

# Western Public Health Casebook 2019

## *Cases from the Schulich Interfaculty Program in Public Health*

*Editors*

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# PREFACE

## INTRODUCTION

The Master of Public Health Program (MPH) at Western University is a 12 month full-time program that incorporates a 12-week practicum. The MPH Program curriculum includes innovations such as case-method learning, Brown Bag seminars, Integrative Workshops, field trips and career counselling. The Brown Bag seminars allow the students to hear from, interact and network with practitioners from the field. The faculty of the MPH Program are drawn from various Faculties across campus, and represent a broad range of disciplines pertinent to public health.

## TEACHING CASES

Western's MPH Program relies extensively on the case based/experiential method of learning. The Program aims to deliver 60% of pedagogic material using the case-based approach – a unique feature not found in other MPH Programs worldwide. The case method of learning is not about the traditional lecture-style classroom setting, but is about the student being an active part of the learning experience, which means learning by doing. It introduces complex and often ambiguous real-world scenarios into the classroom, forcing students to think and make decisions sometimes with incomplete and inaccurate data.

The case method is a three-stage process that builds on each subsequent step. It starts with individual case preparation, followed by a small group discussion, concluding with a large group discussion (in the classroom) so that the learning objectives are met. To facilitate this process, all students are placed in a learning team of 5-6 members from Day 1 of their journey in the Program. The learning team forms the 'home' of the student for the academic year, and is the basis for peer-support, group and case work.

We view the case method as a vehicle to develop transformational learning, along with the students' leadership skills, teamwork ability, critical thinking capacity, and knowledge of disciplinary perspectives. However, case-based pedagogy has been predominantly focused on business cases, which are often not directly suitable for a public health curriculum. In addition, existing health related cases often do not reflect the reality of Canadian and international health systems. While case repositories have a growing number of teaching cases that can be used by programs such as ours, there remains an opportunity for Western's faculty and practitioner colleagues to develop de novo cases by building on their research and practice experiences.

Along with faculty developed cases, Western has adopted an innovative model of building a catalogue of teaching cases in public health authored by students. As part of the MPH Program's Integrative Learning Experience (capstone course), the overall final deliverable for students is a teaching case and teaching note that is based on their Applied Practice Experience (practicum). Faculty members select the best cases, and work with the students to publish them in the annual **Western Public Health Casebook**. Our faculty have actively incorporated these student cases in the curriculum, and we often involve the students (now alumni) in co-teaching these cases.

## WESTERN PUBLIC HEALTH CASEBOOK 2019

It is my pleasure to welcome you to this year's **Western Public Health Casebook**. Herein you will find teaching cases authored by students, faculty members, and community partners. Cases are also available for download at <https://www.schulich.uwo.ca/publichealth/cases/>. Our goal is

to create a searchable database of freely available public health cases on our website, for use by any program across the world. We welcome feedback and comments on these cases. To do this, please be in touch via the program's email: [publichealth@schulich.uwo.ca](mailto:publichealth@schulich.uwo.ca).

*–Dr. Amardeep Thind, Director  
Schulich Interfaculty Program in Public Health*

## ACKNOWLEDGEMENTS

The 2019 Western Public Health Casebook reflects the diversity in, and challenges of public health practice. Each case offers a unique take on a complex public health issue. Our cases go beyond describing the problem; the cases present a narrative around decision makers and stakeholders who are experiencing these challenges firsthand. Readers are encouraged to ‘step into the shoes’ of the protagonist (be they an individual, or a group), and think critically about the complexity and nuances inherent in public health practice. There are no right or wrong answers to each case. In fact, we believe it is the best cases that leave you with more questions than answers. We hope these cases make you think about challenges and better yet, allow you the opportunity to brainstorm meaningful solutions to today’s most challenging issues.

We would like to express our gratitude to the following organizations (and the preceptors/supervisors) who supported the training of our students and the development of the cases in this Casebook: Bruyère Research Institute, Pan American Health Organization (Washington), RESULTS Canada, Niagara Health, Heart and Stroke Foundation of Canada, Aga Khan Foundation Canada, National Institute for Health and Welfare, Learning Disabilities Association of Sudbury, Public Health Agency of Canada, Centre for Addiction and Mental Health (Toronto).

We would also like to thank Dr. Michel Deilgat, Medical Advisor with the Centre for Food-borne, Environmental and Zoonotic Infectious Diseases at the Public Health Agency of Canada. Dr. Deilgat has been a strong supporter of the MPH Program since its inception in 2013. Dr. Deilgat has a strong interest in developing the next generation of public health professionals. Since 2014, he has supervised 16 students from the MPH Program, more than any other supervisor or organization. In 2018, he received the MPH Preceptor Award of Excellence in recognition of his unrelenting mentorship of the students who he has supervised. To quote his students: “Dr. Deilgat most definitely goes above and beyond his duties as a preceptor to help us succeed. Through his actions both inside and outside PHAC, you can tell he tries his best to make sure his students have the most rewarding experience possible”.

The cases that appear in this book are the hard work and dedication of a team we are so proud to be a part of. In particular, thank you to our case authors: you are supporting the pedagogy of public health and providing essential material to help the next generation of public health leaders grow. The final polished look of this book would not be possible without our copy editors and the careful eye of Diana Lee and Rosie Han. As editors, it is our privilege to provide this book as a tool to further the learning, the thinking and the progress of helping the world’s population recognize the goals of public health.

*– Shannon Sibbald and Gerald McKinley*



# **INTRODUCTION TO THE CASEBOOK**



## Contributing to the Development of the Next Generation of Public Health Professionals: A Preceptor's Perspective

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*Michel P. Deilgat, CD, BA, MD, MPA, MEd, MIS (candidate), CCPE  
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Centre for Food-borne, Environmental, and Zoonotic Infectious Diseases  
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### INTRODUCTION

The next few lines are a reflection of my past six years as a preceptor with an outstanding group of graduate students. In the spring of 2014, I was fortunate to be involved with the first cohort of Master of Public Health (MPH) graduate students from Western University. It all started with an email sent by Lisa Metselaar at the end of November 2013, asking me if I would be interested in becoming a preceptor to supervise a student practicum the following spring. At the time, I had just completed my third year at the Public Health Agency of Canada, having spent most of my career in the military as a medical officer. I had had some limited experience as a preceptor with the Public Health and Preventive Medicine Residency Program at the University of Ottawa. That spring, the Centre for Food-borne, Environmental, and Zoonotic Infectious Diseases (CFEZID) had moved to a temporary location at the west end of Ottawa while the main building on Colonnade Road was being revamped to meet the new government Workplace 2.0 Fit-up Standards. Most of the other centres were relocated to Tunney's pasture, which made connecting with other colleagues more challenging. So, Delaney Hines (the practicum student) and I travelled a great deal that summer around the city of Ottawa. Nevertheless, we managed to stay informed about most surveillance, emergency management, and work plan on Lyme disease activities.

### THE ROLE OF A PRECEPTOR

The role of a preceptor is fairly simple. In my view, it is to provide a platform for opportunities to consolidate the student's previous learning and develop new ones, get exposed to various activities related to the field of practice in the daily life of public health professionals and start establishing a network of people with various backgrounds involved in the field. Too often, preparing the new wave of the workforce falls solely under the purview of academic institutions. While the importance of workplace learning is certainly well recognized (e.g., co-op programs at the undergraduate and graduate level), government and nongovernment organizations would benefit even more from these unique opportunities throughout the year. As in real life, solutions are not always clearly provided, which emphasizes the importance of the critical thinking fostered during a practicum. During the last few years of his career as the CEO of General Electric, Jack Welch was spending up to 75% of his time training his staff. Sharing knowledge and developing strategies for change management should be integrated in all types of learning-related activities. On the first day of the practicum, I place significant emphasis on creating a safe environment realizing that, over the past 8 months, the planned academic rigour of Western's MPH Program had achieved its objective. But once the students start their practicum, the pace slows down and there is time for them to integrate, correlate, and, in some instances, contemplate and reflect on their new role in public health.

## Contributing to the Development of the Next Generation of Public Health Professionals: A Preceptor's Perspective

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I keep saying to my own children that learning is not easy. It requires time, energy, sometimes sacrifices, and the willingness to be ready to deconstruct what you have already learned to adapt your new knowledge and perceptions in a different paradigm or conceptual framework. To avoid any form of unnecessary complacency, one foot needs to be outside your zone of comfort otherwise learning may not take place. It may seem like a drastic and unpleasant process but once this mind-set is part of your lifelong learning plan, it becomes second nature and it is quite rewarding to the extent that you always want to learn more about how society works and how to make yourself a valuable asset in your work environment, in your family, and in your community.

The field of public health keeps evolving as information technologies and novel avenues of communication provide new tools and innovative strategies to manage public health data, retrieve information, and practitioners become better positioned to make informed decisions and establish evidence-based policies. For more details on essential skills for public health and the changing world, I highly recommend reading the introductions by Dr. David Jones (Western Public Health Casebook 2018) and Dr. Peter Donnelly (Western Public Health Casebook 2017). I will not reiterate the very formative content of these documents; I will simply use some examples to support the role of a preceptor.

Preceptorship is about developing the skilled human resources that will promote health, engage in the prevention and control of various food-borne and water-borne disease outbreaks, focus at several levels of surveillance on emerging and re-emerging infectious diseases and, to some extent, act as disease detectives to mitigate the risks and sometimes manage the events that may jeopardize the health of the population. It is the mirror-image role of the clinicians who are investigating and treating diseases. Both are complementary; however, the more diseases you prevent the fewer you need to treat. Unfortunately, the link between family medicine and public health is not a strong one. For example, at the Family Medicine Forum—the annual conference for family physicians in Canada—topics related to preventive medicine or infectious diseases are very rare or nonexistent. Over the past two years, we have just started seeing a few presentations on climate change and human health.

Because we are dealing with very different individuals, it is important that we know our students and consider their inspirations in life, their past academic and work experience, their family situation, their countries of origin and languages spoken, and their spiritual and religious beliefs. We must get a thorough picture of the person who we will spend 12 weeks with as we contribute to their development. It may appear somewhat intrusive, but each individual is unique and their practicum needs to be tailored according to their requirements and specific needs. This approach is generally not embraced in the workplace setting because there is a tendency to treat everyone as a uniform group. My outlook is likely a reflection of my career in the military where a close knit environment is required and I learned early that “you must know your people—and you must take care of your people”. The environment in public health is not that different, it is simply a different battlefield.

Over the years, we had the opportunity to be part of “Ex Strategic Play”, a one-week exercise that takes place in downtown Ottawa, mainly involving Canadian Armed Forces, the RCMP, foreign officers, and a few select federal public servants who were chosen to be assigned to senior leadership positions in the government. This is part of a one-year National Security Program course housed at the Canadian Forces College in Toronto that includes significant time on international field trips. My role with the graduate students is to mentor the candidate who plays the part of the Associate Deputy Minister–Public Health throughout a scenario involving a public health disaster in one major Canadian city. Every year, we learn a great deal about risk and crisis communication and how the Deputy Minister–Public Safety handles

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different critical situations. Graduate students are offered the opportunity to share their knowledge, express their thoughts and recommendations about a specific issue, and contribute to the learning of an officer who has no background in public health. S/he could be a fighter pilot, an infantry officer, a military engineer, or could hold any other occupation. Each time, the students really enjoy this activity, which is more than just a regular, run-of-the-mill exercise.

In terms of instruction and learning strategies, hands-on experience, on-the-job-training, and job shadowing are probably some of the preferred teaching approaches in a workplace setting. Friday mornings are normally devoted to the academic half-days with the Public Health and Preventive Medicine Residency Program at the University of Ottawa. One can barely discern the difference between the graduate students and the residents during the discussions and in their capacity to devise solutions. Topics vary from exposure to radon or ionizing radiation, to family violence breastfeeding, and cancer screening. Working with teams and committees that exist already is also fairly easy to coordinate. More targeted learning programs with agencies such as the International Health Regulations National Focal Point office, Quarantine Services, Office of Border Health Services, FluWatch, and other related organizations offer engaging opportunities to explore new fields or simply consolidate what has been learned during the year. The Health Security Infrastructure Branch offers interesting topics to explore as well. As an applied field of practice, I truly believe that public health is best managed at the ground level, i.e., at the municipal level. Regional, provincial, federal, and international levels are important and they have a crucial role to play, but the highest health impact (at least in the short term) is achieved within municipal jurisdictions. One way to develop this expertise is to simulate situations using real scenarios and data and participate in these simulations, whenever possible, in real time. A scenario based on known food-borne or a water-borne illness outbreaks can present such an opportunity. Think of John Snow and the cholera outbreak on Broad Street in 1854 or, more recently, the outbreak of water-borne gastroenteritis that led to the death of six people in Walkerton, Ontario because the water supply was contaminated with *Escherichia coli* and *Campylobacter jejuni*. A simulation requires limited resources and you can never practice your skills during a natural disaster, a deliberate attack (bioterrorism), a pandemic, or during any other situation that may require communication, human resource management, or financial management, just to name a few.

There are adverse public health events occurring almost daily on a small or large scale. The CFEZID has been actively involved with several of them over the past few years. These events have included the H1N1 influenza pandemic of 2009; the 2015 Zika virus outbreak in South America that was declared by the WHO as a public health emergency of international concern; the Ebola outbreaks on the west coast of Africa; and the 2008 Canadian listeriosis outbreak linked to cold cuts processed in a Toronto plant that resulted in 57 confirmed disease cases and 22 deaths. The *Federal Framework on Lyme Disease* is one of our major projects and several MPH graduate students have written their teaching cases using various perspectives on this topic. Because climate change is certainly a major driver in modifying the ecology of infectious diseases, there are several interesting projects to explore in the future. Not only do we need to better understand the impact of these climate-related changes, but we have to acknowledge that as the older adult population in Canada increases, chronic disease rates may surge. This is already the new reality and it is imperative that the public health professionals who can mitigate these crises and intervene through surveillance and health communication have available all the tools they need to accomplish these tasks.

Over the years, some of our graduate students have published their work in our journal *Canada Communicable Disease Report*. Realizing that the practicum starts and after a short time is already completed, it is surprising to see how much gets accomplished in those 12 weeks.

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Although I do not have the authority to hire new public servants at the Agency, some graduate students from previous classes are working here under different contracts. It is rewarding to see the continuity from school life to entering the labour force. I would certainly like to keep most of the MPH students every year. But what motivates me the most about being a preceptor is my appreciation of the dynamic of this next generation of health professionals. I have reached a point now where few people from the latest cohort were born before my youngest child. At first, it hurts to see how fast time flies and by the time this is published I will have reached my 40th year with the Government of Canada, having started at an early age at the Officer Candidate School in Chilliwack, British Columbia. But learning never ends and we always learn from ourselves and from each other. It is a matter of taking the opportunity when an issue presents itself on your screen. Past experiences cannot be neglected but too often there is a tendency to rely on the same solutions even though there are many other ways to resolve new problems. Public health is an interdisciplinary discipline and this is the reason that it is so interesting as a field of practice. Engineers, physicians, lawyers, nurses, epidemiologists, social scientists—no occupation can be excluded when it comes to understanding and finding solutions for the health of the population.

### **ACKNOWLEDGEMENTS**

I would like to pay tribute to all my colleagues from the program without whom I would never have known the rewarding experience of being a preceptor: Delaney Hines, Neha Bhatia, Molly Dion, Dr. Thiha Naing, Elizabeth Fan, Dr. Nitin Mohan, Purathani Shanmuganathan, Chowdhury Anika Nur Saiva, Sukhmeet Singh (Rohan) Sachal, Dr. Shahzadi Zain, Kirandeep Kharpal, and Ruotian Xu—you were simply outstanding. Thank you to Steven Sternthal, the Director General at CFEZID who always supported me having graduate students and residents on our team since the beginning, my co-workers Rukshanda Ahmad and Julie Thériault, and the faculty members and staff from Western.

# CASES



## CASE 1

# Vanishing Volunteers: The Use of Implementation Research to Improve Support for Community Drug Distributors in Côte d'Ivoire

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*Daniel Dilliot, BMSc, MPH (MPH Class of 2018)*

*Alison Krentel, MScPH, PhD (Investigator, Bruyère Research Institute and Assistant Professor, University of Ottawa)*

*Mark Speechley, PhD (Professor, Western University)*

*“There is no point in waiting to define all the barriers before starting because most of the barriers will only be found after the start of the program. If you wait until you know everything, you simply don’t do anything.”*

— Dr. William Foege, President and Co-Founder  
of the Task Force for Global Health

Dr. Emmanuel Koffi let out a long sigh as he leaned back in his chair and covered his eyes with his hands. As he sat with his eyes closed, he could hear the soft pattering of raindrops emanating through the open window of his second floor office at Côte d'Ivoire's Ministry of Health and Public Hygiene. The rainy season was currently in full swing. Emmanuel immersed himself in the peaceful atmosphere and took this brief yet welcomed a moment of tranquility to gather his thoughts. It had been quite a stressful morning. He had just finished reading the latest field reports from his district managers who were spearheading the latest round of mass drug administration (MDA) in rural communities across the N'Zi region. Completely eliminating lymphatic filariasis from his country was turning out to be more difficult than he had anticipated. “You'd think giving out free medication to get rid of one of the most debilitating diseases known to humankind would be easy,” he thought to himself. Not only were the rains causing numerous logistical problems for his district managers, but the turnout from community members was poor in several areas. Reflecting on his lengthy experience as a neglected tropical disease (NTD) program manager with the Ministry of Health and Public Hygiene and his experience organizing two previous MDAs in the region, Emmanuel supposed he should not have been surprised. Unfortunately, there frequently were several challenges and logistical issues associated with the timing of annual MDA campaigns. With so many anti-malarial and vaccination programs running simultaneously throughout the country, his NTD programs often took a back seat. There were a few times throughout the year when the district health centres could spare resources and personnel to help him run the program. He also expected that the turnout from community members would be low, likely because they were more concerned about the recent flooding.

What Emmanuel was not expecting, however, was that in the latest MDA far fewer experienced volunteers, also known as community drug distributors (CDDs), had signed up to help distribute antifilarial medication than in previous years. The report he had been reading earlier mentioned that district managers were suffering from volunteer shortages and needed to intensify their recruitment efforts. Emmanuel knew he was already asking a lot from his volunteers by taking them away from their farm work to help with the medication distribution and offering nothing in return but gratitude and a small sum of money to cover any costs incurred during the

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distribution. He also knew that, without their help, it would not be possible to conduct his MDA campaigns. Front-line health workers in the region were already overworked and there were simply no other sources of trained health human resources available. Furthermore, the previous successes of well-implemented MDA campaigns had demonstrated that community members across Africa generally preferred to receive medication from CDDs who were nominated, selected, or self-volunteered from within the community. Several of these CDDs had spent many years with the program and therefore had extensive knowledge about both lymphatic filariasis and the medications they were distributing. This familiarity and knowledge encouraged the villagers to trust the CDDs, which helped improve program compliance rates. Emmanuel knew that losing these volunteers would be a huge blow to the program.

What could he do stop these CDDs from quitting? Emmanuel had no idea where to start. He knew that he had to devise a way to retain these volunteers, but he was not sure what was prompting them to quit in the first place. Today was August 16, 2018. Côte d'Ivoire was already cutting it close in terms of meeting the 2020 deadline set by the Global Alliance to Eliminate Lymphatic Filariasis (GAELF) for eliminating the disease as a public health problem. Emmanuel began to feel increasingly stressed—he was on a tight schedule and could no longer afford any issues with his MDA campaigns. He needed help but did not know who could provide it. As the program manager for Côte d'Ivoire's NTD elimination and control efforts, he was responsible for solving any problems associated with the programs. As he tried to think of a solution for this lack of personnel, Emmanuel looked over to an NTD information poster hanging on his wall next to the window.

### NEGLECTED TROPICAL DISEASES

The World Health Organization (WHO) has classified 20 infectious diseases that are among leading causes of morbidity and disability amongst the poorest of the world's poor as NTDs (Hotez et al., 2007; WHO, 2018b). Among these are diseases such as schistosomiasis, onchocerciasis, soil-transmitted helminthiasis, and lymphatic filariasis (WHO, 2003, 2018b). These tropical diseases are classified as 'neglected' because they have been given relatively low prioritization by international public health organizations compared with other infectious diseases such as malaria, HIV-AIDS, and tuberculosis (also known as 'the big three') (Hotez, Ottesen, Fenwick, & Molyneux, 2006; WHO, 2003). NTDs have also been relatively overlooked by public health professionals because they are frequently found in isolated, rural communities in developing nations and are considered to be far less lethal than 'the big three' (Hotez et al., 2006). NTDs do not affect industrialized nations or the wealthier populations in developing countries; therefore, the pharmaceutical industry has also generally given lower priority to NTD treatment markets (Hotez et al., 2006; WHO, 2003).

Despite rarely causing death among those who are infected, NTDs nonetheless pose one of the greatest threats to the health of the world's most vulnerable populations (Hotez et al., 2006; WHO, 2003). Not only do patients suffer from debilitating physical symptoms throughout their lives, but they are also burdened with considerable economic and social hardships related to their diseased state (Hotez et al., 2006; WHO, 2003). For example, many people who have NTDs are forced to give up work because of their chronic conditions (WHO, 2003). For families already living on very little income, this additional burden can perpetuate an inescapable cycle of absolute poverty, inevitably leading to poor health outcomes in future generations (WHO, 2003). Similarly, the stigma associated with physical disfigurement and other symptoms can lead to social exclusion of those infected with the disease (WHO, 2003). People who have disfiguring ailments often isolate themselves from their community, which can lead to challenges in providing them with treatment (WHO, 2003).

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Emmanuel had observed this stigma in his own country. It was not uncommon for individuals living in some small, rural communities to believe that people with diseases such as lymphatic filariasis or leprosy were cursed or had received the disease as punishment for wrongdoing. As such, his district managers found that finding infected people in some rural communities and convincing them to seek treatment could be incredibly challenging.

Patients who have NTDs primarily suffer losses related to disability and morbidity, making it unsurprising that organizations had historically paid little attention to these diseases. Before the WHO's Global Burden of Disease study in 1990, the diseases that typically attracted the most attention from funders and international aid organizations were those that contributed the most to high mortality rates. However, with the turn of the new millennium, that began to change. The Global Burden of Disease study and the subsequent creation of the disability-adjusted life year (DALY) metric allowed funders, researchers, and international health organizations to better understand and quantify the impact that NTDs have on the overall health of populations (Murray, Lopez, WHO, World Bank & Harvard School of Public Health, 1996). At last, comparisons could be made between the health burdens caused by NTDs and those caused by 'the big three'. DALYs have been used to show that the global disease burden from NTDs is one-fourth of that from HIV-AIDS, and nearly equal to that of malaria (Hotez et al., 2006).

In 2012, in recognition of the massive contribution that NTDs make to the disease burden of vulnerable populations in lower middle-income countries, several governments, private pharmaceutical companies, international organizations, and international developmental agencies signed the London Declaration on Neglected Tropical Diseases (Dean, 2001). Spearheaded by Margaret Chan, the former Director-General of the WHO, and Bill Gates, the philanthropic CEO of Microsoft, the meeting led to an agreement to unite efforts to control or eliminate 10 NTDs by 2020 (Dean, 2001). In 2015, the NTDs were further recognized when they were given their own target and indicator under the United Nation's third Sustainable Development Goal (United Nations, 2015; United Nations Development Programme, 2016).

Côte d'Ivoire's government has also recognized the impact NTDs have on the country, and it has made it a formal responsibility of the Ministry of Health and Public Hygiene to implement control or elimination strategies. Ultimately, as the program manager of the very small NTD control department within the Ministry of Health and Public Hygiene, this job fell to Emmanuel. While he and his colleagues had achieved some success in several of their NTD control efforts over the past five years, they remained underfunded and have much more work to do. For the past year, Emmanuel's department put a renewed focus on combatting lymphatic filariasis. However, the issues he was facing now stemmed from his efforts working towards eliminating this terrible disease from his country.

### LYMPHATIC FILARIASIS

Lymphatic filariasis ranks second among the leading causes of irreversible and chronic disability worldwide (Dean, 2001; Taylor, Hoerauf, & Bockarie, 2010). It is also considered an ancient disease, thought to have been afflicting humanity since Egypt was ruled by pharaohs (Nunn & Tapp, 2000). Before recent global elimination efforts, the disease was thought to affect more than 120 million people worldwide, with close to 1.2 billion people being considered 'at risk' (Michael, Bundy, & Grenfell, 1996). Approximately one-third of the 120 million people infected were thought to suffer from at least one of the physical and chronic manifestations of the disease (Michael et al., 1996).

Emmanuel looked down to his desk at some of the photos covering the educational pamphlets that his department had recently created about lymphatic filariasis. He frowned in slight

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displeasure at what he saw. Even though he had seen the disease in person many times, the physical symptoms of the disease never failed to make him feel somewhat uncomfortable.

Lymphatic filariasis is characterized by the impairment of proper lymphatic fluid regulation caused by damage of the lymphatic vasculature, leading to the abnormal and painful swelling of body parts (Dean, 2001; Taylor et al., 2010; WHO, 2017). Lymphatic filariasis can sometimes be difficult to detect, however, as many patients go asymptomatic for long periods of time (Taylor et al., 2010; WHO, 2017). While the infection almost never causes death, the horrible disfigurements are incredibly debilitating and have numerous socioeconomic consequences (Dean, 2001; Taylor et al., 2010; WHO, 2017). Patients with symptomatic lymphatic filariasis are often bedridden for weeks and unable to work or attend school, which has negative implications for their well-being (Dean, 2001). In some countries, the physical disfigurement caused by excessive lymphedema can also lead members of rural communities to believe the patient is cursed and ostracize the patient from the community (Dean, 2001). Physical disfigurement and hydrocele can also lead to a loss of social capital, a lower number of marriage prospects, and substantial stigmatization, all of which can negatively influence one's health (Dean, 2001).

There are currently very limited pharmaceutical treatments available to treat those with symptomatic lymphatic filariasis. One of the few effective treatment options available to healthcare providers is a morbidity management and prevention strategy developed by a Brazilian doctor, Dr. Gerusa Dreyer (Dean, 2001). Using simple hygienic and skin care techniques, such as using clean water to bathe affected limbs daily, Dr. Dreyer's method helps alleviate the symptoms of acute lymphedema attacks (Dean, 2001). While Dr. Dreyer's treatment has been instrumental in providing relief to millions of lymphatic filariasis patients, there remains no way to completely cure the disease (Dean, 2001). Instead, public health professionals have turned to preventive chemotherapy using diethylcarbamazine (DEC), ivermectin/Mectizan, and albendazole in their attempts to prevent the transmission of the disease before infection can occur (Taylor et al., 2010).

Emmanuel leaned back in his chair, reflecting on all the information he had received about lymphatic filariasis and the other NTDs during his medical training. It was then that he had first become interested in treating and preventing these debilitating diseases. During his short time practicing medicine, Emmanuel had treated numerous patients who had NTDs and had quickly become discouraged about how hopeless it seemed to prevent people from being infected in the first place. This had led him to his current position within Côte d'Ivoire's Ministry of Health and Public Hygiene. During his tenure with the Ministry, he learned from his colleagues about the potential for eliminating some of these diseases and found that they had prioritized lymphatic filariasis for possible elimination from Côte d'Ivoire.

The parasitic worms that cause lymphatic filariasis are particularly vulnerable parasites: they only have one host, they have very inefficient transmission processes, and they have yet to develop resistance to any antifilarial medications. In 1993, high-profile members of the International Task Force for Disease Eradication (Dean, 2001) determined that this combination of factors made lymphatic filariasis an ideal elimination target. The task force was established by Dr. William Foege and Dr. Donald Hopkins, who were both key players in the eradication of smallpox and polio respectively (Dean, 2001). Lymphatic filariasis was one of only six diseases considered by the task force for eradication. However, it was in 1997 that the World Health Assembly pushed the elimination of lymphatic filariasis as a public health problem to the forefront of the global health agenda (Dean, 2001). All that was needed was a united effort from public health professionals, governments, non-governmental organizations, and private corporations to set the plan in motion.

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### **THE GLOBAL ALLIANCE TO ELIMINATE LYMPHATIC FILARIASIS**

Emmanuel continued to reflect. During the early years of his position with the Ministry of Health and Public Hygiene, he was given the opportunity to attend one of the Global Alliance to Eliminate Lymphatic Filariasis' (GAELF's) annual meetings. It was there that he learned about the international efforts of several countries and organizations to eliminate lymphatic filariasis as a public health problem. After returning to Côte d'Ivoire, Emmanuel remembered feeling hopeful that he would be able to use what he had learned to produce a change in his own country. The contrast between his attitudes then and his attitudes now made him smile. Thinking back to the meeting, he recalled what he had learned about the GAELF's history.

The early beginnings of the GAELF can be traced back to 1997, when the CEO of GlaxoSmithKline (GSK), Jan Leschly, sat next to President Jimmy Carter at a charity event in Washington, DC. At the time, Mr. Leschly was looking for a massive philanthropic project that his company could undertake for the new millennium. He expressed this to President Carter, who quickly contacted the former Executive Director for the Carter Center, Dr. William Foege. Coincidentally, Dr. Foege had recently attended a conference where he learned about how GSK's drug, albendazole, could boost the antifilarial efficacy of DEC when the two were taken together. When he heard about Mr. Leschly's desire from President Carter, Dr. Foege expressed his belief that GSK could take on no better project than providing support for the elimination of lymphatic filariasis.

President Carter facilitated the creation of the partnership by inviting scientists and executives from GSK to meet with Dr. Foege and other representatives from the WHO at the Carter Center. The partnership seemed like the definition of a win-win situation; global health professionals could potentially gain a substantial source of medications, which they could use to begin their long-desired elimination effort. At that time, GSK agreed to donate enough albendazole to cover dual-drug therapy treatments for the next 20 years. Upon reaching this agreement, GSK formalized the deal by signing a Memorandum of Understanding with the WHO.

The signing of this historic document attracted the attention of many other organizations who were highly interested in assisting in the elimination effort. Most notable of these was another pharmaceutical giant, Merck, who had already contributed millions of treatments of Mectizan towards the elimination of onchocerciasis. Together the two pharmaceutical competitors agreed to provide billions of treatments free of charge. Other organizations soon lined up to offer support for the growing alliance. Today, the GAELF has grown to represent a myriad of academic partners, NGOs, UN agencies, private companies and national governments. This represents one of the largest public-private partnerships in the history of public health.

Emmanuel sat up suddenly in his chair; he had an idea. Opening the top drawer of the cabinet next to his desk, he pulled out a small leather-bound contact book and searched for the number of the one person who might be able to help him. Dr. Myriam Kouamé was an Ivorian researcher at the University of Abidjan who had spent the past five years conducting research that was instrumental in helping health program managers across Africa with similar problems. Emmanuel had met her after she had presented at last year's annual GAELF meeting. He had been very impressed by how practical her research results were, and how they were used to improve the way health programs were delivered in other countries. He had made a point of noting Dr. Kouamé's contact information after their discussion just in case he needed help improving his own programs. Now seemed like the time. Picking up the phone on his desk, Emmanuel dialed her number.

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### MASS DRUG ADMINISTRATION

The Global Program to Eliminate Lymphatic Filariasis (GPELF) was launched by the WHO in 2000 (Ichimori et al., 2014). The program is based on two pillars: interrupting disease transmission by using MDA, and alleviating the suffering of those already infected with the disease through morbidity management and disability prevention (Ichimori et al., 2014; WHO, 2016, 2017).

Morbidity management and disability prevention can be achieved by operating on patients who have hydrocele and by using treatment methods similar to those developed by Dr. Dreyer for lymphedema (Dean, 2001; WHO, 2016). However, significant progress has yet to be made on the GPELF's secondary objective because the primary focus of many GPELF stakeholders has been first to break transmission of lymphatic filariasis in endemic countries (Ichimori et al., 2014).

The elimination of lymphatic filariasis can only be achieved by preventing person-to-person transmission of the parasite (Dean, 2001), and this transmission can only be broken by treating infected and uninfected individuals with antifilarial medications. This strategy is known as preventive chemotherapy, which essentially eliminates the human reservoir of the disease and prevents mosquitoes from ingesting the parasite when taking blood meals (Dean, 2001; Ichimori et al., 2014). To achieve complete elimination, at least 65% of the people living in areas where lymphatic filariasis is endemic must take antifilarial medication once or twice annually for four to six years (Ichimori et al., 2014; Ottesen, Duke, Karam, & Behbehani, 1997). To help countries achieve this crucial 65% coverage the WHO has adopted and promoted the strategy of MDA, a form of widespread preventive chemotherapy, which was first developed by the Chinese (Hanson et al., 2012; Hotez et al., 2007; Ichimori et al., 2014).

As the phone rang, Emmanuel wondered how he was going to explain the issues with his MDA efforts to Dr. Kouamé. MDA is much more complex than simply driving into a community with medication and giving it to as many people as possible. Before distributing medications, health workers must conduct several health promotion and health education sessions to properly inform, mobilize, and prepare the community to receive the medication (Silumbwe et al., 2017). Securing buy-in from community leaders and members is essential (Silumbwe et al., 2017). Distributors must be trained before the distribution effort to prepare them for delivering the medications and answering any questions from community members (Silumbwe et al., 2017). A great deal of logistics planning must be done to coordinate the efficient delivery of medication and supplies to the community (Silumbwe et al., 2017). Finally, surveillance and monitoring measures must be put in place to track and manage side effects and adverse events, and to determine the overall coverage achieved by the distribution (Silumbwe et al., 2017). From his experience in organizing MDA programs in communities in his own country, Emmanuel knew that these were all essential components to a successful MDA.

Successful MDA strategies also require partnerships between international organizations such as the WHO, the pharmaceutical companies providing the medication, and the ministries of health in the countries where the disease is endemic (Dean et al., 2016; Hanson et al., 2012). Another layer of partnership is required within the public sector of the affected countries because several government stakeholders, such as ministries of transportation and education, need to work together to deliver treatments and mobilize populations (Hanson et al., 2012). Without these intersectoral partnerships, governments cannot hope to attain the coverage necessary to break transmission of the disease. In addition, a significant amount of technical assistance and funding is required to help countries develop and implement successful MDA programs. To achieve the partnerships and organization necessary to conduct these massive distribution programs, international organizations have been working closely with national

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ministries of health to develop national, integrated NTD programs (Hanson et al., 2012). These efforts have allowed the stakeholders to develop models that countries may use to guide the roll-out of their own national NTD programs in an effective manner (Hanson et al., 2012).

Perhaps fittingly, given its pioneering role in the use of the MDA strategy, China was among the first countries to successfully break the transmission of lymphatic filariasis (Molyneux, 2006). The earliest historical accounts of endemic lymphatic filariasis were recorded in Egypt and it is also one of the first countries to have provided substantial evidence that MDA can be used to successfully eliminate the disease (Molyneux, 2006). From 2000 to 2016, the WHO worked with ministries of health from numerous countries to help them develop their own national NTD programs, all of which included MDA as a core component (Hanson et al., 2012). During this time, the GPELF achieved great success. In 16 years, 11 countries had completely eliminated lymphatic filariasis, with nine more completing their preventive chemotherapy treatment and entering post implementation surveillance to prove elimination had been achieved (WHO, 2017). The WHO reports that, during this time, “6.7 billion treatments were delivered to more than 850 million people at least once in 66 countries, considerably reducing transmission in many places” (WHO, 2017). Overall, the number of people at risk of being infected by the disease-causing parasites has dropped dramatically to about 789 million, primarily because of MDA (Hooper, Chu, Mikhailov, Ottesen, & Bradley, 2014). Aside from the successes of MDA in improving health and preventing disease transmission among these populations, the strategy also provides substantial economic benefit (Gedge, Bettis, Bradley, Hollingsworth, & Turner, 2018). The use of MDA to eliminate lymphatic filariasis has been proven to be cost-effective. From 2000 to 2015, it is estimated to have prevented an overall economic loss of about US\$100.5 billion (Gedge et al., 2018; WHO, 2017).

Despite the substantial gains made by the GPELF, there are still significant challenges that threaten the success of MDA in different contexts. The problems with MDA can be categorized either as challenges with coverage (issues related to distribution) or as challenges with compliance (issues related to treatment uptake within the community). National-level challenges include delays in the delivery of medication to communities, the lack of strategies to track or surveil the migration of individuals into hard-to-reach geographical areas, the requirement of governments to respond to outbreaks of other diseases, and constraints related to limited health human resources (Silumbwe et al., 2017). At the community level, challenges with MDA implementation include the strategy used to distribute medications (distribution posts compared with house-to-house), large coverage areas, the limited funding available for social mobilization, and large numbers of households needing coverage (Silumbwe et al., 2017). Finally, at the level of the individual community member, challenges with MDA implementation include ensuring the community is adequately aware of and knowledgeable about the disease, the treatment, and the causes of adverse events or side effects (Krentel, Fischer, & Weil, 2013). Other individual characteristics that can present challenges in terms of receiving and taking medication in MDA include gender, age, urban living, household income, and personal beliefs (Krentel et al., 2013).

“Allô?” Dr. Kouamé’s voice came through the phone’s receiver. Emmanuel steeled himself for the conversation to come. He just had to convince her to help him determine why CDDs were becoming less willing to volunteer for his MDAs. “Bonjour Dr. Kouamé!” he said, “C’est Dr. Koffi qui vous appelez. Est-ce que vous avez un moment pour parler?”

### COTE D’IVOIRE

The Republic of Côte d'Ivoire is located in West Africa, bordering several other countries to its North, East, and West, and bordering the Atlantic Ocean to its South. The capital of Côte d'Ivoire is Yamoussoukro, a major urban centre, whereas Abidjan is the country’s largest city and major economic powerhouse. As a former French colony, Côte d'Ivoire has retained French

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as its official language. After achieving independence from France in the 1960s and enjoying relative political stability until the early 1990s, Côte d'Ivoire has since suffered from several years of political turmoil. In 1999, the elected government was overthrown in a coup d'état, which was followed by two civil wars from 2002 to 2007 and from 2010 to 2011. Currently, a republican government holds power in Côte d'Ivoire, after being re-elected in 2015.

The population of Côte d'Ivoire is approximately 24 million (The World Bank, 2017a). About 51% of the population live in urban centres such as Yamoussoukro or Abidjan, with Abidjan itself home to more than four million people (The World Bank, 2017b). Côte d'Ivoire is classified as a lower middle-income country; however, since the end of its civil wars, it has had a fairly strong economy for its classification. The country's economy is primarily based on agricultural production, with many people working on cocoa and coffee farms as their primary occupation (Central Intelligence Agency, 2017). Côte d'Ivoire has a gross domestic product of about US\$40 billion, 5.7% of which it spends on health (WHO, 2018a; The World Bank, 2017a).

Côte d'Ivoire is divided into 82 health districts. These are geographical areas defined by the health system to provide health care services to a specific population group. As such, health care in Côte d'Ivoire is decentralized to different degrees, with districts reporting to different administrative authorities. The goal of this decentralization is to achieve a compromise between the benefits of receiving funding and support in a centralized fashion, while also having the system diversified at the local level to reflect differences in population needs and expectations. Health districts were created to increase the access of different populations (i.e., rural or urban) to the system. Implementers of health programs, such as NTD control programs, must consider contextual differences among the health districts and they need to tailor program delivery to each district's specific context if they are to be successful (Dean et al., 2016).

The functioning and organization of Côte d'Ivoire's health care system is overseen by the country's Ministry of Health and Public Hygiene (Ministère de la Santé et de l'Hygiène Publique - Côte d'Ivoire, n.d.). Health care in Côte d'Ivoire is primarily publicly funded and delivered; however, the country also has a private health care sector. As with many other lower middle-income countries, Côte d'Ivoire's overall health system has not been able to produce health outcomes to match those of many higher-income countries. The current life expectancy of the average Ivorian is around 55 years of age (WHO, 2018a). In 2013, the country's under-five mortality rate was 100 per 1000 live births, whereas the maternal mortality rate was approximately 720 per 100,000 live births (WHO, 2018a). The top three contributors to the country's overall disease burden (measured in DALYs) are maternal/neonatal complications, 'the big three', and other infectious diseases such as NTDs (WHO, 2018a). The health system currently suffers from a severe shortage of health care professionals and an uneven distribution of health care service providers.

"D'accord. Je te verrai demain. Au revoir!" Myriam said. Smiling, she pressed the 'end call' button on her cell phone. Placing it in her handbag, she looked out the window of the overcrowded bus she was riding to the university. Watching people darting between Abidjan's many buildings in halfhearted attempts to avoid the rain, she reflected on the conversation she had just had with Dr. Koffi. He had sounded quite distressed as he explained the problems he was having with his lymphatic filariasis program. By the end of the conversation, he was all but begging her to help him determine what was happening with his volunteer base. Myriam was quite humbled that he had decided to reach out to her for help. She could not lie to herself; the thought of leading a major research project in her home country in collaboration with the Ministry of Health and Public Hygiene was very exciting. She was only five years into her current appointment at the University of Abidjan, most of which she had spent conducting implementation research on several different health programs across Africa. It was very difficult

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and arduous research. However, the information she had provided to these health programs was always well worth the effort. While these projects were very important to her, she had yet to be part of something as important as the research that was needed to assist Dr. Koffi in Côte d'Ivoire's lymphatic filariasis elimination efforts. With this in mind, Myriam agreed to help Dr. Koffi determine why his volunteer base was shrinking. They were going to meet tomorrow at the Ministry to develop a plan of action.

Shifting her thoughts back to the issue at hand, Myriam realized that she did not envy Dr. Koffi's position in the slightest. She could only imagine how difficult it must be to deliver millions of antifilarial treatments to people across Côte d'Ivoire using a primarily volunteer-based workforce. Leaning her head against the window, Myriam mused over the information Emmanuel had shared about his use of CDDs for MDA in Côte d'Ivoire.

### **COMMUNITY DRUG DISTRIBUTORS**

To address many of the challenges associated with MDA, including the limited availability of human health resources, national NTD programs across Africa rely heavily on the use of a community-directed intervention (CDI) strategy. The use of a CDI strategy involves the empowerment of a community to take ownership of an intervention and implement it in a manner that they deem appropriate (Amazigo, Leak, Zoure, Njebuome, & Lusamba-Dikassa, 2012; Katarbarwa, Mutabazi, & Richards, 2000). The principles of CDI involve the community discussing the information and intervention plans provided to them by program initiators, designing an implementation approach, evaluating the capacity of the community, gathering resources to implement the intervention, and then creating a plan to implement the intervention (Katarbarwa et al., 2000). After the planning stages of the CDI strategy, the community then takes a central role in carrying out the intervention and monitoring and evaluating the intervention's success (Amazigo et al., 2012; Katarbarwa et al., 2000). The use of well-executed CDI strategies has been shown to be quite effective at improving MDA coverage and compliance in many communities across Africa, and at helping mitigate issues with sustainability, resource shortages, and community buy-in (Amazigo et al., 2012; Gyapong, Gyapong, & Owusu-Banahene, 2001; Katarbarwa et al., 2000; Krentel et al., 2013).

Central to the CDI strategy are the volunteer CDDs who are instrumental in the success of many MDA campaigns. Many communities in Côte d'Ivoire rely primarily on CDDs for distributing vast quantities of antifilarial medication to achieve the coverage necessary for breaking disease transmission. However, the true value of CDDs as a human health resource lies in their inherent effectiveness at ensuring that community members comply with treatment (Corley, Thornton, & Glass, 2016; Krentel et al., 2013). CDDs often have more extensive knowledge about cultural contexts and local languages than international aid workers or national health workers because they are usually volunteers from the community where medication is being distributed (Corley et al., 2016). This makes CDDs effective at educating the community, disseminating information about the disease, and encouraging community participation in MDA programs (Corley et al., 2016). The strategies employed by CDDs to improve a community's uptake of preventive chemotherapy treatments include capitalizing on pre-existing and trusted relationships with community members, directly observing treatment (i.e., watching the person take the medication), taking the medication themselves to prove its safety, and visiting households before the MDA to promote the treatment (Krentel et al., 2013). Although there are many benefits to using CDDs in MDA programs, there are also some inherent risks. For example, in certain African communities, some people are less likely to comply if they perceive the person distributing the medication as unable to do their job well or lacking knowledge about the disease and its treatment (Yirga, Deribe, Woldemichael, Wondafrash, & Kassahun, 2010). Despite this difficulty, the benefits of using CDDs for MDA programs, including the substantially

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lower costs associated with the use of volunteers, arguably far outweigh the risks (Corley et al., 2016).

### CONCLUSION

The next day, Myriam met Emmanuel at the Ministry of Health and Public Hygiene. After briefly catching up, they delved into the task at hand. Emmanuel started to feel apprehensive as he learned more about the funding it would require to design and implement this project. His department's budget was already fairly constrained. Fortunately, after inquiring about additional funding sources at the University of Abidjan, Myriam discovered a funding opportunity from the Bill and Melinda Gates Foundation for NTD-related research in Africa that would almost entirely cover the costs of their project. Unfortunately, the grant application to receive this funding was due by the end of the month, so they would have to work quickly to develop and submit a highly detailed and carefully assessed research proposal. By mid-afternoon, they had spread papers across Emmanuel's office and his whiteboards were covered with questions that still needed answers. Who would they need to include in the project and when would they be needed? What research methods should they use for collecting their data? How could they monitor and evaluate the project? Finally, when it was finished, who would need to know the results and how could the results be used? With time being a large constraint, Emmanuel knew he needed to develop a good plan and begin his research project in order to better support CDD volunteers and prevent them from leaving the program. Without these volunteers, the success of future MDAs, as well as Côte d'Ivoire's ability to meet the GAELF's 2020 deadline, would be severely jeopardized.

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## INSTRUCTOR GUIDANCE

### Vanishing Volunteers: The Use of Implementation Research to Improve Support for Community Drug Distributors in Côte d'Ivoire

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*Alison Krentel, MScPH, PhD (Investigator, Bruyère Research Institute and Assistant Professor, University of Ottawa)*  
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#### BACKGROUND

To be implemented successfully, most large-scale public health interventions, such as mass drug administration (MDA) campaigns for the elimination of lymphatic filariasis, require a large extent of human health resources. For several reasons, health workers and volunteer community drug distributors (CDDs) sometimes feel overwhelmed and unsupported in their work, which can cause them to give up their essential roles. In lower middle-income countries such as Côte d'Ivoire, where volunteers tasked with the distribution of antifilarial medications are already in short supply, losing valuable human health resources can ultimately cause MDA programs to fail. As such, it is crucial for implementers to recognize and address any issues with their health intervention plan that may lead to increased attrition among their workforce. Dr. Emmanuel Koffi, one of the neglected tropical disease program managers at Côte d'Ivoire's Ministry of Health and Public Hygiene, recognizes that research is needed to investigate the factors contributing to increased stress and attrition rates among his volunteer CDDs. The steps that he should take to conduct an effective research project, however, remain uncertain. After reaching out to Dr. Myriam Kouamé at the University of Abidjan, Emmanuel has decided that applying an implementation research strategy may be best for this project. Having little experience with this type of research, he has enlisted Myriam's assistance to develop a research plan that will help him identify how he can better support his volunteers. Emmanuel knows that time is short—the 2020 deadline to eliminate lymphatic filariasis in Côte d'Ivoire is fast approaching, and he must act quickly to ensure that the CDDs are well supported if they are to achieve this elimination goal.

#### OBJECTIVES

1. Adopt a systems-thinking approach to investigate the contextual factors influencing attrition rates and the resilience of CDDs in Côte d'Ivoire.
2. Apply implementation research principles to formulate a research plan to investigate increasing attrition rates among CDDs and identify feasible solutions to improve volunteer motivation and retention.
3. Identify appropriate members of the research team to ensure that there is a multidisciplinary approach
4. Explain the roles and responsibilities of different stakeholders in managing health human resources for MDA in Côte d'Ivoire to determine who to engage in the implementation research process and how.
5. Discuss the challenges associated with conducting implementation research across different contexts and propose strategies to overcome them.
6. Describe how implementation research can be used to improve health equity among people living in lower middle-income countries.

# Vanishing Volunteers: The Use of Implementation Research to Improve Support for Community Drug Distributors in Côte d'Ivoire

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## DISCUSSION QUESTIONS

Before coming to class, learning teams should use the additional resources provided to help them answer the following questions:

1. What is implementation research?
  - a. How can it be used to identify and address the factors you identified above?
  - b. What are some challenges associated with conducting implementation research in lower middle-income countries?
2. Brainstorm a list of contextual factors that could potentially influence the attrition rate of CDDs conducting an MDA in Côte d'Ivoire. What implications could these factors have for the MDA as a whole? Be prepared to share your list with the class.
  - a. Reflecting on your list of contextual factors, what kinds of researchers do you think should be part of the research team and why?
3. Which stakeholders do you think should be involved in the implementation research process?
  - a. At which point during the implementation research process would you involve each stakeholder? Why?
  - b. Which stakeholders would be interested in the results of the research? What aspects of the research would they be most interested in?
  - c. How would you tailor dissemination of the results of your research to each stakeholder?
4. What research methods would you use and what kinds of data would you collect? (e.g., quantitative, qualitative, mixed methods). Explain your reasoning.
5. How do you think implementation research can be used to improve health equity in lower middle-income countries?

The key questions that students will have to consider when they develop their research plan during the in-class exercise are:

1. What is the research question that needs to be answered?
2. What steps need to be taken to answer this question?
3. Which data need to be collected? Who should collect these data?
4. Where will these data be collected (i.e., rural communities, urban communities) and why?
5. What research methodologies can be used to collect these data?
6. How will the findings be used? Who will use the findings?
7. What resources are needed to conduct this research? Who can provide these resources?

## KEYWORDS

Community drug distributors; implementation research; lymphatic filariasis; mass drug administration; neglected tropical diseases

## CASE 2

# Hurricanes and Health: A Systems Thinking Approach to Understanding Complexity and Context<sup>1</sup>

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*Regna Darnell, PhD (Professor, Western University)*  
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To Leona Hernandez it looked like a giant gash had been torn from the very fabric that made up life in Roseau, Dominica. Colourful houses looked empty with their roofs torn clear off and the everyday items that make up families' lives were scattered in the street. Telephone poles and palm trees toppled across roads that ended abruptly as landslides and flooding got the better of modern infrastructure (Exhibit 1). It was Monday October 2, 2017, which officially marked two weeks since Hurricane Maria had made landfall on the island of Dominica and forever changed the lives of its residents.

