Understanding Perspectives of Key Stakeholders in Planning, Producing and Applying Infectious Disease Models

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By: SHEENA GUGLANI, H.B.Sc.

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AUTHOR: Sheena Guglani, H. B. Sc. (McMaster University)

SUPERVISOR: Dr. Andrea Baumann

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ABSTRACT

Background: Infectious disease outbreaks are amongst the most threatening of disasters, capable of affecting the health and economies of millions of people around the world in a single occurrence. Mathematical models are a tool that can be used to synthesize information from different disciplines into a comprehensive model, which can further be used to guide public health in making appropriate economic and social decisions. However, the integration of modelling within public health is not maximized. This study aims to explore perceptions of key stakeholders in planning, producing and applying infectious disease mathematical models in public health.

Methodology: Data was collected using semi-structured key informant interviews with key stakeholder groups (n=19), academic modellers (n=6), government modellers (n=5), government end-users (n=5) and professionals and practitioners who are end-users (n=4). Data was analyzed with thematic analysis with NVivo 11 (QSR International). A stakeholder analysis was used to map out the interrelatedness of key stakeholder issues, and a thematic analysis was used to abstract themes of collaboration between stakeholders, challenges with data and perceptions of predictive modelling.

Results and Conclusion: The findings of this study identify and organize important insights and recommendations required to optimize the utilization of infectious disease

mathematical models in public health decision-making. The findings suggest that models that are most applicable to public health problems often go through iterative collaborations between end-users and modellers. The findings also suggest that there are growing challenges when it comes to the collection and interpretation of sources of infectious disease data and that mathematical models are valuable when used for understanding infectious disease outbreaks and/or interventions, rather than projecting the course of a specific outbreak. This study recommends actions be taken in education, practice and research to minimize the existing gap between mathematical models of infectious disease and their application for public health decision-making.

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The support and encouragement from my peers in the Global Health program as well as close friends kept me going through this process. Their confidence in my abilities meant the world to me. And finally, to my family, my absolute gratitude, and without whom none of this would have been possible.

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LIST OF ABBREVIATIONS

AIDS: Acquired Immunodeficiency Syndrome

BSE: Bovine Spongiform Encephalopathy

CDC: Centre for Disease Control

EID: Emerging Infectious Disease

EWS: Early Warning Systems

EVD: Ebola Virus Disease

FMD: Foot and Mouth Disease

HIV: Human Immunodeficiency virus

NCCID: National Collaborating Centre for Infection Diseases

PanInform: Pandemic Influenza Outbreak Research Modelling

PHAC: Public Health Agency of Canada

PHO: Public Health Ontario

R0: Reproductive Number

SARS: Severe Acute Respiratory Syndrome

Tg: Generation Time

DECLARATION OF ACADEMIC ACHIEVEMENT

The following is a declaration that the content of the research in this document has been completed by Sheena Guglani and recognizes the contributions of Dr. Andrea Baumann, Dr. Jonathan Dushoff, and Dr. Tim O'Shea in both the research process and the completion of the thesis.

CHAPTER ONE: INTRODUCTION

1.1 Global Infectious Disease Outbreaks

Infectious disease outbreaks are amongst the most threatening of disasters, capable of affecting the health and economies of millions of people around the world in a single occurrence (Binder, Levitt, Sacks, and Hughes, 1999; Morens, Folkers, and Fauci 2004). Emergence and re-emergence of infectious disease outbreaks are fuelled by changes in society, technology and microorganisms themselves (Cohen, 2000; Jones, Patel & Levy, 2008; Woolhouse, 2011). Historically, mass infectious disease outbreaks of smallpox, plague, measles, amongst others have left mass casualties. The 1918-1919 influenza pandemic for example, was responsible for over 50 million deaths and even more infections around the world, and has been referred to as the mother of all pandemics (Taubenberger & Morens, 2006).

Through better understanding of infectious disease and preventative measures, most modern day infectious disease outbreaks are contained before they cause mass casualties. In fact, since the 1919 pandemic, advances in treatment, diagnostic tests and public health strategies, led to a significant decrease in casualties caused by infectious disease outbreaks. Pharmaceutical companies followed suit, reducing research towards antibiotics research (Cohen, 2000). However, this optimism didn't last to the end of the century. The world was shaken in the decades after by new and re-emerging diseases and infections: Legionnaires disease, Ebola virus, HIV/AIDS, and bovine spongiform encephalopathy or mad cow disease in both the developed and developing world. An important lesson was learned (Morens et al., 2004; Chan et al., 2013). Without constant vigilance in research, surveillance, development of new technologies, the world is just one step away from reverting back to an era of mass casualties by infectious diseases (Chan et al., 2013).

Emerging infectious diseases (EID), new species or strains of microorganisms, are an example of this threat and actually have been increasing since 1940 (King, Peckham, Waage, Brownlie & Woolhouse, 2006; Morens et al., 2004). The past fifteen years alone have borne witness to numerous infectious disease outbreaks worldwide including severe acute respiratory syndrome (SARS), foot-and-mouth disease (FMD), human immunodeficiency virus (HIV), bovine spongiform encephalopathy (BSE), and pandemic and avian influenza (Heesterbeek et al., 2015; Woolhouse, 2011). According to et al. (2008), between 1940 and 1980, there were 355 emergences of infectious disease. To provide analytical evidence that the threat of EID is increasing and the observations were not merely due to improved surveillance technology and diagnostic methods, but significantly correlated with socio-economic, environmental and ecological factors (Jones et al., 2008). Controlling for reporting bias the authors also concluded a highly significant of increase of EID events as time progressed (Jones et al., 2008).

Other authors have expanded on factors that facilitate the emergence of infectious disease outbreaks. Woolhouse (2011) discusses the ten most cited determinants for an outbreaks. These are changes in land use or agricultural practices, changes in human demographics and society health, poor population and medical hospital procedures, evolution pathogen, contamination of food sources or water supplies, international travel, failure of public health programs, international trade and climate change. Based on the diverse nature of the drivers, infectious disease outbreaks have to be studied and understood from various academic disciplines and professionals.

The success of future efforts to curtail emerging infectious diseases depends on worldwide collaboration among public health officials, medical doctors, epidemiologists, biologists, sociologists, mathematical modellers, amongst others (Bauch et al., 2005). The disease process of an infectious disease is best understood through biologists, biochemists, and clinicians. Behavioural scientists are able to provide insight into the host populations, and how the disease could spread within the population. In addition, a wide variety of other disciplines—climatology, trade, agricultural, economics, law, urban and food science—provide understanding into the process of disease drivers and transmission. For example, adherence and compliance to intervention measures in a population can be understood through the lens of fields such as sociology or social psychology. Last but not least, mathematicians, statisticians and computer scientists are able to provide tools for analyzing infectious disease data and modelling its impacts (Woolhouse, 2011).

Mathematical models are a tool that can be used to synthesize information from different disciplines into a comprehensive model, which can further be used to guide health policy makers and the public in making appropriate and responsible economic and social decisions (Woolhouse, 2011). In addition to providing theoretical insights into transmission dynamics, mathematical modelling provides the only means of estimating the potential for intervention strategies to achieve their intended aims. Therefore mathematical modelling is a valuable tool for understanding past, present and future infectious disease outbreaks.

1.2 Modelling and Forecasting Infectious Disease Outbreaks

In some parts of the world, rain can predict disease and in meningitis outbreaks can be predicted by hot, dry, dusty winds (Ebikeme et al., 2013). In most places however, predicting infectious disease outbreaks requires much more skill and data. Mathematical models that forecast human transmission are an important tool for projecting and therefore minimizing the health, epidemiological and economic impacts of infectious disease outbreaks. However it is an imperfect and complicated science and being able to accurately and precisely predict the course and impacts of an outbreak are still in their infancy (Buczak, Koshute, Babin, Feighner, & Lewis, 2012; Hufnagel, Brockmann, & Geisel, 2004; Woolhouse, 2011). Just as it is difficult to be accurate in predictions of the weather, economics, and other fields, the same is true in the field of predicting the course of an infectious disease outbreak. Factors such as geographical scale, temporal duration, national socioeconomic status among a host of others can be important in establishing good predictions for risk and spread of an epidemic (Chan et al., 2010; Myers, Rogers, Cox, Flahault, & Hay, 2000). There are different types of mathematical and statistical models employed by mathematicians, epidemiologists, statisticians and other professionals to answer questions surrounding prediction of a disease dynamic.

Mathematical models can be irrelevant to public health problems and/or have unreliable results and this can be partly attributed to the disconnect between the professionals involved in creating them (Chubb & Jacobsen, 2010; Driedger, Cooper, & Moghadas, 2014; Moghadas, Haworth-Brockman, Isfeld-Kiely, & Kettner, 2015). Although modelling infectious disease outbreaks is not always accurate in every detail, the exercise of predicting the course of an epidemic can be extremely useful. It provides stakeholders of what might be expected in an outbreak as well as reasonable ground for choosing certain policies over others (Woolhouse, 2011). An epidemic brings with it many factors that must be considered, notably estimation of the current and future burden of disease in order to determine the allocation of community and health resources. Mathematical models are a valuable tool in understanding the epidemic and answering the many questions that arise.

CHAPTER TWO: LITERATURE SEARCH

The first infectious disease model was generated in 1855 by John Snow to map out an infectious disease outbreak of cholera in London, England. The model played a crucial role in understanding and identifying the underlying causes of the outbreak (Snow, 1855; LaDeau, Glass, Hobbs, Latimer, & Ostfeld, 2011). The cause of the outbreak was a naturally occurring aquatic bacteria, *Vibrio cholera,* as identified by the spatiotemporal relationship in the model (Snow, 1855; LaDeau et al., 2011). Ronald Ross was an important figure in establishing the foundation of dynamic modelling. He first released his malaria models in 1908, modelling the dynamics of malaria in India (Mandal, Sarkar, & Sinha, 2011). Using deterministic differential equations, by dividing the human and the mosquito populations into susceptible and infected he was able to generate important insights into malaria transmission (Mandal, Sarkar, & Sinha, 2011). His work has since been seminal in not just understanding malaria but also in the establishment of the field of dynamic mathematical modelling (Smith, Battle, Hay, Barker, Scott, & McKenzie, 2012).

150 years later, and though the mathematical and statistical sophistication of the models have advanced since the first published models as a result of increasingly powerful technology, its fundamental role in helping to understand dynamics of disease have remained constant (Siettos & Russo, 2013; Jones et al., 2008; Heesterbeek et al., 2015). A mathematical model provides a framework to incorporate the observations and data of an infectious disease outbreak together. Data can range from clinical data: onset of

symptoms, hospitalization, death rate, recovery rate to climate data (LaDeau et al., 2011). This information, once synthesized in a model, can be used to estimate various quantities, and predict which interventions might be best suited. Since the cholera outbreak in 1855, models have been used to understand numerous epidemics: AIDS, SARS, Foot-and-Mouth Disease (FMD), Ebola, Influenza, and thus have remained an important tool for managing outbreaks.

2.1 Types of Models

A mathematical model tends to evoke a visual image, one with animated colour graphics, as opposed to the equations and symbols that are fundamental in creating them amongst most people who are not from a mathematical background (Bailey, 1994). Models compute crucial epidemiological quantities, such as the reproduction number (R_0) of an epidemic, which are further required to compute equations that can forecast the course of an epidemic (Bauch et al., 2005). Therefore, mathematical models serve as an important piece of evidence to provide insight for the dynamics of infectious disease outbreaks and how they can be contained. This section will briefly review some examples of the different types of mathematical models: compartmental and deterministic models, stochastic models, agent based and networking models, and phenomenological model.

The most basic of the models, simple compartmental models, are known as the susceptible-infected-recovered (SIR) model (Figure 1) (Kermack & McKendrick, 1927). In this model the relationship between the different populations is modelled using a system of differential equations: the rate at which a susceptible individual becomes infected, and the rate at which an infected individual recovers. This type of model aids in characterizing the transmission and progression of a disease in a population, as well as estimating the R_0 (Figure 1) (Anderson and May, 1992; Chubb & Jacobsen, 2010).

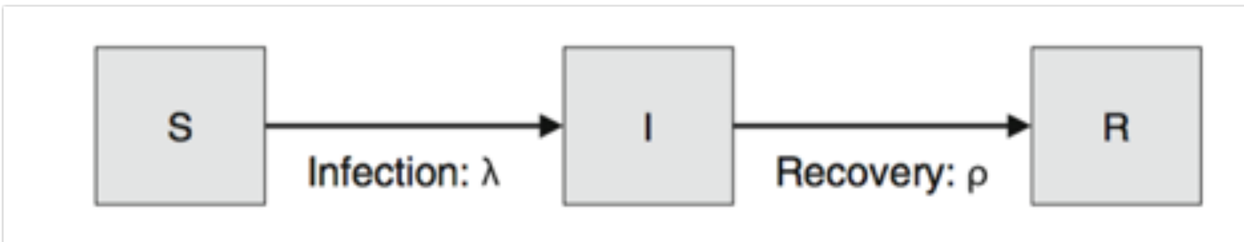

Figure 1: Simple susceptible-infected-recovered (SIR) model
(Figure adapted from Chubb & Jacobsen, 2010)

A slightly more complex SIR model could encompass factors such as the proportion of population that's vaccinated and take factors such as births, deaths and aging into account (Figure 2) (Chubb & Jacobsen, 2010). Other variations of the model include the susceptible-exposed-infected-recovered (SEIR) model and the susceptible-infectious-recovered-susceptible (SIRS) models. These variables of the SIR model are also commonly used to describe the progression of the disease (Corberán-Vallet & Lawson, 2014). The SIR model and variations are not considered suitable for modelling an epidemic that impacts a small number of individuals or when individual-level intervention strategies need to be modelled. This includes interventions such as contact tracing (an epidemiological technique, which identifies diagnosed individuals of the disease of interest that may have come into contact with infected individuals) or other types of interactions need to be modelled (Keeling & Danon, 2009; Regan & Wilson, 2008).

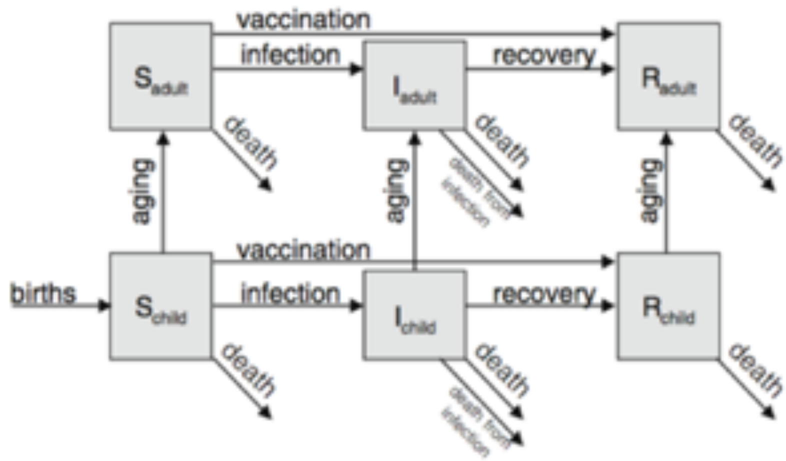

Figure 2: Complex susceptible-infectious-recovered (SIR) model.
Additional parameters include aging, vaccination, infection, recovery, births. Figure adapted from Chubb & Jacobsen, 2010

Deterministic models use ordinary differential equations (ODEs) to define the relationship between the different compartments of the models, such as the SIR populations mentioned above (Bauch et al., 2005). The advantage with this category of models is that they are simple to develop and understand, which is why they are used extensively to provide explanations and predictions for the course of an epidemic, as well as the impact of potential containment strategies (Wilson et al., 2006). However, deterministic models usually reflect the average dynamics of an outbreak, unambiguous results, which do not take into account possible fluctuations in the outbreak (Mishra, Fisman & Boily, 2010. Thus, they may not be truly reflective of an emerging, dynamic infectious disease outbreaks and can be a poor choice for the model structure (Mishra et al., 2010).

A stochastic model takes into account the randomness and unpredictability of behaviours into account. It does so by allowing for random variation in each variables input over time, and estimates the probability distribution of each possible outcome. For example, stochastic models take into account the chance variations in risk of exposure, disease and other illness dynamics (Bauch et al., 2005). These types of models are useful when modelling small populations because random fluctuations are amplified and have a bigger impact on disease dynamics (Bauch et al., 2005).

Agent-based models and networking models incorporate known or hypothesized epidemiological quantities and project behaviour of an individual in a simulated population allowing for prediction of future temporal development under various scenarios (Bauch et al., 2005). These types of models are able to incorporate individual sources of heterogeneity (biological, behavioural, social) as well as stochasticity, allowing these models to better reflect the complicated and dynamic nature of infectious disease spread. On the other hand, the increased complexity results in more nuances and assumptions, making it more difficult for end-users to understand and apply the results of the model (Ladeau et al., 2011). As well, it is often difficult to implement individual-based models in a timely fashion at the onset of an epidemic due to their complex nature. Therefore, compartmental models are typically able to provide more insightful and timely information on the course of the epidemic (Regan et al., 2008)

The last model that will be briefly discussed here is a phenomenological model, which is not used for predicting the dynamics of infectious disease outbreaks but rather establishing associations between variables. For example, a phenomenological model released by Reisen et al. (2008), established a relationship between climate measurements and mosquito abundance. These types of models have also been used to link the incidence to dengue with climate variables (Ladeau et al., 2011).

Even though these models do not necessarily encompass all the factors that are necessary to truly capture how dynamic and multifactorial an infectious disease outbreak actually is, they are invaluable tools for controlling emerging human epidemics (Ladeau et al., 2011). Table 1 provides a summary of the different types of models described above.

Table 1: Examples of mathematical models that can be used to model infectious disease outbreaks. Table adapted from Bauch et al, 2005

Type of Model	**Definition**
Compartmental Model	A model that divides the population into mutually exclusive categories (compartments) based on disease status, age, risk factor, and so on; often abbreviated by letters denoting the compartments included in the model, e.g., susceptible (S), infected but not infectious (E), infectious (I), recovered (R)
Deterministic Model	A model in which the future can be unambiguously determined based on precise knowledge of the present state of the system, e.g., ordinary differential equation models
Stochastic Model	A model in which some or all events are governed by chance (and hence not deterministic); multiple outcomes are possible for a given starting state of the system

Agent-Based Models	A model that explicitly incorporates known or hypothesized epidemiological mechanisms, allowing for prediction of future temporal development under various scenarios, models individuals and is able to incorporate biological, behavioural and social heterogeneity
Phenomenological Model	A model designed to reproduce trends observed in data without specifying the underlying mechanisms (e.g., fitting a curve to data)

2.2 Important Parameters of a Model

A parameter is an independent value, which determines some aspect of the system such as the rates of movement between states in the model, transferability of infection and etc (Mishra et al., 2011). This section will briefly review three important parameters that are generated from and inputted into models: the basic reproductive number (R_0), the generation time (T_g), and the proportion of transmission that occurs before a symptomatic period (θ).

Basic Reproductive Number (R_0)

The basic reproductive number or R_0 has been described as the most important quantity in the study of epidemiology and modelling population dynamics of infectious disease spread and impacts of different control strategies (Heesterbeek, 2002). R_0 is defined as the expected number of secondary infectious caused by an infected individual in an exclusively susceptible population (Bauch et al., 2005; J. A. P. Heesterbeek, 2002; Lessler & Cummings, 2016). A R_0 value of less than one is an indication that an outbreak will not be sustained as the collective number of infected individuals will be unable to infect enough individuals to sustain and grow the number of infectious. On the other hand, a R_0 value of greater than one, on the other hand, is an indication that the number of infected individuals will multiply and grow and thus an epidemic may ensue (Bauch et al., 2005). The value is calculated in its most simplest form as the "product of the duration of infectiousness (D), the number of contacts of an infected individual with susceptible individuals per unit time (c) and the probability of transmission per contact between an infected and a susceptible individual (β)" (Bauch et al., 2005). This is expressed in an equation as:

$$\boxed{R_0}$$

Equation 1: Simplest calculation for determining the Reproductive Number (R_0).

The value of R_0 is generated using mathematical and statistical models and once generated, it can be applied to possibly forecast the dynamics of a disease. Several publications delve into in depth methodology on how to calculate this value (Diekmann and Heesterbeek, 2000; Heesterbeek, 2002). One variation on the basic reproductive number is known as the effective reproductive number (R_E): the average number of secondary infections produced by a typical infected individual in a population that consists of susceptible and non-susceptible individuals (Bauch et al., 2005). A second variation is known as the control reproductive number (R_c): effective reproductive number in the presence of control measures (Bauch et al., 2005).

The Generation Time (T_g)

The generation time or T_g is based on assumptions about the incubation and infectious periods of a disease. T_g represents the mean time interval between the onset of infection in one person and the onset of infection in the people that they infect. From a public health perspective, a large generation time is an indication that more time is available to implement control measures, characterize the pathogen (i.e., gene sequencing, identify epidemiology), educate the public, set up isolation facilities and conduct contact tracing. When the generation time is small, there is a greater chance that the disease will spread out of control even with a modest R_0 value (Bauch et al., 2005).

The proportion of transmissions that occur before a symptomatic period (θ)

θ indicates the proportion of transmission that occurs before the symptoms appear. A large θ indicates a disease in which transmission within the general population will be greater. A small θ indicates a disease, which becomes infectious after symptoms have been exhibited. This is an indication that nosocomial transmission, or transmission occurring in a hospital setting, are more likely as patients would be infectious after being admitted to the hospital for them (Bauch et al., 2005). Intervention strategies, such as quarantine, are usually more effective in this scenario than in outbreaks when θ is small (Bauch et al., 2005).

Other important considerations

The populations that are modelled can vary considerably in age, health status, demographics, susceptibility of infection, age, sex, biological and behavioural characteristics and occupations, all of which are important variables in the spread of infectious disease. The heterogeneity in a population remains one of the challenges in modelling the population dynamics (Mishra, Fisman, & Boily, 2011). Assuming homogeneity, which is often the case with mathematical models, in a population can lead to inaccurate assumptions and modelling results. Heterogeneity is prevalent not only in population demographics but also in spatial transmission and pathogen strain. Often different models released of the same disease compute vastly different results, and factors influencing heterogeneity can account for the different results.

The three parameters discussed above as well as special considerations such as the heterogeneity of a population represent only some of the components necessary in developing a model. During and after the SARS epidemic, a number of models were released. Populations were modelled using different techniques, which affected the R_0 value that was computed. LaDeau et al. (2011) summarize different studies and the values of the reproductive number generated from different studies. The reproductive number in these studies range from 2.2 to 4.8 and depend on the population being modelled and the modelling technique being utilized. The variance in reproductive numbers produced by different mathematical models, affects further predictions that are released by models, and can present challenges for public health professionals as to which recommendation might be the most effective.

