enrolled in Medicaid in 2007 who had HIV, 50 percent had a dual diagnosis with substance use disorders or mental illness.⁵⁵ The structure of the health care system often creates barriers to successful, comprehensive care. These barriers include pre-conditions for entering some systems that make it impossible for whole-person health to be addressed (for instance, you need to be sober to get housing, or you need to have addressed your mental health issues before getting treatment for substance use disorders); structures that require patients to consistently attend appointments or comply with rules they cannot comply with; and stigma, which is associated with being HIV-positive, having mental health and/or substance use disorder issues, being gay, or being a person of color, can compound the challenges for these individuals. People over the age of 50 living with HIV face the additional vulnerabilities of aging. Meeting the needs of the most vulnerable patients requires a commitment to restructure the health care system.

order counselors and/or mental health specialists as barriers to care. As the HIV-positive population ages, interdisciplinary care in a system that supports continuity of care will be increasingly important for several reasons. These include the potential fluctuations that can occur over the course of a person's life (such as changing job situations that may lead to changes in insurance or changing access to housing), as well as the changes in health needs associated with aging, complicated by HIV, and long-term side effects of medications. These barriers also affect HIV risk. Gay and bisexual men, transgender/non-bi-nary individuals, communities of color, people with behavioral health conditions, people who inject drugs and others have complex health care needs that require an integrated system. Additionally, individuals who are incarcerated or recently released from jail face a number of challenges in staying connected to HIV treatment or prevention care. It will not be possible to end the HIV epidemic, in Washington, without addressing these barriers. Fortunately, the *Healthier Washington* initiative calls out a specific focus on *ensuring health care focuses on the whole person* and places major emphasis on removing barriers to providing interdisci-

"It is very difficult to address mental health and substance abuse issues. They are intricately linked but programs often require clients to deal with the other issue first. In order to get mental health services, first get clean and sober. In order to deal with substance abuse, you must be mentally stable. So there is no right door."

— HIV Service Provider

In some instances, this will also require new resources as existing federal programs are poorly designed to pay for the care of the most difficult-to-treat patients. Additionally, women, minorities and people living in rural areas face unique obstacles. Women in need of child care or transportation, or who are afraid to disclose their status for fear of intimate partner violence, may be difficult to engage in or retain in care. Racial and ethnic minorities face cultural and linguistic barriers to care. People in rural areas often cite lack of transportation and difficulty in finding medical providers, substance use dis-

ciplinary care in our health system. Payment systems are integrating payment models so that the care team has payment incentives to look holistically at patients. Plans are being put into place to develop the workforce, increasing the numbers of both clinical (physical and behavioral health) and non-clinical providers to address the needs of the increased number of people using the health care systems. Technology is being developed so that providers can more easily share information and provide support to clients in remote locations via telemedicine/telehealth.

Action Items

Governor's Office and the Legislature

1. Support and enhance work on the recommendations of the *Adult Behavioral Health System Task Force*⁵⁶ to support efforts to end AIDS in Washington. Specifically:

- a. **Align and standardize regulations, reimbursement and incentive structures to eliminate barriers to providing integrated care.**

A fully integrated physical and behavioral health care system will better meet the needs of PLWH and individuals at risk for HIV infection with complex health needs. Integration will help improve health outcomes and help keep PLWH retained in care.

- b. **Increase cultural awareness and create a plan to address the role of stigma in the system through workforce development efforts.**

Stigma remains a significant barrier for PLWH and individuals at risk for HIV infection to engage in behavioral health services. Workforce development should include cultural awareness and responsiveness training aimed to reducing stigma.

- c. **Develop an integrated data system, including the ability to share data between providers in real time.**

Collaboration across provider types is essential to meet the needs of PLWH and individuals at risk for HIV with complex health conditions. A review of the legal, clinical and technological obstacles to sharing data across practice settings will be necessary, with input from PLWH.

- d. **Support a comprehensive substance use disorder service package that includes case management, peer services, recovery supports, medication monitoring/management, access to medication-assisted therapies (including opioid replacement therapy), and harm reduction.**

A comprehensive approach to substance use disorder treatment and harm reduction is needed to meet the diverse needs of PLWH and individuals at risk for HIV infection seeking these services. This approach should include the removal of pre-conditions for access to services; for example, sobriety should not be required to enter mental health treatment. A comprehensive substance use disorder service package can also help PLWH stay retained in care.

- e. **Work with county jail systems and juvenile detention centers to create a continuum of care that spans incarceration and return to the community.**

A comprehensive approach is needed to ensuring access to care – including HIV/STD screening, HIV treatment and medication-assisted therapies for treatment for substance use disorders – for adults and youth while incarcerated and upon release. Upon return to the community, youth and adults need linkage to care, insurance enrollment, housing and other supports in order to remain adherent to care, treatment or prevention regimens.

Business community

1. **Create new, innovative solutions to address the transportation and health care access needs of PLWH to support retention in care.**

HIV service providers are encouraged to partner with local and online businesses to better meet the diverse needs of PLWH. For example, partnering with *Uber* for transportation, *Amazon* for medication delivery, and *Microsoft* for telemedicine would address some of the gaps identified by PLWH and care providers, and would serve as a model for meeting the health care needs of Washingtonians more broadly.

Department of Health

1. **Look for opportunities to make training available to providers through the Practice Transformation Support Hub being developed as an investment of *Healthier Washington*.**

This effort should include resources for providers that address stigma, motivational interviewing, and trauma-informed care. Additionally, the *AIDS Education and Training Center (AETC)* should be engaged as a Hub resource to train on subjects such as working with people who are non-compliant or disruptive, or prescribing antiretroviral therapy to those who have substance use disorder or mental health issues. Both systems and individuals will need support and new skills to change their behaviors.

2. Look for opportunities to expand support of interdisciplinary teams via telehealth models.

Telehealth provides opportunity to connect community-based rural clinicians and other care providers with each other and a panel of specialists. Telehealth and telemedicine models are also an important option for LGBT patients in rural areas, as well as for anyone who perceives stigma or discrimination within their local community that may be exacerbated by a lack of confidentiality.

3. Increase income limits for eligibility for the the Early Intervention Program (EIP).

EIP is Washington's *AIDS Drug Assistance Program*, and currently provides insurance premium support and cost-sharing assistance for PLWH up to 400% of the federal poverty level. Increasing this income limit will reduce cost burdens and expand access to costly HIV care.

4. Simplify six-month eligibility determination processes for PLWH accessing services.

Federal regulations require PLWH accessing HIV services to establish their eligibility in the program every six months, which can be burdensome for some enrollees. DOH is encouraged to simplify this process through a centralized eligibility program.

5. Accelerate adaptation of care team approaches through funding and contracts to support the most vulnerable patients with HIV and support retention in care.

As DOH makes decisions regarding funding HIV community services across the state,

the agency is encouraged to devote resources to supporting care team approaches in delivering HIV services and supports. Some PLWH cannot consistently attend appointments and require substantial social services and outreach to remain engaged with care. Caring for these people is resource intensive, and requires a willingness to restructure medical and social service systems. DOH should invest funds to ensure that our state cares for its most vulnerable PLWH.

6. Ensure that the EIP formulary supports guideline-concordant medication-assisted therapies.

The EIP formulary needs to be fluid in its ability to add medications as they become available/necessary to treat PLWH - not just new anti-retroviral medications but any needed by PLWH with other diagnoses or as the result of aging.

Care teams, health care organizations and systems

1. All members of the care team recognize their own shared accountability to eliminating the barriers to suppressed viral load as an outcome of success in treating PLWH.

Teams need to include navigators and peers. Work should focus on how the patient is supported to stay retained in care outside of the clinic walls, including addressing ongoing substance use disorder or mental health needs.

2. Offer the full range of substance use disorder services, including harm reduction and medication-assisted therapy.

A diversity of services and approaches are essential to meet the needs of PLWH seeking substance use disorder services.

3. Recognize that mental health diagnoses, substance use disorders, and HIV are chronic conditions that can be managed, where triggers are understood and where relapse is recognized as part of the disease pattern.

