## **University of Alberta**

Using Social Media for Health Information: How New Technologies are Being Used in HIV/AIDS Communication

by

## Ali Kira Grotkowski

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#### **ABSTRACT**

Social networking sites, mobile technologies and other information and communications technologies have become popular ways of connecting. The health information field is no exception; however, what are best practices and strategies to effectively use the affordances of these tools, and currently common uses of these changing media? This study examines both how new media are discussed and how tools such as YouTube, Facebook, Twitter, LinkedIn,

Google+, Fropper, blogs, and Flickr are employed using HIV/AIDS as the health topic of focus. A content analysis of sources spanning academic, lay and professional content, in publications, news articles, and websites as well as Web 2.0 examples was conducted. The results show that tools can be interactive and can reach many, not only youth. Implications for practice include the need to effectively use the affect heuristic and emotion to impart messages, and to devote appropriate time and resources to these health communications tasks.

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#### **CHAPTER 1: INTRODUCTION**

In the health sciences it can be crucial to obtain the latest information for the treatment of a particular illness. Similarly, communicating information in a timely manner can positively affect members of the public whether in preventing the spread of an illness or infection by a pathogen. One such illness is Acquired Immune Deficiency Syndrome, known as AIDS, an illness caused by the Human Immunodeficiency Virus, or HIV ("HIV/AIDS," 2011). Indeed, Walensky et al. (2006) indicate that the treatments for AIDS developed in the 1990s have saved more than three million years of life in the United States alone, gains that would not be realized if these new treatments had not been communicated to medical professionals.

Much of the research with regards to HIV/AIDS focuses on Africa, in specific Sub-Saharan Africa, which has the highest HIV prevalence in the world; however, the virus affects people worldwide (UNAIDS, 2013). The International Federation of Library Associations and Institutions (IFLA) has a committee on Freedom of Access to Information and Freedom of Expression (FAIFE) which collects and shares documents within and outside of libraries ("Committee on Freedom of Access to Information and Freedom of Expression (FAIFE)," 2013). One such document was published in 2006: the IFLA/FAIFE theme report on *Libraries and the Fight against HIV/AIDS, Poverty and Corruption* (Seidelin, Jensen, & International Federation of Library Associations and Institutions, 2006). Since then, much has changed technologically. This report includes many articles themed around the issues that information organizations, specifically libraries, have dealt with surrounding the HIV/AIDS epidemic. Yet, the advent of new technologies and the adoption of these said technologies surely have changed the landscape of communication since then. Social media and other Web 2.0 technologies

have become much more widespread. YouTube, Facebook, and Twitter and many other social media did not become widespread until after the beginning of 2006, for example. The prevalence of tablet computers (e.g. the iPad), along with many other types of technology including smart phones has increased since the beginning of 2006. That said, extreme poverty means that many of these types of technology may not penetrate into certain areas of the world; the types of communication strategies that are appropriate in one area may differ from those that are appropriate elsewhere in the world. Penetration of different technologies in areas of differing economic, social and geographic means differs worldwide.

#### Research Problem

The goal of this study was to examine how newer forms of technology and social media are used as communication strategies for HIV/AIDS information. As a result, this study examined works that describe communication strategies for HIV/AIDS information, looking at geographic, cultural, technological and other characteristics, with a focus on communication techniques requiring computers, social media, and other multimedia technology. Using what is learned from these works, some of the source materials of these communication strategies were also examined to determine if and how these factors were reflected in the communication strategies themselves. A mixed methods approach, including both qualitative and quantitative content analysis was used to analyze a maximum variation sample of sources both describing such communication strategies, and forming such strategies to communicate HIV/AIDS information. This study benefits many areas of scholarship because it helps determine just how these newer technological strategies are used. Specifically, the question of how emotion is used, accounted for, and framed forms a frame for the qualitative analysis of these sample communications.

### **HIV/AIDS**

In the United States HIV/AIDS and its devastating effects were first recognized in 1981 (Frey & Odle, 2006). The virus is transmitted in several ways: through sexual contact, in pregnancy from mother to baby, through exposure to contaminated blood or blood products, or through needle sticks, particularly among health care professionals and drug users (Frey & Odle, 2006; LaPensee, 2008). HIV is not spread through insect bites, sharing drinking glasses, touching others, coughing, sneezing, kissing, handshakes or any other casual non-sexual contact ("AIDS Myths and Misunderstandings," 2011; Frey & Odle, 2006; LaPensee, 2008). There were approximately 35.3 million people living with HIV in 2012, 2.3 million newly infected that year, and 1.6 million deaths worldwide (UNAIDS, 2013). AIDS is considered a major worldwide pandemic, and remains a serious incurable disease (Frey & Odle, 2006; "HIV/AIDS," 2011; LaPensee, 2008). One of the reasons for the rapid spread of the disease is that people may not know they are infected, often for years. While HIV is replicating in the lymph nodes, there is a period of up to ten years or more where only mild, flu-like symptoms, swollen glands or no symptoms at all are present (Frey & Odle, 2006; "HIV/AIDS," 2011; LaPensee, 2008). Thus, the infection can go undetected for some time before treatment is sought, and the virus may be transmitted anew. The most advanced stage of the infection is called AIDS, and is characterized by a low number of CD4+ lymphocytes, a type of white blood cell in the immune system (Frey & Odle, 2006). The result of this is the presence and greater risk of a number of opportunistic infections caused by agents such as fungi, protozoa, mycobacteria, bacteria and viruses (Frey & Odle, 2006). Common symptoms from such infections include "persistent coughing and shortness of breath, seizures, lack of coordination, difficult or painful swallowing, confusion or forgetfulness, severe and

persistent diarrhea, fever, vision loss, nausea, abdominal cramps, vomiting, weight loss, extreme fatigue, and severe headaches" (LaPensee, 2008, p. 12). Other symptoms include dementia, muscular inflammations, oral symptoms, and AIDS-related cancers (Frey & Odle, 2006). Quality of life for a person with AIDS is thus not very good, there being the potential for a great deal of suffering. Treatments have the potential to lengthen life, improve quality of life, and increase the length of time before a patient might develop AIDS after initial HIV infection. Given that there is currently no replicable cure for AIDS (Frey & Odle, 2006; "HIV/AIDS," 2011), the importance of both treatment to improve quality of life, and preventative measures to stop the spread of HIV cannot be ignored.

The Joint United Nations Programme on HIV/AIDS focuses on developing programs and otherwise working to bring an end to new HIV infections, discrimination, and AIDS-related deaths (UNAIDS, 2010). UNAIDS' (2009) recommendation is for countries to use an understanding of their individual epidemics when determining their strategies to respond to the AIDS crisis. Yet, the AIDS Epidemic Update 2009 indicates that this often does not happen (UNAIDS, 2009). HIV prevalence changes dramatically within and between geographic areas: for example, Cuba has very low prevalence, whereas the Bahamas has very high adult HIV prevalence (UNAIDS, 2010). Different populations within the same country may also have vastly different infection rates (UNAIDS, 2010).

#### **Importance of HIV/AIDS communication**

The spread and treatment of HIV can be affected by the availability of information and the tools used to communicate it (Djossa Adoun et al., 2011; Johnson et al., 2008; Sangani, Rutherford, & Kennedy, 2004). Health communication with regards to HIV has been happening since soon after the discovery of the first cases of AIDS, this

communication having changed as both the nature of the disease was more well known and as new tools, techniques and technologies have been developed with which to reach audiences (Noar & Edgar, 2008). Mass media campaigns have a lot of potential as tools in fighting the spread of HIV/AIDS and other sexually transmitted infections as they can be cost-effective, utilize one or multiple communication media, and be deployed to reach large diverse audiences (Palmgreen, Noar, & Zimmerman, 2008). This potential of massmedia and other communications aimed at a broader community is often assumed rather than proved with evidence, because evaluation often comes at a cost and following effective campaign design principles is often difficult when resources are scarce (Noar & Edgar, 2008; Palmgreen et al., 2008). As Noar and Edgar (2008) indicate, newer forms of technology can provide opportunities to address HIV/AIDS communication in an international context, reach newer priority populations and target individuals suffering from health disparities. Indeed, it is suggested that all relevant communication channels, including mass media and social media, be used when communicating HIV information to promote behaviour change (Berzins, Greb, Young, & Hardee, 2014). Knowing how the communication of HIV/AIDS information works when using these social media network tools, and new technologies would aid researchers, practitioners, librarians, politicians, the public and many others in the fight to limit the spread of this disease and its many repercussions.

## Research Questions

Given the focus on newer technologies and their use in the communication of HIV/AIDS information, the following are the research questions concerning HIV/AIDS communication strategies which were the focus of this study:

- 1. In what types of literature (professional, scholarly, lay, etc.) are technology, social media or multimedia strategies for communicating information about HIV/AIDS (whether aimed at health-care providers, consumers, etc.) mentioned?
- 2. In this literature describing these communication strategies, how is HIV/AIDS discussed? What are the messages that the texts convey about HIV/AIDS?
  - a. Are there emotive terms (e.g., terms that evoke sadness, rage, anger, disappointment, happiness, hopefulness, praise, confusions, etc.) used in conveying these messages? If so, in what types of literature?
    - i. If emotive messaging is discussed, how does this messaging fit with the theory described by the affect heuristic?
  - b. Are there particular audiences (e.g., gay men; drug users) targeted in these messages? If so who are they and how are they targeted?
  - c. Are there specific religious, social and/or cultural messages conveyed in these documents? What are they and how are these communicated?
  - d. Are any problems mentioned regarding using these methods to communicate this information? If so what are they, and are they the same worldwide, or do they appear more prevalent in some areas than others?

- e. Are specific communication strategies discussed in terms of specific benefits (e.g. awareness, information recall, behaviour changes)? Do we have information re: what works well vs. what doesn't (and in what contexts)?
- 3. In actual examples of HIV/AIDS communication strategies using social media, new technology or multimedia, what are the approaches used to present information?
  - a. Is the message targeted or tailored to the audience of the message? What is the assumed audience? Is it explicit or implicit in the message communicated? How is this accomplished?
  - b. What kind of language/imagery is used in the message itself?
    - i. Are there emotive terms or images (e.g., terms that evoke sadness, rage, anger, disappointment, happiness, hopefulness, praise, confusions, etc.) used in the messages themselves? How are these terms used? Who are the targets of these emotions?
    - ii. What is the affect of these messages? How does the affect heuristic play into the messages?
    - iii. How formal is the language used and/or presentation style of this communication? What kind of language is being used (e.g. jargon or undefined terms and/or reading level, slang, dialect)?How is this language being used?
  - c. What is the intended result of the message is communicated through these communication strategies, e.g. Preventative, ongoing care, research, academic, pedagogical, etc.? How is this communicated?

d. How is the delivery method used appropriate to the message communicated?

#### Relevance

While this topic is of obvious interest to those in public health and other directly health-sciences related fields, this research is of note for many others. This research into communication strategies has the potential to impact the fields of librarianship in general, health science librarianship specifically, the health sciences, public health, technology, the digital humanities, and others who may be interested in communication of information, HIV/AIDS, health information, and related topics, including organizations looking at best practices for health communication.

Health sciences librarianship is a profession consisting of health sciences librarians and informationists who serve people who need information related to the biological sciences, such as patients, medical professionals, academics and others (E. H. Wood, 2008, pp. 3–4). Individuals working in the field of health sciences librarianship are becoming more and more important to researchers, doctors and other health care professionals, whether because of requirements to qualify for grants, or because of their subject expertise when searching for information. Indeed, health sciences librarians are often consulted in order to find and communicate information regarding new treatments, protocols, published information about various conditions, general health information and much more (M. S. Wood, 2008). Because of the nature of their duties and their role with the public and the health care profession, health sciences librarians would certainly benefit from a better understanding of different communication strategies for health information. Health sciences librarians have the responsibility of working with researchers and health care practitioners. With projects such as the Ptolemy project at the University of Toronto,

Canadian health sciences librarians may also aid researchers in less developed nations, making their skills in health communication beyond their local area important (Beveridge, Howard, Burton, & Holder, 2003; "Ptolemy Project," n.d.). A better understanding of social media and new technology communications may inform librarians' choices when choosing how best to use their resources to communicate HIV/AIDS information

Given the increased emphasis on technology both in health sciences librarianship and in general communication, it is of great interest how technology figures into the communication of health sciences information, in particular information surrounding such a deadly disease as AIDS. Certainly, technology is not the sole purview of library and information studies, or of computer scientists. Humanities computing or the digital humanities also focus on how technology figures into the equation when it comes to communication of information. In addition, digital humanists are studying communication strategies in the context of social media, rich prospect browsing, multimedia, text analysis, corpus linguistics, and many other aspects in humanities domains (Hockey, 2004; McCarty, 2005). Not only are the technology aspects and communication styles aspects of humanities computing relevant to these research questions, but this project could lend itself well to future research and eventual visualization. Potentially this information could be used to influence future communication strategy choices; however, care must be taken regarding the extent to which this particular research is transferable. Transferability refers to whether findings from a study might be applicable to another context. This differs from generalizability which refers to findings being applied to a much broader context rather than simply to different context. Transferability is the aim of qualitative research, and this study's

methodology is further described in chapter 3. Recently, the sciences and health sciences have been the focus of much attention; thus, this study of how health information, in specific HIV/AIDS information, is communicated could impact thought about other similar communication strategies going forward.

#### **CHAPTER 2: LITERATURE REVIEW**

### **Communication**

One of the first major well known descriptions for how communication functioned was developed by Claude Shannon and Warren Weaver for Bell Laboratories in 1949. Shannon and Weaver (1949) described the communication system as following mathematical theory. While the mathematical equations they use are complex, their theory tends to be summarized by the following five parts operating in a relatively linear fashion: an information source, a transmitter, the channel, the receiver, and the destination (Shannon & Weaver, 1949). Noise is another factor in this model which describes that which disrupts or otherwise creates an error in what is received at the destination. The information flows in a unidirectional fashion in this model, going from the information source that creates the message to the destination mediated by whatever communication technology, if any, is present. Based on the affordances of the telephone and radio, the prominent technologies of the time, this theory is still used to this day to simplify communication.

Since this time, many other models of information communication have been developed. Some of the more well known models of communication include situations where communication operates in both directions, with each participant operating as both sender and receiver, and with both reacting, listening, to each other's words. Barnlund (1962) describes communication as creating meaning, as happening whenever meaning is given to stimuli, broadening again the field of communication well beyond a simple two-way conversation or communication mediated through some form of technology. His theory of meaning-centered communication (Barnlund, 1962) is very different from that of Shannon and Weaver; however, both are indicative of the breadth of the discipline. These

two theories may indicate the breadth of communication theory, however as Craig (1999) states, "scholars seized upon every idea about communication, whatever its provenance". Indeed the range and complexity of communication theory is so vast that it might be argued that there is no one approach at all. Craig (1999) argues that communication theory as a field is not at all unified, and as a result does not yet exist as an identifiable field, there being no canon of general theory available. Yet, given the disparities of perceptions of communication theory, he also argues that communication theory should become a coherent field, and that all theories are relevant (Craig, 1999). Part of the problem stems from the lack of agreement between disciplines as to what is meant by communication theory, it having appeared in so many academic disciplines independently (Craig, 1999). While an overview of textbooks on communication theory might offer hundreds of definitions for communication theory, Craig (1999) provides a framework of seven traditions of communication theory: rhetorical, semiotic, phenomenological, cybernetic, sociopsychological, sociocultural, and critical. The matrix of how these traditions of communication theory work together provides both the suggestion that these are relevant to interdisciplinary research, but also that there is a disciplinary focus to the work following any of these traditions (Craig, 1999). Indeed, other perspectives are useful when using any one of these approaches to the study of communication.

#### Health communication

Health communication can be considered a whole field unto itself. Not only are the challenges involved with communicating health information very specialized but jargon and other specific terms risk alienating the target audience and/or causing confusion. Communicating health information based on particular types of health sciences information needs is one of the roles of a health sciences librarian (E. H. Wood, 2008).

Advances in the field of health information necessitate continued communication strategy development; even those who are informed need to be kept abreast of the latest developments in the field.

As Kreuter and Wray (2003) indicate, health communication strategies are more effective when they succeed in making relevant the information that is communicated to their intended audience. Two approaches exist to make these messages more relevant: tailoring and targeting, which both have very similar characteristics. Tailored messages are based on a particular individual's status with respect to one or more variables, whereas targeted messages are aimed at a broad audience segment. While both approaches are seen to have more success than having a purely generalized message communicated, tailored messaging tends to fit more accurately to a specific person's needs and results in more favorable response than the more broad targeting technique (Kreuter & Wray, 2003).

While Kreuter and Wray's (2003) approaches of tailoring and targeting messages are key to the success of making messaging meaningful, there are also other factors that affect the success of health communication. Meaningful messages have value and importance for those who are receiving or interacting with them. Abroms and Maibach (2008) describe the effectiveness of mass communication campaigns on health behaviour, stating that large programs of health promotions that are not precisely targeted but which use many communication interventions are very successful. In addition, using the media to help influence the social milieu in which individuals live, their support networks, their communities, their social networks, and the places in which they live has the most potential for success when compared to interventions which only target individuals irrespective of their environments (Abroms & Maibach, 2008). It is important to realize

the importance that people-and-places play in the effectiveness of mass communication to change behaviour, since these factors affect individuals' decisions regarding how they act. Within this people and places framework, social marketing, or the use of marketing to change health behaviour in individuals essentially consists of communication (Maibach, Abroms, & Marosits, 2007). Improving communication and marketing competencies in the area of public health worldwide will help, as the workforce is undertrained in this key area (Maibach et al., 2007). Maximizing the impact of current resources through partnerships and shared knowledge could go a long way to ensuring that public health messages are communicated; however, more is needed in the area of communication and marketing (Maibach et al., 2007).

Yet, health communication is not limited only to communication and marketing: health literacy plays an important role in the success of following through with encouraged health behaviours. As Lanning and Doyle (2010) explain, inadequate health literacy is closely linked to poor health, and inadequate health care access. Still, there is a large category of the population who has low health literacy: as the Public Health Agency of Canada indicates, "60% of adults and 88% of seniors in Canada are not health literate" ("Health Literacy," 2011). Health literacy can be defined as "the ability to access, comprehend, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course" ("Health Literacy," 2011), and is important for people's ability to maintain their health and use health care services effectively (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Lanning & Doyle, 2010). The three levels of functional health literacy are defined as the ability to read health materials such as labels and forms; the ability to understand information from health professionals including both written and oral information; and the ability to act on

health directives such as medicine administration directions, appointment schedules and other procedures (Lanning & Doyle, 2010, p. 155). Effective health communication must take into account the person to whom the message is being communicated, and also his or her degree of participation in the communication process (Lanning & Doyle, 2010). If he or she cannot fulfill the three levels of functional health literacy, then he or she cannot fully participate in the process; indeed it is not enough for the message to be provided, the message must also be understood to be put into practice. So, the language must be at a level that the recipient can understand, using culturally and linguistically appropriate terminology (Lanning & Doyle, 2010). The media used also needs to be appropriate to the culture and specific abilities of the recipient of the message, as does communication style, that is to say that both different learning styles and receptivity to the use of and/or access to a particular media will impact the ability for someone to understand a particular message (Lanning & Doyle, 2010).

