

HEALTH LITERACY, SEXUAL HEALTH, AND GAY MEN

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Current perspectives

Report from a meeting of researchers, policy-makers, service providers and community members funded by the Canadian Institutes of Health Research



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Prepared by:

Mark Gilbert, Ontario HIV Treatment Network / University of British Columbia
Joshun Dulai, Community-based Research Centre for Gay Men's Health
Daniel Wexel, Community-based Research Centre for Gay Men's Health
Olivier Ferlatte, Community-based Research Centre for Gay Men's Health / Simon Fraser University

On behalf of the Health Literacy Planning Grant team:

Barry Adam, University of Windsor / Ontario HIV Treatment Network
Lorie Donelle, Western University
Paul Flowers, Glasgow Caledonian University
Trevor Hart, Ryerson University
Ed Jackson, CATIE
Jody Jollimore, Health Initiative for Men
Rick Marchand, Community-based Research Centre for Gay Men's Health
Lisa McDaid, University of Glasgow
Warren Michelow, University of British Columbia
Wayne Robert, Health Initiative for Men
Irv Rootman, University of Victoria
Len Tooley, CATIE
Terry Trussler, Community-based Research Centre for Gay Men's Health

With key contributions by:

Brent Allan, Living Positive Victoria
Mark Gaspar, Concordia University
Nathan Lachowsky, University of Toronto / BC Centre for Excellence in HIV/AIDS
Susan Martin, University of Glasgow
Ingrid Young, University of Glasgow
James Wilton, CATIE

Report design:

Katherine Murray, Ontario HIV Treatment Network

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EXECUTIVE SUMMARY

Health literacy is the “ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course.” For gay men health literacy skills are critical to sexual health, particularly today given the increasing complexity of HIV risk and prevention information, and wide variety of means through which it is available (especially online). Gay men have been - and continue to be - active creators of practical knowledge by incorporating emerging scientific information into prevention strategies, and many current health promotion efforts for gay men are focused on aspects of health literacy. However, a robust health literacy approach includes focusing not just on gay men as users of information, but also the providers of information (e.g., service providers, health agencies, other sectors), within a broader consideration of social, structural or system factors affecting user-provider relationships.

This report describes the findings from a planning meeting held October 29-31, 2014 in conjunction with the 10th Annual BC Gay Men’s Health Summit, which brought together researchers, service providers, policy-makers and knowledge users to discuss and describe perspectives of health literacy and its relevance to gay men’s sexual health and HIV prevention, in order to establish a foundation for future research on this topic.

The first part of our meeting was based on a series of presentations and discussions integrated within the Summit itself, which are summarized in this report. Topics spanned:

- Review of the core concepts of health literacy and numeracy;
- How these concepts have been or could be applied to gay men’s sexual health;
- Factors which influence how gay men experience or perceive sexual risk;
- Challenges and opportunities for translating or communicating risk information to gay men;
- How gay men use and view the Internet as a source of health information, and appraising how this information is presented on health agency websites;

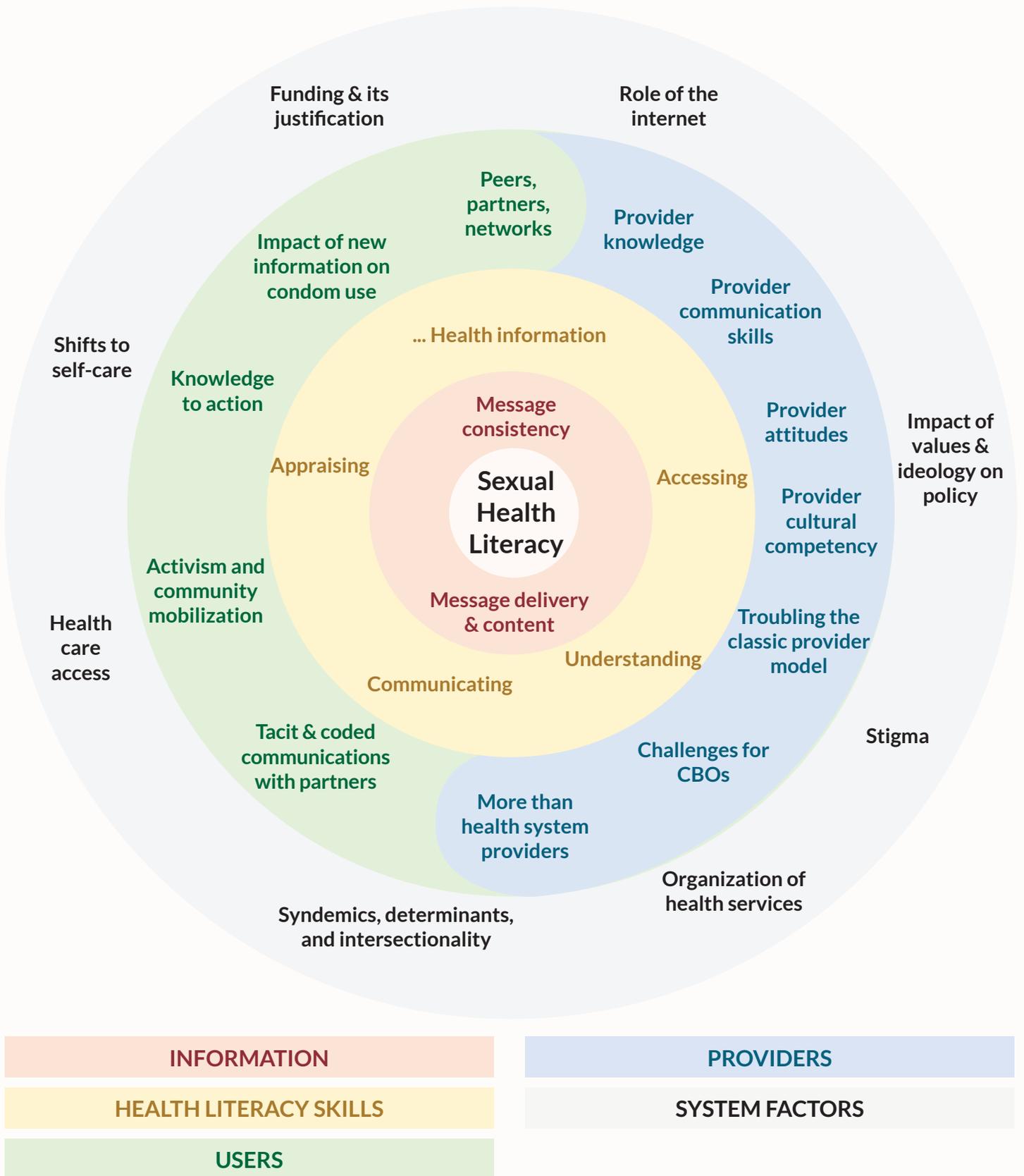
- How gay men understand and make sense of new biomedical HIV prevention technologies; such as pre-exposure prophylaxis, or treatment as prevention.

For the second part of our meeting, we convened a one-day workshop to further discuss the topics raised at the Summit, and to identify key knowledge gaps and research questions related to sexual health literacy for gay men. We used a world café format to foster a collaborative dialogue on the relevance of health literacy to gay men’s sexual health. Discussion notes were organized into themes, along with the knowledge gaps and research questions identified from each theme. Workshop participants also brainstormed possible interventions that could be employed to improve sexual health literacy for gay men.

The information we gathered, both through the Summit presentations and the following workshop, led our team to describe an emerging framework for sexual health literacy for gay men (see Figure 1). This framework recognizes the central importance of the health information itself, the importance of addressing health literacy skills for both users and providers, and a range of user- and provider-specific factors that may be avenues for further research or intervention. The framework also recognizes the fundamental influence of system factors, both social and structural, across all aspects of sexual health literacy.

To move a research agenda forward based on this framework, better understanding existing health literacy skills of gay men and providers, and how these are influenced by identified system factors, is a crucial starting point. We also need research that will lead to developing and testing health literacy interventions of gay men, including ideas proposed during the meeting. Through this planning meeting we have indeed established the foundation for these future research collaborations. At the same time, we have confirmed our need to achieve a fuller understanding of the complex relationships between, and effective interventions for improving, health literacy and sexual health for gay men.

Figure 1: Emerging framework for Sexual Health Literacy for Gay Men



HEALTH LITERACY – WHY IS IT IMPORTANT?

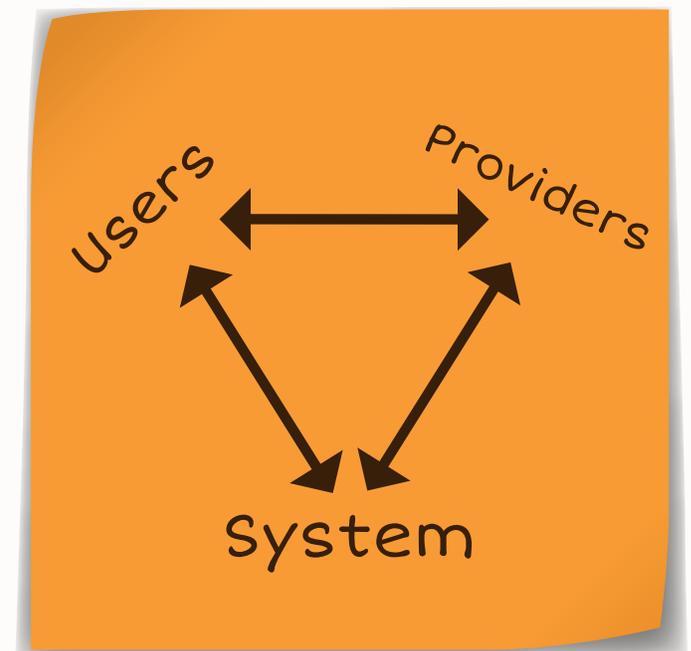
Effectively applying HIV prevention strategies “in the heat of the sexual moment” requires accessing, understanding, and using health information about HIV risk. These skills – called “health literacy” skills – can be challenging to apply as increasingly complex information about HIV prevention strategies emerges (e.g. reduced risk of transmission with undetectable viral load due to HIV treatment, or with post- or pre-exposure prophylaxis (PEP or PrEP)) and due to the significant volume of online information (e.g., websites, social media, or apps). This is particularly relevant for gay men¹, who constitute the population first affected by HIV in Canada and continue to bear a disproportionate burden of HIV today. Also, gay men are not passive consumers of HIV risk information - since the epidemic began in the 1980’s, gay men have been active creators of practical knowledge by incorporating new emergent information about HIV transmission risk into prevention repertoires (e.g., initial widespread adoption of condom use, later development of sero-adaptive strategies such as sero-sorting).

While gay men and gay communities play a key role in health literacy, improving health literacy for gay men means not exclusively focusing just on gay men (as the primary **users** of information), but also to think about the producers or **providers** of information, particularly health care providers and agencies, who also face challenges in navigating this new information landscape. It is also important to recognize that the relationship between information users and providers in this equation is influenced by underlying social, structural and **system** factors, such as different social, cultural and legal perspectives on HIV risk (Figure 2).

1 In this report we use the term “gay men”, as the activities described occurred within the context of a conference focused on gay men. While some of the information contained originated from and may be relevant across communities of men who have romantic or sexual relationships with other men, it is important to recognize that gay men have distinct social and health experiences from bisexual men and other men who have sex with men. Therefore the generalization of the content of this report to all MSM should be done with caution.

The concept of health literacy and appreciation of its importance has emerged over the past few decades, primarily within the realm of chronic disease management. We know little about the relationship between health literacy and sexual health in general, and even less when thinking specifically about gay men. Accordingly, we have little understanding of key information: the effectiveness or reach of different methods for communicating HIV prevention information; how conflicting messages from different health providers are integrated by gay men; how information about risk is incorporated into sexual decision-making; and how the interactions between individual, provider, and system-level factors affect how gay men make sense of sexual health and risk information. Research in this area is only beginning, and given the increasing complexity of information related to HIV prevention there is a pressing need for effective interventions to improve health literacy for gay men.

Figure 2: A conceptual framework for health literacy



ABOUT THIS REPORT

Through a Canadian Institutes of Health Research Planning Grant, we were able to bring together a group of Canadian and international researchers, service providers, policy-makers and knowledge users spanning the fields of health literacy, HIV prevention, and gay men's health for a workshop to begin to discuss these questions, held in conjunction with the Annual British Columbia Gay Men's Health Summit. Our goal was to describe current perspectives on the topic of health literacy and its relevance to gay men's sexual health and HIV prevention and identify

key assumptions and knowledge gaps. By doing so we aimed to lay the foundation for building an interdisciplinary research collaboration for developing a national and international program of research, in order to better understand the relationship between health literacy and HIV prevention for gay men (that looks holistically at user, provider, and system levels). This report summarizes the activities and discussions that occurred during the Summit and the following workshop.

PART 1 – DISCUSSIONS AT THE SUMMIT

The first part of our planning meeting was integrated within the program of the 10th Annual British Columbia Gay Men's Health Summit², held in Vancouver on October 29-31, 2014. The Community-based Research Centre for Gay Men's Health, which organizes the Summit, adopted health literacy as its annual theme (The New Literacy of Gay Men's Health: How do you know what you know?). The Summit is one of Canada's premiere events exclusively focused on gay men's health, and in 2014 was attended by 200 community members, service providers, policy-makers and researchers working in the field across Canada and beyond.

We planned a full day program stream on health literacy on October 31, including plenary presentations, breakout panel sessions, and discussions (see Appendix). Our goal for doing so was two-fold. First, we aimed to establish a common understanding of the importance of health literacy for gay men and HIV prevention, and the state of current theory and research on this topic. Second, by hosting this stream within the Summit, we aimed also to draw on the collective knowledge, questions and concerns related to health literacy within the broader audience. We also conducted mini-interviews with 17 summit attendees to further elicit their perceptions of the notion of health literacy and how this applies to gay men's health, which were recorded and transcribed.

