

# **Global Civil Society and Health Advocacy in Intellectual Property Related Issues**

**by**

**Alexandra Bennett**

M.P.H., Simon Fraser University, 2015  
Master's Project; Capstone

Health Sciences / Simon Fraser University/ Global Health  
Faculty of Health Sciences

**© Alexandra Bennett 2015**

**SIMON FRASER UNIVERSITY**

**Summer 2015**

All rights reserved.

However, in accordance with the *Copyright Act of Canada*, this work may be reproduced, without authorization, under the conditions for "Fair Dealing." Therefore, limited reproduction of this work for the purposes of private study, research, criticism, review and news reporting is likely to be in accordance with the law, particularly if cited appropriately.

# Approval

**Name:** Alexandra Bennett  
**Degree:** Masters of Public Health  
**Title:** *Global Civil Society and Health Advocacy in Intellectual Property Related Issues*

**First name Surname**

Senior Supervisor  
Assistant/Associate/Professor

Dr. Nicole Berry

---

**First name Surname**

Second Reader  
Assistant/Associate/Professor

Dr. John Calvert

---

**Date Defended/Approved:** \_\_\_\_\_

## Ethics Statement



The author, whose name appears on the title page of this work, has obtained, for the research described in this work, either:

- a. human research ethics approval from the Simon Fraser University Office of Research Ethics,

or

- b. advance approval of the animal care protocol from the University Animal Care Committee of Simon Fraser University;

or has conducted the research

- c. as a co-investigator, collaborator or research assistant in a research project approved in advance,

or

- d. as a member of a course approved in advance for minimal risk human research, by the Office of Research Ethics.

A copy of the approval letter has been filed at the Theses Office of the University Library at the time of submission of this thesis or project.

The original application for approval and letter of approval are filed with the relevant offices. Inquiries may be directed to those authorities.

Simon Fraser University Library  
Burnaby, British Columbia, Canada

update Spring 2010

## **Abstract**

Civil society organizations and other non-governmental organizations (NGOs) act as policy watchdogs and often represent the voices of marginalized populations. The importance of advocates in the field of Intellectual Property is apparent now more than ever. The global stage is changing; what were previously considered domestic issues have been thrust onto the international stage by agreements such as the Trade Related Aspects of Intellectual Property Rights agreement (TRIPS) (Sell & Prakash, 2004; Drahos & Braithwaite, 2001). The private sector has the resources to make their position heard; however, most other populations in society do not. Therefore, civil society and NGO groups are integral to advocating for health. The current trend of TRIPS+ style agreements which include much more stringent intellectual property rights (IPRs) laws, mean that the fight for access to medicines and medical technologies is intensifying.

This capstone uses a review of existing literature to explore the emerging concept of a global civil society, and the state of advocacy in Intellectual Property related issues. An interview with an advocate in the field helps inform how civil society organizations pursue their goals in the new IPR regime. The results of this capstone indicate that effective communications, strong relationships between organization and community, and an organizational emphasis on fostering individual work connections are integral to success.

**Keywords:** Intellectual Property; Advocacy; Non-governmental Organization; Civil Society Organization; Global Health; Access to medicines

## **Acknowledgements**

I would like to extend a genuine thank you to all the people selflessly gave their time to support this capstone. I would especially like to thank my Senior Supervisor, Dr. Nicole Berry, for her patience and encouragement. Her careful guidance and attention have been immeasurably helpful in making this capstone what it is today. I also would like to extend my thanks to Dr. John Calvert for his time and insights.

Additionally, I would like to acknowledge the Faculty of Health Sciences at Simon Fraser University and all of the faculty and staff who dedicate themselves to making the Faculty an open and honest learning environment. Finally, thank you to my family and friends, without whom I would have never made it this far.

## Table of Contents

<b>ETHICS STATEMENT</b>	<b>III</b>
<b>ACKNOWLEDGEMENTS</b>	<b>V</b>
<b>LIST OF ACRONYMS</b>	<b>VIII</b>
<b>INTRODUCTION</b>	<b>9</b>
<b>PURPOSE OF THE CAPSTONE</b>	<b>9</b>
<b>BACKGROUND</b>	<b>10</b>
<i>TRIPS AND PUBLIC HEALTH ADVOCACY</i>	<b>10</b>
<i>ACCESS TO MEDICINES (ADVOCACY IN THE FIELD)</i>	<b>13</b>
<i>TERMINOLOGY</i>	<b>14</b>
<i>THE EMERGENCE OF GLOBAL CIVIL SOCIETY</i>	<b>15</b>
<b>RESEARCH DESIGN</b>	<b>16</b>
<i>PHASE 1: LITERATURE REVIEW</i>	<b>17</b>
<i>PHASE 2: KEY INFORMANT INTERVIEW</i>	<b>18</b>
<i>PHASE 3: DATA EVALUATION</i>	<b>18</b>
<i>PHASE 4: CONSTRUCTION OF RECOMMENDATIONS</i>	<b>19</b>
<i>PHASE 5: DISSEMINATION OF RESULTS</i>	<b>19</b>
<b>FINDINGS</b>	<b>19</b>
<i>ARE GLOBAL CIVIL SOCIETY ORGANIZATIONS EFFECTIVE?</i>	<b>21</b>
<i>WHAT MAKES GLOBAL CIVIL SOCIETY ORGANIZATIONS EFFECTIVE - INSIDER VERSUS OUTSIDER STRATEGIES</i>	<b>22</b>
<i>INSIDER COMMUNICATIONS STRATEGIES</i>	<b>23</b>
<i>OUTSIDER COMMUNICATIONS STRATEGIES</i>	<b>25</b>
<i>GATHERING INFORMATION FOR OUTSIDER COMMUNICATIONS</i>	<b>26</b>
<i>RELATIONSHIP-BASED INSIDER STRATEGIES</i>	<b>27</b>
<i>RELATIONSHIP-BASED OUTSIDER STRATEGIES</i>	<b>28</b>
<i>NEW TRENDS IDENTIFIED BY KEY INFORMANT – LANGUAGE OF STRUGGLE</i>	<b>30</b>
<b>DISCUSSION</b>	<b>31</b>

<i>GROWING A CULTURE OF CONNECTION</i>	32
<b><u>WAYS FORWARD</u></b>	<b><u>33</u></b>
<b><u>CRITICAL REFLECTION</u></b>	<b><u>34</u></b>
<b><u>REFERENCES</u></b>	<b><u>36</u></b>
<b><u>APPENDIX A.</u></b>	<b><u>41</u></b>
<i>CODES</i>	41

## List of Acronyms

CETA	Comprehensive Trade and Economic Agreement
CSO	Civil Society Organization
GCS	Global Civil Society
IP	Intellectual Property
IPR	Intellectual Property Rights
NGO	Non-Governmental Organization
TRIPS	Trade-Related Aspects of Intellectual Property Rights
TPP	Trans-Pacific Partnership Agreement
WHO	World Health Organization
WIPO	World Intellectual Property Organization

## Introduction

In this age of high intellectual property (IP) protectionist policies, successful advocates are growing a culture of connection, inside and outside their organizations, through communications activities and relationship-building. In order to effectively limit the current trend of IP protection and expand access to medicines and medical technologies, civil society organizations (CSOs) must concentrate on strengthening and expanding their networks by supporting partnership between their organizations and other like-minded organizations and government allies. Generally, CSOs are advocating for an agenda that conflicts with that of multinational corporations, who have the resources to make their position heard, which most other populations in society do not have (Follér, 2010). Therefore, civil society and NGO groups are integral to advocating for health from non-profit oriented perspectives.

In order to understand the challenges faced by those advocating against IP protection, the context of the field must be explored. The insertion of IP into the World Trade Organization (WTO) under the Trade-Related Aspects of Intellectual Property Rights (TRIPS) Agreement, is the biggest development in IP of the last 30 years. TRIPS brought IP, previously considered a small and specialized section of international law, into the global spotlight by placing it front and center in the newly minted WTO (Helfer, 2009). Furthermore, the TRIPS negotiations represent one of the first times that civil society groups were given space in a global policy discussion (Selian, 2004); civil society groups and NGO's were the voice that attempted to balance that of multinational corporations (Sell & Prakash, 2004). Since TRIPS, civil society organizations of all stripes have been engaging with an ever increasing number of global structures and institutions (Selian, 2004).

