

Health equity and GetChecked: How can we make an online testing service that works for everyone?

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Executive Summary

A range of web-based sexual health services aimed to complement in clinic service delivery are being developed by The British Columbia Online Sexual Health Services team (part of the BC Center for Disease Control Clinical Prevention Services Division). One of these services, called 'GetChecked', is an internet-based system to facilitate the delivery of sexually transmitted infection (STI) and HIV testing online.

A health equity impact assessment was employed to prospectively assess the positive and negative impacts of *GetChecked* as it is scaled up provincially, as well its potential to reinforce or exacerbate social inequities in health in this province. An equity lens was used to evaluate the potential impacts of the program on various populations, placing a priority on those groups traditionally underserved and/or marginalized in BC.

After considering the pathways through which *GetChecked* may reinforce and/or circumvent health inequities related to sexual health and sexual heath services in the province, final recommendations were developed to direct the attention of decision makers toward strategies to mitigate unintended negative impacts, enhance positive ones, and avoid unintentionally making worse or reinforcing unjust patterns of health distribution in this province.

The findings from this report are being used by the BC Online Sexual Health Services team to mitigate potential negative impacts and strategize how to avoid reinforcing health inequities in the ongoing development of *GetChecked*.

Summary of recommendations

PROGRAM PLANNING

- 1. Identify key stakeholders and gatekeepers who may mitigate access to the service in various communities prior to scale up.
- 2. Build in checks and measures to ensure team and program accountability to equity based goals and outcomes.
- 3. Anticipate new impacts (positive, negative, reinforcing health inequity) and acknowledge those that have been remedied/averted.

RESEARCH AND EVALUATION

- 1. Encourage team development and capacity for social epidemiology for program evaluation and data analysis.
- 2. Formally incorporate the steps of the health equity impact assessment into Phase I and Phase II evaluation. This process should include the development of a hierarchy of measurable outcomes detailing expected short-term and long-term outcomes of the service, explicitly noting (and prioritizing) those directly related to changes in health equity.
- 3. Data collection and sampling strategies should reflect current, local research on the social determinants of sexual health.
- 4. Following scale up and evaluation, further development and refinement of future models of *GetChecked* targeting specific populations most in need of this service (still not accessing after provincial scale up) should be considered. This process must take up community

- based, participatory research to gather specialized and local knowledge to inform targeted models and modes of delivery of *GetChecked*.
- 5. Collect accurate and representative data on the sexual health and health systems engagement of transgender and Aboriginal populations in BC.
- 6. Add depth to the online (sexual) health services literature that is theoretically grounded and employs a health equity lens.

SERVICE DEVELOPMENT

- Take advantage of the anonymous aspect of the online service and prioritize the avoidance of common stigmatizing features of the in-clinic experience and other traditional sexual health services (e.g. normative and stigmatizing language, images, and discourses).
- 2. Avoid language and content, which may be challenging for individuals with lower levels of English or health literacy.
- 3. Expand testing options in future models of GetChecked.

SERVICE EXPANSION

- 1. Following scale up, develop tailored versions of *GetChecked* to lower the threshold of access to certain groups for whom the service appears to be relevant and needed. Tailored development should be based on local, community based research.
- 2. Continue to build relationships and equitable partnerships with outreach programs already engaged with a range of populations beyond urban Vancouver.

Part 1: Introduction

1.1 OBJECTIVES

The primary objectives of the health equity impact assessment were to:

- Gather and consider a range of evidence to determine whether *GetChecked* will have differential impacts on certain populations, then gauge whether these impacts are unnecessary, avoidable, inequitable, or reinforce/exacerbate social inequities in health.
- Present findings and make subsequent recommendations to:
 - 1. Incorporate health equity into future planning and evaluation of GetChecked
 - 2. Enhance the potential benefits of GetChecked
 - 3. Mitigate or reduce negative impacts of *GetChecked* and avoid reinforcing health inequities.
- Point to gaps in the literature that can be filled by future GetChecked research and
 evaluation to encourage the presence of health equity in the development of online
 sexual health service delivery.

1.2 BACKGROUND

The BC Center for Disease Control (BCCDC) plays an important role across all levels of government and provincial health authorities to promote and protect the health of British Columbians. Embedded in the Centers' approach to the health of the province is a philosophy of ethical awareness and responsibility (BCCDC Ethics Framework, 2011). While the primary mandate of the organization is to provide public health surveillance, detection, and prevention of disease, these organizational processes are rooted in a culture that not only asks "what should be done?" but also "what ought to be done?" in order to protect and to improve the health of British Columbians. Where health is concerned, these questions often point to sub populations and community members who have historically been or are currently disenfranchised, marginalized, or underserved. In these circumstances, it is of particular importance that special consideration be made to "ensure a decent minimum standard of resources as a means to better health" (BCCDC Ethics Framework, p.8).

Today at the BCCDC, the Online Sexual Health Services team (part of the Clinical Prevention Services Division) is developing a program called *GetChecked*. *GetChecked* will be a complementary program to traditional in-person clinical services, offering access to most steps of certain STI and HIV tests primarily through the internet (for a more detailed description of the service, please see Appendix I). Building on other programs around the world that have successfully delivered sexual health services and testing through online platforms, *GetChecked* aims to lower the threshold of access to STI and HIV testing services, improve uptake and frequency of testing in high prevalence populations, reduce the burden on in-person sexual health services (mainly clinics) and respond to the shifting expectations of the health care consumers toward client-centered care and contemporary technological services.

Initially, *GetChecked* will be piloted at two BCCDC clinics in Vancouver, with targeted promotion to gay men in Vancouver. Implementation and evaluation of the first pilot phase of *GetChecked* is projected to take place during 2013. Following successful completion,

evaluation, and refinement of the pilot phase, the service is projected to expand to other sites throughout the province by 2014. The scaling up of this service offers significant opportunities to extend access to STI and HIV testing throughout the province, a point of interest for considerations of equitable access to health services and outcomes in British Columbia.

There is evidence of the earlier stated organizational values pertaining to ethical awareness and responsibility in the current model and design of GetChecked. Attention to the social determinants of health and the marginalized and vulnerable groups most heavily burdened by HIV/STI's in this province are explicitly identified as the target populations of this project (men who have sex with men, current clinic clients and youth under 25). Proposed research planned for the evaluation of GetChecked (Gilbert, 2009) clearly recognizes the disproportionate concentration of HIV and STI's in socially marginalized groups (e.g. people who inject drugs, Aboriginal people, youth), as well as persistent barriers to adequate sexual health services (especially in rural and Northern BC). Targeted qualitative research (e.g. focus groups and interviews) are planned to further investigate the relevance and potential of GetChecked in groups beyond the initial target populations. Special considerations have been made in the preliminary evaluative plans to monitor and evaluate the Pilot Phase of GetChecked to ensure measurement of any additional barriers or negative impacts the program may have on individual or population outcomes (Gilbert, 2009 p. 4). The goals and anticipated outcomes of the program anticipate that GetChecked has the potential to "improve access for at-risk, socially marginalized populations that currently face barriers to accessing clinic-based testing services, particularly in rural and remote areas" through multiple pathways (Gilbert, 2009, p. 8). GetChecked may have the capacity to lower the threshold of HIV/STI testing access and become a meaningful adjunct to existing clinical STI/HIV services offered in British Columbia.

GetChecked may also reduce the overall health systems cost and in-clinic burden of current STI/HIV testing services. As outlined by Goldman and Lakdawalla (2005), when new medical and health technologies reduce the cost of care, the overall gradient of health care can expand to reach those with fewer resources to invest in their own health. Not only could this advancement free up health systems resources, but the program itself may be more palatable and accessible to individuals who have too little resources to access or take advantage of current modes of STI/HIV testing in BC. However, Goldman and Lakdawalla's economic theory also demonstrates that unless certain conditions are met, the expansion of the health care gradient generally moves in favour of those who are already heavily engaged with the health system (usually the more advantaged members of a society). The authors conclude that to avoid barriers and circumvent health inequities when introducing a new health technology, success is contingent upon a number of other factors related to the new technology itself. This caveat is heavily supported by other theories on the causes of health inequity and inequalities (Chan & Lauderdale 2009; Link, Phelan & Tehranifar 2010). If a new health initiative aims to draw in marginalized groups and avoid reinforcing health inequities. these conditions must be considered throughout program development. A brief review of relevant health theory may be useful in building the rationale for a health equity analysis of GetChecked BC.

1.2.1 RATIONALE

While advancements in technology provide novel and promising opportunities to develop improved health interventions and initiatives (McFarlane & Bull, 2007), the concentration of poor health in marginalized and vulnerable populations has endured, despite countless efforts to close this gap for far more than a century (Link & Phelan, 1995; Link, Phelan & Tehranifar, 2010). This trend is visible in British Columbia, where the prevalence and rates of HIV and STI's have remained persistently high in particular groups, despite decades of innovative health and technological advancements and interventions. Link and Phelan's theory of fundamental causes (1995) and other ancillary theoretical developments (Chang & Lauderdale, 2009; Goldman and Lakdawalla, 2005; Link, Phelan & Tehranifar 2010) provide a helpful lens that reveals the mechanisms that may undercut the potential of new technologies and even lead to the worsening of social inequities in population health outcomes.

