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Risk & Representation: Framing HIV Now

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ABSTRACT The visual history of HIV is powerful and particular. From early on designers gave form to urgent messages and critical stances. In 2012, Truvada for pre-exposure prophylaxis (PrEP) was approved for use in the United States (US). Truvada is an antiretroviral therapy (ART) for HIV that when taken daily by people without HIV can reduce the chances of contracting the virus by more than 90%. The advent of PrEP has created a radically new landscape for people at risk of contracting HIV, as well as a fresh opportunity for redefining sexual health. This article calls for designers to be present and active in creating new visual representations of HIV and risk, and articulating what PrEP means socially. Specifically, the thoughtful use of forums that foster self-authorship, community-constructed meaning, and the distribution of diverse narratives can serve to amplify authentic representation and awareness.

KEYWORDS: HIV; PrEP; narrative; constructivist; self-authorship

The visual representation of HIV has undergone a radical transformation over the last 28 years (Figures 1–3). From blame and stigma to the framing of responsibility to intimacy and prevention, we have come so far in science, policy, and social understanding. At each stage designers have formed a visual narrative that has mirrored, articulated, and fueled the struggle and progress of understanding, changing the lives of people with HIV. An HIV diagnosis was a death sentence from 1981 until 1996, when effective antiretroviral therapy (ART) became available. Yet even with the medical advances that have made HIV a manageable disease, the social stigma of HIV infection has persisted. In 2012, Truvada for pre-exposure prophylaxis (PrEP) was approved for use in the United States (US). Truvada is a pill that when taken daily by people without HIV can reduce their chances of contracting the virus by more than 90% (Centers for Disease Control and Prevention 2017). The advent of PrEP offers the

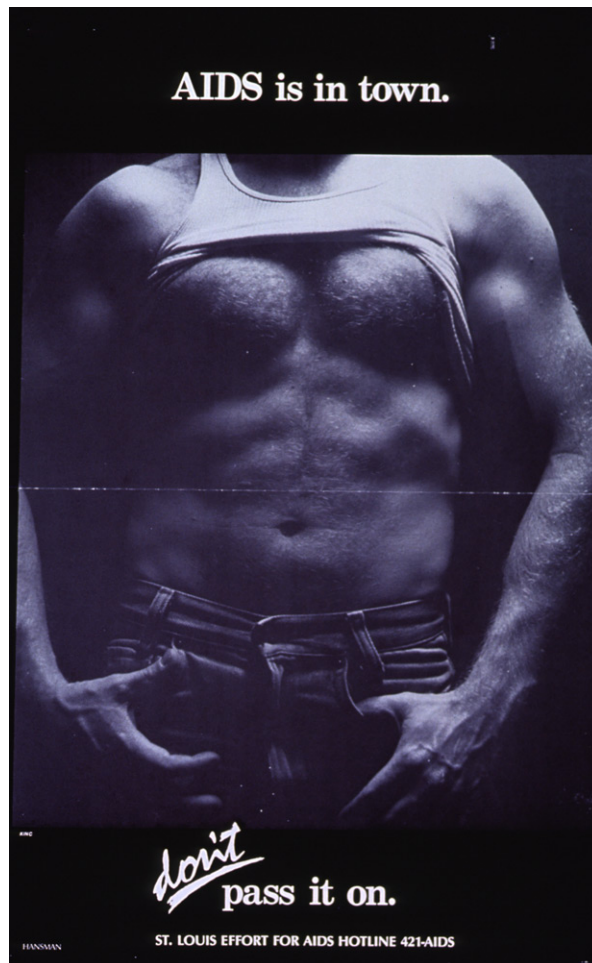


Figure 1

St Louis Effort for AIDS. *AIDS is in town: don't pass it on.* 1980s.



Figure 2

ACT UP. *The Government Has Blood on Its Hands*. 1988.

possibility of a radically new landscape in the form of HIV prevention and sexual health – and this new landscape calls for new visual representation.

