From Risk to Reasons

A Guide for Communicating and Connecting with Black Women about HIV

ViiV Healthcare

Risk to Reasons:
A ViiV Healthcare Initiative

ViiV Healthcare's ***Risk to Reasons*** initiative is designed to reframe and refocus HIV prevention and care for Black women. Guided by advocates across the country, ***Risk to Reasons*** sets out to develop new messages, new messengers and new methods to increase awareness and action around HIV prevention and care to Black women of cis and trans experience. The initiative creates content, funds community action and connects advocates across the country to change the impact of HIV in Black communities and connect more Black women to prevention and care.

The ***Risk to Reasons*** guide was co-created by ViiV Healthcare and the Black Women's Working Group to Reframe Risk. A committee of Black women living with and working in HIV collaborated with ViiV Healthcare to challenge existing HIV prevention approaches and develop new recommendations for communicating and connecting with Black women about HIV. We would like to thank the dedicated members of this group, many of whom are named in this report, as well as all the women who have generously shared their insights, ideas and experiences.

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Reframing Risk: Our Call to Action

We must reframe risk to end the stigma
and find solace in knowing there are sisters
advocating for you, for me, for all of us.
So none of us fall through the cracks.
To normalize health as wealth.

We must reframe risk to leave a
legacy of change, make a difference,
bridge the gap. To learn, to
grow and to share. To be part
of a bigger impact.

We must reframe risk to work collectively. To commit
to Black women. To shift the narrative.

We must reframe risk to show there's
life after HIV. To take control. To delight
in the beauty of our shapes and sizes.
To enjoy happy, healthy and fun sex lives.

We must reframe risk to
affirm that we are creators, that we are
powerful, that we are brilliant, that we are
bold, that we are enough, that we matter.

— The Black Women's Working Group to Reframe Risk

About the Black Women's Working Group to Reframe Risk

When ViiV Healthcare launched *Positive Action for Women (PAFW)* in 2016, our community advisors and partners emphasized the need to "reframe risk" when it comes to HIV and women, particularly in ways that would resonate for Black women. Advocates across the country supplied questions, insights and recommendations for how to proceed to make HIV prevention and care more relevant to women of color disproportionately impacted by HIV.

In 2021, a working group was established as part of ViiV Healthcare's ongoing commitment to improve access to HIV prevention and care for Black women. The goal was to bring together Black women living with and working in HIV to better understand the circumstances, challenges and motivations that impact Black women's awareness, knowledge and use of prevention and care strategies, and to create a new framework and narrative for HIV and Black women. ViiV Healthcare steered a landscape review and analysis of epidemiology, campaigns and toolkits, prevention programs and existing narratives and narrative change approaches related to Black women and HIV.

The inaugural Black Women's Working Group to Reframe Risk included women who are advocates, frontline providers, communication experts and researchers, ranging in age and geography. Members were convened fourteen times from June 2021 through January 2022 to discuss and develop frames, approaches and messages to increase Black women's awareness, knowledge and participation in HIV prevention and care strategies. Topics included sex education, mass media representation, public health interventions, social determinants of health, wellness, intersectional feminism and Black womanhood. Activities took place during and outside of scheduled sessions and included readings, video viewings, polls, discussions, brainstorms, writing exercises, creative production, research and presentations—all designed to distill and clarify the barriers and opportunities related to Black women's access and uptake of HIV prevention and care strategies. Working group members helped set goals, articulate values, craft messages and prioritize audiences and actions deemed essential to building and amplifying a more empowering narrative that reflects the diverse and complex experiences of Black women.

2021 – 2022 Working Group members included:

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HOW TO USE THIS GUIDE

Who is This For?

This guide is both an invitation and a request to rethink and reframe how HIV prevention and services for Black women are discussed and designed. It is a call to adopt an empowering narrative that reflects the diverse and complex experiences of Black women, and to activate individual and collective responses. It is intended to ignite advocates, educators, doctors, nurses, journalists, mothers, lovers, daughters, sisters, wives and friends to catalyze critical conversations and action around HIV in order to support the sexual, mental and physical health and well-being of Black women.

