A DIGITAL HEALTH BASED PERSONALIZED PREOPERATIVE PATIENT EDUCATION SYSTEM FOR PATIENTS UNDERGOING TAVI SURGERY

by

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To My Family

This journey would not have been possible without the support from you. To my parents, thanks for encouraging me in all of my studies and motivating me to follow my dreams. Thank you for supporting me emotionally and financially during this journey. I always knew that you believed in me and wanted the best for me. To my wife, thank you for your patience and constant encouragement over these years. To my son, you have given me special motivation to accomplish this work, and I hope my success is your foundation for your future achievements. I absolutely could not have done this research work without all the love and support provided by my family.

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ABSTRACT

Personalized Patient education is a critical factor in the healthcare service delivery as it contributes to better management of diseases and ultimately enhanced clinical outcomes. TAVI (Trans-catheter Aortic Valve Implantation) is a standard cardiac procedure for patients with severe aortic stenosis. TAVI is a minimally invasive procedure, however; this procedure is still associated with a number of considerable risks based on the condition of the patient before performing this procedure. To obtain an informed consent, it is important to appropriately inform patients and their families about the risks and benefits of TAVI. In this thesis, our research objective is to leverage digital health technologies to develop a "proof-of-concept" personalized preoperative patient education system for TAVI patients "TAVI System". An iterative user-centered approach is used to develop the web-based TAVI system, and its knowledge content is based on digitized evidence and clinical expertise. We use a knowledge management approach to model, computerize, and integrate TAVI patient assessment to generate personalized educational messages for TAVI patients. For evaluating TAVI system, we used scenario-based evaluation to ensure the correctness of the outputs of the system based on the knowledge obtained from experts.

LIST OF ABBREVIATIONS USED

TAVI – Trans-Catheter Aortic Valve Implantation

QEII – Queen Elizabeth II Health Sciences Centre

SDM – Shared Decision Making

PCC – Patient Centered Care

HKM – Healthcare Knowledge Management

IHCAs – Interactive Health Communication Applications

PET – Patient Education Tool

MDT Review – Multidisciplinary Team Review

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CHAPTER ONE: INRODUCTION

1.1 Introduction

Contemporary healthcare makes patient education a right for every patient. Patient education is a significant component of the modern healthcare that covers many areas of patient care that are systematically planned and executed in a sequential and logical manner in clinical settings [1, 2]. Personalized patient education interventions entail a continuous learning and development process that involves health professionals and patients. The goals of patient education interventions are premises on the assessment, prognosis, diagnosis, evaluation, requirements, and individual needs to determine the required interventions [3]. The primary goal of personalized patient education interventions is to promote health outcomes, general wellness, and prevention of illnesses. Therefore, concerning this issue, patients are required to take a more active and informed role in decisions that are related to their health [3].

Web-based interventions are increasingly being used to educate patients about their illness, prevention, and treatments. With increasing access to the internet, more medical content is available to patients. However, despite the introduction of assisted computer-based systems in the healthcare sector, many hospitals are still struggling to incorporate these technologies to personalize patient education programs [4]. Personalized Patient education is a critical factor in the healthcare service delivery as it contributes to better management of diseases and ultimately enhanced clinical outcomes [6,7]. Most importantly, providing patients with personalized education can promote patient self-care [8]. Personalized patient education means providing the patient with the necessary information and excluding irrelevant information to the patient [7, 8, 9]. It allows more intervention specific detail than generic patient education, which attempt to satisfy all situations but usually fail to include specific information [8]. Moreover, personalization enables the 'modification' of content to the level of readability, motivational style, and specific concerns of each patient [8, 10]. In the long term, personalized patient education may assist to obtain informed consent and achieve patient engagement more reliably than the traditional methods [3, 4].

Trans-catheter Aortic Valve Implantation (TAVI), is a unique cardiac procedure that is carried out with elderly patients with severe aortic stenosis [12]. TAVI procedure was born recently due to the high-risk nature of open heart valve replacement in the frail elderly patient population [13]. The frail elderly patients were excluded from heart valve repair or replacement due to prohibitive surgical risk [14]. Innovative procedures such as TAVI have become another option for patients who are considered too high risk for open heart surgery, often due to advanced age and multiple comorbid conditions [13, 14]. Along with medical and surgical innovation, however, must come health promotion through preoperative patient education.

TAVI is a standard procedure for elderly patients with severe aortic stenosis [15]. TAVI is a minimally invasive procedure, however; this procedure is still associated with several considerable risks based on the condition of the patient before performing this procedure [14, 15]. To obtain an informed consent, it is important to appropriately inform patients and their families about the benefits and risks associated with TAVI procedure, so patients and their families are ultimately able to make a decision [15]. One of the main goals in this interaction is the exchange of relevant detailed information about treatment strategies and the associated risks delivered in terminology that is understood by patients and their family [16]. Also, risk tolerance and patient expectations vary across many patient populations [16]. Therefore, providing personalized patient education can be an effective method for preparing each patient undergoing TAVI.

1.2. Research Motivation:

During the preoperative period, patients and their families always require appropriate, easily accessible and understandable information regarding their procedure, to have a better understanding of their conditions and associated risks [16]. Also, most healthcare providers usually have a limited amount of time during the preoperative visits to explain patient's conditions and their associated risks with the procedure in more details [16]. Moreover, studies in general practice settings illustrate that patients and their family had forgotten about half of the information provided by physicians to them within a short period of time after leaving the hospital [17, 18]. It is usually because the information is overwhelming for them or anxiety or fear of the proposed treatment/procedure [17]. In such

situations, patients became unaware and uneducated about their conditions and associated risks with the procedure. In addition, studies suggest that impersonal and general patient education has insignificant impact on patients and health outcomes as compared to the personalized and patient-specific educational interventions [16, 19]. Moreover, many patients prefer to receive information that is personalized to their own health condition(s) [20].

In September 2016, I started shadowing TAVI team members at the Queen Elizabeth II (QEII) Health Sciences Centre to gain knowledge about the clinical pathway of TAVI, focusing on the preoperative stage. Here are some points which illustrate my observations on the patient education process of the current preoperative clinical pathway for TAVI:

- Most of new TAVI patients perform the required diagnostic medical examinations, and come to the first appointment "blind" with no prior information about TAVI.
- Current patient education is mainly done through providing verbal patient education, and watching a short video about TAVI with the nurse, and answering patient's questions.
- Most of the information provided about TAVI is generic.
- Written patient education materials, such as handouts, pamphlets, commercial ads, and patient booklets, are not provided during the clinical encounter.
- Some patients are not well prepared, less comfortable, more anxious about doing the procedure.

1.3. Research Objective:

Our main research objective is to leverage health informatics methodologies and technologies to develop a "proof-of-concept" preoperative personalized patient education system for TAVI patients, that can offer the following functionalities:

- Assist in TAVI patient assessment to highlight associated risks and specific procedural considerations for each patient with respect to the TAVI procedure.
- Select and deliver patient-specific educational messages, based on the patient's TAVI assessment, to help prepare the patient about the TAVI procedure.

- ❖ Improve patient consent by informing the patient about their own associated risks and considerations prior to performing TAVI. This will allow patients to make informed decisions about the procedure.
- ❖ Improve Shared Decision Making (SDM) about TAVI procedure between the patients and physicians.

1.4. Solution Approach:

Based on my observations during my shadowing experience, there is an opportunity to improve TAVI preoperative patient education during the clinical encounter. This improvement can be done by developing a personalized preoperative patient education intervention for TAVI patients in collaboration with TAVI team members at Queen Elizabeth II Health Sciences Centre. This approach aims toward addressing the associated risks and specific considerations of each TAVI patient, before performing the procedure, based on TAVI patient assessment. In this approach, personalized educational messages will be delivered for each TAVI patient prior the procedure. These educational messages will be specific through targeting the condition of the patient. The content of these messages will be based on clinical recommendation and evidence-based literature, which are provided by interventional cardiologists at the QEII hospital. In addition, this system will be useful for improving patient-doctor communication and Shared Decision Making about TAVI procedure between patients and physicians during their clinical encounter. Additionally, this approach aims toward producing well informed patients through having a better recognition of their associated risks and considerations prior performing TAVI.

Our patient education approach will be based on reaching a specific TAVI patient, based on specific characteristics/variables that are unique to that patient, related to the possible risks and considerations associated with this procedure, and have been derived from an individual assessment. In collaboration with the TAVI team at QEII hospital, we have worked on identifying the main risk variables, in the TAVI assessment, which will determine the associated risks and considerations of the patient prior TAVI based on a set of decision rules. After identifying the associated risks, a number of specific educational messages will be delivered to the patient Therefore, in this approach the educational messages will be highly personalized to each TAVI patient based on the results of patient assessment.

The proposed system offers specific educational messages based on clinical expertise and evidence-based literature, which are provided by interventional cardiologists, to each TAVI patient. These personalized messages can assist in reducing the scarcity of the source of the medical knowledge. In addition, these educational messages will be very simple and in a layman language which can be easily understood by patients and their family, as it is usually difficult for them to understand medical terminologies.

1.5. Research Contributions:

This research can potentially yield benefits for healthcare providers, patients, and health informatics professionals. Here are the main benefits:

- ***For patients:***
  - Reducing the level of preoperative anxiety.
  - Improving recognition of the associated risks, complications, and other considerations.
  - Improving health and surgical outcomes.
- ***For healthcare providers:***
  - Increasing patient satisfaction
  - Reducing the number of preoperative visits or the time required in such visits.
  - Determining specific preoperative needs and considerations for each TAVI patient.
- ***For health informatics professionals:***
  - Using health informatics tools to model a clinical pathway from a shadowing experience.
  - Applying health informatics methodologies to model, computerize, and integrate a patient assessment to deliver specific educational content.

1.6. Thesis Outline:

This thesis is organized in the following manner:

- ***Chapter 2:*** "Literature Review", we will review some literature providing:
  - Brief Patient Education History
  - Preoperative Patient Education in Healthcare

- Standard verbal and written patient education materials and their issues
- Usability of Web-Based Interventions in Healthcare
- Rationales for Developing Web-Based Interventions for Preoperative Patient Education
- Related work to Preoperative Patient Education Interventions
- Significance of Personalized Patient Education
- Rationales of Personalized Preoperative Patient Education Interventions for Cardiac Patients.
- Healthcare Knowledge Management & Knowledge Based Systems

❖ ***Chapter 3:*** "Research Methodology", we will discuss the research methodology for the development of our personalized patient education system.

- Re-evaluating the problem statement and research goal and objectives
- Our Patient Education Approach
- Research Methodology

❖ ***Chapter 4:*** "Methods: TAVI System Development", we will detail the steps of developing our system.

- Understanding and modelling the current clinical pathway for TAVI
- TAVI patient assessment components, risk variables, and associated risks and consideration.
- Patient education content
- Developing the set of decision rules
- The proposed clinical pathway for TAVI with our proposed system

❖ ***Chapter 5:*** "Evaluation", we will evaluate our system and have a discussion on the main points of evaluation.

- Scenario-based Evaluation

❖ ***Chapter 6:*** "Discussion & Conclusion", we will conclude and summarize our research work, and we will discuss working limitations along with potential future research directions and implications.

CHAPTER TWO: LITERATURE REVIEW

2.1 Patient Education History and Background

The foundation and idea of Patient Education in health research have developed in last few decades. In 1976, at the First International Conference on Patient Counselling, the first scientific journal based on Patient Education was initiated [1, 21]. In the last few decades, patient education has played an important role in the health sector for improving patients' health outcomes. Patient education became a crucial part of communication between health professionals and patients. Health professionals can educate patients through a variety of means and interventions [1, 21]. Health professionals can use interpersonal communication skills and patient education materials such as pamphlets and booklets. Newly, some health professionals are using web-based and interactive computer-based patient educational interventions [21, 22]. Currently, patient education does not rely on health professionals only, but patients and their families can educate themselves, regarding their illnesses and treatments, through the modern interventions such as Web-based educational interventions [21].

In the past, health professionals were the responsible for educating patients about their illnesses and treatments. Also, in the past the major focus in healthcare was mostly on the management of diseases [21]. The focus on patient education and prevention of diseases through behavioral modifications was less. In 1974, Lalonde illustrated that patients could improve their health outcomes through behavioral and emotional factors related to their life style modifications [23]. Lalonde also illustrated that the focus should not be only on the pathological aspects of the disease conditions in defining health outcomes [23]. There should be a more focus on behavioral and emotional factors for improving health outcomes [21].

In the 1970s, more importance was given to patient education and self-management by some European countries [24], and also by some patient initiatives in the United States of America [25]. These patient education initiatives contained of some patient self-help groups and the self-care managements. In the 1980s, patient education was developed through the use of Information Technology. For example, educational presentations and videos were mostly used in patient education programs [1, 21]. In the 1990s, more

importance was given to the impact of the social factors such as family relationships and social networks on health outcomes [1]. The impact of the social factors on health outcomes introduced behavior change interventions [26, 27]. After that, more emphasis was placed on the Internet which became a common source for the patients to search for information about their health issues and conditions [1]. After the 1990s, patient education had a transition to variety of Interactive Web-based, Computer-based Patient, m-Health Education Programs and applications [1, 21].

2.1.1 Factors Influencing Patient Education

Patient education has had different stages of development over time as we mentioned in the last section. The development of Information Technology has made a significant impact on patient education. As the technology advances, it needs better communication with patients to achieve the ideal level of patients' satisfaction [28, 29, 30]. Another significant factor, which may influence patient education, is aging [29]. Many elder people are taking care of themselves alone and are responsible for managing their daily lives. Chronic diseases such as hypertension, heart diseases, diabetes, and cancer occur more often in the elderly. Thus, elderly people are more prevalent to co-morbidities, and require self-management regularly [29, 31]. Elderly people prefer having communication to learn about their health issues, and that would make the newly developed education interventions and applications are less appropriate for this population [31]. In addition, cultural diversity is another factor that influences patient education [30, 32]. This factor is especially targeting those people who have moved from different parts of the world to settle in Europe and North America, and have different cultural thoughts [1]. Some factors, such as anxiety or interpretation of pain, is related to patients' cultural beliefs and thoughts. Thus, patient education programs and interventions should consider these factors of individual patient and family's cultural values and beliefs, to have an effective patient education and better health outcomes [33].

2.1.2 Patient Education Theories

Patient education theories considered as summaries of formal and non-formal observations in healthcare. These theories are presented in a systematic and structured

order. Patient education theories are useful for explaining, predicting, describing or managing health related behaviors [34]. Modifying health beliefs and behaviors can be done through different patient education interventions and programs. Patient education theories provide few explanatory mechanisms and ways for understanding the communication process during the period of modification through the intervention [35]. Also, patient education theories and models suggest more effective methods for achieving patient compliance, and other behavior change related to the illness and treatment in order to improve the overall health outcome [34, 35]. The high-level categories of patient education theories are: Policy level theories, Community-level theories, Institutional or Organizational- level theories, Interpersonal-level theories, and Intrapersonal-level theories [34]. Some patient education theories focus on the importance of patient education in improving Shared Decision Making which makes medical care more patient oriented. For patient education researches, it is important to look for a patient education approach which supports patient engagement and Shared Decision Making. SDM can be a promising way to improve quality of care [2, 3, 21].

2.1.3 Shared Decision Making

Effective and efficient communication provide successful information exchange between healthcare providers and the patient, which is essential during the clinical visit especially for decision making [36, 37]. There are different models of decision making such as traditional, informed and shared [38]. The traditional model of decision-making involves making the decision by the healthcare providers, and the patient accepts their decision. The traditional approach is based on paternalistic healthcare model, where healthcare providers are domain experts and take decisions on behalf of the patient, best in their opinions and irrespective of patients' preference [38]. The second model is the informed model, which is also called a consumer-oriented model. In this model, the information exchange is still one-way from healthcare providers to patients [38]. The difference in this model is that the patient can take decisions on their own regarding to their health conditions. The role of the physician in this model can be considered as an information source to provide the required information to the patients regarding their health conditions [38].

Nowadays, healthcare is going from the traditional model of decision making towards the Patient-Centered Care (PCC) which supports SDM [3, 39]. Healthcare is moving towards PCC model and strategies [3, 39]. Shared Decision-Making model is considered as the core of Patient-Centered Care, and identified as a crucial component in the process of improving quality in healthcare, as well as improving health outcomes [36, 37]. The idea of PCC approach is to produce more informed and educated patients who can actively contribute in the process of care related to their own health conditions. The Shared Decision-Making model involves interaction between patients and healthcare providers to exchange information, and consider outcome probabilities to proceed towards mutually agreed decision [36, 37]. The SDM model considers needs, wishes, and preferences of the patient rather than depending on clinician-directed decision making only [36]. Every patient should understand the rationale behind treatment modalities and their possible pros and cons. For example, patients who are planning to do an elective surgical procedure should understand the benefits and risks associated with this procedure. To promote Shared Decision-Making process, we should improve the patient education process related to the planned treatment which leads to have a better understanding about the risks and benefits associated with the treatment approach [3, 39]. This improvement can be done through consider patient preference and needs, and barriers to SDM.

2.2 Preoperative Patient Education in Healthcare

Preoperative patient education in healthcare entails the medical interventions that patients get so that they improve their satisfaction of healthcare services that patients receive as well as reducing stress and anxiety in patients before they get healthcare services that are critical or likely to make their life precarious [40]. One of the main objectives of preoperative patient education is to reassure patients and reduce the anxiety, that is associated with their responses accepting or not accepting the elective treatment [40, 41]. When patients do not have sufficient knowledge about the treatment, it is more likely to contribute to their fearing of medical interventions that they are about to get. It may also contribute to the pain that patients get when undergoing a medical operation or experience of post-medical intervention effects like nausea and postoperative pains [40].

In most cases, patients go through at least one preoperative education session with healthcare professionals, such as physicians and nurses, before their medical treatment. Usually this is done within a few days or even hours before they undergo a medical procedure, depending on the type of the medical procedure [42]. Patients known to undergo such procedures and come out with little or no complications may get a limited preoperative education. Preoperative education is important and especially offered to patients undergoing precarious procedures that leave patients psychologically and physically stressed [40, 43]. This education is meant to improve the pre and post-operation state of patients and enhance their experience, recovery, and health outcomes.

Providing sufficient patient education to surgical patients is essential. Some healthcare practitioners do not accord this education the urgency it needs by making it a culture for their institutions or themselves [43]. Hence, this intervention is necessary for reducing pre and post-operative anxiety and other psychological scars. Such patients experience high levels of depression and anxiety because of fear, worry or uncertainties about the surgery they are about to undergo [40]. The fear and depression if not taken care of, can complicate an existing medical condition that is supposed to be rectified through a surgery [40]. Thus, it may complicate preoperative procedures such as application of anesthesia or result in prolonged recovery [42]. Therefore, patient education is used to improve the experience of the patients through the provision of relevant healthcare information, psychological support before surgery and coping skills. When compared with other forms of medical care, preoperative education can be utilized to enhance post-operative outcomes for patients [42]. For instance, an analysis of patients undergoing orthopedic surgery, preoperative education can significantly improve the knowledge and anxiety of patients in a great way [42, 43]. Also, analysis of the impact of this education on cataract surgery indicated that it made them have less anxiety, great understanding of the medical procedures that they undergo and leave them more satisfied [42]. In addition, preoperative interventions are known to reduce pain to patients undergoing various operative procedures [17, 42].

2.3 Standard Verbal and Written Patient Education Materials

Successful healthcare relies heavily on effective communication between health professionals and patients. Medicine entails an art whose creative and magic ability resides in the inter-personal aspects between the physician and the patient. Interpersonal skills and communication are powerful tools in delivering effective medical care [44]. When communication between the patients and clinicians is effective, physicians can gather the required information to make a better diagnosis, offer therapeutic instructions, and establish a caring relationship with their patients [38]. Through this, best health outcomes can be achieved by promoting patient satisfaction [41, 44]. The physician-patient relationship is a two-way affair and beneficial mutually. Patients and physicians have to develop and share perceptions as well as feelings regarding the nature of the problems at hand, the goals and objectives of the treatment required and the necessary psychological support [17, 41].

The basic communication skills alone are insufficient in creating and sustaining a successful relationship between patients and their physician. In most cases, the standard verbal and written patient education materials are often poorly understood by patient because of many reasons. Some of the specialty clinics are operated by physicians, are the busiest in hospitals [45]. Having a busy schedule in the clinic makes the communication poor and inevitable because of the small number of consultations and available time due to the overstretched nature of medical practitioners [41]. Physicians and surgeons rarely get enough consultation time with their patients because they are busy addressing the influx of medical problems and issues that need their solutions [45]. The busy schedule of healthcare professionals makes their verbal communication inefficient to make patients to get various issues concerning their ailments addressed. Also, sometimes physicians use medical terminology that patients have little or no knowledge about it. Terminologies used by physicians to communicate with their patients are mostly inconsistent [41]. Physicians are human beings who are carried by emotions, and this hampers their effective verbal communication with patients. For instance, a physician may sympathize with the condition of a patient making most of their consultations characterized with closed questions that limit the response of the patient [45]. Starting an effective verbal communication is where the problem usually lies. Many patients tend to keep the most important issues until when

their time with the physician is over. It leaves the physicians with the option of interjecting with a series of questions that the patient may both have adequate time to address [45].

Most patients are also known to have problems reading materials given to them by health professionals [46]. For instance, patients may fail to read pamphlets given to them by their physicians. There are also difficulties in first and second languages of patients and those used in written communication with physicians [46]. Patients may also fail to match words like bleeding and hemorrhage thus distorting written communication and making it poor in educating patients [46]. When standard verbal and written patient education is poorly understood, it results in low patient satisfaction, increased anxiety, information recall problems and increasing the number of consultation visits.

2.3.1 Improving Patient Satisfaction

Patient education is a key in ensuring that patients are satisfied with the medical care services that they get from practitioners. Verbal and written communication are good for patient education but has several limitations that lower patient satisfaction [47]. Information is power in enhancing patients to make informed decisions. Verbal communication in healthcare involves physicians who are highly knowledgeable about certain conditions. However, most patients don't have any medical background and their interpretations on conversations and written materials may be hard for them to understand resulting in dissatisfaction [44]. Many patients find written communication through generic materials is not convenient, because they do not have opportunities to get some issues addressed by experts yet, such education is designed to aid the making of decisions by patients [47]. For instance, breast cancer patients have choices of solutions to take that are offered by websites education sites. The web information though good may be a source for lowering patient dissatisfaction [48]. Verbal and written education for breast cancer victims and other chronic illness patients is enormous and is likely to confuse patients about the best options to take [48].

The generic education provided may also make patients preference sensitive. The information given may also make patients to fear about the pending status of their conditions and what is has in store for them regarding the fear of losing life [49]. Some of the written information may be very comprehensive with significant information about the

status of specific conditions and even the survival rates. The more information patients get through verbal and written education documents are also likely to give them conflicting information upon which to make decisions thus lowering patient satisfaction [47]. Verbal communication between patients and physicians is mostly tied to the consultation visits that are in most case short because of time constraints resulting in dissatisfaction [47].