#### HIV/AIDS communication

Many different communication theories have been applied to HIV/AIDS communication in the past. These theories include "the health belief model, the theory of reasoned action, social learning/cognitive theory, diffusion of innovation and social marketing" (Airhihenbuwa & Obregon, 2000, p. 7). These theories were designed from a linear, rational and individual perspective (Airhihenbuwa & Obregon, 2000). Airhihenbuwa and Obregon (2000) indicate that these aforementioned theories, while having a modicum of success in certain societies, appear inadequate when addressing the communication of HIV/AIDS messages in many areas such as Africa, Asia, Latin America and the Caribbean, in part because of the assumptions made when using these theories. Systematic strategic communication is seen as a potentially valuable approach in

response to the HIV/AIDS epidemic, particularly when contrasted with ad hoc HIV/AIDS communication strategies such as designing a poster or a radio spot at one particular moment in time (McKee, Bertrand, & Becker, 2004, p. 26). As McKee, Bertrand and Becker (2004) indicate, while this approach holds much promise, it has been underutilized in the past. Having strategic communication is not enough on its own; the strategy needs to be appropriate to the particular context of the population to which this communication is delivered. Cultural sensitivity ought to be an important aspect of health communication, including using the appropriate medium with which to communicate (Airhihenbuwa & Obregon, 2000; Lanning & Doyle, 2010). The cultural model PEN-3 is an approach that refers not only to the individual but the context, evaluating for positive, existential and negative aspects of the community and allowing the messaging to promote the positive, recognize the existential and contextualize that which is negative (Airhihenbuwa & Obregon, 2000, p. 12). This is a more culturally sensitive approach to HIV/AIDS communication. Airhihenbuwa and Obregon (2000) argue that culture should be an important aspect of HIV/AIDS communication, and that in an HIV/AIDS communication strategy, flexibility should be built in to allow for regional and national differences in communication both in the messaging used and the media through which these messages are communicated.

McKee et al. (2004) indicate that using multiple channels of communication is important for effective strategic communication, as these can be combined to reinforce the message; indeed they argue that the entire question of which channel to use to communicate is an out-dated notion. Many different factors impact what communication channels are being used, including the complexity of the issue communicated, the sensitivity of the issue communicated, the literacy of the target population, the desired reach of the program, the

prevailing social norms, the media habits and other preferences of the intended audience, and the cost of using these channels (McKee et al., 2004, p. 39). Targeted communication aimed at youth, gender, sex workers, men who have sex with men, injecting drug users, mobile populations and populations in conflicts & emergency situations all pose different challenges (King, 1999; McKee et al., 2004). Communities need to be partners (not just targets) in the communication that is occurring with regards to HIV/AIDS (McKee et al., 2004). Mass media is useful for both targeted communications and also for communications for services, so while the choice of channel of communication is not necessarily as important, the choice to use channels is a key part of the communication process in all situations (McKee et al., 2004). In addition, coordination of communication efforts rather than the duplication of these efforts by similar organizations is most effective; this allows for not only reinforcement of the messages communicated, but also affords a better result, as resources need not be spent on two nearly identical campaigns by different organizations for the same population (McKee et al., 2004). Many approaches for HIV/AIDS communication exist, but a few noteworthy examples include the Entertainment-Education method, Peer Education, and the use of Information and Communications Technology (ICTs)(McKee et al., 2004). Combining these approaches with the use of targeting, coordination of communication efforts and the use of multiple communication channels should lead to effective communication campaigns (King, 1999; McKee et al., 2004).

Most theories on which HIV/AIDS prevention interventions are based use the assumption that giving correct information will lead to changes in behaviour, but this alone has not been proven to be the case (King, 1999). While the majority of these theories have been focused on individuals, considering other social theories and models as well as structural

and environmental models helps take into account more factors that influence behavioural change. Finally, constructs used on their own and transtheoretical models have also impacted prevention interventions, as increased perception of risk of activities and increased sexual communication within couples serve to increase protective behaviours (King, 1999). For example, a study by Stevens and Hall (1998) of lesbian and bisexual women undergoing interactions with peer educators showed that these women would become more likely to follow through with protective behaviours once they identified with the peer educators who made the risks of contracting HIV salient. Likewise, Kippax and Race (2003) encourage the framing of HIV/AIDs as a social public health issue, recognizing that behaviours are not individually determined but instead are influenced by the entire social and cultural context of their occurrence.

### The IFLA/FAIFE Theme Report

In 2006, IFLA and FAIFE issued the report "Libraries and the fight against HIV/AIDS," Poverty and Corruption" which addressed poverty, corruption and HIV/AIDS information dissemination with regards to libraries and other information organizations (Seidelin et al., 2006). Some of the themes from this report include the idea that while Internet access is key to providing information to meet the needs of library users, it is unlikely to be the answer in areas where orality is the predominant communication mode, there is varying electricity supply, there is high cost of technology, and where illiteracy is a major problem when implementing ICTs (Seidelin et al., 2006). This report places a strong emphasis on the social issues of libraries and information organizations operating in the world as a whole, and demonstrates the need for such organizations' actions in support of the work against HIV/AIDS, and thus in the facilitation of information communication.

#### The affect heuristic

When it comes to behaviour, Slovic et al. (2007) propose that an affect heuristic is used to make judgments. While not all judgments are made based on an affect heuristic, this type of decision making can also be described as using our instinctive and intuitive reactions to make decisions (Slovic & Peters, 2006). Indeed, Slovic and Peters (2006) describe risk analysis in two ways: risk as analysis, meaning bringing logic, reason and scientific deliberation to a problem; and risk as feelings, or the affect heuristic. These two categories could also be described as the experiential and analytic systems, wherein the affective, or pleasure-pain dimension plays a role on the experiential side whereas the logical plays a role on the analytic side (Slovic, Finucane, Peters, & MacGregor, 2004). This means that representations of the real world, whether as objects or events in people's minds, are associated with affect to varying degrees, and these serve as cues for important decisions, potentially an efficient mental short-cut (Slovic et al., 2007). Interestingly, while risk and benefit are often positively related in the real world with relation to high risk activities, people generally correlate them negatively (Slovic & Peters, 2006). Some of the concepts that are key to the affect heuristic include evaluability, or the precision of the affective impression; proportion dominance, or how attractive one option seems in relation to another; insensitivity to probability, or when there is a particularly strong affective meaning, the variation in probability may not be enough to influence the thought about it as possibility becomes more important than probability; the degree to which a hazard evokes feelings of dread; and how high the benefit is in relation to a risk (Finucane, Alhakami, Slovic, & Johnson, 2000; Slovic et al., 2007). Essentially there is an inverse relationship between perceived risks and benefits. The affect heuristic can be considered to be a repudiation of the informed rational choice model; attempts at

affective manipulation work on language and are not recognized as easily as attempts to persuade (Slovic et al., 2007).

Affect can serve a person in several different ways when making health decisions. It can work to provide context for information when adding affective categories to information to provide meaningful information to supplement decision making, when discussing perceived risk, and when communicating, by acknowledging possible emotional responses to a threat (Peters, Lipkus, & Diefenbach, 2006). Affect as a spotlight, can focus a person's attention on a particular aspect of an item or on a risk or benefit (Peters et al., 2006). For example, as Scherer and Fagerlin (2013) found, people are much more likely to get tested if they think the same test is for a specific form of cancer rather than for an unidentified illness, cancer, or disease, making it evident that judging information by the affective labels influences decision making. Affect serves as a motivator for further information processing and behaviour, for example, ambivalence may trigger information searching to help solve an issue or problem (Peters et al., 2006). Affect may also be thought of as common currency, often allowing a person to compare very disparate aspects or things, as it often comes in two forms: good and bad (Peters et al., 2006). As Slovic and Peters (2006) explain, risk as feelings tends to give too much weight to frightening consequences in certain situations. Still, affect and deliberation both do play a role in making decisions, often based on contextual factors (Peters et al., 2006). Decisions made in a high-pressure time may be influenced more highly by affect than at other times, just as the way that information is presented affects how much logic and reason play into a decision versus how much feelings or intuition play a part (Finucane et al., 2000; Peters et al., 2006). In addition, the affect heuristic can point to why presenting important numerical information as 'dry statistics' does not motivate proper action: it

lacks the affect necessary (Peters et al., 2006; Slovic et al., 2004, 2007). This is an important realization as this points to the fact that adding affect to numbers and statistics can work to make them meaningful for individuals and affect their behavioural decision making.

In risk assessment, the affect heuristic also plays a role alongside race, worldview, and trust (Slovic, 1999). Sex also plays a role wherein men tend to perceive risks as smaller and less problematic when compared to women (Slovic, 1999). Men generally also have both a greater trust in institutions and authorities and a greater anti-egalitarian view wherein these authorities should have the say and not just the general people (Slovic, 1999). Trust in experts is a key aspect as to whether or not the experts' assessments will be followed. When it comes to trust, negative events that destroy trust are much more visible than those that build trust, making it difficult to easily develop this much needed trust in risk communications (Slovic, 1999). In effective risk communication it is important that it is not just what is said that is important, rather how it is said is important (Ropeik & Slovic, 2006). The affect and thus emotion associated with messaging will impact the decisions that are made.

The perception of greater risk is impacted by a number of different factors that may not appeal directly to the rational, but instead fall within the affective dimension (Ropeik & Slovic, 2006). Dread, or intuitive fears impact how risky a behaviour is perceived to be, even if less immediately apparent risks are indeed the more risky. When someone is in control of their circumstances they feel less likely to be at risk when compared to when they are not in control. There is similarly more concern over man-made threats when compared to those which are natural in origin. That which is chosen is thought to be less

likely to be risky when compared to that which is imposed. Risks to children sound worse than risks to adults. That which is new appears more frightening than that which is more well-known. Something we are more aware of is more frightening than what we are less aware. If something is more likely to happen to one's self or someone one is close to it is more frightening. In addition to these factors, there are also the risk benefit relationship that forms part of the affect heuristic, and the factor of how much one trusts the information source (Ropeik & Slovic, 2006).

## **Technology**

Over the course of the past several decades, it is said that we have entered the information age (Darnton, 2000, 2011). Another term used is "e-Age – where everything that is bytesized and scrollable is put up in our densely populated second world – the World Wide Web" (Ansher, 2010). Darnton (2000) argues with this view, stating that "every age was an age of information, each in its own way, and that communication systems have always shaped events". Communication systems affect what is seen as news, affect how news is interpreted, and even affect what information is communicated at all (Darnton, 2000). Wright and Hinson (2008) indicate that blogs and social media have changed public relations and help to make communications more appropriate, including feedback, and other provision of news that is not necessarily mediated by the traditional media. Yet, as Darnton tells us, "new modes of communication do not displace old ones, at least not in the short run" (2011). Indeed what York (2006) calls the Paperless Office Paradox points to the very problem with the assumption that that which has come before will cease to be relevant or exist when adopting new technologies: while personal computing was originally heralded as the end of using paper in the workplace, this led instead to increased paper use. The book and the printed word are and remain major communication

sources. Print journals, books, academic articles, professional publications and other such traditional academic text inform the health sciences today, and will continue to do so in the coming years, whether because of cost or convenience. All information is not available online, nor does it remain stable online for a considerable length of time (Darnton, 2011; Kahle, 1997). Yet, the internet with all of its affordances does provide an avenue for communication of information that should not be ignored. While online sources may be subject to change, inaccessibility or deletion, so are physical sources with disasters such as the burning of libraries being noteworthy examples of information loss (Kahle, 1997; Shepilova, 1992).

Many different communication technologies exist and are used to communicate messages, beyond the printed codex. Examples include Twitter, Facebook and other social media, Websites, interactive tutorials and computer programs, brochures, forums, email lists, presentations, posters, YouTube and other videos, Podcasts, television and radio, and much more besides. Oral and face-to-face communication should not be ignored in the communication landscape either, particularly as this type of communication may be more salient to those who are less able to partake in literate and/or digital communication forms. Enumerating all possible communication technologies that could be used whether multimedia or in one single media would be unlikely if not impossible, but as one can easily tell, the breadth of technologies available beyond the codex and face-to-face communication are many. User-generated media and social media are considered relatively new communication formats. Shao (2009) explains that user-generated media such as Wikipedia, YouTube, and MySpace are used for many reasons including using to obtain information and entertainment, participating to have social interaction and community development, and producing to gain self-expression and

self-actualization. Usability is also of great importance when it comes to such media, as the easier it is to use such communication media, the greater their uptake (Shao, 2009).

Social media can be defined as "a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of User Generated Content" (Kaplan & Haenlein, 2010, p. 61). Web 2.0 really emphasizes the contributions of the users, who can help develop the platform, provide content, and richen the experience of its use (O'Reilly, 2005). Social media allows for the incorporation of many-to-many relationships, that is to say that one message is not only communicated to many people like in a broadcast medium of expression such as that used in most mass media campaigns, but responses may be communicated back to many people and so on and so forth. Collaborative projects, blogs, content communities, social networking sites, virtual game worlds and virtual social worlds all form part of the landscape of social media (Kaplan & Haenlein, 2010). Social media allow for many to view, create, interact with or reply to communication at many of steps of the process.

#### Social media and health information

While traditional media have been a way of reaching the public to provide health information for many years, with an abundance of evidence in the literature, social media is not nearly as well documented (Newbold & Campos, 2011). Still, social media is seen to have a lot of potential for use in public health practice, for example empowering patients to take control of their health (Chou, Hunt, Beckjord, Moser, & Hesse, 2009; Hawn, 2009; Newbold & Campos, 2011). While the use of social media should not replace in-person visits to health practitioners when dealing with issues of great concern, their supplementary information and avenues for communication may allow individuals

to develop deeper relationships with their doctors or help them better ask questions regarding a health need (Hawn, 2009). While issues such as privacy, costs, and legal issues may cause problems with the use of social media in health, this form of interaction has changed communication already (Chou et al., 2009; Eysenbach, 2008; Hawn, 2009). Many approaches have been taken with the use of these technologies, from the ability to text or instant message a doctor or health practitioner, to the use of support groups on the internet (Chou et al., 2009; Hawn, 2009). Chou et al. (2009) indicate that social media can be used to reach populations regardless of socioeconomic and health-related characteristics. While relatively new avenues for health communication, social networking sites, mobile technologies and other tools have potential to significantly impact the delivery and interaction with health information.

#### The digital information divide

In the developing world, simple technologies, such as telephone access and the internet may not be easily accessible, and even if people have access to these technologies other barriers may also prevent easy access to essential health information (Edejer, 2000). Edejer (2000, p. 797) summarizes the problem that developing countries face: "the current digital divide is more dramatic than any other inequity in health or income," stating that interactivity including feedback and change is essential to the future of health information in the developing world. This has potential to truly impact the way that information is communicated for those who have fewer resources to dedicate to the acquisition of and education about various different technologies.

Indeed, the electronic revolution in the developed world is allowing scientists and health practitioners to have immediate access to more information than ever (Godlee, Horton, &

Smith, 2000; Ojo, 2006). While it may be time-consuming and prohibitively expensive to send print copies of various journals to Africa for example, electronic access could potentially have many benefits, allowing for immediate access to information provided appropriate infrastructure is available to allow for its use (Godlee et al., 2000; Ojo, 2006). Thus, free electronic access to health information is both of enormous benefit and flawed: without stable, reliable technological access, initiatives to provide this health information are flawed (Ojo, 2006). Still, when coupled with endeavors to improve access to computers, the internet, and reliable forms of electricity, free digital health information has a lot of potential for developing countries. The economically advantaged developed world is often at odds with what to do with the economically disadvantaged developing world. The health field is no exception. As Horton (2000) states, "the flow of knowledge ... needs to be two-way". This means that not only should developed countries be providing information to the developing nations, but that the converse should be occurring. The barriers to publication in the more recognized developed countries' journals need to be recognized such as language barriers and costs, and the publications in developing countries also need to be recognized (Horton, 2000). Endeavors such as the development of journals using open access, and technologies such as the free open source software, Open Journal Systems, seek to make it easier to publish and reach audiences worldwide ("Open Journal Systems," 2013). A dialogue between the developed and developing countries should and needs to occur. This is the case in both the provision of medical information to doctors and other medical professionals and in the area of public health as well.

Given that many who begin to use online resources are more familiar with the outdated textbooks that they had available prior to their accessing the internet, training can be very

valuable. Unfortunately this is a potential barrier to use, though people such as Lenny Rhine, a retired librarian, continue to work at training and revamping training modules such that individuals can more effectively use resources such as Health Internetwork Access to Research Initiative (HINARI), perhaps the most well-known initiative to ensure access to digital resources for developing countries. As was previously noted, internet connectivity is often not available in developing nations, and without this, online resources are less than useful (Bukachi & Pakenham-Walsh, 2007). However, even if medical professionals have used the internet on a regular basis, if they are unaware of free-access initiatives, they will not access them, and the benefits from initiatives such as HINARI and open access journals will not be accessed (Smith et al., n.d.).

There exist a large number of different endeavours to bring health information to the developing world. That said, some of the most successful endeavours are those that work to bridge the gap between the developed countries and the developing countries with a dialogue wherein both sides are communicating rather than just inundating developing nations with information from developed nations, or communicating within the developed or developing communities exclusively. The situation with HIV/AIDS information is no different. The internet brings with it a great deal of potential for effective communication and future collaboration. Still, the lack of stable reliable internet connectivity in many areas does further disadvantage people, and as such plans to improve the penetration of information technology will serve to improve the potential dissemination of health information.