In this first part of the report, we summarize the key concepts and findings from the presentations, panels and discussions that took place during the BC Gay Men's Health Summit. To do this, we grouped and synthesized presentations from different speakers according to common themes.

1.1 Core concepts of health literacy and numeracy

Health literacy first appeared in the literature in 1974 in an American paper on health education (Simonds, 1974). The researchers argued that health literacy was an outcome that should be measured in school children to determine if they had retained any of the content they learned in their health education programs.

Health Literacy: “the ability to access, understand, evaluate, and communicate information as a way to promote, maintain and improve health in a variety of settings across the life course” (Rootman and Gordon-El-Bihbety, 2008)

“the use of a wide range of skills that improve the ability of people to act on information in order to live healthier lives. These skills include reading, writing, listening, speaking, numeracy, and critical analysis, as well as communication and interaction skills” (Coleman et al., 2009)

2 <http://cbrc.net/summit>

Health literacy is a complex concept and while there is no agreed upon definition, experts on the topic are beginning to agree that health literacy is comprised of four key elements: information, actors, capacities, and contexts (Rootman, 2014; Sørensen et al., 2012):

- When it comes to health **information** an individual can evaluate it on four criteria: the type of information being presented (e.g., prose, numerical, pictorial), the content or subject matter, how it is presented (e.g. oral, electronic), and how easy it is to understand.
- **Actors** can be divided into users of health information and individual or system providers who share health information.
- **Capacities** can be thought of as the skills required to consume or share information. The types of capacities that exist are the abilities to retrieve or locate, understand, evaluate, communicate health information, and use or apply health information.
- When thinking about health literacy it is also important to consider the **context** such as the setting, social or cultural components, characteristics of individuals, and provider or system factors such as public attitudes or structural oppression.

Nutbeam proposed a framework of health literacy with functional, interactive, and critical skills components (Nutbeam, 2000):

- **Functional** health literacy skill consists of basic reading, writing, and numeric skills for everyday use. Functional health literacy skill supports the comprehension and communication of health facts, awareness of health services, and use of the health system.
- **Interactive** health literacy skill includes cognitive, social, and literacy skills that support the development of personal skills in a supportive environment. Interactive health literacy is directed at improving individual motivation and self-confidence to enhance positive health behaviours.
- **Critical** health literacy skill consists of advanced analytical, advocacy, and social skills enabling positive change within communities and at the societal level. The AIDS Coalition to Unleash Power (ACT UP) exemplifies

critical health literacy, as an organization that successfully advocated for social, legislative, and health system change early on during the response to the HIV epidemic.

The different typologies of functional, interactive, and critical health literacy represent knowledge, skills, and attitudes that support greater self-sufficiency and control in personal health management, but extend health literacy to include collective engagement (e.g., groups and communities) with a wider range of health knowledge and skills (e.g., activism and advocacy) to act on the social determinants of health (Hoffman-Goetz, Donelle, Ahmed, 2013; Nutbeam, 2000; Sorensen et.al., 2012).

Links to videos of summit presentations for this section:

- 🔗 [Dr. Irv Rootman, "Health Literacy: Importance for Gay Men's Health and Research"](#)
- 🔗 [Dr. Lorie Donelle, "Health Literacy: Numeracy and Prose"](#)

Health literacy is important because it affects large numbers of people. For instance, approximately 14.8 million adult Canadians (60%) do not meet the minimum level of literacy to manage their health information needs (CCL, 2007). Health literacy is also important because low levels of health literacy are associated with poor health outcomes, such as longer hospitalizations (Baker et al., 1997; 2002), and poor health behaviours, such as difficulties in using the health care system (Davis et al., 1996; Brez & Taylor, 1997). Low health literacy has been shown to lead to poor self-management of chronic diseases (Johnson et al., 2006). Furthermore, low levels of literacy has an effect on the cost of health care in Canada, with estimates ranging from 3 to 5% of total health care cost or \$8 billion of spending a year (Mitic & Rootman, 2012). Thus, improving health literacy can lead to improvements in navigation of the health care system, the ability to share information with providers, self-management of chronic diseases, decision-making and advocacy on health, ability to reduce health risks, and health outcomes and longevity (Rootman, 2014).

It is important to note that there are some communities that are more likely to have lower levels of health literacy such as older adults, newcomers to Canada, individuals with lower levels of education, individuals whose first language is neither English nor French, individuals with limited income, and many others (CCL, 2007). Many studies also find that health information is currently being written at reading levels that exceed that of the average adult (Rudd, 2007). Those with limited health literacy may experience shame, have limited health vocabulary, limited knowledge of anatomy, limited access to health information, late stage diagnosis of disease, and increased utilization of health care resources (Amalraj, Starkweather, Nguyen, & Naeim, 2009; Canadian Council on Learning, 2008; Cho, Lee, Arozullah, & Crittenden, 2008; Davis, Williams, Marin, Parker, & Glass, 2002; Dolan et al., 2004; Gazmarian, Williams, Peel, & Baker, 2003; Mancuso & Rincon, 2006; Mitchell, Sadikova, Jack, & Paasche-Orlow, 2012; Omachi, Sarkar, Yelin, Blanc, & Katz, 2013; Parikh, Parker, Nurss, Baker, & Williams, 1996; Parikh et al., 2007; Torres & Marks, 2009; Viswanath & Ackerson, 2011).

Health Numeracy: “the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information to make effective health decisions” (Golbeck et al., 2005).

One aspect of health literacy is health numeracy. Adequate health numeracy skill enables individuals to contribute meaningfully to health care decision making (e.g., to understand differences in treatment efficacy, the risk of treatment side effects, the chances of recurrency). Health numeracy skill can be divided into four types - basic, computational, analytical, and statistical (Golbeck et al., 2005; Moore et al., 2011):

- **Basic** health numeracy requires only being able to identify and understand numbers in a set of information (e.g. PEP should be taken within 72 hours)
- **Computational** health numeracy requires an individual to perform arithmetic (e.g. PrEP costs about \$900 a month or \$30 a pill)

- **Analytical** health numeracy requires an individual to interpret numerical information across multiple sources (e.g., understand a normal range of laboratory values)
- **Statistical** health numeracy requires individuals to understand probabilities (e.g., the risk of HIV infection is up to 92% lower for men who use PrEP consistently)

In the literature, the levels of competency surrounding health numeracy seems to vary from study to study, but for the most part health numeracy levels appear lower (Lipkus et al., 2001; Woloshin et al., 2001; Sheridan & Pignone, 2002; Sheridan et al., 2003; Davids, 2004; Donelle et al., 2007; Donelle et al., 2008). Those with limited health numeracy have difficulty scheduling appointments, assessing and personalizing risk, and following the instructions for proper medication administration (Donelle, 2014). Access to and understanding health information are foundational components of decision making regarding health care. Fundamental to self-health promotion and chronic disease management are the individual (clients, providers, organizations) literacy and health literacy skills needed to access reliable health information (prose, numeric or risk, document) and make informed health care decisions (Hoffman-Goetz, Donelle, Ahmed, 2013). (See section on health risk communication below).

1.2. Applying health literacy to gay men’s sexual health

As a starting point, we may adapt the existing Canadian Public Health Association definition of health literacy to gay men as “the degree to which gay men are able to access, understand, appraise, and communicate information to engage with the demands of the health context of gay men in order to promote, maintain, and improve health in a variety of settings across the life-course” (Adapted from Kwan, Frankish & Rootman, 2006 and Rootman & El-Bihbety, 2008).

Health literacy is clearly applicable to gay men’s health, including issues related to sexual health and HIV. If we consider HIV testing as an example, getting tested includes considering whether one is at risk of HIV, whether testing services are accessible, consideration of different testing options, understanding the benefits of testing and early diagnosis – all requiring relatively high levels of health

literacy (spanning functional, interactive, and critical skills) (Flowers, 2014). A recent study from Australia demonstrated that health literacy among gay and bisexual men living with HIV was influenced by levels of social support, including emotional, instrumental (e.g., financial or support with housework), and informational support (Allan, 2014). Those with social support tended to have a positive self-image and greater perceived quality of life, which may buffer against adverse life events (Allan, 2014). In addition, gay and bisexual men living with HIV were found to have lower health literacy if they had lower levels of education or were immigrants (Allan, 2014).

Links to videos of summit presentations for this section:

- 🔗 [Dr. Paul Flowers, "Reflections on HIV Testing Amongst Gay Men: Scottish Perspectives"](#)
- 🔗 [Susan Martin, "Sexual Health Literacy and Gay, Bisexual and Other MSM: A Scoping Review of the Literature"](#)
- 🔗 [Brent Allan, "Profiling Health Literacy Needs of Australian Gay Men Living with HIV to Improve Health Outcomes"](#)

However in general, health literacy has not often been applied to HIV or sexual health. Based on a scoping review of the literature, Martin and colleagues (2014) describe sexual health literacy as "an individual's knowledge, beliefs, attitudes, motivations and competencies in accessing, understanding, evaluating and applying sexual health information in everyday life to negotiate and make judgements and decisions concerning sexual healthcare, health promotion, relationships and wellbeing". It can also be thought of as the "the level of sexual health knowledge and the capacity to employ this knowledge within sexual and social contexts", acknowledging that an individual is positioned within socio-cultural, economic, historic and global contexts (Martin, 2014).

The same review demonstrated that little is known

about how health literacy influences the sexual health of gay, bisexual, and other men who have sex with men. From the literature that does exist it seems that gay men do have sufficient knowledge when it comes to topics such as HIV and sexually transmitted infections (STIs) (Bellaby et al., 2007), as has also been seen in Scottish bar-based surveys of gay men (Flowers, 2014). While these findings beg the question of why some gay men have differing knowledge levels, knowledge alone is not directly an assessment of sexual health literacy. The review identified a number of possible factors that may contribute to sexual health literacy among gay men.

Communication: Communication is a key component in understanding the sexual health literacy of gay and bisexual men. Research indicates that associations exist between poor communication with sexual partners and poor sexual health practices (Mollitor et al., 1999; Prestage et al., 2006; Koblin et al., 2011). Nonverbal communication should also be considered when attempting to understand how gay and bisexual men communicate sexual health information with one another, as it is commonly used to negotiate sexual interactions, particularly within group sex contexts (McInnes et al., 2011).

Online interactions: Attention must also be paid to how gay men interact online as most studies currently only look at how gay men interact face-to-face. Gay and bisexual men are more likely to engage in sexual negotiations online than in person and often these conversations include the topic of safer sex practices (Carballo-Diequez et al., 2006; Horvath et al., 2008).

Context: Sexual encounters are comprised of multiple contextual and interpersonal elements that interact to shape sexual practices and risk reduction strategies. Many studies overemphasize the role of individuals and underestimate environmental factors (Beogher et al., 2011). Contextual factors include (Suarez & Kauth, 2001): the type of relationship the person has with their partner, the partner's biological status and sexual practices; the use of anti-HIV measures; forms of stigma; AIDS burnout or fatigue; perceptions of masculinity and power differentials; and features of a relationship such as trust, communication, and commitment. In addition, many current health promotion tactics fail to take into account the role of desire in evaluating risk or the decision-making that occurs during sexual encounters between

gay and bisexual men. Sexual health literacy interventions could be more effective if these contextual factors were considered.

Within the discussions on this theme at the Summit, suggestions for future directions on improving health literacy for gay and bisexual men include: having a definition for health literacy that takes into account the context of gay men's health; focusing on measurement in relation to the users, providers, and systems responsible for health information pertinent to gay men; develop policies and practice research relevant for gay men; undertake research and develop

tools and measures to understand context-specific variation over the life course of gay men; and use multiple methods and approaches including participatory research with gay men (Rootman, 2014). Using multi-dimensional tools could be useful in identifying the health literacy needs of gay and bisexual men, which then can be used to design interventions (Allan, 2014). The gay men's health sector should collaborate with other sectors such as the education, literacy, healthcare, and business sectors, as they may have knowledge or expertise that may be useful for future strategies in health literacy.

Health literacy: is it a buzzword for what we're already doing, or a new approach for improving gay men's health?

Reflections from Interviews with Summit Participants

"I think it's something we're already doing but at the same time I think talking about it in a broader context can really add to what we are already doing and expand on it." — Service Provider

"I think it's a more holistic perspective, and it's very new to me but I'm very excited about this concept of health literacy because I think it

might get at what is missing ... we can promote health until the cows come home, but it doesn't necessarily translate into the outcomes we want to see...we need to look at the process of how that information is received and interpreted and translated. So for me, it's a very encouraging discourse." — Researcher

"It's unfortunate that we haven't actually identified that gay men and our allies created a level of health literacy before the concept of health literacy was even created. ...we invented and created out of crisis the most extraordinary level of health capacity building ever seen in the last fifty, sixty years, if ever. So we're being asked to follow an academic model that didn't even acknowledge us, so we're now becoming patients to the very thing that we actually, as a community, helped create." — Researcher

"Perhaps it's a tool to help us critically analyze what we're doing already." — Researcher

"...it feels like it's work we're already doing. It's just a new way of defining it." — Service provider

1.3. What influences perceptions of risk among gay men?

Technically, risk can be defined as "The probability of an event combined with the magnitude of the losses and gains that it will entail" (Douglas, 1992). However, when thinking about risk we need to consider the social and cultural context in which risk is situated (Gaspar, 2014). For example, individuals may ignore the beneficial aspect of the definition and focus on the danger or the potential harm that may come from

certain activities. Ideas about HIV transmission are always situated alongside culturally specific perceptions of morality, blame and responsibility (Gaspar, 2014).

At-risk can be defined as a state of being where an individual or group is recognized as being more susceptible to a specific harm. At-risk individuals are usually asked to be accountable for their risk or to manage it in some way (Gaspar, 2014). If the information about a risk and measures to prevent it changes, then so to do the experiences of being at-risk.

