

# **The Big Disease with the Little Name**

Retelling the Story of HIV and AIDS in an Evolving New Media Landscape

By Maria Yala

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## CREATIVE COMMONS

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## ABSTRACT

Stories shape our social reality. This research explores new ways of storytelling around the topic of HIV and AIDS by using augmented reality (AR) and electronic literature to experiment with the meaning, structure, and form that a story can take. Employing a mixed methodological approach that combines Research through Design, Transmedia Storytelling and Critical Design methodologies, this thesis unpacks the potential of digital technologies in retelling and revisioning the story of HIV and AIDS as a way to give voice to stories that are often left unheard. *AR Disclosures* is an interactive documentary installation that tells stories about HIV in the form of augmented reality latrinalia. *Once Upon A Virus* is an interactive dystopian fantasy that subverts fairy-tale motifs in order to explore themes of inequality in relation to the AIDS epidemic. These two exploratory prototypes aim to propose new ways in which storytellers might leverage evolving new media technologies and experimental storytelling techniques to tell the story of HIV and AIDS to a new audience, while contributing to a developing definition of what the practice of storytelling is and looks like today.

**Keywords:** electronic literature, interactive fiction, storytelling, HIV, AIDS, hypertext fiction, digital storytelling, narrative, critical design, research through design, activism, social impact, net-art, graffiti, transmedia storytelling

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# **1. INTRODUCTION**

## **1.1 MILES TO GO**

HIV is “the mysterious disease that arrived on the planet’s doorstep in the 80s and quickly invaded the most intimate compulsions, addictions and desires of the human race” (Kult Magazine).

### **1.1.1 Fake News, Stigma, and Discrimination**

Philosopher George Santayana once said that “Those who cannot remember the past are condemned to repeat it” (Santayana 284). When it comes to disease and society’s treatment of the sick, it can sometimes seem like we will never learn, and that history will keep repeating itself. In the wake of the 1980s AIDS epidemic, sociologist Philip Strong in his 1990 seminal paper on “epidemic psychology”, wrote that “a major outbreak of novel, fatal epidemic disease can quickly be followed both by plagues of fear, panic, suspicion and stigma; and by mass outbreaks of moral controversy” noting that “most epidemics, going back to the medieval plagues, exhibit a similar pattern” (Strong 249, Malik). Historically there have been a number of diseases that are not only noteworthy for their contribution to mortality worldwide, and their devastating impacts on civilization, but also for the social stigma attached to them (Davtyan et al. 1).

Early sociologists such as Erving Goffman defined stigma as a deeply discrediting attribute that precludes an individual from social acceptance, reducing the whole individual to a tainted and discounted one (Goffman 11-12). In the context of HIV and AIDS, stigmatized people have included sex workers, gay men and other men who have



sex with men, people who inject drugs, transgender people, prisoners and migrants (“Global AIDS 2018” 7). To be stigmatized is to exist apart from society’s anticipations in a state where an individual is treated as not quite human and is subjected to various kinds of discrimination by those whom society considers “normal” (Goffman 15). According to Goffman, the three distinct kinds of stigma are:

First the abominations of the body in the form of physical deformities; Then blemishes on individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs and dishonesty. These are inferred from a known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behavior. Last is tribal stigma of race, nation and religion, which can be transmitted through lineages to equally contaminate all members of a family. (15)

A pattern in social attitudes towards disease often resulting in “isolation and ostracism, physical violence, and diminished quality of life” can be seen in reactions to diseases from the plague, to leprosy, to cholera and to recent epidemics like HIV/AIDS, Ebola Virus Disease (EVD) and the current coronavirus (1). The coronavirus outbreak that began in Wuhan, China not only indicates how globalization favors the fast spread of disease, but also how it allows for the spread of fear, misinformation, and blame (“The Guardian”). Misinformation often creates stereotypes that perpetuate “old racist tropes about disease and hygiene” as in the case of “many of the offending coronavirus posts in recent weeks that have confidently connected the virus to Chinese people’s purported appetite for bat, which has been labeled disgusting, dangerous, and something people don’t eat ‘in the normal world’” (“The Guardian”, Cummins).

There is a long history of scapegoating and stigmatizing migrants and minorities as carriers of disease and thus the link between the treatment of immigrants and of suspected epidemic cases is not coincidental (Malik). Attitudes quickly take on a

“xenophobic bent” where some newspapers have referred to the coronavirus as “Chinese virus” in the same manner that HIV was once known as the “gay plague” (Kwai). Similarly, in the case of EVD, “African immigrants experienced stigma in the same vein as communities stigmatized by the AIDS epidemic in the ‘80s” (University of Cincinnati). Roger Keil, a professor of environmental studies, when reflecting on the lack of a racial or ethnic backlash for diseases that originate in North America or the UK, says that “only some outbreaks are racialized” (qtd. in Cummins). “Viral diseases don’t have ethnic, racial or national characteristics” Tim Soutphommasane, a professor at the University of Sydney notes (qtd. in Kwai).

HIV is a disease that has not only been racialized but also has been moralized. In 1987, a Gallup poll found that 43% of Americans believed that “AIDS is a punishment for the decline in moral standards” (“HIV/AIDS”). The occurrence of the disease was linked to the idea of punishment and was explained using illogical secular and religious prejudices that unjustly blamed people and jeopardized compassionate care for the sick for reasons such as homosexuality to adultery (Kopelman 231-232). In dominant social and scientific discourses, HIV infection was related to “risk behaviors” believed to index “perverse intimacies” of sex and drug use (Geary 2). Rather than employ a causal concept of responsibility, the “punishment theory of disease” that stated that being bad or doing bad would cause disease or cause another to fall ill, employed a moral concept of blame or responsibility (Kopelman 233).

Whenever a new disease emerges, “some gaps in our knowledge are inevitable” leading to fear, a primal emotion which can be a rational reaction to the possibility of infection (“The Guardian”, Ofri). It is the irrational fears, the ones that are “not necessarily allayed by data” that are troubling because “unfortunately, groundless fears

have never prevented unfounded hostile and discriminatory public attitudes” (Ofri, Wainberg and Lever). The danger of these irrational views is that they have the power to influence policies and cost lives (Kopelman 231). Not only do these stigmatizing attitudes and behaviors devastate familial, social, and economic infrastructures, but they have created barriers to access of prevention and treatment, manifesting in the avoidance of healthcare, reduced adherence to antiretroviral medications, and the emergence of mental health pathologies (Davtyan et al. 2).

“Racism feeds on fear and anxiety” says Soutphommanase, and as public anxiety spreads so does stereotypically racist misinformation, making it even more difficult to decouple disease from its point of origin. (qtd. in Kwai, Cummins). Of the coronavirus, Keil says that “with this new virus, something was triggered that is always latently there, under the surface, which is this fear of the other and the idea that bad things come from elsewhere” (qtd. in Cummins).

Gunilla Carlsson, UNAIDS Executive Director, writes that the “HIV epidemic has put a spotlight on the many fault lines in society”, an idea echoed by Keil and Soutphommanase’s sentiments on how racism feeds on social anxieties (“Global AIDS update 2019” 2). Carlsson adds that “where there are inequalities, power imbalances, violence, marginalization, taboos, and stigma and discrimination, HIV takes hold” (2). Louisa Ortiz-Fonseca, Advocate for Youth’s director of LGBT Initiatives says that, “HIV is an epidemic that’s driven by classism and racism in terms of infrastructure that prevents access to healthcare” (qtd. in Scaccia). The AIDS epidemic is boosted and structured then “not by the deviant behaviors or relations that people engage in, but by the unequal and violent conditions in which they are forced to live and that are embodied as ill-health and vulnerability to disease” (Geary 2).

### **1.1.2 A Prevention Crisis**

HIV (human immunodeficiency virus) is a virus that attacks the cells that help the body fight infection, making a person more vulnerable to other infections and diseases. It is spread by contact with certain bodily fluids of a person with HIV, most commonly during unprotected sex (sex without a condom or HIV medicine to prevent or treat HIV), or through sharing injection drug equipment. If left untreated, HIV can lead to the disease AIDS (acquired immunodeficiency syndrome). The human body can't get rid of HIV and no effective HIV cure exists. So, once you have HIV, you have it for life. (HIV.gov)

Thirty-nine years later, the disease which was first identified in 1981 and considered to be “the cause of one of humanity’s deadliest and most persistent epidemics” is no longer shrouded in mystery but is still surrounded by a lot of “stigma and discrimination which still has terrible consequences” (HIV.gov, UNAIDS 7). Since the beginning of the epidemic, 75 million people have been infected with the HIV virus and about 32 million people have died of HIV with over 37.9 million people living with HIV and in 2018, 770 000 people died of HIV-related illnesses (WHO).

Michel Sidibé, the 2018 UNAIDS Executive Director, wrote of a “prevention crisis” in the fight against HIV/AIDS stating that AIDS related deaths weren’t falling fast enough, funding was decreasing, there was a shortage of health-care workers, and in some countries the number of new HIV infections was rising (“Global AIDS update 2018” 6).

### **1.1.3 My Motivation**

In 2017 I found myself arguing with my 21-year-old cousin over whether HIV could be spread through bananas. At the time there was a viral post online from “CNNNews, a website designed to look like CNN” that ran a story with the headline “HIV Virus’ Detected in Walmart Bananas After 10 Year Old Boy Contracts The Virus” (“Fake”). Although the story was false, a lot of people still shared the post on their social media. It was disappointing that in 2017, articles debunking HIV myths like this were still being written.

From my conversations with my cousin, I realized that there was still a lot of misinformation when it comes to HIV particularly among the Millennials (23-36) and Gen Z (18-22). A majority of new HIV diagnoses are attributed to young people and “surveys show that there is a trend of general confusion and insufficient knowledge of HIV and its transmission, along with the existence of high-risk sexual practices, poor disease management, and stigmatizing behaviors among young adults” (Merck).

As a young Black, Kenyan woman who identifies as a feminist, I found the statistics that “over 6000 adolescent girls and young women become infected with HIV every week” to be very upsetting (“Global AIDS update 2019” 2). “Young women, who make up 67% of new HIV infections are twice as likely to acquire HIV as young men” and those aged 15-24 are particularly vulnerable (“Young”).

This incident with my cousin got me thinking about the types of stories we tell about HIV and AIDS. I found that most of the stories about HIV in the mainstream media have traditionally been cautionary tales of gloom and doom, or ones that are heavily sensationalized. Of late HIV seems to have fallen of the radar.

As a storyteller and a person who uses art and fiction to understand the world around me, the story of HIV is one that I have always been interested in. As a person who is not living with HIV but has lost family and friends to the disease, I believe that HIV is everyone’s problem. Kofi Annan, when addressing a special session of the United Nations in 2001 once said, “We cannot deal with AIDS...by making out it is their fault...Let no one imagine that we can protect ourselves by building barriers between them and us. For in the ruthless world of AIDS, there is no us and them.”

#### **1.1.4 Research Question**

The main research question addressed by this thesis is: In what ways might storytellers leverage new media technologies to retell and revision the story of HIV and AIDS for a new audience?

The objective of this thesis is:

- To explore stories in today's evolving storytelling landscape
- To adapt activist and feminist unconventional storytelling practices to new mediums in the context of the AIDS epidemic
- To investigate the best ways to select appropriate tools and technologies to tell stories
- To experiment with the meaning, structure, and form of a story

#### **1.1.5 Scope & Limitations**

The main challenge of taking on storytelling and the AIDS epidemic is scope. Therefore, this thesis concerns itself mainly with the exploration of new storytelling formats around the topic of HIV and AIDS. I recognize that I will not be able to represent all voices, nor will the depictions in my work speak for everyone. My aim is simply to add to the existing conversation around the disease in the spirit of HIV and AIDS activism. At this stage of the project, I do not have direct access to the HIV community and reaching out to the community at this point was beyond the scope of my thesis. The outcomes of my thesis are informed by the existing canon of AIDS literature and artwork ranging from work from people living with HIV today, writings of those who died from AIDS-related illnesses, people working in the field, and facts and figures from non-governmental organizations.

### **1.1.6 Outline**

Chapter 2 of this thesis document features a literature review around the idea of storytelling and marginalized people. It is organized in subsections that explore the notions of power, stereotypes, counternarratives, fantasy, and literary subversion in relation to the reclamation of stories. In Chapter 3, I present a selection of projects that work to reanimate the discussion around social issues in the context of creating new vocabularies, generating living narratives, and providing room for cultural augmentation. In Chapter 4, I describe my mixed methodological approach which draws upon techniques from Critical Design, Research through Design, and Transmedia Storytelling, concluding the section with a discussion of my creative process and the interdisciplinary methods that are a part of it. In Chapter 5, I present the final work of this thesis: *AR Disclosures* and *Once Upon A Virus*. In Chapter 6, I reflect on the making process, the discoveries made, and the outcomes this thesis project. Chapter 7 concludes with a summary of the entire thesis process and its results, followed by a presentation of what future iterations of the project might look like. This section also includes a reflection and review of the research question and the challenges and successes of the project.

## **2. LITERATURE REVIEW**

The storytelling prototypes, *AR Disclosures* and *Once Upon A Virus*, are shaped around the idea of the use of story by marginalized people as a tool to reclaim and rewrite their own narratives. This section of the literature review considers the role that stories play in our society and the techniques that minority groups use to tell and subvert stories, concluding with a description of how these ideas informed the development of this thesis.

### **2.1 STORYTELLING AND THE MARGINALIZED**

#### **2.1.1 The Role of Stories**

As far back as anyone can remember, people have told stories to each other; and as far back as memory goes, people have told and listened to stories (Rollins 164). This act of telling and listening is one of the many ways that we as human beings make sense of our existence. Stories become a means to communicate our understanding to others, allowing us to share our experiences and feelings, to teach, to learn, to speculate and to ask questions. This inherently multifunctional nature of narratives makes stories worth so much more than their literary value. Consequently, they can be used by anyone for almost any purpose good or bad; “Its very diversity and universality guarantees its use and abuse” (Rosen 229).

This dual nature can be seen in cases of stories used for propaganda or for the perpetuation of fake news. In the case of the AIDS crisis, stories have been used in various forms as a tool to fight, to draw attention, to shock into action, to heal, and to create a sense of community, giving people a chance to fight using their own voices. At the height of the epidemic, those who were affected by the HIV were continually stigmatized using



stories based on old and new myths and urban legends about the origin and spread of the disease, creating a dangerous storyline about those who were ill.

### **2.1.2 The Single Story**

In her TED Global 2009 talk “The Danger of a Single Story”, Chimamanda Adichie warns that the single story creates stereotypes, and “the problem with stereotypes is not that they are untrue, but that they are incomplete; they make one story become the only story” (Adichie). The permeation of dangerous storylines could lead to the spread of dangerous ideas, which continues the spread of misinformation, which in turn means that those people living with HIV or AIDS remain stigmatized, and those without access to proper facts and figures about the disease, remain vulnerable and misinformed, and society endangered. Noted psychologist, Jerome Bruner, in his book *Acts of Meaning* argued that “an endangered society is one whose members can no longer change the stories they tell about themselves” (qtd. in Galavotti et al. 25).

Stories have the power to shape our world view. We carry a script in our heads based on the stories we hear. This script, built on past encounters with different stories, is how we decide who the good and bad guys are. The worthy and unworthy. Critical race theorist Richard Delgado explains that the more we are exposed to one kind of story, the harder it becomes to recognize the stereotypes, likening the effect to that of wearing eyeglasses for a long time to the point where they become invisible on one’s face (Delgado 2413). Delgado writes that we use these stories to scan and interpret the world, constructing a social reality that helps us decide what is, and almost simultaneously, what should be (2415).

