

**User-Centred Requirements Analysis and Evidence-Informed
Design Solutions for a Chronic Disease Self-Management System**

By Maryam Ariaeinejad, B.Eng. MBA

**A thesis submitted in partial fulfilment of the requirements for the degree of
Master of Science in eHealth**

McMaster University © Copyright by Maryam Ariaeinejad, 2016

McMaster University MASTER OF SCIENCE (2016) Hamilton, Ontario

**Title: User-Centred Requirements Analysis and Evidence-Informed Design Solutions for
Chronic Disease Self-Management System**

Author: Maryam Ariaeinejad

Supervisor: Dr. Norm Archer

Committee Members: Dr. Rolf Sebaldt, Dr. Melina Head

External Committee Member: Dr. Ted Rapanos

Number of pages: 90

Abstract

Chronic diseases consume over 40% of the direct costs of healthcare in Canada. It is therefore imperative to limit or reduce this financial burden in order to maintain or improve the quality that Canadians expect from their healthcare system. One way to do this is to devise cost-effective ways to help patients manage their own chronic illnesses better in collaboration with their circles of care (caregivers, care providers, and others who help to care for patients). Providing online support that assists chronically ill patients has been shown to be effective in many scientific studies. Since there are many characteristics of chronic illnesses that are similar, high quality online support is adaptable to a variety of chronic illnesses (e.g. heart disease, diabetes, kidney disease, etc.). This study focuses on the design of an online self-care application MyPADMGT for one specific chronic disease, Peripheral Arterial Disease (PAD), which clinicians, patients with PAD, their informal caregivers, and allied healthcare professionals can use to support and improve patient self-care, potentially leading to better quality of life. Approximately half a million people in Canada suffer from PAD, so this approach to dealing with just this one debilitating chronic disease could give a boost to quality of life for a significant number of patients. This approach is generalizable to patient support for many other chronic illnesses. In this study, using the Persona-Scenario Method, PAD surgeons, patients and their informal caregivers were asked to create Personas and describe the Scenarios in which Personas would interact with the MyPADMGT online application. The results were used to identify patterns in user requirements and preferences, leading to the appropriate evidence-informed design solutions for MyPADMGT.

Dedication

This thesis is dedicated to my parents, who have supported me all the way since the beginning of my studies. It is also dedicated to my brothers, who have been a great source of motivation and inspiration.

Acknowledgements

Dr. Norm Archer has been the ideal thesis supervisor. His sage advice, insightful criticisms, and patient encouragement aided the writing of this thesis in innumerable ways. I would also like to thank Dr. Michael Stacey and Dr. Ted Rapanos whose steadfast support of this project was greatly needed and deeply appreciated.

Table of contents

1. Introduction.....	11
1.1. Chronic Disease Self-Management.....	12
1.2. What is Peripheral Arterial Disease (PAD)?.....	13
1.3. PAD Risk Factors	14
1.4. Health Self-Management Technologies.....	15
2. Study Objectives and Goals	17
2.1. Research Questions Addressed by the Study.....	17
2.2. Review of Existing MyPADMGT Prototype.....	17
2.2.1. Education about Disease Self-Management.....	19
2.2.2. Patient Self-Monitoring Features	19
2.2.3. MyPADMGT User Interface	20
3. Methodology	23
3.1. Personas and Scenarios	23
3.2. Step 1. Recruiting Participants.....	24
3.3. Step 2. Interviewing Process – Designing Personas and Scenarios	25
3.4. Step 3. Analyzing the Results	25
3.4.1. Baseline Demographics.....	26
3.4.2. Personas	27
3.5. Scenario Themes	31
3.5.1. Technology	32
3.5.2. Tool Characteristics	33
3.5.3. Knowledge	34
3.5.4. Willingness	34
3.5.5. Support.....	35

3.5.6. Barriers.....	35
3.6. Ethical Issues	36
4. Research Outcomes.....	37
4.1. Actions and Items	39
4.2. Self-Management Features	51
4.2.1. Illness Needs	52
4.2.2. Activating Resources	53
4.2.3. Living with a Chronic Illness.....	54
4.3. Adoption and Use Flowchart	55
4.4. Process Description.....	56
4.5. Structured Report Design.....	58
5. Discussion.....	60
5.1. Additional Study Findings	61
5.2. Advantages of MyPADMGT	62
5.3. Health Self-Management Barriers	63
5.4. Study Limitations.....	63
5.5. Future Studies	64
6. Conclusions.....	65
7. References.....	68
8. Appendices.....	75
8.1. Appendix A: Research Ethics Board (REB) Approval	75
8.2. Appendix B: Participants Recruitment Form – Patients and Informal Caregivers	76
8.3. Appendix C: Participants Recruitment Survey – Patients and Informal Caregivers.....	77
8.4. Appendix D: Persona-Scenario Session Consent Form	80
8.5. Appendix E: Persona-Scenario Discussion Guide – Clinicians.....	83
8.6. Appendix F: Persona-Scenario Discussion Guide – Patients.....	85

8.7. Appendix G: Persona-Scenario Discussion Guide – Informal Caregivers 87

8.8. Appendix H: Informal Feedback Discussion Questions – Clinicians 89

8.9. Appendix I: Informal Feedback Discussion Questions – Patients and Informal Caregivers 90

List of Figures

Figure 1. MyPADMGT Home Screen

Figure 2. MyPADMGT Blood Pressure Data Entry Screen

Figure 3. MyPADMGT Blood Pressure Chart Presentation

Figure 4. MyPADMGT Adoption and Use Flowchart

Figure 5. MyPADMGT Structured Report

List of Tables

Table 1. Patient Demographics

Table 2. Informal Caregiver Demographics

Table 3. Surgeons Demographics

Table 4. Surgeon Residents Demographics

Table 5. Online User Persona

Table 6. Booklet User Persona

Table 7. Online/Booklet User Persona

Table 8. Informal Caregiver Persona

Table 9. Senior Surgeon Persona

Table 10. Resident Surgeon Persona

Table 11. Scenario Categories and Themes

Table 12. Actions and Items

Table 13. Self-Management Supports and Categories

Table 14. Self-Management: Illness Needs Features

Table 15. Self-Management: Activating Resources Features

Table 16. Self-Management: Living with a Chronic Illness Features

1. Introduction

Chronic diseases are diseases which last for 3 months or more. They are not normally preventable by vaccines nor curable by medication, and some of them stay with the patient for a life time. More than 88 percent of US elders over 65 years of age have at least one chronic disease (as of 1998)[1]. The most common chronic disease risk factors are behavioral, such as tobacco or cigarette smoking, lack of physical activity and exercise, and health damaging diets. The most common chronic diseases in developed nations are arthritis (the leading cause of disability), cardiovascular disease (the leading cause of death), cancer (the second most common cause of death), diabetes, epilepsy and seizures, obesity, and oral health problems [1].

The number of deaths caused by chronic diseases is increasing every year, which makes mitigating the effects of chronic disease so essential worldwide [2]. Effective chronic disease management depends extensively on the patients themselves, so it would be highly suitable to provide patients with systems that support their efforts. A suitable system would educate patients about their diseases and enable them to collaborate with the other members of their circle of care [3], and help them to take responsibility for their own lifestyle management by helping to maintain their health with an appropriate level of exercise, eating a healthy diet, maintaining weight at a proper level, stopping smoking, limiting alcohol intake, and adhering to treatments prescribed by their physicians [4][2]. One barrier to patients managing their own chronic diseases is that they are out of contact with the healthcare system most of the time and thus are less motivated and able to acquire the education, skills and techniques from the healthcare system to be able to manage their diseases. They need continuing access to guidance to do this regularly and on their own time [2].

Although we expect that health self-management education for chronic disease should be effective, the results of different interventions show mixed effects. Some patients prefer self-management, and psycho-educational or psychological interventions seem to be helpful for different groups of people [5][6][7][8]. For example, changes observed from self-management of diabetic patient outcomes like fasting blood glucose levels have often been found to be small and improvements in both their glycosylated hemoglobin (HbA1c) and psychological variables were medium [6][7][9]. Positive changes in outcomes have been observed for systolic blood pressure in hypertension interventions [6][7][8][9]. Fewer positive effects have been observed for arthritis patients with disability, function, impairment, and pain conditions [5][6][9][10]. However, evaluation methods might not be reliable in assessing the real outcomes of chronic disease self-management because researchers normally rely on participant self-reporting. Because the outcomes are

reported by patients to be negligible to small, these evaluations may not be sufficient to assess the true impact of chronic disease self-management education [2].

As an example, more than 80 percent of cardiovascular diseases (CVD) are caused by unhealthy lifestyles and modifiable risk factors, which should be preventable or manageable by self-management programs [11]. Lifestyle intervention programs can change patient behaviours by tracking their physical activity, affecting their diets, reducing risky behaviours like smoking and alcohol intake, and using reminders for taking medications [12]. Prevention programs that focus on changing multiple risky behaviours have shown positive outcomes like decreasing mortality rates and cardiac events, which result in enhancements to patient quality of life [13][14]. Physical barriers to accomplishing these changes through specialist monitoring and management may include lack of transportation [15] over long distances that can reduce direct participation of cardiac patients in rehabilitation programs as much as 50% [16]. An additional barrier may be unaffordable costs to patients (e.g. cost of self-measurement of blood sugar).

Studies show that investment in home-based cardiac rehabilitation, e.g. remote monitoring, providing clinician/patient communication, and educating patients [17], can achieve positive outcomes [18][19] that are similar to direct client/patient interaction. Although the availability and mobility of technological interventions such as computers and smart phones enhances self-management possibilities; patients using these approaches are physically bound to these intervention tools [20].

The aging population and an attendant growth in the need to care for people with serious chronic illnesses has created a demand for online support systems that can assist older adults to self-manage their illnesses. This could play a role in relieving some of the load on the healthcare system. Determining user-centred requirements of older adults for such systems is different from usual requirements analysis because older adults have particular needs, depending upon their chronic illnesses, their ability to manage technology, their access to appropriate technologies, and their cognitive abilities. This thesis discusses in detail the use of the persona-scenario approach to elicit these needs from patients, informal care givers, and physicians. It proposes several suitable design solutions, depending on patient ability to deal with the proposed systems.

1.1. Chronic Disease Self-Management

Chronic disease self-management is defined as active participation of patients in their own care, by recognizing disease symptoms and managing their medical treatments in collaboration with their healthcare providers. This includes having the ability to monitor and help prevent the progression of their illness conditions, and being able to maintain their general health [21]. This is optimized through a coordinated

process among healthcare providers, allied professionals, patients and their caregivers to deal with related complications and barriers, ultimately enhancing clinical outcomes and patient quality of life [21].

Chronic diseases, such as cardiovascular disease, kidney disease, diabetes, etc. are prevalent, costly to treat, and major causes of disabilities and death in North America [22] and elsewhere. All serious chronic illnesses have long term invasive effects on patient lives [23]. Chronic disease self-management has been shown to be an effective strategy in health care [24][25][26]. It is a daily process of engaging the patients in managing their own illness [27], and it is “the ability of the individual, in conjunction with family, community, and healthcare professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions” [28]. Optimal results occur when patients are not only monitoring their illnesses, but they are able in this process to come up with new strategies by employing their own cognitive, behavioral, and emotional abilities [29]. For example, diabetic patients may learn how to manage their blood glucose levels effectively by careful management of diet and exercise without the constant need for daily or more frequent blood tests.

Based on Schulman-Green et al. (2012) health self-management can be divided into three categories: illness needs, activating resources, and living with a chronic illness [30]; each category consists of different processes, tasks and skills. The first category - illness needs - consists of (1) Learning, (2) Taking ownership of health needs, and (3) Performing health promotion activities. The second category - activating resources - consists of (1) Healthcare resources, (2) Psychological resources, (3) Spiritual resources, (4) Social resources, and (5) Community resources. The third category - living with a chronic illness - consists of (1) Processing emotions, (2) Adjusting, (3) Integrating the care of chronic illness into daily life, and (4) Meaning making. In this research, we design a system to assist patients to learn and/or make use of most of these skills to make health self-management as easy as possible. To illustrate the proposed approach to self-management of chronic illness, we will focus on Peripheral Arterial Disease, a serious chronic illness that is described below.

1.2. What is Peripheral Arterial Disease (PAD)?

Peripheral artery disease (PAD) is a condition of narrowing and occlusion of non-cerebral and non-coronary arteries distal to the arch of the aorta [31][32]. PAD has been found to be a strong independent predictor of cardiovascular mortality and all-cause mortality [33]. It is one of the most common chronic illnesses among people over 50 years old – age has a positive correlation with incidence and prevalence of PAD [32][34] – with an estimated worldwide prevalence of 10%, growing to 15-20% in people over 70 years old [35][36].

It affects men slightly more than women [31][32], and more than 27 million people in Europe and North America alone [37].

1.3. PAD Risk Factors

The most important risk factors associated with PAD are age, sex, cigarette smoking (current and former), diabetes mellitus, hypertension, hyperlipidemia, obesity (body-mass index BMI) lack of physical activity, and history of cardiovascular disease [38]. The strongest risk correlations are first with smoking and second with diabetes [39]. Other factors like chronic renal insufficiency, raised haematocrit, and high concentrations of homocysteine or plasma fibrinogen also seem to correlate with PAD occurrence [32].

By far the most important PAD risk factor is smoking [40]. Patients with PAD who smoke can greatly increase their risk for major interventions such as limb amputation [41]. Smoking can also increase the failure rate of surgical bypass grafts by a factor of three. Smoking cessation might help to reverse these negative effects [42].

The second most important PAD risk factor is diabetes mellitus. The odds of PAD incidence for patients with diabetes are twice as likely as for those without diabetes [40], potentially resulting in an increased need for amputation or acute cardiovascular events [43][39][44]. A correlated factor is the increasing level of glycated haemoglobin (HbA1c) in diabetic patients; the risk of developing PAD from a 1% increase in glycated haemoglobin (HbA1c) is associated with a 26% increase in the risk of developing PAD [45]).

The third most important PAD risk factors are hypertension and hyperlipidemia. Studies show that the degree of hypertension is linked to the severity of PAD, but it is possible to control the risk of cardiovascular mortality by controlling this risk factor [46]. Blood pressure over 160/95 mm Hg can increase the risk of intermittent claudication ¹by a factor of 2.5 in men and 4 in women, and a fasting cholesterol concentration over 7 mmol/L can double the risk of claudication [39]. There is also a weak association between PAD and hypercholesterolemia [34].

A 2014 study of 7058 people in the United States who were 40 years or older showed that PAD was mostly observed among elderly, non-Hispanic Blacks, and women [34]. This study also found that risk factors such as smoking, diabetes mellitus, chronic kidney disease, and hypertension tend to affect females and non-Hispanic Blacks more than others [34]. Based on this and other similar studies, chronic kidney disease

¹ A condition in which cramping pain in the leg is induced by exercise, typically caused by obstruction of the arteries.

(CKD) is also an important risk factor for PAD [39][47]. CKD has been known to increase the rates of morbidity, amputation and revascularization failure, and risk of cardiovascular mortality for PAD patients [48]. The above risk factors are modifiable to a certain extent by disease self-management activities that can decrease the risk of life threatening events and limit the progression of PAD conditions [40]. The most important factors to control are smoking cessation, treating diabetic conditions, managing hypercholesterolemia and hypertension, losing weight, and exercising regularly [32]. By concentrating on PAD traditional and novel risk factor reductions [49][50][51], using different PAD therapeutic interventions can decrease the risks of PAD related events, and improve the implementation of preventive measures for PAD patients [52]. Improving patient awareness of their diseases can enhance health self-management, leading to a better quality of life for patients with PAD [40][53]. Multiple studies have shown the importance of increasing awareness of PAD and its most important risk factors, helping to (1) decrease the severity of PAD; (2) decrease the rate of progression of PAD ; (3) improve the quality of life of patients with PAD, leading to lowering the prevalence and risks associated with PAD [34][54].

The effectiveness of PAD interventions can be measured by: (1) Adoption rate, (2) Knowledge increase, (3) Decreased smoking, (4) Mortality rate, (5) Quality of life. Our hope is to accomplish this by helping patients to adopt a less risky life style. To measure outcomes, we can measure: 1) the severity of PAD, using the Ankle Brachial Index (ABI) commonly used by physicians; 2) the reduction in rate of progression of PAD; and 3) the reduction in its prevalence through preventive measures.

1.4. Health Self-Management Technologies

Considering the growing cost of healthcare, health self-management technologies can play an important role in empowering patients to take a proactive role in managing their own health and decrease healthcare costs. Several studies have shown that there are a number of existing interventions that target patients with different chronic diseases to promote health self-management. Most of these interventions focus on patient education, guidelines and reminders for medications, symptom recognition and management, diet plans and monitoring, and instructions for emergencies when patients should contact their doctors [55][56].

The effectiveness of health self-management interventions involves multiple dimensions, including Reach, Efficacy, Adoption, Implementation and Maintenance; named the RE-AIM framework [57]. Reach is participation rate and representativeness of participants; Effectiveness is both primary outcomes and quality-of-life/ negative consequences; Adoption is participation rate and representativeness among settings and staff implementing a program; Implementation is consistency of program delivery; and Maintenance represents sustainability at both patient and setting levels. Previous estimates of interactive Internet

computer modalities ranked medium or high on all five dimensions. In a recent review of 71 published papers applying RE-AIM [57] 21 focused on disease self-management. We believe the long-term effectiveness and continuation of health self-management interventions depends upon acceptably high scores on all these dimensions [58].

Studies have shown that the rate of adoption of health self-management technologies by patients is typically low and the usability of the systems designed for this purpose is far from satisfactory. Based on previous studies, three factors can change the adoption rate: (1) suitability and relevance of the product, (2) perceived usability of the system, and (3) anticipated benefits resulting from system usage [59].

One of the reasons behind the low rate of adoption for health self-management technologies may be due to traditional information technology (IT) development approaches. These often ignore specific user needs and preferences, and design systems without personalizing them for the specific aging patient population. Considering the unique needs and abilities of users, and implementing these in the design, development, trial and adoption processes of products could result in higher rates of adoption and usage. In this study we tried to overcome barriers resulting from ignoring user needs and preferences by engaging users in the early stages of developing the MyPADMGT tool.

The design and development process we will use has four phases: (1) recognizing and analyzing older patient needs and limitations, (2) modelling and integrating their requirements and preferences, (3) making health self-management technologies accessible to users, and (4) evaluating the outcomes. Previous studies show that user-driven development methods which involve users in all the phases can have a better result in acceptance, usefulness, information quality and utilization [60].

