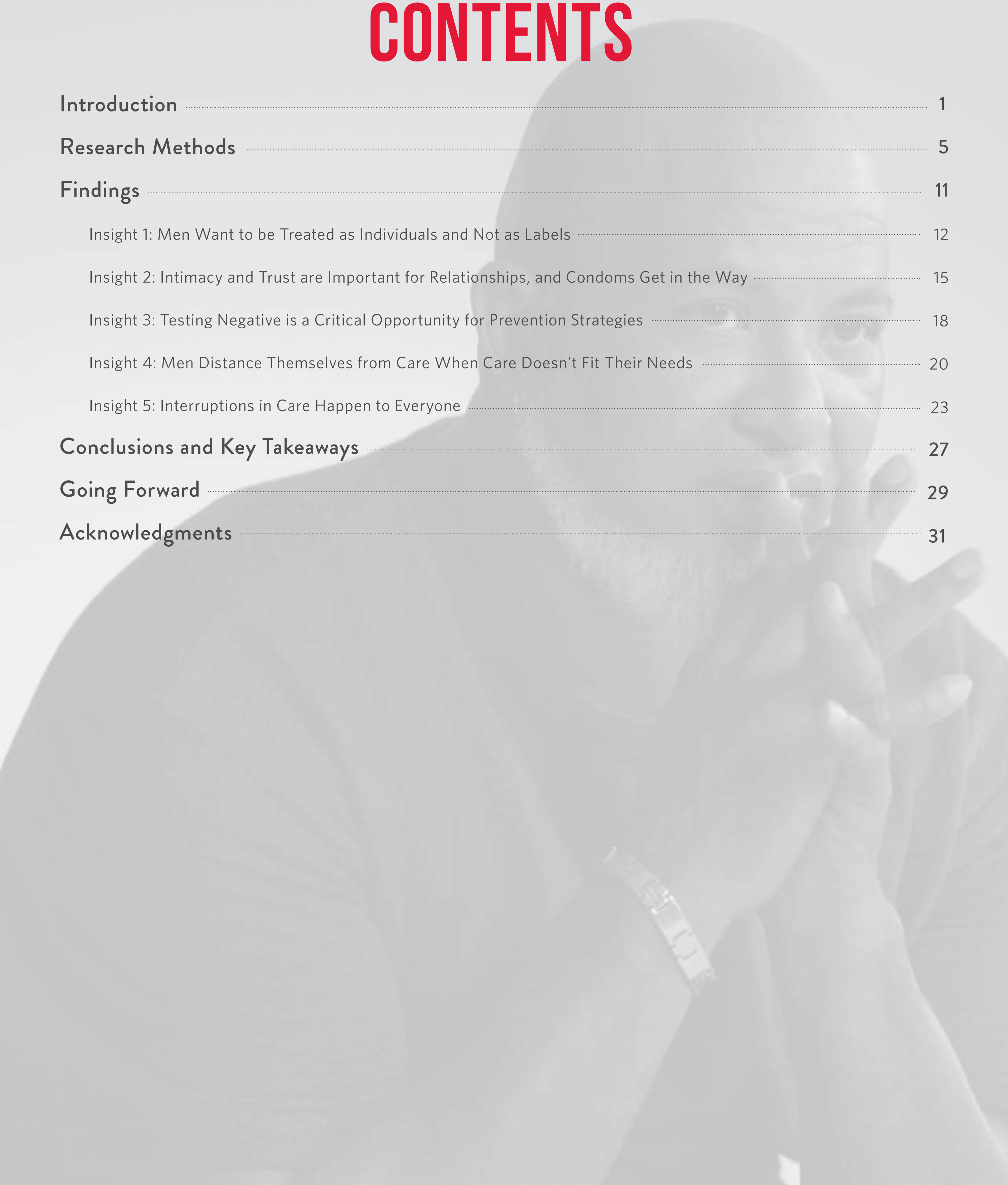
MEET ME WHERE I WANT TO BE

An Ethnographic Research Study of Black Gay Men in Baltimore, Maryland, and Jackson, Mississippi

ViiV Healthcare | ACCELERATE!



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INTRODUCTION

HIV/AIDS is an enduring epidemic that disproportionately impacts the lives of Black gay, bisexual, and other men who have sex with men (MSM).[1] It is estimated that by the time they are 40 years old, these men face a 60% chance of becoming HIV+; in fact, as many as 32% are currently HIV+.[2] As Derrick D. Matthews and his colleagues state in a recent article in *AIDS and Behavior*, "If Black MSM in the US formed a country today, it would have the highest HIV prevalence on the globe."[3] Black men are far less likely to be in treatment and virally suppressed compared with White MSM, and Black men living with HIV are dying at more than six times the rate of White men living with HIV.[4, 5] High infection rates and untimely HIV-related deaths, especially among young Black men, are ravaging communities fighting to beat these odds.

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1. *Black men who have sex with men* is often abbreviated as BMSM. While this can sometimes be a useful analytic construct for quantitative reporting, it does not reflect the expressed identity of the men presented in this research. Some of these men identify as gay, some as bisexual, and some identify with neither of these. Following the principal conclusions from the research presented here, this report will avoid reifying the BMSM as identity, referring instead to "Black gay men" or "men."
2. Centers for Disease Control and Prevention. (2012). Estimated HIV incidence in the United States, 2007–2010. *HIV Surveillance Supplemental Report, 17*(4). Table 5. Retrieved from http://www.cdc.gov/hiv/pdf/statistics_hssr_vol_17_no_4.pdf
3. Matthews, D., et al. (2016). Running backwards: consequences of current HIV incidence rates for the next generation of Black MSM in the United States. *AIDS and Behavior, 20*(1), 7-16.
4. Rosenberg, E. S., Millett, G. A., Sullivan, P. A., del Rio, C., Curran, J. W. (2014). Understanding the HIV disparities between Black and White men who have sex with men in the USA using the HIV care continuum: A modeling study. *The Lancet HIV, 1*(3), e112–e118.
5. Centers for Disease Control and Prevention. (2015). Diagnoses of HIV infection in the United States and Dependent Areas, 2014. *HIV Surveillance Report, 26*. Table 14a. Retrieved from http://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-us.pdf

The statistics are alarming. However, research has consistently found that Black men are equally or less likely than other MSM to engage in "individual risk behaviors," such as needle sharing or unprotected anal intercourse,[6] and that the HIV disparities seen between Black and White men are largely explained by differences in socioeconomic context and HIV prevalence within networks.[7]

Although public health agencies, health organizations, biomedical and behavioral scientists, and pharmaceutical companies have long known of the racial disparities in HIV, the body of research has not adequately translated into improved outcomes for Black gay men.[8] Black gay men, especially young men, are not benefiting sufficiently from the portfolio of existing tools available to reduce the impact of the HIV virus on HIV+ individuals and reduce its transmission.

