Attitudes and Awareness Regarding HIV Testing in Vermont: An Examination of Focus Group and Dyadic Interview Feedback

Prepared for the Vermont Department of Health

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Abstract

Each year, 18,000 Americans perish from AIDS, or acquired immune deficiency syndrome. Of the one million Americans infected with the human immunodeficiency virus (HIV), 20% are unaware they harbor it. Media messaging is one tool employed by health professionals worldwide to address the importance of being tested. The Vermont Department of Health (VDH), following the recommendation of the Centers for Disease Control, encourages all sexually active Vermonters to be tested for HIV. This paper expresses salient themes resulting from focus group and dyadic interview sessions with key informants in Vermont, and compares these results with existing literature concerning previous HIV and health campaigns as well as theories of health behavior and persuasion. We draw conclusions about the most efficacious strategy for developing and deploying media messaging in Vermont.

Introduction

According to the Vermont Department of Health (VDH), there are up to 660 HIV-infected Vermonters (Vermont Department of Health, 2004). At an estimated cost of $360,000 per patient, lifetime care for these individuals could add up to nearly $240 million. For comparison, consider that Vermont’s median household annual income is $50,619 (Kaiser Family Foundation, 2011), and the state’s total yearly healthcare expenditure is approximately $4 billion (Vermont Health Care for All, 2009). Clearly, for both quality-of-life and financial reasons, early detection of the virus is critical.

With around 35 free testing centers in Vermont, distance and cost are not major obstacles to testing. Of these, 24 provide anonymous testing; the remaining 10 provide confidential testing. “Anonymous” testing means that a patient’s name is not linked to a medical file or insurance. Rapid testing produces results in about 20 minutes, but results are considered preliminary only. The oral swab test is available, although blood tests are considered more accurate. Should an individual test positive for the virus, it is illegal for the person’s insurance company to drop coverage; and if the individual does not have health insurance, treatment costs are covered by the state (H. Hauser, personal communication, October 28, 2011).

Even though the CDC recommends that getting an HIV test should be as routine as a cholesterol screening, only about 45% of Americans have been tested (Maugh, 2010), and this includes cases wherein the patient has not specifically requested an HIV test, such as blood donation or pregnancy. In 2009, the Vermont Department of Health and the Vermont HIV/AIDS Community Planning Group conducted a statewide needs assessment. This report concluded the following: many Vermonters are unaware that testing is free in the state; they may have access to medical care but do not seek testing because they do not identify themselves as part of a group at risk for infection; they identify themselves as members of high-risk groups, but avoid testing due to concerns regarding stigmatization; they are under the care of a doctor who does not routinely discuss or offer HIV testing; they lack access to health care (Vermont HIV Prevention, 2010).

The Vermont Department of Health (VDH) therefore seeks to develop messaging to convince different groups of Vermonters to obtain HIV testing, either for free through a testing center or through their insurance with their regular doctor. These groups include: the general Vermont population; men aged 13-24 who have sex with men (MSM); and women aged 13-24 who have sex with men.

A review of relevant literature was conducted to establish a baseline of possible issues. A summary is below.

*Literature Review Results*

Following is a list of important issues regarding individuals’ decisions to get or avoid HIV testing. All items are numbered to permit easy comparison with focus group results.

1. Stigma is a major consideration for people who suspect they may be HIV-positive. Despite the health risks of having HIV and not being treated, stigma can be a strong enough force to prevent people from seeking the test (Gilbert & Walker, 2010; Valdiserri, Holtgrave, & West, 1999). Yet there is also evidence that if the HIV test is part of a suite of tests, testing rates go up even when people claim not to fear stigmatization (Young & Bendavid, 2010).
2. Anonymity is important across all age groups, and, when compared with confidentiality, is likely a factor in boosting testing rates (Valdiserri, Holtgrave, & West, 1999) and so promoting anonymity in testing is recommended (Noar, Palmgreen, Chabot, Dobransky, & Zimmerman, 2009). However, if confidentiality is the best patient protection available, then emphasizing the idea that no one knows but you and your health practitioner is still helpful (Cheng, Savageau, Sattler, & DeWitt, 1993).
3. Adolescents are concerned about whom they test with, with more than half opting to be tested by someone other than their regular physician (Cheng, Savageau, Sattler, & DeWitt, 1993; Rawitscher, Saitz, & Friedman, 1995).
4. Across all age groups, testing levels increase, along with conversation and care, when a physician initiates the conversation (Samet, Winter, Grant & Hingson, 1997); and when testing is presented as routine (Mimiaga et al., 2008). Acceptance rates are higher with physicians than with other health practitioners, and increasingly, doctors are more likely to discuss HIV testing with their patients (Valdiserri, Holtgrave, & West, 1999). When the test requires patients to reveal details regarding their sexuality, refusal rates rise (Irwin, Valdiserri & Holmberg, 1996).
5. Patients did not express a concern about venipuncture (Irwin, Valdiserri, & Holmberg, 1996) so if the oral swab test is not available, a blood test does not seem to be a deterrent, although both rapid testing (with results following in under an hour) and oral swab testing could lead to an increase in tests (Valdiserri, Holtgrave, & West, 1999).
6. There are few straightforward predictors of who will and will not be open to testing, no matter what the risk level is. In general, MSM who are connected to a solid network of advocacy and social contacts test more, as do pregnant women (Irwin, Valdiserri, & Holmberg, 1996). However, some high-risk patients do not wish to know their status (Kellerman et al., 2002). Paradoxically, better therapies may be affecting both the decision to test in a positive way (because of raised efficacy) and a negative way (by lessening a patient’s worry) (Irwin, Valdiserri, & Holmberg, 1996).