We also should be aware that the perceptions of older adults being against technology and not willing to use it [61], are not really true. The real problem is that they are harder to convince that new technologies may be useful and beneficial, and they might also be afraid of failing in attempts to learn about it and use it [59].

2. Study Objectives and Goals

Our main goal is to use one of the user-centred design (UCD) methodologies – personas and scenarios, to design and develop our health self-management application for chronic diseases, and particularly PAD. The persona and scenario approach has been used in other health research, such as developing electronic patient records [62], a cancer public website [63], and a chronic heart failure monitoring device [64]. Our objective is to develop personas and scenarios for our elder user population to identify their healthcare needs and preferences; and inform user requirements, interface design and implementation decisions for an improved MyPADMGT system. (The MyPADMGT system has been in use in prototype form for two years. We will improve on the foundation provided by this prototype).

The other objective of this study is to address the gaps noted above through an innovative approach that provides cost effective self-management support to promote patient adoption and continuing participation. Basically, an effective self-management system should support patients in a manner that fits into the three categories proposed by Schulman-Green et al (2012) for patients who need to self-manage chronic illnesses: a) Illness Needs; b) Activating Resources; and c) Living with a Chronic Illness [30].

2.1. Research Questions Addressed by the Study

After developing the first prototype of MyPADMGT system and working closely with patients and health providers, we noticed their unique needs and preferences. To apply their unique needs, and design and develop a system which satisfies them to the best, we needed a method to answer these three questions:

1. What are the needs, preferences, and abilities of people with chronic illnesses and their informal caregivers, and can disease self-management meet these requirements?
2. What are the needs and preferences of healthcare providers who work with patients utilizing health self-management solutions?
3. What are appropriate design solutions to address the outcomes, satisfaction and sustainability of use among end-users?

2.2. Review of Existing MyPADMGT Prototype

Self-management of chronic illness refers to "the ability of the individual, in conjunction with family, community, and healthcare professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions" [28]. Furthermore, "optimal self-

management entails the ability to monitor the illness and to develop and use cognitive, behavioral, and emotional strategies to maintain a satisfactory quality of life" [29]. The online MyPADMGT self-management system was originally designed without the aid of outpatient involvement. It has been in use by PAD outpatients at a Toronto area hospital since Fall 2013 [65]. The study described in this thesis was undertaken in an attempt to find ways to increase outpatient adoption and acceptance of MyPADMGT and to improve patient outcomes. The original system uses an integrated approach that makes available a number of functions through separate modules that can be selected and adapted to the use of each specific patient. For example, patients needing to lose weight might track their weight on a daily basis either by using a regular bathroom scales and entering daily values online or through wireless tracking that automatically updates the online system. A target weight value is entered into the system at the beginning and daily weight measure is displayed in a graph that shows progress over time relative to the target value. A patient who does not have a weight problem would not necessarily choose to track this measure. The system caters to individual users, it is easy to learn, and simple to use, presenting useful and sometimes amusing information (e.g. a randomized "daily smile" that greets users every time they log in, thereby encouraging users to return regularly).

To enable patients to manage disease self-management, patients need to learn the characteristics of their chronic illnesses and they must be trained in the regular self-management tasks they need to perform on a regular basis between visits to their care providers. This requires an initial face-to-face introduction and training in the use of the system, using a simple teach-back system. On-line support of out-patients includes education about PAD and its future consequences through videos and other materials, and training in the use of the online system for monitoring and tracking blood pressure, heart rate, exercise, weight, and smoking cessation. However, some patients do not have the cognitive ability to remember their tasks or the necessity to perform them. For this reason, caregivers who are close to the patients (spouses, children, or close friends) can play a valuable role in assisting patients with regular self-management tasks. Caregivers can be included in training programs for patients, and they are able to assist patients by finding and displaying educational materials for patients, as well as recording monitor information on their behalf when it is appropriate to do so. Our findings from a national survey of patients with serious chronic illnesses were that approximately 50% of patients with serious chronic illnesses receive at least some help from caregivers. For patients without caregiver support, it may be possible to implement volunteer peer support programs to enhance social and emotional support in addition to assisting patients with daily self-management tasks and helping with contacts and bringing patients to clinical care [66].

2.2.1. Education about Disease Self-Management

The system provides online advice about:

- a) Maintaining a heart-healthy diet and eating well (users can access this information without logging in)
- b) Exercising
- c) Socializing online and in person with family and friends
- d) Weight loss
- e) Smoking cessation
- f) Blood pressure reduction
- g) Managing other specific disease such as diabetes, and other advice to be added over time.

In addition, it provides information about chronic disease(s), including long-term impacts and potential benefits from following a prescribed regimen for combating the disease(s) (in this particular case PAD and hypertension).

2.2.2. Patient Self-Monitoring Features

The system currently provides the capability to monitor, track, and display progress over time on exercise, weight, blood pressure, heart rate, smoking, pain, and other measures to be added if and when needed.

a) Exercise

Exercise Limitations in walking distance are important in assessing the severity of PAD and in monitoring progress. EACH-Q (Estimating Ambulation Capacity by History -- Questionnaire) is a brief validated self-administered four item questionnaire that estimates walking capacity in patients reporting vascular-type claudication [67]. Its resulting single value is stored (as are other measurements) on a secure central server.

b) Weight

Patients can monitor their weight regularly upon arising, using weigh scales that can display and transmit the results wirelessly by blue-tooth or Wi-Fi to local tablets or through Internet transmission to a remote central server.

c) Blood Pressure

Portable automatic home blood pressure cuff monitors are widely available and are normally provided to all participants for measuring and transmitting blood pressure readings, with indications of pre-hypertension

or hypertension > 120 mm Hg (systolic) and equivalently readings <80 mm Hg (diastolic) indicating pre-hypertension or hypotension.

d) Smoking

PAD's most critical lifestyle risk factor is smoking, which results in four times the likelihood of developing intermittent claudication as non-smoking. The best smoking rate is therefore zero per day, and a module is provide to assist patients who want to quit smoking.

e) Pain

Faces Rating Scale: Adults who have difficulty using the numbers on visual/numerical rating scales can be assessed with the use of six facial expressions suggesting various pain intensities. The patient chooses the face that most closely indicates the degree of pain being felt. The far left face indicates 'No hurt' and the far right face indicates 'Hurts worst'. The number recorded for monitoring and tracking purposes is the number of the face chosen.

f) Psychosocial Support

To combat possible social isolation and loneliness, patients will be encouraged to establish online links to family and friends, and others with common interests. This is especially important for patients living alone. System support provides patients with the ability to specify the e-mail addresses of family and friends who are interested in communicating with them regularly, while avoiding unwanted interactions from Internet spammers. Addresses retained by the system will allow patients to automatically link to other individuals by simply clicking on a name on the screen.

g) Communications

Since the system is designed with an e-mail interface, patients can contact their online coach or, in emergencies, their care provider. As well, they can contact their technical support person if they are having problems with the system.

2.2.3. MyPADMGT User Interface

The first page that a user sees after going to the portal link (<https://www.mypadmgt.com/>) is Figure 1. They have access to different educational material in the home page under Today's Health Articles Section, or they can log into the system as a patient or health provider to access other services. For example, one of the services is keeping track of their blood pressure and/or heart rate, where they can enter their blood pressure and/or heart rate in different days in the portal, as in Figure 2, and their data will be accessible to review

for themselves and their health providers in different formats like graphs, as in Figure 3. The health provider also has the option of setting goals for their patients' different measures.



Figure 1. MyPADMGT Home Screen

Patient Portal
PLUS FOR PERIPHERAL ARTERIAL DISEASE

Sign Out • Profile Settings • About Us • Contact Us • Home

WELCOME NORM ARCHER

MY TOOLS MY PHR DISCUSSIONS EDUCATION

Blood Pressure - Enter a Reading Enter a record View Charts View Readings

Please follow these instructions before taking a blood pressure reading.

- Wait 30 minutes after exercise, coffee, or tobacco.
- Empty your bladder.
- Sit upright quietly for 5 minutes.
- Take a reading on your upper arm, keeping your arm level with your heart.

Date: 2015-09-21

Time: 9 AM

Systolic: 120 Diastolic: 80

Optional

Pulse: Select

Reading Category: Left arm Right arm

Low stress Medium Stress High stress

Reading Note:

Submit Reset

Figure 2. MyPADMGT Blood Pressure Data Entry Screen



Figure 3. MyPADMGT Blood Pressure Chart Presentation

3. Methodology

Engaging all the different affected partners in the development process of a new or revised intervention system is necessary to achieve reliable results [68][69]. Different methods that can be used, and that we have considered in this study, to engage users like patients, caregivers, and physicians, include focus groups [68] and interviews [70]. Another method that has been used in the computer systems field to design human-centred interfaces, engages them in the process of development called a persona-scenario exercise. This has been proved to be adaptable to the healthcare sector [70][71][72]. Our goals in this research were first to understand our user (clinicians, patients and informal caregivers) and their preferences and needs; and second to determine the best way of providing a service to meet their needs and preferences optimally, considering their age and health. Considering our main goal of addressing user goals and preferences, the most appropriate method, among existing user-centred methods, is the Persona/Scenario method.

3.1. Personas and Scenarios

Personas are very popular for technology design [73]. They work by defining “hypothetical archetypes of actual users” [74]. Contrary to common market-wise segmentation that utilizes primarily demographic user information, the use of personas and scenarios is an ethnographic approach that focuses on users’ behavioral characteristics, animating them in the minds of designers, developers, and testers. Each persona involves a fictitious person who plays the role of a group of users who will potentially use the system. Personas introduce the goals, hopes, and behaviours of each simulated user group in detail, and what is to be achieved by the proposed new technology. These personas are then allowed to play their roles in user scenarios, resulting in use cases and hence test cases for the proposed intervention.

This approach can be used in the technology development process to engage stakeholders in developing a better understanding of different user groups with their distinctive characteristics, resulting in the design of a more suitable system [75]. Personas include a description of a hypothetical person that includes demographic information and the goals, hopes, and behaviours of the user in detail. What they would like to achieve through access to the proposed new technology, is through scenarios that describe how the technology would be used by this hypothetical person or persona. Personas and scenarios are particularly useful in a technology development process to gain a better understanding of different user groups with their distinctive characteristics, to design the system by engaging potential users [73][75].

Data were collected from six persona-scenario discussion sessions with thirteen participants (n=13) (4 clinicians, 8 patients, and 1 informal caregiver). This gave enough data to estimate the final outcomes of the exercise accurately enough to propose a design that is suitable for all the personas we settled upon. Our study process involved three main steps, as follows:

3.2. Step 1. Recruiting Participants

The first step in developing a persona is to determine the user groups who should participate in the interviews. For patients who have developed a specific disease such as PAD, with treatment being managed primarily by specialists, the groups most commonly involved in the outpatient support process include:

1. Surgeon Specialists (Senior Surgeons and Residents)
2. Outpatients
3. Family Members: Informal Caregivers
4. Family Physicians

In this study, we focused on the first three groups, which were most extensively involved in the self-management process, in order to limit the scope of the work. We anticipate that family physicians (the fourth group) and potentially other allied care providers will be brought into a more extended self-management process system design later.

The relevance to our process of each group of participants was:

- Vascular surgeons who work regularly with PAD outpatients and are very familiar with the needs of patients with PAD and comorbid illnesses
- Outpatients with PAD who were also potential users of a proposed upgrade to the existing prototype MyPADMGT disease self-management system
- Informal caregivers who could help PAD outpatients to perform self-management tasks

Outpatient recruiting was carried out through handouts given to outpatients attending regular vascular clinics, with information on how to contact the researchers if they were interested in volunteering for the study. The participants' recruitment form and survey for patients and informal caregivers can be found in Appendix B and Appendix C. We also interviewed a group of four senior vascular surgeons and residents together. The outpatients and informal caregivers were interviewed separately, either individually or in groups of two. All interviews took place at the Hamilton General Hospital and each interviewee received

40 dollars and parking expenses for their participation. The study was approved by the hospital's Research Ethics Board.

3.3. Step 2. Interviewing Process – Designing Personas and Scenarios

Prior to each interview, the interviewer explained the goal of the interview, that the interviewee would remain anonymous, and obtained permission for recording the interview. Each participant signed an informed consent form and received a signed copy, see Appendix D. Each interview lasted less than 2 hours. Each person received a tailored discussion guide, an introduction to the program components, and support from a facilitator who took notes (the recorded conversations were transcribed later). Persona-scenario discussion guides for clinicians, patients, and informal caregivers can be found in Appendix E, F, and G. In order to design the personas and scenarios, we conducted semi-structured interviews. The interviews consisted of two main parts: the first part, gathering demographic information by focusing on the interviewee characteristics, such as age, gender, education, etc. Patients were asked to think about and describe personas that represented their authentic needs. The second part focused on processes or “scenarios” of how they might deal with a system such as MyPADMGT, based on the persona that the individual or pair of participants had developed. Each participant or pair generated an experience of the self-management program by their persona through one or two scenarios that reflected their attitudes towards available information, measures, the possible frequency of usage, and how they might hear about the system and learn to use it. We needed to learn about the persona's skills, what online technology he/she might be familiar with, wishes and expectations, and finally, in which situations they would use the system. As the interviews were semi-structured, the interviewer was able to discuss any interesting topics that came up during the interviews. At the end of each session the patient or patient group had developed a persona and one or more scenarios. We have asked for their feedback at the end of each session and the informal feedback discussion questions for clinicians, patients, and informal caregivers can be found in Appendix H and I.

3.4. Step 3. Analyzing the Results

Summaries of the persona-scenario exercises were transcribed verbatim and coded for qualitative analysis. Based on themes found from the analysis, a system design was developed, including a design to-do list. From an overview of interviewee responses it became clear that there were three distinctive groups of users and that we should create three personas. The first persona reflected the perceptions of users and/or caregivers who were comfortable with online technology and would use the application on a regular basis.

These patients usually own a home computer or smart phone. The second persona introduced a group of users with/without caregivers who were not comfortable with technology and needed a different kind of tool. These patients usually do not own a computer at home or smart phone, or even if they do, they do not use them very much. Based on our discussions with the surgeons, we found that these patients usually like to have their information on paper. During our sessions with patients and informal caregivers, we brought up the idea of using a booklet, with pages that look very similar to our online version and gives them the ability to write the data on paper instead of going online, and they really liked the idea. The third persona introduced a group of participants very similar to the first persona, but with a difference in that they had limited access to the Internet, because of travelling and other restrictions, so they needed an offline tool. A fourth persona was developed to represent informal caregivers. We also generated two personas for surgeons and surgeon residents respectively to understand their distinct needs, preferences, and perspectives.

3.4.1. Baseline Demographics

All patients and informal caregivers who participated in the study were 45 years of age or over. All the patients had been diagnosed with Peripheral Arterial Disease (PAD). The relationship between the informal caregiver and the patient was spousal. The table 1 shows an overview of the patients who participated in the study:

Table 1. Patient Demographics

Characteristics	Information
Gender	5 male, 3 female
Age	45 – 77
Smoking status	2 smokers 4 former smokers 2 non-smokers
Duration of PAD	2 less than a year 3 between one to two years 2 three years 1 more than 5 years
Experience of medical intervention	6 yes 2 no
Existence of an informal caregiver at home	4 yes 4 no
Access to the Internet	4 yes 2 yes but not using 2 no

Table 2 is an overview of the informal caregiver’s demographics:

Table 2. Informal Caregiver Demographics

Characteristics	Information
Gender	Female
Age	Between 70 to 80
Smoking status of the patient	Former smoker
Duration of PAD for the patient	Less than a month
Experience of medical intervention for the patient	Yes
Informal caregiver relationship	Spousal
Access to the Internet	Yes

Table 3 and 4 are an overview of the surgeons' and surgeon residents' demographics:

Table 3. Surgeons Demographics

Characteristics	Information
Number	2 persons
Gender	Male
Age	~50
Years in Practice	25+

Table 4. Surgeon Resident Demographics

Characteristics	Information
Number	2 persons
Gender	Male
Age	~25
Years in Practice	5+

3.4.2. Personas

Patient personas that were derived are described in Tables 5 to 7, informal caregiver persona in Table 8, and surgeon personas in Tables 9 and 10.

Table 5. Online User Persona

Name	Anna	Short introduction:
Age	50	Anna is an active independent person, who is interested in learning more about her condition – walking difficulties and pain in his legs – and taking care of herself. She is also interested in participating because she believes it can help others as well. She can learn the application if somebody sits with her and teaches her how to use it
Education	High school	
Employment	Staying home mom	
Caregiver	2 daughters	
Smoking status	Former smoker	

Medical intervention	Yes	so he can use it on her own afterwards. She prefers the online version. She also can get some help from her daughters.
Duration of PAD	1 year	
Knowledge about the disease	<p>“I do not know the name of the disease... I did not know that I have this disease, and I do not know anything about it.”</p> <p>“If we have an online dependable service my daughter will use it a lot.”</p>	
Comfort with Technology	“I use computers and I go online I can use a smart phone version as well.”	

Table 6. Booklet User Persona

Name	Pit	Short introduction:
Age	76	Pit is an active independent person, who is interested in learning more about his condition – walking difficulties and pain in his legs – and taking care of himself. He is not comfortable with technology so he would prefer the booklet version. He can learn to fill in the tables himself if somebody sits with him and teaches him where to put stuff and he can use the booklet on his own afterwards.
Education	College	
Employment	Tool and die maker	
Caregiver	Spouse	
Smoking status	Former smoker	
Medical intervention	Yes	
Duration of PAD	3 year	
Knowledge about the disease	<p>“No I did not do research, I was just told what is happening. Some of the things that happened afterward were kind of supersizing for me.”</p> <p>“If there are available materials I would read, because I do not know what I should do with my other leg. I have a problem with that one too. That is why I like to learn.”</p>	
Comfort with Technology	“Not very good, I keep away from it. I do not get on the computers and I do not even have a phone. I should for emergencies but I don’t.”	

Table 7. Online/Booklet User Persona

Name	Fred	Short introduction:
Age	70	Fred is an active independent person, who is not very interested in learning more about his condition – walking difficulties and pain in his legs. He is comfortable with technology but he does not always have access to it, because of travelling. He needs to have the booklet for when he is away. He can learn to fill in the tables himself if
Education	College	
Employment	Mechanical technician	
Caregiver	None at home	

	(children are available to help)	somebody sits with him and teaches him where to put stuff and he can use it on his own afterwards, either online or the booklet version. It is very likely that he would stop using it after a while.
Smoking status	Former smoker	
Medical intervention	No	
Duration of PAD	1 year	
Knowledge about the disease	<p>“I look online for different issues.”</p> <p>“I learned along the way...they did not know what is happening to me and why at first...it was a lot of back and forth till they have found out.”</p>	
Comfort with Technology	“I was reading the newspaper on my phone right now, which means my smart phone is like a toy for me. I also use the computer at home.”	