Often the message in HIV imagery speaks to risk-taking in our most intimate settings. Deeply personal, such directives can disregard the nuances of our negotiations around freedom, sex, mortality, and fear. In any representation designers risk getting the story wrong. In the case of today's HIV epidemic, if designers alienate HIV-positive individuals or those at risk of contracting it then we risk deterring them from identifying with an intervention campaign. Failing to engage further marginalizes individuals and therefore allows the epidemic to continue. Specific narratives may miss their mark. Yet, if our fear of presenting a narrative that imperfectly describes someone

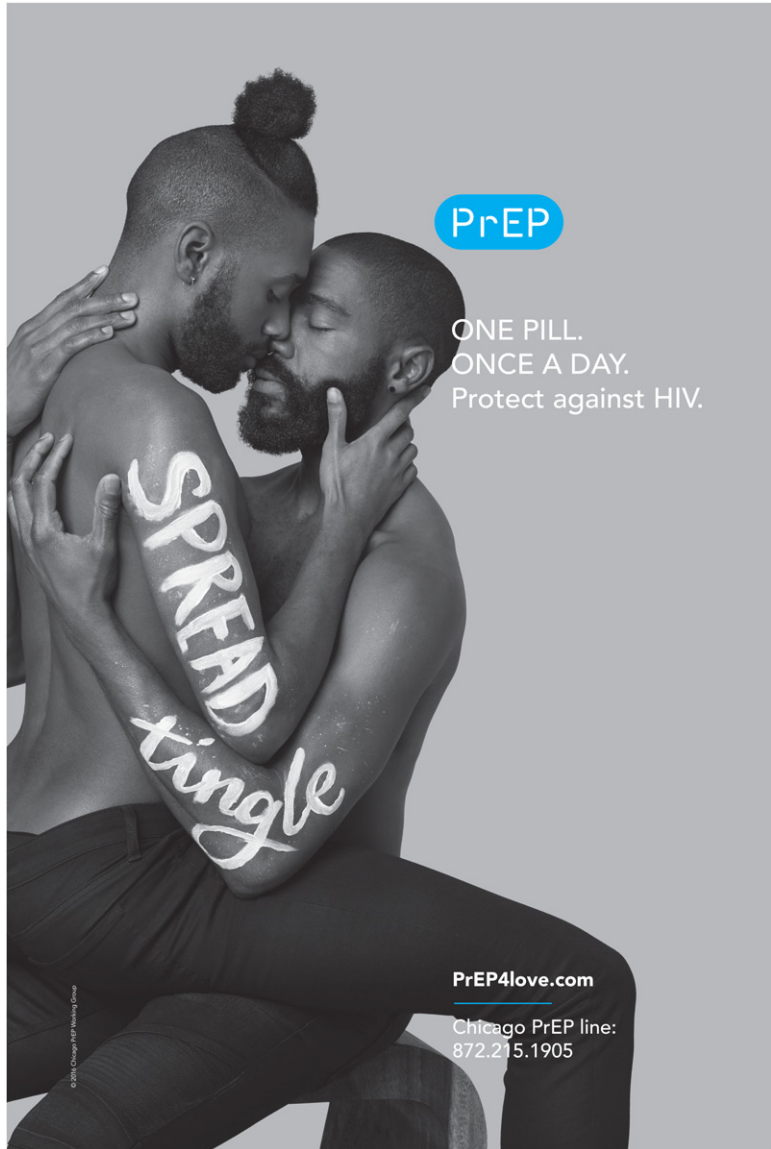
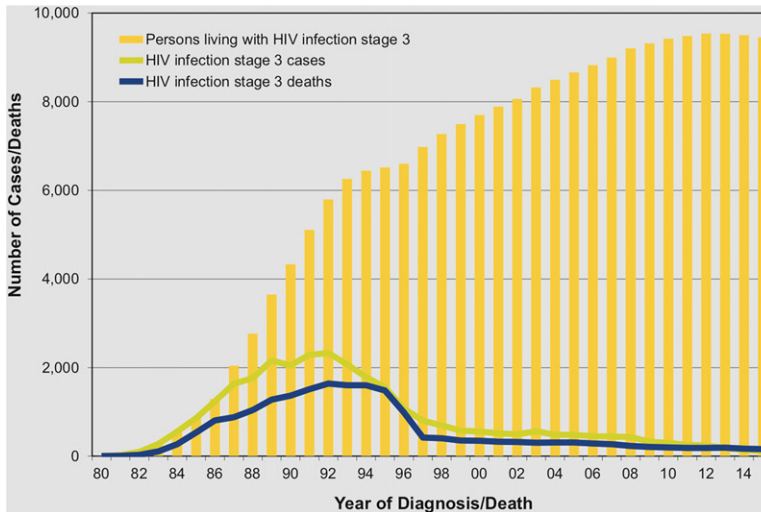


