LOOKING FOR EMERGENCY CONTRACEPTION ONLINE: ANALYSIS OF INTERNET SEARCH PATTERNS AND WEBSITE CONTENT

by

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Abstract

**Background:** Emergency contraception (EC) effectively reduces the risk of pregnancy following unprotected or under-protected sexual intercourse. EC has recently become available without a prescription in Canada and the USA in order to improve its availability and use, especially by young women. At the same time, the Internet is increasingly relied on as a source for health information, and Internet use is now nearly universal in younger age groups. Nevertheless, how people use the web to look for information about EC, and the qualities of information they find, are not well understood. The objectives of this thesis were to: (1) investigate the change in Internet search patterns for EC-related search terms in Canada and the USA over time and through shifts in EC-related policy and (2) assess the qualities (e.g., credibility, readability) and source (e.g., financial affiliations) of web-based information available about EC. **Methods:** The impact of policy changes in Canada and the USA on Internet search volume was estimated using interrupted time series analysis for two search terms: “morning after pill” and “Plan B”. Quality ratings and readability scores were generated for the ten most frequently found websites in Canada and the USA. **Results:** Policy changes making EC available without a prescription in Canada and the USA appear to have had an impact on information-seeking patterns online for EC-related search terms. The university-based website ec.princeton.edu and Wikipedia (en.wikipedia.org) were found frequently in searches for EC-related search terms in both countries. The website sponsored by the makers of Plan B®, www.planb.ca, was found most frequently
in Canadian searches. All websites achieved fair to medium ratings in a systematic quality assessment, and 14 (83%) of websites had a reading grade level higher than the reading grade levels recommended for written health information. **Discussion:**

Regulatory changes making EC available without a prescription appear to have affected the frequency with which people look online for information about EC. Public health agencies may want to improve the quality, readability and prominence of their web pages in online searches for EC-related search terms to ensure easy and convenient access to comprehensible, unbiased, and high quality web-based materials.
Preface

The research in this thesis was conducted according to the guidelines of the University of British Columbia Behavioural Research Ethics Board. Collection of survey data and secondary data analyses were approved by UBC BREB H11-00458.

Under the primary supervision of Dr. Jean Shoveller (PhD, UBC) and co-supervision of Dr. Judith Soon (PhD, UBC) and Dr. Michael Law (PhD, Harvard), M. Elliott conducted the following research activities:

1. **Data collection.** M. Elliott collected the 340 online surveys involved in this thesis.

2. **Data analysis.** Data analysis was primarily conducted by M. Elliott, with ongoing consultation from her supervisory team. Feedback from Drs. Shoveller, Soon and Law were subsequently incorporated into the thesis.

3. **Chapter preparation.** Each chapter was written by M. Elliott; feedback was sought from Drs. Shoveller, Soon and Law and incorporated into subsequent and finalized versions of the thesis.
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Dedication

To mom & dad
Chapter 1.0 Introduction

1.1 Emergency contraception and addressing unintended pregnancy

Of 6.7 million pregnancies in 2006 in the United States, 3.2 million (49%) were unintended (Finer & Zolna, 2011). While no data are available regarding the rate of unintended pregnancies in Canada (Canadian Federation for Sexual Health, 2007), women in the USA experience high rates of unintended pregnancy\(^1\) relative to other industrialized nations (Singh, 2009). Unintended childbearing (the result of carrying an unintended pregnancy to term) is associated with increased rates of alcohol and tobacco use during pregnancy, inadequate and delayed pre-natal care, premature births, low birth weights, and long-term adverse social and health outcomes for the child and parent (Axinn, 1998; Dott, 2010; Hellerstedt, 1998; Mayer, 1997; Orr, 2007).

Rates of unintended pregnancy among women aged 18 to 24 in the USA are higher than the national average: more than one unintended pregnancy occurred for every ten women aged 18 to 24 in 2006, twice the rate for women overall (approximately 5.2 unintended pregnancies per 1000 women) (Finer & Zolna, 2011). Furthermore, rates of unintended pregnancy are increasing among women aged 20 to 24 years; in 2001 there were

\(^1\) These analyses use the National Survey of Family Growth’s definition of unintended pregnancy, which includes both “mistimed” pregnancies, in which the woman wanted to become pregnant but at a later date, and “unwanted” pregnancies, in which the woman did not want to become pregnant at any future point in time (National Survey of Family Growth, 2010). These pregnancies include both those that are carried to term and those that end in abortion. For further discussion regarding the conceptual and methodological challenges of measuring the “intendedness” of pregnancy, see Santelli (2003).
101 pregnancies per 1000 women aged 20 to 24, and in 2006 there were 107 pregnancies per 1000 women aged 20 to 24 (Finer & Zolna, 2011). Most unintended pregnancies result from contraceptive failure (e.g., a broken condom or a missed birth control pill) or the non-use of contraception (Finer & Henshaw, 2006). Emergency contraception (EC) is one means of reducing the risk of unintended pregnancy and public policy initiatives in both Canada and the USA have emerged in recent times to address the uptake of EC.

1.2 Emergency contraception policy in Canada and the USA

Levonorgestrel-only EC\(^2\) is a safe and effective method of reducing the risk of pregnancy when taken within 120 hours of unprotected or under-protected sexual intercourse (Meng, 2009; Rodrigues, 2001; von Hertzen, 2002). EC is a time sensitive agent; the timing of the initial dose is crucial and its efficacy decreases linearly over time (von Hertzen, 2002). Since 2000, a series of regulatory changes have been implemented in Canada

\(^2\) Emergency contraception (EC) is defined by the World Health Organization (WHO) as “back-up methods for contraceptive emergencies which women can use within the first few days after unprotected intercourse to prevent an unwanted pregnancy.” (WHO, 2005). There are two types of EC: hormonal and non-hormonal. Ulipristal acetate can be administered up to five days after unprotected intercourse or contraceptive failure (FDA, 2010). There are two types of hormonal emergency contraception currently available in Canada and the United States: progestin only, which is administered in a single dose of 1.5mg levonorgestrel or two doses of 750 µg levonorgestrel administered 12 hours apart; and combined estrogen and progestin delivered in two doses of 100µg of ethinyl estradiol and 0.5mg of levonorgestrel administered 12 hours apart (this method is sometimes referred to as the Yuzpe method of emergency contraception)(Trussell, 1996). Non-hormonal EC is available in Canada and the USA as a copper bearing intra-uterine device, which can be inserted by a physician up to 5 days following unprotected intercourse (Stewart, 2007; Glasier, 1997). The USA-only EC agent, ulipristal acetate, a progesterone agonist/antagonist used as an EC agent, was approved for sale as a prescription-only product in August 2010. Ulipristal acetate and Copper IUDs will not be discussed. In the current thesis, ‘EC’ will refer to levonorgestrel-only emergency contraceptive pills, either as a single or two pill dose.
and the United States aimed at improving timely and convenient access to EC. In December 2000, pharmacists in British Columbia were the first in Canada to be granted prescriptive authority to dispense EC. Subsequently, in April 2005, the National Association of Pharmacy Regulatory Authorities in Canada (NAPRA) approved EC for “Behind-the-Counter” (BTC) non-prescription status, making it available behind pharmacists’ counters without a prescription (Sibbald, 2005). In May 2008, NAPRA approved EC for over-the-counter (OTC) non-prescription status, making it available on pharmacy shelves in front of pharmacists’ counters (Eggerston, 2008). Regulation of EC in the United States has followed a similar trajectory. In August 2006, the Food and Drug Administration (FDA) approved EC for OTC sales without a prescription to individuals 18 years of age and older (Food and Drug Administration, 2006). In April 2009, OTC sales of EC were approved for individuals aged 17 and older (Food and Drug Administration, 2009). EC remains available prescription-only for individuals aged 16 and younger in the USA. There is currently no BTC status for drugs in the USA.

Research indicates that the rate of EC use increases in response to policy changes making it available without a prescription (Kavanaugh, 2011; Soon, 2005; Moreau, 2006). The most frequent users of EC are women in their late teenage years and twenties (Kavanaugh, 2011; Soon, 2005; Moreau, 2006) and, when EC becomes available without a prescription in pharmacies, more women in this age group access EC in this way than any other (Soon, 2005; Moreau, 2006).

1.3 Emergency contraception online

A large and increasing proportion of North Americans look for information about health online: 70% of Canadian Internet users and 80% of American Internet users report
searching for information about health on the web (Zamaria & Fletcher, 2008; Fox & Jones, 2009). Forty-five percent of American Internet users used the web to look for information about prescription or OTC drugs in 2008, up from 34% in 2002 (Fox & Jones, 2009). Young people use the Internet most frequently: more than 97% of Canadians and 93% of Americans between the ages of 12 and 29 use the Internet (Zamaria & Fletcher, 2008; Fox & Jones, 2009). Socio-economic disparities in Internet access (sometimes referred to as the “first digital divide”) are becoming less pronounced, particularly among younger age groups (Zhao, 2009; Compaine, 2001; Hoffman & Novak, 1998).

Given the frequency with which young people search online, the prevalence of unintended pregnancy in this age group, and the relative frequency with which this age group uses EC, online resources about EC may be important information sources, especially for women under 29 years of age. Despite the potentially substantial role of web-based resources in addressing young women’s reproductive health concerns, research in this area is sparse. Notably, there is a lack of research regarding the nature of online resources available about EC, as well as the ways in which Internet users look for information about EC online. Recent policy and regulatory changes have changed how women (and men) can access EC (e.g., it is now possible to purchase it without consulting a physician or pharmacist), and thereby also may have affected how people access information about this product (e.g., from sources other than their healthcare provider). Addressing this research gap is important in light of the evolving policy and regulatory milieu, in which EC is now available without a prescription.
1.4 Literature review

The following literature review expands on the ideas introduced in the previous section. Specifically, it elucidates the impact of increased availability of EC on rates of EC use, and the relevance of online resources in the shifting “health information landscape”. Further, it provides an overview of the emerging methods researchers are using to investigate large-scale patterns of Internet use and to assess the quality of website content. Finally, the review highlights the importance of understanding how increased availability of EC may impact the way people access information online and the web-based information that they have access to.

1.4.1 Effects of EC-related policy change on rates of EC use

Facilitating convenient access to EC increases rates of use (Polis, 2007; Polis, 2007a). Three recent systematic reviews and meta-analyses have concluded that providing women with a supply of EC to use in case of unprotected or under-protected sex both increases the rate of EC use and decreases the time it takes for women to administer EC following unprotected or under-protected sex (Polis, 2007; Raymond 2007; Polis, 2007a). Minimizing the delay in administering EC is important because it is a time sensitive agent; the sooner EC is taken after unprotected or under-protected intercourse, the more effective it is at preventing pregnancy (von Hertzen, 2002). Population level interventions, such as making EC available BTC or OTC from a pharmacy, increases the number of women who use it (Raymond, 2007; Wells, 1998; Mawhinney, 2004; Soon, 2005; Moreau, 2006; Larsson, 2006).
Soon (2005) evaluated changes in EC use in British Columbia before and after the December 2000 provincial legislative change that enabled specially trained pharmacists to distribute EC without a physician’s prescription. The number of EC treatments provided in British Columbia doubled from a pre-policy mean of 8805 (99% confidence interval [CI] of 7823-9787) yearly from 1996-2000 to 16039 in 2001 and 17794 in 2002 (Soon, 2005). No studies have examined the longitudinal effects of EC availability BTC or OTC on rates of EC use nationwide in Canada.

In the USA, Kavanaugh (2011) examined rates of EC use following the FDA’s 2006 decision that made EC available OTC to women 18 years and older in the USA. Using data from the 2006-2008 National Survey of Family Growth, Kavanaugh found that the number of women who reported that they had ever used EC increased by more than twofold between 2002 and the period between 2006 and 2008, from 4.2% to 9.7% of all sexually active women. The majority – 68% – of EC users surveyed between 2006 and 2008 indicated that the last time they had obtained EC they had done so without a prescription.

Research indicates that rates of EC use are highest among women under the age of 29 in both Canada and the USA (Kavanaugh, 2011; Soon, 2005). Soon (2005) found that both pre- and post policy change, women aged 20-24 had the highest rates of EC use (38.9 EC treatments were provided per 1000 women in 2001-2002). This was followed by women aged 15-19 (26.9 EC treatments per 1000 women post-policy change) and women aged 25-29 (25.1 EC treatments per 1000 women post-policy change). Women in British Columbia aged 20-24 also accessed EC from pharmacies more frequently than any other age group: 14.7 EC treatments per 1000 women aged 20-24 were accessed from a pharmacy in 2001-2002,
compared with 10.8 per 1000 women aged 15-19, and 10.4 per 1000 women aged 25-29 (Soon, 2005). In the USA, the highest rates of EC use were also among women aged 18 to 24: 18.4% of sexually active women in this age group reported that they had ever used EC in 2006 (Kavanaugh, 2011). The second highest rates of EC use were among women aged 25-29 (14.6% of sexually active women), followed by women aged 15-17 (8.2% of sexually active women).

Rates of EC use in North America are relatively low compared with those in countries such as France, where EC has been available without a prescription since 1999 (Moreau, 2006): 16.9% of sexually active women in France reported having ever used EC in 2004. In this study, the highest rates of use were again reported among sexually active women aged 20-24 (31.3%), 18-19 (30.7%) and 15-17 (29.8%).

Increases in EC use do not appear to have occurred concurrently with changes in the counseling practices of physicians or by health clinics. An American study found that in 2006 only 3% of women surveyed indicated that they had received counseling from their healthcare provider about EC in the past year, a rate that had not changed since 2002 (Kavanaugh & Schwartz, 2008; Kavanaugh, 2011). In a survey of 1800 obstetrician-gynecologists across the USA, 51% reported offering EC to all women who they believed were at risk of an unintended pregnancy, 37% reported offering EC to women who said they had had unprotected sex, only 6% never offered EC, and 6% offered it only to victims of sexual assault (Lawrence, 2010). Women who access EC or have questions about it may thus rely on sources other than their healthcare provider for information about EC, including how and where to access it, its mechanisms of action, and side effects.
1.4.2 Looking for information about EC: the role of online resources

The Internet is one element of a wide network of resources people use when looking for answers to questions about their health (Jones & Biddlecom, 2011). Other sources include family, friends, healthcare providers, and traditional media, including magazines and newspapers (Hesse, 2005; Jones & Biddlecom, 2011). However, the convenience and accessibility of web-based media means that they are often the first resort for people looking for health information, that is, people often consult online resources to answer health-related questions before speaking with their healthcare provider (Hesse, 2005). Furthermore, the anonymity and perceived confidentiality of the Internet may make it an appealing resource for sensitive health topics (e.g., those related to reproductive and sexual health) which individuals may be hesitant to address with healthcare providers, friends or family members (Gray, 2005; Fox & Rainie, 2000).

Internet use is nearly universal among individuals 29 and younger; it is estimated that 97% of Canadians and 93% of Americans aged 12-29 are Internet users (Zamaria & Fletcher, 2008; Fox, 2010). Internet use has increased significantly since the late 1990s, when it was estimated that 22% of American adults 18 and older reported that they used the Internet regularly (Hesse, 2005). This figure is now estimated to be 79%, an increase attributed to technological advances (e.g., broadband), which have made the Internet faster, easier and more affordable to use (Hesse, 2005; Zamaria & Fletcher, 2008). Furthermore, while rates of Internet use continue to be lower in rural areas and among individuals with an income below
$30,000/year (67% and 63%, respectively), it appears that the divide in online access is closing, particularly among children in low income and immigrant households (Fox, 2010; Zhao, 2009).

Looking for health information is the third most popular activity online, behind emailing and using a search engine (Fox, 2011a). Eighty percent of American Internet users aged 18 and older, and 70% of Canadian Internet users aged 12 and older report having looked for health information online, representing 59% of all American adults and 54.6% of Canadians aged 12 and older (Zamaria & Fletcher, 2008; Fox & Jones, 2009). Research indicates that when people look for health information online, they tend to do so in response to a specific event, such as a diagnosis or health concern (Eysenbach & Kohler, 2002; Adams, 2006; Fox, 2011a). An incident of unprotected or under-protected sex may provide impetus to search online for information about post-coital birth control methods, such as EC.

Internet users continue to harbor reservations about the trustworthiness and accountability for the quality of health information available online (Jones & Biddlecom, 2011; Gray, 2005; Hesse, 2005). Since the late 1990s, many studies have assessed the quality (e.g., accuracy and completeness), credibility (e.g., source) and usability (e.g., readability) of the online content of wide range of health topics, from a number of user perspectives (Deshpande & Jadad, 2009; Kunst, 2002; Berland, 2001; Szumilas & Kutcher, 2009; Khazaal, 2008; Khazaal, 2008a; Sutherland, 2005). Many studies have found shortcomings in the quality, completeness and accessibility of web-based resources (Deshpande & Jadad, 2009; Eysenbach, 2008).
In response to these concerns, several quality-assessment instruments have been developed to help Internet users locate and evaluate health information online, including: quality labels, evidence-based user guides, filters and portals, codes of conduct, and third-party certification (Deshpande & Jadad, 2009). However, there is currently no international quality standard for health-based materials, and the instruments designed to regulate and/or monitor website quality have met with limited success (e.g., low rates of uptake) (Deshpande & Jadad, 2009; Eysenbach, 2008). Qualitative research examining health seeking behaviour online indicates that people tend instead to rely on personalized strategies to locate and assess the quality and trustworthiness of the health related material they find online (Jones & Biddlecom, 2011; Borzekowski & Rickert, 2001; Adams, 2006; Eysenbach & Kohler, 2002; Eysenbach, 2006; Hu & Sundar, 2009; Laurent & Vickers, 2009).

