

# Western Public Health Casebook 2016

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

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## FOREWORD

As Canada's Chief Public Health Officer, I am delighted to introduce the 2016 edition of the ***Western Public Health Casebook***. As a collection of students' practical experiences, this casebook is a valuable educational resource.

I am proud and honoured to acknowledge the leadership that the Schulich Interfaculty Program in Public Health has demonstrated in furthering public health education. Public health relies on our organized efforts across many disciplines to effectively respond to outbreaks, keep people healthy and prevent injury, illness and premature death. In that same spirit of public health, the case-based approach to learning combined with the collective dedication to share this casebook broadly, is a truly innovative approach. This casebook will benefit many and contribute in a tangible way to building Canadian capacity in public health.

Leaders recognize the importance of collaboration and information sharing in reaching common goals. Those who are being trained and mentored today across Canada will lead the public health workforce of the future, not only in our country, but around the world.

I congratulate all of those who have completed and contributed to this program, and am looking forward to hearing about the future contributions and accomplishments that are sure to come from its graduates.

– ***Dr. Greg Taylor, Chief Public Health Officer of Canada***  
***Public Health Agency of Canada***



# 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. In addition to didactic courses, the MPH program curriculum includes innovations such as 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 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 compared to other MPH Programs worldwide. The case method of learning is not about the traditional lecture-style classroom setting. It 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. The case method 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, there is a paucity of suitable public health cases to use for this purpose. 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 and the issues faced. Case repositories have few teaching cases that can be used in a public health program, creating an opportunity for Western's faculty and practitioner colleagues to develop de novo cases for their courses by building on their research and practice experiences.

Along with faculty developing 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, the overall final deliverable for students (the culminating experience) is a teaching case and teaching note that is based on their practicum experience. 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.

## INTEGRATIVE WORKSHOPS

Three times a year, we schedule a full day ***Integrative Workshop***. The objective of these workshops is to pause to reflect on the past six to eight weeks, and to integrate and synthesize interdisciplinary knowledge and practices learned in the various courses. The workshops model a real public health issue facing the community, with student teams having to make decisions under time pressure, often with imperfect information, and present and justify these decisions to

experts. Topics are chosen to complement rather than duplicate the materials being used in the courses, and reflect the expanded expertise available on campus beyond the course faculty members as well as practice experts and community members. This is a team exercise, where students apply the materials and insights from their courses (in addition to the presentations by experts at the workshop) to answer the question(s) posed. Deliverables vary with the integrative workshop and may include short reports, presentations to a panel of experts, letters to the editor, blog postings or policy briefs.

### **WESTERN PUBLIC HEALTH CASEBOOK 2016**

It is my pleasure to welcome you to this year's ***Western Public Health Casebook***. Herein you will find teaching cases authored by students, a selection of cases authored by faculty members, and summaries of the integrative workshops that were held in 2014/15. Cases are also available for download at <https://www.schulich.uwo.ca/publichealth/cases/index.html>. 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

As the founding director of the Schulich Interfaculty Program in Public Health, Dr. Abdur Rab noted, “Our society needs individuals who are equipped with knowledge and skills to address public health challenges across Canada and beyond”<sup>1</sup>. The ***Western Public Health Casebook*** is one vehicle to support this aim. The efforts of a team of students, faculty, staff, community members and public health organizations came together in the production of this casebook.

We would like to express our gratitude to the following organizations (and the preceptors) who supported the training of our students and the development of the cases in this casebook: Middlesex-London Health Unit; Ontario Public Health Association; Northwest Territories Department of Health and Social Services; Public Health Agency of Canada; University of Ghana - School of Public Health (Kintampo Health Research Centre); Centre for Addiction and Mental Health; and, South West Regional Cancer Program (London Health Sciences Centre).

In particular, we thank Dr. Greg Taylor, Chief Public Health Officer of Canada, and Dr. Sudit Ranade, Medical Officer of Health for Lambton Health, for their important insights contained herein. We appreciate the significant efforts of the MPH staff in producing this casebook, and the faculty of the MPH program in honing its content. We warmly thank our student case authors - members of the MPH Class of 2015!

– ***Amanda Terry and Ava John-Baptiste***

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<sup>1</sup><https://www.youtube.com/watch?v=tSGZlpn9osU&feature=youtu.be&list=PLA0E847DD01B0FA01>



# **INTRODUCTION TO THE CASEBOOK**



## INTRODUCTION

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*Sudit Ranade MD, MPH, MBA, CCFP, FRCPC  
Medical Officer of Health  
County of Lambton | Lambton Public Health*

The use of cases and "real-life" problems to illustrate concepts to students has a long history in health sciences. There are many variations, including case-based learning and problem-based learning (PBL) that are grounded in pedagogical theories. Of the use of PBL in public health training, Trevena says that public health practice "involves considerable problem solving [and] usually involves working within groups and with numerous stakeholders" (p.6). Therefore, public health practitioners "need to be able to obtain and synthesize information from external sources and to apply this to the problems, projects or circumstances before them. Yet, the use of PBL in public health is largely uncharted territory" (p.6). The goal of incorporating cases in the MPH curriculum is to illustrate the application of knowledge and theory in public health practice and to generate an opportunity for students to pose and answer their own questions about an issue. In this program, MPH student cases emerge from student practicum placements, and are authored in collaboration with practicum preceptors. In Canada, the use of cases as a teaching method in graduate public health training is a novel addition to the standard curriculum. Although case-based learning in public health holds a tremendous amount of promise, its impact on students requires an evaluation similar to what has been performed in medical education with regards to PBL. For example, student performance on standardized tests, public health core competencies, or other indicators of knowledge and skill could be used to compare groups of students who trained with and without the use of cases. Also, qualitative interviews with employers and students could provide additional information to improve our understanding of the effects of case-based learning in public health graduate curricula.

In business schools with a history of case development and teaching, the use of cases in the curriculum acts as an interface between academia and practitioners. Teams of students will build a case around one or more issues in conjunction with a practitioner and an academic, to ensure that the structure and content of the case is relevant to practice and has construct validity as well as face validity. Both the creation of a case and its subsequent use are exercises that generate learning and enable reflection.

Cases can be used as a tool to bridge the theory of public health and its practice. Case-based learning in medicine and public health currently follows a unidirectional model. That is, the case is viewed as a mechanism connecting theory to practice. In its simplest form, discussion about a case is centred on the application of one or more theories to the practice of public health. A scenario describing a negative outcome can be viewed through the lens of theory to identify critical points at which different actions could have been taken to ensure success. Cases can also be used to compare and contrast different approaches to public health practice. For example, a case illustration of different governance models in public health might enable students to understand the strengths and challenges of each, and therefore to be effective practitioners within either model of governance. Looking to the future of case-based learning in public health, ***I believe a more comprehensive approach to using cases is to consider their potential as a bidirectional link between theory and practice and back to theory from practice.*** Cases can be used not just to apply theory but also to inform the development of new theories, based on a synthesis of observations in "the field" of practice. This is one reason why

## Introduction

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the use of MPH practicum placements to drive the content of student-generated cases is so exciting and so promising!

In this edition of the ***Western Public Health Casebook***, students have presented a range of relevant problems from "How can rural families in Ghana cook staple food without exposing themselves to harmful combustion products?" to "How should we involve families in the care of patients with mental illness in Ontario?" These problems expose students to real-life complexity and the challenges of arriving at a public health solution that is feasible, socially acceptable, and effective. Bringing these cases back into the curriculum enables current students from diverse professional and cultural backgrounds to consider multiple perspectives while working through the problem with their peers. Hopefully, these cases will also generate ideas for new theories about how public health should work. Helping to solve these problems is a shared goal of both current and future public health leaders, and using real-life examples to refine our students' thinking about public health issues may bring us one step closer to a safer, healthier world for all.

## REFERENCES

1. Trevena, L. (2007). Problem-based learning in public health workforce training: a discussion of educational principles and evidence. *NSW Public Health Bulletin* 18(1-2): 4-8. Retrieved May 5, 2016 from <http://www.health.nsw.gov.au/phb/Documents/2007-1-2.pdf>

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I sincerely thank Giovanna Longo, MPH Class of 2014, for her review and for her thoughtful comments.

# CASES



## CASE 1

## The Fire Under the Shed: The Cornerstone Fuelling Our Plight

*Omolola Oyinkan Adeshina, BSc, MPH (MPH Class of 2015)*  
*Kwaku Poku Asante, MD, MPH, PhD (Head of Research, Kintampo Health Research Centre)*  
*Ava John-Baptiste, PhD (Assistant Professor, Western University)*

*"We must put in the measures now, so we can create a clean, healthy environment where health is no longer dependent only on drugs or vaccines, [where] we eat well, we breathe well, and we reduce pollutants in our agricultural products."*

Sherry Ayithey, Former Ghanaian Minister of Health

The international community, in 2010, undertook a global initiative to save lives and protect the environment from the effects of biomass fuels. The goal was to affect 100 million households by distributing clean cook stoves by 2020 (GACC, 2014). Partnerships were formed under the umbrella of the Global Alliance for Clean Cook stoves (GACC) in 2010. Organizations in the GACC include but are not limited to public-private partners, non-governmental organizations (NGOs), community-based organizations, and women's cooperatives (GACC, 2014).

### AIR POLLUTION

Air pollution from biomass combustion is responsible for approximately 3.1 million deaths annually and 3.2% of the global burden of disease due to acute respiratory infections (ARI) (WHO, 2010). In sub-Saharan Africa (SSA), cooking with biomass fuel is widespread. Approximately 1.1 billion people rely on traditional cook stoves (GACC, 2011). Pollutants from these cook stoves lead to adverse health effects including ischaemic heart disease, chronic obstructive pulmonary disease (COPD), and pneumonia (WHO, 2015b).

Acute Lower Respiratory Infections (ALRI) include diseases such as pneumonia, acute bronchitis, bronchiolitis, influenza, and whooping cough. ALRI are among the leading causes of premature deaths in children under age five in developing countries (GAHP, 2012). ALRI are responsible for three times more deaths than malaria, HIV/AIDS, and measles combined (GACC, 2011). Hence, combating ALRI warrants the same attention given to combatting these diseases but the focus on ALRI has thus far been inadequate. In Ghana for instance, lower respiratory tract infections remain the leading cause of death in children under five (WHO, 2015a) though efforts have been made by the World Health Organization (WHO) and the Ministry of Health to mitigate the problem.

In May 2015, Akosua Agborson began her work as a research fellow at the Kintampo Health Research Centre (KHRC), Ghana. Akosua was a recent graduate who had earned her Master of Public Health degree in Canada and was returning to her native Ghana. During her interview for the position, she had told the KHRC director that the accomplishment of earning a Master's degree would not be complete without fulfilling her goal of helping fellow Ghanaians improve their health and quality of life. The KHRC is one of three research centres of the Ghana Health

Services within the Ministry of Health in Ghana. The Centre conducts research studies that influence health policies in the country. Located in Kintampo Municipality (North and South Districts) in the Brong Ahafo Region in the center of Ghana (see Exhibit 1), the KHRC is one of Africa's demographic surveillance systems for health. KHRC collaborates with several in-country and international institutions, including Navrongo Health Research Centre, the London School of Hygiene and Tropical Medicine (LSHTM), and Columbia University.

Akosua joined a team of KHRC researchers dedicated to reducing the burden of disease from biomass fuel known as the Ghana Randomized Air Pollution and Health Study (GRAPHs). GRAPHs conducted a number of research projects focused on measuring air pollution amongst individuals living in households. On arrival, Akosua consulted with researchers about issues of traditional cook stoves and possible solutions for the problem. Although the GRAPHs' core focus is on reducing air pollution in households, less focus has been placed on monitoring and intervention for those participating in industries with high levels of air pollution. The team was keen on expanding the research focus to include pollution from industrial activities.

The Millennium Development Goals (MDG) specified by the United Nations focused on empowerment of women, gender equality, reducing child mortality, and improving maternal health. The women who would become the focus of Akosua's study had achieved a measure of empowerment through their involvement in the gari industry, but it was this very industry that exposed them and their children to harmful pollutants. Speaking with the workers and gauging knowledge levels would provide a basis for KHRC to design effective interventions to improve the workers' health.

### BIOMASS FUELS

The biomass fuels (wood, charcoal, and animal dung) that are used in traditional cook stoves generally do not undergo complete combustion. They emit smoke, other particulate matter, and gases that have adverse health effects (Kim, Jahan, & Kabir, 2011). In addition, biomass fuels cause reduced birth weight and stillbirths in pregnant women (WHO, 2011). The environmental effects are significant. Smoke from the burning of biomass fuels affects the ozone layer (Patrick, Murray, Sullivan, & Kimmell, 2015), destroys the natural flora, and leads to climate change (WHO, 2011).

Advances in technology have made clean cook stoves affordable and readily available in high-income countries. However, in developing countries, many individuals still use biomass cook stoves (3-stone, charcoal, wood, and others). In Ghana, use of biomass fuel is prevalent among households of low socioeconomic status (SES) (Chakraborty, Mondal, & Datta, 2014). Many cannot afford cook stoves with other fuel types such as liquified petroleum gas (LPG) or electricity. Women involved in commercial activities, such as food processing, face additional challenges in obtaining clean cook stoves due to the cost of the cook stoves and the price of the fuel (Zhou et al., 2011). In comparison, traditional cook stoves can be constructed using readily available materials, at a very low cost, allowing the women to maintain profits.

### PROCESSED CASSAVA (MANIOC) (GARI)

Cassava (manioc) is the most common orphan crop grown in developing countries, and is the most common crop in sub-Saharan Africa (SSA) (Varshney et al., 2012). Cassava can grow in a variety of ecological zones, and is a staple in SSA, Asia, Latin America, and the Caribbean (Okogbenin et al., 2013). Cassava crops have contributed to food security in SSA due to the crops' resilience. When mature, the crops are harvested, peeled manually, and grated with a machine. The grated cassava is bagged in sacks, stacked, allowed to ferment, and pressed with a hydraulic press to extract the starchy water. After the extraction, the compressed grated

cassava is sifted and put in sunken metal sheets (pans) on the biomass fuel cook stove in portions and fried, stirring constantly until a consistent grainy textured product called gari (cassava grits) is produced. Ghana is among the top 10 producers of cassava in the world, with gari production being one of the easiest ways for individuals to earn money from cassava. Production of gari in rural communities represents close to 40% of the gari industry in Ghana (Angelucci, 2013). In fact, many pay a premium for gari that comes from rural communities in Ghana, based on the widespread belief that gari tastes better when prepared on a traditional stove.

Akosua and the GRAPHS team decided that a qualitative research study would be optimal. This would be the first attempt at conducting qualitative research with women involved in gari production. The goal of Akosua's research project was to assess awareness of the adverse effects of smoke on the health of the women whose commercial activities involve biomass fuel use.

The GRAPHS team selected Ntankro, a community in the Kintampo South District. The KHRC collaborates with Ntankro to undertake research on household air pollution. Gari processing is the most common industrial activity for women living in Ntankro, with approximately 90% of the community involved in gari processing. In the gari industry, there are full-time fryers and casual fryers. The casual fryers engage in gari frying on an as-needed basis. For instance, if individuals need immediate funds, they can decide to do the gari frying for three to four days. Full-time fryers work for five days a week and approximately 13 hours each day. Gari is processed in large quantities, and transported semi-weekly to other parts of Ghana, West Africa, and SSA countries. In Ntankro, approximately 75% of women are casual fryers and the remaining work full-time in the industry (Owusu-Agyei et al., 2012). The source of fuel for this activity is firewood, and essentially all rural households in the area cook with firewood.

Akosua reflected on her own personal relationship to gari. In recalling her childhood memories, she could close her eyes and conjure up the smell of gari being cooked on a traditional stove by her mother and grandmother. She could feel the warmth of gathering with family members, the safety of being in her household, and the joy of sharing food. Perhaps better than any non-Ghanaian could, Akosua understood first hand why the notion that being involved in the production of gari, a treasured food, could be difficult for the women to view as harmful. Also, Akosua would have to agree with the general consensus that gari cooked on a traditional stove tasted better than gari from a factory that was cooked on a modern stove. However, the health of these women, their children, and the community, was more important than the taste of the gari.

Although KHRC had previously been engaged with Ntankro, Akosua met three community leaders two weeks prior to the start of her research in order to gain entry into the community. In addition, she went to a government officer in the district, who is responsible for ensuring the community residents have good air quality and access to clean water that is safe from any other environmental pollutants.

After gaining entry into the community, Akosua introduced herself to the commercial gari processors. The women allowed Akosua to watch the gari processing from start to finish. She observed the five stages: cassava peeling, grating, extraction of the starch, sifting of the dough, and frying. For frying, the women had constructed traditional cook stoves in the middle of a shed. Three to four women occupied one such open shed covered by aluminum roofing sheets. The shed was poorly ventilated. The women stood continuously to stir the gari around the pan with wooden spatulas for approximately 13 hours. To further understand the harmful effects of

the smoke on these women, Akosua approached the gari processors in the community in order to ask questions.

Akosua learned through speaking with the women of Ntankro that commercial gari processors were concerned about two problems in addition to the smoke from the biomass fuel. These were the heat from the fire, and the improper waste disposal from the commercial activities (Adetifa & Samuel, 2012). Firstly, the heat from the fire often led to heat stress for the women. For example, normal body temperature is 37 degrees Celsius, but the surface of the gari frying cook stove is approximately 250 degrees Celsius as observed by Ikechukwu & Maduabum, et al. (2012). The temperature of the cook stoves increased the body temperature of gari processors.

Asabe, a 32-year-old gari processor with six years of experience, said: “When the smoke enters your eyes especially on your first day in the gari business, your eyes will be paining you in the night. You cannot sleep and your body will feel hot.”

Secondly, the gari processors had no means for proper disposal of the cassava peels and the eluates from the grated cassava leaked into the ground. The peels were left on the ground for days until livestock farmers collected them as feed. The peels release hydrogen cyanide (HCN), a toxic chemical, when being processed into gari. HCN has adverse effects on both the gari processors and the environment (Adenugba & John, 2014). Symptoms of HCN exposure include, but are not limited to, headache, weakness, chest pains, and cardiovascular diseases (Dhas, Chitra, Jayakumar, & Mary, 2011).

### THE BURDEN OF TRADITIONAL COOK STOVES

During the course of the research, Akosua met with the government officer in the district. He detailed the strategies that had been put in place to enable gari processors to switch from traditional cook stoves to improved cook stoves. In collaboration with the Business Advisory Centre (BAC), the organization responsible for developing small scale businesses or commercial activities and improving the health of individuals involved in the commercial activities, Dr. Frimpong organised workshops for the women in order to teach them about the harms of traditional cook stoves.

According to Dr. Frimpong, the gari processors had insufficient funds to purchase LPGs on their own. To assist with purchasing improved stoves, the BAC linked gari processors to micro finance organizations such as the Brong Ahafo Catholic Cooperative for Social Development (BACCSOD) for loans. With the help of BAC, the gari processors formed cooperative business groups that were then able to open accounts at BACCSOD and access loans for the purchase of the LPGs. The BAC initiative had resulted in 25% of women in the industry purchasing clean cook stoves. Akosua focused her discussions on women who had not yet taken advantage of the BAC funds in order to get a good understanding of the barriers these women faced.

After Akosua’s meeting with Dr. Frimpong, she conducted two focus groups, the first group with 10 women and the second group with seven women. She also conducted in-depth interviews with six of the women to hear more about their experiences in gari processing. Through these interviews, she learned that purchasing the stoves was not the only financial barrier the women faced.

Matilda, a 50-year-old gari processor with 30 years of experience, said: “We use firewood because it produces greater heat compared to charcoal. We need heat and charcoal cannot produce that heat so most women prefer to use firewood. Besides, when we use charcoal, the

## The Fire Under the Shed: The Cornerstone Fuelling Our Plight

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quantity and quality of the gari would be different. For instance, a bag of charcoal cannot even fry a half bag of gari. We could have used gas but we do not have money for it.”

Matilda lived in Ntankro for 50 years. She claimed gas stoves were unaffordable. However, she could afford to purchase the stoves through BACCSOD. The BAC could assist her if she joined a gari processor group in the community. There were similar statements made by other gari processors in a group discussion.

Nana, a 40-year-old gari processor with five years of experience, said: “The work we do, if not the firewood, nothing can be used to fry the gari. Because if you look at the frying pan we use, it cannot be used on any other stove to fry gari. Therefore if we change the fuel, the frying pan has to also change.”

Firewood and charcoal are the two fuel types mainly used in Ntankro. From discussions with Matilda and Nana, they seemed more knowledgeable about the firewood than LPG or electricity for gari processing. After speaking with the two women, Akosua went on to further inspect the traditional cook stove. She noticed the size of the pile of firewood that was stacked in the moulded space dedicated to burning wood inside of the stove. The gari processors used large pieces of firewood rather than chopping the logs into pieces because the smaller sized firewood burned too fast. The women typically fed three large logs of firewood into the burner instead of chopping the firewood to fit the space. They preferred to use the large logs because they could fry approximately four trays of gari and limit the number of times they went to fetch firewood. The smaller sized firewood, which burned faster, could only be used to fry one or two trays at a time (see Exhibit 2).

The women also believed the problem was the size of the pan, because they could not use the pan on a LPG stove. But Akosua had different opinions; the size of the pan or the stove was not the problem but it was the moulded space in the stove where the firewood was stacked. The pan was so small that the large logs could not fit under the pans. If the women were willing to chop the firewood into small pieces, the pan size would not be an issue. The women perceived firewood for the traditional cook stove to burn faster than fuel for clean cook stoves. Responses from the gari processors showed reluctance to move away from sources of fuel they were familiar with in order to use alternative fuels in the LPG cook stove. The women’s decisions were driven by efficiency in producing gari. Moving to LPG stoves would increase their costs, lower productivity, and decrease profits.

Firewood is cost-effective for the women but it is also harmful to their health. Most gari processors opt for firewood because they cannot afford LPGs. Although BAC can assist the women with the LPGs, they would rather weigh the quantity and quality of gari from using firewood to the cost of LPGs. The same day, when Akosua was leaving the community, she saw women walking towards the community carrying stacks of firewood. She wondered about the distance the women travelled to fetch the firewood because some said ‘good’ firewood would determine the volume of smoke emitted. Akosua asked some gari processors to confirm if ‘good’ firewood can be used to control the smoke emitted.

One of the respondents, Asabe, suggested: “What you can do to control the amount of smoke is to use a good fire wood. If you do not get a good fire wood then there will be smoke by all means.”

Asabe believed the quality of wood determined the amount of smoke emitted. So it was vital to spend time searching for ‘good’ firewood. Furthermore, the process of stacking the firewood in

the cook stoves was arduous to the women making the gari. Some gari processors – Rachael and Esi – had contrary views compared to those who assumed no alternative fuel could be used.

Rachael, a 20-year-old gari processor with four years of experience, said: “With the firewood, it is even difficult to set the fire. The firewoods are big. By the time you roll the firewood into the stove you will be tired. So if we would have the strength to use the gas stove, it will be easy for us.”

Esi, a 40-year-old gari processor with 20 years of experience, said: “If we use a gas stove there will be no smoke to disturb us, and we will be comfortable.”

Gari processing is laborious for the women. Akosua observed the gari production activities beginning in the early hours of the morning and ending in the late afternoon. Observing the women, Akosua saw how time consuming the entire process was; the time spent on fetching firewood, peeling and grating the cassava, extracting the starch, sifting the dough through a straw sieve, and finally frying the gari. Moreover, endless fetching of firewood for traditional cook stoves leads to depletion of the resources (Kuunibe, Issahaku, & Nkegbe, 2013). Even though the firewood is available at no cost to the women, depletion of the firewood has long-term consequences, impacting the sustainability of the community. Fetching the firewood also took time, and she wondered if the women could be convinced that alternative fuels have the benefit of saving them the time involved in fetching firewood.

### PERCEPTIONS OF RESPONDENTS ON AIR POLLUTION

The activities of the gari processors in Ntankro resulted in air pollution from the use of biomass fuel (GAHP, 2012) and the pungent smell emitted from undisposed cassava peels when it rains (Okunade & Adekalu, 2013). On two occasions in the field, Akosua experienced the pungent smell following the rain. She spoke to the government officer about it. He said:

“The pollutants, the way they dispose of the waste is not proper. They said people take the cassava waste to feed their animals. I told them that, it’s not good because if people don’t come then the waste will just be there. I have asked them to get someone to clear it cause it can accumulate and lead to a big problem.”

The cook stoves used in the gari processing industry lead to negative health effects on those who use them for their commercial activities and would probably alter the ecological system of the environment (Jeuland & Pattanayak, 2012). Yet, gari processors were unaware of the effects the smoke has on the environment. Gari processors associated the polluted air to dust in the area, refuse dumps, nearby toilets, and not the smoke emitted from the cook stoves. They did not think the smoke from the industry was contributing to the air pollution. Of the 17 women Akosua spoke to, only four attributed air pollutants to the fuel wood. Rather, they linked the destruction of household structures and items, such as roofing sheets, to the smoke.

Matilda, a 50-year-old gari processor with 30 years of experience, said, “The smoke can darken the roofing sheets. It can destroy it. Also, the smoke can destroy the grasses that are used to roof some of the houses. When it enters your room, it can discolour all your clothes.”

Matilda had been in the business for 30 years but did not believe the smoke emitted from the cook stoves polluted the air. Akosua had only been going to Ntankro for a week but she was unsettled by the air quality. The air quality around households was similar to the gari processing areas. There was no difference in air quality because households were surrounded by gari

frying sheds. However, Afua, a 40-year-old gari processor with 20 years of experience, agreed. She understood, “Smoke can also pollute the air”.

She was aware the smoke from the fuel wood was affecting the air quality in the community. The disparity between some gari processors and community leaders surprised Akosua. Community leaders such as Dr. Frimpong were not the main recipients of the smoke but knew the difference between clean air and polluted air. The gari processors were the main recipients but did not consider the air to be polluted.

### **PERCEPTIONS OF RESPONDENTS ON THE HEALTH IMPACTS OF SMOKE INHALATION**

With increasing age, exposure to biomass combustion conditions, such as lung cancer, asthma, cataracts, and tuberculosis may arise with increased atmospheric particulate matters and carbon monoxide (Alim et al., 2014). Akosua approached two gari processors under their shed – Adzoa and Yawo – and asked them for their opinions on the health effects associated with gari frying. But after greetings were exchanged, Akosua felt her eyes smarting. That could only be explained by the smoke emitted from the stove. If she could not endure the burning, she wondered what the women could be experiencing.

In Akosua’s discussions, Adzoa, a 34-year-old gari processor with five years of experience said, “When the smoke enters you as you fry the gari, you can get chest pains and a cough.”

Yawo, a 30-year-old gari processor with 10 years of experience said, “When you stand in the smoke for a long time, your heart will palpitate, and if you do not drink water it will feel like your heart is failing. Therefore, when the smoke enters you, you have to drink water to cool your heart.”

Similarly, the smoke from the firewood directly affects not only the gari processors but also their young children because they also stay by the cook stoves and are particularly susceptible to ALRI (Rodríguez-Martínez, Rodríguez, & Nino, 2015). During discussions with Adzoa and Yawo, Akosua observed young children sleeping or playing right next to the cook stoves. She pondered the effects of the smoke on the children. Fortunately, Adzoa, a 34-year-old gari processor with five years of experience, was willing to discuss this further with her, “It can give a child fever, diarrheal. Also, when the breast gets too warm and the child is breastfed with it, he or she can get fever or cough.”

Akosua asked Adzoa to explain further the relationship between the breast milk and the smoke. Adzoa was unable to explain further and refuted her statements about chest pains and fever. She claimed not to notice any differences in her health nor the childrens’. Thus, she continued taking the children to the gari frying shed. Due to Adzoa’s conflicting responses, Akosua spoke with other breast-feeding mothers who had expressed similar views. These women believed the chemical processes of the breast milk changed during gari frying.

Akosua asked Nana, a 40-year-old gari processor with 5 years of experience, the reasons for taking the children along with them. She said: “Normally, the child is not that affected by the smoke because they stay here for a very short time, however the children sometimes experience a common sickness – fever and malaria.”

Nana seemed perplexed about the illnesses the children experienced because she made contradicting statements. She claimed gari processors experience a common sickness but both women maintained the children were not affected. From the responses, both women were less

knowledgeable on the harmful effects of the fuel wood. They did not know the causes of some of the symptoms but associated them with the heat from the cook stove.

Although some children were either sleeping or playing around the cook stoves, the gari processors did nothing to protect them from the smoke. They continued to take the children to the gari frying shed. This contradicted their assertions that the warm breast milk can cause fever, diarrhea, or cough. If they believed the children were susceptible to these three symptoms, Akosua thought they should stop taking the children with them.

Akosua pondered if a free day care centre would be beneficial to these women, because they expressed concerns of not having someone in the community to babysit. If the women could get attendants to take care of their children while they were at the gari processing site, their children would probably be less exposed to the fumes from the fuel wood. The women would only have to attend to the children to breastfeed. Conversely, one of the community leaders said:

“However, if the women carry their children with them nothing can be done. Mostly, they do that depending on their relationship with their husbands. Because it is a problem even if you go alone to fry the gari or you go with a child.”

The community leader suggested that husbands might not want the women to go alone to do the gari frying, but they might also not appreciate their children being exposed to the smoke. Akosua wondered what would result from communicating the harmful effects of commercial smoke exposure to the men in the community. In addition, some gari processors were pregnant and standing in close proximity to these cook stoves but were unaware of the harmful effects from the smoke on the foetus (Kelly et al., 2011). They continued working until a few days before delivery (see Exhibit 2).

In their defence, Araba, a 40-year-old gari processor with 10 years of experience said, “I think that if there are any effects, doctors are the right people to inform us because even if your child has any problem as a result of the smoke, you would not be able to tell unless a doctor complains to you. But we have never heard anything like that before.”

Araba was one of the gari processors who did not believe the smoke from the firewood could have an effect on the foetus. The gari processors valued and respected the doctor’s opinion so they would not stop gari frying when pregnant unless recommended by doctors. Akosua wondered if the power of the doctor’s opinion could be used to full effect. It seemed that if doctors informed the women about the harms to the foetus, they might discontinue the use of the cook stove until after delivery. Perhaps KHRC could involve the doctor in health promotion visits to Ntankro. There were others who disagreed with the views of these women. Some gari processors acknowledged health risks from using the cook stove. Adzoa was nine months pregnant and discontinued gari frying during her pregnancy.

The perceptions of gari processors differed on the health effects associated with the traditional cook stoves. There were gari processors who were aware of the health effects from inhaling the smoke while some others were unaware. The next phase of the GRAPHS team project was to measure the levels of smoke exposure among the women. Real time personal exposures were monitored at one-minute intervals over a 72-hour period on every woman using portable light weight Lascar EL-USB-CO devices (Lascar Electronics, n.d.). The Lascar monitors showed gari processors were exposed to high CO levels. For instance two gari processors – Asabe and Yawo – had mean CO of 12 in a 24-hour period. Asabe had a maximum minute-averaged CO level of 38.2, while Yawo had a maximum averaged CO level of 306. With such high levels, the

gari processors were at risk of various symptoms and ailments including but not limited to headaches, chest pain, muscle weakness, and cardiovascular diseases (ATSDR, 2012).

### **MEANS OF CONTROLLING ENVIRONMENTAL POLLUTION**

Controlling pollution due to smoke from traditional cook stoves and improper disposal of cassava peels would not be an easy task. KHRC would need to work with community leaders to devise a plan. Perhaps they could construct a gari processing site a few kilometers from the community in addition to improving on the cook stoves. Although BAC and the government officer were in the process of improving the gari processing cook stoves in Ntankro, there was yet to be a solution for the waste disposal site in Ntankro.

Ntankro has a local government established pursuant to Act 462, Local Government Act, 1993 (Government of Ghana, 1993). Parts of Section 10(3) of Act 462 include references to environmental pollution but not in regards to local by-laws. The Act fosters development of industries, mobilization of resources, and supports economic activities at district levels but makes no reference to community levels of air pollution. Without local by-laws, there would be no legal means of controlling pollution in the community.

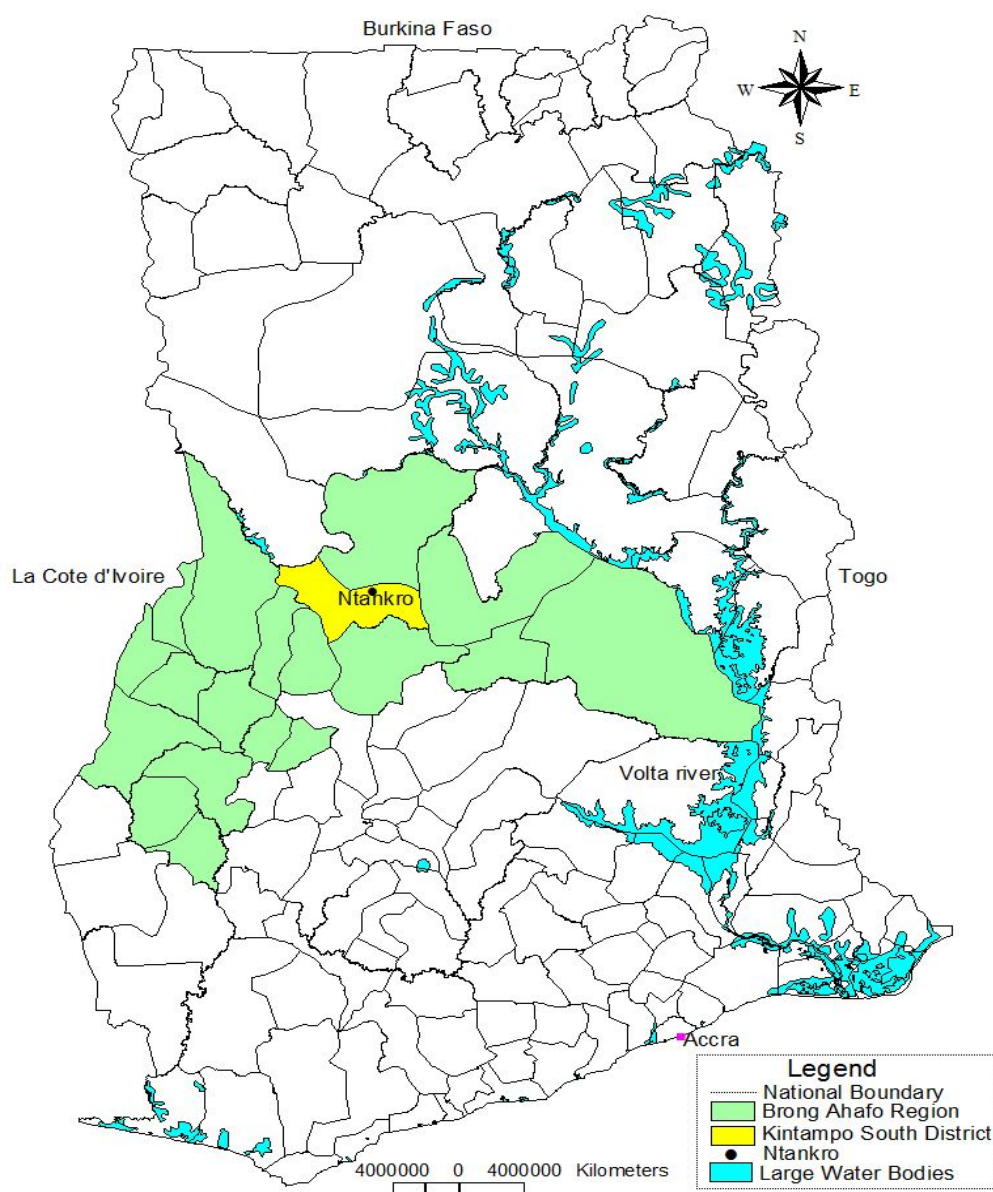
### **UNRESOLVED ISSUES**

Some gari processors in Ntankro expressed a desire for LPG cook stoves while others were opposed to LPGs. The gari processors are the users of the cook stoves. Akosua wondered whether or not the community leaders and other stakeholders at the government and international level considered the women's needs before redesigning the cook stoves. If the women could be included in the process, then they could contribute to the design and performance of the improved cook stoves. Perhaps the KHRC could facilitate a process whereby the women could take ownership over the design of improved stoves.

But are the gari processors aware of the pollutants emitted by the cook stoves and the health effects of inhaling these pollutants? Without awareness, it is clear that the women would not be motivated to improve the stoves and reduce emissions. How could the impact on the profitability of the gari industry be addressed? What could Akosua and the GRAPHS team do to educate the women? What support can community leaders provide for women in the gari industry? Could the gari processors be motivated to work collectively to implement solutions? For example, could gari processors pool resources and assign babysitter roles to reduce exposure of children during working hours?