2.3 Validation of Models

The accuracy of predictive models is important as inaccurate predictions can have extensive far-reaching economic and health-care associated consequences (Binder et al., 1999; Morens et al., 2004). Drastically inaccurate predictions can be immensely problematic as this can result in insufficient mobilization of resources and logistical challenges. Model predictions often dictate the resources, type of efforts and logistics allocated towards the predictive time frame. Thus, an underestimation for a specific time frame may result in insufficient resources and an overestimation could result in increased wastage of resource and time. Since models play a critical role in planning for epidemic outbreaks, insufficiently validated models with large uncertainties can impact critical policy decisions and even fuel and increase the intensity of the epidemic pandemics (Ferguson et al., 2005; Riley, et al., 2003). Bailey (1994) states that there are two methods of validation. The first is "checking whether theoretical expectations are sufficiently close to observed values" and the second is "showing that theoretical constructions that pass the first test can also make verifiable predictions of future events". In the validation technique of model fitting, an error function is applied to a model with a set of parameters and predictive data set. The error function is used to indicate the differences between the predicted set, and the actual values provided by the data. Once the differences are identified, parameters are set in order to minimize the differences between the two data sets (Mishra, Fisman & Boily, 2010).

Hyder et al., (2013) define predictive validation "as a process that explores the deviation between observed and predicted patterns under the assumption that the processes underlying the model are generalizable," and argue that most validation techniques, such as those discussed by Bailey (1994) only address conceptual and operational (whether the model is correct enough for its intended aim and application) validity. This often means that sufficient validation is considered when the model is fitted to just a single epidemic. Hyder et al., (2013) argue that this is not enough to demonstrate the predictive validity of a model. With this definition of predictive validity, a model should be rigorous enough to undergo different scenarios (i.e., different vaccination strategies), and still be able to forecast the alternate scenario with an acceptable degree of accuracy. Models should be robust and have the ability to predict future epidemics based on the data used. This is considered to be a more robust test of predictive model validation than model fitting (Hyder et al., 2013).

Hyder et al., (2013) in their model of influenza examine the predictive ability of a complex model of influenza spread and variables such as peak weak, intensity and duration of the epidemic. Based on this model, the authors noted three steps that Hyder et al., (2013) that should be required for validating a model: “establishing a baseline model, perturbing the baseline model to forecast epidemics and quantifying the differences in epidemic patterns between simulated [forecast] and observed epidemics”. Most epidemic models that were released for the application in public health for complex global spread, determined to be a validated for use, were only simulated for one season’s data (Balcan et al., 2009; Ferguson et al., 2005; Smieszek et al., 2011). This went against the author's argument that a sufficiently predictive model should be able to predict more than one data set in order to be considered robust.

Validation of models also involves a sensitivity and uncertainty analysis. A sensitivity analysis examines the effects of a range of input parameters on the predictions that the model generates (Basu & Andrews, 2013; Mishra et al., 2011). By examining the effects of raising or lowering parameter values, evaluation of the robustness of results, in response to changing conditions, one can also determine the external validity of the model (Mishra et al., 2011). An uncertainty analysis is a type of sensitivity analysis that generates error bars around the model's results by sampling from the probability distributions of the parameter values, in order to quantify the potential error of the model's results (Basu & Andrews, 2013; Mishra et al., 2011). It should be noted that a sensitivity and uncertainty analyses do not necessarily capture the possible range of results that could occur in the real world (Basu & Andrews, 2013). This type of analysis captures the uncertainty in parameters but does not capture the uncertainty due to the model structure itself (Basu & Andrews, 2013). How models are structured and generated also plays a role in the parameter values generated, and directly affects the results.

2.4 Disadvantages and Advantages of Using Mathematical Models

Disadvantages

Mathematical models have several disadvantages that severely limit their ability to accurately predict the course of infectious disease outbreaks. First, it is challenging, especially in outbreaks of emerging infectious diseases of which not much is known about, to have data and understanding of the disease. Limitations in data also place limitations on the mathematical models that require data in order to parameterize the dynamics of an outbreak (Glass, Goodman, Hernán & Same, 2013). Hyder et al., (2014) have demonstrated that inaccurate assumptions or exclusion of the latent and infectious periods can result in underestimation of the reproductive number. Since the reproductive number is so critical in determining the course of an outbreak, underestimation has obvious limitations in the predictive power of the model.

Second, the lack of representation of heterogeneity in a model is a well-identified disadvantage when modelling disease outbreaks (Grassly & Fraser, 2008). As an epidemic progresses, the susceptible proportion of the population usually declines since many of the assumed susceptible population has already been infected or have been in contact with the infection and develop immunity. However, most homogenous modelling studies assume a steady influx of susceptible, which can result in inaccurate predictions about the spread of an epidemic over time (Bauch et al., 2005). The SARS epidemic in 2003 exhibited heterogeneity in spatiotemporal distribution, transmissibility and population susceptibility yet most models released only reflected a homogenous population resulting in inaccurate predictions (Bauch et al., 2005). Several suggestions have been laid out as means to increase the representation of heterogeneity in models. Ladeau et al., (2011) note, "heterogeneity in transmission or contact rates must be included as sources of stochasticity in models of disease processes". Another method in which representation of heterogeneity can be increased is by increasing the number of states in each model to allow "for the differences in transmission parameters for each state" (Ladeau et al., 2011).

Third, models are well researched quantitative, analytical, and methodical in their representation of an infectious disease outbreak. However, an outbreak in real life is usually chaotic. Countless variables of uncertainly make is nearly impossible to precisely map out the dynamics of an epidemic outbreak (Bauch et al., 2005). Yet, without the aid of models, public health officials have little evidence, especially with emerging infectious diseases, to guide them in their quest to minimize and deter the next biggest infectious disease outbreak of the century.

Advantages

There are many advantages to mathematically modelling epidemics. First, models provide an analytical framework that allows for the integration of diverse sources of data. Modelling the disease allows for the creation of a comprehensive picture of the epidemic, a better understanding of its dynamics and how it might spread (Lofgren et al., 2014; Bauch et al., 2005). This can be advantageous for public health officials who are uncertain about how widespread an epidemic might be if appropriate measures aren't taken. This can also pinpoint aspects of the disease, and indicate areas that need to be better researched and understood (Lofgren et al., 2014).

Second, mathematical models can be used to demonstrate and quantify the role of strategies such as quarantine and isolation, barrier precautions, duration of infectiousness and timing of interventions (Bauch et al., 2005). They can especially useful for policy makers in answering the important question of "what might have been" without the intervention of control strategies (Lofgren et al., 2014).

Predictive modelling results released during the 2014 EVD outbreak were highly publicized. The Ebola virus was first discovered in the 1970s and outbreaks have occurred periodically since its initial emergence (Oleribe et al., 2015). However, the 2014 EVD outbreak was of unprecedented spread and magnitude (Oleribe et al., 2015). By April 2016, 28 616 cases were suspected or confirmed as released by the Centres for Disease Control and Prevention (CDC) (2014 Ebola Outbreak in West Africa - Case Counts, 2016). Out of the total number of global cases, there were 11 310 deaths, a case fatality rate of 39.5% (Ebola Map: Virus & Contagious Disease Surveillance, 2016).

In an attempt to forecast the dynamics of what was to become the biggest Ebola epidemic in history, an Ebola response-modelling tool was released by the CDC in September 2014. The organization extrapolated on existing data and estimated that without the deployment of any additional interventions there would be approximately 550 000 EVD cases by January 2015 which, after the authors factored in underreporting, would rise to 1.4 million cases (Meltzer et al., 2014). The results of this model exploded in the media and the public health community and much discussion was held even though the authors note that the prediction was weak. Headlines released proclaimed: *"WHO: Ebola outbreak could last forever"* (Szabo, 2014) and *"Ebola: The ISIS of Biological Agents"* (Cole, 2014).

There were several weaknesses in the model development process of the CDC model. First, the input of accurate data is fundamental for obtaining predictions that might accurately forecast the course of a disease. For example the data of doubling cases (15-20 days for Liberia and 30-40 days for Sierra Leone) was used for the entire time period that the model was forecasting. Parameters such as doubling of cases aren't necessarily the same for each time period; doubling of cases could change weekly. Second, the model used other parameters from previous EVD outbreaks even though each outbreak that occurs is unique, and thus assumptions that carry forth from week to week, or outbreak to outbreak can result in inaccurate results (Lessler & Cummings, 2016). Third, the modellers had also made incorrect assumptions about the mixing of the populations in Sierra Leone and Liberia. For example, the modellers made unsubstantiated assumptions about the mixing of the populations of Sierra Leone - assuming homogeneity of interactions of the two countries. Underlying assumptions such as this impacted the projection of the outbreak and leading to results that were incongruent with what actually occurred. The model also reported that if 70% of the cases were treated and transmission limited (especially the implementation of safe burial practices), the outbreak would be over by January 2015 (Meltzer et al., 2014). However, this alternate prediction of the model did not nearly receive as much attention in the media.

Other organizations such as the WHO Ebola Response Team also released predictive models. Their projections were considerably more conservative (Lessler & Cummings, 2016). These models did not forecast more than two months into the future and they avoided publishing panic-inducing estimations. Instead their estimations were relatively moderate especially compared to the CDC model. The predicted number of cases was 20 000 cases by November 2014, with the actual number of cases being 13 000

(Lessler & Cummings, 2016). By incorporating the impacts of an active response on the reproductive number and thus spread of the disease, the WHO model was better able to align its predictions with reality.

There can be a lot of criticism surrounding the release of the model especially when the reality does pan out to the expectations of the model results (Moghadas et al., 2009). This often occurs if intervention strategies deemed most effective by mathematical models are implemented and results in a change in a populations behaviours ultimate decreasing case counts. In these cases early modelling forecasts, in retrospect, is deemed unreasonably high as was the case in the 2014 Ebola epidemic (Rivers, 2014). However, models helped to inspire and inform the strong international response that helped to bring the epidemic under control. Furthermore, as Lofgren et al., (2014) point, mathematical and computational incorporate known data and also infer the missing data of local communities. This plays a role in hypothesizing the dynamics of the disease and provides guidance to policy makers.

2.5 Types of Data

Woolhouse (2011) outlines in his paper three important types of data categories required to make predictions about outbreaks: the disease, the host and the environment. Data for disease fall into two categories (Woolhouse, 2011). The first is the natural history of the infectious state (latent, incubation and infectious periods) and the pathogenesis of the disease. Woolhouse (2011) comments that there is an asymmetry in the research that's available in this category since the latent period and the incubation period are not always well established as compared to the infectious period. Lack of information on important parameters, especially those important to transmission of the disease can impact subsequent results that predict the patterns of disease spread and effectiveness of interventions. The second type of disease data is surveillance data, which describes the spatiotemporal distribution of a disease. Also included in this category is traditional epidemiology data such as chain of infection (the occurrence of the infectious causing agent transferring from its host or reservoir to a susceptible through some mode of transmission (CDC, 2012).

The second category of data Woolhouse (2011) outlines is host data such as host demography. Key demographic variables include age-sex structures, density and patterns of distribution of population, pattern of movement within the population (i.e., frequency of domestic and international travel), and in some scenarios livestock density and interaction with human beings. The other important aspect of this category is host phenotype (i.e., infectious history, immune status), which affects how an infection will travel through the population.

The third category, environmental data, includes hygiene in hospitals, climate data that influence disease vectors and/or other hosts as well as reservoir host populations (Woolhouse, 2011). Other data that falls in this category might include cultural practices, social networks, as well as formal and informal transportation networks, the context of the interaction between human and animal populations (Lofgren et al., 2015; Woolhouse, 2011).

The topic of data presents two paradoxical situation in the field of epidemic modelling. First, early in the course of an infectious disease outbreak, data are most often scarce. This is also the point in the epidemic when data are most often useful, as modelling control efforts as early as possible in the outbreak is important for determining interventions to mitigate the impact of the outbreak (Matthews and Woolhouse, 2005). However, if an accurate model is released during the start of an epidemic, effective intervention strategies contain the spread of the outbreak and as a result there could be less data available to actually understand the disease and its spread (Matthews and Woolhouse, 2005). This paradox represents one of the challenges in modelling epidemics of emerging diseases. Accurate data is very important to understanding an epidemic and determine important parameters of models such as R_0, T_g, θ. Second, the challenge occurs in incorporating all of this data within a mathematical framework. The more data inputted into a model, the more complicated a model becomes. It is in irony that a better-informed model, one with more data, could also be one that is less accurate as a result of increased complexity (Moghadas, Pizzi, Wu, & Yan, 2009).

Good data requires that the method by which data were collected (i.e., the sensitivity and specificity of the diagnostic test used, patterns of under-reporting and reporting delayed) using reliable methodology as the accuracy of the data collected plays a role in how reliable predictions based on the data will be (Woolhouse, 2011). Data can come from a variety of sources: empirical data, literature reviews, or even expert opinions and are important for the estimation of parameters in a model (Mishra et al., 2011).

2.6 Applications in Public Health

Public Health Data Collection at the Provincial Level In Ontario

Public Health Ontario, in 2014, released a report entitled: Infectious Disease Surveillance Framework: Better data for better action. This report extensively covers how the agency plans on improving the types of problems associated with infectious disease data by the year 2019.

The framework proposed by the PHO has four priorities. Under its first priority PHO recognizes that the data collected by its 36 public health units and each organization within them have, for the most part, different systems and databases or differences in policies and procedures. Under the new proposed framework PHO aims to streamline and improve practices and requirements for data collection as well as produce and support the use of standardized data collection tools. This action can be important for mathematicians working on models, as it would result in higher quality data for them to use. Under its second priority, PHO recognizes that there are gaps in data, which when filled, would allow for better understanding of behaviour risk factors and social determinants of health. To accelerate integrated population health monitoring strategies, the strategy outlines goals to the possible integration of new and existing data sources such as electronic medical records, health care administrative data, and Ontario Laboratories Information

Systems (OLIS). However there are no mentions of also integrating other forms of big data.

The third priority looks to transform data into accessible information knowledge to inform policy, program and practice action. Although PHO regularly disseminates reports to its audiences: Ontario's Chief Medical Officer of Health, MOHLTC and other ministries, local public health units and health system providers and organization across continuum of care, it recognizes the need to continue to develop new tools and products, while refining what is already available. The organization hopes to do this by developing more accessible and timely tool products and evaluate the effectiveness of those tools. The fourth priority is to strengthen collaboration and capacity building with their audiences. Strategy 4.1 under this category aims to expand opportunities for collaboration and Although researchers and mathematicians are not explicitly listed, they should be one of the main groups considered.

Modelling for Public Health

Certain factors which affect disease transmission are increasingly important for public health considerations: spatial heterogeneity, individual heterogeneity, contact and infectiousness, as well as demographic, environmental and social mechanisms, and other factors which affect disease transmission (Hyder et al., 2013). However many models that predict the course of an epidemic or pandemic fail to include the factors listed above. Examples can be found in mathematical models that try to predict influenza outbreaks. Models such as search engine query data models, prediction market models and temporal regression models provide little information that is of interest to public health officials looking consider policies surrounding epidemics (Hyder et al., 2013). Models that are more applicable to public health are more complex spread models and individual based models (Hyder et al., 2013).

Knight et al., (2016) note in their article that expert opinion is heavily relied upon for public health decision-making. This approach does not utilize apparent systematic or transparent methods to address policy questions. Mathematical models on the other hand tools are an empirical tool and can be more rigorous than systematic reviews. They are a valuable asset with which through which public health officials can methodically and transparently ask and answer policy questions (Knight et al., 2016).

However, modelling in public health policy is so far not a fully integrated process. The sheer complexity makes it difficult for end-users of models who are not familiar with mathematical modelling. The intimidation therefore can result in unease and mistrust about using models in their work to influence decisions. Very few publications are available which outline the challenges of applying mathematical models for public health interventions and how key stakeholders in this field view the challenges.

Metcalfe et al., (2014) recognizes some of the challenges that can be associated with integrating them into public health policy. These challenges were grouped into six categories: communicating the limits of modelling, maintaining the value of models in the face of long time horizons, usefully deploying modelling the context of ‘black swans’, integrating modellers and model-building into the policy process, economic analysis and decision support and creating a cycle where results inform decisions and vice-versa. These challenges have been summarized in Table 2.

Table 2: Challenges in modelling for public health policy; adapted from Metcalf et al., 2015

Challenge	Description
Communicating the limits of modelling	End-users expect a clear, single answer as opposed to a range of possibilities and the underlying assumptions with each.
Maintaining the value of models in the face of long time horizons	Difficult to validate and maintain models for long-term predictions and use them for long-term predictions
Usefully deploying modelling in the context of low probability, high impact events	Overestimation results in unnecessary stockpiling and panic
Integrating modellers and model-building into the policy process	Better to have ongoing interactions between policy-makers and modellers rather than one-time interaction
Economic analysis and decision support	A cost analysis is usually necessary to guide one decision in favour over another.
Creating a cycle where results inform decisions and vice versa	As long as modelling practices are considered separate from public health, full integration is not possible. Important to create long-term relationships that foster trust.

However successfully overcoming the challenges and developing models for public health does not necessarily mean its immediate application in a public health problem. A study by Christley et al., 2013 examined the perceptions of uncertainty in modelling of the foot and mouth disease outbreak in the UK by interviewing scientists, policy-makers and advisors as well as analyzing policy documents, scientific publications and reports of major inquiries into key livestock epidemics. In this study they were able to show that the "discourse of uncertainty in infectious disease models is multi-layered, flexible, contingent, embedded in context and plays a critical role in negotiating model credibility". They note that negotiation within networks and discourse in the creation of the model is what truly makes of a usable and stable model (Christley et al., 2013).

Modellers are more aware of the uncertainties that a model presents than end-users, as they are the experts in development and uncertainties surrounding the assimilation of data. In this study, the modellers expressed reluctance in expressing and sharing their concerns and understanding of the uncertainties surrounding a model because it could compromise its application to the decision-making process (Christley et al., 2013). Furthermore the authors caution against any reliance on the interpretation by the modellers owing to a deep investment in their work which makes them more biased in conveying results. Conversely, end-users, being more distant in the developing process of the model, are not as aware of the uncertainties. In this particular study the authors noted that it is only because the model users are ignorant of the processes and the uncertainties involved in the models, that they are able to use and apply the models in their work (Christley et al., 2013).

The use of models is context dependent and participants in the study noted that models have very little impact on decision-making, if it is being used to support a pre-existing policy (Christley et al., 2013). In this scenario, it merely acts as a support tool and might almost be irrelevant because it has very little influence on the decision-making process. The role that models play when the decision is different from what the model predicts depends vastly on the contribution of other sources of knowledge (Christley et al., 2013).

Different professionals, modellers and end-users view the usage, reliability and applications of a model differently (Christley et al., 2013). For example, a parliamentary inquiry uses rhetoric to describe a model that doesn't make room for contingency or alternative scientific views. Whereas the same model when described by microbiologists was noted to be a starting point for discussion and not necessary an iron clad decision for public health. Therefore one of the conclusions of the study by Christley et al., (2013) is that there is a certain degree of interpretive flexibility when it comes with interpreting the same infectious disease model and it is this quality of flexibility, especially in the face of uncertainty that allows models to be useful throughout the decision-making process (Christley et al., 2013).

2.7 The Canadian Context

The Canadian infectious disease modelling landscape changed dramatically after the 2003-2004 SARS outbreak (Moghadas et al., 2015). Before the 2003 SARS epidemic, research interests of individuals or small groups largely drove mathematical, computational and statistical modelling activities, with a significant interest on the theoretical aspects of exploring complex mathematical phenomena. There was limited emphasis on the application of the models (Moghadas et al., 2015) and very little communication between them and public health professionals. Since 2003 models have played a significant role in advising Canadian public health authorities on possible policy implementations, as in the pandemic influenza outbreak. However, although the influence of models has increased, Moghadas et al. (2015) note that it is unclear exactly to what degree mathematical models have impacted policy practice.

There are several groups in Canada that are important for bridging the gap between public health policy and infectious disease modelling. Some of these groups include: York Centre for Disease Modelling, Pandemic Influenza Outbreak Research Modelling (Pan-InfORM) and the National Collaborating Centre for Infectious Diseases (NCCID). Pan-InfORM was established with the mandate to "develop innovative modelling frameworks and knowledge translation methods that inform public health by linking theory, policy and practice" in the early stages of the 2009 H1N1 epidemic.

In October 2014 Pan-InfORM held its fourth bi-annual workshop hosted by the NCCID. The purpose of this workshop was to bring "together public health practitioners and leading research modellers to enhance cross-discipline communication by providing a forum for knowledge to flow freely in a 'jargon-free' setting" (Moghadas et al., 2015). During this workshop it was determined an interdisciplinary team was key during the planning and preparation phases of pandemic influenza. The workshop also resulted in the establishment of a communities of practice (CoP) network. A CoP "refers to groups of people who share a concern, a set of problems or a passion about something they do, and learn how to do it better by interacting regularly" (Braithwaite, Westbrook, Ranmuthugala, et al., 2009). One of the important mandates established for the CoP in this meeting was to develop a lexicon, a common vocabulary, to facilitate the communication between modellers and public health professionals (Moghadas et al., 2015).

Several challenges were also recognized during this workshop. The public health professionals raised other concerns in regard to using models as a means of decision-making tool for policy. Often modelling studies use unrealistic assumptions and scenarios and do not necessarily confront the political reality that must also be taken into account and thus the impacts of models on being able to influence policy can be limited (Moghadas et al., 2009). A senior advisor of the World Health Organization commented that although models are important for the guidance of public health; they may also raise more questions for policymakers than they answer (Moghadas et al., 2009). But models are an excellent way of providing recommendations for a public health professional, and are not meant to actually make decisions in pandemic situations.

Two years after this workshop, the fifth biannual workshop took place in October 2016 at York University. Academic modellers, physicians, government and pharmaceutical representatives from across Canada attended the workshop. The workshop continued to build on the previous meeting recognizing that the full potential of mathematical models in its application for public health policy has not been realized. The aims of this workshop were to identify methods which could increase collaboration between mathematical modellers and public health professionals as well as better integrate and apply models within public health problems. It also aimed to address Grand

Challenges question in the areas of 1) TB, influenza and other respiratory illnesses; 2) the persistent problem of syphilis; 3) climate change and vector-borne diseases; 4) immunization programs; 5) vaccine hesitancy and optimal booster schedules and how models could address problems in these four key communication disease areas. By bringing together the workshop, participants were at the very least be aware of some of the accomplishments and key challenges in knowledge translation and build capacity for modellers and public health professionals to work together. The activity of a group such as the PanInform workshop shows that this topic of integrating modellers better not just within public health at all levels, local, provincial and federal, but also with the pharmaceutical companies, is relevant and better insight is required.

2.8 Conclusion and Objectives of the Study

A strong public health system is key to addressing the challenges of infectious disease outbreaks. Changes in socioeconomic, environmental and demographic factors have led to certain conditions, which facilitate the emergence and spread of infectious disease outbreaks. Therefore it becomes important to anticipate outbreaks and continue to develop tools to better predict and manage them in order to elucidate a rapid and flexible response (Cohen, 2000). Mathematical models provide a flexible tool to be able to synthesize data across disciplines, anticipate the challenges and possible solutions of an outbreak while promoting collaboration and dialogue between modellers and policy makers (Moghadas et al., 2009).