Leona had arrived the previous night in Roseau, the capital of Dominica, and she was tired after eight hours of travelling from Washington, D.C. As a water and sanitation engineer, she had been sent from her corner office in the Emergency Operations Center (EOC) at the Pan American Health Organization (PAHO) headquarters to assist with relief efforts on the ground. Being in the field was one of the things Leona loved most about her job, and she knew her skill set was needed.

The main priority for Leona was to lead the water, sanitation, and hygiene (WASH) coordination group meetings. As in any relief effort post disaster, there was a significant number of partner organizations involved: Dominica Water and Sewage Company Limited (DOWASCO), Caribbean Disaster Emergency Management Agency (CDEMA), United States Agency for International Development (USAID), International Federation of Red Cross (IFRC), Caribbean Electric Utility Services Corporation (CARILEC), and the United Nations Children's Fund (UNICEF), to name a few. Leona was in charge of making sure the organizations were able to fill the necessary response gaps, avoid duplication of effort, and coordinate an effective WASH response. She was also in charge of ensuring that the help each organization provided was in

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<sup>1</sup> *The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of the Secretariat of the Pan American Health Organization concerning the status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by the Pan American Health Organization in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.*

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line with the needs of the people of Dominica. The only way Leona would be able to understand, and advocate for, the needs of different communities would be to visit the people, even in the most remote towns and villages.

### **BACKGROUND**

#### **Small Island Developing States: Defining Vulnerability**

Small Island Developing States (SIDS) are a unique group of nations, including Dominica, recognized by the United Nations as countries confronting distinct environmental and developmental challenges (United Nations, 2015). One of these challenges is the high vulnerability to climate change impacts these nations face despite contributing very little to climate change themselves. With a total population of fewer than 65 million inhabitants, the combined climate change contribution of these SIDS nations is less than 1% of overall global greenhouse gas emissions (United Nations, 2015). However, it is projected that SIDS will experience significant changes to their average temperature, rainfall levels, and sea levels in the coming decade (United Nations, 2015). Most communities, infrastructure, and economic activities are found in the low-lying coastal regions, leaving them especially vulnerable to rising sea levels. Increased risk of tropical storms is another projected impact to SIDS under current climate change predictions (Shultz et al., 2018). Climate change impacts will reach other sectors, devastating both natural environments and social systems. Freshwater security and biodiversity are at risk, and natural environments such as coral reefs are at risk as well. Social systems may also face disruption, particularly with respect to public health, food security, and sustainable development (United Nations, 2015).

#### **Dominica: The Nature Island**

A mountainous island in the Caribbean, Dominica is 750 km<sup>2</sup> and home to 73,162 people (PAHO, 2017). The rugged landscape of the interior has created a narrow band of concentrated development along the coastline where 90% of the residents live, leaving citizens and the infrastructure exposed to the impacts of natural disasters (Global Facility for Disaster Reduction and Recovery, n.d.). Economic development is also vulnerable to natural disasters with the primary drivers of development being agriculture and tourism (Global Facility for Disaster Reduction and Recovery, n.d.).

#### **Hurricane Maria: A Perfect Storm**

During the 2017 hurricane season, the island of Dominica experienced one of the most devastating storms to date. The following is a condensed timeline of events during Hurricane Maria in Dominica (CDEMA, 2017):

Day 1: September 16, 2017, 6:00 p.m. AST

- CDEMA issued a report regarding the formation of Tropical Storm Maria over the Atlantic
- For Dominica, a tropical storm warning was put into effect
- The public was advised to monitor radio or television for progress reports

Day 3: September 18, 2017, 7:00 p.m. AST

- CDEMA updated Hurricane Maria to a category 4 hurricane as it tracked toward the island nation

Day 3: September 18, 2017, 9:35 p.m. AST

- Hurricane Maria made landfall on Dominica with wind speeds of 250 km/h (155 mph), making it a category 5 hurricane

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- Initial reports indicated 100% of the country had been impacted, significant damage had occurred to the housing stock, and there was a need to reestablish communication networks and provide water
- PAHO deployed humanitarian advisors to assist with relief efforts

Day 7: September 22, 2017, 9:00 p.m. AST

- Power and water supplies were disrupted
- Road access was extremely limited due to landslides
- 98% of housing had roof damage and 50% had frame damage, leaving an estimated 17,000 people in need of shelter
- Communications were partially restored
- Daily curfew established from 4:00 p.m. to 8:00 a.m. to ensure people remained indoors

Day 16: October 2, 2017, 9:00 p.m. AST

- 88 shelters remained open—many without power, running water, or proper sanitation, and many faced issues of overcrowding
- Some shelters relied on river water as the primary source of drinking water
- PAHO led the WASH coordination group meetings

### **Providing Technical Cooperation**

The EOC is the heart of the Health Emergencies Department and the touch point for all emergency response operations within the organization (PAHO, n.d.). To ensure PAHO is ready to respond in a timely and effective manner, the EOC is responsible for:

- supporting member countries in assessing the health situation postdisaster
- supporting the coordination of international health assistance
- providing technical cooperation in health-related emergency response activities
- activating and mobilizing institutional response mechanisms (PAHO, n.d.)

Providing technical cooperation includes information management, resource mobilization, and the deployment of experts to the field. Hearing the news of Hurricane Maria, the EOC manager knew it would be important to deploy his best and brightest experts. Having previous experience coordinating a WASH response, Leona was the natural choice to send to Dominica to assist national authorities. Since the start of her career, Leona had been fueled by a mission to create an environment in which all people can be healthy. When she heard the news that she would be deployed, Leona felt ready to tackle the many challenges of providing clean water in Dominica posthurricane.

### **PUBLIC HEALTH IMPACTS OF A HURRICANE**

#### **Temporary Shelter from the Storm**

After leaving Roseau on Tuesday and travelling to the very southern edge of Dominica, Leona arrived in Scotts Head—a small fishing village of 800 residents. The single road leading to Scotts Head had been severely damaged by Hurricane Maria, which made the trip difficult. Leona was travelling with a few other members of the WASH team—Marco of the International Federation of Red Cross and Red Crescent Societies and Dana of the CDEMA. They were there to visit the temporary shelter site and assess the WASH needs.

Parking the truck and making their way through the village to the shelter at the top of the hill, the team had a view of the whole village—or rather, what had been the village. Not a single tree was left standing, turning the once lush green hills to the colour of dirt, interrupted only by the ruins of houses. Even the ocean looked different, suddenly ominous and unfriendly. Talking to

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residents along the way it was clear that Hurricane Maria had changed the lives of the old and young alike:

*“I can’t believe the village I have been in my whole life looks like this. It’s unrecognizable,” said Charles, who sat on a splintered rocking chair on what used to be his front porch.*

*“I have lived here for 27 years. I never thought a storm could do this.” Emilio scanned his surroundings as he spoke as if he still could not believe this new reality.*

*“My four-year-old daughter sticks her fingers in her ears every time it rains.” Ann remarked as she hugged her daughter Isla closer to her chest. Leona could see the fatigue in Ann’s eyes, but she could also see her incredible strength as she comforted and protected her daughter.*

Impacted by the stories of the residents, the WASH team trio paused outside the elementary school-turned-shelter. There was a river running next to the building and it would have almost been peaceful if Leona could have seen past the devastated landscape. Buckets, empty jerry cans, and other containers had been left alongside the riverbed. When she asked about it, the residents confirmed for Leona that they had no access to running water so they had all been drinking, bathing, and washing their clothing in the river. *This is not good, Leona thought, not good at all...with all the people drinking the same water...and the likely chance of water contamination poststorm...*

### **Linking Environment and Health: Leptospirosis**

Leptospirosis is a zoonotic disease that has the potential to become an epidemic, especially after heavy rainfall conditions (Mwachui, Crump, Hartskeerl, Zinsstag & Hattendorf, 2015). A broad range of animals including livestock, pets, and rodents can act as vectors for transmitting leptospirosis to humans—either by direct contact through infected urine or by indirect contact through the environment (Mwachui et al., 2015).

Leona can’t help but think about the potential for an outbreak of leptospirosis in the shelter after seeing the residents’ heavy reliance on river water and knowing the disease is endemic to the island. She saw people engage in many high-risk activities, such as drinking water from untreated sources, bathing in potentially contaminated water, and eating food that had been exposed to the same water (Centers for Disease Control and Prevention, 2017).

The most common symptoms of leptospirosis mimic influenza and include fever, muscle aches, and headaches. There is a chance that those infected can progress to more severe disease states and can suffer jaundice, respiratory problems, organ failure, meningitis and, in rare instances, death (Centers for Disease Control and Prevention, 2018).

Leptospirosis is rarely spread through person-to-person contact; however, an outbreak risk is present when a large number of people use the same drinking water source (Centers for Disease Control and Prevention, 2018). The best way to prevent an outbreak of leptospirosis is to avoid contaminated water sources. Thinking of different ways the WASH team can address the environmental health risk, Leona started to brainstorm solutions, keeping the WASH gold standards in mind (The Sphere Handbook, 2018).

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### Water and Sanitation

The current gold standard for water supply, sanitation, and hygiene promotion is set by the Sphere Project. *The Sphere Handbook* (2018) lists several key activities for WASH programs including promoting good hygiene practices, providing safe drinking water, and reducing environmental health risks. According to the guidelines, the key indicators for access and water quality include:

- Average water use for drinking, cooking, and personal hygiene for each person in any household is at least 15 L/day
- The maximum distance from any household to the nearest water point is 500 m or less (Sphere, 2018)

In addition, general guidelines are provided for the amount of water needed per person per day (adapted from *The Sphere Handbook*, 2018):

Survival needs: water intake (drinking and food)	2.5 L/day to 3 L/day	Depends on the climate and individual physiology
Basic hygiene practices	2 L/day to 6 L/day	Depends on social and cultural norms
Basic cooking needs	3 L/day to 6 L/day	Depends on food type and social and cultural norms
<b>Total basic water needs</b>	<b>7.5 L/day to 15 L/day</b>	

The Sphere guidelines also note that WASH responses should minimize damaging environmental impacts and enhance the long-term goals of the community (Sphere, 2018).

Had the damaging environmental impacts been minimized here? Leona wasn't sure and, while she knew there wasn't a simple solution, she was committed to working with the Scotts Head residents to get them clean water. Leona, Marco, and Dana were quiet as they made their way back down the hill to the truck, each thinking of what they had seen and scribbling field notes to help fill out the official report later.

Dana broke the silence, "I'm really worried about the conditions in the shelter..."

Leona jumped in immediately, "I agree, the conditions are not good."  
Finishing her sentence Dana continued, "mental health has to be our number one priority."

"Mental health?" Leona and Marco exchanged a look of surprise. Unsure of what to say next, Leona proceeded cautiously. "Okay, I'm interested to hear your thoughts on this Dana. What does mental health have to do with water security?"

### Physical Health and Mental Health

"Ever heard of solastalgia?" Dana asked the other two. Both shook their head, wondering what on earth she was talking about. "It boils down to a feeling of being homesick while you're still at home."

"Imagine this, you wake up one day in the same place you have woken up every morning for the past 20 years. Except it's not the same place at all. The trees that used to catch the sunlight, the river that used to bubble along on your walk to town, and your neighbour's sky blue house that stood across the way...all gone overnight. Important places like the rocks by the sea where you

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sat with your grandma, they were swept out by the storm. All you want is for things to go back to the way they were but knowing that's impossible. How would you feel?"

Leona nodded "It's hard to imagine your whole world changing overnight. Then, on top of that, having to live in a shelter environment that doesn't even have running water."

"Exactly," Dana continued, "we cannot ignore the mental health concerns of the residents."

"I agree with you that mental health is important," Marco began, "but I don't think it is more important than providing water in the shelter."

Leona turned her thoughts to trying to balance both concerns. "Maybe by working with the Scotts Head residents we can find a solution that will give them clean water and a way to positively interact with their environment again," she said, thinking out loud.

"But they need water now!" Marco exclaimed, "we don't have time to sit down and come up with different solutions. The only solution is giving them chlorine tablets to purify the river water and remove bacteria. End of story."

Leona looked from Marco to Dana, wondering how the three of them had seen the same shelter, had the same end goal, and yet had such different ideas of what the next step was.

Sensing the group was divided, Marco kept trying to persuade the others. "Our job is to provide families with a way to drink clean water" Marco stated, "So long as they are not drinking river water, their health is not at risk and the job of our organizations is done." Leona thought about Marco's statement... *would their job really be done?*

### **SPECIFIC PROBLEM OF DECISION**

On one hand Leona knew it was important to provide a short-term solution and a way for Dominicans to drink clean water. Marco's chlorine tablets would also reduce the immediate risk of a leptospirosis outbreak. On the other hand, Leona was compelled to explore the more long-term solution that Dana was proposing. A solution that could address mental health concerns and help the residents feel at home once again. But how? It would be more resource intensive, and some organizations were already burned out from responding to the double header of Hurricane Maria after already responding to Hurricane Irma, which had battered the island in 2016.

Questions kept tumbling around Leona's mind. How would she set priorities when responding to the health concerns of a shelter? How should she balance all the competing demands and needs? Which risks are most important to address first: environmental, social, or mental health?

### **CONCLUSION**

As the truck neared the outskirts of Roseau, the three WASH team members had settled into an uncomfortable silence. Leona knew the meeting of the entire WASH team tomorrow would be very important in setting the strategic direction of the response. It needed to happen quickly so the logistics team could begin organizing final details—getting the right materials and expertise to the right place at the right time. In an environment where communication and transportation networks were suboptimal, time was of the essence.

Switching on her phone to see if there was any service, Leona heard two small beeps signalling a new message. Looking at the screen she saw the words:

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*STORM ALERT: POTENTIAL HURRICANE DEVELOPING OFF THE COAST OF DOMINICA*

Speechless, Leona passed the phone to Marco and Dana. What did this mean for the WASH team response? With a new storm approaching, would priorities need to shift or change altogether? Could the small island nation survive another storm?

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### EXHIBIT 1

Roseau, Dominica after Hurricane Maria in October 2017



Source: Pan American Health Organization, 2017.

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### EXHIBIT 2

#### Acronyms used in the Case

EOC—Emergency Operations Center

PAHO—Pan American Health Organization

WASH—water, sanitation and hygiene

DOWASCO—Dominican Water and Sewage Company Limited

CDEMA—Caribbean Disaster Emergency Management Agency

USAID—United States Agency for International Development

IFRC—International Federation of Red Cross and Red Crescent Societies

CARILEC—Caribbean Electric Utility Services Corporation

UNICEF—United Nations Children’s Fund

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## INSTRUCTOR GUIDANCE

### Hurricanes and Health: A Systems Thinking Approach to Understanding Complexity and Context<sup>1</sup>

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#### BACKGROUND

This case examines the complexity of responding to a natural disaster. Leona Hernandez, a water and sanitation engineer from the Pan American Health Organization, is in charge of coordinating the water and sanitation response on the island of Dominica following Hurricane Maria in October of 2017. Upon visiting one of the shelters in the remote fishing village of Scotts Head, she becomes aware of the precarious environmental conditions in the community. Many of the residents are distressed by the complete destruction of their surroundings, and a lack of running water has led to a reliance on drinking from the river. Of immediate concern is the potential for an outbreak of leptospirosis; however, issues of the disaster's impacts on mental health are also emphasized. The Water, Sanitation and Hygiene team members each have a different idea about how to act and which response actions to prioritize. Leona must unite the team and coordinate an effective response, which becomes more complex with another storm system threatening to develop near the island.

#### OBJECTIVES

1. Apply systems thinking to determine the relationship between climate change, natural disasters, human health, and Small Island Developing States.
2. Explore strategies to set priorities and balance competing needs around environmental health and mental health issues following a natural disaster.
3. Use a framework approach to water and sanitation concerns after a disaster and discuss the public health implications.
4. Discuss broader implications of natural disasters and sustainability.

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### DISCUSSION QUESTIONS

1. How important is the role of the environment in determining health? Is it sensitive to change?
2. How do you determine the mental health needs of a community? Who is responsible?
3. How important is the context of a Small Island Developing State? How would the influence diagrams (from the instructor guidance) stay the same and how would they change if we were talking about the response to a hurricane in North America (e.g., Hurricane Harvey in Texas, August 2017)
4. How do you prioritize the response to a disaster? What helps to inform the decision?
5. What does sustainable development mean? Is it about the resilience of the people? The environment? The climate?

### KEYWORDS

Environmental health; mental health; sustainable development; systems thinking

## CASE 3

### The Missing Four Million: Working to Increase the Case Finding Rate for People With TB

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*Shannon L. Sibbald, PhD (Assistant Professor, Western University)*

*“We knew no one who had survived TB or maybe no one spoke about it.” “My doctors had told me not to mention TB to anyone. I realised that there is a silence around TB as if it were my fault.”*

— Nandita Venkatesan, TB Survivor

*“It can be a terrible stigma for your neighbors to know that you have tuberculosis or HIV, so our workers must be savvy enough to know what to look for, and to read between the lines in conversations.”*

— Unknown Author, Operation ASHA

Paru Hari lives in Bihar, one of the poorest states in India. As an Accredited Social Health Activist (ASHA), she is involved in daily outreach within her community to conduct home visits, facilitate community member access to health care facilities, administer medications, treat minor ailments, and generate health awareness. The majority of her work involves antenatal checkups, immunizations, and mild sickness treatments. However, with Bihar reporting approximately 70,000 new cases of tuberculosis (TB) annually, and with many cases going unreported and undiagnosed (Fathima, Varadharajan, Krishnamurthy, Ananthkumar & Mony, 2015; RESULTS Canada, 2018a), Paru decided to take action. She proposed that ASHAs act as TB educators and household screeners for patients who have TB because she was tired of watching people in her community suffer and die from a treatable disease.

As a health activist and advocate, Paru not only wanted to gain a better understanding of TB, but she also wanted to understand the barriers and challenges faced by patients who have the disease and what these patients required from ASHA workers. Paru decided to visit Dr. Tisha Guru, Bihar state’s ASHA Program Director, to share her concerns about how to best integrate TB educational activities and household screening programs into her daily routine. For Paru to gain a clear understanding of what she needed to know to identify patients with TB and what they require during diagnosis and treatment, Dr. Guru suggested that she accompany patients from the initial stages of their diagnosis to the completion of their treatment (Exhibit 1).

In the spring of 2014, Dr. Guru introduced Paru to Nadine Vanita, a 23-year-old woman who had twice been a patient of the Bihar Regional ASHA Program. Being young women living in Bihar, the two had things in common. Nadine described her painful battle with TB and its overwhelming and burdensome treatment (Exhibit 1). Listening to the struggles that Nadine had faced throughout her TB journey upset Paru, especially the side effects from the TB medications, the difficulties in her diagnosis and treatment, and the mental and psychological impacts (Exhibit 1).

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Sadly, Nadine's story was not uncommon. Dr. Guru informed Paru that there were many more women living in the rural region of Bihar who had similar experiences. The long distances patients had to travel to access health care facilities only added to their physical, mental, and psychological stress.

Although she did not have an extensive medical background, Paru knew that the ASHA program required a great deal of funding to ensure that it was sustainable and had the necessary resources to allow TB testing and care integration into their daily work. She knew that action needed to be taken, not only to continue the ASHA program but, more importantly, to help people being overlooked by the current health care system. Paru worked with Dr. Guru to identify the key stakeholders who could effectively communicate the critical need for improved TB surveillance and the inclusion of TB educational activities and household screening programs into the services ASHAs provide.

### BACKGROUND

#### Global Burden of Tuberculosis

Tuberculosis is a curable and preventable disease that affects approximately 10 million people annually (World Health Organization [WHO], 2018a). One of the top 10 overall causes of death globally, it is the leading cause of death by an infectious agent (WHO, 2018a). Tuberculosis "is an infectious bacterial disease caused by *Mycobacterium tuberculosis* and is transmitted from person to person via droplets from the throat and lungs of people with the active respiratory disease" (WHO, 2018b). The disease claimed 1.7 million lives in 2016 alone, which is more deaths than those from HIV/AIDS, Malaria, and Ebola combined (RESULTS Canada, 2018b; WHO, 2018a). Despite global efforts to eradicate the disease, TB continues to be a major public health concern, largely in South-East Asia and in some African countries (Singh et al., 2017). In 2016, an estimated 45% of TB cases occurred in South-East Asia, followed by 25% in Africa, 17% in the Western Pacific Region, 7% in the Eastern Mediterranean Region, 3% in Europe, and 3% in the Americas (WHO, 2018a). What is even more alarming is that TB is currently the number one infectious killer worldwide, with an estimated 10.4 million people falling ill annually (Global TB Caucus, 2017). Of this total, 4 million people are undiagnosed, untreated, and/or missed by the health care system entirely, leaving TB more likely to spread and contribute to the 1.7 million deaths attributed to the disease each year (Global TB Caucus, 2017; WHO, 2018a). It is projected that this disease burden will cost the global economy approximately 1 trillion US dollars by 2030 if action is not taken to reduce its spread (United Nations, 2018).

#### The United Nations Sustainable Development Goals and the End TB Strategy

The Sustainable Development Goals include 17 goals that follow the Millennium Development Goals and offer a "universal call to action to end poverty, protect the planet, and ensure that all people enjoy peace and prosperity" (United Nations Development Programme, 2018). The third Sustainable Development Goal aims to "ensure healthy lives and promote well-being for all at all ages," which includes putting an end to the TB epidemic by 2030 (WHO, 2018a). In addition, the 2014 World Health Assembly introduced the WHO End TB Strategy and called on governments to help with the goal to end the global TB epidemic (WHO, 2018a). Global targets set for the year 2020 aim for a 35% reduction in TB deaths and a 20% reduction in the TB incidence rate (Exhibit 2, WHO, 2018a). Although the annual global TB mortality rates and TB incidence rates are declining each year by approximately 3% and 2%, respectively, these rates need to decline by 4% and 5%, respectively, and the TB case mortality rates need to drop from 16% to 10% by 2020, to successfully reach the first milestones (WHO, 2018a). If the actions outlined in the strategy are not taken, it has been predicted that it will take more than 150 years to end the TB epidemic and achieve the 2030 targets (RESULTS Canada, 2018).

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### **Tuberculosis in India—A Focus on Bihar**

India is considered by the WHO to be a ‘high burden’ country for TB, with two people dying from tuberculosis every three minutes, approximately 1 million people not receiving care for the disease each year, and a further 10 million people spending years suffering from the disease as a result of this lack of care (RESULTS Canada, 2018b; WHO, 2018a). Of the 29 states in India, Bihar alone reports approximately 70,000 new cases of TB annually, with many people affected by TB missed by the health care system (Fathima et al., 2015); Global TB Caucus, 2017; Know India, n.d.; RESULTS Canada, 2018b). Bihar is the third most densely populated state in India, has one of the highest population growths in the country, and has more than 325 people/km<sup>2</sup> (Noble, Dayal, & Dutt 2018; World Health Partners, n.d.). The state is predominantly rural, with 85% of the population residing in compact or clustered villages, and it continually falls below other Indian states in per capita income, with more than half the residents living in poverty (Noble et. al., 2018; RESULTS Canada, 2018b; World Health Partners, n.d.).

### **Health Care, Equity, and Equality in India**

As a result of health care expenditures, approximately 39 million Indian citizens fall into poverty each year, and this number is steadily increasing (Balarajan et al., 2011). This number illustrates India’s challenges in responding to the needs of its most disadvantaged and marginalized populations, and emphasizes the ‘inverse care law’, which states that “those with the greatest need for health care have the greatest difficulty in accessing health services and are least likely to have their health needs met” (Balarajan et. al., 2011, page 3). Many of the health inequities experienced by India’s population result from social, economic, and political factors such as variations in gender, caste (social divisions in which each social group has privileges and limitations passed down through familial generations), wealth, education, income, resource allocation, and physical access (Balarajan et. al., 2011). These inequities are further compounded by rural–urban inequalities in the provision of health care services. In rural India, which accounts for 67% of the overall population, access to health care services is significantly more limited than it is in urban centers (Singh-Cheema, 2017). This has led to 67% of the population facing significant barriers to care (Singh-Cheema, 2017). People living in rural communities are often forced to travel long distances to reach health care facilities, which can lead to lost wages, unemployment, and difficulties in finding childcare (Singh-Cheema, 2017).

India’s public health care system is further plagued by a shortage of health care professionals. In 2016, the country reported a shortage of 500,000 doctors, which primarily affected India’s poorest states of Bihar, Uttar Pradesh, Madhya Pradesh, and Rajasthan (Singh-Cheema, 2017). Despite the effort of nongovernmental organizations to introduce initiatives aimed at combatting India’s inequitable health care system and increasing access to health care for its rural populations, additional funding is required to create sustainable programs that include more training, equipment, and medications (Singh-Cheema, 2017).

### **A Sign of Hope—ASHAs**

Bihar has 82,000 ASHAs for a population of 100 million people (Das et al., 2016). The acronym ASHA also means ‘hope’ in Hindi, and is a title given to formally educated, incentive-based female health workers who are 25 to 45 years of age (Das et al., 2016). Often referred to as “the backbone of primary health care in India’s 600,000 villages”, ASHAs are responsible for overseeing a village of approximately 1000 residents. They are selected by the community, reside in the community, and are trained, deployed, and supported to function in their own villages (Das et al., 2016; Akella, 2017). Accredited under the National Rural Health Mission of the Indian government, an ASHA’s job responsibilities can be broken down into the following three key components (Akella, 2017; Fathima et. al. 2015):

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- link worker (facilitating access and accompanying women and children to health care facilities);
- community health worker (distributing medicines and treating minor ailments); and
- health activist (creating health awareness and a desire for community change).

Essentially, ASHAs act as liaisons between villagers and the public health system (Das et al., 2016). Despite promoting critical health practices such as immunization programs, referrals for maternal, pediatric, sexual, and reproductive health care, and referrals for other critical health care-related activities, ASHAs only receive small incentives (Das et al., 2016).

### WORKING TO INCREASE THE CASE-FINDING RATE FOR PEOPLE WHO HAVE TUBERCULOSIS

Paru and Dr. Guru agreed that there was a need for health care workers to be more proactive in TB diagnosis and detection. They believe that this approach to health care delivery would be most effective at improving the TB case detection rate and increasing care access at the community level. Dr. Guru and Paru also believe that this is when the government and civil society must work together to introduce, implement, and advocate for “innovative and ground-breaking techniques, interventions, approaches, and activities that result in detecting the undetected TB cases, leading to a reduced rate of transmissions and preventing the emergence of drug-resistant forms of TB” (Stop TB Partnership, 2018). Dr. Guru knew that if more residents of Bihar could be reached through improvements to the current health care system, then the case-finding rates for people who have TB would increase, which would positively affect the lives of people in Bihar and across India.

### THE CHALLENGES—BARRIERS IN BIHAR

As per findings from Li et al. (2017), Dr. Guru and Paru discussed the high TB burden and regional inequities in accessing health care. They knew that the TB case-finding strategies were not sufficient and that the health facilities that ASHAs must link patients with are often under-resourced and badly equipped (Saprii, Richards, Kokho, & Theobald, 2015). Unfortunately, this was often because the residents of Bihar faced complex barriers pertaining to money, power, and resources at global, national, and local levels (Viner et. al., 2012). Paru knew that incorporating TB educational activities and household screenings into her daily work would not be easy. As a female resident of Bihar herself, Paru was familiar with many of the social determinants of health that made it challenging for the people of Bihar to access care.

### Social Determinants of Tuberculosis

India has many of the adverse structural and social determinants that contribute to tuberculosis epidemiology (Exhibit 3), which include social, economic, and political inequalities such as variations in gender, caste, wealth, education, income, resource allocation, and physical accessibility, as well as high levels of mobility, rapid urbanization, and population growth (Balarajan et. al., 2011; Hargreaves et. al., 2011).

Paru knew that Bihar in particular had many social determinants of health that presented challenges for patients who have TB. These determinants include poverty, poor ventilation, overcrowding, power imbalances, gender discrimination, food insecurity, malnutrition, lack of health care workers and health care services, low health literacy, lack of education, low socioeconomic status, and poor sanitation, as well as financial, geographic, and cultural barriers to access (Exhibit 3; Hargreaves et. al., 2011; RESULTS Canada, 2018a). Women face additional challenges in accessing care, particularly in terms of travel, with trips to health care facilities often taking hours to days. These long distances put further strain on their already

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compromised immune systems and add to the other stresses they endure, which include finding child care, missing work, losing employment, being harassed, and facing gender-based violence (Hargreaves et. al., 2011; RESULTS Canada, 2018a; Singh-Cheema, 2017).

### **Deficiency of Human Resources**

As a doctor herself, Dr. Guru was keenly aware of the shortage of doctors and warned Paru that patient demands far exceed doctor supply. Dr. Guru and Paru knew this deficit was most prominent in India's poorest states, one of which was Bihar (Singh-Cheema, 2017). Further compounding the doctor shortage was the severe shortage of other health workers such as dentists, nurses, and midwives, among others (Exhibit 4; Hazarika, 2013). Ultimately, human resource shortages are negatively impacting the scale-up and expansion of health services, leading to overburdened health care systems and underserved communities (Hazarika, 2013).

### **THE ACTION PLAN—WHO IS INVOLVED?**

#### **Community Level Engagement**

Dr. Guru decided to accompany Paru on her daily home visits in an effort to best engage the community members and better understand their needs. As an ASHA worker and a member of the community, Paru had already established trusting and meaningful relationships with her patients; because she addressed the needs of these rural and marginalized populations, the community valued her opinions and trusted her judgement.

#### **Regional Stakeholder Engagement**

Dr. Guru and Paru requested a meeting with the National Rural Health Mission, the governing body that oversees management of the ASHA program within the Ministry of Health and Family Welfare. During the winter of 2014, they were invited to the Health Mission's annual meeting to discuss their concerns with national-level stakeholders involved in rural health issues. They communicated the critical need to improve TB screening and expand the role of ASHAs to include TB educational activities and household TB screening in their duties. Attendance at this annual meeting was crucial because it is where policy decisions, program plans, and budget approvals are made at the national level for state-level issues, including challenges pertaining to ASHA training, supervision, performance monitoring, and resources (K4Health, n.d.).

#### **National and Global Partners**

Dr. Guru and Paru then looked to TB REACH, a multilateral funding partnership that uses a 'Transition to Scale Up' grants framework to guide and support grantees who are providing innovative approaches and techniques to support, care, treat, and prevent TB among the world's hardest-to-reach populations (RESULTS Canada, 2018b; Stop TB Partnership, 2018). Paru was particularly excited that, if this initiative were successful, the program would be scaled-up and move beyond TB REACH to support National TB Programs and other external agencies (Stop TB Partnership, 2018). Through the TB REACH program, funding would go toward training, assisting, and providing resources to integrate TB testing and care into the daily community health work undertaken by ASHAs (RESULTS Canada, 2018b).

Dr. Guru also introduced Paru to Sherry Graham, TB Officer for RESULTS India. RESULTS India is a civil society organization that advocates for political support in ending extreme poverty through vaccination and immunization, HIV/AIDS, TB and malaria, water and sanitation, and maternal, newborn, and child health campaigns (RESULTS Canada, 2014). RESULTS India and its citizen advocates are known for their strong and successful history of campaigning for TB REACH India (RESULTS Canada, 2018a). Dr. Guru believed that working with RESULTS India would allow Paru to increase the TB REACH program in the Bihar area.

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After discussing this with Sherry further, Paru discovered that, in 2016, the Government of Canada had announced a funding commitment of \$85 million dollars to support another five years of international TB innovation grants (RESULTS Canada, 2018a). This was a small portion of Canada's Official Development Assistance budget, but Paru and Sherry knew that it could have a huge impact in helping organizations "understand and improve the community impact of their projects and how they might work to reach more people missing out on TB care and cure" (RESULTS Canada, 2018a).

### **THE IMPACT OF ASHAs—ASHAs TO THE RESCUE**

Paru and Dr. Guru decided to research and reflect on the impact ASHAs have had on population health outcomes so far. From their own experiences, Paru and Dr. Guru knew that ASHAs had been successful in improving maternal, newborn, and child health through their active involvement in the reduction of infant polio, malnutrition, and mortality rates in Indian villages (Akella, 2017).

After interacting with community members, civil society organizations, and advocates, Paru and Dr. Guru knew that ASHAs have had a positive impact on the health outcomes of the people of Bihar. When working with rural Indian women diagnosed with AIDS, ASHAs have helped reduce stigma and isolation by promoting active coping techniques and dialogue (Nyamathi et. al., 2013). This has been important in reducing the incidence and prevalence of psychological distress and in increasing the number of people actively seeking access to health care services and adhering to treatments (Nyamathi et. al., 2013). Paru and Dr. Guru wondered whether ASHAs would have the same success in reducing the stigma and stress associated with TB.

After researching Operation ASHA, a not-for-profit organization serving two states in Cambodia and eight states in India (but not Bihar), Paru and Dr. Guru were pleased to learn that ASHAs had successfully reached 6.1 million people who have TB in more than 3,000 slums, villages, and other disadvantaged, hard-to-reach communities (Operation ASHA, 2013). ASHA intervention increased TB detection rates from 50% to 400% over 6 to 18 months, increased job retention via employer counselling, and increased mental health treatment and physician referrals for people who have comorbidities, such as diabetes (Operation ASHA, 2013). This intervention also led to a treatment success rate of 87% (Operation ASHA, 2013). Paru and Dr. Guru were thrilled about these successes because they had learned that, if left untreated, patients who have TB can infect up to 12 people before they die (The Wharton School of Business, 2018). Furthermore, the economic benefits of intervention were vast, with the treatment of one person who has TB having the potential to save the community up to US\$12,000 in medical costs, simply by preventing the spread of the disease (The Wharton School of Business, 2018).

They also learned that not only are ASHA programs proven to be high impact, low-cost, and scalable, but ASHAs are considered to be fundamental at a grass-roots level in providing services to people at their doorsteps (The Wharton School of Business, 2018; Sateesh & Kumar, 2017). As they had suspected, ASHAs were viewed as a sustainable resource that can have a vast impact on vulnerable, marginalized, and hard-to-reach populations (Nyamathi et. al., 2013). They read about other patient encounters with ASHAs and were pleased to learn that patients who have TB noted significant benefits from working with ASHAs. ASHAs ensured that patients who have TB took their daily medications and felt less stigmatized and isolated, and they had an overall positive impact on their patients' mental and physical health (Centers for Disease Control and Prevention, 2013). This was encouraging news for Dr. Guru and Paru; however, they knew that to effectively reach their target population, ASHAs would require

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appropriate training and their services would have to be developed properly (Sateesh & Kumar, 2017).

### **MAKING A DECISION—TO TRAIN OR NOT TO TRAIN?**

Dr. Guru now felt it was critical to introduce an ASHA training program in Bihar to help patients who have TB get diagnosed and treated early. She decided to meet with each ASHA worker in her region to conduct interviews, solicit feedback, and collect patient data. An ASHA worker's only option for monitoring and surveillance was via handwritten medical records because community Internet access was very limited. Dr. Guru and Paru listened to the ASHAs' concerns and brainstormed ideas for increasing TB training that would enable ASHAs to deliver improved health care services to the people of Bihar. Their preference was to develop online training modules, mobile apps, and interactive websites; however, limited electricity, impoverished conditions, and poor infrastructure made it too difficult for most people to have a reliable Internet connection. Consequently, their only option was to create and distribute hard copy resources, although they knew that this introduced further challenges. Dr. Guru and Paru would need to:

- create a comprehensive and culturally appropriate training manual that could benefit all ASHAs working in the various villages of Bihar,
- ensure sufficient monitoring and surveillance of the manual,
- consider appropriate methods that could be used to assess the effectiveness of the training,
- determine how to cover the costs needed for program development and implementation, and
- consider which stakeholders they needed to engage to ensure that the training is effective and implemented at the community level.

### **CONCLUSION—MOVING FORWARD**

Paru and Dr. Guru were unsure how it would all come together but they believed that they could meet their goals. They had passion, persistence, determination, and a strong group of advocates on their side.

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### EXHIBIT 1

#### Paru's Story— Battling Tuberculosis as a Public Health Professional

With a better understanding of the interconnectedness of structural and social determinants of health faced by the residents of Bihar, Paru and Dr. Guru decided that Paru should accompany Nadine through the treatment process step-by-step. This would be the best way for them to make the greatest impact in increasing the number of people who receive TB treatment and in understanding the complex journey faced by patients who have the disease.

Nadine warned Paru that it is harder for Indian women to survive TB than it is for Indian men because of the significant stigma society places on women who have the disease. When women acquire TB, they are blamed for contracting the disease, shamed, isolated, and silenced because many people believe that the women become sick after engaging in “risky behaviour” (Nyamathi et. al., 2013; Survivors Against TB, 2018). This is especially true for Indian women. Because they have low literacy rates, education levels, and employment opportunities, they often lack autonomy, decision-making capacity, and awareness about TB and its negative health implications (Nyamathi et. al., 2013). Nadine continued to share her story, noting that women and girls are often forbidden to disclose their diagnosis. There is a strongly held fear that they will be seen as ‘damaged’, which threatens their hopes of getting married and having children (Nyamathi et. al., 2013; Survivors Against TB, 2018).

Nadine was an 18-year-old college student when she was first diagnosed with an unknown viral infection that she contracted during the rainy season. When the rains ended and her cough persisted, she returned to the doctor to undergo a series of tests. As a consequence of ill-equipped hospital staff and the attitudes of many health care professionals who still stigmatized the disease, Nadine was left to diagnose her own illness. Her condition worsened until she began coughing up blood. Having heard stories of others who had similar symptoms, Nadine suggested that the staff conduct a computed tomography scan to check for TB (Survivors Against TB, 2018).

Not surprisingly, Nadine's concerns came true. During her first year of college exams, Nadine was diagnosed with TB and had to take a daily combination of 15 medications (Survivors Against TB, 2018). She struggled to understand what she was facing and lacked any counselling regarding what to expect, how to adhere to the daily drug regimen, and how to cope with the stigma she experienced from her doctors and her community about her TB diagnosis (Survivors Against TB, 2018). In fact, her doctors repeatedly told Nadine not to discuss her diagnosis with anyone, forcing her to hide her struggle from everyone around her (Survivors Against TB, 2018). As stigma often does, the isolation and fear of judgement for speaking out caused Nadine to suffer further mental health issues and depression (Survivors Against TB, 2018). However, after two long and difficult years battling the disease, Nadine became a survivor—no more medications, no more daily battles—she was free (Survivors Against TB, 2018).

After hearing Nadine's story, Paru realized the magnitude of the silence around TB. She wondered how people suffering from the illness would be able to speak out if Nadine's own doctors refused to listen to her. She assumed this silence was contributing to large numbers of TB cases in Bihar going undiagnosed and unreported each year.

At the age of 23, Nadine found herself in the same situation again, although this time she had Paru by her side. Nadine told Paru how she felt and reported the similar coughing and painful symptoms she had experienced years earlier (Survivors Against TB, 2018). Under Paru's

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supervision, the two women travelled to the nearest health care facility, which was a full day trip of walking and taking public transit. They registered Nadine at a costly private health care facility where she was prescribed antiviral medications. Again, these medications failed and her pain worsened. They returned to the doctor after another long day of travel and Nadine underwent another series of tests. After weeks of waiting for a diagnosis, Nadine was told that her worst fear had come true. She was diagnosed with a TB reinfection, but this time it was a drug-resistant form of the disease. Nadine was told she needed to undergo surgery to remove part of her lung, and that this required a lengthy hospital stay and a trial-and-error drug regimen to find a combination of medications that would work with her daily anti-tuberculosis injections.

Paru accompanied Nadine to her family's home, a small shelter with poor ventilation that housed ten family members. Nadine was forced to leave her already low-paying job and had to inform her family about her high medication costs, the length of her upcoming hospital care and drug treatment, and her lack of access to individualized testing for drug susceptibility. This type of testing specifically determines the drug susceptibility of the TB bacteria a patient is infected with to help determine an optimized treatment plan (WHO, 2010). Paru listened as Nadine's family struggled to find ways to pay for their ailing daughter's treatment while still paying for food and housing costs and caring for elderly family members who had health complications from malnutrition.

Nadine was sent back to the hospital for several months this time because drug-resistant TB is much more difficult to treat, and patients are often quarantined for fear that the dangerous strain of the bacteria will continue to spread. Paru visited Nadine as often as possible during her stay in the hospital to reassure her that she would get through this as she had done once before.

However, nothing could have prepared Paru for her third visit, which was two days after Nadine's 24th birthday. Upon her arrival, Paru was notified that Nadine had permanently lost her hearing, leaving her feeling lost and confused. This was a side effect of one of the many medications Nadine had been taking that had not been disclosed by any health care professional.

Paru knew that she needed to help others before they too had to experience what Nadine and her family had faced. Paru took Nadine's story back to Dr. Guru and pleaded for her to help increase TB training for ASHAs.

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## EXHIBIT 2 The End TB Strategy at a Glance

### BOX 2.3

#### The End TB Strategy at a glance

<b>VISION</b>	<b>A WORLD FREE OF TB</b> — zero deaths, disease and suffering due to TB			
<b>GOAL</b>	<b>END THE GLOBAL TB EPIDEMIC</b>			
<b>INDICATORS</b>	MILESTONES		TARGETS	
	2020	2025	SDG 2030 <sup>a</sup>	END TB 2035
<b>Percentage reduction in the absolute number of TB deaths</b> (compared with 2015 baseline)	35%	75%	90%	95%
<b>Percentage reduction in the TB incidence rate</b> (compared with 2015 baseline)	20%	50%	80%	90%
<b>Percentage of TB-affected households experiencing catastrophic costs due to TB</b> (level in 2015 unknown)	0%	0%	0%	0%

#### PRINCIPLES

1. Government stewardship and accountability, with monitoring and evaluation
2. Strong coalition with civil society organizations and communities
3. Protection and promotion of human rights, ethics and equity
4. Adaptation of the strategy and targets at country level, with global collaboration

#### PILLARS AND COMPONENTS

##### 1. INTEGRATED, PATIENT-CENTRED CARE AND PREVENTION

- A. Early diagnosis of TB including universal drug-susceptibility testing, and systematic screening of contacts and high-risk groups
- B. Treatment of all people with TB including drug-resistant TB, and patient support
- C. Collaborative TB/HIV activities, and management of comorbidities
- D. Preventive treatment of persons at high risk, and vaccination against TB

##### 2. BOLD POLICIES AND SUPPORTIVE SYSTEMS

- A. Political commitment with adequate resources for TB care and prevention
- B. Engagement of communities, civil society organizations, and public and private care providers
- C. Universal health coverage policy, and regulatory frameworks for case notification, vital registration, quality and rational use of medicines, and infection control
- D. Social protection, poverty alleviation and actions on other determinants of TB

##### 3. INTENSIFIED RESEARCH AND INNOVATION

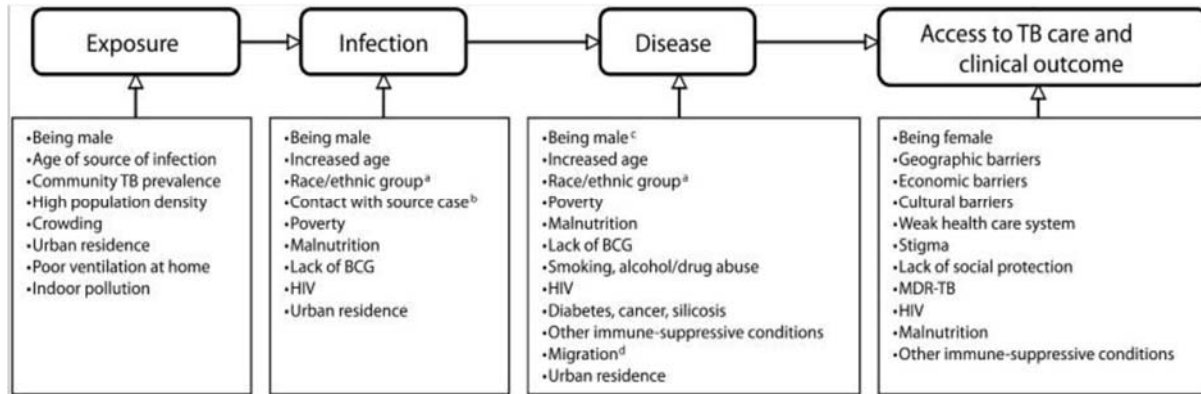
- A. Discovery, development and rapid uptake of new tools, interventions and strategies
- B. Research to optimize implementation and impact, and promote innovations

<sup>a</sup> Targets linked to the Sustainable Development Goals (SDGs).

Source: World Health Organization, 2018a.

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### EXHIBIT 3 Social Determinants of Tuberculosis (TB)



Source: Hargreaves, et. al., 2011. Reproduced with permission from The Sheridan Press.

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### EXHIBIT 4 Availability of Human Resources in India

**Table 1: State-wise availability of doctors, dentists, nurses and midwives – 2009**

States	Population (million) <sup>a</sup>	Health-worker numbers <sup>a</sup>				Health-worker density per 1000 population				Ratio of nurses and midwives per doctor
		Doctors	Dentists	GNMs	ANMs	Doctors	Dentists	Nurses and midwives	Combined <sup>a</sup>	
Andhra Pradesh	83.11	62 349	6510	136 477	112 269	0.75	0.078	2.99	3.74	3.99
North-east states <sup>b</sup>	49.84	19 324	944	20 285	23 375	0.39	0.019	0.88	1.26	2.26
Madhya Pradesh	70.28	25 662	2002	96 574	27 566	0.37	0.028	1.77	2.13	4.84
Bihar	100.94	36 559	2807	8883	7501	0.36	0.028	0.16	0.52	0.45
Chhattisgarh	24.85	2746	407	3945	1900	0.11	0.016	0.24	0.35	2.13
Goa	1.37	2716	687	N/A	N/A	1.99	0.503	N/A	N/A	N/A
Gujarat	58.76	45 058	2684	88 258	36 427	0.77	0.046	2.12	2.89	2.77
Haryana <sup>c</sup>	24.51	4132	2059	17 821	13 727	0.17	0.084	1.29	1.46	7.64
Himachal Pradesh	6.72	705	772	8550	10 152	0.10	0.115	2.78	2.89	26.53
Jammu and Kashmir	12.22	10 906	1090	N/A	N/A	0.89	0.089	N/A	N/A	N/A
Jharkhand	32.06	2933	NA	1998	3405	0.09	NA	0.17	0.26	1.84
Karnataka	59.86	83 177	25 612	136 421	48 509	1.39	0.428	3.09	4.48	2.22
Kerala	32.90	37 835	6655	85 624	28 378	1.15	0.202	3.46	4.61	3.01
Maharashtra	109.27	134 859	18 159	93 032	33 158	1.23	0.166	1.15	2.39	0.94
Orissa	41.20	16 734	537	63 167	49 170	0.41	0.013	2.73	3.13	6.71
Punjab <sup>c</sup>	27.07	38 434	7348	45 801	18 152	1.42	0.271	2.36	3.78	1.66
Rajasthan	66.42	27 654	364	37 667	22 239	0.42	0.005	0.90	1.32	2.17
Tamil Nadu <sup>d</sup>	71.20	84 525	11 609	186 972	54 124	1.19	0.163	3.39	4.57	2.85
Uttar Pradesh	192.62	55 355	5572	21 042	27 328	0.29	0.029	0.25	0.54	0.87
West Bengal	89.65	58 059	2054	48 470	56 302	0.65	0.023	1.17	1.82	1.80
Uttaranchal	9.82	3085	451	92	700	0.31	0.046	0.08	0.39	0.26
Delhi	15.83	8999	6280	26 547	2160	0.57	0.397	1.81	2.38	3.19
India	1183.56	761 806	104 603	1 127 626	576 542	0.64	0.088	1.44	2.08	2.24

GNM=General Nursing and Midwifery, ANM=Auxiliary Nurse Midwifery, N/A=data not available <sup>a</sup>Population data and health-professional statistics for 2009 from references 9-14; <sup>b</sup>include Assam, Manipur, Meghalaya, Mizoram, Nagaland, Tripura and Sikkim; <sup>c</sup>include data from Chandigarh proportionate to state populations, <sup>d</sup>includes the Union Territories, i.e., Chandigarh, Puducherry, Daman and Diu, Lakshwadeep, Andaman and Nicobar and Dadar Nagar Haveli; includes doctors, nurses and midwives

Source: Hazarika, 2013.

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## INSTRUCTOR GUIDANCE

### The Missing Four Million: Working to Increase the Case Finding Rate for People With TB

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#### BACKGROUND

Paru Hari, an Accredited Social Health Activist (ASHA), lives in Bihar, India, one of the poorest states in the country. Paru is involved in daily outreach within her community to facilitate community member access to health care facilities, administer medications, treat minor ailments, and generate health awareness. The majority of her work involves antenatal checkups, immunizations, and mild sickness treatments. However, with Bihar reporting approximately 70,000 new cases of tuberculosis (TB) annually and many cases going unreported and undiagnosed (Fathima, Varadharajan, Krishnamurthy, Ananthkumar & Mony, 2015; RESULTS Canada, 2018b), Paru decided to take action. She proposed that ASHAs act as TB educators and household screeners for patients who have TB because she was tired of watching people in her community suffer and die from a treatable disease.

Paru decided to visit Dr. Tisha Guru, Bihar state's Regional ASHA Program Director, to share her concerns about how best to integrate TB educational activities and household screening programs into her daily routine. For Paru to gain a clear understanding of what she needs to know to identify TB patients and what they require during diagnosis and treatment, Dr. Guru suggested that she accompany patients from the initial stages of their diagnosis through to treatment. Although Paru did not have an extensive medical background, she knew that the ASHA program required a great deal of funding to ensure it was sustainable and that the necessary resources were available for TB testing and care to be integrated into their daily work. Paru knew action needed to be taken, not only to continue the ASHA program but, more importantly, to help patients who were being overlooked by the current health care system. Paru worked alongside Dr. Guru to identify the key stakeholders who could effectively communicate the critical need for improved TB surveillance, educational activities, and household screening programs into the services ASHAs provided.

The goal of this case is to provide readers with the opportunity to develop a real-world, case-based, health care narrative by applying the key theories and concepts learned in the classroom. These concepts include:

1. the knowledge of international health care system components (governance, finance, and organization)
2. potential issues and/or barriers in health care implementation and achieving the Sustainable Development Goals
3. the importance of health equity and cultural competence
4. the relationship between primary health care and public health care, and
5. the seven steps to achieving informed decision making.

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This case will provide students with the opportunity to define the challenges associated with developing effective and equitable health care programs, and to understand and explain how people with infectious diseases are impacted by the social determinants of health (i.e. the role these determinants play in disease development). Students will also be able to brainstorm strategies for:

- identifying and engaging stakeholders and building partnerships for influencing public health outcomes;
- generating culturally appropriate public health content that can be delivered verbally and in writing to marginalized populations;
- applying the social determinants of health to health care and health outcomes; and
- creating effective responses that have culturally and context-relevant strategies for improving population health and reaching marginalized populations at the community level.

