

IN SEARCH OF A MESSAGE TO PROMOTE  
PERSONAL HEALTH INFORMATION MANAGEMENT

By

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INFORMATION MANAGEMENT

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Research has shown that individuals who take an active role in their health and health care have better outcomes, lower costs, and higher functional status than those who take a more passive role. To be an active participant, individuals need information about themselves. However, most individuals are uninterested in taking on the responsibility of personal health information management (PHIM).

Adopting PHIM requires individuals to adopt new behaviors. This study begins to answer the question; What may influence students at an academic medical center to adopt PHIM? People are more likely to accept new ideas or take action when they perceive they will benefit from that idea or action. The most effective way of learning what is personally relevant to the specific target audience is to ask them.

A qualitative research design using focus groups to collect the data was completed at an academic medical center in a medium sized Midwestern city. This site was selected because the university offered students free Web based PHR.

The results of the study can be used to inform a social marketing strategy for promoting PHIM. Through the application of the Motivation, Opportunity, and Ability Model to the research findings, by comparing characteristics of the research participants to those of prior research, and by

integrating the findings into the conceptual framework composed of a matrix of the marketing mix to the MOA Model, potentially personally relevant goals were identified. The students felt personally relevant goals were the need to maintain immunization records in an organized, convenient manner. They perceived that were healthy and had small amount of discretionary time, and favored systems that involved technology.

The message that may influence students to adopt PHIM would include increasing awareness, describing “how to,” and scary story of those who suffered because they did not do PHIM. These messages would best deliver the messages by an authority, a celebrity, or an organization with nothing to gain.

## TABLE OF CONTENTS

Acknowledgements and Dedication	ii
Abstract	iv
Table of Contents	vi
Table List	ix
Figure List	x
<b>Chapter I Introduction</b>	
Background	1
Terms Defined	4
My Interest in Personal Health Information Management (PHIM)	7
Research Problem	8
<b>Chapter II Literature Review</b>	
Introduction	11
Part I Personal Health Information Management Literature Review	11
Part II Social Marketing Literature Review	44
Part III Qualitative Research Design Literature Review	74
Summary	85
<b>Chapter III Research Methods</b>	
Introduction	86
Research Setting and Participants	86

Institutional Review Board Approval	87
Recruiting and Selecting Focus Group Participants	87
Data Collection Methods	89
Data Analysis Methods	92
Methods to Assure Rigor and Trustworthiness of Findings	94
Limitations in Methodology	97
Summary	98
<b>Chapter IV Research Findings</b>	
Introduction	100
Research Context	101
Research Findings Categorized by the Motivation, Opportunity, and Ability (MOA) Model	108
Summary	140
<b>Chapter V Analysis and Interpretation of Research Findings</b>	
Introduction	143
Research Findings Applied to the Building Block Mode of Social Marketing, Part I From Societal Goal to Exchange	150
Research Findings Applied to the Building Block Mode of Social Marketing, Part II Application of the Conceptual Framework and Block Seven The Marketing Mix	1588
Summary	186
<b>Chapter VI Conclusions and Recommendations</b>	
Conclusions and Contributions	189

Recommendations	194
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## **Appendixes**

A. E-mail to student organization leaders	199
B. E-mail to academic program directors	200
C. E-mail to students	201
D. Flier	202
E. Interest Form	203
F. Confirmation letter	205
G. Informed consent	206
H. Rights of research subjects	210
I. Focus Group Participant Information	211
J. Focus group agenda	213
K. Moderator script and focus group questions	214
L. Summary of responses to intake form questions	217
<b>Reference List</b>	<b>219</b>



## TABLE LIST

2.1	Time line: Personal health record	14
2.2	Categories and sub-categories of individuals' perceptions of benefits of PHIM	21
2.3	Categories and sub categories of individuals' perceptions of barriers and concerns about PHIM	35
2.4	Definitions and examples of Building Block Model of Social Marketing	47
2.5	Useful characteristics for market segmentation	54
2.6	Comparison of social marketing to commercial marketing	62
2.7	Motivation, opportunity, and ability summary concepts	68
2.8	Conceptual framework: MOA Model and marketing mix	74
4.1	Demographic descriptions of focus group participants	102
4.2	Participants' free time activities ranked by activity mentioned most often	105
4.3	Comparison of research questions to research findings using the Motivation, Opportunity, and Ability Model	111
5.1	Comparison of PHIM empirical research findings to dissertation research findings	144
5.2	Comparison of participants from dissertation research study to those in the PHIM empirical research	154
5.3	Conceptual framework: MOA Model and marketing mix	157
5.4	Research findings integrated into the conceptual framework comparing the MOA model to the marketing mix	158

## FIGURE LIST

2.1	Benefit Model for Personal Health Information Management	43
2.2	Building Block Model of Social Marketing	46
2.3	Stages of Behavior Change	61
2.4	PSI algorithm to categorize variables by motivation, opportunity, and ability	71
2.5	Relationship between the MOA Model constructs	72
4.1	Participants' age range by focus group	104
4.2	Participants' gender by focus group	105
4.3	PSI algorithm to categorize variables by motivation, opportunity, and ability (Figure 2.4 repeated)	109
4.4	Continuum of motivation	115
4.5	Relationship between MOA Model constructs to research findings and research questions	142
5.1	Stages of behavior change (Figure 2.3 repeated)	185
6.1	Identification of personally relevant issues influencing adoption of PHIM	191

## CHAPTER I: INTRODUCTION

### Background

Today's health care system is fragmented. One individual may have several different doctors, each for a different condition, each at a different location and each affiliated with a different acute care hospital, laboratory or pharmacy. The individual may seek emergency care at yet another location while on vacation or one that is just more convenient. Yet again, the individual may self-medicate with over-the-counter remedies from the local drug store. The only constant is the individual, who is often ill prepared to integrate information across health care settings.

Health care is information dependent. Clinicians need individuals' histories, descriptions of current conditions, results of diagnostic testing, and listing of current medications to determine the best course of treatment. Without this information, treatment is at best an educated guess. Since individuals are the only ones who can describe what happened in various health care settings and in between health care encounters, providers depend on their recall of when and where they were treated. At the very least, individuals must inform their providers where they have been treated, so that providers can obtain health records. No single health care provider maintains a master record for each patient. Individuals have as many records as providers.

Medical records are the information centerpieces of the health care decision-making process and provide an essential means of communication between health care providers. Medical records serve as data repositories for individuals' health history, health status, and health services provided over time. Health care providers depend on medical records to provide proof of services rendered for reimbursement and as rationale

for diagnoses and treatment decisions (Abdelhak, Grostick, Hanken, & Jacobs, 2007). Patients depend on providers to keep these records for their own future use.

The frequent mobility of the population, with Americans moving on average once every five years (Jasper, 2000), increases the number of places where medical records are kept and the difficulty in obtaining access to them. In an emergency, access to an individual's health history can mean the difference between life and health. For example, the aftermath of Hurricane Katrina in 2005 exposed many weaknesses not just in the structural support of the levees but also in the health information infrastructure (Tang & Lansky, 2005). Along with most of their worldly possessions, many people lost access to their medical histories and evidence of their current treatment due to destruction of the providers' paper medical record systems. For some, loss of information was life threatening. Individuals were left to describe their medications as a "little blue pill" to physicians whom they had never seen before ([www.katrinahealth.org](http://www.katrinahealth.org)).

Reports from the Institute of Medicine (IOM) highlighted additional problems of our health care system. In 2000, the IOM published *To Err is Human*. This report revealed that medical errors are the eighth leading cause of death in the United States (Kohn, Corrigan, & Donaldson, 2000). This report was followed by the publication of *Crossing the Quality Chasm* that proposed a design for the health care system that would solve these ills. The title of the report illustrated the enormity of the problem in that the difference between where health care is and where it should be is not a gap but a chasm. The proposed design of the health care system for the 21st century changes the focus of control from the provider to the individual. The report cited numerous studies that showed that informed individuals who actively participate in their health care decisions

have better outcomes, lower costs, and higher functional status than those who take a more passive role (Committee on Quality of Health Care in America Institute of Medicine, 2001).

As health care costs rise, individuals are asked to pay a greater portion of these costs through higher premiums, deductibles, and consumer driven health plans. How can individuals use their health dollars wisely without knowledge of their health conditions (Markle 2008, Moen 2005)? Individuals need to understand their health history in concert with their reimbursement mechanisms to make appropriate choices (Kane, 2002).

Information technology is seen as the solution to many of the health care systems' problems. In the 2004 State of the Union address, President Bush called for the public and private sectors to work together to create an electronic health record (EHR) for the majority of Americans within 10 years. The President believed that better health information technology is essential to his vision of a health care system that puts the needs and the values of patients first and gives patients information they need to make clinical and economic decisions (iHealthBeat, 2004). President Obama is continuing to pursue the implementation of information technology in health care. He said, the health care system needs "to ensure that within five years, all of America's medical records are computerized." Health care IT was included in the economic stimulus package approved in February 2009. Obama said, use of IT in healthcare "will cut waste, eliminate red tape and reduce the need to repeat expensive medical tests. But it just won't save billions of dollars and thousands of jobs — it will save lives by reducing the deadly but preventable medical errors that pervade our health care system" (Ferris, 2009).

Currently health care providers are not connected and data are not easily shared or readily available when needed. Individuals need to fill the missing links and take responsibility for managing their personal health information (Waagemann, 2005), which may be in the form of a personal health record (PHR) or health record bank (HRB) account.

Providing individuals access to the health information is currently a labor intensive and expensive system in the primarily paper based world of medical records. However, individuals are seeing the benefit of having convenient access to their own information in other areas of their lives such as finances and are recognizing the value of personal health information management (PHIM) behaviors. As more individuals push for access to PHI, the sooner providers will adopt systems that facilitate PHIM (Ball, Smith, & Bakalar, 2007; Leonard, Casselman, & Wiljer, 2008; Popovich, 2008).

#### Terms Defined

The National Alliance for Health Information Technology (National Alliance for Health Information Technology, 2008) recently put forth consensus definitions of the electronic health record, electronic medical record and personal health record.

##### *Electronic Health Record (EHR)*

“An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be created, managed, and consulted by authorized clinicians and staff across more than one health care organization” (p. 6)

##### *Electronic Medical Record (EMR)*

“An electronic record of health-related information on an individual that can be created, gathered, managed, and consulted by authorized clinicians and staff within one health care organization” (p. 6).

#### *Personal Health Record (PHR)*

“The PHR is an electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual” (National Alliance for Health Information Technology, 2008, p. 19). A key difference between the PHR and other types of health records such as the EHR and EMR is that the individual controls the information in it. The individual determines the content of the PHR and who may access that information (National Alliance for Health Information Technology, 2008 , p. 19).

#### *Health Record Banking An Alternative To The PHR*

A health record bank (HRB) is modeled after financial institutions. It would serve as the trusted custodian of personal health information “deposited” in an individual’s account. Health information can be deposited by individuals themselves or by “direct deposit” of those authorized to contribute to that account, such as doctors, laboratories, pharmacies, and hospitals. Account holders control who can access what information and have total access to information within the accounts themselves (Ball, et al., 2007; Gold & Ball, 2007). Pilot projects based on the health record bank are being conducted in Kentucky, Oregon and Washington ([www.nhinwatch.com](http://www.nhinwatch.com)).

The benefit of the health record bank over the PHR is that the information would be accessible in a standardized format to individuals, health care providers, and payers

authorized by the “account holder.” With the health record bank serving as the data center, providers would not need to develop connections with other providers to access patient health information (Mandl & Kohane, 2008).

Both the PHR and the health record bank require that individuals manage their personal health information. As of yet, the public has not shown an overwhelming interest in assuming this responsibility. In the 2008 a survey of 1,580 adults showed that almost half (46.5%) were interested in an on-line PHR service but only 2.7% are utilizing one (Westin, 2008). The director of support systems of a 200,000 member Florida insurance company reflected, "utilization is pretty dismal" on the sign up of only 34 members for an “electronic clipboard” that would replace individuals’ need to repeat their medical histories (Versel, 2007). Another survey by Aetna Insurance and the Financial Planning Group found that 64 percent of 2,100 adults said they “do not know or are unsure about what a PHR is” (“Nearly two-thirds of Americans are not familiar with personal health records, a resource available to millions of consumers," 2007)

#### *Personal Health Information Management Defined*

The term personal health information management (PHIM) is used in this study to identify a wide range of behaviors such as asking health care providers for copies of diagnostic test results and other medical records; trending health indicators such as exercise, blood pressure readings or blood glucose levels; sharing personal health information with health providers and care givers; creating, and maintaining a PHR or establishing a HRB account.



### My Interest in Personal Health Information Management (PHIM)

Since I began my career in medical record administration, now known as health information management, 30 plus years ago, I firmly believed that individuals have the right to control and access their own health information. At that time, this practice was not widely accepted by the health care community. Patients were required to get their physicians' permission to see their medical records. Since the beginning of the 21<sup>st</sup> century with the promulgation of the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule and publication of the report from the National Committee on Vital and Health Statistics on *Information for Health: A Strategy for Building the National Health Information Infrastructure (NHII)*, individuals' rights to their own information have moved significantly to the forefront. The HIPAA Privacy Rule gives individuals the right to access and authorize others to access their providers' medical records (Office of Civil Rights & US Department of Health and Human Services, 2002). The NHII went one step further and conceptualized a personal health information domain that would be owned and maintained by the individual (National Committee on Vital and Health Statistics, 2001). With these two major changes that align with my long held ideals, I began my journey toward the doctoral degree and focused all research efforts on adoption of the PHR. For the dissertation, I chose to study individuals' behaviors needed to manage their personal health information or PHIM instead of the PHR for several reasons.

- 1) The PHR is evolving and many models exist including HRB. Information gained about one model may not be relevant to other models.

2) PHR is not a widely known or understood term. Its use in the communications with research participants may divert their attention from the key research questions.

3) Some type of personal health information management behavior is needed for most PHR models.

### Research Problem

Accurate and complete personal health information (PHI) is needed to provide effective and safe health care. PHI is generated both by health care providers when individuals receive health care services and by individuals themselves in every day activities that may affect their health. To provide effective and safe health care, providers need access to the variety of information sources. Currently, to assemble this information from the variety of sources is difficult, which may be an understatement. Individuals, who are at the center of the process, have the most to gain (and lose) from having accurate and complete information about their health care. However, most individuals are uninterested in taking on the responsibility of PHIM (Taylor, 2004; Versel, 2007).

This research study begins to answer the question, “What influences individuals to adopt PHIM behaviors?” People are more likely to accept new ideas or take action when they perceive they will benefit from that idea or action. When thinking about influencing others to adopt behaviors, many mistakenly assume that what motivates me motivates those whose behavior they wish to influence. However, motivation is very individualized. As Aristotle said, “The fool tells me his reason; the wise man persuades me with my own.” Following Aristotle’s advice, the central question of this research study is to discover what will influence students at an academic medical center to adopt

for PHIM through the use of focus groups. The study's findings will inform a social marketing strategy to promote PHIM.

Having laid out the rationale for this research study in Chapter I, I further support the need for this study through a review of empirical research of PHIM in Chapter II. Prior research focused mainly on participants' desired functions and potential used of patient held records and access to electronic systems. The review shows this study to be unique in approaching the topic from influencing individuals' behavior and focusing on a unique target audience of students at an academic medical center. Another distinctive aspect of this study is to use the results to inform a social marketing strategy that would influence PHIM adoption. To provide the background in social marketing, I review the basic concepts and information needed to inform a social marketing strategy. Chapter II concludes with a brief description and rationale for using a qualitative research design with focus group data collection methods.

Chapter III describes methods used to recruit and select research participants, arrange and implement focus groups, collect, analyze, and interpret the research findings. Also included is the description of techniques used to ensure the trustworthiness of the data analysis and the limitations of the methods used. Chapter IV describes the findings from the focus group discussions using the Motivation, Opportunity, and Ability Model. Chapter V explains the analysis of the research findings and concludes with recommendations for social marketing arranged by the 4 P's of the marketing mix, product, price, place, and promotion. In Chapter VI, I propose conclusions and recommendations from the research. The conclusions encompass identification of variables that are personally relevant to this target audience and may influence adoption

of PHIM, health information management by health care providers, and contributions to social marketing. Following the conclusion I recommend the next steps to continue the social marketing strategy for PHIM, practical changes that would encourage PHIM, and suggestions for further research.

## CHAPTER II LITERATURE REVIEW

### Introduction

The purpose of this study is to discern what will influence students at an academic medical center to adopt personal health information management (PHIM) behaviors. The literature review consists of three sections. The first section concentrates on the subject matter of the research study of personal health information management (PHIM). In this section, I review the empirical research that included individuals' perceptions of benefits of and concerns about PHIM. The second section documents the purpose and concepts of social marketing, suggests the rationale of its use in constructing the research design, and describes the conceptual framework to analyze the study's data. The third section provides a brief review of qualitative research design and the use of focus groups for data collection. Review of the literature was a continuous process from development of the research proposal, through data collection, analysis and interpretation.

### Part I

#### Personal Health Information Management

##### Literature Review

Communications systems and access to information are changing rapidly. Tasks that needed an expert in the past, such as completing income tax forms and buying stock, have been simplified. By having continuously accessible personal information and easy to use software programs, many people now perform these tasks themselves. Health care is also evolving with information available through the Internet that previously could only be accessed through medical libraries and understandable to medical professionals. Medline Plus, a Web site for consumers, receives 70 million hits a year

(<http://www.healthinsurance.info/issues-advocacy/advocacy-groups/medline-plus>).

However, health care providers in the United States have been slow to allow individuals' access to and use of their personal health information (Markle Foundation, 2008). One reason may be the cost of providing copies to patients from the current paper based medical record systems. My son recently shared the experience of being told it would take six weeks to receive a copy of an emergency department record.

PHIM is not a new idea. In a 1973 editorial in the *New England Journal of Medicine*, Shenkin and Warner (1973) proposed giving patients access to their medical records. Since this "radical" editorial, physicians expressed concerns about the potential harms associated with giving patients access to their medical records. They worried that patients would misunderstand their medical records and be more likely to sue. With that worry, doctors would not completely document their opinions in medical records (Fowles, et al., 2004). None of these concerns have proved true. In fact, studies showed that patients benefited from having access to their medical records. When patients felt more informed by having information when they needed it, they were less anxious and more satisfied with their health care (Fowles, et al., 2004; Markle Foundation, 2008; Ross, et al., 2005).

Individual access and control of health information through personal health records (PHR) has received much attention since 2000. Important stakeholders in the public and private sector have shown interest in the PHR. The PHR timeline listed in Table 2.1 shows increasing and persistent activity by both public and private organizations including health care providers and payers, large corporations, professional

associations. Most recently PHRs are addressed in government economic stimulus package (Goedert, 2009).

Large employers such as Wal-Mart and Intel, health insurers such as Blue Cross, and the technology giants Google and Microsoft (Goldman, 2007, p. 489; Martin, 2007; Versel, 2006) are promoting their own versions of PHRs. Three influential health information professional organizations, the American Medical Informatics Association along with the American Health Information Management Association and the Health Information Management and Systems Society, released positions statements regarding the PHR (2007; 2007) . The Robert Wood Johnson Foundation funded design and development of eight innovative PHRs with three and a half million dollars (University of Wisconsin-Madison School of Nursing, 2006). Health Level 7, a voluntary standard setting organization, proposed functional standards for the PHR for balloting in August 2007 (“HL7’s EHR Technical Committee Opens Public Comment on Personal Health Record System (PHR-S) Functional Model”, 2007). The National Alliance for Health Information Technology (NAHIT) has proposed a consensus definition of the PHR (National Alliance for Health Information Technology, 2008):

The PHR is an electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual (National Alliance for Health Information Technology, 2008, p. 19).

A workgroup of the Commission on Certification of Health Information Technology (CCHIT) is studying the possibility of developing standards for PHRs (<http://www.cchit.org/phr/members/>).

