

Something to Think About: Informing Canadians about Ethical Concerns in Medical Tourism

by

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Abstract

Medical tourists, persons traveling across international borders with the intention of accessing medical care, are often unaware of safety and ethical concerns related to the practice of medical tourism. Accessing medical care as a medical tourist may result in risks to the health of the patient, as well as negative impacts to both destination and departure country health care systems and global health equity. These ethical considerations are not provided in sources of information commonly accessed by Canadian medical tourists. This interview-based study affirms the usefulness of an iterative process for designing an information sheet for Canadians considering engaging in medical tourism and for communicating ethical considerations to consumers of other services. Perceptions from former Canadian medical tourists indicate that this information sheet is useful in raising awareness of the ethical concerns of medical tourism, which may impact medical tourists' decision-making given adequate additional sources of information and support.

Keywords: medical tourism; public health; ethics; health communication; Canada; qualitative research

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Chapter 1.

Introduction

‘Medical tourism’ is a term that is used to describe the specific activity of persons traveling across borders to purchase a medical procedure out-of-pocket (Crooks, Kingsbury, Snyder & Johnston, 2010a). This definition focuses solely on activities that are paid for privately and excludes formal cross-border arrangements by an individual’s home health system, emergency medical treatment while traveling outside one’s own country, and care that is provided for expatriates living abroad (Johnston et al., 2010). This care may not necessarily be arranged by the individual; it may also be arranged by a medical tourism facilitator or an international insurance agency that arranges trans-national private medical care (Snyder et al., 2011; Alvarez, Chanda & Smith, 2011).

Medical tourism is a contentious term that evokes various reactions regarding the appropriateness of its use. For some researchers, this term wrongly associates this activity with the tourism industry, indicating that this activity is necessarily elective, despite anecdotal evidence of patients experiencing high levels of pain or desperation to access unavailable or unaffordable medical care within their home country (Kangas, 2010). However, linking this activity to the field of tourism may provide a useful contribution to research on this phenomenon, given that sustainability in tourism is an area of research that may contribute valuable information for addressing concerns regarding unavailable or unaffordable medical care accessed abroad (Connell, 2006; Swarbrooke, 1999). For the purpose of my thesis, I will use the term ‘medical tourism’ as it is a more commonly used term by industry members and stakeholders than other terms such as ‘international medical travel’ (Kangas, 2010). Furthermore, the term medical tourism is more focused than the term ‘international medical travel’, which suggests the inclusion of formal cross-border care that does not involve the same ethical concerns as informal cross-border care (Johnston et al., 2010).

My thesis project describes the development of an information sheet designed to inform Canadian patients considering engaging in medical tourism of the ethical dimensions of this practice. This introductory chapter of my thesis provides a background to the medical tourism industry as it relates to public health, particularly public health ethics. This background allows for a greater discussion throughout my thesis of ethical concerns in medical tourism as well as public health responses to these concerns. It is important to acknowledge that the presented analysis does not address transplantation or reproductive surrogacy procedures as these aspects of medical tourism incorporate greater ethical consideration, namely the purchase of human tissues that are distinct from the focus of this discussion.

1.1. What Is Public Health?

The World Health Organization (WHO) defines health as a “state of complete physical, mental, and social well-being and not merely the absence of disease” (WHO, 1948). Health is a relative and continuous state of being, defined by our capacity to live in the social environment. As such, health can be impacted upon across the socioecological framework (Callahan, 2002). This framework recognizes the many levels of influence on a person’s health starting from the biological level, which is influenced by an individual’s immediate social and physical environment, and progressing to increasingly macro factors (Tarlov, 1996). The discipline of public health explores the health status of populations by identifying and measuring threats to the health of populations and effecting policy and interventions to respond to these threats. Public health, then, refers to society’s actions to foster optimal health throughout society itself. This definition builds on the utilitarian model of the greatest good for the greatest number of people to incorporate the societal values of justice and fairness (Beauchamp & Childress, 2001). While society is often equated to populations within borders of the nation-state, particularly from a public health perspective because of the vast difference in health care systems between nations, the socioecological framework demonstrates the necessity to consider multiple scales of society, including all persons in an increasingly globalized world (Chapman, 1994).

With this definition of health in mind, the goal of public health is to foster good health throughout the population in an equitable fashion. The pursuit of equity in health refers to the elimination of health disparities between population groups based on their underlying position in society (Braveman, 2011). The mechanisms used to achieve this goal include policy implementation and specific activities or interventions (Callahan, 2002). As the socioecological framework demonstrates, policy at all levels and across all sectors impact upon the health of populations (Danis & Patrick, 2002). While public health activities must recognize the influence of all policies on health status, I find it useful for the purpose of this thesis to focus on the roles and responsibilities of public health related specifically to health policy, or policy which is created to promote, maintain, and restore the health of populations (Callahan, 2002). This promotion, maintenance and restoration of health, also known as health care or health service delivery, is impacted by the allocation of resources according to health policy (Chapman, 1994). To foster good health throughout a population, public health must take a population health approach to the organization of health care by developing health policy that addresses the needs of all persons in a population throughout the life cycle and regardless of health status. This approach to health service delivery recognizes that health inequalities are inevitable; however, health care that aligns with the goals of public health should serve to reduce pain and suffering by eliminating health inequities, defined as avoidable, unnecessary, and unfair poor health outcomes (Daniels, Kennedy & Kawachi, 2002).

Since the Alma Ata declaration in 1978, the values of population health and equitable resource allocation have been infused in health care and health policy through the advocacy for delivery oriented around Primary Health Care (PHC) (Green, 2007). The PHC model of health care delivery reorients health policy to provide greater attention and resources to the promotion of good health and prevention of disease so as to reduce the burden of diseases requiring biomedical intervention. Despite the development of this model over thirty years ago, health care today demonstrates a continued emphasis on curative and biomedical intervention, leading to greater rationing in medical intervention and neglect for the promotion of good health and prevention of disease (Maclean & Brown, 2009). This continued health policy focus on curative interventions has been attributed to the interpretation of the PHC model's emphasis on

health promotion to indicate greater individual responsibility for one's own health. The increased presence of neoliberal policies has shifted the burden of responsibility for promoting, preserving, and restoring health to the individual without increasing individual empowerment to participate in the development of health-promoting activities and policies (Gauld, 2009). The emphasis in health care on curative interventions and individual responsibility for health without accompanying empowerment limits the abilities for public health to meet its intended goal of equitably fostering good health throughout the population (Maclean & Brown, 2009).

1.2. Ethics in Public Health

The goal of public health is challenged by the inability to concretely determine what constitutes health inequalities that are avoidable, unnecessary, and unfair. Ethical frameworks in public health help to understand and identify roles and responsibilities of health policy and public health activities to enable the realization of these goals (Daniels et al., 2002). While inequalities may be unavoidable, the moral principle of equality of opportunity indicates a responsibility on behalf of society members to procedural justice and fair resource allocation. In public health, decisions on health resource allocation should consider the provision of health care in a way that ensures the realization of "primary social goods". These social goods, including liberty, opportunities, wealth, and self-respect, are considered necessary for the societal value of equal opportunity amongst all members of a society (Daniels et al., 2002). Health is an important enabler to the realization of these social goods, and as such, health resources, including determinants of health, should be allocated in such a manner that promotes good health, prevents and treats disease, and reduces suffering throughout a population (Brock, 2000). With this in mind, the population health approach to public health aligns with the principle of equality of opportunity by providing a model for health care focused on fostering good health in a way that equitably utilizes public resources to reduce pain and suffering throughout an entire population (Labonté et al., 2005).

The application of ethical frameworks to the population health model can be beneficial to further incorporating important moral considerations into public health. General moral considerations in society include: producing benefits; avoiding,

preventing, and removing harms; producing an optimal balance of benefits over harms; distributive justice; respect for autonomous choice; privacy and confidentiality; keeping promises and commitments; disclosing information through transparency; and building and maintaining trust. In certain situations these considerations may come into conflict. In these situations, ethical frameworks help to prioritize different moral considerations (Childress et al., 2002). One ethical framework for navigating these conflicts in public health includes the human rights framework with a “preference for the poor” (Farmer, 2005). This framework prioritizes the values of justice and fairness in public health (Childress et al., 2002). The following discussion will further explore the application of the human rights framework with a “preference for the poor” as a useful ethical framework for guiding the practice of public health in a way that equitably fosters good health.

The Universal Declaration of Human Rights defines the entitlements of all persons to “some good, service, or liberty” (Chapman, 1994, p.4). Rawls uses the term “primary social goods”, although other terms such as “capabilities” are also used, to refer to that to which all humans have entitlements (Sen, 2005). Both terms encompass the outcomes that result from societal actions that recognize the intrinsic value and inherent dignity of all other humans. The Universal Declaration of Human Rights provides a framework for enforcing the recognition of the inherent dignity of all other humans through the upholding of these primary social goods or capabilities (Chapman, 1994). The human rights framework requires policy makers to consider whether a policy or program will violate a human right, whether there is transparency in policymaking and mechanisms for publicly recognizing and responding to human rights violations, and finally, whether policies and programs enhance social public goods or capabilities (Mann, 1997). This form of policy-making encourages public participation in the policy process, a necessity for developing policies that provide equal opportunity for all in society to live ideal livelihoods, including future generations (Boulanger & Brecht, 2005). As such, the Universal Declaration of Human Rights facilitates population-wide decisions with the potential to impact upon the sustainability of a society, similar to those faced by policy-makers in public health (Mann, 1997).

Applying the human rights framework with a “preference for the poor” to public health encourages the use of health care to protect or restore one’s opportunities by

recognizing the link between health and primary social goods or capabilities (Brock, 1994). Furthermore, the explicit “preference for the poor” orientation of this framework recognizes that health care must prioritize those who are most vulnerable (Danis & Patrick, 2002). Policies that give a “preference for the poor” allocate more resources to vulnerable populations to uphold the moral principle of equal opportunity (Farmer, 2005). Without this greater allocation of resources, the disadvantages of vulnerable populations maintain the vulnerability of these populations (Braveman, 2011). By working within the human rights framework with a “preference for the poor”, public health can gain coherence and clarity of its roles and responsibilities in society to encourage socially responsible public health actions (Mann, 1997).

Ethical considerations have often been neglected in public health due to the challenges of applying ethical frameworks to such a vast discipline that incorporates both micro and macro scales of human activity globally (Danis & Patrick, 2002). Only a few nation-states routinely monitor health equity within borders, and there is little monitoring on a global level (Braveman, 2011). Health policy is often highly influenced by differing values and socio-political contexts (Maclean & Brown, 2009). Globalization and neoliberalism have drastically changed health care in the past thirty years by reducing the role of the state in the provision of health care and increasing privatization of health care. This drastic shift has increased the burden of fostering good health to individual “consumers of care” (Danis & Patrick, 2002), which has lead to increasing health inequities both within nations and globally (Maclean & Brown, 2009). Health policy focused on a societal level, particularly beyond nation-state borders, lacks an incorporation of societal values and ethical consideration (Danis & Patrick, 2002). With the shift of responsibility for fostering good health to individual “consumers of care”, health care is responding increasingly to demands of those able to pay for care instead of allocating resources in such a way that protect human rights (Gauld, 2009). Various health care activities including increasingly high technology and costly medical interventions that are only accessible to the wealthiest populations are utilizing large amounts of finite health resources, resulting in health inequities. The application of an ethical framework to public health, such as the human rights approach with a “preference to the poor”, could encourage more fair health resource allocation globally (Farmer, 2005). This is particularly true if public health policy recognizes all persons

globally when considering ethics in public health (Maclean & Brown, 2009). The next section will introduce one form of health care, medical tourism, which illustrates current trends in global health along with potential impacts on the goals of public health and global health equity.

1.3. Medical Tourism

Medical tourism refers to the movement of persons across borders with the intention of accessing non-emergency medical care (Ehrbeck, Guevara, Mango, Cordina & Singhal, 2008; Crooks & Snyder, 2011). While there exist many historical accounts of persons traveling from developing to more developed countries for services that are not available domestically, recent media attention demonstrates the development of a growing industry of private medical care in low and middle income countries specifically marketing this care to individuals in high income countries (Crooks et al., 2011). Individuals in high income countries may be motivated to travel for medical care to avoid long wait lists, access procedures that are domestically unavailable, and/or save costs for elective procedures that are paid for out-of-pocket domestically (Johnston et al., 2010). Researchers indicate that the reduced role of the state in providing health care and increasing commodification of health are central causes of the growing popularity of medical tourism (Ormond, 2013). While individual private medical facilities have previously catered to an international market, the recognition of the economic development potential of the medical tourism industry has resulted in the development of multinational private hospital companies, public-private partnerships, and medical tourism facilitator companies, all which have caused an increase in the visibility of the industry in recent years (Turner, 2007). Countries that are particularly reliant on tourism, such as those in the Caribbean region, have developed strategies for developing a medical tourism industry as a means of diversifying their tourism sector and encouraging economic development (Johnston et al., 2013; Snyder et al., 2013). Some countries such as Cuba and Singapore offer medical care to foreign patients in public hospitals to help finance the public health care system while under the close control of the government. Frequently, public subsidization for the training of health care workers and/or the use of public land contributes to the development of private MT facilities (Johnston et al., 2010). Overall, discussions related to medical tourism commonly focus

around the economic profit potential of the industry and opportunities for employment (Scott, 2012).

Despite increasing discussions about medical tourism in the media and amongst researchers in various fields including health geography, law, tourism, and public health (Cohen, 2010; Connell, 2010), there remains limited empirical data informing the potential impacts of medical tourism (Johnston et al., 2010; Crooks et al., 2013), though this data is growing (Chen & Flood, 2013). Discussions by researchers regarding the development of the industry commonly indicate the potential for significant impacts of medical tourism on public health (Hall, 2011). Researchers mention concerns regarding the individual safety of medical tourists, including a lack of risk communication and informed consent (Penney et al., 2011; Turner, 2007). Information provided to patients may be misleading about the risks or necessity of a procedure. Patients may feel obliged to undergo a treatment despite potentially limited communication with the health care provider after having traveled a long distance with the intention to receive care. This increased pressure may compromise a patient's informed consent (Lunt, Hardey & Mannion, 2010; Penney et al., 2011).

Furthermore, researchers have also discussed concerns for health care systems in destination and departure countries. Concerns for destination countries include: 1) the diversion of resources such as health human resources, public funding and/or public land to support private health care facilities catering to tourists (Meghani, 2010; Sen Gupta, 2008) and 2) the prioritization of the needs of international patients over pressing domestic needs, particularly in the form of increasing training for and development of medical interventions with high profit potential over primary health care (Turner, 2007; Chen & Flood, 2013). While some countries and medical tourism facilities may encourage cross-subsidization where a facility provides a certain service to the community to help compensate for public subsidization, these services provide a form of vertical care which may respond more to the priorities of the private entity providing the service than the needs of the community (Chen & Flood, 2013). Concerns for countries of origin for medical tourism patients include: 1) the use of public resources to treat complications obtained from treatment abroad (Snyder et al., 2012a); 2) The development of two-tier health care where only those able to travel out-of-country for care can access certain care (Johnston et al., 2010); 3) the reduction of pressure for

system reform if patients leave the health care system to access care out-of-country; and 4) the transmission of infectious diseases across borders, particularly from patients returning home after visiting medical facilities (Snyder et al., 2012a). Overall, concerns for the potential impacts of MT at both the individual and societal level indicate potential significant implications of this industry on global public health which necessitate a greater emphasis on global public health ethics in discussions and decision-making regarding medical tourism (Scott, 2012; Ormond, 2012).

Much like consumers of other goods and services, individuals considering traveling out-of-country for medical care often turn to the internet or word-of-mouth as sources of information during the decision-making process (Ormond, 2012). While media reports have brought attention to some individual safety concerns associated with medical tourism, including surgical complications and the potential for poor quality or unnecessary care due to a lack of regulation in the industry (Snyder et al., 2012b), there has been limited discussion in the media about the ethical concerns of medical tourism (Johnston et al., 2010). Existing sources of information may not provide neutral or comprehensive information, particularly as many of these sources may have a profit-driven interest in the provision of information (Johnston et al., 2012). Discussions around recent trends in health care such as medical tourism provide an opportunity to raise awareness about potential safety and ethical concerns of health care to enable public health to meet its intended goals (Pinto & Upshur, 2009).