### **OBJECTIVES**

1. Describe the challenges in developing effective programs in terms of health care and health equity in India.
2. Understand and explain the impact that social determinants of health have on people who have TB, and the role these determinants have in disease development.
3. Propose strategies to identify and engage stakeholders and build partnerships for influencing public health outcomes.
4. Identify culturally appropriate public health content for TB educational programs that can be distributed, both in written and verbal form, to the marginalized populations of Bihar.
5. Formulate an effective response that includes community level approaches and culturally and context-relevant strategies to improve population health for the marginalized populations of Bihar, India who are facing high rates of undiagnosed and unreported TB cases.

### **DISCUSSION QUESTIONS**

1. What is the main problem or issue discussed in the case?
2. Who are the key players in the case and what are their roles?
  - a. Do you feel that the ASHA program is appropriate for increasing the TB case-finding rate?
  - b. Do you have any other ideas or strategies for creating sustainable programs that would be effective in this scenario?
3. What are the differences between the social and structural determinants of TB?
4. How could Dr. Guru and Paru create a comprehensive and culturally appropriate training manual that can benefit all ASHAs working in the villages of Bihar?
  - a. Do you think creating such a manual is possible? Why or why not?
5. How could Dr. Guru and Paru ensure sufficient monitoring and surveillance of the manual's success?
  - a. Can you think of any techniques, strategies, theories, or frameworks they could use?
6. What methods could Dr. Guru and Paru use to assess the effectiveness of the training?
  - a. Would you use quantitative or qualitative data collection methods, or are both appropriate?
7. How would Dr. Guru and Paru cover the costs needed for program development and implementation?
8. Which stakeholders need to be engaged to ensure the training is effective and implemented at the community level?

### **KEYWORDS**

ASHAs; case-finding rate; health equity; social determinants of health; TB burden; tuberculosis

## CASE 4

# Combating the Opioid Crisis: Expanding Naloxone Kit Distribution to Niagara Health Emergency Departments

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### INTRODUCTION

Canada has declared the national opioid crisis a public health emergency that “is a complex health and social issue that needs a response that is comprehensive, collaborative, compassionate, and evidence-based” (Government of Canada, 2018). Opioids—drugs that are used to treat pain—are a highly addictive class of substances available by prescription or by illegal purchase through the black market. In response to this, many provinces are formulating initiatives to combat the crisis. The province of Ontario wants to expand patient accessibility to life-saving harm reduction measures by distributing naloxone kits in hospital emergency departments. Naloxone is a life-saving overdose reversal drug already available at pharmacies and at some community organizations. In response to an increasing number of fatalities from the opioid crisis, the Government of Ontario is prioritizing strategies to address mental health and addictions, specifically targeting the deaths related to these highly habit-forming painkillers. Jessica Corso, a Patient Safety Specialist in the Quality, Patient Safety, and Risk Department at a regional hospital system, has been tasked with introducing this program to the emergency department frontline staff at the hospitals. She has already faced staff reluctance to and disapproval about its implementation. One frontline charge nurse referred to the harm reduction strategy of distributing naloxone kits as “enabling drug users”. Jessica quickly realized that there are serious misconceptions about harm reduction with regard to addictions, and that preconceived notions among hospital workers in the hospital social environment would need to be addressed before implementation took place. Jessica is faced with the task of introducing and explaining the idea of social determinants of health and health equity to health care workers, as it relates to harm reduction and the opioid crisis in this clinical setting. Since health and health care have primarily been viewed through a biomedical lens, hospital staff needed to embrace a more socio-ecological understanding of health if this new initiative were to be successful.

### BACKGROUND

#### Hospital System

This case presents a fictional health system in a fictional region of Ontario to illustrate its intent. This particular hospital system consists of five hospital sites. It is possible that some of these sites will close and new ones will open in the coming years. These hospital sites serve approximately 500,000 residents across ten municipalities. In terms of education and income—two crucial metrics that indicate a population’s well-being—it is important to note that this hospital system serves a community in which 35% of the population have only obtained a high school diploma, and 20% of the population has not graduated from high school. Additionally, one in four families spends more than a third of their income on shelter costs.

## Combatting the Opioid Crisis: Expanding Naloxone Kit Distribution to Niagara Health Emergency Departments

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As a regional health care system, the five hospital sites provide a wide range of inpatient and outpatient services, including acute care, emergency and urgent care, and mental health and addictions care.

### Opioid Crisis

Along with the United States and other countries, Canada has been grappling with the crisis of opioid addiction and opioid-related deaths for decades and has seen a spike in deaths from the epidemic in recent years. Canada had approximately 4,000 opioid-related deaths in 2017, with 92% of them being unintentional or accidental (Government of Canada, 2018a). From January to October of the same year, Ontario had 1,053 opioid-related deaths (Government of Ontario, 2018a). This represented a 52% increase from the same period in 2016, illustrating the growing concern and severity of the crisis (Government of Ontario, 2018a). The province has many initiatives planned as part of *Ontario's Strategy to Prevent Opioid Addiction and Overdose*, which includes the expansion of harm reduction strategies and education pertaining to this approach (Government of Ontario, 2018a):

In 2006, under Federal legislative authority, the notion of drug users as criminals was reinforced with policies implemented by the Conservative Party of Canada throughout its 10-year term, but specifically in October of 2007 with the release of a National Anti-Drug Strategy. This was a strategy that encouraged the condemnation and criminalization of drug use and drug users. Today, under a Liberal Government, the conversation has shifted slightly from condemning to supporting drug users, with recent initiatives such as support for the expansion of safe injection sites and the expansion of Naloxone as a lifesaving medication for opioid overdose. Conceivably, the social construction of individuals with substance use disorders have important implication for policy outcomes (Morin, Eibl, Franklyn, & Marsh, 2017).

Political and social climates can have a significant ability to sway public opinion on a multitude of topics, but more so on complex issues like addiction. It is important to note that more than 50% of people who have an opioid addiction or substance abuse issue also have mental health issues, further highlighting the complexity of the problem (Morin et al., 2017). Although mental health and addictions are rising health care priorities both federally and provincially, they continue to be highly stigmatized. This persistent stigma is arguably one of the main factors contributing to the ongoing crisis. A disconnect exists between the evidence showing the efficacy of harm reduction measures and public support for such initiatives. This illustrates that cultural and societal attitudes toward substance use, especially the attitudes of health care professionals, have the potential to hinder the introduction and use of evidence-based initiatives.

### Regional Opioid Crisis

The region had a 250% increase in suspected overdoses from 2016 to 2017. The most commonly used opioid was the street drug fentanyl, a highly potent and synthetic opioid that puts users at a very high risk of overdose. The highest incidences of overdoses were in three of the ten municipalities. The 911 calls in these areas concerning overdoses were largely from disadvantaged neighbourhoods that have lower incomes and more households affected by housing vulnerabilities. Understanding the social and environmental factors that correlate with high rates of opioid use and overdoses could better inform equitable and appropriate services that are tailored specifically to the opioid users presenting at emergency departments. If the three hospital sites located in these areas distributed naloxone kits in their emergency departments, they could potentially have a tremendous impact on preventing opioid-related deaths.

## Combatting the Opioid Crisis: Expanding Naloxone Kit Distribution to Niagara Health Emergency Departments

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### **Jessica Corso: Patient Safety Specialist**

Jessica Corso, a leader in the Quality, Patient Safety, and Risk department, has been charged with preparing the hospital system for the introduction of naloxone kits to its emergency departments. With 25 years of nursing experience and a Master of Public Health degree, she has a unique perspective for this role and understands both the clinical and broader socio-ecological perspectives of addiction. She empathizes with the overworked and stressed emergency department nursing staff, and understands their biomedical and clinical patient views when it comes to addictions and substance use. After completing her Master's degree in Public Health and working for several years in quality improvement in a hospital setting, she has a broader understanding of health, recognizing that this care is heavily influenced by social, environmental, and cultural factors. Her department focuses on quality improvement and how to continually enhance patient support. She recognizes that the provincial and national opioid crises do not just stem from negative personal choices and behaviours, but are rather fueled by many social determinants of health (Exhibit 1). She also understands that the stigma associated with substance use only hinders any potential progress in health outcomes. She is a strong supporter of applying harm reduction measures and embracing the concept of health equity. She understands that people's experiences and backgrounds can have profound impacts on resulting health disparities. Her goal is to shift the mentality of the frontline hospital workers for increased understanding and acceptance of patients with addictions and substance use disorders. Subsequently, they may recognize that these disorders correlate with mental health issues and many other social determinants of health.

### **Harm Reduction Programs**

Although harm reduction approaches to the opioid crisis are evidence-informed, they remain a controversial topic. Harm reduction is the approach to addiction and substance use that seeks to minimize associated harms from overdoses, reduce the transmission of communicable diseases such as HIV, hepatitis B, and hepatitis C, and prevent other adverse health outcomes (Association of Ontario Health Centres, 2018). The goal of harm reduction is to diminish negative health impacts without requiring drug abstinence, since this expectation is not always an effective or realistic objective. Harm reduction initiatives specific to substance use include supervised consumption services, overdose prevention sites, needle exchange services, and naloxone kit distribution (Association of Ontario Health Centres, 2018). A range of individuals in society across North America have voiced concerns over this approach, suggesting that it enables drug use and does not address the root causes and problems of addiction. However, harm reduction approaches have been shown to reduce the harms associated with drug use; they are therefore likely to be applied more frequently in hospital settings. Additionally, harm reduction is a practice that reduces the stigma and social isolation associated with drug use that have historically only fueled negative health outcomes (Buchanan, 2004). The idea and logic of harm reduction has been embraced and applied in multiple areas of health care and across other sectors. Well-established harm reduction practices include the use of condoms to prevent sexually transmitted diseases, the use of seat belts to prevent driving injuries, and the use of speed limits to reduce potential car accidents.

### *Understanding Naloxone Kits*

Naloxone, also known by its brand name Narcan®, is a medication that temporarily reverses the effects of an opioid overdose (Harm Reduction Coalition, n.d.). It is an 'opioid antagonist' (Exhibit 2) and acts to negate depression of the central nervous and respiratory systems to prevent life-threatening conditions such as respiratory arrest (Harm Reduction Coalition, n.d.). It was first made available to the public through pharmacies in June 2016. The Ministry of Health and Long-Term Care, the government body dedicated to health care in Ontario, has distributed 12,000 naloxone kits at 1,400 different locations across the province (Canadian Addiction Treatment Pharmacy, 2018). Naloxone is effective against prescribed opioids and illicit forms of

## Combating the Opioid Crisis: Expanding Naloxone Kit Distribution to Niagara Health Emergency Departments

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the drug such as fentanyl, morphine, heroin, methadone, and oxycodone. It is available for use via injectable kits or nasal spray kits (Government of Ontario, 2018b).

### Expanding Naloxone Kit Distribution to Emergency Departments

Publicly funded naloxone kits are currently available through three programs across the province. The Ontario Naloxone Program distributes kits through needle syringe and hepatitis C programs, the Ontario Naloxone Program for Pharmacies distributes them through participating pharmacies, and the Provincial Correctional Facilities Take Home Naloxone Program distributes them through participating provincial correction facilities (Ministry of Health and Long-Term Care, 2018). The Ministry of Health and Long-Term Care has recently stated that making naloxone kits available to patients in emergency departments is a hospital-based decision. In other words, each hospital organization across the province has the autonomy to decide whether to incorporate this public health measure. Hospitals are major partners in health care systems, being the largest providers of acute health care services. In 2017, emergency departments across Ontario received 7,658 visits related to opioid overdoses, a 72% increase from the 4,453 visits seen in the previous year (Government of Ontario, 2018a). Exhibit 3 (Public Health Ontario, 2018) shows the spike in opioid-related emergency department cases that have occurred in the region, illustrating an increased need for action in this area. The expansion of naloxone kit access to first responders such as paramedics, firefighters, and police officers is ongoing throughout the province. Increasing access to the kits is known to save lives and reduce the mortality associated with the addictive drugs (Eggertson, 2013). The hospital system, however, is experiencing reluctance from its staff members with regard to acknowledging the complexities of substance use and accepting addiction harm reduction measures.

### THE CHALLENGE

Jessica is tasked with introducing a harm reduction program to a hospital emergency department whose staff are reluctant to adopt such initiatives. Morin et al. (2017) stated that “sadly, perhaps one of the largest barriers limiting our collective ability to address the opioid crisis in Ontario, Canada, is the lack of consensus of the extent of the problem and uncoordinated ideas of appropriate solutions”. Hospital staff are a crucial component of making these types of public health interventions successful. If frontline workers exhibit a lack of understanding or support for harm reduction measures, this has the potential to negatively affect patient access to targeted services. Unfortunately, Jessica is facing several challenges getting hospital employees to accept naloxone kits as a harm reduction measure and distribute them in an effective manner

### CONCLUSION

The hospital organization has a highly clinical, biomedically focused environment. To effectively introduce naloxone kit distribution to the emergency department, Jessica is faced with the problem of having department health care workers look beyond this purely clinical and biomedical perspective so that they can better understand the complex nature of addictions. Having frontline workers in a hospital setting incorporate a more comprehensive understanding of the social determinants of health, and encouraging them to view addictions and mental health through a health equity lens is not an easy task. What approach should Jessica take? What theories and frameworks could she embrace to support her work and help shift the organizational mentality? How can she help staff to adopt a health equity lens when they are working with patients who have addictions and substance use disorders?

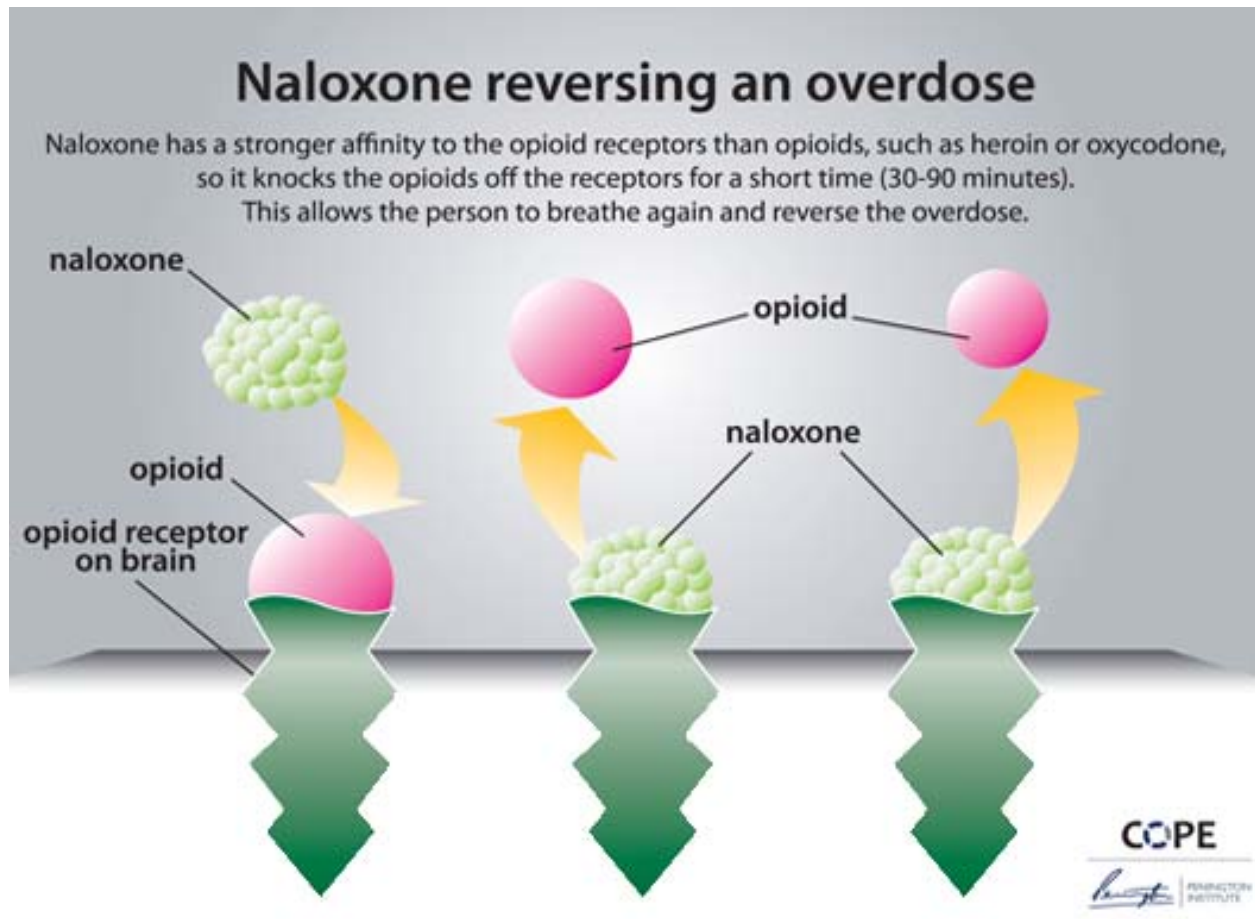
# Combating the Opioid Crisis: Expanding Naloxone Kit Distribution to Niagara Health Emergency Departments

## EXHIBIT 1 Social Determinants of Health



Source: Ministry of Health and Long-Term Care, 2016.

EXHIBIT 2  
How Naloxone Works



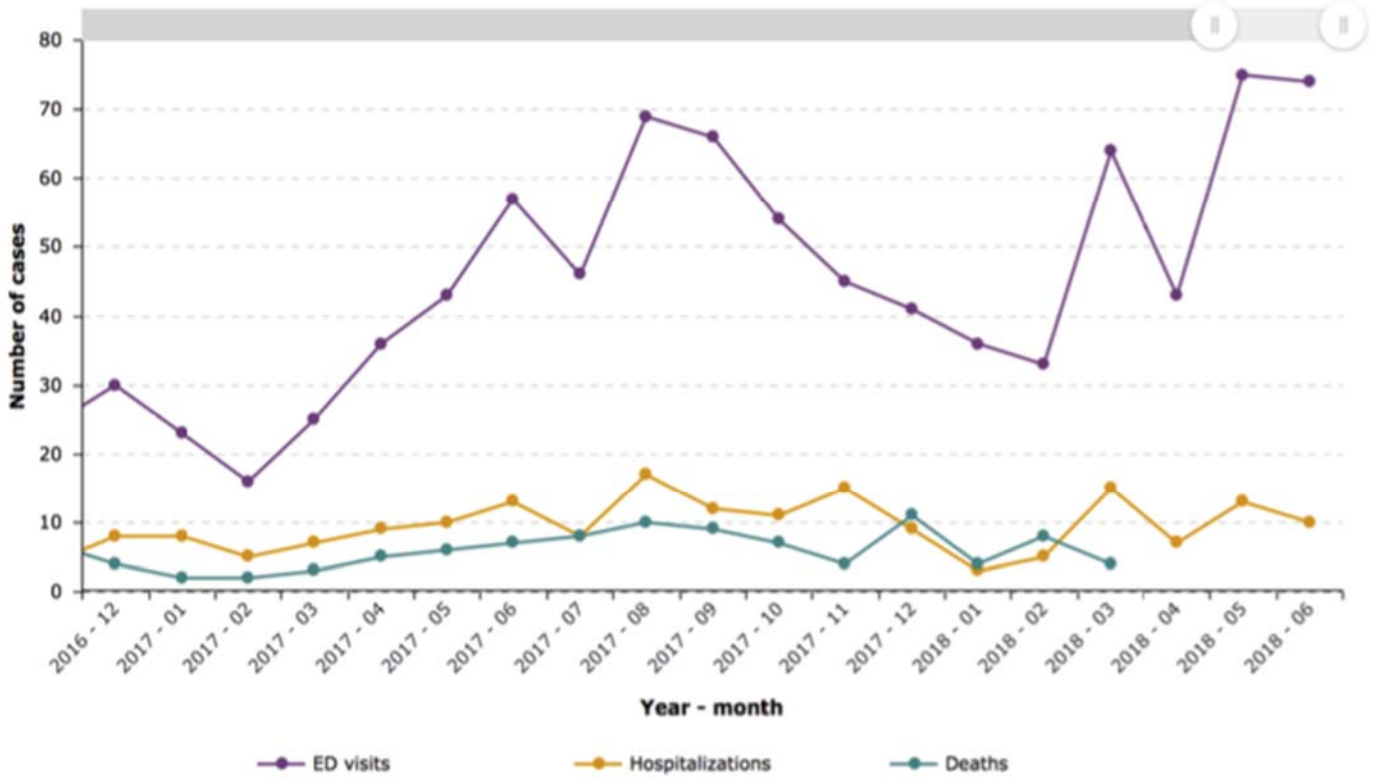
Source: Pennington Institute, 2015. Reproduced with permission from Pennington Institute.

Combating the Opioid Crisis: Expanding Naloxone Kit Distribution to Niagara Health Emergency Departments

EXHIBIT 3  
Regional Opioid-related Cases

Cases of opioid-related morbidity and mortality,

2003 - 01 - 2018 - 06



Source: Public Health Ontario, 2018.

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## INSTRUCTOR GUIDANCE

### Combating the Opioid Crisis: Expanding Naloxone Kit Distribution to Niagara Health Emergency Departments

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#### BACKGROUND

A regional hospital system is exploring the possibility of making naloxone kits accessible to patients in the emergency department of its hospital sites. The current hospital staff are reluctant to distribute these kits. The organization is trying to determine the best approach to guaranteeing program participation. The expansion of hospital access to naloxone kits is a direct response to the ongoing opioid crisis across Canada. Opioid-related deaths have spiked in recent years and various national and provincial initiatives are underway to reduce these deaths. Staff reluctance to distributing lifesaving naloxone kits in emergency departments stems from their lack of understanding and knowledge about the value and benefits of introducing these types of harm-reduction strategies. Unfortunately, many frontline health workers at the hospitals view the distribution of naloxone kits as “enabling drug users”. This stigmatization of patients who have opioid addictions is a complication that is making it much more challenging for Jessica Corso and the Quality, Patient Safety, and Risk Department to introduce this initiative. The problem they face is how to ensure that health workers understand the social constraints that exacerbate addictions and the value of naloxone kit distribution in combatting them. This fictional case focuses on the social determinants of health and health equity, and how best to educate hospital staff so that they gain an understanding of inequities as they relate to health care.

#### OBJECTIVES

1. Apply health behaviour theories and frameworks to address staff reluctance to implementing a public health intervention.
2. Develop an approach to implementing the social–ecological model of health and the idea of health equity into the health care setting of a hospital.
3. Discuss the roles and responsibilities of health care organizations and health care providers in recognizing the complexity of health care issues such as addictions and substance use.
4. Relate health equity to the case as it pertains to managing health services.

#### DISCUSSION QUESTIONS

1. How does the context and setting of the case influence our understanding of the problem being faced?
2. Who are the stakeholders in this case? What are their different perspectives?
3. How can organizational or behaviour theories and concepts be applied to this case?
4. What are some social determinants of health that could be at play with the ongoing opioid crisis?
5. How is this case related to health equity?

#### KEYWORDS

Addictions; emergency departments; harm reduction strategies; health care equity; naloxone; opioids



## CASE 5

### Active Schools: A Method to Combat Sedentary Behaviour?

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Amelia Brooks, Director of Education with Maple Leaf District School Board (MLDSB), was sitting in her office completing a report on improving student engagement within the classroom. As she was working, she received a phone call from a principal, Jessica Myles, who was concerned about the health and well-being of her students. Jessica had been noticing that her students were becoming increasingly inactive during recess, were consuming unhealthy foods high in sugar and fat, and had a decreased interest in partaking in school sports activities. As the head of her school, Jessica felt it was important to make changes, but she needed advice on how to make them.

As many as 54% of families in Canada have faced some degree of financial strain from enrolling their children in extracurricular activities (Ipsos, 2017). Further, as many as 27% of Canadian families incur debt when they place their children in these activities (Ipsos, 2017). However, according to the Canadian 24-Hour Movement Guidelines (Exhibit 1), only one third of children meet the daily recommendations of 60 minutes of moderate-to-vigorous physical activity (MVPA) (Statistics Canada, 2017). Additionally, only 50% of Canadian children adhere to the recommended limit of two sedentary hours per day (Statistics Canada, 2017). It appears that in order for many families to ensure that their children are physically active they are facing some financial constraints.

#### BACKGROUND

As the Director of Education, Amelia is responsible for helping students succeed and ensuring that they have proper access to learning opportunities, programs, and other resources. Amelia is responsible for the implementation of board decisions. Prior to beginning her career in education, Amelia worked as a health promoter, encouraging communities to get active and live healthier lifestyles. Initially, Amelia sought a career in childhood education because she felt that the best time to build healthy habits is during childhood, and she wanted to be a part of the decision-making process within the education system.

After Amelia's phone call with principal Myles, she was reminded of the very reason that she went into education. She realized that she wanted to help students become more active. The Director of Education is an elected position and Amelia was approaching the last three months of her term. Amelia decided that the upcoming Board and Standing Committee meeting would be a good time to make a lasting impression.

### CONCEPTS OF INTEREST

#### **Sedentary Behaviour**

Sedentary behaviour is associated with an increased risk of: type II diabetes, cardiovascular disease, and mortality; all-cause mortality (independent of physical activity); and certain cancers (e.g., colon, endometrial, and lung cancer). Canadian adults are sedentary for most of their waking hours, and evidence demonstrates that children and youth spend a large proportion of their time in sedentary pursuits (Ministry of Health and Long-Term Care, 2018).

Sedentary behaviour is often described as “low energy expenditures and a sitting or reclining posture” for a prolonged period of time (ParticipACTION, 2018). Physical inactivity is described as “failing to achieve the recommended guideline of 150 minutes of MVPA per week” (The Conference Board of Canada, 2014). Although both terms have different meanings, both behaviours are related and can have joint effects on health and well-being. For example, between sitting in a classroom and engaging in screen time, children and youth (defined by ParticipACTION as five to 17 years old) spend too much time being sedentary (ParticipACTION, 2016). In fact, in 2018, ParticipACTION released a report card on physical fitness in which Canadian children and youth received a “D” rating because of the low levels of activity for their respective age groups (ParticipACTION, 2018). Sedentary behaviour has been linked to an increased risk of aggression, weak academic performance, and the development of diabetes, cancers, all-cause mortality, and cardiovascular issues (Wilmot et al., 2012). Sedentary behaviour is associated with hypertension, and vitamin D deficiencies as a result of lack of sunlight exposure, which may lead to various organ malfunctions and bone diseases (Inyang & Okey-Orji, 2015). Low levels of physical inactivity and sedentary behaviour in children puts them at risk for developing chronic disease later in life (Wilmot et al., 2012). Recently, research has also found a link between screen time and mental health conditions such as anxiety and depression (ParticipACTION, 2016). With the increased prevalence of technology, increased human dependence on technological platforms, and increased focus on convenience, one can expect that sedentary behaviour levels will only continue to rise. Although sedentary behaviour is a major public health issue, it is also a modifiable risk factor.

Health is highly influenced by social and economic factors, individual behaviours and conditions, and the physical environment; therefore, to mitigate sedentary behaviour in children and youth, policies and supportive environments are needed (Diaz & Lock, 2016). Childhood is an ideal time to learn new skills and habits because children are particularly impressionable and develop many behaviours and attitudes that remain with them throughout their lives (Whitebread & Bingham, 2013).

In 2005, the Ontario Ministry of Education created Policy/Program Memorandum No.138, which was updated in 2017 to Policy/Program Memorandum No. 138: Daily Physical Activity in Elementary Schools, Grades 1-8 (Ministry of Education, 2017). This policy was introduced to ensure that elementary school students participated in a minimum of 20 minutes of MVPA each day (Public Health Ontario, 2017). However, there is evidence that indicates an inconsistent implementation of the daily physical activity policy (Public Health Ontario, 2017). A supplemental approach encourages secondary school students to become more physically active; however, an alternative strategy or additional program is needed to help ensure that children and youth meet the daily requirement of 60 minutes of physical activity.

#### **The School Environment: Active Schools**

The first 10 years of a child’s life are the most critical for teaching them to have a healthy attitude towards physical activity (Whitehead, MacCallum & Talbot, 2015). If you can get a child to be active from a young age, it is likely that they will continue this behaviour into adulthood,

## Active Schools: A Method to Combat Sedentary Behaviour?

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which then makes them more likely to be active and playful with children of their own (Whitehead, MacCallum & Talbot, 2015).

The ways in which Active Schools operate vary among school jurisdictions. Most Active Schools aim to promote a culture of inclusive physical activity, providing high-quality physical education and encouraging students to partake in 60 minutes or more of moderate-to-vigorous physical activity each day (Whitehead, MacCallum & Talbot, 2015). As an example, British Columbia has engaged in efforts to promote physical activity within schools by revamping its previous education curriculum. The new curriculum includes mental well-being and a more holistic view of health (Healthy Schools BC, 2016). The newly introduced curriculum provides schools with more support through a network of resources and regional staff who offer follow-up support to create and implement action plans, local community connections, workshops, and mentorship opportunities (Healthy Schools BC, 2016). Specifically, teachers learn how to add activities such as aerobics to an arithmetic lesson or incorporate stretching exercises into their science curriculum (Canadian Institutes of Health Research, 2017).

The National Center for Chronic Disease Prevention and Health Promotion created a model called Whole School, Whole Community, Whole Child (WSCC), which encompasses both physical education and physical activity in order to provide students with opportunities to become physically active through their school and community (Centers for Disease Control [CDC], 2017). To ensure that all aspects of the WSCC framework are addressed, the model refers to a more specific and targeted approach called the Comprehensive School Physical Activity Program Framework (CDC, 2013). This framework is used by schools to provide students with an abundance of school-based activities to empower them to stay active and obtain the recommended 60 minutes or more of physical activity per day (CDC, 2013). The framework is made up of five components—physical education, physical activity during school, physical activity before and after school, staff involvement, and family and community engagement (CDC, 2013).

There are many short-term and long-term benefits associated with students attending Active Schools, including higher grades, happiness, improved health outcomes, better sleep, active parenting styles, and lower health care costs (Whitehead, MacCallum & Talbot, 2015). A position statement prepared by the Heart and Stroke Foundation regarding schools and physical activity outlined various recommendations directed at provincial/territorial governments and school boards. The aim was to engage and encourage these organizations to improve physical activity and decrease sedentary behaviour in school-aged children (Heart and Stroke Foundation, 2013). Some suggestions include:

1. Ensure adequate financial support for schools to help implement a strong health and physical education curriculum that emphasizes lifelong physical activity enjoyment skills.
2. Ensure Quality Daily Physical Education programs are in place for all students from kindergarten to grade 12.
3. Assist all students from kindergarten to grade 12 in accumulating 60 minutes of daily physical activity through a variety of activities and programs. For example:
  - Integrate physical activity into lesson plans for subjects other than physical education (e.g., math, science, languages, etc.)
  - Encourage unstructured physical activity and active play during lunch hours and recess
  - Provide intramural opportunities for physical activity at lunch hour and before or after school
4. Include accountability measures within provincial/territorial policies governing school physical activity and physical education in order to ensure that implementation occurs.

## Active Schools: A Method to Combat Sedentary Behaviour?

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5. Where possible, increase the availability of physical education specialists in elementary schools.
6. Emphasize the importance of physical activity for all and take into account the requirements of different age/sex groups, ethnic backgrounds, and previous experience with physical activity.
7. Establish guidelines that place schools in locations that make it easier for children to walk and bike to school. A travelling distance of 1 km or less has been shown to be exceptionally favourable to active transportation. Where this is not possible (e.g., rural areas), implement creative solutions that help children to walk or bike at least some portion of their commute. For example, arrange for buses to drop students off at locations from which they can safely walk or bike the rest of the way.
8. Promote the development of active and safe routes to school. Conduct accompanying promotional and educational activities that address safety and the benefits of active transportation.
9. Establish healthy school environments including the provision of bike racks and crossing guards, as well as safe and appealing playgrounds designed to promote physical activity. Where possible, train playground supervisors to facilitate a wide variety of games that emphasize physical activity.
10. Through the establishment of cooperative agreements between schools and communities, arrange for schools to be open before and after school for physical activity and other programs for children and their families.

### School Stakeholders

Amelia received an e-mail notifying her of the various stakeholders invited to the upcoming Board and Standing Committee meeting: eight members from the Board of Trustees, who ensure that the Director of Education carries out his/her responsibility for implementing board policies; five student trustees, who represent the voice of the students; the Board Chair and Vice Chair, who help to manage and provide leadership throughout the meeting; three teacher representatives; four parent representatives; and, two union representatives. Although all stakeholders will be able to speak and participate in this meeting, only the Board of Trustees will have voting power. In order to pass the motion regarding Active Schools, Amelia will require more than 50% of these trustees to vote in favour of implementing the Active School model (Toronto Catholic District School Board (TCDSB), 2018). At this upcoming meeting, Amelia realizes the importance of informing stakeholders about the costs and benefits associated with active schools (i.e., funding, academic outcomes, burden on teachers, and health outcomes).

### PLANNING MEASURES

Given the success of Active Schools programs in other Canadian provinces and around the world, Amelia felt that implementing this program was the change needed to help encourage children and youth within the MLDSB to get active and get moving. Transforming traditional classrooms into spaces conducive to physical activity will require extensive support and resources. Specifically, this will require financial investment, construction within schools, and convincing various stakeholders such as parents/guardians, educators, students, the school board, and the union to embrace the program.

The focus of the upcoming Board and Standing Committee meeting is to develop a five-year plan to shape and guide the school board's priorities. Amelia decides to present her proposal on Active Schools, hoping to receive funding and support for the program. This will allow her to run a year-long campaign that improves physical education classes, emphasizes physical activity outside of schools, and ensures that teachers add physical activity and movement to various areas of student learning.

## Active Schools: A Method to Combat Sedentary Behaviour?

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At the upcoming meeting, Amelia will be sharing evidence-based findings on the positive impact of Active Schools, and a vote will take place after Amelia presents her proposal. Depending on the outcome of the vote, the school board Chair will be able to declare a motion moving the board forward with acquiring training for teachers to add elements such as nature exploration and active movement into their teachings. The approval of this motion will also create funding opportunities for building new infrastructure that assists with active learning. With enough support, Amelia hopes that she can eventually move this idea up to the Ministry of Education as a provincial strategy for decreasing sedentary behaviour and encouraging more young people to become physically active.

Amelia knows some people may push back and find issues with her suggestion to support the transition to an Active Schools model. The creation of an Active Schools program in the MLDSB will call for an extensive amount of work and upfront costs (approximately \$30 million) just to implement and sustain the program over the next seven years. MLDSB can afford this program if it is budgeted correctly. Additionally, Amelia knows if this Active School idea is accepted by stakeholders, she would most likely be re-elected as the Director of Education. Amelia realizes she may not receive the support she needs, but since she is serving the last three months of her term as Director of Education, she is willing to take that chance.

What would be the best way of communicating this message at the meeting? Amelia decides to use Public Health Ontario's six-step guide (Exhibit 2) to help her create a blueprint for the Active Schools model. This six-step guide provides systematic guidance for planning a health promotion program and will help her coordinate, manage, and effectively use resources to design a communication and implementation plan for the schools within her board.

Amelia considers the following:

1. What should the long-term goals and objectives of the Active Schools model be?
2. How would she develop the six-step health promotion planning model? (Exhibit 2)
3. Perform an audience analysis for the stakeholders (Board of Trustees). What would be put for the following descriptors: demographics, behavioural, and psychographics? (The Health Communication Unit, 2007)
4. How would she go about conducting an analysis to prioritize all stakeholders? (Exhibit 3)
5. What key messages should be included in Amelia's communication at the board meeting?

### CONCLUSION

The meeting is fast approaching and Amelia has exactly two weeks to prepare. Given the diversity of stakeholders at the meeting, Amelia realizes that whatever she communicates must be both targeted and generalizable to apply to all groups—this will be a challenge.

# Active Schools: A Method to Combat Sedentary Behaviour?

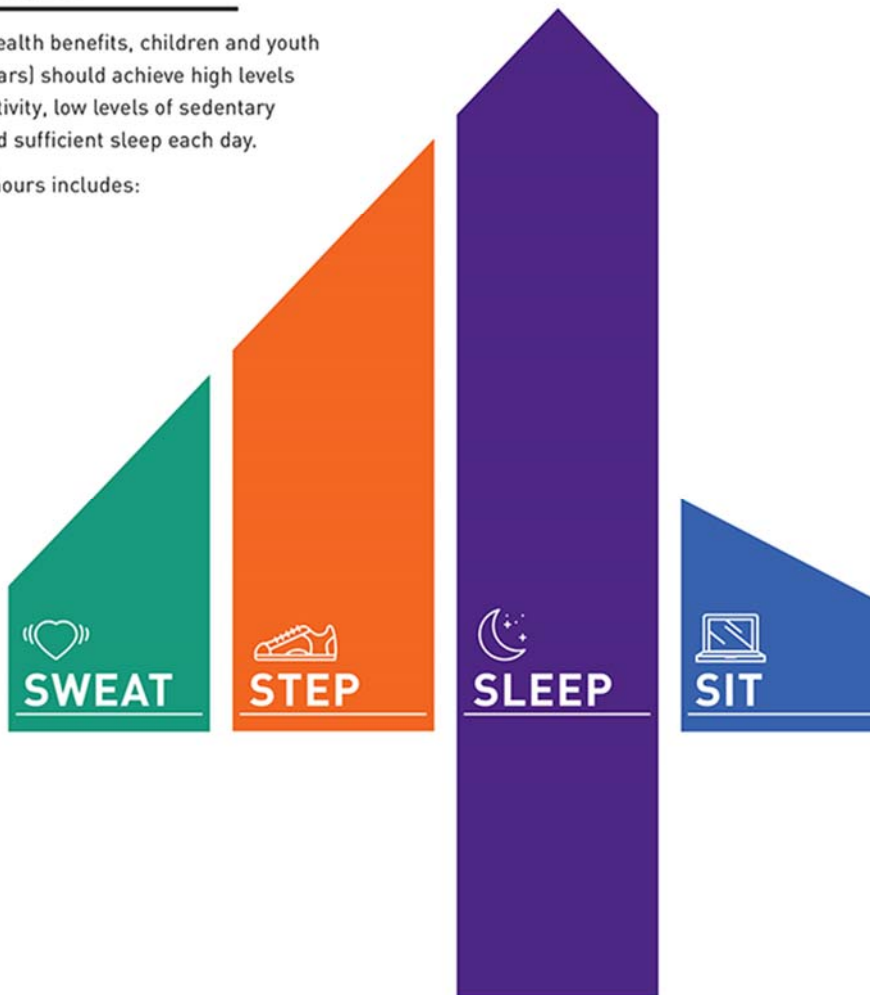
## EXHIBIT 1

### Canadian 24-Hour Movement Guidelines for Children and Youth: An Integration of Physical Activity, Sedentary Behaviour, and Sleep

#### GUIDELINES

For optimal health benefits, children and youth (aged 5–17 years) should achieve high levels of physical activity, low levels of sedentary behaviour, and sufficient sleep each day.

A healthy 24 hours includes:



Preserving sufficient sleep, trading indoor time for outdoor time, and replacing sedentary behaviours and light physical activity with additional moderate to vigorous physical activity can provide greater health benefits.

#### SWEAT

##### MODERATE TO VIGOROUS PHYSICAL ACTIVITY

An accumulation of at least 60 minutes per day of moderate to vigorous physical activity involving a variety of aerobic activities. Vigorous physical activities, and muscle and bone strengthening activities should each be incorporated at least 3 days per week;

#### STEP

##### LIGHT PHYSICAL ACTIVITY

Several hours of a variety of structured and unstructured light physical activities;

#### SLEEP

##### SLEEP

Uninterrupted 9 to 11 hours of sleep per night for those aged 5–13 years and 8 to 10 hours per night for those aged 14–17 years, with consistent bed and wake-up times;

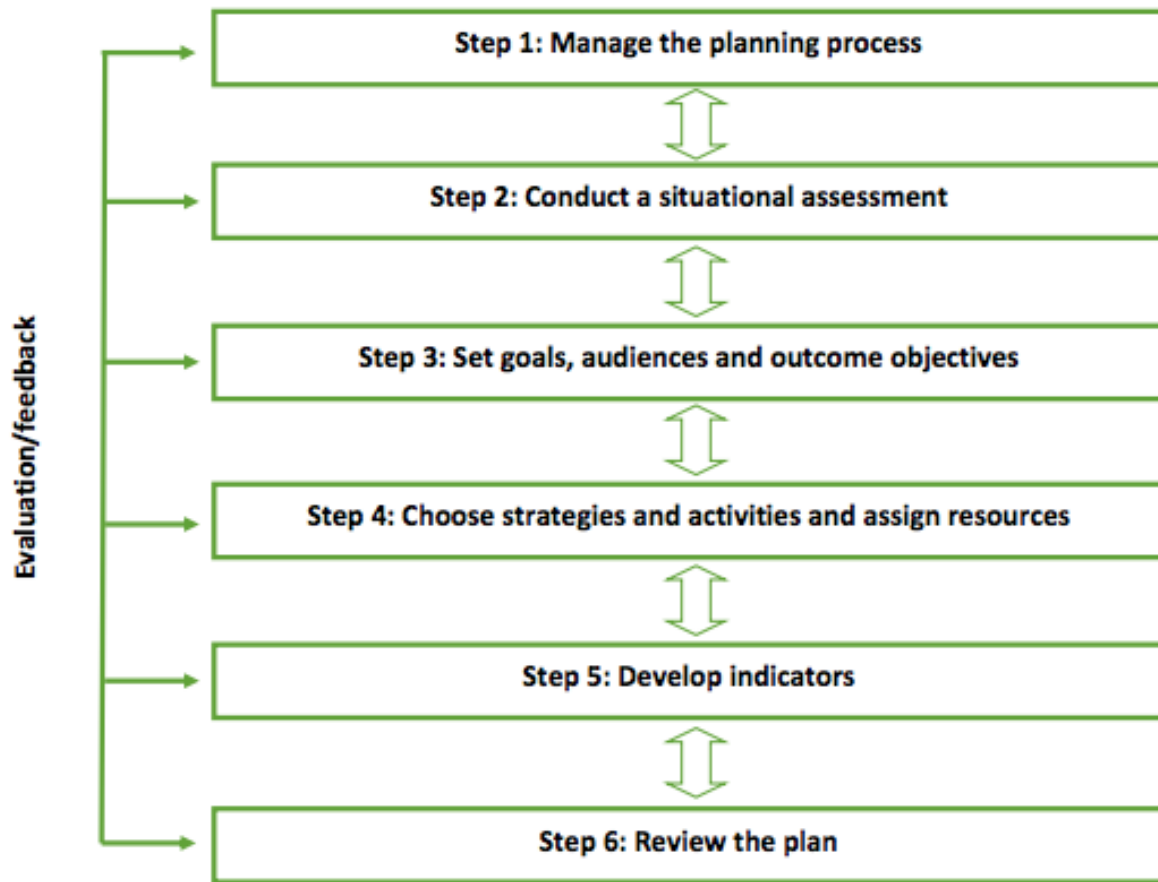
#### SIT

##### SEDENTARY BEHAVIOUR

No more than 2 hours per day of recreational screen time;  
Limited sitting for extended periods.

Source: Tremblay, et al., 2016.

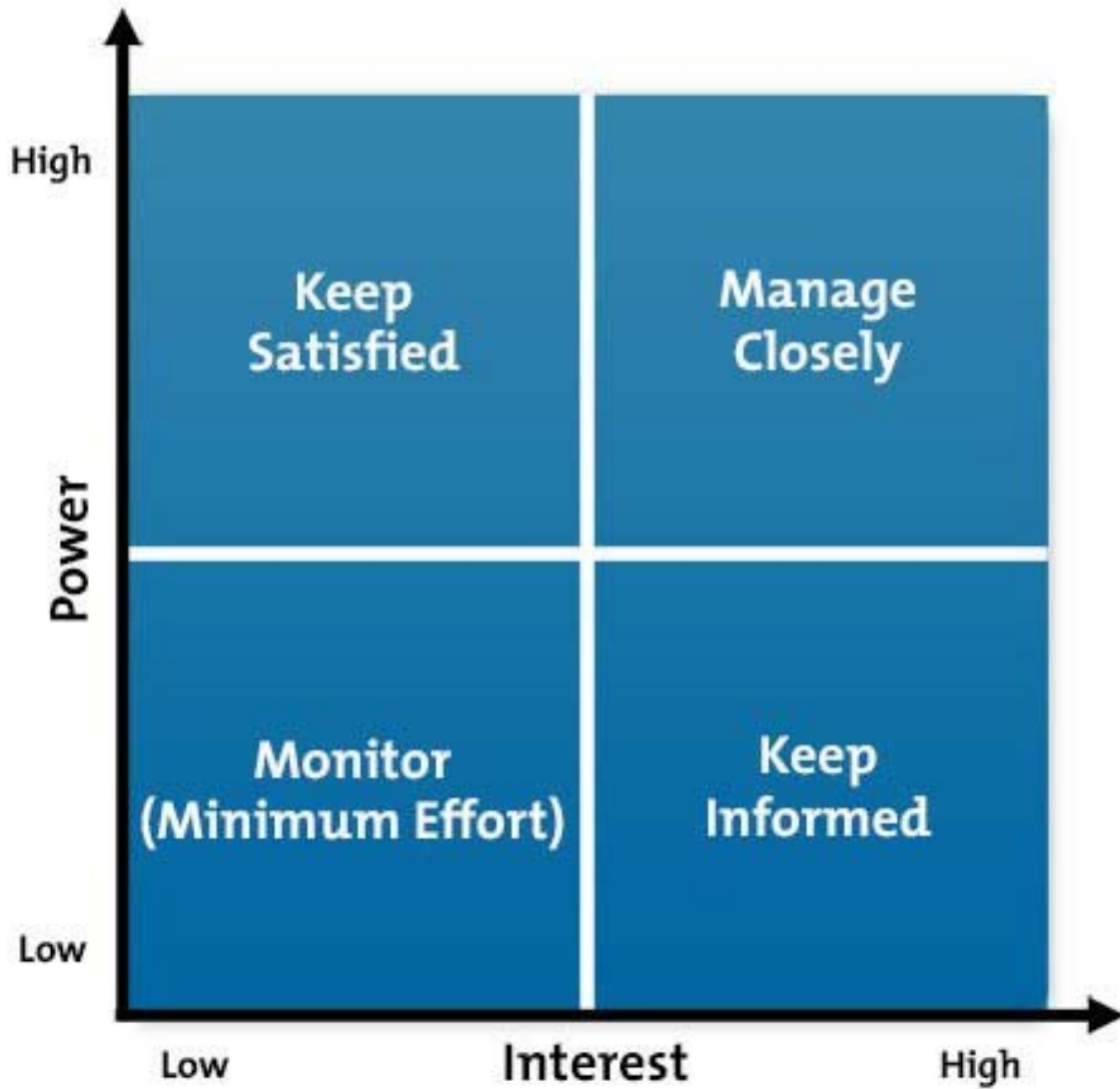
**EXHIBIT 2**  
**Six-Step Planning Model**



Source: Public Health Ontario, 2015.

EXHIBIT 3

Stakeholder/Power Interest Matrix: To Prioritize all Stakeholders



Source: Stakeholder analysis: Winning support for your projects (MindTools, 2016).

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## INSTRUCTOR GUIDANCE

### Active Schools: A Method to Combat Sedentary Behaviour?

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#### BACKGROUND

After a phone call from Jessica Myles, a concerned principal, Amelia Brooks, the Director of Education with Maple Leaf District School Board, decided she needed to reduce sedentary behaviour among many students in her district. As she approached the end of her term as Director of Education, Amelia realized that if she wanted to take action and combat sedentary behaviour, the time was now. As a trained health promoter, Amelia knows the benefits and evidence around Active Schools, not just in improving physical activity, but also in supporting a culture of inclusive physical activity. Most Active Schools aim to promote a culture of inclusive physical activity, providing high-quality physical education and encouraging students to partake in 60 minutes or more of moderate-to-vigorous physical activity (MVPA) each day (Whitehead & Talbot, 2015). Active Schools programs support high quality physical education and encourage students to partake in 60 minutes or more of physical activity each day (Whitehead, MacCallum & Talbot, 2015). The Active School model also has the potential to decrease the levels of sedentary behaviour and physical inactivity in elementary students. Amelia needs to prepare a proposal for an upcoming board meeting that will be attended by key stakeholders. She needs to balance stakeholder interest while keeping the goal of active children central. In order to pass the motion to incorporate Active Schools activities into Maple Leaf District School Board programs, Amelia requires more than 50% of supportive votes from the Board of Trustees. Given the diversity of stakeholders and their range of perspectives and priorities (Board of Trustees, student trustees, and parent and teacher representatives) Amelia realizes the importance of her task.

#### OBJECTIVES

1. Identify key considerations for Amelia in preparing her proposal for the upcoming board meeting.
2. Create a health promotion planning model proposal to be presented at the upcoming board meeting that can be used as a key tool for the implementation of guidelines for Active Schools.
3. Develop a context-specific communication plan to be presented at the upcoming board meeting.
4. Discuss the different values, roles, and responsibilities of stakeholders and determine how their interests can be best prioritized and balanced.

### DISCUSSION QUESTIONS

1. What are the goals and objectives of an Active Schools model?
2. If the board does not embrace the Active Schools proposal, what could be suggested as a temporary or less resource-intensive alternative?
3. What are the roles and perspectives of the various stakeholders? How might they be aligned or different?
4. How might the Active Schools model be used as a form of primary (averting an onset) and secondary (early detection) prevention?

### KEYWORDS

Active Schools; children and youth; communication stakeholder analysis; health promotion planning; physical activity; sedentary behavior

## CASE 6

### AQCESS: Access to Quality Care through Extending and Strengthening Health Systems

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*“Ninety-nine percent [of preventable maternal deaths] occur in developing countries where many women are not attended by a trained midwife, nurse, or doctor during childbirth. [M]any additional deaths can be prevented through basic, affordable, and practical interventions during childbirth and the first days after birth. The presence of a skilled birth attendant and community health workers is particularly critical in decreasing newborn mortality.”*

— Aga Khan Development Network (2014)

#### BACKGROUND

Aga Khan Foundation Canada (AKFC) is an international development organization, a registered charity, and an agency of the Aga Khan Development Network (AKDN). Rachel Pell, Program Manager, Health at AKFC spends 40% of her time travelling internationally and is responsible for grant management on multi-country, multi-partner health projects, including managing in-country partner and donor relationships. Rachel also contributes to the overall development of the health portfolio, including proposal development. To support project delivery and compliance, Rachel works closely with in-country partners through remote communication. She also works with AKFC’s monitoring and evaluation specialists, gender specialists, the finance team, and the public affairs team on a daily basis.

