A Digital Health based Personalized Chronic Disease Risk Assessment and Mitigation
Platform for Citizen's Lifetime Health

by

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DEDICATION

To my mother, Midia, my father, Nasir, and my brother, Omar. Thank you for all your

support and encouragement. I could not have accomplished any of this without all of you.

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ABSTRACT

Chronic diseases are the leading cause of death worldwide. Early risk assessment, monitoring and mitigation at the individual level can significantly prevent the onset of most chronic diseases. Lifetime health is an emerging paradigm that aims to empower individuals to avoid harmful lifecycle choices to mitigate the risk of chronic diseases. In this thesis, we present a digital health platform to empower citizens to self-asses and self-monitor their risk for multiple chronic diseases. We identified interrelationships between risk factors and chronic diseases, and modelled them in terms of a knowledge model that is used to determine the influence of multiple risk factors on the onset of different chronic diseases. We digitized risk assessment tools for 11 chronic diseases, utilized data analytics and health visualization techniques to turn personal health data into meaningful and actionable risk scores. We designed a cross-sectional study to evaluate citizens' behavioural intentions towards using the platform.

LIST OF ABBREVIATIONS USED

CANRISK – Canadian Diabetes Risk Assessment Questionnaire

CAD - Coronary Artery Disease

CDRI - Chronic Disease Risk Index

CVD – Cardiovascular Disease

DALY – Disability Adjusted Life Years

FRS – Framingham Risk Score

HKM – Healthcare Knowledge Management

HRA – Health Risk Assessment

HCRI – Harvard Cancer Risk Index

LI – Lifestyle Index

PAR – Population Attributable Risk

PLCO – Prostate, Lung, Colorectal and Ovarian Cancer Screening Trial

PLS – Partial Least Squares

PPPM – Predictive, Preventive and Personalized Medicine

PRISM – Personalized Risk Investigation, Stratification and Mitigation

RR – Relative Risk

SBP – Systolic Blood Pressure

WHO – World Health Organization

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CHAPTER 1: INTRODUCTION

According to the World Health Organization (WHO), chronic diseases are 'looming epidemics that will take the greatest toll in deaths and disability' [1]. To get a sense of the impact, 68% of all deaths worldwide were attributed to chronic diseases in 2012, with a projection by the WHO that the total annual number of deaths due to chronic disease will increase by 36% by the year 2030 [2]. In Canada, the prevalence of chronic diseases is comparable to the world, with almost half (51.6%) of Canadians over the age of 20 live with at least one chronic disease, and four out of five are at risk of developing a chronic condition [3]. In addition to the enormous impact on one's health and quality of life, chronic diseases create large adverse economic effects on families, communities and health care systems. According to the Public Health Agency of Canada, chronic disease patients consume 67% of all direct health care expenditures and cost the Canadian economy $68 billion in direct health care costs and $122 billion in productivity losses each year [4, 5].

Generally, chronic diseases are regarded as lifestyle diseases, because the incidence of a chronic disease is strongly influenced by the manner a person lives (i.e. their lifestyle). In fact, the major chronic diseases are strongly associated with four lifestyle-related factors: tobacco smoking, unhealthy diet, excessive alcohol consumption and physical inactivity [6]. In addition to the lifestyle-related factors, the development of a chronic disease is also influenced by demographic, environmental, biomedical and genetic factors, which act independently or in combination with lifestyle-related factors [7]. Chronic disease risk factors can be further classified as *modifiable* risk factors, such as smoking and physical

inactivity, and *non-modifiable* risk factors, such as age, gender and family history. It is well understood that if a combination of modifiable risk factors is targeted, at least 80% of premature heart disease, stroke and type 2 diabetes, and 40% of cancers could be prevented [8]. Therefore, identifying, assessing and addressing risk factors at the person-level is a critical task in chronic disease prevention.

Given the complex mutual associations between risk factors and chronic diseases [7], focusing on one risk factor at a time is not an effective approach for the prevention of chronic diseases. Instead, an integrated and health-focused approach is required. From a risk assessment perspective, a health-focused approach, based on the life-course framework, aims to view individuals more holistically by recognizing the impact of a wide range of health determinants on the risk of chronic diseases [7, 9]. While a health-focused approach to chronic disease prevention entails that preventive measures should target individuals of all ages and at various community-based settings [9]. However, to ensure effective preventive care, citizens should be supported and empowered by providing them with the necessary tools and resources required to prevent the risk of chronic diseases [10]. Citizen empowerment entails informing them about personal health risks and the benefits of pursuing preventive care [11].

It has been reported that physicians often fail to counsel individuals on the risks of chronic diseases and preventive measures required to mitigate those risks [12]. As a result, preventive care strategic initiatives are advocating for an innovative, integrated and proactive approach for the early and effective chronic disease risk assessment, monitoring and mitigation at the individual level by providing personalized lifetime health services. Lifetime health is an emerging health paradigm that aims to assist

individuals to achieve long-term health targets, and avoid harmful lifecycle choices to mitigate the risk of chronic diseases.

Recent advances in eHealth technologies, data analytics and health visualizations offer promising opportunities to develop technological-based solutions that aim to tackle the growing burden of chronic diseases. Additionally, novel health informatics methods, such as Healthcare Knowledge Management (HKM) [13], provide the opportunity to develop high-quality knowledge-centric eHealth services, such as: access to evidence-based guidelines and knowledge; collection, integration and presentation of health data in meaningful forms to facilitate and support care; generation of personalized care plans; and facilitation of personalized lifetime healthcare [13].

The Personalized Risk Investigation, Stratification and Mitigation (PRISM) platform developed in this thesis presents a proof-of-concept that a personalized lifetime health approach to chronic disease risk assessment and prevention can transpire through an eHealth-based intervention when guided by citizen empowerment [11], self-care [14] and the life-course framework [9].

1.1. Research Objectives:

This study endeavours to investigate and implement a digital lifetime health platform to empower citizens in pursuing personalized risk assessment, risk monitoring and risk mitigation strategies that aim to prevent the onset of chronic diseases, and help them in leading a healthy and disease-free life. More specifically, we plan to pursue the following research objectives:

1. To identify and select validated chronic disease risk assessment algorithms for the major common chronic diseases and cancers in Canada;

2. To formulate a holistic and personalized approach to chronic disease risk assessment and prevention that considers a wide range of personal health determinants and risk factors, such as: demographic, environmental, socioeconomic, behavioural, biomedical and genetic risk factors;

3. To investigate a cumulative, health-centric (as opposed to disease-centric) risk assessment approach that reflect an individual's multimorbid chronic disease risk and overall health status due to the presence of multiple risk factors;

4. To develop a high-level chronic disease knowledge model that maps the mutual and complex associations and interactions between risk factors and chronic diseases;

5. To investigate and implement a digital health platform that will provide personalized lifetime health services to empower citizens to self-assess, self-monitor and self-manage their health conditions and risk of chronic diseases;

6. To design a pilot study to evaluate behavioural intentions towards using the proposed platform.

Overall, this research takes an interdisciplinary approach by integrating personalized risk assessments, self-monitoring, citizen empowerment and self-care frameworks, knowledge management and ontological modeling, eHealth technologies, data analytics, health data visualizations and a life-course approach to chronic disease prevention to develop an integrated citizen empowerment eco-system that turns personal health and lifestyle data into meaningful health scores to keep citizens healthy and to help them avoid the onset of chronic diseases.

1.2. Research Approach:

The research is premised on the vision outlined in Figure 1.1, which suggests that effective chronic disease prevention at the citizen level can be achieved by subscribing to 4 key elements:

a) A proactive, integrated and health-focused approach to chronic disease risk assessment prevention, based on the life-course framework, represents the most effective strategy towards reducing the shared risks for chronic diseases. In more practical terms, the life-course framework entails viewing people more holistically, and emphasizes on health promotion and early prevention interventions throughout the life [9].

b) For preventive interventions to have a substantial and positive effect on health, citizens must be empowered. The first level of empowerment involves informing individuals about their personal health risks [11].

c) Citizens should be actively engaged in maintaining their healthy status by pursuing adequate self-care. According to the literature, adequate self-care involves: (i) adhering to healthy lifestyle behaviours to maintain a disease-free life; and (ii) pursuing self-care monitoring to become more aware of their health risks and to track their progress while making lifestyle behaviour modifications [14].

d) eHealth-based interventions provide citizens with the appropriate tools and resources to facilitate adoption of the life-course framework, citizen empowerment and adequate self-care.

By combining the abovementioned elements, we can empower citizens, engage them in maintaining their own health and effectively avoid the onset of chronic diseases.
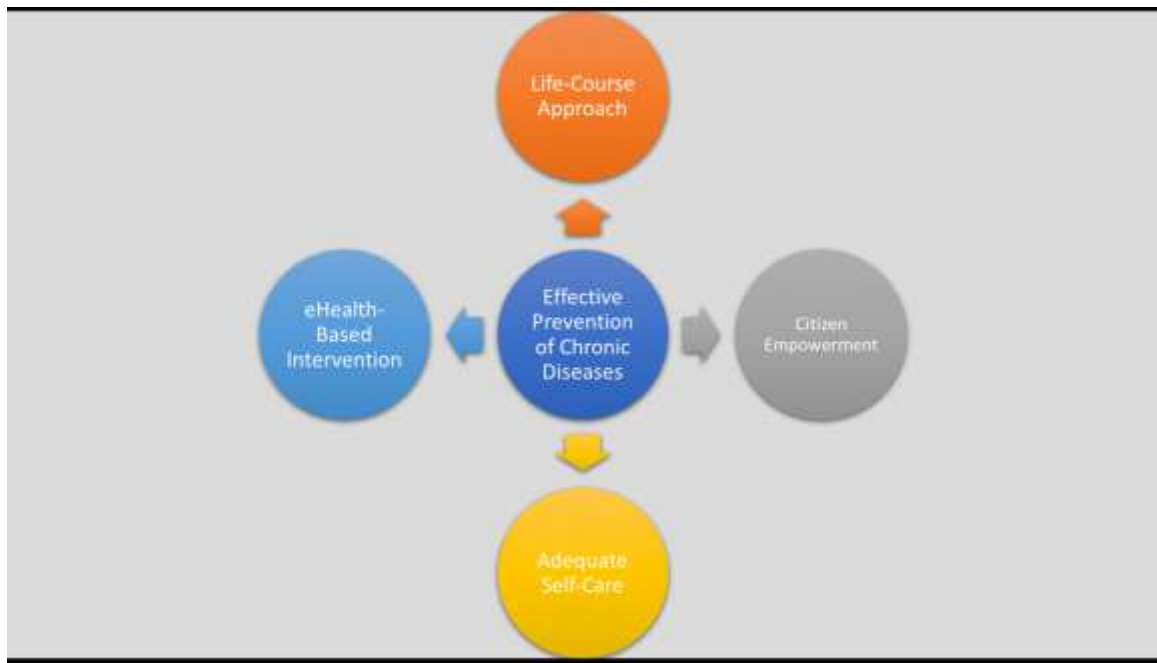
Figure 1.1 - Conceptual Model for Effective Chronic Disease Prevention

As discussed earlier, risk assessment is a critical step towards achieving empowerment. Therefore, to provide citizens with the necessary risk assessment tools and resources, we have taken a HKM approach to [13] to: (i) computerize validated risk assessment tools for 11 chronic diseases and cancers, and (ii) develop a high-level chronic disease knowledge model that maps the mutual associations between risk factors and chronic diseases, based on the evidence presented in the risk assessment tools. The resulting knowledge model is scalable and can accommodate additional chronic diseases, risk factors and risk assessment tools. The model will be utilized to generate personalized risk profiles and will guide the development of the eHealth-based intervention.

The eHealth-based intervention is a web-based health platform that provides personalized lifetime health services to empower citizens, engage them in adequate self-care and help

them in preventing the risk of chronic diseases autonomously. Development of the platform was informed by the Waterfall framework, a validated eHealth systems development framework. The platform incorporates a dashboard that presents citizens with personalized risk information in an intuitive manner using interactive visualizations. Finally, we have designed a quantitative evaluation study to assess citizens' behavioural intention towards the platform. The evaluation is based on a number of technology acceptance models and behavioural theories. We use the Partial Least Squares (PLS) method to construct and validate a structural research model that predicts the factors influencing behavioural intention towards consumer-oriented health platforms.

1.3. Contribution:

In this thesis, we develop a prototype of a personalized lifetime health platform, that aims to empower citizens in pursuing self-assessment and self-monitoring for multiple chronic diseases, using a framework that incorporates a health-focused approach to chronic disease prevention that is based on the life-course framework [9, 10, 88, 110]. Most existing disease risk assessment tools are disease-specific; thus, they have been shown as poor indicators of an individual's overall health status. Therefore, our research is novel in that it involves the integration of multiple disease risk assessments in a high-level knowledge model to generate personalized risk profiles. Further, we demonstrate the formulation of a cumulative and health-centric 'Health Asset Score' that reflects an individual's multimorbid chronic disease risk and overall health status. We believe that by presenting informative and easy-to-understand personalized risk information, we can incentivize individuals to pursue behaviour modification and prevent the onset of chronic diseases [11].

CHAPTER 2: BACKGROUND

2.1. The Growing Burden of Chronic Diseases:

Chronic diseases, such as cardiovascular disease, diabetes, stroke and cancers, are defined as "diseases of long duration and slow progression" [15]. Since the onset of the 20th century there has been a significant epidemiologic shift from predominance of infectious diseases to chronic non-communicable diseases due to globalization, industrialization and urbanization [16]. As countries become more industrialized, peoples' lifestyles and health behaviours change. As a result, chronic diseases are rapidly becoming a global health problem; out of the 56 million deaths worldwide in 2012, 38 million were due to chronic diseases [17]. What were once considered "disease of affluence" (i.e. chronic diseases) have now infiltrated every region of the world. In Canada alone, chronic diseases are responsible for 67% of all deaths and 86% of the total burden of disease [18]. Data from the Public Health Agency of Canada demonstrate that cancers, cardiovascular diseases, COPD and diabetes were responsible for almost half (47.2%) of all deaths in 2012 [19]. Given the reality of Canada's aging population [20], chronic disease prevalence and mortality rates are bound to rise even more significantly. According to recent statistics, almost half of Canadians are at risk of developing cancer in their lifetime [19].

Adding urgency to the burden of chronic disease debate is a phenomenon known as multimorbidity. Research has demonstrated that the presence of one chronic disease increases the risk of developing other concurrent chronic diseases i.e. multimorbidity [7]. The prevalence of multimorbidity among Canadians is 12.9% [21].

In addition to the impact on the burden of disease, chronic diseases have an adverse effect on families, communities and health care systems. Partners of chronic disease patients are directly affected as they experience a significant increase in caregiving responsibilities [22]. A study by Golics et al. (2013) reported that 92% of family members of chronically ill patients experienced a negative emotional impact, 91% of cases reported negative effect on day-to-day activities, and 69% of cases reported adverse effects on family relationships [23]. The economic burden of chronic disease is also significant; it is estimated that chronic disease patients cost the Canadian economy $190 billion annually [4].

2.1.1. Development of Chronic Diseases:

Chronic diseases usually emerge in middle age, or later, after a long period of exposure to various health determinants and risk factors [7, 10]. The development of a chronic disease follows a complex chain of events; whereby health determinants and risk factors contributing to the risk of the disease accumulate, cluster and interact leading to chronic morbidity, disability and, eventually, mortality [7]. Further, evidence suggests that the accumulation of risk factors begins in early stages of life [10]. In general, chronic disease risk factors can be:

1. Demographic: e.g. age, gender, and ethnic background.
2. Environmental: e.g. exposure to chemicals and Ultra Violet light.
3. Socioeconomic: e.g. education, income, and occupation.
4. Behavioural: e.g. smoking, sedentary lifestyle, and excessive alcohol consumption.
5. Biomedical: e.g. high blood pressure, high blood glucose and obesity.

At various stages of life, from birth to adulthood, individuals are exposed to different

environmental, socioeconomic, genetic and behavioural risk factors that contribute to the

incidence of chronic diseases. These risk factors often cluster and interact giving rise to

risk conditions (i.e. biomedical risk factors), which have direct effect on the development

of chronic diseases. Figure 2.1 shows the causal links between major risk factors and

chronic diseases.
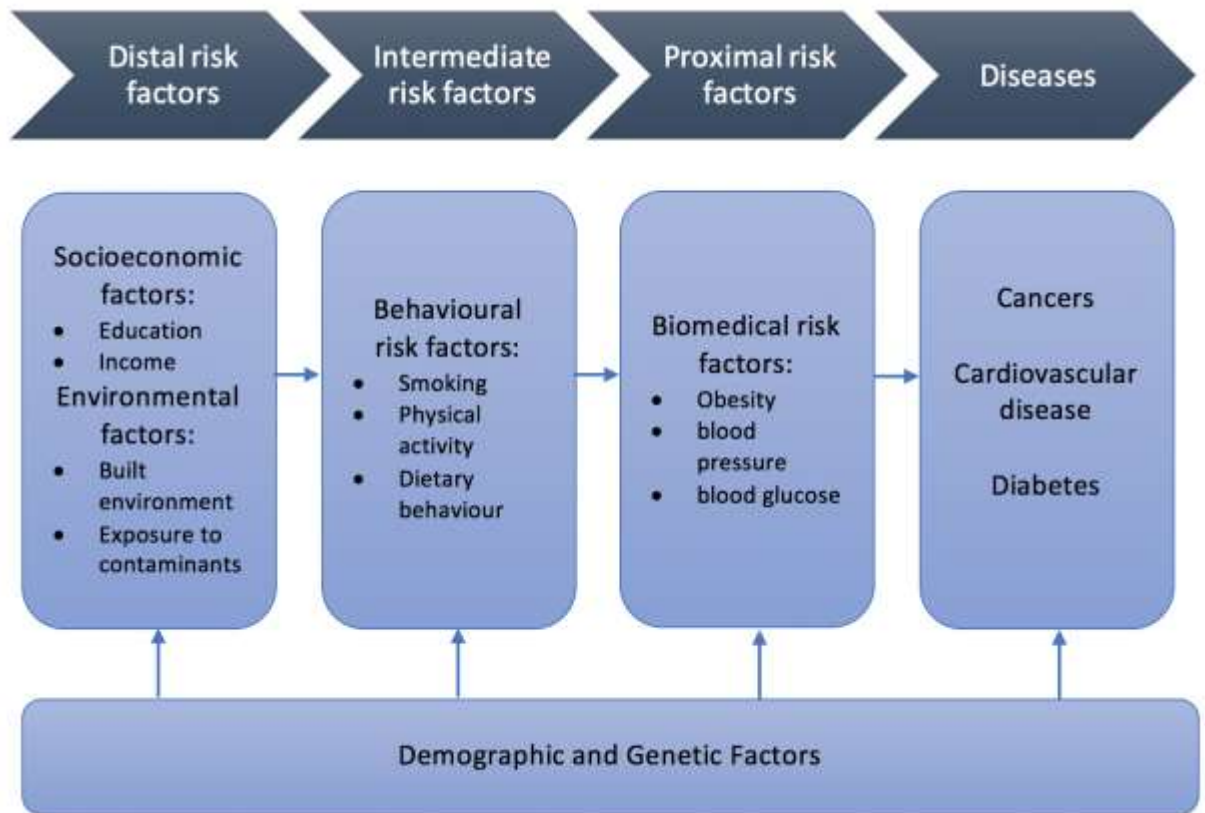
Figure 2.1 - Causal links between risk factors and chronic diseases

In this model (Figure 2.1), risk factors can be: (i) distal, which are several steps away

from the morbidity event; (ii) intermediate, which emerge because of exposure to distal

risk factors and; (iii) proximal, which have a direct effect on the development of chronic

diseases based on established pathophysiological mechanisms [7]. The background risk factors, such as gender, genetic makeup and ageing, underpin all other risk factors.

It is often suggested that there are complex mutual associations between risk factors and chronic diseases [7, 9, 10], such that a risk factor may contribute to the onset of multiple chronic conditions with varying degrees of influence. Table 1.1 shows the relationship between a number of major chronic diseases and associated risk factors [24].

Table 1.1 - Relationship between selected chronic diseases and associated risk factors

Chronic Disease	Behavioural Risk Factors				Biomedical Risk Factors		
	Smoking	Physical Inactivity	Excessive Alcohol Consumption	Poor Dietary Habits	Obesity	High Blood Pressure	High Blood Cholesterol
Heart Disease	✓	✓		✓	✓	✓	✓
Type 2 Diabetes	✓	✓	✓	✓	✓	✓	✓
Colorectal Cancer		✓	✓	✓	✓		
Breast Cancer		✓	✓	✓	✓		

Given the evidence, we can infer that: (a) the likelihood of developing chronic diseases is influenced by exposure to risk factors at various stages of life; and (b) there is a considerable overlap between the risk factors for major chronic diseases. As a result, new public health initiative advocate for a preventive approach that addresses multiple risk factors to avert the risk of multiple chronic diseases.

2.1.2. Prevention of Chronic Diseases:

Despite significant ageing of populations, the substantial burden of chronic conditions can be avoided, as chronic diseases are considered preventable medical conditions. Therefore, it is necessary to identify and address the risk factors that underlie chronic diseases. While many risk factors such as socioeconomic and demographic factors cannot

be controlled or modified, behavioural and biomedical factors can be controlled to reduce or avert the risk of developing a chronic condition. Evidence demonstrates that attainable modifications in risky lifestyle behaviours can prevent most coronary artery disease (CAD), stroke, diabetes, colon cancer and smoking-related cancers [6]. Additionally, given the complex interactions and the many-to-many relationships between risk factors and chronic diseases, focusing on one risk factor at a time is not an effective strategy for the prevention of chronic diseases. According to Willet et al. (2002), over 90% of diabetes, 80% of CAD, 70% of stroke and colon cancer are potentially preventable by combining few lifestyle modificiations: non-smoking, moderate physical activity, moderate alcohol consumption, healthy diet, and maintaining a healthy weight (i.e. avoidance of overweight/obesity) (25). As such, an integrated and health-focused preventive approach is required.