The theory of fundamental causes (Link & Phelan, 1995) explains that the persistence of socially stratified levels of health (particularly those tied to socioeconomic status (SES)) endure beyond novel interventions and bourgeoning technologies because individuals have varying degrees of access to the 'flexible resources' necessary to obtain health in a society. These resources vary and may include money, power, prestige, social capital, leisure time, knowledge, physical ability and more. Flexible resources allow individuals to avoid, minimize and/or effectively mitigate the effects of disease and poor health. They "shape access to broad contexts that vary dramatically in associated risk profiles and protective factors" (Link, Phelan, & Tehranifar, 2010, p. S30). These conditions persist despite the type of health care, intervention, or disease prevalent in a population at one time therefore, regardless of the historical period, cultural context, or disease in question, individuals lacking in resources are persistently less able to obtain better health.

Further, new technologies stand to worsen this divide if the new intervention requires individuals possess certain resources to adopt the beneficial, health-promoting program or behavior (e.g. private internet access; a permanent address; a mobile phone; significant time or heavy demands on individual effort). For example, today there are divisions between health and mortality with modern chronic diseases like cardiovascular disease despite the introduction of statins, expensive pharmaceutical drugs that lower cholesterol levels (Chang & Lauderdale, 2009). The moment a disease becomes preventable by some form of treatment or intervention, which is not readily and equally accessible to all members of the population, the divide is reinforced. A central component of the fundamental cause theory posits that the association between social position and health is reinforced and reproduced over time because the mechanisms that produce social inequities are replaced by new technologies that serve the same reinforcing function. If the new intervention requires additional personal resources to obtain health or reap the benefits of health advancements, it is likely to worsen the inequity (Link, Phelan and Tehranifar, 2010).

On the other hand, it is not inevitable that a new health intervention will reinforce or exacerbate social inequities in health. As discussed earlier, when certain conditions are met, new technologies may contract the gap in health (Goldman and Lakdawalla, 2005). New technologies that raise the productivity of health care tend to benefit only those already engaged and able to take advantage of the current health system. However, if the new technology simultaneously *lowers* the productivity of other inputs like patient effort, then the intervention stands to benefit disadvantaged members of a population more evenly. This is

based on the assumption that individuals with more flexible resources are most likely to adopt complex, costly interventions, and those with less resources will be more likely to adopt interventions that are more simple and cost efficient. The most valuable premise to add here is that a health intervention that is simple and reduces the investment of individual resources for health (including effort and knowledge), is also less likely to exacerbate health inequities and more likely to allow historically disenfranchised individuals and poorer segments of the population to reap the benefits of the new health interventions.

Preliminary research has shown that *GetChecked* is widely acceptable and appealing to initial target populations (Hottes, Farrell, Bondyra, Haag, Shoveller, & Gilbert, Under Review; Shoveller, Knight, Davis, Gilbert, Ogilvie, 2012) and reflects the commonly cited potential of online sexual health services offered by *GetChecked*. By tailoring services and offering standardized care that is sensitive to groups traditionally stigmatized in the health system, *GetChecked* could mitigate many factors currently preventing individuals from accessing STI testing.

However, uptake and reach of the program beyond controlled settings and populations remains unknown. The alluring promise, but widespread lack of delivery by online technologies to expand health and heath access to larger portions of the population, particularly the more marginalized, is widely documented and discussed in the literature (Atkinson and Gold; Bauer 2008; Chang, Bakken, Brown et al, 2004; Gibbons and Casale 2010; Kreps, 2005), adding weight to the concern that the uptake and use of *GetChecked* may be heavily concentrated in populations who already have adequate levels of access or opportunity to engage in the health system. The consequence may mean reduced opportunities to circumvent or reduce existing barriers to individuals and populations unable or unwilling to access STI/HIV testing within the current model in BC. If we keep in mind the mechanisms through which health inequities are reinforced and effectively circumvented with new health technologies, we stand to significantly strengthen the overall relevance, appeal, and ultimate uptake when *GetChecked* is scaled up provincially.

Part 2: The HEIA Process

2.1 WHAT IS A HEALTH EQUITY IMPACT ASSESSMENT?

A Health Equity Impact Assessment is a stepwise process conducted early in program or policy development, which employs a number of different methodologies to investigate whether the expected impacts of an initiative (both positive and negative) will be differentially distributed between certain groups in the population (Elling, 2011; Haber, n.d.; Harris, 2004). This tool facilitates an analysis of whether the (differential) distribution of impacts of a program or policy may reinforce social inequities that currently or historically lead to an inequitable distribution of health (and health access). The framework supports the analysis of a wide range of data and leads to the prioritization of the most critical impacts and populations to be considered. From this analysis flows the means to make decisions in the development and implementation of the program that are informed by a range of data (extracted from both evidence based research and locally relevant data and community members) with explicit consideration of promoting health equity (Elling, 2011; Harris, 2004; Signal, 2008). As stated by Harris et al (2004), an equity-focused HIA aims to:

- 1. Put concern for equity and the reduction of inequalities in health on the planning agenda where it may not otherwise be explicitly considered.
- 2. Provide a flexible, yet structured approach to routinely and consistently identify and determine the possible impacts of policies and practices on different population groups.
- 3. Provide a means for adding evidence about inequalities and the consequences of inequity into all levels of the decision-making processes.

2.1.1 ADAPTING THE TOOL FOR RAPID ASSESSMENT

A number of existing HEIA manuals were consulted for guidance (Elling, 2011; Harris 2004, 2006; Signal, 2008) along with a review of the literature published on the process and evaluation of various health impact assessments (Mindell, 2008). Given the limited amount of time allowed for this assessment, a scaled down version of the HEIA was developed to suit the time constraints. The primary sources for this derivation were the Health Equity Assessment Tool (HEAT) developed by the Ministry of Health in Wellington, New Zealand (Signal, 2008); The Health Equity Impact Assessment (HEIA) Workbook, developed by the Ontario Ministry of Health and the Toronto Central LHIN (Elling, 2011); and The Health Impact Assessment: Background, Methods, and Tools for the Mongolian Mining Sector (Snyder, Wagler, Lkhagvasuren, Laing, Daison & Janes, In Press).

In this case, the initial steps (Screening, Scoping, Impact Assessment) were the basis for developing key recommendations for future planning, development, and evaluation of *GetChecked* as it is scaled up from the Vancouver-based pilot phase to a province-wide program. This project will lay the foundation for the BC Online Sexual Health Services team to carry on with the HEIA process (Monitoring and Evaluation) once the program is implemented.

2. 2 STEP 1: SCREENING

The screening step is designed to determine whether doing a HEIA is relevant to the program or initiative under development (Elling, 2011; Signal, 2008). Given *GetChecked* has the potential to impact sub-sections of the population differently, and the strong possibility that this differential may reinforce current and historical inequities in sexual health, it was decided that the HEIA would be valuable to the development of this program, particularly as a process to inform the provincial scale up and ensure the attainment of programmatic goals relevant to increasing testing access to particular populations in British Columbia.

2. 3 STEP 2: SCOPING

Scoping is a formative step that directs the more rigorous Impact Assessment (Step 3). A preliminary, wide ranging list of potential populations and key impacts were explicitly identified by considering many domains of social health determinants including class, sex/race, gender, ethnicity, ability, age, sexual orientation, level of income/employment, and so on (Elling, 2011; Harris, 2006; Signal, 2008). This step led to the identification of initial groups and impacts of interest, helped direct the literature search, and guide the selection of community members with expertise in particularly relevant areas of interest (e.g. LGBT populations, online sexual health services, youth in BC) for the Impact Assessment.

2. 4 IMPACT ASSESSMENT

2.4.1 LITERATURE REVIEW

Relevant published literature was identified through a search of the following databases: Medline, PsycInfo, and Google Scholar. Key word searches combined the terms, 'internet', 'vulnerable populations', 'health', 'sexual health', 'digital divide', 'healthcare disparities', and 'health services accessibility'. Relevant published reports were also hand selected from existing databases at two research facilities already engaged in Online Sexual Health Service Program development and research (i.e. The School of Population and Public Health Youth Sexual Health Team at the University of British Columbia, and the BC Center for Disease Control). Given the limited amount of published research and evaluation on online sexual health programming (particularly in terms of health equity), articles by scholars and research institutions publishing in this area as well as articles located through reference lists were hand selected.

Articles published in English from the year 2000 until present were included. Research on mobile/cellular technologies as sites for sexual health access and intervention were not considered, given they are not part of the current model of *GetChecked* (although they may become relevant in future phases of the model). The development of online sexual health interventions is currently concentrated in a small number of high-income, Western European countries (Canada; The United States; England; The Netherlands: Australia; Denmark), limiting the review to relatively developed and economically wealthy settings, most of which are relatively comparable to British Columbia, where *GetChecked* will be implemented.