1.4.3 The role of search engines in looking for health information online

Search engines are the most widely used method of looking for information online: 92% of American Internet users use search engines, and 6 in 10 use a search engine every day (Purcell, 2011). By extension, most people searching online for health information start by entering their query into a search engine, rather than typing in a web address or using a field specific portal (Adams, 2006; Fox, 2011a; Mager, 2009; Zamaria & Fletcher, 2008). People who use search engines tend to select either the first or second ranked link, and only very rarely browse beyond the first results page (Granka, 2004; Guan & Cutrell, 2007; Eysenbach &
Kohler, 2002). Search engines thus have a profound effect on the types of information the majority of Internet users have access to.

Google is by far the most widely used search engine in North America: 91% of Canadian Internet users use this search engine (Zamaria & Fletcher, 2008), and searches on Google accounted for 66.1% of all searches performed in the USA in September 2011 (this was followed by Yahoo at 15.22% of all searches) (Experian Hitwise, 2011). In 2008, Google launched Google Insights for Search, a web interface that can be used to map trends in Google searches. These resources have since been used to forecast unemployment rates (Askitas & Zimmerman, 2009; d’Amuri & Marcucci, 2009; Choi & Varian, 2009b), monitor changes in consumer demand and economic activity (Suhoy, 2010; Kholodilin, 2009; Choi & Varian, 2009); and, in the field of public health, have been used to pinpoint and monitor potential outbreaks of influenza (Eysenbach, 2008; Ginsbergh, 2009; Polgreen, 2008; Carneiro & Mylonakis, 2009). Google search trends data also have been used to examine the effects of changes in health policy on health information seeking online (Reis & Brownstein, 2010; Ayers, 2011).

1.4.4 Web-based resources for EC

Two studies have evaluated online searches for EC based resources (Gainer, 2002; Wynn & Trussell, 2005). These studies, conducted between 2000 and 2005, consisted of a quantitative (e.g., recording the number of website visits) and qualitative evaluation (e.g., the types of questions submitted to the website) of specific EC-related websites. Both studies found that after the website homepage, users visited the frequently asked questions page
most frequently. Questions submitted to the website were most frequently related to the appropriate time frame for taking EC, the likelihood of getting pregnant following a single act of unprotected intercourse, side effects and cost (Wynn & Trussell, 2005; Gainer, 2002). Many questions also related to contraception and sexual health in general.

Only one formal content analysis, published over a decade ago in 2000, has evaluated the quality of EC-related information online in USA based searches (Latthe, 2000). This study consisted of an analysis of 32 websites found in web searches for combinations of “emergency contraception” and “patient information”. Each website was assessed using an author-designed rubric, which assessed the quality (defined as the extent to which the website fulfilled its stated objectives), perceived credibility (the source and presence of an editorial review process) and accuracy of the website’s written content. Latthe found that while the majority of websites displayed the source of information, none fully satisfied the author’s quality criteria. However, this study did not use a “consumer centric” search strategy, for example they used technical, rather than more commonly used “lay” terms such as “morning after pill”. Moreover, this study was performed prior to the policy changes making EC available OTC.

In a Canadian-based study completed more recently, Hocevar & Yuksel (2011) evaluated the readability of patient information for the commercial EC product Plan B®, including web-based information. They found that printed packaging information for Plan B had a mean reading grade level of 12.9, and online material had a reading grade level of 13.4. These reading grade levels are well above the 8th reading grade level recommended for
written patient health literature by the Canadian Public Health Association (Canadian Public Health Association, 2011).

1.5 Thesis Objectives

In light of recent changes in EC-related policy and the increasingly pertinent role of the Internet as a source for health information, a study of online search behaviour for EC-related topics and an analysis of available web-based resources regarding EC are warranted. The current thesis includes a quantitative analysis of searches for EC-related search terms on Internet search engines in Canada and the USA across a 6-year period (2004-2010) that includes key milestones in which the policy and regulatory environment related to EC experienced significant changes. An additional chapter includes a description of the results of a content analysis of EC-related web resources. These analyses are intended to help elucidate the broad impact of EC-related regulatory changes making EC available without a prescription on the volume of online searches for EC as well as the nature of the resources that Internet users find when searching for EC-related keywords online.

The objectives of the current thesis are to:

1. Investigate changes in Internet search patterns for EC-related search terms in Canada and the USA over time and through shifts in EC-related policy between 2004-2010.

2. Characterize the nature (e.g., saliency, credibility) and source (e.g., financial affiliations) of available web-based information about EC.
1.6 Thesis Outline

In addition to this introductory chapter, the current thesis includes two empirically-based chapters that report the findings of two separate, but related, analyses (Chapters 2 and 3), and a concluding chapter discussing overall findings (Chapter 4). Chapter 2, entitled ‘Searching for Emergency Contraception Online: Analysis of Google Search Patterns for EC-Related Search Terms’, investigates the changes in Internet search patterns on the Google search engine for EC-related search terms over time and across changes in EC-related policy. Chapter 3, entitled ‘Content Analysis of Web-based resources about Emergency Contraception’, assesses the quality and relevance of web-based information about EC through a content analysis of top search engine results for EC-related search terms. The discussion (Chapter 4) contextualizes and integrates the findings of both previous chapters and highlights their implications for future research and policy interventions.
Chapter 2.0 Searching for Emergency Contraception Online: Analysis of Google Search Patterns for EC-related Search Terms

2.1 Introduction

Unintended pregnancy is a concern for North American women of reproductive age. There is currently no national data on the prevalence of unintended pregnancy in Canada (Canadian Federation for Sexual Health, 2007). However, women in the USA experience high rates of unintended pregnancy relative to other industrialized nations, such as western European countries (e.g., France and the UK) (Singh, 2009). Approximately 49% of all pregnancies in 2006 in the USA were unintended (Finer & Zolna, 2011). Rates of unintended pregnancy are highest among women aged 18 to 24; 68% of all pregnancies among women aged 18 to 24 in 2006 were unintended (Finer & Zolna, 2011).

Emergency contraception (EC) is a safe and effective method of reducing the risk of pregnancy following unprotected or under-protected sexual intercourse (von Hertzen, 2002). However, EC is a time sensitive agent: the timing of the initial dose is crucial and its efficacy decreases linearly over time, that is, the sooner it is taken following unprotected sex, the more effective it is (Rodrigues & Grou, 2001). Since 2000, a series of policy changes have been implemented in Canada and the USA meant to improve timely and convenient access to EC. In April of 2005, EC was made available in Canada behind-the-counter (BTC), meaning that it could be accessed by request from a pharmacist without a doctor’s prescription (Sibbald, 2005).
2008 EC became available over-the-counter (OTC) in Canada, so that it could be accessed from pharmacy shelves in front of pharmacists’ counters, eliminating the need to consult with a pharmacist (Eggerston, 2008). Regulation in the USA has followed a similar trajectory; the Food and Drug Administration (FDA) approved EC for OTC status for individuals aged 18 and older in August 2006, and for individuals aged 17 and older in April 2009 (Food and Drug Administration, 2006; Food and Drug Administration, 2009a). There is currently no BTC status for drugs in the USA.

At the same time as these changes in the regulatory status of EC have been occurring, the Internet has arisen as a major source for health information. 70% of Canadian Internet users and 80% of American Internet users report looking for health information online (Zamaria & Fletcher, 2008; Fox & Rainie, 2000; Fox, 2011). This includes looking for information about drugs online: 45% of American Internet users reported having looked for information about prescription and non-prescription drugs in 2008, up from 34% in 2002 (Fox, 2009). Furthermore, the first “digital divide”, the gap in access to the technology necessary to go online has nearly closed among younger age groups (Fox, 2009; Zamaria & Fletcher, 2008).

Web search engines play a central role in looking for health information online: two-thirds of searches for health information in the USA begin with a search engine (Fox, 2006). Web search patterns have been recognized as an important complementary source of information to traditional methods of public health research and surveillance (Eysenbach, 2006; Brownstein, 2009). For instance, tracking search volume for influenza related search terms has proven to be a useful and timely data source, which can be used in conjunction with traditional surveillance techniques (e.g., reports by physicians of flu related illnesses) to track outbreaks of influenza (Eysenbach, 2006). In 2008, Google launched Google Insights for Search (www.google.com/insights/search/#), a web
interface that can be used to map trends in Google searches over time and in specific geographic locations. Analysis of Google search patterns have since been used to pinpoint and monitor potential outbreaks of infectious diseases, including influenza (Brownstein, 2010; Ginsbergh 2009; Polgreen, 2008; Carneiro & Mylonakis, 2009), listeriosis (Wilson & Brownstein, 2009) and Lyme disease (Seifter, 2010). More recently Google search data has been used to examine the impacts of health policy, including abortion and smoking prevention policies (Ayers, 2011; Reis & Brownstein, 2010).

While previous studies have measured the effect of non-prescription availability of EC on rates of use, STIs, and unintended pregnancy (Raymond, 2007; Dunn, 2008; Kavanaugh, 2011; Raine, 2005; Soon, 2005), little is known about the impact of EC-related policy change on the frequency with which people look for online information about EC. Analysis of Google search data has the potential to elucidate the impact of EC-related policy change on the frequency with which people access information on the web. The present study used Google search data to investigate the longitudinal effects of regulatory changes making EC available without a prescription on online interest in EC-related search terms, in Canada and the USA.

2.1.1 Research aims

The current study aimed to investigate the changes in Google search patterns for EC-related search terms in Canada and the USA over time and across changes in policy that made EC available in pharmacies without a prescription. In Canada, the association was measured between changes in search volume and (1) the April 2005 federal regulatory decision that made EC available BTC and
(2) the May 2008 policy decision that made EC available OTC. In the USA, the association was measured between changes in search volume and (1) the August 2006 decision by the FDA that made EC available OTC for individuals aged 18 and over and (2) the April 2009 decision by the FDA that granted OTC access for individuals aged 17 and over.

2.2 Methods

2.2.1 Data collection

Google search volume data was obtained from the online application Google Insights for Search (www.google.com/insights/search/#). Rather than report raw search numbers, Google Insights reports relative search volume: the raw number of queries is normalized by total search volume in a geographic region of interest and displayed on a scale of 0 to 100, so that the period of peak search volume is assigned a value of 100, and each point below that is represented as a percentage of the maximum search volume (Ayers, 2011). For example a period with half the number of queries as during the peak period of interest is represented as 50.

Google reports search volume monthly for some search terms and weekly for others, and there is overlap between weeks and months. Therefore, in order to compare the two, the average daily query indexes per month for those that were reported weekly were calculated. An initial pool of brand specific and general search terms for EC were selected, including: “Plan B”; “Plan B pill”; “Norlevo”; “Next Step”; “emergency contraception”; and “morning after pill”. From that pool, two search words were selected for analysis based on the two most popular EC-related search words in
Canada and the USA between 2004 and 2010 according to Google Insights for Search: (1) “plan b”, and (2) “morning after pill”. Search volume data was downloaded and analyzed for each search term separately, and for each country separately.

2.2.2 Period of assessment

Search volume was studied from January 2004, the earliest date at which Google Insights for Search reports search data, to December 2010. Two dedicated levonorgestrel-only products were available in Canada during this time: Plan B® which became available with a prescription in 1999, and NorLevo®, which became available in May 2009 (Bayer Inc., 2009). In the USA, the two dose version of Plan B™ became available with a prescription in 1999, and has since been replaced with Plan B One-Step™, a single dose levonorgestrel-only product. Next Choice®, a generic brand of EC, became available in the USA in 2009 (Food and Drug Administration, 2009b).

In Canada, two significant changes to EC’s regulatory status occurred during this time period. In April 2005, Canada’s NAPRA recommended that EC be moved from Schedule I (prescription only) to Schedule II (BTC) status, and in May 2008, from Schedule II to Schedule III status (OTC) (Sibbald, 2005; Eggerston 2008). NAPRA’s recommendations are implemented differently in each province; therefore, these changes took effect on different dates across the country, resulting in some variability across geography. EC has remained BTC in Saskatchewan and by pharmacists’ prescription only in Quebec. EC is currently available OTC in the remaining 8 provinces and 3 territories, meaning that 75% of women aged 15-44 in Canada currently have OTC access to EC (Statistics Canada, 2010). In the USA, the FDA granted Plan B® OTC status in August of 2006 for
individuals aged 18 and older. Plan B remained prescription only for individuals aged 17 and younger (Food and Drug Administration, 2006). In April 2009, the FDA announced it would make Plan B® available to individuals 17 and older without a prescription; meaning that the manufacturer of Plan B™, Duramed Pharmaceuticals, was able to apply to the FDA for approval to market Plan B™ to individuals aged 17 years and older (Food and Drug Administration, 2009). FDA regulations apply across the USA, so that if the FDA designates a drug OTC, it has this status in all states. The FDA currently has a two-tier system, in which drugs are either prescription only, or non-prescription (i.e., OTC).

2.2.3 Statistical analysis

Interrupted time series analysis was used to examine the impact of Canadian and American policy interventions related to EC availability on Google search volumes for EC-related search terms. Interrupted time series is the strongest quasi-experimental design available to evaluate the longitudinal impact of sudden interventions on an outcome. Interrupted time series analysis was used to detect statistically significant changes in search volumes related to the policy changes (Wagner, 2002). Interrupted time series analysis measures changes to two parameters of the outcome of interest: the level (the immediate change in the value of the outcome measure at the beginning of a given time interval) and the trend (the change in the rate of change, i.e., the slope, of the outcome measure during a given interval). A change in level (e.g., a sudden drop or rise) in an outcome following an intervention represents an immediate effect, and a change in trend (the change in the slope or rate of change) in the outcome following an intervention represents a
gradual effect of an intervention over time. Interrupted time series analysis is useful because it allows identification of policy-induced changes while controlling for existing secular trends in the outcome of interest.

A plot of the residuals for each outcome was inspected for autocorrelation between data points (including first order correlation between consecutive data points and higher order autocorrelation such as seasonal variation). Inspection of residuals for each outcome revealed no autocorrelation between data points. Relative policy effects were estimated by subtracting the predicted counterfactual search volume from the search volume observed with the intervention and dividing the estimated percentage change by the counterfactual search volume without the intervention. All statistical analyses were performed using the NLME package for R software for Mac (Version 2.10.1).

2.3 Results

2.3.1 Changes in relative search volume over time

The search volume for “Plan B” increased over the course of the observation period (January 2004 to December 2010), in both Canada and the USA. In contrast, search volume for “morning after pill” declined over the observation period in both countries. See Figure 1 for relative search volume in Canada and the USA over time and shifts in EC-related policy.

In Canada, search volume for “Plan B” was 0% of peak search volume for both search terms in January 2004 and had an overall upward trend over the observation period, reaching 100%
of peak search volume for both search terms in October 2010. Search volume for “morning after pill” was 32% of peak search volume in January of 2004 and reached its peak value of 49% of peak search volume for both search terms in April 2005. At the end of the observation period, search volume for “Plan B” was 3.5 times that of “morning after pill”.

In the USA, search volume for “morning after pill” was initially 2.5 times that of “Plan B”. Search volume for “Plan B” was 10% of peak search volume for both search terms in January 2004, and reached 100% of peak search volume in December 2010. Search volume for “morning after pill” started at 25% of peak search volume for both search terms. Following the initial shift to OTC status in August 2006, search volume for “Plan B” was consistently greater than that for “morning after pill”. This trend continued until the end of the observation period, when the search volume for “Plan B” was 5 times that of “morning after pill”: search volume for “Plan B” was 100% of peak search volume and search volume for “morning after pill” was 20% of peak search volume.

2.3.2 Effects of EC-related policy change on relative search volume

In Canada there was a statistically significant increase of 11.3 standardized units (SU) (95%CI 4.01 SU, 18.59 SU; p-value 0.0033) in search volume for “Plan B” in the month following the April 2005 policy change making EC available BTC. This amounts to a 55.2% relative increase in search volume following the change to BTC status. See Table 1 for parameter estimates, t-statistics, P-values from interrupted time series analysis predicting search volume in Canada for “Plan B” and “morning after pill” over time in response to changes in EC access between 2004 and 2010. Search volume for “Plan B” continued to
increase over time until the May 2008 change to OTC access, after which there was a relative increase in trend of 0.73 SU per month (95%CI 0.36 SU, 1.10 SU; p-value 0.0002) on top of the existing rate of change. In contrast, there were no immediate statistically significant changes in search volume for “morning after pill” in response to the shifts to BTC or OTC access. However, in the long-term there was a change in trend following the May 2008 shift to OTC status in Canada, when there was a statistically significant relative increase of 0.81 SU per month (95%CI 0.40 SU, 1.21 SU; p-value 0.0002) on top of the existing rate of change. As search volume for “morning after pill” decreased over time both before and following the April 2005 shift to BTC status, this increase in long-term trend amounted to a slowing in the decline of searches for “morning after pill” after the shift to OTC in Canada. See Figure 2A for relative monthly search volume for “Plan B” and Figure 2B for relative monthly search volume for “morning after pill” in Canada from January 2004 to December 2010.