2.2. Current Preventive Care Practices in Primary Healthcare:

Despite the development of evidence-based guidelines for chronic disease prevention [26], current levels of preventive care and health promotion in the primary care setting remain low [12]. Primary care physicians often fail to counsel patients and citizens on preventive care and behaviour modification strategies that aim to prevent the onset of chronic diseases [12]. The reason for this disparity between recommended and actual practices is that the current focus of healthcare systems – primary-based healthcare particularly – is on treating diseases that have already developed, rather than focusing on detecting and preventing the onset of diseases [27]. However, there is a growing interest within the medical community to transform the nature of healthcare from *reactive* and *palliative* to *predictive* and *preventive* [5, 27]. Proactive and preventive interventions are

more likely to be effective at preventing chronic diseases than conventional screening programs that identify the early stages of the disease, after it had established [1-]. Therefore, the early identification and assessment of risk factors is becoming a critical component to chronic disease prevention.

2.3. Chronic Disease Risk Assessment:

Disease risk assessment is defined as "systematic evaluation and identification of risk factors responsible for a disease, estimation of risk levels, and finding possible ways to counter the onset and progression of a diseases within a population" (28). Disease risk assessment is also referred to as: Health Risk Assessment (HRA), disease prediction models, or disease risk scores (29). Disease risk assessment include the following components: data collection, risk prediction model, and a report of risk outcome (30). Generally, data collection is through a web- or paper-based questionnaire eliciting self-reported information on demographics, lifestyle behaviours, personal medical history, family medical history, and biomarkers (such as blood pressure, total cholesterol, and blood glucose levels). Furthermore, with the emerging fields of genomics and predictive, preventive and personalized medicine (PPPM) (31), genetic data are starting to be incorporated into some disease risk models. In clinical practice, disease risk assessments are used to gather health data in order to develop personalized risk profiles, use the profiles to predict the likelihood of developing a disease, and provide patients and/or healthy citizens with tailored preventative care measures to reduce their health risks [29]. Several methods exist to develop validated, clinically relevant disease risk assessment scores [29]. For chronic diseases, majority of the risk predictive models are based on multivariate analysis of longitudinal cohort studies [29], which are analytical

investigations conducted on a group of people to identify and gather evidence on probable causes for a disease. Data on disease incidence rates and risk factors are fitted with a model which is used to predict the risk of developing a particular disease.

The Framingham Heart Study, an ongoing cohort-based study, was among the first to develop statistical models to predict the risk of developing chronic diseases: CVD, hypertension, and type 2 diabetes mellitus [32, 33, 34]. Since then, several other publications studied the association between risk factors and various chronic diseases, and developed risk predictive models based on input of modifiable (e.g. diet, smoking) and non-modifiable (e.g. age, gender) risk factors [35, 36, 37]. Given the advances in health informatics and data analytics technology, disease risk assessments are now being transformed into computerized risk assessment tools, which can communicate the predicted risk probability in visual, numeric and verbal formats (38). A review of validated risk assessment models was conducted for this thesis, tables in appendix A provide a summary of several models for common chronic diseases and cancers.

To date, the majority of available validated health risk assessment models evaluate the risk of particular chronic diseases separately based on the causal relationship between a set of risk factors and a given chronic disease, i.e. a disease-focused risk assessment approach. Using novel statistical methods, risk factors for a chronic disease are assigned weights and the risk assessment outcome is expressed in terms of a risk score, absolute risk over a period of time (e.g. 10-year risk), relative risk, or stratified risk categories (i.e. low/moderate/high risk). Predicting risk of chronic disease is a complex process that is influenced by individual health characteristics and lifestyle behaviours. Given that most chronic diseases share a set of common risk factors, it is possible to develop predictive

models to summarize the risk of multiple chronic diseases into a single risk measure. There are several methods for quantifying multiple risk factors ranging from a simple sum of the number risk factors present to complex cluster analysis of relevant risk factors (39).

The Framingham General CVD Risk Score [32] is an example of a risk assessment tool that considers multiple risk factors to generate a composite measure of CVD risk, a class of disease that includes Coronary Artery Disease (CAD), heart failure, peripheral artery disease, and stroke. A number of other studies have developed models to assess the risk of multiple chronic conditions and overall "healthfulness" of citizens [40, 41, 42, 43]. In general, the risk factors selected for these models are modifiable to provide citizens with a practical and actionable assessment of their overall health and risk of chronic conditions. Meng et al. (1999) created the Chronic Disease Risk Index (CDRI) as a composite measure of multiple modifiable lifestyle risk factors in relation to the risk of chronic diseases and cancer mortality (41). CDRI allows for several levels for each risk factor; whereby scores are assigned according to the magnitude of exposure based on empirical dose-response estimates from the literature. The results of the study showed that as CDRI score increases, risk of chronic disease and cancer mortality increase [41]. Using a similar approach, the Lifestyle Index (LI) by Kim et al. was constructed to assess citizens' total healthfulness of lifestyles in relation to chronic health outcomes [42]. The modifiable risk factors included in LI are weighted according to their net effect on long term health – based on Relative Risks (RRs) and Population Attributable Risks (PARs). The LI scores range from 0-100, with higher scores representing healthier lifestyle and lower risk of chronic disease and cancers [42].

Miller et al. (2005) created another Chronic Disease Risk Factor Index (CDRI) that accounts for the proportional impact of each risk factor on the burden of disease – measured in Disability Adjusted Life Years (DALY) [43]. The CDRI by Miller et al. (2005) is more likely to have greater validity than other composite risk measures due to using multiple risk factor levels and weighting based on the impact on loss of DALYs [40]. The weights associated with each risk factor were summed to create a CDRI score, with higher scores indicating higher risk of developing chronic conditions [43].

In order for the risk assessment process to be impactful, the risk information should be clearly translated to individuals in an intuitive manner based on scientific evidence. The following section (section 2.3.1) discusses appropriate methods to communicate and translate risk information to lay individuals.

2.3.1. Risk Communication:

Risk communication has become an integral component of modern healthcare practice (44). Risk communication is defined as "the open two-way exchange of information and opinion about risk that leads to better understanding and informed decision making" (45). Interventions to prevent chronic diseases mainly focus on promoting informed lifestyle choices, risk factor modification and active self-management (50). Well-informed decision making in healthcare is dependent on the understanding and correct perception of the magnitude of risk being described. Therefore, risk communication should essentially involve the probability of the risk occurring, the importance of the risk outcome, and the effect of the event on the individual (51).

For chronic diseases, risk can be presented as a generalized population-based risk estimate (e.g. population average risk of CVD) or as a personalized risk estimate based

on individuals' own risk factors (51). Evidence on the efficacy of generalized risk information is well established in the literature (52). A Cochrane systematic review has investigated the impact of personalized risk communication on the perception and comprehension of risk and informed decision making (53). Evidence from the literature shows that communicating personalized risk of chronic diseases improves accuracy of risk perception and may motivate at-risk individuals to modify their risk factors (54). In a study Edwards et al. (2013) demonstrated the positive impact of personalized calculated risk scores on knowledge and perception/comprehension of risk, whereby participants who received personalized risk scores had improved knowledge and more accurate perception/comprehension of risk compared to participants receiving generalized risk information (53). Furthermore, the study found strong evidence that personalized risk estimates improve informed decision making. Overall, 45% of participants who received personalized risk information made informed choices, compared to 20% of participants who received generalized risk information (53).

Impactful risk communication can be difficult to achieve. One of the most significant barriers to effective risk communication is concerned with the level of health literacy and numeracy (55). Evidence suggests that even highly-educated individuals can have difficulty understanding and interpreting simple numerical concepts (55). However, health literacy and numeracy can be significantly improved by utilizing visual aids to communicate risk accurately. Research shows that the use of visualizations and imagery results in improved understanding of the relevant health risks and, thus, eliminating differences between low and high numeracy (56, 57). Another barrier is the lack of regular access to personal health and risk information. The @Risk trial demonstrated

improved risk perception among participants who received personalized 10-year CVD risk estimates at 2-weeks post intervention compared to the control group, but not at 12-weeks (58). The results of the trial suggest that repeating risk information to individuals helps to maintain their level understanding and knowledge of health risks. The rapidly advancing Health Information Technology (HIT) may help in overcoming some of the barriers concerning effective risk assessment and risk communication. Some HIT-based solutions are discussed in section 2.4.

2.4. eHealth for Chronic Disease Prevention:

The growing burden of chronic diseases in Canada has heightened the urgency to develop new novel approaches in public health to prevent and manage the risk of chronic diseases. The use of eHealth technologies represents one strategy that aims to counter the increasing prevalence and incidence of chronic diseases. Over the past years, eHealth has emerged as "the intersection of medical informatics, public health, and business, referring to health services and information delivered or enhanced through the internet and related technologies" [59]. In 2005, the World Health Organization (WHO) recognized the potential of eHealth research in supporting healthcare and improving the quality, safety and access to health services [60].

According to the literature, eHealth technologies have been used as intervention tools in the form of websites and web portals, mobile applications, emails and text messaging, goal setting, assessment and monitoring/tracking, risk assessments and health educational counselling [61]. From a public health perspective, eHealth technologies hold tremendous potential for enhancing the delivery of primary-based healthcare services, promotion of healthy lifestyle behaviours and, ultimately improving health outcomes by supplementing

the traditional channels for health communication [62]. Furthermore, eHealth technologies have the potential to empower individuals and provide personalized care that may engage them in health behaviour change [63].

Studies involving eHealth interventions to promote lifestyle behaviour change have targeted individuals at-risk of chronic diseases and several major risk factors: cardiovascular disease [64], diabetes [65], obesity [66], physical inactivity [67], and smoking [68]. A Cochrane review of 24 studies suggested that Interactive Health Communication Applications (i.e. eHealth applications) can improve social, cognitive, and clinical outcomes [62]. The emerging evidence on personalized and tailored eHealth interventions also appears promising. Norman et al. (2013), conducted a trial focusing on tailored dietary goal setting for high risk overweight and obese individuals [66]. After 4 months, results of the trial showed significant improvement in healthy eating behaviour and weight loss in the group receiving eHealth-based intervention. Other trials targeting individuals at-risk of cardiovascular disease, via web and mobile eHealth platforms, showed similar results in promoting increased physical activity and facilitating weight loss [69, 70].

In addition to facilitating positive lifestyle behaviour change, eHealth interventions can also improve health literacy outcomes for chronic disease patients and at-risk individuals (13). Studies suggest that low health literacy is associated with poor self-management and health status (71). Rawl et al. (2012) conducted a study to assess the effectiveness of eHealth tailored intervention in increasing peoples' knowledge of colorectal cancer and screening (72). The results show that computer-delivered tailored intervention was associated with improved knowledge of colorectal cancer, perceived colorectal cancer

risk, and screening benefit (72). Improved knowledge and health literacy is a crucial task in prevention of chronic diseases and cancers.

From a technical perspective, eHealth research has led to the development of advanced technologies and health informatics methods. For example, Healthcare Knowledge Management (HKM) has emerged as a pragmatic approach that aims to manage healthcare knowledge to address the gaps existing within healthcare [13]. In terms of chronic disease prevention, HKM approach can be utilized to computerize evidence-based knowledge, such as behaviour change guidelines or risk assessment tools, in order to generate personalized care and risk assessment strategies [13]. Additionally, advances in semantic web technologies provide the opportunity to develop relevant semantic medical concept maps that will allow for evidence-based knowledge to be presented to patients and lay citizens within context [11].

The outlook of eHealth-based interventions in preventing chronic diseases appears promising and far reaching. According to the WHO, a significant proportion of the world population could benefit from the opportunities offered by eHealth interventions and with a relatively low cost [73]. Evidence in the literature shows that personalized and tailored eHealth interventions empower citizens and chronic disease patients to achieve personal health objectives and modify risky health behaviours [74]. Strengthening the impact of eHealth interventions to prevent chronic diseases will require greater integration into primary- and community-based health services, provision of wide range of features to facilitate uptake by consumers, and the use of appropriate preventive care approaches.

2.5. Concluding Remarks:

In this chapter, we demonstrated the significance of the growing burden of chronic diseases and its impact on families, communities and health systems. We explained how chronic diseases develop and how they can be prevented by targeting a combination of risk factors. We also demonstrated the feasibility of developing composite chronic disease risk assessment tools. Chapter 2 also highlighted the importance of effective risk assessment and risk communication for the prevention of chronic diseases. Finally, we discussed the opportunities offered by eHealth interventions in preventive care. We can infer that there is a strong need to develop solutions that can help in bridging the gap between recommended and actual preventive practices. Hence, this research proposes a novel eHealth-based solution that employs an integrated and health-focused approach to chronic disease risk assessment and prevention.

CHAPTER 3: THEORETICAL UNDERPINNINGS OF RESEARCH APPROACH

In this thesis, we are proposing the development of a digital lifetime health management platform to empower citizens to self-assess, monitor and manage their risks for multiple chronic diseases. In response to the growing burden of chronic diseases, empowerment and self-care have emerged as new paradigms in healthcare that aim to assist individuals to adhere to health promoting behaviours, achieve desired short- and long-term health targets, and in turn prevent the onset of chronic diseases. Traditionally, empowerment and self-care have been linked to chronic disease management [75]. However, empowerment and self-care are no less important within the context of chronic disease prevention; which entails active engagement of individuals to modify their risky health behaviours to stay healthy and avoid illness [11]. Conceptually, empowerment and self-care are related, whereby empowerment is the process by which individuals are encouraged to engage in autonomous self-regulation, self-care and self-efficacy to achieve maximum health and wellness [76]. According to Kaldoudi et al., 2015, the first level of empowerment involves awareness of one's own health status and current conditions [11]. In that regard, chronic disease risk assessment is a critical task to empower citizens, and to proactively identify and mitigate the risk of chronic conditions. From a public health perspective, evidence shows that targeting a combination of risk factors presents an efficient strategy towards reducing the shared risks for chronic diseases [6]. Considering the complex and multi-causal ethology of chronic diseases, what is required is a shift from an index disease-centered approach to a holistic, health-focused and citizen-centered approach for the prevention of chronic diseases. Such approach entails the inclusion of a wide range of socioeconomic, environmental,

biomedical and personal lifestyle risk factors to assess the risk of chronic diseases, and the generation of personalized risk mitigation plans based on personalized risk information.

Given the advances in eHealth technologies, we can now develop interactive health systems that provide personalized health services and translate the chronic disease risk assessment and prevention information to the public (i.e. citizens). Evidence shows that eHealth interventions have a positive impact on achieving empowerment and self-autonomy [77].

In this chapter, we discuss the theoretical underpinnings of our research approach to develop the PRISM lifetime health platform. More specifically, we highlight the roles of empowerment (11), self-care (14) and the life-course framework for the prevention of chronic diseases (10). These concepts and frameworks aim to engage individuals in pursuing desired health targets to avert the risk of chronic diseases.

3.1. Citizen Empowerment:

Empowerment is an emerging health paradigm that aims to improve individuals' ability to make autonomous and informed decisions about their health-related behaviours [11]. The concept of empowerment is particularly promising in the prevention and management of chronic diseases. Furthermore, as a central component of the personalized House of Care Model [78], empowerment is directly related to personalized health services, preventive medicine and patient-centered care [11].

Despite the growing interest in empowerment as a healthcare paradigm, finding a concise conceptualization can be difficult. The basic dimensions of empowerment have been identified as: (i) participation, (ii) education, and (iii) control [11]. According to Makoul

et al., individuals can maintain *control* over their quality of life by *obtaining information* about their health condition and *participating* in decisions about their healthcare [79]. Empowerment can therefore be described as a process that involves providing individuals with resources to inform them on their health status to increase their awareness, and actively engage them in autonomous informed decision making and self-care. In a study by Kaloudie et al., (2015), empowerment was described as a cognitive process which is based on three levels of increasing complexity: individuals' awareness of their health condition, engagement and control [11]. First level of the model involves awareness; citizens should be aware of their health status, existing chronic disease risk factors, risk of developing chronic diseases, potential disease progression to other associated comorbidities, and the measures needed to maintain health and avoid onset of chronic diseases [11]. Awareness can be achieved by providing citizens with the necessary tools and resources to inform them about their personal health status/condition, and improve their knowledge and understanding of the information provided. The authors argue that by increasing citizens' awareness, knowledge and understanding of their personal health status, we can promote their engagement in health promoting behaviours and, as a result, develop a sense of control of their lives (i.e. empowered citizens). Control, in this context, refers to mind changing and informed decision making. Mind changing is a cognitive process that refers to the capacity to modify one's intentions [11]. Empowerment is a multidimensional process and, therefore, the outcomes can vary. Some researchers have suggested that the outcome of empowerment is in terms of changes in an individual's health status, while other have proposed that the goal is adequate self-care, self-management, self-efficacy, control over the situation, and

participation in healthcare decision making [76]. In that regard, empowered individuals are able to [80]:

1. Understand their health condition and its impact on long-term health outcomes;

2. Make informed decisions about their healthcare;

3. Participate in decision making with their healthcare providers;

4. Understand the need for modifying risky lifestyle health behaviours to minimize the risk of chronic diseases;

5. Take responsibility of their health; and

6. Actively seek out, evaluate and make use of health information.
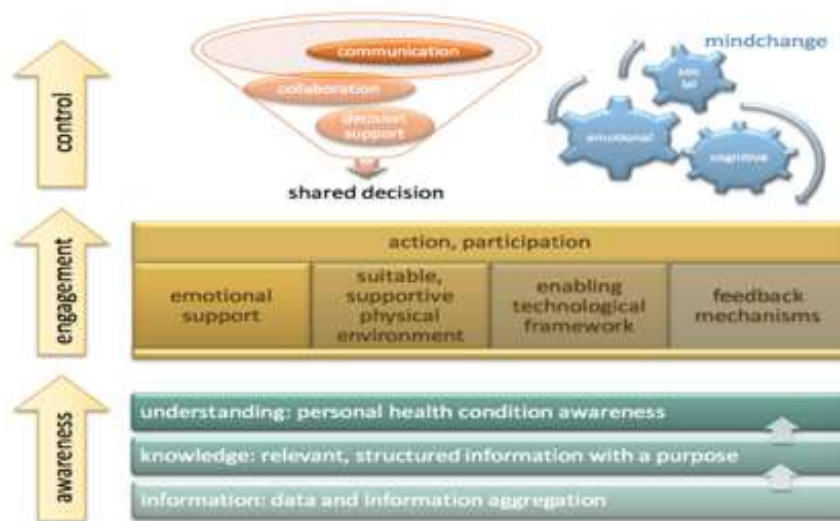
Figure 3.1 - Empowerment as a cognitive process [11]

3.2. Self-Care:

Self-care is essential to maintenance of health, and the prevention and management of chronic diseases [81]. The definition of self-care has evolved over the years [82]. However, a common theme emerges across all definitions; the focus is primarily on

healthy citizens with the intention of enhancing health and preventing diseases [82]. The World Health Organization (WHO) defines self-care as: "The ability of individuals to promote health, prevent disease, and maintain health and to cope with illness and disability with or without the support of a healthcare provider" [83]. According to Riegel et al. (2017), engaging in self-care entails active citizen participation in their own healthcare [81]. In this thesis, we subscribe to a definition of self-care from the Theory of Self-Care of Chronic Illness [14]. In this definition, the core elements of effective self-care are: (i) self-care maintenance, (ii) self-care monitoring, and (iii) self-care management [14]. Citizens engaged in self-care maintenance adhere to health promoting behaviours and practices to maintain physical and emotional stability. Self-care monitoring refers to a process involving monitoring and observing one's own health status and risk of diseases. Self-care management refers to the response to changes in health status or risk of developing a disease [14].

With regards to chronic disease prevention and management, the aim of empowerment and self-care is to help individuals in pursuing autonomous and informed decision making to enhance health and avoid illness [84]. Therefore, empowerment and self-management are conceptually linked; whereby empowerment can be considered as an enabling process that involves assisting individuals to acquire knowledge and resources to facilitate their engagement in self-care and its relevant components (i.e. self-care maintenance, self-care monitoring and self-care management). According to Eyüboglu et al. (2016), empowered individuals are more likely to engage in appropriate self-care [85]. At the citizen/individual level, and in a similar manner to health empowerment, the first and most essential step towards self-care is knowledge of one's health status [81]. In

order to engage in adequate self-care, citizens/individuals need to understand their current personal health status and be aware of their risk for future chronic conditions [81]. In that regard, there is a need to provide citizens with tools and resources to assist them in evaluating their health and assessing their personalized risks for chronic diseases. The emergence of eHealth technologies hold great potential in supporting the different aspects of empowerment and self-care [11]. eHealth technologies also provide the possibility of extending the delivery of efficient and affordable healthcare services, including primary and secondary prevention. Evidence demonstrates the effectiveness of eHealth interventions at improving behavioural modification outcomes, increased knowledge and awareness of personal health condition, and increased participation in healthcare [86].

3.3. Life-course Approach to Chronic Disease Prevention:

The life-course approach has emerged as a new concept in public health to explore how health later in life is influenced by earlier experiences. Evidence based on the Developmental Origins of Health and Disease (DOHaD) concept [87] demonstrated that exposure to risk factors during early life influences one's risk of developing chronic diseases in later stages of life. Therefore, there has been a growing interest in conceptualizing chronic disease aetiology within a life-course framework [88]. The life course approach to chronic disease epidemiology is defined as: "the study of long-term effects on chronic disease risk of physical and social exposures during gestation, childhood, adolescence, young adulthood, and late adult life. It includes studies of the biological, behavioural and psychosocial pathways that operate across an individual's life course to influence the development of chronic diseases" [88]. The life-course framework aims to provide a better understanding of chronic disease development in order to focus

attention on the impact of risk and protective factors on health, and to help shift healthcare services from reactive to proactive [10]. The World Health Organization (WHO) is adopting the life-course approach to health, and had made "investing in health through a life-course approach and empowering people" one of the four priority areas for public health policy [89].