As Rachel was reviewing and consolidating various work plans for the Access to Quality Care through Extending and Strengthening Health Systems (AQCESS) project in Mali, Mozambique, Kenya, and Pakistan, she received an email from a private donor. He stated that he had visited Kenya recently and had seen AQCESS in action in Kilifi County. The donor wanted to meet to discuss further opportunities for expanding AQCESS, based on need, to other regions in East Africa where AKDN was already present. Subsequently, they scheduled an initial meeting at the AKFC office in Ottawa.

#### AGA KHAN DEVELOPMENT NETWORK

The AKDN is a family of organizations and institutions investing in social, cultural, and economic development, striving to improve the living conditions of impoverished people across the world regardless of faith, origin, or gender (AKDN, n.d.). The AKDN is a global leader in the mission to end poverty. It is a network of agencies that partner to mobilize resources and implement initiatives in more than 30 countries, principally in Africa and Asia, managing more than 1,000 programs and institutions in total (AKDN, 2018). The AKDN’s annual budget for nonprofit development activities is approximately US\$950 million (AKDN, 2018). Employing approximately 80,000 people who mainly reside in developing countries, the AKDN is committed

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to fostering self-reliance and achieving long-term, sustainable results in the communities where it works (AKDN, 2018). The ultimate goal of the AKDN is to improve the quality of life by promoting a higher standard of living for vulnerable populations in Asia and Africa. The AKDN uses a comprehensive approach that addresses the social, economic, and cultural dimensions of development. It relies on partnerships between its own agencies and with governments, the private sector, and civil society actors to amplify and sustain results over the long term. A systems strengthening approach is used by AKDN to focus on improving quality and access. There is emphasis on enhancing facilities, education, and training for health professionals and local community members. Additionally, there is great focus on gender equality, social inclusion, environmental sustainability, and economic development. (AKDN, n.d.).

### **AGA KHAN FOUNDATION CANADA**

AKFC, an international development organization and a Canadian charity, is an agency of the AKDN that is committed to breaking the cycle of poverty. In partnership with Global Affairs Canada, other Canadian institutions, and other AKDN agencies, AKFC aims to reduce poverty in 15 countries in Asia and Africa. This is achieved through supporting vulnerable and disadvantaged populations in developing countries by mobilizing Canadian financial, technical and intellectual resources and applying evidence-based research to its work (AKFC, 2017). With the underlying mandate of providing lasting and sustainable change to communities, AKFC believes that ending global poverty requires action on multiple social determinants of health. Communities are at the center of every phase of program development, engaging in all aspects of the process from design and implementation to evaluation (AKFC, 2017).

### **ACCESS TO QUALITY CARE THROUGH EXTENDING AND STRENGTHENING HEALTH SYSTEMS (AQCESS)**

AQCESS is a four-year, \$30.5 million project that works in partnership with underserved populations in Kenya, Pakistan, Mali, and Mozambique to improve maternal, newborn, and child health (MNCH). It is funded through a partnership between Global Affairs Canada and AKFC.

Based on detailed needs assessments conducted in these four countries, AQCESS implements health promotion and behaviour change activities to improve healthy MNCH practices, including advancing gender equality and strengthening community structures. The project focuses on increasing the demand and utilization of MNCH services by awareness of men and women in communities who may benefit from MNCH practices. This is done by delivering and expanding updated health promotion programs and health-seeking behaviours in communities. Through implementation of community-based strategies to address multi-sectoral barriers, scaling up of community-based provision of MNCH services, and empowerment of community health government structures, the project will support healthy, gender-equitable and environmentally sustainable MNCH practices.

AQCESS helps reduce maternal and child mortality in targeted regions by focusing on three key result areas: improved delivery of essential MNCH health services, improved utilization of essential MNCH services by region, and improved dissemination and use of MNCH information and evidence (Exhibit 1). The project targets regions and populations where MNCH indicators such as maternal mortality, under-five mortality, and stunting rates are particularly high, and where women and children still lack access to essential, quality health services.

The regions targeted by the project lack adequate numbers of skilled health providers – including both medical professionals and community health workers – and communities have limited knowledge on how to protect the health of mothers and children. They also have inadequate health system management and high levels of gender inequality, which create

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additional barriers to quality care. In an effort to improve MNCH outcomes, AQCESS addresses these barriers, in particular by emphasizing gender-responsive service delivery environments, enabling women's participation and leadership in household and community decision-making. The AQCESS initiative also strives to educate and engage males as partners in women's and children's health, and to address issues such as gender-based violence, early marriage, and the reproductive health needs of adolescents (AKFC, 2016a).

In Kenya, AQCESS is expected to improve health outcomes for approximately 135,600 women, girls, and boys under the age of five (AKFC, 2016a). Through infrastructure improvement, equipment maintenance, and human resources capacity building, AQCESS will enhance the quality of care offered to women and children in its target communities. To increase the demand for health services and ensure they are used appropriately, community actors will mobilize regions to adopt healthy practices such as family planning.

### **KENYA**

With a maternal mortality rate of 361/100,000 live births and an under-five mortality rate of 73/1000 live births, Kenya did not meet the 2015 Millennium Development Goals for maternal and child health (United Nations Population Fund [UNFPA], 2016). The Millennium Development Goals state that the maternal mortality rate should not exceed 120/100,000 live births and that under-five mortality rates should not exceed 33/1000 live births (UNFPA, 2016).

The health profiles in Kenya vary among its 47 counties and includes vast disparities between rural and urban populations. The Kenyan counties of Kilifi and Kisii (included in the AQCESS project area) fare better in some health indicators compared with other counties. However, significant gaps remain. The top fifteen out of 44 counties in Kenya account for 98.7% of total maternal deaths in Kenya. Kilifi is ranked 6<sup>th</sup> of those 15 counties (UNFPA, 2016). Almost half the women in Kilifi give birth without the support of a skilled health professional (Kenya National Bureau of Statistics, 2014). Kisii County has identified a need to prioritize and invest in prenatal care, essential obstetric and newborn care, immunization, breastfeeding programs, and appropriate management of common childhood illnesses, with additional support given to improve physical access to health facilities as well as the skills of health care providers (Kisii County Government, 2017). There are numerous sociocultural barriers that affect access to MNCH care that must be addressed in these regions in order to improve the health status and quality of life of its residents. In 2016, the percentage of women in Kenya who had used modern contraceptives was rather low. In Kilifi, 75.1% of women were not using any method of modern contraception (Aga Khan Foundation Canada, 2016b). In Kisii, almost half of the women (42.2%) had used some form of modern contraception.

### **THE MEETING**

At the initial meeting with Rachel, the donor expressed interest in supporting a project in East Africa because this is where his family came from. During his travels in Kenya, the donor had observed various deficiencies in MNCH care in the country's rural areas. The donor had also travelled to Tanzania and Uganda and wondered whether these countries also experience similar MNCH challenges and could benefit from a similar program. Rachel noted that AKDN currently supports multi-sectoral development programming in both countries. While each country context is unique, they both face their own challenges. It was agreed Rachel would consult further with partners in Tanzania and Uganda to assess the need for an initiative like AQCESS in their countries. Following an internal assessment, a meeting would be held with the donor to make the case to implement the AQCESS model in either Tanzania or Uganda or both, if both countries would benefit.

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Through project governance structures, AKFC works closely with various stakeholders including donors, implementing partners, and local governments. These collaborations guide project development and strategies to ensure initiatives contribute to local, national, and global health sector priorities and to promote accountability and effectiveness in the use of donor funds. Given that there is a limited amount of funds, Rachel would need to consult with her team at AKFC as well as other AKDN agencies in Tanzania and Uganda to determine the health needs of the regions. Implementing the AQCESS model in a new country would require an in-depth understanding of local needs and priorities related to MNCH.

### **NEXT STEPS**

Rachel needs to determine whether Uganda and Tanzania are in need of an AQCESS project and then present these findings to the donor. To do so, Rachel has to research and identify the available statistics and prepare a needs assessment to determine whether certain regions in the target countries need the program, and then determine which regions have the highest need. She does not yet know how much funding the donor will provide and if a large project scope is feasible. Nonetheless, Rachel plans to prepare data and formulate conclusions on the Tanzanian and Ugandan regions with the highest need for an AQCESS project. Because the project scope and funding is undetermined, Rachel decides to prepare a more restricted community health needs assessment plan (Exhibit 2), focusing only on steps one to four and not on the full nine-step evaluation. Limiting the focus to just the first four steps would allow her to collect the specific data and information she needs to properly analyze, identify, and determine the care requirements in these countries.

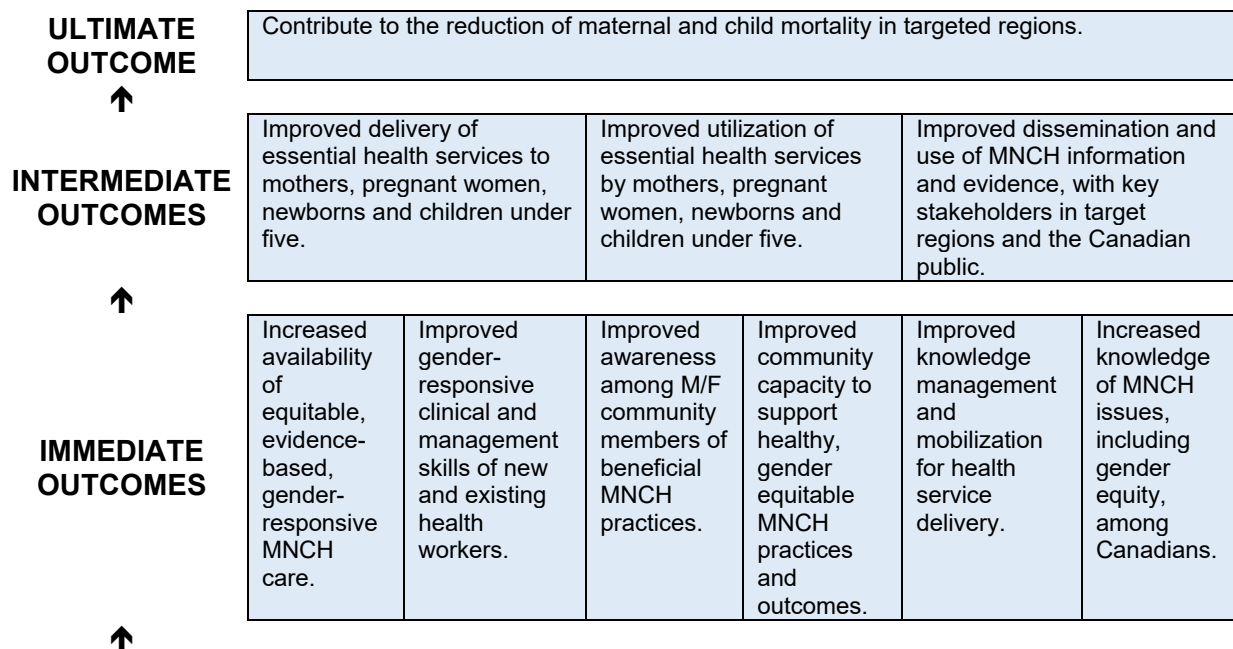
### **CONCLUSION**

As soon as a formal needs assessment has been completed, as well as extensive local and field consultation with multiple stakeholders, Rachel hopes to start planning and implementing the project in Tanzania and/or Uganda, based on community need and available funding. Special care must be taken to ensure the country or regions that are most in need receive help from a project such as AQCESS.

## AQCESS: Access to Quality Care through Extending and Strengthening Health Systems

### EXHIBIT 1

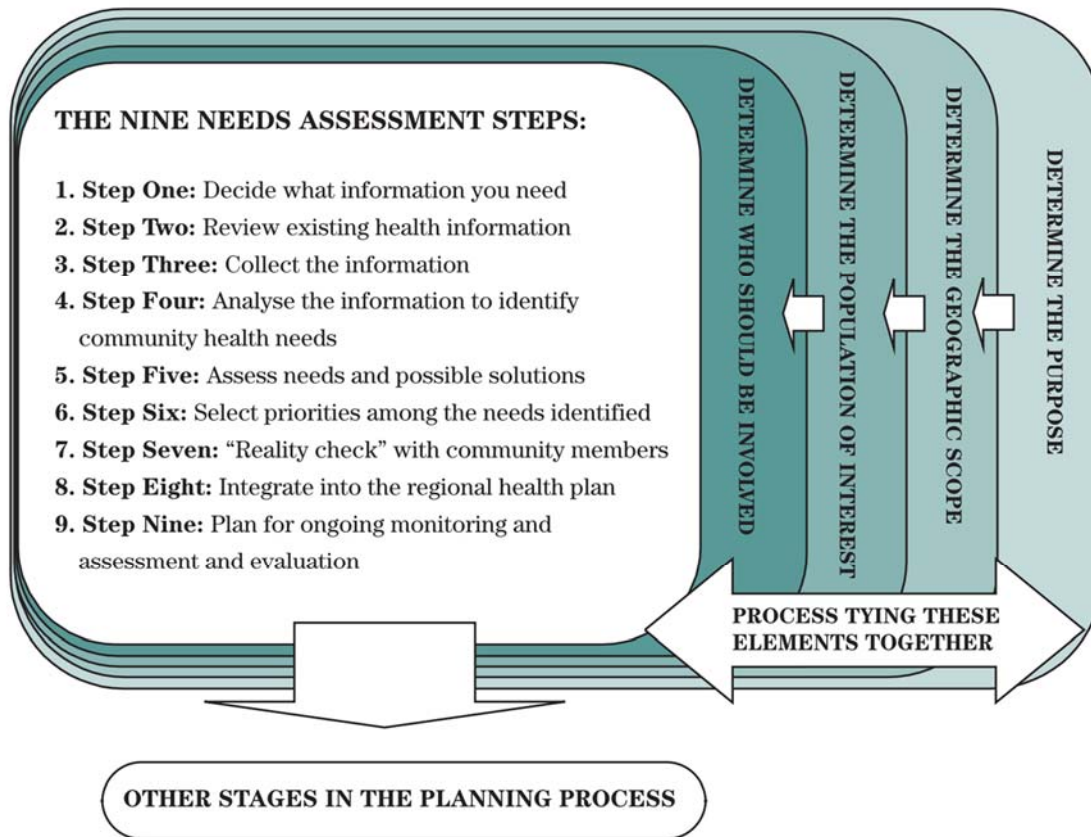
#### Access to Quality Care through Extending and Strengthening Health Systems (AQCESS): 2016–2020



Source: Aga Khan Foundation Canada, 2016.

# AQCESS: Access to Quality Care through Extending and Strengthening Health Systems

## EXHIBIT 2 Core Steps and Activities in a Health Needs Assessment



Source: Ardal et al., 2006. © Queen's Printer for Ontario, 2006.

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## INSTRUCTOR GUIDANCE

### AQCESS: Access to Quality Care through Extending and Strengthening Health Systems

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*Rukhsar Jetha, BHSc, MPH (MPH Class of 2018)*

*Rachel Pell, BA, MSc (Program Manager, Health, Aga Khan Foundation Canada)*

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#### BACKGROUND

Access to Quality Care through Extending and Strengthening Health Systems (AQCESS) is an Aga Khan Development Network (AKDN) initiative that works in partnership with underserved populations in Kenya, Pakistan, Mali, and Mozambique to improve maternal, newborn, and child health. The project targets regions and populations where MNCH indicators such as maternal mortality, under-five mortality, and stunting rates are particularly high. In these regions, women and children still lack access to essential, quality health services. AQCESS projects help reduce maternal and child mortality in targeted regions by focusing on improving delivery of essential MNCH health services, improving utilization of essential MNCH services by region, and improving dissemination of MNCH information and evidence.

Rachel Pell, a Program Manager at Aga Khan Foundation Canada, is approached by a private donor who has seen the positive outcomes of the AQCESS intervention in Kilifi, Kenya. He wants to donate to the Aga Khan Foundation Canada to expand the project to other East African countries, specifically to Tanzania and Uganda, in which AKDN is already present. Rachel realizes that not all communities in these countries have a need for AQCESS. Consequently, she has to prepare a needs assessment to help determine which areas, if any, need such a program. Her goal is to research and identify statistics on the health status in Tanzania and Uganda to determine their health care requirements and present these results to the donor.

Rachel decides to prepare a community health needs assessment plan, focusing only on steps one to four and not on the full nine-step evaluation. By focusing on these specific steps, Rachel can collect the relevant information she needs to analyze and make conclusions about the regional health care requirements. Along with determining whether Tanzania and Uganda need a project such as AQCESS, Rachel must use the available data to determine which specific regions have the highest need.

#### OBJECTIVES

1. Select appropriate data collection methods appropriate for a specific public health context.
2. Interpret the results of data analysis for public health practice.
3. Apply systems thinking tools to demonstrate need in a given public health context.
4. Assess various determinants and factors to determine which regions are more in need.

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### **DISCUSSION QUESTIONS**

1. What types of statistics are needed to make an informed decision and where can they be found?
2. What information is already available?
3. What information is still needed?
4. What determinants or factors should be researched in order to determine which regions in Tanzania and Uganda are in need?
5. Which areas are similar, in terms of health and MNCH statistics and demographics, to the ones AQCESS is currently serving?

### **KEYWORDS**

Maternal, newborn, and child health; health systems strengthening; international development; primary care; sexual and reproductive health and rights



## CASE 7

### Population Health Surveillance in Finland: Threats to Historically Dependable Surveillance Methodology

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*Kristia Maatta, BSc, MPH (MPH Class of 2018)*  
*Katja Borodulin, PhD (National Institute for Health and Welfare)*  
*Ava John-Baptiste, PhD (Assistant Professor, Western University)*

“If we don’t lobby for ourselves, we are going to get left in the dust.” Katja Borodulin and her colleagues at the National Institute for Health and Welfare in Helsinki, Finland were responsible for the National FinHealth Study. The national, population-based survey is administered every five years to monitor population health in Finland (National Institute for Health and Welfare, 2018a). The FinHealth survey generates a large volume of high-quality data on health status and health status trends but collecting the data is expensive. National initiatives to reform health services could lead to a decrease in the FinHealth Study budget. The Ministry of Social Affairs and Health funds the National Institute in addition to financing and managing Finnish health services. Amid reforms to expand access to health services in underserved areas, the Ministry is looking for ways to decrease overall expenses. The prospect of replacing the FinHealth survey with less expensive data sources, such as disease registries, would be one approach to lowering costs. A new Director General was elected at the Institute in the fall of 2018, which has made the situation more precarious. The national health care reform could result in a smaller budget for the FinHealth Study, and this would negatively impact population health surveillance in Finland. The Finnish experience has been influential in the global evolution of population health surveys; therefore, Finland’s reputation as a global leader in population health surveillance is also under threat. The FinHealth team was looking for a way to convey the value of population health surveys to those who did not appreciate the quality of these kinds of data. They had to show that alternative sources of population health data would compromise population health surveillance efforts and could, therefore, compromise population health.

#### BACKGROUND

##### **The National Institute for Health and Welfare**

The National Institute for Health and Welfare operates under the Ministry of Social Affairs and Health, but is largely independent in carrying out its role. The Institute’s responsibility is to serve the Ministry, the government, local and provincial decision makers, the research community, and the general public (National Institute for Health and Welfare, 2017a). The Institute conducts research to support developments in health and social welfare service delivery (National Institute for Health and Welfare, 2018b), with the goal of monitoring and promoting the health and welfare of the Finnish population (National Institute for Health and Welfare, 2017a). Recognized internationally for the quality of its work, the Institute produces a large number of high-quality scientific publications each year (National Institute for Health and Welfare, 2017a). The Institute formed in 2009 when two major governmental organizations, the Public Health Institute and the National Research and Development Centre for Welfare and Health, merged to form a new, expert research agency (National Institute for Health and Welfare, 2017b). The original organizations were formed in 1982 and 1992, respectively; however, their predecessor—The National Board of Health—dates back to 1811 (National Institute for Health

## **Population Health Surveillance in Finland: Threats to Historically Dependable Surveillance Methodology**

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and Welfare, 2017b). The longstanding presence of government institutions designed to promote health and welfare through research has been integral to Finland's remarkable history of population surveillance.

### **History of Population Surveillance in Finland**

The 1930s marked the beginning of a coronary artery disease (CAD) epidemic in the United States that would later manifest in Western European countries (Jousilahti et al., 2016). In the 1950s, Finland saw an increase in CAD mortality, attributed largely to higher incomes and associated changes in diet and lifestyle (Jousilahti et al., 2016). In the 1960s, Finland had the highest rate of cardiovascular disease mortality worldwide (Jousilahti et al., 2016). Large epidemiological studies such as the Seven Countries Study and the Framingham Heart Study, which were conducted on populations outside Finland, had begun to identify behavioural and dietary risk factors for heart disease. Numerous observational studies followed to further support the causal mechanism of such lifestyle factors. Public outcry prompted urgent action to reduce Finland's burden of cardiovascular disease mortality (Puska, 2002). In 1972, the North Karelia Project became Finland's first collaborative, multipronged, community-based intervention designed to decrease the prevalence of risk factors for cardiovascular disease, with the ultimate objective of reducing cardiovascular disease mortality in Finland (Puska, 2002).

The Finnish Minister of Health appointed Pekka Puska, a young physician with a master's degree in social science, to lead The North Karelia Project. Pekka believed that the link between lifestyle factors and CAD risk was clear, and that systems-level changes would be necessary to improve health status (Buettner, 2015). The project prompted widespread lifestyle changes, encouraging citizens to decrease smoking, decrease sodium and saturated fat intake, and increase vegetable consumption (Borodulin et al., 2014). However, the approach also emphasized improvements to the physical and social environments. Pekka lobbied food producers to replace animal fat with vegetable-based products and encouraged farms to freeze native berries to increase fruit consumption throughout the year (Buettner, 2015). Pekka also engaged community members, appointed community ambassadors, and organized cooking classes that taught healthful modifications of traditional dishes (Buettner, 2015). Pekka later served as the Director General of the Public Health Institute, now the National Institute for Health and Welfare, from 2003 to 2013 (Puska, 2013). Before this, he also served as the Director of the Department of Noncommunicable Disease Prevention and Health Promotion at the World Health Organization (Puska, 2013).

The North Karelia Project produced highly favourable results in the Finnish population leading to decreased total serum cholesterol levels, decreased systolic and diastolic blood pressure levels, decreased smoking rates and, ultimately, reduced rates of CAD (Borodulin et al., 2014). From the early 1970s until 2012, CAD decreased by a remarkable 82% in working-age men and by 84% in working-age women (Jousilahti et al., 2016). In the past 10 years, approximately two-thirds of the CAD mortality reduction in Finland has been explained by a reduction in three main risk factors: smoking, elevated systolic blood pressure, and elevated serum cholesterol (Exhibit 1, Jousilahti et al., 2016).

The evaluation of the project's impact was achieved through population-based health monitoring. An important component of the project was the administration of risk factor surveys every five years to allow for continued health surveillance (Jousilahti et al., 2016). Researchers at the Institute have gradually expanded the survey yet have retained many aspects of the original study design to permit comparisons over time. In 2017, past surveillance and monitoring efforts were consolidated and rebranded as the FinHealth 2017 Study.

## **CURRENT SURVEILLANCE EFFORTS AND LOOMING THREATS**

### **Population-based Health Surveys**

The FinHealth 2017 Study is a national, population-based survey designed to monitor population health, assess changes in health, and project future health trends (Koponen et al., 2018). The researchers selected a random sample of participants using a multistage clustered sampling design based on the national population registry. Participants were invited to complete a mail-in questionnaire and asked to attend a physical health examination (National Institute for Health and Welfare, 2018a). Information about an individual's health, health behaviours, and functional capabilities were collected to provide a comprehensive overview of health status (Koponen et al., 2018). Survey sections included demographic information such as age, education, income and marital status, general health status, functioning and welfare, exercise, smoking, nutrition, height, weight, and sleep habits. During the health examination, highly trained nurses took physical measurements such as height, weight, and blood pressure using standardized protocols. Teams of nurses travelled across Finland to a total of 50 different locations to ensure that the data are representative of the entire nation (National Institute for Health and Welfare, 2018a). To reduce seasonal variation, the teams strove to complete all assessments within a short time frame at the same time of year in each survey cycle. A subset of participants was invited to complete a second questionnaire. The second questionnaire obtained more detailed information on illnesses, quality of life, working life, assistance requirements, social relationships, mood, reproductive health, and physician-issued recommendations regarding lifestyle changes.

Researchers in Finland have been collecting data on key health indicators using national surveys and administrative registries for more than 50 years (Kilpeläinen et al., 2016). The cross-sectional surveys allow for quantifying the prevalence of risk factors and identifying targets for public health action. Comparing the results over survey cycles allows for the monitoring of trends using time series analyses. Follow-up with participants using special registries permits the creation of cohorts that can be further studied over time. The findings of the health examinations provide invaluable health information to support targeted health promotion.

Dr. Seppo Koskinen leads the FinHealth 2017 Study. Seppo is a research professor who has worked in the Public Health Solutions Department at the National Institute for Health and Welfare for more than 20 years. Seppo's background and training include medical science, epidemiology, and political science. Before joining the Institute, Seppo worked as a researcher with the Academy of Finland/University of Helsinki, studying mortality and health inequalities. Seppo was keen to see how the upcoming health care reform might reduce inequities in accessing health care. However, he was also concerned that the reform would force the Institute to alter its surveillance methodology, which would diminish the quality of population health surveillance.

Population health surveillance in Finland has inspired the implementation of national, comprehensive health surveys in other countries. For example, Statistics Canada, Health Canada, and The Public Health Agency of Canada developed the Canadian Health Measures Survey to use direct physical measurements to collect robust, objective, and comprehensive data on the health of Canadians. Statistics Canada cited the experiences of countries such as Finland, which have a history of deriving important findings from direct health measures, as influential in providing the rationale for implementing such a survey in Canada. The goal of introducing the Canadian Health Measures Survey was to address knowledge gaps in the health status of Canadians that could not be addressed by questionnaires or interviews alone (Tremblay et al., 2010). Finland's history of health surveillance has also inspired the

## Population Health Surveillance in Finland: Threats to Historically Dependable Surveillance Methodology

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development of the European Health Examination Survey, which aims to standardize national health examination surveys in European countries and to enhance comparability of population health findings (Kuulasmaa & Tolonen, 2016).

Some health officials within the Ministry believe that administrative data and local patient registries would provide adequate substitutes for population health surveillance. Indeed, many patient registries began as cohort studies that grew out of earlier versions of FinHealth surveys. Administrative data reflect utilization of health services, such as physician visits and hospitalizations, provided by the Ministry. Administrative data are fairly comprehensive reflections of health service utilization and contain a unique personal identification code that allows for data linkage across databases and across registries (Kilpeläinen et al., 2015). Some registries also contain information on health service utilization. Linked administrative databases and registries can be used to estimate the prevalence of some conditions and to identify causes of mortality (Kilpeläinen et al., 2015). Pertinent health data found in databases and registries can be analyzed at a minimal cost. However, information on health behaviours, individual perceptions about health, and social determinants of health are lacking (Kilpeläinen et al., 2015). Administrative databases and registries only capture information on people seeking services, while data on apparently healthy or symptom-free people are lacking. Therefore, administrative databases and registries alone do not provide a comprehensive picture of health status at the individual and population level. For example, prevalence estimates from these data may not reflect true population prevalence.

### Health Care Reform in Finland

Despite Finland's universal health care system, many people in Finland still face difficulties accessing services. Access is poorest among people residing in smaller municipalities where the Ministry faces service delivery challenges. As a result, the Ministry plans to launch a national regional government, health and social services reform. In 2020, the Ministry will centralize service delivery, shifting responsibility for service provision from local municipalities to 18 newly formed autonomous counties (Ministry of Social Affairs and Health, 2018a). The goals of the reform are to promote client-centred care along with vertical and horizontal integration of social welfare and health care services. The larger, more financially viable administrative bodies will organize and provide services with the aim of eliminating inequities previously faced by smaller municipalities (National Institute for Health and Welfare, 2018b). The reform will be the largest national-level restructuring of health service delivery in Finnish history and, consequently, has become a highly publicized national priority. The Institute has a key role to play in the coming reform and will be responsible for providing expert assistance through steering groups and anticipatory evaluation (National Institute for Health and Welfare, 2017a).

## ADVOCATING FOR SURVEILLANCE

### An Uncertain Future

Seppo sat with his colleagues Katja, Päivikki, and Kimmo discussing the health care reform. Katja was a research manager and senior researcher in the Health Monitoring Unit at the Institute. Passionate about chronic disease prevention and physical activity, Katja did not want to see cuts to the FinHealth Study budget. Päivikki Koponen was also a research manager in the Health Monitoring Unit, with a background in nursing and public health and an interest in migrant and refugee health. Kimmo Parhiala was the senior planning officer at the Institute, responsible for leading anticipatory evaluation of the reform's impact. The team was discussing how the reform would shape the Institute's research priorities in 2019. With national attention on health care reform, the ever-shrinking budgets for disease prevention and health promotion would make population-based studies a lesser priority. The surveillance and monitoring efforts of the FinHealth Study team would be compromised.

## **Population Health Surveillance in Finland: Threats to Historically Dependable Surveillance Methodology**

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“Right now, our futures are really quite uncertain,” Päivikki said to her colleagues “with the new Director General facing pressure from the Ministry to reduce spending.”

The Director General, who was elected in the fall of 2018, is responsible for all decisions at the Institute. Although the Institute operates independently, it is mandated to support the Ministry of Social Affairs and Health.

“I wonder if the new Director General will be able to justify the cost of retaining health surveys” Katja added. “The former Director General did believe that research is important and that the high-quality data we collect is valuable; however, he was also quoted criticizing population health surveys that have a participation rate of ‘only’ 60%.”

As it was still early in the new Director General’s term, the team was uncertain if he too would feel that participation rates of 60% called into question the value of population health surveys. The team reflected on the background and training of the new Director General, which included training in medical science and experience working at various levels of government (Ministry of Social Affairs and Health, 2018b). The team was anxious to discover if the new Director General would view population-based studies as an important asset both for research and policy decisions. They wondered if he appreciated survey design, data quality, and the cost-effectiveness of prevention.

“It is true that our surveys are expensive; however, the survey data are not only used for surveillance and monitoring, these surveys are also a rich epidemiological data source. I’m not sure that health survey critics are aware of how much our data are used. Within the Institute, in collaboration with local universities, and in international collaborations, our data have revealed quite important findings” commented Päivikki.

Päivikki also expressed concerns about the alternatives to the FinHealth survey. “There are many challenges associated with using administrative data registries such as primary care registries for population health surveillance. There are many different service providers and many different information systems capturing data. Inconsistencies in these information systems, and a lack of integration across different systems make data sharing challenging. Another concern is that not all service providers are collecting data regarding patient characteristics or service use, and others may be collecting the data but not sharing it.”

Katja echoed Päivikki’s concerns about the fragmented systems and shared additional concerns about incomplete data. “Administrative patient registries only capture the use of health care services—they do not signify the need for services. This information is important in planning health promotion and prevention initiatives.”

Seppo examined the figures that Katja and Päivikki had prepared for the meeting. The figures compared discrepancies in prevalence estimates from registry data only with estimates derived from registries and surveys used together (Exhibit 2). Presenting these figures to Ministry officials would illustrate the gaps associated with registry data.

Katja continued. “Patient registries such as primary care registries do not currently cover the private sector. The majority of the working-age population who seek occupational health care from their employer may not be captured by such registries.”

## Population Health Surveillance in Finland: Threats to Historically Dependable Surveillance Methodology

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Seppo listened carefully to Katja and Päivikki. Both had a great deal of experience in the design and administration of population health surveys. Both understood well how study design and data collection processes impacted data reliability and representativeness. Seppo knew that Kimmo held a decidedly different opinion. Confident that the reform would improve equitable access to health care services, Kimmo was less concerned about the source of health surveillance data and more concerned about patient access to necessary services.

“The most problematic aspect of Finland’s current health care system are issues related to access” stated Kimmo. “Those employed are better off, but those not working face challenges with access and high wait times. Smaller municipalities also currently have fewer services and service providers. The reform has the potential to improve access. The reform should also improve the quality of care. We see stark regional differences across municipalities, but we will see some standardization across counties once the reform is in effect. Population health is important, of course, but there is more to the health system.”

Päivikki was quick to respond. “That’s true, there are many aspects to the health system, but with the recent prioritization of the health care reform, health officials are considering *only* health care services. We have to do more than take care of the patients once they come in for service—there is so much more we can do *before* that.”

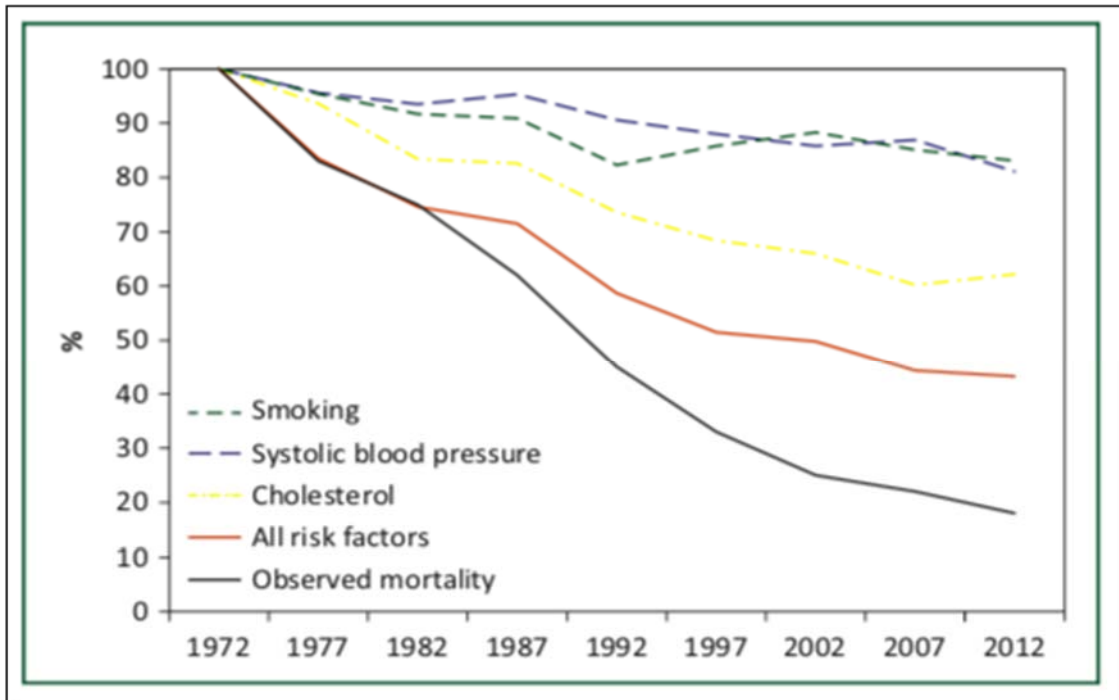
### CONCLUSION

Seppo was quiet. Concerned by the lack of consensus regarding priorities for population health, he reflected on both perspectives. On one side, those responsible for leading and guiding the reform were motivated by improved access to health care services. On the other side, those responsible for population health surveillance resisted changes to historically strong surveillance efforts, motivated by a desire to maintain high quality surveillance data. As the head of the FinHealth 2017 Study, Seppo wondered what he could do to advocate for population health surveys. How could he convey the value of population health surveys to leadership within the Institute and at the Ministry of Social Affairs and Health? How could he illustrate that the long-term, downstream repercussions of compromised surveillance would not be cost saving at all? Ultimately, population surveys had revealed the significant decline in CAD mortality and decrease in risk behaviours after the North Karelia project was implemented. More recently, FinHealth survey data supported research projects on a range of topics including cardiovascular diseases, asthma and allergies, alcohol use, socioeconomic factors, and genetic epidemiology (National Institute for Health and Welfare, 2018c). The push for reforms had been driven by an aging population, inadequate access to care, inefficiencies in service delivery, long wait times, and budget constraints. Without adequate surveillance, how would the Ministry know whether the reforms were achieving intended outcomes?

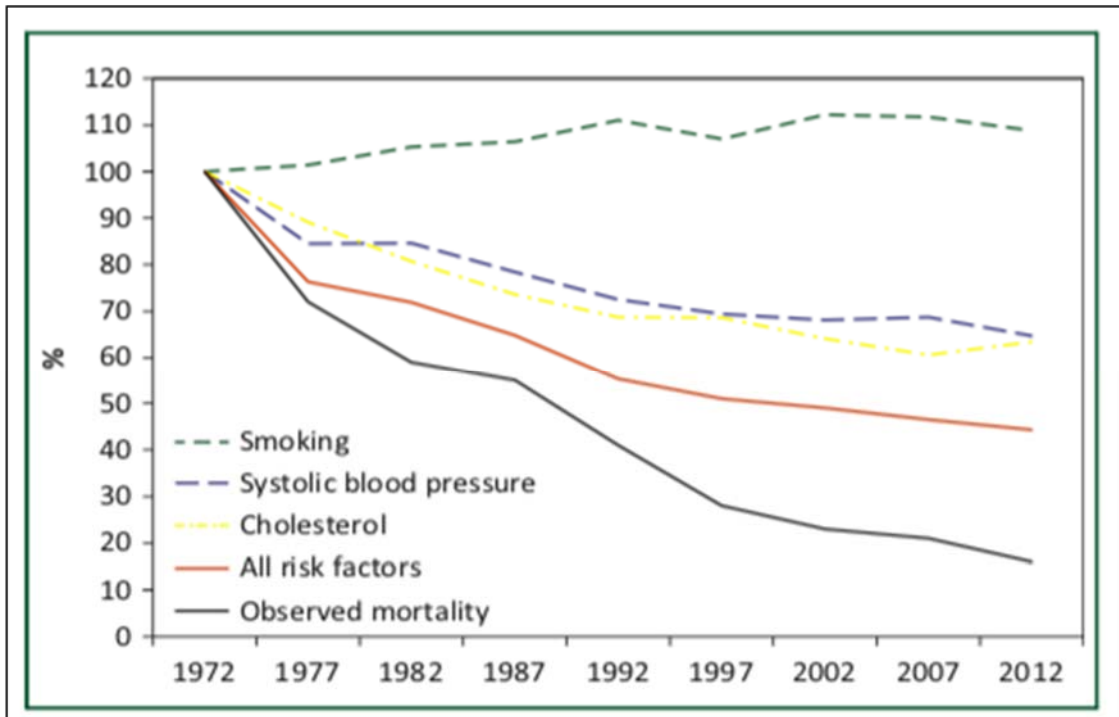
Population Health Surveillance in Finland:  
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EXHIBIT 1

Predicted and Observed Reduction in Coronary Artery Disease Mortality  
from 1972 until 2012 in Eastern Finland



Men 35 to 64 years of age



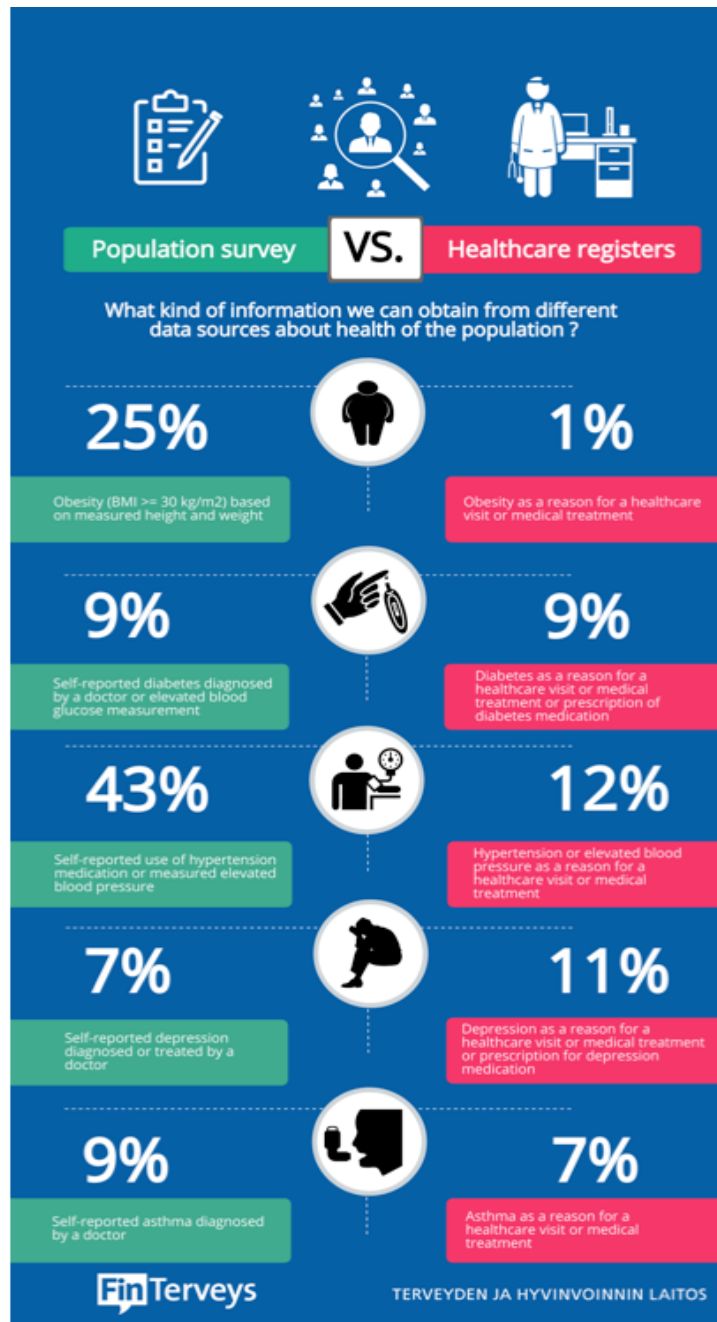
Women 35 to 64 years of age.

Source: Jousilahti et. al., 2016. Permission to reproduce granted by Copyright Clearance Center.

**Population Health Surveillance in Finland:  
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**EXHIBIT 2**

**Discrepancies in Prevalence of Health States Detected Using Alternative Data Sources**



Note: BMI is body mass index

Source: Koponen et al. 2018. Infographic was created by Hanna Tolonen, National Institute for Health and Welfare (THL), Finland and permission to reproduce granted based on the Creative Commons by-NC licence.

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## INSTRUCTOR GUIDANCE

### Population Health Surveillance in Finland: Threats to Historically Dependable Surveillance Methodology

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*Kristia Maatta, BSc, MPH (MPH Class of 2018)*  
*Katja Borodulin, PhD (National Institute for Health and Welfare)*  
*Ava John-Baptiste, PhD (Assistant Professor, Western University)*

#### BACKGROUND

The case outlines the challenges that the National Institute for Health and Welfare in Helsinki, Finland is facing in light of an ongoing national health care reform. The health care reform has taken precedence over other research activities, and the Institute is anticipating changes to population health surveillance methods. The Institute elected a new Director General in the fall of 2018 who will influence decisions about which population surveillance data collection methods are used. The Health Monitoring Unit at the Institute fears that the Director General will decide that all surveillance data will be collected using administrative patient registries with the consequent elimination of population health surveys. The team responsible for the 2017 National FinHealth population health survey must determine how they can advocate for the continued use of survey data in population health surveillance.

#### OBJECTIVES

1. Compare alternative methods for collecting population health data using knowledge of study designs to analyze strengths and inherent sources of bias for each method.
2. Discuss the importance of, but challenges associated with, evidence-informed decision making in public health and practice making decisions with limited or insufficient evidence.
3. Recognize foundational epidemiological concepts such as risk factors, prevalence, simple random sampling, surveillance, study designs, secondary data, and levels of prevention.
4. Illustrate how descriptive epidemiology can be used to quantify population disease burden and support surveillance.

#### DISCUSSION QUESTIONS

1. Explain the stages of the epidemiological research cycle.
2. What is the design of the FinHealth 2017 Study? What are the strengths and weaknesses of different observational study designs?
3. What are the advantages and disadvantages associated with alternative sources of population health data?

#### KEYWORDS

Cross-sectional study; epidemiology; evidence-informed decision-making; population health; prevalence; registry data; surveillance; survey data

## CASE 8

### Reaching the Hard-to-Reach: Conducting Research on Elder Abuse in Toronto's Arab Community

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*Matthew Maelzer, BSc, MPH (MPH Class of 2018)*  
*Sepali Guruge, RN, PhD (Professor and Research Chair in Urban Health, Co-Director, Centre for Global Health and Health Equity, Ryerson University)<sup>1</sup>*  
*Amardeep Thind, MD, PhD (Professor, Western University)*

Caroline opened her office window as far as she could. It was an exceptionally warm morning in Ashcroft, and the air conditioning unit was malfunctioning. The past few summers in the city had seen spells of record heat—a seasonal revolt against the characteristic frigidness of Canadian winters. Because of her experience researching intimate partner violence over the past five years, Caroline had been offered the research coordinator position for the Elder Abuse Project at Ryerson University. Excited to work on a topic that was almost nonexistent within the literature—the prevalence of domestic elder abuse within Ashcroft's Arab community—Caroline had readily accepted the offer and assumed leadership of the research team. Recently, however, she had begun to ask herself whether she had made the right decision. The city's Arab community was proving to be considerably difficult to reach.

Caroline wiped her forehead and opened her laptop to check her email. No new messages. Over the past few weeks, she had gone to great lengths to recruit Canadian Arab participants for focus group interviews on the topic of elder abuse. The qualitative data from these interviews would allow her research team to better understand the experience of Arab elders, identify risk factors for elder abuse in the community, and develop strategies to combat these risks. Unfortunately, she was encountering little success.

Caroline had decided to use standard, purposive sampling methods to find older adults within the community who would be interested in participating in focus groups. She had hired two university undergraduate research assistants to distribute English and Arabic recruitment flyers that described the study to places frequented by Arabic-speaking older adults (Exhibit 1). These locations included community centres and the offices of settlement service providers. After realizing that this recruitment strategy had led to few responses, her team had arranged a meeting with a sympathetic imam who allowed them to formally advertise the study in one of Ashcroft's most heavily attended mosques. With a list of the mosque's attendants made available for focus group recruitment, the team had resorted to cold calling congregants and asking if there was anyone in the household over 60 years of age who would be interested in participating in a study about the experiences of older adult immigrants in Canada. Together, their efforts had yielded eight participants—just enough for one focus group.

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<sup>1</sup> This work could not have been undertaken without the support of the Immigrant Health Research team led by Dr. Sepali Guruge in the School of Nursing at Ryerson University.

## Reaching the Hard-to-Reach: Conducting Research on Elder Abuse in Toronto's Arab Community

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More difficulties arose during the group interview. Of the eight Arabic-speaking older adults who had agreed to participate, only six showed up to the university at the scheduled time, and they were all men. Having experience with research on intimate partner violence, Caroline knew that abuse is often a difficult topic to discuss. She was aware of the necessary confidentiality protocols, and made sure to inform the group that their information would be protected. Expecting that language was likely to pose an issue, she had also ensured that a translator who could speak both Arabic and English was available. This was fortunate because three of the older adults possessed only a limited grasp of the English language and would have otherwise had to rely on the other participants to translate their contributions. It quickly became clear, however, that despite Caroline's efforts, a considerable level of discomfort remained, which hindered the open sharing of information. Caroline asked herself why the approach that had served her so well in the past was failing to yield the same results with this community. The answer made itself apparent when she asked why nobody had shown interest in the refreshments that she had provided. "It's Ramadan," one of the participants answered.

Sitting at her desk, Caroline thought seriously about what had gone wrong. She realized that her team's failures in participant recruitment and focus group facilitation were likely attributable to their adherence to a traditional research approach and a lack of understanding of the Arab community's cultural norms. For the project to continue, she would have to begin developing trust with a community that she knew little about. Caroline realized that she needed to approach the project from a different angle. Taking a sip of her coffee, she called a meeting with the research team to decide where to begin.

### ELDER ABUSE IN ETHNOCULTURAL MINORITY GROUPS

Elder abuse is defined by the World Health Organization as a "single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person" (World Health Organization, 2002). With elders defined as people who are 60 years of age and older, the following types of abuse have been recognized within the research and policy framework: (1) physical abuse, which includes acts done with the intention of causing physical pain or injury; (2) psychological abuse, defined as acts done with the intention of causing emotional pain or injury; (3) sexual assault; (4) material exploitation, involving the misappropriation of the old person's money or property; and (5) neglect, or the failure of a designated caregiver to meet the needs of a dependent old person (Lachs & Pillemer, 2004). It is important to note that a large proportion of elder abuse occurs in the domestic setting, with evidence suggesting that one in seven older adults experiences abuse in some form, though this likely underestimates the true number because of underreporting (Miller, 2012). Abuse is often carried out by children, sons- and daughters-in-law, and grandchildren. Increases in reports and attention mean that elder abuse has been recognized as a major social and public health problem worldwide. This concern may be attributed to demographic shifts in many countries, where the ratio of older to younger adults is rapidly increasing. In addition to a larger vulnerable population, adult children are increasingly called upon to care for their elderly parents, despite the fact that many lack the capacity, skills, or resources to engage in this obligation successfully (Miller, 2012).

Elder abuse is not an isolated phenomenon, and older adults from every racial, ethnic, and cultural group are impacted. The risk for domestic elder abuse and neglect is associated with a combination of characteristics and contextual circumstances surrounding both the victim and the perpetrator. Commonly identified risk factors for elder abuse in ethnocultural minority groups include social isolation, physical or cognitive impairment, intergenerational cohabitation, physical and financial dependence, gender, a lack of stable income, and an inability to speak the local language (Miller, 2012). Current Canadian immigration policies may also act as a

## **Reaching the Hard-to-Reach: Conducting Research on Elder Abuse in Toronto's Arab Community**

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contributing factor. The 10-year residency requirement to qualify for an Old Age Security pension, for example, may place additional financial burdens on caregivers, thereby increasing the likelihood of abuse.

The way elder abuse is defined may also be influenced by cultural norms. Some South Asian communities, for example, may consider the failure to visit older family members as a form of psychological neglect, which is in contrast to the prevalent Western perception that this respects privacy and autonomy (Miller, 2012). These variations in perspective may, therefore, lead to the failure to recognize abusive situations. Culture may also have an influence on the expectations for caregiver roles and responsibilities. Conflict can occur when differences in these expectations arise between older and younger generations (Miller, 2012).