#### **CHAPTER 3: METHOD**

### **Content analysis**

Given the subject area, works that discuss communication strategies for HIV/AIDS information, a content analysis method was chosen to address the aforementioned research questions. Content analysis is used to interpret meaning from sources by categorizing data based on similarities (Hsieh & Shannon, 2005; Julien, 2008; Mayring, 2000; White & Marsh, 2006). This method is commonly used when analyzing a wide variety of types of textual data along with other media, such as drawings, photographs and video (Julien, 2008). The data chosen in a content analysis must transmit information, that is to say it needs to communicate a message from sender to receiver (Krippendorff, 2004; White & Marsh, 2006). Both quantitative (also known as manifest) and qualitative (also known as latent) content analysis are used to discern patterns in data; however, quantitative content analysis is used more to determine what is present, whereas qualitative content analysis helps to determine why this is present and can also be used to look at the perceptions and other aspects of the presentation of that which is found (Julien, 2008; Lee & Kim, 2001). White and Marsh (2006) explain that in Library and Information Studies (LIS) research, it is common that studies are not purist and instead often incorporate aspects of both quantitative and qualitative content analysis. While each method of content analysis was used to a certain degree, qualitative content analysis allowed for greater interpretation for the findings, to discern what exactly is meant in each mention of a communication strategy by reading the text in further depth (Julien, 2008). Simple frequency counts as used in purely quantitative content analysis would be inadequate to answer the research questions, partially because not only is the prevalence of each strategy not the only question asked, but also because sampling for all possible references to HIV/AIDS information communication strategies would be impossible, thus

making prevalence counts inaccurate at best, and misleading at worst. Instead, the focus was on how each of the mentions of HIV/AIDS communication strategies is discussed, and the depth of information that is contained in the text. As Julien (2008) explains, when it comes to the written word, content analysis can lead to the identification of both intended and unintended meanings found in the text. Given the scope of the research questions, including emotive terms surrounding communication strategies, as well as cultural references, this ability to identify meanings found in the text is key to the decision to use content analysis as the method for this study.

#### **Data Collection part 1**

In order to conduct this study, a search for representative documents was conducted, using a maximum variation sampling method. As White and Marsh indicate, in qualitative content analysis there is a focus on the uniqueness of the text (2006), so in this sample, a diversity of sources is important. Each document formed a data unit for the content analysis. Searching was done both online through Google, Google Scholar, Bing and Yahoo, and through databases including MEDLINE, PubMed, CINAHL, Global Health, Scopus, and Social Policy and Practice. Care was taken with the general internet searches not to be logged into any personalized accounts as not to bias the results. This is important as search engines can use past history of searchers to personalize search results, an ability which is alluded to by Goldman (Goldman, 2005). With new social media networks such as Google+ providing the ability to tailor advertising and search results to a user's past history it becomes important to try to mitigate the effects of personalized search results by using a computer that is not logged in to such accounts if at all possible. That said, search engine bias, particularly based upon the geographic location from which one is searching is inevitable. The Firefox webbrowser, which was not logged in to any

accounts was used for this study, which is a webbrowser on my computer that is not used for any other searching tasks but those related to this thesis. Important inclusion and exclusion criteria guided this search. This helped to eliminate analyses where only materials supporting an original hypothesis or viewpoint were included (Lee & Kim, 2001, p. 305). Major search terms included "HIV/AIDS", "HIV", "social media", "new media", "technology", and "communication" in various combinations. Words referring to specific social media networking sites were not used so as not to bias the search results to one networking site. In addition, social media terms such as "Twitter" and "Facebook" often appear in the sidebar of electronic journal sites and other webpages, resulting in nearly all results in a general internet search including such terms, thus not limiting the results appropriately. Searching in Web 2.0 directly was not done for the similar reasons as those listed for search engine bias; many social media sites do not provide for fullfledged search functionality without being logged in to these sites unless one is navigating there from a separate search engine or a link on the web. While it would have been useful to study information within private or password protected social media accounts, or other accounts requiring a logon, doing so could potentially change that which is available within such networks, either because of the creation of a dummy profile, or because of the influence of one joining such a network. Ethical considerations of creating dummy profiles, even those that state outright that they are for the purpose of research only also suggest that this approach should be used with extreme caution. This being the case, it was deemed more prudent to focus on publicly available sources for this study.

Documents were deemed appropriate if they mentioned or discussed using new technology, such as ICTs, social media or multimedia in the communication of HIV/AIDS information with some explanation of how these communication strategies are used. Medical research publications focusing only on HIV/AIDS were excluded, whereas those that dealt exclusively with communication or messaging with specific populations were included if they also included references to new technologies. Searches were not limited to journal articles, though a number of published reports came from such articles. Non-fiction publications were included such as reports on the use of a particular technology or ICT to communicate HIV/AIDS information, while fiction publications including novels and fictional accounts of how messaging with specific populations works were explicitly excluded. While fiction publications would be of interest for a future study of how these stories might impact HIV/AIDS communication, it was excluded to focus the study upon perceived reality, and also to limit the scope of the search, there being much literature available on this topic already. In addition, sources that denied the link between HIV and AIDS and those that indicated that AIDS was a hoax or other fringe articles were not included in the sample. Only items published or created since the beginning of 2006 were included, not only because the focus is on recent materials, but also because this focused on items published from the time of the IFLA/FAIFE report on Libraries and the Fight against HIV/AIDS (Seidelin et al., 2006) and more recently. This report provided a snapshot of how HIV/AIDS information in libraries and other information organizations was distributed at that time; given changes in technology since that point, with the rise of social media, new technological devices, and an increased emphasis on the widespread use of computers, the state of information transmission has changed since then. Given also that this report urged such work on the part of libraries and other information organizations, it is of note to examine how such technologies are being used to aid such work by libraries and other information organizations. This report was also published shortly after the O'Reilly (2005) article

defining Web 2.0, providing another good starting point for any study of social media. Given limitations of the researcher's abilities, time, and scope of a master's level thesis project, the research focused only on texts found in English. The majority of the references examined were in published and other texts online or in physical form, much of which is available through academic or trade specific publications in academic and librarianship related fields, related to communication strategies for HIV/AIDS information

To find these sources, maximum variation sampling was used, aiming to find examples not only describing or directed to many different countries but also using different dimensions such as to whom the communications were targeted, to create a rich yet diverse sample (Patton, 2002). Following Miles and Huberman's (1994) guidelines for qualitative sampling, this type of sampling helped to find appropriate answers to the research questions. Sampling ended when theme saturation was reached, in this case when more data cease to contribute substantial new information to the themes that came from the coding process (Bowen, 2008).

Given the above criteria, specific sources that were sought included:

- o Books (short books or sections of longer books)
- Academic journal articles (both online and in print)
- Trade publications
- Professional journals
- Websites
- News reports (newspapers etc.)

- Social media (e.g. Twitter, Facebook if publicly available, etc.)
- o Blogs

Of the 115 sources that were found to fit the selection criteria based upon abstract or summary and viewing of the full article or document, 40 sources were sub-selected for content analysis including 10 sources each concerning content of International (e.g. UNAIDS Feature Story), National outside of the United States (e.g. Fropper.com Article), United States (e.g. Administration on Aging Document), and Local (e.g. Cleveland.com Article) sources. All sources found were not analyzed for several reasons, chiefly among which is the problem of duplication: many articles described the same communication campaigns or came from the same organizations. Criteria for subselection included being from as different geographic areas as possible and representing different breadths of geographic areas, describing different campaigns or projects, having a variety of publication dates, being different types of sources, and being available for analysis when the subselection process was undertaken. Table 1 lists the subselected sources used in part 1. A full reference for each source is available in Appendix C. As can be seen the part one subselection includes a variety of dates, locations and organizations involved. The search engines where each source was first found along with major search terms leading to the source are also listed, many sources were found through multiple search engines; however, only the first search engine used to find a source is listed. The organizations listed usually refers to the organization involved with either the publication or creation of the source or the journal where the source was published.

**Table 1: Subselected sources for part 1** 

Source identifier (see Appendix C for full reference)	Organization	Location	Search Engine	Search Terms	Date of Article
Public Health & Internet Annual Review	Annual Reviews Public Health	International	Google Scholar	"HIV/AIDS" "Social Media"	2009
Mindjet Blog Post	mindjet	International (Africa)	Google	"HIV/AIDS" "Social Media"	24-Jul- 12
AIDS Care Article	AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV	International	Google Scholar	"HIV/AIDS" "Social Media"	31- Jan-11
Global Health Article	Global Health and Innovation Conference	International	MEDLIN E	(hiv/ or hiv-1/ or hiv-2/) AND (technology/) limit to English and 2006-current	Sep-12
AIDS Conference	International AIDS	International	Google	"HIV/AIDS"	23-Jul-
PowerPoint IEC to IHC	Vaccine Initiative Journal of Health	International	Google	"New Media" "HIV/AIDS"	12 19-
Article	Communication: International Perspectives	international	Scholar	"Social Media"	Nov- 10
PANCAP Article	PANCAP: Pan Caribbean Partnership against HIV&AIDS	International	Google	"HIV/AIDS" "Social Media"	31- Aug- 12
UNAIDS Feature Story	UNAIDS	International	Google	"HIV/AIDS" "Social Media"	02- May- 11
AIDS Conference Presentation and Q&A	XIX International AIDS Conference	International	Google	"HIV/AIDS" "Social Media"	24-Jul- 12
Social Marketing and Children's Media Article		International	Google Scholar	"HIV/AIDS" "Social Media"	Spring 2008
PLWHA Blog Post	People living with HIV and AIDS in Bali	Local (Bali, Indonesia)	Google	"HIV/AIDS" "Social Media"	31-Jul- 12
Washington Blade Article	D.C. HIV Virtual Resource Center and Dream Factory	Local (Washington D.C.)	Google	"HIV/AIDS" "Social Media"	05- May- 11
Cleveland.com Article	MetroHealth Medical Center	Local (Cleveland, Ohio, USA)	Bing	"HIV/AIDS" "Social Media"	18- Sep-12
BeritaJakarta.co m Article	Jakarta AIDS Prevention Commission	Local (Jakarta, Indonesia)	Google	"HIV/AIDS" "Social Media"	27- Sep-12
ModernGhana.co	CMM	Local (knust	Bing	"HIV/AIDS"	17-

HIV/AIDS (London, "Social Sep-1 ON, Canada) Media"  Article  AMIA Article AMIA local PubMed (social media) Oct-1 (Michigan) AND HIV [limited to	
Behavior Article       California)       AND HIV [limited to 2006-present]         Regional HIV/AIDS       Local L	11
HIV/AIDS (London, "Social Sep-1 ON, Canada) Media"  Article  AMIA Article AMIA local PubMed (social media) Oct-1 (Michigan) AND HIV [limited to	
(Michigan) AND HIV [limited to	4- 12
2006-present]	11
NJ.com Article Newark, NJ Local Bing "HIV/AIDS" 04 (Newark, "Social Feb-1 NJ, USA) Media"	4- 10
Canada) Media"	12
HIV and Media Symposium on National Scopus "social media" 07 Workshop HIV, Law and (Canada) AND HIV Oct-1 Human Rights [limited to 2006-present]	1- 11
E-learning Fountain National Google "HIV/AIDS" 200 Environment Publishers, (Uganda) Scholar "Social Article Kampala Media"	
Article Saadhan (India) Scholar "Social Dec-0 Commission Media"	
HIV Education Journal of National PubMed (social media) Jun-1 Article Telemedicine and (Italy) AND HIV Telecare [limited to 2006-present]	12
Sexual and ReproductiveKIT(Royal Tropical Institute)National (Kenya)Global Health(social media)201Desires ChapterJohanesburg Conference[limited to 2006-present, English Language]	10
Brief Madise (Malawi) "New Media" Nov	5- v- 10
Mobile Learning AIDS Research and National Google "HIV/AIDS" 201  Article Therapy (journal) (Peru) Scholar "Social Media"	10
AudiencescapesInterMediaNationalGoogle"HIV/AIDS"201ArticleKnowledge Center(Mozambiqu e)"New Media"	10
, , , , , , , , , , , , , , , , , , ,	4- 08
Turkish Condom Reproductive National Google "HIV/AIDS" 201 Use Article Health Matters (Turkey) Scholar "Social Media"	_
Text Messaging AIDS Care: National Social "communicati May	y-

Article	Psychological and Socio-medical Aspects of AIDS/HIV	(US)	Policy and Practice	on" AND HIV [limit to 2006- current]	11
Administration on Aging Document	US Administration on Aging	National (US)	Google	"HIV/AIDS" "Social Media"	May- 11
Social Media Forum Video	AIDS.gov	National (US)	Google	"HIV/AIDS" "Social Media"	19- Dec-10
amfAR Briefing Article	amfAR	National (US)	Google	"HIV/AIDS" "New Media"	23- Sep-10
Social Media Tool Article	Black AIDS Institute	National (US)	Google	"HIV/AIDS" "Social Media"	27-Jul- 12
CDC Celebs Article	CDC	National (US)	Bing	"HIV/AIDS" "Social Media"	05- Mar- 10
Gemnaspeaks Blog Post	Gemnaspeaks	National (US)	Bing	"HIV/AIDS" "Social Media"	12- Mar- 10
Virtual Mentor Article	Medicine and Society	National (US)	Google	"HIV/AIDS" "New Media"	Dec-09
Retrovirology Article	Retrovirology	National (US)	Scopus	"social media" AND HIV [limited to 2006-present]	22- Oct-09
GoodMenProject Article	The Good Men Project	National (US)	Google	"HIV/AIDS" "Social Media"	01- Dec-10

# **Data Collection part 2**

Along with conducting a content analysis on materials which mention communication strategies for HIV/AIDS information, a similar content analysis was conducted for representative sources of HIV/AIDS communication using new technologies, social media or multimedia. This allowed that which was learned from the first part of the data collection to be compared to sample communication messages. Sources were found via searches through Google, Google Scholar, Bing, Yahoo, YouTube, and through references from the texts viewed in part 1. Search terms used included "HIV/AIDS", "social media", "new media", "Facebook", "HIV", "Twitter", and "YouTube channel" in various combinations. Messaging items were deemed appropriate if they were

communications of HIV/AIDS information using new technology including social media, ICTs, and/or multimedia. Multimedia is defined in this case as media displayed or accessed via interactive media, a computer-delivered electronic system where a user can control, manipulate, combine or otherwise use different types of media, not limited to text alone ("interactive media," 2011). Only items published or created since the beginning of 2006 were included, with a preference for recent sources. These messages were in English. The texts examined represented a wide variety of social media, ICT and multimedia approaches to HIV/AIDS communication available. It was expected that the availability of sources may be limited as a searcher such as myself would have difficulty accessing private sources, password protected sources, and other sources unavailable to people outside a particular target demographic such as those aimed at medical professionals and only distributed through a workplace network. The sample used included examples from different countries and of different intended audiences as much as possible.

#### Examples of sources include:

- Social media (found in the public sphere i.e. without logon necessary to access this information) e.g. Facebook, Twitter, etc.
- Multimedia e.g. interactive programs on computers, online video, etc.
  Unfortunately it was not deemed possible to find examples of new technology such as smart phone technology or tablet technology or computer programs to sample, but care was taken to sample for as many social media and multimedia types as were available.

Of the 72 sources that were found to fit the selection criteria, 46 were sub-selected, including 10 each of YouTube channels, Twitter accounts and Facebook pages. Other sources found for the sample include blogs, Flickr, Fropper, Linkedin, Google+, online

video, individual YouTube videos, and individual tweets. For each of these sources the focus was on the most recent content at the time viewed, around May 8, 2013, being at minimum the most recent 20 tweets, 10 Facebook posts, or one YouTube video when examining Twitter accounts, Facebook pages and YouTube channels respectively, though more content was often viewed to provide context for the in-depth analysis of the content that would follow. Table 2 lists all of the sources that were subselected. Having a wide diversity of sources from the limited number of sources meeting the selection criteria was important for the subselection which focused upon having a large number of organizations represented, from as wide a variety of locations as possible. The vast majority of source found were from the United States, many of which from the same organizations. Care was taken to represent as many types of social networking sites as were found in the search, these often being types mentioned the sources from part 1. Because duplication was not seen as useful when trying to obtain a maximum variation sample, if several sources that focused upon the exact same area and campaign were found, only one was subselected. It was decided that while many organizations have several social media accounts on different social networking sites, that only one social networking site would be examined for each organization, such as to not have overrepresentation in the sample from organizations that use more than one social networking site. When only one source was selected from an organization or for an area and campaign the source that was selected was chosen based upon the type of source and the dates of most recent update for the source. This allowed for the representation of a number of different social networking sites in the sample, and also for a variety of dates for the content as listed in the aspect examined column from Table 2. In addition, the search source and search terms columns list how these sources were found the first time they were found. If those columns list n/a, this indicates that these sources were stumbled

upon without the use of a search engine or search option within the social networking site. It was very difficult to find a broad sample of actual social networking site and other multimedia examples.

