

The “Chick Shot”: Negotiating Gendered Responsibility and Risk through Young Women’s Decisions
about HPV Vaccination

by

Jennafer Marie Roberts
B.A., University of Victoria, 2009
A.A., Camosun College, 2005

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of the Requirements for the Degree of

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Supervisory Committee

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Abstract

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This thesis explores: (1) how young women make decisions about Human Papillomavirus (HPV) vaccination and (2) how they negotiate and evaluate public health discourses that work to promote a responsible female subjectivity to manage the risks of HPV. Public health professionals have promoted HPV vaccination as a responsible and informed choice for young women, whose sexual practices are considered to put them and their sexual partners “at risk” of HPV. I conducted semi-structured interviews with thirteen young women between the ages of 21 and 28. My interviews with women and the public health literature on HPV vaccination reflect cultural and moral priorities regarding the “right” kinds of female sexuality and individual responsibility to manage sexual and reproductive health risks. Many of the women I interviewed were critical of the identification of their sexual practices as putting them and other “at risk” of HPV and maintained that their “safe” sex practices mitigated these risks. All of the women I interviewed prioritized concerns about protecting their reproductive health from cervical cancer over the risks of HPV when discussing their responsibility to be vaccinated. Based on these interviews, I argue that women’s decisions about HPV vaccination are practices of self-making, through which they strive to enact identities as responsible young women, who endeavour to protect themselves, their bodies and health from harm. These decisions are complex, dynamic and reflect their ability to make competent, informed decisions that are inextricably bound to their social and material circumstances.

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Chapter One: Introduction

1.1 Research Topic and Background

Human papillomavirus (HPV) vaccines were first made available to school-age girls and young women in Canada and the U.S. in 2006 and in the UK in 2007. Currently, there are two HPV vaccines available to Canadian consumers: Gardasil® and Cervarix™. Cervarix™ is manufactured and marketed by GlaxoSmithKline and is available only to girls and young women between the ages of ten and twenty-five (GlaxoSmithKline, Inc. 2010). Gardasil® is manufactured and marketed by Merck & Co., Inc. and is available for girls and young women and boys and young men between the ages of nine and twenty-six (Merck & Co., Inc. 2010; Merck Frosst 2009). HPV is a sexually transmitted infection (STI) that is transmitted via skin-to-skin contact and is the most prevalent STI in Canada; approximately 75% of Canadians are likely to have at least one HPV infection in their lifetimes (SOGC 2007a). There are over one hundred known types (also known as strains) of HPV and some of the strains have been associated with different types of genital cancers, including penile, anal, vulvular and cervical cancer (Braun & Phoun 2010). Gardasil® prevents against four “high risk” types of HPV, types 6 and 11, which are associated with genital warts and types 16 and 18, which are associated with cervical cancer¹ (Merck & Co., Inc 2010). Currently, in Canada there is no treatment for HPV, only for the secondary illnesses (*i.e.*, genital warts and cervical cancer). Furthermore, while testing for the virus exists, it is recommended only for women over thirty because most HPV strains are likely to clear up on their own

¹ It is interesting to note that clinical trials for Gardasil® determined the efficacy of the vaccine to prevent precancerous lesions in the cervix, not cervical cancer, which would have required longer and more costly clinical trials (Fisher & Ronald 2010). Fisher and Ronald (2010) argue that healthy women are capable of fighting off not only infection with HPV, but precancerous lesions as well. Moreover, some researchers also argue that other risk factors, like repeated exposure to strains of HPV, co-infection with other STIs and even smoking, are implicated in the development of cervical cancer (see Wailoo *et al.* 2010).

(SOGC 2007b).

Since Health Canada's authorization of the distribution and consumption of Gardasil® in 2006, the Society of Obstetricians and Gynaecologists of Canada (SOGC) has been a major promoter of the vaccine. The SOGC was provided with a 1.5 million dollar grant by Merck Frosst, the Canadian subsidiary of Merck Co. & Inc to develop a public awareness campaign titled "Spread the Word, Not the Disease" (Connell & Hunt 2010). This campaign has been particularly conspicuous in informing Canadians about the risks of contracting and spreading HPV and the need for vaccination against it (SOGC 2009a; Connell & Hunt 2010). The funding has been used by the SOGC to develop and promote a website, HPVinfo.ca, which serves as the "centrepiece of the public awareness campaign" (SOGC 2009b).

Through the "Spread the Word, Not the Disease" campaign, the SOGC provides "neutral" information to individuals to educate them about the risks of HPV and the benefits of vaccination. This information is expected to enable individuals (namely women) to make free and informed choices regarding vaccination. However, the SOGC's assumption that individuals have the freedom to choose whether or not to be vaccinated based upon "neutral" medical information is complicated for a number of reasons. First, the SOGC's public awareness campaign is funded by the pharmaceutical company that manufactures and markets Gardasil®. Second, while individuals have the freedom to choose whether or not to be vaccinated, the vaccine is only available through health professionals and those health professionals, including the SOGC, promote HPV vaccination as the correct, informed decision (see Tissot *et al.* 2007; Duval *et al.* 2007). Third, SOGC's public awareness campaign relies on broader cultural notions of health, risk and responsibility. Through cultural notions of individual responsibility, targeted "at risk" persons are expected to make decisions regarding their reproductive and sexual health that comply with sanctioned medical knowledge and practice. Furthermore, the

assumption that individuals have the freedom to choose to be vaccinated against HPV is predicated on the expectation that decisions about vaccination can or should be made regardless of potential social and economic barriers, such as cost. In Canada, HPV vaccination is voluntary and costs approximately \$400-500. Currently, the B.C. provincial government covers the cost of vaccination for girls in grades six and nine. Undergirding provincial coverage of the vaccine for girls is the presumption that the vaccine is essential and appears to be safe. However, the provincial government is not covering this cost for young women outside of the public school system who may want to be vaccinated (SOGC 2009e; HealthLinkBC 2009).

1.2 Research Objectives and Significance

The central issue I am investigating in this thesis is if and how young women may be negotiating public health discourses that attempt to compel women to behave in medically sanctioned ways. To explore this issue, my research investigates two particular questions: (1) How are young women deciding whether or not to be vaccinated?; (2) How and to what extent are young women engaging with public health discourses that work to promote a particular “responsible” female subjectivity to regulate the risks of HPV? I utilize Gurevich *et al.*'s (2007) notion of “discourse” as not only referring to language, but also to regulated social practice. Thus, “discourses are fundamentally productive of realities (e.g. objects, social institutions, individual subjectivities and ‘subjects’) and they...constitute objects, subjects, bodies, and individual and social identities” (Gurevich *et al.* 2007: 16). In the context of HPV vaccination, public health discourses provide a framework through which women may be thinking about and acting in relation to normative cultural conceptualizations of female reproductive and sexual health, risk, and responsibility. In discussing public health discourses and literature, I draw upon Lupton's (1995: 10) definition of “public health” as a “network of expert advice,

embodied in professionals such as doctors and health promoters, who have dispensed wisdom directed at improving individuals' health through self-regulation." Lupton also recognizes that, as both practice and discourse, public health is implicated in the production and promotion of certain subjects, bodies and rationalities while excluding others (1995: 5).

Currently, there is very little published qualitative research on young women's decisions about HPV vaccination (see Genus 2011). Public health and medical literature regarding the vaccine centres on increasing women's compliance with vaccination uptake. Qualitative studies that assess how people negotiate public health strategies of risk prevention have demonstrated that people may resist or feel responsible to enact these strategies in the context of their sexual and reproductive health. I draw upon the notion of "responsibility" as my central conceptual tool for examining how public health discourses of "risk" and "health" are connected to how women negotiate decisions around vaccination. In this research, I employed semi-structured interviews with young women to investigate how "responsibility," "risk," and "health" may be articulated through their decisions about HPV vaccination.

This qualitative research was conducted in Victoria, B.C. with 13 young women between the ages of 21 and 28. My research contributes to social theory regarding how notions of individual responsibility are used to compel women to enact health maintenance and risk prevention strategies. This project makes a distinctive contribution to social theory by problematizing individualistic conceptions of responsibility. I do this in two ways: (1) by exploring how public health discourses may be reproducing particularly gendered expectations regarding women's responsibility to choose to comply with medical expertise to manage reproductive and sexual health; (2) by exploring if and how young women are negotiating public health discourses about HPV vaccination.

By problematizing individualistic conceptions of responsibility, I argue that "choice" to be

vaccinated against HPV may not reflect compliance with medically sanctioned recommendations. Rather, women negotiate medical knowledges and practices in complex, dynamic ways through the context of their daily lives and in ways that are meaningful to them. Through public health awareness campaigns like the SOGC's "Spread the Word, Not the Disease" campaign, the decision to be vaccinated against HPV is presented as a de-socialized process based on an individual's access to "neutral" medical information. I argue that for some young women, deciding whether or not to be vaccinated against HPV is not based solely on access to "neutral," medically sanctioned information about the risks of HPV and benefits of vaccination. Rather, young women's decisions about HPV vaccination are diverse and negotiated in ways that make sense to them in the context of their lives, including their relationships with others, access to financial resources and existing concerns related to their reproductive and sexual health.

This research contributes to an awareness of social issues regarding power dynamics as they are reflected in women's reproductive and sexual health. How young women conceptualize their health cannot be addressed without considering the authoritative role of public health discourses and medical knowledge and practice in determining what constitutes "good" health and "good" health maintenance strategies. This research project reflects my own concerns regarding HPV vaccination and my desire to recognize women's reproductive and sexual health as not only a biological issue, but as one that is political, social, and economic as well. The HPV vaccine is manufactured and marketed by a pharmaceutical company that has likely benefited considerably by the federal government's recommendation that a substantial portion of Canadian females be vaccinated (see Connell & Hunt 2010). Both Merck Frosst and the SOGC may be implicated in shaping the possibilities for how young women may be thinking about their reproductive and sexual health.

Currently, no research has explored how young women make decisions about HPV vaccination

through public health discourses about the vaccine; nor has any research investigated how young women's conceptualizations of responsibility, risk, and health may align or be at odds with public health discourses about the vaccine. Conducting interviews with young women targeted by public health discourses about HPV vaccination provides a space in which to redress the assumption that with the "right" kind of information, women will seek vaccination against HPV. Through my research, I endeavour to contribute a more complex understanding of how women negotiate decisions about HPV vaccination that are both aligned and at odds with public health discourses which attempt to compel women to behave in particular ways.

1.3 Literature Review

My thesis engages with three bodies of literature: (1) public health and medical literature exploring adult men and women's knowledge of the HPV vaccine to increase vaccination compliance in North America, the UK, and Denmark; (2) social scientific literature that investigates the politics of public health discourses and how such discourses mobilize culturally contingent notions of health, risk, and responsibility to incite women to be vaccinated; (3) qualitative, interview-based research that examines men and women's conceptualizations of their sexual and reproductive health in the context of their experiences, relationships with others and broader discourses that shape these experiences and relationships. Existing social scientific research has addressed the moral, political, and medical discourses embedded in Canadian and U.S. HPV vaccination campaigns (Casper & Carpenter 2008; and Connell & Hunt 2010). Yet, few qualitative anthropological or social scientific studies have been conducted on the ways in which women think about and consume the vaccine as a technology entrenched in these discourses.

I have found two qualitative anthropological studies of women's knowledge and decisions about HPV vaccination. One study was conducted in Vancouver, British Columbia by an anthropology

Masters candidate (Genus 2011). Genus' MA thesis research explores some of the ways young women and men make sense of the vaccine by drawing upon pervasive cultural and moral meanings about sexuality, gender and risk. The other was conducted in Denmark by a consultant anthropologist (Mortensen 2010). Mortensen received funding for this study from Sanofi Pasteur MSD, a European company specializing in vaccines and founded as a joint venture between an HPV vaccine manufacturer, Merck & Co., Inc and Sanofi Pasteur, the largest company in the world devoted to vaccines (Sanofi Pasteur MSD 2005; Sanofi Pasteur 2009). Not coincidentally, her research assesses women's knowledge of HPV and HPV vaccination to increase vaccination uptake.

1.3.1 Public Health and Medical Literature on HPV Vaccination

Medical and public health researchers, including cancer prevention and control researchers, pathologists, immunologists, and paediatricians, have sought to identify and correct "false", non-medical, or inaccurate medical information about the HPV vaccine presented by media (Forster *et al.* 2010; Kelly *et al.* 2009; Keelan *et al.* 2010; Abdelmutti & Hoffman-Goetz 2009). Research by these scientists has also been aimed at "correcting" women's and men's knowledge of HPV and associated health risks, including genital warts in men and women and cervical cancer in women (Kahn *et al.* 2003, Kahn *et al.* 2008; Ingledue *et al.* 2004; Hopenhayn *et al.* 2007; Gerend & Magloire 2008; Baer *et al.* 2000; Allen *et al.* 2009; Caron *et al.* 2009; Mortensen 2010; Stark *et al.* 2008; Tiro *et al.* 2007; Gerend & Sheperd 2011). Both bodies of literature are invested in increasing women's compliance with vaccination campaigns. Medical and health researchers' analyses of media and public discourses about HPV and its vaccines have highlighted the importance of how these discourses are implicated in women's conceptualizations of the vaccine and their negotiation of decisions to be vaccinated. Through both content analysis of news articles and surveys of individuals' knowledge of HPV, Kelly *et al.* (2009) trace the increase in public awareness and knowledge and media coverage of HPV to the U.S.

Food and Drug Administration's (FDA) approval of the HPV vaccine. In an analysis of both Canadian and U.S. newspaper articles, Abdelmutti & Hoffman-Goetz (2009) describe the media's implication in the reproduction and circulation of "fright factors" embedded in discourses about HPV vaccination. Through focusing on the positive or negative valence or tone of the stories about the vaccine, they measured the number and type of "fright factors" in news stories (Abdelmutti & Hoffman-Goetz 2009). Their analysis suggests that Canadian newspapers discussed the HPV vaccine as poorly understood by science and reflected on both the risks and benefits of the vaccine, while U.S. newspapers centred more on debates regarding mandatory vaccination for school-age girls (Abdelmutti & Hoffman-Goetz 2009). Similarly, in the UK, in a content analysis of ninety-two articles from daily and Sunday papers, Forster *et al.* (2010) suggest that concern over the possibility of increased sexual behavior in adolescents after they receive the vaccine can be linked to the UK government announcing its plans for voluntary immunization of girls through a school-based program.

Medical and public health researchers' studies of women's knowledge of the vaccine have emphasized the need to correct "inaccurate" knowledge and increase compliance with vaccination initiatives. Multiple researchers used the Health Belief Model, which examines the relationship between people's health-related beliefs and behaviours, to analyze women's knowledge and activities regarding the vaccine (Ingledue *et al.* 2004; Allen *et al.* 2009). Such a model is premised on the idea that individuals will rationally weigh the benefits and risks of particular medical practices and treatments and resulting actions will lead to the "reasonable" and "logical" decisions to comply with medical recommendations (Ingledue *et al.* 2004; and Stark *et al.* 2008). In the context of HPV vaccination, the Health Belief Model was utilized to determine men and women's ideas and concerns about the vaccine to correct erroneous assumptions and to increase vaccination compliance. In Kahn *et al.* 2003 and Kahn *et al.* 2008, surveys of women's knowledge about HPV and the vaccine were

analyzed through the assumption that vaccination will occur through the “intention to perform the behavior and belief in one’s capacity (self-efficacy) to perform the behavior” (Kahn *et al.* 2003: 1104). Surveys of U.S. college women’s knowledge of HPV and vaccination emphasized the increased prevalence of HPV and its sequelae on college campuses and the need for more accurate knowledge through increased availability of medical knowledge (Gerend & Magloire 2008; Baer *et al.* 2000; Allen *et al.* 2009; Caron *et al.* 2009; Tiro *et al.* 2007; Hopenhayn *et al.* 2007; Hopfer & Clippard 2011; and Gerend & Sheperd 2011). Research that did acknowledge the diverse ways women access information about HPV, like online blogs and speaking with family and friends, suggested that these avenues be utilized to intervene in and correct how women are thinking about the viruses and vaccines (Mortensen 2010; and Keelan *et al.* 2010). For example, Mortensen’s (2010) study with young women aged 16-26 in Denmark suggests that young women’s mothers are crucial in influencing the decisions young women make regarding vaccination.

Medical and public health scholars do not address how women might understand and consume the vaccine in ways that are not limited by the medical risk-benefit analysis or by the assumption that individuals are rational, autonomous actors, whose actions will inevitably comply with medical expertise. Rather, such literature reproduces a deeply medical and privileged idea that individuals can and should choose to comply with sanctioned health maintenance strategies regardless of the material and social circumstances in which they live. Research indicating differential understandings of HPV and vaccination tended to be dismissed as erroneous. In some instances, these understandings were described as conspiratorial and, as such, implicitly considered a sign of pathology. Friedman & Sheperd’s (2007) focus groups with 314 men and women in the U.S. highlight this point. Fears raised by some African American focus group participants about the U.S. government potentially withholding information about the vaccine were deemed “government conspiracy” theories (Friedman &

Shepard 2007). Such disregard for the range of possible discourses through which men and women think about and negotiate vaccination decisions reproduces the legitimization of medical knowledge as accurate, logical, and objective while polarizing and denigrating women and men's knowledge as illogical and subjective. Such knowledge is, therefore, conceptualized via public health literature as "inaccurate" and an impediment to vaccination compliance.

The central limitation of the articles outlining the need for vaccination compliance is the assumption that if women only had the "right" kind of information, particularly medically sanctioned information, they would inevitably seek out the vaccine. Left unstated is the possibility that even after considering medical information about the risks of HPV and the benefits of HPV vaccination some women may "choose" not to be vaccinated. Furthermore, there is no discussion of the "choice" not to be vaccinated as a reasonable and legitimate decision for young women. While some of the researchers acknowledged some of the barriers to vaccination, such as the cost of the vaccine, medical models for determining why women do and don't "choose" to be vaccinated tend to reproduce problematic assumptions of individual responsibility and choice to make rational decisions that comply with medical expertise and recommendations (see Allen *et al.* 2009; and Kahn *et al.* 2003), suggesting that with the correct information, women will want to be vaccinated regardless of "perceived" barriers. Absent from the medical and health literature are discussions of how public health discourses are not value free, but embedded in socially and culturally contingent ideas about risk, responsibility, and health. Public health conceptions of individual responsibility over the maintenance of reproductive and sexual health are implicated in extending the authority of medical knowledge and practice. By determining what constitutes a "responsible individual" and mobilizing this category to incite women to behave in medically sanctioned ways, public health discourses reproduce particular hierarchies of knowledge, privileging medical expertise.

1.3.2 Social Scientific Literature on the Politics of Public Health Discourses

Where medical and public health researchers emphasize the ways in which the media can be mobilized as a vehicle for educating the public on the necessity of the vaccine, nascent social scientific literature highlights the importance of considering the politics of public health discourses. Unlike the medical and public researchers, Connell & Hunt (2010) and Casper & Carpenter (2008) do not suggest that controversies around the HPV vaccination may constrain vaccination uptake. Rather, they outline the vaccine's connection to notions of responsibility, morality, health, and risk. Casper & Carpenter argue that "because the HPV vaccine's target is *sexually* transmitted, it provokes longstanding controversies swirling around sex, gender, and women's bodies in the U.S." (2008: 896). Moral anxieties in the U.S. over young women's sexuality as both vulnerable and in need of control by medical professionals, parents, public health educators, and young women themselves are reflected in public discussions about the HPV vaccine. Casper & Carpenter (2008) suggest that Merck has attempted to promote vaccination by deflecting attention away from tensions about female sexuality and by framing HPV vaccination in terms of the link between HPV and risk of developing cervical cancer. However, Connell & Hunt (2010) assert that, while the HPV vaccine has been marketed as a vaccine against cancer, female sexuality is integral to marketing because girls and young women are targeted as consumers of the vaccine in public health awareness campaigns. They demonstrate that the marketing of the HPV vaccine as a technology of cervical cancer prevention has provided a powerful motive for compliance because it serves as a "risk management strategy," which aims to control the (uncertain) future of girls' and young women's sexual and reproductive health (Connell & Hunt 2010: 67). The responsibility of women to have themselves and their daughters vaccinated is implicit and central to the marketing of the HPV vaccine as a technology of risk prevention. Existing medical and public health analyses emphasize the power of public representations of the vaccine and the need to

control these representations to increase HPV vaccination uptake. These analyses centre on the need to understand how women engage with public discussions about HPV vaccination to increase vaccination uptake. My research assesses: (1) How public health discourses about HPV vaccination mobilize a culturally contingent, gendered notion of responsibility, health, and risk to incite women to be vaccinated; (2) If and to what extent these concepts are negotiated by women as they make decisions about the HPV vaccine.

1.3.3. Qualitative Research on Reproductive and Sexual Health

While I am aware of several anthropological studies of various aspects of the HPV vaccine that are in progress, currently there very little published qualitative interview-based research available on HPV and the HPV vaccine. In this section, I discuss one anthropological study on women's decisions about HPV vaccination and qualitative research about women's experiences of STI, breast, and cervical cancer screening to consider how young women may be thinking about and experiencing risk in the context of their sexual and reproductive health.

Genus (2011) conducted MA thesis research in Vancouver, B.C. on young women's decisions about HPV vaccination. Genus' thesis explores participants' experiences and understandings of gendered risk, as well as their perspectives on a print advertisement targeting women for vaccination with Gardasil®. HPV vaccination is framed, via pharmaceutical marketing, as an individual choice and a form of empowerment for young women, who can choose to prevent cervical cancer. Genus draws upon social theorizations of risk and governmentality to argue that Gardasil® is a technology implicated in historical processes whereby women are socialized to manage their "at risk" and prediseased bodies (Genus 2011). Moreover, she argues that discourses of risk are implicated in how women conceptualize their bodies as vulnerable and their sexual practices as "safe". Genus (2011) found that risk discourses and women's social relationships with family, medical practitioners and

peers primarily influenced their decisions about vaccination. Yet, *Genus* does not explore how young women engage with and negotiate public health discourses about HPV and the vaccine. *Genus* does not investigate how notions of “individual choice” and responsibility to be vaccinated are bound to considerations of young women’s ability to purchase the vaccine and how that may be implicated in their decisions about whether or not to be vaccinated.

Qualitative research on screening technologies demonstrates that women’s perceptions and experiences of risk are inseparable from public health discourses. Indeed, several qualitative interview-based studies have explored the ways in which young women’s sexual and reproductive health are conceptualized via public discourse as “risky” and, as such, require regulation through medical surveillance and intervention. This research has demonstrated how medical conceptions of risk have legitimized practices of surveillance and intervention and how women experience and actively renegotiate such practices in ways that are meaningful to them (Duncan *et al.* 2001; Oster & Cheek 2008; Pliskin 1997). Screening technologies have been particularly important in strategies of risk prevention. In the context of government sponsored preventative health initiatives, STI screening has been utilized as a means to monitor young women and men’s sexual health and practices (Duncan *et al.* 2001; Oster & Cheek 2008; Pliskin 1997).

Duncan *et al.* (2001) conducted research on women’s experiences with a positive diagnosis of Chlamydia through two clinics in Glasgow. Their research suggests that a proposed national STI screening program may conflict with young women’s conceptualizations of risk and responsible behaviour. In their study, young women diagnosed with Chlamydia actively renegotiated medical conceptualizations of risk which potentially threatened their sense of self and identity as morally and physically unpolluted “good girls” (Duncan *et al.* 2001). While medical practitioners at the clinics outlined the biological risks of contracting and spreading the disease, necessary treatment, and the

moral responsibility to disclose infection to sexual partners, women with Chlamydia reframed risks within the context of their relationships to others (Duncan *et al.* 2001). The moral responsibility of women to disclose their diagnosis to potential sexual partners to avoid the risk of spreading the disease was reframed by women as a risk in itself, which threatened their identity as appealing sexually to their partners (Duncan *et al.* 2001). While Duncan *et al.* outline the ways that young women renegotiated the risk of positive diagnosis of Clamydia in the context of relationships with others, they do not address how young women may have accepted medical recommendations. Rather, Duncan *et al.* reproduce the problematic binary between “expert” and “lay” knowledges and assume that medical knowledge and recommendations are at odds with women’s expectations and experiences.

Oster & Cheek (2008) found that Australian men and women diagnosed with genital herpes negotiated medical discourses of regulation and surveillance through the regulation of the “risky self”. They argue that, “while people with genital herpes are ostensibly free to make any choice with regard to their behaviour, choosing the wrong (i.e. non-‘safe’) option renders them susceptible to...the moral proscription of ‘irresponsible sexuality’” (Oster & Cheek 2008: 220). Individuals’ regulation of their “risky selves” manifested in disclosure and condom use with sexual partners. Similar to Duncan *et al.*’s research findings, research participants in Oster & Cheek’s (2008) and Pliskin’s (1997) study resisted medical discourses of risk and responsibility to disclose their diagnosis by prioritizing concerns with the maintenance of a sexually desirable identity over disclosure, which risked stigmatization by potential sexual partners. Yet, Oster & Cheek and Pliskin do not discuss how men and women with a positive STI diagnoses may differentially experience and negotiate expectations around the responsibility to submit themselves to STI screening, manage the risk of spreading infection, and/or disclose positive diagnosis to sexual partners.

Similar to STI prevention programs, cervical and breast cancer screening initiatives have

mobilized the concept of risk as a form of regulatory practice, incorporating women into healthcare strategies of risk reduction and avoidance. Women are expected to be active and responsible participants, willing to submit themselves to screening (Howson 1998 & 1999; Robertson 2000). Choosing not to participate may be regarded as a moral failure or irrational response of women to act responsibly by choosing to maintain their health through risk avoidance (Howson 1998). In this regard, medical and health care specialists, including gynaecologists and general practitioners, may expect women to comply with cervical cancer screening because it is in their “best interests” (Howson 1999). Howson’s (1999) interviews with 23 women, aged 21-62, in Britain suggests that women do not passively submit themselves to regulatory practices, such as cervical cancer screening, but actively take up the task of health maintenance through strategies of risk prevention. Howson’s participants framed their participation in cervical cancer screening as a routine and normal part of being a woman. Compliance was conceptualized by her research participants as a responsibility and obligation toward oneself and as a rational course of action in maintaining their health (Howson 1999). In the context of breast cancer screening, nearly all the women Robertson (2000) interviewed in her Canadian study discussed the individual responsibility that they and all women had to reduce their risks for breast cancer. While not engaging directly with sanctioned public health discourses regarding breast cancer, she suggests that her research participants’ conceptualization of individual responsibility in risk avoidance is representative of a particular “at-risk” consciousness or sense of identity. Moreover, Robertson (2000) argues that this “at-risk” consciousness is amenable to forms of self-surveillance and management integral to medical discourses of health risk.

Official discourses around preventative health strategies, like cancer screening and HPV vaccination, encourage particular knowledges and practices regarding individual responsibility in ensuring health maintenance. The development of this normative sense of responsibility manifests as

an obligation to behave in morally acceptable ways to minimize risks (Bickerstaff *et al.* 2008). As demonstrated by this qualitative literature, women are obliged to choose to submit themselves to medical surveillance and intervention. Yet, this qualitative research on risk and screening technologies demonstrates that women do not passively or uncritically accept medical discourses of risk and responsibility. Rather, they negotiate medical conceptualizations of risk and health in ways that are meaningful to them in the context of their daily lives and relationships with others. This research suggests that, like women's negotiation of screening technologies, women's conceptualizations of risks in the context of HPV vaccination may align or be at odds with sanctioned public health discourse. In the research by Duncan *et al.*, women diagnosed with Chlamydia eschewed medical recommendations of risk management because they threatened women's sense of self as sexually appealing. Their study suggests that women's conceptualizations of risk and responsibility may contradict sanctioned discourses if they disrupt or threaten women's sense of identity. Alternatively, research by Robertson (2000 & 2001) and Howson (1998 & 1999) demonstrate how women actively take up discourses of risk and responsibility as a routinized and normalized part of being a healthy woman.

Like women diagnosed with genital herpes, who are expected to disclose their diagnosis to their sexual partners, discourses about HPV vaccination suggest that it is women who should be responsible for preventing the spread of disease and the harm it may cause to oneself and to others. Such discourses of responsibility evoke Oster & Cheek's notion of the "risky" self. The HPV vaccine is presented through public health discourses as the appropriate medical technology for regulating the "risky" self, which "presents as a risk to others in that, as a contagious body, it is capable of putting others at risk" (Oster & Cheek 2008: 221). Discourses of the "risky" self require individuals to act responsibly in ways that are publicly and medically sanctioned. To be considered a responsible individual requires certain medically proscribed practices of health maintenance. The research investigating women's

experiences of screening programs suggest that medical technologies of risk prevention can be constraining or empowering for women depending on their particular expectations, experiences, and life circumstances. Like these screening technologies, the HPV vaccine can be conceptualized as a medical technology of risk prevention and is presented as a means of facilitating reproductive and sexual health maintenance strategies sanctioned by public health and medical professionals. The expectation of young women, in particular, to take responsibility for their and their potential sexual partners' sexual and reproductive health manifests in the SOGC's (2009a) HPV vaccination awareness campaign, which incites potential consumers to "Spread the Word, Not the Disease". Similarly, Merck Frosst's (2009) Gardasil® website tells users that they should do "everything [they] can" to protect themselves against HPV and associated illnesses. The SOGC and Merck Frosst's public education campaigns both suggest that women's strategies of health maintenance and risk prevention are best achieved with technological solutions. While the SOGC's slogan suggests to women that they are obliged to protect others from harm and Merck Frosst's slogan indicates to women that they should protect themselves from harm, both messages reproduce gendered notions of responsibility by inciting women to behave in medically sanctioned ways.

While there appear to be similarities in public health discourses about screening and HPV vaccination, it is not clear if young women conceptualize the vaccine in ways comparable to the routinized screening technologies discussed above. The HPV vaccine and its public health discourses are distinctive in important ways. The vaccine is implicated in the SOGC's broad construction of an at-risk group of Canadian women not previously encompassed by routine STI screening. The SOGC recommends that routine STI screening in Canada be reserved for a specific group exhibiting "high risk behaviours that contribute significantly to the presence of STIs: 1. commercial sex workers and their clients, 2. street youth, 3. injection drug users, 4. inner city poor" because of the "prohibitive costs of

screening the general population” (SOGC 2009f). Unlike cervical and breast cancer and STI screening for Chlamydia and genital herpes, responsibility over the maintenance of reproductive and sexual health in the context of HPV vaccination is enacted through young women’s consumer choice to be vaccinated. Since vaccination is not paid for under provincial healthcare coverage for women outside of the public school system, young women between the ages of 19 and 26 are expected to pay for the vaccine. While discourses of young women’s responsibility to maintain reproductive and sexual health through risk prevention are similar in both HPV vaccination and STI and breast and cervical cancer screening, discourses differ when considering that screening is federally funded and the HPV vaccine must be purchased by individuals. Because the vaccine is embedded in culturally recognized notions of individual responsibility, health, and risk, it is marketed as a technology that facilitates control over an uncertain and potentially dangerous future.

The research on screening technologies suggests that such technologies carry unanticipated forms of uncertainty for men and women, particularly in regard to how they negotiate positive diagnosis and the social and biological entailments of such diagnoses. However, the HPV vaccine differs from screening technologies notably because it is presented via public health discourse as a technology that offers consumers a form of control that screening does not. As demonstrated in interviews with women diagnosed with STIs, screening potentially creates new social risks associated with diagnosis of infection. While screening generates uncertainty and the potential disruption of a desirable social and sexual identity, vaccination could be conceptualized by women as a technology that circumvents or eliminates those risks. It is unclear how this element of public health discourses about the HPV vaccine may be implicated in women’s decisions about vaccination.

While regular cervical cancer screening via Pap smears are still recommended for young women who choose to be vaccinated against HPV, the vaccine is promoted via sanctioned public health

discourses as the “best” (and only) technological solution to preventing HPV and secondary illnesses. The SOGC attempts to compel women to be vaccinated because the virus is described as highly infectious and, as a result, “total prevention of the HPV virus is not easy” (SOGC 2009g). The SOGC specifies that the vaccine is a “100% effective” means of risk prevention for women targeted as “high risk” for contracting the four types of HPV associated with genital warts and cervical cancer (SOGC 2009d). Women are classified as “high risk” if they exhibit sexual behaviours that contravene those deemed appropriate by public health professionals, namely abstinence, limiting sexual partners, or lifelong monogamy (SOGC 2009g). Such a broad “at-risk” group likely targets a large population of young Canadian women, who are not abstinent, in lifelong, monogamous relationships, and have not had “limited” sexual partners.

