

A Novel Approach  
to Guide Health Promotion Planning  
for Preventive Human Papillomavirus (HPV) Vaccination  
Among Adolescent Girls in an Ontario Public Health Unit

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## Abstract

Human papillomavirus (HPV) is widespread in the population and an important concern for public health. HPV-associated benign and cancerous disease is vaccine preventable yet vaccine uptake has been suboptimal. Adolescents are the primary target group for vaccination yet their perspective has been inadequately examined. Ontario provides population-based preventive HPV vaccination to adolescent girls yet in the program's first 2 years only approximately half of eligible girls received it. Effective strategies to improve vaccine uptake are needed. This thesis proposes a theory and ethics-based model to guide health promotion planning for HPV vaccination. Adopting an adolescent perspective, the model is applied and comprises: 1) a systematic review to identify barriers and facilitators to HPV vaccination from the viewpoint of young females; 2) GIS uses for communicating geospatial health information regarding vaccination; and 3) a roadmap for the future including recommendations for guiding principles, research, intervention development, and health policy.

## *Thoughts and Dedication*

*The inspiration for my thesis work was derived from a poignant connection to cervical cancer developed through my years as an oncology pharmacist watching far too many women suffer and die in the prime of their lives from this preventable disease. With the advent of a vaccine capable of preventing cervical cancer I promptly committed myself to contributing whatever I could to the important work of ensuring that women and girls everywhere would benefit from this scientific and medical breakthrough. In carrying out my thesis work I soon found myself grappling with one new domain after another: health policy and promotion, adolescent health, laws of consent, theories of health behaviour, methodology of every kind, geography, technology; each one with its own extensive history of development and application. I came to realize that I could, in fact, continue to build upon this thesis indefinitely. Preferring to spare myself interminable distress, I have ended it here. Nevertheless, I resolve to continue along the vital path of lifelong learning, having gathered a repertoire of new interests, new ideas, new knowledge, and new respect for the journey; and hopefully I will inspire a few others along the way. It is with this thought that I dedicate this thesis to my two beautiful daughters, Alysha and Rachel. My overarching purpose in this world is to be a worthy role model to each of them. My work in completing this thesis is one small part of that goal.*

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## Introduction

The recent introduction of preventive human papillomavirus (HPV) vaccines has brought to the forefront a new public health concern which has, in turn, generated an accompanying need to examine the broad range of issues surrounding vaccine acceptance. HPV is widely recognized as the most common sexually transmitted infection worldwide.<sup>1;2</sup> It affects both males and females and is most commonly acquired soon after becoming sexually active. Most females will acquire an HPV infection in their lifetime and over half of girls become infected within 48 months of sexual debut.<sup>3</sup> HPV is capable of causing benign, pre-cancerous, and cancerous disease. Certain types of HPV cause genital warts and other types are known to be a necessary cause of cervical cancer. Moreover, HPV infection can be prevented. A systematic review of randomized, controlled trials indicates that preventive HPV vaccines are highly efficacious and safe.<sup>4</sup> In Canada, the first prophylactic vaccine against HPV was approved in June 2006 for girls 9-26 years of age.<sup>5</sup> Subsequently, in February 2010, a second HPV vaccine was approved in Canada, also for girls and young women. Notwithstanding vaccine approval up to age 26, the current recommendations of the National Advisory Committee on Immunization (NACI) state that 9-13 year old females are the preferred target group for vaccination primarily because the vaccine must be administered prior to first sexual activity to confer the greatest benefit.<sup>6</sup> Accordingly, in September 2007, Ontario introduced a population-based HPV immunization program for all grade 8 girls. Yet, even in the setting of a mainly school-based program offering cost-free vaccination, less than 50% of eligible girls received the vaccine in the first year and even fewer completed the full 3 dose schedule.<sup>7</sup> Vaccine uptake improved only marginally in the program's second year. Thus, despite the overwhelming benefit of vaccination, many girls do not receive it.

The achievement of high levels of HPV immunization coverage among adolescent girls is an important public health goal for a number of reasons. In addition to its capacity to target a widespread disease-causing virus, vaccination against HPV

offers a means of primary prevention with the potential to avert most HPV-associated disease entirely. Existing alternatives are only able to provide surveillance against the development of cancer by detecting a disease process that is already underway. Consequently, HPV vaccination is the only modality capable of preventing both premature death due to cervical cancer and the hundreds of times as many cases of benign and pre-cancerous HPV-associated disease requiring follow-up and/or intervention; much of which occurs in adolescence and young adulthood. The fundamental importance of ensuring vaccination among adolescent girls is attributable to the prevalence of HPV infection which peaks shortly following the average age of sexual debut. Protection prior to first sexual contact is consequently of vital importance. Moreover, given that universal vaccination is likely the only way to confer essential protection to the population, it is desirable to target all adolescent girls for vaccination.<sup>8</sup> The cost-effectiveness of vaccination is also dependent upon broad vaccine uptake. And, while current efforts to prompt opportunistic vaccination among adult women will gradually dissipate over time as more young girls become vaccinated, ongoing diligence to ensure high immunization coverage among adolescents will continue to be required over the long term. Furthermore, improvements in public health, such as immunizations against infectious disease, have consistently had a profound impact on health and life expectancy over the last century. Thus, in light of existing suboptimal provincial coverage rates despite the notable potential health benefits associated with vaccination, there is a clear need to improve uptake of preventive HPV vaccination among adolescent girls in Ontario.

Because it is targeted most importantly toward young people, preventive HPV vaccination is fundamentally an adolescent health matter. Adolescence is a time of transitions and marks the commencement of a vital period during which emerging young adults begin to assume added responsibility and start to make important decisions for themselves. Yet from a health care point of view, it is a time period conspicuously characterized by a lack of focus on health. In fact, the

fewest number of visits to health care providers occur in this age range.<sup>9-11</sup> Furthermore, few health policy initiatives are specifically aimed at adolescents, particularly in the domain of health promotion and preventive medicine.<sup>12</sup> Ongoing struggles to deal with adolescent health issues such as obesity, mental health, and physical activity, have revealed an unmet need.<sup>13-15</sup> Yet investments in empowering adolescents to become autonomous custodians of their own health ought to yield important returns in terms of producing young people who are capable of leading themselves confidently into a healthy adulthood. The Life Course Health Development Framework lends support to this view and further asserts that the greatest opportunities for health investment occur during the first twenty years of life.<sup>16</sup> The task of promoting preventive HPV vaccination among adolescents is thus situated in the midst of a complex mix of public health challenges and opportunities.

From a societal perspective it is apparent that the availability of preventive HPV vaccines has introduced complex policy and implementation issues. HPV-related health recommendations are being re-evaluated including new screening methods and guidelines, health care dollars have been allocated to support HPV vaccine programs, and never before has the introduction of a vaccine resulted in more scrutiny in the media.<sup>17</sup> All of this has led to ongoing debate and discord among health care providers, policymakers, and the public. Those targeted for vaccination, as well as their friends and family members may be understandably confused by the ongoing propagation of mixed messages. The complexity of vaccine implementation is further compounded by charged societal values related to a health matter which concerns young people. There is a clear need to optimize promotion and educational efforts to aid in the overall attainment of screening and vaccination goals in the context of these complex societal dynamics.

At the individual adolescent level, numerous factors may arbitrate in HPV vaccination choices. Unfortunately, few studies have examined the perspective of intended adolescent vaccine recipients even though the decision about

vaccination may impact a girl's future health in important ways. The current Ontario school-based immunization program mandates parental consent for HPV vaccination by way of a consent form sent home with students yet it is unknown to what extent girls are involved or desire to be involved in the decision to receive it. In a study conducted among high school students in California, less than half of girls had participated in the decision to become vaccinated and there was no corresponding inquiry regarding their desire to have been involved.<sup>18</sup> Young girls may also perceive particular barriers and/or facilitators to vaccination, and their personal concerns may differ from the concerns of others involved in the decision. Uncovering relevant barriers and facilitators to vaccine uptake is integral to understanding how vaccination rates may be improved, particularly when the viewpoints of adolescent girls themselves are considered. To attend to gaps in evidence and provide direction for future developments, a *Canadian HPV Vaccine Research Priorities* workshop was held in 2005. Participants identified ten top research priorities one of which was the investigation of the knowledge, attitudes, beliefs, and acceptability of HPV vaccination among intended vaccine recipients.<sup>19</sup> Despite such guidance, the vast majority of research published to date has focused on the views of parents, health care providers, and others. A comprehensive and contextual understanding of operative influences, which reflects the diversity of adolescent populations, would offer important insight into ways to assist young girls with vaccination decision-making. To date, the adolescent viewpoint has been understudied and largely overlooked.

Also among the top research priorities identified at the 2005 *Canadian HPV Vaccine Research Priorities* workshop was how to promote HPV vaccination in an acceptable and effective way. However, since the launch of the first preventive HPV vaccine in 2006 promotion of the vaccine has been plagued by negative media attention and opposing views. In part, this turbulent debut resulted because clear, consistent, and trustworthy messages had not been developed and disseminated by appropriate key groups prior to the vaccine's introduction. To date, developments in the field of HPV vaccine health promotion have largely

focused on detailing the problems and complexities of implementation. Knowledge, attitudes, and beliefs about vaccination have been extensively studied but the views of people other than intended adolescent vaccine recipients predominate in the published literature. Many studies suggest the need for educational initiatives or advise particular program requirements but few contribute meaningfully to our understanding of how to effectively translate such recommendations into desired change. Likewise, while existing theoretical and health frameworks may offer important guidance and insight into how to build successful vaccine implementation programs they have not been perceptibly applied.

An implementation model to support the promotion of preventive HPV vaccination is needed. Such a model should aim to provide invulnerable guidance for program planning by pulling together several elements. Based upon a valid theoretical foundation and a sound ethical underpinning, the model should draw on valid research findings yet also be instrumental in eliciting new ideas and driving new research initiatives. Importantly, the model should be comprehensive and take into account multiple levels of influence and foster the involvement of stakeholder groups in all aspects from research design through to implementation and evaluation. The model should ultimately be tied together by an effective means of communication to ensure that in its evolution it can iteratively cultivate an informing-enhancing cycle with the potential to result in important health gains.

## Objectives

The objective of this thesis is to conduct some of the formative work needed to guide health promotion planning for HPV vaccine implementation when viewed from the perspective of adolescent girls - the primary target group for vaccination.

Specific aims of this work are, to pull together and appraise what is known about adolescent views concerning factors which prevent and/or prompt girls to receive

HPV vaccination; to examine issues related to adolescent participation in vaccination decision-making; to consider the potential utility of a geographic information system to effectively communicate HPV vaccination coverage information and yield geospatial information with the potential to enrich initiatives in research and health promotion; and, to propose a health promotion and policy roadmap for the future. Based upon the assimilated knowledge and evidence, the roadmap shall attempt to define a relevant health service implementation model for HPV vaccination, and consider appropriate next steps with respect to research, suitable interventions, and guiding principles for health policy.

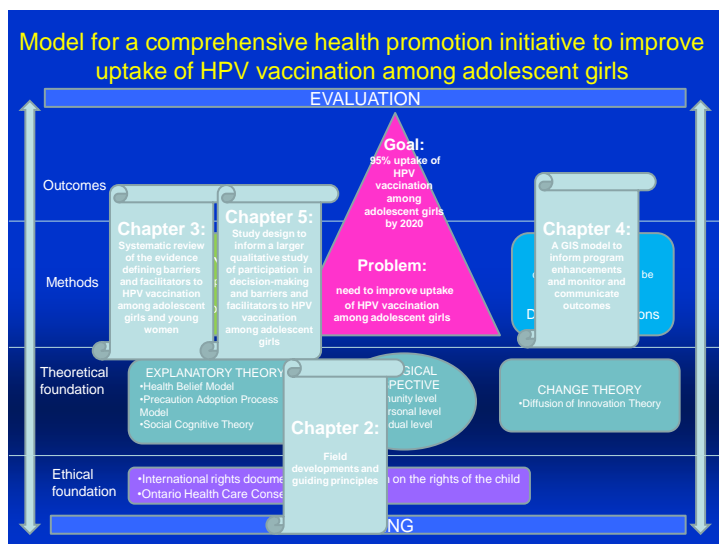
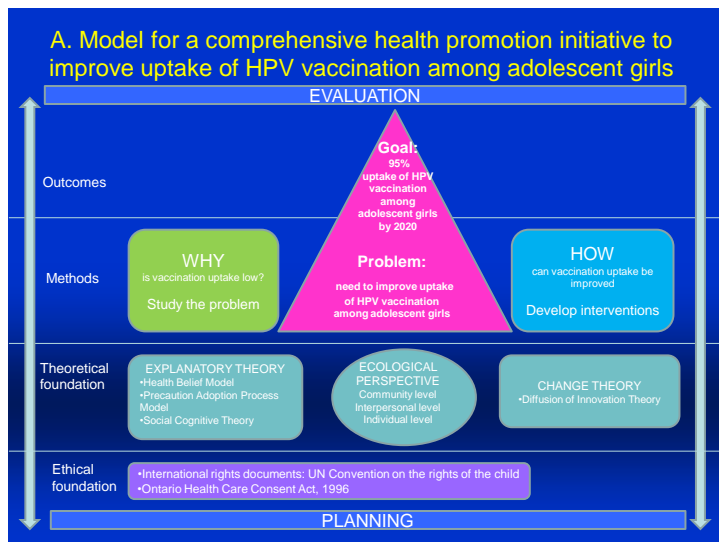
To accomplish this, the thesis is comprised of four constituent parts:

- A literature review of underlying principles (Chapter 2)
- A systematic review of the literature on the subject of self-reported barriers and facilitators to HPV vaccination among adolescent girls and young women (Chapter 3)
- The creation of a geographic information system (GIS) model to communicate provincial and local geographic variation in HPV vaccine uptake (among the 36 public health units in Ontario and among program eligible schools in the City of Ottawa Public Health Unit) (Chapter 4)
- A discussion chapter outlining a roadmap for the future which considers three main elements: a study proposal appropriately designed to address remaining gaps in our understanding of factors which arbitrate in vaccination decision-making among adolescent girls; the design of an intervention aimed at addressing barriers and/or facilitators personal to each girl considering HPV vaccination; and the creation of a process model relevant to the implementation and promotion of preventive HPV vaccination among adolescents (Chapter 5)

Figure 1 illustrates how the chapters of the thesis fit within the health promotion model discussed in Chapter 5.

In summary, there is not presently a strong knowledge or guidance base from which to build programs to promote HPV vaccination whereby we can be reasonable assured of their success. Regardless of the scope of any program, the desired benefits cannot be realized if girls opt not to receive the vaccine. This thesis upholds an adolescent viewpoint and aims to pull together what can guide us from a theoretical basis, should guide us from an ethical standpoint, and what reliable guidance we have from existing research. Moving beyond this, cogent next steps are considered and proposed in terms of prompting the translation of what is known into what can be successfully accomplished.

Figure 1. Health promotion model proposed in thesis



## 2.0 Background

### 2.1 Human papillomaviruses (HPV)

#### 2.1.1 Identification and Epidemiology

Human papillomaviruses are small, species-specific DNA viruses that selectively infect cutaneous and mucosal tissues.<sup>1</sup> In humans approximately 130 types of HPV have been identified to date.<sup>20</sup> Individual virus types are classified as either low risk types, with the potential to cause benign human disease such as warts, while others are classified as high risk types due to their oncogenic potential. Approximately 30-40 viral types may infect the genital tract.<sup>20</sup> HPV types 6 and 11 are responsible for approximately 90% of genital warts. The types most commonly associated with cancer are HPV 16, 18, 31, 33, 35, 45, 52, and 58.<sup>1</sup> Together, HPV 16 and 18 account for more than 70% of cervical cancer cases worldwide.<sup>21;22</sup>

In a large case series, 99.7% of invasive cervical cancer specimens gathered from 22 countries were found to contain HPV DNA.<sup>23</sup> From this study Walboomers et al concluded, "The presence of HPV in virtually all cervical cancers implies the highest worldwide attributable fraction so far reported for a specific cause of any major human cancer."<sup>23</sup> Through this and related work, HPV is now recognized as a necessary cause of cervical cancer.

HPV infection is very common. It is the most common sexually transmitted disease among women affecting approximately three out of every four women at some point in their lives.<sup>24</sup> Normally, infection is asymptomatic and transient, clearing within 4 to 20 months.<sup>25</sup> New HPV infections may be acquired throughout life. At any given time, the prevalence of HPV among Canadian women is

estimated to be in the range of 11 - 29%.<sup>6;26</sup> Prevalence peaks in adolescence and young adulthood (under 25 years of age) then generally declines with age.<sup>27</sup> In a large prevalence study conducted in British Columbia women under the age of 20 were found to have the highest prevalence rates of any HPV, including HPV 16 and 18, the cancer-causing types contained in both available prophylactic vaccines.<sup>28</sup>

## 2.1.2 HPV-associated disease

### 2.1.2.1 Benign disease

Benign HPV disease is usually in the form of warts. Common warts of the skin are associated with low risk types of HPV and, within the genital tract, chondylomata, or genital warts, are caused primarily by HPV types 6 and 11.

A large number of episodes of genital warts are treated each year in Canada.<sup>29</sup> In a study conducted in Manitoba, a population-based database was used to identify incident and prevalent cases of anogenital warts linked to medical claims and hospital records between 1984 and 2004.<sup>30</sup> The study found that, during this time period, the overall incidence and prevalence of anogenital warts among men and women ranged from 0.10 to 0.18% and from 0.12 to 0.20% respectively. Of note, young women aged 20 to 24 had the highest incidence rate across all years. Likewise, prevalence rates peaked for young women at 20 to 24 years of age, and, among 15 to 19 year-olds, the prevalence rate was 3.6 times higher among young women compared to young men. Similarly, in a UK study, 30% of incident cases of first episode genital warts among females were diagnosed in those under the age of 20.<sup>6</sup> These data underscore the fact that genital warts are primarily a health matter affecting young people, particularly young women.

### 2.1.2.2 Pre-cancerous disease

HPV is an endemic sexually transmitted disease with most sexually active women acquiring an HPV infection in their lifetime. Nevertheless, despite the ubiquitous nature of HPV, most infections resolve spontaneously and for those that do not, lesions can be identified through screening surveillance and treated if necessary. Following HPV infection of the female genital tract, pre-cancerous changes of the cervix may occur and persist for many years. In some cases, if the original infection does not clear, a low grade lesion may arise. This type of lesion may subsequently regress or may progressively develop into a high grade lesion. Left untreated, there is a substantial risk that a high grade lesion will progress to invasive cervical cancer. Progression from an oncogenic HPV infection to invasive cancer can take a decade or more.<sup>1</sup>

Pre-cancerous lesions of the cervix must be monitored routinely and treated when necessary to ensure favourable outcomes and avoid progression to cancer. The treatments are often invasive and, in some cases, may result in fertility loss or other psychologically distressing consequences.<sup>31-34</sup> Furthermore, as many as 1 out of every 19 women may be impacted by an abnormality detected through cervical screening.<sup>35</sup> The burden of pre-cancerous HPV disease is often underemphasized with respect to the potential impact of preventive vaccination. There are more than 5.7 million Pap tests performed each year in Canada and available estimates suggest that approximately 300 000 test results require further follow-up and/or management.<sup>35</sup> In addition to the distressing personal consequences, this burden is associated with substantial health care costs. In fact, one can extrapolate that, in Canada, the number of cases of pre-cancerous lesions requiring follow-up or treatment outnumber invasive cervical cancer cases by a factor of more than 200. Furthermore, this does not account for the burden of extragenital HPV disease in women or HPV disease in men.

### 2.1.2.3 Cervical cancer

Cervical cancer is an important cause of preventable cancer death in women. The overwhelming burden of the disease in the developing world places cervical cancer as the second most common cancer and the third most common cause of cancer death among women worldwide.<sup>21</sup> Importantly, cervical cancer commonly affects women in the prime of their lives.

According to Canadian Cancer Statistics 2011, there will be an estimated 1300 new cases of cervical cancer and 350 cervical cancer deaths among Canadian women in 2011.<sup>36</sup> Of this number, an estimated 500 new cases and 140 deaths are expected to occur in Ontario.<sup>36</sup> Though ranked as the 13<sup>th</sup> most common cancer among women in Canada, cervical cancer has been the 2<sup>nd</sup> most common cancer among young women 20-44 years of age, and ranks 4<sup>th</sup> among those age 15-29 years.<sup>37</sup> In the Canadian population, the incidence of cervical cancer peaks among women at around age 40.<sup>37</sup> Cancer Care Ontario's 2006 special report, *Cancer in Young Adults in Canada*, emphasizes that, "cervical cancer is more prominent in young adults (6% of cancers) than in all ages combined (1%)." <sup>37</sup> Because of its prominence among young women, cervical cancer represents an important source of potential years of life lost (PYLL); it is ranked 3<sup>rd</sup> for PYLL due to cancer among women 20-44 years of age.<sup>37</sup>

If detected early cervical cancer can be effectively treated in the vast majority of cases. Advanced cervical cancer, however, is a devastating disease which does not respond well to treatment and is frequently associated with terrible pain and other distressing symptoms and complications.

#### 2.1.2.4 Links to other cancers

Increasingly, HPV is being linked to cancers other than cancer of the cervix. HPV is, to varying degrees, associated with cancers of the anus, vulva, vagina, penis, oral cavity, and oropharynx.<sup>38-40</sup> In fact, based on 2002 data, it has been estimated that HPV is responsible for more than 5% of all cancers worldwide<sup>38</sup>

#### 2.1.3 Disease prevention

Both primary and secondary cervical cancer prevention options are now available in Canada by means of prophylactic HPV vaccination and cervical screening, respectively. Though all eligible Canadian women have access to Pap test screening via the publicly funded universal health insurance system, HPV vaccination is currently only available free of charge to adolescent girls through school- or population-based programs as implemented by the individual provinces and territories. Following the introduction of Pap testing in Canada, cervical cancer incidence and mortality fell sharply initially then transitioned, with time, to a more gradual rate of decline. Cervical cancer mortality is now less than half of what it was in the early 1980s.<sup>36</sup> Despite these significant reductions, it appears that the incidence and mortality for cervical cancer may now be leveling off and, consequently, we may have reached the limit of benefit obtainable through secondary cervical screening.

The Pap test was introduced in Canada in 1949 and has been effective for detecting pre-cancerous changes and cervical cancers at an early stage in their development. Consequently, many deaths from cervical cancer have been prevented. Still, several studies suggest that almost one quarter of Canadian women are not screened according to current recommendations, and both inadequate screening rates and the incidence of cervical cancer in Canada have remained essentially unchanged for nearly a decade.<sup>41;41-43</sup> A persisting

population of never screened and under screened women, failures in the follow-up of abnormalities detected through screening, as well as the occurrence of false negative Pap test results, have all been offered as explanations for this plateau.<sup>6</sup> In fact, failure to screen, or failure to screen according to current recommendations, is presently considered the major risk factor for the development of cervical cancer in Canada.<sup>6</sup> Notably, however, the health benefit achievable with Pap screening is limited in that it can only offer protection against a disease process that has already been set in motion. It does not reduce the overall burden of pre-cancerous cervical disease. Furthermore, there are no screening standards for the detection of other diseases caused by HPV.

Prophylactic HPV vaccination first became available in Canada in June 2006. In 2007 the National Advisory Committee on Immunization (NACI) published its recommendations regarding the appropriate use of HPV vaccination in the Canadian population.<sup>6</sup> In its statement, NACI recommended vaccination for females between 9 and 13 years of age in order to ensure the greatest potential for benefit since this age range is prior to the onset of sexual activity for most girls. The committee further recommended that females between 14 and 26 years of age would also benefit from vaccination if not already infected with vaccine strains of HPV. No recommendations were made regarding the use of HPV vaccination in females over the age of 26 or in males, though more recent evidence lends support for use in these groups as well. Subsequent implementation of specific programs for HPV vaccine delivery was under the purview of the individual provinces and territories. In Ontario, a school-based immunization program was introduced for grade eight girls in the 2007/08 academic year.

In appraising the adequacy of existing public health approaches to HPV disease prevention and management, it is imperative to consider the potential added value associated with HPV vaccination. Because the impact of Pap test screening is limited to detecting disease that has already developed, the value of current screening programs is solely as a means of surveillance that safeguards against

cancer development. Vaccination, on the other hand, may provide broad protection, capable of preventing the full burden of disease associated with the most common types of HPV. Managing the full extent of vaccine preventable HPV-associated disease in Canada consumes significant healthcare resources.<sup>29</sup> Still, the true annual costs related to Pap test screening, follow-up and treatment of abnormal Pap results, invasive management procedures, cervical cancer management, diagnosis and treatment of benign disease and other HPV-linked diseases, and any associated psychological costs are not accurately known. The ability to impact upon these factors would constitute a potential benefit for all vaccinated women, including those already compliant with current screening recommendations. As well, prophylactic HPV vaccination may be able to narrow the gap in attainable disease prevention by reaching females unlikely to be compliant with cervical screening recommendations. It will be crucial to derive incremental benefit by reaching those women at highest risk if vaccination is to be successful at contributing to a further appreciable decline in the incidence of cervical cancer. It is not yet clear, however, whether high risk women will be any more likely to obtain vaccination than to comply with screening. Also, targeting high risk groups exclusively may not result in a reduced population disease burden. Support for universal vaccination comes from reflecting on the experience of hepatitis B vaccine implementation worldwide. In this case, restricting vaccination to high risk groups did not confer population protection and a subsequent shift to universal vaccination resulted in major reductions in the global rate of acute hepatitis B, hepatitis B carriers, and an associated decline in liver cancer.<sup>8;44</sup> Furthermore, it is important to consider additional potential benefits of HPV vaccination such as the protection it may provide against other diseases linked to HPV and which affect both women and men.

Despite the vast potential for additional health benefits associated with HPV vaccination, the reality of such benefits cannot be known until post-vaccination surveillance offers confirmation. Until longer term outcomes associated with HPV vaccination can be observed in the population it is not possible to say whether

vaccination will eventually be able to replace cervical screening. Pap test screening recommendations have not changed and both screening and vaccination strategies must remain fully integrated for the foreseeable future. Combined primary and secondary prevention strategies (Pap screening plus HPV vaccination) are the current focus of HPV disease prevention in Canada. Accordingly, Cancer Care Ontario (CCO) has set specific goals, targeting 95% screening participation and 95% uptake of HPV vaccination (prior to sexual debut) among females by 2020.<sup>45</sup>

## 2.2 Prophylactic human papillomavirus vaccines

### 2.2.1 Available vaccines

Two prophylactic HPV vaccines are currently available. Both vaccines protect against the two most common oncogenic strains of the virus, HPV-16 and HPV-18, and one of the vaccines also protects against HPV-6 and HPV-11, associated with benign genital disease. A systematic review of randomized trials suggests that these vaccines are efficacious and well tolerated.<sup>4</sup>

### 2.2.2 Target groups for vaccination

In its 2007 recommendations, Canada's National Advisory Committee on Immunization specified 9-13 year old females as the primary target group for HPV vaccination.<sup>6</sup> Primarily, this is because the greatest vaccine-conferred protection is possible when vaccination takes place prior to first HPV exposure, which frequently occurs shortly after sexual debut.<sup>3</sup> Data from the Canadian Community Health Survey (cycle 2.1) suggests that the average age of first sexual intercourse in Canada is 15.7 years for both males and females.<sup>6</sup> In addition, vaccine benefits are optimized in this age range as a result of the more robust immune responses attainable at younger ages, and because the physiologic conditions which exist

within the transformation zone of the cervix at puberty render the cervical cells of young girls more susceptible to infection by HPV.<sup>46-48</sup>

Other groups, including females from 14-26 years of age, older women up to the age of 45, women with prior cervical abnormalities, boys, and certain groups of men, have all been investigated as potential targets for vaccination; the basic premise being that vaccine effectiveness will be greatest in those individuals who are not yet infected with an HPV strain that is covered by the vaccine.

### 2.2.3 Population-based vaccination programs

Shortly following Health Canada's approval of the first preventive HPV vaccine in July 2006, the Canadian government announced that \$300 million of the 2007 federal budget would be allocated to fund HPV vaccination programs across the country. Individual provinces and territories subsequently implemented programs in varying years and among varying age cohorts of girls: two programs have been introduced among grade 4 girls, two in grade 5, five in grade 6, two in grade 7, and one in grade 8.<sup>49</sup> It was in August 2007 that Ontario announced its plan to provide vaccination to all grade 8 school-age girls and public health units across the province responded with hurried efforts to have programs in place for the 2007/08 school year. In the City of Ottawa Public Health Unit there are approximately 5000 grade 8 girls distributed across 90-100 schools.<sup>50</sup> Most vaccinations are provided in the schools but some girls are referred to outside clinics or family physicians. Sexual health centres also offer vaccination to eligible girls not attending school. Vaccination coverage information is collected and reported directly to the Ministry of Health and Long-Term Care.

### 2.2.4 Vaccine uptake

Following the introduction of preventive HPV vaccine programs, uptake has been suboptimal in most jurisdictions in Canada. Knowledge and implementation gaps,

public scrutiny, and discord among stakeholder groups are some of the issues which have impeded broad vaccine coverage among target groups. From available information to date, population-based vaccination coverage has been highest in the Atlantic Provinces and Quebec at 80% or more.<sup>49</sup> In British Columbia uptake has been in the range of 62%.<sup>51</sup> In Ontario, vaccine coverage is among the lowest in the country. Ontario's uptake, pursuant to the population-based vaccination program of school pupils, averaged 48% for the administration of all three doses during the 2007/08 academic year, and 52% for the 2008/09 academic year.<sup>52</sup>

### 2.3 Adolescent health

Adolescence is generally defined as the period beginning with puberty and ending with attainment of the age of majority. In their book *Adolescent Health: Policy, Science, and Human Rights* Boyce et al state that, "Adolescence begins with the onset of physiologically normal puberty and ends when an adult identity and behaviour are accepted" and suggest that this corresponds approximately to the period from 10 to 19 years of age.<sup>53</sup>

Adolescence it is a time period ubiquitously characterized by the turmoil associated with transitioning from child to adult. Yet, it is also a period of growth during which young people begin to assume greater responsibility, make important life decisions, and achieve independence. Adults often typify adolescence as an interlude of defiance and detachment and consequently avoid or minimize intrusion believing it to be an unmanageable stage. Even adolescents themselves often tend to believe they are invincible. As well, current initiatives in Canadian health policy reveal that adolescents are largely overlooked. Few adolescents access the medical system for preventive care and, even when they do, opportunities for preventive care are frequently missed.<sup>11;54</sup> Immunization rates among adolescents lag behind rates in young children.<sup>13;54</sup> Notably, many of the health issues of adulthood have important origins in childhood and Canada

has struggled with the delivery of adequate health services to adolescents.<sup>13</sup> The result is a collective gap in society's focus on adolescent health and a breakdown in our recognition that adolescence is an opportune time to impart healthy attitudes and behaviours that can be carried forth into adulthood.

In 1991, Canada ratified the treaty of the United Nations Convention on the Rights of the Child (UNCRC).<sup>55</sup> The UNCRC outlines child rights according to three main categories: survival and protection, development, and participation. Of the three, the right to participation lags behind the other two primarily due to the Convention's emphasis on early childhood. Participation deals with the evolving capacities of young people and Article 12 of the UNRC addresses the views of children, including the right to participate in matters that affect their lives and futures, such as taking part in health decision-making. It further specifies that the duty of parents is to provide guidance in a way that respects the evolving capacities of their children. Despite some limitations with respect to an insufficient focus on adolescents, the UNCRC provides opportunity, and obligation, to apply guiding ethical principles to the creation of effective health policy aimed at improving adolescent health in Canada.

In terms of guidance for adolescent health policy available from research, this too has been deficient in Canada. Rootman and Boyce suggest three research objectives to inform Canadian adolescent health policy development: determination of adolescent health status; identification of the determinants of adolescent health; and demonstration of health intervention effectiveness for adolescents.<sup>53</sup> While national surveys have helped to provide information about health status, research related to health determinants and interventions is limited. A lack of adolescent involvement in research planning and pilot investigations in order to provide feedback and inform changes to study design may further limit the quality and applicability of research and hamper efforts to establish successful interventions. An additional imperative is to explore the views of adolescents: issues that matter to them, their ways a handling them, their attitudes and beliefs,

the role they would like to play in matters which concern them, and their expectations and wishes related to the involvement of others.

Frequent resistance, on the part of parents, schools, and communities, to asking young people about their health and behaviours further complicates matters.

According to Boyce, “Qualitative and survey research that listens to adolescents, and that respects self-reported health information, is of particular significance in fulfilling the principle of adolescent participation in policy development and decisions.”<sup>12</sup>

The concept of participation is of particular relevance to health matters concerning adolescents and has important implications for voluntary-choice health interventions such as preventive HPV vaccination. Several Articles within the UNCRC refer to the rights of young people with respect to participating in matters that affect their lives. The obligations put forth in the Convention with respect to participation rights are highlighted in a commentary by Emily Boyce who states that “Overall, the “evolving capacities of the child” are to be taken into consideration when it is decided how, when, and to what extent a child can exercise his or her rights independent of parents or guardians.”<sup>55</sup> In Canada, adolescents are able to visit health care providers independently regarding confidential medical concerns such as birth control, sexually transmitted infections, or issues related to teen pregnancy. Further, the legal age to consent to sexual intercourse in Canada is 14.<sup>56</sup> Yet, aside from these often undisclosed matters, for many of the voluntary-choice health matters affecting their children that parents are aware of they wish to retain control of the decision and consent process. This is largely the case with preventive HPV vaccination as well. Most jurisdictions require parental consent for vaccination and in many cases it is unclear that adolescents are being provided with any opportunity to participate in the decision. In Ontario, the Health Care Consent Act, 1996 does not specify a particular age for the provision of consent; rather, the right to provide consent is said to relate to a person’s capacity.<sup>57</sup> The Bioethics Committee of the Canadian Paediatric Society also provides recommendations, stating that, “Some children

and adolescents have the ability and desire to make their own decisions. Physicians should carefully assess these factors, encourage decision-making by patients, families and the health care team together, and support capable patients who wish to make their own decisions.” It also advises that, “Disclosure of information and inclusion in decision-making should occur according to the stage of the child or adolescent’s development. Respect for parental wishes and values is important, and the needs and interests of the child or adolescent should prevail.”<sup>58</sup>

Are adolescents competent to make health-related decisions? Do they want to be involved? An empirical study conducted in the early 1980s examined the competency of both 9 year olds and 14 year olds to make informed treatment decisions when compared to adults.<sup>59</sup> In this study, not even the 9 year olds chose to waive their decision making authority, demonstrating the desire of young people to be active participants in matters which affect them. At 9 years of age the children were capable of comprehending the basic facts involved in making health-related decisions and by 14 years of age, participants could competently demonstrate evidence of choice, reasonable outcome, rational reasons, and understanding to a degree equivalent to that of adults. The researchers concluded that, based upon their findings, adolescents should not be presumed to be incapable of providing informed consent for treatments, and that adolescent rights to self-determination should be supported in policies. Others have also supported the view that acts of paternalism preclude the ability to engender adolescent confidence and capacity as autonomous decision makers.<sup>60</sup> The overarching message is well captured by Tonkin et al who highlight the need to embrace the concept of a ‘youth-positive society’ that values “[...] meaningful youth participation and youth empowerment” and that insists upon “[...] greater efforts to ensure the voices of youths are heard at every level and that their meaningful participation in setting youth-related agendas is properly supported.”<sup>56</sup> In Canada, this ought to include a re-examination of adolescent consent rights.