**Table 2: Subselected sources for part 2** 

Source identifier (see Appendix D for full reference)	Organization	Location	Search Source	Search Terms	Description	Aspect examined
Canadian AIDS Society Blog	Canadian AIDS Society	National (Canada)	Yahoo	"HIV/ AIDS" "social media"	Blog	The most recent 5 blog posts, but only the English versions (not the French translations) Nov 24 2011-Apr 27 2012
talkAIDS.co m Blog	Clarissa (individual)	Local (Boston)	Google	"HIV/ AIDS" "social media"	Blog	The most recent 7 blog posts Dec 31, 2010-May 30, 2012
The Red Pump Project Blog	The Red Pump Project	National (US)	Bing	"HIV/ AIDS" "social media"	Blog	The most recent 10 blog posts from Sep 13, 2012- April 10, 2013
AIDS.gov Facebook	AIDS.gov	National (US)	Google	"HIV/ AIDS" "new media"	Facebook	The most recent 10 timeline highlight posts April 26-May 7, 2013
TheBody.co m Facebook	TheBody.com Complete HIV/AIDS Resource	National (US)	Google	"HIV/ AIDS" "social media"	Facebook	The most recent 10 timeline highlight posts May 5- May 8, 2013
BCCFE Facebook	British Columbia Centre for Excellence in HIV/AIDS	Local (British Columbi a)	Google	"HIV/ AIDS" "social media"	Facebook	The most recent 10 timeline highlight posts May 2-

						May 7, 2013
I Talk Because Facebook	Campaign with many involved	Local (New York City)	n/a	n/a	Facebook	The most recent 10 timeline highlight posts Dec 1, 2010-July 14, 2011
BornHIVFre e Facebook	Global Fund	Internati onal	Google	"HIV" "Faceb ook"	Facebook	The most recent 10 timeline highlight posts March 18-April 4, 2013
HIVHaven Facebook	HIV Haven	National (US)	Google	"HIV/ AIDS" "new media"	Facebook	The most recent 10 timeline highlight posts May 1- 7, 2013
HIV Stops With Me Facebook	hivstopswithm e.org	National (US)	Google	"HIV" "Faceb ook"	Facebook	The most recent 10 timeline highlight posts April 27, 2012- April 2, 2013
HIV Vaccine Trials Network Facebook	hopetakesactio n.org	Internati onal	Google	"HIV" "Faceb ook"	Facebook	The most recent 10 timeline highlight posts April 30-May 8, 2013
LIFEbeat Facebook	LIFEbeat	National (US)	Bing	"HIV/ AIDS" "new media"	Facebook	The most recent 10 timeline highlight posts May 3- May 8, 2013
PSLWHA Facebook	Positive Survivors Living with HIV/AIDS	National (Canada)	Google	"HIV" "Faceb ook"	Facebook	The most recent 10 timeline highlight posts April 29-May 7, 2013
Jillian and James Flickr	AIDS Task Force of Northeast Indiana	Local (Fort Wayne, IN, USA)	Bing	"HIV/ AIDS" "new media"	Flickr	Both the photograph and included text and the story included along with it
NWGHAAD	CDC National	National	Google	"HIV/	Facebook	The Facebook

Facebook	Prevention	(US)		AIDS"	note	note
note	Information Network			"social media"		
Red Ribbon Express Fropper	rosepetal01	National (India)	Google Scholar	"HIV/ AIDS" "social media"	Fropper blog post	The full text of this blog posting on Fropper
Miss Red Ribbon Fropper	Fropper.com	National (India)	Google Scholar	"HIV/ AIDS" "social media"	Fropper profile	Main profile, ezblog with postings from Nov 26-Dec 21, 2007
UNAIDS Google+	UNAIDS	Internati onal	Google	"HIV/ AIDS" "social media"	Google+	The main profile and the most recent 10 posts from April 19-May 8, 2013
International AIDS Vaccine Initiative LinkedIn	International AIDS Vaccine Initiative	Internati onal	n/a	n/a	LinkedIn	The main page
HIV/AIDS Alliance Twitter	aidsalliance.or g	Internati onal	Google	"HIV" "twitter "	Twitter	most recent 20 tweets as displayed on account April 29-May 8, 2013
HIV Story Project Twitter	The HIVStoryProj ect.org	Local (San Francisc o)	Google	"HIV" "twitter "	Twitter	most recent 20 tweets as displayed on account March 22- April 11, 2013
ASHM Media Twitter	Australasian Society for HIV Medicine	Internati onal (Australi a and New Zealand)	Google	"HIV/ AIDS" "social media"	Twitter	most recent 20 tweets as displayed on account January 8- April 11, 2013
HIV Insight Twitter	Hawaii AIDS Education and Training Centre	Local (Hawaii)	Google	"HIV/ AIDS" "social media"	Twitter	most recent 20 tweets as displayed on account May 8, 3013
HIVhumanR IGHTS Twitter	hivhumanright snow.org	Internati onal	Google	"HIV" "twitter "	Twitter	most recent 20 tweets as displayed on account March 9- April 26,

						2013
MNT HIV/Aids Twitter	Medical News Today	National (US)	Google	"HIV" "twitter "	Twitter	most recent 20 tweets as displayed on account April 8-May 8, 2013
hivguidelines .org Twitter	NYSDOH AIDS HIV Clinical Guidelines Program	Local (New York State)	Google	"HIV/ AIDS" "social media"	Twitter	most recent 20 tweets as displayed on account Dec 7, 2012-May 1, 2013
HIVPreventi onJustice Twitter	preventionjusti ce.org	National (US)	Google	"HIV" "twitter "	Twitter	most recent 20 tweets as displayed on account April 30-May 3, 2013
RiseUpToHI V Twitter	riseuptohivand hcv	Local (Minnea polis)	Google	"HIV" "twitter "	Twitter	most recent 20 tweets as displayed on account May 5-May 8, 2013
SF AIDS Foundation Twitter	San Francisco AIDS Foundation	Local (San Francisc o)	Google	"HIV/ AIDS" "social media"	Twitter	most recent 20 tweets as displayed on account April 10-May 8, 2013
<b>Cure Tweet</b>	Carl Zimmer	National (US)	n/a	n/a	tweet	the tweet
Prostitutes Tweet	personal twitter account	Local (Oakland , US)	n/a	n/a	tweet	the tweet
<b>School Tweet</b>	Think Progress	National (US)	n/a	n/a	tweet	the tweet
Lifeboat videos	Lifeboat	Internati onal (Europe)	Bing	"HIV/ AIDS" "new media"	short videos	The main page, and stories from Families Jansen and Zimbabwe
AIDSLibrary YouTube	aidslibrary.org	Internati onal	Google	"HIV" "YouT ube channel "	YouTube channel	main page, featured video: Finding Reliable Health Information Online; AIDS Library 25th Anniversary and HIV and

						AIDS Myths
OfficialSING campaign YouTube	The SING Campaign	National (South Africa)	Google	"HIV" "YouT ube channel "	YouTube channel	main page, videos: SING ebay auction - personalized Christmas Card from Annie Lennox, SING ebay auction - large, signed image of Annie Lennox; SING Campaign 5th Anniversary Film
amfAR YouTube	amfAR	Internati onal	Google	"HIV" "YouT ube channel "	YouTube channel	main page, featured video: The Exchange :: Help Us End the Ban :: amfAR; Dr. Chris Beyer talks about amfAR's GMT I, Cinema Against AIDS Sponsorship Reel
Siyayinqoba YouTube	beatit.co.za	National (South Africa)	Google	"HIV" "YouT ube channel "	YouTube channel	main page, feature video: Siyayinqoba Beat It! Ep. 6 - HIV in Eden; ep. 5 and Taking Health Care to the People
CAS SCS YouTube	Canadian AIDS Society	National (Canada)	Yahoo	"HIV/ AIDS" "social media"	YouTube channel	main page, featured video: Do Something Video Submission from Lauren Ward; English AIDS Timeline and ORANGE

						GREEN E3
Regional HIV/AIDS Connection YouTube	hivaidsconnect ion.ca	Local (London, ON, Canada)	Google	"HIV" "YouT ube channel "	YouTube channel	main page, videos: RHAC Promo video, AYDI Videoblog Tuesday, AYDI Monday Videoblog
Ryan White TARGET YouTube	HRSA HIV/AIDS Bureau	National (US)	Google	"HIV" "YouT ube channel "	YouTube channel	main page, favorite videos: USA- Mexico Border/Binati onal HIV Partnerships Reception 2012, RSR form 30,000 Feet: A Great Place to Start!; in+care Campaign
IAS Conference YouTube	IAS Conference on HIV Parthenogenes is	Internati onal	Google	"HIV" "YouT ube channel "	YouTube channel	main page, featured video: IAS 2013 - Promotional Cartoon, Francoise Barre- Sinoussi IAS 2013; Adeeba Kamarulzama n IAS 2013
TeachAIDS YouTube	TeachAIDS	Internati onal	Google	"HIV" "YouT ube channel "	YouTube channel	main page, feature video: What is TeachAIDS? Innovation in HIV education; The Tech Awards 2012 - Microsoft Education Award - TeachAIDS; TeachAIDS; (English - North America) HIV Prevention

						Tutorial
Global Forum YouTube	The Global Forum on MSM & HIV	Internati	Google	"HIV" "YouT ube channel "	YouTube channel	main page, videos: Achieving Universal Access: MSM Advocates Speak; Welcome & Introductions - PART 1 Russian Subtitles; Welcome & Interoductions - PART 2 Russian Subtitles
Status is Everything YouTube Video	Aaogc Newark	Local (Newark, NJ, US)	n/a	n/a	YouTube video	video
My HIV Journey YouTube Video	Aaron Laxton	local (personal	YouTu be	"HIV"	YouTube video	video
Social Media Superstars YouTube Video	C. Allen Media for Texas Southern University's Student Health Center	Local (Texas Southern Universit y)	Google	"HIV/ AIDS" "social media"	YouTube video	video

# **Data Analysis**

Content analysis is an iterative process, returning frequently to the texts in question to reexamine the coding and to ensure that all facets of information are included in the research (Krippendorff, 2004; White & Marsh, 2006). As Mayring (2000) states, these categories used in coding should be carefully decided upon and reviewed, creating a feedback loop. The coding process allows for change, accommodating that which is encountered. Each research question was coded for separately, ensuring that these questions continued to guide the research process, and were not ignored or forgotten at

any stage. Hsieh and Shannon (2005) state that there are three different approaches to qualitative content analysis. The conventional approach is generally used in a study that aims to describe a phenomenon, and allows the categories and names of categories to flow from the data. The directed content analysis approach is used when there is existing theory but the research augments or fills in gaps in the theory. Finally the third approach is a summative content analysis, where one identifies and quantifies the existence of particular words or terms in a text and then reads much more deeply into the context of the appearance of these words or terms, with the intent of finding out how these are used (Hsieh & Shannon, 2005).

While coding for traditional sources, such as print sources, may be considered straightforward, coding of less traditional sources such as images, video, audio, social media items and others may require a slightly different approach, though the same research questions are to be addressed. Certainly coding for that which is said or heard in audible sources is one aspect, but so too are aspects such as the way something is said (in audible sources), colour (in images), and how the information is presented etc.

While various computer and physical methods could be used to facilitate content analysis work, for this project Microsoft Excel was used to keep the coding information organized in the form of different spreadsheets. This relatively low technology solution allowed for a focus on the data found instead of the potentially costly, time consuming task of learning a new form of technology which would not necessarily add much of value to the qualitative in depth analysis of the texts accessed, and could potentially result in errors in judgment due to a lack of familiarity with the technology in question. While the entire coding process could surely be completed on paper however, or through the use of sticky

notes as suggested by Julien (2008), using a program such as Excel prevented the loss of data due to misplacing of a page or the loss of a sticky note. In addition, a quick computer search through the coding information allowed for finding the right code whereas a similar search mechanism by hand is tedious and is potentially subject to a greater degree of human error.

The coding was conducted by answering the appropriate questions about each of the texts and making notes, pulling quotations and otherwise summarizing aspects for the more qualitative questions. Quantitative questions were more easily answered with specific yes/no or other categorical responses, whereas these quotations, summaries and notes in general were needed in order to draw out the themes that were present in the data for the more qualitative questions. This approach was relatively straightforward and is apparent in the coding list found in Appendices A and B, where it is evident that not all coding questions are applicable to any given source.

#### Data analysis part 1

The data collected in part 1 was coded to answer research questions 1-2. A coding list is included in Appendix A, and includes both quantitative and qualitative data. In order to glean the qualitative information desired from the sources, an in-depth reading of the sources was done with the intent to code the texts qualitatively following the conventional method (Hsieh & Shannon, 2005). The conventional method allows for the creation of new categories based on the material that is analyzed. The number of categories grew as coding progressed.

# Data analysis part 2

The data collected in part 2 was coded to answer research question 3. A coding list is included in Appendix B. Directed content analysis (Hsieh & Shannon, 2005) was used to determine how well and to what extent the materials studied fit the affect heuristic (Ropeik & Slovic, 2006; Slovic et al., 2007). The research question: 'What is the affect of these messages?' served as a guiding principle for the work; while it may be impossible to understand from the messages alone what the affect might be, having this question in mind helped for the formation of themes on this topic. In addition, the conventional method was used to help develop new categories to describe these media (Hsieh & Shannon, 2005). Directed content analysis meant that the following themes were coded for: dread, control, natural vs. man-made, choice, children, newness, awareness, can it happen to me?, risk-benefit, and trust, as described by Ropeik and Slovic (2006) in their description of risk perception factors. These texts did not fit smoothly on a continuum with regards to only these factors but rather a close reading of the texts resulted in further themes to examine.

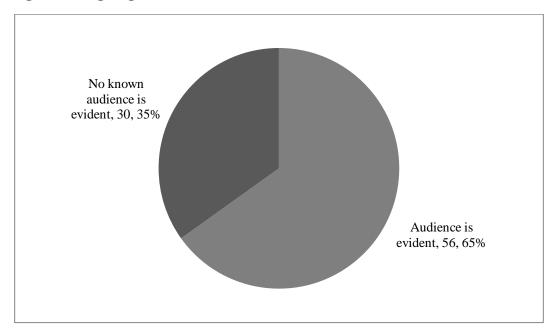
# **CHAPTER 4: RESULTS AND DISCUSSION**

In this results and discussion section, each of the sources analyzed for content have been assigned a unique identifier which consists of a phrase describing the document or source in question, sometimes followed by a number if said source is part of a larger document consulted. The source references are capitalized in the text for ease of identification. For example, the source "Drama and danger: The opportunities and challenges of promoting youth sexual health through online social networks" appears as AMIA Article in the body of the thesis. These sources are fully cited in Appendix C and D for the sources that describe the use of social media or new technology and the examples of social media or new technology respectively. In total there were 40 sources that discussed the use of social media and 46 sources that consist of actual examples of social media or new technology, for a total of 86 sources in all.

# **Reaching audiences**

If one wants to be effective at communicating a message, it seems reasonable that one should know to whom this message is being communicated. Health communication strategies are made more effective when making relevant the information that is communicated to their intended audiences (Kreuter & Wray, 2003). While these messages could be broadly targeting a larger group or more specifically tailored to a particular individual, this knowledge of the group that is being addressed by a particular message or messaging technique is key to the success of this communication, whether it's to address social or physical environments or other characteristics (Abroms & Maibach, 2008; Kreuter & Wray, 2003).

Figure 1: Targeting an Audience



As seen in Figure 1, while the majority or 65% of all sources stated or made evident the intended or expected audience for communication, 30 or 35% did not indicate a particular audience that was being targeted. Table 1 takes the 56 sources where an audience was evident and breaks down the number of sources that mentioned each specific audience. Some sources mention more than one audience type, which is why the sum of the number of sources is far greater than the total number mentioning audiences.

Table 3: Number of sources indicating each audience

Audience	Number of
	sources
Youth	26
HIV positive	10
Men who have Sex with Men	7
African Americans	6
Men	6
Risk groups in general	5
Professional audiences	4
Women	3
Vague audience or public in general	3
Sex workers	2
People at risk of sexual transmission	2
Facebook users	2
Heterosexuals	2
Scholarly audiences	2
rural individuals, syringe users, students, homeless, the media, Indian,	1 mention
health care workers, cell phone owners, government, older adults, friends,	each
family, readers, people interested in the impact of HIV on women and	
children, and advocates	

The largest target of these HIV communication messages was youth. Social media and new technologies are often considered the realm of youth, with the Pew Internet and American Life Project for example showing that "nearly three quarters" of American teenagers and young adults, aged 12 to 29 use social network sites in a given day as of 2009 (Lenhart, Purcell, Smith, & Zickuhr, 2010, p. 18). As the percentage of teenagers and young adults using social media had grown substantially from 2006 until 2009, it is perhaps unsurprising that the penetration of social media use for this population continues to rise as shown by more recent Pew studies in the United States, with the greatest use

continuing in these age demographics (Duggan & Brenner, 2013; Lenhart et al., 2010). While the Pew studies are specific to the United States, social media use is high elsewhere around the world with its use increasing not only for youth but for other demographics as well (Boyd & Ellison, 2007; Duggan & Brenner, 2013; Lenhart et al., 2010). This is corroborated by the sources studied such as the AIDS and Behaviour Article and the UNAIDS Feature Story which indicate that youth are already using social media. Since young people are already using social media it seems like social media and new technologies are reasonable avenues to reach them.

Not all of these sources described youth in the same way; for example the E-learning Environment Article describes the audience as children while the context of the text indicates that it is high school students that are being targeted. Indeed, the E-learning Environment Article even states "the children in high schools today are growing up in an environment which is affected by AIDS epidemic, they can share ideas on the effects of AIDS on society using online social networks and they can construct stories to educate fellow children" (p. 229) explicitly identifying the children targeted as high school students. In the sources consulted, the term youth is generally used to describe individuals from puberty through early adulthood; however not all communications are clear on this aspect. Some, such as the Mindjet Blog Post simply describe "young people" as being the target of outreach opportunities, whereas other sources, such as the Cleveland.com Article, state overtly that the target audience is "people ages 18-30". Some of these texts, such as the Cleveland.com article, which focuses on HIV positive youth in particular, address a more specific subgroup of youth such as students, HIV positive youth, homeless youth, youth of particular sexual orientations, or who live in particular areas. Youth was the most commonly targeted group via social media and new technology for

HIV communications according to these sources. The approach to targeting youth varies between sources, ranging from a mention of youth in the 'about' page of the LIFEbeat Facebook, saying it is "dedicated to reaching America's youth," to the more subtle communication of the TeachAIDS YouTube, where videos feature youth viewing TeachAIDS video content.

In order to bring about behavioural change, King (1999) states that youth who have already begun to have sexual relations should be approached differently than those who have not, and that specific behaviours should be addressed rather than risk in general. The items examined did not focus upon this aspect directly, although those texts that focused on HIV positive individuals, or on encouraging testing often presupposed an earlier exposure to potentially sexually transmitted infections; it can be assumed that some of this communication is aimed toward those who have already had sexual relations as a result. The most overt example of this is the Miss Red Ribbon Fropper (2) where the idea of a sexual passport is described in a blog posting; the fictional character of Miss Red Ribbon explains that "if you are getting into a sexual relationship, then you have to be a bit too careful!... when you meet your online partner, you can call a phone number and get the test results and test date for you, along with identification information so that you are sure about the identity of the person". Another more subtle example is in the Social Media Superstars YouTube Video, which features video clips of a male and a female young adult each preparing to go out, spliced with information about the prevalence of HIV positive status in their age demographic. From the association of these preparation clips and the HIV/AIDS information it can be assumed that these two individuals are preparing for either a night on the town or a date, but it can also be inferred that their

potential actions could put them into contact with HIV should they or their partner(s) for the evening be HIV positive.

*The youth of today are all digital natives, right?* 

Although many sources focus upon using social media and new technology to communicate with youth, there is a varied level of understanding of different technologies among different groups of youth. Not all youth are 'digital natives' nor is this term necessarily indicative that the generation born after 1980 learns in a fundamentally different way than those born before it, as much as these individuals may use technology (Bennett, Maton, & Kervin, 2008). Still, the Audiencescapes Article, UNAIDS Feature Story, Social Media Forum Video, Sexual and Reproductive Desires Chapter, and Text Messaging Article do indicate that some youth may like this form of communication because it allows them to communicate in ways that they are already communicating, through two-way conversations, and providing feedback. There is also a certain cost to factor into participating on these social networks or using these devices, as not all young people have the disposable income to afford a smart phone or other device to communicate; campaigns using these devices may not reach some young people. Still, as evidenced by the AIDS and Behaviour Article, even homeless youth may be active on social media and this technology may be an effective way of reaching individuals who may be hard to reach in other ways. Since the term 'digital natives' may not be an accurate descriptor of this generation, it may be even more important that social media campaigns utilize the affordances of social media for two-way communication to receive feedback and input in the design and use of their social media campaigns. Perhaps one social network may be more appropriate than another depending on the particular youth one is trying to reach. For example, in the AIDS and Behavior Article, a lower

socioeconomic status was found on MySpace because of all the musicians and youth. The amfAR Briefing article indicated that being aware that youth have their own way of influencing their online experiences is key to communicating with them.