*Recommendations*

Based on the literature review, below is a collection of best practices regarding both general health campaigns, and HIV testing-specific ones.

1. To ensure the highest possibility for success, health campaigns should be theory-based and should include formative research, focus groups, interviews, and qualitative and quantitative data; and should use control groups and measure results (Noar, 2006; Noar, Palmgreen, Chabot, Dobransky, & Zimmerman, 2009; Myhre & Flora, 2000).
2. Combining theories of behavior change and information processing provides the highest chance for success (Cappella, 2006).
3. While some academics argue for theoretical purity, others acknowledge the overlapping nature of health theories and advocate for an integrated approach (Devos-Comby & Salovey, 2002; Noar & Zimmerman, 2005).
4. Most of the papers located for this review agreed that the mass media are an effective way of motivating health behavior change (Griffith et al, 1995; McOwan, Gilleece, Chislett & Mandalia, 2002; Ross & Scott, 1992). However, other researchers caution that mass media campaigns are but a good start (Anderson, Ostergaard, Moller & Olesen, 2001) or should have goals more modest than full-on behavior change (Myhre & Flora, 2000); and, a minority have doubts that media campaigns work at all, at least in the case of anti-smoking efforts (Flay, 1987).
5. While campaigns in general relied on many media forms, there is evidence that radio, and TV in particular, were the most effective formats for health messaging (Ross & Scott, 1992) and there is a solid case to be made that they can be relied upon exclusively (Noar, 2006). TV has a greater impact than print advertising or posters (Ross & Scott, 1992), and TV and radio are more effective than print (Noar, 2006). These findings must be carefully weighed in light of the evolving media-scape in which the worldwide web is increasingly being used for information and entertainment.
6. Media campaigns work to alter health behaviors and, even without support such as doctors initiating the testing conversation, or social marketing approaches, mass media alone can have an effect (Noar, 2006) but once media campaigns end, their effects are short-lived (Ross & Scott, 1992). Some research has found that reading has a more impactful effect than passive media consumption (Brinol & Petty, 2006), but this can be creatively addressed in a website.
7. The two primary triggers that convince youth to be tested are a doctor’s recommendation, and symptoms (Futterman et al. 2001).
8. In website messaging, the use of social norms can help visitors combat perceived norms (Noar, Clark, Cole, & Lustria, 2006).
9. The Internet may reach MSM better than traditional media (Bull, McFarlane & King, 2001), and the traditional media can be used to bring people to websites (Noar, 2006). Sites should also be tailored to particular groups in particular states of awareness or change (Noar, Clark, Cole & Lustria, 2006).
10. General knowledge is not enough to change behavior (Myhre & Flora, 2000; Sherr, 1987) but specific knowledge targeted to narrow groups can be helpful (McOwan, Gilleece, Chislett & Mandalia, 2002). Specific appeals targeted to narrow groups can be effective as well (Slater, 2006).
11. Branded messaging works better than generic messaging (Agha, 2003).
12. Fear-based messaging, combined with efficacy appeals, can be very effective (Dillard, Plotnick, Godbold, Freimuth, & Edgar, 1996; Witte, 1992).
13. Ad messaging should appeal to people on an emotional level, and not primarily an informational or logical one (MacKenzie, Lutz & Belch, 1986; Batra & Ray, 1986).
14. Kellerman et al. (2002) provide support for efficacy, but demonstrate that efficacy is a concept that should be handled with care. For instance, while the researchers found that the fear of testing positive was a testing deterrent, they speculate that the availability of relatively recent therapies may have lowered this barrier. On the other hand, messaging must take care not to make HIV seem inconsequential in the face of these new therapies, either (Kellerman et al., 2002).
15. Another tenet of social cognitive theory, the concept of building social support for behavior change, is limited by the length and placement frequency of advertisements as well as the fact that health campaigns do not generally have the money to compete on an even basis with spots for consumer products such as cars or personal products (Slater, 2006).
16. Choosing pronouns can make a significant difference, a position supported by the Elaboration Likelihood Model in its focus on messaging having personal relevance (Slater, 2006), and so simply changing a noun such as “people” to the pronoun, “you” has the power of increasing people’s perceptions of message self-relevance (Brinol & Petty, 2006).
17. Personalization of messaging is closely related to messaging directed to “you”. For instance, testimonial-style spots by people directly involved with HIV somehow (whether from a healthcare provider or patient perspective) may be effective (Freimuth, Hammond, Edgar & Monahan, 1990).
18. In the visual media, employing peer images can help people identify more closely with the message (McOwan, Gilleece, Chislett & Mandalia, 2002).