## Purpose of the Capstone

The aim of this capstone is to investigate the specific tactics (if any) advocates working in areas that face intellectual property and/or patent law challenges are using as a means to further their cause, in order to create possible recommendation for others

working in the same or similar contexts. This capstone approaches the question of how organizations advocate by analyzing tactics highlighted by a literature review and supplemented by a key informant interview. A discussion of the context of the current IP regime and the main concerns of advocates in the field, centers the results of the literature review and interview. The main themes that arise from this analysis will then be discussed and the ways forward presented.

## Background

### *TRIPS and Public Health Advocacy*

Access to medicines has been restricted due to the integration of intellectual property into trade, which began in the 1980s. In part because of pressure from U.S. pharmaceutical companies, the United States began to push for new areas, including services, investment, and intellectual property rights (IPRs), to be included under the purview of the General Agreement on Trade and Tariffs (GATT) (Drahos, 2002). Ultimately, the early 90s saw the creation of the World Trade Organization (WTO) and the shift of IP regulation from the World Intellectual Property Organization (WIPO) to the WTO under TRIPs, one of the WTOs first and most controversial agreements (Helfer, 2009; Drahos, 2002). The ratification of Chapter 17 of the North American Free Trade Agreement (NAFTA) in 1993, prior to TRIPs, in which the United States was a key player, marked a monumental first step toward integrating IP into world trade. However, prior to the institution of TRIPs in the WTO, IPRs were largely seen as separate from all other areas of international law (Helfer, 2009).

There are three main criticisms of the TRIPs agreement (Drahos & Braithwaite, 2001). The first is that TRIPs was not an agreement developed between equal powers, but rather forced on some states by the economically powerful (Drahos and Braithwaite, 2001). Sell describes TRIPs as the result of “tireless... economic coercion” (p. 481, 2001). Including TRIPs in the WTO ensured that countries would sign on to the agreement, lest they be shut out of the global economy; furthermore, the stringent enforcement mechanisms enshrined in the WTO make it easy to enforce TRIPs and persecute non-compliant states (Drahos, 2002;

Drahos & Braithwaite, 2001; Helfer, 2009; Sell, 2001). Second, the agreement was not equally advantageous for economically weaker states (Drahos & Braithwaite, 2001). Not only were economically stronger states largely the creators of TRIPS, but many scholars have noted that the private sector from these economically stronger states was very influential in shaping the specifics of the agreement (Drahos & Braithwaite, 2001; Kapczynski, 2008). Third, many economically weaker states would, in fact, be disadvantaged by ratifying the agreement (Drahos & Braithwaite, 2001).

TRIPS completely changed the way IPRs were treated globally; it extended patents, and effectively removed a state's autonomy by limiting its former ability to decide how to proceed with licensing in their country (Drahos, 2002; Sell, 2001; Sell & Prakash, 2004). TRIPS limited the ability of the state to create policies that were contextually relevant for their needs, instead pushing the adoption of policies that had essentially been passed down from the United States and other economically powerful, developed countries (Drahos, 2002; Ford, 2004; Sell & Prakash, 2004). The overall effect was to take what had been previously considered a national issue, and bring it into an international space where industry interests were prioritized over national sovereignty (Sell, 2001). Drahos makes an important point about the overall importance of IP, especially for developing countries:

If... development is about expanding the ability of people 'to shape their own futures,' then we have a *prima facie* normative reason to be concerned about the loss by developing countries of national sovereignty over standards that impact on sectors such as agriculture, food, environment, health and education (p.765, 2002)

The addition of TRIPS to the WTO package has removed the sovereignty of governments over IP standard setting, by making the ratification of TRIPS a prerequisite to joining the global economy (Drahos, 2002; Ford, 2004; Sell, 2001). Furthermore, Drahos argues that enshrining IP rules in the WTO mirrors to an uncomfortable degree the history of colonization (2002). Previously, there was a general north to south movement of IP standards as colonizers imposed many laws in the colonized country; upon achieving independence, many previously colonized countries were faced with an IP regime which was largely run by the same states which had been their colonizers (Drahos, 2002).

The TRIPS negotiations mark a major increase in advocates' involvement in assessing the impact of intellectual property rights on public health, particularly access to medicines (Matthews, 2006). The combination of the so-called economic coercion and the cost of TRIPS in limiting access to medicines created a space and impetus for civil society organizations and many states to engage with global IPR more directly than had previously been seen (Matthews, 2006; Sell, 2001). Initially, the inclusion of TRIPS in the WTO was met with some resistance; civil society organizations came together along with many developing countries to argue for the reduction of IPRs and TRIPS (Drezner, 2005; Sell & Prakash, 2004). Eventually, the details of the agreement were finalized, including a provision that granted developing economies a ten year transition period, ending in 2005, to comply with the new TRIPS rules.

As the deadline for complete adherence to TRIPS loomed, many developing countries began to raise concerns about the effect of TRIPS, particularly on public health, which were not fully resolved during initial negotiations. Developing country governments brought their concerns to the WTO, buoyed by CSO support, and the TRIPS Council convened on a special session to discuss access to medicines (Baker, 2004). Negotiations eventually resulting in the 'Declaration on the TRIPS Agreement and Public Health,' also known as the Doha Declaration, coming out of the 2001 Doha round of the WTO (Baker, 2004; Drezner, 2005; Sell & Prakash, 2004). The Doha Declaration is meant to support countries in using the pre-established flexibilities in TRIPS such that the agreement minimally impacts health, including underlining a state's ability to invoke compulsory licensing among other mechanisms (Baker, 2004; Ford, 2004). Unfortunately, many countries continue to struggle to take full advantage of these provisions, due in part to the broad legislative reform that must be enacted before countries are able to access all the flexibilities protected by the Doha Declaration (Baker, 2004).

Despite the small victory represented by the Doha Declaration, outside of the WTO, many states, particularly the United States and the European Union, have pursued new bilateral and regional trade agreements that include provisions on IP that are more protective of pharmaceutical patents than TRIPS. These bilateral and multilateral trade agreements are collectively known as "TRIPS+" style agreements and effectively work around the Doha Declaration (Drahos, 2002; Ford, 2004).

### *Access to Medicines (Advocacy in the Field)*

The importance of advocates in the field of Intellectual Property is apparent now more than ever. The current trend of TRIPS+ style agreements means that the fight for access to medicines and medical technologies is intensifying. The commitments in the recently passed Comprehensive Economic and Trade Agreement (CETA) and the current negotiations of the Trans Pacific Partnership Agreement (TPP), both of which build on the standards of patent protection enshrined in TRIPS, highlight the need for organizations advocating against a protectionist IP regimes. While they are not WTO agreements and will not be applied to all countries as nearly universally as TRIPS has been, the TPP and CETA have critics concerned for the health impacts these agreements may pose for their signing partners. For example, by extending rights of patent holders, the CETA, a treaty between Canada and the E.U., has been assessed as potentially costing Canada as much as 2.8 billion dollars annually in increased drug costs (Grootendorst & Hollis, 2011), with current estimates hovering between 850 million and 1.645 billion dollars (Lexchin & Gagnon, 2013). Because of the 'Most Favoured Nation' trading principle, enforced by the WTO, in which a country is not allowed to show preferential treatment to any one trading partner, the IP standards enshrined in bilateral trade agreements like CETA and the TPP can have far-reaching consequences. To continue with the example of Canada and the CETA, the standard of patent protections the CETA grants the E.U. pharmaceutical industry must be equally applied to the pharmaceutical industries of all of Canada's other trading partners, most notably the U.S. pharmaceutical industry.

Because the purchase of medicines can make up the majority of individual health expenditures in some countries, and drain the state's health budget, the cost of medicine is directly connected to whether or not patients are able to access the drugs they require (Ford, 2004). In fact, many critics of TRIPS and TRIPS+ agreements claim these policies harshly limit access to essential medicines in many developing countries (Drezner, 2005; Teegan, Doh, & Vachani, 2004). Ford suggests that in some cases the cost of medicine can be the single determining factor for whether or not a state can afford to treat a particular disease (2004). At the individual level, the high cost of medicines can force patients to choose sub-optimal treatment, take on debt, or receive no treatment

at all (Ford, 2004). As Sell points out, for many advocates of access to medicines “the cost of [the TRIPS] agreement was much steeper than mere dollars, it also was to be paid in human lives.” (Sell, 2001, p.497).