Table 2.1 Time line: Personal health record

Date	Event	Relevance to the PHR
2001	IOM Report: <i>Crossing The Quality Chasm: A New Health System for the 21st Century</i>	Proposes six aim of the health care systems, one of which is patient-centered care and a “rule” to implement is the free flow of information
2001	Publication by National Committee on Vital and Health Statistics: <i>Information for Health: A strategy for building the national health information infrastructure</i>	Describes the personal health dimension as one of three domains of the infrastructure. The other two are the provider and public dimensions
2004	Markle Foundation forms Connecting for Health to realize the full potential of networked information sharing to improve health and health care, while protecting the privacy and security of personal health information	Connecting for Health published several reports leading to establishing a framework to an exchange health information that includes the consumer
2003	Effective date of the HIPAA Privacy Rule	Patients have the right to see and obtain copies of their medical records
2004	President Bush proclaims that, “Majority Americans with have an electronic	National statement of direction for health information technology



Date	Event	Relevance to the PHR
	personal health record by 2014.”	
2004	Office of the National Coordinator (ONC) for Health Information Technology created as part of US Department of Health and Human Services	Established a federal level agency to overcome barriers and stimulate development and implementation of health information technology
2004	American Health Information Community (AHIC) is formed. It is public private advisory body to the ONC	One work group focused on consumer empowerment
August 2005	Hurricane Katrina	Emphasized the need for individuals to keep track of their own information when medical records in both electronic and paper form were destroyed
2006	IOM Report <i>Preventing Medical Errors</i>	Recommends patients maintain a list of their medications and take it with them to encounters with health care providers for review
2006	Representative Patrick Kennedy introduced bill HR 6289 Personalized Health Information Act of 2006	Provides incentives to providers who use interactive personal health records
July	The American Health Information	The statement advocates

<b>Date</b>	<b>Event</b>	<b>Relevance to the PHR</b>
2006	Management Association (AHIMA) along with the American Medical Informatics Association (AMIA) issued a joint position statement on PHRs	empowering individuals to manage their health care through the use of a personal health records (PHR)
2007	Dossia announced	A group of large employers including Wal-Mart, Intel, Pitney Bowes, British Petroleum and others announced that they have joined together to form Dossia, a non profit organization that will provide PHR's for their employees.
2006	Robert Wood Johnson Foundation (RWJF) announced Project Health Design	RWJF funded eight projects to design PHR by involving specific patient groups and encouraging novel approaches to meet the particular information needs of this specific group
July 2007	Health Information Management Systems Society (HIMSS) published PHR position statement	HIMSS is composed of health information technology vendors. The position statement is directed toward this group
August	Health Level 7 publishes PHR-Systems	Functional standards for personal

<b>Date</b>	<b>Event</b>	<b>Relevance to the PHR</b>
2007	standards	health record systems
Oct 4, 2007	Microsoft launches Health Vault	Free web site that includes a health search engine, place for storage of health records, connection to remote monitoring devices
October 2007	Center for Medicare and Medicare Services grant Oregon Department of Health and Human Services funds to implement a HRB	Vision is to improve availability and accessibility of PHI to Oregon residents and improve health and health care
Dec 2007	American Health Information Plans (AHIP) and Blue Cross Blue Shield Association published PHR Implementation Guide	The insurance plans worked together to develop an implementation guide so that personal health data can be transfer PHR data elements between insurance plans
April 2008	National Alliance for Health Information Technology (NAHIT) issues standard definition for PHR	NAHIT formed a work group of public-private stakeholders to define key terms including EHR, EMR, PHR, RHIO, HIE
May 2008	Medicare Pilot Program	Center for Medicare and Medicaid Services (CMS) pilots an online PHR for beneficiaries with

Date	Event	Relevance to the PHR
		<p>traditional Medicare in South Carolina. The PHR will be populated by Medicare claims data. The program was expanded to beneficiaries in Utah and Arizona in 2009</p>
<p>May 2008</p>	<p>Google Health launched</p>	<p>Combines Google search functions with an on line PHR The PHR is stored in the company's' data centers. It includes links and reminders to take medications.</p>
<p>May 2008</p>	<p>Kroger grocery stores begin selling PHRs on a flash drive</p>	<p>PHRs are available and accessible to consumers at all levels.</p>
<p>July 2008</p>	<p>Certification Commission for Healthcare Information Technology (CCHIT) forms a work group to examine standards for PHR</p>	<p>The work group is defining standards to certify various PHR products.</p>
<p>February 2009</p>	<p>Health IT included in President Obama's economic stimulus package and continuance of President Bush's pledge to have EHR by 2014</p>	<p>Impose new consumer protection requirements on vendors of personal health records (Goedert, 2009)</p>

*Empirical Research on Personal Health Information Management*

Along with interest in PHRs on the national landscape, the PHR and various aspects of PHIM are increasingly the focus of research. This section of the literature review describes the contributions of empirical research to gaining an understanding of individuals' perceptions of benefits from and barriers to various aspects of PHIM. The majority of the studies included in this review queried individuals' perceptions of perceived benefits and concerns about accessing specific information systems and types of personal health records. Two studies did involve individuals' perceptions of managing their own health information (Pratt, Unruh, Civan, & Skeels, 2006; Rassin, Zilcha, Berger, & Silner, 2006).

The studies included in this section investigated individuals' responses to a variety of related issues such as feelings of empowerment by having access to their health records. They also explored characteristics of individuals who were interested in reading their medical records, individuals' interest and intention in utilizing compact discs that held copies of their medical records, and desired functionalities of patient access to providers' electronic health records. None of the empirical studies queried individuals directly to learn what may influence them to adopt PHIM.

The studies were useful in providing perceptions that could be grouped into two major categories of benefits and concerns about PHIM or what could be interpreted as positive and negative influences on adopting PHIM. The review focuses on the words individuals used to talk about the benefits of and barriers to various aspects of PHIM. Through examination of research participants' responses to focus group, semi structured interview, and survey questions, I subdivided the categories into sub categories as are

outlined in Table 2.2 [benefits] and Table 2.3 [barriers and concerns]. The sections following each table expand on the tabular information with additional information and quotations that capture individuals' perceptions. Finally, I propose a model, Figure 2.1, showing the relationships between the benefit sub-categories that will be useful to understanding the positive influences on individuals to adopt PHIM behaviors.

Table 2.2 Categories and sub-categories of individuals' perceptions of benefits of PHIM

<b>Manage health Information</b>	<b>Manage health and health care</b>	<b>Improve the effectiveness and safety of health care by providing health information to health care providers</b>	<b>Improve knowledge and understanding about one's health and health care</b>	<b>Positively impact relationship with physicians</b>	<b>Develop positive feelings about oneself and one's health care providers</b>
Provide convenient access to personal health information (Popovich, 2008; Ceclia Pyper, Justin Amery, Marion Watson, & Clarie Crook, 2004a; Ceclia Pyper, Justin Amery, Marion Watson, & Claire Crook, 2004b; Ralston, Revere, Robins, & Goldberg,	Use in autonomous decision-making (Civan, Skeels, Stoylar, & Pratt, 2006; Fowles, et al., 2004; Moen & Brennan, 2005; Pyper, et al., 2004a; Winkelman, Leonard, & Rossos, 2005)	Improve effectiveness and safety of healthcare (Agarwal & Angst, 2006; Civan, et al., 2006; Rassin, et al., 2006; Tobacman, et al., 2003)	Increase knowledge of health condition (Anhoj & Nielsen, 2004; Banet & Felchlia, 1997; Fowles, et al., 2004; Maly, Bourque, & Engelhardt, 1999)	Increase confidence and trust in doctors (Honeyman, Cox, & Fisher, 2005; Pyper, et al., 2004b)	Feel empowered (Honeyman, et al., 2005; Rassin, et al., 2006)

<b>Manage health Information</b>	<b>Manage health and health care</b>	<b>Improve the effectiveness and safety of health care by providing health information to health care providers</b>	<b>Improve knowledge and understanding about one's health and health care</b>	<b>Positively impact relationship with physicians</b>	<b>Develop positive feelings about oneself and one's health care providers</b>
2004; Tang & Lansky, 2005)					
Organize data in useful ways, have one place for vital data (Agarwal & Angst, 2006; Civan, et al., 2006; Tobacman, et al., 2003)	Coordinate health care services, serve as own case manager (Rassin, et al., 2006)	Information available in emergencies (Civan, et al., 2006; Leonard, 2004; Pyper, et al., 2004b)	Increase individuals' understanding, insight, clarification about their health and treatment (De Clercq, 2003; Fischbach, Sionelo-Bayog, Needle, & Delbanco, 1980; Fowles, et al., 2004; Honeyman, et al., 2005; Leonard, 2004;	Prepare for and improve physician office visits (Civan, et al., 2006; Maly, et al., 1999; Pyper, et al., 2004a; Pyper, et al., 2004b; Ross, et al., 2005; Williams, et al., 2001)	Increase sense of control over their health and health care (Liaw, Radford, & Maddocks, 1998; Ross, et al., 2005; Ward & Innes, 2003; Williams,



<b>Manage health Information</b>	<b>Manage health and health care</b>	<b>Improve the effectiveness and safety of health care by providing health information to health care providers</b>	<b>Improve knowledge and understanding about one's health and health care</b>	<b>Positively impact relationship with physicians</b>	<b>Develop positive feelings about oneself and one's health care providers</b>
			Munir & Boaden, 2001; Pyper, et al., 2004a; Pyper, et al., 2004b; Ralston, et al., 2004; Rassin, et al., 2006; Tang & Newcomb, 1998; Williams, et al., 2001)		et al., 2001)
Control access (Civan, et al., 2006; Pratt, et al., 2006)	Track, monitor, and trend (Anhoj & Nielsen, 2004; Banet & Felchlia, 1997; Fowles, et al., 2004;	Share with other health care providers (Denton, 2001; Leonard, 2004; Pyper, et al., 2004b; Rassin, et al., 2006)		Work together on health issues, change dynamic to formulate partnerships (De Clercq, 2003;	Improve patient satisfaction (Maly, et al., 1999; Ralston, et al., 2004; Ross,

<b>Manage health Information</b>	<b>Manage health and health care</b>	<b>Improve the effectiveness and safety of health care by providing health information to health care providers</b>	<b>Improve knowledge and understanding about one's health and health care</b>	<b>Positively impact relationship with physicians</b>	<b>Develop positive feelings about oneself and one's health care providers</b>
	Pyper, et al., 2004b; Ralston, et al., 2004; Williams, et al., 2001)			Fischbach, et al., 1980; Honeyman, et al., 2005; Pyper, et al., 2004b; Tang & Lansky, 2005; Tang & Newcomb, 1998; Winkelman, et al., 2005)	Moore, Earnest, Wittevrongel, & Lin, 2004; Ross, et al., 2005; Tang & Newcomb, 1998)
Assure accurate and complete information in providers' medical records (Fischbach, et	Comply and adhere to instructions and treatment plan (Agarwal & Angst,	Jog memory to construct medical history (Fischbach, et al., 1980; Fowles, et al., 2004)		Improve patient-doctor communication, (Fischbach, et al., 1980; Fowles, et al.,	Feel secure and valued with ongoing monitoring

<b>Manage health Information</b>	<b>Manage health and health care</b>	<b>Improve the effectiveness and safety of health care by providing health information to health care providers</b>	<b>Improve knowledge and understanding about one's health and health care</b>	<b>Positively impact relationship with physicians</b>	<b>Develop positive feelings about oneself and one's health care providers</b>
al., 1980; Fowles, et al., 2004; Maly, et al., 1999; Pyper, et al., 2004a; Pyper, et al., 2004b; Ross, et al., 2005; Ward & Innes, 2003)	2006; Fischbach, et al., 1980; Ross, et al., 2004; Ross, et al., 2005)			2004; Honeyman, et al., 2005; Liaw, et al., 1998; Munir & Boaden, 2001; Pyper, et al., 2004a)	(Ralston, et al., 2004)
Share information with family and friends in social network (Liaw, et al., 1998; Pratt, et al., 2006; Tang &	Support healthy behaviors and disease prevention (Civan, et al., 2006; Fischbach, et al., 1980; Liaw, et				

<b>Manage health Information</b>	<b>Manage health and health care</b>	<b>Improve the effectiveness and safety of health care by providing health information to health care providers</b>	<b>Improve knowledge and understanding about one's health and health care</b>	<b>Positively impact relationship with physicians</b>	<b>Develop positive feelings about oneself and one's health care providers</b>
Newcomb, 1998)	al., 1998; Moen & Brennan, 2005; Popovich, 2008; Pyper, et al., 2004b; Tang & Lansky, 2005; Winkelman, et al., 2005)				

### *Individuals' Perceptions of PHIM Benefits*

Individuals' perceptions of PHIM benefits identified in the research studies fall into the following six categories. PHIM facilitates individuals' ability to:

- Manage their health information
- Manage their health and health care
- Improve the effectiveness and safety of their health care by providing health information to health care providers
- Improve their knowledge and understanding about their own health and health care
- Positively impact their relationships with physicians
- Develop positive feelings about themselves and their health care providers.

*PHIM helps individuals manage their health information.*

A somewhat obvious benefit derived from PHIM is to assist individuals in managing their health information by providing convenient access to personal health information (PHI). They recalled dates and providers of health care services such as immunizations (Popovich, 2008; Pyper, et al., 2004b), and find on-line test results with keys to normal values without waiting for a call from the doctor's office (Ralston, et al., 2004).

Individuals were able to organize their data in meaningful ways (Agarwal & Angst, 2006) and were able to locate vital information such as advanced directives, immunizations, allergies, medications and operations when they needed it (Agarwal & Angst, 2006; Tobacman, et al., 2003). One group of focus group participants recognized

the “need to integrate different types of information from different aspects of their lives; personal, work, and health” (Civan, et al., 2006, p. 159).

Individuals wanted to control access to their personal health information (Civan, et al., 2006; Pratt, et al., 2006). Most did not want to tell their doctor everything. "Just because you're my doctor doesn't mean you can look at everything" (Civan, et al., 2006, p. 159). In contrast, a third of the participants in another study expressed concern that restricting health care provider access to health information could compromise their future health care, especially in an emergency (Pyper, et al., 2004a, p. SR 20).

Through PHIM, individuals were able to improve the content and quality of their providers' medical records (Fowles, et al., 2004; Pyper, et al., 2004b; Ross, et al., 2005; Ward & Innes, 2003). When asked directly, half of the participants in a study performed in the United Kingdom “wanted the option to add information to their records either as corrections, filling gaps, or stating personal wishes” (Pyper, et al., 2004a, p. SR 20).

PHIM was seen as useful in sharing health information with family and friends (Liaw, et al., 1998). An individual could easily answer the question, “What happened at the doctor's office?” with a computer-generated after visit summary (Tang & Newcomb, 1998). Individuals used patient web portals and shared e-mails to connect with their social support network (Pratt, et al., 2006).

*PHIM helps individuals manage their health and health care.*

The majority of health care occurs between encounters with health care providers. PHIM gives individuals information to use to assess, evaluate, and plan for their health and health care; set goals (Pyper, et al., 2004a; Tang & Newcomb, 1998; Winkelman, et al., 2005); figure out what might be wrong (Fowles, et al., 2004); and create treatment

action plans (Civan, et al., 2006). Participants in several studies said that PHIM was especially important for those with chronic diseases. Such individuals needed to identify complications and to know when to involve their health care providers (Moen & Brennan, 2005; Tang & Newcomb, 1998). With the available relevant information, individuals with chronic diseases, such as irritable bowel syndrome, were able to construct healthy lifestyle practices (Winkelman, et al., 2005).

PHIM also assisted individuals to coordinate their own care. Individuals reported, “By keeping documents and deciding to whom and when to show them, the patient functioned as a self-care manager” (Rassin, et al., 2006, p. 867). Coordination of care involves application of health care insurance reimbursement policies to individuals’ specific situation. Individuals found having access to their own information in determining effective use of their limited health care dollars (Moen & Brennan, 2005).

An important function of PHIM, evident in the literature, was providing the means for individuals to track, monitor, and trend their health conditions. They monitored their progress (Fowles, et al., 2004; Pyper, et al., 2004b; Ralston, et al., 2004; Williams, et al., 2001), tracked changes in medications (Anhoj & Nielsen, 2004; Banet & Felchlia, 1997; Fowles, et al., 2004), and with graphic tools trended their lab values and other vital signs. One patient said, “When I get my labs now (on-line), there’ll be a little star when it’s out of range, so I’m aware of what needs to be medicated or worked (on)” (Tang & Newcomb, 1998, p. 3).

PHIM improved individuals’ compliance with health care instructions supporting healthy behavior and disease prevention (Agarwal & Angst, 2006; Civan, et al., 2006; Fischbach, et al., 1980). In a randomized controlled trial, the members of the intervention

group who had access to their medical records had better compliance with medical advice and adherence to medications than individuals in the control group (Ross, et al., 2004; Ross, et al., 2005). Some PHIM systems provided reminders for office visits and preventive interventions such as immunizations and breast self-exams (Civan, et al., 2006; Popovich, 2008; Pyper, et al., 2004b). Individuals reported that their healthy behaviors of diet and exercise improved when they were able to monitor their triglycerides test results through a patient web portal (Tang & Lansky, 2005).

*PHIM improves the effectiveness and safety of health care by providing health information to health care providers.*

Research participants recognized the impact of managing their personal health information on the effectiveness and safety of their health care (Civan, et al., 2006). They recognized that inaccurate and unavailable information could result in errors, even death (Agarwal & Angst, 2006). Accurate and complete information facilitated individuals receiving health services according to their needs (Rassin, et al., 2006). Access to pertinent health information also simply saved both individuals and their health care providers time from searching for information (Tobacman, et al., 2003).

An important benefit of PHIM was for individuals to easily share their health information with providers involved in their care. PHIM “jogs individuals’ memories” to assist in constructing accurate health histories (Fowles, et al., 2004). Lung transplant patients valued sharing information with their family physicians. Having PHI was helpful when moving, when away from home, or in an emergency (Civan, et al., 2006; Denton, 2001; Fowles, et al., 2004; Leonard, 2004; Pyper, et al., 2004b). For example, an 83-year-old woman noted, "When I had a serious heart attack (and was) rushed to the



hospital, the only means of working out my past health problems (and present medications) was my personal health record from this study. It proved very useful" (Liaw, et al., 1998 p. S43).

*PHIM helps improve individuals' knowledge and understanding about their health and health care.*

This category is divided into two subcategories of knowledge and understanding based on *Bloom's Taxonomy of Educational Objectives*. In the taxonomy, attaining knowledge precedes gaining understanding of concepts (Gronlund, 1970). PHIM served as a means to gain knowledge (Banet & Felchlia, 1997; Liaw, et al., 1998), provided links to educational materials (Anhoj & Nielsen, 2004), improved knowledge of health promotion tasks (Liaw, et al., 1998), and increased interest in health-related information (Maly, et al., 1999). Respondents in Fowles' study saw that reading their medical records provided the "most direct information source available about themselves" (Fowles, et al., 2004, p. 797).

PHIM increased individuals' understanding and insight into their health and treatment (Banet & Felchlia, 1997; Fowles, et al., 2004; Honeyman, et al., 2005; Leonard, 2004; Liaw, et al., 1998; Munir & Boaden, 2001; Pyper, et al., 2004a; Ralston, et al., 2004; Ross, et al., 2005; Tang & Newcomb, 1998; Williams, et al., 2001). More specifically, PHIM clarified details regarding medication regimens. (Pyper, et al., 2004b) Again using learning theory, "learning by doing" led to greater understanding (Gronlund, 1970). When individuals entered their own data, decided which documents to bring to a physician office visit, and coauthored their medical records, they gained greater understanding and insight about their own conditions (De Clercq, 2003; Fischbach, et al.,

1980; Rassin, et al., 2006). The results of Fischbach's study showed that, "co authorship of the records is an alternative to the traditional model of teacher (physician)/passive pupil (patient) and allows the patient a voice in what evolves into a mutual learning experience. It is an effective means of conveying more complete, accurate and understandable information to both patient and provider" (Fischbach, et al., 1980, p.3).

*PHIM positively impacts individuals' relationships with their physicians.*

The physician-patient relationship is at the heart of health care. Patients entrust their lives to their doctors. PHIM had a positive impact on this key relationship by providing access to health information and removing some of health care's mystery. By gaining access to their health information, individuals were reassured, more confident and more trustful of their doctors (Honeyman, et al., 2005; Pyper, et al., 2004b; Ross, et al., 2005). Individuals felt that PHIM improved their doctor visits (Maly, et al., 1999) by helping them prepare for visits (Civan, et al., 2006; Williams, et al., 2001), by making it easier to talk to their doctors (Pyper, et al., 2004a), and by being able to use the information during their visits (Denton, 2001).

PHIM enhanced doctor-patient communications (Liaw, et al., 1998) by eliminating individuals' misconceptions when they read their doctors' notes (Fischbach, et al., 1980; Fowles, et al., 2004; Munir & Boaden, 2001), by helping individuals feel understood by their physicians, and by breaking down barriers between patients and their physicians (Honeyman, et al., 2005). Having information "levels the playing field between doctor and patient" changes the dynamic of the physician patient relationship. Patients and doctors form a "therapeutic alliance" working together toward a common goal (De Clercq, 2003; Fischbach, et al., 1980; Winkelman, et al., 2005).

*PHIM promoted development of individuals' positive feelings about themselves and their health care providers.*

Individual comments reported in several studies reflected an affective or emotional type of response to the notion of PHIM. Individuals reported an increased sense of empowerment, control, and improved satisfaction with their health care (Agarwal & Angst, 2006; Honeyman, et al., 2005; Liaw, et al., 1998; Ross, et al., 2005; Ward & Innes, 2003; Williams, et al., 2001). In a study of a diabetes support program, individuals reported feeling secure and valued with a “virtual presence” of the information systems that monitored their conditions. (Ralston, et al., 2004, p. 3). By being involved with their health information, individuals noted that their view of their “illness” was different than the doctor’s view of their “disease.” They felt a “respect for my story” (Ward & Innes, 2003, p. 295).

The research included in this review showed contrary findings of individuals’ feelings of empowerment. Two studies specifically investigated the feeling of empowerment, with one recognizing the difficulty in conceptualizing the feeling. The respondents in both studies did not feel empowered (Munir & Boaden, 2001; Tuil, ten Hoopen, de Vries Robbe, & Kremer, 2006). However, other studies supported the finding that PHIM empowers individuals in their health care (Agarwal & Angst, 2006) and can be summed up in a quote from Rassin’s Israeli study, “A patient’s attention to documents, as keeper and router, results in demonstrations of responsibility and involvement in treatment, consequently empowering the patient” (Rassin, et al., 2006, p. 867) .