According to the framework, an individual's risk of developing chronic diseases is accumulated throughout the life course [10]. Following birth, exposure to risk factors throughout an individual's life course (i.e. during infancy, childhood, adolescence and adulthood) can significantly influence the risk of developing a chronic disease. Figure 3.2. illustrates the accumulation model of the life-course approach, showing how risk is accumulated throughout the life-course and the underlying socioeconomic and environmental impacts on health [10, 90]. Even though risk factors begin to accumulate in early life, the accumulation model shows that the greatest risk increase is acquired in adult life. By the time a chronic disease is manifest in adult life, it usually has been a silent condition for years because of the accumulation of various risk factors [81]. Therefore, early preventive measures are essential to reduce chronic disease risks. Proactive and preventive interventions are more likely to be effective at preventing chronic diseases than conventional screening programs that identify the early stages of the disease, after it had established [10].

Adapted from: Betancourt, M. T., et al. "Monitoring chronic diseases in Canada: the Chronic Disease Indicator Framework." *Maladies Chroniques et Blessures au Canada* 34.1 (2014).
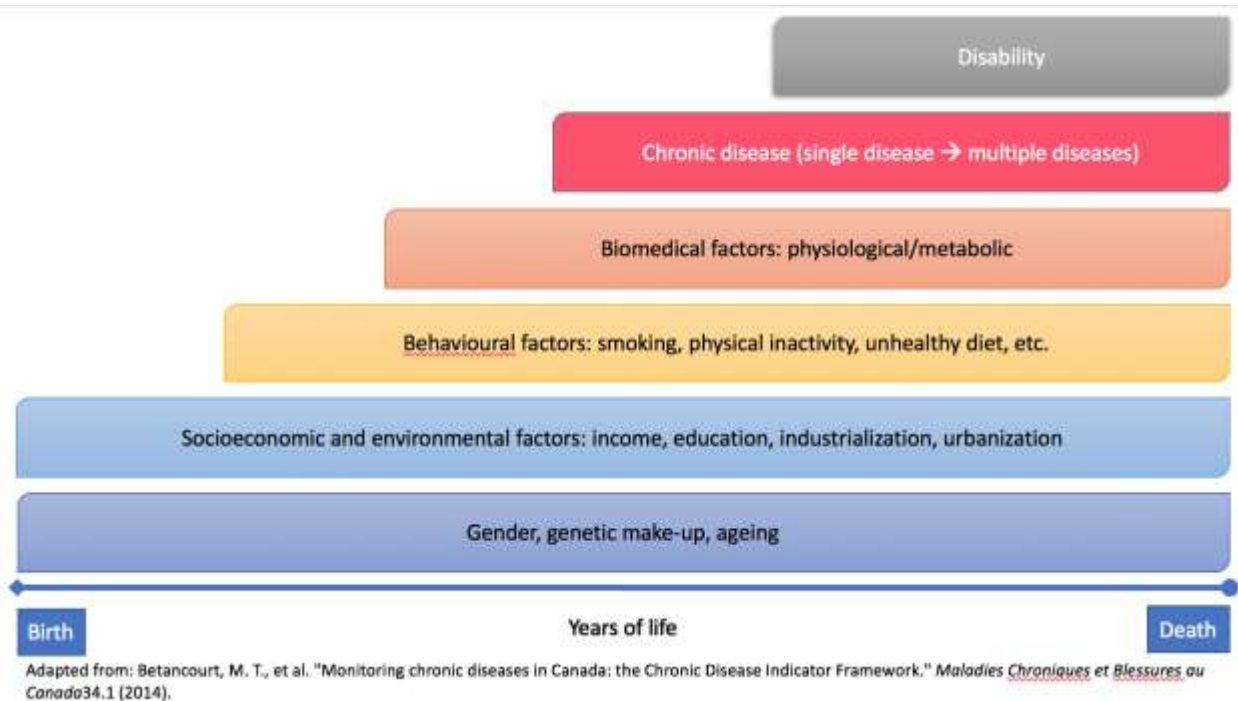
Figure 3.2 - The life-course approach accumulation model

The life-course approach to chronic disease prevention offers an exciting opportunity to reduce the burden of chronic disease. In this approach, the focus is on health, as opposed to specific diseases, and the goal is to view people more holistically by considering a wide range of risk factors, including distal socioeconomic and environmental factors [91].

A life-course approach also emphasizes on the early identification of underlying risk factors for chronic diseases. As such, taking a life-course approach allows for timely prevention strategies, and the effects on later disease risk reduction have the potential to be significant.

The life-course approach is based on the premise that chronic diseases can be prevented or controlled at multiple stages of life [10]. Furthermore, as outlined in the accumulation model, a life course approach recognizes the impact of a wide range of health

determinants on the risk of chronic diseases. This entails that preventive measures should target all ages and stages of life at various community-based settings.

However, to ensure that intervention will have long lasting effects, citizens must be provided with ongoing support to empower them, and build the resilience and capacity needed to promote health and prevent diseases [10]. In order to be empowered, individuals/citizens must be educated and informed about health risks, and the benefits of preventive measures, such as behaviour modification, in reducing the risk of chronic diseases. Promoting self-care and a sense of self-control (i.e. empowered individuals) are essential components to control the risk of chronic diseases across the life-course [92]. Novel eHealth technologies have the potential to empower individuals and promote the life-course approach to chronic disease prevention. The ubiquity of smartphones and personal computers nowadays makes them an obvious channel for the delivery of low-cost, community-based preventive interventions. Furthermore, the reach and accessibility of technology presents an opportunity to deliver the necessary tools and resources needed to support and engage citizens throughout the life-course.

3.4. Conceptualization of the theoretical framework:

In this chapter, we explored the important roles of empowerment, self-care and the life-course framework in preventing the onset of chronic diseases. We also demonstrated the need for novel eHealth platforms to assist citizens of all ages in self-assessing and self-monitoring their health and chronic disease risks. According to Kaldoudie et al. (2015) [11] and the Theory of Self-Care of Chronic Illness [14], knowledge of one's health status and risk of chronic diseases is essential to empower citizens and engage them in

self-care. Finally, we discussed the need for an integrated, health-focused and holistic approach to chronic disease risk assessment and prevention based on the life-course framework.

The abovementioned concepts were used to devise a concept map that guides the theoretical framework for this research (Figure 3.3). The overall aim of this research is to empower citizens to self-assess, monitor and manage their risks for multiple chronic diseases. By leveraging eHealth technologies, we aim to: (i) empower citizens by increasing their awareness of personal risks, (ii) promote self-care by providing the necessary tools and resources required to engage citizens in self-care maintenance, self-care monitoring and self-care management, and (iii) utilize the life-course framework to develop a holistic, health-focused and person-centered approach to chronic disease risk assessment and prevention.

The concepts of empowerment, self-care and the life-course approach are related and support each other to achieve a common goal: maintaining health and averting the risk of chronic diseases. Empowerment is considered as an enabling process, involving education to increase awareness of personal risks, with the intention of promoting adequate self-care, and engaging citizens in self-care maintenance, self-care monitoring and self-care management.

The life-course framework is a broad concept involving various activities and approaches. Empowering individuals and engaging them in self-care are essential components of the life-course approach to prevent and control chronic diseases. Moreover, a life-course approach to chronic disease prevention involves viewing people more holistically. A holistic and health-focused approach to chronic disease prevention

entails considering an individual's entire health profile by including a wide range of health determinants that influence the risk of chronic diseases.
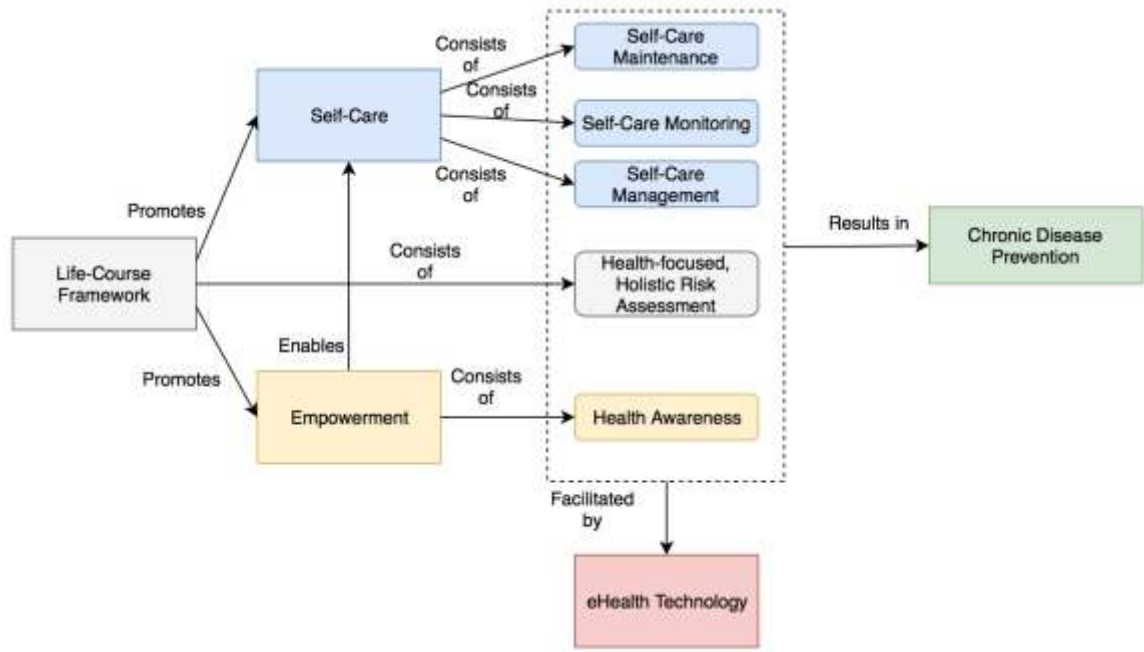
Figure 3.3 - Concept map describing the concepts and theories guiding the research's theoretical framework

3.5. Research Methodology:

The overall objective of this research is to investigate and implement a digital lifetime health platform that aims to empower citizens to pursue self-assessment and self-monitoring of chronic diseases risks. The research methodology was guided by the scientific theories and concepts outlined in this chapter. Furthermore, a concept map was devised (Figure 3.3) to demonstrate the inter-relationships between the concepts/theories and how they combine to achieve a common goal (i.e. prevention of chronic diseases). According to the concept map, effective chronic disease prevention can be achieved by: (i) providing the necessary tools and resources to increase citizens' awareness of their

health status and risk of chronic diseases (i.e. empowerment); (ii) providing a health-focused and holistic risk assessment approach; and (iii) providing appropriate tools to facilitate self-care monitoring, self-care maintenance and self-care management. Recent advances in eHealth technology can support and facilitate the different aspects of empowerment, self-care and the life-course approach. As such, the research methodology involves the following steps:

- **Step 1**: Identification of the major chronic diseases and cancers that contribute the most to the total burden of diseases in Canada.

- **Step 2**: Identification of validated chronic disease risk assessment tools for each of the chronic diseases and cancers identified in Step 1.

- **Step 3**: Identification of the inter-relationships between the risk factors and chronic diseases based on evidence presented in the risk assessment tools identified in Step 3.

- **Step 4**: Developing a high-level chronic disease knowledge model that maps the mutual interactions and associations between risk factors and chronic diseases based on the results of Step 3.

- **Step 5**: Formulation of a cumulative health risk assessment as a composite measure of multimorbid risk based on the aggregation of multiple risk factors.

- **Step 6**: Developing a prototype of an eHealth-based platform that provides citizens with the necessary tools and resources to achieve and facilitate empowerment, adequate self-care and a life-course approach to chronic disease prevention.

- **Step 7**: Evaluation of developed prototype.

Figure 3.4 shows a graphical representation of the research methodology steps, approaches, concepts and theories relevant to the research, and our phased approach to apply the research methodology.
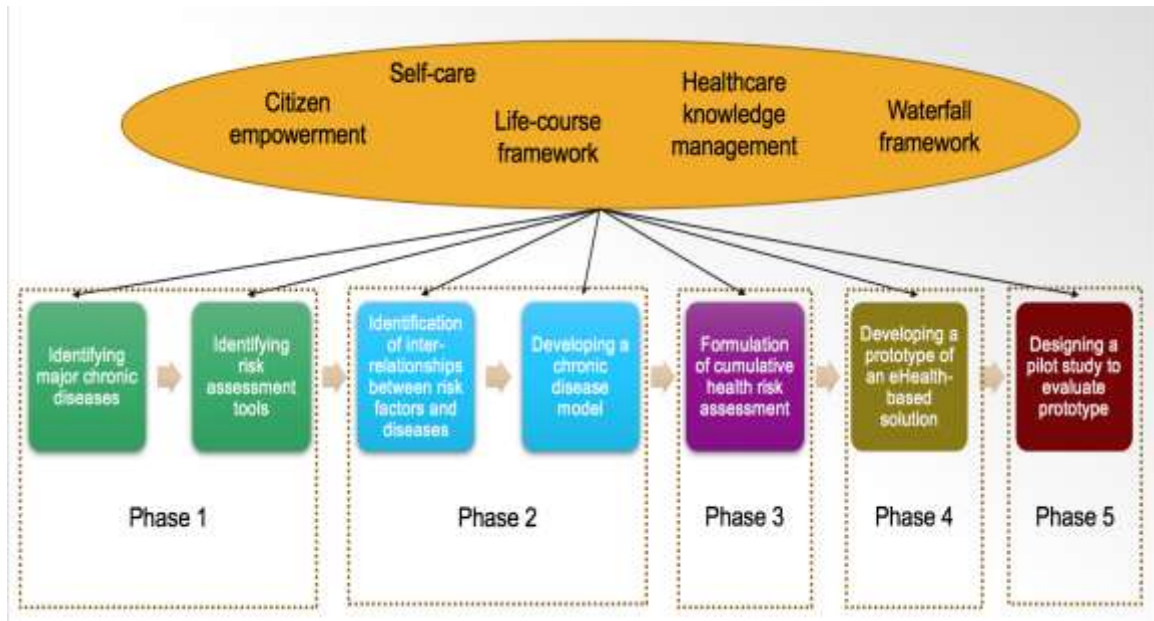
Figure 3.4 - Schematic representation of research methodology, concepts and theories relevant to the research, and the phased approach to apply methodology

CHAPTER 4: METHODS

The overall aim of this research is to develop and implement the PRISM lifetime health platform to empower citizens to self-assess, monitor and manage their risks for chronic diseases. By providing the necessary tools and resources, we can improve citizens' awareness of their personalized health risks and, as a result, engage them in pursuing adequate self-care to maintain a healthy status and prevent the onset of chronic diseases. The specific research objectives are as follows:

1. To identify and select validated chronic disease risk assessment algorithms for the major common chronic diseases and cancers in Canada;

2. To formulate a holistic and personalized approach to chronic disease risk assessment and prevention that considers a wide range of personal health determinants and risk factors, such as: demographic, environmental, socioeconomic, behavioural, biomedical and genetic risk factors;

3. To investigate a cumulative, health-centric (as opposed to disease-centric) risk assessment approach that reflect an individual's multimorbid chronic disease risk and overall health status due to the presence of multiple risk factors;

4. To develop a high-level chronic disease knowledge model that maps the mutual and complex associations and interactions between risk factors and chronic diseases;

5. To investigate and implement a digital health platform that will provide personalized lifetime health services to empower citizens to self-assess, self-monitor and self-manage their health conditions and risk of chronic diseases;

6. To design a pilot study to evaluate behavioural intentions towards using the proposed platform.

The objectives outlined above can be achieved by: (i) leveraging eHealth technologies and eHealth application frameworks to develop and implement a digital lifetime health platform, (ii) utilizing the life-course framework to formulate a holistic, health-focused and personalized approach to chronic disease risk assessment and prevention [10], (iii) utilizing interactive and intuitive risk communication methods and visualizations to improve citizens' knowledge and understanding of their personalized risk information, (iv) using a HKM approach to structure and model a high-level chronic disease knowledge model that can be used to generate personalized risk profiles and plan personalized risk mitigation and behaviour modification strategies [13].

This chapter outlines the research activities involved in the development of the PRISM lifetime health platform. The activities are divided into 4 phases:

Phase 1:

A. Identifying major common chronic diseases and cancers in Canada based on public health resources. This step was done to determine the relevant risk assessment tools to be incorporated into the PRISM platform.

B. Conducting a literature review to identify validated risk assessment tools for common chronic diseases and cancers.

Phase 2:

A. Developing a high-level chronic disease knowledge model to map the mutual associations and interactions between risk factors and chronic diseases using a knowledge management approach.

Phase 3:

A. Formulating the 'Health Asset Score' as a composite measure of multiple chronic disease risk factors.

Phase 4:

A. Developing the PRISM lifetime health platform by utilizing user-centered design and the Waterfall development model. This step also involved designing the functional portfolio and architecture of the platform.

B. Conducting a study to evaluate and determine citizens' behavioural intention towards using the PRISM lifetime health platform.

4.1. Phase 1 – Literature review:

This phase involved two critical research activities; identifying the chronic diseases that contribute the most to the burden of disease in Canada, and conducting a comprehensive review of the literature related to chronic disease risk assessment tools. Our goal was to select validated risk assessment tools for each of the chronic diseases identified in the first part of this phase. The selected risk assessment tools were then computerized using a HKM [13] approach and incorporated into the PRISM health platform.

4.1.1. Chronic diseases in Canada:

The first task of this research involved identifying common chronic diseases and cancers in Canada. Even though the burden of chronic diseases is growing globally, there are some variations in prevalence, incidence, morbidity and mortality rates across countries. The variations are primarily related to differences in environmental, socioeconomic and lifestyle risk factors, public health strategies, and genetic influences [93]. For example,

gastric cancer is four times more common in Japan than in Canada [94] due to differences in genetics and dietary habits between the respective populations [95]. Therefore, considering the regional differences in chronic disease rates is an important task, because these differences reflect the distribution of risk factors among different populations.

To identify the chronic disease most relevant to Canada, we refer to the *Chronic Disease Indicator Framework* [90]. The framework was developed by the Public Health Agency of Canada to enhance the surveillance of chronic diseases and associated risk factors. According to the framework, the major chronic diseases in Canada include: cancers, diabetes, cardiovascular disease and chronic obstructive lung disease [90]. The 4 major chronic diseases are responsible for 67% of all deaths each year, and thus represent the most common chronic conditions in Canada [90]. In addition to the 4 major chronic diseases, we also identified hypertension as a highly prevalent chronic disease [90]. With regards to cancers, there are many different types. Therefore, we limited our selection to the leading types of cancers based on incidence rates. From a preventive healthcare perspective, incidence rates are more useful, since it conveys information about the risk of developing the disease. Prevalence rates on the other hand, is a measure of disease burden with no regard to risk [96]. At this point, a limited number of cancers are considered, as we wanted to avoid the inclusion of rare cancers that make little contribution to the total burden of chronic disease.

The final list of chronic diseases and cancers to be considered for the PRISM platform, along with their incidence rates, are listed in Table 4.1. The selected chronic diseases and cancers represent the most prevalent and most commonly diagnosed chronic conditions in Canada.

Table 4.1 - List of chronic diseases considered for this thesis

Chronic Disease	Incidence Rate – per 1000
Hypertension	16.3
Chronic Obstructive Pulmonary Disease (COPD)	8.6
Diabetes	8.1
Ischaemic Heart Disease*	6.1
Heart Failure*	5.2
Cancer	5.2
Stroke*	2.9
Acute Myocardial Infarction*	2.3

*Cardiovascular diseases

4.1.2. Chronic disease risk assessment tools:

This task involved conducting a comprehensive literature review to identify a number of risk assessment tool for each of the chronic diseases listed in Table 4.2. The search was focused on tools which can be used by lay citizens. Google Scholar, PubMed, Novanet, Cochrane Library, The Lancet and article cross-references were searched without date restrictions up to January 25, 2016. Keywords used included: Chronic Diseases AND (Risk Assessment OR Risk Prediction) AND (Tool OR Algorithm OR Model) AND (Diabetes OR Cardiovascular Disease OR Stroke OR COPD OR Hypertension OR Neoplasms).

Initially, the risk assessment tools were selected using the following criteria: 1) supported by a peer-reviewed publication; 2) were in English; and 3) could be used by lay

individuals, rather than healthcare professionals. Risk assessment tools were excluded if they: 1) assessed the prognosis of those already diagnosed with the disease; 2) predicted the probability of disease-related events, i.e. prediction of cancer metastasis or disease recurrence; 3) assessed the stage of established disease; 4) predicted life expectancy or mortality; and 5) determined the probability of disease heredity. In total, we identified 42 risk assessment tools.

Table 4.2 - Risk assessment tools identified through literature review

Chronic disease	# of risk assessment tools
Cardiovascular disease	7
Diabetes	6
Colorectal cancer	6
Breast cancer	4
Hypertension	3
Pancreatic cancer	3
Melanoma	3
Lung cancer	3
Uterine cancer	2
Ovarian cancer	2
Kidney cancer	2
Chronic Obstructive Pulmonary Disease (COPD)	1

We were not able to identify appropriate risk assessment tools for prostate cancer, bladder cancer, non-Hodgkin's lymphoma, oral cancer and COPD, as the algorithms did not meet our selection criteria. A number of the risk algorithms that were excluded were

those that were intended to screen individuals for early symptoms of an already
established disease, as opposed to assessment of risk factors to predict future risk of the
disease. Additionally, some of the algorithms/models that were not considered were
based on the results of non-routine, disease-specific lab tests such as the Prostate-Specific
Antigen (PSA) for prostate cancer, which is used to detect early stages of the disease
[97].