As services are integrated and the focus shifts to whole-person care, it will be important to identify and minimize the effects of overlapping stigmas patients may face. Different provider practices can share lessons learned and improve the whole team. Building a common understanding among providers about chronic disease management and triggers will help providers in one discipline provide sensitive care to patients with other chronic conditions.

4. Implement a universal screening process, so that there is no ‘wrong door’ though which PLWH can access the services they need.

Not every person on the care team will have expertise in every area, but team members need to be able to flag issues for other team members, including medication adherence issues, intimate partner violence, and risky sexual behavior. For example, given the strong correlation between being a survivor of intimate partner violence and HIV risk in women,⁵⁷ survivors would benefit from better integration between the HIV and intimate partner violence systems. Then, no matter where a patient *presents*, the team member working with that patient can assure that his/her particular circumstances can be correctly flagged for other members of the team.

Health Care Authority and Accountable Communities of Health

1. Incentivize an interdisciplinary approach to care that includes medical providers, dental providers, behavioral health specialists, and other practitioners.

Reimburse all care team members and reward teams for successful management of complex cases.

2. Include project options that address the needs of people with chronic infectious diseases in the Global Medicaid Transformation Waiver projects.

3. Incorporate stigma-reduction strategies in planning the integration of providers and support systems through the ACHs.

Successful intervention will require identifying and mitigating the overlapping stigmas experienced by PLWH, individuals with mental health diagnoses, and individuals with substance use disorders.

4. Remove barriers to accessing medication-assisted therapies.

Pre-authorization requirements and other policies are barriers to accessing medication-assisted therapies, such as suboxone and naloxone, which can be highly successful treatments for substance use disorders.

Action Steps to Address and Reduce HIV-Related Stigma

1. Several action items (*Gov/Leg 1b and DOH 2*) specifically call for training providers to reduce stigma related to HIV and behavioral health diagnoses and treatment. Action item *HCA/ACA 3* also calls for stigma-reduction strategies as provider integration occurs through the *Accountable Communities of Health*.

2. An intended outcome of recognizing HIV, mental health diagnoses, and substance use disorders as chronic conditions (action item *CT/HCOs 3*) is to better understand these conditions as well as the people living with them, and to break down the associated and often overlapping stigmas.

Action Steps to Address and Reduce HIV-Related Disparities

1. An intended outcome of creating a comprehensive substance use disorder service package that meets the needs of PLWH and people at risk for HIV (action item *Gov/Leg 1d*) is to reduce disparities in access to these services, including harm reduction models, experienced by PLWH.

2. An intended outcome of supporting telehealth models for interdisciplinary teams (action item *DOH 3*) is to reduce disparities in access to HIV care and behavioral health services experienced by some individuals living in rural areas.



10

Launch Healthier Washington for Youth: Improve Sexual Health Education, Physical and Behavioral Health Services, and Social Supports and Interventions for Washington Youth

Agencies and Sectors Impacted

Legislature, Governor's Office, affordable housing sector, Department of Commerce, Office of the Superintendent of Public Instruction and local school districts, Department of Health, Health Care Authority, Department of Social and Health Services, Local Health Jurisdictions and serviceproviders, Washington youth, PLWH and members of communities affected by HIV.

Background

Comprehensive, inclusive sexual health education

Young people need to have the information, tools, and resources to understand risks and make sound decisions about their sexual health throughout their lives, and protect themselves against sexually transmitted diseases (STDs), including HIV, and unintended pregnancy. Comprehensive, medically accurate and culturally relevant sexual health education that is LGBT-inclusive equips young people with this information. The *AIDS Omnibus Act*⁵⁸ requires annual instruction in an HIV curriculum for students in Washington public schools, grades 5-12. In 2007, the Washington Legislature passed the *Healthy Youth Act* (HYA), which requires that sexual health education taught in Washington public schools be comprehensive, age-appropriate and medically accurate.⁵⁹ The law does not, however, *require* that schools provide sex education for students. Currently, sex education curricula and practices are randomly surveyed by OSPI, on a biannual basis, to determine what curricula are being used, what topics, taught time allotted, etc. Because the surveys are random and voluntary on the part of school districts, they do not reflect a comprehensive review of compliance with the HYA. Currently there is neither an enforcement mechanism nor funding to ensure that curricula comply with the requirements of the Act. Consequently, the implementation of the *Healthy Youth Act* has been uneven across school districts. More could be done in even the best-performing districts to ensure that the curricula and instruction are updated with current science and are truly inclusive of the needs of LGBT youth, including gay and bisexual young men – who are the population at greatest risk for HIV infection. From 2010 through 2014, 16 percent of newly diagnosed PLWH in Washington were under the age of 25.⁶⁰ Improved curricula, stronger oversight and enforcement, and more support are all needed to help schools provide innovative, state of the art instructional materials such as *Working to Institutionalize Sexual Health Education, Exemplary Sexual Health Education* and *Personal Responsibility Education Program*. These improvements will help ensure the young people of Washington are getting the information they need to make healthy decisions and prevent STDs (including HIV) and unintended pregnancies. Additionally, comprehensive sexual health education programs must reach young people who have left the school system because they have graduated or dropped out, are experiencing or are at risk of homelessness, or are in the juvenile justice system.

"[To get us closer to ending AIDS] I would ensure that every high school in the state has a comprehensive sex ed program which provides information about HIV prevention, using condoms and not sharing needles."

— Recipient of HIV Prevention and/or Care Services

Access to sexual health, mental health and substance use disorder services for youth

Washington state law identifies three areas in which minors can access health care services without parental notification or consent: sexual⁶¹ and reproductive⁶² health, outpatient mental health,⁶³ and outpatient chemical dependency (substance use disorder) treatment.⁶⁴ Schools and school-based health clinics are an important entry point through which young people can access or be referred to these services, yet the availability of in-school services varies widely across the state and many at-risk young people are not engaged in the school system. The most recent results of the *Healthy Youth Survey*^{*65} indicate that increasing numbers of Washington students are experiencing mental health challenges, which suggests young people could greatly benefit from confidential access to fully integrated mental health and physical health services. Because mental health and substance use disorder issues contribute to STD and HIV risk, confidential access to integrated services can empower young people to address the issues that lead to risky behavior and use STD and HIV prevention tools. Additionally, young people enrolled in their parents' health insurance plans may be unwilling to access covered services like HIV/STD testing and reproductive health care out of concern that these services will be disclosed on the explanation of benefits (EOB) sent to the plan subscriber(s). This lack of privacy in EOBs may prevent some young people from seeking needed health care services, including HIV screening, STD treatment and PrEP, creating conditions that can endanger their health and increase HIV and STD transmission risk.

* The Healthy Youth Survey is a survey on health and risk behaviors created by OSPI, DOH, DSHS, and the State Liquor and Cannabis Board, and issued to youth every two years in grades 6, 8, 10 and 12 in Washington public schools. The results inform public health and safety interventions for young people.

LGBT-related stigma and discrimination against youth of color

LGBT youth experience stigma in their schools, communities and, all too often, in their own homes. More than 85 percent of gay and transgender/non-binary youth report being verbally harassed at school due to their sexual orientation or gender identity.⁶⁶ LGBT youth and youth of color are disproportionately likely to experience homelessness. A study by the *Williams Institute* found that 40 percent of youth experiencing or at risk for homelessness identified as LGBT.⁶⁷ The 2014 King County *Count Us In* survey of homeless and unstably housed youth found that 22 percent of respondents identified as LGBT; 51 percent were youth of color.⁶⁸ Homelessness increases the likelihood that these young people will engage in behaviors that increase their risk for HIV, including substance use and transactional sex,⁶⁹ as well as their chances for involvement in the criminal justice system, which disproportionately impacts youth of color. More than 60 percent of homeless LGBT youth attempt suicide.⁷⁰ LGBT youth experiencing or at risk of homelessness can benefit from broad-based social support structures that affirm their sexual and gender identities and work to dismantle anti-LGBT stigma and its effects. Additionally, more culturally appropriate housing and support services are needed to meet the needs of LGBT youth and youth of color.