Table 8. Informal Caregiver Persona

Name	Rose	Short introduction:
Age	77	Rose is an active social women who tries to take care of her husband to the best of her knowledge. If she knows she can do something to improve her husband’s health she will do it. Her husband is not as active as she is, and he has different problems like back pain that stop him from being active. She will easily learn to use the online version with a little help for the first steps, and she will probably try to use it regularly. They have a big family, so there is always someone else to help.
Education	High school	
Employment	Financial services	
Relationship to the patient	Spousal	
Patient’s smoking status	Former smoker	
Patient’s medical intervention	Yes	
Patient’s duration of PAD	1 month	
Knowledge about the disease	<p>“We look things up in the Internet. As I said we liked to know what it is, and have a general idea about what is going on.”</p> <p>“I am not aware of the disease impact, characteristics and treatments. But I need to go online and read a little about it.”</p>	
Comfort with Technology	“I use the Internet all the time and my husband has his own iPad. We both use the Internet. But my phone is just a regular phone because I am home all the time. I don’t text because by type of the phone I have it would take forever to text. We research on the computer, we use Skype and face time with family. So we are not uncomfortable with it.”	

Table 9. Senior Surgeon Persona

Name	John	Short introduction:
Age	50	<p>John is an experienced surgeon who is interested in research because he believes he can make a difference. He is involved in several studies and gives a lot of talks as a specialist in his field. After many years of experience, he is pretty comfortable in his job. He believes that there is no real cure for PAD and technology is just a new band aid, but he also believes it can be used for prevention which is the only successful trend in recent years.</p> <p>He is really interested in using the reports of the MyPADMGT system, which he believes will make his job much easier and provide patients with required information that they need. He will introduce it to the patients and follow up with them to ensure they use it correctly.</p> <p>He is also extremely busy and overwhelmed with the number of new technologies so it is hard to get his attention, so it is better to begin working with his residents.</p>
Education	MD, MSc, FRCS	
Employment	26 years in the hospital system	
Desires	Focused on clinical research and system level approach to patient care	
Attitude	Carefully optimistic – has lost his initial total optimism!	
Hopes and fears about the disease:	<p>“Very conservative after 15 years of seeing a lot of disasters with PAD”</p> <p>“More interested in prevention because it is the only successful trend in these years, rather than tackling the disease after it comes.”</p>	
Comfort with technology :	“Pretty comfortable with existing and new technology”	

Table 10. Resident Surgeon Persona

Name	David	Short introduction:
Age	25	<p>David is a surgeon resident who is interested in being not just a clinician or surgeon, but participating in different areas outside medicine, like technology and entrepreneurship. He is a hybrid version of John. He believes we should change from: “I have always done this in a certain way, and the new technology is intrusive and instructive, slow to learn and slow to teach”, which won’t help us, to: “It seems very inefficient to continue like this, and trying to do everything on my own while there are lots of new technologies out there, so why aren’t we using them?”. He is eager to expand the use of healthcare technology.</p>
Education	Bachelor, MD, second year of residency	
Employment	5 years in the hospital system	
Desires	Forming his approach and learning, more patient centred	

Attitude	More naïve and willing to experiment with new methods	He is easy to approach and introduce the MyPADMGT application and he can introduce it to his seniors later.
Hopes and fears about the disease:	“I do not have a full understanding of PAD, because I have not followed the patients long enough to fully understand the depth of complications that may happen, and the long term effects of PAD on patients’ lives”. “I am still on the hopeful side, by trusting the interventions and new technology to a higher degree, compared to senior surgeons”	
Comfort with technology :	“Pretty comfortable with existing and new technology”	

3.5. Scenario Themes

After reviewing all the scenarios, there were a few repeating patterns in many of them that resulted in themes that reflected the needs of the users. The results of the persona-scenario interviews were coded into 13 themes, which were in turn categorized into 6 categories. Table 11 displays the results from the analysis.

Table 11. Scenario Categories and Themes

Categories	Themes
1. Technology	1.1. Patient or informal caregiver comfort in using computer technology – prefer the online version of MyPADMGT
	1.2. Patient or informal caregiver comfort with smartphones – interest in mobile version of MyPADMGT
	1.3. Patient or informal caregiver discomfort in using technology – prefer the booklet version of MyPADMGT
2. Tool characteristics	2.1. How to introduce the tool
	2.2. Patient expectations
	2.3. Willingness (or not) to use the tool to chat with other patients
3. Knowledge	3.1. Lack of knowledge about the disease and self-management and willingness to learn more
4. Willingness	4.1. Patient willingness to improve their lifestyle
	4.2. Patient willingness to use the tool
5. Support	5.1. Social communication
	5.2. Existence of informal caregiver at home
6. Barriers	6.1. Comorbidity

In the detailed discussion in the following section, relevant quotations are represented by patients with “P”, informal caregivers with “I” and the session coordinator with “C”.

3.5.1. Technology

3.5.1.1. Patient or Informal Caregiver Comfort in Using the Technology – Prefer the Online Version of MyPADMGT

In the persona-scenario discussion, one of the questions we asked patients was their persona’s comfort and experience with technology. We have different themes resulting from answers to this question. One of the personas who preferred the online version of MyPADMGT, had access to a computer at home. This persona had been described to have a medium level of comfort and experience with a computer since the computer was used for simple tasks such as watching videos or reading news. Therefore, the persona would still need good training to use the online application. The online user persona represents a group of users – patients or informal caregivers, who will only be likely to use the online version of the application. This persona represents a group of users who are familiar and comfortable with technology, and prefers it over paper-based solutions. They have access to the Internet and use it regularly for different reasons.

3.5.1.2. Patient or Informal Caregiver Comfort with Smartphones – Interest in Mobile Version of MyPADMGT

One of the questions that we asked during the sessions was related to comfort with smart phones. Some users displayed no interest in using the online application on their phones. Most of them did not own a smart phone and one of them did not even own a regular phone. They claimed that they mostly use their phones for emergencies and they are not comfortable using them for texting or browsing the Internet. However, some said that they have smart phones and they might try the application on it.

3.5.1.3. Patient or Informal Caregiver Discomfort in Using the Technology – Prefer the Booklet Version of MyPADMGT

In the persona-scenario discussion, the third persona is not comfortable with technology, or may not have Internet access, or in some cases might not afford Internet access; and would prefer the paper-based version of MyPADMGT. This persona can be described as having a low level of comfort and experience with a computer since either they do not own a computer at home or they do not use it regularly and do not know much about it. Therefore, this persona will need the booklet

version of MyPADMGT along with extensive training in how to maintain a log of their activities and measures in the booklet. This persona would be most likely to opt for a booklet form of the application.

3.5.2. Tool Characteristics

3.5.2.1. How to Introduce the Tool

One of the questions asked during the persona-scenario discussions concerned how personas expected to learn about the tool. Most of them indicated that the persona would expect to hear about it from their doctor. Further, if the persona knew that the tool would help them and the healthcare providers to use it to improve their health, they would not reject it. Based on this discussion, it is fairly clear that promoting the use of the tool would need to be initiated by the doctors. The tool would also need to be endorsed by clinic nurses by giving patients enough information about how to use it and to continue with follow-up with patients to help them with any problems.

3.5.2.2. Patient Expectations

During the persona-scenario sessions, our findings showed that patients like to be educated about their disease and related symptoms in simple words. They also like to know if their involvement in a study like this will be helpful for them as well as to others. They also want to get sufficient training about how to use the tool, which should be as simple as possible and should not take much of their time. If they were to use the booklet format, they would prefer a pocket size booklet which they can take everywhere they go. Online users would like to see their data in a simple graph so they can easily see how they are progressing. Booklet users would like to have a report summary with graphs so they could observe their performance easily.

3.5.2.3. Willingness (or Not) to Use the Tool to Chat with Other Patients

One class of patients interviewed were reluctant to talk to other people online, and they had different reasons for this:

- First, they do not know who is going to be on the other side of the conversation
- Second, it would make them feel worse if the other person they are talking to is experiencing a worse situation
- Third, they have enough people around and they simply do not feel the need to talk to other people they do not know online.

The other class of people were more willing to talk to other people, but some were not comfortable using the online version and some said that they would prefer to read their comments online and comment on them instead of just talking to one person (similar to a chat line).

3.5.3. Knowledge

3.5.3.1. Lack of knowledge about the disease and self-management, and willingness to learn more

During our persona-scenario discussion, we asked patients and the informal caregiver different questions about the disease, its characteristics, symptoms, and possible future impacts of it on their health, in order to find out about their level of knowledge about the disease. We learned that most had a very limited knowledge of their situations. The apparent reasons for this lack of knowledge were:

- They had been recently diagnosed and they did not have enough time to learn about their condition.
- They may have searched the Internet a little bit but they were not aware of the right words to search.
- They also feel that doctors were too busy to give them enough information about their disease.
- Almost all the patients that we interviewed, believed that they did not know enough about their condition, but they were very interested in learning more.
- One factor that deters patients from searching the Internet to learn more about their disease was that they were not certain they could trust everything that they find online and they preferred to have a trusted source of information.

3.5.4. Willingness

3.5.4.1. Patient Willingness to Improve Their Lifestyle

We asked questions about patient diets, smoking and exercise habits, to determine if they were willing to change to a healthier lifestyle. Most showed a great willingness to do better, especially with their diets. Most of the diabetic patients were following diabetic diet guidelines. For smoking and exercising, although they showed an interest in improving their lifestyles, it was not clear whether they had a real interest in changing. To quit smoking, they would need to register for a smoking cessation program which would help them in the process. Walking programs are designed to help overcome the claudication pain that would result from exercising; most PAD patients experience difficulty walking because of this characteristic of PAD.

3.5.4.2. Patient Willingness to Use the Tool

Most patients showed a great interest in using the MyPADMGT tool since they felt it would help them or others if they did so. In particular, they mentioned that the time needed to monitor their health and record the information was no problem. Their willingness to learn more about their

conditions was one of the motivations behind their interest in this tool. They also mentioned that the record that the tool would create over time would be very useful for both themselves and their doctors.

3.5.5. Support

3.5.5.1. Social Communication

We asked questions about the social activities of patients in order to find out about their level of social communication. We found out about different patterns of social activity:

- Big family group: these have big families; are mostly engaged in their family activities, and with their friends from time to time.
- Small family group: this group has small families - usually only their spouses, and a few children or friends who visit them time to time.
- Group living alone: this group usually lives alone and they have a few friends or children who visit them from time to time.

Two often repeated sentences were “most of my friends passed away” or “I cannot walk enough to be able to go out and socialize”. These appear to be two of the biggest barriers of social communications in this age group.

3.5.5.2. Existence of Informal Caregiver at Home

We were interested whether informal caregivers played a major role in supporting patients. Two repeated patterns were:

- They live with their spouses
- They live alone and their children visit them from time to time.

3.5.6. Barriers

3.5.6.1. Comorbidities

During the discussions, we found that most patients had other problems in addition to PAD. These included diabetes, hypertension and heart disease. Most of the patients were taking different medications for these diseases. Diabetic patients, although taking relevant medications, tended not to focus on regular blood sugar measurement if they could avoid it, because of the cost.

3.5.6.2. Barriers to Self-management

Some of the most frequently mentioned barriers were:

- Patients had trouble walking so it was difficult to get the amount of exercise they need

- It is hard to keep doing the things they need to do to combat their disease. Although they may start out with good intentions, it is hard for them to keep it up and they lose interest in self-managing their disease after a while.
- Other problems such as Alzheimer's were also mentioned by patients

3.6. Ethical Issues

A detailed Research Ethics Board Amendment application was submitted to the Hamilton Integrated Research Ethics Board (HiREB) with all the supporting documents for ethics review and approval. The application received a Full Research Ethics Board level of review and the amendment was approved as submitted. A copy of the HiREB letter can be found in Appendix A.

In the persona-scenario discussion sessions, consent forms were reviewed and signed by all participants. A copy of the consent form can be found in Appendix D. Copies of the signed forms were provided to all participants. Parking expenses were reimbursed and participants were compensated by \$40 CDN for their participation.

Discussion transcripts were all anonymized by using randomly assigned numbers to all participants and session coordinators. All participant personal information was kept confidential and only known by two session coordinators. All the data has been stored in a password-protected personal computer.

4. Research Outcomes

We used the scenarios designed by patients and informal caregivers to find the themes in their behaviour and their preference patterns. The scenarios designed by surgeons and surgeon residents were used to design the process of work and the requirements by health providers. We designed a structured report (Figure 5) with all the data needed by the surgeons. The sessions with surgeons also helped to structure our discussions with patients.

Following the detailed system design process our research outcomes included: a) a multi-faceted health self-management system, based on the existing online prototype of MyPADMGT, upgraded through the results of the persona-scenario studies; b) a comparison of the results from the categories of persona-scenarios, in terms of their contribution to design quality; and ultimately we hope to gather c) measures of success in end-user engagement and satisfaction, from participant feedback questionnaires when the redesigned system is in use.

Three solutions can be used to either extend or replicate online self-management support systems.

- a) The first is the use of cellphones or smartphones [24] to directly monitor and record personal data through reminders and automatic devices such as weigh scales, heart monitors, cameras, etc. Methods from this category can significantly improve the usability and effectiveness of a health self-management system through portability and automation of monitored measures. While this is the most effective approach to educate patients and to help them to monitor their activities, online systems such as this are preferred by less than 40% of older adults, based on our experience with the prototype system. The causes for this is that many older adults lack technological experience, or they may not have Internet access or they may not be able to afford it.
- b) The second method uses Interactive Voice Response (IVR) telephone systems to provide services in support of patient health self-management. However, findings have been consistent that people in general and particularly older people dislike IVR systems because of difficulties completing communication tasks with these systems [25]. These difficulties are in turn related to the impact of poor auditory and working memory that create unnecessary difficulties for older people.
- c) The third method is the use of simplified paper-based logs designed specifically so patients can record important lifestyle data and vital signs weekly or more frequently over a period of time in a format similar to that used for the equivalent online system described in a) above. These data can then be uploaded to the same central online system at regular periods (e.g. during appointments

with physicians) with readers equipped with Optical Character Recognition (OCR) or Optical Mark Recognition (OMR) software. The online data records that resulted would then be similar to records obtained through direct online recording by patients. The advantages of such a system have not been demonstrated in a real application to our knowledge, with most OCR applications being used for professional medical record conversion from paper to digital [26]. We believe that an OCR or OMR system for paper-based patient records for patients unable to work with online data entry is a potential solution for patients with serious chronic illnesses; it has the advantage that it integrates well with a fully online system that can also be used directly by other patients who are able to access the online Internet. It can operate at minimal cost, providing patient status and details online to physicians regularly.

4.1. Actions and Items

All the design categories, their respective themes, their supportive quotations extracted from the persona-scenario sessions, and the identified actions and items for each theme have been gathered in Table 12. The required activities to execute ideas called actions and the required elements to carry out those actions are called items [76]. The actions and items developed in this study will be used as the basis for developing a design solution for MyPADMGT.

Table 12. Actions and Items

Quote	Themes	Action	Item
Category 1: Technology			
<p>P 1: “I have the time to stop and put a little note down. I am comfortable with both. But if I put it on the paper I have to come back here to see you again, but online is easier.”</p> <p>P 1: “I have got five computers at home. I do not own a TV and I watch everything on the Internet. 10 to 12 hours, I do not work.”</p> <p>C: “How comfortable you are with technology (smart phones and computers)?”</p> <p>P 2: “I was reading the newspaper in my phone right now, which means my smart phone is like a toy for me. I also use the computer at home.”</p> <p>P 3: “I am the same.”</p> <p>C: “Do you go online?”</p> <p>P 7: “Yes”</p> <p>C: “Are you comfortable with technology? Computers smart phones iPad?”</p> <p>P 7: “Yes, I use them regularly.”</p> <p>C: “Do you prefer the online version?”</p> <p>P 7: “Yes.”</p>	<p>1.1. Patient or informal caregivers comfort in using the technology – prefer the online version of MyPADMGT</p>	<p>Ensure that the patient or informal caregiver is able to use the online application</p> <p>Train coordinators to sit with the patients and their informal caregivers and teach them step by step how to use the system</p>	<p>1. Adding educational content in the web-based portal – documents to read and videos to watch</p> <p>2. Connect patients to other programs like exercise or smoking cessation programs</p>

<p>I: “I use the internet all the time and my husband – the patient – has his own iPad. We both use internet...we research on the computer, we use skype and face time with family. So we are not uncomfortable with it.”</p> <p>I: “My husband – the patient – looked things up online. As I said we liked to know what is going on, and have a general idea about the disease.”</p> <p>I: “I prefer online, since it is so hard to get an appointment and get down there.”</p>			
<p>P 1: “Smart phones, I know nothing about them.”</p> <p>P 4: “...and I do not even have a phone. I should for emergencies but I don’t.”</p> <p>P 5: “I got my phone in case of emergencies.”</p> <p>C: “Do you a smart phone?”</p> <p>P 6: “I do not have a smart phone, I have an iPad.”</p> <p>C: “Are you comfortable using the app on your iPad?”</p> <p>P 6: “I might be. I need to try it.”</p> <p>C: “Are you comfortable with smart phones?”</p> <p>P 7: “Yes, I can use the smart phone version as well.”</p> <p>P 8: “I have a regular cellphone...I do not go online.”</p> <p>I: “...my phone is just a regular phone because I am home all the time. I don’t text because by type of the phone I have it would take forever to text...”</p>	<p>1.2. Patient or informal caregiver comfort/discomfort with smartphones – interest in mobile version of MyPADMGT</p>	<p>Keep the smart phone features as an extra option and not mandatory</p> <p>Ensure that patients and informal caregivers are aware of the extra features and know how to use it</p>	<ol style="list-style-type: none"> 1. An instruction brochure and video to educate them about the extra features 2. Adding some features like reminder text messages which is not depended on smart phones and are possible with any regular phone 3. Call patients for follow-ups (for different programs)
<p>C: “how is your experience with technology?”</p> <p>P 4: “Not very good, I keep away from it. I do not get on the computers.”</p> <p>P 5: “I have cellphone and computer, but I am not very good at it. I know how to turn my computer on and off...sometimes I pick up something that I did not know before. I am not really high tech.”</p> <p>P 4: “I have the opportunity to do online but I just do not like to go online, I feel like I am wasting my time on it.”</p>	<p>1.3. Patients or informal caregivers discomfort in using the technology – prefer the booklet version of MyPADMGT</p>	<p>Keep the book simple and small</p> <p>Ensure that patients and informal caregivers know where to put the numbers</p>	<ol style="list-style-type: none"> 1. Small pocket-size booklet with pages similar to the online app 2. Educational pages among the booklet fillable templates 3.