> The purpose of this research is to understand the wide range of issues that drive disparate health outcomes by highlighting the thinking, the goals, the voices, and the positive behaviors of the men living in these communities.

Responding to this current situation, ACCELERATE! is a four-year initiative by ViiV Healthcare which has committed $10 million to designing and implementing solutions that put the perspectives of those most affected by HIV at the center of program design and decision-making. Specifically, the initiative seeks to address the HIV epidemic among Black men in Baltimore, Maryland, and Jackson, Mississippi—two cities among the hardest hit by the HIV epidemic and where Black men are affected by challenging social factors when living with HIV.[9]

Based on the belief that the perspectives of those most affected are essential to designing, applying, and evaluating promising projects and programs, ViiV Healthcare engaged ReD Associates to conduct an in-depth ethnographic research project to understand the epidemic through the lens of the men themselves. The purpose of this research is to understand the wide range of issues that drive disparate health

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6. Millet, G. A., Peterson, J. L., Wolitsky, R. J., & Stall, R. (2006). Greater risk for HIV infection of black men who have sex with men: A critical literature review. *American Journal of Public Health, 96*(6), 1007-1019.

7. Sullivan, P. S., Peterson, J., Rosenberg, E. S., Kelley, C. F., Cooper, H., Vaughn, A., . . . Sanchez, T. H. (2014). Understanding racial HIV/STI disparities in Black and White men who have sex with men: A multilevel approach. *PLoS One, 9*(3), e90514.

8. Wilson, P. A., Valera, P., Martos, A. J., Wittlin, N. M., Munoz-Laboy, M. A., & Parker, R. G. (2015). Contributions of qualitative research in informing HIV/AIDS interventions targeting Black MSM in the United States. *Journal of Sex Research, 4*, 1–13.

9. Centers for Disease Control and Prevention. (2015). Diagnosed HIV infection among adults and adolescents in metropolitan statistical areas–United States and Puerto Rico, 2013. *HIV Surveillance Supplemental Report, 20*(4). Table 10. Retrieved from http://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillancereport-vol20-no4.pdf

outcomes by highlighting the thinking, the goals, the voices, and the positive behaviors of the men living in these communities. The data collection methods and the grounded theory analytical approach, drawn from the qualitative social sciences, focus on lived experiences and provide findings that not only add depth to existing quantitative findings but uncover insights that cannot be revealed with large sample sizes and statistical data. ViiV Healthcare's goal is to build on these insights to make improvements to health care delivery and outreach messaging in the short term and, ultimately, to support the long-term structural changes that are needed.

Over the past year, the ACCELERATE! team conducted a series of activities to better understand individuals' journeys through prevention, care, and treatment; understand their needs and aspirations; and identify opportunities for action and investment. This process began with a comprehensive literature review, looking at both the qualitative and quantitative research that had been conducted on HIV/AIDS, with special attention to qualitative work that had been conducted with Black gay men. Not only was this particular subset of the research found to be limited, but it pointed more to future potential rather than to concrete recommendations for immediate implementation in real-world settings.[10]

Following up on directions emerging from the literature review and paying special attention to the areas highlighted as having the most potential for impact, the next step was an environmental scan of the two cities, including a literature review of the specific cities, and interviews with local leadership, providers, and others involved in the HIV/AIDS care

ON THE SURFACE

Information; description and perceptions

- *How often do people visit the doctor?*
- *What percentage of men report using condoms?*
- *How do people rate their satisfaction at their clinics?*
- *How do people feel about side effects of treatment?*

BELOW THE SURFACE

Understanding; explanations and causalities

- *Why do people visit the doctor?*
- *How do men choose whether to use a condom or not?*
- *Why don't people switch clinics when they dislike them?*
- *Why do people decide to try a new treatment?*

Ethnographic research reveals what is below the surface.

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[10] Wilson, P. A., Valera, P., Martos, A. J., Wittlin, N. M., Munoz-Laboy, M. A., & Parker, R. G. (2015). Contributions of qualitative research in informing HIV/AIDS interventions targeting Black MSM in the United States. *Journal of Sex Research, 4*, 1-13.

environment. This was followed by local observations and an extensive review of media, images, and messages that shape the discourse around HIV/AIDS more broadly to familiarize the team with daily life and establish an understanding about the contexts in which men operate.

This initial work guided the in-depth ethnographic research by ReD Associates. From July 2015 to September 2015, the PhD-level ethnographic research team spent days observing and conversing with 30 men, as well as their friends, family members, and influencers. In terms of HIV status, five of the men had not yet been tested, six tested negative for HIV, and 19 were living with HIV, spanning the Gardner Cascade from never in care to having an undetectable HIV viral load. They ranged in age from 19 to 53 (though mostly younger than 30), and they varied in income levels (though mostly below $24,000 per year). The research took a careful look at current efforts to address HIV among Black gay and bisexual men and compared those with the practices and the patterns of thinking among individual men in Baltimore and Jackson, above and beyond HIV. By illuminating the gaps between what men want for themselves and the prevention, care, and related services they receive, this report provides a roadmap for the ways HIV/AIDS-related health care could play a more meaningful role in men's lives. The report first details the research that was conducted and the five insights identified. With these findings, coupled with input from the local communities and national advisors, the report then identifies four strategic opportunities to serve as the foundation of future programming for ACCELERATE!

RESEARCH METHODS

Drawing on established methods from cultural anthropology and other qualitative social sciences, the ethnographic research focused on improving understanding of what could be considered “self-care” by individual Black men in Baltimore and Jackson—the ways that men protected, maintained, and enhanced their health and well-being. In contrast to statistical surveys or other quantitative methods, ethnographic methods are particularly well suited to exploring men’s lives because they allow researchers to gain a valuable depth of understanding (especially on sensitive topics) and a holistic picture. Researchers employed a combination of ethnographic methods to improve understanding of individual men and the way they approached self-care; this included encouraging men to document their self-care practices with photo diaries. In addition, researchers conducted complementary methods to understand the societal and public health messages about Black gay and bisexual men and HIV.

» Participant observation at sites:

The cornerstone of ethnographic research is participant observation, a method by which researchers immerse themselves in the lives of those they seek to understand—participating in daily activities alongside them, while also asking questions and taking field notes. For this project, researchers conducted participant observation at key sites in both Jackson and Baltimore—including community centers, bars and clubs, Gay Pride Festivals, health centers, and malls.