After compiling the initial list of risk assessment tools, we collected the following
information for each risk assessment tool to inform our final selection process:

1. Risk factors included in the tool;

2. Disease outcomes assessed;

3. Method of conveying risk information;

4. Validation of the model; and

5. The data source used to develop the tool.

Our aim was to identify and select risk assessment tools based on the following criteria:
1) risk tool endorsed by Canadian clinical practice guidelines; 2) includes a wide range of
risk factors and protective factors; 3) includes actionable risk factors - i.e. risk factors
which can be modified by behavioural or clinical interventions; 4) presents risk
information in the form of short-term risk, as opposed to lifetime risk of disease; and 5)
risk tool translates risk 'score' into risk categories - i.e. low/moderate/high risk. Risk
assessment tools were excluded if: 1) risk tool focuses on non-modifiable risk factors
(e.g. past medical history and family history); and 2) risk tool cannot be computerized -
i.e. if publication does not provide sufficient information on the risk algorithm.
Since our approach to chronic disease risk assessment is based on the life-course

framework, we emphasize on the inclusion of risk assessment tools that incorporate a wide range of modifiable and non-modifiable factors that reflect the demographic, socioeconomic, environmental, behavioural and biomedical aspects of an individual's life. Furthermore, it is essential that we consider inclusion of risk assessment tools that focus on actionable (i.e. modifiable) risk factors in order to engage citizens in self-care and health promoting behaviours.

According to our inclusion/exclusion criteria, we selected the following risk assessment tools to be incorporated in the PRISM lifetime health platform:

A. Framingham General Cardiovascular Risk Score [32]:

The Framingham General Cardiovascular Risk Score was created as part of the Framingham Heart Study, and is among the most widely validated and used risk assessment tool for cardiovascular disease. FRS is recommended by the national guidelines for cardiovascular diseases in Canada and US. Furthermore, the Framingham risk prediction tool has received class I recommendation from the American College of Cardiology and American Heart Association [98]. The tool predicts an individual's 10-year risk for the following outcomes: coronary death, myocardial infarction, coronary insufficiency, angina, ischemic stroke, hemorrhagic stroke, transient ischemic attach, peripheral artery disease and heart failure. The tool collects information on age, gender, history of diabetes, history of hypertension, smoking habits, total cholesterol, HDL cholesterol, BMI, and systolic blood pressure. The tool was selected because it is well-known and has been validated in many different populations.

B. Framingham Hypertension Risk Score [34]:

The Framingham Hypertension Risk Score predicts an individual's risk of hypertension

over 4-years. The tool was developed based on an algorithm from the Framingham Heart Study (FHS). The risk factors assessed include: age, gender, systolic and diastolic blood pressure, BMI, family history of hypertension, and smoking habits. The tool is well calibrated and shows high discriminative power. Furthermore, the tool has been validated in various populations, with good calibration and discrimination.

C. Canadian Diabetes Risk Assessment Questionnaire (CANRISK) [99]:

CANRISK was developed by Canadian diabetes experts based on the Finish Diabetes Risk model (FINDRISC) with modifications to reflect Canada's multi-ethnic population. Robinson et. al demonstrated that CANRISK is a valid tool for assessing risk of Type 2 Diabetes in multi-ethnic populations. The Canadian Diabetes Association has recommended the use of CANRISK in its clinical practice guideline for the screening of diabetes [100]. Moreover, online versions of the risk assessment tool are hosted at the websites of Government of Canada and the Canadian Diabetes Association [100]. The tool assesses a the 10-year risk of developing diabetes based 12 risk factors representing demographic, socioeconomic, behavioural and biomedical aspects of an individual's life.

D. Harvard Cancer Risk Index (HCRI) [101]:

HCRI is a risk assessment tool designed to predict the risk of developing the different types of cancers for both sexes. The tool was developed by a group of clinicians and epidemiologists to generate personalized risk estimates based on an individuals' exposure to known risk factors of cancer. For each type of cancer, the HCRI tool provides a list of relevant risk factors. Thus, the tool allows individuals to identify behavioural and lifestyle risk factors that could be changed to reduce one's cancer specific risk. The HCRI also includes a wide range of non-modifiable risk factors representing demographic,

socioeconomic and environmental aspects of an individual's health profile. The incorporated algorithm presents the risk information in the form of relative risks (i.e. risk relative to the general population), in addition to the 10-year risk of developing cancer. The types of cancers assessed include: Colon cancer, breast cancer, ovarian cancer, melanoma, kidney cancer, pancreatic cancer and uterine cancer. The HCRI has been validated in various studies [102, 103].

E. *PLCO$_{m2012}$ lung cancer risk assessment tool [104]:*

PLCO$_{m2012}$ was developed as part of the Prostate, Lung, Colorectal and Ovarian Cancer Screening Trial (PLCO). The tool estimates 6-year risk of lung cancer in ever-smokers based on a number of risk factors that influence the development of lung cancer. PLCO$_{m2012}$ incorporates smoking intensity, duration and years quit as variable to predict the risk of lung cancer, in addition to demographic, socioeconomic and health-related factors. Individuals are stratified into low/moderate/high risk groups. The tool has been validated in various recent studies, and found to have high predictive performance [105].

In conclusion, we identified 5 risk assessment tools that met our inclusion/exclusion criteria. We aim to computerize and incorporate the above-mentioned risk assessment tools into the PRISM lifetime health management platform. The selected risk assessment tools allow individuals to assess their risks for 11 chronic diseases and cancers. We believe that the selected risk assessment tools can capture a person's entire health profile with respect to demographic, socioeconomic, environmental, behavioural and biomedical risk factors. Furthermore, the risk assessment tools included in the PRISM health platform provides individuals with a comprehensive list of modifiable risk factors that

can have a significant impact on reducing their personalized risks for chronic diseases and cancers.

4.2. Phase 2 – HKM approach to chronic disease modelling:

In this phase, we develop a high-level chronic disease knowledge model. Our aim is to structure and organize information related to chronic diseases, their associated risk factors and the risk assessment tools by using a HKM approach [13]. The chronic disease knowledge model will be utilized to develop the data model for the PRISM lifetime health platform in phase 3. Also, the knowledge model can be used to map citizen-specific risk factors to the relevant chronic diseases and cancers. By doing so, we can develop personalized risk mitigation and behaviour modification plans.

The second activity in this phase involves developing the Health Asset Score, as a proof-of-concept, based on the aggregation of multiple chronic disease risk factors. Our idea is to provide citizens with an intuitive and easy to understand health score that demonstrates their overall health status with respect to risk of chronic diseases and multi-morbidities.

4.2.1. Chronic disease knowledge model:

The development of chronic diseases generally follows a complex chain of events, whereby various health determinants and risk factors cluster and interact throughout an individuals' life-course resulting in chronic morbidity, disability and, eventually, mortality. We discussed the different categories of chronic disease risk factors, and the mutual interaction between the factors in Chapter 2.

According to the life-course framework, chronic diseases share many risk factors, such that a single risk factor can influence the risk of developing multiple chronic conditions.

As an example, obesity is a well-established risk factor for cardiovascular disease [32], diabetes [100], and breast cancer [106]. Therefore, it is quite common to find more than one chronic disease in a single patient (i.e. multi-morbidity). Figure 4.1 illustrates the mutual interactions between various risk factors, and their influence on the development of ischemic heart disease [24].
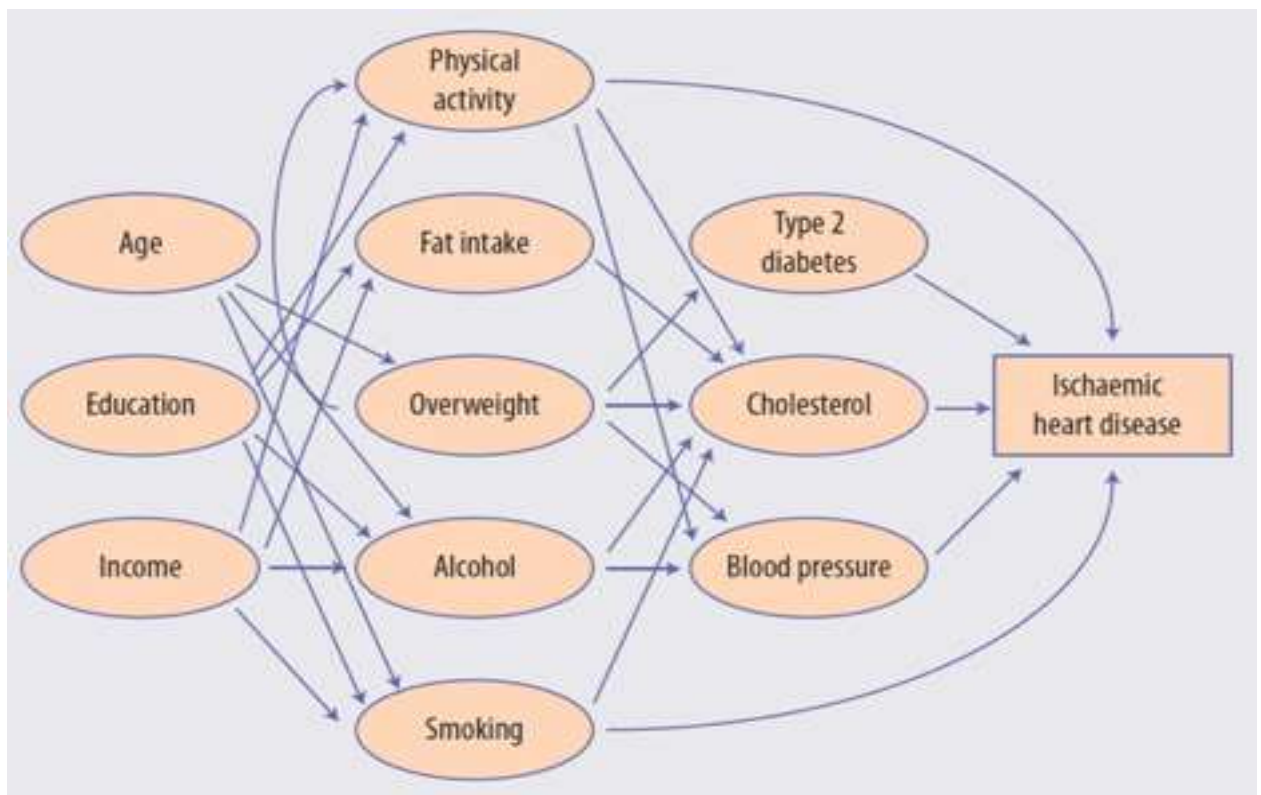
Figure 4.1 - Mutual interactions between risk factors and heart disease [24]

The diagram also shows the influence of Type 2 Diabetes, a chronic disease, on the risk of developing another chronic disease (ischemic heart disease). Evidence suggests that the onset of a chronic disease can increase the risk of developing other associated chronic diseases [10, 24]. As a result, chronic diseases themselves can be risk factors for other

chronic conditions.

In this regard, one of our research objectives were to develop a chronic disease knowledge model to capture and map the mutual associations and interactions between risk factors and chronic diseases. By doing so, we can systematically relate and organize the information related to risk factors, chronic diseases, and risk assessment algorithms within a single chronic disease knowledge model that will inform the design and development of the PRISM lifetime health platform data model.

In this thesis, we have taken a HKM approach [13] to develop our proposed chronic disease knowledge model. HKM is defined as "the systematic *creation*, *modeling*, *sharing*, *operationalization* and *translation* of healthcare knowledge to improve the quality of patient care" [13]. From a functional perspective, the activities of HKM include: capturing, modeling and organizing heterogeneous healthcare knowledge to bring about comprehensive and validated healthcare knowledge resources that are readily available for access by relevant stakeholders [13]. As such, a HKM approach allows for the integration and modeling of various healthcare knowledge resources. In this thesis, the healthcare knowledge resources are related to: (i) chronic diseases; (ii) risk factors; and (iii) risk associations between risk factors and chronic diseases, based on the identified risk assessment tools.

In terms of knowledge modeling, the most common approach entails the use of ontologies [13]. However, at this stage, we believe that developing a conceptual chronic disease knowledge model, as opposed to ontological modeling, is sufficient to inform: (a) the development of the PRISM platform data model; and (b) the computerization of risk

assessment models/algorithms. Ontological modeling would be more useful once chronic disease preventive measures are incorporated into the platform in order to develop personalized risk mitigation and behaviour modification plans.

To develop a conceptual chronic disease knowledge model, we subscribe to the knowledge modeling methodology proposed by Abidi, (2008). The methodology was developed to inform the modeling of healthcare knowledge artifacts, and involves the following tasks [13]:

1. *Knowledge classification:*

This step involves the overall classification of the relevant knowledge domain [13]. The knowledge domain and the healthcare knowledge resources (i.e. artifacts) were identified in phase 1. First, we classified chronic diseases according to the type (tumor based disease vs. non-tumor based diseases) and gender (gender specific diseases vs. non-gender specific diseases). Risk factors were classified by type (modifiable vs. non-modifiable) and category (genetic, demographic, environmental, socioeconomic, behavioural and biomedical). Furthermore, given that chronic diseases can be risk factors themselves, we further classified biomedical risk factors as follows: diseases, disorders, and conditions. A disease is defined as a condition characterized by functional or structural impairment and is manifested by specific clinical signs and symptoms [107]. A disorder is characterized by functional impairment but not structural change, and signs and symptoms do not have to be present to classify a medical condition as a disorder [107] - e.g. dyslipidemia, hyperglycemia. Finally, a condition is a state of health whether well or ill [107] - e.g. obesity, pregnancy.

2. Knowledge Selection:

This step involves the selection of healthcare knowledge artifacts. For our purposes, the knowledge artifacts are evidence-based, validated risk assessment models/algorithms. We discussed the steps taken to identify appropriate risk models/algorithms in phase 1.

3. Knowledge Abstraction:

In this step, we develop a conceptual chronic disease knowledge model through *knowledge abstraction* [13, 108]. The process of knowledge abstraction is guided by the underlying principles of grounded theory; involving the collection and analysis of knowledge with the aim of constructing an explanatory model of the phenomenon under study [109]. This entails deconstructing the knowledge domain concepts into identifiable components, and analyzing how these components relate with one another [13].

Our proposed chronic disease knowledge model consists of the following concepts:

  i.   **Risk elements**: denoting all health-related factors that influence the risk of chronic diseases. Given that chronic diseases can influence the risk of other chronic conditions, we opted to represent all risk-causing factors in one classification. As such, the concept of *Risk Elements* would include all diseases, disorders and medical conditions relevant to chronic diseases, in addition to the conventional risk factors, e.g. demographic, environmental and lifestyle risk factors.

  ii.   **Observables:** a measure, metric or biomarker of *Risk Elements*. *Observables* are essentially citizens' measurable health attributes which can be used to

quantify the exposure to a specific risk factor. In terms of risk assessment, *Observables* will be used to determine the risk association between a risk factor and a given chronic disease. Each *Risk Element* would be associated with 1 or more observables. Examples of *Risk Elements* (i.e. risk factors) and associated *Observables* are outlined in the table below (Table 4.3).

Table 4.3 - Examples of Risk Elements and associated Observables

Risk element	Associated observable
Obesity	Body Mass Index (BMI)
Cardiovascular disease	History of cardiovascular diagnosis: yes/no
Hypertension (high blood pressure)	Systolic and diastolic blood pressure
Smoking	Number of cigarettes per day

    iii.   **Risk Association:** a concept that describes the association between risk factors (source of risk) and chronic diseases (target of risk). Here, we refer to the factors influencing the risk of chronic diseases as *Source of Risk Element* and chronic diseases as *Target of Risk Element.* In order to determine the risk association, we have to state a specific observable that provides a measure of the source of risk (i.e. risk factor), and the specific condition under which the association becomes true.

The chronic disease knowledge model is based on health-related factors that influence the risk of developing chronic diseases. The objective is to capture and model associations and relationships between risk factors and chronic diseases. The primary concepts and their relationships are outlined in the diagram below (Figure 4.2).
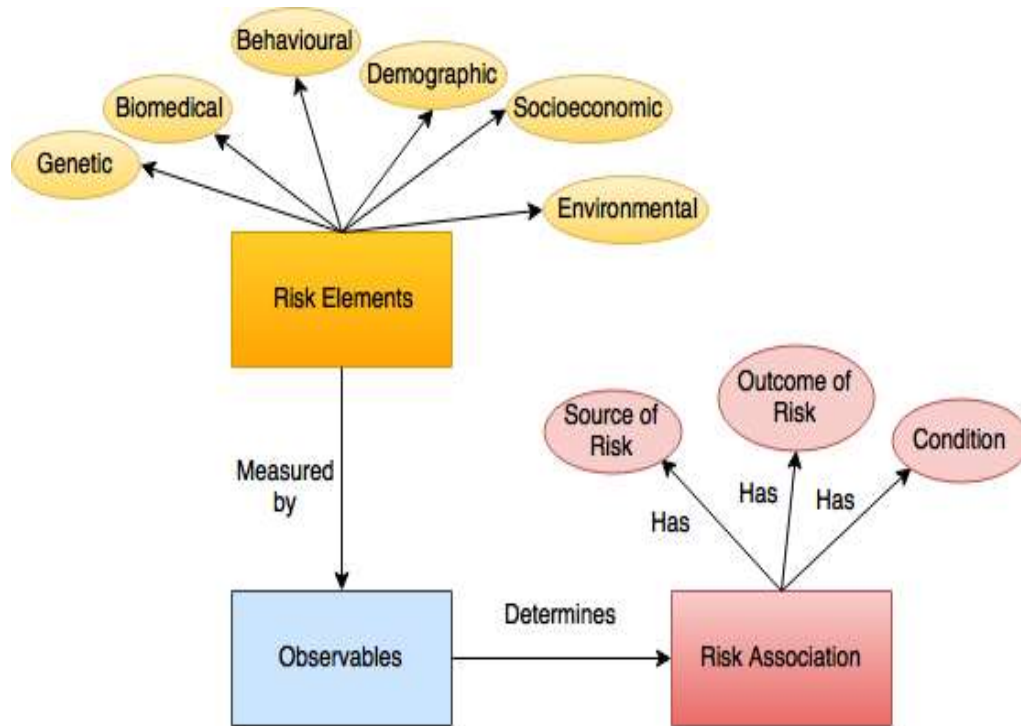
Figure 4.2 - Knowledge model primary concepts and their relationships

4.3. Phase 3 – Formulation of a cumulative health score:

In phase 3, we develop a proof-of-concept 'Health Asset Score' based on the integration of multiple chronic disease risk factors. Current chronic disease risk assessment tools are disease-focused, as opposed to health-focused - i.e. we are not measuring the overall health status of individuals in terms of the net effect of the presence/absence of multiple chronic disease risk factors. The aetiology of chronic diseases is complex and multi-causal, therefore isolation the aetiology of a disease to a unique set of risk factors is not realistic. Furthermore, pursuing a disease-centric view risk assessment approach is not helpful in illustrating the overall 'health' status of an individual. In line with the life-course framework [9, 10, 88, 110], we propose that a health-focused approach can provide a single objective health status measure (i.e. a cumulative health score) of a person's health, and accounts for the risk of multi-morbidity.

We believe that a health score, representing one's overall health status and risk of multi-morbidity will: a) provide individuals with an overall assessment of their health and the influence of harmful risk factors towards the onset of chronic diseases, and b) facilitate the design of personalized risk mitigation and behaviour modification plans that target the attainment of lifetime health, such that the effect of risk modification transcends to multiple related/associated diseases so that the net effect is an overall risk aversion and improvement of the person's health score.

By extending on previous work done on chronic disease and health risk scores [41, 42, 43, 101], we develop the 'Heath Asset Score' as a measure of a person's overall health and risk of multi-morbidity based on the integration of multiple impactful risk factors. The impact of risk factors is assessed according to their contribution to the total burden of diseases in Canada. We describe our approach for determining the health score risk variables (henceforth referred to as risk elements) and our proposed method for the calculation of the 'Health Asset Score' in the following steps:

1. Determining 'Health Asset Score' risk elements (section 4.3.1.)

2. Proposed method for the calculation of the 'Health Asset Score' (section 4.3.2.)

3. Constructing the 'Health Asset Score' (section 4.3.3.)

4.3.1. Determining 'Health Asset Score' risk elements:

To ensure the inclusion of a comprehensive set of health variables for the 'Health Asset Score', we refer to the *Chronic Disease Indicator Framework.* The framework was developed by the Public Health Agency of Canada to inform the public and stakeholders on chronic disease indicators that affect the health of the population [90]. The framework identifies six core domains to group eligible indicators that constitute the framework:

social and environmental factors, early life/childhood factors, behavioural risk factors, risk conditions, disease prevention practices and health outcomes/status. The indicators and/or risk factors (i.e. risk elements) were selected based on the following inclusion criteria: a) potentially actionable (i.e. subject to modification by clinical or behavioural intervention); and b) have substantial impact on the burden of chronic disease in Canada. The risk elements included for the calculation of the *'Health Asset Score'* are described in Table 4.4. We excluded risk elements in the socioeconomic, environmental and early life/childhood factor categories, since they have little impact on the burden of chronic diseases in Canada [111]. Additionally, the risk elements in the disease prevention practices domain (i.e. disease screening), since they are primarily related to secondary and/or tertiary prevention of chronic diseases, as opposed to primary prevention [90]. The framework also incorporates health outcomes and/or status domain, which provides information on the impact of risk elements (i.e. chronic diseases and associated risk factors) on quality of life, disability and premature death. These elements are considered for the calculation of the 'Health Asset Score' in the form of weights assigned to each risk element according to their impact on the total burden of diseases in Canada.

Table 4.4 – Risk elements included in the Health Asset Score

Core Domain	Risk Element
Behavioural risks	Smoking
	Physical activity
	Dietary habits
	Alcohol intake
Risk conditions	Obesity (high body mass index)
	Elevated blood pressure

Core Domain	Risk Element
Risk Conditions	Elevated blood glucose
	Elevated blood cholesterol

4.3.2. Proposed method for the calculation of the 'Health Asset Score':

Our aim is to provide citizens with a cumulative health score that summarizes the impact of multiple risk factors and risk conditions. An important consideration is that some risk factors have stronger associations with chronic diseases than others. Therefore, the selected risk variables are weighted differentially according to their contribution to the total burden of disease in Canada.