Within our social reality, there exist divergent narratives that create a kind of war between the “dominant” and “minority” stories we hear. The dominant story belongs to what Delgado calls an “ingroup” and minority stories belong to an “outgroup”. According to Delgado, the ingroup, the dominant societal group, creates its own stories to remind itself of its identity in relation to outgroups, providing a form of shared reality where its own superior position is seen as natural (Delgado 2412). The outgroup, the group whose marginality defines the boundaries of the mainstream, whose voice and perspective has been suppressed, devalued and abnormalized, also creates its own stories as a kind of counter-reality to the ingroup reality (2412). Outgroups can internalize the images that society thrusts upon them which Adichie explains as the creation of the single story. She writes, “That is how to create a single story, show a people as one thing, as only one thing, over and over again, and that is what they become” (Adichie). Counterstories thus act as a form of self-preservation, offering the outgroup the chance to get acquainted with the facts of their own historic oppression, not to deepen the despair of the oppressed but as a form of therapy through storytelling that can lead to liberation and better mental health (Delgado 2437).

### **2.1.3 Counterstories as a reclamation of power**

Author Salman Rushdie once said, “Those who do not have power over the story that dominates their lives, the power to re-tell it, re-think it, deconstruct it, joke about it and change it as times change – truly are powerless because they cannot think new thoughts” (“Excerpts”). The ability to “retell” (complicate the original by adding to the world or characters) or “revision” (create a new version while maintaining signature elements from the original) the dominant narrative allows the outgroup to create stories that can “shatter

complacency and challenge the status quo” (Delgado 2414). To lessen their own oppression, subordinated groups like Black enslaved people, Indigenous peoples, Mexican Americans, and women, have always told stories whether in written or oral form, as a tool for their own survival and liberation (2436). According to narratologist Andrea Macrae, “there is a privilege and a power that comes from shaping a narrative, and it’s one that shouldn’t be taken lightly” (qtd. in Taylor).

In the beginning of the AIDS crisis, the dominant narrative was that HIV was a disease that only affected homosexuals, hemophiliacs, “junkies”, and Haitians so many people were not worried about it (Daly). Complacency born of the dominant “comforting” stories such as this is a major stumbling block to progress and this complacency can be attacked using counterstories (Delgado 2438). The attack on complacency is made possible by the “destructive function” of stories and counterstories which can show the ingroup that their dominant narrative is “ridiculous, self-serving, or cruel” (Delgado 2415). Marginalized groups took it upon themselves to tell their own counternarratives in a bid to fight complacency and raise awareness about the AIDS epidemic. One such group, founded in 1987, was the AIDS Coalition To Unleash Power (ACT UP).

ACT UP employed innovative and often risky protest strategies, such as engaging in direct action and civil disobedience to interrupt the business-as-usual laissez-faire attitude held towards the sick and dying people infected with HIV; the carrying out of sex positive sex education among both out and closeted gay men; exchanging used hypodermic needles for new ones; in-your-face activism (such as the use of stage blood, die-ins, kiss-ins, and stage makeup worn on faces to make them look like skulls); and especially exploiting public fears through the rendering of the dangerous, contagious, and terrifying body of the infected (or presumed to be infected) person as a performative protest object. (López 43)

#### **2.1.4 Literature of Subversion**

There is a power in taking a story and making it your own, whether by naming it, or by taking its elements and subverting them, turning them inside out so

that the seams – and the seems – of the story show, and then putting them back together. Maybe the pieces don't fit, not exactly. Maybe the princess is now a witch. (Howard).

At the height of the epidemic, news media such as television, newspapers, and radio served as an important source of information on the state of the crisis, not just as a health story but also as a news story that informed on the epidemic through the lens of topics such as the arts, culture, taboo, sexuality, religion, celebrity, business, and politics, on a local, national, and global level (Brodie et. al 1). Almost 40 years into the crisis, HIV is no longer “news” and seems to have fallen off the radar with the public experiencing a kind of AIDS “fatigue”. “The old adage that the media doesn't tell the public what to think, but does tell them what to think *about*” could suggest that the declining coverage of HIV and AIDS in the news might have some relationship to the public's declining perception of the urgency of the problem (Brodie et. al 1).

The challenge for journalists and storytellers is how to cover HIV and AIDS in new ways in order to keep their audience engaged in a story that may not meet editorial standards for “news” as clearly as it once did (Brodie et. al 7). Some of the reasons that the story may no longer be “newsworthy” are: the disease that was once an absolute death sentence is now considered a chronic illness, there have been no major new developments in terms of vaccines or treatments, and the disease is considered to affect a small and increasingly marginalized population (Brodie et. al 7).

One such way to tell the story of AIDS could be through literature. According to Paul Reed, one of the first major writers of HIV and AIDS themed literature:

Fiction and drama hold the power to touch people at a level unreachable by news reports, statistics, prayers, or memorial services. To alert people to the calamity of AIDS by telling a story, to explore multiple facets of the epidemic and its wider meanings, to educate the general readership and influence public opinion through vivid imagery – these are all valuable and very real products

of AIDS literature. AIDS writing may not produce a cure, but it can produce a climate in which a cure is more likely. (Reed 94)

Historically, queer and female writers have used “the fantastic as a way to access the real” by using fiction and fantasy to explore marginalized experiences and “the strangeness of occupying a queer or female body” (Haggard). Fabulist stories “make physical what is otherwise ephemeral or ineffable” allowing writers to explore difficult topics such as love, loss, and transition (Haggard). Fantasy author Kat Howard notes that writers used fairy tales “to observe society from its edges and use magic and wonder and strangeness to critique the pieces of it that try to define what happily ever after is, and who deserves the chance at one” (Howard). By combining elements from stories and our current reality, we can open new windows into reality, showing the possibility of the construction of a new world richer than the one we currently inhabit (Delgado 2415).

### **2.1.5 Why New Media?**

The arrival of the printing press in 1440 and printing of books allowed religious authorities and publishers to essentially “lock” the words and control the content and distribution of stories that were once told orally; consequently, the authors started to “own” the audience and these oral stories that had once belonged to the community (McDowell 105). With advancements in digital technologies, the power to own or affect a story has shifted back to the audience, who are no longer just media consumers but are invited to become not just witnesses but active participants. Since the late 1990s, new media technologies have provided means for stories to be created quickly and shared widely, opening up opportunities for non-expert storytellers to tell their own stories through the use of open-source software (Hancox 50).

When the term “new media” was first introduced in the mid-1990s it portrayed other media such as television, newspapers, and radio as “old” or “dead” (Chun 1). The term is often conflated with “new technology” and theorists such as Wendy Hui Kyong Chun argue that new media is simply not “digital media” but rather an interactive medium or form of distribution as independent as the information it relayed (Chun 1). According to Chun, it is a myth that new media is “new” because it “contains within itself repetition” thus suggesting that new media involves building on or refreshing a previous form (2-3). Theorists Jay David Bolter and Richard Grusin write that what is “new” about new media comes from the “particular ways in which they refashion older media and the ways in which older media refashion themselves to answer the challenges of new media” (15).

## **2.2 SUMMARY**

As previously discussed in this chapter, there is a power in being able to tell one’s story; stories about the state of the AIDS epidemic today and what it is like living with HIV should not exist in a vacuum. The purpose of storytelling projects like *AR Disclosures* and *Once Upon A Virus* is to bring these stories into public discourse in a novel way so as to challenge “AIDS fatigue”. Using new media tools and platforms, digital storytelling offers marginalized people a space for self-representation, allowing them to create counternarratives as an act of creative empowerment. The final outcome of this thesis draws on theory presented in this chapter as the foundation of the creation of an augmented reality installation of latrinalia and an interactive fiction dystopian fairy tale. These counternarratives which use fact, fiction, fantasy, and reality, to question and highlight injustices, serve to challenge complacency and the idea that AIDS is over.

### **3. CONTEXT REVIEW**

The multidisciplinary nature of my thesis is reflected in this context review which explores the ways that marginalized creators i.e. people of color, women, and members of the LGBTQIA+ community have used art, fairy tales, unconventional story formats, new media technologies, and transmedia approaches to reanimate discussions on social issues. The selection of projects in this section is organized around concepts that have influenced my final outcome and are reviewed based on the challenges and opportunities that the mediums present. In this chapter I discuss the following topics: creating new vocabularies, living narratives, cultural augmentation, critical devices, and dynamic stories. The chapter concludes with a contextualization of *AR Disclosures* and *Once Upon A Time* within these areas.

#### **3.1 REANIMATING THE DISCOURSE**

##### **3.1.1 Creating a New Visual Vocabulary**

A crucial element of reanimating the discussions around HIV was to find a new way to speak about it. A new vocabulary. John Walter's *Alien Sex Club* ('ASC') installation is an exploration of how to speak about HIV in a contemporary art context. The transmedia project comprises of a series of mixed media artworks that incorporate sculpture, painting, video and performance art, which each contribute to the understanding of the complexities of contemporary sexual health. 'ASC' presents Walter's attempt to create a "new visual vocabulary" in an approach that injects some needed humor and life into the subject by coming at the topic from a satirical angle that aims to make a point using exaggeration. Although, the visual style of 'ASC' shifts from that of the 80s aesthetic of

AIDS activism which was more brash, urgent and in your face, it maintains the spirit of inundating people with imagery. Walter explains that “almost subliminally you’ll come out understanding something. It’s pedagogy in a casual way” (Walter).

In my own explorations for *AR Disclosures*, a design challenge I tackled was how to present the topic of HIV to an audience that had varying degrees of knowledge on the subject. The information presented needed to be simple enough so as not to confuse or overwhelm, and yet interesting and fresh enough so as not to bore those who had already heard it before. Walter’s solution for “making specialist knowledge available to everybody” was to use recognizable pop-culture references and visual metaphors to simplify complex medical information (Walter).

Using visual art, Walter explores the evolution of the virus from an incurable disease to a treatable condition, organizing his installation in the form of a maze that guides viewers along the journey of HIV. The artwork in the exhibit contains visual representations of what a life with HIV was like at the beginning of the epidemic and what that life looks like today. There is a series of digital paintings, which illustrate the evolution of the HIV pill burden, depicting a woman carrying a basket of HIV medication, where with each new painting there are less and less drugs in her basket, creating a simple timeline of the medical advances that have occurred. Speaking of his choice of a maze, which was based on the idea of typical cruising spaces such as saunas, gay bathhouses, and sex clubs, the artist describes the cruise maze as a “space you can get lost in” you are bombarded on all fronts – it’s playful, it’s not scary, it’s not dark” (Walter). By subverting the idea of a stereotypical cruising space, which we expect to be dark, mysterious and shrouded in shadows, Walter presents a powerful counternarrative; everything is out in the open, bathed in bright lights, creating a sense of hope and optimism. There’s nothing



to hide and this creates the sentiment that HIV is a topic that should be out in the open too.

With *AR Disclosures* by keeping disclosures in the virtual space, I sought to highlight the fact that people still felt like they had to hide their HIV status. My hope was that by engaging with the augmented reality latrinalia, people would come away with the idea that HIV was nothing to hide and an understanding of why people felt like they still had to hide. My design of the different latrinalia borrows from the idea of appropriating recognizable cultural imagery. Each latrinalia functions as a micro-fiction on its own, with the aim of telling a little piece of the story of HIV.

### **3.1.2 Graffiti as a Living Narrative**

Early storytelling processes involved the collaboration of multiple storytellers who created mythologies that were passed and would evolve from generation to generation (McDowell 105). An important part of this thesis for me was to create works that would have the ability to continually evolve. The two prototypes thus act as a kind of storytelling frame whose content is dynamic. It was crucial for me that *AR Disclosures* was a project that could create room for different voices to tell their own stories in the future. This greatly influenced the choice to use latrinalia as the form to speak about stigma and disclosures.

Narratologist Andrea Macrae, describes street graffiti as a kind of “living narrative” that is in constant evolution, creating a “tissue of text” that keeps changing as new tags are added or old tags are covered up (qtd. in Taylor). For my work, the latrinalia form was beneficial in that, it was familiar for many people and also not intimidating; to create latrinalia, one simply requires a writing implement to write on the wall. No art skills are required; therefore, different demographics of people can both produce and appreciate

graffiti. As a storytelling device, graffiti is a form of “rebellious expression of views that aren’t often allowed into mainstream media” such as in projects like *Street Stories* (qtd. in Taylor).

During the course of exploring public storytelling methods, I came across *Street Stories*, a transmedia storytelling project by the charity DePaul UK, that uses graffiti to raise funds and awareness about homelessness among the youth. The campaign called “Don’t Let Their Stories End on the Streets” features the work of different artists and illustrators, who created artwork on the streets of the East End of London. The project features an accompanying website that displays a virtual version of the mural, inviting viewers to buy a tile on the mural to clean over as a metaphor for erasing homelessness on the street. As the tiles are bought up, the virtual mural is obscured from view. On the website, members of the public are able to read and watch videos of the youth whose story inspired the street art. In this way, the public can hear from the people themselves thus meaning that the issue of homelessness and invisible people, is brought to a new audience. When walking on the street you might overlook a homeless person, but people will stop to look at the art, take pictures, and read the story incorporated into the art.

Graffiti is an art “widely understood as an anarchic aesthetic of communication and rebellion against political disenfranchisement and social invisibility” (Pabón 78). The choice to use latrinalia in *AR Disclosures* was informed by the notion that graffiti writing offers new ways of being seen. Messages that are left on the bathroom wall are “compact due to the characteristics of the space and arguably time available to work with. Graffiti artists are thus forced to get straight to the point, so to speak. This establishes latrinalia as a uniquely direct form of expression” (Trahan 92). The constraint that latrinalia then presents with its compactness, led to the idea of creating micro-fictions around the

latrinalia so that each latrinalia would tell a story that when experienced on its own or together with other latrinalia in the installation, would contribute to the larger topic of disclosures.

The choice was also solidified by my experience at an OCAD University women's bathroom where I found myself reading about an anonymous person's parents' divorce on the bathroom wall, and people's challenges with their classes and relationships. It was fascinating to me how the bathroom wall offered this communal storytelling space where people could "talk" about their lives in a safe and anonymous way. The scholar Adam Trahan, who muses on the fact that people do not write latrinalia on the walls of their own home's private bathrooms, posits that "we write them on the walls of public bathrooms, in part, because we know people will read them" but also interestingly enough, because of the nature of the bathroom stall itself (94). Trahan explains that the public bathroom and latrinalia exist as a unique mix of privacy and publicity because graffiti are written in private but become public shortly after (94). This idea was important to me particularly dealing with a sensitive topic like HIV. Because I was inviting people to act upon the space by adding onto the latrinalia, I wanted the bathroom stall to feel like a safe space to make a disclosure. The bathroom stall offers privacy and most of all anonymity. Trahan describes privacy as "freedom from observation where no one is watching" and anonymity as "freedom from identification" (94).

### **3.1.3 Augmented Reality as Cultural Augmentation**

In Asad J. Malik's interactive augmented reality documentary, *Terminal 3*, participants are invited to play the role of a US customs officer and asked to interrogate holographic characters who "appear to be Muslim" in order to determine whether or not to let them into the country. The work critiques discriminatory practices against Muslim

travelers and by creating holograms based on real people telling their own stories, opens up a space for people to explore the idea of a contemporary Muslim identity.