In the USA, there was a statistically significant immediate increase in search volume level of 15.68 SU (95% CI 10.18SU, 21.19SU; p-value 0.0000) in search volume for “Plan B” in the month following the August 2006 shift to OTC for 18 year olds and older. This amounted to a relative increase of 87.7% in search volume following the shift to OTC status for 18 year olds and older. See Table 2 for regression coefficients, t-statistics, P-values and percent relative change from interrupted time series analysis predicting search volume in USA for “Plan B” and “morning after pill” over time in response to changes in EC access between 2004 and 2010. Search volume for “Plan B” continued to increase over time at the same rate between August 2006 and the May 2009 shift to OTC access for 17 year olds and older. Following the shift to OTC availability for 17 year olds and older there was a statistically significant increase in the trend of 1.76 SU per month (95%CI
0.86SU, 2.65SU; p-value 0.0003) in search volume for “Plan B” on top of the existing trend. See Figure 3A for relative monthly search volume for “Plan B” in the USA and Figure 3B for relative monthly search volume for “morning after pill” in the USA between January 2004 to December 2010. In the month following the August 2006 policy change there was a statistically significant increase in level of search volume for “morning after pill” of 10.59SU (95%CI 4.58SU, 16.60SU; p-value 0.0009). This amounted to an 18.5% relative increase in search volume. However, in the long term, the trend for search volume for “morning after pill” decreased from its rate before the policy change by 0.68 SU per month (95%CI -1.03SU, -0.33SU; p-value 0.0003). There was no statistically significant immediate change in search volume for “morning after pill” following the May 2009 shift to OTC for 17 year olds and older. However, there was a statistically significant increase in trend in search volume for “morning after pill” of 0.72 SU per month (95%CI 0.21 SU, 1.22 SU; p-value 0.0070) on top of the existing trend before the policy change. There also appeared to have been an increase in search volume for “Plan B” between August 2008 and January 2009 prior to the 2009 FDA announcement. However, this change did not occur contemporaneously with any changes in FDA policy regarding EC availability.
Table 2.1 Parameter estimates, t-statistics, P-values from interrupted time series analysis predicting search volume in Canada for (A) “Plan B” and (B) “morning after pill” over time in response to BTC and OTC access to EC (2004-2010). BTC stands for behind-the-counter status, OTC stands for over-the-counter status.

<table>
<thead>
<tr>
<th>Search Term</th>
<th>Variable</th>
<th>Regression Coefficient (95% CI)</th>
<th>t-statistic</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plan B</td>
<td>Intercept $\beta_0$</td>
<td>10.53 (3.10, 17.96)</td>
<td>2.78</td>
<td>0.0068</td>
</tr>
<tr>
<td></td>
<td>Baseline Trend $\beta_1$</td>
<td>0.59 (-0.18, 1.37)</td>
<td>1.50</td>
<td>0.1388</td>
</tr>
<tr>
<td></td>
<td>Level change after BTC $\beta_2$</td>
<td>11.3 (4.01, 18.59)</td>
<td>3.04</td>
<td>0.0033*</td>
</tr>
<tr>
<td></td>
<td>Trend change after BTC $\beta_3$</td>
<td>-0.27 (-1.10, 0.57)</td>
<td>-0.62</td>
<td>0.5346</td>
</tr>
<tr>
<td></td>
<td>Level change after OTC $\beta_4$</td>
<td>1.89 (-4.55, 8.33)</td>
<td>0.58</td>
<td>0.5668</td>
</tr>
<tr>
<td></td>
<td>Trend change after OTC $\beta_5$</td>
<td>0.73 (0.36, 1.10)</td>
<td>3.86</td>
<td>0.0002*</td>
</tr>
<tr>
<td>morning after</td>
<td>Intercept $\beta_0$</td>
<td>65.09 (56.7, 73.5)</td>
<td>15.24</td>
<td>0.0000*</td>
</tr>
<tr>
<td>pill</td>
<td>Baseline Trend $\beta_1$</td>
<td>-0.17 (-1.06, 0.72)</td>
<td>-0.38</td>
<td>0.7075</td>
</tr>
<tr>
<td></td>
<td>Level change after BTC $\beta_2$</td>
<td>7.48 (-1.18, 16.14)</td>
<td>1.69</td>
<td>0.0943</td>
</tr>
<tr>
<td></td>
<td>Trend change after BTC $\beta_3$</td>
<td>-0.63 (-1.58, 0.31)</td>
<td>-1.31</td>
<td>0.1928</td>
</tr>
<tr>
<td></td>
<td>Level change after OTC $\beta_4$</td>
<td>4.23 (-3.21, 11.7)</td>
<td>1.11</td>
<td>0.2684</td>
</tr>
<tr>
<td></td>
<td>Trend change after OTC $\beta_5$</td>
<td>0.81 (0.40, 1.21)</td>
<td>3.90</td>
<td>0.0002*</td>
</tr>
</tbody>
</table>

*Statistically significant at the 0.05 level*
Table 2.2 Parameter estimates, t-statistics, P-values from interrupted time series analysis predicting search volume in the USA for (A) “Plan B” and (B) “morning after pill” over time in response to OTC for 18+ and 17+ access (2004-2010). OTC18+ stands for over-the-counter status for individuals over 18, and OTC17+ stands for over-the-counter status for individuals over 17.

<table>
<thead>
<tr>
<th>Search Term</th>
<th>Variable</th>
<th>Regression Coefficient (95% CI)</th>
<th>t-statistic</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plan B</td>
<td>Intercept ( \beta_0 )</td>
<td>10.07 (1.19, 18.96)</td>
<td>2.22</td>
<td>0.0291</td>
</tr>
<tr>
<td></td>
<td>Baseline Trend ( \beta_1 )</td>
<td>0.24 (-0.18, 0.66)</td>
<td>1.11</td>
<td>0.2698</td>
</tr>
<tr>
<td></td>
<td>Level change after OTC 18+ ( \beta_2 )</td>
<td>15.68 (10.18, 21.19)</td>
<td>5.58</td>
<td>0.0000*</td>
</tr>
<tr>
<td></td>
<td>Trend change after OTC 18+ ( \beta_3 )</td>
<td>-0.10 (-0.80, 0.60)</td>
<td>-0.28</td>
<td>0.7820</td>
</tr>
<tr>
<td></td>
<td>Level change after OTC 17+ ( \beta_4 )</td>
<td>-0.65 (-6.29, 4.98)</td>
<td>-0.23</td>
<td>0.8205</td>
</tr>
<tr>
<td></td>
<td>Trend change after OTC 17+ ( \beta_5 )</td>
<td>1.76 (0.86, 2.65)</td>
<td>3.83</td>
<td>0.0003*</td>
</tr>
<tr>
<td>morning after pill</td>
<td>Intercept ( \beta_0 )</td>
<td>57.57 (52.97, 62.17)</td>
<td>24.55</td>
<td>0.0000*</td>
</tr>
<tr>
<td></td>
<td>Baseline Trend ( \beta_1 )</td>
<td>-0.13 (-0.38, 0.12)</td>
<td>-1.03</td>
<td>0.3082</td>
</tr>
<tr>
<td></td>
<td>Level change after OTC 18+ ( \beta_2 )</td>
<td>10.59 (4.58, 16.60)</td>
<td>3.45</td>
<td>0.0009*</td>
</tr>
<tr>
<td></td>
<td>Trend change after OTC 18+ ( \beta_3 )</td>
<td>-0.68 (-0.33, -1.03)</td>
<td>-3.81</td>
<td>0.0003*</td>
</tr>
<tr>
<td></td>
<td>Level change after OTC 17+ ( \beta_4 )</td>
<td>1.82 (-4.83, 8.48)</td>
<td>0.54</td>
<td>0.5932</td>
</tr>
<tr>
<td></td>
<td>Trend change after OTC 17+ ( \beta_5 )</td>
<td>0.72 (0.21, 1.22)</td>
<td>2.77</td>
<td>0.0070*</td>
</tr>
</tbody>
</table>

*Statistically significant at the 0.05 level*
Figure 2.1A Relative weekly search volume of “Plan B” and “morning after pill” in Canada over time from January 2004 to December 2010 including the April 2005 shift to behind-the-counter availability and May 2008 shift to over-the-counter availability. BTC stands for behind-
the-counter status, OTC stands for over-the-counter status.

Figure 2.1B Relative weekly search volume of “Plan B” and “morning after pill” in the USA over time from January 2004 to December 2010, including the August 2009 shift to over-the-counter availability for aged 18+ and the April 2009 shift to over-the-counter for aged 17+ in April 2009. OTC stands for over-the-counter status.
Figure 2.2A Relative monthly search volume for “Plan B” in Canada between January 2004 and December 2010. L indicates a significant change in level of search volume, T indicates a significant change in trend. + and – indicate the direction of the change. BTC stands for behind-the-counter status, OTC stands for over-the-counter status.
Figure 2.2B Relative monthly search volume for “morning after pill” in Canada between January 2004 and December 2010. L indicates a significant change in level of search volume, T indicates a significant change in trend. + and – indicate the direction of the change. BTC stands for behind-the-counter status, OTC stands for over-the-counter status.
Figure 2.3A Relative monthly search volume for “Plan B” in the USA between January 2004 and December 2010. L indicates a significant change in level of search volume, T indicates a significant change in trend. + and – indicate the direction of the change. OTC stands for over-the-counter status.
Figure 2.3B Relative monthly search volume for “morning after pill” in USA between January 2004 and December 2010. L indicates a significant change in level of search volume, T indicates a significant change in trend. + and – indicate the direction of the change. BTC stands for behind-the-counter status, OTC stands for over-the-counter status.
2.4 Discussion

These results indicate that immediate and long-term changes in the frequency of online searches for EC-related search terms followed shifts in regulatory policy in Canada and the USA facilitating pharmacy access to EC. A sharp increase in search volume for the commercial brand Plan B® in Canada and Plan B One-Step™ in the USA occurred following the initial shift to availability without a prescription. Search volumes for “morning after pill” also rose sharply in the USA following the 2006 change. The same jump in search volume was not seen following the later changes (i.e. OTC availability in Canada and OTC availability for 17 year olds and older in the USA). However, these later changes did appear to initiate a long-term increase in search volume trend (i.e. slope) for “morning after pill” and “Plan B” in both Canada and the USA.

Online resources may be particularly important in an OTC context, given that potential users of OTC drugs may not have the opportunity to ask their healthcare providers questions about effectiveness or potential side effects. In the case of EC, the Internet may be an appealing source of information for the additional reason that users are able to browse for information confidentially and anonymously (Gilbert, 2005; Suzuki & Calzo, 2004). Previous research has demonstrated that feelings of embarrassment or being judged may act as a deterrent for individuals, particularly youth and young adults, from asking their pharmacist or healthcare provider about EC (Calabretto, 2004). Furthermore, though the Canadian Contraception Consensus Guidelines state that “women and men of reproductive age should be counseled about emergency contraception” and that “women should be offered a
prescription in advance of need”, research indicates that there is significant variation in the degree to which letter of these guidelines is followed in Canada (Fisher & Black, 2007). In the USA, few primary care physicians counsel their patients about EC: Kavanaugh (2011) found that among the 63% of women surveyed who reported having received a Pap test or pelvic examination in the past 12 months, only 4% reported having received counseling about EC.

These findings suggest that there has been a divergence in the popularity of searches for “morning after pill” and “Plan B” following non-prescription availability of EC; search volume for “Plan B” surpassed that for “morning after pill” consistently in both Canada and the USA following the regulatory change to BTC and OTC, respectively. This may suggest a broader tendency of Internet users to search by brand, rather than generic or “lay” name, when searching online for EC. However, a more comprehensive study of the search patterns of a complete suite of brand and generic names for EC is suggested before conclusions are drawn.

2.4.1 Limitations

These results should be interpreted in light of a number of limitations. Google Insights for Search does not allow for disambiguation of queries (e.g., limiting searches referring to emergency contraception only). Consequently, search patterns may be obscured by searches for alternative uses of the term “Plan B”. For example, searches for Plan B also yielded results for an English musician (www.myspace.com/time4planb), and an American skateboard company (www.planbskateboards.com). Furthermore, because Google Insights
for Search only reports the relative number of searches scaled by region, information about the absolute number of searches, including the number of unique searches, is not available.

Interrupted time series analysis also assumes that the outcome has a linear trend over the entire length of a given segment, an assumption that may hold for only part of a segment (Wagner, 2002). Further, interrupted time series analysis can be biased if an event other than the intervention that is related to the outcome occurs at the same time. In order to separate the effects of concurrent events from those of the intervention, a control group that is not exposed to the intervention is required for comparison (Wagner, 2002). With EC, such a comparison group was not available. However, no evidence was found of concurrent news stories or policy changes that may have led to the increase in search volumes that were observed. Nevertheless, there was a marked increase in search volume for “Plan B” in the USA between August 2008 and January 2009, which occurred in absence of a federal regulatory change. Further investigation of factors beyond BTC and OTC access that might have a detectable effect on search volume for “morning after pill” and “Plan B” presents a potentially informative avenue of study.

2.4.2 Implications

A large and increasing number of individuals are looking for health information online, and a significant proportion use search engines to initiate their queries. Changes in federal drug policy have the potential to directly affect the number of people who search for related resources online, and the strategies (e.g., search words) they choose to use. It is
essential that regulatory agencies take this into account as they implement changes in drug policy and ensure that those who would benefit most from these changes (e.g., young women of reproductive age) have convenient access to accurate, up-to-date, unbiased, and easy to read information online.

Variability in the quality and completeness of online information about health has been a subject of concern, and a significant amount of research, since the 1990s (Eysenbach & Diepgen, 1998; Crocco, 2002; Deshpande & Jadad, 2009; Wilson, 2002). However, interventions to filter low quality health information, for instance by using quality labeling systems (Boyer, 1998) and user rating tools (Charnock, 2004), have met with limited success, both in terms of preventing the availability of misinformation on the web, and aiding consumers to discern good from bad (Deshpande & Jadad, 2009; Eysenbach, 2008).

Understanding the way people access health information online provides a basis to effectively target reliable, high quality resources and make sure that Internet users have convenient access to them.

One recent example of a targeted intervention is the National Institutes of Health partnership with Google, which ensures that the first result in searches for generic drug names is the NIH drug information page. Unfortunately however, no such partnership currently exists in Canada, nor does this arrangement apply to drugs once they become available OTC. Law (2011) found that in the absence of this agreement that web searches for brand name and generic names for prescription pharmaceuticals led to most often to Wikipedia and/or industry sponsored sites. Previous studies have raised concerns about the quality and completeness of Wikipedia drug entries (Davis, 2007), as well as the objectivity of
industry sponsored websites (e.g., providing a full account of the risks and adverse side effects) (Clauson, 2008).

Increases in search volume for EC-related search terms may suggest that there has been a significant rise in EC use since it became available in pharmacies. Previous research has shown that peaks in online searches for specific commercial products are related to increases in sales of those products, implying that people search for products they intend to purchase (Choi & Varian, 2009a; Choi & Varian, 2009b). The Canadian based study by Soon (2005) found that rates of EC use in BC increased dramatically following the province-wide regulatory shift to pharmacy availability in December of 2000. The changes in search volume may reflect changes in EC use. For example, the rise in search volume for “Plan B” following the 2005 change to BTC in Canada may indicate that there was a concurrent nationwide increase in sales of Plan B® in Canada at this time. Analysis of data collected by the National Family Growth Survey performed by Kavanaugh (2011) also showed that there was an increase in self-reported EC use by women following the 2006 shift to OTC, from 4.2% to 9.7% of all sexually active women. The long and short term increases in search volume for EC-related search terms (e.g., the immediate increase in search volume for “morning after pill” and “Plan B” in the USA following the 2006 shift to OTC availability for 18 year olds and older) may therefore mirror increases in EC use in the USA. Further quantitative (e.g., interrupted time series analysis of sales of Plan B® data in Canada and Plan B One-Step™ in the USA and an analysis of prescription and provision patterns by clinicians of EC) and qualitative analysis (e.g., an exploration of the attitudes and knowledge of EC among clinicians, pharmacists, and
potential EC users) is recommended in order to fully elucidate the impact of policy change on patterns of EC use in North America.

As a convenient and free source of information, search volume data is emerging as an important public health tool to examine the broad impacts of health policy (Ayers, 2011; Reis & Brownstein, 2010). This is the first study to examine the longitudinal effects of policy change on search term popularity using interrupted time series analysis. This approach could be extended to examine the impact of policy changes on the online popularity of other search terms, for instance on other prescription and non-prescription drugs.