Figure 3

AIDS Foundation of Chicago. *PrEP4Love*. 2016.

drives us to avoid that narrative entirely, we risk making a message that is not really for anyone – and a character with no narrative touches no one. In our recent past, health messages have dictated meaning. A more potent design approach acknowledges self-authorship and is more interactive.

This article calls for designers to be present and active in creating new visual representations of HIV and risk, and articulating what PrEP means socially. Specifically, the thoughtful use of forums that foster self-authorship, community constructed meaning, and the

**Figure 4**

San Francisco Department of Public Health Epidemiology Report. 2012.

distribution of diverse narratives, can serve to amplify authentic representation and awareness.

Resistance to PrEP

Dramatic changes in both the HIV epidemic in the US and a revolution in how we communicate have occurred since the 1980s. A table from the San Francisco Department of Public Health HIV Epidemiology report in 2015 shows that both death from HIV-related disease (blue) and late-stage diagnoses (when patients arrive for care already very sick, green) peaked in 1992 (Figure 4). The co-evolution of social attitudes, knowledge, and representation, public policy and funding, and science and medicine that began in the 1980s has changed the face of HIV. We now find ourselves in the yellow part of the graph, with a large HIV-positive population and an even larger population of people at risk of contracting HIV. Individuals are being diagnosed earlier, living longer, and in need of lifelong treatment with ART. Living with, not dying from, HIV is now a normal state for many, due in large part to successful treatment. At this moment there is no cure, and the large yellow area of the graph has medicine focused on both treatment and preventing new infections. The design scaffolds that describe, build, reflect, and propose the meaning of PrEP are set to have an important impact on the next stage of how HIV is understood and navigated socially.

Despite its revolutionary possibilities, the uptake of PrEP has been slow and fiercely challenged by both private individuals and advocacy groups. This is in part a response to the controversy over the drug's social meaning. Regan Hofmann, the former editor-in-chief of *Poz*, a magazine for people living with HIV, called PrEP a “profit-driven sex

toy for rich Westerners” (Glazek 2013). Michael Weinstein, the CEO of the AIDS Healthcare Foundation (AHF), the largest AIDS service organization in the US, has also been a vocal critic. Although an outlier opinion within the medical and public health field, he has expressed concern over resistant viral strains coming from inconsistent use of the medication; risk compensation – a medical term describing a rise in risk-taking behavior because of a perceived protection – potentially leading to a rise in other sexually transmitted infections; the loss of decades of work that has gone into the normalization of condoms; and concerns around the cost of the medication for HIV-negative people. Weinstein has also objected to the funding that Gilead Sciences, who make Truvada (the pill being used for PrEP), has given to third parties in order to produce public service announcements about PrEP. Weinstein argues that funding an externally produced, government-supported project is less transparent than a traditional advertising campaign (AIDS Health Foundation 2016). On the other hand, numerous voices from within the medical and public health fields have denounced Weinstein’s views on PrEP as regressive.