Unlike Virtual Reality (VR) which immerses a user inside a synthetic virtual environment, obscuring the real world around them, Augmented Reality (AR) superimposes virtual 3D content onto the real world in real time, therefore supplementing reality, rather than completely replacing it (Azuma 355-356). Tools like VR and AR shift away from linear narrative, the fixed or controlled frame, into a new multi-dimensional narrative space; “it begins to look as if we have returned to the tribal narrative, the oral, non-linear, collaborative and evolutionary origins of story” (McDowell 105).

According to Malik, AR has the ability to affect a user’s perception of their own space, making them look at the space differently, once the AR experience is over (1RIC). With *AR Disclosures*, I was intrigued by this idea of the user being affected beyond their interactions with the piece, and possibly thinking of HIV whenever they came across latrinalia elsewhere. Malik considers his work to be a kind of “cultural augmentation” explaining that, “when you can bring a hologram of a person into a space that they wouldn’t be able to inhabit in real life, it challenges people by forcing them to share presence with ideologies and humans that they otherwise wouldn’t cross paths with” (qtd. in Byager).

Having identified stigma and discrimination as one of the deterrents to ending the AIDS epidemic, I wanted to explore the topic of silence, stigma and shame around HIV disclosures. My intention was to tell stories around the idea of revelations, particularly about the things that are left unsaid when somebody makes a disclosure.

To determine what kind of digital medium I wanted to explore to tell the story, I began by exploring the definition of disclosure which the Oxford Learner's dictionary defines as "the act of making something known or public that was previously secret or private". When reviewing the kinds of digital tools that would allow me to engage with the idea of revealing, I settled on augmented reality (AR). For me, AR provided the perfect avenue to thematically speak to the idea of hidden things. In order to experience an augmented reality artwork, the viewer has to look through a screen to make visible artifacts that are "there" or exist only in the virtual space. In this way they reveal the augmentations and this act of "revealing" using AR tied in thematically with my idea to use latrinalia to reveal these attitudes towards HIV that are there around us but for one reason or another we may not be aware of.

The latrinalia artifacts in the artwork consist of what I call primary and secondary disclosures. Primary disclosures exist in the physical world while secondary disclosures are only visible through the screen of a device via an AR application. The AR latrinalia that make up the primary and secondary disclosures are a kind of micro-fiction, a pictorial distillation of true stories and accounts related to the AIDS crisis. By choosing to use latrinalia as the form for *AR Disclosures*, the format provides the opportunity to bring together different voices that would perhaps normally not exist in the same space. In order to bring together diverse voices, I sourced the stories in the different latrinalia from social media sites such as public Twitter threads, Reddit channels and Instagram accounts archiving HIV history. As I did not have direct access to people living with HIV or those who had lived experience, social media and the Internet provided me indirect access to these communities. This collection of stories, that I amassed for over a year, represented

a personal curation of stories and topics that I found interesting and important in relation to the state of the epidemic today.

Latrinalia can be democratic and can be seen by “all” depending on who has access to the space; it is free to be made on any surface and anywhere. In his book, “Graffiti Lives: Beyond the Tag in New York’s Urban Underground,” author Gregory J. Snyder writes that “in its purest form, graffiti is a democratic art form...you don’t need money, or special knowledge, or the right outfit, or a car, or an ID to see it” (5). Unlike street art which is often tagged with artists’ signatures, latrinalia can be considered “free and open discourse” as it normally features an absence of individual or group identifiers, meaning that those who see it cannot tell who wrote it; therefore, the hierarchies such as wealth, power, and status that privilege some members of society and their voices, are irrelevant and suspended within latrinalia (Trahan 95).

Theorists Bolter and Grusin explain that new media doesn’t make older media obsolete but instead transforms it either by adopting or discarding some of its features (59). The choice to represent stories about stigma and discrimination, in pictorial form as augmented reality latrinalia, is an act of remediation, which is defined as the act of representing one medium in another, providing a new way to access the old (Bolter and Grusin 45).

### **3.1.4 Fairy Tales and Fantasy as a Critical Device**

The earliest tribal storytellers told evolving stories and used metaphor to explain complex concepts in ways that their communities could understand. In *Grimm Reality* Akshita Chandra uses an interactive paper book to critique the moralising nature of fairy tales. Using recognizable fairy tale motifs and reinterpreting them for an Indian context, Chandra critiques the way that morals in fairy tales become rules that blame girls for the

dangers that befall them, instead of blaming those who prey on them. On the book's cover, Chandra writes poetry that reads:

Cinderella, conforming to her curfew / Ran back home on time to validate her virtue; / Snow White, taken in by the dwarfs to do house chores / Was strictly instructed not to venture outdoors. / Violated, Little Red only had herself to blame – / Being out so late alone surely brought her shame; / Rapunzel shouldn't have let down her long hair – / She was banished because of her pre-marital affair. (Chandra)

The pages of the book are designed in the style of pull-tab or pop-up books and draw on familiar fairy tale motifs such as the big bad wolf, baskets of goodies, and Disney style ballgown aesthetics to create mini games that readers can interact with. By interacting with the pages, the user is able to discover different things about the story: no matter how early the reader sets the time that Red comes home, all the hands on the clock will point to statements that victim blame; all the prizes for Snow to win in the bear-claw game are housekeeping and domestic objects – sewing machines, mops, pots and pans; readers play dress up and are asked to pick “decent” clothes that will “ensure absolute safety”. Through the use of allegory and metaphor, Chandra is able to comment on the “restrictive” and “poisonous” rules placed on young Indian women and the way the morals become an excuse to judge girls who do not follow the “rules”.

Author T.E Apter writes that “fantasy must be understood not as an escape from reality but as an investigation of it” (2). My prototype *Once Upon A Virus* draws upon the idea of subverting iconic fairy tale motifs to critique issues such as transphobia, violence against women, homophobia, and pharmaceutical greed. Using fantasy as a device for social critique, I created a fantasy world where these social issues were presented in an amplified manner in order to draw attention them. Fantasy and fairy tales in particular, presented as the best avenue to speak about these topics in a novel way that could tackle

the issue of “AIDS fatigue” because the genre can be both escapist and subversive. “Fantasy fictions are uniquely designed to approach reality from a different angle” as they “often rely on the formulaic to satisfy and entertain their audiences but, in doing so, manipulate those formulae to comment upon the shortcomings of our current society” (Radek 15-16). Fairy tale scholar, Kate Bernheimer, describes the fairy tale as “the skeleton of stories” and as a unique form that is adaptable to a diverse range of narrative styles and shapes (62-65). The narrative style of *Once Upon A Virus* was influenced by the four characteristics of the fairy tale form which Bernheimer lists as: flatness, abstraction, intuitive logic, and normalized magic (64).

The creation of *Once Upon A Virus* involved reading stories about HIV and exploring fairy tale motifs that could be subverted to provide a fantastical way to engage with the stories. When thinking about metaphors I read and analyzed what had already been published and depicted onscreen. I found that whenever allegories of HIV and queerness were made in fiction or films within the fantasy context, they would often be interwoven with the idea of body horror and monstrosity where the allegorical characters depicted would normally be a kind of monster: werewolf, vampire, or alien such as the werewolf Remus Lupin in the *Harry Potter* series and the vampires in the fictional Bon Temps on the tv show *True Blood*. Alan Ball, *True Blood*'s creator warns that “To look at these vampires on the show as metaphors for gays and lesbians is kind of lazy and could be very homophobic because vampires are dangerous; they kill, they're amoral” and yet the show “dips into imagery that has real roots” depicting images such as “God Hates Fangs” or AIDS-like viruses like the fictional Hep-V, thus making it easy for viewers to draw parallels even if misleading or incorrect (Cunningham). On her website Pottermore, J.K Rowling wrote “Lupin's condition of lycanthropy (being a werewolf) was a metaphor



for those illnesses that carry a stigma, like HIV and AIDS. All kinds of superstitions seem to surround blood-borne conditions, probably due to taboos surrounding blood itself. The wizarding community is as prone to hysteria and prejudice as the Muggle one, and the character of Lupin gave me a chance to examine those attitudes" (Rowling). The problem with this kind of allegory is that it reinforces the stereotype that people with HIV are to be feared because people have legitimate reasons to fear these monsters. Critics have called these kinds of allegories "ill-considered" writing that:

They are depicted as inherently more aggressive, more prone to violence, and less human as a result of their condition. They "target" other humans, can lose their sense of their morals, and turn against anyone who does not share their illness. Using them as a metaphor for people with HIV and AIDS is not a progressive move. (Leszkiewicz)

It was important for me that the metaphors and allegories for those who were affected by the plague in the *Once Upon A Virus* story, did not re-stigmatize people; therefore, I made the conscious decision to stay away from monster metaphors.

### **3.1.5 Telling Dynamic Stories that Grow and Change**

Shelley Jackson's *My Body: A Wunderkammer*, is a 1997 semi-autobiographical hypertext memoir consisting of an assemblage of minor narratives; anecdotes, reflections, and meditations of the author's body. Hypertext is a text-based type of digital fiction which consists of a structure of linked non-linear stories (Hayles). Electronic literature (e-lit), also known as digital fiction, is fiction that is created on and written to be read or played on a computer, and through its existence online and onscreen is able to take advantage of the context and affordances of the web to bring together different media in interesting ways (Hayles). E-lit works would lose either their form or meaning if they were to be printed. This nature of being unique to digital and needing to be created on a computer, is known as being "born-digital"; According to Hayles, these highly

“experimental” and “creative” works originate in digital form to “test the boundaries of the literary and challenge us to rethink our assumptions of what literature can do and be” (Hayles).

*My Body* takes advantage of the medium of hypertext to lean into the idea of a “wunderkammer”, the German word for “a cabinet of curiosities”. Jackson’s story is organized using this strategy of a cabinet where hyperlinked body parts act like drawers which reveal more wonders of the story of the author’s body when clicked. This idea of a collection of stories contributing to the whole is utilized in *Once Upon A Virus* where stories are told from different perspectives but connected using hyperlinks to create a web of narratives. I was drawn to interconnected stories as I wanted to refer back to the manner in which HIV is a disease of inequality and is driven by diverse yet intersectional issues. Thematically, the chaos and confusion that a hypertext work can create, reflects the manner in which I myself learned about the virus; in pieces, and with conflicting information from all sides.

The theme of exploring one’s body is reflected in a story-map, a kind of table of contents that depicts a black and white wood-cut illustration of a naked woman’s body. Instead of the usual list of words with page numbers indicating the structure of the story that we have come to associate with a table of contents, *My Body*’s story sections are arranged anatomically as a kind of patchwork female body. A reader thus explores the intertwined vignettes by exploring the female anatomy at the start of the story. The work, which features text, images, and sound, is interactive in the sense that it allows for a non-linear kind of navigation using hyperlinks. The choice of where to start depends on which body part the reader wants to begin with. There is no correct order on where to start as there is no designated beginning or designated end to the stories.

A non-linear text is an object of verbal communication that is not simply one fixed sequence of letters, words, and sentences but one in which the words or sequence of words may differ from reading to reading because of the shape, conventions, or mechanisms of the text. For a text to be non-linear, it must have a positive distinction: the ability to vary, to produce different courses. (Aarseth 41)

This feature of allowing the audience to choose how the narrative unfolds or to control their experience of it, suggests interactivity. Steve Dixon, author of *“Performing” Interactivity* writes that digital interactive artworks give the audience the ability to “activate, affect, play with, input into, build, or entirely change” the artwork (559). Other theorists and academics like Simon Penny’s definition of interactivity implies a real-time response while Janet Murray’s stresses on the importance of agency (560). According to Dixon, many products that are labelled as interactive should be referred to as “reactive” instead as they do not leave room for dialogue between the user and technology or product (561).

Interactive fiction (IF) is often thought of as a work where the story “cannot proceed without input from the user” (Hayles). This concept of “interactive fiction” or “non-linear fiction” is one that is often contested using the reasoning that: all literature is to some extent indeterminate, non-linear, and different for every reading; the reader has to make choices in order to make sense of the text; a text cannot really be non-linear because the reader can read it only once sequence at a time anyway (Aarseth 2).

The Cyberculture theorist, Espen Aarseth, argues that, in fact, there is such a thing as “interactive fiction,” explaining that the difference between IF and regular literature remains a mystery until one tries the medium out firsthand (2).

The distinction lies in the fact that when you read from a cybertext, you are constantly reminded of inaccessible strategies and paths not taken, voices not heard. Each decision will make some parts of the text more, and others less, accessible, and you may never know the exact results of your choices; that is,

exactly what you missed. This is very different from the ambiguities of a linear text. (3)

The distinction between IF and regular literature is not only structural but also in what is demanded of the readers. Heather Albano, a science fiction author and independent narrative designer, in her 2015 Game Developers Conference (GDC) talk “Harvesting Interactive Fiction,” spoke of the modern interactive fiction techniques – poetry, ambiguity, and complicity – which turn readers into players (Albano). Poetry is described in relation to the quality of prose where IF storytellers use short, beautiful prose that “hits hard” (Albano). The effect of this is that the function of words changes from that of exposition as in regular fiction to that of “implying the world, characters, and the story” (Albano). By implying rather than exposing, the readers/players are encouraged to fill in the blanks for themselves and in turn they are brought deeper into the experience. Albano states that ambiguity is an unavoidable by-product of the medium that leaves room for the player to draw their own conclusions and meaningfully insert themselves into the narrative. The final technique, complicity, involves creating a “feeling of ownership over the plot” by giving the player actual choices that affect the narrative (Albano). It is this idea of reader agency that is echoed in Aarseth’s defense of a difference between the reader of literature and reader of interactive fiction or cybertext:

A reader, however, strongly engaged in the unfolding narrative, is powerless. Like a spectator at a soccer game, he may speculate, conjecture, extrapolate, even shout abuse, but he is not a player. Like a passenger on a train, he can study and interpret the shifting landscapes, he may rest his eyes wherever he pleases, even release the emergency brake and step off, but he is not free to move the tracks in a different direction. He cannot have the player’s pleasure of influence: “Let’s see what happens when I do this”. The reader’s pleasure of the voyeur. Safe but impotent. The cybertext reader, on the other hand, is not safe and therefore, it can be argued, she is not a reader. The cybertext puts its would-be reader at risk: the risk of rejection. The effort and energy demanded by the cybertext of its reader raises the stakes of interpretation to those of

intervention. The struggle isn't merely for interpretative insight but also for narrative control. (Aarseth 4-5)

According to Dixon, in order to distinguish the different types and levels of interactivity in an artwork or performance, one can consider the openness of the system and depth of user interaction in relation to four hierarchical categories: navigation, participation, conversation, and collaboration (563). Navigation within an artwork can range from systems where the artwork is “relatively structured and constrained” to works where choice and navigation is wide open giving users the agency to go wherever they wish (564). It is considered the “simplest form of interaction” (566). Participation involves more than just “joining in” and can mean a “genuine and meaningful dialogue between the user and the artwork” leading to a kind of conversation (564). “In works that operate on a ‘conversational interactive paradigm, there is often a complex relationship or negotiation established between the user/audience and the work” (585). Collaboration involves the user’s input meaningfully altering the artwork itself or resulting in the construction of “new art” in collaboration with the computer (565).