The SOGC’s representation of abstinence, limited sexual partners, and lifelong monogamy as “low-risk” behaviours carry an assumption of morally responsible sexual behaviour. This discourse suggests to women that if they choose not to behave sexually in ways that are morally acceptable, then, as women at “high risk” of contracting HPV, it is their responsibility to obviate spreading HPV to their sexual partners by choosing to be vaccinated. This sentiment is further amplified when women are expected to consider that HPV can be spread to sexual partners without any manifestation of symptoms (SOGC 2009h). In public health discourses that construct a large population of young Canadian women as “high risk” for HPV, vaccination against the virus signifies a morally responsible choice for women to protect themselves and existing or future sexual partners.

My research builds upon qualitative literature regarding women’s negotiations and experiences of public discourses of sexual and reproductive risk, health and responsibility. Yet, there are a number of questions about HPV vaccination that remain unanswered by the reviewed medical and social scientific literature about how young women may be engaging with public health discourses instructing

them to make “good” decisions about sexual and reproductive health maintenance strategies: Do young women consider the vaccine as a technology that presents an element of control over sexual health risks and an uncertain future? How is the vaccine implicated in sexual relationships? Do women think that the vaccine is for certain sexual practices and relationships and not others? Is vaccination a decision negotiated with sexual partners? Do women feel an obligation to be vaccinated? Do women conceptualize the vaccine as a routine part of being sexually active and responsible?

Arguably, HPV vaccination could be implicated in the expansion of an “at-risk” group of women not previously targeted for STI screening programs because of limited federal and provincial funding. It is unclear, however, if and how young women experience or negotiate this “at-risk” designation and medical expectations of them to behave responsibly by complying with medical expertise. Further, it is unclear how this expectation is mediated within the context of women having to purchase the vaccine. My research explores: (1) how young women conceptualize responsibility, risk, and health in the context of reproductive and sexual health; (2) how their notions of responsibility, risk, and health may align or be at odds with public health discourses of HPV that adopt moral ideals about “responsible” sexual behaviour and risk prevention to incite women to behave responsibly.

1.4 Conceptual Framework

In this section, I highlight the ways in which responsibility has been theorized as central to public health discourses of “health” and “risk” and discuss how I use these concepts in examining women’s decisions around HPV vaccination. In public health and medical discourses about HPV vaccination, such as those found on the HPVinfo website, responsibility is conceptualized as a form of self-management, in which it is a right and duty of individuals to “maintain, contribute to and ensure their health status” (Nettleton 1997: 208). In their theorizations of responsibility, social scientists, particularly sociologists, have critiqued the ways responsibility operates not only as a form of self-

management, but as an obligation or duty toward others, particularly through strategies of risk prevention (*i.e.*, preventing the spread of STIs to sexual partners) (Gurevich *et al.* 2007; Oster & Cheek 2008). Social scientists have also argued that responsibility serves as a form of moral obligation, motivating individuals to enact strategies of self-transformation, -knowledge, and -improvement that are aligned with official public health goals (Lupton 1999; Jardine 2004). Related to concerns of self-transformation, responsibility has been theorized as a form of empowerment, whereby active individuals seek out medical resources to enhance their health and express their self-sufficiency or autonomy (Stokes 2008; Peterson 2003). Social scientists have demonstrated how expressions of responsibility through self-sufficiency have been utilized as a measure of an individual's competence (Lindbladh *et al.* 1998; Katainen 2006; Borovoy & Hine 2008). In medical and public health discourses, competence is narrowly determined by individuals' ability to minimize their contribution to health care costs by becoming independent health care consumers and by their ability to comply with sanctioned expert medical knowledge to minimize health risks (Peterson 2003; Robertson 2001 & 2000). Public health conceptualizations of competence suggest that individuals can choose to make responsible choices and, thus, achieve "good" health, regardless of broader social contexts, including individuals' life circumstances and experiences.

However, anthropological research has demonstrated that the concept of responsibility is negotiated within historical, political, economic, and cultural contexts that shape its meaning (Borovoy & Hine 2008; Gammeltoft 2007; Garro 1995; Donahue & McGuire 1995; Lock 1998). Gammeltoft's (2007) ethnographic research on Vietnamese women's struggles with decisions about abortion amidst uncertain diagnoses of fetal impairment demonstrates that the responsibility to make decisions is connected to duties toward the nation-state and family. In her research, responsibility is demonstrated not through a sense of individual moral standards or autonomy, but through a sense of social

responsibility, “as members of families toward which they have duties and as citizens of a nation-state to which they owe respect and commitment” (Gammeltoft 2007: 160). In contrast, sanctioned public health discourses construct “responsible” individuals as desiring the ability to make autonomous decisions regarding health maintenance. The “autonomous, responsible individual” appears to operate as a category independent of particular cultural, economic, political, and historical contexts. The idealized “responsible individual” is conceptualized through public health discourses as an abstract, rational decision-maker, unencumbered by social, economic, and political constraints that may limit the ability to acquire medical resources to maintain health and prevent risks (Peterson 2003; Burchell 1993). In relation to this conception of the rational, responsible individual, much emphasis has been placed on individuals’ rights to know about health risks and strategies of prevention, as well as the right to choose resources among the range of available options.

The assertion that individuals have the right to choose among a range of options suggests that “good” health can be achieved by making “good” choices. This idealized notion of the autonomous responsible individual mobilized in public health discourses can be theorized as a means of regulating the actions of individuals. While public health discourses about individual responsibility, autonomy, and empowerment suggest that individuals are able to and will manage themselves freely, these very discourses shape the possibilities for how individuals are able to act on and enact responsibilities (Burchell 1993). The SOGC’s “Spread the Word, Not the Disease” campaign utilizes notions of competence, empowerment, and morality to incite women to be vaccinated against HPV. The SOGC’s HPVinfo website presents HPV vaccination as a choice young Canadian women must make as responsible, autonomous individuals, whose sexual behaviours place them and their current and future sexual partners at “high risk” of infection. Currently, there is no published research demonstrating how this discursive strategy shapes women’s decisions or investigating how young women considering HPV

vaccination are invoking notions of responsibility and whether these notions align with or contradict the SOGC's conception of responsibility.

Two key ideas in public health discourses regarding individual responsibility to choose HPV vaccination are “health” and “risk”. These ideas were also important to young women making decisions about vaccination against HPV. Like the concept of responsibility, “health” cannot be considered outside of the cultural, historical, economic, and political contexts in which it is produced (Lock 1998). Health is “never simply an absence of disease” but rather, is “rooted in cultural norms and values that extend beyond the state of the physical body” (Adelson 1998: 6). In dominant public health discourses, “health” is framed in terms of morality and self-transformation, as a goal to work toward, thus terms such as “‘health maintenance,’ ‘health promotion,’ and ‘healthy living’ highlight the mandate for work and attention toward attaining and maintaining health” (Clarke *et al.* 2003: 172). A nebulous and unattainable, yet omnipresent sense of what constitutes “good” or “normal” health frames the need for self-maintenance. Lifestyles and daily practices, particularly regarding sex, diet, exercise, and stress, have become vehicles for urging individuals to scrutinize and monitor themselves (Armstrong 1995). According to social theorists of individual responsibility, internalization of such forms of surveillance by individuals is guaranteed by the complication of what characterizes “normal” health (Armstrong 1995; Lupton 1995). Paradoxically, in its current pervasive social construction, “normal” health continues to be both an impossibility, as all individuals are considered in need of medical intervention, and a goal toward which “responsible” individuals should strive. This current construction of health frequently engages with current assessments of risk.

Risk-avoidance is implicated in the moral rhetoric of the “responsible individual”, one who makes “good” choices to achieve “good” health. The concept of risk is framed in public health discourses as an epidemiological and statistical measure that links “illness and disease with their causal

variables in the attempt to predict health outcomes and thus...better control them and reduce health risks” (Lupton 1999: 96-97). Through the use of statistical measures of risk, certain groups of people come to be scrutinized and rendered as “at risk” or “high risk” (*i.e.*, sexually active women) and in turn, require particular forms of medical intervention and management (Lupton 2006; Nettleton 1997). Coupled with ideals of individual responsibility, risk can be understood as a medical technology of management through the moral proscription to behave in particular ways that comply with medical expertise. Public health and medical constructions of risk enable the management of individuals through diverse networks of actors and institutions (Lupton 1999). Through these conceptualizations of risk, the acceptance of personal responsibility in avoiding risk is presented as an individual’s ability to make choices about the conduct of his or her life (Lupton 1999).

Public health constructions of risk categories compel targeted “at risk” and “high risk” individuals to avoid risks by behaving responsibly. Behaving responsibly requires that individuals inform themselves with expert medical knowledge about risk-avoidance and make the “best” choices to maintain their health based on this knowledge. Yet, expert constructions of risk as an objective, epidemiological measure fail to take into account the complicated ways in which individuals may think about risk in the context of their lives. Public health discourses suggest that negotiating strategies of risk avoidance by making “good” choices indicates an individual’s responsible behavior and ability to make rational and autonomous decisions, independent of social circumstances. However, individuals do not negotiate decisions of health management unencumbered by social circumstances. Rather, individuals negotiate decisions regarding their health through these circumstances.

No research has investigated how public health discourses about HPV attempt to compel “at risk” and “high risk” women to behave in particularly gendered, sexually responsible ways to avoid the risks associated with the virus by choosing to be vaccinated. The moral mandate of responsibility to

make the “right” choices about health maintenance through risk prevention strategies is particularly visible in the SOGC’s public health awareness campaign that urges women to choose to “Spread the Word, Not the Disease”. This example of public health discourse utilizes powerful culturally recognized values about individual responsibility toward the self and others to manage health through risk prevention. The category of the “responsible individual” in relation to health maintenance relies on and reproduces notions of autonomy and the ability to make decisions free from social constraints. Public health discourses about HPV vaccination demonstrate that the burden of responsibility rests largely with women to protect themselves, their daughters, and their potential sexual partners from the risk of contracting HPV by choosing to be vaccinated.

In my research, I explore women’s ideas and experiences of responsibility to theorize how they make decisions about HPV vaccination. Through women’s negotiations of public health discourses and their decisions about HPV vaccination, I determine how the concept of responsibility (re)produces particular social expectations about gender and a gendered obligation to manage health. I utilize and build upon existing theories of responsibility, risk, and health by investigating how gender emerges as a salient aspect of responsibility in public health discourses that implore women to choose to be vaccinated against HPV. However, my research makes a distinctive contribution to social scientific theory about responsibility. I investigate not only how discourses of individual responsibility to make the “right” choices about health maintenance operate through public health discourses about HPV, but how those discourses are negotiated by young women.

I investigate how medical and public health discourses, which simultaneously reproduce the cultural value of individual autonomy and choice and women’s gendered responsibility to behave in medically sanctioned ways, are negotiated by young women. Public health discourse about the HPV vaccine suggest that, with the “right” kind of knowledge about the risks and benefits of vaccination,

women will inevitably act as responsible individuals and “choose” vaccination. However, my research complicates such individualistic conceptualizations of responsibility and choice as they are reproduced through public health discourses and theorized by social scientists. By exploring how women, as complex social actors, make decisions about the HPV vaccine, I argue that they simultaneously reproduce, resist and rework notions of both gendered and individual responsibility to demonstrate how they are invested in protecting themselves and their reproductive health.

1.5 Terminology

In this section, I provide some operational definitions for key terms that are used throughout this thesis. The definitions provided in this section are intended to provide a basis for initiating a discussion of the ways that, (1) public health researchers have articulated expectations about HPV vaccination, and (2) the ways in which participants understand and experience these expectations as part of their decision-making practices. The terms and definitions provided here will be explored and expanded upon throughout this thesis.

When referring to *discourse(s)*, particularly public health discourses, I utilize Gurevich *et al.*'s (2007) definition as not only referring to language, but to regulated social practice. In this regard, “discourses are fundamentally productive of realities (e.g. objects, social institutions, individual subjectivities and ‘subjects’) and they...constitute objects, subjects, bodies, and individual and social identities” (Gurevich *et al.* 2007: 16).

In defining *autonomy*, I draw on bioethical conceptualizations of the term. In this regard, autonomy refers to the right of individuals to make “rational,” informed choices regarding their health in ways free from any intervention or personal constraint (Dodds 2000). Bioethical conceptualizations of autonomy emphasize the individual’s right to know about health risks and strategies of prevention and the right to choose among a range of available options in enacting strategies of health maintenance

(Peterson 2003). I revisit this term in Chapter Three, when discussing how participants emphasized their desire to make responsible decisions regarding HPV vaccination.

In my literature review, I identified *risk*, *responsibility* and *health* as key terms in public health discourses regarding HPV vaccination. The concept of *risk* is framed in public health discourses as an epidemiological and statistical measure that links “illness and disease with their causal variables in the attempt to predict health outcomes and thus...better control them and reduce health risks” (Lupton 1999: 96-97). These measures compel “at risk” individuals to avoid risks by complying with medical expertise, thus by behaving responsibly. In Chapter Four, I focus on participants’ articulations of risk and their thoughts on being “at risk” of HPV in regard to their decisions about vaccination.

Responsibility is a culturally contingent concept that, in the context of public health and medical discourses, refers to a form of self-management (Nettleton 1997) and a moral obligation to others to prevent risks (Oster & Cheek 2008). Responsibility can also refer to a form of empowerment through the expression of autonomy and a measure of a person’s competence (Stokes 2008; Peterson 2003). I discuss the ways in which participants articulate a sense of responsibility regarding their decisions about HPV vaccination in Chapter Three. In public health discourses, *health* is framed in terms of morality and self-transformation, as a goal to work toward, thus terms such as “‘health maintenance,’ ‘health promotion,’ and ‘healthy living’ highlight the mandate for work and attention toward attaining and maintaining health” (Clarke *et al.* 2003: 172)

Gender and *sex* are terms that have framed both public health discourses and participants’ perspectives about HPV vaccination. As a means of providing an initial definition from which to discuss gender, I utilize Laslett and Brenner’s (1989: 382) definition of gender as “socially constructed and historically variable relationships, cultural meanings, and identities through which biological sex differences become socially significant.” Similarly, I define sex as biological or physical markers that

identify individuals along a spectrum, with male or female on opposite ends (Jacobs & Roberts 1989). I explore these terms in Chapter Five when providing an analysis of my findings of the interviews with young women.

1.6 Overview of Thesis

This chapter has highlighted the dearth of qualitative research investigating how young women are negotiating decisions about HPV vaccination through public health discourses. Medical and public health research on women's knowledge and decisions about HPV vaccination have centred on correcting "inaccurate" information to increase vaccination compliance. I have identified the way that this agenda to increase HPV vaccination in young women relies on the implicit cultural assumption that health is a biological state of being and that health maintenance is a matter of individual choice and a civic and social responsibility. My thesis contributes to broader theoretical issues regarding the notions of responsibility, health, and risk. The focus on public health discourses of HPV vaccination and if and how young women negotiate these discourses to make decisions about the vaccine makes this research project unique. This thesis builds upon existing theories of responsibility, risk, and health. However, it makes a distinctive contribution to social scientific research by demonstrating that women's decisions about HPV vaccination reveal the ways they produce meaningful identities as responsible young women by resisting and reworking public health discourses of risk and individual responsibility.

Chapter Two details the methodological considerations and methods employed in this research. I discuss the research context, and recruitment and interviewing of participants. In this chapter, I also explain my methodological position and the ways in which this position shapes this research project.

In Chapter Three, I provide a summary of the participants' perspectives on responsibility. I explore how their ideas and experiences of responsibility are implicated in these women's decisions about HPV vaccination. This chapter also highlights participants' engagement with public health

discourses regarding responsibility.

Chapter Four focuses on participants' discussions and experiences of "risk" as they related to their decisions about HPV vaccination. This chapter highlights the differential ways the women talked about and experienced risk in relation to their decisions about HPV vaccination.

In Chapter Five, I provide an in-depth exploration of my research findings among the women I interviewed. I utilize social scientific theories of risk and responsibility to examine how the participants form meaningful identities as young women responsible for protecting their reproductive health.

Chapter 6 provides my final conclusions for this research. I also address the implications of this project and the possibilities for future research projects.

Chapter Two: Methodological Considerations

Chapter Two provides a description of the methods used in this research project. I first discuss the reason why I chose this research topic. In the second section, I describe my recruitment methods. In the next section, I provide a description of the young women who were interviewed in this research, while discussing the difficulties of categorizing them in order to provide context for their discussions about HPV vaccination. Section four provides an overview of the interviews and how participants and I negotiated our expectations and thoughts regarding the interview process. In the fifth section, I describe the HPVinfo website content and the ways that the site exemplifies public health initiatives that encourage women's responsibility for maintaining their reproductive and sexual health. Section six details the methods of transcription and analysis used on the interview data. In the last section, I describe some of the ethical considerations related to conducting this research project.

2.1 Choice of Topic

This research was conducted in Victoria, B.C. and more specifically on the University of Victoria campus. All of the participants, myself included, were living in Victoria and attending the University of Victoria as students. I have considered Victoria to be my home for the past seven years. Pragmatically, the financial constraints of being a student with limited income dictated that I could not travel to another country to conduct research. The location and topic of this research project did not allow for a distinct and separate boundary between researcher and research subject, nor did I intend for this separation. I began this project from the position of a researcher and as a young woman concerned about being "at risk" of HPV and as part of the target age group for vaccination. I was drawn to this research topic because of my own concerns regarding the HPV vaccine. Moreover, I was drawn to

HPV vaccination as a research topic because of my interest in the how women's reproductive and sexual health are treated as medical problems in need of medical solutions. These academic interests and personal experiences led me to consider how other young women in Victoria think about the vaccine and how they make decisions regarding whether or not to be vaccinated.

2.2 Recruitment

I chose to recruit participants through two clinics in Victoria based on the demographic of their clientele. One of the clinics offers services to University of Victoria students. While the clinic's services are limited specifically to students, I had anticipated that their clientele would likely be diverse in regard to gender, age and sexual orientation. The other clinic offered services to all Victoria residents of all ages, genders, sexual orientations and identities. I contacted the clinics via email, introducing myself and my research and provided the contact person with my Recruitment Letter to Organizations (see Appendix I), explaining that I sought their help in recruiting participants for my research. Written approval was provided by clinic administration after I met and discussed my research more thoroughly with clinic administrators. I provided the written approval from the clinics to the joint UVic/VIHA ethics committee, from whom I was granted ethics approval to conduct this research.

Participants were recruited through clinics in two different ways. First, flyers advertising the research project and contact information were posted at each clinic (see Appendix II). Second, clinic staff was asked to refer potential participants to this study by providing them with the Recruitment Letter to Participants (see Appendix III). Participants were also recruited on the University of Victoria campus by posting recruitment flyers containing information about this research project and my contact information on designated information bulletin boards across campus. Flyers were approved by the Graduate Student Society office before they were distributed across campus. Interestingly, I had initially assumed that recruiting participants through the clinics would be most successful since this

method was a more “active” form of recruitment, where clinic staff would provide potential participants with information about the research. Furthermore, I thought that young women might be more inclined to participate because they were provided by clinic staff with more detailed information through the Recruitment Letter to Participants. However, most of the young women who contacted me, expressed an interest in participating after seeing the flyers posted around campus.

Recruitment took place over a period of four months and in the form of target sampling (Bernard 2006). I had three recruitment inclusion criteria: (1) the participant is a self-identified woman; (2) the participant is between the ages of 19 and 26; and (3) the participant has heard of and is considering HPV vaccination. I set out with the goal of recruiting between ten and fifteen participants and ended up with thirteen young women participating. I discuss in more detail these young women in the next section in this chapter. I employed snowball sampling, as a “network sampling method” (Bernard 2006). Snowball sampling allowed me to recruit new participants by asking existing research participants to invite young women within their social networks to contact me. This method ended up being successful, with four young women contacting me and participating after learning about the research from another participant.

Young women interested in participating were asked to contact me via email or phone. During the initial contact, I confirmed with participants that they fit within my research criteria and provided them with the Recruitment Letter to Participants. The letter was intended to inform them of project goals, time investment and potential risks involved in participating and allow them an opportunity to ask questions about the research before they decided to provide consent. I elected to seek consent from participants at the beginning of the first interview, rather than before it. I assumed that it would be potentially difficult and time consuming for young women to schedule separate meetings to provide consent and then conduct the interview. The women were asked to sign and date two copies of the

Informed Consent Form (see Appendix IV). I retained one copy and provided them with the other. Ongoing consent was obtained verbally, via digital recorder, during the second interview by reminding interview participants that they could withdraw from participating in the research project at any time (see Appendix V). I also offered young women interested in participating the opportunity to review my interview questions (see Appendix VI and VII) prior to their decision to provide consent.

2.3 Participants

Thirteen young women between the ages of 21 and 28 participated in this research. Initially, I recruited young women between the ages of 19 and 26 for two reasons: (1) at the age of 19, young women no longer have provincially funded access to vaccination via the public school system and vaccination is no longer tied to government-initiated childhood immunization programs. I anticipated that around the age of 19, young women considering the vaccine may be engaging with public health discourses about HPV vaccination in ways different from childhood immunization programs, which largely centre on parental responsibility to protect children through vaccination (see Lenselink *et al.* 2008; Dempsey *et al.* 2009; Ogilvie *et al.* 2007). Conversely, public health professionals recommending vaccination of young women demonstrate their responsibility to make “good” decisions about their sexual and reproductive health without parental permission and through the consumer choice to be vaccinated; (2) the HPV vaccine is available to women up to 26 years of age. Twelve of the 13 participating women were under 26, but I did interview one woman, Kay, who was 28 years old and outside of the initial age range for this project. However, she expressed an interest in participating, in part it seemed, because of her experiences of being pressured by her gynaecologist to be vaccinated. I came to realize that it was necessary to broaden the age range particularly if recruitment became difficult. Not all of the participants disclosed their age. However, they were made

aware of the recruitment parameters of this research during our initial contact when I provided them with the Letter to Participants.

I asked each participant to choose a pseudonym to use in the transcripts and thesis. By asking participants to choose pseudonyms rather than choosing them myself, I intended for the young women to be able to identify how they were represented in this thesis if they choose to read it. I asked no specific demographic questions about the young women; rather, we began each interview with participants telling me a little about themselves. I discuss the interviews in more detail in the next section. Initially, the impetus behind asking the young women to tell me about themselves was to provide them with the opportunity to choose information that they were comfortable providing and that they considered relevant to the interview. This open-ended question and the participants' responses gained new relevance as I began to reflect on the process through which they were deciding whether or not to be vaccinated.

This research focuses not just on young women's final decisions about vaccination, but also on the process through which they arrive at those decisions, if they can or do arrive at decisions at all. The open-ended question complicated the possibilities for locating participants in stable demographic categories that could easily be connected to similarly static decisions about the vaccine. Furthermore, the information they decided to share demonstrated to me the ways that aspects of their identities, including their relationships with sexual partners and their status as students, became relevant in particular moments during the interviews and less relevant during others. In presenting descriptive information about the young women, I do not use this information to typify or categorize them. Rather, this information is intended to provide context to their thoughts, experiences and decisions related to HPV vaccination.

The diversity of the research participants was somewhat limited. While I sought to include non-university students by recruiting through clinics not located on campus, all of the young women who participated in this research identified themselves as University of Victoria students. At the time of the interviews, seven participants were undergraduates, three were Masters students and three were PhD students. The relationship between their thoughts about the HPV vaccine and being students became salient when discussing their ability to access information about the vaccine and their concerns about the cost of the vaccine. Among the thirteen participants, Dawn had already completed the three injections needed to be vaccinated against HPV and Leigh had begun the process of being vaccinated. I hesitate to categorize the women as “vaccinated” and “non-vaccinated” because of the complexity behind these decisions. For example, Helena wanted to be vaccinated, but was unable to because the financial constraints of being a student limited her decisions about vaccination. While Dawn was vaccinated, her “choice” was complicated by the pressure she experienced from her nurse practitioner to choose to be vaccinated. These examples unsettle the assumption in public health literature that decisions about HPV vaccination are informed, made free from intervention and regardless of “perceived” barriers. I discuss their experiences and decisions about the vaccine in Chapter Three and Four.

Through my recruitment, I welcomed any potential participants who self-identified as women and did not limit my recruitment to any specific sexual orientation. This could have included cisgender, transgender, transsexual, queer, lesbian, bi- and pansexual women. All of the participants made references to being female, particularly when discussing concerns about cervical cancer. When discussing their relationships and sexual practices, all of the women referred to engaging in these activities with men. Six of the young women, Dawn, Leigh, Michelle, Joyce, Sarah and Kay, informed me that they were in long-term monogamous relationships with male partners. Six participants,

Isabelle, Breanne, Ace, Alice, Lynn and Helena, were not in monogamous relationships at the time of the interviews. One of the women, Wendy, had been dating a man for approximately five months. Sexual relationships and practices were important for the women when discussing whether they considered themselves “at risk” of HPV and how they protected themselves and their partners from sexual health risks. I describe their thoughts and experiences about their sexual practices in relation to their reproductive and sexual health and the vaccine in Chapter Three and Chapter Four.

2.4 Interviews

The women were asked to participate in two semi-structured interviews. While previous public health research has utilized similar research methods to investigate women’s knowledge about HPV vaccination, my use of semi-structured interviews was not intended to identify and correct “erroneous” assumptions in their knowledge about HPV or to increase vaccination compliance. Rather, I dispute public health and medical professionals’ claims that if women only had the “right” kind of information, they would inevitably “choose” to be vaccinated. This research method allowed for an exploration of: (1) young women’s ideas, thoughts, and decisions about the vaccine as they are negotiated within complex material and social circumstances of their lives; (2) the extent to which young women were using public health discourses to make decisions about HPV vaccination. As a gesture of gratitude, I provided all of the research participants with a ten dollar gift card to Fairway Foods at the end of the second interview.

As a method of investigation, semi-structured interviews are “formally bracketed, and set off in time and space as something different from usual social interaction between ethnographer and informant” (Davies 1999: 95). The environment in which interviews take place may shape the way participants respond to interview questions. All of the interviews took place on the University of Victoria campus. A less formal environment may have elicited different responses to the same

interview questions. However, the campus was also a location with which the young women, as students, were familiar and many requested that the interviews be scheduled on campus.

I consider semi-structured interviews to be expedient for my research because the interviews are guided by open-ended questions that facilitate and maintain the direction of discussion, but allow informants to feel unrestricted in their responses (Davies 1999; Bernard 2006). While there are a set of formal, written questions, semi-structured interviews are flexible in that they allow the interviewer to alter wording in questions, ask supplementary questions, and encourage interview participants to elaborate on their responses (Davies 1999).

The interviews became a context in which both the young women and I negotiated our understandings of HPV, the vaccine and the interview itself. For some participants, the interview was a space through which they articulated shifting perspectives about the vaccine. During our interview, Leigh was surprised with herself for not considering the reasons why the vaccine was offered only to women after I asked her about men being vaccinated and my questions compelled her to research the vaccine further outside of the interview. Similarly, Lynn described to me her thoughts about the ways the marketing of the vaccine excluded transgender, transsexual and genderqueer people from HPV vaccination after I asked her about whom the HPVinfo site targeted. The interview process became a learning experience for me as a new researcher as well. The interviews became a space in which my own position on the vaccine shifted along with participants'. My position on the vaccine began to reflect the thoughts and experience of the young women participating in the interviews. However, particularly after interviewing Sarah and learning about her experiences of developing precancerous cells in her cervix, my position became more complicated and nuanced. I began to better understand the diverse reasons why young women might be considering vaccination and how their thoughts and experiences related to larger issues regarding the medicalization of their health.

During the interviews, I naïvely realized that I was not the only person to have particular reasons for participating in this research. While all of the participants were interested in the research topic itself, some, like Isabelle and Leigh expressed an interest in qualitative research methods as part of the impetus to participating. Breanne, Helena and Michelle identified their similar research interests and methodologies as part of the reason behind their participation. Ace informed me that she wanted to participate, at least in part, because of the need to have medical practitioners understand the constraints she and other students face in accessing medical care. Similarly, participants and I also had expectations regarding the interviews themselves. Some of the participants, such as Leigh and Michelle, told me they were unable to discern my opinion about HPV vaccination when they reflected on the interview questions at the end of the interview. Comments such as these usually led to a conversation where the women asked about my thoughts on the vaccine. Underlying these comments was an understanding that the interviewer's opinions or position regarding the topic should not be known by interviewees so as not to introduce "bias" into the interview.

The value of researcher "objectivity" manifested in my interviews with Sarah when at the end of one of our interviews, she informed me that she felt "guided" by one of my questions. The interview transcripts reveal my anxiety and concern that she may have felt led into answering questions in ways that made her uncomfortable. We spend the last minutes of the interview discussing the question she felt guided by ("How do you think a woman who has had multiple sexual partners would respond after she read [the Prevention Section]?") and ways that I may have been able to ask it differently. When we worked through her concerns together, Sarah decided that the question was "legitimate" and that the nature of the topic itself was contentious and could not be considered impartially. After the interview, I reflected on my own perspectives and sense of unease regarding researcher objectivity as they related to the interviews with participants. The interview with Sarah made me realize the ways that my relative

comfort with my interview questions reflecting my research agenda clashed in some ways with the expectations of participants.

I present this information about experiences not as a way of undermining the process of interviewing in this research project. Rather, by discussing the ways that interviews can be challenging and dynamic, I want to demonstrate that interviews can be an awkward negotiation between researcher and participant. Each person brings with them expectations about the interview process and the topic of the research itself and these expectations can also shift within the context of the interview.

Before each interview, I provided participants with the informed consent form (see Appendix IV) and an explanation of the purpose of this research project and each interview (see Appendix VI and VII). With permission of the participants, the interviews were recorded with a digital voice recorder. I also took hand-written notes. As previously mentioned, all of the interviews were conducted on campus. Many of the participants requested that the interviews be held on campus as a convenient location for them, particularly if they were attending classes before or after the interview. Because all of the participants were students, many were juggling schedules that included school and work commitments. Initially, I had hoped to conduct the two semi-structured interviews with participants within approximately two weeks of each other at a time and location convenient to them. Scheduling interviews two weeks apart proved to be understandably difficult and some participants were unable to meet for the second interview up to a month after the first. One participant, Kay, did not complete both interviews. When I attempted to contact her via email, she did not respond to schedule the second interview.

The length of time for first interview was dependent upon each participant. Originally, I allocated approximately an hour and a half for the first interview. For some participants, this interview lasted less than thirty minutes, for others, the interview lasted over an hour. Similarly, I had allocated

approximately one hour for the second interview and the length of time ranged from thirty minutes to an hour and a half depending on the participant. Pragmatically, I decided it was necessary to conduct two interviews because of the time commitments required of research participants. Combining the interviews into one long session would have presented a burden to interview participants. As a result, I sought written consent from women during the first interview and on-going verbal consent to participate during the second interview. The purpose of the first interview was to explore young women's ideas and decisions about HPV vaccination. This interview was important to my research because it addressed my first research question regarding how women are deciding whether or not to be vaccinated by investigating topics that address where women access information about the HPV vaccine, what information about the vaccine is important to them, how gender and responsibility may be related to vaccination, and what it means to be "at risk" of HPV.

The purpose of the second interview was to investigate how young women engage with public health discourses about HPV vaccination specifically through the Society of Obstetricians and Gynaecologists' HPVinfo.ca website. In the next section, I describe the content of the HPVinfo site and why I choose the site as part of my research. In the second interview, I asked participants to take a few minutes at the beginning of the interview to familiarize themselves with the website, after which we examined selected sections of the site's content together, focusing on images, graphics, and text. I asked participants to reflect on how certain images represent the "typical" woman who chooses to be vaccinated, on the ways in which the site represents sexual behaviours as "right" and "wrong" and how the "typical" woman is expected to prevent risks associated with these sexual behaviours. This interview addressed the participants' perceptions of the website's representation of risk and responsibility through images and text, the gendered representations of who should be vaccinated, and what information on the site is pertinent to participants in making decisions about the vaccine.

2.5 Description of the HPVinfo Website

In this section, I provide a brief description of the HPVinfo website based on my analysis of the discourses and content of the site. My intention is not to provide a full visual and textual analysis of the website nor is my thesis an analysis of the site. In the next section, I discuss in more detail the methods I used to analyze the site. The second interview consisted entirely of participants and me talking about the website together. The questions I asked during this interview were developed from my analysis of the website. This interview was particularly important in allowing me to address my second research question about the extent to which young women may be engaging with public health information to make decisions about the HPV vaccine. The HPVinfo website was designed by the SOGC to be an educational site about HPV that provides a “broad spectrum of information in order to facilitate the ability of users to make knowledgeable choices” that are “well informed and appropriate to each individual” (SOGC 2007c).

I do not have permission from the SOGC to incorporate images from the site into this thesis, so no images are included in my description of the site. Since I conducted the interviews with the young women, the SOGC has modified the HPVinfo site content, including the homepage. My description reflects the appearance of the website at the time of the interviews between November of 2010 and March of 2011. The site’s design provided multiple media, including images, text, video clips and animation. The primary colours used throughout the website were green, yellow and pink. There were a total of five images and two video clips on the homepage. The focal point of this page were the five continuously scrolling images with cursive writing that appears below the image as it scrolls onto the screen. The images and the writing indicate who the images represented and the site’s intended audience: teens, adults, parents, teachers and health-care professionals.