*Individuals' Perceptions of Barriers and Concerns about PHIM*

When examining the benefits that may influence individuals to adopt new behaviors, the barriers to and concerns about those behaviors must also be considered. Even when individuals are motivated to change, the barriers may be too great to overcome. However, this review uncovered few barriers and concerns that may stand in the way of adopting PHIM. I grouped individuals' perceptions of the barriers and concerns about PHIM into the following five sub- categories.

- Privacy and security of health information
- Difficulty understanding medical language and the medical record
- Problems in getting medical records from health care providers and organizing the information obtained
- Avoidance of information about illness
- No need, interest, or ability and do not want the responsibility for PHIM

Table 2.3 Categories and sub categories of individuals' perceptions of barriers and concerns about PHIM

<b>Privacy and security</b>	<b>Difficulty understanding medical language and or the medical record</b>	<b>Difficulty organizing and getting records from providers</b>	<b>Avoidance of information about illness</b>	<b>No need, interest, ability and or do not want the responsibility</b>
Concern for system security, including unauthorized access and backup (Civan, et al., 2006)	Did not understand and difficult to use the medical record (Banet & Felchlia, 1997; Moen & Brennan, 2005; Pyper, et al., 2004a; Ross, et al., 2005)	Frustrated getting copies of records from providers (Civan, et al., 2006; Pratt, et al., 2006)	Did not want to focus on their disease (Anhoj & Nielsen, 2004; De Clercq, 2003)	No need or interest in accessing their medical records (Munir & Boaden, 2001; Rassin, et al., 2006; Ward & Innes, 2003)
Did not prefer records stored on Internet (Denton, 2001; Honeyman, et al., 2005; Ross, et al., 2005)	Did not understand medical terms (De Clercq, 2003; Pyper, et al., 2004b; Ward & Innes, 2003)	Needed to integrate diverse types of information (Civan, et al., 2006; Pratt, et al., 2006)	Wanted to receive information directly from health care provider (Pyper, et al., 2004b)	Unable to use computers (Pyper, et al., 2004a)

<b>Privacy and security</b>	<b>Difficulty understanding medical language and or the medical record</b>	<b>Difficulty organizing and getting records from providers</b>	<b>Avoidance of information about illness</b>	<b>No need, interest, ability and or do not want the responsibility</b>
			Anticipated frightening health information (Pyper, et al., 2004a; Winkelman, et al., 2005)	Did not want the responsibility of maintaining their medical records (Munir & Boaden, 2001; Ward & Innes, 2003)

*Privacy and security of health information.*

When the discussion topic involves personal health information, privacy and security of the information are usually near the top of the list of concerns. In the studies included in this review, individuals had varying degrees of concern regarding the privacy and security of their information. The degree of concern depended on the setting where access to health information took place and the type of record storage. In semi-structured interviews following individuals' access to their EHR through a kiosk in their providers' waiting room, more than three-quarters of the respondents were a little or not concerned with the security of the EHR (Honeyman, et al., 2005). When the Internet was the method of access and/or storage; individuals in several studies were worried about their privacy and expressed a preference for paper records or use of their own computer for records storage (Denton, 2001; Pyper, et al., 2004b; Ross, et al., 2005).

Individuals are willing to give up some of their privacy in exchange for specific benefits and functions. Most individuals recognize the need for disclosure of personal health information to achieve effective and safe health care. Seventy-three percent of respondents in Leonard's study were not concerned about family physicians, family members, or other medical specialists having access to their records (Leonard, 2004). Individuals recognized the tradeoff between providing access and maintaining security of their health information (Civan, et al., 2006). As stated previously, some feared that overly restricting access to their health information might compromise patient care especially in an emergency (Pyper, et al., 2004a). Individuals were concerned about the need for backups of electronic health information to assure the information is available when needed and not corrupted (Civan, et al., 2006).

As mentioned previously, individuals desired the right to control access to their health information (Ward & Innes, 2003). Control by the record subject has been seen as one way to address privacy concerns of PHIM. Individuals' roles as gatekeepers to their health information will provide them with a "greater-than-customary" control and require new knowledge and behaviors that most are not ready to accept (Project HealthDesign, 2007).

*Difficulty understanding medical language and the medical record.*

Because medical records are designed to be used by health care professionals, laypersons generally have some difficulty in understanding medical terms (Civan, et al., 2006; De Clercq, 2003; Ward & Innes, 2003), in locating information within the record (Banet & Felchlia, 1997; Moen & Brennan, 2005; Ross, et al., 2005), and in reading providers' handwriting (Pyper, et al., 2004a). One research study addressed this difficulty by providing a glossary for frequently used terms (Pyper, et al., 2004b).

*Problems in getting medical records from health care providers and organizing the information obtained.*

Individuals who want to manage their health information must obtain copies of their medical records from their health care providers. Participants in two studies, where the PHIM functionality was not connected to specific health care providers, shared the frustrations they experienced when requesting copies of their medical records from health care providers (Civan, et al., 2006; Pratt, et al., 2006). This finding is contrasted with the research studies focused on the organization's medical record systems. Several of the studies addressed individuals' interest in getting copies of their records. Some individuals valued the service so much they said that providing "after visit summaries"



would be a criteria for selecting a future provider (Tang & Newcomb, 1998). The participants in the two studies where the PHIM was not connected to health care organizations also reported on difficulty in organizing information from various aspects of their lives, including their health information. Participants in a study of patients with breast cancer had trouble “detailing their interactions with clinicians, tracking unaddressed health issues, and maintaining running lists of questions and concerns” (Civan, et al., 2006; Pratt, et al., 2006, p 54).

*Avoidance of information about illness.*

Not everyone wants access to his or her health information. One patient stated that, “she did not want diabetes to rule her life” (De Clercq, 2003). In another study, an asthmatic patient said, "You can get so focused on it [the disease] at times. Sometimes it is better to pretend nothing is wrong. It's a balance, you know" (Anhoj & Nielsen, 2004). By avoiding information about their conditions, individuals may feel more hopeful than they would if they knew the degree of their illness (Winkelman, et al., 2005). Individuals might also find the content of their health record frightening and thus may want to avoid it (Pyper, et al., 2004a).

Giving individuals access to their diagnostic test results through an electronic patient portal raises the issue of who should deliver “bad news.” Some individuals would rather receive bad news directly from their health care providers (Pyper, et al., 2004a). In California, there is no choice; by law, some information, such as an abnormal Pap smear, may not be reported to the patient electronically (Tang & Lansky, 2005).

*No need, interest, or ability and do not want the responsibility for PHIM.*

Individuals reported lack of interest in PHIM. Eighty-eight percent of respondents in Munir's study of individuals' interest in viewing their EHR had not looked at their records because they never "felt the need" (Munir & Boaden, 2001, p. 664). Respondents in two additional studies did not want to control their medical records (Ward & Innes, 2003) where control was defined as "being fully responsible for your own health record" (Munir & Boaden, 2001 p. 664; Ward & Innes, 2003). In addition to lack of interest in managing their own health information, individuals also expressed concern about their ability to do so (Rassin, et al., 2006) or about being "too old to use computers" (Pyper, et al., 2004a; Rassin, et al., 2006, p SR 20). Some were also concerned about taking up someone's time or being a bother when someone had to explain the system to them (Honeyman, et al., 2005). In contrast, others in another study would willingly pay for this assistance (Tuil, et al., 2006).

#### *The Research Settings and Participants' Characteristics*

As is discussed later in this chapter, consumer orientation is a foundational principle of social marketing (Andreasen, 1995; Kotler & Roberto, 1989; Kotler, Roberto, & Lee, 2002). This principle states that most effective marketing efforts are those that address the target groups' personally relevant goals (Rothschild, 1999). The best way to discover personally relevant goals is to gather them directly from the population whose behavior is the focus of the social marketing strategy (Maibach, Rothchild, & Novelli, 2002). To use the PHIM empirical research literature as a basis for comparison with this study's research findings, understanding the study context and the participants' characteristics is critical.

### *Settings for the PHIM Empirical Research Studies*

Researchers often solicit study participants from easily accessible populations. In the studies reviewed, the majority of participants were solicited through various health care systems with which the research was connected. These health care systems included the Veterans Administration (Tobacman, et al., 2003), academic medical centers (Leonard, 2004; Ross, et al., 2005; Winkelman, et al., 2005), health maintenance organizations (Ralston, et al., 2004), and community-based programs (Moen & Brennan, 2005). The purpose of these research studies involved the participants' perceptions of the record/information systems used in these health care organizations. Given this research design, many of the individuals' comments reflect the interaction with their health care providers and health care providers' records.

### *Characteristics of Participants in PHIM Empirical Research*

The authors of the PHIM empirical research reviewed in this section described the participants as having chronic condition (55% of the studies), patients, at specified health care organizations (24%), students (7%), and no defining characteristics (10%). A logical assumption is that individuals with chronic diseases and those who are frequent users of health care would be the most interested in PHIM. This assumption may have led to limiting the research to focusing the majority of the research on these two groups. Two studies found that having a chronic condition was not indicative of those interested in reading their medical records (Fowles, et al., 2004) and finding value in accessing providers' electronic medical record (Winkelman & Leonard, 2004). Fowles et al (2004) found that interest in reading medical records was "driven by a general concern about health, independent of health status, and by an interest in health information" (p. 795).

The researcher labeled this characteristic “health information seeking.” Health information seeking was described as ‘subscribing to a health magazine or newsletter, using a health resource book in the last few months, and seeing the Internet as a very important resource of health information’ (Fowles, et al., 2004, p. 796). In identifying characteristics of individuals likely to adopt PHIM, Winkelman found that “illness ownership” was more common than having chronic illness. Illness ownership is defined as patients feeling that they had the power to knowingly participate in their care (Winkelman & Leonard, 2004, p. 309).

### *Benefit Model for PHIM*

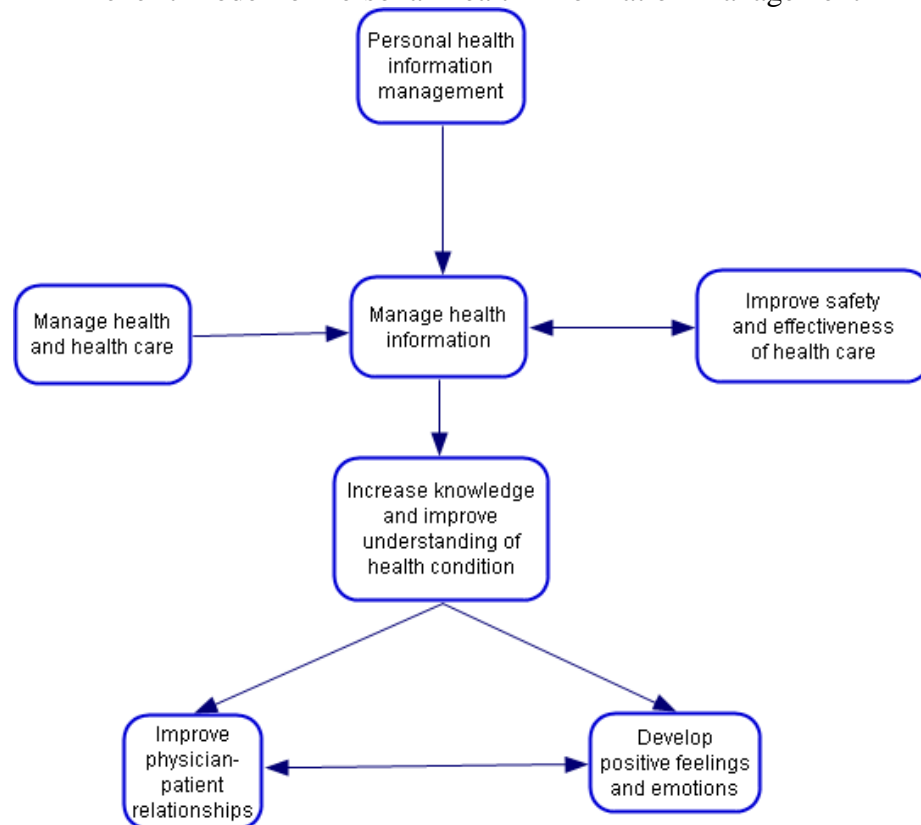
The benefit model for PHIM in Figure 2.1 proposes relationships between the benefit categories. The process of managing one’s own health information is in the center of the diagram from which the other benefit categories flow. Having access to and control of the information allows individuals to care for themselves, make autonomous decisions, and focus on health promotion and disease prevention. Without their information, managing one’s own health and health care is difficult. Individuals’ management of their health and health care produces more information that is useful to health care providers. Personal health information flows from the individuals’ management of their health and health care to their providers to use in giving safe and effective health care services.

Managing one’s health information leads to increased knowledge and understanding about one’s health condition. Having access to information will hopefully lead to a better-informed and healthier population. Being better informed leads to improved relations and communications between doctors and patients, and positive

emotions and feelings. These two categories would most likely interact because usually the more positive one feels, the better interpersonal relations are likely to be and reversed as well.

The layout of Figure 2.1 was not intended to resemble a stick figure. However, this stick figure image will be informative in the search for influences and development of a social marketing strategy to promote PHIM and use of the student PHR. When marketers mount a campaign, they create a persona representing the individuals who are most likely to purchase their product or service (Weinreich, 2006). The benefit model may form the basis of a persona of those who would be likely to adopt PHIM and could serve as a resource for the next steps in the search for a message.

Figure 2.1  
Benefit Model for Personal Health Information Management



## Part II

### Social Marketing Literature Review

The central question of this research study is to discover what may influence students at an academic medical center to adopt PHIM behaviors. Research has shown that when individuals are managing their health information they are more likely to take an active role in their health and health care. Individuals who are actively involved in their health and health care have demonstrated positive changes in both (Committee on Quality of Health Care in America Institute of Medicine, 2001). Given this research goal, social marketing is a natural fit for the research project because its goal is to influence behavior for the good of the target audience and society (Kotler & Roberto, 1989).

Social marketing is not a theory or a unique set of techniques, but is a process for developing social change programs based on private sector marketing methods (Andreasen, 1994). Social marketing has been used successfully in varied settings and for many purposes such as increasing fruit and vegetable consumption with the '5 a day program,' promoting breastfeeding to new moms, vaccinating children in developing countries, increasing physical activity among preteens (Grier & Bryant, 2005), preventing drug abuse and binge drinking among college students, and encouraging organ donation (Weinreich, 2006). Formulation of a social marketing strategy begins with gaining an understanding of the target group in relation to the behavior of interest. Thus, I selected social marketing to identify information needed to influence adoption of PHIM behaviors by students at an academic medical center.

By defining and describing distinctive characteristics of social marketing, this section of the literature review outlines the types of information needed to develop an

effective social marketing strategy. To gain a greater understanding of social marketing, it is compared to commercial marketing and other methods of persuasion and health promotion, and examines several potential ethical limitations. The section concludes with proposition of a conceptual framework based on a matrix that compares the Motivation, Opportunity, and Ability (MOA) Model to the marketing mix for use in analyzing the data collected through this dissertation study.

In the well-known text of *Health Behavior and Health Education* (2002), Maibach, Rothschild, and Novelli, identified five critical attributes of social marketing from the most often quoted social marketing definitions (p. 438-440).

1. The “bottom line” of social marketing is to influence adoption of voluntary behavior of the target audience (Andreasen, 1994, 2002; Hastings, MacFadyen, & Anderson, 2000).
2. Social marketing programs offer the target market benefits from adopting the behavior and reduce or remove obstacles to performing the behavior (Kotler & Roberto, 1989).
3. Social marketing seeks to benefit the target market and society at large and not the marketer (Andreasen, 1994, 1995).
4. Social marketing identifies how the behavior will assist the target market to fulfill their self-interest by performing the behavior (Rothschild, 1999).
5. Social marketing incorporates the principle of voluntary exchange meaning the target audience gives up something of value in turn for the benefits gained (Rothschild, 1999).

Through analysis of these definitions and the “benchmark criteria” which are used to

distinguish social marketing from other types of health promotion ([www.nsms.org.uk](http://www.nsms.org.uk)), I derived the Building Block Model of Social Marketing, Figure 2.2. I used the analogy of building blocks to underscore the foundational nature of the constructs. An understanding of constructs included in one block builds on the knowledge of the concept represented by the block beneath it. Each block of the model is narrower than the underlying block to denote increased specificity of the information needed to achieve the goal of sustained behavior change in the target group.

Figure 2.2  
Building Block Model of Social Marketing



As an overview, Table 2.4 includes a brief description of each block and applies it to the situation of encouraging parents to have their children wear helmets while riding bicycles. Each block is explained in more detail in the following sections.



Table 2.4 Definitions and examples of Building Block Model of Social Marketing

<b>Building Block</b>	<b>Definition</b>	<b>Example</b>
Societal goal or social problem	The problem or concern that is being addressed by the social marketing strategy. The behavior changes that will lead to resolution of the problem or concern.	Decrease incidence of head and neck injuries in children, age 5 – 14, due to bicycle accidents  Desired behaviors needed to achieve the goal are for parents to obtain helmets for their children and enforce children wearing helmets while riding bicycles.
Consumer orientation	Focus on the population whose behavior is to change with the belief that the audience is best information source about their wants, values, and attitudes in regards to the desired behavior change	The audience is the parents of children 5 to 14 and the children at the upper end of the age range.
Theory or Model	Used to show relationship between concepts	Theories that may help understand the relationships are social norms because of the potential influence of children's and parents peer groups.
Market segmentation	Identify groups within the larger population who have similar lifestyles, attitudes and beliefs in regards to the	Parents of children who ride bicycles and do not wear helmets

<b>Building Block</b>	<b>Definition</b>	<b>Example</b>
	behavior of interest.	
Competition	Current behaviors that compete with the desired behavior  Messages to the target group that may compete with messages about the desired behavior	Parents do not want to fight with the kids about wearing helmets  Helmets are “not cool” for the older children  Helmets are expensive and children rapidly outgrow them
Exchange	Individuals get something of value in return for the costs of performing the behavior. Goal of the social marketing strategy is to reduce the costs and increase the benefits.	The benefits from wearing helmets in exchange for not suffering from head and neck injuries
Marketing Mix (4 P's)		
Product	The desired behavior and associated benefits	Safe bicycle riding with avoidance of head and neck injuries
Price	Monetary and non monetary loss from performing the behavior, may include time away from other activities,	Cost of the helmet  Complaints from the children due to discomfort and

Building Block	Definition	Example
	“psychic costs” of emotional loss, physical discomfort	loss of self esteem
Promotion	Incentives, events, publicity, advertising	<p>Discount coupons to purchase helmets</p> <p>Exchanges for helmets the kids out grow</p> <p>Increasing awareness of seriousness of effects of accidents when children were not wearing helmets during the TV programs watched by parents</p> <p>Provide safety checks on helmets</p>
Place	Location for the distribution of the product or service, might also be called distribution channel	Sell helmets in the grocery stores and other places parents are likely to frequent
Sustained behavior change	Specific observable actions that lead to the societal goal including means of measuring the behavior change	Monitor the number of head and neck injuries due to bicycle accidents when helmets were not in use through the trauma registry

## *Social Marketing Constructs*

### *Societal Goal*

The foundation block of the Building Block Model (BBM) is comprised of the societal goal or stated in the negative as the social problem to be addressed by the social marketing strategy. The focus on the social problem is the primary characteristic that distinguishes social marketing from commercial marketing. I choose to follow Brekert's (2002) lead and lay the foundation of the BBM with the societal goal instead of the consumer orientation as discussed by the majority of social marketing experts including Andreasen and Kotler. The rationale for selecting the societal goal, as the foundation is, as in any planning process, the goal must be delineated and affirmed to develop a strategy to reach the goal as well as measure the effectiveness of the strategy. A clear definition of the societal goal provides direction to the planning process. Brekert (2002) said, "if marketers are honest with themselves, they know they must understand the societal goal to determine how individual behavior can be influenced to reach the target and really do not begin with consumer orientation" (p.18).

The description of the social problem to be addressed through social marketing also includes identification of the behaviors that will achieve the societal goals. The more specific the behavior the easier it is to formulate programs to influence it (Andreasen, 1995). Identifying the goal and the realm of behaviors that would achieve the goal to be addressed by the social marketing strategy lays out the path for gaining an understanding of the building blocks that sit upon it. The societal goal broadly identifies the group of individuals who are affected by this social issue and provides the foundation leading to the next block of consumer orientation.

*Consumer Orientation*

This second block of the BBM addresses learning about the individuals whose behaviors are to be influenced by the social marketing strategy. Marketers need to understand “the reality of the consumers’ everyday lives and experiences, and what moves and motivates them” (Andreasen, 1994, p. 111; French & Blair-Stevens, 2008, slide 12). Social marketing programs need information on what is important to consumers, what do they want, need, think, what gets in their way, and how do they spend their time. What messages capture their attention, when, why, and with what affect? (Walsh, Rudd, Moeykens, & Moloney, 1993)

William Smith (2006) outlined the following questions to get to know the target group:

- How are people different so that their specific wants can be targeted?
- What benefits do people care about most?
- Where are people most likely to want to go to get our products and services?
- What barriers are the toughest for people to deal with, and how can those barriers be lowered?
- How important is the “price” of a new behavior to different users?
- What messages (language, metaphors, images) break through the clutter of other messages and resonate as authentic for them? (p. 40)

Social marketers must think like the audience rather than persuade the audience to think like the marketer. The social marketing strategy must be consumer driven and not expert driven with the implication of “we know what is in your best interest.” Individuals are most qualified to say what their needs are and how those needs should be met (Fine,

1990). This is especially true considering that often social marketers want “to convince people to do things that do not seem to be in their self interest or perhaps the benefit is the absence of something occurring, you won’t get lung cancer, or the benefit is years away, but which carry significant societal benefit” (Smith, (no date)).