## *Terminology*

Before moving further with this capstone, terminology must be discussed. The focus of this project is on the work of advocates in the field of intellectual property; however, these advocates may be found working in a variety of settings for a variety of organizations. In order to simplify the language, the paper will refer to all organizations for which those advocates are working as ‘civil society.’

In general, a civil society organization (CSO) refers to any social organization that is not a form of family, economic, or government organizations (Follér, 2010; Hoksbergen, 2005; Teegan et al., 2004). This definition can be further refined to exclude for-profit organizations (Bhan, Singh, Upshur, Singer, & Daar, 2007; Hoksbergen, 2005; Teegan et al., 2004). Bhan and colleagues describe ‘civil society’ as an umbrella term for five types of organizations: Non Government Organizations (NGOs); community-based organizations, which are specifically made up of members from a target community; faith-based organizations, the purpose of which is directly influenced or derived from a particular religious orientation; volunteer-based health organizations; and networks of groups or individuals (2007). All these may be labeled as ‘civil society’ and are not limited in the geographic or target area in which they work. Importantly, the distinction is made between CSOs and industry action or lobbyist groups. In this paper, the term CSO is applied to any organization that falls under one of the categories described by Bhan and colleagues.

The common thread for the categories described above lies in how the organization operates (Hoksbergen, 2005; Teegan et al., 2004). Specifically, civil society organizations are based on voluntary membership, oriented toward a common goal or purpose (Hoksbergen, 2005; Teegan et al., 2004). Civil society provides a platform for a variety of actors to come together to mutually own and work towards solving public problems; in many cases, CSOs provide a channel for citizens to become involved in directing the

state (Hoksbergen 2005). As such, partnership is a core tenet of civil society; without it, the collective actions carried out by civil society organizations would not be possible. Naturally, it should follow that the practice of partnership that exists within civil society should be extended to those relationships civil society fosters between organizations.

Civil society organizations operate in nearly every field; however, in health, CSOs typically focus on providing services, social welfare or community development, and are involved in research and advocacy (Bhan et al., 2007; Hoksbergen, 2005; Teegan et al., 2004). Most importantly, CSOs provide an essential interface between healthcare initiatives or Research and Development (R&D) and a target population, helping to ensure relevancy and promote the population's interest (Bhan et al., 2007; Hoksbergen, 2005; Teegan et al., 2004).

### *The Emergence of Global Civil Society*

While the participation of civil society at the global level is not a new phenomenon, prior to World War II its involvement was limited; the United Nations granted civil society organizations the right to a voice after the wartime negotiations and the first consultative status was awarded in 1948 (Howell et al., 2008; Selian, 2004). In the 1990s the rules governing civil society participation were further relaxed and by the mid-2000s roughly 2500 organizations held consultative status with the UN and many more were engaged in similar relationships with other international bodies (Selian, 2004). Unfortunately the September 11, 2001, attacks on the United States resulted in a general increase in states' security measures and a decrease in the ability of civil society to liaise with the state (Howell et al., 2008). During this time, the effectiveness of civil society organizations was called into question, many critics citing the lack of cohesive direction between CSOs, which is nicely summed up by Howell and colleagues as the "cacophony of diverse and sometimes conflicting voices of civil society" (2008, p 83). Since then, while the GCS has reportedly had some success in achieving their goals, a number of scholars remain hesitant in naming GSC as a global force to be reckoned with (Aart Scholte, 2007; Drezner, 2005; Jacobs & Maldonado, 2005).

Beginning in the late 1990s, much research began to focus on how and if GCS affect global policy-making (Drezner, 2005). Previously, CSOs were described simply as national, non-governmental actors, but underwent what Selian describes as the “Third Sector” movement in the early to mid 2000s, wherein CSOs are taking on more duties previously performed by the state (2004). The ultimate goal of this “Third Sector” movement is not a shift in power away from the state, but rather describes the practice of CSOs taking a more active role in policy, acting as a compliment, rather than an alternative, to government institutions (Selian, 2004). The “Third Sector” movement also sees CSO scaling up into the international arena, creating a new breed of global civil society (GSC), which may be made up of actors from a single state, or of trans-national civil society coming together around a common goal (Follér, 2010; Jacobs & Maldonado, 2005; Selian, 2004; Teegan et al., 2004).

The change in the space within which civil society is acting has profound effects on the global political economic scene; civil society has become part of the conversation on globalization, both propagating and reacting to globalization (Teegan et al., 2004). Buoyed by the citizenry’s floundering trust in state institutions, civil society has grown to bridge the gaps and offer a mechanism by which to protect community interests and grow social capital (Teegan et al., 2004). Teegan and colleagues suggest that the globalization of previously domestic social movements is providing the space for these organizations to join and influence global political, economic and business systems (2004). Now, some scholars believe civil society is beginning to influence their own governments, the governments of other states, and global institutions (Teegan et al., 2004).

## Research Design

Though the role played by industry, civil society, and NGOs in the TRIPS negotiations has been well documented (Drahos & Braithwaite, 2001; Sell & Prakash, 2004), less is known about how health advocates have responded to the outcome of the TRIPS negotiation and the effect more rigorous intellectual property rights, enforced by global institutions, have had on the advocacy process . This capstone proposes to investigate how advocates and advocacy groups, including civil society and NGOs, have responded to the change in laws and policies surrounding IPRs, and to draft best practices in this field. Specifically, the capstone is

intended to ascertain if and how advocates in the field of IP and health are navigating new, global intellectual property and patent laws in order to achieve their goals and advocate for health.

The research for this capstone was made up of 5 phases, which are as follows: literature review, key informant interview, data evaluation, construction of recommendations, and dissemination of results. The methods are detailed in brief below.

### *Phase 1: Literature Review*

A literature review was undertaken to better understand the thoughts and opinions expressed in the literature on GCS and what is known about how GCS functions. The purpose of the search was to collect articles or reports describing the nature of interactions between civil society organization and other international actors in promoting their individual agendas in connection with the international patents or the IPR regime initially imposed by the WTO. Reviewing these articles helped to give a broad understanding of the state of the advocacy work in IP related issues and began to solidify types of advocacy approaches.

A search of the range of peer-reviewed works published in English in electronic databases between Jan 1, 1980 to February 2015 was conducted. The databases used in the search were google scholar, MEDLINE, PubMed, and JSTOR. The following search terms were used: “intellectual property” or “patent”, “NGO” or “civil society”, “advocacy”, “health”, and “partner\*.” 5010 results were returned from this search, which were screened for relevancy first by the title, and then by abstract, and finally were screened for rigour through an analysis of the text. Titles were considered relevant if they made some reference to either intellectual property or advocacy. Abstracts were used to determine that the article dealt with the aspects of IP that affect health, and that the article took a global perspective – even if it was a case study. Articles that dealt with advocacy and IP at international institutions were sought in particular. The full texts of the remaining articles were then reviewed, and articles that were focused on the nuances of IP law were eliminated. Additional articles were identified through an examination of the reference lists of the rigorous and highly cited sources. The review was deemed to have reached saturation when the most cited sources had been acquired and new or different advocacy

activities were not being described. In total, thirty-one articles were read in full and analyzed, and the final review is based on twelve relevant articles published between 1993 and 2009.

### *Phase 2: Key informant Interview*

Ethical approval for the study was sought and obtained from Simon Fraser University's Research Ethics Board. Data collection proceeded via semi-structured interview. The interview took approximately 25 – 30 minutes and was done by telephone, recorded, transcribed and scrubbed of identifying information.

### *Phase 3: Data Evaluation*

The strategies found in the literature and key informant interview were summarized, and then evaluated using an iterative thematic analysis. An iterative thematic analysis was chosen, because it allows for a more complex analysis than simply word or phrase frequencies, and seeks to uncover the ideas that shape the data. Thematic analyses allow the context of a phrase or code to be taken into consideration and an iterative process allows the findings to be checked back against the data, thus ensuring all interpretations match the raw data.