Despite the concerns that have been raised, PrEP has increasingly been embraced by the public health community as a critical tool for preventing the spread of HIV. In the 2014 article “Sex without Fear,” *New York Magazine* writer Tim Murphy explains: “For the generation of gay men who came of age post-AIDS, anxiety has essentially preceded lust as a first response to thoughts of sex.” He quotes Sarit Golub, a Hunter College psychology professor who is leading a study at Callen-Lorde which indicates that half of gay men think of HIV all or most of the time during sex: “That, to me, is a psychological tragedy” (Murphy 2014). And yet so many people feel suspicious and judgmental of anyone willing to try this new prevention option. Gilead Sciences did not advertise the prevention tool directly for the first four years it was available for fear of the potential PR disaster, and has only recently begun to release advertising on social media sites and actively market it as a product (Lee 2017). Public health departments in major US cities are disseminating information about PrEP as they initiate their “getting to zero” campaigns, which are modeled on the Joint United Nations Programme on HIV/AIDS (UNAIDS) set of strategies to end new infections, but many people at risk of contracting HIV still do not know that PrEP is an option. Given all of this, designers have a clear opportunity to invite the public to reflect on the use of PrEP and co-navigate the social meaning of the therapy.

What would success in a project representing PrEP look like? Is it possible to enhance agency through the simple dissemination of information? Does success mean that more people are on PrEP? Dr Sean Haley, Ph.D., M.P.H., Assistant Professor of Public Health at the City University of New York, says success is simple: fewer infections. As with most public health challenges, no single solution to HIV transmission is effective (conversations with Sean Haley, 2016–17). The notion that PrEP could be the new condom, or could

work for everyone, is shortsighted. Our approach to ending HIV needs to be as diverse and responsive as the people at risk. PrEP is an important addition to a growing arsenal of measures that prevent transmission, and people deserve the chance to consider whether or not it may be effective for them. Of course, the way that PrEP looks in this moment will affect how many people consider trying it. Could design play a more central part in this reimagining by representing and creating platforms to invite meaning-making from diverse voices? Without an active attempt to shape the cultural meaning of PrEP, rumors, fear, and judgement can make a disproportionately high claim in the minds of potential users.

The User's Voice

The moralizing messages about PrEP echo the resistance to birth control pills of the 1960s, when people feared that oral contraceptives would promote promiscuity and saw – quite accurately – that they changed the power dynamics of intimacy and sex. Like PrEP, the pill offered a temporal separation between prevention and intimacy, allowing rational risk assessment to occur well before the unpredictability of passion. The pill originally came in a glass bottle like other pharmaceuticals, but engineer David Wagner made and patented a prototype that resembles the ubiquitous dial pack we know today, to make it easier for both he and his wife to keep track of whether or not her pills had been taken. Further iterations turned the now familiar dial pack into something that could be mistaken for a makeup case thrown casually into a purse. Because the pill was a prescription intended for healthy people, it needed to be packaged accordingly (Cherney 2017). Like PrEP, its place in our bags and minds required careful consideration. Concerns over the safety of the pill led to congressional hearings that famously invited only men to sit on the panel. Women demanded a voice in the hearings, arguing that the use of a new medication or treatment must be negotiated in a conversation with its users, a standard now enshrined in US Food and Drug Administration (FDA) policy.

PrEP currently comes in a standard pharmacy bottle, and ads and educational videos sometimes show people using seven-day pill planners to track doses. The problem is that this visual cue is often interpreted as indicating infirmity. Repackaging PrEP could change that and help to frame it as routine health maintenance. To best position a new idea for acceptance, it helps to make it look like an already accepted idea. Some have asked if we might piggyback on the hard-won normalization of the dial pack and sell Truvada for PrEP in round, foil pack compacts that look like birth control, rather than the standard plastic pharmacy bottles (Sobo 2013). Underlining historical similarities through visible measures could work in favor of destigmatizing the prophylactic: “The word is out, and the time for engaging in contentious theoretical debates is over. It’s time to roll up our sleeves and get our hands dirty. The question cannot any longer be *if* we



Figure 5
IDEO. *Nano*. 2016.

implement PrEP, but *how*” (Sobo 2013). Health workers, the media, and designers all have a role to place in answering this question.

Here is an example of the role that designers can play in HIV-related health management. In 2016, IDEO undertook a project for Gilead Sciences which opened up a dialog between HIV-positive patients and their doctors that emphasizes choice (Figure 5). Extensive interviews have revealed that people living with HIV do not feel that they have permission to bring up pill size – and it seems that physicians are not thinking about this when they write prescriptions (Frenz 2017). In response, IDEO designed a tray with a line of pills that made the evolving treatment options both visible and concrete. This design solution collapsed the spatially and temporally disparate steps of science developed in laboratories, read about in journals, prescribed by physicians, delivered by pharmacists, and taken by patients into a discrete doctor–patient interaction, literally putting conversations about daily health management on the table. An advertisement for a specific regimen risks isolating it as the only option, but a tool like this one enables patients to engage in frank discussions about their treatment options.