The gari frying process is fundamental to this industry but little has been done to help those involved. The BAC and the government leaders have implemented workshops to inform women about means of controlling pollution from the gari industry and constructed a cook stove with a chimney but the interventions have thus far been inadequate. For many years, traditional cook stoves in the gari industry have been putting the health of individuals and communities at risk. Yet, gari is a major source of food security. Could intervention from the government cause the benefits of the improved cook stoves to outweigh the familiarity and profit potential associated with the traditional stoves?

**EXHIBIT 1**  
**Map of Ghana Showing Ntankro**



Source: Kintampo Health Research Centre, 2015.

**EXHIBIT 2**  
**Pregnant Woman Using Cook Stove**



Source: Captured by author.

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## INSTRUCTOR GUIDANCE

### The Fire Under the Shed: The Cornerstone Fuelling Our Plight

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#### BACKGROUND

In Ghana, smoke from biomass fuel cook stoves leads to acute lower respiratory infections (ALRI) in children under five. Akosua Agborson, a research fellow, had the opportunity to work with the Ghana Randomized Air Pollution and Health Study (GRAPHS) team at the Kintampo Health Research Centre to address this public health issue. The GRAPHS team is responsible for reducing air pollution and improving cook stoves for households in Ghana. Akosua decided to support the GRAPHS team by doing a case research study on gari processing involving biomass fuel. She focused on gari processors because Ghana is the sixth largest producer of gari (cassava grits) in the world. Akosua and the GRAPHS team interviewed gari processors, community leaders, and the district government officer in order to understand the levels of knowledge about health risks and the perceptions of air pollution attributable to biomass fuel used in the gari processing industry.

#### OBJECTIVES

1. To illustrate the challenges of overcoming a lack of health knowledge among vulnerable people.
2. To identify the optimal strategy for promoting health and motivating change.
3. To develop a plan for health promotion that is informed by an understanding of the context.
4. To navigate the complexities of industry and innovation in formulating public health strategy.

#### DISCUSSION QUESTIONS

1. What is the willingness of gari processors to adopt clean cook stoves?
2. What strategies can improve gari processors' knowledge base on the health risks from smoke inhalation?
3. What strategies can be implemented to reduce harm from exposure to pollutants in the short-term?
4. What is the optimal approach to designing improved cook stoves for use in the gari processing industry?
5. How can the cost of improved cook stoves be subsidized to minimize the financial impact on the women?
6. How beneficial would an alternative source of fuel be to the gari industry?

#### KEYWORDS

Air pollution; biomass fuel; cook stoves; cassava; manioc; gari; gari processing industry; health knowledge; health promotion; Ghana.

## CASE 2

### Teleophthalmology Screening: Economic Evaluations in Health Care Decision Making

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Funds for public health are scarce across Canada, as they are in most of the world. Funds for ocular public health programs are even more limited, demanding strategic resource allocation. Yet, that is not the main obstacle in achieving better ocular health in the Province of Ontario; it is that vision care is not covered by the Ontario Health Insurance Plan (OHIP). This means that acquiring treatments presents a challenge to many members of the public, and negatively affects eye health.

Dr. Hodge, the Chair Ophthalmologist-in-Chief at the Ivey Eye Institute, had finished examining Doug, a 52 year old patient, and was about to tell him that the recent laser treatment slowed down the progression of his diabetic retinopathy (DR) but did not cure it, which is why his vision was getting worse (see Exhibit 1). According to the Canadian Diabetes Association, DR is the leading cause of blindness in people of working age (Cheng et al., 2013). It is mostly due to late diagnosis that DR progresses rapidly. Early diagnosis makes treatment easier and is more likely to preserve vision.

The next provincial budget was going to be released in six months. Dr. Hodge was looking for evidence of the cost-effectiveness of teleophthalmology screening programs. Thus, a formal systematic review of studies, which examined cost-effectiveness of screening for retinopathy, would provide information to help him advocate for a teleophthalmology screening program. He believed that obtaining the best outcomes for every dollar spent was an essential public health perspective that was needed to help guide policy makers in making the best possible decisions.

#### DIABETIC RETINOPATHY

Diabetic retinopathy (DR) is one of the complications of diabetes mellitus, which is an illness that affects how the body handles sugar usage and storage. Excess sugar in the body may lead to complications in the circulatory system of the retina resulting in DR. Any changes that happen to the blood vessels in the retina such as swelling, leaking, or even ischemia can result in retinal damage. Duration of diabetes is a risk factor for the incidence of DR (Cheng et al., 2013).

Diabetic retinopathy is usually divided into two types: non-proliferative diabetic retinopathy (NPDR) and proliferative diabetic retinopathy (PDR). NPDR is the first period of the illness when minimal or no vision related symptoms exist (American Diabetes Association, 2015a). This is why yearly eye examinations are recommended in diabetic patients to catch this early stage of the disease before progressive retinal damage leads to vision loss (American Diabetes Association, 2015b). PDR represents a more advanced stage of the illness in which abnormal blood vessels start developing. These vessels often leak blood into the vitreous, resulting in

## **Teleophthalmology Screening: Economic Evaluations in Health Care Decision Making**

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severe visual consequences. Retinal detachment and glaucoma may occur as complications of DR.

Treatment of DR is based on the stage of the illness. For non-proliferative retinopathy no treatment is usually required unless there is diabetic macular edema (DME). As for patients suffering from proliferative or severe non-proliferative retinopathy, DME, or vitreous hemorrhage, anti vascular endothelial growth factor therapy, laser therapy and/or vitrectomy is the recommended treatment. The time at which treatment is given is critical in DR. It is optimal before leakage of the new abnormal blood vessels occurs. Nonetheless, treatment may still be beneficial if started after leakage occurs, provided it is small (American Diabetes Association, 2015b).

Diabetic retinopathy is a common cause of blindness in adults (Kempen et al 2004). Data from the United States indicate that while prevalence of retinopathy in adult diabetics is approximately 40%, visual loss occurs in nearly one in 10 such patients (Kempen et al 2004). Visual loss can lead to increased risk of falls, hip fractures, and increased mortality (Vu, Keefe, McCarty & Taylor, 2005).

The challenge in treating DR lies in the fact that it has a long preclinical phase (which may last up to seven years) during which diagnosis is difficult as the patient does not report any vision changes (Engerman & Kern, 1987; Sander, Larsen, Engler, Lund-Andersen, & Parving, 1994; Wilkinson et al., 2003). Usually, the patient seeks medical care after retinal damage has occurred, for which treatment may be less effective (Ciulla, Amador, & Zinman, 2003).

### **VISION CARE IN CANADA**

Canada's healthcare system is perceived as being publicly funded. In reality though, less than three quarters of the money spent on healthcare comes from the public, while the remainder of expenses are covered privately (Canadian Institute of Health Information, 2015).

The breadth of coverage of the public health insurance plan varies slightly across provinces. Usually, the plan covers all medically necessary costs incurred by physicians and hospitals. Other services including dental care, physiotherapy, many drugs, and eye care are privately paid for by patients. The Ontario Health Insurance Plan (OHIP) follows this model.

An example of the variation in coverage is Nova Scotia, which has an "Optometric Benefit", which covers visual analysis by optometrists (Health Canada, 2008). Vision analysis is defined as "an examination that includes the determination of 1) the refractive status of the eye; 2) the presence of any observed abnormality in the visual system, and all necessary tests and prescriptions connected with such determination" (Health Canada, 2008). This plan applies to residents under 10 years and those over 65 years of age, where one routine vision analysis is covered every two years. Otherwise, patients between 10 and 65 are covered and receive care in medical emergencies but not for routine checkup visits. Provinces also cover services like prescription drugs, eye exams, and eyeglasses for vulnerable populations such as low-income families and children 18 and younger (Unite for Sight, 2015).

Barriers to optimal care identified in Canada include an increased demand for services from an ageing population, limited resources, gaps in provincial health plans, lack of provider coordination, low reimbursement rates for vision care services, lack of provider knowledge about availability of vision rehabilitation, and a low compliance with referral among patients (Unite for Sight 2015; Gold & Zuvela, 2005).

## **Teleophthalmology Screening: Economic Evaluations in Health Care Decision Making**

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### **IMPORTANCE OF SCREENING**

“Research has shown that 95 percent of the cases of blindness caused by diabetic retinopathy are preventable, if the disease is detected and treated promptly” (Erikson, 2015).

Despite being preventable, DR is one of the leading causes of blindness in adults (Cheng et al., 2013). As described above, a long preclinical phase and lack of early symptoms make early detection challenging. In addition, diabetic patients tend to be non-compliant to eye examination guidelines; less than 50% attend annual screening as advised by the American Academy of Ophthalmology (Coronado, 2014). Low availability of eye care professionals to assess DR, lack of awareness about the effects of diabetes on vision, and reluctance to undergo a dilated eye examination are among the main reasons for noncompliance (Coronado, 2014). Teleophthalmology screening could be a potential mechanism to address this public health crisis.

Most of the diabetic patients who develop DR do not complain of symptoms of the illness until they develop macular edema (ME) and/or the disease progresses into the proliferative type, thus making screening imperative. An additional impetus for screening is that laser therapy is effective in preventing further progressive visual loss from PDR and ME (rather than making lessened visual acuity better) (McCulloch, 2015). Therefore, early detection of DR is critical in order to preserve vision (McCulloch, 2015).

In addition to the health benefits screening provides, economic benefits may also result from an effective screening program. A recent population based study in Sweden concluded that progression of DR in patients is directly related to their healthcare expenses, which implies costs could be reduced by halting the progression of DR (Heintz, Wiréhn, Peebo, Rosenqvist, & Levin, 2010). Evidence from the Indian Health Service Division of Diabetes Treatment and Prevention in Arizona suggests that teleophthalmology saves hundreds of millions of dollars a year in medical care and support services that would be required for people who go blind (Erikson, 2015).

### **TELEOPHTHALMOLOGY SCREENING**

Teleophthalmology, a branch of telemedicine, which is a fusion between telecommunication and information technologies, is utilized in situations where health care is optimally provided at a distance. Distance and access to services are barriers that often face patients in need of clinical care especially in communities that are distant or rural. Teleophthalmology provides a solution for such barriers and thus enhances the public health of such communities. In teleophthalmology, skilled professionals take images of the eye which can be helpful in screening, diagnosing, and monitoring ophthalmic disease when patients are far away from eye specialists (Yogesana, Cuadros, & Goldschmidt, 2012).

The teleophthalmology service, if funded, would be covered and just require a requisition from the primary care practitioners of patients diagnosed with diabetes. Screening would be carried out at a local health unit or community health center. Results of the screening would then be forwarded to the primary care physicians who would review it and refer patients who need more thorough eye care or follow up according to the screening results. In this way, patients with diabetes would be monitored more closely and any effect from their illness to their eyes would be caught early. This increases the chance of halting the progression of disease, which may otherwise lead to blindness.

## **Teleophthalmology Screening: Economic Evaluations in Health Care Decision Making**

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### **ECONOMIC EVALUATIONS**

Teleophthalmology is an example of an intervention that is often introduced to facilitate health care delivery and benefit the health of the public. Yet, resources are not always at hand to fund such new propositions and often there is more than one intervention that may be beneficial if implemented. The decision then lies in the hands of decision makers at various positions who are faced with the tough job of choosing and supporting one intervention over another. Though they rely on many factors to make their choice, costs are often of paramount importance – especially in situations where resources are limited, which happens to be the more common situation. Interventions are then considered optimal and worth implementing if they prove to be cost effective, which simply means that they are worth spending the money on and will be beneficial once adopted.

To measure the cost of an intervention and its possible effects on the public an analysis of the situation needs to be undertaken in the form of an economic appraisal or evaluation. The cost of an intervention is measured in monetary units but the benefits may vary according to the type of economic evaluation. Different types of economic evaluations exist including cost benefit analysis where the benefits are measured in monetary units; cost-utility analysis where the benefits are measured in quality adjusted life years (QALYs); and cost-effectiveness analysis where benefits are measured in natural units such as life years gained.

### **COST-EFFECTIVENESS ANALYSIS (CEA)**

Economic evaluation is “the comparative analysis of alternative courses of action in terms of both their costs and consequences” (Drummond et al, 2015). Cost-Effectiveness Analysis (CEA) is one type of economic evaluation that may be used optimally to assess the effects and benefits of healthcare interventions that may not be monetized. CEA is usually expressed as a ratio where the denominator is a measure of health gained (for example, years of life, etc.) and the numerator is the cost incurred for that health gain (Gupta, 2009). When two interventions are compared, the difference in costs (incremental cost) between the two divided by the difference in health gain (incremental gain) is called the incremental cost-effectiveness ratio (ICER).

Cost-effectiveness analyses can be interpreted as a plane with four quadrants (Sandrucci, 2014). The x-axis represents the incremental gains, while the y-axis represents the incremental costs (see Exhibit 2). Outcomes plotted in the top right quadrant are more effective and more costly. Those placed in the bottom right quadrant are more effective and less costly representing the most desirable option. Others that may be plotted in the bottom left quadrant are less effective and less costly, which would not be optimal but may be considered in certain situations. Interventions whose ICER places them in the top left quadrant are less effective and more expensive, which means that they should be rejected. The allocation of an intervention in one of these quadrants in comparison to an existing status aids decision making to determine whether the proposed intervention would be desirable or not.

The dotted line in Exhibit 2 represents the threshold ICER, above which new interventions in general, including treatments as shown in the graph, would not be desirable and below which, would. In other words, it represents a cost-effectiveness threshold. Choosing the threshold depends on the perspective from which the analysis is performed; whether it is of the payers, of the patients, or of the government, which will determine whose costs and gains are explored. Other factors affecting the choice of the threshold are the values the decision maker places on health outcomes and on money, the level of willingness to substitute health for money, and the attitude about risk (Owens, 1998). Availability of resources would also affect the choice of cost-effectiveness threshold.

## **Teleophthalmology Screening: Economic Evaluations in Health Care Decision Making**

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Economic evaluations in the form of assessing cost-effectiveness constitute an important part of the process of deciding whether an intervention is worth implementing. Due to the importance of such assessment measures, agencies are built specializing in evaluation of health technology. One such agency that is recognized worldwide is the National Institute for Health and Care Excellence (NICE) in the United Kingdom, which is considered one of the leaders in implementing cost-effectiveness analysis in decision-making.

### **IMPLICATIONS OF CEA**

Although cost-effectiveness analysis is valued as useful when determining the fate of an intervention, it cannot be interpreted similarly in every situation. Thus, certain issues are present that need consideration when choosing cost-effectiveness analysis as an aid in the decision making process. Such issues include:

- When given more than one choice of an intervention that needs implementation, cost-effectiveness analysis may help guide the choice and reveal which route will provide the best value for money. Yet, when faced with comparisons across different healthcare sectors, the cost-effectiveness analysis may not provide a similar effectiveness measure due to the difference in outcome measures that may be adopted. This idea presents a conditional comparative requisite, where as long as the outcome measures are the same, the cost-effectiveness analysis may provide an acceptable interpretation of the situation.
- One of the important factors of a reliable cost-effectiveness analysis is the presence of a detailed sensitivity analysis in the study. The role of the sensitivity analysis is to assess the extent to which variations in any of the parameters adopted in the study may lead to changes in the final results obtained. Exhibit 3 shows a useful checklist that can be used in assessing cost-effectiveness studies.
- In reality, decisions are not based solely on cost-effectiveness analysis. Economic evaluations represent only one factor amongst many others that need considering, reviewing, and assessing during the decision making process. Other factors include whether or not a community actually needs the proposed intervention and whether the suggested project is a priority in terms of burden of illness. Issues of equity should also be explored during the decision making process to determine whether the intervention under evaluation addresses and considers equity in its application.

### **HEALTHCARE DECISION MAKING**

It is commonly perceived that cost-effectiveness analysis is all about minimizing costs. However, it is important to consider CEA as a tool to prevent wasting of money and resources. Its proper use helps decision makers in avoiding investments in interventions that may turn out to be minimally beneficial to the community in relation to their incurred costs. In fact, this is where cost-effectiveness analysis is most effective during decision making. Its role is not only to explore whether or not an intervention would bring about health benefits in relation to its costs; it also helps decision makers understand what they can expect their community to gain due to their investment in health care.

As mentioned earlier, CEAs are only one of many factors that need examination and consideration when evaluating interventions. It is a tool worth using but cannot be expected to take the place of value judgments that may be provided by experienced professionals aware of current circumstances and needs. Such valuable opinions may help decision makers determine the amount of money they are willing to spend in order to improve their community's health.

## **Teleophthalmology Screening: Economic Evaluations in Health Care Decision Making**

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Healthcare decision-making is a process that is overwhelming and complex. It involves more than one institution and is not limited to one profession. It is a crucial component to the globally desired enhancement and reform of healthcare. It needs careful consideration of many issues and cannot be driven by a single imperative.

### **AT THE IVEY EYE INSTITUTE**

Dr. Hodge, being an eyewitness to the burden of DR in his patient population, intends to propose a teleophthalmology screening program. Teleophthalmology screening would be implemented as one of the public health strategies to mitigate the visual disabilities caused by DR which, along with diabetes, represent a growing health problem worldwide. He believes that teleophthalmology screening has the potential to provide another way of diagnosis that would be more convenient and accessible to some patients. It will also address the low availability of eye care specialists since teleophthalmology screening does not require one.

However, given the scarcity of funds for public health interventions, he feels the need to back up his proposal by a review of the cost-effectiveness of screening in order to guide decision-making in favor of his proposal.

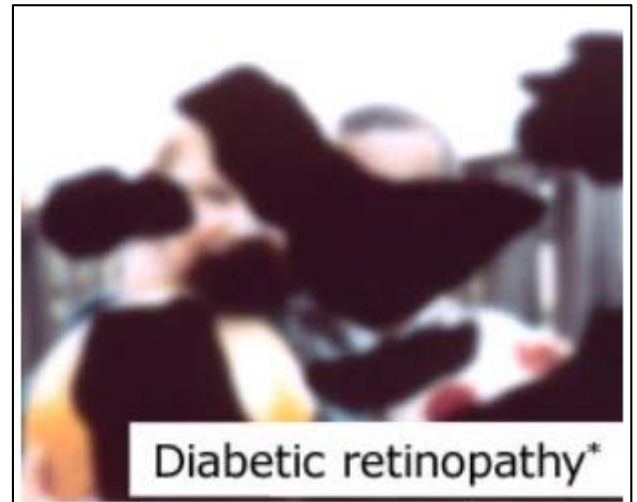
Dr. Hodge feels that such a review would provide a sound source of evidence through the rigorous examination of research material relevant to the topic in question. Systematic review evidence is a necessary ingredient for making good decisions. He thus hopes that presenting a high quality review could satisfy the need for decision makers to explore the benefits of any proposed intervention they would consider. It would provide the information on the effectiveness and meaningfulness of implementing teleophthalmology screening for DR.

On the other hand, Dr. Hodge knows that such a review would also be beneficial to future research endeavours through facilitating knowledge synthesis. Being a researcher himself, he recognizes how such a review could be useful to researchers who usually examine high quality reviews to guide their work and direct their objectives in new projects.

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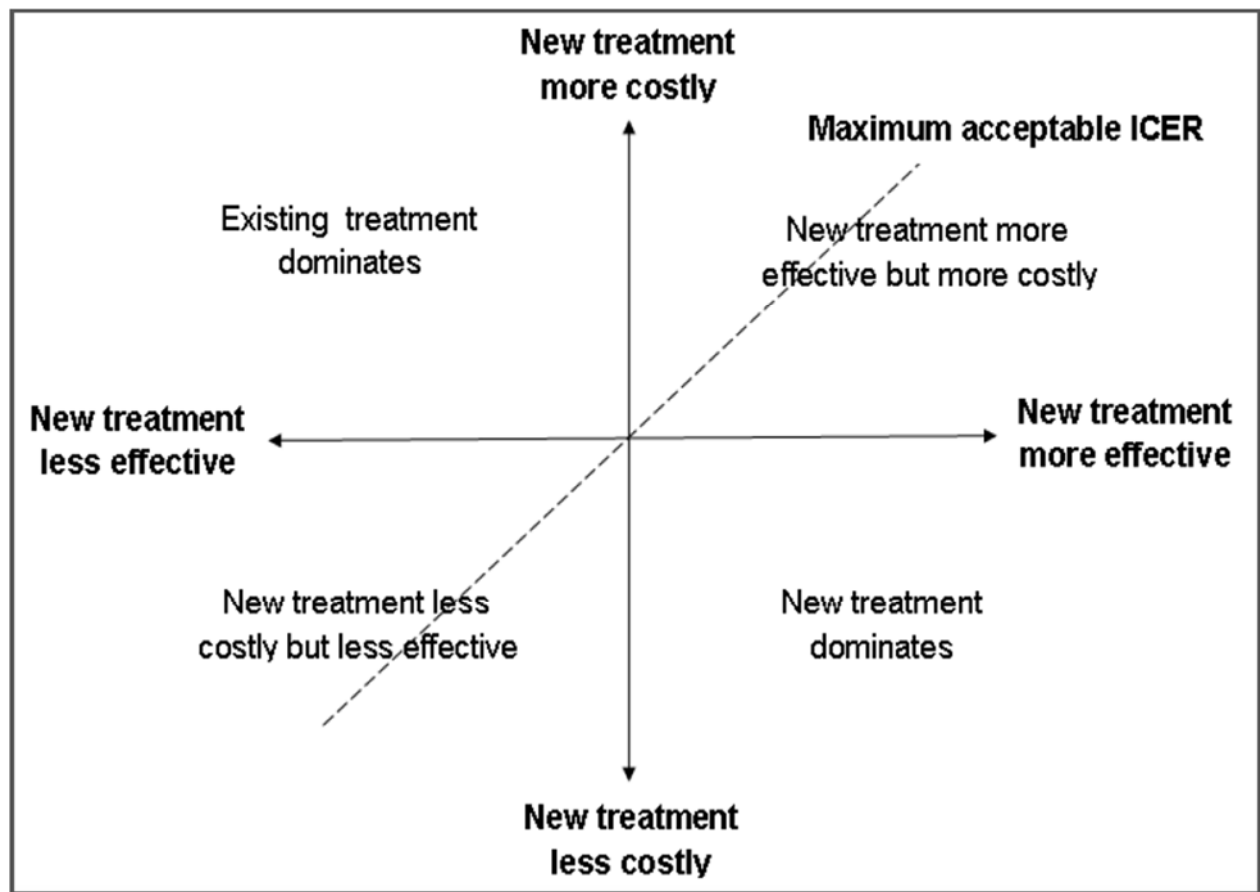
**EXHIBIT 1**



Source: CNIB.ca, 2015.

## Teleophthalmology Screening: Economic Evaluations in Health Care Decision Making

**EXHIBIT 2**  
**Cost-Effectiveness Plane**



Source: Hounton & Newlands, 2012.

## Teleophthalmology Screening: Economic Evaluations in Health Care Decision Making

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### EXHIBIT 3 Checklist for Assessing Cost-Effectiveness Studies

#### Study design

- (1) The research question is stated
- (2) The economic importance of the research question is stated
- (3) The viewpoint(s) of the analysis are clearly stated and justified
- (4) The rationale for choosing the alternative programmes or interventions compared is stated
- (5) The alternatives being compared are clearly described
- (6) The form of economic evaluation used is stated
- (7) The choice of form of economic evaluation is justified in relation to the questions addressed

#### Data collection

- (8) The source(s) of effectiveness estimates used are stated
- (9) Details of the design and results of effectiveness study are given (if based on a single study)
- (10) Details of the method of synthesis or meta-analysis of estimates are given (if based on an overview of a number of effectiveness studies)
- (11) The primary outcome measure(s) for the economic evaluation are clearly stated
- (12) Methods to value health states and other benefits are stated
- (13) Details of the subjects from whom valuations were obtained are given
- (14) Productivity changes (if included) are reported separately
- (15) The relevance of productivity changes to the study question is discussed
- (16) Quantities of resources are reported separately from their unit costs
- (17) Methods for the estimation of quantities and unit costs are described
- (18) Currency and price data are recorded
- (19) Details of currency of price adjustments for inflation or currency conversion are given
- (20) Details of any model used are given
- (21) The choice of model used and the key parameters on which it is based are justified

#### Analysis and interpretation of results

- (22) Time horizon of costs and benefits is stated
- (23) The discount rate(s) is stated
- (24) The choice of rate(s) is justified
- (25) An explanation is given if costs or benefits are not discounted
- (26) Details of statistical tests and confidence intervals are given for stochastic data
- (27) The approach to sensitivity analysis is given
- (28) The choice of variables for sensitivity analysis is justified
- (29) The ranges over which the variables are varied are stated
- (30) Relevant alternatives are compared
- (31) Incremental analysis is reported
- (32) Major outcomes are presented in a disaggregated as well as aggregated form
- (33) The answer to the study question is given
- (34) Conclusions follow from the data reported
- (35) Conclusions are accompanied by the appropriate caveats

Source: Drummond & Jefferson, 1996, p. 281 (by permission of BMJ Publishing Group Ltd.).

## Teleophthalmology Screening: Economic Evaluations in Health Care Decision Making

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## INSTRUCTOR GUIDANCE

### Teleophthalmology Screening: Economic Evaluations in Health Care Decision Making

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*Faten Bahnacy, MD, MPH (MPH Class of 2015)*

*William Hodge, MD, PhD*

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

#### BACKGROUND

This case presents a dilemma that can happen to anyone with an intervention to offer, which they are confident would alleviate a problem they believe is worth addressing. Many public health professionals will find themselves in one of two positions. The first, a position of believing so much in a proposal but not sure of how to make it go through. The second, a position of a decision maker who would be faced with more than one needed, effective, feasible, and sustainable proposal but could implement one or a few due to limited resources.

The case is meant to shed light on both situations with more focus on Dr. Hodge's position, wanting to advocate for a teleophthalmology screening program. Through introduction of this situation the case presents vision care status in Canada, economic evaluation concepts, cost-effectiveness analysis, and health care decision-making.

This case would be suitable for use in a health economics course, to provide real life situations that facilitate understanding of its dominant theoretical content. Health economics is an essential aspect of decision making that can be utilized in most public health career positions. At one point or another money will be scarce and the ability to understand costs in relation to public health will be a necessary skill.

#### OBJECTIVES

1. To learn that there are different types of economic evaluations, with various measuring units.
2. To understand the role of economic evaluation in health care decision-making.
3. To learn about cost-effectiveness analysis in relation to public health.
4. To have a basic understanding of key concepts of economic evaluations such as QALYs, ICER, and threshold of ICER in the economic context.
5. To recognize the importance of looking at incremental costs and interpreting the ICER.

#### DISCUSSION QUESTIONS

1. In this case, a review of economic evaluations of teleophthalmology screening is recommended to support implementation of a new intervention by proving that it maximizes the benefits from healthcare spending. What are some other uses of economic evaluations in health care decision making?

## **Teleophthalmology Screening: Economic Evaluations in Health Care Decision Making**

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2. In this case, cost-effectiveness was a factor, which Dr. Hodge addressed to support his proposal. What other factors would decision makers have to examine before funding a proposal?
3. Who else may benefit from the systematic review Dr. Hodge plans to undertake?
4. Would a different approach altogether be more effective in supporting his proposal?

### **KEYWORDS**

Healthcare decision making; systematic reviews; health economics; economic evaluations; cost-effectiveness analysis; ICER.



## CASE 3

### Ciguatera Fish Poison: An Emerging Risk Associated with Climate Change?

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*"I have never felt so sick in my life. It's like all my energy is gone and all I can do is lay in bed, sweating, nauseous ... We are all down. We are all poisoned."*

– Crew from MV El Faro

#### BACKGROUND

Dr. Turner<sup>1</sup>, the Chief Medical Officer of Health for the Bahamas, received a phone call from an unknown and long distance phone number. It was Ms. Gagnon from the Public Health Agency of Canada (PHAC). "We have 14 very sick seamen here. The whole crew of the MV El Faro has been admitted to hospital. Several are in dire states of dehydration. Their last port of call was Nassau. This is why I am calling you."

"You know, Ms. Gagnon, sailors are famous for misbehaving. Perhaps they are just exhausted from their shore leave – maybe too much sun?"

"Doctor, I assure you that we have one of the best outbreak forensic teams along the Atlantic coast. This is not a trivial matter. We've eliminated contaminated food in the galley and poor refrigeration that might lead to scombroid poisoning. It's also not gastrointestinal such as *Campylobacter jejuni* or *Vibrio parahaemolyticus* – no evidence in their stool samples. But they all ate fish that they claimed to have caught in Nassau. Within 24 hours they were all feeling bad – with sweating, chills, and a stiff neck – and several were confined to sick bay within 48 hours. The odd thing was that their hosts weren't sick – or at least not that we know."

Dr. Turner was now more interested and contributed, "I bet they were down at Haywire Cove – it's near the marine park. The coral fish are easy to catch and are big." Together, they agreed it was Ciguatera Fish Poisoning in one of Canada's provincial ports.

Ms. Gagnon was nervous. These occurrences were rare in Canada, but PHAC was concerned about having cases of imported Ciguatera Fish Poisoning (CFP) and also wanted to assess whether this was a concern for their citizens going to the Bahamas, as well as other Caribbean countries. "This isn't a Canadian issue, Dr. Turner. This is a Bahamian issue. We need to keep our citizens safe from this fish poison, whether that's through fish imports or as tourists to your country."

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<sup>1</sup>All names have been altered but represent real individuals in real situations.

The conversation ended. The issue was now Dr. Turner's to handle. While this was a rare incident in Canada, CFP seemed to be on the rise in the Bahamas. While it was not a home-grown problem in Canada, that was not the case in the Bahamas. Still, it was PHAC's responsibility to report the occurrence to the country that was the source as per the 2005 International Health Regulations (IHRs). But now that it was brought to Dr. Turner's attention, what really could be done? While Dr. Turner knew of Ciguatera Fish Poisoning, he was unaware of the complex intricacies linked to the rising incidence of CFP. The name "Ciguatera" was popping up everywhere now. Was this a new environmental problem? Why have we not had this problem before? He knew little about how it would affect his country and his people. Was it a tourism issue? An exportation and trade issue? Was it a health problem or an environmental problem? Should he be coordinating with the Ministry of the Environment and Housing and Ministry of Tourism? Dr. Turner realized that an integrative, collaborative, and holistic approach was necessary in order to combat this issue and that working towards a solution was going to involve more than just him and his team.

### **CIGUATERA FISH POISON – THE PROBLEM AND SYMPTOMS**

Ciguatera is a foodborne illness that is caused by eating reef fish contaminated with a toxin called "ciguatoxin" (Goater, Derne, & Weinstein, 2011; Llewellyn, Tester, & Hallegraef, 2013; Epelboin et al., 2014; Mattei et al., 2014; Muecke et al., 2015). Ciguatoxin is colourless, odourless, and tasteless. The toxin cannot be destroyed by cooking, smoking, freezing, canning, salting, or drying (Goater et al., 2011; Llewellyn et al., 2013). The poison is produced by small organisms (dinoflagellates) that attach to sea grasses and corals growing in warm ocean reef areas. Small plant-eating fish ingest these toxic algae and are then eaten by larger predatory fish, which are in turn consumed by humans. Symptoms of CFP can occur quickly, but the first symptoms are usually gastrointestinal. Within 24 hours patients develop nausea, vomiting, abdominal pain and diarrhoea, which is followed later by neurological symptoms such as dizziness, weakness, and numbness. Cardiovascular symptoms such as low blood pressure and heart rhythm abnormalities appear at a later stage. (Government of Canada, 2016; Donati, 2006). Although there is no specific treatment, hospitalization may be required for intravenous rehydration, cardiac monitoring, and the treatment of complications. Recent research has suggested that climate change could increase the burden of CFP by expanding the range of suitable warm water habitats (Tester et al., 2010b; Gingold, Strickland, & Hess, 2014).

Contaminated seafood is a concern among many nations in the world that depend on the sea for protein. In Canada, the Canadian Food Inspection Agency is mandated to assess the likelihood of the most common forms of contamination – usually bacterial contamination of poorly maintained or processed product. CFP differs from the usual food safety risk as the toxin/poison is integral to the fish tissue, does not affect the health of the fish, and becomes a foodborne illness on consumption of reef fish that are contaminated with a neurotoxin (Goater et al., 2011; Llewellyn et al., 2013; Epelboin et al., 2014; Mattei et al., 2014). While CFP has not historically been a Canadian issue, it is endemic to areas such as the Pacific and Indian Oceans as well as the Caribbean (Goater et al., 2011), areas that the global Canadian traveller commonly visit.

CFP has been estimated to affect between 250-500 thousand individuals globally every year – exclusively in tropical regions. Two global hot-spots are the central South Pacific Island nations (such as Kiribati, Samoa, and Cook Islands) and the islands of the Caribbean (Jamaica, Virgin Islands, etc.). However, global numbers are most likely grossly underestimated due to under-reporting and misdiagnosis (Goater et al., 2011; Llewellyn et al., 2013; Mattei et al., 2014). Presently, CFP cannot be confirmed through a laboratory diagnostic test in humans (Llewellyn

et al., 2013). If food specimens are available, they can be collected and tested for presence of ciguatera toxin and, if positive, confirm the diagnosis.

### **Historical Changes in Ciguatera**

The study of CFP is far more complex than most seafood safety problems. To comprehend the challenges posed by CFP, historical trends, changes in affluence (tourism and travel), social economics (attracting tourists into marine protected areas, the restriction of subsistence fishing), and environment (water quality, climate change, and over-fishing) must all be understood. Thus, an integrated public health approach is required to assess CFP occurrences.

CFP has been known to be part of Bahamian waters for centuries (Caribbean Epidemiology Centre [CAREC], 2010). Ship logs from the 1600's often reported symptoms when the sailors were fed barracuda – one of the top, older living predators of coral reefs. The first register of CFP was started in 1995 and indicated about 20-30 cases per year. Recent reports for 2010-2015 average approximately 170 cases per year. The incidence rate is about six cases per 10,000. It is generally understood that the reporting rate is very low (< 10%) indicating that there are likely over 1,000 cases per year in the Bahaman islands.

While it is largely unknown what causes an increase in CFP cases, researchers have suggested that the increase in global seafood trade, enhanced local fishing, and increased tourism place human consumers in the direct path of exposure, leading to a higher probability of an encounter with CFP-laden fish (Llewellyn et al., 2013). Additionally, there is ample evidence that the probability and intensity of CFP toxin production have also increased in many coastal reserves as ocean temperatures increase. Between 2002 and 2007, there was a notable increase in the Caribbean sea's temperature between 0.4°C-0.8°C, which coincided with a six-fold increase in reported CFP cases (Tester et al., 2010b). This seems like a small change in temperature, but it extends the range of coral fish in the Caribbean substantially north. The further north the range goes the closer to the Gulf Stream. The Gulf Stream could cause the cells that make the toxin to move into Florida and up the Atlantic seaboard to North Carolina. Here, the Cape Hatteras extension of the State of North Carolina will push the water away from North America – protecting the coastal communities of Washington, D.C., New York, and Boston.

For the Bahamian people, fish is a significant component of their diet. Local fishermen appear to be much more knowledgeable and tend to apply traditional knowledge and practice when fishing to provide for themselves and their families (Tester et al., 2010a). These traditional practices vary from merely catching and ingesting smaller fish, fish species that do not notably contain CFP, and in some areas, feeding the caught fish to their pets to see if they get sick post ingestion (Copeland, Palmer, & Bienfang, 2014; Friedman et al., 2008). Challenges arise when non-local fishermen such as refugees begin fishing in the area and contract CFP. Non-locals may be unaware of CFP and the species that can cause outbreaks, consequently catching and ingesting the larger and slower species such as grouper and snapper, with no knowledge of the symptoms of CFP.

## **THE BAHAMAS**

### **Background**

The Commonwealth of the Bahamas is an English-speaking cluster of islands in the Caribbean region, with a population of approximately 347,000 (WHO, 2013). After gaining its independence in 1973 from the British Government, the Bahamas became a sovereign state and a member of the United Nations ("The Bahamas", 2015). It has become one of the wealthiest nations of the Caribbean, with tourism being their main industry and contributing approximately 50% to the

## **Ciguatera Fish Poison: An Emerging Risk Associated with Climate Change?**

total Gross Domestic Product (GDP). While incomes have increased steadily, wealth distribution remains widely disparate (Pan American Health Organization [PAHO], 2012).

Approximately 20% of the Bahamian population are documented and undocumented Haitian immigrants (PAHO, 2012), which contributes to wealth disparity. This Haitian population experiences an unemployment rate of 28.6% compared to the regular 14.2% nationally (PAHO, 2012).

### **Government and Political Context**

Similar to Canada, the Bahamas is a commonwealth country and has adopted a parliamentary democracy, governed by a Prime Minister, Cabinet, Parliament, and a Governor General (The Government of the Bahamas, 2011). Individual islands are administered by elected district councils (PAHO, 2012). Due to their convenient location, close to Florida, the Bahamas is a staging ground for drug and illegal immigrant smuggling into the U.S. Consequently, this has resulted in a great deal of corruption within all levels of government (Economic Freedom – The Bahamas, 2015).