1.4. Promoting Ethical Decision-Making in Medical Tourism

Despite discussion amongst academics of ethical concerns for medical tourism, research indicates that there is limited consideration for these issues by medical tourism stakeholders, including medical tourists and policy-makers (Crooks et al., 2013). The debate in the policy realm is often shaped by public opinion (Adams & Raisborough, 2010). Common sources of information to the public regarding medical tourism include the internet or word-of-mouth, typically by persons who stand to profit from increasing growth of the industry (Johnston et al., 2010). Researchers have indicated that this information is heavily biased towards promotional materials which support medical tourism businesses (Ormond, 2012). Researchers point to a gap in the public discussion

around ethical issues relating to medical tourism, particularly by those considering traveling as a medical tourist. With biased and incomplete information, medical tourists are generally unaware of many potential ethical implications of this practice. In particular, while medical tourists may consider ethical issues related to barriers to their personal access to health care within their country, the contribution of medical tourism to global health inequity or third party impacts has had minimal consideration (Snyder et al., 2012a). Discussions which emphasize engagement with ethical values may be a useful way of bringing the ethical concerns of medical tourism into the public debate and policy considerations. The development of these discussions may benefit from an analysis of the success of “ethical consumption” promotional materials in increasing public awareness of responsible consumption (Adams & Raisborough, 2010).

Increased awareness of the impacts of one’s consumption choices has shaped a new form of activism in which consumers demand companies to produce more ethical products and services (Adams & Raisborough, 2010). Critiques of the “ethical consumption” trend are wary of “green-washing” and of ethical certification used simply as a marketing tool without advocacy for increased equity. However, research demonstrates that ethical consumption campaigns may have a significant impact on individuals’ awareness of certain ethical values, potentially leading to societal changes (Clarke et al., 2007). By ascribing various responsibilities to consumers, consumption is brought into the sociopolitical realm, which encourages contemplation of responsible citizenship and citizenly acts. This increased contemplation may impact more than just consumer behavior by also empowering persons to advocate for change in the policy realm. As such, ethical consumption campaigns such as ethical guidelines represent one strategy for bringing into awareness the politics of consumption and moral considerations related to these politics. By connecting persons’ individual actions with the upholding of societal values, ethical guidelines may serve to reinforce individuals’ understanding of themselves as global citizens with certain roles and responsibilities (Clarke et al., 2007). Researchers indicate that strategies that engage individuals in this process of considering their individual actions as contributing to the upholding of societal values are part of this new individualistic activism (Barnett, Clarke, Cloke & Malpass, 2005).

As a relatively new industry, consumption guidelines in medical tourism are nearly nonexistent besides a few select examples of guidebooks written by physicians or industry members (Gahlinger, 2008; Hancock, 2006; Marsek & Sharpe, 2009; Schult, 2006). An analysis of these guidebooks reveals the current framing of medical tourism in public discussion and identifies the subsequent lack of ethical consideration within this public discussion. This analysis indicates that these guidebooks encourage individuals' to take greater responsibility for their own health through engagement in medical tourism (Ormond, 2012). As such, the guidebooks demonstrate alignment between current trends in medical tourism discussions and neoliberal strategies to health care delivery that emphasize the individual's role in promoting, maintaining, and restoring one's own health (Scott, 2012). While these guidebooks encourage individuals to use medical tourism to achieve their ideal health, the guidebooks never address the impacts of one's socioeconomic status on their ability to participate in this "journey", as the medical tourism trip is commonly referred to. Furthermore, the guidebooks never mention any potential impacts of medical tourism on the ability of third parties to access care to attain their ideal health, or health systems to equitably deliver health care (Ormond, 2013). These guidebooks encourage engagement with health care that allows the market to determine one's choice of health care consumption, resulting in information aimed at encouraging individual consumption of health care which profits the medical tourism industry (Scott, 2012).

Guidance provided by sources of information on the internet, typically medical tourism facilitator websites, pay limited attention to individual risks and ethical concerns (Penney et al., 2011). The biased and incomplete information commonly provided to medical tourists leads to concerns for sustainability of destination communities if health care planning and delivery prioritizes the needs of foreigners over locals (Turner, 2007). The potential negative impacts of tourism on sustainability has been well researched and resulted in a large number of discussions around strategies for promoting sustainable or ethical tourism and responsible engagement in tourism activities and regulation by nation-states (UNWTO, 2005). While guidelines for both individuals and policy-makers are common strategies for promoting ethical engagement in tourism, no such guidelines exist for medical tourism and as such certain ethical considerations do not typically inform prospective medical tourists' decision-making (Snyder et al., 2012b).

Given the current sources of information for medical tourists, researchers indicate that there is a need for more information about medical tourists' decision-making and, subsequently, opportunities to encourage more informed decision-making in medical tourism (Ormond, 2012; Snyder et al., 2012b). In particular, researchers suggest the development of studies that engage with medical tourism stakeholders regarding the consideration of ethical concerns in decision-making. This research could help identify effective means of promoting social responsibility amongst medical tourism stakeholders (Scott, 2012). The inclusion of public discussion in health policy and planning ensures health care delivery meets the needs of the larger public according to agreed upon societal values. However, research demonstrates that often, despite intentions to involve the public in health planning activities, public involvement may be minimal (Gauld, 2007). This is particularly true with rapid changes in health care leading to potential misinformation and misunderstanding in public awareness (Greenberg and Danis, 2002). The recent growth of privatized health care and medical tourism in conjunction with rapid globalization may be resulting in limited or biased information informing the public discussion (Ormond, 2013), indicating the need for strategies to communicate this information to the public and to encourage them to help make health care consumption choices that are more supportive of health equity and other public health goals (Alvarez et al., 2011).

The field of health communication provides insight into strategies for communicating health information to the public (Parvanta, Nelson, Parvanta & Harner, 2010). Social marketing is one strategy that encourages increased communication between health care users and providers to encourage appropriate dissemination of knowledge for improved health outcomes and health equity (Lefebvre & Flora, 1988). According to social marketing, formative research strategies provide methods of developing effective communication with the intention to inform a certain population about health information (Parvanta et al., 2010). Shaping the public discussion through ethical dialogue can lead to consensus building which is useful for policy making, particularly through the development of advocacy which pushes for better health policy that adheres to the human rights framework and supports global health equity (Churchill et al., 2002).

1.5. Thesis Overview

This thesis describes research conducted as part of a larger study funded by a Catalyst: Ethics grant from the Canadian Institute of Health Research, led by my supervisor Dr. Jeremy Snyder. In this section, I describe the development of my thesis research objectives from my involvement with this larger study, as well as an outline of my thesis structure.

The research study led by Dr. Snyder intends to develop an information tool which promotes greater awareness of safety and ethical concerns to Canadians considering engaging in medical tourism. This study was developed in response to a knowledge gap identified by researchers regarding neutral and comprehensive information currently available for Canadian medical tourists to make informed and socially responsible decisions. This study intends to explore the potential for an information tool to increase awareness of the ethical concerns of medical tourism amongst Canadians considering engaging in medical tourism, with the potential for this awareness to shape the public discussion leading to more informed, equity-promoting, and socially responsible decision-making. As part of this research study, I conducted both a literature review of existing ethical guidelines and interviews with twenty-four former Canadian medical tourists. The analysis of both the literature review and interviews informs my thesis.

My involvement with this larger study led to the development of my thesis research objectives. To develop the final information tool, the research group underwent an iterative process that began with a review of ethical guidelines in related domains, including voluntourism (medical volunteering abroad), ecotourism, and responsible use of public health care resources. During the literature review, the research group identified common ethical values emerging from existing ethical guidelines which would be relevant to the practice of medical tourism. These ethical values informed the development of an initial draft ethical information tool. The term “guideline” was replaced at this time by “information sheet” due to a lack of empirical evidence regarding the potential impacts of medical tourism. Without adequate evidence on the potential impacts of medical tourism, this research study does not intend to guide action but instead provide information which creates awareness of the potential impacts for more

informed decision-making. Through this process, the research group identified the methodology for developing the information sheet as a useful activity for exploring effective means of communicating ethical concerns to health care users. The iterative process used to develop such a document informed the following research objective for my first thesis analysis (Chapter 2): Describe the process, strengths, and limitations of the methodology used to develop the information tool for potential replicability of this methodology and further development of tools for communicating ethical concerns to the public.

As part of the methodology used to develop the information tool, the research group conducted formative research to improve upon the tool and explore the potential impacts of such a tool on decision-making. As part of this formative research, I conducted twenty-four semi-structured phone interviews with former Canadian medical tourists to garner feedback on the draft information tool. After reviewing the transcripts from these interviews, the following research objectives emerged for the second analysis of my thesis (Chapter 3): 1) Identify and describe the perceptions of former Canadian medical tourists on the usefulness of the information tool according to different contexts; 2) Identify and describe the potential impact of the information tool on medical tourists' awareness of ethical concerns of medical tourism; 3) Identify and describe existing knowledge gaps regarding the communication of ethical concerns of medical tourism to inform future research with the intention of better informing Canadians of these concerns.

Throughout this thesis research, methodological rigour was established through extensive researcher collaboration to allow for divergent viewpoints to inform the methods of data collection, analysis, and the discussion of findings. Rigour is established in qualitative research to avoid research bias and enhance reliability of findings (Mays & Pope, 1995). Investigator and data triangulation was employed during the literature review by ensuring all guidelines were reviewed by two researchers. Interview transcripts were also read by multiple researchers to foster consideration of different opinions. During the information tool development process, regular face-to-face team meetings encouraged continuous communication between all team members to reach consensus. The use of investigator and data triangulation and continual research team communication built authenticity into the research process by providing a

mechanism for divergent opinions to foster openly critical discussions during decision-making. Detailed recordings of meetings, decisions made and all processes which contributed to the research findings were recorded to provide an audit trail and enhance transparency of this process for discussion of the research findings in light of the methodology used and research judgements (Baxter & Eyles, 1997; Whittemore et al., 2001).

Rigour was also established through the recruitment of interview participants. The eligibility criteria for participation in the study was carefully selected and detailed in the methods section of both analyses to enable exploration of a particular social phenomenon. By utilizing more narrow participation eligibility, this allows more deliberate sampling to access a depth of knowledge, rather than a representative sample (Mays & Pope, 1995). To avoid selection bias, multiple channels of recruitment were utilized to ensure multivocality of perspectives. Recruitment continued until reaching adequate saturation of feedback for a meaningful discussion of participant perspectives (Whittemore et al., 2001).

Finally, rigour was also established through continuous researcher reflexivity. To ensure reflexivity throughout this research process, I maintained conscious deliberation of my positionality to consider the way I relate to participants and vice versa, the way I relate and engage with other members of the research team, and the impacts of my position on the interpretation of findings. This conscious deliberation allows for a discussion of findings that positions the significance of this study in terms of the research situation and addresses the limitations of these findings in regards to generalizability (Baxter & Eyles, 1997). By paying careful attention to my position as a researcher throughout the research process, I provide a discussion of the potential implications of the research findings while situating these findings within a particular context (Mays & Pope, 1995).

1.5.1. Thesis Outline

This introductory section concludes the first of four chapters in this thesis. The second and third chapters respond to the research objectives described above. Each of these two chapters is structured as a peer-reviewed journal article. Chapter 2 provides

an analysis of the strengths and limitations of the methodology utilized for developing the information tool and discusses the potential for future application of this methodology. This analysis centers on what is learned from the use of formative research to increase communication between researchers discussing the ethical concerns of medical tourism and Canadians that may be considering these concerns. This chapter describes the outcome of this communication on revisions to the information tool and future considerations for effectively communicating ethical concerns to the public. By articulating these considerations, this paper intends to generate further discussion and utilization of this methodology in the effective communication of ethical concerns.

Chapter 3 of this thesis focuses on one stage of the formative research process: feedback from former medical tourists. The analysis of interviews with former Canadian medical tourists explores participants' engagement with the information provided in the document and reveals the potential impacts of this engagement. By speaking to former medical tourists about their decision-making process and the potential impacts of reading such a document on that process, this paper addresses an existing knowledge gap regarding the contemplation of ethical issues by prospective medical tourists. This analysis identifies participants' perceptions on the information provided in the document in terms of the potential for this information to increase awareness of ethical concerns of medical tourism. By identifying these perceptions, this paper identifies areas for further research regarding increasing awareness of these ethical concerns and the potential for this awareness to lead to increased social responsibility in the practice of medical tourism and less resulting inequities. In this way, the project fits within larger debates in public health around promoting health equity in a context where neoliberal values are increasingly shifting responsibility for health to individuals.

The final chapter of this thesis summarizes the emerging themes from this research. A combined exploration of the findings that emerged from both analyses helps to identify the contribution of this body of knowledge to the promotion of social responsibility in health care utilization and provision, particularly in regards to medical tourism. This section identifies emerging questions for future research in public health ethics and medical tourism.

Chapter 2.

Developing a Guideline for Ethical Engagement in Medical Tourism

2.1. Abstract

2.1.1. *Background*

Medical tourism, the practice of persons intentionally traveling across international boundaries to access medical care, has drawn increasing attention from researchers, particularly in relation to potential ethical concerns of this practice. In particular, researchers have expressed concern for potential negative impacts to individual safety, public health within both countries of origin for medical tourists and destination countries, and global health equity. However, these ethical concerns are not discussed within the sources of information commonly provided to medical tourists, and as such, medical tourists may not be aware of these concerns when engaging in medical tourism. This paper describes the methodology utilized to develop an information sheet intended to be disseminated to Canadian medical tourists to encourage contemplation and further public discussion of the ethical concerns in medical tourism.

2.1.2. *Methods*

This section outlines the methodology that was developed to produce an information sheet for dissemination to Canadian patients considering participating in medical tourism as well as other Canadian medical tourism stakeholders. This methodology includes a literature review as well as formative research with Canadian public health professionals and former medical tourists. This section describes the revisions to the information sheet at each stage of the methodology that resulted in the final information sheet.

2.1.3. *Conclusions*

The final information sheet underwent numerous revisions throughout the formative research process according to feedback from medical tourism stakeholders. These revisions focused primarily on making the information sheet concise with points that encourage individuals considering travelling for medical tourism to do further research regarding their safety both within the destination country, while travelling, and once returning to Canada, and the potential impacts of their trip on third parties. This methodology may be replicated for the development of information sheets intending to communicate ethical concerns of other practices to providers or consumers of a certain service.

2.2. Background

Medical tourism is the term used to describe patients travelling across international boundaries with the intent of accessing non-emergency medical interventions (Ehrbeck et al., 2008; Crooks & Snyder, 2010). While historical accounts of persons receiving health care across borders exist, particularly in the case of patients travelling from developing to more developed countries for services that are not domestically available, a new trend appears to be emerging. Recent studies and media coverage indicate that patients from more developed countries in North America and Europe are intentionally leaving their countries of residence to access health care abroad (Crooks et al., 2011a). This health care is paid for out of pocket and may be motivated by long wait lists, unavailable medical procedures, and/or reduced costs for elective procedures requiring out-of-pocket payment domestically (Hopkins et al., 2012).

Media coverage of medical tourism has given attention to some of the practical dangers associated with this practice, including: surgical complications, risk of patients developing blood clots due to flying so soon after surgery, and potential for poor quality or unnecessary care due to a lack of regulation in the industry (Snyder et al., 2012a). Increasingly, researchers have also discussed the ethical implications of medical tourism, such as potential negative impacts of health equity both within and between nations (Meghani, 2011). We expand on these ethical implications in the section that

follows. Research indicates, however, that medical tourists are often unaware of ethical implications and practical dangers associated with medical tourism (Snyder et al., 2012a).

