Project Summary

The PrEP-NET Study is a 2 year, mixed methods, translational research project that identifies the important barriers to the adoption of pre-exposure prophylaxis (PrEP) by black men who have sex with men in Milwaukee (MSM). Researchers from UW Madison along with a consortium of stakeholders including the Wisconsin Division of Public Health and Diverse & Resilient, worked to pursue the following research aims:

Aim 1: To describe attitudes, normative beliefs, and individual-level barriers to using PrEP for HIV prevention among young, black MSM.

Aim 2: To identify structural barriers to PrEP implementation through formal assessment of community readiness among relevant stakeholders.

Aim 3: To leverage data obtained from formative research to develop and pilot test a computerized tailored behavioral intervention for increasing use of PrEP and decreasing risky sexual behaviors, in preparation for a subsequent larger, multi-site clinical trial.

During year one of the project, Diverse & Resilient was tasked with facilitating this community readiness assessment (CRA) in order to determine the Milwaukee community’s level of readiness to address the issue of the use of PrEP as a prevention tool for sexually active African American men who have sex with men (AAMSM). This CRA focuses on AAMSM due to the racial disparities in the rate of HIV infection in Wisconsin. Despite accounting for less than 1% of the population in Wisconsin, black men between the ages of 15-29 accounted for 28% of HIV diagnoses in 2014. The results of this readiness assessment will be used to guide and tailor recommendations for community and agency interventions that are based on the community’s specific level of readiness.

Community Readiness Model (CRM)

The Community Readiness Model is an evidence-based tool developed at Colorado State University’s Tri-Ethnic Center for Prevention Research. It is a Stages of Change model (Prochaska & DiClemente, 1992) that assists in program planning by helping to determine a community’s level of readiness to address a particular issue (e.g., the use of PrEP as a prevention tool for sexually active AAMSM). For a given issue, a community will fall somewhere on the continuum illustrated below, with 1
being no awareness that the issue exists or is significant generally or locally, and 9
being a high level of community ownership and awareness of the issue. Once the
readiness level of a community has been established, interventions that are
appropriate for their issue-specific readiness level can be selected for
implementation (Tri-Ethnic Center for Prevention Research, 2014).

Levels of Readiness

<table>
<thead>
<tr>
<th>Stages of Change</th>
<th>Levels of Readiness</th>
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<tbody>
<tr>
<td>Maintenance</td>
<td>9. High Level of Community Ownership</td>
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<tr>
<td>Action</td>
<td>8. Confirmation/Expansion</td>
</tr>
<tr>
<td>Preparation</td>
<td>7. Stabilization</td>
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<td>Contemplation</td>
<td>6. Initiation</td>
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<td>Pre-contemplation</td>
<td>5. Preparation</td>
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<tr>
<td></td>
<td>4. Preplanning</td>
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<tr>
<td></td>
<td>3. Vague Awareness</td>
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<tr>
<td></td>
<td>2. Denial/Resistance</td>
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<td></td>
<td>1. No Awareness</td>
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Community Readiness Assessment (CRA)

To determine a community’s level of readiness, a community readiness assessment
(CRA) must be conducted. This CRA entails a series of structured interviews with
diverse members of the defined community. For the purpose of this project, the
goal was to answer the following broad question: What is the Milwaukee
community’s level of readiness to address the issue of the use of PrEP as a
prevention tool for sexually active AAMSM? Our community of interest was the
Milwaukee community, which included six stakeholder groups, illustrated below
along with the total number of interviews completed for each group.
A minimum of four individuals in each stakeholder group were interviewed as part of the assessment, for a total of 28 interviews. Interview participants were asked a set of 36 questions that fell into the five dimensions of readiness, described below.

1) **Community Knowledge of Efforts:** How much does the Milwaukee community know about the current programs and activities related to the issue of the use of PrEP as a prevention tool for sexually active AAMSM?

2) **Leadership:** What is the attitude of the leadership in the Milwaukee community with respect to addressing the issue of the use of PrEP as a prevention tool for sexually active AAMSM?

3) **Community Climate:** What is the overall attitude in the Milwaukee community toward addressing the issue of the use of PrEP as a prevention tool for sexually active AAMSM?

4) **Community Knowledge about the Issue:** How much does the Milwaukee community know about the issue of the use of PrEP as a prevention tool for sexually active AAMSM?

5) **Resources Related to the Issue:** What are the resources in the Milwaukee community that are currently being used or could be used to address the issue of the use of PrEP as a prevention tool for sexually active AAMSM?