Improving patient education process and communication may have a positive impact in improving patient satisfaction. Patient's satisfaction can be improved through efficient and effective communication between healthcare providers and patients. For example, research studies have shown that, patient satisfaction is strongly correlated to the patients' understanding of their conditions, diagnostic procedures, and surgical or other interventions [17, 44, 50], and also depends on efficient communication between the healthcare providers and the patients [28]. Based on Patient-Centered Care approach, healthcare providers should always consider new methods for improving their patient education process to produce informed and active patients who can participate in decision making through an effective and efficient communication [36, 37].

2.3.2 Anxiety Levels

Some medical procedures are known to increase the level of anxiety in patients. Some types of verbal and written education material for patients may increase the anxiety levels in patients depending on the nature of material accessed concerning those procedures. Written material is mostly detailed and gives patients no option of further guidance as in physical relationship with a medical practitioner [51]. Patients are left with no option of evaluating and understanding some medical terminologies. This might leave them with high levels of anxiety. For instance, procedures like cardiac catheterization may increase the anxiety of patients because of their precarious nature and the uncertainty associated with them. The procedures are regarded with possible complications [52].

In addition, the level of anxiety in patients increase for a number of reasons such as the wait time before their condition is addressed. Their anxiety level will increase when there is inadequate information concerning their conditions [40, 50]. For instance, verbal conversations with patients are hardly enough to address all patient concerns [40, 47]. The anxiety may also increase when written-based education materials accessed by patient's

lack teaching aids that are tailored to their needs and lack of relation techniques and emotional support for patients about to undergo life-threatening procedures that they are researching [53]. When patients do not have enough consulting time with their physicians, they are likely to get the levels of their anxiety increased. Inappropriate training before some procedure is taken also increases the stress level in patients, thus increasing the anxiety levels [53].

The literature suggests using patient-concerted interventions during the patient education process which may have a positive impact on reducing the level of anxiety level in patients. For example, a study illustrated that an empathic Patient-Centered intervention can be useful for reducing preoperative anxiety level in patients and increasing surgical recovery [40, 54]. Another study found that the level of anxiety can be reduced through providing enough information to patients about their conditions prior performing the proposed treatment [40, 54]. Also, other studies suggested using different interventions during the patient education process such as using multimedia interventions, interactive educational interventions, and personalized interventions which can produce more informed patients and reduce the level of anxiety [40, 50, 53].

2.3.3 Information Recall problems

Many health initiatives keep improving the ability of patient to make decisions about their illness and treatment. While these initiatives use different interventions that increase the abilities of patients in making decisions as compared to other care programs, recalling information that patients have in their mind from prior sources is hard. Written education material posted on the internet can be posted by anybody [51]. There is also limited avenues to classify the information regarding significant subjects like healthcare area. Because of this, unqualified information may find its way to patients for their use making it hard to recall [18]. Also, some of the information are conflicted and different from a source to another, making it hard to determine the standard information that patents should use. This leaves patients with conflicting information that makes it necessary to seek expert advice from physicians [18]. Thus, recalling large tracts of information on written material is hard. Verbal communication is also done by different physicians who

have different levels of experience and expertise. Information already propagated in patient mindset may prove difficult to change or recall [55].

2.3.4 The Number of Consultation Visits

Standard verbal and written patient education materials are often poorly understood by patients. This makes it necessary for them to keep going back to physicians to seek more consultations to clear out issues that they do not understand [47]. Many written education materials have terminologies and information that is hard to understand by patients on their own [46]. This makes it necessary to increase the number of consultation visits by patients [47]. Because of the anxiety associated with procedures for patients with chronic illnesses, increasing consultation visits enhances their relationship with doctors and clearly understands the status of their illnesses. Through more consultation visits, patients seek to have issues that they do not understand addressed [46, 47]. This strategy also helps in reducing poor verbal and written communication between them and their healthcare providers. They also find increasing of consultation hours is also good because it will help in recalling some healthcare information that is difficult to recall. Consultation visits are also good in following up on progress and development of patient conditions. On the other hand, increasing the number of visits will lead to an increase in the workload pressure on healthcare providers who are already have busy schedules [2]. In addition, it will lead to an increase in the healthcare cost. These important points lead to think about other patient education intervention that can be used to reduce number of consultation visits by patients [2].

2.4 Web-Based Interventions in Healthcare

Web-based patient education interventions are contemporary interventions that help in promoting the exchange of patient education information by online mechanisms. These interventions provide flexibility in the type and amount of patient education content, and provide an easy access for patient to get the information [49, 56]. A comprehensive review of the literature should be done to be able to determine the educational content in the web-based intervention [56]. In addition, the educational content should cover the basic learning needs of the patient prior or following a particular medical procedure [49].

Web-based interventions in healthcare management continue to be popular among patients with various life-threatening illnesses. Use of web-based information is a cost-effective means for delivering patient education information to patients, comparing to the cost of other interventions such as written materials [49, 56]. Web-based interventions are now easily accessible even on electronic devices that are internet enabled [45]. This makes them convenient for most users because users now access them from the comfort of where they are. The internet uses tools that patients can easily understand, and offers help links that help patients in addressing issues that they do not understand [56]. There are also specific websites that patients are guided to use to access authentic information. Web-based applications also have portals that patients have to register to access qualified information. Through the websites, patients can post queries and wait for expert response [20, 22].

Contemporary healthcare information users also have a good perception of information contained on the internet. The efficiency, effectiveness and satisfaction about web-based interventions are relative and depend from user to another [8, 57]. However, many platforms on the internet offer healthcare information. Most internet users consider access to information over different websites easy because of universal access with a few portals having requirements for registering as users to access information [58, 59]. In any case, those that require log in details are also easy to register and use. Other factors that influence the use of web-based interventions are the behavioral variables like cultural association to other patient education interventions like face-to-face consultations among other options [30, 44]. Furthermore, the increasing access to the internet continues to increase the usability of web-based interventions in offering patient healthcare services and information. The web is significantly increasing as an important tool for communication and information access. Web platform users have an overall perception about the sites which is positive hence enhancing usability of web-based interventions [60].

There are different approaches for web-based educational interventions. For example, web-based educational interventions can be used for patients and families. These educational interventions can focus on several areas related to the patient such as delivering specific knowledge related to symptoms and treatment, health behavior change, self-management and decision making [61, 62]. On the other hand, web-based educational interventions can be used for clinicians. For instance, these interventions can be used for

skill development and improvement, and decision support [63, 64]. Also, web-based educational interventions can use general educational methods such as multimedia, educational videos, and providing general information regarding a disease or treatment [10, 50, 65]. These interventions can be also personalized which focus on specific clinical characteristics. The personalized interventions can produce and deliver customized information, targeting the needs and conditions of the user.

2.4.1 Effectiveness, Advantages, Importance

Web-based interventions have increasingly been effective in helping patients with chronic and long-term illnesses to access care. These interventions have provided a shortcut that gives patients many information that they would have obtained from physicians. Because of the efficiency of web-based applications, the use of the internet in delivering healthcare solutions and information is increasing rapidly [49, 60]. Different methods are used like databases that are specific to different medical conditions. Patients can identify information, retrieve it, analyze it and access it according to the established quality and criteria for inclusion or exclusion in a specific area of study. This boost satisfaction levels of patients that only require little or no other interventions to manage their health education needs [49, 60].

Advantages of web-based interventions include its universal accessibility as long as one is connected to the internet. This makes it possible for patients from remote regions to access essential information as long as they are connected to the internet [66]. Web-based interventions also give patients true cost leadership as the cost of accessing information is relatively low [49]. In fact, costs associated with web-based interventions are those of internet access. With advancements in internet technology, the cost of the internet continues to reduce [49]. Web-based interventions education is also efficient because information can be delivered anywhere [60]. Web-based interventions are also accessible on other communication devices like tablets, smartphones and other devices that make it convenient and efficient [60]. Web-based interventions also allow video conversations between physicians and patients helping patients to cut on distance barriers and emotional appeals and ensuring that both the doctor and patient have an emotional attachment and relationship [66].

Web-based medical interventions are important because they complement other interventions that are available in the medical field [49]. These interventions also bridge the access gap that making healthcare more inclusive [60]. Also, these interventions help reduce the distance between the patients and their physicians [66]. The outcomes of patients using these responses have also shown great improvements and behavioral changes that are good for various medical conditions [60, 67]. Web-based interventions have made self-management and self-care possible because patients are encouraged to change their behavior and effectively managing chronic illnesses or conditions because of education, knowledge sharing and understanding of medical conditions [8, 56]. Patients are also saved the pain of staying in hospitals and associated costs as they can learn knowledge and apply it to suit their needs [56]. Web-based interventions have also brought many opportunities in the management of chronic conditions thus leaving patients and caregivers satisfied [49]. The innovative interventions can address deficiencies in patients through knowledge and self-management skills. Lastly, web-based interventions continue to gather information, transform and improve it and disseminate it to patients and physicians for better management of various medical conditions [49, 60].

2.4.2 Challenging Areas

Generally, web-based education interventions in the healthcare field face several challenges such as measuring the effectiveness and the ability of implementation [49, 68]. Many systematic reviews have illustrated a positive impact of web-based intervention on outcomes of interest in the healthcare field. Questions around effect sizes and the range of successful is still remaining [60, 68]. There is always a need for more research work to determine why some web-based interventions work and others do not. These researches should consider the mechanism of action of these web-based interventions and the context in which they are used [68]. Also, researchers should focus on identifying what factors that promote or inhibit the success of these interventions. Addressing the challenges can be done through applying theories for developing, evaluating, and implementing web-based interventions [49, 68]. This involves building a strong theoretical foundation, proposing and developing a pathway of action, making sure that the evaluation sufficiently reflects this proposed pathway, and considering implementation from the first stage of the

development process. Other challenges are related to the implementation and adoption of the intervention. For example, healthcare providers should be convinced about the effectiveness of the intervention and how this intervention can improve the quality of care, to be able to adopt this intervention in their clinical work [49, 68]. Another challenge is personalizing the patient education intervention [4]. The literature suggests using algorithms and computer programs to be able to personalize the content of the web-based intervention [69, 70]. Personalized web-based interventions consider one of the most effective methods for producing well informed patients [3, 4, 6].

2.4.3 Web-Based Interventions Usability

Specific applications of web-based healthcare education combine healthcare information to various types of support. For example, decision support, social support or behavioral change supports are highly influenced by Interactive Health Communication Applications (IHCAs) that are available on the internet [22]. These interventions have high powers of improving the knowledge, motivation, involvement and self-efficacy of users, which results in enhanced patient empowerment [71]. Web-based interventions are known to improve the empowerment of users into initiating changes in their health behaviors that result in improved clinical outcomes. For instance, a review of internet interventions found that IHCAs have positive effects on self-efficacy, knowledge, behavior, and clinical outcomes. Health professionals agree that these interventions used differ in suitability when used in addressing different chronic conditions [8, 56]. Web-based interventions empower patients with knowledge about the disease they are suffering from. In addition, they course treatment options and provide abilities for involvement in making informed medical decisions. These interventions also help patients on how to manage their health behavior as well as treatment regimens [8, 56]. However, web-based interventions should be accompanied by volitional components on the part of patients to predict positive changes in the behavior of an individual with chronic ailments [60, 68].

Furthermore, the literature illustrates that visual and written interventions of educating blood donors are good in improving blood donation attitude and intention [72]. However, Web-based donor preparation intervention can be a timely and cost-effective intervention to improve and encourage donation behavior, comparing to other interventions

[72]. Also, there are other advantages such as reducing anxiety level and improve confidence among donors and non-donors alike [72]. The literature mentions that patients and caregivers were less likely to ask health professionals questions related to their treatment after using a Web-based patient education intervention [73]. This is a promising finding, which may indicate that the number of consultation visits can be reduced through educating patient via Web-based interventions, resulting in reducing the pressure load on health professionals and reducing healthcare costs [73].

The interactive online decision aid (BresDex) was developed to support the surgical decision making of women who are diagnosed with early breast cancer in the UK [48]. The findings suggest that interactive Web-based patient education intervention can strengthen surgery intentions through improving readiness to make a decision for doing the surgery [48]. Therefore, interactive Web-based patient education intervention would be ideal for patients who are less ready to make a decision regarding a specific type of surgery. Another significant finding is related to informed consent. One of the important steps in the surgical pathway is obtaining informed consent such as for elective orthopedic surgery [41, 74]. The literature illustrates that Web-based patient education intervention enhances the informed consent through improving the knowledge of the proposed surgery, and increasing patient satisfaction [41, 74]. This lead to a critical question, whether health professionals should direct patients to Web-based educational interventions to obtain their consent instead of using verbal and written approaches. Additionally, this intervention can be useful in improving patient knowledge recall through having some patient education tutorials prior the elective surgery [74]. In addition, the literature suggests using educational video intervention especially for patients undergoing an elective medical procedure [75]. Using video intervention can reduce the preoperational anxiety level among patients. Based on this finding, adding the video as a part of the educational content of the Web-based intervention, will make the intervention more effective in reducing the anxiety level among patients [75].

The literature also suggests using strategies like personalization and individualization of information, and interactive presentation that helps to increase the effectiveness of web-delivered interventions. With personalization of web-based education sources will focus more on health behavior change with great variability [4, 6, 57]. Despite

the challenges in determining which interventions can offer proximal outcomes for patients with different illnesses, web-based interventions are the most sustainable [57].

2.5 Rationales for Developing Web-Based Interventions for Preoperative Patient Education

As noted, web-based health education interventions are meant to complement existing healthcare interventions by offering workable and convenient solutions. The aim of web-based interventions is to integrate medical science, computer science, and information technology in managing and communicating data, knowledge, and information in healthcare management [67]. Thus, web-based interventions seek to facilitate the integration of information and data to help patients in making informed decisions [6]. Health informatics facilitates the integration of data, information, and knowledge to support patients and health professionals in their decision making, and influencing behavior of patients in management of chronic conditions [6, 60, 67].

Web-based interventions also aim to enhance the efficiency of healthcare providers. For instance, healthcare practitioners working in shifts can access information that is helpful to them whenever there are fewer personnel or resources [45]. Also, web-based applications can help health professionals to anticipate and manage specific type of procedures by referring to web-based resources [76]. Healthcare personnel can also review information regarding procedures they are about to undertake at their convenience before they actualize it. This enhances efficiency because best practice model can be used in providing preoperative care. To enhance efficiency, traveling practitioners may access web-based interventions to orient themselves about procedures they are about to do thus enhancing efficiency [76].

Another rationale is to get knowledge and continuity management in healthcare. Web-based interventions are compiled through gathering, accumulation, and dissemination of information over a period [42]. This helps in establishing trends and improvements overtime. Accumulated knowledge pool over time can enhance recruitment strategies or healthcare institutions in their professional development and team building to offer the best care to their clients [67].

2.6 Related Work to The field of Preoperative Patient Education

Preoperative anxiety in ambulatory surgery [54]	
Focus	Preoperative anxiety and surgical outcomes in ambulatory surgery patients.
Methods/Delivery Medium	Delivering personalized information to patients through an empathic patient-centered interview prior surgery.
Main Outcomes	• The empathic patient-centered intervention has a positive impact on reducing preoperative anxiety and increasing surgical recovery, wound healing and patient satisfaction. • This approach is applicable in pre-surgical interviews
Preoperative Cognitive-Behavioral Patient Education Versus Standard Care for Lumbar Spinal Fusion Patients [77]	
Focus	Assessing the cost-effectiveness of a preoperative cognitive-behavioral therapy (CBT) intervention compared to usual care for patients undergoing (LSF surgery).
Methods/Delivery Medium	Investigating on 90 patients undergoing LSF, who were randomly assigned to usual care (control group) or usual care & a preoperative CBT intervention (CBT group).
Main Outcomes	Preoperative CBT intervention can be more effective and cost neutral when considering the overall healthcare sector and labor market perspective.
Multimedia support in preoperative patient education for radical prostatectomy [78]	
Focus	Using multimedia supported preoperative educations for radical prostatectomy
Methods/Delivery Medium	Evaluating the view of eight physicians who educated 203 patients for radical prostatectomy by using multimedia intervention
Main Outcomes	• Both patients and physicians profit from multimedia support for education and counseling. • The readiness of physicians is a possible challenge to this improvement, as their view is a key factor for the transition to everyday routine
Preoperative Incentive Spirometry Patient Education on Patient Outcomes in the Knee and Hip Joint Replacement Population [43]	
Focus	Exploring the effects of preoperative incentive spirometry education on postoperative outcomes for knee and hip total joint replacement patients
Methods/Delivery Medium	Comparing two groups of patients where group one received intervention that consisted of formal instruction preoperatively for IS home use, postoperative use, and IS volumes documentation, while group two patients received no intervention.
Main Outcomes	• (IS) volumes were not significantly different between the two groups • Patients who used the preoperative intervention had better outcomes and ranked the intervention as helpful.
Preoperative Patient Education on the Risk of Dislocation [79]	
Focus	Assessing the impact of preoperative patient education on the incidence of hip dislocation within six months after Primary Total Hip Arthroplasty

Methods/Delivery Medium	The preoperative patient education session included advice on muscle strengthening exercises, and postoperative restrictions of range of motion as means for dislocation prevention.
Main Outcomes	The findings suggest that patients who participate in the preoperative patient education session may reduce the risk of dislocation within six months after THA.
(PET) for postmenopausal women with osteoporosis [9]	
Focus	Developing a personalized patient education intervention for decision making for postmenopausal women with osteoporosis.
Methods/Delivery Medium	Testing the PET intervention on women at risk for osteoporosis
Main Outcomes	• All women indicated that the PET intervention could be helpful for their decision to select a treatment. • Both physicians and patients expressed a positive attitude towards the use of the proposed PET intervention.
Personalized 3D printed model of kidney and tumor anatomy [80]	
Focus	Assessing the impact of 3D printed models, as a tool for patient education, of renal tumor on patient's understanding of their conditions.
Methods/Delivery Medium	Testing the intervention on seven patients with a primary diagnosis of kidney tumor, focusing on patient knowledge before and after the intervention
Main Outcomes	Patients demonstrated an improvement in understanding of basic kidney physiology, anatomy, and planned surgical procedure after using the intervention.
Total Knee Arthroplasty (TKA) Preoperative nurse-led education program [81]	
Focus	Exploring the impact of preoperative patient education on the rate of in-hospital falls after primary TKA
Methods/Delivery Medium	72 patients of one surgeon were enrolled in a preoperative nurse-led education program
Main Outcomes	• Preoperative patient education intervention reduced the rate of falls. • The intervention has become mandatory for patients undergoing TKA at the institution.
Information protocol for planned cardiac surgery patients [82]	
Focus	• Examining the effects of implementing an information protocol on the process of preoperative education. • Planned cardiac surgery patients, (CABG and/or valve replacement), waiting for admission.
Methods/Delivery Medium	Dialogues between health educators and patients were videotaped and analyzed at the preoperative clinic.
Main Outcomes	• Implementation of the information protocol led to a better inter-disciplinary division of labor • The preoperative education is tailored more to the needs of the patient, and psychosocial items were mentioned more frequently. • This intervention led to fewer gaps in knowledge, and the information provided through this intervention was in line with the information provided by various healthcare providers.
Surgical Consent with a Preoperative Multimedia Patient Education Tool [83]	

Focus	• Assessing the efficacy of a multimedia education tool to improve patient's understanding • Used as an adjunct to the usual verbal consent process regarding first metatarsophalangeal joint (MTPJ) arthrodesis surgery
Methods/Delivery Medium	• Well-rehearsed, standardized and thorough information regarding the surgery, its risks, benefits, and usual post-operative course were supplied verbally to 31 patients • Each patient completed a multimedia educational program • Questionnaire, including supplementary questions regarding ease of understanding and satisfaction with the two methods
Main Outcomes	Incorporation of a computer-based, multimedia education intervention into to the surgical consent process can improve patient understanding of the risks, benefits and usual postoperative course following first MTPJ arthrodesis surgery.
Knee Osteoarthritis Patient Education Questionnaire (KOPEQ) [84]	
Focus	Assessing the validity of a preoperative educational intervention and to make a preliminary test of its psychometric properties.
Methods/Delivery Medium	The feasibility and interpretability of administering the KOPEQ was tested through conducting interviews with targeted patients.
Main Outcomes	The KOPEQ intervention can help to provide health professionals with reliable feedback on how patients assessed the applied patient education intervention
Improved patient information for Hemorrhoidectomy patients [85]	
Focus	The impact of improving patient information, in the setting of day-case hemorrhoidectomy, in terms of patient satisfaction and whether medical attention was sought after the operation
Methods/Delivery Medium	• Group one: 60 patients undergoing day-case hemorrhoidectomy. Group two: 60 patients undergoing the same operation with improved verbal and written patient information. • Comparisons were made between the groups regarding patient satisfaction scores, seeking medical attention, the numbers of patients requesting an outpatient follow-up and the reasons for seeking medical advice.
Main Outcomes	• There was a significant improvement in the patient satisfaction scores with group two who received the improved information. • Seeking medical attention was significantly less in this group, and they felt less need for a routine follow-up. • There are indications for financial benefits for the institution and improvement of quality of patient care.
Educational Video Intervention Effects on Peri-procedural Anxiety Levels Among Cardiac Catheterization Patients [75]	
Focus	Exploring the effectiveness of an educational video intervention in lowering peri-procedural anxiety among Jordanian patients hospitalized for cardiac catheterization (CATH).
Methods/Delivery Medium	• A randomized controlled trial took place in a specialized heart institute in Jordan. • The sample size was 186 patients who had undergone CATH procedure.