<p>P 6: "I do not go online much. I just play games and watch some videos... I prefer the booklet...I can write down the information."</p> <p>C: "Do you have anybody who helps you to put the data into the system, or you would go to the hospital to give it to the nurse?"</p> <p>P 6: "I would probably go to the hospital to put it into the system."</p> <p>C: "Are you comfortable with technology?"</p> <p>P 7: "No, I do not use computers and I have a regular cellphone. I do not go online."</p> <p>P 8: "I do not know anything about computers and I cannot afford it...I want the booklet."</p>			
Category 2: Tool characteristics			
<p>P 1: "If the doctor says I need to use it, I will"</p> <p>P 1: "It is probably better if a doctor or a nurse tell me verbal, because you cannot trust everything you find online."</p> <p>P 2: "I think you need to teach me whatever I need to do, where I should put the numbers."</p> <p>P 3: "I will come to the clinic to get some basic help to get me started."</p> <p>P 6: "Whatever they tell me I have to do I would do."</p>	<p>2.1. How to introduce the tool</p>	<p>The doctor needs to emphasize the importance of the system for patients and healthcare providers in the circle of care</p> <p>A person to sit with patients and ensure that they understand the importance and how to use it – web-based, paper-based, or both</p>	<ol style="list-style-type: none"> 1. Instruction package for patients to take home for review 2. Instruction videos to facilitate training – also available at home to watch again 3. Mechanism to teach the trainers and enable them to educate the patients and their informal caregivers
<p>P 1: "Just be honest with people. Describe the problem and how you will fix it. You do not need to use medical terms...we are not silly people out there."</p> <p>P 1: "I would like to help other people and myself as well"</p>		<p>They need detailed instruction, like how many times, when,</p>	<ol style="list-style-type: none"> 1. Design a small simple booklet

<p>C: "Do you think having a summary your appointment will help you to follow that for next session?"</p> <p>P 1: "Yes, that would be nice."</p> <p>P 3: "What is the minimum frequency?"</p> <p>P 3: "Is there any particular day suggested to do this?"</p> <p>C: "And you also can see all of it summarized in a graph."</p> <p>P 3: "Yeah that is pretty neat."</p> <p>P 3: "Keep the booklets really simple and not many categories."</p> <p>P 2: "Pocket booklets are the bests"</p> <p>P 4: "It depends on how many questions I need to answer and how much time it takes."</p>	<p>2.2. Patient expectations</p>	<p>what kind of data to put in</p> <p>They expect it to be simple and easy so it does not take much time</p> <p>They would like to have it all in a small booklet</p>	<p>2. Design detailed instructions</p>
<p>P 1: "I think talking with other people would be awkward and it does not interest me... Who is going to sit there?!"</p> <p>C: "Do you like to the other patients online, who have the same problems as you?"</p> <p>P 2: "No"</p> <p>P3: "No"</p> <p>P 4: "No and I am not sure if I am interested. Because sometimes it makes you feel worse when they have worse problems than you."</p> <p>P 6: "I probably would. I do not know if I do it regularly."</p> <p>P 7: "I would read what they say and I would put my comments down."</p> <p>P 8: "I would like that, then they can tell me about them and I can tell them about me." But she does not have a computer or smart cellphone.</p> <p>C: "If the application give you the opportunity to talk to other people online, do you think you would use it?"</p> <p>I: "No not at the moment, maybe down the road but not now."</p>	<p>2.3. Willingness (or not) to use the tool to chat with other patients</p>	<p>Keep the chatting option instead of one to one, putting posts and comments, so everybody is able to read and put their ideas down</p>	<p>1. Design a timeline so they can write on it and comment on each other, keep one to one chatting as an option</p>
<p>Category 3: Knowledge</p>			

<p>P 1: "I just got diagnosed recently in a month and I did not have a time to think about managing the disease"</p> <p>P 1: "I did search a little bit. I have brought up a picture that shows what it (the disease) does and what doctors do"</p> <p>P 1: "Nobody really says what it (the disease) is. It is cut and dry. Here is what to be expected and what not to be expected."</p> <p>P 1: "Not enough information. They just give you enough to get you by. It could be a little more intensive and boring"</p> <p>C: "Do you what have caused this disease?"</p> <p>P 1: "I do not know"</p> <p>C: "Did your doctor tell you the amount of exercise that you should have?"</p> <p>P 1: "No, I will see him for my second follow-up after my surgery to talk about it."</p> <p>C: "Did they give you information about your disease and what is happening inside your body and what should you do to take care of yourself?"</p> <p>P 3: "They gave you the pills! I looked online for some other issues."</p> <p>C: "Do you know how does the disease impact your health in future?"</p> <p>P 3: "I do not know what could be the damage and fertility. I was shocked when one of the doctor said that they might need to amputate my leg if I don't look after myself. I think he was a little severe about that, but he must have a reason to say that!"</p> <p>P 4: "No I did not do a research, I was just told what is happening. Some of the things that happened afterward was kind of supersizing for me. I did not expect my legs to be numb after the operation, it still is after 10 months."</p> <p>C: "How much do you about arterial disease?"</p> <p>P 4: "No much."</p> <p>C: "Did you ask somebody else? Searching or reading somewhere to know more?"</p> <p>P 5: "No. You pick it up as you go along. My doctor only said I might have some blood circulation problem."</p>	<p>3.1. Lack of knowledge about the disease and self-management but willingness to learn more</p>	<p>Gather all the related information to the disease in simple words and easy to access for everyone; in future we can add different diseases</p>	<p>1. Make a knowledge base part of the portal and put all the related information there, in a simple and easy structure for patients to find and read</p>
--	---	---	--

<p>C: "So do you know the steps and how this disease is going to grow?"</p> <p>P 4: "Not really"</p> <p>C: "Did they give you enough information? Or did you do some research yourself?"</p> <p>P 6: "No. I have very little knowledge about what they were doing...I just know that I have some problem with my leg. It was very awkward the first time that the doctor came in and told me that we are going to do this and that and he left. Maybe this time that I go in he explains more about what is going on."</p> <p>P 6: "I did not know that I have a disease, all I know is that I have a green filter. I never heard about it (PAD). I only saw the doctor for 5 minutes that one time I went in. I did not even see the doctor in my operation, because the interns did it. I am in the dark and I do not know anything."</p> <p>C: "Have you searched about your diseases?"</p> <p>P 7: "Not anymore. My daughters have done that, and all they have found more problems and that made me worried so we decided not to do that anymore and we will wait for doctors to tell us. Because everything we have found was leading to some kind of cancer so we just avoid it all."</p> <p>C: "Do you know the name of your disease? The impacts and others..."</p> <p>P 7: "No, I do not know the name. I did not know that I have this disease (PAD), and I do not know anything about it."</p> <p>P 8: "I do not know the name of the disease. I do not know anything like that, I just know that I have a blocked artery. No one said anything or they said and I do not remember." She continued asking about what is the disease...</p> <p>C: "Have you ever searched about the disease to see what is going on?"</p> <p>I: "...as I said I was not aware of the fact that what was going on, otherwise I would have. So what I should look for online?"</p> <p>I: "...I am not aware of the disease impact, characteristics and treatments."</p> <p>I: "The blood pressure machine takes the heart rate as well. But I do not know how much it should be..."</p>			
Category 4: Willingness			

<p>P 1: "I have changed my diet because I am diabetic, and I watch what I eat as well as I can"</p> <p>P 1: "Yes, I am trying to quit smoking"</p> <p>P 3: "...I have changed my diet afterwards to have fish, turkey, chicken and salad and rarely red meet anymore."</p> <p>P 3: "I know in my heart, if I don't keep active, I might age quicker and that effects my body in every aspect."</p> <p>P 6: "I go to weight club so I monitor what I eat, and I have lost 40 pounds. And I feel better because I lost the weight."</p> <p>P 6: "...I am not just sitting around doing nothing but I cannot walk for 4 hours...I was in a program to do 6 minutes' walks, I can do it sometimes and sometimes I cannot."</p> <p>C: "How willing are you to change to a healthy life-style?"</p> <p>P 6: "I would try."</p> <p>P 7: "I quitted 1 month and half ago. I did not have cravings afterwards."</p> <p>C: "Do you like to have an exercising program?"</p> <p>P 7: "I go to YWCA for exercise, and I really enjoyed doing it. And when I get better I will do it again."</p> <p>P 8: "I do like to know more. Can you send me papers about it?" She continued asking about what is the disease...</p> <p>P 8: "I do like to do exercise at home if I know what to do."</p> <p>I: "...He walks as much as he can, and we try to do as much as we can."</p>	<p>4.1. Patient willingness to improve their lifestyles</p>	<p>Most of the patients are willing to improve their life style, but they need help and instructions; also follow-up to ensure they are doing well</p>	<p>1. Connect patients to essential programs like walking or smoking cessation program so they can give them the plans and follow-up with them</p>
<p>P 1: "I am comfortable to put any kind of information which is helpful, to me and other people."</p> <p>C: "Would you put time to watch the videos and read stuff related to your disease online?"</p> <p>P 1: "Yes, I am retired, I got nothing to do"</p>	<p>4.2. Patient willingness to use the tool</p>	<p>Most patients are very interested in using the tool; to keep them interested</p>	<p>1. We need to follow-up with them after they have started using the system, after a short time, we</p>

<p>C: "Would you put the time at night to write the information?"</p> <p>P 1: "Sure, I do"</p> <p>C: "If we introduce you to an online application which helps you to manage your disease, would you go online to use it?"</p> <p>P 2: "Yes"</p> <p>P 3: "Yes"</p> <p>P 3: "It is kind of interesting to see the results for aging reason since you are not getting younger."</p> <p>P 2: "I found the information interesting. I would never refuse this program!"</p> <p>P 3: "I think it is a very good idea. If you want to stay healthy and you have issues, it is a very good record for yourself, never mind the doctor. It encourages you to keep track of things. That has a positive effect probably. And you have to train yourself to do it."</p> <p>C: "So if you have material available that you can read about it and knowing what is going on, would that be helpful for you?"</p> <p>P 4: "Probably yeah. I would read, because I do not know what I should do with my other leg. I have a problem with that one too. That is why I like to learn."</p> <p>C: "Do you think you will write down your walking or diet to the booklet?"</p> <p>P 5: "I think I can do that."</p> <p>P 4: "It is not a problem"</p> <p>C: "Do you think you would take the booklet with you on travel?"</p> <p>P 4: "I would, there are lots of time in the airplane."</p> <p>P 6: "Whatever they tell me I have to do I would do."</p> <p>P 7: "If we have an online dependable source my daughter will use it a lot."</p> <p>P 7: "I like to have my numbers...I check my blood sugar 3 times a day...I can write down my meals everyday as well."</p>		<p>we need to ensure we meet their needs</p>	<p>need to ensure they are using the tool correctly and hear their suggestions and complains</p>
---	--	--	--

<p>P 8: “Where can I get the booklet? I want the booklet.” She continued asking about what is the disease...</p> <p>I: “It would be good to understand what is going on. It is not unusual for me to get online and search something out, because you feel better when you know what you are dealing with.”</p> <p>I: “...I need to go online and read a little bit about it...”</p> <p>C: “Do you think you might be interested in a diet diary?”</p> <p>I: “I might.”</p> <p>C: “How about writing down the information about the walking?”</p> <p>I: “I might”</p> <p>C: “How regular do you think you will put the information?”</p> <p>I: “Maybe three times a week, or once a week.”</p> <p>C: “How about weight?”</p> <p>I: “Yes, I can write that as well.”</p> <p>C: “How about blood pressure?”</p> <p>I: “We have our own blood pressure machine at home and we can do it on daily basis or whenever it should be done.”</p> <p>C: “How about blood sugar?”</p> <p>I: “He check it but not every day, sporadically here and there.”</p> <p>C: “How about heart rate?”</p> <p>I: “The blood pressure machine takes the heart rate as well.”</p> <p>I: “Yes, I will use it and I think they – other physicians – should have access and these information should be shared.”</p>			
Category 5: Support			

<p>P 1: “I have brought up a picture in the Internet that shows what it does and what doctors do, and I have put that on the Facebook so people know what I am going through, and I have put some scar pictures out”</p> <p>P 1: “No, I do not deal with anybody...I had a couple of bodies who passed away. I moved out of the city and I have changed my life style, I do not like coming to the city anymore and I have not get involved with people and places”</p> <p>P 5: “I go out with my lady friend and we talk to other people and friends.”</p> <p>P 6: “I have 2 kids and 6 grand kids, and 2 sisters and my husband has two brothers. I have a few friends and we see each other for having brunch, swimming, and going to pub.”</p> <p>P 7: “I have a couple of friends I see them every few days.”</p> <p>P 8: “...in the winter it is hard to go out. I have a best friend she is 81 years old.”</p> <p>I: “Most of his friends passed away. And because of the situation he has, it is hard for him to get out and socialize. But we are a big family so there is not much time to socialize.”</p>	<p>5.1. Social communication</p>	<p>Most of the patients have a circle of people with whom they communicate, but for those who do not, we can organize a support group program and connect them to each other</p>	<p>1. Set up a support group program and let patients join it online and talk; help them to get together and share their stories</p>
<p>C: “So if something happens your daughter is around to help you?”</p> <p>P 1: “Yes”</p> <p>P 2: “my son and daughter”</p> <p>P 5: “I go out with my lady friend and we talk to other people and friends”</p> <p>P 6: “I live with my husband”</p> <p>P 7: “I live with my daughters”</p> <p>P 8: “I live alone”</p> <p>I: “Yes, I (the wife) will do it – using the tool...”</p>	<p>5.2. Existence of informal caregiver at home</p>	<p>Most have some kind of help at home</p>	<p>1. Teach their informal caregiver as well, involve them in their care process, and give access to the caregiver with patient’s consent</p>
<p>Category 6: Barriers</p>			
<p>P 1: “I have been diagnosed with diabetes for 8 – 10 years and I am taking medication for that”</p> <p>C: “How long is it you have diabetes?”</p>	<p>6.1. Comorbidities</p>	<p>Most patients have different diseases and they usually have different medication</p>	<p>1. Adding a medication reminder to the tool</p>

<p>P 1: "At least 10 years, that's why I am on diet."</p> <p>P 2: "I had angiogram...I have statins and I take Lipitor, the highest dosage 70% and I have to take it the rest of my life."</p> <p>P 2: "I have blood pressure and diabetes and I am taking medication for it."</p> <p>P 3: "I had a benign brain tumor...and I had a bypass a year ago on my heart."</p> <p>P 4: "I have some problems besides the vain problem, I have arthritis in the knees."</p> <p>P 5: "I also have sciatic nerves problems since the accident."</p> <p>P 4: "I am taking medicine for high blood pressure and cholesterol."</p> <p>P 5: "I take medicine for my diabetes, and I have to watch my blood pressure so I take medicine for that one as well."</p> <p>P 6: "I have asthma and two inhalers for that matter. I have PMR (Polymyalgia rheumatic) and I take medication for that as well. I have high blood pressure and cholesterol and I take medication for them."</p> <p>P 7: "I have diabetes and I take insulin for that, cholesterol and high blood pressure pill, I take the pill to heal my kidneys because my diabetes hurt my kidneys. I also have anxiety and panic attacks, and I take medications for that as well. I take almost 10 pills now."</p> <p>P 8: "I have angina, I am taking medication for high blood pressure and cholesterol."</p> <p>I: "He – the patient – had his back surgery...one time he had a heart attack..."</p> <p>I: "He – the patient – had diabetes at one time...he takes cholesterol pills...he is on pill for his kidney function and they cut it in half since it effects his blood pressure..."</p>		<p>for each of them which makes it harder to manage, and we need to ensure they take all their medication on time.</p>	
<p>P 1: "Well. Because I couldn't walk any distance, so I could not have any kind of exercise"</p> <p>C: "Do you think if your wife knows more about your disease would it help?"</p> <p>P 1: "she understands my diabetes, she tries to not bring sweets and junk foods around me, but that is the way she is"</p> <p>P 2: "I have problems to walk"</p>	<p>6.2. Barriers for self-management</p>	<p>Most of the barriers are related to their health conditions that make it hard for them to exercise</p>	<p>1. Giving them and their families enough information about their situation can</p>

<p>P 3: "It is a hard thing to do when you are in holidays and you are travelling, if you are acting and travelling around a lot."</p> <p>P 2: "I was very good in the beginning taking care of my diabetes, then I start doing it in weekly basis, then I stopped that. I was happy to see the numbers of the test and seeing that I'm doing well."</p> <p>P 2: "For monitoring blood sugar, you have to ensure that you do not get some kind of disease, so you have to be very clean."</p> <p>P 4: "I can only walk so far because of the arthritis in the knees and I have to stop."</p> <p>P 5: "My knee bothers me as well, I used to like the walking but now I cannot walk and have to stop from time to time. But it is not arthritis."</p> <p>P 4: "My problem is that my wife is vegan, so if I want to eat, I have to cook it, and otherwise I go hungry."</p> <p>P 5: "We have a small GYM in the basement but I don't go down there anymore."</p> <p>P 4: "I do have an exercise machine but I don' use it anymore"</p> <p>P 5: "I have lots of time, but it is related to if I want to take my time to do that."</p> <p>I: "The problem is that he – the patient – cannot walk much, he uses the walker to get around, and for longer distances we use the wheelchair. He got to the point that he gets tired very quickly if he walks."</p> <p>P 6: "I do not do a lot of walking, my husband had an operation so we do as much walking between us as we can do. We go out to the mall for shopping or groceries. In winter time we do not walk much because we are afraid of falling. And we go swimming twice a week. I am not just sitting around doing nothing but I cannot walk for 4 hours! I might be able to walk around our block because I have asthma and also PMR (Polymyalgia rheumatic). When I feel tired I sit on my walker and then I walk again."</p> <p>I: "Yes, I (the wife) will do it – using the tool; because he forgets things."</p>		<p>The other barriers are mostly related to family problems</p>	<p>help them to overcome the barriers</p>
---	--	---	---

4.2. Self-Management Features

After reviewing all the outcomes of our study and reviewing the Schulman-Green et al. (2012) health self-management study and their three suggested categories: a) illness needs, b) activating resources, and c) living with a chronic illness [30]; we can identify eight Self-Management supports in Table 13 that our system should provide, with the three categories applicable in each case. A more detailed feature suggestion list in each of the health self-management categories is provided later in this section.