**Data Analysis**

Completed interviews were analyzed using two processes. The first, a scoring process outlined in the CRM Handbook (*Community Readiness for Community Change*), was conducted by two trained scorers at the University of Wisconsin-Milwaukee Zilber School of Public Health. Scorers reviewed each completed interview separately, and then met to score them together to address any concerns for inter-rater reliability. Finally, the scorers calculated the readiness scores for each key stakeholder group, each dimension of readiness, and the entire Milwaukee community.

In addition to this scoring process, Diverse & Resilient’s staff also conducted thematic analysis of the interviews in order to extract more detailed qualitative data. Three members of the assessment team (two contracted interviewers and one public health intern) reviewed all completed interviews, searching for initial codes independently and then working together to develop a slightly more condensed list of initial themes. These initial themes were then presented to a small group of individuals, including the interviewers, scorers, and other Diverse & Resilient staff members. Using an affinity process, these individuals grouped the initial list of themes into categories based on similarity, resulting in a final list of six main themes. The results of both the scoring process and the thematic analysis process, as well as associated recommendations, are described in the following pages.
Quantitative Results

<table>
<thead>
<tr>
<th>Dimension Total</th>
<th>Community Knowledge of Efforts</th>
<th>Leadership</th>
<th>Community Climate</th>
<th>Community Knowledge of the Issues</th>
<th>Resources</th>
<th>Overall Community Readiness Score</th>
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<tbody>
<tr>
<td>Total</td>
<td>2.27</td>
<td>4.63</td>
<td>3.95</td>
<td>2.34</td>
<td>3.38</td>
<td>3.31 (Vague Awareness)</td>
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**Description of Scores**

Based on the 28 interviews conducted, the Milwaukee community received a readiness score of 3, which indicates *Vague Awareness* of the issue of the use of PrEP as a prevention tool for sexually active AAMSM. Unlike a community staged at a 1 or 2, a community staged at a 3 recognizes that the issue is of concern in their community and that something should be done about it, but immediate motivation is insufficient to act on the issue. This means that some members of the Milwaukee community believe that the use of PrEP as a prevention tool for sexually active AAMSM is an issue that may be a concern in the community, but they only have vague knowledge about the issue and know little about local efforts to address the issue.

In examining the five individual dimensions of readiness, the Milwaukee community received the highest score, a 4 (*Preplanning*) in leadership. This indicates that at least some of the Milwaukee leadership believes that the use of PrEP as a prevention tool for sexually active AAMSM is an important issue and that something should be done to address it. For both community climate and resources, the Milwaukee community received a 3 (*Vague Awareness*). This means that while some members of the community believe the use of PrEP as a prevention tool for sexually active AAMSM might be a concern and there are some resources that could be used to address the issue, it is not seen as a priority and little to no resources are being allocated for this purpose. Finally the Milwaukee community received a 2 (*Denial/Resistance*) for both community knowledge of efforts and community knowledge of the issue. A level 2 score at these dimensions indicates that only a few members of the community have any knowledge about the issue and the local efforts to address the use of PrEP as a prevention tool for sexually active AAMSM. At this level, there may be misconceptions or incorrect knowledge among many community members.
The stakeholder group-specific scores displayed above show that the lowest scoring group was the community leaders, who received a score of 2 (Denial/Resistance). A score of 2 can indicate that the leadership believes that either this issue is not a concern in their community or that nothing can or should be done to address the issue. However, this contradicts the leadership dimension score, which placed the leadership at a 4, and does not accurately reflect what was said in the interviews. The four community leaders interviewed all knew about PrEP; their low score is a reflection of where they see the community. The community leaders felt PrEP was an important issue, but they felt the community’s knowledge about the issue and willingness to address the issue was low, which is reflected in how they scored the Community’s Knowledge of Efforts at 1.88 (No Awareness) and the Community’s Knowledge of the Issue at 1.81 (No Awareness).

All other stakeholder groups received a score of 3 (Vague Awareness), which is consistent with the overall community score and indicates that community members have a vague awareness of the issue and may believe that this issue is a concern to the community but show no immediate motivation to act on the issue.

During thematic analysis, the interviewers, scorers, and Diverse & Resilient staff discussed the possibility that the overall readiness score of 3 was inflated due to
the lengthy timeframe of executing a CRA and co-occurring PrEP awareness activities during this period. Additionally, many of the target population who were interviewed were connected to Diverse & Resilient in some way, leading us to believe that there was some selection bias. Staff working on this CRA believe a more accurate reflection of the Milwaukee community’s readiness would be a score of 2 (Denial/Resistance).
Qualitative Results

Primary Themes

1. Internalized Mistrust and Historical Trauma: Within the African American community, there is an internalized mistrust of doctors and the medical community stemming from the historical trauma, abuse, and mistreatment of African Americans by medical professionals. For some in the African American community, suspicion around efforts that appear to target African Americans and a lack of trust of the medical community is a barrier to getting on PrEP. African Americans have not forgotten the past wrongdoings of the medical community and as a result may be not be receptive to outreach promoting PrEP.