Sexual and reproductive health in adolescence is another domain where research and policy are conspicuously lacking in Canada.<sup>56</sup> The UNCRC itself lacks focus on the subject of adolescent sexuality. Furthermore, adult discomfort in speaking to adolescents about sexual health issues is commonplace and means that these young people are frequently left with little guidance. They are, for the most part, left to their own devices and often turn to peers for advice. This unfortunate arrangement is counter to the principle of ensuring that adolescents are appropriately supported as they mature and develop into sexually healthy adults. Sexuality is an important matter to adolescents and a normal part of growing up. With respect to preventive HPV vaccination, a number of vaccination refusals are a result of parental beliefs that getting a vaccine which affords protection against a sexually transmitted disease will promote promiscuity among adolescents.<sup>61</sup> It should rather be viewed as an opportunity for open and supportive discussion about the responsibilities associated with the onset of sexual activity. In Canada, the average age of sexual debut is estimated to be 15.7 years and adolescents need to begin learning about the subject well in advance. There is an obvious need in Canada to address the gaps in research, policy, and guidance related to sexuality and reproductive health in adolescence. From a policy perspective, Tonkin et al suggest that targeted approaches rather than legislative ones will be most effective.<sup>56</sup>

Emily and William Boyce assert that, “Adolescent health and well-being has yet to become well established as a substantive focus for health promotion policy development in Canada” and they suggest three main reasons for this: a lack of the formative research needed to define a comprehensive inventory of pertinent adolescent health issues; a notable absence of recognizing adolescents as a distinct group with corresponding distinct needs; and a need for explicit emphasis on adolescent rights in international human rights consensus documents.<sup>62</sup> Their belief is that human rights and science go hand in hand when it comes to designing the most effective health policies for adolescents in Canada.

## 2.4 Health Promotion

Health promotion is characterized by a multidisciplinary approach to empowering and enabling people to be in command of their own health. The First International Conference on Health Promotion was held in Canada's capital city in 1986 and resulted in the World Health Organization's (WHO) Ottawa Charter, which spawned a health promotion movement in Canada. The Charter called for health promotion action through healthy public policy, supportive environments, community actions, personal skills development, and reorientation of health services.<sup>63</sup> Despite the evolution of health promotion in Canada, there has been a shortage of specific efforts to promote health among adolescents. Yet it is in youth that many lasting behaviours become entrenched. Large scale advertisers, for instance, have long known that because young people are particularly impressionable, they represent the ideal target group in terms of generating life-long brand preferences.<sup>64</sup> In fact, an estimated 10 billion dollars is spent on advertising to young people each year in the United States.<sup>15</sup> In a similar way, adolescence can be viewed as the ideal time to impart the skills and behaviours integral to becoming, and remaining, healthy adults; and with the potential for far healthier returns on the investment. Promoting health at the beginning of life leads to improved health and well-being throughout life which in turn holds promise for associated reductions in health care costs.<sup>16</sup>

In addressing the distinct needs of adolescents, health promotion efforts should emphasize the development of skills and abilities related to health matters, including decision-making, and a sense of self-responsibility for healthy adult behaviours. Health may be promoted by teaching adolescents to think carefully and critically about health issues and health decisions. Above all, health promotion efforts need to be constructed upon a foundation of respect for every adolescent's capacity and right to participate.

### 2.4.1 Schools as venues for promoting health

In a socio-ecological approach to health the environment is a key feature since distinct settings and social contexts exert important, and reciprocal, influences in shaping behaviours. Accordingly, schools represent unique venues for promoting health because they are the fundamental social community for most adolescents, because they offer a setting through which most adolescents can be reached, and because schools are the seminal institutions for teaching young people how to participate and thrive in society.

To achieve health-related goals in school settings a collaborative and mutually supportive relationship between health and education is required.<sup>65</sup> Internationally, promoting the health of young people has been a longstanding goal of agencies such as WHO, UNESCO, and UNICEF. A report of a WHO Expert Committee on promoting health through schools, convened in 1995, described the concept of *'health-promoting schools'* and emphasized that successful health promotion through schools, " [...] is a reflection of an organized, coherent approach to a wide range of health issues, implemented through comprehensive and holistic strategies."<sup>66</sup> In Canada, adoption of the principles set forth in the WHO's Ottawa Charter led Health Canada, the Canadian Association of School Health, and educational bodies from across the country to develop *Comprehensive School Health (CSH)*, a framework for fostering planned, integrated, and holistic improvements to school health through programs, policies, activities, and services.<sup>67;68</sup> The guiding principles set forth in CSH demonstrate recognition of the significant role schools play in shaping healthy lives for young people. Adolescents themselves have most commonly identified school as their source of information about HPV. At a local level, communities must come together to foster a spirit of collective responsibility for personal and community health and support schools through multidisciplinary collaboration aimed at creating effective policies and programs. It is not without considerable challenges that the goals of CSH can be achieved; there is a need to maintain a sense of connectedness with school among students; to develop a

formal health curriculum; to harness the expertise of external participants; to involve the students themselves; and to engage school principals and teachers to become enthusiastic participants in the process. Teachers, for instance, receive little formal training for teaching health education and it does not appear to be a priority area for professional development.<sup>65</sup> Despite existing challenges, every effort must be made to overcome barriers; all students should graduate with a sense of autonomy and personal empowerment in matters related to health as well as knowledge of how to manage health decisions.

## 2.4.2 Selected theories in Health Promotion

Health behaviour adoption and change is a complex, multifaceted, and multilevel process. Conceptualizing programs or interventions aimed at promoting healthy behaviours requires careful thought; those built upon an appropriate theoretical framework are likely to yield a broader and deeper understanding of the salient issues, provide a foundation for innovating and strengthening initiatives, and supply a basis from which to evaluate outcomes. Furthermore, programs with a theoretical underpinning are more likely to be successful.<sup>69-71</sup> A comprehensive approach to health promotion must also take into account both behavioural and environmental elements, supplying a corresponding set of interventions aimed at multiple levels. As such, approaches in health promotion practice typically adopt an ecological perspective which encompasses the interdependence of a multitude of factors and takes into account both multiple levels of influence (individual, interpersonal, and community) and the reciprocal nature of one's influential relationship with their social environment. To correspond with this perspective, selected theories in health promotion practice, applicable at various levels of influence, are discussed:

### *Health Belief Model*<sup>71;72</sup>

The Health Belief Model is comprised of six constructs that may influence an individual's decision regarding whether to comply with an advised action for a

particular health condition: perceived susceptibility (one's belief that a particular condition may affect them personally); perceived severity (one's belief that the condition is serious or may be associated with serious consequences); perceived benefits (one's belief that taking action will protect them from the condition); perceived barriers (one's belief that the risks of taking action outweigh the benefits); cues to action (the degree to which one is influenced by external factors that attempt to prompt action regarding a particular condition); and self-efficacy (one's belief that they can successfully perform the specified action). The model focuses on an individual's motivation and provides a good fit for exploring strategies to address problem or high risk health behaviours.

#### *Stages of Change (Transtheoretical) Model<sup>71;73</sup>*

This model is based upon the premise that health behaviour change is accomplished as a process (as opposed to an event), and is achieved by progressing through 5 stages: precontemplation, contemplation, preparation, action, and maintenance. Due to the circuitous and iterative nature of the theory, it is well suited to health behaviour change in which one's progress toward a desired behavioural goal may be accompanied by occasional set-backs or multiple attempts at change, such as efforts to quit smoking or lose weight.

#### *Theory of Planned Behaviour<sup>71;74</sup>*

This theory is comprised of four constructs: behavioural intention, attitude, subjective norms, and perceived behavioural control. It assumes that behavioural intention is the most important factor in determining particular health behaviours and that one's intention is formed by his/her attitude toward the behaviour and belief that others who are important to them support the behaviour. It also takes into account one's belief that they are able to control the behaviour as opposed to feeling that it is influenced by factors beyond their control. This theory may offer a specific benefit when considering issues related to an individual's participation or perceived control in decision-making about health matters.

### *Precaution Adoption Process Model*<sup>75</sup>

This theory is comprised of seven stages that depict a passage from lack of awareness to the adoption of a particular behaviour: unaware of issue; unengaged by issue; deciding about acting; decided not to act; decided to act; acting; and maintenance. Initially, one may be entirely unaware of a particular health matter which has the potential to affect him/her personally. After developing awareness of the issue one must become engaged and may experience different barriers in decision-making compared to others progressing through the various stages of the model for the same health matter. This theory is well suited to addressing health behaviours for which particular emphasis on experiences that precede decision-making is warranted.

### *Social Cognitive Theory*<sup>76</sup>

This theory has an interpersonal focus and highlights three main factors considered central to health behaviour change: self-efficacy; goals; and outcome expectancies. There are six constructs: reciprocal determinism; behavioural capability; expectations; self-efficacy; observational learning (modeling); and reinforcements. The theory asserts that when prompted to make a particular health behaviour change there is an ensuing interplay of influences: environmental factors, personal factors, and behaviour. Behaviour change is said to be more likely when one possesses knowledge about the health issue, expects positive outcomes as a result of taking action, and has confidence in his/her ability to take action and overcome any associated barriers. External factors, such as the observed actions of others, may also influence the likelihood of behaviour change. This model is useful whenever the importance of interpersonal factors related to the change in health behaviour is deemed central to the issue.

### *Diffusion of Innovation Theory*<sup>77</sup>

This community level theory is one of social change and is comprised of five components: the innovation; the adopter; the social system; the individual adoption process; and the diffusion system. The basic premise is that new

innovations are adopted, over time, by various levels of adopters, and as a consequence of an individual's need to resolve uncertainty related to new information, their inherent need to consider the opinions and actions of others whom they consider credible, and general feelings of social pressure to conform. The innovation itself is considered on the basis of its attributes (particularly relative to alternatives), its complexity, its compatibility with target groups and other established means of achieving the same goals, the potential to observe its outcomes, and its amenability to trial before any commitment to adoption is made. Adopters themselves may be classified according to their propensity for adopting new innovations and their desire to await external validation by others. The first to adopt are known as innovators, followed by early adopters, early majority adopters, late majority adopters, and laggards. In the social context, opinion leaders maintain an influential role in driving the rate of diffusion as do perceptions of social pressure to adopt. Social networks, for example, often exert resistance to innovations or system change. The adoption process itself is modeled on the basis of a progression through stages of awareness, persuasion, decision, implementation, and continuation. The diffusion system draws on agents of change to recruit key individuals who may possess influential currency with the target population. There is an overall duality of importance linking information and influence. This theory is particularly useful in addressing the implementation of voluntary-choice interventions.

## 2.5 Promoting preventive HPV vaccination: considerations related to theory, research gaps, and rights gaps from the perspective of adolescent health and health promotion

It is possible to envisage a range of potentially effective strategies for promoting preventive HPV vaccination. Yet in order to prioritize where such efforts should begin it seems wise to consider how well various issues pertinent to HPV vaccine implementation fit with some of the key requirements for improving adolescent

health and to also consider whether sufficient formative work has been completed. By drawing on various concerns and concepts central to adolescent health and health promotion an attempt has been made to simultaneously consider some of the main issues surrounding HPV vaccine implementation with the aim of breaking new ground in terms of stipulating explicit directives for sensible next steps.

First, from a theoretical perspective, behaviours relevant to HPV vaccination decision-making fit well within an ecological perspective of health promotion. Schools, therefore, appear to be ideal venues for implementing interventions which either originate in or are linked to the school environment. For example, because HPV vaccination is a matter connected to the emerging sexuality of adolescents it seems ideal to consider aligning interventions with sexual and health education components of the curriculum. In addition to their value as settings rich in social exchange and influence, schools are also the location in which most adolescents receive the HPV vaccine. Furthermore, existing research suggests that social norms are highly relevant to HPV vaccine decision-making.<sup>78</sup> Combining these environmental and interpersonal aspects with a fundamental consideration for the diversity of individual characteristics capable of influencing behaviours among adolescents supports a holistic approach to identifying interventions and developing policies to support HPV vaccination. It is likely that multilevel strategies which simultaneously offer community-based, targeted, and tailored options to enable HPV vaccine decision-making will have the greatest potential for success. Also of importance is that health interventions grounded in theory are more likely to be successful. Still, the choice of a theoretical framework to underpin research and policy development efforts related to HPV vaccination is not an obvious one; many of the theories of health behaviour contain relevant elements and it is likely that the most suitable model will be one that is a composite of several theories. In Table 1 several theories have been considered with respect to their constituent constructs and considerations deemed applicable to HPV vaccine implementation. Additionally, in an elegant review on dissemination science and the application of Diffusion of Innovation theory to

intervention development, James Dearing proposed ten dissemination mistakes commonly made in practice.<sup>79</sup> In Table 2 an attempt has been made to assess these concerns relative to the goal of implementing effective strategies to promote widespread adoption of HPV vaccination among adolescent girls.

Second, on account of the significant gaps in adolescent health policy and the lack of supporting research to inform it, the complex mix of issues surrounding HPV vaccine implementation seems to confer a myriad of ideal opportunities to carry out research that may help to address several unmet needs. Although intervention development and implementation will eventually lend itself well to process and outcome evaluations, the present lack of empirical guidance to inform these activities reveals clearly that formative research is the necessary first step. There is a particular need to explore the problems faced by adolescents in considering and ultimately receiving (or not receiving) HPV vaccination. What are the barriers they perceive? What information do they receive? What information do they want? Who do they turn to for advice? Are they involved in the decision making process? Do they want to decide for themselves? Do they understand the possible consequences of the decision? These questions are representative of some of the many issues worth investigating but, above all, are questions fundamentally in need of answers before unwisely proceeding to design and evaluate interventions with unrealistic expectations of their success.

Third, from a health rights perspective, it seems imperative to explore the rights of adolescents to participate in the voluntary-choice health decision concerning HPV vaccination. Importantly, the downstream effects of vaccination choices have the potential to confer significant future health consequences to adolescents. Prior research has demonstrated that not even 9 year olds wished to waive their right to make health decisions, and that 14 year olds were capable of health decision-making.<sup>59</sup> This notion is further backed by the United Nations Convention on the Rights of the Child and by existing Canadian laws. There is sufficient evidence to suggest that, at minimum, adolescents should participate in HPV vaccination

decisions, and, moreover, that many adolescents, if provided with the appropriate information, have the capacity, and likely the desire, to decide. Adolescents themselves have expressed interest in learning more about the prevention of sexually transmitted infections and have also suggested the use of peer educators for sex education.<sup>56</sup> There is ample reason to believe that not only do adolescents want to be involved; they stand to benefit immensely from doing so.

The work that is possible in the area of HPV vaccine implementation has tremendous potential to contribute substantial gains to adolescent health and to produce advancements toward the worthy goal of fostering empowerment and autonomy among young people for the benefit of all adolescents and for society as a whole.

Table 1. Application of health behaviour theory to HPV vaccine implementation

Level	Theory	Constructs	Considerations for HPV vaccination	Constructs applicable to HPV vaccination
Individual	<b>Health Belief Model</b>	<ul style="list-style-type: none"> <li>•perceived susceptibility</li> <li>•perceived severity</li> <li>•perceived benefits</li> <li>•perceived barriers</li> <li>•cues to action</li> <li>•self-efficacy</li> </ul>	<ul style="list-style-type: none"> <li>•constructs relevant to both the short and long term consequences of HPV infection</li> <li>•adolescents may lack general consideration for long-term health consequences or may not yet be sexually active and, as a result, may not feel susceptible to HPV</li> <li>•model has been used in prior HPV vaccination research</li> <li>•self-efficacy is an important determinant of health among adolescents</li> </ul>	<ul style="list-style-type: none"> <li>•perceived susceptibility</li> <li>•perceived severity</li> <li>•perceived benefit</li> <li>•perceived barriers</li> <li>•cues to action</li> <li>•self-efficacy</li> </ul>
Individual	<b>Stages of Change Model</b>	<ul style="list-style-type: none"> <li>•precontemplation</li> <li>•contemplation</li> <li>•preparation</li> <li>•action</li> <li>•maintenance</li> </ul>	<ul style="list-style-type: none"> <li>•not particularly applicable to the one-time choice nature of HPV vaccination</li> <li>•may have some application to investigating vaccine completion rates (3 doses)</li> <li>•model has been used in at least one HPV vaccine acceptability study</li> </ul>	
Individual	<b>Theory of Planned Behaviour</b>	<ul style="list-style-type: none"> <li>•behavioural intention</li> <li>•attitude</li> <li>•subjective norms</li> <li>•perceived behavioural control</li> </ul>	<ul style="list-style-type: none"> <li>•subjective norms is an applicable construct since adolescents often look to others they consider credible for advice and approval</li> <li>•the construct of perceived behavioural control is particularly applicable to examining how much control adolescents feel they have in making HPV vaccine decisions and the influence this exerts on their behaviour</li> <li>•otherwise limited since it has been demonstrated that intention does not necessarily lead to action in the case of HPV vaccination</li> <li>•model has been used in prior HPV vaccination research</li> </ul>	<ul style="list-style-type: none"> <li>•subjective norms</li> <li>•perceived behavioural control</li> </ul>

Level	Theory	Constructs	Considerations for HPV vaccination	Constructs applicable to HPV vaccination
Individual	<b>Precaution Adoption Process Model</b>	<ul style="list-style-type: none"> <li>•unaware of issue</li> <li>•unengaged by issue</li> <li>•deciding about acting</li> <li>•deciding not to act</li> <li>•deciding to act</li> <li>•acting</li> <li>•maintenance</li> </ul>	<ul style="list-style-type: none"> <li>•seems relevant to HPV vaccination in that the vaccine is relatively new; many adolescents lack sufficient knowledge about HPV and need to make the full journey from lack of awareness to action (or inaction)</li> <li>•model places pertinent emphasis on issues preceding a decision</li> <li>•maintenance may be applicable in examining compliance with all 3 vaccine doses</li> <li>•model not known to have been previously used in studying HPV vaccine uptake</li> </ul>	<ul style="list-style-type: none"> <li>•unaware of issue</li> <li>•unengaged by issue</li> <li>•deciding about acting</li> <li>•deciding not to act</li> <li>•deciding to act</li> <li>•acting</li> </ul>
Interpersonal	<b>Social Cognitive Theory</b>	<ul style="list-style-type: none"> <li>•reciprocal determinism</li> <li>•behavioural capability</li> <li>•expectations</li> <li>•self-efficacy</li> <li>•observational learning</li> <li>•reinforcements</li> </ul>	<ul style="list-style-type: none"> <li>•interplay of interpersonal and environmental factors are highly relevant to HPV vaccination among adolescents and the model is applicable to the dynamic social milieu in which influences impact behaviour</li> <li>•observational learning would be relevant to short term rather than long term factors (such as immediate side effects or fear of needles)</li> <li>•reinforcement may have application in examining compliance with all 3 vaccine doses</li> <li>•model has been used in prior HPV vaccination research</li> </ul>	<ul style="list-style-type: none"> <li>•reciprocal determinism</li> <li>•behavioural capability</li> <li>•expectations</li> <li>•self-efficacy</li> <li>•observational learning</li> </ul>
Community	<b>Diffusion of Innovation Theory</b>	<ul style="list-style-type: none"> <li>•relative advantage</li> <li>•compatibility</li> <li>•complexity</li> <li>•trialability</li> <li>•observability</li> </ul>	<ul style="list-style-type: none"> <li>•constructs appear highly relevant to a new intervention such as the HPV vaccine</li> <li>•offers a societal perspective</li> <li>•model conducive to a multilevel change process among diverse settings and populations</li> <li>•construct of observability limited since results of vaccination cannot be observed within a reasonable time frame (other than immediate side effects and issues related to a fear of needles)</li> <li>•model not known to have been previously used in studying HPV vaccine uptake</li> </ul>	<ul style="list-style-type: none"> <li>•relative advantage</li> <li>•compatibility</li> <li>•complexity</li> <li>•observability</li> </ul>

**Table 2. Top 10 Dissemination Mistakes and considerations related to HPV vaccine implementation<sup>79</sup>**

<b>1</b>	<p><i><b>We assume that evidence matters in the decision making of potential adopters.</b></i></p> <p><i>Interventions of unknown effectiveness and of known ineffectiveness often spread while effective interventions do not. Evidence is most important to only a subset of early adopters and is most often used by them to reject interventions. Solution: Emphasize other variables in the communication of innovations such as compatibility, cost, and simplicity</i></p> <p>For HPV vaccination emphasize the ease of having a free program set up at school for convenience: variables such as the need for only 3 injections to confer long-lasting benefit; that the vaccine is provided free of charge; in a convenient location (at school); no need to remember to get each shot since reminders are inherent in the program; be sure to address fears about vaccine side effects and fear of needles; may also promote friends telling friends that they ‘got the shot’ because social norms are important</p>
<b>2</b>	<p><i><b>We substitute our perceptions for those of potential adopters.</b></i></p> <p><i>Inadequate and poorly performed formative evaluation is common as experts in the intervention topical domain engage in dissemination. Solution: Seek out and listen to representative potential adopters to learn wants, information sources, advice-seeking behaviour, and reactions to prototype interventions.</i></p> <p>This emphasizes the importance of designing studies to reveal an exhaustive list of potential barriers and facilitators from self-reports of diverse groups of adolescent girls. The quality of the evidence would be enhanced through the use of open-ended questioning and sufficient qualitative inquiry. Exploration of adolescents’ information sources and ways of seeking advice would also yield vital information. Any resulting prototype interventions should be tested and trialed by adolescents prior to implementation.</p>
<b>3</b>	<p><i><b>We use intervention creators as intervention communicators.</b></i></p> <p><i>While the creators of interventions are sometimes effective communicators, the opposite condition is much more common. Solution: Enable access to the experts, but rely on others whom we know will elicit attention and information-seeking by potential adopters.</i></p> <p>In promoting HPV vaccination use a spectrum of potential communicators: include links to expert advice but also incorporate sources of popular influence (written, web-based, interpersonal contact). Peer-led interventions should be considered. Recruiting teachers into initiatives would also enrich programs and likely improve the chances of program success owing to their proximity to adolescents; they can also help guide adolescents in their search for credible information.</p>
<b>4</b>	<p><i><b>We introduce interventions before they are ready.</b></i></p> <p><i>Interventions are often shown as they are created and tested. Viewers often perceive uncertainty and complexity as a result. Solution: Publicize interventions only after clear results and the preparation of messages that elicit positive reactions from potential adopters.</i></p> <p>In many jurisdictions HPV vaccination was introduced before clear and consistent messages had been fully developed by reputable sources. Initial acceptance and uptake could likely have been improved if methods of initial introduction had been more carefully considered including the preparation of clear messages about vaccine safety and vaccination benefits. The introduction of HPV vaccines should also have included better promotion as a scientific breakthrough. Messages to promote the vaccine should involve stakeholders, including intended recipients, in their development and should be tested prior to being introduced to permit feedback and revision.</p>
<b>5</b>	<p><i><b>We assume that information will influence decision making.</b></i></p> <p><i>Information is necessary and can be sufficient for adoption decisions about inconsequential innovations, but for consequential interventions that imply changes in organizational routines or individual behaviours, influence is typically required. Solution: Pair information resources with social influence in an overall dissemination strategy.</i></p> <p>Peer-involved and peer-led interventions are promising strategies to explore. Involving adolescents in all stages of intervention design for influential effect among intended adolescent vaccine recipients. Call upon young female ‘celebrities’ (local athletes, artists, musicians, etc.)</p>

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**6** *We confuse authority with influence.*

*Persons high in positional or formal authority may also be regarded as influential by others, but often this is not the case. Solution: Gather data about who among potential adopters is sought out for advice and intervene with them to propel dissemination.*

Some of the sources of influence and social dynamics among adolescents may not be fully recognized. This emphasizes the importance of conducting formative research to gather information about relevant sources of influence, social networks, and interrelationships from a diversity of adolescents. For example, adolescents highly influenced by their parents are often not perceived as influential among peer groups whereas adolescents regarded as highly influential among their peers are frequently influenced by non-parental sources.

**7** *We allow the first to adopt (innovators) to self-select into our dissemination efforts.*

*The first to adopt often do so for counter-normative reasons and their low social status can become associated with an intervention. Solution: Learn the relational structure that ties together potential adopters so that influential members can be identified and recruited.*

For example, ‘only the nerds do it’. It would be useful to gather contextual information in order to delineate social dynamics and reveal factors commonly at play within a diversity of adolescent circles of influence. This information could be gainfully applied to the design of targeted implementation strategies expected to be well received by influential members of differing adolescent social networks. Also, the ability to specifically identify and recruit influential girls within individual schools or peer groups may yield opportunities to implement the most effective peer led interventions.

**8** *We fail to distinguish among change agents, authority figures, opinion leaders, and innovation champions.*

*It is unusual for the same persons to effectively play multiple roles in dissemination into and within communities and complex organizations. Solution: Use formative evaluation to determine the functions that different persons are able to fulfill.*

Research could be conducted among adolescents to determine what sources of information they want and who they want to provide it. Appropriate individuals could then be more easily matched to constituent roles (appropriately supported with valid information). Links to sources of reputable information could also be promoted. Overall advocacy for an accepted compilation of resources, interventions, and groups/persons could occur by means of collective endorsement by key stakeholder and knowledge groups.

**9** *We select demonstration sites on criteria of motivation and capacity.*

*Criteria of interest and ability make sense when effective implementation is the only objective. But spread relies on the perceptions by others of initial adopters. Solution: Consider which sites will positively influence other sites when selecting demonstration sites.*

Prototype interventions could be trialed in a diverse selection of schools (different boards, ethnic mixes etc) and feedback on the both the intervention and the process should be sought. Feedback received from schools with more negative views could be used to improve the intervention and schools that received the intervention positively could be used to promote the intervention to others. Vaccination rates among schools could also be examined and if trends exist by school board, rural/urban distribution, size, etc these factors could be used to diversify interventions. Enthusiastic schools might become innovation champions. Non-school settings, such as sexual health clinics that may reach homeless girls not attending school should also be considered.

**10** *We advocate single interventions as the solution to a problem.*

*Potential adopters differ by clientele, setting, resources, etc., so one intervention is unlikely to fit all. Solution: Communicate a cluster of evidence-based practices so that potential adopters can get closer to a best fit of intervention to organization prior to adaptation.*

In addition to approaches that target schools, schools would have the opportunity to get involved and adapt interventions to meet their own needs. However, to confer the greatest chance of widespread HPV vaccine adoption, it is likely that tailored interventions will also need to be implemented. In tailored interventions girls would be able to self-select information which meets their personal needs; and through an integrated feedback mechanism additional valuable information could be obtained to permit adaptation of the intervention over time. This would help to address the fact that although there may be trends by school, or community, some girls in any given location will be different from the majority and there need to be ways of reaching them and meeting their needs.

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Adapted from: James W. Dearing. Applying Diffusion of Innovation Theory to Intervention Development. Res Soc Work Pract. 2009 September 1; 19(5): 503-518. doi: 10.1177/1049731509335569.

### 3.0 Systematic review of self-reported barriers and facilitators to preventive HPV vaccination among adolescent girls and young women

#### 3.1 Plain language summary

Human papillomavirus (HPV) is a necessary cause of cervical cancer and vaccines that protect against the most common cancer-causing strains of HPV are now available. This has made it possible to prevent the development of pre-cancerous disease caused by HPV, the need for invasive diagnostic tests and procedures often required as a consequence of HPV infection, and the subsequent development of cervical cancer. Despite the vaccine's potential, many young women and girls decline vaccination, even when it is offered free of charge as part of a vaccination program. If young women and girls decide against vaccination, the potential for primary prevention of HPV disease and cervical cancer is lost. Numerous reports in the literature have described the acceptability of HPV vaccination from the perspective of parents, health care providers, or other groups. Yet factors which influence an adolescent girl or young woman's decision to become vaccinated are not well understood. The objective of this review is to systematically review the literature to draw together, summarize, and apprise the body of evidence concerning self-reported barriers and facilitators to preventive HPV vaccination from the viewpoint of adolescent girls and young women.

#### 3.2 Rationale and Objective

Human papillomavirus (HPV) is an important target in public health. HPV causes cancer, pre-cancerous and benign disease, and is widespread in the population. Moreover, HPV disease can be prevented. In addition, managing the impact of HPV in the population consumes valuable health care resources. A preventive HPV vaccine against four strains of HPV became available in many countries in

the world in 2006. Shortly thereafter, the National Advisory Committee on Immunization in Canada and the Advisory Committee on Immunization Practices in the United States issued recommendations to advise that all adolescent girls should receive vaccination to prevent HPV infection and that the vaccine should be administered at an age prior to sexual debut.<sup>6;80</sup>

HPV vaccination and the issues surrounding it were promptly taken up by a broad range of stakeholders. A diverse set of attitudes and beliefs quickly emerged and have contributed to poor vaccine uptake. Previous studies have demonstrated that at the time the quadrivalent vaccine was launched, knowledge about HPV and HPV vaccination was deficient, even among clinicians.<sup>81</sup> As well, reaction to the ensuing vaccine controversy spawned a deluge of studies examining HPV vaccine acceptability among various groups. These studies have revealed concerns related to vaccine effectiveness, vaccine safety, and perceived disease risk.<sup>78</sup> Also, acceptance for vaccination was generally found to be higher if supported by a health care provider recommendation and lower if considered cost prohibitive.<sup>78</sup> The idea of a vaccine to prevent a sexually transmitted infection in young girls was also considered by some as a means of promoting promiscuity and risky sexual behaviour.<sup>78</sup> Furthermore, media coverage was often negative and served to fortify the discord.<sup>17;82;83</sup>

Achievement of widespread HPV vaccine uptake among adolescents, by way of population-based immunization programs, should be considered an imperative. Lessons learned from the introduction of other vaccines, such as hepatitis B, have revealed the importance of universal vaccination for reducing disease burden in the community since selectively vaccinating high-risk target groups failed to achieve population disease reduction.<sup>8;44;84</sup> Unfortunately, HPV vaccine uptake has been poor in most jurisdictions in Canada and the United States, even when provided through cost-free programs.

Societal support is a crucial component of any successfully implemented immunization program and understanding reported barriers and facilitators to HPV vaccination is therefore integral to understanding how uptake can be improved. To date, however, the vast majority of studies conducted have examined issues related to HPV vaccine acceptability from the perspective of parents, care providers, and policymakers. In addition, much of the current evidence comes from studies conducted at a time prior to vaccine availability or shortly after its introduction. Literature examining vaccine acceptability from the viewpoint of intended recipients is lacking. In particular, barriers and facilitators to vaccination as reported by intended adolescent recipients seem to be inadequately addressed.

Explicating barriers and facilitators to HPV vaccination from the adolescent perspective is important. For public health, reducing HPV-associated disease burden in the population depends upon universal uptake among target adolescent groups. For health policy, information may be obtained regarding optimal health promotion strategies which are accurately focused on gaps, ensure wise use of health care dollars, and have the greatest potential to translate into positive health outcomes. And, for adolescents, it aims to acknowledge and address their needs more specifically which may, in turn, cultivate healthy behaviours commencing at an early and impressionable age.

The purpose of this review is to systematically review the literature in order to draw together, summarize, and apprise the body of evidence that has examined self-reported barriers and facilitators to preventive HPV vaccination from the viewpoint of adolescent girls and young women in Canada and the United States. The review aims not only to collate pertinent mediating factors but also to interpret the trustworthiness of the findings in terms of guiding HPV vaccine health promotion program development.

## 3.3 Methods

### 3.3.1 Protocol development and eligibility criteria

#### *Protocol*

The present systematic review was conducted based upon a full review protocol developed in advance and was submitted to a methodologist for critical appraisal and feedback. The PRISMA statement was used to guide the content and reporting of the review.<sup>85</sup>

#### *Eligibility*

We included quantitative and qualitative studies examining self-reported barriers and facilitators to preventive HPV vaccination conducted among adolescent girls and young women in Canada and the United States. Studies included were written in English, and conducted after June 2006 to correspond with the date of licensure of the first available prophylactic HPV vaccine. Studies of true self-reports of barriers and facilitators were sought as opposed to those which were based upon correlations inferred from statistical associations with demographic features.

#### *Population*

Adolescent girls and young women from 9 to 26 years of age were considered eligible for the review. This age range was selected because it encompasses the fundamental target age for vaccination and also because it coincides with the age range of females included in the original randomized trials of HPV vaccine efficacy and for which the vaccine was subsequently licensed in 2006. Studies with a broader age range of participants were included if data for the age range eligible for this review were reported separately. Women over 26 years of age and males were not the focus of this review. Preventive HPV vaccination was not approved for use in either of these groups over the period encompassed by the review and, in addition, we expect that many of the influential factors prompting vaccination

among these groups may be quite different compared to those affecting adolescent girls and young women.

Although all study settings were included, only studies conducted in Canada and the United States were considered for the review. Differences in culture, religion, population demographics, messaging in the media, and other nation-specific factors may all contribute to relevant barriers and facilitators among intended vaccine recipients in a particular geographic location, and efforts to improve vaccine uptake will likely need to take such variation into consideration. The aim of our geographic focus was to offer the greatest potential for insight into possible strategies to improve HPV vaccine uptake among adolescents and young women living in Canada and the United States.

#### *Intervention*

Studies examining barriers and facilitators to acceptability or uptake of either the bivalent or quadrivalent prophylactic HPV vaccine were included. Studies involving both vaccinated and unvaccinated participants were considered eligible.

#### *Outcome measures*

##### *Primary outcome:*

The primary outcome of the review was self-reported barriers and facilitators to preventive HPV vaccination among females 9-26 years of age. For quantitative analyses this included both barriers and facilitators found to be statistically significantly associated with vaccination intention or uptake, and other less frequently reported barriers and facilitators which did not reach statistical significance. For qualitative data this included all barriers and facilitators reported by study participants. A barrier was defined as any factor reported by an intended vaccine recipient as being negatively associated with the likelihood of vaccination or vaccine uptake. Conversely, a facilitator was defined as a factor positively associated with vaccination likelihood or uptake.

*Secondary outcome:*

We also sought to explicitly determine what is known about barriers and facilitators to HPV vaccination from the perspective of adolescents, which is generally defined as the period commencing with puberty and ending when age 18 or 19 years is reached. Therefore, self-reported barriers and facilitators specifically reported for girls within the age range of 9-17 years formed the secondary outcome for the review. Examining this age group separately also more closely approximates the distinct target group for preventive vaccination against HPV: 11-12 year old females in the United States, as recommended by the Advisory Committee on Immunization Practices; and 9-13 year old females in Canada, as recommended by the National Advisory Committee on Immunization. Beyond these ages catch-up vaccination is recommended by both advisory committees up to age 26.<sup>6;80</sup>

For studies which collected self-reported information and then analyzed the data for associations with vaccination intent or uptake, only correlations with attitudes or vaccination perceptions were considered. Outcomes based upon associations with demographics, behaviours, and HPV or HPV vaccine knowledge were excluded. The inclusion and exclusion criteria for the review are summarized in Table 3.