2.5 Conclusion

This analysis revealed that there were significant changes in search patterns for EC-related search terms associated with regulatory changes making EC available without a prescription. At the end of 2010, searches for the commercial brand Plan B® and Plan B One-Step™ surpassed those for the more general term “morning after pill” in Canada and the USA. The association between changes in regulatory policy making EC available BTC and OTC and search volume for EC-related search terms suggest that short term increases in search popularity for “Plan B”, and in the USA “morning after pill”, were due in part to its availability without a prescription. Analysis of web-based search patterns may be used to assess changes in the online popularity of prescription and non-prescription drugs over time and across changes in policy.
Chapter 3.0 Content Analysis of Web-based Resources about Emergency Contraception

3.1 Introduction

Unintended pregnancy is a concern for young women: women aged 18 to 24 experience higher rates of unintended pregnancy than any other age group in the USA (Finer & Zolna, 2011). One effective means of reducing the risk of unintended pregnancy following unprotected or under-protected intercourse is using EC (von Hertzen, 2002). A series of regulatory changes in Canada and the USA have enabled the provision of EC OTC, which means that the product is accessible without a physician’s prescription on shelves in front of pharmacists’ counters (Eggerston, 2008; Food and Drug Administration, 2006). Young women between the ages of 18 and 24 are the most frequent users of EC, and access it from the pharmacy without a prescription more often than any other age group (Moreau, 2006; Kavanaugh & Schwartz, 2008; Soon, 2005).

The web is increasingly used as a source of health information, with approximately 70% of Canadian Internet users and 80% of American Internet users reporting that they look online for information about health (Zamaria & Fletcher, 2008; Fox & Jones, 2009). Forty-five percent of Internet users in the USA have used the web to look specifically for information about prescription or OTC drugs (Fox & Jones, 2009). Online resources may be an especially important source for health information among younger age groups, who are the most frequent and heaviest Internet users (Zamaria & Fletcher, 2008; Fox, 2010).
Studies have found that online health materials are highly variable with respect to their accuracy, completeness, and comprehensibility (Deshpande & Jadad, 2009; Eysenbach, 2008; Lee, 2009). Deficiencies have been identified in websites relating to prescription and OTC drugs (Clauson, 2008; Davis, 2007). Clauson (2008) found that drug entries in Wikipedia had high rates of errors of omission, and were generally narrower in scope and less complete than those in the Medscape Drug Reference website. Davis (2007) found that websites sponsored by pharmaceutical companies were unlikely to fully communicate risk information, including information about major adverse effects.

Only two studies have assessed the quality, completeness, and/or comprehensibility of the information available about EC online. The last study to evaluate the quality of online resources for EC was conducted more than ten years ago, in 2000 (Latthe, 2000). The study assessed the content of 32 EC-related websites found in searches for the key words ‘emergency contraception’ and ‘patient information’ on two search engines and two web-based medical health subject guides. Hocevar & Yuksel (2011) evaluated the readability of patient materials for the commercial brand of EC Plan B® in Canada, including online, found that reading grade levels were higher than the 8th grade reading level recommended by the Canadian Public Health Association for written health materials. Web-based resources for EC in Canada and the USA should be re-evaluated in light of several significant developments that have taken place over the last decade, including: OTC availability of dedicated levonorgestrel products in Canada and the USA, changes in online resources, and changes in the way people search for
information online (e.g., the rise in popularity of the Google search engine). This study describes a systematic analysis of the source, quality, reliability and readability of websites found in Canadian and American based searches for EC-related search terms on the Google search engine.

3.1.1 Research Aims

The current study aimed to assess the nature (e.g., saliency, credibility) and source (e.g., financial affiliations) of available web-based information about EC by: (1) identifying the websites appearing on the first results page in online searches for EC-related search terms and the organizations that maintain and sponsor these sites; and (2) systematically assessing the quality, reliability and readability of information available in the identified sites.

3.2 Methods

3.2.1 Identification of websites

A list of brand specific and general search terms for EC was compiled, informed by relevant key terms found in peer-reviewed literature and popular media (e.g., news stories), as well as from Google’s ‘Autocomplete’ function, which suggests possible search terms based on the characters a searcher has entered as a query (Google Inc. 2011). This initial list included: “Plan B”, “Plan B pill”, “Plan B drug”, “Norlevo”, “Next Choice”, “morning after pill”, “day after pill”, “emergency contraception pill” and
“emergency contraception”. Google (Google.ca and Google.com) is the most frequently used search engine in North America: searches from Google account for 91% of all searches performed in Canada and the USA (Neilsen, 2009; Zamaria & Fletcher, 2008). The five most widely used Google EC search terms in Canada and the USA were selected by comparing the relative search volume for each search term in 2010 using Google’s Google Insights for Search (http://www.google.com/insights/search/#). Google Insights for Search is an application designed by Google that tracks search volume over time and by geographic location. The five EC search terms selected based on search volume were: “Plan B”, “morning after pill”, “Plan B pill”, “Plan B side effects”, and “emergency contraception”.

Eligible websites were identified by entering these five search terms into the Canadian Google and American Google search engines. As Google tailors results according to geographic location and search history (Google Inc., 2011a), searches for the five search terms were performed from two geographically separate Canadian IP addresses (in Vancouver & Toronto) and two geographically separate American IP addresses (in Seattle & New York City) on Google.ca and Google.com, respectively. Searches were performed between April and July 2011.

Previous studies indicate that search engine users rarely browse beyond the first page of search results (Granka, 2004; Guan & Cutrell, 2007; Eysenbach & Kohler, 2002). Therefore, only websites found on the first page of each search were included. Website addresses and related information were recorded from the first page of each search (rank of the website on the search page, name and type of the website’s sponsor, the
search term, name of searcher, and the location and date of search of each website).

Sites found in Canadian and American based searches were documented separately.

News stories, books, chat rooms, videos, websites not directly related to emergency contraception, advertisements, as well as “starred” links (those suggested by Google based on previous browsing history) were excluded. The USA based searches on Google.com included links that appeared at the bottom of the search page under the heading “Links suggested by Google”; these were also excluded.

Ten websites from Canadian based searches and ten websites from American based searches were selected for analysis. The top ten websites were selected by ranking websites according to the number of times they were mentioned in searches for the five search terms in the country in question, from most to least frequently. Ties were resolved by ranking websites according to their mean page rank (i.e. position they appeared in on the first search page) in the searches they appeared in; searches in which the website did not appear did not count toward the calculation of mean page rank. The top ten websites from each country according to this ranking algorithm were selected for analysis. In cases where the same website appeared in the top ten list of both countries, the website was analyzed only once. Similarly, in cases with different website addresses, but where written content was identical, content was analyzed only once. Variations on this “consumer-centric” search strategy have been used in other web content analyses (van der Marel, 2009; Ipser, 2007; Molassiotis & Xu, 2004; Tallgren, 2009). This search strategy was selected to collect the information most likely to be accessed by a lay consumer seeking information about EC online.
Website sponsors were categorized into six types: pharmaceutical company; university; user-generated; not-for-profit organization; commercial (non-pharmaceutical) organization; and government agency. These categories are similar to those which have been used in previous literature and reflect a wide range of possible website sponsorship (Law, 2011).

3.2.2 Assessment of website quality and reliability

The DISCERN instrument was used to assess the quality and reliability of websites (Charnock, 1998). DISCERN is a validated questionnaire-based rating tool developed to help consumers and information providers judge the quality and reliability of written health information about treatment choices. DISCERN does not evaluate the scientific quality or accuracy (e.g., methodological validity) of the evidence on which a website’s content is based, as this would involve a critical assessment of the original publications (Charnock, 1999). Rather, the questions in the DISCERN instrument assess whether the website: clearly states its aims; includes signs of potential bias; includes references and/or additional sources of information; includes sources of uncertainty in the literature; enumerates all potential treatment options; and includes a statement of risks and benefits of a potential treatment (including the risks and benefits of no treatment). The instrument is composed of 16 items rated on a five-point Likert scale. Section 1 (Questions 1-8) addresses the reliability of the publication, section 2 (Questions 9-15) focuses on the quality of information, and section 3 (Question 16)
assigns an overall rating from 1 (low quality) to 5 (high quality). Websites were grouped into five categories based on their overall DISCERN score (i.e. the sum of Q1 to Q15): excellent (63–75), good (51–62), fair (39–50), poor (27–38), and very poor (15–26) in content. These categories were based on those used in previous studies using DISCERN to assess website content (Hargrave, 2006; Stinson, 2009; Van der Marel, 2009).

DISCERN was originally developed to assess information published in written form (e.g., leaflets or pamphlets). Nevertheless, it has proven to be a valid method of evaluating the reliability and accuracy of web-based health information (Charnock & Shepperd, 2004). DISCERN has been used to assess a range of online health materials including those related to: asthma and atopic dermatitis (Batchelor & Ohya, 2009); anxiety disorders (Ipser, 2007); herbal medicines to treat cancer (Molassiotis & Xu, 2004); general anesthesia (Tallgren, 2009); depression (Griffiths & Christensen, 2000); chronic pain (Kaicker, 2010); childhood brain cancers (Hargrave, 2006; Lau, 2006); osteoporosis (Wallace, 2005); pathological gambling (Khazaal, 2008); carotid artery stenosis (Sadat, 2008); inflammatory bowel disease (Langille, 2010, van der Marel, 2009); bipolar disorder (Barnes, 2009); oral cancer and diseases (Lopez-Jornet & Comacho-Alonso, 2010); and juvenile arthritis (Stinson, 2009). DISCERN is strictly a tool designed to evaluate the written content of a publication, and does not assess the formal qualities of a website such as readability, use of graphics, layout, or issues specific to web-based media, such as interactivity or usability.
3.2.3 Raters

Raters were recruited through the Amazon Mechanical Turk Website (www.mturk.com/mturk/welcome). Amazon Mechanical Turk is a web platform where tasks are posted for workers to complete for pay. Raters were paid USD2.00 for completing the DISCERN instrument. Twenty non-expert Internet users rated each website, for a total of 20 x n questionnaires (n being the number of websites). The DISCERN instrument was posted, unmodified, with two questions requesting information about the rater’s age and sex, as well as three quality control questions and a link to the website to be evaluated. Raters were asked to read an informed consent form included with the instrument, and their completion of the DISCERN instrument signaled their consent. Following completion, surveys were screened and incomplete questionnaires or those in which the quality control questions were answered incorrectly were rejected, and the surveys re-posted on the Mechanical Turk site to be completed by another rater. This process was repeated until a total of 20 reviews were collected for each website. Questionnaires were completed between May and July 2011. Ethics approval was obtained from the University of British Columbia Behavioural Research Ethics Board, reference number H11-00458.

3.2.4 Assessment of website readability

Readability was assessed using the Flesch-Kincaid Grade Level and Flesch Reading Ease score. These tests measure the readability of written text based on the number of words per sentence and the number of syllables per word (Flesch, 1948).
The Flesch Reading Ease score is measured on a scale of 1 to 100, and a higher score indicates that the material is easier to read (Flesch, 1948). The Flesch-Kincaid Grade Level translates the Flesch Reading Ease score into a scale of 0 to 12, corresponding to USA school grade levels. A lower Flesch-Kincaid Grade Level indicates that the material is easier to read. These tests were selected because they are widely used to assess the readability of online health information (Langille, 2010; Khazaal, 2008; Barnes, 2009; Hargrave, 2006; Ipser, 2007; Kaicker, 2010). The Canadian Public Health association recommends that health information be written below 8th grade reading level and the American Food and Drug Administration recommends that health information be written between the 6th and 8th grade level (Canadian Public Health Association, 2011; U.S. Department of Health and Human Services, 2006). The text from each website was cut and pasted into Microsoft® Word 2008 for Mac (version 12.3.0), and used the spelling and grammar tool to generate a Flesch–Kincaid Grade Level and a Flesch Reading Ease score for each website.

### 3.2.5 Inter-rater agreement

Fleiss’ kappa statistical measure was used to evaluate inter-rater agreement. Fleiss’ kappa is related to Cohen’s unweighted kappa, which is a chance corrected statistical method commonly used to assess the proportion of agreement between the responses of two raters (Cohen, 1968; Fleiss, 1971). Fleiss’ kappa is generalized to evaluate concordance between multiple raters in cases where subjects are rated by the same number of raters but where the raters rating one subject aren’t necessarily the
same as those rating another. Acceptable levels of agreement vary between studies, and cutoffs are typically assigned arbitrarily. Categories recommended by Landis & Koch (1977) were used to interpret kappa values: kappa < 0 implies poor agreement; between 0.01 – 0.20 implies slight agreement; between 0.21 – 0.40 implies fair agreement; between 0.41 – 0.60 implies moderate agreement; between 0.61 – 0.80 implies substantial agreement; and between 0.81 – 1.00 implies almost perfect agreement between raters.

3.2.6 Statistical analyses

Descriptive statistical analyses were performed on each variable (overall DISCERN scores, Flesch Reading Ease score and Flesch-Kincaid Grade Level). Overall DISCERN scores were calculated by adding the scores for questions 1 to 15 and calculating the average score across all raters.

Simple linear regression was performed to determine whether there was an association between overall DISCERN score and sponsor type, country, and mean page rank. All statistical analyses were performed using R software for Mac (Version 2.10.1).

3.3 Results

3.3.1 Website characteristics

One hundred and forty five websites were initially identified in searches on www.google.com and 116 websites in searches on www.google.ca. See Figure 3.1 for a
detailed flowchart of website selection. After excluding duplicates (including links to different pages within the same website), news stories, books, chat rooms, videos, websites not directly related to emergency contraception, advertisements, suggested links, and "starred" results, 21 unique Canadian and 28 unique American websites remained. The mean page rank of the eliminated pages in both countries was 7.0, while the mean page rank of all pages that were included was 5.1; none of the eliminated sites achieved a page rank higher than two (data not shown). The top ten websites for each country were selected for analysis based on the number of hits for that website in searches for all five search terms, and ties were resolved using the mean page rank across searches for all five search terms. Two Canadian websites (www.steadyhealth.com and bodyandhealth.canada.com) had identical content generated by the same health information company, Mediresource Inc., so content from these websites was analysed only once. Two websites (ec.princeton.edu and en.wikipedia.org) appeared in the top ten in both countries and were rated only once. Readability and DISCERN scores were therefore generated for 17 websites, eight appearing in Canadian based searches (including two websites with identical content, which were treated as the same website), eight appearing in USA based searches and two appearing in both.

Table 3.1 describes the number of times a website appeared in searches in Canada and the USA, the mean search page rank (i.e. the mean position of the website on the first search page across searches for all five search terms), and the type of website sponsor. Among the most frequently found websites in Canadian and American
based searches, six (33.3%) websites were affiliated with not-for-profit organizations, two (11.1%) with pharmaceutical companies, one (5.6%) was user-generated, one (5.6%) website was associated with a university, six (33.3%) with commercial non-pharmaceutical companies, and two (11.1%) with governmental organizations. The website that appeared most frequently in Canadian based searches was www.planb.ca, the website sponsored by Paladin Labs, the pharmaceutical company that manufactures Plan B® in Canada. This website appeared 24 times on the first search page in Canadian based searches and had a mean page rank of 5.2. The second most frequently found page in Canadian based searches was ec.princeton.edu, the website is sponsored by the Office of Population Research at Princeton University, which appeared a total of nine times and had a mean page rank of 3.5. Ec.princeton.edu was the website that was found most frequently in American based search, appearing 12 times on the first search page, with a mean page rank of 2.5. The Wikipedia drug entry for EC was also found frequently in Canadian and American based searches, appearing eight times. Wikipedia ranked higher in Canadian based searches than in American based searches, with a mean page rank of 1.4 versus a mean page rank of 5.4.

3.3.2 Rater characteristics

Table 3.2 describes the self-identified socio-demographic characteristics of the raters. Three hundred and forty unique raters were recruited through the Amazon Mechanical Turk website and completed the DISCERN instrument. The mean age of
raters was 29.9 years (95%CI 10.8, 49.0). 57.1% of raters were women, and 42.9% were men. The mean time to complete one questionnaire was 78.8 minutes.

3.3.3 DISCERN ratings

Raters used the DISCERN instrument to assess the quality and reliability of the written content in the EC-related websites selected for analysis. Table 3.3 describes overall DISCERN scores (i.e. the sum of DISCERN questions 1 through 15) for websites found most frequently in Canadian and American based searches. The majority (83%) of websites in this study achieved a ‘good’ overall rating, and no website achieved lower than a ‘fair’ rating. The mean overall DISCERN score for all websites was 55.2 out of a possible 75.

Ec.princeton.edu achieved the highest overall DISCERN score of 60.6. The lowest overall DISCERN score of 47.9 was obtained by the website www.hasslefreeclinic.org, which was found in Canadian-based searches and is sponsored by the Hassle Free Clinic in downtown Toronto. The lowest overall score obtained by a website found in American-based searches was 49.3 by www.fda.gov, the website sponsored by the USA’s Food and Drug Administration.

The median DISCERN score for Question 16 for all websites, which rates the overall quality of the website, was 4 (IQR 4.0, 4.0). See Table 3.3 for scores for Question 16 of the DISCERN instrument for each website found most frequently in Canadian and American based searches. The websites sponsored by the Office of Population Research at Princeton University, ec.princeton.edu, received the highest possible score
of 5.0. The lowest overall quality score was given to the Canadian Women’s Health Network website (www.cwhn.ca) and www.morningafterpill.org, the website sponsored by the American Life League, both of which scored 3.0 out of a possible 5.0.