Canada is considered to be a forerunner in the field of mathematical model methodology, but lags behind in its integration with public health in comparison to other countries such as the United Kingdom and the United States (Moghadas et al., 2009). This is primarily attributed to the lack of appropriate infrastructure to allow for multiple discipline groups to merge as well as lack of incentives for modellers to develop more realistic models.

In order to fully translate modelling results in the context of public health, and appreciate the value that both fields can add to each other, it is necessary to better integrate the two fields together, however not all challenges are still understood (Moghadas et al., 2009). Therefore this research aims to understand the perceptions of public health and mathematicians to identify further challenges and methods through which this gap can be minimized.

Objectives of the Study

The purpose of this research project is to gain an understanding of the perceptions mathematical modellers and end-users in planning, producing, and applying predictive infectious disease models. This project has four objectives:

1. To summarize the experience and perceptions of key stakeholders using stakeholder analysis methodology;
2. To identify the role of collaborative networks between mathematical modellers and end-users;

3. To determine the perceptions of challenges associated with infectious disease data;
4. To describe end-user perceptions on the application and impact of predictive models for infectious disease on decision-making.

CHAPTER THREE: STUDY METHODOLOGY

3.1 Purpose and Overview of Study Design

Infectious disease outbreaks are an inherently complex public health issue, that occurs periodically (Schiller et al., 2013). Increased interconnectedness at the community, regional, provincial, national and international levels pave the way for outbreaks to spread rapidly. The past decade has been peppered with outbreaks of SARS, Ebola virus, and the swine flu amongst others (Heesterbeek et al., 2015). Effective and evidence-informed public health policies are important to contain infectious disease outbreaks. Mathematical models can be used to quantify the risks of an infection disease outbreak and by doing so minimize its epidemiological and economic impacts (Hufnagel et al., 2004).

The impact of stakeholders in health research is increasingly recognized and so is the critical and valuable insight that stakeholders can provide in understanding the issues (Schiller et al., 2013). A disconnect between two important stakeholder groups, modellers and end-users has been previously identified as being one of the reasons why mathematical models are not optimally used in determining public health policy for infectious disease outbreaks (Chubb and Jacobsen, 2010; Driedger et al., 2014; Moghadas et al., 2015). The intent of this study is to understand the perceptions of mathematical modellers and end-users of models in planning, producing, and applying predictive infectious disease models to public health decisions.

This study utilizes a descriptive qualitative design. A stakeholder analysis methodology was used to better understand the perceptions of key informants in the field in regard to the creation and application of predictive mathematical models. Stakeholders can provide different perspectives about the use and efficacy into the matter of effectively utilizing mathematical modelling for containing infectious disease outbreaks. The study also utilizes thematic analysis (Boyatzis, 1998) to identify important and emerging themes that converge and diverge between different stakeholder groups.

3.2 Research Objectives

The purpose of this research project is to gain an understanding of the perceptions mathematical modellers and end-users in planning, producing, and applying predictive infectious disease models. This project has four objectives: 1) to summarize the experience and perceptions of key stakeholders using stakeholder analysis methodology; 2) to identify the role of collaborative networks between mathematical modellers and end-users; 3) to determine the perceptions of challenges associated with infectious disease data; 4) to describe end-user perceptions on the application and impact of predictive models for infectious disease on decision-making.

3.3 Study Procedures

Approval, Consent and Confidentiality

This research was submitted to the Hamilton Integrated Research Ethics Board (HiREB). HiREB determined the project was exempt from requiring ethical approval from the board based on the objectives of the study (Appendix A).

Consent, date, time and location of interviews were determined either through email or telephone (Appendix B). An email with further details was sent if requested by the participants. Prior to the start of the interview, the researcher went over the purpose of the study and the content of the letter of information (Appendix C) highlighting that there are no known potential harms or risks associated with this study. Participants were informed that they had the option of declining to answer any questions that caused them discomfort and could also choose to stop the interview process all together, without any adverse consequences on them, their organization or the researchers, and they could do so by notifying the interviewer at any time during the process. Written consent (Appendix D) was obtained for in-person interviews and verbal consent for interviews that took place over teleconference or Skype. Consent forms were kept in a locked room only accessible by the primary researcher.

In order to ensure participant confidentiality, each audio interview was saved under a personal identification number (PIN) unique to the participant. Audio files were transferred to a secure, password-protected laptop immediately after the interview and deleted from the recording device. Files were kept only on the researcher's laptop and backed up on a USB key that was kept locked up in a cabinet only accessible by the researcher.

Any paper copies of the interviews with notes were kept in the locked room along with the consent forms and USB key. In order to ensure confidentiality and privacy of data, transcripts were only accessible by the research team. Data from the laptop will be deleted from the laptop three years after completion of the study. Information will be safeguarded until then for use in future papers or journal articles if researchers ever require clarification of the data in the future.

Stakeholder Analysis and Identification of Stakeholder Categories

The classic definition of a stakeholder arose from the seminal work of Freeman (1984) who states that a stakeholder is: "any group or individual who can affect or is affected by the achievements of the [organization's] objective". It is a broad description and can be more specific depending on the context of the discussion of the study (Reed et al., 2009).

Reed et al. (2009) define stakeholder analysis as a process that "defines aspect of a social and natural phenomenon affected by a decision or action; identifies individuals, groups and organizations who are affected by or can affect those parts of the phenomenon; and prioritizes these individuals and groups for involvement in the decision-making process". The phenomenon under examination is the role of mathematical models in predicting the course of infectious disease outbreaks and how they can impact end-users who influence public health policy. To date only one study resembling a stakeholder analysis has attempted to understand and describe the role, and interactions between infectious disease mathematical modellers and public health professionals and the impact that it has on public health policy (Christley et al., 2013).

A stakeholder analysis is important in identifying and solving problems. Increasing literature and research with this methodology has brought it into greater recognition and practice in business, policy and other fields in the past 30 years (Bryson, 2004; Reed et al., 2009). Bryson (2004) argues that stakeholder analysis "are now…more important than ever because of the increasingly interconnected nature of the world" because problems "encompasses or affects numerous people, groups, and organizations". However, stakeholders are often identified on an *ad hoc* basis that has the potential to marginalize important groups, bias results and jeopardize long-term viability and support for the process (Reed et al., 2009). To identify the stakeholders a systematic approach developed by Schiller et al., (2013) was utilized. This approach identifies different categories of stakeholders: policy makers and government, research community, practitioners and professionals, public, private business, civil society organizations, health and social service providers. The categories emerged from a study examining the intersection between built and social environments of older adult mobility (Schiller et al., 2013). This research project is examining the phenomenon of infectious disease outbreaks on public health policy, a field primary driven by government and research groups. Therefore the categories presented are not all necessary and certain categories were eliminated and others modified in order to better reflect the relevant stakeholders.

Private businesses were excluded as most modelling based practices are funded by or affiliated with a government or research institution. Civil society organizations such as non-governmental organizations, interest groups or think tanks were also excluded. Many non-governmental organizations that utilize modelling such as the Ontario HIV Treatment Network work with academic research communities but do not exclusively hire internal modellers for their organization. Health and social service providers, of which examples include housing and accommodations, health insurance providers, transportation, was not a relevant group for inclusion in the study. The public, although relevant, as the models released are depicting the effect on the population, play no direct role in contributing to the creation of model or applying their results to a relevant public health problem. Thus the final categories from this framework that were included were policy makers and government, research community, and practitioners and professionals. The category of government was divided into government modellers and government end-users. The research community consisted of academic modellers although some government modellers were also involved in research projects as well. Practitioners and professionals included stakeholders such as physicians, journalist and infection control practitioner nurse.

3.4 Data Collection

Qualitative Approach and Interviews

Interview questions were developed based on recommendations in the literature. DiCicco-Bloom and Crabtree (2006) recommend that between 5 and 10 specific questions be asked to delve into the different aspects of the research issue. The interview guide contained twenty questions, with additional probes and sub-questions, organized into four distinct categories. The first category explored the experience of the stakeholder as a producer or end-user of the model. The second category pertained to perceptions about data collection, quality, and challenges as well as the early processes in planning and producing. The third category inquired about perceived issues pertaining to use and impact of predictive models. The fourth category focused on to collaboration in the field and identification of key collaborators. Finally participants were also asked at the very end whether there were any final, additional comments.

The semi-structured interview questionnaire (Appendix E) was developed to ensure that questions were open-ended in order to allow the study population to give as many detailed answers as possible and to minimize directly influencing the stakeholder with evocative or judgmental phrases (Gall, Gall, & Borg, 2003; Turner, 2010). The researcher was prepared for all interviews with a recording device and a notepad for taking notes throughout the interview. The researcher prescribed to a series of recommendations by Turner (2010) when conducting the interview including but not limited to: ensuring the recording device continues to function in the duration of the interview, encouraging responses with the occasional nod of head, or verbal affirmations such as "uh huh" and being cognizant of a neutral tone of voice is neutral when delivering and listening to questions and answers.

Data collection took place over seven weeks in an iterative process with data analysis. This entailed a process of continuously extending and deepening the analysis until all important stakeholders were identified. Data was collected using one-on-one semi-structured interviews that lasted between 20 and 52 minutes.

Interviews were transcribed verbatim on a password-protected laptop within three days of recording. The process of word-for-word transcription is extremely important as it reflects the accuracy and authenticity of the data collected (Milne and Oberle, 2005). The researcher was cognizant of the difficulties of capturing the spoken word into text format when transcribing data: mistaking of words and phrases, insertions of commas and periods, sentence structure, run on sentences and use of quotations (DiCicco-Bloom and Crabtree, 2006). The researcher made judgment calls to address these issues and consulted another researcher, for a second opinion when issues of ambiguity were evident. This process was enhanced by re-readings of the transcribed data. Transcription of data solely by the researcher allowed for an in-depth and thorough understanding of the data.

Thematic saturation occurs in the iterative process of data collection and analysis when the data does not generate any new themes (DiCicco-Bloom and Crabtree, 2006). Saturation of themes started to emerge after nine interviews. Similarities in perceptions of using mathematical models as a predictive tool of policy, the challenges in data collection, and quality started to emerge. An additional ten interviews were completed in order to clarify and supplement previous views in each stakeholder category as well as to ensure that the full range of problems had been captured.

Recruitment and Sampling

In order to be eligible to participate in the study, participants were required to be 18+. Key stakeholders were identified using convenience purposeful sampling. Purposeful sampling is sampling method which selects for "information-rich cases to study, cases that by their nature and substance will illuminate the inquiry question being investigated" (Patton, 2015 pg. 311). The strengths in purposeful sampling according to

Patton (2015, pg. 311) are that they allow for selection of information-rich participants that allow for an in-depth study. Information-rich cases were experts in the field of infectious disease modelling or experts in another field such as public health and work in some capacity with infectious disease models and who had great knowledge or influence in the field (Patton, 2015, 268). Stakeholders who replied to the inquiry and were accessible during the during the study period were interviewed.

Three types of strategies were used to recruit information-rich informants: key names appearing in peer reviewed literature as well as publications on the Public Health Ontario and Ministry of Health websites; systematic web searches to identify any potential stakeholders outside of academia and government (such as media personnel or private businesses); and snowball sampling. Snowball sampling is a technique in which key informants identify other relevant experts (Patton, 2015, pg. 270). If key stakeholders were unavailable for an interview, a follow-up email was sent to ask whether they could recommend other professionals in the field with similar expertise. Furthermore, during the interview, key stakeholders were asked in interviews to provide names of other experts in the field that could be useful for the study.

Determining the sample size in qualitative research using purposeful sampling is one of judgment and negotiation (Patton, 2015, 314). Guest et al., (2006) empirically studied the number of interviews it would take to reach data saturation for qualitative research. In those findings saturation occurred within 12 interviews and broader themes emerged after 6. However as Ruford & Potts (2015), comment “one problem with this empirical approach is that it does not provide a straightforward prediction for when to stop; for any given study, the saturation point may vary, making planning difficult". Therefore the study design, including the sample size, remained flexible and emergent as has been recommended by Patton (2015, pg. 311).

3.5 Data Analysis

Literature Review

The literature search was conducted using the following databases: Medline, Embase and Global Health as well as Google Scholar. The following keywords were utilized to identify articles that would be relevant: communicable disease, infectious disease, emerging infectious disease, mathematical models, predictive models, forecasting, forecast models, dynamic models, public health policy, global health, stakeholders, data input, data quality. Appropriate and relevant articles were identified, and snowballing technique was used to identify any additional articles. Inclusion criteria for the articles was a comprehensive background into infectious disease outbreaks, background on the types of mathematical models used and produced, the Canadian context of using models for policy decisions, the advantages of models, or data collection. The literature review integrated into Chapter 1 and Chapter 2 to help situate the context of this study in the current landscape. The documents included peer reviewed literature, chapters from textbooks, grey literature such as documents from public health websites, Public Health Agency of Canada (PHAC) and Public Health Ontario (PHO) as well as media content such as published newspaper articles on depicting the release of mathematical models.

Open-Coding with NVivo 11 using Inductive and Deductive Methods

Nineteen interviews were conducted in the study. The primary researcher solely transcribed all nineteen digital recordings. Data analysis occurred concurrently with data collection using QSR International's NVivo 11 software (Turner, 2010). The use of the NVivo 11 (QSR International) software allows for handling of large data making the process of coding, searching, and retrieving data easier and speedier than not using a qualitative data software. It is a platform for the researcher to organize, reorganize and explore relationships between concepts (McLafferty et al., 2006). Furthermore the software provides a platform on which to attach notes and memos to data, which aids insight into emerging themes and a more introspective, detailed analysis (McLafferty et al., 2006). Though there are numerous benefits, automatic search queries offered by the program does not provide a way of analyzing data that would be insightful, meaningful and appreciative of the depth of qualitative research data (McLafferty et al., 2006).

All transcripts were read and re-read after transcription in order to identify the major recurring themes and codes with open coding, and inductive and deductive coding methods. Two methods were used to analyze the data. Automatic text and phrase search queries in the NVivo 11 software (QSR International), which only generated a few insights. A further in-depth analysis was undertaken manually through open-coding.

Open coding is a process in which anything that might be relevant from as many different perspectives as possible is identified. The process of open coding allows for opportunities for emergence of various themes and categories as well as potential relationships between them (Hutchinson, 1986). A code is defined as: "words or phrases are developed by the researcher that serve as labels for sections of data. This may be a list of themes, a complex model with themes, indicators, and qualifications that are causally related; or something in between these two-forms" (Boyatzis, 1998, p. vii). Memo writing occurred concurrently with open coding. Memos, in the format of notes and observations, were written to further examine the relevance and relatability of the codes with other emerging themes in the data.

Codes were manually generated using a deductive and inductive approach. A deductive coding approach is one during which the thematic content analysis is carried out based on previously identified themes or codes. The literature review as well as the questionnaire provided the basis for deductive coding (Hsieh & Shannon, 2005; Vaismoradi, Turunen & Bondas, 2013). An inductive coding approach generates codes directly from the text data in which codes are not preconceived and are derived directly from the data (Fugard & Potts, 2015).

Transcribed data were analyzed in two steps. In the first step, or level one, each code was viewed independently, providing the researcher with a decontextualized perspective on each coded category providing a deeper understanding of each concept (Bazeley & Jackson, 2007). Memos and annotations were used to mark down any observations and notes that could be used for the next step. In step two, transcripts were read and re-read along with any notes taken during the interview and sliced into increasingly specific codes. Codes were viewed in conjunction with other codes, opening up analytical possibilities and emerging relationships were examined (Bazeley & Jackson 2007). Notes from annotations and memos written in step 1 were helpful in identifying emerging relationships.

Thematic Analysis

A thematic analysis is method for identifying, analyzing and reporting patterns or themes within data (Braun and Clark, 2006). A theme is defined by Boyatzis (1998, p. 161) as "a pattern in the information that at minimum describes and organizes the possible observations and at maximum interprets aspects of the phenomenon". It minimally organizes and describes the data set in [full/rich] detail and a foundational method for qualitative analysis (Braun and Clark, 2006; Boyatzis, 1998). Boyatzis (1998) and Ryan & Bernard (2000) characterize it as not as a specific method, but as a tool across different qualitative methodology although Braun and Clark, (2006) argue that thematic analysis should be considered a method in its own right.

Stakeholder Analysis

Stakeholder analysis is used to understand the diverse range of potentially conflicting stakeholder interests. A growing interest in this methodology has led to the development of a collection of methods that can be used to conduct it. Donaldson and Preston (1995) and Friedman and Miles (2006) classified the different approaches into descriptive, normative and instrumental. For the purposes of this study a normative approach is used. Normative stakeholder research takes place in order to understand how appropriate stakeholders can be effectively involved in decision-making (Reed et al., 2009). It is used to contribute to the understanding of the opinions, and interrelationships of stakeholders and further used as a tool to contribute to negotiations and [learnings] between stakeholders. The type of analysis recognizes a constructivist view, which recognizes that there are multiple perspectives to a phenomenon (Reed et al., 2009).

A method adapted from Andersen et al., (2004) was used to describe the data: the area of interest of the stakeholder, the contributions of the stakeholder, the expectations of the stakeholder, the power of the stakeholder, the appropriate strategy to work with the stakeholder, the person responsible for implementing the strategy (Andersen et al., 2004). This tool was modified to better fit the data being analyzed for each stakeholder group: their professional interests and contributions, their influence, defined as the closeness of their working relationship with decision makers and recommendations. Recommendations were divided into two sections, strategies for how to improve collaboration between different stakeholder groups and responsibility, who might take an important role in carrying forth the strategies. Data is organized and presented in matrices, a method of displaying qualitative data with rows and columns. For the next level of analysis, a stakeholder-problem methodology is utilized. This methodology helps to visualize the issues and which stakeholder groups have an interest vested in them. By creating a diagram it becomes easy to visualize converging and diverging interests (Bryson, 2004).

3.6 Quality and Rigor

Qualitative studies "aim to describe and understand the nature of reality through participants' eyes with careful and on-going attention to context" (Milne and Oberle, 2005). Due to the subjective nature of qualitative studies, concerns about the quality of a qualitative study are often under scrutiny (Shenton, 2004). Thus it is important to establish rigor and trustworthiness in the study. The constructs as outlined by Lincoln and Guba (1985) offer a criteria to ensure this: credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985; Shenton, 2004)

Credibility asks "how congruent are the findings with reality?" and is one of the most important factors for demonstrating the trustworthiness of a study (Merriam, 1998; Lincoln & Guba, 1985). Two methods were used in the study to promote credibility: triangulation and thick description. Triangulation refers to the collection of data from various sources (Shenton, 2004). Data was collected in the form of semi-structured interviews from key informants who represented different groups of stakeholders and thus offered different perspectives: policy makers and government, research community, and practitioners and professionals. Documents or resources mentioned by the key stakeholders during the interview were also examined to supplement the views of the stakeholders. Furthermore, peer-reviewed literature, grey literature, government websites and knowledge gained from two conference on Infectious Disease was used to supplement the data collected.

Thick description provides insight on the circumstances and context surrounding the actual situation that is being investigated (Shenton, 2004). The credibility of the study is increased by the study being related to the existing body of literature by the researcher and is a key criterion for the evaluation of qualitative descriptive studies (Shenton, 2004).

The transferability of a study is also enhanced by a sufficient thick description as it allows for a thorough understanding of the issues presented and allows the researcher and the reader to determine how it compares to similar emerging situations. Furthermore to make apparent to the reader of the research in whether transferability in a study can occur, the researcher must provide information on the following: “a) the number of organizations taking part in the study and where they are based; b) any restrictions in the type of people who contributed data; c) the number of participants involved in the fieldwork; d) the data collection methods that were employed; e) the number and length of the data collection sessions; f) the time period over which the data was collected” (Shelton, 2004). All of these criteria have been provided in this study.

The changing nature of the phenomenon usually under examination by qualitative descriptive research renders it difficult for the dependability to be defined as “if the work were repeated, in the same context, with the same methods and with the same participants, similar results would be obtained” (Fidel, 1993). Instead to increase dependability of the qualitative study, and the readers should be provided with the following detail on methodology: “a) the research design and its implementation, describing what was planned and executed on a strategic level; strategies for ensuring trustworthiness in qualitative research projects b) the operational detail of data gathering, addressing the minutiae of what was done in the field; c) reflective appraisal of the project, evaluating the effectiveness of the process of inquiry undertaken.”

Finally conformability refers to the researcher’s ability to maintain objectivity in the duration of the qualitative study and is enhanced by triangulations and an audit trail (Shenton, 2004; Lincoln & Guba, 1985). “Audit trails document the course of development of the completed analysis. In developing an audit trail, a researcher provides an account of all research decisions and activities throughout the study” (Carcary, 2009). A journal was maintained throughout the research process which contained notes and observations during interviews in addition to memos created during data analysis, supported by the NVivo 11 software, to maintain a record of analytic observations. The use of the NVivo 11 software also allowed for easier maintenance and organization of data enabling easier access to the audit trail.

3.7 Limitations

Varvasovszky and Brugha (2000) note that: “The [stakeholder] analysis provides snapshots of what may be a rapidly changing context, where positions and influence are subject to change from internal events, external events and possibly the stakeholder analysis process itself”. Therefore, one of the disadvantages to doing a non-continuous stakeholder analysis is that the cross-sectional perspectives that it provides are only relevant to a snapshot in time. A more effective strategy would be to conduct a stakeholder analysis on an ongoing basis. Varvasovszky and Brugha (2000) also note “the time frame of the project cycle, including project deadlines and resource limitations, frequently determines the scope of the analysis”. Since this was a master’s level thesis project with a timeline that provided a detailed plan for completion of thesis, the number of stakeholders and the resulting depth of analysis was limited.

There are also some limitations with the methodology used to analyze the results. For example, the stakeholder-interrelationship diagram, while an excellent tool for examining the issues at play, does a poor job of displaying the heterogeneity of perspectives within each group. However, this is a byproduct of attempting to simplify the results as much as possible into core issues. This limitation also occurs because stakeholders were asked a very broad question: “What type of further support would you require to advance the field of infectious disease modelling and their applications?” and “Do you have any recommendations to improve collaboration and communication between different groups?”. Therefore, the answers received were highly varied. However, by keeping the questionnaire open-ended and broad, allowed for stakeholders to expand on issues that were pertinent to them, and they were able to elaborate. The wide range of issues that were brought up might not have otherwise been recognized if the questions had been more directed.

CHAPTER FOUR: FINDINGS PART ONE

The findings of the study are presented in the next two chapters. This chapter will look at the perceptions of key stakeholder groups as they relate to mathematical models of infectious diseases and public health policy. The demographic profile of the study population will be presented. The findings in this chapter will address objective one and two of the study: to summarize the experience, influence, and recommendations of key stakeholders and to identify the role of collaborative networks between mathematical modellers and end-users.

Infectious disease outbreaks can be a complex health issue to mitigate. Public health policy makers increasingly rely on scientific evidence to implement the most effective interventions to minimize the impact of outbreaks on the population. The field of mathematical modelling and public health operate under two very different languages, purpose, data and therefore the disconnect between the key stakeholders can limit the influence of field to another. By understanding the perceptions of the key stakeholders in these groups, their perceived challenges and solutions, the gap between modellers and end users could be diminished and mathematical models could be more effectively used for public health policy. in order to improve management of infectious disease outbreak.