### 3.3.2 Information sources and search

Electronic literature searches were conducted in MEDLINE, including In-Process and Other Non-Indexed Citations (1948 to April week 1 2011), EMBASE (1947 to 2011 April 13), CINAHL, and PsycINFO (2002 to April week 1 2011).

All search strategies were developed and executed by an experienced information specialist using relevant mesh terms and terms identified from other reviews on HPV vaccine acceptability. The search strategy primarily involved terms which identified HPV vaccination and terms related to health behaviour. The final,

developed search strategies were reviewed by the primary reviewer prior to being executed. The Medline database search was also reviewed to ensure coverage of key journals. The fully developed electronic search strategy for the Medline and EMBASE databases are presented in Appendix 1. All other searches were customized for each database separately.

The electronic search was supplemented by searching the ProQuest Theses and Dissertations database, scanning the reference lists of included studies, and scanning the references of relevant narrative reviews published in 2010 and 2011.

#### *Search Limits*

- English reports
- Years (only 2006 and later)

#### *Language*

Although non-English language reports were excluded from the review, the search of the Medline database was additionally run without language restriction. The set of non-English citations was examined for studies which otherwise would have met the criteria for inclusion and a screening log was maintained on file.

#### *Years*

The search was limited to 2006 and later, and included in process databases. The first preventive HPV vaccine was approved and marketed in June 2006 and the focus of this review was an examination of barriers and facilitators in a post-licensure environment. Our aim was to capture all relevant studies which were carried out at a time when at least one preventive HPV vaccine was licensed and available to adolescent girls and young women.

#### *Scoping*

The review also included a scoping component. In keeping with the goal of providing a comprehensive synthesis of available evidence, no limits based upon

population, geography, or age were applied to the search. This was done to ensure literature saturation and also to approximate the size of the body of literature dealing with the population of interest compared to the number of reports dealing with other stakeholder populations, such as parents, health care providers, males etc.

Table 3. Summary of Inclusion and Exclusion criteria for systematic review

	Included	Excluded
<b>Population</b>	<p>Adolescent girls Young women</p> <p>Age 9-26 years</p> <p>Intended recipients of HPV vaccine</p> <p>Study conducted in Canada or USA</p>	<p><b>Studies that involve some females age 26 years or younger but without the ability to isolate data specific to participants age 9-26 years</b></p> <p><b>Any reports of individuals who are not the intended recipient of the vaccine</b></p>
<b>Exposure</b>	<p>A method designed to gather self-reported information regarding barriers and facilitators to preventive HPV vaccination (bivalent or quadrivalent vaccine)</p> <p>Either pre or post vaccination</p> <p>Subjects may have either positive or negative intention to become vaccinated, or may have received or declined actual vaccination</p> <p>Self reports of attitudes and/or perceptions associated with HPV vaccination intent or uptake included</p>	<p><b>Retrospective or prospective data collection methods that did not involve self-reports or that were designed to examine associations between HPV vaccination and demographic, behavioural, or knowledge characteristics of the study population</b></p>
<b>Outcome</b>	<p>Primary:</p> <ul style="list-style-type: none"> <li>• Statistically significant self-reported barriers and facilitators to HPV vaccination intent or uptake</li> <li>• Self-reported barriers and facilitators to HPV vaccination intent or uptake not reported as statistically significant in quantitative studies</li> <li>• Barriers and facilitators to HPV vaccination intent or uptake reported by respondents in qualitative studies</li> </ul> <p>Secondary:</p> <ul style="list-style-type: none"> <li>• As above but for girls 9-17 years of age</li> </ul>	<p><b>Associations with self-reports of demographics, behavioural information, or knowledge of HPV or HPV vaccine</b></p> <p><b>Associations with intent or receipt of vaccination not based upon self-reported information</b></p>
<b>Studies</b>	<p>Qualitative and quantitative primary data collection</p> <p>Studies conducted post quadrivalent HPV vaccine licensure in June 2006</p> <p>English language reports</p>	<p><b>Reports without original primary data collection (eg. reviews, editorials)</b></p> <p><b>Studies conducted prior to June 2006</b></p> <p><b>Non-English reports</b></p>

### 3.3.3 Study selection

The collective set of records identified through the full search strategy was assembled in Reference Manager and duplicate references were removed manually. Two reviewers performed all levels of screening independently and in duplicate. Reasons for exclusion were documented in all cases. During the initial broad screening of titles and abstracts of all identified records (Level 1) only those agreed upon for exclusion by both reviewers were eliminated. For all records not eliminated at this step, including any discrepancies, the full text article was obtained for further review (Level 2). Two reviewers then independently assessed the full-text articles according to the inclusion and exclusion criteria for the review (population, intervention, outcome, and study characteristics). Discrepancies were resolved by consensus or the involvement of a third reviewer. Study authors were contacted in several instances to determine eligibility for the review.

Categories of exclusion were pre-specified and included: studies of parental acceptance, studies of health care provider acceptance, studies of acceptance among other stakeholder groups, studies in older age populations, studies in males, and review or commentary pieces. Excluded studies were categorized into one of these pre-defined categories whenever possible. Other categories were created according to the nature of the remaining excluded citations identified during screening. The outcome of Level 1 and Level 2 screening was summarized in separate screening logs (Appendix 2)

### 3.3.4 Data collection

A data abstraction form was developed *a priori* using Excel and pilot-tested by two reviewers. Two reviewers then performed all data abstraction independently. The data collection process was not blinded. Authors were contacted regarding missing information when necessary.

Data abstracted from each report included demographic characteristics pertaining to the participants in the study (eg. age, ethnicity, relationship status, sexual history, education level, etc), the study setting (eg. country, university versus medical clinic, etc), study details (study type, funding sources, sampling and data collection methods, theoretical framework, etc), and the outcomes assessed (ie. barriers and facilitators to vaccination). Study conclusions were also collected.

### 3.3.5 Quality assessment of studies

To assess for bias in included studies, quality assessments were conducted according to a 16 item scale developed and evaluated for appraising studies with diverse designs.<sup>86</sup> The tool, based upon a 4-point scoring system for each item, permitted assessment of the overall quality of mixed qualitative and quantitative evidence using a unified set of criteria (Appendix 3). An overall score was calculated to reflect the quality of the body of evidence. Additional quality assessments were conducted to appraise the reliability and validity of the data pertaining to important outcomes reported in each of the studies. This involved reviewer evaluation of the study-imposed limitations on self-reports of barriers and facilitators by respondents and correlation of outcomes with vaccination interest, acceptability, or intent versus actual uptake in each of the studies. Quality scoring and assessments were performed independently by two reviewers. Discrepancies were resolved through an iterative consensus approach and by consulting a methodologist when required. In instances where scores remained different after consultation, reviewers sometimes settled on a score that was in between the two originally awarded scores. Inter-rater reliability was not formally tested since the use of a 4-point scoring scale would limit the likelihood of agreement.<sup>86</sup> The quality assessment process was not blinded.

### 3.3.6 Data Synthesis

Qualitative synthesis of abstracted data was completed for all included studies with respect to study characteristics, study outcomes, and study quality. Heterogeneity among studies precluded quantitative synthesis of data. However, sources of clinical and methodological heterogeneity were considered in the review and described.

#### *Study Characteristics*

Study characteristics collected during the abstraction process were collated and tabulated to permit thorough between-study comparisons (Table 4).

#### *Study Outcomes*

Data abstracted from both qualitative and quantitative studies were synthesized and reported together since the body of evidence brought together in this review attends to the formative groundwork required to cultivate a deeper understanding of the barriers and facilitators adolescents and young women face when considering preventive HPV vaccination and to better define defensible future directions. Both qualitative and quantitative findings are equally important in this regard and form an essential foundation.

Primary and secondary outcomes for the review were tabulated to illustrate the following: the collective inventory of barriers and facilitators brought to light by available evidence; the category of outcome results (statistically significant results; proportions or other results from quantitative investigation; results from qualitative investigation) and the outcome's rank according to the number of studies in which a given barrier or facilitator to HPV vaccination was reported or the proportion of respondents who mentioned each barrier or facilitator. To provide additional perspective, information about the number of studies in which the particular barrier or facilitator had been assessed was also reported. Common themes were used to group barriers and facilitators together when necessary and were based upon

the predominantly applied theoretical constructs among included studies whenever possible. It should also be noted that a given barrier or facilitator can be viewed as either a barrier or a facilitator, depending on the direction of the statement. For example, social norms can be viewed as a facilitator if the questioning and response lead a study participant to report, “I want to get it if my friends are getting it” versus another style of questioning which may elicit the response, “I don’t want to get it if my friends aren’t getting it.” In the review, the direction of the responses was maintained in all cases and barriers and facilitators were reported as identified in the original studies.

Study quality was synthesized by tabulating the proportion of studies meeting each of the specified quality components. To provide an overall indication of the quality of the body of research, a total score was calculated for all studies and expressed as a percentage of the potentially attainable score.<sup>86</sup> Additional assessments were made to evaluate bias across studies. This involved appraisal of investigator selected outcomes and the associated methods and instruments used to measure the outcomes of interest such that potential bias associated with study and review outcomes could be evaluated.

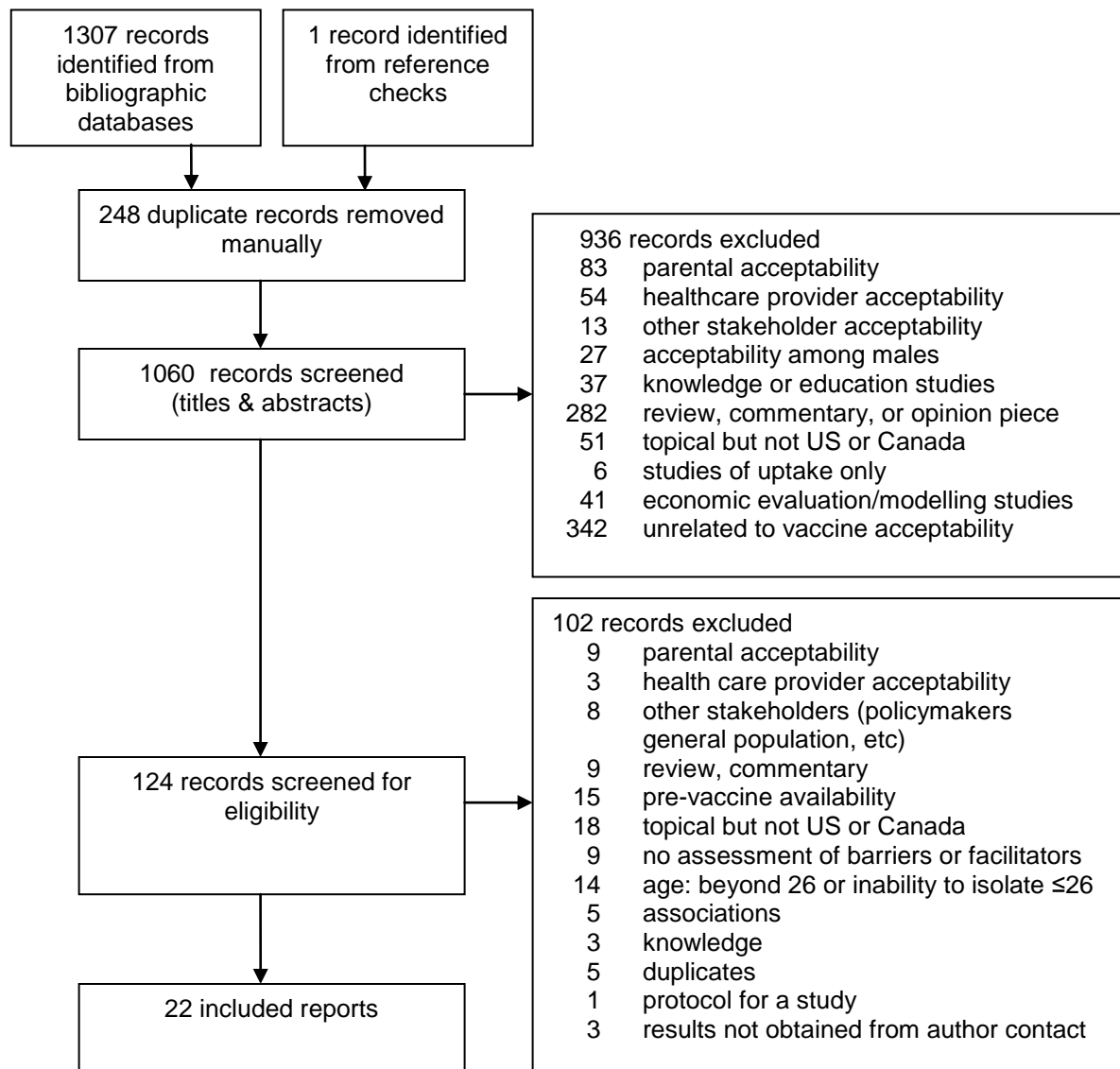
## 3.4 Results

### 3.4.1 Study selection

A total of 1308 records were identified from the literature and screened. Of these, 123 potentially relevant full-text reports were obtained and reviewed, yielding 22 unique studies which met the inclusion criteria for the review: 19 of these were published articles, 1 was a report of data which otherwise met the inclusion criteria, and 2 were thesis dissertations.

According to the pre-specified exclusion categories 92 studies were excluded because they dealt with parental acceptance of vaccination; 57 were studies of health care provider acceptance; 21 concerned acceptance among other stakeholder groups; 14 addressed older age groups, 27 dealt with vaccination among males; and 291 were review or commentary pieces. Others reasons for exclusions included studies that dealt exclusively with HPV knowledge, uptake or economic evaluations and modeling studies. Among studies that may otherwise have been topical, 51 were not conducted in Canada or the United States, 15 were conducted prior to HPV vaccine availability and a further 3 were excluded because contact with authors did not yield data for the review. Figure 1 displays the details of record selection for the review.

Figure 2: Flow diagram of record selection



### 3.4.2 Study characteristics

Of the 22 unique studies, 21 were conducted in the United States, and 1 was conducted in Canada. 19 were quantitative studies, 1 was a qualitative study, and 2 used mixed methods. Twenty of the studies used questionnaires that were conducted in either paper format, over the telephone, or electronically and 2 studies used in-depth interviews conducted with each study participant individually. All studies were conducted post vaccine availability. The earliest study began recruiting participants in October 2006 and the most recent study completed its enrollment in the fall of 2009. Most of the studies (14) were designed to address multiple objectives in addition to addressing barriers and facilitators to vaccine uptake; such as knowledge, awareness, rates of uptake, sexual behaviour, education, and HPV prevalence. In 7 of the publications the authors reported that the design of the study was based upon an established theoretical framework or constructs. Nine of the studies were conducted in educational settings, 8 were conducted in locations related to the provision of health care services, and in 5 studies participants were selected from among the general population.

Among the 22 studies, a total of 8079 adolescent girls and young women age 26 years or younger from diverse groups contributed their views (based upon the 21 studies that reported a sample number). In 3 cases the studies also enrolled older women; however, outcome data were reported separately for participants 26 years of age or younger and thus satisfied our inclusion criteria for the review. Twelve studies involved mainly White participants and in 5 studies participants were primarily Black. Hispanics comprised the next most common race represented among studies. Collectively, from those studies which reported vaccination status (19), approximately 70% of the population of adolescent girls and young women were unvaccinated and 30% had received at least one dose of an HPV vaccine. Almost all participants were aware of HPV or the HPV vaccine, but this was only reported in 9 of the studies. Five studies gave an indication of

HPV or HPV vaccine related knowledge and from these reports the knowledge base of study participants was variable ranging from approximately 40% to over 70% on knowledge tests that were conducted as a part of the study. Based upon 9 reports, more than half of the girls and young women were sexually active, except in one case where 71% of participants at a religiously conservative Lutheran university had never had vaginal intercourse. Some of the participants had had prior sexually transmitted infections, abnormal Pap smear tests, or prior HPV infection but this information was only reported in 5 or fewer of the included studies.

Further details of the characteristics of included studies are presented in Table 1. Studies have been listed according to the data collection period for each study in order to chronologically illustrate the time periods during which the girls and young women provided their views.

Table 4. Characteristics of included studies

Author and year of publication	Study period	Study Type	Study objectives	Theoretical framework	Study setting	Sample Size	Sample Characteristics	Characteristics of participants	Vaccination status	Age range (mean) in years	Funding
Kahn 2008 <sup>87</sup>	Oct 06- May 07	Quantitative	1. est rates of hpv vacc 2. factors assoc with intention and belief in ability to receive vacc 3. prevalence of vaccine type hpv	Theory of Planned Behaviour, Social Cognitive Theory	3 primary care clinics (hospital-based teen health centre, obs/gyn clinic in a community health centre, STD clinic affiliated with health dept)	418 approached 409 completed study	racially and ethnically diverse sample of low income 13-26 yr old young women at time of primary health care visits	low income young women, had to have had prior sexual contact, 62% black, 29% white, 18% other, primarily unmarried, knowledge of HPV (mean score 40% on a 12 item scale), many had history of STD, abnormal Pap, and prior pregnancy	primarily unvaccinated (5% had at least 1 dose, 0.2% had all 3 doses)	13-26 (18.7)	Charlotte R Schmidlapp Women's Scholar Award
Lenehan 2008 <sup>88</sup>	Jan - March 2007	Quantitative	1. knowledge of cervical cancer, hpv and hpv vaccination 2. attitudes toward vaccination 3. actual or intended behaviour regarding vaccination	NR	hospital-based, outpatient obs/gyn clinic	108 approached 103 consent 98 analyses only 13 < 26 yrs of age	all women attending obstetrician-gynecologist appointments at an outpatient clinic	Not reported for subgroup	NR	NR	NR
Gerend 2008 <sup>89</sup>	Feb - March 2007	Quantitative	1. identify correlates of hpv awareness, knowledge, and beliefs 2. student's interest in hpv education 3. identify predictors of women's interest in receiving the hpv vaccine	NR	campuses of Florida State University and Florida Agricultural and Mechanical University	97 (64 were women, 60 were unvaccinated women)	racially diverse sample of young adults in a university setting	most were undergraduate students, most were black or African-American 57%; 32% white, all were single (2/3 dating or in a committed relationship)	64 women in study: 4 were vaccinated 60 were unvaccinated	18-26 (19.03)	NR
Bynum 2009 <sup>90</sup>	Jan- Apr 2007	Mixed	1. knowledge 2. beliefs 3. attitudes	NR	teen clinic in Columbia, South Carolina (urban)	73 completed questionnaire, 68 completed in-depth interview	low income African American adolescent females	African American 80%; most insured; most with high school education; most sexually active; 1/4 with past history of STI; 4% reported an HPV diagnosis	NR	14-20 (17.9)	NR
Allen 2009 <sup>91</sup>	Feb - March 2007	Quantitative	assess factors associated with intention to obtain the vaccine among female college students	Transtheoretical Model of Change, Health Belief Model, Theory of Reasoned Action, Social Cognitive Theory	private New England university	1897 consented, 1696 completed more than 50% of survey, final sample 1401	students enrolled full time at a private university	no prior history of cervical cancer or HPV, most white(78%), almost all had heard of HPV and the vaccine, almost half had never had a Pap test, most had never been diagnosed with an STI, almost half were currently sexually active	1226 unvaccinated (87%); 175 (13%) vaccinated	18-22 (NR) (only reported in abstract)	NR
Costar 2008 <sup>92</sup>	Spring 2007	Mixed	to examine whether the level of consideration of future consequences reported by female college students, paired with the temporal framing of benefits and risks within a health message about the hpv vaccine, had an effect upon whether or not these women formed the intention to get vaccinated against hpv	Theory of Planned Behaviour, Theory of Reasoned Action	University of Maryland, University of Maine, University of Massachusetts, Dartmouth, University of Virginia	251	18-24 yr old female undergraduates at 2 Eastern and 2 Eastern Atlantic universities in the US	75% Caucasian two thirds sexually active 94% with health insurance low to moderate levels of knowledge about HPV (mean score 3.3/7) and the HPV vaccine (mean score 3.02/7)	unvaccinated	18-24 (19.7)	NR
Jain 2009 <sup>93</sup>	May - Aug 2007	Quantitative	report awareness of hpv and hpv vaccine in a nationally representative sample of US women aged 18-49; estimate vaccine initiation; describe factors associated with early uptake among women aged 18-26 years	NR	USA households	1102 for whole study; 168 for subgroup	representative sample of US population age 18-49 years (divided into 2 subgroups: 18-26 and 27-49)	Not reported for subgroup	mostly unvaccinated (10% had initiated vaccination)	18-49 for whole study; subgroup 18-26	NR

Author and year of publication	Study period	Study Type	Study objectives	Theoretical framework	Study setting	Sample Size	Sample Characteristics	Characteristics of participants	Vaccination status	Age range (mean) in years	Funding
<b>Read 2010<sup>84</sup></b>	Jan 07 - June 08	Quantitative	to determine adolescent and parent's attitudes and perceptions and possible barriers to acceptance of hpv vaccine in a predominantly urban, minority population	NR	urban, adolescent medicine clinic	175	13-19 yr old Caribbean and African American girls attending an urban, adolescent medicine clinic	African American 51%; Caribbean 39%; 76% in high school or less than a high school education; nearly half sexually active; most with more than 1 prior sexual partner; 27% reported ever having an STI; over half knew what HPV is	NR	13-21(NR); more than half were under 16	NR
<b>Conroy 2009<sup>85</sup></b>	June-Dec 2007	Quantitative	1.describe rates of hpv vaccination 2. identify, demographic, attitudinal, behavioural, and health-systems factors correlated with vaccine uptake 3. identify self-reported barriers to hpv vaccination among those unvaccinated	NR	urban, hospital-based teen health centre	189	13-26 year old, low-income, minority women receiving care at a teen health centre	All with prior sexual contact mostly black low-income had received information about hpv and the vaccine previously in the baseline study majority insured most with history of prior STI	36% had initiated vaccination; 13% had completed vaccination;	13-26 (17.5)	NR
<b>Grant 2009<sup>86</sup></b>	2007	data report		n/a	California households	NR	18-26 year olds in California who were not interested in receiving the HPV vaccine	NR	unvaccinated	18-26 (NR)	many non-proprietary sources
<b>Caskey 2009<sup>87</sup></b>	Nov 2007	quantitative	document knowledge about hpv and vaccine; identify barriers to adoption of the vaccine; identify sources of vaccine information; identify correlates of early vaccine receipt	NR	USA households	2143 1011 completed questionnaire 412 age 13-17 599 age 18-26	representative sample of US population age 13-26 (divided into 2 subgroups age 13-17 and 18-26)	approximately half had less than high school education (due to age) mostly white, 17% Hispanic, 13% black average household income most had heard of hpv and the vaccine	124 (30%) of girls 13-17 had initiated vaccination; 57 (9%) of girls age 8-26 had initiated vaccination	13-26 (19.4)	supported in part by an unrestricted pilot grant from the University of Chicago Program in Pharmaceutical Policy funded by the Merck Foundation
<b>Rand 2011<sup>88</sup></b>	Mar 07- Apr 08	quantitative	to examine parent-physician interaction and parental beliefs related to hpv vaccination by assessment of hpv vaccine acceptance and refusal and how it relates to patient characteristics and provider communication	Health Belief Model	5 urban and 4 suburban primary care practices in Monroe County New York	119 female adolescents age 15-17 (calculated based on info provided in report); total sample was 638 including both parents and adolescents	parents and teens arriving for health care visits at one of 9 primary care practices in Monroe County, New York	mostly white; non-Hispanic; parental income >\$50 000; at least some parental college education; most had discussed HPV vaccine with a health care provider;	65% vaccinated (at least 1 dose)	15-17 (subgroup of older adolescents)	Centers for Disease Control and Prevention
<b>Mathur 2010<sup>18</sup></b>	Aug 07- Feb 08	quantitative	determine the proportion of high school girls who participated in making a decision about getting vaccinated; identify factors and attitudes related to uptake; knowledge about hpv and vaccine	NR	private all-girls high school and public co-educational high school in San Francisco	175 (100 at private school; 75 at public school)	high school girls attending a private all-girls or public co-educational high school in California	grade 9, 10, 11, and 12 students; average HPV-related knowledge; 48% participated in the decision about receiving vaccination	37.8% vaccinated; 45.5% unvaccinated; 16.7% unsure if they had been vaccinated	range NR; (16.1 for vaccinated girls; 15.7 for unvaccinated girls)	NR
<b>Watts 2009<sup>89</sup></b>	Aug 07- Apr 08	quantitative	examine what motivates vaccination of self and children; women's attitudes toward vaccinating sons; effect of vaccination on women's attitudes toward their sexual behaviour and cervical cancer screening practices	NR	general medicine, gynecology, or pediatric units at the Massachusetts General Hospital	91 vaccine eligible participants age 18-26 yrs (subgroup)	18-55 yr old Latino and non-Latino women attending clinics at an academic hospital in Massachusetts	not reported for subgroup	44% vaccinated among vaccine eligible population (18-26)	NR for subgroup	NR

Author and year of publication	Study period	Study Type	Study objectives	Theoretical framework	Study setting	Sample Size	Sample Characteristics	Characteristics of participants	Vaccination status	Age range (mean) in years	Funding
Moore 2010 <sup>100</sup>	Oct 07- May 08	quantitative	describe hpv vaccine uptake and its correlates among a sample of university women under conditions in which the vaccine was offered at no cost	NR	waiting area for gynaecological care at university health services at the University of Kentucky	235 eligible; 209 analysed	18-24 yr old university students attending the university health services for gynaecologic care	mostly white (82%); African American (12%);	unvaccinated	18-24 (20.7)	supported in part by the William Gallion Family Foundation through the University of Kentucky's Markey Cancer Center
Licht 2010 <sup>101</sup>	NR	quantitative	assess rates of hpv vaccination among female college students; examine whether knowledge and risk perceptions regarding hpv are associated with the reported use of the vaccine among female college students	NR	two US universities in New York State	406	18-26 yr old females attending general education or psychology classes at 2 US universities	all had previous knowledge of hpv; mostly white; some Asian, African American;	44% vaccinated; 56% unvaccinated	18-26 (NR)	NR
Zimet 2010 <sup>102</sup>	Apr-May 08	quantitative	to explore in greater depth the reasons for limited uptake of hpv vaccine among young adult women who have yet to be vaccinated	NR	USA households	185	insured 19-26 yr olds in the United States	80% white; mostly unmarried; most with good to excellent health status; most with at least some college education; all insured; almost all had heard of the hpv vaccine	unvaccinated	19-26	Merck & Co
Hopfer 2011 <sup>103</sup>	Apr-May 08	qualitative	better understand college women's hpv vaccine attitudes and beliefs focused on family, peer, and health care provider messages that college women report receiving about hpv; how college women interpret, respond to and incorporate these messages to shape their own hpv vaccine attitudes and decisions	Focus Theory of Norms; Culture-centric Narrative Theory for Health Promotion	a large northeastern university in the US	36	18-26 yr old college women from speech courses at a large northeastern US university	90% white; almost all with insurance; 3/4 raised in suburban neighbourhoods; all had heard of the HPV vaccine; more than half sexually active; 81% accepting of vaccination	39% vaccinated; 61% unvaccinated	18-26 (20)	grant support from the Centers for Disease Control and Prevention
Rosenthal 2011 <sup>104</sup>	Apr-May 08	quantitative		NR	USA households	530	insured 19-26 yr olds in the United States	80% white; mostly unmarried; most with good to excellent health status; most with at least some college education; all insured	345 vaccinated with at least one dose (65%); 185 unvaccinated (35%)	19-26 (21.2 vaccinated group); (22.4 unvaccinated group)	NR (one author from Merck)
Dillard 2010 <sup>105</sup>	Fall 2008	quantitative	examine relationships between presumed sources of information with knowledge and barriers; examine relationship of actual risky sexual behaviour with knowledge of hpv and perceived barriers to vaccination; examine the potential for social groups to influence knowledge and barriers	NR	Penn State University	396	18-26 yr old undergraduate women attending Penn State University	96% had heard of hpv; 98% had heard of the vaccine; 89% white;	53% vaccinated; 47% unvaccinated	18-24	NR
Janousek 2011 <sup>106</sup>	Fall 2009	quantitative	to determine the knowledge, attitudes, beliefs, and predictors of accepting the vaccine among college students at a Lutheran university	Social Cognitive Theory, Theory of Planned Behaviour, Health Belief Model	religiously conservative Lutheran university in Nebraska	203	18-26 yr old females attending a Lutheran university in a rural town in the Midwest	96.6% white; over half not dating; over half enrolled in a church work related major; 71% had never had vaginal sexual intercourse; good knowledge of HPV (80% had ≥7/10 on knowledge questions) 66% not accepting of the vaccine 85% with a high religiosity score	20.7% vaccinated; 79.3% unvaccinated	18-25 (NR)	NR

Author and year of publication	Study period	Study Type	Study objectives	Theoretical framework	Study setting	Sample Size	Sample Characteristics	Characteristics of participants	Vaccination status	Age range (mean) in years	Funding
Bendik 2011 <sup>107</sup>	NR	quantitative	describe belief factors most common among women that have already received hpv vaccine; describe women's likelihood to receive vaccine in the future; assess the hpv-related knowledge among college-aged women	Health Belief Model	large, southeastern US university	1975	18-24 yr old female undergraduates at a large southeastern US university	90% white; 95% had heard of HPV; 2/3 had ever had sex; mean HPV knowledge score was 6.85/10	37.7% vaccinated with at least one dose; 62.3% unvaccinated	18-23 (20)	Clemson University Calhoun Honors College Departmental Honors Grant and the Clemson University Department of Public Health Sciences Mary Lohr Fund

### 3.4.3 Outcomes

A total of 21 barriers, and 11 facilitators to preventive HPV vaccination were reported by the collective set of studies. Three studies reported outcome data specific to adolescent girls.

#### *Primary Outcome (adolescent girls and young women age 9-26 years)*

Of the 21 different barriers reported among studies for the combined 9-26 year age range, 7 were identified as statistically significant results from quantitative studies; 18 were reported as proportions in quantitative studies; and 12 were identified from 3 qualitative investigations. Cost was reported as a barrier in the highest number of studies (10). Feeling that the vaccine was not needed for various reasons, and concerns related to vaccine safety and potential side effects were the next most commonly reported barriers; each was reported in 9 of the studies. Of the 11 different facilitators reported among studies, 8 were identified as statistically significant results, 7 as proportions from quantitative studies, and 6 from qualitative investigation. The most commonly reported facilitators were perceived benefit of the vaccine and receiving a recommendation from a health care provider, which were each reported in 6 of the studies. Social norms was the next most commonly reported facilitator and was reported in 5 of the studies. Additional barriers and facilitators identified from the studies are displayed in Table 6.

#### *Secondary outcome (adolescent girls age 9-17 years)*

From the three studies which reported results specifically for adolescent girls under the age of 18 years, 706 adolescent girls are represented. A total of 10 barriers and 6 facilitators were reported. All were reported from quantitative studies which reported proportions of girls who identified each barrier or facilitator to vaccination. Not being sexually active was the barrier reported by the highest proportion of girls (47% in the one study which identified this barrier). This was followed by a feeling of not being at risk, which was reported by 36% of girls in a

different study. Two of the studies reported concerns about vaccine safety as a barrier (reported by 26% and 25% of adolescent girls in each of the studies, respectively). Additional details regarding reports of barriers and facilitators among adolescent girls are shown in Table 7.