Overall, websites achieved high median scores between 4.0 and 5.0 for 10 of the 16 DISCERN questions. See Table 3.4 for median scores for each of the 16 questions of the DISCERN instrument across all websites. Overall, raters indicated that they felt websites clearly stated and achieved their aims. Websites achieved a median score of 5 for question 3, indicating that overall, raters also felt that website content was relevant. Websites also received high ratings for question 9, indicating that raters felt that websites provided a thorough description of how emergency contraception works. Lower scores were observed on questions relating to whether they clearly stated where the information in their websites came from (question 4, median score 3.0, Interquartile range [IQR], 2.5, 4.0) and when it was produced (question 5, median score 3.5, IQR 1.0, 4.5). Scores were most inconsistent for these questions. Websites did not score as well on questions relating to whether the websites referred to areas of uncertainty in the literature (question 8, median score 3.5, IQR 3.0, 4.0). Similarly, websites did not rate highly on questions relating to the provision of information on how treatment choices affect overall quality of life (question 13, median score 3.0, IQR 2.3, 3.9) and support for shared decision-making (question 14, median score 3.5, IQR 3.0, 4.0).
3.3.4 Inter-rater agreement

The overall Fleiss’ Kappa statistic for inter-rater agreement was 0.12, implying slight agreement between raters based on categories recommended by Landis & Koch (1977).

3.3.5 Website readability

The mean Flesch Reading Ease Score across all websites was 47.2 and the mean Flesch-Kincaid Grade Level was 10.0. See Table 3.3 for Flesch Reading Ease scores and Flesch-Kincaid Grade Levels for websites found in Canadian and American based searches. Only three (11%) websites, run by the Caring for Kids (www.caringforkids.cps.ca), the Public Health Agency of Canada (www.phac-aspc.gc.ca) and the Hassle Free Clinic (www.hasslefreeclinic.ca) were written between the 6 and 8th reading grade level recommended for written health materials by the Food and Drug Administration (U.S. Department of Health and Human Services, 2006) and below the 8th reading grade level recommended by the Canadian Public Health Association (Canadian Public Health Association, 2011). No websites found in USA based searches were written below the 9th reading grade level. The website that appeared most frequently in Canadian and American based searches, the commercial site for Plan B® www.planb.ca and Office for Population Health Research’s website, ec.princeton.edu, were written at an 8.8 and 12 grade level, both above the reading grade levels recommended by the FDA and CPHA.

Misinformation persists in frequently found websites related to EC. For instance,
www.morningafterpill.org, a website sponsored by the organization The American Life League, describes EC as a substance that induces the termination of an existing pregnancy (an abortifacient). This website appeared on the first page in 6 (60%) of searches for 5 EC-related search terms in American based searches, and had an average page ranking of 6.3. It is therefore likely that Internet users may find this website in their searches.

3.3.6 Effect of sponsor type & country on overall DISCERN scores

See Table 3.5 for overall DISCERN scores by sponsor type. University (ec.princeton.edu), and user-generated sites (en.wikipedia.edu) appeared frequently and achieved relatively high mean overall DISCERN scores: 60.6, and 59.7 respectively. Sites sponsored by pharmaceutical companies also appeared frequently and ranked high on search pages. This is not surprising considering that two of the search terms used to identify websites (“Plan B” and “Plan B pill”) were related to the brand name EC products Plan B One-Step™ in the U.S.A and Plan B® in Canada. However, because “Plan B” and “Plan B Pill” are among the most popular EC-related search terms, it is likely that these sites are among those most frequently found in EC-related queries. Sites sponsored by the government agencies, including the Public Health Agency of Canada, www.phac-aspc.gc.ca and the USA’s Food and Drug Administration, www.fda.gov appeared less frequently and achieved relatively low overall DISCERN scores.
See Table 3.6. for the results of linear regression model of the association between sponsor type, and country of search with overall DISCERN score (Question 1-15). University and user-generated websites had significantly higher overall DISCERN scores than the reference group. University website DISCERN scores were 7.04 times greater than the reference group (95%CI 1.89, 12.18, p-value 0.00767), and user-generated websites had a 5.84 times greater DISCERN score than the reference group (95%CI 0.69, 10.98, p-value 0.02677).

3.4 Discussion

Internet use among youth and young adults is nearly ubiquitous (Zamaria & Fletcher, 2008; Fox, 2010). Web-based resources thus offer the potential to provide the age group most vulnerable to unintended pregnancy with complete, accurate, and easy to read information about their reproductive health, including emergency contraception. The importance of online resources for EC may have increased since it became available on pharmacy shelves without a prescription, as EC-users may no longer be required to consult with their primary healthcare provider or pharmacist in order to receive the medication.

The user-generated website, Wikipedia, the university-sponsored website ec.princeton.edu, and websites sponsored by pharmaceutical companies were found most frequently in online searches for EC. In contrast, sites maintained by governmental (including public health) agencies did not appear as frequently in searches for EC-related search terms. This is in keeping with Law(2011), who found that in
searches for generic drug names Wikipedia ranked prominently, while searches for brand name drugs often yielded pharmaceutical company websites as the top search result.

Websites identified in this study were given higher DISCERN ratings than in previous studies of health information websites using DISCERN: 83% of websites in this study achieved a ‘good’ overall rating, and the remaining 17% achieved a ‘fair’ rating. In Stinson’s (2009) analysis of 58 websites with information about juvenile idiopathic arthritis, 42 (72%) rated ‘poor’ or ‘very poor’. In Van der Marel (2009), 43 (57%) of 76 websites relating to Inflammatory Bowel Disease were rated as ‘fair’ or ‘poor’. In Hargrave (2006), 39% of 115 websites about pediatric neuro-oncology were rated as ‘poor’, and 21% were rated as ‘very poor’. This may indicate that the majority of online materials available on these subjects were had significant deficiencies in terms of their quality and reliability.

The high ratings assigned in the current study may be because online material about EC is of higher quality than other health information online. Alternatively, this difference may be indicative of divergent views regarding quality and trustworthiness of web-based resources in the academic community and “lay” Internet users. Previous studies (including all of those mentioned, above) using the DISCERN instrument have largely used a panel of "expert" raters, including experts in the field (e.g., physicians or PhDs), and/or graduate or undergraduate students (Stinson, 2009; Barnes, 2009; Hargrave, 2006; Batchelor & Ohya, 2009; Griffiths & Christensen, 2000; Sadat, 2008;
Figure 3.1 Flowchart of website selection
Table 3.1  Websites found most frequently in Canadian and American based searches on google.ca and google.com for 5 EC-related search terms: “Plan B”, “morning after pill”, “Plan B pill”, “emergency contraception” and “Plan B side effects”. URL, search rank, number of times the websites appeared in searches for all 5 search terms, and the type of website sponsor. *ec.princeton.edu and en.wikipedia.org were found in both American and Canadian based searches.

<table>
<thead>
<tr>
<th>Website Address</th>
<th>Type of Sponsor</th>
<th>Number of Times the Website Appeared in Searches for All 5 Search Terms</th>
<th>Mean Search Rank of the Website in Searches for all 5 Search Terms</th>
</tr>
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<tr>
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<td>3.5</td>
</tr>
<tr>
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<td>1.4</td>
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<td>1.2</td>
</tr>
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<td>*en.wikipedia.org</td>
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<td>5.4</td>
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<td>4</td>
<td>7.3</td>
</tr>
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<td>3.0</td>
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<td>2</td>
<td>5.0</td>
</tr>
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<td>women.emedtv.com</td>
<td>Commercial (non-pharmaceutical)</td>
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<td>7.7</td>
</tr>
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Table 3.2. Self-identified characteristics of raters

<table>
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<th>AGE GROUP</th>
<th>(n=340)</th>
<th>Percent</th>
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<td>50-59</td>
<td>11</td>
<td>3.2%</td>
</tr>
<tr>
<td>60+</td>
<td>4</td>
<td>1.2%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SEX</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>146</td>
<td>42.9%</td>
</tr>
<tr>
<td>Female</td>
<td>194</td>
<td>57.1%</td>
</tr>
<tr>
<td>Rank (based on mean overall DISCERN score)</td>
<td>Website Address</td>
<td>Mean Overall DISCERN Score Q1-Q15 (95% CI)</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>-------------------------------</td>
<td>---------------------------------------------</td>
</tr>
<tr>
<td>1</td>
<td>*ec.princeton.edu</td>
<td>60.6 (57.1, 64.0)</td>
</tr>
<tr>
<td>2</td>
<td>*en.wikipedia.org</td>
<td>59.7 (56.3, 63.0)</td>
</tr>
<tr>
<td>3</td>
<td><a href="http://www.netdoctor.co.uk">www.netdoctor.co.uk</a></td>
<td>58.1 (53.4, 62.8)</td>
</tr>
<tr>
<td>4</td>
<td><a href="http://www.planbonestep.com">www.planbonestep.com</a></td>
<td>57.9 (54.6, 61.2)</td>
</tr>
<tr>
<td>5</td>
<td><a href="http://www.mayoclinic.com">www.mayoclinic.com</a></td>
<td>57.9 (54.4, 61.4)</td>
</tr>
<tr>
<td>6</td>
<td><a href="http://www.caringforkids.cps.ca">www.caringforkids.cps.ca</a></td>
<td>57.4 (52.1, 62.7)</td>
</tr>
<tr>
<td>7</td>
<td>women.emedtv.com</td>
<td>56.9 (53.2, 60.5)</td>
</tr>
<tr>
<td>8</td>
<td><a href="http://www.drugs.com">www.drugs.com</a></td>
<td>56.3 (53.0, 59.6)</td>
</tr>
<tr>
<td>9</td>
<td><a href="http://www.phac-aspc.gc.ca">www.phac-aspc.gc.ca</a></td>
<td>56.0 (52.0, 60.0)</td>
</tr>
<tr>
<td>10</td>
<td><a href="http://www.planb.ca">www.planb.ca</a></td>
<td>55.1 (52.0, 58.2)</td>
</tr>
<tr>
<td>11</td>
<td>**bodyandhealth.canada.ca</td>
<td>55.0 (44.0, 52.7)</td>
</tr>
<tr>
<td>12</td>
<td>**chealth.canoe.ca</td>
<td>55.0 (44.0, 52.7)</td>
</tr>
<tr>
<td>13</td>
<td><a href="http://www.plannedparenthood.org">www.plannedparenthood.org</a></td>
<td>54.6 (58.2, 50.9)</td>
</tr>
<tr>
<td>14</td>
<td><a href="http://www.rxlist.com">www.rxlist.com</a></td>
<td>54.6 (50.0, 59.1)</td>
</tr>
<tr>
<td>15</td>
<td><a href="http://www.morningafterpill.org">www.morningafterpill.org</a></td>
<td>53.8 (48.3, 59.3)</td>
</tr>
<tr>
<td>16</td>
<td><a href="http://www.fda.gov">www.fda.gov</a></td>
<td>49.3 (44.7, 53.9)</td>
</tr>
<tr>
<td>17</td>
<td><a href="http://www.cwhn.ca">www.cwhn.ca</a></td>
<td>48.4 (44.0, 52.7)</td>
</tr>
<tr>
<td>18</td>
<td><a href="http://www.hasslefreeclinic.org">www.hasslefreeclinic.org</a></td>
<td>47.9 (44.5, 51.2)</td>
</tr>
</tbody>
</table>

*ec.princeton.edu and en.wikipedia.org appeared in Canadian and American based searches.

**content of chealth.canoe.ca and bodyandhealth.canada.ca was identical and generated by the same health information company, therefore content was analyzed only once.

† F-K Reading grade level within the 6 to 8th grade reading level recommended by the FDA for written health materials and below the 8th grade reading level recommended by the CPHA.
Table 3.4 Scores for each question in DISCERN instrument for all websites (1 = no/low; 2–4 = partially/moderate; 5 = yes/high), expressed as median (Inter Quartile Range [range]).

<table>
<thead>
<tr>
<th>Section</th>
<th>Question</th>
<th>Median Score (IQR[range])</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Section 1: Is the publication reliable?</strong></td>
<td>Q1. Are the aims clear?</td>
<td>5.0 (5.0, 5.0 [4.0, 5.0])</td>
</tr>
<tr>
<td></td>
<td>Q2. Does it achieve its aims?</td>
<td>5.0 (4.1, 5.0 [4.0, 5.0])</td>
</tr>
<tr>
<td></td>
<td>Q3. Is it relevant?</td>
<td>5.0 (5.0, 5.0 [4.0, 5.0])</td>
</tr>
<tr>
<td></td>
<td>Q4. Is it clear what sources of information were used to compile the publication (author or producer)?</td>
<td>3.0 (2.5, 4.0 [1.0, 5.0])</td>
</tr>
<tr>
<td></td>
<td>Q5. Is it clear when the information used or reported in the publication was produced?</td>
<td>3.5 (2.6, 4.0 [1.0, 4.5])</td>
</tr>
<tr>
<td></td>
<td>Q6. Is it balanced and unbiased?</td>
<td>4.0 (4.0, 4.0 [2.0, 5.0])</td>
</tr>
<tr>
<td></td>
<td>Q7. Does it provide details of additional sources of support and information?</td>
<td>4.0 (3.0, 4.4 [2.5, 5.0])</td>
</tr>
<tr>
<td></td>
<td>Q8. Does it refer to areas of uncertainty?</td>
<td>3.5 (3.0, 4.0 [3.0, 4.0])</td>
</tr>
<tr>
<td><strong>Section 2: How good is the quality of information on treatment choices?</strong></td>
<td>Q9. Does it describe how each treatment works?</td>
<td>4.8 (4.0, 5.0 [2.0, 5.0])</td>
</tr>
<tr>
<td></td>
<td>Q10. Does it describe the benefits of each treatment?</td>
<td>4.0 (4.0, 4.9 [3.0, 5.0])</td>
</tr>
<tr>
<td></td>
<td>Q11. Does it describe the risks of each treatment?</td>
<td>4.5 (4.0, 5.0 [1.0, 5.0])</td>
</tr>
<tr>
<td></td>
<td>Q12. Does it describe what would happen if no treatment is used?</td>
<td>4.0 (3.5, 4.0 [2.5, 4.5])</td>
</tr>
<tr>
<td></td>
<td>Q13. Does it describe how the treatment choices affect overall quality of life?</td>
<td>3.0 (2.3, 3.9 [2.0, 4.0])</td>
</tr>
<tr>
<td></td>
<td>Q14. Is it clear that there may be more than one possible treatment choice?</td>
<td>4.0 (3.1, 4.0 [2.0, 5.0])</td>
</tr>
<tr>
<td></td>
<td>Q15. Does it provide support for shared decision-making?</td>
<td>3.5 (3.0, 4.0 [2.0, 4.0])</td>
</tr>
<tr>
<td><strong>Section 3: Overall Rating of the Publication</strong></td>
<td>Q16. Based on the answers of to all the above questions, rate the overall quality of the publication as a source of information about treatment choices</td>
<td>4.0 (4.0, 4.0 [3.0, 5.0])</td>
</tr>
</tbody>
</table>
Table 3.5  Overall DISCERN scores by Sponsor Type.