Articles for review were selected based on their relevance to the *GetChecked* program (as an online sexual health intervention) and British Columbia as the setting (e.g. sociopolitical and economic climate; current and historically disadvantaged groups; internet accessibility). Any information providing insight on the potential positive and negative impacts of the implementation of *GetChecked* across British Columbia, and the potential for an online sexual health testing service to reinforce or exacerbate social inequities in the distribution of sexual health in this province was considered. The HEIA is an iterative process that incorporates stakeholder and community input with evidence-based literature; as the assessment progressed, certain areas of the literature were more closely examined to adequately inform the nature of particular impacts on specific populations in British Columbia.

2.4.2 LOCAL SCOPING AND CONSULTATION

Prioritizing the insight of community members and stakeholders is central to the HEIA process (Harris, 2004; Signal, 2008; Elling, 2011). The purpose of community consultation is to go beyond epidemiological surveillance data and other domains of research by contextualizing and then removing dependence on traditional 'risk factor' approaches to 'at risk populations'. Instead, specialist, contextualized and/or local knowledge is considered as directly relevant to program development (Harris, 2004). Ideally, HEIA consultation includes community members and target groups in addition to those with expert knowledge on the subject at hand; however time constraints made the inclusion of such a range of insights impossible for this particular HEIA.

Members of the BC Online Sexual Health Services team, the UBC Youth Sexual Health Team, and members of community working groups who were already engaged in community consultation for the development of *GetChecked* were engaged in guided discussions on the potential health equity impact of the program. A 'scoping' tool was adapted (Snyder et al., 2011) to facilitate discussion on the population groups expected to be most heavily impacted by *GetChecked* (in both positive and negative respects) and elicit opinions based in experience and local knowledge as to whether those impacts would reinforce barriers to certain groups experiencing or accessing better sexual health.

To begin the conversation, a number of different understandings of health equity (and equality) were presented to stimulate more nuanced discussions of equity required in HEIAs. Individuals were asked to share their opinion on which population groups they expected would be impacted by *GetChecked* (positively, negatively, not at all) along with a rationale. Next, they were asked to consider how the positive and negative (or null) impacts would be distributed and whether differential impacts should be considered inequitable. These impacts were then discussed relative to which groups in the community/province were currently or historically at a disadvantage in terms of (sexual) health and services, and also in light of which groups were currently identified as the primary 'target groups' of *GetChecked*. The information and opinions shared in these discussions were recorded and proved to be useful modes of insight throughout the HEIA process.

2.4.3 ASSESSMENT OF IMPACTS

Following completion of the literature review and expert consultations, the impacts were appraised through an equity lens. This is a complicated step where there is, as Harris

and colleagues note (2004), "no right answer to the judgments required." The step begins by matching the evidence from the literature and expert consultation, then drawing attention to the priorities expressed by expert/community members and locally relevant research and data. The data was assessed based on the following criteria (Harris et al, 2004):

- 1. The nature of the health impacts identified and the extent of differential distribution according to social determinant or other factors.
- 2. The differences, similarities or gaps in evidence collected from the various sources.
- 3. The judgments about dimensions of equity (i.e. whether the impacts are fair, avoidable).
- 4. Consideration of the needs of the organization, and the stakeholders.

After compiling and summarizing the evidence from the community consultations and literature review, the primary impacts and the most highly implicated population groups were distilled and listed in no meaningful order. Then, the impacts were considered in terms of their health equity impact on particular groups. The population impacts were prioritized using an equity lens by asking whether each one was unfair, avoidable, and/or unjust, as well as how likely the impact was for each population. This analysis resulted in a list of five populations or groups (presented as tradition epidemiological categories) to consider in the scale up of *GetChecked*, in addition to a list of nine potential impacts that may disproportionately affect different portions of the population.

2.5 LIMITATIONS

There are several limitations to this project. Given the short period of time and resources available to complete the analysis, the steps were expedited and the level and depth of literature and community engagement were limited. Most of the community members consulted were internally engaged representatives from agencies working with various community populations based in Vancouver. While valuable, it is important to acknowledge that these opinions cannot fully represent or reflect the needs and experiences of the heterogeneous populations, which were the focus of our discussions. This is a challenge of most health equity work, and this limitation provides the rationale for future community based and participatory research relevant to the development of *GetChecked*. The final two steps of the HEIA (Monitoring and Evaluation) were not completed, as they must be executed during and after the implementation of the program. Also, as noted earlier, many of the articles identified for the literature review were chosen through related links and local research databases already focused on relevant subjects. For this reason, it is likely that some relevant studies were not included.

Part 3: Findings

3.1 LITERATURE REVIEW FINDINGS

3.1.1 British Columbia STI/HIV Surveillance Data

According to the 2009 Annual Surveillance Report for STI and HIV in British Columbia (BCCDC, 2009), men who have sex with men continue to experience the highest number of new positive HIV tests, accounting for 45.6% of the total new positives in 2009. People who use injection drugs account for 18.6%, while heterosexual individuals account for 26.6% of new positive tests in BC. Historically, both men who have sex with men and heterosexual numbers of tests and proportions of the total have remained relatively steady, while people who use intravenous drugs have shown a significant overall decrease in recent years. Aboriginal populations experience an extremely high burden of HIV infection, accounting for 16.6% and 14.6% of the total new positive tests in women and men respectively. Overall, men have the highest numbers of new HIV tests, accounting for 79% of the total 338 new positive tests in 2009. After Vancouver, the health service delivery areas most affected in 2009 were rural and remote areas of the province, with the Northwest, and Northern Interior reporting the next highest numbers of new positive tests in 2009. Historically, this is a common trend in British Columbia.

The provincial data on STI (*Chlamydia*, gonorrhea and infectious syphilis) echo the HIV figures in terms of the disproportionate amount of infection in rural and remote areas of the population (currently and historically). Much like HIV, infectious syphilis tends to be heavily concentrated in men who have sex with men, gay men and Aboriginal women, with the majority of total infections (87% of a total 216 cases) reported in men. Numbers have decreased overall in men who have sex with men, street involved people, and sex workers and their patrons, but remain stable in heterosexual populations (22.2% of total cases).

Reports of genital *Chlamydia* have continued to increase for both men and women since 1998, with women accounting for 65% of the total 11 173 cases reported in 2009. Conversely, men constitute 61.5% of the 1307 cases of genital gonorrhea in this province. Rates of *Chlamydia* and gonorrhea remain highest (and rising) in youth under 25, with women primarily between 15 and 24 years of age, and men generally between 20 and 29. Unfortunately, there is no data describing the ethnic breakdown of *Chlamydia* or gonorrhea infection in this province. Similarly, data on transgender HIV/STI burden is poor and does not provide any insight to the state of sexual health in this population group in British Columbia today.

3.1.2 CONTEXTUALIZING 'HIGH IMPACT GROUPS'

Surveillance data provides the foundation for public health to plan and direct sexual health services (including STI/HIV testing services, outreach and targeted promotion). However, it is important to contextualize this data with research and local knowledge on the social determinants of sexual health to more clearly understand the 'need' and relevance of *GetChecked* to different populations in this province. Across those groups of people who are

highly exposed to these infections, structural barriers like heterosexism, lack of anonymity/confidentiality in health services, and problems accessing clinics that suit the needs of the individual (McFarlane & Bull, 2007) contribute to socially stratified disparities in access to health services and the distribution of sexual health in this province (Shoveller, Johnson, Rosenberg, Greaves, Patrick, Oliffe, & Knight, 2009). The stigma associated with STI, HIV, sexual orientation and other social locations overlap with experiences of race/ethnicity, age, class/SES, education, and gender, which contribute to population levels of HIV and STI through multiple complex pathways (Aral, 2002; Joy, Druyts, Brandson, 2008; Poundstone, 2004; Springer, 2010, Zierler & Krieger, 1998). This literature review explores and contextualizes the population groups most frequently addressed in expert consultations. For each population, relevant and available literature on HIV/STI exposure and burden is reviewed as well as population access to the internet and relevance to internet health services in general.

MEN WHO HAVE SEX WITH MEN:

Methods for researching and understanding STI/HIV infection and prevalence in gay men and men who have sex with men often frame this population as a relatively homogenous entity (Wilton, 2009) with limited attention given to the broader social factors that influence all levels of sexual health and related behaviour for men who have sex with men. As Zierler and Krieger (1998) have discussed with relevance to HIV transmission in women in the United States, research on men who have sex with men could be similarly approached through asking how issues of sexual orientation, race/ethnicity, class, gender and other social categories affect exposure to HIV among different stratifications of this segment of the population. Being a non-gay identified or married man who has sex with men (Pathela, Hajat, Schillinger, Blank, Sell & Mostashari, 2006; Weatherburn, Hickson & Reid, 2003), being racialized (Wilton, 2009) and living in a rural setting (Williams, Bowen, 2008; Shoveller, Johnson, Rosenberg et al. 2009) exacerbate barriers to sexual health access and are frequently linked to higher levels of unsafe sexual behaviour and HIV in sub populations of men who have sex with men. Neighborhood levels of disorder are linked to psychological stressors that stimulate types of sexual behaviour that encourage the transmission of infection (Latkin, Curry, Hua & Davey, 2007). Similarly, other neighborhood factors (living in a community with strong gay community presence) were linked to STI/HIV preventative sexual health behaviours when compared to men who have sex with men living outside of such a community (Frye, Koblin, Chin et al., 2010). Men who have sex with men experience significant barriers to testing, including prevalent heterosexism and homophobia in the health system and clinic experience, particularly in rural areas (Shoveller, et al., 2009). Many men in Vancouver do not know where to access anonymous sexual health care or health services that are sensitive and accepting of men who have sex with men (Ferlatte, 2007).