### **THE ELDER ABUSE PROJECT**

Caroline and her team hope to achieve two research goals through the Elder Abuse Project. In the project's first phase, they aim to identify the key risk factors for elder abuse in Ashcroft's Arab community. Once these have been identified and understood, they will be used in the second phase as the basis for developing culturally relevant strategies to address these risks.

The research team will begin by collecting qualitative data through focus group interviews held with three separate stakeholder groups—older adults from the community, the older adults' family members, and formal service providers. Examples of formal service providers include settlement workers, providers of legal services, and health care workers. The team plans to conduct four separate focus group sessions with each of the stakeholder groups, with a range of eight to 10 participants at each interview. Knowing that focus groups are less rigid and give historically silenced participants the opportunity to tell their own stories, Caroline selected this type of group as the procedure of choice for data collection. Each focus group would be audio recorded and facilitated by research assistants who have been trained in group interviewing techniques.

After this step is completed, research assistants will transcribe the recordings into text, code the results, and extrapolate the themes. Data will be analyzed to compile a list of risk factors for elder abuse that have been self-defined by Ashcroft's Arab community. Though these risk factors are often similar across many ethnocultural minority groups, they frequently differ in their level of significance to a particular community. Caroline and her team will, therefore, be able to utilize the findings of the project's first phase to generate targeted strategies to address these risks and improve health outcomes.

### **THE CANADIAN ARAB COMMUNITY OF ASHCROFT**

#### **Demographics**

Located in Southern Ontario, Ashcroft is a large city with a population of 1,126,243. A long history of immigration to the region means that, similar to many major Canadian cities, Ashcroft is rich in ethnocultural diversity. In 2010, the immigration of Arabs to Canada reached record numbers, second only to the immigration of Filipinos. Large numbers of these immigrants chose to settle in Ashcroft and the surrounding area, meaning that 18% of the Canadian Arab population can now be found in this region. According to census data, this represents a visible minority community of 53,025, or 4.71% of the total population of the city. Canadian Arabs are themselves a diverse population, originating from countries such as Egypt, Lebanon, Somalia, Iraq, Palestine, Syria, Morocco, and Algeria, among others. This diversity means that a significant amount of internal variability exists within the population, manifesting in differences of language, religion, history, and tradition. Nevertheless, a strong sense of ethnic identity helps to ensure that Ashcroft's Arab communities remain unified.

## Reaching the Hard-to-Reach: Conducting Research on Elder Abuse in Toronto's Arab Community

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Many Canadian Arabs have settled in Quebec or Ontario since 1985, meaning that relative to a number of well-established immigrant groups in Ashcroft, the Arab community is newer to the city and less established. In Ashcroft's Arab newcomer families, the rate of children, stepchildren, and grandchildren who live in the same dwelling as their parents is much higher than in the general population, meaning that these children are less likely to live independently as single adults. Furthermore, 81% of Canadian Arabs living in the city are Canadian citizens and 74% have completed a postsecondary education; however, they have not yet achieved the same standards of living as the rest of the population, especially in terms of employment and income (Exhibit 2). A higher rate of unemployment within the Arab community is a significant concern, as is the gap in average total income between the community and the general population of Ashcroft. With the onset of the Syrian civil war, the city has also seen a massive influx of Syrian refugees. Along with difficulties faced in obtaining stable employment and affordable housing, their shared experience of violence and brutal conflict means that many of these Syrian newcomers suffer from negative health outcomes related to trauma (Chung et al., 2018).

### Religion

In Ashcroft, 49% of the Arab community practises the Muslim faith whereas 41% of the community practises Christianity. Numerous mosques are available to people in the city who practise Islam, particularly in areas where the Arab community is most densely settled. Specific to the religion is the yearly observation of fasting during Ramadan—the ninth month of the Islamic lunar calendar. During Ramadan, Muslims do not eat or drink from sunrise to sunset but they break their daily fasts through shared meals with family and friends. Because Ramadan occurs according to the Islamic lunar calendar, it moves backward approximately 10 days every year relative to the Gregorian calendar (Nicks, 2016). In years when it occurs during the summer, high temperatures mean that fasting can be especially challenging.

In accordance with the five pillars of Islam, *Salat* (or daily prayers) is performed five times daily at dawn, in the middle of the day, during the late afternoon, immediately after sunset, and in between sunset and midnight (British Broadcasting Corporation, 2009). Although mosques are the preferred place of congregational prayer, Muslims may perform *Salat* in any environment that is clean and free from impurities (Kabbani, 2018). Additionally, worshippers are called to attend a noon prayer held at their local mosque every Friday throughout the year (Why Islam, 2017).

### Language

Although Arabic is the most commonly shared language of Canadian Arabs and is spoken by more than half the population, dispersal, among other factors, has caused more Canadian Arabs to adopt English and French (Dajani, 2014a). Differing levels of proficiency and frequency of practise of all three languages across ethnic groups within the Canadian Arab community reflect its diversity in country of origin and cultural heritage, as well as the level of integration achieved by Canadian Arabs in adopting Canada's official languages as their own (Dajani, 2014a). For instance, current statistics illustrate that the most prevalent language spoken at home for Lebanese, Syrian, and Egyptian Canadians is English (Dajani, 2014a). Canadian Arabs of other ethnic origins, including those from Palestine and Somalia, appear to speak English and Arabic at home more equally (Dajani, 2014a).

### Social and Familial Norms

Marriage is an integral aspect of Canadian Arab culture, with a large percentage of Canadian Arabs acknowledging its value and indicating a cultural commitment to the institution (Dajani,

## **Reaching the Hard-to-Reach: Conducting Research on Elder Abuse in Toronto's Arab Community**

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2015). Central to Arab family life is the importance of honour, “emphasizing reputation and maintaining the status quo” (Rasmi & Daly, 2015). Based on this principle, there is a strong expectation that children respect and obey their parents, though the relationship is simultaneously characterized by “warm and interconnected” qualities (Rasmi, Chuang, & Hennig, 2016). Moreover, strong familial ties within the Canadian Arab population foster a collectivist culture often contrasted by Western individualism. This particular collision of beliefs can lead to acculturation gaps—a process whereby children and their parents develop conflicting cultural values—that have the potential to disrupt the family equilibrium (Rasmi et al., 2016).

Recognizing that significant differences in perspective can arise from contrasting cultural norms and beliefs, Caroline understands that incorporating a better comprehension of the Canadian Arab culture into her research practice would greatly benefit the Elder Abuse Project. Improving the cultural competence of her research team could help them address and mitigate participants’ mistrust of the academic process.

### **SERVICE PROVIDERS FOR THE ARAB COMMUNITY IN ASHCROFT**

#### **New Foundations Community Centre**

Established in 1976, the New Foundations Community Centre (NFCC) is a not-for-profit organization that assists immigrants with networking and issues related to settlement and social services. Although the Centre is actively involved with individuals from all cultures, religions, and ethnicities, and it is not affiliated with any specific religion or political sector, it primarily serves members of Ashcroft’s Arab community. Located in the city’s east district, the Centre ultimately acts as a hub for anyone in the area wishing to access social services and become active citizens in their new country.

Extending to a broad range of age groups and newcomers, the NFCC’s services include programs for sponsored immigrants, seniors, women, children and youth, newcomers, and refugees. The Centre also assists people with social services such as housing referrals, and applying for social insurance numbers, Ontario Health Insurance Plan cards, driver’s licenses, and Canadian citizenship. Ensuring immigrants receive the appropriate documentation is necessary at the most basic level to having them become healthy and active participants in Canadian daily life. The NFCC additionally offers aid with specialized settlement issues, including advice regarding legal and immigration concerns, information about cultural safety within the Canadian environment, and counselling services on domestic violence and gambling issues. Regular information sessions are held at the Centre to discuss family reunification, peoples’ rights and responsibilities in Canada, and financial issues such as banking and budgeting. These services and classes can be invaluable to newcomers to Canada who may not speak English and are still adjusting to the cultural differences of their new home.

The organization has recently initiated the Foundations for Syrian Newcomers Program, which was launched to assist Syrian refugees with accessing services and building social capital so that they can better navigate the challenges inherent to their transition. With an emphasis on providing ongoing support through counselling and services, and connecting newcomers from Syria to the Arab community and to the city’s other populations, the Foundations for Syrian Newcomers Program and the NFCC have the potential to positively impact this vulnerable population.

#### **ORIGIN Immigrant Services**

With four locations across Greater Ashcroft, ORIGIN is a multicultural organization that provides services to hundreds of diverse immigrant communities and newcomers requiring assistance. In order to meet the needs of each population accessing various social services, ORIGIN offers

## **Reaching the Hard-to-Reach: Conducting Research on Elder Abuse in Toronto's Arab Community**

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assistance in more than 15 languages, and helps ensure each group feels recognized and empowered. The organization's emphasis on policies including non-discrimination, anti-racism, and accessibility helps it achieve these desired outcomes. Furthermore, ORIGIN offers services pertaining to family and mental health, including medical clinics, crisis and elder abuse counselling, intervention groups for men and women, and other relevant services for youth, seniors, refugees, women, and people looking for specific opportunities. With a variety of services and programs available, ORIGIN's primary mission is to assist newcomers and immigrants in becoming self-sufficient members of their new country. Although its focus is not specific to Ashcroft's Arab community, ORIGIN has recently expanded its outreach to include more than 1000 Canadian Arabs, many of whom are older adults.

### **COMMUNITY-BASED PARTICIPATORY RESEARCH**

Community-based participatory research (CBPR) has emerged as an alternative paradigm to traditional research practice. Current "outside expert" perspectives have proven to be problematic when addressing issues faced by historically marginalized populations and in solving problems that stem from racial and ethnic health disparities. Furthermore, among these vulnerable groups, histories of exploitation and neglect in research have led to mistrust of the academic process. Reflecting on their inability to recruit participants from Ashcroft's Arab community, Caroline and her research team understand the need to step back from their top-down approach. Defined as the "systematic investigation with the participation of those affected by an issue for purposes of education and action or affecting social change", CBPR emphasizes equal participation by community members, organizational representatives, and academic researchers (Green, George, & Daniel, 1995). It offers the opportunity to develop partnerships with the intended communities such that research questions target issues that reflect the self-defined concerns of the pertinent community members. Further, implementing CBPR principles can improve the cultural sensitivity of interventions created to address these concerns.

Often, outside researchers maintain an inaccurate and unrealistic understanding about how a community functions. Therefore, within the CBPR process, it is critical that academic researchers are able to meet a community where it is and on its own terms. Community members, organizational representatives, and academic researchers can collaborate to recruit participants, building on community assets and pre-existing structures (Hergenrather, Geishecker, McGuire-Kuletz, Gitlin, & Rhodes, 2010). This collaborative effort can significantly improve outcomes in the recruitment and retention of participants.

As an outsider to the Arab community, Caroline realized that her team lacks the perspective and lived experience of community members that could better inform strategies to engage this hard-to-reach group. As representatives from an academic institution, it is essential that they first establish a rapport with their target population to build trust with potential participants. Caroline made a list of the organizations that provide services to the Arab community in Ashcroft and identified those organizations that work regularly with older adult immigrants. She knew that cultivating positive relationships with these organizations would prove invaluable to the project. How could the research team begin to develop partnerships with community service providers and other key stakeholders? In what ways could these partnerships improve project outcomes? Keeping these questions in mind, Caroline arranged a meeting first with a representative from the NFCC.

### **NEXT STEPS**

Caroline and her research team's current approach to the Elder Abuse Project is not working. Participant recruitment from this hard-to-reach population has slowed to a standstill. Mistrust with the research process and the team's failure to consider the cultural norms of Ashcroft's

## **Reaching the Hard-to-Reach: Conducting Research on Elder Abuse in Toronto's Arab Community**

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Arab community have significantly inhibited the sharing of information within focus groups. A new approach is needed.

Caroline stepped out of her office and began her journey to the NFCC for her meeting with one of their representatives, Abeer Said. She understood that her team's most significant barriers were their limited relationship with the Arab community and their inadequate understanding of the community's cultural norms. She hoped that both problems could be solved by developing a close partnership with the NFCC, one of the city's most reputable service providers. If these principles proved effective in practice, they could potentially be applied to other marginalized groups in the future. Though cultural contexts differ, the necessity of community partnerships and the benefits derived from giving communities autonomy over their own health would apply universally to any group. How can the research team shift from using an ineffective traditional research approach to using a CBPR paradigm? What steps can Caroline take to develop relationships between academia and the community and ensure the building of trust? How can Caroline incorporate cultural competency into her research practice, and to what extent can this incorporation improve study outcomes?

**Reaching the Hard-to-Reach: Conducting Research on  
Elder Abuse in Toronto's Arab Community**

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**EXHIBIT 1**

**Sample Flyer for Recruiting Older Adults from the Arab Community of Ashcroft**

(SAMPLE RECRUITMENT FLYER)

**Department of Immigrant Health  
Rudyard University**

**PARTICIPANTS NEEDED FOR  
RESEARCH ON ELDER ABUSE**

**Are you:**

- 60 years or older?
- An immigrant to Canada who identifies as Arab?
- Currently living in Ashcroft, Ontario or the Greater Ashcroft Area?
- Someone who has experienced abuse or neglect while living in Canada? OR do you know an older person from the Arab community who has been abused or neglected?

If you answered yes to the questions above, you are invited to take part in a study to understand why older immigrants experience abuse.

As a participant in this study, you would be asked to:

1. Complete a survey about elder abuse in your community
2. Participate in a group discussion about older adults' experience of elder abuse in the Arab community

Compensation for your time, and travel expenses will be provided

For more information about this study, or to volunteer for this study, please contact:

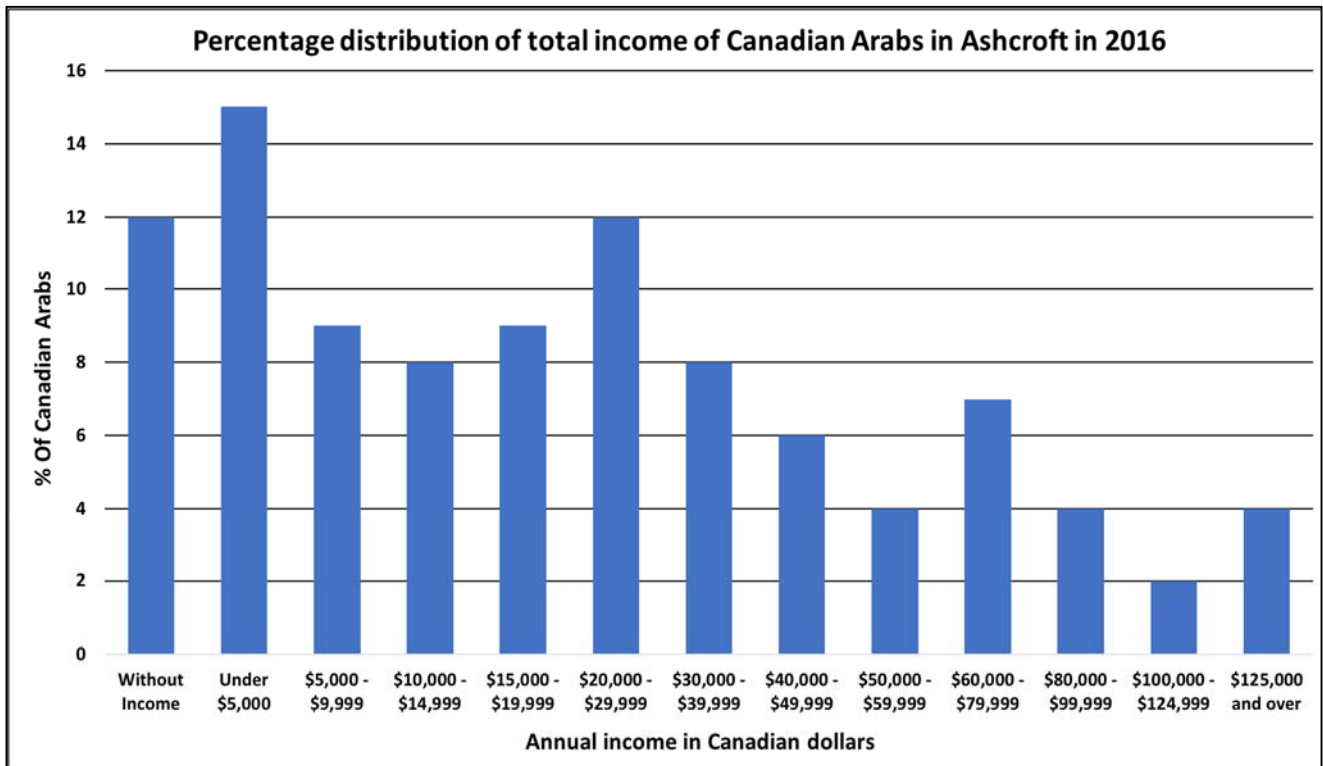
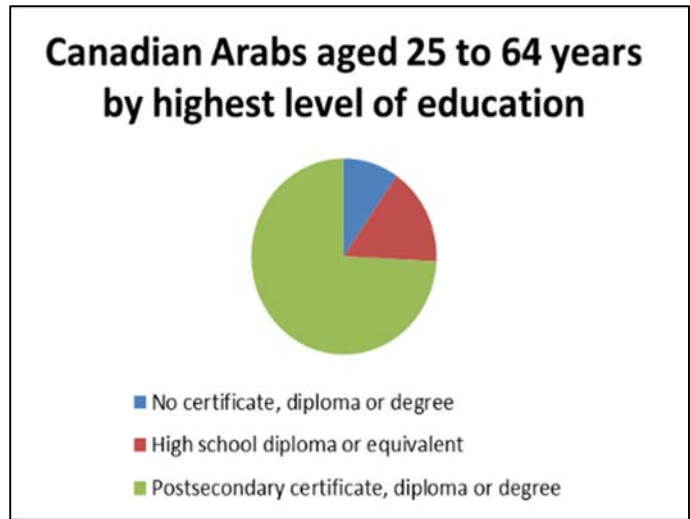
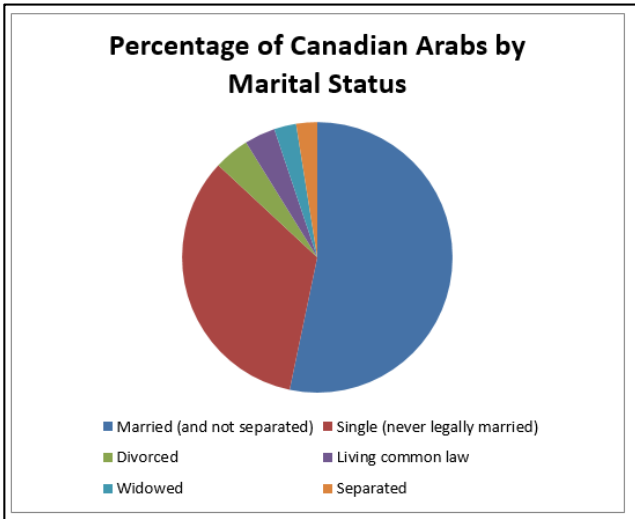
**Caroline Rochester**  
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Source: Created by authors.

## Reaching the Hard-to-Reach: Conducting Research on Elder Abuse in Toronto's Arab Community

### EXHIBIT 2

#### Demographics of the Arab Community of Ashcroft



Source: Dajani, 2014b; Dajani, 2015. Reproduced with permission from the Canadian Arab Institute.

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## INSTRUCTOR GUIDANCE

### Reaching the Hard-to-Reach: Conducting Research on Elder Abuse in Toronto's Arab Community

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*Matthew Maelzer, BSc, MPH (MPH Class of 2018)*  
*Sepali Guruge, RN, PhD (Professor and Research Chair in Urban Health, Co-Director, Centre for Global Health and Health Equity, Ryerson University)<sup>1</sup>*  
*Amardeep Thind, MD, PhD (Professor, Western University)*

#### BACKGROUND

A number of factors common to the post-migration context have been shown to negatively impact the lives of new immigrants to Canada. Within the Arab community in Ashcroft, certain factors such as sponsorship requirements, intergenerational cohabitation practices, financial dependence, language barriers, and cultural stigmas often act as risk factors, increasing the vulnerability of older adults to abuse. Caroline Rochester has recently accepted the research coordinator position for the Elder Abuse Project at Rudyard University. The goal of the study is to identify the key factors that increase the risk of abuse of elders in the Arab community. Once these factors are better understood, it will be possible to develop culturally relevant strategies to address the risks that are amenable to change.

Caroline's team wants to collect qualitative data by organizing focus group interviews with community members; however, she is running into numerous difficulties conducting research with this hard-to-reach population. Mistrust of the research process and the absence of mutually beneficial relationships with the community have brought participant recruitment to a standstill. Moreover, the team's failure to consider the cultural context of the population being studied has directly inhibited the progress of the project. It is clear that the current research methodology is not working and that a new approach is required. Caroline wonders what actions she should take to improve the research process.

The goal of this case is to introduce readers to a number of commonly encountered concerns when conducting research with hard-to-reach and vulnerable populations. Through the development of solutions to the problems faced by the protagonist, readers will become more familiar with the principles of community-based participatory research and gain an understanding of the importance of cultural competence in research practice.

#### OBJECTIVES

1. Recognize the effect of intersecting risk factors in increasing the vulnerability of specific populations to elder abuse.
2. Understand the application of focus group methodology when conducting qualitative research.
3. Identify strategies to recruit research participants from hard-to-reach populations.

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<sup>1</sup> This work could not have been undertaken without the support of the Immigrant Health Research team led by Dr. Sepali Guruge in the School of Nursing at Ryerson University.

## **Reaching the Hard-to-Reach: Conducting Research on Elder Abuse in Toronto's Arab Community**

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4. Describe the importance of maintaining cultural competence in research practice.
5. Apply principles of community-based participatory research to improve project outcomes.

### **DISCUSSION QUESTIONS**

1. Why are older adults within the Arab community considered 'hard-to-reach'?
2. Define 'community-based participatory research'. What are the key principles of this research paradigm?
3. Create definitions of 'culture' and 'cultural competency' with your learning team. What aspects of culture should be considered when conducting research on elder abuse in Ashcroft's Arab community?
4. How can the research team gain the trust of the focus group participants? Suggest some strategies.
5. Is the use of focus groups appropriate for this research project? What issues might arise from their use?

### **KEYWORDS**

Community-based participatory research; cultural competency; elder abuse; hard-to-reach populations; intersectionality

## CASE 9

# Achieving Health Equity in Ontario: Increasing Capacity for Relationship Building with Indigenous Communities

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Ryan McConnell, BPHE, MPH (MPH Class of 2018)  
Lloy Wylie, PhD (Assistant Professor, Western University)

### INTRODUCTION

Paul Green sat down at his desk and stared blankly at the document in front of him. He had been anticipating the arrival of the new *Health Equity Guideline, 2018* (Ministry of Health and Long-Term Care [MOHLTC], 2018a), which was intended to assist boards of health in implementing the requirements established in the modernized *Ontario Public Health Standards' Health Equity Standard* (MOHLTC, 2017). As the newly hired Health Equity Manager at Turtle Creek Public Health (TCPH), Paul knew that it was his responsibility to ensure that the organization complied with the *Health Equity Standard* in its entirety. While he believed that TCPH was already meeting the Standards' requirements in relation to the assessment of population health inequities, Paul was concerned that his organization did not possess the capacity to build meaningful relationships with Indigenous communities. His worries were primarily rooted in the findings of an internal environmental scan that he had conducted just two weeks earlier, which revealed that many TCPH staff members were looking for further direction on how to work with local Indigenous communities.

Having grown up in Northern Ontario and worked as a Public Health Inspector for nearly 20 years at his local public health unit (PHU), Paul had established many close relationships with Indigenous colleagues and clients. While he was confident that he could draw upon his own lived experiences to devise a plausible solution for TCPH, Paul was unsure about how he should proceed. How could he foster organizational capacity for health equity action? What could he do to support his colleagues in the development of meaningful relationships with local Indigenous communities? At next week's strategic planning meeting with executive staff, Paul would need to provide a set of recommendations for organizational action, and he knew that time was of the essence. After taking a sip from his mug of coffee, Paul sighed deeply and logged into his desktop computer. He knew that he had his work cut out for him.

### BACKGROUND

#### Health Equity

As stated in the *Health Equity Guideline, 2018*, "health equity means that all people can reach their full health potential without disadvantage due to social position or other socially determined circumstance, such as ability, age, culture, ethnicity, family status, gender, language, race, religion, sex, social class, or socioeconomic status" (MOHLTC, 2018a, p.5). Health Equity is one of the four Foundational Standards that "underlie and support" all of the Ontario Public Health Standards' *Program Standards* (MOHLTC, 2017, p.15). To comply with the *Health Equity Standard*, boards of health must meet four main requirements. Although the first, second, and fourth requirements relate to the identification of effective local health strategies, orientation of public health interventions, and development of policy, the third requirement of the *Health Equity Standard* necessitates that boards of health "engage in multisectoral collaboration with

## **Achieving Health Equity in Ontario: Increasing Capacity for Relationship Building with Indigenous Communities**

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municipalities, Local Health Integration Networks (LHINs), and other relevant stakeholders” to decrease health inequities (MOHLTC, 2018a, p.4). In addition, the third requirement mandates engagement with Indigenous communities and organizations that must include the “fostering and creation of meaningful relationships, starting with engagement through to collaborative partnerships” (MOHLTC, 2018a, p.4).

### **Turtle Creek Public Health (TCPH)**

TCPH is a PHU that delivers public health programs and services in the province of Ontario. It is located along the northern shoreline of Moccasin Lake and serves approximately 100,000 people. While collaborating with primary care providers to facilitate community clinics for immunization, STI screening, and dental services, TCPH also offers educational workshops on prenatal care, breastfeeding, and smoking cessation. In the catchment area served by TCPH, there are many residents of Indigenous heritage. Although some of these individuals live in urban areas, the large majority are habitants of one of the region’s three main Indigenous communities.

### **Community A**

Community A is a rural settlement territory that is populated by just 1,000 residents. It is home to a small recreation facility where Elders and community members participate in traditional ceremonies, hand-drumming circles, and crafting workshops on a monthly basis. Although primary care services are not presently available to residents in the community, Community A recently received federal funding to establish a new Child and Family Health Centre, which will provide Indigenous children, families, and caregivers with access to culturally responsive programming. When completed in 2020, the Centre will offer traditional language education classes, family cooking classes, beading workshops, and other initiatives to support healthy family and child development.

### **Community B**

Community B is a remote territory that is inhabited by nearly 2,000 residents. It is home to a Community Healing and Wellness Centre that offers family-centered health services to both Indigenous and non-Indigenous clients. While delivering holistic health programming that aims to support healthy parenting, early childhood development, chronic disease management, and mental wellness, the Centre also provides community members with access to primary care services via the Ontario Telemedicine Network.

### **Community C**

Community C is a lakeside settlement territory that is populated by approximately 2,400 residents. While home to a community recreation complex, an elementary school, and a collegiate education centre, Community C recently constructed a Community Wellness Centre to address local health disparities. Staffed by an interdisciplinary team of Registered Nurses, Well-Being Counsellors, and Community Support Workers, the Community Wellness Centre delivers a range of culturally appropriate health programs to residents of all ages and abilities. These include a diabetes education program, a family and child development program, and a mental health program that addresses issues such as substance abuse and addiction through one-on-one counseling sessions, peer support groups, fasting camps, sweat lodges, and traditional ceremonies.

## **PUBLIC HEALTH UNIT SURVEY: CURRENT CAPACITY FOR RELATIONSHIP BUILDING WITH INDIGENOUS COMMUNITIES**

In 2017, a Locally Driven Collaborative Project was initiated in Northern Ontario to identify current engagement practices as well as perceived successes and challenges within the context

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of engagement between Ontario PHUs and First Nations communities (Public Health Ontario, 2018). Although it consisted of multiple phases, the second step of the project involved distributing a comprehensive survey to 14 Ontario PHUs whose catchment areas intersect with a First Nations community. The results of the survey revealed that 79% of the respondents did not feel that their PHU possessed the “skills or knowledge to effectively engage with First Nations communities” (Public Health Ontario, 2018, p. 31). In addition, more than 75% of the respondents reported that their PHU required further resources to support First Nations community engagement (Public Health Ontario, 2018).

After a series of questions pertaining to organizational hiring protocols and First Nations representation on boards of health, the participating PHUs were asked to outline any barriers that they had encountered when attempting to foster relationships with First Nations communities. While a number of different challenges were highlighted, the large majority of the respondents indicated that their PHU was grappling with at least one of the issues highlighted below.

### **Jurisdictional Ambiguities**

Ontario PHUs reported that jurisdictional ambiguities prevented them from engaging with First Nations communities. Many respondents expressed that they were unsure if their organization was most responsible or appropriate for the provision of programs and services in First Nations communities, as health service delivery is also a responsibility of the federal government (Public Health Ontario, 2018). Additionally, a number of the respondents indicated that the presence of multiple PHUs in proximity to a given First Nations community led to uncertainty about who should offer to deliver services. These respondents stated that they were hesitant to reach out due to concerns about infringing upon relationship building with a First Nations community whose boundaries intersect with a different health unit.

### **Funding Shortages**

More than 75% of the responding PHUs stated that further resources were required to support engagement with First Nations communities (Public Health Ontario, 2018). Additionally, 100% of the PHUs that indicated the need for additional support checked off the “programming dollars for PHUs” box when prompted by the survey. Moreover, 77% of the respondents indicated that allocating programming dollars to First Nations communities would also be of significant benefit to facilitating the development of meaningful relationships (Public Health Ontario 2018). When asked about how additional funding could be utilized, a number of the PHUs suggested investing in additional human resources and cultural competency training for internal staff (Public Health Ontario, 2018).

### **Absence of Indigenous Health Data**

A number of the PHUs reported that data on Indigenous health was insufficient (Public Health Ontario, 2018). These respondents later added that the absence of data created difficulties with respect to the development and delivery of evidence-based programming in First Nations communities (Public Health Ontario, 2018). While four of the participating PHUs reported that they were in the process of developing a data-sharing agreement with a First Nations community, just one of the PHUs indicated that they actually had a formalized agreement in place (Public Health Ontario, 2018).

## **TWO WEEKS EARLIER: THE ENVIRONMENTAL SCAN**

After hearing about the results of the Northern Ontario PHU survey from his organization’s Medical Officer of Health, Paul decided to conduct an internal environmental scan to explore the nature and quality of existing relationships between TCPH program areas and local Indigenous

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communities. The health unit had hired an MPH student named Riley Woods for the summer, and Paul recruited Riley to join his team and assist with the completion of the environmental scan. To obtain the information needed, Paul sat down for an audio-recorded interview with each of TCPH's six program managers. As anticipated, his conversations revealed variability with respect to levels of engagement between different TCPH program areas and Indigenous community partners. While five of the program managers reported having some contact with service providers in Community C, only three stated that they had reached out to stakeholders in Community B. In addition, just two of the program managers reported that they had engaged with partners in Community A. Surprisingly, three program managers were not aware that Community A and Community B were located within the catchment area of TCPH.

After his interviews with the TCPH program managers, Paul asked Riley to review each of the interview transcripts for the purpose of identifying common themes. Riley quickly pinpointed *engagement type* as a predominant concept and decided to code the interview transcripts in accordance with Arnstein's "Ladder of Citizen Participation" (Exhibit 1). Through coding, Riley determined that the large majority of TCPH's interactions with local Indigenous communities could be characterized as varying degrees of *tokenism*. According to Arnstein (1969, p. 217), tokenism is an engagement approach whereby "citizens may indeed hear and be heard, but under these conditions, lack the power to ensure that their views will be heeded by the powerful". Riley prepared a briefing note to report the key findings to Paul and set up a meeting to discuss the next steps for the organization.

To validate the findings of the environmental scan, Paul asked Riley to carry out a second interview with each program manager, focusing on the existing capacities and unique needs of their respective program areas for the development of meaningful relationships with local Indigenous communities. During the follow-up interviews, many of the program managers spoke about experiencing similar barriers to those reported in the Northern Ontario PHU survey. Others simply stated that their department required further direction on how to work with local Indigenous communities. When prompting each manager to speak about existing knowledge gaps with respect to Indigenous peoples, the majority reported that they did not fully understand how relationships between Indigenous and non-Indigenous peoples came to be so fragile.

### THE HISTORICAL ROOTS OF FRAGMENTED RELATIONSHIPS: COLONIALISM AND ITS IMPACT ON INDIGENOUS PEOPLES IN CANADA

Colonialism is defined as a set of policies and practices where a political power from one territory exerts control or influence over a different territory (Social Sciences and Humanities Research Council of Canada, 2016). It involves the exploitation of a nation's resources and forced assimilation of its people into a dominant culture or group (Czyzewski, 2011). In Canada, colonialism is often cited as an impetus for the fractured relationship that currently exists between Indigenous and non-Indigenous peoples. Over hundreds of years, non-Indigenous settlers forcibly displaced Indigenous peoples from their traditional lands and established colonial policies and systems in an effort to eradicate Indigenous languages and cultures. Some of these policies and systems are outlined in Exhibit 2.

### THE SOCIAL DETERMINANTS OF INDIGENOUS HEALTH

Social determinants of health (SDOH) are the conditions in which people are born, grow, live, work, and age (World Health Organization, 2018). For Canada's Indigenous peoples, SDOH may be further delineated as circumstances, environments, structures, and institutions that influence the development and maintenance of health along a continuum of excellent to poor (National Collaborating Centre for Aboriginal Health [NCCA], 2015). While direct causal relationships are difficult to establish, there is growing evidence to suggest that social

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determinants such as colonialism and self-determination are closely linked to the adverse health issues observed in many Indigenous communities today (Czyzewski, 2011). These social determinants largely stem from colonial policies and historical events, which have fractured relationships between Indigenous and non-Indigenous Canadians. To illustrate the magnitude of their impact on the physical, emotional, mental, and spiritual domains of Indigenous well-being, the NCCAH (2015) categorizes social determinants of Indigenous health as distal, intermediate, or proximal in nature (Exhibit 3).

### DISTAL DETERMINANTS

#### Self-Determination

Self-determination has been cited as the most important determinant of health among Indigenous peoples as it greatly influences other social determinants such as education, housing, safety, and access to health services (MOHLTC, 2018b). In Canada, the persistence of colonial structures, policies, and legislation has resulted in the unequal participation of Indigenous peoples in the political systems under which they are governed (NCCAH, 2015). Under the *Indian Act*, 1985, restrictions are placed upon Indigenous peoples with respect to the lands that they may use for hunting, fishing, and harvesting resources (Mashford-Pringle, 2016). Additionally, the *Indian Act* limits Indigenous governance over community decision-making and constrains the services available to Indigenous peoples on reserves (Mashford-Pringle, 2016). Consequently, the absence of autonomy in relation to decision-making surrounding legal property, economic assets, education systems, and health services has been linked to the manifestation of adverse physical and mental health outcomes among Indigenous peoples (Reading & Wein, 2009). Research conducted by Reading & Wein (2009) links the absence of control or self-determination among Indigenous peoples to low self-esteem, anxiety, depression, and substance use disorders.

### INTERMEDIATE DETERMINANTS

#### Health Care Systems

Early Western health care systems were underpinned by an agenda that sought to sustain Canada's colonial legacy, with the ratification of the *Indian Act* leading to the enforcement of regulations that permitted the sanitation of Indigenous reserves (Kelm, 1998). During the 20th century, thousands of Indigenous peoples were forcibly removed from their homes and admitted to Indian hospitals for treatment of diseases such as whooping cough and tuberculosis, with the large majority never returning to their communities (Lux, 2010). These historical events are the premise of long-held apprehensions among many Indigenous peoples with respect to accessing health care services from Western institutions today. At present, many Indigenous peoples have yet to obtain appropriate physical, political, and social access to the Canadian health care system, and this prevents them from achieving their fullest health potential (NCCAH, 2015). While insufficient access to health services on reserves remains the most pressing health inequity experienced by Indigenous peoples, the fragmentation of the federal system for health care delivery has resulted in a large number of individuals who have unmet health needs (NCCAH, 2015). Furthermore, the existing structure of the health care system significantly impacts the health outcomes of many Indigenous peoples, who are often unable to pursue educational opportunities, obtain employment, or maintain social support networks due to the damaging repercussions of chronic health conditions (NCCAH, 2015).

### PROXIMAL DETERMINANTS

#### Physical Environments

Physical environments that are detrimental to the health of Indigenous peoples have been imposed through the historic dispossession of traditional territory (NCCAH, 2015). Following the introduction of the Indian reserve system, many Indigenous peoples in Canada lost access to

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lands that were once available for hunting, fishing, and trapping, which has subsequently created issues related to food insecurity and poverty (Kelm, 1998). In addition, thousands of Indigenous families do not have adequate housing and are unable to access safe drinking water on reserves, as their ancestors were forced to settle on small tracts of land scattered across rural and remote regions of the country (NCCAH, 2015). On many Indigenous reserves, inadequate housing has caused overcrowding to become commonplace, with multiple families often residing under the same roof. These living conditions place many Indigenous peoples at an increased risk of developing adverse health conditions (NCCAH, 2015). In addition to creating situations of overcrowding, the loss of traditional lands through colonization has also reduced opportunities for Indigenous peoples to engage in traditional practices, resulting in the loss of cultural identity (NCCAH, 2015). According to Wexler (2009), the loss of cultural identity has been linked to high rates of suicide among Indigenous peoples, with cultural connection cited as an integral component of Indigenous well-being.

### APPROACHING SOCIAL DETERMINANTS OF INDIGENOUS HEALTH AT TCPH

To develop recommendations for his organization's next steps, Paul would need to consider the social determinants of Indigenous health and their impact on Indigenous peoples residing within the catchment area of TCPH. While understanding that Indigenous communities in Canada are being disproportionately burdened by many of the proximal, intermediate, and distal determinants of Indigenous health, he was unsure about the magnitude of their impact within the three local Indigenous communities. He was also unsure about whether the scope of his work at TCPH would allow him to address all of the issues that stemmed from these determinants. He didn't believe that his organization could effectively tackle social determinants like self-determination without the assistance of Indigenous community partners, and realized that meaningful progress could not be made without establishing meaningful relationships.

### FOUNDATIONAL PRINCIPLES FOR RELATIONSHIP BUILDING

In 2017, a literature review was conducted by an interdisciplinary project team from Northern Ontario in collaboration with Public Health Ontario to identify mutually beneficial, respectful, and effective principles and practices for engagement between First Nations communities and Ontario PHUs (Public Health Ontario, 2017). Through a comprehensive analysis of both grey and published literature, four foundational principles emerged. These include the following:

#### Trust

Trust is the foundation to building respectful and mutually empowering long-term relationships with Indigenous peoples (Public Health Ontario, 2017). When attempting to cultivate relationships with members of Indigenous communities, it is imperative to acknowledge the historical events and colonial policies that have contributed to feelings of mistrust internalized by many Indigenous peoples today (Public Health Ontario, 2017). It is also important that organizations and agencies reach out to Indigenous communities that they wish to partner with and initiate early dialogue, as fostering trust requires a significant amount of time and should not be rushed (Public Health Ontario, 2017). Finally, it is essential that non-Indigenous peoples and organizations connect with Elders and spiritual leaders in the Indigenous communities that they hope to engage, as these individuals often play an integral role in building bridges between Western organizations/agencies and members of their community (Public Health Ontario, 2017).

#### Respect

Respect is a rudimentary principle that encompasses traditional practices such as honouring, knowing, and understanding (Public Health Ontario, 2017). It delineates the need for non-Indigenous peoples to acknowledge and appreciate both the history and current context of Indigenous peoples in Canada (Public Health Ontario, 2017). This includes recognizing cultural

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practices, traditions, protocols, values, and views while acknowledging the existence and impact of assimilationist, colonizing, oppressive, and suppressive policies and actions within legal, political, social, economic, and health-related contexts (Public Health Ontario, 2017). When aiming to cultivate relationships with Indigenous communities, it is imperative that non-Indigenous peoples actively seek to enhance their cultural competency, pursuing opportunities for personal growth through educational training or community mentorship (Public Health Ontario, 2017).

### **Self-Determination**

Self-determination is the inherent right of Indigenous peoples to freely choose their own pathways and to make decisions about all aspects of their communities and livelihoods (Public Health Ontario, 2017). It supports cultural preservation and ensures that sovereignty is respected in a way that provides clear benefits to Indigenous peoples and communities. To honour the principle of self-determination, those working with Indigenous peoples must strive to establish partnerships that are Indigenous-driven and strengths-based, building upon the capacities and assets that Indigenous communities possess (Public Health Ontario, 2017). Additionally, those engaging with Indigenous peoples are more likely to be successful if they operate within a framework where self-determination is consistently acknowledged, understood, and honoured (Public Health Ontario, 2017).

### **Commitment**

Commitment is a principle that supports prosperous engagement if appropriate practices are in place (Public Health Ontario, 2017). These practices include exploring ways to work in a more culturally appropriate manner and the prioritization of Indigenous self-determination. In accordance with the principle of commitment, relationship building with Indigenous peoples must be viewed as a long-term process, as it requires time, patience, and meaningful dialogue. The process of engagement with Indigenous communities must also be deliberate and adaptive, while facilitated by people who are fully committed to Indigenous empowerment, priority setting, and decision-making (Public Health Ontario, 2017). To cultivate meaningful partnerships with Indigenous peoples, organizations and agencies must aim to establish an authentic presence in the communities they are working with, attending community events when invited and supporting community-led initiatives. In addition, non-Indigenous peoples may strengthen relationships with their Indigenous counterparts by routinely engaging in the practice of self-reflection, acknowledging the balance of power within a partnership while identifying opportunities for personal growth (Public Health Ontario, 2017).

### **INTERNALIZING PRINCIPLES FOR RELATIONSHIP BUILDING AT TCPH**

To develop an appropriate set of recommendations for TCPH, Paul would also need to be cognizant of the foundational principles for relationship building with First Nations communities. While confident that his approach should be guided by trust, respect, self-determination, and commitment, he was unsure about how he could encourage staff within his organization to internalize and employ these principles when engaging and working with Indigenous peoples. He was also unsure about what each of the aforementioned principles meant to those residing within the three Indigenous communities located in TCPH's catchment area, and understood that this knowledge could only be obtained by cultivating meaningful partnerships.

### **A WORD OF ADVICE**

After a counterproductive morning of brainstorming possible recommendations for organizational action, Paul dejectedly retreated to the lunchroom. As his plastic container of chicken and veggies sizzled in the microwave, he was approached by Jen Girard, TCPH's new Community Engagement Liaison. Over lunch, the pair engaged in a spirited conversation, with

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Paul explaining his dilemma and expressing that he needed assistance. Having collaborated with an Indigenous community on a health promotion initiative at her previous place of employment, Jen recommended that Paul consider the development of an Indigenous Relationship Building Strategy for TCPH. She expressed that meaningful relationships with local Indigenous communities could not be established if TCPH staff did not first develop an understanding of each community's unique history, current context, and preferences for engagement. After taking a moment to reflect upon Jen's remarks, Paul began to wonder about how he might obtain the information required to educate his staff and develop an organizational strategy. At a recent conference, Paul had learned about a new planning tool developed by Public Health Ontario called a *Situational Assessment*, and wondered if he could utilize this approach to assist TCPH in developing a preliminary understanding of how to effectively, appropriately, and meaningfully build relationships with local Indigenous communities.

### SITUATIONAL ASSESSMENT

A situational assessment is a systematic process to gather, analyze, synthesize, and communicate data to inform planning decisions [(Public Health Ontario (PHO), 2015)]. It is the second step of PHO's six-step model for planning a health promotion program (PHO, 2015). While often used to gather information that can inform decisions regarding strategies or frameworks, a situational assessment may be carried out to learn more about a population of interest and identify the wants, needs, and assets of a community (PHO, 2015). According to PHO (2015), a situational assessment must consist of the following steps:

1. Identify key questions to be answered
2. Develop a data-gathering plan
3. Gather the data
4. Organize, synthesize, and summarize the data
5. Communicate the information
6. Consider how to proceed with planning

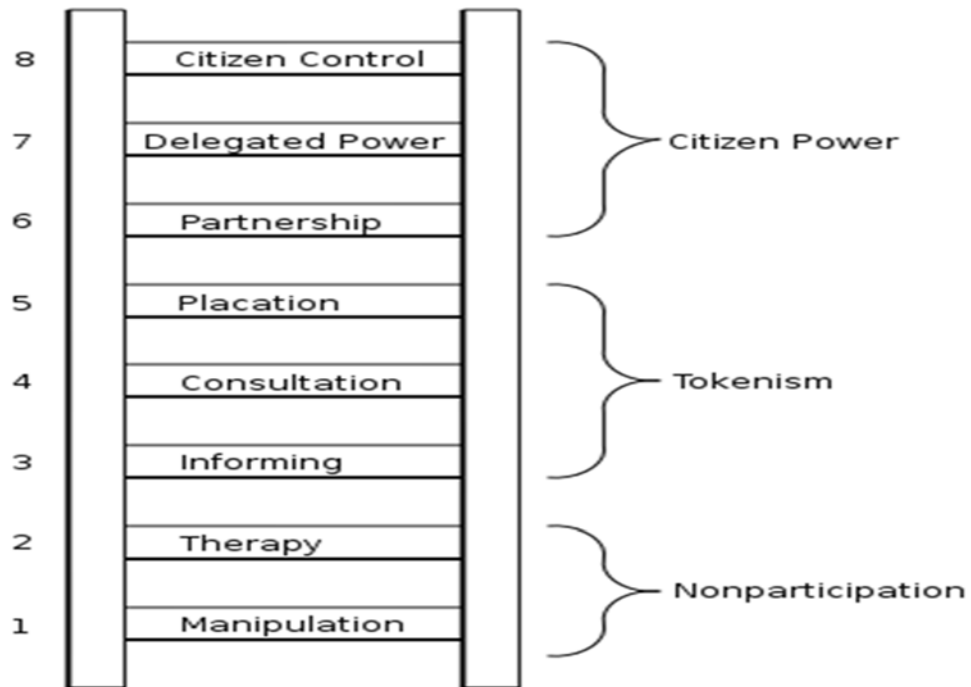
### PAUL'S NEXT STEPS

After mulling over his colleague's advice for the remainder of the afternoon, Paul decided that conducting a situational assessment using PHO's six strategic steps would be crucial to inform the development of an Indigenous Relationship Building Strategy for TCPH. While allowing him to identify the assets and opportunities that could be leveraged in local Indigenous communities to support the development of meaningful relationships, an organizational strategy could provide his colleagues with the guidance they had requested. In addition, an Indigenous Relationship Building Strategy could foster organizational capacity for health equity action, and assist TCPH in meeting each of the requirements outlined in the *Health Equity Standard*.

With time remaining in Riley's placement at TCPH, Paul wanted to get him started on the situational assessment right away. However, Paul was unsure about where to begin. What questions should be asked? What important considerations needed to be made? After pausing to reflect, Paul collected himself and prepared to face the many challenges ahead. With the support of his team at TCPH, he was confident that meaningful relationships could be developed with Indigenous peoples and communities for generations to come.

EXHIBIT 1

Arnstein's Ladder of Citizen Participation



Source: Arnstein, 1969. © The American Planning Association, [www.planning.org](http://www.planning.org), reprinted by permission of Taylor & Francis Ltd, <http://www.tandfonline.com> on behalf of The American Planning Association.

**EXHIBIT 2**

**The Historical Roots of Fragmented Relationships**

**Early Land Treaties**

Following the conclusion of the Seven Years' War in 1763, King George III established the *Royal Proclamation*, a foundational document that set guidelines for European settlement on Indigenous lands (Government of Canada, 2016). While explicitly stating that the lands of North America are to be considered the "hunting grounds" of Indigenous peoples, the document declares that any territory occupied by Indigenous peoples cannot be ceded unless the Crown purchases the land and sells it on their behalf (Government of Canada, 2016). Between 1871 and 1921, 11 land surrender treaties were signed between Indigenous leaders and the Crown, which allowed thousands of European colonists to settle upon Indigenous lands (Usher et al., 1992). In recent years, the federal government has fielded a number of complaints in relation to the legitimacy of the land surrender treaties. Several Indigenous groups have voiced their belief in the notion that the treaties were rushed, fraudulent, incomplete, and in many cases, breached by governing bodies (Government of Canada, 2011).

**The Indian Act**

The *Indian Act, 1876* is a statute through which the federal government may determine who can and cannot legally be considered a "Status Indian" (Allan & Smylie, 2015). It is largely responsible for the relocation of Indigenous peoples to Indian reserves from their traditional lands. In the establishment of the Indian reserve system, the federal government appointed Indian Agents for each community and granted them the authority to restrict the movement of residents on and off reserves using a written pass system (Allan & Smylie, 2015). Under the *Indian Act*, "Indian" identity was once rooted in male lineage, and legal status was stripped away from any woman who chose to marry a partner who did not meet the federally imposed definition of Indian (Mikkonen & Raphael, 2010). Although it has undergone a number of amendments since it was passed in 1876, the *Indian Act* remains in place today and largely retains its original form.

**Residential School System**

In the late 1880s, the federal government sponsored religious organizations to operate residential schools with the intention of "kill[ing] the Indian in the child" and forcing Indigenous youth to assimilate into dominant Canadian culture (Bombay et al., 2014; Smith et al., 2005). Over a period of nearly 100 years, it is estimated that nearly 150,000 Indigenous children were removed from the care of their families for the purpose of attending a residential schooling institution (Bombay et al., 2014). Under the instruction of religious missionaries and government officials, students of Indigenous heritage were taught to be ashamed of their languages, cultures, and beliefs. At residential schools, thousands of Indigenous children became the subjects of unethical experiments and endured various forms of physical, mental, and sexual abuse, with many eventually losing their lives (Bombay et al., 2014). Although the last institution closed down in the mid-1990s, residential schools have had "rippling, multigenerational effects on survivors, negatively impacting the health of their children, grandchildren, and great-grandchildren" (Allan & Smylie, 2015, p. 7).