2.2.1. Ethical Issues in Medical Tourism

Medical tourism may impact the health and well-being of individual patients as well as the general public of both destination and departure countries (Turner, 2007). These impacts result in ethical concerns regarding the development of the medical tourism industry, in particular, concerns for patient health, and national and global public health (Snyder et al., 2012b). Concerns for patient health include inadequate communication of risks to patients and failure to achieve informed consent (Penney et al., 2011). These concerns are particularly relevant to the practice of medical tourism as there may exist certain challenges to communicating risk such as language barriers, time constraints of the medical tourism process, and/or financial interests of the medical tourism facility resulting in inadequate disclosure of risks (Snyder et al., 2012b; Turner, 2013).

Discussions about ethical concerns of medical tourism have also focused on potential impacts on public health in both destination and departure countries. In destination countries, medical tourism may divert resources from the public to private sector, including health human resources and public funding (Meghani, 2011; Sen Gupta, 2008; Garud, 2005). Furthermore, the development of medical tourism industries may reorient the emphasis of public health in these countries on developing and providing health care which prioritizes the needs of international patients over domestic health needs (Turner, 2007). This industry may also further privatize health care in these destinations, resulting in reduced access to health care for persons unable to pay (Johnston et al., 2010). For countries of origin for medical tourists, there is concern that resources may be diverted from public health care to treat complications obtained from treatment abroad while persons leaving the country may reduce the pressure for health care system reform needed to meet the health needs of the population (Snyder et al., 2012b). With this in mind, persons that are unable to travel for medical care may be unable to access needed health care through medical tourism (Johnston et al., 2010)

Finally, all of the ethical concerns for medical tourism have implications for global public health, particularly global public health equity (Chen & Flood, 2013). First of all, the movement of patients across borders may increase the transmission of infectious disease across borders (Snyder et al., 2012b). The medical tourism industry may increase the provision of highly specialized medical treatment resulting in decreased provision of primary health care globally. This may result in increased global health inequity as health resources are concentrated in treating patients able to pay for specialized health care (Hopkins et al., 2010).

This summary of some of the primary ethical concerns related to medical tourism is not exhaustive and scholarship in this area continues to expand, including empirical research into the realized impacts of medical tourism (Snyder, Crooks & Turner, 2011b). Existing research shows that these concerns, particularly relating to third party impacts on members of the medical tourist's home and destination countries, have not informed patient decision-making (Hopkins et al., 2010; Chen & Flood, 2013). In fact, patient health and safety experts in Canada have indicated a particular concern about uninformed decision making amongst Canadian medical tourists related to both safety and ethical considerations, indicating a need to better inform patients of these concerns (Crooks et al., 2013). It is for this reason that we have undertaken the development of an informational tool aimed at Canadians considering medical tourism.

2.2.2. *Ethical Guidelines*

Guidelines that inform individual decision-making exist in many domains with the aim of guiding persons' actions to attain a result that is considered more ethical (Eriksson, Hoglund & Helgesson, 2008). Ethical buying guidelines provide information on potential impacts of individual choices so consumers can make an informed decision while also creating an incentive for ethical practices by providers in response to consumer demands for more ethical goods and services (Beauchamp & Childress, 2001). Guidelines may support the development of social responsibility, which is the term used to describe the moral responsibility of an individual or group of individuals to promote the welfare of the communities to which they belong or with which they interact (Snyder et al., 2011b).

Globalization has resulted in the introduction of guidelines for social responsibility beyond borders, particularly corporate social responsibility for multinational corporations, as well as individual social responsibility for persons consuming goods and services beyond borders (Ite, 2004). Sustainability is a core value for the development of many of these guidelines as this value encompasses environmental, social, and economic impacts of consumption (Farrell, 1999). Guidelines are commonly used as tools to promote sustainability by providing planners with goals and actions which contribute to sustainability and providing consumers with the know-how to purchase and act sustainably (UNWTO, 2005). However, despite the increasing awareness of the role of public health and health equity in sustainability, guidelines for social responsibility are focused primarily on economic and environmental sustainability and less so on social sustainability, including use of health resources (von Schirnding, 2002).

According to a collective ethical perspective, patients have a responsibility to use health resources efficiently and in ways that are beneficial to the community's health (Abramson, 1984). Despite the existence of guidelines for social responsibility in practices involving other dimensions of sustainability, there is a concern about the lack of tools to support persons participating in activities that may impact upon global health equity (Snyder et al., 2011). As consumers of privately provided health care services, the development of tools to inform the decision making of medical tourists can draw on ethical values communicated in ethical guidelines that already exist for the consumption and use of goods and services in related areas, particularly ethical guidelines focused on achieving social sustainability.

While guidelines are used to promote social responsibility in sustainable tourism, medical "voluntouring" abroad, and the use of medical resources, all of which are global practices that involve the movement of people and/or resources between countries, medical tourists are provided with little or no guidance on their social responsibilities (Snyder et al., 2011; Ormond & Sothern, 2012). Given a lack of empirical data regarding impacts of medical tourism on individuals, destination and departure communities, and global health equity, a traditional ethical guideline that presents users with rigid rules for decision making is inappropriate. Instead, medical tourists can benefit from a tool that provides information regarding the ethical issues associated with medical tourism that they can then use to guide them in making decisions that they deem ethical, equitable,

and safe (Parvanta et al., 2010). We use the term “information sheet” for such a tool instead of “guideline” as the former term more clearly describes the intention to inform as a means of advocating for sustainability and enabling potential medical tourists to incorporate ethical considerations into their decision-making and not to persuade persons to take particular actions (Parvanta et al.. 2010) Informing patients about ethical issues in medical tourism may promote more ethical practices in medical tourism and may also result in improved patient health and safety (Snyder & Crooks, 2012).

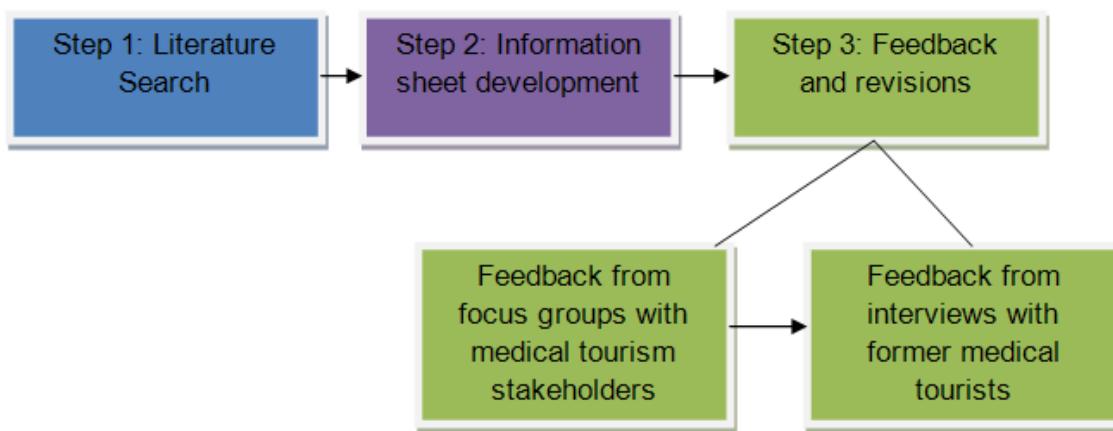
In this article, we describe the development of an informational tool that can be used to better inform the decision making of Canadians considering engaging in medical tourism with a focus on increasing their awareness of the practical dangers and ethical concerns associated with this global health service practice. Our development of this tool addresses a practical gap in the information available to potential medical tourists that has been identified by ethics and legal scholars in particular (Ormond & Sothern, 2012). This activity was informed by existing ethical guidelines intended to promote social responsibility in the global community as well as emerging research on ethical issues surrounding medical tourism. According to the literature, little has been done to develop methodology which incorporates health care consumer input (Nilsen, Myrhaug, Johansen, Oliver & Oxman, 2006). Thus, the methodology that is described in this paper responds to a knowledge gap in the development and adaptation of ethical guidelines to consumers of health care. While the process described here is specific to an information tool for potential medical tourists, we believe this process can be meaningfully applied to other informational tools aiming to incorporate ethical considerations into decision making. This process will be particularly relevant to practices whose impacts on third parties are not well understood, as is the case with medical tourism presently.

2.3. Methods

The research team underwent an iterative process to develop an information sheet intended to promote more ethical decision-making in medical tourism. Given that the only existing guidelines for persons considering accessing medical care in the medical tourism industry are developed by sources with a vested interest in the profitability of the industry (Ormond, 2012), this process was undertaken to develop a

comprehensive and neutral source of information for prospective medical tourists. As no models of comprehensive informational tools regarding the ethical considerations of medical tourism exist, the development of this tool utilized an iterative process that began with a review of existing literature regarding communicating information to promote socially responsible decision-making in consumption or service usage. The following section describes in detail the literature review, information sheet development, and subsequent revisions to the information sheet. This methodology may be useful for the development of information sheets in related domains, particularly where comprehensive and neutral resources do not exist. Figure 1 illustrates the multi-step process that composes this methodology.

Figure 1. Multi-step process for information tool development



2.3.1. Step 1: Literature Search

The development of an initial information tool for medical tourists took place through an iterative process that was informed by the use of existing ethical guidelines in areas that overlapped with the activities and concerns of medical tourists. Initially, we identified three relevant practices with established ethical guidelines, all representing one significant ethical domain of medical tourism. The selected practices include: tourism, the charitable provision of medical care abroad, and the use of domestic health care resources.

A separate search for ethical guidelines was conducted for each of the three identified domains related to medical tourism. Table 1 below details the domains from which we reviewed existing ethical guidelines.

Table 1. Selection of Guidelines for Literature Review

Guideline Domains	Guideline Intention	Ethical Concerns Parallel to MT	Search Terms Utilized	Additional Agencies Searched
Sustainable Tourism	Encourage the use of local operations and activities that are environmentally friendly and culturally sensitive (Malloy & Fennel, 1998).	Concerns about negative impacts to the local economy, environment, and local culture due to tourist activities	'Guide', 'frame', 'framework', and 'principle' were each combined with the terms 'sustainable tourism', 'social sustainability', 'economic sustainability', and 'ecotourism'	1) Caribbean Tourism Organization 2) Canadian Tourism Industry Association 3) Fair Trade in Tourism South Africa 4) The World Trade Organization 5) The Institute for Policy Studies 6) The Department for Communities and Local Organization 7) The Rainforest Alliance
Voluntourism	Guide health providers volunteering abroad to respect local standards, culture, and local access to health care (Provenzano, 2010)	Concerns about negative impacts of medical volunteers on sustainability of health care services, impacts on local standards, and impacts on local culture	'guide', 'frame', 'framework', and 'principle' were each combined with 'voluntourism', 'medical volunteering', and 'medical training abroad'	1) Medical school websites in Canada 2) Websites for professional bodies from Canada, the US, Australia, New Zealand, and the UK.
Use of publicly funded health resources	Encourage responsible use of finite health resources for individual patients and health care providers (Smith, 2002; Commission on the Future of Health Care in Canada, 2002)	Concerns about negative impacts of individual health resource consumption on equitable distribution of health resources	'guide', 'frame', 'framework', and 'principle' were each combined with 'patient responsibility', and 'patient use of health care'	1) Canadian provincial and national level health ministry websites 2) National health association and ministry websites in the US, Australia, New Zealand, and the UK. 1) U.S. websites for Medicaid and Medicare

To begin the search for guidelines, the databases Global Health, Medline, and Google Scholar were utilized. These databases were selected in consultation with a health sciences librarian and chosen with the aim of searching a wide variety of academic and policy sources and disciplines. As many guidelines are likely to be published by professional bodies, additional search strategies were also used to obtain a more comprehensive collection of guidelines for the selected practices. The additional search strategies for each topic of interest are explained in the following paragraphs.

The search for guidelines was conducted based on the team's familiarity with academic and policy literature in the related areas. Search parameters included only English language documents identified using the search terms in Medline as provided in Table 1 as well as searches on specific websites, also provided in Table 1. This process was done within a two-week period of time, at which point the research team decided there were sufficient guidelines to review to reach saturation of information. Overall, the research team found a large body of knowledge existing for sustainable tourism, as this is a growing and well developed practice aimed at developing long term solutions to mitigating stakeholder and environmental harms of tourism and sharing benefits among stakeholder groups (UNWTO, 2005; D'Amore, 1992). Less information was available for medical volunteering and responsible use of health resources. However, searching specific websites and venues throughout the English speaking world, allowed for the inclusion of diverse guidelines which meet the inclusion criteria. Documents that were identified through this search process were included in the literature review if they included actionable recommendations to individuals considering participating in the activity.

2.3.2. Step 2: Information Sheet Development

Once the initial search for guidelines had been completed and we were satisfied that an adequate number of guidelines had been gathered for review, we had accumulated a total of 35 guidelines (18 guidelines on sustainable tourism, 11 guidelines on medical volunteering, and 6 guidelines on the responsible use of health care). After compiling reference details for the guidelines into a spreadsheet, each was reviewed by two members of the research team. Information was also independently recorded in the spreadsheet from each team member on the intended audience of the guideline, values

promoted by the guideline, format of the guideline, and themes of the guideline. After completing this activity, we reviewed the spreadsheet and then met to discuss important findings from this activity. From this meeting, we agreed to focus first on identifying common ethical values that emerged from the various guidelines that would be relevant to ethically engaging in medical tourism. Our purpose in identifying ethical values was to inform the recommendations provided to medical tourists with these values to ensure the development of a comprehensive tool. These values were independently identified by each team member and then were discussed in a meeting, after which consensus was reached on 9 values including: sustainability, efficiency, stewardship, equity, reciprocity, non-maleficence, autonomy, empathy, procedural justice.

Following identification of the nine values that were commonly included in the 35 reviewed guidelines, we next met to discuss how to use these values to inform the development of a tool that could successfully inform potential Canadian medical tourists about ethical issues with medical tourism. At this point it was agreed that we needed to shift these 'high level' ethical values into precise and actionable recommendations for intended informational tool users. We determined that sets of both goals and actions should be included on the tool. The goals would provide overall desired indicators of an ethical medical tourism industry drawn from all nine of the values. The list of actions would be drawn from the values and goals but would be more specific by providing examples of actions that would help achieve the desired goals.

To create goals that would inform the actions of each stakeholder, we identified stakeholder groups that could contribute to the realization of a more ethical medical tourism industry. The identification of stakeholders and involvement of various stakeholders in tourism planning and development is considered a necessity to ensuring sustainable tourism industries and practices (Byrd, 2007). Using previous knowledge of the literature on medical tourism, we identified three stakeholder groups as having the most influence over an ethical medical tourism industry: patients engaging in medical tourism, providers of medical tourism services, and members of the destination communities. These stakeholders were identified as each having control over broad domains of the practice of medical tourism including individual patient choices, provision of medical services aboard, and governance of the provision of medical services abroad.

With this set of stakeholders in mind, we next underwent the process of developing goals and actions to populate an informational tool for the development of ethical medical tourism for each of these stakeholder groups. Using information gained through the process of reviewing the guidelines in related practices and familiarity with the literature on medical tourism, based on the ethical values established we independently created a list of goals for each stakeholder group. This list of goals was meant to depict medical tourism practices that address ethical concerns with the impacts of medical tourism and is reflective to the full list of values for all stakeholder groups. Through a process of review and consensus, fifteen goals were selected that were determined to represent all elements of the objective of creating a more ethical practice of medical tourism across the three stakeholder groups.

Once the list of goals had been determined, we met again to establish actions that could help achieve these goals. We focused on each stakeholder group individually and developed categories of actions that would address the fifteen goals. As each stakeholder group has a distinct range of authority and influence, it was felt that the actions for each group should be distinguished from one another. We individually created a list of possible actions for each stakeholder group, and listed the goals that informed each action. These actions were developed in response to the goals but were not intended to represent a one-to-one correlation with each goal. After discussing all of the suggested actions, we established a final list of actions for each stakeholder group that synthesized the lists from each team member.

The list of values, goals and actions were reviewed once more in a collaborative meeting in order to make final edits to the wording and inclusion of values, goals, and actions. While editing, we decided to identify one primary goal that informed each action, whereas multiple goals of varying relevance had previously been identified. We went through the action lists and agreed via consensus on the primary goal informing each action. At the end of this activity, we verified that all goals were represented by an action and eliminated any goals that did not inform the finalized lists of actions. This resulted in the elimination of two goals (maintains confidentiality for international patients; recognizes the global interconnectedness of the medical tourism industry) to create a final list of thirteen goals. Table 2 below provides the finalized list of goals while Table 3 provides the final list of actions.