In this guide, we share insights, reflections and recommendations to strengthen communications with and about Black women with regards to HIV prevention. These insights will help advocates, service providers, communicators, researchers and the broad networks surrounding Black women better understand the circumstances, challenges and motivations that impact Black women's use of prevention and care strategies.

The content of this guide represents the next step in a collective journey to improve communication with and about Black women and HIV, strengthen connections to prevention and care and disrupt the disproportionate impact of HIV among Black women. While many of the insights in this guide are focused on HIV prevention, the findings and recommendations for "reasons" apply to all facets of HIV care. The systems, circumstances and events that shape Black women's health and inform their choices do not adhere to the boundaries of an HIV diagnosis. Nor can best practices for prevention and care be considered in siloes.

The following stakeholders are well-situated to engage in and encourage dialogue or action:

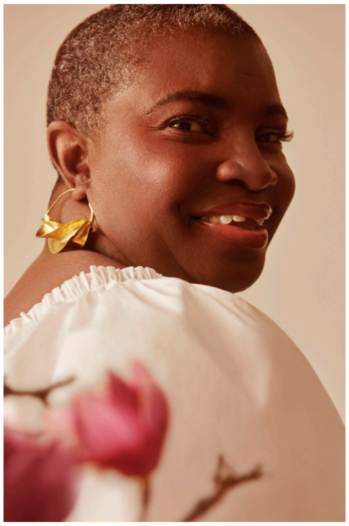
+ HIV service providers, advocates and grassroots groups
+ Doctors, nurses and public health professionals
+ Researchers
+ Journalists, publishers and media-makers
+ Community organizations
+ Educational organizations and institutions
+ Policy professionals
+ Funders

How to Take Action

We hope this guide inspires users to make new materials and take action in their everyday lives and professional activities.

This includes prioritizing changes to:

+ Advocacy and awareness campaigns
+ Intake guidelines for health screenings and assessments
+ Trainings for navigators, outreach workers, doctors, nurses and care providers
+ Guidelines for journalists, creative writers, TV and film producers
+ Sexual health and self-advocacy resources and curricula
+ Research studies
+ Public health interventions
+ Arts, culture and storytelling initiatives



WHY REFRAME RISK?

WHY REFRAME RISK

The Language of “Risk”

When it comes to HIV, the very language designed to raise women’s awareness and motivate them to practice prevention—“risk”—is often counterproductive and off-putting. Terms like “at-risk,” “high-risk,” “risk-factors” and “risky behaviors” abound. Community members, advocates and providers from the HIV movement have known for years that in the context of HIV, the word “risk” is unspecific and stigmatizing. It can cause people to disassociate, rather than reflect on their potential prevention needs.[1]

For Black women, the greatest “risk” for HIV may be poverty, homelessness, where you live, intimate partner violence or other social determinants—which are rarely captured in the campaign messages, questionnaires or intake materials used to identify who should be counseled on or connected to preventive HIV care. To disrupt the disproportionate impact of HIV among Black women, new approaches are needed that empower women to protect their health and reflect the diverse and complex experiences of Black women.

Focusing on “risky behaviors” also fails to communicate the range of prevention options available. HIV prevention strategies for Black women range from behavioral to biomedical, and include abstinence, condom use, avoiding sharing needles and prevention medications such as PrEP (pre-exposure prophylaxis) and PEP (post-exposure prophylaxis).[2] For women living with HIV, prevention strategies may also include taking medications as prescribed to eliminate the likelihood of transmitting HIV to their partners. Because Black women’s sexuality has been policed and pathologized throughout history, it is especially important to find language and approaches that support their desires, address their unique circumstances, enhance intimacy and avoid stigma, shame and re-traumatization.