Tens of thousands of these trays have been produced and distributed to clinics: “I was in a center for homeless and transgender youth living with HIV last month and I nearly fell over when I saw the pill tray on their clinician’s desk,” wrote Caricia Catalani from IDEO in an email (2017). Clinicians have reported that the design has also resulted in greater patient adherence to treatment regimens (Frenz 2017). This is but one of many opportunities for design to frame narratives, enable conversations, and facilitate treatment options

through projects that generate exchange rather than dictating solutions.

Narrative, Learning, and Self-Determination

Designed narratives can help us to see, feel, and intuit parallels and alignments in ways that didactic teaching and physician recommendations cannot. A narrative allows us to grasp a model for thinking and feeling when the actual complexities of events can be too large to hold. Narratives can provide an alternative space in which to navigate the nuances of experience and beliefs:

literary texts can ... attempt to make sense of AIDS in a way that is not strictly scientific, theoretical, or rationalistic. The writing of literature, as a creative or imaginative endeavor, can inscribe what is often unwritable in more strictly organized and limited forms of discourse such as the medical text or the theoretical inquiry. In this way, literature provides a context in which one might attempt to read the illegible. (Piggford 2000, 179)

The visual nature of design, coupled with the current aspirational value of accessibility and inclusivity in much of design culture, also positions design to wield this abstract but powerful descriptive power. An image can sometimes encompass both historical and present momentum in a way that written language cannot. In the 1980s, the inversion of the Nazis' pink triangle and the development of the "Silence = Death" icon – conceived by five designers and given to the AIDS Coalition to Unleash Power (ACT UP) – galvanized political will, making a historical parallel to genocide and negligence. ACT UP printed the icon on shirts and buttons, branding and uniting the movement. This need to describe an unfamiliar landscape is present now as it was then. Through scientific inquiry we can reach forward to what we do not know. Through abstract representation we can build access to formerly unarticulated understanding. And through the language and dispersal methods of design we offer form and symbol to help users navigate their options.

When we talk about health and risk navigation, we are talking about decision-making. The role of the designer in health communication should not be that of the didact, but of the translator. Through translation, the designer can make the options and their significance accessible to the user. In opening conversations through juxtaposed pill sizes, or writing a new narrative for the social meaning of HIV through activism and image, the designer opens up opportunities for meaning-making both in and between users. Ideally the designer invites the users to think critically about their options by giving form and content as a provocation. Seeking answers together, through dialog rather than lecture or mandate, remains an effective and radical act more than two millennia after Socrates.

Consider the writings of Paulo Freire on education, and the notion that freedom and true learning comes from navigating toward one's own answers. Freire (2016, 79) argues that didactic teaching conceives of the student or user as an object rather than a living subject: "Liberating education consists in acts of cognition, not transfers of information." Freire's work is foundational in constructivist education, the model that positions students to construct knowledge and understanding through experience and reflection. If we draw a parallel with designers translating information and options, could we not also use what Freire calls "problem posing" – or, in the context of this article, provocative narratives that invite a response – in order to allow users to come to their own authentic conclusions?