Table 2. Goals to develop a medical tourism sector

List of goals to develop a medical tourism sector that:
1. is adaptable to local and global changes;
2. promotes capacity building in the public and private health sectors;
3. promotes and maintains the health of international patients and local populations;
4. has consideration for the wellbeing and needs of local populations and international patients;
5. is consistent with local cultural values and exhibits cultural awareness for members of local populations;
6. distributes the benefits created by this sector fairly;
7. protects all stakeholder groups from new harms;
8. promotes and empowers informed decision making by international patients;
9. promotes collaborative decision making by local stakeholders;
10. is responsive to power imbalances among stakeholders in the development of the sector and distribution of its benefits;
11. protects and enables the integrity and dignity of all stakeholders;
12. exhibits shared responsibility among stakeholders for the impacts of the sector; and
13. promotes transparency in decision making around the development, administration, and impacts of the sector.

Table 3. List of actions

Inform oneself about the impacts of medical tourism on different stakeholder groups
<ul style="list-style-type: none">• Relates to Goal 8• Question a variety of stakeholders including providers, industry representatives, medical tourism facilitators, and other sources of information about the impacts of the industry on destination communities. Example: Contact the Canadian Foreign Trade Office in the destination country to ask about the impacts of engaging in medical tourism.
Choose facilities that are consistent with these ethical goals
<ul style="list-style-type: none">• Relates to Goal 8• Ask facilities questions regarding their policies and practices and select facilities that can clearly indicate their ability to minimize risks to the local community and public health care system. Example: Ask a facility about its policies regarding offering subsidized care for local patients.
Communicate to the industry your expectations concerning ethical practices
<ul style="list-style-type: none">• Relates to Goal 12• Be upfront in expressing your desire to have care consistent with the values and goals in this guideline. Example: Communicate to providers that you value eliminating any negative impacts of medical tourism on other stakeholders.

-
- Communicate experiences, including barriers, to other potential patients
- Relates to Goal 8
 - Share information with potential medical tourists regarding practices and facilities which do [not] align with the ethical goals of this guideline. Example: Post on an online patient board about whether or not health workers were treated fairly and with respect in the facility you visited.
-

- Draw on one's resources to address observed inequitable or unethical situations
- Relates to Goal 4
 - Donate goods and services to the local community where this may help cover one's use of resources such as public health infrastructure and communicate concerns to other stakeholders about observed unethical situations. Example: Donate money to a charity that provides access to health care in the country you visited once home.
-

- Advocate for others to respond to observed inequitable or unethical situations
- Relates to Goal 12
 - If inequities or other ethical failings are observed during the process of engaging in medical tourism, make sure that these concerns are voiced. Example: Contact your local paper about your concerns once you have returned home and encourage them to carry a story highlighting what you observed.
-

Using the finalized lists of values, goals, and actions, a first draft of the information tool was created. The format of this draft tool was informed by a template of a guideline for sustainable tourism developed by the Tourism Industry Association of Canada (Tourism Industry Association of Canada, n.d.). This structure was identified as a good format in comparison to other guidelines that were reviewed as its structure and layout clearly demonstrates the specific actions that can contribute to ethical medical tourism, as well as informs users of the underlying values that inform these actions. We also incorporated examples paired to each action as part of the draft tool to better inform stakeholders on potential impacts of medical tourism. Each action was coupled with both general examples that would apply in all situations, as well as a more context-specific example to help illustrate the action described. All members of the research team reviewed the draft tool and made any necessary revisions to create the first version of the draft tool, as seen in Appendix A.

2.3.3. Step 3: Feedback and Revisions

According to social marketing methods, formative research is a critical component in the development of public health interventions that advocate for behavior change (Lefebvre & Flora, 1988). Formative research includes pretesting concepts and

materials with the intended audience and/or gatekeepers to this audience (Parvanta et al., 2010). To begin this formative research stage, we conducted three focus groups with medical tourism stakeholders. The cities of Vancouver, Montreal, and Toronto were selected as focus group sites as they are all large and diverse Canadian metropolitan centres that have significant numbers of local members who are active in the medical tourism industry and Canadian public health care activities, while representing geographic, cultural, linguistic and economic diversity within Canada. The purpose of these focus groups was to allow for feedback on the draft tool created in Step 2 from stakeholders across Canada. We identified relevant stakeholder groups including public health representatives, health authority officials, family physicians, former medical tourists, and patient advocates. Participants from each of these groups were invited to attend the focus groups.

We developed an agenda for facilitating the focus groups, which included an overview of the meeting goals, a background to medical tourism and key ethical issues in the medical tourism literature, followed by an open discussion around three questions: 1) What are the anticipated ethical concerns created by medical tourism; 2) Based on your previous review of the draft informational tool, what additions, alterations, and cuts should be made to its content; and 3) What means are available for informing potential medical tourists about these ethical issues and for most effectively distributing this tool? The focus groups lasted two hours each and were recorded for verbatim transcription. Notes were also taken by one of the members of the research team. Eight stakeholders participated in each of the Montreal and Toronto events, while nine participated in Vancouver.

We reviewed the transcripts from these focus groups and identified six primary recommended changes to the informational tool according to the expert opinions of the focus group participants. These recommendations included: 1) shortening the tool; 2) developing a background section on ethical concerns; 3) removing the list of values; 4) providing more practical sample questions and using a checklist format; 5) developing a webpage for further information; and 6) using language that clearly does not appear to endorse medical tourism. Table 4 below provides supporting quotes from focus group participants for these recommendations. With these recommendations in mind, we discussed strategies for revising the tool to fit with the feedback provided by focus group

participants while still meeting the aim of the tool itself and acknowledging limitations in time, resources, and data. At this point in the revision process we agreed that a traditional guideline document that guided the decision-making process of potential medical tourists would be impractical given the dearth of data on the impacts of medical tourism on stakeholders. For this reason, we narrowed our focus to an information tool that would raise awareness for users of the potential of medical tourism to create ethical problems, among other issues. As a result, we shortened the draft tool, eliminating the list of values, created three separate sections for ease of use, and adjusted the language so that it reads more like a checklist with prompts for potential medical tourists to better inform themselves about a variety of potential impacts of medical tourism.

Table 4. Focus Group Recommendations

Key Recommendation	Supporting Quote
Shortening the tool	"I think this should be as concise as possible"
Developing a background section on ethical concerns	"that could be somewhere in the document saying here are some of the impacts medical tourism has"
Removing the list of values	"it's not obvious to me why you chose those values and not other values or what they mean in this case"
Providing more practical sample questions	"The more you put in and the more general you get the more the small things they can do are going to get lost"
Developing a webpage for further information	"I think there's a need to have a more in-depth reflection analysis of each of these points"
Using language that clearly does not endorse medical tourism	"there's an assumption there that medical tourism is okay... although that might not be the intention, it does presuppose that"

The finalized information sheet following revisions recommended from the focus groups includes the following subtitles, used to create three separate sections in the document: My Health, My Home, and My Journey. Under each of the sections, the document has three questions asking readers to consider whether or not they have certain information related to the individual patient's health, the impacts of medical tourism on the patient's home country, and the impacts of medical tourism on destination countries.

Following the completion of the revisions to the information sheet, we pre-tested the tool (as seen in Appendix B) with the intended users of this tool by conducting semi-

structured interviews with Canadians who had already opted to engage in medical tourism (Parvanta et al., 2010). As the target audience includes all Canadians that may be considering traveling out of country for care or do not intend immediate action but may contemplate such a decision in the future, we developed a tool that aims to inform not persuade, as suggested by the Transtheoretical Model of Behavior Change (Prochaska, Redding & Evers, 2002). This target audience is difficult to identify, and as a result, we pretested our tool with Canadians that have already travelled out of country for medical care. This participant group was well positioned to provide insight on the usefulness of such a tool having already engaged in decision-making around opting to seek private medical care abroad (Parvanta et al., 2010).

Recruitment of interviewees through Craigslist postings, Facebook postings on patient advocacy groups, advertisement in a local free weekly newspaper, as well as contact information in newspaper articles about medical tourism resulted in 24 interview participants. Recruitment and interviewing occurred simultaneously until a predetermined termination date. Before beginning the interview, participants confirmed their eligibility for the study, were provided with details about the study, and provided consent to participate. Eligibility criteria for the study required participants to be: 1) 18 years or older; 2) a holder of a provincial medical card; 3) someone who successfully pursued a surgical procedure outside of Canada that was neither a transplantation nor a reproductive surgery (as these procedures often involve third parties and raise distinct ethical issues); and 4) someone who paid privately for the surgery sought abroad and for whom the procedure was not performed based on a referral from a Canadian physician.

The first author performed twenty-three of the interviews, while the second author performed one. All interviews were recorded and transcribed verbatim. Interviews lasted on average 45 minutes and interviewers asked questions from a semi-structured interview guide. This guide had four components: the first component consisted of basic background demographics, followed by a section on background information on decision-making, a section regarding the decision-making process of deciding to travel for medical care, and finally a section with questions asking for feedback on the draft informational tool. All participants were provided with a copy of the information tool prior to the interview and were instructed to read it in advance as well as have a copy on hand during the interview to provide as detailed of feedback as possible.

After all of the interviews were completed, transcripts were read in their entirety by the first author. Three transcripts selected as being a representative sample of positive and negative feedback on the informational tool were read in full by all group members. Each member was also assigned three unique transcripts to read, once again representing a range of feedback on the tool as well as a range of medical procedures. Following independent transcript review, we met to discuss common themes emerging from the interview participants and implications for this feedback for subsequent revisions to the tool. To ease this process, sections of the transcript specifically dealing with feedback on the tool and recommendations for changes to the tool were extracted by the first author and compiled into one document with positive and negative feedback divided into separate sections. This document was also read independently by all members of the research team.

Following the above-mentioned steps for transcript review, the research team focused on addressing the recommendations provided in Table 5 below. Based on feedback about formatting, we also discussed formatting strategies and decided to look to other sources of health communication to aid in this process. Similar to methods used at the beginning of this process, to finalize the tool we once again consulted published materials to determine formatting strategies for communicating desired information. In this case, we focused on collecting health information tools from travel clinics and doctors' offices to gain insight from existing health communication tools in these intended dissemination locations. Formatting ideas from these existing tools were taken into consideration, including: 1) Using bold words and colour effectively to enhance key messages; and 2) Minimizing extra or repetitive wording. A graphic designer was hired to implement the design we sought. Multiple formatting samples were created and were shared within our networks for feedback to ultimately determine a final format of the information sheet, as provided in Appendix C.

Table 5. Recommendations for revisions following interviews

Key Recommendation	Supporting Quote
Adding examples to clarify statements	"Like it's just not clear to me what it is you're trying to say. If you think that a patient should be taking their medical history with them then you should say that."
Removing inaccurate statements	"there's no way of getting [foreign blood service] information and we wouldn't even know where to refer you to get the information"
Altering language to enhance neutrality of the document	"The language sort of comparing everything to Canada makes it seem like Canada's at the top... it's not conducive to having an open mind."
Using bold words and colour to effectively enhance key messages	"it's very wordy and plain"
Minimizing extra or repetitive wording	"the only suggestion about the document is try and form a way to re-ask the question, like did you know this is repeated twenty times"

2.4. Discussion

Medical tourism is an emerging global health practice and despite its growing popularity there is a significant dearth of third party, or non-industry-driven, information available for patients considering purchasing such. In response, we sought to create an informational tool for Canadians considering medical tourism that would inform them of things they should give attention to before purchasing private medical care abroad. Some patient-specific informational tools for medical tourism do exist for specific procedure types. For example, the International Society for Stem Cell Research has developed a list of key questions for patients considering engaging in stem cell tourism (ISSCR, 2008). These eight questions focus on raising patient awareness about safety issues tied to unproven stem cell technologies and increasing credulity about claims made by industry members, especially around success rates for and the safety of these treatments. Similarly, the American Society of Plastic Surgeons lists questions for patients considering traveling abroad for care that focus on obtaining follow up care, protecting patient safety, and encouraging more critical approaches to surgeons' claims (ASPS, 2012). A more general patient guide produced by the International Medical

Travel Journal advises patients on decision-making, finding a clinic to suit their needs, locating aftercare, and patient safety issues (IMTJ, 2012). The concerns raised in these existing tools are much narrower than in our own, focusing on the impacts of medical tourism on the patient rather than also on other stakeholders. Thus, the method for developing the information tool described here fills an important gap in the limited set of resources available and helps to raise awareness of the impacts of medical tourism on a wider range of stakeholders.

Our approach to developing an information tool for informing patients about the ethical dimensions of engaging in medical tourism includes three distinct advantages. First, this method allows the development of a tool that draws from the content, structure, and diversity of guidelines in other, related practices. In this way, the process of developing a new information tool for a practice does not ignore but rather incorporates successful models developed elsewhere. Rather than simply parroting the concerns raised within the literature on the practice for which the guideline is being developed, this method ensures that the scope of values, goals, and actions is broadened in light of the experiences in other practices. This method is particularly helpful for a relatively new and developing practice such as medical tourism where discussion of the ethical dimensions of this practice is still evolving and a consensus regarding responses to these concerns has not been reached (Turner, 2007; Snyder et al., 2012a). In this case, reference to the well-established guidelines for eco- and sustainable tourism was particularly helpful for adapting a structure for the medical tourism information tool. Furthermore, by looking to ethical guidelines in related practices to first identify the values that informed our tool, the development of this information tool is grounded in theories of sustainability (Hopwood, Mellor & O'Brien, 2005). While the concept of "sustainability" is not clearly defined, it is used in this case to describe the outcome of collective agreement on current and future livelihoods, with a focus on social justice. Research in the area of sustainability has indicated a need for methods of deliberation that engage communities and individuals in contemplating and deciding on the future they want to create as the core component to attaining sustainability (Robinson, 2004). By using methods that engage with the values of sustainability, this tool encourages social responsibility by engaging individuals in a process of deliberation.

Second, the collaborative methodology used here ensures that no single voice or perspective has dominated in development of the information tool. While each of us completed reviews of other guidelines and initial lists of values, goals, and actions independently, the collaborative process of comparing lists and finalizing a draft tool was extremely important for improving the quality and usefulness of the final product. We initially felt that face-to-face time for this process would be minimal, but ultimately found that settling on a structure for the information tool and final content required extensive discussion – in our case well over twelve hours of discussion over five meetings, not including follow-up discussion via email. We strongly believe that this collaborative method is an important advantage and irreplaceable aspect of the tool design process we developed. Furthermore, by utilizing both focus groups and interviews with different target audiences, multiple perspectives informed the revisions to this tool. Participants of the focus groups provided useful feedback from an audience that regularly provides health information and would potentially be involved in the dissemination of such a product, otherwise known as the gatekeepers in health communication literature (Parvanta et al., 2010). Interview participants provided useful feedback from the intended audience and encouraged further revisions to enhance the appeal and utility of such a tool. By utilizing methods found in health communication literature including social marketing, this methodology maximizes the effectiveness of the tool as a public health intervention (Lefebvre & Flora, 1988).

Finally, the methodology described here can be easily adapted to other practices. As the choice of other practice domains to review was based on locating practices that overlapped with significant aspects of medical tourism, other domains can be determined for other practices. In this way, new information tools can be developed in a way that challenges the assumptions of that practice through reviewing other, related practices and through a collaborative methodology. These advantages should accrue both for relatively new practices like medical tourism that have very few existing guidelines for any stakeholder groups, but it can also be used to challenge the assumptions and develop new sources of information for consumers of practices with more established guidelines as well.