A NEW FRAMEWORK FOR COMMUNICATION

Guiding Values

Effective strategies to engage Black women in HIV prevention and care must be informed by current lived realities. Strategies must also be built upon a foundation of values that enhance and encourage Black women's engagement in their sexual health. Articulating core values for Black women's HIV prevention helps establish a foundation whereby communications connect and resonate with Black women, and interventions reinforce women's autonomy to choose and prioritize prevention. These core values can underscore efforts to communicate and engage with Black women around HIV across the continuum of prevention and care.

Whether they are articulated or not, values are always at play—helping guide how initiatives are designed, what behaviors and beliefs are reinforced, what is explicitly or implicitly communicated and what is considered or left out.

The values set forth here represent the four fundamental pillars articulated by the Black Women's Working Group to Reframe Risk when it comes to developing prevention and care efforts and communicating with and about Black women and HIV. Weaving them into messages, campaigns and communications efforts can engage women on an emotional level and build an empowering, cohesive narrative over the long term. Communicators, health providers, advocates, policymakers and researchers should consider each of these four values when seeking to engage Black women in HIV prevention. Media-makers should center these values when representing Black women living with and impacted by HIV. These values should be integrated with strategies that center the voices and experiences of real women, and specifically the transformational power of peer communications that underscore the most effective interventions and initiatives within the field of HIV care.

Four Core Values for Communicating and Connecting with Black Women About HIV Prevention

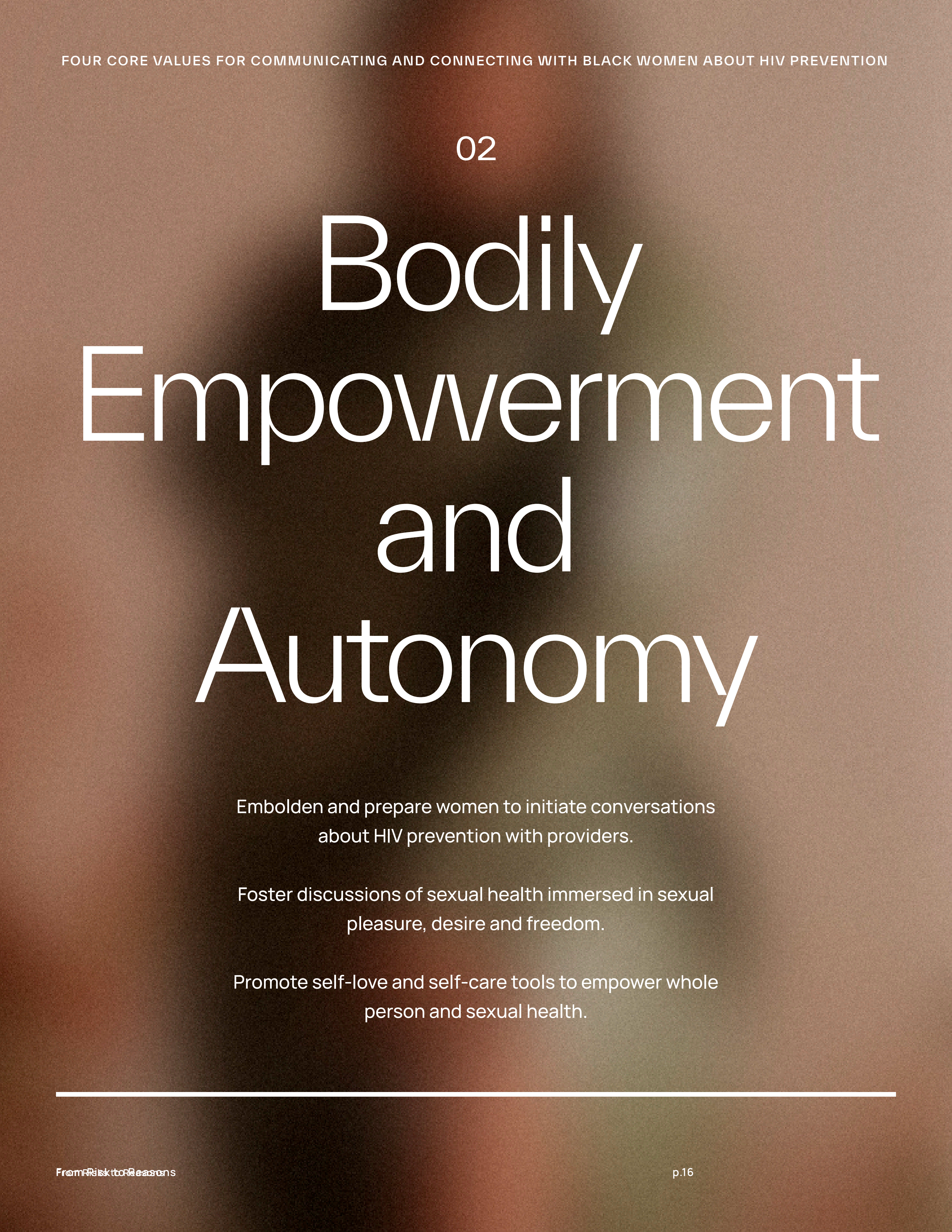
01 Respect and Recognition of the Whole Person
02 Bodily Empowerment and Autonomy
03 Freedom from Fear and Shame
04 HIV Stigma-free Communications and Treatment