Table 5. Self-reported barriers and facilitators to preventive HPV vaccination among adolescent girls and young women reported in studies in systematic review

Author and year of publication	Facilitators (reported as % participants who mentioned each facilitator or rank order)	Barriers (reported as % participants who mentioned each barrier or rank order)	Facilitators (reported as statistically significant)	Barriers (reported as statistically significant)	Qualitative data
Kahn 2008 <sup>87</sup>			with intention: normative beliefs, perceived severity of hpv-related disease with belief in ones ability: perceived severity of hpv infection	with intention: barriers related to vaccine safety with belief in ones ability: practical barriers related to vaccination	
Lenehan 2008 <sup>88</sup>	in order of most to least important: doctor recommendation, no cost, 5yr efficacy (don't know how this was worded), the need for 3 injections (don't know how this was worded)	Cost became more of a barrier as the hypothetical cost of vaccination increased			
Gerend 2008 <sup>89</sup>			perceived risk of hpv infection		
Bynum 2009 <sup>90</sup>		cost 34%; lack of transportation 22%; fear of vaccines 19%; social norms 19%; subjective norms 14%; feeling unable to talk to parent or caregiver 11%; fear of needles 9%; don't think it will work 4%; need for 3 doses 3%			difficulty understanding what their doctors communicated to them
Allen 2009 <sup>91</sup>			subjective and social norms associated with planning to obtain vaccine after 30 days; perceived benefit of vaccination; subjective and social norms associated with planning to obtain vaccine within the next 30 days; perceived benefits; subjective and social norms associated with having already obtained the vaccine	perceived severity (among those undecided about whether to obtain the vaccine or planning to receive the vaccine after 30 days); perceived barriers (among those who had already obtained the vaccine)	
Costar 2008 <sup>92</sup>			positive attitude toward receiving the vaccine; perceived behavioural control (self-efficacy); social norms		<u>facilitators</u> : benefits of prevention; benefits of reducing worry; perceiving self at risk; attitude toward vaccination; social norms; <u>barriers</u> : pros do not outweigh cons ; increased anxiety (fear of needles, side effects); don't perceive self at risk; negative attitudes toward vaccination ; social norms; perceived behavioural control (self-efficacy)
Jain 2009 <sup>93</sup>	Provider recommendation 90% (of the 49 females who were not aware of the vaccine)	no need because not sexually active 28%; not time to make an appointment 21%; no need because healthy or not at risk 20%; vaccine too new or might have side effects 11%; costs and insurance issues 7%; fear of needles 6%; already exposed to hpv 6%; not aware of hpv or the vaccine 2%			
Read 2010 <sup>94</sup>		don't know enough about the vaccine because the vaccine is too new (40%); belief that they were too young to think about or have sex (31.4%)			
Conroy 2009 <sup>95</sup>		among those who refused vaccination: concern about insurance coverage 13/15 (86.7%); among unvaccinated : not returned to the clinic since the baseline visit 45%;returned to the clinic but not offered the vaccine 42%; concerns about safety and efficacy	normative beliefs (subjective norms)		
Grant 2009 <sup>96</sup>		don't know enough about the vaccine (31%) worried about safety (7%) don't need the vaccine (19%) other (37%)			

Author and year of publication	Facilitators (reported as % participants who mentioned each facilitator or rank order)	Barriers (reported as % participants who mentioned each barrier or rank order)	Facilitators (reported as statistically significant)	Barriers (reported as statistically significant)	Qualitative data
Caskey 2009 <sup>97</sup>	among unvaccinated participants: for total population: health provider recommendation (83%); parent recommendation (82%); cost covered (74%); if had past abnormal Pap test (79%); many close friends getting it (55%); for age 13-17yrs: parent recommendation (89%); health provider recommendation (78%); past abnormal Pap test (78%); cost covered (68%); many close friends getting it (52%)	for total population: not sexually active (29%); concerns about vaccine safety (27%); cost (16%); unsure if vaccine works (14%); doctor doesn't think vaccine needed (5%); other (eg. pregnant, married, already have hpv )(9%) for age 13-17 years: not sexually active (47%); safety concerns (26%); unsure if vaccine works (16%); other (13%); cost (10%); vaccine not available (2%); doctor doesn't think it's needed (1%)	not assessed for attitudinal factors		
Rand 2011 <sup>98</sup>	among those vaccinated: doctor recommended it; preventing a serious and common disease (proportions NR)	among those who refused vaccination: not at risk (36%); perception that vaccine had not been studied enough (21%); not wanting to receive a shot (11%); want to do more research to make an informed decision (5%)			
Mathur 2010 <sup>18</sup>		Don't consider the vaccine safe (25% among those who participated in the decision; 8.5% among unvaccinated girls)			
Watts 2009 <sup>99</sup>	anti-cancer benefit 81%; anti-warts benefit 3%	cost (46%)			
Moore 2010 <sup>100</sup>			perception that mother would want them to get vaccinated (multivariate model)	time required to return to clinic for doses 2 and 3 (multivariate model)	
Licht 2010 <sup>101</sup>			NS (perceived risk)		
Zimet 2010 <sup>102</sup>		being married or in a monogamous relationship (54.9%); vaccine too new (35.4%); not enough information about the vaccine (31.7%); concern about side effects (24.4%); unsure if cost would be covered by insurance (24.4%); can't afford cost (14.6%); pregnant or trying to conceive (11%); not sexually active (9.8%); doctor recommended against vaccination (4.9%) ;			
Hopfer 2011 <sup>103</sup>					<u>Facilitators (acceptance)</u> : supportive family messages; explicit health care provider endorsement; peer descriptive norms reducing stigma of vaccination; disease framing (cancer) shaping vaccine benefit perceptions. <u>Barriers (resistance)</u> : skepticism of vaccine safety, invoking alternative prevention strategies (eg. safe and unriskey sexual behaviour); articulating stigmatizing hpv messages; overcoming self-efficacy barriers (cost, availability, time, fear of parental disclosure); delay strategies (for all women relationship status framed perception of susceptibility to hpv)
Rosenthal 2011 <sup>104</sup>			personal importance of the vaccine		
Dillard 2010 <sup>105</sup>		hasn't been enough research to justify getting the vaccine (46%); not convinced vaccine is really effective (35%); not sexually active so don't need it (26%); cost (24%); not comfortable discussing the vaccine with parents (19%); don't trust pharmaceutical companies (18%); don't need vaccine because in a monogamous relationship (12%); make smart decisions about sex so not at risk (12%); not at risk because don't sleep around (9%); wouldn't be effective because already sexually active (3%)			
Janousek 2011 <sup>106</sup>			belief that getting cervical cancer would be a serious health problem	religiosity; cost; wanting to do what the church thinks is right; vaccine hurting	
Bendik 2011 <sup>107</sup>	among those unvaccinated (what would motivate them most to receive the vaccine): doctor advises getting vaccinated (35.4%); a way to pay for the vaccine (19.5%); parental endorsement (16.4%); becoming sexually active (14%); start having sex with more partners (9.6%)		facilitators found by association among those already vaccinated: perceived importance of hpv; perceived severity of hpv; perceived severity of cervical cancer		

Table 6. Self-reported barriers and facilitators to preventive HPV vaccination among 9-26 year old females according to number of studies in which identified in systematic review

	Identified in a quantitative study and reported as a statistically significant result (# of studies)	Identified in a quantitative study and reported as a proportion or ranked result (# of studies)	Identified in a qualitative study (# of studies)	Total number of studies in which identified
<b>Barriers to preventive HPV vaccination identified among studies</b>				
Cost	✓ (1)	✓ (8)	✓ (1)	10
Don't need it (eg. perceived risk, perceived severity, in a relationship)	✓ (1)	✓ (6)	✓ (2)	9
Concerns about safety and side effects	✓ (1)	✓ (6)	✓ (2)	9
Practical barriers (eg. requires 3 doses, booking an appointment, transportation)	✓ (2)	✓ (4)	✓ (1)	7
Fear of needles	✓ (1)	✓ (3)	✓ (1)	5
Too new		✓ (5)		5
Not sexually active		✓ (5)		5
Doctor related (doesn't think it's needed, recommended against it, didn't mention it, difficulty understanding what was communicated)		✓ (3)	✓ (1)	4
Efficacy concerns		✓ (4)		4
Social norms		✓ (1)	✓ (2)	3
Unable to talk to parents about it (eg. uncomfortable, fear of disclosure)		✓ (2)	✓ (1)	3
Want more information (eg. to make an informed decision)		✓ (3)		3
No benefit (eg. already exposed to HPV, sexually active)		✓ (3)		3
Anti-vaccination views		✓ (1)	✓ (1)	2

	Identified in a quantitative study and reported as a statistically significant result (# of studies)	Identified in a quantitative study and reported as a proportion or ranked result (# of studies)	Identified in a qualitative study (# of studies)	Total number of studies in which identified
Subjective norms	✓ (1)	✓ (1)		2
Pregnant or trying to conceive		✓ (2)		2
Self-efficacy			✓ (2)	2
Pros do not outweigh cons or general feelings of barriers	✓ (1)		✓ (1)	2
Unaware of HPV or the vaccine		✓ (1)		1
Mistrust of pharmaceutical companies		✓ (1)		1
Alternative strategies available (safe and unriskey sexual behaviour)			✓ (1)	1
<b>Facilitators to preventive HPV vaccination identified among studies</b>				
Perceived benefit	✓ (2)	✓ (2)	✓ (2)	6
Health care provider recommendation		✓ (5)	✓ (1)	6
Social norms	✓ (2)	✓ (1)	✓ (2)	5
Parental endorsement	✓ (1)	✓ (2)	✓ (1)	4
Perceived risk	✓ (1)	✓ (2)	✓ (1)	4
Cost-free		✓ (3)		3
Subjective norms	✓ (3)			3
Perceived severity	✓ (3)			3
Positive attitude toward the vaccine or personal importance of the vaccine	✓ (2)		✓ (1)	3
Self-efficacy	✓ (1)			1
Vaccine efficacy (for at least 5 years)		✓ (1)		1

Table 7. Self-reported barriers and facilitators to preventive HPV vaccination among adolescent girls <18 years of age: proportion of girls reporting each barrier or facilitator among studies

Based upon data from 3 studies and a total sample of 706 adolescent girls	Identified in a quantitative study and reported as a statistically significant result (no studies)	Identified in a quantitative study and reported as a proportion (proportion of adolescent girls who reported each barrier or facilitator)	Identified in a qualitative study (no studies)
<b>Barriers to preventive HPV vaccination identified among studies</b>		<b>Total 3 studies:</b> Caskey 2009 <sup>97</sup> among those who considered vaccination but declined Rand 2011 <sup>98</sup> among those who refused vaccination Mathur 2010 <sup>18</sup> among those who participated in the decision (to not be vaccinated)	
Not sexually active		✓ 47% (Caskey)	
Not at risk		✓ 36% (Rand)	
Concerns about vaccine safety		✓ 26% (Caskey) 25% (Mathur) (8.5% among unvaccinated girls - whether they participated in the decision or not)	
Too new (not studied enough)		✓ 21% (Rand)	
Concern about efficacy (not sure if vaccine works)		✓ 16% (Caskey)	
Not wanting to receive a shot		✓ 11% (Rand)	
Cost		✓ 10% (Caskey)	
Wanting to do more research to make an informed decision		✓ 5% (Rand)	
Vaccine not available		✓ 2% (Caskey)	
Doctor doesn't think it's needed		✓ 1% (Caskey)	
<b>Facilitators to preventive HPV vaccination identified among studies</b>		<b>Total 2 studies:</b> Caskey 2009 <sup>97</sup> "Likelihood of getting vaccine if ...." Rand 2011 <sup>98</sup> among those who had already received the vaccine	
Parent recommendation		✓ 89% (Caskey)	
Health provider recommendation		✓ 78%(Caskey) ✓ NR (Rand)	
Past abnormal Pap test		✓ 78% (Caskey)	
Cost covered		✓ 68% (Caskey)	
Many close friends getting it		✓ 52% (Caskey)	
Preventing a serious and common disease		✓ NR (Rand)	

NR = not reported

### 3.4.4 Quality and risk of bias assessment

#### *Methods*

Twenty-one of the 22 included studies were evaluated for quality, as one was a report of outcome results only. Among the evaluated studies, 7 reported the application a specific theoretical framework or constructs upon which to base their investigation, and in 5 cases reporting was judged to be complete in describing the application of the theory. Eleven of the studies completely identified their objectives, and research setting. None of the studies were judged to have used a sample that was completely representative of the target population. However, many were designed to address a specific subgroup of the target population, such as racially and ethnically diverse groups of adolescent girls and young women. The procedures used in collecting data were described in detail in 12 of the studies. However, the rationalization for the choice of data collection tools and the fit of the data collection method with the stated research questions were judged as slight or moderate in almost all studies. The content of the data collection instruments were highly investigator driven in most instances and questioning primarily involved fixed responses and closed-ended questioning. Specific questions asked in the studies were only provided in 7 of the reports. Three other reports provided some information about the questions used and 2 studies mentioned that the information was available from the authors upon request. Among the studies there was not a great deal of evidence to suggest that investigators had attempted to assess the reliability and validity of the measurement tools used. Some of the studies mentioned that these assessments had been made in prior studies but details were not provided. In none of the studies was complete justification provided for the choice of analytical methods in the context of the study's stated research questions. The fit between the analytical methods and study research questions was judged as moderate in most cases. There was some evidence of user involvement in the design of 9 of the studies but this usually entailed the involvement of other experts in the field as opposed to the end users of the research who might be

able to apply the results, such as public health personnel and policy-makers; the involvement of adolescent girls and young women themselves was infrequently reported. In some cases authors mentioned cognitive and field testing of data collection instruments but the population used for these assessments was not always clear.

### *Outcomes*

In the majority of studies the outcomes of interest were a composite of knowledge, behaviours, attitudes, and predictors of vaccination; few were designed to specifically address the question of barriers and facilitators to HPV vaccination in the population of interest. The vaccination endpoint with which barriers and facilitators were correlated varied among the studies and along the continuum from being interested in the vaccine to having actually received it. Previous studies have demonstrated that HPV vaccination intent does not always predict uptake thus it was considered important to assess outcomes in this context among the studies.<sup>95;100</sup> Of the 21 studies, 2 addressed barriers and facilitators that impacted upon interest in receiving the vaccine; 2 correlated barriers and facilitators with acceptability; 1 with willingness; 1 with belief in one's ability to get vaccinated; and 4 with the intention to get vaccinated. The remaining 11 studies correlated the outcomes with various stages of uptake, and one study used a composite of intention and uptake which they called acceptability. Notably, the move to correlating barriers and facilitators with actual vaccine uptake occurred among the subset of studies which had commenced at the time point that corresponded with the vaccine having been available for approximately one year. Among those that examined barriers and facilitators to vaccine uptake, many included all stages of uptake which ranged from initiation to completion. Only one study restricted participation to young women who had received all 3 doses of the vaccine. However, the outcomes in this study may be subject to some degree of selection bias as participants were first recruited and then provided with a coupon for free HPV vaccine to simulate optimal conditions in which there were no cost barriers to vaccination. As a result, participants may

have been more likely to get vaccinated and less likely to consider barriers. For other studies, while the assurance of intended action is implicit among vaccinated girls, the definitive action of those who were unvaccinated was not usually clear. For instance, unvaccinated girls may have held views that ranged anywhere from against vaccination to very positive about vaccination and intending to receive the vaccine at a later date. Without this more specific information about the study populations, it is difficult to assess the level of outcome bias that may or may not be associated with the findings.

#### *Strengths and limitations*

There was a broad range of how well authors discussed the strengths and limitation of their studies. The inability to judge the discussion as complete was most often associated with the absence of any mention of the impact of the data collection instruments and methods on the validity that could be ascribed to the study's outcomes.

Additional details about the quality rating for individual studies are presented in Table 8. A synthesis of the quality components among studies is presented in Table 9. Judged against a framework of criteria, the body of evidence was awarded on overall quality score of 53%. Additional outcome details for individual studies can be found in Table 10, including the vaccination endpoint used, data collection methods, type of questioning (open versus closed-ended), available details about measurement tools used, and study conclusions.

Table 8. Quality assessment using the tool developed by Sirriyeh et al for diverse study designs<sup>86</sup> (combined reviewer scores)

Author and year of publication	Study type	Item																Total score for study
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	
Kahn 2008	QT	3	3	2	0	2	3	2	0	2	2	n/a	2	2	n/a	0	3	26
Lenehan 2008	QT	0	3	3	0	1	2	2	1	1	1	n/a	0	1	n/a	0	1	16
Gerend 2008	QT	0	2	3	0	1	3	2	0	0	1	n/a	2	2	n/a	0	3	19
Bynum 2009	M	0	2	3	0	1	3	2	0	1	2	2	2	1	2	1	3	25
Allen 2009	QT	3	3	2	2	2	3	2	2	2	3	n/a	2	2	n/a	3	3	34
Costar 2008	M	3	3	3	2	2	3	2	2	2	2	2	0	1	2	2	3	34
Jain 2009	QT	0	3	2	2	2	3	0	2	1	2	n/a	2	2	n/a	3	2	26
Read 2010	QT	0	2	1	0	1	1	0	1	1	2	n/a	2	0	n/a	0	2	13
Conroy 2009	QT	0	3	3	0	2	3	0	2	2	2	n/a	2	0	n/a	0	2	21
Caskey 2009	QT	0	3	3	0	2	3	2	1	0	2	n/a	2	2	n/a	0	2	22
Rand 2011	QT	2	2	2	2	2	2	2	2	2	2	n/a	2	2	n/a	2	1	27
Mathur 2010	QT	0	3	3	0	1	3	1	2	2	2	n/a	2	1	n/a	2	2	24
Watts 2009	QT	0	2	3	3	2	3	2	2	2	2	n/a	2	2	n/a	2	0	27
Moore 2010	QT	0	2	3	0	1	2	2	2	0	1	n/a	2	2	n/a	0	1	18
Licht 2010	QT	0	2	2	0	2	2	0	2	0	2	n/a	1	2	n/a	0	1	16
Zimet 2010	QT	0	2	2	2	1	2	0	2	0	2	n/a	2	1	n/a	0	2	18
Hopfer 2011	QL	3	3	3	0	1	3	2	2	n/a	n/a	3	3	2	2	1	2	30
Rosenthal 2011	QT	0	2	2	0	2	2	2	2	0	1	n/a	2	0	n/a	0	2	17
Dillard 2010	QT	0	3	2	0	1	2	1	2	1	1	n/a	2	1	n/a	2	2	20
Janousek2011	QT	3	3	3	3	2	3	2	3	1	1	n/a	3	1	n/a	0	1	29
Bendik 2011	QT	1	2	2	0	2	1	1	1	0	1	n/a	2	1	n/a	0	1	15

QT = quantitative QL= qualitative M = mixed methods  
Criteria (scoring items)

- 1 = explicit theoretical framework
- 2 = statement of aims/objectives in main body of report
- 3 = clear description of research setting
- 4 = evidence of sample size considered in terms of analysis
- 5 = representative sample of target group of a reasonable size
- 6 = description of procedure for data collection
- 7 = rationale for choice of data collection tool(s)
- 8 = detailed recruitment data
- 9 = statistical assessment of reliability and validity of measurement tool(s) (quantitative only)
- 10 = fit between stated research question and method of data collection (quantitative)
- 11 = fit between stated research question and format and content of data collection tool (eg. interview schedule) (qualitative)
- 12 = fit between research question and method of analysis
- 13 = good justification for analytical method selected
- 14 = assessment of reliability of analytical process (qualitative only)
- 15 = evidence of user involvement in design
- 16 = strengths and limitations critically discussed

### Scoring System

- 0 = not at all
- 1 = very slightly
- 2 = moderately
- 3 = complete

Table 9. Quality synthesis for studies included in systematic review

Criteria	Number of studies in which criterion was scored as complete	Total possible score for the body of evidence	Total awarded score for the body of evidence	
1	Explicit theoretical framework	5	63	<b>18</b>
2	Statement of aims/objectives in main body of report	11	63	<b>53</b>
3	Clear description of research setting	11	63	<b>52</b>
4	Evidence of sample size considered in terms of analysis	2	63	<b>16</b>
5	Representative sample of target group of a reasonable size	0	63	<b>33</b>
6	Description of procedure for data collection	12	63	<b>52</b>
7	Rationale for choice of data collection tool(s)	0	63	<b>29</b>
8	Detailed recruitment data	1	63	<b>33</b>
9	Statistical assessment of reliability and validity of measurement tool(s) (quantitative only)	0	60	<b>20</b>
10	Fit between stated research question and method of data collection (quantitative)	1	60	<b>34</b>
11	Fit between stated research question and format and content of data collection tool (eg. interview schedule) (qualitative)	1 (out of 3)	9	<b>7</b>
12	Fit between research question and method of analysis	2	63	<b>39</b>
13	Good justification for analytic method selected	0	63	<b>28</b>
14	Assessment of reliability of analytic process (qualitative only)	0 (out of 3)	9	<b>6</b>
15	Evidence of user involvement in design	2	63	<b>18</b>
16	<b>Strengths and limitations critically discussed</b>	5	63	<b>39</b>
	Totals	<b>n/a</b>	<b>894</b>	<b>477</b>

Overall quality score awarded for body of evidence (%)

**53%**

Table 10. Risk of bias assessment for systematic review: outcome level

Author and year of publication	barriers and facilitators correlated with what vaccination endpoint	Data collection method	Questioning	Measure(s) of outcome/ barriers and facilitators examined	were specific survey questions reported	main study conclusions
Kahn 2008 <sup>87</sup>	1. intention 2. belief in ones ability to be vaccinated	participant completed questionnaire	closed questioning using response scales	32 items on questionnaire to assess beliefs about HPV and HPV vaccination (10 factors: normative beliefs (ie approval of others), safety barriers, practical barriers, knowledge barriers, vaccine benefits re health and safety, vaccine benefits re self and partner hpv protection, perceived severity of hpv disease, perceived severity of hpv infection, perceived susceptibility to hpv, fear of shots)	no	need a comprehensive approach to implementation that involves diverse stakeholders
Lenehan 2008 <sup>88</sup>	willingness to receive the vaccine	anonymous, self administered 58 item questionnaire (21 items re attitudes and beliefs about hpv vaccination: 5-point scale; 12 items re current or intended behaviours)	closed	a series of statements that began with "I would get the HPV vaccine if..." conditions included doctor recommendation, requirement for 3 injections, despite requirement for continued Pap tests, efficacy (5 yr), costs (\$150.300,450), strength of agreement rated 1-5	no	women with presumably higher levels of risk based on number of past sexual partners) are not more inclined to seek out hpv vaccination; reportedly strong effect of physician recommendation on a woman's decision to get the hpv vaccine
Gerend 2008 <sup>89</sup>	interest in receiving the vaccine	anonymous 20 question survey	closed	2 hpv-related beliefs were assessed on a five-point scale (perceived risk of hpv infection, and perceived shame associated with an hpv diagnosis) "I am at risk for HPV infection", "I would feel ashamed if I found out I had HPV"	yes	low levels of hpv knowledge, low perceptions of risk could weaken HPV vaccination efforts, awareness may be increasing, campaigns to further increase understanding of the prevalence and consequences of hpv are needed, along with efforts to promote hpv prevention and routine cervical screening
Bynum 2009 <sup>108</sup>	acceptability and belief about the vaccine	questionnaire and in-depth interview guide (one on one)	closed for questionnaire, open questioning for interviews	questionnaire included items about HPV vaccine beliefs and in-depth interview guide included questions about general health concerns, patient-provider communication, hpv and cervical cancer, CIN, and hpv positivity	some	need for age appropriate educational efforts in the clinical setting
Allen 2009 <sup>91</sup>	stages of adoption: pre-contemplation(unaware of hpv or availability of vaccine); contemplation (planning to be vaccinated in the future but not in the next 30 days or received 1-2 doses); pre-preparation (planning to be vaccinated in the next 30 days); action (already vaccinated with all 3 doses); undecided; decided against	electronic mail survey (120 items)	closed	questions about perceived susceptibility to HPV, genital warts, cervical cancer; perceived severity of hpv, genital warts, cervical cancer including beliefs about future health and fertility; perceived benefits of the vaccine; perceived barriers including cost, safety, side effects; social norms (peers receipt of vaccine); subjective norms (approval of others)	no	consider peer-led interventions and peer role models; successful public health efforts must address individual characteristics, socio-cultural influences and institutional factors that influence vaccination behaviours; future research needed to examine predictors among more colleges with more diverse populations; need focus on characteristics and decision-making processes of those who are knowledgeable but refuse vaccination
Costar 2008 <sup>92</sup>	intention	internet survey	fixed response and open-ended questions	consideration of future consequences, attitudes toward vaccination, social norms, perceived behavioural control (self-efficacy)	yes	consideration of future consequences alone is not a useful predictor of vaccination intent; attitude toward vaccination was the strongest predictor of intention to vaccinate; tailor messages about hpv vaccine to address critical attitudes toward vaccine safety or perceived susceptibility
Jain 2009 <sup>93</sup>	intention	telephone questionnaire	fixed response and one open-ended question	7 questions in total;5 dealing with awareness and uptake; 1 questions asking if a recommendation by a health care provider was a facilitator; 1 open-ended question asking about the most important barrier or facilitator to uptake	yes	most women were aware of hpv and the vaccine; most said they would receive it if provider recommended; future monitoring of vaccine coverage in the survey to ensure successful vaccine implementation; main barrier not being sexually active or feeling the vaccine was not needed
Read 2010 <sup>94</sup>	interest	structured, anonymous self-administered questionnaire	NR	NR	no	did not identify concern for promoting sexual activity; level of vaccine acceptance was lower than for other racial/ethnic popns; education about hpv and its association with cervical cancer can improve the perception and acceptance of the hpv vaccine in this popn

Author and year of publication	barriers and facilitators correlated with what vaccination endpoint	Data collection method	Questioning	Measure(s) of outcome/ barriers and facilitators examined	were specific survey questions reported	main study conclusions
Conroy 2009 <sup>95</sup>	uptake	telephone survey	fixed response and open-ended question	predictors of uptake (ie facilitators) established by statistical correlation with information collected during a baseline study; among unvaccinated participants only those who had returned to their MD since the baseline study and had been offered the vaccine but refused (n=15) were asked about barriers (10 possible reasons(knowledge related barriers; practical barriers; safety related barriers; fear of shots; normative beliefs; perceived severity of hpv-related disease; self-efficacy to receive vaccine; plus an open-ended response category)); those who had initiated vaccination but were late for subsequent doses (n=26) were also asked about reasons (8 possible reasons plus an open-ended response category)	no	findings reflect short-term predictors of vaccination due to the relatively short follow-up time of the study; information useful to design of interventions that may address barriers (recall systems, and clinician office-based interventions to avoid missed opportunities for vaccination; ensure that women can afford the vaccine to improve uptake
Grant 2009 <sup>96</sup>	intention not to get the vaccine	California Health Interview Survey (CHIS 2007)	NR	NR	yes	
Caskey 2009 <sup>97</sup>	uptake	survey conducted with internet access via WebTV	fixed responses and an 'other' category  "I would be likely to get vaccine if..."	Barriers: not sexually active; concerns about safety; cost; unsure if vaccine works; doctor doesn't think vaccine needed; vaccine not available. Facilitators: health care provider recommendation; parent recommendation; cost covered; past abnormal Pap; many close friends getting the vaccine	no	adolescents and young women have variable knowledge about hpv, do not possess false beliefs that the vaccine will protect them from STIs other than hpv or that they will no longer need cervical screening; health care providers and family members are influential regarding hpv vaccine education and adoption
Rand 2011 <sup>98</sup>	uptake	telephone survey	at least some were open-ended but not specifically reported regarding all questions	open ended questioning about acceptance or refusal of vaccination and reasoning for either choice	no	hpv vaccine refusal is substantially higher than refusal of other childhood vaccines; providers should address cultural and vaccine safety concerns in discussions about hpv vaccine; most parents and older adolescents view hpv vaccine positively
Mathur 2010 <sup>18</sup>	1. participation in the decision about receiving vaccination 2. uptake	internet survey for private school girls; paper survey in class at public school	fixed response	6 page 59 multiple choice question survey; nature of questioning regarding attitudes, barriers or facilitators is unclear and not reported	some	high school girls are participating in the decision to be vaccinated; they still have knowledge gaps despite being involved in the decision; the study has broad implications for adolescent health education and public policy
Watts 2009 <sup>99</sup>	acceptability	language appropriate survey	NR	cost; ability to prevent genital warts; ability to prevent cancer;	no	need for targeted strategies based on specific needs and values of different racial groups; healthcare providers rather than the media can offer culturally sensitive approach to education and provide accurate info re efficacy, safety, risk, benefit
Moore 2010 <sup>100</sup>	uptake (all 3 doses)	self administered questionnaire	fixed response	endorsement by friends; endorsement by mother; endorsement by father; health care provider recommendation; perceived risk of hpv; perceived severity of hpv; fear of needles; side effects; vaccine safety; positivity about vaccines in general; avoidance of seeking medical care in general; time requirement to return for 2nd and 3rd dose; excessive time in waiting rooms; don't want a sexual history taken; don't want parents to know; requirement of 3 doses; friends getting the vaccine;	yes	uptake among women age 18-24 may be quite low; maternal endorsement and time needed to return to clinic for subsequent doses are important determinants of uptake
Licht 2010 <sup>101</sup>	uptake (at least first dose)	self-administered questionnaire (classroom setting at one university; internet-based at another)	fixed response	perceived risk of hpv acquisition; perceived risk of hpv transmission	no (need this information to properly evaluate study since vaccinated women may have felt they had a low risk of acquisition and transmission because they had received vaccination - it is interesting that perceived risk of acquisition and transmission was lower among vaccinated respondents which suggest a problem with the question	knowledge deficits and misperceptions are potential themes for educational campaigns; uptake higher than other college-based studies possibly related to greater time interval from availability of vaccine; 18 yr olds were more likely to report vaccination than 19-26 yr olds; respondents who know the vaccine protected against genital warts were more likely to report vaccination; few students recognized the high risk of both hpv acquisition and transmission

Author and year of publication	barriers and facilitators correlated with what vaccination endpoint	Data collection method	Questioning	Measure(s) of outcome/ barriers and facilitators examined	were specific survey questions reported	main study conclusions
Zimet 2010 <sup>102</sup>	uptake (first dose)	mailed survey	fixed response plus an open-ended response option	not sexually active; vaccine is too new; married or in a monogamous relationship; unsure if cost would be covered; don't have enough information about the vaccine; side effects; pregnant or trying to conceive; doctor recommended against vaccination; can't afford it; other (n=82), assessed among respondents who were somewhat, very, or extremely likely to 'do nothing to get the vaccine'	additional file of survey questions available from authors	educational interventions needed
Hopfer 2011 <sup>103</sup>	uptake	40 minute in-person interview	open-ended	open-ended questioning probing health care provider, family, and peer messages	some (but complete interview guide available on request from author)	four themes: relationship status frames relevance of HPV to women/ vaccine accessibility important; it may be useful for practitioners to explore family HPV vaccine norms when discussing vaccination; importance of dispelling myths about HPV transmission
Rosenthal 2011 <sup>104</sup>	uptake (first dose)	mailed survey	fixed response	personal importance of the vaccine by means of the question "how important do you think the vaccine to help prevent cervical cancer is for you?"	some	strength of physician recommendation is important; need focus on patient and provider attitudes; health care providers need to be well informed about hpv vaccination
Dillard 2010 <sup>105</sup>	uptake	online survey	fixed response	vaccine research; vaccine effectiveness; perceived risk (not sexually active, monogamous, unriskey sexual behaviour, condom use); cost; uncomfortable discussing with parents; mistrust of pharmaceutical companies; lack of perceived benefit (already sexually active)	yes	awareness is high; misconceptions about hpv exist; 4 topics should be addressed: understanding of protection against genital warts; vaccine efficacy; quality of supporting research; accurate perception of risk for hpv among women
Janousek 2011 <sup>106</sup>	composite of intention and uptake (called acceptability)	self-administered, in-class questionnaire	fixed response	perceived benefits; needle would hurt; safety; permit more risky sexual behaviour; cost; self-efficacy, subjective norms (including wanting to do what the church thinks you should do in terms of vaccination); perceived risk; religiosity (as measured by the Santa Clara strength of religious faith questionnaire);	yes	educational strategies aimed at clearing up hpv knowledge gaps; education of parents and health care providers; program planning incorporating an understanding of barriers and predictors among catch-up eligible college students
Bendik 2011 <sup>107</sup>	uptake (at least first dose)	electronic mail survey (42 items)	fixed response	importance of hpv; perceived severity of hpv; perceived severity of cervical cancer; perceived likelihood of acquiring hpv; perceived likelihood of acquiring cervical cancer;	no	educational interventions about the vaccine and the prevalence and consequences of hpv; inform physicians and parents about the benefits of vaccination; further research into factors associated with hpv knowledge and uptake

### 3.5 Discussion

Our systematic review regarding the views of adolescent girls and young women with respect to barriers and facilitators to preventive HPV vaccination identified 22 studies encompassing 8079 representative females from the United States and Canada. These young females were 9-26 years of age, mostly unvaccinated, and primarily from the United States. Only one study was conducted in Canada. Previous reviews have examined studies of vaccine acceptability at a time prior to federal vaccine approval and have grouped the views of parents, health care providers, and others. Consequently, prior reviews have not addressed actual vaccine uptake nor have they isolated the views of intended vaccine recipients. In this review we have aimed to call attention to the views of adolescent girls and young women since they are the primary target group for vaccination and the group which stands to benefit most from receiving preventive immunization against HPV. We acknowledge the indispensable role that parents, health care providers, and others play in prompting vaccination and therefore encourage the results of our systematic review to be considered in context with evidence related to the views of these influential others. The data presented here may provide guidance for the development of health promotion programs concerning HPV vaccination. By taking into consideration the views of the adolescent girls and young women who will be targeted for vaccination such programs are more likely to be successful.

From the combined evidence for 9-26 year old females participant self-reports revealed 22 barriers and 11 facilitators to HPV vaccination. The complete inventory of our findings is presented in Table 6 and Table 7. Cost was the most commonly identified barrier and our findings indicate that when cost is a factor in vaccine access it dominates as a barrier to vaccination. This lends support to the approach of having publicly funded vaccination programs for target groups. Still, it is important to also consider that cost concerns may be heightened by a lack of perceived value in receiving preventive HPV vaccination. In fact, feelings of not

needing the vaccine predominated as the second most common barrier to vaccination. Young women frequently viewed themselves as not at risk of acquiring HPV or that the severity of HPV infection did not warrant getting vaccinated. Among the included studies perceptions of benefit, risk, and severity appeared to have some relationship with sexual activity. Population with more sexually active young women, who may also have had prior sexually transmitted infections, tended to favour vaccination due to a perception that they were at risk for HPV. The opposite appeared to be true among young women who were not sexually active. These young women tended to focus more on the benefits of vaccination. In general, when deciding about vaccination, there seemed to be a tendency for young women to consider their present circumstances with respect to sexual activity and relationship status as opposed to considering the potential future consequences of HPV infection. Overall, our findings suggest that young women need to perceive themselves at risk in order to view vaccination as personally valuable. This suggests that educational initiatives should aim to improve awareness of HPV transmission and health consequences, including pre-cancerous disease significance.

Our results also indicate that concerns about safety and side effects are deterrents to HPV vaccine uptake among young women. Practical barriers were also revealed as an important obstacle to vaccination, such as the need to make health care appointments, arrange transportation, and remember to get all 3 vaccine doses; issues rarely exposed by earlier studies that used hypothetical 'intention to vaccinate' outcomes. Many of these factors appeared to be particularly relevant among ethnically diverse and low income populations. Barriers related to lack of knowledge and awareness about HPV, though diminishing as vaccination becomes more widespread, continue to exist and do arbitrate as important barriers when present.

Of the 11 facilitators of vaccination identified in our review, perceived benefit and health care provider recommendation were most commonly identified. Data

related to the perceived benefits of vaccination came mostly from studies conducted among private school and university students. Other, more diverse populations tended to frame their attitudes toward vaccination mainly from personal experiences, such as an abnormal Pap test result, rather than from a perception of future benefits. Although, one study in our review found that young women consider the cancer benefits of vaccination more important than anti-warts benefits. Also evident from our findings is the important role health care providers play in the delivery of HPV vaccine messages. Yet while health care provider recommendations are of consistently identified importance in studies which examine this subject, the relative importance of such recommendations is not well understood as they have not typically been examined in the context of other potential barriers and facilitators. It is also notable that health care provider influence can have an effect in both directions: doctor-related barriers such as missed opportunities to discuss vaccination, poor communication, and discouragement of vaccination were also identified in our review. One study revealed that health care provider messages are often not delivered in a way that is clearly and easily understood by young women.

In order to gain a deeper understanding of aspects central to vaccination decisions among adolescents, the evidence compiled in our review was further distilled to yield a subset of 706 nine to seventeen year old girls (represented by 3 studies). Among these adolescents, not believing there was a need for vaccination, either because of sexual inactivity or not believing they were at risk, formed the predominant obstacle to vaccination. Adolescent girls were most encouraged to seek vaccination if backed by parental or health care provider endorsement. Our findings also highlight some issues that may be primarily relevant to a younger population, such a fear of needles and social norms. Of note, our review did not find any qualitative studies conducted among adolescent girls aimed at eliciting their unprompted views.

A previously conducted systematic review by Brewer et al examined hypothetical HPV vaccine acceptability among adolescents, young adults, and parents.<sup>78</sup> All studies were carried out prior to HPV vaccine availability. Their review identified perceived effectiveness of the vaccine and physician recommendations as key cues to action while barriers to acceptability included cost and the belief that vaccination would promote sexual activity. Despite some similarities with our findings, the validity of their findings is limited by the questionable relationship between vaccine acceptability and actual vaccine uptake, and also by the kaleidoscope of represented views with small numbers of adolescents. The concerns of adolescent girls are unique to their stage of life and future research should aim to consider their views independently. Although our review was limited to girls and young women 9-26 years of age, the tendency to merge populations of adolescents and adults in behavioural HPV research was also evident in our review. Of the 22 included studies only 3 considered adolescents separately. Furthermore, from our literature search, we found that the number of studies that examined barriers and facilitators to HPV vaccination from the perspective of individuals other than adolescents themselves outnumbered adolescent studies by a factor of more than 7 to 1. It is further worth noting that many of the titles of excluded studies were misleading and implied an adolescent or young woman's perspective whereas upon closer examination the study itself typically addressed the views of parents, health professionals, or others.