2.4.1. *Limitations*

This information tool development method faces several limitations. First, while the collaborative nature of the development process ensures that the viewpoint of a single team member does not dominate the content of the tool, in this case we had been collaborating with one another on research projects related to medical tourism and co-authoring papers for over two years. While this existing relationship did not mean that we would share the same perspective in the tool development process, particularly as we represent distinct disciplinary backgrounds, it does imply a degree of insularity to the development process and reduces the range of perspectives and challenging voices that will be heard. While others using this method may not face this limitation, it is likely that other well-established research teams will use this process as the team must be familiar with the literature on the practice for which the tool is being developed in order to successfully populate the tool. Presentation of draft versions of the guide to other stakeholders helps to ensure that any insularity in the core tool development group will be overcome. While doing so increases the time and financial resources needed to develop an information tool, we feel strongly that it greatly enhanced the quality and usability of the final product.

A second limitation of the methodology described here is the uncertainty of whether the tool conveys the ethical values that were originally intended to be addressed in this document. Interview participants expressed frustration about the lack of actionable recommendations in the tool, indicating that the information may not be taken into further consideration as intended. The purpose of the tool is to provide information that prompts further deliberation and research by individuals when considering accessing medical care outside of Canada; however, it is unclear from the interviews whether the statements provided in the tool accomplish this aim. This uncertainty is in part caused by the fact that we interviewed former medical tourists, which resulted in interviewees focusing on the utility of the tool during preparations for traveling as a medical tourist. This focus may have limited their consideration of tool utility during initial contemplation of medical tourism. While we attempted to orient the participants by starting the interview with questions that had them consider their general decision making behaviours and the decision-making process they underwent for their experience

with medical tourism, it is unclear how this information may have been considered by individuals who had not already traveled for medical tourism.

Many participants in both the interviews and focus groups indicated that they did not see the tool as addressing the full scope of ethical concerns with medical tourism. For example, when engaging in discussion about ethical concerns, interview participants often focused on what they perceived as the unethical and inequitable nature of the Canadian health care system and how this pushed them into obtaining medical care abroad. This created a challenge for us in terms of developing an understanding of the target audience's engagement with the various ethical issues related to medical tourism and means of increasing this engagement. While the ethical issues raised by engaging in medical tourism have been a longstanding interest of our own and other academics in this field, it is also not clear that the target stakeholders share these same concerns; therefore, they may not be motivated to use the tool even if the content is accessible to them (Snyder et al., 2012b).

Finally, as our focus is on tool development we have not addressed the issue of dissemination here, which may be a particular challenge with our target audience (Parvanta et al., 2010). While potential medical tourists have been found to engage in research on the internet prior to engaging in medical tourism (Johnston et al., 2012; Lunt & Carrera, 2011), we anticipate that it will be difficult to ensure the visibility of any new information tool amidst the many competing sources of information, particularly those in the medical tourism industry. According to social marketing methods, dissemination of health communication materials requires substantial consideration of barriers to use, recognition of benefits by the target audience, appropriate location for dissemination, as well as promotional strategies of the information tool (Lefebvre & Flora, 1988). This process requires further time and resources to ensure effective dissemination and use. Additionally, this requires buy-in by stakeholders to support the dissemination of this tool. Our own future steps are to develop a dissemination strategy for the tool that is consistent with stakeholder feedback, to create a complementary website for the tool where additional information can be shared, and to develop an evaluation strategy both for uptake of the tool as well as its utility.

2.5. Conclusions

This paper responds to a gap in existing methodology for developing ethical guidelines for healthcare consumers. The paper explores the development of one such collaborative methodology. By describing the steps and considerations of developing the information sheet, including a literature review, group meetings to develop the tool, and feedback and revisions from medical tourism stakeholders as well as the strengths and limitations of this process, this paper provides a discussion of the ability for such a methodology to develop an information tool for communicating ethical concerns.

While the tool development process outlined in this paper has focused on the issue of medical tourism, we contend that there is wider potential use for this process so as to generate information tools for other distinct practices. This is particularly true for other practices where information about its impact on third parties is limited such as with environmental impacts on health. The process outlined herein can be adopted fully in such cases or adapted so as to be more relevant to the practice at hand. In either case we encourage researchers to document the process by which they have developed their informational tools so as to enhance transparency about the research-to-action cycle around the creation of ethics-informed resources and guidelines.

The practice of engaging in research and shifting research into action often has unanticipated benefits. In our case, we were surprised both by the degree to which this tool development process challenged our own assumptions about the preferred shape of the tool being developed and the degree to which continued discussion was needed to arrive at consensus about the final content of the tool. The research team had initially assumed the tool could take a very similar shape to other ethical guidelines, but was surprised at feedback which suggested removing explicit mention of ethics. In the end, the tool ended up looking very different from the first draft as the intention of the tool shifted with increased discussion and formative research. In effect, the tool development process was also a team building process as it afforded us the opportunity to unpack assumptions, challenge opinions, and build true consensus. We see this as a significant strength of having undertaken the process outlined in this paper.

Chapter 3.

Promoting Social Responsibility amongst Health Care Users: Medical Tourists' Perspectives on an Information Sheet Regarding Ethical Concerns in Medical Tourism

3.1. Abstract

3.1.1. *Background*

Medical tourists, persons that travel across international borders with the intention to access non-emergency medical care, may not be adequately informed of safety and ethical concerns related to the practice of medical tourism. Researchers indicate that the sources of information frequently used by medical tourists during their decision-making process may be biased and/or lack comprehensive information regarding individual safety and treatment outcomes, as well as potential impacts of the medical tourism industry on third parties. This paper explores the feedback from former Canadian medical tourists regarding the use of an information sheet to address this knowledge gap and raise awareness of the safety and ethical concerns related to medical tourism.

3.1.2. *Methods*

Researchers conducted twenty-four semi-structured phone interviews with former Canadian medical tourists. Interviews were transcribed verbatim for further analysis.

3.1.3. *Conclusions*

The overall perceptions of former medical tourists indicate that an information sheet may promote further consideration of ethical concerns of medical tourism. However, given that these interviews were performed with former medical tourists, it remains unknown whether such a document might impact upon the decision-making of prospective medical tourists. Furthermore, participants indicated a need for an additional tool such as a website for continued discussion about these concerns. Along with dissemination of the information sheet, future research should include the development of a website for ongoing discussion that could contribute to a raised awareness of these concerns and potentially increase social responsibility in the medical tourism industry.

3.2. *Background*

Medical tourism, the practice of patients traveling out of country with the intention to receive medical care paid for out of pocket, is considered an expanding industry globally (Johnston et al., 2010; Penney et al., 2011). While there is a dearth of empirical evidence on patient flows and the impacts of medical tourism, media coverage often provides anecdotal stories that indicate the potential for surgical complications, and poor quality or unnecessary care due to a lack of regulation in the industry (Snyder et al., 2012a). Partially due to the lack of empirical evidence available about medical tourism, researchers are concerned about the gaps in the information medical tourists may be accessing regarding potential impacts of medical tourism on both individual safety and health equity (Lunt & Carrera, 2011; Crooks et al., 2013).

Medical tourism is receiving increasing attention, both as a developing industry and a topic of research interest (Connell, 2013; Snyder et al., 2012a). While there appears to be a wide variety of medical tourism flows, including travel between both countries of similar and different levels of economic development, information available to medical tourists demonstrates a concerted effort on behalf of low and middle income countries to entice persons to travel from developed to developing countries for medical care (Hopkins et al., 2010; Pocock & Hong Phua, 2011). This recent trend of travel from more developed to developing countries has become a focus for research on the

impacts of medical tourism on global health equity (Horowitz et al., 2007). Discussions by researchers about growing health inequities globally have identified the growth of the medical tourism industry as potentially one cause of these inequities (Widdows, 2011). The rise of neoliberalism and economic globalization in the past few decades has resulted in health care being increasingly conceptualized as a tradable commodity across borders. The medical tourism industry markets to patients as consumers of health care, encouraging individuals to take responsibility for their health by taking advantage of potential cost savings of medical treatment in developing countries and high quality care available in private facilities catering to medical tourists (Ormond, 2011). Patients may be motivated to travel to access procedures which are domestically unavailable or require undesired waiting times, receive care and recover in a relaxing or exotic landscape, and/or reduce costs for procedures domestically paid for out-of-pocket (Hopkins et al., 2010).

Research indicates that many Canadian medical tourists use word-of-mouth or the internet to inform their decisions regarding this practice, which may result in decision-making that is uninformed or biased around individual safety and treatment outcomes (Johnston et al., 2012). Canadian medical tourists may also be unaware of ethical concerns regarding potential impacts of medical tourism on global health equity, particularly potential impacts to destination and departure country health resources and health care systems (Turner, 2007; Snyder et al., 2012b). While researchers are increasingly discussing these potential ethical concerns related to medical tourism, medical tourists may be unable to act in a socially responsible manner if uninformed of these impacts (Snyder & Crooks, 2012).

Here we explore the responses of Canadian medical tourists to an information sheet intended to encourage more informed and ethical decision-making around medical tourism. This tool was developed through an iterative process that drew on values from guidelines in related domains as well as public health communication research to effectively inform Canadians about ethical concerns related to medical tourism. Through analyzing feedback received in one-on-one interviews with former Canadian medical tourists, in this paper we examine the potential usefulness and impacts of such a tool on patients' decision-making, as well as the contexts in which such a tool might better inform and promote social responsibility amongst Canadian medical tourists and

ultimately a more ethical medical tourism. This research provides insight into considerations for the field of public health in promoting social responsibility in the provision and utilization of health care.

3.2.1. Awareness of Ethical Issues in Medical Tourism

Despite a lack of empirical evidence on the impacts of medical tourism, researchers have indicated several ethical concerns relating to medical tourism's potential impact on both an individual and societal level within destination and departure countries, as well as on a global scale (Snyder et al., 2012b; Turner, 2007). Medical tourism may negatively impact upon individual health due to a lack of risk communication to patients and/or inadequate informed consent (Snyder et al., 2012b; Penney et al., 2011). Furthermore, the medical tourism industry may divert resources from the public to private sector. Increasing privatization of health care may reorient priorities in the provision of health care to provide more profitable specialized care, including care which meets the needs of foreign patients traveling for some form of specialized care (Meghani, 2010; Turner, 2007; Ormond, 2013). This reorientation of health care may reduce access to desired health care for local patients in medical tourism destination communities (Johnston et al., 2010). In countries of origin for medical tourists, potential complications affiliated with procedures obtained abroad, particularly due to a lack of regulation in the industry, may divert resources to treat these complications. Reduced pressure for system reform if patients leave the health care system to seek out care abroad may result in only those persons able to travel as a medical tourist accessing health care (Johnston et al., 2010; Turner, 2007). Finally, increased movement of patients across borders to access medical care may increase the transmission of infectious diseases (Crooks et al., 2011b). Concerns for medical tourism's negative impacts on health outcomes and health equity indicate a burden of responsibility for those engaging in medical tourism to consider these impacts and act in a socially responsible manner when providing and utilizing health care (Snyder et al., 2012b).

The primary ethical concerns surrounding the development of medical tourism and its impacts are also related to larger impacts on global health equity. While countries that are promoting themselves as medical tourism destinations cite economic

motivations for industry growth (Terry, 2007), these economic advantages may come at the cost of undermining initiatives that intend to improve health equity both within and between nations. Increases in privatized health care globally have detracted from health care system strengthening required to meet the goals of “Health for All” outlined in the World Health Organization’s Declaration of Alma Ata (Walley et al., 2008) and protect the human right to health (Ostlin et al., 2011). While some medical tourism stakeholders have mentioned potential benefits of the practice to health outcomes and health equity, including improved quality control due to international accreditation of medical tourism facilities, increased training opportunities for health professionals treating foreign patients, and health worker retention in places experiencing high levels of brain drain to other countries, lack of regulation by some destination governments and the industry itself may neglect considerations for health outcomes and health equity in stakeholder decision-making (Snyder et al., 2013; Horowitz et al., 2007).

Ethical concerns for medical tourists’ destination and departure countries are related to the provision of health care within national borders. For destination countries, concerns about the growth of the medical tourism sector are related to the impacts of medical tourism on public health care due to the potential growth of the private sector (Pocock & Hong Phua, 2011). The promotion of medical care to foreign patients may encourage a shift in health resource allocation resulting in a potential brain drain of health human resources from the public to the private sector and the diversion of public resources such as land or public finances to medical tourism businesses (Sen Gupta, 2005). Medical tourism may incentivize training of health workers for more curative, costly and complicated procedures that are appealing to medical tourists (Hopkins et al., 2010). This emphasis on more curative care may result in neglect for the provision of appropriate primary health care to local populations and an increasing normalization of privatized health care (Johnston et al., 2010). For departure countries, medical tourism raises concerns for these countries’ health systems due to the potential diversion of resources to treat medical complications resulting from patients engaging in medical tourism (Snyder et al., 2012b). Medical tourism raises concerns for health equity within nations if only patients willing and able to travel for medical care are able to access certain medical procedures (Johnston et al., 2010).

Ethical concerns regarding patient health in medical tourism are particularly focused on the lack of neutral information provided to medical tourists regarding risks and safety concerns and the implications of this for patients' abilities to achieve informed consent. These safety concerns include potential medical complications related to the procedure itself, potential medical complications from traveling following a medical procedure, and/or inadequate continuity of care after returning home (Crooks et al., 2011b). Patients may be unaware of these safety concerns due to lacking familiarity with the destination health care system, language or cultural barriers to adequate communication between medical tourists and health care workers, and/or lacking transparency regarding quality of medical facilities or health care workers (Penney et al., 2011).

Medical tourists and stakeholders in the medical tourism industry may be unaware of the ethical concerns outlined above, and if so, are unable to act in a socially responsible manner (Snyder et al., 2012b). This lack of awareness may be due to biased sources of information, including sources with a vested interest in the profitability of the medical tourism industry (Lunt et al., 2010). Socially responsible engagement in the medical tourism industry requires individuals to act in a manner that respects the inherent dignity of all other humans (Chapman, 1994). Individuals are thus responsible for encouraging the development of social sustainability, defined as the creation of conditions that enable people to lead lives of personal value (Marmot et al., 2012). Improved health outcomes and health equity are increasingly recognized as cornerstones of social sustainability (von Schirnding, 2002). The provision and utilization of health care contributes to social sustainability and necessitates responsible allocation and use of health resources in such a manner that optimizes health outcomes and health equity (Graces et al., 2003), even in relation to the private medical tourism industry. We contend that creating awareness of the ethical concerns of medical tourism will encourage socially responsible actions by individuals engaging in medical tourism, stakeholders in the medical tourism industry, and policy makers developing regulations for the industry (Snyder et al., 2012a). It is for this reason that we have made an informational tool for Canadians considering medical tourism that prompts consideration of ethical, equity, and safety issues alike.

Informing individuals such as medical tourists about health issues can be done most effectively following extensive formative research to better understand the target audience and determine the ideal means of providing the information (Parvanta et al., 2010). In the remainder of this article we present the findings of the formative, qualitative research we conducted in order to inform the development of an information tool for Canadians considering medical tourism that prompts consideration of ethical, equity, and safety issues. The process of formative research is useful for tailoring message points and determining effective dissemination of the information. Formative research helps identify gatekeepers to the primary audience who either encourage or discourage information being provided to the primary audience (Parvanta et al., 2010). Formative research activities such as focus groups and pre-testing of informational tools with primary target audiences and gatekeepers provide valuable insights that can be used for tool refinement and implementation (Parvanta et al., 2010; Bernhardt, 2004). With this in mind, in the sections that follow we examine feedback provided to us by intended users of the informational tool so as to assess the potential impact of such an information tool, inform revision and improvement upon the tool, and determine future steps for effective dissemination of the tool leading to more informed decision-making by Canadians considering medical tourism.

3.3. Methods

To develop the information tool on which the current formative study is based, an iterative process was utilized. This multi-step process is summarized in Figure 1, provided in Chapter 2 of this thesis. Here we report exclusively on the findings from the interviews with former Canadian medical tourists in Step 3 of this process. Although this tool was developed using ethical values and principles as a way to enhance consideration of ethical issues during the decision-making process, words such as ‘ethics’ and ‘values’ were deliberately excluded from the text as our previous research has shown that medical tourists can respond negatively to such terms, interpreting them to be explicitly judgmental. Instead, ethical concerns, along with equity and safety concerns were shared throughout the tool without being framed as such. As a health communication tool with the objective of informing and not guiding individual action, the target audience includes all Canadians that may be in the pre-contemplation or

contemplation stage of decision-making regarding accessing care out of Canada as a medical tourist (Lefebvre & Flora, 1988). While this tool may provide useful information to all Canadians regarding this growing industry, it is intended to encourage more informed decision-making when considering or planning to travel out of country for private medical care. This stage of formative research focused on gaining feedback through semi-structured interviews with Canadians that have already traveled as medical tourists.