### **Employment Industries**

Currently, the Tourism and Travel industry supports over 108 thousand jobs, both directly and indirectly (World Travel and Tourism Council [WTTC], 2014). There are approximately 1.5 million international tourists to the Bahamas every year.

### **Health and Health Services**

Health services in the Bahamas are available through both private and public sectors, with health sector service areas provided by the Ministry of Health, Department of Public Health, Public Hospitals Authority, and the private sector. Public services are financed primarily through taxation while other services can be financed through both out-of-pocket payments and private insurance (PAHO, 2012).

<b>Bahamas Island Health Indicators</b>	
Total population (2011) <sup>1</sup>	347,000
% Population under 15 (2011) <sup>1</sup>	22
Population distribution % urban (2011) <sup>1</sup>	84
Life expectancy at birth (2011) <sup>1</sup>	
Total	75
Male	72
Female	78
Infant mortality rate per 1000 live births (2011) <sup>1</sup>	14
Maternal mortality ratio per 100 000 live births (2010) <sup>1</sup>	47
Total expenditure on health as % of GDP (2010) <sup>1</sup>	7.5
General government expenditure on health as % of total government expenditure (2011) <sup>1</sup>	15.2

## **Ciguatera Fish Poison: An Emerging Risk Associated with Climate Change?**

<b>Bahamas Island Health Indicators</b>	
Total poverty rate % (2012) <sup>2</sup>	9.3
Total unemployment rate % (2012) <sup>2</sup>	14.2

Sources: World Health Organization, 2013<sup>1</sup>; PAHO, 2012<sup>2</sup>

Locals and non-locals can receive medical services from both public and private clinics and hospitals; however, the government-sponsored clinics provide the majority of the medical care (PAHO, 2012). Despite this, one-third of the population purchases private insurance. While the poorest citizens report insufficient time and cost as the main barriers to receiving health care services, they also report the highest rates of receiving social welfare assistance (PAHO, 2012). The Haitian refugee population has experienced a greater burden of disease and accounts for a longer average stay within the public hospitals (PAHO, 2012). The most common causes of mortality are chronic non-communicable diseases, such as hypertensive and ischemic heart diseases, closely followed by HIV/AIDs.

Public school health services ensure immunization coverage rates that are on average 97% for all vaccine-preventable diseases (PAHO, 2012).

### **INTERNATIONAL HEALTH REGULATIONS**

With the increase of globalization, there is a much greater opportunity for illnesses to spread and emerge in areas where they were previously non-existent. A crucial role of the World Health Organization (WHO) is the management and control of the international spread of diseases (WHO, 2005). The World Health Assembly – which is comprised of WHO member states – adopted the International Health Regulations (IHRs) in 1969 to ensure the prevention and control of diseases (WHO, 2005).

The purpose of the IHRs is “to prevent, protect against, control and provide a public health response to the international spread of disease in ways that are commensurate with and restricted to public health risks, and which avoid unnecessary interference with international traffic and trade” (WHO, 2005, pg. 1). The IHRs – which are considered legally binding documents – have specific requirements and responsibilities for each Member State to uphold (WHO, 2005).

As an emerging issue, associated with climate change, the routes of impact are not fully realized. Tourists contracting CFP or industry bringing contaminated fish into Canada could cause a serious outbreak that might not be identified, reported, properly treated, or contained, especially since it is not a well-known illness in the region.

### **SURVEILLANCE AND REPORTING**

Surveillance of emerging diseases is a crucial component of increasing capacity for prevention and control of communicable diseases – as is the surveillance of “upstream” disease reservoirs. Ecological surveillance also provides the opportunity for more accurate and realistic incidence levels and morbidity, estimation of health impacts, and earlier notification of illness (Todd, 2006). Surveillance would also aid in identifying regions of concern or heightened transmission, which would be useful for CFP monitoring.

In regards to CFP, there is no surveillance system in place nor is it a nationally notifiable disease in Canada, the United States of America, or The Caribbean Public Health Agency

## **Ciguatera Fish Poison: An Emerging Risk Associated with Climate Change?**

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(CARPHA). While all regions are capable of conducting surveillance, monitoring, and ensuring reportability, currently nothing is being done or has ever been done. Surveillance for CFP not only could include increasing diagnosis and reporting of the illness, but also monitoring aspects known to contribute to the increase of CFP cases. This could include measuring the ocean temperature, monitoring known affected reefs, and testing different species of fish to identify those that are contaminated with CFP.

CFP affects a large number of tourists, which decreases the accuracy of reporting and surveillance systems. Tourists are more likely to return to their home country and see their primary physician, and CFP may go unreported as their doctors may be unfamiliar with CFP.

### **TOURISM AS A PUBLIC HEALTH ISSUE**

With 1.5 million tourists every year, and that number estimated to double within the next ten years, the effects of tourism in the Bahamas can be both beneficial and detrimental.

Tourism contributes to the economy, development, and sustainability of the Bahamas. Without this incredibly large industry, the Bahamas would not be one of the richest and most developed countries in the Caribbean, as it is today. Tourism has provided a large number of jobs, consequently decreasing unemployment rates for the Bahamian population. It has also allowed for an increase in the minimum wage and annual salaries.

The tourism industry sells the idea of the “Four S’s” – sea, sun, sand, and sex (Rodriguez-Garcia, 2001). The Four S’s have been highlighted to encourage tourism in developing countries in order to create an opportunity for new industries and development. However, the Four S’s are accompanied by behaviours damaging to the health of both travellers and locals. Seas are being polluted through the abuse of boats, due to fishing and recreational sports, with sewage encouraging infectious diseases. Additionally, activities such as scuba diving and snorkelling disturb natural reefs and fish habitats. Over-exposure to sun leads to an increase in skin cancer, as well as sunburn and heat exhaustion. Behaviours such as over-use of alcohol and drugs can encourage unsafe sexual practices and domestic abuse, amongst tourists and locals. As it is, HIV rates are relatively high within the Bahamas, due to tourism and local practices.

### **LOCAL HEALTH IMPLICATIONS OF CFP**

While local fishermen may be more aware of CFP and may use traditional knowledge to prevent contraction, a large number of the population is unaware of CFP prevention methods and treatment. They, like many tourists and members of other countries, assume it is merely food poisoning and will not seek medical care. The barriers preventing many citizens from receiving care also adds to the under-reporting of CFP.

To ensure that a large number of tourists do not contract CFP, hotels and restaurants are paying great attention to the size, species, and origin of the fish they purchase. This has led to fishermen providing the best fish to their purchasers, and whatever is left over goes to local markets and their own use.

### **WHO IS RESPONSIBLE FOR CFP?**

CFP is a complex disease that depends on several different factors. There are international, federal, and municipal components that all contribute to both the control and spread of CFP. WHO has valuable rules and regulations dictating how to control the spread of CFP and has made recommendations on how to prevent the ecological incubators that harbour CFP.

## **Ciguatera Fish Poison: An Emerging Risk Associated with Climate Change?**

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After much deliberation and research, Dr. Turner called together the Minister of the Environment and Housing, Minister of Finance, Minister of Tourism, and Minister of Health to discuss this current and pressing issue. Since CFP is affected by multiple factors, such as tourism and the environment, he decided it was crucial to have these parties involved in any decision making.

Each member stated their priorities and interests related to this problem, identifying common issues. Dr. Turner questioned what information was actually available for common use in regards to CFP. The group searched online to see what information existed, and noticed that everything available was merely for tourists coming from first world developed countries. While important, it left the members questioning how their own people were protecting themselves and what their government was doing to protect them. While obvious issues associated with CFP were identified, what were they missing, to what extent was this an emerging issue, and how could they work to control and prevent it?

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## INSTRUCTOR GUIDANCE

### Ciguatera Fish Poison: An Emerging Risk Associated with Climate Change?

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#### BACKGROUND

This case takes place in the Bahamas and surrounds a complex toxic illness, Ciguatera Fish Poisoning (CFP). It discusses how CFP is contracted and where it is most common, as well as prevention and diagnosis methods. It then goes into the context of the Bahamas, setting the stage in terms of health care, health of the population, government, and various employment industries. Due to its location in the Caribbean, the Bahamas has a large number of tourists each year contributing to the number of CFP cases, as well as affecting the local populations in a variety of ways. This case analyzes an environmental health issue, tourism, and social determinants of health.

#### OBJECTIVES

1. To consider the social, economic, and public health consequences of a complex toxic illness. CFP is a complex toxic illness with environmental, social, and community health implications. An objective of this case is to encourage students to identify solutions that are outside the normal public health sphere of influence.
2. To identify how climate change may contribute to emerging issues of public health concern. CFP represents a problem where systems thinking is required for both understanding the problem and finding a solution. Therefore, an objective of this case is to provide an opportunity for students to learn the intricacies of multiple systems working together to find a solution.
3. To introduce the concept of “decision making in a world of uncertainty”. Most of these terms would be new to Master of Public Health students (a great reminder that MPH is a path, not a destination).

#### DISCUSSION QUESTIONS

1. Who are the different stakeholders involved in this issue?
2. What could each department/stakeholder contribute or suggest to mitigate this issue?
3. Looking at the entire picture, what are the first steps to be taken to improve the situation?
4. How could tourism be involved to decrease the rates of CFP?
5. What could be done to improve surveillance and reporting, as well as proper diagnosis?
6. Create an influence diagram to show influencing factors and negative effects of CFP.

### **KEYWORDS**

Environmental health; food borne illness; social determinants of health; eco-health; climate change; stakeholders; developing country; surveillance; reporting.



## CASE 4

### The Unique Role of Leadership in Public Health

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Leadership in public health is defined by the Public Health Agency of Canada as “the ability of an individual to influence, motivate, and enable others to contribute toward the effectiveness and success of their community and/or the organization in which they work. It involves inspiring people to craft and achieve a vision and goals. Leaders provide mentoring, coaching and recognition. They encourage empowerment, allowing other leaders to emerge” (Public Health Agency of Canada, 2007).

On May 11, 2015, Sarah Johnson started working on a challenging project at the Ontario Public Health Association (OPHA) as a Project Coordinator. Her task was to create a Public Health Leadership Hub within the OPHA website that would provide resources for leadership development among professionals in the public health sector. Another task was to work on a draft curriculum for an intensive leadership development program. Both of these tasks would be a part of the development of a Leadership Center in OPHA. Sarah went through some of the background work already completed at OPHA, including a program proposal. As she began discussing ideas about this innovative service with the Executive Director, Pegeen Walsh, a number of questions struck her. How can leadership training specific to public health make a difference when there are other successful leadership programs already in place? What is so unique about leadership in public health that makes it different from the leadership of other professionals in Ontario’s health system?

To search for answers, she started looking at OPHA’s vision, mission, and mandate. Since its creation as a charity in 1949, OPHA’s mission, “To provide leadership on issues affecting the public’s health and to strengthen the impact of people who are active in public and community health throughout Ontario” (OPHA, n.d.a) has driven its activities. It achieves its mission in part, by “leading the development of expertise in public and community health through collaboration, consultation, and partnerships” (OPHA, n.d.a). OPHA’s vision is to be “a dynamic and innovative force for enhancing and reshaping public health” (OPHA, n.d.a). To realize this vision and mission, OPHA is committed to supporting leadership development among public health professionals at all levels. OPHA’s 2013-16 strategic plan calls for formalizing and expanding its efforts in leadership development through the creation of a Public Health Leadership Center (OPHA, n.d.b).

Sarah began to conduct an environmental scan to identify resources focused on public health leadership across Canada and internationally. She was overwhelmed by the number and type of resources, ranging from articles in journals to videos, podcasts, reports, and other publications. She found that there were limited resources from Canada. There were a number of platforms in the United States where professionals working in public health could enhance their leadership skills, but similar opportunities were lacking in Canada. Although a few Canadian public health

programs include leadership courses, a significant amount of public health professionals are left without academic training in public health leadership. Thus, Sarah embarked on the task of working on the various components of OPHA's Leadership Center that she thought would be helpful in achieving the desired results.

### BACKGROUND

In 2013, the Community Health Nurses of Canada (CHNC), in partnership with the Canadian Institute of Public Health Inspectors (CIPHI) and the Manitoba Public Health Managers Network (MPHMN), were funded by the Public Health Agency of Canada (PHAC) to develop leadership competencies for public health practice in Canada. The group performed an environmental scan as the initial step in the process of specifying leadership competencies for public health practice in Canada (Vollman, Thurston, Meadows, & Strudsholm, 2014). The results of a literature review conducted as part of the environmental scan identified personal qualities, enablers, and barriers to public health leadership. Among the barriers identified were: "lack of mentoring; lack of education/training; and limited opportunities for continuing education". These were subsequently ranked by public health stakeholders in the top five personal barriers to leadership in public health (Vollman et al., 2014). Thus, with Sarah's own initial findings along with those of the CHNC report, it became clear that the existing knowledge gaps could be addressed through the provision of learning resources, combined with an educational program designed to meet these specific gaps.

### UNIQUE ROLE OF LEADERSHIP IN PUBLIC HEALTH

In comparison with other professionals in Ontario's health system, public health professionals require specialized leadership skills because of their unique roles. In addition to collaborating with health care organizations, they often work with others outside of the health sector, such as schools and school boards, municipal planners and transportation engineers, local businesses and workplaces, environmental associations, community groups, and policy developers. In Ontario, public health professionals have a shared accountability to provincial and municipal governments and rely heavily on citizen engagement to achieve their goals. These professionals work in a wide range of areas including preventing chronic disease, addressing social determinants of health, advocating for healthy public policy and positive built environments, as well as other areas that impact community health and well-being. The work often addresses problems with no clear set of answers or immediate and apparent results. Multi-sectorial partnerships and collaborations are often required to gain expertise and address complex issues.

At the provincial level, developing capacity in leadership for public health professionals is a priority, evidenced by a goal within Public Health Ontario's (PHO) strategic plan to "support learning, individual and team development, and build leadership capacity" (Public Health Ontario, 2015). One initiative to achieve this goal is the establishment of a leadership framework and development strategy (Public Health Ontario, 2015). OPHA's plan to develop a leadership center was thus aligned with PHO's mandate, and could address existing knowledge gaps. Sarah wondered what the best method of delivering this program would be. How would she determine the priorities for leadership training and support?

Sarah looked to examples from other jurisdictions to help her answer these questions. In the United States, she found a number of platforms for supporting leadership training and professional development. The Centers for Disease Control and Prevention (CDC) strive to empower and build the capacity of public health professionals. To do this, the CDC provides support to the Public Health Institute for Health Leadership and Practice, which maintains the National Leadership Academy for the Public's Health (NLAPH). The Academy brings

together teams of leaders belonging to a wide range of sectors in public health and encourages advancement of knowledge, attitude, and practices (NLAPH, 2013). The results of a cross-sectional survey that involved all leaders from the program's 15 cohorts, along with telephone interviews, found that graduates "worked to restructure services, reorganize agencies, catalyze new laws, and develop programs" (Umble et al., 2011).

An evaluation of the American National Public Health Leadership Institute Program, a four-day training course, found that program graduates from 1991-2006 had remarkable achievements. This team-based applied leadership program focuses on developing the leadership capacity of teams of public health leaders (NLAPH, 2013). It aims to bring about community health improvements by promoting effective work across sectors. Teams were "required to identify a 'real world' community health improvement project" that they worked on throughout the program (NLAPH, 2013). The findings of this project were:

- "75% of teams indicated that they had made more progress in leadership learning than they had expected"
- "84% of teams reported that participation in NLAPH at least somewhat impacted their team's ability to successfully engage other sectors in their project, which increased the ability to work across sectors, thus improving the ability to bring in key stakeholders and increase collaboration"
- "56% of teams reported that they made more progress on their project than they expected" (NLAPH, 2013)

The evaluations concluded that "in its pilot year, NLAPH was successful in advancing participants' leadership skills, strengthening team functioning, increasing intersectoral collaboration, and helping teams make progress on their community health improvement project" (NLAPH, 2013).

### THE SITUATION

Sarah was concerned about finding a source of funding for the project given the limited budgets of public health organizations in Ontario. An expert in leadership training and adult education was needed to help develop a funding proposal and to create the curriculum for this intensive public health leadership program. Despite these challenges, OPHA was able to frame an initial draft of the program proposal and approach some pharmaceutical companies for funding. The companies showed initial interest, but they required more details. Was it in the capacity of OPHA to draft a comprehensive program proposal? Sarah conducted a scan on public health leadership development programs outside of Canada, and assessed the lessons learned that could assist with the development of the OPHA Leadership Center web-page. Thus began the process of searching and brainstorming ideas. A Leadership Reference Group was created to find the best ways of program delivery, possible participants, speakers, teaching methods, and duration. This reference group included representatives from OPHA's Board of Directors, academics and long-time public health leaders, OPHA's Executive Director, staff members, and Sarah.

Based on an assessment of gaps and opportunities, the group decided OPHA's Public Health Leadership Center should focus on five areas:

1. Mentoring and coaching, enabling students and new professionals to learn from established leaders.
2. Leadership Development and Training for public health professionals at all levels.

3. Networking and Communities of Practice so that like-minded professionals could connect and learn from each other.
4. Leadership Research and Resource Center, partnering with researchers to advance knowledge and provide a web based repository of key resources, tools, and links.
5. An Annual Leadership Summit and Leadership Awards so that professionals could connect, be inspired, hear about the latest developments, recognize excellence and innovation, and honour champions.

Partnerships would be developed to achieve shared goals, particularly with the academic sector, to frame a sound curriculum and certification. Other collaborations would ensure that the planned activities would be complementary to those currently existing, could address gaps, and build on promising and innovative practices.

Even after coming up with the program components and possible teaching methods, the question remained: How could a comprehensive program plan be developed without any available funding to hire an expert in proposal and curriculum development?

### THE REFERENCE GROUP'S DECISION

The OPHA Leadership Reference Group decided to initially focus on two components of the Leadership Center: An Online Public Health Leadership Hub and an initial framework for developing an intensive program curriculum. As Sarah started working on these components, CHNC was about to release its final report on “Leadership Competencies for Public Health Practice in Canada”. Sarah was eagerly awaiting this report as it would provide guidance for the development of the program curriculum. The program competencies were to be based on the environmental scan report earlier released by CHNC.

The Leadership Reference Group made another important decision. To make this program more accessible and thus useful for professionals, it would approach funders who were willing to subsidize participants' registration and travel. Along with investing its own resources, OPHA decided to seek financial support from various private, public, and non-profit sources to make it easier for a wide range of public and community health professionals to participate and access leading edge programming and resources.

### CONCLUSION

After all her background work, Sarah was convinced that having a Leadership Center needed to happen. She began to think about what was required to be done to move this initiative forward. It became evident that there was a knowledge gap in public health leadership development amongst professionals. There were certain aspects that she expected the OPHA Leadership Center program would address. It would include principles of social justice with attention to equity and social determinants of health. She also wanted the Leadership Center to be equally accessible for everyone. For that reason, she started to look for suitable funders who would be interested in contributing to this program.

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## INSTRUCTOR GUIDANCE

### The Unique Role of Leadership in Public Health

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*Amanda Terry, PhD (Assistant Professor, Western University)*

#### BACKGROUND

Sarah Johnson was given the task to create a Public Health Leadership Hub within the OPHA website that could provide resources for development of leadership for professionals in the Public Health sector. Another task was to work on developing an initial curriculum for an intensive leadership development program. Both of these tasks would be a part of the development of a Leadership Center at OPHA. Some of the ground work was already done by the Ontario Public Health Association, including a program proposal.

Sarah started doing a scan on developments taking place in this field in Canada and other parts of the world. Sarah's own findings, along with a report from the Community Health Nurses of Canada, made it clear to her that there was a possibility of addressing this knowledge gap through the provision of learning resources combined with an educational program.

A Leadership Reference Group was created to provide advice on the program content, delivery, possible participants, speakers, teaching methods, and duration. This reference group included representatives from OPHA's Board of Directors, academics, long time public health leaders, OPHA's Executive Director, some staff members, and Sarah.

Based on an assessment of gaps and opportunities, OPHA's Public Health Leadership Center planned to focus on five areas:

1. Mentoring and Coaching
2. Leadership Development and Training
3. Networking and Communities of Practice
4. Leadership Research and Resource Center
5. An Annual Leadership Summit and Leadership Awards

#### OBJECTIVES

1. Understand the unique role of public health leadership from that of other health care professionals.
2. Recognize the importance of formal leadership training and the difference it can make in the way that people work.
3. Identify the best mode of delivering training/resources and recognize the participants who would benefit the most.
4. Develop evaluation measures to test the effectiveness of a leadership program.

### DISCUSSION QUESTIONS

1. What does Sarah need to consider/know more to move ahead?
2. What are the various complex issues that can be addressed through leadership development?
3. What would be the best source of funding for this particular program?
4. What is the relationship between strong leadership and community health and well-being?
5. How should support be built for leadership training and promotion of the program?

### KEYWORDS

Public health leadership; leadership training and education; intersectoral collaboration; environmental scan.



## CASE 5

### Vaccination Under the Midnight Sun: Validation of an Immunization Registry in the Northwest Territories

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Although some might refer to New York as the city that never sleeps, during the summer the Northwest Territories' capital city, Yellowknife, is the city that truly never sleeps. During the summer, Yellowknife receives an average of 20 hours of sunlight with no true darkness. The midnight sun provides residents with the unique opportunity to fish all through the night and for children to play outside late into the summer evenings.

#### BACKGROUND

The mission of the Northwest Territories (NWT) Department of Health and Social Services (DHSS) is "to promote, protect and provide for the health and well-being of the people of the Northwest Territories" (Northwest Territories Department of Health and Social Services, 2009). The Epidemiology and Disease Registries Unit within the Population Health Division works on several projects that promote, protect, and enhance the health and wellbeing of all NWT residents by providing direction to stakeholders involved in these projects. For example, the Epidemiology and Disease Registries Unit is responsible for maintaining a territorial database of tuberculosis patient files dating back to the 1950s. This database allows public health nurses to easily retrieve patient files and make clinical decisions based on past treatment and diagnoses. The NWT Immunization Registry is another example of a project conducted by the Epidemiology and Disease Registries Unit that works toward the DHSS mission.

In 2012, the NWT Public Health Act mandated that health care providers report all immunizations administered in the territory to the Chief Public Health Officer (Northwest Territories Department of Health and Social Services, 2012). The immunization registry was thus established to provide an electronic record of all immunizations reported to the Office of the Chief Public Health Officer. After the introduction of the immunization registry, each community health centre was required to submit a spreadsheet at the end of each month indicating all vaccines they had administered. The health centres were obligated to record and report the information outlined in the NWT Public Health Act, including health care number, name, date of birth, gender, date of immunization, vaccine name, vaccine brand, manufacturer, lot number, route of immunization, site of immunization, immunization series, and volume/quantity of immunization. When a child is vaccinated, the health care professional records the required information on the child's immunization card, also referred to as a physical immunization record. The vaccine information is then entered into a spreadsheet, normally by an administrative assistant, which the health centre would submit at the end of the month. Exhibit 1 highlights the process from vaccination to reporting all vaccines administered at the health centre to the Office of the Chief Public Health Officer.

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The NWT's DHSS tasked an intern, Janet, with conducting an immunization coverage analysis to establish the level of immunizations delivered throughout the NWT among the cohort of children born between 2012 and 2014 inclusive. Janet was also tasked with conducting an audit of the immunizations that were recorded for the same cohort of children. The immunization coverage analysis identifies the territories' vulnerability to vaccine preventable diseases; however, Janet could not conduct this analysis until an evaluation of the immunization registries data was completed. Conducting the audit first was crucial to determine if a vaccination record was incomplete or incorrect prior to determining the percentage of the population that was fully vaccinated. For example, during the audit Janet discovered that there were several children born outside the NWT who were fully vaccinated, but had incomplete immunization records (i.e. no date of immunization). Not conducting the audit first would likely result in dismissing vaccines that were administered outside of the NWT (due to incomplete vaccine record) and therefore, children born outside of the NWT would likely have been reported as having incomplete vaccination records. The Territorial Epidemiologist, Laura Young, also challenged Janet to identify creative solutions that would enhance the reliability and validity of the data within the NWT Immunization Registry.

In the NWT, physicians or community health nurses administer publicly funded vaccines. At the time of administration, the physician or community health nurse records the vaccine name, manufacturer, lot number, quantity, etc. into the patient's chart. The vaccination record is then entered into a spreadsheet by the community health nurse or administrative staff. At the beginning of every month, the community health nurses are required to submit the spreadsheet, containing all vaccines administered in the previous month, to the Office of the Chief Public Health Officer. Each month the DHSS receives 33 spreadsheets, one for each community in the NWT. The Disease Registry Officer (DRO) validates demographic information such as patient name, date of birth, gender, and residence with information in the spreadsheet and the NWT Healthcare Management Information System. Exhibit 1 demonstrates how vaccines are administered and reported in Community Health Centres with the purple arrows.

To begin an audit of the existing immunization registry, Janet needed to locate and collect all newborn vaccine records to establish a true source for comparison against the existing registry. Since the NWT does not require health professionals to report vaccines that patients have received outside the NWT, the existing immunization registry presents incomplete records for several children. The physical immunization records present a complete record of all vaccines children have received, including vaccines administered outside the NWT. Therefore, the true source used for the NWT immunization registry audit was an amalgamation of all physical immunization records submitted to the DHSS. Furthermore, it was essential to use the original data submitted to the DHSS for comparison against the true source, as this would provide the ability to capture all errors in the original data submitted by the community health centres.

Janet began the audit by sending a request to all 27 health centres in the NWT asking that all immunization cards (i.e. paper records) for children born between 2012 and 2014, inclusive, be faxed through the DHSS's secure fax line. When the immunization cards arrived at the DHSS Janet abstracted the information and compiled the data in a spreadsheet. It took Janet almost six weeks to enter approximately 3,000 physical immunization records, equaling 26,000 immunizations, into the spreadsheet. Once the data were entered they needed to be cleaned: duplicate immunizations removed and missing immunizations identified. After the cleaning process was completed, Janet summarized the audit and conducted a full coverage analysis. The gray arrows in Exhibit 1 summarize the steps performed by Janet to complete the audit of the NWT Immunization Registry.

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### UNDERSTANDING THE NORTH

Receiving an average of 20 hours of sunlight during the summer and five hours in the winter, the Northwest Territories is the home of 11 official languages (Canadian Immigrant, 2011). The 43,234 residents of the NWT are dispersed throughout 33 different communities, 21 of which are fly-in only. These communities vary in population size from 70 to 20,000 residents (NWT Bureau Statistics, n.d.). Residents of NWT's fly-in communities face multiple challenges from high transportation costs on most consumer goods, to the inability to foster further economic development due to lack of education and training opportunities near their communities.

Northern public health also presents several challenges, particularly around remote northern communities where resources are limited. In the NWT there are only three birthing hospitals. All of the other communities are equipped with a health centre with trained nurses. Mothers from outside a birthing community are required to fly to the nearest birthing community four weeks prior to their due date to prepare for child birth. The birthing communities have established boarding homes for mothers and their families that offer various services, such as a shuttle to and from the hospital. Furthermore, the NWT has a difficult time recruiting and maintaining health care professionals in their remote and rural communities, which makes it difficult to meet the mission of the DHSS to protect and provide for the health and well-being for all of the NWT (NWT DHSS, n.d.). Due to the limited number of nurses at some of the community health centres, communication between the health centres and the DHSS is often quite difficult. Emails from the DHSS can sit in the health centre's inbox for weeks before the DHSS receives a reply, often due to limited staff, new staff, or the centre's hours of operation. In several health centres across the NWT there is only one nurse, referred to as the nurse in charge, who is responsible for everything from immunizations to traumas and daily paperwork.

During Janet's practicum with the DHSS she quickly began to understand the impact of living in a small Northern community. When a community of merely 100 individuals is faced with an outbreak, the DHSS is often confronted with several barriers they need to overcome to protect the health and well-being of the NWT. Laura Young realized that not all rules and guidelines proposed by the Centers for Disease Control and Prevention (CDC) or the Public Health Agency of Canada (PHAC) could be directly applied in the Northern setting. For example, in January of 2015, several cases of Pertussis were reported in *Community X*. It was later discovered that the index case attended a daycare facility, and, as per CDC guidelines, the daycare centre was closed down, and parents were forced to find alternative childcare. After the closure of the day care facility several small in-home day care facilities started. Unfortunately, the creation of multiple in-home day care facilities did not eliminate the transfer of disease among the children. Of the 22 children who attended the day care, 12 were confirmed Pertussis cases, while an additional 17 of 78 third party contacts were also identified as confirmed Pertussis cases. During outbreaks public health officials are often under a lot of pressure to stabilize the situation; therefore, having guidelines can help them manage it. However, the 2015 NWT Pertussis case emphasized that guidelines are only as good as the environment for which they are designed.

### DATA QUALITY

The Government of the Northwest Territories' Population Health Division's projects focus on monitoring the health of residents in the NWT and evaluating different health services that are offered throughout the territory. The immunization registry is used to document all immunizations administered within the NWT. It is essential that the Division has reliable and accurate public health data to monitor the health of the territory and evaluate health services offered throughout. When conducting the audit, Janet came to realize that the data in the immunization registry was far from complete.

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The NWT population is constantly fluctuating, as the territory often attracts workers and their families from southern parts of Canada. Furthermore, NWT residents are also very mobile and do not tend to reside in one location for very long. With a transient population, several challenges arose in maintaining a complete health record for people in the territory. Janet focused on the challenges specific to maintaining a complete immunization record for newborns. The immunization registry was not designed to track children's immunizations administered outside the NWT. When families move to the NWT and visit the community health centre they are required to bring their child's immunization card with them to inform the health centre of immunizations they have already received. Unfortunately, it has been estimated that 30% of parents and legal guardians lose their child's immunization card before they are seven years old (Laroche, 2012). Referring back to Exhibit 1, after the child receives their vaccination it is recorded on their physical immunization card by the healthcare provider. A copy of the child's immunization card is kept in their patient chart, while another copy is kept with the child's parent or legal guardian.

There is currently no policy in place regarding the transcription of child immunization records from their previous province/territory. The inconsistency in record entries amongst community health nurses presented a gap in the NWT immunization registry. For example, Janet identified that when a child's previous immunization record was available, some nurses would manually copy all of the information onto the child's new NWT child immunization card, while others would only copy the date. However, when a child's immunization records were not available, nurses often consulted the child's parent (or legal guardian) to determine which immunizations the child has already received. When Janet entered the data from the individual immunization records into the spreadsheet, she started to question the integrity and validity of the data on the cards that had been transcribed from immunization records in other jurisdictions. Janet discovered that there were a lot of data that went missing during the transcription process.

Some communities record a single immunization event in up to three different locations (e.g. patient chart, spreadsheet for reporting to the Office of the Chief Public Health Officer, and electronic information system). The information that is documented by the health care professional on the immunization card is normally passed along to an administrative assistant to manually enter into the reporting spreadsheet. Unfortunately, the administrative assistants may not know the abbreviations for vaccines, routes, manufacturers, etc. and do their best to transcribe the cards. For these reasons, notations such as "LUL" instead of "LVL" (an abbreviation used by some nurses for left vastus lateralis) are used.

While conducting an audit of the immunization registry, Janet obtained the names, health care numbers, and addresses of children born between 2012 and 2014, inclusive, from the DHSS Healthcare Management Information System. This data not only provided Janet with the opportunity to validate the data she entered, but also to determine if there were children born between 2012 and 2014 who did not receive any immunizations. Exhibit 2 highlights the errors that were identified during the comparison between the electronic immunization records and paper immunization records for a single community.

Exhibit 3 highlights a few high problem areas including Brand Name, Health Care Number, Route, Date of Birth, and Name. Several communities have had the tendency to use trade names instead of brand names, resulting in large error rates in four of the five regions. The format of dates was also a common error in all regions. Some of the larger regions did not have this problem because they had an information system that auto-populated demographic information. Accents and multiple names (i.e. joined by dashes or space) were often the cause of errors with respect to name. It is important to note that the NWT health care number begins with a letter and is followed by seven unique characters. The letter at the beginning of the health

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care number identifies the child's aboriginal status. When a child is first born they receive a health care number in the format of N#####, where 'N' represents Non-Aboriginal. Parents must apply to have their child's health care number changed to match their aboriginal status; for example, H##### is consistent with an individual who identifies themselves as Métis. The majority of health care number errors were caused by incorrect status characters. Since NWT health care cards do not expire for three years, if a child's status is changed during this time period it will not be reflected on their physical card until they receive a new card at their third birthday. Therefore, every time they present their health care card to obtain health services they will be incorrectly identified as non-aboriginal.

Without reliable and accurate data the DHSS cannot determine how vulnerable a population is to certain vaccine preventable diseases. How reliable is a spreadsheet as a population health registry? How can real-time analysis be conducted in the middle of an outbreak with 33 rural and remote communities? These questions were lingering in Janet's mind as she prepared to establish a creative solution to address the data integrity issues with which Laura Young had challenged her.

### IMMUNIZATION COVERAGE

Immunization coverage analysis helps the DHSS determine how well protected the NWT is from vaccine-preventable diseases. The analysis also helps evaluate the effectiveness of programs in the different communities, as well as the parental perspective of immunization. High rates of immunization coverage in a community present the opportunity for that community to reach herd immunity, whereby individuals who did not receive their immunizations will be protected by the rest of their community who have been immunized. The concept of herd immunity exists due to the fact that the probability of disease transmission decreases with an increase in the number of individuals who are immunized (Public Health Agency of Canada, 2010).

While examining the 2012 to 2014 cohort, Janet noticed that several parents were deferring their child's immunizations, and even more were refusing them all together. Health professionals have several theories for parents' refusal of immunizations, varying from celebrity influence to misleading and conflicting online resources (Busby & Chesterley, n.d.). In fact 59 (3%) parents in the 2012 to 2014 cohort refused to vaccinate their children. There is currently no place for healthcare providers to identify that an immunization has been deferred or refused. Since Janet obtained all of the original paper immunization records from the communities and entered them all into the computer, she was able to track those where the healthcare provider had written 'refused' on the card. It is likely that the true number of refusals is higher.

Janet conducted a thorough immunization coverage analysis of the cohort of children born between 2012 and 2014, inclusive, who had at least one immunization record at the DHSS. Children born in 2012 were considered fully vaccinated if they received all seventeen immunizations by their second birthday with the correct spacing as indicated by the NWT immunization schedule. Similarly, children born in 2013 were considered fully vaccinated if they received all fifteen immunizations by their first birthday with the correct spacing as indicated by the NWT immunization schedule. Children born in 2014 were considered fully vaccinated if they received all doses of the vaccines on the NWT immunization schedule with the correct timing by the end of the follow up period. Children who did not receive all doses of a vaccine, or did not follow the NWT immunization timing, were considered partially vaccinated. Children who did not receive any immunizations were considered not vaccinated. Although data was collected in May of 2015, for children born in 2012 child immunization status was assessed on their second birthday. Janet also conducted a follow up analysis to assess coverage after the cohort turned two years old, and those who were completely immunized were now considered "completely

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vaccinated by end of follow up". Exhibit 4 includes results from the coverage analysis for Community X.

### **FEASIBILITY**

While working on the immunization audit Janet began to question whether the DHSS should continue to use its current immunization registry or invest in a new information system to support the immunization registry. The DHSS employs one full time Disease Registries Officer to maintain the existing immunization registry. It is the responsibility of the Disease Registries Officer to validate the information submitted to the DHSS in the spreadsheets from the community health centres regarding immunizations administered in the past month. The Disease Registries Officer then amalgamates the spreadsheets from all the communities to form the existing immunization registry. The process of data validation is timely, tedious, and sometimes incomplete.

If the DHSS conducts an immunization coverage analysis without requesting the paper immunization records it is likely that the NWT immunization coverage rate would be underestimated. Exhibit 2 highlights the tremendous discrepancy between the number of immunization records reported monthly to the DHSS through the spreadsheet and those from the physical immunization cards. This table emphasizes the importance of collecting the physical immunization records from the communities prior to conducting a coverage analysis. For example, Region 4 was missing 58% of its immunizations records. Therefore, conducting an immunization coverage analysis with the registries' data alone would not provide accurate community level projections. Although it was a cumbersome task, if Janet had not entered all child immunization records, the DHSS would have missed 36% of vaccinations.

As the end of Janet's placement approached, she realized that the key to Laura's challenge was not only to be creative, but also to be resourceful and collaborative. With an extremely high turnover of nurses in the communities any data integrity solution was only going to be as good as its end user. Therefore, incorporating the nurses in the planning process was essential to success.

### **RECOMMENDATIONS**

Although the DHSS was working toward the implementation of a new information system to support the immunization registry, it was unclear as to when implementation of the system would take place. In the meantime, there were several things that needed to be taken into consideration to improve data quality. A large portion of the errors could be eliminated with the creation of a new data entry template with vaccine, brand, manufacturer, site, and route names embedded in the program. Janet also identified that errors in name, date of birth, and community could also be minimized by auto-populating the corresponding fields by health care number. Janet's creative solution to Laura's challenge involved creating a data entry form in Microsoft Excel to be sent to each community health centre to enter their monthly vaccines administered.