Table 13. Self-Management Supports and Categories

Support	Category	Description
1	a)	Educate patients about chronic illnesses and related comorbidities
2	a); c)	Train patients about chronic illness self-management approaches (e.g. monitoring blood pressure, heart rate, weight), problem-solving, coping techniques, and decision support
3	a); c)	Modify lifestyles (regularly exercising, smoking cessation, etc.)
4	b); c)	Provide links to counseling, advice and other support services
5	b)	Help personal caregivers, such as spouses, to assist patients in managing their chronic illnesses
6	b); c)	Access community health, social resources, family, and friends to combat social isolation and loneliness
7	a); b); c)	Motivate patients to adhere to self-management regimens, using creative mechanisms
8	a); b); c)	Engage patients through effective user-friendly interface designs

4.2.1. Illness Needs

Table 14. Self-Management: Illness Needs Features

Processes	Tasks	Features
Learning	Learning about their disease and healthy life-styles	The tool will provide patients with a dependable source of information to learn about what they need to be able to self-manage their condition and improve their life-style
		The tool will enable patients to maintain records of their regimen, smoking and walking history, and their clinical information like blood pressure, blood sugar and heart rate, and get the proposed strategies to improve their condition from their healthcare providers
Taking ownership of health needs	Recognizing and managing body responses	To be able to use the tool, patients need to learn how to monitor and manage their symptoms, side effects, and body responses; we need a mechanism to teach patients
		Doctors will help patients by adjusting their treatment regimen to manage symptoms and side effects of their medications
	Completing the health tasks	The tool will enable doctors to keep their appointment notes and share them with patients themselves and other healthcare providers
		We will add a feature in the tool in future to enable the patients to keep a history of their medications
		The tool will enable healthcare providers to perform treatments and keep up with changes in the patient's regimen, also it improves the ability of patients to manage their own health changes
	Helping patients to become experts in their own healthcare process	Doctors will set the goals and strategies for patients and at the same time enable them to set goals and strategies for themselves by sharing the information
Having all patient information in one package improves patient and doctor ability for problem solving, planning, prioritizing and pacing		

		Empowering patients to see the effects of different regimens so they know if and when to take a break from a regimen
		Improving confidence and self-efficacy in patients by improving their knowledge and control over their own health
		It also enables both patients and doctors to evaluate effectiveness of self-management by seeing the results
Performing health promotion activities	Changing patient behaviors to minimize their disease impacts	Helping patients to modify their diet, nutrition, smoking, and physical activity to improve their health condition
		Reducing patient stress by improving their knowledge
		The tool enables patients to take actions faster by being aware of their condition and prevent complications
	Sustaining health promotion activities	The tool also enables them to keep up with lifestyle modifications by seeing the results

4.2.2. Activating Resources

Table 15. Self-Management: Activating Resources Features

Processes	Tasks	Features
Healthcare resources	Enable patients to create and maintain relationships with their healthcare providers	The tool enables the patients to find the right provider(s) by having the information in their hands and being aware of their condition
		The tool enables the patients and healthcare providers to communicate effectively
		The tool enables healthcare providers to make decisions collaboratively and reach better results
	Navigating the healthcare system	The tool enables everyone in the healthcare system to coordinate services better by having access to all the information needed, and use the resources effectively
		The tool also enables healthcare providers to create and revisit advance care plans by having access to all the information

Psychological resources	Identifying and benefiting from psychological resources	Cultivating courage, discipline, and motivation in patients by improving their knowledge
		Improving patient hope and self-worth by enabling them to advocate for themselves
Social resources	Obtaining and managing social support	Increasing the support of family and friends by giving them an opportunity to actively participate in the patients' healthcare process
		Creating an opportunity to talk to other patients with similar experiences to overcome isolation problems

4.2.3. Living with a Chronic Illness

Table 16. Self-Management: Living with a Chronic Illness Features

Processes	Tasks	Features
Processing emotions	Processing and sharing emotions	Enable patients to share their emotions with each other and overcome the shock of diagnosis, self-blame, and guilt by their friend's, family's or other patient's support
		Giving them an opportunity to choose when and to whom to disclose their illness
Adjusting	Adjusting to illness	Enabling patients to understand and accept their illness by identifying and confronting change and loss (e.g., changes in physical function)
		Enable patients to manage the uncertainty by giving them access to their condition's information
Integrating illness into daily life	Modifying lifestyle to adapt to disease	Reorganizing their everyday life by keeping a record of their diet, exercise, smoking, and others; and being able to get assistance with their daily activities
Meaning making	Personal growth	Empowering patients to learn about their personal strengths and limitations, and create a sense of purpose for them to strive for personal satisfaction

4.3. Adoption and Use Flowchart

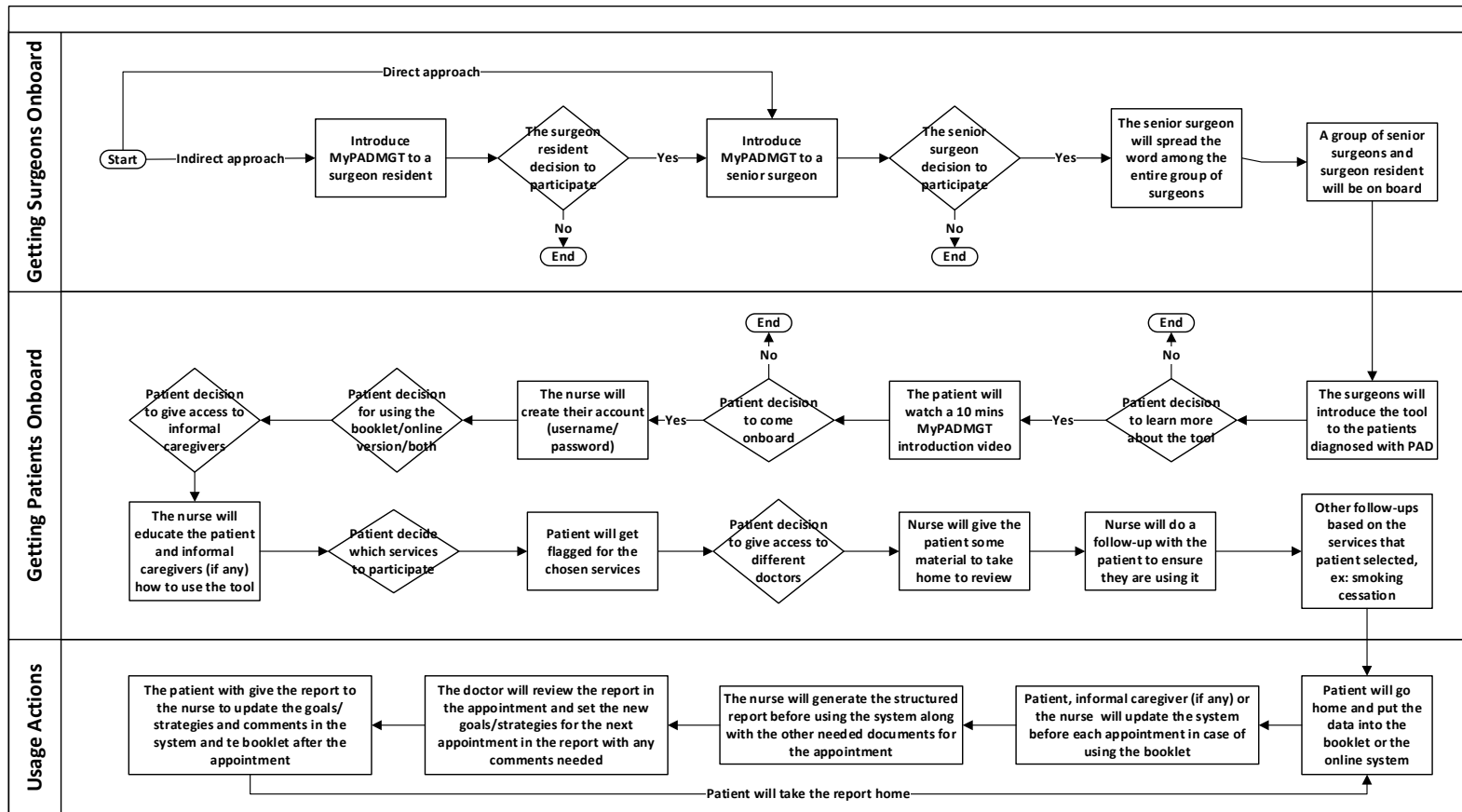


Figure 4. MyPADMGT Adoption and Use Flowchart

This Adoption and Use Flowchart demonstrates the proposed MyPADMGT system process, designed to accommodate PAD outpatients who may choose either the fully online system or the paper-based booklet system.

4.4. Process Description

In this section, we describe the process of how the system will be introduced to health providers and patients, based on our findings in discussions with surgeons, patients, and informal caregivers. Most of this process is based on our discussion with surgeons and what they think is possible. Afterwards, it was revised based on discussions with patients and caregivers, and what they have pointed out as their needs. The process is as follows:

- We will introduce the redesigned, developed, and tested MyPADMGT tool to a resident surgeon, who will be asked to take responsibility for managing the system. The resident will introduce it to the surgeons. It is very good if the surgeon has already heard about it at a conference, or has seen the brochures before. It is usually hard to get surgeons' attention, because there are so many new technologies that are competing for their attention and it is hard for them to find time for a dedicated session with vendors to learn about their applications. The best way might be instead to approach the institution indirectly by introducing it to the residents and if they find it helpful, they will introduce it to the senior surgeons and we can have an education session later to introduce it to the entire group of residents and senior surgeons.
- After the surgeons have agreed to a trial of the system, they will introduce the application to the patients who come to the hospital, if they are diagnosed with PAD and they are interested in participating. The nurse or a trained coordinator can sit with the patients and educate the patients and their informal caregivers, at the same time (if they do not have a caregiver with them coming to clinic, they are most probably independent). We have found that patients are more likely to adopt using the system if it is recommended to them by their surgeons.
- There will be a computer available in the hospital clinic where patients can watch a video introduction to the system. The coordinator will give patients the opportunity to view the video and then sign up for either the online or booklet form of the system. Additional educational materials will be given to patients signing up for the booklet form, while online users will be able to view educational videos online at home any time. The coordinator will sit down with patients, talk to them about the system, and help them to use it step by step, while they are at the clinic. Follow-up phone calls with the patients may be necessary to help get patients started using the system.
- If patients are eligible and they are interested in participating, their office record will be flagged, and their doctors and nurses will know that they are participating. A patient's doctor will define a series of certain goals and the best applicable factors for the patient, e.g. smoking cessation, walking

program, etc. The privacy issue should be considered by asking the patient to give their physician permission to access their health record.

- Family doctors have an important role in the circle of care because they can be a check point and patients normally see them more often than specialists. Therefore, there is a value in notifying the patient's family doctor that the patient is using the application. The patients can take their results to their family doctors and share the results with them.
- The application gives the specialist a standardized report (see figure 5). It has different parts to summarize every session like smoking cessation or walking programs, and previous and future goals for each activity. The clinical nurse will get the patient report ready along with all the other information, like ultrasound, before the patient's appointment, so in the appointment the surgeon will be able to review the report with the patient. The patient may also share it with family physicians and other health providers. Patients can keep their reports and take them home after the nurse updates the system with the new goals and strategies which have been set during the appointment.
- Based on my observations in the interviews, the biggest barrier will be getting patients to use the tool regularly, because many of them talked about adopting different diets or interventions for a short while and then they stopped for no particular reason. Reminders in the online application help to remind patients to log in when they forget to put their data into the system, and for some of the patients who do not have smart phones, computers, or access to the Internet, patients will be able to track their progress in a small booklet with pages that can be replaced at any visit to their physician. They will have the option of choosing the booklet or the application, and the booklet pages will be very similar to the online application, including:
 - Different colour coded and tabbed pages for different goals (e.g. walking/blood pressure/diet)
 - Small tables, times, dates: like a calendar (pre-filled forms); they can just circle the data, which can be on a scale, and for some parts they can enter the actual data
- When patients with booklets come to the clinic, the nurse or coordinator will ask for their booklets, which will then be used to update the data online through an online OCR/OMR system. Patients can also enter the data online to the computer, by themselves or their caregiver every few days, weeks, months or so before the appointment. Instead of manual data entry it can be uploaded via smart scan through readers equipped with Optical Character Recognition/Optical Mark Recognition software. This allows patients (usually older adults) to record data regularly and then

upload it at the clinic to the secure database which also holds other patient records that are being entered directly.

- The booklets can also include educational pages on vascular self-care. There will be different permanent educational pages and links in the booklet, whereas the pages where data are entered will be replaceable after the data have been uploaded to the online secure system.

The booklets can be a proof of concept for the application. While a booklet may work well for older adults, in the long term there will be more people familiar with technology. When that happens, the booklet approach will be out of date and it can be replaced completely with online applications.

There are some advantages to using the booklet, for example: when the patient goes home with the booklet instead of access to an online application, their children and relatives will take more interest in it, helping to improve the self-care process by involving more people in the patient's circle of care. According to one of the vascular surgeons: "older patients love to have papers when they leave the office, because they will have something to look forward to until their next session."

Moreover to make it easier for patients to keep track of their progress a very simple automatic tracking method like a simple version of *Fitbit* can be used to track their activities. The same could be done for blood pressure by providing an automatic blood pressure device.

One favourable impact of this system is that patients will be able to share their information with everybody else in their circle of care. This will help to improve communications, which eventually improve the quality of care by sharing ideas, concepts and goals. It can also serve to improve the link between patients and healthcare providers and also among healthcare providers.

The communication option among patients using the application can also help to improve their social support. Getting together to share experiences may help to improve self-care and overcome social isolation.

4.5. Structured Report Design

The structured report design in Figure 5 shows an example structured report that would be generated by the system at the time a patient attends a regular appointment at the outpatient clinic. The report shows patient progress towards goals previously agreed with the patient's physician, and goals agreed for the next appointment (up to six months) in the future. Note that the graphs shown in Figure 5 do not reflect particular realities and are for demonstration purposes only.

Structured Report		
First Name:	Last Name:	Phone Number:
ID:	Other Info:	
Exercise	Smoking	Weight
New Goal:	New Goal:	New Goal:
Previous Goal:	Previous Goal:	Previous Goal:
Last Month data: Time/distance Frequency	Last Month data: Numbers Frequency	Last Month data: Number
Last visit data: Time/distance Frequency	Last visit data: Numbers Frequency	Last visit data: Number
Blood Pressure	Blood Sugar	Heart Rate
Exercise		
New Strategy:		
<ul style="list-style-type: none"> Option 1 Option 2 Others: 		
Previous Strategy:		
<ul style="list-style-type: none"> 		
Smoking		
New Strategy:		
<ul style="list-style-type: none"> Option 1 Option 2 Others: 		
Previous Strategy:		
<ul style="list-style-type: none"> 		
Weight		
New Strategy:		
<ul style="list-style-type: none"> Option 1 Option 2 Others: 		
Previous Strategy:		
<ul style="list-style-type: none"> 		
General Comments:		
Doctor Signature:		

Figure 5. MyPADMGT Structured Report

5. Discussion

Based on our finding we have answered the three questions we had at the start of this study:

1. What are the needs, preferences, and abilities of people with chronic illnesses and their informal caregivers, and can disease self-management meet these requirements?

We have identified the unique needs, preferences, and abilities of people with chronic illnesses and their informal caregivers. The top 5 are:

- Easy to learn and use
- Easy to access
- Enough training
- Reliable source of information
- Real benefit in using it for themselves as well as healthcare providers

2. What are the needs and preferences of healthcare providers who work with patients utilizing health self-management solutions?

We have learned about the needs and preferences of healthcare providers who work with patients, among which the top 5 are:

- Fast and simple
- Inexpensive to provide to patients
- Reliable
- Adaptable to different patient's requirements
- A list of data that they need from patients

3. What are appropriate design solutions to address the outcomes, satisfaction and sustainability of use among end-users?

We learned that patients because of their age, condition, and limited capabilities that some of them might have, need to have different versions of our tool. We decided to provide them with two different options:

- Online version: MyPADMGT Portal
- Paper-based version: MyPADMGT Booklet

Moreover, to provide surgeons with a fast simple solution with all the data that they need, we have designed:

- MyPADMGT Structured Report

The report is customizable based on different patients' needs.

In future, we could consider linking the MyPADMGT portal to the hospital lab portal, which can automatically update the lab results to patient profiles, making them available to all users including healthcare providers, patients, and their informal caregivers.

5.1. Additional Study Findings

In this study, we found that interviews with surgeons were very helpful, because developing personas and scenarios requires a deep understanding of different groups of patients. Most surgeons, especially the surgeons that we interviewed, spend time with their patients and know them very well. They had a deep knowledge of their patients, and they were able to categorize them in different groups which makes segmentation much easier. Having a deep understanding about their patients' capabilities helps the interview process to be very productive in developing good solutions.

Patient interviews were mostly focused on learning the details of patients' lives and understanding their needs, preferences, and capabilities that could contribute to the development of personas. It was not easy to ask patients to come up with scenarios, because of their limited knowledge of the technology and its features, and also they were not able to generalize their needs to a group of people. It is understandable that it would be much easier for surgeons to be able to see the patterns, since they are in interaction with lots of different patients, and after enough years of experience they are familiar with different patient segments' behaviours and needs. We did not notice much male-female differences among the patients that we interviewed; since the sample size was very small, this is understandable.

I have also noticed differences in interviewing a pair of patients vs. one person at a time. In paired interviews, the patients were more proactive and they remind each other of their different experiences which could bring up more but sometimes much unrelated information. The advantage of interviewing one person at a time was that I was able to build trust which helps patients to share more information compared to sharing in front of another patient. Therefore, I had deeper conversations in single person interviews. Also, in interviewing pairs, if one person was talkative, it was hard to get the other person speak up. I would suggest using combinations of both styles in a study to cover different type of outcomes.