Codes were drawn from the literature, based on the researchers' knowledge of the subject, and the themes that were presented developed in the key informant interview. Themes from the literature and key informant interview were constructed from the codes and were evaluated based on how they compared or contrasted with each other.

#### *Phase 4: Construction of Recommendations*

Based on the evaluation, a framework for understanding the trends in intellectual property health advocacy was developed and a set of recommendations, or 'best practices,' were constructed.

#### *Phase 5: Dissemination of Results*

Upon the completion of the study, and the construction of recommendations based on the data analysis, an executive summary was returned to the key informant along with the completed project.

### **Findings**

During the summer of 2014, I was fortunate enough to secure a practicum placement with the Doctors without Borders (MSF) Access Campaign, Delhi Chapter, over the course of which I found the inspiration for this capstone. The Access Campaign contests the political, legal and commercial restrictions that limit medical advancements and patients' access to essential medicines. In India, the Access Campaign office is particularly involved in monitoring patents being approved by the Indian government, which would stop the production of generics medicines that India is known for; because of its strong generics industry, India is considered the 'pharmacy to the developing world,' supplying affordable medications to many developing countries.

India has been, and continues to be, a hotbed of political and advocacy action aimed at curbing the negative effect of IP laws on health. Access to affordable medicines is supported by India's innovative patent laws that restrict the patentability of new drug products; when India implemented its full legal commitments under TRIPS in 2005, it ensured its Patent Act made full use of the flexibilities contained within TRIPS to safeguard public health (Gabble & Kohler, 2014; Kochhar, 2014; Lofgren, 2013). Perhaps the most well known example of the use of TRIPS flexibilities within India's Patent Act is the Section 3(d), which requires medicines to be

proven to represent a marked improvement on their predecessor as a requirement for patenting. These requirements are intended to curb the process of 'evergreening' in which minor modifications are made to drug formulations so they can be re-patented and the drug company's monopoly may be continued (Gabble & Kohler, 2014; Kochhar, 2014; Lofgren, 2013).

Not long before I arrived in India, the legal battle over the patentability of Glivec (imatinab mesylate), a cancer medication produced by Novartis, that spanned nearly from 1994 to 2013, finally came to a close. Gabble and Kohler outline the progression of the case, beginning in 1993, when Novartis developed the precursor to Glivec, imatinib, but did not seek to patent it in India due to India's changing patent regime; in 1997 Novartis developed Glivec and applied to patent the drug in India. Generic companies had already begun to manufacture Glivec in India, but were prohibited from continuing production until the Indian Patent Office could review the application (Gabble & Kohler, 2014). Citing Section 3(d), in 2006 the Indian Patent Office refused to grant a patent for Glivec, which it found did not represent a significant increase in efficacy of the existing drug imatinib (Gabble & Kohler, 2014). Novartis reacted by filing two challenges against the Indian government, appealing the rejection of the patent and disputing Section 3(d), both of which were rejected. The final legal battle was waged in the Indian Supreme Court, where Novartis attempted to contest the legitimacy of the previous rulings. In April, 2013, both rulings were upheld in the Supreme Court's decision (Gabble & Kohler, 2014).

The Indian Patent Office continues to make controversial decisions on the patentability of drugs, and MSF constantly monitors the outcome of patent applications. At the time of my practicum, as part of their work with monitoring patents, MSF was collaborating on a comprehensive document that detailed over a dozen Hepatitis C drug related patents, including the exact mechanism or compound in the patent, and the status of each of the patents at various patent offices around the global south. As I researched the status of these patents in India, I learned that many patents offices will evaluate the decision to grant patents, in part, on whether or not the same patent has been granted in another country. By compiling this information about the Hepatitis C drugs, MSF and their partners were hoping to help local CSOs, in India and elsewhere, advocate against the passing of certain patents by their respective patents office.

I was intrigued by my experience with the Hepatitis C patents, because of the global mobilization that occurred to support domestic goals. Previously, I had assumed that most advocacy work was aimed toward the government of the country in which a CSO resides, or toward the international institutions that govern IP laws. I returned to Simon Fraser University interested in exploring the idea that CSOs might be supporting each other in endeavours that may have no direct impact on their specific community. This capstone represents the culmination of my research into how CSOs work to further their goals, and, more specifically, how organizations are finding novel ways to support the movement's overall agenda.

In order to explore how CSOs work to further their goals, and how partnership plays a role in finding novel ways to support the movement's overall agenda, a literature review strengthened by a key informant interview was undertaken. The literature presented a variety of thoughts on how CSOs operate at the international level, but after a brief analysis of the results of the initial search, it was determined that the field remains relatively young, with most of the papers focused on the events of the initial TRIPS negotiations (1986-1994). The literature was supported with the analysis of themes extracted from the key informant interview. The key informant interview provides both a sense of the current state of health advocacy in IP related issues and a standard against which to compare the tactics described in the literature.

### *Are Global Civil Society Organizations Effective?*

The effectiveness of GCS is important to the discussion of health advocacy in IP related issues, as the GCS framework is currently being employed to advocate for the health interests of populations at international forums (including in IP related issues). Nevertheless, there is no real consensus on the effectiveness of global civil society organizations in the literature; While some scholars seem to have embraced GCS as an agent of policy change (Drahos & Braithwaite, 2001; Helfer, 2009; Matthews, 2006; Sell, 2001; Teegan et al., 2004), others are more hesitant to give complete credit to these organizations (Dany, 2006; Drezner 2005; Dür and De Bièvre, 2007).

While some literature may attribute great successes to the efforts of GCS and others argue the effectiveness has been over-hyped, most agree that GCS is creating some change, though how much, and how permanent is up for debate. Drezner points out two issues with research crediting GCS with overwhelming effectiveness; he argues that alternate explanations for the so-called effects of GCS are not adequately explored, and even when the activities of GCS can be traced to a policy change, the impact of the policy change is overstated (2005). An analysis of the impact of civil society organizations at the World Summit on the Information Society, often held to be a shining example of non-state actors' inclusion on the global stage, concludes that civil society's impact at the Summit was small, mainly because their arguments were ignored by the WSIS, despite organizers having extended CSOs the invitation to participate (Dany, 2006). A common theme, illustrated by the WSIS example, is that non-state actors fail to have much more than minimal effects on policy, even when they have the attention of policy makers (Dür and De Bièvre, 2007). These examples do not serve to say that GCS is having no effect at all, but rather to lend a critical lens to the discussion.

### *What Makes Global Civil Society Organizations Effective - Insider versus Outsider Strategies*

The literature reviewed reports a number of methods used by GSC organizations, which taken together describe a comprehensive framework for engaging in effective advocacy in the field of IP. Though each the methods described by the literature are made up of discrete activities, they must be taken together to support the overall goal of the organization. Edwards suggests that organizations not separate their activities into "advocacy" and "non-advocacy" as such a division fails to account for the informal advocacy in which organizations may engage (1993). Instead, he suggests that advocacy be built into the organization in every facet of its workings (Edwards, 1993). In the spirit of Edwards' 'advocacy in all things' style of organization-building, the methods described in the literature support the creation of what was described previously in this capstone as a 'culture of connection'.

In order to understand these methods outside of the context in which they were employed and discussed in the literature, it is necessary to provide a system of classification. Teegan and colleagues describe GCS practices as being insider or outsider oriented (2004). In the former, the organization works within formal channels to pursue their goal, such as pursuing public private

partnerships, or working directly with policymakers. In the latter category, GCS works outside formal channels to affect public opinion through a variety of means, in order to influence formal decision making (Teegan et al. 2004). The 'insider-outsider' framework gives some cohesion to the activities found in the literature and described by the key informant, and helps to structure the data in this capstone.

### *Insider Communications Strategies*

Regardless of where the author stands on the ability of GCS to influence political actions, there is an overwhelming emphasis on the importance of the dissemination of information by civil society, within and beyond their own networks. In fact, GCS groups are essentially a network of information exchange. The overall effectiveness of GCS relates to how dense their networks are and the "voluntary, reciprocal and horizontal... communication" (p.6) that occurs between each level, or node, of the network (Drezner, 2005). When information is shared with the appropriate node, it may then be leveraged in order to best advocate for health.