Homeless Youth Prevention and Protection Act

The Legislature and Governor Inslee recognize the need for collaboration across agencies and sectors to prevent youth homelessness and help young people currently experiencing homelessness.⁷¹ On April 25, 2015, Governor Inslee signed the *Homeless Youth Prevention and Protection Act*, which establishes the Office of Homeless Youth Prevention and Pro-

tection Programs and sets the expectation that state systems, such as foster care and the juvenile justice, will no longer discharge youth and young adults into homelessness.

Action Items

Governor's Office

- 1. Create a Youth Health Council to advise the Governor's Office, state agencies and the Legislature on health issues of importance to young people in Washington.**

The *Youth Health Council* will comprise young Washington residents from diverse racial and cultural backgrounds, sexual and gender identities, geographic locations, educational and vocational experiences, socio-economic backgrounds, and experiences with systems including mental health and substance use disorder treatment, housing support and homelessness interventions, foster care, and juvenile justice. The purpose of the *Youth Health Council* is to empower Washington youth, particularly those from marginalized communities, to research, debate and propose policy solutions and interventions to support whole-person youth health and wellness and reduce disparities among youth. Youth leadership in implementing the action steps in this set of recommendations will better ensure the interventions and policies are relevant to the needs of young people, particularly LGBT youth and youth of color. From the nonprofit sector, the *United Way of King County* provides an example of a youth advisory council. The youth on this council convened in 2013 to inform decisions around the *United Way of King County's* investments in older youth.⁷²

Legislature

- 1. Enact a mandate that all public schools in Washington teach age-appropriate, comprehensive, medically accurate, and LGBT-inclusive sexual health education.**

The 2007 *Healthy Youth Act* is a strong foundation. It is now time to pass legislation

to build on the HYA to ensure that *all* young Washington residents are receiving comprehensive, medically accurate, and LGBT-inclusive sexual and relationship health education that includes the most current science on STDs, HIV, and prevention methods. Additional resources and mechanisms will be needed to monitor curricula in use and enforce full compliance with the *Healthy Youth Act*. This effort should seek to decrease HIV/STDs, unintended pregnancy, and stigma experienced by sexual minorities, and should foster greater understanding and acceptance of all sexual and gender identities among all Washington State youth and staff in public schools. Current OSPI efforts in this area should be strongly supported, but the mandate is the key action needed now.

- 2. Establish clock hours requirements or teachers, counselors, school nurses, coaches and other school staff to be trained on LGBT cultural awareness and how to discuss sexual health with students.**

In order to foster a socially supportive environment for LGBT youth and all students with questions about sexual health, all faculty and staff should be required to be trained on LGBT cultural awareness and how to discuss sexual health issues. The training curricula should be developed by OSPI and DOH, partnering with *Welcoming Schools*, and with the input of local school districts, educators, and young people.

Office of the Superintendent of Public Instruction (OSPI), Washington youth

- 1. Develop innovative online modules and mobile apps for sexual health education, designed by youth.**

Schools and the Office of the Superintendent of Public Instruction should also look to innovative models, such as online modules and mobile apps, to deliver sexual health education to young people in ways that are accessible. Such modules and apps would allow curricula to be tailored to the needs of individual students, providing in-depth,

relevant education to LGBT youth in their preferred languages. Content development and design should include significant participation by young people themselves, to empower peers in their own sexual health care and to better ensure that the material is relevant and accessible for the intended audiences. Online modules and apps would serve the purpose of providing a confidential space for young people to seek information they might not be comfortable asking in front of their peers; complementing information provided during classroom instruction; and helping to meet the needs of young people no longer attending school.

Legislature, local school districts, health care organizations, and youth services providers

- 1. Increase access to confidential sexual and behavioral health care services in primary care offices, schools and other community settings where youth, in and out of school, are most comfortable getting services. Support the expansion of networks of school-based clinics and wide availability of condoms. Identify ways to provide access to PrEP and sterile syringes to young people at risk for HIV and young people who inject drugs.**

School-based clinics increase access to care, including access to HIV/STD testing and other care related to sexual health. Washington State should greatly expand the number of school-based clinics and foster partnerships between medical providers and public schools to provide confidential sexual health care services, including HIV screening and family planning. Additionally, organizations like shelters and community and youth centers are encouraged to partner with medical providers to meet the needs of young people using those services. Such clinics should also provide more comprehensive care and referrals for mental health care and substance use disorder treatment. Services should be culturally responsive and meet the needs of all young people enrolled in school or accessing services, including youth identifying as

LGBT. Recognizing that for sexually active people, no matter their age, condoms, when properly used, offer protection from STDs. It is imperative that condom distribution programs be widely available. Young people at risk for HIV also need access to PrEP, and those who inject drugs need access to sterile syringes. Measures to protect the privacy of young people enrolled in their parents' health insurance when seeking services like HIV or STD testing are also recommended, and are described in more detail in the *Insurance Recommendation*, action item OIC1.

- 2. Increase condom availability and distribution for youth outside of schools.**

To reach as many young people as possible, in-school condom distribution programs should be complemented by condom availability in places, like parks and community centers, where young people not engaged in the school system congregate.

- 3. Increase harm reduction support and syringe services for youth.**

The recent increase in opioid use could mean that more young people are injecting drugs, and the increased likelihood that street-involved young people are coming into contact with discarded syringes. More support is needed to make sure that young people, including homeless youth, have access to sterile syringes and have information about harm reduction if they are injecting drugs. Syringe service programs also help keep used syringes out of public areas, including parks and urban encampments.

Office of Homeless Youth Prevention and Protection Programs (Department of Commerce)

- 1. Increase support for youth sporadically engaged with or outside of the school system, including youth who have dropped out or aged out of the K-12 system, unaccompanied homeless youth, youth in the foster care system, and youth in the juvenile justice system, with an emphasis on culturally appropriate services for LGBT youth and youth of color.**

Leverage opportunities with the *Homeless Youth Prevention and Protection Act* and the new *Office of Homeless Youth Prevention and Protection Programs* to increase the shelter, housing, education and employment training options for LGBT youth transitioning between various systems and institutions. Because many of these young people are disproportionately from communities of color, successful interventions must recognize the intersectional barriers faced by homeless and unstably housed youth of color. Specific actions include, but are not limited to, sexual health education and services for young people outside of the school system; access to HIV and STD testing and other preventive services for incarcerated youth; and access to fully integrated physical and behavioral health services for all youth.

2. Increase support for and outreach to LGBT youth and other young people engaged in commercial sex work and/or being trafficked.

Further develop resources inside and outside of schools to reach out to and better serve young LGBT youth and other young people being sex trafficked and/or engaged in commercial sex work. Many of these young people are homeless or unstably housed and are often not in the school system. They are at increased risk for HIV and other STDs, as well as other behavioral health challenges.

Local school districts, youth services providers

1. Strengthen social supports for LGBT youth and youth of color to reduce anti-LGBT stigma and the health consequences of racism, and support self-esteem, self-determination, and healthy relationships.

Social support systems for LGBT youth and youth of color are an important intervention against the effects of stigma and racism. Additionally, a strong and visible social sup-

port network for LGBT youth and youth of color will help break down stigma in schools and the community. Safe spaces, mentoring and leadership development opportunities, and other activities for LGBT youth and youth of color will improve overall wellness and counter the negative physical and mental health effects of stigma and racism.

**OSPI and local school districts,
Department of Health**

1. Evaluate the success of these efforts through the Healthy Youth Survey and expand the survey distribution beyond school settings.

The *Healthy Youth Survey* is administered every two years to Washington students in grades 6, 8, 10 and 12, and asks questions about a variety of topics including safety and violence, nutrition, substance use, and sexual activity.⁷³ However, the questions on sexual activity are limited and schools are not required to include them, thereby limiting the quantity and the quality of the data. All Washington public schools should administer the *Healthy Youth Survey* involving as many of their students as possible and include comprehensive questions about students' sexual activity, sexual and gender identities, and behaviors. Additionally, OSPI and DOH should look to additional distribution channels to better ensure that youth not engaged in public school settings are participating in the survey. This will enable an equitable assessment of youth needs in every community.