In terms of online sexual health service provision, men who have sex with men are an ideal target population (Mimiaga, 2008; Weatherburn 2003). A large proportion of men who have sex with men are online (Weatherburn), and an increasing number of these men are meeting partners online as well (Jenness, Neaigus, Hagan, Wendel, Gelpi-Acosta & Murrill, 2010; Ogilvie, Taylor, Trussler, Marchand, Gilbert, Moniruzzaman, & Rekart, 2008). Recent efforts to establish similar online sexual health services for gay men and other men who have sex with men were acceptable and highly successful (Bowen, Horvath & Williams, 2007; Carpenter, Stoner, Mikko, Dhanak & Parsons, 2010; Koekenbier, 2007). In a broader sample

of eHealth¹ users, Bull, McFarlane and King (2001) found that the majority of a large sample of eHealth users were white, middle to high SES men with higher levels of education (it should be noted, that this group was not compiled of men who have sex with men alone). This finding was reflected in eHealth research specific to rural men who have sex with men, where the majority of the sample that completed an online HIV prevention intervention were under 30 years of age, white, single and gay-identified (Williams, Bowen, & Ei, 2010). The likelihood of uptake with online HIV prevention interventions for rural men who had sex with men were dependent on factors like SES, quality of Internet access, having at-home access and ease of navigation (Williams et al.). While this population appears to be a ready target population for eHealth interventions, the literature expands and contextualizes this group and suggests that a number of sub-sections of men who have sex with men (who may be most in need of *GetChecked*) may require innovative and targeted methods to be adequately reached by this program.

YOUTH:

Youth experience unique barriers to sexual health and sexual health services. Many youth feel excluded from 'adult sexuality' and sexual health resources (Shoveller, Johnson, Langille, 2004), an experience likely complicated by the fact that nearly 20% of Canadian youth were not born in Canada and may live with socio-cultural norms about sexuality that diverge from norms central to Western approaches to sexuality and sexual health (Shoveller et al., 2004). Youth are reluctant to disclose information about their sexual behaviour and find it difficult to access truly anonymous and confidential clinical experiences at their own accord, particularly in rural areas (Shoveller et al., 2009). Often, the relational and physical experience of clinical settings is pervasively heterosexist and focused on female reproductive health, which is often cited as a deterrent for 'LGBT' youth and young men from accessing health services (Shoveller et al, 2009). Many additional factors overlap to influence sexual behaviour and STI/HIV transmission in street involved youth, such as couch surfing/unstable housing, substance use along with sexual activity, economic hardship, and degree of social support (Marshall, 2008). It is evident that multiple complex factors shape the environment in which youth live and experience their sexual lives. Often, the same factors may make it difficult for youth to access health services in person and also through the internet.

It is often assumed that technology is highly acceptable to youth, however research recently conducted in the Netherlands demonstrated that most youth did not have the internet skills necessary to find or take advantage of pertinent eHealth information and services (van Deursen & van Dijk, 2011). A sample of Canadian adolescents said they felt comfortable accessing sexual health information at school (Shoveller, Johnson, Prkachin, & Patrick 2007), yet both first² and second³ level digital divides are shown to exist in Canadian high schools and were stratified by gender, parental education, geographic location and urban vs. rural

1

¹ eHealth is a general term used to describe the application of information and communications technologies in the health sector. While often applied in reference to networked health information systems the term can also be used to refer to the organization and delivery of health services using the internet, and it is used in that context here (Catwell & Sheikh, 2009).

² The first-level digital divide refers to any inequalities between groups in terms of basic access to internet and computer based technology (e.g. no internet access, no available computers, etc.).

³ The second-level digital divide refers to any inequalities between groups in terms of access to internet and computer based technology due to quality of internet connection, level of internet skill performance and experience, language literacy, interpretation and understanding of information once connected and so on.

setting (Looker and Thiessen, 2003). Further, unique barriers exist blocking youths' access to the internet, particularly for sexual health information. Parents and teachers communicate a strong assumption that youth will access needed sexual information online, alleviating embarrassing responsibilities to ask and teach about sexuality (Shoveller, Johnson, Prkachin & Patrick, 2007), yet there are simultaneous feelings of resistance and evidence of gate keeping in terms of parent/guardian control over youth access to sexual content on the internet (Guan & Subrahmanyam, 2003; Rice, Monro, Barman-Adhikari & Scott, 2010). This is particularly evident with street involved youth, who may benefit substantially from internet access, but are at the mercy of 'gatekeepers' who often weigh the benefits of access with their desire to prevent 'troubled' youth from soliciting themselves for sex online (Rice, et al.).

Still, online interventions aimed to increase Chlamydia testing in youth populations have been very successful (Blake, Kearney, Oakes, Druker & Bibace, 2003; Gaydos, Barnes, Aumakhan, Quinn, Agreda, Whittle & Hogan, 2009). Gaydos and colleagues found online testing that included at-home specimen collection relieved women's experiences of stigma and concerns about privacy and increased uptake of Chlamydia testing. While the program was available to women of all ages, it attracted a large proportion of youth; nearly 60% were under 25 years old. Prevalence of Chlamydia was high in the under 21-age cohort (15.2%), pointing to the value this kind of service holds for youth. Blake and colleagues (2003) also found that online sexual health testing alleviated youths' fears about privacy and provided the information they needed to dispel STI misconceptions. Tercyak and colleagues (2008) found that regardless of youths' level of internet access, those with singular and multiple behavioural factors that increased their chances of contracting sexually transmitted infections were interested and willing to use eHealth strategies to access health services, particularly those that were interactive. However Bull, Pratte, Whitesell and colleagues (2008) warn that significant effort needs to be invested to effectively reach youth, particularly those deemed by society as 'high risk,' in order to influence meaningful uptake. Gaydos and colleagues similarly acknowledge that many of the same predictors of Chlamydia infection overlap with the barriers to online access (2009).

ABORIGINAL POPULATIONS:

Research on sexual behaviour and STI/HIV testing and transmission in Aboriginal peoples in BC and Canada is limited (Wardman, Quantz & Clement, 2006). It is clear, however, that Aboriginal populations constitute a disproportionate amount of HIV infection, particularly for women (BCCDC, 2009) and those who use injection drugs (Wardman, et al.). Aboriginal populations in Canada experience heavy health burdens and have consistently experienced unjust social exclusion and treatment as a result of colonialism and structural racism (amongst other factors) in Canada (Browne, Smye, Rodney, Tang, Mussell & On'Neil, 2011; Tang & Browne, 2008). Steenbeek (2004) adds that these factors make it exceptionally critical, albeit challenging, to make sexual health services and programs genuinely empowering and meaningful for Aboriginal peoples. There is, however, evidence from Australia that when developed with the close involvement of community members from indigenous populations, new, computer-mediated health technologies were taken up and became meaningful and acceptable to indigenous populations, particularly when used as a complementary resource to clinic based services (Hunter, Travers & McCulloch, 2003; Penn, Simpson, Leggett, Hawgood, Wood, Yellowlees, Leo & Edie, 2005). Aboriginal populations require tailored and culturally sensitive approaches to sexual health that are sensitive to and

address structural and interpersonal determinants of health simultaneously (Dhamoon & Hankivsky, 2011). Delivering services on reserve may require special attention to these and other factors unique to the reserve setting (Devries, Free, Morrison, Saewyc, 2008) where individuals may have limited (or no) access to private internet points, particularly in rural and remote regions (Crompton, 2004). While outdated, a study in 2004 (Crompton) showed that Canadian Aboriginal populations were gaining access to the internet, but that many users from Aboriginal communities were relatively new (had been using for one year or less), suggesting they may not have developed the full range of internet skills necessary to take advantage of eHealth services (van Deursen & van Dijk, 2011) at that time. More up to date research focusing on Aboriginal internet usage both on and off reserve is necessary to refine this discussion.