Through collaboration with the DHSS Communicable Disease Consultant in charge of the NWT immunization program, Janet also recommended that the vaccine names, brand names, and manufacturer names be consistent and up to date with those provided by the National Advisory Committee on Immunizations (NACI). The most common variable that community health nurses substitute with their own terminology is 'site' (location on body where child was vaccinated); therefore, it is likely that the list provided on the current immunization registry was not comprehensive. Sequential roll out of the new data entry template would provide the DHSS Disease Registries Officer more time to deal with inquiries (i.e. calls and emails) from front line

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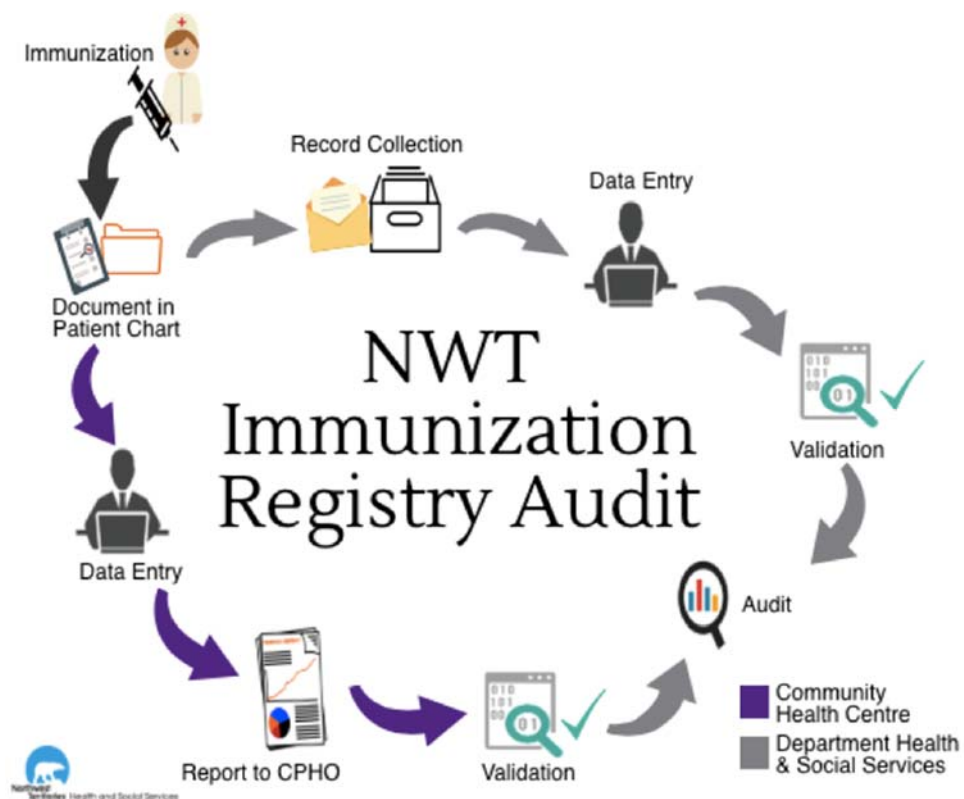
staff. Furthermore, feedback during each roll out could be used to improve the data entry form for the next community.

### **CONCLUSION**

The NWT is very unique and the health care guidelines followed should resemble its uniqueness in hopes of protecting the health and well-being of its people. Even though we might live in a time period where technological advancements have provided us with an increased access to data, by no means does this imply that the data are accurate and dependable. Although it is a time consuming process, data validation is crucial for maintaining an immunization registry that is reliable and accurate.

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## EXHIBIT 1 NWT Immunization Registry Audit



Source: Created by author.

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### EXHIBIT 2 Discrepancies Between Electronic Immunization Records and Paper Immunization Records

Health Centre	Cohort Summary		
	Paper records	Missing electronic records	Total flags
REGION 1	1620	646(39%)	1510(93%)
REGION 2	1467	354 (24%)	1145 (78%)
REGION 3	517	96 (19%)	424(82%)
REGION 4	737	431 (58%)	593(80%)
REGION 5	645	261 (40%)	550(85%)
TOTAL	4986	1778 (36%)	4222(85%)

Total records = Total number of unique immunization records

Missing records = Number of paper immunization cards that were not in the electronic immunization registry

Total flags = Total number of records that had one or more errors

Source: Northwest Territories Department of Health and Social Services, n.d.

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### EXHIBIT 3 NWT Immunization Registry Audit

Health Centre	Total Records	Name	Health Care No.	Date of Birth	Vaccine Date	Vaccine Name	Brand	Manufacturer	Lot Number	Route	Site	Series	Quantity
<b>Region 1</b>	4566	17.1%	47.4%	5.7%	7.5%	1.0%	23.3%	36.9%	9.8%	18.3%	2.5%	13.4%	1.1%
<b>Region 2</b>	3788	10.2%	58.4%	3.1%	5.2%	0.3%	22.2%	28.4%	8.4%	16.5%	1.4%	12.5%	1.0%
<b>Region 3</b>	1515	12.3%	55.8%	4.9%	9.4%	2.0%	21.1%	28.1%	9.2%	19.3%	1.3%	21.8%	2.2%
<b>Region 4</b>	2255	8.7%	34.7%	2.0%	6.4%	9.9%	13.5%	11.3%	8.2%	3.3%	0.0%	6.6%	3.0%
<b>Region 5</b>	10647	6.6%	43.4%	1.5%	5.9%	0.4%	16.0%	15.2%	7.6%	7.1%	0.7%	17.4%	1.3%
<b>TOTAL</b>	22,771	9.9%	46.7%	2.9%	6.4%	1.6%	18.6%	22.2%	8.3%	11.3%	1.2%	15.0%	1.4%

\*\*NOTE: Numbers are not representative of real regions in the NWT. The numbers have been changed for confidentiality purposes until the report is released to the authorities.

Source: Northwest Territories Department of Health and Social Services, n.d.

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### EXHIBIT 4 Community X n=237 Percent of Cohort Receiving Immunizations

Vaccine	Number of doses	% coverage rate (95%CI)
Hepatitis B	2	49.1 (43.0-55.1)
Bacillus Calmette-Guerin	1	85.7 (80.6-89.6)
Diphtheria, tetanus, acellular pertussis, inactivated polio, Haemophilus influenza type B	4	65.2 (59.1-70.9)
Meningococcal conjugate C	2	90.4 (86.1-93.5)
Pneumococcal conjugate 13	4	52.7 (46.6-58.8)
Measles Mumps Rubella	2	81.86 (76.67-86.13)
Varicella	2	81.5 (76.1-85.9)
Rotavirus	2	46.3 (41.6-51.0)

\*\*NOTE: Numbers are not representative of a real population in the NWT. The numbers have been changed for confidentiality purposes until the coverage analysis is released to the public.

Source: Northwest Territories Department of Health and Social Services, n.d.

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## INSTRUCTOR GUIDANCE

### Vaccination Under the Midnight Sun: Validation of an Immunization Registry in the Northwest Territories

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*Amanda Terry, PhD (Assistant Professor, Western University)*

#### BACKGROUND

With the implementation of mandatory reporting of all immunizations in the Northwest Territories (NWT) in 2012, the Department of Health and Social Services' (DHSS) Disease Registry Unit was working toward the implementation of a new immunization registry similar to those implemented across the country. However, the current immunization registry was in the format of an Excel workbook. The DHSS noticed several issues with the quality of the data maintained in the spreadsheets. As part of Janet's practicum, she conducted an audit of the immunizations for the cohort of children born between 2012 and 2014, inclusive, within the registry.

Community health centres are required to submit immunizations they have administered via a monthly spreadsheet. The Disease Registry team then validates and cleans the information submitted and consolidates all the data into the immunization registry on one master Excel workbook. It is important to note that the original data submitted to the DHSS from the health centres is only added to the immunization registry after the Disease Registries Officer has confirmed that the data are clean.

To assess the validity and reliability of the data, the community health centres were contacted and asked to submit all paper immunization records for children in this cohort, which were then entered into another spreadsheet. The cohort spreadsheet and the immunization registry were compared to determine the number of errors across various variables.

To summarize, the audit was a comparison of the original community spreadsheet submitted to the DHSS with the paper immunization cards, which Janet entered into a separate spreadsheet to easily compare the two datasets.

#### OBJECTIVES

1. Recognize the challenges that arise when dealing with data from health services in remote northern communities.
2. Understand the importance of data quality when assessing a population's vulnerability to disease and public health initiatives.
3. Indicate the benefits of implementing a new information system to support the existing immunization registry in the NWT.
4. Interpret immunization coverage data.

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### **DISCUSSION QUESTIONS**

1. Why did Janet compare the spreadsheet she created (i.e. populated with data from paper immunization records) with the original immunization data (i.e. spreadsheets submitted from the community), instead of directly comparing it with the existing immunization registry?
2. What are some of the difficulties working with population level data in northern remote communities?
3. What are the advantages and disadvantages of establishing an Immunization Registry in the NWT?
4. Why would the DHSS be under-reporting immunization coverage if they did not perform an audit of paper immunization records?
5. What limitations does the NWT's mobile population present with respect to conducting a coverage analysis with the current immunization registry?

### **KEYWORDS**

Immunization coverage; immunization registry; information system; original immunization data; paper immunization records.

## CASE 6

### Safe Needles Save Lives

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*Zhe Li, BSc, MPH (MPH Class of 2015)*

*Shaya Dhinsa, BScN, MEd (Manager, Sexual Health, Middlesex-London Health Unit)*

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

“Anything else?” Maria, the director of Counterpoint Harm Reduction Service in Regional HIV/AIDS Connection (RHAC), asked as the needle exchange meeting ended. Silvia, the manager of the Sexual Health Department at the Middlesex-London Health Unit (MLHU), felt challenged when she was asked to present recommendations for the development of the needle exchange programs in London. She knew how important the needle exchange service was, but she also realized how far behind this service was in London.

#### BACKGROUND

Silvia had been working at the MLHU for 11 years, responsible for managing programs and personnel in the Sexual Health Department. The Department is committed to offering sexual health education, promoting healthy decisions, and providing a confidential and comfortable atmosphere for discussing sexual health questions or concerns (Middlesex-London Health Unit, n.d.b.). It runs a clinic for birth control and Sexually Transmitted Infections (STIs). In collaboration with RHAC, the MLHU has operated the Counterpoint Needle Exchange service through the sexual health clinic. People who inject drugs can dispose of used needles and pick up clean injection equipment through a needle exchange service. Public health nurses give out sterile needles/syringes to drug users without limitations. Supplemented by health education, the needle exchange service aims to help prevent needle sharing and thus, reduce the possibility of transmitting diseases such as HIV, Hepatitis B, and Hepatitis C.

In 2014, a young child was injured by a used needle in a park, prompting public concern. Parents feared for the safety of their children playing in parks, and residents blamed the City for not managing needles and addressing the issues around injection drug use effectively. Some people even questioned the needle exchange service, arguing that health workers contribute to the increase of needles in society. Concerned by the public reaction, Maria called for a meeting to discuss possible measures of responding to the public's concerns. The MLHU, London Community Addiction Response Strategy (London CARES), The London Police Service, RHAC, My Sister's Place, and two community representatives gathered in downtown London to share opinions about London's needle exchange program.

The first meeting was held on April 17, 2015. Responsible for managing harm reduction services in RHAC, Maria was asked to facilitate the meeting. During the meeting, the needle exchange program in London was reviewed. Project details such as who distributes and collects needles and how services are managed were summarized. “It is important for us to improve the needle exchange program in London because more and more used needles have been found in public areas. We need to protect residents from needle stick injuries. Safe injection and safe needle disposal are our goals,” Maria said.

“We have been committed to collecting used needles and keeping the street free of discarded syringes. Seventeen stationary needle collection bins have been installed at locations in

downtown and priority areas for safe needle disposal. Outreach team members also take responsibility to pick up needles that have been discarded inappropriately,” said Paul, the representative of London CARES.

“Do you think we should install more stationary needle collection bins?” asked Kris, the representative of London Police. “If more collection bins are available, dirty needles that drug users discard inappropriately might be fewer.”

“I don’t think the number of collection bins is the sole issue. I know some residents complain about needle exchange services, suggesting that needle exchange programs attract more drug users. Public awareness is too low,” Silvia replied.

“The number of clients coming to the Counterpoint Needle Exchange program dropped recently, and the number of clean needles distributed this season was lower than that of last season,” Maria said.

“We understand the importance of needle exchange services and really appreciate what public health organizations have done to promote safe drug injection, but I have to say that residents in our communities are afraid of these services. The installation of stationary needle collection bins attracts more drug users to our communities, which makes many parents worry about their children,” opined Mandy, the representative of South London Communities.

“It cannot be denied that there are still many residents not supporting our services,” Maria noted to Silvia.

Silvia asked the group, “Maybe we have to advocate health education campaigns to increase public awareness about safe needle disposal?”

“Do you have evidence to support the needle exchange program?” Kris asked. “My duty is to keep the city free of crimes and I do not want to see more criminal cases result from needle exchange.”

“Absolutely. Scientific evidence has shown the value of needle exchange programs. Many clients in our organizations have reflected that these services are helpful,” Maria replied.

“I know you are the director of RHAC and your priority is the health of intravenous drug users, but we have to consider the public’s perception. They are afraid of used needles that are discarded inappropriately in parks and public toilets. How could you persuade residents to accept these services and how do you ensure their safety?” Kris countered.

“I agree that taking actions to improve these services to ensure safety is important,” Mandy said.

Though possible measures were discussed in the meeting, without sufficient evidence it was hard to determine how to improve the needle exchange program in London. “I suggest that we review national and international needle exchange programs to see what services they offer and how needle exchange programs are operated in other areas. After comparing programs in different areas, we can identify the gaps. By addressing these gaps, I believe it will be easier for us to improve London’s needle exchange program,” Silvia said.

Everyone agreed with Silvia’s opinion, and since she had the most experience in managing needle exchange programs, she was asked to perform the task of reviewing national and

international programs to make recommendations for the development of London's needle exchange program.

Ten minutes after the meeting ended, Maria and Silvia were still sitting in the office. "People seem to have different opinions about program improvement," Maria said.

"It's because they have different priorities." Silvia looked at her to-do list in the calendar, feeling stressed by the task. The next meeting would be held in four months. How to promote safe injection and safe needle disposal remained an urgent issue in London. She decided to review national and international needle exchange programs first, and then discuss the gaps with the sexual health team before she started writing the report to present her recommendations.

### **THE HARM REDUCTION AND NEEDLE EXCHANGE PROGRAM IN LONDON**

Harm reduction practices have been identified as an effective and promising approach to drug use. Instead of focusing on getting drug users to quit using, the principles of harm reduction are to reduce the harms associated with drug addiction (Ontario Harm Reduction Distribution Program, n.d.). By providing clean needles and syringes without a limit on the amount, the harm reduction approach encourages drug users to access the supplies needed to ensure they are injecting drugs safely and prevent the spread of blood-borne diseases. Scientific evidence has shown the value of needle exchange services, and needle exchange programs have been developed in various countries (Ontario Harm Reduction Distribution Program, n.d.).

In response to the increasing incidence of intravenous drug use and disease transmission, the Counterpoint Needle Exchange program began in London, Ontario in 1992. In collaboration with the RHAC, the MLHU has operated the needle exchange service through the sexual health clinic (Regional HIV/AIDS Connection, n.d.). Funded by the Ministry of Health and Long-Term Care, this program provides people who inject drugs with injecting equipment (e.g. syringes, needles, cookers, alcohol swabs, safer inhalation kits, and filters), education, referrals, and naloxone training. To serve more people, the street and mobile outreach team travels in an unmarked van to pick up used needles as well as respond to calls to the needle exchange service. This service is available in London from Monday to Friday, 11am-6pm (Regional HIV/AIDS Connection, n.d.).

All needle exchange fixed sites and mobile outreach units offer services for safe needle disposal. To increase safety, London CARES, initiated in 2008 by the City of London, set up a syringe recovery program as a small part of their Homeless Coalition and focused on picking up used needles on the street. Funded by the City of London, "London CARES is a highly collaborative community-based Housing First service aimed at improving the health and housing outcomes of individuals experiencing homelessness" (City of London, 2016a). The outreach team works 24 hours a day, seven days a week in London to keep the street free of used needles and decrease risk of transmission and exposure to blood-borne infections. In order to assist with safe needle disposal, the City of London has installed seventeen stationary needle collection bins throughout the city, primarily in the downtown core and in priority locations (City of London, 2016b). The outreach team with London CARES takes responsibility of maintaining stationary needle bins and going to "hotspots" to pick up needles that have been discarded inappropriately (City of London, 2016a). Before the establishment of London CARES, all needles were exchanged through needle exchange programs with one person providing mobile outreach with limited hours, and there was no outreach team picking up needles across the city available 24 hours a day, seven days a week (S. Dhinsa, personal communication, July 10, 2015).

The different stationary needle bins managed by London CArES are located around and outside the city and are primarily located for easy access for IDUs (S. Dhinsa, personal communication, July 10, 2015). Even though the original intent was for disposal of prescription syringes, such as those used for insulin etc., these containers are often used by intravenous drug users (IDUs).

According to statistics, 1,582,888 needles were distributed and 31,647 returned through Counterpoint in 2014 (2% return rate), and 642,922 distributed and 1,002,800 returned through IDU outreach (156% return rate). The overall needle return rate in 2014 was 46%. In the last 2.5 years, the return rate at the Counterpoint fixed site was 25%, and IDU outreach achieved 56%. The total rate was 43% in the last 2.5 years (S. Dhinsa, personal communication, July 10, 2015).

### **TWO MONTHS LATER...**

It had been two months since the first meeting ended. In this period, Silvia and her team had scanned and reviewed national and international needle exchange programs (see Exhibit 1) and broadly identified the gaps in London's needle exchange program compared to other jurisdictions. Before the recommendations were to be presented, a town hall meeting was held on June 23, where discussion of safe injection and safe needle disposal took place.

"Currently, there is a research project in London. The City wants to see if a Safe Injection Site is feasible. There is also a Community Drug Strategy. It has been launched for safe drug injection. I heard from RHAC and London CArES that they are organizing a campaign, which will focus on community clean-up and the needle exchange program. Based on the result of the environmental scan, what do you think we should do to improve the needle exchange program?" Silvia asked.

"The gaps between London and other areas were identified. Compared with Toronto's needle exchange services, London's needle exchange program does not have a strong partnership with communities. In Toronto, the City of Toronto, Toronto Public Health, community health centers, non-profit health organizations, and hospitals have participated in needle exchange programs. However, in London, the current service providers include only the MLHU, RHAC, My Sister's Place, and London CArES. It seems that creating a stronger partnership with communities should be the initial step to improve our program," Kandy, one of Silvia's colleagues, said.

"I believe we should install more needle recovery bins first. As you can see, the number of needle bins in Ottawa is more than four times that in London. I personally believe that the number of needle bins in Ottawa is closely related to their higher return rate. To protect residents from needle stick injuries, we need to ensure that no needles are thrown in public areas," Sean, another colleague, said.

"I agree, and I think we need to encourage more businesses to participate in safe needle disposal. I think we can follow Melbourne's footsteps to encourage restaurants, libraries, theatres, gyms, etc. to install needle bins," Kandy replied.

"Don't you think we should focus on health education first? Compared with Vancouver, London has had less public involvement. Some communities refuse to install needle bins in their neighbourhoods because they are afraid of drug users. I think we could take some of the lessons learned from Edmonton, by designing posters and a safe needle disposal toolkit, giving presentations in the community to educate people that drug use should not be discriminated

against, and teaching the public how to deal with used needles safely. Public awareness is very important,” Silvia said.

“Personally, I believe we should try to use social media platforms to engage with more people. It may be helpful to educate people about the existence of needle exchange services in London,” Andy, the program coordinator said.

“We also need more service models. Pharmacies are not controlled by the City of London, so they do not provide needle exchange services. Some drug users are not willing to access services because most are offered by governmental organizations. An option to explore may be to install needle vending machines and encourage pharmacies to provide services to increase availability and accessibility,” Andy continued.

The town hall meeting made Silvia feel that there were many areas that needed to be further analyzed. She had completed the program review, and her next challenge would be how to find the best practice examples of needle exchange services and make effective recommendations. The next meeting was scheduled for one month away. “How can I make recommendations that are effective and realistic? How can we promote safe drug injection and safe needle disposal?” she wondered.

**EXHIBIT 1**

**Environmental Scan Table: Needle Exchange Program Overview**

Note: This exhibit is an amalgamation of information on distribution, collection, exchange and disposal services from different sources that has been adapted or taken verbatim from the sources cited.

**Toronto**

**The Works**

The Works is Toronto Public Health's Harm Reduction Program for people who use drugs. Toronto Public Health (TPH) provides programs and services to reduce drug related harms for people who use drugs including preventing the spread of communicable diseases.

The Works opened its doors on August 9, 1989. During the last 25 years, The Works has played an integral role in reducing drug use related harms in Toronto by taking leadership in the area of harm reduction" (City of Toronto, n.d.a.).

Harm Reduction Supplies and Counselling

The Works in partnership with community agencies provides counselling and distribution of free harm reduction supplies (City of Toronto, n.d.a.).

Mobile Outreach

The Works Van is on the road Monday to Saturday from 6:30 pm – 11:30 pm. Services include: distributing harm reduction supplies & Counselling. POINT training, testing and vaccinations are also available (City of Toronto, n.d.a.).

Supervised Injection Sites

A recent Toronto Public Health report showed that the majority of participants (84-96% of residents) in a community consultation saw the benefits associated with implementing supervised injection services in Toronto (City of Toronto, n.d.a.).

Support for Community Agencies

In order to increase harm reduction access in Toronto, The Works provides safer drug use supplies, education and program support to many community agencies across the city (City of Toronto, n.d.a.).

Operated by City of Toronto and Toronto Public Health, The Works needle exchange program is responsible for disposal of discarded needles. The return rate of The Works in 2010 was 74%, and the average return rate between 2010-2015 was 70%.

### **Street Health**

Street Health is a non-profit community based agency that strives to improve the health and well-being of homeless and under-housed people in downtown Toronto. It offers physical and mental health programs, as well as supports that improve clients' ability to access other services. Its work is focused in the neighborhood around Dundas and Sherbourne Streets, an area with the largest concentration of homeless shelters and drop-in centres in Canada. On an average day, 115 clients visit Street Health, and it has approximately 40,000 client visits each year (Street Health, n.d.a.).

Street Health clients have lives characterized by extreme poverty, chronic unemployment, housing insecurity, poor nutrition, high stress and loneliness. They also have more frequent and serious illnesses, and die younger on average than the general population (Street Health, n.d.a.).

In addition, people who are homeless, and those experiencing income insecurity, often cannot afford or have difficulty following medical treatment plans. Many people living on the street have difficulty accessing mainstream health services due to barriers such as lack of valid ID, the cost of transportation or social stigma (Street Health, n.d.a.).

Street Health's Harm Reduction program provides supports for community members dealing with addiction issues and the risks associated with substance use. It offers a needle exchange and stem distribution, as well as education and drop-in programming (Street Health, n.d.a.).

Safer drug use kits for both injection and smoking are also provided. These can be obtained on site at Street Health during office hours or through outreach services. (Street Health, n.d.b.).

Street Health employs a team of dedicated peer workers, who have lived experience with drug use and homelessness, to help facilitate drop-in programs, distribute supplies and educational materials on site, as well as provide street outreach (Street Health, n.d.b.).

### **2 Spirited People of the 1st Nations**

2 Spirited People of the 1st Nations is a non-profit organization that strives to support Aboriginal people with HIV/AIDS. It offers services such as HIV/AIDS education and prevention, needle exchange, same sex domestic violence information, referrals, etc. (2 Spirited People of the 1st Nations, 2015).

### **Regent Park Community Health Centre**

Regent Park Community Health Centre (RPCHC) was established in 1973, and is a non-profit, community-based organization dedicated to improving the health of Regent Park area residents (Regent Park Community Health Centre, n.d.a.).

Its staff distribute harm reduction information and materials on site and during outreach shifts. Workers provide information, referral and support to health and social services. Needle exchange supplies include stem kits, sharp containers, distilled water, ascorbic acid, syringes, alcohol swabs, filters and condoms (Regent Park Community Health Centre, n.d.b.).

### **Coordinated Access to Addiction Service, St. Michael's Hospital**

Coordinated Access to Addictions Services is a central number...that individuals, family members and community agencies can call for addiction support within the City of Toronto (St. Michael's Hospital, 2013).

Coordinated Access has links to 35 addiction support provides as well as a number of community based networks, including:

- Residential, day and community withdrawal services
- Residential and community treatment
- Services for people with concurrent mental health and substance use problems
- Services to minimize the harm caused by an addiction (e.g. needle exchange programs)
- Rapid access to medical clinics
- Community case workers
- Family programs

(St. Michael's Hospital, 2013).

The emergency department [of St. Michael's Hospital] offers a 24 hours per day, seven days per week needles exchange for injection drug users (St. Michael's Hospital, n.d.).

### **City of Toronto**

#### City Parks

In Toronto, residents can contact 311 to submit a service request for pick-up if sharps have been discarded on the road, sidewalk, or boulevard. If needles are found in city parks, residents can report the incident to the park supervisor (City of Toronto, n.d.b.).

#### School Property

Custodial staff check school property every morning for needles. If they find a needle, it is usually reported to the school principal, and is placed in a sharps container and retained in a safe location. The school board coordinates the collection of all sharps containers for proper disposal (City of Toronto, n.d.b.).

#### Private Property

According to the City of Toronto, "individuals are responsible for disposal of sharps found on their residential property. Property management of an apartment building/commercial building is responsible for picking up and disposing of discarded sharps found on the property" (City of Toronto, n.d.b.).

## **Ottawa**

### **City of Ottawa**

The City of Ottawa's Clean Needle Syringe has been in operation since 1991 and provides the following services:

- General counselling and support
- Health education/promotion
- Substance use counselling
- Harm Reduction supplies

- Needle/syringe disposal
- Condoms and lube
- Confidential hepatitis B and C testing
- Confidential testing for gonorrhea, chlamydia and syphilis
- Hepatitis A/B and influenza vaccination
- Anonymous HIV testing
- Emergency Contraception (Plan B)
- Pregnancy testing
- Referral to health and social service agencies including drug treatment services
- Peer Overdose Prevention Program (POPP)

(City of Ottawa, n.d.a.).

Fixed-site services are open from Monday to Friday, 8:30-4:30. The mobile outreach van works 7 days a week from 5pm to 11:30pm (City of Ottawa, n.d.a.).

### Needle Hunters Program

The Needle Hunters Program is a part of the City of Ottawa's corporate response to discarded drug paraphernalia including needles and crack pipes. The Needle Hunters are a group of people who proactively search for and dispose of these items in priority neighbourhoods across the City (City of Ottawa, n.d.b.). In 2015, the Needle Hunters recovered 17,169 needles and 1,531 crack pipes (City of Ottawa, n.d.b.).

### **Sandy Hill Community Health Centre**

The Sandy Hill Centre provides medical and social services for people living with, or concerned about HIV and/or hepatitis C, and who encounter barriers to services because they use street drugs, have a mental illness, are homeless or are involved in the sex trade. Its services include a drop-in center, medical staff, counselling, street health outreach, an experienced dietitian, needle exchange services and complementary care (Sandy Hill Community Health Centre, 2014).

### **Wabano Centre for Aboriginal Health**

The award-winning Wabano Centre for Aboriginal Health provides a wide range of medical clinics, social services and support, and youth programs for Ottawa's nearly 40,000 Aboriginal people (Wabano Centre for Aboriginal Health, n.d.b.).

### **Ottawa Public Health**

#### Needle Drop Box Program

It is illegal to dispose of needles, crack pipes (glass stems), or other sharps in the garbage or recycling as per the City of Ottawa's by-laws (By-law 2009-396 Schedule J). As a result Ottawa Public Health has created the Needle Drop Box Program, which provides secure and tamper-proof drop boxes located at 78 locations across the City to allow for the safe and convenient disposal of sharps. In 2015, approximately 876,765 needles were retrieved from the Needle Drop Boxes (City of Ottawa, n.d.b.).

### Working with City services to quickly respond to discarded needles

Ottawa Public Health works with other City departments through the City Contact Centre 3-1-1 to respond to requests for the pick-up of improperly discarded used needles. The City targets a response time of one hour for all needle retrieval requests (City of Ottawa, n.d.b.).

### Working with individuals who use needles

Ottawa Public Health operates the Site Clean Needle Syringe Program, which is based on the principle harm reduction by providing clients with an adequate amount of sterile needles to meet their requirements for safe injecting. The main goal of this program is to prevent the spread of communicable diseases, primarily HIV and Hepatitis C, and minimize the risks associated with substance use in the greater community. It also educates intravenous drug users on proper safe needle disposal, provides sharps containers and information on disposal locations. In 2015, the Site Clean Needle Syringe Program and its partners retrieved approximately 453,371 discarded needles (City of Ottawa, n.d.b.).

According to the Needle Report, in 2009, 366,895 sterile needle syringes were distributed through the Site Clean Needle Syringe Program, and the needles recovered by Ottawa Public Health and City partners, as well as Needle Hunters and needle drop boxes were 516,242 needles (141% retrieval rate) (Steve, 2009).

## Edmonton

### **Streetworks Needle Exchange Program (“Streetworks”)**

Established in 1989, Streetworks is funded by the Alberta Community HIV Fund, Alberta Health Services, and Alberta Health. The Streetworks team is composed of a Team Leader, three Nurses and four Outreach workers (Streetworks, n.d.). It offers services for injection drug users or those working in the sex trade. Services include nursing services (e.g. basic health check, HIV testing, and counselling), outreach services, referrals, harm reduction supplies, and prison programs (Streetworks, n.d.).

It also offers a free needle exchange service with six sites and a mobile van, and exchanges nearly 800,000 needles each year (University of Alberta, n.d.).

### **City of Edmonton**

#### Capital City Clean Up (CCCU)

Capital City Clean Up is the City of Edmonton’s year-round litter and graffiti management program (City of Edmonton, n.d.b.).

The City has installed 10 safe needles boxes in Edmonton for safe needle disposal, including two Eco Stations for safe needle retrieval (City of Edmonton, n.d.a.).

Other services provided include:

- An online Safe Needle Disposal Tool Kit
- Posters about needle safety aimed at children, general public and needle users.
- Information on how communities can explore the need for a safe needle box in their neighbourhood

(City of Edmonton, 2012).

#### Pharmacies

Pharmacies also provide needle disposal services (City of Edmonton, n.d.a.).

## Vancouver

### Insite

Insite is North America's first legal supervised injection site. Opening in 2003, it is operated by Vancouver Coastal Health which provides all the funding, senior administrative and health care workers for the facility (Vancouver Coastal Health, n.d.a.).

Insite operates on a harm-reduction model, with the aim of reducing the adverse health, social and economic consequences of drug use without requiring abstinence from drug use (Vancouver Coastal Health, n.d.a.).

### Services provided

The 13 injection booths where clients inject pre-obtained illicit drugs are overseen by a team of nurses, counsellors, mental health workers and peer support workers (Vancouver Coastal Health, n.d.b.). It also supplies clean injection equipment such as syringes, cookers, filters, water and tourniquets (Vancouver Coastal Health, n.d.b.).

Nurses provide overdose resuscitation, wound care and immunizations. Research shows that since InSite opened, overdoses in the vicinity of the site have decreased by 35% - compared to a 9% decrease in the city overall (Vancouver Coastal Health, n.d.b.).

Other staff at InSite connect clients to community resources such as housing, addictions treatment, and other supportive services (Vancouver Coastal Health, n.d.b.).

In 2014, crack pipe vending machines were installed at two locations in the Downtown Eastside. Much like the idea of giving out free needles, crack pipe vending machines are expected to improve health and safety on the streets by offering crack pipes for 25 cents apiece (CTV News, 2014).

The success of supervised injection sites and crack pipe vending machines reveals strong public support for harm reduction programs. Vancouver Coastal Health, the BC Centre for Disease Control, AIDS Vancouver Island, among others, are providing harm reduction supplies. Some programs offer peer group services. For example, DTES HIV/IDU Consumers' Board is an entirely peer-driven non-profit organization. It operates needle exchange 18 hours per day and 365 days per year. Statistics show that DTES HIV/IDU Consumers' Board distributes around 15,000 syringes per year (DTES HIV/IDU Consumers' Board, n.d.). A telephone survey of BC residents showed that 78% of people support harm reduction, 75% support needle distribution, and 54% support the distribution of safer inhalation equipment (Tzemis, Kuo, Harm Reduction Strategies and Services & Buxton, 2012).

### City of Vancouver

The Needle Recovery Program "coordinates recovery and safe disposal of inappropriately discarded needs" (City of Vancouver, n.d.).

### Australia

#### Needle distribution in Australia

The first Australian needle and syringe program began in Sydney in 1986. Since then, needle and syringe programs in Australia have aligned with the harm reduction framework, to reduce the spread of infections such as HIV and hepatitis C among IDUs (Dolan, MacDonald, Silins, & Topp, 2005). Currently, the service models for needle and syringe programs (NSPs) operated in Australia are needle and syringe exchange programs, health service-based NSPs, pharmacy-based NSPs, and needle vending machines (Dolan, MacDonald, Silins, & Topp, 2005).

Clean needles and syringes are provided to users through needle and syringe exchange programs. Typical examples are the Western Australian Substance Users' Association (WASUA) and the Western Australian AIDS Council (WAAC). These two non-government organizations receive funding from the Sexual Health and Blood-borne Virus Program (SHBBVP) (Communicable Disease Control Directorate, 2008). WASUA and WAAC are peer-based organizations and provide needle exchange services at fixed sites.

Fixed sites provide a range of services including injecting equipment, swabs, sterile water, filters, tourniquets, vein care cream, testing for blood-borne viruses (BBVs) and sexually transmitted infections (STIs), vaccinations, pharmacotherapy advocacy and education, and referral to support services (Communicable Disease Control Directorate, 2008).

WAAC operates a mobile van, making stops at ten sites within the metropolitan areas. The mobile van provides injection equipment, education, and referrals services (Communicable Disease Control Directorate, 2008).

Health service-based NSPs are provided by regional and rural hospitals, public health units, and community health centres (Government of Western Australia, 2014). Fitpacks® (five sterile needles and syringes, five plastic disposal sleeves, and information pamphlets), which are provided by the SHBBVP, are given to injection drug users (Communicable Disease Control Directorate, 2008). Fitpacks® are labeled with specific safe disposal information to educate people on how to dispose of used needles safely. Regional and rural hospitals that provide emergency after-hours services are also required to provide after-hours access to needles and syringes (Communicable Disease Control Directorate, 2008).

Pharmacy-based NSPs in Australia are run on a commercial basis. In Australia, all pharmacies can sell packaged injection equipment if they hold approval from the local health department (Dolan, MacDonald, Silins, & Topp, 2005). The packaged injection equipment is distributed in Fitpacks®, offered by City Council and Substance Use Association. Each Fitpack® is \$6 to \$8. Pharmacy-based NSPs are available during business hours, but they do not offer needle disposal services (Dolan, MacDonald, Silins, & Topp, 2005).

In Australia, syringe vending machines usually operate 24 hours and provide clean needles and syringes to IDUs who do not want to access health service-based NSPs. Syringe vending machines dispense needles and syringe in the form of Fitpacks® (Communicable Disease Control Directorate, 2008). Syringe vending machines are normally located in hospitals, community or sexual health centers. A safe needle bin is located at each vending machine to allow for safe disposal. NSP staff are responsible for monitoring and restocking these machines (Communicable Disease Control Directorate, 2008).

### Needle collection in Australia

In Australia, City Councils take a variety of measures to keep public areas safe and clean. In the City of Melbourne for example, 400 syringe disposal bins have been installed across the municipality (including in public toilets) to collect used needles and syringes. The Cleanup team works five days a week to pick up used needles in priority areas (City of Melbourne, n.d.). If people find an inappropriately discarded syringe in the City of Melbourne, they can contact the City to arrange free disposal (City of Melbourne, n.d.). Residents in Melbourne can access free syringe containers from the City if they are interested in needle disposal.

The City of Melbourne encourages eligible businesses to participate in safe needle disposal. Businesses that have public toilets or facilities accessible to the public such as restaurants, cafes, carparks, shopping malls, cinemas, churches, community centers, universities, gyms, etc. are viewed eligible to install needle bins (City of Melbourne, n.d.).

## **United Kingdom**

### Needle Distribution in the United Kingdom

In the United Kingdom, pharmacy-based NSPs play a vital role in needle and syringe distribution. Some pharmacies provide injection equipment in the form of pre-prepared packs, which contain needles and syringes, and other paraphernalia such as swabs and condoms. Some pharmacies allow clients to choose different injection equipment. In 2008, pharmacies provided over 70% of needle exchange services in England (Dima, Dawn, David, & National Treatment Agency, 2007).