Depending upon their particular experiences, whether favourable or unfavourable, simple or complicated, an at-risk individual's disposition to HIV and sexual risk can shift—either becoming more risk tolerant or more risk averse. An individual's disposition toward risk fundamentally shapes how he processes newly acquired knowledge about prevention and how he interacts with others in potential at-risk moments.

Based on interviews with 34 gay- or queer-identified HIV negative or status-unknown men with experiences of being unsure of their HIV status, Gaspar (2014) proposed the following **framework for understanding experiences of being at-risk of HIV**:

- **Knowledge and health literacy:** Interviewees had a broad range of expertise, with knowledge related to proximity to the gay/queer community and the HIV/AIDS response. Experiences of being at-risk were key learning moments; however, participants appeared to poorly understand what it is like to live with HIV, with concepts like undetectable viral load, PEP or PrEP being recognized but not well understood.
- **Institutional experiences:** Experiences of health-related services and policies affected relationships to HIV risks (from testing services to immigration policies to safer sex education)
- **Sexual experiences and intimacies:** Pleasurable and non-pleasurable sexual experiences, and different versions of relationships and intimacy, shifted notions of risk.
- **Orientation to sexual and community politics:** Among men interviewed, orientation to sex and community politics altered perceptions and experiences of risk (e.g., gay versus queer political orientation, slut shaming versus slut pride)
- **Social positionality and intersectionality:** The intersections of one's various identities were involved in shaping and shifting experiences of risk.

Characteristics of risks themselves are also important to how risks are perceived, which is particularly well described in public health with respect to communicating environmental health risks (Gilbert

2014). Knowledge from this discipline may be relevant to thinking about how gay men perceive sexual risk.

There is often a poor correlation between the actual level of risk and the amount of worry that it causes (Gilbert 2014). Psychological and social factors that may influence how risk is processed, include apathy, overconfidence or optimism, desire and demand for certainty, and willingness to change strongly held beliefs. Factors can also raise or lower the perception of risk; for instance, risks that are voluntary or viewed as being under one's control are perceived as less risky than those that are involuntary or imposed upon individuals (Gilbert, 2014). Risks may be perceived as less risky if they are familiar, appear equally distributed in a population, have an apparent benefit, are easy to understand, or are certain. Hence the essence of risk communication is not merely explaining the level of risk, but requires addressing these factors to increase or decrease perceptions of risk.

Links to videos of summit presentations for this section:

🔗 [Dr. Mark Gilbert, "What makes risks risky?"](#)

1.4. How to translate risk information

Since the onset of the HIV epidemic, health care providers, public health institutions and community agencies have played a critical role in communicating HIV risk information to gay men. However, HIV risk information can be complex and translating these into prevention messages is fraught with challenges: uncertainties are unavoidable, assessing one's vulnerability is complicated by many variables, including behavioural and biological factors; probabilities are often difficult to understand; and, one's understanding of risk is subjective and individuals have different levels of risk they are willing to accept.

Wilton (2014) described several concepts that are

challenges in the translation, communication, and understanding of HIV risk information for gay men and providers alike:

Absolute vs. relative risk: Risk is usually communicated in terms of absolute or relative risk. Absolute risk refers to what someone's risk actually is (e.g., one's average risk of acquiring HIV during a single act of receptive anal sex is 1.5%). Relative risk describes the change in risk due to the presence of a given factor or because a prevention strategy is used (e.g., consistent use of treatment reduces the risk of HIV transmission by 95%). Not understanding the difference between absolute and relative risk can result in erroneous information being conveyed, particularly when translating a relative risk into an absolute risk.

Qualitative vs. quantitative approach: Absolute and relative risk can be communicated using a qualitative or quantitative approach. A typical approach to communicating absolute HIV risk is the use of qualitative categories, such as stating a behavior is "low risk" or "high risk" for infection. On the other hand, providers may be compelled to use a quantitative approach to describe absolute risk, as many providers report that gay men prefer to have their risk quantified as a number. However, numbers can be difficult to understand and can bring a false sense of certainty (e.g., the average risk of acquiring HIV through anal sex is 1.5%, but this number is not static and can be much higher if certain biological factors are present, such as a higher viral load).

Risk per-act vs. cumulative risk: Community workers and care providers may be asked by gay men to quantify the risk per-act, which can often seem low if communicated as a number. Further, risk per-act numbers can also be difficult to interpret. Wilton gave the example of an individual who thought that he needed to be exposed 71 times to HIV before infection can occur after hearing that the act pre-transmission for receptive anal sex was 1 in 71 exposures (1 in 71 is equivalent to 1.5%). Communication of HIV risk often focuses on the risk per-act. However, focusing on per-act transmission rates ignores that many gay men have multiple exposures to HIV, and when communicating risk, it is important to take into account the accumulation of one's exposures. HIV risks that appear to be small in the short term can accumulate and become larger over multiple exposures.

Zero risk and confidence intervals: When translating research information, it may be important to take confidence intervals into account. For example, in one study PrEP appeared to reduce the relative risk of HIV infection by 100%, and in another there were no HIV infections among serodiscordant couples where the HIV-positive partner had an undetectable viral load (i.e. a 0% absolute risk of HIV transmission). Statistically, it is impossible to prove an intervention is 100% effective or that there is a 0% risk of HIV transmission, therefore confidence intervals are critical to assess how confident one can be about these results, adding a layer of complexity that needs to be translated to gay men.

Links to videos of summit presentations for this section:

- ✦ [Brent Sawlor, "From AIDS to HIV to Undetectable: Using New Language to Change How We Talk about HIV"](#)
- ✦ [James Wilton, "Understanding HIV Risk: Exploring Technical Aspects and Models for Communication"](#)

Wilton also described some important considerations for risk communication:

- Not all factors change HIV risk by the same amount (e.g., there are highly effective prevention strategies such as condoms, but others like strategic positioning that have less of a protective effect).
- In addition to presenting risk reduction as a percentage, relative risk can be presented as a fold or times change, which may be interpreted differently. For example, a 96% reduction of HIV transmission due to treatment is an equivalent to a 26-fold or times change — meaning it is 26 times less likely that infection will occur while on treatment. Although these numbers are equivalent, 96 is a larger number than 26 and this may affect one's interpretation of the effectiveness of treatment.
- Effectiveness of prevention strategies is not

static, particularly if they are not used consistently and correctly. It is therefore important to present the effectiveness of strategies with the array of factors that could reduce it.

- There are still many gaps in the research of HIV risk and the impact of new prevention technologies. More so, those wishing to communicate risk information are sometimes confronted with conflicting evidences and evidence with varying degrees of quality. Consensus statements are critical for HIV prevention agencies and workers to provide the best possible advice to gay men about risk.
- Providers can experience challenges in keeping the message nuanced enough to be accurate, while at the same time keeping the message simple enough to be meaningful to gay and bisexual men.
- There is no simple and single message as there are a diversity of experiences among gay and bisexual, including in terms of behaviours, risk taking and capacity to comprehend information.

Currently, the only national guidelines in Canada that exist to assess and communicate HIV risk come from the Canadian AIDS Society³. These guidelines use qualitative risk categories to describe the risk associated with different activities. Many care providers and HIV prevention workers rely on these guidelines, but little research has been done about how effective they are and how they are understood by populations at risk of HIV, including gay men. These guidelines may not reflect the most up to date scientific evidence about HIV transmission and prevention. For example, the activities in the “high-risk” category in the guidelines do not all have the same level of risk (anal and vaginal sex). More so, these guidelines do not take into account factors such as undetectable viral load and the use of PrEP and PEP. They also leave much room for interpretation – for example “high risk” can mean different things to different people.

While complicated and challenging, innovative approaches have been emerging to communicate HIV risk information to gay men. Len Tooley presented a new model of HIV risk reduction under development

3 <http://www.cdnaids.ca/hivtransmissionguidelinesforassessi>

by CATIE, which aims to provide practical advice to gay men by emphasizing correct and consistent use of strategies, the level of effectiveness of different HIV prevention strategies, and bridging the divide between HIV-negative and positive men. The proposed model has three steps:

1. Choose a highly effective prevention option (such as condoms, PrEP, undetectable viral load, monogamy, abstinence, or serosorting).
2. Add on risk reduction strategies (such as strategic positioning, PEP, pulling out).
3. Prepare for possible outcomes (such as preparing for testing, understanding treatment).

As another example, Brent Sawlor presented an innovative initiative from AIDS Vancouver, a campaign to increase awareness of the importance and implications of undetectable viral load⁴. The project emerged from a realization that public health and community discourses around HIV had not been updated in regards of the new research and scientific evidence. Specifically, the project sought to expand the use of the term “undetectable” and its new meaning in HIV prevention, as the term better conveys new medical realities, reduces stigma and experience of discrimination, and is an important “tool” in the prevention of HIV transmission.

1.5. The Internet as a source of information

Research exploring different ways of obtaining information such as mass media sources (e.g., newspapers, magazines, the Internet, television) has implications for equity in accessing health information, services, and support. Differences in how people attend to, understand, and make use of health information depends in part on their literacy and health literacy skills (Viswanath & Ackerson, 2011). Literacy and health literacy skills influence the source of health information that individuals specifically seek out. For example, newspapers, magazines, and the Internet are health information sources typically accessed by individuals with well developed literacy skills; in contrast, information seekers with limited literacy skills tend to rely more on passive information sources such as television and radio to learn about health

4 <http://www.aidsvancouver.org/undetectable>

issues. This research challenges the concept of equitable access to quality of the health information (e.g., the accuracy, detail, and clarity) from the diverse information sources (Hoffman-Goetz, Donelle, Ahmed, 2013).

The Internet is a preferred method of communication for gay men because of the perceived anonymity, accessibility, and safety it ensures (Davis et al, 2006; McKie et al., 2005). Furthermore, many gay and bisexual men prefer to use the Internet to look for health information over talking to healthcare providers, because it is easier to access and does not come with any communication barriers that arise from dealing with providers (Gust et al., 2013). Those who look for sexual partners online may lack basic knowledge about HIV and feel that the resources located within their communities are unable to meet their needs (Rhodes et al., 2010). Berry and researchers (2008) have also found that gay men who seek sexual partners online were more likely to report behaviours that could place them at risk for seroconversion in comparison with gay men who do not look for sexual partners online.

Link to videos of summit presentations for this section:

- 🔗 [Dr. Nathan Lachowsky, "The Use and Impact of Online Outreach Services Among Gay Men in Ontario"](#)
- 🔗 [Dr. Mark Gilbert, "What Information Are We Providing to Gay Men and How? Environmental Scan of HIV Websites in Canada"](#)
- 🔗 [Dr. Nathan Lachowsky, "What health info are gay men in Ontario searching for online & where are they getting the answers?"](#)

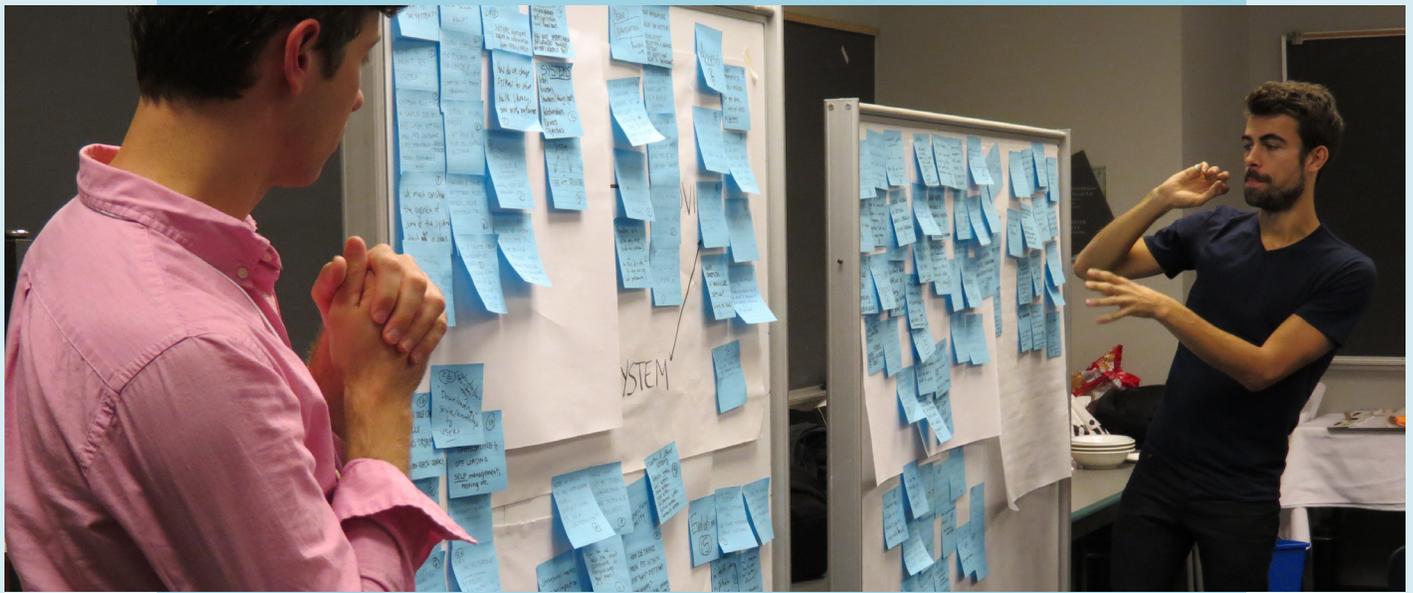
In a recent online survey of gay, bisexual and men who have sex with men in Ontario conducted by Lachowsky and colleagues (2014), men reported commonly looking for health information online about sex (43%), STIs (38%), HIV (31%) and HIV/STI

testing (27%). The average number of hours spent per week looking for sexual health information was 1.3 with almost all men using the Internet to look for sexual health information at some point in their lives. Most men reported finding the information themselves with the next most common ways to find information being through banner ads or apps, or online outreach workers. Sexual health topics that gay men would be most interested in researching were centred around forming relationships with other men (dating, relationships, connecting with other gay men in their community), with HIV prevention methods such as PreP and PEP being much lower on the list.