4.1 Demographic Profiles of Stakeholder Groups

Four groups of stakeholders were identified for this study: academic modellers, government modellers, policy makers and government end-users, practitioners and professionals (end-users). The research community was divided into two parts academic modellers, who are currently working at the university and government modellers. This was an important distinction to make because both groups have different priorities and objectives and thus differed in the responses that they provided in the study.

Modellers are defined as those who are currently involved, in their daily work building, and analyzing models. All modellers had an advanced degree, PhD or equivalent in mathematics, statistics or epidemiology. End-users are defined as stakeholders who do not in their current capacity build models, but use, or have used models in order to evaluate an infectious disease outbreak scenario. Some end-users actually use modelling results to make decisions or convey recommendations to decision makers, while others are observers, who not of the predictive results of models as a means to be aware of the evolving situation at hand, but don't directly use the results for decision-making.

Out of the nineteen stakeholders interviewed, six were academic research modellers, five were working in government agencies as modellers, four were working in government agencies and used models to either help them in their decisions for infectious disease outbreaks or to present to decision makers and finally four were practitioners and professionals, who were end-users of models.

The range of work experience for mathematical modellers was 7 years to 20 years. The range of government modellers ranged from 3 years to 25 years. For government end-users, experience ranged from 2 years to 20 years and for the last group, practitioners and professionals, experience ranged from 10 years to 26 years. Table 3 presents the summary of the demographics data.

Table 3: Work experience of Key Stakeholder Groups

No. of years	Academic Research Community (Modellers)		Government Research Community (Modellers)		Policy Makers and Government (End-Users)		Practitioners and Professionals (End-Users)		**Total**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
0-5	1	5.2	1	5.2	2	10.5	0	0	4	20.9
5-10	2	10.5	1	5.2	1	5.2	0	0	4	20.9
10-15	1	5.2	0	0	0	0	3	15.8	4	21
>15	2	10.5	3	15.8	1	5.2	1	5.2	7	36.7
Total	6	31.6	5	26.3	4	21	4	21	19	100

4.2 Stakeholder Analysis

The first part of the chapter present findings for objective 1: to summarize the experience, influence and recommendations of key stakeholders. Recommendations by stakeholders included strategies to enhance the communication between the two groups as well as which stakeholder group should take the steps necessary to ensure the bridging of experts. A stakeholder analysis that was conducted to better understand the perceptions and experiences of the key stakeholders that have expertise with mathematical models, public health or both. For each stakeholder group, the area of expertise and the contributions of the stakeholder is discussed. Then the relation of each stakeholder to public health, labelled as influence and strategies that were recommended to enhance the communication and collaboration in the field are summarized. Additionally, under recommendations, the perceived responsibility of who should carry out the strategies, if shared by stakeholders, is also summarized.

Academic Research Modellers

Area of Expertise and Contributions

Six researchers, mathematical modellers, were interviewed in this study. All key stakeholders in this category of research community worked in academia and were affiliated with a university. All of them had expertise in developing mathematical models. Their contribution and area of expertise have been summarized in Table 4.

"My role is to develop models and publish theoretical models or work that's kind of more focused on is don't know proofs and that sort of thing." [AM1]

"...at the moment I used mostly agent based modelling, but in the past I used deterministic and stochastic models." [AM2]

"The development of models, and the analysis of the models themselves. And developing the model also involves trying to integrate some of the data." [AM3]

"I spend most of my time thinking mathematically" [AM4]

"...our contribution is somewhere around modelling in the epi [epidemiology] that comes together" [AM6]

Table 4: Key characteristics of academic modellers

Stakeholder	Area of Expertise	Contributions (Role)

Academic Modeller 1 (AM1)	Mathematical Modelling	Develops theoretical models, works on mathematical proofs
Academic Modeller 2 (AM2)	Mathematical Modelling	Develops agent based, deterministic, stochastic models
Academic Modeller 3 (AM3)	Mathematical Modelling	Develops theoretical models, works on analysis of models
Academic Modeller 4 (AM4)	Mathematical Modelling	Develops mathematical models; specific research interests in how infectious microorganisms survive in the human population
Academic Modeller 5 (AM5)	Mathematical Modelling	Develops mathematical models; specific research interest on models that connect populations in different locations (meta-population)
Academic Modeller 6 (AM6)	Mathematical Models, Clinician	Develops mathematical models; specific research interests in endemic and epidemic HIV. Clinical practice, HIV clinic

Influence of and strategies proposed by academic modellers

Three modellers in this category were identified as having close relationships with public health. There was one identified expert in the area of HIV/AIDS modelling who was also a clinician working in an HIV clinic. One of the stakeholders (AM1) in this category had previously worked in the government. These two stakeholders along with one more (AM2) currently have close working relationships in working with public health agencies.

"In that case I was embedded in the public health agency of Canada

and kind of served as a technical expert in developing models but with

> much more formally linked with people who use models and as an academic so kind of two different roles depending on what year you're referring to." [AM1]
>
> "But because of the use of agent based modelling, that is you know majority of my work is there, umm I'm more into addressing a specific question for public health" [AM2]
>
> "I guess my background is I'm a clinician, but our group, we develop models. Uhh yea I guess the best way to frame it, I feel like we're probably epidemiologists who use, develop and contribute models to epidemiology and to public health." [AM6]

The remaining three worked more closely on academic projects, with few interactions or formal ties with public health and policy makers (AM3, AM4, AM5).

> "Yea because I personally am not in direct contact with individual collaborations with people in public health. I have contacts with them at conferences and workshops but I do not develop models with them...It's me not having access to it, or not being in direct collaboration with people who have access to it." [AM3]
>
> "But it's not the main sort of thing, that gets, that I'm kinda doing. But I absolutely do interact with them [public health professionals] from time

to time….those aren't the interactions that are typically driving a research question that I'm interested in" [AM4]

"I haven't done any of that for a few years now...I was, uhh involved in pandemic planning, uhh so in particular we would, we did a lot of consultation with PHAC…" [AM5]

When probed about the recommendations that they had for improving communication, and collaboration between different stakeholder groups, different perspectives emerged. These perspectives have been summarized in Table 5. They will be discussed in more detail later on in the chapter under objective 2.

Table 5: Influence, recommendations of academic modellers

	Influence	**Recommendations**	
		Strategy to bridge the gap between modellers and PH	**Responsible**
AM1	Past government scientist, contributes modelling expertise to government modelling questions through personal connections	Better integration of newer modellers within existing networks	New graduates - build relationships with long-term professionals in the field
AM2	Lead in workshops connecting mathematicians and public health professionals	Continuing to build on the network, Organizing workshops to bring groups together	Mathematical modellers and public health community

AM 3	Currently no active involvement with public health professionals	Public health should be more aware of long-term potential benefits of mathematical models	Education for public health
AM 4	Currently no active involvement with public health professionals	Academic researchers should be used as a reservoir of expertise to advise during outbreaks	Establishment of a committee of academic modellers to be accessed to outbreak emergencies
AM 5	Currently no active involvement with public health professionals	Funding for extra-support (post-docs), reorganization and funding of organizations such as Centre for Disease Modelling (CDM)	Increase government funding
AM 6	Develops models for public health, mostly related to HIV	Finding more spaces to work with other professionals, working more closely with knowledge translation professionals	Mathematicians working more closely with knowledge translation professionals to better explain their work

Government Research/Modelling Community

Area of Expertise and Contributions

Five modellers within government public health agencies were interviewed. Four worked in, or had previously worked with a federal public health agency and one was currently employed in building models for a provincial public health agency.

> "I'm a statistician. Special statistician meaning I'm more on the applied side" [GM1]
>
> "Myself, later joined by two others and the maximum size of my team, at one point grew up to 10 people and right now we have 6. So some years we are bigger, some years we are smaller. And then

so I'm the manager of the team. In terms of expertise, we have 3 statisticians including myself." [GM2]

"So I'm kind of an epidemiologist, but then sort of I guess through experience, through work, I'm kind of a mathematician doing mathematical modelling...where my role is using mathematical and statistical models, umm to help inform, sort of policy and decision-making, umm, at the federal level" [GM3]

"I'm more on the mathematical modelling side....lead a group of, we have a team of mathematical modellers" [GM4]

"We build models from scratch. We use historical data and build model to predict future." [GM5]

Table 6: Key characteristics of government modellers

Stakeholder	Area of Interest	Contributions
Government Modeller 1 (GM1)	Statistical Modelling, Federal Agency	Applied Statistical model, data analysis
Government Modeller 2 (GM2)	Statistical Modelling, Federal Agency	Manager of an interdisciplinary team in a federal agency that develops mathematical models at the request of end-users
Government Modeller 3 (GM3)	Mathematical Modelling, PhD Epidemiology, Federal Agency	Uses mathematical models for daily work. Previous projects include models for Ebola healthcare team, Zika and Chikungunya spread.

Government Modeller 4 (GM4)	Mathematical Modelling, Federal Agency	Leads an interdisciplinary team in developing models. Previous and current projects include models for vector borne diseases, food borne diseases, water borne diseases and primarily obviously zoonotic infections
Government Modeller 5 (GM5)	Statistician, Provincial Agency	Surveillance Modelling, Predictive Modelling for the province of Ontario

Influence of and strategies proposed by government modellers

The government modellers interviewed worked closely with end-users in their organizations.

> "So usually end-users are people within the agency. So we get requests from different departments in the agency and usually it's the policy department. Or the outbreak response department. So they're the ones that actually come to us and ask us these questions." [GM3]

Furthermore, the kinds of questions that government modellers are interested in directly impact public health policy decisions during outbreaks. These include questions such as how to mitigate risk, protect the Canadian population from imported infectious diseases via traveller's, best use of isolation and quarantine policies.

> "Our mandate is always sort of to help the Canadians...I mean the common theme in what I model would be, it would have a focus on

Canadians... so I'm always modelling the impact on Canadians." [GM3]

Therefore because of their close proximity to policy makers as well as the focus of their models to specifically address public health issues, government modellers have more of an impact on policy than academic modellers might. These perspectives have been summarized in Table 7. They will be discussed in more detail in this chapter and the next.

Table 7: Influence, recommendations of government modellers

Stakeholder	Influence	Recommendations	
		Strategy to bridge the gap between modellers and PH	Responsible
GM1	Works with policy-makers and researchers	Education for end-users to gain better understanding of timelines and the utilization of models for long-terms projections	Public health
GM2	Manager of an interdisciplinary team in a federal agency	Better understanding by end-users of how mathematical models can be used for public health decision making	Universities - better education students on mathematical methods that are applicable to public health modelling, the understanding can be improved.

GM3	Works at a federal agency with decision makers to modify research questions appropriate for modelling	Improve understanding of policy makers as to the usefulness of models, improve risk communication	Did not specify
GM4	Works with decision makers when initially developing modelling questions	Modellers should initiate modelling projects	Universities - better training of students through co-op programs to prepare them to understand both mathematical modelling and their applications in public health policy
GM5	Provides technical, modelling, statistical expertise of ministry to answer their specific questions	Did not specify	Did not specify

Government End-Users

Area of Expertise and Contributions

Four end-users of models were from government were interviewed, two at a provincial public health agency, and two at a federal public health agency. The two federal government end-users had previously worked as modellers, but in their current role worked as end-users, allowing them a unique position of being able to intricately understand the models and how they might influence policy.

> "Now I'm more a sort of end-user, if you like, for modelling. Or the person who sort of directs that modelling be done, to involve umm planning or policy." [GEU 2]

The two provincial government end-users were public health physicians with no training in building mathematical models. Their roles included providing science and technical information to policymakers directly and to key audiences of Public Health Ontario such as the public health system, the local public health units, the health care system, physicians, nurse practitioners, nurses, whether they're in acute care, long-term care, community based care or primary care. One (GEU3) had more experience in interpreting and working with models than the other (GEU4).

> "So all of this is, umm you know, I tend to look at models, but I also need to be a critical user of models. I need to say, this is timely, I can understand, it's well constructed...I can understand the assumptions. I can understand the parameters. I can understand whether they've done reasonable sensitivity analysis." [GEU 3]

> "Uhh I probably, well not the, probably not the methods. Like what they did exactly, or what the formulas are...I don't need to look into the actual model part that goes into designing it." [GEU 4]

Table 8: Key characteristics of government end-users

Stakeholder	Area of Interest	Contributions

Government End-User 1 (GEU1)	Epidemiologist, PhD	Works with models to assess global situations and potential impact and risk for Canada to inform decisions
Government End-User 2 (GEU2)	End-user at the federal level, previous modeller	Looks at predictive models of pandemic by engaging both in-house and external modellers
Government End-User 3 (GEU3)	Public Health, Provincial Agency, MD	Outbreak response and providing medical technical advice to public health unit
Government End-User 4 (GEU4)	Public Health, Provincial Agency, MD	Outbreak response and providing science, technical support to key audiences

Influence of and strategies proposed by government end-users

Mathematical models are just one of the tools that is available to these end-users from which to pull evidence from in order to make decisions and inform policy makers.

> "I've got to be able to say, do I pay attention to this. Why? How will it help me? You know in decisions I might have to make and how I'm planning, preparing for, responding to, you know a given say outbreak or epidemic or something" [GEU 3]
>
> "I'm more involved in, umm sort of outbreak response and uhh providing medical technical advice to public health units." [GEU4]

The two federal end-users were involved in using mathematical modellers in order to inform policy makers using the results of the models. Therefore, their influence on decision-making, due to their close physical approximation and collaboration with end-users, can be considered greater than someone working on isolated academic research projects.

> "I'm more on the epidemiology and advice side of things and that then leads up to senior management or others who are in those positions to making decisions based on what we have." [GEU 1]

These perspectives have been summarized in Table 9. They will be discussed in more detail in this chapter and the next.

Table 9: Influence, recommendations of government end-users

Stakeholder	Influence	Recommendations	
		Strategy to bridge the gap between modellers and PH	Responsible
GEU1	Collaboration with policy makers at federal level	Building a Centralized Network for outbreaks	Status quo has worked well so far
GEU 2	Pandemic preparedness development — engaged both in-house and external modellers looking at models for impact on Canada	Training for public health (around languages and increasing the use of models), galvanize disease modelling communities in Canada	Knowledge translation professionals who can bridge the gap between the two groups

GEU 3	Participates in provincial outbreak response and provides medical technical advice to public health units	Improve data collection systems	Development of guidelines for end-users to better critically understand models
GEU 4	Public health physicians providing specialist science, technical support to key audiences	Modellers to recognize evolving situation and develop models	Did not specify

Practitioners and Professionals (End-Users)

Area of Expertise and Contributions

Four professionals were interviewed under this category, who came from a diverse range of backgrounds such as infectious disease physician, infection control practitioner, public health physician working with the WHO, and a journalist reporting on infectious disease outbreaks. None of the end-users in this category had any experience or background in mathematical modelling. All stakeholders some experience in working with mathematical models and two had experience in developing policy for outbreaks as well.

> "I mean I haven't worked in research in predictive mathematical modelling. I read about predictive mathematical modelling...I don't have any direct experience with doing it. Or working with people who are doing it. I'm a consumer of mathematical models." [PEU 1]

Table 10: Key characteristics of practitioner and professionals (end-users)

Stakeholder	Area of Interest	Contributions
Professional (End-User) 1	Clinical Practice and Hospital/Public Health Policy	Clinician, travelled to West Africa during Ebola outbreak, helped form policies during SARS outbreak
Professional (End-User) 2	Infection control practitioner	Look after patients, data collection and hospital surveillance for infection
Professional (End-User) 3	International Public Health Policy	Worked on numerous consulting projects including tainted blood scandal, Ebola, pandemic influenza
Professional (End-User) 4	Journalist specializing in reporting infectious disease outbreaks	Alerting the public to infectious disease outbreak

Influence of and strategies proposed by academic modellers

Three out of the four end-users noted that predictive modelling of infectious disease outbreaks were not the best tool to use for policy decision based on their past experience with inaccurate predictions.

PEU 1 is an infectious disease clinician who has previously worked on policies related to SARS and had been directly impacted by predictive mathematical models released during the Ebola outbreak. PEU 2 is an infection control practitioner at a hospital with no experience public health policy, and therefore had little interest or influence in mathematical models and policy. At the hospital level community predictive mathematical models allowed for increased awareness of the possibilities and probabilities of infectious disease that may come through the hospital doors. PEU 3 is a public health physician with extensive experience working on outbreaks such as SARS, pandemic influenza and Ebola with no background in building models. This key stakeholder was previously involved with the federal government as well as the WHO and helped create policy around pandemic influenza of 2009 and the Ebola outbreak of 2014. PEU 4 is an infectious disease journalist with no experience in building models. By writing about infectious disease outbreaks, they are able to alert the general public to infectious disease outbreaks, but no direct influence on public health policy.

Table 11: Influence, recommendations of practitioners and professionals (end-users)

Stake holder	Influence	Recommendations	
		Strategy to bridge the gap between modellers and PH	**Responsible**
PEU1	Helped form policies during SARS epidemic	Increase availability of modellers who are knowledgeable about hospital transmission	Mathematicians should develop models to retrospectively understand outbreaks, and apply that to future outbreaks
PEU 2	Has previously worked on hospital policy during outbreak — no public health influence	**N/A**...satisfied with public health's current recommendations	**N/A**...satisfied with public health's current recommendations
PEU 3	Helped form policies during Ebola epidemic, Pandemic Influenza	Improve risk communication between modellers, public health and media	Public health professionals to understand the modelling and ask the right questions to modellers, conjoin release of models with public health professionals so they are aware of questions that might arise

PEU 4	Has worked on hospital policy, is a consumer of surveillance models	**N/A** doesn't believe models should be used a lot when reporting on infectious diseases	**N/A** doesn't believe models should be used a lot when reporting on infectious diseases

Analysis of Results: Stakeholder-Interrelationship Diagram

A stakeholder-interrelationship diagram as described by Bryson (2004) was used to further analyze the data. The stakeholder interrelationship diagram allows for the visual identification of stakeholder groups and the issues they consider themselves to be connected to as well as other stakeholder groups who have also identified that as an issue. For example, using education as a means to improve awareness of mathematical models is brought up in two different contexts by different stakeholder groups.

First, universities should take a stake in education students, both mathematicians and public health students, on the applications and integrations of the two fields by offering a class. Ideally this class would minimize the amount of complicated math in order for public health students to comprehend the material. The reasoning behind this was that through this initiative, public health students would be better informed of the tools that were at their disposal, and what they were ideally suited for even before entering the public health workforce. This was a recommendation laid out by the government workers, both end-users and modellers, who worked in more integrated environments and saw students struggling to grasp how and when to utilize mathematical models and apply them to public health problems.

Second, education proposal was aimed at professionals already in the field. There was a repetitive theme amongst modellers, both in academia and government, that the value of their work was not entirely understood by public health professionals and by increasing education about how and when mathematical models were best suited for would help public health problems. Professional end-users also agreed that more education was necessary but in the form of risk communication — something both modellers and end users could benefit from. Modellers could benefit from being able to communicate about the models more accurately and end-users being able to ask appropriate questions as well as communicate results to other stakeholder groups where necessary.

Academic modellers were in agreement that more funding — to hire post docs and expand the scope of their work would be helpful to the field, however no other group mentioned the need for increased resources or recommended that increased funding be directed towards researchers in academia. Although several government workers felt that academic modellers should take initiative and produce models when they felt the skill could benefit in minimizing infectious disease outbreaks, one government end-user did not feel as if that was the best use of resources. This differing of opinions is not reflected in the stakeholder-interrelationship diagram.

The federal government agency, PHAC, was the only organization in which modellers and public health professionals worked in the same organization and often together when the need arose. In other academic institutions or public health agencies at the provincial level, the close approximation of the two groups was not as prevalent, even though modellers and end-users did work together through other means of communication. Thus it was brought up by both an academic modeller and government worker that a common space, for modellers and end-users to come together, especially during times of infectious disease epidemics could be rewarding. These views are discussed in detail later on this chapter. Furthermore, to further bridge the gaps between the two groups, the integration of knowledge translation professionals is recommended, experts who have an in depth understanding of both modelling and public health and are able to communicate to each group as to the message of the other. At PHAC, GEU who had experience in modelling informally took on this role. In other places, such as the agencies with whom AM6 worked with, this was a designated role, by a knowledge translation professional.

Academic and government modellers recognized the difficulties new modellers face in building trust, and networks in the community that ultimately allow them to apply their skill to public health problems. Thus, ensuring that new modellers have a method of being integrated into the current fold of the modelling-public health landscape was considered an important issue by both groups. This point has discussed in the next section of this chapter. Finally, government end-users and modellers expressed some dissatisfaction with current data collection systems. As this issue was recognized from both a modelling perspective and the end-user perspective, it is important to consider the current issues regarding data and how to improve it. Chapter five goes into further detail about the challenges stakeholders expressed with data.

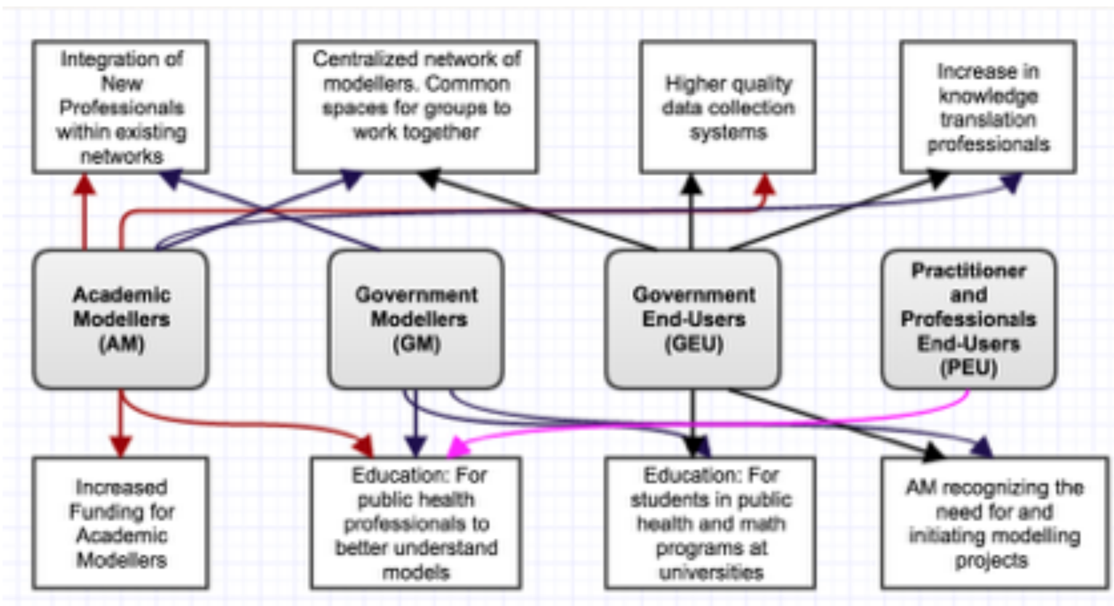

Figure 3: Stakeholder-interrelationship diagram.
Stakeholders are linked to the issues they perceive to be key in improving the current landscape of mathematical modelling within the infectious disease and public health context. [AM, academic modellers; GM, government modellers; GEU, government end-users; PEU, professionals who are also end-users.]