	• Patients anxiety levels were measured by physiological parameters of anxiety (blood pressure, heart rate, and respiratory rate) and by the Spielberger State Anxiety Inventory (SAI) • The intervention group received the education session and materials in Arabic by the principal investigator. All patients were admitted to cardiac care units in the hospital, were placed in separated rooms prior to, and after a CATH procedure.
Main Outcomes	• The results show the effectiveness of using educational video intervention about CATH in lowering peri-procedural anxiety associated with the procedure. • Using this educational video may not significantly affect physiological parameters associated with anxiety.
Orthoanswer.org [41]	
Focus	Exploring the effectiveness of using a patient information website as an augment patient education and informed consent regarding elective orthopedic procedures
Methods/Delivery Medium	• A randomized controlled trial was conducted comparing the quality of informed consent provided by a standard discussion with the surgeon compared to augmentation of this discussion with an online education resource (www.orthoanswer.org). • Participants were recruited from orthopedic outpatient clinics.
Main Outcomes	• There was a statistically significant increase in patient knowledge for the intervention group as compared to the control group. • The intervention group had an average score of 69.25% correct answers as compared to 47.38% in the control group. • The use of this intervention as an augment to informed consent improves patient knowledge about their planned operation as well as satisfaction with the consent process. • The intervention did not increase the anxiety levels.
A preoperative education intervention to reduce anxiety and improve recovery among Chinese cardiac patients [53]	
Focus	Determining whether a preoperative patient education intervention designed for Chinese cardiac patients can reduce anxiety and improve recovery.
Methods/Delivery Medium	153 adult patients undergoing cardiac surgery were randomized into the trial, 77 to a usual care control group and 76 to preoperative education group comprising usual care in addition to an information leaflet and verbal advice.
Main Outcomes	• Participants who received preoperative education demonstrated a greater decrease in anxiety score, and a greater decrease in depression score compared with the control group. • The intervention is effective in reducing anxiety among Chinese cardiac surgery patients. • The intervention should be incorporated into routine practice to prepare Chinese cardiac patients for surgery.
Accessibility-enhanced multimedia informational education (AEMIE) [50]	
Focus	Evaluating the effectiveness of an accessibility-enhanced multimedia informational educational programme in reducing the level of anxiety

	and increasing patient satisfaction with the information and materials received by patients undergoing cardiac catheterization.
Methods/Delivery Medium	• 123 consecutive patients were randomly assigned to one of three groups: regular patient education; (group 1), accessibility-enhanced multimedia informational education (group 2) and instructional digital videodisc education (group 3). • Anxiety was measured with Spielberger's State Anxiety Inventory
Main Outcomes	• All patients experienced moderate anxiety at T0 to low anxiety at T3. • Accessibility-enhanced multimedia informational education intervention had significantly lower anxiety levels and felt the most satisfied with the information and materials received compared with patients in (groups 1) and (group 3).
Early education & patient anxiety: waiting for elective cardiac catheterization [86]	
Focus	Examining the impact of a psychoeducational nursing intervention on patient anxiety during the waiting time for elective CATH
Methods/Delivery Medium	• Two groups randomized controlled trial. • Intervention patients received a nurse-delivered, detailed patient education session within two weeks of being placed on the waiting list for elective CATH. • Control group patients received usual care
Main Outcomes	• The waiting period prior to elective CATH has a negative impact on patients' perceived anxiety and quality of life. • Providing detailed patient education at the beginning of the waiting period, may positively affect the experience of waiting.
Web-based audiovisual patient information system - preoperative patient Education [65]	
Focus	Investigating patient satisfaction and assessing the preoperative patient information dialogue from the patient's and the neurosurgical surgeon's point of view through a web-based audiovisual patient information system.
Methods/Delivery Medium	• 52 consecutive stationary patients, who were scheduled for an elective lumbar disc operation, were asked to use a web-based audiovisual patient information system. • A combination of pictures, text, tone and video about the planned procedure was installed on a tablet personal computer presented the day before procedure. • All patients were asked to complete a questionnaire.
Main Outcomes	• 84% of all participants found that the audiovisual patient information system lead to a better understanding of the planned procedure. • 82% found that the system was a very helpful for preparation before the pre-surgical interview with the surgeon. • 90% of participants considered it meaningful to provide this kind of preoperative education • 90% of participants recommended this system to other patients who planned to undergo other surgical interventions.
Web-Based Education Prior to Knee Arthroscopy [74]	
Focus	Evaluating the effect of a web-based multimedia patient education tool on the preoperative experience of patients undergoing first-time knee arthroscopy for a meniscal tear

Methods/Delivery Medium	• Adult patients undergoing knee arthroscopy for the first time for a primary diagnosis of a meniscal tear • Patients were equally randomized to a control group, who received standard preoperative counseling, or the intervention group, who completed web-based multimedia tutorial, in addition to standard counseling, prior to the preoperative visit. • Patients completed surveys that evaluated their readiness for procedure and knowledge recall at the preoperative visit, on the day of surgery, and after the first postoperative visit.
Main Outcomes	• Patients who completed the web-based tutorial had improved preoperative knowledge and readiness as well as enhanced postoperative knowledge recall regarding their procedure. • Participants were satisfied with using the tutorial and recommended this tool an effective method for enhancing the patients' perioperative experience

Table 1: Related work to the field of preoperative patient education

After reviewing these related works to the field of preoperative patient education, we have concluded that there is always a need for more patient education interventions to increase patient satisfaction and activation during the clinical care. Moreover, we have developed an understanding of the importance of Patient-Centered Care model. There is a need for more patient-oriented interventions which consider the concerns and preferences of patients, and allow them to be more informed and active during the process of care [36]. For example, there is a need for using personalization methods in patient education interventions which can target specific needs/conditions of the patients. Some of the current preoperative computer based interventions provide general patient education which have insignificant impact on health outcomes as compared with personalized interventions [16, 19]. Moreover, we have reviewed the current TAVI patient education at the QEII hospital and other institutions in Canada, and we noticed that all of their interventions are not personalized. Based on the literature, personalization methods can produce more educated patients through delivering specific patient education content, and that would assist in promoting Shared Decision-Making. As we discussed earlier, healthcare is going from the paternalistic model of medical decision making towards the PCC model [38]. The paternalistic model of medical decision-making, in which healthcare providers make decisions on behalf of the patient, has been outdated and healthcare nowadays is moving towards Patient-Centered Care methods and strategies which support the idea of SDM and increase patient satisfaction. Therefore, our research work focuses on personalized patient

education that supports patient oriented care and promotes patient activation and Shared Decision-Making process.

2.7 Significance of Personalized Patient Education

Personalization of patient education is a practical approach to the healthcare sector. The benefits of this method range from increased health behaviors to enhanced management of chronic illness and high satisfaction level of the health services [19]. However, for the success of patient's education, there is a need to personalize it in a way it can help healthcare providers to deliver effective needs to the individual recipient [19]. A study research conducted on personalized patient educational intervention for cardiovascular risk management found that this approach enhanced self-management of chronic illness [7, 10, 11]. Buranarach et al. insist that patient self-management increases awareness and knowledge about illness [8]. Within the big number of peer-reviewed publications, there are important arguments researchers tend to make, and one of them is increased self-management of chronic disorders. The other argument is effective risk management of chronic disease by using computer-based personalized education systems. Therefore, using this method will be useful to make critical therapeutic decisions and health behaviors.

Human behavior is the key determinant for enhancing health, but the significance of designing computer-based patient-specific education programs has not been appreciated fully. Personalization method has become a critical intervention technique for addressing health issues in the current healthcare industry. Healthcare providers can relate decision logic to relevant aspects based on a given patient profile [7]. Besides, mapping matrix was developed to help them to identify risk conditions and potential messages for making informed health decisions. To attain the proposed research finding, researchers conducted a survey-based study where they presented about 22 questions using 5-point Likert scales. The outcome indicated that personalized patient information is useful in managing cardiovascular risks [7]. Furthermore, with the use of computer-based technology systems, healthcare practitioners can capture patient data and systematically record health behavior, attitudes, and risk factors.

Hiligsmann et al conducted a study and found that the development of a personalized patient education tool for decision making (PET) plays a critical role in managing health conditions [9]. The researcher constructed a prototype and refined it by engaging different patients and healthcare professionals. Besides, they expressed their attitudes towards the use of PET in the assisting postmenopausal women with osteoporosis in making health care decisions. The PET was based on the systematic process in which different patients and healthcare professionals were interviewed using semi-structured data collection method. The study found that developing PET is a useful technique for enhancing risk factors for osteoporotic fracture in postmenopausal women [9]. Drawing on these resources, it is clear that nurses who employ PET are likely to improve the health and the general well-being of the patient.

Health information is significant not only for health care professionals but also for patients. For instance, it helps in educating patients about diagnosis, treatments, and ultimately allowing them to respond to therapy efficiently. In fact, most of the current clinical practices focus on gathering information and acting on it [11]. For instance, studies related to health information use in hospitals indicate that this method enhances patient safety, medical quality of record keeping, patient privacy, and confidentiality level toward access to healthcare services [58, 70]. As a result, this study implies that health information is a critical aspect of managing patient disorders and other health related issues.

As far as healthcare is concerned, the use of the web-based system for personalizing patient information reduces health care costs and improves compliances to care management. The economic significance of therapy compliance has augmented recently due to the widespread use of the Internet services. In fact, enhanced care compliance can lead to cost reduction and the quality of care services given to patients [20]. In a survey where 30 patients were recruited randomly, the outcome indicated that web-based systems offered potential economic benefits [20]. Besides, the systems helped patients to become highly informed about their medical problems and to respond to risk factors through lifestyle changes [20]. However, this study recommends further investigations on cost-efficiency of systems to disease management.

2.8 Rationales of Personalized Preoperative Patient Education Interventions for Cardiac Patients

Many studies have been conducted to look at the educational needs of cardiac surgery patients [87]. Healthcare professionals are increasingly recognizing that providing effective patient education and recommendations is important for cardiac patients to cope with their illness. The desire to reduce the amount of distress and anxiety in patients undergoing cardiac surgery has led to the development of different preoperative patient education interventions. Preoperative patient education is targeted to the cardiovascular patient because of the life-threatening nature of such complications. With the global population hitting many billions, cases of cardiovascular complications have increased ten-fold in the recent years [56]. It underlines the essence of preoperative patient education. Cardiac surgery patients have high anxiety, pain, and fear because of the nature of their medical conditions. Procedures like Cardiac Catheterization (CC) raise high anxiety because of its delicate nature and uncertainty of its outcomes, the procedure itself and associated complications [56]. Therefore, preoperative patient education interventions have the potential for mitigating these effects on the side of patients and practitioners.

It is important that cardiac patients and their family have enough accurate medical information about their condition to educate and prepare themselves before and after undergoing medical procedures. The popularization of the Internet changes the way patients search for and retrieve medical information prior cardiac surgery [40]. Regarding the impact of using several websites, patients reported some advantages from online information. However, there are some significant concerns about the quality, reliability, and source of health-related information that is available on these websites. Although the Internet is a powerful tool for improving preoperative patient education, patients should be aware of the potential for misinformation present in unprofessional websites, and should always consider the source of information provided. Therefore, preoperative patient education interventions, which are based on clinical research and practice, can be a solution for providing accurate medical information regarding the condition of the patient [40].

Preoperative patient assessment and communication between physicians and patients are important for effective informed consent and Shared Decision Making prior any surgical procedure [2, 3]. SDM is considered as a vital component of Patient-Centered

Care. Moreover, evidence suggests that there is a potential for improving the informed consent and Shared Decision-Making processes between physicians and patients before cardiac procedures [88]. Use of personalized preoperative patient education can improve the quality of the informed consent and SDM process by providing a personalized information of a patient's risk of post-operative complications. In addition, evidence suggests that sharing information of patient-specific risks may enhance patient trust in healthcare providers [35, 88]. Also, although both verbal and audio-visual patient education improved patient comprehension, there are some challenges still exist in educating patients about anticipated medical procedures regarding their medical condition. The literatures illustrate that there is a room for improving patient comprehension, and that can be done through personalized patient education [16].

Transcatheter Aortic Valve Implantation (TAVI) is a minimally invasive procedure because a new heart valve is implanted without the need of removing the damaged one. Personalized preoperative patient education interventions can be a solution for managing anxiety, increasing patient satisfaction, reducing pain and increasing healing abilities for cardiac patients. Also, these interventions promise to complement to the knowledge pool in cardiac surgery and other chronic conditions by improving the positive outcomes of cardiac procedures done. Additionally, those interventions will help physicians and patients in knowing what to expect and how to go through these specialized procedures and aspects of cardiac surgery with the bottom-line impact being total satisfaction for all stakeholders. Thus, the evidence suggests using a personalized preoperative web-based intervention that provide the ability for patients to have a better understanding of the associated risks, complications, and other considerations related to the cardiac surgery [16, 49, 82].

2.9 Healthcare Knowledge Management and Knowledge Based Systems

Healthcare Knowledge Management (HKM) can be defined as the "systematic creation, modeling, sharing, operationalization and translation of healthcare knowledge to improve the quality of patient care" [89]. HKM aims at promoting and providing healthcare knowledge to healthcare providers and patients [89]. Moreover, HKM aims at assisting healthcare providers and patients in making more informed and cost-effective patient care

decisions [89]. Computing systems that integrate knowledge are called knowledge-based systems [89, 90]. Knowledge management field includes the essential aspects for developing knowledge-based systems [89, 90]. Generally, knowledge based systems is minimally composed of two main components which are; knowledge base and reasoning engine [90].

- **Knowledge base:** This component includes domain knowledge in a highly structured form which is encoded in some knowledge representation formalism. All of the represented knowledge is known as asserted facts or asserted knowledge [90].
- **Reasoning engine:** This component includes mechanisms which support automated reasoning. Reasoning task involves deducing new facts from already asserted facts. The deduction process is known as inference or entailment. The new facts deduced from the already asserted facts are called the inferred or entailed facts. Reasoning task can be done through different ways such as forward and backward reasoning. The reasoning engine can use multiple means to entail new facts from asserted facts [90].

2.9.1 Rule Based Systems

Rule based system can be considered as one of the simplest forms of artificial intelligence [91]. In a rule based system, rules are used as the knowledge representation for knowledge coded into the system. Rule based systems mimic the reasoning of human expert in solving a knowledge intensive problem [91]. Instead of representing knowledge in a declarative, these systems represent knowledge in terms of a set of rules that tells what to do/provide or what to conclude based on the situation. A rule-based system involves encoding a requisite expertise in a fairly narrow area into an automated computerized system [91, 92]. To create a rule-based system, there is a need for using a set of assertions and a set of rules that identify how to act on the assertion set. Usually the rules of this system are expressed as a set of IF-THEN statements, and they are called IF-THEN rules or production rules [92, 93]. Rule-based systems can be considered as simple models which can be adapted and applied for a large kind of problems [93]. One of the main requirements to be considered is that the knowledge on the problem area can be expressed in the IF-

THEN rules form [92]. Moreover, the problem area should not be very large because a high number of rules may lead to having an inefficient system.

A rule-based system consists of the following basic elements [91]:

- *A set of facts (knowledge):* This knowledge is actually the assertions and should be relevant to the problem area of the proposed system.
- *A set of rules:* This set contains all the actions that must be taken within the scope of the problem to specify how to act on the assertion set. Basically, a rule should relate the knowledge/fact in the IF part to an action in the THEN part.
- *A decision criterion:* This element is important to determine whether a solution has been found or that none exists. This is required to terminate some rule-based systems that find themselves in infinite loops otherwise.

2.9.1.1 The Principle Components of Rule Based Systems:

Rule based systems are minimally composed of the following three main components [92, 93, 94]:

- **Knowledge Base**: Knowledge base considered as one of the most important components of the rule based system. The knowledge base stores the knowledge for a specific domain of the rule based system. This component is the power of any knowledge based system essentially in the integration of knowledge representation forms used for a specific domain. This component includes a database which provides the context of the problem domain, and what are considered to be a set of facts. In rule based systems, these facts are essential because they could be used to satisfy the premise part of the decision rules. For example, the '*A*' parts of possible assertions of the form 'IF *A* THEN *B*'.
- **Rule Base**: This component contains the set of decision rules which are used in reasoning. Many of these systems use production rules, "IF-THEN" format, as a method for knowledge representation. These rules represent the knowledge provided by the user and/or an expert of the problem domain.
- **Inference Engine:** This component can be considered as a rule interpreter which controls how the decision rules are applied to the facts. The inference engine matches facts against decision rules in the rule base, and it determines which rules should be fired according to the reasoning method. Thus, the inference engine

derives new information based on given information, and derives conclusions based on new and given information through a reasoning strategy.

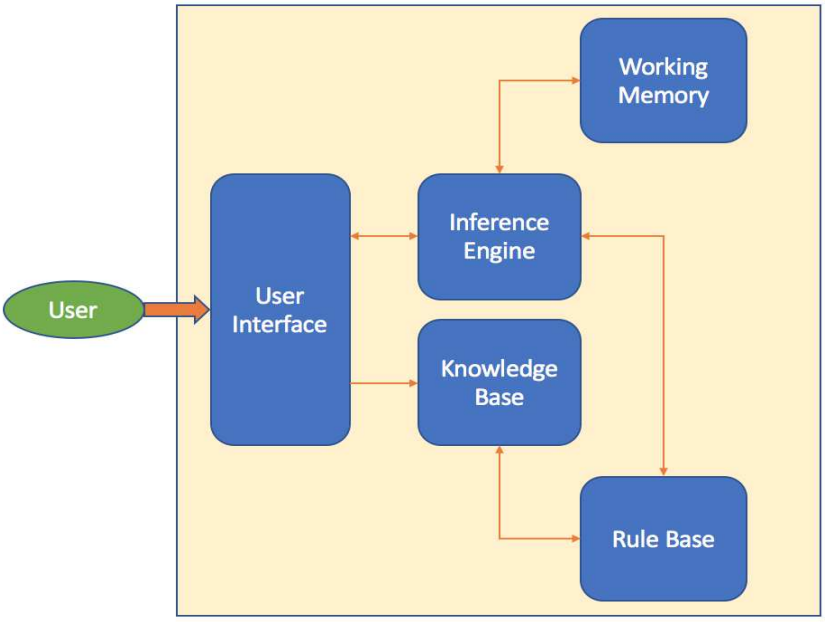

Figure 3: Basic Rule based System Architecture

2.10 Concluding Remarks

In this chapter, we have discussed patient education background, Shared Decision Making and related work in the field of preoperative patient education. Moreover, we illustrated the need of using more personalized patient education interventions, and the rationale of using these interventions with cardiac patients. Based on the overall discussion in this chapter, the patient education approach for our personalized patient education system is based on Patient Centered-Care model to deliver personalized patient education massages, in order to produce more informed patients and improve Shared Decision Making and health outcomes. Our proposed system is a rule based system, and the methodology of developing this system will be discussed in the next chapter.

CHAPTER THREE: RESEARCH METHODOLOGY

In this chapter, we will discuss the research methodology for the development of our personalized patient education system "TAVI System" to provide patient-specific educational messages to TAVI patients before performing the procedure, in order to improve their recognition of the associated risks, complications, and other procedural considerations.

3.1 Problem Statement and Research Objectives

During the pre-procedure visits, patients and their family always require appropriate, easily understandable information regarding their procedure to have a better recognition of their conditions and associated risks. Efficient and effective communication between the healthcare providers and patients is an essential key factor during pre-procedure visits. Therefore, successful information exchange between healthcare providers and patients is important in clinical settings [25, 28, 57]. In addition, patient's satisfaction is related with patient's efficient communication between healthcare providers and patients. Research studies have shown that, patient satisfaction and activation are strongly correlated to the patients' understanding of their conditions, diagnostic procedures, and treatment options [17, 44, 50], and also depend on efficient communication between the healthcare providers and the patients [38]. Furthermore, efficient communication between the healthcare providers and patients is an important key factor in improving patient's consent. On the other hand, most healthcare providers have a limited amount of time during the clinical encounter to explain patient's conditions and their associated risks with the type of intervention in more details [2, 60, 76]. Additionally, patients forget almost half of the things which their healthcare providers said to them after leaving the hospital [18].

Patients are mostly getting generic information about their disease conditions. Such generic information is not specific for their disease condition or collection of disease conditions. Usually patients have collection of risks/considerations associated with the planned intervention. As a result, generic information provided to the patients does not cover all the collection of risks/considerations associated with the intervention. Studies have shown that, generic, lengthy and non-relevant information has insignificant impact on patients and health outcomes or sometimes even worsens the condition(s) [19, 95]. As not all information is knowledge, and sometimes some information could produce anxiety

and distress to patients and their families. Thus, we argue that providing personalized and patient-specific information through educational interventions have a better impact on improving patient's knowledge and health outcomes as compared to impersonal and generic information.

During my shadowing experience with TAVI team members at QEII hospital, I observed some issues with TAVI pre-procedure patient education process. For example, the current patient education process includes providing verbal patient education, watching a short video about TAVI procedure with the nurse, and answering patient's questions. Most of the delivered information about TAVI procedure is generic. Also, written patient education materials are not provided during the clinical encounter. As a result, some patients are not well prepared, less comfortable, more anxious about doing the procedure. Based on these observations, there is an opportunity to improve TAVI pre-procedure patient education during the clinical encounter. Based on the literature review, this improvement can be done through developing a personalized pre-procedure patient education intervention for TAVI patients in collaboration with the TAVI team at QEII hospital [6, 8, 9, 11]. The use of personalized patient education systems can be a choice to consider in order to deliver specific information to the patients regarding their own risks and other procedural considerations based on their condition(s) before the intervention.

The main objective of this research is to leverage health informatics methodologies and technologies to develop a "proof-of-concept" preoperative personalized patient education system for TAVI patients. This system can offer the several functionalities such as:

- Assist in TAVI patient assessment to highlight associated risks and specific procedural considerations for each patient with respect to the TAVI procedure. This can be achieved through using the obtained knowledge from experts and literature review. To achieve this objective, it is important to organize and format the obtained knowledge in a structure that can be programmed. After programming the obtained knowledge, our rule based system will be able to highlight the associated risks/considerations based on the results of TAVI patient assessment.
- Select and deliver patient-specific educational messages, based on the patient's TAVI assessment, to help prepare the patient about the TAVI procedure. This can

be achieved through the knowledge base of the system which includes the educational content that should be delivered to the patient. Each TAVI patient will receive specific educational messages based on the results of the assessment.

- Improve patient consent by informing the patient about their own associated risks and considerations prior to performing TAVI. This will allow patients to make informed decisions about the procedure. The process of obtaining informed consent can be improved through providing specific educational messages to patients based on their conditions. Providing specific educational content can lead to improve patient satisfaction which is an important key factor in improving patient consent.
- Improve Shared Decision Making about TAVI procedure between the patients and physicians. We are expecting that this can be achieved through following the Patient Centered Care model which supports preparing well informed and participatory patients. Providing personalized patient education can enhance the recognition of the associated procedural risks and considerations, and produce more informed patients and families who can be more active and confident in the process of decision making. Thus, we are expecting that this system can enhance SDM based on the literature findings.