Additionally, to account for dose-response relationships between risk factors and chronic diseases, the total weight for each variable can be divided across levels of exposure. The weight can be distributed according to the estimated relative risk of chronic disease for each level of exposure to the risk element (i.e. risk factor) based on evidence-based epidemiological research. This method takes into account the linear associations between risk factor exposure and risk of chronic diseases.

4.3.3. Constructing the 'Health Asset Score':

Following the approach proposed by Miller (2005) [112], first, we assigned weights for each risk variable according to its contribution to the total burden of diseases in Canada. The risk variables are weighted relative to dietary risks (set at a score of 1) since non-adherence to healthy diet contributes most to the total burden of disease in Canada. Table 4.5 outlines the initial weight assignment for each risk variable.

Table 4.5 - Initial weight assignments for the Health Asset Score variables

Risk element	Contribution to total burden of disease (%)	Assigned weight
Dietary risks	9.54%	1
Smoking	9.34%	0.98
BMI	6.76%	0.71
Elevated blood pressure	6.52%	0.68
Elevated blood glucose	6.33%	0.66
Elevated total cholesterol	3.85%	0.4
Alcohol consumption	3.68%	0.39
Physical activity	2.09%	0.22

Following the assignment of weights, we created 8 levels of relative risks; each level is given a score according to the strength of association for a range of relative risk values [36, 113]. Generally, relative risks are used to compare the risks between two groups - i.e. group exposed to risk vs. group not exposed to risk. A relative risk greater than 1 indicates that the risk of a negative health outcome is greater compared to the other group (i.e. group without exposure to risk factor). Conversely, a relative risk less than 1 indicates that the risk is lower compared to the risk in individuals with the given risk factor. Therefore, relative risks greater than 1 indicate a positive strength of association with the disease, and relative risks less than 1 indicate a negative strength of association

with the disease.

As a result, we created 8 levels of relative risks, whereby each level was assigned a positive or negative score indicating the magnitude of association (Table 4.6).

Table 4.6 - Relative risk levels with corresponding magnitude of association score

Relative risk	Magnitude of association score
0.7-0.9	-1
>0.9 to 1.1	0
>1.1 to 1.5	1
>1.5 to 2.5	2
>2.5 to 3.5	3
>3.5 to 4.5	4
>4.5 to 6	5
>6	6

Finally, each selected risk element in the 'Health Asset Score' was divided across varying levels of exposure. Defining risk exposure levels was determined based on epidemiological evidence in the literature. The final 'Health Asset Score' is calculated by multiplying the burden of disease weights by the relative risk strength of association scores. The cumulative 'Health Asset Score' is the sum of scores of all 8 risk elements (Table 4.7), with higher scores indicating higher risk for chronic diseases and multi-morbidities. The scores range from -1.2 to 10.86, and can be rescaled into a 100-point scale.

Table 4.7 - Final scores associated with each risk element for the Health Asset Score

Risk element	Score
Dietary risk*	• ≤7 points = 0

Risk element	Score
Dietary risk*	• >7 points = -1
Smoking	• Non-smoker = 0 • Former smoker = 0.98 • Current light smoker = 0.98 • Current moderate smoker = 1.96 • Current heavy smoker = 1.96
Body Mass Index (BMI)	• <30 kg/m^2 = 0 • 30-34.9 kg/m^2 = 0.7 • >35 kg/m^2 = 1.4
Systolic Blood Pressure (SBP)	• SBP < 120 = 0 • SBP 120– 139 = 0.7 • SBP ≥ 140 = 1.4
Blood glucose	• 3.9-5.4 mmol/L = 0 • 5.5 -7.7 mmol/L = 0.7 • 7.8 -11 mmol/L = 1.9 • ≥11.1 mmol/L = 3.3
Total cholesterol	• ≤4 mmol/L = 0 • 4.1 – 5.1 mmol/L = 0.4 • 5.2 – 6.2 mmol/L = 0.8 • 6.3 – 7.7 mmol/L = 2 • ≥ 7.8 mmol/L = 2.4
Alcohol consumption	• < 7 per week = 0 • ≥ 7 per week = 0.4
Physical activity	• ≥2.5 hrs per week = -0.2 • <2.5 hrs per week = 0

*Dietary risks are calculated based on a validated 14-item questionnaire of

Mediterranean diet adherence.

4.4. Phase 4 – Development of the PRISM lifetime health platform:

In this phase, we describe the approach and steps taken to develop the PRISM lifetime

health platform. The aim is to develop a citizen empowerment ecosystem that provides a

suite of personalized lifetime health services to help them lead a disease-free, healthy life.

More specifically, the objective is to develop a web-based health platform that provides

citizens with the necessary tools are resources to assist them to self-assess, self-monitor

and, as a result, self-manage their health and chronic disease risks. The PRISM lifetime

health platform intervention principles are based on key elements of the following

theories and frameworks:

1. Empowerment as a cognitive process [11] – Awareness of one's health status.

2. Theory of self-care of chronic illness [14] – Self-monitoring.

3. Life-course framework [9, 10, 88, 110] – Holistic, health-focused risk assessment

   approach by considering multiple chronic diseases and citizens' comprehensive

   risk profile.

The diagram below (Figure 4.3) outlines the steps taken to design and develop the

PRISM lifetime health platform. The steps are described in detail in the following

sections.
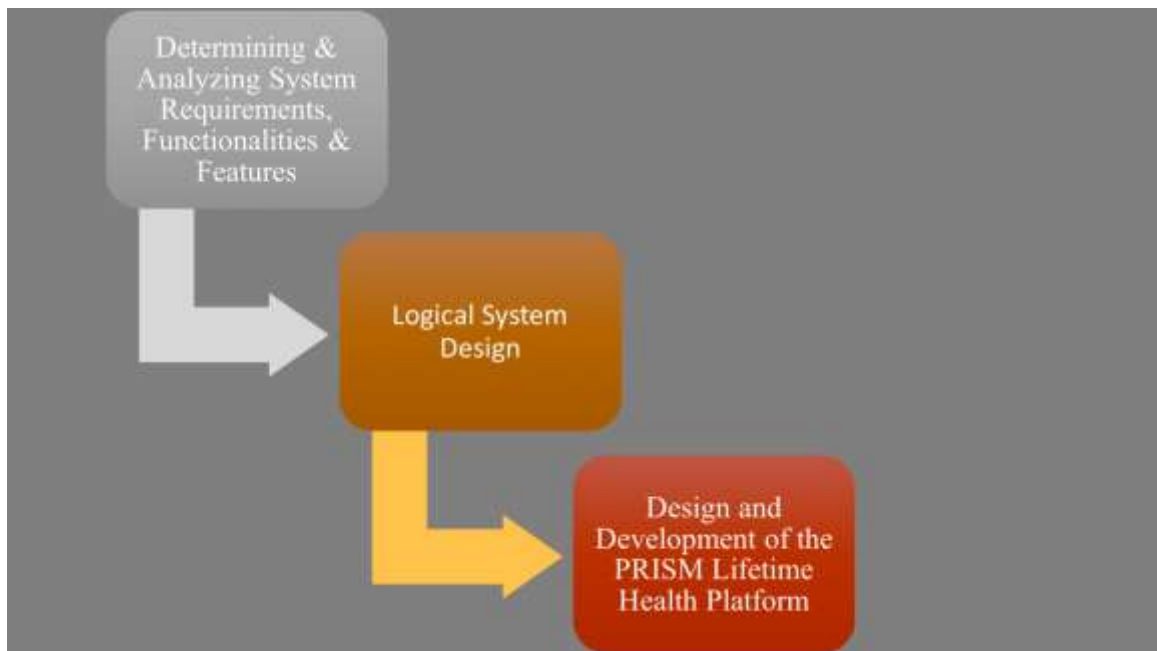
Figure 4.3 - Steps taken to develop and design PRISM

4.4.1. Determining & analyzing system requirements, functionalities & features:

In the Systems Development Life Cycle (SDLC) the first phase of development involves planning and determining the proposed platform's scope [114]. For our purposes, the scope is determined by the research objectives outlined in this thesis. Therefore, the scope of the PRISM lifetime health platform, at this stage of its development, is limited to providing citizens with: 1) tools and resources to help them self-assess their overall health status and chronic disease risks; 2) interactive visualizations to translate their personalized health and chronic disease risk information; and 3) tools to facilitate self-monitoring.

After determining the scope, the next important task involves determining and analyzing requirements of the proposed platform [114]. In this task, we carefully study the targeted research domains (i.e. personalized chronic disease risk assessment and self-monitoring) and existing eHealth development frameworks to identify what is required from the proposed platform in terms of features and functionalities. As a result, this task will inform the development of the platform's functional architecture and functional portfolio. To date, few frameworks have been developed to guide the design and development of eHealth applications [115, 116, 117]. Such frameworks are developed to address the issues and challenges inherent within the complex environment of healthcare [117]. Furthermore, the frameworks provide a systematic method to design and develop eHealth applications/platforms in a way that ensures the proposed technology achieves its maximum intended potential [115, 117].

However, despite the growing number of consumer-oriented eHealth applications and/or platforms, most lack a validated theoretical framework/foundation [118]. For this thesis,

we refer to the Waterfall Framework [117]. According to Wilhide III et al. (2016),

application of the framework results in an iterative process for the identification of key

features and content to be incorporated into the proposed platform [117]. The framework

consists of 3 primary domains to guide the development of eHealth systems: strategic,

intervention design and product features and content. The framework is described as a

"waterfall process" since the output of each domain feeds into the next domain (Figure

4.4) [117].
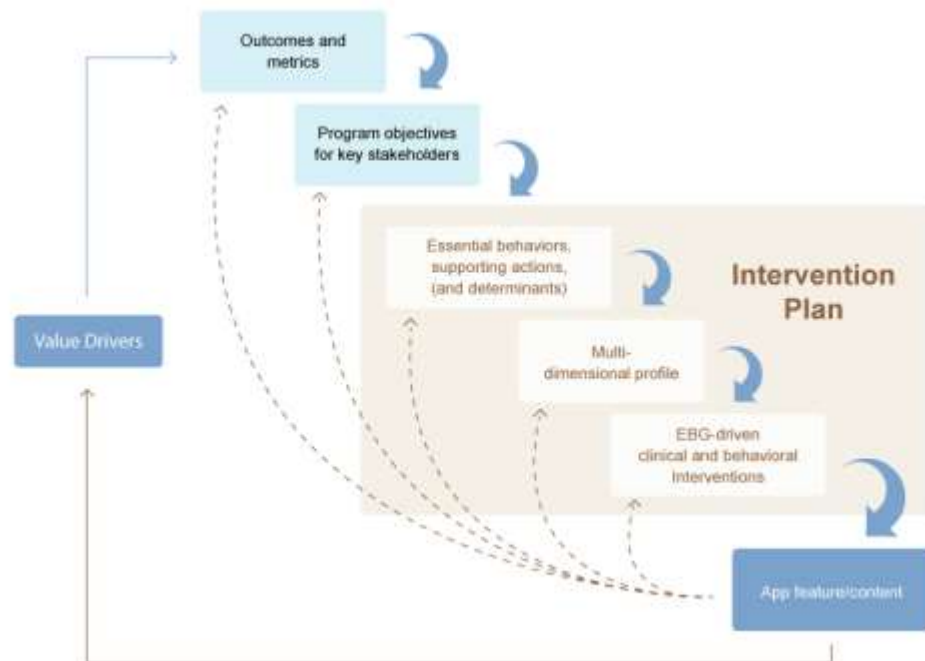
Figure 4.4 - The waterfall framework

1. Strategic Domain:

The first strategic domains (*value drivers, outcomes and program objectives*) set the

course for the development of the platform and, as a result, guide the identification of

subsequent domains and subdomains. *Value drivers* are defined as "the entities that

increase the value of a product or a service" [117]. For our purposes, the value drivers are

derived from the overall goals and objectives of the research: empower citizens to self-

assess and self-monitor overall health status and risks of chronic diseases. The *outcomes domain*, guided by value drivers, are defined as the required/desired results of the program (i.e. the PRISM health platform). We have identified short- and long-term outcomes:

- Short-term outcome (related to self-assessment and self-monitoring): increased knowledge and awareness of one's health.

- Long-term outcomes (related to citizen empowerment): improved health status and avoidance of chronic illness.

Value drivers and program outcomes inform the definition of the final strategic domain: *program goals for key stakeholders*. In our case, the key stakeholders are citizens using the platform. Program goals for key stakeholders are typically broad general statements that indicate the achievements attained based on sustained engagement with the PRISM health platform: effective decision making, improved knowledge of chronic diseases and existing personal risk factors, and engaging citizens in managing their health and risks for multiple chronic diseases.

2. Intervention Domain:

The intervention domain includes 3 subdomains: *essential behaviours/supporting actions, multi-dimensional profiles, and clinical/behavioural intervention* [117]. These domains inform the identification and design of interventions that result in improved health outcomes and reduction in risk of chronic diseases. The *essential behaviours/supporting actions* subdomain refers to "a behaviour that should be emphasized through program interventions because of its impact on public health" [119]. For this thesis, we derived the elements for the essential behaviour domain from the strategic domain and the following

theories and frameworks: (i) theory of self-care for chronic illness, which emphasizes on self-monitoring [14]; (ii) citizen empowerment framework, which emphasizes on engaging individuals and increasing awareness of their health status [11]; and (iii) the life-course framework, which emphasizes on engaging individuals in the early identification of risk factors by pursuing self-assessment for the risk of chronic diseases [9, 10, 88, 110].

The second subdomain of the intervention domain (*multi-dimensional profile*) refers to the individualization of a user's experience through the customized delivery of services [117]. In our case, we can achieve customization by presenting personalized health risk profiles based on personal health and lifestyle data. Furthermore, the content can be customized by tailoring the risk assessment tools and resources according to a user's gender and health profile (e.g. breast cancer risk assessment for female users; lung cancer risk assessment for smokers).

The last component of the intervention domain (*evidence based interventions*) refers to evidence-based interventions and services that can help users achieve the defined outcomes. For our purposes, we categorized evidence-based interventions according to their strategic intent: a) self-assessment support – validated chronic disease risk assessment tools, and b) knowledge/information support – evidence-based risk communication methods, including intuitive visualizations, to translate risk information to lay citizens.

3. Platform features and content:

This domain involves translating elements of the strategic and intervention domains into the platform functionalities, features and content. The objective here is to develop the

platform's features, functionalities and content in the most effective means possible, by leveraging eHealth and data analytics technology with the goal of a highly engaging user experience [117]. Since the framework is based on a "waterfall process", the features, functionalities and content are informed by abovementioned domains and developed using an iterative approach [117]. The waterfall framework [117] was applied to design and develop the PRISM lifetime health platform. Table 4.8 links the design elements to the various framework domains.

Table 4.8 - Application of the waterfall framework

Framework Domain	Subdomain	Platform elements
Strategic domain	Value drivers	Empowered and engaged citizens
	Outcomes	Increased knowledge and awareness of one's health status; improved overall health and avoidance of chronic diseases
	Program objectives for stakeholders	Effective decision making; improved knowledge of chronic diseases and existing personal risk factors; engaging citizens in managing their health and risks for multiple chronic diseases
Intervention domain	Essential behaviours/Supporting actions	Effective self-monitoring; effective self-assessment; seeking and understanding personal chronic disease risk information
	Multi-dimensional profile	Personalized risk assessment, personalized risk profile, tailored risk assessment tools and resources
	Evidence-based interventions	Validated risk assessment tools to support the self-assessment of chronic disease risks; evidence-based risk communication methods to support the translation of chronic disease knowledge and risk information

Framework Domain	Subdomain	Platform elements
Platform features and contents	Features, functionalities and content	• Features: interactive and intuitive visualizations to translate risk information and facilitate self-monitoring; 'logbook' to input updated personal health and lifestyle data. • Functionalities: alerts and reminders in response to changes in risk scores; self-monitoring; self-assessment of chronic disease risks and overall health status. • Content: personalized and validated risk assessment tools for multiple chronic diseases; cumulative health score (i.e. Health Asset Score)

4.4.2. Logical System design:

In this task, the detailed description of requirements, features, functionalities and contents are translated into a logical model that describes all the functional components of the PRISM health platform. The logical design will inform the final task i.e. physical design and development of the PRISM lifetime health platform.

The PRISM lifetime health platform consists of the following five layers (Figure 4.5):
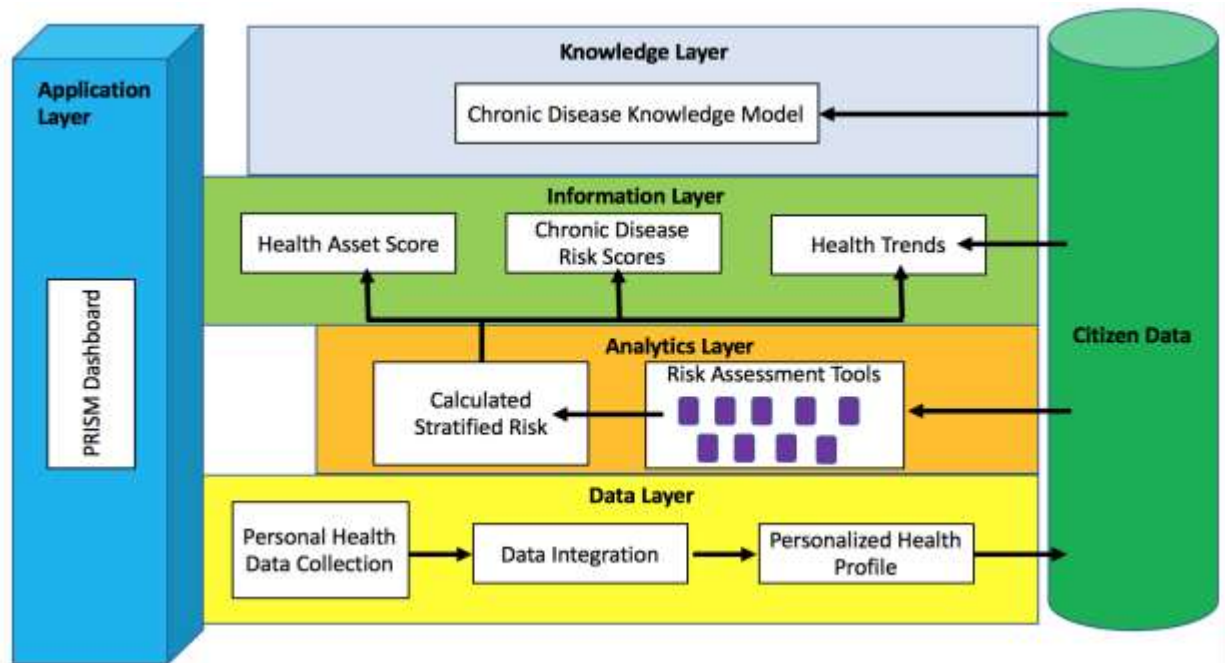
Figure 4.5 - The PRISM health platform functional layers

1. **Application layer**: This layer hosts the front-end applications and serves as the web interface for the end-user. The layer comprises the following applications: (a) PRISM dashboard that offers a secure, interactive and personalized dashboard for individuals to (i) receive their overall health and disease-specific risk scores via intuitive visualizations to effectively translate risk information, and (ii) receive alerts and reminders in response to changes in risk scores; (b) PRISM self-monitoring tool to facilitate tracking of risk information, personal health data and lifestyle data; and (c) PRISM health profile 'logbook' to provide users with a user-friendly interface that facilitates the input of personal health and lifestyle information.

2. **Data Layer**: This layer is responsible for the collection and integration of personal health data to generate a fine-grained health profile of an individual

citizen. Following the life-course approach to chronic disease risk assessment, the objective here is to generate a personalized and dynamic health profile that integrates multiple determinants of health, including socioeconomic, environmental, lifestyle biomedical, and demographic.

3. **Analytics Layer:** This layer is responsible for analyzing the personal health data to assess and stratify chronic disease risks. To perform the risk assessment and stratification analysis, this layer utilizes the validated chronic disease risk assessment tools. Given personal health data (i.e. a health profile), the analytics layer will generate personalized individual chronic disease risks and a cumulative health score for an individual.

4. **Information Layer:** This layer provides a comprehensive overview of a person's health in terms of a personalized health score, individual chronic disease risks, health profile trend over time, and present risk factors and how they are influencing the risk for chronic diseases. The information layer uses state-of-the-art visual analytics techniques to create an intuitive and interactive 'PRISM dashboard' where citizen can visualize their personalized health and risk information.

5. **Knowledge Layer:** The knowledge layer serves as a repository that holds all the risk assessment algorithms and the chronic disease knowledge model. The chronic disease knowledge model is transformed, via a forward engineering process, into a repository that represents the complex associations and interactions between risk factors and chronic diseases. As a result, the knowledge layer can be utilized to determine how individual risk factors influence the onset of multiple chronic diseases. Furthermore, we can quantify the association between various risk factors

and chronic diseases in terms of relative risks and odds ratios, based on evidence

from validated chronic disease risk models. In the future, the aim is to utilize this

knowledge layer to transform the chronic disease knowledge model into a formal

ontology using semantic web technologies. Our goal is to utilize the ontology to

generate personalized risk mitigation strategies based on citizens' personal health

data.

4.4.3. Design and development of the PRISM lifetime health platform:

Following specification of requirements and developing the platform's functional logical

model, the final task involved developing and implementing the PRISM lifetime health

platform. The development task was a joint collaborative effort between the author of this

thesis and software and database developers.

The underlying data model for the PRISM platform was defined by a process of forward

engineering using the chronic disease knowledge model (developed in phase 2). The

PRISM data are physically stored in a MySQL database, and managed using the MySQL

workbench. The PRISM dashboard (i.e. application layer) was developed using the

AngularJS open-source web-application platform. Using the AngularJS platform was

based on the developer's decision. AngularJS is a powerful JavaScript-based web

development framework that can be used to develop user-friendly web-applications

[120].