Driving around Jackson.

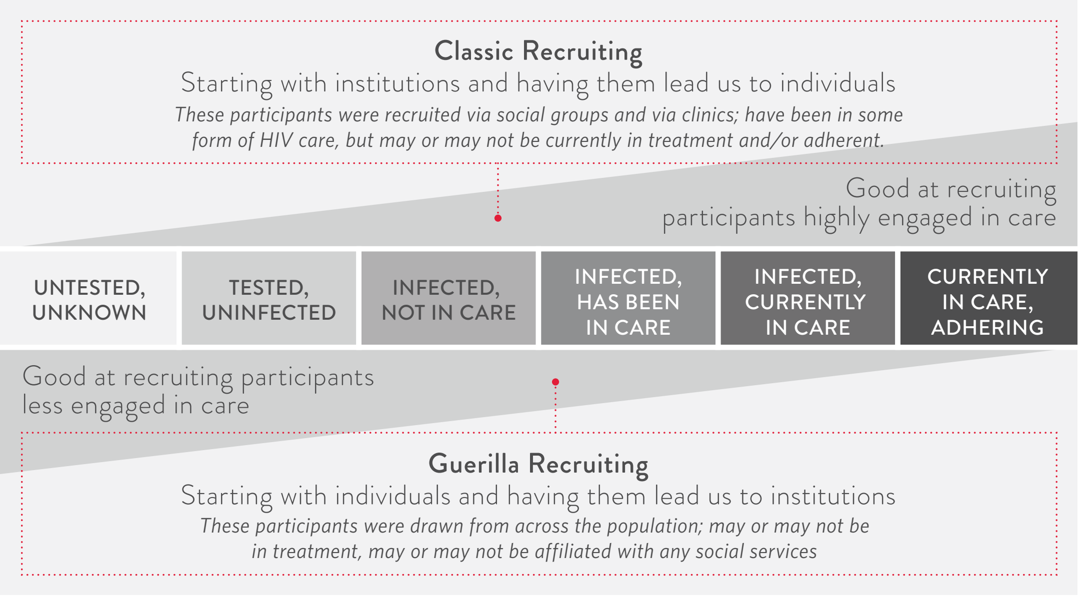
Resources at an AIDS clinic in Baltimore.

Prior to working with the individuals, researchers immersed themselves in the Baltimore and Jackson communities to familiarize themselves with daily life and establish a baseline of understanding about the contexts in which the participants operated. This was especially important in these two cities, although for different reasons. In Baltimore, because of the presence of a number of large care providers with significant research capacity, Black gay and bisexual men felt accustomed to being invited to participate in public health HIV studies; they talked about their suspicions of researchers and other health care professionals, whom the men saw as "using" them without really understanding or caring about their lives. In Jackson, people said they were skeptical for other reasons. They felt race and sexuality were taboo topics and held a profoundly fatalistic idea that nothing productive would come from the research. Participating in the everyday experiences and the flow of activity at key sites in the two cities was critical prework for subsequent research with individuals. Researchers also continued participant observations at sites after the research with the individual men in order to broaden and deepen understanding.

» Participant observation with men:

Unlike surveys and quantitative methods with large sample sizes, participant observation focuses on a small group of individuals in order to provide depth of understanding of these individuals, as well as a breadth of their experiences in the varied contexts of their lives. For this project, researchers immersed themselves for several days in the lives of individual Black men—16 men in Baltimore and 14 men in Jackson—looking at interactions with their social worlds (e.g., boyfriends or partners, friends, gyms, shopping, coworkers, barbers, families), health care worlds (e.g., nurses, volunteers, clinicians, social workers, case managers, health educators, doctors), public health worlds (e.g., sex ed, health insurance, universities, advocacy), and the broader public context (e.g., morals, cultural tenets, media messages, entertainment, religion).

The men were all self-identified as Black or African-American and all had had sex with a man in the last year. Aside from these requirements, the men varied in age (as described above), socioeconomic status, HIV status, engagement with health care, and identification as gay, bisexual, or neither (although the majority identified as gay). To ensure a variety of participants with diverse experiences and a broad spectrum of sexual identifications, men were recruited on Craigslist and through gay dating apps on smartphones. Researchers talked with outreach workers and with initial participants in order to grow (or "snowball") the sample of participants. By recruiting people through dating apps and then snowballing for more participants through the initial recruits, it was possible to meet and include people who were removed from institutions such as clinics or AIDS service organizations—individuals not typically included in research on this topic.



Classic Recruiting

Starting with institutions and having them lead us to individuals

These participants were recruited via social groups and via clinics; have been in some form of HIV care, but may or may not be currently in treatment and/or adherent.

Good at recruiting participants highly engaged in care

Good at recruiting participants less engaged in care

Guerilla Recruiting

Starting with individuals and having them lead us to institutions

These participants were drawn from across the population; may or may not be in treatment, may or may not be affiliated with any social services

Innovative recruiting engaged men with a wide range of care involvement.

- **Semi-structured interviews with men:**

  In addition to participant observation with the 30 men, researchers conducted four- to six-hour in-depth interviews with those participants in various contexts. This was to ensure that, once researchers had begun to develop a holistic perspective on the men's lives, all participants were given a chance to talk about specific topics, such as life histories, self-care practices, dating, love, relationships, sexuality, formal health care, and HIV. Although all topics were covered with each participant, researchers left the pacing and the order open in order to follow the most logical and productive lines of questioning.

- **Photo diaries from men:**

  Supplementing participant observation and interviews, the men in the study maintained daily journals with photo documentation for two weeks—one week prior to the interview and one week after. This allowed for more in-depth understanding of the cycle of men's daily lives, including their habits and practices but also their feelings and self-presentation regarding those habits and practices. The journals also allowed the men to experientially express ideas about their lives that might be difficult to put into words or constrained by habits of language and communicative interactions.

» Clinic interviews and roundtable discussions with stakeholders:

Researchers conducted one-on-one interviews and roundtable group discussions with stakeholders across clinic types. Researchers interviewed doctors, nurses, therapists, social workers, civic leaders, local youth, and outreach workers in three health clinics that served Black men and people living with HIV in Jackson, one HIV/AIDS adolescent clinic in Baltimore, and two nonprofit outreach organizations, also in Baltimore. These interviews were designed to uncover how health care workers understood the men in their priority populations and to improve understanding of the challenges and daily practices of those delivering HIV care in these local contexts.