### *Theory or Model*

The third block of the BBM is theory or model. Theory aids in understanding the key influences on individuals’ behaviors and aims at answering the question of “why they do it” (Lefebvre, 2000)? Theory is useful to understanding the relationships between variables in different situations. In 1986 Kerlinger, as quoted in Glanz (2002), defined theory as:

A set of interrelated constructs (concepts), definitions, and propositions that presents a systematic view of phenomena by specifying relationships among variables, with the purpose of explaining and predicting phenomena (p. 27).

Social marketing is a planning model that is theory driven and consumer focused (Thackeray & Neiger, 2000). “Theories and models for social marketing abound, with little formal consensus on which types of models for what types of social problems in what kinds of situations are most appropriate” (Lefebvre & Flora, 1988, p. 19). The United Kingdom’s Social Marketing Centre revealed more than 50 potential theories that could be used (French & Blair-Stevens, 2008, slide 76). Social marketers would most likely agree with Dostoevsky who said, “Don’t let us forget that the causes of human actions are usually immeasurably more complex than our subsequent explanations” ([http://literary-quotations.com/d/fyodor\\_dostoevsky.html](http://literary-quotations.com/d/fyodor_dostoevsky.html)).

Theory is useful in determining the social marketing strategy to:

- A. Segment the target audience by their wants and needs, benefits and barriers, readiness to change, influences (Evans, 2006)
- B. Understand the determinants of behavior that can be modified and can impact the specific behavior of the specific audience in the specific culture (Evans, 2006)
- C. Describe interactions between behavior and environmental contexts (National Cancer Institute, 2005)
- D. Interpret findings from formative research and the situation (National Cancer Institute, 2005)
- E. Guide decisions on design, procedures, and measurements for the social marketing program (National Cancer Institute, 2005)

### *Market Segmentation*

The fourth block, market segmentation, involves a process of examining a population or 'market' to identify distinct groups or segments that may have similar needs, attitudes or behaviors. Market segmentation is based on the principles expressed in the consumer orientation block and guided by the theory selected to orient the social marketing strategy. The purpose of segmentation is to determine a sub group who share certain qualities that lead them to relate to the marketing efforts in a similar way (Maibach, et al., 2002). The strategies are tailored to the sub group based on various characteristics including current behaviors (e.g., heavy versus light smoking), future intentions, readiness to change, product loyalty, and/or psychographics (e.g., lifestyle, values, personality characteristics) (Grier & Bryant, 2005). Table 2.5 shows various characteristics that may be used to segment target markets.

Table 2.5 Useful characteristics for market segmentation

<b>BEHAVIORS</b>	<b>SOCIO-DEMOGRAPHIC</b>	<b>ATTITUDES</b>
<b>(What people do)</b>	<b>(What people are)</b>	<b>(How people think &amp; feel)</b>
Frequency	Gender	<b>Needs, benefits, motivations</b>
Place	Family – age & life stage	Beliefs, desires, wants
Time	Household composition	Need, convenience, reliability, support
Occasion	Level of education	Deep seated drivers (love, hope)
Extent of use (a little/a lot)	Occupation	<b>Attitudes &amp; beliefs</b>
Persistency (loyalty)	Urban, suburban, rural	About life in general
<b>Activities &amp; interest</b>	Geographic region	About the sponsoring organization
Type of activity (sport)	Socioeconomic status	Life style (health, food, exercise)
Lifestyle	Ethnicity	<b>Influences</b>
Mode of transportation	Social structure (worksites, churches, voluntary agencies)	Authority figures (teachers, doctors, police, social workers)
Leisure interests		Parents, friends &



<b>BEHAVIORS</b>	<b>SOCIO-DEMOGRAPHIC</b>	<b>ATTITUDES</b>
		peers
Discretionary spending		Role models – community influences
<b>Media consumption,</b>		
TV channels, radio, press		
Source of most information		
Internet & digital use		
Comprehension in information		

Source: (French & Blair-Stevens, 2008; Lefebvre & Flora, 1988, p. 303-304)

### *Competition*

Kotler, Roberto and Lee, (2002) define competition as:

- Behaviors and benefits preferred to the ones being promoted (e.g. taking long versus short showers)
- Behaviors that they have been doing “forever” and would have to give up (e.g. driving alone to work)
- Organizations and individuals who send messages that counter or oppose the desired behavior (e.g. Marlboro Man) (p. 174)

Ling (1992) added “competing messages or ‘the exploding commercial clutter’ that fills daily life” (p. 354) to the above list. Understanding of what competes with the behaviors

being encouraged is gained through understanding the wants and needs of the market segment.

Methods designed to address the competition need to remove the external competition by making the behavior easier to do and the internal competitors by teaching coping strategies to obviate the social influences (Stead, Gordon, Angus, & McDermott, 2007). For example, Weight Watchers' is an excellent example of addressing competitors to behaviors facilitating weight loss. It provides Internet based tools to track food intake and prepackaged foods that are easy to prepare and control portion size. The coping strategies are communicated through weekly meetings and on-line articles and message boards ([www.weightwatchers.com](http://www.weightwatchers.com)).

### *Exchange*

Exchange is the core phenomena of marketing (Bagozzi, 1974) and distinguishes it from other forms of persuasion such as education and the law (Rothschild, 1999). Exchange views individuals acting primarily out of self-interest to get what gives them the greatest benefit in exchange for the least cost. Benefits are easier to see in commercial marketing as in wearing the latest fashions helps teens' self-esteem. Benefits in social marketing are difficult to realize. As mentioned earlier, they may not directly benefit individuals who are being asked to change their behaviors but benefit society as a whole such as a recycling program. The social marketers' challenge is to make the benefit more immediate and appealing to the identified target audience. Asking smokers to give up smoking so they will not taste like an ashtray when kissing would be a more immediate benefit than prevention of lung and heart disease in the future (Lefebvre & Flora, 1988).

The costs attached to a change in behavior are many and again are specific to the group and behavior involved. They can include monetary costs, time, physical and cognitive effort, inconvenience, and incongruence with culture. Costs might be not “looking cool” when wearing a helmet or needing to find a new peer group when giving up drinking (Lefebvre, 1988). The exchange block’s importance is to remind social marketers that the benefits must be truly valued by those whose behavior is being addressed and that intangible costs, such as time and discomfort are associated with the behavior change (Hastings, 2000). Incentives, recognition, rewards and disincentives need to be considered and tailored to specific values of the audience (French & Blair-Stevens, 2006).

### *Marketing Mix*

The marketing mix block contains what is referred to as the 4 P’s of marketing: product, price, place and promotion. The term “mix” is used because the context determines the amount of each of the four P’s. The objective is to blend the mix appropriate to the situation (Kotler, 1971). The knowledge gained through understanding of each of the prior six blocks leads to development of the social marketing strategy in the form of the four P’s.

#### *Product.*

The product in social marketing is the desired behavior and its associated benefits. Marketers need to be aware of the core product and create various tangible products or services which are buyable and which advance the social objective (Kotler & Zaltman, 1971). The data gathered about the audience segment includes their perception of the behavior and what is important to them. An example is the campaign against drunk

driving focuses on designating a (sober) driver or calling a cab instead of “not drinking”.

Marketing is most effective if the incentives that encourage participation are real and occur shortly after the behavior is practiced (Lefebvre, 1988). By framing the benefit in positive feelings and attributes that the audience derives from the behavior is most effective. An example is to use the “loving bond” developed between mother and baby as the message to encourage mothers to breast feed their infants instead of advancing breast-feeding because it is best for the child’s long-term health (Turning Point National Program Office at the University of Washington, 2003).

*Price.*

Price is what the individual must give up to obtain the product. Costs are identified in the exchange block. The goal of the social marketing strategy is to reduce the cost and make the benefits seem more desirable. When costs outweigh the benefits, it is unlikely that the behavior will be adopted. If the benefits are perceived as greater than the cost, chances of trial and adoption of the behavior is much greater. Identifying the costs that create the most significant barriers for this target segment aid in making informed decisions on how best to use resources to market the product/behavior (Maibach, et al., 2002).

*Place.*

Place is the channel through which the product/service reaches the consumer (Weinreich, 2006). The examination of how the market segment spends their time reveals their “life path points” such as the laundromat, hairstyle salon, work place, church, and community center. Place has price implications. The product or service must be easy to access decreasing cost by removing barriers (Lefebvre, 1988). For social

marketing, place can be translated into making the behavior easy to perform. Referring again to Weight Watchers, incorporating their food diary into their Internet site made monitoring one's food intake easy for those who have frequent and easy access to the Internet. Tracking one's food intake is an important behavior change leading to weight management and sustained weight loss ([www.weightwatchers.com](http://www.weightwatchers.com)).

### *Promotion.*

Promotion is often thought to be synonymous with the concept of marketing. However, it is only one ingredient of the marketing mix and depends on understanding of the other three facets to be effective. Promotion is an integrated approach that may include advertising, public relations, promotions, media advocacy, personal selling, and entertainment vehicles (Weinreich, 2006). Its focus is on creating and sustaining demand for the product or behavior change. Promotion appeals to the market segment's emotions (Lefebvre, 1988). Successful marketers "tap into emotion laden core values such as desire for control or independence and desire to care for their families" (Kotler & Roberto, 1989). Lack of understanding of the market segment often explains promoting the wrong benefits to the wrong people. The messages and the behaviors must appeal to the target group. For example, promoting healthy nutrition through the use of food pyramids, food groups and other abstract concepts would not compete with food that looks good, tastes good, is economical and is easily prepared (McDermott, 2000).

### *Sustained Behavior Change*

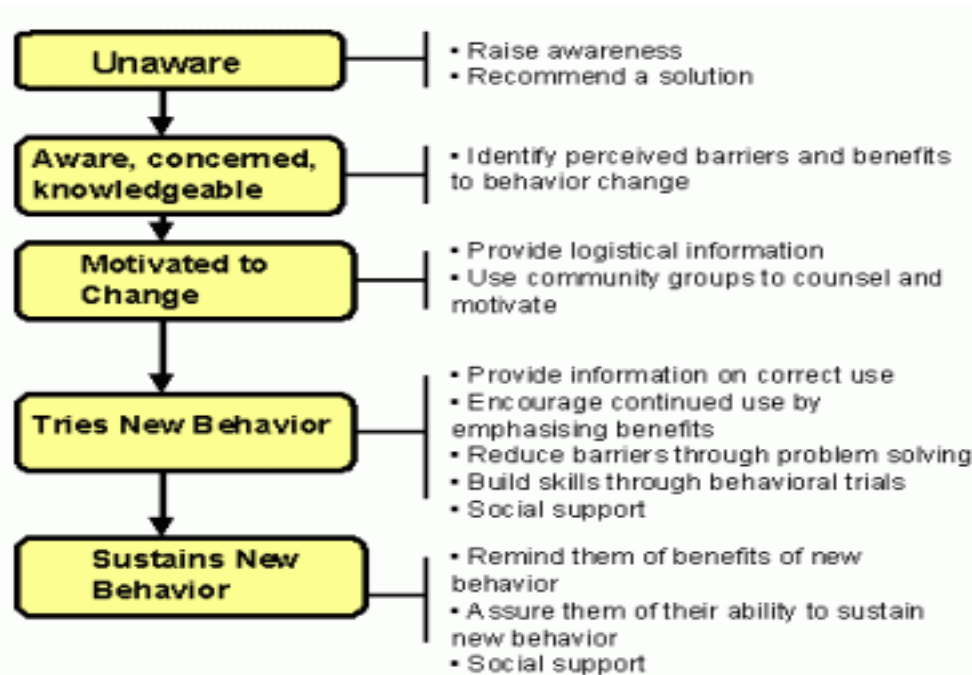
Sustained behavior change, as the top block of the BBM, reflects the goal of social marketing. Andreasen (1994) is often quoted as saying, "sustained behavior change is the bottom line of social marketing" (p. 110). The goal is not to have individuals

perform the behavior once or for a day or week, but for it to become a part of their daily lives. The societal goal of improved health for smokers will only result when smokers give up tobacco not for a day or even a month but for a lifetime.

To achieve sustained behavior change Rachlin (1970) as referenced in Rothschild (1979) said that, “establishment or maintenance of behaviors needs ongoing reinforcement of benefits that fulfills individuals’ self interest, of conditions to facilitate the behavior, and of support for the behavior changes from the group’s peers. Behavior changes that result from internal motivation have a greater chance of lasting than those that result from external requirements” (p. 12).

Commercial marketers measure their success by the number of items sold or services provided and often depend on a one-time purchase. Social marketing depends on creating sustained behavior change. Behavior change takes time and often individuals bounce back and forth between doing and not doing the behavior. Several models and theories provide means to understanding the stages of behavior change (Prochaska, DiClemente, & Norcross, 1992; Weinstein & Sandman, 2002). Figure 2.3 is a simplified version of these models and illustrates the stages individuals may go through and the techniques used to arrive at sustained behavior change. Recognizing the groups’ location on the continuum of stages of change affects the design of promotional materials (Andreasen, 1995).

Figure 2.3  
Stages of Behavior Change



Communication for Behavior Change - The World Bank, 1996, by Cecilia Cabanero-Verzosa p 4 - Figure 2 <http://www.comminit.com/en/node/27036/36> on 8/27/08

*Social Marketing Compared to Other Types of Persuasion*

With the foundational and distinguishing concepts of social marketing laid out in the BBM, it can be more easily distinguished from other types of persuasion as in commercial marketing, cause related marketing, and societal marketing. The identifying characteristic of social marketing is its aim at improving societal welfare and not increasing profits, even if making money is necessary to do social good as in health care organizations.

*Compared to Commercial Marketing*

Social marketing grew out of commercial marketing when the need was recognized to influence behavior change for the social good. Philip Kotler (1971), known for coining the term “social marketing,” continues to reference “the use of marketing principles and techniques” in later definitions (2002, p.5). These methodologies include

many of the previously discussed blocks of consumer orientation, market segmentation, competition, exchange and marketing mix.

The differences between social and commercial marketing stem from their divergent goals. Social marketing aims at influencing voluntary behavior for the societal good, while commercial marketing seeks to increase the fiscal profits of an organization. Sometimes the goals can be blurred between the two types of marketing as when breakfast cereals promote health risk-reducing properties. However to clarify the issue, one need look no further than the company's goal which was to increase their market share (Lefebvre, 1988). For social marketers the bottom line is to meet society's desire to improve the citizen's quality of life, a much more ambitious goal.

Table 2.6 highlights the differences between social and commercial marketing.

Table 2.6 Comparison of social marketing to commercial marketing

	<b>Social marketing</b>	<b>Commercial marketing</b>
<b>Purpose</b>	Influence voluntary behavior change for the good of the individual and society	Increase revenues, sales, utilization of services, etc.
<b>Goals</b>	Behavior shifts of 20-30%	Shift of large market 1 to 2%
<b>Success</b>	Difficult to measure	Measured in profits and market share
<b>Time line</b>	Long term behavior change	Short term purchase behavior
<b>Accountable</b>	To the public	To the private concerns
<b>Funding</b>	Taxes and donations	Investments and sales
<b>Culture</b>	Public sector – risk adverse	Commercial culture- risk



	<b>Social marketing</b>	<b>Commercial marketing</b>
		taking often evident
<b>Market segmentation</b>	Hard to reach populations and disadvantaged groups whose behavior may be difficult to change	Focus on those most likely to purchase product or use the service
<b>Competition</b>	Inertia, apathy, behavioral options that compete with desired behavior	Brands of similar products or services that satisfy similar wants and needs as the product being promoted
<b>Exchange</b>	Benefits not always directly to consumer maybe to society as a whole	Consumer receives direct benefit
<b>Product</b>	Often intangible, difficult to show in promotion	Tangible
<b>Demand for product</b>	Difficult to create demand that does not produce immediate and direct benefit for the consumer	Create demand by demonstrating benefits for consumer
<b>Price</b>	Not tied to actual cost of service. Cost to the individual is intangible and include time, inconvenience,	Tied to cost of producing product and or providing service

	<b>Social marketing</b>	<b>Commercial marketing</b>
	and behavior change to either start doing something or stop doing something	
<b>Controversy</b>	Behavior may be controversial, e.g., teenagers having protected sex	Typically uncontroversial products/ services

Source: (Andreasen, 2001; French & Blair-Stevens, 2008; Rothschild, 1979)

*Cause related marketing* refers to cooperative efforts between businesses and charities. One example, from the local metropolitan area, is the “Goodwill Sale” at a department store. The store gives a discount coupon to use at the store for every item donated to Goodwill Industries during that time period (personal experience).

*Societal marketing*, also known as socially responsible marketing, describes the promotion of a company’s positive business practices such as recycling and reducing pollution (Brenkert, 2002).

#### *Ethics and Social Marketing*

Simply stated, ethics is about making decisions in situations when two seemingly “right” principles are in conflict (Smith, 2001) or two or more valid concerns come into conflict (Andreasen, 2001). This section will highlight the potential conflicting right principles in four blocks of the BBM, the societal goal, consumer orientation, market segmentation, and the influence on behavior change. Ethical concerns arise when influencing individuals’ voluntary behavior is the question.

Selecting the societal goal for the social marketing strategy in itself raises its own

ethical issues. Who is to say what is “social good?” “Who speaks for society?” The answer can be all or some of the following: the government through its elected officials, private charitable organizations whose missions are to improve the welfare of specific groups, e.g., the YWCA program against domestic violence, social marketers, or the individuals themselves who are the target audience of the social marketing efforts (Brenkert, 2002). The ethical need is to balance the potential power of social marketing with the obligation for societal improvement (Andreasen, 2001). Some societal goals are unproblematic such as control of communicable disease and violence prevention. Other goals might be inconsistent with the cultural setting, such as female circumcision in African countries (Brenkert, 2002). Social marketers are accountable to the people being served and ethically should not influence behavior change under the guise of it will be “for their own good” (Walsh, et al., 1993).

Because social marketing aims to benefit individuals and society, choosing the target market cannot focus only on those individuals likely to change their behavior and avoid those who are difficult to reach and or unlikely to change their behavior (Rothschild, 2000). For example efforts at promoting family planning should address those ready to change behaviors and those who have less education and are poorer and take more resources with limited results. Social marketers must use standards of fairness, honesty, trust, and respect for the individual in influencing the behavior change (Andreasen, 1995).

Some social marketing decisions about market segmentation involve balancing individuals’ right to choose their behavior and the rights of others not to have resulting externalities or costs imposed on them (Rothschild 1999, 2000). For example, smokers

wish to smoke where and when they choose. However, the cost to others who inhale their smoke second hand has proven to outweigh smokers' freedom ([www.lungusa.org](http://www.lungusa.org)).

The consumer orientation of social marketing emphasizes the importance of understanding the wants and needs of the target audience and uses that understanding to build a social marketing strategy. Skillfully appealing to the consumers' own wants and needs could be seen as controlling the consumers' choices. Even though marketing is based on the premise of voluntary behavior change, the ethical question is, is the choice really voluntary if the benefit is seen as too good to refuse (McDermott, 2000). This ethical issue can be addressed by providing enough information on the pros and cons of the behavior so that individuals can truly make informed decisions (Rothschild, 2000).

Social marketing's focus on influencing individual behavior has also been seen as "victim blaming." Individuals' behaviors need to be seen in the context of their environment and other external forces over which they have little control, e.g., economic status, working conditions, policy, and laws (Hastings, et al., 2000; Ling, et al., 1992). Some social marketers do include policy issues and infrastructure in their goals of influencing change (Grier & Bryant, 2005).

#### *Conceptual Framework Based on the*

#### *Motivation, Opportunity, and Ability (MOA) Model and the Marketing Mix*

As identified in the prior section, the goal of social marketing and the ultimate goal of this study coincide to influence behavior change, PHIM, for the individual and social good. The first step is to determine what will influence the target audience, students studying to become health care professionals or scientists, to adopt the behavior (PHIM). A conceptual framework is needed to "explain graphically or in narrative form,

the main things to be studied – the key factors, constructs, or variables – and the presumed relationships among them. Frameworks can be rudimentary or elaborate, theory-driven or commonsensical, descriptive or causal” (Miles & Huberman, 1994, p. 18). This section of the literature review describes the MOA model and compares it to the marketing mix in formulation of the conceptual framework (Chapman & Patel, 2004).

The MOA Model has been described as a meta-model using “summary concepts” of motivation, opportunity, and ability (Chapman, 2004). Definitions of motivation, opportunity, and ability are based in the disciplines of consumer behavior, marketing, advertising, public health, social psychology, and economics (MacInnes, Moorman, & Jaworski, 1991). Population Services International (PSI), as the leading nonprofit social marketing organization in the world, bases their projects on the MOA Model. The foundational belief is that “opportunity, ability, and motivation facilitate or inhibit the behavior, and they can be enhanced, increased, or positively changed within the target audience by the social marketing agency. When opportunity, ability, and motivation are increased, the probability of behavior change is increased” (Chapman & Patel, 2004, p. 7). Table 2.7 includes for each summary concept, brief definitions, constructs used by PSI, and examples of the construct again applying it to children wearing helmets when bicycle riding. Expanded discussion of the constructs follows the table.