Navigating *My Body* was overwhelming and confusing at times, which is an unfortunate side-effect of non-linear storytelling for large stories. I found that there seemed to be too many links per page and I quickly grew weary of having to decide which one I wanted to click next. The links also looked similar in terms of aesthetics and as there were so many, it was difficult to discern a hierarchy to them in terms of how to continue on a narrative path. The reading experience grew more confusing as I read on, particularly because there was no “back”, or “home” button incorporated to take the reader back to the story map. As I went deeper into the inner pages, I soon became disoriented because I couldn't figure out where I was in the text, what body parts I had read and hadn't read

yet. I felt trapped in certain parts of the story because there was no easy way to switch to a different body part other than clicking the “back” button on the browser until I got back to the map. In *Once Upon A Virus* I wanted to tackle the user interface by providing links back to the story map that would help the reader situate themselves.

### **3.2 SUMMARY**

In this chapter, I reviewed the storytelling techniques that a selection of marginalized artists have used to reanimate the discourse on social issues using media and formats such as visual art, graffiti, augmented reality, fairy tales, and hypertext fiction to tell their stories. I review the ways in which *AR Disclosures*, strives to create a cultural augmentation of the discourse surrounding stigma using augmented reality, while at the same time, using latrinalia to create a living narrative that provides a new visual language for the disease. Latrinalia is presented here as a democratic storytelling platform that is free and accessible. *Once Upon A Virus*, draws on the idea of fantasy as a critical device for societal commentary, doing away with the monster metaphors that are often common in allegorical representations of HIV in favor of subverting iconic fairy tale motifs. The work also leans into the metaphor of a web, using hypertext fiction to reflect the chaos of the disease and the ways in which the issues that affect HIV are interconnected.

## **4. METHODOLOGIES AND METHODS**

This thesis uses a mixed methodologies approach drawing upon Critical Design, Game Design, Transmedia Storytelling, and Research through Design methodologies as a reflection of my own interdisciplinary practices as an artist, storyteller and designer. My creative practice relies heavily on an iterative approach and the development of this thesis involved the following methods: brainstorming, mind maps, sketchbooks, comparative works analysis, user testing (observation and questionnaires), case studies, documentation (photography & video), and a reflective journal (blog). The aforementioned methodologies and methods and their incorporation into my thesis development process are reviewed in this section.

### **4.1 METHODOLOGIES**

#### **4.1.1 Critical Design**

The term “critical design” popularized by the designers Anthony Dunne and Fiona Raby is defined, in their *Critical Design FAQ*, as using design as a form of critique and as “more of an attitude than a methodology”. This attitude can be found in a number of fields not limited to activism, cautionary tales, satire, social fiction and speculative design. It is easy to see how a critical design mindset can fit in the aforementioned fields, as the goal of critical design is not only “mainly to make us think but also to raise awareness, expose assumptions, provoke action, spark debate, and even entertain in an intellectual sort of way, like literature and film” (Dunne and Raby). This definition of critical design is not one that is set in stone and one’s understanding of the term varies according to one’s design practice.

A theme that comes across many critical designs works I have encountered is that of design as a mirror or reflection of cultures. Lindsay Grace, a videogame designer, artist and professor, writes of the different critical design perspectives that design scholars use to frame their work, stating that Mary Flanagan, uses critical design as a “socio-cultural mirror that voices itself in play and games” and her perspective differs from that of Dunne and Raby which “champions commentary on modern society through the production of industrial design” and that of Ian Bogost which frames “critical games as a way of understanding our world thus serving as a kind of cultural translation alternative to the mainstream cannon” (Grace 4).

Like Dunne and Raby who use “design as a means to stimulate conversation and debate among other designers, the industry, and the public on a variety of issues”, my aim is to do the same in regard to new ways to tell the story of HIV and AIDS (Dunne and Raby). I intend to reflect the critical design attitude in my storytelling prototypes in relation to issues such as stigma, criminalization of HIV, and Big Pharma greed amongst others. Although the final research outcomes will not be critical design projects, their creation is informed by the attitude of a critical design methodology, which provides a space for me to think of how critical works can be made and how they function in society, allowing me to experiment with story and its different forms and meanings.

#### **4.1.2 Research Through Design**

Research through Design (RtD), a term used in Interaction Design and Human Computer Interaction (HCI) fields, is an “informal methodological approach that is more of a foundational concept for practice-based inquiry with the aim of generating transferable knowledge (Durrant et al 3). Like *critical design*, there is no one clear cut definition of *research through design* and it is one that is constantly evolving. Research



through Design involves the construction of a design object that is at the core of the research. It involves doing design as part of the research where design is used to produce different forms of knowledge. RtD recognizes the design process as a legitimate research activity and is constituted by the design process itself – materials research, development work, recording and communicating steps, experiments, and iterations of design (Martin and Hanington 146).

In this design approach, the quality of the design and the designer’s activities contribute to the *knowledge outcome*, especially in instances that “introduce prototypes into the world, and reflect, measure, discuss, and analyze the effect, sometimes of coming-into-being, of these artifacts” (Stappers and Giaccardi). These prototypes are normally understood to be works-in-progress that are iterative in nature and are presented as “research outcomes that reveal aspects of the research” as the artifacts are understood as “ongoing and unfinished works” (Durrant et al 8). How this works is that a designer produces a series of prototypes in steps where each step of a prototype produces knowledge that informs the next step and artifacts can address different parts of the research problem.

#### **4.1.3 Transmedia Storytelling**

Transmedia storytelling is a “design philosophy” that approaches storytelling across multiple platforms and in a way that the whole experience is greater than the sum of the parts (Pratten 2). A platform can be described as something that supports a channel (method of communication such as video, audio, image) and media (an embodiment of a channel such as a text file or .mp4 file), allowing others to access the channel or media (Pratten 2). Examples of a platform are YouTube, Instagram, a website, a television, the cinema and so on. With transmedia storytelling the audience is placed at the center of the

decision to select platforms in terms of the size, time, and place of the platform in a bid to create a profitable, cohesive and rewarding experience (Pratten 4). The goal of transmedia is not to adapt the story but to tell something new where the resulting individual stories are part of a larger story world. Transmedia-style story creation involves one of two processes: “either you take a single story and you splinter it across multiple media, or you start with one story and you keep adding pieces on to it ad infinitum” (Phillips 15).

Although a clear definition of transmedia does not exist, transmedia writer and game designer Andrea Phillips explains that there are two main types:

The first, Hollywood or franchise transmedia, consists of multiple big pieces of media: feature films, video games and is grounded in big-business commercial storytelling. The stories in these projects are interwoven, but lightly; each piece can be consumed on its own, and you’ll still come away with the idea that you were given a complete story. An example is *Star Wars*, where multiple films, books, TV series, and so on combine to tell the story of a galaxy far, far away. The second kind of transmedia tends to be more interactive, and much more web-centric. It overlaps heavily with the traditions of independent film, theater, and interactive art. These projects make heavy use of social media and are often run once over a set period of time rather than persisting forever. The plot is so tightly woven between media that you might not fully understand what’s going on if you don’t actively seek out multiple pieces of the story.

Transmedia storytelling employs a multiplatform approach mimicking the manner in which we tell stories and the notion that “no single media satisfies our curiosity and no single platform our lifestyle” (Pratten 4). The general agreed upon criteria for transmedia

storytelling are: “multiple media, a single unified story or experience, and an avoidance of redundancy between media” (Phillips 15).

Contemporary transmedia stories are “increasingly a constellation of media, forms and modes of storytelling that create a holistic narrative in which different aspects of the story are told in a way that brings together rooms and content to create a unique aesthetic” (Hancox 50). At the height of the AIDS crisis, activist groups like ACT UP used a variety of media such as “stickers, buttons, placards, posters,” clothing, and even their own bodies to share their message (Weiner 103). The transmedia technique lends itself well to activist forms of storytelling in that, it “allows for the audience to experience an issue through multiple perspectives, and in turn, to build a deeper understanding due to the ability of transmedia to present a number of points of view, and to authentically depict or represent complex ecologies and issues” (Hancox 55).

I was drawn to this idea of exploring different story formats because of the scope of the topic of HIV. It would have been difficult to attempt to thematically explore multiple facets of the disease in one medium. For my final works, I wanted to use each format to explore a different aspect of HIV: *AR Disclosures* explores the idea of stigma and discrimination and the history of the disease in the form of augmented reality latrinalia. On the other hand, *Once Upon A Virus* engages with the theme of the societal attitudes towards disease that have driven the virus, using the form of a hypertext story. One approach engages with reality and facts whilst the other engages with fantasy and fictions.

## **4.2 METHODS**

### **4.2.1 Creative Process**

Research in my personal creative practice involves a combination of research methods and a three-part overarching guideline that dictates the kind of HIV and AIDS literature and works I use as a reference in my research:

- Single story = stereotypes
- #ownvoices
- Facts not Fiction

**Single story = stereotypes** is inspired by Chimamanda Adichie's idea of the single story; I want to ensure that the points of view I present are inclusive and that the characters I create are diverse. I try to remain cognizant of this guideline throughout the creation process as a kind of reminder to keep watch so that my work does not reinforce existing stereotypes.

**#ownvoices** is based on a term, frequently used in the young-adult (YA) online book community, that differs slightly depending on the community it refers to, but basically means people, particularly marginalized ones, telling their own stories. This step comes into play in the inspiration and ideation process and is used during brainstorming. In order to gain insights into the AIDS crisis, I carried out secondary research into published works of prose and poetry and art by people with lived experiences and collected accounts of stories from those who had passed away.

**Facts not fiction**, deals with the fact that I will rely on factual expert-sourced information to guide my research. This step aided the identification of an appropriate target demographic, and the possible gaps that storytelling could fill.

The methods that are carried out in my creative process were used in different stages of the thesis development process; the ideation and definition stage involved brainstorming, mind maps, sketchbooks, and comparative works analysis; the

development stage involved iterative prototypes and sketches, user testing (observation and questionnaires), case studies, documentation (photography & video), and a reflective journal (blog).

#### 4.2.2 Brainstorming

Once I had settled on the idea of latrinalia, I began collecting images of latrinalia in order to further understand how they appeared on bathroom walls. I found that people “often mark the walls of public bathrooms with thoughtful commentaries and critiques of political, social, cultural, and economic issues” among the humorous and non-sensical drawings which would involve multiple authors and cases where sometimes people would “write about deeply personal issues that confront them” (Trahan 92). My intention for this real-world research exploration was so that when I designed micro-fictions and my own latrinalia, they would authentically mimic and fit in with the kinds of latrinalia that would appear on a bathroom wall. I found that latrinalia can be positive in the form of advice, similar stories, or numbers to helplines, or negative...ranging across a wide variety of topics: sexuality, religion, politics, humor, love and relationships, and hostility.



Figure 1: A collection of photographs of latrinalia taken in the OCAD university men's and women's bathrooms

### 4.2.3 Mindmapping

My brainstorming sessions for *Once Upon A Time* included the creation of two mind maps: one for real facts, stories, and ideas about HIV and another for those ideas subverted in a fairytale fantasy context. The information collected here helped in the creation of my story world.

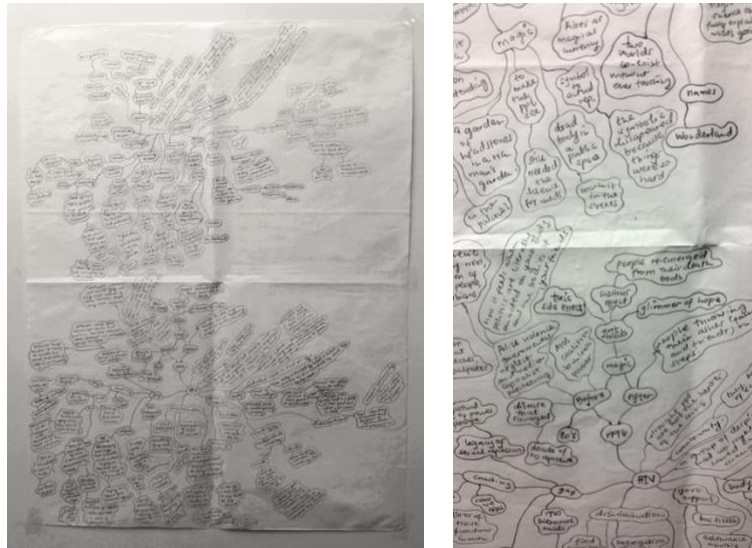


Figure 2: Mind maps collecting ideas for fairy tale elements to subvert & a close-up of maps

### 4.2.4 Sketchbooks

This process involved reading accounts of people's experiences of disclosure and distilling those into short sentences like "Nah! Jesus and I are tight" in response to "HIV is a punishment from God". I attempted to draw latrinalia that acted as a kind of visual metaphor for the phrases that would be revealed.

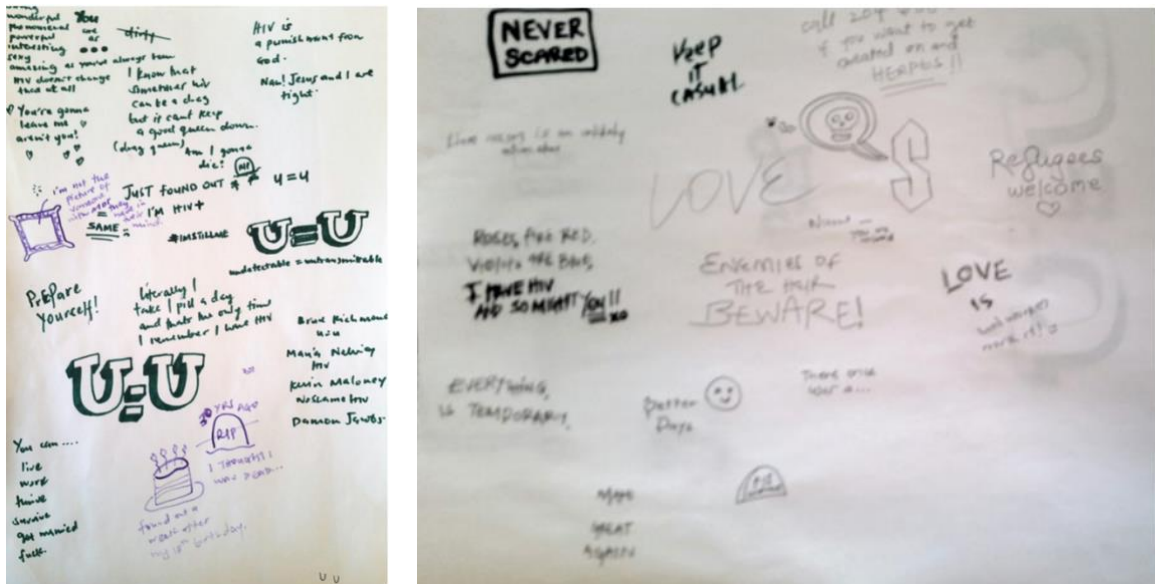


Figure 3: Sketchbook exploration of latrinalia designs for AR Disclosures

#### 4.2.5 Iterative Prototypes

The creation of *AR Disclosures* drew on the Research through Design methodology in an iterative process where each iteration of the three prototypes evolved based on the research outcomes. The first iteration focused on the disclosure “Just found out I’m HIV+” and the emotions: anger, anxiety, hope, and fear. This iteration was a proof of concept, created as a single webpage that represented the “bathroom wall” where users were encouraged to “look” around using a mouse that simulated a handheld device; animated images would be revealed whenever the user hovered over certain sections. The first prototype revealed that the aesthetics I had chosen for the latrinalia were not a good fit; the emojis did not look like something one would find on a bathroom wall. The latrinalia that resonated the most were those that looked hand drawn. (See Appendix A)

For the second iteration of *AR Disclosures*, I explored AR applications that I could use so that I could demonstrate my concept using mobile devices rather than on a laptop; the AR app chosen for this iteration was EyeJack. In order to keep a hand drawn aesthetic,

I drew my own latrinalia which I then scanned and digitized in Adobe Photoshop. As I was dealing with more latrinalia at this stage, I kept a theme and issue matrix that would help organize the ideas for illustrations. The aesthetics of the latrinalia were better received and people who tried out the prototype using EyeJack were receptive to the experience. (See Appendix B)

The third iteration included latrinalia that incorporated color and more animations. This was also the first version of the prototype to be exhibited for an audience of people who were unfamiliar with the project. The new hand drawn latrinalia, that acted as AR markers, were printed as stickers and placed on a 16x20 foam board. The EyeJack app was used once again to interact with the poster as the alternative WebAR technology, ended up not being a good fit; WebAR needs graphics to track that are simple and symmetrical, and this was not the case with my illustrations. Additionally, WebAR requires that all AR markers be surrounded by a black border; this was not going to work for the aesthetics and functionality of my project. (See Appendix C)

The fourth iteration was informed mostly by the technological challenges I experienced with the third iteration of *AR Disclosures*. As I loaded more illustrations onto EyeJack, the application would “switch off” the tracking after it was running for a certain time and in order to continue tracking them, I would have to manually switch them back on. This quickly interfered with the experience especially in a highly trafficked installation setting. EyeJack was no longer a viable option and I decided to create a custom application on Unity.