» Interviews with academic experts:

Researchers interviewed ten experts in fields related to Black male identity (specifically in Baltimore and Jackson), HIV/AIDS, public health, urban economics, and gender studies. These interviews were conducted in order to situate this current research within the rich body of previous research on these topics and to put individual perspectives and behaviors in context within larger social, cultural, and medical histories. Interviews with these experts heavily informed the research methodology strategy, as well as the specific field and interview guides.

» Discourse analysis on campaign and public media messages:

To identify explicit and implicit meanings behind the images and messages surrounding the men, researchers observed and analyzed public media campaigns and mass audience HIV/AIDS education/outreach efforts, as well as messages about Black gay men more broadly. Knowing how these messages attempt to reach men enables this report to recommend improvements to the messages.

Examples of HIV prevention campaigns and media messages targeting Black men.

Taken together, these methods provided rich data not commonly collected from research on these topics. Subsequently, ReD Associates used grounded theory analysis to let the voices of the men come through in their own words and on their own terms rather than in response to predetermined categories of analysis. All research designs have limitations. In this case, the limitations were that the sample size was small (30 men) and the time spent with each of the participants was relatively short. In addition, broad interpretation of the findings was limited, as the sample included men from only two cities. To address these limitations, the research design included the multiple methods described above. For example, photo diaries supplemented participant observation and interviews with the men to expand the time of data collection. Additionally, interviews with academic experts and participant observation at key sites enabled researchers to fit individual-level findings into larger societal and cultural contexts. Finally, the authors noted that although the sample size was small, it was within the established norms for applied research of this type and still allowed researchers to identify important findings and suggest broader conclusions with new directions about ways to communicate and engage men with care.

FINDINGS

Integrating the findings across the different methods, researchers found that men in this study had common aspirations—to get ahead in the world, to be healthy and strong, to find satisfying love and sex, to have choices and dignity in health care, and to be treated as individuals. What stood out with this particular group of men was the extent to which they were constantly fighting strong societal stereotypes—stereotypes about race, about sexuality, and about HIV/AIDS. For them, the confluence of these stereotypes got wrapped up in a concept commonly referred to among the group as being "messy." Being messy was often associated with qualities such as being loud, materialistic, gossipy, indiscreet, insular, poor, promiscuous, flamboyant, low class, uneducated, dramatic, and HIV+.[11] Understanding these stereotypes and stigmas, and that Black gay men often feel that getting ahead means "beating the odds" (including, but not limited to, HIV), is critical to building responsive health interventions to meet the men "where they want to be."

The next section draws on the research to identify five key insights.

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[11] The concept of *messiness* here is being understood as a foil against which the men presented their own identities and aspirations rather than an ontological reality. The inclusion of HIV+ in this concept of messiness highlights a pervasive negative judgment related to a positive HIV status and should be considered in strategies involving mobilization, testing, and disclosure.

INSIGHT 1: MEN WANT TO BE TREATED AS INDIVIDUALS AND NOT AS LABELS.

» Men don't define their identities solely by their sexuality.

The participants in this study constructed their identities in complex ways from many different aspects of their lives—family, work, faith, friends, and community. Although sex was an important factor in the way they thought of themselves and their lives, it was not the only way and not necessarily the predominant way. They rejected the notion that their identity and their sexuality should define the experiences they had in their lives and with their health care providers. The men wanted to be taken seriously as individuals rather than as representatives of a type or as defined by their sexuality.

> “
> I don't want to get an assumption on me just [because of who] they think I am. Because I'm already getting assumptions for being Black and being male. So I don't need any more negatives or anything else, or anything they could think is negative. I want them to see me for my attributes, for what I bring to the table. I try to let my work speak for me.
> — *Jackson participant*

> “
> I'm not 'gay'—I'm Kyle.
> — *Baltimore participant*

Understanding these stereotypes and stigmas, and that Black gay men often feel that getting ahead means "beating the odds," is critical to building responsive health interventions to meet the men "where they want to be."

» Men want control over their identities.

For many of the men, perceptions around sexual identity were considered messy and therefore not representative of who they wanted to be. In particular, health care messages that implied that men should be "out and proud" were seen to conflict with the importance men placed on having control over what they presented to the world and how they did it. This was especially salient because of the strong stigma associated with being HIV+.

> "
> It's okay if everyone knows you sleep with men, but being 'out' means talking about your sex life, which is messy behavior and not okay.
> — *Jackson participant*

Another participant from Jackson explained that not being open about his sexuality allowed him to "hide" a little from the realities and the messiness of HIV and to be more discreet. For the most part, the men were proud, not ashamed, of their sexuality, but they wanted to be actively in control of their presentation to the world. They were engaged in the process of constructing their identities and their public narratives in a way that felt true to themselves but also allowed them to control that construction—to have privacy when they wanted it and to protect and care for themselves the way they saw fit.

» Implications for the field:

Analyzing stakeholder interviews and public messages reveals that many in the public health field assume that Black gay men should have a shared identity as out and proud. The public health messages imply that these men are ashamed of their identity and that they must be brought out with a clearly defined identity and positive messages. The thinking is that this will attract men to care. As was described above, however, men consider their identities in complex holistic ways. The research suggests that they want to be approached by people and by messages as individuals, with sexuality comprising only one part of that individual identity. These men wanted to have control over their identities rather than feel pushed to conform to prescribed ways of being, not only in terms of sexuality but in terms of race/ethnicity. The men rejected the idea that their sexuality or race/ethnicity should be the most salient "filters" for the kind of care that they received.

INSIGHT 2: INTIMACY AND TRUST ARE IMPORTANT FOR RELATIONSHIPS, AND CONDOMS GET IN THE WAY.

» Men want long-term, intimate relationships.

Most of the men in this study, especially the younger men, desired long-term, intimate relationships. Whether looking by way of clubs or dating apps, the men were seeking long-term relationships and marriage; that was the expectation. In addition, they saw long-term, stable relationships as an integral part of the way they conceptualized their own identities and where they saw themselves going in the world.

> “
>
> I already have strikes on me—being Black, gay, having HIV… I want to be a proud, Black man with a boyfriend.
>
> — *Jackson participant*

» Condoms are a barrier to closeness.

When researchers analyzed the health care messaging around condoms and prevention, they found implicit messages that condoms demonstrated that a man cared for his partner. For men in this study, however, the opposite was true. Condoms did not signify love, caring, trust, or commitment. On the contrary, they were associated with early-stage dating/sex and a lack of the intimacy that came with a more serious relationship. Participants were clear that if they did not know someone well, they would always use a condom.