Non-pharmacy NSPs such as specialist-based NSPs, outreach services, and hospital-based services are important in the UK as well. Specialist-based NSPs are operated by public health organizations. Service providers distribute clean needles and educate IDUs on how to dispose of needles and syringes appropriately. Testing, referrals, and counselling are also available (Dima, Dawn, David, & National Treatment Agency, 2007). Outreach services, taking the form of a mobile unit (e.g. van or bus) on the street, are usually offered to a particular sub-population of drug users, especially those who have difficulty accessing services provided during business hours. Hospital-based services offer 24 hours a day needle exchange services for IDUs (Dima, Dawn, David, & National Treatment Agency, 2007). Needle and syringe dispensing machines in the UK operate on a 'one for one' basis, which means a used syringe or a token has to be deposited for a clean one to be dispensed (Dima, Dawn, David, & National Treatment Agency, 2007).

Scotland imposes limits on the equipment that can be provided during a visit. The current limits on needle and syringe provision are:

- Maximum 20 needles/syringes on the first visit (up from 5)
- Maximum 60 needles/syringes on subsequent visits (up from 15)
- An exceptional upper limit of 120 for holiday periods when facilities are closed or where facilities are difficult to access (up from 30)

(Griesbach, Abdulrahim, Gordon, & Dowell, 2006).

### Needle collection in the United Kingdom

In the United Kingdom, City Councils take responsibility for disposal of needles. Safe needle drop boxes are installed across the city, and needle disposal bins are placed in public toilets. For example, Belfast set up the first needle disposal bins in the toilets for IDUs in 2014. Since then, more needle disposal bins have been installed in public toilets (Robbie, 2015). Residents can return used needles through needle and syringe programs as well.

### EXHIBIT 2 Needle Bin Location Information

241 Simcoe Street – The London and Middlesex Housing Corporation
580 Dundas Street – The London and Middlesex Housing Corporation
130 King Street – Covent Garden Market, Market Lane
459 York Street – Mission Services, The Gathering Place
Forks of the Thames
Victoria Park
Harris Park
186 King Street – Regional HIV/AIDS Connection
London Police Service – underground sallyport
Bathurst Street at Clarence
Bathurst Street at The Salvation Army Centre of Hope
Municipal Parking Lot – Queens and Adelaide
Municipal Parking Lot – Queens and Lyle
Campbell Park – 380 Dundas Street
Carfrae Park West (entrance to the park)
Carfrae Bridge (north side)
Municipal Parking Lot – King and Adelaide (near Tolpuddle Housing Co-op)

Source: City of London, 2016b.

### EXHIBIT 3 Needle Recovery Fact Sheet

#### What should I do if I come across a needle in the community?

If needles are found on public property, please contact:  
London CARES: 519-667-2273

#### To dispose of found sharps or broken glass:

- Use caution at all times.
- If possible, only use tongs to pick sharp up.
- If tongs are not available, use thick gloves or a thick cloth; do not touch the sharp/edge.
- Teach children to never touch sharps but to tell an adult when they find one.



#### For more information on sharps disposal contact:



London CARES (city outdoor disposal bins):  
519-667-2273  
[www.london.ca/residents/neighbourhoods/Pages/London-CAREs.aspx](http://www.london.ca/residents/neighbourhoods/Pages/London-CAREs.aspx)



Regional HIV/AIDS Connection:  
519-434-1601  
[www.hivaidsconnection.ca/safe-needle-disposal](http://www.hivaidsconnection.ca/safe-needle-disposal)



Middlesex- London Health Unit:  
519-663-5317 ext. 2330  
[www.healthunit.com/sharps-disposal](http://www.healthunit.com/sharps-disposal)



#### What are Sharps?

- Used syringes with needles attached
- Used needles
- Used razor blades
- Broken glass that has come in contact with blood or other bodily fluids
- Lancets

#### Why should sharps be handled safely?

- Sharps may have blood from other people and this blood can carry infections like hepatitis B, hepatitis C, and HIV.

#### How should I handle my own sharps in a safe manner?

- Do not recap, clip, bend or break syringes or needles.
- Package in a hard plastic container or metal tin can with a tight fitting lid. Tape the lid and mark the container with "biohazard".
- Do not use glass or cardboard containers to dispose of sharps.



Source: City of London, 2014.

**EXHIBIT 4**  
**Outdoor Stationery Needle Bin**



Source: Middlesex-London Health Unit, n.d.a.

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## INSTRUCTOR GUIDANCE

### Safe Needles Save Lives

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#### BACKGROUND

Harm reduction practices have been identified as effective and promising approaches to drug use. Instead of focusing on drug users giving up using drugs, the principles of harm reduction aim to reduce the harms associated with drug addiction (Ontario Harm Reduction Distribution Program, n.d.). Providing clean needles and syringes without a limit on the amount, harm reduction practices encourage drug users to access the supplies needed to ensure they are injecting drugs safely and prevent the spread of blood-borne diseases (Ontario Harm Reduction Distribution Program, n.d.).

In response to the increasing incidences of intravenous drug use and disease transmission, the Counterpoint needle exchange program began in London, Ontario in 1992. In collaboration with the Regional HIV/AIDS Connection, the Middlesex-London Health Unit has operated the needle exchange service through the sexual health clinic (Regional HIV/AIDS Connection, n.d.). In 2008, fully supported by the City of London through the London Homeless Prevention System, London CARES was established, and one of its roles was to keep public areas free of discarded needles (Regional HIV/AIDS Connection, n.d.).

In 2014, a six-year-old boy got a needle stick injury in a public toilet. This accident immediately created public panic, engendering a public discussion on how to manage needles safely and educating needle users on safe needle disposal. To improve the needle exchange program in London, it is important to understand project details and review the landscape of community programs, policies, and activities related to needle/syringe disposal. By comparing different programs, similarities and differences will be identified.

#### OBJECTIVES

1. Understand the principles of the harm reduction approach and the operation of needle exchange programs.
2. Environmental scan: review national and international needle exchange programs, and understand project details
  - a. Areas: London, Toronto, Ottawa, Edmonton, Vancouver, Australia, United Kingdom, Europe
  - b. Project details:
    - Existing community programs, policies, and activities related to needles/syringe disposal
    - Who distributes and collects needles? How?
    - Relevant stakeholders and their interests
    - What services each organization offers and how these services are operated.

3. Analyze the similarities and differences between programs, evaluate needle exchange programs in London, and identify the gaps between London and other areas.
4. Recognize best practice examples of programs and learn how to make recommendations for program development.
5. Understand how to promote safe drug injection and safe needle disposal.

### DISCUSSION QUESTIONS

1. Discuss the definition of a harm reduction approach and needle exchange programs.
  - a. What are the values and potentials of a harm reduction approach?
  - b. How do you evaluate the implementation and operation of needle exchange programs?
2. Discuss the gaps in needle exchange programs between London and other areas.
  - a. What are similarities and differences between programs?
  - b. Can you describe the gaps between London and other areas?
  - c. If the gaps cannot be identified clearly, what information do you think is absent?
3. Discuss the recommendations for safe drug injection and safe needle disposal in London.
  - a. What recommendations will you present to improve needle exchange programs in London?
  - b. What is the most urgent issue?
  - c. What are the main barriers and how can we address these barriers?

### KEYWORDS

Harm reduction; needle exchange programs; safe drug injection; HIV prevention; infectious disease prevention; safe needle disposal.

## CASE 7

### What Do We Do About the Families?

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#### BACKGROUND

The Centre for Addiction and Mental Health (CAMH) is a hospital and academic health sciences research centre. CAMH provides client-centred care driven by a philosophy that in addition to medical needs, each client's social, physical, emotional, spiritual, and psychological needs should be addressed (CAMH, 2015a). The CAMH vision is "transforming lives" based upon values of courage, respect, and excellence (CAMH, 2015a). CAMH prides itself upon working with its staff, clients, and families to "continuously improve" quality of care (CAMH, 2015a). The main campus of CAMH is located in Toronto, Ontario and there are 19 satellite locations throughout Ontario.

Dhilan Mohan stood in the cafeteria line at CAMH in downtown Toronto. "Oh, I'll take a BLT sandwich," Dhilan responded to the cafeteria employee. His question had snapped him out of a bout of intense thinking. The employee was a former CAMH client. In fact, all of the cafeteria employees and managers were former and current clients. Employing clients is one example of how CAMH works in collaboration with them to provide solutions that are rewarding to the entire CAMH community (Porter, 2013).

As Director of Client and Community Relations at CAMH, Dhilan's portfolio included fielding client and community concerns/suggestions and increasing client and community engagement. His role required him to respond to concerns expressed by patients and family members about the CAMH services. In fulfilling this role, Dhilan often considered 'community engagement' as a criteria for good quality care.

Dhilan brought his BLT sandwich back to his office. His busy schedule meant that he rarely ate in the cafeteria. Dhilan scratched absently at his moustache as he sat at his desk. What was he going to do about the families? There were more and more concerns brought to him about families who wanted to be more involved in the care of their loved ones at the hospital. Many patients were vocal in their agreement with their family members. Does family involvement improve patient care? Does family involvement alter the determinants of health? Could family involvement result in unintended adverse effects? What kinds of supports would families require in order to improve patient health? The Board of Trustees had asked for a set of

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recommendations on what to do about family engagement. Dhilan would need to consider these complex issues in making his recommendations to the Board.

Families frequently play an important role in patient care. They often provide care before and after patients are admitted to hospital. Families are a source of financial, emotional, and social support. The role of families in supporting individuals with mental illness is even more important due to the diminished capacity to accomplish daily activities as a result of disease symptoms. Families often play a crucial role in meeting the needs of patients with mental illness.

Families are knowledgeable about their loved one's needs and preferences, and also have information on the patient's personal and medical history. For clinicians treating these patients, the information can be extremely useful and sometimes significantly alter treatment plans. Examples include history of medications, prior and concurrent diagnoses, allergies, important personal/social history, and details from previous hospital stays. Families also have insight into preferred treatments, indicating what treatments have been more effective in the past, and what treatments should be avoided. Families understand the personal beliefs of their loved ones and how these may influence their choices. These insights are ones that would not only aid the clinical team, but might also lead to a more effective recovery for the patient.

Insights from family members are especially relevant for patients with mental illnesses because the symptoms often prevent the patient from being able to share this information with the clinical care team. Just last month, Dhilan saw a patient with schizophrenia experiencing an acute psychotic episode. The young man was experiencing disorganized thought and speech patterns that are characteristic of the disorder. When he was admitted to the hospital he was not coherent. The young man's recollection and account of his medical history was not consistent with reality. Patients may also experience hallucinations or delusions that make collecting a useful history very difficult.

Dhilan was also faced with a new problem: some of the families involved with the patients at CAMH provided so much support to their loved ones that they were clearly experiencing 'caregiver burden'. Did CAMH have a responsibility to provide support in alleviating this caregiver burden?

### CAREGIVER BURDEN

Caregiver burden can be defined as both the tasks and functions associated with caregiving and the way in which the person performing these tasks/functions experiences and appraises the performance of these tasks (Hoenig & Hamilton, 1966). Depending on the particular needs of the patient, the caregiving duties will be different, and these needs often change over time.

Mental illnesses are varied in their scope and symptomatology, and so are the corresponding needs of the individuals who experience them. Some families may not experience the amount of caregiver burden that others do. Some families deal with this responsibility with greater ease depending on the time and resources they can put towards care.

Caregiving can sometimes result in families providing many resources to their loved ones including financial support, housing, transportation, assisting with daily living tasks, etc.

Caregiver burden is not a problem unique to mental health. Approximately 28% or more than eight million Canadians aged 15 or older have provided care for a family member or friend with a serious illness (Turcotte, 2013).

Dhylan sighed loudly. ‘The family problem’ was more complicated than it first appeared. CAMH as an organization clearly has a responsibility to aid in the recovery of their patients. As an organization dedicated to health promotion in the community, it has a social responsibility to aid in alleviating any potential caregiver burden that families might have in providing support to patients. CAMH has a responsibility to do even more: it should attempt to prevent the potential factors resulting in caregiver burden if at all possible. But Dhylan’s new problem now was how?

Families are valuable resources to patients and often are valuable resources within the clinical care setting. Is it possible that the impact of families on the health of their loved ones could be enhanced through increased knowledge of the problems that their loved ones face? Many families already provide support that increases a patient’s resilience and responsiveness to therapy.

Strategies to increase knowledge could include information on access to resources to help families address caregiver burden. These might include information on financial and social supports available for caregivers; strategies on how to deal with specific symptoms their loved ones face; and recovery programs to provide caregivers with respite and support.

Maybe these benefits could be increased through strategies focused on increasing family members’ health literacy?

### HEALTH LITERACY

Health literacy includes being able to comprehend, access, evaluate, and communicate the information necessary to improve, maintain, and promote health across a lifespan (Public Health Agency of Canada [PHAC], 2014). Researchers have proposed various measures of health literacy including the International Adult Literacy and Skills Survey (IALSS), Test of Functional Health Literacy in Adults (TOFHLA), and the Rapid Estimate of Adult Literacy in Medicine (REALM) as well as other health literacy scales (Collins, Currie, Bakken, Vawdrey, & Stone, 2012). The IALSS contains four domains (prose literacy, document literacy, numeracy, and problem solving), consisting of 15 blocks and a varying number of questions (Rootman & Gordon-Ei-Bihbety, 2008). The TOFHLA contains 17 numeracy items and three prose passages using health and medical related information including pill bottles and appointment slips (Collins et al., 2012). The REALM does not test understanding, but does provide a reading level estimate (Collins et al., 2012). According to PHAC, as many as 60% of adults and 88% of seniors in Canada may not be health literate based on the PHAC definition (PHAC, 2014). The PHAC study surveyed adults and seniors about literacy using the IALSS. Another study revealed that increased IALSS scores were correlated with excellent health. Low health literacy was also related to negative health outcomes (PHAC, 2014).

Are literacy levels and health literacy related? One argument is that health literacy is merely an extension of literacy. Another might be that they are related but separate concepts. Undoubtedly a low literacy level would suggest a low health literacy level because of the decrease in ability to access, evaluate, and comprehend health information that might be useful to one’s own health.

### MENTAL HEALTH LITERACY

Jorm et al. (1997) introduced the term mental health literacy, and it is related to health literacy in the same manner as the latter is related to the term ‘literacy’. Jorm et al. defined the term as “knowledge and beliefs about mental disorders which aid their recognition, management or prevention” (Jorm et al., 1997). Both health literacy and mental health literacy incorporate the capacity for comprehension, access, evaluation, and communication of health related knowledge and skills. Both share a common model, but mental health literacy is specific to

## What Do We Do About the Families?

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knowledge and skills surrounding mental illness/mental health. These skills and knowledge are unique and require different strategies to increase capacity within mental health literacy. Mental health literacy includes seven attributes grouped into three key areas: “recognition, knowledge of factors relating to mental health, and attitudes and beliefs about mental disorders” (O'Connor, Casey, & Clough, 2014). A framework for mental health literacy including all seven attributes is included in Exhibit 1.

Existing mental health literacy tools include a “Vignette Interview” designed by Jorm et al. (Jorm et al., 1997), which provides a vignette of a person experiencing mental health symptoms and difficulties. The person is then asked a series of questions to evaluate their understanding of key attributes. Mental health literacy tools measure beliefs about psychosis, including negative beliefs and stigma. Another goal of measurement is to gauge the ability to identify specific mental illnesses (Canadian Alliance on Mental Illness and Mental Health, 2007). The tools available for evaluating mental health literacy are still evolving and there is no widely accepted standard tool. Often new research on mental health literacy will be assessed using a survey or tool developed specifically for the research being described.

The potential benefits of improving health literacy amongst family members can be illustrated through Dhilan's experience with a patient named Steve. Steve's family was supportive, but the family might have benefitted from strategies aimed at increasing knowledge of mental health prevention, management, and recognition.

Steve was a 21 year old who was brought to CAMH by ambulance after he was found unresponsive in his apartment by his parents. After he arrived he was stabilized (for a combination of alcohol and acetaminophen toxicity) and assessed. Steve was having trouble getting good grades in his engineering program. He was also having trouble paying his rent and tuition on time. When asked how all this made him feel he said: “Feel? I dunno man, this is all just...it's too much... it's too hard. It's not supposed to be so hard. I just want it all to stop. I'm going to make it stop”. When asked more questions he just repeated variations of the same sentiments. He fit a diagnosis of depression and the psychiatric resident felt that he posed a danger to himself and should remain in the hospital.

The resident spoke to Steve's parents to get more of Steve's history. His parents were very concerned. They had seen their son go from being very optimistic about his future career to being very concerned about his future. He was also always upset by his finances. His parents wanted to help him more financially but Steve wanted to ‘do it on his own’. They had noticed Steve had lost weight in the last few months. He was also very irritable and slept more when he came for visits. When asked if Steve had ever “tried something like this” his parents had very different responses.

His mother said, “Tried what? So what he had a couple of Tylenol and a drink or two and took a nap ... he's kind of a heavy sleeper so he didn't wake up when we tried to wake him. I think his father was over-reacting by calling for an ambulance.” When the resident asked if she thought he had any reason to kill himself her response was, “Kill himself? He wouldn't do that. He's going through a rough patch right now, but he's not weak! He would never do something like that!”

His father's response was more solemn. “I know Steve is having a hard time at school. We tried to help him out with rent – but he thought this was something he needed to do himself. He lets us give him some grocery money but not much more. At Christmastime, I noticed he was drinking a lot ... and when he stayed over on Christmas Eve there was something like what

happened tonight. I found him lying on the sofa, and there was a glass of vodka next to him and a bottle of Tylenol. I shook him awake and he was fine. He was a little groggy, but I just thought he had a headache or something. He said he just had one drink and must have nodded off. I can't believe I didn't see all this coming. I'm a terrible father. I don't know how I let it get to this. I want to help him, but I don't know what to do."

After four days Steve went home with his parents. On discharge he was given a prescription for an anti-depressant and a follow up appointment in two weeks with the psychiatrist who had been treating him. His parents had been asked to fill in a feedback form at the hospital. On it they indicated several concerns. What could they do to help Steve? What should they do if Steve didn't want their help? Should they try to get Steve to stay with them instead of going back to his full time studies? What is the course of recovery for depression? How could they help prevent another suicide attempt? Since Steve was a student how was he supposed to pay for his medication? Who should they get to answer their questions? Is there a website or something? What did other parents who were involved in this kind of thing do?

Dhylan was asked many questions about how a patient's recovery could be enhanced by increasing family members' understanding of mental health and their loved one's particular needs. The practical nature of how to do this led to many possibilities, but also to many questions: what is the best way to increase the 'mental health literacy' of families?

While it was something that might result in better patient recovery, it also begged the question: should the hospital be doing this? Families are not the direct client of hospitals – the patient is. The hospital is responsible for helping to empower the patient towards their own recovery, but does that include doing so by increasing the capacity of a third party that the hospital has no formal relationship with?

Dhylan thought back to some of the successful strategies for providing patients with support. There were many positive results from peer support programs where patients provided each other with support and helped disseminate information and knowledge amongst their peer group. Dhylan began drafting a proposal for a new peer support program aimed at families and caregivers for patients with mental illnesses. This would simultaneously provide support and aim at increasing mental health literacy in families who chose to participate.

### PEER SUPPORT

Peer support is a model based upon supportive relationships between people who have a lived experience in common (Mental Health Commission of Canada [MHCC], 2015). The programs that use this model focus on building support, encouragement, and hope amongst participants (MHCC, 2015). Support of this kind facilitates recovery (McLellan et al., 1998). Participants often share an illness or common event in the past. The experiences that peers have are unique but the pathology or common event is shared (Davison, Pennebaker, & Dickerson, 2000). The model itself is simple enough to be used in various settings, and for various shared backgrounds. The definition of 'peer support' is wide and also inclusive of 'self-help'.

While the peer support model is considered to be evolving, for this case it should be perceived as inclusive of the ideas of social support and social networks working towards positive changes and/or coping with present conditions (MHCC, 2015).

This support has been provided both within and outside of formal healthcare structures; it has also occurred within formalized programs and independently. It includes one-to-one relationships as well as groups of varying sizes. Often the shared experience between peers is

their common experience of the healthcare system, and may be related to their common experience within a particular healthcare setting (such as within a psychiatric unit) (Hardiman, Theriot, & Hodges, 2005). This can often be the 'consumer experience' (Mead & MacNeil, 2006) they share as consumers of healthcare services. It may also include the 'illness experience' of a shared pathology. One caveat might be that these experiences are often negative and moving forward in recovery and coping with present situations might be difficult while focusing on negative experiences. A contrasting argument might be that common negative experiences also bind individuals together into groups who move forward and draw strength from a shared sense of social justice.

Within the discussion at hand, examples involving health related issues are most relevant. Peer support has been used successfully in providing support to people experiencing mental health concerns, and a large amount of literature has focused on peer support in mental health. Within mental health, peer support has varied in form from grassroots self-help groups to formalized peer support programs with 'peer support workers' who have further training and a shared background of 'lived experience'. Peer support workers are paid employees/consultants who work in varied roles within organizations. Their roles range from providing one-on-one support to participating in community treatment teams performing formal assessments and providing treatment.

While peer support and peer support workers are used widely in mental health they are also used in providing support to people experiencing other health pathologies including diabetes (Balagopal, Kamalamma, Patel, & Misra, 2012), stroke (Goldfinger et al., 2012), and cancer (Hoey, Ieropoli, White, & Jefford, 2008). The current healthcare model would certainly benefit from including the support and resources inherent in sharing lived experiences.

Peer support and peer support workers are methods of supporting people directly experiencing health related pathology, but they are also used in supporting people around them. Family and caregivers often have experiences related to the problems their loved ones face. These experiences sometimes result in stress, hardships, and related health concerns.

CAMH offers a number of peer support and self-help oriented groups/workshops and sessions for family members of patients to seek support and knowledge about their loved one's care. Many of these groups are well attended and appreciated by the family members. But was this sort of support enough? Could more be done to help support family members of patients?

Dhylan bit into his BLT. The sandwich was really good. Dhylan thought about how this sandwich was made by clients and CAMH working together. This collaboration gave Dhylan ideas about how the families should be more involved with the care of their loved ones at CAMH.

Families needed more than just information on their loved one's care, or to be able to share vital information concerning their family member's history with the clinical team. They also needed more than just support to alleviate any 'caregiver burden'. They needed to be involved more with the community of CAMH. Families held the information about what they needed, how they could best serve patients' needs, and how they could have their own needs supported. They needed to actually be part of the decision-making process and to be able to advocate for themselves.

### **THE EMPOWERMENT COUNCIL**

CAMH has an 'Empowerment Council' that aims to act as an advocate for current and ex-patients within CAMH. The Council is an independent organization, which aims to collectively

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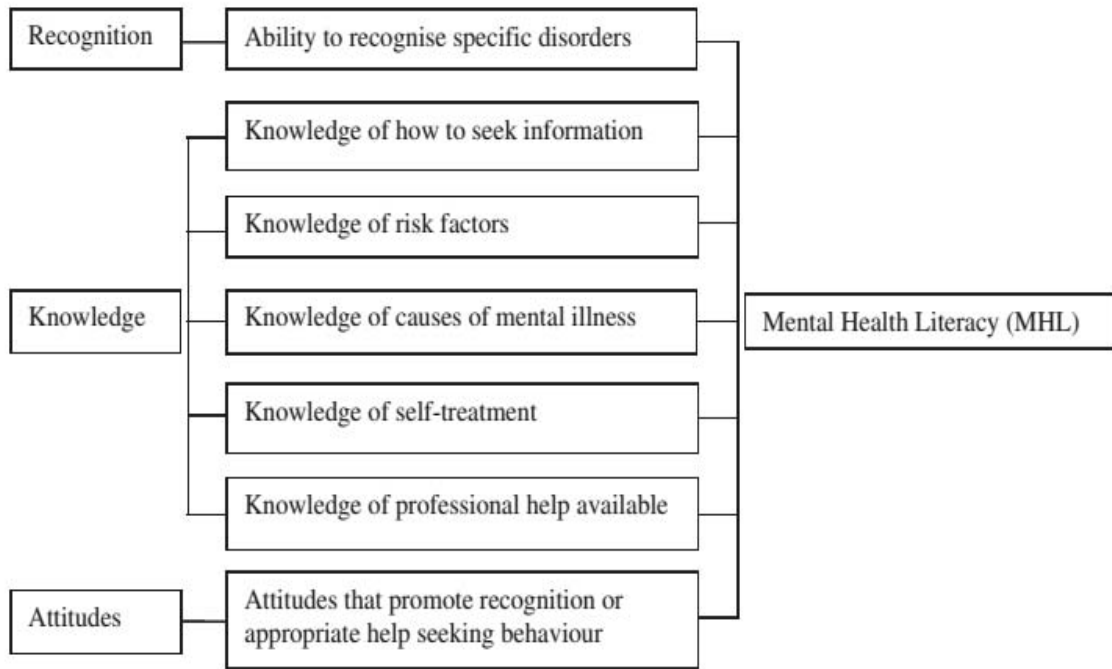
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involve the patient 'voice' via participation in committees, work groups, and other decision-making structures at CAMH and via government (Empowerment Council, 2009). Its Board and membership are comprised of clients and ex-clients of CAMH and other addiction and mental health services (Empowerment Council, 2009). It does not handle individual patient advocacy, which is overseen by a Patient Advocate Officer at CAMH.

The Council also shares information with patients concerning rights, self-advocacy, and empowerment. Similar sharing/training is done with health care providers and staff at CAMH and on a systemic level. The Empowerment Council is also dedicated to outreach and community development with CAMH patients. In collaboration with CAMH there is now a CAMH Bill of Client Rights (see Exhibit 2).

Dhylan wondered if it would be possible to develop an Empowerment Council for families. Families might benefit from having a 'voice' advocate for their needs both at CAMH and in the greater community. Dhylan had many ideas to consider now about how families could be involved more at CAMH. The Empowerment Council was an example of how collaboration with patients worked well. It was clear 'the family problem' was complex. It required CAMH to consider more collaboration with families. It also required that CAMH consider helping families become better advocates for themselves and their loved ones.

### EXHIBIT 1 Mental Health Literacy Framework



Source: O'Connor et al., 2014, p. 198 (by permission of Taylor & Francis Ltd.).

### **EXHIBIT 2** **CAMH Bill of Client Rights**

Right #1: Right to be Treated with Respect

Right #2: Right to Freedom from Harm

Right #3: Right to Dignity and Independence

Right #4: Right to Quality Services that Comply with Standards

Right #5: Right to Effective Communication

Right #6: Right to be Fully Informed

Right #7: Right to Make an Informed Choice, and Give Informed Consent to Treatment

Right #8: The Right to Support

Right #9: Rights in Respect of Research or Teaching

Right #10: Right to Complain

A detailed description of each right can be accessed at:

[http://www.camh.ca/en/hospital/visiting\\_camh/rights\\_and\\_policies/Pages/bill\\_of\\_client\\_rights.aspx](http://www.camh.ca/en/hospital/visiting_camh/rights_and_policies/Pages/bill_of_client_rights.aspx)

Source: CAMH, 2015b.

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## INSTRUCTOR GUIDANCE

### What Do We Do About the Families?

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#### BACKGROUND

Families are involved in the support of many people with mental health conditions. Support ranges from financial, housing, help with ADL (activities of daily living) etc. Families can also be useful sources of clinical information/history during inpatient treatment. Families generally want to be more involved in the care of their loved ones while they are in hospital.

Mental health literacy includes knowledge and information on access and evaluation related to mental health pathology/issues. This includes being able to assess and identify mental health pathology and symptoms. Increasing mental health literacy (and health literacy) among family members can lead to improved health outcomes in patients. It can also lead to better health among family members.

Families who support loved ones with mental health conditions can face caregiver burden. This can be related to the amount of physical and emotional resources required to deal with their loved ones. CAMH tries to address issues involving caregiver burden via peer support initiatives and training/workshops.

Peer support is a model that includes building relationships based on shared experiences. The peer support model includes 'self-help' initiatives and peer support groups.

The above issues faced by families should be brought together in a way that facilitates the families advocating for changes that involve them and their loved ones. Families need to be consulted to gather information on how to best address their needs, but their role should also be more participatory in nature.

#### OBJECTIVES

1. Review and define the terms Health Literacy and Mental Health Literacy and how they apply to individuals and groups seeking to increase their health.
2. Review the Peer Support model and Peer Support workers and discuss their role within healthcare.
3. Review and discuss the role of families of mental health care patients/clients in providing support.

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4. Review and discuss the idea of 'continuity of care' and how families are involved in supporting patients over the long term.
5. Review and discuss caregiver burden.
6. Review and discuss the idea of families and patients being involved in healthcare in a decision-making capacity.

### DISCUSSION QUESTIONS

1. How can families contribute to the care of individuals within the healthcare setting and within the community? What problems might this pose?
2. Why is peer support of value? Attempt to research (online) a few examples of peer support. These do not have to be limited to mental health. Can you find examples of peer support workers?
3. Is there any potential conflict that peer support workers might face in healthcare settings? (Consider how their roles might overlap with the responsibilities of other staff in healthcare settings.)
4. How does health literacy and mental health literacy change the health of individuals? How would increasing the health literacy or mental health literacy of families affect the outcome of their loved ones? Discuss examples in your learning teams.
5. Does CAMH have a responsibility to provide support for families to alleviate caregiver burden?

### KEYWORDS

Health literacy; mental health literacy; peer support; peer support worker; self-care; caregiver burden; mental health; community engagement.



## CASE 8

### iSMILE Project – Improving Seniors' Mouthcare in Long-Term Care Establishments

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*"Oral health is an important part of overall health and a determinant of quality of life."*

The World Health Organization (2003)

#### BACKGROUND

Dr. Dawn DaSilva, Dental Consultant at Vanes Health Unit (VHU), was faced with the issue of poor oral health status of seniors (adults 65 years and older) in the City of Vanes and area in Ontario, Canada. As a dental consultant, her responsibilities included responding to dental public health issues in the area. She also provided status reports on the oral health of Vanians (residents in Vanes), and evaluation reports on the dental programs and services offered by VHU to the board of health.

The problem of poor oral health status amongst seniors has been a long-existing and an ongoing issue not just in Ontario or Canada but also globally (Petersen & Yamamoto, 2005). Oral health in general has received little attention within the medical community and its importance has been understated at local levels and internationally. However, in 2012, Ontario's Chief Medical Officer of Health (CMOH), in her report *Oral Health – More than Just Cavities*, expressed her concern about the state of oral health of Ontarians.

*"I am concerned about oral health and its consequences and that not every Ontarian has access to important preventive dental interventions. I am particularly concerned about lower income Ontarians, including children in low-income families, and the profound importance of access to dental care in early life. We know that limited access to dental services can lead to severe health complications and negative social consequences. Ontario has made significant progress in enabling better access to dental care for children, and especially for children in low-income families, but we can do more. I am also concerned about seniors, including those in long-term care homes, and lack of access to adequate dental care."*

Arlene King, Ontario's Chief Medical Officer of Health (2012)

The Chief Medical Officer, Dr. King, had just confirmed what had been on Dr. DaSilva's mind – the time had come for something to be done about the oral health of seniors in the Vanes area. This created the opportunity for Dr. DaSilva to look into what could be done to improve the oral health of seniors in Vanes and area.

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She knew she had to consult with Dr. Charles Oakwood, the Manager of the Oral Health Unit, about the need to create a position in the department for someone to look solely into how to promote the oral health of seniors in long-term care establishments (LTCEs) in the Vanes area.

### **INTRODUCTION**

Similar to other provinces in Canada, Ontario has a universal publicly funded healthcare system which provides health coverage to its residents through Ontario Health Insurance Plan (OHIP). OHIP is single-payer program with the province, Ontario, as the payer. OHIP covers a range of medically necessary health services provided by physicians; it provides limited eye care and dental services (Matthews et al., 2012; Ontario's Ministry of Health and Long-Term Care, 2014). Publicly funded provincial dental programs and services primarily target children and youth. They also target adult clients and their families in receipt of social assistance benefits, neglecting other vulnerable groups such as seniors, especially those in establishments LTCEs.

### **Oral Disease and Oral Health Care**

Dental plaque is one of the main causes of gum disease, caries, and other dental conditions (Marsh, 2004). Dental plaque is a soft biofilm present on the surface of the tooth and around the margin of the gums composed of microorganisms, and organic and inorganic materials (Marsh, 2004). The microorganisms are mainly responsible for periodontitis and caries. Gum disease or periodontitis and dental caries are some of the most prevalent dental conditions amongst seniors (Marsh, 2004). The microorganisms in plaque metabolize sugars present on the tooth surface to produce acid, which destroys the tooth structure causing tooth decay or caries.

Personal oral care or oral hygiene for residents of long-term care establishments may include brushing and/or caring for dentures provided by the individual or assisted by personal support workers. Dental hygienists or dentists usually provide professional care such as scaling and polishing (cleaning), restorative treatments, etc.

Providing good oral hygiene care through tooth-brushing is known to reduce the accumulation of plaque. This physical disruption reduces the risk of developing periodontitis or, where the disease is already present, reduces the severity.

Plaque buildup is also reduced through routine cleaning provided by dental professionals (Marsh, 2004). Plaque can also accumulate on dentures. Proper cleaning of dentures before and after food reduces the risks of periodontitis and helps to maintain the health of remaining teeth (for those with partial dentures). The presence of dental plaque and calculus (calcified plaque) also causes mouth odour. Mouth odour could affect residents' nutrition or appetite and their self-esteem and mental health. Dental pain from periodontitis or caries could also result in reduced appetite or weight loss eventually affecting overall health (King, 2012). Studies have shown that providing good oral care leads to good oral health (King, 2012; MacEntee, MacInnis, McKeown, & Sarapuchiello, 2008).

### **SENIORS IN VANES AREA**

Seniors 65 years and older are retaining their natural teeth longer than previous generations (Health Canada, 2010). With Canadians living longer and keeping their dentition longer as well, dental diseases have also increased in this subgroup (Canadian Dental Association [CDA], 2008). Seniors in LTCEs are more susceptible to dental diseases and have poorer oral health than community dwelling seniors (CDA, 2008; Matthews et al., 2012). Studies have shown a high prevalence of untreated oral disease amongst this subgroup in LTCEs (Helgeson & Smith, 1996; Frenkel, Harvey, & Newcombe, 2001; Lukes, Janssen, Thacker, & Wadhawan, 2014).

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They are faced with different dental diseases ranging from caries to gingivitis to denture-related problems.

This poor oral health was of major public health concern; dental disease and its consequences had the potential to increase the financial burden on the healthcare system and incur societal costs as well. Including oral health into provincial health plans would obviously improve oral health of seniors and impact their overall health as lack of insurance is an influential factor that predisposes individuals to severe disease (Health Canada, 2010; Kelsall & O'Keefe, 2014).

Dr. DaSilva approached Dr. Charles Oakswood, the Manager of Oral Health at VHU, to discuss the problem with him. They were faced with the challenge public health is constantly faced with – very limited resources. They knew that if oral health services were included among the medical and diagnostic services covered by OHIP, access to dental care and treatment would improve for all Ontarians. However, this decision was outside their jurisdiction and did not seem possible in the near future; hence they needed other solutions. They also knew that although this was a priority population, there was no government funded dental program serving local seniors. They wondered how to proceed with limited resources.

Having considered the challenges before them, Drs. DaSilva and Oakswood decided that they needed to research the reasons for poor oral health of seniors in LTCEs in the Vanes area before they could devise solutions to improve their oral health. They decided that they needed to identify the major causes of poor oral health for seniors in LTCEs in Vanes as a first step.

### **Causes of Poor Oral Health Amongst Seniors in LTCEs**

Studies have identified cost of care as a major cause of poor oral health for seniors in LTCEs – most seniors are retired and therefore no longer have dental benefits associated with employment (Matthews et al., 2012; Kelsall & O'Keefe, 2014). Statistics revealed that 53% of seniors in Canada do not have dental insurance and about 40% are covered by private plans (Health Canada, 2010). The cost of dental services for those without insurance coverage and who cannot afford to pay out of pocket creates a barrier to accessing dental services and eventually leads to poor oral health. Seniors in LTCEs are usually on several medications, for their medical needs, which usually results in xerostomia (dry mouth) and leads to caries and worsens other oral conditions (CDA, 2008).

Another cause is reduced capability and insufficient time for oral care. Many seniors or residents in LTCEs have reduced visual, mental, and physical capacities and are thus reliant on caregivers to provide oral care for them (Jablonski, Munro, Grap, & Elswick, 2005; Dharamsi, Jivani, Dean, & Wyatt, 2009; Matthews et al., 2012).