The PRISM lifetime health platform incorporates various interactive and intuitive

visualizations to facilitate the translation of risk information and self-monitoring of risk

scores and personal health data. The visualizations were developed using D3.JS, which is

a JavaScript-based Scalar Vector Graphics (SVG) library [121]. Using the D3.JS library

provided the flexibility of developing dynamic visualizations from "scratch" according to our needs and requirements.

4.4.4. Presentation layer:

The actual presentation layer of the PRISM lifetime health platform is shown in the figures below (Figures 4.6, 4.7, 4.8). First time users are required to register before logging in. After successful and secure login into the platform, users encounter the PRISM dashboard page which displays a summary of the user's latest health status and risk information. Furthermore, the dashboard page displays important notifications and/or reminders for users. The PRISM dashboard provides users with a complete overview of their health status, risk of multiple chronic diseases, and status of major risk factors. Therefore, we have chosen the *Health Graph*, also referred to as hGraph in other publications [122] as the central visual component of the dashboard. The *Health Graph,* developed by Ledesma et al. (2016), consists of a circular figure, with a purple area defined by circumferences (Figure 4.6). The number in the centre of the *Health Graph* represents the Health Asset Score or disease-specific absolute 10-year risks. The *Health Graph* also includes various data points, which represent the status of health determinants and/or risk factors. Data points placed within the purple area suggests that the risk factor or health determinant is within the health recommended range, while data points placed outside the purple area suggest that its outside the recommended healthy range [122]. As a result, users can quickly determine which risk factors or health determinants are within or outside the recommended healthy range. This can help citizens in determining impactful existing risk factors that should be modified, via lifestyle or behavioural interventions, in order to avoid the onset of chronic diseases.

Figure 4.6 - PRISM dashboard screen

The *Health Graph* is a dynamic and flexible visual component; by clicking individual data points users can view the values of specific risk factors. Furthermore, users can change the *Health Graph* to show chronic disease-specific risk scores and risk factors. As an example, the *Health Graph* initially shows a user's Health Asset Score, however users can select different chronic disease risk information to be displayed on the graph. Complete and accurate visualizations of personal health data (e.g. personalized chronic disease risk scores) can potentially empower citizens to better understand their health status and make informed decisions regarding their healthcare [123, 124, 125]. The *Health Graph* was tested by conducting a usability study, which showed favourable results indicating its effectiveness in helping lay individuals to understand their health status and personal health data [122].
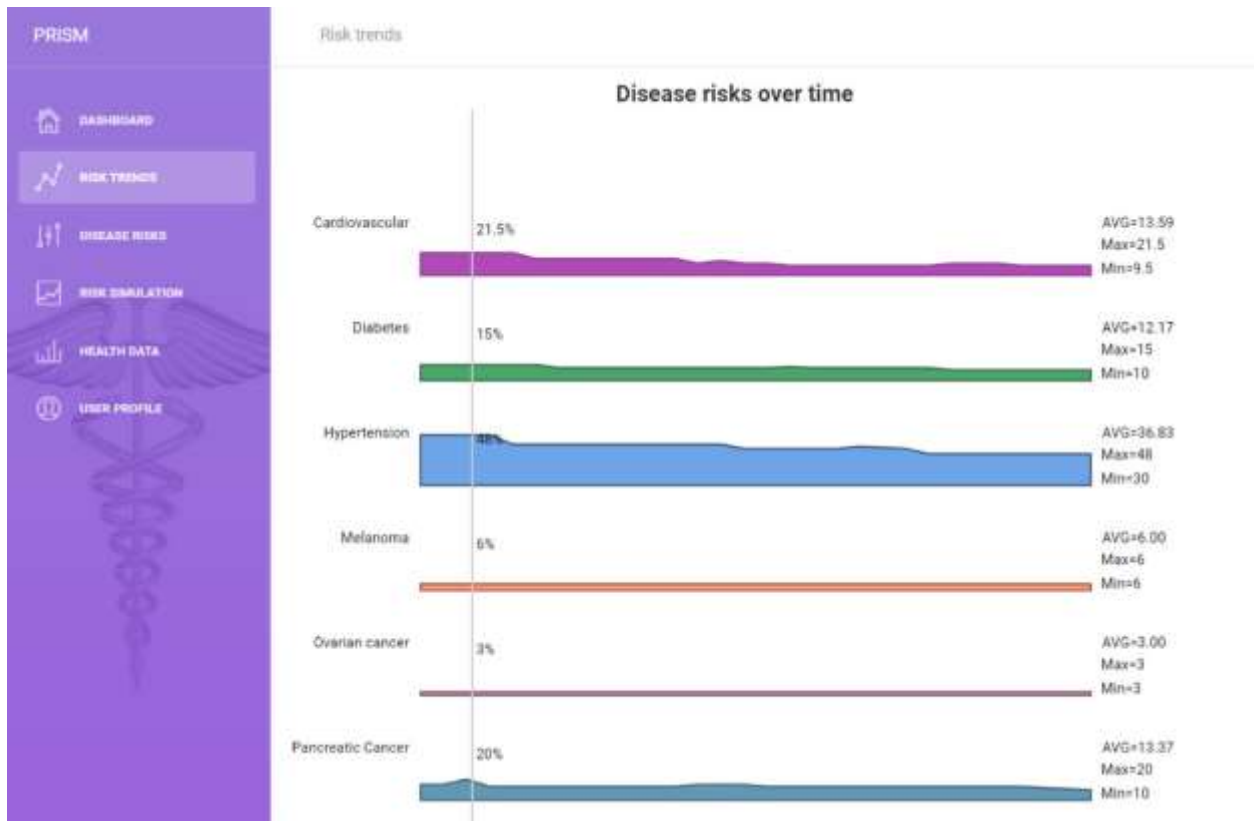
Figure 4.7 - Risk trends screen

The PRISM health platform also incorporates other interactive visualizations to facilitate self-monitoring of chronic disease risk scores. Figure 4.7 shows the disease trends page, which consists of a series of timeline graphs showing an individual's personalized 10-year risks for multiple chronic diseases and cancers. Timeline graphs can effectively convey time-varying data in a linear layout. As a result, timeline graphs are considered ideal for continuous variables such as personal health data and chronic disease risk information. Our goal is to provide citizens with intuitive visualizations that facilitate tracking and comparing of personal risk trends for multiple chronic diseases. Therefore, we have designed the timeline graphs such that they all have a common *x*-axis (i.e. the

timeline), in addition to an interactive common tooltip that cuts across all line graphs to facilitate the comparison of risk trends between different chronic diseases. In addition to self-tracking, we believe that the timeline graph can illustrate to high-risk individuals the influence of a chronic disease on other chronic diseases.

Figure 4.8 - Disease risks screen

The PRISM platform also provides users with the opportunity to view their personalized risk information at an individual disease level in a more detailed format via the Disease Risks screen (Figure 4.8). The Disease Risks screen incorporates several visualizations that can facilitate the translation of disease-specific risk information to lay citizens:

a. Dynamic gauge charts: Two gauge charts are used to communicate personalized, disease-specific 10-year absolute risk and optimal risk. The disease-specific

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optimal risks essentially describe a situation where the user/citizen has 'ideal' levels of modifiable risk factors. The optimal risks are personalized/tailored according to each citizen's unique health profile, and are calculated based on modified versions of the risk assessment algorithms which consider citizens' existing modifiable and non-modifiable risk factors. The charts are defined by three colours that signify the level of risk; green indicating low risk, yellow indicating moderate risk, and red indicating high risk. An arrow pointer within the chart determines the level of risk for each chronic disease or cancer. The pointers change position dynamically in response to changes in the risk assessment scores. Finally, the charts are placed next to each other in the Disease Risks screen (Figure 4.8) to facilitate the comparison of current 10-year risk and an optimal risk based on 'ideal' levels of modifiable risk factors. That way users can determine at a glance their personalized 10-year risk, risk category (i.e. low, moderate or high) and optimal risk for a given disease.

b. Pictographs: The pictographs, also referred to as icon arrays, are matrices of icons that describes a potentially at-risk population [125]. Pictographs are frequently used to present probabilistic information, such as absolute 10-year risk of CVD. Within the array, groups of icons are distinctly coloured to show the number of individuals who will experience a particular risk or condition, while the remaining icons represent those who will not be affected [125]. Growing body of evidence suggests that pictographs are particularly effective in communicating risk statistics to lay individuals [126, 127, 128]. Part of the appeal is because pictographs represent the risk as a frequency rather than a probability [128]. In the

Disease Risks screen (Figure 4.8), the pictograph consists of red icons (representing those who will be affected) and blue icons (representing those who will not be affected). Our aim is to translate the disease risk probability in percentage format (i.e. 10-year absolute risk) into a simple visualization to increase the user's awareness of their risks.

c. Timeline graphs: The Disease Risks screen (Figure 4.8) includes a series of timeline graphs to facilitate self-monitoring of impactful risk factors that contribute to the risk of a particular chronic disease or cancer. Figure 4.8 shows three graphs representing impactful CVD risk factors, with a common x-axis (i.e. the timeline). Our idea here is to engage users to think critically by linking/relating the latest disease-specific risk information to recent variations in the status of impactful risk factors. By doing so, we can demonstrate the impact of modifiable risk factors on the risk of chronic diseases and/or cancers.

4.5. Phase 5 – Evaluation study design:

This Phase involved conducting an evaluation study. In this study, we collect quantitative data with a self-administered survey to evaluate citizens' attitudes and behavioural intention towards using the PRISM lifetime health platform. We base our evaluation on a number of technology acceptance and behavioural models. The following sections outline the purpose of the evaluation study, the study design and steps taken to conduct the study.

4.5.1. Attitudes and Behaviours Towards Consumer Health Applications:

Over the past years, Health Information Technology (HIT) have been developed primarily to support healthcare professionals and managers [129]. However, recently,

patients and citizens have shifted their roles from passive recipients to active consumers of health information and services [130]. As a result, consumer-oriented health applications are becoming increasingly popular nowadays [131]. Furthermore, there is an ongoing interest in reaching patients and citizens directly through consumer-oriented health applications [129]. However, there is gap in the literature regarding knowledge of citizens' perceptions and attitudes towards using any type of Health Information Technology (HIT) [131, 132], including consumer-oriented health applications [133]. This gap is creating major challenges in developing comprehensive HIT systems for consumers [129]. Other common challenges and barriers to to consumer use of interactive health applications include: lack of perceived usefulness, lack of convenience and a lack of trust of the health information provided [129].

Therefore, the purpose of this study to construct and validate a structural research model that predicts and evaluates the factors that influence citizens' behavioural intention towards using consumer health applications (i.e. the PRISM platform). This knowledge could aid researchers and developers in guiding the design and development process of consumer-oriented health applications. The results would also provide insight into the potential use of health IT chronic disease prevention programs. Finally, the evaluation study will help in identifying potential modifications required to improve the design, content user experience of the PRISM health platform and enhance its adoption for use.

4.5.2. Study Design:

We use a cross-sectional design, collect quantitative data with a self-administered survey to evaluate citizens' behavioural intentions towards using the PRISM lifetime health

platform. Ethics approval (REB# 2017-4304) was received from Dalhousie University's Research Ethics Board. A summary of the study design is presented in table 4.9.

Table 4.9 - Summary of study design

Study Type	Cross-sectional quantitative pilot study
Target Population	Residents of Halifax Regional Municipality
Sample Size	40 participants
Materials Used	Laptop and desktop computers; wireless Internet
Study Procedure	Each participant completes two task-based scenarios within a 1 hour study session. Participants then complete a post-study survey.
Data Analysis Method	Quantitative data analysis using Partial Least Square (PLS) method

From a theoretical perspective, we base our evaluation on the Technology Acceptance Model (TAM) [134], Combined Technology Acceptance Model and Theory of Planned Behaviour (C-TAM-TPB) [135], the Unified Theory of Acceptance and Use of Technology (UTAUT) [136], and the Model of PC Utilization [137]. According to TAM, believing that a particular system would improve his or her tasks (i.e. perceived usefulness) has a positive effect on attitude, which in turn affects behavioural intention positively [134, 138]. Similarly, the C-TAM-TPB model indicates that attitude influences one's behavioural intention to use [135, 138]. The UTAUT model suggests that behavioural intention to use is directly affected by perceived usefulness [136, 138]. Finally, the Model of PC Utilization indicates that one of the factors influencing

behaviour is task-technology fit or job fit (i.e. the correspondence between tasks and capabilities of the system to support the tasks) [137, 138]. In a study by Khaneghah et al. (2016), results demonstrated that there is a statistically significant and positive correlation between job fit and attitude towards using patient health portals [133]. As a result, we have developed our structural research model constructs (Figure 4.9) based on the behavioural theories discussed above. Task-technology fit or job fit is referred to as Primary Task Support (PTS) in our structural model.
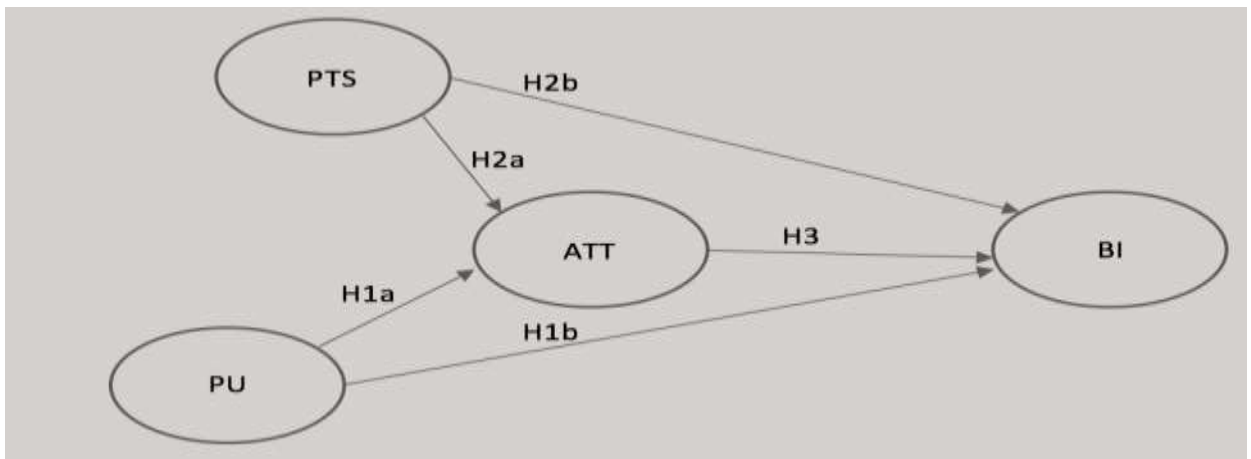
Figure 4.9 - Research structural model

The arrows between constructs represent the hypotheses. We are assuming that the relationships between constructs are positive (e.g. PTS has a positive impact on BI). Our research model proposes the following hypotheses:

- H1a: Perceived Usefulness (PU) has a positive influence on Attitude (ATT)

- H1b: Perceived Usefulness (PU) has a positive influence on Behavioural Intention to use (BI)

- H2a: Primary Task Support (PTS) has a positive effect on Attitude (ATT)

- H2b: Primary Task Support (PTS) has a positive effect on Behavioural Intention to use (BI)

- H3: Attitude (ATT) has a positive impact on Behavioural Inention to use (BI)

We designed two sets of paper-based surveys for this study: a demographic pre-study survey and a post-study survey. The pre-study survey captured demographic information, such as age, gender and highest level of education, and included questions related to the use of computer and use of web-based risk assessment tools. The post-study survey was designed to measure the constructs that make up our structural research model (Figure 4.9): (i) perceived usefulness (PU); (ii) attitude towards using PRISM (ATT); (iii) primary task support (PTS), which covers the means to aid citizens in performing their primary task (i.e. risk assessment, self-monitoring, and self-management of risk factors); and (iv) behavioural intention to use PRISM (BI). The items within constructs were adopted from validated questionnaires used in the literature: Items for Perceived Usefulness (PU) construct were adopted from Davis et al.1989 [134], items for Behavioural Intention (BI) and Primary Task Support (PTS) were adopted from Lehto et al. 2012 [129], and items for Attitude (ATT) were derived from Khaneghah et al. 2016 [133]. The post-study survey used a 5-point Likert scale that ranges from strongly disagree to strongly agree. Additionally, the post-study survey included several open-ended questions to elicit participants' overall impressions and recommendations, to identify areas for improvement.

4.5.3. Study Sample:

One of the advantages of using the PLS method is the minimal demands on sample size [139]. It is often suggested in the literature that the minimum sample size required for PLS analysis should be equal to the larger of the following [139, 140, 141]:

1. Ten times the largest number of indicators used to measure a single construct, or

2. Ten times the largest number of structural paths directed at a particular construct in the structural model.

The abovementioned rules are referred to as the 10-times rule in the literature. According to our structural model (Figure 4.9), the maximum number of indicators associated with a construct is three. Likewise, the largest number of structural paths directed at a particular construct is also three. Therefore, using the 10-times rule, the recommended sample size for this study is 30.

An alternative method to calculating the sample size is using the G*Power software [142, 143]. To achieve a statistical power of 0.8 with a medium to large effect size (f^2=0.35), the recommended sample size for this study was determined to be 36.

Therefore, based on the 10-times rule and the G*Power software calculations, a sample size of 30-40 participants would be adequate. However, to be on the safe side we recruited 40 participants which satisfies both the 10-times rule and the G*Power sample size calculations.

The targeted population for this study are residents of Halifax Regional Municipality. Recruitment of participants is based on the following inclusion criteria: (a) Fluency in the English language at an intermediate level – i.e. ability to read and understand simple newspaper articles in addition to ability to take part in casual conversations and (b) not visually impaired. There are no further inclusion/exclusion criteria.

Participants are recruited by posting a study recruitment notice on bulletin boards around Dalhousie University campus, hospitals, pharmacies, food retailers and other locations around the city of Halifax. Furthermore, email announcements regarding study recruitment were sent via Dalhousie University Notice Digest and the computer science

mailing list. Additionally, recruitment announcement was posted on social media (Facebook) to recruit more participants using a snowball effect.

4.5.4. Study Procedure:

Participants who respond to the recruitment notice are invited to the NICHE research lab at the faculty of Computer Science at Dalhousie University or a mutually agreed location (where Internet was available and privacy could be maintained). Paper-based informed consent forms are given to participants, and the study procedure is explained clearly before commencement of the study. After signing consent forms, participants are asked to complete the pre-study survey to capture demographic information. Thereafter, study participants are given task-based scenarios (Appendix D) which includes a list of tasks to be completed using the PRISM health platform. We developed 2 task-based scenarios to cover all male and female specific chronic diseases and cancer risk assessments within PRISM. The task-based scenarios are used to: (i) guide participants in navigating PRISM; (ii) view the interactive visualizations incorporated and; (iii) explore the functionalities of the platform.

Following participants' interaction with PRISM, the post-study surveys are distributed. The study is concluded once the survey is completed.

4.5.5. Data Collection and Analysis Methods:

A paper-based data collection method is used throughout the study. We capture quantitative data using 2 self-administered surveys: a pre-study background survey to capture demographic data and a post-study survey to evaluate participants' behavioural intention towards using PRISM. The contents of both surveys are described in section 4.5.2.

The captured quantitative data are analyzed using: (a) descriptive statistics; and (b) PLS method. We utilize R and SmartPLS statistical software to analyze the collected quantitative data. SmartPLS is a component-based path modeling application based on the PLS method [144]. The PLS method is similar to linear regression in that the purpose is to demonstrate high R-squared values and significant t-values, thus rejecting the null hypothesis of no effect [129]. PLS analysis is a 2-step process: (i) assessment of reliability and validity of the measurement model (i.e. post-study survey), and (ii) assessment of the structural model [129].

CHAPTER 5: DISCUSSION AND CONCLUSION

In this thesis, we have taken a novel interdisciplinary approach to demonstrate the feasibility of promoting citizen empowerment, adequate self-care, and a personalized, health-focused approach to risk assessment via an eHealth-based intervention. As described earlier, a health-focused approach to chronic disease risk assessment, based on the life-course framework, entails considering a wide range of risk factors that influence the risk of multiple chronic diseases across an individual's lifespan. As a result, this thesis demonstrated the integration of multiple validated chronic disease risk assessment tools into a high-level knowledge model that serves to provide citizens with personalized risk information. By utilizing evidence presented in the risk assessment tools, we identified the inter-relationships between risk factors and chronic diseases, which were incorporated in our knowledge model. Moreover, we extended previous work done on cumulative health scores to formulate a proof-of-concept *Health Asset Score* that reflects a person's multimorbid chronic disease risk.

The outcome of this research is in terms of a population-based lifetime health platform (i.e. PRISM) that aims to empower citizens to pursue self-assessment and self-monitoring of their general health status and risk of chronic diseases. Therefore, the significance of PRISM lies in engaging citizens to pursue adequate self-care to prevent the onset of chronic diseases and maintain a healthy living status [14]. Most eHealth-based preventive interventions are directed towards high-risk individuals. However, we take a population-wide approach; in that PRISM is directed towards citizens of *all* ages and at *any* level of risk (as opposed to exclusively high-risk individuals). Population-wide interventions represent the most effective, yet underused, strategy for the prevention of chronic

diseases [157]. The excessive focus on high-risk prevention strategies and lack of

population-wide approaches are often suggested as the main reasons for inefficient

preventive care practices [157]. Therefore, in addition to offering a novel approach to

chronic disease prevention, our research helps in bridging the gaps that exist in current

public health practices due to the lack of population-wide prevention strategies.