<table>
<thead>
<tr>
<th>Rank (based on overall DISCERN score)</th>
<th>SPONSOR TYPE (17 websites)</th>
<th>MEAN OVERALL DISCERN SCORE Q1-Q15 (95% CI)</th>
<th>MEDIAN DISCERN SCORE Q16 (IQR [Range])</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>University (1)</td>
<td>60.6 (57.1, 64.0)</td>
<td>5.0 (4.0, 5.0 [3.0, 5.0])</td>
</tr>
<tr>
<td>2</td>
<td>User-generated (1)</td>
<td>59.7 (56.3, 63.0)</td>
<td>4.0 (4.0, 5.0 [3.0, 5.0])</td>
</tr>
<tr>
<td>3</td>
<td>Pharmaceutical (2)</td>
<td>56.5 (54.2, 58.8)</td>
<td>4.0 (3.0, 4.0 [2.0, 5.0])</td>
</tr>
<tr>
<td>4</td>
<td>Commercial (non-pharmaceutical) (6)</td>
<td>56.0 (54.3, 57.6)</td>
<td>4.0 (3.0, 5.0 [1.0, 5.0])</td>
</tr>
<tr>
<td>5</td>
<td>Not-for-profit (6)</td>
<td>53.3 (51.4, 55.2)</td>
<td>4.0 (3.0, 5.0 [1.0, 5.0])</td>
</tr>
<tr>
<td>6</td>
<td>Government (2)</td>
<td>52.6 (49.5, 55.8)</td>
<td>3.0 (1.0, 4.0 [1.0, 5.0])</td>
</tr>
</tbody>
</table>
Table 3.6  Parameter estimates, t-statistics, P-values from linear regression analysis predicting overall DISCERN score (Question 1-15), predictor variables include country of search (Canada, USA) and website sponsor type.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Regression Coefficient (95% CI)</th>
<th>t-statistic</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>72.86 (70.56, 75.15)</td>
<td>33.5</td>
<td>&lt; 2e-16*</td>
</tr>
<tr>
<td>Sponsor Type</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Commercial (non-pharmaceutical)</td>
<td>2.54 (-2.44, 7.53)</td>
<td>0.871</td>
<td>0.38439</td>
</tr>
<tr>
<td>Government agency</td>
<td>-3.53 (-8.67, 1.62)</td>
<td>-1.344</td>
<td>0.17978</td>
</tr>
<tr>
<td>Not-for-profit organization</td>
<td>-2.62 (-6.71, 1.47)</td>
<td>-1.254</td>
<td>0.21046</td>
</tr>
<tr>
<td>Pharmaceutical company</td>
<td>1.64 (-3.51, 6.78)</td>
<td>0.624</td>
<td>0.53306</td>
</tr>
<tr>
<td>University</td>
<td>7.04 (1.89, 12.18)</td>
<td>2.681</td>
<td>0.00767*</td>
</tr>
<tr>
<td>User-generated</td>
<td>5.84 (0.69, 10.98)</td>
<td>2.224</td>
<td>0.02677*</td>
</tr>
<tr>
<td>Country</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>Reference group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>USA</td>
<td>1.676 (-1.22, 4.57)</td>
<td>1.136</td>
<td>0.25665</td>
</tr>
</tbody>
</table>

*Statistically significant at the 0.05 level
Khazaal, 2008). In contrast, the 340 raters in this study were “lay” reviewers recruited online, who were likely to have minimal expertise in reproductive health and little to no experience using the DISCERN instrument. Previous studies have shown that DISCERN ratings by consumers and health professionals are significantly correlated (Griffiths & Christensen 2000; Charnock, 2004). For instance, in this study, Wikipedia was given the second highest overall DISCERN score, while previous studies have identified major deficiencies in Wikipedia drug entries, especially in the areas of scope and completeness (Clauson, 2008). It may be difficult for the lay Internet user, with little to no expertise, to identify ‘missing’ information (i.e., information that is omitted either deliberately or inadvertently) even with help of the DISCERN tool, while “expert” raters may be able to better identify information gaps.

Overall the reading grade levels of the websites in this study were very high, particularly in websites found in American based searches. Fifteen of the 18 websites reviewed were written at a level above the reading grade level for written health materials recommended by the FDA and CPHA. This is in keeping with the findings of Hocevar & Yuksel (2011), who found that the mean reading grade level of online Plan B® information in Canada was 13.4, well beyond that recommended by the CPHA (Canadian Public Health Association, 2011). In the USA, 43% of adults function with basic literacy skill, meaning they can perform simple or everyday literacy activities, or below basic literacy skills, meaning that they have no more than the most simple and concrete literacy skills (National Center for Educational Statistics, 2006). In Canada, 32% of adults aged 16 to 65 do not possess the literacy skills necessary to meet most everyday reading
requirements.

Women who have not completed high school are over-represented among women who have had an unintended pregnancy (Finer & Zolna, 2011). The high literacy levels required to read and understand the EC-related information currently available online is a significant barrier to communicating this essential information effectively to a demographic that is particularly vulnerable to unintended pregnancy. The readability of online medical material is currently not regulated. Furthermore, while there are guidelines for written health materials, there are currently no recommended reading level guidelines tailored to online health materials in Canada or the USA.

3.4.1 Limitations

DISCERN is designed to assess written content only, and does not evaluate the formal aspects of a publication, including features unique to web-based media such as usability (ease with which a website user can use and learn how to navigate a site) and searchability (the ease with which a website may be searched by a user for a query). The DISCERN instrument does not examine issues related to direct-to-consumer advertising of non-prescription and/or prescription drugs, such as stating sponsorship or advertising, using inducements, using emotional appeals, noting the target audience or whether the website states their specific target audience. Furthermore, DISCERN does not assess the scientific quality or accuracy of the evidence on which a publication is based, as it does not require checking against other sources (Charnock, 1998).
The inter-rater agreement, as measured using the Fleiss’ Kappa statistic, was relatively low (Kappa=0.12) indicating only slight inter-rater agreement according to categories described by Fleiss (1971). This may reflect diversity in the rater sample, their lack of expertise in the subject, and their lack of experience using the DISCERN instrument. Research indicates that higher levels of expertise and training with DISCERN are associated with high inter-rater agreement scores (Charnock, 1999). However, low inter-rater agreement also highlights the subjective nature of website “quality” and “reliability”, and the difficulty in designing a reliable tool for lay-internet users to objectively assess online health materials.

3.5 Conclusion

While the majority of websites found most frequently in searches for EC-related search terms achieved high DISCERN rankings, they performed poorly in readability tests. Currently, while the CPHA and FDA have developed recommended reading grade guidelines for written health materials, there are currently no recommended readability requirements specifically for online health materials, which is reflected in the low readability of the online materials identified in this study. Regulatory authorities in Canada and the USA should design readability guidelines for the sponsors of websites to follow so that they are accessible to all individuals along the spectrum of literacy (from low to high) who may be searching online for information about EC.
The websites sponsored by government agencies did not feature prominently in
search results for EC-related search terms, and received relatively low DISCERN ratings.
Government agencies may wish to focus on improving the quality of their web page
content and, in the case of the FDA, improving readability to meet their recommended
reading grade level for health materials (between 6\textsuperscript{th} and 8\textsuperscript{th} reading grade level).
Chapter 4.0 Discussion

4.1 Overview of findings

The current thesis advances our understanding of the impact of changes in the availability of EC on the volume of online searches for EC, as well as of the qualities of online information available about EC. While previous research indicates that rates of EC use increase following the implementation of regulatory changes making it available without a prescription (Soon, 2005; Kavanaugh 2011; Moreau, 2006; Raymond, 2007), Chapter 2, ‘Searching for Emergency Contraception Online: Analysis of Google Search Patterns for EC-Related Search Terms’, showed that such policy changes also have a detectable effect on the ways people search online for information about EC. For example, there were significant short-term increases in search volume for the commercial brand Plan B® in Canada and Plan B One-Step™ in the USA when EC became available without a prescription. Further, there were long term increases in searches for Plan B® and Plan B One-Step™ following more recent policy changes making EC available over-the-counter in Canada and for women aged 17 and older in the USA, respectively.

Chapter 3, ‘Content Analysis of Web-based resources about Emergency Contraception’, provided a cross-sectional description of the nature and the source of websites most frequently found in online searches for EC in Canada and the USA. Websites found frequently in both countries included the university sponsored website, ec.princeton.edu, and the user-generated site, Wikipedia (en.wikipedia.org). The website sponsored by the makers of Plan B®, www.planb.ca, was found most frequently
in Canadian searches. Websites sponsored by government agencies, specifically the Public Health Agency of Canada and the U.S. Food and Drug Administration (FDA), did not appear as frequently, and the FDA site appeared on average less prominently on search pages than the websites mentioned previously. Most websites achieved DISCERN ratings higher than in previous studies examining the quality of online health information. This may be because the sites for EC are in fact of higher quality than those reviewed in previous studies, or because the raters we used were not as experienced with the DISCERN instrument and were not familiar with the subject matter, making it more difficult for them to identify missing or false information.

Chapter 3 pinpointed significant shortcomings in the websites identified in online searches for EC. Notably, the reading grade levels of the websites were very high; 83% of websites were written at a level exceeding the reading grade level recommended for health materials by the FDA. The complexity of the language in EC-related websites is a significant barrier to the 32% of Canadians and 43% of Americans who possess basic or below basic literacy skills (National Center for Educational Statistics, 2006; Statistics Canada, 2003). Furthermore, misinformation about the mechanism by which EC functions – i.e., portrayals of EC as an abortifacient (a substance that causes the termination of an existing pregnancy) – persists in one of the most frequently found websites in online searches for EC, www.morningafterpill.org, which is sponsored by the anti-choice organization, the American Life League.
4.2 Implications for future research

The current thesis employed novel approaches to collect and analyze data, which may be adapted to address other research questions. In Chapter 2, interrupted time series analysis was used to examine the impact of policy changes on Google search volume over time. This methodology may be used in future to examine the short and long term impact of other discrete policy or regulatory ‘events’ on Google search volume (e.g., the introduction of a generic drug to the market, or a change in the insurance coverage of a prescription drug). Additionally, although outside the purpose or scope of the current study, there is potential for the methodological insights accumulated here to inform further research efforts to ascertain quality information about the rates of EC use in North America, which is sparse at this time and primarily relies on self-reports (Kavanaugh, 2011; Lawson, 1994; Landry, 2006; Macaluso, 2003; Walsh, 2006; Galvao, 2005; Rogers, 2005). A retrospective evaluation of EC usage patterns in Canada and the USA through time and across policy changes would help to elucidate the impact of making EC available without a prescription on rates of use.

Furthermore, while previous studies have used the DISCERN instrument to examine the quality of online health materials, the majority used a small sample of raters with high levels of expertise in the field. In Chapter 3, 20 lay raters per website were recruited through Amazon’s online platform, Amazon Mechanical Turk. This study was the first to collect DISCERN ratings from a sample of Internet users, whose experience with the DISCERN instrument and familiarity with the subject matter arguably more closely resemble those of the people looking for information related to
EC online, than a graduate student or expert in reproductive health. Given the fair but acceptable levels of inter-rater reliability, the Amazon Mechanical Turk platform may potentially be used to recruit samples of Internet users in the future.

4.3 Implications for policy and programmatic interventions

Evidence suggests that the “first digital divide” – the gap in access to the technology necessary to go online – is closing rapidly (Zamaria & Fletcher, 2008; Fox, 2009; Zhao, 2009). The majority of North Americans, and nearly all individuals between the ages of 12 and 29, have access to a functional computer and Internet connection (Zamaria & Fletcher, 2008; Fox, 2009). However, inequalities among people with formal access to the web persist. These differences are shaped by Internet users’ socio-structural context (e.g., race, gender and socio-economic status) and determine the ease and extent to which individuals are able to use the web to enhance their access to relevant, high quality information (DiMaggio, 2004; Cashen, 2004). As it applies to public health, this ability is often described as “health literacy”, or the capacity to seek out, understand, and interpret health information and apply it to improve personal health status (Joint Committee on National Health Education Standards, 1995). For instance, research suggests that men and women who have low-incomes, who have not graduated from high school, and who are visible minorities are less likely to use the Internet to look for health information, and consequently less likely to employ online resources to inform decisions about their health and well-being (Zhao, 2009).

It is far beyond the scope of online resources to address the underlying social structures that determine variations in Internet use, or in health outcomes (e.g.,
unintended pregnancy and EC use). However, as Cashen (2004) points out, in order “to effectively promote and support the appropriate use of [online] resources, clinicians must recognize the role of health literacy, cultural and ethnic diversity, health status, and poverty in societal function”. Public health agencies may therefore wish to consider these factors in designing appropriate online resources about EC that attend to the social determinants of EC uptake. For instance, they could improve the readability of their websites to ensure that written online materials accommodate people with basic levels of reading comprehension. They could also include information in their websites about ways to access low-cost or no-cost EC from physicians or walk in clinics and point out that physicians and pharmacists (and in some jurisdictions nurses) continue to have the authority to prescribe EC. This could be accompanied by information outlining how to seek reimbursement for the cost of prescribed EC from insurance companies. If shared online, this type of information may help women (and men) make informed decisions about how and where they prefer to access EC, rather than allowing them to erroneously assume that EC is now only available BTC or OTC at an out-of-pocket expense (and where it can cost upwards of $45-$50 per unit). Furthermore, although online communication is one of many public health approaches, their careful design and implementation can also help to address (or at least avoid perpetuating or exacerbating) persistent myths, most notably that EC is an abortifacient.

Efforts to filter online health information based on quality (e.g., via medical portals or third party accreditation) have met with only partial success, in part because of limited uptake by both the makers and consumers of online information (Deshpande
& Jadad, 2009). Search engines, and Google in particular, are the tools the majority of Internet users rely on to organize and filter information online (Zamaria & Fletcher, 2008; Fox, 2010). Future efforts to provide people searching for information about EC on the web with high quality, reliable resources should take advantage of this widespread reliance on search engines by enhancing efforts to make the best information the easiest to find. One example of a simple and effective strategy to enhance the profile of high quality information in online searches for health information is the partnership established in 2010 between Google and the National Institutes of Health. This agreement ensures that the first Google hit for generic drug names is the National Library of Medicine drug information page.

A potentially important source of high quality information about EC is web resources provided by governmental public health agencies. However, the results of Chapter 3 indicate that such resources do not feature prominently in web searches for EC-related search terms. This suggests that public health agencies should work to improve the prominence of their web pages in online searches for EC-related search terms. Government agencies in Canada (e.g., the Public Health Agency of Canada) may wish to consider a partnership similar to the one described above between Google and the National Library of Medicine (Law, 2011). Chapter 2 indicates that searches for “Plan B” (and in the case of the 2006 shift to OTC in the USA, searches for “morning after pill”) increased after EC became available without a prescription. This suggests that such partnerships would be beneficial if extended to apply to OTC drugs, not just those accessible by prescription only (as is the case now in the USA). Furthermore,
given that the number of online searches for EC-related search terms changes in concert with policy shifts, such cooperative arrangements between government agencies and search engine companies should be articulated alongside shifts in policy or regulation that affect provision.

4.4 Mobilizing the 'Information Network': Online resources in context

Research suggests that the web is one of a suite of resources people use to answer questions about their sexual and reproductive health (Jones & Biddlecom, 2011; Gray, 2005; Eysenbach, 2008; Zhao, 2009). Other sources include healthcare providers, teachers, friends, parents, as well as television and other forms of popular media (Jones & Biddlecom, 2011). The current thesis explored online information seeking, one facet of the ‘information network’ available to the public. Coordinated efforts by all segments of this network of resources, including Public Health departments, primary healthcare providers, and educators, are essential to close the information gap about EC. Without this kind of coordination and other facilitative efforts to enhance uptake, it seems likely that rates of EC use will remain low in the US and Canada relative to other countries (Kavanaugh, 2011; Moreau, 2006), despite it having been available OTC since 2006 in the USA and BTC since 2005 in Canada.

A large and increasing number of people look to the Internet for information about their health, particularly the young men and women who have grown up in the digital age. Public health agencies could demonstrate leadership by promoting an integration of online strategies with other facets of the “information network” in order to help close the knowledge gap related to EC and hopefully facilitate its uptake.
References


[http://www.who.int/mediacentre/factsheets/fs244/en/](http://www.who.int/mediacentre/factsheets/fs244/en/)


Appendices

A.1 Consent Agreement Form

THE UNIVERSITY OF BRITISH COLUMBIA
School of Population and Public Health

Informed Consent Form

Purpose of Research Study: This questionnaire is part of a study designed to assess the quality of information available on the Internet about Emergency Contraception (EC). This data will be aggregated, and may be published in an academic journal and used to make recommendations to improve the quality of web-based information about EC.

This survey should take about 20 minutes to complete, and asks questions about the quality and completeness of health information included in the website provided. Following completion of the survey you will be reimbursed in the amount of USD 2.00.

Benefits: You may learn more about how to assess the quality of information on health websites. Your participation will contribute to making recommendations to improve the quality of information available about emergency contraception on the web.

Risks: There are no known risks to participating in this study.

Confidentiality: This online survey company is hosted by a websurvey company located in the USA and as such is subject to U.S. laws. In particular, the US Patriot Act which allows authorities access to the records of internet service providers. This survey or questionnaire does not ask for personal identifiers or any information that may be used to identify you. The websurvey company servers record incoming IP addresses of the computer that you use to access the survey but no connection is made between your data and your computer’s IP address. If you choose to participate in the survey, you understand that your responses to the survey questions will be stored and accessed in the USA. The security and privacy policy for the websurvey company can be found at the following link: https://www.mturk.com/mturk/privacynotice.
Questions/concerns: If you have any questions or concerns about the survey, please contact Miranda Elliott at miranda.elliott@ubc.ca, or by phone 604-822-6535. If you have any concerns about your treatment you may contact the Research Subject Information Line in the UBC Office of Research Services by email at RSIL@ors.ubc.ca or toll free at 1-877-822-8598.

Your participation is entirely voluntary and you are free to withdraw at any time. By clicking on the “Accept Hit” button, you are providing your consent.

We very much appreciate your participation. Kind Regards,

Dr Jean Shoveller, PhD
Professor, School of Population and Public Health at the University of British Columbia
2206 East Mall, Vancouver, BC Canada V6T 1Z3. Tel. 604-822-3724 Fax: 604-822-4994

Miranda Elliott, BSc
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A.2 Amazon Mechanical Turk Questionnaire

Instructions:

• The survey will take about 20 minutes to complete.

• Please complete all sections before submitting your work. Incomplete HITs will be rejected.

Before starting, please:

• Read the informed consent form. By clicking the “Accept Hit” button, you are signaling that you have read and understood this consent form and agree to its conditions.

• Before starting please read the General Instructions in the drop down menu, below. Instructions and examples for each question are included in the drop down menus below each question, please read the question and instructions carefully before selecting your answer.

• Read all the information in the following URL, including those in internal links, and answer the questions below to the best of your ability: www.example.com. Do not include information contained in external links.