Table 2.7 Motivation, opportunity and ability summary concepts

	<b>Definition</b>	<b>Constructs included in each summary concept in PSI Model</b>	<b>Example: Decreasing the number of head and neck injuries in children from not wearing helmets</b>
<b>Motivation</b>	Goal directed arousal or readiness to act	Attitude Belief Intention Locus of control Outcome expectation Subjective norm Threat (risk) Willingness to pay	Avoidance of life altering injuries for children
<b>Opportunity</b>	Environmental, social, and contextual factors that either impede or facilitate performance of behavior	Availability Brand appeal Brand attributes Effective health care Social norm	Cost of helmets and the need to have new helmets when children outgrow them Older children fear of not “looking cool” when wearing helmets Decreasing cost of helmets and still maintain safety by subsidizing purchase for low income families Inspecting used helmets for safety

<b>Ability</b>	Knowledge, skills and experience to perform the behavior	Knowledge Self-efficacy Social support	Knowledge of need to wear helmets to answer children's concerns about wearing them.  Knowledge of the correct fit and safety factors for helmets
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*Motivation* has been defined as goal directed readiness to act. The motivated consumer is “energized, ready, and willing to engage in a goal directed activity” (Hoyer & MacInnes, 2004, p. 55). The goal is personally relevant to individuals when it addresses their self-interest (Batra & Ray, 1986). This internal state energizes the individual to take action to achieve the goal. Motivation does not always result in action or the action may vary in intensity and direction. In the context of the situation, individuals may be just unmotivated (Binney, Hall, & Shaw, 2003). When trying to influence behavior change, marketers must remember that motivation alone does not cause behavior change.

*Opportunity* describes the external environment and is composed of factors that both facilitate and impede performing the behavior. Factors that aid behavior change include having easy access to the resources needed to perform the behavior, e.g., the availability of health professionals and vaccine to immunize children in developing countries. Barriers or restrictions to the behavior may include having time to perform the behavior, infrequent and or unavailable information about the benefits of performing the behavior (Hoyer & MacInnes, 2004), distractions, and lack of support for the behavior

from the social network (Hughes, 2007), or lack of the financial resources to adopt the behaviors (Binney, Hall, & Shaw, 2003).

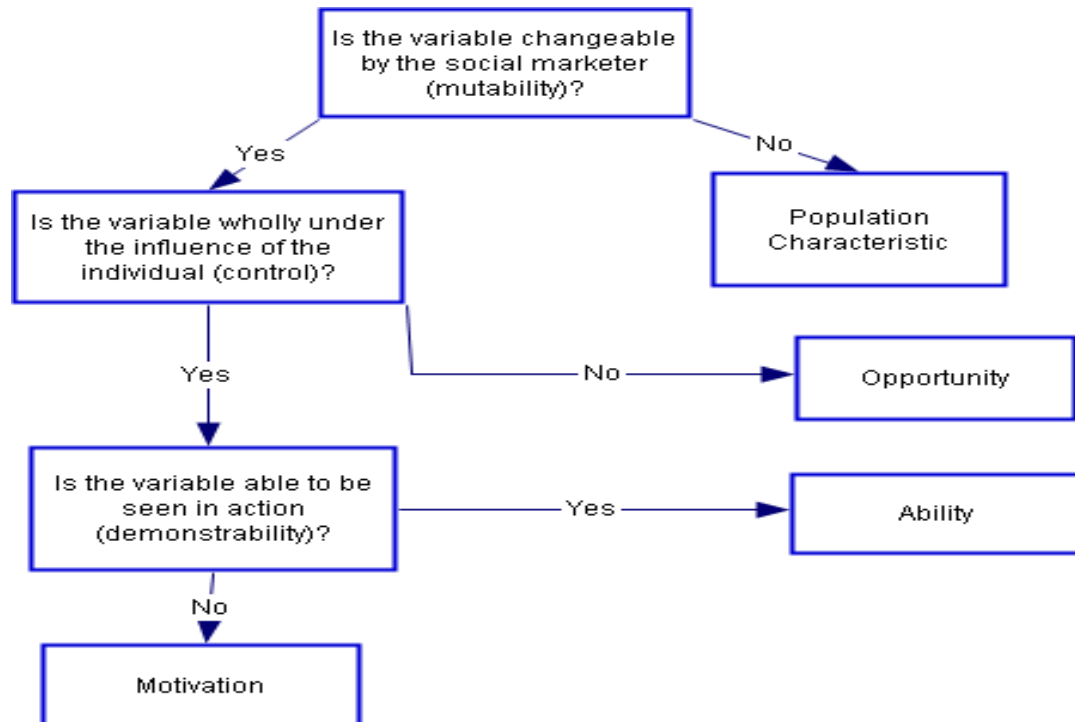
*Ability* refers to the individuals' skills and capabilities to perform the behavior (Hughes, 2007). These skills and abilities emanate from the individuals' experience, knowledge, and capability to process information that may be impacted by their age and education. Gruen (2005) in a discussion of e-commerce distinguished between content and process ability that could affect ability in certain situations.

*Grouping variables into motivation, opportunity, or ability categories.*

Chapman and Patel (2004) in a concept paper for PSI proposed a three layer algorithm to determine the usefulness of social marketing to influence behavior and to categorize the variables by motivation, opportunity, and ability (p. 9-11). Prior to this proposal, the definitions were the only guide to grouping variables. A flowchart of the algorithm is reproduced in Figure 2. 4.



Figure 2. 4  
PSI Algorithm to  
Categorize Variables by Motivation, Opportunity and Ability  
(Chapman & Patel, 2004, p.10)



The three decision points are explained as:

- Mutability is the extent to which the social marketing strategy is theoretically or empirically able to enhance, increase, or modify the variable through the 4 P's of the social marketing mix.
- Control is the degree to which the targeted individual has direct influence over the variable.
- Demonstrability is the extent to which the variable can be observed through or the potential to be seen in the targeted individual's overt action (Chapman & Patel, 2004, p. 9).

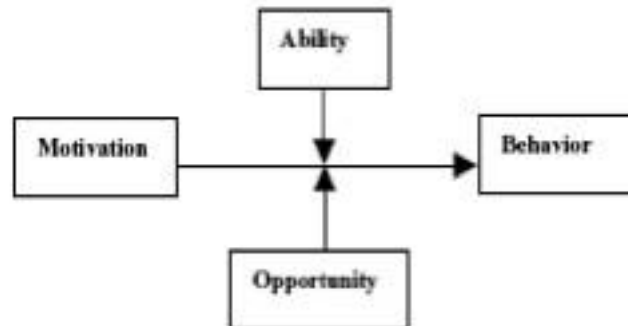
The variables need to be mutually exclusive and well conceptualized to facilitate their measurement and tested for purposes of segmentation, monitoring and evaluating

audiences and intervention activities.

*Relationship between MOA Constructs*

Hughes illustrated the relationships of the model as in Figure 2.5 (Section 2).

Figure 2.5  
Relationship between the MOA Model constructs



As stated in the description of motivation, being goal directed is not enough to achieve the behavior; motivation is influenced by ability and opportunity (Hughes, 2007; MacInnes & Jaworski, 1989). In addition, Binney, Hall and Shaw (2003) found that more effective behaviors result with concentration on motivation and ability rather than opportunity (Chapman & Patel, 2004; Hughes, 2007). The study showed that lack of opportunity could be overcome if ability or motivation are high (Binney, et al., 2003, p. 410).

*Conceptual Framework: Compares the Marketing Mix to the MOA Model*

As a meta-model, the MOA Model allows for a high level of abstraction or grouping of various antecedents into one construct. This type of model is useful to describe “summary concepts” of antecedents to behavior change and to group constructs applicable to a given situation and the behavior of interest (Chapman & Patel, 2004; Hughes, 2007). Hughes, in his application of the MOA Model to the adoption of

information systems, showed that knowledge of particular software applications would affect the probability of adoption of the behavior. Knowledge of various information systems could be grouped into the summary concept of ability without having to create a new model for every type of software (Hughes, 2007, section 3.2). Population Services International (PSI) uses the MOA Model to guide their social marketing efforts in developing countries by framing their evidence gained through research “in easy to understand packages of information, instead of speaking of each determinant and indicator” (Chapman & Patel, 2004, p. 7).

My decision to use the MOA Model as part of the conceptual framework grew from the review of numerous theories used in social marketing. As discussed in the theory building block of social marketing, more than 50 different theories have been used to develop social marketing strategies. The MOA Model is useful to summarize many of the theoretical concepts in easy to understand categories.

The MOA Model supports the common sense approach of devising a conceptual framework. Common sense tells us that individuals are more likely to adopt behaviors that are of value to them. PSI researchers, Chapman and Patel (2004) took the MOA Model one step further by relating the MOA constructs to social marketing strategies. They said, “Opportunity gaps require activities related to the health system, product, or community. Ability needs mandate strategies that engage individuals in learning and practice. Motivation gaps require persuasive communication efforts to address issues” (p. 11). I propose using these concepts to form a matrix and conceptual framework formed by the comparison of the marketing mix to the MOA Model, Table 2.8. Using Chapman and Patel’s above suggestions, I indicated the intersection of the marketing mix

and the MOA Model with an X. I left the price row blank to indicate that the PSI researches omitted application to the price aspect of the marketing mix. I utilized this conceptual framework to analyze and interpret the findings in Chapter V.

Table 2. 8: Conceptual framework: MOA Model and marketing mix

	<b>MOA Model</b>		
<b>Marketing Mix</b>	<b>Motivation</b>	<b>Opportunity</b>	<b>Ability</b>
Product	X	X	X
Price			
Place		X	
Promotion	X		X

### Part III

#### Qualitative Research Design Literature Review

This section of the literature review explains the philosophical foundations and common characteristics of qualitative research. The background on qualitative methods of inquiry will serve as the rationale for its selection for this dissertation research.

##### *Qualitative Methodology Explores New Phenomena*

The research purpose is the heart of the study and guides the selection of the method of inquiry. Sofaer (1999) described research methods as falling along a continuum from using qualitative methods when the purpose is exploratory because phenomena are unknown as compared to confirmatory when the research purpose is to support existing theories. The continuum is illustrated in the degree of structure used to collect research data from open, flexible questions used in interviews for qualitative

studies to concrete static questions in surveys used in quantitative studies (p.1103).

Qualitative methods are most appropriate when the research goal is not to control and predict but to understand (Tesch, 1990).

### *Constructivist Philosophy Guides Qualitative Methods*

Qualitative inquiry is best described through its underlying constructivist philosophical assumptions, also known as worldviews or paradigms. Paradigms are composed of sets of beliefs that “provide direction without a long philosophical discussion”(Deevers, 1999). In qualitative research, the worldviews are expressed in terms of the philosophical assumptions of ontology and epistemology. Ontology answers the question, “What is the nature of reality? What is real or true?” There is no absolute truth in qualitative research. Truth is relative and is posed through the subjective reality of the participants. Qualitative methods aim to discover the “meaning” individuals and or groups attribute to the phenomena (Creswell, 2007; Deevers, 1999; Denzin & Lincoln, 2008; Sofaer, 1999). Individuals’ perceptions are influenced by their gender, race, social class, and ethnicity as well as the context of the event (Deevers, 1999; Denzin & Lincoln, 2008). Given this belief that truth comes through participants’ descriptions of their reality, data collection methods used in qualitative research gather data directly from participants through interviews, focus, groups, observations, review of documents and images (Thorne, Kirkham, & O’Flynn-Magee, 2004).

Data collection directly from participants leads to discussion of epistemology, the second philosophical assumption. Epistemology describes the proximity of the researcher to the researched. In qualitative inquiry, researchers are the key research instruments collecting data themselves instead of using static measures that have been

used by others (Denzin & Lincoln, 2008). Data are collected in as natural a setting as possible. By immersing themselves in the setting, researchers learn more about the participants than merely what they say.

Criticisms of potential bias and loss of objectivity have been made because of the researchers' role and closeness to the participants. To avoid perceptions of bias and subjectivity, qualitative researchers acknowledge their values and experiences and reflect on how their background affects the research methods and outcomes (Creswell, 2007). The term reflexivity is used to describe the researchers' beliefs about and motivations for the study topic, previous personal and professional experiences, and theoretical and conceptual foundations related to the phenomena (Malterud, 2001). Bias is accounted for and acknowledged though not eliminated.

#### *Qualitative Methods Generate Text As Data*

The goal of qualitative research is to search for the participants' meaning or "truth" about the phenomena described in their own voice. To stay close to the participants' natural language, research data occurs in words in the form of transcripts of interviews and focus groups, field notes from participant observations, images or other documents. The data are not quantifiable. Qualitative methods make the data accessible (Creswell, 2002; Polkinghorne, 2005).

#### *Qualitative Data Guide The Analysis and Interpretation*

Analysis of data from qualitative research is an inductive iterative process of discovering patterns, relationships, explanations, similarities and differences: making interpretations, and developing critiques or theories (Hatch, 2002). Richards and Morse (2007) described it as having a "dialogue with the data," a two-way communication "up

from” the data to categories or codes and then “down to” the text to verify and examine the data that generated the code (p. 123-5). Wolcott (cited in Hatch, 2002, p. 148) called it “mind work” as the human mind is the tool used in this process. Qualitative research analysis methods do have structure using coding that is a process of linking rather than labeling ideas (Richards & Morse, 2007)

Researchers as research instruments make qualitative data analysis an individualized process driven by the individuals performing the process. The researcher’s beliefs and worldview, as in the collection of data, affect the analysis and interpretation. Interpretations cannot be separated from researchers’ background, history, context, or prior understandings (Creswell, 2007; Sandelowski, 2000). The findings are in part a result of where researchers look and what they decide to report (Miles & Huberman, 1994).

#### *Criteria Identify “Good” Qualitative Research*

In 1985, Guba and Lincoln proposed criteria to evaluate qualitative research and distinguish it from that used to judge quantitative research. These criteria continue to be referenced in current publications (Creswell, 2007; Deevers, 1999; Denzin & Lincoln, 2008)The criteria are listed below and include potential methods of identifying “good” qualitative research.

- Credible: the "truth" of the findings, as viewed through the eyes of the research participants and within the context in which the research is carried out.

Credibility is demonstrated when data are gathered from more than one participant as in holding multiple focus groups, conferring with the research team

after each focus group session, and comparing the research findings with other data sources.

- **Transferable:** the usefulness of the research findings in other contexts describes transferability. The key aspects of the research context must be clearly stated so that potential users will be able to judge if the findings are applicable to their setting.
- **Dependable:** the description of the research methods allows for it to be replicated and arrive at similar findings. Factors that contribute to dependability are using the same or similar questions and setting for each focus group.
- **Confirmable:** evidence from other sources besides the researcher, supports the findings. The sources include the research participants themselves, the members of the research team, and providing sufficient detail of the research process along with the rationale of why methods were used (Deevers, 1999; Denzin & Lincoln, 2008; Morrison-Beedy, Cote-Arsenault, & Feinstein, 2001).

### *Focus Group Literature*

This section of the literature review provides a background on uses of focus groups, their differentiating characteristics that affect their execution, type of data produced, and analysis of the data.

#### *Focus groups defined and described.*

Focus groups are defined as “a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non threatening environment ” (Krueger & Casey, 2000, p. 5). The researcher provides the focus, while the data come from the participants and group interactions (Morgan, 1997).



*Group interaction key to focus group success and weakness.*

The hallmark of focus group methods is to create interactions among the participants that produce data and insights that would be less accessible without group interaction. “Knowledge and attitudes are not entirely capsulated in reasoned responses to direct questions” (Kitzinger, 1995 p. 299). The interaction between the participants creates an environment that allows for the free flow of ideas and opinions, indepth exploration of topics (Manoff, 1985), finding a range of opinions across several groups, and simulating more life like environments where individuals influence and are influencing others (Krueger & Casey, 2000). Although the social context in a focus group is not a natural one, the use of focus groups presents an opportunity to observe group interactions within this social context (Morgan, 1996). For example, researchers can observe participants sharing ideas, opinions, and experiences, and even debating each other and encouraging others’ comments (Duggleby, 2005).

Interaction of the participants, one of the greatest assets of focus groups, is also one of its greatest weaknesses. As mentioned above, by virtue of presence of others and their influence on each other, data are generated that would not have otherwise occurred. The influence could be negative causing some individuals to remain silent while others might become more talkative. Presence of others affects what people say and how they say it (Morgan 15).

*Researcher as instrument in the role of the moderator.*

As with other qualitative methods, the researcher interacts directly with the participants (Denzin & Lincoln, 2008). The researcher is ‘up close and personal’ with the participants to learn who they are, their thoughts, their worries, their motivations, their

trusted resources, in their own vocabulary (Andreasen, 1995, p. 115). “The richness of data is in the multitude of perceptions of the participants’ daily experiences” (Nyamathi, p.1282).

Because of the nature of groups and the need to guide the discussion, the moderator’s skills are extremely important. Moderators need to multitask. They need to pay attention to group dynamics and ensure the discussion addresses the questions posed (Denzin & Lincoln, 2008). Moderators must be good listeners attending to the participants’ views rather than their own (Anhoj & Nielsen, 2004), and be flexible if the discussion strays off track and offers potential to the research (Kidd & Parshall, 2000).

#### *Focus group participants.*

When selecting individuals to participate in focus groups and determining the composition of each group, the goal is to achieve a balance between similarity and differences of participants. Too much similarity leads to fewer diverse opinions and experiences while some differences may lead to perceptions of power causing some individuals to not fully engage in the discussion (Litoselliti, 2003). Kreuger and Casey (2000) and Hatch (2002) recommended composing groups of individuals who do not know each other to minimize the chance of side conversations. Morgan (1997) also favored focus groups composed of strangers because although acquaintances can converse more readily, they rely on assumptions that are not shared with the group and deprive the research of this data.

#### *Analysis of focus group data.*

Sim (1998) advocated that the researcher approach analysis of focus group data with a critical eye to understand the group dynamics, the relevance of the discussion, and

the range and breadth of the discussion. Every utterance is not necessarily relevant to the research purpose, just because someone said it during a focus group.

Morgan addressed the issue of interest and importance. Participants might find the discussion of an issue interesting, but not necessarily important. To achieve the focus group's purpose, the researcher needs to determine what matters to the participants. The best way to find out what is important is to build the question into the focus group script and ask them (p. 62). When participants agree about an issue, they might not spend a lot of time discussing it.

A "hierarchy of credibility" can be used to distinguish between relevance of various types of comments. Participants' stories of personal experiences provide better evidence of their perceptions than statements expressing their opinions (Kidd & Parshall, 2000; Nyamathi & Shuler, 1990). Dialogue about experiences also generates more discussion, as most people are more comfortable comparing their experiences than challenging someone's opinion (Morgan, 1997).

In analysis of focus group data, it is important to remember their purpose as succinctly stated by Krueger and Casey (2000).

The intent of focus groups is not to infer but to understand, not to generalize but to determine the range and not to make statements about the populations but to provide insights about how people in the groups perceive a situation (p. 83).

*Analysis of participant interaction.*

Group interaction sets the focus group method of data collection apart from other qualitative methods and is a source of data itself. Data analysis should indicate the impact of the group dynamic on the individual and distinguish between individual

opinions expressed in spite of the group from group consensus. Researchers are concerned with the influence of the group on the individual and the potential for “bandwagon effect similar to ‘group think’” (Carey, 1995, p. 489). The individuals present, the context and the dynamics of the group at the time and place of the discussion significantly influence focus group data. If the group were to be reconvened at a later date, the data may look very different making verification of the data’s credibility through “member checking” difficult (Carey, 1995).

“As in all qualitative analysis, deviant case analysis is important--that is, attention must be given to minority opinions and examples that do not fit with the researcher's overall theory” (Kitzinger, 1995, Section: Analysis and Writing Up). Types of group interaction that may be relevant to the study include censoring, conformity, dominance of one person, heated debate, humor, shared and common knowledge (Carey, 1995; Kidd & Parshall, 2000; Kitzinger, 1994; Nyamathi & Shuler, 1990).

Sequence analysis identifies participants’ change of point of view over the course of the discussion (Kitzinger, 1994; Webb & Kevern, 2001). Following a discussion thread and comparing comments made at the beginning and end of the session may show “evolving consensus and debate, where assertions are qualified and challenged, where statements are confirmed and, qualified by others, and where new ideas and directions are introduced” (Reed & Payton, 1997, p. 768).

*Units of analysis include the participants and the groups.*

Several known focus group experts have acknowledged a controversy of whether the individual or the group is the unit of analysis (Carey, 1995; Kidd & Parshall, 2000; Morgan, 1997). All agree that attention must be given to both. They cannot be

separated. The individuals who compose a group affect the group's interactions. If different individuals made up the group, the group's dynamic would be different. The group's context also affects the group members (Morgan, 1997). "The trick is to devise analytical approaches sufficiently flexible to identify any undue influence of the group on any individual participant(s), or vice versa, before drawing one's conclusions" (Kidd & Parshall, 2000, p. 299).

*Comparison with other types of qualitative data collection.*

Focus groups provide data in a unique way by including individual comments along with group interactions and influence. As compared to participant observation and individual interviews, focus groups are not as strong as each method used alone. Through participant observation, researchers study the phenomena in context. Individual interviews provide an in-depth understanding of the individuals' perspective on the phenomena in a private setting. Collecting data through focus groups allows for both viewing of context through individual interactions and discovering individuals' beliefs and attitudes although in a public setting (Morgan, 1997).