3.3.1. *Recruitment*

Former medical tourists were selected to participate in this formative research as both a convenient sample to access in comparison to Canadians that may be considering participating in medical tourism, as well as a rich source of information regarding the impact of such a tool during the decision-making process given their experience. Participants were recruited using the following channels simultaneously: 1) Craigslist advertisements posted on sites for all major Canadian cities; 2) advertisement in a Vancouver newspaper; 3) posting invitations to participate in online medical tourism forums; and 4) snowball sampling through interview and focus group participants' networks. Information was provided for interested persons to contact either a toll-free phone number or email for further information and assessment of eligibility. Eligible potential participants were provided with a consent form to be read and signed before commencement of the interview. Participants were informed that prior to recruitment, the study was granted ethics approval from the Office of Research Ethics at Simon Fraser University.

Eligibility criteria for study required participants to be: 1) 18 years or older; 2) a holder of a provincial medical card; 3) someone who successfully pursued a surgical procedure outside of Canada that was neither a transplantation nor a reproductive surgery (as these procedures often involve third parties and raise distinct ethical issues); and 4) someone who paid privately for the surgery sought abroad and for whom the procedure was not performed based on a referral from a Canadian physician. Canadians who had traveled for transplantation or reproductive procedures were not included in this study due to the additional ethical concerns with these practices that are not covered in the information tool.

3.3.2. *Data Collection*

Twenty-four semi-structured interviews were completed between October 2012 and December 2012. We conducted as many interviews as possible during this two-month period, after which we planned to cease data collection. The interviews were all conducted over the phone and recorded for future transcription. The shortest interview lasted just over 20 minutes, with the longest lasting nearly an hour and a half. The majority of interviews lasted approximately 45 minutes. The range in interview times is due to the semi-structured approach which provided some questions to guide the discussion and ensure meaningful feedback, but allowed for freedom for the participants to speak openly, which may broaden the understanding of the topic at hand (Denzin & Lincoln, 2011).

Twenty-three interviews were conducted by the first author and one interview was conducted by the second author. We used a semi-structured interview guide containing questions divided into four parts. The first part addressed basic background information of the participant including demographics, general health, and past travel experience. The second part asked questions relating to the participants' general decision-making behaviour. The third section asked questions related to participant's experiences as a medical tourist, particularly in terms of how they made the decisions relating to their trip. Both the second and third section probed the participant about the types of information they were considering during their decision-making process as a medical tourist. The final section of the interview guide contained questions asking for feedback on a draft version of the information sheet (see Appendix B), particularly the usefulness of such a tool in the participants' context and recommendations for improving the document.

3.3.3. *Data Analysis*

Interviews were transcribed verbatim. The first author reviewed all of the transcripts and extracted basic demographic information, basic procedure and trip information, as well as general feedback (positive or negative) on the information tool for each participant into a spreadsheet. She then assigned 6 transcripts for independent review by each team member. Three of these transcripts were the same across all

members while three were unique. This strategy was used to minimize redundancy in transcript review and ensure that all members would encounter the range of opinions shared by participants. Following transcript review, we met to discuss emerging themes in participant feedback on the tool. Given the practical or applied nature of this formative study, the themes identified were primarily a priori or deductive in nature in that they focused on tangible improvements to specific aspects of the informational tool. After these themes were identified, the first author hand reviewed the transcripts and extracted segments that pertained to each into a Word document organized under six headings: positive feedback, negative feedback, specific recommendations, impacts of the tool on decision-making, potential places to access such an information tool, and type/tone of information conveyed in the tool.

3.4. Results

Overall, the twenty-four interview participants ranged in age from twenty-four to sixty-five. Nine participants identified themselves as male and the remainder as female. The majority of participants had some post-secondary education, either at a college or university, with one participant having completed a master's degree, and three participants having completed secondary school education. Fifteen of the participants had traveled out of Canada for the Chronic Cerebrospinal Venous Insufficiency (CCSVI) procedure, also called renal or jugular angioplasty by participants. The remaining nine participants accessed a lumbar disc replacement surgery, a dental surgery, a gastric band surgery, a tattoo removal through surgical incision, a vertical sleeve gastrectomy, an eye-lid surgery, a meniscus surgery, and a cholecystectomy. Five of the twenty-four participants indicated that they had existing family connections in the destination where they underwent the medical procedures, with four of these five participants having emigrated to Canada from that country. When examining destination choice amongst CCSVI patients, seven out of fifteen participants had traveled to the United States, with the remainder traveling to Bulgaria, Poland, Mexico, India, Germany, and Egypt. Non-CCSVI patients traveled to Egypt, Germany, Spain, Philippines, Venezuela, Thailand, Hong Kong, Romania, Mexico and India for surgery. Overall, five participants had participated in multiple medical tourism trips, with four out of five repeating the CCSVI

procedure in a different location, and one traveling for three separate medical procedures in three different locations.

The twenty-four participants all read the information sheet prior to commencing the interview to allow for discussion on this document during the interview. The feedback provided by these participants is described in the remainder of this section. This feedback indicates the perceptions of these persons on the information sheet itself, with a particular focus on the format, usefulness and potential influence of the document on medical tourists' decision-making.

3.4.1. *Feedback on Format*

Overall, participant feedback was generally positive when discussing the format of the tool. Positive feedback relating to format indicates that participants appreciated the concision of the document, including its short sentences and "conversational" language. Participants indicated that the document is "easy to read", relating this ease to both layout and language. Feedback on the format specifically indicates that the language is "very clear" and "basic". This was particularly important because many participants commented that the language and level of detail contained in the document must be easily accessible to persons with "standard education" and "standard English speaking" abilities. Furthermore, participants indicated that the short one-page format is favourable as the limited text is "not boring". The question-style format of the document was well-received by some participants who found this style encouraged persons to reflect on the information and take this information to do further research on their own, while others preferred that it be populated entirely with standard sentences.

While there were very few negative comments about the format of the document in terms of layout, participants provided formatting suggestions to improve the appeal of the document. Some participants recommended more of a checklist format over the question-style format. This format was recommended to avoid the document being "wordy and plain". Several participants also indicated that some of the repetition in wording was not appealing and made the document seem repetitive and condescending. The most common recommendation for improving the format of the document was to include pictures, images or more colours to increase the visual appeal.

In terms of language, while all participants agreed that the language was easy to understand, some participants pointed out areas where the information provided did not lend itself to specific actions. These participants demonstrated frustration with being unsure what the information in the tool was trying to convey. One participant indicated that education level would really impact whether a “person’s going to give it a second thought or not” and suggested that while the language may be clear, the intended information may not be fully understood by all persons. Some participants suggested that readers may have made up their mind before accessing the tool and may not have an open mind when reading the document, indicating challenges in conveying intended information through the format of an information tool.

Another suggestion by participants for maintaining the concision of the document while providing useful information was the inclusion of small anecdotes or stories. Participants indicated that describing personal experiences through anecdotes helps empathize with the reader by creating a “personal touch”. They felt that a format with anecdotes illustrating both positive and negative experiences would prompt persons to do further research while creating a neutral tone.

3.4.2. Feedback on Usefulness

Positive feedback on the usefulness of the information in the tool was fairly congruent, with similar feedback coming from participants who had traveled to different countries for distinct procedures. In general, participants provided positive feedback on the usefulness of the document for prompting further research by those considering medical tourism. Many participants stressed the importance of medical tourists doing “as much research as you can” after reading the document and felt that this document is successful in “giv[ing] you things to think about” while engaging in this research. Some participants indicated specific examples of points of information from the document that they had not previously considered that encouraged serious contemplation when reading the tool. Participants that indicated the tool would be useful for promoting further contemplation and research of medical tourism generally felt that the information was relevant to anyone traveling out of country for medical care, regardless of procedure.

Only a small minority of participants indicated that they did not think the informational tool would be useful for Canadians considering medical tourism. There were two main bases for this perspective: 1) even if the document does prompt a reader to do further research, it does not provide enough guidance or insight into how to do this research, or 2) the information presented in the document is not relevant to their experience. Regarding the first basis, some participants indicated frustration after reading this document and wanting to know more about the issues being raised but not being sure of where to turn to access it. While the tool does provide a link to our own research website at the bottom of the page, some participants would have liked to have seen links to sources of information for each point. Furthermore, some participants, particularly CCSVI patients, were unsure what to do if they wanted to go abroad for surgery that they were denied access to domestically in that they felt this circumstance raised unique issues. Overall, participants who were unsure as to how to do further research after reading the document felt that the tool was “unrealistic” as it lacked the sufficient amount of information necessary to make informed decisions regarding the points raised in the tool as well as direction on where to search out further information.

Participants who did not find the tool particularly relevant indicated that while they feel it is important to do a great deal of research before traveling as a medical tourist, often the motivations for traveling involve some level of desperation which really impacts upon the decision-making process. In other words, they seemed to think that this search for hope or push abroad out of desperation impacts the usefulness of the tool in that this reality far outweighs the importance of any of the prompts shared in the document. This desperation for medical treatment makes further research about the information contained in the document a “bit of a tall order”. Many participants said that at the time of deciding whether or not to travel out of Canada for medical care, they were in a lot of pain and this would have impacted their abilities to spend time searching for additional information to guide them in their decision-making both in terms of energy levels and because it would be “something else to worry about”.

Some participants did not agree with all of the potential negative impacts of medical tourism suggested in the tool. They were most critical of suggestions that local citizens may not benefit from medical tourism hospitals and clinics. These participants often cited witnessing locals being treated at the facilities they visited or the undeniable

economic gain to the community as providing confidence that medical tourism does not negatively impact destination communities. One participant said that he or she was “keeping the faith that us being there would provide more money” into the local economy, indicating that she assumed an overall positive benefit of medical tourism on the local community. Likewise, some participants disagreed with points in the document related to potential negative impacts on Canada, indicating that leaving Canada for care would provide overall benefits such as “reduce[d] waiting times” and “decrease[d] costs”.

3.4.3. Potential Influence of the Information Sheet on Decision-Making

When participants were asked whether or not the information tool would have impacted their decision-making, many indicated that they probably would have still traveled out of country for their medical procedure but that it would have prompted them into conducting more research before leaving Canada. They indicated that the document might specifically impact upon intended users’ expectations by encouraging further research, the outcome of which would provide more realistic expectations when considering or planning a medical tourism trip. On the other hand, some participants clearly stated that they would not have considered the information in this tool, either because they perceived that the document was implicitly and explicitly biased against medical tourism that would have turned them off from reading the tool, or because they had already considered all of the information contained in this document.

When asked directly about ethical prompts included in the tool, most participants said they were not apparent to them in their review of the document. One participant said that it did not raise any ethical concerns to him or her because the tool “is just stating a fact” and “not [presenting medical tourism] as either pro or con”, indicating that the perceived neutrality of the document impacted his or her perception on whether the information presents ethical concerns. The few participants that felt that the information in the tool raised ethical concerns did not see this tool as being explicit enough when raising these concerns, with one stating that “the document doesn’t really bring out the ethical concern of monopolizing [health] resources” and another saying “I don’t see how this document raises those type of concerns; however, they’re [concerns about patients in destination countries accessing medical] very valid concerns... that could be an

ethical issue. But, if you bring it back to the document, I don't see how that's really linked to the type of questioning you ask in the document".

3.5. Discussion

The feedback provided by Canadians who had previously traveled for medical tourism demonstrate varied opinions regarding the format, usefulness, and potential impact of an information tool for Canadians considering engaging in medical tourism. Although there was not complete agreement amongst all participants in terms of their opinion of the tool, the findings shared above demonstrate recurring themes throughout the feedback. While feedback on tool format was overall quite positive, feedback on the potential usefulness and impact of the tool was divided between a few different opinions that ranged from strongly positive to strongly negative. The positive feedback indicated that the concision of the tool and language accessibility were generally appealing to participants. Furthermore, the overall positive feedback on usefulness of the tool indicated that as a source of information that prompts further research and contemplation about medical tourism prior to coming to a final decision, this tool will be of interest to a wide range of persons considering medical tourism as it is not guiding any particular action. This positive feedback leaves us encouraged that a broadly disseminated tool would be appropriate for the intended target audience and could result in increased awareness of ethical concerns of medical tourism.

Negative feedback about the tool identified potential barriers to increasing awareness of ethical concerns for medical tourism. First of all, strong negative feedback on the document focused on the perceived negative or biased tone of the document and indicated that this might dissuade people from considering the information presented in the document. However, we expect that participants may have been more likely to view the tone as negative given that they had already traveled as medical tourists and may be more likely to reject information indicating potential negative impacts of medical tourism or to feel defensive around the choice they made (Johnston et al., 2012). For example, many participants described in detail their experiences accessing high quality medical care as a medical tourist and this may have biased their view on the potential safety concerns related to this practice. Similarly, participants that disagreed with potential

negative impacts on access to medical care for destination populations might have been impacted by their experiences with a particular community, which might not be the case for persons that have not already traveled as a medical tourist.

Negative feedback on the usefulness of the document did highlight a lack of 'know-how' for what to do next with the information provided in the tool. Even when participants acknowledged that this tool increased their awareness of potential impacts of medical tourism, many were unsure how this might translate to action. Participants experiencing chronic pain said that, given their desperation to access care, their focus on improving their individual quality of life would likely have prevented them from considering potential societal impacts had they read this document before traveling for care. These results are similar to previous studies that have found Canadian medical tourists are less inclined to consider potential societal impacts resulting from medical tourism when asked about ethical concerns, and more likely to discuss concerns about the Canadian health care system contributing to their decision to participate in medical tourism (Snyder et al., 2012b). In fact, medical tourists are most likely to travel for medical care in response to their experiences of feeling 'abandoned' by their own health care system (Perfetto & Dholakia, 2010). As the majority of participants in this study were diagnosed with multiple sclerosis and traveled outside of Canada to access an unavailable procedure, many participants likely experienced high levels of frustration trying to access care in the Canadian health care system before deciding to travel outside of Canada for the CCSVI procedure. The interviews demonstrated that the suggestion to contemplate potential ethical and health equity impacts of medical tourism on the Canadian health care system or health care systems globally may further frustrate patients that feel abandoned by the health care system and are desperate to access care. These findings agree with previous research that describes medical tourists as escaping the constraints of a national health care system by expanding their health care system to a global scale (Perfetto & Dholakia, 2010).

Participants mentioned several times that their desperation resulted in quick decision-making around medical tourism, which may limit informed consent, an existing problem in medical tourism (Penney et al., 2011). This tool intends to encourage further consideration of information regarding potential impacts of medical tourism but, as demonstrated in the results, this may be frustrating for participants who feel as though

they are in a desperate situation, face time constraints, and/or are unsure where to begin this research. However, we believe this frustration, if voiced, could potentially have a positive impact by promoting a need for greater research and regulatory structures within the medical tourism industry that facilitate more ethical decision-making and informed consent by medical tourists. Research on policy development indicates that shaping the public debate may have a large impact on resulting policy outcomes (Waddell et al., 2005) and an information tool such as this one can definitely play a role in shaping the public debate around medical tourism in Canada and increasing advocacy surrounding ethical medical tourism and health service provision and utilization.

Following analysis of feedback from interview participants, the research team utilized this feedback to further revise the information provided in the document. We took into consideration feedback on document format from the interview participants as well as consultation with existing one-page health communication documents provided to patients in travel health clinics to guide the design of a document for dissemination. This final document can be seen in Figure 3 in the appendix. Dissemination of this document will take place through distributing copies to travel health clinics, primary health care providers, health authorities, and other groups interested in providing this document to persons using their services.