Action Steps to Address and Reduce HIV-Related Stigma

1. An intended outcome of the creation of a *Youth Health Council* (action item Gov 1) is to reduce stigma LGBT youth and youth of color may experience, through engagement and empowerment.
2. An intended outcome of strengthening the mandate for Washington's sexual health education law (action item Leg 1) and creating online modules and apps for compre-

hensive and inclusive sexual health education (action item *OSPI 1*) is to make LGBT health needs more visible, thereby reducing LGBT-related stigma.

3. An intended outcome of requiring training for school faculty and staff in LGBT-awareness and how to discuss sexual health (action item *OSPI/WY 1*) and youth service providers (action item *OHYPPP 1*), and providing social support for LGBT youth and youth of color in schools (action item *LS 1*) is to reduce stigma(s) LGBT youth and youth of color may experience in school settings and when seeking services.

Action Steps to Address and Reduce HIV-Related Disparities

1. An intended outcome of increasing access to HIV/STD screening and behavioral health

services at youth-serving organizations (action item *Leg/LS 1*) and increasing condom availability for youth outside of schools (action item *Leg/LS 2*) is to reduce disparities in health care and prevention access experienced by young people who are homeless, unstably housed, or simply not in the school system. Similarly, creating online modules and apps for sexual health information (action item *OSPI 1*) will reduce disparities in access to knowledge about sexual wellness experienced by young people not attending school.

2. An intended outcome of working with the newly created *Office of Homeless Youth Prevention and Protection Programs* (action item *OHYPPP 1*) is to address and reduce disparities affecting homeless youth, including those being trafficked and/or commercial sex workers, who are disproportionately LGBT.



Invigorate and Strengthen Meaningful Community Engagement and Empowerment for People and Communities Disproportionately Affected by HIV-Related Disparities and Stigma

Agencies and Sectors Impacted

PLWH and members of communities affected by HIV, Department of Health, health care organizations and systems, Local Health Jurisdictions and service providers

Background

PLWH have been at the forefront of the policy and programmatic interventions since the beginning of the epidemic. These efforts have directly contributed to a dramatic increase in HIV awareness and access to and retention in HIV-related medical care. Many planning bodies, including *Ryan White Planning Councils*, require representation of PLWH. Yet survey responses and comments in community forums during the *End AIDS* project indicate that our public and private sector HIV services could do more to fully engage and empower PLWH and communities disproportionately affected by HIV. This request for inclusion and leadership opportunities in design and decision making is not only about community empowerment – a worthwhile goal in itself – it is also about making all HIV community services more responsive to community needs and therefore more effective in achieving the goals of *End AIDS Washington*.

Using HIV-related disparities and the multiple forms of stigma as the lens, there are many opportunities to strengthen community engagement as a key element of ending the HIV epidemic in our state. A Steering Team member noted: *I think we want a genuinely collaborative process, one that involves PLWH and affected communities, but also involves medical and social service providers, government, and health care organizations.* One of the key early conversations with each community (see definition below) will be to come to a shared understanding of what a *genuinely collaborative process* means and what behaviors and actions can make this happen.

The *communities* to engage more fully could be defined by HIV status, sexual orientation, geography, racial-ethnic background, age, mental health status, gender identity, or other factors that describe or define why they may be stigmatized or experience disparities. The word *community* will have many meanings. Even though some community members may have been involved in the past, there are additional community members who will likely wish to participate in the future.

Members of many communities often prefer that the engagement takes place on their *turf* and include leadership roles by leaders in their group. *Turf* could be a community center, church, restaurant, home or other venue where members of the community feel at home. Members of the community would have many options for providing their ideas, including speaking, writing comments, recording comments, being interviewed, etc. Multiple languages are supported by interpreters and translated materials. The goal is to offer many pathways to participation by members of the community.



Part of the process is devoted to creating space for members of a group or community to share their own lived experiences and have these experiences heard by decision makers. This could include a parallel process of capturing the stories of the community in short interviews or in writing, as part of the *End AIDS Washington* communications campaign. These stories provide context and opportunity for fuller awareness and understanding on the part of funders, policy makers, program designers, service organizations, etc.

The HPSG upholds the reality that words and names matter. The choice of language to identify individuals, groups, or behaviors is important and people may disagree about the most appropriate terminology. Different constituencies may use terms differently. An effort is made in this report to select and use descriptive language consistently, as one effort to provide clarity about the work that we believe needs to be done to end AIDS.

The HPSG strongly supports the *Community Engagement* recommendation and processes in this report and envisions these community conversations as a way to hear more clearly from people what descriptive language is meaningful for them, recognizing that even within a group, there may be a variety of perspectives about the most appropriate and relevant language. Preferred language is likely to change and evolve over time, as language is alive. The *Glossary* identifies a number of terms used in the report and the alternative wording that has been identified. The HPSG looks forward to additional discussion about language and other aspects of the *End AIDS* report.

A genuinely collaborative community engaged process will take time and will be, at times, challenging to all parties involved. There are no easy, quick solutions, because long-term stigma experienced by our communities (such as homophobia, transphobia, and racism) has done much damage over the years. Undoing that damage and creating new ways to work with communities harmed by stigma and disparities will take time, patience, new learning, and flexibility in the face of uncertainty.

The exciting part is that there is a true desire on the part of public health, service organizations, and people affected by HIV to work together in new ways, using clear data about the HIV-related issues that need to be addressed.

More broadly, the reforms envisioned in the *Affordable Care Act* support this kind of work within the health care system. *Accountable Communities of Health*, which are locally focused, are working with partners in many other sectors to look at social determinants of health and associated health disparities and to carry out community-based needs assessments. Out of that work, new community engagement strategies are being considered and designed.

At the same time, health care practice transformation calls for a much stronger focus on patient-centered care, looking not only at the patient's specific health condition, but his whole life, his family, community and other factors (and social determinants) that affect his quality of life.

This recommendation:

- Creates new opportunities for public health to address social determinants and disparities at the grass-roots and granular level.
- Builds upon and significantly expands current community engagement work being done by DOH, LHJs and CBOs under the current *HIV Prevention Framework*.
- Builds on *Healthier Washington* goals around ACHS, community assessments, and community involvement.
- Builds on *Healthier Washington* goals around patient-centered care and practice transformation.
- Links to equity-related initiatives such as *Health in Every Policy, Public Health System of the Future*, etc.

The recommendation includes actions steps both at the macro (health system) level and at the HIV-specific level.

"Any intervention needs to start from bottom up, especially when we speak about racial and ethnic disparities. There are so many HIV-positive people who are not engaged because of several factors, to mention some: stigma, medical coverage and lack of understanding how the system works. It will help the intervention succeed if expertise from the communities is involved in designing the intervention."

— HIV Service Provider

The HPSG further emphasizes that the effort to end AIDS is an active, ongoing, passionate effort. The work is iterative, meaning that as implementation begins and progresses, the voices of the communities most affected by HIV will be welcomed. Implementation will consider experience about what works and what doesn't, additional and new scientific or medical findings, and new information from others working to end AIDS. While the goals and recommendations of this report (the WHAT of *End AIDS*) stand themselves as a finished product, updates to the report will be developed, and implementation plans (the HOW of *End AIDS*) will reflect new information and learning.

Leadership for community engagement work

While recommending that public health take the lead in community engagement work, the HPSG also expressed that for this type of work (and for stigma reduction and disparities reduction work) to be successful, it is critical that the leadership conceptualize and implement this work in new ways (specifically to include community member input and leadership of the design and implementation processes). The HPSG's recommendations about HOW to move forward are found in the *Implementation and Next Steps* section of this report.

Macro Action Item

- 1. Public health should take the lead in articulating the community engagement vision in partnership with members of affected communities, Health Care Authority, Accountable Communities of Health, and interested health systems.**

It is essential that all of the agencies engaged in health systems integration and innovation work collaboratively to ensure meaningful community engagement.

HIV-Specific Action Items

Community engagement action steps specific to communities affected by HIV have been identified that DOH staff and its community partners can implement. Note that all of these HIV-specific ideas provide models that can be adapted for other areas of focus within the health care system.