### Using the right language

What might be an effective communication strategy for youth in one area of the world may not be as effective elsewhere, or with a group of youth of differing characteristics. As the Game On Article shows, using a computer game to communicate HIV information is a great example of edutainment; however, this game may not work on computers with different characteristics for example, and may have content specific to the area in the world where the game is distributed. This is useful for the targeted individuals in that local area, but may not be relevant for individuals outside of this target group. As the article states, a third of all Thai female respondents of a recent study thought it "acceptable to lose their virginity on Valentine's Day". In addition to working against specific ideas local to the area, this game is in Thai, making it ineffective for audiences who do not understand this language. Similarly, the Fropper.com Article, Miss Red Ribbon Fropper (1), and Red Ribbon Express Fropper sources show the colloquial language used on Fropper.com, an Indian social media network. If one is less familiar with this social network or with the type of language used, one might not understand that "scraps" are essentially comments on an article, profile or blog posting similar to how one might post content to another user's Facebook wall or timeline. The Fropper sources examined featured many grammatical and typographical errors and casual language, such as "Don't get fcuked!" from the Miss Red Ribbon Fropper (2) or the unusual capitalization found in the phrase "We all know Aid is a dreadful disease" from the Red

Ribbon Express Fropper. This casual language might put local readers who are used to this colloquial language at ease as it is present elsewhere on this social networking site.

Colloquial language is used in the majority of actual social media or new technology examples examined in this study, with 25 of the 46 sources or 54% using colloquial language to communicate messages. The Status is Everything YouTube Video ends the video by describing someone as "your boo" for example, which as the Urban Dictionary indicates is slang for one's boyfriend or girlfriend ("boo," n.d.). The Communication Brief also indicates that the youth of Malawi would appreciate communication in their colloquial language of choice. Understanding youth and using the appropriate language to reach youth seems to be of importance when communicating. This cultural sensitivity and choice of medium for HIV/AIDS communication is key as Airhihenbuwa & Obregon (2000) indicate. The use of appropriate language for a particular community is also important in the area of health literacy as it allows people to comprehend health care topics rather than being confused by jargon (Lanning & Doyle, 2010). Finding the appropriate language with which to communicate with youth may be very difficult however. Youth language and culture changes rapidly and slang may be very specific to particular sub-groups within the broader category of youth, even as this form of communication is influenced by youth worldwide because of the use of online media (Bucholtz, 2000). While English may be a dominant language on the internet, it is also often used in hybrid with shared languages of particular populations, which can lead to styles of online communication unique to a particular group (Danet & Herring, 2003; Lam, 2008). So, while using colloquial language may be common, it may require considerable effort to understand what balance of colloquialisms would be appropriate

when communicating with a group unless one is adequately familiar with their modes of communication.

Reaching youth, who else?

Evidently the users of social media and new technologies are not only youth, indeed even older adults are targeted in social media campaigns as shown by the Administration on Aging Document. This is significant, as Dickson and Walker (2008, p. 157) indicate: "one of the fastest growing populations that is at risk for HIV/AIDS [is] the elderly" with ageism, racism, social issues, medical issues and lack knowledge contributing to poor treatment and prevention (Dickson & Walker, 2008; Levy-Dweck, 2005). Getting information to this group that is stigmatized for even bringing up their sexual practices and which is undereducated about the disease is key not only to preventing the spread of HIV but also to maintaining health and well-being (Dickson & Walker, 2008; Levy-Dweck, 2005). While the Pew Internet and American Life study indicates that a lower percentage of internet-using adults aged 50-65 and 65+ use social networking sites, compared to younger adults, these numbers are still as high as 52% and 32% in 2012 (Duggan & Brenner, 2013). So, the Administration on Aging Document which suggests ways of combating unawareness of HIV/AIDS information through sample tweets and Facebook status postings would be a valuable tool to spread the word to these older adults.

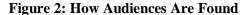
Returning to Table 1, the large variety of groups targeted other than youth is quite evident. HIV-positive individuals are a significant target group, as communication with them via mobile apps (for example) may be used to encourage them to continue to get appropriate treatment, particularly when health worker visits are not available. This may

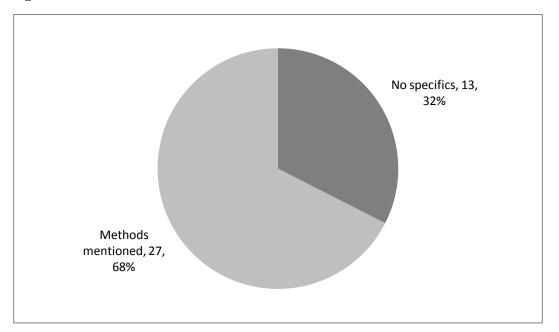
help improve quality of life when compared to only sporadically taking their medication or having other treatment, as the Mindjet Blog Post suggests. This type of messaging, designed to encourage and maintain treatment regimens may help prolong health in this population as adherence to treatment is strongly linked to better health outcomes and lower likelihood of developing health complications (Bangsberg et al., 2001; Gebo, Keruly, & Moore, 2003; Paterson et al., 2000). Men who have sex with men were mentioned in seven sources, which included the use of Twitter for broadcasting of a health alert with regards to a sexually transmitted illness outbreak among gay men in New York as in the hivguidelines.org Twitter source. The spread of this type of warning message could help promote caution and hopefully encourage safe sexbehaviour. African Americans were mentioned in six sources, which is noteworthy because they are a population that is highly affected by HIV in the United States which is emphasized in the Gemnaspeaks Blog Post. Directing messaging at African Americans was seen as stigmatizing or blaming them for the epidemic according to one study of text messaging with young male African Americans as reported in the Text Messaging Article. This result suggests that messaging needs to take into account the reactions of the groups that are being targeted to prevent frustrations and other negative reactions.

Men were mentioned in six sources, and women were mentioned in three sources, which is also of note because as UNAIDS indicates 50% of all people living with HIV are women, yet women continue to be at a disadvantage with regards to prevention, treatment, and support ("Women, girls, gender equality and HIV Fact Sheet," 2012). There are several reasons that men could be mentioned more than women in the sample of sources analyzed. One is that HIV/AIDS is more prevalent in African American males when compared to females in the United States, with "1 in 16 black men and 1 in 32

black women" will be diagnosed with HIV in their lifetimes if the current trends do not change in the United States ("HIV in the United States: At A Glance," 2013). Another potential reason is simply the fact that "The needs and rights of women and girls are not being adequately addressed in the AIDS response" ("Women, girls, gender equality and HIV Fact Sheet," 2012). As can be seen in Table 1, while there is overlap between some of these groups targeted by the sources studied, the range and scope of the audiences targeted by social media and new technology based communications indicate that youth may be one of the main audiences, but they are clearly not the only focus.

*How are these populations targeted?* 





The populations that are targeted in social media and new technology communications are found in multiple ways as shown by the sources describing these campaigns. Of the 40 sources describing such campaigns, 13 or 33% provided no specifics whatsoever of how they were targeting their audience.

Table 4: How audiences are targeted

Method	Number
	of sources
Social Media	16
Visiting a website	2
individuals contacting the organization; the use of student brand	1 mention
ambassadors on campus; video; recruiting through HIV/AIDS treatment;	each
radio; television; theatre; a game distributed through schools, events and	
online; on the internet in general; through blogs; using the internet to tailor	
to individuals; through a local organization; through a campaign; via	
texting; through traditional venues; using computer algorithms	

As shown in Table 2, 16 sources or 40% mentioned social media as the source used to target their audiences; however most of these mentions were very vague and provided no other information about how specifically to target using social media. Those that did provide information about recruiting an audience used unique methods; no two articles mentioned the same specific technique when describing how to recruit from within social media. Finding the right social media to use for any particular campaign is key to the campaign's success: one must go where the audience and/or the affordances of the social media are appropriate to one's needs (Kaplan & Haenlein, 2010). This is a feature found in common with most of the sources that recruited their audiences directly from within social media itself. In the HIV Education Article study of HIV education and counseling using Facebook, the population was targeted simply by using the social network as one would use it in one's daily life. This suggests that a person or organization using this method to target an audience would have to be quite familiar with how one uses this social network in their own daily life, and would be less likely to work without a great deal of education if this social networking site is not already in use. The Fropper.com Article shows how another approach was used on the Indian social network Fropper,

where a fictional character named Miss Red Ribbon was created with the role of informing youth about HIV and safe sex by fielding questions and providing social media friends with knowledge. This fictional profile acts as if it was another actual user's profile on the site, and could be found through the social network as one would find any other individual. The AIDS and Behavior Article study of homeless youth recommended finding out where one's target population is located online and using that social media tool to reach them, which echoes the recommendation of Kaplan & Haenlein (2010) with regards to how to find a social media audience. Similarly, the AIDS Conference Presentation and Q&A advocated going where the online communities are already and using a youth-led strategy to reach these individuals. The UNAIDS Feature Story focused on the affordance of two-way communication to find one's audience. Both the youth-led strategy and the two-way communication provide the opportunity for the potential audience to influence how the campaign is structured, and potentially make the campaign more relevant to their own demographics. The Turkish Condom Use Article showed how a condom promotion campaign used Facebook ads to encourage participation with the Facebook page and with other aspects of the discussion online; the sponsors chose to pay more to reach female audience members to help balance the genders interacting with the Facebook page. All of these sources that used social media as their recruitment tool for social media campaigns assumed that their audience was already using these media and created content within these media to communicate.

While using social media itself is the primary method described of finding one's audience for social media and new technology communication a myriad of other techniques were used as seen in Table 2, the most common of which, mentioned twice, is from visiting a website. This makes sense as if one is already online one is much more likely to be

capable of visiting a social networking site or a social media campaign than if it is uncertain whether or not one has access to the internet; the Pew Internet and American Life survey statistics regarding the prevalence of social networking site use all refer to the percentage of internet users who use social networking sites (Duggan & Brenner, 2013; Lenhart et al., 2010). All of the other techniques were only mentioned once each and are listed in Table 2. These methods span both digital and non-technological venues, and also include in-person interaction rather than only occurring online, as although one is aiming to reach computer savvy or technologically savvy individuals, traditional methods are still useful to begin communication strategies. Social networking sites are known to primarily support offline connections (Boyd & Ellison, 2007), and as such, recruiting offline may make sense depending on the purpose of this communication. In addition by using these traditional methods one can encourage those who are not already familiar with one's social media presence to interact or join the conversation.

#### **Providing information**

As has been shown, finding the audience for communication efforts is key for the use of social media and new technology to communicate HIV/AIDS information, but what precisely is the information that is provided? What is the purpose of this information communication?

*Information for information's sake?* 

Information is in high demand, particularly about HIV/AIDS. The HIV and the Media Workshop communicated that "demand for information is increasing exponentially and the use of social media has become even more appealing as a result" (p. 77). Of the 46 examples of social media or new technology communication examined in this study, 16

(or 36% of the sample) can be described as purely sharing information as the main purpose behind their communication. All sources transmit information; however, these sources mainly shared information such as news items or promoted the sites or organizations themselves. These sources could be described as news feeds for the aspect of the HIV/AIDS epidemic that one is interested in following. An example is the BCCFE Facebook (1) source, which has a timeline that is essentially a number of links of articles and other media surrounding the centre and the HIV/AIDS cause. In one post on the BCCFE Facebook (1) source, the title of a YouTube video "Screening hoped to removed HIV stimga [sic]" is quoted and the video from AlJazeeraEnglish of a news report with that title is linked (see the BCCFE Facebook (2) source).

Similarly, the HIV Insight Twitter (1) page mainly consists of news items surrounding HIV/AIDS, the social issues surrounding the disease, and other sexually transmitted illnesses. An example news item might be like the HIV Insight Twitter (2) tweet: "Moderate Levels of Depression Predict Sexual Transmission Risk in HIV+ MSM [a] <a href="http://ht.ly/kMkMH">http://ht.ly/kMkMH</a> HT <a href="http://ht.ly/kMkMH">@HarvardMed</a>", which provides a shortened form of an article title and links to an abstract in the PubMed database for this article, while also indicating where this news source was found. The tweet indicates that it was HT, which can mean either heard through or hat tip, in both cases this is an acknowledgement that <a href="#@@HarvardMed">@@HarvardMed</a>, the Twitter account for the Harvard Medical School is the source that brought this information to the attention of the HIV Insight Twitter account maintainer responsible for posting this tweet ("Hat Tip," 2006). This type of news article sharing, regardless of the media source used, seems to be simply providing access to information. Certainly this information fits the views of whoever is administering the social media account on which it appears, however it does not seem to be provided with another overt

purpose but to share this information with whomever is following the accounts. These postings do not seem to be interacted with much on these accounts, garnering few 'likes' on Facebook or comments on other media sources, at least not that are easily visible upon analysis. If this topic is of interest, one might choose to follow these accounts to keep on top of new developments in this area just to stay informed. Indeed, accounts such as the HIV/AIDS Alliance Twitter account or the HIV Story Project Twitter account are each followed by over four thousand Twitter users, showing that some sort of value is found in simply following these news sharing accounts, even if they do not take advantage of all of the affordances of the medium with regards to interacting with their followers (Boyd & Ellison, 2007; Kaplan & Haenlein, 2010).

This trend of using social media and new technology as news feeds is found in Facebook, Twitter, blogs, and even YouTube to a certain extent, and is not limited to the sources that do not use these communication methods for other reasons. Sources incorporate aspects of a news feed into their Facebook timeline, Twitter feed, blog postings or YouTube channel but may also use these media for other purposes as well. The value of a news feed could be seen in which articles are curated to appear there, or in other words, people might choose to follow a particular Twitter account or Facebook page because of the strength of the news feed articles in providing information of interest to them. King (1999) indicates that simple information provision alone is not likely to change behaviour, so these news feed social media accounts with little interaction serve mainly as information sources for their respective audiences. That said, they may aid in finding information online for professionals, academics, and others interested, and may serve the function of helping people stay abreast of the latest developments in the area of HIV/AIDS that interests them. Such use of social media is interesting partially as it

recalls the function of librarians curating information for patrons, and may be useful both for health professionals, academics, and others who happen to be interested in particular developments or areas of HIV/AIDS research.

Information for information's sake can seem limited when given the full range of affordances that social media and new technology provide; but sites such as Twitter include a fair bit of news feed following as a matter of course. In fact, by studying the reciprocity of users on Twitter, one can conclude that many users use Twitter as a "source of information [rather] than [as] a social networking site" (Kwak, Lee, Park, & Moon, 2010, p. 593). Twitter is an unusual social networking site, in this sense, as it is used this way quite frequently, having a potentially one-sided relationship and a retweeting mechanism that allows for information diffusion, reaching around 1000 followers with a retweet (Kwak et al., 2010). Twitter can be more similar to the culture of consumption rather than the culture of participation (Cocciolo, 2009); however, it does not have to be this way: the affordances are there to participate, just as with many other social networking sites. The two sources that described social media use, which also stressed knowledge recall being influenced by social media, were not describing Twitter directly, but rather more fully fledged uses of social media affordances, including for example two-way communication. Each of these two sources focused on the use of social media by youth: recall of social media campaign messages, in particular those from an HIV/AIDS information campaign, was emphasized in the Social Marketing and Children's Media Article, and using social media to talk about love and safe sex was associated with an increased knowledge about HIV in the AIDS and Behavior Article.

Link sharing and crossposting of content

Social media accounts do a lot of news provision via linking to news stories posted elsewhere. This is partially due to the constraints of a short status update on Facebook or the 140-character limit of Twitter. Given the news media aspect of Twitter, where a user might use Twitter as a news consumption utility rather than as a method of two-way communication, this is also logical: it provides a way of sharing the news (Kwak et al., 2010). The I Talk Because Facebook campaign mainly used their Facebook status postings to crosspost their video content from their YouTube account without any further explanation of why to watch these videos. This was not an exception as many organizations chose to crosspost content from their other social media presences on each of their social media accounts. As only one social media presence was chosen for analysis from any given organization, rather than examining in depth all of the social media channels for a given organization, this linkage is not examined in more detail at this time; however, this type of content linking to external sources was also common outside of crossposting an organization's content to different social media platforms. Crossposting of content without providing any further content specific to the social media platform, may be easy to do and cost effective for an organization (Bakker, 2012), but does not utilize all the affordances of any given social media platform fully. As discussed before, tailoring communication to a given social media platform is seen as important, as is learning how to effectively use the platform rather than simply using it to post the same information regardless of the format it is being presented upon. Another example of not using a social media platform to its fullest potential can be shown by the use of many hashtags on the HIV Vaccine Trials Network Facebook and the PSLWHA Facebook. Hashtags are generally a Twitter convention, and using them on Facebook before they

were officially implemented on Facebook makes the postings that were also crossposted from another medium, for example Twitter, even more obvious when compared to sharing natively produced content. Third party content may still drive internet traffic to a particular site, increasing the audience even though it may not be new or tailored to the social networking site on which it is found (Bakker, 2012).

Link sharing on its own is not necessarily a bad thing, as following an organization on a social media platform can be a way of following a news feed of interesting links or news stories. Indeed many Twitter feeds are operated in this fashion when they're not being engaged with by their followers. An example is HIV Insight Twitter (1), which lists interesting news stories relevant to the audience of this Twitter account as tweets among others. One such tweet is "Dual HIV Risk - Receptive Syringe Sharing & Unprotected Sex  $\rightarrow$  HIV-Neg Injection Drug Users, #NYC [a] http://ht.ly/kJEVQ HT @nycHealthy" as shared on HIV Insight Twitter (3), and links to the news story one could read for more information. Sharing these links may still drive traffic to the information or to the original information article. This can serve to generate advertising money through page views, or perhaps more importantly more views of the original information, although the source is simply copy and pasting a link from one social networking site to another (Bakker, 2012).