01

Respect and Recognition of the Whole Person

Acknowledge multi-faceted aspects to women's lives that are part of a whole: race, gender, sexuality, sexual pleasure, motherhood and social determinants (e.g., housing, income, employment, mental health, education).

Accept imperfection:
"You are enough."
"You are not defined by a single choice or aspect of your identity."



02

Bodily Empowerment and Autonomy

Embolden and prepare women to initiate conversations about HIV prevention with providers.

Foster discussions of sexual health immersed in sexual pleasure, desire and freedom.

Promote self-love and self-care tools to empower whole person and sexual health.

03

Freedom from Fear and Shame

Nurture open dialogue around sex.

Foster discussions, messages and policies promoting sexual pleasure, desire and freedom.

Challenge the threats and dangers of living as a Black woman in the U.S.

Combat threats and dangers of living with HIV.

04

HIV Stigma-free Communications and Treatment

Normalize conversations about HIV prevention as part of standard care, similar to common conversations about breast exams or screening for diabetes.

Recognize individual choices around acceptance, disclosure and viral suppression.

Encourage personable provider engagement.

From Risk to Reasons: A New Paradigm

The public health paradigm of "risk" must be retired—it's unspecific, stigmatizing and can cause people to disconnect, rather than engage and act on their potential prevention needs. To challenge this framework and the way it structures the relationship between Black women and HIV, we shifted our focus to better understanding when, why and how women do prioritize prevention and care. How do women think of their choices? What bolsters women's action? What can providers, navigators and public health workers do to help Black women assess and take action on strategies and reasons to protect themselves from HIV? The recommendation is to move from a place of risk, to a place of "reasons for HIV prevention".

The new framework of "reasons" offers an opportunity to rethink and redefine the relationship between Black women and HIV. The "reasons" frame provides a more expansive, inclusive and affirming lens with the potential to authentically reflect the complex lived realities of Black women. Reasons invoke personal choices, power, autonomy and privacy. Reasons don't automatically carry stigma, and instead suggest the positive outcomes and motivations for a specific action—in this case, ensuring one's health. This frame speaks to the many factors that can influence the likelihood of an HIV diagnosis, while capturing the deeply personal relationships between a woman and her own body.

Language and Concepts to Retire

~~"Women at risk for HIV"~~
~~"Risky behavior"~~
~~"High-risk sex"~~
~~Shame and blame~~
~~Men On the downlow~~
~~Fear~~

Language and Concepts to Elevate

"Women with reasons for HIV prevention"
"I've got my reasons"
"My reasons are my own"
Whole-person health
Practicing and prioritizing prevention

Three Motivating Reasons for Prevention

Three main categories emerged that underscore why Black women pursue HIV prevention. These motivations reflect the four core values for communicating and connecting with Black women about HIV. They are not mutually exclusive and often appear in combination. A woman's reasons may shift over the course of a day, a week or her lifetime. The goal is not to tell women what her reasons are but to help her assess and articulate them for herself.