*Research Questions*

RQ1: What themes will arise through focus group and dyadic interviews that correlate with the existing literature?

RQ2: What themes will arise that do not correlate with the existing literature?

RQ3: What messaging strategies will be suggested by focus group and interview respondents?

Focus Group and Dyadic Interview Feedback

A review of relevant literature provides a strong foundation for an approach, but focus group and interview data of a qualitative nature help form important correlations. Therefore, we conducted sessions in order to probe issues brought up in the literature review—such as stigma, cost issues and level of knowledge--as well as other points of interest, including participants’ choices of web search terms (Figure 1), local or regional differences, media choices (Figure 2), and so on. Focus groups have been held in various settings (classroom, place of business, community room) and have comprised from four to 11 individuals per group. Interviews have involved key informants who fall into the following groups: clinicians, HIV/AIDS activists, social workers, people living with HIV, and public health officials. So far, we have conducted five focus groups (with a minimum of four more planned) and seven interviews (with a minimum of five more planned). Our research has been approved by the Institutional Review Board of Northern Arizona University.

The numbers in the following section correspond to the numbers in the previous one. By matching numbers, the reader can compare literature review findings with focus group/interview findings. So, for instance, number 1 below is a response on number 1 in the previous section. In the cases where no corresponding number is provided, there was no focus group/ interview information generated.

1. Across all ages, genders and orientations, stigma was a significant issue and it expressed itself in ways both obvious and subtle. One focus group respondent reported,

*Once you go and you do (test), you find out that you test positive. It’s documented down. Granted, it’s supposed to be private. But, it’s still the fear of it being in writing out there and there is going to be the medical field that will have access to that.*

Stigma is a many-branched tree. Respondents noted several other stigmas:

* The act of walking into a clinic and the potential of being seen.
* The disclosure of information to a doctor or health practitioner.
* In the case of a positive test, disclosing information to friends and family.
* Having an HIV-positive status would have an effect on friendships, spouses, and potential sexual partners.

2., 3. While it is important to note that some individuals preferred to visit their own doctor for a test, the majority expressed that they would prefer to go to a health center where they did not know their practitioner.

*If I'm going to be the one to initiate it, I'd like that level of anonymity. Going somewhere where I don’t know them, I’ve never seen them before, they’ve never seen me, you know, I don’t know if you have to write your name down or anything like that … But if I were to do it, I’d want that you don’t know me, I don’t know you.*

4. Focus group members stated that if the conversation were started by their physician, in an entirely neutral fashion (that is, without hinting at issues of orientation, drug use or sexual habits), then they would be very likely to get an HIV test.

*I think it’s almost more convincing if I was in a physical and a doctor said “you know you should really get tested for HIV, you’re 25 years old, you’re at a high risk age and you’ve never been tested, it’s part of your insurance. You should consider doing this. It can’t hurt, it can only help you.” And I think I’d be much more comfortable already being at the doctor’s office than taking the step to go and making a day trip out of going to get tested for HIV.*

The other issue, however, is that often physicians do not start the conversation at all. Two respondents reported asking their physician for a test and being told they did not need it. A registered nurse reported,

*Providers are not thinking about HIV by and large. There are lots of blood draws for Chlamydia and Gonorrhea but not HIV, which is a complete no-no according to the U.S. Preventative Services Task Force, part of the Agency of Health and Human Services. Every time blood is tested for an STD, it should be tested for HIV as well.*

5. Respondents expressed an overall preference for the oral swab versus the blood test, which was inconsistent with literature review research.