3.5.1. *Wider Relevance*

The results and discussion of feedback from interview participants provide insight into the challenges and useful considerations that researchers, policy makers, and health care providers may wish to contemplate when considering the communication of ethics in health care utilization and provision. Global health researchers have identified a need for the application of ethical frameworks and tools to public health to encourage more fair and just allocation of health resources globally (Farmer, 2005; Maclean & Brown, 2009). Consumer guidelines utilize a format that has been effective at increasing public discussion about some of the existing ethical issues in practices such as tourism. This public discussion may serve to introduce and reinforce more ethical practices through increased awareness of one's social responsibilities (Clarke et al., 2007). This research study suggests that guidelines or information sheets tailored to health care users may provide an effective means of engaging persons accessing health care into

conversations and further contemplation about one's social responsibilities when accessing health care. As such, this research may be of interest to persons interested in promoting more just and fair allocation of health resources.

3.5.2. *Limitations*

This study is limited in its ability to develop an understanding of persons' actions following the consideration of information provided in this document. As the methods utilized for this analysis involved one-time interviews with persons that had already traveled for medical tourism, these persons did not speak on any future actions that they might take. While this study explored contexts in which this information may not be considered by someone reading the document, for those who did consider this information useful to the decision-making process, this study is limited in its ability to provide insight into the actual use of this information in this decision-making process. The ability for this study to understand the effectiveness of the information sheet is limited.

Given that the majority of participants ($n= 21$) had some level of post-secondary education, these findings suggest that while participants generally found the information to be understandable, this particular participant sample may have high health literacy levels compared to the tool dissemination audience. The inclusion of a health literacy test such as the Test of Functional Health Literacy in Adults might provide a reliable indicator of patient ability to read health-related material (Parker, Baker, Williams & Nurss, 1995).

3.5.3. *Future Directions*

While the findings of this formative study suggest that an information tool focused on ethical concerns with medical tourism can play a useful role in raising awareness about these concerns and advocating for more ethical practice in the industry regardless of procedure, more research is needed to further explore this potential given the limitations of this study. For example, feedback from persons who have not already traveled as medical tourists could provide additional insight on the potential impact of this information tool. Additionally, there was limited feedback provided by participants on

their understanding or potential engagement with the information provided in the tool. While participants easily engaged in conversation about potential impacts of medical tourism in previous questions, when asked about their thoughts on whether the information in this tool presented them with any ethical concerns, the use of the word “ethics” seemed to limit participants’ engagement. This may be due to participants feeling uncomfortable discussing the ethics of an activity in which they have already engaged. This more limited discussion of ethics resulted in some lack of clarity regarding comprehension of the information presented in the tool. It would be beneficial to determine participant’s conceptualization of the term “ethics” to better understand this relationship. This suggests that future research with persons contemplating medical tourism should focus on greater in depth-discussion about the impacts of such a tool in terms of engagement with the information presented within and the ethical considerations of medical tourism. An additional resource such as a website could provide greater details, including anecdotes and alternative methods of describing the ethical concerns of medical tourism. The link to the website could be provided on the information tool, and further research could explore feedback on the usefulness of such a website.

3.6. Conclusion

This paper has explored the use of an information sheet as a means of increasing individuals’ awareness of ethical concerns in medical tourism to enable Canadians to make more informed decisions about private health care utilization abroad. With existing sources of information for medical tourists commonly demonstrating a lack of neutral guidance (Johnston et al., 2012), this tool responds to a pressing, practical knowledge gap. According to feedback from interviews with former Canadian medical tourists, the tool we have developed has the potential to raise awareness of ethical concerns during the decision-making process. However, it is unknown at this point whether this awareness will lead to shifts in attitude and changes in behaviour at both the individual and societal level to contribute to social responsibility in health care provision and utilization, and ultimately improved global health equity (Bernhardt, 2004). Moving beyond the formative research presented herein, implementation of the tool and

evaluation of its uptake and utilization will shed light on whether or not such awareness will lead to these types of shifts and changes.

Chapter 4.

Conclusion

4.1. Overview

The two analyses that inform this thesis provide new insight about medical tourism as an activity requiring public health attention. Chapter 2 provides a discussion of findings from a literature review of existing ethical guidelines in related domains and the methodology used to develop an information sheet for informing medical tourists about ethical issues related to medical tourism. While specifically targeting the practice of medical tourism, this novel methodology can be applied to other practices as well. Chapter 3 presents the findings from interviews conducted with former Canadian medical tourists to develop an analysis of potential impacts of such an information sheet on raising awareness and promoting ethical decision-making related to medical tourism. Together, these two chapters meet my intended objectives and contribute to both the larger CIHR-funded study as well as the body of knowledge on medical tourism and health communication strategies for promoting ethical utilization and provision of health care services.

The remainder of this chapter will revisit my research objectives and summarize and discuss the relevant findings from these two analyses in light of my intended objectives. I explore each objective separately and then discuss the overall significance of this thesis, including a discussion on both strengths and limitations of this body of research as well as recommendations for future research directions.

4.2. Summary of Analyses

4.2.1. Information Sheet Methodology Development

The first objective of my thesis research is to describe the process, strengths, and limitations of the methodology used to develop the information sheet to provide for potential replicability of this methodology and further development of tools for communicating ethical concerns to the public. Chapter 2 addresses this objective by describing the methodology used to create an information sheet intended to communicate ethical concerns related to medical tourism to potential medical tourists. In response to the existing gap in neutral and comprehensive information available to medical tourists (Turner, 2007; Ormond, 2012), the research team developed this information sheet using methodology informed by ethical consumption guidelines. This process began with a literature review of ethical guidelines for consumers of services in related domains, given the demonstrated value of ethical consumption guidelines in advocating for societal change (Clarke et al., 2007). The process of communicating information in a way that increases individual contemplation of the impacts of one's actions on the upholding of societal values is a form of activism which may serve to reinforce one's roles and responsibilities as global citizens (Pattie et al., 2003). The goal of the information sheet is to promote this form of individual contemplation with regard to medical tourism.

The methodology that the research team utilized was developed through an iterative process of literature review followed by extensive collaborative discussion and formative research. This process challenged the researchers' assumptions regarding the communication of health information regarding ethical considerations in medical tourism. First of all, the researchers originally intended to develop a guideline with more specific guiding actions for persons considering engaging in medical tourism. However, after exploring health communication literature, the research group decided that given the limited empirical information regarding the impact of medical tourism on individuals and on a societal level, providing specific actionable guidance is impractical (Parvanta et al., 2010; Guttman & Salmon, 2004). As such, the research team decided to create an information sheet focused on raising awareness of ethical concerns related to medical tourism.

Overall, the iterative nature of this methodology allowed for multiple revisions of the information sheet that respond to user and gatekeeper feedback, as intended in health communication (Parvanta et al., 2010). Furthermore, continuous collaboration and discussion amongst the research team following the literature review, during interpretation of the feedback from stakeholder groups, and when revising the information sheet, allowed for multiple perspectives to enhance the usefulness and effectiveness of the tool. By challenging the researchers' assumptions regarding the intention and preferred format and information provided in the information tool, this methodology may effectively provide information which brings the ethical concerns of medical tourism into public discourse and policy considerations (Adams & Raisborough, 2010).

4.2.2. Perceptions of Medical Tourists on the Information Sheet

The second objective of my thesis research is to identify and describe the perceptions of former Canadian medical tourists on the format, usefulness, and potential impacts of the information sheet. The analysis presented in Chapter 3 presents findings related to this objective. This analysis focuses on themes from semi-structured interviews with 24 former Canadian medical tourists that display the perceptions of participants on the information sheet. While feedback on the format of the sheet was generally positive, overall negative feedback on the information sheet included a perceived condescending and/or biased tone of the document and a lack of actionable guidance or instruction on what to do with the provided information. This negative feedback came primarily from participants that had described themselves as "desperate" for some form of health care, due to pain, poor quality of life, and other related contexts. These findings are important considerations to the dissemination of the information sheet as public health communication may have unintended unethical impacts, such as labeling, stigmatizing, and expanding social gaps (Guttman & Salmon, 2004). These findings can help guide revisions of the sheet to consider the potential unintended impacts of this health communication.

The findings from the formative research prompted the research team to change certain language throughout the document to ensure that the information provided encourages persons to do their own research. While participants did indicate frustration

at a lack of actionable guidance, the discussion in Chapter 3 suggests that this frustration may actually serve a useful purpose. With the intended goal of the information sheet to create awareness that increases public discussion around ethical concerns of medical tourism, this frustration may actually help meet this goal by encouraging increasing debate about the concerns presented in the information sheet.

4.2.3. Impact of the Information Sheet on Raising Awareness of Ethical Considerations of Medical Tourism

The third objective of my thesis research is to identify and describe the potential impact of the information tool on medical tourists' awareness of the ethical concerns related to medical tourism. The analysis in Chapter 3 describes findings related to this objective. In particular, this analysis indicates many participants find the tool useful in "giv[ing] [them] something to think about", which may help create the intended public discussion about these ethical concerns. However, many participants did not feel that this awareness would have changed their decision-making, citing potential barriers to accessing desired health care within Canada as the reason. Many participants mentioned desperation as a key barrier to further contemplation of the information presented in the document. These findings indicate that there may be structural barriers to advocating for more ethical decision-making in medical tourism.

4.2.4. Knowledge Gaps in the Effective Communication of Ethical Considerations of Medical Tourism

The final objective of my thesis research is to identify and describe existing knowledge gaps regarding the communication of ethical concerns of medical tourism to inform future research with the intention of better informing Canadians of these concerns. Chapter 3 in particular responds to this objective by identifying other voices that may help determine the effectiveness of the information sheet in creating awareness of the ethical concerns of medical tourism. Following the interviews with former medical tourists, it remains unknown whether the perceptions of persons that have not yet traveled for medical tourism might be different from former medical tourists. Naturally, the group of former medical tourists does not include persons who were dissuaded from traveling abroad for care. In the interviews, participants often spoke about their positive

experiences accessing care outside of Canada which may have impacted their willingness to consider potential negative impacts of medical tourism. Future research with persons who have not participated in medical tourism and would potentially access a document such as this from a health care provider or on the internet may contribute useful insight into the impacts of this information sheet on effectively raising awareness about the ethical concerns of medical tourism.

4.3. Study Significance

4.3.1. Strengths of this Study

There are several strengths of this thesis research in terms of its contribution to the body of knowledge on the promotion of socially responsible actions in health care utilization and provision, particularly in relation to medical tourism. First, the findings of this thesis research provide insight into the overall goal of the larger study, specifically to create a document for effective communication of the ethical concerns of medical tourism to Canadians considering traveling for medical care. While Chapter 2 explains the methods and rationale for the information tool, Chapter 3 provides a discussion of the potential usefulness and impacts of such a tool on creating awareness of the ethical concerns of medical tourism. By providing an analysis of both the methodology utilized to develop the information sheet, as well as analyzing the feedback of former Canadian medical tourists, this thesis research contributes to the further development and effective dissemination of the tool, which may contribute to more ethical decision-making in medical tourism.

By grounding the information sheet development methodology in values found frequently in existing ethical guidelines in related domains, this thesis research demonstrates methods of incorporating ethical values related to social sustainability into the information provided to health care users. Ethical guidelines for consumers or service users have been shown to be effective in contributing to more sustainable practices in fields such as ecotourism (Clarke et al., 2007; Adams & Raisborough, 2010). This thesis research demonstrates the potential usefulness of ethical guidelines in the area of health care utilization to contribute to improved health equity as increased

contemplation of these ethical concerns may empower individuals to advocate for change to health care provisions in order to enhance health equity (Chen & Flood, 2013). This may be particularly true in situations where individuals face an increasing burden of responsibility for their health due to health care privatization (Maclean & Brown, 2009) and where neutral and comprehensive information is lacking, as is the case with medical tourism (Ormond, 2012; Turner, 2007; Snyder et al., 2012a).

The findings of this research agree with and build on existing literature that suggests ethical consumption guidelines may encourage the contemplation of responsible citizenship and citizenly acts (Clarke et al., 2007). According to the feedback provided in the interviews with former Canadian medical tourists, the majority of participants indicated that the information sheet would likely encourage further contemplation of the issues presented in the document. By speaking to persons who had previously traveled for medical tourism, this research study was able to explore stories about the decision-making process for these participants, particularly in relation to their desperation in seeking health care. This discussion provides insight into the reality of individuals' contemplation of ethical issues in the context of desperation for medical care. As these discussions show, different groups of patients seeking out differing procedures will be more or less receptive to incorporating ethical concerns into their decision-making depending on the level of desperation facing the different patient groups. This agrees with previous literature on social marketing that emphasizes the importance of audience segmentation when communicating health information (Parvanta et al., 2010). This may mean that different messages are needed for these different groups, a project that should be considered in the future.

Overall, participants who did not find the information sheet to be useful indicated frustration that the document focuses on providing information to individuals, given that these individuals have faced numerous barriers to accessing desired health care in the health care system. By engaging in conversations with persons who had traveled for medical tourism and read the information sheet developed by the research team, this research provides a new understanding of the ways in which Canadians considering accessing medical care out of Canada might engage with information on the ethical concerns of medical tourism given their interactions with the Canadian health care system. Moreover, these interviews identified room for additional efforts at raising

awareness of these ethical concerns in the future, including the development of an informational website for potential medical tourists.

4.3.2. *Overall Limitations*

While the previous section describes the significant findings from this study, this thesis research is limited in its ability to provide further understanding of participants' interpretation of the ethical concerns presented in the document and the potential impacts of such a document on medical tourist decision-making. As many interview participants did not engage in questions asking specifically about ethics, it remains unknown whether an increased awareness of the information provided in the document does promote greater discussion and contemplation of ethics regarding medical tourism. While the interview feedback indicated that the information sheet resulted in participants "taking the time to think through things more", the information sheet was also dismissed by some participants that felt it was just "something else to worry about" when these participants already had a great deal of stress and desperation in trying to access health care. While the information sheet may affect decision-making by some patients, it will certainly not enjoy a receptive audience in all cases.

If the information tool does exacerbate the perception of an increased burden of responsibility placed upon persons considering traveling as a medical tourist, it is unknown from this research what the impacts of this might be. In some cases, individuals feel constrained in their decision-making by certain structural barriers, including desperation to access unavailable procedures in Canada. While the information sheet may introduce ethical issues into these patients' decision-making, it remains unknown how best to present this information and support these persons in light of these structural barriers. As health care-related policy plays an important role in exacerbating or eliminating structural barriers to engaging in socially responsible decision-making in health care utilization, including accessing medical care as a medical tourist (Chen & Flood, 2013), this thesis research has shed light on a need for more research regarding structural barriers to accessing desired health care in Canada and the impacts of these barriers on global health equity.

Finally, the process of data collection and analysis in this study faced certain limitations which impacted upon the study findings. First of all, when developing the information sheet, the research team recognized the value of the iterative process we used to revise the document using further information and feedback from medical tourism stakeholders. However, as a static document, continuous revisions which enhance the usefulness of the document are not possible. The value of input from various stakeholders (Parvanta et al., 2010) suggests that websites which enable continual revision and addition may be a useful addition to this information sheet, particularly since medical tourists commonly cite the internet as a source of information during their decision-making (Johnston et al., 2012). While the static nature of the information sheet limits the ability for this document to easily be revised, this research study demonstrates that a website may provide a good platform for continuing the iterative nature of this methodology.

Additionally, the implications of this thesis research are limited by researcher and sampling bias (Baxter & Eyles, 1997). First of all, my interactions within the research team during the development of the information tool were highly informed by my previous collaboration within the research group. This previous collaboration may restrict the amount of diversity in the various viewpoints of the research team. My position as a researcher, graduate student, and young female informed my interactions with interview participants, as well as my interpretation of findings. In particular, after spending over twenty-five hours listening to the stories from fellow Canadians seeking health care outside of Canada because they are desperate to find some form of relief from their pain and/or improve their quality of life, I developed an emotional reaction to these stories and my data analysis was highly informed by these experiences. I focused much of my analysis on the discussions from participants on their desperation and/or frustration with trying to access medical care as I became most interested in sharing the stories of these Canadians to develop awareness and continued research into the types of information that might better support Canadians facing these frustrations. As the majority of participants were diagnosed with multiple sclerosis and were traveling for the unavailable CCSVI procedure, my analysis and subsequent discussion might differ with a wider variety of procedures for which participants traveled, depending on the level of desperation experienced by participants.