Importantly, these three reasons also represent many women's motivations for accessing and utilizing HIV care, offering a pathway for motivational conversations and engagement for Black women living with HIV. Regardless of HIV status, knowing one's personal reasons for HIV prevention and care is essential to health and power.

These motivating reasons must be elevated in conversations, communications and interventions with Black women to help them better evaluate and manage their own HIV-related needs. Communicators, health providers, advocates, policymakers and researchers should consider each of these three reasons when seeking to engage Black women in HIV prevention and care.

01

Power, Circumstances and Control

HIV prevention can increase women's control over their own bodies and health, particularly in the face of inequality, lack of stability and unpredictable situations. In the context of homelessness, sex work, intimate partner violence, substance use and medical racism—all of which disproportionately impact Black women—prevention offers choices, control and autonomy.

02

Intimacy and Desire

HIV prevention helps women enjoy sex more by reducing the worry of being exposed to HIV. Prevention can let women focus on the moment and reduce stress about a partner's status or potential exposure. Prevention can also reduce undesirable negotiations or difficult conversations with partners around condom use, HIV status or past partners.

03

Normalizing Self-Care

HIV prevention is part of how women take care of their overall health and well-being, an essential part of self-care that extends to the whole body. Prevention is an expression of self-love and self-worth, a conscious decision to prioritize ones physical, mental and emotional health.

Sample Messages in Action

Power, Circumstances and Control

Peer to Peer		For Providers, Advocates and Allies
01	I know you can't tell a person's HIV status by looking at them, and that's plenty of reason for HIV prevention.	It's not always about what you're doing, it's sometimes about what's going on around you. Prevention can give you choices to take care of yourself on your own terms, take that control back and keep you healthy.
02	There are few things I can control in this world. A medicine that can keep me healthy? Say less.	No matter where you live or what you do in life, you have choices and you have the right to the same HIV prevention services, access and quality of care that everybody else has.
03	As a member of the sex work community, my reason for prevention is about not sacrificing my safety or their pleasure.	Prevention can mean you don't have to stress about your partner's HIV status or talk about your own status until you're ready.*

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* In 12 states, laws require people with HIV who are aware of their status to disclose their status to sex partners.

Intimacy and Desire

Peer to Peer

01 My reason for HIV prevention? I'm independent and f*** who I want, when I want, how I want.

02 Sex should be enjoyable for us, too. This is something that can make it SO much better!

03 Prevention makes sex more pleasurable, because it gives me peace of mind and helps me enjoy the moment.

For Providers, Advocates and Allies

01 Wanting to be closer and more intimate with your partner, or wanting your relationship to be more open and flexible—those are reasons for HIV prevention.

02 Prevention can put your mind at ease and let you explore your sexuality safely and on your own terms.

03 Sex should feel good to you, too. Prevention can help you enjoy the moment without fear or stress.

Normalizing Self-care

Peer to Peer

01 I'm the one in charge of my body. Practicing prevention is how I show love and respect for myself.

02 As Black women, we are always prioritizing other people. This is about taking care of ME.

03 My kids are my reason for being. If HIV prevention keeps me healthy for them, I'm all in.

For Providers, Advocates and Allies

01 Taking care of your WHOLE self means your physical, mental and sexual health. That's all a part of self-care and we owe it to ourselves.

02 You are your own best reason for prevention. You're worth it, and you deserve to keep yourself healthy now and in the future.

03 Your kids, your family, your community—they all want and need you to be around for them. HIV prevention is how you can show love for yourself and for them.

Although these messages were formulated to communicate with Black women about prevention, they are also relevant for communicating about HIV care across the continuum. Messages can be adapted for communicating with women about HIV regardless of their status either by substituting “care” for “prevention” or generalizing the message to broadly discuss preventative health services, screenings and taking care of one’s sexual health.

CATALYZING
CONVERSATIONS
IN KEY SPACES

Recommendations for Key Points of Intervention

In seeking to address the needs of Black women and the systematic forces that shape the likelihood of an HIV diagnosis, several areas of priority consistently rise to the top.