**EXHIBIT 3**

**Social Determinants of Indigenous Health**

**DISTAL DETERMINANTS**

**Colonialism**

There is increasing consensus that the oppressive and colonial structure within which Indigenous peoples live produces social, political, and economic inequities that prevent many individuals from maintaining a connection to their Indigenous heritage (Waldram, Herring, & Young, 2006; NCCAH, 2015). Primary examples of this are the traumatic experiences of Indigenous children who attended residential schools. While stripping many Survivors of their cultural identities, residential schools have also been cited as an impetus for the manifestation of physical and mental health disparities among Indigenous peoples (Waldram, Herring, & Young, 2006). Butler-Jones (2008) stated that “diminished life expectancy, disproportional burden of chronic disease, communicable illness, addictions, and social violence have all been linked to an overarching colonial structure”. In short, these adverse health outcomes may subsequently influence educational achievement, likelihood of employment, socioeconomic status, and living conditions of Indigenous peoples (Czyzewski, 2011). As such, the aforementioned consequences of diminished health may subsequently cycle into future generations of Indigenous families if those affected are unable to access the supports they desire to heal from unresolved trauma (NCCAH, 2015).

**INTERMEDIATE DETERMINANTS**

**Education Systems**

Although the number of Indigenous children pursuing an education continues to trend upwards, there is limited Indigenous involvement in the development of school curricula in Canada (Neegan, 2005). Across the nation, culturally appropriate education continues to be denied to Indigenous children and youth, as mainstream education systems pay little attention to the social determinants that place Indigenous students at a disadvantage in relation to their non-Indigenous peers (NCCAH, 2015). Existing curricula are largely devoid of Indigenous-specific content and fail to acknowledge the intergenerational impacts of residential schools and other colonial events that have shaped the current contexts of Indigenous communities in Canada (Neegan, 2005). These glaring oversights may subsequently have profound consequences for many Indigenous youth, impeding the acquisition of knowledge and skills that are needed to pursue higher education, obtain stable employment, and secure adequate housing (NCCAH, 2015). According to Statistics Canada (2010), approximately 22% of Indigenous youth in Canada drop out or are “pushed out” of high schools in comparison to just 8.5% of non-Indigenous youth.

**PROXIMAL DETERMINANTS**

**Health Behaviours**

Intergenerational trauma stemming from colonialism and historical oppression has greatly shaped the health behaviours of Indigenous peoples in Canada (NCCAH, 2015). High rates of alcohol consumption, drug use, and smoking are observed among many Indigenous Canadians, which significantly increases their likelihood of suffering from heart disease or lung cancer, and increases their risk of all-cause mortality (NCCAH, 2015). With respect to Indigenous populations, adverse health behaviours are often adopted as a means through which to cope with injury, illness, stress, or pain associated with unfavourable social conditions or traumatic events (Frohlich, Ross, & Richmond, 2006). According to Physicians for a Smoke-Free Canada (2013), the smoking rate among Canada’s Indigenous population is nearly twice that of non-Indigenous Canadians (39% compared with 20.5%). Upon further analysis of population subgroups, the disparity between Indigenous and non-Indigenous smoking rates increases significantly, with the prevalence of smoking estimated to be three times higher for Indigenous youth than it is for non-Indigenous youth (Jetty, 2017).

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## INSTRUCTOR GUIDANCE

# Achieving Health Equity in Ontario: Increasing Capacity for Relationship Building with Indigenous Communities

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*Ryan McConnell, BPHE, MPH (MPH Class of 2018)*  
*Lloy Wylie, PhD (Assistant Professor, Western University)*

### BACKGROUND

Paul Green is concerned that his organization is not meeting the requirements of the modernized *Ontario Public Health Standards' Health Equity Standard* after his colleagues ask for direction on working with local Indigenous communities. Under the third requirement of the new *Health Equity Standard*, all boards of health must engage with Indigenous communities and organizations, which must include the “fostering and creation of meaningful relationships”. As the new Health Equity Manager at Turtle Creek Public Health (TCPH), Paul is tasked with developing a set of recommendations for organizational action. After receiving advice from a colleague, Paul decides that the next step for his organization is to conduct a situational assessment to explore how it may effectively, appropriately, and meaningfully build relationships with local Indigenous communities. However, Paul is unsure about where to begin. What questions should be asked? What important considerations need to be made? By developing an understanding of community histories, current contexts, colonial policies, historical events, social determinants of Indigenous health, and the foundational principles for relationship building with First Nations communities, meaningful partnerships may be cultivated with stakeholders and organizations in Indigenous communities across the province.

### OBJECTIVES

1. Identify existing barriers to relationship building with Indigenous communities from the perspective of public health units in the province of Ontario.
2. Discuss the means by which historical events and colonial policies undermine Indigenous health and create challenges to achieving health equity at organizational, community, and societal levels.
3. Identify and differentiate between the proximal, intermediate, and distal determinants of health that affect Indigenous peoples in Canada.
4. Develop an understanding of what a meaningful relationship might look like and how a meaningful relationship may be cultivated with Indigenous peoples.
5. Develop a context-specific situational assessment plan for a public health unit wanting to create an Indigenous Relationship Building Strategy.

### DISCUSSION QUESTIONS

1. What were some of the barriers encountered by Ontario public health units when attempting to build relationships with Indigenous communities?
  - Have you ever encountered any of these barriers during a volunteer or work experience? Were you able to overcome this barrier? If so, how?
2. List the social determinants of health that are present in the case.
  - In which categories do each of these determinants fit?
3. Explain the link between the social determinants of Indigenous health and the colonial policies and historical events outlined in the Case Note/required readings.

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4. Define each of the four foundational principles to relationship building with First Nations communities.
5. What is a meaningful relationship? What might a meaningful relationship look like? How might a meaningful relationship be fostered?
6. What is a situational assessment? Why might a situational assessment be conducted? How might a situational assessment support engagement and the development of meaningful relationships?
7. Can a situational assessment plan that is developed for working with a particular Indigenous community be utilized to work with another Indigenous community? Why or why not?
8. Some Indigenous peoples are hesitant to participate in research initiatives due to the mistreatment of their ancestors and family members in previous studies. How could you appropriately and respectfully engage Indigenous communities to encourage their participation?
9. Describe the achievements or challenges that your learning team experienced during the situational assessment planning activity.
10. Highlight a key aspect of another learning team's situational assessment plan that your learning team did not consider during the activity. How might this aspect or element have strengthened your learning team's plan?

### KEYWORDS

Health equity; Indigenous communities; relationship building; social determinants of health; situational assessment



## CASE 10

### Supporting Students with Learning Disabilities: Reducing Secondary School Non-Completion and its Associated Health Disparities

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*Avery Prince, BPHE, MPH (MPH Class of 2018)*

*Mary-Liz Warwick, BA, MA (c) (Executive Director, The Learning Disabilities Association of Sudbury & the Northern Ontario for Learning Differences)*

*Wendy Larouche (Resource Facilitator and Community Outreach,  
Learning Disabilities Associate of Sudbury)*

*Gerald McKinley, PhD (Assistant Professor, Western University)*

*Data on the prevalence of learning disabilities (LDs) among children is not readily available at the national level... for reasons including lack of diagnosis and parent reluctance to identify because of stigmatization. Ten percent having LDs is a low estimate, but can apply to the childhood and adult populations.*

*— Public Health Agency of Canada, 2009*

It was a cloudy spring day and Shelley van Dam was sitting at her desk, sifting through and organizing her emails. As the Executive Director of the Learning Disabilities Association of Sudbury (LDAS), Shelley spends most of her time ensuring that the organization's programs and services are effectively provided to local youth and adolescents who have been diagnosed as having a learning disability (LD).

The LDAS is in its third and final year of an Ontario Trillium Foundation funding cycle for a grant that allows Shelley to employ resource facilitators in satellite offices located in North Bay, Timmins, and Sault Ste. Marie. These facilitators help support students who have LDs and their families, and they help them navigate the education system. Shelley continues to grow uneasy about the looming possibility that her satellite operations may lose funding and have to close. Losing access to these additional facilitators could negatively impact the rates of high school graduation for students who live in these smaller cities and have LDs because this would put additional strain on the Sudbury employees who would then be required to travel longer distances. In addition, the families in the other cities would not have a local advocate to fight for their children, which would result in more students falling through the cracks of the education system.

Shelley is aware of some dated literature and statistics concerning the graduation success rates of students who have LDs, with the most pertinent information coming from a 2007 study conducted by the Learning Disabilities Association of Canada (LDAC-ACTA). She remembers that even after LDAC-ACTA was incorporated in 1971, results from the 2007 study found that 28.3% of Canadians who had LDs had attained an education level of "less than high school" compared with 14.9% of the general population (LDAC-ACTA, 2007). She was concerned about the risks of not having support in the satellite cities, and how the lack of assistance would impact the education experiences of students who have LDs.

## Supporting Students with Learning Disabilities: Reducing Secondary School Non-Completion and its Associated Health Disparities

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Shelley hopes to obtain funding from a more sustainable source such as the Ministry of Children, Community and Social Services. Sustainable funding would allow the organization to operate as is, while also expanding current programs to include other categories of learning differences. Her first step was to write a report to her board detailing the issue, outlining some recommendations and devising a proposal for the next steps. She wasn't sure where to begin, so she opened up her web browser and typed "recent literature on learning disabilities".

### BACKGROUND

Learning disabilities refer to various disorders that affect the acquisition, retention, understanding, and organization of verbal and/or nonverbal information. The LDAC-ACTA report from 2007 states that LDs are specific (oral language, reading, math skills, or written language), and are categorized separately from intellectual disabilities. This report also states that people who have learning disabilities may also have difficulties with organizational skills, social perception, social interaction, and perspective taking. These disabilities are caused by genetic and/or neurobiological factors, or result from injuries that alter brain functioning in a manner that affects processes related to learning. Individuals who have learning disabilities have average- to above-average intelligence and are very capable of learning, but stigma accompanying the word "disability" or "inability to achieve" persists (LDAC-ACTA, 2007). Learning disabilities are commonly downplayed by affected people and their parents, and disclosure of a disability is sometimes avoided due to fear of being stigmatized (Waterfield & Whelan, 2017).

The LDAC-ACTA was founded in 1963 to act as a national voice for people who have learning disabilities and those who support these people. The LDAC-ACTA provides public awareness by advocating, conducting research, and focusing on health and education (LDAC-ACTA, 2017). The Learning Disabilities Association of Canada (LDAC-ACTA) operates across the nation, with an extended network of chapters throughout more than 55 communities. The Sudbury chapter, or the LDAS, aims to "support all individuals with learning disabilities in reaching their full potential, within a community that values their unique contributions and abilities" (LDAS, 2015). This has proven to be a continued challenge for the organization because they must provide quality support throughout the entire City of Greater Sudbury. This alone acts as a barrier to the LDAS providing adequate services because the City of Greater Sudbury is geographically larger (3,627 km<sup>2</sup>) than any other municipality in Ontario and is the second largest municipality in Canada (Greater Sudbury, 2018). The organization's geographical area of operations not only includes Sudbury and the surrounding area, but the LDAS also maintains a presence in smaller cities across Northeastern Ontario, including North Bay, Sault Ste. Marie, and Timmins. Each of the aforementioned cities contains satellite LDAS offices that employ a resource facilitator who easily and efficiently meets the needs of the various school boards, youth with learning disabilities, and their families or caregivers. The organization has prioritized four different strategies with the hope of ensuring that the best possible services are provided:

#### 1. Reaching Families

Reach more families of children and youth who have learning differences through an expansion of operations, as it is expected that through engagement, feedback, and collaboration, children, youth, and families will receive the necessary services in an efficient manner.

#### 2. Developing a Youth Organization

Create a youth-led body that will provide a supportive environment for teens who have learning disabilities in order to help develop their emotional and social skills, which should also help teens and other youth who have learning disabilities reach their true potential.

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### 3. Sustainability

Maintain high-quality programs, services, and support for years to come. Expansion of services provided can include all differences, and is the basis of the newly created Northern Ontario Centre for Learning Differences.

### 4. Community Awareness

Increase the public's overall level of understanding and awareness of learning disabilities, including the programs and services LDAS provides. Community awareness is necessary so that the challenges and stigma facing children and youth who have learning disabilities can be better explained; this can be achieved through the creation of community awareness events.

## DEFINING LEARNING DISABILITIES

The LDAC-ACTA (2017) uses the following parameters when defining learning disabilities:

- Learning disabilities are distinct from global intellectual deficiencies
- Learning disabilities result from impairments in one or more processes related to perceiving, thinking, remembering, or learning
- Learning disabilities range in severity and may affect any or several areas of life
- Learning disabilities are lifelong
- Learning disabilities are neurobiological and/or genetic in origin

Another Canadian nonprofit organization, The National Institute for Learning Development, which is dedicated to training educators to work with children and adults who have learning difficulties through individualized educational therapy, has also characterized learning deficits. The organization states that learning disabilities are a pattern of neurological dysfunctions in the brain that cause a person to have difficulty correctly receiving information (perception), correctly processing information (cognition/thinking), or appropriately responding to information (written and verbal expression, visual–motor coordination, etc.), with such deficits mainly falling into three basic categories (National Institute for Learning Development, 2017):

1. Dyslexia: Difficulty with words (deficits in the ability to hear words and manipulate sounds, in addition to deficits in the ability to read and spell words accurately and fluently).
2. Dysgraphia: Difficulty with writing (deficits with spelling, with the motor skills necessary to write on paper, and with the thinking needed for vocabulary retrieval).
3. Dyscalculia: Difficulty with calculations and mathematics (deficits with basic number sense and early number concepts in addition to math calculations and math reasoning).

The American LDAC-ACTA counterpart, or Learning Disabilities Association of America, uses its own definition for learning disabilities, which includes neurologically based processing problems that can interfere with learning basic skills such as reading, writing, and/or math, in addition to interfering with other skills such as organization, time planning, abstract reasoning, long- or short-term memory, and attention (Learning Disabilities Association of America, 2018). According to the *Individuals with Disabilities Education Act* from American legislation, the proper term that describes learning disabilities is *specific learning disability*, and includes the following disorders:

1. Auditory Processing Disorder: affects how sound that travels unimpeded through the ear is processed or interpreted by the brain (difficulty distinguishing between subtle sounds in words, or when sounds are loud and clear enough to be heard).
2. Dyscalculia: affects a person's ability to understand numbers and learn math facts.

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3. Dysgraphia: affects a person's handwriting ability and fine motor skills.
4. Dyslexia: affects reading and related language-based processing skills.
5. Language Processing Disorder: a specific type of auditory processing disorder that makes it difficult for a person to attach meaning to sound groups that form words, sentences, and stories.
6. Nonverbal Learning Disabilities: significant discrepancy between higher verbal skills and weaker motor, visual-spatial, and social skills.
7. Visual Perception/Visual Motor Deficit: affects the understanding of information that a person sees, or the ability to draw or copy.

Literature focusing on learning disabilities in a Canadian context is lacking and there is limited agreement on learning disability definitions and terms within the existing, largely American, evidence base (Waterfield & Whelan, 2017). The largest difference in the definitions comes from the inclusion of attention in the American definition of a learning disability, which often stops Shelley from using any programs or procedures that may be deemed beneficial south of the border. She thinks that it would be beneficial to agree about how to categorize learning disabilities, not just within the Canadian context, but also within an American and international context. This would be a great first step in helping to implement new and innovative practices that could better identify and accommodate students who have learning disabilities, but she doubts it will happen any time soon.

### EDUCATION

Having a high school diploma is essential in today's labour market. Researchers state that "high school dropout often leads to long-term economic hardships that impair health and family function, which in turn can perpetuate inequalities across generations" (Dupéré et al., 2018). Education is a strong predictor of health outcomes, including mortality, since less education is commonly associated with smaller social support networks and risky health behaviours such as smoking and maintaining unhealthy eating habits. Education, or lack thereof, is also associated with attaining less income (on average), which can lead to poorer eating habits, unsafe or unhealthy living conditions, and increased mental health concerns (Lansford, Dodge, Pettit, & Bates, 2016).

Shelley found information from the 2016 federal census stating that 14% of all Canadians aged 25 and over reported their highest education level as "less than high school graduation" (Statistics Canada, 2017). This motivated Shelley to dig deeper and find more information about high school non-completion—how to define the problem, identify the options, and hopefully find a solution that will lead to increased funding. Shelley was aware of the *Putting a Canadian Face on Learning Disabilities* (PACFOLD) report that was completed by LDAC-ACTA in 2007, which revealed some alarming statistics. The study showed that 28.3% of Canadians aged 22 to 29 years old had reported not completing high school, and how much worse that percentage was compared with the general population rate of 14% (LDAC-ACTA, 2007; Statistics Canada, 2016). She wanted to find more recent statistics and was thankful to find a 2012 census that provided a more relevant snapshot of learning disabilities throughout Canada. She learned that approximately 622,300 people, or 2.3% of the Canadian adult population aged 15 and up, reported having a learning disability (Statistics Canada, 2015). In addition, the census revealed that 33% of adults who have learning disabilities attained a highest level of education of "less than high school," compared with 13.1% of adults who do not have a learning disability (Exhibit 1). Therefore, students who have learning disabilities were approximately 2.5 times more likely not to graduate compared with the general population, despite the presence of the LDAC-ACTA and other such organizations across Canada. Shelley wondered how drastically that number would increase if her organization was unable to continue providing the resources and assistance to the students in Northeastern Ontario who have learning disabilities. After

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seeing that fewer than 36% of adults who have learning disabilities had achieved a postsecondary level of education compared with 61.1% of those who do not have learning disabilities (Exhibit 1), she further understood why her role and work were so crucial.

After gaining a more comprehensive understanding of the success of students who have learning disabilities, and an understanding of the sheer number of Canadians who have learning disabilities who drop out of high school compared with the general population, Shelley came across another article. It was a 2008 report to the Canadian Council on Learning written by Dr. Olena Hankivsky, a professor at Simon Fraser University, discussing the costs associated with dropping out of high school in Canada (Hankivsky, 2008). Although the report was more than 10 years old, Shelley was still excited to see the cost estimates, broken down per year and over a 35-year life span, that were attributable to dropping out of high school. She had always wondered what the price of high school non-completion was because she assumed that it was high both for the person who dropped out and for the public. But after seeing what the average costs per dropout were, and noticing the total aggregated costs across various categories, she knew that the problem was much worse than she had previously estimated. Shelley read, for example, that the average public cost of social assistance per dropout was \$4,230 annually, for an overall total of \$969 million annually across Canada (Exhibit 4). She also saw that, on average, the annual health care costs for the individual were \$8,098, or \$211,471 across the lifetime of a single high school dropout. It amazed Shelley to see such high costs both for the individual and for the public. She felt hopeful that these numbers would allow her organization to continue providing services that would help minimize the number of students who have learning disabilities from dropping out of high school.

### HEALTH

Health and wellness can be impacted by educational attainment, which Shelley has seen within her own social network. She knows that, on average, people who have more education and greater average incomes are generally healthier and in better shape. However, she was not sure exactly how this translated to those who dropped out of high school, and she wanted to examine this specifically in the context of students who have learning disabilities, particularly in terms of negative outcomes. She found a study by Cook, Li, and Heinrich (2015) that examined whether there was an association between obesity, physical activity, and sedentary behaviour among youth who have learning disabilities and Attention Deficit Hyperactivity Disorder (ADHD). She learned that youth who have learning disabilities only, ADHD only, or comorbid LD/ADHD were significantly less likely to meet recommended levels of physical activity, and that youth who have learning disabilities were significantly more likely to exceed recommended levels of sedentary behaviour (Cook et al., 2015).

Since there is little research available regarding the health outcomes of people who have learning disabilities, Shelley shifted her focus to the health outcomes of the general population who do not graduate from high school. She found that people who do not complete upper secondary school or high school are at higher risk of experiencing poorer health and engaging in criminal behaviour (Holen, Waaktaar, & Sagatun, 2017). Some of the predicting, non-completion factors for high school included family-related determinants such as low levels of parental education, low family income, and living in a single-parent household. Another study examined whether there was an association between chronic disease and dropping out of high school (Vaughn, Salas-Wright, & Maynard, 2014). Shelley was surprised to find that there were statistically significant associations between multiple chronic diseases and dropping out. The strongest associated health concern is the occurrence of strokes, with an adjusted odds ratio of 1.55 (Vaughn et al., 2014). Asthma, diabetes, and heart disease also had statistically significant adjusted odds ratios of 1.27, 1.32, and 1.18 respectively, for people who did not complete high school compared with those who did. Shelley determined that this must have contributed to the

## Supporting Students with Learning Disabilities: Reducing Secondary School Non-Completion and its Associated Health Disparities

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higher health care costs for people lacking a high school diploma, and she felt very concerned for people who have learning disabilities because they are at far greater risk of not graduating from high school and consequently experiencing greater difficulties with their health.

### FOOD SECURITY

Individuals who are unable to achieve post-secondary levels of education often have inconsistent access to food. Food and nutrition are also important factors in achieving educational success (Tarasuk et al., 2015). Shelley wondered whether adults who have learning disabilities and failed to graduate high school were at increased risk of experiencing food insecurity or having unhealthy eating behaviours. Even before discovering any information related to education, Shelley found some studies that examined the association between overall health and household food insecurity. One study showed there were drastic changes in annual health care costs between households that were food secure and those that were not. Compared with total annual health care costs in food secure households, the adjusted annual health care costs were \$235 (16%) higher in marginally insecure households and \$1092 (76%) higher in households that experienced severe food insecurity (Tarasuk et al., 2015). She remembered Hankivsky's cost of dropping out report and wondered whether part of the personal health care costs per high school dropout were attributable to these increased health care costs. A more recent study showed that, compared with people who have food security, people who were marginally food secure used mental health care services 1.15 times more, and people who were severely food insecure used mental health services 1.5 times more (Tarasuk, Cheng, Gundersen, de Oliveira, & Kurdyak, 2018). In this study, 9.5% of people who had not graduated from high school were food secure, 16% were marginally food insecure, 21.2% were moderately food insecure, and 25.1% were severely food insecure. Shelley found that 33% of the people who had severe food insecurities relied on social assistance as their main source of income, compared with just 1.3% of those who were food secure. It was all starting to connect. This study alone clearly showed that people who could not regularly access good-quality food used health care services more often, which in turn cost the province and taxpayers more. Shelley knew that unless the LDAS could continue its advocacy and provide the necessary programs and services for local students who had learning disabilities, more Canadians would be faced with similar health disparities, which included food insecurity, increased health care costs, and barriers to achieving higher levels of education.

### CRIME

Shelley remembered attending a community gala and discussing some of the initiatives funded by the police with Sudbury's Chief of Police. These initiatives aimed to improve later life outcomes for children and youth before they are negatively introduced to law enforcement. She was wondering whether there was an opportunity for a partnership since she remembered hearing that high school dropouts may be more likely to commit crimes than the general population.

A study by Mallett (2014) showed that 28% to 45% of all incarcerated youth also had special education disabilities. Among the detained youth offenders who had special education disabilities, 48% had an identified emotional disturbance and another 39% had a specific learning disability. The author noted some risk factors that increased the likelihood of having a learning disability, including living in poverty, being male, experiencing poor family functioning, and having lower household education attainment. Unsurprisingly, these factors mirror the risk factors for juvenile delinquency. Children at risk for academic failure in elementary schools often had unidentified special education and learning disability needs, with those unidentified adolescents disproportionately representing those who were suspended, expelled, and/or dropped out of high school (Mallett, 2014). The article also described how adolescents who have learning disabilities face a two to three times greater risk of being involved in offending activities

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than those who do not have learning disabilities, which is exactly what Shelley had suspected. Another study demonstrated that an estimated 30% to 50% of adult prisoners had a learning disability and that correctional education programs did not regularly support these people, even though research has shown that correctional education decreases recidivism rates (Koo, 2015). In 2004, 36% of state prisoners had attained less than a high school education compared with only 19% of the general American population aged 16 and up. What surprised Shelley was that the research by Koo had shown that although only 3% to 15% of all adults have a learning disability, as many as 30% to 50% of the adult prison population have one. Stewart, Wilton, & Sapers (2016) showed that, in a Canadian prison population, offenders who had cognitive deficits were three times more likely to have a learning disability (44.3%) than offenders who had none (14.7%).

### **SOCIOECONOMIC STATUS**

Shelley wondered what other health concerns could be attributed to Canadians who had learning disabilities as a result of this intergenerational cycle of high school non-completion. There were some disheartening statistics in the two different censuses she had read. For instance, across all reported age groups, people who have learning disabilities were disproportionately more likely to be unemployed (Exhibit 2) (Statistics Canada, 2015). The same data also showed that people who had attained a highest education level of “less than high school” also had higher unemployment rates than people in all other categories (Exhibit 3).

One study demonstrated that, in terms of the likelihood of children having ADHD, there was an association between household income and parental ADHD diagnosis (Rowland et al., 2018). The researchers found that the overall socioeconomic status (SES) gradient was stronger in families who did not have a parent with ADHD, and weaker for children in families who did. Children from low-income households had astonishing odds (after adjusting for covariates) of having ADHD, at 6.2 times higher than children from high-income families. Results from this study further proved that SES and parental ADHD history were both strong risk factors for an ADHD diagnosis. Although Shelley understands that the LDAS does not provide support for students who have ADHD, she was still intrigued by these findings. Fitzpatrick et al. (2015) determined that people who had low personal and household incomes, attained less than postsecondary education, and lived in neighbourhoods with a high dependency on social support had greatly increased odds of becoming future high-cost users of Ontario’s health care system. They also noted that although Canadians have universal health coverage through their publicly funded health care systems, there was still an observable relationship between SES and frequent use of primary care. After the researchers adjusted for covariates such as area, age, and gender, the strongest associations of becoming a high-cost health care user related to homeownership and food security. Fitzpatrick et al. (2015) determined that low SES is also linked to increased risk of preventable hospitalizations, higher rates of hospitalization, longer stays if admitted, more frequent emergency department use, and poorer continuity of care. The research showed that income, education, homeownership, food security, and neighbourhood marginalization were all considered to be strongly associated indicators of SES for future high-cost health care users.

Shelley reflected on the findings by Dupéré et al. (2018) that showed that dropping out of high school often leads to other long-term hardships that impair health and family function and can perpetuate inequalities across generations. She also came across studies describing the association between economic hardship and child maltreatment and how this can contribute to reduced access to education. She read that children whose families were struggling economically were more likely to have developmental concerns and were at a significantly increased risk of becoming victims of maltreatment (Lefebvre, Fallon, Van Wert, & Filippelli, 2017). The researchers found it interesting that a child’s relationship with at least one stable,

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caring, responsive, and supportive adult had been determined to be the most critical developmental protective factor for promoting resilience. A related study showed that high-quality teacher–child relationships predicted low levels of externalizing behaviours or risk taking, and also acted as a protective factor for helping to prevent children with high levels of internalizing problems from developing long-term mental health concerns (Holen et al., 2017).

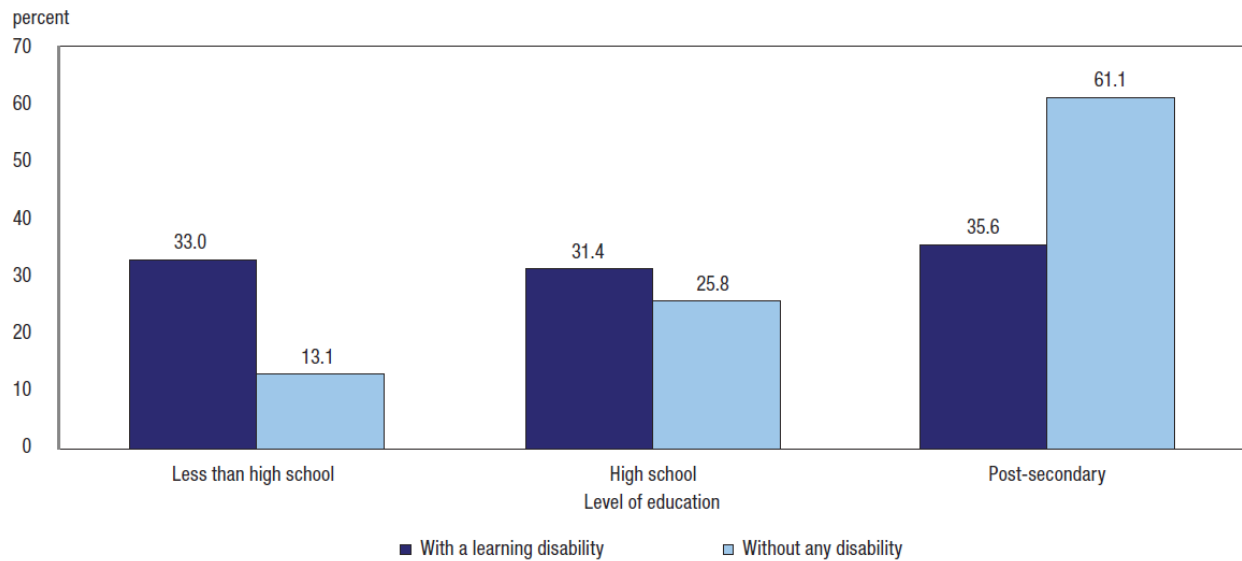
### CONCLUSION

Shelley was satisfied and excited about the amount of information that she had gathered. Finding the socioeconomic costs associated with high school non-completion in Canada was extremely beneficial, as was her discovery of recent statistics about the proportion of Canadian students who have learning disabilities who were unable to successfully graduate from high school. These statistics, along with other data supporting a public health perspective of the overall impact that high school non-completion has on a person's future health and well-being should give the LDAS a fighting chance to obtain a crucial, sustainable source of funding that will keep her offices in Timmins, North Bay, and Sault Ste. Marie operating. She smiled and turned her chair to look out the window of the local university where this information would hopefully help the local youth with learning disabilities in their future endeavours. Now, she needed to decide which evidence to use that was most pertinent to her region. She sat at her desk with a blank template that read "Report to the Board". She needed to convince the board about the importance of the issue and the feasibility of the solutions. Funding was tight, but she knew she could come up with a plan that the board would be able to support. Her long day of searching the literature was done, but she knew the real work of synthesizing and disseminating this information was just starting.

# Supporting Students with Learning Disabilities: Reducing Secondary School Non-Completion and its Associated Health Disparities

## EXHIBIT 1

**Chart 3: Proportion of Adults with a Learning Disability Compared to Those without a Disability, by Highest Level of Education Aged 15 To 64, Canada, 2012**



Notes: Excludes population still in school. Post-secondary includes trades certificates, college diplomas, university certificates below bachelor level and university degrees.  
Source: Statistics Canada, Canadian Survey on Disability, 2012.

Source: Statistics Canada, 2015, pg 7.

## Supporting Students with Learning Disabilities: Reducing Secondary School Non-Completion and its Associated Health Disparities

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### EXHIBIT 2 Estimated Tangible Costs of High School Non-Completion in Canada (2008 Dollars)

	Estimated cost per dropout		Aggregated total in Canada	
	Annual	Lifetime	Annual	Lifetime
<b>Tangible Costs</b>				
Health (private <sup>a</sup> )	\$8,098	\$211,471 <sup>b</sup>	\$23.8 billion	\$623 billion <sup>b</sup>
Social Assistance (public)	\$4,230		\$969 million	
Crime (public)	\$224		\$350 million	
<b>Labour and Employment</b>				
Earning loss (private)	\$3,491	\$104,222 <sup>c</sup>	\$10.3 billion	\$307 billion <sup>c</sup>
Tax revenue loss (public)	\$226	\$6,882	\$378 million	\$11.5 billion
Revenue loss in employment insurance premium (public)	\$68	\$2,063	\$201 million	\$6.1 billion
Employment insurance cost (public)	\$2,767		\$1.1 billion	

<sup>a</sup>Data on public costs are not available.

<sup>b</sup>"Lifetime" costs related to health reflect earning loss over a 35 years.

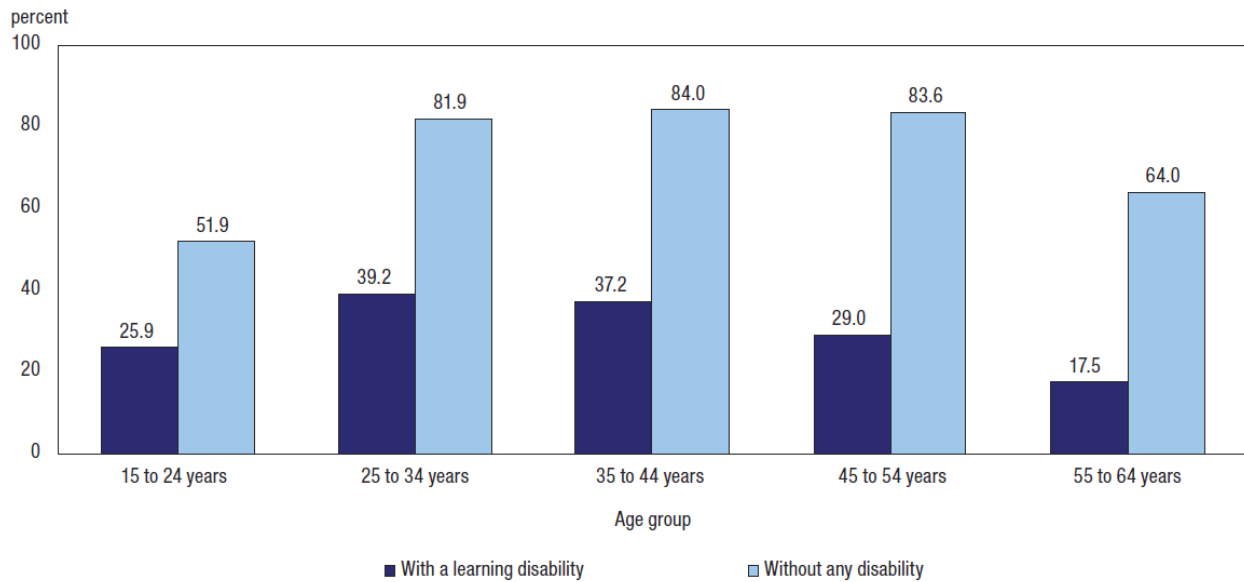
<sup>c</sup>"Lifetime" costs related to income reflect earning loss over a 35-year span (assuming lifetime earnings start from age 20 through 54). ""

Source: Hankivsky, 2008, pg. 5.

## Supporting Students with Learning Disabilities: Reducing Secondary School Non-Completion and its Associated Health Disparities

### EXHIBIT 3

**Chart 5: Employment Rates of Adults with a Learning Disability and without any Disability by Age Group, Aged 15 to 64 years, Canada, 2012**



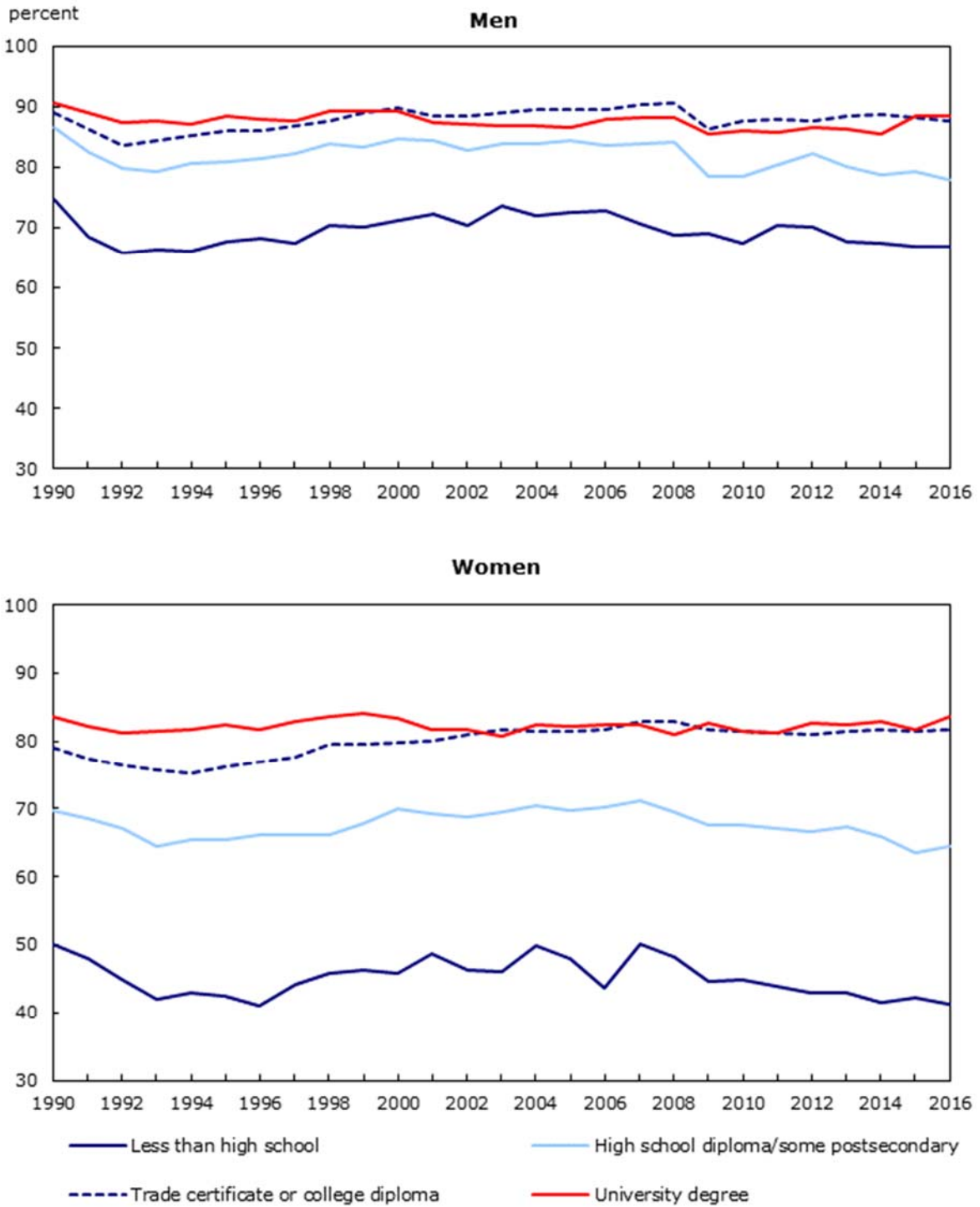
Source: Statistics Canada, Canadian Survey on Disability, 2012.

Source: Statistics Canada, 2015, pg. 9.

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EXHIBIT 4

Chart 4: Unemployment Rate, Men and Women Aged 25 to 34 by Level of Education, 1990 to 2016



Source: Statistics Canada, Labour Force Survey, 1990 to 2016.

Source: Statistics Canada, 2017, pg. 7.

## Supporting Students with Learning Disabilities: Reducing Secondary School Non-Completion and its Associated Health Disparities

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## INSTRUCTOR GUIDANCE

### Supporting Students with Learning Disabilities: Reducing Secondary School Non-Completion and its Associated Health Disparities

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*Avery Prince, BPHE, MPH (MPH Class of 2018)*

*Mary-Liz Warwick, BA, MA (c) (Executive Director, The Learning Disabilities Association of Sudbury & the Northern Ontario for Learning Differences)*

*Wendy Larouche (Resource Facilitator and Community Outreach,  
Learning Disabilities Associate of Sudbury)*

*Gerald McKinley, PhD (Assistant Professor, Western University)*

#### BACKGROUND

Shelley van Dam needs to write a policy brief for her board on the effects of learning disabilities. This policy brief is a response to the upcoming termination of some of the funding for the Learning Disabilities Association of Sudbury (LDAS). The LDAS provides various programs that support students and families that have, or are in the process of being identified as having, a learning disability. The LDAS is a not-for-profit organization that operates throughout Greater Sudbury and across Northeastern Ontario to provide assistance to students who have learning disabilities so they attain the highest level of education possible. Some funding sources are available in the short term, including an Ontario Trillium Foundation grant that allows the LDAS to hire part-time employees in the organization's satellite offices located in North Bay, Sault Ste. Marie, and Timmins. With this Ontario Trillium Foundation grant ending soon, Shelley realized that the LDAS would not be able to continue employing these people, and ultimately knew that the students in those regions who have learning disabilities would suffer. Shelley identified one possible solution that may help the organization avoid having to cease operations at their satellite offices—looking for more sustainable sources of funding from provincial ministries such as the Ministry of Children, Community and Social Services.

In order to develop the appropriate policy brief required by her board, she needed to gather and present the most up-to-date information available. Students who have learning disabilities have average- to above-average intelligence but require different teaching methods in order to successfully complete school. Shelley found recent data from Statistics Canada (2015) showing the proportion of students who have learning disabilities dropping out of high school was 33% of total students with learning disabilities, compared with 13.1% of the total student population without learning disabilities. She wanted to discuss how socioeconomic status plays a role in one's health and the importance of successfully obtaining at least a high school education, as that opens the door for other post-secondary educational opportunities. Graduating from high school is necessary in today's job market because many jobs require post-secondary credentials as a prerequisite to employment. Shelley found research discussing how a lack of education for Canadians who have learning disabilities can fuel further inequities including food scarcity, incarceration and crime. The ecological systems theory, social learning theory, and strain theory were all discussed to better understand some underlying problems that may contribute to the continued, cyclical health disparities faced by Canadians who do not have a high school diploma. By including this information, Shelley hopes to highlight the effects of inadequate support for students who have learning disabilities throughout their academic

## **Supporting Students with Learning Disabilities: Reducing Secondary School Non-Completion and its Associated Health Disparities**

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careers, and how this can increase health care costs not only to the individual, but to society as a whole.

### **OBJECTIVES**

1. Understand why knowledge gaps exist regarding learning disabilities and how these gaps contribute to stigmatization.
2. Explore the complex interaction between social and cultural determinants of health in local contexts and how this interaction affects specific population groups (Canadians who have learning disabilities).
3. Consider how the ecological systems, social learning, and strain theories, and the varying definitions of learning disabilities, contribute to the negative cycle of social and cultural determinants of health for Canadians who have learning disabilities.
4. Synthesize evidence to create a concise evidence brief.

### **DISCUSSION QUESTIONS**

1. How important is education in terms of the present job market? (Is an undergraduate degree equivalent to a high school degree 30 years ago?)
2. In what ways can education impact the health of individuals and their families?
3. Define learning disability.
4. What misconceptions exist in the school setting about students who have learning disabilities?
5. What problems and barriers did the learning teams identify for Canadians who have learning disabilities? What problems and barriers did the learning teams identify for other identified vulnerable populations?
6. What problems would Shelley face if the LDAS was unable to continue providing its advocacy, support, and programs to people who have learning disabilities?

### **KEYWORDS**

Education; learning disabilities; social determinants of health; socioeconomic status; unemployment; high school non-completion

## CASE 11

### ***Crypto Climate Creep: The Movement of Tropical Infectious Disease to the Arctic***

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*Sukhmeet Singh Sachal, BSc, MPH (MPH Class of 2018)*

*Michel Deilgat, MD (Medical Advisor, Centre for Food-borne, Environmental and Zoonotic Infectious Diseases, Public Health Agency of Canada)*

*Mark Speechley, PhD (Professor, Western University)*

The Inuvik Sunrise Festival is an annual festival that takes place in early January and is a time when everyone participates in feasts and festivals to celebrate the return of the sun after many weeks of complete darkness. Dr. Jacob Sanders, an epidemiologist and public health physician, was excited to attend the event and see many of his old friends.

Jacob was eager to have his favourite traditional foods at the feast, especially Muktuk (beluga blubber), beaver, caribou, bearded seal, and blue mussels. Just like the old days, Jacob felt back at home after eating these traditional foods. During the festival, there was a severe snowstorm and the feast was cut short.

The next morning, Jacob does not feel well. He has a bad case of diarrhea and assumes the Muktuk, beaver, caribou, bearded seal, or the blue mussels is the reason for his ill health. Celina, Jacob's wife and an environmentalist and Indigenous public health expert, is worried about Jacob's condition and has him admitted to Inuvik Regional Hospital. They take stool, urine, and blood samples. While they are waiting, friends from the feast are arriving at the hospital with the same symptoms. A lack of laboratory equipment for diagnosing the cause of the illness means the stool samples are sent to Nunavik, Quebec, where the public health unit has onsite molecular testing capabilities and specialized equipment to determine the problem. After a few days, the diagnosis is revealed—Jacob has contracted a parasite known as *Cryptosporidium*. This is a surprise, since there have never been any cases of cryptosporidiosis reported in Inuvik and it is a tropical parasite that is not native to the Arctic.

Through collaboration with the National Enteric Surveillance Program at the Public Health Agency of Canada (PHAC), and the provincial/territorial governments of Quebec and the Northwest Territories, Jacob is notified that the last outbreak of cryptosporidiosis was in 10 communities in Nunavik in 2013. How did cryptosporidiosis spread to Inuvik? What is the host(s)? How can a tropical parasite survive in the cold Arctic environment?

#### **BACKGROUND**

##### **Jacob and Celina**

Dr. Jacob Sanders and Dr. Celina Roy live in Inuvik in the Northwest Territories. This community is a special place for both Jacob and Celina. They met here 10 years earlier when Jacob was completing his residency training and Celina was finishing her thesis on a zoonotic infectious disease called toxoplasmosis. Jacob is an Inuvialuit epidemiologist and public health physician working for the Infectious Disease Prevention and Control Branch at the PHAC. He is married to Celina, a Gwich'in senior environmentalist and Indigenous public health expert at the First Nations and Inuit Health Branch (FNIHB) of Indigenous Services Canada.

## Crypto Climate Creep: The Movement of Tropical Infectious Disease to the Arctic

After living in Canada's capital city for 10 years, Jacob and Celina moved to Inuvik, where Jacob works at the Inuvik Regional Hospital and Celina works at the Inuvik public health unit. As part of her work, Celina wanted to expand the surveillance systems for infectious diseases and coordinate these systems with climate monitoring. The beginning of Celina's new job could not have been more timely because surveillance reports generated by the Centre for Food-Borne, Environmental and Zoonotic Infectious Diseases (CFEZID) at the PHAC showed a rise in zoonotic and water-borne infectious diseases in the Arctic. Social and ecological determinants of health play a major role in the livelihood of the Indigenous peoples living in the Arctic as a result of historical trauma, colonization, and the residential school system (Inuit Tapiriit Kanatami, 2014). The negative effects these determinants of health have on Indigenous communities have amplified the negative impacts of *Cryptosporidium* in this population.

Jacob and Celina wanted to work with the Indigenous nurses at the public health unit in Inuvik to investigate the prevalence and incidence of certain zoonotic infectious diseases. They want to see whether the rates have decreased, increased, or remained relatively the same over the past 10 years.

### **The Canadian Arctic**

The Canadian Arctic comprises the regions north of approximately 55 degrees latitude. It includes the Yukon, the Northwest Territories, Nunavut, Northern Quebec, and Northern Labrador, making up around 40% of Canada's landmass (Government of Canada, 2017). A majority of the approximately 100,000 people living in the Canadian Arctic are Indigenous peoples from different groups such as First Nations people and the Inuit (Government of Canada, 2013). The winters are long and cold, lasting for most of the year, with a few warmer summer months. Permafrost covers most of the region with little year-round vegetation (Exhibit 1).

### **Inuvik, Northwest Territories**

The town of Inuvik is situated 200 km above the Arctic Circle and 80 km below the Arctic Ocean. Located in the Beaufort Sea region, Inuvik is next to the Mackenzie River and is home to more than 3,000 people. The population breakdown is as follows: 38.9% Inuvialuit, 18.4% Gwich'in, 4.7% Métis, 1.2% other Aboriginal, and 36.7% nonnative (Statistics Canada, 2017). Inuvik has the Inuvik public health unit and one hospital, Inuvik Regional Hospital.

### **Nunavik, Quebec**

Nunavik is located in the northern region of Quebec and is considered to be a part of the Canadian Arctic. It has about 12,000 people, 90% of whom are Inuit. Nunavik is also home to many dog sledding races, with teams attending from all over the world to compete (Nunavik Tourism Association, 2010). While most people now travel by snowmobile, dogs were essential to the survival of the Inuit in the Arctic in the past.

## **ZOONOTIC INFECTIOUS DISEASES**

An increase in population, diminishing resources, and increased exposure to the virosphere results in a higher chance of people becoming exposed to infectious diseases. The coexistence of humans with animals can be a potential passageway for the spread of disease that can impact the physical, social, and economic well-being of a population (Centers for Disease Control and Prevention, 2017a). The transmission of disease from animals to humans is known as zoonosis, and can occur through direct or indirect contact. Direct contact involves contact with the saliva, blood, urine, or feces of an infected animal. Indirect contact includes the spread of zoonoses via water, food, or the environment. Zoonotic diseases can be caused by viruses, bacteria, parasites, or fungi. Depending on the severity, they can lead to many types of illnesses in animals and humans, ranging from mild sickness to death (World Health Organization, 2009).

## Crypto Climate Creep: The Movement of Tropical Infectious Disease to the Arctic

Approximately 60% of infections in humans have a zoonotic component (Centers for Disease Control and Prevention, 2017a). Three of every four new or emerging infectious diseases are zoonotic. Some common zoonotic infectious diseases are Trichinosis, Toxoplasmosis, Botulism, Brucellosis, and Cryptosporidiosis.

### **CRYPTOSPORIDIOSIS**

*Cryptosporidium* is a microscopic parasite that lives in the intestines of vertebrates and can cause cryptosporidiosis infection in humans or other animals. Cryptosporidiosis is transmitted by *Cryptosporidium* oocysts that contaminate food or water sources. There are many different species of *Cryptosporidium* that can infect humans and animals, although *C. parvum* and *C. hominis* are the most common (Safe Drinking Water Foundation, n.d.; Thivierge et al., 2016, Exhibits 2 and 3). See Appendix A for more information.

### **Outbreaks**

The first case of cryptosporidiosis in humans was reported in 1976 (Thivierge et al., 2016). Since then, it has become one of the most common causes of water-borne disease, found in 95 countries around the world. Through contact tracing, many outbreaks in humans have been linked to contaminated drinking water, recreational water use, and food products. While it is more commonly found in tropical countries and developing countries in Africa and South America, there have been large outbreaks of cryptosporidiosis in the United States and Canada. In 1993, 50% of the people in Milwaukee, Wisconsin were infected with *C. parvum* because of a contaminated water supply (MacKenzie et al., 1995). In 2001, the Saskatchewan Health Authority reported 1,200 cases of cryptosporidiosis in North Battleford as a result of water supply contamination (Wallis et al., 2003). In 2010, there were 86 cases of the *Cryptosporidium* transmitted from animals to humans in Nunavut (Goldfarb et al., 2013). This was the first case reported as far north as the Arctic. In 2013, there was a *C. hominis* outbreak in Nunavik, Quebec, with 69 cases resulting from human-to-human transmission. This was 250 times higher than the expected number of outbreaks of the parasite in southern Canada (Murphy, 2016; Thivierge et al., 2016). In 2015, there were 872 reported cases of cryptosporidiosis across Canada because of poor-quality rural water sources and ineffective water treatment (Safe Drinking Water Foundation, n.d.).