From a population health perspective, PRISM can be described as an integrated and

scalable public health platform that can be utilized to disseminate evidence-based

preventive care knowledge to the public. Dissemination is a formal and planned process

with the goal of spreading health-related knowledge to improve health outcomes at the

population-level [158]. However, current levels of public awareness of chronic diseases

and associated risk factors is low due to ineffective knowledge dissemination strategies

[159]. We believe that the *web-based* PRISM health platform can help in closing this gap

by: (i) increasing the reach of knowledge dissemination to a variety of audiences,

including low, intermediate and high risk citizens; (ii) utilizing the interactive

visualizations incorporated to translate preventive care knowledge to lay citizens; and

(iii) displaying tailored recommendations by linking preventive care knowledge to

citizens' personalized risk profiles.

From an epidemiological perspective, PRISM holds tremendous potential in monitoring

chronic disease risks and associated risk factors at a population-level – i.e. chronic

disease surveillance. Once fully implemented, the platform could be used by federal and

provincial public health agencies in Canada to collect and analyze citizens' personal

health data for chronic disease surveillance purposes. Disease surveillance is critical to

devise future public health policies and strategies that aim to reduce the health and

economic burden of chronic diseases. Furthermore, and in line with Canada's

surveillance and population health assessment initiatives [160], our work in developing

the chronic disease knowledge model could help in further developing Canada's first

national Indicator Framework for Chronic Diseases and Associated Determinants, which

considers the interaction between determinants of health, risk factors and health outcomes

across the life-course [90]. This will support public health stakeholders and policy

makers in identifying and addressing the multiple facets of chronic diseases.

As described in Chapter 3, the theoretical framework for this research is premised on: (a)

theory of self-care, (b) citizen empowerment and (c) the life-course approach to chronic

disease prevention. These theories and concepts are directly related to the emerging

paradigm of *Predictive, Preventive and Personalized Medicine* (PPPM) [31]. In the

context of chronic diseases, PPPM aims to pervasively monitor citizens' health by

proactively assessing and predicting chronic disease risks based on a personalized and

tailored risk assessment approach that considers an individual's demographic,

environmental, socioeconomic, behavioural and biomedical factors. Furthermore, PPPM

entails customizing risk mitigation and behaviour modification strategies according to the

personalized risk assessment. As a result, a personalized risk assessment represents an

accurate and effective approach to chronic disease prevention. In general, personalized

healthcare provides many benefits to chronic disease patients, citizens at-risk and health

systems such as: identification of risks at earlier stages; stratification of individuals into

groups that enable the selection of optimal preventive strategies; and shift the emphasis

from reaction to prevention and from disease to wellness.

5.1. Limitations:

A major limitation of the PRISM health platform is that it is a standalone application that is not integrated with patient health records or personal wearable health devices. For PRISM to achieve its intended purpose of citizen empowerment and facilitating self-monitoring, integration with wearable health devices is an important aspect to be considered in the future. Moreover, the integration could lead to flow of continuous streams of health data that will result in rich datasets that can be used to provide accurate risk assessments.

Another limiting factor is related to the formulation of the *Health Asset Score* as we were not able to validate our method and approach due to time restrictions and lack of appropriate data which would have been used for validation.

Finally, there were limitations related to the research ethics restrictions. The evaluation study could not be approved to collect participants' personal health information to protect their privacy and confidentiality. As a result, we used task-scenarios based on hypothetical health data. This would affect the analysis of participants' behavioural intent towards using the platform, as they may not relate to the risk information provided and, as a result, they may not realize the benefits of using the platform.

5.2. Future Work:

First and foremost, the PRISM platform design and functionalities should be revised based on the study feedback. Furthermore, in order for the PRISM platform to achieve its intended purpose of empowering citizens, the next logical step would be incorporating evidence-based risk mitigation and behaviour modification strategies to enable them in preventing the onset of chronic diseases. At its current state, the platform provides

personalized risk information without a guide on how to mitigate personal risks. As a result, citizens using the platform can only achieve the first stage of empowerment – i.e. increased awareness of personal health risks [11]. The second stage of empowerment requires active citizen engagement and taking action to modify risky health behaviours by adhering to evidence-based and personalized behaviour modification plans.

Future work should also consider the inclusion of even a wider range of risk factors and health determinants, specifically environmental, socioeconomic and genetic factors, to further personalize risk assessments. Despite our efforts of attempting to include wide range of risk factors, we did not have the resources or time to explore additional genetic, environmental and socioeconomic chronic disease risk factors. Personalized healthcare models, such as the Predictive, Preventive, and Personalized Medicine (PPPM) model, promote the integration of personal genomic data with personal health data to generate highly personalized risk profiles and care plans [27].

Currently, the platform incorporates 11 risk assessment tools for prevalent chronic diseases and cancers. However, we were not able to identify risk assessment tools for other relatively prevalent chronic diseases, such as COPD, osteoporosis, osteoarthritis, prostate cancer, and bladder cancer. Therefore, future work should consider identifying additional validated risk assessment tools to cover all prevalent chronic diseases. Psychiatric disorders, such as anxiety and depression, are also becoming highly prevalent in Canada [145]. Moreover, there are mutual associations between chronic diseases and psychiatric conditions; individuals with depression or anxiety are at-risk of developing multimorbid chronic diseases, and chronic disease patients are more likely to develop depression and anxiety [145, 146, 147, 148]. Therefore, future work should incorporate

risk factors, risk associations and risk assessment tools for prevalent psychiatric disorders.

Additionally, future work should involve the development of a mobile application as a component of the PRISM platform. This could result in increased adoption and usage of PRISM, especially among young adults, as mobile devices are becoming the primary platform for consumer-oriented health applications.

5.3. Conclusion:

This research employed an interdisciplinary approach to develop PRISM; a citizen empowerment eco-system that aims to assist citizens in avoiding the onset of multiple chronic diseases by providing personalized risk information in an intuitive and interactive manner and facilitating self-monitoring of personal risk factors. Our novel approach involved four key elements to support citizens in pursuing effective chronic disease preventive measures:

1. The life-course framework to devise a personalized, health-focused and holistic approach to chronic disease risk assessment and prevention;

2. Empowering citizens by increasing their awareness of personal health risks;

3. Engaging citizens in pursuing adequate self-care, including self-care monitoring;

4. eHealth-based interventions to facilitate the different aspects of the life-course approach, citizen empowerment and self-care, and to support citizens in maintaining a healthy, disease-free life.

To reiterate, the most effective strategy for the prevention of chronic diseases is based on the life-course framework; which entails a *proactive* and *health-focused* approach, and stresses on the importance of a *population-wide preventive strategy* – i.e. targeting

citizens of all ages across various settings of life. However, for any preventive strategy to have a positive effect on health outcomes, citizens must have adequate knowledge and awareness of their personal health risks. – this is referred to as the first level of empowerment. Empowered citizens can make informed decisions regarding their health and are actively engaged in adequate self-care and self-care monitoring. Self-care monitoring helps citizens in tracking their progress and staying motivated while pursuing behaviour modifications [81]. Finally, eHealth-based interventions play an important role in supporting citizens to maintain health and avoid the onset of chronic diseases.

In this thesis, we have applied the life-course framework by integrating multiple validated chronic disease risk assessment tools that consider a wide range of risk factors and health determinants that can accumulate throughout a citizen's lifespan, including demographic, environmental, socioeconomic, behavioural and biomedical risk factors. Furthermore, we demonstrated the feasibility of formulating a cumulative health assessment tool that reflects a person's multimorbid chronic disease risk. As a result, our approach to chronic disease risk assessment is health-focused and holistic; in that we focus on the shared risk factors and health determinants impacting a citizen's risk of major chronic diseases and overall health status – as opposed to disease-specific risk factors.

Empowerment is achieved by providing citizens with personalized risk information in an intuitive manner to inform them about their health and chronic disease risks. We utilize evidence-based risk communication methods and interactive visualizations to translate personalized risk information to lay citizens.

Finally, citizen engagement in adequate self-care is achieved by providing them with an eHealth-based platform that provides a suite of lifetime health services to facilitate self-assessment and self-monitoring of chronic disease risks.

From a health informatics perspective, our research achieved the following unique innovations: (a) it utilized a HKM approach [13] to map the mutual and complex relationships between risk factors and chronic diseases; (b) it computerized validated risk assessment tools for 11 chronic diseases and cancers; and (c) it developed dynamic and interactive visualizations to translate personalized risk information to lay citizens in an intuitive manner.

Our chronic disease knowledge model serves as an evidence-based knowledge resource that can be used to generate personalized risk profiles and demonstrate the impact of a given risk factor on the risk of developing multiple chronic diseases. The knowledge model can be extended to include additional risk factors, diseases, risk associations and risk assessment models.

To conclude this thesis, PRISM is an innovative population-based lifetime health platform that is designed to empower citizens to pursue personalized risk assessment and self-monitoring of existing risk factors. The platform offers the opportunity to deliver community-based preventive services targeting citizens of all ages and risk groups. As such, PRISM will help citizens in maintaining a healthy status, and help the health care system by potentially reducing the cost associated with managing chronic diseases.

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APPENDIX A: CHRONIC DISEASE RISK ASSESSMENT TOOLS IDENTIFIED IN LITERATURE
*Blank cells indicate that information was not available.

Table A.1: Breast Cancer

Risk model	Cohort/data source	Target audience	Outcomes assessed	Risk factors	Validation	Risk presentation
Gail model	Case-control data from the Breast Cancer Detection Demonstration Project (BCDDP) & Women's Contraceptive and Reporoductive Experiences (CARE) study & Study of Tamoxifen and Raloxifene (STAR) trial	White and African American females	Risk of Breast Cancer	Age, age at menarche, number of biopsies, age at first live birth, ethnicity, family history of breast cancer (first degree relatives)	External validation	% 5-year risk of developing breast cancer % lifetime risk of developing breast cancer
Cuzick-Tryer model	International Breast Intervention Study (IBIS)	British females	Risk of Breast Cancer	Age, Body Mass Index (BMI), age at menarche, age at first birth, age at menopause, history of breast biopsy, history of atypical hyperplasia, history of LCIS, use of Hormonal Replacement Therapy (HRT), family history of breast cancer (first degree and second degree relatives), family history of ovarian cancer,	External validation	% lifetime risk of developing breast cancer % 10-year risk of developing breast cancer Risk presented in numeric and visual formats (i.e. line graph) and compared to population average risk.
Harvard Cancer Risk Index (HCRI) – Breast	Estimated parameters from published epidemiologica	Females with no history of cancer	Risk of breast cancer	Age, height, BMI, family history of breast cancer	Unknown	% 10-year risk of developing breast cancer

Cancer	l studies and cumulative 10-year risk of cancer from Surveillance Epidemiology and End Results (SEER)			(first degree relative), age at menarche, age at menopause, age at first birth, use of Hormone Replacement Therapy (HRT), use of SERMs, use of OCPs, alcohol intake, breastfeeding history, physical activity, multivitamins use, ethnicity, adult weight gain, personal history of benign breast disease		Relative risk of developing breast cancer
QCancer – breast	Data of primary care patients from the QResearch database	Females 25-84 years of age with no history of breast cancer	Risk of developing breast cancer	Age, Body Mass Index (BMI), ethnicity, Townsend deprivation score, alcohol intake, family history of breast cancer, personal history of benign breast disease, use of OCPs, use of HRTs, personal history of manic depression, personal history of cancer	Unknown	% 10-year risk of developing breast cancer

Table A.2: Colon Cancer

Risk model	Data source/cohort	Target population	Outcome(s) assessed	Risk factors	Validation	Risk presentation
Colorectal Cancer Risk Assessment Tool (CCRAT)	Data from two population-based case control studies	Non-Hispanic white men and women ≥ 50 years of age	Colorectal cancer (CRC)	Age, family history of CRC (first degree relatives), history of colonoscopy and/or sigmoidoscopy, history of polyps, use of multivitamins, dietary risks (red meat, fruit and vegetables), alcohol intake, BMI, smoking, use of aspirin, physical activity, use of Hormone Replacement Therapy (HRT)	External validation	% lifetime risk of developing CRC % 5-year risk of developing CRC % 10-year risk of developing CRC
Cleveland's colon cancer risk assessment tool	Unknown	Males and females	Colon cancer	Age, gender, ethnicity, weight and height, personal history of colon cancer and/or polyps, colon cancer screening, dietary risks (fruits and vegetables), smoking, physical activity, family history of colon cancer and/or polyps (first and second degree relatives), age at diagnosis of cancer, age at diagnosis of polyp	Unknown	Provides a risk score and category (i.e. low/intermediate/high) for developing colon cancer

ColoRectal Cancer Predicted Risk Online (CRC-PRO)	Data from the Multiethnic Cohort (MEC) study	Multiethnic males and females ≥ 45 years of age	Colorectal cancer (CRC)	Age, gender, ethnicity, BMI, diabetes, use of multivitamins, use of aspirin, smoking, alcohol intake, physical activity, use of Hormone Replacement Therapy (HRT), years of education	Unknown	% 10-year risk of developing colorectal cancer
QCancer – colorectal	Data of primary care patients from the QResearch database	Males and females aged 25-84 years with no history of colorectal cancer	Colorectal cancer	Age, gender, ethnicity, smoking status, alcohol intake, family history of bowel cancer, personal history of ulcerative colitis, personal history of colonic polyps, personal history of diabetes, personal history of cancer	External validation	% 10-year risk of developing colorectal cancer
Colorectal cancer Prediction Risk Score	Data from the Physician's Health Study (PHS)	Males 40-84 years of age with no history of cancer	Colorectal cancer	Age, history of smoking, alcohol intake, Body Mass Index (BMI)	Unknown	20-year risk of developing colorectal cancer. Risk presented in: Risk points and stratified into one of 3 risk categories accordingly (low, intermediate, high)
Harvard Cancer Risk Index (HCRI) – colon cancer	Estimated parameters from published epidemiological studies and cumulative 10-year risk of cancer from Surveillance Epidemiology and End	Males and females with no personal history of cancer	Colon cancer	Age, gender, height, Body Mass Index (BMI), personal history of IBD, history of colorectal cancer screening, family history	External validation	% 10-year risk of developing colon cancer Relative risk of developing colon cancer

	Results (SEER)			of colon cancer, long term aspirin use, OCP use, HRT use, alcohol intake, red meat intake, multivitamin intake, dairy products or calcium supplement intake, vitamin D supplement, physical activity		

Table A.3: Lung Cancer

Risk model	Data source/cohort	Target population	Outcomes assessed	Risk factors	Validation	Risk presentation
PLCO m2012	Data from Prostate, Lung, Colorectal, and Ovarian (PLCO) cancer screening trial and National Lung Screening Trial (NLST)	Smokers and/or former smokers	Lung cancer	Age, ethnicity, Body Mass Index (BMI), level of education, personal history of cancer, personal history of COPD, family history of lung cancer, smoking status, smoking intensity, duration of smoking, smoking quit time	External validation	% 6-year risk of developing lung cancer
QCancer - Lung	Data of primary care patients from the QResearch database	(British) Males and females aged 25-84 years with no history of lung cancer	Lung cancer	Age, gender, ethnicity, smoking status, family history of lung cancer, personal history of COPD, personal history of asthma, personal history of any cancer	External validation	% 10-year risk of developing lung cancer
Bach model	Data from Carotene and Retinol Efficacy Trial (CARET)	Males and females who are current or former heavy smokers (≥ 20 pack-years) aged 50-69 years and asbestos exposed males aged 45-69 years	Lung cancer	Age, gender, asbestos exposure history, smoking history	External validation	% 10-year risk of lung cancer

Table A.4: Melanoma

Risk model	Data source/cohort	Target population	Outcomes assessed	Risk factors	Validation	Risk presentation
Harvard Cancer Risk Index (HCRI) - Melanoma	Estimated parameters from published epidemiological studies and cumulative 10-year risk of cancer from Surveillance Epidemiology and End Results (SEER)	Males and females with no personal history of any cancer	Risk of melanoma	Age, gender, natural blonde/red hair colour, natural blue/green eye colour, fair skin, moles on arms, personal history of immunosuppressive medication use, personal history of blistering sunburns, family history of melanoma	Unknown	% 10-year risk of developing melanoma Relative risk of developing melanoma
Melanoma risk model	Data from the Victorian Melanoma Services	Males and females	Risk of developing melanoma	Personal history of non-melanoma cancer, family history of melanoma, common neavi, atypical neavi, hair colour, freckles	Unknown	% 5-year risk of developing melanoma
Brief Skin Cancer Risk Assessment Tool (BRAT)	Data collection as part of project SCAPE (Skin Care Awareness, Prevention and Education)	Males and females	Risk of developing melanoma	Ethnicity, personal history of skin cancer, number of large moles, skin colour, hair colour, ability to tan, skin burns easily in sun (y/n), location of childhood residence, history of sunburns, freckles	Unknown	Melanoma risk points stratified into 3 categories: low/intermediate/high risk

Table A.5: Ovarian Cancer

Risk model	Data source/cohort	Target population	Outcomes assessed	Risk factors	Validation	Risk presentation
Harvard Cancer Risk Index (HCRI)	Estimated parameters from published epidemiological studies and cumulative 10-year risk of cancer from Surveillance Epidemiology and End Results (SEER)	Females with no personal history of any cancer	Ovarian cancer	Age, height, number of childbirths, breastfeeding history, use of OCPs, personal history of tubal ligation, personal history of hysterectomy, family history of ovarian cancer	Unknown	% 10-year risk of developing ovarian cancer Relative risk of developing ovarian cancer
QCancer - Ovarian	Data of primary care patients from the QResearch database	Females aged 25-84 years with no personal history of ovarian cancer	Ovarian cancer	Age, Body Mass Index (BMI), family history of ovarian cancer, use of OCPs, personal history of breast cancer, personal history of cervical cancer	Unknown	% 10-year risk of developing ovarian cancer

Table A.6: Pancreatic Cancer

Risk model	Data source/cohort	Target population	Outcomes assessed	Risk factors	Validation	Risk presentation
PancPro	Data from the National Familial Pancreas Tumor Registry (NFPTR)	Males and females	Risk of developing pancreatic cancer	Age, family history of pancreatic cancer, personal history of pancreatic cancer, age at diagnosis	Unknown	Probability of developing pancreatic cancer
QCancer - Pancreatic	Data of primary care patients from the QResearch database	Males and females aged 25-84 years with no personal history of pancreatic cancer	Risk of developing pancreatic cancer	Age, gender, Body Mass Index (BMI), Townsend deprivation score, personal history of diabetes, personal history of chronic pancreatitis, personal history of breast cancer, personal history of renal cancer	Unknown	% 10-year risk of developing pancreatic cancer
Harvard Cancer Risk Index (HCRI) – Pancreatic cancer	Estimated parameters from published epidemiological studies and cumulative 10-year risk of cancer from Surveillance Epidemiology and End Results (SEER)	Males and females with no personal history of any cancer	Risk of developing pancreatic cancer	Age, gender, height, Body Mass Index (BMI), personal history of diabetes, personal history of chronic pancreatitis, smoking status, vegetables intake, family history of pancreatic cancer	Unknown	% 10-year risk of developing pancreatic cancer Relative risk of developing pancreatic cancer

Table A.7: Cardiovascular Disease

Risk model	Data source/cohort	Target population	Outcomes assessed	Risk factors	Validation	Risk presentation
PROCAM	Data from Prospective Cardiovascular Munster (PROCAM) study	Males and females aged 35-65 years	Risk of acute coronary event (fatal/nonfatal myocardial infarction or acute coronary death)	Age, LDL cholesterol, HDL cholesterol, triglycerides, personal history of diabetes, family history of myocardial infarction, systolic blood pressure	External validation	% 10-year risk of acute coronary event Risk score
SCORE	Data from cohort studies from 12 European countries	European males and females with no history of heart disease	Risk of fatal cardiovascular disease	Age, gender, smoking status, systolic blood pressure, total cholesterol: HDL cholesterol ratio	External validation	% 10-year risk of fatal cardiovascular disease
Reynolds Risk Score (women)	Data from Women's Health Study (WHS)	Females ≥ 45 years of age with no history of CVD and cancer	Risk of fatal CVD, MI, stroke, and coronary revascularization	Age, systolic blood pressure, smoking, total cholesterol, HDL cholesterol, family history of MI prior to 60 years (first degree relative), hsCRP	External validation	% 10-year risk for global CVD
Reynolds Risk Score (men)	Data from Physician's Health Study-II (PHS-II)	Males ≥ 50 years with no history of CVD, cancer, and diabetes	Risk of fatal CVD, MI, stroke, and coronary revascularization	Age, systolic blood pressure, smoking, total cholesterol, HDL cholesterol, family history of MI prior to 60 years (first degree relative), C-reactive protein	External validation	% 10-year risk for global CVD

QRisk3	Data of primary care patients from the QResearch database	Males and females 25-84 years of age with no history of CVD	Risk of CVD as a composite outcome of: coronary heart disease, ischemic stroke, or transient ischemic attack	Age, ethnicity, Townsend deprivation score, systolic blood pressure, body mass index (BMI), total cholesterol: HDL cholesterol ratio, smoking status, family history of coronary heart disease prior to 60 years (first degree relatives), personal history of: diabetes, hypertension, rheumatoid arthritis, atrial fibrillation, chronic kidney disease (stage 4 or 5), SLE, severe mental illness, HIV, erectile dysfunction, and migraine, use of corticosteroids, use of atypical antipsychotics	Unknown	% 10-year risk of CVD
ASSIGN Risk Score	Data from the Scottish Heart Health Extended Cohort (SHHEC)	Males and females 30-74 years of age with no history of coronary heart disease or stroke	Risk of CVD	Age, gender, Scottish Index of Multiple Deprivation, family history of CVD, smoking status, smoking frequency, systolic blood pressure, total cholesterol, HDL cholesterol	External validation	% 10-year risk of CVD