The first iteration of *Once Upon A Virus* was created using Twine, “an open-source tool for telling interactive, non-linear stories” in the form of webpages (“Twine”). This version drew on ideas from experimental writing to combine short pieces of text with



poetry in an interactive format. (See Appendix E). For the second iteration, having found that Twine did not allow for a lot of room to customize the interactive experience, I created the hypertext using pure HTML5, CSS, and JavaScript and kept Twine as a tool to visualize the web of stories. (See Appendix F). This allowed me to customize the user-interface in the way that suited my project best. Unfortunately, with this I lost Twine features such as the ability to remember the last story section a reader had been reading. (See Appendix D)

#### **4.2.6 Observation**

While I did not conduct formal user-testing, I had the opportunity to publicly exhibit the work and gather casual observations and reflections that influenced the development of the work. From my observations of the members of the public interacting with the work, I found that iPad Mini and Air provided the best amount of real estate to view the virtual augmentations on the poster. I discovered that placing the poster at eye-level provided the most comfortable height for interacting with the work. Many people would try and tap on the virtual content and some even asked whether there would be links to educational material and resources about HIV beyond the project.

#### **4.2.7 User-Testing**

For *Once Upon A Virus*, eight participants partook in user testing sessions, as approved by OCADU's Research Ethics Board (REB Approval No. 2020-14), that involved a 10-question questionnaire and optional interview which occurred once the user had tested the 2<sup>nd</sup> prototype. From this activity I found that many people were intrigued by the metaphors and abstracted fairy tale motifs. I had initially worried about the metaphors going over people's heads and had included an explanation of some of them in the "how to read" section. Multiple participants commented that they would have liked to

not have had the abstractions explained to them as they wanted to discover things by themselves. They however appreciated the inclusion of a content warning.

Some users felt that the user interface was bare and would have liked to see some illustrations whilst others liked the opportunity to simply get lost in the text without any pictorial aids. A graphic designer offered some suggestions to improve the user-interface in order to create some hierarchy to the text. There was a suggestion to vary the colors of the links as indicators to what had been already read and also which chapter or storyline one was following.

One participant mentioned that they viewed the story map listing chapters as hierarchical whilst another read it as a poem. Almost all the participants asked for a longer story and stated that the story's length would determine whether or not they would keep rereading. Even though I carried out the user-tests in a relatively quiet area, I had not considered the possibility of distractions and was asked if I could provide headphones and perhaps incorporate sound in order to immerse the reader into the story even more.

For many participants their most memorable part of the reading experience was the characters, particularly Mr. Wolf and the Stepmother. Participant #1F2006 commented, "Although it's disguised as commonly told folklore, there were many moments in the story that were too close to reality and this realization was profound".

In response to whether or not the story affected their perceptions on AIDS participant #1F2005 said, "I think it really hit me, the story is something I can relate with, and in the nicest way it told stories behind AIDS that I hadn't think about before. Maybe not think but reflected on". Another participant #1F2004 said, "It's nice to get what feels like a first-hand account, in a perspective that's unusual" while #1F2001 answered, "It

made the topic more approachable and helped me understand the feelings surrounding the AIDS crisis”.

### **4.3 SUMMARY**

The combination of methodologies and methods presented in this section reflects my own interdisciplinary practice as an artist, storyteller and designer. These methodologies and methods were highly appealing to me as I wanted to explore not just one way to tell a story but numerous ways in which I could use digital media to explore storytelling and to view the AIDS epidemic in different ways. The final work of this thesis draws on Research through Design in the creation process using an iterative approach where knowledge outcomes from each prototyping stage inform the next, particularly for *AR Disclosures*. Critical Design is used as a guide on how to use a personal game, *Once Upon A Virus*, as a social critique using the techniques of contrast and subversion to challenge the status quo. A Transmedia Storytelling approach allowed me to create two prototypes that address different parts of my research question and explore the challenge of storytelling around HIV from different angles.

## 5. THE WORK

This section presents a reflection on the two research outcomes of my thesis exploration into new media storytelling around the topic of HIV and AIDS: the major work *AR Disclosures*, an augmented reality interactive documentary and the companion piece *Once Upon A Virus*, an interactive dystopian fairy tale retelling.

### 5.1 AR DISCLOSURES

*AR Disclosures* is an augmented reality interactive documentary that employs a guerilla spirit and a transmedia storytelling approach to explore stories from the canon of AIDS literature in an unconventional manner, as a kind of cultural augmentation and critique of the culture of silence around the topic of HIV. (See Appendix C)

This work draws on the idea of unconventional storytelling similar to projects that employed a spirit of grassroots activism and a kind of public domain storytelling such as public AIDS memorials, HIV activist art projects like PosterVirus, and zine and graphic novel culture. AIDS activist Ted Kerr writes that memorials like the NAMES Project's AIDS Memorial Quilt and the Texas AIDS Memorial garden served a "multivalent purpose: to honor the dead, provide shape to the crisis, educate the public, increase AIDS awareness and provide a platform for activism" (Kerr). Jessica Whitbread, one of PosterVirus' creators stated that the project was inspired by groups from the early years of the AIDS crisis who used graphic design and posters as a form of activism (qtd. in Green). *AR Disclosures* uses the idea of interactive latrinalia, toilet graffiti, to present micro-fictions that disclose stories, facts, and attitudes about HIV sourced from social media. Consequently, the work leans into the idea of creating a visual language using art and pop-culture as a public intervention to subvert, reclaim and draw attention to

dominant narratives about HIV. The interactivity in this work is primarily in the form of non-linear navigation where there is no defined beginning, middle, or end to the installation pieces; to begin a viewer simply has to start with the latrinalia that draws their eye, or to look around the installation to figure out which latrinalia have been augmented.

The design of the primary disclosures, physical latrinalia, is that they are designed to blend into the bathroom environment and also to draw one in to want to look and find out more. A primary disclosure might be a statement such as “what to do about love?” accompanied with a drawing of a heart and the secondary disclosure would be the revelation “I am afraid to be with someone who is afraid of what I am, which is poz, undetectable, but still poz”. The secondary disclosures, virtual latrinalia, on the other hand reveal more, providing an added layer of depth to the physical content. In some cases, secondary disclosures include different voices, such as in cases where threads occur, indicating other people responding to the original primary disclosure. These could be voices that support the original primary disclosures or they could be negative messages, representing the stigma and discrimination that still exists today.

An element of interactivity in terms of participation and collaboration exists, although it occurs outside the digital realm. Viewers of the installation are invited to act upon the space – to leave their own latrinalia in addition to or in response to the existing ones. In this way the work becomes a living narrative. These additions converse with the existing micro-fictions, thus adding to, in a kind of collaboration with the creator of the work and others who leave latrinalia. The work also incorporates elements of remediation by providing new ways to access old media such as photographs, newspaper articles, and archival documents.

## 5.2 ONCE UPON A VIRUS

*Once Upon A Virus* is a personal game of interactive fiction that uses fantasy as a critical device by employing fairy tales to retell and revision the story of HIV. The goal was to critique societal attitudes towards disease through the creation of a fantasy world where the attitudes being critiqued are presented in an amplified manner as a way of challenging the status quo. (See Appendix E)

This work draws on queer and feminist writers' practice of subverting literature as an act of resistance, reflection and therapy. Using fairy tales, the work brings the HIV virus into a fantasy realm through the creation of a dynamic work of fiction that grows and changes, revealing more layers as it is read and interacted with. Using Dixon's theories on the types of interactivity, the work allows the reader agency over how they navigate the story through its non-linear hypertext structure (Dixon 563). The hypertext structured web of stories thematically extends the metaphor of the HIV virus and the way that the story of HIV changes depending on who is telling it. This work employs critical design in the techniques it uses to take advantage of the digital medium in order to thematically reflect, draw attention to, or subvert and critique themes of inequality. The story also acts as a counternarrative and upon further reflection I realize that the work provided a kind of self-therapy and escape as it was easy to become disheartened when I was digging around in the historical AIDS archive, and coming across numerous stories of stigma, discrimination, violence, and death. The work became a kind of way to process those emotions and to reflect upon the stories I was coming across.

## **6. REFLECTIONS**

### **6.1 CREATING TRANSMEDIA WORKS**

An important factor to consider when talking about storytelling and the marginalized is who has the power to tell stories and what stories are most amplified. The dominant narrative of people living with HIV in the mainstream media has historically been from the perspective of the “gay white male”. Transmedia storytelling afforded me the ability to create works that could incorporate diverse voices. I did not want to create a work where I merely erased the “gay white male” perspective. Instead, I wanted to find a way to bring in stories from other demographics and tell them in unison with the stories that we already know. The artist Zoe Leonard says that “this story is a collective story, complicated and multi-sided,” and I strongly believe that the stories we tell about HIV should reflect that (Leonard 69). I decided to explore different storytelling formats because I believe that it is in the nature of activist works to be transmedia. Additionally, I did not want my final works to live in a gallery space. I was interested in the idea of having them transform and evolve. Dr. Donna Hancox writes that there is potential for interactive and immersive storytelling tools to amplify under-represented voices through the utilization of transmedia storytelling conventions and the borrowing of elements of digital storytelling and documentary film making (50). Hancox explains that a central philosophy of transmedia activist projects is to decentralize the concept of authorship so as not to privilege one voice, one part of the story, or one platform over another (51).

### **6.2 CHOOSING THE RIGHT NEW MEDIA TECHNOLOGY**

At the beginning of this project, I had intended to use an AR comic book to speak about stigma. I had chosen the medium simply because I thought it would be cool;

however, during my comparative works analysis of AR novels and comic-books, I found that AR as a reading tool was often seen as a gimmick. I was not able to find many forms of AR novels or AR comic-books and the genre seemed to be relegated to children's picture books in the style of 3D pop-up books. I came to the conclusion that AR books for adults hadn't quite taken off because they created an awkward reading experience, having to read a longform work through a screen and then turning pages in the real. Computer scientist Ronald Azuma argues that what makes augmented reality storytelling compelling is the manner in which the real and the virtual are combined into the core experience.

If the experience is based on reality by itself, with little contributed by augmentations, then there is no point in using AR. Conversely, if the core of the experience comes solely from virtual content, then the augmentation part is only a novelty and it will not be a viable form of media. (Azuma 261)

Azuma goes on to write that there are three techniques one can use to ensure that the real and the virtual form critical parts of the experience: reinforce, reskin, or remember. For *AR Disclosures*, I employed the reinforce technique which involves the selection of "a real environment that is inherently compelling by itself, without augmentation and then add AR to it as a complement to the power inherent in reality" thus forming a new kind of experience that ends up being more compelling than either the real or virtual elements by themselves (262).

In my case the real environment was the bathroom stall where interesting latrinalia already normally existed. I was attempting to create a kind of cultural augmentation by then adding virtual latrinalia about HIV to the environment, thus creating a new more compelling kind of way to experience that latrinalia and HIV. In this way, AR was a great fit to transform that bathroom environment. This discovery influenced my choice of



making a site-specific bathroom installation, as exhibiting *AR Disclosures* as a poster loses the thematic and symbolic significance that latrinalia provides.

A con of this reinforcing approach is that although the “real world does some of the work providing the meaningful experience, as reality is already compelling on its own,” the project becomes tied to a specific location and its real-world characteristics (Azuma 266). An upside of this is that a project can be scaled up and designed to create different experiences in different locations.

### **6.3 USING FANTASY METAPHORS TO SPEAK ABOUT HIV**

I had expected that perhaps the fairy tale and fantasy metaphors in *Once Upon A Virus* would have been too abstract for readers, however, I was pleasantly surprised by the results of the user testing. Many participants were able to deduce that the story was about HIV and others who didn't read the bit in the beginning that revealed the metaphors, brought up similarities in the themes to the current coronavirus. I do not think it is necessary to know exactly what a metaphor is derived from in the history of HIV; the story's main goal is to explore societal attitudes towards disease, and this comes across even with the fairy tale abstractions and metaphors.

### **6.4 AUTHOR VISION VS. AUDIENCE AGENCY**

The creation of the story itself was challenging as I had a lot of trouble balancing my vision for what the story was and the need to satisfy the audience's want for agency over an interactive story. By providing choices in a choose-your-own-adventure style type format, this implied that that the reader was in control or at least expected their choices to have a meaningful impact on the narrative and for me also meant that the narrative could grow exponentially. As a writer, this hindered my creation process as I began to feel stifled by the pressure to create meaningful choices for the reader. The story also began

to feel more like a game and less like the tale I wanted to tell. Because I had a very specific story in mind, I decided to lean into the idea of revelations, and interconnected lives and stories, thus transforming the story into a tale with interactive elements. This way readers understood that their control over that narrative was in how they experienced it and how things were revealed to them, instead of them influencing the characters actions.

## **6.5 WORKING WITH DIGITAL MEDIA TOOLS**

One main advantage of working with digital tools during this thesis was that they provide the opportunity for self-publication in the storytelling process, especially using open-source tools like Twine. Digital media makes the process of distributing the stories much easier and opens up the storyteller to a wider audience. However, a challenge for me was the learning curves on using certain technologies such as Twine and Unity. I found that they added a lot of steps to the storytelling process and at times I felt like my storytelling was constrained by the technology. My solution to this was to repurposing the technologies like Twine as a visual aid so that I could see an overview of the story's web and create the *Once Upon A Virus* hypertext from scratch thus allowing me to add in different elements like p5.js, a JavaScript creative code library, which I was unable to do when solely using Twine. This allowed me to make my user interface more engaging.