### **Diagnosis**

It is difficult to identify cryptosporidiosis in the Canadian Arctic because equipment and testing facilities are limited. After the outbreak in Nunavik, Quebec, onsite molecular testing equipment was set up to test for *Cryptosporidium* along with other zoonotic infectious diseases. This site reduced the testing wait time from two weeks to same day diagnosis, helping to minimize transmission of *Cryptosporidium* at home and in schools (Thivierge et al., 2016).

### **CLIMATE CHANGE IN THE ARCTIC**

The Canadian Arctic is particularly susceptible to anthropogenic climate change because of the sensitivity of the cryosphere, which is made up of sea ice, snow, iced-over rivers and lakes, and permafrost. The Arctic has experienced warming increases of about 2°C to 3°C over the past 30 years (Furgal & Seguin, 2006). By the end of the 21st century, there will be an estimated 30% increase in precipitation levels in the Arctic region (Furgal & Seguin, 2006). Warmer temperatures in some areas of the Arctic will limit snow accumulation on the ground, which will negatively impact a wide range of ecological processes. If temperatures continue to rise, rivers and lakes may not remain frozen as long as they have in previous ice seasons, and the average thickness of the ice will decrease (Johannessen et al., 2004). Warming temperatures will also have significant effects on the melting of permafrost, which will subsequently lead to the release of trapped methane and carbon dioxide (Johannessen et al., 2004). Disruptions to the environmental balance will change the Arctic environment into a land foreign to its inhabitants.

### **Effects of Climate Change on the Emergence of Infectious Diseases**

The spread, frequency, and intensity of infectious diseases across Canada could be influenced by climate change in the upcoming years and decades. Increased precipitation will result in increased water turbidity from high water velocity. Rapid snowmelt also contributes to an increase in cases of gastrointestinal illness. Both the increased precipitation and rapid snowmelt will mix and transport more pathogens into water sources and increase the risk of water-borne infectious disease transmission (Lindgren, 2015). Rising temperatures will increase food-borne illnesses and result in food spoilage and proliferation of disease organisms. In the Arctic specifically, melting permafrost will disrupt traditional food storage methods that involve canning, fermentation, and outdoor food storage. Air-drying of meat will increase the risk of exposure to pathogens as a result of climate change and increased temperatures (Parkinson & Evengård, 2009). This can increase the incidence of botulism, salmonella, campylobacteriosis, and other food-borne diseases (Parkinson & Evengård, 2009). Climate change warming will also expand the range of habitats for animal hosts migrating farther north. This will cause animal hosts to proliferate and will increase the transmission of zoonotic infections.

### **Effects of Climate Change on the Livelihood of Indigenous Peoples**

Indigenous peoples living in the Canadian Arctic face many health disparities due to community remoteness, reduced access to health care, inadequate infrastructure, food insecurity, decreased mental wellness, and environmental pollution. These effects are already exacerbated by climate change. Many communities face drinking water problems from water contamination and, as a result, have sporadic boil water advisories. With warmer temperatures reducing the thickness of the sea ice, delaying the formation of the ice, and melting the permafrost, people in the Arctic will have a limited ability to sustain themselves using traditional food practices. Food scarcity affects 24% to 46% of households in the Canadian Arctic (Thivierge et al., 2016). Climate change will result in less food to eat because animal migratory patterns will change and the contaminated water will make it unsafe to eat marine animals. Hunting will become challenging, if not impossible, since depleted sea ice will make it difficult to commute on land (Furgal & Seguin, 2006). These changes will also threaten Indigenous traditions and culture. These conditions make Indigenous populations in the Arctic especially vulnerable to the effects of emerging infectious diseases as a consequence of climate change.

### **PUBLIC HEALTH RESPONSE AND STAKEHOLDERS**

There are various stakeholders involved in public health responses to zoonotic infectious diseases. The PHAC was created in 2004 to respond to public health emergencies and to protect the health of all Canadians (PHAC, 2013). To facilitate a multijurisdictional response, the PHAC works alongside Health Canada, the Canadian Food Inspection Agency, and various other stakeholders by following the steps laid out in Canada's Foodborne Illness Outbreak Response Protocol (FIORP) (PHAC, 2013). The FIORP was developed to enhance multijurisdictional collaboration and streamline roles and actions during food-borne illness outbreaks (Canadian Food Inspection Agency, 2018). The FIORP seeks to minimize the impacts of food-borne illnesses/morbidity, mortality, increased health care burden, economic losses, and lost productivity in the event of an outbreak. In addition to working with FIORP, the PHAC has an Infectious Diseases and Climate Change Program that includes a climate change infectious disease toolkit, and a public health and water-borne illness research tool to assess the burden of gastrointestinal illness and adaptation to climate change in the Canadian North (PHAC, 2013). Another important stakeholder is the FNIHB. The FNIHB is a branch within the newly created Indigenous Services Canada (Government of Canada, 2018a). It works with a nationwide organization known as the Inuit Tapiriit Kanatami (ITK). The organization represents more than 60,000 Inuit living in the Northwest Territories, Northern Quebec, and Northern Labrador in an effort to highlight environmental, social, cultural, and political issues facing the

## **Crypto Climate Creep: The Movement of Tropical Infectious Disease to the Arctic**

Inuit peoples of Canada (ITK, 2018). See Appendix B for more information on the specific stakeholders.

### **BACK TO THE PROBLEM**

*C. hominis* was identified for the first time in the Canadian Arctic in Nunavik, Quebec in 2013. Now, with another outbreak of cryptosporidiosis in Inuvik, public health professionals need to act fast to mitigate this problem. The recognition of widespread human cryptosporidiosis in this region is a public health concern because of the possible long-term effects on growth and development of children in Inuit communities who already face many other challenges. Cryptosporidiosis may be one of the first tropical diseases discovered in the Arctic, but it will not be the last. It is up to all circumpolar countries to look at this outbreak as a sign of the Arctic's future, where pathogens will proliferate and spread diseases from animals to humans. Steps need to be taken today so that the Arctic does not become the new danger zone for zoonotic infectious diseases.

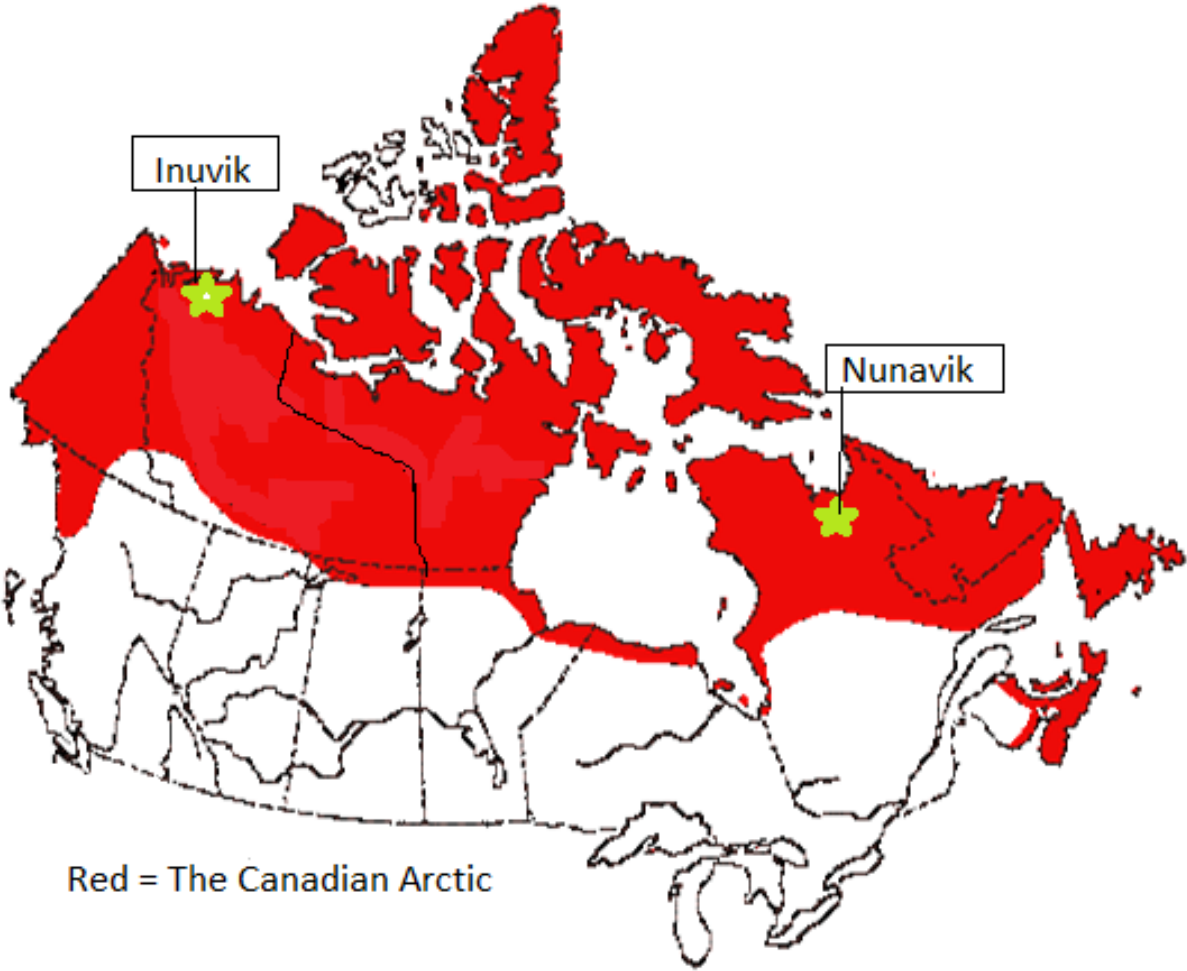
### **CONCLUSION**

From West Nile virus and Lyme disease in Canada's south to cryptosporidiosis in the north, the geographical spread of infectious diseases is creating new public health challenges. It is also exacerbating the existing socioeconomic determinants of health affecting Indigenous peoples in the Arctic. Northern communities already deal with food scarcity, mental health issues, antiquated infrastructure, trauma from colonization and residential schools, and environmental changes. The emerging health threats of zoonotic infectious diseases will only worsen health outcomes in the generations to come. Surveillance of climate-sensitive infectious diseases should be strengthened. With consultation from Indigenous peoples, culturally appropriate adaptation and mitigation strategies to tackle new emerging infectious diseases in the Canadian Arctic and in the global context can be identified.

### **WHAT'S NEXT?**

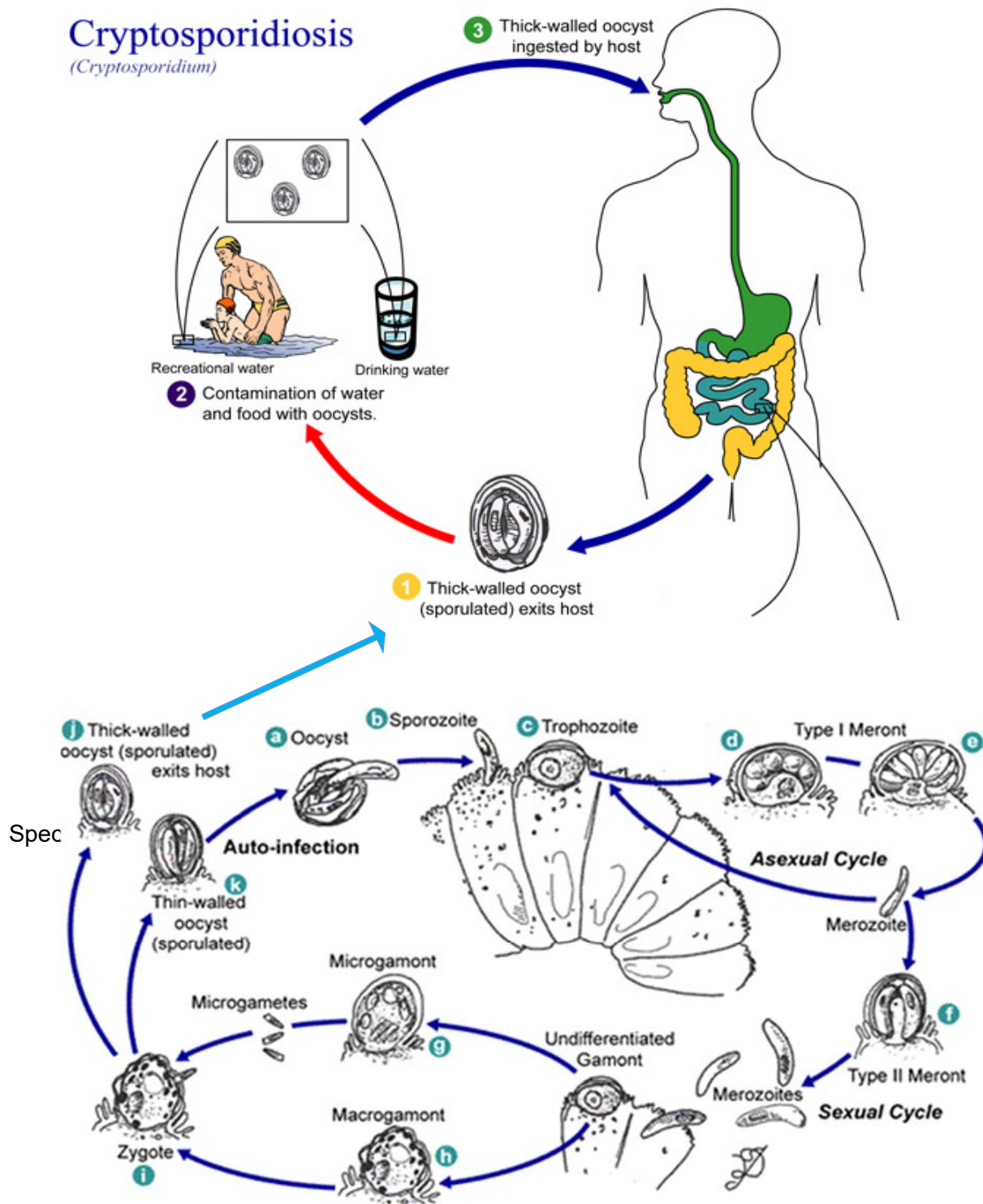
Using a systems-thinking approach, Celina wants this problem viewed using the One Health Model—a transdisciplinary model incorporating animal, human, and ecosystem health. This model will allow for an integrated and holistic approach to solving the problem. There is a dynamic interplay between infectious disease incidence and climate change, and the close connection of Indigenous peoples with their land in the Canadian Arctic. Celina is now looking to conduct contact tracing to identify how the tropical parasite *Cryptosporidium* is present in the Arctic. As a public health professional, it is important for her to disseminate the information to various audiences in a time-sensitive manner. Depending on the type of audience, whether it is the general public, technical experts, or governmental officials, the risk communication and public health messaging will have to be tailored accordingly.

**EXHIBIT 1**  
**Map of the Canadian Arctic**



Source: Adapted from the Government of Canada, 2017.

**EXHIBIT 2**  
**Life Cycle of *Cryptosporidium***



Source: Adapted from Centers for Disease Control and Prevention, 2017b and Safe Drinking Water Foundation, n.d.

**EXHIBIT 3**  
**Cryptosporidium Species**

Number	Species of <i>Cryptosporidium</i>	Major Hosts	Zoonotic Status
1	<i>C. andersoni</i>	Cattle	Yes
2	<i>C. baileyi</i>	Birds	No
3	<i>C. bovis</i>	Cattle	Yes
4	<i>C. canis</i>	Dogs	Yes
5	<i>C. cuniculus</i>	Rabbits	Yes
6	<i>C. erinacei</i>	Hedgehogs and horses	Yes
7	<i>C. fayeri</i>	Marsupials	Yes
8	<i>C. felis</i>	Cats	Yes
9	<i>C. fragile</i>	Toads	No
10	<i>C. galli</i>	Birds	No
11	<i>C. hominis</i>	Humans	Most common species in humans
12	<i>C. macropodum</i>	Marsupials	No
13	<i>C. meleagridis</i>	Humans and birds	Yes
14	<i>C. molnari</i>	Fish	No
15	<i>C. muris</i>	Rodents	Yes
16	<i>C. parvum</i>	Ruminants	Yes
17	<i>C. ryanae</i>	Cattle	No
18	<i>C. scrofarum</i>	Pigs	Yes
19	<i>C. serpentis</i>	Snakes and lizards	No
20	<i>C. suis</i>	Pigs	Yes
21	<i>C. tyzzeri</i>	Rodents	Yes
22	<i>C. ubiquitum</i>	Primates, ruminants	Yes
23	<i>C. varanii</i>	Lizards	No
24	<i>C. viatorum</i>	Humans	Least common species in humans
25	<i>C. wrairi</i>	Guinea pigs	No
26	<i>C. xiaoi</i>	Sheep and goats	Yes

Source: Adapted from Zahedi et al., 2016.

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### APPENDIX A

#### **CRYPTOSPORIDIOSIS**

##### **Life Cycle**

*Cryptosporidium* starts as an oocyst, which consists of a tough shell containing four parasites. Once the oocyst is swallowed by the host, the shell opens and releases the parasites into the small intestine. The parasites can then develop and reproduce in the same host or start another cycle of infection by being excreted via feces and infecting other hosts. The infection is usually limited to the intestinal tract; however, in immunocompromised individuals and animals, it can spread to other areas of the body (Exhibit 2, Safe Drinking Water Foundation, n.d., Thivierge et al., 2016).

##### **Spread of Infection**

*Cryptosporidium* has a low infectious dose: a host needs to be in contact with only 10 to 30 oocysts to acquire the infection (Putignani & Menichella, 2010). After four days of infection, oocysts are shed into the feces at a rate of 1 to 10 billion per day (Putignani & Menichella, 2010). On average, this shedding lasts three to 12 days in animals and 18 days in humans. *C. parvum* oocysts can live up to 18 months in an environment that is cool and damp/wet (Safe Drinking Water Foundation, n.d.). They can be found in soil, food, or water contaminated with feces from infected humans or animals. The feces can contaminate nearby water sources when rainfall causes runoff. Vegetation can also become infected if the fertilizer is contaminated or if the water used to wash the vegetation is contaminated.

##### **Symptoms**

The most common symptom of cryptosporidiosis is watery diarrhea. This is in part because the body's immune system tries to fight the infection by sending immune cells into the intestine, which end up destroying the intestinal cells. In addition to diarrhea, an individual can also have stomach cramps, nausea, vomiting, dehydration, fever, fatigue, and weight loss depending on the severity of the infection. These symptoms can last from two to 10 days after infection in normally healthy individuals. However, for people who are immunocompromised (e.g., have HIV), the infection can last for several weeks and may require hospitalization. In some cases, the infection can become chronic and an individual can shed oocysts for months after not showing any symptoms. The symptoms are also more severe in young children, and this can lead to long-term negative impacts on a child's cognitive development (Murphy, 2016; Thivierge et al., 2016).

##### **Treatment and Prevention**

*C. parvum* has a thick-walled oocyst that allows it to survive outside the body for a long time and makes it resistant to chlorine. Thus, treatment of water contaminated with *Cryptosporidium* becomes difficult (Lindgren, 2015). Because of its contagious nature, hand washing before preparing food and after going to the washroom is highly recommended. An infected person should not swim in recreational water and should avoid exposing other people to their fecal matter. While there are no current treatments for cryptosporidiosis, the best method of control is prevention. Supportive treatments include hydration therapy and antidiarrheal drugs. For immunocompromised people who have cryptosporidiosis, antiretroviral therapy can reduce oocyst excretion and diarrhea (Lindgren, 2015; Safe Drinking Water Foundation, n.d.). To purify water, filters with a pore size of one to two micrometres should be used so they can block the four micrometre *C. parvum* from entering the water supply. Boiling water for at least one-minute can also decrease the number of oocysts present (Lindgren, 2015).

### **APPENDIX B**

#### **PUBLIC HEALTH RESPONSE AND STAKEHOLDERS**

##### **The Public Health Agency of Canada**

The PHAC was created in 2004 to respond to public health emergencies and to protect the health of all Canadians (PHAC, 2013). One of the four branches of PHAC is the Infectious Diseases Prevention and Control Branch, which investigates the risks of infectious diseases in Canada and how they can be mitigated. Within the Infectious Diseases Prevention and Control Branch is a department known as CFEZID. The CFEZID analyzes data on emerging zoonotic, enteric, food-borne, and water-borne diseases in Canada in order to assess the associated risks and reduce their impact on the Canadian population (Public Health Agency of Canada, 2013). The CFEZID also helps the various levels of government develop policies about infectious diseases by providing evidence-based recommendations. The PHAC is not the only level of government involved in outbreak investigation; local, provincial/territorial governments, and other sectors are also involved in the process. In order to facilitate a multijurisdictional response, the PHAC works alongside Health Canada, the Canadian Food Inspection Agency, and various levels of stakeholders by following the steps laid out in Canada's FIORP (PHAC, 2013).

##### **Canada's Foodborne Illness Outbreak Response Protocol (FIORP)**

The FIORP was created by the PHAC, Health Canada, and the Canadian Food Inspection Agency in partnership with provincial and territorial sectors. Stakeholders developed this response protocol to enhance multijurisdictional collaboration and streamline roles and actions during food-borne illness outbreaks (Canadian Food Inspection Agency, 2018). The protocol is important in helping minimize the negative impacts that may result from food-borne illness outbreaks, including the morbidity and mortality, increased health care burden, economic losses, and lost productivity. Because Indigenous populations rely heavily on hunting animals and fish, they are especially susceptible to food-borne illness outbreaks arising from raw meat. The FIORP uses enhanced enteric illness surveillance networks to regulate all stakeholders responsible for human health in relation to food safety. Scientists working for the FIORP conduct molecular subtyping in order to initiate outbreak investigation by detecting case linkages. Because of the potential severity of food-borne illnesses, the FIORP provides ongoing public awareness about food safety measures in a timely manner to prevent further illness. It improves the efficacy and effectiveness of the response to food-borne outbreaks from the local, provincial/territorial, and federal governments and other relevant organizations (Canadian Food Inspection Agency, 2018).

##### **National Enteric Surveillance Program (NESP)**

The NESP is a Canada-wide surveillance system administered by the CFEZID and the National Microbiology Laboratory. It looks at the national incidence of food-borne pathogens to help identify any potential enteric disease outbreaks. A software program known as PulseNet Canada helps to link the databases of public health laboratories across Canada together for streamlined analysis of trends in emerging infectious diseases (Government of Canada, 2018b). The NESP system is important for creating policies and programs that are supported by evidence.

##### **Preventative Public Health Systems and Adaptation to a Changing Climate Program**

The PHAC has implemented an Infectious Diseases and Climate Change Program to inform decision-making and adaptation strategies to mitigate infectious diseases in order to protect the health of Canadians. The projects associated with this program include a climate change infectious disease toolkit, a public health and water-borne illness research tool, and an assessment of the burden of gastrointestinal illness and adaptation to climate change in the Canadian North (PHAC of Canada, 2013). However, there is still a lack of syndromic and

## **Crypto Climate Creep: The Movement of Tropical Infectious Disease to the Arctic**

disease surveillance data that is coupled with climate observations. This makes it difficult to identify any epidemiological changes and infectious diseases trends in the Arctic.

### **First Nations and Inuit Health Branch (FNIHB)**

The FNIHB is a branch under the newly created Indigenous Services Canada (Government of Canada, 2018a). Previously a part of Health Canada, the FNIHB has been committed to First Nations and Inuit health since 2012. It works with a nationwide organization known as the Inuit Tapiriit Kanatami (ITK). The organization represents more than 60,000 Inuit living in the Northwest Territories, Northern Quebec, and Northern Labrador to highlight the environmental, social, cultural, and political issues facing Inuit peoples of Canada (ITK, 2018). The ITK has five priorities: (1) community education and mobilization; (2) intersectoral partnership to address social determinants of Inuit health; (3) evidence-based Inuit-appropriate programs; (4) improved surveillance and research; and (5) better evaluation and reporting (Indigenous Services Canada, 2013; ITK, 2018). The FNIHB also works with the local and territorial/provincial governments to identify their needs and address them at the federal level (Government of Canada, 2018a).

## INSTRUCTOR GUIDANCE

### ***Crypto* Climate Creep: The Movement of Tropical Infectious Disease to the Arctic**

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#### **BACKGROUND**

Dr. Jacob Sanders was excited to attend the Inuvik Sunrise Festival and see friends, old and new. The evening was cut short due to the snowstorm, but the next morning, Jacob was very ill. Not knowing the cause, he assumed it was the food: Muktuk (beluga blubber), beaver, caribou, bearded seal, or blue mussels. Severely dehydrated from diarrhea, he was admitted to Inuvik Regional Hospital. Insufficient lab equipment at the hospital meant the stool samples had to be sent far away to Nunavik, Quebec where the public health unit had an onsite molecular test to diagnose the problem. When the diagnosis was finally revealed, he was shocked to learn it was a disease unknown to the Inuvik region, and nearly unseen for the past decade—cryptosporidiosis.

Cryptosporidiosis is a zoonotic infectious disease transmitted by a microscopic parasite known as *Cryptosporidium*. This transmission occurs via oocysts that can contaminate food or water sources. Symptoms of cryptosporidiosis include diarrhea, stomach cramps, nausea, vomiting, dehydration, fever, fatigue, and weight loss. Although it is typically a tropical disease, it was first discovered in 2013 in the Canadian Arctic in Nunavik, Quebec. The recognition of widespread human cryptosporidiosis in the Canadian Arctic is a public health concern because of its possible long-term effects on the growth and development of children in Inuit communities who already face many other challenges.

Climate change has been linked to the emergence of new infectious diseases in Northern Canada. Increased precipitation from climate change will result in increased water turbidity from high water velocity. As a result, this will mix and transport more pathogens into water sources and increase the risk of water-borne infectious disease transmission. The warmer temperatures associated with climate change will also expand the range of habitats for animal hosts and allow them to migrate further north. Consequently, this will cause animal hosts to proliferate and will increase the transmission of zoonotic infections. The Centre for Food-borne, Environmental and Zoonotic Infectious Diseases at the Public Health Agency of Canada is looking to inform decision-making and adaptation strategies to mitigate infectious diseases to protect the health of Canadians, especially for those living in the Arctic Circle.

#### **OBJECTIVES**

1. Demonstrate knowledge about the effects of environmental factors that affect a population's health.
2. Assess the links between the quality of the environment and population health and exposure to infectious diseases, with an emphasis on systems thinking.

## Crypto Climate Creep: The Movement of Tropical Infectious Disease to the Arctic

3. Demonstrate knowledge about the One Health Model, which encompasses animals, humans, and the environment.
4. Learn about the public health response and the various levels of government involved in containing an infectious disease outbreak.
5. Evaluate the impact of changes in the environment on the biology, behaviour, and psychology of populations at risk.
6. Explain how globalization affects global burdens of disease.

### DISCUSSION QUESTIONS

1. Create a CASE and DPSEEA model for *Cryptosporidium*. Be prepared to discuss this briefly in class.
  - a. List the potential indirect health impacts from climate change issues (such as an increase in temperature, change in snow composition, or change in the range and activity of infective agents) on Indigenous peoples living in the Arctic.
2. Discuss the One Health Model and how this approach could be valuable in this case.
3. Create an influence diagram to show your understanding of a systems thinking approach to this problem.
4. Discuss the effects of the following issues and brainstorm coping/adaptation strategies to address them:
  - a. Warmer temperatures in summer and year-around
  - b. Increased precipitation
  - c. Contaminated food and water sources
  - d. Changing animal migration routes
5. In collaboration with Indigenous Services Canada, discuss what actions the Public Health Agency of Canada can take to limit the exposure of Indigenous communities in Northern Canada to zoonotic infectious diseases such as *Cryptosporidium*? Students should look at the strategic plan of the Infectious Disease Prevention and Control Branch at the agency in order to facilitate the discussion.
6. Discuss the steps that can be taken to avoid a future outbreak of cryptosporidiosis in the Canadian Arctic.

### KEYWORDS

Climate change; *Cryptosporidium*; One Health Model; systems thinking; zoonotic infectious diseases; Arctic Region; Indigenous peoples



## CASE 12

### Policy Window – When Lyme is in the Limelight

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*Shahzadi Zain, BSc, MBBS, MPH (MPH Class of 2018)*

*Michel Deilgat, MD (Medical Advisor, Centre for Food-borne, Environmental and Zoonotic Infectious Diseases, Public Health Agency of Canada)*

*Amardeep Thind, MD, PhD (Professor, Western University)*

It was a bright sunny morning, which was recently an unusual sight for Ottawa, Ontario. Melissa Doug, a senior policy analyst at the Centre for Food-Borne, Environmental and Zoonotic Infectious Diseases (CFEZID), was on duty to prepare Question Period (QP) notes. The CFEZID, which is part of the Infectious Disease Prevention and Control Branch at the Public Health Agency of Canada (PHAC), was where Melissa started as a policy analyst almost seven years ago. After waking up at 7:30 in the morning, she reached for her phone and was not surprised to see a request to prepare a QP note for the Minister of Health. The QP note was to contain an update on the status of the activities being undertaken for the *Action Plan on Lyme Disease* (PHAC, 2017). The request was triggered by the recent media attention on the alarming rise of Lyme disease cases in Nova Scotia. Melissa was aiming to have the Director's approval by 8:30 a.m. so the QP note with information about current statistics on Lyme disease cases in Canada could be forwarded to the Minister of Health for the upcoming roundtable discussion.

#### **BACKGROUND: LYME DISEASE IN CANADA**

Lyme disease is an emerging, vector-borne infectious disease in Canada and is caused by the bacterium *Borrelia burgdorferi*. This bacterium is transmitted to people through the bite of an infected tick. There are approximately 40 species of ticks in Canada (CFEZID, 2017), but only some of them transmit the pathogens causing human illness. *B. burgdorferi* is exclusively transmitted by blacklegged ticks (also called deer ticks) and western blacklegged ticks (CFEZID, 2017). Lyme disease is the most common tick-borne illness in Canada, and the risk of contracting Lyme disease exists in southern parts of British Columbia and Manitoba, Southern and Eastern Ontario, Southern Quebec, New Brunswick, and some areas in Nova Scotia (Ogden, Koffi, Pelcat, & Lindsay, 2014). In 2018, the PHAC released a map of Lyme disease risk areas in Canada (Exhibit 1). The geographical distribution of Lyme disease risk is expanding because of warming weather, and the consequent geographical invasion of alternate host animals such as migratory birds and dusky-footed wood rats carrying ticks (Ogden et al., 2014).

People engaging in outdoor activities in affected forested areas for either occupational or leisure activities such as camping, hiking, gardening, golfing, dog walking, hunting, fishing, or simply sitting outdoors or near compost piles, are at a higher risk of acquiring the disease from tick bites (CFEZID, 2017).

Lyme disease became nationally notifiable in 2009 to allow the authorities to monitor and control the rising incidence of the disease. About 144 cases were reported that year and were estimated to have been underreported because of insufficient awareness about the disease among frontline clinicians. Since then, the number of newly diagnosed cases has been steadily

increasing and almost 1,000 Canadians were diagnosed with Lyme disease in 2016 (CFEZID, 2017). The rise in the number of Lyme disease cases reported may be attributed to the implementation of a new surveillance system, as well as the advancement in disease knowledge and diagnostic procedures. However, there is still some likelihood that cases are underreported because of gaps in both the surveillance system and the reporting system (CFEZID, 2017). Nova Scotia reported the highest incidence of Lyme disease in Canada in 2016 at 34.4 per 100,000 people, which is 12.7 times the national average (PHAC, 2018b).

### **EVOLUTION OF THE FEDERAL RESPONSE ON LYME DISEASE—THE CHALLENGE**

Lyme disease poses a rapidly evolving challenge for public health professionals and frontline clinicians. Inconsistencies in clinical practices, such as variable diagnostic approaches (clinical diagnosis versus laboratory diagnosis), variable treatment protocols (post-exposure antibiotic prophylaxis versus symptomatic treatment), and controversies surrounding the reliability of laboratory testing technology necessitate that the best practice guidelines for Lyme disease be developed at the national level (CFEZID, 2017). Tick bites may go unnoticed because of the extremely small size of the ticks and the painless nature of the bite. This may result in a delayed or inaccurate diagnosis and potential for illness to become severe, which makes primary prevention even more important. Capturing the exact number of people with Lyme disease by compiling data collected from provincial and territorial public health authorities is another challenging aspect of Lyme disease surveillance because of the discrepancies in data on travel-acquired cases and the dynamic and varying provincial disease reporting systems (PHAC, 2018b).

These challenges, along with the emerging nature of Lyme disease and its link to climate change, led to a unified public health response to Lyme disease in the form of a federal framework. The *Federal Framework on Lyme Disease Act* was assented in 2014 and mandated the Minister of Health to organize a conference to develop the federal response on tackling Lyme disease (Federal Framework on Lyme Disease Act, 2014). Six months later, the Canadian Institutes of Health Research, in collaboration with the PHAC, organized a Best Brains Exchange<sup>1</sup> (Canadian Institutes of Health Research, 2016). This meeting provided an opportunity to exchange and brainstorm ideas for effective and evidence-based diagnostic and treatment protocols for Lyme disease. Participants included national and international experts, including policy-makers, researchers, and other key stakeholders. In May 2016, the PHAC, on behalf of the Minister of Health, organized a national conference to inform and guide policy direction on Lyme disease (PHAC, 2017). Representatives from health care provider associations, all levels of government, academia, patients, and advocacy groups participated in the conference and provided feedback on the draft federal framework on Lyme disease.

The final version of the framework was published in May 2017. It outlines three key pillars for the federal public health response in the areas of adequate prevention, early diagnosis, and timely treatment of Lyme disease. The three pillars—surveillance, education and awareness, and guidelines and best practices—lay the foundation for the PHAC *Action Plan on Lyme Disease* (PHAC, 2017).

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<sup>1</sup> *Best Brains Exchanges* are one-day, in-camera gatherings for policy makers, researchers, and field specialists with expertise on a topic that has been recognized as a high priority by provincial/territorial ministries of health and the Health Portfolio (the Canadian Food Inspection Agency, the Canadian Institutes of Health Research, Health Canada, the Patented Medicine Prices Review Board, and the PHAC) in order to support and facilitate the exchange and use of information for mutual learning and benefit (Canadian Institutes of Health Research, 2018).

### FEDERAL FRAMEWORK ON LYME DISEASE—ENGAGEMENT STRATEGY

A comprehensive approach to Lyme disease prevention and control requires multidisciplinary collaboration with relevant stakeholders and partners. Stakeholders hold a diverse range of concerns and perspectives regarding the prevention, diagnosis, treatment, and control of Lyme disease. They are also concerned with the usefulness, consistency, and comprehensiveness of the information available to public health and primary health care practitioners, as well as the general population, on the topic of Lyme disease.

Melissa is a part of the Lyme Disease Working Group at the PHAC. Melissa and her team have prepared an engagement strategy to facilitate the implementation of the *Action Plan on Lyme Disease* (PHAC, 2018c). The Lyme Disease Working Group consists of policy analysts, a technical lead on epidemiology, and a Health Professional Task Force, and it is divided into a policy arm and a health professional arm. The policy analysts synthesize evidence into policy and keep the rest of the department informed on all policy aspects related to Lyme disease. The technical lead supports the team by tracking and keeping the group updated on surveillance activities. The health care professional task force consists of medical advisors and nurse consultants who positively influence evidence-based decision making, provide insight into best practices and guidelines, and synthesize educational and health promotional material for primary care practitioners. The policy analysts and the health professional groups hold biweekly meetings to collaborate as needed, to debrief the department about *Action Plan on Lyme Disease* activities, and to ensure that their work is progressing and is mutually inclusive.

The engagement strategy also aims to encourage information sharing, knowledge translation, and partnership building to establish a mutually beneficial relationship between the Government of Canada and various Lyme disease stakeholders (PHAC, 2018c). Building coalitions and engaging stakeholders are central to achieving effective outcomes in terms of the three pillars of the Action Plan. Working collaboratively with partners and stakeholders to improve educational and awareness tools will enrich existing prevention and control efforts. The engagement activities also enable stakeholders to share their expertise and personal experience to devise innovative methods for surveillance and control (PHAC, 2018c). Feedback received from various stakeholders about knowledge available to public health practitioners, physicians, and the public about Lyme disease helps to identify the gaps in public health response and research (PHAC, 2018c).

Stakeholder engagement is crucial at each step of the Action Plan, from planning to implementation and then to evaluation. A multipronged approach is required to address the needs and interests of different participants (Mitton, Smith, Peacock, Evoy, & Abelson, 2009). For example, requests for feedback on the documents can be combined with technical workshops depending on the expertise, experience, or interest of the audience. Audience segmentation can guide the right approach and the appropriate platform for developing and exercising engagement activities. Keeping in mind their level of technical expertise and busy schedules, health care professionals may benefit more from technical webinars and workshops. Conversely, online consultation tools might benefit individuals with a general interest and investment in Lyme disease. Potential platforms useful for engagement activities include email notifications, government websites, social media channels, and bilateral meetings.

### STAKEHOLDERS

The engagement strategy aims to identify and attract a broad range of interested partners who have diverse areas of expertise, knowledge, and viewpoints. Potential stakeholders include public health practitioners at all levels of government (municipal, provincial/territorial, and federal), academia, researchers, health care professionals, professional associations,

nongovernment organizations, advocacy groups, patients and their caregivers, at-risk populations, the media, and the general public (PHAC, 2018c).

Identification and acknowledgement of various influential groups' perspectives is followed by interacting and managing the stakeholders in an appropriate way (Brugha & Varvasovszky, 2000). Analyzing various characteristics of the stakeholder groups such as level of interest and commitment, level of influence, public perception, supporting or opposing positions, priorities, sources of funding, and conflicts of interest is one method of managing the wide variety of groups involved (Brugha & Varvasovszky, 2000). The management of stakeholders and the implementation of the Action Plan run in a positive feedback loop, where better engagement of the stakeholders improves the implementation process, which in turn attracts more stakeholders important to program implementation.

### **1. Federal Government**

The Minister of Health is responsible for protecting and promoting the health of Canadians, and this role is supported by the Health Portfolio (Health Canada, 2017). The Health Portfolio comprises Health Canada, the PHAC, the Canadian Institutes of Health Research, the Patented Medicine Prices Review Board, and the Canadian Food Inspection Agency. The PHAC is the federal lead in mobilizing pan-Canadian action to maintain and improve public health, and to prevent disease through building and sustaining a public health network in an open, transparent, and relevant fashion (Health Canada, 2017).

### **2. Provincial Governments**

The Ontario Ministry of Health and Long-Term Care, Manitoba Health, the Saskatchewan Ministry of Health, the New Brunswick Department of Health, and the Institut National de Santé Publique du Québec are the provincial actors who have an important role in policy decisions regarding the prevention and control of Lyme disease in their respective provinces (PHAC, 2018c). These actors have set up visions, goals, objectives, and standards in order to play their respective roles using a collaborative public health response and coordinated care approach in their communities.

### **3. Health Professionals**

The Canadian Medical Association is the professional association of Canadian physicians, uniting more than 85,000 members on health and medical matters. The Association's rich history of advocacy for evidence-based practice led to some of Canada's most important health policy modifications (Canadian Medical Association, n.d.). The Association of Medical Microbiology and Infectious Disease Canada (AMMI Canada) represents physicians, clinical microbiologists, and researchers from microbiology and infectious diseases fields. AMMI Canada aims to serve the public through education, research, and clinical practice (AMMI Canada, 2018). The College of Family Physicians of Canada regulates family physicians and establishes standards for their training, certification, and professional development (The College of Family Physicians of Canada, n.d.). Infection Prevention and Control Canada is a multidisciplinary association committed to the well-being and safety of Canadians by educating, standardizing, and advocating for infection control and prevention strategies (Infection Prevention and Control Canada, 2018). These health professional organizations operate at the national level and their representation in the engagement strategy will strengthen the Canada-wide policy perspective.

### **4. Academia and Research**

Queen's University, Mount Allison University, Bishop's University, the G. Magnotta Foundation, and Lakehead University are some Canadian institutes located in Lyme

disease-affected provinces. These institutes are also involved in the engagement process in order to contribute the most current knowledge and evidence-based methods and practices.

### 5. Patient Groups

LymeHope, Voices of Canadians about Lyme (VOCAL), and the Canadian Lyme Disease Foundation (CanLyme) are some of the patient advocacy groups at the national level. Provincial Lyme disease associations include Manitoba Lyme Disease, Lyme Ontario, the Lyme Disease Association of Alberta, the Saskatchewan Lyme Disease Association, and the Nova Scotia Lyme Disease Support Group. These patient advocacy groups have been at the forefront of pushing the government's response to Lyme disease in Canada (PHAC, 2018c). They advocate for patients to be equal partners in Lyme disease policy development and push to standardize educational material for health care providers.

### WHAT CAN THEY BRING?

Stakeholders bring various perspectives, expertise, and opinions. Valuing these viewpoints and integrating these competencies can produce the most coordinated and holistic response to Lyme disease (PHAC, 2018c). Researchers, for example, can contribute by providing the most up-to-date knowledge and scientific evidence. Health care professionals can provide valuable insight into effective clinical methods, highlight gaps in current best practices, and iterate challenges related to clinical diagnoses and treatment. Representatives from Indigenous populations can identify the impact of increasing incidence of Lyme disease on their cultural practices. At-risk and vulnerable populations require a more tailored approach for effective health protection and promotion awareness and activities. The employees of governmental organizations, such as Parks Canada, can highlight the hardships of maintaining health promotion and protection protocols in daily work-related activities. For example, employees may not be able to wear long-sleeved shirts and light-coloured clothing because of extreme heat or dress code requirements. Patients, families, and their caregivers can bring their personal and lived experiences in challenges of diagnosis, treatment, and recovery.

### ROUNDTABLE DISCUSSION

Melissa thought about all the engagement activities undertaken so far to refine and guide the implementation of the *Action Plan on Lyme Disease* and updated the summary of recent activities in her QP note. She also included an update about the upcoming roundtable meeting with stakeholders as part of the engagement strategy. The roundtable discussion is one of the major coalition activities planned as part of the strategy, involving many of the stakeholders and partner groups. She has been preparing for this discussion with her manager and colleagues for the past six weeks. She understands that Lyme disease is not only an emerging public health concern, but that it is also a politically charged topic because of the ideological differences various stakeholders have regarding possible solutions for this problem. Patients' perspectives on missed Lyme disease diagnosis and lack of universal guidelines for diagnosis and treatment make it a particularly sensitive topic for many groups. The political nature of Lyme disease and sensitivity attached to this topic make it a controversial subject. Disapproval of the term *chronic Lyme disease* in medical literature and the recommendation against long term antibiotic treatment add to the controversy (R. Ahmed, personal communication, 2018). Because of these factors, Melissa is skeptical about the end results of the roundtable discussion.

The roundtable discussion will be an all-day event held in Ottawa. A large U-shaped table will be set up to let everyone listen to information and opinions firsthand and to foster new partnerships among participants. An external professional facilitator has been hired to facilitate the discussion and minimize bias in proposing concrete actionable items and identifying future roles and responsibilities. In the spirit of openness and transparency, the final list of attendees and their affiliations has been shared with all who will attend. The roundtable discussion will be

conducted in both official languages to ensure full participation from all attendees. Melissa and her team understand the importance of performing a detailed stakeholder analysis to facilitate the implementation of the Action Plan and discern the policy context. They have also prepared a logic model to appraise the feasibility of future directions of policy making. The team is aware of the theories of policy development and their implication on future modifications in forming Lyme disease policy.

### WHY ROUNDTABLE?

The *Federal Framework on Lyme Disease Act* mandates the preparation and implementation of the Action Plan and the engagement of relevant stakeholders. The roundtable discussion is an important activity in the engagement strategy because it will not only bring a diverse group of partners together to have an open dialogue, but it will also help obtain a broad range of values and perspectives on the three pillars of the framework (Exhibit 2). A roundtable discussion is an excellent opportunity to explore answers to some crucial questions, including: What are the possible ways to expand data collection methods to include people who do not fit the classic case definition? What roles and responsibilities can be delegated to various stakeholders in order to advance collaborative work on Lyme disease? Which health care professionals should be targeted for best practices guidelines preparation? What should the public awareness campaign focus on? And what should the Lyme disease research network, which was recently granted \$4 million to expand its research, prioritize? Although the long-term outcome of the engagement strategy is to protect Canadians from potential health risks associated with Lyme disease, the immediate outcome of the activities will determine the timeline and strategy for achieving this long-term outcome.

The Health Professional Task Force at the PHAC invited potentially interested stakeholders to participate in the discussion. The team is hoping to have strong representation from all sectors at the national level to identify opportunities for collaboration and to continue to advance work on Lyme disease. Most of the organizations have accepted the invitations; others have decided to send a delegate to represent the organization; and a few have declined, stating that Lyme disease is not a priority task for them at the moment (Exhibit 3). It is critical to have a strong voice supporting the incorporation of evidence-based research into the unified federal response, and to be able to successfully achieve positive long-term outcomes for the Lyme disease strategy.

### CONTROVERSY

Lyme disease is a politically charged topic. The Government of Canada emphasizes developing a national surveillance program, best practice guidelines, and standard educational materials to increase Canadians' awareness about Lyme disease by exclusively using scientifically proven and evidence-informed methods and practices. Some of the Lyme disease advocacy groups have been at the forefront to push the federal response toward implementing a Lyme disease care model similar to the American model, which is based on partially validated methods of diagnosis and treatment. These patient groups advocate for patients to be considered equal partners in decision-making at the policy level. Although patients' perspectives are critical to understanding the gaps related to diagnosis, treatment, and recovery, their experiences must be balanced with evidence-based information and expert opinion. There are many conflicts of ideology between patient advocacy groups and technical experts, which is why successful implementation of the roundtable discussion is critical for a smooth advancement of the Action Plan.

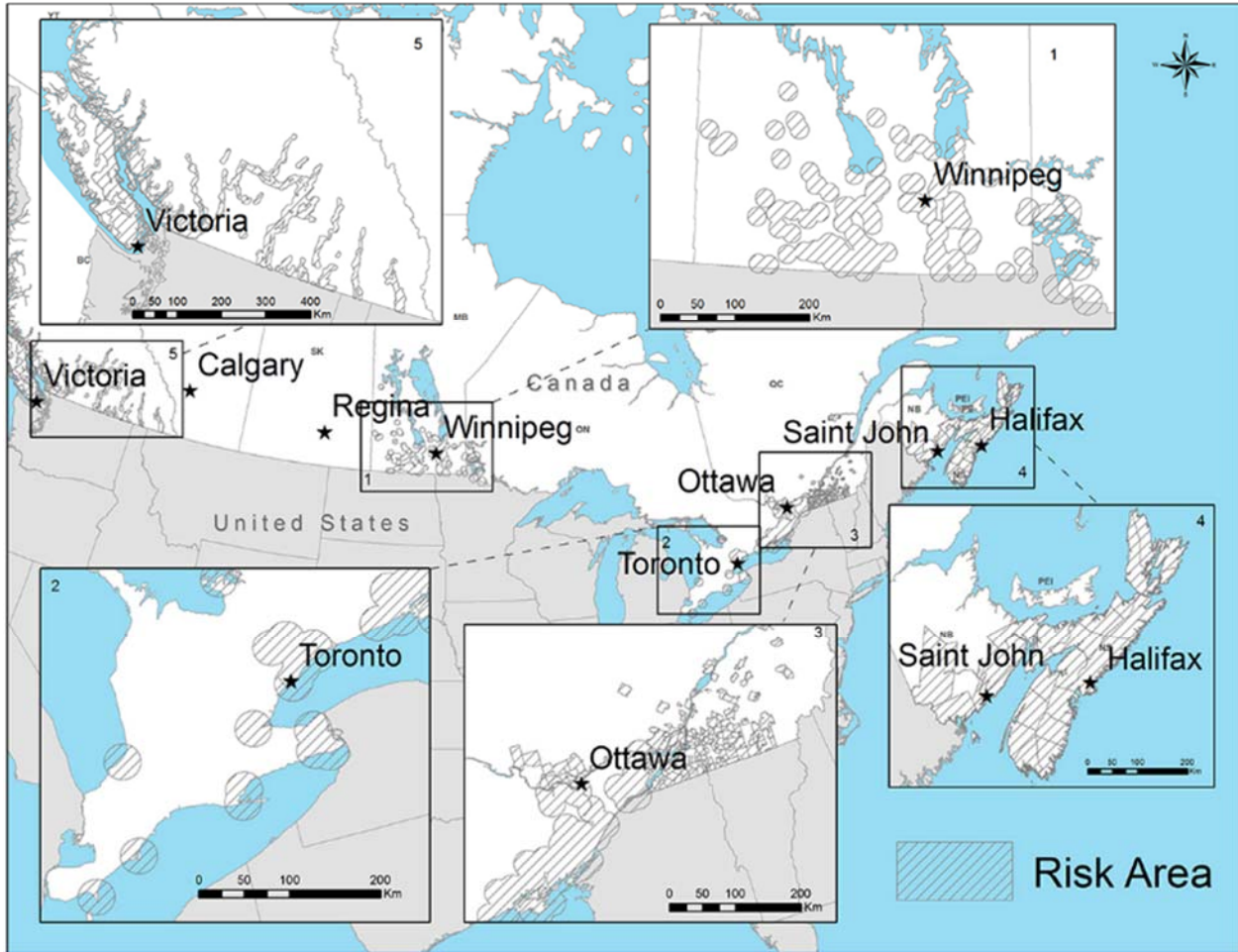
Melissa finished her QP note and sent it to the Director so it could be approved and forwarded to the Minister's office via the single window of the Infectious Disease Prevention and Control Branch. It was now 8:30 a.m. and she rolled out of bed and peeked inside her mother's room.

Her mother has suffered from arthritis for the past nine years. She was initially labelled as a 'suspected case of Lyme' but laboratory testing did not provide a formal diagnosis. Looking at the clock again, Melissa gets ready to go to the PHAC office at 130 Colonnade Road. On her drive, she thinks about her journey with Lyme disease so far and the uncertainties about the outcomes of the roundtable discussion.