The images also included text intended to be associated with the concerns of their target audience. For instance, the “health professionals” image included the statement, “My patients look to me for answers. I look here for the resources I need”. There were seven women and two men in these images with one man in the “adults” image only partially visible and next to a young woman, who is the focal point in the image. To the right of the scrolling images were two video clips that rotate when the homepage is “refreshed” or returned to from one of the subpages. One of the clips was of “Jay”, a young man describing his experiences after developing genital warts, their connection to HPV and the stigma he experiences of contracting the STI. The other clip was of “Cathy,” the mother of an eleven year old girl, whom Cathy is worried about contracting HPV when the girl is older. The homepage was the main portal through which users access information about HPV. The homepage had a considerable amount of content, which may have made navigation difficult for site users.

The site was “nested” and organized with the homepage directing users to linked subpages arranged according to the targeted audience. The site’s primary colours, green, yellow and pink, appeared on all of the site’s pages as part of the backgrounds, fonts and banners. While the template of the homepage was different from the subpages, the colours served as the device that linked together the different pages. The links were located above scrolling images of the targeted users and next to the pink, circular “Spread the Word, Not the Disease” slogan for the SOGC’s HPV public awareness campaign. The links titled, “teens,” “adults,” “health care professionals,” “parents” and “teachers” were intended to direct users to subpages with information about HPV specific to each category of person.

The organization of the site was a means of managing how users may engage with the site and explore the information provided. I discuss how young women, as users of the site, engage with the site context in the subsequent chapters of this thesis. The template for the subpages was consistent and includes an image of the targeted person (*i.e.*, an image of an adult woman) at the top of the page and a

menu on the right side indicating to whom the information is directed. This menu further organized information about HPV into specific categories including, “Myths about HPV” and “Prevention of HPV”. As a form of public health discourse, the SOGC’s HPVinfo website exemplifies the role of public health initiatives in encouraging the responsibility of women to manage their own, their daughter’s, and their potential sexual partners’ reproductive and sexual health.

Miah and Rich (2008: 48) argue that the Internet is increasingly being used “by various health-promoting agencies and companies as a means of broadcasting health promotion advertisements, tools, services and products.” Under the auspices of individual responsibility over health, consumers of medical knowledge and resources can utilize public health information websites to learn more about risk prevention and health maintenance strategies. The SOGC’s HPVinfo website represents the use of the Internet as a tool to promote responsible health maintenance strategies by suggesting to women that they can inform themselves with the “right” kind of knowledge needed to make “good” decisions about HPV prevention. Through the website, the SOGC informs women that HPV can be contracted and passed onto sexual partners without any manifestation of symptoms, that the STI is linked to secondary illnesses like genital warts and cervical cancer and that there is currently no screening program or treatment for HPV, only the secondary illnesses (SOGC 2009c). While condoms and regular Pap tests are advocated as ways to minimize the risk of contracting and spreading HPV, the SOGC maintains that it is the HPV vaccine that is 100% effective against the STI (SOGC 2009d). Discussions of the risks associated with HPV play on a deep sense of uncertainty about the future of girls’ and young women’s sexual and reproductive health. By outlining public health risks of HPV, the HPVinfo website evokes culturally produced notions of individual responsibility to advise women that it is in their best interests to choose to be vaccinated. Vaccination against HPV is presented to women as a responsible choice

and, thus, a form of empowerment. The SOGC's website demonstrates to women that it is their right and responsibility to make "good" and "informed" choices about their and their daughters' sexual and reproductive health and vaccination against HPV should be among those choices.

2.6 Methods of Analysis for Interview Data

In this research project, I employed thematic analysis to analyze data from participants' interviews (Ryan & Bernard 2003). I also utilized content and thematic analysis for my analysis of the HPVinfo website. I transcribed all interviews. It is important to acknowledge that transcripts are not neutral records of events. Rather, they represent the social exchange that occurs during the interview and the researcher's interpretation of that exchange (Bailey 2008; Oliver *et al.* 2005; McLellan *et al.* 2003).

I acknowledge that the questions I asked participants during the interview shaped the way in which they responded. To provide a nuanced representation of the social exchange between myself and interview participants, transcription included emphasis, speed, and tone of voice, timing and pauses between words, laughter, and bodily gestures that were recorded digitally and via hand-written notes during the interview. I utilized Bailey's (2008) "Transcription Conventions" as a guide to transcribing the interviews in this research project (see Appendix VIII). McLellen *et al.* (2003) suggest that the level of transcription should complement the level of analysis. Detailed representation of the interviews through transcription were important to my analysis for two reasons: (1) facilitating an in-depth analysis of participants' responses to interview questions about their ideas, beliefs, and experiences regarding HPV vaccination; and (2) determining salient themes, patterns, and variations that emerge through comparison of the interview data (McLellen *et al.* 2003). However, similar to the ways that interviews are not neutral records of events, it is integral to acknowledge that the way I interpreted and

transcribed the social exchange during the interviews also influenced the way I analyzed the interview material.

Thematic analysis entails identifying dominant themes and variations of themes in raw data (Thomas 2003; Ryan & Bernard 2003). Ryan and Bernard identify themes as “abstract constructs” and expressions (2003: 87) that are identified through repetition of topics, metaphors and analogies that occur in interview data. Thematic analysis involves exploring similarities and differences in raw data by comparing participants’ responses. The abstract similarities and differences determined through comparisons generate themes and subthemes, if differences in degree or kind emerge (Ryan & Bernard). I used the “constant comparison” method to ascertain when data saturation or repetition occurred by moving back and forth between interview data and emergent categories and themes (Tucket 2004). Constant comparison allowed me to determine and code the significance and variation in themes (Markovic 2006; Ryan & Bernard 2003).

My analysis of the interview data employed both deductive and inductive methods. I assumed, deductively, that notions of responsibility, risk, and health may be important to women as they make decisions about HPV vaccination. However, I was interested in inductively investigating how women negotiate these concepts through public health discourses about HPV and how they were conceptualizing responsibility, risk, and health in ways that parallel or differ from these discourses. While my interview questions structured participants’ responses, thematic analysis provided flexibility in determining how and what aspects of these concepts were meaningful to them. I employed inductive coding to the interview data. This method of coding enabled the generation of a “grounded theory” approach to my analysis by determining prominent themes and variations as they emerge through the interview data (Thomas 2003; Ryan & Bernard 2003; Bernard 2006). Utilizing inductive coding to

facilitate thematic analysis of interview data allowed me to develop theoretical claims about responsibility, risk, and health that are grounded in participants' responses.

Similar to the process of interview transcription, analysis of the interview material requires interpretation on the part of the researcher. Because "data do not speak for themselves," it is the researcher's responsibility to determine what the data mean and how they should be represented (Ramazanoğlu & Holland 2002: 160). Because there is a certain amount of interpretation during analysis of interview material, it is conceivable that both my research participants and other researchers may identify other themes as more salient (Ramazanoğlu & Holland 2002).

My analysis of interview data was not straight forward or without difficulty. Organizing the interview material into categories and themes proved to be difficult because my research focuses on the process of decision-making about HPV vaccination and not just the final decision itself. As a result, I realized that there were no perfect themes and the themes that did emerge through my analysis of the interview material did not have clearly delineated boundaries. Rather, the themes were connected to and mutually constitutive of each other. For example, in discussing young women's experiences of being "at risk" of HPV, it was not easy to separate these experiences from their understandings of what they considered responsible practices of protecting themselves and others from sexual health risks, which I discuss in more detail in Chapters Three and Four. Analysis of the interview material was an on-going process throughout the research project. New ideas and themes emerged and became salient as I began to write up the research results and I began to identify connections that I had not previously made while I studied the interview transcripts.

In my analysis of the HPVinfo website, I utilized both content and thematic analysis to draw attention to the ways the site's text and images are enmeshed in and reveal cultural narratives about risk, responsibility and gender. Content analysis is a "method for studying communication messages

and developing inferences concerning the relationship between messages and their environment” (Weare & Lin 2000: 272). I employed content analysis to draw attention to the key features of the site, including text, images, colours and the site structure and layout. My analysis of the website is not intended to be exhaustive. Rather, I identified some of the key features of the site and underlying cultural narratives about women’s responsibility over reproductive and sexual health to determine how women engage with these features and narratives.

2.7 Ethical Considerations

I am aware that many feminist researchers have highlighted the politics of knowledge production, particularly who controls knowledge and the way in which it is used (see Haraway 1988; Gailey 1998; Wolf 1996; Lal 1996; D’Amico-Samuels 1991). Further, feminist anthropological research entails investigating issues from an engaged position, whereby researchers study “issues and conflicts as both analysts and actors aware of the political stakes in their interpretations and modes of presentation” (Ginsburg & Rapp 1991: 317). In remaining attentive to these concerns, the goal of the knowledge produced through this project is not to increase vaccination uptake by aiding women in obtaining the HPV vaccine. Rather, it is to provide participants with a space in which to potentially work through some of their thoughts and concerns as they negotiate decisions about the vaccine. Participants will be provided with a summary report about the results of this research that specifically discusses how young women make decisions about the HPV vaccine.

Maintaining an awareness of the ethical considerations of conducting research requires accountability toward research participants and on-going self-reflexivity. Self-reflexivity is the recognition that the every aspect of designing and implementing a research project is framed by the researcher’s concerns, interests, and social positioning, including gender, class, ethnicity, and age (Gailey 1998). My age and gender may have made research participants feel somewhat comfortable

speaking with me about their thoughts on and decisions about the vaccine. While I am located within the same target group as the young women I interviewed, it is necessary to consider some of the ways in which power differences exist between myself, as the researcher, and the research participants.

This research entails three particular ethical considerations regarding potential power differentials. First, interviews elicited potentially sensitive information regarding young women's sexual health and practices. I endeavoured to minimize the potential discomfort of participants during interviews by framing potentially uncomfortable questions about sexual practices and health in the context of "other" women's experiences, including friends or acquaintances (*i.e.*, "What are some of the things women are expected to do to protect their sexual health?") (Bernard 2006). Framing questions in such a way allowed participants to respond without revealing information they felt was private.

Regardless, women discussed personal information about their sexual practices and partners. Some of their responses to my questions about sexual practices were prefaced with concerns about whether they were providing me with "too much" personal information that might make me uncomfortable. For example, in our first interview, Breanne stated, "I don't know if this is gonna be too much information for you" before discussing how many sexual partners she had had. Some participants reaffirmed that they were comfortable discussing personal information about their sexual practices with explicit statements about being "open" to discussing the topic. I considered many of the interviews to be fairly relaxed. However, I stopped the first interview with Ace to ask if she was okay and express my concern after she spoke of her frustration about the cost of the vaccine and had begun to cry. She stated that she was fine and indicated that she wanted to continue the interview. Her response to my questions brought into sharp focus the way she, as a student considering the HPV vaccine, was clearly constrained by limited financial resources.

The second ethical consideration centres on the knowledge information gap between myself and participants regarding information about the HPV vaccine. Anthropologists (Lewin 2006; Abu-Lughod 2006; D'Amico-Samuels 1991) have noted a tension between anthropological and feminist research methods with regard to the positionality of the researcher as either a silent/invisible or an active/visible participant in the research process. I attempted to negotiate this tension during the interviews by finding a balance between sharing my opinions and knowledge with the women in some instances and electing to remain silent in others. My intent was not to privilege my perspective or understandings, but rather those of the participants. For example, during the second interview, I did not tell participants that the SOGC received funding from Merck Co., Inc to develop the HPVinfo website.

Providing this information may have changed the women's perspectives on the website as an "authoritative" body of information about HPV and the vaccine. However, this assumption may be problematic since women's perspectives about the website were diverse. Some of the women were suspicious of the website as primarily promoting the vaccine; other women trusted the information because the SOGC is recognized as a professional organization of medical practitioners. I do not assume that because the SOGC received funding by a pharmaceutical organization that the SOGC are disingenuous in their recommendation of the vaccine. Moreover, I do not know the circumstances in which the SOGC and Merck negotiated the way the funding was allocated and used for the SOGC "Spread the Word, Not the Disease" campaign.

Third, I have the power to represent interview participants through my thesis and subsequent written and disseminated material. It is integral that participants are represented respectfully. Some research projects involve a considerable amount of participation on the part of research subjects at different stages of the project. For example, participatory action research is designed and implemented in consultation with research participants (see van Willigen 2002; Singer & Erickson 2011; Ervin

2000). I endeavoured to seek some input by participants with regard to their interview data to ensure that they were represented in ways they felt comfortable. However, because of the institutional constraints of developing and facilitating an MA research project, including limited time and funding, I was unable seek participants' continued assessment of the interview data throughout the process of writing my thesis and in the dissemination of the research results. To mitigate this issue, the women were asked to select pseudonyms; this ensured confidentiality throughout the research project.

Each participant was offered the option of having a transcribed copy of their interview to read over and make changes to before my analysis of the research data. Seven participants requested copies of their interview transcripts. However, while most were amused with the number of “ums” and “uhs” in their transcripts, none of these participants sought any changes to the interview material. I also reminded the women that they could choose not to answer any questions with which they were uncomfortable, could withdraw from the study at any time, and choose not to have their data included in the study if they choose to withdraw. There were no instances where participants chose not to answer any questions, nor did any of the women request that data be removed before I began my analysis of the interviews. One of the participants did not complete the second interview and withdrew from the study. However, she indicated in her informed consent form that her interview material could be used; therefore, I included the material in this study.

2.8 Chapter Summary

In this chapter, I have provided descriptions of the methods used in this research project. Employing semi-structured interviews with women enabled them to discuss a variety of issues regarding HPV vaccination that they considered important. Moreover, focusing the second interview on the HPVinfo website, as a salient example of public health awareness campaigns about the vaccine, allowed me to see how participants engaged with and evaluated public health information directed at

them. However, I also recognize that their evaluations were directed by the questions I asked. Ethical considerations arose during and after the interviews, particularly with regard to providing women with certain kinds of information regarding the HPVinfo website. In these instances, I attempted to seek out a balance between engaging in a dialogue with participants and remaining silent in an attempt to foreground their perspectives without intervening. Ethical considerations about representation were also of paramount importance to me. I sought some feedback from participants by providing them with the option of seeing and editing copies of their transcripts. Furthermore, I purposefully chose not to locate women within stable demographic categories like age and education from which to make assumptions about their decisions about the vaccine. Rather, I have focused on the ways aspects of their identities become more or less salient through the process of their decision-making. The next chapter examines the interview data and explores the ways women articulated notions of “responsibility” through their decisions about the HPV vaccine.

Chapter Three: Young Women's Perspectives on Responsibility

This chapter provides an overview of how ideas of responsibility shape the thoughts and experiences of the young women regarding their decisions about HPV vaccination. In Chapter One, I identified the different ways that responsibility had been theorized by social scientists as a form of obligation toward oneself and others (see Gurevich et al. 2007; Oster & Cheek 2008) and as a form of empowerment whereby individuals demonstrate their self-sufficiency (see Stokes 2008; Peterson 2003). The women I interviewed articulated notions of responsibility that primarily reflected a concern about taking care of themselves and about considering how the vaccine would positively and negatively impact their lives. At the beginning of this project, I had anticipated that risk would be central to young women's thoughts and decisions about the vaccine. Social scientists (see Beck 1992; Lupton 1999; Douglas 1992) have theorized the prevalence and effects of risk discourses in the lives of individuals and populations, particularly in relation to the health. Furthermore, I identified risk as a key concept in the public health literature regarding HPV vaccination reviewed in Chapter One. However, I was surprised to find that the women's ideas about responsibility figured much more prominently than did their ideas about risk in their decisions about HPV vaccination. In Chapter Four, I discuss their perspectives on risk and HPV vaccination.

When women described their decisions about the vaccine, they often drew upon the language of "informed choice" and articulated representations of themselves as autonomous individuals, responsible for protect themselves from the risks of bodily harm. The first section of this chapter highlights how notions of autonomy were implicated in participants' expectations that they make informed choices about the vaccine. In the second section, I discuss how the women's expectations of

autonomy were constrained by the limited accessibility of the vaccine. The third section examines participants' thoughts regarding gendered expectations that women be responsible for reproductive and sexual health and how these expectations of responsibility were implicated in their thoughts about HPV vaccination.

3.1 Autonomy

In this section, I discuss how young women evoked and engaged with notions of “autonomy” through their endeavours to make “informed” choices about HPV vaccination. In biomedical models of health-related decision making practices, autonomy has been conceptualized as an individual's right to make decisions free from coercion and based on adequate unbiased information (Dodds 2000). However, feminist researchers have problematized biomedical understandings of autonomy, critiquing them as limited in perspective and failing to account for the social contexts in which individuals negotiate decisions. Some feminists have called for a reconceptualization of autonomy as an expression of a person's agency to make decisions that are best-suited to them in the context of their social circumstances (see Dodds 2000; McLeod & Sherwin 2000; Sherwin 1998).

The women I interviewed drew upon longstanding biomedical conceptualizations of autonomy when discussing their decisions about the vaccine. Access to “balanced” information about the HPV vaccine was a crucial aspect to making an informed choice about vaccination. Women often conceptualized making an “informed” choice or decision about the vaccine as both a right and a responsibility they had toward themselves. Their emphasis on the importance of autonomy was implicated in the sense of responsibility they felt to make “right” kinds of decisions based on having access to “good” information about the vaccine.

3.1.1 Choice

Being “informed” and making “informed” choices was of particular importance for participants. Often, their discussions of choice would implicitly evoke rights-based discourses, in which all individuals should have the freedom to make choices about their health without intervention or coercion by others:

I think people need to make their own decisions. Um, I don't think you can force things like vaccinations upon people, um, cause I think that takes their r- like if that had been forced upon me, I think that would feel like it was taking away part of my freedom. Um, it's my body and that would feel pretty dictatory [sic] to just be like, yeah, you need to put that in you (Sarah, Interview 1)

I think it is a personal decision and, um, I think for everyone to choose whether to be vaccinated or not is a very personal choice (Joyce, Interview 1)

I think it's your choice and, yeah, whatever- whatever feels right for you and I think that's kind of the way it- it should be in all matters of health, right. You gotta find out what works for you and what's gonna make you feel comfortable with what you're doing, so (Wendy, Interview 1)

The value that the women placed on choice was also evident when they discussed seeking input from their partner(s) about the vaccine. Some talked about the importance of seeking the advice of their partners, but reasserted their right ultimately to choose what they felt was best for them and their bodies:

I don't think that I'd really want his input on it, it's not really his health, it's mine, it's my decision to make about my own health (Alice, Interview 1)

When it comes down to it, the decision's mine to make. It's going in my body, um, but I mean, input's good, open discussion is good (Michelle, Interview 1)

Um, I think it would still be my decision, yeah. But it would be, yeah, if he had something to say particularly about it, then it would be definitely something I would take into consideration probably way strongly...But, I still think in the end, it would be my decision, it wouldn't be like, he'd be like, I think you should get it, and I'd be like, okay, you know (Wendy, Interview 1)

Most young women referred to “informed” decision-making when talking about the “freedom” to “choose” whether or not to be vaccinated. Informed decision-making was enabled by the ability to have access to “unbiased,” “balanced,” and comprehensible information. Participants expected that these kinds of information would provide them with the “whole picture” regarding the risks and benefits of the vaccine:

Pretty much everybody I've talked it, it's been like a decision that they've made and, I mean, that's all that you can really ask that people are actually weighing the pros and cons (Michelle, Interview 1)

I would just, I guess, like- you know, kind of like a summary article, like a meta-analysis or something (laughs) of- of everything that's been done, kind of what general conclusions we can draw and how many of those have been done independently and not through drug companies, you know, because drug companies publish only the things that they wanna publish, right and things that are gonna help them, they're not gonna publish stuff that says, you know, twenty percent of people on this got really sick or twenty percent of people actually ended up with cervical cancer or something, right, that's not helpful for them to sell the drug, so I'd like to have that kind of information outside of it (Wendy, Interview 1)

I'd also want to know if there were any side effects that'd been noted already in the research. Um, or any potential for long term consequences. I'd wanna know kind of what the vaccine was made of and what kind of- there's a lot of times things are related to other vaccines that've already been developed. Um, and some of them are, you know, fantastically safe, so if it was, kind of, piggy-backing on that kind of a scientific model, I'd feel more comfortable with it, I think. I generally like to be over-informed (Alice, Interview 1)

A few women spoke of the importance of “doing research” as a means of drawing upon a range of available, unbiased information to facilitate informed decision-making practices. “Doing research” entailed exploring multiple sources of information, including academic articles, newspaper articles, online forums and websites. When I asked participants if the HPVinfo website would help them make a decision about the vaccine, many emphasized the site as one option among the range of information sources available:

Um, and, so this website seems to be, like- it's in totally layman's terms, it's easy to read, like a fourteen year old could read it fine. Um, so, I don't think misinterpretation of information is such a huge issue, but, I just think that- that it's an extra information source. It's not like, the be-all, end-all (Sarah, Interview 2)

I think that I would recommend- like, I would look at this and then at the end, I would probably still have questions and I would end up search[ing] on a different website or journal or something like that. I guess it was- like, it was a really good starting point (Isabelle, Interview 2)

Some described what they considered to be an uninformed or ill-advised decision, whereby a person didn't undertake the necessary actions to acquire a sufficient amount of information to understand the implications of her decision. Leigh and Isabelle's thoughts on ill-advised decisions reflect what they considered to be, perhaps implicitly, an "irresponsible" choice about HPV vaccination:

I have a younger sister and I think that we talked about it at one point and she, um, was definitely encouraged to get it in high school, um, but I think that she- she's- she's one of those people that's just sort of really carefree, so she's like, eh, maybe. She just hasn't really thought it through (Isabelle, Interview 1)

[I]t's just, like immediately, like, riles me up to- to hear people be, like, eh, well, you know, I don't know, and it just, like- those are kinda the decisions that- I just, like- I don't consider them decisions and I think that they're, like, bad and wrong and unhealthy and that y- you know- so, for instance, if somebody w- choose not to get the vaccine, but it was genuinely, like, you know, I- I've weighed the pros and cons- the- the risks and benefits, I've decided that I'm gonna, you know, just, um, be really careful instead, safer sex, all this kinda thing, then I would respect that, but it's the- it's the decision that's based on, you know, like- cause, just like not taking an action that I really, yeah, have a problem with (Leigh, Interview 1)

3.1.2 (Dis)Trust in Medical Practitioners

Through my analysis of the interviews, I often saw a tension between women's trust and their suspicion of medical practitioners. It became clear that they recognized the authority of medical practitioners to make recommendations about the HPV vaccine based on their expert knowledge.

However, it also became clear that, for some of the women, medical practitioners' authority to make these recommendations was unwelcome and considered tacitly coercive.

For the majority of the women I interviewed, medical knowledge was respected as expert knowledge that could facilitate informed decision-making. In our first interview, Helena referred specifically to medical practitioners as sources of important information for people, whose decisions against vaccination she deemed potentially misinformed:

I would just hope that they just speak to their public health practitioner and, maybe, express their reasons why. I know some people are quite freaked out about getting vaccines. You know and maybe they're misinformed about vaccines or, um, don't have enough information (Helena, Interview 1)

Sarah emphasized her trust in medical practitioners' knowledge and expertise to make recommendations about her health. She reflected on her decision not to be vaccinated before she developed precancerous cells in her cervix and her disregard of her doctor's recommendation at the time that she be vaccinated against HPV:

[M]y doctor told me get it, like, you should listen to your doctor, they know more than you do at- as- as [an alternative medicine] student, I'm like, no, I don't need that. And now I just- I feel like an idiot, like, listen to your doctor, they are the experts and- and if your doctor believes that it's- that the benefit outweighs the risk then I think you should go for it, um, in hindsight (Sarah, Interview 2)

For some participants, like Alice and Leigh, trust in medical practitioners was based upon both practitioners' expert knowledge and the relationship they had established with these practitioners:

[H]e [the medical practitioner] does know a fair bit about my health and the various conditions that I've had in my life and if it was his recommendation that, based on my history, this is something that would be advisable for me then I would definitely listen to it (Alice, Interview 1)

[I]t would also genuinely depend on which doctor because, um- because of my, like, [anxiety disorder] and all this kind of stuff- I have kind of a personal relationship with some doctors that I- you know, like my family doctor at home and- and some of the ones here. So, um, it would definitely depend on, sort of,

how long I've known that doctor? Like, if I went to, like, a walk-in clinic and a doctor told me, like, oh, yeah, you should get it, I'd probably be like, eh, okay, cool, like, do you have some information. But, if it was, like, you know, um, [medical practitioner], I'd probably just trust the guy, I guess (Leigh, Interview 1)

While some of the young women trusted medical practitioners' knowledge and expertise with regard to HPV vaccination, some also described feeling pressured by medical practitioners to comply with their professional recommendations:

[I]t was a walk-in, and he was a more elderly gentleman and he was say, like- he was talking about how he made all of his daughters get it and he- like, I zoned out at it cause it was so long, but it was this huge rant about how the HPV vaccine was so awesome and I should get it and it was not related at all to what I'd been there to see him for and it was- I didn't- like, I said, I'll think about it, but I'm not really sure. So, it was kind of really sort of invasive how he went in there and gave me this huge speech (Lynn, Interview 1)

I mean, when I see the doctor, they make it sound like it's no big deal, everybody's doing it, you know, you should do it, why haven't you, kind of like this, well how come you haven't been vaccinated yet, like, you have to kind of justify for you why you haven't done it, like, to them it's like this, well everyone should- should do it (Wendy, Interview 1)

[W]hen I was in my undergrad, I used the on campus, um, health services. So, every time I went, I'd have a different doctor and I remember going for my yearly physical, which was, I think, another, at least, another time that happened, like, I said I didn't want the vaccine and they would write me a prescription anyways and be like, okay, if you change your mind, here's a prescription. It's like, okay (Breanne, Interview 1)

Many participants told me that medical practitioners often initiated discussions about the HPV vaccine in the context of routine appointments, annual check-ups, Paps, and renewals of birth control prescriptions. Dawn's decision to be vaccinated against HPV was predicated on pressure from her nurse practitioner, whom she had visited for her yearly Pap. At the appointment, her nurse practitioner recommended vaccination. Dawn declined, informing the nurse practitioner that she was in a monogamous relationship and therefore didn't want to be vaccinated. However, the practitioner

persisted and Dawn acquiesced to being vaccinated:

Dawn: She recommended it and gave me the literature. It was really not a discussion, it was just, you should get this because you're within a- within a demographic that I typically recommend it to and I think she suggested that I took- take a look at the information and get back to her

Jen: Okay and in this- so, she gave you the information to kind of go away and then think about it and then there was a second appointment with her?

Dawn: Mmhm.

Jen: And brought it up again?

Dawn: Yeah.

Jen: Okay.

Dawn: And both times I think I was- suggested that I was reluctant, um, you know, just kind of like, I'm gonna wait a bit, but she kept- she was, uh, very pressuring (Dawn, Interview 1)

Medical expertise was often evaluated by participants in juxtaposition with pharmaceutical marketing. Medical practitioners were viewed as more trustworthy and likely to provide accurate, impartial information regarding vaccination. Most of the women expressed suspicion of pharmaceutical marketing for the vaccines that they had seen via print and television ads and on websites. They were particularly suspicious of the way the vaccine was marketed as a responsible decision for preventing what could be the horrifying consequences of contracting HPV. Some of the young women thought that advertisements represented the profit-driven agendas of pharmaceutical organizations.

For Helena, who volunteers at a health clinic in Victoria, there was a clear distinction between pharmaceutical marketing and public health information regarding HPV and vaccination:

I think- yeah, the media is definitely the scare tactic, um, and I just think about, like, the commercial for [Cervarix]. Yeah, like that's- it's- I'm sure you've seen it, it's the one where the woman's, like, sad and she breaks the glass and blahblah, like that's- it's really powerful, but also, like, really terrifying, you know? Like, it's definitely, like, the scare tactic and the, make you want to get it. But then, my- yeah, my healthcare professional has given me more balanced information, where it's not necessarily, like- it's not a scary thing that HPV is so prevalent, but that, it um- yeah, if- if you are sexually active that it would be smart to get....So, I think that most of the scare tactics come from the media campaign, definitely (Helena, Interview 1)

Women were critical of fear-mongering or scare tactics as pharmaceutical marketing strategies to promote HPV vaccination as a responsible and integral choice to mitigating the risks of HPV:

[Y]ou know the one [advertisement] I'm talking about, the big blurred out area on her vagina- it just, like, your vagina is a scary thing, like (laughs) um, you know, I didn't know that I was at risk, like, they're kind of making it seem like this potential horror story that you have to, you know, save yourself from (Michelle, Interview 1)

[T]here's an HPV vaccine commercial- something like, every two or three minutes and it's, like- it's urging, you're getting older and as you're getting older, we're not gonna be able to vaccinate you- you've got to get vaccinated now, you're gonna die terribly (Kay, Interview 1)

Breanne and Kay's awareness of HPV was linked to the advertisements they had seen for the HPV vaccines. They connected their surprise in learning about the severity of HPV and its secondary illnesses with their suspicion of pharmaceutical marketing and the use of scare tactics:

[U]ntil I heard about the HPV vaccine, I really hadn't heard about the Human Papillomavirus at- at all, like none of my friends have had it, um and my friends are talkative, so, if they had it, I would, unfortunately, know about it. But, like nobody- nobody I even know- like- like a friend of a friend has had it- I don't know anyone- ...it's a virus that sprang up over night and all of a sudden, they're like, this is going to destroy all women, everywhere and I had never heard of it before. (Kay, Interview 1)

Like, it's almost like a scare tactic they've used, like, you know, there's this- there's this huge risk and like, girls everywhere should be getting this and I just feel like it's not necessarily the- the best way to go about it and I- I don't know, I just feel like I want more information or, um, you know, give me other options or something. Like I- and it- it seems like it was just all the sudden- like, no one was talking about it and all of the sudden there's like, commercials every half an hour about like, these girls should be getting this vaccine because if they get HPV, they're gonna get cervical cancer and I just remember thinking, where did this come from (Breanne, Interview 1)

Some participants also highlighted the use of “empowerment” in the pharmaceutical advertisements to promote HPV vaccination. In our first interview, Isabelle discussed the Cervarix™ “Tattoo Punch” advertisement’s use of “feminist” notions of empowerment to promote the vaccine as a

responsible choice for women. Isabelle was critical of the disregard in the advertisement for how women decide whether or not to be vaccinated:

Isabelle: I don't know, I think that it's been a little over the top with, like, the- just the feminist tones have been a little extreme in my opinion, but....

Jen: What- what do you mean by feminist tones?

Isabelle: Like- like the really- like the making women really empowered- that, you know, um, their sexual health is their choice and their decision, which is totally true and I completely agree with that, um, but I think that if you push that sort of agenda too hard, you're gonna lose a really big demographic of women, who are like, well, yeah, like, I consider my sexual health to be me, which it is, but, you know, I'm not this, like, angry feminist. Like, I'm not doing it because I'm a woman and I have the right and na na na, I'm doing it because I'm concerned about, you know, the risks that I may or may not come across in my life (Isabelle, Interview 1)

When I asked Isabelle if she could imagine any ways that the Cervarix™ ad might look different, she stated that the ads failed to address the important aspects of young women's lives that are related to their thoughts and decisions about the vaccine:

Yeah, something that- that just something puts in more in context, like, even just, like, a woman and her partner being like, so there's this vaccine and you know this is what it does because these are their like- these are the statistics that cervical cancer has to do with women and that HPV has to do with woman and that sort of thing and, you know, it's something to consider and na na na na na, something more like that as op- cause, like, just having the stats and then having this woman screaming and breaking glass, it, like, it has no context. You see the stats and then you're like, oh! and then you see this woman punching her arm through a pane of glass and you're like, oh. Like, they just- they're so disconnected and so having something that actually flows logically to me would make more sense. (Isabelle, Interview 1)

Leigh discussed the ways that pharmaceutical marketing attempted to control how people think about illnesses and treatments to entice them into purchasing drugs, even negating the possibility of making an informed decision about being vaccinated:

I'm kind of adverse to look at those things because they're just- you know, the- like these smiling people and just, kind of, all this- like, oh, it's so wonderful, blablablah, like- and there's always like, links- like, click here to read more, like you have to keep going deeper and it's not portrayed in that same sort of, like,

doctor's office brochure format, like, straight forward information. Um, and it's always like, you know, FAQs that are kind of written hoping to sort of, you know, preemptively answer your questions, which allows them to, sort of put those questions in your head almost? Like, they are probably questions that you have, but it's like- because they're specifically targeting those ones to answer, they're not just kind of giving you the information and letting you, like, parse through it. Um, it's all just kind of shiny and there's, like, really t- tiny fine print and, just, you know. And, plus, obviously, it's, like, knowledge about corporations and money and all that kind of good stuff (Leigh, Interview 1)

Other participants questioned the authority and expertise of medical practitioners and “impartial” information they provided to patients. In these instances, women did not maintain a distinct boundary between medical practitioners’ knowledge and pharmaceutical companies’ profit-driven advertisements.