PLWH and members of communities affected by HIV, Department of Health, health care organizations and systems, Local Health Jurisdictions and service providers

- 1. Design the implementation structure and accountability for the recommendations in the *End AIDS Washington* report. Identify a dedicated staff person at the state level (DOH) whose sole assignment is *End AIDS Washington*.**

The HPSG will discuss implementation options early in 2016, including the HPSG's role, the role of other work groups or committees, and the desirability of having an overall *End AIDS* implementation team. Any group organized and/or designated to help with implementation should reflect a variety of perspectives and include communities most affected, in accordance with the community engagement principles in this report. The DOH *Infectious Disease* staff person should have *End AIDS* as their sole responsibility. *End AIDS* work should not be added to the workload of an existing position. The recommendations in this document are only the first step in achieving the goals of *End AIDS Washington*. Successful implementation efforts must have community support and leadership.

- 2. Partner with existing community-based groups, such as consumer advisory panels and research community advisory boards, to engage members of affected communities to implement community empowerment strategies. Engage communities in building a shared vision of the 'genuinely collaborative process' so that everyone can work toward making this collaboration happen.**

This effort should be led by members of affected communities, who are in a position to authentically engage fellow community members and facilitate planning that develops leadership at the community level. These efforts should include defining *community*, recommending ways to engage individuals who do not identify as members to speak openly and constructively about their experiences interacting with and/or receiving services from public health entities and CBOs.

- 3. Ensure sufficient representation of PLWH and members of affected communities on all other decision-making bodies, including paid staff.**

All planning and advisory bodies, including the HPSG and any implementation body designated specifically for *End AIDS*, should have sufficient representation by PLWH and members of affected communities that allows for meaningful participation. Additionally, public and private sector staff who make decisions about HIV prevention and care/treatment investments and programs must include sufficient representation by PLWH and communities disproportionately affected by HIV. This is not a recommendation to remove any HIV professionals from their current positions, but rather to be intentional about representation as staffing changes naturally occur over time.

- 4. Include capacity building for PLWH and members of affected communities in HIV funding opportunities.**

In order for PLWH and members of communities disproportionately affected by HIV to be successful, participants and leaders in

decision-making bodies and as paid staff members, public and private sectors need to invest both time and financial resources to build the capacity of community members as well as develop new processes that engage communities creatively and effectively. To emphasize the importance of capacity building, it should be specifically funded as part of comprehensive HIV prevention and care/treatment programs. Whenever possible, these capacity building programs should be peer-designed and peer-led.

- 5. Establish additional ways for PLWH and members of affected communities to be involved in HIV planning, program development, or evaluation without joining a board or planning body.**

Not everyone has the time or desire to sit on a board or to join the staff of an organization. There should be additional, more time-limited ways for PLWH and members of affected communities to be consulted for their expertise in staying healthy and accessing services. The HPSG HIV Stakeholder Villages are one example of this model. Through the Villages, which have no formal membership, community members can get information from the HPSG and DOH on current and proposed HIV strategies and programs and in turn ask questions and provide feedback.⁷⁴

- 6. Direct HIV resources to fund peer support, peer navigators, and vocational opportunities for PLWH and members of affected communities.**

Engagement of peers in service delivery is empowering for PLWH and members of affected communities and makes health care and support systems more accessible. Increased social support and vocational opportunities for PLWH who want to work likewise reduce HIV-related stigma and contribute to a higher quality of life for PLWH. The same holds true for members of affected communities. For example, the new *Enhanced HIV Community Services* portfolio will provide opportunities to employ

peers. Whenever possible, credentialing requirements should be experience-based as well as academic-based to minimize barriers to employing PLWH and members of affected communities in this field.

7. Message and program development should be led by the communities these interventions are meant to benefit.

Successful HIV prevention and care/treatment messages and programs for specific communities must be informed and disseminated by members of those same communities. This is essential to creating messages and programs that are accessible and responsive to communities' assets and needs.

8. All outreach, educational, eligibility, and programmatic materials should be language accessible and culturally appropriate, including American Sign Language in video format.

To engage everyone living with or at risk of HIV in their own well-being, all HIV-related materials must be available in the recipients' preferred languages and at appropriate reading levels. Sufficient funding must

be provided to support content development, translation, and interpretation services, including community-relevant colloquialisms and slang expressions.

Action Steps to Address and Reduce HIV-Related Stigma

1. All of the action items in this section are designed to reduce the impact of stigma(s) experienced by PLWH and members of disproportionately affected communities through authentic community engagement, leadership, and empowerment.

Action Steps to Address and Reduce HIV-Related Disparities

1. All of the action items in this section are designed to reduce disparities affecting PLWH and members of disproportionately affected communities by empowering community members to lead *End AIDS Washington* implementation efforts, including program design, implementation and evaluation, in a way that is responsive to PLWH and members of underserved communities.



"I think it's especially important within the gay community to have insurance. We have a high rate of transmission of HIV and other STDs and if you don't have insurance to get tested and treated, then the cost can be astounding, so it's huge to have insurance."

— *Blaine*

IMPLEMENTATION AND NEXT STEPS

45-Day Public Comment Period

The *End AIDS Washington* report, recommendations and action steps were posted on the DOH and *End AIDS Washington* websites on December 1, 2015, for public review and comments. At the close of the comment period (January 15, 2016), the Steering Team and the HPSG reviewed comments and incorporated revisions, including one new recommendation and a number of *Next Steps* and *Future Work* items. The final report and recommendations will be sent to Governor Inslee and to DOH in the summer of 2016 to begin the coordination of implementation of the recommendations.

Implementation of the End AIDS Washington Recommendations and Action Items

Implementation of the recommendations and action items will require strong coordination, meaningful community engagement and empowerment, and leadership across sectors to achieve the goals of *End AIDS Washington*.

The HPSG emphasizes that the effort to end AIDS is an active, ongoing, passionate effort. The work is iterative, meaning that as implementation begins and progresses, the voices of the communities most affected by HIV will be welcomed. Implementation will consider experience about what works and what doesn't, additional and new scientific or medical findings, and new information from others working to end AIDS. While the goals and recommendations of this report (the WHAT of *End AIDS*) stand themselves as a finished product, updates to the report will be developed, and implementation plans (the HOW of *End AIDS*) will reflect new information and learning.

The Steering Team recommends that the following work be addressed in implementing the *End AIDS* recommendations:

Leadership

Overall leadership and coordination of the future work and implementation of the End AIDS project

While the Director of the Infectious Disease Office within DOH will oversee this work, the person tasked with the actual work assignment (*End AIDS* staff person) needs to be identified. This is new work and cannot be added to the existing workload of a staff person.

The *End AIDS* staff person (action item PLWH/DOH/HCOs 1 in the *Community Engagement* section) and any group created to help with implementation should identify leadership across the sectors identified in the above recommendations as an initial step in drafting and executing implementation plans.

The dedicated *End AIDS* staff person will be an essential point of accountability and organization for the entire *End AIDS Washington* initiative. That is why funding, as well as institutional and community support, for this position and the person serving in this role will be essential.

Leadership for the work to be done in implementing the Reducing Stigma, Reducing HIV-related Disparities and Community Engagement recommendations

While recommending that DOH be the *entity in charge* for these three recommendations, the HPSG also expressed that for stigma and disparity reduction work and community engagement work to be effective, it is critical that the leadership conceptualize and implement this work in new ways (specifically to include community member input and leadership of the design and implementation processes).

The HPSG proposes the following conceptual framework for HOW this work would move forward.

To address stigma, health disparities, and community engagement, it is important to incorporate ongoing learning processes which develop the deep understanding of the lived experience of people whose circumstances are very different from ours. This is necessary for the profound mindset and attitude changes needed to build relationships and collaborations that equitably and respectfully move us beyond present experience. Done well, this is a thoughtful, time-intensive, sincere process. Visionary, fully committed leadership is key at all levels.