1. Please choose a 6 digit number and enter it, below:

   [ ]
General instructions

The questions
DISCERN consists of 15 key questions plus an overall quality rating. Each of the 15 key questions represents a separate quality criterion – an essential feature or standard that is an important part of good quality information on treatment choices.

The questions on DISCERN are organised in three sections as follows:

- **Questions 1 - 8** address the reliability of the publication and should help you consider whether it can be trusted as a source of information about treatment choices
- **Questions 9 - 15** focus on specific details of the information about treatment choices. Please note: apart from **Question 14**, the questions are concerned with the treatment choice or choices described in the publication, and not with all possible treatment choices. **Questions 9 to 11** are concerned with the ‘active’ treatments described in the publication and can include self-care. ‘No treatment’ options are dealt with separately in **Question 12**
- **Question 16** is the overall quality rating at the end of the instrument. Your answer to this question should be based on your judgement of the quality of the publication as a source of information about treatment choices after rating each of the 15 preceding questions. However, you should only rate a publication as good quality if it rated well on the majority of questions.

Occasionally, a question is not appropriate for a publication. For example, the question about no treatment options would not be appropriate for a publication about labour and birth. You should use your judgement to exclude a question that is not relevant. However, DISCERN has been developed as an appraisal process and should be used in its entirety. You must not use individual questions or sets of questions separately. You will find it easiest to read the publication fully before answering the DISCERN questions.

The rating scale
Each question is rated on a 5-point scale ranging from No to Yes. The rating scale has been designed to help you decide whether the quality criterion in question is present or has been ‘fulfilled’ by the publication.

General guidelines are as follows:

- **5** should be given if your answer to the question is a definite 'yes' - the quality criterion has been completely fulfilled
- **Partially (2-4)** should be given if you feel the publication being considered meets the criterion in question to some extent. How high or low you rate 'partially' will depend on your judgement of the extent of these shortcomings
- **1** should be given if the answer to the question is a definite 'no' - the quality criterion has not been fulfilled at all

Hints
A number of hints are given after each question. These are designed to provide you with things to look for or consider when deciding your response to a question. The hints should act as a guide rather than as hard and fast rules and your own judgement will also be important. The rating process is clear-cut for most questions, although more subjective decisions may occasionally be needed. The hints should help you to use your judgement effectively in all cases. More specific instructions are given for questions 2, 4 and 5.

Additional guidance
Additional guidance for rating each question is provided with the instrument. Click on 'Rating this question' if you are having difficulties or would like to understand the issues underlying a question more fully. We have included an example of a Yes, Partially and No rating wherever possible. The examples have been developed from written consumer health information and are purely fictitious. Any resemblance to a real publication is coincidental. In some cases, it has not been possible to provide concise examples of the full range of ratings, but you should be able to work out an appropriate response from the instructions and examples given.

Remember: throughout the DISCERN instrument and website:

- treatment includes self care
- treatment choices are possible treatment options including no treatment
- information refers to information about treatment choices only
- a publication is any written item that provides information about treatment choices specifically for health consumers, and can include printed and online materials.
Instructions Question 2: Are the aims clear?

What the question is about and why it is important

A good quality publication will have clear aims. A publication should commence with an overview indicating what it is about, what it covers and who it is meant to be for. Clear aims at the beginning of a publication are important because they indicate what aspects of the condition and its treatment will be addressed and help you to judge whether the publication is likely to contain the information you want. It is particularly important to know what may not be included, as you may need additional information before you can make an informed decision about treatment.

Rating the question

Examine the opening paragraphs or home page for a description of the content, scope and target audience of the publication. Although the publication’s title or URL/address may be descriptive, the aims should be clearly outlined in the text at the beginning if the publication is to get a good rating.

Guidelines for rating the question:

- **5: Yes** - the publication has clear aims.
- **2 - 4**: Partially - the publication has aims but they are unclear or incomplete.
- **1: No** - the publication does not include any indication of its aims.

Examples

5 rating

"This booklet has been written to help you understand more about Jones' disease. We hope it answers some of the questions you may have about its diagnosis and treatment. It may also be useful for partners, friends, families and carers and to everyone who is concerned about how Jones' disease affects people and what can be done about it. Occasionally, Jones' disease can affect children. This booklet includes some brief reference to treatment for children but a fuller discussion is outlined in our leaflet entitled "Jones' disease in children"

'Treatments for this condition include dietary advice, drug therapy and surgery. This leaflet has been written for those patients who are considering or have been recommended surgery. It will outline why surgery may have been recommended, what it involves and how it may help you.'

Partially rating

'This booklet is about some of the treatments for depression.' (No other indication of the aims or contents is provided).

1 rating:

A publication is entitled "Treatments for epilepsy" but there are no other indications of what the publication is about or who it is written for. The opening paragraph consists of a brief description of the condition and its diagnosis and each subsequent paragraph describes a drug treatment.
3. Does the website achieve its aims?

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Instructions Question 3: Does it achieve its aims?

What the question is about and why it is important

A good quality publication will provide the information it has aimed to provide. Question 2 is designed to help you assess whether the information about a treatment choice or choices that was promised at the beginning of the publication has actually been provided. This question is important because a publication that does not achieve its aims is incomplete and you may need more information before you can make a decision about treatment.

Rating the question

After reading the publication, you should refer back to the aims and consider whether all of the information about treatment choices that you were led to expect has been provided.

Guidelines for rating the question:

- **5: Yes** - all the information you were expecting from a description of the aims has been provided.
- **2 - 4: Partially** - some of the information you were expecting from the aims has been provided.
- **1: No - none** of the information you were expecting from the aims has been provided.

If the publication did not have clear aims (rated ‘1’ on Question 1), Question 2 is irrelevant and should not be answered. If aims were outlined but were not clear or were incomplete (rated ‘partial’ on Question 1), you need to use your judgement to decide what expectations the aims had raised and then rate to what extent those expectations have been fulfilled.

Examples

5 rating:

A leaflet aims to inform consumers about surgical treatments for a condition. The aims indicate that options other than surgery are available (drugs, diet) but that these are not the subject of the publication. In accordance with its aims, the leaflet provides an explanation of why surgery may have been recommended, and describes in detail what it involves and how it may treat the condition.

Partially rating:

A publication aims to provide information about treatment for AIDS, with no mention of any particular focus or omissions. However, the publication provides detailed information about vitamin therapies but does not refer to any other forms of treatment.

1 rating:

A leaflet written for people with a neurological condition aims to help them look after themselves and offers self-help strategies. The leaflet provides a detailed account of the symptoms and diagnosis of the condition, and focuses on employment and benefit rights. The only reference to self-help as a treatment choice is a brief sentence about the importance of avoiding stress, but there is no advice about how this can be done or of the outcomes of any stress management techniques.
Instructions Question 4: Is it relevant?

*What the question is about and why it is important*

A good quality publication will be suited to users’ needs. It is important that the information about a treatment choice or choices is relevant to your lifestyle and circumstances. The publication should not make recommendations that are unrealistic or contain assumptions or language that you find inappropriate or offensive.

*Rating the question*

Your judgement will be very important for rating this question. Your rating can take into account both the content and the presentation of the information about treatment choices.

Guidelines for rating the question:

- **5: Yes** - the information is relevant.
- **2 - 4: Partially** - the information is relevant to some extent.
- **1: No** - the information is not at all relevant.

*Examples*

5 rating:

You are a middle-aged Asian man with high cholesterol. You have a large family, commute long distances and have very little spare time. Your diet consists of a mixture of Asian and English food. Your GP has given you a leaflet describing self-help treatment for high cholesterol. The leaflet provides dietary recommendations suited to various ethnic groups and tastes that can be easily incorporated into family meals. The leaflet also outlines a simple home-based exercise programme that can be included in your daily routine.

Partially rating:

You are a young person recently diagnosed with diabetes. You work long hours in a manual job and rent a room during the week. You are about to start daily insulin injections and your doctor has given you a booklet written especially for young people with diabetes. The information is technical but it is easy to understand and the style suits you. However, the information about using the treatment, its outcomes and impact on daily life assumes that all young people will be living at home with family and does not describe the implications of treatment for those living without family support or working.

1 rating:

You are a young pregnant mother with depression who is unsure whether to ask the doctor for some help. You picked up a leaflet written for women with depression at your local child health clinic. The leaflet describes drug therapies. The description of these treatments does not include any discussion of the use of such treatments during pregnancy or breastfeeding. No other treatment choices are mentioned.

You are a single, self-employed businesswoman who travels a lot and you live on your own. You are about to undergo surgery for a gynaecological problem and hope to get back to work quickly. The hospital has provided you with a factsheet about the procedure. However, the author assumes that all readers are married housewives, and discussion of the treatment and post-surgical care outlines the important role of the ‘husband’ and a return to ‘domestic duties’ only.
5. Is it clear what sources of information were used to compile the publication?

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Instructions Question 5: Is it clear what sources of information were used to compile the publication (other than the author or producer)?

What the question is about and why it is important

Information about treatment choices should be accurate and based on the best available scientific evidence. DISCERN cannot be used to tell you whether information is true or based on sound evidence, as this would require checking against other sources. However, a good quality publication will make it clear where the evidence for the information about treatment choices has come from. Details of the sources of evidence are important, as they enable you to check the information or decide to seek further information. Sources of evidence can include research articles and the opinions of experts such as clinicians and representatives from self-help organisations. The author or producer is not considered a source for this question, as this information is nearly always provided and will not help you discriminate between good and poor quality publications.

Rating the question

There are two parts to the question that are reflected in the hints:

1. a main statement or ‘fact’ about a treatment choice should be accompanied by a reference to the source of evidence in the text in the main part of the publication [e.g. ‘Treatment using X has been found to be successful (reference)’]

2. a source of evidence should be listed in a bibliography or reference list at the end of the publication, or inserted as an external link to another online publication or organisation.

These two parts may not both be present.

It is not possible to make recommendations as to how many statements about treatment choices should be referenced or how many references should be listed at the end of the publication or included as links.

Additional sources of support and information, such as ‘Further reading’ or ‘Useful addresses’, should not be rated as the sources of evidence for the information about treatment choices. The information provided by ‘additional’ sources will not necessarily have been used to compile this publication, and in many cases may provide very different information (see Question 7).

Guidelines for rating the question:

- 5: Yes - the sources of evidence are very clear and the publication enables you to link the source mentioned in the text to a full reference at the end of the publication or to another online source of information. It is possible that a publication referring to a single source in both the text and the reference list or link will rate high on this question. Judging the quality of a publication based on a single source of information is a separate issue that is addressed in Question 6.

- 2 - 4: Partially - the sources of evidence are clear to some extent. Give a partial rating if one of the hints is fulfilled. You may also give a partial rating to a publication which quotes a reference in the text for some but not all of the main statements or ‘facts’ about treatment choices, although you will need to use your judgement to decide when a reference would be expected.

- 1: No - no sources of evidence for the information are mentioned.

Remember: a high rating on this question does not mean that the information is accurate or of good scientific quality. It tells you it meets our criterion of the sources of evidence being explicit.

It is not yet common practice to include references and therefore it is very unlikely that many publications will rate highly on this question.

Examples

<table>
<thead>
<tr>
<th>Hint 1 (in the text)</th>
<th>Hint 2 (1(b) and 2(b) will be in a reference list or bibliography at the end)</th>
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<tbody>
<tr>
<td>1 (a) ‘In the short-term, treatment X can halt the weight loss associated with Jones’ disease. It can also reduce the symptoms of pain and breathlessness (Jones and Jones, 1995).’</td>
<td>1 (b) Jones J, Jones A. ‘The Diagnosis and Management of Jones’ Disease’. London: Jones &amp; Co. 1995, 2nd edition.</td>
</tr>
<tr>
<td>2 (a) ‘The most common side-effects you may experience with treatment X are sleepiness and slight confusion, but there are no known long-term side-effects or risks associated with this treatment.’</td>
<td>2 (b) Jones SS. A randomised controlled trial of treatment X for Jones’ disease. ‘Journal of Jones’ Science’, 1998; 3: 11 - 20.</td>
</tr>
<tr>
<td>3 (a) ‘According to the Jones’ Disease Association, patients who decide to postpone treatment do not run any greater risk of lung damage later in life than those opting for early treatment.’</td>
<td>3 (b) External link: takes you the Jones’ Disease Association website.</td>
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In each example, a 5 rating is appropriate if both parts (a) and (b) are provided, whilst a partial rating will be given if part (a) or part (b) only is provided. If statements or ‘facts’ are presented with no accompanying reference and there is no reference list or link to the sources used, the publication will be rated 1.
Instructions Question 6: Is it clear when the information used or reported in the publication was produced?

What the question is about and why it is important
Evidence about effective treatments and choices for treatment can change and it is important that information includes the latest developments in knowledge and practice. DISCERN cannot be used to assess how ‘up-to-date’ the information is, as the rate of change will vary with each medical condition and treatment. However, a good quality publication will make the date of the information about treatment choices explicit. An indication of the age of the information is important, as it may lead you to question whether the information is current and to seek further information about the most recent developments.

Rating the question
The hints guide you to look not only for the date the publication itself was produced, but also for the dates of the main sources of evidence used and reported in the publication. The publication cannot be older than the sources of evidence, whereas the sources of evidence can be much older than the publication. Therefore, in order to fulfil the quality criterion for Question 5, the dates for the sources of evidence identified in Question 4 must be clear. A publication that has rated 1 on Question 4 cannot rate high on Question 5.

Hint 1: Dates of sources used
Print sources: dates for print sources will be found either with the references in the text or in the details of the references in the bibliography or reference list (see instructions for rating Question 4).

Online sources: Dates for online sources such as webpages should be checked as outlined below. The date for a source such as email from a discussion group or a newsgroup is the posting date of the original message.

Hints 2 and 3: Date of the publication
Print publications: the date of a print publication is usually found on the back page of a leaflet or on one of the title pages of a book (usually copyright date). A revised publication has been changed or updated since initial publication, and you should use the date for the revised edition to rate the question. It is possible that a publication will not have been revised and therefore Hint 3 can be fulfilled without Hint 2. A reprinted publication will not contain new information and you should use the copyright date.

Online publications: A copyright date on a webpage or website indicates the date the information was originally produced, either in print or online. As with print publications, the date of the last revision, update or amendment indicates the date of the most recent changes to a webpage and you should use this date to rate this question if it is available. You will usually find these dates on a home page or at the bottom of individual webpages.

The date for an email publication such as a discussion or newsgroup item will be the date it was posted.

Guidelines for rating the question:
- 5: Yes - dates for all acknowledged sources are clear.
- 2 - 4: Partially - only the date of the publication itself is clear, or dates for some but not all acknowledged sources have been given.
- 1: No - no dates have been given.

Remember: although the dates of the sources may be clear and the publication gets a high rating on this question, it is possible that the information on which the sources are based is not ‘up-to-date’. Similarly, it is unlikely that you will be able to tell which aspects of a revised publication have been changed. Question 5 will enable you to judge whether the dates are explicit, but not whether the information is current.

It is not yet common practice to include all of these dates and therefore it is very unlikely that many publications will rate highly on this question.
Instructions Question 7: Is it balanced and unbiased?

What the question is about and why it is important

A good quality publication will provide fair and impartial information. It is important that information about a treatment choice or choices is presented in a way that enables you to choose what is in your best interests. A publication should be honest and informative. It should not influence you by ‘promoting’ particular treatment choices or by using ‘shock tactics’.

Rating the question

Your rating should be based on your impression of the information about treatment choices as a whole. The hints will help you develop a ‘feel’ for the balance and bias of the information, but your own judgement will also be important. Here are some additional points to help you.

- You should judge the information on its own merits and you should not be influenced by what you know about the author or producer. Well-respected individuals (including doctors and charities) can produce poor quality information, and an unknown author or producer can produce information that meets high standards.
- Publications describing one particular treatment choice can be acceptable if the author has made this clear (Question 1) and has acknowledged that other treatment choices may be available (Question 14). In all cases, the information about the treatment choice or choices should be drawn from a range of research and experience. You should not give a high rating to a publication that relies solely on a single source of evidence or has not revealed any sources (Question 4).
- Ideally, a publication should be independently reviewed and approved by an expert, professional organisation or consumer group. Evidence of an external assessment provides readers with some assurance that the information is unprejudiced. However, this is not yet common practice and a publication that omits this information can still achieve a good rating on this question.

Guidelines for rating the question:

- 5: Yes - the information is completely balanced and unbiased.
- 2 - 4: Partially - some aspects of the information are unbalanced or biased.
- 1: No - the information is completely unbalanced or biased.

Example

1 rating:

A webpage describes a single treatment for a skin condition. The page is written by a doctor and is found in the section on treatments on a national self-help organisation's website. The sources of evidence quoted are the scientist who developed and sells the treatment and the case of one of the doctor’s patients who has experienced a ‘miraculous’ cure. The only reference to other treatment choices is the statement that ‘all other treatments for the condition are associated with unacceptable side-effects’ and the possibility of ‘permanent disfigurement’ if no treatment is used. The patient’s search for a cure is described as ‘torture’ that led him to try other treatments that left him ‘scarred’ and ‘suicidal’. The treatment is said to produce ‘stunning and permanent results after a few applications with no risks or side-effects’. The author recommends the treatment as ‘suitable for anyone’ and ‘bringing hope to all those who have despairs of finding relief from this devastating and unsightly condition’.
8. Does the website provide details of additional sources of support and information?