Michelle was critical of pharmaceutical companies providing public health information about HPV vaccination to medical practitioners. She questioned the impartiality of this information and was concerned about the potential lack of critical assessment by those deciding whether or not to be vaccinated:

[W]e have the idea, you know, if you pick up one of the pamphlets at the doctor's office or if it's given to you by a practitioner that it's gonna be reliable, um, bias-free information and I mean, it's not, you flip it over and, you know, published by Pfizer or whoever ...I think a lot of people don't get that that the information they're reading has, you know, an inherent bias. I mean, even the doctors are being prepped by the drug reps that come in (Michelle, interview 1)

For some participants, “doing research” online was a way of seeking out sources of impartial information that would allow them to make decisions about their health without necessarily speaking with health professionals:

[Y]eah, use the Internet as a jumping off point. Kind of get an idea of what's out there and then- I guess it really depends on what I was interested in if it was this [HPV] specifically, then, um, I guess if I had questions, then I'd make an appointment to see my doctor or something like that, but it's- it's a good source of information without having to go into your doctor right away (Joyce, Interview 2)

I don't use it as, like, a textbook or anything, you can't take it as like- when you want to go to, like, sites that are, like, set up by doctors or something, you don't wanna just go to, like, a forum of (laughs) like, health info for friends. Um, but, yeah, I think- I think most people go to sites where health-related stuff, um- or to some extent, right, like, you're still gonna have other questions for your doctor, but if you're not gonna see your doctor until the next week, then you're like, I'm curious (Sarah, Interview 2)

When we discussed the HPVinfo website, Alice conveyed some of the reasons why she preferred online information over speaking with her medical practitioner:

Well, the reason that I prefer to go to a website is- and this website is one that I'd prefer to go to- is that, um, I feel like all of the information that I could be looking to get is listed in sort of ways that I could get it, so, I mean, if I wanted to know what the disease was and how it's transmitted and what I should be doing to protect myself and how the injection could assist me in doing that, um, what my risks are, what my odds are, you know, the likelihood of it working, all of that information is there. But if I were to go to my doctor and ask him to have that whole picture? He wouldn't have the statistical information that goes behind it and he wouldn't have all the details. I'd be relying on what, uh, he would remember of the information he'd been given? and there's no guarantee that that's as complete. Besides which, it's considered designed by a sponsoring body that I suspect would have a pretty solid idea (laughs) of what they're doing. (Alice, Interview 2)

Some of the young women expressed trust in the HPVinfo website because it was designed by a professional organization of health practitioners, the Society of Obstetricians and Gynaecologists of Canada (SOGC). Furthermore, the website was considered trustworthy because the SOGC was believed to be motivated by the need to provide accurate information about HPV and the vaccines.

Alice believed that there was a clear distinction in the motivations of pharmaceutical and medical organizations in promoting HPV vaccination:

When a drug company wants to get a drug approved, it's for commercial gain and when a, uh, campaign like this is sponsored by a public health body it's to provide the most protection for the most people (Alice, Interview 2)

Leigh and Wendy articulated similar responses:

I just don't figure that, like, the Society of Gynaecologists or whatever would just kind of be like, eh, whatever, you know. I mean, maybe if they all really believe in- in the vaccine, then they would be encouraging whoever's writing the copy to frame it in, like a really positive way, which they clearly are, but if that's what the evidence is- is behind, then, yeah (Leigh, Interview 2)

Um, the other thing I really liked about it [HPVinfo website] was that it seemed- like, it's not sponsored by one of the companies, right, so to me, it was like, providing unbiased information about what's- what's going on. Um, it still seemed a little towards, yes, you should get it, um, which is fine, I mean, it's- as general, this, you know- what is it, the Obstetricians of Canada or something- they think that it's gonna be beneficial to people, then I think it's kind of okay that it leans one way or the other, but it was definitely provided, I think both sides, uh, of the debate (Wendy, Interview 2)

Although the website's information seemed impartial to others, Breanne thought it was similar to pharmaceutical marketing for the vaccines:

Like, obviously it's a huge industry and it's a big money maker so, you know, it's going to push that, like, this is- you know, like, take this drug, this is this is your only option, um, and a lot of the time, there- there is another route that you can go that's better for your body....[L]ike, it- most of it was good, I thought, but sometimes, I just feel like there's like a scare tactic there, you know, like, saying- well, I guess they wouldn't lie about the statistics that, like, seventy percent of people get it, but, like, it's just kinda scary and I wonder, you know, knowing how statistics can work, like, is there some sort of manipulation that happens and like, what's their sample and, um, yeah, like, I just wonder- like, it is, Gardasil is from a pharmaceutical company, like, obviously they're making a lot of money off of this vaccine, so, like, I just wonder if there's- if there's more to it or, like, if the data has been skewed in some way, you know (Breanne, Interview 1)

Ace was also critical of the authoritative language, including statistics, on the HPVinfo website to convey information about HPV, the vaccine, and the recommended best practices for preventing HPV. She characterized this language as “fluffy”:

Okay, so there's a bunch of different kinds of marketing and they're saying, like, professionals agree. What do the professionals- let me see their names. Who exactly voted on this, like, you know what I mean, like, yes, it's the Society for Obstetricians and Gynaecologists and, uh, yeah- like, okay, teachers, which teachers. Like, you know what I mean, like, it's just using authority figure and I don't think that that's fair....It's like- something in social psychology about

believing people of authority and I have an issue with authority figures throwing their weight around too much as it is and I don't think that it's a very good pattern to be teaching people. (Ace, Interview 2)

Ace was suspicious that medical practitioners received incentives from pharmaceutical companies to promote HPV vaccination. Like Michelle, Ace blurred the boundaries between medical practitioners and pharmaceutical companies. She stated that the HPVinfo website represented an unnecessary amount of advertising for the vaccine:

I think that it's too much advertising involved. I think the more advertising you associate with the vaccine, it means the least effective it truly is and there's a lot of advertising for HPV. I think it makes it less credible. Cause, why do you need to advertise it. Why do you need to advertise it. Like, a lot of emphasis on that- if it's so great, why is advertisement necessary. Like, that's my biggest concern- like, that's the biggest question- if it's so great why are you pushing it. If it's that good, people would just say, yes, I need it (Ace, Interview 2)

Women's narratives clearly indicate their awareness of medical professionals' expert authority to make recommendations on women's health care decisions. However, how women negotiated this authority differed. For some participants, medical practitioners were trustworthy by virtue of their expertise. For others, this trust was predicated on establishing a meaningful relationship with their health care professionals. For a few of the women, the expertise of medical professionals did not go unquestioned.

3.1.3 Seeking Balanced Information and Making a Decision

Women's engagement with the information they accessed about the vaccine demonstrate the ways they actively evaluated it in terms of bias and usefulness. Their emphasis on the importance of seeking out "balanced" information about HPV and the vaccine also reveal that such endeavours are not easily accomplished.

While most participants discussed the importance of seeking out "balanced" information that allowed them to understand the pros and cons of the vaccine, the decisions this information enabled

varied. For some, like Dawn, having access to “balanced” information led to an informed decision to be vaccinated; for others, like Alice, the information led to the choice not to be vaccinated:

Um, I looked up some journal articles, um, to try and figure things out, but I think it was really just, um, I think subconsciously, I probably knew I would eventually get it, I just wanted to be well-informed before I did (Dawn, Interview 1)

I think the people who have decided not to get it are probably more likely to have spent the time considering the possibilities and whether or not they should get it than people who have decided to get it (Alice, Interview 1)

Available information left some participants undecided as to whether or not to be vaccinated, particularly when the information could not address the concerns they had about the vaccine:

I just want, like, you know, the basics, overall, this was what's been found, these people are preventing cancer, there's been no adverse reactions or if there are, like, how many people are having them, you know...has there been a study on a bunch of people fifty years ago, who had the vaccine and don't have cancer now or is this something that we've only done on rats and we're not really sure if this is really applicable to humans. Like, sure, it might prevent cancer, but do we really know that? (Wendy, Interview 1)

I just wanna know about like other- maybe other people, who have taken it and- I don't know how far back their information goes, but, like, if you can give me information from someone, who's taken it like ten years ago and they're still fine and there's nothing weird that's happening (laughs) to them then I think that would make me feel a little more comfortable (Breanne, Interview 1)

While “balanced” information was valued by most participants, the instances in which it was confusing or conflicting suggest that this kind of information does not necessarily allow one to make the desired, informed decision. Rather, the information could be disconcerting, especially when it appears polarized as to the value of HPV vaccination:

[Y]ou're kind of in the middle somewhere, like, you're not really quite sure if this is a good thing that we're doing it, what kind of long-term impact will this have on our population, that sort of thing (Joyce, Interview 1)

Um, it [information about HPV] all varies pretty wildly as far as whether it's a good thing or whether it's really bad. Um, I think the only thing they can really

agree on is that, like, it covers two or three different strains of HPV and that one of the strains, I think, is pretty prevalent in causing cervical cancer but, yeah. So, it- it's really kind of hard to see where a neutral kind of ground point is cause everything is usually either one way or the other (Lynn, Interview 1)

The HPVinfo website was an instance of “unbiased” public health information that was nonetheless confusing and unsettling for a few participants:

[I]n one section, they're saying that if you have had HPV, um, and you're over the age of twenty-two, still get the vaccine, um, cause otherwise, it's all geared towards like- I think it's something like, nine to thirteen is the ages- or something like that, but yeah, so I was kind of- there's information in there saying like, even people, who're beyond the age bracket should still get it, um, and then I'll see something like that, where it's like, there's no other cause like, this is- so, it's kind of back and forth for good and negative information, so it's kind of hard to make a decision. So, I just keep sitting on the fence (Lynn, Interview 2)

I looked at their frequently asked questions page and- which, like, was a lot of back and forth about, like, well, if you get, like, the bad kind, you can get cervical cancer and that's super scary, but you may even have it and not know and they might not even test for you because it's ineffective and it might go away in two years and, like, so then, what do I do? (Helena, Interview 2)

Seeking out information to make the right choice for them figured prominently in women's views. Yet, the value of talking to people in their social networks was also emphasized, especially in the face of the uncertainties of available information about the vaccine:

[M]ore than anything, for me, personally, like, trying to make a decision about the vaccine- it's been more just, like, hashing it out with friends and family and just like, getting other people's opinions, not like, about me personally, like, do you think I should get the vaccine, but just in general, like, what are your thoughts on it (Isabelle, Interview 2)

Um, you know, like, I just think that, um- that as women, it's something we need to talk about and discuss ...and to get information about- and to share with each other our experiences and, um, you know cause- cause that's how we learn, that's who, um- you know, like, to put the decision all on the individual, um, you're kind of left floundering and even if you have a doctor, kind of going, yeah, I think this is the best thing for you to do, um, I felt like I was- like I didn't have enough information and I felt- like, I think when people don't have enough information, they get scared (Sarah, Interview 1)

[E]ven just talking to other women and feeling around, seeing if there's other people, who have taken it and why or if they haven't, you know, what're-what're their thoughts about that (Breanne, Interview 1)

In sum, participants expected that balanced and comprehensive information would enable them to make autonomous decisions about HPV vaccination, in which they were free to choose whether or not to be vaccinated without intervention by anyone else. However, autonomous decision-making was difficult when the information was unsettling, difficult to access or potentially created by pharmaceutical organizations and thus driven by profit. Many participants recognized the authority medical practitioners had to make recommendations about HPV vaccination. Those who questioned the expertise and authority of medical practitioners stated that practitioners were groomed or offered incentive by pharmaceutical companies. Participants' reliance on their social networks illustrated the importance of shared knowledge and experiences as part of their decision-making practices about the vaccine. The processes through which women attempt to make informed decisions also highlights how they demonstrate their competence in being able to evaluate "biased" and "unbiased" information.

3.2 Accessibility

Young women's expectations about autonomous and informed choices about vaccination were complicated by their concerns regarding the accessibility of the vaccine. The women I interviewed were students and many had limited financial resources. The cost and time involved in seeking out the vaccines loomed large in their narratives:

[F]or me, like, a big thing is cost and, yeah, I don't think it's covered under our Blue Cross- Blue Shield, which, like, that's a lot of money. That being said, like, it's a worthwhile financial, but that's the big thing that's informing my decision right now, is finances and if I can afford it (Helena, Interview 1)

I haven't gotten the HPV vaccine, but, um, when I was thinking about it, I don't think I was- no, I was on health insurance, so it wasn't an issue but, like, I have really good insurance through my dad, so it's also if they can afford it. I'm not

sure if it's covered by MSP. (Lynn, Interview 1)

I think the bottom line with most university students really does come down to the numbers in your bank account and the funds you have access to (Ace, Interview 1)

Length of time and difficulty in scheduling to be vaccinated were of concern for the women, particularly when the vaccine requires specific spacing in between each shot. This concern was especially pressing for women without a regular physician. Some had to rely on walk-in clinics, where wait-times are often long and the medical practitioners unfamiliar:

I've talked to a few friends who've either just, you know, figured that it wasn't worth the hassle or, uh, that it hasn't been out long enough and- I mean, it is quite the process to go on the vaccine as well. I mean, you've got, I think it's four injections, um, and they all have to be equally spaced, I mean, try getting that done at the [health clinic], you know, it'd be like putting in two weeks of sitting around (Michelle, Interview 1)

[O]ne of the things I'm finding hard at UVic...is that every time I'm there, I see a different doctor, you know what I mean? And, so I find it really difficult to kind of make that connection with somebody, right? Like, I went to [out of province university] for my undergrad and masters and, so there, at the clinic, I had the same doctor the whole time. So, it's somebody that I get comfortable with, somebody, who knows me, who knows my history, you know, who's not reading other people's notes about conversations with me. Um, so I definitely think it's a harder conversation to have with somebody when you're seeing a new doctor every single time, you know (Wendy, Interview 1)

Some framed their concerns about vaccination costs as a form of sacrifice particularly for university students with few financial resources and little or no insurance coverage. These women prioritized more immediate concerns in their lives, like the ability to afford food and rent over the vaccine:

[E]veryone is at risk in a way, but what I'm saying is when it comes to six hundred dollars, which is not eating for like three months for me, I'd rather have the food and take my chances and that's really where it comes down to it at the end of the day (Ace, Interview 1)

And even though it's definitely a risk, like, there's other stuff that seems more

important to me, like being able to a conference or something, you know? With that kind of money- or pay my rent or groceries or whatever. So, for something that seems so far away and a problem that may or may not occur to me, like, it seems to be- I don't know, not a waste of my money, but, like, I would rather put it somewhere else I guess (Wendy, Interview 1)

Some expected that the high cost of the vaccine should guarantee the vaccine's purported effectiveness without unanticipated side effects:

[U]m, it's not covered by the health plan, to my knowledge and I actually like- I'm still covered under my dad because I'm a student and, um, UVic- and he has a really good health plan and it's not even covered under that. So, I think they told me it was around four hundred dollars for the vaccine. And it just seems like a lot of money for something that I don't feel I have enough information about or even long term, like, how- what will happen- like, I haven't seen any studies of like, you know, in twenty years what can happen to people, who've taken this drug (Breanne, Interview 1)

Sarah and Ace told me that having to purchase the vaccine highlights disparities between those who can and cannot afford it. They were critical of the expectation that women have to pay for the vaccine. They believed that the government should make the vaccine accessible to all people:

I think that, if people need it and it's gonna help our health care system, the government should be making th- the, um, the investment because it's the government, Medicare, that's gonna be looking after us if we get cancer, so the government should be making the investment, not us and there's really no incentive for us to make the investment besides not getting cancer because it's just reducing the risk, it's an insurance policy, really, so the government should buying that insurance for us or at least giving to us at a much reduced rate that we can actually afford at our age and they need to account how much spending money someone of our age actually has (Ace, Interview 1)

I am in the position that my family can afford it, right, but, not everybody's family can afford it and I don't- I don't think that that's fair that just because we're in the position that we can and that other people can't. There's a bit of- so there's a bit of, like, (laughs) socialism in me, you know, that I think- I think that, um, like we live in Canada, our medical system should be providing for everyone and, um, yeah, so I don't think that some people who have money should just have the advantage of it (Sarah, Interview 1)

Sarah stated that women were targeted for HPV vaccination because they would pay the full price for the vaccine to protect their reproductive health. She told me that if men were targeted for vaccination as well, the cost would be lower:

I think women will pay more for their health and I think the government knows that, um, or whoever's, um, you know, we will- we will pay more for our health than men will and that's why I think there's women that will take this vaccination and bite the bullet and- of the cost, but that- I don't think a lot of men would and so- and so they'll know that and they'll go, well, I guess we'll have to lower it if you want guys to take this (Sarah, Interview 1)

Concerns regarding the accessibility of the vaccine were also apparent when we discussed advertisements. Helena and Kay talked about commercials presenting vaccination as a responsible choice free from constraint. These ads also appealed to consumers through images of young women with whom they are expected to identify:

[S]eeing the campaign and the woman like smash the glass and that's, like a terrifying, powerful commercial and then talking to your health practitioner and then being like, well, it's gonna be over four hundred dollars. So, it's really not as accessible as the marketing makes it seem should be, you know (Helena, Interview 1)

[A] lot of the girls between those ages are generally single or have a boyfriend and they aren't getting married soon cause they're still in school or they're just starting out careers and, um, so they're kind of solo and independent, so they feel that they should look out for their own sexual health and I think that's kind of what the commercials are picking up on, that I don't need to talk to a bunch of people just to the individual considering getting the vaccine (Kay, Interview 1)

Most of the women problematized images used in the HPV vaccine advertisements. When discussing the HPVinfo website, many suggested that the images of people on the site reflected class- and race-based assumptions of wealth, affirming that the vaccines are not accessible for everyone. Breanne's discussion of the HPVinfo site's images exemplifies participants' concerns about accessibility:

Breanne: Um, well, I guess, like, beyond women, it doesn't seem, like, socio-economically speaking...it doesn't seem, um- not that there's a picture that you can kind of show to grasp a lower SES [socio-economic status] person, but, um, like, it does seem like it's more middle class, well, there's one African American woman, but, predominantly white women.

Jen: Is there something about it that makes it feel middle class to you?

Breanne: Just the way that they look. Like, not to, you know, typify people or whatever, (laughs) but, like, you know, they just have, like, a, um, I don't want to say- I don't want to say certain words because it sounds bad (laughs). But, like- I don't know- they just look- they just look well- not well off, but like, well kept and, um, yeah, like, you're not gonna see, like, a prostitute here, you know (laughs) (Breanne, Interview 2)

Similarly, when I asked Ace if the images and text suggested who the website's target audience might be, she identified particular physical markers indicative of the material wealth of the people represented:

[Y]ou know, like braces [referring to image titled, "Teens" depicting girl with braces] for example- that's expensive- like, braces are thousands and thousands of dollars- uh, you know, like, to be- to be that thin- honestly, to me, to be thin and that healthy looking, that- that costs money, like, you- you know, like, most people from my hometown are overweight because all they do is eat McDonalds cause that's all they can afford. Like, they- you know, like, you have to have leisure time to go to the gym- if you're going to high school and you're working like twenty-five hours a week, you're not gonna have leisure time to go to the gym, you're not gonna have the money to eat vegetables to be looking like these people look- upper-middle class, for sure, no doubt in my mind- like, middle class at the worst, but even still, they're probably, like, middle class people who really manage their time and money, um, and even then, no, because they wouldn't have the money to buy it and- I don't know, they look like normal people- what I would like to see people look like, you know what I mean (Ace, Interview 2)

Breanne and Ace's comments here echo Helena and Kay's discussion of the implicit expectation in the ads that young women could purchase the vaccine without worrying about the high cost. When I asked participants how they might make the HPVinfo website more accessible, some emphasized the necessity of considering the circumstances of people's lives:

I'm not sure actually, how you could, picture-wise, but even, um, just having a thing about, uh, financially how- how someone could afford Gardasil, like I

think that's- that's a big thing that, even for me, like, I would consider myself middle-class and like, that's a lot of money to- to fork over for something, um, and I think that's- it's, like- the fact that it's not there is assuming that people, who are accessing this, that it's not a big deal for them to just, you know, cough up four hundred dollars when, you know, they could be on food stamps or you know, only having five dollars a day to spend on food, like, um- I think that's a big thing (Breanne, Interview2)

I don't think it said that you have to go three times and that like, yeah, obviously the cost varies based on province. Um, I just think the cost is a big thing and like, yeah, if you're a student, you may be covered, make sure to talk to your school, you know what I mean or, like your employer may cover it (Helena, Interview 2)

As some women suggested, the HPVinfo website's images projected an idealized conceptualization of who is choosing to be vaccinated. In Ace's words, the website images are supposed to represent "normal" people. However, as women noted, these images do not account for those unable to occupy the idealized category of "normal" or unable to access the vaccine. For some of the women, making a responsible decision about vaccination entailed consideration of their lived circumstances. Their concerns regarding accessibility demonstrate the ways that enacting autonomous, responsible decisions reflects implicit assumptions of material wealth that were reproduced in ads for the vaccine and the HPVinfo website.

3.3 Protection

Protection was a key concern when the women discussed their sense of responsibility in maintaining their reproductive and sexual health. They evoked ideas of control and security when they discussed diseases that could potentially threaten their and their partners' reproductive and sexual health and lives more broadly. All participants discussed routine ways they sought to mitigate sexual and reproductive health risks. However, many also argued that women were overwhelmingly responsible for these routine practices in their sexual activities and relationships with men. How young women discussed these responsibilities was implicated in their thoughts about the HPV vaccine as a

woman's vaccine. They understood the vaccine to protect women against cervical cancer.

Most participants talked about the routine preventative practices that they expected of themselves and others as part of being a responsible sexually active person:

Um, I think being careful about who you sleep with? Um, I guess always using protection, right, which seems like a no-brainer, but it can often be forgotten in the- in the moment, especially if you've been drinking. Um, (laughs) so, yeah, and other than that, I think just u- taking care of yourself and getting your pap, you know, and I think it's something that- I don't want to say, my generation, but, I guess, in my- where I am in life, I'm s-still getting- you know, I'm still on birth control, I'm still getting my pap every week- every year because I have to, right.... I think it's something that an- an easy thing to do to prevent this and to be, you know, just checking your- your general health anyway. So, I think, yeah, getting your pap every- every year is a good- good idea to just, you know, double check and find it early if you can (Wendy, Interview 1)

[Y]eah, just be uber, uber conscious of who you're sleeping with and, um, I th- yeah, get tested. Tested, tested, tested and get tested regularly because, like, especially if you're in a new relationship- like, how many times are people still dating other people and sleeping with them whe- at- like, you know? (Sarah, Interview 1)

[T]o me, it's- I guess, um, I'm always on the pill. Um, I guess the man, wearing a condom. For me though, it's also about, like, knowing the person, like, I don't want to- and this is fine for other people, but I personally don't want to sleep with some random person that I don't know. Um, I think if I- if I know the person, I'm more comfortable with them, not that that means that they could or could not have HPV, but, um I think that that's something that's important for me, um, yeah (Breanne, Interview 1)

While Breanne emphasized the importance of knowing the person(s) one sleeps with, Isabelle and Helena discussed situations where that expectation is not always easily accomplished. They described the difficulty and awkwardness of negotiating safe sex practices with casual sexual partners, including communication about STI testing and provision of condoms and other contraceptives:

[B]oth parties should be, you know, as safe as possible and as um, informative about what could or could not be risks, um, but I- I think that that's something that people say and don't necessarily always follow through on in their practices, so....[I]ntentions might be there, but the heat of the moment will prevent you from carrying on with said intentions, um, that you know, sitting

down and having that conversation, if you're not in, like, a specific place in a relationship, like, if you're just kind of, like, hanging out with somebody and things are getting a little bit heated, but, you know, you're not official or anything, you don't, you know- you don't want to sit down and be like, so, I was tested a month ago and I know that I'm clear of everything, I don't really know what your situation is, cause you might not feel comfortable having had that conversation if you haven't had the, like, so are we dating conversation yet, both, you know, that's not necessarily going to stop everybody from fooling around, so, yeah. (Isabelle, Interview 1)

I think it's hard if there's somebody you're not committed to and you just like to sleep with them. You don't know when they've gotten tested, if they're being truthful and you just kind of hope that condoms will be enough which, to me, personally, very scary cause it's not always enough, right? (Helena, Interview 1)

Alice thought that protecting reproductive and sexual health was each individual's responsibility, particularly because others could not be trusted to share that responsibility. She drew upon her experiences of growing up in a religious family and attending a religious school, where she was provided abstinence-only sex education, to emphasize the importance of each person taking control of their reproductive and sexual health:

[W]hen I graduated and joined the real world, I realized that wasn't enough, so I went out and educated myself and part of educating myself was learning that I have to be assertive and- and be in charge of my own reproductive health because nobody else is gonna do it for me. I mean, if they wouldn't even tell me (laughs) that there are things you can get that aren't pregnant that are bad for you, like- no one's gonna take care of me, that's my job (Alice, Interview 1)

She drew upon the analogy of defensive driving to explain that each person is responsible for their reproductive and sexual health:

It's kind of the same as driving, like you should be a defensive driver because not everybody on the road is. If you can do that to keep yourself from dying, then you should have the same attitude towards your genitals (Alice, Interview 1)

All of the women made reference to the differential expectations between men and women to protect their and their sexual partners' reproductive and sexual health. All of the participants felt that

women carried the burden of responsibility:

[S]exuality is like, a woman's problem pretty much and that, like, any consequences that have to do with sex, whether it's like, children or, like, anything like that, um, is a woman's problem pretty much and a woman's prerogative (Helena, Interview 1)

[M]ost stuff that has to do, uh, with, uh sex and reproductive organs seems to sort of fall solely on the woman, like, you have the uterus, it should be your job (Kay, Interview 1)

(laughs) Oh, yes, it's always girls, who have to do everything. Like, it's- oh, God, sometimes it's sick. I mean, we have to shave our legs, you have to, you know, have a friggin' period every month, (laughs) you know, we have to take birth control, we have to do- like, it's just seems like everything is our problem (Wendy, Interview 1)

For some participants, women may be empowered by this responsibility, but they may also be constrained by it and face blame or stigma when they cannot enact this responsibility or when their strategies of protection fail:

Like, it was kind of like, on the woman- if you didn't tell the guy to wear a condom, then, you know, it was clearly your fault, not his fault (Kay, Interview 1)

Leigh: Um, there's definitely- you know, women are- are empowered by these kind of tools, but also, um, are given more of the responsibility and definitely, you know, after something happens, the stigma is different for men and women and, uh-

Jen: The stigma?

Leigh: Uh of getting an STD- of getting pregnant and anything kind of unwanted happening? As a result of sex, um- it's, uh sort of not, like overtly or literally, but, like, just kind of, like, subconsciously, less forgivable for women, I guess. Seems to be- not, like, forgivable, but, just, um- you know, it's like, if the tools are marketed and they're out there and, you know, women can take control of their own sexuality then they don't, well, you know, that's- that's their fault versus not as much marketed towards men and so, it's not their fault (Leigh, Interview 1)

While most participants were critical of the expectation that women were responsible for reproductive and sexual health in general, a more complicated picture emerged when we discussed

HPV vaccination. The majority of participants referred to the vaccine as specifically protecting women's reproductive health:

Yeah, and, um- yeah, exactly, just- it's definitely part of, um, that whole, like, system of, um, sort of, self-ownership through self-defense, if you will- you know, it's kind of a weird term, but, um- one of the sort of tools that a woman can use to continue to, um, make her own decisions around her lifestyle and, um, to do what, you know, she wants with her body and while being aware of the risks and making that informed decision is definitely a good tool, one of the many, yeah (Leigh, Interview 1)

I think in theory that it's [the vaccine] a really great idea because, I mean, cancer of any sort is unpleasant and nobody really wants to get it and if we found a way of preventing cervical cancer, which is so prominent in women (Isabelle, Interview 1)

[T]he way things are put a lot of weight and a lot of pressure on the woman and not so much on the men, but I don't think that the HPV thing really has anything to do with men because it's a woman's body (Ace, Interview 1)

All of the participants referred to their reproductive health and the risks of developing cervical cancer when discussing the benefits of HPV vaccination specifically for women. The protection offered by the vaccine was less against the HPV virus and more specifically against the possibility of developing cervical cancer:

I guess the brand name is Gardasil...that's the one that I'm getting and, uh, that it, um, protects against some forms, maybe, like, the most common forms of, uh, Human Papilloma- Papillomavirus, um, which, uh, can- if you get infected and, like, so many people are infected and, like, just don't know about it or whatever, um, can- I can't remember if it's like- can either lead to cervical cancer or puts you at, like huge risk, or, not like, huge risk, but, like, increased risk for cervical cancer, so, yeah, in a round about way, a vaccine to protect against cervical cancer (Leigh, Interview 1)

I think that as far as HPV goes, there's def- maybe not- not, like, an enforced sort of role that it is for women, but it's sort of like an assumed because it's more prominent to cause cervical cancer, um, so therefore women are the one's with cervixes, so it makes sense that they are the ones that should be responsible in this regard (Isabelle, Interview 2)

Jen: All right. Um, do you think that being a woman has anything to do with getting the vaccine?

Dawn: Yes.

Jen: Okay (laughs). Is there anything specifically that makes you think that?

Dawn: Because I have a cervix and I can get cervical cancer (Dawn, Interview 1)

When I asked if women were being targeted for vaccination more than men, many responded with confusion or asked me if men could be vaccinated:

Jen: Um, do you think that being a woman has anything to do with getting the vaccine?

Joyce: Um- I'm not sure what you mean.

Jen: Um, I'm just trying to think of how I could explain it differently. Um, well, maybe I'll start with- I'll- I'll flip another question around. What do you think about guys getting the vaccine?

Joyce: Oh, I didn't even know that was possible (laughs). I just assumed it was for women only. Um, yeah, I guess that's why the first question threw me off because I just thought women take it and men wouldn't, so. Yeah (Joyce, Interview 1)

Jen: Do you think that being a woman has anything to do with getting the vaccine?

Breanne: Yes (laughs). Can't only women get it?

Jen: Um, as of February of last year, two thousand and ten, uh, it was made available to men.

Breanne: Really? Wow, I would never- I did not know that. Especially- yeah, all the- all the commercials I feel like are- are of women. Hm. I didn't know that. (Breanne, Interview 1)

Some participants attributed their understanding that the vaccine was for women to the advertisements:

[T]he ads all feature women and they're all in kind of pastel colours and smiley faces and, like, it's definitely a girl vaccine. No man is ever gonna see one of these ads and be like, you know what I feel I should get is this chick shot, it'll keep my cervix nice and safe (Alice, Interview 1)

[T]here's tonnes of commercials for women. So, like, why isn't there for guys if there is a vaccine. And if it is supposed to be, you know, an equal thing within sexual reproduction, like, men and women protecting themselves like, why wouldn't there be commercials for guys (Breanne, Interview 1)

[T]he commercials, they were showing women, I s- think, I could be totally wrong, but, um, showing pictures of young women in the advertisements so then you just kind of associate the- the vaccine with women, um, yeah, I don't really remember men being mentioned, but maybe- yeah, I just didn't pay attention (laughs) cause I was concerned about women and us and, like, that sort of thing (Joyce, Interview 1)

When some women refocused their attention on the connection between cervical cancer and HPV as a sexually transmitted disease, criticisms of the differential responsibilities of men and women to protect reproductive and sexual health resurfaced:

[I]t seems to me that the purpose of the vaccine is less about, um, preventing infection with HPV as it is about preventing infection with HPV that causes cervical cancer. Um, so it seems that the natural thing to do is to protect the part of the population that's going to get cervical cancer...It makes sense to me to- I don't know- that- that part makes sense to me, I can see why it was a women's vaccine first, but when you look at the way that it protects against cancer, um, about- against that particular woman cancer, uh, then it should be automatic that you prevent against the same infection in men. I mean, not everyone, like myself- not everyone woman is going to get the vaccination, but, if the guys that I'm sleeping with have had it then my odds of getting it are less (Alice, Interview 1)

I think that the option should be there if the options are for women, it should be for men, um, I don't think that it should be shoved down anybody's throats by health practitioners or by marketing. Um, I think that it- it potentially shows kind of a movement, um, towards this idea that men should also be responsible for, um, safe sex, uh, for their own bodies and for their partners bodies....Yeah, and, I mean, I- unfortunately, I feel like there wouldn't a heck of a lot of men going out to get this vaccine. Um, I think that there's a lot of changes that need to be made, uh, as far as masculinity and sex and what men see their responsibilities to be before men are gonna be going out and protecting themselves in this way or others, I mean there's been talk about male birth control, there's been, you know, talk just about getting regular testing done (Michelle, Interview 1)

Leigh regarded the vaccine as a tool that offered women some control and security over their reproductive and sexual health, particularly in preventing cervical cancer. Yet, on the topic of men being vaccinated against HPV, her perspective on the vaccine as a form of protection against cervical cancer shifted as she questioned why women were targeted and men were not:

Well, you know what? I hadn't thought about it until right now when you said it, but I guess it's like- unless, I mean, I don't know, I guess, enough about the biology of- of it, but if it's just to protect against the virus, then shouldn't everybody get it? Holy crap! I don't know why I never thought about that. And, yeah, like, I've- mm, now I really want to go and like- my- my Google is kicking in, I guess- it's like- I- I hadn't thought about it- if, you know...if what it does is just protect against the virus and has nothing to do with kind of, um, how the virus affects your body? Um, then it would make so much sense for men to get it too because...they're like, carriers of it too. Holy crap. (softly) Smart question. Holy crap (Leigh, Interview 1)

Related to some of the women's thoughts and decisions about vaccination was whether their routine preventative strategies would mitigate the risk of HPV and secondary illnesses. Though HPV tests are unavailable in Canada, for some of the women, these routine "safe sex" strategies provided assurances of protection against HPV:

I get regular Pap smears, I'm in a monogamous relationship, I didn't consider myself to be at a huge risk for it particularly seeing that, you know, I am careful about regular Pap smears (Michelle, Interview 1)

I tend to think that I'm fairly well informed about my sexual health and that I'm fairly okay with, you know, taking precautions and being aware and asking the questions that needed to be asked, but, um, I think that the caution that I take makes me at a lower risk for any kind of STD, including HPV (Alice, Interview 1)

Um and I spoke to my doctor at- at that point, when they [HPV vaccines] had first come out, um, and then I was in a relationship- I'd been in a relationship for two years and it was quite serious and, so, I was kind of like, yeah, I don't really feel like I need to get it, like, I'm not, you know, sleeping around with other people and so, I'm not really that concerned, um, about, you know, getting the virus or- um, and I'm getting regular Paps, right? So, it's kind of like- doesn't feel to me like it's a huge concern (Wendy, Interview 1)

For other young women, the vaccines offered protection in ways not necessarily provided by routine practices. For those who had decided to be vaccinated, the vaccine was not a "fix-all" or "cure-all." Rather, it offered additional protection against HPV, which they knew was prevalent.