4.3 Collaborative Networks between Modellers and End-Users

The second part of the chapter will focus on the second objective of the study: to identify the role of collaborative networks between mathematical modellers and end-users. For this objective three overarching themes emerged: the importance of collaborative network, challenges in developing and establishing collaborative networks and improving the quality of collaboration.

Importance of Collaborative Networks

A major theme that was identified was the beneficial nature of collaborative networks in the context of mathematical modelling. Existing collaborative networks were viewed as being beneficial and necessary by the key stakeholders interviewed in this study. Key stakeholders spoke of others in their respective fields, along with many other professionals such as biologists, epidemiologists, laboratory scientists, and economists with whom they collaborate with as well. Mathematicians were perceived as being available, willing and connected to end-users and other mathematicians. Key stakeholders talked about the importance of building trust through extensive collaboration between modellers and end users and identified the iterative nature of building models requires that collaboration be central to the process.

Building trust through extensive collaboration

The existing networks that facilitate collaboration were repeatedly noted to be most effective when the professional relationships had existed for long-term and trust had developed. This was considered important for being able to reach out within the network for insight into building models, evaluation of models and data collection.

> "Ideally you've worked in the field long enough to have collaborators who are happy to, kind of do the analysis and send you aggregate estimates and distributions, of parameters you can put into the data." [AM6]

> "I mean there's a certain level of trust and of umm reputation that's been established and I mean so for me it's easy to I mean the public health agency calls me up and says what do you think about this or that we have this data and we have these questions, is this something that you could help us with or not?...They happen to know me, they trust me, I feel as if though I have a good reputation with them." [AM1]

> "There's some people I know, who I know how to do mathematical models and do them well. And so I'm less likely to be critical about how they've built their models, because I have faith that they know what they're doing and the structure will be ok. But if I was doing something critical to, something in that model, something in that model was critical to policy then I might take it to [name] or [name] and somebody say, okay just like look at this, look at the structure of this model and tell me

> whether the structure of the model makes sense to you and what you think the gaps might be of the mode" [PEU 1]
>
> "So I used to work at Public Health Ontario for years. So I've worked with a lot of the people there. So informally you'd pick up the phone, you'd talk to them or maybe email them." [GM3]

It can be difficult to establish new relationships, especially during infectious disease outbreaks. Therefore the existing, well-established relationships become especially important during this time when time is of essence and decisions regarding how to control, mitigate and reduce infectious disease outbreaks are required in a timely manner.

> "Because it takes time to engage with people. So we don't have time during an outbreak. We have to get on with it...And what hasn't been helpful, I would say is that during SARS, there would be people, they would just come up and send me emails, and just wanna call me and then I'd have "we picked up still in the newspapers and the publications from...and we've got a model for you". We get tons of that. And that to me is difficult to deal with because I actually don't have a lot of capacity to digest that information. Or make use of it." [GEU2]

Iterative process of building models

The importance of having functional networks was brought out in two emerging themes from key stakeholders. The first was that collaborative relationships between mathematical modellers and end-users were important in clarifying, refining and optimizing the question that a model would answer. The second theme was that communication between stakeholder groups allowed for leveraging the expertise of mathematical modellers, not for mathematical models necessarily, but rather for simplifying and diversifying ideas of end-users.

First, the development of the modelling question is an iterative process that requires time and communication to clarify, refine and optimize. This step is not a matter of an end-user asking a question and a modeller developing it, without any communication in between. This was a theme stressed by government modellers, government end-users and the academic modellers who are more closely involved with public health professionals.

> "So many people who want to use models for decision-making, and so it requires a little bit of a back and forth in a process in which very generic types of questions typically posed. A lot of times you have to answer those generic questions, you have to go back to the decision maker and go through a loop of refining the questions." [GM4]

> "Well, what questions should you ask modellers? Now what questions could you ask modellers because modellers can pretty much model anything that you wanna do. So it's the type of right question posed to

> modellers I find lacking. And it needs a lot of back and forth for mutual understanding, for what they can do for you." [GEU2]
>
> "You may have to do a lot of digging and a lot of background research. Umm into the area to fully understand what the question is." [GM1]
>
> "Umm so I mean we will develop the model and then go back to our collaborators and say you know here's kind of the general structure based on the conversations, here's how we envision this working umm does this seem right? Do you think there are changes that need to be made. So so its kind of an iterative process." [AM1]

One academic researcher commented that being involved in a group that consists of mostly end-users who have realized there's no need for a mathematical model, can still prove to be beneficial in conceptualizing a different modelling question that might not have otherwise been conceived.

> "Definitely happy to still stay involved and our group will still contribute in how we can, particularly because that question once answered might lead to a modelling question" [AM6]

Second, the value of predictive models lies is in the process of model development and the expertise of the mathematical modellers and not necessarily the actual predictions outputted. One key stakeholder, an academic modeller, shared his interaction with an end-user who didn't see the value of a mathematical modeller, instead finding the value to be in the expertise of a modeller who might be able to simplify problems better than problems.

> "So we were discussing, he said well you know I, I don't like, I actually often don't listen to the results of models but I love talking to modellers because they really get my thoughts organized. So I think that's, that's a benefit even though, uhh it's not something that you would necessarily claim everywhere. People don't listen to us, but they like talking to us." [AM5]

Challenges in developing and establishing collaborative networks

Several challenges were brought up during the key stakeholder interviews about the difficulties of maintaining or establishing a network. Key themes that emerged included: turnover of teams, integration of newer experts, access to modellers, and different priorities key stakeholder groups.

Turnover of teams and leadership

Establishing trusting professional relationships between modellers and end-users takes time. It's an education process for both groups in understanding the nuances, and caveats of the other field. However, once that understanding is established, it can be difficult to sustain it within an organization because of turnover team members. This process has to start all over again when new personnel are hired, making it one of the challenges in being able to establish long-term trusting teams. This was mentioned by a modeller who worked within a federal agency for over 20 years and has seen this cycle take place repeatedly.

> "And then if we happened to be engaged with the same group over a matter of two years. Usually these people become convergent, they are more attuned to, its just repeated presentations. I will say almost like an education process. And also, the modelling itself, I think from inside, ourselves, may not make an impact but internationally the same group of people, they travel to the World Health Organization. They travel to UK, to some places in the US and then they get to big conferences and then some big modellers really try to sell what they're doing and then they come back saying: "huh where are, where are our modellers? Why are we not doing the same?" And so there's kind of a stimulation from outside and so on and so forth. And then, then things become much closer and then we get more buy in and then people leave. And organizations change and so on. And then we end up with a new group of people, that starts all over again and all over again. So that's just a cycle I've had, I've had many cycles like this. Where you have to go back to square one and start all over again for the next one for the next few years. Hopefully people stay in their jobs." [GM2]

> "…we used to have together to organize workshops together in Banff centre and the brainstorming of some new challenges. But also engage with similar people in York University, UFT and UBC, Edmonton, Alberta and so on. We used to have such a network. But then the only challenge is for that kind of network across universities, there needs to be a leader, a strong leader. So we used to have such a person. Very very energetic and good at lead and get people together and get some things going. But then things changed. Once you have a leader who is not as strong, or weaker, then things start to fall apart. So that's how I feel right now." [GM2]

Integration of modellers and organizations

Another challenge in establishing long-term relationships is the integration of new professionals in the field. This especially holds true for modellers, as was mentioned by an academic modeller, especially if they are looking to work with a public health focus. It can be challenging initially to build these relationships and establish trust so others in the field can comfortably reach out.

> "There's lots of academics doing really great modelling work maybe don't have that sort of linkage and umm and that's a real challenge right? You might have really good modelling questions but if you can't

> find someone who's going to be able to collaborate with you fully." [AM1]

It's not only individuals who might have difficulties with this, but also companies who focus on modelling, to integrate with government agencies. One government end-user shared their experience with unsuccessfully being able to collaborate with an organization who was looking to do so.

> "The person with a lot of interactions, come to think of it is [name], who's been sort of trying to get involved with us. But he's been a bit of disappointed by that. He hasn't been able to provide a solid, there hasn't been a solid interface between the agency and [organization], which is you know his company." [GEU2]
>
> "We were not able to find a good mechanism essentially, financially or otherwise to work with him. But what we've been able to work with him is research, so grant applications, that kind of thing. And that can help a lot. And he's somebody that's wanted to collaborate with government but he's situated outside of government. And I think he's managed to work with the CDC much better than he's managed to work with us." [GEU2]

Access to modellers: Internal versus External

Federal public health agencies in Canada house mathematical modellers within the organization, internal modellers, which policy makers, and other end-users can have access to. End-users within the organization prioritize accessing the internal modellers.

> "Our first approach will be internal...let's see what we can do internally together first...we haven't gone directly to a modeller outside and said: "hey let's work together on this" [GEU1]
>
> "I have engaged both in-house and external modellers in, of course, looking at some predictive models on the impacts of the pandemic for Canada" [GEU2]

At the provincial government level, public health does not currently house an internal modeller. During the 2009 pandemic influenza outbreak, a group of modellers worked internally with the provincial agency. However, no modeller currently works there. The lack of ease of accessibility makes it less likely for mathematical modellers to work with public health professionals and policy makers, simply because they are not present internally within the organization.

> "We had [name] working here back during the early years, especially during the early part of the pandemic H1N1. He left to take a position at [organization]. We work with him, but I don't think we've got anyone on staff who would say yes, I'm a mathematical modeller." [GEU3]

> "I mean I loved working with [name], and as well as not only was [name] here for a period, but there was a whole bunch of graduate students that he had working with him...It was a lovely group to have" [GEU3]

This also holds true at the hospital level. While the nature of hospital outbreaks is different from community outbreaks, and thus mathematical modellers would need to specialize in that, simply the lack of presence of one makes it less likely for practitioners in the hospital to seek one out to answer questions about emerging outbreaks. The presence of mathematical modellers would make it more likely for them to be used.

> "So you know there are, there are people who understand hospitals and have done some modelling in the hospitals, but at Mount Sinai, no." [PEU1]
>
> **"…**but I might if there were modellers around I might, you know. I might collaborate with more modelling if there were more of them." [PEU1]

Different Priorities and Perspectives

Different priorities can cause tension between different groups of key stakeholders resulting in frustration. These frustrations between government modellers and academic modellers, policy makers and academic modellers, the clinic and modellers arises from different priorities that each stakeholder group has.

Academic Modellers and Government Modellers

First, government modellers prioritize directly answering a question with some practical, applicable value whereas academic modellers are not necessarily driven by questions that have immediate practical applicability. Thus when collaborations between the two groups occurs, different priorities can cause some frustration between the two groups as was mentioned by key stakeholders in both groups.

> "I would say that something that, umm, you know I often found like people in public health, you know when you interact with them, why don't you just work on this question or that question. And its like, I don't find that exciting. You know and it would take so much effort for me to, to work on that." [AM4]

> "And the, another challenge is, from my perspective, we're working on, we're driven by priorities but for the academic perspective, it's mainly driven by academic interest. So sometimes, there's a little bit disagreement." [GM2]

> "And then what happens is, may happen, is they're not exactly answering the right question. So when I was in that group I used to use a term. It's always better, basically I'm talking to academia, mathematicians. Its

> better to be able to provide a proximate answer to the right question, rather than a precise answer to the wrong question. And the kind of the disconnection is, once the project goes to purely into the hands of an academia, sometimes they start to explore, in their own way and may not answer the right question. And so those are the kind of challenges I used to have when I collaborated with academia." [GM2]

Academic Modellers and Public Health

Second, public health and policy makers are limited in what they do by the supplies that they have and by the logistics of delivering supplies during outbreaks. Mathematical models predictions prescribe possible interventions, rather than determining the logistics of their results. Thus from the perspective of public health professionals, models don't always confront logistical limitations and thus can be difficult to apply when making decisions that are reasonable and feasible. Although this was recognized by one of an academic modeller with some public health experience, one academic modeller, whose priorities were driven by research, expressed his frustration at having potential previous models disregarded by public health. An end-user also acknowledged that mathematical model recommendations provided to the agency are not always considered or useful since the results might not be feasible to carry out.

> "Particularly since, so often you like, you could try and do what they want and then they ignore it. For, for because of all sorts of political reasons and that's just very frustrating, you know" [AM4]

"And now, they have to make decisions, which one is the most effective one?...So you know I could say vaccines, the most effective interventions need to target this age group, this age group and with that many vaccines, for that period of time. But there are reality to, you know, implementing these types of policies." [AM2]

"...that models can forecast, uhh you know, things that could happen and we could, we need to do, but they have to actually confront political reality" [AM2]

"So and that means no matter what you say, public health has to make decisions based on their assumptions too. But at the same time there are limitations that public health would look at. But overall public health will look at this result, and make decisions, at least informed decisions based on their assumptions too. And there are logistical challenges involved in it too….You can say that you can vaccinate, if you vaccinate the Canadian population in two weeks, then we don't have any pandemic…but that's not possible. You can't vaccinate 30-40 million individuals in two weeks. It's logistically impossible." [AM2]

"If the model suggests some level of coverage…you can make predictions on how wide the coverage of vaccination has to be….Someone has to decide whether you're really willing to put the

> efforts and the energy and the investment of money to get that coverage…that's a political decision." [AM3]

Modellers and Other Professionals

Finally, one clinician, with no background experience in modelling, commented on how there can be tension between clinicians and modellers answering questions at the hospital level. The differences between these two stakeholder groups arises from different languages, priorities and lack of communication about the model.

> "There's also, I mean I think there's always a tension between umm the people who do and understand the models and people who do and understand the clinical pieces of it. And so, it, the, the language of modellers is different than the language of us clinicians. So there's still sometimes a barrier between, umm, my understanding of what's happening in models and modellers understanding of you know what I'm trying to explain to them about what we know about the epidemiology of a particular circumstance." [PEU1]

Improving quality of collaborative networks

Stakeholders identified that there is still room for improvement in the efficiency of existing collaborative networks. Perspectives on how this could be carried out clustered around four subthemes: better integration of newer "experts" entering the field, improving risk communication, improving training and education, and building a central network.

Better integration of newer experts entering the field

The benefits of well established networks and relationships has already been discussed. However, those relationships take time to build and when new graduates and professionals enter the field, their lack of existing network and relationships, can make it difficult for them to carry out projects. It was identified that it can even be difficult for them to simply join the conversation as well.

> "It's a bit more that people sometimes try to join in those conversations as well...And some people are not necessarily in those conversations. So there's room for improvement." [FM4]

> "I mean they might say it's a great idea and yes it might be useful but in order to do the model you need access to data, you need access to those types of resources. So sometimes that's very hard especially if you're new for people to be like "oh sure we'll just send you all of our data." Right folks feel kind of anxious about those sorts of stuff' [AM1]

Closer communication between public health professionals and modellers

When mathematical models are released, the onus of communicating them to the media often fall on the shoulders of public health professionals who are more easily accessible to the media in times of infectious disease outbreaks. One key stakeholder, brought up the issue of release of mathematical models, especially models that address a key hot topic such as the Zika or Ebola outbreak, without communicating fully about the caveats and nuances associated with the model to public health professionals or policymakers, who are ultimately responsible for answering media questions about the predictions. Not doing so can result in public health being blindsided and unprepared to account for model predictions and questions that arise because of it.

> "And ideally, it would be good if there was sort of joint release of information, joint release of results….uhh you know public health professionals, policy makers, having to sort of deal with almost a reaction to the results of models" [PEU 3]
>
> "Especially that modellers are at least aware of the fact that a policy makers, public health physician, risk communications are gonna be put on the spot if that kind of information is released without a heads up, without some kind of discussion ahead of time." [PEU3]

Increasing Resources

Key stakeholders repeatedly brought up the need for more resources in order to increase systematic training of professionals in the field in order to improve the communication and understanding between modellers and public health. It was indicated that increased training should be targeted towards bridging the gap between the two groups cause by the different language.

> "We can't focus on [modelling], we speak different languages. So I think that, you know is frequently the case." [GEU2]
>
> "Maybe some training around, because we speak different languages, so training public health. I know they exist, but I mean I've seen some good things, umm training for epidemiologists on modelling for example. And it can be done, it just hasn't been systematically done but." [FE3]

Finally, increased funding to improve capacity of being able to build models that are useful was also expressed by both government and academic modellers. This increased capacity was recommended in terms of increased funding for hiring more students and post docs.

> "I guess we get, we get a lot of requests and so it, what would help me would be to have more resources...whether it be funding for students, umm to help out with projects or to actually employ additional researchers to take on umm some of the projects that we, we can't take on, that are important to the [workload]." [FM4]
>
> "…works much better if we have uhh help. And so uhh for example…post-docs are a great help…And it's very expensive to pay for post-docs. So funding towards postdocs would definitely help a lot…" [AM5]

> "The other sort of weakness I think in models is, I think they have a shortage in terms of capacity to actually develop models to affect decision that could benefit from modelling. And as a result we are often unable to develop models to help the decision-making process because we don't have the capacity to develop them. So decisions often get made a little bit more of a crude evaluation of the evidence" [GM4]

Improving training and education

Increased training and education for public health professions regarding the untapped potential of models was another theme that emerged. Frustration was expressed by both academic and government modellers that end-user do not necessarily understand what models are capable of doing and their untapped potential.

> "I think the, not all public health people are aware of the usefulness of modelling. Umm many still use a more statistical approach. Which is good for short term predictions, but to understanding the mechanisms, and the long-term predictions is not so effective. So having public health people, more aware of the usefulness of modelling would probably help." [AM3]
>
> "So typically there's sort of a waste of effort and resource because there isn't a clear understanding of how important the question is for the way a model is designed to answer the question. So you end up a lot of times

with models that might have been able to answer the question that the decision maker actually has in mind a lot better but in a way that's designed to be as general as possible. And we don't necessarily satisfy the question." [GM4]

"And usually I have this frustration over the years. At the beginning, I'm dealing with a group of people and they types of questions they say could be what, just tell me what's the usefulness of the model? Is it a model for most people, they just want one word, which could mean anything. They do not know the difference between statistic model, which is mainly data science versus computer model simulations versus economic model or [incomprehensible], some buzzword or some mathematical equation. And for most at the beginning, the modeller or modelling is one term. And without any subtlety and of course the challenge, useful or useless. So that is always a doubt." [GM2]

"So in more traditional infectious disease areas like airborne transmission, influenza and that kind of stuff, I think there's a greater understanding and appreciation of models and how they can be used for decision-making. So you look at vaccines and vaccination rate estimates and looking at coming up with R values for infectious diseases as the outbreak is occurring. I think that is well ingrained in the public health field. That anyone working in public health is familiar with those

> concepts and understands them. As soon as you get beyond the basic infectious disease models, and you get into the models that are describing new systems and using public health as a metric, you get into more current agent based models and so on, then you get into the problem of people haven't been trained in those areas both at the practitioner and at the resource, decision maker end." [FM5]

Building a Central Network

During infectious disease outbreaks, there is very little time to build connections and make models to determine how the outbreak might pan out. It was recommended during the interviews that a central body of modellers be established, that would be available in times of outbreaks. Mentioned by both an academic modellers and a government end-user about how a pre-established pool of modellers might be beneficial during infectious disease outbreaks to optimally tap into the skills of the researchers.

> "If there were some team of people who you could just, when there was an outbreak, you could sort of help guide them. Without having to worry about how to fund them and without having to take months of your own time to work on these problems. Probably you get a lot of bang for buck invested in that…But making it easier for academics, who are not required to do any work for public health…to make, to want to because there's a lot of support, if they do that...if I had a

> programmer who was always there, who I could ask to do that, maybe I would…" [AM4]
>
> "I'm not sure whether this may or may not work, but you know having linkages to modelling expertise around the country, certainly working on an ongoing bases, but tapping into them in a time of crisis and then saying..." [FE3]

This chapter outlined the characteristics of the key stakeholders interviewed in the further and further detailed what their knowledge was in building mathematical models, and their interactions and influence on public health policy. The chapter further went on to talk about the importance of established collaborative networks, some challenges that occur when building these relationships and how to improve these networks so that expertise, of both mathematical modellers and public health professionals could be better leveraged.

Analysis of Results: Complex Adaptive Systems

One of the common themes that emerged from both end-users and modellers who were working with public health, was the complexity of communication required between the different stakeholder groups to develop the models. Determining the right type of question to model, how to model it and how to improve and tweak the model once it's developed requires constant communication and collaboration. Even amongst the researchers who are not necessarily involved with public health professionals in determining the research question and type of model to develop, are nonetheless in constant communication and collaboration with other professionals, such as biologists, clinicians, virologists and sociologists that would be necessary to inputting in their models.

This necessity of functioning, networks and going back and forth between the different stakeholders in order to develop a functioning, applicable and accurate model can be understood using complexity theory. This theory, as it applies to social systems is useful in understanding the complexity of interactions between academic and government modellers as well as government and professional end-users in developing models that are most comprehensive, accurate and applicable to the challenges in public health. Different frameworks exist within the theory that can be used to observe and understand complexity in public administration and social sciences, and for the purposes of this discussion the complex systems adaptive diagram (CAS), similar to the one applied by Rhodes (2008) is used. The CAS framework (Figure 4) accommodates the interaction of independent, heterogeneous agents over time in a dynamic context (Rhodes, 2008). The framework identifies agents in a system that " act and interact in the pursuit of their individual or collective objectives, and to study how agent behaviour and the interdependencies among agents result in systemic outcomes". Furthermore it is able to interact novel incoming information, and feedback from outgoing results of the system.

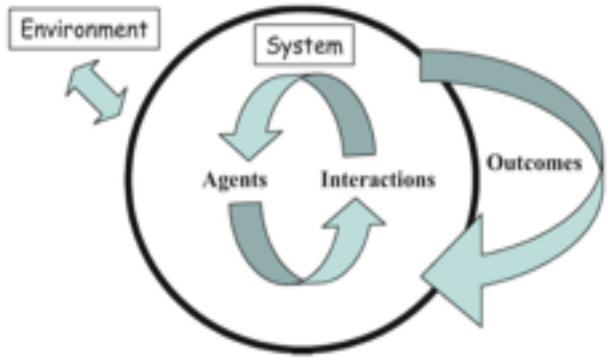

Figure 4: A schematic representation of the complex adaptive system (CAS). Components of CAS include the environment, system, agents, interactions and outcomes; adapted from Rhodes, 2008.