Insider communications strategies require the sharing of information with policymakers or those who are otherwise poised to make key decisions about IP in government or international multilateral institutions. Just as is the case for communications within GCS networks, communication between GCS and key policy actors must be reciprocal. Of course, the nature of the institutions that deal with IP standard setting post-TRIPS, necessitate a different approach than what could have previously been taken when governments had autonomy over their IP laws.

Importantly, though CSOs are increasingly invited to participate in international forums, Matthews notes that many groups miss out on important opportunities to promote their agendas by not taking full advantage of the techniques which promote effective communication with delegates (2006). Matthews includes raising awareness of policy issues among delegates, holding seminars to help orient incoming delegates, and maintaining an open dialogue for the transfer of ideas between GCS and delegates as the most effective communications techniques GCS is using at international forums. The importance of open lines of communication between

GCS and delegates cannot be overstated; close contact helps facilitate the movement of ideas between the two parties and can allow GCS some insight into the awareness and orientation of delegates on policy issues (Matthews, 2006).

The best recognized example of GCS organizations using insider communications activities is the way in which developing country governments and delegates shared information with GCS during the TRIPS negotiations. GCS organizations brought their concerns about TRIPS to the attention of governments, particularly those of developing countries who held similar concerns, which lead to increased support for the inclusion of certain flexibilities within TRIPS, intended to protect developing countries' ability to meet the health needs of their citizen (Baker, 2004).

As was discussed previously, nearly a decade after the TRIPS experience, civil society and developing governments once again pressed for flexibilities under TRIPS, resulting in the creation of the 2001 Declaration on the TRIPS Agreement and Public Health, which recognizes countries' right to protect access to essential drugs and, in so doing, protect the health of their citizens (Baker, 2004; Drezner, 2005; Sell & Prakash, 2004). The communications activities the GCS employed were crucial to advocating for health, allowing organizations to leverage their policy concerns and promote their agendas.

The examples of insider communications found in the literature were supported by the key informant interview, reinforcing the importance of such activities in post-TRIPS health advocacy. Specifically, the key informant interview cited the ability of different organizations to network successfully with different governments and officials at international forums as a benefit of building relationships and working with other organizations. Furthermore, the key informant suggested that community partners can be successfully involved in raising awareness to policy makers through insider techniques, such as acting as petitioners of patent oppositions. The connection drawn by the key informant between insider communications activities and relationship-building reinforces why advocacy activities must be understood to be a part of every aspect of GCS, rather than distinct one part of facet of an organization.

## *Outsider Communications Strategies*

Communications strategies that take place outside of official policy channels have also proven to be important to advocating for health from non-profit oriented perspectives. Most communications activities described in the literature that could fall under the category of ‘outsider’ strategies cover some type of public awareness campaign, from newsletters, petitions, public conferences, hearings, consultations and letter writing campaigns, to hosting campaign websites, blogs, list-serves, and other social media strategies (Drezner, 2005; Matthews, 2006; Sell & Prakash, 2004; Teegan et al., 2004). In general, the literature mentioned a few of these types of activities by name, but did not explore them in any great detail, because they consisted of familiar techniques that were very context driven. Drezner highlights why such communications tactics are important in his analysis of the mechanisms by which GCS affected TRIPS; by engaging in outsider communications activities, GCS raised public awareness of TRIPS in developed countries and promoted public pressure on governments. Not only did these communications activities spread awareness, but they also provided an alternate framing of IP issues to the link between patents and economic growth, which had been the dominant frame until then (Sell & Prakash, 2004).

The key informant interview suggested that the majority of the communications work that particular organization is involved in falls into the category of “outsider communications.” Highlighting letter writing campaigns and public demonstrations as two outsider communications strategies integral to their work, the key informant acknowledged the importance of engaging with allies outside the CSO. Most often, these allies come from the communities which the organization seeks to represent. As the key informant stated:

*All of us, all civil society organizations, are quite willing to fight battles [through] media, by writing papers, [and] by writing letters to ministry, but when it comes to getting down on [the] road and protesting, really showing anger to the government and catch[ing] their attention instantly, it's the [community].*

Such an acknowledgement underscores how community involvement can effectively raise awareness of an issue, and that many community members are more than willing to engage in public action and help direct social movements. Engaging with ideas from the community and the value of the knowledge and lived experience of community members to the advocacy efforts of the organization was emphasized by the key informant. During the interview it was noted that capacity building should be balanced with learning from the community during community-organization interactions. In fact, the organization of which the key informant is a member has a strong orientation toward community engagement, including taking on projects that are a priority for the community, but may not align directly with the goal of the organization. In this case, it was made clear that it is important to have flexible goals, or a broad understanding of what constitutes success.

### *Gathering Information for Outsider Communications*

While organizations may engage in raising awareness about the general issues stringent IPRs represent, having stories of specific negative health outcomes or other infringements of IP on health may help to engage the public. For this reason, the literature makes note of organizations taking on the role of a watchdog, wherein the actions of government and non-government stakeholders are monitored (Drezner, 2005; Sell, 2001; Teegan et al., 2004). Data from the key informant interview suggest that many “watchdog” activities are employed by organizations; much work is being done to monitor governments’ actions and interpret which direction policy changes may take. Areas of particular interest are policy changes that are expected to have a large impact on the community. The key informant interview pointed in particular to activities associated with keeping track of how governments of developing countries may attempt to placate larger countries in a bid to gain a better international standing.

In order to secure an effective channel for communicating with the public and raising public awareness, the key interview recounts engaging with journalists. Opening GCS networks to include journalists involves forming a stable relationship with journalists in which stories and articles are being published on a regular basis. The benefits of such an arrangement with journalists

include promoting awareness, increasing the number of voices calling out those actors championing protectionist IP policies, and stopping the GCS from appearing overly critical of governments or powerful stakeholders.

### *Relationship-Based Insider Strategies*

The majority of communications activities described in the literature and key informant interview were linked in some way to specific interpersonal interactions. As is emphasized by the successes in communication described in the previous section, building relationships outside of one's organization can facilitate the advocacy process. In the field of IP health advocacy, "insider" relationship-based strategies involve building relationships with key allies who work within the government or multinational institutions that have the power to affect IP related policy change.

Matthews provides a discussion of relationship building between GCS actors and delegates to international institutions. He describes strategies that emphasize building lasting, stable relationships, though he does note that many short-term, issue specific relationships may be advantageous for GCS and delegates (2006). These interactions are based on trust and availability, which Matthews refers to as 'timing' (2006). As such, being 'available' to delegates and maintaining regular and consistent contact with policymakers makes CSOs with offices in major international cities, like Geneva, more successful (Matthews, 2006). The key informant was silent on the practical functioning of relationships with policymakers; however, as mentioned previously, the key informant did suggest that an organization's established relationships with policymakers makes it more attractive as a potential partner to other CSOs.

Matthews further describes partnership activities present at international forums between members of multiple GCS organizations (2006). Primarily Matthews outlines the creation of networks of like-minded organizations that are working to present a united front at international forums; however, he acknowledges that many of these networks still do not agree on their position on key issues, which detracts from their overall effectiveness as networks (2006). Aside from formalized networks, a set calendar of formal meetings open to all CSOs working in IP represents another form of partnership between GCS organizations (Matthews, 2006). These meetings do

not require the participants to agree on key issues, but allow the division of activities to be settled in order to avoid duplications. Unfortunately, Matthews cites the focus of donors on tangible outcomes as a factor that is edging out the possibility of such activities by strictly directing funds (Matthews, 2006).

### *Relationship-Based Outsider Strategies*

Communications activities are facilitated by what the literature stressed as an important facet of GCS mechanics – partnerships. Successful advocacy is based on building connections with both the community and other CSOs with similar organizational goals: activities that fall under the category of relationship-based outsider strategies. Such strategies involve activities that build relationships with partners who are not part of an institution that directs IP policy. These “outsider” relationships include those formed with other CSOs and those formed between an organization and community members or community groups.

The literature uses both “network” and “coalition” to describe relationships that are pursued and maintained between organizations. While in some cases the literature used the term “network” to describe what was effectively a coalition, these terms are not entirely interchangeable. A coalition refers to a network in which each member has close links to each other member; a network of organizations may not have connections between each node, and some organizations may only be indirectly connected.