5.2. Advantages of MyPADMGT

In the current system, vascular surgeons usually get the blood pressure and blood sugar results because someone else has ordered it and it comes with the patients' charts. Family doctors usually get these in order to have a more holistic picture of their patients' health. But this application allows all the healthcare providers to have a better look at overall patient health, including smoking, exercise and diet which are not something that they actively watch.

The reason why vascular surgeons might not order lab tests is that if they order a test they have to follow-up within a month, and they cannot wait 6 months to see their patients. They also have to see the patients to modify patient regimens, which will make additional work. But it is valuable to have the information so they can communicate with the patients' family physician if any adjustments are needed for the patient's medications. They can also refer patients to diabetic specialists or other physicians.

What most physicians focus on for PAD patients are?

- Smoking cessation
- Walking and exercise program
- Weight, closely related to diet
- Making sure that they are on medications for blood pressure, diabetes, etc.

Therefore, physicians focus during each visit on goals and strategies to set, and on reviewing blood pressure, blood sugar (for diabetics), weight, and heart rate to ensure everything is going well.

An additional option is for patients to create a diet diary. This will help patients to keep thinking about and recording their diet, so they can have a realistic discussion with their physicians during their appointments.

Since smoking cessation is so crucial to self-managing PAD, smokers need to set up a diary to track their cigarette consumption. In addition, they will also have the option to note any specific problems they have that inhibit quitting, such as work stress, family struggles, etc. This will help physicians or other professionals in counselling them about this issue. The diary will be very helpful since it gives patients a chance to think about this issue as they note what their associated problems are in relation to smoking cessation.

5.3. Health Self-Management Barriers

Based on the literature, possible barriers to successful health self-management could be low patient confidence in performing related activities [77][78], lack of health self-management education (health literacy) [79], financial constrains [80], low self-efficacy and perceived benefits or lack of benefits in health self-management [81]. Moreover, older patients with chronic diseases often have special physical conditions like deterioration in eyesight, hearing, executive function, working memory, and physical abilities; these can all have a negative effect on health self-management performance [82][83]. The physical condition of the patients can affect their interaction with technology [84] and their health literacy can affect their ability to use and navigate through the Internet [85][86]. Poor working memory and executive function can also increase the time needed to learn new technologies for older patients [87]. Therefore, we need to be aware of their particular conditions and allocate enough time and technological assistance to older adults to enable them to adapt to the new healthcare technology [88][89].

Based on our discussion with the surgeons, their biggest barrier is not about telling the patients what to do or not to do – because most of the time the patients know what is bad for them (For example smoking cessation). The actual barrier is helping patients to be more compliant or adherent to recommended regimens, including the regular use of MyPADMGT to achieve and maintain lifestyle changes. Surgeon have mentioned that patients hear what their doctors say but remember little of it, so taking booklets with appropriate information home to read, or accessing the online system can provide encouragement to achieve their goals of lifestyle change.

The focus of vascular specialists for outpatients with PAD is on care that prevents worsening of PAD symptoms. This involves prescribing the right medication and encouraging them to live healthy life-styles. The latter is what our system can support well. It is therefore critical for the MyPADMGT system to be available and to support specialists to encourage a healthy lifestyle and promote a better quality of life.

5.4. Study Limitations

The small sample of users is a limitation of this study, since it makes it difficult to generalize the results to all patients and informal caregivers. However, after a few discussion sessions with patients we started to see repeated patterns which made us more confident in arriving at conclusions and finalizing outcomes. For more detailed outcomes and features, a larger study with more discussion sessions would be required.

Not being able to show patients a sample of the booklet was the second limitation of our study. During the discussions, most of the patients asked to see a version of the booklet to be able to share their thoughts.

Additional study with patients will be needed to test proposed booklet designs before proceeding with their use.

In the bigger picture two other factors can also affect the adoption rate of health self-management interventions: (1) patient motivation to engage in health self-management, and (2) patient readiness to engage in lifestyle changes. These two factors may be more important than the first three. Measuring the latter two factors was outside the scope of this study since participant recruitment was a convenience process that was biased towards “willing and motivated” people. The outcomes of this study cannot therefore be generalized to the domain of “all PAD patients” who might be candidates to use this tool.

5.5. Future Studies

Future studies will explore patient feedback during the system design and development process while the booklet and the extended MyPADMGT system are tested and finally put into operation. This will include booklet design and interface, integration of the booklet upload feature with the online system, and sharing the new online user interface and the booklet with patients and informal caregivers. In addition, the outcomes and the structured reports for healthcare providers will need to be tested. After the first round of study we can evaluate and redesign the tool if needed. The second round of study would come after finalizing the tool and onboarding the patients to use the system for at least a month, reviewing the results and their feedback after real usage to finalize the tool design and the operations process. We also anticipate that family physicians and potentially other allied care providers will be brought into a more extended self-management process system design later.

For the bigger picture, we need to consider the well-known longstanding model called the "Stages of Change" Model[90] that describes these patient stages in the continuum of effecting behaviour change: not ready – getting ready – ready – action – maintenance. We need to ensure that the patients get to the ready stage before they enter the realm for potential users of the PAD tool.

6. Conclusions

Our conclusions, based on findings from the patient persona-scenario exercises are as follows. In order to be adopted and used by our target clientele (patients with PAD) our system must be:

- Inexpensive
 - As long as we are in the prototype stage and need to show that the system works, we cannot charge patients much, to start with. Therefore, we need an inexpensive system to survive the prototype and validation phases until it shows real benefits so we can justify full financial support.
- Reliable
 - The information and intervention system implemented in the system should be approved by family physicians and specialists to be reliable for patients to use.
 - The system should be secure and provide dependable reports in a timely manner.
- Easy to learn
 - The system should be easy to learn for both patients and health providers. Special condition of the patients – age, illness condition, and etc. – make it hard for patients to deal with complex systems. Health providers are also very busy with very limited time to spend explaining a new system to patients in addition to their regular work; this is only possible if the system is easy to learn.
- Easy to use
 - Other than being easy to learn during its initial usage stage, it should be very easy to use for users. A complicated system will be abandoned very quickly by its users. Bluetooth embedded systems which can record data automatically could be a good solution for this matter.
- Adaptable to individual requirements
 - The system should be customizable for different user needs. For example patients can decide which program they want to participate in, or their physician can set up the related interventions for the patient (e.g. smoking cessation, weight loss, etc.).
- Able to provide a link between outpatients and their providers as appropriate
 - One of the advantages of this system could be providing patients with the possibility of communicating with each other, or for physicians to communicate with the patients

anytime they need to provide a patient or a group of patients with important information or news.

- Help outpatients to understand and manage their chronic illness(es)
 - Access to enough knowledge about their disease is very popular for patients. Since the healthcare providers are too busy to educate their patients, a system like this can play a role as a good teaching assistant to patients and healthcare providers.
- Support record integration with records created by users of paper booklet logs that are compatible in format with those saved by fully online system users
 - By adding a paper-based option we can support patients who are not comfortable with technology, or who do not have access to it regularly. By keeping the content design consistent between the online version and paper-based option, we can make it easier to add data to the online system from the paper-based version.

We note that both our solutions – online portal and booklet – satisfy these criteria. A major finding of our study is that, even if patients had Internet access, they often indicated that they preferred the non-technical solution, using booklets to help patients track their progress. Fortunately, the use of paper booklets is available to support those who either can't or won't adopt direct access to a fully online system.

Our conclusions, based on the RE-AIM framework [57]: (our study were more focused on the Reach and Adoption components of this framework)

- Reach: the combination of online and paper-based tools are expected to increase the participation rate and representativeness of participants based on their own statements in interviews.
- Effectiveness: by providing a tool to simplify self-management for patients, we expect to see improved quality-of-life for our users. We will also work closely with healthcare providers to ensure that the system is working effectively and limit the negative consequences (if any) during the process of health or disease self-management.
- Adoption: we expect that adding the structured report to the online tool will increase the participation rate and satisfaction of healthcare providers, because it has been designed based on their special needs.
- Implementation: we need to ensure that the system is consistent in program delivery, whether it uses the online version or the booklet-based version.

- Maintenance: we need to track the rate of users who stop using the system, find out why this happens in each case, to ensure that usage is sustainable at both patient and healthcare provider levels.

The intent in a long run is to expand users of this tool from PAD patients, to people with chronic diseases in general. Furthermore, the revised MyPADMGT system will be a platform for supporting preventive medicine for users of all ages, since maintaining a healthy life-style can improve everybody's health and quality of life.

7. References

- [1] “Chronic disease definition - MedicineNet - Health and Medical Information Produced by Doctors,” 2016. [Online]. Available: <http://www.medicinenet.com/script/main/art.asp?articlekey=33490>. [Accessed: 07-Feb-2016].
- [2] S. Nolte, “A systematic review of outcomes of chronic disease self-management interventions,” *Qual. Life Res.*, vol. 22, no. 7, pp. 1805 – 1816, 2013.
- [3] J. J. Ofman, E. Badamgarav, J. M. Henning, K. Knight, A. D. Gano, R. K. Levan, S. Gur-Arie, M. S. Richards, V. Hasselblad, and S. R. Weingarten, “Does disease management improve clinical and economic outcomes in patients with chronic diseases? A systematic review,” *Am. J. Med.*, vol. 117, no. 3, pp. 182–192, Aug. 2004.
- [4] S. Newman and L. S. K. Mulligan, “Self-management interventions for chronic illness,” *Lancet*, vol. 364, no. 9444, pp. 1523 – 1537, 2004.
- [5] J. A. Astin, W. Beckner, K. Soeken, M. C. Hochberg, and B. Berman, “Psychological interventions for rheumatoid arthritis: a meta-analysis of randomized controlled trials.,” *Arthritis Rheum.*, vol. 47, no. 3, pp. 291–302, Jun. 2002.
- [6] M. et al. Chodosh, Joshua; Morton, Sally C; Mojica, Walter; Maglione, “Meta-Analysis: Chronic disease self-management programs for older adults.,” *Ann. Intern. Med. Intern. Med.*, vol. 143, no. 6, pp. 427–38, 2005.
- [7] K. Ismail, K. Winkley, and S. Rabe-Hesketh, “Systematic review and meta-analysis of randomised controlled trials of psychological interventions to improve glycaemic control in patients with type 2 diabetes,” *Lancet*, vol. 363, no. 9421, pp. 1589 – 1597, 2004.
- [8] P. D. Mullen, E. A. Laville, A. K. Biddle, and K. Lorig, “Efficacy of psychoeducational interventions on pain, depression, and disability in people with arthritis: a meta-analysis.,” *J. Rheumatol. Suppl.*, vol. 14 Suppl 1, pp. 33–9, Aug. 1987.
- [9] A. Warsi, P. S. Wang, M. P. LaValley, J. Avorn, and D. H. Solomon, “Self-management Education Programs in Chronic Disease,” *Arch. Intern. Med.*, vol. 164, no. 15, p. 1641, Aug. 2004.
- [10] A. Warsi, M. P. LaValley, P. S. Wang, J. Avorn, and D. H. Solomon, “Arthritis self-management education programs: a meta-analysis of the effect on pain and disability.,” *Arthritis Rheum.*, vol. 48, no. 8, pp. 2207–13, Aug. 2003.
- [11] “WHO | Cardiovascular diseases (CVDs),” 2015. [Online]. Available: <http://www.who.int/mediacentre/factsheets/fs317/en/>. [Accessed: 02-Feb-2016].
- [12] M. F. Piepoli, U. Corrà, S. Adamopoulos, W. Benzer, B. Bjarnason-Wehrens, M. Cupples, P. Dendale, P. Doherty, D. Gaita, S. Höfer, H. McGee, M. Mendes, J. Niebauer, N. Pogosova, E. Garcia-Porrero, B. Rauch, J. P. Schmid, and P. Giannuzzi, “Secondary prevention in the clinical management of patients with cardiovascular diseases. Core components, standards and outcome measures for referral and delivery: a policy statement from the cardiac rehabilitation section of the European Association for,” *Eur. J. Prev. Cardiol.*, vol. 21, no. 6, pp. 664–81, Jun. 2014.
- [13] F. Müller-Riemenschneider, C. Meinhard, K. Damm, C. Vauth, A. Bockelbrink, W. Greiner, and S. N. Willich, “Effectiveness of nonpharmacological secondary prevention of coronary heart disease.,” *Eur. J. Cardiovasc. Prev. Rehabil.*, vol. 17, no. 6, pp. 688–700, Dec. 2010.

- [14] B. Whalley, "Psychological Interventions for Coronary Heart Disease: Cochrane Systematic Review and Meta-analysis," *Int. J. Behav. Med.*, vol. 21, no. 1, pp. 109 – 121, 2014.
- [15] L. Neubeck, S. B. Freedman, A. M. Clark, T. Briffa, A. Bauman, and J. Redfern, "Participating in cardiac rehabilitation: a systematic review and meta-synthesis of qualitative data," *Eur. J. Prev. Cardiol.*, vol. 19, no. 3, pp. 494–503, May 2011.
- [16] K. I. Turk-Adawi and S. L. Grace, "Narrative review comparing the benefits of and participation in cardiac rehabilitation in high-, middle- and low-income countries.," *Heart. Lung Circ.*, vol. 24, no. 5, pp. 510–20, May 2015.
- [17] L. Neubeck, J. Redfern, R. Fernandez, T. Briffa, A. Bauman, and S. Ben Freedman, "Telehealth interventions for the secondary prevention of coronary heart disease: a systematic review.," *Eur. J. Cardiovasc. Prev. Rehabil.*, vol. 16, no. 3, pp. 281–9, Jun. 2009.
- [18] H. M. Dalal, A. Zawada, K. Jolly, T. Moxham, and R. S. Taylor, "Home based versus centre based cardiac rehabilitation: Cochrane systematic review and meta-analysis.," *BMJ*, vol. 340, no. jan19_4, p. b5631, Jan. 2010.
- [19] K. Huang, W. Liu, D. He, B. Huang, D. Xiao, Y. Peng, Y. He, H. Hu, M. Chen, and D. Huang, "Telehealth interventions versus center-based cardiac rehabilitation of coronary artery disease: A systematic review and meta-analysis.," *Eur. J. Prev. Cardiol.*, vol. 22, no. 8, pp. 959–71, Aug. 2015.
- [20] L. Pfaeffli Dale, R. Dobson, R. Whittaker, and R. Maddison, "The effectiveness of mobile-health behaviour change interventions for cardiovascular disease self-management: A systematic review.," *Eur. J. Prev. Cardiol.*, p. 2047487315613462–, 2015.
- [21] M. Novak, L. Costantini, S. Schneider, and H. Beanlands, "Approaches to Self-Management in Chronic Illness," *Semin. Dial.*, vol. 26, no. 2, pp. 188–194, 2013.
- [22] "Chronic Disease Prevention and Health Promotion - Chronic Diseases: The Leading Causes of Death and Disability in the United States." [Online]. Available: <http://www.cdc.gov/chronicdisease/overview/index.htm>. [Accessed: 27-Jan-2016].
- [23] P. D. Larsen and Lubkin, *Chronic Illness: Impact and Intervention*, 7th ed. Jones & Bartlett Learning, 2009.
- [24] C. Dowrick, "What is chronic illness?," *Chronic Illn.*, vol. 1, no. 1, pp. 1 – 6, 2005.
- [25] P. W. Harvey, J. N. Petkov, G. Misan, J. Fuller, M. W. Battersby, T. N. Cayetano, K. Warren, and P. Holmes, "Self-management support and training for patients with chronic and complex conditions improves health-related behaviour and health outcomes," *Aust. Heal. Rev.*, vol. 32, no. 2, p. 330, May 2008.
- [26] D. Swendeman, B. L. Ingram, and M. J. Rotheram-Borus, "Common elements in self-management of HIV and other chronic illnesses: an integrative framework.," *AIDS Care*, vol. 21, no. 10, pp. 1321–34, Oct. 2009.
- [27] K. Lorig, "Self-management education: History, definition, outcomes, and mechanisms," *Ann. Behav. Med.*, vol. 26, no. 1, pp. 1 – 7, 2003.
- [28] A. A. Richard and K. Shea, "Delineation of self-care and associated concepts.," *J. Nurs. Scholarsh.*, vol. 43, no. 3, pp. 255–64, Sep. 2011.
- [29] J. Barlow, C. Wright, J. Sheasby, A. Turner, and J. Hainsworth, "Self-management approaches for

- people with chronic conditions: a review,” *Patient Educ. Couns.*, vol. 48, no. 2, pp. 177–187, Oct. 2002.
- [30] D. Schulman-Green, S. Jaser, F. Martin, A. Alonzo, M. Grey, R. McCorkle, N. S. Redeker, N. Reynolds, and R. Whittlemore, “Processes of Self-Management in Chronic Illness,” *J. Nurs. Scholarsh.*, vol. 44, no. 2, pp. 136–144, 2012.
- [31] K. Cassar, “Peripheral Vascular disease,” *BMJ Clin. Evid.*, no. May 2010, pp. 1–74, 2011.
- [32] G. Peach, M. Griffin, M. M. Thompson, and R. J. Hinchliffe, “Diagnosis and management of peripheral arterial disease,” *Br. Med. J.*, vol. 5208, no. August, pp. 1–8, 2012.
- [33] M. H. Criqui, “Progression of Peripheral Arterial Disease Predicts Cardiovascular Disease Morbidity and Mortality,” *J. Am. Coll. Cardiol.*, vol. 52, no. 21, pp. 1736–1742, 2008.
- [34] L. H. Eraso, E. Fukaya, E. R. Mohler, D. Xie, D. Sha, and J. S. Berger, “Peripheral arterial disease, prevalence and cumulative risk factor profile analysis.,” *Eur. J. Prev. Cardiol.*, vol. 21, no. 6, pp. 704–711, 2012.
- [35] B. D. Criqui MH1, Langer RD, Fronck A, Feigelson HS, Klauber MR, McCann TJ, “Mortality over a period of 10 years in patients with peripheral arterial disease.,” *PubMed*. 1992.
- [36] W. R. Hiatt, S. Hoag, and R. F. Hamman, “Effect of Diagnostic Criteria on the Prevalence of Peripheral Arterial Disease : The San Luis Valley Diabetes Study,” *Circulation*, vol. 91, no. 5, pp. 1472–1479, Mar. 1995.
- [37] J. J. F. Belch, E. J. Topol, G. Agnelli, M. Bertrand, R. M. Califf, D. L. Clement, M. A. Creager, J. D. Easton, J. R. Gavin, P. Greenland, G. Hankey, P. Hanrath, A. T. Hirsch, J. Meyer, S. C. Smith, F. Sullivan, and M. A. Weber, “Critical issues in peripheral arterial disease detection and management: a call to action.,” *Arch. Intern. Med.*, vol. 163, no. 8, pp. 884–92, Apr. 2003.
- [38] F. G. R. Fowkes, D. Rudan, I. Rudan, V. Aboyans, J. O. Denenberg, M. M. McDermott, P. E. Norman, U. K. Sampson, L. J. Williams, G. A. Mensah, and M. H. Criqui, “Comparison of global estimates of prevalence and risk factors for peripheral artery disease in 2000 and 2010: a systematic review and analysis,” *Lancet*, vol. 382, no. 9901, pp. 1329–1340, 2013.
- [39] J. M. Murabito, R. B. D’Agostino, H. Silbershatz, and W. F. Wilson, “Intermittent claudication. A risk profile from The Framingham Heart Study.,” *Circulation*, vol. 96, no. 1, pp. 44–9, Jul. 1997.
- [40] L. Norgren, W. R. Hiatt, J. A. Dormandy, M. R. Nehler, K. A. Harris, F. G. R. Fowkes, K. Bell, J. Caporusso, I. Durand-Zaleski, K. Komori, J. Lammer, C. Liapis, S. Novo, M. Razavi, J. Robbs, N. Schaper, H. Shigematsu, M. Sapoal, C. White, J. White, D. Clement, M. Creager, M. Jaff, E. Mohler, R. B. Rutherford, P. Sheehan, H. Sillesen, and K. Rosenfield, “Inter-Society Consensus for the Management of Peripheral Arterial Disease (TASC II).,” *Eur. J. Vasc. Endovasc. Surg.*, vol. 33 Suppl 1, no. 1, pp. S1–75, Jan. 2007.
- [41] F. G. R. FOWKES, E. HOUSLEY, E. H. H. CAWOOD, C. C. A. MACINTYRE, C. V RUCKLEY, and R. J. PRESCOTT, “Edinburgh Artery Study: Prevalence of Asymptomatic and Symptomatic Peripheral Arterial Disease in the General Population,” *Int. J. Epidemiol.*, vol. 20, no. 2, pp. 384–392, Jun. 1991.
- [42] E. M. Willigendael, J. A. W. Teijink, M.-L. Bartelink, R. J. G. Peters, H. R. Büller, and M. H. Prins, “Smoking and the patency of lower extremity bypass grafts: a meta-analysis.,” *J. Vasc. Surg.*, vol. 42, no. 1, pp. 67–74, Jul. 2005.