Clearly, conclusions around sex, health, and risk can only be made by individuals. One approach to this mismatch between the public health need to address sexual behavior and our resistance to paternalism in such messages is self-authorship. Similar in motivation to Freire's description of liberating education, self-authorship allows the subject to write the truth of his or her own identity. In his book, *Exile & Pride: Disability, Queerness, and Liberation*, author Eli Clare writes about power, representation, and sexuality, describing the value of and need for both seeing one's sexual likeness in public images and, at times, having the chance to produce those images – to form a growing body of truer references. As Clare describes, there is a link between "the struggles for self-determination and for a self-defined, recognized sexuality" (Clare 1999, 122). In order to possess what he describes as self-determination – the right and power to direct our own lives – Clare argues that we need to both see legitimizing images that we identify with and have the platforms on which to author those images ourselves. Clare's point is that narratives which feel familiar, combined with opportunities to also create our own meaning, increase agency. In Clare's focus on the body and disability, he posits that describing oneself as "able" affects one's agency to direct one's own life. By analogy, describing our sexual identity as "intimate" rather than "risky" returns us to our central and rightful position in the sexual act – that of authoring our own identity. Golub, Operario, and Gorbach (2010) argue for an interdisciplinary lens for studying HIV prevention, specifically noting that a "preventionist identity" could form for people identifying with PrEP use. Clare refers to paintings, poetry, and billboards alike, but the reproducible, distributable nature of the things that designers make means a wider audience than other images – and the structure of exposure, whether large and public on a billboard, in the pill case in one's purse, or privately viewed by thousands in a sidebar screen next to ads for shoes, is particular to design in our own time. Designed platforms about sex and sexual health have the potential to deliver permission and encouragement for self-authorship through cues of belonging, inclusivity, and invitation. The design approach to discussing sex and risk should be a dual offering of both diverse images to reflect our

population and platforms that encourage individuals to describe how they themselves navigate sexuality and risk.

Making Collaborative Meaning

We rely on science and policy to recommend and innovate, but science relies on design to make innovations clear, accessible, and part of common language. Sex and health are at once common ground and deeply individualized. Design should both recognize and respond to this. The images and ideas in this section show attempts to do just this. They look to appeal to the intimate and the hidden, but in visible and widely disseminated formats. They deploy design principles like user ethnography, aesthetic parallels, and dense symbols in order to describe users and viewers as important and their histories, needs, and desires as valid and meaningful. Ideally, viewers will see enough of themselves in this work to engage in and, in some cases, contribute meaning to it, thus building both an individual platform and a shared understanding of HIV care and prevention. Visual language can navigate these subtleties and build a bridge between an individual's values and better health. Good design is obliged to create platforms through which sex and health can be navigated, articulated, and discovered on an individual's terms.

In 2012, David Duran wrote a controversial article for the *Huffington Post* entitled “Truvada Whores?” (Duran 2012). In it, he describes the same fears voiced by Weinstein of the AHF and others. Duran's title was appropriated by San Francisco-based AIDS activist Adam Zeboski, who started the #truvadawhore movement, selling T-shirts in Truvada blue with his hashtag across the front and encouraging people to post photos of themselves wearing them (Figure 6). These T-shirts marked their wearers as united in a visual backlash against the article's slut-shaming, as well as serving a larger purpose:

While reclaiming a disparaging term, the hashtag also creates a memorable and accessible route to get information about PrEP through social media and the Internet in general. It was never just about me. Anyone can use social media to share their opinions and experiences with PrEP by using the hashtag. The t-shirts often start a conversation that social media can finish by connecting people to reliable sources of information. (Zeboski 2014)

Duran went on to change his stance, and credits Zeboski and others with influencing his opinion (Duran 2014). One strand of meaning inspires or provokes another. Design reflects, records, participates in, and affects these steps of evolving meaning. Design in this case is the T-shirt, the color that references the pill itself, the website that enables the ease of production of custom-printed T-shirts, the social norm of such production, the visible dissemination of not only the T-shirts but also rapidly captured and shared images of people wearing



Figure 6

Adam Zeboski, from "I am a Truvada Whore," <http://myprepexperience.blogspot.com>. 2014.

them, and the scaffolded steps that link resonance and curiosity with experience and information. The historically important tool of appropriation, a simple design, and the growing arena of custom printing and publishing can together challenge and redistribute power from a published author to a large pool of respondents. As we articulate our beliefs and concretize them in visual terms, we find our own paths to meaning – and, in this case, to our self-authored definition of health.