## **6.6 CREATING DURING A GLOBAL PANDEMIC**

I think my two research outcomes as living narratives. What this means is that the works are designed to be constantly evolving and changing, whether through their form or their content. Unfortunately, as the spread of the coronavirus, now known as COVID-19, widened, I was unable to physically install the *AR Disclosures* project. Being forced to pivot at such a crucial stage in the thesis process, I found myself leaning into the idea of transmedia activism. In this way, the lockdown and calls for social-distancing gave me a

chance to push the transmedia aspects of the work with the creation of an interactive web-version of *AR Disclosures*. The web version was created using p5.js and features a few of the primary disclosures “installed” on a 4500-pixel wide HTML canvas. When a user hovers over the primary disclosures with a mouse, a secondary disclosure is triggered and revealed. This exploration of the project in a different format provided an opportunity for me to also learn more about the technical challenges that could come about when translating work to different formats. I realized that the same project would not always be successful in another medium; the web version does not load on mobile devices such as phones as the canvas was too large. To counter this, I created a screengrab video of the web version on a desktop and whenever a person visits on a mobile device, they are presented with the video instead of a blank screen.

My project, which was inspired and created to tell the story of one epidemic, ended up being disrupted by a global pandemic. What this experience revealed to me was that our society’s attitudes towards certain diseases hasn’t truly evolved. When I began my research and news of the coronavirus was emerging, I noticed certain xenophobic attitudes towards Asian communities and was unaware of how much worse these would get as time went on. The coronavirus revealed the cracks in our society, not only through xenophobia but also through the lack of support for the poor and communities of color. In some ways, some aspects of the COVID-19 situation are similar to those of HIV, however conflating the two risks erasing the unique aspects that led to the horrors of the AIDS crisis. Particularly, because as we are now told that “we are all in this together” as people all around the world are on lockdown, during the height of the AIDS crisis there was no such option, and it was more or an us-against-them situation.

## **7. CONCLUSIONS AND FUTURE WORK**

### **7.1 SUMMARY**

This thesis was inspired in part by my frustration over the fact that almost four decades into the AIDS epidemic, stigma and discrimination still plays a factor in slowdown of progress in the fight against HIV and AIDS. I set out to explore new forms of storytelling in a bid to find creative and unconventional formats to tell the story of HIV. Through my work, I wanted to add to the existing conversation about the disease as a way to raise awareness that HIV and AIDS are far from over. The need to explore storytelling also stemmed from the fact that I had not been able to find depictions of HIV that fell in the fictional, fantasy context. To fill this gap, I explored transmedia storytelling in the form of an augmented reality interactive documentary and an interactive dystopian fairy tale retelling as an example of how storytellers could develop new vocabularies to talk about the epidemic. The goal of this project is to give voice to the stories and perspectives of marginalized groups that often go unheard.

To support this endeavor, I constructed research into the history of the disease, storytelling tactics used by AIDS activist groups, experimental storytelling techniques, queer and feminist writing practices, and zine culture as a form of self-expression and activism. I additionally carried out an extensive exploration of the existing HIV and AIDS related canon and literature ranging from non-governmental reports, documentaries, social media memorial accounts, fiction, poetry collections, and art created by people with lived experiences and those working in the field. The project was informed by my background as an artist, storyteller, and designer and by my own experiences as an avid reader of science fiction and fantasy.

Armed with this research and experience, I engaged in an iterative research through design process that drew upon Critical Design, Transmedia Storytelling, and Research through Design methodologies. My first prototype was *AR Disclosures* a living narrative which explored storytelling around the topic of disclosures using augmented reality latrinalia as a form of cultural augmentation. The second prototype was *Once Upon A Virus*, a hypertext fiction of interwoven stories which explored themes of inequality, that drove the AIDS epidemic by subverting and retelling fairytales.

## **7.2 RESEARCH QUESTION REVIEW**

This work is guided by the following research questions:

In what ways might storytellers leverage new media technologies to retell and revision the story of HIV and AIDS for a new audience?

This thesis found that when selecting new media technologies to tell stories about HIV, in order to avoid falling into the trap of picking a technology just because it seems cool, a storyteller should attempt to marry the theme of the technology they choose to that of the story. In other words, the affordances of the technology should complement the story either by enhancing, contrasting, or emphasizing them. In *AR Disclosures*, AR's affordances of revealing virtual content speaks to the idea of revelations and disclosures while the interconnected web-based hypertext medium speaks to the idea of the chaos of the epidemic, multiple intersectional voices, and a story that is constantly evolving depending on who you listen to. Therefore, the choice of new media tool depends on the "language" the storyteller wants to use and the metaphors that can be created from it. This in turn will affect the form and structure of the stories being told. *AR Disclosures* is concerned with creating a visual language and tells stories using the form of latrinalia illustrations, while *Once Upon A Virus* is concerned with creating a new figurative

language and tells stories using allegory and metaphors through the form of a fairy tale. In order to come up with these new languages and formats of approaching the topic of HIV, this thesis found that appropriating unconventional and experimental storytelling formats could lead to the discovery of novel new media forms such as through borrowing and remediating from graffiti art practices and queer and feminist storytelling practices.

### **7.3 FUTURE WORK**

The next step for *AR Disclosures* is to open the project up to potentially the HIV community in a participatory design context, where people can tell their own stories as latrinalia. I believe this will add a new layer of depth to the project to depict what living with HIV is like today. I would like to run latrinalia drawing workshops as a way to generate stories; the call for latrinalia that was put out as part of this thesis was unsuccessful in part, I suspect, because of the many steps it involved in asking potential participants to send in digitized illustrations. The goal of the workshops would be to create a space for real-time creation or generation of latrinalia by reducing the technical steps that were a part of the initial call for latrinalia. In this way, the burden of capturing and generating augmented latrinalia in programs like Unity3D can fall on me, while the other participants can focus on simply telling stories through latrinalia drawings. I also believe that such workshops could offer the opportunity to teach the creation of AR latrinalia on a beginner level for those interested, using apps such as Eyejack which simplify the process by only requiring digital photos and .gif files. This could add a layer of empowerment to the project, as other people would be able to create their own latrinalia or even set-up their own installations or similar projects.

The *Once Upon A Virus* story is a personal project whose story world continues to grow the more I read and discover about HIV. I would like to add audio and images to

enhance the narrative. I want to eventually extend the fairy tale into a full-length novel format in order to flesh out the characters and their experiences. I have also been toying with the idea of using social media formats to tell the events of the story in real-time on platforms such as Instagram which a large portion of Millennials and Gen Z use.

I believe that counterstories have the power and potential to influence attitudes and thinking around HIV, and that there is a need for even more diverse and creative ways to tell these stories about the state of the epidemic because AIDS is far from over.

## WORKS CITED

- 1RIC. "Terminal 3 by Asad J. Malik." *1RIC*, <https://1ric.com/terminal-3>. Accessed 5 Mar. 2020.
- Aarseth, Espen J. *Cybertext: Perspectives on Ergodic Literature*. JHU Press, 1997.
- Adichie, Chimamanda Ngozi. *The Danger of a Single Story*.  
[https://www.ted.com/talks/chimamanda\\_adichie\\_the\\_danger\\_of\\_a\\_single\\_story](https://www.ted.com/talks/chimamanda_adichie_the_danger_of_a_single_story).
- Albano, Heather. *Harvesting Interactive Fiction*. <https://www.gdcvault.com/play/1022034/Harvesting-Interactive>. Game Developers Conference 2015.
- "Amplified Activism: Transmedia Storytelling and Social Change." *The Writing Platform*, 10 Jan. 2014, <http://thewritingplatform.com/2014/01/amplified-activism-transmedia-storytelling-and-social-change/>.
- Andersen, Peter Bøgh. "Adapting and Extending Structuralist Methods." *A Theory of Computer Semiotics: Semiotic Approaches to Construction and Assessment of Computer Systems*, 1991, pp. 75–188, doi:10.1017/CBO9780511665660.
- Anthropy, Anna. *Queers in Love at the End of the World*. 2013, <https://w.itch.io/end-of-the-world>.
- Apter, T. E. "Introduction: Fantasy and Psychoanalysis." *Fantasy Literatur: An Approach to Reality*, pp. 1–12.
- "Augmented Reality's Documentary Potential." *International Documentary Association*, 21 Sept. 2018, <https://www.documentary.org/feature/augmented-realitys-documentary-potential>.
- Azuma, Ronald. "Location-Based Mixed and Augmented Reality Storytelling." *Fundamentals of Wearable Computers and Augmented Reality, Second Edition*, edited by Woodrow Barfield, CRC Press, 2015, pp. 259–76. DOI.org (Crossref), doi:10.1201/b18703-15.
- Azuma, Ronald T. *Malibu, CA 90265 Azuma@isl.Hrl.Hac.Com*. pp. 355–85.
- Bernheimer, Kate. *Fairy Tale Is Form, Form Is Fairy Tale*. <https://d3ml8cfhn9inlg.cloudfront.net/wp-content/uploads/2014/07/Fairy20Tale20is20Form-1.pdf>. Accessed 15 Feb. 2020.
- Bittanti, Matteo. "GAME ART: RAÚL ENTTER & MÓNICA RIKIĆ'S WE WILL NEVER FORGET (2019)." *GAMESCENES*, 21 June 2019, <https://www.gamescenes.org/2019/06/game-art-ra%C3%BA-entter-m%C3%B3nica-riki%C4%87s-we-will-never-forget-2019.html>.
- Bolter, Jay David, and Richard Grusin. "Immediacy, Hypermediacy, and Remediation." *Remediation: Understanding New Media*, pp. 20–50, <https://mitpress.mit.edu/books/remediation>. Accessed 19 Feb. 2020.
- . "Introduction: The Double Logic of Remediation." *Remediation: Understanding New Media*, pp. 1–15, <https://mitpress.mit.edu/books/remediation>. Accessed 19 Feb. 2020.
- Bookchin, Natalie. *The Intruder*. 1999, <https://bookchin.net/projects/the-intruder/>.
- Bouchardon, Serge. *Mind the Gap! 10 Gaps for Digital Literature?* 5 May 2019, <http://electronicbookreview.com/essay/mind-the-gap-10-gaps-for-digital-literature/>.
- Byager, Laura. "This AR Documentary Lets You Know How It Really Feels to Interrogate Someone at Immigration." *Mashable*, <https://mashable.com/article/augmented-reality-documentary-immigration/>. Accessed 5 Mar. 2020.
- Chandra, Akshita. "Grimm Reality." *Akshita Chandra*, <https://akshitachandra.com/p5284685/>. Accessed 6 Mar. 2020.
- Chun, Wendy Hui Kyong. "Did Someone Say New Media." *New Media, Old Media: A History and Theory Reader*, Routledge, 2006. *Open WorldCat*, <http://site.ebrary.com/id/10196282>.
- CNN, By Doug Gross. "Pulitzer Winner to Publish New Story, One Tweet at a Time." *CNN*, <https://www.cnn.com/2012/05/24/tech/social-media/new-yorker-story-twitter/index.html>. Accessed 12 Feb. 2020.
- "Coronavirus: Fear and Stigma in Paris's Chinatown." *France 24*, 5 Feb. 2020, <https://www.france24.com/en/20200205-coronavirus-fear-and-stigma-in-paris-s-chinatown>.
- Cotter, Holland. "Act up New York." *The New York Times*, 15 Oct. 2010. *NYTimes.com*, <https://www.nytimes.com/2010/10/15/arts/artsspecial/15galleries-03.html>.
- Cummins, Eleanor. "The New Coronavirus Is Not an Excuse to Be Racist." *The Verge*, 4 Feb. 2020, <https://www.theverge.com/2020/2/4/21121358/coronavirus-racism-social-media-east-asian-chinese-xenophobia>.
- Cunningham, Shawn. "Is True Blood About Gay Rights? Fan Theory Debunked." *ScreenRant*, 13 Feb. 2020, <https://screenrant.com/true-blood-series-not-gay-rights-commentary-reason/>.



- Davtyan, Mariam, et al. "Addressing Ebola-Related Stigma: Lessons Learned from HIV/AIDS." *Global Health Action*, vol. 7, Nov. 2014. *PubMed Central*, doi:10.3402/gha.v7.26058.
- Delgado, Richard. "Storytelling for Oppositionists and Others: A Plea for Narrative." *Michigan Law Review*, vol. 87, no. 8, 1989, pp. 2411–41. *JSTOR*, *JSTOR*, doi:10.2307/1289308.
- Dunne, Anthony, and Fiona Raby. *Critical Design FAQ*.  
<http://dunneandraby.co.uk/content/bydandr/13/0>. Accessed 7 Aug. 2019.
- Durrant, Abigail C., et al. "Research Through Design: Twenty-First Century Makers and Materialities." *Design Issues*, vol. 33, no. 3, July 2017, pp. 3–10. *DOI.org (Crossref)*, doi:10.1162/DESI\_a\_00447.
- Entter, Raul, and Mónica Rikić. *We Will Never Forget*. 2019, <https://monicarikic.com/we-will-never-forget/>.
- "Excerpts From Rushdie's Address: 1,000 Days 'Trapped Inside a Metaphor.'" *The New York Times*, 12 Dec. 1991. *NYTimes.com*, <https://www.nytimes.com/1991/12/12/nyregion/excerpts-from-rushdie-s-address-1000-days-trapped-inside-a-metaphor.html>.
- "Fake News Alert: Eight Children Contract HIV From Walmart Bananas." *POZ*, 9 Feb. 2017, <https://www.poz.com/article/fake-news-alert-eight-children-contract-hiv-walmart-bananas>.
- Flanagan, Mary. "Critical Computer Games." *Critical Play: Radical Game Design*, MIT Press, 2009, pp. 223–49.
- . "Designing for Critical Play." *Critical Play: Radical Game Design*, MIT Press, 2009, pp. 251–62.
- Galavotti, Christine, et al. "New Narratives for Africa: Using Stories to Fight HIV/AIDS." *Storytelling, Self, Society*, vol. 1, no. 2, Jan. 2005, <https://digitalcommons.wayne.edu/storytelling/vol1/iss2/3>.
- Geary, Adam M. "Rethinking AIDS in Black America." *Antiblack Racism and the AIDS Epidemic: State Intimacies*, edited by Adam M. Geary, Palgrave Macmillan US, 2014, pp. 1–29. *Springer Link*, doi:10.1057/9781137438034\_1.
- Global AIDS Update 2018 — Miles to Go—Closing Gaps, Breaking Barriers, Righting Injustices | UNAIDS*. 13 Aug. 2018, <https://www.unaids.org/en/resources/documents/2018/global-aids-update>.
- Global AIDS Update 2019 — Communities at the Centre — Defending Rights, Breaking Barriers, Reaching People with HIV Services*. p. 316.
- Goffman, Erving. *Stigma Notes on the Management of Spoiled Identity*. Prentice-Hall, 1963. *Open WorldCat*, <https://www.worldcat.org/title/stigma-notes-on-the-management-of-spoiled-identity/oclc/560026772>.
- Grace, Lindsay. "Critical Games: Critical Design in Independent Games." *DiGRA 2014 — <Active Noun> the <Verb> of Game <Plural Noun>*, 2014, p. 10. *Zotero*, <http://www.lgrace.com/documents/Critical%20Games%20Critical%20Design%20in%20Independent%20Games.pdf>.
- "Granny's Dancing on the Table - a GRANNY-INVASION!" *Kickstarter*, <https://www.kickstarter.com/projects/370814120/grannys-dancing-on-the-table-a-granny-invasion>. Accessed 9 Mar. 2020.
- Green, Alicia. "PosterVirus Returns to Raise HIV Awareness!" *POZ*, 28 Nov. 2016, <https://www.poz.com/article/postervirus-returns>.
- Haggard, Kit. "How a Queer Fabulism Came to Dominate Contemporary Women's Writing." *The Outline*, <https://theoutline.com/post/5751/fabulism-fiction-carmen-maria-machado-daisy-johnson-melissa-broder>. Accessed 15 Feb. 2020.
- Hancox, Donna. "From Subject to Collaborator: Transmedia Storytelling and Social Research." *Convergence*, Jan. 2017. Sage UK: London, England, *journals.sagepub.com*, doi:10.1177/1354856516675252.
- Hayles, Katherine. *Electronic Literature: What Is It?* <https://eliterature.org/pad/elp.html>. Accessed 19 Nov. 2019.
- "HIV/AIDS at 30: A Public Opinion Perspective." *The Henry J. Kaiser Family Foundation*, 1 June 2011, <https://www.kff.org/report-section/hiv-aids-at-30-section-1/>.
- HIV.gov. "What Are HIV and AIDS?" *HIV.Gov*, 17 June 2019, <https://www.hiv.gov/hiv-basics/overview/about-hiv-and-aids/what-are-hiv-and-aids>.
- "How AIDS Anxiety Is Changing New York -- New York Magazine - Nymag." *New York Magazine*, <https://nymag.com/news/features/47175/>. Accessed 18 Feb. 2020.
- Jackson, Shelley. *"My Body" - a Wunderkammer*. 1997, [http://collection.eliterature.org/1/works/jackson\\_my\\_body\\_a\\_wunderkammer/index.html](http://collection.eliterature.org/1/works/jackson_my_body_a_wunderkammer/index.html).