3.2 Our Patient Education Approach

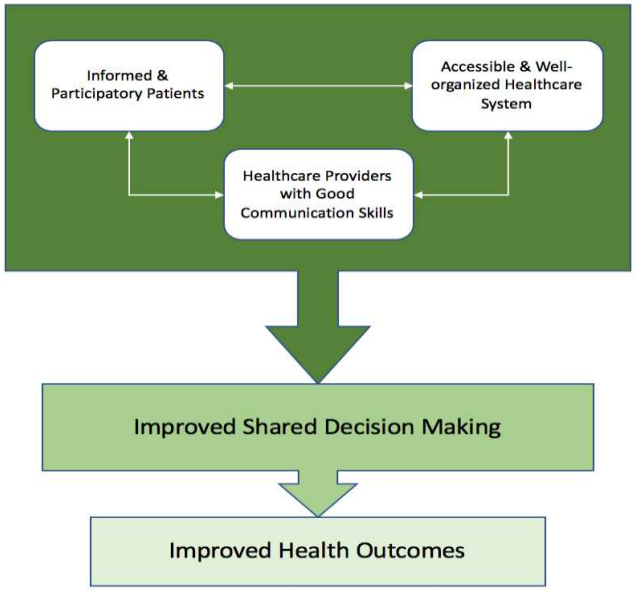

Figure 1: Patient-Centered Care Model [96]

As we discussed in the previous chapter, patient engagement in healthcare become a priority for healthcare providers with the goal of improving the quality and efficacy of healthcare delivery system [4]. Our patient education approach is based on the Patient-Centered Care Model [96]. Patient education and empowerment are essential components of the PCC model. PCC model includes promoting good communication between patients and their healthcare providers; developing and disseminating evidence-based information to educate patients and their families about the planned treatment; and improving Shared Decision Making [96]. Thus, this model supports informed and participatory patients and families to improve SDM which matches our research objectives. In this research work, we are targeting producing more educated TAVI patients and families who can actively participate in the medical decision making. Our patient education approach aims toward addressing the associated risks and specific procedural considerations of each TAVI patient, before performing the procedure, based on the results of TAVI patient assessment. We consider patient activation through providing patients and their families with specific patient education content, and that aims at increasing their knowledge and confidence in the process of medical decision making [4]. By being more informed and increasing confidence, patients and their families can be motivated to communicate with their healthcare providers, and express their health concerns and preferences.

In line with Patient-Centered Care model, our patient education approach will be highly personalized and TAVI patients will be our main focus. TAVI patients and their families require trusted and specific information to be able to take a decision regarding this procedure. Providing TAVI patients with personalized educational content can produce more informed patients, and may have a positive impact on Shared Decision Making. Improving SDM can lead to consider the concerns and preferences of TAVI patients, and involving them as decisions about this procedure. Therefore, our proposed system can be a useful intervention for activating TAVI patients and their families, through increasing their knowledge and confidence, to take an active role to improve procedure and overall health outcomes.

3.3 Research Methodology:

Due the circumstance surrounding this research, in particular time constraint, we have chosen evolutionary prototyping as the system development methodology for our proposed system. When the thesis stared, the problem domain and the system requirements are often not clearly understood. In order to maximize the likelihood of on-time delivery and to minimize time, it can be useful to construct an initial prototype system. The prototyping model can be beneficial in identifying the system requirements and in minimizing uncertainty around these requirements.

3.3.1 Iterative Framework:

Many traditional approaches of system development may require long time to analyze, design and implement a system. To avoid such delays, many system developers use prototyping models to develop smaller systems such as Decision Support Systems and Expert Systems [97, 98]. Prototyping models found to be more dynamic and responsive to user requirements, as well as less risky and more efficient [99, 100]. The main goal of the iterative approach is to develop a pilot version called a prototype [99]. A prototype is a usable system which is built at a lesser cost during a shorter time, and with the intention of being modifying or replacing it by a full operational system in future. Iterative framework can be considered as a user-centric approach, because user feedback is essential to develop subsequent prototypes and, eventually, the final system [101]. As users work with the prototype, they will be able to provide recommendations about the ways to improve this system. Developers combine these recommendations into another prototype, which is also used and evaluated and so on. Finally, when a prototype is developed that satisfies all user requirements, either it is advanced and turned into the final system or it is scrapped [100]. If the prototype is scrapped, developers can use the knowledge gained from building this prototype to develop the real system.

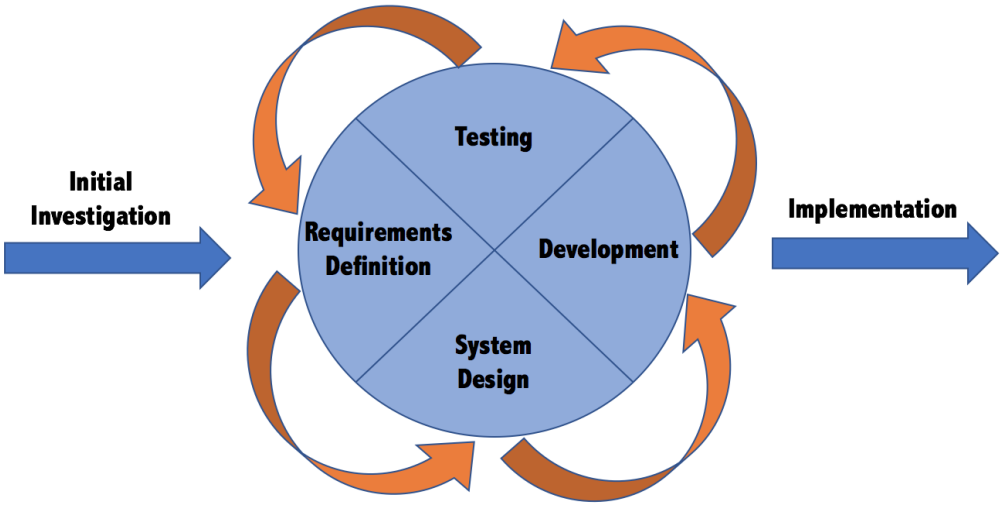

Figure 2: Iterative Approach [99, 100]

3.3.1.1 Using the Iterative Approach to Develop TAVI System

The iterative framework can be briefly viewed as a series of four main phases [99, 100]:

- ***Phase One: Identify and Analyze Information System Requirements:***

In this phase, fundamental system requirements have to be identified to build the initial prototype [99, 100]. Requirements definition is one of the most crucial parts of this research. This phase should focus on identifying and analyzing the main requirements and resources of the system, which will include collecting information regarding these requirements. Basically, a requirement is a description of what a system should provide or do. The process of identifying the initial requirements can be done through doing a literature review, having discussions with potential users and supervisors, and reviewing other related research works [99, 100]. At the end of this phase, the researcher will have a better understanding on what the system should do or provide.

For our research work, we have identified TAVI fundamental system requirements to be able to build the initial prototype. In this phase, we collected and analyzed information regarding the requirements of TAVI system. Through having several consultations with potential users, we have identified what the system should provide based on the research objectives. Identifying the initial requirements was also done

through doing a literature review about preoperative patient education interventions, and reviewing other related research works in this area. Knowledge acquisition was an important process in this phase. Gathering knowledge from experts was essential to prepare the knowledge base of the proposed system, which includes information about the risks and considerations associated with TAVI and educational content. Knowledge representation was another important process in this phase. After collecting the required knowledge from experts, we were able to format this knowledge as a set of decision rules to be used as a rule base for this system. Finally, we were able to have a clear idea on what the system should provide, and how this system can be developed, based on our consultations with potential users and supervisors and literature review.

- ***Phase Two: Develop the Initial Prototype:***

In this phase, initial system design begins by using the collected information regarding system requirements from phase one [99, 100]. The collected information is revised to ensure a design and prototype structure. Developing the initial design is considered as the connecting link between the existing set of requirements and building the prototype [99, 100]. After that, the researchers develop the initial prototype. The prototype is iteratively modified to match the requirements of the system. The initial prototype underlines such system characteristics such as simplicity, flexibility, and ease of use. These characteristics allow users to interact with the inputs, display screens, menus, and outputs of the pilot version [99, 100].

In our research work, we were able to develop an initial TAVI system design after identifying the main fundamental requirements of TAVI system. TAVI architectural design, model specification, and interface design were developed and revised several times with supervisors and potential users to ensure the structure of the proposed system. After that, the development team were able to develop the initial prototype. In this phase, there was a need to iteratively modify the prototype to match the requirements and expectations of the system.

- ***Phase Three: Test and Revise:***

After finishing the development of the initial prototype, the researchers and potential users should evaluate the prototype to determine whether or not this version meets the expectations [99, 100]. The feedback from end-users regarding their likes and dislikes

about the system is important to recommend changes. By using this feedback, the researchers can modify the prototype as necessary and then provide the revised version to system users for reevaluation.

In this research work, we were able to evaluate TAVI system prototype to determine whether or not this version meets the expectations. In this phase, we used scenario-based evaluation to evaluate the knowledge inferencing and transfer of the system through testing the ability of this prototype in performing the function of logical inferencing to reach the expected conclusion. The final conclusion should match the knowledge obtained from experts. Finding some issues, whether they are technical or knowledge issues, leads to modify the prototype as necessary. Thus, iterative process of modification and reevaluation continues until meeting the goals and expectations of this system.

- ***Phase Four: Obtain User Approval:***

After satisfying the potential users, users should formally approve the final version of the prototype. This approval means the users should follow the final model, which includes what the system will, and will not, do or provide, and there is no need for substantial changes at the time of releasing the final version [99, 100]. For this research work, we had to obtain approval from supervisors and potential users regarding this prototype version after meeting the expectations.

Through analyzing these four main phases, we can notice that this approach could provide results within a shorter period of time and offer greater flexibility regarding system development. Using the iterative approach allowed us to divide our research project into small parts. Moreover, this allowed us to demonstrate results earlier on in the process and obtain valuable user feedback.

3.3.2 A Knowledge Management Approach to Develop TAVI System

Designing and developing TAVI system is based on knowledge management approach. Basically, this approach involves capturing, modeling, and appropriately representing the knowledge to be used in the system [89]. Here we will discuss the processes that we followed to develop our rule based system:

- ***Knowledge Acquisition:***

The knowledge acquisition process includes identifying the basic knowledge required for solving a problem in a given domain and organizing that expertise in a way that is amenable to knowledge modeling [89, 91]. Obtaining this knowledge can either be from a human expert or gathered from non-human resources. The knowledge can be gathered through direct interaction with a human expert, and this process is called knowledge elicitation [93]. Gathering the knowledge from human experts can be done through various methods. Some examples include; interviews, consultations, observations, and concept sorting. On the other hand, the knowledge can be collected from non-human resources, and this process is called knowledge discovery [93]. Some examples of non-human resources include electronic documents, databases, and internet. Knowledge elicitation includes interacting with the expert to elicit the required knowledge in some systematic way. After obtaining the knowledge, this knowledge is usually stored in some form of human friendly intermediate representation. The intermediate representation of the knowledge is compiled into an executable form**,** such as decision rules, that the inference engine can process.

In this research work, the main source for knowledge acquisition for designing and developing TAVI system is consultations and meetings with interventional cardiologists at the QEII hospital. These consultations provide us with the knowledge required to identify the main risks and considerations, associated with TAVI procedure, on TAVI patient assessment. Also, these consultations are important to identify and obtain the personalized educational content related to each risk/consideration. After gathering the knowledge required for our system, we have to organize the knowledge in a systematic way to be able to proceed to the next process of knowledge management.

- ***Knowledge Representation:***

This process involves formatting the obtained knowledge as a set of rules that can be easily coded into a program [91]. In our research work, "IF-THEN" rules are the main type of knowledge representation used in TAVI system. We used these rules to link specific risk variables with different types of risks and consideration associated with TAVI. We also used these rules to link specific risks and considerations with the patient educational

content which we obtained from experts. Using these rules in a rule based system is essential to capture reasoning that experts apparently often employ [91, 102].

- ***Knowledge Inferencing:***

In this process, the inference engine of the rule based system performs the function of logical inferencing to reach the final conclusion. When the user of the TAVI system provides the necessary information as to an existing condition, the inference engine will allow processing of a set of decision rules to arrive at a decision or recommendation by reasoning through the rule base [93].

- ***Knowledge Transfer:***

This process involves reporting the final decision/recommendation, which should match human expert decision, to the user of the rule based system [91]. The rule based system ultimately provides a decision or recommended solution to users through the user interface [91]. TAVI system should provide the user with the main risks/considerations of each TAVI patient, and recommend a number of personalized educational messages based on the results of patient assessment.

3.4 Steps of TAVI System Development Methodology:

Our proposed system, TAVI System, is a rule based system. Developing TAVI system will be realized in the following steps which follow the iterative methodology of system development and knowledge management approach. These steps with their results will be discussed more in depth in the next chapter.

Step 1*: Understanding and modelling the current preoperative clinical pathway for TAVI:* This step is important to gain knowledge and understand the different stages of care processes for TAVI, focusing on the preoperative patient education. In this step, we focused on the clinical workflow specification and modeling.

Step 2*: Obtaining the data collection protocol from TAVI team*: "TAVI patient assessment" is the basis of this proof-of-concept system.

Step 3*: Identifying risk variables in TAVI patient assessment*: This step is essential

to identify, understand, categorize preoperative risks and considerations associated with TAVI procedure.

Step 4: *Obtaining educational content*: The content will be used to prepare the general and personalized patient education messages that should be delivered to each TAVI patient. This content is a part of the knowledge base of this system.

Step 5: *Developing decision rules:* The system will work based on two sets of decision rules which will determine the number and type of risks/considerations and personalized educational messages based on the results of the patient assessment.

Step 6: *Developing templates of personalized patient education documents and patient reports.*

Step 7: *Developing the initial prototype*

Step 8: *Evaluating and Revising the initial prototype*

3.5 Research Methodology Summary:

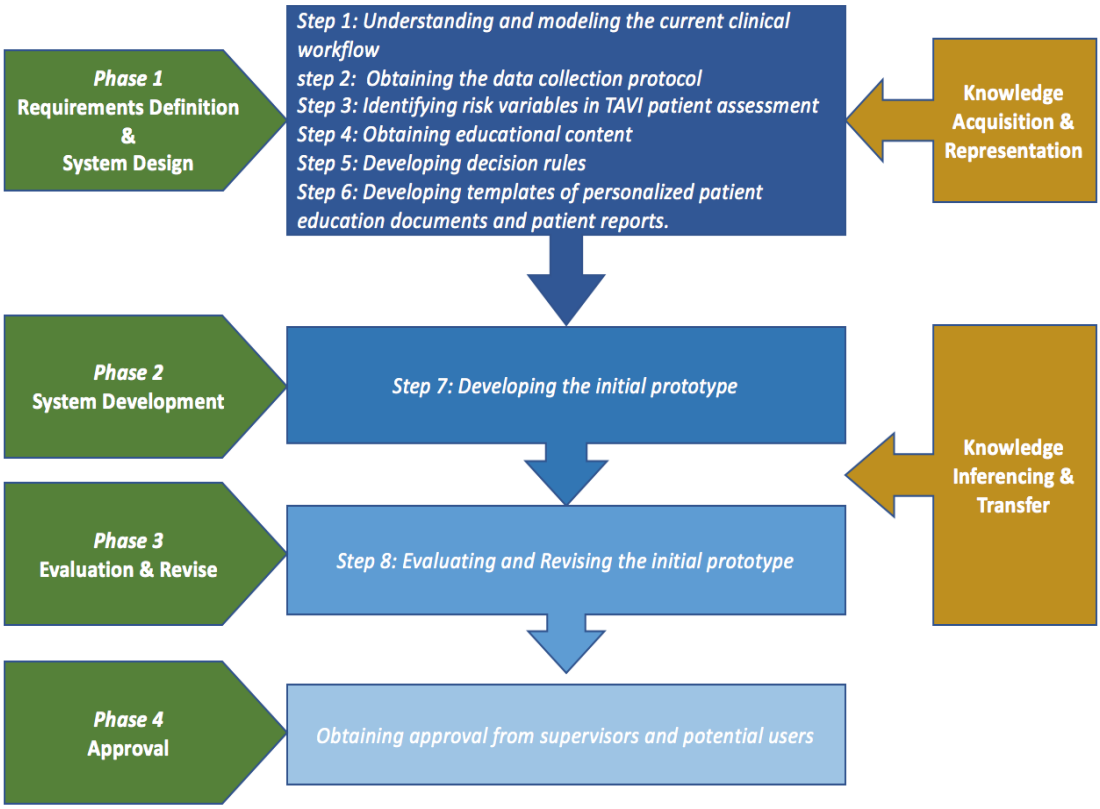

Figure 3: Our research methodology for developing TAVI system

Figure 3 illustrates a summary of our research methodology for developing TAVI system. TAVI system development includes four main phases. The first development phase is defining the requirements and the design of the system. This phase has six steps which involve knowledge acquisition and knowledge representation processes. Knowledge acquisition process includes understanding and modelling the current clinical pathway for TAVI, obtaining the data collection protocol, identifying risk variables in TAVI patient assessment, and obtaining educational content. Knowledge representation process includes developing decision rules and developing templates of the outputs of the system. The second development phase is system development which includes developing the initial prototype of TAVI system. The Third development phase is evaluation and revise which includes evaluating and modifying the initial prototype based on the results of the evaluation. Knowledge inferencing and knowledge transfer processes are involved in the second and third development phases. The fourth development phase is approval which is basically obtaining the approval from supervisors and potential users.

3.6 Concluding Remarks

In this chapter, we presented the main development phases of developing TAVI system which are based on an iterative approach, and informed by evidence-based research and clinical expertise. We also presented the processes of the knowledge management approach that we used to model, computerize, and integrate TAVI patient assessment to generate personalized educational messages for TAVI patients. In the next chapter, we will discuss and provide more details about the development and implementation steps.

CHAPTER FOUR: METHODS
TAVI SYSTEM DEVELOPMENT

4.1 A Brief Overview of TAVI System:

The proposed TAVI System is a rule based system. The user, a TAVI team member, is presented with a patient assessment, in the interactive window, where the user has to enter the patient data into the components of patient assessment. Based on the entered data, the system searches the knowledge base for possible pattern matches according to the decision rules. "IF-THEN" rules are the main type of knowledge representation used in the proposed TAVI system. If there is a rule in the knowledge base which matches the risk variables in the patient assessment, the system identifies the possible risks/considerations and the educational content based on the patient data. The knowledge base contains educational content that should be personalized based on the rules of the system [94, 103]. The primary source for knowledge acquisition for the TAVI System was consultations and meetings with interventional cardiologists at the QEII hospital. The knowledge base consisted of identifying the risks and procedural considerations associated with TAVI procedure with their risk variables in the patient assessment, and the educational content related to these risks and considerations.

4.2 TAVI Information Model

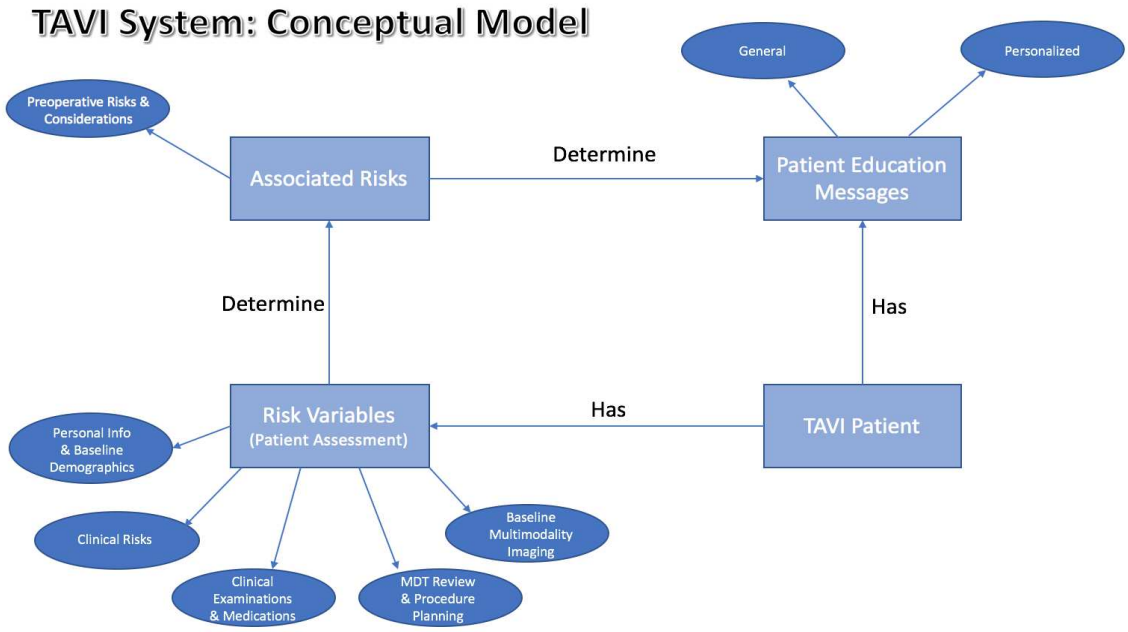

Figure 4: Conceptual Model for the TAVI system

The figure shown above represents the conceptual model of the personalized patient education system "TAVI system". This model illustrates how the system works. The model contains four major elements; TAVI patient, risk variables which are included in the patient assessment, associated risks/considerations and patient education messages. In this model, each TAVI patient has risk variables in TAVI patient assessment. All the risk variables are included in the main five components of TAVI Assessment which are:

- *Personal Information & Baseline Demographics*
- *Clinical Risks*
- *Clinical Examinations & Medications*
- *Multidisciplinary Team Review & Procedure Planning*
- *Baseline Multimodality Imaging*

Furthermore, associated risks element includes preoperative risks and considerations associated with TAVI, while the patient education messages element contains the educational content of the messages which are subdivided into general and personalized messages. An analysis of the model shows that risk variables element is the key in determining the number and types of preoperative risks and considerations associated with TAVI of the patient based on a set of decision rules. After determining the preoperative risks/considerations of the patient, the system will be able to identify the number and type of patient education messages that should be delivered to the patient based on another set of decision rules.

4.3 Functionality of TAVI System

Basically, our proposed personalized education system will be used during the clinical visit in TAVI clinic where some medical examinations are undertaken. This enables the TAVI team members to enter patient information into the system from different sources. Determining risks/consideration associated with TAVI will depend on the results of TAVI patient assessment. TAVI team will be entering patient information into each component of TAVI assessment. All the medical information of the patient that might influence the successful of TAVI procedure are considered in the assessment. The system will analyze the information and identify the risks/considerations through their risk variables. This leads to the last step of the TAVI system, which is generating a patient

report and a personalized patient education document. The patient report will be useful for TAVI team to assist them in determining the eligibility of the patient to perform TAVI procedure based on the results of the assessment. The patient education document will contain generic and personalized messages based on the results of the assessment. The personalized document will have a specific focus on being laid on disseminating information that is personalized and specific in informing the patients about their conditions, risks associated with the procedure, and possible outcomes.