These spaces represent three of the most important areas where critical conversations about HIV can have the greatest impact on Black women's awareness, understanding and uptake of HIV prevention and care.

Peer-Based Outreach and Communications Efforts

When it comes to HIV prevention and care, where you live matters. Local social and sexual networks that lack access to the standard of care drive women's vulnerability around HIV. Peer communications, navigation and direct outreach to women in their own cities and communities underscore many of the most effective initiatives within the field of HIV prevention and care. The messengers matter—women need to hear from other women they can relate to. This means that women whose lives have been shaped by incarceration, homelessness, substance use or sex work must hear from other women with that lived experience to better consider their own reasons for prevention in a judgment-free conversation. Women with this lived experience need to be included in the creation, design and delivery of prevention efforts, and more systematically recruited, trained and compensated to carry out this essential work. They must be resourced to reach women where they are, share critical information and prompt healthy reflections on reasons for HIV prevention.

For media-based campaigns, evidence shows that messenger images should be women who core audiences can identify with as a model of their "best self." This must include a range of body types, ages and skin tones. Increasing visibility and representation of women engaged in HIV prevention or living with HIV can go a long way towards awareness and prevention. Seeing women portrayed this way in the context of prevention helps women overcome real and perceived stigma about social approval of HIV prevention.

Conversations with Providers

The role of providers in addressing the HIV epidemic among Black women cannot be overemphasized. Women want and need to learn about HIV prevention from their providers in the context of informative, personable and judgment-free conversations. Research has shown that when it comes to HIV testing and counseling, providers face barriers: they did not feel they have enough time to deliver HIV counseling; they did not feel familiar enough or prepared to deliver HIV counseling; and they did not fully appreciate the relevance of HIV for their patients.[4] Additionally, bias, transphobia, racism and sexism shape the specific interactions between Black women and their providers. It's not uncommon for Black women to have trouble accessing providers who will be responsive to their reasons for HIV prevention.

To begin to transform this essential space for HIV prevention, change is needed on two fronts. Providers must receive more training and resources to understand and address Black women's HIV prevention needs, including how to better deliver information about Black women's prevention options; how to better consider social determinants when supporting Black women's health needs; how to better identify who can benefit from prevention; and how to hold personable and stigma-free conversations with Black women about their sexual health.

At the same time, Black women must also receive support and resources to initiate and navigate conversations with their providers, including support for self-advocacy in health settings; access to information about their prevention options; and social support for prioritizing, protecting and sustaining their sexual health.

Intersecting Services

Resources should focus on women with compounded reasons for HIV prevention. We know that experiences with poverty, homelessness, incarceration, intimate partner violence, sexual abuse, sex work and substance use correlate to a higher chance of an HIV diagnosis. The current systems and organizations serving women with these experiences must be leveraged to increase Black women's awareness, knowledge and participation in HIV prevention and care strategies in a hyper-local way. This includes trainings and resources for intersecting service providers who may not feel they have the time, resources or expertise to deliver HIV prevention services such as testing, counseling and linkage to prevention and care. Training and resources can prepare these organizations to develop infrastructure and networks for Black women and deliver on-site HIV counseling and conversation series, either through independent events, arts and culture activities or ongoing social support groups that integrate HIV prevention and care.

Programs and interventions must take into account the social determinants of health that drive HIV among Black women. Effective strategies must consider economic empowerment interventions that use financial incentives or activities to increase women's incomes, and as such their opportunities and capacities to make voluntary and empowered choices about their sexual health. Studies show that many women prefer microeconomic interventions that address structural determinants of HIV vulnerability over behavior change methods that focus on HIV-related knowledge, attitudes and intentions.[5] Intersecting service providers are well-positioned to help develop and deliver programs that target the ways in which housing, poverty, intimate partner violence, incarceration, sex work, substance use and unemployment drive HIV rates.