- Jenkins, Henry. "Searching for the Origami Unicorn | The Matrix and Transmedia Storytelling." *Convergence Culture: Where Old and New Media Collide*, New York University Press, 2006, pp. 93–130. *Library of Congress ISBN*, <https://www.hse.ru/data/2016/03/15/1127638366/Henry%20Jenkins%20Convergence%20culture%20where%20old%20and%20new%20media%20collide%20%202006.pdf>.
- "J.K. Rowling's Allegory Fail: Werewolves Are Not a Useful Metaphor for HIV/AIDS." *Salon*, 13 Sept. 2016, <https://www.salon.com/2016/09/12/j-k-rowlings-allegory-fail-werewolves-are-not-a-useful-metaphor-for-hiv-aids/>.
- Kejriwal, Rohini. "An Artist Looks at Grimms' Fairy Tales and Finds Sexist Stereotypes That Are Common in India." *Scroll.In*, <https://scroll.in/magazine/923726/an-artist-looks-at-grimms-fairy-tales-and-finds-sexist-stereotypes-that-are-common-in-india>. Accessed 6 Mar. 2020.
- Kember, Sarah, and Joanna Zylińska. "Introduction: New Media, Old Hat." *Life after New Media: Mediation as a Vital Process*, MIT, 2015.
- Kerr, Theodore. "How to Have an AIDS Memorial in an Epidemic." *C Magazine Issue 142*, no. 142, June 2019, p. 34.
- Kiefer, Elizabeth. "Meet the Girls Who Developed the Internet's Most Talked-About (and Addictive, and Awesome) New Game, 'Tampon Run.'" *Teen Vogue*, 19 Sept. 2014, <https://www.teenvogue.com/story/tampon-run-game>.
- Kopelman, Loretta M. "If HIV/AIDS Is Punishment, Who Is Bad?" *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine*, vol. 27, no. 2, Jan. 2002, pp. 231–43. *academic.oup.com*, doi:10.1076/jmep.27.2.231.2987.
- Kult Magazine. *Issue #03 - AIDS*. <https://kultstore.online/products/issue-03-aids>. Accessed 8 Feb. 2020.
- Kwai, Isabella. "An Outbreak of Racist Sentiment as Coronavirus Reaches Australia." *The New York Times*, 31 Jan. 2020. *NYTimes.com*, <https://www.nytimes.com/2020/01/31/world/australia/coronavirus-racism-chinese.html>.
- Leonard, Zoe. "Muscle Memory." *Coming After*, pp. 66–70.
- López, Adriana Garriga. "Boricuas ACTing UP in New York and San Juan: Diasporic AIDS Activism, Colonialism, and Anthropology." *New Proposals: Journal of Marxism and Interdisciplinary Inquiry*, vol. 2, no. 2, May 2009, pp. 38–44.
- Malik, Kenan. "Locked-down Wuhan and Why We Always Overplay the Threat of the New | Kenan Malik." *The Guardian*, 2 Feb. 2020. *www.theguardian.com*, <https://www.theguardian.com/commentisfree/2020/feb/02/coronavirus-wuhan-lockdown-breeding-ground-fear-stigma>.
- Martin, Bella, and Bruce M. Hanington. *Universal Methods of Design: 100 Ways to Research Complex Problems, Develop Innovative Ideas, and Design Effective Solutions*. Digital ed, Rockport Publishers, 2012.
- McDowell, Alex. "Storytelling Shapes the Future." *Journal of Futures Studies*, Mar. 2019.
- Merck. "New Survey of Young Adults Uncovers Low Levels of Accurate Knowledge About HIV." *MultiVu | Merck*, 25 Nov. 2019, <https://www.multivu.com/players/English/8614851-merck-owning-hiv/>.
- Montfort, Nick, and Noah Wardrip-Fruin. *Acid-Free Bits: Recommendations for Long-Lasting Electronic Literature*. <http://eliterature.org/pad/afb.html>. Accessed 19 Nov. 2019.
- Needle, Chael. *Owning HIV: Misinformation & Stigma Among Youth | A&U Magazine*. <https://aumag.org/2020/01/17/owning-hiv-misinformation-stigma-among-youth/>. Accessed 8 Feb. 2020.
- Ofri, Danielle. "With Coronavirus, as with AIDS, We Must Move beyond the Fear." *STAT*, 30 Jan. 2020, <https://www.statnews.com/2020/01/30/coronavirus-aids-ebola-moving-beyond-fear/>.
- P5.Js*. <https://p5js.org/>. Accessed 10 Mar. 2020.
- Pavlik, John V., and Frank Bridges. "The Emergence of Augmented Reality (AR) as a Storytelling Medium in Journalism." *Journalism & Communication Monographs*, vol. 15, no. 1, Mar. 2013, pp. 4–59. *SAGE Journals*, doi:10.1177/1522637912470819.
- Pratten, Robert. "Introduction to Transmedia." *Getting Started with Transmedia Storytelling: A Practical Guide for Beginners*, 2nd Edition, pp. 1–11.
- Radek, Kimberly M. *Using Fantasy to Save Reality, or the Importance of the Quest to Understanding Gendered and Religious Identity Construction*. Union Institute and University, 2016. *ProQuest*, <https://search.proquest.com/docview/1844966842/abstract/BF7CD489748F471BPQ/1>.

- Reed, Paul. "Early AIDS Fiction." *Confronting AIDS through Literature: The Responsibilities of Representation*, 1st ed., University of Illinois Press, 1993, <https://www.press.uillinois.edu/books/catalog/44tgx5tn9780252019890.html>.
- Rollins, Charlemae. "StoryTelling - Its Value and Importance." *Elementary English*, vol. 34, no. 3, 1957, pp. 164–66. JSTOR.
- Ronson, Jon. "How One Stupid Tweet Blew Up Justine Sacco's Life." *The New York Times*, 12 Feb. 2015. *NYTimes.com*, <https://www.nytimes.com/2015/02/15/magazine/how-one-stupid-tweet-ruined-justine-saccos-life.html>.
- Rose, Frank. "The Art of Immersion: Why Do We Tell Stories?" *Wired*, Mar. 2011. *www.wired.com*, <https://www.wired.com/2011/03/why-do-we-tell-stories/>.
- Rosen, Harold. "The Importance of Story." *Language Arts*, vol. 63, no. 3, 1986, pp. 226–37. JSTOR.
- Rowling, J. K. *Remus Lupin | Wizarding World*. <https://www.wizardingworld.com/writing-by-jk-rowling/remus-lupin>. Accessed 18 Feb. 2020.
- Santayana, George. *The Life of Reason; or, The Phases of Human Progress*. New York : C. Scribner's Sons, 1905. *Internet Archive*, <http://archive.org/details/lifeofreasonorpho1sant>.
- Santayana, George | Internet Encyclopedia of Philosophy*. <https://www.iep.utm.edu/santayan/>. Accessed 7 Feb. 2020.
- Sassón-Henry, Perla. "North Meets South: Jorge Luis Borges's 'The Interloper' and Natalie Bookchin's Media Experiment The Intruder." *Borges 2:00: From Texts to Virtual Worlds*, 2007, pp. 101–12, <https://bookchin.net/wp-content/uploads/2015/09/borges2.0.pdf>.
- Scaccia, Annamarya. "Why You NEED to Get an HIV Test — Even If You Don't Think You're at Risk." *Teen Vogue*, <https://www.teenvogue.com/story/why-young-people-dont-get-tested-for-hiv>. Accessed 8 Feb. 2020.
- Snyder, Gregory J. "Getting In." *Graffiti Lives: Beyond the Tag in New York's Urban Underground*, pp. 1–12.
- Stappers, Pieter, and Elisa Giaccardi. "Research through Design." *The Encyclopedia of Human-Computer Interaction*, 2nd ed., Interaction Design Foundation. *www.interaction-design.org*, <https://www.interaction-design.org/literature/book/the-encyclopedia-of-human-computer-interaction-2nd-ed/research-through-design>. Accessed 21 Jan. 2020.
- Storyspace: Storyspace*. <http://www.eastgate.com/storyspace/index.html>. Accessed 19 Feb. 2020.
- Street Stories - Street Art That Helps Homeless Kids off the Street*. <http://streetstories.org.uk/>. Accessed 14 Feb. 2020.
- Street Stories - Street Art That Helps Homeless Kids off the Street*.---. <http://streetstories.org.uk/>. Accessed 21 Feb. 2020.
- Strong, Philip. "Epidemic Psychology: A Model." *Sociology of Health & Illness*, vol. 12, no. 3, 1990, pp. 249–59. *Wiley Online Library*, doi:10.1111/1467-9566.ep11347150.
- Taylor, Josh. "Bat Soup, Dodgy Cures and 'Diseasology': The Spread of Coronavirus Misinformation." *The Guardian*, 31 Jan. 2020. *www.theguardian.com*, <https://www.theguardian.com/world/2020/jan/31/bat-soup-dodgy-cures-and-diseasology-the-spread-of-coronavirus-bunkum>.
- Taylor, Tracey. "Narratologist Andrea Macrae on Narratives That Define, Defy, and Tell Us Who We Are." *LOCAL LEGENDS*, <http://www.local-legends.org/people/2017/8/13/you-need-to-have-a-set-of-conventions-in-order-to-rebel-against-them>. Accessed 14 Feb. 2020.
- "The Guardian View on China and the Coronavirus: Scrutiny, Not Stigma | Editorial." *The Guardian*, 29 Jan. 2020. *www.theguardian.com*, <https://www.theguardian.com/commentisfree/2020/jan/29/the-guardian-view-on-china-and-the-coronavirus-scrutiny-not-stigma>.
- The Princess and the Witch by Kat Howard | Fantasy Magazine*. <http://www.fantasy-magazine.com/new/new-nonfiction/the-princess-and-the-witch/>. Accessed 11 Feb. 2020.
- Tiku, Nitasha. "Teenage Coders behind Tampon Run Take Their Feminist Game to the App Store." *The Verge*, 3 Feb. 2015, <https://www.theverge.com/2015/2/3/7964667/tampon-run-feminist-game-girls-who-code>.
- Twine / An Open-Source Tool for Telling Interactive, Nonlinear Stories*. <https://twinery.org/>. Accessed 19 Feb. 2020.
- University of Cincinnati. "How the Ebola Scare Stigmatized African Immigrants in the US." *ScienceDaily*, 11 Feb. 2015, <https://www.sciencedaily.com/releases/2015/11/151102131515.htm>.

- Wainberg, Mark A., and Andrew M. L. Lever. "How Will the Ebola Crisis Impact the HIV Epidemic?" *Retrovirology*, vol. 11, no. 1, Nov. 2014, p. 110. *BioMed Central*, doi:10.1186/s12977-014-0110-z.
- Walker, Jill. "Distributed Narrative: Telling Stories Across Networks." *Ubiquity?*, 2004, <http://jilltxt.net/txt/Walker-AoIR-3500words.pdf>.
- Walter, John. *Alien Sex Club*. 2018 2015, <https://wellcomecollection.org/exhibitions/XFximBAAAPkAioWn>.
- . "John Walter on 'Alien Sex Club.'" *Wellcome Collection*, <https://wellcomecollection.org/articles/Wqqc7SAAAB4AH9-T>. Accessed 16 July 2019.
- Weiner, Andrew. "Disposable Media, Expendable Populations – ACT UP New York: Activism, Art, and the AIDS Crisis, 1987–1993." *Journal of Visual Culture*, May 2012. Sage UK: London, England, [journals.sagepub.com](http://journals.sagepub.com), doi:10.1177/1470412911430584.
- WHO. "Global Health Observatory (GHO) Data." *WHO | HIV/AIDS*, <http://www.who.int/gho/hiv/en/>. Accessed 8 Feb. 2020.
- Wilson, Ciann Larose, et al. "Narratives of Resistance: (Re) Telling the Story of the HIV/AIDS Movement – Because the Lives and Legacies of Black, Indigenous, and People of Colour Communities Depend on It." *Health Tomorrow: Interdisciplinarity and Internationality*, vol. 4, no. 1, 2016. [ht.journals.yorku.ca](http://ht.journals.yorku.ca), <https://ht.journals.yorku.ca/index.php/ht/article/view/40213>.
- "Young People, HIV and AIDS." *Avert*, 20 July 2015, <https://www.avert.org/professionals/hiv-social-issues/key-affected-populations/young-people>.
- Zimmerman, Amelie. *Blurring the Line Between Fiction and Reality. Functional Transmedia Storytelling in the German TV Series About:Kate*. no. 22, July 2015, <http://www.gib.uni-tuebingen.de/own/journal/upload/bb53f351f013a250142bad066e4156b5.pdf>.