Leigh's decision to be vaccinated against HPV made sense in the context of her trust in vaccines to prevent contracting disease:

I didn't really think about the implications of deciding to get the vaccine in terms of, like, I am making a decision to not, sort of, let my sex life be, you know, shaped by fear of, like, you know, getting a virus or whatever, um, but just sort of good decisions being guided by knowledge- the, like- realism about the fact that it's out there (Leigh, Interview 1)

Part of Helena's desire to be vaccinated was motivated by her experiences of volunteering at a health clinic, where she interacted with people who had HPV. Vaccination became part of what she considered responsible practices in protecting reproductive and sexual health, particularly after seeing how HPV affected people:

Um, I don't feel pressure and, like, the obligation, I guess is just more my own health, but I've definitely become more aware since I started at the clinic about, like, the very real risk of HPV- of getting HPV and um, the consequences of it, I guess, yeah. (Helena, Interview 1)

Before she developed precancerous cells in her cervix and similar to some of the other women's perspectives, Sarah stated that routine safe sex practices would protect her from the virus. However, her experience of developing precancerous cells persuaded her to reconsider her earlier decision against vaccination. She discussed the sense of security the vaccine could provide her and others:

[Y]eah, so, the extra benefit, um, I think would just be, um- would be any, like, kind of security that you could give yourself and- and there's other strains I don't have and, um, and I think that I need to be, um, not like, proactive- like, it's just like- um, there is a potential that I will have another partner and I don't know what they're gonna be coming into the relationship with. Every year you get older it seems that it gets scarier to have sex- (laughs) more people have things and, um, so, I think, just, um- just to plan for anything that could happen, um, just to kind of give myself the most safety that I could have. And I- I think, like, vaccinations are- are out there not just for the individual, they're out there to, um, prevent the spread around populations, right, and the spread is pretty huge, um, right now for HPV and so really anything that you can do to lower that and to lower the contraction rate, um, I think is- is really important, um, because, like, cervical cancer is really preventable and, um- and, so- yeah, you

don't- you don't want to be messing with your baby making bits (laughs) (Sarah, Interview 1)

When we discussed the HPVinfo website's "Prevention of HPV" section, which identifies best practices for prevention of HPV, women's responses were divided as to the usefulness of the information. The prevention section states that abstinence is the only absolute way of preventing HPV, while monogamy, limiting the number of sexual partners, condom use and regular Pap tests help to lower the risks of contracting the virus (SOGC 2009g). Highlighting what they perceived as the site's implicit judgment of some sexual practices as irresponsible, some participants questioned or problematized the assumption that all women would find prevention strategies in this section effective:

I think it definitely, um, kind of sets an assuming tone that peop- the m- that young adults, who're having sexual relationships are not always careful and may not always know the person that they are having sexual relations with, which is the case sometimes, but I think it's a pretty big assumption to make...like, the fact that they have to define lifelong monogamy is kind of- yeah, I don't know... it all kind of implies that young adults are these promiscuous, eager people who just- yeah, jump at the first opportunity to get it on with anybody, like, it kind of sets that tone. (Isabelle, Interview 2)

[E]ven limiting shouldn't be there, it should be, like, uh, it's a fact that the l- le- the less sexual partners you have, the lower risk you'll be at kind of thing- that should be there, but not limiting the number of partners because girls don't try to be promiscuous, we don't...I got called promiscuous a little while ago and I was like, um, no! I'm not promiscuous, I just date a lot of assholes and then it doesn't work out (Ace, Interview 2)

I just think the whole thing about, like, knocking promiscuity because, obviously, if you are promiscuous, then you're not having safe sex, the two are equated, then that constantly goes hand-in-hand (Helena, Interview 2)

For other participants, the "Prevention of HPV" section on the website provided what they considered non-judgmental facts of HPV transmission and the types of "high" and "low" risk sexual practices:

[T]hey're just saying, kind of, the- the straight-up facts...you know, no morality enters into it, which is good, um, in my opinion and they're just saying things

that are kinda hard to, um, argue against, that you know, like, monogamy and, like, abstinence and then- or- or abstinence and monogamy and limiting your number, like, basically, um, in terms of just straight up biology and the way these thing work (Leigh, Interview 2)

[I]t's presenting the only way of absolutely preventing the disease, which is absolute abstinence or lifelong monogamy with a partner, who's also being only monogamous with you, um, but also recognizing that that's not a behaviour that most people are going to end up with (Alice, Interview 2)

Some women viewed the HPVinfo website as promoting HPV vaccination. They suggested that because the Prevention of HPV section's limited strategies for preventing HPV were unlikely to be useful for the majority of young women, the only alternative appeared to be HPV vaccination:

It- it doesn't seem like there's really strategies for them, like, they're not abstinent, they're not going to be monogamous, they've had many partners, so, okay, you're at high risk and they're most likely using condoms, um, so it just doesn't seem like there's- there's really options for that person, other than to, like, get vaccinated, I guess, which is, I guess, another reason why it seems like it's targeted towards young people, very young people. Um, if you're- if you are talking to really young people, then perhaps, you know, these three points would- would be valid and kind of resonate with them (Breanne, Interview 1)

I think it is one of the- the reasons why- why the site's created in a lot of ways- you need to- to get information about the vaccine and encourage people to get vaccinated, so it's interesting that they're making that connection rather subtly (Michelle, Interview 2)

For a few women, the HPVinfo site offered a reminder of strategies to protect reproductive and sexual health without promoting vaccination:

[I]t's not just- that there are things that you can do that will protect yourself, if not prevent the disease, um, that don't require a lifestyle change and those being presumably, um, using condoms and getting regularly tested and having regular pap smears. Like, it doesn't say sort of, well, if you don't fall into these categories, it's pretty much over for you, you know. Have fun with your- your cervical cancer (Alice, Interview 2)

[T]hey're also telling you, like, you can go and get Pap smears and that sort of thing, so I think even if a person was like, oh my gosh, I've slept with so many people, at least there's a way to kind of check to see if you have it or not, whereas, that's not the case for men. If you have a really promiscuous man,

well, he has no real way of knowing whether he has it or not, so that would, maybe, be more stressful (Joyce, Interview 2)

Joyce's comment reflects some of the other participants' thoughts regarding the HPVinfo site.

Many stated that website reproduced the heteronormative expectation of women's responsibility for protecting reproductive and sexual health when we discussed who the site targeted:

[I]t's primarily geared towards women, for one thing. There's a lot of pink, (laughs) um, and then it-it would seem to me that it's- it's geared more towards young women, uh, which I suppose is- it's the target group of the vaccine (Alice, Interview 2)

[I]t all felt very directed towards heterosexual females, um, the- the fact that the little logo is pink and all of the writing is quite soft (Isabelle, Interview 2)

Even like, yeah, like the mom hugging her daughter, like all the images are very woman-centric, which is- I don't know... again, what we talked about before in the last interview, like, it's the woman's responsibility- the woman's responsibility in a heteronormative relationship to take care and prevent any sort of STIs. So, that's reinforced (Helena, Interview 2)

While many of the participants thought the site overwhelmingly represented and targeted women, Isabelle and Lynn felt the site was fairly balanced:

HPV is only one of many STIs and that sort of thing so, um, I think as far as, like, getting the vaccine would go, it sort of pushes, like, a female role in it more than a male role, but um, like the site does mention, um, using condoms and that sort of thing and I think that in that regard, it all sounded fairly, um- uh, what's the word- like, equal in- like it didn't- to me, it didn't come across as being either party's specific (Isabelle, Interview 2)

Um, well, it does talk a lot about condoms frequently, um, and there is information on there about men getting the vaccine too, so I don't think it really puts the onus on either sex. Like, it- it is- like, it'll be a little bit skewed towards women because of, like the information about cervical cancer, but, it- it was very- well, it was more neutral (Lynn, Interview 2)

In the context of discussing men's use of the HPVinfo website, many participants suggested that men likely were not considering HPV vaccination because women were the primarily targeted for vaccination:

[T]he fact that it's so directed towards women, the- the fact that they talk about pelvic exams and pap tests so much, but they don't really talk about- I mean, pap tests have no relevance to guys, um, they don't talk about, like, any of the male medical checks that they should be getting (Isabelle, Interview 2)

I don't think that, in general, a young man is gonna go on a site with a bunch of pink on it and look at it, no, the only way a guy's gonna pay attention to this is if somebody, like gets him to look at it. Like, it would have to be, like, some woman in his life, whether it be his girlfriend, his mom, whatever, his sister (Ace, Interview 2)

All of the participants were critical of these expectations that women alone bore the responsibility for protecting reproductive and sexual health. Some participants revisited this expectation of women's responsibility when discussing HPV vaccination. In focussing on the vaccine as a tool for protecting their reproductive health, women attenuated the connection between cervical cancer, HPV and sexual transmission of HPV. When participants focused on transmission of HPV through sexual activities, they were critical of the expectation that women were responsible for choosing to be vaccinated.

3.5 Chapter Summary

This chapter explored young women's ideas of responsibility in relation to their thoughts and decisions about HPV vaccination. Their perspectives highlight the complex and dynamic ways that a sense of responsibility emerges in their thoughts and practices about reproductive and sexual health in general and HPV vaccination specifically. Women endeavoured to make informed choices about the vaccine by accessing and evaluating what they deemed "balanced" information about the vaccine. Their understandings of informed, personal choices reflect public health conceptions of "responsible" decision-making. However, informed decision-making for women also required consideration of their social circumstances, including their financial constraints. Furthermore, women also demonstrated their responsibility through their ability to protect themselves from harm, including cervical cancer.

Participants constituted forms of responsibility toward themselves through their abilities to make decisions about their health in ways that reflect the context of their daily lives. Their decisions, then, unsettle some of the assumptions in the public health literature that women can or should make decisions in isolation of these circumstances. In the next chapter, I discuss the ways women conceptualized risk in relation to their decisions about HPV vaccination. In so doing, I build upon women's concerns with being "at risk" and with protecting themselves

Chapter Four: Young Women's Perspectives on Risk

This chapter focuses on young women's thoughts and experiences regarding "risk" particularly as these related to their ideas and decisions about HPV vaccination. The pervasiveness of "risk" as it relates to HPV in the public health literature about HPV vaccination led me to anticipate that "risk" might loom large in women's thoughts and concerns regarding HPV vaccination. The work of social theorists (Beck 1992; Douglas 1992; Peterson 2003; Lupton 1995) indicates that "risk" is particularly pervasive in how people think about and enact strategies of health maintenance. However, as noted in my introduction to Chapter Three, women's narratives about "risk" were less prevalent than their narratives regarding "responsibility" when discussing HPV vaccination. When women evoked the language of risk, they were primarily concerned with being "at risk", wherein they identified potential threats to their health. Risk has been differently theorized as an epidemiological measure of probability, fate, danger and chance (Kavanagh & Broom 1998). The women I interviewed conceptualized risk as harm from which they needed to protect themselves.

4.1 Trust and Distrust of Vaccines and Medication

In this section, I discuss participants' thoughts regarding trust or distrust of the HPV vaccine. All thirteen of the participants reflected on the safety of the HPV vaccine when they discussed whether or not to be vaccinated. Some of the women talked about vaccines as "risky" or being vaccinated as putting themselves "at risk" of potential unknown side effects. Some reflected on how the lack of long-term research regarding the vaccine led them to express suspicion of it. The young women often drew analogy to other medications or vaccines that they expected I would be familiar with when they discussed their thoughts on the HPV vaccine. A number of participants' distrust of the HPV vaccine

was connected to their knowledge of the length of time other medications had been researched, tested and available to people. Comparably, the HPV vaccine was too new. Other participants were wary of the vaccine because they were suspicious of medications in general. Negative experiences or knowledge of other people's negative experiences with vaccines also led some of the young women to express suspicion of the HPV vaccine's purported safety and efficacy.

The length of time in which the HPV vaccine has been available to young women and girls was a key concern to participants, particularly because they didn't know what the potential effects of the vaccine might be in the future. As part of their strategies of making an "informed" decision about the vaccine, participants felt they did not have information about the potential for negative effects of the vaccine in the future and emphasized the need for more long-term research:

I get that, um, and they also wanna get it out because then they can make money, right. They're not making any money from a drug that they have to do research for ten or fifteen years on, right? So, like, I get it that they wanna get it out there, but it is is- it's just- I mean, I don't know- five years and I mean, that's since it's been out, right. Like, before that, there's nothing, there's nothing, you know. And how many- how many rats got this, you know, like- like, you know and what it really is- I mean, I know there's all- if you see a lot of similarities, but, really, what are the complications that could happen by putting it in humans and that- but we haven't tested it on humans. How ethical is that? (Wendy, Interview 2)

Like, do I take the vaccine and potentially protect myself from getting HPV? Or do I take it and in twenty years, I have some weird thing that they're like, oh yeah, in the two thousands, all these girls took Gardasil and we didn't know what was gonna happen and now there's th- thousands of girls, who have this condition, or whatever, you know? So, I guess (laughs) that's what my thing is about vaccines, yeah (Breanne, Interview 1)

[I]t hasn't been tested for a long period of time, it's relatively new. I would rather have a vaccine that's been around for a really long time, that I know people've grown up and had healthy pregnancies after and all that kind of stuff. I don't really know the facts on the- the long term effect on the vaccine (Dawn, Interview 1)

Like Dawn, many of the young women used their knowledge of other vaccines and medications to make sense of the HPV vaccine when describing their thoughts on whether or not to be vaccinated. When reflecting on their concerns about HPV vaccination, most drew analogy to other vaccines and medications. However, how these analogies were connected to their trust or distrust regarding the vaccine varied. Alice, Kay and Sarah linked their concerns about the HPV vaccine to medications that have been around for a longer period of time. Their distrust in the vaccine was articulated through their knowledge that other medications' effects, whether intended or unintended, were better understood and documented than the HPV vaccine, which is relatively new. Through their comparisons to other medications, they questioned the safety of the HPV vaccine:

I'd also want to know if there were any side effects that'd been noted already in the research, um, or any potential for long term consequences. I'd wanna know kind of what the vaccine was made of and what kind of- there's a lot of times things are related to other vaccines that've already been. Um, and some of them are, you know, fantastically safe, so if it was, kind of, piggy-backing on that kind of a scientific model, I'd feel more comfortable with it, I think. (Alice, Interview 1)

[I]f someone's gonna walk up to you and be like, you haven't been vaccinated for polio, do you want a polio vaccine? And, you know, that's probably okay cause that vaccine has been around for quite a while but the HPV vaccine- I think I was just uncomfortable cause it hadn't been around for a long time (Kay, Interview 1)

It's not there yet. I don't think it's [HPV vaccine] even close to where birth control is. Um, I think- birth control has a huge history of what, um- what the contraindications are, what, um- what the side effects could possibly be, like, you know, if you smoke that you have a higher risk of strokes, like, you know, it's really, really documented, it's been around for a long time, we know exactly how it works, and, um- and- but, there's still people that don't even like putting birth control into their body, right (Sarah, Interview 1)

Some of the women's suspicion of the HPV vaccine was associated with their knowledge of other medications that have had unanticipated side effects, which could cause potential harm to their

health. Their comments reflect concerns over control, where vaccines are expected to offer control over diseases or “bugs”, but can have uncontrollable and dangerous consequences:

I don't know, I just have this thing against vaccines, I don't know. I'm just like, you know, the flu shot and stuff, I just feel, it's so- it just feels like everything's trying to be so contaminated- or not contaminated, but like, not contaminated, you know, everything's gonna be so pristine and clean and, like, get this shot and don't get that and get- like, I don't know, I think it's good for us to have a bit of exposure to- to some bugs, not that like, HPV is just exposure to a bug, but, like, I don't know, there's something about it that just doesn't feel really right (Wendy, Interview 1)

I- I'm not comfortable with it, and even things that aren't as publicized as, like, thalidomide that they- you know, everything was tested and they thought that was great and then babies started being born without arms (Alice, Interview 1)

I don't know, I guess, just, my entire family, we're just kind of skeptical of the vaccine and- I don't know, I've seen and read a lot of stuff especially with the whole H1N1 scare, um, and looking back- what was it, like, twenty years ago, um, when H1N1 happened and there was all these people, who got, um, psychological damage and people, who were, I don't know, paralyzed and stuff like that (Breanne, Interview 1)

Five of the young women related their thoughts and decisions about the risks of the HPV vaccine to their experiences with other medications or their knowledge of other people's negative experiences regarding vaccines and medications:

I had a friend who got a flu vaccine a couple years ago who almost died from getting her flu vaccine. I don't know what they did to it or something, but she had to be hospitalized for, like, two weeks, um, and, so I ended up- I- I've had a interesting run with people getting- not specifically this vaccine, but just vaccines in general that had been, like, well, I think I'm just gonna sit back and wait and watch what's gonna happen....Um, my friend has really bad asthma and, uh, she- people- everyone was yelling at her to get vaccinated for the swine flu and she's like, I can't get the vaccination for the fli- swine flu because if it'll- if the vaccine, which had been making people, in particular, uh, sick in [out of province] ...so they were telling her to fly home and get it for free and then come back- um, she like, if there's any, any complication at all from the vaccine I'll- she- she would just die because her asthma's so bad, there was- there would've been no time to, like, hospitalize her and get her better. She would've simply just died (Kay, Interview 1)

I was on Depo Provera for quite some time and the longer I was on it, the more public they were becoming about this, um- these potential problems for, uh, bone density and so I think that it made me a little bit more cautious about going on something that hadn't been on the market for a long time (Michelle, Interview 1)

Well and I've had some long-term effects from all of my random, different health disorders, so I'm really concerned about that and anytime I'd had a vaccine, I'd be down for at least a couple days and the- there were two years that I got the flu shot and it made me completely ill for at least a month each time. So, I've just been wary of vaccines just because they make me so sick. And then there's- there's all the- the information out there about vaccines causing like, autism and stuff, so it's kind of- I'm not sure- there was- I can't remember exactly what it was, but they were talking about the sort of constituents that the viruses and stuff are floated in and that's what's causing issues, so that's kind of where I'm going (Lynn, Interview 1)

Several of the women regarded the HPV vaccine as different from vaccines for measles, mumps and rubella (MMR), flu, and hepatitis because of the association between HPV and sexual health. Isabelle and Sarah were particularly concerned about the long term effects or risks of the vaccine might have on their reproductive health:

[M]y only concerns about it are the long term effects of it because it's such a recent development and such a recent vaccine. So far everything has turned out- well to the best of my knowledge, but um, you know, as women that'd have it start to go through menopause or that sort of thing, um, that's where my thoughts about it get a little iffy (Isabelle, Interview 1)

Um, in the beginning, I was just, like, I don't wanna put something I don't know what I- what's in it, I don't know what kind of, um, contraindications it will have or long term effects, um, and- and I think, because it had to do with, like, um- like, for me, like, there's just been, like, a fear of, like, um- like, it has to do with your reproductive system, right, and I'm like, I just don't want to mess with that and, um- and, so even though I'm pretty dang sure you're not gonna become, like, sterile or something from, like, taking a vaccine, it's just something that's, like probab- it's more of a sensitive issue, right, than just getting a general flu (Sarah, Interview 1)

Leigh, whose trust in vaccines persuaded her to be vaccinated against HPV, referred to other participants' concerns regarding the harmful effects of the vaccine and medications as “theoretical

risks”. When I asked her how she might help a hypothetical friend decide whether or not to be vaccinated against HPV, she emphasized her trust in vaccines to protect against what she termed the “real risks” of diseases over the “theoretical risks” of vaccines’ unknown side effects:

I would probably be like, oh yeah, and, like they- I mean, they test vaccines, you know, like, they totally- like, they- health- public Health Canada wouldn't, like, release a vaccine to us as, like, guinea pigs, although they kinda did that in Ontario, but, you know. Um, as somebody who's studied a lot of biology, it's just that kind of- um, I have a sort of personal campaigner for science and I kinda feel like, you know, these- these kinds of drugs go through a lot of testing before they actually reach the public so- um, if there's no evidence against it, but there is strong evidence that it will protect you against something real, then I would, kind of, want my friend to think about the real risk of HPV, which is definitely out there, versus any sort of theoretical risk (Leigh, Interview 1)

Three of the participants considered vaccines to be a normal or routine part of taking care of one's health and even an obligation:

Um, the, what's it called, the flu vaccine? That people get and nobody seems to have any problems with it and everyone's, you know- they think it's a- like, a natural thing to do, they tell you if you're working with kids to get it, if you're working with the elderly. I went to- I was living in a [college outside of Canada] and they said to get it (Alice, Interview 1)

[P]eople seem to kind of push vaccines a little bit too much as, like, the solution for, um, all the world's ills and I think that some vaccines are perfect and fine and you don't need to, uh- you don't need to worry about them, I suppose... so I- I don't know- I think that vaccines are a good idea and I am glad for the vaccines that I have gotten, uh, but I don't think that they should just be so casually accepted some- sometimes (Kay, Interview 1)

Dawn: Hm, I don't know, I guess vaccines always are kind of like, they don't- I don't feel like I have control over them, like they're just kind of like- they're- they seem like they're just, um- they don't seem like an option to me. Well, like, when you get, um, hepatitis vaccine in, uh, elementary school and these kinds of things, they don't- they're just part of living, not something that you have to actually put effort into or choose to do.

Jen: So, kind of like, it's just something that you're supposed to do?

Dawn: I guess something that you're supposed to do, but it- it's not like I- like something that you, like it doesn't feel like a law or something, it just feels like par- something that happens, not like, um, that it's wrong not to do

it, but it's just like, oh, it's time to get your vaccines. You give it to your kids and grow up getting vaccines (Dawn, Interview 1)

Young women acknowledged the value of vaccines in reducing the risk of diseases, but regarded the HPV vaccine as risky and potentially harmful to their health. Many also expressed concerns about the risks associated with the “newness” of the vaccine and lack of long-term research and questioned its safety as a medication that is supposed to protect women’s health.

4.2 Ubiquity of Risk

In this section, I focus on what I have termed the “ubiquity of risk” where the young women expressed an understanding that all sexually active people, including themselves, are at risk of HPV. Some of the participants distinguished different kinds of risk in terms of “high” and “low” as well as the practices associated with them. However, they argued that all sexually active people were “at risk” regardless of their sexual practices, partners and prevention strategies they employed to protect their reproductive and sexual health:

[B]eing high risk doesn't really differentiate you from being low risk in the sense that it doesn't take doing something over and over and over again, really, to get you the virus, it just enhances your probability (Ace, Interview 1)

[I]f you're sexually active and you're having lots of other partners or if you're having unprotected sex, but I also understand that HPV, you know, it can be transmitted, even if you are having, uh, protected sex. So, that's a tough one, I mean, obviously, if you're having multiple partners, you're more at risk, um, but, you know, shit happens (laughs) even if you are in a monogamous relationship (Michelle, Interview 1)

[L]ike, everyone always says, I never thought it would happen to me. Um, but- but, yeah, like, I definitely- I know that I'm in- in the group of people, who are at risk. I think unless you're celibate, you're basically the only group wouldn't be at risk (Breanne, Interview 2)

[L]ike, if somebody says that sentence, that you're at risk of getting HPV, I would kind of think, yeah, so are all of my friends, like, so is everybody that I know that's sexual, like, everybody's at risk of getting HPV if they're, you

know, engaging in that sort of activity (Isabelle, Interview 1)

For a few participants, the HPVinfo website affirmed what they understood to be the pervasiveness of risk in everyday life. In Chapter Three, I described some of the ways that some participants found what they expected to be “balanced” information provided via the HPVinfo website unsettling. Yet, with regard to the HPVinfo site’s information about the widespread risks of HPV, some participants said it provided a “good” or “complete” picture about the virus:

Um, well like I said, it’s good information, but, it’s really but, I mean unless you’re gonna wear, like a rubber suit that completely- like, there’s not really anything you can do (Lynn, Interview 2)

I guess it’s good that, um, they chose a man to tell his story, um, I like that they said, you know, the more people you sleep with, the higher your chances, but he said you could- you know, it could happen on your first time. No one knows who has it, you can’t tell by looking at people. Um, yeah, I thought it was good (Breanne, Interview 2)

[I]t’s presenting here that that’s- you’re not gonna be a hundred percent fine no matter what you do, there are always going to be risk factors, um, and possibilities for infection and all sorts of things. I think it’s done a very good job of giving, like, a very complete picture (Alice, Interview 2)

A few young women regarded the website’s presentation of the pervasiveness of HPV risk as simultaneously normal and alarming, particularly when they were uncertain about how to protect themselves from the virus:

[T]he information it was giving you was, there could be this scary, you know, potentially life-threatening, um, infectious disease that you have at the same time, or communicable disease at the same time, it’s not necessarily tested for in Canada and you really shouldn’t worry about it, so, yeah, just very- I felt it was very conflicting information (Helena, Interview 2)

I guess the other thing that makes the story of HPV difficult is the fact that they’re saying that there’s kind of, like, a almost like, sleeper HPV, that you can have it and not know you have it and so, unintentionally pass it on to others, I think that it’s hard for people to hear that- that they can be carrying it and not know it. I think people want to know whether they have it or not and that might be a little- a little disconcerting [sic]....So, it’s kind of one of

those situations where, you know, it'd be nice if we all had this little litmus test telling us whether we had it or not because yeah, you could have one of the viruses and not even know it, that's kind of scary and they seem to really emphasize that most of them are normal, that, you know, it's okay that you have it, there's just very specific strains that are kind of dangerous and can lead to cancer and that sort of thing. So, I think they do a good job of trying to balancing that message about like, being reassuring, but also, you know, don't freak out about it, like it's kind of normal almost. Um, so, it's a difficult story to tell, it's complicated and people want simple stories, but I think this is one of those viruses where it's just complicated (Joyce, Interview 2)

[I]f they're assuming that people are reading these things in order of the way that they're presented there [in the Prevention Section] then, like, on the- the headings on the side, then they would've already read the whole thing about how, you know, chances are nothing will happen and, you know, there's so many kinds that even if you do get it, nothing'll happen and all these kind of things, so with that in mind, you know (Leigh, Interview 2)

In Chapter Three, I described the routine ways that participants protected their own and their partners' reproductive and sexual health, which included condom use and limiting the number of sexual partners. While many participants emphasized the importance of these routine practices they also recognized that these practices would not mitigate the risk of contracting HPV particularly because there are so many strains of the virus. Their awareness that routine practices did not prevent the risks of HPV amplified their concerns regarding the pervasiveness of risk when we looked at the "Prevention Section" on the HPVinfo website:

Um, and then limiting the number of partners, like, we just talked about it, you know- it's true that the more partners you have, the higher your risk, but then at the same time, they just showed in the video, like, your first partner could be- you could contract from that, um, and then, condom use, like, you can use a condom, but still get it, so I don't know, it just seems like they're not- they're not really very good prevention strategies (Breanne, Interview 2)

[O]ne thing I didn't- I did not know this is that you cannot get tested for it in your Pap everywhere in Canada and that they probably won't even do it necessarily because it goes away- like a lot of the strains go away in two years- I did not know that and that to me is kind of like, well, fuck, like- sorry- (laughs) like, how do you even know if you have it, you know what I mean, like, to me, this was almost more discouraging to read this kind of

information? (Helena, Interview 2)

[T]hey do, um, suggest that, you know, seventy-five percent of Canadians will have HPV, uh, in their lifetime, um, you're im- I'm not sure how clear they are about whether- that it can be harmless, but, um- well, it's kind of interesting as you- they say over and over again, you know condoms might not always, you know, prevent HPV and infection, but it's just like, well then what? Like, this is implicit idea that, like, abstinence is best and abstinence is, um, likely. Which for the vast majority of people, it's not (Michelle, Interview 2)

Women were aware that they might be at risk from numerous strains of HPV yet the vaccine offered protection against only four strains. Furthermore, most participants suggested that the virus “clears up” on its own:

[S]ince it only protects against two strains, it's kind of- like, it's- it's good that it would help protect against cervical cancer, but since there's so many other strains of HPV out there, it's- it's like a needle in a haystack kind of thing (Lynn, Interview 1)

[I]t's one of those things too, like, it's a virus. It changes, it- you know, it has different strains, so, I mean, I might get vaccinated and who- like, you know, and especially- I mean, I get vaccinated, I'm only vaccinated against two strands that cause cancer, like, I- and I think he said there was five or something- like, well, what about those other three? You know, so don't try to tell me that if I get this HPV vaccine, I'm not gonna get cervical cancer because, a, there's still other things out there that could cause cervical cancer and who knows in ten years if there's not five other strains that can cause cervical cancer, right. So, to me, it doesn't seem like a- a sure thing? (Wendy, Interview 1)

Um, I've heard that it protects about five or six different strains of HPV and mainly, um, the cancer causing ones, I don't [know] if it has anything to do with, like, the genital warts, um, and- and so I think- I think that was it too- it was like- like to me five or six strains where there's, like, a hundred and fifty some or something forms of HPV. That just didn't seem like very much protect[ion] to me for seven hundred dollars, but, um, my- my understanding is that those are the more common ones, right (Sarah, Interview 1)

While Sarah expressed ambivalence about the efficacy of the HPV vaccine, she was one of the few participants to tell me that she wanted to be vaccinated. Concerned about being at risk of the numerous strains of HPV, she felt routine safe sex practices were not enough protection:

I think just because it's so, so prevalent, um, I- like, and it really- like there-like, I didn't even know that you could get HPV with, like, just genital to genital contact, right like you don't even- it doesn't even need to be, like, a fluid exchange and- and I think that's the really freaky part because you think you're being safe by having sex with condoms, but that's not good enough and so I think- I think when it's- when it's that easy to contract, anything you can do to- and when so many people have it, right and when guys don't have any signs, um, or symptoms and they're not gonna know if they're carrying HPV (Sarah, Interview 1)

This section explored the ways young women thought about and experienced the prevalence of risk related to HPV. For some, this ubiquity of risk was normal, for others it was alarming. For nearly all participants, knowing the vaccine protected them against four out of numerous strains of HPV inspired little confidence in the vaccine's effectiveness.

4.3 Contingency of Risk

When participants talked about the pervasiveness of risk, they understood that all sexually active people are at risk regardless of their how they are sexually active. In this section, I discuss what I have termed the “contingency of risk” by describing how participants thought about and experienced risk in the context of their sexual practices and relationships. A complex narrative emerged when we discussed their sexual relationships in association with being “at risk” of HPV. Similar to the routine strategies women employed to mitigate sexual health risks (see Chapter Three), they viewed different kinds of sexual relationships and practices as “high” or “low” risk.