The survey also demonstrated that approximately 13% of guys had experienced some form of online outreach, reporting that online providers were friendly, easy to understand, helpful, prompt, and knowledgeable (Brennan et al., 2014). Half of them reported that they had received a useful referral and most (almost 90%) said that the outreach experience had some impact on them in the sense that they were either more knowledgeable on a topic, or had made changes to their behaviour. For those who had not experienced online outreach, 68% stated that they "don't need these services" and almost a third of gay men remarked that they were unaware that online outreach services existed on the websites or apps they were using.

When gay men were asked about the kinds of sexual health information they would like to have more readily available to them online, their responses seemed to revolve around six different themes (Lachowsky et al., 2014). Men were looking for information on:

- Viral loads, undetectability, and sex with HIV-positive men.
- Risk associated with various sexual practices and for different gender identities.
- Debunking myths around risk and transmission.
- Where to find free, anonymous testing services and what to expect when going to get tested for HIV and STIs.
- Encouraging or uplifting information, focusing on reducing harm rather than shame- or deficits-based approaches
- HIV (non-disclosure) criminalization and around disclosing one's HIV status.



Most gay men looked for information using online search engines, with the next most common responses being looking on public health, government sites, or community websites (Lachowsky et al., 2014). Most reported finding the information they were looking for and almost two-thirds reported that the information also seemed to be reliable. When asked about which online resources should have relevant sexual health information, participants reported wanting to see information on many different type of sites (from cruising/dating apps and websites to social media and government and community health agencies websites). In addition, when asked about the key features of valuable resources, participants listed that information be accessible, comprehensive, relevant, confidential, anonymous, and safe; to have real-time access to providers 24 hours a day; to include scientifically supported information with citations and links to other resources; and to be accessible across a variety of platforms and devices.

To assess how well agencies met these expectations, Gilbert and colleagues (2014) presented preliminary findings from a review of Canadian community and health agency websites (funded through the planning grant). The most prevalent risk and prevention topics present on community and health agency websites are related to transmission or physical barrier methods such as condoms and lubricants. Many websites

did not include information on more recent risk and prevention strategies such as serosorting, viral load, acute HIV, Treatment as Prevention, or PrEP.

In terms of how the information is presented, most websites did not explicitly compare risk information or prevention strategies (45% and 11%, respectively). Almost all sites used prose to present information, with fewer using tables, images, or interactive features. Risk information was often presented as a statement (e.g., unprotected anal sex is a risk factor), and it was equally common to see risk information presented in absolute or relative terms. The impact of prevention strategies were most commonly presented in relative terms.

Most websites used plain language when presenting information (e.g. sex) versus colloquial language (e.g. fucking) with scientific language (e.g. intercourse) being the next most common. Other web features that may engage visitors were less common with animation, videos, clinic finders, and “Ask a question” among those most commonly used. The websites on average had a reading grade level of 10, which is high considering it is recommended that information be presented at a grade 6 reading level. In terms of how easy the websites were to use, the clarity and consistency of website design were generally good, but website functionality and engagement were often lower.

1.6. How gay men understand and make sense of new prevention technologies

There is a growing body of research (predominantly from the U.S.) examining the awareness among gay men of new prevention technologies and methods, how they understand them, and how they utilize them. The findings of three recent research projects presented at the Summit on this topic shed insights from other geographic locales, and in recognizing the social complexities and contexts of new prevention technologies offer an expanded or deepened understanding of these issues.

Carter and colleagues (2014) used data from the Momentum Study to explore awareness of Treatment as Prevention (TasP) among gay and bisexual men in Metro Vancouver, what factors impact their awareness, and qualitatively how that awareness translates into self-articulated knowledge. Preliminary data from the ongoing Canada-wide Resonance Project (Adam, Jackson 2014) focused on the awareness and perceptions of pre-exposure prophylaxis (PrEP) in HIV-negative partners and undetectable viral load in HIV-positive partners as a potential HIV prevention tool. Young et al (2014) examined the perceptions and acceptability of TasP and PrEP in the Scottish context, seeking to understand how these interventions fit into the lives several groups, including gay and bisexual men. Though each study is distinct in its focus, methodology, and population/sample there are many parallels relevant to gay men's health literacy among their findings and conclusions.

After learning the efficacy of TasP and PrEP, participants in both Young et al (2014) and the Resonance Project were surprised that these strategies were not more widely promoted, although that did not preclude their skepticism, often grounded in earlier and conflicting prevention messaging. For example, some Resonance Project participants voiced uncertainty about the toxicity of PrEP, an uncertainty informed by the high toxicity of earlier HIV treatments. This question of conflicting messaging reappeared in a generational difference among participants in that study, where older men who had adapted to a prevention landscape with different biomedical interventions were more resistant to these newer technologies that challenge so much previously well repeated and accepted messaging.

Another potentially overlooked but critical consideration was the perceived trustworthiness of the information. For example, participants in a focus group of Young et al (2014) doubted the stated efficacy of PrEP as explained to them, doubt which to the researchers' surprise persisted after the participants were reassured that the data came from a governmental source. The researchers' assumption that since they trusted the source, that it would be trusted more generally reinforced the need to question all such assumptions. Resonance Project participants echoed this, continuing to question whether condoms would still need to be used concurrently with PrEP after having its efficacy described.

Link to videos of summit presentations for this section:

- 🔗 [Dr. Ingrid Young, "Exploring the Acceptability of PrEP and TasP among Gay and Bisexual Men in Scotland"](#)
- 🔗 [Dr. Nathan Lachowsky, "Awareness & Knowledge of TasP among HIV-positive and HIV-negative gay, bi and other MSM"](#)
- 🔗 [Dr. Barry Adam, Ed Jackson, "Resonance: What's the Buzz on HIV Prevention Among Gay Men?"](#)

Even when accepted, potential barriers to the effective use of new prevention technologies were identified. Participant reactions in Young et al (2014) underscored how communication must be clear, and provide not only information but the critical literacy skill to use that information. One participant's response to statistics of reduced risk by using new technologies emphasized how having such information without the skills to properly use it negates much of its potential effectiveness, while on the other hand, a highly health literate participant's critical appraisal of simplified prevention messaging stressed the need to fully inform people and not assume the simplest message is necessarily the clearest and most effective.

This question of effective messaging and someone's ability to use that information was implicit in the findings of Lachowsky and colleagues (2014) on the sources and accuracy of information on TasP. HIV-positive men were far likelier than HIV-negative men to have heard of TasP, with HIV-positive men learning most frequently from their doctor, followed by community organizations, and then gay media, while HIV-negative men learned most often from gay media, followed by friends, and then community organizations. Of those aware of TasP, HIV-positive were more likely to articulate a full definition of TasP as defined by the study (including ARV use, viral suppression, and prevention of HIV transmission) compared with HIV-negative men.

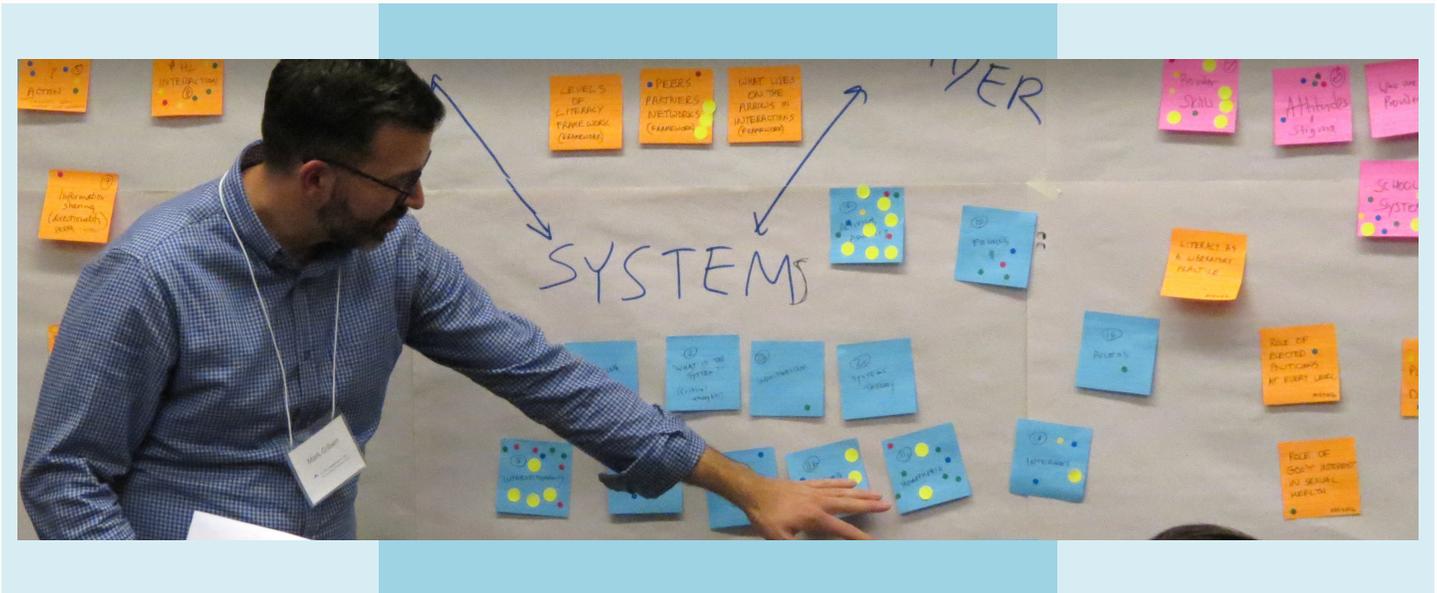
Being aware of TasP and having an undetectable viral load were cited by participants in both the Resonance Project and Young's (2014) study as having a positive impact on HIV-positive men's mental health and in tempering HIV stigma. Informing one HIV-positive man of TasP and what implications that could have for him personally powerfully illustrated to Young et al (2014) the positive impact that greater health literacy can have on individuals and the negative effects of not having promoted such information. Yet among the HIV-negative Resonance Project participants, HIV stigma remained, with little distinction made between being HIV-positive and having an undetectable viral load. Potential impacts of such resistance and perpetuation of stigma were demonstrated among participants in Young et al (2014). HIV-positive men in several instances were reluctant to integrate fully or even speak of their knowledge on HIV prevention, TasP, and undetectability for fear of the reaction of HIV-negative partners and community members who did not have that information.

Despite this, HIV-positive participants in the Resonance Project and Young et al (2014) still found themselves fulfilling the role of educator to friends and sexual partners, a role that some voiced frustration at needing to fill due to the lack of awareness they encountered in the community. Friends and sexual partners were not primary sources of learning about TasP according to Carter et al (2014), but the described reluctance of some HIV-positive men to share their information for fear of a stigmatized reaction was not explored. HIV status was the most determinative factor associated with higher or lower awareness of TasP in Carter et al (2014), with

HIV-positive men being far more aware. Considering the findings across all three studies, this disparity in awareness and the resulting reluctance among HIV-positive men unsure of their less aware partner's reaction undermined the ability of those aware HIV-positive men to fully utilize these strategies and technologies.

On the basis of these findings, Young et al (2014) recommended that when approaching emerging technologies and prevention options and the messaging surrounding them, it is important to consider a message's impact on other prevention information already promoted, the inequalities in HIV literacy and diverse critical HIV literacy skills, and the role of HIV stigma in accessing, using, or applying both existing or new HIV information. To those ends, the most pressing need is to identify language, tools and techniques to support the HIV literacy and well-being of gay men.

Similarly, Carter and colleagues (2014) concluded that to be effective and equitable, TasP promotion strategies must be created that are grounded in and culturally relevant to the diverse communities of gay men. A division among participants in their perceptions of and reactions to PrEP uncovered in the Resonance Project echoed the need for this effective, understanding communication. Some participants saw PrEP users as "good gay citizens" calculating risks and responding rationally, where PrEP lowered risk and removed barriers to sexual satisfaction with no change in the types of sex pursued. Other participants saw PrEP as providing a false sense of security in the pursuit of unprotected sex, thus facilitating unprotected sex and making men less cautious. The question of who is a "good gay citizen" with regards to these new prevention technologies more widely is already under debate, and thus to improve gay men's health literacy is a question on which researchers and service providers must learn to effectively communicate.



PART 2 – DISCUSSIONS AT THE WORKSHOP

Following the Summit, on November 1, 2014 we held a one-day workshop bringing together a group of 38 national and international researchers, service providers, policy makers and knowledge users working in the field of health literacy, gay men's health or HIV prevention (see Appendix 2 for list of participants). All workshop participants had attended the Summit, and the workshop included the majority of Summit presenters on the theme of health literacy, permitting a direct connection to the conversations held over the previous two days. The aim of the workshop was to build on the foundation established over the previous two days and through discussions identify key knowledge gaps and research questions related to sexual health literacy for gay men. We also wanted to begin discussions as to what possible interventions related to sexual health literacy for gay men could look like, and begin to think about next steps for research.

The day was framed by referring to key concepts discussed during the Summit, notably the “User-Provider-System” triangle of health literacy (Figure 1) and the definitions of health literacy and sexual health literacy presented above. There were three main activities to the day, each of which are summarized below.