Focus groups are believed to produce greater amounts of information than individual interviews. This belief has not been supported by research. Morgan (1997) reports on a study by Fey in 1982 that showed that the number of ideas gathered from two eight-person focus groups equaled that of ten individual interviews. The benefit however is that the two focus groups could be completed in a shorter period of time than the individual interviews.

As stated previously, the true benefit of focus groups as compared to other data collection methods is the presence of the group. Andreasen (1995) summed up the advantages of focus groups over interviews.

- Synergism – The participants respond to, elaborate on, criticize, modify, or otherwise react to comments of other group members.
- Minimal interviewer effects – The interviewer/moderator’s role is to stimulate and move the discussion in a particular direction. The participants are most likely to respond to others in the group and worry less about pleasing or impressing the moderator.
- Increased spontaneity – The participants don’t need to speak if they don’t want to. The lack of pressure tends to make more comfortable, spontaneous and enthusiastic in their participation (p. 116).

*Rationale for Using Focus Groups to Study Students’ Perceptions of PHIM*

Focus groups are used extensively in market research to gather opinions of consumers about particular products and services. They are also used “to develop the messages and materials used in social marketing campaigns and educational interventions. Focus groups can be of particular assistance in identifying ‘hot button’ concerns of potential audiences and in helping to craft key messages”(Sofaer, 1999, p. 1108). Social marketing guided the design of this study and the incorporation of focus groups as the data collection methods. Based on research, social marketing has a rich tradition of going directly to the target audience to discover who they are and their perceptions of the desired behaviors.

## Summary

Individuals who see a personally relevant goal resulting from behavior change are more likely to adopt the new behavior when achieving the goal offers greater benefit than the “cost” of the behavior. In the empirical research reviewed, the studies’ authors did not use this approach to gain an understanding of a specified target group’s personally relevant goals in adopting PHIM. In spite of the differing research goals, I was able to cull from the empirical research participants’ views on the benefits and barriers to PHIM in Part I. Part II focuses on social marketing constructs in the form of the Building Block Model (BBM). Using the BBM as an organizing and explanatory structure, I identify the types of information needed about the target audience to develop an effective strategy to influence behavior change. I propose a conceptual framework composed of the 4 P’s of the marketing mix to the MOA Model. This framework is used to analyze and interpret the study’s findings in Chapter V. In Part III, I describe the rationale for using a qualitative research design and focus group as a method of data collection.

## CHAPTER III RESEARCH METHODS

### Introduction

This dissertation uses qualitative methodology with focus groups as the data collection method. In this chapter, I explain the rationale for selecting the research design and setting, the processes I used to identify study participants, collect and analyze data, and examine credibility and trustworthiness of the findings.

I selected qualitative research design with focus groups as the data collection method because it was congruent with the research's purpose and exploratory nature (Caelli, Ray, & Mill, 2003). This study's central research question is to discover what may influence students at an academic medical center to adopt personal health information management (PHIM).

The sub questions are:

RQ 1: What distinguishes individuals who have adopted or are ready to adopt personal health information management from those who are less interested in adopting the behavior?

RQ 2: What facilitates and encourages individuals to adopt personal health information management?

RQ 3: What are anticipated barriers and concerns to adoption of personal health information management?

### Research Setting and Participants

The research was conducted at the main medical center campus of a state university located in a medium sized Midwestern city. The university medical center is composed of Colleges of Dentistry, Medicine, Nursing, Pharmacy, Allied Health, Public



Health and Graduate Studies. The university partners with a tertiary teaching hospital located on the same campus. This study was limited to students enrolled in programs on the main campus because in January 2007, this student population was offered the free use of a Web based personal health record. Students were informed of this benefit through e-mails from the student senate president. As with other PHR offerings (Taylor, 2004; Versel, 2007), the response has been small. As of December 2007, 101 students out of an enrollment of 3067 have signed up for this service (Morien, 2007).

An additional criterion for study participants was that they be at least 19 years old. Students needed to be at least 19 years old to be considered adults by State law (State. Rev. Stat. § 43-2101). As adults they have the right to authorize access to their medical records, a PHIM behavior.

#### Institutional Review Board Approval

I applied for and received approval from the UNMC Institutional Review Board to complete this research project (IRB #429-07-EP).

#### Recruiting and Selecting Focus Group Participants

I used a variety of strategies to contact students with e-mail being the most effective. I sent messages to leaders of student organizations, academic program directors and the students themselves, Appendices A, B, and C. I also spoke at the meetings of the Graduate Student Association and the Student Nurses Association and posted fliers, Appendix D, in places where students were likely to see them. Incentives of a light meal and compensation, \$40, were used to encourage students to participate in the focus groups.

Students indicated their interest in participating and their availability on interest forms, Appendix E, that were attached to the e-mails mentioned above. In all, 45 students returned interest forms. Using the availability information, I selected the dates and times convenient to the most students. Once the focus group participants were identified, I sent them confirmation e-mails, Appendix F, with the specific date, time and place. The informed consent, Appendix G, and rights of research subjects, Appendix H, were attached to the confirmation message.

I used purposeful and static methods to select the participants. As recommended by Polkinghorne, I used the term selection instead of sampling to refer to determining the focus group participants. The term selection is preferred because it describes the actual process. The term sampling, used mostly in quantitative research, connotes that the participants represent a larger group and that the study results can be generalized to that group (Polkinghorne, 2005). Purposeful selection is defined by Spradley (1979) and quoted in Richards and Morse as selecting participants “who know the information required, are willing to reflect on the phenomena of interest, have the time and are willing to participate” (Richards & Morse, 2007, p. 195) . Because the study topic was explained in all communications with the potential participants, all students who completed interest forms were considered to be knowledgeable and willing to take the time to participate in the focus group discussion. The recruitment and selection of students occurred once because of limitations of time and resources. This is known as static selection (Polkinghorne, 2005).

No attempt was made to ensure that the participants did not know each other and avoid potential problems of distracting side conversation and reluctance to discuss

information because of who was present in the group (Krueger & Casey, 2000; Reed & Payton, 1997). These distractions were not observed even though some students appeared to know each other. On the whole, the students were very polite and did not interrupt each other or exhibit disrespectful behaviors.

#### Data Collection Methods

The data for the research study are comprised of transcripts of the focus group discussions, typed flip chart notes, handwritten notes from the focus groups and debriefing, the intake forms completed by the study participants, and the researcher's journal.

Data were collected through three focus groups held on the main campus over the noon hour on February 18, 25 and 26, 2008. Three focus groups were held because the nature of the research topic study is not one likely to cause heated debates, and the number of students interested and available to participate at convenient times was sufficient to comprise three groups. The participants were similar in age, life stage, health care, and health information practices. Participant characteristics are discussed in depth in Chapter IV: Findings. Using three focus groups falls within the recommended number of three to five. As Morgan (1997) stated, "The most important factor in determining the number of groups is the variability of the participants both within and across groups" (p. 43). More groups are required when the participants are diverse. Using the same questions for each group is another factor affecting the number of groups held. The more standardized the questions asked of each group, the fewer groups are needed (Morgan, 1997).

The groups met in rooms convenient for the students participating in the group. For example, the second group, composed primarily of nursing students, was held in the College of Nursing. Pizza and soft drinks were served to each group.

To start off, I asked participants to read and sign the informed consent, and to complete the intake forms, Appendix I. I reviewed the ground rules as listed them on the agenda, Appendix J. I reiterated the purpose of the research and asked if anyone had questions. I moderated each group's discussion following the script in Appendix K. I Two research associates (RA) assisted me in the management of the focus groups. One RA concurrently highlighted the discussion on flip charts and the other monitored the audio equipment and took notes of the discussion.

To make the participants feel comfortable and more willing to participate, each focus group discussion began with introductions of the research staff and self-introductions of the participants. As an icebreaker, participants were asked to share what they like to do in their free time. After introductions, the first question for each participant was, "What types of information does the term 'personal health information' bring to mind?" This question was intended to kick off the discussion with the participants' perceptions of personal health information. Responses to this question were useful for both the participants and the moderator to reflect back on later in the discussion.

Each focus group ended with each participant reflecting on "the most meaningful thing about PHIM that was said here today." Responses to this question provided a useful summary and elicited the participants' perceptions of the importance of topics discussed. Each group lasted approximately an hour.

As the moderator, I used various methods to stimulate discussion and encourage participation of all the students. These methods included asking both the first and last question in a “round robin” sequence, asking for clarification, and watching body language that indicated the individual wished to add to the discussion. By identifying participants by nametags in the first session and more easily readable table tents in the second and third, I called each participant by name.

After each focus group, the research team held a debriefing session and reviewed the discussion for potential themes, comparison with prior focus groups, and determination if there were any surprising contributions. I took notes from these discussions. After the third focus group session, the research team felt we had reached saturation and additional groups would not generate any different understanding (Glaser & Strauss, 1967).

Following completion of the focus groups, I aggregated the data from the intake forms. The transcriptionist transcribed the audio recordings verbatim and typed the flip chart notes. I checked the transcribed reports against the audiotapes and adjusted the reports for accuracy.

As recommended by various authors on qualitative research methods (Maykut & Morehouse, 1994), I kept a journal over the last two years of various thoughts and ideas that related to my research project. The journal included personal musings, insights, beginning understandings, working hunches, recurring words or phrases, ideas, questions, to do lists, concerns and decisions.

## Data Analysis Methods

I followed a combination of inductive and deductive data analysis process referred to as an integrated approach by Bradley, Currey, and Deevers (2007). The inductive analysis began with the focus groups transcripts, the main source of data. By listening to the audiotapes to check the accuracy of the transcripts, I immersed myself in proceedings (Creswell, 2007). Using the questions posed to the focus groups (Krueger & Casey, 2000) and the data itself, I constructed a coding scheme. Coding is needed to bring order to material that without it would be difficult to analyze (Tesch, 1990).

The coding structure grew and became meaningful through an iterative process of decontextualizing and recontextualizing the data. The transcript was segmented or decontextualized by assigning codes to meaning units. A meaning unit is a segment of the transcript that is, “comprehensible by itself and contains one idea, episode, or piece of information” (Tesch, 1990, p. 116). I labeled each segment with a term or phrase that best summarized the content of the segment. The code names came from participants’ words, also known as in vivo coding (Chesler, 1987), from the focus groups questions, from PHIM and focus group literature, and from my experience in health information management (Morgan, 1997; Tesch, 1990). Some meaning units were labeled with more than one code. To recontextualize the data, I created reports to include all data segments with the same codes. By moving back and forth between whole transcript and coded segments, I ensured consistent coding and revised code names to best describe the data (Tesch, 1990).

I began the analysis process manually by, writing notes in the margin of the transcript. After review and rereading the transcripts and margin notes, I moved to using

*HyperResearch*, computerized software for qualitative research. The software has the functionality to highlight and code sections of text, to describe types of information assigned to codes, to search for words and phrases in the narrative text using a ‘find’ command, to sort text segments by code(s), and to report frequency of codes. The software does not constrain the number or nature of codes assigned to text segments, nor does it limit the amount of text that can be classified by a code. To consistently code the data, I developed a type of “data dictionary” to describe the type of meaning units included in each code (Shenton, 2004).

I utilized the coding process and the computer software to address additional questions and assist in interpretation of the findings. I used codes to distinguish between participants’ own experiences and beliefs and those situations they observed. In this way, I was able to derive key finding based on the “hierarchy of credibility” (Kidd & Parshall, 2000; Nyamathi & Shuler, 1990).

I performed content analysis, counting frequencies of occurrences of words, phrases or categories, to get a feel for the data and to compare the groups’ discussions. This process is useful to identify the codes and categories that were more prevalent in one group than the others (Kidd & Parshall, 2000; Webb & Kevern, 2001). I compared the discussion topics with the participants’ demographics from the intake forms to discover potential relationships between gender and topic, program of study and topic, age and topic. Content analysis was also used to discern patterns and trends in participants’ responses to the concluding question, “What was most meaningful thing about PHIM that was said here today?”

After consulting with a faculty member skilled in qualitative research, I returned to the social marketing literature to locate a conceptual framework for use in data analysis. From the more extensive review of social marketing literature, I found reference to more than 50 potential theories and models (French & Blair-Stevens, 2008). I also recognized I needed to learn much more about social marketing to understand the research findings and apply them to social marketing. Through this more indepth of the review social marketing literature, I discovered the Motivation, Opportunity, and Ability (MOA) Model that would serve as the deductive phase of the analysis. The goal was not to test the MOA Model but to utilize it to organize the findings, apply it to the situation, and to facilitate understanding the various influences on the target audience.

#### Methods to Assure Rigor and Trustworthiness of Findings

A number of researchers have discussed various strategies to ensure the scientific rigor and trustworthiness of research findings from focus group studies (Bender & Ewbank, 1994; Carey, 1995; Kidd & Parshall, 2000; Morrison-Beedy, et al., 2001; Nyamathi & Shuler, 1990; Polkinghorne, 2005; Reed & Payton, 1997; Twinn, 2000). Morrison-Beedy (2001) specifically linked the four criteria that Guba and Lincoln put forth in 1988 to focus group techniques (p. 51). The methods I used to meet the four criteria are described below.

#### *Credibility*

In qualitative research, credibility refers to “confidence in the truth value of the data and reflective of multiple realities” (Morrison-Beedy, et al., 2001). I followed the suggested techniques found in the focus group literature to achieve credible data. The techniques I used are (a) holding multiple groups, (b) following a detailed interview



guide, (b) encouraging all participants to share their perceptions, (Bender & Ewbank, 1994; Nyamathi & Shuler, 1990; Polkinghorne, 2005; Twinn, 2000), and (c) debriefing with the research team at the end of each focus group (Morrison-Beedy, et al., 2001).

To address credibility, qualitative researchers also recommend 'member checking' by having research participants review transcripts for accuracy. Because the unit of analysis for focus groups is both the participants and the group, member checking would require reconvening the whole group. Even if it were possible to gather the whole group together, recreating the same group dynamic that created the transcript would be impossible (Carey, 1995; Kidd & Parshall, 2000). In its place, Kidd and Parshall (2000) recommends member checking in real time during the focus group process. This was accomplished in two ways. First, during each focus group, the RA visibly wrote the main discussion points on flip charts. The participants could suggest changes if the points did not accurately reflect the discussion. Second, the final question asked the participants what they found most meaningful to them from the discussion. The students' final responses confirmed the points discussed earlier.

Credibility is also supported by participant consensus within the groups and between groups (Kidd & Parshall, 2000). Analysis of the student focus group transcripts revealed substantially similar perceptions by most of the participants in all three groups. No issues were debated. The lack of disagreement could mean that they all agreed on the content, they did not wish to argue about an issue, or they were not interested enough to offer a contradictory statement (Carey, 1995). Triangulation of the findings by comparing them to another data source also addresses credibility (Morrison-Beedy, et al., 2001). I did this in two ways. First, I piloted the questions on a group of friends and on a small

group of college students to make sure that I would generate meaningful data that answered the research questions. Second, I compared the findings of this study to the existing body of knowledge as discussed in Chapter V: Findings.

#### *Dependability*

Findings are dependable when they are stable over time and if similar findings would result when the process is repeated (Morrison-Beedy, 2001). I used the following methods that support dependability: holding the three focus groups in similar settings, following similar procedures, and asking the same interview questions to each group. Data collection methods overlapped with augmenting the focus group transcripts with the demographic data collected on the intake forms. The focus groups were audio recorded so a verbatim transcript could be produced for analysis.

#### *Confirmability*

The findings are confirmable when the researchers agree on codes and themes. Due to the research team's time constraints, team coding was not used. "Some authors argue that a single researcher conducting all the coding is both sufficient and preferred" (Bradley, et al., 2007, p. 1761). To try to address the reliability of the coding system, I enlisted the aid of the Education Department Chair at a small university to review the application of the codes to the transcripts. I also compared my coding scheme to the other sources of data: flip chart reports, field and debriefing notes, and the researcher's journal to determine potential omissions from the analysis.

The RAs who assisted in managing the focus groups developed a coding scheme based on what they heard and observed during the focus groups and the flip chart reports. The intent was to apply this structure to the text. Not wanting to rely solely on their

work, I referenced the literature on analysis of focus group data and chose to let the data define the coding scheme. The process is described previously. Once completed, I compared my coding scheme to that of the RAs and found them to be very similar.

### *Transferability*

Whether the results of this research can be transferred to a similar setting depends on the completeness of the detailed description of the setting and participants. The setting is described earlier in the methods section and the participants are described through the demographics and quotes included in Chapter IV: Findings.

### Limitations in Methodology

The assistance and the moderation of the focus groups limited the types of data available for analysis. This limitation was due to lack of experience in collecting data for research through focus groups and extensive experience in facilitating classroom discussion. Due to my inexperience in using focus group transcripts for research, I did not instruct the research assistant to collect information on who said what and was unable to derive this information from the seating chart and notes. Kidd (2000) recommends that by identifying who said what, the researcher could discern if most of the comments in a category came from one individual or a subgroup and avoid over coding concerns not shared by several participants. Also without identifying the speakers, I was unable to tell if others affected participants in the group.

My comfort from experience in leading classroom discussions in combination with the participants being students may have led to a more classroom feel than an open dialogue. There was little interaction between participants. In the second focus group that was held in a classroom, a couple students raised their hands to talk. However, the

topic of discussion was not one that any of the participants exhibited strong feelings that may have lead to an active debate.

Video taping the focus groups would have facilitated capturing who said what as well as participants' non-verbal behaviors. Nonverbal behaviors would have provided additional information and richer interpretation of the participants' discussion. Watching the video after the first group would also have helped me to identify my "teacher" behavior and give me an opportunity to change it for the second and third group.

### Summary

The purpose of this study is to determine what may influence students at an academic medical center to adopt PHIM. I used a qualitative research design collecting data through focus groups to learn directly from the students and collect their views in their own words. Thirty-three students participated in three focus groups. The transcribed reports of the focus groups' discussion were the main source of data. I used an inductive iterative process to analyze the data. Using qualitative software of *HyperResearch* to decontextualize and recontextualize transcript segments, I constructed a hierarchical coding structure. Various techniques were used to assure the trustworthiness of research findings. These methods included using consistent and detailed procedures to conduct the focus groups, using multiple sources of data, audio recording the focus groups, using verbatim transcribed reports of the focus groups sessions as main source of data, and comparing the coding structures of the research team members. A deductive approach through application of the MOA Model and conceptual framework to the findings lead to interpreting and formulating the study's conclusions. The limitations of the methods used were due to not attributing comments to individual

participants and moderating the groups more like a class discussion than an interactive dialogue.

The focus groups provided a rich source of data to answer the research questions:

- 1) What distinguishes individuals who have adopted or are ready to adopt personal health information management from those who are not interested in adopting the behavior?
- 2) What facilitates and encourages individuals to adopt personal health information management?
- 3) What are anticipated barriers and concerns to adoption of personal health information management?

## CHAPTER IV RESEARCH FINDINGS

### Introduction

The findings in this qualitative research study are derived from the analysis of the focus group transcripts. To give the readers some basis for understanding of the focus group comments, Chapter IV begins with description of the research context, the target audience of students at an academic medical center, and in particular focus groups participants. The description of the participants includes their perceptions of personal health information (PHI), personal health information management (PHIM), and their disinterest in the personal health record (PHR) offered by the university.

As recommended by Bloomberg and Volpe (2008) who said, “Whatever tradition one adopts, perhaps the most fundamental underlying operation in the analysis of qualitative data is that of discovering significant classes or sets of things, persons, and events and the properties that characterize them” (p. 98). The classes used to analyze the data are the summary concepts of motivation, opportunity, and ability as described in the MOA Model in Chapter II. By grouping the findings into positive and negative aspects of the MOA Model, I outline the answers to the research questions in Table 4.6.

I selected the findings to include in this and later chapters based on the “hierarchy of credibility.” The most credible comments are those that reflect the participants’ personal experiences (Kidd & Parshall, 2000; Nyamathi & Shuler, 1990). I also included some comments on participants’ observations of others, but relied mainly on statements about their own experiences and beliefs.

## Research Context

The research took place at the main campus of the state university's academic medical center located in a medium sized Midwestern city. The academic medical center is one of four campuses of the state university. It is composed of the Colleges of Dentistry, Medicine, Nursing, Pharmacy, Allied Health, Public Health, and Graduate Studies and enrolls over 3000 students. The university's mission is:

To improve the health of (state) through premier educational programs, innovative research, the highest quality patient care and outreach to underserved populations

Its vision is:

- To be a world-renowned health sciences center, continuing the commitment to community health, providing state-of-the art health care
- To rank as a leading research center
- To deliver the best-educated health professionals and scientists into the practice world (university Web site)

I conducted this study at the medical center campus because the students were offered a free Web-based personal health record (PHR). The PHR has been the focus of my graduate studies since I started the program in 2002. I saw the university offering PHRs to students as an expression of interest in adoption of behaviors that would support the PHR or what I call personal health information management (PHIM). I believe that individuals adopt PHIM behaviors if they felt the behavior fulfills personally relevant goals. The study was undertaken to understand this target group of students at

an academic medical center in a medium sized Midwestern city and identify their personally relevant goals to be achieved through PHIM.