- While DOH can convene the Stigma SEW, the HPSG recommends that the SEW Workgroup itself address questions about leadership, key roles, and who should fill those roles. Similarly, the HPSG believes that leadership roles need to be specified for moving the *Disparities* and *Community Engagement* work ahead.
- Communities that would be engaged in this work would include people based on the nature of the disparity or stigma—i.e., HIV-related, gay and bisexual men of all races and ethnicities, African American gay and bisexual men, immigrant Latino men, gay and bisexual men of all races and ethnicities, people who inject drugs, women, etc.) These recommendations assume new participants as well as continued involvement by current participants.
- The following leadership questions should be considered for each recommendation:
 - Who is the accountable entity?
 - Who is the champion or sponsor?
 - Who will provide resources (staffing, funding, etc.)?
 - Who is already doing this work and how can we engage them?
 - Who has expertise in this area?
 - Who are the key partners and how do we partner with them?
 - Who convenes, listens, facilitates community folks and how is the convener relevant to the particular group being engaged?

- How does the community-gathered information lead to the development of action steps?
- Who is responsible for carrying out the action steps?
- How do community members become leaders in this work?
- How does this work reflect the values and principles in the *Community Engagement* recommendation?
- How does this work tie in with other health equity work being done in communities?
- How can the work be tied to the *End AIDS* goals and appropriate measures?

Implementation and Data

- **End AIDS Implementation Plan**

An implementation plan needs to be developed and address such topics as setting priorities and timelines, including the phasing-in of work as appropriate. Action Items that can be implemented quickly should move ahead quickly, while the ground work for longer term, more aspirational action items is laid. Those accountable for achieving progress should be clearly identified.

- **Specific metrics for reducing HIV-related disparities for the groups detailed in the Special Emphasis Workgroup on HIV-related Disparities**

This recommendation is also identified in action item *DOH-SEW 1* in the *Disparities* section. To reduce health inequities related to HIV and health outcomes, specific metrics must be established, and progress monitored. DOH has reconvened the SEW, and this group (including new members as needed) assisted DOH in developing the metrics for measuring reduction in the identified disparities. These metrics are in the introduction to this report.

- **Data development**

Additional data development is needed, including numerical measures specific to End AIDS goals and recommendations - particularly as a way to measure progress.



"It is important for poz people to talk to their doctors about getting on treatment. I am on treatment, not only for my health, but also for the people that I care about."

— Steven Griffith, Seattle, Leather Daddy (2015)

FUTURE WORK

Areas Identified by the HIV Planning Steering Group and through Public Comment, That Require Further Work

While producing the *End AIDS Washington* report, recommendations, and action items, the Steering Team and the HPSG identified areas in which work should be done to reduce gaps and disparities and increase access to HIV treatment and prevention. Similarly, when the report was posted for public comment, commenters provided ideas about additional future work items.

All of these suggestions require more analysis and discussion among public health, community members, other systems, and subject matter experts. While some of these areas are mentioned in the above recommendations and action items, there was not enough time to develop them in detail and they are described here in more detail to guide future work.

- **New recommendation #6: Improve HIV Prevention, Care and Treatment Among Substance Users, Including People Who Inject Drugs. Identify key partners to collaborate in refining and carrying out the action items listed for this recommendation.**

Public comment requested that this recommendation be added. The HPSG agreed. While finalizing the report, there was not sufficient time to reach out to prospective partners to determine which partners might help address which action items. As a result, this work with partners is the first task needed for this recommendation. When the work with partners is complete, each action item will specify key communities and agencies to participate in moving the action item forward.

- **Robust goals and programs for additional populations experiencing HIV-related disparities, including transgender/non-binary individuals, documented and undocumented immigrants, people who inject drugs, commercial sex workers, Native Americans, Pacific Islanders/Native Hawaiians, and others.**

The HPSG expressed concern that numerous groups experience disparities, beyond the po-

pulations detailed in the Special Emphasis Workgroup on HIV-Related Disparities, related to HIV risk, access to care, and health outcomes. While there are some action items specific to these groups (e.g. action item *DOH/HCOs 1*, on transgender/non-binary health care, in the *Health Care System Meets the Needs of Sexual Minorities* section), more work is needed to better respond to the needs of these communities and reduce the barriers and disparities they experience.

- **Language related to transgender people.**

The HPSG received comments expressing concern that the recommendations do not acknowledge transgender people clearly enough as a distinct group. Commenters pointed out that transgender people are unique and cannot be lumped together with other groups at risk of HIV or living with HIV. Commenters noted that while the report does include the term *transgender people* throughout, this often results in transgender women being included with gay and bisexual men, in terms of proposed or actual services. Commenters pointed out that greater clarity is needed for transgender people's unique circumstances.

The HPSG welcomes this insight and particularly appreciates the caution about not assuming that a recommendation or action item developed to respond to the need of a gay or bisexual man is also applicable to a transgender woman. The HPSG recognizes that significant effort must be made to engage with transgender people and hear more about their lived experience and how the *End AIDS* recommendations and action items might be appropriately designed specifically for transgender people.

The HPSG prioritizes this as a topic for future work, as designing or refining action items to speak to the unique circumstances of transgender people is a significant body of work to be done both through deep listening and engagement with transgender people and in being skillful in thinking about how best to reach and serve transgender people at risk for or living with HIV.

- **Language related to people over the age of 50 living with HIV.**

The HPSG received eloquent public comment about the feeling of *invisibility* of people over the age of 50 living with HIV, not only in this report, but within the HIV service delivery system and in society at large. This was particularly profound given that nearly 50% of all people living with HIV in Washington State are age 50 or older (*Office of Infectious Disease, 2016*). Public comment noted that in addition to the medical issues that people over 50 living with HIV face from taking earlier-generation medications (some with unanticipated side effects), they also are affected by limited incomes, lack of housing, and the isolation experienced by many older Washingtonians.

The HPSG welcomes this insight and recognizes that a significant effort must be made to engage with people over 50 living with HIV and hear directly about the unique experiences of people in this group before action items can be developed or modified to be relevant to them.

The HPSG prioritizes this as a topic for future work, as it is likely that meaningful inclusion of people over 50 living with HIV will affect, at a minimum, the current action items in the *Stigma, Disparities, Health Care System for Sexual Minorities, Housing, and Community Engagement* recommendations. The broad impact of these comments and the need for deep listening to members of this group underscore the importance of adding this as a separate topic for future work, rather than just adding the phrase *people over the age of 50 living with HIV* to each of the existing recommendations.

- **Increasing engagement in the care continuum for PLWH who are justice system-involved.**

This concept is identified in action item *Gov/Leg 1* in the *Whole Person Health Care* section, but requires further attention to ensure that there is a robust response to the barriers PLWH face in staying engaged in care while justice system-involved (in jail or prison and/or who are under community supervision upon release). Significant work is needed in this area.

- **Design and carry out specific work to address the hepatitis C virus (HCV) epidemic.**

While there is overlap between the populations living with or at risk for HIV and HCV, as well as the HIV and HCV treatment and prevention systems and service providers, there is a critical need to address HCV in its own right. While the Governor's *Proclamation* and this report are specific to the HIV epidemic in Washington, there are opportunities to leverage the action items to benefit people living with and at risk for HCV, some of whom are also living with HIV. These include requiring and implementing routine testing for HCV at the same time as HIV, and addressing the high cost of specialty medications for HCV as well as HIV. These are noted in the *Routine Testing* and *PrEP* recommendations above.

- **The HPSG recognizes the need and importance of addressing HCV as its own issue.**

To that end, the HPSG recommends that a planning process similar to the *End AIDS* process be implemented for HCV, analyzing the current situation and developing specific plans and recommendations for addressing HCV in Washington State. Dedicated staff at DOH should be identified for this HCV work and an effort of the magnitude envisioned here should have its own staff resource, not be added to the work load of an existing staff person.

Detailed suggestions for implementation

A number of the public comments related to implementation. The *End AIDS* recommendations are designed as a framework document; one that provides direction and inspiration—in short, the big picture. The HPSG believes that attempting to address the implementation comments at this level would be premature. However, these comments are crucial to effective implementation. The table in the following pages summarizes these comments and discusses potential implications for implementation. Also note that the full text of all public comments is included in the appendices.