2.1. World Café

We used a World Café methodology⁵ to further explore the topic of sexual health literacy for gay men, a method which fosters a collaborative dialogue around a topic of importance, by rotating participants through small groups and progressive rounds of discussion. We created three rounds of discussion (30 minutes each) that aimed to identify knowledge gaps and assumptions at each of user (round 1), provider (round 2) and system levels (round 3). Discussion within small groups was facilitated by hosts at each table through prepared questions (Box 1), with participants encouraged to record their ideas on post-it notes which were collected following each round of discussion. For the first round, participants were divided randomly into five small groups of 7-8 people each; following the first round participants were encouraged to switch tables and talk to new people allowing for multi-layered discussions.

Following all three discussion rounds, the combined notes from each round were displayed on a wall.

5 Brown, J. and Isaacs, D. (2005) *The world café – Shaping our futures through conversations that Matters*. Berrett-Koehler; San Francisco p 242

Organizing into three groups, we then reviewed all notes within each round, grouping post-it notes by theme. Once themes were identified, each group of notes was summarized by a single note/theme. This final set of notes from each round were then merged into one final display of themes across the user, provider, and system framework. As a group, we reviewed these final themes, and through discussion added any additional themes that appeared to be missing. Participants were then provided with stickers to attach to the post-it notes describing themes they believed to be most important.

Box 1: Discussion questions

Round 1: What do or don't we know about sexual health literacy and **gay men**?

- Gay men are literate about their sexual health: true or false?
- How do we know that improving health literacy for gay men will make a difference?
- What's one thing we can do to improve sexual health literacy for gay men?
- Health literacy & numeracy for gay men: same or different?

Round 2: What do or don't we know about sexual literacy and **providers**?

- Are health care providers capable of talking about sexual health with gay men?
- When do agencies find it easy to communicate sexual health information to gay men?
- Improving the sexual health literacy of providers: where do we begin?

Round 3: What do or don't we know about **system factors** that affect health literacy?

- There are parts of the information landscape that we just can't influence: true or false?
- Are system factors the same or different for gay men and providers?
- Which system factors are most critical for sexual health literacy?

This World Café created a rich dataset of ideas from workshop participants. For this report, we transcribed each individual post-it note into a document organized by the themes identified by workshop

participants. These were further organized through an iterative review process by a single reviewer, which identified new themes that became apparent on reviewing the entire set of data, distinguishing between assumptions and knowledge gaps or research questions. **The findings are summarized below by theme, with identified gaps or questions for each theme in the boxes immediately following. Themes (or sub-themes within sections) which were ranked highly during the ranking activity are indicated by an asterisk (*).**

Over-arching themes

Better defining sexual health literacy for gay men and its outcomes: Within the sphere of sexual health, participants voiced how sexual health literacy should be broadened beyond HIV and STI to include relationships, pleasure and intimacy. Sexual health literacy should not be separated from mental or emotional health, and needs to be considered using a holistic health and wellness perspective. Participants also acknowledged a lack of consensus on what we are trying to achieve by improving sexual health literacy (e.g., is it to reduce HIV, to have a better life, to improve knowledge for its own sake?).

How do we better define sexual health literacy for gay men?

How do we measure it? Do we adapt or adopt standardized health literacy measures, or develop new ones?

What is the value of health literacy for gay men? What difference does it make?

How do we assess the impact of high/low literacy? What are the outcomes?

Can we think of more creative outcomes for sexual health literacy, such as sexual pleasure?

When are gay men satisfied with their own health literacy?

What is the importance of health literacy to gay men?

The information and message itself is central to sexual health literacy, as reflected by the following themes:

i) Consistency of messages:

The uncertainties and inconsistencies of scientific evidence make it difficult for providers to communicate sexual health information, and leads to gay men getting different advice for the same topic (e.g., HIV test window period, effectiveness of PrEP). There is a lack of consensus on messaging, which is reflected in the lack of guidelines or clinical standards for gay men's health.

Who is best able to achieve this consensus — community agencies, government agencies, or both?

ii) Delivery and content of messages:

Agencies are focused on and good at delivering “bad news” or disease, but focus less on “good news” or health (and are less experienced in doing so). While participants perceived a need for gay men to be better engaged about HIV prevention, they acknowledged that we are not good at creating engaging messages. In general, participants perceived gay men to live in a highly sexualized environment where there are few sex positive conversations about real life sexuality, including the role of **pleasure and desire (*)** on sexual decision-making. We could be more engaging by talking about issues gay men value but have questions about — such as how to have successful relationships, or how to talk about health information with sexual partners.

How do we create engaging messages? Do we need to be cutting edge, share conflicting information, or provocative? Do we need cues to action?

Themes related to users

Most gay men are perceived to be health literate*: Overall, participants felt that gay men have higher sexual health literacy than other groups even though this hasn't been formally measured. This may be

related to the importance of the topic — there is a burden on, and expectation of, all gay men to be literate about sexual health as men are forced to respond to sexual health and HIV. Participants did think there may be gaps, with some groups potentially having different knowledge and understanding of gay men's sexual health (for example, participants thought health literacy may be lower for youth, immigrants, men from ethnocultural minorities, non-gay-identified men; and may be higher for HIV positive men). Identified factors that participants identified as potentially affecting health literacy levels included one's actual or perceived level of risk, ability to read and write, learning style, degree of exposure (e.g., connection to gay community, or receiving information provided as part of ongoing HIV care), whether men see themselves represented in health promotion efforts, and whether providers are or are perceived to be culturally competent. Some participants pointed out that gay men may want to quantify the magnitude of their level of risk; however, the numeracy levels of gay men may be poorer, with numerical risk information mis-interpreted and de-contextualized from sexual decision-making.

Which gay men have the highest health literacy and how has this been acquired?

What do they have that others don't? How can we use this understanding to improve health literacy among those with lower health literacy?

Is the language that we use understandable by gay men?

What do gay men need to know and how does that vary?

Is HIV a priority for all gay men? Does every gay guy have to know what undetectable is?

Accessing the information: In the face of increasing amounts of information, with conflicting and sometimes problematic messages from providers, participants felt that learning to navigate and access information was as important for gay men as learning the content. Being able to access the information at the right time is important; perceived gaps included physical access to information (e.g., lack of services in

rural areas or small cities) and timing (e.g., information rarely received before gay men become sexually active). Context was thought to influence access as well; for example, men may look for reassuring information after taking risk, or selectively look for information that agrees with their pre-conceptions.

Navigating the system: what does this mean, involve, imply?

Where do gay men get the skills to navigate the information? What media are gay men accessing and using?

Are we focusing on the literate already — gay men who come forward to access the information? Who is left out or excluded?

Where is the ideal place and time to learn sexual health literacy?

How is the information received?

Are gay men health literate?

“Overall, I would say yes, although it would probably depend on the gay man, or it would depend on factors like their demographics or their education level or things like that...if their basic needs aren't being covered they're probably focusing on that as opposed to seeking out extra information about their health?” — Researcher

From knowledge to action*: While sexual health knowledge in general was perceived to be high among gay men, participants noted this was insufficient for behavior change — and that there was a disconnect between having the knowledge, having the tools (e.g., knowing what services there are and how to use/navigate them) and then actually using them. Some participants highlighted the need to move beyond the “rational actor” model when thinking about sexual behaviour, and that applying knowledge is contingent on multiple factors including context, motivation to change, personality type, innate ability, connection to gay communities, lived experience, and syndemic factors such as mental health or substance use problems.

How do these factors influence the ability of gay men to apply knowledge?

How do gay men apply and act on knowledge? What is their motivation for doing so?

Peers, partners and networks*: Participants felt that sharing of information among peers is common and plays an important and positive role for gay men (e.g., gay men relaying their lived experience, teaching each other about sex by talking and doing). While this was thought to be particularly common among younger men, sharing of information across generations also occurs. However, participants felt that the value, importance and effectiveness of peer health care providers (such as peer navigators) were not well recognized.

What is the role of friends, peers and social/sexual networks in sexual health literacy for gay men?

Take a critical look at peer navigators — are they advocates, or a cheap fix for a broken system (and thereby making a broken system acceptable)?

Is there an issue of pay equity for peers versus professionals?

Tacit and coded communications*: When looking for or negotiating sex, participants described that some gay men use coded language such as “undetectable”, “safe sex all the time”, or “needs discussion” rather than talking directly about HIV status, which leads to assumptions about partners or screening of partners on the basis of language used. Some participants attributed this to HIV stigma, while others suggested this may be related to conceptions of masculinity and how men talk to each other.

What are these underlying assumptions, and how do gay men reach consensus about them?

How do these “rules of the game” relate to gaps in sexual health literacy?



“...we’ve created a very strong medical model which creates experts in health, which has historically taken away the responsibility from the individual to look for their own health information and I think that’s a big part of what we’re trying to change. ...[but] how much do you give autonomy to the ‘patient’, for want of a better word, and how much responsibility do you still put on the healthcare provider?”
—Service Provider

Impact of new information on condom use: Participants discussed how use of condoms was influenced by many factors (such as attitudes, intimacy, pleasure, erectile function), and highlighted how new information about prevention technologies (such as undetectable viral load, or PrEP) was leading to shifts in condom promotion, perception and use.

Do we still talk about condoms?
Do new technologies lead to pressure not to use condoms?
Are gay men running too far with selective pieces of data (e.g., condoms not important anymore)?

Themes related to providers

Troubling the classic provider model: Participants considered the traditional provider model to be “top-down” – for providers to hold the power, to be the experts, to provide information their way, and to not adapt to what gay men need. Participants also recognized that it isn’t just about “information giving” and providers (individual and agency providers alike) need to think of the other side of the equation – that

health literacy is a shared responsibility between users and providers. Many participants emphasized that gay men are not just knowledge users, but are also creators of knowledge.

How do providers perceive themselves in relation to users?
Experts, allies, regulators, partners?
What are their assumptions regarding the direction of knowledge transfer?

How do provider roles, training, expectations, regulations, and laws influence this?

How do we approach sexual health literacy such that it includes knowledge translation and exchange?

How can the public be partners in the education of providers?

What expertise do we have in gay communities? How do we know the things we do, and how did we learn them?

Provider attitudes: Gay men were thought to be affected by how providers provide knowledge (e.g., whether it is sympathetic, or sex positive), with the literacy of health care providers and their ability to effectively communicate with gay men negatively affected by provider heteronormativity and homophobia. What providers communicate about sexual health or HIV prevention was thought to be a reflection of their own beliefs or attitudes towards sex (e.g., general discomfort discussing sex). Stigma (related to HIV or sexual orientation) was also considered an underlying driver, leading both to providers providing

incorrect information, as well as creating or enacting stigma perceived by gay men (e.g., by providing care to or labelling gay men in differently than other patients). Why do gay men change their doctors?

Provider cultural competency*⁶: For providers working with gay men to be culturally competent is essential, as gay men's personal history of experience with the health care system affects their access to sexual health services and their sexual health literacy. Yet participants highlighted that during training programs providers receive little to no training in LGBTQ cultures and issues (and if providers are interested, they need to seek it out independently). In particular, participants felt that engaging physicians in improving cultural competency is challenging.

What determines if providers are culturally competent? Expectations, interest, responsibilities, ethics, self-perception, cultural knowledge, relationship to gay men? How much is propensity versus training? What is the incentive (pay, altruism)?

Where do providers find training to be culturally competent? Who trains providers in how to work with gay, trans, or bisexual men?

How do we help providers be culturally appropriate and use non-judgmental language?

Provider knowledge*: Participants felt that many providers do not have adequate knowledge of sexual health information relevant to gay men, with the result being that gay men often need to educate their own health care providers (and this may be more marked for some groups such as trans-men or men living with HIV). Providers who are specialized in HIV and sexual health are important, but we may also need to look beyond these existing silos and engage

⁶ Culturally competent providers provide effective, equitable, understandable and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy and other communication needs (U.S. Department of Health and Human Services, Office of Minority Health; <http://minorityhealth.hhs.gov>)

less educated providers. Getting the most current information to providers could also help to reduce inconsistencies in health messages received by gay men.

What are standards of care for LGBTQ health in the health system?

Who is responsible to make sure providers have the right information and don't make incorrect assumptions?

How do we facilitate knowledge sharing between organizations and health care providers? Infrastructure? Policy?

How can non-specialists support sexual health?

What mechanisms are there to reach healthcare providers when they are out of school? What are GP's reading?

What is the version of Totally Outright for providers? Can people get credit for it at secondary/post-secondary institutions?

How do we get providers the time they need to learn?

Provider communication skills*: While having adequate sexual health knowledge is critical, participants emphasized that effective health communication skills are needed, with providers needing to seek and understand the needs, desires, goals and values of the user and integrate these with their own goals as a provider. The lack of training in this skills was considered to be an important issue.

What are core competencies for service providers working in gay men's health?

Are providers capable of talking about sexuality per se?

Challenges for community-based organizations: Providers working in community-based organizations (such as AIDS-service organizations) were perceived to play an important role in influencing the

information landscape, although their impact may be blunted as information provided by community-based workers may be at odds with, or unsupported by, other providers such as public health. Participants described how attracting people to community-based work and retaining them is difficult, with high turn-over creating problems for educating staff on current health issues or skills training. Participants highlighted how insufficient funding for community-based organizations is a barrier and limits ability to retain staff, as well as for supporting health literacy efforts (e.g., funding to update or revise websites).

What is the capacity of AIDS-service organizations for health literacy?

How do we get public health to “buy” into the idea of critical health literacy/action?

What role should diverse communities and community organizations play in developing, implementing and evaluating health literacy interventions?

More than health system providers: “Providers” was considered to be a very broad category that begged further definition, as more than traditional health system providers are involved with sexual health literacy for gay men (see Box 2). Participants described important roles played by other sectors outside of health which affect gay men’s sexual health literacy, that need to be educated on gay men’s sexual health issues. The diversity of providers was acknowledged to pose challenges in creating a collective response with respect to a health issue. In addition to the central role of **peers** as providers discussed above, particular emphasis within the workshop was given to the role of **porn** as a provider of information about sexual health, and **cruising websites/apps** as an opportunity to facilitate information provision at the time of sex. The **school system** (*) was also highlighted; improving the explicitness and specificity of sexual health education in primary and secondary education for gay men was considered to have the potential for a big impact (e.g., at a younger age before onset of sexual debut or becoming set in sexual behaviours).