Another systematic review was identified which described HPV vaccine acceptance among women in the Asian Pacific.<sup>109</sup> In this review, the population of interest was intended vaccine recipients. While knowledge gaps and concerns about vaccine safety and efficacy were identified, the results of this review support the notion that many of the barriers and facilitators relevant to vaccination uptake are culture and population-specific. Many of the women in the included studies were worried about factors such as how the vaccine would affect their fertility or appearance, or that their partner would disapprove. Our review integrated studies from both Canada and the United States in order to

maintain a particular cultural context and because it was not clear at the outset if restricting inclusion to Canadian studies alone would yield sufficient evidence.

The results of our review have revealed a Canadian research gap. There is a pressing need for future Canadian studies to address adolescent views toward HPV vaccination, the results of which may inform optimal intervention design to assist adolescents with HPV vaccination decisions. According to Boyce and Rootman, in a text on *Improvements to Research to Benefit Policy*, there appears to be a general "...lack of [Canadian] evidence regarding the effectiveness of interventions to address the problems that face adolescents," yet "...we know that the effectiveness of such interventions is highly dependent on the particular context and setting in which they are applied – effectiveness evidence from other countries is of questionable utility for developing adolescent health policy in Canada."<sup>110</sup>

The evidence collated in our review adds to our knowledge concerning some of the barriers and facilitators adolescent girls and young women experience when considering HPV vaccination. It comprises the full body of evidence available from studies conducted in Canada and the United States since the time the first preventive HPV vaccine became available. Individually the included studies may or may not be particularly useful in guiding program or intervention development but collectively the body of evidence forms a foundation from which to build a common knowledge base in the field. The multifaceted issues associated with preventive HPV vaccination deal with diverse populations, beliefs, and ranges of influence. Consideration of a diverse compilation of evidence is recognized as beneficial to gaining comprehensive insight into complex health care issues.<sup>86;111</sup> Accordingly, the diversity of the evidence presented here is valuable in broadening the scope of our understanding of the myriad of issues surrounding HPV vaccination decisions.

A particular strength of this body of evidence is in its focus on collecting self-reported information from intended HPV vaccine recipients and thereby balancing a field of research that is presently skewed toward establishing what others think about the issues. This basic guiding principle is not only important for successfully promoting HPV vaccination, it is crucial to the support structure needed to empower young people to take responsibility for their own health.

There are several limitations that must be considered when interpreting the results of our systematic review. One important limitation of the constituent studies pertains to the methods and tools used for data collection. From the evidence it is difficult to ascertain if the views of adolescents are truly reflected in the reported outcomes since the questioning in most instances was pre-established and to a large extent chosen by the investigators. There was very often no detail reported regarding questions asked or themes explored. Differences in findings could as easily be explained by differing methods between studies as by differing viewpoints among adolescents. In most studies particular barriers and facilitators to vaccination were exposed as a direct consequence of the questions asked by the investigators. This weakness is largely due to a lack of qualitative inquiry to solicit spontaneous responses concerning barriers and facilitators experienced by adolescent girls. Research findings from both qualitative and quantitative studies are complementary and offer a range of insight. More qualitative investigation is required to improve the breadth of our understanding of the salient issues.

Only seven of the studies included in our review mentioned the application of a theoretical framework to underpin the research and even fewer justified their model selection or explained how the theory was used to inform the study design. Theories of health behaviour provide important insight into behavioural mediators relevant to health decision-making. Some theories, such as the Health Belief Model, have been found to effectively predict vaccination behaviours. Yet from an adolescent perspective there is little guidance from the literature

regarding the optimal choice of a theoretical framework to predict the health behaviours of these young people. Of the seven studies that mentioned using a theoretical framework, constructs from the Theory of Planned Behaviour, the Health Belief Model, and Social Cognitive Theory were most commonly applied. Other theories reported were the Focus Theory of Norms, Culture-centric Narrative Theory for Health Promotion, and the Transtheoretical Model of Change. It was apparent that some studies made use of theoretical constructs to design survey questions while in other studies constructs were used to thematically categorize outcomes. However, the use of theory-driven questions may still deliver mainly solicited responses. In contrast, the use of theory to categorize outcomes related to vaccination barriers and facilitators may yield valuable information for identifying which theories may best explain adolescent behaviour with respect to HPV vaccination decision-making. Linked with qualitative inquiry this approach offers the opportunity to construct a theoretical foundation upon which to base subsequent research. In our review, the incomplete and suboptimal use of theory among studies limited our ability to ascribe superlative relevance to any one particular theory or construct to guide future research or program planning.

An additional limitation to consider when interpreting the results of our review is that most of the included studies were designed to investigate multiple objectives and in most cases the primary objective of the study was not to investigate the self-reports of barriers and facilitators in vaccination decisions. Often, only small subsets of the overall study population were the source of information about barriers and facilitators to vaccination among adolescent girls and young women. Overall study populations were mixed and often included, for the most part, women over 26 years of age, and parents. More studies specifically designed to address self-reported barriers and facilitators to HPV vaccination, particularly among adolescents, are necessary.

To alleviate shortcomings related to the reliability of outcome data in our review, we have opted to report all barriers and facilitators identified among studies and not just those which attained statistical significance or were reported by the highest proportion respondents. And, though listed according to the number of studies in which they were reported, drawing conclusions about the relative importance of any particular barrier or facilitator should be done with caution due to the possibility of being misled. Also, we have reported a sufficient level of detail about individual studies such that users are able to selectively draw on the evidence according to individual needs. Our findings specific to adolescent girls, while informative, should also be interpreted in context. Only 3 studies looked at this age group and the self-reported information was, at least in part, attributable to the investigator driven nature of questioning.

The question posed by our review has important implications for cultivating a deeper understanding of barriers and facilitators to preventive HPV vaccination among adolescent girls and young women. Taken together, our findings may have broad application to sectors such as public health and policy-makers in terms of program development and intervention design. Although the evidence may be of inadequate quality to draw conclusions about the relative importance of particular barriers and facilitators, it is important to bear in mind that if the goal is to help each girl overcome barriers relevant to her own experience then it is of little consequence whether a particular barrier or facilitator was found to be statistically significant in a particular study. Accordingly, tailored interventions may well represent the optimal choice for a complex health intervention such as preventive HPV vaccination. Whereas targeted approaches to intervention design will rely on an understanding of the salient mediating factors, such guidance is as yet scant from currently available evidence. Conversely, the data brought together in our review may be appropriately used to design tailored interventions that are amenable to adaptation as new research findings become available. Almost all of the studies in our review recommended age appropriate educational initiatives.

As we look to the future of preventive HPV vaccination we must consider that current initiatives to promote the vaccine among various catch-up populations will gradually disappear, leaving us with an unchanging need to ensure vaccine uptake among adolescent girls. Our efforts will help young people transition into healthy adults who are not adversely impacted by numerous health-related consequences including those associated with HPV.

### 3.6 Conclusion

In our systematic review, we have aimed to place the viewpoints of the essential target group for preventive HPV vaccination at the centre of our inquiry into factors which arbitrate in their decisions. As a result, we have found that young women up to the age of 26 often feel that they do not need the HPV vaccine, either because they do not perceive themselves to be at risk or because of a perception that the consequences of HPV are not severe. Cost is another important barrier to vaccination as are concerns about safety and side effects. Conversely, we found that if young women perceive a benefit to vaccination they are most encouraged to seek vaccination. Endorsement by influential others, such as parents and health care providers, also appear to be important factors in prompting vaccination but communication is often suboptimal or unclear. Our findings further suggest that adolescent girls do not perceive a need to get vaccinated until becoming sexually active, report the importance of parental approval, commonly fear needles, and want more information about vaccine safety and efficacy.

We caution that the reliability and utility of our findings is somewhat limited by the quality of individual studies. The results of our review suggest that further studies are necessary to generate comprehensive and trustworthy data that can be applied to health promotion interventions aimed at improving the uptake of HPV vaccination among young girls. Specifically, we have revealed a need for 1) more

Canadian research, 2) more qualitative inquiry, and 3) more studies among adolescents.

Considering the nature and dependability of the data brought together in our review, we provide the following recommendations for program and intervention development: 1) the development of clear health messages which address the transmission and health consequences associated with HPV; 2) tailored intervention design based upon the full compilation of barriers and facilitators found in our review; and 3) the application of health behaviour theory to underpin research design and program development.

## 4.0 The use of a geographic information system (GIS) to guide health promotion planning for preventive HPV vaccination among adolescent girls

### 4.1 Rationale and objectives

In Ontario, a school-based preventive HPV vaccination program was introduced in 2007 and although there is some perception that vaccine uptake has been poor since the program's introduction, accurate knowledge of vaccination coverage is uncommon among most stakeholder groups. Knowledge of vaccination goals and the ability to quantify and communicate vaccination rates with respect to defined goals establishes a logical foundation from which to move forward. Furthermore, the opportunity to note particular areas where vaccination rates either lag behind or exceed norms makes it possible to postulate explanations for existing problems. On closer examination, it may be easier to determine the nature and complexity of exposed problems, establish the need for intervention, and more readily decide the types of interventions most likely to be appropriate and successful including the way in which they can be delivered most effectively.

It is important to promote broad uptake of HPV vaccination. As a preventive health strategy, significant gains in disease prevention are not otherwise likely to be observed. We have already learned this from the introduction of hepatitis B vaccination, where community disease rates only declined following the introduction of a universal vaccination program. In addition, awareness of the goal of achieving 95% vaccination coverage among adolescent girls prior to sexual debut by the year 2020, as put forth by Cancer Care Ontario in their *Action Plan 2020*, is likely rare beyond the medical community.<sup>112</sup> A shared recognition of this goal among all stakeholders is apt to be an effective element in prompting more girls to seek vaccination.

At a *Canadian HPV Vaccine Research Priorities* workshop in 2005 participants called for effective methods of promoting HPV vaccination. Effectiveness, however, will likely depend upon ensuring that key stakeholder groups remain linked and informed regarding the changing nature of problems associated with vaccine uptake, and of accomplishments with respect to finding tenable solutions. Furthermore, a recent publication by Howlett et al advises that promotion and social marketing efforts to ensure optimal vaccine uptake are required and must be targeted and community based.<sup>45</sup> The authors further advise of the need to establish methods for monitoring vaccine uptake in order to provide population-based information regarding vaccine effectiveness. Taken together, these calls to action highlight a need to bring together multiple levels of influence and ensure that groups remain connected throughout the process of implementing HPV vaccines and maintaining optimal vaccination rates over time.

Determinants of vaccination uptake may be further understood by examining the constituent diversity within a given population and learning the relational structure that ties populations together. For example, an ability to identify areas of low vaccine uptake compared to those with higher uptake, or areas where certain barriers predominate compared to other areas may assist in planning public health initiatives. Prior studies have demonstrated that geographic variation exists in the utilization of health services.<sup>113</sup> With respect to cervical cancer screening, a 2005 study by Fehringer et al showed large variations in Pap test rates across public health units in Ontario.<sup>114</sup> Similar investigations may demonstrate variation in HPV vaccination rates yet should take additional steps to examine reasons for any dissimilarity.

Geographic information systems (GIS) are a software-based means of analyzing data and presenting information that is linked to location. They have vast potential for improving health service delivery by communicating spatial health information in an easily comprehensible format using maps.<sup>115</sup> A study conducted

in the United States has shown that program directors perceive policy or research advantages from the use of GIS for cancer control.<sup>116</sup> And, policy-makers believe that raising understanding and ensuring that research findings are transferred to users more effectively can add value to the policy process.<sup>117</sup> It has also been found that the understanding of health information can be enhanced by simplifying the presentation of statistical information because low numeracy skills are common, even among highly educated people, including those with medical training.<sup>118</sup>

The overall aim of this proposed use of GIS to support health promotion of HPV vaccination was to demonstrate how GIS may be applied to communicate health information pertinent to HPV vaccine uptake within Ontario's population-based preventive HPV vaccination program that would be meaningful, easily understood, and usable by a broad range of stakeholder groups

Specific objectives were to:

- demonstrate GIS as a means of monitoring and communicating HPV vaccine uptake over time including trends toward a defined goal
- investigate comprehension and perceived uses for HPV vaccination health information presented using GIS among various stakeholder audiences
- propose how GIS may be used in conjunction with HPV vaccination research and program planning to support and sustain progress over time
- consider potential future uses of GIS for HPV vaccination including the potential to reveal geospatially relevant associations warranting further investigation

## 4.2 Methods

### Coursework:

An introductory GIS course was completed to learn the basic functionality of GIS and to acquire the basic skills and knowledge required to work with GIS, create maps, and perform basic spatial analysis. This resulted in a certificate from ESRI Canada for the course, *ArcGIS Desktop I: Getting Started with GIS*.

### Process:

A review by Bell et al on the use of GIS to effectively communicate health information was used to guide the development of the GIS model.<sup>119</sup> The review discusses aspects of successfully using GIS applications to communicate public health information to a range of stakeholder audiences.

### Significance:

The purpose of this proposed use of GIS is to communicate geospatial information about preventive HPV vaccine uptake that is interpretable and usable by a broad range of stakeholders.

### Specification of audiences:

Given the goal of communicating geospatial health information with the potential to foster understanding and be applicable to a broad range of relevant audiences, the following stakeholder groups were identified:

#### *Policymakers*

Provided with specific knowledge and a thorough understanding of the diverse features of constituent populations, local policymakers may be able to consider targeted strategies for promoting HPV vaccination in favour of more traditional campaigns which are often broad and may fail to address unique needs. Various government agencies from domains such as public health, cancer care, adolescent health, health promotion, education, and research all have roles to

play in advancing preventive health initiatives such as HPV vaccination and should possess insight into the complexity of the associated issues, including current awareness of vaccination status in the population and vaccination goals, and be involved in all stages of the implementation process whenever possible.

### *School officials*

The current publicly funded program for preventive HPV vaccination is primarily delivered to eligible girls in schools where grade 8 is offered. Thus, school staff members are a particularly important resource for students faced with the decision about whether or not to receive vaccination. Adolescents have identified school as the most common place from which they receive information about HPV.<sup>96</sup> Teachers can play a fundamental role in helping students articulate their concerns and guide them in finding reputable sources of information. Those instructing sexual health education classes have a particularly important responsibility in this regard yet they are often not adequately content trained for the role and may not be aware of the HPV vaccination program's successes, failures, and challenges, even within their own schools. Accordingly, School Board officials should also possess a constructive understanding of health promotion for HPV vaccination and look to form collaborative relationships with the health care sector so that they may demonstrate the leadership necessary to institute improved sexual and health education delivery.

### *Clinicians*

It is obvious that clinicians have a role to play in promoting HPV vaccination to young girls. Many studies have reported the importance of a health care provider recommendation in prompting vaccination. Family and specialist physicians should be aware of trends and issues related to local vaccination coverage. Besides physicians, however, it is essential to consider the value of other health care providers. Few adolescents visit a physician for preventive health care.<sup>9-11</sup> As a result, there is a need to consider providing preventive health care services to adolescents in locations which are more in keeping with an adolescent

lifestyle, such as from pharmacists and public health nurses.<sup>9</sup> The potential for other care providers to become involved, however, begins with an awareness of the issues.

### *The Public*

Because HPV is so prevalent in the population, vaccination may eventually be recommended for many groups. Vaccination is now approved for use in older women and boys, and further indications are being evaluated. Although adolescent girls remain the primary target group for HPV vaccination, parents have been very involved in vaccination decisions for their children. Public interest groups have also taken up the issues and have played a role in disseminating both positive and negative messages about vaccination. All of this amounts to a public health matter that affects a vast majority of the population. Efforts to identify and address public concerns are critical to the success of any vaccine implementation approach.

### *Adolescents*

Adolescent girls are the primary intended recipients of preventive HPV vaccination. Access to easily comprehensible information about vaccine uptake may help to broaden their understanding and provide them with some of the information they seek and consider important in making an informed choice. It may additionally prove to be instrumental in improving vaccination uptake since normative beliefs appear to be crucial elements in adolescent health decision-making.

### *The Media*

The media has had a powerful and frequently negative influence on vaccine acceptability.<sup>17</sup> This may be because of greater media access to negative information about vaccination, or because negative stories tend to elicit stronger reactions and greater interest. Increased efforts to ensure media awareness of

vaccination benefits, goals, and barriers to success may enhance possibilities to foster greater synergy in promoting preventive health behaviours.

Collectively, each of the identified groups may be able to use geospatial information about HPV vaccination in different ways to identify opportunities for intervention, or may find that the information establishes a common ground from which to move forward with collaborative approaches.

Scope:

The scope of this GIS project was the school-based HPV vaccination program administered according to the Publicly Funded Immunization Schedules for Ontario and under the purview of the Immunization of School Pupils Act (ISPA).<sup>120</sup>

Choice of media:

GIS was used to produce a series of static and dynamic maps, supported by the use of graphics and explanatory text as necessary to facilitate understanding of the intended messages. Maps were created using the software ArcGIS Desktop 10, ESRI. A geospatial information specialist was consulted to provide iterative content feedback regarding map design. Maps were designed with the goal of being easily understood by all intended audiences. In general, maps were designed to have a single purpose since it has previously been reported that conveying too much information in one map may obscure the message and confuse readers.

Choice of map messages:

The desired messages to be communicated in the maps were selected as follows:

- HPV vaccination coverage in Ontario by Public Health Unit over the first 2 years of the vaccination program

- Trends in HPV vaccination coverage in Ontario, by Public Health Unit over the first 2 years of the vaccination program
- Goals of vaccination: to have 95% of young women receive the HPV vaccine before they become sexually active, in accordance with Cancer Care Ontario's *Cancer 2020* action plan
- Current levels of provincial HPV vaccination coverage relative to the defined goal
- Geospatial distribution of schools with enrolled grade 8 girls within the City of Ottawa Public Health Unit by size and School Board
- Hypothetical HPV vaccination coverage information and trends by School Board within the City of Ottawa Public Health Unit over the first 2 years of the vaccination program
- Hypothetical school-specific HPV vaccination coverage information and trends relative to provincial vaccination goals for the City of Ottawa Public Health Unit over the first 2 years of the vaccination program
- Hypothetical school-specific barriers and facilitators to HPV vaccination for the City of Ottawa Public Health Unit

*Map 1: Province of Ontario Public Health Unit Map: HPV Vaccination Coverage:*

A classed choropleth map of provincial HPV vaccination coverage in Ontario's school-based immunization program, by Public Health Unit was created using ArcMap 10. An ESRI ArcGIS web mapping service using a Web Mercator projection provided a world topographical base map upon which to display features from a geodatabase file containing Public Health Unit vaccination coverage and boundary data. Vaccination rates were classified according to the standard colour codes used by the World Health Organization (WHO) AFRO: red for coverage below 50%; yellow for coverage between 50-80%; and green for coverage above 80%.<sup>121</sup> An additional classification was introduced, using a different shade of green, to incorporate the range of vaccination coverage which corresponds to the provincial goal, defined as Cancer Care Ontario's *Action Plan*

2020 target of 95% HPV vaccine uptake prior to first sexual activity among young women by the year 2020.<sup>112</sup> Provincial vaccination coverage maps displaying vaccination rates for the school years 2007/08 and 2008/09 were placed adjacent to one another in the map layout to permit comparison between years. The information was supplemented with a bar graph to display individual Public Health Unit vaccination rates for each of the two years, relative to the 95% goal for vaccine uptake. Finally, the overall Ontario HPV vaccination coverage rate, expressed as the mean of all PHU values, was featured on the map, displayed within the designated WHO vaccination colour classification to enhance the visual message.

*Map 2: City of Ottawa Public Health Unit Map: HPV Vaccination Coverage:*

A graduated and proportional symbols map of the City of Ottawa Public Health Unit was created using ArcMap10 using the same methods for the base map and boundary data as was used for the provincial map. A geodatabase file was created that included the names of all schools in the City of Ottawa Public Health Unit offering grade 8 to girls as well as school demographic information. Points representing the location of each school were plotted on the base map using the latitude and longitude of each school. School-specific enrollment of grade 8 girls for 2007/08 and 2008/09 was estimated based upon the number of HPV vaccine information mail outs sent to individual schools (these numbers formed the denominators for calculating vaccination uptake rates per school). Because it was not possible to obtain individual school-level data, hypothetical numbers of girls who received vaccination at each school (numerators) were generated by selecting arbitrary numbers that produced uptake rates within +/- 10% of the actual vaccination rate for the City of Ottawa PHU for each school year and which achieved an overall mean equivalent to the actual overall PHU vaccination rate. Three map layouts were then produced:

Map 2A. Schools offering grade 8:

This map was designed to display the location of all schools within the City of Ottawa PHU that offer grade 8. Symbology for the map was selected to reflect school size and an accompanying graph of school size distribution was created and displayed. Information about where girls receive HPV vaccination was also portrayed as was information about where eligible girls not enrolled in school may obtain vaccination.

Map 2B. Schools by School Board; Vaccine coverage by School Board:

This map was designed to display the distribution of schools within the City of Ottawa PHU by School Board. There are 4 School Boards within the City of Ottawa PHU (French Catholic, French Public, Public, Catholic) plus several independent schools and these were labeled as A,B,C,D,E (in no particular order) on the map for the purposes of the messages to be conveyed. Using the hypothetical uptake data previously specified a display of vaccine uptake by School Board was presented including representations of School Board trends over the first 2 years of the vaccination program.

Map 2C. Preventive HPV vaccine uptake by school:

This map was designed to display the concept of presenting individual school-level HPV vaccine uptake within the City of Ottawa PHU. Hypothetical data, as previously specified, was used to display a stacked bar graph for each school. The total height of each bar represented the goal of 95% vaccine uptake. Each bar showed the school's HPV vaccine uptake for the 2007/08 school year, the incremental gain in uptake during the 2008/09 school year, and the uptake proportion still required to reach a vaccination uptake goal of 95%.

Map 3: Exploring Barriers to HPV vaccine uptake by school: City of Ottawa Public Health Unit:

A third proportional symbols map was created to conceptually depict how our knowledge about barriers to HPV vaccination among adolescent girls could be

communicated to support the creation of targeted and tailored health promotion initiatives. Barriers and facilitators to HPV vaccine uptake were selected from a topical systematic review and used to create pie charts which were then displayed at a geographic point location for each school. Hypothetical data pertaining to specific barriers and facilitators at each school on the map was generated and arbitrarily apportioned among the schools to model variation.

#### *Map Dynamics and Accessibility:*

Because the use of the Internet has become a familiar part of everyday life, ways to maintain the dynamic aspects of the GIS project through web-based technology were explored. It has been suggested that online information using an interactive format may have the greatest potential for increasing understanding of complex health information and influencing audiences.<sup>119</sup> Mappetizer, ©2002-2011 web mapping software was used to create dynamic, user-based maps viewable within a web browser. A web domain name was purchased for further development of the dynamic aspects of the project. ([www.healthyme.name](http://www.healthyme.name) )

#### *Data Sources:*

##### *Topographical base map*

Maps were created using a topographical base map selected from an ArcGIS web mapping service (WMS):World\_Topo\_Map which uses a Web Mercator projection. <http://services.arcgisonline.com/ArcGIS/services>

##### *Public Health Unit boundary data*

Health region data to define the boundaries of all 36 public health units in the province of Ontario were obtained from the cartographic resources of Statistics Canada. <http://www.statcan.gc.ca/pub/82-402-x/2005001/4152507-eng.htm>

##### *Provincial HPV vaccination uptake data*

Provincial HPV vaccination uptake data was obtained from the Immunization coverage report for school pupils for the school years 2007/08 and 2008/09

released by the Ministry of Health and Long-term Care Public Health Division.<sup>52</sup> Individual PHU data are from coverage reports generated from the Immunization Record Information System (IRIS) database. All vaccination rates are expressed as 'complete for age' meaning that girls had received all 3 vaccine doses.

#### *Schools with grade 8 girls*

Basic demographic data for schools with eligible grade 8 girls were obtained from Ottawa Public Health for all four school boards in the City of Ottawa plus independent schools. This data included the number of eligible grade 8 girls enrolled in each of the schools and specified which schools offered a school-based vaccination clinic and which schools referred eligible girls to catch-up clinics or other practitioners. The City of Ottawa eMap was used as the source for determining the latitude and longitude of each school.

#### *School-specific HPV vaccination uptake data*

For the purpose of this thesis it was necessary to utilize hypothetical data related to vaccination uptake. Numerous issues related to data ownership, confidentiality, and other circumstances precluded the use of actual school-specific uptake data.

#### *School-specific data related to barriers and facilitators to HPV vaccination*

For the conceptual display of school-specific barriers and facilitators to HPV vaccine uptake, 7 items were arbitrarily selected from among those identified in a systematic review of self-reported barriers and facilitators to HPV vaccination among adolescent girls and young women.<sup>122</sup> The proportional data for each school represented in the map was hypothetically generated and apportioned among the schools to model variation.

#### *Map testing:*

Three maps were selected for testing to evaluate whether they effectively communicated the intended messages. This was done by seeking feedback from

representatives of each of the pre-specified stakeholder audiences. An interview questionnaire was developed for this purpose (Appendix 4). Each representative was asked to answer a series of questions designed to evaluate the maps for message clarity, perceived usability, and potential for misinterpretation. The interviewer guided each representative through the questions and documented their responses. The amount of time taken to review each map and answer all of the questions was recorded to provide additional information about the ease with which the various audience representatives could find and interpret the map information. Interviews were conducted either in person or by using telephone and internet communication. One interviewer (LR) conducted all interviews.

The following representatives were selected:

- Ottawa Public Health (immunization role)
- Principal from a City of Ottawa independent school
- School parent council member
- Gynaecologic oncologist
- Pharmacist
- Nurse practitioner from sexual assault clinic
- Mother of a 12 year old girl
- Adolescent girl
- Media representative

### 4.3 Results

#### Map messages:

##### *Map 1: Province of Ontario Public Health Unit Map: HPV Vaccination Coverage*

For the 2007/08 school year, of the 36 Ontario PHUs, 27 reported vaccination coverage rates of less than 50% and 9 reported coverage of 50-80%. No PHU had a vaccination coverage rate above 80%. Overall, the provincial average for

2007/08 was 47.98% which falls within the lowest of the WHO (AFRO) classifications for vaccination coverage. For the 2008/09 school year, 12 PHUs reported vaccination coverage rates of less than 50% and 24 reported coverage between 50-80%. No PHU had vaccination coverage exceeding 80%. The 2008/09 provincial vaccination rate was 52.46% which falls within the second lowest of the WHO (AFRO) classifications for vaccination coverage and represents an increase of approximately 4.5% over the first year of the program. The distribution of vaccination coverage appeared similar across PHUs with a few exceptions: Eastern Ontario (vaccination coverage rate of 3.24% in 2008/09); Peel Region (no vaccination coverage data); Toronto (no coverage data for 2008/09); Wellington-Dufferin-Guelph (vaccination coverage of 70.45% in 2008/09). Please refer to Map 1.

*Map 2 & 3: City of Ottawa Public Health Unit Map: HPV Vaccination Coverage Schools*

Within the City of Ottawa Public Health Unit there are 120 schools that offer grade 8 to female students and approximately 5418 grade 8 girls enrolled in school.<sup>50</sup> Vaccination coverage for the City of Ottawa PHU was higher than the provincial average in both the 2007/08 and 2008/09 school years; rates were 48.65% versus 47.98% and 61.20% versus 52.46%, respectively (Maps 2 and 2A).

*School Boards*

This map hypothetically demonstrates how demographic and vaccine uptake data may be presented by School Board. In the example produced, School Board D represents almost half of the schools in the PHU (47%). Distribution of the remaining schools by School Board is: A (5%), B (6%), C (29%), and E (13%). Please refer to Map 2B. The bar graph displays hypothetical HPV vaccine uptake for 2 school years in each of the School Boards. Based upon the hypothetical data, uptake in 2007/08 ranged from a low of 45.7% at Board E to a high of 57% at Board B. In 2008/9 uptake ranged from 56.5% to 65.5% at Board E and B,

respectively. There was therefore an 11% difference between School Boards in the first year of the vaccination program and a 9% difference the following year. School Board E had the lowest HPV vaccine uptake in both 2007/08 and 2008/09 whereas School Board B had the highest uptake in both years.

#### *School-specific HPV vaccine uptake*

Map 2C displays the concept of displaying each school's vaccine uptake relative to a defined vaccination goal. In this map, it is possible to compare vaccine uptake between schools. Each school's vaccination rate over the first 2 school years of the program is displayed.

#### *School-level barriers and facilitators to HPV vaccination*

Map 3 conceptually displays pie charts, at the geographic point location of each school, of hypothetical data depicting school-specific information about barriers and facilitators to HPV vaccination among adolescent girls. The map portrays the breakdown of barriers and facilitators at individual schools. The visual depiction of apportioned barriers and facilitators also permits comparisons between schools. For example, there is a predominance and similarity between the purple segments of the pie charts at each of the 2 schools in the northeast corner of the map suggesting the existence of a common concern about side effects among girls at each of these schools.

#### Map testing:

Maps 1, 2B, 2C, and 3 were selected for map testing. Interviews were arranged and conducted with an Ottawa Public Health immunization representative, a school parent council member, a gynaecologic oncologist, a pharmacist, a mother of 2 daughters, and an adolescent girl. Three of the interviews were conducted in person and 3 were conducted by telephone/email communication. Detailed results of stakeholder feedback are displayed in Table 11.

*Map 1:*

In open-ended questioning almost all respondents reported noticing the two provincial maps first and commenting that it appeared to show a significant change from one year to the next. However, upon examining the map more closely many reported that, overall, provincial vaccination coverage had not improved appreciably. All of the content questions were answered correctly by all respondents. In terms of potential uses, most respondents stated that the map conveyed interesting information but did not feel the information was necessary for them personally. Rather, they expressed feelings of appreciating the awareness. The Ottawa Public Health immunization representative felt the information could have practical uses for making comparisons with neighbouring Public Health Units, serve as a quick visual support at business meetings, and provide a good tool for communicating with School Boards.

*Map 2B:*

Initial comments revealed that some respondents misinterpreted the pie chart and mistook it for HPV vaccine uptake by School Board. There were also some problems with the colours on the map. Respondents seemed to hesitate in interpreting the map as a consequence of becoming confused by the colour choices. The colour used for one of the School Boards was too similar to one of the colours used for the bar graph showing vaccination trends by School Board. This caused some misinterpretation of information. The order in which the legend colours were displayed was also not ideal. Respondents could not conceive of particular uses for the information displayed other than as information School Board officials should be aware of. The Public Health representative reported that this type of comparative information would politically be considered confidential and too sensitive. A School Board representative was not interviewed.

*Map 2C:*

All respondents were able to interpret this map without difficulty. The numbers used to identify schools (to replace authentic identifiers) caused some confusion. Some respondents felt the map contained information that would be useful to individual schools for designing school-specific initiatives, or for comparisons between schools which may serve to stimulate a sense of competition toward the attainment of vaccination goals. The Public Health representative pointed out that this type of use would be considered too sensitive by schools and was unlikely to be supported. Notably, the parent council member, who possessed views somewhat against vaccination, interpreted map information in ways that could be used to discourage vaccination efforts. The adolescent girl felt that health teachers should know the information such that it could be shared with students in health class. The mother wanted school and health officials to be familiar with the information.

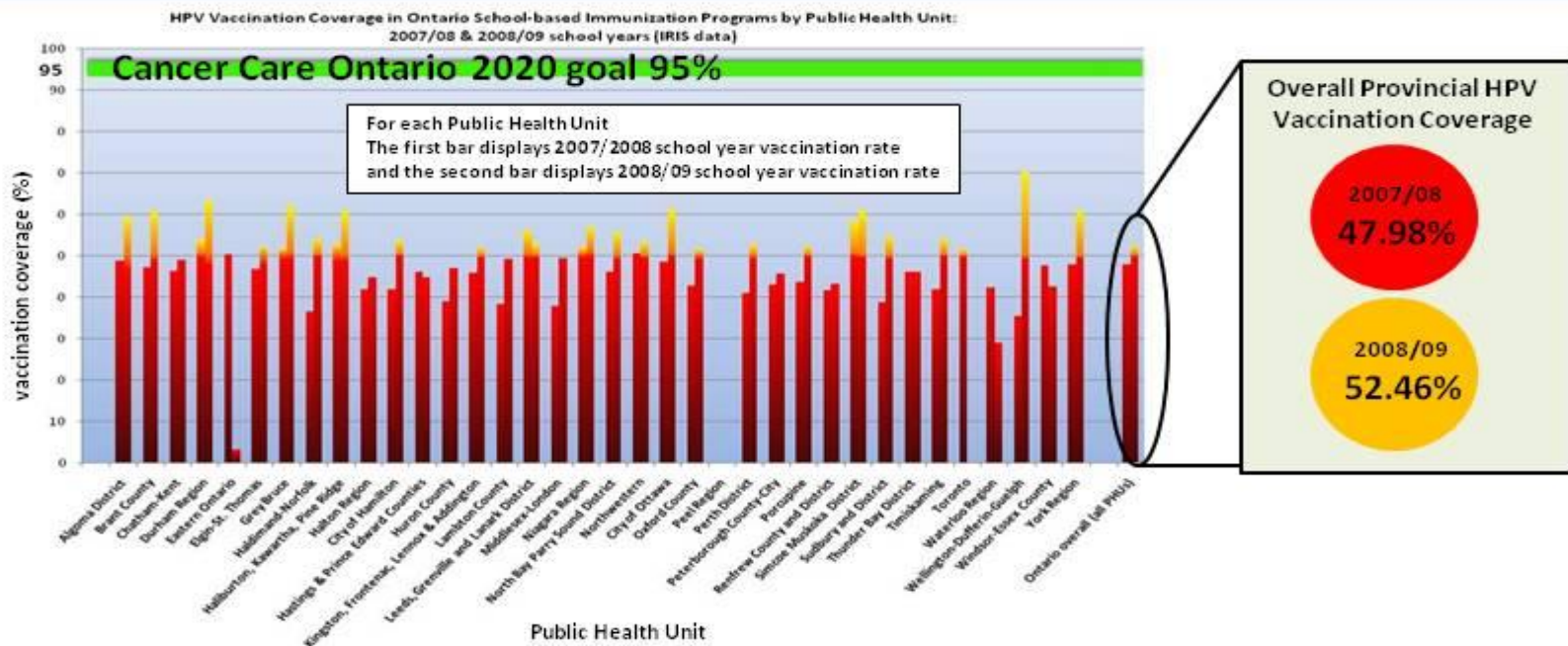
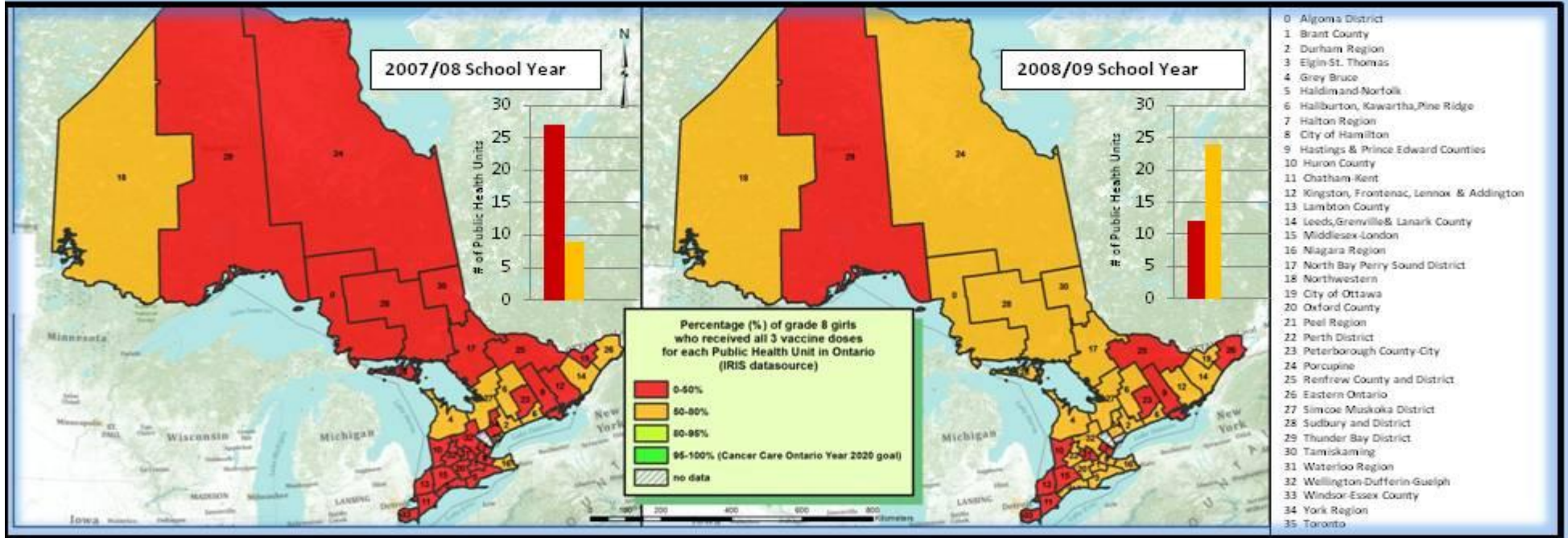
*Map 3:*

This map was the preferred map among all respondents. The colours received positive feedback as did the use of pie charts. There was no misinterpretation of the map. However, the adolescent girl verified that each pie chart represented a school (though school identifiers were absent on maps to maintain anonymity). All respondents felt the information had broad application. Everyone felt they had a role to play in addressing a 'piece of the pie' in the promotion of health for the girls; it was in reviewing this map that everyone felt they had a personal role to play.