Condoms did not signify love, caring, trust, or commitment. Perhaps even more important, condomless sex was seen as *marking* the transition to a serious relationship and *proving* trust in the partner.

> “
> With the dudes that I actually dated, which was not a lot of them—four in my entire lifetime—those are the ones I did not use a condom for. Those that I did not date or where it was just a fling thing, I made sure I had a condom. I'm not going to be with you for the rest of my life, I'm not going to be with you tomorrow. I don't know what you got, so we're wrapping it up.
>
> — *Baltimore participant*

At some point into a relationship, not using a condom during sex sent a message of seriousness and trust that men saw as critical for continuing to deepen the relationship and achieve their relationship goals. Perhaps even more important, condomless sex was seen as *marking* the transition to a serious relationship and *proving* trust in the partner. One Jackson participant, for example, explained that intimacy meant two things—deleting his Adam4Adam profile and not using condoms. After this participant had been with his boyfriend for 3 to 4 months, someone asked him if he was using protection and he responded, *“No . . . this is my boyfriend so why should I?”* He explained, “The main thing that mattered to me was that I got a lover and the only thing that matter[ed] to me was to have someone—to have someone to call my own.” The desire for intimate relationships trumps condom use. In fact, all the men in the study reported having sex without condoms with current or past boyfriends. The closeness of a boyfriend actually made condomless sex feel less risky, as most of the men cognitively mapped increasing intimacy with decreased risk. Subsequently, most of the men in the study who were HIV+ reported contracting HIV from a boyfriend or other intimate relationship.

At some point in men's relationships, the desire for trust and intimacy will win out over condoms, no matter how important or exciting the messages are about condom usage.

» Implications for the field:

Messages resting on assumptions that condoms show you care about your partner and that long-term condom usage will drive down infections do not resonate with the men in this study. This research shows that messaging about condoms through campaigns or sexual health education must acknowledge that condoms take on different significances for men depending on context and relationship status. At some point in men's relationships, the desire for trust and intimacy will win out over condoms, no matter how important or exciting the messages are about condom usage. Messaging must take into account men's desires for intimate, long-term relationships, and promote strategies, such as pre-exposure prophylaxis (PrEP), that align rather than conflict with or undermine this powerful goal.

INSIGHT 3: TESTING NEGATIVE IS A CRITICAL OPPORTUNITY FOR PREVENTION STRATEGIES.

» Testing is taken for granted.

HIV testing was widely available and accepted as part of life for men in this study, particularly when they were not in serious relationships. In fact, during recruiting for this research, it was a challenge to find anyone who had not been tested within the last 2 years. One Jackson participant explained that he got tested every 4 to 6 months and that, after a while, he knew “everybody at the clinic. It was like, okay cool, I’m fine, I’m out.” Testing happened in many locations and was characterized as routine and matter-of-fact, even though the specific rationale, frequency, and triggers for getting tested were not always clearly communicated by the staff to the men. Several participants in Baltimore even considered testing something that men did to help the researchers and health care professionals “get their numbers” rather than something important for their own health. Nevertheless, everyone in this study talked about getting tested fairly regularly when not in a serious relationship—even those who were ambivalent about it. However, the men also talked about not getting tested once they were in an intimate, trusting relationship.

> “
>
> When I started having sex I would get tested every 3 months at the Jackson medical mall. But in 2011, I met this guy at a gas station that was connected to my friend-girl and we started dating. I wasn’t really educated about *[testing while in a relationship]*. I just trusted him and thought we would be together *[and so did not continue getting tested]*.
>
> *— Jackson participant*

» Without more engagement, testing negative becomes a “green light” for men’s own prevention strategies.

The research highlights that the meaning assigned to testing is dramatically different for the men in the study than for the public health field. Based on our research with health workers and in the messaging analysis, a common assumption was that men got tested to find out if they were positive; if they were, they would then get care. The research shows, however, that many men did not get tested with an eye toward starting treatment; they got tested to confirm their negative status. That result, along with a lack of further engagement, became a validating “green light” for them to continue with the strategies they were using, acting on the best (but limited) information and tools they had at their disposal.

» Implications for the field:

The fact that men have come to accept frequent testing is an opportunity for the field to cast a wide net in reaching men with prevention strategies. Testing can be an optimal time for coupling education with strategies to more effectively prevent infection after testing (including sexually transmitted infection [STI] testing and treatment, PrEP, and post-exposure prophylaxis [PEP]) and for improving health care in general. With this leverage, negative results can serve as useful behavior reinforcers. The research conducted for this study showed that this kind of post-testing education was often not happening or that it was not memorable to participants.

Because men expect to test negative, they may not be prepared to start thinking about care. A number of participants who tested positive did not enter into care, and among those who were linked to care, a number were not ready to be adherent. Getting tested did not necessarily mean being ready to act on the results. For many men, testing was not the pathway to care that it could be, whether they tested positive or negative.

INSIGHT 4: MEN DISTANCE THEMSELVES FROM CARE WHEN CARE DOESN'T FIT THEIR NEEDS.

» Men need and want different things from their care.

In both Baltimore and Jackson, almost all the men living with HIV in this study had been to a clinic and had interrupted their treatments in search of better clinics, or had dropped out of care altogether. While external factors (such as moving to a new state, getting a new job, or changing insurance plans) sometimes precipitated the distancing from care, most of the time men dropped out of care because of the disconnect between the care they wanted and the care they encountered. Participants expressed wide-ranging sentiments about the care they wanted and needed. For example, some men wanted personalized attention, while others sought anonymity. Some wanted detailed instructions, while to others that felt condescending.

> “
> I wanted someone to talk to me about what it means to live with HIV/AIDS.
> — *Baltimore participant*

> “
> All I wanted from them was to tell me what meds to take, but I met with three different case workers.
> — *Baltimore participant*

» According to participants, finding good care is difficult.

Many participants in the study expressed frustration with some aspect of care, whether it was a doctor, nurse, insurance company, clinic, or the environment more broadly. Sometimes this dissatisfaction flowed directly from not receiving the care that they wanted in the way that they wanted it. For example, one Baltimore participant explained that he had tried to get the facts about his HIV+ diagnosis but, in the process, felt that he was being “treated like a child” by his clinic. He was offended at the assumption that he needed so much hand-holding with paperwork and with the steps of entering care. Others explained that they needed guidance and orientation but did not get it. One man described encountering a terse and efficient doctor who was focused on the necessary blood work and prescriptions but little else.