*My biggest phobia in the world is needles. So, I know there’s a lot of people in my family that have the same phobia, so um, if you could tell somebody that they were in and out, I mean yeah I have my shots when I go get my physical every year or two, you know, get blood drawn, but if it was simply that easy to be in and out 20 minutes cotton swab, or even something I could take myself at home and mail it in or something like that, oh yeah, I’d be all over that opposed to the needle.*

6. Focus group research showed that age was the most significant factor in people’s openness to the idea of being tested. In general, people in their late teens and early twenties expressed relatively little concern over testing. People in their late 20’s to late 40’s expressed mild to significant reluctance regarding testing, particularly because of fear of having other people know they were getting tested. The statistically insignificant exception to this involved two MSM in their 40’s who, consistent with the literature, considered testing to be an important, non-stigmatic action.

 Also, whereas the literature review showed that high-risk individuals were likely in many cases to avoid testing, focus group respondents mentioned that, even though they do not consider themselves in a high-risk category, they, too, would be reluctant to be tested out of fear of a positive test. Two quotes follow: *“I feel like if I was in that situation, I’d be pretty intimidated with what they are going to come back with.” “Do I really want to know the answer? Sometimes, ignorance is bliss, you know. Not knowing, exactly.”*

10. Respondents look to mass media—whether in the form of advertisement messaging, statements from public figures (such as Magic Johnson) or news stories—to improve and guide their knowledge of issues. Many expressed general disappointment with media or the government for failing to publicize HIV-related issues more effectively.

*Um, I think cancer is the new sexy disease. Back in the 90’s and 80’s it was Magic Johnson, “Philadelphia”, HIV was out there. Everyone talked about it, everyone knew about it. Everyone protected themselves from it. And then it all comes back to, and I hate to relate this, but a “South Park” episode I saw, where Cartman was like trying to get free flights and he said he had HIV and the stewardess was like no, no one has HIV anymore, they have cancer, cancer is the new disease. So like the awareness, the people doing campaigns and stuff, it’s not out there for HIV … they don’t talk about it in the media, they don’t talk about it on TV, movies, all that stuff anymore it’s all about—everyone has cancer. So, you know I think that’s you know sort of a big thing about, it’s almost like dumbing yourself down to admit that you have HIV. Like Hey I got HIV, and like really you didn’t protect yourself? You didn’t take precautions? So I think that’s another thing, the people don't put it out there, so if it is a state or federal thing, saying hey we do these programs and … you know, put it out there, don’t make it this unknown.*

11. In terms of traditional media, respondents reported that TV was the most common medium for receiving messages (Figure 2). In one group of younger respondents (aged 22-32), magazines and newspapers were slightly more popular than TV. However, all groups, involving a range of ages from 19 to 70, reported that the medium they spent the most time engaged with on a weekly basis is the Internet. This includes watching traditional TV programs on sites such as Hulu. Broadcast radio may indeed be a proven medium for the delivery of convincing health messages, but in terms of usage, it ranked either lowest or close to the lowest in terms of weekly engagement. However, this fact is balanced by the existence of “sliver populations” in Vermont including those who are illiterate and therefore incapable of conducting a web search (D. Kutzco, personal communication, December 20, 2011). Further, many areas in Vermont do not have high-speed Internet service.

12. Respondents agree that mass media—even in the absence of social marketing techniques or doctors taking a more active stance regarding testing—can be persuasive. One respondent said,

*I think if tomorrow, they were to put it in the Free Press, big front page article, by the way, HIV testing is free and coverage and bills and things like that are free in the state of Vermont, people would get tested like crazy.*

13. Respondents agreed that if their doctor urged them to get tested in a matter-of-fact way, their only concern would be cost; otherwise, testing would not be an issue.

14. As noted previously, the potential embarrassment of asking one’s doctor for a test, or of being seen by an acquaintance in a testing center, seemed to be an issue that increased with the age of the respondents. The Theory of Planned Behavior holds that beliefs about norms, as well as intentions, attitude and control can serve as a predictor of willingness to test (Ajzen, 1991). Therefore, it seems logical to consider the use of a website (as well as advertising messages) to normalize the behavior of testing.

15. Traditional advertising has proven effective in driving traffic to websites. Focus group respondents reported heavy use of both television and the Internet. This suggests a two-pronged approach whereby colorful, emotionally appealing messages bring people to websites where different, more targeted messaging works to further persuade people to be tested.