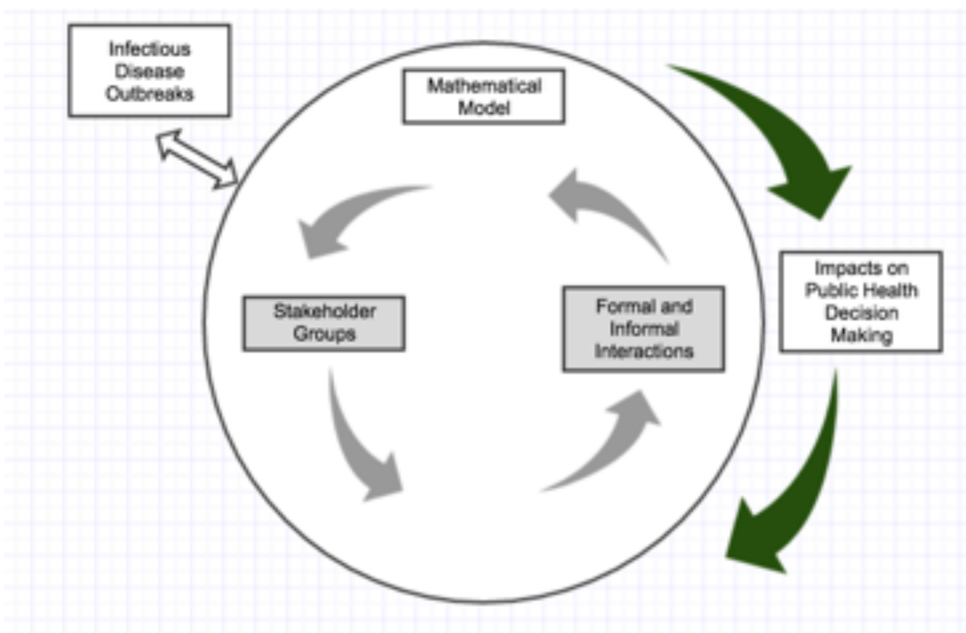

Figure 5: Complex adaptive system (CAS) applied to mathematical modelling for public health. Building mathematical models in response to infectious disease outbreaks involves interactions between different stakeholder groups. The eventual outcome is a mathematical model that has the potential to influence public health decisions.

The CAS framework acts as an analytical aid in studying the different components of this study. Following the diagram provided (Figure 4), the environment, which is the predominant input into the system, is the infectious disease outbreaks. It is the outbreak that stimulates the production of the system, development of mathematical models in reaction to the outbreak. The agents fell into four different stakeholder groups: academic modellers, government modellers, government end-users and practitioners and professionals who were also end-users of models. Outside of the key stakeholder groups mentioned are also biologists, virologists, clinicians, sociologists, behaviourists, and other experts who study collect data and study aspects of a specific infectious disease. The interaction between these professionals either through formal (meetings, conferences), or informal interactions results in the creation and input of a modelling question and a model. The outcome of these interactions, either a research question or modelling results, is then further used to refine the question or model in question.

The use of this framework allows for an analysis for how systems of developing mathematical models for infectious disease outbreak work. It is important in helping to recognize that development of models is not a solitary matter. A mathematician skilled with the ability to compute the dynamics of infectious disease outbreak isn't always equipped with knowledge of the knowledge of the most relevant public health issues that require modelling. And vice versa, public health professionals, might have questions, that can be answered using models after they have been refined. Furthermore, this frameworks aids in recognizing that the development and maintenance of models is a continuous and ongoing feat. Infectious disease outbreaks change over time. Interventions are put into place, the affected population changes their behaviour and therefore the system must be able to adapt to accommodate the changes that will occur (Figure 5). The nature of the agents and interactions themselves are heterogeneous.

CHAPTER FIVE: FINDINGS PART TWO

Mathematical models can be an important tool for public health decision makers in emerging infectious disease outbreaks. However, the reliance on predictions models make often depend on how the data used to generate them. In this chapter, the findings of perceptions related to data as well as of the impact of predictive models on end-users will be described. The chapter will address objective 3 and 4 of the study: to determine the perceptions of challenges associated with infectious disease data and to describe perceptions on the application and impact of predictive models for infectious disease. The findings are derived from the perceptions of four stakeholder groups: academic models (AM), government modellers (GM), government end-users (GEU) and practitioners and professionals who are also end-users of mathematical models (PEU). Within each objective several themes and sub-themes emerged. Each theme is derived from and therefore substantiated by the qualitative data collected from the key stakeholders in the study.

5.1 Challenges of Infectious Disease Data

The first part of the chapter will focus on data and the challenges associated with using infectious disease outbreak data in mathematical models. Data in a mathematical model are used for calibrating parameters in a model. It is with these parameters that the dynamics of a disease, such as how the disease might spread, how many people might be impacts, what the peak intensity of the outbreak might be, can be better understood. However many challenges exist with data, such as inaccuracy and unavailability that can present in difficulties when constructing a model using them. Themes that emerged when key stakeholders were interviewed about this topic were the challenges in data collection, the plight of poor data and Global and Canadian data collection systems.

Nature of Infectious Diseases

Infectious diseases lie on a spectrum that ranges from longitudinal to episodic. HIV is an example of an infectious disease that is longitudinal and chronic versus Zika, which is considered episodic and emergent. The nature of the infectious disease outbreak depends highly on these traits amongst others. Therefore collecting data for each type of disease, comes with its own challenges. For example, it can be difficult to collect data if a disease that is hard to detect, or has a long latent period. A government modeller spoke of his experience with HIV and how difficult it can be to collect data to gauge the extent of an HIV epidemic.

> "For example, for let's say using HIV as an example again. The time from new infection in a person of HIV to the time that person is diagnosed, could be very long. Could be several years, especially if the diagnosis is AIDS. That means it could be 10 years or longer compared to the time of infection of that person. Right now without the increase, testing again. There's a reason why a person needs to be tested. Could be soon, close to infection. Could be a few years after the infection. So whatever data that we observe are based on diagnosis of HIV, which does not reflect the trend of new infections going out in the population." [GM2]

For emerging infectious diseases, it is equally if not even more challenging to gather timely data. For example, taking a disease like Ebola or Zika, which might not have been studied extensively in the past, a further delay in data can be caused by the fact that not much is known about the disease. One end-user spoke of his experience with the current outbreak of Zika, and how more insight into the disease takes time to research and uncover. Thus, certain data need to be collected before models are able to use the data to more accurately predict the course of the infectious disease outbreak.

> "We haven't quantified the risk of male to female transmission because we still don't know a good enough understanding of the persistence of the Zika virus in semen." [GEU3]
>
> "You know we're slowly clarifying those sorts of data…" [GEU3]
>
> "Again, you know we're getting a better handle on that, so you know those parameters might become, umm more evident or at least we could get parameters that we could start considering using the mathematical models." [GEU3]
>
> "Now we've got more now than we had 6 months ago. And that fog-of-war will lift a bit as more time, more umm well resourced, well carried out studies occur. But it's a whole array of information." [GEU3]

Furthermore, it is even more difficult during an infectious disease outbreak, there are other priorities, such as clinical management of a disease during an outbreak, that place data collection as a secondary or tertiary priority.

> "...you were quite aware that the staff were over loaded and there were announcements coming out all the time that they had to focus. That they could not just focus on the volume of tests. They were limiting who was going to be giving testing and given priority." [GM1]
>
> "Uhh there was uhh, a lot of typing of cases that was ongoing at the beginning of the epidemic. Uh and then about 3 or 4 weeks into the epidemic, people uhh, the authorities decided that there would not be any typing anymore because we weren't in the pandemic. And umm, I think that was a missed opportunity because one thing that seems to be quite important in many diseases asymptomaticity." [AM5]

The data challenges associated with an epidemic are to be expected as there isn't time for data collection. Data collection during the time of outbreaks faces many unique challenges that when referring only to surveillance in non-epidemic times. However, problems with surveillance system are exemplified during outbreaks as the system is placed under increasing strain. Thus, a good surveillance systems are essential for collecting infectious disease outbreak data.

Dependability and Trustworthiness of Data Sources

Model developers use data from many different sources. Some of the more reputable sources mentioned repeatedly by the modellers interviewed were published data from peer reviewed journals or data released by provincial, federal or international public health data:

> "For Zika and Ebola, we rely on WHO or PAHO to release that data." [GM3]
>
> "...or any sort of published, umm, data in peer reviewed journals…" [GM3]
>
> "...published data…" [AM3]
>
> "But generally, we try to look for reputable websites. So WHO, PAHO… umm there's a lot of infectious disease modellers that will upload data onto GitHub, which is a shared sort of database resource, umm, that we may sometime download data from." [GM3]
>
> "...on Public Health Canada at the time…the weekly reports…" [AM3]
>
> "...data that I deal with are mostly time series of incidence, or mortality so that means so, weekly cases or daily cases of some infectious disease or deaths from infectious disease…" [AM4]
>
> "...for example for population, you need to look at, you know which population you looking at, you need to go there and find census data for

> that population. You need to parameterize your system for the age distribution of that population…" [AM2]

When probed about the trust in the data used, many expressed the concerns associated with it, but in light of no other available alternative, felt that this was the best data available for them to use.

Challenges in Data Collection

The inevitability of poor data

The challenges in data collection are a wide range. From being able to detect the presence of an infection through adequately sensitive tests, to the competency of the individual collecting the data to the system set up to feed data into organizations, each step in the data collection process holds some caveats. These limitations are reflected in the accuracy of the data collected and then in the precision of the predictions produced by the models that use that data. Thus with each step, it is only a necessary fact of data that no matter what is presented, it will never be a true reflection of an outbreak.

> "...my rule of thumb is that it will be inaccurate, uhh and is more indicative than really reflective of a true situation…" [AM5]

Systemic Challenges

The concerns expressed around systemic data collection from participants clustered around two major themes. First, the nature of the data collection systems and whether the surveillance systems in place, and the data variables collected give an adequate reflection of the nature of infectious disease outbreaks. A government end user and academic modeller commented on these concerns.

> "The nature of the surveillance systems, the way in which they are set up to receive inputs of data is fundamentally flawed" [GEU 3]
>
> "So there's a whole series of issues that means that when I look at reportable diseases, I mean I can see time trends and I can see how things change over time. But the real problem for me is, you know I have an incomplete, imperfect measure but at least if its imperfect for the same reasons over time, you know its sort of consistently imperfect and so I can still learn things from it" [GEU 3]
>
> "I mean I would love to have, you know the periodic opportunity to do more intensive collection in a community...So other types of systems, you know that you can't do, you can't deploy on a routine, day by day basis but would give you much better data that will allow you to understand, at least for that period of time within this population….But those are the types of data that I would prefer to have because they would be more comprehensive. They would give me a much better, broader, more nuanced picture of a given infectious disease." [GEU 3]

> "You know, it's the basis for the predictions. So in a statistical model, in a clinical prediction rule for pneumonia for example, if you only have 5 variables in your data set that you can look at. That's all you can use. But maybe those are not the best 5 variables." [AM6]

Second, the accuracy of the data collected is questionable. When looking at data collection at the cases level, two end users shared their experience of data collection. For example, when individuals collect case data as is the case in a hospital setting, nurses and other practitioners are given definitions by which to follow. So theoretically, data collection at the individual level should be consistent, provided that everybody is consistent in following the definitions.

> "Well, the data collected, I don't have difficulties with it because the definitions, as long as you follow the definitions. From the definitions, it says it's a health care associated infection, or a health care acquired infection. If everybody follows that definition, then I see no problems with the data. But everybody has to follow the same thing." [PEU2]

However, it can occur that unknowingly to the team, an individual is not collecting the data. This was the experience of one end-user who was involved in an outbreak data collection study as part of the CDC.

> "And I, we went out in teams and one time I went out with one person, and another time I went out with another person. And one of the times I noticed that one of the questions, wasn't, one of the questions in the questionnaire wasn't being asked….And I think it was a situation where she was embarrassed so she didn't do it. You know when you're calculating the data, that question is useless because some people ask it and one person didn't but didn't tell anybody she didn't ask it. So you know, there's a chance that data on that question would've been useful. It was an eye opener for me." [PEU4]

Therefore although data is important and necessary, because of the nature of data collection systems and the individuals who collect them, data is inherently flawed.

Furthermore, the actual infectious disease being examined can present difficulties in being able to collect data in a timely manner as well as the added weight that comes with outbreaks of infectious diseases, data collection is often set aside for more pressing clinical matters. As well, in Canada, there is a limited verification processes of the data that's fed from individual regional systems into the provincial database and then further into the federal data base. Each of the LHINS units in Ontario collects its own data, and by the time the data reaches the federal level, there isn't much that can be done to insure accuracy, reliability and validity of the data across the 14 individuals units.

These systemic challenges exist in part because changing the system is difficult and surveillance itself is very expensive. In the words of another user, data collection is expensive and improving the system requires more investment, which few are willing to do.

> "...the first thing I think to know about collecting data, is that everybody thinks that collecting data is really simple. But it's not. It's expensive and difficult. You want good surveillance programs that get you to answers to questions. You have to spend much more money on them than we think you have to spend. So the substantial piece in the absence of data is respective of the fact that we're just not willing to pay for it. I'm not saying that's wrong, it's all a question of your priorities but collecting data is... surveillance systems are one of those things in life, that are much more expensive than anybody thinks they ought to be. So people are not willing to spend money on them." [PEU1]

The Plight of Poor Data

Data that is imperfectly collected and not validated before being inputted into models to generate predictions can present a lot of problems. A case study was presented by an end-user and a modeller in regard to the 2009 pandemic influenza and how poor data gave way to ill-prepared systems and caused panic.

Early predictions of the 2009 models anticipated the influenza outbreak to start in Southeast Asia. These predictions were inaccurate and the pandemic actually started in Mexico. Preparations for mitigating the impact of the pandemic were based entirely on the results of the model. Two key stakeholders discuss how poor data resulted in those inaccurate predictions.

> "Uhh and therefore all those predictions about where it might occur, umm, because of the incidence of avian influenza, were totally wrong. Umm now I'm not saying that was a fault of mathematical modelling per se. Because it was in fact umm trying to use the best data." [PEU3]
>
> "Again, umm not saying those models were wrong except the data that were used for that were pretty, umm, limited because it was related to that pandemic back in 1918" [PEU3]
>
> "Which I felt in that case, I think that was in The Lancet, I may be able to dig that out, is I think that was poor modelling because the data that they used in terms of, the data that they used for the models was really, really problematic in my opinion" [PEU3]
>
> "So not saying that was the fault of modelling. On the other hand it was a downside of the use of the data for those models." [PEU3]

Once the pandemic was under way in 2009, poor data collection, once again caused panic when it shouldn't have.

> "The first cases in Mexico, umm and they were looking at sort of very high mortality rates. You could see if you were looking at the system that generated the data, that's exactly what you would expect. But that's not the question the models were looking for and so they tend to take the data and you plug it in without understanding the limitations of the data were. And so they came out very early with the comments of the mortality rates in Mexico and that was much higher that it was." [GM1]

Global and Canadian Data Collection Systems

Stakeholders commented that there are fewer community infectious disease outbreaks in Canada as compared to the rest of the world. Instead, models that have been created at the federal level often look at the impacts of global outbreaks on the Canadian population and this includes the importation of disease through travelling Canadians. Thus, these models rely on data released by other countries, many of whom have subpar surveillance systems. Using data systems from other countries to examine what the impact might be on Canadians can be challenging. Several examples discussed by key stakeholders focused on the importation of diseases such as Ebola and Zika from countries that don't have the best disease surveillance. Furthermore, modellers in Canada might be challenged to even obtain data from other parts of the world, making it more difficult for them to model the impacts on the Canadian population from an infectious disease outbreak occurring in a different part of the world. The challenge overseas in some countries remains improving the actual systems.

> "Data collection systems in Canada, surveillance systems are good. Better that other countries." [PEU2]
>
> "Looking at how could data be improved? It would be sort of better surveillance on the ground in these countries, but that's really difficult to do because a lot of times these countries are poor countries" [GM3]
>
> "...you were talking about data before, you were asking about this and one of the problems we have is, uhh there's a few labs in the world that have very good connections." [AM5]

The challenge for Canada, as expressed by key stakeholders, is being able to understand, connect and synthesize high volumes of data. The amount of public health data available can be overwhelming and knowing how to cohesively connect pieces of data so that it presents a reflection of what is happening remains a big challenge. This point does not necessarily apply for emerging infectious disease outbreaks, for which very little data might be available.

> "It's not that more data is needed, but rather better utilization and synthesis of data is needed" [PEU2]

> "And I think that's something that public health needs to continually work on. With more and more data being available to us and figure out, like I said, how to use it." [GEU1]

Data are necessary to understanding infectious disease outbreaks. However, they should be approached with caution as challenges in data collection can lead to inaccuracies in mathematical models, ultimately steering an outbreak response in the wrong direction. The next section discusses the fourth objective, the perspectives of modellers and end-users regarding the usefulness and impacts of models. This section will look at the Advantages and disadvantages of mathematical models, the concern surrounding overuse and overhype of models and the skepticism and caution of using models as has been expressed by both modellers and end-users.

5.2 Perception of Utilizing Infectious Disease Models

Understanding an Outbreak

Mathematical models are a valuable tool as was expressed repeatedly by participants in the study. Their ability to recreate scenarios, and help the understanding of infectious disease outbreaks, and repeatedly model epidemics to understand the nature of an outbreak was cited to be unparalleled when comparing to other tools that are available.

> "So I still think the, the primary value of, the primary value of modelling is not necessarily during an outbreaks, it's about helping and understand how things work." [PEU 1]

> "Like for example, is not even ethical so for example test an epidemic in a population. You can't just spread the disease in a population and try to collect data and see what happens and implement the intervention and test it. These are things that, that impossible to do and models can help you. Because you basically trying to say, what are the plausible scenarios and the different assumptions." [AM2]

> "And the model can do it easily, without going to these challenges. And even if you were to actually implement an epidemic in a population, regardless of ethical issues at this point. You would need to implement that epidemic, a million times to see what are the different possible outcomes, and that's again impossible. But in a model, you can actually

> simulate different scenarios, millions and millions of times and look at a wide variety of things that can happen." [AM2]

Mathematical models allow for an insight into the dynamics of outbreaks by incorporating data from different aspects of a disease such as its biological characteristics, clinical manifestations and transmissibility. Furthermore, they provide insight into what other sorts of data might be needed in order to better understand dynamics. These points were unanimously expressed by both mathematical modellers and end-users.

> "...but overall picture is that models can also give feedback to how you do those experiments better and potentially what kind of data is missing. And you go after a type of data that is missing to collect it." [AM2]

> "As a tool, mathematical models prove to be resourceful. They can be created relatively easily, and are cheaper to produce than other forms of scientific evidence might be." [AM5]

> "It's a cheap, uhh, it's a cheap device for making hypothesis and seeing what the consequence of hypothesis are of decisions...But yea, otherwise a cheap laboratory I would say. And you can do things that you can't do in real life." [AM5]

Still one stakeholder underlined the role that mathematical models play not just during infectious disease outbreaks, but prior to. Even though each outbreak is unique, models can be used to understand outbreaks that occurred in the past, to better understand outbreaks in the future. This again was also expressed by both researchers who build mathematical models as well as end-users of models.

> "If you don't understand what happened in the past, you've no hope of making any sense of the future. It doesn't mean that the work that you do on the 1918 flu is directly applicable to Ebola. Right? It..it, but uhh if you figure out that certain types of models have enabled you to explain these epidemics that occur in the past, then you have a great deal more confidence in using the same type of methodology for, for other diseases." [AM4]
>
> "It gives you a kind of a nice explanation for why the first cities in North America, were the first cities in North America. Ok? That's cool but it was retrospective, okay? Now that doesn't mean it's not useful right? Because it's a piece of understanding. You know, it added to the evidence about aircraft travel being important in the transmission of influenza. And since we're gonna have another influenza pandemic, it's useful in thinking about umm what, you know, faced with the beginning of a pandemic who knows where." [PEU 1]

Uncertainties, Ranges, Confidence Intervals

The value of models was noted to not be in absolute predictions, but rather in the uncertainties, the ranges and confidence intervals it provided for a given outbreak.

> "Even the best model is going to have umm you know confidence intervals around those estimates and I think that's really where the value lies. Because it gives us a range of possibilities that we can plan for and I think that's a useful take home and I think that public health is really starting to better understand that really it's being able to put bookends on that uncertainty, in terms of planning purposes." [AM1]
>
> "You know you'd want to be prepared if that turns out to be right, but with other parameters as well." [GEU 4]
>
> "I guess what I'm saying, sometimes it's not the models, it's the estimates that becomes more important" [GM 1]
>
> "I think the, the most important factor is to have a range, range of options. So like in the Ebola case, you give a range of minimum and maximum values, contact rates. So you can make predictions, in a range of values." [AM3]
>
> "The intent there is to capture the range of uncertainties and variability in systems and models. So that the answer is not in a fixed number but rather a range of possible numbers that are [held] by certain bounds." [FM5]

This allowed for a better understanding of an outbreak might pan out, and allowing for the recognition that mathematical models cannot be exact in their predictions, because it is unable to account for every single variable in an outbreak.

Having a range presented allows for the preparation of several different possible scenarios and less shock if a certain prediction doesn't pan out as it was originally thought to.

Emerging Infectious Disease Outbreaks

Mathematical models can take anywhere from days to weeks to months to years to construct and validate. However, in situations where an unanticipated, unprecedented infectious disease outbreak is threatening to turn into a pandemic, the lack of time and limited data (as discussed elsewhere) makes it incredibly difficult to create mathematical models that can accurately predict what the nature of the outbreak might be. However, even in these tight situations, mathematical models present with some advantages.

Two case studies were presented by different stakeholders that illustrate how predictive models, that were not be accurate, were ultimately beneficial to receding the outbreak. The first case was the pandemic influenza of 2009. As the end-user pointed out, pandemics have occurred throughout human history. Yet, anticipating, predicting the course of an epidemic is unprecedented, as it is only not that mathematical models can be used as tools to do so.

> "Pandemics happened. Nobody had planned the development of pandemic vaccine, in any kind of proactive way. This is totally new, and therefore we didn't have anything to go off. So the models were it to be honest." [PEU3]

As is usually the case with newly emerging epidemics, there is limited information available as each outbreak or epidemic has unique characteristics: geography, biological pathogen and demographics of the population. Thus, in the case of the 2009 pandemic influenza, the preparation for the responses exclusively occurred as a result of the predictions of models.

> "But to be honest in terms of the, umm, being able to develop pandemic preparedness plans, i.e., umm both surveillance, then immediate response, for example, isolation, quarantine. That was developed really as a direct result of those models, direct result of those models." [PEU3]

Bringing attention to the outbreak

The second case study was of the 2014 Ebola Outbreak in West Africa. The release of models by several groups and the unprecedented projection of unexpectedly high number of cases brought attention of the growing problem in West Africa to the rest of the world. The release of the models first prompted media personnel to report on the outrageous findings:

> "I reported on the first one that I mentioned that I think was in *Eurosurveillance* and I'm definitely sure that I reported on the CDC one. Couldn't have the CDC saying that 1.4 people might be infected with Ebola and not cover it." [PEU 4]

The prediction of the models, in part because of their outrageously high number, which were later determined to be inaccurate, news proving to be advantageous .