Some messaging of course simply helps to spread the word that PrEP is even an option. But the messages that will be most accepted and effective are those in which not just the models but also the experiences and meanings are diverse, and which invite and support continued conversation. Consider the AIDS Foundation of Chicago's sex- (and love-) positive campaign PrEP4Love, which used social media to recruit real-life couples from around the city and photograph them in intimate embraces, with phrases such as "catch desire" painted on their bodies. The campaign's tagline – "Love is contractible. Lust is transmittable. Touch is contagious. Catch feelings, not HIV" – and the accompanying images depict intimacy in a respectful, appealing, and believable fashion. The campaign is powered by the AIDS Foundation of Chicago but produced through a

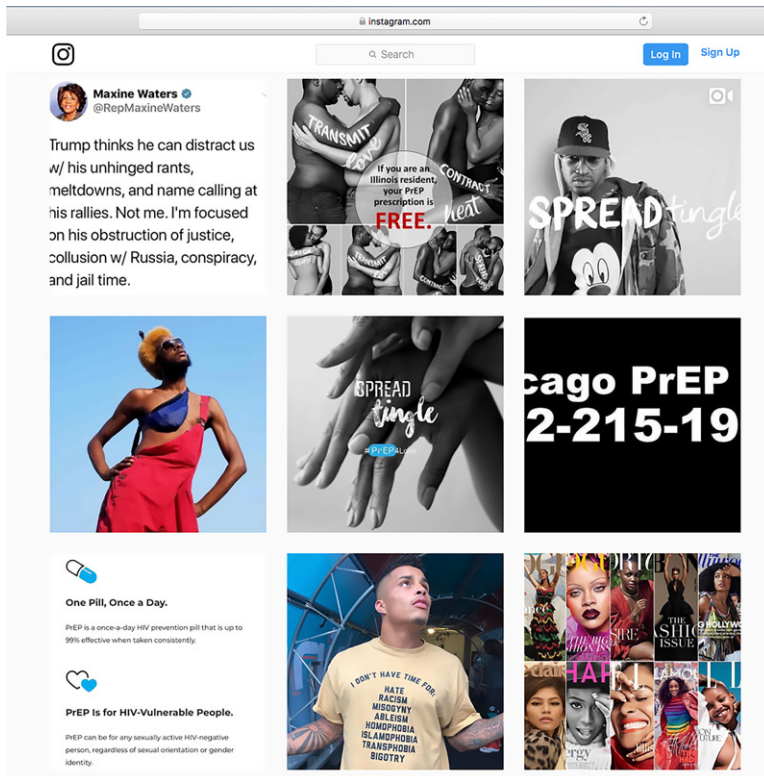



Figure 7
PrEP4Love.com Instagram. 2018.

collaboration of graphic designers, health professionals, and academic researchers, with support from seventeen other community partners. Design is almost always a multidirectional partnership involving clients, designers, and users; the challenge of describing HIV is no different. It is not the job of design to prescribe medication or plan responses to health crises; rather, it is the job of design to help to discover and make visible our options and values.

PrEP4Love's website does not include public comments, but it does take advantage of social media platforms to support continuing conversations. The Instagram link at the top of the page takes us to ever-changing, publicly posted images, where the entire conversation is had through photographs both directly from PrEP4Love and reposted by the campaign from other sites, with corresponding hashtags creating a curated, community-authored bulletin board (Figure 7). There has already been an important shift from top-down public health message publication to self-publishing platforms.

Examples of self-authored platforms are abundant. For instance, <http://myprepexperience.blogspot.com> – also managed by PrEP4Love – offers an invitation to viewers to articulate their reflections on sex, sexuality, and risk in an unedited and protected space.

YouTube Search



AIDS
AIDS, byname of acquired immunodeficiency syndrome, transmissible disease of the immune system caused by the human immunodeficiency virus (HIV). HIV is a lentivirus (literally meaning "slow virus"; a member of the retrovirus family) that slowly attacks and destroys the immune system, the body's defense against infection...
[Encyclopedia Britannica](#)

I Like To Party
59,637 views 100 likes 46 comments SHARE ...