16. We found support for the idea that specific information targeted to defined groups can be powerful. Focus groups were presented with the following scenario: considering that it can take 15 years for HIV to turn into AIDS, during which time a person may remain asymptomatic, this means that a person may be 35 and married for many years and still possibly experience full-blown AIDS. Respondents in all cases found this surprising, interesting, and a cause for testing.

17. The question of the effectiveness of fear-based messaging drew varied responses, with more people than not saying that fear was an inappropriate tactic. *“When you frighten people about HIV, you make people who have HIV frightening”* said one interview subject. However, it is noteworthy that in all cases, respondents were not discussing a fear/efficacy mix but rather an appeal based on fear alone, which has been a common public health approach. A youth sex education counselor said that fear was the most effective way to impress upon young people the seriousness of HIV. One participant offered an important piece of support for the use of a fear/efficacy mix. Referring to AIDS videos he saw as a schoolchild, he said,

*The videos tried to scare you away from participating in any behavior that could potentially put you at risk, but what they should be doing instead of that is recognizing that these behaviors exist so how do, you know, lessen your risk?*

19. Ad messages that appeal on an emotional level have been shown to be more effective than information-based appeals. However, there are two important points to be made. One, this does not preclude the inclusion of important information in messages, particularly since there is so much information that is relevant in the case of HIV testing, including: free, accessible and anonymous testing; the availability of the oral swab test; quick test results; financial help; and more. So, appeals can be created which are thematically consistent with important information. And two, surprise was one of the emotional appeals proven to be effective. In this case, some of the information goes beyond being merely helpful; for instance, the idea that in the United States, one might take advantage of free healthcare regarding an expensive disease is novel, indeed.

21. Especially given respondents’ media habits in a fractured media-scape, it is expensive to build into 15, 30 or 60-second ads the idea of social support for behavior change. The worldwide web is the place where respondents spend most of their media time, and it is the primary place they go to for health information. Therefore, as noted in #14, a website can theoretically provide the sort of normative social support that creates behavior change.

22.-24. Making HIV testing relevant to every sexually active individual is not an easy task. However, focus group members said that they react in positive ways to information relevant to them. Additionally, they displayed a diversity of attitudes toward testing. So, a potentially promising approach would be to create somewhat personalized website paths for people to follow, using information relevant to particular groups, and using language relevant to the particular health stage they are currently in, which conforms to the Transtheoretical Model (Diclemente et al., 1991). For reasons of norming, among others, the use of peer images and/or testimonials should be strongly considered.

*Other Considerations*

 The focus groups and interview subjects brought up other important points as well, several of which either did not appear in the literature located for this review, or were mentioned only peripherally. Many of these comments correlate with the Vermont Department of Health’s own research (mentioned on page one of this document). These comments are below.

*Money*

 Money was a significant concern for focus group members, including co-pays, insurance rates, waiting periods between coverage, additional tests, time, deductibles and other cost-related issues. Below are several illuminating quotes.

* *I go to the doctor; that costs money; I take the test, that costs money; finding out from my insurance what do you guys cover for HIV testing and coverage and then them saying we cover this, three months later, oh we can no longer cover you. Um, I think there's a huge, huge fear factor with insurances dropping people these days, that they’re not, I'm not going to be able to afford my payments anyways, and now you guys are going to drop me, so now I really can’t afford them.*
* *I mean like yeah I could go to a free clinic and there’s a chance I’d test positive; where do I go from there? Who’s going to pay for you know however many prescriptions I need on a daily basis? Where do I go to get help for those? Um, you know I think that’s big.*
* *Health insurance is too complicated. I’ll tell you that. I mean it’s like, they say they come with this, they say they come with that, you get a bill in the mail, and you are like what the hell.*
* *Something that they (the medical community) could have done in one visit they strung out like across a bunch of visits, so it’s like she kept getting bills and bills and bills, and it’s like you know, you are paying these co-pays and it’s like you might as well pay for the whole thing one time, instead of paying for health insurance for the full year, you know. What is the point?*
* *“I didn’t even know that you could do it free, without health insurance or anything. Like someone who doesn’t know that and doesn’t have health insurance, it’s like there’s no way that they would go get tested.”*

*Lack of Knowledge*

A related issue is lack of knowledge regarding HIV. For instance, people generally regard it as a virus that will eventually kill the infected person. This is not the case, although at this point, HIV patients do need to be on medication for life.