Mathematical models attempting to predict the course of a new emerging infectious disease outbreak, though limited in their ability to accurately predict the course of an outbreak, can nonetheless be highly valuable in bringing attention to the problem, which can play a huge role in mobilizing resources. Two end-users commented on the value that models released by the CDC and Eurosurveillance, though highly controversial in their unprecedented predictions, nonetheless were valuable for the attention they brought to the growing problem at hand.

> "And then in Ebola, umm again models that produced the estimates of possible cases of Ebola. Yeah I mean, now we know they're way off. Now I'm not saying that was really problematic to be honest, because it got people's attention. Umm and I don't think it made a huge amount of difference" [PEU 3]

> "There are times when they are really useful. Even though they were all wrong, it was, the models in the fall of 2014 that were projecting out the Ebola outbreak as you might, might know, were incredibly useful for getting people's attention the problem, and the scale of the problem. Um and explaining to people a concept that they might have no way of otherwise understanding. That you know, you're gonna get an exponential

> growth and then we're all going to hell on a handout you know. I mean that was useful but they were all wrong." [Ref 5]

In the case of one end-user, the release of the mathematical models brought attention to the problem for them, and prompted them to go to West Africa and help out the outbreak.

> "I went to Liberia in part because of the CDC mathematical modelling. It wasn't, you know from my perspective, you could, you could see what was happening to the outbreak. So I'm not sure the mathematical model that...the CDC predicts mathematical model provided a mechanism for getting people to pay attention to the outbreak. So, and so the response to it, and I part of the response, was, it was in some ways related to mathematical model." [PEU2]

Disadvantages - Predicting Emerging Infectious Disease Outbreaks

Although all key stakeholder saw models as being a positive and useful tool for infectious disease outbreaks, there was a lot of skepticism associated with them as well. This was usually in reference to situations in which models were utilized when they should not have been. Mathematical models for emerging infectious diseases were viewed as being unreliable, whereas models that sought to compare interventions, or attempt to understand the dynamics of a well established and understood disease such as HIV were seen as being more useful. This section will look at the disadvantages with inaccurate predictions and the overuse and overhype of mathematical models

The difficulties of prediction

Though overall considered a very valuable tool, mathematical models present many disadvantages depending on what they are trying to model. Due to the complexity of infectious disease outbreak, predicting the start or course of an outbreak is difficult. It was expressed that during emerging infectious disease outbreaks, the use of models presented quite some limitations, especially by the end-users.

It was determined in the earlier section that models are most advantageous when released in advance or in the early stages of an epidemic. However, as stakeholders noted, it is difficult to anticipate what an outbreak might look like and what factors should be modelled. For example, in the 2009 pandemic, models had predicted that the pandemic would start in South Asia and thus the focus of all the preparations was in the regions that were predicted to be most affected. In a surprising turn of events, the pandemic actually started in Mexico, something that models had failed to foresee and predict, which played a role in exacerbating the pandemic. Therefore, preparations that occur as a direct result of the models released can be a waste of resources and funds if those predictions fail to come through.

> "Umm out in Mexico no one expected that. No one ever modelled possibilities of even starting it in North or Central America at all. And therefore it led to the pandemic" [PEU 3]
>
> "And that was what all the plans were laid on and all our exercises such as countries in Southeast Asia. Totally off the wall. It didn't actually happen that way at all." [PEU 3]

Overplay of Mathematical models

One of the dangers that comes with not having enough education about the uncertainties about mathematical models is that they can be overused and overhyped. Over reliance on models can lead to uninformed decisions if not supplemented by other pieces of evidence. Significant overhype can also lead to a complete disillusionment and lack of trust with models if the predictions made fail to materialize. Specific examples were provided by key stakeholders, both government modellers and end-user, who noted that the visual simplification of a model presented, made the model very appealing to policy makers. The appeal of the simplification, without the consideration of the assumptions that went into making the model, led to an over-reliance on models as was expressed by key stakeholders. These examples specifically referred to the UK where models are required to be part of every grant application.

> "I think that politicians in particular were quite taken with the models and when they didn't really sort of as it were quote 'come true" and this is a milder scenario than what they were suggesting I think…some credibility was lost and it's also might have focused experts in that domain in a not helpful way perhaps." [GEU2]
>
> "Umm but because, I actually think it's partly because they're visual, which is usually incredible, which I like because policy makers are much better at a visual, a map, projections and things remain to a well played scenario but because they look so real, folks believe them…that reality as opposed to you know, it may you know, it's probably not going to happen." [GEU2]
>
> "...is that the models that can jump on the bandwagon…" [PEU3]
>
> "...then try to produce models where in fact they shouldn't be produced…"[PEU3] "...However interesting the issue was, it should've have been so…" [PEU3]
>
> "So that's the danger when people take the model, in a sense too seriously." [AM3]

Overuse was cited as a danger of using models, in both academia, government and the media. This was an issue that seemed to have in the UK.

> "And I think, at least in some corners in the media, there's more credence put on models than is necessary useful I think" [PEU4]
>
> "...and so the authors of this type of paper, there's, every single public health crisis now well there's groups of people, a lot are in the UK, publish papers in Science or nature, where they make that type of thing" [GM2]

The overhype and overuse is dangerous because not every situation is conducive to being modelled appropriately. Furthermore models are not always accurate and when predictions fail to follow through with their goal. When models fail to follow through, there is a significant lost of interest, funding of them.

> "...what happened then in 2009 when the pandemic was happened but was nowhere near severe as what had been predicted by some. There was essentially a disillusion with the whole concept of prediction." [GEU2]
>
> "...that malaria post Ebola, I think illustrates there are times when because research dollars are available to use in things such as Ebola and there's a lot of attention on something like Ebola [PEU3]

This leads into the skepticism and caution expressed by both modellers and end-users in using the results of mathematical models not as a definite result, but rather as a tool to be used in conjunction with other evidence.

Skepticism and Caution in Using Mathematical Models

Whether models or expert opinion should be used received a mix response from the key stakeholders. Predictably, modellers felt more strongly about using models for policy decisions, as opposed to crude calculations. Whereas end-users, though not dismissing the value that mathematical models add for infectious disease outbreaks, were more likely to cite using experience and common sense to make decisions and policies regarding infectious disease models. Skepticism regarding predicting emerging outbreaks was also expressed by modellers.

> "…I dislike this type of work actually. I would never…umm, for me the predictions of models…if it's predicting numbers of people infected, uhh that should not really be the case. I think the strength of models, is to evaluate uhh, scenarios as I was saying." [AM5]
>
> "but again this goes back to how much confidence do I have in this? You don't want to take a particular action or response based on poor data or poor model. So you have to be confident in what you're getting, so you can make the right decisions." [GEU 1]
>
> "So I, again, the circumstances in which you make policy decisions based on mathematical modelling I think are, in, in real time at the moment are limited." [PEU 1]

> "statistic is just a tool, and mathematically really people should use more of their judgement and using their expertise and using statistical, using statistics as help them to make decisions. So I'll say I don't know. It should not play a big role in terms of policy, but it just a tool for people." [GM5]

> "Umm well you could plan around the worst case scenario, you could plan around the best case scenario. You could plan around the model predictions. You could, uhh, you could just make sure that you have capacity for a bunch of different things. So you don't plan for any particular scenario. You could plan so that, you know you're able to respond to whatever. You can build capacity and you can then scale up or scale down." [GEU4]

Being prepared with or without models was also cited by professionals at the hospital level.

> "Well, beforehand a lot of preparation goes into, into that. Like we had a, we would have prepared for a pandemic influenza. And yes we would've had a lot of, umm guidelines that we would've had to follow…" [PEU 2]

> "...we would have some guidelines that we would have to follow like, [who was admitted], etc., what to look for and, umm but we didn't actually have

> any of those patients to actually put it in place but yes, we had a lot of planning…" [PEU2]
>
> "In the hospital, you would have your own baseline, based on the number of beds you have. And you'll be, because you're noting it all the time, you can see if there's a change right? You can see and then you know what your baseline is and then you say: Hey! Something is happening here." [PEU2]

The preference of end-users to use expert opinion in some cases, was expressed by a modeller who felt that models should play a bigger role.

> "I guess you could say I've become a little more skeptical over the years. So first, when I first began, I assumed that it was just a matter of time before models would be used more and people would understand a) what the limitations with models are and b) you know how what sort of questions can they answer, it would organically occur. But that really hasn't happened as has been has sort of my experience over the years. Pretty much became [information] as far as I can tell." [GM4]

Therefore this dynamic between modellers and end-users about the importance of mathematical models, and finding a balance between overuse and underuse due to skepticism is something that still needs to be resolved. Though widely agreed that mathematical models are a necessary tool in the cases of infectious disease outbreaks, distrust amongst end users was expressed. Their limitations were recognized.

> "I don't think, I mean it depends. I think, I mean I personally am not that big fan of models." [PEU 4]
>
> "I'm not honestly a fan of predictive mathematical modelling" [PEU 1]

The necessity of some predictions was questioned, and whether common sense could just as well predict the kinds of predictions predictive models were likely to make. One end-user pointed out that no matter what predictions the models released, the hospital and the community should nonetheless be prepared, bringing into question whether the predictions would affect anything at all. These skeptic concerns were brought forth by end-users of models, those with no mathematical model experience but more clinical and public health expertise.

> "You know it's a, that you wouldn't do already. Ok so, you know yea we might get measles in Toronto. So we're gonna tell people if they go to Disney world to get vaccinated before they go. Well, I can figure that out without a model." [PEU1]
>
> "...perhaps people didn't depend on models and they were just worried it was going to spread in our country" [PEU3]
>
> "therefore it doesn't matter what the model says" [PEU3]

> "it's less of a concern because you already sort of know that there's a huge magnitude of illness in those parts of the world that are affected" [GEU3]
>
> "If [name] and his group, sort of the BlueDot, are quantifying it a bit better, great, but we sort of know, you know, it's a huge impact on those countries." [GEU3]
>
> "Now I already know there's a huge amount of cases down there." [GEU3]
>
> "You know we're throwing around millions. Its at that level." [GEU3]
>
> "So the quantification done by that work doesn't really alter too much, you know how I perceive or what I think about in terms of the risk here in Ontario, what we need to do in Ontario." [GEU3]

Risk communication: What are mathematical models saying?

The misinterpretation of models, as a result of poor communication by model-developers was perceived to be an emerging theme in this study. End-users and modellers expressed that the risks of not being able to appropriately communication the assumptions, caveats and ranges that a model presents, usually resulted in misinterpretation and misuse or results. Lack of risk communication makes a model into a "black box" that makes it difficult for end-users, and indeed other modellers, to understand and trust.

> "The modellers aren't the best at risk communication" [PEU 3]
>
> "But of course there's a lot of modellers who are not as good as that [explaining models]. And explaining what the models can or cannot do for policy makers as" [GEU 2]
>
> "And also modelling to many people, especially if we do not present well, it either becomes a black box" [GM2]

Another communication challenge is the misconception by end-users about what models should optimally be used for. Although the end-users interviewed in the study had a good understanding of the nuances and assumptions that accompany modelling results, several modellers raised the concern that many end-users that they have previously worked with did not. Part of this challenges arises in part from end-users who believe that models should be able to provide absolute certain values as results, as opposed to a range of possibilities.

> "Most people who want to use models, want to have nice clean numbers that they can use. They're not comfortable with having the distribution values that say the answer could be anywhere from here to here. Umm and there's a 95% confidence interval here. They want to have a number and that's all they want." [FM3]

This preconceived notion can also result in risk communication difficulties.

Another challenge comes when end-users such as policy makers are asked to communicate about the model to other stakeholders, such as the media. The end-users have to be able to understand the model completely, the caveats and the assumptions, and be able to communicate about the risks to other groups, when needed.

> "...just means as a risk communicator, you, you do have to have some understanding of models…" [PEU 3]
>
> "...if a reporter says ok what about results of this particular study, then you have to have a sufficient understanding of what the modelling is about to be then able to respond to that…" [PEU 3]
>
> "Umm because in the heat of the moment, it could blindside you if you don't have a sense of understanding." [PEU 3]
>
> "Especially that modellers are at least aware of the fact that a policy makers, public health physician, risk communications are gonna be put on the spot if that kind of information is released without a heads up, without some kind of discussion ahead of time" [PEU 3]
>
> "Because you do not policy makers blindsided by result of models, because then they, policy makers then have to deal with the responsibility or politicians for that matter have to respond to." [PEU 3]

Miscommunication to the end-user and then further miscommunication to the media can place the key stakeholders under intense scrutiny. One academic modeller empathized with public health officials who received bad press from the media, recognizing that translating evidence, such as modelling results, into policy isn't as clear cut as it seems to be. Others recognized that the scrutiny can be reduced as long as the outcomes of the model are communicated clearly.

> "So I think people are taking that into account but, as a matter of policy and just the politics it doesn't come out as neatly as it should be. And at least for the purpose of the public health people, I mean they get a bad press for the wrong reasons I believe." [AM3]
>
> "So I think as long as you're able to explain things at the outset, I think modelling could be quite useful." [GEU2]

Finally, it was repeatedly expressed that communicating effectively and clearly about the uncertainties clearly about the models is still an area that requires some work.

> "There's still some work to be done in terms of how to present that uncertainty." [AM 6]
>
> "The modellers aren't the best at risk communication" [PEU 6]
>
> "Umm and our lack of ability to really communicate the challenges with those kind of models" [PEU 6]

"And secondly, umm the numbers that counted as possible outcomes of pandemic, just used the upper limits that were predicted and created huge, huge concern" [PEU 6]

CHAPTER SIX: DISCUSSION

The purpose of this study is to understand the perceptions of mathematical modellers and end-users in planning, producing, and applying predictive infectious disease models. The findings of this study can aid mathematical modellers as well government, hospitals, and agencies end-users to share common challenges and to discuss the potential of applying mathematical models in outbreaks. This study was divided into four objectives, the findings of which are presented in detail in chapters four and five. This chapter discusses the insights and significance of the results as they relate to the current literature as well as recommendations and opportunities for mathematicians, public health professionals for better integration of mathematical modelling evidence into public health decisions.

6.1 Summary of Findings Part One

Part one of this study addresses the first two objectives: to summarize the experience and perceptions of key stakeholders using stakeholder analysis methodology and to identify the role of collaborative networks between mathematical modellers and end-users.

Stakeholder Analysis

The results of the stakeholder analysis presented in chapter four provides an overview of the issues that mathematical modellers and end-users face, and how stakeholders and groups intersect with the issues presented. By recognizing who has a stake in which problems, stakeholder groups can be brought together to implement pragmatic solutions and ultimately improve the application of infectious disease modelling in public health policy.

Tables 4-11 summarize the key characteristics of each stakeholder groups as well as the influence and key recommendations. Figure 3 captures some of the key strategies recommended by stakeholders and the interrelatedness of the issues between the different stakeholder groups. For example academic and government modellers and professional end-users groups all noted the importance of better educating end-users on the applications and process of developing mathematical models for infectious disease outbreaks. Academic modellers and government end-users also brought up the importance of having centralized spaces in which modellers and end-users could connect.

Collaborative Networks between Modellers and End-Users

The second objective of the study was to identify the role of collaborative networks between mathematical modellers and end-users. All stakeholders alluded to the importance of having collaborative networks. Almost all end-users interviewed knew or had previously worked with a mathematical modeller. One end user, an infection control practitioner, was solely a consumer of surveillance models released by PHO and never collaborated or interacted with mathematicians.

Some academic modellers commented on the well connected modelling community in Canada, although the challenges were also recognized. Academic and government stakeholders recognized that their different priorities led to some misunderstandings and difficulties in working with the other group. Government workers also pointed to turnover of personnel as contributing to difficulties in establishing and working with a team in the long-term. Furthermore, modellers felt that recently graduated modellers entering the field could be better integrated, noting that it can be difficult at the start of a career to have the experience and trust of their peers for collaborative projects. The importance of communication was almost unanimously agreed on by modellers and public health end-users. This was considered essential for a variety of reasons including the identification of research questions.

Many public health end-users and mathematical modellers who worked together to develop models of infectious disease spread, had spent years and decades building a relationship of trust. End-users who were part of these networks noted the importance of being able to trust the work of a mathematician, since they, themselves, have limited understanding of developing models. They were less likely to question the results of a model if it had been developed, or verified by one of their trusted peers. Stakeholders identified that developing a model was an iterative process, not an isolated one and required communication between the model developers and end-users. The complexity of the interactions and relationships necessary for model development was analyzed using a complex adaptive systems framework, adapted from Rhodes (2008).

6.2 Summary of Findings: Part Two

The second part of this chapter discusses the major findings of the third and fourth objectives of the study: to determine the perceptions of challenges associated with infectious disease data and to describe perceptions on the application and impact of predictive models.

Challenges with Infectious Disease Data

Infectious disease data can help a mathematical model to parameterize to the outbreak it is investigating. The majority of stakeholders interviewed recognize that infectious disease data collected have inherent limitations, such as human error, but accept it as an inevitable aspect of the data collection process. Limitations also occur because of the nature of infectious diseases themselves. It can take up to twenty years to collect data on diseases with long incubation periods such as HIV/AIDS. It can also be difficult to simultaneously track and collect data on infectious diseases with a short incubation period, such as influenza. Modellers are aware of the possible imperfections of the data released by government agencies such as PHO and PHAC and the possible impacts it has on modelling results, but consider alternative sources of data to be even less reliable. Modellers unanimously preferred to use public health data that was publicly available rather than seek for data from sources that required permission to access, citing that there are less bureaucratic hurdles using publicly available data for modelling studies.

From the perspective of one end-user interviewed at the provincial level, the data collection system itself, at the regional and provincial levels isn't set up to accurately reflect what epidemics, or infectious diseases are actually occurring in the population. Though for the most part, stakeholders did agree that the amount of infectious disease and public health data available in Canada is sufficient. In fact, modellers described that their expectation is that the volume of data is only going to continue to grow. Their main concern for the future was being able to manage and extract meaningful information about infectious diseases and health. All stakeholders concurred that a major challenge with data is going to be able to manage the sheer volume and extract from it the relevant information needed to detect, and/or predict infectious disease outbreaks.

Integrating mathematical modelling into public health

The fourth and final objective of the study is to describe end-user perceptions on the application and impact of predictive models for infectious disease. All stakeholders had a positive outlook on mathematical models, believing that they provided valuable input in understanding outbreaks, presenting uncertainties, ranges, and confidence intervals. Models can be applied to the specific outbreak occurring to synthesize the best available data, compare control strategies, and identify important areas of uncertainty that may present and provide background for economic evaluations. Stakeholder commented that models are relatively easier, and more realistic to generate and maintain as compared to other forms of data collection studies such as randomized control trials.

The perspectives of predictive models were not as favourable. Over-predictions often led to over-use and waste or resources and under-prediction led to lack of preparedness for an oncoming epidemic. Predictive models have difficulties integrating the ongoing interventions. Therefore the public health professionals raised concerns regarding using models as a means of decision-making tool for policy. Academic modellers viewed real value in attaining deep understanding of models, rather than prediction. Although over-prediction can result in a waste of resources, without predictive modelling epidemic such as the 2014 Ebola outbreak, the 2009 influenza outbreak would not have received as much attention, and therefore funding and resources, necessary to mitigate their potential impacts.

When stakeholders were asked whether predictive models should be used to influence policy, most stakeholders agreed that models are only a part of how decisions in public health are made. Other types of evidence and expertise also has to be taken into account in order for informed decisions to be made. Stakeholders recognized that models presented practical limitations such as their timeliness, a range of possibilities rather than a definitive answer, making it difficult to adopt into a feasible, and practical policy with immediate applications to the outbreak at hand. Furthermore, since policy makers, decision-makers don't always have the mathematical background required to understand, and critique models, the range of possibilities that a model provides can be a daunting task to interpret. If the translation of modelling results are not communicated properly, it result of poor risk communication, and decisions could be poor and not appropriate for the epidemic. Despite some of the challenges with predictive modelling, they are still considered a productive and useful tool and should be better integrated within Public Health.

6.3 Bringing together collaborative networks

The most active group in Canada currently working to bridge the gap between public health policy and mathematical modelling is the Pan-Inform group, based out of York University in Ontario. The group hosts biannual workshops to bring together the disciplines. As discussed in chapter two under *The Canadian Context,* the fourth biannual workshop took place in October of 2014 where key stakeholders were able to come together and determine that there was a necessity to establish a communities of practice and develop a common vocabulary document to better facilitate the communication between the two groups (Moghadas et al., 2009; Moghadas et al., 2015). The fifth biannual workshop took place in October 2016 at York University and had a similar aim to further the collaboration between modellers and public health professionals in order to better integrate and apply models for public health problems. However the sparse occurrences of these workshop, though a great platform for stakeholders to physically meet and discuss current issues, might not be enough for the sustained development of relationships between groups.

A second platform that aims to bring together modellers and end-users is the group Modelling for Public Health (mod4PH). Based on LinkedIn, an online professional, employment-oriented social networking platform, the group started in January 2016. It provides an opportunity to exchange ideas and address challenges in respective practices to bridge gaps in knowledge, allowing professionals to gain insight into another field, build networks, and develop resources that will be beneficial to public health. However, since the inception of the forum only 117 members have joined, most of whom have never been active. Furthermore, although there were some fruitful discussions that were started and facilitated by a knowledge translation professional in the group to six months after initiation, only a few people ever replied and the group has been relatively dormant since May 2016.

There could be several reasons for the limited activity on the account. The group has only one moderator. By increasing the number of moderators in a group, more discussions can potentially be initiated. Since the inception of the group, there has not been any infectious disease outbreak that might require instant communication. However, it is important to consider that the relationships between modellers and end-users should be built during the off-times so that they can be maximally leveraged during times of crisis. It requires time and commitment to participate in discussions, something that many professionals might not have to spare. Thus even having a mode of communication, such as a blog or podcast, that does not require active participating can be beneficial in connecting different stakeholders and being better prepared during times of crisis.

6.4 Surveillance, data and the application of mathematical models

The literature argues that surveillance is key but ongoing data collection is essential and the best weapon available to avert epidemics (Choi, 2012; Hay et al., 2013; Buczak et al., 2012). Therefore, it is important to maintain a state of high alert and assure that the data collected remains relevant and can be used by a variety of stakeholder including the modellers. With the advent of big data discussion there is a recognition that data collection is key for a variety of stakeholder perspectives. This trend does assist modellers because there is further investment in collection and accuracy.

In Ontario, infectious disease data is collected at the hospital level by physicians, nurses, infection control practitioners. These data, are sent back to government agencies, are then aggregated and released to the various audiences through reports distributed periodically. However there challenges in the traditional public health data collected from government which impact the accuracy and integrity of the data. The actionable and detailed plan laid out by PHO, discussed in chapter 2 is reassurance that the provincial agency considers infectious disease data collection and surveillance systems to be of priority to the agency (Ontario Agency for Health Protection and Promotion, 2014). The plan laid out to better communicate data and develop new tools and reports to analyze data can be beneficial for mathematical modellers. PHO recognizes that it may be necessary to expand its internal capacity and incorporate professionals from other fields such as computers sciences and health informatics to be able to implement some of these tools. It does not however specifically refer to the hiring and integration of mathematicians.