> “
> Doctors were really insensitive. They want to talk to only about the physical things. Nothing personal. There was no personal attention. I didn't feel like he *[the doctor]* cared for me.
> — *Baltimore participant*

Other factors made men feel uncomfortable at clinics, such as all the questions about their sex life or even the specific personalities and actions of those who worked there.

> “
> A lot of people don’t like coming here because there is a guy that works here who hits on a lot of the guys.... He is very arrogant.... I don’t like him because I feel like he knows everyone’s status; he has that over us.”
> — *Jackson participant*

» Care doesn’t fit with the way men see themselves.

An additional reason some men distanced themselves from care is that care was often yet another source of stigma in action, effectively making them feel messy, which did not fit with the way they saw themselves or “where they were going.”

> “
> I really don’t want that reminder right now. It’s just... the one thing I tried not to be a part of, I became. Now I’m a statistic. I wasn’t trying to be a statistic; I was just trying to be in love. I’m a statistic now... and with medication, that’s not going to change.
> — *Jackson participant*

One Jackson participant explained that he was ashamed to be seen receiving care in STI/LGBT (lesbian, gay, bisexual, and transgender)-identified clinical settings. He explained that his reason for avoiding care was not disappointment in the clinic itself, but rather the way the social stigma from friends affected his identity. Everything about the clinical interaction, even just rattling pill bottles, was described as a form of vulnerability. Another participant, also from Jackson, reported that his doctor had promised him confidentiality, but that the many clinic mailings to his home where he lived with his family made him feel exposed. In addition, many men described feeling alienated by the assumptions that were being made about them because of their race. They felt that clinics had expectations about what a Black man should be, and those expectations did not fit with the way they saw themselves. Others felt alienated by assumptions that they needed a Black doctor, when in fact all they really cared about was having a good, professional doctor.

Effective care will assess what individual men want and will be able to deliver that personalized care to them—to meet those men “where they want to be.”

» Implications for the field:

Analysis of health care stakeholders and popular discourse messages and materials reveals a common underlying assumption that men do not start or stick with care because they do not take their health seriously; responsibility for men’s distance from care is squarely placed on the men themselves. This research shows a more complicated picture—that men do often take their health seriously (e.g., watching their diet, going to the gym) and that there are a variety of reasons why men distance themselves from care when it does not fit their needs. In order to facilitate more interest in care, providers must understand that men often feel that care can be inconvenient, frustrating, cold, confusing, and condescending. In the face of a shift in HIV status, these perceptions can alienate men and inhibit their ability to receive effective care. In addition, different men want different things from their care. Some want to be carefully guided through steps, while others do not want to feel as if they are being coddled. Effective care will assess what individual men want and will be able to deliver that personalized care to them—to meet those men “where they want to be.”

INSIGHT 5: INTERRUPTIONS IN CARE HAPPEN TO EVERYONE.

» Even under the best circumstances, men fall in and out of health care.

The research showed that multiple factors influenced men's starting, continuing, and stopping or pausing care. Even in the best possible circumstances, in which men were doing well financially and were living in stable conditions, they still started and stopped care for a variety of reasons.

> “
> I take drug holidays for months. I just stop taking medications voluntarily.
> I get tired of taking them.
>
> — *Jackson participant*

Men took breaks from care visits, from support groups, and from taking medication. Participants talked, for example, about pausing care because of being in prison and the impossibility of being discreet in that situation; they talked about depression and other illnesses; they talked about moving; and they mentioned changes in jobs and health insurance. Even positive changes could lead to a break in care that would make it extremely challenging to start care again. One participant from Jackson, for example, talked about getting a new job and being offered health insurance for the first time, but he feared that he would have to change doctors and upend his life. He did not know how to figure out the way this change would affect his care. Another participant talked about the significant work he had dedicated to sensitizing a previous doctor from when he lived in a different city. After putting in so much work and finally building a solid relationship with that doctor, he was reluctant to go through all that trouble again when he moved to Jackson; so he did not restart care, holding onto hope of moving back to his previous city in a few months. While patient navigators were described as being emotionally supportive, men such as that one continued to experience logistical challenges with getting back into care after a hiatus.

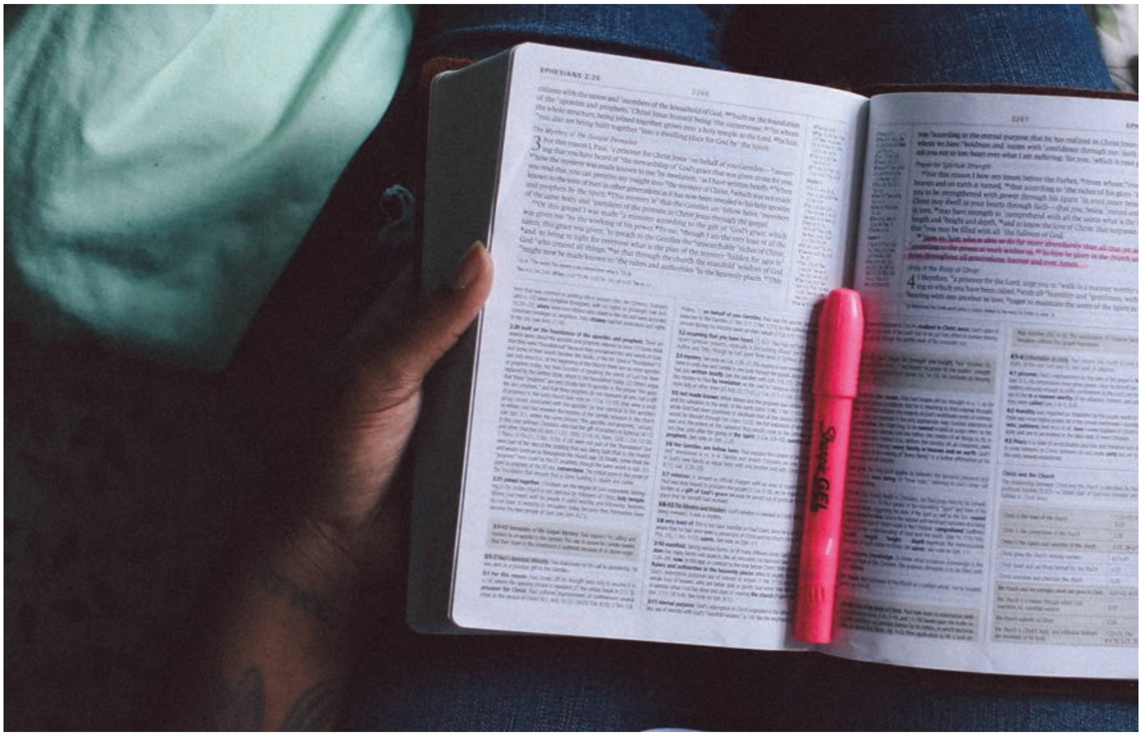
It is important to note that knowledge about HIV/AIDS did not necessarily keep people from dropping out or pausing care; in fact, the participants sometimes felt empowered by this knowledge to make their own calculations about when and how to drop out of treatment, often while they cared for their health in other ways.