*I mean there are ways that people live with it. Right? I mean I’m pretty sure I’ve heard of, besides Magic Johnson, there are a lot of people who survive. This is a big one that needs to be broken down. Some people don’t know that. They are afraid that finding out may be the end of their life.*

Respondents were unaware of the availability of instant testing, which provides preliminary results in around a half-hour. Referring to an assumed waiting time of a couple of weeks, one focus group member said, *“The time it takes for the results to come back on top of that test, too, I mean, you are sitting there waiting, thinking and your life is flashing before you.”*

It is important to note, however, that, while instant testing results in no false negatives, there is a false positive rate of 50% (D. Kutzco, personal communication, December 20, 2011). Several people, upon hearing this, said that they would rather wait two weeks for a verified result.

People were unaware that it is illegal for an insurance company to drop coverage based on a positive HIV diagnosis, and they did not know that in Vermont, inability to pay for HIV treatment is not a barrier to care. While each case is negotiated individually, up to 100% coverage is available.

*I know for me, I check my bank account ten times a day because I'm living to the penny, and ninety percent of the words that come out of my mouth revolve around money and like spending money, making money, bills that I have to pay, student loans, and everything, so I think if I were to talk to my friends, my personal group of friends, if I lead with “hey we should do this together, its free.” Everyone would be like, ooh, free? Yeah, I would definitely just start with free.*

Focus group respondents agreed with the following statement by one of their fellow members.

*I think it might have been like two weeks ago like down on Church Street, I think it was. It was one side of the street, and they had a sign that said like “free HIV testing today.” To me, that meant today it’s free. If the way that it’s been advertised, like I've lived here for like almost 10 years now and I’ve seen signs like that before, but to me it’s like, OK, today it’s free. During this time frame, during this window. So in my head, it’s like, oh it’s going to be busy; oh it’s going to be packed. Like when they do like blood drives, it’s really busy, but you can go donate blood anytime you want. But I feel like I didn’t know it was free all the time.*

*Other*

One focus group discussed the difference between men’s health and women’s health, mentioning that there is no gynecologist for males, that is, a practitioner whose main job is to discuss sexual health with men. The conversation spread into the idea that gender classes in college are about women. And this led to a conversation of gender roles, as explained below.

*We as men aren’t supposed to go to the doctor, because we’re not supposed to get sick, but we’re supposed to have a ton of sexual partners and you know, be out there every weekend hitting up a new girl. Um, but, it’s that whole stigma of having to go to the doctor’s to do what I need to do and then get out of there. You don’t think to ask these questions, you don’t think to do anything, because I'm a guy, I'm not supposed to. Um so, I think that’s what needs to change as well, how do we educate men to be comfortable doing it and how do we then put it out there to men to get tested and this and that, that you know, it’s not just women … it’s you’re a guy, it doesn’t matter, go get tested.*

A focus group member asserted that, unless there is something specifically wrong, there is little reason to be tested.

 *And it’s not something you think about unless there’s an actual problem attached to that. Or like, or if you did something really, really stupid and you need to correct it. But like unless you, like have a conscious idea that there’s an issue here, like most people aren’t going to just go get tested or even ask about where to go get tested, just because of that stigma.*

Comparing an HIV test to publicity surrounding the HPV shot, one respondent offered the following.

*I remember in high school everyone was like “oh I got the shot, oh I got it” like it’s common. So if they make it common for everyone, I feel like it would be a lot easier and people wouldn’t be so freaked or ask about it.*

The idea of milestones was introduced in this way: *“Maybe even getting tested, like as a couple or something, like if you’re dating somebody it would make sense, even if before you start dating.”* This comment correlates with research regarding Cognitive Dissonance Theory (Chiou & Wan, 2007).

Several group members discussed the importance of norming the behavior.

* *I don’t think I would want to be, it’s already scary enough, I don’t need to be scared into doing it. Like I think it just needs to be integrated into society as no big deal, you know, not “oh this is like this really scary thing that I have to get done.” That’s totally not going to work.*
* *If you even say, oh, I’m going to get tested; do you want to come with me? So, not making it about them, but saying, “Oh well I’m doing this and I’m, I might be at very low risk, but it might be a good idea for you to just come with me.*

The following comments are from an HIV-positive male: *“I’m healthier now than before. I eat better, I’ve lost weight; I’m more attentive to my health.” “Find out so that you can take the preventative steps so you don’t have to take the drugs because once you start, you have to keep taking the drugs. So, put off taking the drugs as long as possible.”*

The following comments are from people who are either clinicians or work in public health.