In order to achieve strong networks and coalitions, an organizational commitment to relationship building between individual members is essential. Members’ individual advocacy networks with individuals outside of other organizations must be promoted and networking facilitated. The key informant highlighted that successful long term work relationships are supported, at least at first, by the organization; the organization provides the venue for individual networking through work events or institutional connections. The data from the interview suggest the development of personal contacts occurs mainly via meetings at field-specific events like conferences, demonstrations, or seminars. Furthermore, the deinstitutionalization of power imbalances that formal networking

processes may promote, by creating multiple points of partnership between individual members of power-imbalanced organizations, underlines the significance of an organizational culture which supports individual networking.

Moreover, data from the interview suggest that short-term, issue specific relationships are flourishing between domestic CSOs. These relationships do not require as much commitment as entering into networks or coalitions, but are more dependent on crises or major policy events. While issue specific relationships may be prompted by major field-specific events, the instability of such relationships may lead organizations to drift apart unless there is a specific issue on which they may focus their attentions. Such outside events, like pressure from a larger government on a smaller one, may influence the work dynamic of the organizations; the interview data suggest that organizations that have drifted apart to work in their own areas may come together during perceived times of crisis. The key informant was quick to denounce the trend of CSOs focusing on work in separate 'silo's', rather than working together. Siloing may be related to the sense of competition between organizations, despite apparently working towards the same goals and not competing for funding. In order to counteract prevent slipping into separate silos, organizations must make specific efforts to work in tandem with other CSOs. Fortunately, the data suggest that much is done to coordinate with other organizations domestically to streamline efforts. There is an understanding that in order to have a lasting, long-term policy impact, there must be a unified effort to create change.

Streamlining efforts by way of dense networks of interaction, or coalitions, helps to facilitate organizations working in tandem, amplifying the effectiveness of activities, and eliminating some overlap in efforts. Brown and Fox evaluate eight cases of GCS campaigns, specifically those seeking to influence World Bank policies, highlighting the strengths and weaknesses of GCS coalitions (2001). They propose that through coalitions small, local organizations may create a global impact. This greater range of influence, according to Brown and Fox, is based on the ability of separate actors to “[bridge]... differences, [understand] their institutional targets, and [learn] from both failure and success” (p.56, 2001). Unfortunately, successful coalitions that include partnerships between organizations of unequal size or funding are difficult to achieve. In particular, North-South partnerships have been deemed particularly problematic (Edwards, 1993; Hoksbergen, 2005; Matthews, 2006). North-South partnerships are made difficult due to the

emphasis on the flow of Northern funding to the Southern partner, as well as the pressure on the Southern partner to accept capacity building as a condition of said funding (Hoksbergen, 2005).

Hoksbergen provides an analysis of the issues plaguing North-South civil society partnerships and suggests a framework for the promotion of “authentic partnerships” (2005). In order to overcome the aforementioned obstacles, Hoksbergen suggests a deeply contextually relevant partnership model. A focus on equality in the relationship, which is supported by “[making] covenants, not contracts” (P. 23), equally supporting each partner’s vision, and constantly evaluating the status of the relationship make up the gist of Hoksbergen’s suggestions (2005). Successful partnership allows GCS groups to work more effectively, transfer resources from North to South, transfer knowledge between North and South, and open new donor networks to Southern NGOs, all of which leads to the presentation of a stronger, united front at the global level. Hoksbergen presents twelve facets that characterize an “authentic” North-South partnership, focusing on factors that influence the equality of the relationship (2005).

### *New Trends Identified by Key Informant – Language of Struggle*

The key informant interview highlighted an interesting trend which had not been described in the literature. Throughout the interview, the key informant repeatedly related organizational activities to battles or struggles. Organizations or causes were described as being ‘attacked’, and several references were made to fighting and winning battles or winning wars. More moderate language included references to anger, passion, intensity, barriers, hindrances, and opposition. This is suggestive of a feeling of persecution, and an “us versus them” mentality. This language manifests itself in some of the ways in which organizations may interact with each other and with those seen as their opponents. For example, the key informant specifically pointed out that a benefit of coordinating work with other organizations is that networks may protect any one organization from being singled out and harassed by those with power. This is similar for the justification that was given for working with journalists – that pressure could be applied to policy makers from multiple sources, stopping any one source from appearing excessively critical.

Furthermore, the key informant suggested that there are at least some instances of organizations choosing to work independently, and even in competition with one another, despite having little reason to compete. Given the language of struggle that emerged from the data, it is important that organizations do not let this sense of struggle turn inwards, and work to ensure that it does not unintentionally affect working relationships.

## Discussion

Based on the literature and key informant interview, it became clear that effective advocates are working to increase the density of their insider and outsider networks as much as possible. Denser networks facilitate better communication and partnerships, and, if actions meant to grow network density are made a core focus of organizational growth, result in an organizational 'culture of connection'. Because the literature and key informant placed so much emphasis on what was being done, through communication or partnership, to increase network activity, I found it useful to review the "insider/outsider" dichotomy initially proposed by Teegan and colleagues (2004). While this distinction provides a good starting point for understanding the documented tactics used by advocates in the field of intellectual property rights, I propose that the tactics may also be split into either communications-based, or relationship-based categories. The communications category deals with the movement of information between people, communities, organizations, or nodes of a network, and can be both insider and outsider tactics. Relationship-based tactics deal with interpersonal, inter-organizational, or inter-network activities that facilitate or support the goals of the members of the relationship; these activities may also be considered insider and outsider techniques. Activities may contain both components of communications and relationship building; however, the context will determine whether communications activities or relational activities are emphasized.

A change in the framing of organizational activities matters because in a practical sense, many CSOs do not interact directly with policymaking institutions or through formal channels, as is the nature of "insider" advocacy activities, thus eliminating an entire branch of potential advocacy work. Since recognizing the advocacy potential in all organizational activities helps to ensure no

possibility for advocacy is overlooked, any framework which automatically discounts an organization from taking part in half of its activities leaves something to be desired. For example, there is some data in the key informant interview to suggest that some of the insider tactics the literature suggested for relationship building at multinational institutions, specifically the proximity of partners and flow of information which leads to stable relationships, may also be valuable for relationship building between GCS organizations. A communication-relationship framework creates a more holistic and accessible picture of activities in which organizations may take part.

### *Growing a Culture of Connection*

Given the data collected from the literature review and the key informant interview, activities that grow a 'culture of connection' become vital to the advocacy process. As suggested in the communications/relationship-building framework I have proposed, the main objective of a 'culture of connection' is growing a strong network of advocacy with a variety of key stakeholders. The literature suggests that while forming inter-organizational networks is necessary to achieving success (Brown & Fox, 2006; Edwards, 1993; Hoksbergen, 2005); growing as a CSO includes maintaining a link with the social movements from which the organization may have originated and the communities they aim to represent (Matthews, 2006; Sell & Prakash, 2004; Teegan et al., 2004). The data from the key informant interview reinforces that communities are integral to achieving success, and in some instances may, in fact, define what constitutes success. A close relationship with the community further ensures that the work being done by the CSO is in the best interest of the community they represent, and that there is a broad base of support for awareness activities or public action. While community engagement may not help an organization interact with delegates at international institutions, a strong community base will help inform the direction an organization should take when at a cross-roads. In order to best ground action in community context, a connection with the community should be fostered.

Whether it is at international multilateral institutions or within the communities an organization seeks to represent, the data suggest that supporting individuals in growing their contacts is essential to growing a dense network of advocacy and successfully

promoting an organizations agenda. The key informant describes the development of an individual's set of professional contacts over the course of a career; established professionals may bring their own set of contacts to an organization when they move into a new position. Unfortunately, the network remains somewhat closed to individuals unless they are backed by experience or a parent organization. Therefore, it is essential that managers foster a culture of connection. Ensuring members of the organization participate in field-specific events such as conferences or seminars, even less formal events such as public demonstrations, will ultimately help strengthen local and global organizational networks.