“I would imagine that maybe among older people, or people with a really good understanding of the interface between people of color, medicine, etc. [they] may be suspicious about this direct marketing to the AAMSM community.”

“I have heard that this is something implemented by the government to kill us off faster... a lot of people have felt that it’s just a way to kill us off.”

“People are uninformed about PrEP, what it is, who it’s aimed at, there might even be backlash associated with paranoia from African-Americans being experimented on, Tuskegee type hysteria.”

“The community is also going to be extremely leery, especially if there is not more education about what this is, about giving our young black men a pill to stop HIV in its tracks.”

“People are suspicious of doctors and public health efforts- we all know Tuskegee.”

2. Community Attitudes: Community attitudes surrounding HIV/AIDS and homosexuality prevent people from supporting the use of PrEP. Interview participants identified numerous beliefs held by community members that are barriers to people supporting the use of PrEP; these beliefs range from a general apathy towards the issue to more targeted moral oppositions towards PrEP and homosexuality. Some community members do not care about the issue because they do not see it as affecting them personally; they do not think HIV is a big issue and therefore do not see the need for PrEP; or they may believe that there is a better use for funds than supporting PrEP. In addition, some community members feel that HIV is a result of bad choices and that people deserve it. Finally, other community members see PrEP will perpetuate risky sexual behaviors or condone behaviors that they are morally opposed to.
3. **Stigma:** Stigma and fear of stigmatization prevent both homosexuality, HIV, and PrEP from being discussed. Stigma surrounding homosexuality and HIV exists in the African American community. This prevents PrEP from being discussed and has contributed to it not being made a priority in Milwaukee. People within the African American community may be afraid to publicly show their support for PrEP because, by doing so, their sexual orientation would be called into question. Among members of the AAMSM population, there is a fear that by taking PrEP they could potentially be outed or people would assume that they have HIV. There is also stigma that taking PrEP means you participate in risky behavior and might be labeled a whore.

“I have 5,000 Twitter followers. Anytime I post something about anything going on in central city I get a few hundred responses. If I post something about the LGBT community it’s like crickets, they’re worried they’ll be viewed in a certain way, like they’re gay. In the very beginning when I posted things, I had people ask me what my sexual orientation was. People talk about stigma, there’s stigma even if you spread information, they’ll question your own sexual orientation.”

“...being ‘out’ if they are in the closet with their families, the stigma of maybe somebody thinking they are HIV positive if they are taking these meds.”
4. Knowledge/ Awareness of PrEP & HIV: There is not enough knowledge or awareness about PrEP or the HIV incidence and prevalence rates in Milwaukee to make supporting PrEP a priority. Knowledge and awareness about PrEP is limited to people working in HIV prevention; people outside the field have little to no awareness. Misconceptions about HIV and PrEP are widespread and the community needs more education about both to better understand what it is and how it works.

“I’ve seen within the HIV/ medical community a great priority but not within the greater community... It’s not something I’ve seen on bus stops or out in the world, unless I’m not looking and missing it. But it doesn’t impact them so there are other bigger fires for political people.”

“For people who aren’t in the field, HIV isn’t on your radar.”

“I think first of all a lot of the general population doesn’t even know about it. It’s not a matter of not being supportive.”

“There’s just not enough conversation about it and talk about it, education about it. It’s not something you see actively talked about. You just really don’t see a lot of information. It’s just not something you see coming across as a way to prevent and then it’s just not a conversation.”

“It probably gives them a false sense of confidence that it protects them from other STIs.”
5. **Logistical Barriers:** Successfully getting and keeping individuals on PrEP is difficult due to numerous logistical barriers. Getting on PrEP and staying on PrEP requires regular doctor visits for blood tests and getting the prescription refilled (every three months). For individuals who are not already in the healthcare system, getting, keeping, and securing transportation to multiple appointments can be difficult. PrEP can be very expensive and while there are insurance programs available to help make PrEP affordable, they are not advertised by Gilead. If people are not aware of these programs, the high cost of PrEP could be deterrent. For people who are aware of these programs, the task of gathering and filling out the necessary paperwork could be a deterrent. Support is needed to get people on PrEP and help them stay compliant.

6. **Leadership & Outreach:** Milwaukee leadership is not talking about PrEP and there are no effective outreach campaigns promoting PrEP. Not enough outreach is being done to increase knowledge and awareness about PrEP or raise its visibility. While there have been a few community meetings about PrEP, they had limited success because people still left confused. When addressing the target population it is important that the messaging is tailored to them, avoids jargon, and includes speakers and leaders who are
representative of the population. Leadership that could have an impact is not involved and elected officials do not advocate for PrEP or HIV/STI prevention programs. People are not advocating for sexual health or safe sex in general in Milwaukee and the little information about PrEP that is available is not Milwaukee specific.