- [43] W. T. Meijer, A. W. Hoes, D. Rutgers, M. L. Bots, A. Hofman, and D. E. Grobbee, "Peripheral Arterial Disease in the Elderly : The Rotterdam Study," *Arterioscler. Thromb. Vasc. Biol.*, vol. 18, no. 2, pp. 185–192, Feb. 1998.
- [44] T. F. Lüscher, M. A. Creager, J. A. Beckman, and F. Cosentino, "Diabetes and vascular disease: pathophysiology, clinical consequences, and medical therapy: Part II.," *Circulation*, vol. 108, no. 13, pp. 1655–61, Sep. 2003.
- [45] E. Selvin, S. Marinopoulos, G. Berkenblit, T. Rami, F. L. Brancati, N. R. Powe, and S. H. Golden, "Glycosylated Hemoglobin and Cardiovascular Disease in Diabetes Mellitus," *Ann. Intern. Med.*, vol. 141, pp. 421–431, 2004.
- [46] "Effects of an angiotensin-converting-enzyme inhibitor, ramipril, on Cardiovascular Events in High-Risk Patients," *N. Engl. J. Med.*, vol. 342, pp. 145–153, 2000.
- [47] K. Wattanakit, A. R. Folsom, E. Selvin, J. Coresh, A. T. Hirsch, and B. D. Weatherley, "Kidney function and risk of peripheral arterial disease: results from the Atherosclerosis Risk in Communities (ARIC) Study.," *J. Am. Soc. Nephrol.*, vol. 18, no. 2, pp. 629–36, Feb. 2007.
- [48] A. M. O'Hare, A. N. Sidawy, J. Feinglass, K. M. Merine, J. Daley, S. Khuri, W. G. Henderson, and K. L. Johansen, "Influence of renal insufficiency on limb loss and mortality after initial lower extremity surgical revascularization.," *J. Vasc. Surg.*, vol. 39, no. 4, pp. 709–16, Apr. 2004.
- [49] J. S. Berger, L. H. Eraso, D. Xie, D. Sha, and E. R. Mohler, "Mean platelet volume and prevalence of peripheral artery disease, the National Health and Nutrition Examination Survey, 1999-2004.," *Atherosclerosis*, vol. 213, no. 2, pp. 586–91, Dec. 2010.
- [50] Z. Ali, "Association of serum myeloperoxidase with the ankle-brachial index and peripheral arterial disease," *Vasc. Med.*, vol. 14, no. 3, pp. 215 – 220, 2009.
- [51] L. H. Eraso, N. Ginwala, A. N. Qasim, N. N. Mehta, R. Dlugash, S. Kapoor, S. Schwartz, M. Schutta, N. Iqbal, E. R. Mohler, and M. P. Reilly, "Association of lower plasma fetuin-a levels with peripheral arterial disease in type 2 diabetes.," *Diabetes Care*, vol. 33, no. 2, pp. 408–10, Feb. 2010.
- [52] R. L. Pande, T. S. Perlstein, J. A. Beckman, and M. A. Creager, "Secondary Prevention and Mortality in Peripheral Artery Disease: National Health and Nutrition Examination Study, 1999 to 2004," *Circulation*, vol. 124, no. 1, pp. 17–23, Jun. 2011.
- [53] S. Novo, G. Coppola, and G. Milio, "Critical Limb Ischemia: Definition and Natural History," *Curr. Drug Target -Cardiovascular Hematol. Disord.*, vol. 4, no. 3, pp. 219–225, Sep. 2004.
- [54] D. Conen, B. M. Everett, T. Kurth, M. A. Creager, J. E. Buring, P. M. Ridker, and A. D. Pradhan, "Smoking, smoking cessation, and risk for symptomatic peripheral artery disease in women: A Prospective Study," *Ann. Intern. Med.*, vol. 154, no. 11, pp. 719–26, Jun. 2011.
- [55] K. Dickstein, A. Cohen-Solal, G. Filippatos, J. J. V McMurray, P. Ponikowski, P. A. Poole-Wilson, A. Strömberg, D. J. van Veldhuisen, D. Atar, A. W. Hoes, A. Keren, A. Mebazaa, M. Nieminen, S. G. Priori, and K. Swedberg, "ESC guidelines for the diagnosis and treatment of acute and chronic heart failure 2008: the Task Force for the diagnosis and treatment of acute and chronic heart failure 2008 of the European Society of Cardiology. Developed in collaboration with the Heart," *Eur. J. Heart Fail.*, vol. 10, no. 10, pp. 933–89, Oct. 2008.
- [56] A. Jovicic, J. M. Holroyd-Leduc, and S. E. Straus, "Effects of self-management intervention on health outcomes of patients with heart failure: a systematic review of randomized controlled trials.,"

- BMC Cardiovasc. Disord.*, vol. 6, no. 1, p. 43, Jan. 2006.
- [57] R. E. Glasgow, “The RE-AIM framework for evaluating interventions: what can it tell us about approaches to chronic illness management?,” *Patient Educ. Couns.*, vol. 44, no. 2, pp. 119 – 127.
- [58] R. Kessler, “What Does It Mean to ‘Employ’ the RE-AIM Model?,” *Eval. Health Prof.*, vol. 36, no. 1, pp. 44 – 66, 2013.
- [59] C. LeRouge, J. Ma, S. Sneha, and K. Tolle, “User profiles and personas in the design and development of consumer health technologies,” *Int. J. Med. Inform.*, vol. 82, no. 11, pp. e251–e268, 2013.
- [60] D. Roberts, D. Berry, S. Isensee, and J. Mullaly, “Designing for the User with OVID: Bridging the Gap Between Software Engineering and User Interface Design,” Sep. 1998.
- [61] E. B. Ryan, B. Szechtman, and J. Bodkin, “Attitudes Toward Younger and Older Adults Learning To Use Computers,” *J. Gerontol.*, vol. 47, no. 2, pp. P96–P101, Mar. 1992.
- [62] K. Bredies, “Using System Analysis and Personas for e-Health Interaction Design.” 06-Aug-2009.
- [63] L. Goldberg, “Usability and Accessibility in Consumer Health Informatics,” *Am. J. Prev. Med.*, vol. 40, no. 5, 2011.
- [64] J. A. Jacko, Ed., *Human-Computer Interaction. Interaction Platforms and Techniques*, vol. 4551. Berlin, Heidelberg: Springer Berlin Heidelberg, 2007.
- [65] R. Aria, M. Khan, T. Moloney, C. Demers, and N. Archer, “Online Disease Self-Management Support System for Peripheral Arterial Disease Patients,” *eHealth 2015 Conf. Toronto ON, May 31-June 3*, 2015.
- [66] M. Heisler, “Different models to mobilize peer support to improve diabetes self-management and clinical outcomes: evidence, logistics, evaluation considerations and needs for future research.,” *Fam. Pract.*, vol. 27 Suppl 1, pp. i23–32, Jun. 2010.
- [67] N. Ouedraogo, G. Mahe, J. Marchand, K. Saïdi, G. Leftheriotis, and P. Abraham, “Validation of a new simple questionnaire to ‘estimate ambulation capacity by history’ (EACH) in patients with claudication.,” *J. Vasc. Surg.*, vol. 54, no. 1, pp. 133–8, Jul. 2011.
- [68] P. Bate and G. Robert, “Experience-based design: from redesigning the system around the patient to co-designing services with the patient.,” *Qual. Saf. Health Care*, vol. 15, no. 5, pp. 307–10, Oct. 2006.
- [69] R. D. Ellis and Sri H. Kurniawan, “Increasing the Usability of Online Information for Older Users: A Case Study in Participatory Design,” *Int. J. Hum. Comput. Interact.*, vol. 12, no. 2, pp. 263 – 276, 2000.
- [70] B. Reeder and A. M. Turner, “Scenario-based design: a method for connecting information system design with public health operations and emergency management.,” *J. Biomed. Inform.*, vol. 44, no. 6, pp. 978–88, Dec. 2011.
- [71] J. M. Carroll, “Five reasons for scenario-based design,” *Interact. Comput.*, vol. 13, no. 1, pp. 43–60, Sep. 2000.
- [72] D. Idoughi, A. Seffah, and C. Kolski, “Adding user experience into the interactive service design loop: a persona-based approach,” *Behav. Inf. Technol.*, vol. 31, no. 3, pp. 287–303, Mar. 2012.

- [73] L. van Velsen, L. van Gemert-pijnen, N. Nijland, D. Beaujean, and J. van Steenberg, "Personas : The Linking Pin in Holistic Design for eHealth," *Proc. 4th Int. Conf. eHealth, Telemedicine, Soc. Med.*, no. c, pp. 128–133, 2012.
- [74] A. Cooper, *The inmates are running the asylum. Why high-tech products drive us crazy and how to restore the sanity*. Indianapolis, Indiana: SAMS, 1999.
- [75] J. Pruitt and T. Adlin, *The Persona Lifecycle: Keeping People in Mind Throughout Product Design*. Morgan Kaufmann, 2010.
- [76] R. Valaitis, J. Longaphy, and K. Nair, "Persona-scenario exercise for codesigning primary care interventions," *Can. Fam. Physician*, vol. 60, pp. 294–296, 2014.
- [77] B. Carlson, "Self-care abilities of patients with heart failure," *Hear. Lung J. Acute Crit. Care*, vol. 30, no. 5, pp. 0351 – 0359.
- [78] L. S. Evangelista and M. A. Shinnick, "What do we know about adherence and self-care?," *J. Cardiovasc. Nurs.*, vol. 23, no. 3, pp. 250–7, Jan. .
- [79] A. Macabasco-O'Connell, D. A. DeWalt, K. A. Broucksou, V. Hawk, D. W. Baker, D. Schillinger, B. Ruo, K. Bibbins-Domingo, G. M. Holmes, B. Erman, M. Weinberger, and M. Pignone, "Relationship between literacy, knowledge, self-care behaviors, and heart failure-related quality of life among patients with heart failure.," *J. Gen. Intern. Med.*, vol. 26, no. 9, pp. 979–86, Sep. 2011.
- [80] A. F. Jerant, "Patients' perceived barriers to active self-management of chronic conditions," *Patient Educ. Couns.*, vol. 57, no. 3, pp. 300 – 307.
- [81] E. Seto, K. J. Leonard, J. a Cafazzo, C. Masino, J. Barnsley, and H. J. Ross, "Self-care and quality of life of heart failure patients at a multidisciplinary heart function clinic.," *J. Cardiovasc. Nurs.*, vol. 26, no. 5, pp. 377–85, 2011.
- [82] D. Harman, "The aging process.," *Proc. Natl. Acad. Sci.*, vol. 78, no. 11, pp. 7124–7128, Nov. 1981.
- [83] S. Sneha, "Enabling ubiquitous patient monitoring: Model, decision protocols, opportunities and challenges," *Decis. Support Syst.*, vol. 46, no. 3, pp. 606 – 619, 2009.
- [84] N. Charness and W. R. Boot, "Aging and Information Technology Use: Potential and Barriers," *Curr. Dir. Psychol. Sci.*, vol. 18, no. 5, pp. 253–258, Oct. 2009.
- [85] M. S. Birru, V. M. Monaco, L. Charles, H. Drew, V. Njie, T. Bierria, E. Detlefsen, and R. A. Steinman, "Internet usage by low-literacy adults seeking health information: an observational analysis.," *J. Med. Internet Res.*, vol. 6, no. 3, p. e25, Sep. 2004.
- [86] J. P. Schprechman, E. C. Gathright, C. M. Goldstein, K. a Guerini, M. a Dolansky, J. Redle, and J. W. Hughes, "Health literacy and global cognitive function predict e-mail but not internet use in heart failure patients.," *Nurs. Res. Pract.*, vol. 2013, p. 507910, 2013.
- [87] N. Charness, C. L. Kelley, E. A. Bosman, and M. Mottoram, "Word-Processing Training and Retraining: Effects of Adult Age, Experience, and Interface," *Am. Psychol. Assoc.*, vol. 16, no. 1, pp. 110 – 127, 2001.
- [88] A.-S. Melenhorst, W. A. Rogers, and D. G. Bouwhuis, "Older adults' motivated choice for technological innovation: evidence for benefit-driven selectivity.," *Psychol. Aging*, vol. 21, no. 1, pp. 190–5, Mar. 2006.

- [89] N. Selwyn, "The information aged: A qualitative study of older adults' use of information and communications technology," *J. Aging Stud.*, vol. 18, no. 4, pp. 369 – 384.
- [90] J. O. Prochaska, W. F. Velicer, J. S. Rossi, M. G. Goldstein, B. H. Marcus, W. Rakowski, C. Fiore, L. L. Harlow, C. A. Redding, D. Rosenbloom, and Susan R. Rossi, "Stages of change and decisional balance for 12 problem behaviors.," *Heal. Psychol.*, vol. 13, no. 1, pp. 39–46, 1994.

8. Appendices

8.1. Appendix A: Research Ethics Board (REB) Approval



Hamilton Integrated Research Ethics Board

December 1 2015

Project Number:0638

Project Title:Designing an Online Patient Interface for a Chronic Disease Self-Management System

Student Principal Investigator:Ms. Maryam Arnaeimejad

Local Principal Investigator:Dr. Michael Stacey

We have completed our review of your study and are please to issue our final approval. You may now begin your study.

The following documents have been approved on both ethical and scientific grounds:

Document Name	Document Date	Document Version
Consent to Participate in a Research Study Nov 26 2015 Maryam NPA	11/26/2015	3
Invitation to Participate in a Research Study NPA	11/11/2015	1
Maryam HiREB Proposal 2015 NPA Final	11/11/2015	2
Persona Development and Discussion Guide for Clinicians NPA	08/25/2015	1
Persona Development and Discussion Guide NPA	08/25/2015	1

Any changes to this study must be submitted with an Amendment Request Form before they can be implemented.

This approval is effective for 12 months from the date of this letter. Upon completion of your study please submit a [Study Completion Form](#).

If you require more time to complete your study, you must request an extension in writing before this approval expires. Please submit an [Annual Review Form](#) with your request.

PLEASE QUOTE THE ABOVE REFERENCED PROJECT NUMBER ON ALL FUTURE CORRESPONDENCE

Good luck with your research,

A handwritten signature in black ink, appearing to read 'Kristina Trim'.

Kristina Trim, PhD, RSW
Chair, HiREB Student Research Committee
Health Research Services, HSC 3H9, McMaster University

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

8.2. Appendix B: Participants Recruitment Form – Patients and Informal Caregivers



Participation in a Research Study

Peripheral Arterial Disease

Online Self-Management

Purpose of the Study

We are researchers at McMaster University who are trying to improve the quality of life of people with peripheral arterial disease and other serious chronic illnesses, through better disease self-management. **If you are an out-patient who has been diagnosed with peripheral arterial disease, and you have Internet access, we invite you to participate** with us in designing an online system that will help support you in self-managing this disease. This online system will be offered to assist out-patients, their caregivers, and medical practitioners. We believe that the findings from this study will be helpful in the ongoing exploration of the needs, functionalities and content provided by online support for chronically ill patients. This study has been approved by the Hamilton Integrated Research Ethics Board (905-521-2100 Ext. 42013)

Reimbursement:

****You will be reimbursed for the parking plus \$40 gift card for your participation****

**If you are interested please use the link below to read more about the study.
Please submit your application and we will contact you soon.**

**<https://www.surveymonkey.com/r/QS7BJZY>
(9 simple questions which will take less than 2 minutes)**

Thanks for your participation

8.3. Appendix C: Participants Recruitment Survey – Patients and Informal Caregivers

Participation in a Research Study: Peripheral Arterial Disease Online Self-Management

Purpose of the Study

We are researchers at McMaster University who are trying to improve the quality of life of people with peripheral arterial disease and other serious chronic illnesses, through better disease self-management. **If you are an out-patient who has been diagnosed with peripheral arterial disease, and you have Internet access, we invite you to participate** with us in designing an online system that will help support you in self-managing this disease. This online system will be offered to assist out-patients, their caregivers, and medical practitioners. We believe that the findings from this study will be helpful in the ongoing exploration of the needs, functionalities and content provided by online support for chronically ill patients. This study has been approved by the Hamilton Integrated Research Ethics Board (905-521-2100 Ext. 42013)

What Will Happen During the Study?