FACING
THE
NUMBERS

HIV Prevention and Black Women

Numbers only tell one part of the story when it comes to Black women and HIV, and in some cases, data itself can be part of the narrative problem we need to address. Statistics can mislead us, bias our attention towards things that can be measured and overshadow the humanity and complexity of the individual experiences behind each data point. Little evidence exists in peer-reviewed literature about sex, pleasure, self-care, health and power navigation among women, Black women and particularly Black women of trans experience. This dearth of data can allow problems to go unaddressed. And yet we know data is essential for demonstrating and mobilizing resources to combat the disproportionate impacts of HIV.

The data indeed show that the disproportionate impacts of HIV for Black women are consistent, historic and undeniable. Black women comprise 55% of new HIV diagnoses among cisgender women and 46% of new diagnoses among transgender women, despite making up less than 15% of the female population.[6] Black women continue to be diagnosed late—21% with a concurrent HIV and AIDS diagnosis—and are often shocked when they receive their diagnosis.[7] Each year, more than 4,100 Black women receive an HIV diagnosis, and in 2019 more than 146,00 Black women were living with HIV, more than 48% of whom were not benefiting from the care they need.[8] This data is particularly striking in the face of breakthroughs in prevention options over the last decade, including ones that can be controlled by women.

However, nearly ten years after PrEP first became available, only 10% of women who could benefit from it were prescribed it, and there is insufficient data to understand how many Black cis and trans women are engaged.[9] These persistent disparities illuminate the gaps in awareness and access to the information and care that Black women deserve, and the failure of current models to identify and respond to those who have reasons for HIV prevention.

For Black cisgender women, a historic focus on gay men when it comes to HIV has left women's needs overlooked and ignored. Providers fail to routinely or effectively discuss HIV with female patients, and women's stories and experiences are often absent from HIV media storylines, campaigns and clinical testing. Studies show that only 20 to 30% of women are even aware of PrEP. [10] [11]

For Black women of trans experience, conversations about HIV are more commonplace and PrEP awareness is higher than for cisgender women. Yet Black transgender women have one of the highest rates of HIV of any population in the US, with one study finding that 62% of Black transgender women had HIV and nearly 60% of those living with HIV were undiagnosed.[12] Barriers like violence, stigma, discrimination, lack of cultural competency among providers and inaccessibility of health facilities via public transportation prevent Black transgender women from accessing HIV testing, prevention and care.[13]

For all Black women, new approaches are needed to empower women to protect their health. New strategies must account for the ways that structural racism—including anti-Black racism—and social determinants like incarceration, a lack of access to medical care, homelessness, physical assault and intimate partner violence increase the likelihood of an HIV diagnosis, while decreasing women's ability to access and maintain medical care.[14] Ending the HIV epidemic requires prevention and care that works for Black women.

WHAT'S NEXT

This guide represents the next step in a collective journey to improve communication with and about Black women and HIV. It is both an invitation and a request to rethink and reframe how HIV prevention and services for Black women are discussed and designed in order to strengthen support for and access to prevention and care, and disrupt the disproportionate impact of HIV among Black women. It is a call to adopt an empowering narrative that reflects the diverse and complex experiences of Black women, and to activate individual and collective responses. It is intended to ignite advocates, educators, doctors, nurses, journalists, mothers, lovers, daughters, sisters, wives and friends to catalyze critical conversations and activations around HIV in order to support the sexual, mental and physical health and well-being of Black women. We urge readers to consider and adapt the content of this guide to strengthen and inform communications and services for women living with HIV, while recognizing the urgent need for a shift in how HIV prevention is discussed and approached with Black women.

The *Risk to Reasons* Initiative

As part of this next step, ViiV Healthcare has committed $5 million in community grants to reframe and refocus HIV prevention and care for Black women. Through the *Risk to Reasons* initiative, ViiV Healthcare will continue to develop new messages, new messengers and new methods to increase awareness and action around HIV prevention for Black women. Guided by advocates across the country, the initiative is creating content, funding community action and connecting advocates across the country to change the impact of HIV in Black communities and get more Black women connected to prevention and care.

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