“I see things from community groups but nothing from the Milwaukee leadership. There is no HIV champion that I’m aware of. No newspaper person or someone financially supporting our efforts.”

“[The meeting] wasn’t as effective as it might have been. It was possible that the materials were not adjusted to the education level of the attendees... The presentation I would just say it was geared toward other medical professionals.”

“The people delivering the information don’t really reflect the population that they are speaking to... It could be more effective if delivered by someone from the same demographic.”

“From my alderman to my local assemblyman to the mayor to my congressman, I’ve not heard any feedback to anything relating to STD programs treatment. None whatsoever.”

“As long as the mayor has been here, I have never seen him advocate for PrEP or other issues like this. It’s not part of his policy... the biggest advocates pushing for this awareness are those who cater to the projected, positive population. It’s not a part of our local officials’ efforts.”

“It’s funny, because Chicago has a website, an organization that sends out information on PrEP. Milwaukee doesn’t have anything like this. Only thing I know is because of D&R. I got into the forums, and I have had flyers from them. I can’t really go to real articles, if I searched for Milwaukee and PrEP I’d have a hard time.”
Recommendations

Based on the results of the scoring process and the thematic analysis, there are a number of strategies and activities that could be beneficial in improving the support for the use of PrEP as a prevention tool for sexually active AAMSM in Milwaukee. These recommendation are divided into two broad categories, increasing the knowledge of the AAMSM community and increasing the knowledge of the general community. The following recommendations should be approached with culturally appropriate interventions that recognize the effects of stigma, homophobia, minority stress, and internalized mistrust that exist in the community. These social determinants of health are at the core of this issue and contribute to the barriers listed above.

A. Increase the knowledge of the AAMSM community. To do this we recommend the following actions:

1. Recruit a group of existing opinion leaders within the AAMSM community, some of whom may be on PrEP, to be advocates for this issue within their community.
   - These advocates will perform outreach and assist in increasing the sense of community among AAMSM.
   - Plan activities and events at which these advocates can interact with the AAMSM community in a safe and comfortable space.
2. Provide ongoing education to the AAMSM community on STIs, HIV/AIDS, and PrEP, emphasizing how HIV/AIDS and STIs affect the whole community and are not just an individual issue.
   - Provide information and resources to existing and established unrelated small groups that AAMSM may belong to.
3. Develop clear and consistent guidelines and standardized information on PrEP, how to get on PrEP, and how and where to access PrEP that is specific to Milwaukee.
   - Create fact sheet with information about what PrEP is and how it works for the AAMSM community.
   - Distribute and share this information with organizations in Milwaukee and utilize online outreach to access individuals who may be excluded from traditional outreach methods.
   - Create an online presence about PrEP in Milwaukee.

B. Increase the knowledge of the general community. To do this we recommend the following actions:
1. Conduct individual outreach and one-on-one meetings with community and religious leaders in an effort to educate them on the issue.
   - Stress why is this is an important issue to the whole community and not just an issue for African Americans or MSM.
   - Explain how larger systemic community issues can impact an individual’s health, including HIV status, and that it therefore should not be looked at in isolation nor through a lens of fault and blame.
2. Visit existing and unrelated groups in an effort to increase awareness about STIs and HIV/AIDS in Milwaukee and increase knowledge about PrEP.
   - Emphasize how STIs and HIV/AIDS affect the whole community and are not just an individual issue or an MSM issue.
   - Focus on PrEP as a prevention tool for anyone who is at risk (ex. discordant couples or heterosexual men or women who do not regularly use condoms during sex with partners of unknown HIV status), not one that is just for AAMSM.
   - Highlight how there are no down sides to improving sexual health knowledge and how more open dialogue about sexual health will benefit everyone in the community.
3. Create a PrEP Fact Sheet with Guidelines for medical providers and the general public.
   - Include information regarding the issue of internalized mistrust of the medical community and stigma in an effort to improve cultural competence.
   - Disseminate the Fact Sheet to primary care providers and the larger Milwaukee medical community, focusing on those who are not already working in HIV prevention.
   - If deemed useful, provider trainings can be offered in addition to fact sheet distribution.
4. Provide cultural competency trainings to medical professionals, community and religious leaders, and elected officials.

This report was written by Diverse & Resilient staff and consultants, including Erika Christenson, MPH Candidate, Zilber School of Public Health; Dan Ruge, MA; and Nicole Fumo, MPH.