### **Personal Support Workers and Nurses in LTCEs**

Long-term care homes provide nursing care and residence to people unable to care for themselves with the majority of their residents being seniors (Frenkel et al., 2001). Nursing staff in these homes include registered nurses (RNs), registered practical nurses (RPNs), and nursing assistants, also called personal support workers (PSWs). PSWs mainly provide assistance with activities of daily living like hygiene and personal care – bathing, oral care, toileting, amongst others. RPNs perform similar tasks to PSWs with additional responsibilities that may include administering medications, and attending to wounds. The RNs are regulated professionals and are the most senior in hierarchy amongst the nursing staff and supervise nursing activities provided by the other nursing staff (MacEntee et al., 2008). They provide complex care to residents such as antibiotic treatments and other medications, administration of intravenous therapy and oxygen, as well as supervise RPNs, PSWs, and nurse aides. They also consult with physicians or geriatricians. The Director of the LTCE is usually an RN who

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oversees the affairs of the home and supervises all staff, both nursing and non-nursing (Helgeson & Smith, 1996). Caregivers in LTCEs have many responsibilities and many residents to attend to; as a result they may have insufficient time to allot to oral care (Altani & Wyatt, 2002).

Studies have shown that caregivers spend an average of 16.2 seconds brushing a resident's teeth as compared to the recommended 2 minutes (Stein & Henry, 2009). Other identified causes of poor oral health of seniors include lack of oral health education and awareness for caregivers in LTCEs. Studies also showed that only 16% of residents receive oral care and only 5% who request to have their teeth brushed actually have their request granted (Stein & Henry, 2009). This was attributed to caregivers' lack of awareness of the importance of oral health (Altani & Wyatt, 2002).

### **THE 'iSMILE' PROJECT**

After a series of brainstorming sessions reviewing the results of the literature review, Drs. DaSilva and Oakswood decided on a health promotion initiative targeted at caregivers in LTCEs as they were responsible for oral care for all residents in the home. The literature suggests that the provision of oral health education and promotion to caregivers can lead to improved oral care delivery to the seniors.

For example, a study by MacEntree et al. (2008) found that educating institutional staff improved the oral health of LTC residents. Also, in a randomized controlled trial done in Avon, United Kingdom, residents whose caregivers received oral health education had improved oral hygiene and overall better oral health status as compared to residents whose caregivers did not receive the training (Frenkel et al., 2001). Studies have also shown that one of the most effective ways of educating LTC staff is by providing educational programs in-service to LTC caregivers through presentations, videos or audiovisual aids, demonstrations using models or print materials, and group discussions (Frenkel et al., 2001).

Having decided on their strategy, Drs. DaSilva and Oakswood delegated the project to Michaela Joseph, a Health Promoter recently hired to the Oral Health Team. The Oral Health Unit had recently received a community funded grant, hence their decision to hire a Health Promoter to carry out the project. The project was titled the iSMILE project – improving Seniors' Mouthcare In Long-term care Establishments.

Michaela was excited about the project she had just been assigned. Trained as a Dentist in Nigeria, she was quite passionate about oral health practice, delivery, and promotion. Having worked with several vulnerable populations in Nigeria promoting oral health, she was certain she could deliver on the project she had just been assigned. She was confident she could improve the smiles of seniors in LTCEs.

### **THE iSMILE PROJECT GOAL AND OBJECTIVES**

The goal of the iSMILE project was to improve the oral care delivery to residents in LTCEs in order to improve their oral health. It had the following objectives:

- Identify information and knowledge needs of the caregivers in providing oral care;
- Describe the extent of health needs;
- Prioritize identified needs;
- Evaluate existing services or resources to address these needs and identify best practices;

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- Identify the best Information, Education, and Communication (IEC) materials for the caregivers; and
- Make recommendations

### **NEEDS ASSESSMENT**

Michaela's first task in meeting the objectives of the project was to conduct a needs assessment to determine what information was needed. She would need information regarding the target population, the geographical area, and other stakeholders, etc. Vanes and area has about 28 long-term care homes. Though Michaela was aware she would be unable to visit all LTCEs with the limited 12-week timeline for the project, she was hoping to visit at least a third of the homes (the project was limited to 12 weeks based on the funding available for the project). She wanted to know how oral care was provided in the LTCEs, what barriers or challenges they faced in providing oral care, and what resources and support they had access to, etc. Michaela also wondered about the policies in LTCEs; if they had oral care policies and if these policies were being enforced. Studies had shown oral care policies were not enforced in some LTCEs (Pyle, Jasinevicius, Sawyer, & Madsen, 2005). It was at this point she conducted more research and discovered the Long-Term Care Homes Act (2007) (see Exhibit 1) which mandates oral care to be provided to residents in LTCEs. It specifies what oral care procedures are to be carried out and who is responsible for the care. She decided that she would need to include management staff as a secondary audience with the caregivers being the primary audience. However, she would have to make contacts within the LTCEs first, in order to find out what the needs were.

Having decided what information she needed, the next thing was to identify where to get the information she needed and how to gain access into the LTCEs. For this she did a literature search and set up consultation meetings with experts who had worked with LTCEs to provide insight on how they were operated, what policies were in place, who provided oral care for the residents, etc. Experts consulted were VHU staff that had worked at LTCEs previously, other health units in the province, and dental professionals in Vanes. Expert opinion revealed that the frontline providers responsible for providing personal (including oral) care for residents were personal support workers (PSWs). Nurses had other responsibilities relating to medications, dietary supervision, and more complicated medical needs. The data from experts was collected through face-to-face interviews and telephone surveys. They provided insight into operations and staffing of LTCEs, challenges faced by residents, as well as an overview of the oral health status of residents in the home. These subject matter experts also initiated the process of contacting the LTCEs to establish rapport and allow Michaela access into the home in order to speak with caregivers and management staff.

Having also consulted with experts from other health units who offer dental programs for seniors, Michaela decided to do further research to find out what work other municipalities, provinces, and places outside of Canada were engaged in around the oral health of their seniors. Her literature review revealed several successful oral health promotion strategies and other resource tool kits that could be used to assist care providers in providing better oral care delivery to clients. Michaela was glad that despite the lack of a provincial-level effort to address the needs of this vulnerable population, some Ontario municipalities and other provinces had developed programs and resources. This information was particularly important to Michaela who was passionate about health promotion, particularly oral health promotion.

Next on Michaela's agenda was to conduct a needs assessment amongst the care providers and management staff. The methods used were focus group discussions and face-to-face interviews. These served as a means of collecting data and educating staff. A study by Frenkel

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et al. (2001) showed that group discussions were an effective way of educating LTCE staff. The discussions and interviews were scheduled for a maximum of 40 minutes due to the busy schedule at LTCEs. Questions for focus group discussions and interviews were prepared prior to visiting the homes (see Exhibits 2 and 3).

### **RESULTS AND ANALYSIS OF NEEDS ASSESSMENT**

The focus group discussion participants were mainly PSWs and some nurses. Most of the PSW participants had a fair understanding of oral health and its importance to general health, while the nurse participants seemed to have more knowledge. They reported that among their clients; the main dental conditions were bleeding gums, decayed teeth, bad breath, and dry mouth. The needs assessment showed that the main barriers to good oral health for residents were:

- Time
- Resident attitude
- Lack of financial resources
- Lack of access to dental services
- Lack of an oral care champion
- Lack of oral health awareness by family members of residents

#### **Time**

This was the biggest barrier. Some homes have only one PSW for 8-12 residents, so spending 2 minutes twice a day with a senior was very challenging. The nurses and PSWs had to wake all residents by 6 am and have them showered, dressed, and seated for breakfast by 8:15 a.m. Given all they had to do within such a short time, oral care was given less priority. Understaffing was a constant theme occurring in all the homes surveyed and was the main reason for insufficient time. With fewer hands available to attend to the needs of the residents, caregivers could not give every aspect of care the attention it deserved, leaving oral care to suffer.

The process of the needs assessment revealed a lack of adequate oral care training amongst the PSWs. Though the caregivers did not categorically state they did not have sufficient oral health education and training, Michaela knew there was still an opportunity to try additional training (Altani & Wyatt, 2002). Though several caregivers were unaware of techniques used to provide oral care to residents with resistive behaviours, they did state that insufficient time was a major barrier to adequate oral care. One of the PSWs stated, "insufficient time is the main reason for giving up on seniors who are resistive to oral care – there is just not enough time to battle with them simply to clean their teeth."

#### **Resident Attitude**

Incompliant or aggressive seniors who kick, bite, or spit on care providers posed special challenges. PSWs noted that providing oral care was easier for residents who were interested in their oral health as opposed to those who were not. However, the lack of interest could sometimes be attributed to deteriorating general health or cognitive capacity.

#### **Lack of Financial Resources**

Residents who had a dental plan or who could afford dental care were more likely to have better oral health than a resident who could not afford dental treatments.

#### **Access to Dental Services**

Some LTCEs have dental companies visit the LTCE to provide dental services on-site. For LTCEs without dental offices or dental services, residents would have to visit private dental

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offices in the community. Use of these services would depend on those who could afford to pay for such services or who had insurance, and the transportation costs associated with travel.

### **Lack of an Oral Care Champion (OCC)**

A champion is an advocate for a program, belief, innovation, or an agenda (USAID, 2010). Several LTCEs have a 'falls' champion, an 'incontinence' champion, a 'mental health' champion, etc. They advocate for these areas by speaking to and motivating the staff. Only one LTCE among the five surveyed had an oral care champion. It was noticed that the oral care delivery and oral health status of residents in this particular LTCE was better than that in the other LTCEs. Though other factors contributed to the good oral health status (such as a geriatrician-dental hygienist team who provided oral health education to caregivers), it seemed highly likely that a PSW who was also the champion had its impact in improving oral health of LTC residents. The findings from the needs assessment in this home did suggest that the oral health education and promotion strategy initially planned by Drs. DaSilva and Oakswood could work.

### **Lack of Oral Health Awareness by Family Members of Residents**

This was a recurring theme in most homes visited. Caregivers mentioned that family members were often unaware of the impact oral health could have on the overall health of their relative. Some residents are admitted into LTCEs with already compromised oral health; such residents could be at an increased risk for further deterioration of their oral health and overall health eventually. Though some families may not be aware of the importance of oral health, others feel oral health was not a priority as compared to other medical challenges their relative may be facing. Thus the need to educate family members and relatives of seniors in LTCEs is important.

Michaela then proceeded to the next phase of her qualitative research – doing a needs assessment of the senior management staff (see Exhibit 4). She approached this from a different perspective compared to that for the PSWs. She enquired as to the ways they felt oral care, and ultimately oral health, in the home could improve and what part they could play in making good oral health a reality for the seniors in their care. The interviews revealed that all the homes surveyed had oral care policies and procedures. While some homes enforced all the policies, others only partially enforced them. The interviews also revealed that while some homes provided comprehensive oral care training and education for their staff, other homes had little to no training regarding oral care. The reason some homes gave for this lack of training was that oral health education is not a specifically mandated training requirement by the Ministry of Health and Long-Term Care.

### **HOW TO PROCEED**

Michaela was faced with a major challenge after the focus group discussions with the caregivers. Despite the fact that she had identified the lack of adequate oral health education and motivation amongst the caregivers, they themselves did not identify this as a barrier to providing care nor did they think they needed additional training. They did mention that there were oral care policies in the home that required oral care to be provided to the residents and that they had the basic knowledge to provide adequate oral care, but the barriers listed above (time, resident's attitudes, etc.) were beyond their control. It appeared to be more of a systemic problem to them than what role they could play in improving oral care of seniors. During the discussion, Michaela asked about their access to health resources and materials as well as in-service presentations and how useful they were. She then inquired as to what they felt would be effective in assisting them provide better oral care to residents. They did offer some suggestions as to what could benefit them.

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Michaela started the needs assessment with the aim to develop health promotion strategies to educate and empower caregivers to improve oral care delivery to residents based on her initial research findings which showed caregivers played a major role in oral care of residents (Altani & Wyatt, 2002). However, her findings from the analysis of her qualitative research showed it was not as simple as she had initially thought. What could she do? What recommendations can she make? What solutions can she come up with in order to improve the oral health of this vulnerable population? How else could she work with the caregivers to provide better oral care to residents? Where does she proceed from here? What recommendations or interventions could she make keeping in mind that funding is minimal?

She thought about possible options:

1. Does she develop educational materials for families of residents emphasizing the importance of oral health as a part of general health and the part they could play in improving the oral health of seniors?
2. Does she develop oral health training resources and educational materials to be included as part of the orientation and annual trainings for staff? Would this serve to improve oral care delivery if the caregivers do not see this as their main barrier or even a barrier at all?
3. Does she approach dental hygienists and dentists to offer pro-bono services to residents in the home once a month or thereabout? What incentives can she come up with to motivate these dental professionals to visit the homes?
4. Should she conduct more research; this time a needs assessment of the residents and present the findings to the ministry with the hope of acquiring public funding for programs for this group of people?

Where should Michaela go from here and what should she do?

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### EXHIBIT 1 Oral Care Policies for LTCEs

#### Section 34 – Oral Care

Every resident must receive oral care that includes:

- Morning and evening mouth care, including the cleaning of dentures;
- Physical assistance or cuing as needed to brush his or her own teeth;
- Assistance, if required, to insert dentures prior to meals and at any other time as requested by the resident or required by the resident's plan of care; and
- An offer of an annual dental assessment or other preventive dental services, subject to payment being authorized by the resident or the resident's substitute decision-maker, if payment is required.

Source: Ontario's Ministry of Health and Long-Term Care, 2007.

## iSMILE Project – Improving Seniors' Mouthcare in Long-Term Care Establishments

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### EXHIBIT 2

#### Needs Assessment Questionnaire (1) - Focus Group Discussions for caregivers

##### Questions for focus group discussions for PSWs (30-40 minutes)

1. When you think about oral health, what comes to mind? (Open-ended question to get into concerns about dental issues in the home.)
2. Do you think oral health has an impact on general health? If no or yes, how?
3. Among your daily routines for caring for the elderly, what constitutes oral care? (E.g. oral hygiene, denture cleaning/insertion, assessments, etc.)
4. How do you go about providing oral care? (E.g. how many times a day is brushing done per resident and for how long, are dentures labelled, how are they cleaned and stored, etc.)
5. Do you think oral health of residents in the home is a problem? If no or yes, why do you think so?
6. How do you find providing oral care to the residents? Good? Okay? Not bad? Challenging? Why do you think this is the case? (I expect them to talk about challenges here.)
7. What do you think can be done to improve the oral health of seniors? What part do you think you can play in it?
8. What do you think you'll need in order to assist the residents in attaining good oral health? (Likely to talk about resources such as: access to training resources or educational materials and/or which forms of media are preferred – video, prints, posters, pamphlets, etc.)

Source: Created by author.

## iSMILE Project – Improving Seniors' Mouthcare in Long-Term Care Establishments

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### EXHIBIT 3

#### Needs Assessment Questionnaire (2) - Interviews for caregivers

##### Questionnaire for Seniors' Oral Health in Long-Term Care Establishments to Survey Nurses, Personal Support Workers

Seniors, particularly those in Long-Term Care (LTC) homes, have been identified to be vulnerable to dental diseases. The aim of this project is to identify barriers or challenges faced by healthcare providers and administrative staff to providing good oral health of seniors in LTC homes and to identify possible solutions with the assistance of these care providers. Please answer the following questions below, thank you!

1. **What is the name of your home?** \_\_\_\_\_

2. **What position do you occupy?**

- ☐ Nurse
- ☐ PSW
- ☐ Residential care aide
- ☐ Other

3. **What dental diseases are most common in the home?** *Please indicate all that apply:*

- ☐ Cavities
- ☐ Broken teeth
- ☐ Loose teeth
- ☐ Tooth sensitivity
- ☐ Bleeding gums or gum disease
- ☐ Unhealthy oral tissues (ulcer, swollen or patches)
- ☐ Unhealthy tongue (ulcer, bleeding, swollen or patches)
- ☐ Mouth odour
- ☐ Dry mouth
- ☐ Unhealthy lips (ulcer, bleeding, swollen or patches)
- ☐ Other: \_\_\_\_\_

4. **What oral care procedures do you do for the residents?** *Please indicate all that apply:*

- ☐ Daily brushing                      ☐ Twice daily brushing                      ☐ More than twice daily brushing
- ☐ Flossing
- ☐ Denture labelling
- ☐ Denture cleaning
- ☐ Denture insertion and removal
- ☐ Oral health assessments                      How often? \_\_\_\_\_
- ☐ Other: \_\_\_\_\_

5. **I find it challenging to provide oral care to residents because ...** *Please indicate all that apply:*

- ☐ I don't have enough time to attend to the needs of all the residents, let alone dental needs
- ☐ I don't have enough time to attend specifically to dental so only deal with medical needs
- ☐ I forget sometimes
- ☐ Positioning the patient for oral hygiene care is difficult to do
- ☐ It's difficult to see inside the mouth while performing oral care
- ☐ Some residents won't open their mouth
- ☐ Some residents refuse oral hygiene care
- ☐ Some residents are aggressive (may kick or bite)
- ☐ Some residents can't rinse or spit
- ☐ Some residents have complex needs and providing oral care would be too challenging
- ☐ There is little support from admin/management

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☐ I don't know much about how to provide oral care to seniors

☐ Other: *please specify* \_\_\_\_\_

**6. Do you currently have access to training resources / education materials for providing oral healthcare to seniors?**

☐ No

☐ Yes    How often? \_\_\_\_\_

What type of education/training tools have you had access to? *Please indicate all that apply:*

☐ Presentations by dentists/hygienists or other dental health professionals

☐ Educational prints: brochures/pamphlets/fact sheets, etc.

☐ Online modules/resources

☐ Videos

☐ Workshops

☐ Other: *Please specify* \_\_\_\_\_

How effective/useful have these resources been in enabling you to provide oral care?

(N-E = Not Effective, S-E = Somewhat Effective, E = Effective, V-E = Very Effective)

	N-E	S-E	E	V-E	Access Not Available
Presentations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Educational prints	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Videos	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Online modules	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Workshops	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**7. Please specify any other comments, concerns, or questions in the box below**

Thank you for your time!

Source: Created by author.

## ISMLE Project – Improving Seniors' Mouthcare in Long-Term Care Establishments

### EXHIBIT 4

#### Needs Assessment Questionnaire (3) - Interviews for Directors of LTCEs

##### Questionnaire for Seniors' Oral Health in Long-Term Care Establishments Survey

Seniors, particularly those in Long-Term Care (LTC) homes, have been identified to be vulnerable to dental diseases. The aim of this informal survey is to identify barriers or challenges faced by healthcare providers and administrative staff to providing good oral health of seniors in LTC homes and to identify possible solutions with the assistance of these care providers. Please answer the following questions below, thank you!

1. Do you have a dental facility on-site? ☐ Yes ☐ No

2. Do you have a specific dentist affiliated with your centre? ☐ Yes ☐ No

If yes, who is it? \_\_\_\_\_

3. Do you have a specific dental hygienist affiliated with your centre? ☐ Yes ☐ No

If yes, who is it? \_\_\_\_\_

4. Do you have a specific denturist affiliated with your centre? ☐ Yes ☐ No

If yes, who is it? \_\_\_\_\_

5. Does the home have visits from dental companies? ☐ Yes ☐ No

6. Does the home offer transport to local dental offices? ☐ Yes ☐ No

If yes, at whose expense?

☐ Home

☐ Resident

☐ Other: *Please specify* \_\_\_\_\_

7. Do you have oral healthcare policies in the home? ☐ Yes ☐ No

– Are Oral Health Assessments performed on admission and at other times?

☐ Yes ☐ No Other: *Please specify* \_\_\_\_\_

– Do residents receive daily oral hygiene?

☐ Yes ☐ No

☐ Mornings

☐ Evenings

☐ Mornings and evenings

☐ Other: *Please specify* \_\_\_\_\_

– Is denture cleaning, care, and insertion offered to residents?

☐ Yes ☐ No

– What other policies are in place and enforced? *Please mention briefly in box below.*

8. Who provides oral healthcare to residents?

☐ Resident

☐ PSW or residential care aides

☐ Nurse

☐ Resident's family

☐ Other: *Please specify* \_\_\_\_\_

*Please mention any other comments/questions/concerns in box below.*

Thank you for your time!

Source: Created by author.

## ISMLE Project – Improving Seniors' Mouthcare in Long-Term Care Establishments

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## INSTRUCTOR GUIDANCE

### iSMILE Project – Improving Seniors' Mouthcare In Long-term care Establishments

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#### BACKGROUND

The Ontario universal healthcare coverage through the Ontario Health Insurance Plan (OHIP) was established to provide for the health needs of Ontarians ranging from children to the elderly. However, it does not include oral healthcare. Publicly funded programs that provide dental services are offered to children from low income families, recipients of Ontario works, and Ontario Disability Support with no program for seniors. With most seniors already retired and no longer receiving employment derived dental benefits, those in need of dental services would have to purchase private insurance or pay out-of-pocket. The cost of dental treatment for those who cannot afford it serves as a barrier to accessing dental services and leads to poor oral health. Seniors, especially those at a long-term care establishment (LTCE), are more susceptible to dental diseases. With many seniors retaining their natural teeth compared to previous generations, dental diseases tend to thrive and there is the increased need for dental services.

The Vanes Health Unit (VHU) Oral Health Department, under the leadership of Dr. Dawn DaSilva and Dr. Charles Oakwood, identified this vulnerable subgroup and in 2014 decided to take on the challenge to promote seniors' oral health while working with limited resources. Out of this situation the iSMILE project (improving Seniors' Mouthcare In Long-term care Establishments) was born. It is a health promotion initiative aimed at improving seniors' mouthcare by targeting caregivers – personal support workers (PSWs) mainly (in some homes nurses as well). This was done through a needs assessment first to determine what oral health meant to caregivers and their knowledge of its impact on general health, how oral care is carried out in the home, challenges and barriers faced. The project also targeted management staff as a secondary audience.

In May 2014, Michaela Josepshs, a new member of the VHU-Oral Health Team, was tasked with the responsibility to carry out the iSMILE project and to eventually develop oral health education and promotional resources that could be used by the caregivers in LTCEs. The iSMILE project was a community funded grant. Michaela had a 12-week timeline to carry out the project based on the amount of funding provided. She reviewed the findings from Dr. DaSilva and Dr. Oakwood's literature review on causes of poor oral health status of seniors in LTCEs. Michaela also conducted several literature searches and consulted with several experts to gather information about the priority population, the different target audiences, and to gain access into the LTCEs. Having done this she then proceeded to the LTCEs where she conducted a series of focus group discussions and interviews with PSWs and management staff.

## **iSMILE Project – Improving Seniors' Mouthcare in Long-Term Care Establishments**

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### **OBJECTIVES**

1. Identify underserved/vulnerable populations.
2. Appreciate the difference between priority populations and target audience for public health interventions (e.g. a nutrition education program to reduce obesity in children; target audience for the intervention/program is parents but priority population is the children).
3. Recognize political, economic, social, and other determinants of health in vulnerable populations.
4. Learn how to conduct a needs assessment:
  - a) Identify how to access information already available through literature reviews, expert consultations, and other sources.
  - b) Effectively identify and engage all stakeholders – primary and secondary audience, experts and others.
  - c) Identify and prioritize needs.
  - d) Develop a range of solutions; analyse and appraise each option.
  - e) Determine what is feasible given the local context, environmental factors, and resources available.

### **DISCUSSION QUESTIONS**

1. What is the public health challenge Drs. DaSilva and Oakwood are faced with and what is the local context?
2. Who are the priority population and the target audiences?
3. What are the identified causes of poor oral health of seniors?
4. What steps did Michaela take in conducting the needs assessment?
5. What are the barriers to good oral health for seniors identified by the PSWs?
6. What dilemma is Michaela faced with?
7. Discuss the different options and come up with alternative options (while also considering the local context and influencing factors).
8. How should Michaela implement the options?

### **KEYWORDS**

Oral care; needs assessment; personal support workers; seniors; residents; long-term care establishments.



## CASE 9

### Shifting Culture Between Patients and Health Care Teams to Impact Symptom Screen and Management

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#### BACKGROUND

Cancer patients often receive a combination of treatments to optimize the fight against cancerous cells. Along with desired outcomes of treatment, healthy tissue is also damaged and symptoms manifest. Patients typically suffer from multiple symptoms that range from mild to severe, which impact their daily functions and quality of life. Thus, an essential part of cancer care is symptom management as it gravely influences patients' quality of life. Palliative care attempts to prevent and treat symptoms caused by the disease and/or the disease's treatment. In 2007, Cancer Care Ontario adopted the Edmonton Symptoms Assessment Screening (ESAS) tool (Barbera et al., 2015). The aim of ESAS is to ensure and improve symptom management.

In July 2012, the percentage of cancer patients who were screened at least once with ESAS was 61.5% at the London Regional Cancer Program (LRCP) (Cancer Care Ontario, 2014). Since that time, the number of patients completing ESAS has declined. In March 2014, the proportion of all cancer patients screened at least once with ESAS was 39%; below the provincial average of 58.4% and substantially under the provincial target of 70% (Cancer Care Ontario, 2014). Accordingly, Cancer Care Ontario placed LRCP on a formalized performance management escalation plan. This plan aimed to investigate reasons for the decline and outline progressive steps to increase the ESAS rate. LRCP created the Symptom Screening and Management Project, which aimed to increase the ESAS completion rate by patients, and address care team members' actions on following up with moderate to severe ESAS scores.

In September 2014, the project was underway but lacked a program manager to take ownership of the program. LRCP appointed Lisa Grey as program manager. Grey was a Regional Program Specialist at South West Regional Cancer Program (SWRCP) and had several years of experience working with health promotion and facilitating similar programs in Windsor, Ontario. She was knowledgeable with ESAS and was able to help facilitate the transition of the tool to other South West centres. Leaders at LRCP felt that she would be a great asset to the team to build buy-in and generate a successful outcome. When Grey joined the project, she noted with concern that the ESAS rate had drastically dropped in the ESAS Usage Reports. Since 2012, the number of patients who had completed ESAS at least once during their cancer journey had reduced to just over 20%. In September 2014, the percentage of all cancer patients who were screened at least once with ESAS was 36%. Grey was determined to strengthen cancer symptom screening and management. As program manager, Grey was in charge of leading the

## **Shifting Culture Between Patients and Health Care Teams to Impact Symptom Screen and Management**

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Symptom Screening and Management Project. Her role was to assess the performance measures, be consistently aware of changes involving ESAS, monitor the percentage of patients completing ESAS, evaluate patient and health care team barriers, supervise and maintain communication among five work streams dedicated to promoting ESAS usage, and investigate options to arrive at high-level recommendations.

### **AGENCIES**

Cancer Care Ontario is an agency of the Government of Ontario that focuses on cancer prevention, screening, care, management, delivery, and access. It provides funding to 14 Regional Cancer Programs across Ontario. The South West Regional Cancer Program oversees local cancer issues and assists health care teams and centres such as the LRCP. Cancer Care Ontario had recently launched the Ontario Cancer Plan IV – a roadmap for how the government and partners across the province would work together to develop and deliver cancer services over the next four years. This Plan was structured around improving the patient experience. By adopting ESAS, Cancer Care Ontario aimed to improve symptom management by encouraging communication between patients and their health care teams to ensure patient-centered care. Doing so involves flagging and discussing moderate to severe symptoms and providing appropriate care in a timely manner.

### **EDMONTON SYMPTOMS ASSESSMENT SCREENING (ESAS)**

ESAS is an interactive validated assessment tool (Chang, Hwang, & Feuerman, 2000). It allows for a self-assessment of patient symptoms on a standardized scale, and is accessible at a private kiosk where patients may be more likely to answer and rate their symptoms honestly. When patients are asked open-ended questions by clinicians, two-thirds of information is lost and patients underreport their experience (Homsí et al., 2006). ESAS screens nine symptoms: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath; brief definitions are included to explain each symptom (see Exhibit 1). This tool helps patients and health care providers by allowing them to track symptom changes during the patient's cancer journey. Ideally, patients complete ESAS after registration and at each patient review and clinical appointment visit. The results are then used by health care providers to conduct a deeper assessment, and to implement clinical measures and interventions into the patient's care plan.

ESAS provides an opportunity to identify symptoms earlier and reduce negative health outcomes through the management of these symptoms. It has been identified that patients with higher symptom scores have a greater chance of using an emergency room (Barbera et al., 2013). ESAS screening is associated with fewer emergency room visits (Barbera et al., 2015). In a population-based cohort study of elderly patients with cancer, one-third of patients who had reported high pain scores had not received a prescription for opioids (Barbera et al., 2012). Additionally, symptom scores may be an indication of death approaching. Symptoms such as fatigue, poor well-being, poor appetite, and drowsiness tend to increase during the last months of life, whereas pain, nausea, anxiety, and scores for depression remain constant (Seow et al., 2011). A survey of patients identified that ESAS is valued and contributes to their care plan (Green, 2012).

### **DECLINING USE OF ESAS**

To discover barriers that contributed to the lack of ESAS use, LRCP conducted surveys and focus groups among both the health care team and patients. The goal of the research was to identify existing attitudes, values, and beliefs about symptom screening and management.

## Shifting Culture Between Patients and Health Care Teams to Impact Symptom Screen and Management

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The following were investigated:

- Patient understanding of ESAS
- Patient concern about ESAS
- ESAS accessibility and user friendliness
- ESAS orientation
- Patient-health care team communication about ESAS results and symptom management
- Health care team familiarity with ESAS
- Health care members' roles in relation to ESAS
- Health care team access of screening and management resources and guidelines

### BARRIERS

The surveys and focus groups completed by LRCP revealed aspects of team culture and patient culture. The work streams also gave insight to barriers.

Team culture among health care employees has a significant impact on patient use of the tool. Unfortunately, at LRCP, there were many factors that contributed to the breakdown of how staff encouraged and facilitated the use of the tool. For example, at patient registration for appointments, clerks were not asking patients to complete ESAS. Allied staff failed to direct patients to complete the screen when given the opportunity. Volunteers that stand at the kiosks to assist and orient patients to ESAS felt uncomfortable approaching patients because of privacy concerns. These factors all contributed to a lack of consistency in orienting patients to the kiosks. Some health care team members had lost confidence in the use of the tool and did not believe that it improved patient outcomes, and that symptom assessments were being completed during patient appointments regardless of the tool. Other care providers believed they were making use of ESAS, but did not directly refer to the tool when discussing symptoms with patients. The staff at LRCP used paper charting to document assessments. ESAS, however, is generated electronically and requires clinicians to access the ESAS results on a computer. This adds to their workload because in addition to completing the paper chart, they need to find an available computer and log in to view the results. Clinicians felt that accessing ESAS was time-consuming and that it took away from patient interaction.

Patient culture was another barrier that contributed to the decline of ESAS use. First, patients felt a lack of confidentiality when being assisted by volunteers. A lack of confidentiality and privacy was also due to the location of the kiosks in open areas within LRCP. It was reported that the placement of the kiosks on the walls was not accessible, nor user-friendly to patients in wheelchairs or those who wanted to complete ESAS while seated. Furthermore, the term kiosk had been used to reinforce the simplicity of completing ESAS electronically. However, there was an inconsistency with the use of the term and it has also been referred to as a computer. Some older patients were uncomfortable using computers and felt threatened by technology. While ESAS is offered in English and French, the number of languages spoken in London's multicultural community meant that some language barriers were present. There were also misperceptions of what the program was, why the ESAS should be completed, and where the information went. Some patients felt that the hospital was trying to take shortcuts in care and minimize patient-care provider interaction. These misperceptions are a result of insufficient orientation of patients with ESAS and a resulting lack of knowledge about program objectives.

### IMPACTING ESAS

In June 2015, the Symptom Screening and Management Project (SSMP) continued, with revised goals:

## Shifting Culture Between Patients and Health Care Teams to Impact Symptom Screen and Management

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- Ensure that at least 70% of patients seen at LRCP in a given month would complete ESAS at least once by March 2016.
- Ensure care team members take action to address symptom concerns in 100% of patients who identify moderate to severe symptoms by March 2016.

Project Manager Grey oversaw and ensured communication among five work streams, which included: 1) Process, Nursing, and Respiratory Therapist (RT) Engagement; 2) Patient and Volunteer Promotion and Resource; 3) Leadership Engagement and Accountability; 4) Volunteer and Clerk Engagement; and 5) Physician Engagement.

1. The Process, Nursing, and RT Engagement aims to improve processes related to cancer symptom screening and management in clinics and patient review, as well as define and communicate nurse and RT roles and symptom screening and management expectations.
2. Patient and Volunteer Promotion and Resources support patients and volunteers by creating educational and promotional material.
3. Leadership Engagement and Accountability defines and communicates leadership roles and symptom screening expectations. In addition to building and integrating accountability related to symptom screening and management across all levels, this work stream is responsible for monitoring and communicating program successes and potential areas for improvement over time.
4. Volunteer and Clerk Engagement aims to define and communicate the roles of volunteers and clerks and outline symptom screening expectations. This work stream also focuses on how to orient patients to ESAS.
5. Physician Engagement focuses on defining and communicating physician roles. This work stream also outlines physician symptom screening and management expectations.

The work streams developed a symptom screening and management strategy to build value in ESAS and outline specific tactics to change the health care team and patient culture. The vital behaviours they planned included prompting patients to complete ESAS, encouraging patient-care team discussions about symptom concerns, and empowering care teams to take action when addressing symptoms.

### MAKING CHANGES

Grey entered the boardroom just in time for the teleconference with the Promotion and Education work stream. Present at the meeting were Patient Educators Matilda Cage and Veronica Darcy, Publicity and Marketing Specialist Lauren Spades, and Marketing Associate Arianna Spence. In a previous meeting, it was decided that these individuals would create posters and pop-up banners to prompt patients, and a postcard that would be a symptom screening overview for patients to explain why and how to complete ESAS. When these materials were completed, they were given to the steering committee for evaluation. With the steering committee's feedback, Spades and Spence made sure that messaging was clear, the wording reinforced positive messaging, and the colours used were consistent with the SSMP materials (see Exhibit 2: Postcard-Symptom Screening Overview). In this meeting, these materials were approved and team members continued to discuss patient engagement. They collaborated on where to place the posters and pop-up banners in LRCP. It was decided that the banners would be placed at patient entrances, across from the main elevators, at the blood lab, at the patient review, and in appointment rooms (see Exhibit 3: LRCP Map) with the goal of stimulating conversation about ESAS, and reminding patients to complete the screen after registration. They also decided to place wall stripes and decals behind each kiosk to increase

## Shifting Culture Between Patients and Health Care Teams to Impact Symptom Screen and Management

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their visual identity in the often crowded waiting room. The meeting concluded and Grey sent out a communication memo to update the other work streams about the pending initiatives.

The collaboration of all work streams continued to develop ways to change patient culture and promote ESAS completion. In an effort to address patient feedback and the lack of understanding about ESAS, the My Care Binder was updated. The My Care Binder is given to patients on their first visit to LRCP. It is an educational resource that includes information on care, support, and services, and is also a place for patients to record and organize information throughout their cancer journey. Updates to the binder include information about what ESAS is and the importance of completing it. Furthermore, information was reorganized on the LHSC website (Symptom Screening page) and more resources were provided, including: symptom screening overview, symptom screening key messages, symptom screening Frequently Asked Questions document, and a symptom screening management video. Another tactic was to add welcome and exit key messages to the kiosks to reinforce reasons for completion. At the initial orientation, volunteers guide patients with the use of the touch screen technology at the kiosks and help them answer questions. At this time, patients also receive a postcard with instructions on how to complete the screen and messages about how the information is used. To address feedback about privacy, a hood was created to shelter the kiosk. This was piloted to see if it would be effective in decreasing privacy concerns and if supported, the hood would be implemented at all kiosks. Lastly, to make the kiosks more accessible, the screen height was made adjustable for patients in wheelchairs or those who wanted to complete it while seated. The combination of these tactics was believed to have highlighted the value of using ESAS on a consistent basis.

### NEXT STEPS

With the implementation of patient-focused tactics, LRCP began to see an increase in ESAS use, but Grey knew that in order to see further improvements, there needed to be a greater focus on the internal culture at LRCP. The health care team was a fundamental factor in symptom screening and management. Buy-in was needed from the health care team and from management in order to achieve the project goals. The work streams proposed that the following needed to be addressed:

- Consistent messaging for ESAS
- Identify health care team roles and responsibilities
- Create leadership and communication related to symptom screening and management
- Create resources
- Refresh the health care team on available resources addressing management
- Strengthen patient-health care team communication

Grey had several meetings lined up with each work stream to discuss how to tackle these issues. As she prepared for the upcoming week, Grey knew that supporting symptom screening and management by changing the attitudes and values of the health care team would strengthen the cancer program and positively impact the quality of life for cancer patients at LRCP.