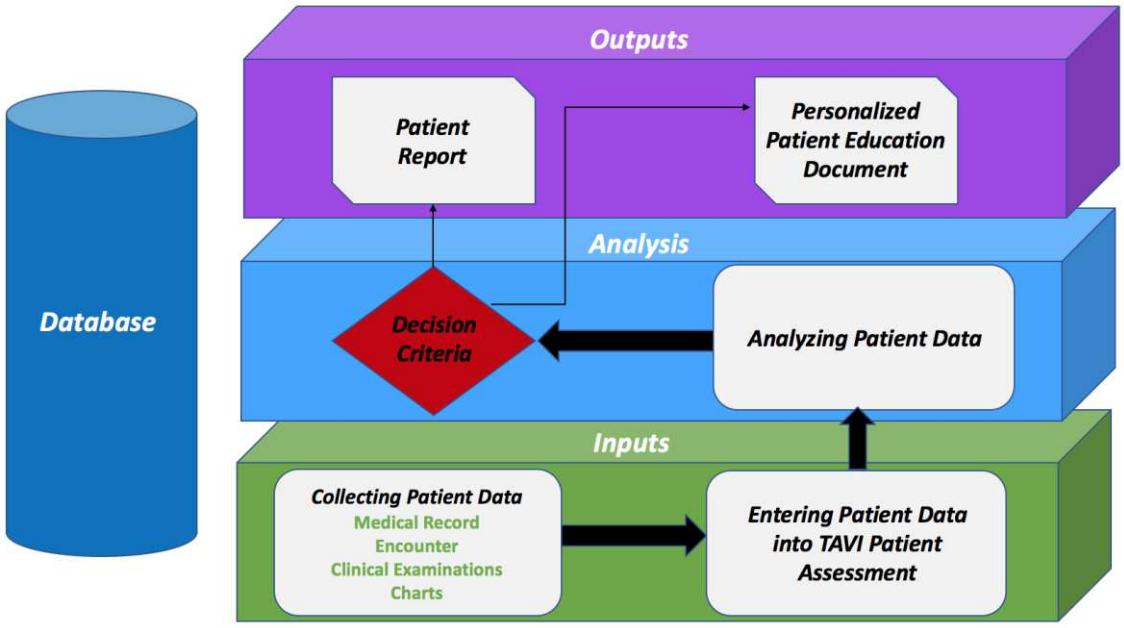

Figure 5: TAVI System: Functional Layers

Figure 5 builds on the conceptual model for TAVI system illustrated in figure 4. Figure 5 outlines functional layers of TAVI system. The first layer is composed of inputs, the second layer entails analysis of the inputs, and the third layer is output which is stored in a database. The input layer involves collection of patient data from medical records, clinical charts, clinical examinations, and encounters. Collecting patient data in the first layer will be done by TAVI team which involves booking clerks, physicians and nurses. This leads to the second step of entering the collected patient data into the components of patient assessment in TAVI system. The process progresses to the second layer, which involves analyzing the patient data and making a decision criterion based on two sets of decision rules. The analysis layer is conducted by the inferencing engine which performs the function of logical inferencing to reach the final conclusion. The decision criterion

facilitates generation of two primary outputs; personalized patient education document and patient report. After generating the outputs, they will be available to nurses and physicians who can review, edit, and download the generated outputs. It is expected that the system will go through all the functional layers in a period ranging from 45 minutes to one hour. Figure 6 summarizes the fundamentals of TAVI system including users, main tasks and outputs.

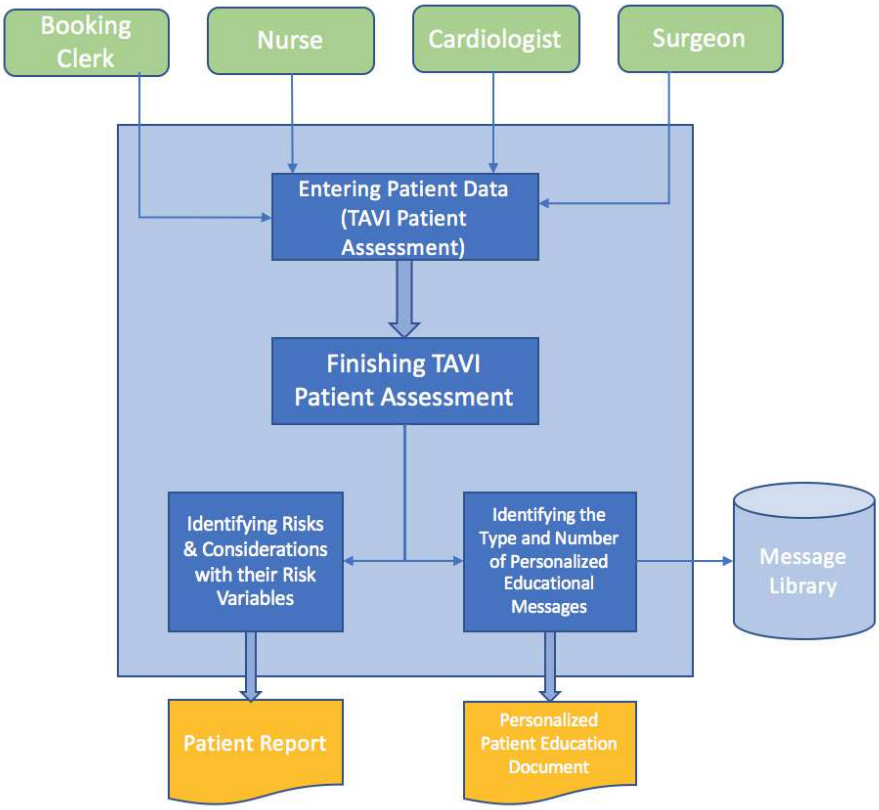

Figure 6: Fundamentals of TAVI System

In this chapter, we will discuss the results of our research which is developing TAVI system. We will explain in more details the steps that we used to develop this system based on our research methodology that we discussed in the previous chapter.

4.4 TAVI System Development:

Developing TAVI system will be realized in the following steps which follow the iterative methodology of system development:

4.4.1 Understanding and modelling the Current Preoperative Clinical Pathway

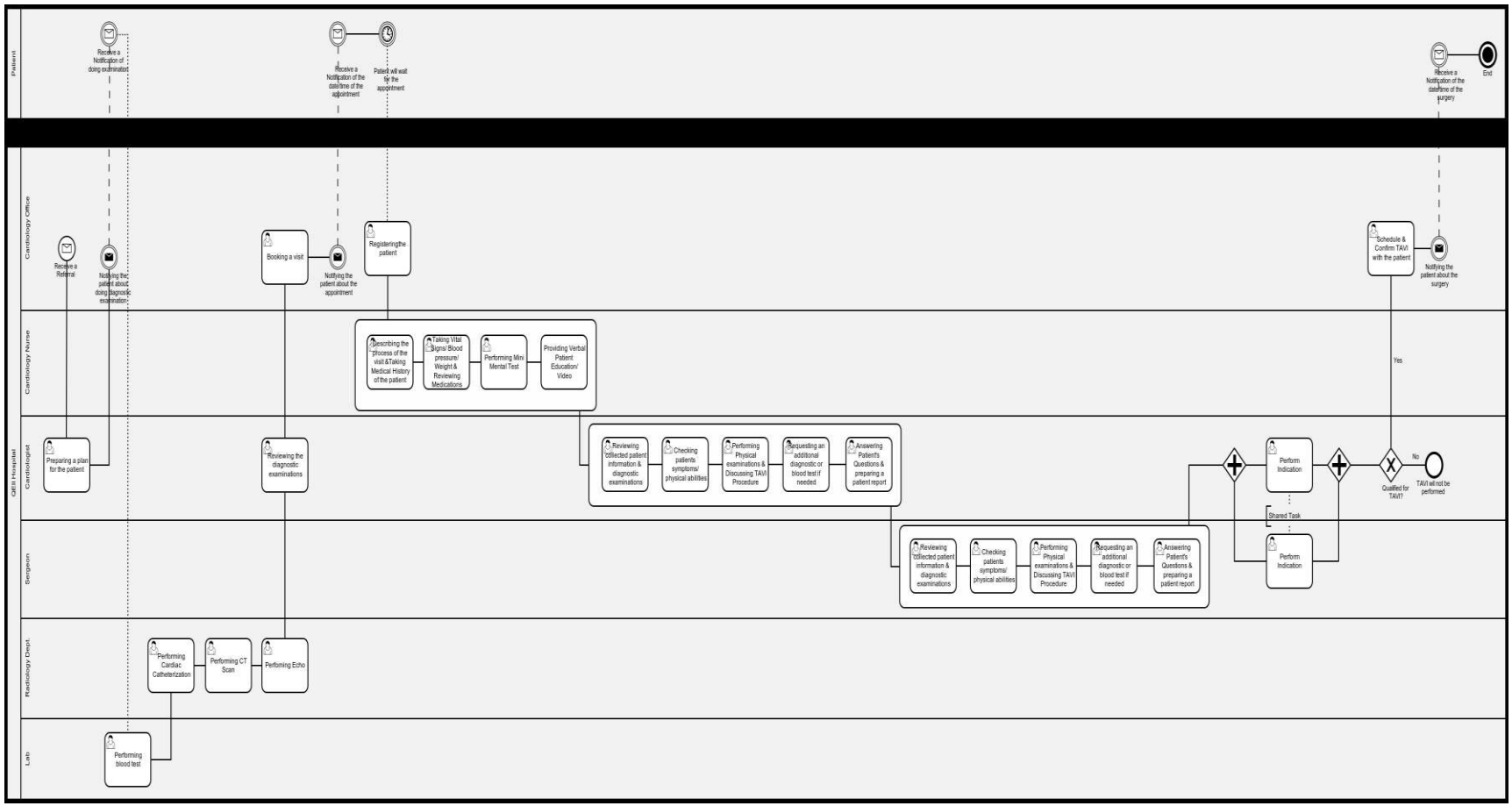

Figure 7: BPMN Diagram: The current preoperative clinical pathway for TAVI

As noted in the previous chapter, the solution approach encompasses six steps. The first step is to understand the current clinical pathway for TAVI. The care processes engage TAVI team members at the QEII hospital. In this research work, shadowing TAVI team members was undertaken in September 2016 to understand the clinical pathway focusing on the preoperative stage. The main purpose of this shadowing was to understand the current preoperative clinical pathway for TAVI, focusing on patient education process, and identify how we can improve this process through our research. The shadowing experience was conducted for three weeks, for a span of two days in each week. During this shadowing, we had a chance to shadow five new TAVI patients during their first clinical visits. In addition, we had a chance to shadow three follow-up TAVI patients.

- ***Modelling the Clinical Workflow***

For the purpose of improving the preoperative patient education in TAVI clinic, we had to understand the current patient education process. First, we had to model the current clinical pathway for TAVI. Then, we had to look at the opportunities for improvements. Then, we had to choose the most important improvements and the best solution approach based on the literature review and consultations with supervisors. Finally, we had to model the proposed clinical pathway for TAVI with the proposed solution. After having a better understanding of the current clinical pathway for TAVI patients, we have worked on modeling this pathway to illustrate the full picture of the preoperative clinical pathway for TAVI. We have modeled this clinical workflow through developing a graphical representation "Business Process Model and Notation" BPMN diagram as shown in figure 7. BPMN can be considered as a graphical representation for specifying business (organizational) processes in a workflow. Our particular interest in the use of BPMN in this research is its simplicity in providing a language that is easy to understand and can be used by individuals with different roles and training. BPMN diagrams can help to understand business processes in hospitals which are usually complex and variable. In order to model the current clinical workflow for TAVI, we had to organize and manage the obtained information from the shadowing experience.

- ***Explaining the Clinical Workflow Model***

As illustrated in figure 7, the current preoperative clinical pathway for TAVI begins with receiving a referral from a family physician of the patient. This is followed by

preparation of a plan by an interventional cardiologist based on the information provided by the family physician of the patient. The cardiology office then requests the patient to perform some diagnostic examinations. These examinations include performing a CT scan, echocardiography, cardiac catheterization and blood tests. The results of these examinations are forwarded to the cardiologist, and the cardiology office books an appointment for the patient for the first visit. Usually the first clinical visit entails seeing a nurse, cardiologist, and surgeon. The nurse starts with describing the process of this visit to the patient. Then, the nurse takes the medical history of the patient, vital signs, blood pressure, height and weight. Also, the nurse reviews the medications of the patient, and performs a mini mental test. The nurse provides verbal patient education, followed by an online short educational video about TAVI procedure.

After debriefing by the nurse, the patient is required to see a surgeon and a cardiologist. These two specialists review the patient's diagnostic examinations and medical reports as updated by the nurse. Then, they check the physical ability of the patient, in addition to analyzing other symptoms related to the patients' health and wellness. Then, they discuss with the patient if TAVI procedure will be the best treatment option based on the patient symptoms. In some instances, additional diagnostic and physical examination will be required to decide on the best treatment option for the patient. Finally, the physicians answer any question related to the procedure, and prepare a patient report. Furthermore, TAVI team members have a weekly meeting to make decisions regarding the eligibility of patients to perform TAVI. The patient will then be notified of the final decision. If the patient is eligible, the cardiology office will schedule and confirm a TAVI procedure to be performed on the patient. Also, a clinical visit should be scheduled before TAVI to describe the procedure in more details and obtain patient consent.

We have discussed the clinical workflow model with supervisors and potential users to look at opportunities for improving the preoperative patient education process. Based on the literature review, we proposed a transition from providing generic patient education to personalized patient education. This can be done through developing a personalized patient education intervention which can be used in clinic to deliver specific educational messages based on the results of TAVI patient assessment.

4.4.2 Obtaining Data Collection Protocol

TAVI patient assessment is the basis of this proof-of-concept system. TAVI patient assessment was obtained from the TAVI team at the QEII hospital. The assessment is intended for new TAVI patients in order to assess their eligibility for a TAVI procedure. The assessment contains five main components:

- ***Personal Information and Baseline Demographic***: (Personal Details, Referral Details, Booking Office Details, Clinical Evaluations & Consultations, Procedures & Follow-up Details, Demographics Information)
- ***Clinical Risks***: (Clinical Characteristics, Risk Factors / Assessment, Previous Cardiac Procedures, Blood Works)
- ***Clinical Examinations and Medications***: (Baseline Cognition & Frailty Assessment, Medications Review, Clinical Examination)
- ***Multidisciplinary Team Review and Procedure Planning***: (Initial TAVI Screening & Assessment (MDT), Procedure Planning, Research Study Screening, Procedural Status, PCI Performed: (Prior to TAVI), Wait-time Assessment)
- ***Baseline Multimodality Imaging***: (Cath/Angiography, CT Angiogram, Echocardiography)

There are different medical variables under each component, which will describe the condition of the patient. Patient data will be collected from the patient during the encounter, patient medical record, clinical examinations results, and clinical charts. This assessment helps TAVI team member to have a better understanding about the condition of the patient before TAVI. Therefore, our proposed system was built and developed based on this data collection protocol because it has all the medical information of the patient that might influence the outcomes of TAVI procedure.

4.4.3 Identifying Associated Preoperative Considerations/Risks with their Risk Variables

Because of the nature of TAVI patients, each patient considering TAVI procedure is supposed to have a number of associated risks and procedural considerations. It is necessary to identify risk variables to determine the number and types of risks and considerations associated with TAVI procedure based on patient assessment. Through consulting TAVI team members, we have identified 13 possible associated risks and

considerations on the TAVI patient assessment. These possible risks and considerations are:

1) *Increase Risk of Vascular Complication*
2) *Increase Risk of Stroke*
3) *Increase Procedural Risk*
4) *Increase Risk of Pacemaker*
5) *Increase Predictor of Mortality*
6) *Needs Specific Anesthetic Consideration*
7) *Increase Prolonged Hospital Stay*
8) *Increase of Kidney Damage*
9) *Needs to Check Blood Products Availability*
10) *Active Cancer – Information Prognosis*
11) *Wait time Assessment Special Consideration*
12) *Increase Risk of Infection Endocarditis*
13) *Eligibility for Research Study*

After identifying these risks and considerations, we have worked on identifying the risk variables attached to each of the risk identified. Our contribution was to organize and categorize these risk variables based on the type of the risk/consideration. This is summarized in table 2 below;

Risk/Consideration	***Risk Variable: (Value/Status)***
Increase Risk of Vascular Complication	1. Peripheral Vascular Dis.: Yes 2. Min femoral diameter: <6 mm 3. Min Iliac diameter: <6 mm 4. Vascular Access Site Calcification: Femoral (Left): Circumferential 5. Vascular Access Site Calcification: Femoral (Right): Circumferential 6. Vascular Access Site Calcification: Common/External Iliac (L): Circumferential 7. Vascular Access Site Calcification: Common/External Iliac (R): Circumferential 8. Degree of tortuosity (L): Severe 9. Degree of tortuosity (R): Severe 10. BMI > 35. 11. Vascular Access Approach: Alternative 12. Vascular Issues – IR requested = Yes
Increase Risk of Stroke	1. Baseline card. Rhythm & Conduction Abnormality = PAF OR Permanent 2. Cerebrovascular disease: Yes 3. Cerebrovascular event: Yes
Increase Procedural Risk	1. LV function: LVEF = 21- 30% OR LVEF ≤ 20% 2. Coronary Reserve: Borderline OR Limited

	3. Sinus Valsalva: ≤ 30 4. ST Junction: ≤ 30 5. ST Height: < 15 6. LCA Height: < 10 7. RCA Height: < 10 8. Morphology: Bicuspid 9. Annulus Area by Diameter: <300 OR >686 mm 10. Minor Dimension: <18 11. Major Dimension: >29 12. Annular Perimeter: >85 mm 13. LVOT Calcium: Yes & Moderate OR Severe 14. VTC: <6 mm 15. LVOT: ≤ 30 mm 16. Aortic Valve Morphology: Bicuspid 17. Aortic Valve Annulus Size: TTE > 27 mm 18. Aortic Valve Annulus Size: TEE > 27 mm 19. Aortic Regurgitation: Moderate OR Severe 20. Mitral Regurgitation: Severe 21. Mitral Annular Calcification (MAC): Severe
Increase Risk of Pacemaker	1. Baseline card. Rhythm & Conduction Abnormality: RBBB
Increase Predictor of Mortality	1. Dialysis dependent: Yes 2. Pulmonary Hypertension: Yes & Severe >55 mmHg 3. Chronic lung disease: Severe 4. Home Oxygen: Yes 5. PA Systolic: >= 50 mmHg 6. LV Angiogram: Mitral Regurgitation Severe 7. RVSP: >=56 mm/Hg 8. Mitral Stenosis: Severe 9. ECHO: Mitral Regurgitation Severe
Needs Specific Anesthetic Consideration	1. Pulmonary function: Yes & FEV1 ≤ 1.2 (50%) DLCO ≤ (50%) 2. Special Anesthesia Considerations: Yes 3. Echo Special Considerations: Yes 4. Vascular Issues – IR requested: Yes 5. Candidate Salvage SAVR: Yes 6. Urinary Catheter: Yes 7. Early Discharge Candidate: Yes 8. Chronic lung disease = Severe 9. Home Oxygen = Yes 10. PCI Performed = Yes
Increase Prolonged Hospital Stay	1. Pulmonary function: Yes & FEV1 >= 1.2 (50%) DLCO >= (50%)
Increase of Kidney Damage	1. Renal Impairment: Moderate (CC > 50 & <85) OR Severe (CC <50)
Needs to Check Blood Products Availability	1. Prior Blood Products Use: Yes & Antibody Screen: Positive
Active Cancer – Information Prognosis	1. History of cancer: Yes

Wait time Assessment Special Consideration	1. Wait-Time 1 (Referral to MDT TAVI Acceptance): Wait-time > 12 weeks: Yes 2. Wait-Time 1 (Referral to MDT TAVI Acceptance): ED Visit or Hospital Admission: Yes 3. Wait-Time 1 (TAVI Acceptance to TAVI Procedure): Wait-time > 6 weeks: Yes 4. Wait-Time 1 (TAVI Acceptance to TAVI Procedure): ED Visit or Hospital Admission: Yes
Increase Risk of Infection Endocarditis	1. Immunosuppressed: Yes
Eligible for Research Study	1. Research Study Screening Performed: Yes

Table 2: Associated risks and considerations with their risk variables

4.4.4 Obtaining Educational Content

The identification of main risks and considerations, as well as their risk variables, enabled us to proceed to the next step of obtaining educational content of the messages that should be generated after finishing TAVI patient assessment. The content of these specific messages was obtained from Dr. Beydoun and Dr. Nadeem. Both of them are interventional cardiologists at the QEII hospital located in Halifax, NS. The cardiologists played an essential role in the provision of educational content which was based on their medical expertise and clinical protocols. The educational content was guided by 10 out of 13 risks and considerations earlier identified, thus leading to the consideration for 10 categories of educational messages. After consultations with the cardiologists, we have linked 26 risk variables to the educational content leading to the formation of 19 personalized educational messages. In addition to the personalized patient educational messages, seven general educational messages were created to be generated for all TAVI patients. This totaled to 26 messages for the system. The educational content to be included in the TAVI system were summarized as follows:

Personalized Patient Education Messages		
#	*Risk Variable(s)*	*Message Content*
INCREASE PROCEDURAL RISK:		
M1	*LV Function*	*Pumping Function of Heart (LV Ejection Fraction): You have reduced pumping function of the heart. This is associated with increase in the procedural risk for heart attack or death. We will*

		minimize the need of rapid heart pacing to reduce the risk further. Generally, risk of heart attack with TAVI procedure is less than 1%.
M2	*Coronary Reserve*	*Blood flow (Coronary) Reserve to Heart Muscle: You have significant blockage or narrowing of the heart arteries, supplying blood to the heart muscles. This is associated with an increase in the procedural risk. Generally, risk of heart attack with TAVI procedure is less than 1%.*
M3	*LCA Height OR RCA Height*	*Close Proximity of Coronary Arteries to Heart Valve Implant Site: The origin of coronary arteries supplying blood to the heart muscle is in close proximity to the site of new heart valve implant. We will be fully assessing this risk at the time of procedure by doing careful pictures at the time of TAVI procedure. The associated risks include obstruction or occlusion of coronary arteries resulting in heart attack or death. The Risk of heart attack with TAVI procedure is between 1 to 3%.*
M4	*Aortic Valve Morphology OR LVOT CALCIUM*	*Aortic Valve Anatomy: Based on the anatomy of your aortic valve heart, there is a chance to have a leak around the new heart valve. We have given special consideration by selecting the most appropriate TAVI valve to minimize the chances of residual leak around the new heart valve. Moderate to severe residual leak can result in increased risk for subsequent heart failure and death.*
INCREASE RISK OF VASCULAR COMPLICATIONS:		
M5	*General*	*Based on your assessment, you have smaller caliber blood vessels (with or without the presence of significant calcium). We have given special consideration for new heart valve device selection to minimize the risk. Overall, vascular complication from the procedure is ranging between 2 to 5%. It may lead to emergency surgery and/or use of blood products and/or extended hospital stay.*
M6	*Vascular Issues – IR requested*	*You are at a risk of increased vascular complications because your disease and/or small vessels calipers in the groin arteries, you may need balloon dilatation and/or stand pelvis to your arteries.*
M7	*Alternate TAVI*	*Because of significantly diseased/small caliper peripheral blood vessels we may not able to deliver new heart valve from the groin.*