### Teaching purposes

Looking at the literature that describes how social media and new technology are used, along with their benefits, two of the sources described pedagogy as being potentially one of the best uses of social media and new technology. The AIDS Conference Presentation and Q&A focused on how to use social media in less traditional ways and mentioned education both of the public and of healthcare professionals as being good reasons to use

social media. In a similar but slightly different vein, the IEC to IHC Article focused on the importance of creating interactive e-learning courses and other professional education for educators and health workers. Here the focus was on the interactivity that is an option in new technology; the article stressed the importance of going beyond the unidirectional transmission of information from the past, instead using technology to allow for such interaction. Instead of focusing on simple information provision, the interactivity of social media and new technologies can be used to educate and provide health literacy, augmenting older communication and education styles with the affordances of the newer technologies as shown by the IEC to IHC Article. As Heatley and Lattimer (2013, p. 9) indicate, "social media not only enables teachers and students to connect with one another, but it also allows for continued learning outside traditional classroom learning hours". The sources examined do not assume that one is in a classroom when learning the material presented and definitely fit this model. Similarly, by being a participatory environment these social media provide the opportunity to communicate content outside of the bounds of an academic course of study allowing one to view others' contributions and contribute themselves (Cocciolo, 2009). Social media provide affordances including those to take agency and make choices about one's own learning such as the choice of which tools to use, how and where to use them, and the ability to not just consume information but rather to engage with content and participate in two-way communication (McLoughlin & Lee, 2007).

While all the examined social media and new technology sources shared information, only eight sources, or 17% included aspects that were overtly pedagogical, meaning that they were used to teach their audience. Interestingly, of these eight sources, seven were video-based, whereas only one was predominantly text dominated. Of the seven video-

based sources six were YouTube channels and one was the Lifeboat Videos site, which has videos about families living with HIV. While these sources are all used for educational reasons, the type of education can differ greatly among the sources. The video-based sources ranged in their educational goals and content. The TeachAIDS YouTube channel was perhaps the most overtly educational as it consists of videos used to educate the world about HIV/AIDS in ways that are linguistically and culturally appropriate. This TeachAIDS YouTube source includes sample videos that help to debunk HIV/AIDS myths and explain precisely how one might become infected. These educational videos go into great detail of situations that do and do not spread HIV for example, and resemble being in a classroom or in a lecture watching this information be presented on the screen. While overt education through debunking myths is done by TeachAIDS YouTube and the CAS SCS YouTube, there are other uses of video for educational purposes. The Lifeboat Videos are used as examples in educational programming. The Lifeboat Videos are essentially documentaries, which are organized thematically and show families living with HIV. Sharing these stories serves to educate others about the issues that these families that have HIV positive people in them face, along with hopefully reducing associated stigma. The Regional HIV/AIDS Connection YouTube (1) videos include content focusing on the work of outreach educators, showing a bit of how these individuals do their jobs and work together. All of these videos focus on bringing awareness of HIV/AIDS to the public or educating people about the work that HIV/AIDS educators or these organizations are doing.

The only predominantly text-based educative source examined was Miss Red Ribbon Fropper (1) on Fropper.com, an Indian social network. It states overtly that "I'm here to talk about sex... safe sex" in the about me section of the profile. The Fropper.com profile

includes an ezBlog which is used to answer Fropper users' questions about HIV/AIDS and share information about ways that one can protect oneself from becoming infected (Miss Red Ribbon Fropper (2)). An example question that Miss Red Ribbon answered was about how to have safe sex without condoms. The provided answer on Miss Red Ribbon Fropper (2) was "Hey! You MUST wear a condom. If you don't have it and the girl is not wearing one either, then don't have sex, especially not if you don't know the girl well enough". Not only does this blog serve to answer questions posed about general HIV infection concerns, but it serves to dispel myths and other misconceptions regarding HIV. By stating the original misconception before explaining the actual accurate information, this source is acknowledging a limitation in the readers' knowledge before providing the information to improve this situation (Sánchez & García-Rodicio, 2013; Tippett, 2010). This is a good practice as it gives context to this information and an impetus to change one's previous flawed knowledge of a situation.

A different educational approach is taken in many of the Ryan White TARGET YouTube videos. This YouTube channel includes in depth videos that provide step by step technical assistance for people who are trying to administer the Ryan White grant system, which includes a lot of required programmatic knowledge ("About the Ryan White HIV/AIDS Program," 2010). The Ryan White Program is administered by the American government and serves to award Federal funds to agencies that care for more than half a million individuals who do not have enough health care coverage or other financial resources to care for their HIV disease, filling in gaps not provided by these other sources ("About the Ryan White HIV/AIDS Program," 2010). Technical assistance is a very different type of education when compared to dispelling HIV/AIDS myths, or answering HIV/AIDS questions, but it serves the needs of people by helping these administrators

and others working in the healthcare system provide HIV-related services to American citizens. Without this type of instruction for the administration of these complicated grants it is easy to imagine that individuals served by these grants would not receive the support that they need and could either transmit the illness to others or have their health conditions unnecessarily worsen. Video is a great method of providing this type of technical assistance or training as one can watch and see precisely how to interact with forms by watching the explanation. In addition, this resource is handy as one can watch the videos multiple times or find the segments that are pertinent to the problem or to the step in the process that is appropriate at a particular time rather than having to wait for in person help.

## Changing behaviours

Behaviour change is an outcome of health communication that is certainly of great importance; however, social media and new technology are difficult to study for a direct relationship between intervention and outcome. Only two articles list actual statistics concerning behavioural change. A poster presentation summary in the Retrovirology Article source listed the importance of social media in finding participants for HIV vaccine clinical trials: "Social media sources account for nearly 25% of referring domains for website traffic and 16% of referral sources named by VRC clinical trial participants", showing that social media was a useful tool for encouraging people to become involved in testing of HIV vaccines. The other source to describe behavioural change with actual statistics was the Social Marketing and Children's Media Article, which listed behaviour effects as being in the 5-10% range.

While only two of the articles discussing how social media and new technology could be used for HIV/AIDS communication discussed actual statistics of successful behavioural change, many social media and new technology sources had behavioural change as one of the intended results of messaging. In fact, 61%, or 28 of the 46 social media and new technology sources examined focused on behavioural change and 38% or 15 of the 40 sources that described how social media and new technology is or should be used listed behavioural change aspects as benefits. There are three types of behavioural change encouraged through this messaging: preventative care messaging, ongoing care messaging, and messaging to get involved in one way or another with the campaign.

The HIV Education Article source states, "shifting to Web 2.0 social networking sites may increase the effectiveness of prevention messages" showing the emphasis of preventative messaging on social media sites. Preventative care messaging was found in 10 or 25% of the sources that described social media and new technology, and in 17 or 40% of the examples of social media and new technology. Increasing testing rates, reducing unsafe sexual behaviour and associated transmission, and improving condom use are all behaviours associated with preventative care messaging. The importance of getting tested is a message found in seven of the sources overall, being a frequently used preventative message. A noteworthy example of a promotion of getting tested message is in the Social Media Superstars YouTube Video, which is a video from the Texas Southern University's Student Health Center. This video provides specific information regarding when testing is happening on campus, using awareness of an easy way to get tested as encouragement to actually take that preventative action and know one's own status. Since finding sexual partners online is common for homeless youth it is noteworthy that the AIDS and Behavior Article found that using social networks online to

talk about love and safe sex is related to decreases in exchange sex, increases in sexually transmitted illness testing and an increased knowledge of HIV. The Turkish Condom Use Article found that condom use encouragement is also a huge area of preventative messaging, with online investment in condom advertising via social media providing a low cost per condom sold method of increasing safe sex. Prevention messaging with regards to HIV/AIDS revolves around behaviour change because, as the Jillian and James Flickr source says, "your life depends upon it"; it is simply that important to individuals and organizations to communicate these behaviour change messages. People's longstanding beliefs about their behaviours impact the ability of messaging to incite behavioural change, so while there is much preventative messaging, increased exposure to the messaging may be necessary to further encourage these preventative changes (Spence & Lachlan, 2008).

Ongoing care messaging was found in three or 8% of the sources that described social media and new technology. It was not found in the social media examples; however it is suspected that it would be found in more private communication via mobile text messaging or private messages on social media to specific HIV+ individuals rather than in openly available public social media postings. Improving ongoing care of those who are already HIV positive is the aim of the messaging. As the Mindjet Blog Post indicates, SMS, or text messaging has increased adherence to antiretroviral therapy regimes. Still, Klein and Knight Lapinski's (2008) review indicates that many studies only provided limited information about the details of particular interventions and their evaluations, showing inadequacies in reporting. An area that is suggested for future ongoing care messaging is in the area of communication outcomes: if a partner knows a person's HIV

status it is more likely that he or she might encourage safer sex behaviour for example (Klein & Knight Lapinski, 2008).

Messaging that encourages involvement in the cause was discussed less in the sources surrounding social media and new technology, only appearing in three sources or 8% of those examined; however it was present in 37% or 17 of the actual examples examined. The only two ways to get involved in the cause described in the literature surrounding social media and new technology was to: (1) change how government was involved with the cause, whether by expanding government response or by encouraging change in legislation as shown in the AIDS Conference Presentation and Q&A and in the Social Media Forum Video, and (2) to "spark a movement" to end the disease as part of the Social Media Tool Article. Though the sources describing social media did not focus upon getting involved with the cause, this was an aim that was common in the social media sources whether it was simply to participate on social media, to attend a webinar or a conference, or to lobby the government to change a policy as the amfAR YouTube (1), HIVPreventionJustice Twitter, IAS Conference YouTube, LIFEbeat Facebook, and RiseUpToHIV Twitter sources show. The policy change example, of lobbying for an end to the ban on federal funding for needle exchanges in the United States from the amfAR YouTube (2) is one of the more involved aspects of getting involved in the cause when compared to simply posting content or interacting with a social media account. Another way social media is used to encourage getting involved is the use of LinkedIn as a method of advertising for potential job opportunities from the International AIDS Vaccine Initiative LinkedIn. Working for an organization devoted to combating HIV/AIDS is certainly one way of getting involved to a very large degree. Hands on volunteer involvement to get involved with the HIV cause is another way of getting

involved, but it is not listed by the sources consulted, possibly because one needs a more specialized skill set or needs to live in a specific area to be useful (Zachariah et al., 2006). This method of getting involved is far more intense than any of the examples seen in the sources studied; however, encouraging volunteer-minded individuals to become involved is similar to encouraging people to become involved at other levels (Zachariah et al., 2006).

Information can be used and interacted with for many different reasons, be it as news information, educational resources or impetuous to cause behavioural change.

Volunteering is very hands on; however, simply interacting with social media provides a way of communicating and utilizing information that differs from other forms of media.

### Making interactivity work

One of the greatest potential strengths of social media is the ability to have a many-to-many relationship in communicating with people. As Kaplan and Haenlein (2010, p. 61) define it, social media encompasses "a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of User Generated Content". This speaks to the interactive element in social media and new technology. Indeed twelve of the forty sources discussing the use of social media and new technologies for HIV/AIDS communication, or 30%, focused on the interactive elements of the media.

#### Limitations of staff

Utilizing social media effectively from an organizational perspective is not as easy as one might imagine, as the sources discussing social media use indicate. Certainly, it does not

require much to sign one's organization up for an account on social media sites, many of which are free and relatively straightforward to use, contributing to their large user base; but simply having an account does not make one's use of social media or new technology effective. People working with social media need to learn how to use email and social media first, which may take considerable time depending on what level of knowledge was present prior to these efforts as the PLWHA Blog Post indicates. However, one cannot stop learning, as social media continues to change and it is important to be patient with this changing communication method as the HIV and Media Workshop shows. In order to be effective as an organization one must sacrifice time to this endeavor and be engaging individuals frequently, if not constantly; it is almost another job as the OntarioHIVTreatment Video indicates. Unless an organization has one or more staff members able and willing to devote adequate time and resources to this task, it is difficult to use social media effectively. The audience one is trying to reach with a particular social media campaign of interactive communication is not often solely available on a business hours basis. As the Social Media Tool Article shows, limiting one's social media presence to the hours of 9am until 5pm for example risks losing precisely the individuals that one is looking to reach. The HIV and Media Workshop also emphasizes the fact that consistent use of social media is important: people will disengage from a social media outlet or from a conversation if there is not continued participation. Even with sufficient staff, it is easy to be either too professional and miss the audience one is trying to engage, or do the opposite and not be deemed credible, and the HIV and Media Workshop focuses on the importance of credibility (Kaplan & Haenlein, 2010). Staff may not be the best suited to communicate with a particular group unless already familiar with the language used by this group, given that it's important to use the language of the people with whom one is communicating on social media, and this language may include dialect, slang and

other colloquialisms that do not normally form part of professional speech as the Communication Brief shows.

The limitations that an organization's staff have when maintaining actual social media accounts can be seen in more detail when examining these accounts directly. The AIDS Library YouTube account explains this explicitly on their about us page: "We have disabled comments on our videos because we don't have the capacity to respond fully to them (treating Youtube comments like reference questions does not work), BUT we will answer your questions all the time via our youtube inbox or regular email (library AT aidslibrary.org). You can also find out more about our services at our website, http://www.aidslibrary.org/". Most organizations are not this explicit with regards to not being able to properly reply to messages or follow or engage with other users of social media content. The MNT HIV/Aids Twitter account is a good example of this: it only shares content and does not engage with other Twitter accounts. This can be seen by the fact that this account does not follow any other Twitter accounts, and all of its posts are links to its own news content rather than fully using Twitter's abilities to find and report on content, to retweet or to reply to followers. This corresponds to the use of Twitter as a news medium rather than as a social media site, broadcasting content rather than utilizing the full set of affordances that Twitter offers (Kwak et al., 2010). Many of these functions of Twitter are limited if not impossible without actually following other Twitter users' accounts.

Using media to full potential?

Several sources discussing the use of social media or new technology emphasized the importance of using the appropriate social media form for different types of intended

interactions. The Washington Blade Article indicated that video was not used enough, and that folks should be learning from others and adopting best practices. One's strategy on social media needs to depend upon the outcomes desired and the audience one wants to reach as the OntarioHIVTreatment Video shows. The potential of social media includes the fact that it allows for interactivity, with a focus on dialogue or two-way communication as the Public Health & Internet Annual Review and the Social Media Forum Video indicate, but also allows the target users of said social media to inform each other and teach each other about the subject matter discussed, whether on their own or through collaboration with any organizations facilitating such interaction (Cocciolo, 2009; Kaplan & Haenlein, 2010). Peer-to-peer education was emphasized by the Mindjet Blog Post, the E-learning Environment Article and the AMIA Article, as opposed to only using the question and answer interactive discussions used by the Turkish Condom Use Article, and the Text Messaging Article. Still, interactivity is not limited to Facebook, YouTube or Twitter; mobile phones with back and forth communication capability via text messages, games, incentive programs including gamification and giveaways, and interactive e-learning courses are all other new technology methods that focus upon the interactive element as shown by the Public Health & Internet Annual Review, the Game On Article, the amfAR Briefing Article, the Mindjet Blog Post, the E-learning Environment Article, the IEC to IHC Article, the AMIA Article, and the Text Messaging Article. A good example of this interactivity is a game that was distributed via schools in Bangkok, youth clubs, and a game exhibition and as a free download in Thailand. This game provides a method of edutainment: not only does the game entertain and engage the students playing it, but it educates these individuals about HIV/AIDS, which the Game On Article described.

When looking at the examples of social media studied, 18 or 39% used at least some of the interactive elements available, six or 13% quite overtly used none at all, and for the remaining 23 sources (or 50%) this interactivity was not the emphasis of the elements examined. Many social media accounts do not reply back to followers' or friends' queries, so while the account is on social media it is being used in an uni-directional way: the audience may engage with the social media account but the account is not responding to their interactions. Examples of social media accounts that were used in a unidirectional manner for the sample examined include the AIDS.gov Facebook, the BCCFE Facebook, and the HIVHaven Facebook. However, some social media accounts reply to their followers when they have questions such as the HIV Vaccine Trials Network Facebook page. The type of engagement apparently varies depending on the social media account, for example retweets on Twitter, public replies to queries on Facebook, and responses to comments on YouTube are easily visible. However, most social media platforms provide a method of messaging which may be outside the public view without being logged into a particular account, and these forms of communication were not studied in this project. Still it is evident that the majority of the social media examples studied did not use all of the interactive features of the social media platforms. Given the increase in audience for any tweet retweeted and also the fact that Twitter is a good example of a social networking site that can easily be used as if it were simply a news medium (Kwak et al., 2010), the use of social media in broadcast form is less surprising.

## The emotional dimension

Emotion plays a role in HIV/AIDS communication; however, not all emotive terms are used for the same effect, nor are these emotions necessarily explicit in all uses. Emotions featured in just under half of all sources examined, being more frequently observed in

actual examples of social media and new technology rather than in texts that discussed or described these sources. In most of the sources that described the use of social media or new technology for HIV/AIDS communication, emotion was not discussed overtly as a method of engaging the audience; instead, emotion was used as part of an example or as a descriptor of the epidemic. However, the Text Messaging Article included a suggestion to use humor to engage recipients of text messages. This suggestion to use emotion in the form of humor to engage an audience is interesting given the lack of other overt encouragement to use emotion in social media or new technology. Is it simply taboo to talk about using other emotions, perhaps even negative emotions, to engage an audience or to influence possible users of the technology or social media communication form? The use of humor to engage an audience with relation to a health topic is not unusual; indeed humor is used to help deal with anxiety or to introduce sensitive topics at support group meetings for prostate cancer for example (Oliffe, Ogrodniczuk, Bottorff, Hislop, & Halpin, 2009). Humor elevates the mood, and provides relief from anxiety, stress, or tension along with many other health benefits (Lynch, 2002; Oliffe et al., 2009); dealing with health concerns is potentially very stressful, making humor entirely appropriate in this way. The lack of suggestions or best practices for emotional messaging in the other sources regarding the use of new technologies and social media suggests that such emotional messaging is either already assumed to take place, or that this aspect is being neglected in the literature specifically with regards to HIV/AIDS communication. This emotional messaging can be seen in the sources discussing social media and new technology, so it is clear that emotions can be used for a purpose, even if these sources do not overtly explain why or how.

Visual and auditory media provide opportunities to convey emotions differently than do textual sources. YouTube is an intensely visual medium, and several YouTube channels used this ability to convey emotion without just using words, featuring individuals' facial expressions on screen. Music can also convey emotional meaning. For example, the Ryan White TARGET YouTube channel featured a video about the in+care campaign which had music similar to that featured in a horror movie, seeming to evoke fear and then later hope, while several other video sources such as the AIDSLibrary YouTube, amfAR YouTube, and the Regional HIV/AIDS Connection YouTube included people either in tears or on the verge of tears, or music that evoked sadness. Music that conveyed such emotions only featured in two of the YouTube videos seen, but it was easily discerned by the similarities to music from the horror movie genre in the video that conveyed fear and hope with classical music edited together in the Ryan White TARGET YouTube, and by the lyrics and style of the song used in the video that conveyed sadness and loss in the Regional HIV/AIDS Connection YouTube (2) video. Still, the vast majority of sources that used emotional cues, whether in text, words spoken, music, or visible signs were explicit and used words such as "scared", "sadly", "love", or "excitement" to convey these emotions, including the Canadian AIDS Society Blog, the IAS Conference YouTube, the Regional HIV/AIDS Connection YouTube (1), the RiseUpToHIV Twitter, and the Siyayinqoba YouTube. These words may have been spoken or shown via text, depending on the medium. None of the examined sources that described social media or new technology use for communication described any best practices with regards to how to use emotions in the form of visual or auditory media. This could be because these new media are still regarded as frightening, or because of fears of displacing the traditional textual communication forms with new media formats, although Darnton argues that newer communication modes do not actually displace the old in the short term (2011).