* *Men don’t generally get it from women; women get it from men. So, gear ads to women in the older heterosexual category …. Of older people who are diagnosed, I believe most are women.*
* *If you come in 15 years later, we can make you better, but we can’t make you well.*
* *HIV is now considered a chronic, not deadly, disease with a nearly normal life expectancy.*
* *Community centers can help ease nervousness. It’s important to meet people where they live.*
* *Anonymity means the test results are not linked to a name, medical file or insurance.*
* *Anonymity is very important in Vermont*
* *If we treat you when you’re pregnant, you don’t have an infected baby.*
* *We can keep you having a normal life if you come in early enough …The amount of money, stress and illness that could be avoided is horrifying.*
* *A major barrier is physicians.*
* *If a person has current insurance, it is illegal for that insurance to drop them. It must be covered under their current insurance. If the person does NOT have insurance, they would fit under a "pre-existing condition" clause. There is a one year waiting period, at which time the insurance has to pick them up. During that period of time, VMAP would cover all drugs necessary, although doctor’s visits and lab (costs) may potentially fall to the individual.*
* *Any sexual contact outside of a monogamous, tested relationship is basis for testing.*
* *Eight percent of positives in the last year were immediately given AIDS diagnoses.*

*Campaign Ideas*

Focus groups were asked in both roundabout and straightforward ways about how to use the media to convince people to be tested, and what to avoid saying as well. Below are selected quotes.

* *I think that the key, I mean, even for a guy, if you can go in there like when you’re boys and be like, yeah, let’s do this together. You just have to look at it like let’s grow old together, you know, let’s see what each other looks like. I'd like to see as many of those days as I can before my time’s up.*
* *Chances are, you’re not HIV-positive. Find out for sure. Isn’t it better to know for sure? Your odds are excellent. One hundred Vermonters don’t know. You want to know if you’re one of them.*
* *I think that people like nowadays can see right through that (scare tactics) and they identify more with like humor. So if you could kind of, even though it’s not a funny situation, like there has to be a way you can kind of make people laugh and feel ok about it.*
* *I feel like we should go for more like a knowledge-is-power message than like a “you’ll-be- healthier” message. ‘Cause the reason you are healthier is because you know and like whether you know either way, you’re going to be healthier by knowing.*
* *I have a friend and somehow we got into a conversation about, he got tested, it was for a different STD or something, but he said when he walked out of the clinic, he had a negative result, or whatever, and he said that was such a weight off his shoulders.*
* *I think that a lot of people right now view testing as something you have to do, versus being a proactive thing that you should be doing. You know, it is something that you should do; getting tested is something that you should do because it is good for your health.*
* *If you get tested and you test negative, and you are healthy, you are on your step. And, if you have HIV then you have things you have to do to; you know you have to get on a regimen. So either way, getting tested leads to a healthier life.*
* *Everyone has 15 minutes, it doesn’t matter how busy you are, you have 15 minutes to take a test that will affect you for the rest of your life.*
* *Make the resources more visible. So, there aren’t necessarily an actual lack of resources, but I think that a lot of people think that there are, so if you let people know that they can go to Fletcher Allen here or wherever, whether it is an online database of here are 50 places that you can go for an HIV test, within 10 miles, or whatever it is, I think making people understand that it is a lot easier than they think it is.*
* *For me if would be like if I had a lingering doubt, it wouldn’t be like oh, like I have to call my insurance company and make sure they cover it, and I have to make an appointment, you know if you go to a walk-in clinic and they are like, oh you’d like an HIV test, do you have insurance, and like you know, will the insurance cover it, or you don’t, okay, here you go. Like let’s just do this and make sure that you are all right.*
* *It doesn’t matter if you have it or you don’t, you still have to live life for what it is, so you might as well make sure that you are good to go, and if not, you can start getting treatment. It is not going to wait around for you.*
* *It’s like the HPV virus; it’s like, that was like thrown so much in our faces that everybody got the shots, you know, when you go to the doctors, they hand you pamphlets and it was just like, they made it so regular, so I don’t see why they couldn’t do the same thing with HIV.*

Discussion

The primary purpose of this document is to identify areas of agreement and disagreement between the literature from studies around the world, and the focus group/ interview research conducted locally. The points at which the information correlated provide an informed opportunity to create strategy and messaging. On the other hand, the focus groups and interview subjects introduced new thoughts into the conversation.

There are four main issues for VDH’s messaging to address: Stigma; a sense of vulnerability; information; and the process of normalizing behavior. These are, perhaps unsurprisingly, all related. In different proportions, all these issues are relevant to our target groups.

Stigma, as mentioned earlier, has many variations. However, what these variations share is the concept that HIV is an embarrassing virus to harbor because of assumptions regarding how one contracted it. While it is unreasonable to assume that a media campaign can change this perception, it is within the realm of possibility that a campaign can lessen stigma around the idea of being tested for HIV as part of a healthy lifestyle.