### CONCLUSION

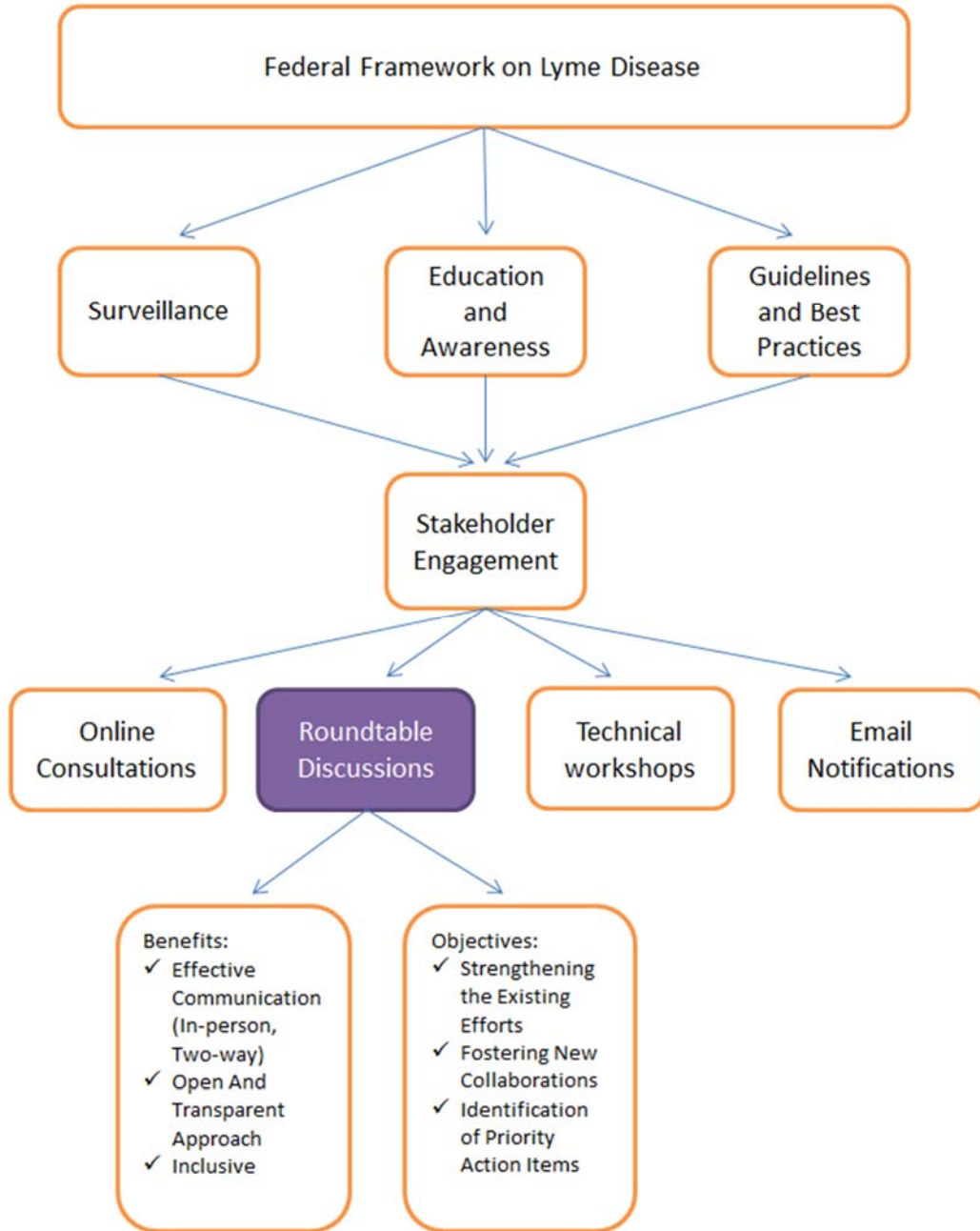
Melissa has seen the *Action Plan on Lyme Disease* pass through evolutionary steps. As a very sensitive issue for a lot of people (for her also because of her mother's condition), Lyme disease brings out many controversies and concerns among all stakeholders. Having an open dialogue to establish clear-cut responsibilities and expectations is the key to a successful implementation of the Action Plan. While going up the stairs, she thinks about the logistics and operations of the roundtable discussion and keeps asking the following questions: What will happen at the roundtable discussion? Who will represent the different organizations? Will the representatives be able to truly represent their organizational perspectives? Will they be able to stand by the evidence-based research approach? Will they be able to dissociate their personal experiences with Lyme disease diagnoses from their professional opinions? Will they be able to control their tone and tailor their messages according to the audience? Will this roundtable be able to advance the Action Plan further or push it back? Four years' worth of her team's time, energy, and efforts depend on the outcomes of this roundtable discussion.

**EXHIBIT 1**  
**Five Locations Where Tick Bite and Lyme Disease Risks Are Known**



Source: Public Health Agency of Canada, 2018a.

EXHIBIT 2



Source: Created by Author, derived from Public Health Agency of Canada, 2018.

### EXHIBIT 3

#### List of Stakeholder Organizations (Accepted Invitation)

##### Federal Government

- Public Health Agency of Canada

##### Provincial Government

- New Brunswick Department of Health
- Ontario Ministry of Health and Long-Term Care
- Institut national de santé publique du Québec
- Manitoba Health
- Saskatchewan Ministry of Health

##### Health Professionals

- Indigenous Physicians Association of Canada
- Association of Medical Microbiology and Infectious Disease Canada
- Canadian Association of Naturopathic Doctors
- Canadian Association of Schools of Nursing
- Centre for Effective Practice
- College of Family Physicians of Canada
- Medical Prof. Corp.
- Naturopathic Family Medicine Inc.
- Society of Obstetricians and Gynecologists of Canada
- Canadian Veterinary Medical Association

##### Patient Groups

- LymeHope
- CanLyme
- Voices of Canadians About Lyme (VOCAL)
- Nova Scotia Lyme Disease Support Group
- Manitoba Lyme Disease
- LymeNB
- Ontario Lyme Alliance
- Lyme Ontario
- Lyme Disease Association of Alberta
- Saskatchewan Lyme Disease Association

##### Academia/Research

- Queen's University
- G. Magnotta Lyme Disease Research Lab (University of Guelph)
- G. Magnotta Foundation

#### List of Stakeholder Organizations (Regrets)

- Canadian Medical Association
- Ministère de la Santé et des Services sociaux
- Association québécoise de la maladie de Lyme
- Bishop's University
- Infection Prevention and Control Canada
- Mount Allison University
- Canadian Nurses Association
- Canadian Paediatric Society
- Lakehead University

Source: Public Health Agency of Canada, 2018c.

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## INSTRUCTOR GUIDANCE

### Policy Window – When Lyme is in the Limelight

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*Amardeep Thind, MD, PhD (Professor, Western University)*

#### BACKGROUND

Melissa Doug is a senior policy analyst at the Centre for Food-Borne, Environmental and Zoonotic Infectious Diseases at the Public Health Agency of Canada. She has been tasked with preparing Question Period (QP) notes for the Minister of Health. She has very little time to prepare a clear, succinct, and jargon-free note by 8:30 a.m. for the Director's approval. Once the note is approved, the Director will forward it to the Minister of Health with an update on the status of activities being undertaken for the *Action Plan on Lyme Disease*. The QP note also includes an update on the upcoming roundtable discussion with stakeholders as part of the Lyme disease engagement strategy. Melissa has been working on Lyme disease policy for more than four years and her team's energy and efforts will come to fruition during this roundtable discussion.

Lyme disease is a rapidly growing public health challenge in Canada. The absence of a consolidated national response to Lyme disease led to the *Federal Framework on Lyme Disease Act*, which mandated the Minister of Health to call a national conference on the issue. The Public Health Agency of Canada developed the federal *Action Plan on Lyme Disease* on behalf of the Minister of Health. The Action Plan is based on three pillars—surveillance, education and awareness, and guidelines and best practices. Developing the plan requires comprehensive consultation with all stakeholder groups to ensure that diverse perspectives in policy development and implementation are incorporated. Stakeholder engagement in the implementation process is key to addressing the specific needs of at-risk groups and narrowing the gaps in current practices at the policy level.

The purpose of this case is to underscore the importance of stakeholder analysis and management in defining future policy directions and successful program implementation. Incorporating the real-world perspectives of diverse stakeholders is an essential component of an effective policy-making process.

#### OBJECTIVES

1. Develop strategies for stakeholder identification to inform population-based policies.
2. Analyze the significance of various stakeholder analysis techniques in order to address emerging public health issues.
3. Construct a map of relevant stakeholders on an interest–influence matrix for a structured approach to stakeholder analysis.
4. Practice compiling evidence to synthesize policy brief communication with imperfect and incomplete information regarding emerging infectious diseases.
5. Appraise the value of building partnerships to advocate for evidence-informed policies.

### DISCUSSION QUESTIONS

1. What is the role of evidence-based research in policy development?
2. What are the facilitators and barriers of stakeholder engagement activities?
3. How does stakeholder engagement facilitate the implementation of an action plan?
4. What are the various characteristics of the stakeholders interested in Lyme disease engagement strategy?
5. Can international guidelines regarding emerging vector-borne infections be used to inform best practice guidelines in Canada?
6. How does the federal government perspective on Lyme disease differ from that of nonfederal and other external organizational perspectives? How does it impact stakeholder engagement?

### KEYWORDS

Communication; federal framework; Lyme disease; policy development; stakeholder analysis



## CASE 13

### Sustainable mHealth Innovations – Repurposing The Collective Comfort Pilot Project

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*Shannon L. Sibbald, PhD (Assistant Professor, Western University)*

#### INTRODUCTION

It was a rainy Monday morning in April and Heather Grohl—the Director of the Education Department at the Centre for Addiction and Mental Health (CAMH)—was anxiously tapping her fingers on her desk. In her other hand was a paper with her presentation notes that listed the points that she needed to announce at today’s pivotal Board of Directors meeting.

Heather glanced at her watch as she impatiently awaited the clock to reach 10 a.m. She could feel her heart pounding in her chest and accelerating as each moment passed. Heather knew what was coming and needed a distraction. She pulled out her cell phone and touched The CC icon, which opened an app called *The Collective Comfort* (Exhibit 1). Heather then navigated to *Relaxation Tips*. This forum listed *Box Breathing Technique*, so she decided to close her eyes and give this method a try. After taking a dozen deep breaths while focused on tracing a visual square in her mind, she felt the pressure and uneasiness fade away. She opened her eyes to see the time on the clock was 9:57 a.m. It was now time to head to the meeting.

#### BACKGROUND

##### Heather Grohl

Heather Grohl has been the Director of Education at CAMH for the past seven years. Previously, Heather had worked at several other teaching hospitals and, although she enjoyed her work, there was no match to the sense of accomplishment she feels while working at CAMH. Heather revels in the sense of purpose she feels every day as she works to improve the lives of people dealing with mental health and addiction issues.

##### The Centre for Addiction and Mental Health

In addition to being Canada’s largest mental health teaching hospital, CAMH is a well-respected and world-renowned leader in the field of mental health and addictions research (CAMH, n.d.a). There are more than 3,000 CAMH clinicians, physicians, researchers, educators, and support staff who provide care to more than 34,000 patients every year (CAMH, n.d.a). CAMH develops innovative health promotion and prevention strategies while advocating at all levels of government for critical public policy issues (CAMH, n.d.a).

CAMH is dedicated to transforming the lives of individuals who suffer from mental illness and addiction (CAMH, n.d.a). In their 2017–2018 annual report, CAMH first declared themselves as the leaders of a movement of change (CAMH, 2017a). That change is to create a world where every person understands and believes that “mental health is health” by improving access to

## **Sustainable mHealth Innovations – Repurposing The Collective Comfort Pilot Project**

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care, building community capacity by creating and sharing knowledge with the community and, finally, inspiring hope through discovery (CAMH, 2017a).

Heather's department was no exception to this innovative effort. Heather works to ensure that the CAMH Education department meets its strategic objective of mental health advocacy through "improved access to mental health services through mobile health solutions" (CAMH, 2017b, p.11). Under Heather's leadership, the Education department's Digital Innovation team has expertly created numerous mobile applications adapted from CAMH's evidence-based mental health publications. This includes The Collective Comfort project—known as The CC project for short—the latest in the line-up from the Digital Innovation team. It is a mobile health (mHealth) pilot project that provides instant social support for people everywhere who have anxiety disorders. The CC project and other CAMH applications share the goal of initiating ground-level change by bridging the gap between high-level academic professionals and increasing accessibility to mental health resources for people who experience mental illness.

### **The Issue at Hand: Mental Health**

The effects of mental illness are far-reaching and contribute to a significant portion of the increasing burden of disease worldwide (Reijneveld, 2005). The World Health Organization (WHO) defines mental health as "a state of well-being in which every individual realizes his or her own potential, can cope with the normal stress of life, can work productively and fruitfully, and is able to make a contribution to her or his community" (WHO, 2014). Mental health is highly intertwined with other forms of health such as physical, social, spiritual, and emotional health and well-being (WHO, 2014). For instance, people who have poor mental health reported having weaker social support networks and other social determinants of health, such as low socioeconomic status and level of education.

Mental illness is a highly prevalent public health issue, with one in five Canadians experiencing a mental illness during their lifetime (CAMH, n.d.b). By the age of 40, half of Canadians have had or still have a mental illness, with 70% of mental health problems beginning in adolescence or childhood (CAMH, n.d.b). People suffering from a mental illness have a 10 to 20 year decreased life expectancy compared with the general population (CAMH, n.d.b). Furthermore, mental illness is a leading cause of disability in Canada, with more than 4,000 Canadians dying by suicide each year (CAMH, n.d.b). Mental illness does not discriminate on the basis of age, gender, religion, sexual orientation, or race—it affects individuals from all walks of life.

### **Social Support: Key Determinant of Mental Health**

The WHO (2017) recognized social support as a key social determinant of mental health. The Canadian Mental Health Association (n.d.) defines social support as "the physical and emotional comfort given to us by our family, friends, coworkers, and others. It's knowing that we are part of a community of people who love and care for us, and value and think well of us". Additionally, the effects of stressors have been found to be buffered by strong social support networks because these support networks reduce perceived stigmas and increase a sense of belonging (WHO, 2017). Increasing social support networks is a key social determinant of mental health that should be targeted in mental health interventions with the goal of improving an individual's mental well-being.

### **The Collective Comfort: An mHealth Pilot Project**

The Collective Comfort platform (Exhibit 1) enables users such as Heather to connect via a group thread on the mobile phone application. The application includes *Comfort Chat* categories consisting of forums such as 'Relaxation Tips' that people can select. Comfort chats allow people who mutually share an issue to come together and offer support to one another. The

## Sustainable mHealth Innovations – Repurposing The Collective Comfort Pilot Project

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shared commonality among members creates a free, online social support system. The goal is to create a safe, stigma-free, mobile social support network for people who may otherwise not have, or feel comfortable seeking, other forms of mental health assistance such as a psychiatrist. The forum also provides a certain level of anonymity for users who are not yet comfortable revealing their identity. Heather's vision for The CC project was to help create a world in which nobody who has a mental illness feels like they are alone.

The Board of Directors meeting would determine the fate of The CC pilot project. Heather and her team had tirelessly spent the past 18 months dedicated to this pilot and, after 18 months the grant had expired and left The CC project at a new stage of uncertainty. However, Heather refused to lay the pilot project to rest. Fortunately, she had attended a Public Health Digital Innovation think tank session earlier that month and learned of a major gap in the system that The CC app could address. Several organizations such as the Alzheimer Society of Toronto, Homeless Hub, and Veterans Affairs Canada, indicated that there were currently no mobile, digitally accessible platforms for their support groups. This sparked Heather's idea to determine whether The Collective Comfort application may be transferrable to other populations in need, beyond people who have anxiety disorders.

### HEATHER'S PRESENTATION

Heather was presenting The Collective Comfort app's journey to the Board of Directors, including its successful outcome evaluation and its supporting engagement metrics, to prove the wider benefits of this mHealth application. She made it clear that The CC project's successes did not have to end after the pilot funding expired because it had great potential to fill other gaps in the health system. Specifically, The CC app could fulfill the needs of organizations external to CAMH, which were seeking an innovative way to expand their support programs.

#### 1. **Alzheimer Society of Toronto**

"The role of the Alzheimer Society of Toronto is to offer support, information, and education to people with dementia, their families, and their caregivers, to increase public awareness of dementia, to promote research, and to advocate for services that respect the dignity of the individual" (Alzheimer Society of Toronto, n.d.).

#### 2. **Homeless Hub**

The Homeless Hub is "a web-based research library and information centre representing an innovative step forward in the use of technology to enhance knowledge mobilization and networking" that is devoted to homelessness in Canada (Homeless Hub, n.d.).

#### 3. **Veterans Affairs Canada—Mental Health Advisory Group**

Veterans Affairs Canada is the department within the Government of Canada responsible for providing services, including mental health services, to any former member of the Canadian Armed Forces (Government of Canada, n.d.).

Heather explained to the Board of Directors that these three organizations have the potential to benefit from the groundwork that The CC project had already completed. The application could be repurposed to meet the new needs of these external organizations. Heather argued that the CC application is highly transferrable because it was originally designed to be a mobile social support network, meaning that one could strip the surface level of the app and rework the template to meet a new program's specific needs and goals.

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### **THE CHALLENGE OF SUSTAINABLE INNOVATION**

The field of innovation is fast-paced and constantly changing. Heather is facing a challenge common with technological innovations, which is ensuring that the mobile application remains sustainable from both a financial and technological standpoint.

Once the app has been created and is circulating, the application developers should:

- ensure the application is updated by the organization itself, the vendor who created the application, or a third party contracted for various ongoing and future software issues
- involve the same parties for general maintenance of the application, depending on the scope of information that may need to be kept updated
- address changes in industry standards that must be continually checked and met: software framework, compatibility (e.g., Apple made a new software compatibility rule that all apps must be compatible with iPads as well as iPhones and Androids)
- explore the future scalability of the application because as the user population becomes larger, greater resources will be required to maintain and expand the application
- secure ongoing funding support to maintain the above, whether from grants, from the organization itself, or from users paying for the application. The application will require a source of income to ensure it is kept up and running

### **NEXT STEPS**

Heather's boss, the President of CAMH Education, has approved her plan to pitch to an external organization, but has determined that, because of time and labour shortages, the pitch should focus on one of the three organizations. Heather must decide which organization to select and how best to develop the pitch. Her tight timeline of three days adds even more stress to this difficult decision. She needs to understand the needs and goals of each organization. Thankfully, she has teams that will help her by conducting external research on each organization to develop user personas, problem scenarios, user stories, and a prototype that is based on The Collective Comfort's template design. The teams are also expected to propose one new, innovative app feature that they believe will be useful for their specific organization. Once done, Heather and the President of CAMH Education will decide the final winning pitch based on which pitch best balances both creativity and feasibility.

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### EXHIBIT 1

#### *The Collective Comfort Application on an Apple iPhone Interface*

The home page of a mobile device, where the inconspicuous, teal icon that accesses The Collective Comfort application can be found.



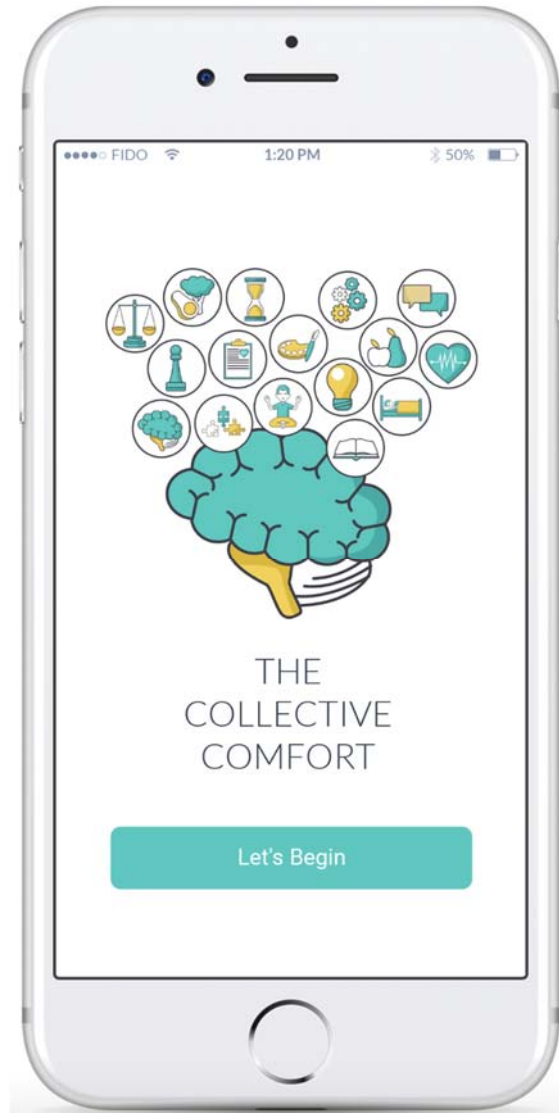
Source: Created by Author.

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### EXHIBIT 1 (cont'd)

The home page of the actual application (The Collective Comfort) opens once the icon is tapped.

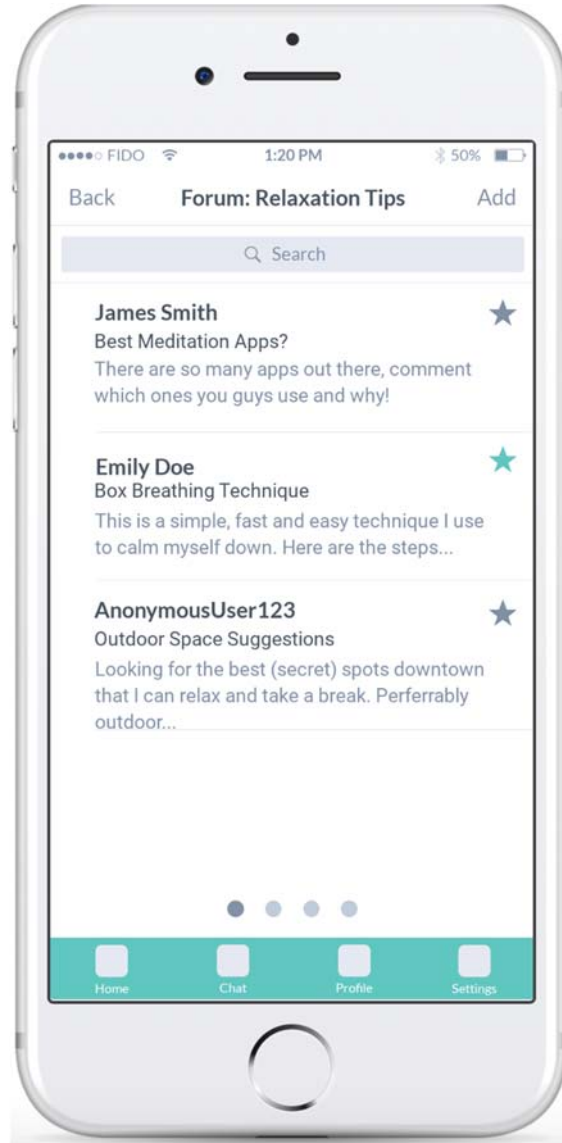


Source: Created by Author.

## Sustainable mHealth Innovations – Repurposing The Collective Comfort Pilot Project

### EXHIBIT 1 (cont'd)

After signing in, a user is able to access any of the forums. For example, Heather selects the *Relaxation Tips* forum in which she can view other forum posts from users and “favourite” the ones she likes (represented by the teal star).



Source: Created by Author.

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## INSTRUCTOR GUIDANCE

### Sustainable mHealth Innovations – Repurposing The Collective Comfort Pilot Project

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*Shannon L. Sibbald, PhD (Assistant Professor, Western University)*

#### BACKGROUND

The *Collective Comfort* project (CC project) is a mobile health (mHealth) pilot project created by the Digital Innovation team in the Education Department at the Centre for Addiction and Mental Health (CAMH). The CC project provides safe, online social support networks—a crucial social determinant of health—that are accessible everywhere to people who have anxiety disorders.

Unfortunately, funding has come to an end for this pilot project. CAMH's Director of Education, Heather Grohl, and her team are tasked with repurposing the CC project mobile application for three organizations—the Alzheimer Society of Toronto, Homeless Hub, and Veterans Affairs Canada. These organizations are seeking a digital innovation that would allow their social support groups to be accessed through mobile phones. However, Heather's boss, the President of CAMH Education, has only approved pitching to one organization. Therefore, her team must divide into three smaller teams to develop a proposal appropriate for each organization. The pitch will consist of a user persona, problem scenarios, user stories, and a prototype that is based on the CC project's template design. Each pitch will be specifically tailored to the respective organization's unique needs. The teams are also expected to develop one new innovative feature for the mHealth application that they believe would be useful for their specific organization. For example, an application for the Homeless Hub could incorporate a feature that displays homeless shelters in the area. Each of the teams will then present their prospective pitches to Heather and the President of CAMH Education, who will together decide the winning proposal based on which one best balances both creativity and feasibility.

#### OBJECTIVES

1. Understand and critically discuss the strengths and challenges of an mHealth innovation.
2. Identify the unique needs of a specific population using research and experience to:
  - design a population-based mHealth social support application that meets the unique needs of its users (population) while working under a time constraint with incomplete and imperfect information
  - present the audience-appropriate, public health informatics context both orally and in writing

## **Development of an Electronic Health Record Strategy at the Glenburn Public Health Unit**

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### **DISCUSSION QUESTIONS**

1. Why and how is social support a crucial social determinant of mental health? What is the role of mobile technology applications in providing social support?
2. What are the major strengths and major challenges of using mHealth technology to address mental health issues in the field of public health?
3. What processes and resources would be required to find the information necessary to best create these personas, problem scenarios, user stories, and prototypes for each organization?
4. How could the financial and technological sustainability of an mHealth intervention be maintained?

### **KEYWORDS**

Health technology; innovation; mental health; mHealth application; public health informatics; social support

# **FACULTY CASE**



## CASE 14

### Development of an Electronic Health Record Strategy at the Glenburn Public Health Unit

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#### BACKGROUND

In 2016, the management team met to review the state of client documentation and recordkeeping at the Glenburn Public Health Unit (GPHU).<sup>1</sup> This included reviewing a long list of complaints, issues, and requests from GPHU staff. GPHU teams that used paper forms to document client interactions reported that they were drowning in paper. These teams also reported that analyzing trends over time or across client groups was tedious work. Staff reported that clients were increasingly asking for self-serve access to personal health information such as immunization records. Clients noted that self-serve, online patient portals were becoming common in local family physician offices. These GPHU teams wanted to replace paper forms with an electronic system, either by purchasing existing software or by working with a software developer to create a customized system. The GPHU records manager echoed these concerns and projected that offsite storage costs would steadily rise if these teams continued using paper records. This was especially true since, by law, some GPHU records had to be retained forever. GPHU teams that already had electronic client documentation/recordkeeping systems also requested funding to modify or upgrade outdated systems. However, the Information Technology (IT) team said they faced challenges maintaining the many different electronic client recordkeeping systems already in place.

The management team reflected on these issues. Through their day-to-day interactions with health workers and clients, management team members were familiar with the issues raised by staff. As leaders within the health unit, the management team was also familiar with the limitations regarding privacy, analytics, client self-service, and cross-team collaboration presented by GPHU's current client documentation and recordkeeping practices. However, addressing all these issues would be expensive and difficult, if not impossible. The management team knew that other health units had replaced multiple electronic and paper systems with one or two robust electronic health record (EHR) systems that served multiple teams. The management team decided GPHU needed to explore the feasibility of using a robust EHR system. They identified this effort as one of GPHU's top strategic priorities and they created an interdisciplinary staff committee (the EHR Committee) to gather relevant information to help the management team develop a long-term EHR strategy for GPHU. The management team requested that the Manager of Strategic Projects, Sabrina Khan, and the IT Manager, Lee Golden, lead the EHR Committee and provide the team with periodic updates on the

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<sup>1</sup>This case is based on real events, but uses fictitious names for organizations, people, and software.

## **Development of an Electronic Health Record Strategy at the Glenburn Public Health Unit**

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Committee's progress. The management team asked the Committee to provide them with a report outlining:

- GPHU's current client document/recordkeeping systems and IT capacity (an internal scan)
- EHR systems in use at other health units and partner agencies, as well as possible funding sources to support EHR development and implementation (an external scan)
- EHR strategy options, including a recommended option

The overall goal was to develop an EHR strategy that would help the GPHU improve client documentation and recordkeeping practices, which, in turn, should improve client service delivery. Ideally, the use of an electronic solution would also support collaboration and communication across GPHU programs and services.

### **GLENBURN PUBLIC HEALTH UNIT**

GPHU is one of more than 30 public health units in Ontario. GPHU staff provide a broad range of public health programs and services in accordance with Ontario's *Health Protection and Promotion Act* (Government of Ontario, 1990) and the *Ontario Public Health Standards* published by the Ministry of Health and Long Term Care (2018). GPHU serves people residing in the Town of Glenburn and throughout Hunt County. GPHU services include school health programs, a sexual health clinic, a needle exchange program, a dental clinic, home visits to new mothers, restaurant inspections, parenting classes, immunization clinics, and tobacco law enforcement. As one of the smallest health units in Ontario, GPHU serves a population of approximately 70,000, including one First Nations community.

A board of health oversees all GPHU activities. The GPHU Board of Health comprises five provincial representatives, three Hunt County representatives, and three Town of Glenburn representatives. GPHU receives funding from multiple sources, including all three levels of government. GPHU's funding is provided via a cost-sharing arrangement between the province of Ontario and municipalities within GPHU's district. This funding is to deliver mandatory programs specified in the *Health Protection and Promotion Act*. Other GPHU programs and services are funded by the provincial Ministry of Child and Youth Services, and the Ministry of Health and Long Term Care. GPHU has approximately 65 staff, 40 volunteers, and an operating budget of \$14 million.

GPHU is required to maintain high-quality records about its operations and the interactions its staff have with its patients/clients (including individuals, groups, and private businesses). This is accomplished using proper documentation and recordkeeping practices that ensure information accuracy, security, privacy, and access. Furthermore, many GPHU staff are regulated health professionals (such as nurses, physicians, and dietitians) that have discipline-specific requirements regarding client documentation and recordkeeping.

### **THE MINISTRY OF HEALTH AND LONG TERM CARE**

As noted, the Ministry funds the majority of public health and general health care services in Ontario. In this way, the Ministry acts as *the* leader of Ontario's health system, providing overall direction on the system's goals, and then allocating resources and establishing standards to achieve those goals. The Ministry funds, regulates, and evaluates health units across Ontario, including GPHU, to provide local public health services. The Ministry also funds public health laboratories and a provincial public health agency (Public Health Ontario) and contributes to various national and international public health initiatives. Ontario also has a provincial Medical

## Development of an Electronic Health Record Strategy at the Glenburn Public Health Unit

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Officer of Health and a Division of Public Health within the Ministry that oversee most of the provincial public health system.

### ELECTRONIC HEALTH RECORDS

An EHR is a software or web-based documentation and recordkeeping platform that records and describes an individual's health and care history (Naylor et al., 2015). EHRs aim to keep a record of the health information and "events" a person experiences throughout their life, such as visits to their family physician, surgeries, test results, medical diagnoses, and family health history. There are countless formats and types of EHRs, most created by private IT companies. Although EHRs can exist within a single organization such as a hospital, many EHRs provide a secure connection for access to patient health information between authorized organizations and health service providers, such as hospitals, private laboratories, and family physician offices (Canada Health Infoway, 2019). Some EHRs offer self-serve access to information so people can monitor and contribute to their own record (often referred to as a "patient portal"). Given that public health represents only approximately 5% of government health system spending in developed countries, the vast majority of EHRs focus on *medical* experiences, not interactions with public health. This means most EHRs are best equipped to capture information from hospitals, doctors, pharmacies, and laboratories, but not from public health practitioners such as public health nurses or public health inspectors. The term EHR is often used synonymously with the term electronic medical record, given the focus on medical experiences (Gheorghiu & Hagens, 2016). However, EHR is generally accepted to be a broader term than electronic medical record, capturing both health status information and medical treatment experiences.

Implementing an EHR is complex and challenging work for a health service provider. Technically, a health service provider can either purchase an EHR from a company or create a new one by hiring software developers. However, providers rarely hire developers to create new EHRs given the complexity of EHR software and the number of cost-effective EHR options already available. Organizations such as hospitals and health units collect massive amounts of sensitive client information every day. Provincial laws dictate that organizations take great care in how this information is collected, stored, used, accessed, shared, analyzed, and destroyed. This affects all levels of the health organization and, when an EHR is implemented, this can present barriers to all stakeholders, including frontline clinicians, management, executive leaders, and governance bodies. Key barriers include limitations on which software can be selected, tight controls on what and how information is shared, and staffing requirements to ensure proper data storage and system auditing.

There are many valid reasons that health service providers seek to replace their paper systems with EHRs. If successfully adopted, a wide range of benefits can be realized by health providers, patients, and the health system (Canada Health Infoway, 2013). EHRs have the potential to decrease errors in medication administration, improve patient privacy, increase equitable access to health care services, improve the quality and safety of health service delivery, and, overall, contribute to a more efficient health care system (Canada Health Infoway, 2013; Cavoukian, 2010; Naylor et al., 2015; Office of the Chief Coroner, 2011). Similarly, the management team identified a number of specific benefits it sought from an EHR for GPHU:

- Improved services by facilitating collection and synthesis of more accurate and complete information among GPHU staff
- Reduced wait times for access to records
- Reduced data entry duplications

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- Allowance for process improvement and automated workflows (e.g., online appointment scheduling)
- Reduced paper usage and paper storage costs
- Improved security of confidential health information through modern, encrypted data protection systems
- Ability to provide GPHU staff with immediate, accurate, and secure access to client/premise information, even when staff are working in the community
- Reduced potential for errors and uncoordinated service provision

The management team also wanted to explore the ability of the system to facilitate information sharing among local organizations when appropriate (e.g., between children's services and local hospitals) and to contribute to enhancing public health across the province by improving communication with public health laboratories and provincial agencies.

### **INTERNAL SCAN**

The EHR Committee began the scan by meeting with staff from each GPHU team. Committee members collected relevant documents on the current state of client documentation and recordkeeping. They found GPHU's approach to this was best described as decentralized. This meant that GPHU program teams had autonomy as to how they created and kept records. All software design/purchase and implementation decisions were left to individual teams. IT staff were then tasked with maintaining these systems. While many teams used paper-based systems, more than half of the teams had also used a "basic" client record software solution (such as a Microsoft Excel or Microsoft Access database). A few teams had purchased more advanced software tailored to their specific needs. The end result was that many different electronic client systems were in use. For example, the Department of Occupational and Sexual Health was using 27 different electronic client systems. Each was a standalone system that was not connected to other systems. The scan also revealed that a few teams were required to maintain Ministry software so client information could be shared provincially. Overall, there were 65 unique electronic client recordkeeping systems in use at GPHU (Exhibit 1). While the scan results identified the broad range of services provided by GPHU, there were several constraints with having many different systems, such as challenges ensuring privacy and security as well as system maintenance.

The internal scan also showed that GPHU had foundational IT issues. GPHU lacked suitable IT infrastructure to implement an EHR across its programs. For example, there was no capacity for staff to have offsite access to GPHU's IT network. However, it was determined that GPHU could address these deficits by continuing to strengthen its IT department. GPHU had made significant investments in IT in recent years, but additional investment was required. Golden had been hired as IT Manager 6 months earlier and the IT department had expanded from four to seven staff. The IT department had also begun updating all GPHU servers, software, and hardware. With this augmented IT team and technology, GPHU was better equipped to implement an EHR, but there were still some foundational issues to be addressed.

### **EXTERNAL SCAN**

The EHR Committee then conducted its external scan. The Committee found that the Ministry would fund EHR implementation in health care settings, but not in public health units (including the GPHU). However, the Ministry's strategic plan (2013) for the Ontario public health sector stated that developing a sector-wide IT and EHR strategy was a priority over the next three years. Despite the Ministry's plan, there was no guarantee that this goal would be realized in a

## Development of an Electronic Health Record Strategy at the Glenburn Public Health Unit

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timely manner or that sufficient investments would be made to cover all EHR implementation costs.

The Ministry's current budget guidelines required any health unit that wanted to procure an EHR system to select one that was "provincially certified." The term provincially certified referred to software that has been evaluated and approved by OntarioMD, which is a joint venture between the Ministry and the Ontario Medical Association created to advance EHR adoption in Ontario. OntarioMD had approved 17 types of EHR software from 10 vendors (2017). However, Ministry budget guidelines also reported that it would not fund EHRs in health units at the time. Through conversations with colleagues at other health units, Ms. Khan found that before these budget guidelines had been determined, some health units had received one-time funding from the Ministry to implement an EHR.

The external scan revealed that, generally, most other health units in Ontario used a mix of Ministry-mandated and program-specific client record software solutions, similar to GPHU. EHRs were most commonly used to support sexual health clinics. The Committee also found that while some health units had complied with the Ministry requirement to purchase a provincially certified EHR, other health units had not. Two health units already used the non-approved IntraHealth software and another health unit was in the process of implementing the IntraHealth program. Two other health units were using the approved docSAFE software for some of their services. One health unit used docSAFE for mental health services and influenza clinics. It also planned to implement docSAFE in its sexual health clinic. The other health unit planned to start using docSAFE in its sexual health clinic soon. The Associate Medical Officer of Health at one of the health units using docSAFE was a vocal advocate of the software, hoping to establish it as the EHR system for many, if not all, Ontario health units. The scan also showed that health units using EHRs had made personnel investments while implementing docSAFE, such as hiring project managers, business analysts, and software developers.

The Committee also connected with its community partners. GPHU partners with many organizations across multiple sectors to deliver its broad range of programs and services. The Committee contacted some of GPHU's key local partners as part of the external scan to assess their experience with EHRs. The scan revealed that GPHU's partners did not use a consistent approach and instead had used multiple strategies and approaches to electronic client documentation and recordkeeping (Exhibit 2). However, two initiatives stood out to the Committee: the *Connecting South West Ontario* (cSWO) initiative and the Association of Ontario Health Centres' (AOHC) sector-wide approach to implementing an EHR.

The cSWO program was a large regional initiative funded by eHealth Ontario (an agency of the Ministry). cSWO aimed to deploy robust, integrated EHR services for health care providers across Southwestern Ontario—namely to hospitals, laboratories, and primary care offices. cSWO enabled access to hospital data for partner organizations and an online portal for clinicians to access hospital and community-based treatment information about their patients. A related component, called Southwest Physicians Interface with Regional EMR's (SPIRE) enabled family physicians to download patient hospital data. Through these services, cSWO allowed health care providers to securely access health information far more quickly than they could using slower methods such as fax, telephone, or mail. Since GPHU is located within Southwestern Ontario, the cSWO leadership team was keen to connect with GPHU about its interest in pursuing an EHR.

The scan also showed that more than 100 community health centres in Ontario had collectively purchased and implemented an EHR. This effort was coordinated by their provincial

## Development of an Electronic Health Record Strategy at the Glenburn Public Health Unit

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association, the AOHC. The Association had a comprehensive IT team that gathered resources and requirements from its member health centres. The AOHC then launched a request-for-proposals process to invite submissions from EHR vendors. The provincially OntarioMD certified Nightingale system was selected and is now being implemented across Ontario. The local health centre that GPHU partnered with reported that participating in a sector-wide implementation was effective because each centre alone lacked the IT skills to purchase/develop and maintain an EHR. However, they reported that it took time for over 100 centres to accept that a sector-wide approach meant every centre may not get its unique EHR needs met.

The Committee also commissioned Dr. Molly Vollmer, a local health system evaluation consultant, to review the literature on EHRs in public health. This was undertaken to ensure the strategy determined by the management team aligned with the best evidence presented and allowed GPHU to benefit from the experience of other health units that have reported their experience with EHR implementation.

### PROGRESS UPDATE

After reviewing the results of the internal and external scans, Ms. Khan and the EHR Committee identified two potentially promising opportunities for GPHU to pursue an EHR as part of a partnership:

- 1. Public Health Sector Partnership.** The health units using docSAFE expressed interest in partnering with GPHU to implement docSAFE and share the significant costs associated with software licensing, maintenance, and development. Although this partnership could support data-sharing within the public health sector, it might constrain GPHU's ability to implement and modify docSAFE according to its specific needs.
- 2. Southwestern Ontario Partnership.** cSWO leadership expressed interest in having GPHU join their initiative. This partnership would focus on local and regional information sharing between GPHU and its health care partners, and it could coincide with the docSAFE partnership since docSAFE was a Ministry-approved system.

Ms. Khan provided the management team with a progress report, including the two partnership opportunities identified. The management team was pleased with the Committee's progress, and they were interested in learning more about the partnership opportunities, especially with the knowledge that the Ministry would not fund an EHR at this time. The team made it clear that funding an EHR implementation initiative would be a significant challenge since it would restrict funding available for other GPHU projects. The management team asked the Committee to engage GPHU staff about the potential of an EHR to assess staff perceptions about the benefits and challenges of implementing an EHR, as well as the service areas of highest need.

### STAFF ENGAGEMENT

Ms. Khan and the Committee organized a staff engagement event to obtain staff input on the EHR strategy. A representative from each of the management, administrative support, and front-line teams was invited to participate. The event included staff rotating through four different activity stations where they were asked specific questions about EHR implementation. This format was chosen to ensure the event was engaging and that information was collected from all attendees on many different topics. The different station formats also allowed staff with different preferences to fully participate (i.e. feedback could be provided at stations via anonymous feedback forms or through the participation in group discussion stations). An online survey was also conducted with participants afterwards.

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Nearly all participants reported a strong interest in having GPHU use an EHR system. Overall, staff felt an EHR would improve GPHU's productivity. They reported a desire to implement an EHR that was fast, reliable, user-friendly, and allowed for remote/offsite access. Participants also stated the importance of having adequate training to accompany the implementation of a new EHR. The participants perceived the benefits of potential EHRs included the following: improved service delivery through facilitating better communication among clients, staff, and GPHU teams; improved tracking of client progress and interactions; improved accuracy in documentation; and improved reporting to support planning and decision-making. Participants additionally perceived some potential negative effects associated with using an EHR system. Some of these consequences included the introduction of new issues (e.g. relating to privacy, data security), the extensive transition period, the creation of rigid client interactions (caused by staff having to type their personal information instead of write on paper forms), and the duplication of data entered into the EHR and Ministry systems.

The engagement event results validated the importance of developing an EHR strategy at GPHU. Teams using paper-based systems reported that they had waited for this opportunity for a long time. Teams using electronic systems were similarly frustrated with the limited capacity of their systems, which hindered service delivery and constrained service improvements. The engagement event also highlighted some important technical considerations of implementing an EHR. Each team had specific needs that a potential EHR system would have to address. Ideally, each team wanted a system that best suited their specific needs; however, this might not be possible if one EHR was implemented across teams. Golden, the IT Manager, noted that the ability to collaborate between teams and analyze data would potentially be gained at the expense of team customization. During the engagement event, the Committee had informed participants that having many systems posed potential challenges for the IT department. This was not known to some staff, who were primarily focused on their team's documentation and recordkeeping needs. Some participants had even suggested implementing more than one EHR system to prevent these IT challenges.

### **STRATEGIES**

Ms. Khan and the Committee reflected on the information they had gathered. Rather than revealing one clear direction or recommendation, the information revealed three key questions for the management team to consider. Each question had important implications for GPHU's budget, programs, and services over the next few years:

#### **1. Should GPHU wait for a provincial strategy or begin down the path towards EHR implementation right now?**

Although implementing an EHR in all health units was a Ministry priority, it was unclear how long the provincial EHR strategy would take to develop, and whether it would support EHR implementation and maintenance costs. Considering this uncertainty, and the impact of the potential delay (i.e., suboptimal service delivery, collaboration, and recordkeeping), was it acceptable for GPHU to wait? On the other hand, self-funding an EHR system would likely mean reductions to funding for other programs and services.

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- 2. If GPHU decides to implement an EHR now, should it use one EHR for all teams, several different EHR systems, or as many different EHRs as required to meet specific team needs?**

All teams want an EHR, but they want a system that best suits their unique needs. One EHR system would be ideal for the IT group, but it would not meet the needs of all other teams. Conversely, having many different EHRs would be ideal for some teams but would be more difficult for IT to support.

- 3. If GPHU decides to use one or more EHR systems, should it implement an EHR on its own to meet its specific needs or undertake the endeavor as part of a partnership?**

Independent implementation of an EHR would provide GPHU with total flexibility, but it would limit the ability for cost sharing and local/sector integration. Conversely, if GPHU established a partnership, there would be financial benefits but less flexibility and ability for customization.

### **PRESENTATION TO THE MANAGEMENT TEAM**

Ms. Khan and Mr. Golden presented their report, including the key questions, to the management team. There was no clear path forward since no funding sources were identified. While GPHU staff supported EHR adoption, staff were divided over whether one system or many systems should be pursued. The management team discussed the information presented by the Committee. The team was discouraged that the Ministry was no longer supporting EHR costs, but they were pleased to learn that GPHU had options, both in terms of EHR system type and implementation approach (i.e., alone or via a partnership). The management team was also pleased to learn that some health units had progressed further than GPHU on EHR implementation and GPHU could learn from their experiences. It was now time for the management team to determine an EHR strategy for GPHU.

### **CONCLUSION**

As of August 2017, months had passed, and GPHU had still not implemented an EHR system. The management team decided to wait for either the provincial strategy to be developed or for another funding source to be identified. Unfortunately, the Ministry has not yet announced its EHR strategy for Ontario health units and it appears many units are in a similar position to GPHU. The cSWO initiative has continued to develop and now includes 74 local hospitals and 44,241 health care providers (2018). Similarly, the docSAFE EHR system continues to be promoted by some health units as the best option for client documentation and recordkeeping.

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**EXHIBIT 1**

**Results of an Internal Scan of Glenburn Public Health Unit  
Electronic Documentation/Recordkeeping Systems**

<b>GPHU Department</b>	<b>Documentation/ Recordkeeping System</b>	<b>Type</b>	<b>Number of Electronic Systems</b>
Occupational and Sexual Health	Client/Server	Vendor Product	9
	MS Access	Custom (GPHU created)	7
	MS Excel	Custom (GPHU created)	2
	Online	Custom (developer created)	5
	Online	Ministry Mandated	4
Disease and Disaster Prevention	Client/Server	Ministry Mandated	1
	MS Access	Custom (developer created)	1
	MS Access	Custom (GPHU created)	2
	Other Database	Vendor Product	3
	MS Excel	Custom (GPHU created)	4
	MS Word	Custom (GPHU created)	2
	Online	Custom (developer created)	3
Epidemiology, Children's Services and Healthy Public Policy	Client/Server	Custom (developer created)	2
	Client/Server	Ministry Mandated	1
	Client/Server	Vendor Product	2
	MS Access	Custom (developer created)	3
	Other Database	Ministry Mandated	3
	Other Database	Vendor Product	8
	Online	Custom (developer created)	2
	Online	Ministry Mandated	1
<b>Total</b>			<b>65</b>

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**EXHIBIT 2**

**Key Glenburn Public Health Unit Partner–Client Documentation/Recordkeeping Systems**

<b>Partner</b>	<b>Description</b>
Ontario Community Health Centres	Recently completed a sector-wide electronic health record (EHR) procurement process coordinated by their association (which included approximately 100 member organizations such as Community Health Centres, Aboriginal Health Access Centres, and Community Family Health Teams) (n.d.). This resulted in a contract to use OntarioMD-approved Nightingale software.
Family Physicians	Incentivized to purchase an OntarioMD-approved EHR using OntarioMD funding. More than 6,000 physician offices are being funded. Health units are not eligible for this funding.
Nurse Practitioner Clinics	Incentivized similar to family physicians, but the program is administered by the Ministry.
Local Hospitals	Have moved toward EHRs, but also use paper records. Hospitals in Southwestern Ontario connect with laboratory and other provincial systems via the regional <i>Connecting South West Ontario</i> program (2015) funded by eHealth Ontario, as part of <i>Ontario's eHealth Blueprint</i> strategy (2014).
Community Care Access Centres	Have a robust electronic documentation and recordkeeping system that monitors payments to contracted service providers and monitors key client outcomes, not client health status.
Glenburn Police	Have a robust electronic documentation and recordkeeping system that is developed specifically for policing purposes (including remote access, personnel identification, and risk assessment supports).
Local Children's Aid Society	Use both electronic and paper recordkeeping (practitioners can choose preferred documentation method). Their software was developed specifically for Children's Aid Societies, but does not communicate between organizations. Their current focus is digitally scanning paper records.

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## INSTRUCTOR GUIDANCE

### Development of an Electronic Health Record Strategy at the Glenburn Public Health Unit

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#### BACKGROUND

Medical or electronic health records (EHR) are electronic databases that capture an individual's health and care history throughout their life. EHRs are often used as a single repository of patient information that is shared among multiple health care providers (such as hospitals, laboratories, and family physicians). The Ontario Ministry of Health and Long-Term Care requires all EHR systems in public health units be provincially certified; however, their budget does not provide units with the necessary funding for EHR implementation. The Glenburn Public Health Unit (GPHU) is conducting a review of their recordkeeping practices and has identified a need to streamline their methods for client documentation. There are currently inconsistencies across the unit's many health teams that result in communication, logistical, and technical issues with respect to document storage and delivery. To address these issues, GPHU must develop an EHR strategy that seeks to improve current recordkeeping practices and, as a result, improves client service delivery.

#### OBJECTIVES

1. Define key goals and/or objectives for an EHR strategy.
2. Analyze the benefits and challenges of EHR implementation in regard to partnerships and the use of single or multiple EHR systems.
3. Recommend the most effective EHR strategy in this case using the information provided and course tools and theories.
4. Document the complexities, challenges, and implementation considerations senior leaders should understand about EHR systems.

#### DISCUSSION QUESTIONS

1. What are some benefits associated with EHRs?
  - a. Which stakeholders benefit the most? Does anyone suffer from EHR use?
  - b. Are there any risks associated with EHRs for public health units?
2. What are the benefits and challenges associated with implementing a single EHR system versus multiple EHR systems in a public health unit?
  - a. How can the challenges associated with the use of single and/or multiple EHR systems be overcome?
  - b. Which stakeholders benefit the most from which approach? Why?
  - c. Do clients have different perspectives about the benefits and challenges of EHR use? If so, how?

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3. Compare and contrast the advantages and disadvantages associated with implementing EHRs as part of a partnership versus a lone venture.
  - a. Which stakeholders benefit the most from which approach? Why?
  - b. Do the benefits and challenges differ from the perspective of a client? If so, how?
4. What theories or models may be applied to develop an effective EHR strategy?
5. How might EHRs enhance collaboration within a single health unit and across networks of multiple public health units?
  - a. How may this further benefit overall population health and client care?
  - b. Are there associated risks? Why or why not?

### **KEYWORDS**

Electronic health record; electronic medical record; environmental scan; patient documentation; public health; strategy; information technology