We will meet with small groups of out-patients for approximately two hours and use an approach called the “persona-scenario method” to gather information about what you might need from an online self-management support system. If you rely at home on the support of a caregiver (spouse, son, daughter, etc.) we strongly encourage you to bring your caregiver with you. First, we will discuss the study with the group and will then pair up participants with similar backgrounds, such as age and experience level. Each pair will receive a discussion guide and will work with a facilitator who will take notes. Once completed, each pair will meet with the other participants to discuss their results.

Risks

This study is limited to out-patients with Internet access who have peripheral arterial disease, and one of their caregivers (if any) who are at least 18 years of age. It is unlikely that your participation will cause any discomfort or harm.

Reimbursement:

****You will be reimbursed for the parking plus \$40 gift card for your participation****

Confidentiality

You will be participating in this study anonymously. Nobody, other than the researchers, will have access to the data. All information collected will be stored securely and kept in strict confidence. Participants will not be identified individually in any reports or analyses resulting from this research project.

Withdrawal

You may stop participating in the study at any time that you wish. You will be given an opportunity at the end of the study to review your remarks, and modify or remove portions of these if you do not agree with them. If you withdraw, data you have provided will be destroyed, and you will only be compensated for your parking expenses.

****If you are interested please fill the form below and we will contact you soon****
Thanks for your participation

1. Contact Information (Please share your information with us so we can contact you):

Name

Gender

Email Address

Phone Number

2. Age:

40-50

50-60

60-70

70-80

80-90

90+

3. What is your smoking status?

- Smoker
- Non-smoker
- Former smoker

4. How long have you been diagnosed with peripheral arterial disease?

Less than a year

1 - 2 Years

3 - 4 Years

5 + Years

5. Did you have an Intervention of any kind? (Surgery, Bypass, ...)

- Yes
- No

Please specify:

6. Do you have a caregiver at home who helps you to manage your disease?

Yes

No

7. Is your caregiver interested in participating in this study?

Yes

No

8. Do you have any problems walking?

Yes

No

Comments:

9. Is it convenient for you to come to the hospital to participate in the research study?

Yes

No

Comments:

10. Do you personally use the Internet at home?

Yes

No

8.4. Appendix D: Persona-Scenario Session Consent Form



Inspiring Innovation and Discovery

Consent to Participate in a Research Study Chronic Illness Self-Management



Consumer/Patient Survey Investigator Name and Title	Contact Information
<p>Local Principal Investigator:</p> <p>Dr. Michael Stacey, DS W. Aust. FRACS</p> <p>Professor</p> <p>Surgeon in Chief</p> <p>Division of Vascular Surgery</p>	<p>Hamilton General Hospital</p> <p>237 Barton St. East</p> <p>Hamilton, ON L8L 2X2</p> <p>Phone: 905-527-0271 Ext. 73881</p> <p>Email: famad@hhsc.ca</p>
<p>Co-investigator:</p> <p>Dr. Norm Archer, PhD</p> <p>Professor Emeritus</p> <p>Information Systems</p>	<p>DeGroote School of Business,</p> <p>McMaster University,</p> <p>Hamilton, ON L8S 4M4</p> <p>Phone: 905-525-9140 Ext. 23944</p> <p>Email: archer@mcmaster.ca</p>
<p>Master's Student:</p> <p>Ms. Maryam Ariaeinejad, MBA</p> <p>eHealth Candidate</p>	<p>DeGroote School of Business,</p> <p>McMaster University</p> <p>Hamilton, ON L8S4M4</p> <p>Phone: 647-774-3282</p> <p>E-mail: ariaeim@mcmaster.ca</p>

Purpose of the Study

The objective of this study is to prepare an upgraded design of a prototype online health self-management application for patients with peripheral arterial disease (PAD) and related chronic comorbidities. This may help to improve the quality of life of people with serious chronic illnesses through better disease self-management and better coordination of care among patient circles of care (care providers, caregivers, and patients). We believe that the findings from this study will be helpful to consumers and medical practitioners in the ongoing exploration of the need, functionalities and content provided by online support systems for chronically ill patients.

What Will Happen During the Study?

We will use an approach called the “persona-scenario method”. First, we will pair up participants with similar backgrounds, such as age and experience level, so that each pair can prepare a relatively authentic persona (an imaginary person who has a certain chronic illness). Each group will receive a tailored discussion guide, an introduction to the program components, and a facilitator will take notes. The goal of the exercise is for each pair to consider how their persona might experience one or more scenarios where they need information and assistance to help self-manage their illness. Each pair of participants typically will create one or two scenarios for their persona. The exercise will be less than 2 hours.

Risks

This study is limited to consumers 18 years of age or over. It is unlikely that your participation in this study will cause any discomfort or harm. Some of the questions may cause you to reflect on issues or decisions that may be a source of concern or worry for you. Any responses you provide will be treated confidentially by the researchers named in the table above.

Reimbursement

You will be reimbursed for parking plus \$40 gift card for your participation.

Confidentiality

Your participation in this study will be de-identified. Nobody, other than the researchers named above, will have access to the data or will know that you have participated. All information collected will be stored securely and kept in strict confidence. Participants will not be identified individually in any reports or analyses resulting from this research project. Data will be retained for a period of one year in a secure filing cabinet or a desktop computer with password access in a secure office at McMaster University. It will then be destroyed.

Withdrawal

You do not have to take part in this research if you do not wish to do so. You may stop participating in the study at any time that you wish. You will be given an opportunity at the end of the study to review your remarks, and you can ask to modify or remove portions of these if you do not agree with these notes. If you withdraw, any data you have provided to that point will be destroyed, and you will only be compensated for your parking expenses.

Questions about the Study

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.

Certificate of Consent

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

I will receive a signed copy of this form.

Print Name of Participant _____

Signature of Participant _____

Date _____
Day/month/year

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands the procedure. I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Print Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____
Day/month/year

8.5. Appendix E: Persona-Scenario Discussion Guide – Clinicians

This study will be collecting data from potential users (patients, clinicians, and caregivers) of an Online Chronic Disease Self-Management System for patients with Peripheral Arterial Disease (PAD). The goal is to upgrade the design of a current prototype of such a system being used for patients with peripheral arterial disease (PAD) and related chronic comorbidities. Upgrading this system is important because it can help to improve the quality of life of people who have serious chronic illnesses, through better disease self-management and better coordination of care among the patient's circle of care (care providers, care givers, and patients). The study will help to improve our understanding of the needs, preferences, and abilities of clinicians, and older adults with chronic illnesses such as PAD and their informal caregivers; it may also help to overcome the patients' social isolation and loneliness and to educate them about disease self-management.

The result of this study will improve the basis for the design of an effective online system to:

1. Educate patients about PAD and related comorbidities;
2. Train patients about PAD and other chronic illness self-management (e.g. monitor blood pressure, heart rate, weight), problem-solving, coping techniques, and decision support;
3. Modify lifestyles (e.g. exercise and smoking cessation);
4. Provide counseling, advice and other support services;
5. Help personal caregivers, such as spouses to assist the patients;
6. Access community health, social resources, family, and friends to combat social isolation;
7. Motivate patients to adhere to self-management regimens, with creative online mechanisms;
8. Provide effective user-friendly interface design for patients.

Procedure: Please note that all notes taken and discussions recorded will be treated as confidential and participant identities will not be revealed to anyone except the researchers. The results of this work will not identify anyone involved in these sessions. By participating in this study, you are agreeing to have your discussion recorded for further analysis and use in system design and development.

The persona-scenario method will be used to gather user input for system design. Clinicians with similar backgrounds will be paired so that personas (imaginary clinicians) they prepare will represent authentic people. Each group will receive a tailored discussion guide, an introduction to the online system's features, and will be supported by a facilitator to take notes. The goal is to create a detailed and realistic persona and to have that persona experience different aspects of the program, i.e. A scenario. Each participant pair will typically create one persona and one or two scenarios.

Summaries of the persona-scenario exercises presented by participants will be transcribed later and evaluated to understand how the personas chose to use the online system. These results will then be converted into a modified system design that supports users when programmed into the upgraded system.

Based on your knowledge and experience as a clinician, create a fictitious (but believable) “persona” and at least one “scenario” for each “persona” interacting with the self-care intervention program.

STEP 1: Create a Persona (10 minutes)

Your persona will be working in a multidisciplinary health team that supports patients that are using an online PAD self-management system. Give your health care provider “Persona”- some personality. Briefly describe the following:

1. A name
2. Age, gender
3. Education and employment background
4. Desires, attitudes about work
5. Years of service with current employer/organization
6. Experience with primary health care team members (physicians, nurses, social workers, pharmacists, etc.)
7. Comfort and experience with technology
8. Hopes and fears about PAD disease management

STEP 2. Create a scenario (25 - 30 minutes each)

Create a scenario for your persona who is involved in the health self-management program. Describe the following:

1. How does the health care provider persona become involved with this self-care program? How does the patient and caregiver persona?
2. What are the following personas doing in the scenario? (What, where, when, how?)
 - a) Patients (i.e. - In what ways are they using the online PAD self-management application?)
 - b) Health care providers (What information do they need to help manage disease and improve communication with patients?);
 - c) Any other important participants (e.g. care givers)
3. How the various personas are interacting? That is, how do individuals relate to each other (patients, clinicians, visiting nurses, volunteers, and care givers) and to the online system (e.g. online contacts with friends and family; contacts with clinicians)?
4. What happens when they (all personas involved) interact with the online system?
5. What happens after each interaction is complete?
6. What are the results/outcomes of these interactions? For patients; health care providers?

8.6. Appendix F: Persona-Scenario Discussion Guide – Patients

This study will be collecting data from potential users (patients, clinicians, and caregivers) of an Online Chronic Disease Self-Management System for patients with Peripheral Arterial Disease (PAD). The goal is to upgrade the design of a current prototype of such a system being used for patients with peripheral arterial disease (PAD) and related chronic comorbidities. Upgrading this system is important because it can help to improve the quality of life of people who have serious chronic illnesses, through better disease self-management and better coordination of care among the patient's circle of care (care providers, care givers, and patients). The study will help to improve our understanding of the needs, preferences, and abilities of clinicians, and older adults with chronic illnesses such as PAD and their informal caregivers; it may also help to overcome the patients' social isolation and loneliness and to educate them about disease self-management.

The result of this study will improve the basis for the design of an effective online system to:

1. Educate patients about PAD and related comorbidities;
2. Train patients about PAD and other chronic illness self-management (e.g. monitor blood pressure, heart rate, weight), problem-solving, coping techniques, and decision support;
3. Modify lifestyles (e.g. exercise and smoking cessation);
4. Provide counseling, advice and other support services;
5. Help personal caregivers, such as spouses to assist the patients;
6. Access community health, social resources, family, and friends to combat social isolation;
7. Motivate patients to adhere to self-management regimens, with creative online mechanisms;
8. Provide effective user-friendly interface design for patients.

Procedure: Please note that all notes taken and discussions recorded will be treated as confidential and participant identities will not be revealed to anyone except the researchers. The results of this work will not identify anyone involved in these sessions. By participating in this study, you are agreeing to have your discussion recorded for further analysis and use in system design and development.

The persona-scenario method will be used to gather user input for system design. Clinicians with similar backgrounds will be paired so that personas (imaginary clinicians) they prepare will represent authentic people. Each group will receive a tailored discussion guide, an introduction to the online system's features, and will be supported by a facilitator to take notes. The goal is to create a detailed and realistic persona and to have that persona experience different aspects of the program, i.e. A scenario. Each participant pair will typically create one persona and one or two scenarios.

Summaries of the persona-scenario exercises presented by participants will be transcribed later and evaluated to understand how the personas chose to use the online system. These results will then be converted into a modified system design that supports users when programmed into the upgraded system.

Based on your knowledge and experience as a patient, create a fictitious (but believable) “persona” and at least one “scenario” for each “persona” interacting with the self-care intervention program.

STEP 1: Create a Persona (10 minutes)

Your persona will be carrying out health self-management tasks and recording the results from these tasks online, such as recording weight, exercise, and measuring blood pressure at least once each week. Give your “Persona”- some personality. Briefly describe the following:

1. A name

2. Age, gender
3. Education and employment background
4. Desires, attitudes about work
5. Years of service with current employer/organization
6. Experience with primary health care team members (physicians, nurses, social workers, pharmacists, etc.)
7. Comfort and experience with technology
8. Hopes and fears about PAD disease management
 - Do you know what peripheral arterial disease is?
 - Are you aware of what future impact this disease can have on your patient's health if not treated diligently and properly?
 - Have you concentrated seriously on treating your patient's disease since you learned that he/she has PAD?

STEP 2. Create a Scenario (25 - 30 minutes each)

Create a scenario (or two) for your persona who is using the online system to participate in the self-management program. Describe the following:

1. How does the patient persona become involved with this self-care program? How does the healthcare provider persona help your patient persona's involvement? How does the informal caregiver persona?
2. What are the following personas doing in each scenario? (What, where, when, how?)
 - a. Patients (In what ways are they using the online PAD self-management application?);
 - b. Health care providers (What information do they need to help manage disease and improve communication with patients?);
 - c. Any other important characters such as caregivers.
3. How do the various personas interact? That is, how do individuals relate and communicate to each other (patients, visiting nurses, volunteers) and use the technologies to help them (e.g. online contacts with friends and family; plotting recorded data that show trends and accomplishments)?
4. What happens when (all personas involved) interact with the online system?
5. What happens after each interaction is complete?
6. What are the results / outcomes of this interaction? For patients; health care providers; caregivers?

8.7. Appendix G: Persona-Scenario Discussion Guide – Informal Caregivers

This study will be collecting data from potential users (patients, clinicians, and caregivers) of an Online Chronic Disease Self-Management System for patients with Peripheral Arterial Disease (PAD). The goal is to upgrade the design of a current prototype of such a system being used for patients with peripheral arterial disease (PAD) and related chronic comorbidities. Upgrading this system is important because it can help to improve the quality of life of people who have serious chronic illnesses, through better disease self-management and better coordination of care among the patient's circle of care (care providers, care givers, and patients). The study will help to improve our understanding of the needs, preferences, and abilities of clinicians, and older adults with chronic illnesses such as PAD and their informal caregivers; it may also help to overcome the patients' social isolation and loneliness and to educate them about disease self-management.

The result of this study will improve the basis for the design of an effective online system to:

1. Educate patients about PAD and related comorbidities;
2. Train patients about PAD and other chronic illness self-management (e.g. monitor blood pressure, heart rate, weight), problem-solving, coping techniques, and decision support;
3. Modify lifestyles (e.g. exercise and smoking cessation);
4. Provide counseling, advice and other support services;
5. Help personal caregivers, such as spouses to assist the patients;
6. Access community health, social resources, family, and friends to combat social isolation;
7. Motivate patients to adhere to self-management regimens, with creative online mechanisms;
8. Provide effective user-friendly interface design for patients.

Procedure: Please note that all notes taken and discussions recorded will be treated as confidential and participant identities will not be revealed to anyone except the researchers. The results of this work will not identify anyone involved in these sessions. By participating in this study, you are agreeing to have your discussion recorded for further analysis and use in system design and development.

The persona-scenario method will be used to gather user input for system design. Clinicians with similar backgrounds will be paired so that personas (imaginary clinicians) they prepare will represent authentic people. Each group will receive a tailored discussion guide, an introduction to the online system's features, and will be supported by a facilitator to take notes. The goal is to create a detailed and realistic persona and to have that persona experience different aspects of the program, i.e. A scenario. Each participant pair will typically create one persona and one or two scenarios.

Summaries of the persona-scenario exercises presented by participants will be transcribed later and evaluated to understand how the personas chose to use the online system. These results will then be converted into a modified system design that supports users when programmed into the upgraded system.

Based on your knowledge and experience as an Informal caregiver, create a fictitious (but believable) “persona” and at least one “scenario” for each “persona” interacting with the self-care intervention program.

STEP 1: Create a Persona (10 minutes)

Your persona will be working in a multidisciplinary health team that supports patients that are using an online PAD self-management system. Give your health care provider “Persona”- some personality. Briefly describe the following:

1. A name
2. Age, gender
3. Education and employment background
4. Desires, attitudes about work
5. Years of service with current employer/organization
6. Experience with primary health care team members (physicians, nurses, social workers, pharmacists, etc.)
7. Comfort and experience with technology
8. Hopes and fears about PAD disease management
 - Do you know what peripheral arterial disease is?
 - Are you aware of what future impact this disease can have on your patient's health if not treated diligently and properly?
 - Have you concentrated seriously on treating your patient's disease since you learned that your patient has PAD?

STEP 2. Create a scenario (25 - 30 minutes each)

Create a scenario for your persona who is involved in the health self-management program. Describe the following:

1. How does the informal caregiver persona become involved with this self-care program? How does the patient and health provider?
2. What are the following personas doing in the scenario? (What, where, when, how?)
 - a. Informal caregiver (i.e. - In what ways are they using the online PAD self-management application?)
 - b. Patients (i.e. - In what ways are they using the online PAD self-management application?)
 - c. Health care providers (What information do they need to help manage disease and improve communication with patients?);
3. How the various personas are interacting? That is, how do individuals relate to each other (patients, clinicians, visiting nurses, volunteers, and care givers) and to the online system (e.g. online contacts with friends and family; contacts with clinicians)?
4. What happens when they (all personas involved) interact with the online system?
5. What happens after each interaction is complete?
6. What are the results/outcomes of these interactions? For patients; health care providers?

8.8. Appendix H: Informal Feedback Discussion Questions – Clinicians

1. Do you have any feedback about the study procedure in this session?
2. What did you like about the discussion today?
3. What did not you like?
4. Was it easy to pick up the method and complete the task?
5. Is there any way that you would like us to improve the discussion style?
6. Where you comfortable working in group?

7. What kind of different PAD patients you think we will have in the study? What kind of questions will help us to pair them better?
8. What kind of different informal caregivers you think we will have in the study? What kind of questions will help us to pair them better?
9. Do you think there could be another kind of Clinician (PAD Surgeons) persona?

8.9. Appendix I: Informal Feedback Discussion Questions – Patients and Informal Caregivers

1. Do you have any feedback about the study procedure in this session?
2. What did you like about the discussion today?
3. What did not you like?
4. Was it easy to pick up the method and complete the task?
5. Is there any way that you would like us to improve the discussion style?
6. Where you comfortable working in group (pairs)?