### *Focus Group Participants*

Thirty-three students participated in the focus groups that were held during the noon hour on February 18, 25, and 26 in 2008. I will refer to the groups by the sequence in which they took place: Group 1 on February 18, Group 2 on February 25, and Group 3 on February 26. Because I was unable to identify the comments as being made by specific individuals, I refer to their comments by the focus group number. When quotations include those made by more than one person, I refer to each participant as participant 1, participant 2 and so on. Participant 1 in one sequence of quotes is most likely a different person than Participant 1 in a different sequence. When participants are referred to by name, I used a pseudonym and placed it within quotation marks to let the reader know that is not the participants' actual name. I refer to myself as moderator.

The demographics of those who participated in the focus groups are listed in Table 4.1. The students were similar in age, race, and gender. All were younger than 32 and two-thirds were younger than 25 years old. The summary of all responses to the questions on the intake form is listed in Appendix L.

Table 4.1 Demographic descriptions of focus group participants

	<b>Group 1</b>	<b>Group 2</b>	<b>Group 3</b>	<b>Total</b>	<b>Percentage of Total</b>
<b>Number of Participants</b>	9	13	11	33	100



	<b>Group 1</b>	<b>Group 2</b>	<b>Group 3</b>	<b>Total</b>	<b>Percentage of Total</b>
<b>Age</b>					
19-24	5	12	5	22	66.67
25-30	4	0	6	10	30.30
31-34	0	1	0	1	3.03
<b>Gender</b>					
Male	1	0	4	5	15.15
Female	8	13	7	28	84.85
<b>Program of Study</b>					
Graduate Studies	3	0	2	5	15.15
Medicine	3	1	8	12	36.36
Nursing	3	9	0	12	36.36
Pharmacy	0	0	1	1	3.03
Physician Assistant	0	3	0	3	9.09
<b>Life Stage</b>					
Single no children	4	11	4	19	57.6
Committed relationship no	5	1	4	10	30.3

	<b>Group 1</b>	<b>Group 2</b>	<b>Group 3</b>	<b>Total</b>	<b>Percentage of Total</b>
children					
Committed relationship with children		1	3	4	12.1

The demographics of students in the three groups differed from each other as illustrated on the graphs in Figures 4.1 and 4.2. Group 2 was the most unique because of its homogeneity. The students were all female and 9 of the 13 (69.2%) were in the nursing program. Group 3 was composed of a larger number of males and more medical students (72%) than the other two groups. Students in Group 1 were equally divided in their fields of study with 33% in each of nursing, medicine, and graduate studies.

Figure 4.1 Student age range by focus groups

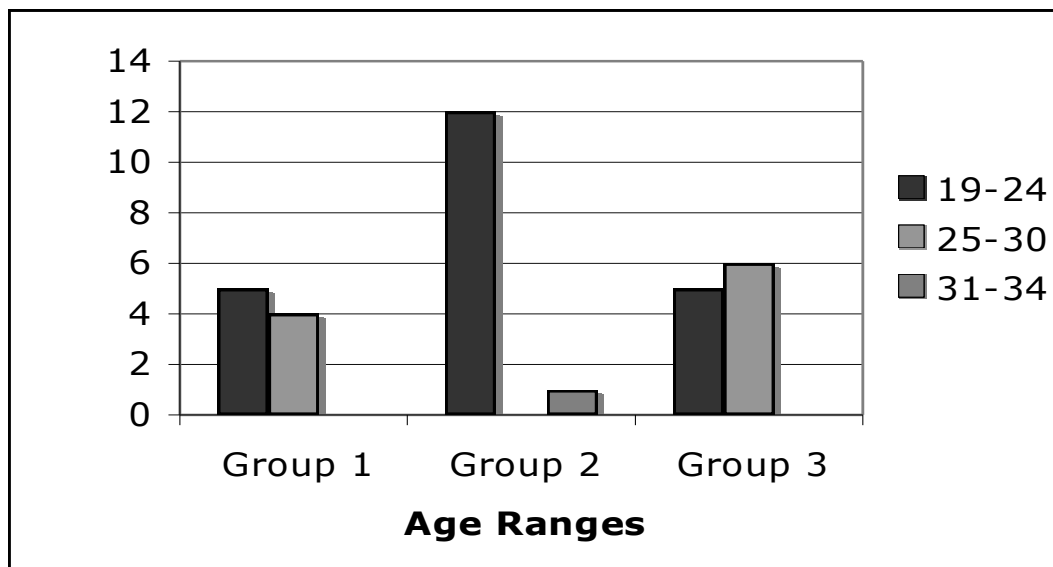
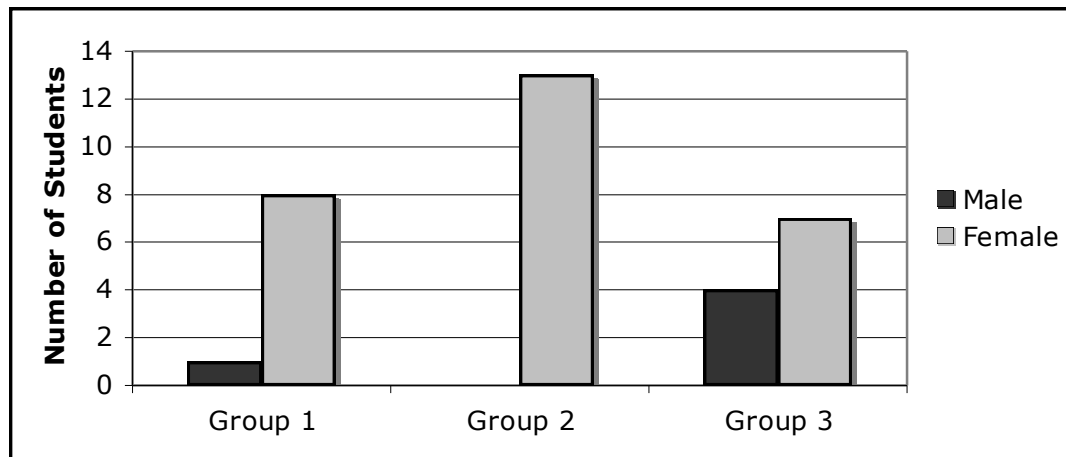


Figure 4.2 Participants' gender by focus group



The participants' responses to the icebreaker question were useful in providing additional data about the target group. The question was, How do you spend your free time? Their responses included both activities and people with whom they would like to spend their free time. In Table 4.2, the responses are listed in rank order to demonstrate the most frequent response.

Table 4.2 Participants' free time activities ranked by activity mentioned most often

Activity	Number of participants	Percentage of Total Responses	Rank by number of students
Sports including working out	11	33%	1
Spend time with family & friends	9	27%	2
Read	6	18%	3
Domestic tasks	3	9%	4
Relax	3	9%	4

<b>Activity</b>	<b>Number of participants</b>	<b>Percentage of Total Responses</b>	<b>Rank by number of students</b>
Spend time with pets	3	9%	4
Video games and TV	3	9%	4
Travel	2	6%	5
Board games	1	3%	6

*Participants' Perceptions of Personal Health Information and  
Personal Health Information Management*

To create a frame of reference for the focus group discussion, I asked the students, on both the Intake Form, Appendix I, and in the beginning of the discussion, questions to get a sense of their experience with PHIM. On the intake form 28 out of 33 (84.8%) participants answered yes to the question “Do you keep track of health information for yourself or anyone else? The most frequent response to the first question after the icebreaker, “What do you think of when you hear the term personal health information (PHI)?” was vaccination/immunization records. For example, one woman said, “Yeah, the first thing I thought of was the little vaccination card that my mom has kept for me since I was a baby.” (Group 3) Participants frequently referred to their vaccination records throughout the focus group discussions.

Other descriptions of PHI varied and included the following statements:

Participant 1: Lab test results

Participant 2: Medication list

Participant 3: Vitals, like blood pressure and weight, and I don't know. I guess more like when you, just to make sure, they are within normal limits.

Participant 4: I think of like the charts that they have when I go to the clinic; what's inside them!

Participant 5: Maybe long-term medical ailments like diabetes and anything, any sequelae related to those.

Participant 6: Like kids' growth charts (Group 1)

If you had any x-rays or you've maybe gone to somebody special like a chiropractor. Just, you know a record of when you do those things. (Group 2)

I guess I have a file of uh, like old receipts from doctors' visits and stuff, health insurance stuff. (Group 3)

### *The University Personal Health Record*

On the intake questionnaire, students were asked about their knowledge and use of university's PHR. Thirteen or 39% knew that the university offered students a Web-based PHR available on Blackboard. Twenty or 61% did not know about it. All the participants, 100%, had not looked at the PHR. The students did refer to it during the discussion and admitted they had not taken the time to look at it. For example, one participant said,

I got those emails as well and I know that we have ways, like on Blackboard, that we can manage our own health care. But, I didn't ever take an initiative to do anything about it. I just read the email and went on with my life. (Group 1)

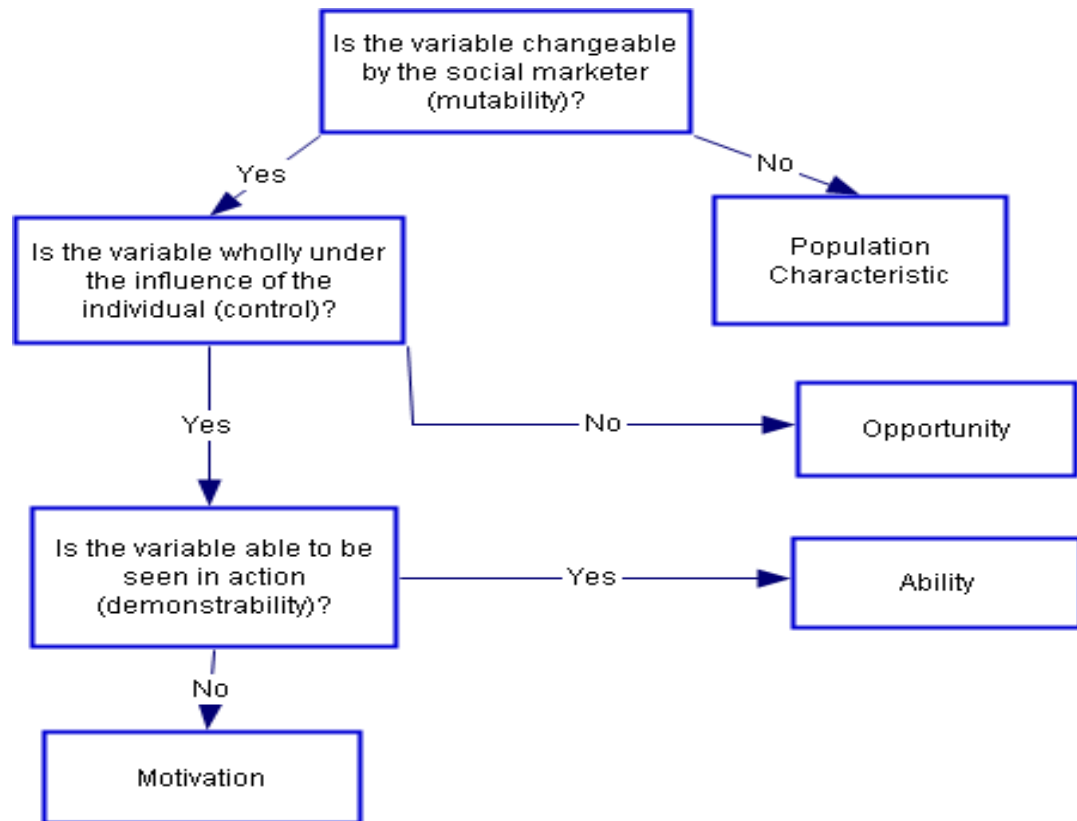
On a positive note, several participants indicated they might use the university PHR in the future. One student said: “I need to get all the stuff, at least try one time to get it all together, and then I'll check out the student Web site before I'm no longer being a student.” (Group 3) Another referred to it as a “good summer project.” (Group 2)

### Research Findings Categorized by the Motivation, Opportunity, and Ability (MOA) Model

#### *Overview*

As the organizing structure, the Motivation, Opportunity and Ability (MOA) Model provides a means to operationalize the concepts of motivation, opportunity, and ability through application to the research context, the target audience of students, and the PHIM behavior. The variables identified through the coding process were sifted through the Population Services International (PSI) algorithm in Figure 2.4 and repeated in Figure 4.3 to group into the categories of motivation, opportunity, or ability.

Figure 4.3  
PSI algorithm to categorize variables by motivation, opportunity and ability



As conceptualized in Table 4.3, I organized the findings by the positive and negative aspects of the motivation, opportunity, and ability constructs. Individuals can be influenced positively, negatively, or not at all. In this situation, positive influences encourage or facilitate PHIM behavior and negative influences cause avoidance or are barriers to PHIM behavior. The neutral aspect of motivation is ambivalent. I think it is important to examine the range of responses from positive to negative because the social marketing strategy would fail if it did not address factors that may influence the individuals to avoid or serve as barriers to the behavior. Table 4.3 also shows the findings relationships to the research sub questions. All of Table 4.3 addresses the central research question and research question 1. The positive aspects of MOA respond to RQ2, and the negative aspects address RQ3. Following the table, each finding is

supported by evidence in the form of participant quotes from the focus group discussions.



Table 4.3 Comparison of research questions to research findings using the Motivation, Opportunity, and Ability Model

Research Questions			Motivation	Opportunity	Ability
RQ1: What distinguishes individuals who have adopted or are ready to adopt personal health information management from those		Neutral	I'm healthy, different from those that have health issues		
			Not motivated		
RQ 3: What are anticipated barriers and concerns to adoption of personal health information management from those	RQ 3: What are anticipated barriers and concerns to adoption of personal health information management from those	Negative	Fear information used against you	Lack of time - too busy to do PHIM	Lack of knowledge on how to get information, what information to keep, and rights to the information
			Feel lack of control over information	Difficulty getting information from	Not "computer savvy"

Research Questions			Motivation	Opportunity	Ability
who are less interested in adopting the behavior?	information management?			providers	
				Multiple providers with different pieces of information	
				Reliance on others to do PHIM	
RQ2: What facilitates and encourages individuals to adopt personal		Positive	Belief benefits of “do it now” avoid “hassle” of doing it later (Desire for convenience)	Providers offering patients copies of records without being asked	Transition in life stage
			Belief individuals responsible for own information	Meeting expectations of others and fulfilling	Being organized

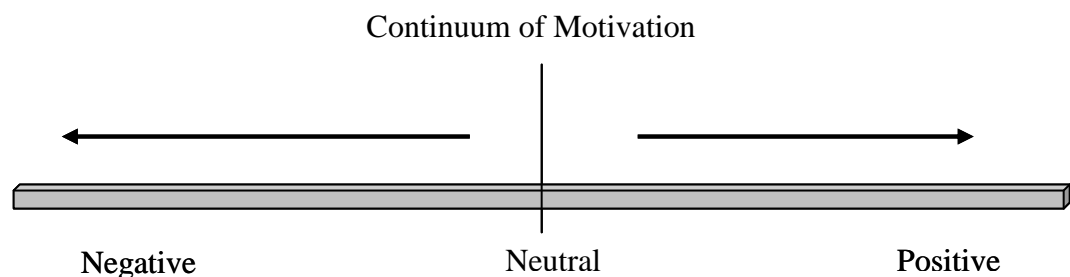
<b>Research Questions</b>			<b>Motivation</b>	<b>Opportunity</b>	<b>Ability</b>
	health information management?			requirements	
			Management of their own or others' health and health care	Incentives	
			Avoid repeating the same information over and over	Save money	
			Memory aid	Information technology system that connects providers and patients	

<b>Research Questions</b>			<b>Motivation</b>	<b>Opportunity</b>	<b>Ability</b>
			<p>Improve effectiveness and safety of healthy care when complete information is available including when traveling or relocating</p>		

### *Motivation*

Motivation as defined in the literature review is goal directed arousal or readiness to act. Individuals are energized toward a goal that is personally relevant to them (Rothschild, 1999). This section of the findings explores the thoughts and beliefs that the students expressed about personally relevant goals and the items that would influence them to act or serve as barriers to action. The students discussed beliefs that would motivate them toward adopting the behavior, those that caused them to avoid the behavior, and those that had neither a positive or negative effect. In other words the items grouped into the motivation concept form a continuum of motivation, Figure 4.4.

Figure 4.4



#### *Neutral toward PHIM*

*I'm healthy.*

Starting at the neutral position, participants indicated that keeping track of their own health information was not a personally relevant goal. Many believed that because they were healthy, they did not need this information. A student said,

You know for me, assuming most people our age, if you don't have a lot of health issues or major health issues, so it's not a big deal anyways. I know that I'm

healthy. And, I go for my check-ups and I'm okay, then I don't, I'm not really motivated to keep [track of] all my visits and that....(Group 2)

Some compared themselves to those who they have observed who are not “healthy” and their need to have accessible information about their conditions.

I think it is interesting, I mean people who have been generally healthy very often don't seem to know a lot about our health. I mean and so you know, they'll be, almost never know anything about their health. But, if you look at like the transplant patients, those people carry them [medical records] around in their purses. You know, they'll have a DVD of all their health information; it's amazing, and so, I see that a lot. I mean I've had patients come into the ER or something and show up with a CD and say this is my health information and I'm like, WOW! (laugh) (Group 3)

*Not motivated.*

Motivation is key to behavior change. A person can have the ability and opportunity, but if not motivated will not adopt the new behavior (MacInnes, et al., 1991). The following comments exemplify this situation. This medical student had the knowledge and the opportunity, but did not feel it was important.

Participant: I think for me, it is a matter of personal motivation. I know most of the things that were said, I know that it is a good idea to keep it. ....But ... I also have ... I have to get lab work checked at least yearly if not more often because it affects the dose of medication that I take, and I don't have a copy of those lab values. I know that the last time they checked it they were normal, but I have not

taken that to heart yet, so I think it's not just knowledge, but it's personal motivation too. And, I guess I'm lacking that a little bit.

Moderator: What do you think might motivate you to take that step?

Participant: Well, that's what I'm trying to decide. (laughing) If there's anything external that would be more of a motivation and I, I have not come up with anything to be honest.

Moderator: So, what keeps you from doing it?

Participant: Laziness, I mean, frankly, that's kind of what it boils down to. (Group 1)

### *Avoiding PHIM*

*Fear information being used against you.*

At the avoidance end of the motivation continuum where individuals chose not to adopt the behavior is the belief that the behavior will result in negative outcomes. With PHIM, one student felt that documenting information in addition to what her health care provider documented would end up in the “wrong hands” of an insurance company and cause her harm in the future. The student said,

I think a big thing for me is just about how the insurance companies work. I personally don't want to give them any more information than I have to. You know, I don't want to tell them how often I work out. I don't want to fill out paper work and things that say, you know I don't eat right, I don't work out enough, because anything that you give them on top of what your physician says, you know they could potentially come back and use it against you.... I don't want to come back in a few years and the health insurance company says, well we have

this file and it says that, you know, back in 2007, you didn't do anything. So, I think that's kind of one of my fears. (Group 3)

This same person followed with further explanation.

I'm not so much concerned with having it, as far as the information stored electronically because I ...pay bills online, I shop online, I give them my credit card, and my social security online, and I feel comfortable with that because it's never come back to bite me. Maybe it will. Rather, than just electronically storing it, it would be a matter of who would have access to it which would concern me the most and, in which case, I mean that would be disclosed. But, still, it's more who has access rather than it just being electronic. (Group 3)

The above statement influenced another participant in the same focus group to respond to the question of, "What was most meaningful to her?" with the following comment.

One thing that was mentioned that is meaningful to me is the fear of having individual's personal health information on the Internet or easy accessibility for the insurance companies to kind of manipulate. So, that's something I kind of forget about and just brought it to my attention again. (Group 3)

*Feel lack of control over information.*

Another participant's comment reflected avoidance of PHIM. She said, "Also lack of, really lack of control. Like, you kind of feel that the doctor has all the control so you just let them deal with it." (Group 2) She was the only one in all the focus groups to express the belief that not having control led her to not wanting to manage her PHI.



*Motivated Toward PHIM*

At the opposite end of the motivation spectrum is the drive toward adoption of PHIM. Participants' comments exemplify a variety of positive influences including a "do it now" belief that would avoid frustrations later, an attitude of responsibility for their own (and family members) information, needing information to manage their own or others health and health care, and the view that positive outcomes could result from PHIM.

*"Do it now" to avoid "hassle" of doing it later.*

Those participants who tended not to procrastinate could see the benefits of managing their health information as they go along rather than waiting until they needed it. It would also be more difficult with more information to seek out and maintain.

I think that this kind of made me realize that I need to start before there's so much information piling up, and probably I need to start taking care of my husband's too..... (Group 3)

Personally, I would just do it out of convenience. I mean, some reiteration of what other people have said about the vaccinations; I have no clue about all my vaccinations.... Or, maybe I guess when my next job or residency or however, but when it comes up next time when I have to show them when my last vaccinations were, I'm not going to know. So, personally, I think just a convenience factor. (Group 3)

*Belief individuals are responsible for their own information.*

Participants in Group 2 expressed this viewpoint most frequently. Their discussion centered on the recent death of a young actor due to an interaction of medications. If the provider only knew the medication the actor was taking, the doctor would not have prescribed one that caused a fatal interaction. This is summarized by the following comment.