		You will be assessed for alternative approach which may include small incision in your chest wall or neck. This may prolong post procedure hospital stay.
RISK OF DEATH: (INCREASE PREDICTOR OF MORTALITY)		
M8	*General*	*The risk of death associated with TAVI procedure is about 1 to 2%*
M9	*Dialysis dependent*	*You have a significant kidney damage which is associated with increased risk of death.*
M10	*Pulmonary hypertension OR PA systolic OR RVSP*	*It is well known that patients with elevated systolic pulmonary artery hypertension are at increased risk from TAVI procedure as the high pulmonary artery pressure is a reflection of advanced aortic valve disease.*
M11	*LV Angiogram OR Echo MR*	*The presence of significant mitral valve leakage has been associated with increased risk of adverse outcome.*
RISK OF STROKE		
M12	*PAF*	*Irregular Heart Rhythm (Atrial Fibrillation): Because you have irregular heartbeat, you may be at increase the risk of stroke. Overall, the risk of stroke during the TAVI procedure is about 1 to 3%. We will discuss with you the optimal medical treatment to reduce the risk of stroke.*
M13	*Cerebrovascular Disease OR Cerebrovascular Event*	*Previous Stroke: Because you have a previous stroke, you are at increased risk for subsequent stroke. Overall, the risk of stroke during the TAVI procedure is about 1 to 3%. We will discuss with you the optimal medical treatment to reduce the risk of stroke.*
NEEDS SPECIFIC PROCEDURAL CONSIDERATION		
M14	*Chronic lung disease OR Home oxygen*	*Because of your advanced lung disease you may continue to have symptoms of shortness of breath despite correcting the aortic valve disease. You may require prolonged hospital stay following TAVI procedure.*

M15	*PCI Planned*	*You may require opening blockage in the coronary arteries that supply the muscles of the heart with balloons and stents prior to TAVI procedure in such a way to make the procedure safer.*
M16	*Early Discharge*	*Following your initial assessment, you may be a candidate for early post procedure discharge. Our TAVI nurse/coordinator will discuss with you the details of the discharge plan.*
NEED FOR EMERGENCY OPEN HEART SURGERY		
M17	*General*	*One of the risks of the TAVI procedure is the need for emergency open heart surgery to correct emergency life threatening complications such as the newly replaced valve moving from its position to the chambers of the heart or the main artery of the aorta or closing down of the coronary arteries that supply the muscles of the heart.*
INCREASE RISK OF PACEMAKER		
M18	*General*	*Generally, the risk of requiring a new permanent pacemaker is dependent upon the type of device selected. There are two types of devices, balloon expandable or self-expandable. The decision to use the appropriate device is based on technical factors, depending on the size of blood vessels and the features of your own heart valve.* *The rate of new permanent pacemaker with balloon expandable is between 5 to 10% whereas the risk of pacemaker requirement by self-expandable valve is between 10 to 20%.*
M19	*RBBB*	*You have an electrical abnormality on ECG called RBBB (right bundle branch block). This increases your risk of requiring pacemaker by 2 to 3 folds.*
INCREASE RISK OF INFECTION ENDOCARDITIS		
M20	*General*	*All new heart valve implants are at increased risk of infection in comparison to the native heart valves. Some invasive procedures and surgeries such as dental work and surgery involving urinary or gastrointestinal tract can be associated with increased risk of infections as well as skin cuts and laceration. Therefore,*

		appropriate prophylactic and active antibiotics treatment is important. *Please inform your dentist/ surgeon that you have artificial heart valve. They will provide you with prescription for appropriate antibiotic coverage*
M21	*Endocarditis*	*Based on your assessment, you are identified to have additional factors which will increase your risk of infection. Our TAVI team will discuss this with you in more details.*
INCREASE OF KIDNEY DAMAGE		
M22	*General*	*Screening tests and preparation for TAVI procedure include: a dye test and specialized CAT scan. A medical dye (contrast) will be used, during both tests and TAVI procedure, which may increase the risk of kidney damage. With normal baseline kidney function, the risk is exceedingly the low and it is less than 1%*
M23	*Renal Impairment (Moderate)*	*You have a moderate baseline kidney damage which increases the risk of further kidney damage with these procedures. The risk of temporary worsening kidney function is about 3 to 5% which may require extended hospital stay. The risk of requiring long term dialysis is less than 1%*
M24	*Renal Impairment (Severe)*	*You have a severe baseline kidney damage which increases the risk of further kidney damage with these procedures. The risk of temporary worsening kidney function is about 5 to 10% which may require extended hospital stay. The risk of requiring long term dialysis is equal or less than 5%*
ELIGIBLE FOR RESEARCH STUDY		
M25	*General*	*QEII hospital is a university teaching hospital. We will screen our patients for eligibility for potential research studies. One of our TAVI member will discuss with you further details if you are eligible for a research study. Please inform us if you are not interested in any research protocol.*
M26	*Eligible*	*You are eligible for a research study. One of our TAVI coordinators will speak with you for further details.*

Table 3: Personalized patient education messages with the related risk variables

4.4.5 Developing Decision Rules

A rule-based system is a system that includes set(s) of rules that are used to describe certain patterns [102, 103]. Patient data are collected and evaluated using these rules. Rule-based systems can be used for analyzing patient data since they can naturally represent the way experts reason and provide information related to the identified problem [94, 103]. For instance, if one of the rules is logically satisfied, the pattern will be identified, and a problem or information associated with that pattern will be suggested [94, 103]. In addition, decision rules can be considered as a decision support tool that works based on analyzing patient information. Decision rules provide a more specific and purposeful analysis through separating irrelevant information from the essential scope [94, 102, 103]. In this research work, decision rules are important for our personalized patient education system since they enable the system to limit the number of educational messages delivered to a patient based on the results of the patient assessment. We have developed decision rules based on the knowledge which was obtained from the interventional cardiologists at the QEII hospital. Our main contribution in this step was to link the risk variables with the associated risks/considerations and the educational messages, so that we can develop the decision rules. Therefore, developing decision rules from the knowledge base is the main method of personalizing patient information for the purpose of this research.

Two sets of decision rules were developed. The first set of rules is important to determine the number and types of risks and considerations that could arise from the TAVI procedure based on the results of patient assessment. The rules are based on an analysis and categorization of risk variables identified after assessing a patient. For example, if a TAVI patient has “severe pulmonary hypertension”, which is one of the risk variables, then there is an identification of the risk of “increasing predictor of mortality”. The system will arrive at this conclusion by analyzing the information collected in the patient assessment as supported by the 63 rules under the first set of rules. The second set of rules is equally important since it enables the system to determine the number and types of personalized patient educational messages that should be delivered to each TAVI patient. The second set of decision rules is composed of 19 rules. The main purpose of the second set of rules is to link specific risk variables from the same patient assessment to the educational messages. A reflection at the example of a patient having severe pulmonary hypertension

shows that the system should identify the risk of increasing predictor of mortality. The system will further analyze the results according to the second set of rules. This will enable it to deliver a specific message to the patient on increasing predictor of mortality, specifically from having severe pulmonary hypertension. This example highlights the ability of the personalized patient education system to provide specific and personalized educational messages for TAVI patients. Our rule-based approach uses IF-THEN type rules. Here are some examples of the two sets of decision rules that we used in our system:

Set #1 Examples:

- R1: IF LVEF = 21- 30% OR LVEF ≤ 20% THEN *Increase Procedural Risk*
- R2: IF Baseline card. Rhythm & Conduction Abnormality = RBBB THEN *Increase Risk of Pacemaker*
- R3: IF Baseline card. Rhythm & Conduction Abnormality = PAF OR Permanent THEN *Increase Risk of Stroke*
- R4: IF Dialysis dependent = Yes THEN *Increase Predictor of Mortality*
- R5: IF Peripheral Vascular Dis. = Yes THEN *Increase Risk of Vascular Complication*
- R6: IF Cerebrovascular disease = Yes THEN *Increase Risk of Stroke*
- R7: IF Cerebrovascular event = Yes THEN *Increase Risk of Stroke*
- R8: IF Pulmonary Hypertension = Yes AND Severe: >55 mmHg THEN *Increase Predictor of Mortality*
- R9: IF Chronic lung disease = Severe THEN *Increase Predictor of Mortality AND Needs Specific Procedural Consideration*
- R10: IF Home Oxygen = Yes THEN *Increase Predictor of Mortality AND Needs Specific Procedural Consideration*

Set #2 Examples:

- IF {R1} THEN Message 1 (M1)
- IF {R2} THEN Message 19 (M19)
- IF {R3} THEN Message 12 (M12)
- IF {R4} THEN Message 9 (M9)
- IF {R6 + R7} THEN Message 13 (M13)
- IF {R9 + R10} THEN Message 14 (M14)

4.4.6 Developing Patient Report and Personalized Patient Education Document Templates

After developing decision rules, we have developed two templates representing the main outputs of the system; the patient report and personalized patient education document. The patient report contains the patient's information in terms of basic identification of information, and a list of preoperative risks and considerations with their risk variables based on the results of the patient assessment. The personalized patient education document contains the main personal information of the patient as well as a list of preoperative risks and considerations with specific educational messages based on the results of the patient assessment. Access to the outputs of the system will be limited to physicians and nurses. Both of the outputs can be downloadable, and TAVI team can use these outputs during their meetings to assess the eligibility of the patient to perform TAVI procedure.

4.4.7 Developing the Initial Prototype

In this step, we have developed an initial TAVI system design by using the obtained information regarding system requirements from the previous steps. In this step, the architectural design, model specification, and interface design were developed and revised. Suggestions and feedback from supervisors and potential users were important to ensure the right structure of this prototype. After that, the development team were able to develop the initial prototype. This prototype was iteratively modified by developers to match the expectations and goals of this research work.

4.4.8 Evaluating and Revising the Initial Prototype

After developing the initial prototype, we were able to evaluate the prototype to determine whether or not this version meets the goals and expectations of this project. For evaluating the prototype, we used an internal validation method to assess the knowledge inferencing of the system through testing the ability of this prototype in performing the function of logical inferencing to reach the expected conclusion. The final conclusion should match the obtained knowledge from interventional cardiologists. Finding some programming or knowledge issues leads to modify the prototype as necessary. Therefore,

iterative process of modification and reevaluation continues until meeting the expectations of this system. This step will be further explained and discussed in the evaluation chapter.

4.5 Proposed Clinical Pathway for TAVI with Using Our Proposed System

Based on our observations from the shadowing experience at the TAVI clinic (QEII Hospital), we are proposing the introduction of a personalized patient education web-based system. The system will be vital during the clinical visits for new TAVI patients. As illustrated in our research methods, TAVI patient assessment will be the main component of the system. Our research is proposing the adoption of the TAVI system that generates two main outputs into the current clinical pathway illustrated in this chapter.

- ***The proposed Improvements and Solution Approach***

The main difference in this proposed clinical pathway is entering patient data into TAVI system during or after the interaction with the patient. In addition to the current pathway, entering patient data task will be required from the booking clerks, nurses, cardiologists, and surgeons at the TAVI clinic. For instance, when a new TAVI patient checks in at the TAVI clinic, the booking clerk will be responsible for entering the main personal information into the personal information component in TAVI system. The data of other components in the patient assessment will be shared and entered by the nurse, cardiologist, and surgeon who are interacting with the patient during the clinical visit. After assessing the patient and having the diagnostic examinations results ready, each one of the TAVI team members will be responsible to enter these data during or after the interaction with the patient. After entering all the required data and finishing the assessment, the proposed system will generate a patient report and a personalized patient education document based on the results of the patient assessment. The patient report will assist TAVI team in their decision of determining the eligibility of the patient to perform TAVI procedure as an option for the treatment. If the patient is eligible for TAVI procedure, the cardiology office or the nurse can send the generated personalized patient education document by mail or email to the patient with the notification of the procedure. This document will be very specific regarding the condition of the patient, and it will assist in improving the recognition of possible risks and considerations associated with this

procedure. Based on the literature review, improving patient's understanding may increase patient activation and enhance Shared Decision-Making process in regard to TAVI procedures. The personalized patient education document can also be shared with the family members of the patient to encourage them to contribute towards decision making and informed consent. Also, the system should be effective in improving patient consent, comparing to using generic patient education at the clinic, since it provides specific educational messages that improve understanding the risks and considerations associated with TAVI procedure.

- ***Modeling the Proposed Clinical Workflow***

After we had a better understanding of the solution approach, we had to organize and model the approach through using BPMN language. The proposed clinical pathway for TAVI with using TAVI system is detailed in figure 8 (BPMN Diagram). This diagram includes the proposed tasks (process) that should be introduced, based on our solution approach, to the current clinical workflow processes which was illustrates in figure 7. The main process is entering patient data into the components of TAVI patient assessment in TAVI system. Each TAVI team members (booking clerk, nurse, cardiologist, and surgeon) will be responsible for this task during or after the interaction with the patient. Another process will be sending the personalized patient education document to patients who are eligible for performing TAVI. The cardiology office will be responsible for this task. Therefore, the proposed solution approach focuses on integrating TAVI system with the current clinical workflow.

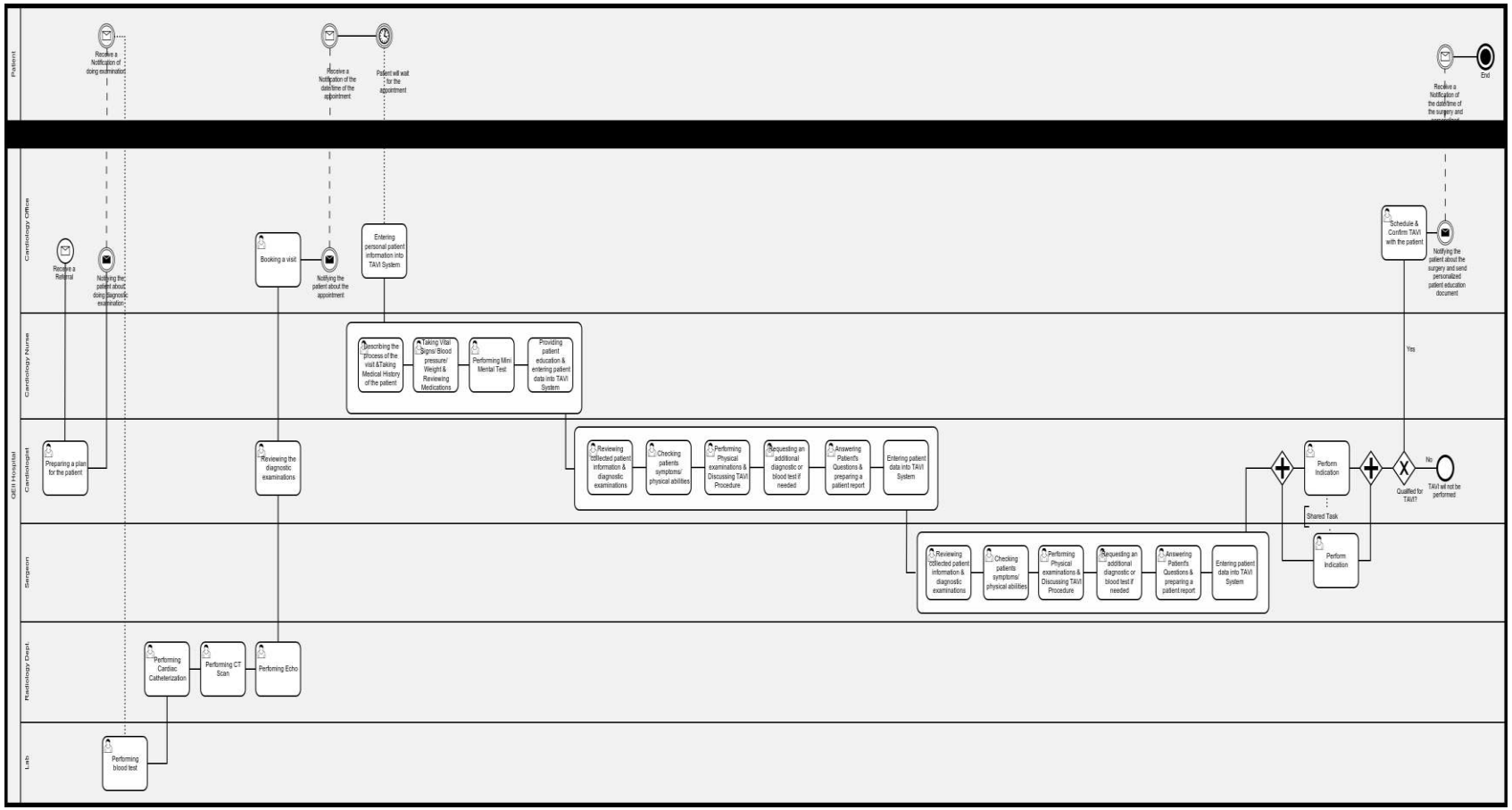

Figure 8: BPMN Diagram: The proposed clinical pathway for TAVI with using our proposed system

CHAPTER FIVE: SYSTEM EVALUATION

This chapter presents evaluating TAVI system to ensure the validity of this proposed system. We assessed the construction of our proposed system on the grounds whether it correctly implements the requirements and meets our research goals. For this purpose, we used scenario-based evaluation to ensure that TAVI system meets the requirements and expectations.

5.1 Evaluation Approach:

Before listing our evaluation criteria, it is important to highlight the differences between validation and verification of rule based systems. Validation and verification of a rule-based system are the processes of making sure that the decision rules meet specifications and match the intended purpose [93, 104]. Verification is "the process of evaluating the rule definitions to determine whether the imposed specification is fulfilled" [93, 104]. In other words, it refers to building the rule based system in the correct manner. An example of verification is making sure there is no error crept in while using the system. On the other hand, validation is "the process of evaluating the rules, either during or following the rule execution, to determine whether they satisfy the end-user requirements" [93, 104]. In other words, it refers to making sure that the outputs of the system match the needs and expectations of the potential user. Moreover, validation is a useful method to ensure correctness of the knowledge encoded within the system. Scenario-based evaluation was selected for evaluating our proposed system "TAVI System".

5.2 Scenario-based Evaluation:

The purpose of scenario-based evaluation is to determine whether the TAVI system produces the desired output or not. We used three main steps in this process which are:

5.2.1 Preparing Case Scenarios:

For this evaluation, we have prepared 40 hypothetical case scenarios. We divided these case scenarios into four groups (10 case scenarios for each group) based on the largest four categories of the risks and considerations associated with TAVI procedure, and we also added other risks and considerations from the other categories that have a fewer

number of risk variables. The largest four categories are procedural risks, vascular complications, risk of mortality, special procedural considerations. These case scenarios were validated for clinical correctness through reviewing some literatures related to TAVI patients [105, 106, 107]. Through this review, we developed a better understanding of the health conditions of these patients before performing TAVI, and that helped us in preparing these case scenarios. In this evaluation, we made sure that the input, (value/status of each risk variable), will satisfy the rules in order to generate outputs. These are four examples, from the main four groups, that we used during our evaluation:

- ***Example 1 (Group1: Procedural risk, risk of stroke, risk of pacemaker):***

Case #1:
Erika Adams, a 75-year-old female. TAVI log # 301, Health Card # 100200301

- ***Patient Data:***

Variable	Value/Status	Source
LV function	LVEF = 25%	*Clinical characteristic*
LCA Height	8mm	*CT Angiogram*
Baseline card. Rhythm & Conduction Abnormality	PAF & RBBB	*Clinical Characteristics*
Sinus Valsalva	20-25mm	*CT Angiogram*
ST Junction:	27-30mm	*CT Angiogram*

Table 4: Case Scenario: Example 1

- ***Example 2 (Group 2: Vascular complications, risk of kidney damages, and others):***

Case #15:
Antonio Ford, a 76-year-old Male. TAVI log # 315, Health Card # 100200315

- ***Patient Data:***

Variable	Value/Status	Source
***Vascular Issues – IR requested**	Yes	*Procedure planning*
Renal Impairment	CC > 50 & <85 (Moderate)	*Blood work*
Immunosuppressed	Yes	*Risk Factors / Assessment*
Degree of tortuosity (L)	Severe	*CT Angiogram*
Degree of tortuosity (R)	Severe	*CT Angiogram*
History of cancer	Yes	*Risk Factors/ Assessment*

Table 5: Case Scenario: Example 2

➢ ***Example 3 (Group 3: Risk of mortality and others):***

Case #21:
Alice Wing, a 69-year-old Female. TAVI log # 321, Health Card # 100200321

❖ ***Patient Data:***

Variable	Value/Status	Source
Dialysis dependent	Yes	*Risk Factors / Assessment*
LV Angiogram	Severe	*Cath / Angiography*
Research Study Screening Performed	Yes	*Research Study*
Wait-Time 1 (Referral to MDT TAVI Acceptance) Wait-time > 12 weeks:	Yes	*Wait-time assessment*
Prior Blood Products Use: **Antibody Screen:**	Yes Positive	*Blood work*

Table 6: Case Scenario: Example 3

➢ ***Example 4 (Group 4: Special procedural consideration and others):***

Case #31:
Jasmine Robert, a 72-year-old Female. TAVI log # 331, Health Card # 100200331

❖ ***Patient Data:***

Variable	Value/Status	Source
Chronic lung disease	Severe	*Risk Factors / Assessment*
PCI Performed: (Prior to TAVI)	Yes	*Procedure planning*
Pulmonary function	FEV1= (40%) DLCO = (35%)	*Risk Factors / Assessment*
Candidate Salvage SAVR	Yes	*Procedure planning*
Wait-Time 1 (Referral to MDT TAVI Acceptance) Wait-time > 12 weeks:	Yes	*Wait-time assessment*
History of cancer	Yes	*Risk Factors/ Assessment*

Table 7: Case Scenario: Example 4

5.2.2 Setting up Result Expectations:

After preparing the case scenarios, we had to set up the result expectation for each case scenario. Expectations refers to the desired output and correct conclusions that should be generated by the system based on the input entered and knowledge obtained from experts. We divided our expectations into two types which are reasoner-specific

expectations and content-specific expectations. Reasoner-specific expectations refers to whether the risk variable with its educational message should present or not based on the input entered. This will be useful to ensure that the required types of risks/education messages are presented and the other ones are not. Content-specific expectations refers to whether the system produce the correct content of the outputs or not comparing to the desired outcomes. This will be useful to check the link between the risk variables and type of risks/educational messages. These are the result expectations for each case based on the four examples that we provided earlier:

- ***Result Expectations: Example 1***

Type of Risk/Consideration	Risk Variable	Personalized Message
Increase Procedural Risk	LV function: LVEF = 21- 30%	M1
	LCA Height < 10	M3
	Sinus Valsalva: ≤ 30	-
	ST Junction ≤ 30	-
Increase Risk of Stroke	Baseline card. Rhythm & Conduction Abnormality: PAF	M12
Increase Risk of Pacemaker	Baseline card. Rhythm & Conduction Abnormality: RBBB	M19