As the IPR debate is rekindled by agreements like the CETA ad the TPP, advocates must do all in their power to promote health and reframe the IPR discussion. The origins of the GCS in public movements, the connections with communities, international networks, and key contacts in government and international multilateral institutions position GCS organizations as a valuable method for representing alternative viewpoints and advocating for health over profits. Strengthening connections with policymakers, other CSOs, and the community will best position GCS to be successful in their objectives.

## **Ways Forward**

Future research should be aimed at expanding on the communicational-relational dichotomy I have highlighted in this capstone and exploring of how to best foster a culture of connection. The data that was gathered from the key informant in this capstone was incredibly rich, supporting an initial exploration of the practices employed by advocates working in the field of intellectual property, and future research should aim to collect more data from other key informants. Concrete activities that support networking and sharing should be investigated, including whether pursuing formal networking practices, such as sponsoring employees to attend conferences, or informal practices, such as creating manager training that highlights the importance of developing contacts, is more effective in promoting the advancement of advocacy in an organization focused on intellectual property issues.

## Critical Reflection

The inspiration from this capstone grew from the time I spent with the Access Campaign in India, and I found that many of the lessons I learned about public health practice during that time were also applicable to the capstone process. In practice, I strive to approach all situations with an open mind, and non-judgemental attitude; however, I accept that the environment in which I reside, and that in which I was brought up both affect my perceptions and outlook in imperceptible, but powerful, ways. As such, I realize I came to the capstone with some preconceived notions about how it should proceed and what should come of it. Beginning the capstone, I had hoped to realize a fully developed set of concrete recommendations about advocacy in the field of IP and health. As the capstone progressed, I realized that my idea of how the research would happen did not match the reality of how it was developing. In particular, the differences between my context and that of my key informant presented barriers that I was surprised to encounter.

I feel that navigating research in which I was physically on the opposite side of the globe from participants represented a number of barriers to the progress of this capstone. While increasing access to communications technologies makes sharing information across time-zones and contexts easier, certain barriers still remain. Taking a cue from the findings of this capstone, the “partnership” between me and my key informant suffered because of my low availability; being removed geographically presented issues with maintaining consistent contact through in-person meetings, and institutional requirements, such as the consent process, presented issues with regular electronic communications. These barriers added a layer of complexity to the research, which I had difficulty navigating.

The nature of the day-to-day mechanics of working in advocacy is inherently at odds with the nature of the institutional requirements of this capstone. During my practicum experience, I was impressed by the sheer amount of work a small number of advocates were able to complete; however, the workload of each member of the team results in the streamlining of institutional protocols out of necessity. For example, extraneous forms are limited and signed only once; verbal agreements tend to be the

currency of working relationships. Furthermore, the priority of tasks is constantly being reordered and if a major project bumps a smaller one, it may take some time or creative scheduling to complete them both. I felt that the institutional requirements by which I had to abide were not congruent with this style of work. For example, the ethics I obtained prohibited me from 1) contacting my participants directly, unless I had been invited to do so, 2) following up more than once every fourteen days and 3) following up more than two times. Restricting the flow of communication between me and my informants, seemed to slow the progress of the capstone and curb the breadth of informants I was able to access. I may not have represented a heavyweight in terms of the power relationship, but my backing institution certainly did, and as such, the consent process placed an undue burden on the interview.

My experience with this capstone is not meant to show that consent should not be sought. However, the consent procedure I was required to follow seemed to come from a place of Western thinking that expects all institutions and people to follow a linear, bureaucratic model of operation. Here, forms are the light to the often complex and somewhat redundant path of institutional permissions. In this case, I felt requiring my interviewees to sign consent forms and adhere to the snowball sampling protocol for which I was approved, was in a sense forcing them to submit to Western institutional bureaucracy and therefore putting them at a power disadvantage. The way in which the consent process proceeded felt inconsiderate to my interviewee; while they understood the need for ethical research and obtaining consent, if they did not comply with our bureaucratic standards, they were barred from participation.

In the future, I would change the consent process that I used in order to be less intrusive, if possible. Certainly all research is a tricky procedure, and the ethics we follow as researchers are put in place to minimize the potential negative impacts of the research. We must, however, be mindful of whose definition of minimal impact is being used, and what following institutional policies can mean for participants in practice.

## References

Baker, B. K. (2003). Arthritic flexibilities for accessing medicines: Analysis of WTO action regarding paragraph 6 of the Doha Declaration on the TRIPS agreement and public health. *Ind. Int'l & Comp. L. Rev.*, 14, 613-715.

Bhan, A., Singh, J. A., Upshur, R. E., Singer, P. A., & Daar, A. S. (2007). Grand challenges in global health: engaging civil society organizations in biomedical research in developing countries. *PLoS medicine*, 4(9), e272.

Brown, L.D., Fox, J. (2001). "Transnational Civil Society Coalitions and the World Bank: Lessons from Project and Policy Influence Campaigns," in Michael Edwards and John Gaventa, eds., *Global Citizen Action*, Boulder: Lynne Rienner Press

Dany, C. (2006). The impact of participation: how civil society organizations contribute to the democratic quality of the UN world summit on the information society. *TranState working papers*, 43.

Drahos, P., Braithwaite, J. (2001). Intellectual property, corporate strategy, globalization: TRIPS in context. *Wisconsin International Law Journal*, 20(3): 451-80.

Drahos, P. (2002). Developing Countries and International Intellectual Property Standard-Setting. *Journal of World Intellectual Property*, 5(5): 765-89.

- Drezner D.W. (2005) Gauging the power of global civil society: Intellectual property and public health. In *annual meeting of the American Political Science Association, Marriott Wardman Park, Omni Shoreham, Washington Hilton, Washington, DC.*
- Dür, A., & De Bièvre, D. (2007) Inclusion without Influence? NGOs in European Trade Policy. *Journal of Public Policy* 27(1):79-101
- Edwards, M. (1993). 'Does the doormat influence the boot?': critical thoughts on UK NGOs and international advocacy. *Development in Practice*, 3(3), 163-175.
- Follér, M. L. (2010). Civil society organizations and Brazilian South-South AIDS cooperation. *The global south*, 4(1), 199-218.
- Ford, N. (2004). Patents, access to medicines and the role of non-governmental organizations. *Journal of Generic Medicines: The Business Journal for the Generic Medicines Sector* 1(2): 137-45.
- Gabble, R., & Kohler, J. C. (2014). To patent or not to patent?'the case of Novartis' cancer drug Glivec in India. *Glob Health*, 10(3), 1-6.
- Grootendorst, P., & Hollis, A. (2011). The 2011 Canada-European Union Comprehensive Economic and Trade Agreement: an economic impact assessment of the EU's proposed pharmaceutical intellectual property provisions. *Journal of Generic Medicines: The Business Journal for the Generic Medicines Sector*, 8(2), 81-103.

- Hoksbergen, R. (2005). Building civil society through partnership: lessons from a case study of the Christian Reformed World Relief Committee. *Development in Practice*, 15(1), 16-27.
- Howell, J., Ishkanian, A., Obadare, E., Seckinelgin, H., & Glasius, M. (2008). The backlash against civil society in the wake of the Long War on Terror. *Development in practice*, 18(1), 82-93.
- Jacobs, J. E., & Maldonado, M. (2005). Civil society in Argentina: opportunities and challenges for national and transnational organisation. *Journal of Latin American Studies*, 37(01), 141-172.
- Kapczynski, A. (2008). The access to knowledge mobilization and the new politics of intellectual property. *Yale Law Journal*, 117: 804-85.
- Kochhar, R. (2014). Indian pharmaceutical industry: policies, achievements and challenges. *Current Science*, 106(10), 1345-47.
- Lexchin, J., & Gagnon, M. A. (October 2013). CETA and pharmaceuticals: impact of the trade agreement between Europe and Canada on the costs of patented drugs. *CPPA, Briefing Paper*, 1-6. Retrieved From:  
<https://www.policyalternatives.ca/publications/reports/ceta-and-pharmaceuticals>
- Lofgren, H. (2013). Novartis vs. the government of India: patents and public health. *East Asia forum*, Retrieved From:  
<http://dro.deakin.edu.au/view/DU:30059363>

Lunsford T., Lunsford B. (1995). The research Sample, Part I: Sampling. *JPO (7) 3*: 105-112

Matthews, D. (2006). NGOs, intellectual property rights and multilateral institutions. Retrieved from: <http://www.ipngos.org/Report/IP-NGOs%20final%20report%20December%202006.pdf>

Orr, S & Menzies, J. (2012). Using social networks and the Guanxi in case study research on Australian firms doing business in China. *Australasian journal of market & social research*, 20(1): 22-33

Selian, A. N. (2004). The World Summit on the Information Society and civil society participation. *The Information Society*, 20(3), 201-215.