The sample population interviewed in this study included persons who had already traveled for medical care, which may not reflect the opinions of prospective medical tourists. While this particular population was selected to provide feedback on the information sheet as a means of describing the potential impacts of the information on their decision-making process, it is possible that participants were less likely to engage in discussions about ethics or potential negative impacts of medical tourism as they had already traveled as medical tourists. The emotional experience of having undertaken a medical tourism trip informed participants' responses. None of the participants interviewed in this study had experienced major complications while engaged in medical tourism, indicating participants may also have been more likely to participate in this study having had a positive experience as a medical tourist. Given that participants had already engaged in medical tourism, those who had experienced positive results from their trip may have been less likely to consider any potential negative impacts on their safety or on third parties. While the interview specifically probed participants' accounts of their experiences to better understand their decision-making before asking participants' opinions on the information sheet, this probe may have contributed to participants emphasizing their perceived positive impacts of medical tourism. This potential sampling bias indicates a need for future research to include the perspectives of medical tourists who experienced complications or challenges during their medical tourism experience.

4.4. Conclusion

When conducting the data collection for this research, I was often surprised at how little participants would mention regarding potential negative impacts of medical tourism. Many participants did describe in great detail their pain, poor quality of life, and/or desire for medical care. In this way, their challenges accessing medical care in Canada were often framed as ethical concerns. As these individuals were often quite frustrated with access to certain medical procedures in Canada, I became quite sensitive to the participants' concerns regarding the health care system. This lead me to further consider the sources of information available to medical tourists regarding ethical provision and utilization of health care resources, and the perceptions of Canadians on information about these ethical issues.

The growth of medical tourism is discussed as a phenomenon resulting from current interactions within and between health care systems which further complicates these health care systems in an increasingly globalized world (Ormond, 2013). Research on medical tourism builds on our understanding of the impacts of neoliberal strategies on health care provision (Maclean & Brown, 2009), as well as the shifting role of the individual and government in promoting health equity (Gauld, 2009). By exploring government and regional strategies for developing medical tourism industries to enhance investment, researchers can develop a better understanding of the impacts of these strategies on primary health care provision, and as a result health equity (Ormond, 2013). Furthermore, research that explores decision-making in medical tourism can develop a better understanding of individual contemplation of individual health and safety risks and societal impacts of medical tourism. This understanding can contribute to the development of information and health communication which encourages socially responsible provision and utilization of health care (Johnston et al., 2012), particularly as research demonstrates that medical tourists rarely consider the potential third party impacts of medical tourism (Snyder et al., 2011).

My thesis research focuses on generating further understanding of individuals' decision-making process regarding medical tourism through the development of an information sheet describing the ethical concerns of medical tourism. The information sheet incorporates the successful methods and ethical values communicated in other ethical guidelines and utilizes feedback from former medical tourists to guide revisions. In this way, this research analyzes the potential impacts of such a tool on individual awareness and contemplation of these ethical concerns when considering traveling out of country for medical care. Through the analysis presented in previous chapters of this thesis, this research helps build the conversation about the structural barriers facing individuals to the incorporation of ethical considerations in decision-making involving medical tourism and how to address these barriers.

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Appendices

Appendix A.

Draft Information Sheet, Version 1

Ethical Guidelines for Medical Tourism

Purpose

To encourage the development of ethical medical tourism practices amongst stakeholders by helping inform their decision-making processes.

Medical Tourism Defined

Medical tourism is a practice where patients privately seek non-emergency medical treatment abroad, usually paid for out-of-pocket and outside of planned cross-border care programs.

Ethical Values

This guideline is informed by the ethical values of *sustainability, efficiency, stewardship, equity, reciprocity, non-maleficence, autonomy, empathy, and procedural justice*.

Ethical Goals

To develop a medical tourism sector that:

- is *adaptable* to local and global changes;
- promotes *capacity building* in the public and private health sectors;
- promotes and maintains the *health* of international patients and the local population;
- has *consideration* for the wellbeing and needs of local populations and international patients;
- is consistent with local *cultural values* and exhibits *cultural awareness* for members of local populations;
- *distributes* the benefits created by this sector fairly;
- *protects* all stakeholder groups from new harms;
- promotes and empowers *informed decision making* by international patients;
- promotes *collaborative decision making* by local stakeholders;
- is responsive to *power imbalances* among stakeholders in the development of the sector and distribution of its benefits;
- protects and enables the *integrity* and *dignity* of all stakeholders;
- exhibits *shared responsibility* among stakeholders for the impacts of the sector; and
- promotes *transparency* in decision making around the development, administration, and impacts of the sector.

Stakeholders

To achieve these goals, the following stakeholder groups must be considered as contributors to the development of ethical medical tourism practices.

Patients/ Users: International patients that travel abroad to access non-emergency medical care

Providers: Members of the medical tourism industry that provide or facilitate care for foreign patients in the destination nation

Destination community: Non-provider members of the local or national community in medical tourism destinations, including government agencies and community groups.

Stakeholder Actions

Actions of each of the stakeholders that will achieve the ethical goals outlined in this guideline include:

For Patients / Users:

Inform oneself about the impacts of medical tourism on different stakeholder groups

Relates to Goal 8

Question a variety of stakeholders including providers, industry representatives, medical tourism facilitators, and other sources of information about the impacts of the industry on destination communities. Example: Contact your family physician to ask about the impacts of engaging in medical tourism.

Choose facilities that are consistent with these ethical goals

Relates to Goal 8

Ask facilities questions regarding their policies and practices and select facilities that can clearly indicate their ability to minimize risks to the local community and public health care system. Example: Explain to facility that you are unwilling to use its services unless it offers subsidized treatment to locals.

Communicate to the industry your expectations concerning ethical practices

Relates to Goal 14

Be upfront in expressing your desire to have care consistent with the values and goals in this guideline. Example: Communicate to providers that you value capacity building in the local health workforce.

Communicate experiences, including barriers, to other potential patients

Relates to Goal 8

Share information with potential medical tourists regarding practices and facilities which do [not] align with the ethical goals of this guideline. Example: Post on an online patient board about your experiences sharing your values with medical tourism providers.

Draw on one's resources to address observed inequitable or unethical situations

Relates to Goal 4

Donate goods and services to the local community where this may help cover one's use of resources such as public health infrastructure and communicate concerns to other stakeholders about observed unethical situations. Example: Locate and donate money to a charity addressing access to health care in the country you visited once home.

Advocate for others to respond to observed inequitable or unethical situations

Relates to Goal 14

If inequities or other ethical failings are observed during the process of engaging in medical tourism, make sure that these concerns are voiced. Example: Contact your local paper about your concerns once you have returned home from obtaining care abroad.

For Providers/ Industry:

Provides benefits to local populations.

Relates to Goal 6

Develop policies to ensure that your business provides a net benefit to the local population. Example: Use local businesses whenever possible.

Provide high quality safe care in accordance with recognized safety standards where possible

Relates to Goal 3

Remain up-to-date with the most recent medical research and ensure ongoing regulation and monitoring of safety standards. Example: Take special care to keep abreast of methods to ensure that multiple drug resistant bacteria are not spread to patients traveling abroad for care.

Provide care that is in keeping with local customs, protocols, and laws while meeting the needs of international patients

Relates to Goal 5

Do not engage in procedures that stigmatize foreign patients or members of local communities. Example: Refrain from the use of reproductive surrogates as they may perpetuate stigma against local women participating in this practice.

Be aware of and develop responses to new threats to all stakeholder groups

Relates to Goal 7

The impacts of medical tourism may change over time, requiring reassessment into the impacts of this practice. Example: Establish an annual review of the impact of hiring practices on the public health system.

Make available information on possible inequities caused by medical tourism and efforts to combat them

Relates to Goal 10

Engaging in ethical medical tourism requires communication of this practice's effects and efforts to ameliorate them. Example: Provide information on the facility website regarding the impacts of medical tourism on health equity locally.

Do not harm the public health sector and where possible contribute to the improvement of the public health sector

Relates to Goal 2

Medical tourism has the potential to negatively impact the public health sector, requiring interventions by industry members. Example: Coordinate with the public health sector regarding the health workforce and provide training opportunities for health service providers.

Develop business practices that protect patient confidentiality

Relates to Goal 11

The international dimension of medical tourism requires additional steps by providers to protect patient confidentiality. Example: Develop processes to securely transmit patient data over the internet.

Make information available about how you are going about meeting the ethical goals outlined in this guideline

Relates to Goal 14

Information should be published on facility websites that detail ethical practices. Example: Provide information on the facility website regarding specific efforts by your facility to avoid negative impacts on health equity.

Provide information to patients necessary to achieve informed consent

Relates to Goal 8

Provide information about the risks of treatment, success rates, after care, and treatment costs. Example: Provide information on the dangers of flying after hip replacement surgery.

Plan a sustainable business

Relates to Goal 1

Plan responses to the development of local dependencies on the goods, services, and employment offered by your business. Example: Develop a contingency plan with the local health system for the local provision of fertility treatment should your business no longer be able to provide these services.

Be aware of and responsive to changes in patient needs

Relates to Goal 1

Remain engaged in the literature on recent medical research and developments in trends in the aftercare needs of patients. Example: Make a regular assessment on techniques for reducing the danger of deep vein thrombosis to travelers.

Consult with local stakeholders

Relates to Goal 9

Hold regular meetings with local stakeholders to receive feedback and ensure practices in the facility remain up-to-date in terms of cultural sensitivity and addressing public health needs of the community. Example: Develop a regular consultation with interest groups on the acceptability of providing plastic surgery in the community.

For Destination Community:

Develop regulations that aim for equitable long-term public benefit

Relates to Goal 6

Encourage businesses that are utilized by medical tourists to have long-term, sustainable plans that are not dependant on medical tourists and keep profits within the local community. Example: Work with local hotels to diversify beyond providing services for medical tourists.

Establish and enforce oversight mechanisms that monitor the industry

Relates to Goal 13

Ensure that monitoring and enforcement of regulations takes place. Example: Develop mechanisms for reporting the complication rates of private medical facilities operating locally.

Develop regulations for safety in the industry, including for international patients and health workers

Relates to Goal 3

Regulations are needed to ensure both patient and worker safety. Example: Create regulations for preventing the spread of infectious disease to health workers within medical tourism facilities.

Serve as an advocate for an equitable and ethical industry

Relates to Goal 11

Ensure public awareness of the positive and negative equity impacts of medical tourism.

Example: Voice observed concerns about the industry at public town hall fora.

Develop and implement restrictions on procedures that are not consistent with local values

Relates to Goal 5

Develop criteria for procedures that meet local values and coordinate with medical tourism facilities for regular monitoring of procedures being performed according to these criteria.

Example: Develop regulations regarding the sale of human reproductive materials.

Set up channels and procedures for local input into industry regulation

Relates to Goal 9

Organize regular meetings with multiple stakeholders and industry representatives to ensure the needs of the local community are addressed by decision-makers in this industry. Example: Develop a regular consultation with local nursing schools to discuss hiring patterns of recent graduates.

Articulate public and private system needs and disseminate this information through industry stakeholders

Relates to Goal 14

Ensure that information regarding health system needs is understood by stakeholder groups.

Example: Include public health officials in the decision-making process within the industry.

Coordinate with medical tourism providers to manage the health workforce across the public and private systems

Relates to Goal 2

Identify any shortages of health workers across public and private systems and coordinate with medical tourism providers to continuously monitor and eliminate shortages. Example: Develop training opportunities within a medical tourism facility in response to local shortages among operating theatre nurses.

Establish procedures for transparency around decision-making

Relates to Goal 14

Ensure that decision-making processes are understood and available to stakeholder groups.

Example: Make information publicly available regarding selection of members of medical tourism advisory boards.

Provide avenues for raising awareness about local culture and customs

Relates to Goal 5

Use medical tourism as an opportunity to educate foreigners about local culture. Example: Coordinate with medical tourism facilities to provide information to foreign patients on how to act in a culturally sensitive manner while in the community.

Appendix B.

Draft Information Sheet, Version 2

Medical Tourism & Me

Thinking about going abroad for surgery or other medical care? This is referred to as medical tourism. Here's some important information for you to consider before deciding whether or not to become a medical tourist.

My Health

1. Did you know that not all countries have the same hospital quality control standards we use here in Canada?

Before you decide whether to go, contact the Canadian Blood Services Agency to ask if they are aware of any blood supply or storage concerns in the country you are thinking about visiting.

2. Did you know that your medical record here in Canada should include your entire health history, even for medical care given in other countries?

Before you decide whether to go, ask the hospital you are planning to book your procedure with if they will give you records in English or French to bring home with you.

3. Did you know that diseases contracted abroad could be brought back home with you?

Before you decide whether to go, visit a travel clinic and make sure you get all recommended vaccines.

My Home

1. Did you know that some types of medical care require follow-up appointments or aftercare treatment?

Before you decide whether to go, make sure that you will be able to get the aftercare or follow-up appointments you need by talking to your regular doctor here about this.

2. Did you know that before you consent to any medical care you should know the risks of the procedure?

Before you decide whether to go, be sure to obtain information on procedure risks, ideally from a trusted source.

3. Did you know that your own decision to go abroad for medical care could actually impact other Canadians as well?

Before you decide whether to go, consider that if you experience medical complications you may need to be treated for these in Canada and that doing so may lessen other patients' access to this medical care.

My Journey

1. Did you know that not all countries have the same patient and consumer protection laws we do here in Canada?

Before you decide whether to go, learn about malpractice laws in the countries you are considering visiting and make certain that your rights as a patient will be protected.

2. Did you know that some countries offer medical procedures to international patients that you cannot get here in Canada?

Before you decide whether to go, find out if the procedure you are considering has been shown to be safe and effective by a reputable agency.

3. Did you know that health care is a scarce resource around the world?

Before you decide whether to go, inform yourself about the most pressing health care challenges in the countries you are thinking about visiting and consider whether medical tourism may help or worsen them.

Be informed and share your thoughts, ideas, and experiences with others.

For more information go to: www.sfu.ca/medicaltourism/guide

Appendix C.

Final Information Sheet

Are you a Canadian thinking about going abroad for surgery or other medical care?



This is referred to as medical tourism. Here's some important information for you to consider before deciding whether or not to become a medical tourist.

My Health

- ***Traveling abroad for care might generate unforeseen costs***

Before you decide whether to go, contact your travel insurance agency to see if emergency hospitalization and other unanticipated events are covered.

- ***Your medical record here in Canada should include your entire health history, even for medical care received in other countries***

Before you decide whether to go, ask the hospital you are planning to book your procedure with if they will give you records in English or French to bring home with you.

- ***Before you consent to any medical care you need to know the risks of the procedure***

Before you decide whether to go, be sure to obtain information on procedure risks from a source you trust.

My Home

- ***Some types of medical care require follow-up appointments or aftercare treatments***

Before you decide whether to go, make sure that you will be able to get the aftercare (e.g. blood tests) or follow-up appointments you need by talking to your regular doctor here about this.

- ***Diseases contracted abroad could be brought back home with you***

Before you decide whether to go, visit a travel medicine clinic and make sure you get all recommended vaccines.

- ***Your own decision to go abroad for medical care could impact other Canadians***

Before you decide whether to go, consider that if you experience medical complications you may need to be treated for these in Canada and this may increase wait times for other Canadians.

My Journey

- ***Not all countries have the same patient and consumer protection laws we do here in Canada***

Before you decide whether to go, learn about malpractice laws in the countries you are considering visiting and make certain that your rights as a patient will be protected.

- ***Some countries offer medical procedures to international patients that you cannot get here in Canada***

Before you decide whether to go, find out if the procedure you are considering has been shown to be safe and effective by an agency you find reputable.

- ***Health care is a scarce resource around the world***

Before you decide whether to go, inform yourself about the most pressing health care challenges in the countries you are thinking about visiting and consider whether medical tourism may help or worsen them.

Be informed and share your thoughts, ideas, and experiences with others.

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