> “
> I've been taking medication for years; I know how much of a break I can get away with.
>
> — *Baltimore participant*

These men had forged deep, irreplaceable *individual* relationships with God that existed outside the formality of the church.

» Staying in care is facilitated by emotional, psychological, and spiritual supports.

HIV+ men in this study did not feel that stopping or pausing care was going to kill them. One Jackson participant, for example, explained that he did not need medication until his numbers were in a certain range, and that as long as he took it eventually, he would be fine. Because men did not feel the immediate urgency, staying on medication or in care was occasionally trumped by other life circumstances and decisions. Many adherent participants relied on emotional, psychological, and spiritual support to stay in care. Most participants who stayed in care and continued taking regular medication relied on set routines, such as taking pills at a specific time and place. One Baltimore participant described taking his medication at lunchtime, for example, because that was his most consistent meal and he could go home for lunch, preferring not to carry around his medication bottle.



Participants' individual connections with God helped them stay in care.

Participants also developed spiritual connections with nature and with religion that contributed to adhering to self-care practices. The research showed that some men attended church, especially when the congregation was gay-friendly or when singing in the choir was important. Most of the men, however, had found churches alienating, particularly because of their stances on homosexuality. These men had forged deep, irreplaceable individual relationships with God that existed outside the formality of the church. In addition, most participants relied heavily on their closest personal supports, such as friends and family.

> “
> My grandfather was a pastor, so I grew up in it. But I found my own way. Religion is man-made. God is not. I don't need some other people's ideas of religion to have a relationship with God.
>
> — *Jackson participant*

> “
> I pray and believe in God, but I don't believe in the Bible.
>
> — *Baltimore participant*

> “
> I don't need a name *[for my religious practice]*. *[At the end of each day]* the day is done, and I thank him for letting me see another day. I want to show gratitude.
>
> — *Baltimore participant*

> “
> My dad will occasionally come on doctor's visits, because he wants to check in and make sure I'm doing okay.... My mother is constantly like: 'When are you going to take your medicine?' My grandmother is the same way—'You told me you're going to the doctor today.... What are you going to do this time? Are you going to do what they ask you to do?' Stuff like that. Everybody's just waiting on me.
>
> — *Jackson participant*

» Implications for the field:

For many clinicians, keeping patients engaged in routine health care is synonymous with keeping them on treatment. However, even in the best circumstances, almost all patients go off treatment at some point; out of our 19 HIV+ respondents, 13 had full viral suppression at one point, yet only 8 reported being fully virally suppressed. When men stop treatment, they are often considered noncompliant or "not in care," and their relationships with health care professionals often deteriorate, leading to them dropping out altogether. Keeping these men in care may be improved by understanding this and developing systems to emotionally support and reconnect with them in ways that reflect that understanding. In addition, providers must build on what they already know about adherence—that it is not accomplished by individual willpower alone but by successful supports, routines, and networks.

CONCLUSIONS AND KEY TAKEAWAYS

The goal of this deep ethnographic investigation was to better understand the patterns of thinking, the practices, and the goals of Black gay men as they navigated the different contexts of their lives. The patterns of thinking that men brought to bear on the issues of identity, love, trust, sex, faith, and health affected the way they processed messages from and interactions with the field and the way they made their life decisions.

Meet Me Where I Want To Be answers calls in the literature for deeper understanding of several key themes—including "heterogeneity among Black MSM; stigma tied to intersectional identities of race, ethnicity, sexual orientation, gender, social class, and HIV status; factors influencing sexual risk behavior, substance use, and mental health among Black MSM; and the associated factors of resilience and community engagement."[10] The aim of this research, however, is not solely to advance knowledge but to *inform practice*. The ethnographic research presented here has immediate implications for strategies for and messages about care. The insights show that care cannot be delivered effectively by assuming homogenous identities, by equating knowledge of disease information with action, or by ignoring men's aspirations. In addition to the conclusions presented here, the following are some of the key takeaways for shifting the approach:

The insights show that care cannot be delivered effectively by assuming homogenous identities, by equating knowledge of disease information with action, or by ignoring men’s aspirations.

- **Care is for everyone, not just for those who are HIV+ and in treatment.** Addressing messages, clear information, and holistic strategies for everyone should result in fewer infections, more sustained care, and less stigma.
- **Men need a reason to enter and stay in care.** Current efforts emphasize vague, abstract, or unclear goals about the long-term future, when the reasons should be clear and concrete—beating the odds, staying strong, and staying healthy.
- **Concrete individual benefits—rather than abstract and potentially unrealistic goals, like stopping HIV or improving society—should be emphasized.**
- **Messages shouldn’t treat Black gay men as a single, homogenous group.**
- **With men focused on growth and self-improvement, messages need to acknowledge men’s ambitions and offer them choices that are in line with those personal aspirations.**

In addition, the research points to the importance of continued research. Productive future research directions could include (a) expanding the in-depth ethnographic research to a larger number of participants in these and other cities, (b) including women and other racial/ethnic groups as participants, (c) testing and evaluating newly developed programs and communications for their effectiveness, and (d) following up with participants in this study for a more longitudinal understanding of the men’s lives.

GOING FORWARD

Over the past year, these insights were shared with community members, public health leaders, front-line providers, advocates, academicians, government leaders, and people living with HIV in Baltimore and Jackson. Stakeholder listening sessions, including workshops, one-on-one conversations, and small-group discussions, as well as convenings, engaged participants to vet the findings and provide feedback for effective implementation of four strategic opportunities to be rolled out over the coming years.

Grounded in these insights and the urgency of the epidemic, ACCELERATE! is taking a community- and person-centered approach to support bold solutions that give men clear reasons, more choices, and better options so they can choose, and get and stay connected with, health care that works for them. This research, in concert with the listening sessions, illuminated four key investment opportunities for ACCELERATE!