Table 8: Result expectations: Example 1

- ***Result Expectations: Example 2***

Type of Risk/Consideration	Risk Variable	Personalized Message
Increase Risk of Vascular Complication	Vascular Issues – IR requested = Yes	M6
	Degree of tortuosity (L) = Severe	-
	Degree of tortuosity (R) = Severe	-
Active Cancer – Information Prognosis	History of cancer = Yes	-
Increase Risk of Infection Endocarditis	Immunosuppressed = Yes	M21
Increase of Kidney Damage	Renal Impairment = Moderate (CC > 50 & <85)	M23

Table 9: Result expectations: Example 2

- ***Result Expectations: Example 3***

Type of Risk/Consideration	Risk Variable	Personalized Message
Increase Predictor of Mortality	Dialysis dependent = Yes	M9
	LV Angiogram = Severe	M11

Wait Time Assessment Special Consideration	Wait-Time 1 (Referral to MDT TAVI Acceptance): Wait-time > 12 weeks = Yes	-
Needs to Check Blood Products Availability	Prior Blood Products Use = Yes AND Antibody Screen = Positive	-
Eligible for Research Study	Research Study Screening Performed = Yes	M26

Table 10: Result expectations: Example 3

- ***Result Expectations: Example 4***

Type of Risk/Consideration	Risk Variable	Personalized Message
Needs Specific Procedural Consideration	Chronic lung disease = Severe	M14
	PCI Performed = Yes	M15
	Pulmonary function = Yes AND FEV1 ≤ (50%) AND DLCO ≤ (50%)	-
	Candidate Salvage SAVR = Yes	-
Wait Time Assessment Special Consideration	Wait-Time 1 (Referral to MDT TAVI Acceptance): Wait-time > 12 weeks = Yes	-
Active Cancer – Information Prognosis	History of cancer = Yes	-

Table 11: Result expectations: Example 4

5.2.3 Evaluating and Reporting the Results:

We run the 40 case scenarios in TAVI system, and we made an excel sheet to report and evaluate the results manually. In this sheet, we included all the possible risks/considerations with the desired outcomes of each case scenario. For each case, we had to indicate what risk variables with their personalized messages are expected to be presented in the outputs of the system based on the obtained knowledge from experts. Also, we had to indicate whether the generated outcomes match the desired outcomes or not. After that, we gave two accuracy grades for each case scenario. The first grade "RV Grade" was calculated manually to measure the accuracy of the system in detecting the correct number of risk variables based on the desired outcomes. For each case, the RV grade was calculated by:

$$\boldsymbol{RV\ Grade} = \frac{\boldsymbol{Actual\ Outcomes\ of\ Risk\ Variables}}{\boldsymbol{Desired\ Outcomes\ of\ Risk\ Variables}}$$

$$\boldsymbol{RV\ Accuracy}\ \% = \boldsymbol{RV\ Grade\ X\ 100}$$

The second grade "PM Grade" was calculated manually to measure the accuracy of the system in detecting the correct number of personalized messages based on the desired outcomes. For each case, the PM grade was calculated by:

$$\boldsymbol{PM\ Grade} = \frac{\boldsymbol{Actual\ Outcomes\ of\ Personalized\ Messages}}{\boldsymbol{Desired\ Outcomes\ of\ Personalized\ Messages}}$$

$$\boldsymbol{PM\ Accuracy}\ \% = \boldsymbol{PM\ Grade\ X\ 100}$$

Furthermore, during this evaluation we highlighted and reported the issues with some of the rules to be fixed in the next phase. Here are some examples of evaluating and reporting the results based on our previous examples:

- **Reporting the results of example 1:**

Case 1

Risk/consideration	Risk Variable	P-Message	Should Present	Correct	RV Grade	PM Grade	RV Accuracy %	PM Accuracy %
Increase Procedural Risk	LV function: LVEF = 21- 30%	M1	1	1	6|6	4|4	100%	100%
	LCA Height < 10	M3	1	1				
	Sinus Valsalva: ≤ 30	..	1	1				
	ST Junction ≤ 30	..	1	1				
Increase Risk of Vascular Complication			0					
Increase Predictor of Mortality			0					
Increase Risk of Stroke	Baseline card. Rhythm & Conduction Abnormality: PAF	M12	1	1				
Needs Specific Procedural Consideration			0					
Wait Time Assessment Special Consideration			0					
Increase Risk of Pacemaker	Baseline card. Rhythm & Conduction Abnormality: RBBB	M19	1	1				
Active Cancer – Information Prognosis			0					
Increase Risk of Infection Endocarditis			0					
Probability of Death for Surgical Aortic Replacement			0					
Increase of Kidney Damage			0					
Needs to Check Blood Products Availability			0					
Eligible for Research Study			0					

Figure 9: Reporting the results: Example 1

- **Reporting the results of example 2:**

Case 15

Risk/consideration	Risk Variable	P-Message	Should Present	Correct	RV Grade	PM Grade	RV Accuracy %	PM Accuracy %
Increase Procedural Risk			0		4|6	3|3	66.66%	100%
Increase Risk of Vascular Complication	Vascular Issues – IR requested = Yes	M6	1	1				
	Degree of tortuosity (L) = Severe	..	1	0				
	Degree of tortuosity (R) = Severe	..	1	0				
Increase Predictor of Mortality			0					
Increase Risk of Stroke			0					
Needs Specific Procedural Consideration			0					
Wait Time Assessment Special Consideration			0					
Increase Risk of Pacemaker			0					
Active Cancer – Information Prognosis	History of cancer = Yes	..	1	1				
Increase Risk of Infection Endocarditis	Immunosuppressed = Yes	M21	1	1				
Probability of Death for Surgical Aortic Replacement			0					
Increase of Kidney Damage	Renal Impairment = Moderate (CC > 50 & <85)	M23	1	1				
Needs to Check Blood Products Availability			0					
Eligible for Research Study			0					

Figure 10: Reporting the results: Example 2

- **Reporting the results of example 3:**

Case 21

Risk/consideration	Risk Variable	P-Message	Should Present	Correct	RV Grade	PM Grade	RV Accuracy %	PM Accuracy %
Increase Procedural Risk			0					
Increase Risk of Vascular Complication			0					
Increase Predictor of Mortality	Dialysis dependent = Yes	M9	1	1				
	LV Angiogram = Severe	M11	1	1				
			0					
Increase Risk of Stroke			0					
Needs Specific Procedural Consideration			0					
Wait Time Assessment Special Consideration	Wait-Time 1 (Referral to MDT TAVI Acceptance): Wait-time > 12 weeks = Yes	..	1	1	4|5	2|3	80%	66.66%
Increase Risk of Pacemaker			0					
Active Cancer – Information Prognosis			0					
Increase Risk of Infection Endocarditis			0					
Probability of Death for Surgical Aortic Replacement			0					
Increase of Kidney Damage			0					
Needs to Check Blood Products Availability	Prior Blood Products Use = Yes AND Antibody Screen = Positive	..	1	1				
Eligible for Research Study	Research Study Screening Performed = Yes	M26	1	0				

Figure 11: Reporting the results: Example 3

- **Reporting the results of example 4:**

Case 31

Risk/consideration	Risk Variable	P-Message	Should Present	Correct	RV Grade	PM Grade	RV Accuracy %	PM Accuracy %
Increase Procedural Risk			0					
Increase Risk of Vascular Complication			0					
Increase Predictor of Mortality			0					
Increase Risk of Stroke			0					
Needs Specific Procedural Consideration	Chronic lung disease = Severe	M14	1	1				
	PCI Performed = Yes	M15	1	0				
	Pulmonary function = Yes AND FEV1 ≤ (50%) AND DLCO ≤ (50%)	..	1	1				
	Candidate Salvage SAVR = Yes	..	1	1				
Wait Time Assessment Special Consideration	Wait-Time 1 (Referral to MDT TAVI Acceptance): Wait-time > 12 weeks = Yes	..	1	1	5|6	1|2	83.33%	50%
Increase Risk of Pacemaker			0					
Active Cancer – Information Prognosis	History of cancer = Yes	..	1	1				
Increase Risk of Infection Endocarditis			0					
Probability of Death for Surgical Aortic Replacement			0					
Increase of Kidney Damage			0					
Needs to Check Blood Products Availability			0					
Eligible for Research Study			0					

Figure 12: Reporting the results: Example 4

5.3 Evaluation Results

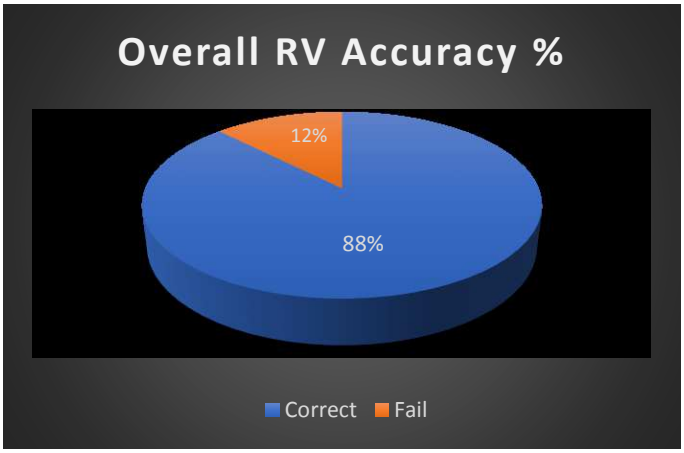

Figure 13: Overall RV Accuracy Percentage

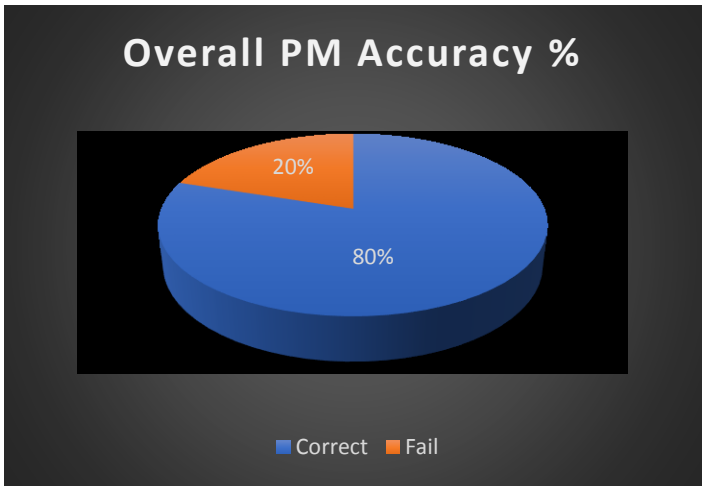

Figure 14: Overall PM Accuracy Percentage

Overall, based on our evaluation, TAVI system was able to detect about 88% of the desired risk variables correctly. TAVI system failed to detect about 12% of the desired risk variables. In addition, TAVI system was able to detect approximately 80% of the desired personalized messages correctly. The system failed to detect about 20% of the desired personalized messages. Here are more details about the overall results of this evaluation for each group:

Group #	RV Accuracy %	PM Accuracy %
Group 1	90.13%	100.00%
Group 2	83.66%	76.66%
Group 3	87.33%	74.99%
Group 4	89.33%	68.33%
Overall Accuracy	**87.61%**	**79.99%**

Table 12: Overall RV & PM Accuracy Percentage for Each Group

From table 11, we can notice that RV and PM accuracy percentages vary from a group to another. The highest RV and PM accuracy percentages were in group 1. The lowest RV accuracy percentage was in group 2, while the lowest PM accuracy percentage was in group 4. To be more specific, we have highlighted the main issues with the rules. Here are more details about the parts of the rules that did not fire and failed to present in the generated outcomes comparing to the desired outcomes:

#	Set #-Rule #	Failed Part	Affects PM	Number of Fails
1	**Set #1 - R55**	LVOT ≤ 30 mm	No	2 times
2	**Set #1 - R63**	Mitral Annular Calcification (MAC) = Severe	No	3 times
3	**Set #1 - R48**	Min Iliac diameter <6 mm	No	2 times
4	**Set #1 - R27**	PCI Performed = Yes	Yes	6 times
5	**Set #1 - R51**	Vascular Access Site Calcification: Common/External Iliac (L) = Circumferential	No	1 time
6	**Set #1 - R52**	Vascular Access Site Calcification: Common/External Iliac (R) = Circumferential	No	3 times
7	**Set #1 - R53**	Degree of tortuosity (L) = Severe	No	2 times
8	**Set #1 - R54**	Degree of tortuosity (R) = Severe	No	1 time
9	**Set #1 - R26**	Research Study Screening Performed = Yes	Yes	4 times
10	**Set #1 - R56**	RVSP >=56 mm/Hg	Yes	3 times
11	**Set #2 - R18**	Message 24	Yes	7 times

Table 13: System Implementation (Programming) Issues: Failed Rules

This evaluation was useful to identify 11 issues with our rule based system. All of these issues were programming issues. After identifying these issues, the development team was able to fix them and make sure they work. To ensure these issues are fixed, we re-evaluated the system through running a few cases which include the rules that did not fire in the beginning. In addition, it is important to note that we did not face any issue with the knowledge part during this evaluation. For example, the knowledge content of the generated outcomes was accurate and consistent with obtained knowledge from experts.

5.4 Concluding Remarks:

This chapter presented evaluating TAVI system to ensure the validity of this proposed system. We were able to evaluate the prototype to determine whether or not this version

meets the expectations of this project. In this evaluation, we used scenario-based evaluation to determine whether the TAVI system produces the desired output or not. The results of this evaluation are promising and demonstrated the ability of this system to meet the goal of providing personalized patient education. Also, this evaluation was very helpful to detect some programming issues, and these issues were fixed accordingly.

CHAPTER SIX: DISCUSSION & CONCLUSION

6.1 Revisiting the Problem Statement

TAVI is as a unique cardiac procedure that is carried out with elderly patients with severe aortic stenosis. TAVI is a minimally invasive procedure, however; this procedure is still associated with several considerable risks based on the condition of the patient prior performing this procedure. To obtain an informed consent, it is important to appropriately inform patients and their families about the risks and benefits associated with TAVI procedure. This will help patients and their family in the decision-making process. During the preoperative time, patients and their families always require appropriate, easily accessible and understandable information regarding their procedure, to have a better understanding of their conditions and associated risks. Furthermore, studies suggest that impersonal and general patient education has insignificant impact on patients and health outcomes as compared to the personalized and patient-specific educational interventions [16, 19]. Moreover, many patients prefer to receive information that is specific to their own health conditions [20]. Based on my observations during my shadowing experience at QEII hospital, there is an opportunity to improve TAVI preoperative patient education during the clinical encounter in TAVI clinic. This improvement can be done through developing a preoperative personalized patient education intervention for TAVI patients in collaboration with TAVI team members.

6.2 Discussion Around Our Research Achievements

We re-visited our research objectives, and analyzed what we have accomplished in this research. By using health informatics methodologies and technologies, we developed a "proof-of-concept" preoperative personalized patient education system for TAVI patients which can provide the following functionalities as shown by evaluation in Chapter 5:

- *Assist in TAVI patient assessment to highlight associated risks and specific procedural considerations for each patient with respect to the TAVI procedure.*
  In this research, we have demonstrated the ability of TAVI system to highlight the risks and considerations associated with TAVI procedure based on the results of

TAVI patient assessment. Based on evaluation, the initial TAVI system prototype was able to detect approximately 88% of the desired risk variables correctly. Therefore, TAVI system has the ability to underline these risks and considerations for each TAVI patient and illustrate the results in the patient report to be used by TAVI team. This report can assist TAVI team members in making decisions regarding the eligibility of the patient to do TAVI procedure.

- *Select and deliver patient-specific educational messages, based on the patient's TAVI assessment, to help prepare the patient about the TAVI procedure.*

  We demonstrated the ability of TAVI system to select and deliver personalized educational messages based on the results of TAVI patient assessment. Based on our evaluation, the initial TAVI system prototype was able to detect about 80% of the desired personalized messages correctly. Thus, TAVI system has the ability to deliver personalized educational messages for each TAVI patient. These personalized messages are presented in the patient education document which can be provided to each TAVI patient prior performing the procedure.

- *Improve patient consent by informing the patient about their own associated risks and considerations prior to performing TAVI. This will allow patients to make informed decisions about the procedure.*

  We were unable to evaluate this objective in this time frame; it can be a potential future work. Patient consent can be improved by informing TAVI patients and improving their understanding about their own risks and considerations associated with TAVI procedure. After receiving the personalized patient education document, TAVI patients and their families will have a better understanding of these risks and considerations. This can lead to improve and ease the process of obtaining patient consent. There is a need for more research studies to explore the impact of using TAVI system for improving patient consent.

- *Improve Shared Decision Making about TAVI procedure between the patients and physicians.*

We were unable to evaluate this objective in this time frame; it can be a potential future work. By following Patient-Centered Care model, we are expecting that this system will have a positive impact on promoting good communication between TAVI patients and their healthcare providers. This can be done through improving their recognition of the risks and complications associated with TAVI procedure by providing the personalized patient education document to each TAVI patient. Our patient education approach targets producing more informed patients and families who can actively participate in the medical decision making. Thus, we believe that by being more informed and increasing confidence, TAVI patients and their families can be motivated to communicate with their healthcare providers, and express their health concerns and preferences regarding this procedure. More research studies are required to explore the impact of TAVI system on SDM.

6.3 Research Benefits:

This research can carry some potential benefits for both healthcare providers and patients. Here are the main benefits for patients and healthcare providers:

- *TAVI Patients:*
  - By highlighting the main procedural risks and considerations and providing personalized patient education messages to each TAVI patient, this system can improve shared decision making between patients and physicians during the process of clinical care, and improve procedural outcomes. Improving the recognition of the associated risks, complications, and other considerations related to TAVI will result in producing more informed patients before signing the consent form of procedure.
  - Providing personalized patient education messages through this system may assist in reducing the level of preoperative anxiety for TAVI patients by targeting their specific procedural risks and considerations associated with this procedure. Providing patients with the necessary information and excluding irrelevant information to patients based on their assessment may be useful for reducing the level of preoperative anxiety.

- *TAVI Team:*
  - This system can act as a decision support system (DSS) for TAVI team to assist them in determining the eligibility of the patient to perform TAVI procedure based on his/her assessment.
  - Addressing the main risks and considerations of each patient, providing specific educational messages, and improving Shared Decision Making will increase patient satisfaction.
  - This system may assist in reducing the number of preoperative visits/calls or the time required in such visits/calls.

6.4 Research Limitations:

- TAVI system is not a fully implemented patient education system. This system is a prototype which means it has limited purposes, capabilities, and functionalities. Our prototype included limited functionalities that satisfy the scope of this research only.
- Unfortunately, this research work did not include an evaluation study which should focus on the end-user feedback. It is important to receive a feedback regarding the learnability, user interface, educational content, and overall usability. Thus, the end-user feedback would be useful to identify some potential areas of modifications to improve the usability of the system.
- Some of our research objectives focused on improving patient consent, producing well informed patients, and improving communication and Shared Decision Making regarding TAVI procedure. These potential objectives were not assessed during this research work because they need deployment and real-world application and evaluation, which can be a potential future work.

6.5 Future Directions:

There is a need to evaluate this system more in depth through performing some studies for different purposes.

- A usability study is needed to assess how well TAVI system meets the goals and usability needs of end-users (TAVI team) in terms of educating TAVI patients before the procedure. This study is also needed to receive end-user feedback in order to identify potential areas of modifications that are needed to improve content suitability and system usability to enhance its overall usability. This study can clarify some points such as potential issues with respect to the usability and suitability of the educational content, the correctness of the patient education output based on patient assessment, and modifications needed to make the educational content more correct, clear, understandable, useful and helpful.
- Other research studies are needed to examine the effectiveness of this system in improving overall preoperative patient education and Shared Decision Making, and reducing the level of preoperative anxiety for TAVI patients. This study can be done through comparing two groups of TAVI patients with and without using the system during their clinical visit. In this way, we can compare the improvement of knowledge, patient activation, and level of anxiety between the current patient education method (group1) and the new method that includes using TAVI system in clinic (group2).

Another potential future work can be integrating risk assessment tools with this system. Risk assessment tools can be useful for determining and identifying high, moderate, and low risk patients which will assist TAVI team in recommending appropriate strategies to reduce the risk of cardiac complications over the entire preoperative period for each group. Risk assessment tools may also provide an estimation of developing other cardiac problems or worsening the condition of the patient in future. Furthermore, additional studies would be beneficial to assess whether or not this approach could also be used for other types of cardiac procedures.

6.6 Conclusion:

Many studies have illustrated that patient education is tremendously important, and play a critical role in improving health outcomes in clinical practice in past few decades. Based on our research, we argued that producing more informed and educated patients and families is important to improve Shared Decision Making. The main result of our research

was the development of personalized preoperative patient education system for TAVI patients. This proof of concept system aimed toward highlighting the associated risks and specific procedural considerations for each patient with respect to the TAVI procedure. Our system demonstrated that personalized patient education systems can generate personalized messages by facilitating the collection and assessment of patient data, and then using decision rules to generate personalized patient education messages. These personalized massages, which are based on experts' knowledge, can reduce the scarcity of the source of the medical knowledge and increase patient interest. The next step should be assessing how well this system meets the goals and needs of end-users in terms of educating TAVI patients before the procedure. Also, we argue that surgical outcomes can be improved by improving preoperative patient education through using this system, however; there is a need for more work to examine this potential objective. In addition, more work is needed to assess the effectiveness of this system in improving the recognition of the risks associated with TAVI, and reducing the level of preoperative anxiety for TAVI patients. At the end, personalized patient education interventions emerge to be a promising potential solution to support producing more informed patients and families who can actively participate in the medical decision-making process. This may not only improve the quality of care for patients but also save the time of healthcare providers as well as economize the delivery of healthcare services.