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Instructions Question 8: Does it provide details of additional sources of support and information?

What the question is about and why it is important

A good quality publication will enable you to find other sources. Details of other sources of support and information about treatment choices are important, as the publication may not provide you with all the information you need and you should be able to trace further information easily.

Rating the question

Additional sources of information and support can be reading materials and other organisations, which may be located via printed details or online links. Additional sources are often listed under headings such as "Useful addresses" and "Further reading" (a reference list or bibliography can also be considered further reading).

When rating print or conventional sources, the details provided should enable you to find them easily e.g. name, address and telephone number in the case of an organisation, and author, title, publisher or producer in the case of reading material (and ISBN and date if the material is known to be a book). Similarly, if details of additional online sources are provided, they should enable you to locate them on the internet easily e.g. the name of an organisation and its email address in the case of an online support group or mailing list; and the website address (URL) either in full or as an external link in the case of an online journal article, newsgroup or national self-help organisation. As the internet expands, it is becoming common for print and online publications to provide both types of details.

Many publications provide details of branches of the same organisation. Whilst these may be useful for information about local services, they are unlikely to provide different information about treatment choices, and you should not give a high rating to a publication which only provides these details.

Guidelines for rating the question:

- **5: Yes** - the publication provides full details of any additional source other than local branches of the same organisation.
- **2 - 4: Partially** - the publication provides details of an additional source or sources, but the details are incomplete or consist only of local branches of the same organisation.
- **1: No** - no additional sources of information are provided.

Examples

5 rating:

Further reading:


Useful addresses:

The Jones’ Disease Association, 79 Jones Drive, Jones Town. Tel: 5666 5666 or

More information can be obtained from the Jones' Disease Association by visiting their website at http://www.iones.org.uk or sending email to enquiries@iones.org.uk.
9. Does the website refer to areas of uncertainty? 

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**Instructions**

**Question 9: Does it refer to areas of uncertainty?**

*What the question is about and why it is important*

A good quality publication will include a reference to ‘grey’ areas where there is uncertainty about the most effective treatment. This uncertainty may be because:

- no evidence about effective treatment choices exists
- the existing evidence is contradictory
- there is uncertainty as to who is most likely to benefit or be at risk from the treatment choice.

A good quality publication will highlight the fact that the choice of the most suitable treatment may not be clear-cut and that it may not be possible to predict the most likely outcome for you.

**Rating the question**

Your judgement will be very important for rating this question.

Guidelines for rating the question:

- **5: Yes** - the publication includes a clear reference to any uncertainty regarding treatment choices: this may be linked to each treatment choice or may be covered in a more general discussion or summary of the choices mentioned in the publication.
- **2 - 4: Partially** - uncertainty is mentioned but the information is unclear or incomplete.
- **1: No** - no uncertainty about treatment choices is mentioned.

The question cannot be used to assess whether all aspects of uncertainty regarding a treatment choice or choices have been covered by the publication (as this would involve checking against other sources).

**Examples**

**5 rating:**

‘A minority of women will experience side-effects, but it is not always possible to know who these women will be until after treatment has started.’

‘Doctors may give you vague answers to your questions, or may not be able to answer them all. Different doctors may give you different advice. You may be able to find out about the overall success rate of a treatment but doctors may not be able to tell you whether the treatment will definitely work for you. Some people find dealing with this uncertainty difficult. You may find it helpful to discuss your concerns with family or friends or someone from a support group.’

**1 rating:**

A webpage describes a single treatment for a skin condition. The page is written by a doctor and is found in the section on treatments on a national self-help organisation’s website. The sources of evidence quoted are the scientist who developed and sells the treatment and the case of one of the doctor’s patients who has experienced a ‘miraculous’ cure. The only reference to other treatment choices is the statement that ‘all other treatments for the condition are associated with unacceptable side-effects’ and the possibility of ‘permanent disfigurement’ if no treatment is used. The patient’s search for a cure is described as ‘torture’ that led him to try other treatments that left him ‘scarred’ and ‘suicidal’. The treatment is said to produce ‘stunning and permanent results after a few applications with no risks or side-effects’. The author recommends the treatment as ‘suitable for anyone’ and ‘bringing hope to all those who have despaired of finding relief from this devastating and unsightly condition’.
10. Please enter 2 for this question |   No | Partially | Yes |
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Instructions Question 11: Does it describe how each treatment works?

**What the question is about and why it is important**
A good quality publication will include information about how a treatment acts on the body and in what way it ‘treats’ or affects the condition or its symptoms. This may include details of how the treatment is given (or administered). Details of how a treatment works are important, as they enable you to understand a treatment and help you to decide whether it is appropriate for you.

**Rating the question**
The question is only concerned with the treatment or treatments described in the publication.

Guidelines for rating the question:
- 5: Yes - the description of each treatment includes details of how it works.
- 2 - 4: Partially - the description of some but not all of the treatments includes details of how treatment works, or the details provided are unclear or incomplete.
- 1: No - none of the descriptions about treatments include details of how treatment works.

**Example**
5 rating (a single treatment publication):
‘Treatment X will stabilise your condition. The treatment is given as a high dosage daily injection over a period of two to three weeks. As the treatment circulates in the blood stream, it reaches cells all over the body and prevents the virus from reproducing and spreading.’

A publication concerned with more than one treatment will be rated 5 if similar descriptions are provided for each treatment mentioned.
12. Does the website describe the benefits of each treatment?

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**Instructions Question 12: Does it describe the benefits of each treatment?**

*What the question is about and why it is important*

A good quality publication will describe the benefits of each treatment. Most treatments have some benefits or advantages. It is important to be aware of the benefits so that you know what to expect from a treatment and can decide whether it is associated with an outcome that is important for you.

*Rating the question*

The question is only concerned with the treatment or treatments described in the publication, and simply requires you to rate whether any benefit is mentioned for each of the treatments described. The question is not concerned with the size of the benefit or who is most likely to benefit. The question cannot be used to assess whether all of the benefits associated with each treatment have been described as this would involve checking against other sources.

Guidelines for rating the question:

- **5:** Yes a benefit is described for each treatment.
- **2 - 4:** Partially a benefit is described for some but not all of the treatments.
- **1:** No no benefits are described for any of the treatments.

*Examples*

**5 rating** (a single treatment publication):

‘For most people, the treatment will provide a complete cure within a few weeks.’

‘In the short-term, treatment X can halt the weight loss in sufferers from Jones’ disease. It can also reduce the symptoms of pain and breathlessness. Whilst it cannot cure the condition, treatment X can provide long-term stabilisation and will prevent the condition from worsening.’

A publication concerned with more than one treatment will be rated **5** if similar descriptions are provided for each treatment mentioned.
### Instructions

**Question 13:** Does it describe the risks of each treatment?

**What the question is about and why it is important**

*A good quality publication will describe the risks of each treatment.* Most treatments involve some risks or disadvantages. It is important to be aware of the risks so that you know what to expect from a treatment and can decide whether it is associated with an outcome that is important for you.

**Rating the question**

The question is only concerned with the treatment or treatments described in the publication, and simply requires you to rate whether *any* risk is mentioned for each of the treatments described. The question is not concerned with the size of the risk or who is most likely to be at risk. The question cannot be used to assess whether *all* of the risks associated with each treatment have been described as this would involve checking against other sources.

**Guidelines for rating the question:**

- **5: Yes** - a risk is described for each treatment.
- **2 - 4: Partially** - a risk is described for some but not all of the treatments.
- **1: No** - no risks are described for any of the treatments.

**Examples**

*5 rating (a single treatment publication):*

’Side-effects include dizziness, muscle pain and insomnia.’

‘The research revealed the main side-effects were generally mild and reversible and included a dry mouth and nausea. The treatment did not seem to have a harmful effect on any major organs when taken over a short period. However, some users developed kidney problems after prolonged use and the treatment should be carefully monitored.’

A publication concerned with more than one treatment will be rated **5** if similar descriptions are provided for each treatment mentioned.
14. Does the website describe what would happen if no treatment is used?  

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Instructions Question 14: Does it describe what would happen if no treatment is used?  

What the question is about and why it is important  
A good quality publication will include a description of what would happen if the condition is left ‘untreated’. It is important to be aware of the outcomes of not using any treatment so that you know what to expect and can decide whether not using any treatment is associated with an outcome that is important for you.

Rating the question  
The question simply requires you to rate whether any outcome associated with not using treatment is mentioned. The question is not concerned with the size of the risks or benefits or who is most likely to be at risk or to benefit from no treatment options. It is not possible to assess whether all the risks or benefits of each no treatment option have been described as this would involve checking against other sources.

Guidelines for rating the question:

- **5: Yes** - there is a clear description of a risk or a benefit associated with any no treatment option.
- **2 - 4: Partially** - a risk or benefit associated with a no treatment option is mentioned, but the information is unclear or incomplete.
- **1: No** - the publication does not include any reference to the risks or benefits of no treatment options.

Examples

5 rating:
‘You may decide that none of the treatments described would suit you and that you would rather wait to see what happens without treatment. Although your symptoms may cause you some discomfort and you may want to consider some pain control techniques, the condition should not worsen and there are no major disadvantages associated with not using treatment.’
‘Many women with Jones’ disease may safely put off treatment until there is no longer any chance of them becoming pregnant. However, treatment at some stage is recommended, as it becomes less effective after the menopause and there is a risk of lung damage if no treatment is used.’
‘This is a rapidly progressing, life-threatening condition and early treatment is recommended. Unfortunately, delaying treatment can result in long-term damage to the heart’
15. Does the website describe how treatment choices affect overall quality of life?

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**Instructions Question 15: Does it describe how the treatment choices affect overall quality of life?**

*What the question is about and why it is important*

A good quality publication will include a description of the broader aspects of treatment choices - not just risks and benefits, but the overall impact of a treatment choice or choices on day-to-day living. This question is important because a treatment choice may involve major changes in lifestyle or circumstances or have important effects on those close to you that you need to be aware of and consider before making a decision.

**Rating the question**

This question is only concerned with the treatment choices outlined in the publication. No treatment options are included as a treatment choice for this question if Question 12 was rated above 1. Guidelines for rating the question:

- **5: Yes** - the publication includes a clear reference to overall quality of life in relation to any of the treatment choices mentioned.
- **2 - 4: Partially** - the publication includes a reference to overall quality of life in relation to treatment choices, but the information is unclear or incomplete.
- **1: No** - there is no reference to overall quality of life in relation to treatment choices.

**Examples**

5 rating:

‘Patients are monitored continuously in hospital for a week before the procedure is carried out, and recovery time can vary from several days to several weeks. If you are undergoing this form of treatment, you may need to take a lot of time off work and to have someone to care for you when you come home.’

‘Because Treatment X is normally given as a course of injections, you will need to visit your GP’s surgery daily throughout the weeks of treatment. As there is a slight risk of fainting during the initial stages of treatment, you need to ensure that your family and work mates are able to look out for you, and you will not be able to drive or operate heavy machinery.’

‘You may feel depressed and confused for a while following surgery. You may feel that you are not the same person and that you can no longer achieve or enjoy the things you used to. Take time to adjust to your new physique and to get used to a few limitations on your physical activity.’
16. Is it clear that there may be more than one possible treatment choice?  

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**Instructions Question 16: Is it clear that there may be more than one possible treatment choice?**

**What the question is about and why it is important**

A good quality publication will indicate that there is a choice about treatment. The publication should indicate that the treatment choices described may be suited to some people more than others, and that there is nearly always a choice of treatment, even if a full account of alternatives has not been presented in the publication.

**Rating the question.**

Your judgement will be important for rating this question. Consider the publication as a whole and use the hints to help you decide whether it has highlighted the issue of treatment choice for each consumer or patient.

**Guidelines for rating the question:**

- **5: Yes** - the publication makes it very clear that there may be more than one possible treatment choice.
- **2 - 4: Partially** - the publication indicates that there may be more than one possible choice, but the information is unclear or incomplete.
- **1: No** - the publication does not give any indication that there may be a choice about treatment.

**Examples**

**5 rating:**

A publication provides information about a new treatment for a form of cancer. The treatment is reported to be the most effective treatment available for the majority of people with this condition, and the authors describe the factors known to be associated with good treatment outcomes (such as treatment at an early stage of the disease and the absence of other medical conditions). The authors highlight some unpleasant short-term side-effects associated with the treatment and the possibility that a minority of patients may experience serious long-term consequences as a result of treatment, including the development of other cancers. A brief description of the natural progress of the disease and what is likely to happen without any treatment is also included. Other treatments are mentioned briefly and the authors refer readers to several other publications for more details. The authors conclude that they cannot recommend what would be best for an individual patient.

**1 rating:**

A webpage describes a single treatment for a skin condition. The page is written by a doctor and is found in the section on treatments on a national self-help organisation's website. The sources of evidence quoted are the scientist who developed and sells the treatment and the case of one of the doctor's patients who has experienced a 'miraculous' cure. The only reference to other treatment choices is the statement that 'all other treatments for the condition are associated with unacceptable side-effects' and the possibility of 'permanent disfigurement' if no treatment is used. The patient's search for a cure is described as 'torture' that led him to try other treatments that left him 'scarred' and 'suicidal'. The treatment is said to produce 'stunning and permanent results after a few applications with no risks or side-effects'. The author recommends the treatment as 'suitable for anyone' and 'bringing hope to all those who have despaired of finding relief from this devastating and unsightly condition'.

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17. Does the website provide support for shared decision making?

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**Instructions Question 17: Does it provide support for shared decision-making?**

**What the question is about and why it is important**

A good quality publication will raise issues for you to discuss with all those involved in your care about the best treatment choice for you. The information about a treatment choice or choices provided by the publication should enable you to prepare for a consultation with a health professional or to talk through issues that might affect your family, friends or carers regarding your treatment choices.

**Rating the question**

Consider the publication as a whole and decide whether it has enabled you to prepare a list of specific issues to consider and discuss concerning your treatment choices. These issues should be made clear throughout the publication, rather than merely being queries arising from its deficiencies and gaps. How high you rate the publication will depend on your judgement of how much it will support you in sharing decisions about treatment choices. If you do not wish to share in decision-making about your treatment, rate the publication from the point of view of a carer or relative who wants to know more about your treatment choices.

Guidelines for rating the question:

- **5: Yes** - the publication provides very good support for shared decision-making.
- **2 - 4: Partially** - the publication provides some support for shared decision-making.
- **1: No** - the publication does not provide any support for shared decision-making.

**Examples**

Issues to consider and discuss are usually presented at various points throughout the publication. Here are some simple examples:

**5 rating:**

‘You may want to know whether your treatment will work or whether you can stay well without treatment. Your partner or carer may also have a lot of concerns and questions about how they can help you and how your condition and treatment will affect them. Try to find out as much as you can about your treatment options and make a list of questions you want to ask your doctor.’

‘Treatment can last several years and you are advised not to get pregnant during this time. If you had planned to have a baby soon or are worried about contraception, you should talk to your doctor before you start treatment. If you have a partner, try to discuss these issues together with your doctor.’
### Instructions Question 18: Based on the answers to all of the above questions, rate the overall quality of the publication as a source of information about treatment choices

**What the question is about and why it is important**

Question 16 is an ‘intuitive summary’ of your responses to the preceding 15 questions. All publications will have deficiencies, and it is unlikely that any one publication will rate high on all of the questions. However, after completing all of the questions on DISCERN, you should have developed some feeling for the overall quality of the publication which will help you decide whether it is a useful and appropriate source of information about your treatment choices.

**Rating the question**

The guidelines below should help you to rate this question, but your judgement is also very important. It may encourage you to know that during the development and testing of the instrument, users independently reached very similar conclusions about the overall quality of the publications they were rating even though we did not provide very specific instructions for this question. DISCERN has been designed to help you develop your critical skills, so trust your own opinion!

**Guidelines for rating the question:**

- **High (5)** - the publication rated high (4 or above) on the majority of questions. A high overall quality rating indicates the publication is ‘good’ quality - it is a useful and appropriate source of information about treatment choices.
- **Moderate (3)** - the publication rated high and low on a similar number of questions, or the majority of questions rated in the mid-ranges (3). A moderate overall quality rating indicates the publication is ‘fair’ quality - it is a useful source of information about treatment choices but has some limitations. Additional information or support would definitely be needed.
- **Low (1)** - the publication rated low (2 or below) on the majority of questions. A low overall quality rating indicates the publication is ‘poor’ quality - it has serious shortcomings and is not a useful or appropriate source of information about treatment choices. It is unlikely to be of any benefit and should not be used.

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19. What is your sex?

male
female

20. What is your age?

21. Please re-enter the 6 digit number you chose in question 1, below.

Thank you for your participation!

We appreciate your feedback. If you have any comments or recommendations about the HIT, please write them in the box, below.

Alternatively, if you have questions about the HIT, you can contact us directly at miranda.elliott@ubc.ca.