# Shifting Culture Between Patients and Health Care Teams to Impact Symptom Screen and Management

## EXHIBIT 1 ESAS

<b>Cancer Care Ontario</b> <b>Action Cancer Ontario</b>											<b>Edmonton Symptom Assessment System:</b> (revised version) (ESAS-R)	
Please circle the number that best describes how you feel NOW:												
No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
No Tiredness	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
<i>(Tiredness = lack of energy)</i>												
No Drowsiness	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
<i>(Drowsiness = feeling sleepy)</i>												
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
No Depression	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
<i>(Depression = feeling sad)</i>												
No Anxiety	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
<i>(Anxiety = feeling nervous)</i>												
Best Wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing
<i>(Wellbeing = how you feel overall)</i>												
No _____	0	1	2	3	4	5	6	7	8	9	10	Worst Possible _____
<i>Other Problem (for example constipation)</i>												
Patient's Name _____ Date _____ Time _____											Completed by (check one): <input type="checkbox"/> Patient <input type="checkbox"/> Family caregiver <input type="checkbox"/> Health care professional caregiver <input type="checkbox"/> Caregiver-assisted	
<b>ESAS-r</b> Revised: November 2010											<b>BODY DIAGRAM ON REVERSE SIDE</b>	

Source: Cancer Care Ontario, 2010.

## Shifting Culture Between Patients and Health Care Teams to Impact Symptom Screen and Management

### EXHIBIT 2

#### Postcard – Symptom Screening Overview

**You know how you are feeling.  
We know how to help.**

**Completing the symptom screen helps you and your health care team to identify symptoms that may be of concern.**

Your results are kept confidential and stored in your electronic medical record. Your health care team will review your scores before they meet with you. During your appointment, they will ask about the symptoms you have flagged as a concern to you. Ask about any symptoms of concern that are not part of the symptom screen.

We want to help manage your symptoms to help you feel better. There may be changes we can make to your care plan or other health care team members who can help (e.g., social workers, dietitians).



#### Completing the symptom screen:

1. Complete at every clinic and patient review appointment after registering – it takes less than five minutes
  2. Use a touch screen kiosk located in the clinic and patient review waiting areas
  3. Log in with your Ontario Health Card
  4. Touch the kiosk screen to enter your answers
  5. Rate your symptoms based on how you are feeling at that time
- A score of zero means no symptom and ten means worst possible symptom

**Ask a volunteer for help if needed.**

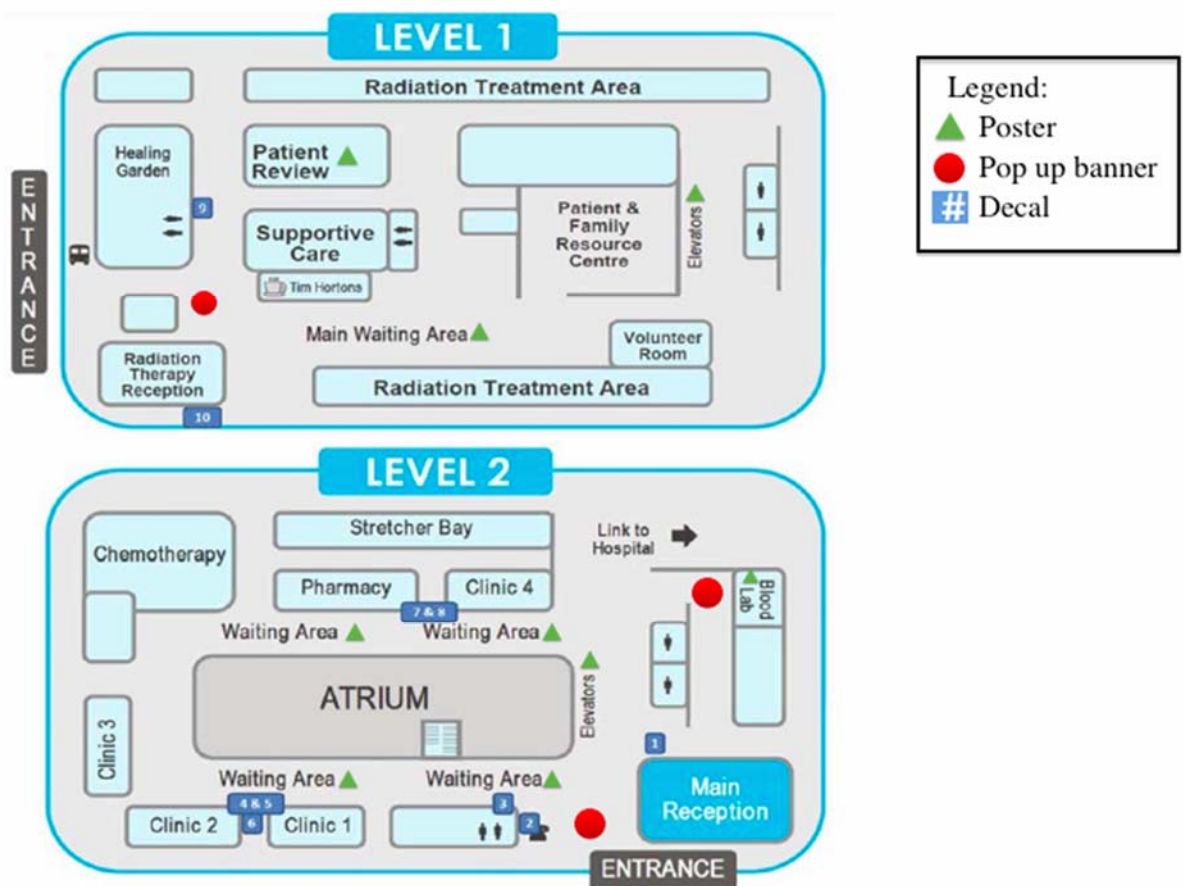
#### Key terms:

**Tiredness** = lack of energy or low energy level  
**Drowsiness** = feeling sleepy  
**Depression** = feeling sad  
**Anxiety** = feeling nervous or restless  
**Well-being** = how you feel overall

Source: London Health Sciences Centre, 2015.

## Shifting Culture Between Patients and Health Care Teams to Impact Symptom Screen and Management

### EXHIBIT 3 LRCP Map



Source: London Health Science Centre, n.d.

## Shifting Culture Between Patients and Health Care Teams to Impact Symptom Screen and Management

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## INSTRUCTOR GUIDANCE

### Shifting Culture Between Patients and Health Care Teams To Impact Symptom Screen and Management

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#### BACKGROUND

Health Promotion Specialist Lisa Grey is faced with the task of strengthening patient and health care team culture using the Edmonton Symptoms Assessment Screening (ESAS) tool. ESAS is a standardized symptom screening tool used in health care settings across Ontario and is completed by patients at each clinic visit. The tool measures and tracks a patient's symptom severity relating to nine common cancer symptoms. Symptoms are an indication of the progression of cancer and patient health status. ESAS gives an opportunity to identify symptoms earlier on, prevent emergency admission, and manage symptoms such as pain (Barbera et al., 2012; Barbera et al., 2015). The percentage of total cancer patients who were screened at least once with ESAS had declined at the London Regional Cancer Program; screening rates were below the provincial target of 70% and the provincial average of 58.4% (Cancer Care Ontario, 2014). Grey oversees five work streams in an effort to change attitudes and beliefs among patients and health care employees, and highlight the value of using ESAS on a consistent basis.

#### OBJECTIVES

1. Understand the factors that influence patient and health care team culture.
2. Develop a strategy based on survey and focus group feedback.
3. Analyze and develop applicable health communication methods.
4. Apply a behaviour change model to the case.

#### DISCUSSION QUESTIONS

1. What are health communication methods and strategies that can be used to improve patient culture relating to participating in symptom screening?
2. What are the advantages and disadvantages of using these methods and strategies?
3. What partnerships are necessary to facilitate health care team (e.g. management, clerks, volunteers, nurses, physicians, and other allied health) culture changes?
4. Identify the key tensions related to the health care team culture.
5. Develop a strategy to address the issues in 'Next Steps' to increase symptom screening and management use among health care teams.

#### KEYWORDS

Patient culture; health care team culture; symptom screening and management; ESAS.

# **FACULTY CASES**



## CASE 10

### Babies and Budgets: Balancing Costs and Consequences in Postpartum Screening<sup>1</sup>

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“What would be the impact if we adopted a different model?” This was the question posed by Dr. Philip Singe, the Medical Officer of Health for King Public Health in the Region of King. He was meeting with the health unit leadership to discuss the Family Health portfolio, particularly the Healthy Babies, Healthy Children (HBHC) Program. Philip had been poring over the program budget for weeks. Ministry funding for the program had been stagnant for years, forcing him to make two key decisions. First, he had to decide which part of the HBHC suite of programs to prioritize. The unit’s high contact, high intensity approach to in-hospital postpartum screening meant that the other main area of the HBHC program suffered. High-risk women scheduled for home visits after being discharged from the hospital spent a long time on the waiting list. The unit could rearrange the services, use less staff in the hospital, and redirect staff to home visits. Second, he had to decide whether or not to subsidize the HBHC program using the health unit’s operating funds, or reduce the number of HBHC staff in order to stay within the program budget. In the conference room adjacent to his office, Philip sat with the program manager, Praveen Gill, and the director of the Family Health portfolio, Vanessa Thomas. Praveen and Vanessa had been tasked with addressing the challenges. The two had spoken extensively with hospital partners involved in postpartum screening. It was time for a decision on whether or not King Public Health would change the way it delivered services under this program.

The Ontario provincial government introduced the Healthy Babies, Healthy Children (HBHC) program in 1998. The program vision is to ensure that “every child at risk (prenatal to age six) in Ontario will be provided with opportunities to achieve his/her optimal potential” and “... have access to effective integrated programs and services that support healthy child development” (Ministry of Health and Long-Term Care, 2001). HBHC identifies children at risk of “physical, cognitive, communicative and/or psychosocial problems” and links children and their families to preventive and early intervention services (Ministry of Health and Long-Term Care, 2001). Program components include prenatal and postpartum screening, home-visiting services for children prenatal to age six that have been identified as high risk, and case management services linking children and families to community-based health and social services (Ministry of

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<sup>1</sup>The case contains fictional elements, including the Region of King, the municipalities of Weston, Keewatin, and Oxford, King Public Health Unit, and its personnel. Hospital names and financial data are also fictional. All other elements, including the Province of Ontario, Greater Toronto Area, other health units, the history, goals, and components of the Healthy Babies, Health Children (HBHC) program, are real.

## Babies and Budgets: Balancing Costs and Consequences in Postpartum Screening

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Health and Long-Term Care, 2001). HBHC utilizes a screening tool that can be administered to pregnant women to identify factors that put them at risk for adverse outcomes (see Exhibit 1).

The HBHC program aims to take advantage of several opportunities to connect with pregnant women. The majority of screens are administered postpartum, in-hospital, prior to discharge. Additional opportunities such as during registration at the hospital prior to giving birth, or in the community where primary caregivers can fax completed screens to the health unit, are less frequently utilized. The women and children identified as being at risk for adverse events receive a home visit by a public health nurse. During home visits, the nurse assesses parents and families using a risk-screening tool and develops a plan with the family to address these risks. This may involve connecting them to social services and other community supports. The Ontario Ministry of Child and Youth Services (MCYS) allocates funding each year to the boards of health, which govern the province's public health units, specifically targeted to the HBHC program. The organization and management of program components is under the discretion of each public health unit.

Since 2013, Ministry funding of the HBHC program has remained stationary. This funding freeze necessitated changes to the program. At the provincial level, the intended scope of the program shifted from universal to targeted. Initially, the program had been directed at ensuring that all children and families received a home visit. The focus moved toward optimizing screening services. Prenatal and postpartum screening were used to target home visits to high-risk mothers and children who were most in need of those services. At the local level, public health units reduced staff and experimented with their service delivery models. Each health unit delivered services in different ways. Some emphasized prenatal and postpartum screening, ensuring that public health nurses devoted their time to support busy hospital staff. Others relied more on hospital staff to complete prenatal and postpartum screening, focusing on post-discharge follow-up. The funding freeze was operationally equivalent to a funding cut, as it resulted in operating shortfalls for public health units. For example, operating costs increased annually due to collective agreements, which mandated a 3% annual rise in the salaries of program employees.

At King Public Health, a significant proportion of the HBHC program resources were consumed by administering postpartum screens in the hospital, while the waiting list for home visits continued to grow. Philip had called this meeting to discuss changes to program delivery. The goal was to reduce the cost of postpartum screening in order to redirect resources to home visits and to reduce the overall cost of the HBHC services in order to remain within the allocated MCYS budget. With the end of 2015 fast approaching, King Public Health needed to consider implementing changes, if any, by April 1st, the beginning of the 2016 fiscal year. Philip reviewed the numbers with his team in the hopes of better informing their decision. He faced the challenge of addressing funding shortfalls resulting from static funding and rising operating costs.

The province of Ontario accounts for one-third of the approximately 35 million people in Canada. King Public Health is one of 36 public health units in Ontario. The Region of King has 1,384,000 residents in the municipalities of Weston, Keewatin, and Oxford. It is located northeast of the City of Toronto. The size of the population served by King Public Health makes it a mid-sized health unit. In comparison, Toronto Public Health serves 2.8 million people. Smaller health units, like Lambton and Elgin St. Thomas Public Health, serve communities of less than 150,000 residents. During the first decade of the twenty-first century, King Region experienced tremendous growth, which was only partly driven by births. Migrants from other

## Babies and Budgets: Balancing Costs and Consequences in Postpartum Screening

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regions and the arrival of new Canadians accounted for the majority of the growth. As the largest city in Canada, Toronto is an attractive destination, but the high cost of real estate within the city boundaries means that people increasingly choose to live in one of the suburban communities of the Greater Toronto Area. Population forecasting suggests that the number of live births in King Region will remain stable for the next few years.

“The budgetary constraints necessitate a change in the way we operate.” Philip added, “Our staff and resources need to be utilized more efficiently. The goal is to modify service delivery while preserving or even enhancing effectiveness. This is a tall order since we also need to cut the overall cost of the HBHC program in order to remain within the MCYS budget. Waiting lists for home visits continue to grow. Praveen, can you tell me how long families are waiting?”

Praveen shuffled through the sheets of paper in front of her. “The average wait time during the 2014 fiscal year was eight weeks.” She looked at the next sheet of paper and said, “This past year, we’ve been looking at wait times of almost 12 weeks.” Praveen looked up and added, “We have been addressing this challenge in different ways. As you know, we make an initial telephone contact. We then perform program triage – the home-visit nurses prioritize contact for families most in need. We follow up with the families just prior to the home visit, to ensure that the home address is the same – to make sure they haven’t moved. The wait list has grown so rapidly, I’ve considered making telephone contact at the six-week point to ensure the family hasn’t moved. Anyway, we’ve been addressing the challenge by attempting to reduce the amount of time the case manager spends with each family. We used to book two home visits per day for each nurse, we now book three home visits per day, paying attention to proximity of course...”

“Just to clarify, the 12-week wait time is for the lower priority triage families?” asked Philip.

“Yes, for the most part. I would say that the triage system means we get to extremely high-risk families within days, so those are families where there is a real suspicion that the newborn will suffer immediate harm. For those extreme cases, we make contact immediately and bring in social services. Of course, those families require many repeat contacts, but I guess that’s a discussion for another day. The vast majority can be considered intermediate risk, and that’s what the 12-week wait time pertains to,” responded Praveen.

“Okay, so how have the nurses responded to the changes?” asked Philip. “It must be difficult to visit three families each day when you’re used to visiting two.”

“It’s difficult to say...” Praveen hesitated. “I think the nurses’ opinions reflect mine. On the one hand, taking a long time to visit the home is damaging to the overall program objectives, so any changes we can implement to reduce wait times are welcome. We don’t want to show up at families’ homes after a new mother has suffered for months with a critical situation or established poor coping mechanisms, and has no knowledge of the community services available.” Praveen paused. “We also don’t want to rush those encounters with families and new mothers when we finally do get the chance to visit them. It’s a complicated situation...”

“Philip, my concern about the HBHC portfolio is that a large proportion of the budget is allocated to screening,” Vanessa Thomas offered. “If we can redirect additional resources to home visits, to free up some staff time to assist with home visits, I think the overall effectiveness of the program would be improved. I think we can work with the hospital partners to ensure their staff complete the screens accurately and then we can allocate more resources to home visits” (see

## Babies and Budgets: Balancing Costs and Consequences in Postpartum Screening

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Exhibit 2). Vanessa spoke with the candor of a professional with 25 years of experience in all facets of public health. While some might mistake her usually unsmiling expression for a lack of compassion, Philip understood her reliability and dedication to her job to be her expression of compassion. He appreciated her breadth of knowledge. If she believed that in-hospital postpartum screening could continue with fewer personnel, it was a recommendation he would seriously consider despite his reservations.

“How many screens did we administer last year?” Philip asked.

Praveen Gill looked down at the numbers on the first page in front of her. “In fiscal 2014, there were 8,210 live-births in King Region. We administered 7,553 screens, 5,663 at Kanesatake Health Network and 1,890 at Weston General.” Praveen looked up and continued, “... so we’re at 92% coverage.”

“That is amongst the best coverage in the province,” interjected Vanessa Thomas. “We complete screens on 92% of families within 48 hours of birth. Only two public health units in the province are performing better.”

Praveen added, “Achieving coverage of 92% is remarkable. When you consider the number of births occurring on Friday afternoons and on the weekends, the screens that we miss are the Monday morning screens just outside the 48 hour window that have already been discharged from hospital.” The younger Praveen had been an excellent hire. Balancing professionalism and empathy, she directed the work of nurses who were stretched to the limit with many responsibilities. Somehow, Praveen managed to ensure that the program ran smoothly while making every attempt to address the challenges faced by the nurses.

“I’ve prepared a breakdown of the budget for the program,” said Vanessa (see Exhibit 3).

“Thank you for this,” Philip said. “So we have nine public health nurses allocated full-time to the HBHC program. Was it five you said Praveen that work full-time on home visits?”

“Yes, that’s correct,” affirmed Praveen.

“And so that means four work full-time on screening.” Philip paused for a moment. “Let’s review how the screening is structured.”

Praveen responded, “As you know, King Public Health utilizes the liaison PHNs, or Public Health Nurses, to build capacity at the hospital and to administer the tool when necessary. It is the responsibility of hospital staff to administer the screens, which include the consulting physicians, obstetrics nurses, and trainees. The PHNs are tasked with playing a supportive role. Currently three nurses work at Kanesatake Health Network and one works at Weston General,” Praveen Gill volunteered. “I would say we have roughly one PHN per 1,900 births. Each morning, the PHNs review the screens, finish incomplete screens if necessary, finalize the screens, and bring them back to the health unit for program triage.”

“So the PHN role is quality assurance?” asked Philip.

“Yes. That’s correct,” responded Praveen.

## Babies and Budgets: Balancing Costs and Consequences in Postpartum Screening

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“And this is the screening tool...” Philip quickly reviewed the document. It had been some time since he looked at it in depth. “There are 36 questions.” (Ministry of Children and Youth Services, 2012, p. 92.)

“The PHNs also train the hospital staff in how to administer the screening tool,” added Vanessa. “So you can see the PHN role already includes education, and this is what I would like to enhance by changing our care delivery model. I believe that this screening tool is quite sensitive in the hands of a health professional with sufficient training. Currently the PHNs train hospital staff on administering the tool approximately four times each year. If we pull three full-time equivalents (FTEs) from the hospitals, we could then allocate more PHNs to home visits. To offset the loss of the PHNs in the hospital, we would increase the quality and frequency of training, so that we will be able to rely on the hospital staff to complete the screens comprehensively and accurately. Instead of one every four months, we would hold training sessions every two weeks. This way, new hospital staff and trainees would have more opportunities for training.”

“And the plan would be to move one PHN out of HBHC altogether,” said Philip.

“Yes, that would bring us under budget and within the MCYS funding allocation,” Vanessa interjected. Two FTEs would help with home visits and one would be assigned to another area of family health outside of HBHC.

Philip was concerned about the HBHC program being over-budget and he had asked Vanessa to find solutions, but he also wanted to ensure that the overall program goals would not suffer. “How often are the screens incomplete?”

Praveen began to express an opinion that it appeared she had come prepared to share. “Listen, I completely understand any reservations about this proposed change. In the mornings, and particularly Monday morning, after the weekend, the PHNs arrive in the hospital to many incomplete screens. Frequently, they have to scramble to reconnect with staff and patients to fill in the gaps. The hospital staff often cite the issue as time. But, I suspect part of it is new staff being unfamiliar with the tool, and knowing that the liaison PHN is responsible for finalizing the screens.”

“And that can be easily remedied,” said Vanessa.

Praveen continued, “The PHNs frequently revisit completed screens. For instance, they may notice potential inconsistencies such as a single mother who indicated no concern about money. On one hand, it may be a wealthy single mother. On the other hand, it may be that the hospital staff missed subtle cues that the mother was concerned about money but too embarrassed to say so. In that case our liaison PHN will follow up with that mother if she is still in the hospital or flag the screen as high-risk herself.”

“Yes, we know quality is dependent on the skills of the person administering it. The need to be attentive to non-verbal cues will form a significant part of our enhanced training,” said Vanessa.

“What are the most common risk factors?” asked Philip.

Praveen shuffled through the sheets in front of her once again. “Our records for 2014 show that 27% had labour and delivery complications, 20% experienced a previous loss of a pregnancy or

## Babies and Budgets: Balancing Costs and Consequences in Postpartum Screening

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baby, 19% implied concerns about the wellbeing of the client by the healthcare professional, 15% showed maternal cigarette smoking during pregnancy to be a risk factor, and 14% were low birth weight babies, less than 4000 grams. Overall, 32% were identified as at risk – some had multiple factors.” Praveen paused “I think these pieces of information are important because they tell us about our intended target population.”

“The data also suggest the healthcare professional role in identifying at risk mothers is significant. Okay, now let’s talk in-depth about what you propose we should do.” Philip directed his statement to Vanessa.

“Under the proposed model, the PHN would act as an enhanced resource for health professionals who administer the tool. The PHN would provide information about the HBHC program and conduct frequent training and refresher sessions. The doctors and nurses in the hospital would administer the screening tool as they currently do, but our liaison would not be responsible for quality assurance.”

“The screenings would be taken on mainly by the professionals at the hospital,” Philip reiterated, speaking slowly. “I see your rationale for suggesting this, and in a way this is what the hospital staff are supposed to do and already do to some extent, but would we be taxing an already taxed system?”

“Philip, there is no denying it. The hospital administration suggested it would be challenging to administer such a long questionnaire, but as you stated, the staff already do this. The incomplete questionnaires during the evenings and weekends are related, at least in part, to staff knowing that the liaison nurse’s role is to complete the screens. When we stress the requirement to complete the screens, provide training and suggestions on how to be sensitive and efficient in completing the screens, I believe that we can stay close to maintaining our coverage levels,” asserted Vanessa. “For example, there are additional processes that could be implemented, to assist with their workflows. Consent for the postpartum screening is obtained around the 36th week of a woman’s pregnancy during her preadmission clinic appointment. This is a window of opportunity for screening that could be taken advantage of. The hospital staff could begin completing the screening document at the time of consent and this would minimize the number of items that would need to be completed postpartum. Most health units of our size employ this model. While we have done our best to maintain this high level of involvement of the liaison nurses in the birthing units, because of the costs we cannot continue to operate this way. Two additional PHNs performing home visits can improve the overall effectiveness of the HBHC program.”

“What would be the impact on other costs? What about the travel budget?” asked Philip.

“I anticipate that the travel budget for postpartum screening would be cut by 50%. By assigning two additional PHNs to home visiting the travel budget for home visiting will increase by 40%. Would you agree with that Praveen?” asked Vanessa.

“Yes, that sounds reasonable to me,” Praveen responded. “I would expect no changes in the supplies and office equipment for screening. We would still provide the same number of forms to the hospitals. For home visits, I expect a 40% increase in the cost of supplies.”

Philip asked, “So what do you think is the worst case scenario in terms of coverage? How much could our coverage levels fall?”

## Babies and Budgets: Balancing Costs and Consequences in Postpartum Screening

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"I think at most our coverage levels would fall by 10%," Vanessa offered. "That would put us at the current provincial average of all PHUs."

"Is that acceptable?" Philip asked. "How good are the liaison PHNs at correctly identifying high risk families and how good can the hospital staff be?"

"The sensitivity?" asked Vanessa.

"Yes," responded Philip. "What is the worst case scenario in terms of the sensitivity of detecting high risk families?"

"It's a difficult number to estimate," said Vanessa.

"Okay, let's think this through. Would you say that our liaison PHNs miss high risk mothers?" Philip rephrased.

"I think that's highly unlikely," responded Vanessa. "Let's say that if our liaison PHNs interview a high risk mother, they will identify her 90% of the time."

"We have to consider the sensitivity of screening, much like a diagnostic test sensitivity..." Philip began to write on his notepad. "Out of 7,553 screened, the liaison public health nurses identified 32% of those screened as at risk. They identified 2,417 as at risk and this represents 90% of those truly at risk. If we divide 2,417 by 0.9 we get the number truly at risk... 2,686. Of all women screened, the number truly at risk is 2,686 and the percent truly at risk is 36%." Philip looked up from his notepad. Do you think the hospital staff would function at the same level?"

"With enhanced training, I would trust that hospital staff would identify high risk mothers 85% of the time," said Vanessa.

"Where would you put that number," Philip asked Praveen.

"I must admit, I would put the number a bit lower," Praveen said. "I'm thinking 80% of the time..."

"Also, let's not forget," Vanessa volunteered, "Community partners also identify high risk women and submit completed screens to the PHU. There are other ways mothers at risk are identified."

Vanessa's support of the model change was motivated by pragmatism and the need to operate within budget. It was clear that the strain of keeping up with the requirements of the home visit program, and the missed opportunities to intervene, were wearing on her. "Two more home-visit PHNs means we can reduce wait times and get to families sooner."

"You're right Vanessa. But we have to consider the possibility that with busy schedules, hospital staff may find it difficult to pick up on subtle cues when asking sensitive questions," added Praveen.

"I know that at this point, remaining with our current model is not an option unless we allocate additional funds to HBHC," Philip said. "The operating costs are soaring, the Ministry hasn't increased funding and so we are left with making the best of this situation." Philip paused before continuing, "When I was the Associate Medical Officer of Health for Lambton Public Health, the

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unit oversaw screening for approximately 800 live births each year. We employed one liaison screening PHN and employed the screening model we currently use here at King. We shifted resources from our operating budget into the program to supplement the Ministry funding and ensure adequate staffing for postpartum screens. I am willing to consider allocating additional funds to the HBHC program if we believe we cannot maintain high levels of quality, but that would be dependent on the evidence of the impact of the program. I want to be certain that we don't compromise the effectiveness of the whole program, including the postpartum screening component. I appreciate the budgetary constraints, but the time of birth may be the best opportunity to identify families at risk and intervene. Given that the acute care system is already taxed, shifting screening responsibility entirely to this sector would surely reduce coverage and sensitivity. The question is whether we accept the reductions, knowing that we will be improving home visiting."

All in the conference room were silent. Each knew there were no easy answers.

As Philip contemplated King Health Unit's HBHC screening program, he thought about the trade-offs involved in the decision. "I don't want to rely on an educated guess or a gut feeling. Let's evaluate our options systematically..."

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### EXHIBIT 1 Risk Factors Addressed by the Postpartum Screening Tool

Economic and Social Risk Factors	Infant Health Risks	Parent Health Risks
<p>Lack of social support</p> <p>Social, geographic or cultural isolation</p> <p>Low level of education</p> <p>Sole-support parenting</p> <p>Adolescent mothers</p> <p>Low income</p>	<p>Low birth weight</p> <p>Congenital defects and/or syndromes</p> <p>Parent(s) with a physical or development disability</p>	<p>Parent(s) with a psychiatric illness</p> <p>Parent(s) with substance abuse problems</p> <p>Parent(s) with dual diagnosis</p> <p>A history of domestic violence and abuse</p>

Source: The table is a summary of the risk factors outlined by the Ministry of Health and Long-Term Care, 2001.

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### EXHIBIT 2

#### Description of HBHC Postpartum Screening Models

The HBHC program follows the Screening Liaison Model, a model that promotes partnerships and collaboration while ensuring a quality screening process is followed.

##### **Current Model**

King Public Health employs a high nurse to births ratio in the hospital. The liaison public health nurses (PHNs) are a consistent resource ensuring high coverage and accuracy of postpartum screening.

- Four liaison PHNs, three at Kanesatake Health Network, and one at Weston General, oversee screening for approximately 1,900 births per nurse.
- Liaison PHNs conduct training sessions infrequently, once every four months at each hospital.
- Doctors and nurses who work in the hospital maternity units administer the screening tool, but many screens are incomplete and contain inconsistencies. Due to infrequent training sessions, newer staff are not properly trained.

PHNs spend much of their time following up with women while still in the hospital to fill in missing information and investigate inconsistencies.

##### **Proposed Model**

Under the proposed model, the role of the liaison PHN would be to build capacity through enhanced training, ensuring the hospital staff understand the importance of the tool and are attentive to non-verbal communication.

- One liaison PHN would remain at the hospital to conduct more frequent training sessions at Kanesatake Health Network (5,663 births) and Weston General (1,887 births).
- Doctors and nurses who work in the hospital maternity units would continue to administer the screening tool. The goal of more frequent training sessions would be to improve the coverage and accuracy of hospital staff in administering the screening tool in-hospital.
- The liaison PHN would not be responsible for ensuring the completeness and accuracy of every screen. He or she would instead work with the hospital staff to improve completeness and accuracy.
- Two of the PHNs would be redirected to the home visiting component of the HBHC program in order to reduce the wait-time. Another PHN would be redirected to another area of King Public Health to bring the HBHC program under budget and within the MCYS funding allotment.

Source: Author created.

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### EXHIBIT 3 HBHC Program Budget by Fiscal Year (Current Model)

	2015 (actual)	2016 (estimate)	2017 (estimate)	2018 (estimate)
<b>Revenues</b>				
<b>MCYS Funding</b>	\$837,000	\$837,000	\$837,000	\$837,000
<b>Expenditures</b>				
<b>Salaries &amp; Benefits – Home Visits</b>	\$447,500.00	\$460,925.00	\$474,752.75	\$488,995.33
<b>Travel – Home Visits</b>	\$12,250.00	\$12,495.00	\$12,744.90	\$12,999.80
<b>Supplies &amp; Office Equipment - Home Visits</b>	\$4,250.00	\$4,335.00	\$4,421.70	\$4,510.13
<b><i>Subtotal – Home Visits</i></b>	<b><i>\$464,000.00</i></b>	<b><i>\$477,755.00</i></b>	<b><i>\$491,919.35</i></b>	<b><i>\$506,505.26</i></b>
<b>Salaries &amp; Benefits – Hospital-Based Screening</b>	\$358,000.00	\$368,740.00	\$379,802.20	\$391,196.27
<b>Travel – Hospital-Based Screening</b>	\$2,750.00	\$2,805.00	\$2,861.10	\$2,918.32
<b>Supplies &amp; Office Equipment – Hospital-Based Screening</b>	\$1,750.00	\$1,785.00	\$1,820.70	\$1,857.11
<b><i>Subtotal – Hospital-Based Screening</i></b>	<b><i>\$362,500.00</i></b>	<b><i>\$373,330.00</i></b>	<b><i>\$384,484.00</i></b>	<b><i>\$395,971.70</i></b>
<b>Total Expenditures</b>	\$826,500.00	\$851,085.00	\$876,403.35	\$902,476.97
<b>Net</b>	\$10,500.00	(\$14,085.00)	(\$39,403.35)	(\$65,476.97)

**Notes:**

1. This budget represents the entire HBHC Program (Hospital-Based Screening + Home Visiting).
2. There are nine full-time public health nurses (PHNs) staffing the HBHC program and four of these are allocated to the hospital-based screening portion of the program. In 2015, each PHN salary was \$89,500 (which includes 25% benefits).
3. Salaries are projected to grow at 3% per annum. Cost of supplies and travel costs are expected to grow at 2% per annum. Ministry funding is expected to be frozen at 2015 levels until 2018.

Source: Author created.

## Babies and Budgets: Balancing Costs and Consequences in Postpartum Screening

### Worksheet 1 HBHC Program Budget by Fiscal Year (Proposed Model)

	2015 (actual)	2016 (estimate)	2017 (estimate)	2018 (estimate)
<b>Revenues</b>				
<b>MCYS Funding</b>	\$837,000	\$837,000	\$837,000	\$837,000
<b>Expenditures</b>				
<b>Salaries &amp; Benefits – Home Visits</b>	\$447,500.00			
<b>Travel – Home Visits</b>	\$12,250.00			
<b>Supplies &amp; Office Equipment – Home Visits</b>	\$4,250.00			
<b><i>Subtotal – Home Visits</i></b>	<b><i>\$464,000.00</i></b>			
<b>Salaries &amp; Benefits – Hospital-Based Screening</b>	\$358,000.00			
<b>Travel – Hospital-Based Screening</b>	\$2,750.00			
<b>Supplies &amp; Office Equipment – Hospital-Based Screening</b>	\$1,750.00			
<b><i>Subtotal – Hospital-Based Screening</i></b>	<b><i>\$362,500.00</i></b>			
<b>Total Expenditures</b>	\$826,500.00			
<b>Net</b>	\$10,500.00			

#### Notes:

1. This budget represents the entire HBHC Program (Screening + Home Visiting).
2. One PHN would be removed from the HBHC program and assigned to another area of the health unit. This would leave eight full-time PHNs staffing the HBHC program. One PHN would remain at the hospitals and would enhance the training of hospital staff to deliver screens. Two additional PHNs would conduct home visits for a total of seven PHNs responsible for home visits. In 2015, each PHN salary was \$89,500 (which includes 25% benefits).
3. Travel costs, supplies, and office equipment for home visits would be expected to increase by 40%. Travel costs for hospital-based screening would be expected to decrease by 50%.
4. Salaries are projected to grow at 3% per annum. Costs of travel and supplies are expected to grow at 2% per annum. Ministry funding is expected to be frozen at 2015 levels until 2018.

Source: Author created.

## Babies and Budgets: Balancing Costs and Consequences in Postpartum Screening

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### Worksheet 2

#### Worksheet of Forecasted Costs and Consequences for Postpartum Screening in 2016\*

	<b>Current Model</b>	<b>Proposed Model</b>	<b>Difference (Proposed – Current)</b>
<b>Consequences</b>			
Number of births in King Region each year (based on historical data)	8,210	8,210	
Coverage (i.e. percentage screened within 48 hours of birth)	92%		
Number screened	7,553		
Percent truly at risk	36%	36%	
Number truly at risk amongst the number screened	2719		
Sensitivity of the screen (percent at risk that are correctly identified)	90%		
Number correctly identified at risk	2447		
<b>Cost of home visits</b>	\$477,755.00		
<b>Cost of hospital-based screening</b>	\$373,330.00		
<b>Cost of the program</b>	\$851,085.00		

\*It is recommended that rounding to the nearest ones value be conducted at each step.

Source: Author created.

## Babies and Budgets: Balancing Costs and Consequences in Postpartum Screening

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### REFERENCES

1. Ministry of Children and Youth Services. (2012). *Healthy babies healthy children guidance document*. Retrieved from [http://www.health.gov.on.ca/en/pro/programs/publichealth/oph\\_standards/docs/guidance/hbhc\\_gd.pdf](http://www.health.gov.on.ca/en/pro/programs/publichealth/oph_standards/docs/guidance/hbhc_gd.pdf)
2. Ministry of Health and Long-Term Care. (2001). *Implementation guidelines for the healthy babies, healthy children program – Phase 1*. Retrieved from [http://www.health.gov.on.ca/english/providers/pub/child/hbabies/implem\\_phase1.html#332](http://www.health.gov.on.ca/english/providers/pub/child/hbabies/implem_phase1.html#332)

## INSTRUCTOR GUIDANCE

### Babies and Budgets: Balancing Costs and Consequences in Postpartum Screening

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#### BACKGROUND

Dr. Philip Singe, the Medical Officer of Health at the King Public Health Unit, is in a meeting with Praveen Gill, manager of the Healthy Babies, Healthy Children (HBHC) program, and Vanessa Thomas, the director of the Family Health portfolio. The group is discussing options for delivering postpartum screening services under the provincially funded HBHC program. While program costs have increased steadily, funding from the provincial Ministry responsible for oversight of HBHC has been stagnant. The group must decide whether or not to cut costs by reducing the number of staff responsible for screening. Faced with the challenge of maintaining the effectiveness of screening services, the group weighs each option. Using expert opinion and historical information, the team must forecast costs and consequences to compare options systematically. The case includes worksheets for budgeting and cost-consequence analysis. Instructors can obtain a copy of the answer key from the MPH Program Office.

#### OBJECTIVES

1. Understand the financial challenges posed by inflationary pressures and stagnant funding.
2. Use cost-consequence analysis to articulate the trade-offs between a more intensive and a less intensive program.
3. Develop a budget and identify opportunity costs that are not reflected in the budget.
4. Informed by historical data and expert opinion, forecast health consequences and resource use.
5. Perform a cost-consequence analysis from the perspective of the public health unit.
6. Conduct a sensitivity analysis, varying key input parameters in order to appraise the effect of uncertainty on analysis results.