TRANSGENDERED POPULATIONS:

Similarly, transgendered⁴ and other non- cisgendered⁵ people presently and historically experience systemic exclusion and stigmatization in health care (Bauer, Hammond, Travers, Kaay, Hohenadel & Boyce, 2009). Operario and Nemoto (2010) warn this should be acknowledged with thoughtful development and implementation of STI/HIV prevention and control efforts that take into account transgendered and other non-cisgenderd perspectives, even though this group is almost absent in the population level data in this province (BCCDC, 2009). This low instance of infection in transgender populations may be due to measurement or selection bias in data collection. It may also suggest that transgendered individuals are not engaging with the health system. This problem is sometimes referred to as 'informational erasure,' which "encompasses both a lack of knowledge regarding trans people and trans issues and the assumption that such knowledge does not exist even when it may" (Bauer, et al., 2009, p. 352). This and other forms of erasure often lead to the invisibility of transgendered bodies and experience in research and practice related to sexual health.

Trans- and non-cisgendered people experience multiple factors that increase the likelihood of exposure to unsafe forms of sexual behaviour; factors include persistent unemployment and poverty, lack of social support, substance use to cope with heightened psychological distress, and selling sex to earn money, food, or accommodation (Namaste, 2000). Additional barriers to health services include: stigmatization, lack of understanding and representation in the health system (Operario & Nemoto, 2010), systemic social service barriers that necessitate individual documents (Care Card, passport, license, birth certificate) match gender presentation, mental health problems and limited information on relevant relationship and sexual health concerns (Bauer et al.). For these reasons, STI/HIV testing services must become more sensitive and accommodating to this group (Operario 2010). Operario (2010) suggests they are best bundled with already existing services and health interventions that reach trans and other non-cisgendered populations.

⁴ Transgender is an umbrella term that encompasses a diverse group of people whose gender identity or expression diverts from prevailing societal expectations. Trans includes transsexual, transitioned, transgender, and gender queer people, as well as some two-spirit people (Bauer et al. 2009, p. 348 – 349).

⁵ Cisgender is a term that corresponds to transgender, which typically describes non-trans people, whose gender identity aligns with the sex they were assigned at birth (Bauer et al.)

No relevant literature was found on transgendered access or use of internet or eHealth services specifically. Given what we do know about transgendered experience of health and public services, it could be suggested that online health services may be out of reach and often not targeted or friendly to transgendered people.

IMMIGRANT POPULATIONS AND SOCIO-CULTURALLY DIVERSE GROUPS:

As Kreps and Sparks (2008) have highlighted, immigrant populations often suffer poorer health than the general population as well as some of the most significant barriers to accessing health information and health care. This is often due to barriers around language, literacy, and health literacy plus considerable socio-cultural disparities from western North American cultural norms around sexuality, sexual health and health care utilization. Sexual taboos in non-western cultures are often distinct for women, men, youth, LGBT, and transgendered people (to name a few) and often influence unique sexual and test seeking behaviour, depending on the prescribed cultural norms and expectations. For example, Pathela, Hajat, Schillinger, Blank, Sell and Mostashari (2006) found that 12% of a sample of married men in New York had sex with other men. A large portion of these men cited they were married due to cultural pressures, were foreign born and belonged to a cultural or ethnic minority. In comparison to gay-identified men, these married men who had sex with men were more likely to have had unprotected sex and less likely to have been tested for HIV in the past year.

For women and youth, accessing testing in conservative sexual cultures is also extremely difficult, particularly when there are significant barriers to anonymity and confidentiality in tightknit communities during visits to the family doctor or a community clinic (Dixon-Woods, Stokes, Young, Phelps, Windridge & Shukla, 2001; Shoveller, Chabot, Soon & Levine 2007; Shoveller, Johnson, Langille, Mitchell, 2004).

There are significant barriers across socio-cultural groups and immigrant populations specific to online health services as well. The style of online communication may not translate across various sociocultural values and needs. In their extensive review of cancer related eHealth literature and socio-cultural sensitivity, Neuhauser and Kreps (2008) discuss the challenges of reaching different populations via online communication and eHealth for cancer related education and services:

The significant racial and ethnic disparities in cancer morbidity, mortality, and participation in cancer prevention, screening, and treatment have prompted increasing research about whether online cancer communication is accessible to and culturally appropriate for minority groups. In addition to communication that meets users' linguistic and literacy requirements, research is increasingly identifying values, beliefs, risk perceptions, norms, practices, motivations, family and community relationships, and many other cultural factors that may affect the acceptance and use of cancer communication among diverse racial/ethnic groups (p. 370).

The review highlights that moving cancer related information and health services online *can* overcome traditional barriers to health access, reduce cancer risk, improve screening, and enhance patient care. However, individuals with literacy, cultural, and

language related differences from the general population might not benefit from the same services.

Still, the authors highlight that many minority populations in the United States still access cancer-related health information online (one large population based survey showed 49.6% of whites, 43.2% of African Americans, 36.6% of Hispanics, and 48.2% of non-Hispanic other groups), surpassing efforts in all population groups to access cancer information from health care providers or printed materials. In conclusion, Kreps and Neuhauser suggest that because developing culturally sensitive information is so complex, individuals from relevant population groups must be included in the design and testing of online content and usability (2008).

RURAL AND REMOTE REGIONS OF BRITISH COLUMBIA:

There is a significant burden of HIV and STI in rural and remote regions of BC, particularly in the Northern Health Authority (BCCDC, 2009). As already discussed, access to quality, sensitive, appropriate sexual health services is extremely difficult (if not impossible) for many people in rural and remote parts of the province, particularly for stigmatized and/or marginalized populations (Goldenberg, Shoveller, Shoveller, Ostry & Koehoorn, 2009; Hanlon & Halseth, 2005; Peters & Self, 2005; Sandstra, Gold, Jones, Harris & Taylor, 2008; Wathen & Harris, 2007). For example, Peters and Self (2005) found that many individuals who had negative experiences with 'the system' (health, government, etc) refused to enter buildings or use services run by, or associated with 'the system.' Given there were no alternative health services offered in these remote regions, these individuals ended up not accessing health services at all. Further, there is a lack of targeted outreach for stigmatized and other populations disproportionately exposed to HIV/STI transmission (e.g. people who use injection drugs; sex workers and their patrons; transgendered and LGBT populations) (Peters & Self, 2005) that often experience extreme levels of stigmatization, exclusion, and invisibility in these areas (Goldenberg, et al. 2009; Peters & Self, 2005). These factors, along with the general migration of health services to urban centers, have contributed to the absence of health services in rural areas today in BC (Hanlon and Halseth, 2005). People (particularly women) living in rural Canadian communities report a lack of confidence in the knowledge and skills of the health professionals in their area (Wathen & Harris, 2007) and Hansen, Barnett, Wong and Rekart (2005) found that Canadian physicians working in rural communities express they have very limited opportunities to update their sexual health knowledge and skills.

Finally, the majority of research and literature on STI, HIV, or online sexual health interventions have primarily been conducted in urban centers (Sandstra, et al. 2008) and/or with STI clinic populations (Manhart, Aral, Holmes, Critchlow, Hughes, Whittington, & Foxman, 2004; Ross, Copas, Stephenson, Fellows, & Gilleran, 2007), both of which have been found to be quantitatively and qualitatively different from rural and non-clinic population experiences of access to sexual health care and testing, and STI/HIV related behaviour/burden (Sandstra et al; Manhart, et al.). It is important to heed warnings that the potential of eHealth should not be oversold in rural populations without first enquiring within to discover whether it is a health resource that can take root and be useful to the target population and others in need (Wathen & Harris).

3.1.4 CAUTIONARY WORDS FROM EHEALTH LITERATURE ON 'VULNERABLE POPULATIONS'

For many of the vulnerable and marginalized populations discussed, the social and structural factors that increase the likelihood an individual has an STI or HIV (and therefore should have access STI/HIV testing) may simultaneously increase the barriers individuals experience to online health services. A body of literature from the United States on eHealth developed over the last fifteen years suggests today that the greatest determinant of population and individual level benefit from online health information and services is individual level of education and (health) literacy (Atkinson & Gold, 2002; Baur, 2008; Gibbons & Casale 2010; Hsu, Huang, Kinsman, Fireman, Miller, Selby, & Ortiz, 2005; Kalichman, Weinhardt, & Cherry, 2002; Kreps & Neuhauser 2010; Miller & West, 2009; Parker & Kreps 2005; Ross, et al. 2007; Shim, 2008). Measures of SES, income, race, ethnicity, age, culture, language spoken, and country of origin are valuable proxies for internet and health access (as well as HIV/STI vulnerability), but studies often find that when factors like SES and ethnicity are controlled for, education and literacy levels are the greatest underlying factor when it comes to accessing and benefitting from online services (Atkinson; Baur; Lorence, Park and Fox, 2006; van Deursen & van Diik).

Concerns over physical access to a computer and internet connection (the first digital divide) are valid, particularly in rural and remote areas of the province (Looker & Thiessen, 2003) and for Aboriginal populations living on reserve (Crompton, 2004). However, it is generally agreed that the second digital divide is the deciding factor of an online health programs' success in a population, particularly for marginalized groups (Dart 2008; Hsu, et al; Lorence, 2008; Neuhauser & Kreps, 2008; Shim). To date, most eHealth websites are only in English, and far exceed the language and health literacy capacity of the general population, particularly in racial minorities and low SES groups (Kreps & Neuhauser, 2010; Kreps & Sparks, 2008; Neuhauser & Kreps 2008). While it is widely acknowledged that the delivery of health information and services online has the potential to decrease social inequities in health, the overall promise of eHealth interventions is still seen as widely unmet and contingent upon many factors.