Table A.8: Type 2 Diabetes

Risk model	Data source/cohort	Target population	Outcomes assessed	Risk factors	Validation	Risk presentation
Diabetes Risk Calculator (DRC)	Data from the Third National Health and Nutrition Examination Survey (NHANES)	Males and females > 20 years of age	Risk of diabetes and pre-diabetes	Age, waist circumference, height, ethnicity, personal history of gestational diabetes, personal history of hypertension, family history of diabetes, physical activity	Unknown	Risk of diabetes stratified into: low/intermediate/high
QDScore	Data of primary care patients from the QResearch database	Males and females 25-79 years of age with no history of diabetes	Risk of diabetes	Age, gender, ethnicity, body mass index (BMI), smoking status, Townsend deprivation score, personal history of hypertension, personal history of CVD, family history of diabetes, current use of corticosteroids	External validation	% 10-year risk of diabetes
FINDRISK	Data from the National Population Register and the FINRISK study	Males and females 25-64 years of age with no history of diabetes	Risk of Type 2 Diabetes Mellitus	Age, BMI, waist circumference, physical activity, dietary consumption of fruits and vegetables, personal history of high blood glucose, use of antihypertensive medications	External validation	10-year risk of diabetes\n\nDiabetes risk score (stratified into: low/moderate/high risk groups)

CANRISK	CANRISK Canadian cohort from 7 provinces	Males and females 19-78 years of age from various ethnic backgrounds	Risk of Type 2 Diabetes Mellitus	Gender, age, ethnicity, level of education, waist circumference, Body Mass Index (BMI), physical activity, dietary consumption of fruits and vegetables, history, personal history of high blood glucose, personal history of hypertension, personal history of gestational diabetes, family history of diabetes	Unknown	% 10-year risk of diabetes Diabetes risk score (stratified into: low/moderate/high risk groups)
German Diabetes Risk Score (GDRS)	Data from the European Prospective Investigation into Cancer and Nutrition (EPIC)-post dam study	Males and females 35-65 years of age	Risk of Type 2 Diabetes Mellitus	Age, height, waist circumference, smoking status, physical activity, alcohol intake, dietary intake of: coffee, whole grain bread, and red meat, personal history of hypertension, family history of diabetes	External validation	% 5-year risk of Type 2 Diabetes Mellitus
Framingham Diabetes Risk Score	Data from the Framingham Offspring Study	White non-Hispanic males and females 45-64 years of age	Risk of Type 2 Diabetes Mellitus	Age, gender, fasting glucose level, Body Mass Index (BMI), HDL cholesterol, triglyceride, systolic blood pressure, family history of diabetes	External validation	% 8-year risk of Type 2 Diabetes Mellitus

Table A.9 Hypertension

Risk model	Data source/cohort	Target population	Outcomes assessed	Risk factors	Validation	Risk presentation
Hypertension Risk Prediction model	Data from the Women's Health Study (WHS)	American females ≥ 45 years of age with normal blood pressure	Risk of incident hypertension (defined as systolic blood pressure ≥ 140 mm Hg or diastolic blood pressure (DBP) ≥ 90 mm Hg)	Age, Body Mass Index (BMI), ethnicity, systolic and diastolic blood pressure, total cholesterol: HDL cholesterol ratio, apolipoprotein B, lipoprotein a, C-reactive protein, dietary consumption of grain	Unknown	% 8-year risk of hypertension
Hypertension Risk Score	Data from 2 non-concurrent cohort studies: the Atherosclerosis Risk in Communities (ARIC) study and the Cardiovascular Health Study (CHS)	Males and females 45-64 years of age with no personal history of hypertension	Risk of incident hypertension (defined as systolic blood pressure ≥ 140 mm Hg or diastolic blood pressure (DBP) ≥ 90 mm Hg)	Age, gender, Body Mass Index (BMI), smoking status, physical activity, systolic and diastolic blood pressure, personal history of diabetes, family history of hypertension	Unknown	% 3-, 6-, and 9-year risk of incident hypertension Hypertension risk score
Framingham Hypertension Risk Score	Data from the Framingham Offspring Study	Males and females 20-69 years of age with no history of hypertension and/or cardiovascular disease	Risk of hypertension (defined as systolic blood pressure ≥ 140 mm Hg or diastolic blood pressure (DBP) ≥ 90 mm Hg)	Age, gender, Body Mass Index (BMI), systolic and diastolic blood pressure, smoking status, family history of hypertension (first degree relative)	External validation	% 1-, 2-, and 4-year risk of incident hypertension Hypertension risk score

APPENDIX B: *HEALTH ASSET SCORE* **VARIABLES BY LEVEL OF EXPOSURE AND RELATIVE RISK**

Variable	Relative Risk (95% CI)	Reference
Dietary risks (adherence to Med Diet vs. non-adherence)	• Adherence RR= 0.77-0.89 • Non-adherence RR = 1.0	[149]
Smoking (current vs. non-smoker, former vs. non-smoker)	• Non-smoker RR = 1.0 • Former smoker RR = 1.17 • Current light smoker RR = 1.31 • Current moderate smoker RR = 1.73 • Current heavy smoker RR = 2.04	[150, 151]
Blood pressure (HTN vs. normotensive)	• Systolic blood pressure < 120 mmHg RR = 1 • Systolic blood pressure 120-139 mmHg RR = 1.5 • Systolic blood pressure ≥ 140 mmHg RR = 2.5	[152, 153]
Random blood glucose (high normal vs. normal, moderately elevated vs. normal, severely elevated vs. normal)	• Normal glucose level RR = 1.0 • High normal glucose level RR = 1.2 • Moderately elevated glucose level RR = 2.5 • Severely elevated glucose level RR = 3.2	[153]
Total cholesterol	• ≤4 mmol/L RR = 1.0 • 4.1 – 5.1 mmol/L RR = 1.3 • 5.2 – 6.2 mmol/L RR = 2.25 • 6.3 – 7.7 mmol/L RR = 5.0 • ≥ 7.8 mmol/L RR = 7.0	[154]
Alcohol consumption (<7 vs. ≥7 drinks per week)	• < 7 drinks/week RR = 1.02 • ≥ 7 drinks/week RR = 1.14-1.45	[155]
Physical activity (150-300 minutes vs. <150 minutes per week)	• < 150 minutes/week RR = 1.0 • 150 – 300 minutes/week RR = 0.74-0.86	[156]

APPENDIX C: PRE-STUDY BACKGROUND AND DEMOGRAPHIC SURVEY

Please fill the following information

1. Age: _____ (years)
2. Gender:
   - Male
   - Female
   - Other
3. Highest level of education completed:
   - Less than high school
   - High school diploma or equivalent
   - Postsecondary degree
   - Graduate degree
4. How comfortable do you feel using computers in general?
   - Very comfortable
   - Moderately comfortable
   - Neither comfortable nor uncomfortable
   - Moderately uncomfortable
   - Very uncomfortable
5. How often do you use the Internet for personal use, including e-mail, social media etc. from home, work, or any other location? (please circle only one)
   - Less than once a week
   - Once a week
   - Twice a week
   - Three times a week
   - Four times a week
   - Five times a week
   - Six times a week
   - Daily
   - More than once per day
   - Never
6. Do you seek health information on the Internet?
   - Yes
   - No
7. Do you seek health information on risks of chronic diseases and cancers?
   - Yes
   - No
8. Have you ever used a web-based chronic disease and/or cancer risk assessment tool recently?
   - Yes
   - No

APPENDIX D: EVALUATION STUDY TASK SCENARIOS

Scenario A:

Sarah is a 49-year old-woman. Her sister was diagnosed with Type 2 Diabetes recently, which prompted her to look for an online tool to assess and monitor her risk for chronic conditions. She is technologically savvy and has been using PRISM for the past 2 months. Her goal is to learn about and monitor her risk factors for chronic diseases and cancers, in order to make healthier lifestyle choices to improve her overall health status and prevent the development of chronic conditions. Over the past month, Sarah has made significant progress in reducing her weight, improving dietary habits, and limiting alcohol consumption to recommended levels. She would like to update her health profile on PRISM and review her latest chronic disease and cancer risk scores.

Tasks (Scenario A):
1. Please open PRISM and login by entering the username and password provided.
2. Please fill out the fields in the "health profile" page using the information provided below.
3. Please open the "dashboard" page and view the health graph and bullet charts.
    a. Click on the health metrics shown on the health graph to go into details of each metric.
    b. Thereafter, click on the bullet charts to view specific chronic disease and cancer risks on the health graph.
4. Please open the "risk trends" page to view disease risk trends as displayed on the line graphs.
    a. Move the mouse cursor over the line graphs to make a single-point comparison of the disease risks simultaneously.
5. Please open the "disease risks" page to view individual disease risks.
    a. Next, select a chronic disease or cancer using the drop-down menu.
    b. Using the pointers on the gauge chart, compare the disease risk, based on hypothetical data, with the optimal risk.
    c. Thereafter, move the mouse cursor over the line graphs below to make a single-point comparison of the disease risk and top risk factors.

Health Profile (Scenario A):
 i. Body measurements
    a. Weight: 55 lbs
 ii. Lifestyle factors:
    a. Alcohol consumption: 3 drinks per week
 iii. Dietary habits:
    a. Fruit intake: 3 servings per day
    b. Vegetable intake: 4 servings per day
    c. Red meat or processed meat intake: 3 servings per week
    d. Dairy products intake: 2 servings per day

Scenario B:

Michael is a 40-year old man who works as a software programmer. Due to the nature of his job, he has a sedentary lifestyle and is physically inactive. He has no significant personal medical history. However, he has been worried about his health for some time due to his excessive weight and smoking habits. His Body Mass Index (BMI) is 31 kg/m^2 and has smoked 1 pack of cigarettes per day for the past 23 years. He has been using PRISM to assess and monitor his risks for chronic diseases and cancers. Michael's objective is to lower his disease risk scores by modifying his risk factors and risky health behaviours. Over the past month, he has cut down number of cigarettes smoked per day from 1 pack (20 cigarettes) to 5 cigarettes. He also started to exercise regularly and improve his dietary habits by following Canada's Food Guide. Michael got his lab test results from the GP's office today and wants to update his health profile on PRISM.

Tasks (Scenario B):
1. Please open PRISM and login by entering the username and password provided.
2. Please fill out the fields in the "health profile" page using the information provided below.
3. Please open the "dashboard" page and view the health graph and bullet charts.

      a.   Click on the health metrics shown on the health graph to go into details of each metric.
      b.   Thereafter, click on the bullet charts to view specific chronic disease and cancer risks on the health graph.
4.   Please open the "risk trends" page to view disease risk trends as displayed on the line graphs.
      a.   Move the mouse cursor over the line graphs to make a single-point comparison of the disease risks simultaneously.
5.   Please open the "disease risks" page to view individual disease risks.
      a.   Next, select a chronic disease or cancer using the drop-down menu.
      b.   Using the pointers on the gauge chart, compare the disease risk, based on hypothetical data, with the optimal risk.
      c.   Thereafter, move the mouse cursor over the line graphs below to make a single-point comparison of the disease risk and top risk factors.

Health Profile (Scenario B):
  i.   Body measurements:
      a.   Weight: 210 lbs
  ii.   Lifestyle factors:
      a.   Smoking: 5 cigarettes per day
      b.   Physical activity: 3 hours per week
 iii.   Dietary habits:
      a.   Fruit intake: 4 servings per day
      b.   Vegetable intake: 5 servings per day
      c.   Dairy products intake: 2 servings per day
      d.   Red or processed meat intake: 1 serving per week
      e.   Sweetened beverages consumption: 0 per day
 iv.   Lab tests:
      a.   Blood pressure: 130/85 mm Hg
      b.   Total cholesterol: 5.4 mmol/L
      c.   HDL cholesterol: 0.95 mmol/L

APPENDIX E: POST STUDY SURVEY

Please respond to each statement using the following scale: –

1	2	3	4	5
Strongly Disagree	Moderately Disagree	Neither Agree nor Disagree	Moderately Agree	Strongly Agree

1. Attitude

	Attitude towards PRISM	1	2	3	4	5
1	I am interested in changing my lifestyle if it will help to reduce my risk of getting a chronic condition (such as diabetes, cancer, hypertension, etc.)					
2	I have confidence in this technology					

2. Primary task support

	Primary Task Support	1	2	3	4	5
1	PRISM could help me to evaluate the effect of my lifestyle on my health					
2	PRISM could help me to set and reach my goals regarding modifying my risk lifestyle behaviors					
3	PRISM could aid me in realizing the potential need for change in my lifestyle habits					

3. Perceived usefulness

	Perceived usefulness of PRISM	1	2	3	4	5
1	Using PRISM would enable me to assess, monitor and manage my risks for multiple chronic diseases and cancers more quickly.					
2	Using PRISM would make it easier for me to self-monitor and self-manage my health risks					
3	I would find PRISM to be a useful health tool for the assessment, monitoring and					

		1	2	3	4	5
	management of chronic disease and cancer risks.					

4. Behavioural intention

	Behavioural intention to use PRISM	**1**	**2**	**3**	**4**	**5**
1	I would consider using PRISM to learn about my health risks					
2	I would consider using PRISM to manage and monitor my risk factors for chronic diseases and cancers					
3	I would be willing to engage with the PRISM platform in the future					

Q1. What feature do you think are the most useful in PRISM that can help you assess, monitor and manage your risk for chronic diseases?

Ans._____

_____

_____

_____

_____

_____

Q2. Is there anything you least like about PRISM?

Ans._____

_____

_____

_____

_____

_____

Q3. In what way could PRISM be improved?

Ans._____

_____

_____

Evaluation of perceptions and behavioural intentions towards using PRISM: Personalized Risk Investigation, Stratification and Mitigation – Letter of Informed Consent

Principal Investigators: Ali Daowd, Master of Health Informatics (MHI) student

Dr. Raza Abidi, Professor, Faculty of Computer Science
and Director of Health Informatics

Contact Person: Ali Daowd. E-mail: ali.daowd@dal.ca

Introduction

We invite you to take part in a research study being conducted by Ali Daowd, who is a Master of Health Informatics (MHI) student, under the supervision of Dr. Raza Abidi (Professor, Faculty of Computer Science and Director of Health Informatics). You can withdraw at any time during the study session. Once you have informed the researcher (Ali Daowd) of your intent to withdraw, all your identification information, e.g., name, pseudonym/ID along with any data we may have collected from you will be destroyed immediately. The study is described below. This description tells you about the risks, inconvenience or discomfort that you may experience. You should discuss any questions you have about the study with Ali Daowd.

Purpose of the Study

The purpose of this study is to gauge end-users' attitude and perception towards using the PRISM (Personalized Risk Investigation, Stratification and Mitigation) health platform and provide feedback on areas of improvement. PRISM is a health-based digital platform that is designed to help citizens like you in assessing, monitoring and managing their health and chronic disease risks. You will be requested to complete a 1-1.5-hour session in which you will be given a scenario and a set of easy-to-do tasks using the PRISM platform. Before the session starts, you will be given a demographics and background survey to be completed. After the session, you will be given a post-study questionnaire to evaluate attitude and perception towards using the PRISM platform.

Study Design and what will you be asked to do?

At the beginning of the study, an investigator will meet with you at a set time and location. A computer will be used for this study. The study and its procedure will be explained to you and you will be asked to give consent to participate in the study. You will then be asked to complete a demographic and background questionnaire detailing your experience with using computers, the Internet and web-based chronic disease risk assessment tools. After this you will be provided with two hypothetical scenarios of individuals using PRISM and a small set of tasks. You will use these scenarios and tasks to interact with PRISM. Finally, at the end of the study you will fill a five-point Likert scale questionnaire that also contains a few open-ended questions. The questionnaire will inquire about your perception and behavioural intention towards PRISM. Your answers to the open-ended questions will help us in identifying areas for improvement for later stages of the platform design and implementation. Please note that you will not be quoted in any future publications or reports. An investigator will be available in person to answer any questions you may have or address any problems that you may experience while performing the study.

All personal and identifying data will be kept confidential in academic publications. Anonymity of data will be preserved by using pseudonyms. All collected data will use pseudonyms (e.g. an ID number) to ensure your confidentiality. The informed consent form and all research data will be kept in a secure location under confidentiality.

Who Can Participate in the Study?

Any person who has an intermediate level of English fluency (reading and understanding a simple newspaper article and the ability to take part in casual conversations) and is not visually impaired can participate in the study.

Who will be conducting research?

The research team consists of the primary investigator, Ali Daowd, and supervising investigator, Dr Raza Abidi, Professor, Faculty of Computer Science and Director of Health Informatics at Dalhousie University. The primary investigator will be conducting this study. He is currently a Master of Health Informatics (MHI) student at Dalhousie University.

Possible Risks and Discomforts

There are very minimal risks associated with the study that you might become frustrated, discouraged or embarrassed if you experience some difficulty in performing tasks or completing a scenario during the study. An investigator will always be present to respond to any queries or apprehension you might have during this study. Moreover, all data will be treated confidentially.

Possible Benefits

There are no direct benefits to you in this study.

Indirect benefits include advancing knowledge on user's attitudes and perceptions towards consumer-centric health systems.

Anonymity and Confidentiality

All personal and identifying data will be kept confidential in academic publications. Anonymity of data will be preserved by using pseudonyms. All collected data will use pseudonyms (e.g. an ID number) to ensure your confidentiality. The informed consent form and all research data will be kept in a secure location under confidentiality. Electronic data will be password protected and stored in the researcher's (Ali Daowd) computer, that no one has access to.

Problems or concerns

In the event that you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact Catherine Connors, Director, Office of Research Ethics Administration at Dalhousie University's Office of Human Research Ethics for assistance: phone: (902) 494-1462, email: catherine.connors@dal.ca.

"*I have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I hereby consent to take part in the study. However, I understand that my participation is voluntary and that I am free to withdraw from the study at any time.*"

Participant   **Researcher**

Name: _____   Name:

_____
Signature: _____   Signature:

_____
Date: _____   *Date:*

_____

APPENDIX G: RESEARCH ETHICS BOARD LETTER OF APPROVAL
Social Sciences & Humanities Research Ethics Board
Letter of Approval October 05, 2017
Ali Daowd
Computer Science\Computer Science

Dear Ali,

REB #:   2017-4304 **Project Title:**   A Personalized Risk Investigation, Stratification and Mitigation (PRISM) Platform for Citizen's Lifetime Healthcare

Effective Date: October 05, 2017 **Expiry Date:**   October 05, 2018
The Social Sciences & Humanities Research Ethics Board has reviewed your application for research involving humans and found the proposed research to be in accordance with the Tri-Council Policy Statement on *Ethical Conduct for Research Involving Humans.* This approval will be in effect for 12 months as indicated above. This approval is subject to the conditions listed below which constitute your on-going responsibilities with respect to the ethical conduct of this research.
Sincerely,

Dr. Karen Beazley, Chair

Post REB Approval: On-going Responsibilities of Researchers
After receiving ethical approval for the conduct of research involving humans, there are several ongoing responsibilities that researchers must meet to remain in compliance with University and Tri-Council policies.
1. Additional Research Ethics approval
Prior to conducting any research, researchers must ensure that all required research ethics approvals are secured (in addition to this one). This includes, but is not limited to, securing appropriate research ethics approvals from: other institutions with whom the PI is affiliated; the research institutions of research team members; the institution at which participants may be recruited or from which data may be collected; organizations or groups (e.g. school boards, Aboriginal communities, correctional services, long-term care facilities, service agencies and community groups) and from any other responsible review body or bodies at the research site

2. Reporting adverse events
Any significant adverse events experienced by research participants must be reported **in writing** to Research Ethics **within 24 hours** of their occurrence. Examples of what might be considered "significant" include: an emotional breakdown of a participant during an interview, a negative physical reaction by a participant (e.g. fainting, nausea, unexpected pain, allergic reaction), report by a participant of some sort of negative repercussion from their participation (e.g. reaction of spouse or employer) or complaint by a participant with respect to their participation. The above list is indicative but not all-inclusive. The written report must include details of the adverse event and actions taken by the researcher in response to the incident.

3. Seeking approval for protocol / consent form changes
Prior to implementing any changes to your research plan, whether to the protocol or consent form, researchers must submit a description of the proposed changes to the Research Ethics Board for review and approval. This is done by completing an Amendment Request (available on the website). Please note that no reviews are conducted in August.

4. Submitting annual reports
Ethics approvals are valid for up to 12 months. Prior to the end of the project's approval deadline, the

researcher must complete an Annual Report (available on the website) and return it to Research Ethics for review and approval before the approval end date in order to prevent a lapse of ethics approval for the research. Researchers should note that no research involving humans may be conducted in the absence of a valid ethical approval and that allowing REB approval to lapse is a violation of University policy, inconsistent with the TCPS (article 6.14) and may result in suspension of research and research funding, as required by the funding agency.

5. Submitting final reports

When the researcher is confident that no further data collection or participant contact will be required, a Final Report (available on the website) must be submitted to Research Ethics. After review and approval of the Final Report, the Research Ethics file will be closed.

6. Retaining records in a secure manner

Researchers must ensure that both during and after the research project, data is securely retained and/or disposed of in such a manner as to comply with confidentiality provisions specified in the protocol and consent forms. This may involve destruction of the data, or continued arrangements for secure storage. Casual storage of old data is not acceptable.

It is the Principal Investigator's responsibility to keep a copy of the REB approval letters. This can be important to demonstrate that research was undertaken with Board approval, which can be a requirement to publish.

Please note that the University will securely store your REB project file for 5 years after the study closure date at which point the file records may be permanently destroyed.

7. Current contact information and university affiliation

The Principal Investigator must inform the Research Ethics office of any changes to contact information for the PI (and supervisor, if appropriate), especially the electronic mail address, for the duration of the REB approval. The PI must inform Research Ethics if there is a termination or interruption of his or her affiliation with Dalhousie University.

8. Legal Counsel

The Principal Investigator agrees to comply with all legislative and regulatory requirements that apply to the project. The Principal Investigator agrees to notify the University Legal Counsel office in the event that he or she receives a notice of non-compliance, complaint or other proceeding relating to such requirements.

9. Supervision of students

Faculty must ensure that students conducting research under their supervision are aware of their responsibilities as described above, and have adequate support to conduct their research in a safe and ethical manner.