The challenges of traditional surveillance systems including reporting delays, inconsistent population coverage and poor sensitivity to detect emerging diseases are addressed by Brownstein et al. (2010). In an effort to supplement the gaps in current public health data collection, the authors recommend that the integration of new and traditional approaches to surveillance might be the most effective strategy for surveillance of diseases like influenza and other emerging diseases (Brownstein et al., 2010). However, the PHO surveillance report does not specifically indicate in either priorities or strategies, an intention to integrate new forms of data such as participatory data, which includes data from online sources such as Google Flu, Health Map or other platforms which collect data from social media sites.

A big data strategy would potentially incorporate current existing forms of data such as reportable and emerging infectious disease data, laboratory data, and participatory data, as described above. The key opportunity in a meaningful big data strategy is the identification of potential risk. Although as the data and data sources increase so does number of false alarms for outbreaks. Therefore being able to extract useful, reliable information from the daunting number of sources and then analyzing it with advanced computing methods, new statistical tools and interdisciplinary teams becomes very important (Obereyer, 2016). The sheer volume of the data can be overwhelming as though but if these challenges can be effectively managed, and false or irrelevant data is minimized, the potential for big data in the identification of disease trends, and origin of outbreaks is rewarding (Khoury and Ioannidis, 2014). Data is an issue both before an outbreak and during an outbreak and therefore it is important to address these challenges with infectious disease data.

All stakeholders agree infectious disease modelling is invaluable, but many recognized that predicting the scope and depth of an infectious disease outbreak is complicated. Key stakeholder groups were generally skeptical of applying mathematical modelling forecasts for outbreak planning. This view has been agreed upon in literature by authors such as Metcalf et al. (2015), who view the true value of models as being able to compare interventions, or project numerous scenarios rather than predicting the course of a novel outbreak. Increased skepticism by end-users especially was due to modelling studies using unrealistic assumptions and scenarios. As Moghadas et al. (2009) notes, they do not necessarily confront the political reality that must also be taken into account and thus their actual impacts on public health decision-making can be limiting. Therefore although models are important for the guidance of public health, they may also raise more questions for policymakers (Moghadas et al., 2009).

Models are an excellent way of providing recommendations for a public health professional, and as a platform for discussing the issue at hand as opposed to making decisions in pandemic situations. Overall, despite modelling being an important tool for public health, there are still existing gaps for its integration within public health decision-making. There are very few descriptive qualitative studies to date that examine the perceptions of different key stakeholder groups and therefore this study provides valuable insight into the perceptions of stakeholder groups regarding the challenges and possible methods to overcome these challenges. By doing so, the existing gap in integrating mathematical modelling within public health can be decreased.

CHAPTER SEVEN: CONCLUSION AND RECOMMENDATIONS

In conclusion the findings of this study identify and organize important insights and recommendations from key stakeholders required to optimize the utilization of infectious disease mathematical models in public health decision-making. The findings confirm that infectious disease modelling is important. Models that are most applicable to public health problems often go through iterative collaborations between end-users and modellers in order to better understand the problems and how a model can be best applied to it. Without an established trust, it can be difficult for modellers to actively work with end-users and therefore why it is difficult for newer modellers entering the field. The findings also suggest that there are growing challenges when it comes to the collection and interpretation of sources of infectious disease data and that mathematical models are valuable when used for understanding infectious disease outbreaks and/or interventions, rather than projecting the course of a specific outbreak.

Canada has the capacity and the technology for the development of advanced, sophisticated mathematical models as well as a strong public health infrastructure. However the integration of these two fields is not yet maximized. Despite the advancements in public health to reduce the number and impacts of infectious disease outbreaks, the number of outbreaks have been increasing and are projected to continue to do so (King et al.2006; Morens et al., 2004; Woolhouse et al., 2011). This is in part due to modern factors that facilitate the emergence of spread of infectious diseases. Important decisions must be made during infectious disease outbreaks and models provide an excellent way to systematically synthesize evidence to understand the disease process and the ability of models to provide visual representation of how outbreaks can spread and impact a population makes them an invaluable tool in the public health tool box.

As a result of increasingly sophisticated software tools, mathematical models have advanced over the years — from simple, classic, compartmental SIR models, to complex, advanced individual agent based models, which are able to model outbreaks with more precision. The trend for the future is for increases in the amount and type of data that will be available for mathematicians. Therefore studying the impact of models on public health policy is an important undertaking.

Recommendations

Canada is a forefront in its ability to develop models, however the findings illustrate that there are still gaps between public health decision-making for infectious disease outbreaks and the integration of mathematical models that can be used to make them. These gaps span across the collaborative process, knowledge translation and education for students and professionals. Therefore this study has implications across three important areas — education, practice and research as listed below.

Education

Develop online educational modules to educate professionals about the complexities and relevance of mathematical models

End-users who have worked in the public health field for a number of years aren't always aware of the process and time involved in building mathematical models as well as the types of questions that models are best suited to answer. Without having any experience building the model, there can be unrealistic expectations of what to expect from the model. Developing online modules that can be easily dispensed to end-users across the country can help end-users to gauge how to better integrate and apply models within their public health practice.

Develop an online transdisciplinary course that targets students at the undergraduate and graduate levels about the [overlap] between modelling and public health

A transdisciplinary course at the undergraduate level can help create interest among students in emerging infectious disease outbreaks and the role of modelling in managing and understanding them to pursue this type of work. The target group for this might be laboratory students, mathematics students or allied health profession students. A course at the master's level could have more practical applications for the professional or research roles. Students can thus be better prepared to in their professional roles to integrate and apply models, or in their research roles to build models applicable to public health infectious disease crisis.

Increase the number of educational programs for knowledge translation professionals.

There is a gap of knowledge between how modellers perceive their projects can be used and how public health professional perceive what models can answer. By having more professionals that understand both realms, the current gap in knowledge and utilization of infectious disease mathematical models in public health decision-making can be bridged. Knowledge translation professionals can be key in building platforms that engage modellers and end-users together from around the country.

Practice

Establish an emergency response team consisting of modellers and public health professionals to collaborate during infectious disease outbreaks

During infectious disease outbreaks, time is of the essence. Therefore by having a team already in place designated to handle emerging outbreaks can prove to be beneficial. The recommendation is that a core team comprising of public health professionals, researchers, mathematicians, statisticians be established. Then, an advisory board consisting of academic researchers should be created. This board can offer technical advice during emergencies about how models should be developed.

Develop a communication platform to integrate newly graduated modellers and public health professionals in the field.

Trust between mathematical modellers and public health professional groups is built through established, long-term relationships. These relationships are important for understanding the other disciplinary perspectives by discussing data, and analyzing modelling results. New mathematical modellers or public health professionals entering the field don't necessarily have these types of relationships, making it harder for them to develop and share their ideas with other groups. Starting an initiative that specifically recognizes this, and aims to connect mathematical modellers with public health professional in the field could potentially help to narrow the gap between modelling and public health.

Build active space of communication for modellers and public health (i.e. interactive blogs, podcasts)

In order to increase connectivity between modellers and public health, a blog or website should be launched. A platform such as this could summarize the latest research, needs of public health, and other relevant topics. Multimedia tools such as podcasts, webinars of different professionals in the field can also be useful. This recommendation can be an effective means for various stakeholder groups to have an idea of what is occurring in the field. This platform can potentially be run students who will eventually enter the field after graduation, and can also aid them in integrating within the existing networks.

Research

Increase targeted research funding for building mathematical models applicable to infectious disease outbreaks

There are limited resources for researchers to be able to develop insightful models when required in a timely manner during infectious disease outbreaks. Increasing funding for researchers would allow for increased resources, such as the hiring of post docs, and aid in the development of more models. By lobbying funding agencies for more targeted funding to build more infectious disease mathematical models, modellers can be better equipped to handle emerging infectious disease outbreaks.

Carry out research studies to better understand how integration of modelling in public health can be optimized.

Certain academic centres in countries such as the United Kingdom and United States are known to have better access to infectious disease data and better integrate modelling components within public health policy. Therefore by adopting a stakeholder analysis methodology, key stakeholders in other nations where integration of modelling into public health is a common practice should be identified. Doing so will allow for further examination of the issues related to collaborative networks between stakeholders, challenges in data as well as perceptions on predictive modelling. By conducting studies to understand how well established nations bridge the gap between the two fields, researchers and public health professional in Canada can take similar steps.

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APPENDICIES

A: Letter of Research Ethics Approval

HiREB
Hamilton Integrated Research Ethics Board

Date: 11 May 2016

Project Number: 1776

Project Title: Impacts of infectious disease models, a stakeholder analysis

Principal Investigator: Dr Andrea Baumann

Upon initial review of the above project, we have deemed this project exempt from HiREB review based on the following:

As noted in the protocol, one objective of the project is to identify key stakeholders, distinguishing between modellers and end-users. A second stated objective is to obtain the perspectives of the key stakeholders in planning, producing and refining predictive models. Your project includes interviewing professionals about their roles and their professional opinions about the given topic.

This type of activity does not require ethics approval from the HiREB.

Your study is being returned and the file closed out with the HiREB. If you wish to discuss this further please contact the HiREB office.

Kristina Trim, PhD, RSW
Chair, HiREB Student Research Committee

McMaster University

The Hamilton Integrated Research Ethics Board operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practices; Part C Division 5 of the Food and Drug Regulations of Health Canada, and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations;**for studies conducted at St. Joseph's Hospital, HiREB complies with the health ethics guide of the Catholic Alliance of Canada**

B: Key Stakeholders Semi-Structured Interview Guide

I am a M.Sc. Candidate in the Global Health program at McMaster University. I am conducting a study on **"**Understanding perspectives in planning, producing and applying predictive infectious disease models" by exploring perspectives of stakeholders who are either modellers involved in the producing infectious disease models, or end-users involved in applying the results of the models. The intent of this interview is to better understand your role, opinions and perspectives in regards to predictive infectious disease models.

Section 1: Background

1. How long have you worked in the field of developing or using mathematical models?
    a. In what capacity do you work with models (i.e. developer, database manager, policy maker, etc)
    b. What models have you worked with or on in the past?
    c. What current projects involving predictive infectious disease models are you involved in?
2. Specifically, does your work relate to the development/validation/application of infectious disease models?
    a. Are you involved in any capacity in improving the science behind the development of infectious disease models (i.e. development of best practice guideline)?
2. How does the release of forecasting infectious disease models influence your professional role?

Section 2: Data Quality, Planning and Production of Predictive Models

3. a. Modellers: What sources of data do you use to build the models? (i.e. hospital data, public health data)
    a. How is the data collected?
    b. Is this data available to the public?
    c. What means do you use to verify the accuracy of the data that is inputted into models?

    b. End-users: Do you collect data that is used in the models?
        a. How is the data collected?

b. Is this data available to the public?
c. What means do you use to verify the accuracy of the data that is inputted into models?

4. a. Modellers: In your opinion, what additional types of data would strengthen the accuracy of predictive models?
   b. End-Users: Are you aware what sources of data are used for the models that you work with?
5. Modellers: How long does it typically take to produce a predictive infectious disease model?
   b. End-users: In your opinion at which point in the epidemic is it most useful to have a predictive model? After which point is it irrelevant whether there is a model available to guide policy?
6. In your opinion what variable/factor/outcome do you consider most important to mode**l/use** in predictive infectious disease models (i.e. absolute intensity of an epidemic, epidemic duration, intervention strategies).
7. What breadth of population do predictive models often encompass (i.e. city, provincial, national, international)?
   a. In your opinion, what breadth of modelling is the most practical for accurately forecasting epidemics?
   b. End-users: What breadth of population is most useful for you for applicability?
8. a. Modellers: Are the models produced with end users in mind (i.e. ease of use and understanding by an individual who does not have a background in mathematical models)?
   b. End-users: Are the models you use relatively simple to understand?
   How do you gain access to predictive developed infectious disease models?

Section 3: Use and Impacts of Predictive Models

9. What do you see as the advantages of predictive infectious disease models [to you and your organization]?
   a. Probe for Modeller: As a modeller does the release of a predictive infectious disease model give insight into how the science can be improved? Are you able to provide a specific example?

   b. Probe for End-user: As an end user how do predictive infectious disease models help you or your organization make decisions regarding public health? Are you able to provide a specific example?

10. What do you see as the disadvantages of predictive infectious disease models [to you and your organization]? Are you able to provide any specific examples?
11. In what scenarios do you think predictive models should be used to influence decisions or policy made by public health officials? Are they currently being used in this capacity?
12. a. Modellers: What are some methods in which you validate predictive infectious disease models?
    b. End users: What are some methods in which you ensure that the predictive infectious disease models you utilize have been validated?
13. In your opinion are there better alternatives to understanding infectious disease dynamics than mathematical models?
14. How does policy (existing or in its development stages) influence the development (impact, influence) of infectious disease models?
15. What is your perception/experience of the accuracy of the models?
    a. Modellers: Despite the uncertainties inevitably associated with having a model, are you confident that they should still be used to inform policy?
    b. End users: Recognizing that models are prone to uncertainty, are you comfortable using them to inform policy?

Section 4: Identification and collaboration of Key Stakeholders

17. Please identify which academic disciplines and other organizations are important in the development of infectious disease models?

   c. Are you able to specify any national or international experts (i.e. field of economics, field of epidemiology, field of biostatistics, field of mathematics, etc)?

18. With respect to your professional role in the area of infectious disease modelling what groups or persons do you consider important for collaboration?

   d. In what capacity do you interact/collaborate with these individuals?
   e. How do you communicate with these individuals?
   f. What are some factors that facilitate communication?
   g. What are some factors that hinder communication?

h. What would you recommend to enhance communication between the key stakeholders to better forecast emerging infectious diseases?

19. What type of further support would you require to advance the field of infectious disease modelling and their applications?

Section 5: **Final Comments**

20. Are there any additional comments you would like to add?

C: Letter of Information/Consent Form

LETTER OF INFORMATION / CONSENT

Understanding perspective in planning, production and impacts of predictive infectious disease models: A Stakeholder Analysis

Investigators:

Local Principal Investigator:	**Student Investigator:**
Dr. Andrea Baumann Department of Global Health McMaster University Hamilton, Ontario, Canada **(905) 525-9140 ext. 26631** **E-mail: baumanna@mcmaster.ca**	Sheena Guglani Department of Global Health McMaster University Hamilton, Ontario, Canada **416-219-0903** E-mail: guglans@mcmaster.ca

Thank you for accepting our invitation to be interviewed. The following information will describe the purpose of our study and the care we have taken to protect your privacy and confidentiality. With your permission we will take a few minutes before the interview, to review the information and answer any questions or concerns you have with regards to the interview and the research study.

Purpose of the Study:

The study is called, "Understanding perspective in planning, production and impacts of predictive infectious disease models: A Stakeholder Analysis".

It will be conducted by Sheena Guglani, Global Health Master's student at McMaster University under the supervision of Dr. Andrea Baumann, as part of her Master's thesis requirements. The study aims to understand the development and impacts of predictive infectious disease modelling by understanding the perspective of stakeholders who are either experts in the field of developing mathematical models or work with them in some capacity. The intent of the interview is to understand the extent of collaboration between professionals when developing models, understanding the planning and production of models and in what ways they can impact individuals, organizations and governments.

Procedures:

As a key informant and participant in this study, you will be asked to participate in an interview lasting between 30-60 minutes to share your perspectives on infectious disease models. Your participation in this interview is voluntary and confidential. You can refuse to answer any question at any time and/or withdraw fro the study at any time by contacting Sheena Guglani or Dr. Andrea Baumann. The interview will be recorded and transcribed at a later date will all information being kept under a pin number that will not be easily identifiable with your name or any other identifying characteristics.

Potential Harms, Risks or Discomforts:

There are no known potential harms or risks associated with this study. You have the option of skipping any questions that cause you discomfort or ask to stop the interview process all together. Several measures will be taken to protect your privacy. This includes issuing a personal identification number to use in all the transcripts. Project materials, reports or any published material will not reveal your identity, or organization. You have the freedom to skip any questions that might cause you discomfort or request to stop the interview at any time, without any adverse consequences on you, your organization or the researchers.

Potential Benefits:

There are no known potential direct benefits of this study. However, common themes and/or concerns that might emerge from the perspectives of the different stakeholders will contribute in improving the field of generating and using infectious disease models. Improving the quality and accuracy of predictive models will aid in better allocating resources and prevention methods for infectious disease outbreaks.

Confidentiality:

Protocol is in place to protect your personal information confidential. You will be assigned a personal identification number under which all your personal information will be kept and will be used instead of directly identifying information such as your name. The interview script, transcript, audiotapes and digital audio files will be kept under the personalized pin and stored on a secure server at McMaster University. All of the data will be secured, password protected and locked in the Global Health Office at McMaster University with only the research team having access to the information. The data will be destroyed when the project is complete. You have the right to listen to the tape for your session or read the transcript in which you participated. The research team is committed to protecting your privacy and confidentiality. Your decision to participate or withdraw from the study will not affect your role in your organization or institution as the information will only be shared with the research team.

Participation and Withdrawal:

Your participation in this study is voluntary and confidential. If you do not wish to answer a particular question, you have the option of skipping it. You also have the option of withdrawing from the study at any point during the interview process or after by contacting Sheena Guglani or Dr. Andrea Baumann. Your information will be destroyed at your request. This applies even after the consent form has been signed.

Study Debriefing:

If you are interested in the findings, we will be happy to mail or email them to you after study completion. We ask that you provide your contact information so that we can follow through on this request.

Questions:

If you have any questions about this study, please call Sheena Guglani at 416-219-0903 or Dr. Andrea Baumann at McMaster University at 905-525-9140 ext. 22205.

CONSENT

By signing this form, I agree that:

1. I understand the purpose of the study, “Understanding perspectives in planning, producing and applying predictive infectious disease models” conducted by Sheena Guglani and Dr. Andrea Baumann of McMaster University.
2. I understand that information gathered for the study will not infringe upon my rights and provisions are in place to protect my privacy and that I will not be identified in reports or publications.
3. I have had an opportunity to ask questions and they have been answered to my satisfaction. I know the procedure to ask additional questions.
4. I understand the research interview will be recorded.
5. I understand that I may withdraw from the study at any time, and know the procedures to do so. If I choose to do so, and that doing so will not affect my employment in the organization.
6. I will be given a copy of this form.

I would like to receive a summary of the study’s results. Yes No

If yes, where would you like the results sent:
Email: ____

Mailing address: ____
____
____

Written Consent

________________________ ________________________ ________________
Name of Participant (Printed) Signature Date

Consent form explained in person by:

________________________ ________________________ ________________
Name of Interviewer (Printed) Signature Date

Oral Consent (*Interviewee gave oral consent (recorded)):*

________________________ ________________________ ________________
Name of Interviewer (Printed) Signature Date

If you have any questions about this study, please call Sheena Guglani at 416-219-0903 or Dr. Andrea Baumann at McMaster University at 905-525-9140 ext. 22205.

D: Email Invitation to Potential Stakeholders

Subject line: Perspectives in Predictive Infectious Disease Models - Invitation to Participate in Research

Message: We invite you to take part in a research study that is collecting expert perspectives about planning, production and impacts of predictive models of infectious disease outbreaks. This is part of a study on, "Understanding perspective in planning, producing and applying mathematical models of infectious disease models".

We are studying the development and impacts of predictive infectious disease modelling by understanding the perspective of stakeholders who are either experts in the field of developing mathematical models or work with them in some capacity. The intent of the interview is to understand the extent of collaboration between professionals when developing models, understanding the planning and production of models and in what ways they can impact individuals, organizations and governments. After the completion of my study, I will be able to share the summary of my results with you if it could be something of use to your own research interests.

The study is conducted by Sheena Guglani, Global Health Master's student at McMaster University under the supervision of Dr. Andrea Baumann, as part of her Master's thesis requirements. If you would like to take part in this study and share your point of view, please contact the principal investigator, Sheena at guglans@mcmaster.ca or 416 219 0903; or Dr. Andrea Baumann at baumanna@mcmaster.ca or 905-525-9140, extension 26631.

Participation in the project is voluntary and confidential. The in interview will take place either in-person or via telephone and will be approximately 30 to 60 minutes. The interview will be audio recorded, and all information collected will not be identified with your name and/or organization. Steps will be taken to ensure that identify information is blurred, and that final results and report so no explicit indicate towards your identification.

We hope that you will consider contributing your valuable expertise in the field being an important stakeholder in the field of mathematical modelling of infectious diseases. Your time, help and expertise is essential to this project, and deeply appreciated.

Sheena Guglani
Master's Candidate, Global Heath, McMaster University
Email: guglans@mcmaster.ca
Phone Number: (416)-219-0903

E: Telephone Script, Invitation to Potential Stakeholders

A. Introduction to office staff or any support staff that pick up the phone	Hello, my name is Sheena Guglani, I am a Master's Candidate at McMaster University currently working on my thesis project, trying to understand the perspectives of the sky stakeholders involved with infectious disease modelling. Would it be possible to speak to ________?
B. When desired person picks up the phone directly or I am transferred to them.	Hello ______? I am a Masters student at McMaster University conducting a study on understanding the perspectives of key stakeholders in the field of infectious disease modelling. **Explain how I received the individual's information** *[e.g. "I was referred to you by ______?" or "I came across a paper that you wrote on this topic"]* I am conducting interviews to understand the perceptions of experts in the field for this study, that should last anywhere from 30 to 60 minutes. Would it be possible to set up a date and time with you to have a chat about your field of expertise? This is completely voluntary and there are protocols in place to ensure that any information you share will remain confidential. I would be happy to send a follow up email with my information along with further details of the study. I can be reached at 416-219-0903 or guglans@mcmaster.ca. I will be sure to provide all of my information in my follow up email. ***Note down email address*** **IF NO, GO TO STEP E**
C. If desired person is not available	"Is there a better day and time to reach _________?" *Leave my phone number (416-219-0903) and email (guglans@mcmaster.ca) *Request their email. "Thank you. I will try to call back then" **End call** *Follow up with email and call back at a more convenient time.

D. If prompted to leave a voicemail	Hello, my name is Sheena Guglani, I am a Master's Candidate at McMaster University currently working on my thesis project, trying to understand the perspectives of the sky stakeholders involved with infectious disease modelling. **Explain how I received the individual's information** *[e.g. "I was referred to you by* **______***?" or "I came across a paper that you wrote on this topic"]* I am conducting interviews to understand the perceptions of experts in the field for this study, that should last anywhere from 30 to 60 minutes. Would it be possible to set up a date and time with you to have a chat about your field of expertise? This is completely voluntary and there are protocols in place to ensure that any information you share will remain confidential. I would be happy to send a follow up email (if I already have their email) with my information along with further details of the study. I can be reached at 416-219-0903 or guglans@mcmaster.ca. I will be sure to provide all of my information in my follow up email. Thank you for your time. I hope to hear back from you soon.
E. If interrupted or strong immediate refusal	Is there another time I can call you back? **IF YES**, Thank you. We will try to call back then. **Note date and time** **IF NO/NOT INTERESTED**, Okay, thank you for your time. **End call.**