The most commonly cited contingent aspects of eHealth that moderate the appeal and access of online health services to vulnerable populations are: readability and usability of content (i.e. language and health literacy and internet skills competence) (Parker and Kreps, 2005; van Deursen & van dijk 2011; Miller & west; Lorence Park & Fox 2006), cultural appropriateness and sensitivity to sexual minorities (Atkinson, 2002; Baur; Hunter & Travers, 2003; Kreps & Neuhauser, 2010), and the degree to which end users from marginalized groups are involved in program development. Mehra, Merkel and Bishop (2004) caution against the assumption that moving services and information online will automatically reach and/or empower people to act and learn in kind. The authors suggests that if we want to enable and empower people through the internet, we must stop treating it as if it is a "phenomenon isolated from social realities of disadvantaged user communities" (p. 799) and acknowledge the situated nature of technology and internet use by first considering the feasibility and readiness for eHealth in a community, followed by qualitative research involving the community in the development of the service.

3.1.5 REACHING THE 'HARD TO REACH' WITH EHEALTH

Customization, user-centered design, the freedom to go beyond 'risk' categories (that is, avoid explicitly categorizing patients as belonging to a particular 'risk group' during patient interview or 'risk assessment'), the ability to access people across time, place and culture, 24/7 convenience for clients, and platforms for question/answer and interactive learning opportunities have been identified as the greatest benefits eHealth services can offer marginalized populations (Kreps & Neuhauser, 2010). Removing the face to face component may provide more consistency in service delivery, improve clarity for the client, reduce costs and increase reporting of sensitive sexual health risk behaviours (Ross, et al. 2007) while decreasing individual reluctance to provide sexual health information, circumventing barriers related to restricted clinic times, reducing the number of trips to health clinics/labs for those who have transportation and distance barriers (Shoveller et al 2009; Youth Sexual Health Team, 2007).

3.2 FINDINGS FROM SCOPING CONSULTATIONS

Individuals from teams at the BCCDC and the UBC Youth Sexual Health Team (who have built a research partnership with together to investigate online sexual health services pertaining to youth) who had considerable 'insider' knowledge were consulted for health equity discussions on the potential benefits and unintended consequences of *GetChecked*. Similarly, other BCCDC staff and individuals from outside of these organizations from a variety of community groups that were involved with the long-term development of *GetChecked* were engaged in the same discussion. In total, five BCCDC staff members from the Online Sexual Health Services team, three members from the UBC Youth Sexual Health Team, and four community agency representatives (two of whom were also BCCDC staff members) completed the health equity scoping exercise.

Although somewhat limited, these consultations provided valuable insight and opinions on the potential health equity impact of the program. Common themes from these conversations were distilled and summarized to provide a basis for the literature review, predictions of potential impacts, and rationale for the final recommendations.

3.2.1 PROGRAM STRENGTHS AND POTENTIAL BENEFITS

The most enthusiasm and recognition of advantageous opportunities presented by *GetChecked* were paid in reference to the reduction of **embarrassment** and **stigmatization**, and the enhancement of **anonymity** and **confidentiality** offered by the *GetChecked* model. Stigma, embarrassment, and shame were described as barriers to testing that were experienced across most groups of people. Removing the face-to-face clinic encounter from the front end of STI testing may lower the threshold of access for a large portion of the general population who are simply 'avoiders' and/or 'procrastinators'. For this group, the added level of **convenience**, **ease**, and requiring **fewer appointments** may also be a major selling point. These 'first adopters' were projected to be able people living in an urban center with higher levels of education, and the means to access the model easily (e.g. already engaged with the health system, high level of internet access and skill). A second, more powerful level of value that could be added by removing the initial clinic visit involved client **anonymity** and **confidentiality** for individuals who experience judgment and stigmatization when accessing (sexual) health care (e.g. patrons of sex workers; non-gay identified men who have sex with men, rural youth, women from sexually conservative cultures, trans and non-cisgendered

individuals). The opportunity to access STI testing through a computer-mediated program may provide a critical chance to circumvent real life barriers and avoid significant personal costs. In these discussions, *GetChecked* was linked most to historically stigmatized populations that frequently experience discrimination and structural violence in government systems (trans and non cis-gendered people; Aboriginal populations; LGBT people; sex workers) and those who require more privacy or confidentiality than that offered by local, accessible, in person clinical services.

3.2.2 POTENTIAL UNINTENDED CONSEQUENCES

These health equity discussions provided valuable opportunities to ground and contextualize some of the expectations anticipated by offering a sexual health service online. One of the biggest concerns was whether GetChecked would reinforce the normative discourses present in current-clinic care and promotional campaigns that convey messages about who should be testing for STIs (usually gay men and single women). Another aspect of this concern was that common approaches used to appeal to women and gay men for STI/HIV testing may not reach beyond 'mainstream' populations, thereby running the risk of continuing to access the 'same' portions of the population who already have access to testing. All individuals engaged in scoping discussions firmly recognized that reaching beyond the 'mainstream' with sensitive, novel, thoughtful, and specialized promotional efforts will be necessary. This concern was most strongly expressed in reference to: i. youth who are LGBT/queer/questioning and/or from culturally conservative communities, ii. non-gay identified men who have sex with men, and iii. heterosexual men (particularly youth/young adult). An extension of this concern was that while GetChecked may lower the threshold of access to STI testing enough to increase uptake in 'the middle of the distribution' it may not lower the threshold of access enough to lead to greater access for the BC populations that persistently suffer the greatest burden of STI, and also the greatest barriers to in-person STI testing. Physical access to the internet, the quality of internet access/experience, the ability to use the internet, language, English and health literacy, and having a lab and/or clinic (to receive positive results) within a reasonable distance were all major factors mentioned as possible barriers to making GetChecked more broadly accessible, particularly beyond the Vancouver center and for individuals possessing less flexible resources (especially literacy, income, education, and ability to read English).

3.2.3 SHIFTING PERSPECTIVES ABOUT 'HARD TO REACH' POPULATIONS

Some insights accentuated experiences that troubled common language and approaches to 'vulnerable populations'. For example, one person stressed that certain populations are only 'hard to reach' because services are designed for the 'mainstream' and not for needs of more marginalized groups. While it is essential to design a broad population based intervention in a way that appeals to people in general, we must also take into consideration the potential to reinforce inequities in health with this very approach (Frohlich & Potvin, 2008). This question, commonly debated in public health spheres, was regularly grappled with during these discussions. Many discussed ways to prevent structural violence and 'othering' in *GetChecked* by taking extreme precautions to avoid normative language, images, values and discourses on the *GetChecked* site and the linked sites and services (including BCCDC's new sexual health website under development, *SmartSexResource*), particularly in terms of avoiding gender binaries, heterosexism, narrowing or dichotomizing the

meaning of sexual orientations (e.g. assumptions that users are either hetero- or homo-sexual and this accurately reflects their sexual behaviour). Many pointed to the importance of considering that 'Vancouver/urban-centric' approaches that embrace harm reduction and 'safer sex' approaches may not be welcomed in smaller or more rural or conservative centers. Some populations were noted as decidedly 'hard to reach' due to geographical distance, isolation and the transient nature of some groups (e.g. those that are insecurely housed or transient worker populations in the oil and gas industry or resort communities). All of these communities were deemed as needing more adequate STI testing services, which could not be answered by *GetChecked* alone. One common hope was the potential for *GetChecked* to relieve some health systems burden, thereby freeing up some resources to be redistributed to targeted outreach and efforts to these areas.

3.2.4 WHAT'S MISSING?

A number of concerns linked to the translation of in-clinic services to an online platform, especially removing the face-to-face interaction with a clinician, were of concern. For example, the loss of opportunities for tailored education, additional medical care and counseling (e.g. providing mental health support/treatment) and opportunities to promote safer sexual behaviours (especially after negative test results) were frequently mentioned. Many felt GetChecked might reinforce ideas that testing for STI/HIV is an adequate way to prevent infection, or that sexual health is only about controlling infection. Some clinic experiences were recognized as indispensible, meaning that creative methods would be necessary in the future to translate them online (e.g. tailored pre/post test counseling; targeted sexual health information and education; provision of appropriate resources through links, downloads, etc). Other opportunities not met by the present model of *GetChecked* that were moderately to very problematic were: not being available in languages other than English; not offering pharyngeal and rectal swabs; and not offering Hepatitis C testing. Finally, while GetChecked may reduce the number of visits necessary to a health clinic, many felt that the same stigmatizing, embarrassing, unconcealed experience would still occur in a trip to the lab, particularly in rural and remote settings and other small communities. This fact was seen as undermining an otherwise non-judgmental, concealed experience.