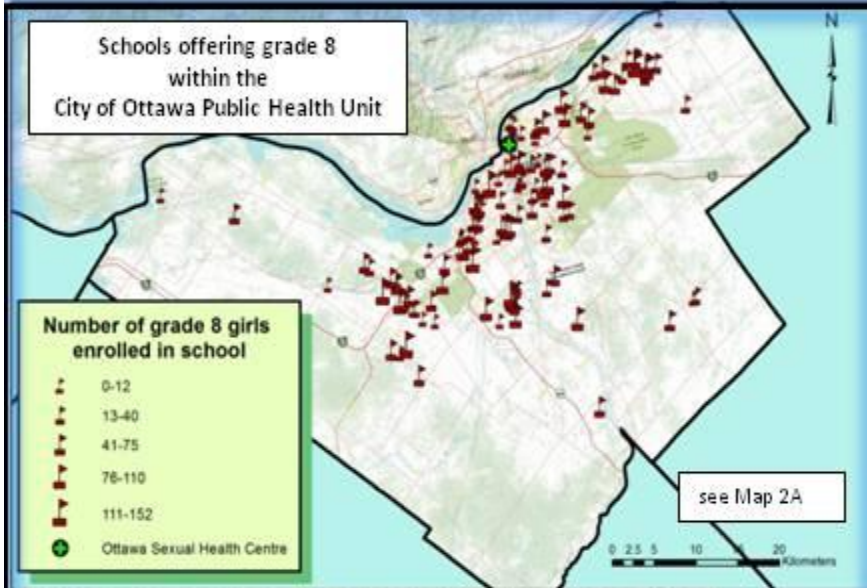
*Timing*

It took respondents from 3-11 minutes to complete the questions pertaining to each map. Time spent did not appear to depend upon the age or HPV-related knowledge of respondents but rather on person styles of thinking; some respondents provided answers immediately, while others preferred to digest details in the map before responding.

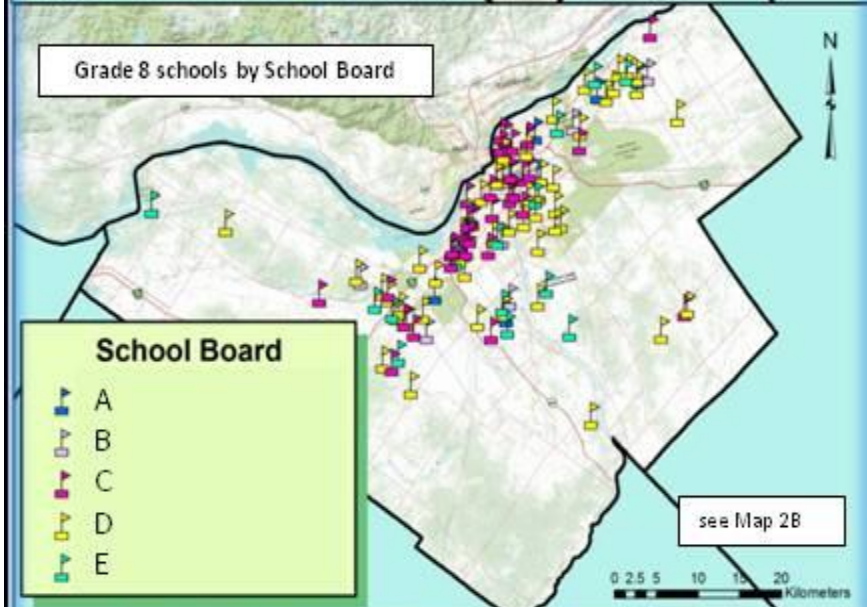
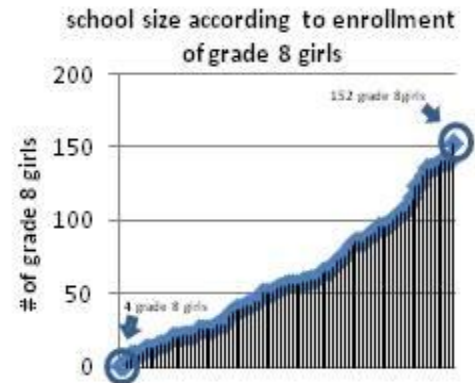
# HPV Vaccination Coverage in Ontario School-based programs, by Public Health Unit: 2007/08 & 2008/09 School Years



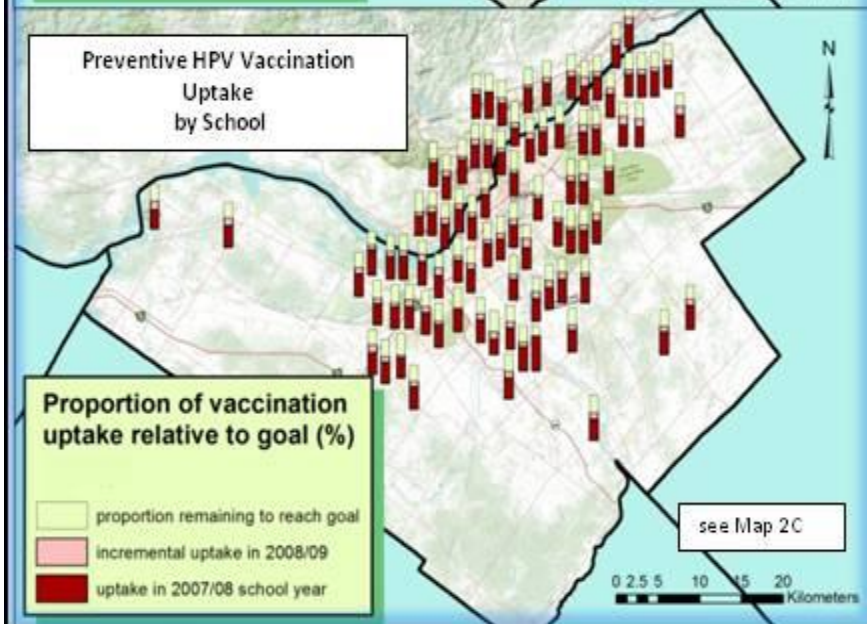
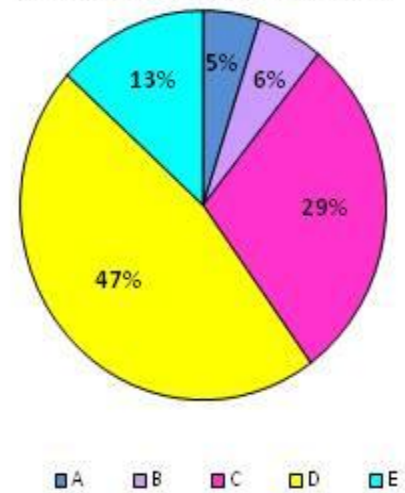
# School-based Preventive HPV Vaccination Program: City of Ottawa Public Health Unit



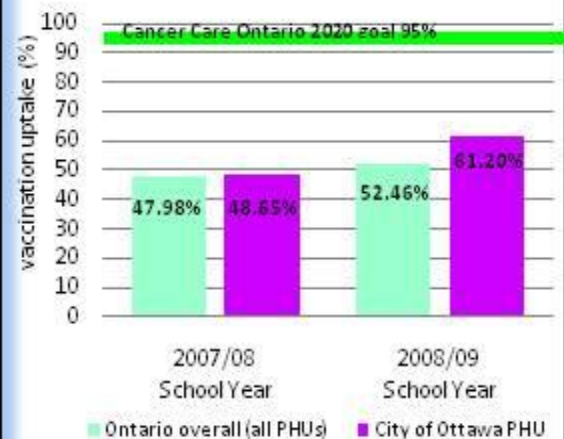
Total number of schools: 120  
Total number of grade 8 girls: 5418



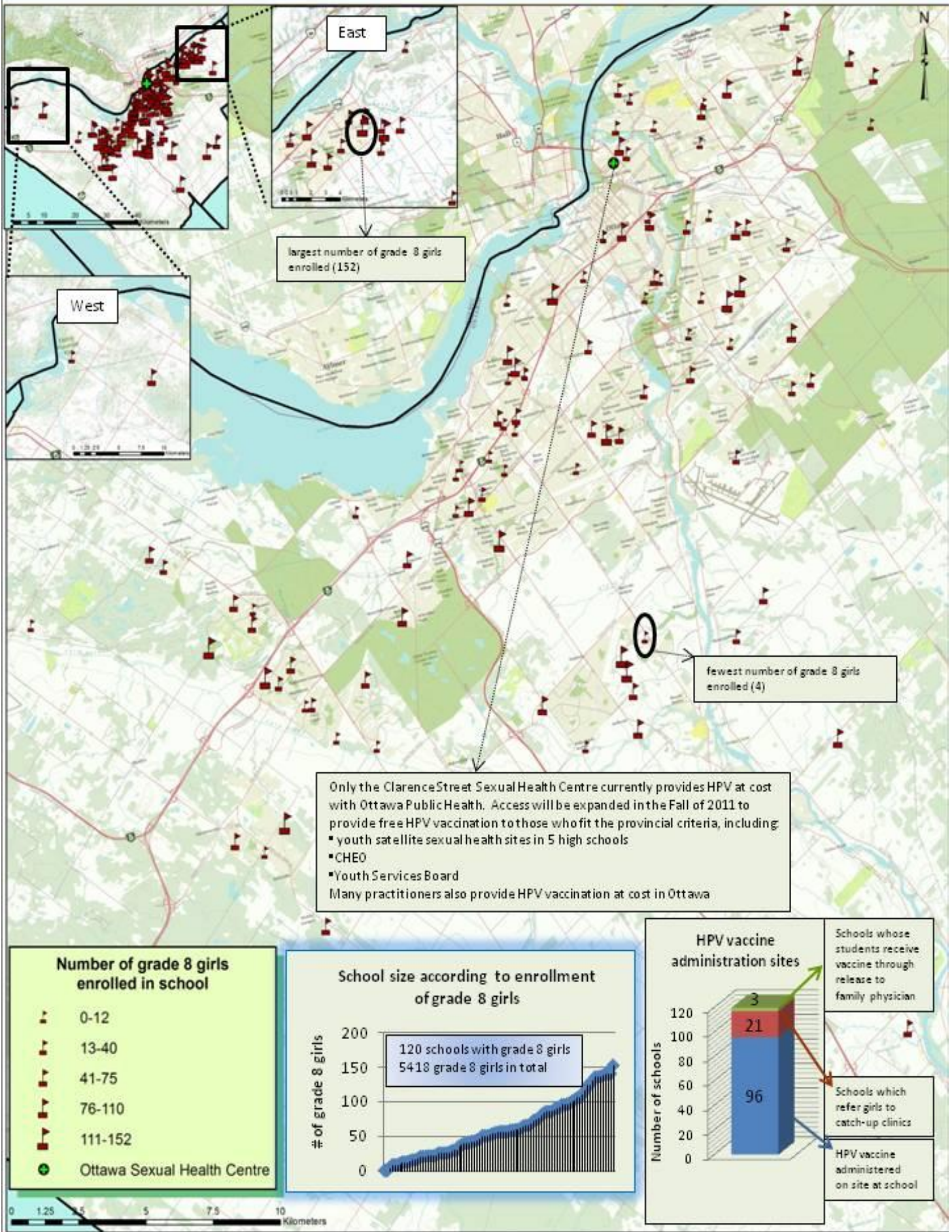
Proportion of schools by School Board



HPV vaccine uptake  
City of Ottawa Public Health Unit (PHU)  
compared to Provincial average

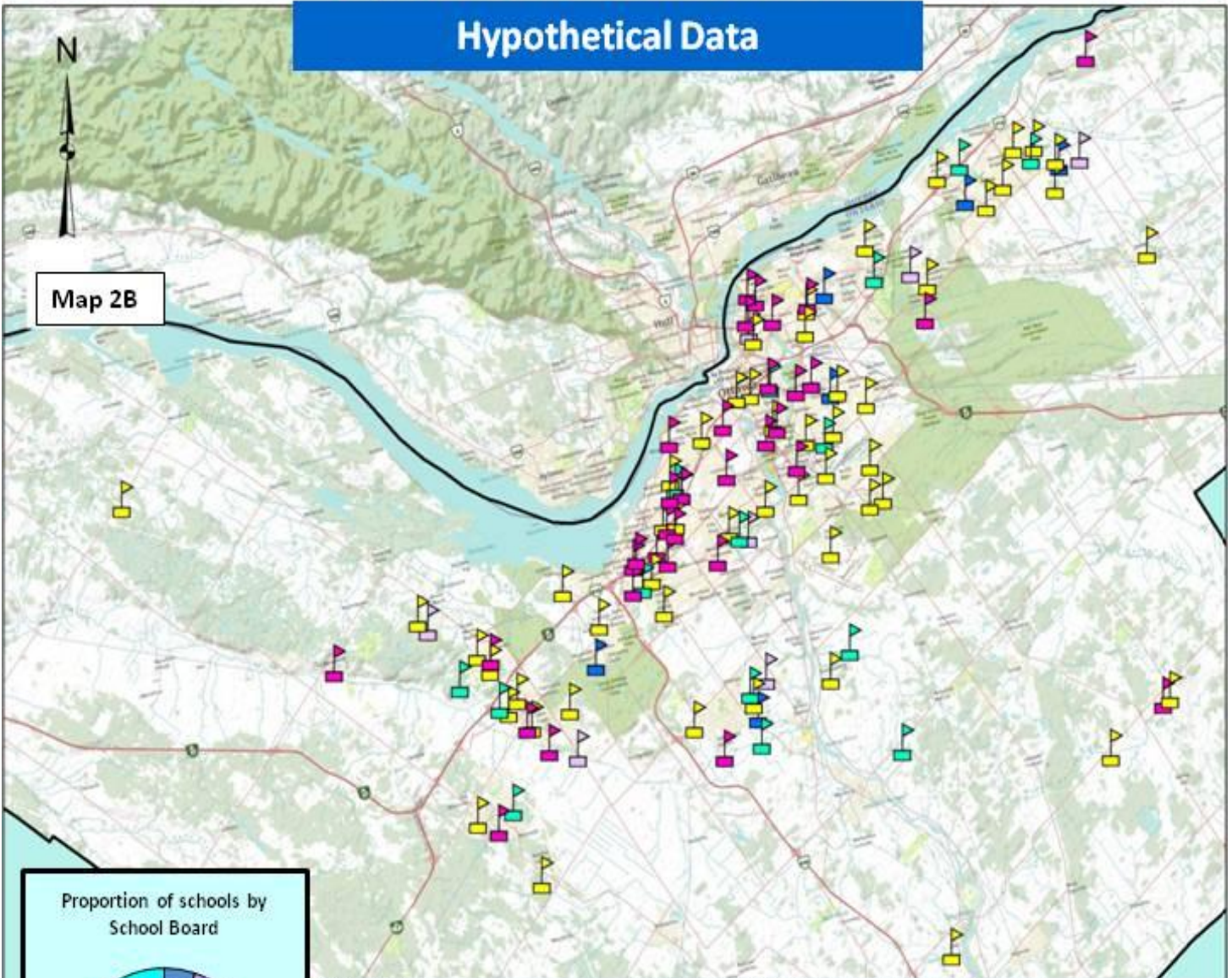


# Schools offering grade 8 in the City of Ottawa Public Health Unit



# HPV Vaccination Coverage by School Board City of Ottawa Public Health Unit

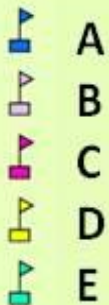
## Hypothetical Data



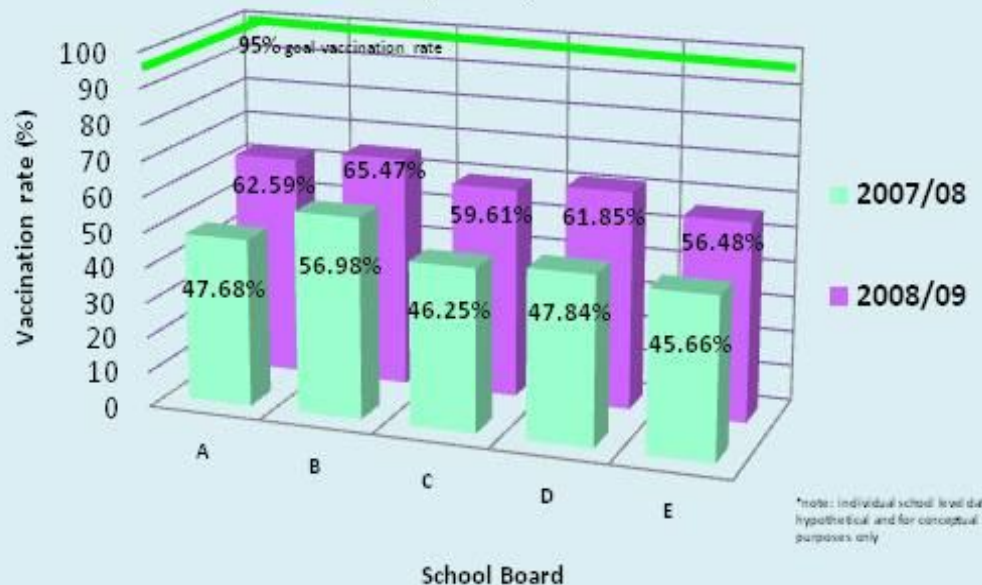
Proportion of schools by School Board



School Board



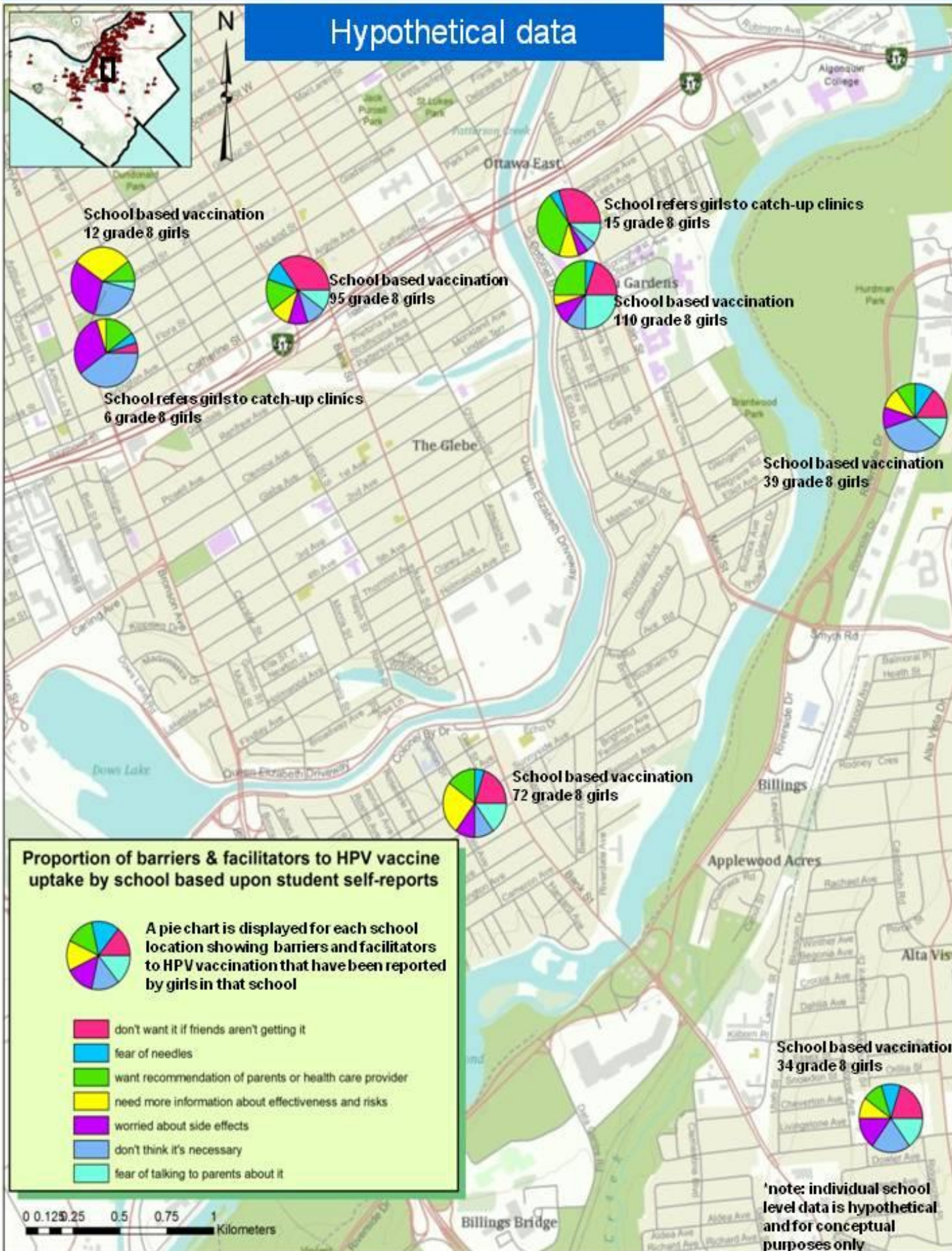
HPV vaccine uptake by School Board





# Exploring Barriers & Facilitators to Preventive HPV Vaccination in the City of Ottawa Public Health Unit

## Hypothetical data



## Comparison of data sources for HPV vaccination coverage estimates

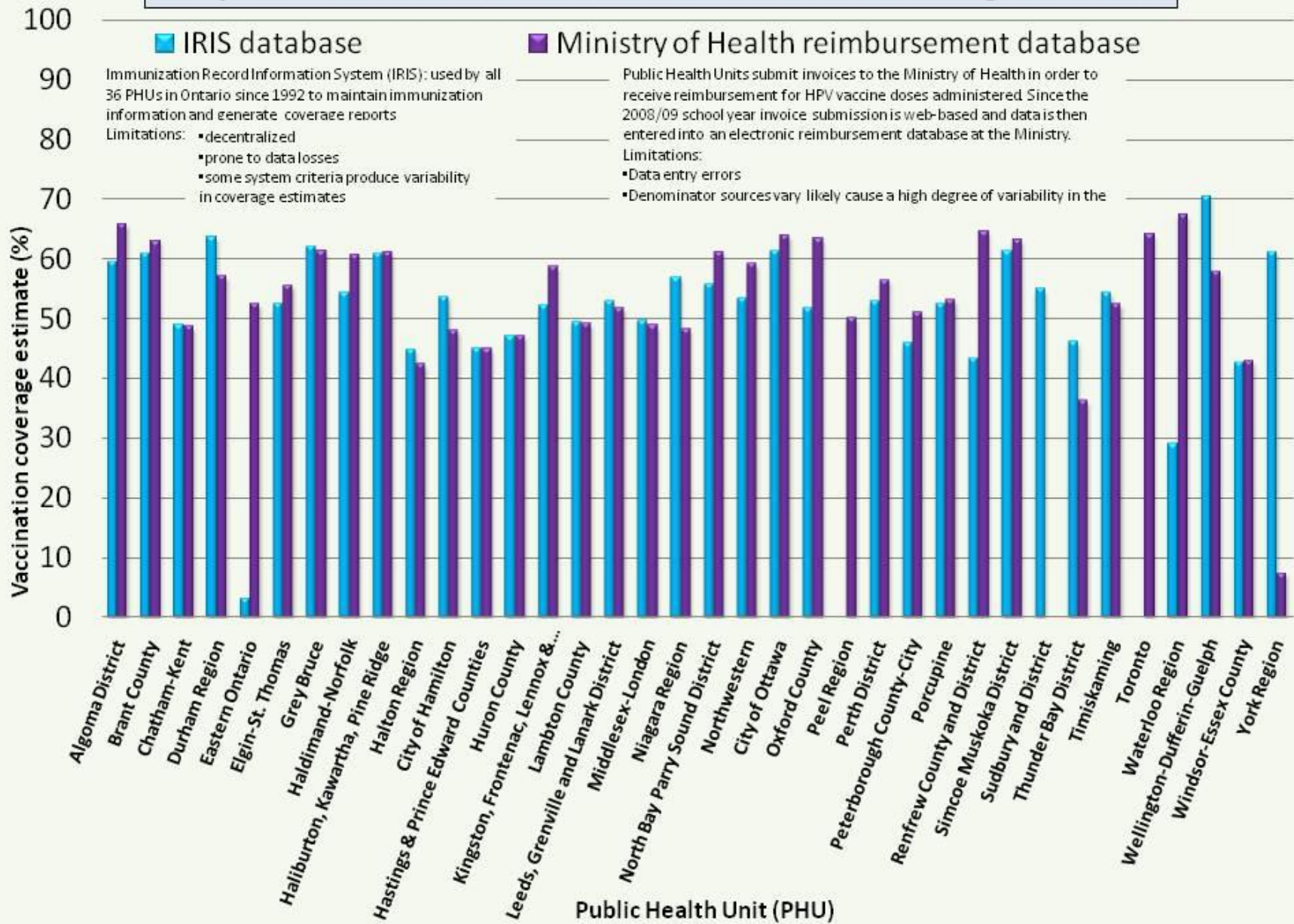


Table 11. Results of Map feedback regarding clarity, uses, and possibility for misinterpretation

	Ottawa Public Health (immunization)	School principal	School parent council member	Gynaecologic oncologist	Pharmacist	Nurse (sexual assault)	Mother (of 2 daughters)	Adolescent girl (11yrs, 10mos of age)	media
<b>Map 1. Province of Ontario Public Health Unit Map: HPV vaccination coverage</b>									
<b>Q1 open-ended question about map message</b>	Lots of red – looks like low uptake; majority of PHUs under 50%;	Unable to arrange (to be completed at a later date)	That by 2008/09 many more girls have been vaccinated	Vast majority at or below 50% of vaccination completion then dramatic change the next year (increased uptake)	That the map goes from red to gold which is an improvement and I see the 2 circles with the overall percentages	Unable to arrange (to be completed at a later date)	Increase in vaccination between years	I can see the goal	Unable to arrange (to be completed at a later date)
<b>Q2 which school year had higher coverage</b>	2008/09		Answered above	Answered above	2008/09		Answered above	2008/09	
<b>Q3 have we reached goal in Ontario</b>	No		No	No	No		No	No	
<b>Q4 perceived use to your representative group</b>	A quick visual for business (specific role) cases to know what's happening in other PHUs		Not really	Yes. Not in practice but important to know what's going on in the province	Yes I think we should be aware of this information if we are going to advise patients about it		I would want to see what the goal is, it's nice to see the movement	Ya – I get to know how many girls are getting it now	
<b>Q5 perceived use for others</b>	Other health units for ranking and to know where each stands; tool for communicating with school boards; good for partner comparisons (ie neighbouring PHUs etc)		People who would probably get the vaccine but aren't sure if it's widely accepted yet	Family doctors, paediatricians, Gynaecologists	Public health and government so they can see if there is a problem		Mothers, health care professional in the related area	My friends or kinds that are going to get it that haven't yet	
<b>Q6 possibility of misinterpretation</b>	No		It makes it look like there has been a lot of improvement but really there has not been	No it's clear	The bar graphs are a bit difficult to interpret because there is no label on the x axis		No it 's factual	The number of Public Health Units – I don't really get that too much	
<b>Q7 comments/questions</b>	Still requires a while to process info		no	It would be useful if it was possible to get close up (zoom in or blow up the southern region)	No		Maps above make it look like a bigger increase than the actual numbers (only a 4% increase)	Why is there no data for some	
<b>Time</b>	4 minutes		3 minutes	5 minutes	4 minutes		5 minutes	5 minutes	
<b>Interviewer notes</b>				Upper maps appear to give the impression of substantial improvement but after looking at all aspects of the map the overall expression was that uptake is poor				Had to re-phase some questions; asked what misinterpreted meant	
<b>Map 2B. Schools by School Board ; Vaccine Coverage by School Board</b>									
<b>Q1 open-ended question about map message</b>	Pie tells breakdown of school boards and trend in uptake by school board; geographical spread is interesting and may reveal trends		D seems to have the highest uptake of the vaccine	All school boards had better uptake in 2008/09; school board B highest	That there are 5 school boards and where they are located in Ottawa		All school boards; distribution; every school board had an increase	I see the colours I think it's trying to show how many schools there are that get it	
<b>Q2 number of School Boards</b>	5		5	5	5		5	5	

	Ottawa Public Health (immunization)	School principal	School parent council member	Gynaecologic oncologist	Pharmacist	Nurse (sexual assault)	Mother (of 2 daughters)	Adolescent girl (11yrs, 10mos of age)	media
<b>Q3 difference in vaccination between School Boards</b>	All increased 2 <sup>nd</sup> yr; about 11% spread between school boards then 9% second yr; and a long way to go to reach goals		Pretty close to the same	similar	They all look about the same		B seems a bit higher; all pretty much the same but all have increased in the second year	Different. Because graph shows 5%, 13% etc	
<b>Q4 perceived use to your representative group</b>	Have info already but it gives a nice visual for concepts and comparisons		No	No	Not really		Not so much but some parents may want to be aware if their school board is up to par	No	
<b>Q5 perceived use for others</b>	Useful to people unfamiliar with Ottawa; public		Health statisticians;	Medical Officer of Health Public health nurses too (I suppose)	I think the School Boards should know that information		School boards; health departments;	Adults like people giving the vaccine	
<b>Q6 possibility of misinterpretation</b>	Would want it dynamic because hard to hone in on details of interest;		The legend on the graph seems backwards	No	No		Colours used for uptake bars are the same as some of the colours used for the school boards	No	
<b>Q7 comments/questions</b>	Too sensitive to provide info by school board; they don't want to be shown in a poor light			No	No		No	no	
<b>Time</b>	5 minutes		5 minutes	4 minutes	4 minutes		8 minutes	5 minutes	
<b>Interviewer notes</b>	Risk tolerance for issues of disparity; policy and councilors(political) want to stay far away from it							Misinterpreted the differences in vaccination rate for the distribution of School Boards; asked what uptake means	
<b>Map 2C. Preventive HPV vaccine uptake by school</b>									
<b>Q1 open-ended question about map message</b>	Uptake by school		Appears that we are only half way to our goals in almost every school	Each school and what uptake is – where we are and the shortfall in reaching goal	How the different schools compare for the vaccination		Showing a fair amount left to reach goal in all the schools	Shows how much we have left to get to goal	
<b>Q2 what does each bar show</b>	Uptake, increment, remaining needed to reach goal		Uptake 07, increase in 08, and then how far we have to go to get to our goal	Uptake in 2007 year and then increment in 2008, and the shortfall; quantitatively shows what's been achieved and what needs to be gained	The exact vaccination at each school		Each bar is a school and it shows the uptake in the first year, then how much more was achieved in the second year and how much more needed to reach goal	Respondent read the legend but did not interpret it	
<b>Q3 what determines the location of each bar</b>	Not initially clear that each bar is a school (because identifiers removed)		Where the school is	School	Where the school is located		The school	That's where the schools are	
<b>Q4 has any school on map reached goal</b>	No		No	No	No		No	No – that would mean that the bar would be full	

	Ottawa Public Health (immunization)	School principal	School parent council member	Gynaecologic oncologist	Pharmacist	Nurse (sexual assault)	Mother (of 2 daughters)	Adolescent girl (11yrs, 10mos of age)	media
<b>Q5 perceived use to your representative group</b>	Definitely; could use to plan and identify problem areas so needs can be addressed		If our school is way below goal why should we continue to pressure apply pressure for kids to get it	Yes. Good to know but would not change my day to day role	That much detail is probably not needed for what I do		Makes me interested in the goal and why aren't we increasing more	Sort of – because girls might want to know what percent have got it. Like if less than half got it they wouldn't want to get it, but if more than half got they probably would get it	
<b>Q6 perceived use for others</b>	Planning for sexual health; low areas may signal other STI and sexual health issues in the area thus reveal where to set up satellites; tying it in with other GIS initiatives at the city planning level		Health professionals; policy-makers;	Public Health, schools	The schools;		Individual schools; health departments; cancer care Ontario; and who is responsible for getting this message out – I would expect them to know this data	Health teachers so they could tell their students about it in health class; and parents might want to know if their child is making the right decision	
<b>Q7 possibility of misinterpretation</b>	Looks as though it involves Quebec schools as well due to bar placement on inset map		No	The green cross	The numbers under the bars – don't know what they are for		No	Not really	
<b>Q8 questions/comments</b>	Sensitive information – may not to foster a positive drive for improvement but rather a sense of singling schools out; would be more useful if dynamic			Comparing - each school could see how they are doing and could have rewards for reaching goals (if ethical)			Don't display the sexual health centre if you are not going to talk about it at all	What does incremental mean?; what does that little map in the corner mean	
<b>Time</b>	4 minutes		4 minutes	5 minutes	3 minutes		11 minutes	7 minutes	
<b>Interviewer notes</b>	Sensitivity raised as an issue again						Some of the map font may be too small to read	Didn't understand the purpose of the inset map but said it made sense when explained	
<b>Map 3. Exploring Barriers to HPV Vaccine Uptake by School: City of Ottawa Public Health Unit</b>									
<b>Q1 open-ended question about map message</b>	Changes in barriers depending on school		Best map because it shows true barriers from the people who are actually supposed to get the vaccine	Shows why the uptake is low	The reason girls might not get vaccinated at each school		Some of the map font may be too small to read	Showing in school areas which pieces of the pie – like how many girls have the most different amount of reasons for not getting it	
<b>Q2 what does each pie chart represent</b>	Breakdown of issues at schools		Breakdown of reasons for not getting the vaccine	At a school reasons barriers and to HPV vaccine uptake by what the students say	A breakdown of the reasons students at the school aren't getting the vaccine		A school	Reasons for not getting it and why	
<b>Q3 one reason a girl might not want vaccine</b>	Don't think it's necessary		Need more information about effectiveness and risks	If her friends don't want it	Worried about side effects		Don't want to get it if my friends aren't getting it	Fear of needles	

	Ottawa Public Health (immunization)	School principal	School parent council member	Gynaecologic oncologist	Pharmacist	Nurse (sexual assault)	Mother (of 2 daughters)	Adolescent girl (11yrs, 10mos of age)	media
<b>Q4 perceived use to your representative group</b>	Needs in specific communities; schools close by one another with same barriers sends an alert that maybe there is a community based issue that needs to be addressed		Yes. So I know the barriers to vaccination for the girls and we can then look into why we should push girls to get it if there are too many barriers	Yes. For education; and patients may need to hear from us about some of the barriers; and the message delivered needs to be consistent	I don't think I need to know the exact information for each school but I would like to know what the barriers are – maybe we can help with things like the side effects		Interesting to know what the girls are thinking; can help get different messages out to the different communities	Yes – we want to know how many girls actually have that problem because it might help us in getting through the problem and then a girl might have less of a problem getting it	
<b>Q5 perceived use for others</b>	Public health; schools		Front line health educators; health educators in schools	Paediatricians General practioners	Schools should know; and whoever gives the vaccine		Public health; schools; cancer care Ontario;	Principals – to know why the girls aren't getting it so they can help the girls; and nurses	
<b>Q6 possibility of misinterpretation</b>	No		No	No	No it's very clear		No	No	
<b>Q7 comments/questions</b>	Best map; like pie charts for showing info		Best map	Good map	I like the colours		No	No	
<b>Time</b>	5 minutes		4 minutes	5 minutes	4 minutes		8 minutes	6 minutes	
<b>Interviewer notes</b>	Respondent liked this map best and felt it had many applications							Asked for clarification if the pie charts represent where the schools are	

## 4.4 Discussion

Poor uptake of preventive HPV vaccination among adolescent girls is an important public health concern. To date, population-based HPV vaccination coverage has been suboptimal in most Canadian jurisdictions with Ontario's vaccine uptake situated among the lowest. There is a need to improve vaccine uptake among adolescent girls. To garner success, ongoing monitoring of HPV vaccine uptake and the effectiveness of health promotion programs is needed. Policy, research, health care, and education sectors, as well as the views of adolescents and others have not been effectively brought together by any means. GIS holds considerable potential to foster communication and link key sectors in the quest toward a common goal.