Box 2: Providers affecting sexual health literacy for gay men, described by participants

- Doctors, nurses
- Community / ASO workers
- Pharmacists
- Policy makers (government)
- Regulators/Law makers (justice system)
- Public health
- Media
- Pornography
- Internet
- Teachers (school system)
- Friends
- Peers
- Social and sexual networks
- Family
- Church
- Researchers
- Pharmaceutical industry

For each type of provider, what incentives would be most effective to encourage their engagement with sexual health literacy? What are their biases?

What sectors or systems can we influence? For example, can we have an influence on the media?

How do we create strategic alliances to leverage better health literacy and support practice?

What is the role of pornography or websites/apps as a provider and can this be used? Can we learn from their channels and formats?

Do we have influence on the school system?

Themes related to the system

Understanding the system: Participants considered systems to affect both providers and users, in similar or different ways, and discussed how these systems need to be better defined. For example, if thinking about systems of sexual health information: today’s systems were considered out-dated and often based on information from the 1980’s-1990’s; may not be

built for an excess of knowledge and choices; and may not relevant to how men consume information today or maintain their sexual health, or to training of providers. But systems can also be more broadly defined, with sexual health literacy at the intersection of different systems (e.g., research, government, social, legal, biomedical, political, community systems).

In the “user-provider-system” triangle, what is the “system”?

How can we create stories that transform the system?

How have systems been influenced towards gay men’s health literacy in the past?

Apply critical social theory – what is the agenda of the systems that are in place?

Apply systems theory – what are the actors, processes, structures, relationships, drivers, objectives, self-regulation, feedback loops?

How can we do a better job at health literacy?

Summit participants

“I think health literacy has a long way to go. As you can see at the conference, most of the attendees are older individuals, mostly white, which is kind of a sign who is primarily in charge of health services and who may have access to it. ...this is not the ideal population you’d want to reach.”
– Community member

“I would say, for the gay men who are interested in finding out about health information we do a really great job of packaging that information in a way that’s accessible, but probably if I go right back to those three demographics that we’re already identifying as being missed – so people with low income, without university education, and older populations – I don’t know as we’re necessarily doing a great job with that.”
– Community member

Syndemics, determinants, and intersectionality*:

Participants emphasized the importance of recognizing disease syndemics⁷, including mental health disorders such as depression and anxiety, or problematic substance use, as determinants of sexual health literacy. Similarly, broader social and structural factors are likely critical in affecting how people “acquire” and “implement” health literacy (e.g., experiences of marginalization, language barriers). Participants felt that sexual health literacy requires an integrated, holistic approach with explicit links to social and structural determinants, such as intersectionality-based⁸ approaches.

How can we help the most vulnerable or marginalized gay men?

How do trans men fit within our “gay” system? Immigrants? People with disabilities or chronic disease?

Stigma*: Stigma was widely acknowledged to be a fundamental determinant of gay men’s sexual health literacy, affecting both users and providers – with some participants going so far as to say that it may be impossible to improve sexual health literacy for gay men if stigma is not addressed. Participants described how at a policy level, HIV stigma is enacted through blood donation policies, criminalization, immigration, funding, and harm reduction policies. In addition to HIV stigma, stigma associated with sexual orientation was acknowledged to affect health literacy; a deeply-rooted homophobia exists across systems, and gay

7 Syndemic refers to the concentration and deleterious interaction of two or more diseases or other health conditions in a population as consequences of social inequity and the unjust exercise of power (Singer, M. 2009. *Introduction to Syndemics: A critical Systems approach to public and Community Health*, Jossey-Bass: San Francisco. p.XV)

8 Intersectionality promotes an understanding of human experiences – such as health and health literacy – as shaped by the interactions of different social locations (e.g. sexuality, “race”/ethnicity, Indigeneity, gender, class, etc.), as well as the impact of systems and processes of power and domination (e.g. homophobia, colonialism, racism, classism, etc.). (Hankivsky, 2012. Women’s health, men’s health, and gender and health: Implication of intersectionality, *Social Science and Medicine*, 74 1712-1720)

men who are hiding their sexuality may be afraid of, or have a negative perception of, seeking knowledge about HIV and sexual health.

What is the relationship between health literacy and stigma?

Does our assumption that gay men need to be health literate put the onus on gay men to be responsible for HIV prevention, which can lead to blaming of gay men and reinforce stigma?

How do you address and rectify deeply entrenched homophobia?

Health care access and organization*: System factors influencing **access to health care** were considered to affect sexual health literacy, including access to specialist care, transportation to access services, internet access — and these may or may not be modifiable. The **organization** of the health system was also considered influential; for example, provider time constraints (and lack of remuneration for counseling/education), lack of interdisciplinary care, reliance on non-specialist care providers (who may be less knowledgeable), and the lack of connection between community-based and other health care providers. Ideally, participants felt that gay men should have access to a single system (“one stop shopping”) for gay men’s health, but recognized that this may not be feasible in some settings.

What constitutes a “health care setting”? Clinic versus bar?

Where are the LGBTQ health centres in Canada?

What role does geography play on sexual health literacy?

How do we engage mental health system and providers? And who is responsible for doing this?

How do we encourage more interdisciplinary teams?

If you could change one thing to improve health literacy for gay men:

“...just simplifying the system completely, like completely streamlining the system to get information, medication, especially mental healthcare, making it way simpler and removing a lot of the middlemen that are there.”
— Service Provider

The shift to self-care: A general trend in health care is a shift towards self-care, which participants felt was patient-driven and a “democratization” of health care services, but at the same time a reflection of neo-liberalism (where the focus on the costs and sustainability of health care leads to austerity measures and less funding for social and support services). Accordingly, participants highlighted the challenge in finding the balance between self-care, and down- or off-loading of services and knowledge to users. This focus on self-care was thought to be a radical change to the health system, placing additional requirements for health literacy on gay men.

Models of self-care: do we challenge them, or be pragmatic and accept them?

Role of the internet*: In addition to engaging messages, we need engaging methods of delivering information. The internet is an important tool for many reasons: gay men spend more and more time in virtual space; information can be widely accessible and disseminated (e.g., viral campaigns); anonymity of sites can facilitate dialogue; sites can use interactive features that are more engaging. On the flip side, participants noted that the decentralized nature of the internet makes it difficult to control what information is available and how accurate it is.

How should we think about digital media — who is included and excluded, and what new social and sexual networks do they create?

What opportunities and constraints does the use of digital technology bring to thinking about health literacy?

The influence of values and ideology on policy: The systems related to health literacy were considered to be shaped by ideologies, values, and politics (e.g., the perception that HIV is not an important health issue in Canada). Systems may be apathetic, ambivalent, or oppressive, such as the silencing of gay men in institutional policies and practice. These values and ideology determine what information is available and presented to gay men (for example, influencing research priorities and determining what kinds of research is conducted).

What is the value of health literacy to “the system”? How do we change health systems to value health literacy over acute outcomes?

Conduct a policy analysis — what is the visibility of gay men in policy?

Who are the holders of power when it comes to sexual health literacy (gatekeepers, regulators, academics, enforcers, leaders, influencers, denialists)?

What is the role of public versus private institutions?

How do legislative changes shape health literacy?

Funding and its justification: Participants spoke to how government or public health agencies provide funding for specific activities according to their institutional policies or strategies, which is highly influential in determining what gets done and how, ultimately directing and determining the information landscape. This can be constraining for community-based providers (e.g., preferring a broader focus on gay men’s sexual health, or discussion of topics such as sexual pleasure), and at times in conflict with their role as advocates on behalf of their clients and communicating their needs to funders. Participants described how receiving funding is often tied to specific activities or outcomes (such as the number of clients served or condoms distributed), and health literacy initiatives may be hard to justify as the benefits of sexual health literacy are not easily measured and existing measures of health literacy are poor.

Where can we find new funding for gay men’s health literacy?

Who controls or dictates spending?
Where are the levers for funding decisions?

Can pharmaceutical funding be co-opted to engage in wider, socially nuanced work? Or are we complicit in “their” agenda if we take the money?

Are there enough gay funding dollars?
Will there be positions for new researchers and providers in gay men’s health?

Conduct a critical examination of funding structures/systems for gay men’s sexual health literacy

Activism and community mobilization*: Participants discussed how there is a political dimension to health literacy that needs to be acknowledged, as the gay men’s health movement remains a critical influence on sexual health literacy. Gay men have a history of activism and creation of knowledge in response to HIV that participants felt remained particularly important today. Literacy was considered a potentially liberating practice and a tool to achieve social justice, which is an essential component of critical health literacy (or “action literacy”). Grass-roots or “ground up” approaches were considered key to change, and that these may require co-opting or subversive tactics, or building alliances among community agencies serving different populations.

How has the historical exclusion of gay men affected current levels of sexual health literacy?

Do we keep or dismiss our history? Are gay men aware of the causes and impacts of issues such as HIV/AIDS?

What are the “bottom-up” levers for improving sexual health literacy? How does knowledge move from the bottom-up in a top-down funding system?

How can we get thought leaders to use/integrate this knowledge? Are subversive tactics the only way?

Do we have / can we create critical mass for change?

2.2. Brainstorming Interventions

During the summit, the general lack of evidence regarding formal interventions to improve health literacy was identified as a challenge. What research has been conducted has often been focused at the individual level, such as interventions based on patient-provider interactions as part of clinical care (such as the Teach-back⁹ or Ask Me 3 techniques¹⁰). As acknowledged above, many existing interventions or programs related to sexual health or HIV prevention for gay men do address aspects of health literacy, even if not formally defined as such (e.g., social marketing campaigns, or the Totally Outright program for young gay men which increases knowledge, skills, and advocacy on these topics).

During the World Café, participants did note opportunities or ideas for interventions related to themes as they were discussed, which are captured in Appendix 3. To focus more explicitly on possible interventions, in this session participants were divided into five groups and asked to come up with a “big, bold and innovative idea that could be implemented nationwide to improve sexual health literacy for gay men.”

Each group then pitched their idea to the full group. Across the five ideas, the following themes emerged (each idea is described separately in Appendix 4):

- To create a central hub, institute, or “one-stop-shop” for gay men’s health information and health care (online, or in the real world)
- To use community mobilization and participatory approaches such that gay men design, lead, and implement interventions
- To intervene through advocacy, with system change as a key outcome
- To draw on digital technologies, multiple media, and participatory online approaches
- To focus on increasing provider cultural competency and communication skills

- To focus on effective methods for communicating information
- To draw on the strengths of peers and peer networks

Groups also spoke of the importance of research and evaluation, and suggested that implementation research may be a useful framework (i.e., focusing on the translation of research evidence into practice or health system change).

2.3. Next steps for research

The closing session of the workshop was an open discussion of ideas regarding possible next steps towards a research proposal (or proposals), and possible funding opportunities. In general, there was interest in using the momentum gained through the Summit and workshop to develop an international research collaboration or network related to sexual health literacy for gay men.

Participants raised the point that aspects of health literacy are currently under study in various ongoing research projects related to HIV and gay men in Canada (e.g., Momentum, Resonance, Sex Now), although these research questions have not been articulated under a health literacy framework. There may be options to see how other questions specific to health literacy could be incorporated within existing studies, such as through adding health literacy scales to existing surveys, or questions related to health literacy within ongoing interviews or focus groups. This may help us to answer basic fundamental questions regarding the level of health literacy and differences among gay men.

As noted above, one approach that may have merit to both the question and potential funders is implementation research. This would involve several phases; the first phase would be exploratory, and use mixed methods to elicit priorities for health literacy and what knowledge and strategies already exist in gay communities. From this an intervention would be designed and then tested through trial or natural experiment. To design this study would require more preliminary work, such as describing the current state of research in the field (including relevant findings from the Canadian studies mentioned above) and what evidence exists already. This would help to justify the development of a focused intervention (for

9 Weiss B. (2007). *Health literacy and patient safety: Help patients understand. Manual for clinicians* (2nd ed.) Chicago: American Medical Association Foundation and American Medical Association).

10 <http://www.npsf.org/default.asp?page=askme3>

example, reviewing the known health literacy impact of communication campaigns targeting gay men).

In general there were considered to be several options to explore for research funding, depending on the question and approach. In Canada, Social Sciences and Humanities Research funding has been accessed for health literacy research in the past, and may be aligned with questions related to political systems or leadership development (such as around community mobilization). CIHR may be an option although funding is increasingly competitive. The planning grant that funded this workshop was funded through CIHR and may indicate support for research in this area in the future (e.g., a catalyst grant), particularly as much that has been discussed is aligned with integrated knowledge translation approaches. There are other provincial or regional sources of funding

that may be accessible under a health literacy lens (e.g., in British Columbia: Michael Smith, Vancouver Foundation, Vancouver Coastal Health Smart Fund). Funding may be available in the United Kingdom, particularly if an implementation research approach is adopted.

Other suggestions included developing a series of grants which could be put forward that are mutually supportive, and not competitive, which build on the work which has or currently is being done, and emphasize our growing international collaboration in this area. There may also be advantages to collaborating with researchers from other disciplines/health areas. For example, it may increase the likelihood of funding if we considered health literacy more broadly, or do work related to HIV under a chronic disease or self-management lens.

MOVING FORWARD

It became clear during the Summit and the following workshop that the subject of health literacy engendered a high degree of enthusiasm and engagement. For many people, including members of the planning grant research team, health literacy was a new concept, although as was apparent through discussions not necessarily a new idea in practice. Many people identified health literacy as being at the core of the gay men's health movement since the early days of the HIV epidemic, when community activism and advocacy resulted in the access, uptake, understanding and application of HIV prevention knowledge by gay men, as well as policy, legislative and health system changes to respond to the epidemic. These critical health literacy skills continue to be evident among providers and advocates working in the field of gay men's health today.