PUBLIC COMMENT AND IMPLEMENTATION IMPLICATIONS

Public Comment	Potential Implementation Implications
Importance of alignment of the multiple frameworks being used to plan and implement HIV prevention, treatment, and care services and the need to clarify relationship of <i>End AIDS</i> work to existing efforts	This is a critically important early implementation step that will be addressed by the Implementation Team
Revise the wording of goal statements and the data elements to measure them. Consider the addition of performance measures	It is important to have people affected by HIV, epidemiologists, physicians and scientists help clarify and tighten up the goals and measures. DOH looks forward to further discussion about this, in the earliest stage of implementation.
Develop plan to publicize <i>End AIDS Washington</i> recommendations	This is a step that will be addressed by the Implementation Team
Greater focus on condoms	Condom use is currently addressed in the <i>HIV Prevention Framework</i> ; evaluate to see if this work is sufficient or if additional work should be considered
Insurer concerns regarding cost and cost-shifting if PrEP is more widely utilized, the consideration of <i>Truvada</i> ® as preventative, tax implications related to ACA, and any policy work likely to result in regulatory changes	This is a long-term conversation that is part of the larger debate about the cost of medication and payers' roles in helping to solve this problem. Implementation of the <i>Insurance</i> recommendation will need to take these concerns into account.
Clarify the language of the <i>Housing</i> and <i>Insurance</i> recommendations, addressing smoking cessation, etc.	Work with subject matters experts to clarify language
Clarify what will be done in support of modernization of HIV-related legislation	The implementation team will address this work

Public Comment

The need for greater specificity regarding efforts to end stigma and reduce health disparities, the exploration of immigration status issues in Eastern and Western Washington as it relates to disparity, an expanded discussion of social determinants of health and a commitment to the inclusion of PLWH of varying demographics in stigma workgroups

Specific suggestions to change the language, laws, and availability of testing, prevention measures, and treatment

Specific suggestions for community engagement

Specific suggestions regarding the *Healthier Washington for Youth* initiative

Clarification of funding for *End AIDS* work

Specific recommendations are not included for women with HIV

Specific recommendations are not included for justice system-involved individuals, including people in jail or prison or under community supervision

Potential Implementation Implications

Special emphasis workgroups [comprised of subject matter experts and those persons affected], that will focus on reducing stigma and reducing health disparities, will address these concerns during implementation

These comments will be reviewed and considered in the implementation phase for the *Routine, Standardized HIV Screening* recommendation

These comments will be reviewed and considered in the implementation phase for the *Meaningful Community Engagement* recommendation

These comments will be reviewed and considered in the implementation phase for the *Healthier Washington for Youth* recommendation

Implementation teams for individual recommendations will conduct a resource inventory in order to determine capacity and suggest opportunities to leverage existing funding and/or determine additional funding needed for implementation

Women living with HIV have needs which may differ from those of men; these differences will be explored as future work during the implementation phase

Justice system-involved persons living with HIV need unique interventions; this is future work that will be undertaken in the implementation phase

CONCLUSION

This is an exciting and hope-filled time. Based on the innovative and ground-breaking work already done, and these far-sighted recommendations for the future, Washington State stands on the threshold of Ending AIDS. The HPSG commends Governor Inslee for providing bold leadership for this initiative and thanks the hundreds of Washingtonians who provided their personal experiences, ideas, comments and suggestions for improvement. The HPSG looks forward with enthusiasm to working with key partners—communities affected by HIV; state agencies such as the Department of Health, the Health Care Authority, Office of Insurance Commissioner, Office of Superintendent of Public Instruction, and others; local health jurisdictions and community-based organizations—to achieve system-level improvements that will help End AIDS.

As the HPSG stated in the opening section of this report:

The end of AIDS is possible. Until there is a cure, Washington State is committed to innovative and collaborative public and private sector interventions to reach every person living with and at risk for HIV to provide the tools and resources needed to protect their health and well-being, to measurably reduce HIV-related disparities, and to prevent new HIV diagnoses. Washington will be a model for other states and jurisdictions in tackling their HIV epidemics. Successful implementation of these recommendations will rely on passionate and inspired leadership, a willingness and capacity for self-reflection, and a commitment to honoring the fundamental humanity of every person touched by and in this effort to end the HIV epidemic. The HPSG is confident that Washington State has these key ingredients in abundance and looks forward to the day when we can all celebrate the end of AIDS.

Please join us in this exciting work!

— *The HIV Planning Steering Group*

APPENDICES

- A. Governor's Proclamation
www.doh.wa.gov/Portals/1/Documents/pubs/410-069-EAW-AppendixA.pdf
- B. End AIDS Glossary
www.doh.wa.gov/Portals/1/Documents/pubs/410-069-EAW-AppendixB.pdf
- C. Washington State Strategic HIV Prevention Framework
www.doh.wa.gov/Portals/1/Documents/pubs/410-069-EAW-AppendixC.pdf
- D. Enhancing HIV Community Services Framework
www.doh.wa.gov/Portals/1/Documents/pubs/410-069-EAW-AppendixD.pdf
- E. HIV-Related Health Disparities Special Emphasis Report
www.doh.wa.gov/Portals/1/Documents/pubs/410-069-EAW-AppendixE.pdf
- F. End AIDS Washington Community Feedback Survey
www.doh.wa.gov/Portals/1/Documents/pubs/410-069-EAW-AppendixF.pdf
- G. End AIDS Washington Public Comments
www.doh.wa.gov/Portals/1/Documents/pubs/410-069-EAW-AppendixG.pdf
- H. Measuring Progress Toward Achieving End AIDS 2020 Goals
www.doh.wa.gov/Portals/1/Documents/pubs/410-069-EAW-AppendixH.pdf