In this chapter of the thesis, the utility of GIS for communicating health information related to HPV vaccine implementation was examined. GIS was applied to create a series of maps intended to communicate provincial and local preventive HPV vaccination coverage and implementation information. The map depicting provincial vaccination coverage demonstrates that over the first two years of the school-based HPV vaccination program, vaccination coverage across the 36 Public Health Units (PHUs) in Ontario was suboptimal at around 50%. The 4.5% gain in coverage in the second year was small but did move the majority of PHUs into a higher vaccination category (50-80%) defined according to a WHO standard for vaccination surveillance. Visually, this resulted in a substantial colour change on the inset maps. A supplementary bar graph displayed individual PHU vaccine uptake in relation to a visually emphasized vaccination goal. Overall this map emphasized 1) HPV vaccination uptake is around 50% for the province of Ontario 2) vaccination uptake is similar across PHUs 3) vaccination uptake improved; though only marginally between the two school years, and 4) vaccination uptake is only about half way to a defined goal. A second, dynamic map was created to depict the demographic features of the population-based vaccination program implemented in the City of Ottawa Public

Health Unit. This map visually emphasized the geographic distribution of schools with grade 8 girls. Map symbology was applied to depict school size according to the number of enrolled grade 8 girls. The map also communicated the location of non school-based settings where vaccination may be obtained. The dynamic features of the map permit users to zoom in on individual schools in order to access further school-specific information. Subsequently, three additional maps were created to conceptually depict how GIS could be used to convey geospatially relevant vaccination uptake information. Hypothetical data was used to illustrate concepts. One map was designed to illustrate how HPV vaccination uptake information could be presented by School Board. A second map portrayed vaccine uptake at the individual school level and in relation to vaccination goals. A third map was created to depict a conceptual model for communicating barriers and facilitators to HPV vaccination at the individual school level.

To ensure that map designs are able to communicate the intended messages, testing with representatives of the intended audience is recommended. Informal testing with stakeholder representatives was selected as the initial means of obtaining feedback regarding the proposed use of GIS for communicating HPV vaccination messages. A small stakeholder audience was selected that included a public health immunization representative, a school principal, a school parent council member, a specialist physician in gynaecologic cancer, a pharmacist, a nurse from a sexual assault centre, a mother of 2 daughters, a media representative, and an adolescent girl (feedback from the school principal, sexual assault nurse, and media representative were not obtained due to availability issues). Overall, information presented in the maps tended to register with audiences more readily than messages in charts and graphs. This seems to be in agreement with literature suggesting that simplifying the presentation of statistical information can improve understanding. Visual messages associated with colour were also noted more readily by respondents. However, this did not necessarily imply accuracy of interpretation. For example, when interpreting Map 1 all

respondents commented first on the colour change between the companion maps and felt there had been a substantial improvement in provincial vaccine uptake between years because the maps went from being primarily red to being primarily yellow. The actual percentage values of provincial vaccine uptake were only subsequently noted, despite also being prominently featured on the map layout. Thus, map messages delivered using visual cues, such as colour coding, seem to send a strong visual message and may even overemphasize messages, potentially causing readers to be misled.

Respondent feedback regarding Map 2A yielded some important advice with respect to visual presentation and content. Visually, some overlapping colour choices were a source of confusion and from a content perspective, the information communicated seemed too far removed from the situation and influence of most respondents. Because school officials may be influential, future map testing should include representatives from the education sector, including School Boards to incorporate their unique perspectives. The message in Map 2B was displayed using a bar graph for each school which represented the individual school's vaccine uptake, the incremental gain in uptake in the second year of the program, and the gain the school still required in order to meet the provincial goal. Communication of the messages in this map was limited by the absence of school identifiers, a lack of explanatory text about how the information might be used, and the inability of respondents to explore the dynamic features of the map which convey additional school-specific details.

Map 3 received the most positive feedback from respondents, both for its visual appeal and for its content. Respondents generally preferred pie graphs to bar graphs and found them easier to interpret. In terms of the content, respondents seemed to connect with the communication about barriers to HPV vaccine uptake both from an interest and action perspective. The information seemed to have broad and meaningful uses among all stakeholder audiences and inspired many messages about collaboration. A key strategy for ensuring the success of

dissemination efforts involves identifying with stakeholders; audience representatives felt that this map represented a good communication tool for collaborating across sectors. For example, upon noting a trend among schools in a particular community, the public health representative commented that the information could be particularly useful in planning targeted health promotion interventions specific to that community's needs.

Occasionally, the intended message of the maps was lost. For example, the school parent council member seemed to conclude that because uptake was so low and there seemed to be so many barriers, the information should be used as evidence that girls do not really want the vaccine and should not be pressured to receive it. This provided valuable insight into realizing that presented information can be received in different ways and that pre-existing views may be important factors in framing the interpretation of various audiences regardless of intentions. In this particular instance the respondent's interpretation had the potential to be used in ways counter to health promotion efforts related to HPV vaccination.

An unexpected finding from map testing was the tendency for respondents to define uses for specific stakeholder groups that were framed by their own roles and work. For example, the physician respondent tended to recommend use by other physician groups, the public health representative tended to see uses for other public health personnel, mothers thought other mothers would want to know, and the adolescent girl thought her friends might find the information interesting. This noteworthy finding lends support to the approach of including multiple levels of stakeholders in research and policy planning.

Several limitations must be taken into account when considering the value of GIS as a modality to support health promotion communication and planning for HPV vaccination. First, the value of the communicated messages relies on the quality of the underlying data. In Ontario, data sources for immunization coverage are subject to many limitations. The IRIS software that is used to capture coverage

information is decentralized and prone to data losses and variability in coverage estimates. Consequently, some Public Health Units have not consistently submitted coverage information and this has led to gaps in the data. Also, because each Public Health Unit is responsible to input their own information there is a high degree of variability in the denominator figures submitted which can also adversely impact data quality. For example, some PHUs use census data to estimate the number of girls eligible for vaccination while others use school enrollment figures.

Notwithstanding data quality, messages communicated using GIS maps may be misinterpreted. Unsuitable use of colour and symbology, audience biases, and audience knowledge and experience all affected the way in which messages were received in this examination of GIS uses. For instance, in the map of provincial vaccination coverage northern public health units were very large compared to the smaller but more populated public health units in the southeastern part of the province. Efforts to distort the maps to better reflect population numbers may be less misleading to readers. Map testing with representative audiences and the use of interactive maps which permit users to explore the data in greater detail are ways to minimize the risk of misinterpretation.

Privacy and confidentiality are a further concern limiting detailed data reporting. Personal health information is sensitive information and is protected by governing privacy legislation and ethical standards. Particularly when dealing with small denominators such as numbers of vaccine eligible girls at individual schools, communicating health information can become untenable.

Politics, too, play a central role in health policy and motivating factors do not appear to always be health related. The public health respondent drew attention to the fact that it would likely be considered too sensitive to report vaccine uptake information specific to School Boards or individual schools. Highlighting

disparities may be seen to cast certain schools or Boards in poor light; a situation policy-makers and political councilors want to avoid.

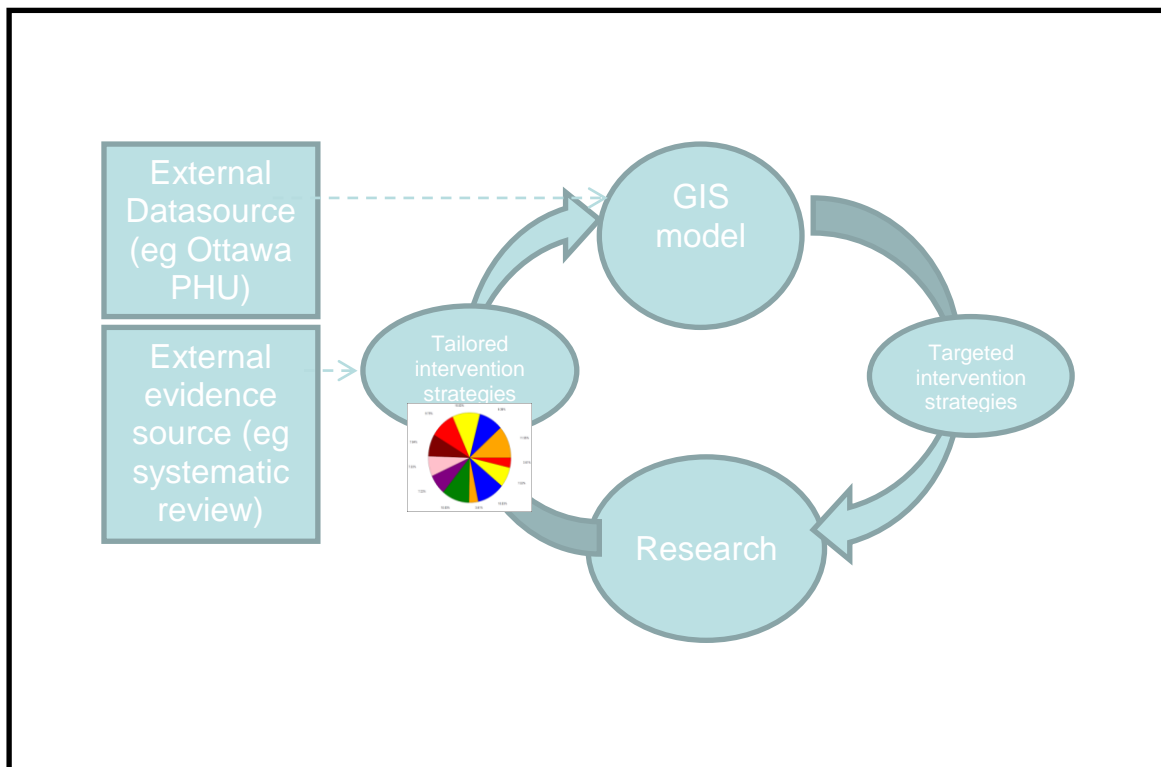
Despite its limitations, GIS may have broad applications in health promotion applied to HPV vaccination. There is clear potential to apply GIS for monitoring and communicating HPV vaccine uptake information over time. Additionally, GIS may provide dynamic and relational communication support for a more comprehensive program designed to raise awareness and understanding of the health problem, transfer research finding to users effectively, inform intervention design, stimulate and support new research ideas, and communicate outcomes.

Figure 4 illustrates how elements may be linked conceptually to incorporate GIS as the communication system to drive the informing-enhancing dynamics of a relationship between research and program development. The model is iterative in nature and committed to the ongoing progress toward a goal of improving HPV vaccine uptake among adolescent girls, and thus the health of women. It is also a collaborative model and enables multidisciplinary inputs.

Considering the elements in the thesis, the first iteration of the model could draw on data from two external sources: population-based vaccination uptake data for the City of Ottawa Public Health Unit and the results of a systematic review of self-reported barriers and facilitators to HPV vaccination among adolescent girls. This could lead to two initial outputs: communication of vaccination coverage information using GIS as demonstrated in this chapter of the thesis, and the creation of a tailored intervention for adolescent girls designed to address personal barriers to vaccination (see *Healthy Me* in Chapter 5). The tailored intervention itself could have a simultaneous research purpose by being designed to also capture data from users concerning barriers and facilitators to vaccination. These data, combined with new research findings from the literature, such as the contribution of evidence from further Canadian studies and from qualitative studies, could be used to enhance the tailored intervention tool over

time. GIS could then communicate back updated vaccination uptake information. And, if linked with school health education curriculums, in order to encourage use, the tailored intervention could provide information from the ongoing capture of school-specific data that could also be communicated using GIS. In this way the concept of communicating school-specific barriers to vaccination as illustrated in Map 3 could become a reality. Schools could then view locally relevant information that could be used to plan targeted interventions focused on addressing the predominant barriers within their own school. This would further allow teachers, students, and parents to become involved in health promotion for HPV vaccination. As well, if privacy is an overriding concern, access to certain school-level information could be restricted to the individual schools. Furthermore, if the call for more Canadian and qualitative research yields further studies of self-reported barriers and facilitators to HPV vaccination, a subsequent update of the systematic review, as presented in Chapter 3 of the thesis, could

Figure 4. GIS model for linking health research and program planning in the promotion of preventive HPV vaccination



supply a sufficient body of quality Canadian evidence to inform the design of targeted and community-level interventions for HPV vaccine promotion. GIS could continue to communicate trends in HPV vaccination uptake yet could also be used to communicate other program successes; for example, how initially identified predominant barriers are overcome with time and effective targeted intervention.

It would be a challenge to make such a model work in real time, but with committed policy support and broad stakeholder involvement it would have the potential to be a true community success.

#### 4.5 Additional opportunities for HPV and GIS

In the future it will be increasingly possible to link together health information from many data sources. This will provide additional opportunities to apply GIS to HPV vaccination initiatives such as looking for spatial associations that can confirm the impact of vaccination.

Some examples are as follows:

##### *Pap test rates*

With the ability to obtain more reliable data, it may be possible to investigate whether a relationship exists between areas of low Pap test screening and low HPV vaccine uptake. This would have the potential to identify a population of women at high risk for developing cervical cancer despite the availability of both primary and secondary prevention options. For example, Pap test data was obtained from a 2001 comparison of Pap test rates across Ontario and displayed on top of the HPV coverage rates for the province. In this application it was possible to see if areas of low screening overlap with areas of low vaccine uptake. Though conceptually interesting, conclusions are considerably limited by the quality of the data used.

GIS could also be used to examine the relationship between HPV vaccination and changes in the burden of HPV-associated disease such as the spatial association between HPV vaccination uptake and observed decreases in abnormal Pap test results.

#### *Cervical cancer prevalence and incidence*

Similarly, it may be possible to use information about cervical cancer incidence and prevalence to investigate relationships with HPV vaccination. Vaccine uptake could be displayed on a background of cervical cancer cases to detect any correlation between areas of low vaccine uptake and areas of cervical cancer incidence or prevalence. Of course, this would involve making inferences about the relationship between the girls getting vaccinated and the women developing cervical cancer but there may well be community level effects involved.

## 4.6 Conclusion

GIS is a novel means of monitoring and communicating HPV vaccine uptake information that is linked to geographic location. Through the use of maps, vaccination information can be conveyed in a way that is easily understood and usable by a broad range of potential audiences. The dynamic aspects of GIS may further enhance understanding by encouraging user exploration of map details such as the demographic features of distinct populations.

In this appraisal of GIS, the maps produced were able to convey information related to population-based preventive HPV vaccine uptake among adolescent school girls in the City of Ottawa Public Health Unit. Representatives from key stakeholder audiences provided feedback on the maps regarding message comprehension and perceived uses for the communicated information. Stakeholders also expressed a common willingness to collaborate across sectors to improve health. Some revisions to the maps are recommended with respect to

map layout, symbology, colour choices, and supplementary information. Subsequent formal usability testing is recommended.

GIS has substantial potential for linking stakeholder audiences, supporting research and program development over time, and communicating outcomes. As such, a model to incorporate GIS into HPV vaccination program planning was proposed. The potential for GIS applications to HPV vaccine health promotion will further develop with the availability of improved data sources.

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## 5.0 Health policy recommendations for preventive HPV vaccination among adolescent girls in an Ontario public health unit: a roadmap for the future

In this chapter of the thesis 4 key next steps to developing HPV-related health policy are discussed: 1) the importance of defining principles to guide HPV vaccine policy development; 2) the need for a qualitative study to provide a deeper and more thorough understanding of preventive HPV vaccination decision-making among adolescent girls in the Canadian context; 3) the development of a tailored intervention to assist a diversity of adolescent girls with preventive HPV vaccine decision-making; 4) the value of a model to support health policy planning and promotion of preventive HPV vaccination among adolescent girls.

The following ideas related to preventive HPV vaccine health promotion planning and research are proposed as a logical extension of developments in the field framed by solid guiding principles. The aim is to pull prominent concepts together into a roadmap for moving forward.

### 5.1 Developments and guiding principles

In June of 2006, when the first preventive human papillomavirus (HPV) vaccine was approved, cervical cancer became a vaccine-preventable disease. Through research that had commenced in the 1980s it became established that this sexually transmitted virus was causally linked to cervical cancer.<sup>23</sup> By early 2007 the vaccine had been approved in 80 countries worldwide. In Canada, the National Advisory Committee on Immunization issued an official report in February of 2007<sup>6</sup> which included recommendations stating that it was most advantageous to administer the vaccine to adolescent girls prior to sexual debut,

and by the start of the school year in 2007, Ontario had a program in place to offer the vaccine free of charge to all grade 8 school girls.

The haste, with which this new innovation appeared to be advancing in Canada, engendered a sense of widespread uncertainty and skepticism. There was conflicting and negative reaction from both the professional community and the media.<sup>123,124</sup> A clear and consistent plan had not been established in advance for the delivery of positive messages to promote the HPV vaccine and, consequently, less than half of eligible girls received the vaccine in the first year of the school-based program in Ontario.<sup>52</sup> Introducing new interventions before they are ready is a common dissemination mistake.<sup>79</sup> It is interesting to contrast the Canadian experience with what happened in Australia where an Australian doctor, who was credited with the discovery of the HPV vaccine, had been awarded Australian of the year in 2006. Following this, when the HPV vaccine became available, Australians were celebrating a national hero and the vaccine was viewed as a medical and scientific breakthrough. Subsequent vaccine uptake of over 70% was achieved in the first year of their school-based program and the Cancer Council of Victoria has more recently reported, “Unprecedented cervical cancer vaccine uptake”.<sup>125,126</sup>

In Ontario, HPV vaccine uptake remains suboptimal. In the first 2 years of the population-based program, provincial vaccination coverage increased by only 4.5%, from 48% to 52.5%.<sup>52</sup> There is a need for intervention. Improvements in vaccination coverage have great potential to positively impact the health of adolescents. Yet establishing effective interventions depends upon an understanding of the types of interventions adolescents themselves would view as necessary and acceptable. It is first important to gain a more complete understanding of factors which arbitrate in the decision-making process among adolescents. The systematic review reported in Chapter 3 of this thesis<sup>122</sup> has assembled known barriers and facilitators to HPV vaccination from the viewpoint of intended young female vaccine recipients. However, the review has also

revealed a gap in our current understanding of factors which mediate in HPV vaccination decisions that are relevant to a Canadian adolescent population. An additional concern is that little attention has been paid to adolescent participation in vaccination decision-making. Only one study was found that examined this issue.<sup>18</sup> Among girls at a private all-girls school and a public co-educational high school in California, 48.4% had participated in the decision about whether or not to receive the vaccine. Participation in the decision to receive the vaccine was more common than participation in the decision not to receive the vaccine (39.2% vs 9.2%) suggesting that views against vaccination may be obstructive to open dialogue about the relative benefits and risks. There was no corresponding investigation of the girls' desire to have been involved in the decision.

The United Nations Convention on the Rights of the Child, professional societies, and current Canadian laws respectively obligate, support, and impose no barrier to adolescent participation and their ability to provide consent for medical interventions. Yet we do not even know if adolescents are involved in the decision to become vaccinated against HPV. Nor do we have evidence regarding their desire to be involved. We do know, however, that most are likely capable of making a decision. In an empirical study designed to evaluate competency for making informed treatment decisions, assessed according to legal standards, 14 year olds were found to be as competent as adults.<sup>59</sup> The authors concluded that, "The findings [...] do not lend support to policies which deny adolescents the right to self-determination in treatment situations on the basis of a presumption of incapacity to provide informed consent." Interestingly, this study was published in 1982 and it does not appear that the idea was carried forward or substantiated by additional research. The current consent document for HPV vaccination used by Ottawa Public Health is addressed to parents and requires their signed consent; no reference is made to including daughters in the decision-making process. Furthermore, it should be emphasized that an adolescent girl may wish to apply her right to participate in several ways, including deferring the decision to a parent, establishing a consensus involving parents and health care providers,

making the decision backed by parental support, or by making the decision independently.<sup>18</sup>

There is a clear gap in our understanding of the salient issues related to HPV vaccine decision-making, particularly in the context of adolescent-perceived barriers and facilitators to uptake and adolescent participation in vaccination decisions. Dissemination of innovation theory advises of the need to understand and take into account the perceptions of intended recipients: who and what influences their decisions; the diversity of target populations; and the need for a range of solutions to meet individual needs. Research concerning the views of intended recipients of health care interventions is integral to successful health policy.<sup>127</sup>

Successful health policy and programs are also more likely when derived from a sound theoretical basis. Theories of health behaviour and their constituent constructs are instrumental for gaining insight into real or potential successes and failures related to health service planning and implementation. Unfortunately, theoretical constructs and frameworks relevant to the implementation of vaccination among adolescent populations have not been established and this is a fundamentally important step that must not be passed over with respect to HPV vaccination.

From a health policy perspective, there is a need to clearly affirm guiding principles for moving forward. Accordingly, established health behaviour theories and international ethical principles should be selected as the constituent elements to underpin preventive HPV vaccine program development.

## 5.2 Outline for a qualitative study of self-reported barriers, facilitators, and participation in decision-making related to preventive HPV vaccination among adolescent girls

From an adolescent health policy perspective, suitable consideration of adolescent views may improve the chances of program success. As revealed by the work presented in this thesis, there is a need for a broader and deeper understanding of barriers and facilitators to preventive HPV vaccination from the viewpoint of intended adolescent recipients. The systematic review presented in Chapter 3 specifically calls for 1) more research conducted among adolescents; 2) more Canadian studies; and 3) more qualitative inquiry.

Accordingly, a qualitative study is proposed with the following main objectives:

- To determine self-reported barriers and facilitators to preventive HPV vaccination among adolescent girls
- To examine participation in HPV vaccination decision-making among adolescent girls
- To determine which theoretical constructs may be most suitable to explain adolescent health behaviours with respect to preventive HPV vaccination

### *Study design*

The study will use a qualitative research design. Qualitative inquiry is needed to complement the quantitative findings which currently predominate in the HPV vaccine acceptability literature. Integrating both quantitative and qualitative inquiry provides broad information that deepens the understanding of multifaceted issues.<sup>127</sup>

In addition, the study design will have an explicit theoretical basis and apply constructs deemed relevant to adolescent health behaviours associated with preventive HPV vaccination

The study will also involve a research team. A meta-analysis of over fifty studies on research utilization found that the single most important factor in the research process is the involvement of policy and program personnel.<sup>117</sup> Accordingly, a research team will be formed and will include representatives from key stakeholder populations including the sectors of education (teacher, principal, and/or School Board representation), health care (public health, health policy, and health professional representation), the community (parental, media representation), and users (adolescent girls themselves). Girls in grade 9 would likely be a suitable choice since they would have experience with the HPV immunization program yet still be proximal enough to recall the experience and identify with the girls. Adolescent girls have been purposefully included on the research team in order to foster improved opportunities for meaningful adolescent participation in shaping health policies which concern them.<sup>56</sup> All members of the research team will have input into the study design and investigative process. Notably, the primary investigator will deliver a presentation of the *Systematic review of self-reported barriers and facilitators to preventive HPV vaccination among adolescent girls and young women*<sup>122</sup> to familiarize the research team with the existing body of evidence and highlight research gaps and the purpose of the study. Members of the research team will also share their relevant knowledge and experience to provide a unified focus and foundation upon which to conduct the research work.

#### *Specification of research questions*

Specific research questions will include:

- What are the barriers and facilitators to HPV vaccination reported by diverse populations of adolescent girls within the City of Ottawa Public Health Unit?
- Do adolescent girls within the City of Ottawa Public Health Unit participate in the HPV vaccination decision?

- Among adolescent girls who participated in the HPV vaccination decision what was the nature of their involvement?
- Among adolescent girls who both participated and did not participate in the vaccination decision, did they wish to have participated in the decision?
- Among adolescent girls who both participated and did not participate in the vaccination decision, what type of involvement would they like (have liked) to have? What influences are important to them?
- From the self-reports of adolescent girls, descriptions of barriers and facilitators to vaccination are most suitably categorized to which theoretical constructs

#### *Study sample*

The research setting will be the City of Ottawa Public Health Unit. It will involve adolescent girls from both the school setting and non school settings.

Importantly, HPV vaccination must reach adolescent girls who do not attend school as well as those who do since girls not attending school are among those at highest risk for the health consequences of HPV. For example, 42% of sexually active street youths in British Columbia report contracting a sexually transmitted infection or becoming pregnant compared to only 12% of sexually active youths attending school and this has important implications concerning the risk of coming into contact with HPV.<sup>56</sup>

Methods for ensuring that the study population is representative of the target population will draw on what is known about the determinants of adolescent health and various geospatial factors identified in the GIS component of this thesis. Although the determinants of adolescent health have not been extensively studied, some of the important known predictors are wealth, parent relationships, school experiences, and social integration with peers.<sup>53</sup> Insofar as possible, adolescents from each end of the spectrum of these determinants will be selected to participate in the study. Likewise, as discernible from the GIS maps,

girls from large and small schools, rural and urban schools, schools with low and high vaccination uptake, and from each School Board will be included. Attempts will also be made to recruit girls from ethnically diverse populations and girls living with disabilities. As described, sampling girls not attending school will be of particular importance and they will likely be recruited from sexual health clinics in the City of Ottawa.

It is recognized that some of these recruitment factors may be difficult or too sensitive to determine for individual girls. In some instances it may be necessary to use a school's characteristics as a proxy for representation, such as selecting from an affluent private school to correspond with wealth or including a school for students with disabilities. Above all, privacy and confidentiality will need to be explicitly respected and the final study design will need to be flexible to accommodate this. It is likely that school principals will be called upon to assist with participant selection.

The other factor that must be addressed is the stage of adoption of the HPV vaccine among the study participants. Since it has previously been demonstrated that HPV vaccination intention does not necessarily translate into vaccination action, a population of adolescents that has already acted by having either received or not received the HPV vaccine will be used. The question of whether to use a time point after the first dose of the vaccine or after all three doses have been administered is somewhat debatable. However, it may be wise to opt for the time point following the first dose since by the time the third dose is administered a time span of 6 months will have elapsed and girls may be less likely to recall all of the factors which arbitrated at the time of the decision. Mediators of vaccination completion could be addressed in a companion investigation if Public Health Unit data reveals that many girls initiate but do not complete vaccination

The study sample will also include 2 parents (differing vaccination views if possible), 2 public health nurses (who administer the HPV vaccine), and 2 teachers (health education). These interviews will serve as a means of cross-checking the data.

#### *Sample size*

The aim will be to recruit two adolescent girls from each of the representative groups selected for the study. One will be a girl who received the vaccine and one will be a girl who did not. This could mean up to as many as 50 girls recruited through purposive sampling

#### *Inclusion criteria*

- Adolescent girl eligible to receive publicly funded preventive HPV vaccination in the City of Ottawa Public Health Unit
- Has either received the first dose of the HPV vaccine or has expressly declined vaccination and the date designated for the vaccination clinic has passed (expressly declined is intended to mean the girl has deliberately rejected vaccination to try to be as sure as possible that a 'no' decision for vaccination has been made as opposed to a decision that has possibly been put off at the time and may later be reconsidered). This will need to be established by means of a protocol-specified process to be applied at the time of consent. For girls not attending school this will be defined as an expression of vaccination rejection that is judged as deliberate).

#### *Exclusion criteria*

- Unable or unwilling to provide consent
- Declines or does not receive HPV vaccination on the scheduled vaccination clinic day (for school girls) but is still somewhat uncertain since this correlates with intention rather than actual uptake (established as above at the time of consent)

### *Recruitment process*

Schools will be categorized according to the sample characteristics sought. Contact will then be made with selected schools and with the sexual health centre to describe the study and solicit interest. School and sexual health representatives will assist with the selection of study candidates.

Each girl identified and approached for the study will be provided with written information about the study and will be able to take the form home to review with her parents. All girls will be asked to provide written consent. It will likely be required that both parent and girl sign consent since precedents for having girls give consent independently are presently rare. To maintain the anonymity of the girls, the following process may be used: signed consent forms will be returned to the school; the school principal will review the consent form and provide the study team with a proxy consent form signed by the principal to indicate consent to participate; the study team will maintain the proxy consent form with the study records.

For girls who have provided signed consent to participate in the study, private interviews, approximately 30 minutes in length, will be arranged. Interviews will be arranged by the school and study personnel will not be provided with the names of the girls. Interviews will take place on school premises and will not interfere with academic time. Girls will be offered a gift card for participation (eg. iTunes, Chapters)

In order to produce an accurate participation rate, data will also be collected with respect to the number of girls approached for the study and the numbers of refusals, including any girls who decline participation at the time of the interview. This may provide useful information to the research team since some representative groups of girls may be less willing to participate. Reasons for declining participation will be collected if possible. Similar methods will be used to recruit girls from the sexual health centre and parents.

### *Data collection*

#### *Method*

Narrative, in-depth interviews will be used. This approach is expected to yield a deeper understanding of the complex issues associated with HPV vaccination decisions. One interviewer will meet privately with each girl according to a process decided upon by the school. One or two trained interviewers will be used to conduct all interviews.

Interviews will be recorded (this will have been explained in the participant information sheet sent home). At the start of each recording, willingness to participate in the interview will be confirmed. Some demographic information will also be collected including school name, participant ethnicity, peer relationships, parental relationships and occupations, attitude toward school, and approximate grade average.

#### *Content*

An interview guide will be developed for the study. It will concentrate on barriers and facilitators to HPV vaccination and participation in vaccination decisions. The approach will be flexible and open-ended inquiry. Questions may include:

- Have you heard of HPV?
- Are you aware that there is a vaccine that protects against HPV?
- Tell me a bit about what you know about HPV and the vaccine?
- Does this issue matter to you?
- Tell me a bit about your general attitude and beliefs about vaccination?
- Did you receive the vaccine? (if no, 'was this a final decision or is it still possible that you might receive the vaccine in the future)
- How did you handle the decision?
- Who would you say primarily made the decision about receiving the HPV vaccine?
- Were you involved in the decision?

- If yes, how involved would you say you were?
- Did you want to be involved in the decision?
- What did you think about what other people said about the vaccine?
- How do you feel about being involved in making decisions related to your own health? Do you feel capable of deciding? Do you feel it is important to be involved?
- How would you have felt about making the decision on your own?
- Tell me as much as possible about things that (might have) prevented you from getting the vaccine
- Tell me as much as possible about things that you (might have) found helped you decide to get the vaccine
- Is there anything else you can think of that affected your decision (either positively or negatively) to receive the vaccine?

#### *Pilot testing*

The interview guide developed will be reviewed to verify that the content appears to address the research questions and pre-tested on at least two adolescent girls for clarity and choice of words. Methodological opinion suggests that pilot work is essential to the process of scientific inquiry into the views of adolescents yet this step has been frequently omitted in previous studies.<sup>127</sup> The absence of pilot work has the potential to yield study findings that are more in line with the assumptions of the researchers than they are a reflection of the views of the adolescent participants.<sup>127</sup>

#### *Outcomes*

The correlative endpoint for this study is vaccine uptake. Constructs from the following health behaviour theoretical models will be used to categorize outcomes: Health Belief Model, Theory of Planned Behaviour, Precaution Adoption Process Model, and Social Cognitive Theory. The outcomes of interest are barriers and facilitators to HPV vaccination, participation in the vaccination

decision (actual, desired, extent, importance), and the theoretical constructs most consistent with participant responses.

#### *Analytic considerations*

Data from the recordings of all in-depth interviews will be transcribed verbatim. Any names mentioned in the recorded information will be removed for confidentiality. Repeated review of the recordings will be conducted for data immersion. Data coding will take place by tagging, labeling, and categorizing interview information according to theoretical constructs. The valence of interview responses will also be coded since this will determine whether responses were being expressed in the context of a barrier or a facilitator. Two study investigators will complete the coding process independently. Consistent interpretation in coding will be ensured through an iterative discussion process. Interrater agreement for the assignment of valence will be assessed using Cohen's kappa.

The analysis of trustworthiness will be addressed using appropriate qualitative methods. Credibility will be evaluated using triangulation by involving an adolescent in the data review and coding; dependability will be ensured primarily through the use of purposive sampling and the involvement of a theoretical basis; transferability will be evaluated based upon the diversity of the study population and the transparency in reporting such that readers can determine the potential to extrapolate to other populations. Bias may be introduced into the study as a result of investigator views, and from the selection of participants.