Sell, S. K. (2009, September). Cat and Mouse: Forum-Shifting in the Battle over Intellectual Property Enforcement. In *American Political Science Association Meeting* (pp. 3-6).

Sell, S. K. (2001). TRIPS and the Access to Medicines Campaign. *Wis. Int'l LJ*, 20, 481.

Sell, K, Prakash, A. 2004. Using Ideas Strategically: The Contest Between Business and NGO Networks in Intellectual Property Rights. *International Studies Quarterly*, 8 (1): 143-75.

Teegen, H., Doh, J. P., & Vachani, S. (2004). The importance of nongovernmental organizations (NGOs) in global governance and value creation: An international business research agenda. *Journal of International Business Studies*, 35(6), 463-483

Wise, J. (2014). Patent wars: affordable medicines versus intellectual property rights. *BMJ*, 348.

## Appendix A.

### Codes

	Insider	Sources	Outsider	Sources
Communications	Raise Awareness <ul style="list-style-type: none"> <li>- Raise policy awareness</li> <li>- Focus attention on issue</li> <li>- Make statements to delegates during forum meetings</li> <li>- Leverage policy concerns</li> <li>- Leverage crises</li> </ul>	Matthews, 2006; Sell & Prakash, 2004	Raise Awareness <ul style="list-style-type: none"> <li>- Hold public conferences</li> <li>- Newsletters</li> <li>- Involve media</li> <li>- Internet posts</li> <li>- Write open letters</li> <li>- Petitions</li> <li>- Awareness events</li> <li>- Citizen tribunals</li> <li>- Community participation/information exchange</li> <li>- Public consultations</li> <li>- Public hearings</li> <li>- Boycotts</li> <li>- List servers</li> <li>- ICT use</li> <li>- Campaign websites</li> </ul>	Matthews, 2006; Drezner, 2005; Sell & Prakash, 2004; Teegan et al., 2004
	Facilitate Information Consistency <ul style="list-style-type: none"> <li>- Inform new delegates</li> <li>- Hold meetings to share information</li> <li>- Hold seminars to share information</li> </ul>	Matthews, 2006		
	Open communication with Policy Makers <ul style="list-style-type: none"> <li>- Share information, but also accept information to reorient themselves</li> <li>- Take delegate position into account to make their own activities more efficient and effective</li> </ul>	Matthews, 2006	Conduct research <ul style="list-style-type: none"> <li>- Provide an alternate source of information</li> <li>- Begin research in neglected areas</li> </ul>	Drezner, 2005; Teegan et al., 2004
			Watchdog <ul style="list-style-type: none"> <li>- Monitor and expose actions or inactions</li> </ul>	Teegan et al., 2004; Drezner, 2005; Sell,

	<ul style="list-style-type: none"> <li>- Be responsive to information needs of delegate.</li> </ul>			2001
Communications – Relationship, context dependent.	<p>Regime Shifting</p> <ul style="list-style-type: none"> <li>- Bring issue to International from domestic</li> <li>- Move issue to alternate forum</li> <li>- Pursue issue simultaneously in multiple forums</li> <li>- Pursue a precedent</li> </ul>	<p>Helper, 2009; Sell, 2009</p>		
	<p>Lobbying</p> <ul style="list-style-type: none"> <li>- Support Patent offices</li> <li>- Influence government officials</li> </ul>	<p>Sell &amp; Prakash, 2004; Drahos &amp; Braithwaite, 2001</p>		
	<p>Providing Expertise</p> <ul style="list-style-type: none"> <li>- Technical expertise</li> <li>- Legal expertise</li> <li>- Academic expertise</li> <li>- Enhance and support delegate’s ability to negotiate</li> <li>- Strengthen relationship with developing country</li> </ul>	<p>Matthews, 2006; Drezner, 2005; Teegan et al., 2004</p>		

Relationship	<p>Maintaining Stable Relationships</p> <ul style="list-style-type: none"> <li>- Trust</li> <li>- Engage with established relationship <ul style="list-style-type: none"> <li>o Personal contacts</li> <li>o Long-term relationships</li> </ul> </li> <li>- Engage with positive relationship</li> <li>- Permanent representation of GCS in the relationship</li> <li>- Interact with delegates in formal settings</li> <li>- Interact with delegates in informal settings</li> <li>- Engage on a regular basis <ul style="list-style-type: none"> <li>o In person is best</li> <li>o Forums with no fixed location require regular correspondence/briefings between GCS and delegates in lieu of in person contact.</li> </ul> </li> </ul>	Matthews, 2006	Public Action	<ul style="list-style-type: none"> <li>- Demonstrations/marches</li> <li>- Community based research</li> <li>- Generate social movements</li> </ul>	Matthews, 2006; Sell & Prakash, 2004; Teegan et al., 2004
	<p>Temporary relationships</p> <ul style="list-style-type: none"> <li>- Focus on one pressing issue</li> <li>- Specific to that issue and may not interact outside of it</li> </ul>	Matthews, 2006	Coalitions and networks	<p>Within organization</p> <ul style="list-style-type: none"> <li>- Common vision</li> <li>- Clear goals</li> <li>- Complementary strengths</li> <li>- Equal/equitable size</li> <li>- Similar character of organizations</li> <li>- All organizations prioritize same stakeholders' opinions</li> <li>- Share responsibility</li> <li>- Share accountability</li> <li>- Share decision-making</li> <li>- Transparent communication</li> <li>- Pre-determined (constructive) conflict-resolution</li> <li>- Compromise</li> <li>- Environment of learning</li> <li>- Cross-dissemination of ideas</li> <li>- Understand and agree on future of partnership</li> </ul>	Hoksbergen, 2005
	<p>Relationship with Other GCS Actors</p> <ul style="list-style-type: none"> <li>- Work in tandem <ul style="list-style-type: none"> <li>o Joint work</li> </ul> </li> <li>- Avoid duplication</li> </ul>	Matthews, 2006		<p>Organizational targets</p> <ul style="list-style-type: none"> <li>- Ensure campaign is appropriate for target</li> <li>- Engage with intra-institutional</li> </ul>	Matthews, 2006; Brown & Fox, 2001

	<ul style="list-style-type: none"> <li>○ Coordination meetings</li> <li>- Division of activities</li> </ul>			<p>relationships</p> <ul style="list-style-type: none"> <li>- Broaden acceptable measures of success</li> <li>- Open up field for other stakeholders (ex: long-term institutional change)</li> <li>- Ensure to specify who the organization is accountable to</li> <li>- Invest in “broad social base”</li> <li>- “foster horizontal connections” to “enable credible local voices”</li> <li>- Invest in building trust/relationships across power gaps</li> <li>- Mutual influence and trust facilitates unified responses</li> </ul> <p>Coordinate with other CSOs</p> <ul style="list-style-type: none"> <li>- Work in tandem <ul style="list-style-type: none"> <li>○ Joint work</li> </ul> </li> <li>- Avoid duplication <ul style="list-style-type: none"> <li>○ Coordination meetings</li> <li>○ Division of activities</li> </ul> </li> </ul>	
	<p>Public Private Partnerships</p> <ul style="list-style-type: none"> <li>- Often used as a way to influence the R&amp;D agenda within industry.</li> </ul>	<p>Matthews, 2006</p>	<p>Individual relationships</p> <ul style="list-style-type: none"> <li>- Individuals may play key roles in bridge building, support individual connections</li> <li>- “Policy entrepreneurs” – key individuals who shape overall strategy</li> <li>- Advocacy work may proceed as informal chats</li> <li>- Individuals engage in informal advocacy</li> </ul>		<p>Sell &amp; Prakash, 2004; Brown &amp; Fox, 2001; Edwards, 1993</p>