Most participants juxtaposed multiple sexual partners with long-term relationships with one partner, describing long-term relationship as safer. In this way, certain sexual relationships (*i.e.*,

monogamous relationships) were viewed as less risky and more responsible than others. Women linked multiple sexual partners whose sexual history was unknown with unsafe, risky behaviour and increased risk of HPV:

[W]henever you introduce more partners, you introduce more risk. It's just that simple. We don't live in a glorious world that's disease free and you can go have as many sexual partners as you'd like and just have fun. It just doesn't work like that and, like- and you take other people's safety into your hands and so I think people need to know that (Sarah, Interview 2)

[T]he assumption is that if you're in an at risk group for a sexually transmitted disease it's because you're not being particularly careful, you're sleeping around, you know. Or, I don't know, you don't have to be sleeping around, you could just be not asking the guys that you're with the questions that need to be asked (Alice, Interview 1)

So, if I'm talking about me and my other friend, where we have different, um, sort of ways we go about our sexuality? Um, I would say we're both at risk because we both have sex, um, but you could also say she's more at risk because she has more partners and is more willing to have more partners (Lynn, Interview 1)

Um, I guess just that you're- you're vulnerable to getting it, but for me, like, if you're at risk for getting HPV then there's also l- actions that have to be going along with that, right, like- I don't know, at risk for contracting the flu virus, like, you're- you're not necessarily doing something, like, you could just be out in the world and you can get- you can be at risk of getting the flu. Whereas, with HPV, like, there's actions that have to be going along to be at risk (Breanne, Interview 1)

Many of the young women drew upon their sexual relationships and practices to discuss whether or not they considered themselves to be at risk of HPV. Those engaging in sexual activities with multiple partners tended to consider themselves more at risk of HPV, whereas those in long-term monogamous relationships tended to identify as not at risk:

Um, well, I got out of a long term relationship not that long ago and then- so I was in a monogamous relationship with a man for years, so, committed to him and then I got out of the relationship, I started being more promiscuous. And so that definitely, like- right away, I thought about the risk- because I was in a long term relationship, I was concerned about the risk, we'd both

gotten tested [for STIs] and committed to each other, so now that I'm not, that was, like, at the forefront of my mind, that I am now- because I chose to make these decisions, I'm also- I'm also increasing my risk than being in a monogamous relationship (Helena, Interview 1)

Breanne: I don't think I'm taking the actions that would put me in that position, which may be a naïve position to have. But, um- I guess in my head- and this may be horrible to say- but I- I just feel like, someone who is at risk would probably be having more partners, um, and I am not (laughs). I don't know if that's correct or not or- I don't know.

Jen: So, in terms of the actions, having more, um, sexual partners.

Breanne: Well, I guess, like, it could- it could take one person, like, someone could be with their- it could be their first time and they could get HPV. Um, so I guess it's not necessarily grounded in the best- (laughs) in all the right facts, but I don't know why, that's just what I think- like, I- I think that I'm not- I just think I'm not at risk for- for some reason, like, I'm not, um, sleeping with people that I don't know or that, you know, they've had a lot of sexual partners or, you know, doing risky things or- I don't know (Breanne, Interview 1)

I hate saying this cause I know how it sounds to just say, like, I know my boyfriend would not, you know, cheat on me or do anything like that, but, like, I really do, like, we just have, like way- like, he- he's pathologically incapable of lying, like, to a fault. Um, and you know, I've just- you know- I would never do that, obviously- well, not obviously, but, um, yeah, it's one of those- like, I hate how, like, it sounds cause if you listen to someone else, you're like, oh, nonono. Like, our relationship, like, it's perfect. Like, we would never- he would never cheat on me. You would instantly think, like, oh, yeah, sure, but, you know, I guess it's- as far as I know, that's kind of- everything leans toward that, so, I feel like, no, I'm not really at risk (Leigh, Interview 1)

Although most of the young women identified monogamous relationships as relatively safer and presenting less risk of contracting HPV, their thoughts were somewhat divided about HPV vaccination. Some thought vaccination was unnecessary because they did not consider themselves at risk of HPV:

I'm in a long-term, monogamous relationship, um, so it's not necessarily like being sexually active, it's how I'm sexually active, um, perhaps a couple years ago, when I was single and, you know, had more infrequent partners, um, my thoughts would've been a little bit different (Michelle, Interview 1)

Being sexually- cause I wasn't with anybody last year and I'd had a f- I think maybe three or four partners over the year and so that something that definitely would factor into it, like, had the doctor suggested it to me last year in the middle of the year that it would be a good idea, then I probably would've been much more inclined, you know, because I'm not with a s- you know, monogamous partner, so I'm not really sure, you know, I started dating someone and sleeping with them, it's not like I'm like, geez, I think you've been exposed to the HPV virus, right, you know. So definitely, I think that that would put me- I would feel much more at risk then and, um, I would definitely be more inclined to- to, like, really seriously consider getting the vaccine (Wendy, Interview 1)

Other participants in long term relationships, including those who identified themselves as being at less risk, were still considering being vaccinated against HPV, usually because of risks associated with future relationships:

I don't know, I heard on some- on a radio station about people, um, not wanting to get it because they were in a committed relationship and then they- they suggested that if the other person were to cheat, um, and bring in, um, a disease? Then it would be- you would be protected against that and I guess that kind of, um- I don't know, not that I would expect him to cheat, but that idea kind of came across my mind and that's one of the reasons I chose to get it, um, as well as the fact that we could- I could end up having another sexual partner, we could break up (Dawn, Interview 1)

[S]o now I'm kind of at the place where I'm in a long-term relationship and feel pretty stable in that, um, but there's still- there's still part of me that's like, well, maybe I should get the vaccination even though I've had it to prevent anything else that could possibly happen in the future and- so then there's part of me that is kind of like, well, that's kind of like admitting that I'm gonna go sleep with other guys, so that- that part I'm kind of like- I don't want to kind of, um- I don't want to be stupid and not kind of prepare for a future even where we might not be together, but I also kind of, um- it's kind of like admitting that you- your relationships (laughs) has a great possibility of not working out, so- so, there's that kind of (Sarah, Interview 1)

Participants in long-term relationships who were considering the vaccine or had already been vaccinated were concerned that being vaccinated against HPV called into question the commitment participants had with their partners. None of the women in monogamous relationships identified the possibility that their partners might already be carriers of the virus. Being at risk of HPV potentially

signified a lack of trust in the relationship and the possibility of admitting that the relationship could end or one partner might have other sexual partners. Breanne's experiences with a doctor recommending that she be vaccinated against HPV illustrates the way being labelled at risk calls into question the commitment of a long-term, monogamous relationship:

Um, well I think have said just why, like why do I need to take it, especially when I was still with my boyfriend of, I guess at the time, four years, we were with each other for five years, I just wanted to know, like, why would- why would it be something that I would take if, you know- if my knowledge of it is basically- I don't want to use the term, sleeping around, but like, for women, who are- who have multiple sex partners and it's a concern that they could contract something then it would be a better idea for them to take it. So in my position of, you know, being- being with one person, I was like, well, why would I- in my position, why would I benefit from taking this and I guess I just never- I didn't get a good answer, they were just like, well, you know, you should just- you should take or, you know, circumstances could change and especially in that position, I was like, well, that's kinda not a very nice thing to say (Breanne, Interview 1)

In discussing what it meant to be at risk of HPV and in a committed monogamous relationship, participants worked to reaffirm their commitment to their partners while also acknowledging their desire to be vaccinated:

I think I held off on it, um, this far because I, um- I wanna believe that I'll be with my current partner, um, I kind of don't wanna, um- I don't wanna plan ahead just because that would, like, admit that there could be some sort of failure in that relationship, you know, and I wouldn't- I wouldn't want that, um, and, um, you know, and I'm like, I wouldn't want it to be- like it's- it's kind of like- I'm like that kind of would- to me- cause I don't see not being with him, so it would be like, what, would I cheat on him or something or would he cheat on me and that's how it would be brought in, um, to the relationship again or something in a different form, um, and so- but- but I've had lots of boyfriends in the past and (laughs) so, I'm like, well, I probably thought I was gonna be with them too and, so- actually, that's completely not true, but- (laughs) I didn't think I was gonna be with them forever, but, um- but, you know, like, it's- it's not a guarantee that I will be and- and so that's why I probably would- that's why I'm opting to go for the vaccine (Sarah, Interview 2)

I mean, this sounds like, you know, it's one of those things where- um, my partner and I are, like, you know- we're- we're pretty much set, like, we have been like- this relationship is kind of ridiculously perfect, like, we're- we're totally happy, we're, um, you know- we're definitely- uh, we are- are plans, like, like, getting married and all this stuff, but, like, not in any rush because we're so comfortable with ar- each other and our relationship that we're kind of just- we just know we're going to be together- well, you can't know and that's kind of the reason that I wanna do it because, like, really, any risk that I've had for the virus, um, in my mind is kind of, like, over, but, I am too reasonable to make a health decision based on my idealism, so, yeah (Leigh, Interview 1)

In sum, the young women's understandings of being at risk and "high" and "low" risk were described and experienced through their relationships and sexual practices with others. Most of the participants identified engaging in sexual activities with multiple partners as unsafe and therefore as a "high" risk activity that increased the possibility of contracting HPV. Long-term relationships with one partner was considered "low" risk by participants and relatively safer, decreasing the risk of contracting HPV. Participants in long-term, monogamous relationships identified themselves as "low" risk or not at risk of contracting HPV. Aside from Sarah, none of the other women in monogamous relationships acknowledged the possibility that they or their partners might already have a strain of HPV. For some, decisions against HPV vaccination were related to being in long-term, monogamous relationships. For the young women in monogamous relationships, who had already been vaccinated or were considering vaccination, they emphasized the possibility that their relationships might change. However, the acknowledgement that they were still at risk of HPV had the unsettling effect of calling into question the commitment each partner made to the other or that the relationship might not last. In these instances, participants worked to justify their decision to be vaccinated against HPV and reaffirm the longevity and commitment of their relationships.

4.4 Chapter Summary

In this Chapter, I discussed young women's thoughts and experiences of "risk" in association with their decisions about the vaccine. Risk was primarily conceptualized by these women as threats of harm from which they wanted to protect themselves. In this way, women thought of the vaccine as a technology that could enable them to prevent harm to their health. However, they discussed the vaccine as a relatively new technology and as such, could have unintended and possibly dangerous side effects over which they may have little control. Many of the women drew on their knowledge of other vaccines and medications as a way of explaining whether or not they trusted the vaccine to protect them or put them at further risk. Quite a few of the women also worked to contextualize different types of risk, particularly in instances where their sexual practices put them "at risk". Alternatively, a number of women suggested that all people were at risk by virtue of being sexually active. In Chapter Five, I address my research questions by exploring the women's narratives in association with social theories of risk and responsibility.

Chapter Five: Discussion

Guiding this research were two central questions that emerged after identifying gaps in the reviewed literature on HPV vaccination: (1) How do young women make decisions about HPV vaccination? and (2) How and to what extent are young women engaging with and evaluating public health discourses that work to promote a particular “responsible” female subjectivity to regulate the risks of HPV? Here, I address these questions by discussing the interview data explored in Chapters Three and Four in association with social scientific theorizations of responsibility and risk. Both public health literature and the thirteen young women I interviewed enacted neoliberal notions of the responsible individual in relation to women’s decisions about HPV vaccination. However, there are divergences between the literature and women’s perspectives regarding how this responsible individual-self is articulated.

I argue that young women’s decisions about the HPV vaccine are practices of self-making that enact gendered forms of individual responsibility primarily toward themselves, rather than their partners or others. In the first section of this chapter, I summarize the five key findings of my research. In the second, I discuss the ways public health literature and women, similarly and differently, constitute understandings of informed “choice” and individual responsibility. Finally, I analyze variations in how public health professionals and women articulate notions of risk to maintain young women’s responsibility to choose to be vaccinated against HPV.

5.1 Results

There are five main findings which result from my research. One, young women actively evaluated public health information about HPV vaccination rather than accepting it uncritically as

impartial or bias-free. Many of the women described their intent to make what they referred to as an “informed decision” or “informed choice” free from intervention by others, including their partners, by using public health information about the vaccine. They referred to this process of making an “informed decision” as “doing research,” thus actively seeking public health information to enable them to make decisions about vaccination.

However, having access to public health information about the vaccination did not necessarily result in the decision to be vaccinated. Furthermore, women’s decision about vaccination did not necessarily constitute what public health officials considered an “informed choice,” that is, the use of medically sanctioned information to weigh the risks and benefits before choosing to be vaccinated. For young women such as Joyce, Breanne and Alice, available public health information did not address their concerns about the long-term effects and potential risks of the vaccine to their health. Lynn described the information as polarized and lacking consensus in terms of whether vaccination was “good” or “bad.” Helena, Ace and Wendy also considered their immediate financial concerns. Paying rent and buying food took priority over purchasing the vaccine, which was expensive and not covered under their health care plans. A few women also described the importance of discussing HPV vaccination with people in their social networks, contending that public health information did not address their concerns. In these instances, they emphasized the value of sharing their concerns with, and seeking input from, other women as they struggled with whether or not to be vaccinated. Moreover, for some of the women, participating in my research may have been a part of working through the process of making a decision.

Two, most of the women felt their routine “safe sex” practices, including condom use, communication with sexual partners and STI testing, mitigated risks of contracting and spreading HPV to others. When I asked if men were also expected to protect their own and their partners’ sexual health,

the participants identified and were critical of differential expectations between men and women. The women spoke of their frustration with having to carry the burden of responsibility to protect themselves and their partners from sexual health risks. Helena and Wendy both referred to sexual health as a woman's "problem." Their discussions reflect a sense of gendered responsibility to manage reproductive and sexual health risks in heterosexual relationships. For some women, managing these risks could be empowering and for others, constraining if, for example, these safe sex practices failed.

Three, all of the young women were less troubled by the risks of contracting and transmitting HPV and more concerned about the risk of developing cervical cancer. All thirteen women considered the vaccine to be a protective measure, primarily against cervical cancer rather than HPV, which only a few of the women identified as a trigger for cervical cancer. All of the women described the vaccine as a means of protecting women's reproductive health against the risks of cervical cancer and as both a woman's choice and responsibility with regard to her body and health. When I asked what they thought about men being vaccinated against HPV, many of the women simply reasserted the purpose of the vaccine as a means of protecting women against cervical cancer or were unaware that the vaccine was available for men.

Four, not all of the respondents expressed concern or identified themselves as being "at risk", despite being identified thus by public health professionals, based on their age and sexual activities. Rather, many of the women associated simply being sexually active with being "at risk" for HPV. For some women, this pervasive sense of risk was not alarming, particularly considering that numerous strains of HPV are relatively harmless and clear up without medication. Furthermore, they called into question the efficacy of a vaccine able to provide protection against only four out of over one hundred strains of HPV. Lynn, for example, drew on the analogy of a "needle in a haystack" when questioning the necessity of being vaccinated against so few strains of the virus.

Women also discussed their sexual relationships and practices in association with whether or not they identified as “at risk”. Those in long-term, monogamous relationships tended to locate themselves outside the boundaries of the “at risk” category, while associating women with multiple sexual partners as having an increased risk for contracting HPV. Other women, such as Isabelle, Lynn and Alice, who were not in long-term monogamous relationships, described their “safe sex” practices as mitigating the risk of contracting HPV.

Five, closely linked to the third finding, many of the women engaged more with the language of “responsibility” than with “risk” when discussing their decisions about HPV vaccination. In the public health literature, the language of risk was key to emphasizing the impetus behind increasing HPV vaccination in young women. Social theorists (see Peterson 2003; Burchell 1993; Lupton 1995, 1999 & 2006; Nettleton 1997) have also identified risk discourses as integral to the way that people think about, experience and manage their health. Yet, women’s thoughts about HPV vaccination reflect an emphasis on their responsible practices with regard to protecting their sexual health, rather than concerns about being “at risk” of HPV. When the women discussed the kinds of sexual relationships and practices with which they engaged, particularly their monogamous relationships and practices of “safe sex”, they often evoked the language of “responsibility”. Many of the women associated these responsible practices with not being “at risk” of HPV, thereby demonstrating that as responsible, sexually active women, they circumvented the possibility of being “at risk”.

5.2 The Individual and “Choice”

In this section, I discuss women’s decisions about HPV vaccination in the context of discourses of “risk” and “responsibility” that framed much of the public health literature on HPV vaccination. As I outlined in Chapter One, public health professionals anticipate that providing medical knowledge to “at risk” women will enable those women to behave “responsibly” by complying with medical

recommendations that they “choose” vaccination. In the next section, I discuss the three prominent assumptions in the public health literature regarding women’s decisions about HPV vaccination. I then focus on how women discussed their ideas and decisions about the vaccine. I argue that both women and public health professionals mobilize culturally and historically produced notions of the neoliberal individual-self when articulating HPV vaccination as a responsible choice. However, by examining women’s narratives and decisions about the vaccine, I also argue that women and public health professionals produced contrasting understandings of the relationship between the individual and “choice”. In public health literature that I reviewed, responsible decisions about HPV vaccination are enacted in isolation from the contexts in which the women live. However, women’s thoughts about HPV vaccination reveal that they articulate identities as responsible individuals by drawing upon their social circumstances to inform these important decisions.

5.2.1 Assumptions in the Public Health Literature

Three assumptions underlie public health literature on women’s decisions about HPV vaccination. These assumptions reflect cultural priorities of the self as an autonomous individual, capable of making “rational” choices about health, based on sanctioned medical information. First, public health professionals assume that access to “balanced”, *i.e.*, medically sanctioned information will enable women to weigh risks and benefits “rationally” and to make “responsible” choices (see Tiro *et al.* 2006; Kelly *et al.* 2009). Public health practitioners assume that informed choices require individuals to use medical information with sufficient understanding to make responsible decisions about their health. Compliance with medical recommendations to be vaccinated is considered the rational outcome (see Ingledue *et al.* 2004; Stark *et al.* 2008; Friedman & Sheppard 2007; Abdelmutti & Hoffman-Goetz 2009).

Second, public health professionals identify women’s “inaccurate” knowledge about HPV and

the vaccine as an impediment to making “informed” and “rational” choices. Moreover, inaccurate knowledge is defined in juxtaposition with medical knowledge through the use of surveys and questionnaires that assess women and men’s knowledge about the “facts” of HPV (see Kahn *et al.* 2003, Kahn *et al.* 2008; Ingledue *et al.* 2004; Hopenhayn *et al.* 2007; Gerend & Magloire 2008; Baer *et al.* 2000; Allen *et al.* 2009; Caron *et al.* 2009; Mortensen 2010; Stark *et al.* 2008; Tiro *et al.* 2007). In this literature, it is assumed that correcting this “inaccurate” knowledge by providing individuals with medically sanctioned information about HPV will result in women’s ability to make informed choices and, thus, increase vaccination uptake.

Third, public health professionals assume that the “choice” to be vaccinated can or should be made by individuals in ways free from barriers or limitations, including financial constraints, intervention by others, and erroneous information. In this literature, barriers or limitations are identified as impediments to “informed” and “rational” choice and assumed to prevent vaccination uptake (see Allen *et al.* 2009; Kahn *et al.* 2003; Kahn *et al.* 2008). Some of the public health literature acknowledges that women may draw on social networks and relationships, such as or friends and family, to make decisions about the vaccine. However, in this literature, professionals identify these relationships as potential sites of intervention to provide women with “correct” medical information to enable them to make the “right” choice to be vaccinated. Mortensen, for instance, identifies “proactive mothers” as having “great power to persuade their daughters to take active steps toward intervention” (2010: 12).

Underlying these assumptions is a set of dominant cultural, neoliberal discourses of the self as an autonomous and rational individual existing “in contrast to, indeed in struggle against, the demands of public life” (Nelkin 1983: 105). Anthropologists and other social theorists have situated the conduct of North American and European individuals in the context of neoliberal strategies of governance,

where individuals are expected to regulate themselves autonomously, making choices that appear to be “free” from state intervention and coercion (Peterson 2003; Ilcan 2009; Clarke 2004; Redden 2002; Morgan & Maskovsky 2003). Social scientific theorizations (Lupton 1995 & 1999; Armstrong 1995; Peterson 2003) have tended to construct the “neoliberal individual” as unencumbered by economic, political, or social constraints, and as a monolithic entity bound only by neoliberal discourses. Consequently, no consideration is given to how women and men produce meaningful identities by simultaneously resisting, reproducing and reworking neoliberal notions of the autonomous, responsible individual.

Recently, however, anthropologists (see Kingfisher & Maskovsky 2008; Morgan & Gonzales 2008) have called for a recognition of neoliberalism as a “project whose totalizing desires are rarely fully realized because it never operates in a vacuum” (Kingfisher & Maskovsky 2008: 118). Closer examination of this anthropological perspective challenges theoretical claims of the neoliberal responsible individual as a monolithic entity. Indeed, my research findings demonstrate that individual responsibility as articulated in public health discourses is different from its emergence in women’s practices of self-making. Women, in particular, negotiate identities that re-work the neoliberal individual-self in dynamic ways that are inextricably bound to their material and social circumstances, including financial constraints and relationships with others. The emphasis in the public health literature on “informed”, “rational” choice about HPV vaccination made by assessing “balanced” medical information suggests that individual responsibility is predicated upon, and demonstrated by, the right kinds of choices that comply with medical expertise. However, women’s representations of themselves as responsible, sexually active women differ from public health discourses in important ways. While women utilize the language of “informed choice,” their decisions indicate a different set of priorities and expectations about what is an informed choice and how informed choices are made.

5.2.2 Individual Responsibility and Informed, Rational Choice

In this section, I discuss the assumptions in the public health literature in association with young women's decisions about HPV vaccination. The public health literature emphasizes the importance of women making "informed" and "rational" choices about vaccination, premised upon women having access to accurate medical information about HPV. Public health professionals anticipate that increased access to medical information about the risks of HPV will compel "at risk" women to be vaccinated. The decision to be vaccinated, then, reflects a "rational" and "informed" choice. In this literature, women's ability to make such choices is implicitly demonstrable of their competence and responsibility in relation to managing their sexual and reproductive health and associated risks. Young women's decisions about the vaccine both overlapped with and diverged from the public health literature with regard to "informed" choice. Similar to the language of that literature, the young women mobilized a language of "informed choice" and individual responsibility in decision-making about vaccination. They regarded the ability to make an informed choice about vaccination as indicative of their responsibility to take care of what they referred to as "my body" and "my health," rather than mitigate the risks of HPV. These references emphasize both their sense of ownership of their bodies and health and that the choice must be autonomous or free from intervention by anyone else. For example, when I asked Sarah how she would respond if a doctor suggested she should be vaccinated, her response reflected pervasive discourses of both an individual's right and freedom to make decisions about one's health:

I think people need to make their own decisions. Um, I don't think you can force things like vaccinations upon people, um, cause I think that takes their r- like if that had been forced upon me, I think that would feel like it was taking away part of my freedom. Um, it's my body and that would feel pretty dictatory [sic] to just be like, yeah, you need to put that in you (Sarah, Interview 1)

Sarah's evocation of rights-based discourses to describe her decision to be vaccinated as "part of [her] freedom" with regard to her body reflects cultural narratives of the self as "a quasi-sacred, legal, moral, and psychological entity, whose rights are only limited by the rights of other equally autonomous individuals" (Scheper-Hughes & Lock 1987). Furthermore, her comments indicate the expectation that individuals should have the "right" to make decisions about their health, free from intervention or coercion by others.

A number of the women referred to "doing research," which included seeking out academic and medical literature and reading online news articles and blogs, to facilitate "informed" choices about the vaccine. They expected that the information they sought would be "balanced" and "impartial" in presenting equally the risks and benefits of the vaccine and would enable them to make that informed decision. Underlying these expectations was an understanding that actively seeking out information was an important way of demonstrating one's responsibility to make the best decisions about her health. Such thoughts marshal the neoliberal logic of the responsible individual as a "proactive" decision-maker, who actively seeks out information, which is assumed to enable an "informed choice" (see Ilcan 2009 and Clarke 2004). The failure to make informed decisions was flagged by some of the women as a form of irresponsibility toward oneself that is, as Leigh suggested in our first interview, "bad and wrong and unhealthy." These thoughts suggest a concern with the ways "uninformed" decisions can be potentially harmful to one's health. In public health literature, choosing vaccination constitutes an "informed" choice based on accurate medical information. However, not all women considered vaccination as the only informed choice. For example, Alice suggested that those, who had taken the time to explore the benefits and risks of the vaccine, would feel less inclination to be vaccinated.

In public health literature, women's knowledge about HPV and the vaccine is frequently

identified as “erroneous,” while medical information is presented as “accurate” and “unbiased.” This literature suggests that women need to have “the necessary information and resources to make an informed choice about the HPV vaccine based on clear and unbiased risk communication that empowers them to take charge of their health” (Abdelmutti & Hoffman-Goetz 2009). Such assumptions implicitly suggest that women cannot make “rational” decisions about HPV vaccination without utilizing public health or medical information. Moreover, these assumptions imply that failure to use public health information is also a failure on the part of women to act rationally. Sherwin (1998: 24) adds that in this model of rational and informed choice, “decisions are constructed as a product of objective calculation on the basis of near perfect information.” As noted, the women I interviewed spoke of actively seeking out that “objective” medical information about the vaccine. All were University of Victoria students enmeshed in an academic environment that encourages students to learn by seeking out and evaluating scholarly information. As such, they not only had access to a broad range of “accurate” sources of public health information about the vaccine, but also they understood that the impartiality of such information should be questioned. Women evaluated medical information on the basis of it being trustworthy and impartial, or sufficiently biased as to be unreliable for making decisions.

Many of the women expressed trust in medical practitioners’ expertise and knowledge in making recommendations about their health. However, some of the participants questioned the agenda that promoted HPV vaccination. While a number of the women, such as Sarah, Leigh, Joyce and Helena, spoke of their trust in medical professionals, others, including Ace, Breanne and Michelle, questioned the impartiality of medical information by suggesting that medical professionals sought financial incentives when promoting vaccination. In the public health literature I reviewed, some professionals (e.g., Abdelmutti & Hoffman-Goetz 2009; Keelan *et al.* 2010; Kelly *et al.* 2009;

Calloway *et al.* 2006) suggested that media sources, including newspapers and television, may negatively influence vaccination uptake because of erroneous, fear-inducing information about the HPV vaccine. However, women disputed these statements in the literature and, instead, identified vaccination compliance as a corollary of fear-mongering in the media and profit-seeking on the part of pharmaceutical organizations. Breanne and Ace were particularly suspicious of the impartiality of information on the HPVinfo website. Breanne, for example, drew parallels between the aesthetics of pharmaceutical advertisements and the HPVinfo site to articulate her skepticism about the neutrality of the medical information on the site. Ace described the site's content as "fluffy" and maintained that the site's authoritative language was used to persuade the targeted audience to be vaccinated. She also stated that the website represented an unnecessary amount of advertising for the vaccine. For her, the number of advertisements promoting HPV vaccination was confirmation that the vaccine was bound to financial profit and did not reflect genuine concern for the health and well-being of targeted consumers. Similarly, Michelle challenged the impartiality of available medical information by directing attention to the ways that public health professionals were "groomed" by, and received financial incentives from, pharmaceutical organizations.

Feminist scholars (e.g., Franklin 1995; Haraway 1988; Harding 1989; Rose 1994), persuasively call for a repositioning of scientific knowledge and truth claims within the discursive, cultural contexts in which it is produced. Furthermore, they argue convincingly that scientific knowledge cannot be removed from particular cultural priorities. Haraway (1988) further maintains that, historically, scientific knowledge has been located in opposition to, and privileged over, women's knowledge. By questioning the motives and agenda of public health professionals, Michelle, Ace and Breanne's assessments of public health information indicate their suspicion of the kinds of facts and truth claims made in this information, particularly the SOGC's HPVinfo website. By questioning public health

professionals' investment in increasing vaccination uptake, these three young women also confronted the presumed objectivity and accuracy of medical information, particularly in terms of enabling an informed decision about the vaccine. Their critiques also challenged polarization in the literature where medical information is accepted as rational and objective, while women's knowledge about HPV and the vaccine is understood as irrational, uninformed and subjective.

A number of women identified a lack of consensus within medical reports. This lack of consensus further complicates public health professionals' assumptions that using this medical information should lead to choosing vaccination. These women were frustrated when medical statements about vaccination failed to help them make informed decisions. Helena, for example, stated that HPVinfo website information about various high and low risk strains of HPV left her confused about whether or not to be vaccinated, particularly after reading that some strains of HPV were relatively harmless. Related to this frustration was the failure of available information to address key issues for women. All of the women interviewed identified concerns about potential side effects or long term consequences of HPV vaccination often comparing the vaccine to other medications that have resulted in unintended and dangerous side effects. In these instances, women cited the dearth of long-term studies about the vaccine as part of the reason they were hesitant to be vaccinated. Two women, Isabelle and Lynn, attributed their inability to make a decision about vaccination to this lack of consensus. Unlike public health professionals' assumptions that vaccination was the informed and rational choice, Lynn and Isabelle's indecision constituted a legitimate, rational response as they attempted to become better "informed". Clearly, while medical information did provide the women with "balanced" perspective about the risks and benefits of HPV vaccination, it failed to provide the kind of direction they sought.

In the public health literature, the decision to be vaccinated is regarded as an asocial process

isolated from social and material circumstances in which women live and negotiate decisions about their health. My research, in contrast, contends that the processes by which women make decisions are inseparable from these circumstances. Moreover, their interviews brought into focus the ways the vaccine and women's considerations of this technology are mediated by and made meaningful through social relationships. Many of the women first learned about the HPV vaccine from medical practitioners in the context of routine appointments related to birth control prescriptions or annual Paps. Some described feeling considerable pressure from medical practitioners to be vaccinated. Breanne continued to be pressured by medical practitioners who repeatedly wrote her prescriptions for Gardasil®, even after she declined to be vaccinated. Wendy recited the questions medical practitioners asked that required her to justify why she hadn't been vaccinated. Dawn's decision to be vaccinated was inextricably bound to her nurse-practitioner's repeated recommendation that she choose to be vaccinated. Dawn declared repeatedly that because she did not identify as "at risk" for HPV, she did not want to be vaccinated. Nevertheless, she eventually complied in part from the repeated recommendation of her nurse-practitioner.

Women's experiences of doctors pressuring them into making decisions about the vaccine underscore the evidence that medical practitioners can and do exert considerable authority and, in some cases, pressure, over women's abilities to make "choices" about the vaccine. Some of the women's experiences complicate public health professionals' assumption that women should make decisions free from intervention. Their experiences direct attention to how notions of "informed" choice are contingent upon women's "ability" to behave in medically sanctioned ways. Thus, from public health and medical perspectives, vaccination non-compliance indicates irrational decision-making and is justifiable grounds for intervention on the part of medical professionals, as demonstrated by Dawn's experiences.

In public health literature, women are considered free to choose to be vaccinated regardless of “perceived barriers,” through what Kahn *et al.* (2003:1104) refer to as the “belief in one’s capacity (self-efficacy) to perform the behavior.” Despite this assumption, restrictions or “barriers” to women’s abilities to access the vaccine were enmeshed in, and in some instances constitutive of, their decisions. Women’s financial barriers do not negate their “self efficacy”; rather, financial barriers shape the possibilities through which women articulate and perform their conceptualizations of responsibility. Such conceptualizations complicate public health assumptions that “rational” and “informed” choices are made primarily based on accurate medical information. By implying that barriers can and should be overcome, public health descriptions of “barriers to vaccination” minimize the impact that “choosing” to be vaccinated may have on women’s lives. All of the women interviewed were university students, who had limited financial resources and insurance coverage with which to purchase the vaccine. Many prioritized more exigent concerns in their lives, including paying rent and buying food which they might have to forgo if they chose to be vaccinated. Neoliberal assumptions of constraint-free choice were exemplified in the HPVinfo website’s lack of information regarding financial aid for targeted consumers of the vaccine. Women were also critical of the way the site’s images of mostly young, thin, white women reproduced expectations of wealth, particularly as it intersects with race and class. Breanne’s poignant statement, “you’re not gonna see, like, a prostitute here” and Ace’s comment that the site’s images are of “normal” people or what she would “like to see people look like” reveal these underlying assumptions. Moreover, their statements draw attention to how representations of wealth on the website are bound to neoliberal discourses of “choice” and the (in)ability to enact medically sanctioned notions of individual responsibility.

Numerous medical anthropologists (see Abel & Browner 1998; Lock and Kaufert 1998; Mitchell 2001; Rapp 2000) have argued that women do not passively accept medical and technological

interventions regarding their reproductive and sexual health, nor are they inherently resistant to them. Rather, as Lock and Kaufert (1998) suggest, women's relationships with medical technologies are negotiated within the context of women's lives. All of the women recognized and expected that being "informed" was part of making a responsible choice regarding vaccination and expressed a desire to make this choice free from intervention. However, their experiences complicate neoliberal, individualistic models of decision-making fundamental to public health professionals' notions of "informed choice". Some of the women highlighted the importance of sharing their thoughts with and seeking advice from friends or family, especially when they were unsure and/or undecided about the vaccine. Such practices demonstrate that the vaccine, as a new technology bound up in uncertainty, and even anxiety, is made meaningful through their relationships with others, whose advice and support they trust and value. Leigh was among the few women to state that her decision to be vaccinated was predicated on her trust in medical reports on the number of tests that new medications undergo and her understanding that vaccines were a common sense choice for effective protection against diseases.