These media sources provide additional opportunities to communicate and reinforce the emotional cues displayed rather than confusing the audience by saying one thing and displaying another; the music, facial expressions, and other emotional cues are more likely to support the text that is spoken or read on the screen. As Darnton tells us, these newer communication modes provide potential ways of reinforcing that which would have been communicated in a more traditional fashion in the past, adding to this communication rather than supplanting it (2011).

Fear of the new is perhaps a great example of the affect heuristic at work (Ropeik & Slovic, 2006). While not all emotions used in the texts are negative, the affect heuristic argues that dread or intuitive fears are used as scare tactics and influence how risky behaviours are perceived to be (Ropeik & Slovic, 2006). The most frequently mentioned emotion in the texts fell in the category of fear, dread, or other intuitive fears. However, sadness and other negative emotions were also frequently present and could be interpreted as being used for the same or similar purpose: to provide the affect that impacts decision making in the form of scare tactics. Fear occurred most frequently in the texts and ranged from the "fear and stigma that surrounds testing" in the Regional HIV/AIDS Connection Article and the "fear of transmitting the disease" in the PLWHA Blog Post, to talking about the "worst fear" where "nobody loves you" because one's HIV positive status is disclosed in the Lifeboat Videos. Most instances of fear were used in conjunction with the disease though at least one article discussed fear in more general terms, referring to the "fear in their general lives" when describing the social situation of urban youth who perceived themselves to be at risk not just of HIV/AIDS but of violence and other concerns as well in the AMIA Article. Fear is not only used to describe how people fear the illnesses associated with HIV/AIDS but rather how they would be treated

should their gender/sexual identity be known, their HIV status be known, how their children would be treated if it were known they were HIV positive, or otherwise as seen in the Canadian AIDS Society Blog, the PLWHA Blog Post, the PSLWHA Facebook, and the Regional HIV/AIDS Connection Article. Sadness and other negative emotions (including but not limited to depression, shame, concern, anxiety and worry) were featured in texts as examples to scare people away from the behaviours that lead to these negative emotions. For example, a story told in conjunction with a photograph shared on the Jillian and James Flickr described how Jillian was "in total shock and cried all the way home" when she discovered she was HIV positive and she "let [her] family down". Fear of the unknown is often used in the sources examined as well to encourage behaviour change. One example is a posting on Fropper, an Indian social network, about an endeavor to develop a sexual passport to encourage testing of potential online sexual partners and the confidential sharing of these results before meeting in person for engagement in this potentially risky behaviour as shared in the Miss Red Ribbon Fropper (1). This fear also fits with the hazard and outrage model of risk communication, which involves "scaring people' and 'calming people down" (Spence & Lachlan, 2008, p. 50). This type of risk communication is used to incite behavioural change.

While using emotions to deliberately to incite behavioural change (Waters, 2008), it is important to be cautious of just how one is doing this: too extreme of an approach might lead to backlash and/or to resistance by an audience who might be paralyzed by fear instead of willing to change. Likewise, encouraging behavioural change through deliberate or overt emotional messaging might be ethically problematic if one chooses to exaggerate out of hand. With health messaging it may be prudent to use emotion only insofar as it is realistic. One may not want to scare people to the point of their thinking

they are helpless to combat a particular health threat such as HIV, but rather to encourage positive health behaviours. As Waters (2008) indicates, the influence of affect on risk-likelihood judgments is large enough that ignoring it may lead to a misrepresentation of the link between perceived risk and preventative health behaviours.

While scare tactics are one method of influencing behaviour through communication, quite a number of actual sources used emotion to persuade their intended audiences to take particular actions, whether to engage with a campaign on the internet, to get tested, to attend a conference or otherwise. These persuasive messages did not always use dread or intuitive fears to encourage said behaviours but did often use the affect heuristic. In fact, the element of control, the attractiveness of options, the likelihood of things happening, seeing children or youth at risk, and the trust of an information source are used as reasons to be persuaded by emotional language in these sources studied. These reasons are among the main reasons listed by Ropeik and Slovic (2006) along with others who study the affect heuristic (Finucane et al., 2000; Slovic et al., 2007). The element of control and empowerment, particularly empowerment of women, is a huge part of The Red Pump Project Blog and also some of the communications efforts by AIDS.gov as part of the AIDS.gov Facebook and the NWGHAAD Facebook note. In these efforts, positive emotional language, using words such as "proud", "excited", and the hashtag "#EMPOWERED", is used to encourage engagement with the campaigns. Similarly, positive emotional messaging is used to position easy attractive options against more risky behaviours. As blog author Clarissa (no last name given) indicates on her talkAIDS.com Blog, one can "show your love" and "save lives" through actions as simple as sponsoring someone in an event, buying a smart phone through a particular shop, or otherwise engaging with a cause online. These options become much more

attractive than letting people die or attempting a much more difficult action. Seeing children at risk is coupled with negative emotions but the affect heuristic predicts that this exposure will more likely result in action than the same exposure to adults at risk (Ropeik & Slovic, 2006). The AIDS.gov Facebook, the HIV Vaccine Trials Network Facebook, and the Lifeboat Videos provide examples of children being at risk. Information source trust is used to persuade people to engage with social media, to feel that it is okay to feel certain emotions, and also to provide factual information regarding the epidemic in several sources such as the AIDSLibrary YouTube, the Canadian AIDS Society Blog and the My HIV Journey YouTube Video. Trust can be defined as the willingness to be vulnerable, whereas trustworthiness is the conditions that lead one person to trust another (Mayer & Norman, 2004). The My HIV Journey YouTube Video features Aaron Laxton, vlogging (or video blogging) about his HIV positive journey. He says, "I can't say I've never cried over being HIV positive", and provides a resource with which others can engage to learn more about living with HIV. His videos may be seen as being trustworthy because of this first person perspective; while he may not be the most informed person about all aspects of HIV or AIDS, he is the subject expert on his own experiences and this first person account can persuade his audience to engage with his questions. He asks them "did you feel upset, did you feel angry" regarding when they found out they too were HIV positive in the My HIV Journey YouTube Video. Laxton should have the ability to talk about what it is like to discover he is HIV positive, ability being one of the three major factors leading to the trustworthiness of a source (Mayer & Norman, 2004). He is also able to fulfill the two other traits of integrity and benevolence as he is seen to be voluntarily sharing this useful information with the world via YouTube, and integrity as he is seen to have loyalty to his community of followers online (Mayer & Norman, 2004).

Emotions, whether shared or simply provided can also be used as examples of other aspects of the HIV/AIDS epidemic. A perceived increase in pleasure when not using condoms is one of the reasons listed on the HIVPreventionJustice Twitter account for why they are not used as a preventative measure more frequently. In South Africa, emotions such as fear, hunger, suffering and desperation are listed as examples for why people live in a particular housing development, how they felt before medical treatment was available in a particular way with medicine delivery, and of general suffering as shown by the Siyayinqoba YouTube account. The ability to "laugh together" and "cry a little" is used to encourage folks to connect at a pre-conference meeting regarding men who have sex with men and HIV as part of the Global Forum YouTube account. The range and scope of how emotions are used in these texts is noteworthy as it indicates a certain prevalence of such communication strategies as used in the social media sources examined and also in the sources that describe social media and new technologies and HIV/AIDS.

# **Working Against Circumstances**

A lot of what can be done with mobile technologies, social media and other computer and technology-based interventions can help people and groups fight disadvantageous circumstances. Whether these situations are geographically, financially, culturally or otherwise based, these tools can empower individuals to accomplish great things. That said, none of these tools are perfect, and a number of problems may emerge, some of which involve the very tools and technologies that solve other issues.

The mobile playground and mHealth for professionals

The sources that discuss social media indicate that there are a number of potentially positive uses of mobile technologies for health care, with five of the 40 or 13% describing this type of use. Interventions can be designed to take into account the affordances of mobile technology for health care (Lefebvre, 2009) and this seems to be emphasized by the sources studied. Indeed, mobile technologies can offer a lot of different benefits, particularly in low-income countries. One example is the use of mobile technologies to circumvent expensive 911 dispatch systems as described in the Global Health Article. Mobile phone technology may also be used to improve HIV awareness, support HIV positive patients and increase HIV testing, and even to reduce mother to child HIV transmission as the Global Health Article and the IEC to IHC Article show. mHealth applications may help patients manage their treatments when health workers are unable to visit regularly because of cost, geographic or other reasons; SMS has helped improve adherence to antiretroviral drug therapy regimens as the Mindjet Blog Post indicates.

The low cost of hand-held or mobile devices goes a long way to encouraging their use, particularly for spreading messages as the Social Marketing and Children's Media Article shows. Scaling up while maintaining cost and quality, and thus the sustainability of any given intervention with mobile technologies is often difficult; what might be cost effective on a small scale may be difficult to reproduce on a larger scale with the same attention to quality as the Global Health Article and the IEC to IHC Article show. Still, the use of mobile technologies is often effective for reducing costs; if a smart phone can replace full-scale computers for access to and transmission of drug and patient records there may be considerable cost savings as the IEC to IHC Article and the Mindjet Blog Post indicate. Cost savings may lead to an increased amount of resources that may be able

to be used elsewhere in the fight against HIV/AIDS, or may mean that these technological resources may be used in an otherwise disadvantageous area. Past mass media campaigns' cost effectiveness has been questionable; however, these campaigns are not generally enacted in isolation, rather other interventions are attempted at the same time (Walker, 2003).

The Mindjet Blog Post, the IEC to IHC Article and the Mobile Learning Article support the idea that mobile technology can also be used effectively for information sharing between health professionals, as well as video conferencing and other online training for health workers. The IEC to IHC Article goes on to say that social media through mobile phones can help for peer-to-peer education both for professionals and members of the public. Additionally, the Mobile Learning article shows that combining a mobile phone with solar charging technology can help combat electricity reliability issues as well in more remote areas where health professionals need to work. While this technology does not solve all problems, it does go a long way to improving access to information for those who may not be located in a major center or who cannot or choose not to afford a more expensive internet connection or larger computer workstation, which is not limited to the developing world but rather affects those who are less affluent the world over, cost being a major factor in the implementation of any HIV/AIDS communication intervention (Walker, 2003).

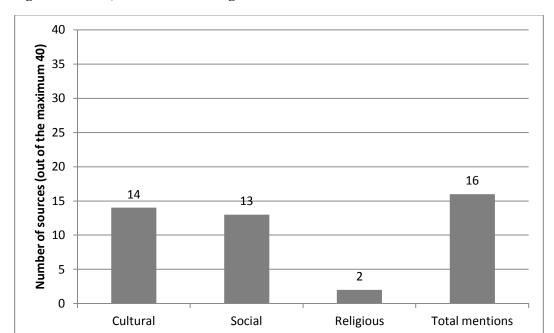


Figure 3: Social, Cultural and Religious Issues

As can be seen from Figure 3, social, cultural and religious issues arose in 16 or 40% of the 40 sources concerning social media and new technologies. As sources often mentioned these issues in combination, the total number of mentions is thus not much greater than the number of social or cultural messages; religious issues being the least often mentioned in these sources. Cultural and language issues may pose a barrier to HIV communication, and the sources studied show this with 14 or 35% of the 40 sources talking about social media mentioning these issues. Materials regarding HIV must be presented in culturally appropriate ways and should be available in local languages with appropriate visual presentation materials as the IEC to IHC Article and the Communication Brief show. As the IEC to IHC article says, sometimes talking face-to-face about sensitive topics is just too difficult for an individual; however, using a computer interface can sometimes circumvent this problem and allow an individual to answer risk questions and otherwise bridge information gaps. Indeed, talking about these

topics isn't just difficult for members of the public, it is potentially awkward and difficult for physicians as well, this awkwardness likely contributing to a number of these conversations not happening at times when they probably should for the health and well-being of the patient (Epstein et al., 1998). Similarly, it may be difficult to track down or encourage sex workers and individuals in more remote areas to come to an event, but they can be contacted via mobile phone technology provided that they have access as the UNAIDS Feature story shows.

Changing the dialogue surrounding particular social mores is an approach that can be taken to help decrease the spread of HIV. Thirteen or 33% of the 40 sources mentioned social messages, while religious messages were only mentioned in two or 5% of the sources. The Social Marketing and Children's Media Article provides an example of this with communications valuing abstinence, delaying initiation of sexual activity, encouraging decreases in sexual partners and encouraging increased condom use. Morality certainly impacts behaviour. Looking at diverse cultural messaging, the appeal of sexual activity and the potentially conflicting ideas surrounding religious beliefs both influence how individuals will respond to social media messages, or so the BeritaJakarta.com Article argues. In this article, it can be seen that the idea that youth are prone to free sex or that a danger of free sex is present is seen to impact the messaging that surrounds HIV/AIDS in Jakarta. As the Communication Brief indicates, youth in Malawi are impacted by "socio-economic factors that render them unable to negotiate for safe sex, cultural factors such as initiation ceremonies which expose them to HIV, and most importantly, unprotected sex with multiple partners among the youth in general". In Thailand, some of the beliefs and practices that need to be dealt with include the fact that "a third of female respondents said they thought it was acceptable to lose their virginity

on Valentine's Day and only a third of sexually active males reported using condoms" as listed in the Game On Article. In Turkey conservative cultural norms surrounding sex mean that people do not discuss sex, accidental pregnancy is high and the most common form of contraception is withdrawal; additionally it is difficult to reach women, possibly because of their traditional role with regards to sex as the Turkish Condom Use Article shows. Even in the United States there continues to be misconceptions, and social and cultural mores that need to be combated. For example there is the misconception that older adults do not have sexual relations or use drugs; this misconception leads to a lack of testing for HIV as the Administration on Aging Document shows (Dickson & Walker, 2008; Levy-Dweck, 2005). These country and culturally specific social and cultural circumstances provide a difficult backdrop against which to communicate appropriate HIV prevention behaviours. The privacy provided by going online rather than talking face to face about some of these topics allows for them to be discussed and for education to occur. Framing discussions online without associated stigma is one of the potential benefits from social media and new technologies when compared to more traditional media as the Social Media Tool Article shows.

Just because someone is located in a remote area should not mean that this person shouldn't have access to information. The IEC to IHC Article explains that community centers with internet access can provide otherwise disadvantaged people the ability to access HIV risk programs and information. The AIDS and Behavior Article shows that since homeless youth in the United States use social media and may find sexual partners online, the provision of information online through social media is particularly salient to members of this group. The Sexual and Reproductive Desires Chapter indicates that most Kenyan youth, especially HIV positive youth, are not given support or education

regarding sexuality, social empowerment and rights issues, so mobile options can help to improve this as well as educate individuals regarding HIV. The range of issues against which one must work to communicate proper HIV/AIDS prevention and treatment behaviour could be overwhelming but given the help of these tools the process can become a little bit easier, according to the sources examined.

# Rising against the establishment

There are a number of activities that are aided by the use of social media and new technologies with regards to changing the status quo. Whether this means increasing education of HIV/AIDS issues, changing legislation or otherwise working against what is the normal in one country, area, or simply in public awareness, a number of examples of this type of activity are seen in the sources examined. The AIDS Conference Presentation and Q&A shows that in Russia, social media has been used to circumvent government censorship and also to help influence public opinion, in turn helping recognize and reduce stock-outs, situations where important HIV drugs are not available. Some of the tactics mentioned in the AIDS Conference Presentation and Q&A that are used to help promote the cause when fighting the government's approach include using social media, choosing to "Google bomb" or Googlewashing to impact what appears on the search engine when one searches for a particular term, and of course the use of mobile phones and SMS for situations where internet connectivity is low. Googlewashing is a term that refers to the act of changing a term's perceived meaning by affecting what the top Google search engine result is for that term ("What is Googlewashing?," n.d.). This is often done by creating a large number of links to direct internet traffic to a particular site supporting the desired definition of a term. Other tactics to encourage change include the amfAR YouTube (2) video which aims to end the federal ban in the United States on needle

exchanges. A more subtle way of impacting views regarding legislation and the establishment is the School Tweet regarding the status of the HIV infection rate in the Southern United States and the education system. Such a tweet could incite action from the public to lobby for changes with regards to policy on education in this area. While each of these actions using social media or new technologies may affect policy and legislation to differing degrees, it can be shown that these forms of communication can be used toward these ends, whether it is through the sharing of a YouTube video, the spreading of a message in the form of a tweet or the more concerted efforts of using an all out social media campaign in conjunction with Googlewashing to impact public and government opinions and actions.

# **Tracking Successes**

While social media or new technology use may not be easy, depending on the skills, time, and resources available, it seems even more difficult to assess the success of these endeavors. Certainly there has been some success; mobile campaigns can reach extremely wide audiences in places such as Africa as the Mindjet Blog Post shows. While one may be able to track follower counts on Twitter, likes on a Facebook page, views on a YouTube video, or the number of educational HIV/AIDS games distributed at an event, it is less easy to determine whether the efforts put into creating and/or maintaining this content, interaction, programming etc. are effective. Even if these are effective, what are they accomplishing?

The herculean task of collecting evidence

If it is important to learn from others and replicate best practices according to the Washington Blade Article; how are we to know what the best practices are if not by

studying them? One metric for determining if a campaign is successful may not work for another campaign. For example, if a campaign is encouraging celebrities to turn off their Facebook feeds and Twitter accounts to represent digital deaths until a certain amount of money is raised to support children and families dealing with HIV/AIDS in developing nations as in the GoodMenProject Article, the amount of money raised toward that goal could be considered a sign of success. However, of the 40 sources that discuss social media and new technology in HIV/AIDS communication that were studied, only this one campaign mentioned as part of one source had the main objective of raising money. It is similarly easy enough to track where website traffic comes from and ask participants of vaccine clinical trials how they found out about the opportunity in the case of the Vaccine Research Center Clinical Trials Core communications using social media as in the Retrovirology Article, but this is also only one of the forty sources that is tracking how people got involved. It makes sense to track this data for the Vaccine Research Center; however, this type of tracking would not be seen as positively in many other social media situations, as HIV/AIDS topics are seen as potentially sensitive topics (Epstein et al., 1998), and privacy may be valued by the individuals who are learning more about HIV prevention or otherwise interacting as the AIDS Conference Presentation and Q&A, the AIDS Conference PowerPoint, and the AMIA Article indicate.