3.2.5 GROUNDED ADVICE

Some of the most common suggestions for avoiding harm and enhancing the benefits of *GetChecked* included targeted qualitative research to determine *GetChecked*'s relevance to the key identified groups, especially those we know less about (sub-populations of men who have sex with men, rural women, street involved youth, transgender and Aboriginal populations), linking with community partners beyond the Vancouver area and dovetailing *GetChecked* outreach through existing services and community relationships (like Chee Mamuk, QMUNITY, BCCDC Street Nurse Online Outreach, HIM, Positive Women's Network, etc). Finding new avenues for promotion, particularly on the internet and through less intuitive mediums (e.g. local, non-English websites and print publications to reach marginalized communities) was highly recommended. Some caution was advised in terms of pushing the technology of *GetChecked* forward to meet the preferences of the greater population (e.g. youth intolerant of older technologies) at the cost of making the services further out of reach to many marginalized populations. In this case, it was advised that keeping many options (rather than discarding old ones) was key; for example if *GetChecked* moves to electronic or mobile

requisitioning, keeping the printing option was important. Eventually offering mobile and text technologies was also discussed being meaningful for street involved women and youth who have cell phones. Finally, electronic requisitioning was widely discussed as an attractive option for all potential users.

3.2.6. HEALTH EQUITY REQUIRES A NUANCED APPROACH TO 'NEED'

One of the most challenging aspects of these discussions was distinguishing the subtle but important differences between meanings of health equity and equality. Considering different ways to think of 'need' in terms of equity forces us to look beyond the epidemiology and need based on the numbers (and questions like, 'do different populations in BC have equal access to testing'), and instead focus simultaneously on multiple levels of consideration including who currently needs the service most, who currently (and historically) has less access to testing, and who can cope with potential negative consequences more easily. In this case, it is those who have suffered systemic exclusion and continue to suffer multiple overlapping barriers to inclusion that are considered most 'in need'. For example, by this approach 'mainstream' gay identified men and straight identified men and women who are well educated, from middle to high SES, and from urban centers may not need GetChecked most. Similarly, GetChecked may not be needed by street involved youth, IDU, and sex workers in Vancouver, because of multiple opportunities to test through urban outreach services. However, these support services do not exist in non-urban areas of British Columbia, pointing to a need to increase access to testing in these groups outside of urban Vancouver.

3.3 SUMMARY OF FINDINGS

After compiling and reviewing the range of data and information, the next step of the HEIA analyzes all forms of 'evidence' together and draws attention to the most pertinent and likely potential impacts of the program under analysis. To do this, the information collected in scoping interviews was listed alongside locally relevant data and the outcomes of the literature review. Mentions of potential impacts were recorded, and judgments on the dimensions of equity of the impacts (whether the impacts were fair or avoidable) were noted. The impacts and population groups mentioned were distilled and listed in no meaningful order. Dimensions of equity discussed for each helped prioritize the importance of each impact and population group. The nature of the health impacts, the extent of differential distribution according to social determinants, gaps in evidence, and considerations of the relative needs of local communities and groups were also taken into consideration.

All mentioned impacts were prioritized by asking whether each one was unfair, avoidable, and/or unjust, as well as how likely the impact was for each population. This analysis resulted in a list of six populations or groups (presented mainly as traditional epidemiological categories) to be explicitly considered prior to program scale up, in addition to a list of nine potential impacts that may disproportionately affect different portions of the population.

As highlighted in the literature review section, the primary population groups to be considered in the scale up of *GetChecked* were (in no meaningful order): gay men and other men who have sex with men; youth; Aboriginal populations; transgendered and other non-

cisgendered people; groups who fall into diverse socio-cultural groups (including those who have immigrated to Canada); and people living in rural and remote regions of British Columbia. There may be considerable overlap between these groups, and future research may call for reassessment.

The primary impacts highlighted across the research literature, local data and local consultations were:

- More broadly, it was commonly recognized that moving services online may reinforce or exacerbate the already unjust social division of:
 - STI/HIV testing and health access
 - Population burden of STI/HIV

by level of education, race, ethnicity, sexual orientation, gender, or SES, geographical region and so on [reinforce inequity].

- More specifically, targeted marketing to traditional epidemiological 'risk categories' informed by surveillance data alone may result in uptake in groups already exposed to testing information and services, without expanding to 'non-testers', especially in marginalized populations [reinforce inequity].
- Some marketing styles commonly used to promote testing may not be appropriate for many sub-populations of groups with higher exposure to HIV (for example, sexualized messaging targeted toward gay men may not capture the attention of non-gay identified men who have sex with men). Similarly, marketing may also reinforce problematic norms about who 'needs' to get tested (e.g. gay men; young women) or suggest GetChecked is only 'for' certain people or populations [reinforce inequity].
- Many of the greatest individual and socio-demographic factors that create the circumstances for STI/HIV risk and vulnerability simultaneously present major barriers to internet access and individual capacity to take advantage of online health services. This may mean that those most in need of GetChecked may require greater reductions in the threshold of access to the internet and related testing services before they can benefit from GetChecked [reinforce inequity].
- Language, pictures, and wording of the site may 'other' traditionally underserved or marginalized groups, contributing to the continued 'erasure' of certain people within government and health systems. This may also discourage uptake among these groups who may 'need' the service most [reinforce inequity].
- Given the multiple barriers and gatekeepers (private internet access; parents; community elders; conservative or religious values; transportation; printer and so on) GetChecked may not adequately reach youth, one of the primary target populations [reinforce inequity].
- ❖ GetChecked may not translate well to non-urban/non-Vancouver areas, including those with persistently high HIV/STI burden [reinforce inequity].

- ❖ Given the limited number and type of tests available through the program, there is considerable potential for missed infection, particularly for men who have sex with men and people who use intravenous drugs [cost].
- Men who have sex with men living in urban areas are well suited to this technology. It is expected that they, along with current clinic clients, will readily take up the program during pilot implementation, potentially increasing testing frequency in these populations [benefit].

Part 4: Recommendations

4.1 ASPECTS OF HEALTH EQUITY ALREADY UNDER CONSIDERATION AT BCCDC

The BC Online Sexual Health Services team has already begun to mitigate potential negative impacts and strategize how to avoid reinforcing health inequities in the ongoing development of *GetChecked*. For example, the team continues to build existing community partnerships and integrate local opinions and feedback at regular intervals into program development. Further, multi level qualitative and quantitative data collection (including postal code) is planned for Pilot Phase evaluation in addition to research conducted in partnership with the UBC Youth Sexual Health Team, with a focus on health equity and youth access to sexual health services in this province. The team is also considering options for including rectal and pharyngeal swabs as well as Hepatitis C testing in future models of *GetChecked* and has committed to facilitating focus groups and usability testing beyond initial target populations.

4.2 RECOMMENDATIONS:

GetChecked is an opportunity to leverage modern technology to improve population health access and outcomes. At this juncture, it is the responsibility of informed public health practitioners to thoughtfully introduce these new technologies in ways that provide heightened health care access and better health to all members of the BC population. As a practical tool, the HEIA directs public health practitioners' attention to the barriers and opportunities specific to GetChecked. Heeding the results of the HEIA will be integral to meeting goals for achieving greater equity and access when the service is scaled up provincially. The following are recommendations structured to encourage explicit commitment to health equity and the development of a service that can meet the needs of multiple populations across the province who stand to benefit from this service. How can we make the service usable for everyone?

PROGRAM PLANNING

- 1. Identify key stakeholders and gatekeepers who may mitigate access to the service in various communities prior to scale up.
 - This may be especially relevant to youth (high school age) with limited access to a computer, transportation, etc.
 - Similar considerations may be necessary in more resistant or closed communities, for example Aboriginal populations on reserve, or more sexually conservative or religious cities and communities (see Shoveller et al, 2007).
- 2. Throughout the program planning and implementation process, build in checks and measures to ensure team and program accountability to equity based goals and outcomes.
- 3. Anticipate new impacts (positive, negative, reinforcing health inequity) and acknowledge those that have been remedied/averted.

- 7. Encourage team development and capacity for social epidemiology for program evaluation and data analysis.
- 8. During both Phase I and Phase II evaluation the following should be prioritized:
 - o Completion and review of first Health Equity Impact Assessment
 - o Integration of a second, long term Health Equity Impact Assessment with a scope inclusive of provincial scale up.
 - During scale up, it will be important to integrate the development of a hierarchy of measurable outcomes recognizing short-term and long-term outcomes as well as those directly related to changes in health equity.

See section 3.4 of Signal, 2008 (included in Appendix II) for further discussion and guidance on developing a hierarchy of outcomes as a tool for implementing health equity into evaluation.

9. Collect data reflecting the social determinants of sexual health evaluation.

<u>Data Collection</u>: Add measures of **ethnicity** and **education level** (in addition to collecting postal code) for all GetChecked evaluation activities. Add **non-binary measures of gender and sexual orientation** to data collection format.