Enmeshed in both public health literature and women's endeavours to make "informed choices" are notions of the neoliberal individual, whose responsibility is demonstrated through the ability to make the "right" informed choices. According to the public health material, the ability to make "rational" and "responsible" decisions about the vaccine is demonstrated through women's abilities to assess medical information "competently," in ways removed from their daily lives. Yet, women's decisions about the vaccine reveal a tension between public health notions of neoliberal individual responsibility and women's enactments of responsibilities toward themselves.

Women engage in and produce notions of individual responsibility in dynamic ways that draw upon, rework and resist these neoliberal discourses. These discourses are implicated in women's efforts to make "informed choices". Yet, the processes through which they attempt to make these choices also

challenge such discourses. Their consideration of their financial circumstances and efforts to seek advice and support from people in their social networks complicate the neoliberal logic of individual responsibility enacted in isolation from the social, political and economic realities that effect women. Thus, their representations of themselves as responsible individuals also rework and challenge longstanding notions of the neoliberal self that is isolated from lived circumstances (see Peterson 2003). Their thoughts and decisions about the vaccine indicate notions of rational, informed decision-making premised upon contextual considerations of their circumstances. Rational decisions, then, are not predicated solely on having access to public health information about the risks of the vaccine. Rather, public health information was incorporated into their decision-making practices about the vaccine to aid them in their decisions. Women who sought advice and support from friends and family challenge the neoliberal individual responsibility promoted in the public health literature by demonstrating that women make sense of the vaccine through, not in isolation of, their relationships with others. These women worked to construct responsible selves that are grounded foremost in the social milieu in which they live, rather than removed from it.

5.3 Responsibility and Risk as Regulatory Practice

In this section, I connect theories of risk as regulatory practice to notions of the “risky” self, implicated in the SOGC’s construction of the group of young women “at risk” of HPV. Social theorists have directed our attention to the ways that risk has multiple and diffuse meanings (Lupton 1995 & 1999; Peterson 2003; Burchell 1993; Beck 1992; Douglas 1992). Risk has been theorized as a measurement of probability, danger, and chance or fate (Kavanagh & Broom 1998). The concept of risk is implicated in the ways that individuals conduct themselves in relation to their thoughts and decisions about health maintenance through risk prevention (Lupton 1995; Peterson 2003). Risk discourses both enable and constrain forms of regulatory practice, shaping possibilities for how individuals take up the

task of engaging in “responsible” prevention practices (Howson 1998 & 1999). Moreover, in the context of HPV vaccination, public health discourses of risk convey officials’ authority to determine what constitutes “best practices” regarding how women should conduct and regulate themselves “responsibly” to prevent reproductive and sexual health risks. Cultural understandings of gender, sexuality and risk are implicated in and produced through these discourses and women’s decisions about HPV vaccination. However, while women engaged in regulatory practices of risk management, the ways that they articulate gendered identities through their regulation of sexual and reproductive health risks differs from public health discourses about HPV.

5.3.1 Responsibility and Regulation of the “Risky” Self

Oster and Cheek’s (2008) differentiation between the “at risk” and the “risky” self are helpful in elucidating young women’s thoughts about HPV vaccination. The “risky” self presents as a risk to others and, as such, “risky” individuals are bound by a moral obligation to manage or regulate themselves so that they protect others from harm (Oster & Cheek 2008). Unlike the “risky” self, the “at risk” self must protect herself from risk or harm caused by others. Research (Duncan *et al.* 2001; Oster and Cheek 2008) on men and women’s experiences of positive STI diagnoses suggests that the “risky” self is bound up in powerful moral judgments of irresponsible sexual practices and “risky” sexuality. In the STI screening research, differential expectations emerged between public health professionals and individuals who had contracted STIs regarding how sexual risks should be managed. One study (Duncan *et al.* 2001) points out that public health officials expected women to disclose their positive diagnosis for Chlamydia to potential sexual partners. Disclosure was regarded by these professionals as morally responsible behaviour required to mitigate risks to others. However, because of the gendered stigma associated with STIs, and the potential to be labelled “polluted” and not a “nice girl,” women were reluctant to threaten their sexual desirability by relaying this diagnosis (Duncan *et*

al. 2001: 173). Public health discourses label these “risky” individuals “irresponsible”, while simultaneously anticipating that they will comply with medical recommendations that diminish those risks.

In practice, the boundary between the “at risk” and the “risky” self is not as sharp as Oster and Cheek suggest. The “risky” self is integral to the SOGC’s identification of the target group of women “at risk” of HPV and cervical cancer and is behind the impetus for increasing HPV vaccination. The SOGC’s construction of the “at risk” group of women is entangled in pervasive cultural assumptions about young women’s sexuality and sexual practices as potentially promiscuous and in need of control. The SOGC emphasizes women’s “risky” sexual practices when describing the etiology of the HPV virus and highlighting how it can be contracted and transmitted. Through the HPVinfo website, the SOGC (2009g) informs women that the virus can be transmitted with no manifestation of symptoms and identifies sexual activity and numerous sexual partners as risk factors in contracting and transmitting the virus. As mentioned in Chapter One, through their promotion of the HPV vaccine, the SOGC has constructed a broad “at risk” group that was not previously targeted for STI screening in Canada. The SOGC’s campaign slogan, “Spread the Word, Not the Disease,” evokes notions of the “risky” self and reflects a moral obligation of individuals, namely women, to be “responsible” sexual persons. “At risk” women are informed that through their sexual practices, they are both a source of risk to others by potentially spreading HPV and at risk from others through the possibility of contracting HPV and developing cervical cancer. By identifying women’s sexual practices as “risky”, the SOGC conceptualizes women as both carriers of risk and vulnerable to it. Correspondingly, young Canadian women identified by the SOGC as “at risk” of HPV due to their “risky” sexual practices are told that the vaccine is the best way of regulating those risks to themselves and others. Both the “risky” and “at risk” discourses at play in the SOGC’s HPV information mobilize and reproduce hetero-

normative, gendered expectations of women's responsibility to manage risks. Both risk discourses are intended by the SOGC to have the same outcome: young women, whose sexual practices put them "at risk" and make them "risky," will choose to be vaccinated against HPV. However, women I interviewed thought about, and responded to, the SOGC's "risky" and "at risk" discourses in diverse ways that did not always align with the SOGC's perceptions of young women's sexuality.

In the SOGC's risk discourses, the subjectivity from which they construct their target audience privileges certain cultural norms and values regarding the "right" kinds of sexuality. Here I draw on Ortner's definition of subjectivity as "modes of perception, affect, thought, desire, fear, and so forth that animate acting subjects...as well the cultural and social formations that shape, organize, and provoke those modes of affect, thought and so on" (2005: 31). Through the HPVinfo website, heterosexuality is positioned as the norm from which to indicate to presumably heterosexual women that their sexual practices put them at risk. "Alternative" sexualities, such as bi-, pan- and homosexuality, are not acknowledged by the SOGC, while vaginal intercourse between women and men is constitutive of "normal" or "real" sex. This emphasis on women's heterosexuality also suggests that sexuality exists specifically as a fixed trait within individuals rather than being constituted through sexual practices and relationships (see Lupton 1995; Morris 1995) Furthermore, in assuming heterosexuality as the only legitimate form of sexuality, the SOGC narrows its focus on women's heterosexuality as a key site of risk for intervention. Through descriptions of how HPV is contracted and transmitted, women are told that their sexual practices may put them and their (presumably) male sexual partners at risk. Women are informed that abstinence, monogamy and limited sexual partners reduce the risk of contracting HPV. Correspondingly, though not explicitly described by the SOGC, what is surely a large portion of young women in Canada who are not abstinent and have multiple (male) sexual partners are categorized as "at risk" of HPV.

Braun and Gavey (1999) have argued that discourses of risk related to STIs polarize women's sexual behaviour as morally "good" or "bad". The "good girl" is "sexually responsible, has one (preferably spousal) sexual partner, and does not get STDs" (Braun & Gavey 1999: 204). She is constituted in opposition to the "bad girl", who "is sexually irresponsible, has many sexual partners... gets STDs (and is thereby punished)" (Braun & Gavey 1999: 204). Promiscuity, characterized here as a form of sexual "irresponsibility," is a gender-specific concept (Braun & Gavey 1999). Heterosexual women are often identified as promiscuous through their sexual practices; heterosexual men rarely are (Braun & Gavey 1999). The judgment or "moral proscription of 'irresponsible sexuality'" (Oster & Cheek 2008: 220) applied solely to heterosexual women manifests in public health risk discourses about HPV, which inform women that their "irresponsible" sexual practices put them and others at risk. Moreover, public health professionals have the expert authority to determine what constitutes good, responsible sexual practices and ways to regulate the risks women pose to themselves and others. The SOGC's HPVinfo website exemplifies the manner in which women's sexuality is scrutinized and rendered "dangerous" or "bad" and in need of control and regulation through medical interventions, including HPV vaccination. It is notable, for example, that there are no public health initiatives, including public awareness campaigns, specifically directed at educating men about the risks of HPV². In this regard, the "objective" medical language of risk simultaneously obscures and reproduces the cultural and moralistic judgments of women's sexual practices by rendering women's sexuality a public health "problem" in need of public health "solutions" (Lupton 1995).

Public health discourses frame the risks of HPV as "lifestyle risks", (Kavanagh and Broom 1998; Lupton 1995) which are a result of a person's actions or failures to act. Unlike environmental

² At the time that I was writing up the results of this thesis, no public awareness campaigns targeted young men for HPV vaccination.

risks, such as pollution, over which individuals may have little perceived control, lifestyle risks are associated with the choices individuals make and the actions associated with them (Kavanagh & Broom 1998; Lupton 1995; Bickerstaff et al. 2008). Lifestyle risks recall cultural and neoliberal notions of the self by suggesting that these risks are the result of “poor” choices, which can be prevented if only individuals make the “right” choices. Public health discourses frame both lifestyle risks and preventative strategies for these risks as a matter of individual choice, responsibility, and intent³. Through their “Spread the Word, Not the Disease” campaign, the SOGC informs sexually “irresponsible” women “at risk” of HPV and possibly cervical cancer that they can also choose to regulate these risks by being vaccinated. However, what is interesting to note are the ways that public health discourses work to shape the possibilities for considering HPV as a problem and HPV vaccination as the appropriate and seemingly inevitable solution. The underlying assumption in the SOGC’s risk discourses is that young women are “choosing” to engage in “irresponsible” sexual practices that put themselves and others “at risk” of HPV, genital warts and cervical cancer. The SOGC’s risk discourses work to constitute heterosexual female subjectivity as “risky”, yet capable of managing those risks “responsibly” by choosing to be vaccinated.

While the SOGC’s risk discourses identify women as “at risk” of HPV, how young women think about and negotiate this subject position demonstrates the contingency of these discourses. In theorizing the ways that public health discourses constitute particular, sanctioned subjectivities, Armstrong (2007), Peterson (2003), Kavanagh & Broom (1998) and Lupton (1995) have argued that the ways individuals interpret and experience such subjectivities are not predetermined. Rather, as Lupton (1995: 137) states, “subjects are neither wholly governed by discourse nor fully capable of

³ I have been unable to find any discussion about HPV vaccination and cervical cancer that considers how environmental factors may be linked to the development of cervical cancer.

stepping out of discourse.” Women’s negotiations of the SOGC’s discourses of risk as they relate to women’s “risky” sexuality demonstrate how women resist and simultaneously occupy subject positions framed by these discourses.

The women I interviewed rarely evoked notions of “riskiness” when describing how they managed risks through “safe sex”. Sarah was the only women to identify herself as a potential risk to her sexual partners when discussing her practices of managing sexual health risks. Her experience of contracting a “high risk” strain of HPV was connected to her sense of being a risk to others. When we explored the HPVinfo website, a few of the participants were critical of the SOGC’s framing of certain sexual practices as risky. In the research by Duncan *et al.* (2001), women diagnosed with Chlamydia were acutely aware that women with STIs may be regarded as “polluted” or no longer “good girls,” contravening cultural standards of acceptable sexual practices for women. In similar ways, all but three the women in my research regarded the SOGC’s description of “responsible” sexual practices, including abstinence and monogamy, as a moral judgment of women’s sexuality. Helena, Isabelle and Ace were especially critical of the site’s description of these sexual practices. Helena and Isabelle both took issue with the ways the site equates promiscuity with riskiness and irresponsibility where, as Isabelle suggests, “young adults, who’re having sexual relationships are not always careful” (Interview 2). Similarly, Helena identified the site’s description of “responsible” sexual practices as a perpetuation of a “Madonna/Whore” dichotomy. This dichotomy restricts women’s sexuality, forcing women to occupy one moral category or another, where promiscuity (being a “whore”) is always associated with dangerous and irresponsible sexual behaviour. After Helena and I watched the video of Jay, a fictitious young man who developed genital warts, on the HPVinfo website, she described the emphasis on abstinence and monogamy as

[A]bit of a shaming campaign, like- I don't know, like, I get it, obviously, that- I don't know, I just think the whole thing about, like, knocking promiscuity because, obviously, if you are promiscuous, then you're not having safe sex, the two are equated, then that constantly goes hand-in-hand (Helena, Interview 2)

Helena was one of only two women to identify her sexual practices, particularly her decision to have multiple sexual partners, as part of the reason why she should be vaccinated against HPV. While Helena contested the way the SOGC equated promiscuity with risky behaviour, Ace was insulted by the site's implication that women are voluntarily promiscuous, stating that "girls don't try to be promiscuous" (Interview 2). Her criticism makes visible insidious cultural and moral judgments regarding young women's (hetero)sexuality and brings to light some of the ways in which young women are subtly informed about what constitutes "good" (*i.e.*, abstinence) and "bad" (*i.e.*, promiscuity) sexual practices for women.

A few of the women rejected discourses of the "risky" self by explaining how they engaged in responsible sexual practices. Some of the women in long-term monogamous relationships described their relationships as mitigating the risk of HPV. For a couple of the women, being "at risk" of the virus called into question the commitment that they and their partners made to each other and suggested that one or both partners were not "safe". None of the women in monogamous relationships discussed the possibility that either they or their partners could have contracted and transmitted the virus to each other at the beginning of their relationships. The corollary of women's associations between monogamy and not identifying as "at risk" was the acknowledgement that increasing the number of sexual partners did expose women to risk. However, these women tended not to judge promiscuity as immoral. Many, including those in monogamous relationships, recalled their "safe sex" practices when telling me that they did not identify themselves as "at risk" of HPV. Alternatively, Isabelle pragmatically, and without alarm, stated that all sexually active people were at risk of HPV. As their

frustration with the SOGC's description of women's "risky" sexual practices indicates, underlying these risk discourses are cultural narratives that reduce women's (hetero)sexuality to a binary of morally acceptable and responsible or unacceptable and irresponsible practices. Their critical engagement with the HPVinfo website also makes visible the SOGC's attempts to compel "risky" young women to be vaccinated because they put themselves "at risk".

In ways similar to their critique of the SOGC's implicit condemnation of women's "risky" sexual practices, all of the women were frustrated by what they identified as an expectation that women were responsible for managing sexual health risks. Women's practices of "safe sex" and their annoyance with the expectation that they can and should be managing sexual risks direct attention to the way this form of responsibility is gendered. A few of the women, such as Kay, Wendy and Leigh, described this expectation as not only a "woman's problem" but also as a failure on the part of women if sexual health risks could not be managed. Leigh identified safe sex practices as both empowering and constraining for women, stating that it was women who bore the stigma of the consequences of "failed" safe sex practices, such as STIs and pregnancy. Kay described the ways that these expectations negatively impacted women and men:

[M]ost stuff that's- has to do, uh, with, uh sex and reproductive organs seems to sort of fall solely on the woman, like, you have the uterus, it should be your job....Like it was kind of like, on the woman- if you didn't tell the guy to wear a condom, then, you know, it was clearly your fault, not his fault cause- well, it made- it was unfair to guys too cause it kind of makes them look like hulking idiots, like, well, you can't expect him to remember to put a condom on cause he's just a guy, so, we're gonna be unfair to both parties (Kay, Interview 1)

However, similar to Howson (1999 & 1998) and Robertson's (2000 & 2001) findings that women actively participated in screening programs, all of the women I interviewed stated that they did employ routine practices of risk management for sexual health. In doing so, they presented themselves as responsible for managing sexual health risks. Their explanations of "safe sex" practices evoked less

concern with the “risky self” and, instead, an emphasis on the “at risk” self. Most of the women discussed “safe sex” practices in reference to protecting their sexual health. Leigh referred to the HPV vaccine as a form of “self-ownership through self defense” in which women were empowered to protect themselves (Interview 1). Alice employed the analogy of defensive driving, explaining that if a person can be a defensive driver “to keep yourself from dying, then you should have the same attitude toward your genitals” (Interview 1). Both of their comments evoke the notion of the “at risk” self, which requires protection from others.

Women’s practices of “safe sex” indicated a kind of self-regulatory practice. However, in stating that “safe sex” strategies prevented the risks of HPV and in describing the reasons why they would consider being vaccinated, women prioritized concerns about being “at risk” of cervical cancer over HPV. In the next section, I discuss the ways that women take up regulatory practices of risk management in their discussions of HPV vaccination and preventing risks of cervical cancer. I also discuss how women articulate a particular form of individualistic, gendered responsibility toward themselves as young women “at risk” of cervical cancer.

5.3.2 Responsibility and the Regulation of the “At Risk” Self

Women’s assessments of the SOGC’s construction of the “at risk” group of women indicate that these risk discourses are not rigid, nor do they determine women’s experiences and practices related to their health. Rather, these discourses are negotiated and reworked in ways that illustrate women’s priorities about their reproductive health. In contrast to the advice on the HPVinfo website, many of the women did not consider HPV vaccination to be the only, or even the best, solution to mitigating the risks of HPV. How women framed risk points toward a tension between how they were labeled and how they identified as “at risk”. Their discussions of whether or not they identified as “at risk” of HPV unsettles the logic of the SOGC’s risk discourses and the categorization of “at risk” women. Several of

the women stated that all sexually active people are “at risk” in one way or another, but the degree of “risk” is dependent on their sexual activities and relationships with others. Furthermore, all of the women questioned the efficacy and safety of the HPV vaccine. They disrupted the SOGC’s claim that the vaccine is a technology that protects *against* risks and reframed the vaccine as a potential risk *to* their health and, for some, their reproductive health in particular.

When discussing the reasons why they might consider being vaccinated, women evoked ideas of responsibility toward the “at risk” self that were both gendered and individualistic in ways different from public health discourses. Women’s thoughts on HPV vaccination reflected less of an engagement with notions of “risky” sexuality, as promulgated by the SOGC, and more of a concern with self-protection. Unlike the “risky” person who poses a risk to others, and therefore must behave responsibly by protecting others from herself, the “at risk” person’s responsibility is demonstrated primarily by protecting herself, not others, from harm (Oster & Cheek 2008). A few women acknowledged HPV as a trigger for cervical cancer, but they were not as concerned with preventing the virus, because they believed it to be less harmful. Furthermore, these women considered the risks of HPV more difficult to manage because the vaccine only protected against four out of numerous strains of the virus. As I discussed in the previous section, most women were critical of the SOGC’s assertion that they engaged in risky sexual practices and explained that their “safe sex” practices or monogamous relationships would protect them. All of the women considered the vaccine as a tool that could potentially enable them to prevent cervical cancer and protect their reproductive health.

Previous anthropological research on women’s perceptions of cervical cancer indicates that some women do draw explicit, causal connections between promiscuity and cervical cancer (see Chavez *et al.* 2001; Gregg 2000 & 2011). However, in contrast to these findings, the women I interviewed prioritized concerns about their reproductive health and the risks of cervical cancer in ways

that were isolated from their sexual practices. My findings are similar to Howson (1998 & 1999) and Robertson's (2000 & 2001) research on cervical and breast cancer screening. The women in their studies produced identities as responsible women by maintaining and protecting their reproductive health. Howson (1998 & 1999) and Robertson's (2000 & 2001) research highlights the extent to which public health discourses of risk serve as a form of regulatory practice that shapes the way women enact strategies to protect themselves from breast and cervical cancer. These authors argue that women's perspectives on cervical and breast cancer screening reflect a moral obligation to enact responsible identities by complying with medical recommendations⁴ Thus, Howson states that compliance with screening is "the expected response to what might be seen as part and parcel to the range of interventions which are perceived as a routine and normal aspect of female embodiment" (1999: 412). In cancer screening initiatives, regulating oneself through compliance with medical recommendations is considered by public health professionals to be in the "best interests" of women. "Choosing" not to participate in risk prevention initiatives, such as breast and cervical cancer screening may be considered an irrational and moral failure of women to act as "responsible" individuals (Robertson 2000 & 2001; Howson 1998 & 1999).

Howson (1998 & 1999) and Robertson's (2000 & 2001) research on women's perspectives on breast and cervical cancer screening neglects to attribute agency to women's practices of forming responsible identities. Their analyses tend to focus specifically on how neoliberal notions of responsibility and risk discourses control and constrain women's activities, including the ways they form gendered identities. Moreover, this research suggests that women's participation in regulatory

⁴ Interestingly, recent debates have centred on "excessive" and unnecessary breast cancer screening of Canadian women. The Canadian Broadcast Corporation (CBC) produced an article that documents medical professionals' reticence to promote routine breast cancer screening for women at "average risk", which may result in over-diagnoses and unnecessary biopsies (CBC News 2011).

practices like cancer screening initiatives is a form of compliance with medical expectations. In contrast to Howson and Robertson, I find it productive to highlight the tension between women's criticisms of risk discourses and their ability to mobilize and reconfigure such discourses to form meaningful identities as responsible young women. Threaded through women's discussions about HPV vaccination, the risks of cervical cancer and the vaccine itself, was their persistent concern about their reproductive health. Women established this responsibility primarily through their considerations of possibility that the vaccine may or may not protect them from cervical cancer.

The women described the vaccine as being specifically for women and about protecting women's health. They all made reference to cervical cancer and women's reproductive health when describing the reasons why they might choose to be vaccinated. In doing so, the women worked to distinguish the vaccine from HPV and sexual health. They were aware and critical of the cultural, gendered expectation that women manage their sexual health in heterosexual relationships. In creating a boundary between their sexual practices and the risks of cervical cancer, a different kind of gendered responsibility emerged through women's discussions. When participants and I talked about men being vaccinated, quite a few either asked if men could be vaccinated or argued that the purpose of the vaccine was not to prevent HPV, but to prevent cervical cancer. Alice's designation of cervical cancer as a "woman cancer" and the HPV vaccine as a "chick shot" underscores the widespread acceptance of the vaccine as a "woman's vaccine":

[I]t's a vaccine to protect women's health, right. I mean, it's less about- it seems to me that the purpose of the vaccine is less about, um, preventing infection with HPV as it is about preventing infection with HPV that causes cervical cancer. Um, so it seems that the natural thing to do is to protect the part of the population that's going to get cervical cancer (Alice Interview 1)

Emerging in the context of women's discussions about cervical cancer were particularly reductive conceptualizations of gender regarding the distinctions between men and women's

reproductive health. Most of the women were highly critical of the inequitable gender differences between men and women's responsibility to regulate sexual health risks. However, interestingly, these women reinforced gender distinctions between themselves and men when they discussed their reproductive health as the impetus behind being vaccinated against HPV. My questions about whether being a woman was related to HPV vaccination and whether men should be vaccinated revealed underlying cultural understandings of gender differences grounded in biological and reproductive distinctions between men and women. In drawing on these biological sex differences, the women mobilized powerful cultural understandings of gender based on a male and female binary and naturalized their sense of responsibility to protect their bodies. Not only did the women naturalize gendered differences between men and women, but also, these distinctions were implicated in their understandings of their responsibility to protect themselves from bodily harm caused by cervical cancer. Thus, when I asked Dawn how being a woman might relate to HPV vaccination, she responded by referring to biological understandings of gender to emphasize her sense of responsibility toward herself:

Jen: All right. Um, do you think that being a woman has anything to do with getting the vaccine?

Dawn: Yes.

Jen: Okay (laughs). Is there anything specifically that makes you think that?

Dawn: Because I have a cervix and I can get cervical cancer (Dawn, Interview 1)

Quite a few of the women considered HPV vaccination for men to be unnecessary. They drew on their understandings that men and women have different reproductive health concerns to argue that men did not have cervixes and therefore did not need to be vaccinated. Isabelle (Interview 2), for example, stated that “it’s sort of like an assumed because it’s more prominent to cause cervical cancer, um, so therefore women are the ones with cervixes, so it makes sense that they are the ones that should be responsible in this regard.”

Women's discussions about the vaccine preventing cervical cancer and their references to "my body" and "my health" as justification for their right to make a decision about the vaccine reflect an individualistic obligation toward protecting a particularly gendered "at risk" self. In this way, their thoughts aligned with public health discourses about risk management to the extent that the vaccine presented the possibility of enabling "at risk" women to manage risk through the choice to be vaccinated. Thus, choosing to be vaccinated suggests that women can choose to control the possibility of developing cervical cancer. The SOGC and public health literature inform women that the vaccine constitutes a responsible choice for mitigating the sexual health risks women pose to themselves and others. However, women I interviewed considered the vaccine a responsible decision to protect their bodies from harm. Wendy and Ace were the only two women who questioned the inevitability of developing cervical cancer from a "high risk" strain of HPV and the efficacy of the vaccine to protect them from cancer:

[Y]ou know, cancer is something that doesn't seem to have preferences for who it strikes, so I mean, it could come to me, it could not come to me, but, what's one little thing I'm gonna- gonna do, I'm probably gonna get cancer anyway, which the odds are- you know, so preventing one particular strain of virus that causes one particular type of cancer seems like a very small piece of the pie in terms of cancer in general (Wendy, Interview 1)

The research on STI, cervical and breast cancer screening suggests that, while screening is intended to mitigate potential risks, new forms of uncertainty emerge through these technologies, whereupon women may be forced to grapple with and make sense of positive diagnoses. Quite a few women in this study considered the HPV vaccine a technology that could provide them with some control over their risk of cervical cancer. Yet, while most of the women took up cancer screening initiatives as a routine part of being women, all were somewhat wary of the vaccine as a relatively new technology that might pose a risk to their bodies and health. All thirteen women described the potential for the

HPV vaccine to harm their health. All expressed concern about the possible unanticipated side-effects of the vaccine. While the vaccine might enable women to control the risk of cancer, they also conceptualized the vaccine as a potential risk in itself. Women cited lack of long-term studies and drew upon analogies to other vaccines and medications as cautionary tales of horrific, unknown and unintended side-effects that might cause considerable harm to their health. Two of the participants, Sarah and Isabelle, were particularly concerned with the way the vaccine could harm their reproductive health. Sarah stated,

I think, because it had to do with, like, um- like, for me, like, there's just been, like, a fear of, like, um- like, it has to do with your reproductive system, right, and I'm like, I just don't want to mess with that and, um- and, so even though I'm pretty dang sure you're not gonna become, like, sterile or something from, like, taking a vaccine, it's just something that's, like probab- it's more of a sensitive issue, right, than just getting a general flu (Sarah, Interview 1)

While the public health literature on HPV suggest that the vaccine will provide protection against the risks of the virus and secondary illnesses, women's thoughts demonstrate the ways the vaccine carried its own set of risks from which they needed to protect themselves. The common thread in women's concerns about the risks of cervical cancer and the risks of the vaccine itself is the responsibility they felt toward protecting themselves and, in particular, their reproductive health.

Women's decisions about the vaccine indicate a gendering of both risk and responsibility. Their reconfigurations of public health discourses about "risky" female sexuality demonstrate the tension women experience regarding gendered expectations and their desires to engage in "safe sex" practices. Many of the women I interviewed were critical of these expectations, yet continued to engage in them with the knowledge that they occupied a precarious position of being empowered, yet constrained, by this gendered responsibility. Moreover, through their identifications of the vaccine as a preventative technology for cervical cancer, women carved out a particular kind of gendered risk expressed through

salient understandings of bodily and reproductive differences between men and women. In this way, women remade the vaccine specifically as a tool for women to prevent a form cancer so thoroughly anchored to women's reproductive health. Thus, women I interviewed made HPV vaccination women's responsibility, yet did so in ways that circumvent public health discourses that potentially stigmatize women's sexuality.

5.4 Chapter Summary

In this chapter, I have argued that, in the context of HPV vaccination, both public health professionals and the young women I interviewed produce gendered, neoliberal notions of individual responsibility. Public health literature about the vaccine reproduces both an asocial, individualistic approach to decision-making and informs women that their "risky" sexuality places them and their partners "at risk" of HPV. The women I interviewed reconfigured long-standing notions of the neoliberal individual-self by demonstrating that making decisions about the vaccine were inextricably bound to their social circumstances. Furthermore, women created a separation between their sexual practices and cervical cancer, simultaneously resisting public health discourses that label their sexuality as "risky" by identifying themselves as "at risk" of cervical cancer. These women prioritized their responsibilities toward themselves and their reproductive health and in doing so, reproduced gendered differences between men and women's responsibility to maintain reproductive and sexual health. In the next chapter, I discuss my main conclusions as well as the implications of my research findings and possibilities for future research.

Chapter Six: Conclusion

In this chapter, I discuss my main conclusions. Thirteen young women participated in this research. Based on my semi-structured interviews with these women, I argue that their decisions about HPV vaccination are complex, dynamic and inextricably bound to, not isolated from, their lives. Women's decisions are also practices of self-making, through which they strove to enact identities as young women responsible for protecting themselves, their bodies and health from harm. After outlining my conclusions, I describe the potential implications of this study for public health research about women's attitudes regarding HPV vaccination. Finally, I discuss some of the possibilities for future research.

6.1 Conclusions

The purpose of this research was twofold: (1) investigate the processes through which women make decisions about HPV vaccination, and (2) determine the extent to which women engage with and evaluate public health information that attempts to promote a "responsible" female subjectivity to regulate the risks of HPV. In the public health literature on women's decisions about the vaccine, the vaccine is considered safe and in women's best interests. Moreover, public health professionals assume that with the right kinds of medically sanctioned information, women will comply with medical recommendations to make the "informed" choice to be vaccinated. In these studies, decision-making is idealized as an asocial process, removed from the contexts of individuals' lives. Medical anthropologists (see Adelson 1998; Gammeltoft 2007; Lock 1998; Scheper-Hughes & Lock 1987) demonstrate that health conceptualizations and experiences of "health" are enmeshed in the cultural, social, political and economic worlds of individuals. My interviews with women and the public health literature on HPV vaccination reflect cultural and moral priorities regarding the "right" kinds of female

sexuality and neoliberal individual responsibility to manage health risks. While the language of “risk” was pervasive in the public health literature and key to the impetus behind increasing vaccination in young women, “responsibility” was more prominent in women’s decisions.

Through my research, I found that the responsibility women expressed over protecting themselves from the risks of cervical cancer reworked public health discourses of the gendered, sexual self. Neoliberal notions of individual responsibility are implicated in both public health discourses of risk and women’s thoughts about the vaccine. Moreover, cultural understandings of gender and sexuality are entangled in the ways public health discourses compel women to be vaccinated and in the ways women enact responsible identities through their decisions. The SOGC places the burden of responsibility on young women to protect themselves and others from their “risky” sexual practices by “choosing” to be vaccinated. However, interviews with women indicate that they articulate their identities as responsible young women by both engaging and re-working notions of neoliberal individual responsibility, gender and sexuality that align with and resist public health discourses. Through their decisions about HPV vaccination, the women resisted the SOGC’s moralizing of their “risky” (hetero)sexuality in a number of ways. First, a couple of the women contested the confluence of risk and promiscuity, suggesting that having multiple sexual partners does not always entail risk. Second, some women identified their monogamous relationships as mitigating the risk of HPV. Third, women described their “safe sex” practices as a way of managing the risks of HPV. Finally, all of the women were highly critical, yet somewhat accepting, of dominant cultural expectations reproduced by the SOGC’s heteronormative expectation that women manage sexual risks.

Armstrong (2007: 74) suggests that discourses work through individual agency, particularly when the “subject position advocated is identified by the individual as compatible with their interests.” Correspondingly, when discourses are incompatible with an individual’s interests, the space necessary

for resistance is opened (Armstrong 2007: 74). However, Armstrong assumes that by resisting discourses, individuals can and will step outside of the discursive boundaries that regulate them. I found that the women I interviewed were critical of public health discourses of “risky” sexuality. Yet, in some ways, women’s resistances to the SOGC’s identification of women’s sexuality as “risky” reflected more of a concern with demonstrating that they engaged in culturally and medically sanctioned “good” or “safe” sexual practices. Thus, they did not necessarily step outside of the powerful discursive boundaries of risk and responsibility to demonstrate their ability to engage in sexual practices “responsibly”. Rather, while they were critical of the way their sexuality is framed as “risky,” they mobilized cultural understandings of “good” and “safe” sexual practices to demonstrate that they are morally “good” sexually active women who should not be categorized as “at risk” of HPV.