With regards to safe sex behaviours, in general, computer-based interventions result in improving condom use with effects "similar to those produced by previously tested human-delivered messages" (p. 983) as the AIDS Care Article states. For social media campaigns to promote condom sales, online investment is quite effective, as there is a low cost for each condom sold as the Turkish Condom Use Article shows. That said, it is a battle to encourage condom use as this is often perceived as less pleasurable as

indicated by the HIVPreventionJustice Twitter account. This link, between pleasure and the lack of condom use, has far reaching implications as can be shown by the relationship between the price for sex charged by Calcutta prostitutes and their condom use (Rao, Gupta, Lokshin, & Jana, 2003). With regards to HIV treatment, text messaging is estimated to have improved adherence as the Mindjet Blog Post indicates. So, some studies are certainly able to track some indicative results. Still, although results might seem positive, there may still be some uncertainty, not only in how related the campaign is to the results but also in the nature of the seemingly good results themselves. The Regional HIV/AIDS Connection Article describes an outcome of more people getting tested from a social media campaign, but mentions that positive results may mean either more actual HIV/AIDS cases, or just that more people are being tested, putting into doubt the positive correlation between a social media campaign and better behaviour surrounding HIV and testing.

Specific data are more readily available from studies where the variables can be somewhat controlled rather than from general social media campaigns, although the E-learning Environment Article recommends that people be interviewed to determine what they are getting from material. The Text Messaging Article pilot study on how a text messaging campaign for HIV prevention could function indicates that the study participants would prefer the texting to go both ways, and that quizzes and the asking of questions, along with building of community were all helpful in keeping black male adolescents engaged and interested. Similarly, the Mobile Learning Article says that sharing of experiences is valuable as it helps reinforce what is learned when describing using mhealth interventions to train healthcare workers. Still, evaluation metrics are seen to be a problem when studying social media and other new technologies, with the Social

Marketing and Children's Media Article, the HIV Education Article, and the Sexual and Reproductive Desires Chapter mentioning limited or mixed results partially due to evaluation issues. Social media will continue to be difficult to be evaluated for its influence on behaviour change and improvements in health, with Neiger et al. (2012) suggesting that such evaluation metrics should focus instead on engagement with audiences and promotion of programs, products and services.

*It is hard to control details, and other limitations* 

Social media and new technologies do not operate in a vacuum. Indeed, many factors beyond an organization's control will impact how a particular campaign, posting, interaction or other use will be interpreted, used, received, or interacted with. Internetbased public health interventions generally have high attrition or low retention rates as shown by the Public Health & Internet Annual Review, and the AIDS Care Article, and this can certainly impact how able one is to collect best practices information. How does one know why an individual ceased to interact with a social media profile without asking them directly? It would be difficult to question those who have already left and are no longer in contact with an educational or public health campaign, even if only to ask their reasons for leaving. Safety and privacy concerns, fears of being identified and stigmatized, and the need for flexibility and anonymity when using social media and discussing topics of a potentially sensitive nature, particularly given that fighting, gossip and misinformation may be present on social media, are some reasons that individuals may choose to only spend limited time interacting with a particular social media discussion or platform as shown by the AIDS Conference Presentation and Q&A, AIDS Conference PowerPoint, and the AMIA Article. It is difficult to allocate resources to monitor all aspects of a social media campaign and thus prevent the presence of negative

comments or behaviours by users of social media. Sometimes the difficult decision of shutting down a certain form of interaction can prevent negative interactions on a social media site as shown by the AIDSLibrary YouTube decision to disable comments on their videos, preventing a need for continued moderation and response. Not only is it hard to evaluate social media campaign successes or failures, but it is hard to determine just how technology and social media figures into behaviour and other decisions.

Social media and new technology have the potential to impact many aspects of HIV/AIDS communication whether for youth or other groups. This potential, however is not easily evaluated, nor are the benefits entirely clear. They do not operate in a vacuum, nor is using a particular social networking site on its own a panacea. Multiple approaches are currently in use by organizations and individuals and while some use the affordances of the social networking sites that are available to them, many social media accounts do not take advantage of all the features that are available, instead using social media to broadcast information and become a type of news feed (Kwak et al., 2010). The diversity in approaches used by the 86 sources that either describe or are part of social media and new technology show a diversity of approaches but also show the potential that lies in this media for HIV/AIDS communication.

#### **CHAPTER 5: CONCLUSION**

This study examined a maximum variation sample of both sources discussing how social media and new technology were and could be used in HIV/AIDS communication, and examples of social media sources actually in use during the time period between 2006 and 2013. The sources examined ranged from blog postings and tweets to academic articles and published news stories, including public facing, scholarly and professional sources. Given the use of a content analysis method, the research questions charted what information was recorded from each source, forming the data from which themes were found.

# **Key Findings**

While many communications did not have a clearly stated audience, those that did often focused on youth among other groups. Social media use is increasing with many demographics including but not limited to youth (Boyd & Ellison, 2007; Duggan & Brenner, 2013; Lenhart et al., 2010), so the focus upon social media to reach these many different groups is logical. As individuals are already expected to be using social media, rather than encouraging individuals to learn a new method of communicating, sources often focus upon going where people are already located, on the social media networks themselves, and using social networking sites that are already in use by particular audiences.

Passing on information, whether to communicate news, share links or to teach a concept is the major purpose of social media and new technology communication. While the affordances of social media and new technologies allow for interactivity and a potential many to many relationship in communicating with information sources, not all

communications use these affordances, and instead utilize these technologies more as news feeds. This potential for interactivity may provide additional avenues for outcomes, but changing behaviours is difficult. In order to change behaviour, the reliance upon an affect heuristic points to the use of emotion as a method of effective communication. The affect heuristic, while not overtly present in sources discussing social media, is very apparent in actual sources attempting to encourage behaviour change. Indeed, scare tactics to incite behaviour change, humor to alleviate tension, and shared emotions provide major reasons for the use of emotion in the sources studied; however, proof of said behaviour change from this communication does not seem present in the majority of sources studied.

Circumstances such as cost, social, cultural and religious issues, and government approaches to health care and information are all potential areas against which social media and new technologies can work. These factors may impact how messaging needs to be displayed to receive the appropriate response from an audience, or may impact the ability to utilize a particular technology in a poorer area or population. While mobile technologies may be less costly, knowledge is important with relation to how these technologies may be used and the devices on which they are implemented as crossplatform compatibility may not be assumed in a constantly changing technological milieu.

## **Implications for Practice**

Best practices with relation to social media and new technology use seem difficult as the number of approaches taken with regards to these types of communication vary widely in this study; it is difficult to control all the variables involved, there being many outside

factors impacting the interactions of individuals with social media and technology. Still, this study indicates much of the breadth of the area of social media and new technology with relation to HIV/AIDS communication in the time since the publication of the IFLA/FAIFE theme report on *Libraries and the Fight against HIV/AIDS*, *Poverty and Corruption* in 2006 (Seidelin et al., 2006), and O'Reilly's (2005) article about Web 2.0. Libraries and other information organizations continue to improve the equitable access of individuals to information regarding HIV/AIDS. Now, in the time after this report was published, additional tools are available at the disposal of librarians and others communicating HIV/AIDS information. The results of this study, while certainly not exhaustive, suggest some potential considerations for future practice.

While youth are a large population of interest for social media and new technology campaigns, older adults, who are becoming more technologically savvy, can be reached via social media and should not be ignored. This group is in great need of information, particularly given that misconceptions surrounding their sexual relations and drug use can lead to a lack of HIV testing (Dickson & Walker, 2008; Levy-Dweck, 2005), and the fact that they are often not health literate ("Health Literacy," 2011). Targeting older adults for example and other populations is key to the success of a health communication campaign, but one must take into account reactions of the groups targeted and work to avoid stigma. The approach needs to be appropriate to the group, particularly when taking into account language: appropriate colloquial language or dialect suitable for the target audience is important.

A successful social media campaign may need to have skilled staff with adequate time and willingness to continue learning as the media changes rapidly. It is important to

become familiar with how people generally use social media, in particular the social networking sites or tools, and their affordances. A communication strategy should be allowing for a range of behaviours including two-way communication, curating information into news feeds and responding to and engaging with those with whom the organization is communicating. The reliance upon an affect heuristic suggests that using emotion to engage those participating in discussions, reading the news feeds and otherwise engaging with communication may be effective in influencing behaviour change, so emotions such as humor, fear and dread need to be used appropriately. Finally, a successful social media campaign should have evaluation metrics to determine if indeed such a campaign is accomplishing its aims. While it may be difficult to determine the success of a multi-faceted communication strategy, knowing when one is being effective, whether by a rise in followers, an increase in interaction or engagement, or another change is helpful moving forward.

#### **Limitations of the Study**

This study encountered a number of difficulties, some inherent in the nature of the materials studied and others due to the scope of the material and the maximum variation sample chosen for use. Given that it was limited to sources in English, countries such as the United States and Canada are present in many of the sources, though certainly many of these sources are also discussing the situation elsewhere in the world. Certain areas are under-represented, including many areas where English is not the dominant language of publication whether online or elsewhere. Social media tends to change quite quickly making it difficult to return to some of these sources at later date, if they have been changed, altered, removed, or made private since the last viewing, which makes the study of it very much tied to the time it was viewed. The study results may have been very

different had these social media accounts been accessed at a different time, just as the social networking sites' affordances may change over time, as those involved in designing and maintaining them add or remove features. All sources viewed were in the public domain meaning that no logins were required to view these sources. This means that older social media source material, particularly on Facebook are not visible, and also that private messaging is not available for study in the social media sources in question. The social networking site material is biased toward more recent sources partially for this reason: it is much more difficult to find and access materials past the most recent postings, particularly on more active accounts without logging into a particular social media account. The other reason logging into social media accounts was not done is because doing so may change what social media sites display including showing certain content over other content including advertisements and other users' information depending on whether these other users choose to block or follow a particular social media account for example. In addition, mobile messaging in the form of text messages and other application specific communication is not available for perusal, as it is private and not available in the public domain. This means that while a number of sources describe forms of communication using newer mobile technologies, examples of such technology use is mostly absent from this content analysis. Similarly virtual worlds, game worlds and other aspects of social media with relation to HIV/AIDS communication that either could not be accessed or found were not included in this study. Also, given my situation in Canada rather than in a poorer or more technologically disadvantaged country it was difficult to see what social media exposure individuals in these areas would be exposed to, outside of simply reading and analyzing the sources that discuss mobile and other technologies that could be used in these areas; social media sources from these areas were simply not found in my sample and could not be included.

Other limitations of this study include the fact that the social networking sites studied are limited to mainly Twitter, Facebook, LinkedIn, Google+, Flickr, YouTube and Fropper, while there exist many other social networking sites with which I may not be familiar, and where my search methods did not lead me to sources. Here, the limitation of using only English language sources may also play a role, as other social networking sites are popular areas where other languages are predominant. In addition, when sampling it was decided to not sample from sources that included AIDS deniers and others who denied the link between HIV and AIDS or who consisted of conspiracy theorists. This may have biased the sample toward sources that had certain approaches toward HIV/AIDS communications, however it would have been exceedingly difficult to search for and obtain a reasonably balanced sample while including such viewpoints. While the aim was to obtain a maximum variation sample and the sample obtained does include a great deal of variety, it is quite possible that there are even more documents and areas that are not studied due to the limitations of the particular sources selected.

## **Avenues for Future Research**

Many of the sources described the good that could come from social media use or new technology, which indicates that this area needs further study. Generally it is difficult to control for variables in a real world study of social media or new technologies, and it may be unethical to create a control sample to whom no HIV/AIDS communication is attempted; however there are ways to study the benefits of this type of communication even if it requires smaller populations or very specific sampling techniques. Longitudinal studies or studying particular groups with which an organization is already in communication could provide interesting data surrounding social media and new

technology use. Additionally, interviews, focus groups, and other research with human subjects could provide additional perspectives that simply studying the social media postings and articles on this topic does not provide. When interviewing individuals one could inquire as to how the social media postings made them feel for example. Another aspect one could learn more about would be how much particular individuals interacted with or saw of social networking site content. It would also be interesting to note whether individuals, for example HIV-positive individuals, or individuals living in a geographic area with higher incidence of HIV, thought that the communications targeted at them were appropriate and effective from their personal experiences with them.

Ongoing care is a specific area that could be studied for the use of mobile messaging, social media, and other new technology use to encourage adherence to treatment regimes and thus the maintenance of good health in those who are HIV positive. This would likely need more than simply viewing social media postings but rather research participant participation whether in the form of a study of particular text messaging, interviews, focus groups, the use of a particular application for instant messaging, or some sort of study of a reminder system implemented by a health group. Still, it may be difficult to study some populations of HIV positive individuals as this status may prove to be a sensitive topic for some who fear having this information revealed.

Another research area of interest would be the examination of different social networking sites in depth, comparing and contrasting how different organizations or individuals use any particular social networking site. Comparing mass media campaigns augmented with social media and new technology to those that are not using these tools might be another study to undertake. In addition comparing how different social media are used over time

may be useful to determine how these social media are used with relation to health communication as their users change and become more familiar with the affordances of the networks, and also as these affordances change. The number of ways one could study HIV/AIDS communication and social media and new technologies are quite numerous. Still this study does give an idea of the range of uses these technologies have and also their limitations.

## **Final Comments**

The potential that social media and new technologies have with relation to HIV/AIDS communication is vast, ranging from professional communications to public education campaigns and include everything from computer games to short microblogging postings. This potential needs to be studied in more depth to more fully flesh out what social media and new technology best practices there may be for any given technology, social networking site, or type of communication. However, these technologies and forms of communication are being used currently and are likely here to stay in one form or another for quite some time. As the HIV/AIDS epidemic continues, and as scholarly, public, and health care provider communication uses these technologies it behooves us to further understand these tools, their benefits and their problems. This study sought to better understand the landscape of health communications using these technologies, with the focus on HIV/AIDS as a specific case and provides groundwork for future studies in this area.

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# **APPENDIX A: CODING LIST FOR PART 1**

Question	Additional Details
Where	International, National (outside the USA), American (National in the USA), or Local and state where (city, state, nation etc.)
Type of literature	Academic, Professional, or Lay and describe in more detail the source
Emotive terms	Are there emotive terms (yes/no), if so list these terms and their frequency, and whether they fit the affect heuristic (yes/no), if yes explain why (precision of affective impression, attractiveness of options, insensitivity to probability, dread or intuitive fears [scare tactics], benefit to risk, element of control, unknown, manmade or natural risk, children vs. adults at risk, likelihood of happening, info source trust)
Particular audience	Is there a particular known audience targeted (yes/no), if yes, indicate the audience (youth, males, females, sex workers, men who have sex with men [MSM], male-to-female transgender women, injecting drug users, mobile populations, populations in conflicts and emergency situations, other [if other, please describe]), also if yes, indicate how this audience is targeted (describe communication plan if possible and mode of communication to target if possible)
Religious, Social, and/or Cultural messages	Are there any particular religious, social or cultural messages listed (yes/no), if yes list them, describe how these messages are communicated in the source
Problems with communication method	Are there any mentioned problems with this communication method (yes/no), if yes, please list these problems to the extent that they are described in the source

Specific benefits for this communication method	Are there any mentioned specific benefits with this communication method (yes/no), if yes please list these benefits
Any information regarding what works well versus what does not?	Is there any stated best practice information in the source (yes/no), if so please list this information

## **APPENDIX B: CODING LIST FOR PART 2**

Question	Additional Details
Type of source	Mode of communication (choose from Twitter account, individual tweet, Facebook, Facebook note, blog, YouTube video, YouTube channel, Fropper profile, Fropper blog, short videos, Flickr, LinkedIn, or Google+), description of source (in own words), and aspect of source examined (generally most recent content at the time it was examined, but this lists dates of this content, how many postings were viewed, and other pertinent information about what was viewed)
Where	International, National (outside the USA), American (National in the USA), or Local and state where (city, state, nation etc.)
Particular audience	Is there an assumed audience targeted (yes/no), if yes, indicate who this assumed audience is as best as one can tell (in own words), if yes also indicate if this targeting is implicit or explicit or both, and quote or describe why this is deemed to be the case.
Emotive terms	Are there emotive terms (yes/no), if so list these terms, also indicate what these terms evoke (e.g. sadness, rage, anger, disappointment, happiness, hopefulness, praise, confusions etc.), how they are used (persuasion, scare tactics, used as an example, etc.), who the targets of this emotion are (intended audience, imaginary others, family members, practitioners etc.), an initial impression of what the affect of the messaging is, if it fits the affect heuristic (yes/no) and how this fits the affect heuristic (precision of affective impression, attractiveness of options, insensitivity to probability, dread or intuitive fears [scare tactics], benefit to risk, element of control, unknown, man-

	made or natural risk, children vs. adults at risk, likelihood of happening, info source trust)
Language used	Indicate the formality of the language used (first person, second person, third person [personal vs. impersonal]; passive vs. active; quotes or citations), Indicate also the kind of language used (colloquial, slang, dialect, jargon, txt speak, emoticons, etc.)
Aim of messaging	Indicate the general intended result of the message (preventative, ongoing care, research, academic, pedagogical, to get involved, informational), describe how this aim is communicated
Delivery method appropriateness	Indicate if this delivery method is appropriate and to what extent (yes/no/other [state any other answer]), describe why this might be the case

### APPENDIX C: PART 1 SOURCES ANALYZED FOR CONTENT

## ANALYSIS (sources that describe the use of social media or new technology)

Here, each of the sources that were consulted in phase 1 of the content analysis are listed and given a unique identifier for reference in the text of this thesis. The identifiers are in italics, with references leading to the actual sources following each identifier. The identifiers are alphabetized for ease of finding them.

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### APPENDIX D: PART 2 SOURCES ANALYZED FOR CONTENT

## **ANALYSIS** (examples of social media or new technology)

Here, each of the sources that were consulted in phase 2 of the content analysis are listed and given a unique identifier for reference in the text of this thesis. The identifiers are in italics, with references leading to the actual sources following each identifier. If a particular tweet or video is also cited as part of a larger source that is identified with an appropriate citation and identifier (numbered). The identifiers are alphabetized for ease of finding them.

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amfAR, The Foundation for AIDS Research. (2013, April 12). *YouTube*. Retrieved May 9, 2013, from http://www.youtube.com/user/AIDSResearch

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amfAR. (2013, February 13). The Exchange :: Help Us End the Ban :: amfAR [Video file]. Retrieved July 28, 2013 from http://www.youtube.com/watch?v=Q0qcu3F7\_BY&feature=youtube\_gdata\_play ASHM Media Twitter

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(1) – main account

HIV Insight Twitter (sources 1, 2, and 3)

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