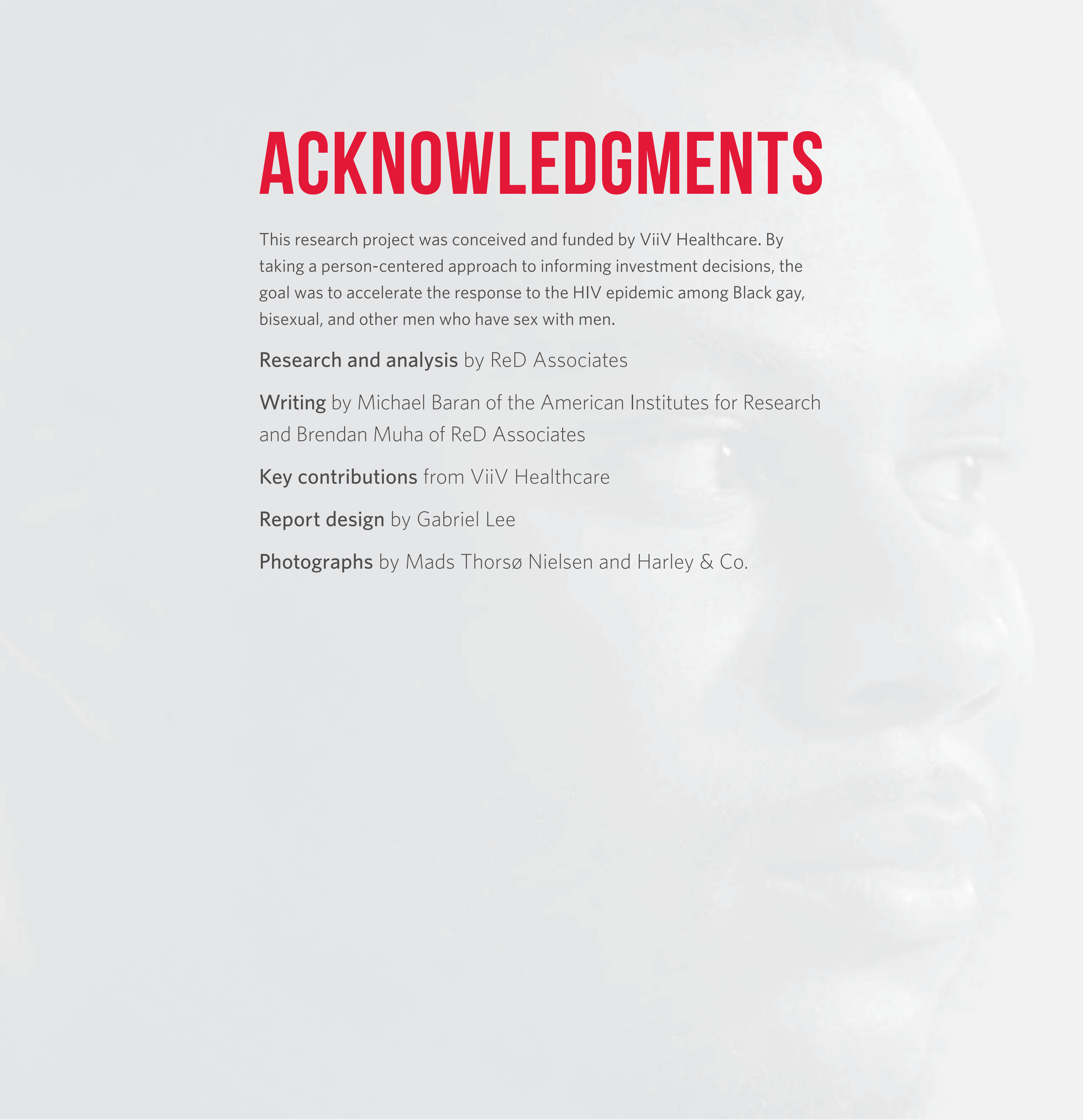
1. **Boost empowerment and strengthen networks** to break down isolation and stigma, connect men to networks of support, and expand knowledge of HIV prevention and care.
2. **Make sex ed relevant** with enhanced content for adults that reflects today's context and can be delivered in person and online.
3. **Make testing a bridge to prevention and care** by piloting a revised protocol for men who test negative for HIV, to better link them to health care, PEP, and PrEP, as well as other community supports.
4. **Strengthen navigation services** with excellent "concierge-like" services and new tools that help men navigate complex systems and make it easier for them to get back into care.

In addition to these four investments, ViiV Healthcare is committed to improving the quality of care and services received by people living with and vulnerable to HIV. Through ACCELERATE!, ViiV will provide communities with education and resources to increase awareness of the current HIV treatment guidelines and standards of care available in the United States. ViiV's holistic approach aims to widely disseminate this information to improve the experiences with care and quality of life for all individuals.

Over the next several years, ACCELERATE! will work to support and strengthen solutions in each of the complementary and interconnected investment opportunities in Baltimore and Jackson—infusing the initiative's collaborative work with the perspectives, experiences, insights, and diverse, unique needs of Black gay men. Ensuring that men have access and connection to quality HIV and holistic health care will require partners from inside and outside of the HIV field. ViiV Healthcare's ACCELERATE! initiative will propel programs and partnerships that engage and collaborate differently, with the shared goal of forging a path for current and future generations of Black men to thrive and prevail.

For more on *Meet Me Where I Want To Be* research, contact Kali Lindsey at kali.d.lindsey@viivhealthcare.com.

To learn more about ACCELERATE!, visit www.viivhealthcare.com.



ACKNOWLEDGMENTS

This research project was conceived and funded by ViiV Healthcare. By taking a person-centered approach to informing investment decisions, the goal was to accelerate the response to the HIV epidemic among Black gay, bisexual, and other men who have sex with men.

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ViiV Healthcare was established to take an innovative approach to the challenge of HIV—and we do. It's who we are.

An innovative approach means we go beyond developing new medicines. We seek insights to better understand the unmet needs of people living with HIV. We connect individuals and communities to help drive solutions focused on providing the same standard of care for all people living with HIV. We develop and support community programs that focus on HIV prevention, care, and treatment. The voice of the HIV community informs everything we do.

As the only company solely focused on HIV, we think differently, act differently, and connect differently to improve the lives and outcomes for all people affected by HIV.

To learn more, visit viivhealthcare.com/us and follow us @ViiVUS

The **Meet Me Where I Want To Be** research project was made possible through funding from ViiV Healthcare, a company established to take an innovative approach to the challenge of HIV. The study is a foundational element of ACCELERATE!, ViiV's four-year $10M initiative to fund innovative and promising projects that support the health and well-being of Black gay men in the two cities hardest hit by HIV—Baltimore, Maryland, and Jackson, Mississippi. The study was designed to gain deep insights from the perspectives of those most affected by HIV so that their views are at the center of the initiative's design and implementation.

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