In focusing on their reproductive health as a site of risk, women’s biologized understandings of what constitutes gender differences between men and women were the primary means by which they distinguished between men and women’s responsibilities toward their health. These differences also translated into the ways women work to form identities as responsible young women, who are concerned with protecting their reproductive health by choosing whether or not to be vaccinated. Their discussions about HPV vaccination and cervical cancer reveal concerns that foreground their individual bodies as their primary consideration for choosing to be vaccinated. Women’s perspectives of the vaccine as a technology to prevent cancer indicated cultural and neoliberal notions of individual responsibility to protect a gendered self through the ability to make good consumer choices about their health. Such choices indicate neoliberal notions of individual responsibility because of the expectation that through the right kinds of choices, namely the choice to purchase and consume the vaccine, they can prevent particular kinds of diseases. Yet, because the vaccine is not covered under provincial health care, the ability to make responsible or “good” choices is constrained by women’s (in)ability to

purchase the vaccine.

The presumed causal relationship between HPV, cervical cancer and the vaccine's ability to prevent cancer is paramount in the context of these decisions. This causal relationship is drawn upon in both the public health literature and through women's decisions. As a technology of risk prevention, the HPV vaccine eliminates the uncertainty and danger of cervical cancer and renders the disease both knowable and controllable. Most of the women did not question the causal relationship between HPV and cervical cancer. Arguably, women's decisions to be vaccinated were also decisions to control the risk of developing cancer. Deliberating on such decisions also reveals the ways that women conceptualized cervical cancer as a disease isolated from environmental, social and economic contexts that contribute to its development. Moreover, participants drew upon particular configurations of cervical cancer as a non-infectious disease that affects only the female body to legitimate the reasons why the vaccine was intended for women. Women's decisions, then, reflect a kind of gendered "at risk" self, who enacts and demonstrates her responsibility by controlling the sense of uncertainty of potentially developing a disease that effects women's health by making the "right" health choices.

Social scientists have identified how, particularly in the pharmaceutical marketing of the HPV vaccine, cervical cancer has been described as an "innocent" disease, removed from the moral turpitude of women's "risky" sexuality and sexual practices (see Braun & Phoun 2010; Mamo *et al.* 2010). In ways similar to the pharmaceutical marketing, the women I interviewed were less inclined to consider how their sexual practices were implicated in the risks of cervical cancer and, in doing so, legitimated women's responsibility to protect themselves by choosing whether or not to be vaccinated. Women attempted to separate their decisions about the vaccine from their sexual practices. However, the association between HPV and cervical cancer should not be dismissed because this association has been a crucial aspect to public health promotion of the vaccine. Both women's accounts of being "at

risk” of cervical cancer and the SOGC’s identification of women’s “risky” sexual practices as putting them “at risk” for HPV reproduced the cultural expectation that women are managers and sources of reproductive and sexual health risks. By resisting the SOGC’s identification of women’s sexuality as “risky”, the women I interviewed produced different kinds of neoliberal, gendered responsibility situated in their concerns about protecting their reproductive health. The ways women attempt to create identities as responsible young women, who endeavour to take care of themselves, demonstrate their ability to skillfully shift the focus away from potentially stigmatizing public health discourses about their sexuality. However, by shifting attention away from their sexual practices toward their reproductive health, the women reified and biologized gender differences between men and women, and the kinds of responsibilities men and women had toward maintaining reproductive and sexual health.

6.2 Implications

My goal in conducting this research has never been to increase vaccination compliance in young women, nor has it been to dissuade women from being vaccinated. Moreover, it is not my intent to have this research used for the purposes of persuading or dissuading women from being vaccinated. Rather, I began the project with the intent to unpack some of the public health expectations related to women’s decision-making practices about HPV vaccination. Throughout, I have been invested in providing a nuanced discussion about the processes and circumstances through which young women attempt to make decisions about the vaccine. In this section, I discuss some of the possible implications of my research.

First, women’s perspectives and experiences related to HPV vaccination need better representation in public health literature. In the literature that I reviewed, the impetus behind increasing

HPV vaccination was predicated upon the categorization of a specific group of women as simultaneously “risky” and “at risk”: women who are not abstinent, have had multiple sexual partners and are not in lifelong monogamous relationships. While public health professionals have constructed this “at risk”/“risky” category of women, my research demonstrates that there is variation in how women think about and identify as “at risk”. Moreover, there were differences between the public health material and women’s thoughts regarding what constitutes “responsible” ways of maintaining reproductive and sexual health, and how these understandings are woven through decisions about vaccination.

Attending to the process through which women negotiate decisions would provide public health professionals with an opportunity to understand not only women’s attitudes or perspectives on the vaccine, but the circumstances and contexts in which they negotiate these decisions. This would also complicate professionals’ assumptions that educating women with public health and medical information about HPV and the vaccine will enable women to choose to be vaccinated. My research indicates that women do not passively accept the truth claims made by public health professionals. Rather, through the process of deciding whether or not to be vaccinated, they actively evaluate and are, in some instances, quite critical of information about HPV and the vaccine. Including women’s perspectives and experiences in public health research may enable public health professionals to better understand the realities in which women think about themselves as responsible sexually active young women considering HPV vaccination.

Second, women can and do make competent, well-reasoned choices about their reproductive and sexual health and HPV vaccination in ways that may not align with public health professionals’ expectations. A few women that I interviewed discussed incidents where they felt pressured by medical professionals to be vaccinated against HPV, despite stating that they did not want to be. Similarly, in

the public health literature that I reviewed, HPV vaccination was positioned as a medical technology that is safe, benefits women, and is in their “best interests”.

Women’s discussions throw into relief the unequal power dynamics between public health and medical professionals and patients in determining what constitutes the “best” decisions in regard to patients’ health. It is clear from my interviews that not all women agreed with the sentiment that the HPV vaccination was in their best interests. Moreover, for some women, who did consider vaccination to be in their best interests, the vaccine remained inaccessible to them because of its exorbitant cost or other factors, such as the lack of a family doctor or scheduling challenges. Underlying public health professionals’ expectation that “informed choices” are best made with medical information is the assumption that women should trust this information. However, little consideration is given to the necessity of trusting women, who may or may not decide to be vaccinated against HPV. I argue that public health professionals need to take more seriously women’s ability to make good decisions about their reproductive and sexual health, decisions which may not align with public health recommendations. Such decisions, though not necessarily predicated solely on having access to accurate medical information, are nevertheless well-reasoned, rational and inseparable from their social worlds.

Third, underlying discussions in the public health literature about women’s decisions is the assumption that these decisions are or should be predicated on a desire to manage reproductive and sexual health risk by being vaccinated. However, my interviews with young women demonstrate that their decisions about HPV vaccination may not be principally about risk management. Women’s decisions about the vaccine are also moments of self-making.

Professionals identify women’s “risky” sexual practices as putting them and others “at risk” of HPV and reproduce the expectation that women should manage these risks by complying with public

health recommendations to be vaccinated. However, many of the women's discussions about the vaccine reveal the ways notions of "responsibility," rather than "risk," are foregrounded in their decisions and their practices of self-making. Through their considerations of the vaccine, young women strove to construct responsible selves by drawing upon, resisting and reworking ideas about the self, gender and sexuality that are entangled in public health discourses.

6.3 Future Research

My study has opened up at least four possibilities for future research. First, research is needed on how marginalized women may be negotiating decisions about HPV vaccination. Some social scientific and medical researchers (see Graham & Mishra 2011; Lexchin *et al.* 2010; Lippman *et al.* 2007) argue that high incidences of cervical cancer disproportionately affect poor Canadian women of colour, who, ostensibly, may benefit from HPV vaccination as a purported preventative measure against cervical cancer. However, there has been little consideration of how young, social and economically marginalized women, especially women of colour, think about HPV vaccination. I draw attention to this point to suggest that more research is needed in regard to marginalized young women's considerations of HPV vaccination and the relationship between poverty, access to health care and marginalized women's reproductive and sexual health.

It would be particularly pertinent to explore the ways marginalized women, who face higher incidences of cervical cancer, engage with public health literature about the vaccine and the linkages between HPV and cervical cancer. It is notable that, in the interviews, only two of the women questioned the causal relationship between HPV and cervical cancer, postulating that environmental factors, exercise and (lack of) access to "good" food may be implicated in the development of cancer. My interviews with women and my assessment of public health literature indicate an understanding of

HPV and cervical cancer as causally linked, suggesting that women can choose to prevent cervical cancer by choosing to be vaccinated. Such perspectives are amenable to neoliberal expectations that disease prevention is achieved through the right kinds of consumer choices, predicated on having the financial resources to purchase and participate in recommended medical procedures. It is unclear if and how marginalized women make sense of HPV vaccination and cervical cancer. Nor is it clear how public health and neoliberal discourses of individual responsibility to prevent HPV and cervical cancer through vaccination may be implicated in marginalized or impoverished women's thoughts and decisions about the vaccine.

Second, now that Gardasil® is available to young Canadian men, investigation into their perspectives about HPV vaccination would be especially fruitful. My research indicates that the HPV vaccine is entangled in particular social meanings and experiences of gendered responsibility and risk, which emerged through young women's articulations of an "at risk" self, whose reproductive health may be harmed. Women's decisions and the public health literature I reviewed reflect a kind of "feminization" (Carpenter & Casper 2009) of the vaccine as a technology that is bound up in cultural and moral discourses related to women's sexuality and reproductive health. This project was limited to interviews with young women. It would be interesting to expand upon this research by conducting interviews with young men who may be considering HPV vaccination. As discussed in Chapter One, Gardasil® has been available to Canadian men and boys since February 2010. Public health research indicates that HPV vaccination for men may provide protection against strains of the virus that are associated with genital warts and throat and neck cancer (Ferris et al. 2009) and protect their presumably female sexual partners from cervical cancer (Gerend & Barley 2009; Gaipert 2005; Giuliano 2007). Research is needed on how young men think about the vaccine in relation to their sexual practices and sexual and reproductive health concerns, particularly in light of the vaccine's

association with cervical cancer.

Third, research with men and women of various sexual identities who may be considering HPV vaccination is needed. As indicated, all of the women I interviewed described sexual relationship with men. Heteronormative representations of sexuality are well-entrenched in much of the public health and pharmaceutical promotion of HPV vaccination. The public health literature I reviewed and the SOGC's HPVinfo website presumes the heterosexuality of women targeted for HPV vaccination. Implicated in the heteronormativity of this literature, and a key source of tension for the women I interviewed, is the expectation of women's responsibility to manage reproductive and sexual health of themselves and their (male) sexual partners. It is not clear how notions of gendered responsibility are implicated in non-heterosexual men and women's decisions about the vaccine. Moreover, the presumption of heterosexuality of targeted consumers erases both the sexual identities of non-heterosexual men and women and the reproductive and sexual health care that they may want and need. For example, Epstein's research (2010) on anal cancer and the disappearance of gay men's sexual health in the marketing of Gardasil® underscores the invisibility and continuing stigma of non-heterosexual identities. In the public health literature that I have reviewed, sexual practices between men and women are deeply connected to the impetus behind increasing HPV vaccination in "at risk" heterosexual women. Considering how public health professionals have categorized "at risk" populations, it would be pertinent to explore how women and men of diverse sexual identities (do not) identify as "at risk" of HPV and secondary illnesses and how they may be negotiating decisions about the vaccine, if at all.

Finally, research on HPV vaccination is needed that is developed more specifically with participants' priorities, concerns and needs as the central focus to the project. Such priorities might include better access to reproductive and sexual health care or developing financial assistance programs

for individuals who want or need, yet cannot afford, HPV vaccination. Participants' involvement in this study was restricted. Within the constraints of developing a Masters thesis project, I attempted to seek some input from participants. Yet, this was limited to seeking feedback, if they elected to provide it, on the interview transcripts before I began analyzing the data. Focusing on the priorities of participants would shape the outcomes of the research project, which could potentially have more grounded, applicable results for participants, such as marginalized women who may or may not want and need access to HPV vaccination. Projects that are developed in consultation with participants could better inform public health and medical policy on HPV vaccination, as well as local health clinics that provide services related to reproductive and sexual health to a diverse population of patients.

To conclude: while the HPV vaccine is a relatively recent technology, it cannot be isolated from the discourses, relationships and experiences that both give it meaning and shape its use(s). Indeed, the vaccine is bound to a particularly fraught social landscape that is textured by already present and pervasive cultural anxieties about cervical cancer and female sexuality and, arguably, endeavours to control both. The kinds of decisions women make about the vaccine and knowledges produced by public health professionals are not separable from this landscape. Rather, it is within this context that public health professionals produce knowledges that operate as truth claims about the HPV vaccine and that women draw meaning about this technology and struggle to negotiate decisions about whether vaccination is the "right choice" for them.

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Appendix I: Recruitment Letter to Organizations

My name is Jen Roberts. I am an anthropology graduate student in the Department of Anthropology at the University of Victoria. As the major component of my MA program, I will be researching how young women decide whether or not to be vaccinated against the Human Papillomavirus (HPV) and how they may use public health information about the vaccine to make that decision. This research project is titled, “Young Women’s Perspectives on the Human Papillomavirus: Negotiating responsibility, health and risk”.

I am contacting you to see if the [Organization] would be interested in helping me recruit participants for this research project. I am hoping to recruit 10 to 15 young women between the ages of 19-26 who have heard of and are considering HPV vaccination. I hope to begin recruitment in September 2010, but for now, I am writing to enquire if you would be interested in hearing more about my research and to determine whether or not it would be possible recruit at [Organization]. I would be happy to meet with you to discuss my project and the possibility of recruitment in greater detail.

Research Background: Currently, there is no research available on how young women make decisions about the HPV vaccine. My research will explore how women make decisions about HPV vaccination and how public health information about the vaccine may be part of those decisions. As well as exploring young women’s decisions about the vaccine, my research investigates how they think about responsibility, health, and risk in the context of their reproductive and sexual health and practices. This research will contribute to understanding young women’s decisions about maintaining reproductive and sexual health and preventing health risks.

Information about the Researcher: I will be the primary researcher in this study. I have received funding for this project from the Social Sciences and Humanities Research Council of Canada and by the University of Victoria Faculty of Graduate Studies. In 2009, I completed a Bachelors of Arts with Distinction in Anthropology at the University of Victoria. I completed five research methods classes including a class in ethnographic research methods, two classes in feminist research methods, and an advanced graduate seminar on qualitative research methodology tailored to my research project. These classes provide the necessary theoretical and practical background to develop and conduct the scholarly research I am proposing.

Research Methods: This research project involves two interviews with each participant. The first interview will take approximately 90 minutes. The purpose of this interview is to explore young women’s ideas and decisions about HPV vaccination. It will address how young women make decisions about vaccination, how they access information about the vaccine, which information they value, what it means to them to be at-risk of HPV, and how ideas about responsibility, health, and risk may be part of their decisions about the vaccine. In the second interview (about 60 minutes long), I use the Society of Obstetricians and Gynaecologists of Canada’s HPVinfo.ca website to explore participants views of an example of public health information about HPV vaccination.

Dissemination of Research Findings, Consent, and Ethical Considerations: This research project

requires ethics approval from the joint UVic-VIHA Research Ethics Board. The information I gather through interviews will be used in my thesis and in articles submitted to scholarly magazines for publication. Consent to participate in this project is completely voluntary. To maintain confidentiality of participants in the disseminated results of this research, their real names will not be used and they will be asked to select pseudonyms. If participants consent, they may choose not to answer any questions during the interviews and may withdraw from the study at any time without explanation and without consequence.

Contact Information: Your assistance in recruiting young women to join this study would be greatly appreciated. If you have any questions or concerns regarding this research project or would like to discuss the possibility of assisting me in recruitment, please feel free to contact me at XXX-XXX-XXXX or XXXXXXXXX@uvic.ca.

Enclosed with this letter is a copy of my Participant Informed Consent Form. Thank you for taking the time to read this letter.

Kind regards,

Jen Roberts

Appendix II: Recruitment Flyer

Are **YOU** a **SELF-IDENTIFIED WOMAN** **BETWEEN THE AGES OF 19 AND 26 WHO IS** **CONSIDERING THE HPV VACCINE?**

I am a graduate student in the Department of Anthropology at the University of Victoria. My Master of Arts thesis research project explores young women's ideas and decisions about the HPV vaccine.

If you participate:

- You will be interviewed twice
- The first interview will take about 90 minutes
- The second interview will take about 60 minutes



Image Credit: <http://open.salon.com/files/thinking1242103763.jpg>

If you are interested in participating in this research project, please contact me as soon as possible for more information.

JEN ROBERTS, MA CANDIDATE

XXX-XXX-XXXX or XXXXXXXX@uvic.ca

Supervisor: Dr. Lisa M. Mitchell at XXX@uvic.ca or XXX-XXX-XXXX

Appendix III: Recruitment Letter to Participants

My name is Jen Roberts. I am an anthropology graduate student in the Department of Anthropology at the University of Victoria. As the major component of my MA program, I will be researching how young women decide whether or not to be vaccinated against the Human Papillomavirus (HPV) and how they may use public health information about the vaccine to make that decision. This research project is titled, “Young Women’s Perspectives on the Human Papillomavirus: Negotiating responsibility, health and risk”.

Research Background: Currently, there is no research available on how young women make decisions about the HPV vaccine. My research will explore how young women make decisions about HPV vaccination and how public health information about the vaccine may be part of those decisions. My research will also explore how they think about responsibility, health, and risk in the context of their reproductive and sexual health and practices. This research will contribute to an understanding of young women’s decisions maintaining reproductive and sexual health maintenance and risk prevention strategies. This research is being funded by the Social Sciences and Humanities Research Council of Canada and by the University of Victoria Faculty of Graduate Studies.

Purpose and Benefits of this Research: This research will provide information about how choices about reproductive and sexual health may not depend solely on having access to public health information. Decisions about HPV vaccination may also depend on the context of women’s lives, including sexual relationships with others and access to economic resources. The findings from this research will be used to develop a summary report for participants focusing on the ways in which young women in this study are making decisions about the HPV vaccine.

Research Methods: This research project involves two separate interviews with each participant. The interviews will be scheduled at a time and location convenient to participants. Possible interview locations could be in the UVic Department of Anthropology interview room or in the participants’ home. The first interview will take approximately 90 minutes. This interview will explore young women’s thoughts and decisions about HPV vaccination. It will address how young women make decisions about vaccination, how they access information about the vaccine, which information they value, and how ideas about responsibility, health, and risk may be part of their decisions about the vaccine. The second interview (about 60 minutes long) looks at how young women engage with public health information about HPV vaccination. This interview addresses the participants’ perceptions of a public health website’s text- and image-based representation of health, responsibility and risk in relation to the vaccine.

Dissemination of Research Findings and Confidentiality: This research project requires ethics approval from the joint UVic-VIHA ethics committee. The information I gather through interviews will be used in my thesis. Research findings may be presented at conferences and published in academic journals. Findings may also be used to develop a summary report for participants. The identities of participants will not be revealed in the disseminated results. To maintain confidentiality of participants in the disseminated results, their real names will not be used and they will be asked to select

pseudonyms. There may be some limits to confidentiality if participants have been referred to this research project by others.

Possible Risks, Consent and Right to Withdraw: Participation in this research is completely voluntary. There are no consequences if people decline to participate in any part of the research project. Participants can withdraw from the project at any time without explanation. It is possible that participants may feel embarrassed or experience emotional discomfort with some of the interview questions regarding sexual health. Participants may also feel fatigued due to the length of time required to complete the interviews. Participants can choose not to answer any interview questions and stop either interview at any time without consequence. They are welcome to take a break during the interview or reschedule the interview for another time. There may be some topics or questions that participants do not want to discuss. Participants are welcome to see the interview questions before consenting to participate and before each interview begins. I am fine with participants choosing not to answer any interview questions. If participants decide to withdraw from the research project, they can decide whether the information they provided will be used in the final research analysis.

Some Questions You Might Want to Think About: Do you have any questions about the purpose of this research project? Do you think you will be comfortable talking about the topics of this research project? Are there any topics you are not comfortable talking about that might pertain to this research? Do you have any questions about the methods or activities I will use in this research project? Do you have any questions about how the results of this research will be disseminated? Do you have questions about confidentiality? Do you have any other questions for me?

Contact Information: If you have any questions or concerns regarding this research project or would like to discuss the possibility of being a research participant, please feel free to contact me at XXX-XXX-XXXX or XXXXXXXX@uvic.ca. If you decide to participate, you can contact me at anytime during or after the research project finishes. You can also contact my graduate supervisor at the University of Victoria, Dr. Lisa Mitchell, at XXX-XXX-XXXX or at XXX@uvic.ca. You can verify that I have received ethics approval for this research or raise any concerns you might have by contacting the Human Research Ethics Board at the University of Victoria at 250 472 4545 or ethics@uvic.ca or the Vancouver Island Health Authority, Research Ethics Office at 250 370 8620.

Thank you for taking the time to read this letter.

Kind regards,

Jen Roberts

Appendix IV: Informed Consent Form

Project Title: Young Women's Perspectives on the Human Papillomavirus: Negotiating responsibility, health and risk

Researcher: Jennafer Roberts, Department of Anthropology at the University of Victoria

My name is Jen Roberts. I am an anthropology graduate student in the Department of Anthropology at the University of Victoria. I am required to conduct research as part of the requirements of my MA program. My research investigates how young women make decisions about being vaccinated against the Human Papillomavirus (HPV). My research asks two questions: (1) How do young women decide whether or not to be vaccinated against HPV; (2) To what extent and how do young women use public health and medical information to make a decision about HPV vaccination? This research is being funded by the Social Sciences and Humanities Research Council of Canada and by the Faculty of Graduate Studies at the University of Victoria.

The potential benefits of your participation in this research include contributing to knowledge about young women's decisions about being vaccinated against HPV. After this research project is completed, I will also write a summary report for research participants that discusses how the young women in this study make decisions about the HPV vaccine. You can choose whether or not you would like to have this report.

You are being asked to participate in this study because you are a self-identified woman between the ages of 19 and 26 and you are considering being vaccinated against HPV. If you consent, your participation will include two interviews scheduled at a time and location convenient to you. Possible interview locations could be in the UVic Department of Anthropology interview room or your home. If you consent, I will use a digital audio recorder to record both interviews. If you do not consent to digital recording, I will only write notes during the interviews. This first interview focuses on what you've heard about the vaccine and some of your thoughts on it. The second interview explores your thoughts about how the HPV vaccine is discussed in public health information. In the second interview, we will look at an example of this information together and talk about some of the images and text.

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without explanation and without any consequences. There are no consequences if you choose not to answer any interview questions. If you decide to withdraw from the research project, you can decide whether or not the information you provided will be used in the final research analysis. If you wish not to have your interview data included in the final analysis, I will give you any notes I have written during the interview and erase any digitally recorded material.

Because this research project involves two interviews that will take place at two separate times, your on-going consent is required. Before beginning the second interview, I will seek verbal consent from you. To do this, I will remind you that your participation must be completely voluntary, that you may choose not to answer any interview questions, and that you may withdraw at anytime without consequence.

If you choose to remain in the study, the data from your interview will be transcribed. I will keep a hardcopies of the notes written during the interview and a transcription of the interview. Additionally, if you consent to digital audio recording of the interview, this recording will be digitally stored on a password-protected USB drive. All hardcopies of the interview, including written notes and transcription, and the USB drive will be locked in a filing cabinet in my home for five years. After five years, the USB drive will be wiped and the transcribed interviews will be shredded.

Participation in this study may cause some inconvenience to you, including the length of time required to participate in both interviews. You are welcome to take a break during either interview or reschedule either interview for another time. Participation in this research may cause some potential risks, including feeling uncomfortable or embarrassed with some of the interview questions that deal with sexual health. You are welcome to see the interview questions before consenting to participate and before each interview begins. Questions that may make you uncomfortable are framed so that you do not have to reveal any personal information about yourself. You can choose not to answer any interview questions that may make you uncomfortable. You can also discontinue the interview at any time if you are uncomfortable. If you decide not to answer any questions or no longer participate as a result, you can request to have your interview data destroyed and not included in the final research analysis. You can have a copy of your transcribed interview. You are welcome to make changes to the transcript or omit details that you do not wish to have included. If you do request changes, I will make those changes to the transcript before I begin analyzing the interview data.

As a way to compensate you for any inconvenience related to your participation, you will be given a \$10 gift card to Fairway Market. If you agree to participate in this study, this form of compensation to you must not be coercive. It is unethical to provide undue compensation or inducements to research participants. If you would not participate if the compensation was not offered, then you should decline. If you withdraw at any point after the study has begun, you will still be provided with compensation.

The information I gather through interviews will be used in my thesis. Research findings may be presented at conferences and published in academic journals. Findings will be used in a summary report available to all participants. Your identity will not be revealed in the disseminated results. To maintain confidentiality throughout this research project, including in the disseminated results, your real name will not be used. You can choose a pseudonym to be used in the interview and disseminated material.

Do you have any questions about the purpose of this research project? Do you think you will be comfortable talking about the topics of this research project? Are there any topics you are not comfortable talking about that might pertain to this research? Do you have any questions about the methods or activities I will use in this research project? Do you have any questions about how the results of this research will be disseminated? Do you have questions about confidentiality? Do you have any other questions for me?

If you have any questions or concerns anytime during or after this research project is completed, please contact me at XXX-XXX-XXXX or XXXXXXXXX@uvic.ca. You can also contact my graduate supervisor at the University of Victoria, Dr. Lisa Mitchell, at XXX-XXX-XXXX or at XXX@uvic.ca. You may verify the ethical approval of this study, or raise any concerns you might have, by contacting

the Human Research Ethics Office at the University of Victoria at 250 472 4545 or ethics@uvic.ca or the Vancouver Island Health Authority, Research Ethics Office at 250 370 8620.

Written Consent:

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researcher.

Please circle below if you give consent to do the following:

Record your voice during the interview	Yes / No
Analyze your interview if you choose to withdraw	Yes / No
Provide you with a transcript of your interview	Yes / No
Provide you with a summary report of the research	Yes / No

_____	_____	_____
<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Please indicate by signing below if I have provided you with a copy of the consent form.

_____	_____	_____
<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>

Appendix V: On-Going Verbal Consent Script for Second Interview

I want to remind you that your on-going consent is required before we can begin this second interview. Your participation in this study is completely voluntary. You can choose to withdraw from the study at any time without consequence. You can choose to see the interview questions before providing on-going consent and before beginning this interview. You can choose not to answer any interview questions without consequence. If you choose to withdraw from this study, you can choose to have your interview data destroyed or not included in the final research analysis. Your identity will not be revealed and I will use the pseudonym you chose to protect your identity in any material disseminated as a result of this research. Do you give your continued consent to participate in this project?

Appendix VI: First Interview Questions

Purpose of interview and introduction:

My research addresses how young women make decisions about the HPV vaccine and what information they are using to make these decisions. To look at this, I'm doing two sets of interviews. This first interview focuses on what you've heard about the vaccine and some of your thoughts on it. The second interview explores your thoughts about how the HPV vaccine is discussed in public health information. In the second interview, we will look at an example of this information together and talk about some of the images and text.

Before we can begin this interview, we need to go over the Participant Consent Form. To remind you: The first interview should take about an hour and a half. None of the questions are meant to trick or deceive you. There are no right or wrong answers. You can choose not to answer any questions you don't want to and you can choose to discontinue the interview at any time. If you decide that you no longer want to participate, you can choose whether or not the interview data you have provided so far can be used in this research project. If you decide that you do not want the interview data used, I will immediately erase the digitally recorded material and give you the notes I've written. This interview will be confidential and your real name will not be used. Would you like to choose a pseudonym? Do you have any questions before we begin?

Questions:

- Can you please tell me about yourself?
- Can you please tell me some of your thoughts on the HPV vaccine?
- How did you hear about the vaccine?
- What have you heard about the vaccine?
- What kind of information are you using to make decisions about the vaccine?
- Where do you get this information?
- What do you think about it?
- If you had a friend come to you and tell you that she was thinking about getting the vaccine, but was unsure, what would you say to help her make a decision?
 - What do you think is important for her to consider before making a decision?
- How would you respond if a doctor recommended that you should be vaccinated?
- Why might you considering getting vaccinated?
 - What are some of the factors that might make you consider HPV vaccination? What factors would make you consider against it?
 - Is HPV something you're concerned about?
 - Do you consider yourself to be "at risk" of getting HPV?
 - What do you think it means to be "at risk"?
- Do you feel pressure or obligation to be vaccinated?
- Do you think being a woman has anything to do with getting this vaccine?
- Are there other ways that you think women might protect themselves from HPV?
- What are some of the things women are expected to do to protect their sexual health in general?
 - Is the vaccine part of these expectations?

- Are men expected to do these things as well?
- What do you think about guys getting the vaccine?
 - Why (shouldn't) guys get the vaccine?
- Are you currently sexual active?
 - Does this factor into your thoughts about the vaccine? In what ways?
- Do you or would you speak with your sexual partner(s) about HPV and vaccination?
- Do you know anyone who has decided to (not) get it?
 - What have they said about it?
 - What do you think about people who might not get it?
- Do you have any other thoughts you would like to share?

Wrap-up: Thank you for participating. For the second interview, we're going to be looking at the Society of Obstetricians and Gynaecologists of Canada's HPVinfo website as an example of public health material. If you have a bit of time before the second interview, could you please have a look at the site to familiarize yourself with it? If not, we will look at it when we start the interview.

Appendix VII: Second Interview Questions

Purpose of interview and introduction:

Before we begin this interview, I will need to obtain your on-going consent to participate [read verbal consent script]. In the last interview, we talked about your thoughts on the HPV vaccine and some of the things you've heard about it. Today, I'm interested in your thoughts about public health materials about HPV and the vaccine. We're going to look at just one example of this material, which is the HPVinfo website, created by the Society of Obstetricians and Gynaecologists of Canada. It provides information about HPV, like symptoms and treatment, to users of the site. We'll look at some of the site content together and then talk about some of the things we're seeing on it. This interview should take about an hour. This interview isn't a test of your knowledge and there are no right or wrong answers. You can choose not to answer any questions you don't want to and you can choose to discontinue the interview at any time. If you decide that you no longer want to participate, I will immediately erase the digitally recorded material and give you the notes I've written. This interview will be confidential and your real name will not be used. I will continue to use the pseudonym you chose for the first interview. Do you have any questions before we begin? Did you have a chance to look at the website? If not, would you mind spending a few minutes looking at the site to get a feel for it? After that, we can go through it together to discuss the site.

Questions:

- What are some of your initial thoughts about or reactions to the site after having a look at it?
- Have you been to or heard of this site before?
- Would this site be somewhere you'd go to get information about HPV?
- Do you ever get health-related information off the web?
- Does this HPV site provide you with the info you feel is important to make decisions about getting the vaccine?
- What information would you take away from this site to help you in thinking about getting the vaccine?
- What isn't addressed and would you want to know more about?
- Who do you think it's meant for? Why is that?
 - Do the images and text suggest anything about who is responsible for maintaining sexual health in relationships?
 - In looking at the images of people on the site, who do you think they're supposed to represent?
 - If you think the website is geared toward a particular group of people (*i.e.*, women or respondent's answer to above question), how do you think the website would look different if it were meant for another group (*i.e.*, men)?
- What do you think about the video of "Jay" talking about HPV?
- Do you think that video is important for guys to watch?
- Do you think guys would use this website for information about HPV and the vaccine?
 - Why or why not?
- What comes to mind when you read the website's slogan, "spread the word, not the disease"?
 - What do you think are some of the expectations related to this slogan?

- What do you think are some of the risks about HPV that are conveyed through the site?
- Do you think these risks apply to you?
 - How might they apply to you?
- What do you think about how the Prevention of HPV section talks about sexual relationships and behaviours?
 - How are different kinds of sexual behaviours related to concerns around HPV?
 - How do you think a woman who has had multiple sexual partners would respond after she read that?
- Do you have any other thoughts you would like to share?

Wrap-up: Do you have any questions? Thank you for participating in these interviews. As a small gesture of gratitude, I have a gift card for you.

Appendix VIII: Transcription Conventions (Bailey 2008)

(?)	talk too obscure to transcribe.
Hhhhh	audible out-breath
.hhh	in-breath
[overlapping talk begins
]	overlapping talk ends
(.)	silence, less than half a second
(..)	silence, less than one second
(2.8)	silence measured in 10ths of a second
:::	lengthening of a sound
Becau-	cut off, interruption of a sound
<u>he</u> says.	emphasis
=	no silence at all between sounds
LOUD	sounds
?	rising intonation
(nod)	body movement
[notes, comments]	