#### DISCUSSION QUESTIONS

1. Should the public health unit continue hospital-based postpartum screening at the same level of intensity?
2. Are there additional factors that are not referenced in the case that may influence this decision?
3. How would the hospital sector be influenced if the public health unit reduced the number of staff in the hospital?
4. What additional cost items would be incorporated in the analysis if it were conducted from the perspective of the Province of Ontario?
5. Is there a threshold level of effectiveness, below which it would be unethical to remove resources from the postpartum screening program?
6. Using a cost-effectiveness plane, plot the cost savings and the reduction in the number correctly identified at risk.

## Babies and Budgets: Balancing Costs and Consequences in Postpartum Screening

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### KEYWORDS

Economic evaluation; cost-effectiveness analysis; cost-consequence analysis; decision analysis; maternal and child health; public health unit.

## CASE 11

The Case of the Long-Lived Orchestra Conductors

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Mark Speechley, PhD (Professor, University of Western Ontario)

## PREFACE

What does it mean to ‘think like an epidemiologist’? If you Google that phrase you will get over 100,000 hits. One top link is to a contest held as part of a Science Olympiad, where students devise and test an epidemiological hypothesis, which helps them “develop and use a variety of epidemiologic skills efficiently and effectively”, using “judgment and innovation” (Teach Epidemiology, n.d.). A second link is to the University of California at Los Angeles’ website to memorialize the famous English physician John Snow, whose large controlled 1854 study showed that cholera was eight and a half times more frequent among London homes whose drinking water came from a particularly polluted part of the River Thames (Page, 2000). (Not enough, incidentally, to nudge the medical establishment from their stubborn belief that crowd diseases were caused by ‘foul and dank emanations’ rather than passed from person to person by thousands of people drinking each other’s diluted sewage.) A third site is an online course also aimed at infectious disease outbreak investigation. Students “master the scientific process, experimental design, data collection, logical reasoning, and statistical analysis ... build a hypothesis, and balance the health, economic and media challenges of containing an outbreak”, all part of doing science “thoughtfully, ethically, and efficiently” (Duke Talent Identification Program, n.d.).

To summarize the main themes: reason and logical thinking, creating hypotheses, and efficiently collecting and analyzing data to test them. These are all part of thinking like an epidemiologist. But (epidemiological) thinking starts even before we create hypotheses to search for causes of health outcomes. It begins by applying critical thinking skills to ensure that the original observations are valid and the purported health issue is real. How do we know it’s a problem? How is it defined? Are the data valid and reliable? Has the definition changed? Is it possible that an increasing trend is not real, but is merely an artifact of the way the data were collected?

The fourth link from the Google search has a perfect example of this, based on a typical sensational headline “ADHD diagnoses soar 43% in the United States” (Boyes, 2016). The author asks readers to list some “possible environmental or psychosocial explanations for why the rate of ADHD might have increased since the year 2000” (Boyes, 2016). He then invokes alternative explanations: what might cause the **rate of diagnosed ADHD** to increase even if the **underlying prevalence stayed the same**? Finally, he asks readers to design studies to sort out the environmental/psychosocial hypotheses from the alternative explanations.

That, to me, is the first principle of ‘thinking like an epidemiologist’: an adaptable skillset in critical appraisal that always begins with the assumption that original observations about health issues are more often *apparently caused* by the application of methods than *actually caused* by something in our environment or our behaviours. The purpose of this case is to introduce this

## The Case of the Long-Lived Orchestra Conductors

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skill with an example that does not require extensive background knowledge: the Case of the Long-Lived Orchestra Conductors.

### BACKGROUND

We are bombarded by causal claims about things that keep us healthy, make us sick, and help us get healthy again. Evaluating causal claims using epidemiological skills is an important part of public health practice. While fully evaluating causal claims involves subject matter expertise (biological, psychological, and sociological knowledge about the exposure and the outcome), critical appraisal of any causal claim begins with fundamental epidemiological questions – a skillset known as ‘thinking like an epidemiologist’.

If you read newspapers or health blogs, you may have come across a variation of the following:

“Did you know orchestra conductors live longer than nearly any other group of people? It's true. Many of the famous conductors of the past lived well into their 80s and 90s – Leopold Stokowski, 95, Pablo Casals, 96, Nadia Boulanger, 90, and Arturo Toscanini, 89, to name a few. And they were from a time when the average life expectancy was around 50 years old. There are two main reasons why:

1. Conductors flap their arms around for many hours a day. Upper body exercises are a great cardio-vascular workout because they expand the muscles of the chest and open the lungs. Plus, the movements cause your heart to pump strongly, so blood and nutrients flow to your muscles and organs.

The result - conductors have low blood pressure. Their minds are sharpened because they get more blood circulation to their brains.

2. But there's one more vital ingredient that explains why conductors enjoy longer and healthier lives. Think about it. Why are they flapping their arms? What's being generated as a result? A cascade of gorgeous orchestral music. Beautifully arching melodies with superior rejuvenating powers. Intricate harmonies that create new brain cells and higher IQs. Alpha-state inducing rhythms that calm and sustain inner peace.

Day after day conductors repeat this life-enhancing exercise.” (French, n.d.)

### QUESTION 1

Before reading ahead, recall your previous learning of the different aspects of the scientific method, and think of how you might (or might not) be able to apply them to this causal question.

Many elements of the scientific method are difficult to apply to this example:

- We use randomization (randomly assigning people to different exposure groups) because it lets chance alone determine the distribution in the exposure groups of all other factors that could cause the outcome. If a causal factor is unevenly distributed between groups, our estimate of the causal effect of our exposure of primary interest is confounded. Often it is unethical, impractical, or both, to apply randomization. In this case, at the very least, randomizing people to be conductors or not, and then following them until they die, is impractical.

## The Case of the Long-Lived Orchestra Conductors

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- Blinding (or masking) is done to minimize measurement bias. For example, if coroners who complete death certificates consciously or subconsciously recorded older ages at death for deceased conductors, the observation of older age at death in conductors would be partly due to biased measurement of the outcome. It is *possible* that medico-legal officials have a bias in favour of the hypothesis that being a conductor causes one to live longer, but we have no evidence to support this. While just a hunch rather than hard evidence, most people would agree that of all the potential sources of bias in epidemiological research, we probably do not have to worry much about biased ascertainment of the age of conductors relative to non-conductors as an explanation of the finding that conductors live longer than other groups.
- Causal mechanism/biological plausibility: causal mechanisms are important to science because they are the link between theory and observation. There are two causal mechanisms proposed:
  - The first is a cardiovascular mechanism, because conductors move their arms, which pumps blood and nutrients to muscles and organs, and lowers blood pressure while also increasing blood circulation to the brain. There are hundreds of studies supporting the positive cardiovascular effects of physical activity, and this mechanistic claim is not by itself controversial. (Although it must be pointed out that conductors are not the only occupation who engage in vigorous upper body activity.)
  - The second, more 'vital' causal mechanism concerns the 'superior rejuvenating powers' of the 'beautifully arching melodies' and 'intricate harmonies' of 'gorgeous orchestral music' that create brain cells and increase intelligence. At the same time, musical rhythms induce an 'alpha-state' that calms and sustains inner peace. It would be much more difficult to find as many studies of high quality supporting these mechanisms as the cardiovascular one. In particular, the claim that music actually 'create[s] brain cells' is pretty far-reaching.

The potential application of some other parts of the scientific method, like controls, seems clearer.

### QUESTION 2

What is the purpose of controls? Who would be an appropriate control group for this research question? (See "Section Summary" for answers.)

In addition to the basic elements of the Scientific Method like 'making observations' and 'formulating hypotheses', epidemiologists have developed expertise in sampling and measurement, and approach causal questions by thinking about:

1. Sampling:
  - Where did the sample of people being observed come from? Who collected the observations? Why?
  - Is the sample 'representative' of some larger population? Which larger population?
    - In what ways is it special or different?
2. Measurement:
  - What is the main outcome measure?
  - Is it appropriate to this causal question?

## The Case of the Long-Lived Orchestra Conductors

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The choice of outcome measure is extremely important in epidemiology. Often there are many choices, and some expertise is required to select the most appropriate one:

1. Life expectancy at birth: “Average number of years a newborn baby can be expected to live if current mortality trends continue” (Porta, 2008).
  - Life expectancy is calculated from the **mortality experiences of previous entire birth cohorts** (people born in the same year), which are then extrapolated in today’s newborns (hence the important qualifier, “if current mortality trends continue”).
2. Average age at death: The arithmetic mean of the age at death of people who have died.
  - In contrast to average life expectancy, **average age at death can be calculated on groups of any size**:
    - Dr. Albert Hoffman, the Swiss chemist who discovered LSD and took it several times, lived to 102. Thus, the average age at death of a habitual LSD user =  $102/1 = 102$ .

### MORE QUESTIONS ABOUT AVERAGE AGE AT DEATH

#### QUESTION 3

Seven people are observed for one year. What is the average age at death?

**{Mary is 98. Fred is 62. Svetlana is 106. Ijeoma is 2. Manny is 8. Ahmed died, aged 21. Jerome died, aged 28.}**

#### QUESTION 4

Who was included in the calculation of average age at death? Who did it not capture? Describe how that might be a limitation when we use average age at death as a **measure of average survival**.

#### QUESTION 5

Suppose you want to underwrite life insurance policies and you have the following data – **knowing nothing else**, which group would you rather insure?

**Group1: 1,000 people, average age at death, 4 years.**

**Group2: 1,000 people, average age at death, 95 years.**

#### QUESTION 6

Thinking of your answer to Q5, what additional information would you like to have before you underwrite any insurance?

### BRIEF SECTION SUMMARY

An ideal control group would be **different on the main exposure variable of interest** (i.e. they would not be orchestra conductors) but **would be similar on all other factors related to the outcome**, which is mortality (e.g. they would be of the same age and sex, geographic location, time in history, etc.). However, the vast majority of people from any population are not orchestra conductors, so how exactly would we pick our controls from this huge group? **Choosing appropriate controls is one of the most challenging aspects of epidemiology**. (We return to this below on ‘Lack of Controls’).

## The Case of the Long-Lived Orchestra Conductors

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The average age at death of the 7 people in Q3 =  $(21 + 28) / 2 = 24.5$ . Average age at death is based **only on those who die**. It ignores people who survive the period of observation. Thus, it can be a very misleading statistic and is particularly ill-suited for comparisons of average survival time or probability of survival between groups. In Q5, if Group 1 was 1,000 children in a daycare, one of whom died at age 4, and Group 2 was 1,000 people in a long-term care facility, 70% of whom died at 95 on average, you would make much more money insuring Group 1 than Group 2 (assuming identical premiums and payouts). So at a minimum, you would want to know the ages of the thousand people whose lives you are insuring.

### THINKING MORE DEEPLY ABOUT AVERAGE LIFE EXPECTANCY STATISTICS

According to the CBC ("Life expectancy in Canada hits 80 for men, 84 for women", 2014):

#### Average life expectancy for Canadian babies born in 2012:

Females	84
Males	80

But in a Globe and Mail article called "Why it's time to stop planning your 100<sup>th</sup> birthday party" (McFarland, 2014):

#### Canadian life expectancies at age 65 (2012):

Females	22	(added to 65 = 87 years)
Males	19.2	(added to 65 = 84.2 years)

### QUESTION 7

How would you explain that babies born today are expected to die at a **younger age** than people who are 65?

1. 'You can prove anything with statistics': These statistics are meaningless because epidemiology is a junk science (and while we're at it, let's besmirch demography too).
2. Another, even darker, interpretation is that because 65 year olds today will live longer than babies born today, we have reached the peak of civilization, and are witnessing the beginning of the apocalypse, a foul decay as surely as the fall of Rome, due to our hedonistic lifestyle, lack of discipline, deficit financing, and consumption of very unhealthy (if rather tasty) snacks.

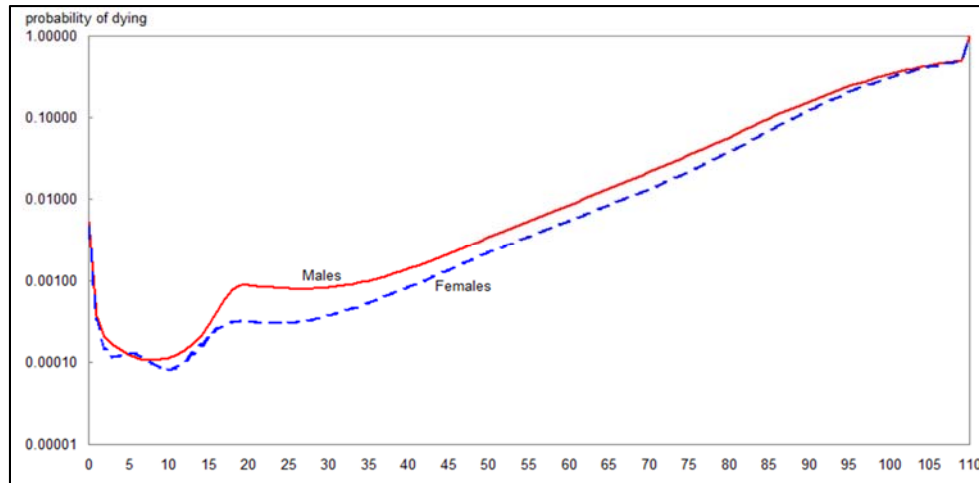
### QUESTION 8

Before we jump to either preposterous conclusion, there is something subtle at work. Can you put your finger on it?

- Hint 1: Since we're talking about life expectancy, what important thing have 65 year olds done that newborns haven't?
- Hint 2: Of all the years you have lived, at what age did you have the lowest probability of surviving until your next birthday? At what age did you have the highest probability of surviving to your next birthday?

### EXHIBIT 1

#### Probability of Dying by Age and Sex, Canada, 2007



Source: Statistics Canada, 2015.

### QUESTION 9

If you want to evaluate the longevity effect of being a conductor, can you think of a more appropriate statistic to use than life expectancy at birth? This section of the original source provides a clue: “Take for example, Leopold Stokowski (1882-1977) who made his official conducting debut in 1909.... Or, famed conductor Blanche Honnegger Moyse, born in 1909, who died in February of this year at the age of 102. After 40 years as a violinist, she was forced to retire due to a bow-arm ailment and so began conducting. Moyse made her Carnegie Hall debut 20 years later at age 78 and continued to conduct well into her 90's” (French, n.d.).

### SECTION SUMMARY

One big difference between babies and 65 year olds is that the latter have survived six and a half decades of exposure to all causes of mortality. The riskiest day of life for a newborn is Day 1, followed by Day 2, and then Day 3. We don't face the same risk of dying again until we are well into middle age. (The exact age when we regain our neonatal mortality risk differs by time and place. From Exhibit 1 you can see that in Canada it is somewhere around age 55. Many epidemiology students who are in their twenties are surprised to learn that the birthday at which they had the highest probability of surviving to their next birthday happened at least ten years earlier.)

There are two important points to be drawn from this:

1. Preventing early life mortality has a much larger effect on increasing average life expectancy than reducing mortality at older ages. Many people assume we doubled life expectancy in developed societies from  $\approx 40$  years to  $\approx 80$  years by building hospitals that helped large numbers of people survive from 50 to 60, or from 75 to 80, using life-saving medical and surgical treatments. In fact, much of the improvement came from reducing neonatal mortality, which occurred due to low-tech care in the period before, during, and the first week after birth. Nearly 80% of neonatal deaths are due to prematurity, low birth weight, asphyxia, and birth trauma (WHO, 2016).

2. **A 65 year old has already survived the high risk of the neonatal period as well as all the causes of death of children, adolescents, and early and middle-aged adults.** With that kind of survival success, it's no wonder a 65 year old today will live to an older age (on average) than a baby today.

So, the ideal statistic to judge the longevity of being a conductor would be the life expectancy of non-conductors starting at the same age(s) as people become conductors, which is usually in the thirties, although Maestro Stokowski was 27. When this is done, the survival advantage of conductors is much smaller – about 1.4 years in one re-analysis (see<sup>1</sup> for an extended statistical discussion of this issue).

### QUESTION 10

Even the appropriate life expectancy statistic would not make this a problem-free analysis. There are **important differences between symphony orchestra conductors and members of the general population that might affect their life expectancy**. Can you name some? Refer to your earlier answer about the role of controls (Q1) in the scientific method.

### LACK OF CONTROLS AND APPLYING LOGIC TO CAUSAL INFERENCES

We know that conductors are at the top of the socioeconomic hierarchy of their occupational group: compared to other orchestra musicians, they occupy the i) top position of authority, ii) are better paid, iii) have higher prestige, and iv) have more decision latitude regarding what pieces of music the orchestra will play, when the rehearsals will be, who will get to play the solos, and even who gets fired. **There is a huge literature showing gradients in health advantage across various measures of socioeconomic status (Google 'social determinants of health')**. But professional orchestra **musicians** are exposed to the same 'glorious overarching melodies' as the conductors. Comparing survival in conductors to other orchestral musicians would control for the effect of the overarching melodies but not the different socioeconomic status. Controlling for arm-waving is difficult because violinists move their bow arm a fair bit too.

### TESTABLE PREDICTIONS

A strong part of the epidemiological method involves making **testable predictions**. If the vigorousness of the arm-waving is supposed to be causal, we could predict longer survival in conductors who conduct more compositions written with *molto allegro* (fast) tempos than conductors who conduct more pieces with slower *andante* or plodding *largo* tempos, but this still leaves a problem: classical musicians are probably not representative of other occupations in society, particularly those in dangerous occupations, regarding their life expectancy. So, even if we used the appropriate life expectancy statistic, all of these very complex socioeconomic effects have been completely ignored and would have to be considered before we could begin to conclude that i) orchestra conductors really do live longer, ii) because they move their arms a lot, and iii) in the presence of beautiful melodies.

### SOURCE OF OBSERVATIONS

Finally, we ought to consider where these observations come from. Because the 'long-lived orchestra conductor' is fairly well-known in newsmedia circles, any time a conductor dies at an old age there is a good chance it will make the lighter side of the day's news.

Confirmation bias: "In psychology and cognitive science, confirmation bias (or confirmatory bias) is a tendency to search for or interpret information in a way that confirms one's preconceptions, leading to statistical errors" (ScienceDaily, n.d.).

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<sup>1</sup> Ableson RP. Statistics as Principled Argument. 1995:4. New York: Taylor & Francis.

**By contrast, conductors dying at ages under the average life expectancy are less likely to be reported on** because they do not support the original myth. Exceptions can be seen in serious papers like *The Guardian*. In 2001, after Guiseppi Sinopoli died suddenly *while conducting* at age 54, reporter Norman Lebrecht (2001) wrote an article listing the following conductors' premature deaths. That some died while conducting (i.e. exposed to the melodies), and of cardiovascular causes, would seem to directly contradict the original theory:

- Felix Motl, 56
- Guiseppi Patane, 57
- Eduard van Beinum, 58
- Joseph Keilberth, 59
- Fran Konwitschny, 60
- Dmitri Mitropolous, 64

### SUMMARY POINTS

1. Inappropriate outcome measures applied to small uncontrolled groups can yield causal inferences that are probably incorrect.
2. Controls are important, and choosing appropriate controls is one of the more difficult parts of the application of the scientific method to epidemiology.
3. Apparent replications of an original observation may actually be the result of confirmation bias, especially in the absence of controls.
4. A biologically plausible theory does not make it true.
5. One can make testable predictions from a presumed underlying causal mechanism and systematically critically test them, but this requires a familiarity with logic and availability of suitable data, and is often not done.

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## INSTRUCTOR GUIDANCE

### The Case of the Long-Lived Orchestra Conductors

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

#### BACKGROUND

There may be no part of epidemiology more central to public health practice than the evaluation of causal claims about exposures that keep us healthy, make us sick, and help us get better again. Some causal claims are sufficiently self-evident that we learn them as toddlers: hot stoves cause “owwies”. But causal questions in public health are much more complex, and to approach them we need to learn to ‘think like an epidemiologist’.

This requires us to think critically about causal claims as we develop our skills in applying the logic of causal inference. When faced with a causal claim most epidemiologists immediately question the source of data, the appropriateness of the measures, and the soundness of the analysis underlying the causal claim. Epidemiology is firmly grounded in the scientific method, but the components of the scientific method have been modified for use outside the laboratory, as applied to large groups of ‘free range’ humans. Learning these adaptations can be challenging.

This case introduces causal critical appraisal using, as an example, the claim that orchestra conductors live longer than members of other occupational groups *because they are conductors*. It is a suitable introductory case because it does not require subject matter expertise in theories of longevity or causes of death. Learners progress from basic to higher-level concepts, beginning by recalling parts of the scientific method (e.g. control groups), and thinking about how each might be applied to this causal question. A mid-level objective is evaluating the appropriateness of the outcome measure, which requires understanding how average age at death is a poor measure compared to average life expectancy at birth, which in turn is less appropriate than average life expectancy at the age people typically become orchestra conductors. The case concludes by introducing confounding and confirmation bias.

#### OBJECTIVES

To get learners to start ‘thinking like an epidemiologist’ about:

1. The epidemiological application of the scientific method.
2. Causal claims and the logic of causal inferences.
3. Source and appropriateness of data and measures.

#### DISCUSSION QUESTIONS

Nine questions suitable for individual or group work are included in the Case Note. For example, “How would you apply the scientific method to thinking about a causal question?”

#### KEYWORDS

Causation; causal claims; causal mechanism; life expectancy; average life expectancy (at birth; at age X); average age at death; bias (measurement/ascertainment, sampling, confirmation); scientific method (randomization/random assignment, blinding/masking, biological plausibility; control group).

# **INTEGRATIVE WORKSHOPS**



## INTEGRATIVE WORKSHOPS

As described in the preface to this casebook, the MPH program holds integrative workshops three times a year for its students. These day-long workshops present students with an opportunity to bring the knowledge they have gained in the program to bear on a topical issue in public health. The following section provides an outline of each workshop held during 2014/15, with a view to sharing examples for others interested in this type of approach to teaching.

### INTEGRATIVE WORKSHOP #1 Framing the Debate on the Public Health Aspects of Electronic (E-)Cigarettes

#### Speakers

*Frank Welsh, PhD*

Director, Policy Development, Canadian Public Health Association

*Lynn T. Kozlowski, PhD*

Professor, Department of Community Health and Health Behavior, University at Buffalo, The State University of New York

#### Scenario

You have been hired as a consultancy to advise Helen Angus, Associate Deputy Minister, Ontario Ministry of Health and Long-Term Care. Ms. Angus is head of the Policy and Transformation portfolio consisting of four divisions, one of which is the Health System Strategy and Policy division.

The Government of Ontario website states the following about the Health System Strategy and Policy Division:

*"The division sets strategic directions for Ontario's health system and supports them with legislation and policy; monitors alignment with the strategic directions; selects and manages portfolios of initiatives within the ministry to further health system goals; and provides health research investments oversight."*

<http://www.infogo.gov.on.ca/infogo/office.do?actionType=servicedirectory&infoType=service&unitId=UNT0003118&locale=en>

Your consultancy (Learning Team) has been asked to advise the division on e-cigarettes. One of the features distinguishing your consultancy from others is your integrated expertise across the diverse disciplines of epidemiology, biostatistics, research methods, environmental health and socio-cultural determinants of health. Quickly inventory your knowledge base and understanding of this public health issue. The mandate of the Health System Strategy and Policy Division includes financing research and developing expert communication strategies.

*Cont'd*

## Integrative Workshops

### Schedule

8:30 – 8:45	Introduction
8:45 – 9:10	Speaker 1 – Dr. Frank Welsh
9:10 – 9:35	Speaker 2 – Dr. Lynn Kozlowski
9:35 – 9:45	Brief questions for clarification
9:45 – 10:00	Break
10:00 – 10:30	Deliverable 1 (released on OWL at 8:15 am) <b>Due</b> on OWL by 10:25 a.m.
10:30 – 11:30	Question and Answer with the experts
11:30 – 12:30	Lunch (will be provided)
12:30 – 3:00	Learning Teams Prepare Deliverables 2 and 3 (released on OWL at 11:25 am) <b>Due</b> on OWL by 2:55 p.m.
3:00 – 4:30	Presentations
4:30 – 4:45	Faculty Discussion
4:45 – 5:00	Feedback from Faculty

## INTEGRATIVE WORKSHOP #2 Organizational Response in Urgent Times

### Background

The purpose of this workshop is to introduce you to the concepts of organizational response and communication during an urgent situation. In addition, you will be using your research skills to conduct an investigation of a health issue which has emerged in the City of London.

### Learning Objectives

1. To apply epidemiologic and other skills in conducting an investigation of a health issue.
2. To develop skills in organizational response and crisis communication.
3. To gain an understanding of multiple stakeholder roles and responses in urgent public health situations.
4. To practice making decisions quickly under pressure.

### Speakers

Peter Slade  
Senior Director, Science and Technology  
Maple Leaf Foods

Fatih Sekercioglu  
Manager, Environmental Health  
Middlesex-London Health Unit

Dan Huggins  
Water Quality Manager  
The Corporation of the City of London

*Cont'd*

## Integrative Workshops

### Schedule

#### Location: Classroom

8:30-8:45am Introductions & Overview of the Workshop Day  
8:45-9:35am Peter Slade - "Leading through Crisis"  
9:35-9:55am Fatih Sekercioglu - "The MLHU: We do more than..."  
9:55-10:10am Dan Huggins - "An Overview of London's Drinking Water Distribution System"

#### Location: Learning Team Rooms

10:10-10:15am Learning Teams Assemble  
10:15-10:40am Learning Team Work

#### Location: Classroom

10:45-11:00am Situation Assessment – "The Case"

#### Location: Learning Team Rooms

11:05-11:55am Learning Team Work

#### Location: Classroom

11:55-12:15pm Situation Assessment – "The Case"  
12:15-1:00pm Lunch

#### Location: Classroom

1:00-1:15pm Peter Slade – "A Primer on Risk Communication"

#### Location: Learning Team Rooms

1:15-3:15pm Learning Teams to Discuss Organizational Response, Crisis Management, Communication, and Prepare Press Conference Statement

#### Location: Classroom

3:15-4:15pm Learning Teams Press Conference Statements and Responses (8 min each including time for questions)  
4:15-4:25pm Guest Expert and Faculty Feedback  
4:25-4:30pm Conclusion & Close of Workshop

### LEARNING TEAM TASKS

#### Prior to the Workshop

Read: Executive Summary of the "Report of the Independent Investigator into the 2008 Listeriosis Outbreak" – posted in OWL MPH 9015Y Announcements

Review: Middlesex London Health Unit Environmental Health Division Website – posted in OWL MPH 9015Y Announcements

#### Day of the Workshop

Presentations will be made by guest speakers from 8:45 to 10:10am, which will assist you with your tasks for the rest of the workshop. Each Learning Team will have five deliverables.

*Cont'd*

## Integrative Workshops

### INTEGRATIVE WORKSHOP - PART 1

On February 20, 2015, Dr. Blogs, MD, MPH, a family physician in London ON, notices an apparent familiar cluster of 3 cases of an unusual dermatological condition. Dr. Blogs consults with a dermatology colleague to try to establish the diagnosis. On a hunch, possibly due to public health training, Dr. Blogs also sends photos of the condition to a colleague at the Middlesex-London Health Unit.

**10:15-10:40 WHAT IS THE CONDITION?** Viewing the pictures that have been distributed (in OWL MPH 9015Y), your task is to identify the condition presented.

**DELIVERABLE 1:** By 10:40, each Learning Team will post their best 3 guesses to OWL MPH 9015Y Assignments and return to the classroom by 10:45 where they will present their best guesses about the condition and their rationale for this decision (1 minute for each Learning Team). This segment will end at 11:00am.

### INTEGRATIVE WORKSHOP - PART 2

Later that day, Dr. Blogs' Middlesex-London Health Unit colleague receives 3 other reports of the condition. Dr. Blogs and the Middlesex-London Health Unit decide to conduct a Case-Control study by telephone-interviewing.

**11:05-11:35 WHAT CAUSED THE CONDITION?** (Learning Team Rooms)

**DELIVERABLE 2:** Beginning at 11:05am, Learning Teams will work on creating a questionnaire to assess exposures. These questionnaires are to be posted to OWL in MPH 9015Y Assignments by 11:20am.

At 11:20am, Learning Teams will receive the results of the interviews in 2 x 2 tables.

**DELIVERABLE 3:** Learning Teams will have 15 minutes (11:20 – 11:35) to calculate odds ratios using the 2 x 2 tables, and identify the most likely exposure. Post to OWL MPH 9015Y Assignments.

### INTEGRATIVE WORKSHOP - PART 3

**11:35-12:15 WHAT IS THE SOURCE?** Dr. Blogs and the Middlesex-London Health Unit have now identified the condition, and the most likely exposure. They now turn to identifying the source of the exposure.

**DELIVERABLE 4:** Learning Teams will have 20 minutes (11:35 – 11:55, Learning Team Rooms) to create 3 questions they would like to ask to help identify the source of the exposure. Learning teams will post these questions to OWL MPH 9015Y Assignments, and return to the **CLASSROOM** at 11:55. Additional clues will be provided at this time & further discussion to identify the source will occur from 11:55-12:15pm.

*Cont'd*

## Integrative Workshops

### INTEGRATIVE WORKSHOP - PART 4

At 12:15pm, Learning Teams will be assigned roles to take on for the rest of the workshop. From 1:15pm to 3:15pm, Learning Teams will work on organizational response, crisis management, and communication according to their assigned roles. (Learning Team Rooms)

**DELIVERABLE 5 – Press Conference:** At 3:15pm, Learning Teams assemble in the classroom. Each Learning Team will have a role and will participate in a press conference at this time. Learning Teams will need to prepare a statement that will be presented at the press conference according to the role they are assigned. (Classroom)

### INTEGRATIVE WORKSHOP #3 POLICY DEVELOPMENT

#### **PART 1:**

The morning will feature Sudit Ranade (MoH from Lambton Public Health), who will provide insight into the types of policy challenges facing Medical Officers of Health in Ontario. In addition, he will discuss the type of evidence needed to support policy decisions.

This will be followed by a presentation from Frank Welsh, (Director of Policy, CPHA) about their role in policy advocacy and influencing the policy agenda at the National level.

We will then hear from Kevin Churchill (Manager of Health Promotion, Lambton Public Health), who will discuss the local political environment that shapes public health, emphasizing strategies for getting political buy-in for initiatives in a context where the health board is comprised of local politicians, many without a health background.

#### **Part 2:**

We will have expert guests discuss cross cutting issues of public health and the social determinants of health. Then our guests will present a policy brief on an issue they are currently working on. The goal of the workshop is to provide students with a practical application of policy brief exercise.

Other guests include:

- Giovanna Longo, Social Determinants of Health Nurse, LPH;
- Simone Edginton, Registered Dietician, LPH;
- Lori Fellner, MLHU;
- Cross Cultural Learners Centre (Immigrant and Refugee Health) reps
- Erika Chamberlain, MPH and Law, Western

MPH students will work with our guests to come up with actionable items to deal with a current policy challenge in public health. The students and guests will work together to come up with recommended policy options. At the end of the day, students will present on the topics area. After the presentation, our guests will comment on the usefulness and feasibility of the plan. Students will prepare a policy brief to share with our guests.

*Cont'd*

## Integrative Workshops

### **Learning Team Preparation beforehand:**

1. Readings on policy development processes
2. Background readings on issues and best practices in the areas identified by our guests

### **Group Deliverables (end of workshop):**

1. Presentation (slides)
2. Policy brief for MPH 9010 (Managing Health Services) (Group assignment due next day)

### **Schedule**

**8:00-8:30** Arrival, coffee & tea

#### **Part 1**

**8:30-8:40** Introduction to the day – Dr. Lloy Wylie

**8:40-10:30** ***Public Health Policy and Healthy Public Policy***

- **Dr. Sudit Ranade**, Ontario Public Health Policy: Issues and Evidence for Decision Making
- **Dr. Frank Welsh**, Policy Advocacy and Agenda Setting at the National Level
- **Kevin Churchill**, Politics and Policies in Public Health at the Local Level

**10:30-10:45** ***Health Break***

#### **Part 2**

**10:45-11:25** ***Topic Briefs (10 min each max)***

1. Making Healthier Choices Act – (**Simone Edginton**, Lambton Public Health)
2. Immigrant & Refugee Health - (**Rita VanMeyel**, London Health Sciences Centre, **Val Marochko**, London Cross Cultural Learners Centre)
3. Smoke Free Movies (**Lori Fellman**, MLHU)
4. Alcohol Policy (**Dr. Erika Chamberlain**, MPH and Law, Western)

**11:25-12:15** ***Cross Cutting Challenges***

- **Giovanna and Lloy facilitate guest discussion panel on topics including**
  - Public Health Competencies to address policy
  - Social Determinants of Health
  - Health Equity
  - Evidence for Policy
  - Public Health Roles

**Wrap up**

**Instructions for Policy Action Session**

**12:15-1:00** Lunch

#### **Part 3:**

**1:00 – 3:00** **Policy Action Session**

**3:00** Teams submit presentations online

**3:00 – 3:10** **Break**

**3:10-4:30** Presentations (10min presentation + 5minQ) + Guest Debrief (5min each)

**4:30-4:45** Workshop Wrap Up

*Cont'd*

## Integrative Workshops

### **Policy Action Session**

In your policy area group, students and guests will discuss the issues and policy ideas. The group will narrow the focus to two policy options, with 1 taken up by each sub-team (team 1 and 2). The group will prepare a presentation for the afternoon. Each policy sub team will prepare a policy brief due the following day at 12 pm.

Groups will stay put whilst 'expert panels' made up of guests and faculty circulate from group to group

- Panel A: Frank and Shannon
- Panel B: Giovanna and Lloy
- Panel C: MPH Faculty

### **Purpose:**

This Integrative Workshop is one of the learning activities for MPH 9015Y Transforming Public Health. Its purpose is to introduce students to an exercise of synthesis and integration of the body of knowledge developed to date in the MPH Program.

Each of the specific situations presented in the Integrative Workshop are meant to provide a backdrop and a context to which key concepts and learnings from each of the courses can be synthesized and integrated. The most advanced team presentation will demonstrate holistic integration of learning across courses.

Objectives of the Integrative Workshop (same as the course MPH 9015Y Transforming Public Health):

By engaging with your colleagues and professors after studying and thinking deeply about the material presented, you will be able to:

1. Analyze information from multiple disciplinary and indigenous stakeholder perspectives to determine appropriate implications, uses, gaps and limitations in a specific situation;
2. Determine the meaning of this information, considering the current ethical, political, scientific, socio-cultural and economic contexts;
3. Synthesize and integrate knowledge across disciplines, situation specific information and meaning of this information;
4. Recommend specific actions based on the analysis, synthesis and integration of information from multiple disciplinary and indigenous stakeholder perspectives; and
5. Revise judgments and change behaviour in light of new evidence.

### **Competencies Assessed:**

1. Demonstrate knowledge of the systems in which public health functions, including current public health challenges.
2. Recognize how the determinants of health (biological, social, cultural, economic and physical) influence the health and well-being of specific population groups.
3. Critically appraise the literature to understand patterns of health and ill health, establish causal associations, and recommend courses of actions.
4. Demonstrate a professional appreciation of the ethical, legal and social issues in public health policy & practice.
5. Develop and implement a sustainable plan to address public health challenge(s).

## Integrative Workshops

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6. Discuss the legal framework of public health practice including legislative authority, rights, obligations and risks, at the federal, provincial and municipal levels.
7. Optimize organizational performance by applying systems thinking.

### **Grading:**

Consistent with the overall grading for MPH 9015Y, the deliverable from the integrative workshop will be a pass/fail. The presentation is intended to be a team effort.

### **Resources:**

#### ***General Resources***

Policy Brief – a How to guide:

[http://www.idrc.ca/EN/Resources/Tools\\_and\\_Training/Documents/how-to-write-a-policy-brief.pdf](http://www.idrc.ca/EN/Resources/Tools_and_Training/Documents/how-to-write-a-policy-brief.pdf)

#### **Other Public Health Policy papers**

*National Collaborating Centre for Healthy Public Policy* <http://www.ncchpp.ca/en/>

#### **Making Healthy Food Choices Act**

[http://www.ontla.on.ca/web/bills/bills\\_detail.do?locale=en&BillID=2939](http://www.ontla.on.ca/web/bills/bills_detail.do?locale=en&BillID=2939)

<http://www.nyc.gov/html/doh/html/living/agency-food-standards.shtml>

#### **Immigrant and Refugee Health:**

<http://www.cmaj.ca/content/early/2010/06/07/cmaj.090313.full.pdf+html>

<http://www.kidsnewtocanada.ca/>

<http://www.ccirhken.ca/Resources.html>

#### **Smoke Free Movies:**

<http://otru.org/category/special-reports/> : Exposure to Onscreen Tobacco in Movies among ON Youth 2004-2013

<http://smokefreemovies.ucsf.edu/>

#### **Alcohol Policy**

[www.publichealthontario.ca/en/eRepository/Making\\_the\\_Case\\_2013.pdf](http://www.publichealthontario.ca/en/eRepository/Making_the_Case_2013.pdf)

<http://www.apolnet.ca/>