## APPENDIX A: *AR Disclosures* 1st Prototype



Figure 4: A mock-up of the "Just found out I am HIV+" and "U=U" latrinalia in a bathroom environment

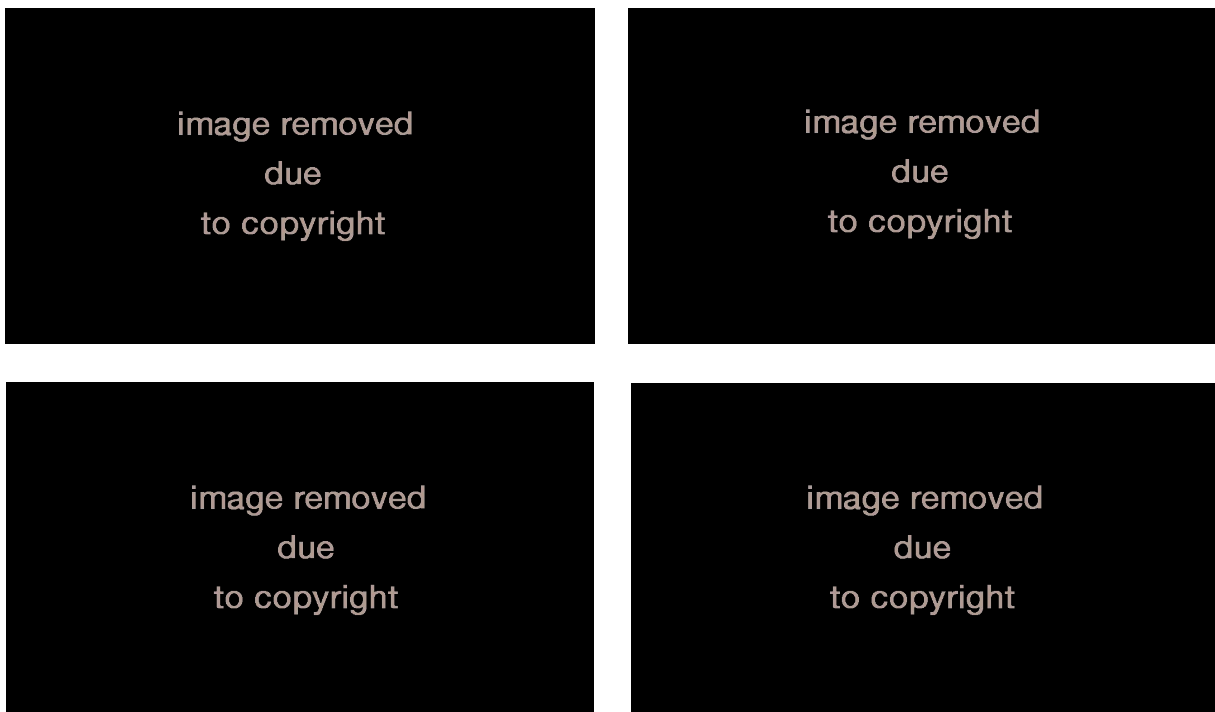


Figure 5: A screenshot from the first prototype website for *AR Disclosures* showing revelations of different quadrants of the “bathroom wall” sections

The anger section was the first quadrant on the screen and revealed that not only was the person angry, but they were freaking out. The second quadrant was anxiety and this one revealed that the person was wondering how long they had to live. The third quadrant was hope which included illustrations of medicine bottles and a .gif of a person dancing with the words “it’s not the end of the world”. The last quadrant was fear, and this one revealed that the person was afraid that after making the disclosure “Just found out I’m HIV+” their lover would leave them.

## APPENDIX B: AR Disclosures 2nd Prototype

THEME / TOPIC	PRIMARY DISCLOSURE IDEA	SECONDARY DISCLOSURE IDEA
Safe sex	The word "PrEp" in reference to medication that can prevent you from becoming positive	"PrEP" would become "Prepare yourself. [BE SAFE]"
Day one found out	A birthday cake	Text that says "found out three days before my 18 <sup>th</sup> birthday"
Disclosure	"Just found out I'm HIV+"	Multiple secondary disclosures that would say "same" "#IMSTILLME". "Am I gonna die?"
Humor / Testing	"Roses are red / violets are blue..."	"I have HIV / And so might you! Xoxo"
Stigma / HIV can happen to anyone	A sketch of two stick people looking at an empty picture frame	"I'm not the picture of someone with AIDS in your mind". Text will show up in the picture frame
Hope	"You can..."	List of word scrolling "Live+, work+, thrive+, survive+, get married+, fuck+..."
Humor	Doodle drawing of a drag queen. "I know that sometimes HIV can be a drag..."	"...but it can't keep a good queen down!" (animate the drag queen)
Stigma	"HIV is a punishment from God..."	"Nah! Jesus and I are tight!"
HIV isn't the end of the world	"Better Days" scrawled next to a smiley face	"Literally take 1 pill a day and that's the only time I remember I have HIV"

Figure 6: Table showing the theme and issue matrix created for 2nd prototype iteration of AR Disclosures

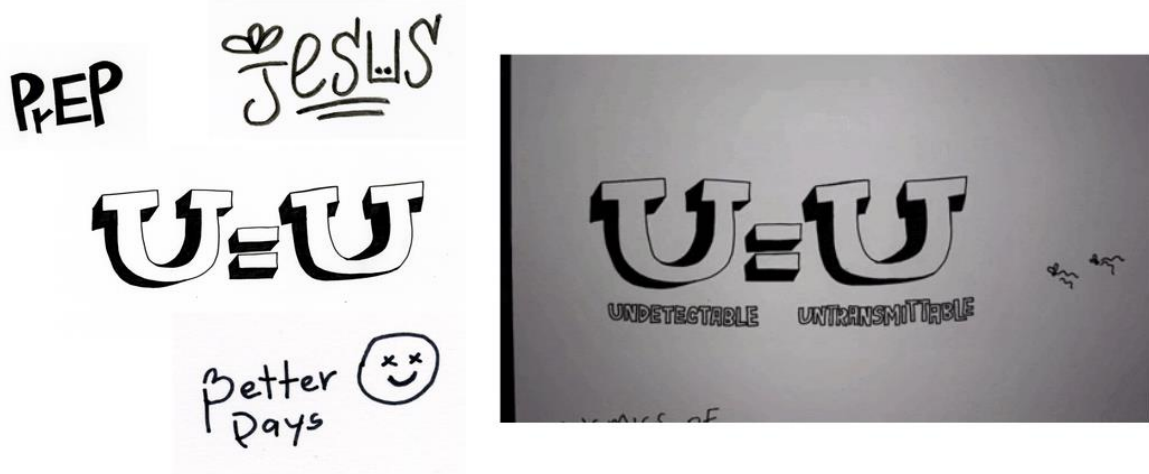


Figure 7: Some of the hand drawn primary disclosures and a screenshot of the AR secondary disclosure when viewed using EyeJack

## APPENDIX C: AR Disclosures 3rd Prototype

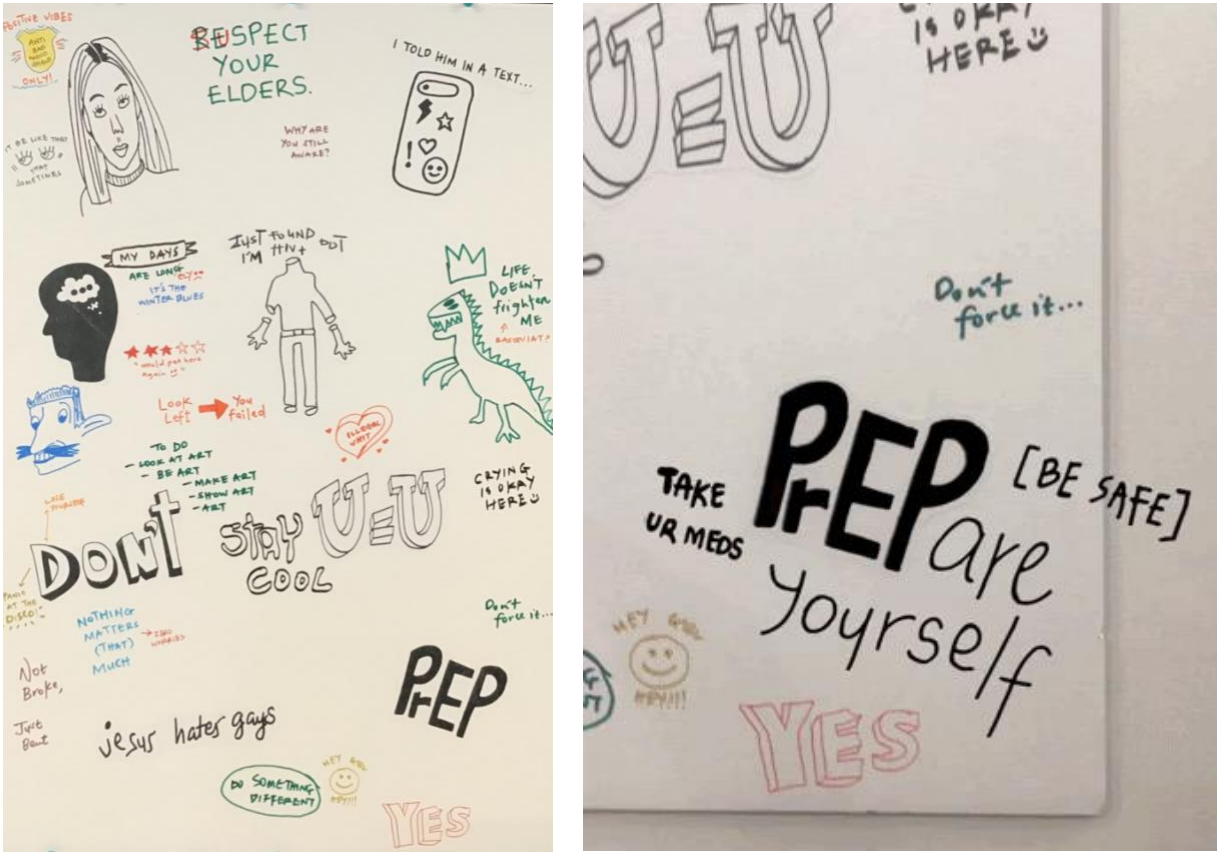


Figure 8: The 16x20 augmented reality poster featuring a number of AR primary disclosures, a screengrab of the augmentation of the PrEP illustration viewed using Eyejack



Figure 9: Closeups of different AR secondary disclosures on the 3rd iteration poster for AR Disclosures





Figure 10: The 3rd iteration of AR Disclosures installed for public exhibitions at OCAD University



# APPENDIX D: *Once Upon A Virus* 1st Prototype

## CURSED

Once upon a time, in a place, neither near nor far, and a time neither now nor then, an illness swept through the land of Mira. It was unlike anything anyone had ever seen. Like a hurricane sweeping up everything and everyone in its path, the plague did not care about the who, the which, or the where. It came, it took, and many felt like it would never really leave.

So terrible was the devastation that soon a great fear spread across all of the realm. People began to speak of witches and curses, those who believed spoke of punishments from Above, urging others to repent. Neighbours started to eye each other with suspicion and soon even brother turned against brother.

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*Once Upon A Virus*

RESTART

## SIGNS

It was easy at first to tell those who had been marked by the plague. First came the fever, then the small purplish/reddish lesions indicating that it was only a matter of time before the inevitable.

Death.

Many began to monitor their own bodies anxiously awaiting the signs of infection – swelling, weight-loss, pale skin, shortness of breath... They tried many remedies, old and new, tried and true, to heal the sick but nothing worked, for all the fairy godpeople and all the wizards and witches of the kingdom could not magic the sickness away.

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*Once Upon A Virus*

RESTART

## UNTOUCHABLE

The story, changed as all stories do when they move from one set of lips to the next. The monster. A shadow. A spectre. A plague. A beast. A curse...The damned. Those who were ill soon found themselves isolated and alone for even their own families were afraid to touch them or drink after them. They became untouchable. It came to the attention of some that most of those who fell ill first were fae – members of community who were outside society's graces – And because the history of such things is that someone will be blamed, the fae were blamed. It was decided that to stop further spread of infection, the fae were to be quarantined to the outskirts of the kingdom and a wall was erected to keep the rest of the kingdom safe.

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*Once Upon A Virus*

RESTART

## BLOOD

And just like that all over the kingdom everyone was thinking about BLOOD.

It was passed on through BLOOD

bad BLOOD  
good BLOOD  
BLOOD test  
BLOOD runs cold  
poisoned BLOOD  
clean BLOOD  
dirty BLOOD  
BLOOD curse  
BLOOD magic  
in your blood BLOOD  
BLOOD will tell  
flesh and BLOOD  
BLOOD is thicker than water  
new BLOOD  
old BLOOD  
young BLOOD  
fresh BLOOD  
blue BLOOD  
BLOOD money  
BLOOD on your hands  
BLOOD boils

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*Once Upon A Virus*

RESTART

Figure 11: Pages from the 1st prototype of *Once Upon A Virus*, created using Twine

## APPENDIX E: *Once Upon A Virus* 2<sup>nd</sup> Prototype



Figure 12: Pages from the 2<sup>nd</sup> Prototype of *Once Upon A Virus* created using HTML5, JavaScript and CSS

# APPENDIX F: *Once Upon A Virus* 2nd Prototype Map

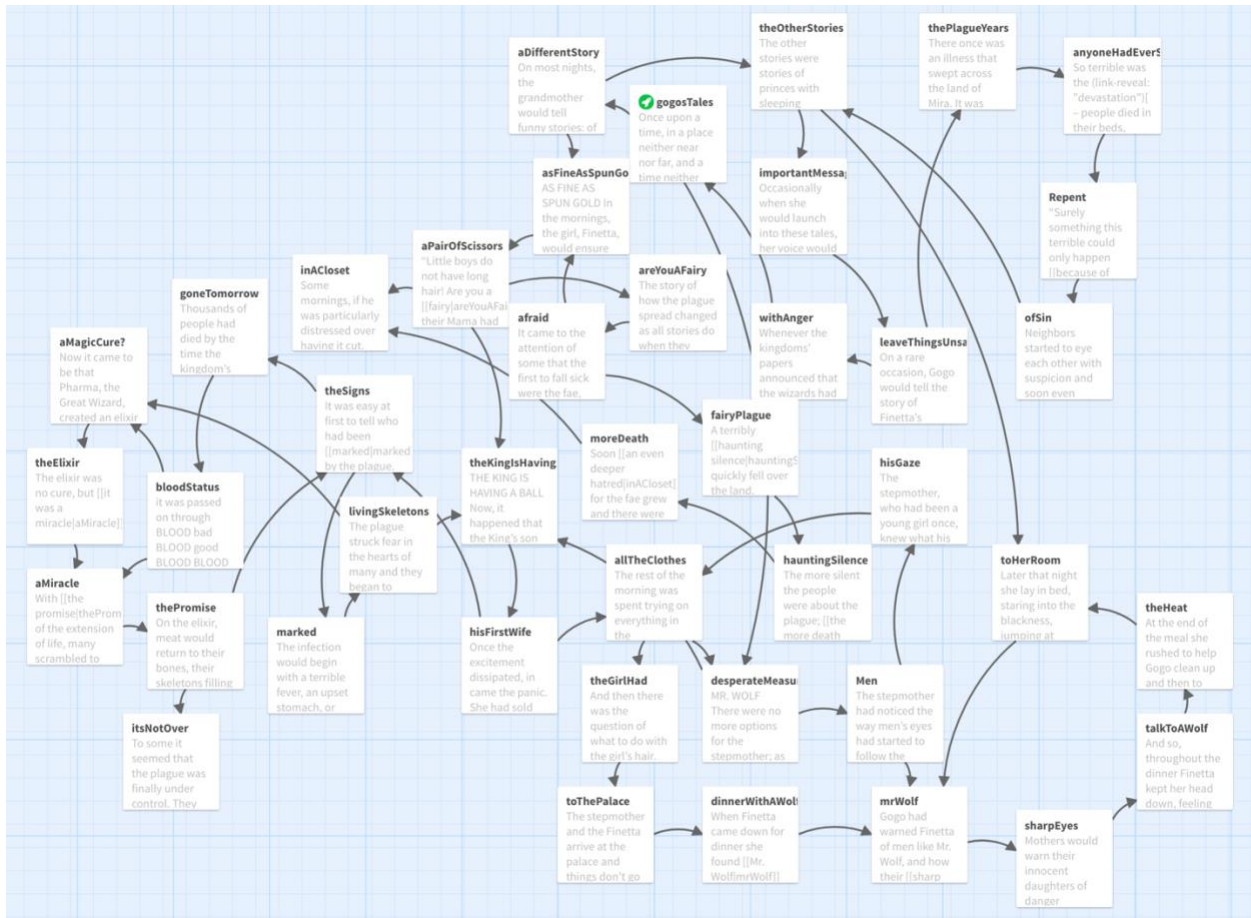


Figure 13: The *Once Upon A Virus* 2nd prototype Twine map showing linked story sections