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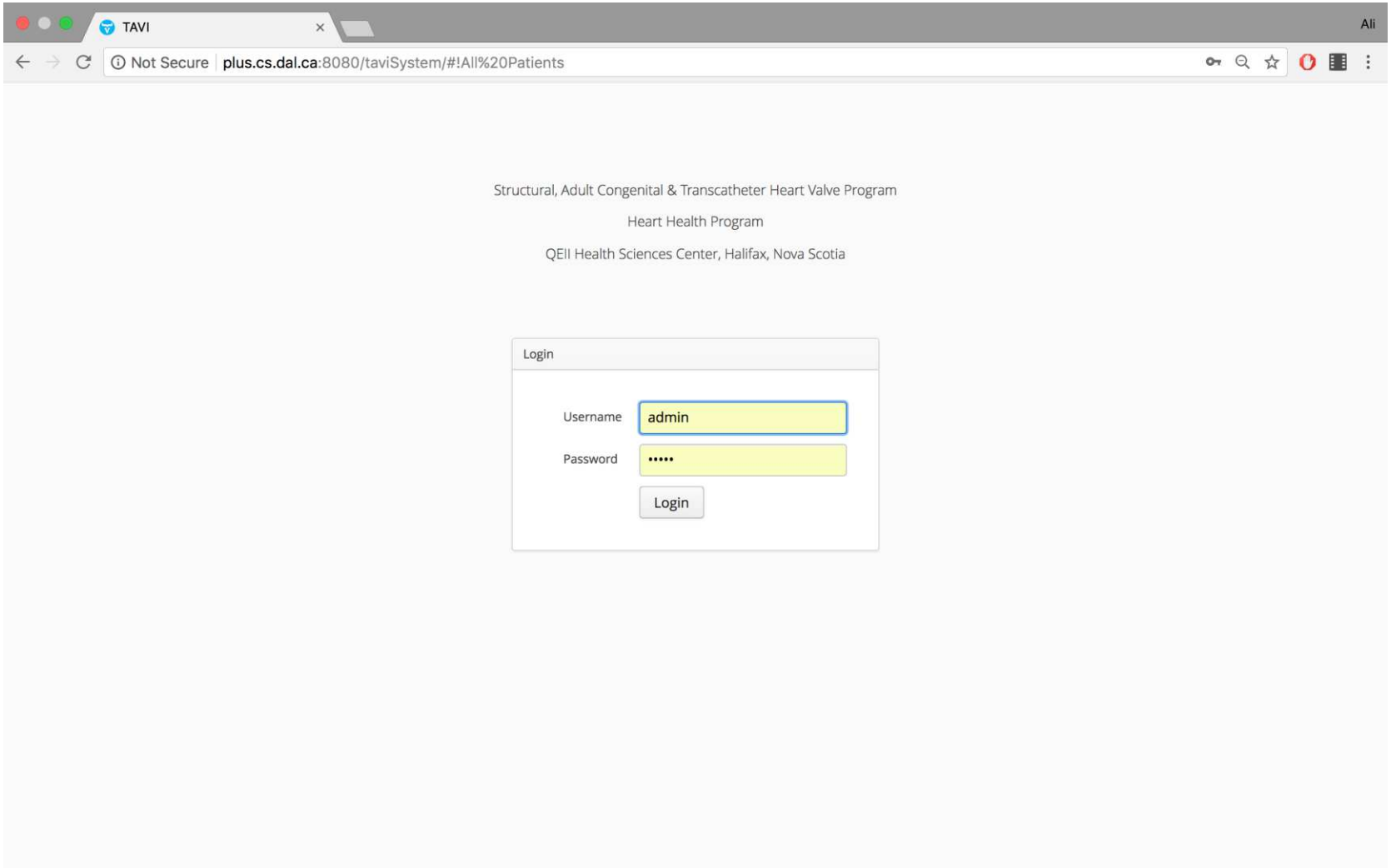
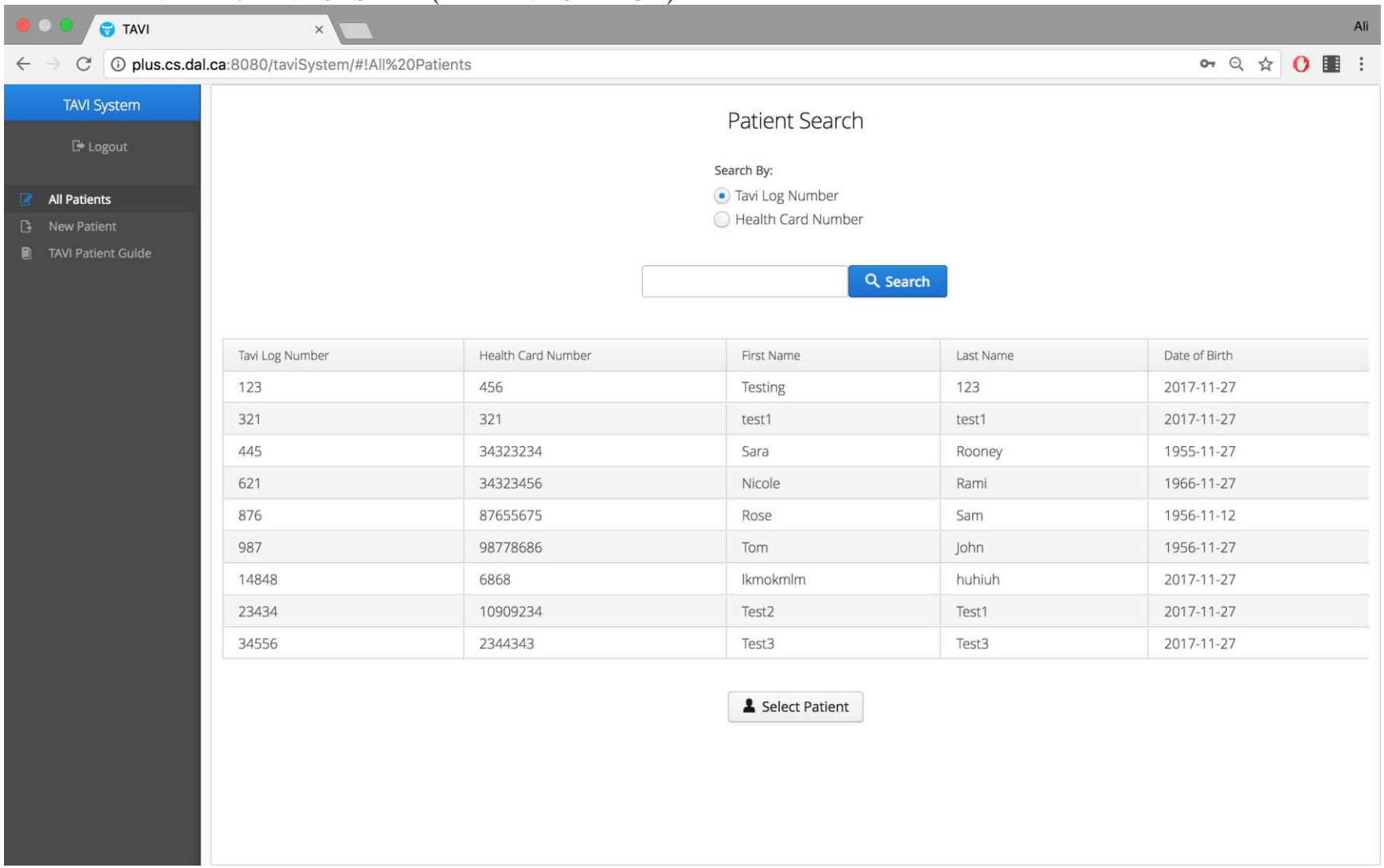
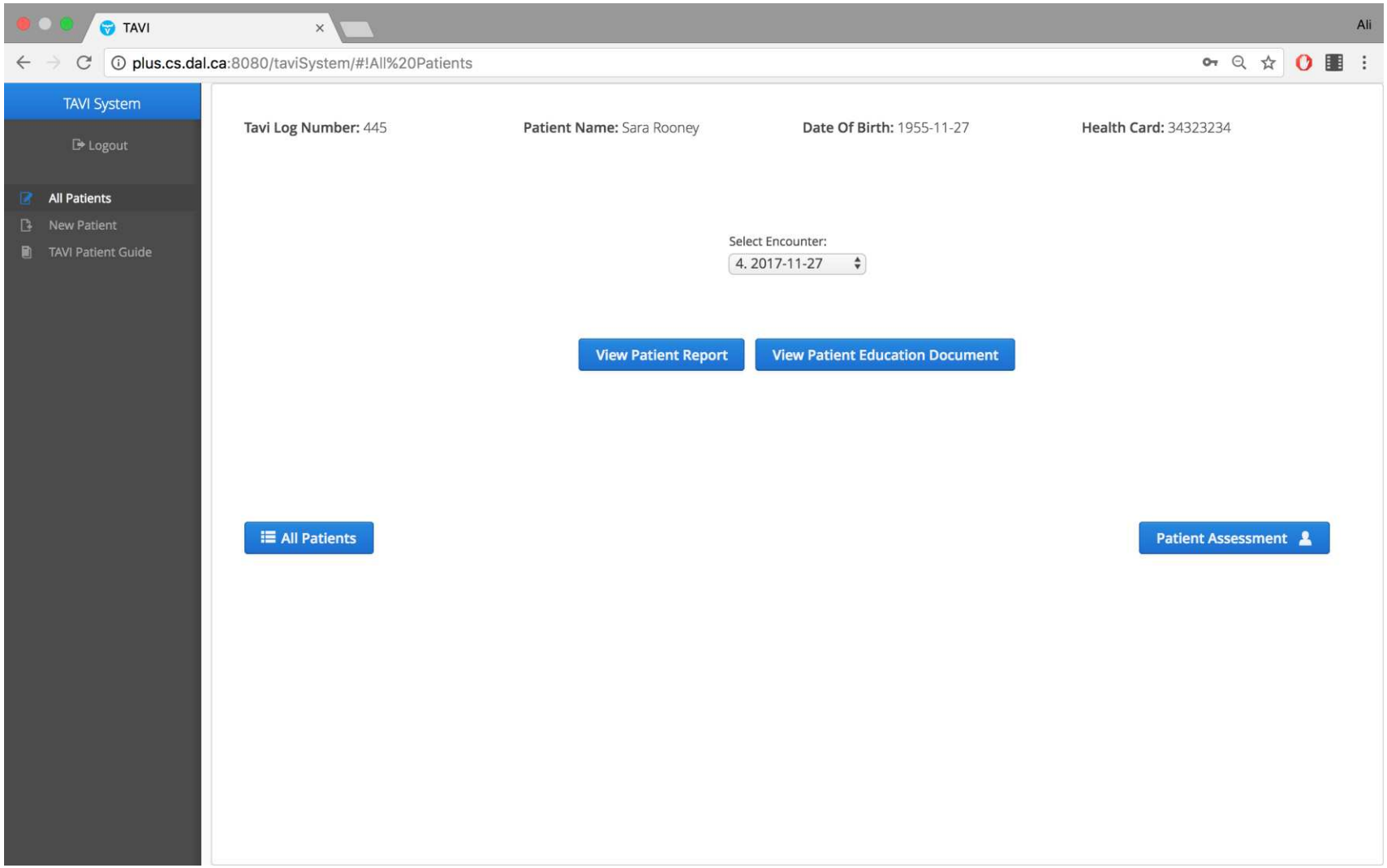
APPENDIX A: TAVI SYSTEM (LOGIN)



APPENDIX B: TAVI SYSTEM (PATIENT SEARCH)



APPENDIX C: TAVI SYSTEM (TAVI PATIENT SELECTION)



APPENDIX C: TAVI SYSTEM (PATIENT REPORT)

TAVI Log Number:	1	**Health Card Number:**	1
Last Name:	Tom	**First Name:**	James
Home Contact:	1995-09-01	**Date of 1st Consult:**	NULL
Referring Physician:	2017-10-10	**Accepting Physician:**	NULL
Family Physician:	NULL	**Patient wait location at referral:**	NULL
Interventional Cardiologist:	Out-Patient	**Cardiac Surgeon:**	-1
Nurse/Coordinator:	-1	**Geriatrics/PATH:**	-1

Patient Report Based on CRF: Preoperative Considerations

INCREASE PREDICTOR OF MORTALITY

PA SYSTOLIC >= 50 MMHG

LV ANGIOGRAM = SEVERE

WAIT TIME ASSESSMENT SPECIAL CONSIDERATION

WAIT-TIME > 6 WEEKS = YES

PROBABILITY OF DEATH FOR SURGICAL AORTIC REPLACEMENT

STS SCORE = HIGH (>= 8%)

NEEDS TO CHECK BLOOD PRODUCTS AVAILABILITY

PRIOR BLOOD PRODUCTS USE = YES AND ANTIBODY SCREEN = POSITIVE

APPENDIX D: TAVI SYSTEM (PERSONALIZED PATIENT EDUCATION DOCUMENT)

TAVI Log Number:	1	**Health Card Number:**	1
Last Name:	Tom	**First Name:**	James
Home Contact:	1995-09-01	**Date of 1st Consult:**	NULL
Referring Physician:	2017-10-10	**Accepting Physician:**	NULL
Family Physician:	NULL	**Patient wait location at referral:**	NULL
Interventional Cardiologist:	Out-Patient	**Cardiac Surgeon:**	-1
Nurse/Coordinator:	-1	**Geriatrics/PATH:**	-1

Personalized Patient Education Document

TAVI is a standard procedure for elderly patients with aortic stenosis. It is considered to be a minimally invasive procedure, however; this procedure is still associated with a number of considerable risks based on the condition of the patient before performing this procedure. Based on your assessment, here are a list of risks and considerations that you should be aware of before TAVI.

DETERMINATION OF RISK FOR DAMAGE TO BLOOD VESSELS (VASCULAR COMPLICATIONS):

Based on your assessment, you have smaller caliber blood vessels (with or without the presence of significant calcium). We have given special consideration for new heart valve device selection to minimize the risk. Overall, vascular complication from the procedure is ranging between 2 to 5%. It may lead to emergency surgery and/or use of blood products and/or extended hospital stay.

RISK OF DEATH:

The risk of death associated with TAVI procedure is about 1 to 2%.

1. PULMONARY HYPERTENSION, PULMONARY ARTERIES SYSTOLIC PRESSURE, RIGHT VENTRICULAR SYSTOLIC PRESSURE:
It is well known that patients with elevated systolic pulmonary artery hypertension are at increased risk from TAVI procedure as the high pulmonary artery pressure is a reflection of advanced aortic valve disease.

2. LV ANGIOGRAM & ECHO MITRAL REGURGITATION:
The presence of significant mitral valve leakage has been associated with increased risk of adverse

outcome.

NEED FOR EMERGENCY OPEN HEART SURGERY:

One of the risks of the TAVI procedure is the need for emergency open heart surgery to correct emergency life threatening complications such as the newly replaced valve moving from its position to the chambers of the heart or the main artery of the aorta or closing down of the coronary arteries that supply the muscles of the heart.

INCREASE RISK OF PACEMAKER

Generally, the risk of requiring a new permanent pacemaker is dependent upon the type of device selected. There are two types of devices, balloon expandable or self-expandable. The decision to use the appropriate device is based on technical factors, depending on the size of blood vessels and the features of your own heart valve. The rate of new permanent pacemaker with balloon expandable is between 5 to 10% whereas the risk of pacemaker requirement by self-expandable valve is between 10 to 20%.

INCREASE RISK OF INFECTION ENDOCARDITIS

All new heart valve implants are at increased risk of infection in comparison to the native heart valves. Some invasive procedures and surgeries such as dental work and surgery involving urinary or gastrointestinal tract can be associated with increased risk of infections as well as skin cuts and laceration. Therefore, appropriate prophylactic and active antibiotics treatment is important. Please inform your dentist/ surgeon that you have artificial heart valve. They will provide you with prescription for appropriate antibiotic coverage

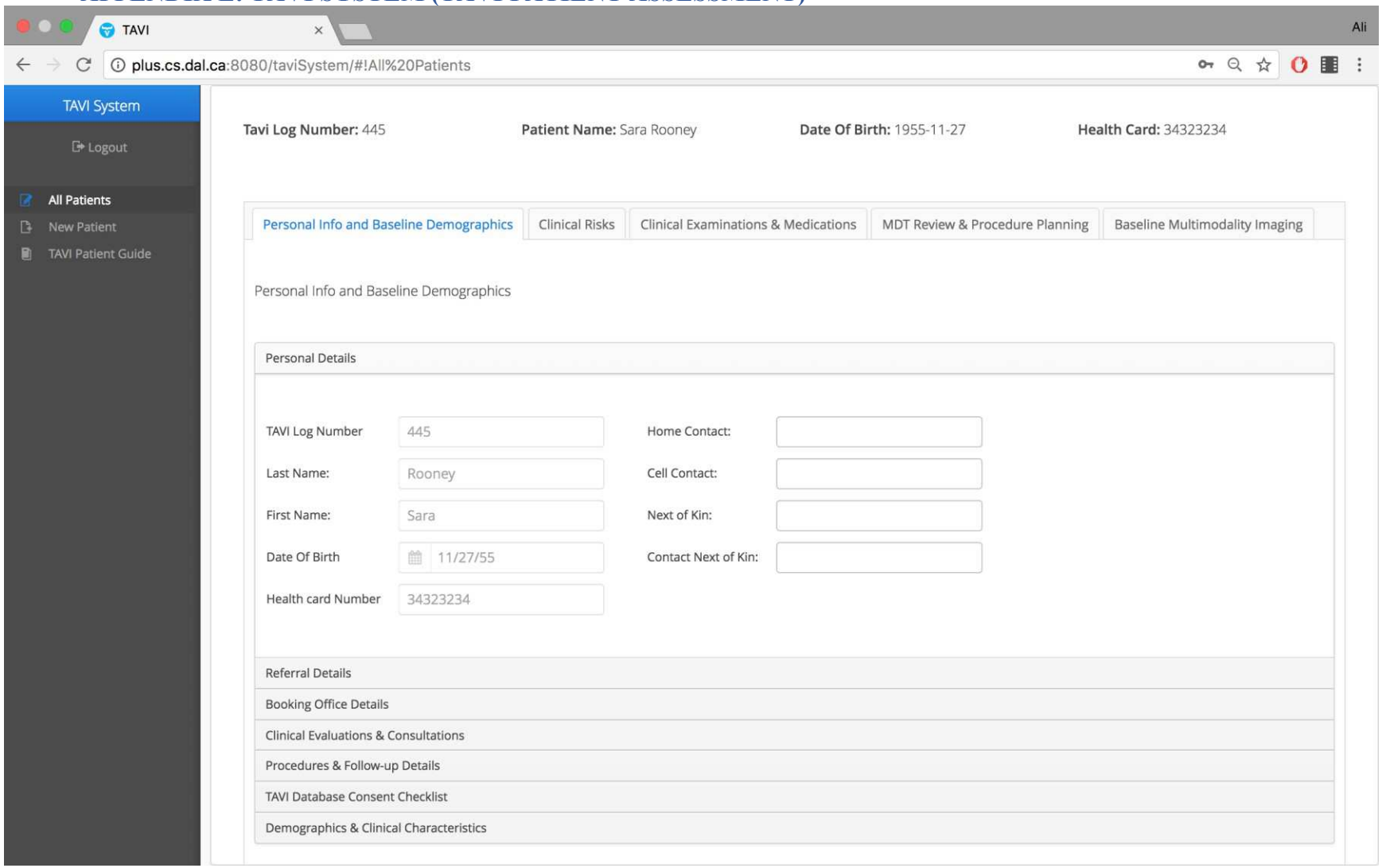
INCREASE OF KIDNEY DAMAGE

1. SCREENING TESTS AND PREPARATION FOR TAVI PROCEDURE INCLUDE:
A dye test and specialized CAT scan. A medical dye (contrast) will be used, during both tests and TAVI procedure, which may increase the risk of kidney damage. With normal baseline kidney function, the risk is exceedingly the low and it is less than 1%.

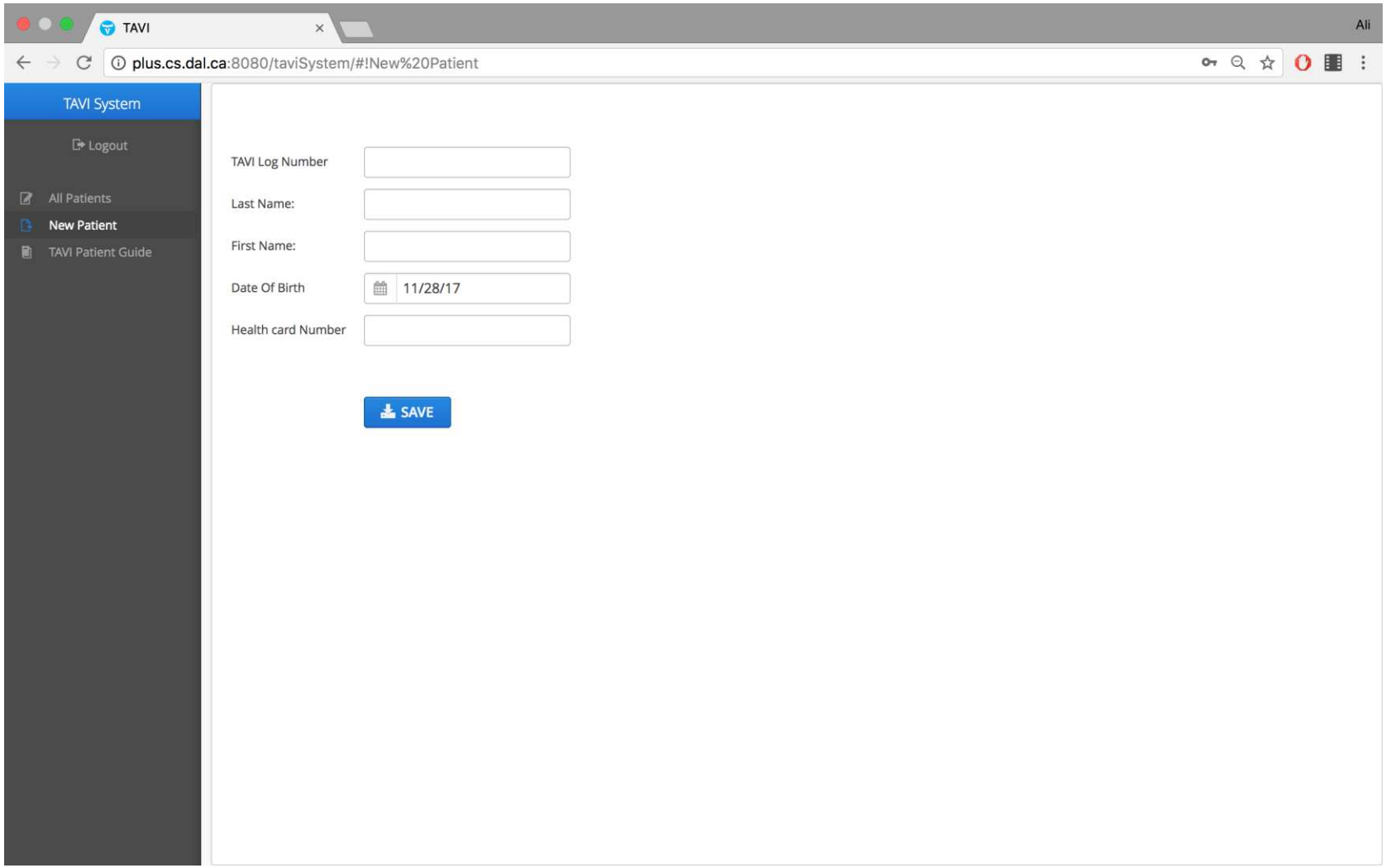
ELIGIBLE FOR RESEARCH STUDY

QEII hospital is a university teaching hospital. We will screen our patients for eligibility for potential research studies. One of our TAVI member will discuss with you further details if you are eligible for a research study. Please inform us if you are not interested in any research protocol.

APPENDIX E: TAVI SYSTEM (TAVI PATIENT ASSESSMENT)



APPENDIX F: TAVI SYSTEM (NEW TAVI PATIENT)



APPENDIX G: TAVI SYSTEM (TAVI PATIENT GUIDE)