ENDNOTES

- ¹www.doh.wa.gov/Portals/1/Documents/Pubs/150-030-HIVSurveillanceSemiAnnualReport1-2015.pdf
- ²<http://nih.gov/researchmatters/august2015/08102015hiv.htm>
- ³www.hptn.org/research_studies/hptn052.asp
- ⁴www.medscape.com/viewarticle/850579
- ⁵<http://we-are-one.org/resources/hiv-aids>
- ⁶<http://nih.gov/researchmatters/august2015/08102015hiv.htm>
- ⁷www.doh.wa.gov/Portals/1/Documents/Pubs/150-071-HIVHealthDisparitiesSEWReportMar2015.pdf
- ⁸www.aids.gov/federal-resources/national-hiv-aids-strategy/nhas-update.pdf
- ⁹HIV-Related Special Emphasis Workgroup, *HIV-Related Health Disparities*, Washington State Department of Health, February 19, 2015
- ¹⁰White House Office of National AIDS Policy, *National HIV/AIDS Strategy for the United States: Updated to 2020*. July 2015
- ¹¹Dombrowski JC, Harrington RD, Golden MR. *Evidence for the long-term stability of HIV transmission-associated sexual behavior after HIV diagnosis*. Sex Transm Dis. 2013;40(1):41-45.
- ¹²Grant, R.M., Lama, J.R., Anderson, P.L., et al. (2010). *Prevention of HIV-1 Infection with Early Anti-retroviral Therapy Preexposure Chemoprophylaxis for HIV Prevention in Men Who Have Sex with Men*. New England Journal of Medicine, 363, 2587-2599. Retrieved from <http://www.nejm.org/doi/full/10.1056/NEJMoa1011205>
- ¹³Cohen MS, Chen YQ, McCauley M, et al. *Prevention of HIV-1 infection with early anti-retroviral therapy*. N Engl J Med. 2011;365(6):493-505.
- ¹⁴www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm
- ¹⁵www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/human-immunodeficiency-virus-hiv-infection-screening
- ¹⁶HIV-Related Special Emphasis Workgroup, *HIV-Related Health Disparities*. Washington State Department of Health, February 19, 2015
- ¹⁷www.doh.wa.gov/portals/1/Documents/Pubs/430-033-HIVTestProviders.pdf
- ¹⁸www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm
- ¹⁹www.kingcounty.gov/healthservices/health/communicable/hiv/providers/msmstd.aspx
- ²⁰www.aids.gov/federal-resources/national-hiv-aids-strategy/nhas-update.pdf
- ²¹www.cdc.gov/hiv/pdf/guidelines/PrEPguidelines2014.pdf
- ²²<http://news.coveredca.com/2015/05/covered-california-board-protects.html>
- ²³www.uspreventiveservicestaskforce.org/Page/Name/nominating-recommendation-statement-topics
- ²⁴Purcell DW, Johnson CH, Lansky A, et al. *Estimating the population size of men who have sex with men in the United States to obtain HIV and syphilis rates*. Open AIDS J. 2012;6:98-107
- ²⁵Hamel I, Firth F, Hoff T, Kates J, Levine S, Dawson L. *HIV/AIDS In The Lives Of Gay And Bisexual Men In The United States*. Kaiser Family Foundation;2014
- ²⁶Khosropour C. University of Washington Public Health Capacity Building Center. Personal communication.
- ²⁷Branson BM, Handsfield HH, Lampe MA, et al. *Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings*. MMWR Recomm Rep. 2006;55(RR-14):1-17; quiz CE11-14
- ²⁸*Public Health - Seattle & King County HIV testing and STD screening* recommendations for men who have sex with men (MSM) 2010*. Seattle, Washington. 2010. www.kingcounty.gov/healthservices/health/communicable/hiv/providers/msmstd.aspx
- ²⁹www.transhealth.ucsf.edu/pdf/Sevelius_HIV_Specialist_Dec13.pdf
- ³⁰Thiede H, Jenkins RA, Carey JW, et al. *Determinants of recent HIV infection among Seattle-area men who have sex with men*. Am J Public Health. 2009;99 Suppl 1:S157-164
- ³¹Menza TW, Hughes JP, Celum CL, Golden MR. *Prediction of HIV acquisition among men who have sex with men*. Sex Transm Dis. 2009;36(9):547-555
- ³²Buskin S, Hood JE, Katz DA, et al. *Estimating the population-level impact of methamphetamine use on HIV acquisition among men who have sex with men using a population attributable risk percent - a powerful and underused planning tool*. Paper presented at: International AIDS Society Conference on HIV Pathogenesis, Treatment and Prevention July 2015, 2015; Vancouver, BC
- ³³Dombrowski JC, Simoni JM, Katz DA, Golden MR. *Barriers to HIV Care and Treatment Among Participants in a Public Health HIV Care Relinkage Program*. AIDS Patient Care STDS. 2015;29(5):279-287
- ³⁴Kingston S, Banta-Green C. *Results from 2015 Drug Injector Health Survey*. On-line report available at <http://adai.uw.edu/pubs/>
- ³⁵Washburn K, Goodwin C, Pathela P, Blank S. *Insurance and billing concerns among patients seeking free and confidential sexually transmitted disease care: New York City sexually transmitted disease clinics 2012*. Sex Transm Dis. 2014;41(7):463-466
- ³⁶Dombrowski JC, Simoni JM, Katz DA, Golden MR. *Barriers to HIV Care and Treatment Among Participants in a Public Health HIV Care Relinkage Program*. AIDS Patient Care STDS. 2015;29(5):279-287

- ³⁷www.uspreventiveservicestaskforce.org/Page/Name/nominating-recommendation-statement-topics
- ³⁸www.lgbtqnation.com/2015/09/life-insurance-company-denies-coverage-to-man-taking-truvada/2/
- ³⁹Health Insurance Marketplace Quality Initiatives online at www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Health-Insurance-Marketplace-Quality-Initiatives.htm
- ⁴⁰<http://news.coveredca.com/2015/05/covered-california-board-protects.html>
- ⁴¹Holtgrave, D.R. (2009). *Housing as HIV prevention and care*. Presented at the White House Office of National AIDS Policy HIV and Housing Consultation, December 17, 2009; Holtgrave, et al., 2007
- ⁴²www.hudexchange.info/resources/documents/The-Connection-Between-Housing-and-Improved-Outcomes-Along-the-HIV-Care-Continuum.pdf
- ⁴³www.hivhousingsummit.org/2012/Presentations/Aidala_Housing-is-Prevention.pdf
- ⁴⁴<http://nationalaidshousing.org/PDF/FactSheet.pdf>
- ⁴⁵www.hudexchange.info/reports/HOPWA_Perf_Natl_Comb_2013.pdf
- ⁴⁶www.hivhousingsummit.org/2012/Presentations/Aidala_Housing-is-Prevention.pdf
- ⁴⁷Ibid.
- ⁴⁸www.pewtrusts.org/~/media/Assets/2015/05/OHFApolicybrief_May2014.pdf?la=en
- ⁴⁹www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/hiv_care_cascade_nychopwa.pdf
- ⁵⁰www.seattletimes.com/seattle-news/13-rental-properties-in-seattle-accused-of-discrimination/
- ⁵¹Ashman JJ, Conviser R, Pounds MB. *Associations between HIV-positive individuals' receipt of ancillary services and medical care receipt and retention*. *AIDS Care* 2002;14(Suppl1):S109-18
- ⁵²Sherer R, Stieglitz K, Narra J. et al. *HIV multidisciplinary teams work: support services improve access to and retention in HIV primary care*. *AIDS Care* 2002;14:S31-44
- ⁵³Messerli PA, Abramson DM, Aidala AA, et al. *The impact of ancillary HIV services on engagement in medical care in New York City*, *AIDS Care* 2002;14(Suppl 1):S15-29
- ⁵⁴Ojikutu B, Holman J, Kunches L, Landers S, Perlmutter D, Ward M, Fant G, Hirschhorn L. *Interdisciplinary HIV care in a changing healthcare environment in the USA*. *AIDS Care* 2014;26(6):731-5. doi:10.1080/09540121.2013.85299 Epub 2013 Nov 6
- ⁵⁵Henry J. Kaiser Family Foundation (KFF). *Medicaid and HIV: A National Analysis*. 2011. Available at <http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8218.pdf>
- ⁵⁶<http://leg.wa.gov/JOINTCOMMITTEES/ABHS/Pages/default.aspx>
- ⁵⁷www.whitehouse.gov/sites/default/files/docs/vaw-hiv_working_group_report_final_-_9-6--2013.pdf
- ⁵⁸www.k12.wa.us/HIVSexualhealth/PreventionEdRequirements.aspx
- ⁵⁹<http://apps.leg.wa.gov/RCW/default.aspx?cite=28A.300.475>
- ⁶⁰www.doh.wa.gov/Portals/1/Documents/Pubs/150-030-HIVSurveillanceSemiAnnualReport1-2015.pdf
- ⁶¹<http://apps.leg.wa.gov/RCW/default.aspx?cite=70.24.110>
- ⁶²<http://apps.leg.wa.gov/rcw/default.aspx?cite=9.02.100>
- ⁶³<http://apps.leg.wa.gov/RCW/dispo.aspx?cite=71.34.030>
- ⁶⁴<http://apps.leg.wa.gov/RCW/default.aspx?cite=70.96A.230>
- ⁶⁵www.askhys.net/Docs/BHSIA-News-Release-Healthy-Youth-Survey-FINAL.PDF
- ⁶⁶www.americanprogress.org/issues/lgbt/news/2010/06/21/7980/gay-and-transgender-youth-homelessness-by-the-numbers/
- ⁶⁷williamsinstitute.law.ucla.edu/wp-content/uploads/Durso-Gates-LGBT-Homeless-Youth-Survey-July-2012.pdf
- ⁶⁸www.cehkc.org/doc_reports/CUI2014FINALReport.pdf
- ⁶⁹www.hivhousingsummit.org/2012/Presentations/Aidala_Housing-is-Prevention.pdf
- ⁷⁰www.americanprogress.org/issues/lgbt/news/2010/06/21/7980/gay-and-transgender-youth-homelessness-by-the-numbers/
- ⁷¹<http://app.leg.wa.gov/billinfo/summary.aspx?bill=5404&year=2015>
- ⁷²www.childrenand youth.org/what/sacy/youth-engagement/youth-advisory-council/
- ⁷³www.k12.wa.us/SafetyCenter/HealthyYouthSurvey/default.aspx
- ⁷⁴www.doh.wa.gov/YouandYourFamily/illnessandDisease/HIVAIDS/Planning/HIVStakeholderVillage