Public Health Solutions
Published on Nov 4, 2015 **SUBSCRIBE 71**

Category: **Nonprofits & Activism**

103 Comments SORT BY

- JordanJamesX** 2 years ago
the commercial also seems to advocate using crystal meth the line when I like to party is often used by gay men in seek of drugs. wrong message going on here.
4 likes 1 reply **View 9 replies**
- JordanJamesX** 2 years ago
I heard this medication is not a cure.
2 likes 1 reply **View 3 replies**
- JordanJamesX** 2 years ago
I do not understand the anti condom vibe by some guys on this thread. if you want to stay safe use a condom! condoms protect you from many sexually transmitted diseases. please use condoms do not listen to this commercial. talk to your doctor.
1 like 1 reply
- mechalp** 2 years ago
That choice of spokes model though...
8 likes 1 reply **View reply**
- Ben A** 2 years ago
This is basically the fagwhore equivalent of a tic-tac commercial. They come in wintergreen and blue raspberry.
4 likes 1 reply **View reply**
- Aaron Hudson** 2 years ago
If you stop the video at the two second mark you can clearly see that its pills he has in the plastic baggie not crystal meth.
3 likes 1 reply **View reply**
- MrBennyDiction** 2 years ago
ohhhhh god. why 'I like to party'... why selling prep with euphemisms for meth
3 likes 1 reply

Figure 8
Public Health Solutions, <http://healthsolutions.org>. *I Like to Party*. YouTube. 2016.

In a review of studies assessing the effectiveness of social media sites addressing HIV, Gunther Eysenbach found that “seven studies including adolescents noted that social media platforms such as SMS text message and Facebook allowed them to communicate about topics they felt uncomfortable discussing in-person, such as condom use and HIV testing” (Eysenbach 2015). The option of anonymity supports our ability to reveal our sexual selves publicly. Some of this work will remain in the purview of community outreach and healthcare, but the role of artists and designers to produce and distribute images and interfaces that invite individuals to identify with and articulate meaning for themselves remains important.

Take, for example, the Public Health Solution YouTube series *Time to Prep*, produced in and focused on residents of New York City. The videos present a handful of scenarios, including a young man on his way to a club, two men who meet on an app, and a series of couples in committed relationships, all discussing the meaning of PrEP in their lives. Via the layout of YouTube, the videos are followed by comments that become a kind of community dialog. One video, entitled “I Like to Party,” inspired ire for its permissive implications in both its plot and its title (Figure 8). The responses range from fearful slut-shaming to anti-moralistic realism to the celebration of the potential personal liberation offered by PrEP.

As designers we can take note of this format, which incorporates the user ethnography we are trained in but does not close the dialog of meaning at production. The product is not simply the video but the coupling of the video with the conversation. This kind of thinking should be part of how we design for health. The IDEO pill tray is a highly designed, static object, but its true function is in the conversations that it makes possible. The simple narrative of pill evolution is only the beginning.

Conclusion

Effectively using political will, resources, and long-term public health planning to fight HIV, with PrEP as one of many available tools, is the responsibility of public health professionals and doctors. But designers can and should play a central role in democratizing our social understanding at the intersection of sex, HIV, and risk. PrEP is a tool that can reduce infection rates; therefore, we should create campaigns and objects that open up and extend opportunities to construct meaning. It is not only description but also the user-populated platforms’ offer of agency and discovery that invites self-authorship and brings us closer to self-determination. By initiating conversations as in the case of the IDEO pill tray, or instigating responses as in Public Health Solutions’ “I Like to Party” video on YouTube, design positions the individual as someone with valid questions, comments, and beliefs.

The balance between a strong, consistent narrative and the flexibility of interactive, self-authored forums is an important trend in

contemporary design generally. As we see adaptable design taking hold, users are demanding both recognition and agency to influence the evolving shape of products and platforms. The rise of proposal-based, open-ended, speculative design reveals a desire to pose provocations and put evolving meaning into the hands of users. As designers seek to enable the most powerful and enduring solutions to the crises of our time, including and beyond the HIV epidemic – such as resource inequality, the coexistence of heterogeneous populations, migration, and climate change – we may begin to recognize that one of our greatest resources is understanding how our individual narratives are woven into the diversity of experiences of others.

Disclosure Statement

No potential conflict of interest was reported by the authors.

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