#### *Ethical considerations*

A participant information handout and consent form will be designed. Participant privacy will be maintained as described. All tapes and documents will be maintained in a locked office; all electronic documents will be password protected (encryption); and only designated study personnel will have access to study data. Records will be kept for 15 years and shredded and/or deleted thereafter. The

study will be submitted to an appropriate Research Ethics Board for review and approval.

### 5.3 A tailored intervention to support preventive HPV vaccine decision-making among adolescent girls

The design of an effective tailored intervention to address barriers to HPV vaccination experienced by adolescent girls does not depend upon knowing which factors are more significant than others. Tailored interventions are thus ideal for meeting the needs of a diversity of adolescent girls. Based upon currently available evidence a prototype tailored intervention design is plausible. Here, a web-based intervention tool called *Healthy Me* is proposed (Figure 5). It incorporates barriers identified from a topical systematic review and from personal communication with a public health nurse about some common concerns expressed by girls at the time of vaccination. A pie chart was used to depict potential barriers since there is no associated implication concerning the relevance of any particular barrier and because pie charts were found to be visually appealing to communicate HPV vaccine information among an audience of representative stakeholders, which included an adolescent girl (Chapter 4).

In using the tool, girls click on barriers of personal interest or relevance, and simple yet thorough explanations are presented. The tool encourages user feedback by asking girls to rate how well the explanation addressed their concern. Options are also provided for girls to submit a suggestion or a barrier not covered by the tool. Facilitators to vaccination may also be submitted. The ongoing capture of information from adolescent girls fosters enhancements to the tool over time and new research findings may also be routinely incorporated.

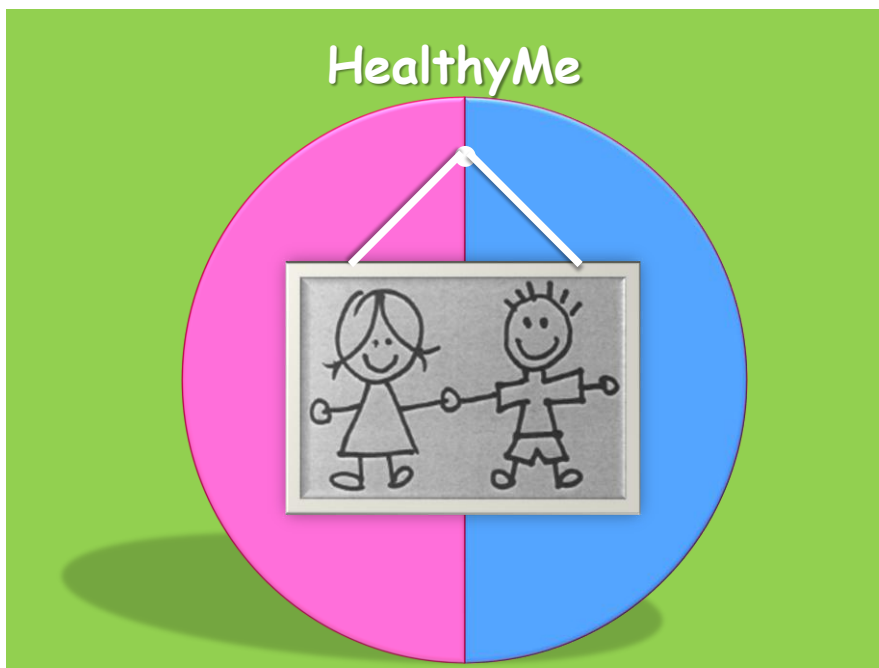
The greatest potential for acceptance and impact of the tool would likely occur if introduced as an educational component consistent with requirements of the health education curriculum. From a health policy perspective, the tool could be

introduced as an initiative under Canada's *Comprehensive School Health* framework.

One of the objectives of health research relevant to health policy development is the demonstration of intervention effectiveness.<sup>53</sup> The impact of the tool could be evaluated by observing trends in vaccination uptake in schools where it had been implemented compared to schools not using the tool. Furthermore, using GIS, it may be possible to observe and investigate a geospatial relationship, at the school level, between use of the tool and the uptake of preventive HPV vaccination.

If adapted to permit ranking of barriers according to personal relevance, the tool could also yield school-level data offering the potential to design peer-led targeted interventions aimed at addressing predominant school-specific barriers to vaccination.

Figure 5. A tailored intervention design to support preventive HPV vaccine decision-making among adolescent girls



## Helping you decide about getting the HPV vaccine



I think I can get HPV from the vaccine

It's a bit like a chicken and egg story:



An egg has the stuff inside that can produce a chicken

But if you put the empty shell back together it will never be able to produce a chicken

The HPV vaccine is just like an empty shell that is made to look exactly like the outside of the HPV virus. There is none of the bad stuff inside that can cause an infection. Your immune system works by recognizing the outside (shell). So, that is how the vaccine is able to signal your body to make antibodies that will protect you if you ever become infected with an HPV virus that has the same looking shell.

On a scale of 1 to 5 how well did this response address your concern

1 2 3 4 5

Not well at all

Very well

Submit a suggestion

Submit a new barrier

Submit something that would help you decide



## 5.4 A health policy model to support the promotion of preventive HPV vaccination among adolescent girls

Based upon the tapestry of evidence and thought presented in this thesis, a comprehensive approach to health program design is recommended to maximize uptake of preventive HPV vaccination in the City of Ottawa Public Health Unit and sustain vaccination rates over the long term. The approach should comprise:

- A defined goal
- An ethical foundation
- A theoretical foundation
- An ecological perspective (individual, interpersonal, community-level considerations)
- Multidisciplinary and broad stakeholder involvement at all levels (planning, implementation, evaluation)
- Evaluation (process, outcome)
- Communication (goals, gaps, outcomes)
- Focused commitment until the year 2020 and maintenance thereafter

To coordinate such an approach, a program model is proposed (Figure 6).

### *Definition of a goal for preventive HPV vaccination*

High levels of vaccination uptake among adolescent girls are needed to decrease the burden of HPV-associated disease in the population (though herd immunity is also a consideration with the extension of vaccination to boys). Presently, Cancer Care Ontario is the only known agency to have put forth a clearly expressed goal for preventive HPV vaccination. In their report, *Action Plan 2020*, they have called for the attainment of 95% vaccination coverage among adolescent girls prior to sexual debut by the year 2020.<sup>112</sup> Additional agencies, societies, and

organizations with a key role to play in promoting HPV vaccination are encouraged to endorse clear goals for uptake.

#### *Ethical foundation*

International rights documents such as the *United Nations Convention on the Rights of the Child* obligate us to value the rights of adolescents to participate in matters that concern their health. Furthermore, Canadian laws do not prohibit adolescents from providing consent for health interventions such as HPV vaccination. Empirical evidence, though deficient, provides some additional support for believing that adolescents are both capable and eager to participate in health decision-making. Canadian consent legislation should be reviewed and additional clarity should be provided with respect to adolescents specifically. Policymakers should build programs with the evolving capacities of adolescents in mind, such as including them in the consent process for receiving HPV vaccination.

#### *Theoretical foundation*

Health promotion programs are more likely to be successful if built upon a theoretical foundation. Preventive HPV vaccination is a complex health intervention and program planning should adopt an ecological perspective. At the community level it is important to consider how change theory may explain the implementation of HPV vaccination. Diffusion of innovation theory supplies a relevant basis for considering how this new innovation may be taken up within the community. For example, this theory advises us to be cautious about using prior evidence to guide future planning because early adopters differ from late adopters and different approaches are likely needed. Programs must therefore be adaptable to the changing needs of individuals if they are to be successful.

At an individual and interpersonal level, the Health Belief Model, Theory of Planned Behaviour, Precaution Adoption Process Model, and Social Cognitive Theory appear to offer constructs relevant to understanding adolescent health

behaviours related to HPV vaccination. However, even these explanatory theories have not been broadly tested or validated for adolescent populations and consequently the potential limitations of these theories, with respect to adolescents, must be considered along with their strengths. This is an area where further research may supply vital information to health policy planning.

### *Ecological perspective*

Successful programs in public health promotion typically address behavioural change at multiple levels. Individual behaviours are linked to the environmental context in which they occur. This is particularly true for HPV vaccination. Although adolescents may possess their own views regarding vaccination they are simultaneously exposed to numerous intervening pressures and influences from external sources such as peers, parents, and the media. Programs that draw on recognized health behavioural theory and which effectively integrate targeted approaches with broader community- level initiatives are more likely to lead to improved vaccine uptake. An ecological perspective also encourages us to remain effectively focused on improving health for everyone in the target population, not just a select few, or merely the 'statistically significant' majority. There is a need for a range of strategies that take into account multiple levels of influence.

### *Stakeholders*

The adoption of an ecological perspective also reminds us to include a broad range of stakeholders in all aspects of research and program development. Furthermore, although the work in this thesis has adopted the unique adolescent viewpoint it is recognized that it must also be complementary to work dealing with the viewpoints of others such as parents, health care providers, education groups, and the general public. Findings must be integrated in an approach that considers multiple levels of influence and multiple points of view. This work emphasizes the importance of including adolescents, not only as the subjects of

research and interventions, but also in the planning, testing, and evaluation phases of research and program development.

#### *Process and outcome evaluation*

The proposed model also emphasizes that, along the way, we must evaluate what we do to help us understand why particular initiatives may or may not lead to success. In this way we may be able to identify strengths and challenges in the implementation and delivery of preventive HPV vaccination programs.

The model also depicts the fundamental importance of outcome evaluations to determine the success of health promotion programs for preventive HPV vaccination. The overarching goal of the model is to maximize vaccination among adolescent girls.

Although beyond the scope of this thesis, there is an extensive body of literature outlining effective methods for conducting process and outcomes evaluations.

#### *Communication*

It is of fundamental importance that programs and policies are able to promote and sustain HPV vaccination rates over the long term. The assertion in this model is that to achieve this, communication of outcomes from all levels of intervention is central to ongoing progress. GIS is proposed as a candidate system for effectively communicating vaccination goals and outcomes with the associated potential to portray geospatial relationships in a dynamic and relational way.

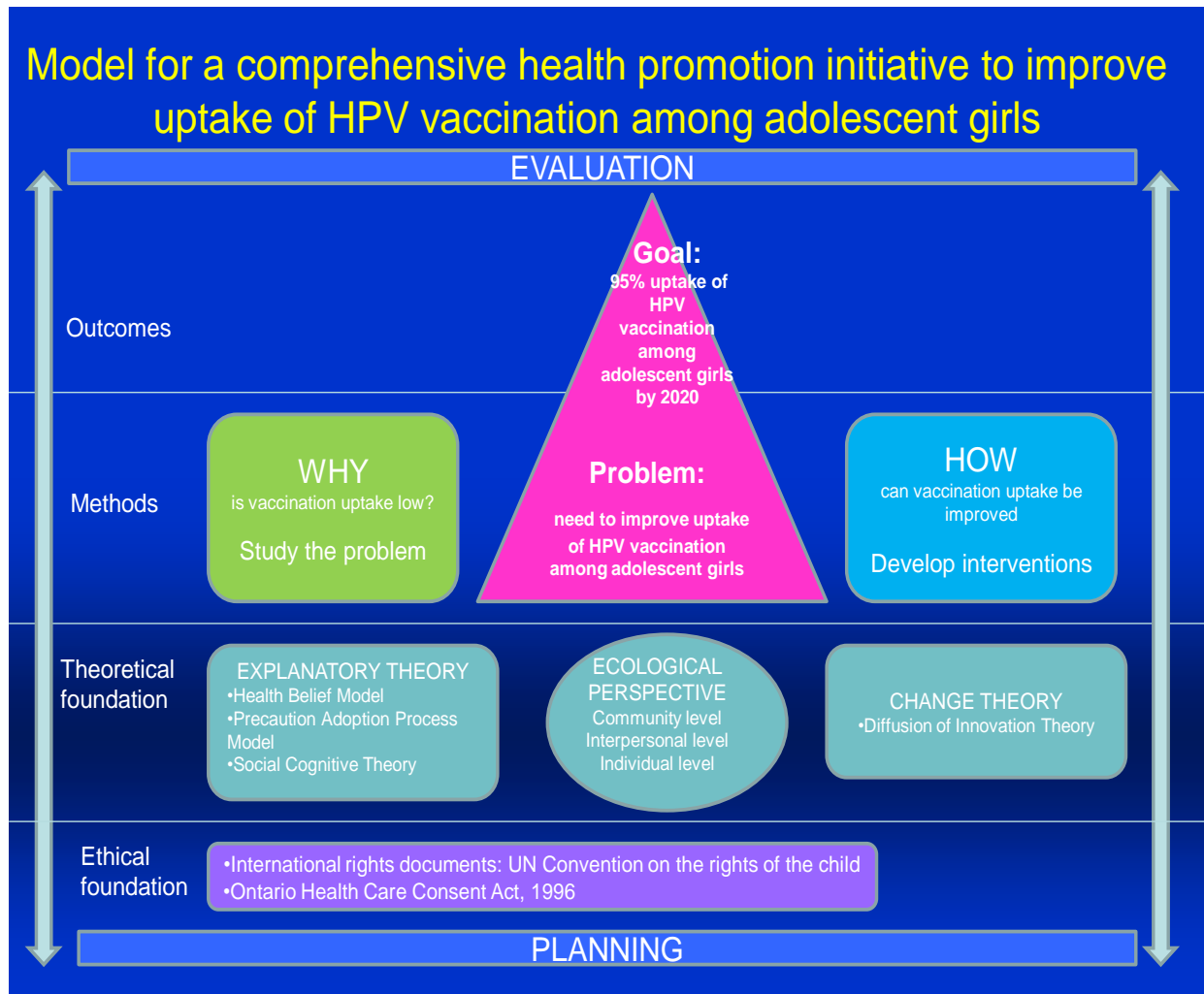
#### *Policy commitment*

Taken together, the work in this thesis satisfies the necessary first steps in building a strong foundation from which to develop health promotion programs for preventive HPV vaccination with reason and rationale for their success.

Vaccination as a means of achieving important gains in women's health through

primary prevention of HPV-associated disease is now available. Delays in moving forward have the potential to result in increasing numbers of young women being placed at an unnecessary risk for the health consequences of HPV infection. There is an immediate need for policymakers to commit to the goal of improving and maintaining preventive HPV vaccine uptake among adolescent girls and to align themselves with a comprehensive model for HPV vaccine health promotion.

Figure 6. Model for a comprehensive approach to health promotion for preventive HPV vaccination among adolescent girls



## 6.0 Appendices

### Appendix 1. Search Strategies: MEDLINE and EMBASE databases

#### MEDLINE search (to April 1, 2011)

Database: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R)  
<1948 to Present>

Search Strategy:

- 
- 1 Papillomavirus Vaccines/ (2322)
  - 2 ((Papillomavirus or hpv or papilloma virus) and (vaccin\$ or immuniz\$)).tw. (4204)
  - 3 or/1-2 (4559)
  - 4 Health Knowledge, Attitudes, Practice/ (53635)
  - 5 Attitude/ (35709)
  - 6 Perception/ (16290)
  - 7 (attitude\$ or belief or beliefs or knowledge or percept\$).tw. (493487)
  - 8 decision making/ or choice behavior/ (70118)
  - 9 "Attitude to Health"/ (64533)
  - 10 Intention/ or intention\$.tw. (36997)
  - 11 communication barriers/ or barrier\$.tw. or facilitat\$.tw. (349334)
  - 12 exp "Patient Acceptance of Health Care"/ (130942)
  - 13 (acceptance or acceptability or rejection).tw. (100639)
  - 14 or/4-13 (1158852)
  - 15 3 and 14 (836)
  - 16 limit 15 to yr="2005 - 2011" (739)
  - 17 limit 16 to english language (702)
  - 18 remove duplicates from 17 (695)
  - 19 animals/ not humans/ (3471083)
  - 20 18 not 19 (680)

## EMBASE search (to April 1, 2011)

Database: EMBASE Classic+EMBASE <1947 to 2011 April 13>, Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1948 to Present>

Search Strategy:

- 
- 1 Wart virus vaccine/ (4012)
  - 2 ((Papillomavirus or hpv or papilloma virus) and (vaccin\$ or immuniz\$)).tw. (9495)
  - 3 1 or 2 (10968)
  - 4 patient attitude/ (39103)
  - 5 ATTITUDE/ or attitude to health/ (211534)
  - 6 PERCEPTION/ (67763)
  - 7 (attitude\$ or belief or beliefs or knowledge or percept\$).tw. (1118810)
  - 8 barrier\$.tw. (259847)
  - 9 decision making/ (165176)
  - 10 (decision adj1 making).tw. (104074)
  - 11 choice behavior?.tw. (1262)
  - 12 (accept\$ or rejection or willingness).tw. (677985)
  - 13 health behavior/ or motivation/ (151134)
  - 14 (intention\$ or motivat\$).tw. (198221)
  - 15 or/4-14 (2528604)
  - 16 3 and 15 (1865)
  - 17 ("201113" or "201114" or "201115").em. (66806)
  - 18 16 not 17 (1848)
  - 19 limit 18 to (english language and yr="2006 - 2011") (1482)
  - 20 19 use emczd (856)
  - 21 Papillomavirus Vaccines/ (6371)
  - 22 ((Papillomavirus or hpv or papilloma virus) and (vaccin\$ or immuniz\$)).tw. (9495)
  - 23 21 or 22 (11325)
  - 24 Health Knowledge, Attitudes, Practice/ (115745)
  - 25 Attitude/ (86256)
  - 26 Perception/ (67763)
  - 27 (attitude\$ or belief or beliefs or knowledge or percept\$).tw. (1118810)
  - 28 decision making/ or choice behavior/ (180036)
  - 29 "Attitude to Health"/ (126444)
  - 30 Intention/ or intention\$.tw. (191831)
  - 31 communication barriers/ or barrier\$.tw. or facilitat\$.tw. (773473)
  - 32 exp "Patient Acceptance of Health Care"/ (318394)
  - 33 (acceptance or acceptability or rejection).tw. (230739)
  - 34 or/24-33 (2715846)
  - 35 23 and 34 (1934)
  - 36 limit 35 to yr="2006 - 2011" (1671)
  - 37 limit 36 to english language (1574)
  - 38 animals/ not humans/ (4744319)
  - 39 37 not 38 (1559)
  - 40 39 use prmz (672)
  - 41 20 or 40 (1528)
  - 42 remove duplicates from 41

**EMBASE Classic+EMBASE <1947 to 2011 April 13> (339)**

Appendix 2.  
Screening Logs: Level I and Level II

Level 1 (Title/Abstract) Broad Screening Log

- A. Total number of records identified by the search strategy: \_\_\_\_\_
- B. Elimination of records at Level 1:

Note: only records agreed upon for exclusion by both reviewers will be eliminated at Level 1 screening (ie. for discrepancies, the full text article will be obtained for review at Level 2 screening)

Reasons for elimination:

Studies investigating parental acceptance: # \_\_\_\_\_  
Studies investigating health care provider acceptance: # \_\_\_\_\_  
Studies investigating acceptance among other stakeholders: # \_\_\_\_\_  
Studies of older age groups of women: # \_\_\_\_\_  
Studies of acceptance among males: # \_\_\_\_\_  
Review or commentary pieces about acceptability: # \_\_\_\_\_

Other reasons (specify):

\_\_\_\_\_ # \_\_\_\_\_  
\_\_\_\_\_ # \_\_\_\_\_  
\_\_\_\_\_ # \_\_\_\_\_  
\_\_\_\_\_ # \_\_\_\_\_  
\_\_\_\_\_ # \_\_\_\_\_  
\_\_\_\_\_ # \_\_\_\_\_

Total studies remaining after Level 1 Broad Screening: # \_\_\_\_\_(L1)

Names of reviewers:

- 1. \_\_\_\_\_
- 2. \_\_\_\_\_

Documentation of eliminated records:

All records eliminated at Level 1 screening will be maintained in a separate file in Reference Manager.

File name and location:

---

## Level 2 (Full text screening) Relevance Assessment

Assessment made according to PICOS

C. Total number of records reviewed at level 2 Screening: \_\_\_\_\_

Same as number (L1) from Level 1 screening

D. Elimination of records at Level 2:

Reasons for elimination:

Studies investigating parental acceptance: # \_\_\_\_\_

Studies investigating health care provider acceptance: # \_\_\_\_\_

Studies investigating acceptance among other stakeholders: # \_\_\_\_\_

Studies of older age groups of women: # \_\_\_\_\_

Studies of acceptance among males: # \_\_\_\_\_

Review or commentary pieces about acceptability: # \_\_\_\_\_

Other reasons (specify):

\_\_\_\_\_ # \_\_\_\_\_

\_\_\_\_\_ # \_\_\_\_\_

\_\_\_\_\_ # \_\_\_\_\_

\_\_\_\_\_ # \_\_\_\_\_

\_\_\_\_\_ # \_\_\_\_\_

\_\_\_\_\_ # \_\_\_\_\_

Total studies remaining after Level 2 full text screening: # \_\_\_\_\_ (L2)

Names of reviewers:

1. \_\_\_\_\_

2. \_\_\_\_\_

Discrepancies:

Discrepancies will be discussed for consensus. If necessary a third reviewer will be asked to review the article for relevance.

Name of 3<sup>rd</sup> reviewer (if required): \_\_\_\_\_

Documentation of eliminated records:

All records eliminated at Level 2 screening will be maintained in separate file in Reference Manager.

File name & location:

---

### Appendix 3. Quality scores for systematic review by 2 independent reviewers and consensus decisions

Author and year of publication	Study type	explicit theoretical framework	statement of aims/objectives in main body of report	clear description of research setting	evidence of sample size considered in terms of analysis	representative sample of target group of a reasonable size	description of procedure for data collection	rationale for choice of data collection tool(s)	detailed recruitment data	statistical assessment of reliability and validity of measurement tool(s) (quantitative only)	fit between stated research question and method of data collection (quantitative)	fit between stated research question and format and content of data collection tool eg. Interview schedule (qualitative)	fit between research question and method of analysis	good justification for analytical method selected	assessment of reliability of analytical process (qualitative only)	evidence of user involvement in design	strengths and limitations critically discussed
Kahn 2008	QT	3	3	3	0	2	3	3	2 don't know how initial 418 were selected	3	2	n/a	2	3	n/a	1 mentioned validation in a prior study but do not know details	3
Kahn 2008		3	3	2	2	2	3	2	0	1	2/3?	0	2/3?	2	0	0	3
consensus		3	3	2	0	2	3	2	0	2	2	n/a	2	2	n/a	0	3
Lenehan 2008	QT	0	3	3	0	1	2	2	2 don't know how initial 108 were selected	1 mentioned referring to other studies	1	n/a	0	1	n/a	0	1 no mention re narrow range of barriers and facilitators evaluated
Lenehan 2008		0	2	3	0	2	2	2	1	1	1	n/a	1	1	n/a	0	0
consensus		0	3	3	0	1	2	2	1	1	1	n/a	0	1	n/a	0	1
Gerend 2008	QT	0	3	3	0	1	3	2	1	0	1	n/a	2	2	n/a	0	3
Gerend 2008		0	2	1	1	2	3	2	0	0	1		2	2	0	0	3
consensus		0	2	3	0	1	3	2	0	0	1	n/a	2	2	n/a	0	3
Bynum 2009	pilot study	0	2	3	0	1	3	1	1	1	2	2	2	1	2	2	2
Bynum 2009	M	0	3	1	1	2	3	2	0	1	2/3?	3	3?	2	0	1	3
consensus			2	3	0	1	3	2	0	1	2	2	2	1	2	1	3
Allen 2009	QT	3	3	3	1 all students	2	3	3	3	3	2	n/a	2	3	n/a	3	3
Allen 2009		3	3	2	2	2	3	2	2	1	3		3?	2		1	3
consensus		3	3	2	2	2	3	2	2	2	3	n/a	2	2	n/a	3	3
Costar 2008	M	3	3	3	3	2	3	3	2	3	2	2	2	1	3	2	3
		3	3	3	2	2	3	2	2	2	3	2	0	1	2	2	3
consensus		3	3	3	2	2	3	2	2	2	2	2	0	1	2	2	3
Jain 2009	QT	0	3	3	2	2	3	0	3	2	2 not the best to capture 18-26 year olds	n/a	2	3	n/a	3	2 only really one response allowed for Q7 =relative inability to elucidate range of barriers &

Author and year of publication	Study type	explicit theoretical framework	statement of aims/objectives in main body of report	clear description of research setting	evidence of sample size considered in terms of analysis	representative sample of target group of a reasonable size	description of procedure for data collection	rationale for choice of data collection tool(s)	detailed recruitment data	statistical assessment of reliability and validity of measurement tool(s) (quantitative only)	fit between stated research question and method of data collection (quantitative)	fit between stated research question and format and content of data collection tool eg. Interview schedule (qualitative)	fit between research question and method of analysis	good justification for analytical method selected	assessment of reliability of analytical process (qualitative only)	evidence of user involvement in design	strengths and limitations critically discussed
																	facilitators
Jain 2009		0	3	2	2	2	3	3	2	1	2		2	2		1	3
consensus		0	3	2	2	2	3	0	2	1	2	n/a	2	2	n/a	3	2
Read 2010	QT	0	2	3	0	1	3	0	2	0	1	n/a	1	0	n/a	0	2
Read 2010		0	2	1	1	1	1	1	1	1	2		2	1		1	2
consensus		0	2	1	0	1	1	0	1	1	2	n/a	2	0	n/a	0	2
Conroy 2009	QT	0	3	3	0	1	2	0	2	2	2	n/a	1	0 self-reported barriers was secondary aim of study		0	2 limitations of survey instrument itself not discussed nor the way self-report info analysed&presented
Conroy 2009		0	3	3	2	2	3	3	2	2	3		2	3		1	3
consensus		0	3	3	0	2	3	0	2	2	2	n/a	2	0	n/a	0	2
Caskey 2009	QT	0	3	3	0	2	2	1	2	0	1	n/a	2 barriers from 'other' category could have been included for better depth of understanding	2	n/a	0	1
Caskey 2009		0	3	3	3	3	3	3	3	2	2		2	3		1	3
consensus		0	3	3	0	2	3	2	1	0	2	n/a	2	2	n/a	0	2
Rand 2011	QT	2	2	3	3	2	2	2	2	2	2	n/a	1	2	n/a	3	1
Rand 2011		0	1	1	2	1	2	1	1	2	2	2	2	1	?	1	3
consensus		2	2	2	2	2	2	2	2	2	2	n/a	2	2	n/a	2	1
Mathur 2010	QT	0	3	3	0	1	3	2	2	2	2	n/a	2	1	n/a	3	2
Mathur 2010		0	3	3	1	2	3	1	2	2	2		2	1		1	3
consensus		0	3	3	0	1	3	1	2	2	2	n/a	2	1	n/a	2	2

Author and year of publication	Study type	explicit theoretical framework	statement of aims/objectives in main body of report	clear description of research setting	evidence of sample size considered in terms of analysis	representative sample of target group of a reasonable size	description of procedure for data collection	rationale for choice of data collection tool(s)	detailed recruitment data	statistical assessment of reliability and validity of measurement tool(s) (quantitative only)	fit between stated research question and method of data collection (quantitative)	fit between stated research question and format and content of data collection tool eg. Interview schedule (qualitative)	fit between research question and method of analysis	good justification for analytical method selected	assessment of reliability of analytical process (qualitative only)	evidence of user involvement in design	strengths and limitations critically discussed
Watts 2009	QT	0	2	3	3	2	3	2	2 detailed but numbers don't seem to add up	2	1	n/a	2	1	n/a	3	0
Watts 2009		0	3	3	3	3	3	3	3	2	3		2	3		1	3
consensus		0	2	3	3	2	3	2	2	2	2	n/a	2	2	n/a	2	0
Moore 2010	QT	0	2	3	0	1	2	2	2	0	1	n/a	2	2	n/a	0	1
Moore 2010		0	3	3	2	2	3	3	2	2	2		2	3		1	3
consensus		0	2	3	0	1	2	2	2	0	1	n/a	2	2	n/a	0	1
Licht 2010	QT	0	2	3	0	2	2 emailed author for time frame	0	2	0	1	n/a	1	1	n/a	0	1
Licht 2010		0	3	2	1	2	2	1	1	2	2		2	3		1	3
consensus		0	2	2	0	2	2	0	2	0	2	n/a	1	2	n/a	0	1
Zimet 2010	QT	0	2	3	1	1	3	0	3	0	2	n/a	2	1	n/a	0	2
Zimet 2010		0	3	1	3	2	2	1	2	2	2		2	1		1	1
consensus		0	2	2	2	1	2	0	2	0	2	n/a	2	1	n/a	0	2
Hopfer 2011	QL	3	3	3	1	1	3	3	3	n/a	n/a	3	3	3	3	1	2
Hopfer 2011		?	3	3	0	1	3	2	2			3	3	2	1	1	3
consensus		3	3	3	0	1	3	2	2	n/a	n/a	3	3	2	2	1	2
Rosenthal 2011	QT	0	2	3	0	2	3	2	3	0	2	n/a	1	0	n/a	0	2
Rosenthal 2011		0	2	1	1	2	1	1	1	1	1		2	2		1	2
consensus		0	2	2	0	2	2	2	2	0	1	n/a	2	0	n/a	0	2
Dillard 2010	QT	0	3	3	0	1	3	1	2	1	1	n/a	1	1	n/a	2	2
Dillard 2010		0	3	2	1	2	2	1	2	1	2		2	2		1	3
consensus		0	3	2	0	1	2	1	2	1	1	n/a	2	1	n/a	2	2

Author and year of publication	Study type	explicit theoretical framework	statement of aims/objectives in main body of report	clear description of research setting	evidence of sample size considered in terms of analysis	representative sample of target group of a reasonable size	description of procedure for data collection	rationale for choice of data collection tool(s)	detailed recruitment data	statistical assessment of reliability and validity of measurement tool(s) (quantitative only)	fit between stated research question and method of data collection (quantitative)	fit between stated research question and format and content of data collection tool eg. Interview schedule (qualitative)	fit between research question and method of analysis	good justification for analytical method selected	assessment of reliability of analytical process (qualitative only)	evidence of user involvement in design	strengths and limitations critically discussed
Janousek 2011	QT	3	3	3	3	2	3	2	3	1	2	n/a	2	1	n/a	0	1
Janousek 2011		3	3	3	3	3	3	3	3	3	3		3	3		3	3
consensus		3	3	3	3	2	3	2	3	1	1	n/a	3	1	n/a	0	1
Bendik 2011	QT	1	2	3	0	2	2 emailed author for time frame	2	2	0	1	n/a	1	1	n/a	0	1
Bendik 2011		0	3	2	1	2	1	1	1	2	2		2	3		1	3
		1	2	2	0	2	1	1	1	0	1	n/a	2	1	n/a	0	1

## Appendix 4. Map testing: interview questionnaire

The following is a presentation of 4 maps. By asking a few questions, I would like to find out your impressions of the maps in terms of their clarity in communicating intended messages, their uses, and any potential for misinterpretation. Please keep in mind that this is a test of the map's ability to communicate information and not a test of you (for instance if you work in an area related to HPV you may already know the answers to some of the questions. Please provide answers only based upon what you see in the maps. Also, it is hoped that the maps will be able to communicate information to many different types of potential users who have a role to play in health promotion for HPV vaccination, and in this test of the maps you are representing the viewpoint of: \_\_\_\_\_ (*insert stakeholder audience role*)\_\_\_\_\_

### **Map 1: *Map 1: Province of Ontario Public Health Unit Map: HPV Vaccination Coverage***

Please take a look at the map. The province of Ontario has been divided into its 36 Public Health Units.

**Q1.** After you have had a chance to look at the map please describe out loud the main message (or messages) you can see in the map.

**Q2.** Was the HPV vaccination rate among girls higher in the 2007/08 school year or the 2008/09 school year?

**Q3.** Have we reached HPV vaccination goals in Ontario?

**Q4.** Do you find that the presentation of the information on the map may be useful to you as a (*stakeholder audience role*). Please explain briefly.

**Q5.** Is there anyone else you think may find this information useful? How?

**Q6.** Do you see any information on the map that you think may be misinterpreted?

**Q7.** Do you have any other comments or questions about the map?

Record the amount of time taken to review Map 1 here:

### **Map 2B. *Schools by School Board; Vaccine coverage by School Board***

Please take a look at the map. This map of the City of Ottawa Public Health Unit does not contain any real data about HPV vaccination. It has been created to show the information could be presented.

**Q1.** After you have had a chance to look at the map please describe out loud the main message (or messages) you can see in the map.

**Q2.** How many School Boards are there within the City of Ottawa Public Health Unit?

**Q3.** Does the HPV vaccination rate between the School Boards appear to be the same or different?

**Q4.** Remembering your role, do you find that the presentation of the information on the map may be useful to you? Please explain briefly.

**Q5.** Is there anyone else you think may find this information useful?

**Q6.** Do you see any information on the map may that you think may be misinterpreted?

**Q7.** Do you have any other comments or questions about the map?

Record the amount of time taken to review Map 2B here:

The following is a presentation of 4 maps. By asking a few questions, I would like to find out your impressions of the maps in terms of their clarity in communicating intended messages, their uses, and any potential for misinterpretation. Please keep in mind that this is a test of the map's ability to communicate information and not a test of you (for instance if you work in an area related to HPV you may already know the answers to some of the questions. Please provide answers only based upon what you see in the maps. Also, it is hoped that the maps will be able to communicate information to many different types of potential users who have a role to play in health promotion for HPV vaccination, and in this test of the maps you are representing the viewpoint of: \_\_\_(insert stakeholder audience role)\_\_\_\_\_

**Map 2C. Preventive HPV vaccine uptake in the City of Ottawa Public Health Unit**

Please take a look at the map. This map does not contain real data about HPV vaccination. It has been created to show how the information could be presented.

Q1. After you have had a chance to look at the map please describe out loud the main message (or messages) you can see in the map.

Q2. There are several bars shown on the graph. What does each bar tell you?

Q3. What determines the location of each bar on the map?

Q4. Has any school that you can see on the map reached the goal of having 95% of grade 8 girls vaccinated?

Q5. Remembering your role, do you find that the presentation of the information on the map may be useful to you? Please explain briefly.

Q6. Is there anyone else you think may find this information useful?

Q7. Do you see any information on the map may that you think may be misinterpreted?

Q8. Do you have any other comments or questions about the map?

Record the amount of time taken to review Map 2C here:

**Map 3. Exploring Barriers to HPV vaccine uptake by school: City of Ottawa Public Health Unit**

Please take a look at the map. This map does not contain any real data. It has been created to show how the information could be presented.

Q1. After you have had a chance to look at the map please describe out loud the main message (or messages) you can see in the map.

Q2. What does each pie chart represent?

Q3. What is one of the reasons a girl might not want to receive the HPV vaccine according to the map?

Q4. Remembering your role, do you find that the presentation of the information on the map may be useful to you? Please explain briefly.

Q5. Is there anyone else you think may find this information useful?

Q6. Do you see any information on the map may that you think may be misinterpreted?

Q7. Do you have any other comments or questions about the map?

Record the amount of time taken to review Map 3 here:

Thank you for your time and participation!

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