<u>Sampling Strategies</u>: Strategic sampling strategies may be employed in future **focus groups**, **client interviews** and **usability testing** to contextualize understanding and locate meaning of *GetChecked* in unexplored populations. Initial groups to consider should include:

- a. Aboriginal people from various geographical locations across BC (including on and off-reserve)
- b. Non-gay identified men who have sex with men
- c. Heterosexual individuals from clinic client population
- d. Non white/Non Canadian born individuals
- e. Street Youth
- f. Transgendered people
- g. LGBT youth
- h. Rural and Remote populations (including and especially Aboriginal, youth, women, men who have sex with men, LGBT)
- 10. Following scale up and evaluation, further development and refinement of future models of GetChecked targeting specific populations most in need of this service (and still not accessing after provincial scale up) should be considered. This process must involve:

<u>Community based, participatory research:</u> in populations who still experience significant barriers to *GetChecked*, but stand to benefit and need the service. This approach, if done properly can:

- Create awareness, enthusiasm and increased uptake in 'hard to reach' populations
- Provide insight on the relevance and potential for *GetChecked* for each population or geographical area
- Provide grounded, local knowledge to inform targeted program development
- Help determine if and where GetChecked might work in rural parts of BC with heavy HIV and/or STI burden
- Provide additional opportunities to engage and sensitize rural/remote clinicians
 to issues of health equity and sensitive ways to deal with vulnerable
 populations (to minimize impact of negative lab and clinic visits) while also
 encouraging them to use and promote the service to people in their community.

11. Collect accurate and representative data on the sexual health and engagement of transgender and Aboriginal populations in BC

- Given the dearth of research that considers transgendered and Aboriginal sexual health in BC, this is a valuable opportunity to collect relevant data to further contextualize our understanding of the sexual health of array of diverse individuals who fall into these categories in British Columbia.
- This research needs to be done in partnership with representatives and agencies from these populations, in order to ensure appropriate stewardship of the data.

12. Add depth to the online (sexual) health services literature.

- Many researchers are calling for the work to go beyond usability to discover the mechanism by which these interventions are taken up.
- o Identify and build collaborations with other eHealth researchers who are interested or already engaged in equity-focused work with respect to online health services.
- Add theoretical lens to intervention development as well as issues of access and equity to online sexual health program discussion.

SERVICE DEVELOPMENT

- 4. Take advantage of the anonymous aspect of the online service and prioritize the avoidance of common stigmatizing features of the in clinic experience and other traditional sexual health services (e.g. normative and stigmatizing language, images, and discourses).
 - o Avoid language/images that reinforce the 'gendering' of testing services.
 - o Avoid overly sexualizing the service; maintain sex positive language.
 - Avoiding images and language that infer the service is most important for individuals (usually men) with same sex partners.
 - Avoid using only heteronormative, homonormative, cisnormative, or racializing language or images.

5. Avoid language and content, which may be challenging for individuals with lower levels of English or health literacy.

 The online system and testing process should be as simple as possible (prioritizing minimal client input, knowledge and effort for program usage, see Goldman & Lakdawalla, 2005).

- Use minimal text, and maximize non-text based modes of communication and information when possible/appropriate.
- Balance between providing necessary versus too much background information (unnecessary background information may overwhelm users).
- o Pay particular attention to level of English and health literacy needed to use site.
- o Provide links whenever possible to sensitive question/answer platforms and other interactive learning opportunities for users.

6. Expand testing options in future models of GetChecked. For example:

- Add pharyngeal and rectal swabs.
- Add Hepatitis C testing.
- Consider creative options for specimen collection outside of the lab (particularly for rural/urban areas).
- Explore options for electronic ordering and linking the service to mobile technologies (e.g. smart phones and text based services).

SERVICE EXPANSION

- 3. Following scale up, consider developing tailored versions of *GetChecked* to lower the threshold of access to certain groups based on local, community based research. Based on this initial HEIA, recommended groups might include:
 - Rural and Remote (particularly men who have sex with men, Aboriginal peoples, Women, Youth).
 - Men who have sex with men, and gay men who are less connected to gay community.
 - o Aboriginal populations, particularly those living on reserve.
 - o Ethnic minorities and immigrant populations.

4. Build relationships with outreach programs already engaged with populations beyond urban Vancouver.

- Engaging in community partnerships and integrating community feedback has been an integral aspect of developing GetChecked since it's inception. As development shifts toward provincial scale up, community partnerships and insight must extend significantly beyond the urban center.
- o Challenges should be anticipated due to geographical barriers and other factors.

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Appendix I:

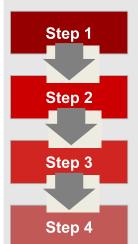




As part of a broader initiative called **BC Online Sexual Health Services** (OSHS), this new program (**GetCheckedBC**) will allow individuals to access testing for sexually transmitted infections (STIs) and HIV through the internet. This program focuses on the integration of online and clinic-based sexual health services to provide more comprehensive services for clients and reduce barriers to accessing testing.

BUILDING ON THE EXPERIENCE OF OTHERS... Internet testing programs for STIs and HIV have been successfully implemented at numerous sites in the US, the Netherlands, and the UK. We are talking to these sites and learning carefully from their experience as we build this service in British Columbia.

HOW IT WORKS



Go to GetCheckedBC

Client enters information and creates an account Completes assessment questions and accesses pre-test resources Tests are recommended

Get tested

Client prints lab requisition form and takes form to a laboratory
Specimens are collected (urine: chlamydia, gonorrhea, blood: HIV, syphilis)

Get results

Client logs into website

Negative results are provided online, positive results by phone or in person

Get treated

Clients who test positive receive referral to clinic for treatment Counseling, follow-up and partner notification is done as per current process

We ultimately expect to support a spectrum of clients, some of whom will only access online testing services, some who will only access in-person clinic services, and many in-between who will rely on both types of service.

why test online? Internet-based testing provides an opportunity to reduce at least some existing barriers to accessing testing—e.g, reluctance or inability to come to a clinic. It is also a way to increase the frequency of testing among those who need to test regularly. From a clinic perspective, internet



testing can reduce the number of people needing to be seen for routine screening and can free up more time to see clients who are symptomatic or who need treatment.

WHEN WILL IT HAPPEN? The first two years of this project are dedicated to planning, consultation, and development. We are currently designing how the testing platform will work, in collaboration with clinicians, community and public health stakeholders, and end users. In the third year (2012), we will pilot and evaluate the internet testing platform at Vancouver STI clinics operated by BCCDC. Following a successful pilot, we will work with the regional health authorities to implement the program at other sites throughout the province (2014).

Contact us. If you have any questions or comments about this initiative, you can email us at OSHSP@bccdc.ca or visit our blog at http://bclovebytes.wordpress.com.

Appendix II: Measuring Health Equity in Evaluation (Signal, 2008)

EVALUATING THE IMPACTS AND OUTCOMES OF THE INTERVENTION

How will you know if health inequities have been reduced?

Evaluating and measuring initiatives – policies, programmes and services – is essential to ensure that they are effective and fair. This will be likely to include evaluation of effectiveness by ethnicity, deprivation, gender, geography and disability. As noted under question one, **this should be planned from the initial development stage.**

Just as the causes of inequalities can be linked in a causal chain, the outcomes of any intervention can be placed in a hierarchy of outcomes that will ultimately connect to, and contribute towards, a reduction in health inequalities. In developing an outcomes hierarchy for your intervention, consider what short-term impacts lay the foundation for the achievement of which long-term outcomes, which, in turn, provide a basis for a reduction in inequalities.

Each outcome will also be linked with one or more indicators that describe the information that needs to be collected to be able to tell whether an outcome has been achieved. For example, your intervention may be about making a primary health-care provider more accessible for people with disabilities, in order to contribute to a reduction in primary impacts around 'access' lead to a long-term outcome of 'better health-care delivery' which, in turn, contributes to a reduction in disparities.

How will you know that the short-term impact of access has been achieved? What will you measure to assess the success of the service in achieving this outcome? These measures or indicators might include, for example, attendance rates and measures of consumer satisfaction. Similarly, the long-term outcome. How will you know that it too has been achieved? You may need to look at patient records for health improvements over the time that they have been attending the clinic.

The aim of evaluation is to gather evidence to be able to confidently attribute changes to a planned intervention.

MEASURING INTERVENTION OUTCOMES:

Think about the short-term impacts that you are expecting to see as a result of your intervention. How will you know that these impacts have been achieved? What measures of success will you use?

When these short-term impacts are achieved, what are the long-term outcomes that you would then want to see? How will you know that these outcomes have been achieved? What measures of success will you use?

How will you monitor whether health inequalities have been reduced? Record your answers in the template below.

How will you know if inequalities have been reduced?		
Outcomes Hierarchy	Outcomes	Measuring Outcomes
What is the outcome hierarchy proposed for your intervention?	What are the outcomes that you want your Intervention to achieve?	How will you measure whether these outcomes have been achieved?
Short Term Impacts		
Long Term Impacts		
Health Equity Outcomes		