A chief way to do this is to use media messaging to promote novel information. People can be tested for free, near where they live or far away, with a practitioner they have never met, at a health center that is not HIV-specific, and anonymously. If they test positive, there are no financial barriers to full care, regardless of one’s financial or insurance status.

Information also works to raise individuals’ perceptions of their own vulnerability. In the MSM group, information will likely comprise most of the message. This information concerns the where, how and at what cost testing is available. In the group of young women who have sex with men, relevant information includes inducing a sense of vulnerability, and informing them that testing is available and anonymous. For the general population, clinical information on the virus is more important. Because HIV can be dormant for many years before turning into AIDS, individuals cannot assume that they are safe just because they have been in very few monogamous relationships in the last several years.

Given individuals’ concern over stigma, using a fear approach to induce a sense of vulnerability may be one of a very limited number of tools powerful enough to overcome the idea that ignorance is bliss.

Normalizing testing behavior is most simply done in the offices of primary care physicians. If physicians followed the CDC-recommended approach of offering testing to all sexually active patients, a media campaign would be mostly unneeded. Since this is not happening, then it is worth considering a messaging approach that involves and targets doctors as well as the general population. For instance, a doctor would say in an ad, “You should be tested, and I should be asking you. If I don’t, ask me.” From a norming perspective, two kinds of physicians would be called upon—unknown ones in great numbers; and known ones, such as VDH Commissioner Dr. Harry Chen and former governor and presidential candidate, Dr. Howard Dean. The primary philosophy behind the message would be to normalize the idea of being tested for patients, but the secondary one would be normalizing the idea of suggesting it for doctors.

It is difficult to generalize media choices because the media are always changing, because media are particular to locale, and because target groups partake of different media. So, while the two safest areas—and places to use most production resources—are TV and the Internet, we do not recommend limiting the messaging to these media.

We plan to use the GetTestedVermont.org . website as both an information and a messaging center. The web experience for visitors will be somewhat personalized by profile and perception of risk. So, a visitor can choose a web “path” based on gender, sexual orientation, age and relationship status. As the visitor works his or her way through the site, messages—both in print and multimedia form—speak to their risk factors. In the case of the least risk, the end message may be as simple as, “Next time you’re in for your checkup, get everything checked” accompanied by the abovementioned message from the doctor. In the case of a rural Vermonter without insurance who has not acknowledged his sexual orientation to friends or family, the message will be more urgent and the final piece will be information regarding the nearest free and anonymous testing center.

Nevertheless, we can presume that few people who do not feel themselves at risk will come upon the GetTestedVermont website. Further, it is not likely that people with slow Internet connections or who are illiterate will use the site. So, traditional media advertising will be needed to both induce a sense of vulnerability and to supply efficacy, and these messages must be stand-alone in the sense that they deliver the complete message without relying on a website to supply critical information.

*Limitations*

 While our focus groups have proven, in general, uncommonly communicative and insightful, and while we have benefited greatly from the educated, experienced and considered opinions of our key informants, our sample size is relatively small. Our focus group participants will not exceed 90 people when all research is completed. Further, we did not collect anything more than general demographic data, nor did we make more than general observations as to the age of certain respondents.

Conclusion

This document is useful in two ways. First, as mentioned above, there are several themes and approaches suggested by the literature and by our focus group and interview research. Second, we intend to use this document to address these issues in our ad message survey, which we will use to collect demographic data on, with luck, several hundred respondents.

In summary, the literature review research and our focus group/ key informant interview research leads to the following conclusions regarding the creation of ad messaging:

* The use of an integrated theory approach, using both behavior and persuasion theories. It will be important to not only get attention or to provoke intention, but to increase the rate of testing.
* Reliance on messaging via TV and the GetTestedVermont website, but with significant concessions made by media market, meaning that web banner ads, print, and radio will also be included.
* Branded messaging is likely important in order to maximize media dollars. The “brand” might simply be the Vermont Department of Health.
* The use of a fear-efficacy mix, aided by elements of other behavior theories. For instance, social norming is important, but so is stages-of-belief messaging. Fear is lever, but not an end in itself, and must be combined with efficacy, and in any case does not speak to all audiences.
* Messaging that both works directly to compel attitude change and also compels the audience to visit a website.
* A website option to click a link to make an appointment for a free test, or at least a utility to enable the site visitor to easily locate the nearest testing site.

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**Figure 1. This figure represents focus group members’ most likely Internet search terms if they sought information on HIV testing in Vermont.**

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**Figure 2. This figure represents group members’ media choices.**