Health literacy is well aligned with current theoretical models for improving gay men's health, by sharing a strong emphasis on addressing social, systemic and syndemic factors. However, considering health literacy specifically does draw attention to the importance of all aspects of accessing, understanding, appraising, and communicating information which may not otherwise be appreciated. Furthermore, health literacy

shifts the responsibility for health literacy from individual gay men to include the providers of information, which are conceptualized as not just individual service providers but also government and community-based health agencies, and even more broadly as other sectors (such as education or legal systems).

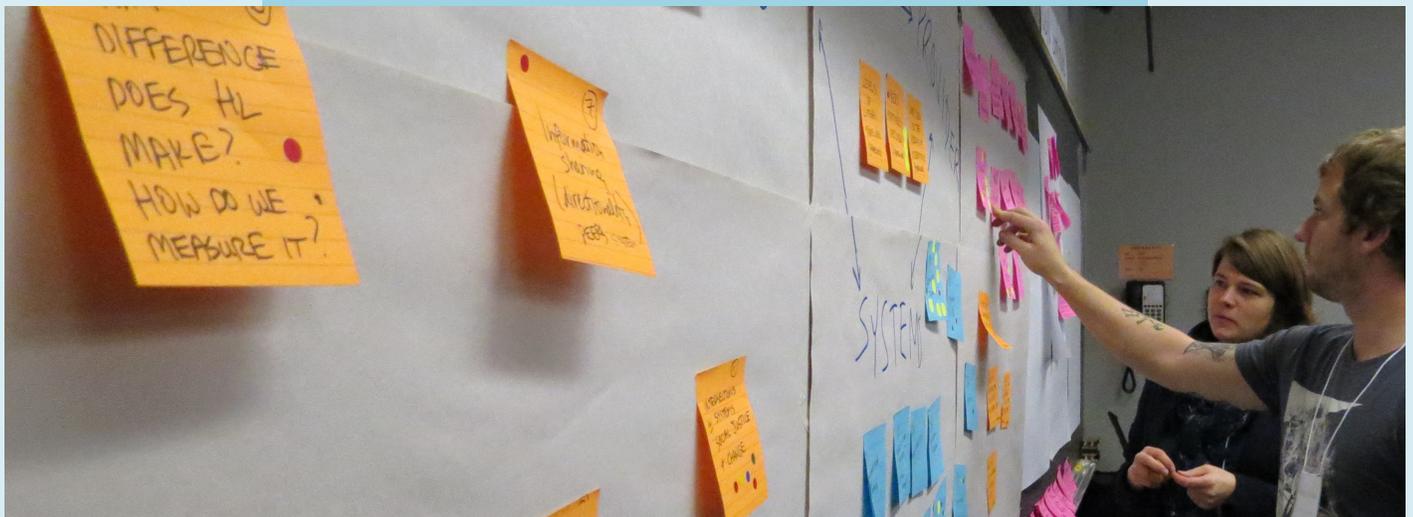
As a result of this workshop, we have been able to describe an emerging framework for sexual health literacy for gay men (Figure 3), which recognizes the central importance of the health information itself, the importance of addressing health literacy skills for both users and providers, as well as user- and provider- specific factors. The framework also recognizes the fundamental influence of system factors, both social and structural, across all aspects of sexual health literacy.

Key knowledge gaps that merit future research:

Summit and workshop participants commonly assumed that sexual health literacy is high for gay men, and research has suggested high levels of sexual health knowledge among some groups of gay men. However, we do not yet have a good understanding of the state of broader aspects of sexual health literacy among gay men (e.g., functional, interactive

and critical health literacy skills), nor do we know the best way to measure or assess these. Also, the experience of providers working in the field and research presented on aspects of health literacy (e.g., levels of knowledge about biomedical interventions) did identify concerns about gaps in health literacy for some groups of men (such as youth, immigrants, or men from ethnocultural minorities). We also do not well understand differences in sexual health literacy among gay men based on HIV status, although

experiences with and proximity to HIV are likely influential. Ultimately, gay communities are diverse and gay men hold many other social positions beyond their sexuality that may affect their health literacy (such as class, ethnicities, age). Rather than treating gay men as a homogenous population, further research on sexual health literacy should investigate how these different social positions held by gay men (and their intersection) affect their health literacy.



As sexual health literacy does not exist in isolation of other health determinants, further research needs to consider other factors that contribute to gay men's health and wellness, including mental and emotional health. Furthermore, developing effective interventions requires involvement of affected communities, and adopting community-based and participatory research approaches are necessary in order to have a meaningful impact on health literacy. Further research also needs to investigate the impact of power on health literacy, given the importance attached to homophobia, HIV stigma, and other forms of power as determinants of health literacy in this report. Specifically, research should investigate how these forms of power shape gay men's relationships with providers, with systems, and other gay men – and how these relationships promote or hinder health literacy.

The important role of health care provider factors in

relation to health literacy - such as cultural competency, or homophobia and stigma within the health system - are not new ideas in relation to determinants of gay men's health. However, this report highlights the importance of understanding the sexual health literacy of providers themselves and flags this as a possible area for intervention, and there is little research in this area. In so doing, we also need to consider how the "sexual health" component of health literacy is defined, and by whom, as there are likely differences between gay men and providers in the values attached to sexual health (such as sexual safety, freedom, or pleasure).

Where do we go from here?

One key gap that became evident during these discussions was the paucity of information regarding the effectiveness of health literacy interventions (in general, and for gay men specifically). At the Summit

and during the workshop, there was a clear appetite for a package of community-based interventions aimed at improving sexual health literacy. The creation of a one-stop-shop, central hub (or hubs), whether virtual or in the real world was described as the ideal solution for promoting health literacy and health in general among gay men. Consensus statements on risk and prevention technologies were also desired so that health care providers and community workers can provide the best information to gay men, using consistent messaging – in conjunction with provider educational and skills-building interventions. Online approaches and digital technologies were often referenced as potentially effective and patient-centred mechanisms by which to deliver health literacy interventions, although at the same time, recognizing the paradox as to use these tools may require a higher personal level of health literacy skills. Reflecting on these discussions, it would seem that adopting research approaches that are based on designing, implementing, evaluating, refining and scaling-up effective interventions (such as implementation research) would hold promise for advancing this field.

With this planning grant, we set out to bring together a group of researchers, service providers,

policy-makers, and knowledge users to develop a thorough understanding of the current state of knowledge regarding sexual health literacy for gay men. One of the themes that emerged repeatedly in our discussions was the idea of a center or network for health literacy for gay men, both in terms of intervention (e.g., to develop state-of-the-art health literacy interventions, including online and off-line interventions) and in terms of furthering research and practice collaborations to investigate the questions and address the knowledge gaps outlined throughout this report.

We believe that through this planning grant we have started on this path, and an international network of researchers and providers interested in further exploring sexual health literacy for gay men is forming as a result of this workshop. These conversations have continued beyond these three days, and opportunities for further research collaborations are being explored – which achieves our original objective for this planning grant. Together we aim to continue our journey towards a fuller understanding of the complex relationships between, and effective interventions for improving, health literacy and sexual health for gay men.

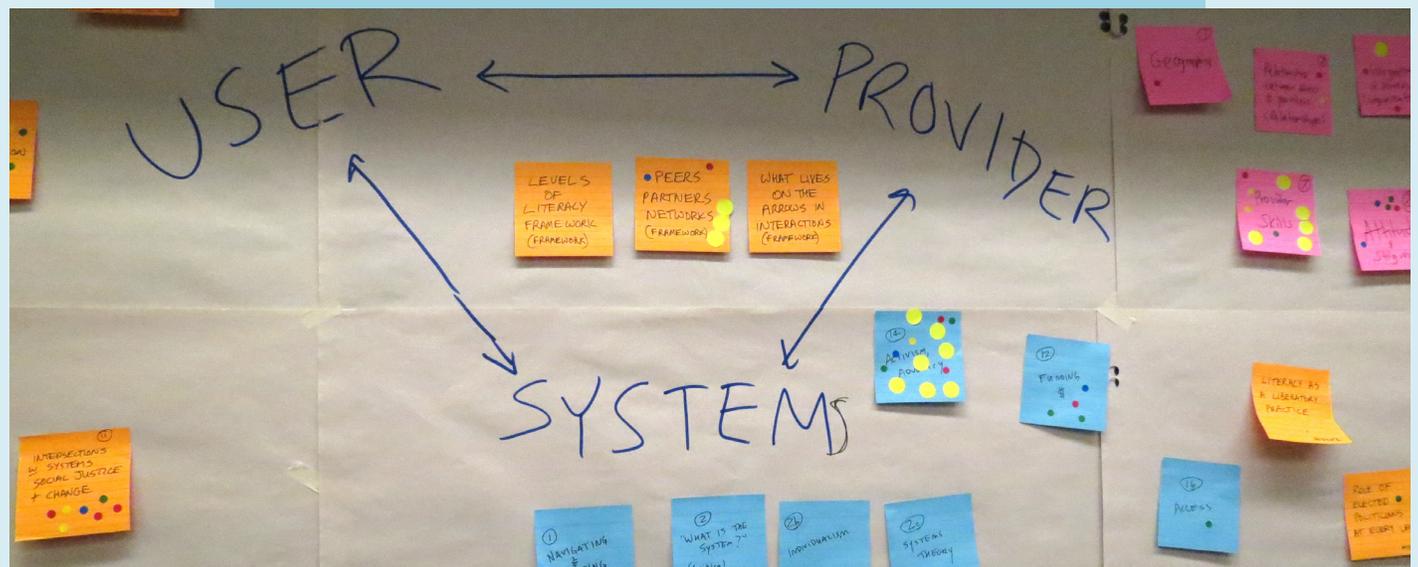
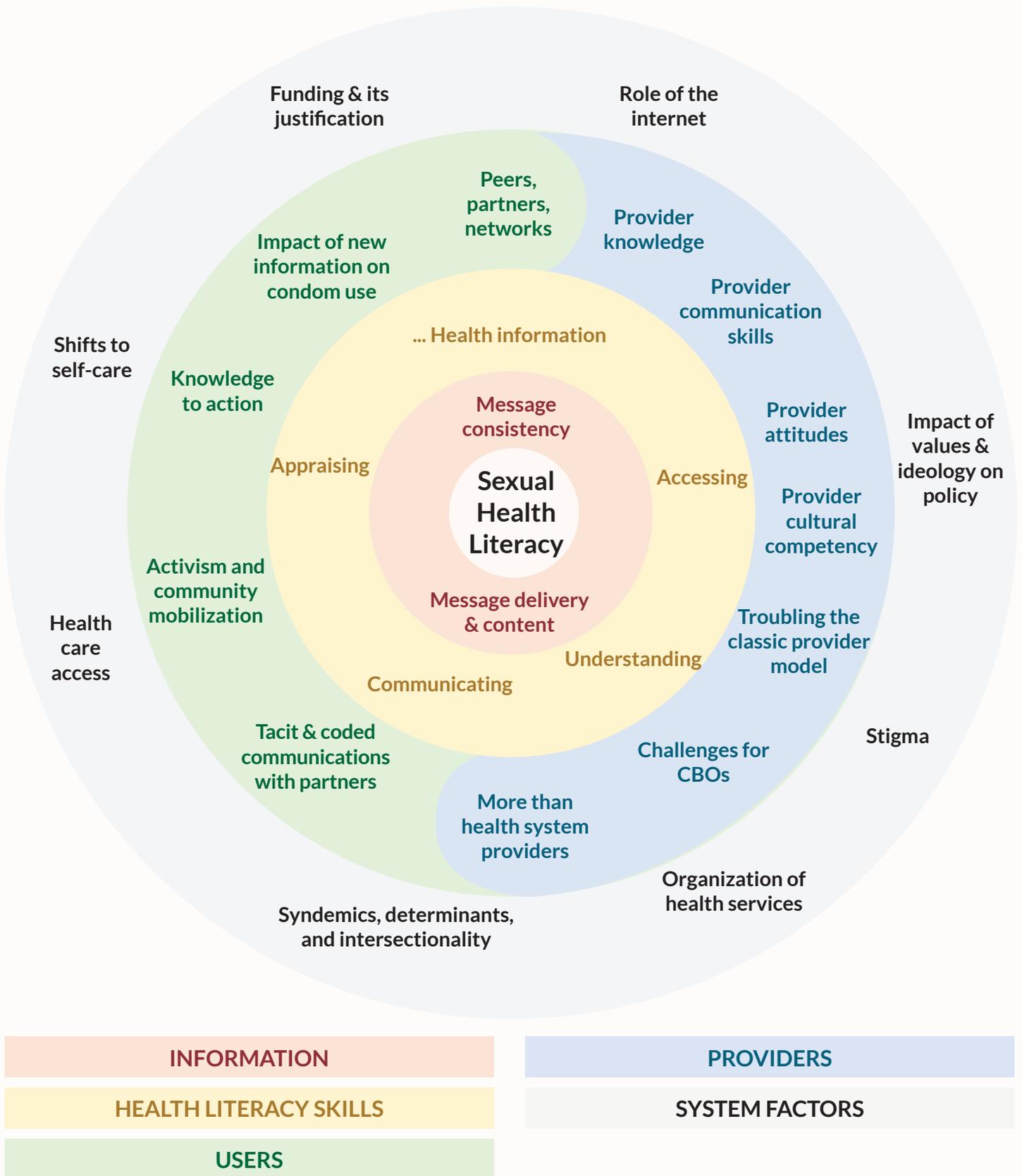


Figure 3: Emerging framework for Sexual Health Literacy for Gay Men



SUMMIT PRESENTERS:

- ✍ [Dr. Irv Rootman, "Health Literacy: Importance for Gay Men's Health and Research"](#)
- ✍ [Dr. Lorie Donelle, "Health Literacy: Numeracy and Prose"](#)
- ✍ [Dr. Paul Flowers, "Reflections on HIV Testing Amongst Gay Men: Scottish Perspectives"](#)
- ✍ [Susan Martin, "Sexual Health Literacy and Gay, Bisexual and Other MSM: A Scoping Review of the Literature"](#)
- ✍ [Brent Allan, "HIV Positive Health Literacy in Australia: Profiling Health Literacy Needs of Australian Gay Men Living with HIV to Improve Health Outcomes"](#)
- Mark Gaspar, "HIV Risk and Gay Men's Realities: Putting Sexual Health Knowledge into Social Context and Practice"
- ✍ [Dr. Mark Gilbert, "What makes risks risky?"](#)
- Len Tooley, "Risk, Realness and the (many) Roads Forward: CATIE's Gay Men's Risk Communication Project"
- ✍ [Brent Sawlor, "From AIDS to HIV to Undetectable: Using New Language to Change How We Talk about HIV"](#)
- ✍ [James Wilton, "Understanding HIV Risk: Exploring Technical Aspects and Models for Communication"](#)
- ✍ [Dr. Nathan Lachowsky, "The Use and Impact of Online Outreach Services Among Gay Men in Ontario"](#)
- ✍ [Dr. Mark Gilbert, "What Information Are We Providing to Gay Men and How? Environmental Scan of HIV Websites in Canada"](#)
- ✍ [Dr. Nathan Lachowsky, "What health info are gay men in Ontario searching for online & where are they getting the answers?"](#)
- ✍ [Dr. Ingrid Young, "Exploring the Acceptability of PrEP and TasP among Gay and Bisexual Men in Scotland"](#)
- ✍ [Dr. Nathan Lachowsky, "Awareness & Knowledge of TasP among HIV-positive and HIV-negative gay, bi and other MSM"](#)
- ✍ [Dr. Barry Adam, Ed Jackson, "Resonance: What's the Buzz on HIV Prevention Among Gay Men?"](#)

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APPENDIX 1 – PROGRAM

Friday October 31:

Workshop Day 1: Establishing a Common Understanding [Summit 2014 day 2]

- Today's activities are integrated within the program of the Summit 2014 and are open to all Summit participants.

Time	Description of activity
8:00-9:00	Coffee, muffins, fruit. We'll be gathering in a corner of the room – look for the signs! * Registration is in the Central Concourse for workshop attendees who were not able to attend the first day of the Summit.
9:00-10:00	Keynote: Health Literacy: why it is important for gay men's health. Irving Rootman, University of Victoria Moderator: Mark Gilbert, Ontario HIV Treatment Network
10:00-10:30	Break
10:30-12:00	Concurrent Session: Unpacking health literacy: numeracy, measurement and risk communication. Moderator: Warren Michelow, University of British Columbia <ul style="list-style-type: none"> • Health literacy & numeracy and relevance to gay men's health. Lorie Donelle, University of Western Ontario • Profiling the health literacy needs of Australian gay men living with HIV: To improve outcomes & reduce inequities. Brent Allan, Living Positive Victoria, Australia • What makes risks risky? Mark Gilbert, OHTN • Understanding HIV risk: technical aspects & models for communication. James Wilton, CATIE
12:00-1:00	Lunch

Time	Description of activity
1:00-2:30	<p>Concurrent session: Sexual health literacy for gay men: what do we know?</p> <p>Moderator: Olivier Ferlatte, CBRC</p> <ul style="list-style-type: none"> • Environmental scan of HIV prevention websites: Mark Gilbert, OHTN • Sexual health literacy & gay, bisexual & other MSM: findings from a literature review. Susan Martin, University of Glasgow, Scotland • What health information are gay men in Ontario searching for online and where are they getting the answers? Nate Lachowsky, University of Toronto / BC Centre for Excellence in HIV/AIDS • New HIV prevention technologies & critical HIV literacy: exploring the acceptability of PrEP and TasP among gay and bisexual men in Scotland. Ingrid Young, University of Glasgow, Scotland
2:30-3:00	Break
3:00-4:00	<p>Panel: Impact of information about HIV risk on Gay Men</p> <p>Moderator: Trevor Hart, Ryerson University</p> <ul style="list-style-type: none"> • Advancing Gay Men's Health Literacy: Awareness & Knowledge of TasP among HIV-positive & HIV-negative gay, bisexual and MSM in BC. Nate Lachowsky, BC Centre for Excellence in HIV/AIDS • The Resonance Project. Barry Adam, OHTN & Ed Jackson, CATIE
4:00-4:45	<p>Closing Dialogue: Gay Health Literacy: where do we go from here?</p> <p>Moderator: Mark Gilbert, OHTN</p> <p>Panelists:</p> <ul style="list-style-type: none"> • Paul Flowers, Glasgow Caledonian University, Scotland • Terry Trussler, Community-Based Research Centre • Brent Allan, Living Positive Victoria • Sarah Chown, HIV/AIDS Resources & Community Health • Irv Rootman, University of Victoria
4:45-5:00	Closing and Acknowledgements
6:30	Dinner (optional, at own expense). Location TBD but will be close to SFU Harbour Centre and the Delta Suites.

Saturday, November 1:

Workshop Day 2: Establishing a Research Agenda

Time	Description of activity
8:30-9:00	Continental breakfast
9:00-10:00	Orientation and Summary of previous days <ul style="list-style-type: none"> • Setting up the day's activities & Introductions: Mark Gilbert, OHTN • Rapporteur's report: Joshun Dulai, Daniel Wexel, CBRC • Reflections from Service Providers: CATIE Rapporteurs
10:00-10:30	World Café round #1: What do we know about health literacy and gay men? We'll be using a world café approach to facilitate small group discussions about health literacy based on our framework of individuals, providers, and system factors that contribute to health literacy. In each round, we will discuss our assumptions, what we know, and where we think the gaps in knowledge are.
10:30-11:00	World Café round #2: What do we know about health literacy and providers?
11:00-11:15	Break
11:15-11:45	World Café round #3: What do we know about system factors that affect health literacy?
11:45-12:30	Report back by World Café hosts and discussion of general impressions as a group
12:30-1:15	Lunch
1:15-2:45	Group discussion: Synthesis and interpretation As a group, we will organize the assumptions and questions raised by theme, identifying areas of convergence and overlap; and identify any remaining gaps. The objective of this session is to arrive at a final set of potential research questions.
2:45-3:00	Ranking Activity (over coffee) Participants will be asked to rank research questions according to what they think are most important.
3:00-4:00	Breakout session #1: What would a health literacy intervention look like? Breakout session #2: How do we move the research agenda forward? In this session, participants will brainstorm potential interventions to improve health literacy for gay men, providers, and at system levels. In this session, participants will review the ranked questions and discuss next steps for developing a research proposal(s) on the topic of health literacy, including reviewing current funding opportunities.
4:00-4:30	Report back and discussion as a group
4:30-4:45	Wrap-up & next steps

APPENDIX 2 – LIST OF WORKSHOP PARTICIPANTS

- Barry Adam
University of Windsor
Ontario HIV Treatment Network
- Brent Allan
Living Positive Victoria
- Martin Bilodeau
Portail VIH/sida du Québec
- Sarah Chown
YouthCO HIV and Hepatitis C Society
- Denis Delorey
Sidaction Mauricie
- Lorie Donelle
Western University
- Joshun Dulai
Community-based Research Centre for Gay Men's Health
- Olivier Ferlatte
Community-based Research Centre for Gay Men's Health
- Paul Flowers
Glasgow Caledonian University
- Luis Fonseca
Action Positive
- Samuel Gauthier
BRAS Outaouais
- Mark Gaspar
Concordia University
- Mark Gilbert
Ontario HIV Treatment Network
- Trevor Hart
Ryerson University
- Devon Haag
BC Centre for Disease Control
- Travis Salway Hottes
University of Toronto
- Carlos Idibouo
Arc-en-ciel d'Afrique
- Ed Jackson
CATIE
- Jody Jollimore
Health Initiative for Men
- Michael Kwag
Health Initiative for Men
- Eric Lefebvre
REZO
- Maggie MacAulay
Simon Fraser University
- Rick Marchand
Community-based Research Centre for Gay Men's Health
- Susan Martin
University of Glasgow
- Warren Michelow
University of British Columbia
- Greg Oudman
Health Initiative for Men
- Lief Pagalan
Community-based Research Centre
- Marie-Christine Rochefort
GRIS Québec
- Irv Rootman
University of Victoria
- Brent Sawlor
AIDS Vancouver
- Michael St. Gelais
MIELS Québec
- Kimberly Thomson
University of British Columbia
- Len Tooley
CATIE
- Terry Trussler
Community-based Research Centre for Gay Men's Health
- Sophie Wertheimer
CATIE
- Daniel Wexel
Community-based Research Centre for Gay Men's Health
- James Wilton
CATIE
- Ingrid Young
University of Glasgow

APPENDIX 3 – OPPORTUNITIES AND IDEAS FOR INTERVENTION

This appendix documents the opportunities or ideas for possible intervention related to health literacy that were documented on post-it notes during the World Café.

1. Overarching themes:

- Develop guidelines and consensus on messaging
- Include information about relationships, dating and sex
- Create fun messaging, using understandable language
- Have information available in multiple languages
- Websites where consistent messages available, that can be tailored to different health and literacy needs of gay men (functional and critical)
- Interactive, engaging online approaches (that are mobile friendly): storyboarding, social media, anonymous posting, video, games, Q&A forums
- Service provider 101
- Continuing medical education events and courses for General Practitioners
- Workshops on communication skills
- Develop training module on how to communicate about sexual health issues, and offer to provider organizations
- Design tools that gay men can bring to their providers (e.g., Check Me Out campaign)
- Provide information for providers with pharmaceutical packaging/messaging
- Podcasts or other “blasts”
- Database of resources that providers can access
- Engage public health nurses – they can be part of the solution

2. User level:

- Peer navigators
- Encouraging dialogue and having spaces for gay men to discuss health literacy
- Recognize and provide for different learning methods (e.g., numbers, pictures, text).
- New tools such as online risk calculators can be illuminating.
- Ensure that numerical information is appropriately contextualized.
- Teaching people to be good knowledge providers to their peers
- Facilitated how-tos
- Social support groups, “dirty talk” workshops

3. Provider level:

- Learn from the reproductive health sector regarding interventions to improve provider attitudes about sex
- Interventions such as workshops for providers to recognize pre-existing beliefs and motivations, and address stigma and discomfort with sex
- Internships in gay friendly clinics/services
- Ensure gay cultural competency is core to all health professional training
- Sensitivity training in schools

4. System level:

- Make ideas such as intersectionality and syndemics more accessible to providers.
- One-stop-shopping for comprehensive LGBTQ care including primary care, STI's and HIV, social and mental health
- Criminalization as an opportunity to reinvigorate health as a political matter, and help gay men to see themselves as political subjects
- Funding from the pharmaceutical industry for health literacy initiatives
- Alliances/integration with other community movements (e.g., ethnic minority and immigrant groups)

APPENDIX 4 – BRAINSTORMED INTERVENTIONS

Team 1 – TV Show: Draw from the success of home renovation shows, but now, let's renovate society! For each one-hour episode, identify an intervention to improve health literacy, such as stigma reduction through a gay-straight alliance in schools, or a program to improve health care provider attitudes in a hospital. Then film before, during, and one-year after the intervention to show the impact of the intervention. This will yield data to show how these interventions can improve health and well-being, and feed into changes in policy. Using advocacy, TV, multiple media, and merchandising will engage different audiences.

Team 2 – Institute for Gay Literacy: Use a community mobilization approach to draw on the expertise that already exists among gay men, to understand how gay men think about health learning. This would be formally mapped out as an intervention, which could be a type of Institute. The Institute would be a virtual and real place to foster peer networking, including paid peer mentors and health providers that are multidisciplinary and inter-generational, and works on crowd-sourcing/collaborative principles (drawing inspiration from The Institute of Many, from Australia⁹).

Team 3 – Canadian Health Institute for Communication: Develop a model for integrated health care that incorporates a community-based participatory program, with health communication as central component (e.g., Fenway Health model¹⁰), either specific to gay men's health or as part of a men's health institute. This model would draw on social and community psychology to figure out how best to communicate risk for different types of learning, and focus on provider competency across disciplines (e.g., medicine, nursing, health admin, public health), including educational programs during professional training and intensive continuing medical education programs.

Team 4 – Two-for-one intervention: Consider two interventions, each accompanied by a rigorous research study to assess their impact. The first, to be set in both rural and urban communities, would be a two day workshop for providers to learn the teach-back method for providing health information, using mock patients based on real people with real experiences. Outcome measures for this intervention include provider skills and abilities to talk to patients about outcomes. The second intervention would be a one-stop-shop for gay men's health with accessible hours, multidisciplinary providers, social support groups, as well as an online component (like Oprah's Lifeclass¹¹). Outcome measures for this intervention would include engagement, sexual happiness, and men's comfort with making informed choices.

Team 5 – Centre for Gay Men: To improve gay men's and providers' sexual health literacy requires a new kind of system that overcomes existing barriers (such as many gay men not having a provider they feel comfortable coming out to). We propose a Centre for Gay Men, which could be a one-stop-shop for primary care, including mental health, with a telemedicine component (to allow access across the country) and dedicated space for programs such as Totally Outright. We would use an implementation research approach, starting with a pilot and then expanding such that there is one centre in the largest cities in each province, and monitoring their impact.

9 <http://www.theinstituteofmany.org>

10 <http://www.fenwayhealth.org>

11 <http://www.oprah.com/app/oprahs-lifeclass.html>