I know, one of my friends has actually asked me; I don't know how he [the actor] had all these medications for the same condition. So, like if they don't tell the doctor, they're not going to know about it. And, she was just like, well, why didn't he tell them? I said, because he [the actor] probably didn't know. And, if he wasn't informed like what he needed to tell the doctor like, 'oh this is what I'm having problems with.' You also need to tell them your history and need to tell them like medications you're on. (Group 2)

A few participants' experiences led them to believe that providers were not keeping track of their information. As individuals who care most about the information, the participants expressed interest in managing it themselves.

I think it really boils down to the fact that you have to be, as an individual, responsible, because no one else is going to take care of that. You know, once you reach a certain stage in life. Once your mom doesn't do it for you any more, or you're not on your parents' insurance. You have to be an individual responsible for your own healthcare. (Group 2)

I guess I believe that the physicians or physician's assistants are not keeping track of it [PHI] themselves, so that kind of motivates me to like have a record of my immunizations now. (Group 2)

*Management of their own or other's health and health care.*

Beyond being responsible for informing health care providers about their health history, participants also recognized the utility of personal health information for managing their own and others' health including preventive measures. PHIM afforded them the ability to know when they needed updates of their shots, to keep their children on schedule, and to serve as durable power of attorney for health care for their parents.

What a big help and benefit that could be for you when you go to seek health care. Because, then you're just more aware and like, by the way, I haven't had a tetanus shot and you know. You could keep track of that, then. (Group 2)

And, I almost wish I knew that I could have asked for that stuff. Because, when I was 20. So I have really dense breast tissue so it's really hard to tell if I have actual lumps or not, because I have a lot of lumps. So, I got really worried when I became more aware of cancer and everything. So, and my, my new nurse practitioner got a little worried too, so I had an ultrasound done and showed it was normal. But, I wish I would have those records. And, yeah, they're in New Mexico... But, I just thought of that today and I would kind of like to have them for the future. (Group 1)

Several participants saw that being responsible for their children's health and health care would influence them to perform PHIM. In Group 3, I asked a male student about the records he had on his son. His response was:

Male student: Yeah, I have much better records on him [his two-year-old son] than I do of myself. So, we are very organized with his stuff and keep it all in one place. It just seems like when I'm taking care of someone else's stuff, I'm much better with it than my with my own stuff, so.

Moderator: Any comments?

Male student: Kids have to have their schedule. You know, no one's telling me to have a check-up ever. So when a kid needs to go every three months, then you go every three months and then they do all the crap on our kids. (Group 3)

I was thinking the same thing, like you know, if you become pregnant. Well, that's a good time to start keeping track because you know, you'll be responsible for this child now. So, pregnancy would be a big one for me...to start keeping track of health information. (Group 2)

In Group 3, several participants were or anticipated becoming their parents' surrogate decision maker. They recognized that as durable power of attorney for health care for their parents they would need access their parents' health information.

I guess I, today is the first time I thought of it from the standpoint of taking care of my parents in the future. I know, especially my dad already has quite a bit of stuff built up from over the years from things he's had done and, if I'm not able to access that when I need to know it, that could be difficult. So, not so much a

disadvantage for me, but even for my parents in the future, I would like to do a better job with their health care. (Group 3)

As witnesses of others' behaviors regarding their health, the participants recognized the need of those with chronic conditions such as diabetes to keep track of pertinent health information. The following discussion took place in the second group.

Participant 1: Well, my best friend's dad just got diagnosed with diabetes, and before, he, you know, all along his daughter is a nurse, and she was telling him all along like he's not eating healthy and you know, he needs to do all this stuff and exercise, and never did. He didn't care what he ate; he would eat like Burger King two times a day, never exercise. Well, he got diabetes and the doctor said if you continue doing what you're doing, you know, you will end up in the hospital and you know, have multiple complications with your disease and, so he got on the right track. And, he like, he does a diet plan now and exercises.

Moderator: Does he keep track of everything?

Participant 1: Uh huh. He has logs and, of course, now there is the blood sugar that has to be done.

Participant 2: Yeah, I think diabetes is an excellent example because you have people that they have to keep track of stuff and all of a sudden they go in, and now it's like they have to check your sugar, like three times a day, and you're supposed to keep a record of that, and then if they get insulin or something too. It's like you go from nothing to a whole lot of stuff that you have to keep track of and keep detailed records of. (Group 2)

I think even watching someone else's declining illness, like say your sister or your mother or whatever. Somebody got this illness, you know it could have been earlier, and they put everything together and stuff like that motivates a lot of people to start keeping track of themselves better. (Group 2)

*Expectation of positive outcomes from PHIM.*

Participants who expected that PHIM would bring positive outcomes were motivated to adopt the behavior. The positive outcomes include:

- Avoid repeating the same information
- Serve as a memory aid
- Receive better quality of care by having information available including when traveling or relocating

The participants saw that having their own health information would replace the need to repeat the same information over and over again with each new provider.

Individuals find this tiresome and wonder why, with technology currently available, health care has not adopted systems as in banking and travel industry (Cochrane, 2001).

Like he was talking about because you could just have your file and give that to them instead of filling out all the pages and pages of paper work each time.

(Group 3)

With the current, fragmented information systems used in health care, individuals are expected to remember their health history. Participants saw that PHIM would serve as a memory aid in responding to questions and in filling out forms. A participant's comment summed it up as, "It's hard to keep all that stuff in your head, so it's important to have it." (Group 2)

[In response to the question, what do you think of when you hear the phrase\personal health information?]

Just, you know a record of when you do those things, because otherwise you forget. Like, I don't remember a lot of things like when I had a special work up done and that's very important to keep a record of. (Group 2)

A few participants referenced their clinical experiences in acknowledging that by having pertinent health information such as medication lists enabled providers to give more timely and effective health care. One student shared an experience from her clinical rotation.

Uh, I think sometimes people don't know how important, like a list of medications with their doses is. And then that can really affect the way a doctor handles their treatment, whether they increase a medication or add on a new medication. I've seen patients have to come in again the next week and bring that correct list before anything can be changed. And then there's a whole week gone by, you know, that something could have been done but wasn't, simply because they didn't have a medication list with correct doses. (Group 1)

Students who travel felt it would be important to access their information when on a trip, possibly in another country, and relocating. Keeping track of your own health information would be very helpful in remembering what was done when and where especially when living in different places.

I think it's good, in my life, because I like to do a lot of international travel. So, having access to those records and taking them with you to another country because they are not going to be able to get them over there. (Group 1)

Maybe moving a lot would be reason to keep track of health information. Moving from city to city, for the average person really needs to take care of your own self more. (Group 1)

### *Opportunity*

As defined in the literature review, the opportunity construct incorporates those items that are external to the individual whose behavior is being influenced. For this situation, many of the external barriers related to two key themes, time and health care providers. Findings also included in the opportunity category are reliance on others for PHIM, meeting expectations of others or fulfilling requirements, and incentives.

### *Time*

Reference to time permeated the discussions and is most evident in placing it as a barrier to adopting PHIM behaviors. With frequent reference to the time it would take to keep track of their information, participants would put it off as shown in the following comments.

It seems like a lot of work to get it started and then it kind of seems like, well I'll do that later when I have more time. It's easy to put off. (Group 3)

I, at least, feel kind of overwhelmed by it. Uh kind of from a time issue, um, like I, I know for example, the students here have that personal health information, I



don't know what it's called, thing available to us and I saw it, but just like, I felt like I don't have the time. (Group 3)

Contrary to the belief of not having time to manage their health information, several students who thought doing PHIM now would save them time later, were descriptive on how that affects them.

I don't think I would listen to anyone unless I thought I was going to save time or live longer because I did that. I mean, as long as I knew it was possible, I could go on the Internet, type some stuff in, request some...my only motivation would be saving myself time. (Group 2)

I think it's kind of a convenience thing for me too because my time is so important to me since I don't have very much of it that knowing if I have everything organized, then I know what I've had done and I know where my records are, it will save me time. (Group 3)

#### *Inherent in Health Care Providers' Systems*

##### *Difficulty getting information from providers.*

In references to providers' roles in PHIM, participants described their frustrations in requesting copies of their medical records and the knowledge that multiple providers held their health information. Several participants experienced difficulty in retrieving information from their health care providers. They thought the providers' procedures used to respond to requests for PHI seemed unreasonable as explained in the following comments.

I think it is discouraging that like, when I moved to Omaha, I tried to get my records from a previous physician and the fact that you have to either pay for those or you know pay for them to be sent to another doctor when you're trying to be responsible for your own care. That's a pretty big downfall, to manage your own information. (Group 1)

My husband and I lived in Orange County, California, and I saw a physician there and to transfer my records, they wanted me to fax a form, so I did. But, they said that the signatures were different. So, in order for me to get my records, I actually had to go there, me in person, with my driver's license, to pick them up. (Group 3)

*Multiple providers with different pieces of information.*

The participants saw that one of the biggest barriers to managing their own health information is that multiple providers have different pieces of it. They found it difficult to remember who had what information. They said that assembling all ones' information from the various providers would be very time consuming and just a "hassle."

Yeah, it seems like every provider that you have ever had has a different chunk of your records and if ever you needed a full set, it would take a lot of phone calls and a lot of time and a lot of effort to get those all together. (Group 2)

Understanding that if you go to your gynecologist that your primary care physician doesn't have access to that, so you know, if you got your cholesterol there, your primary care is not going to know that. (Group 2)

I had a lot of trouble with that, ... when we got accepted into medical school, I had to find out where I got all my vaccinations done and when I was a kid, we had moved around a little bit and so we had different doctors and trying to figure out where are these records and where are those records. It was all very disjointed and I didn't have it organized at all. (Group 3)

*Providers offering patients copies of their medical records without being asked.*

In contrast to the prior experiences, several participants were surprised to be offered copies of their PHI without asking for them. The following quotes demonstrate this occurrence.

I just realized that today I was at the doctor and she asked me if I wanted a copy of my lab test and I was surprised. Because, never in my life have I had a physician ask me if I want a copy of lab results. And, I was like, 'Is that allowed? Am I allowed to have that?' (Group 1)

*Reliance on others to do PHIM for them.*

Several participants relied on others to manage their health information. These “others” ranged from mom keeping track of their immunizations in their baby books, to a primary care physician who took on the role of record custodian, and to an employer. The participants saw this reliance facilitating PHIM. The following comments describe these practices.

My place of employment has my records. Every time I need them I have to go back up there to get them. (Group 2)

I have had really good experiences with my physician. They have always kept track of it [medical records] very well and every time I've needed it, I just contact them, went and picked it up, and it was just really convenient for me that they had it all put together. So, I think the idea of me managing everything by myself is kind of a big task because I think it is something that is really important to manage, but I just don't know if I would be responsible enough to keep that all together and to stay on top of managing it. (Group 1)

*Meeting expectations of others and fulfilling requirements.*

External facilitators of PHIM behaviors include circumstances that involve recommendations and expectations of individuals to do PHIM. The participants frequently referred to the requirements to produce their immunization records. They also mentioned that their behavior would be influenced by expectations of another, and/or recommendations by their health care provider to keep track of health information.

You know, it is important to keep track of your own information and I wouldn't have thought of it maybe if someone didn't tell me I should or if there wasn't a requirement to get your immunizations, then I probably would have never had that information on file. (Group 1)

I feel like if my physician or PA mentioned to me that they would like me to let them know if I ever see a specialist or anything like that, it would just be kind of a little red flag in my mind that if I ever do anything outside of my, you know, my

family care physician, that I need to keep track of that in order to tell them.

Almost like if you're responsible to another person for it. (Group 2)

*Incentives.*

Participants in Groups 2 and 3 discussed the use of incentives for PHIM in response to the question of what may motivate individuals to adopt PHIM? A participant in Group 3 saw incentives as a positive influence on PHIM behavior. He said:

Participant: I think if we had some kind of a monetary benefit from your insurance company, maybe they said if you keep track of this stuff and you show us that you have a log of whatever, you know, we'll reduce your premiums or whatever.

Moderator: So, if "Joe" here turns in his work out log and his heart rate, he might get a reduced premium.

Participant: Yea, that would be cool. (Group 3)

*Saving money.*

Participants also recognized that having copies of their own health information including x-rays would save them money from having to repeat tests or having titers drawn when they could not produce their immunization records.

I had an x-ray done of my skull for my orthodontist, and-well, even that wasn't that big of a deal, but for my dentist, they needed a sideways x-ray also, and I guess you're only supposed to get those every five years. Well, that's what my insurance will cover. And my dentist didn't tell me that, so I wasn't aware and I

could have gotten it sent from my old dentist to my new dentist, so I had to pay a lot of money for that x-ray (laughing). (Group 1)

*Information technology systems that connect providers and patients.*

Participants in all three focus groups discussed as well as selected as the “most meaningful” idea the need for information technology systems that connected health care providers and saved participants from having to keep track of the information themselves. A few participants in Group 3 liked the idea of implanting microchips with their health information on their person as is done for pet identification. The following statements exemplify these ideas.

Why can't we just have some kind of system like, she mentioned that she, like some of her results were in New Mexico-like why there can't be just like an online website that every medical personnel has to go to and like put it online, and like you would have a user name and password that you have for everything else and you could go on and access your own information. Along with any care provider could see all your history and it wouldn't be a question as to like getting it from someone else because it would all be; I think that would be the most ideal thing. (Group 1)

Um, I think it would be good to have it all in one spot like on the Internet or something, where if I was in, even in another state, I would be able to get my records even if in an emergency or something like that. I think that's very important. It's hard to keep all that stuff in your head, so it's important to have it. (Group 2)

Participant 1: You know, when, I think humans have an internal fear of what happens to their health care information and they have issues of microchips, like my dog has all of her health information on a microchip in the back, and it is really handy. (laughing)

Participant 2: I would so get micro chipped. (laughing) I really would. I guess you would have it all with you all the time. (Group 3)

### *Ability*

The last major construct in examining the potential influencers on students to adopt PHIM behavior is ability. The students expressed these abilities in both positive and negative terms, negative in needing the ability and positive in having the ability.

*Lack of knowledge about how to get copies, what to keep, and rights to the information.*

Participants in all three groups raised the concern about not knowing how to go about getting their PHI from providers, selecting information important to maintain, and understanding the information in their records. Many were not aware they had the right to access and have copies of their PHI. Some spoke from personal experience and some from perceptions of patients and other students. One student was concerned about her lack of computer skills, but she was interested in learning more about them.

I think some guidance on what I need to keep track of versus what isn't important. So, for me, right now immunizations are important. But, I don't need to know that when I was 12, I was treated for a sinus infection. So, keeping track of every single doctor's note probably isn't necessary. So, I don't know, I think that would

motivate me more if I knew specifics that I needed to....(didn't finish sentence)

(Group 1)

Participant 1: I think it's just overwhelming. Cause if you would give someone like a print out of all the labs that you've had done, you know, they wouldn't even understand that and would not...it would probably intimidate them more than help them.

Participant 2: Like this doesn't mean anything to me?

Participant 1: Yeah, you don't have the key.

Participant 2: And, there's always like abbreviations and everything, so it would be like trying to read a foreign language. (Group 2)

I thought it was interesting to hear that one of the biggest things ... is just the confusion of where to start and not knowing and saying, what am I supposed to do? Like, it's, whether this concerns people and why it's [PHIM] not happening. So, it is interesting. (Group 3)

I think that I, that it is very daunting to look at the system from the outside. I mean, I would guess most of the students don't know where to go to get your own health records on campus. I mean, there's 23,000 people on this campus and most people probably don't know where to go. I mean, it's very daunting just because of the size of the system; ....I mean, you just don't know about it until you do it. I



think it is intimidating and I think it is probably a big reason for people not to start, because they don't know where to start. (Group 3)

*Having the ability.*

In contrast to the above remarks, many participants did not express any unease with accessing their health information or lack of knowledge in how to go about it or what was important. They felt confident not because they were future health professionals but because of personal characteristics such as managing transitions in life stage from being dependent on their parents to being independent adults and being organized. Considering the predominant ages of the participants was under 25, see Table 4.1 and Figure 4.1, many had experienced the transition from not being responsible for much to becoming responsible for their own health care and health information. As the following comment summarizes:

Yeah, and at the same time, like before you make those big transitions, like when I was in undergrad, I only knew that that one time when I was you know starting school and I just would call my mom, because my mom has always kept track of my shots and everything. But, when I moved to Omaha for graduate school, I realized I really need to start keeping track of those for myself, because you know, I'm an adult now and....I had to find my own doctors here and everything, so. It is important to realize that even though you're healthy, you probably just have like a yearly check-up; it's good to start keeping track. (Group 1)

Participants in the all female generally younger, mostly nursing students Group 2, frequently referred to needing to be organized in managing their health information. The comments reflected an ability to manage the information and a discomfort when they

were not organized. They felt organization would simplify this “task” so it would take less time and be more useful. The oldest student, 31, in Group 2 and one of the few students in all the focus groups who had children, summed up this feeling in response to what was most meaningful to her as, “Organization. That is a happening word for me, on all levels. Just to keep everything up to date and organized, where I can get to it when I need it.” (Group 2) Another student said, “I haven't really thought of it before now. But, now, I'll probably try to figure out a way to get myself organized with all that information about myself today.” (Group 2) And another commented, “If you, along that line is too, you would save time if you had it all organized too. You wouldn't have to run around finding all that information or searching through your folder.” (Group 2)

In summing up, participants thought that they should be responsible for managing their own health and health information regardless of being healthy. One participant said the following was most meaningful to her from the discussion.

I guess what I gained from this [discussion] today, is that even though you are [healthy], you just still need to take an initiative and just know where you're at and if doctors would happen to lose my immunization or something like that, then I would have a back-up for it. (Group 1)

### *The Message*

A potential use of the findings from this research study is to inform development of a social marketing strategy to influence students at an academic medical center to adopt PHIM behaviors. A key element of a social marketing strategy is the promotional messages that will resonate with this target audience. For this reason, I asked the focus group participants the following questions.

- What type of messages or stories might motivate individuals such as yourselves to take a more active role in PHIM?
- Where and when would be the most effective methods to reach individuals similar to you with this message?
- Who (in terms of characteristics) would be most effective in delivering these messages?

### *The Message Content*

The suggested content of the message varied from awareness of the importance of PHIM, to how to go about getting your health information including the type of the information to be maintained, to “scary stories” of how someone was harmed because of not having their own health information. The following comments reflect this variety.

I'll go with awareness as the first step, ... I haven't really thought of it before now. But, now, I'll probably try to figure out a way to get myself organized with all that information about myself today. (Group 2)

I think some sort of instruction would kind of motivate me, almost from an advertiser. You see a commercial on TV and they're like, go buy this today. If someone told me, you know do step 1, 2, and 3, and it was convenient and I knew exactly how to get started and they just spoon fed that to me, then that would motivate me if I felt that I could take that first step. (Group 3)

Unfortunately, I think that sometimes the scary stories are more motivating than the positive stories. You know, the scary stories of patients who got mistreated

because they didn't have their health information sometimes are more motivating than the story of a patient who got treated correctly because they brought records from, you know, that they had at home. (Group 1)

You know, and all of a sudden I'm not taking it [health] seriously unless I know someone who didn't and something bad happened. You know. It's almost, it's funny that way that even the people that you trust with everything else, it's almost as if health care really isn't taken as seriously unless you see a bad thing could come of it. Such a shock value almost. (Group 2)

*Means for Delivering the Message*

The participants had different opinions on the medium or setting by which the message is delivered. Some wanted in-person step-by-step instructions on obtaining PHI from their providers and advice on the types of information to keep. One suggested using methods similar to that used to provide information on Medicare prescription drug benefits. The following are some of the recommended processes.

There is someone physically there that you can talk to about it and then can take you through the steps of setting it up. I think that would be, because a lot of people, once again, they don't know where to start and they need help and maybe going online, you know that interface is not as good as face to face. (Group 3)

I think one-on-one interaction is most effective for me. If someone is looking me in the eye and telling me something, we're more apt to hear it than just something passing on the radio. (Group 1)

Those who seemed to favor what I called “scary stories” wanted it delivered through television, the Internet, or newspapers. Participants in group 2 favored using mass media and celebrities as expressed in the following comments.

Moderator: So, the bad news, as I was going to ask “Jenny,” did it impact you (seeing Katie Couric have a colonoscopy on TV) because it was a star so-to-speak?

Participant 1[Jenny]: Yeah, I think so. I mean, I never heard about it until we talked about it in class. So, it didn't impact me personally, but um, I would imagine a lot of people, or like Oprah Winfrey is always doing stuff, and she has a strong influence on a large number of people.

Participant 2: Like if a regular person would have done their colonoscopy on live TV, it would have been like, oh really? Yeah, it would be. But, why was she doing that.

Participant 3: Yeah, Oprah is a good example. I mean, so I love Dr. Oz and so, a lot of people get most of our health information from Dr. Oz, at least it's from a doctor. But, yeah...that star power behind you. (Group 2)

### *The Spokesperson*

Others were concerned that to be credible the person or organization to convey the message should not gain from it. Some thought their personal physician or someone with authority should instruct them on PHIM. One participant said, “it was from that

standpoint maybe where they didn't really stand to gain money from it, but it was more of for public well-being, then I might participate.” (Group 3) Another reflected the same belief.

I think like organizations like the Red Cross or the American Heart Association. You know, those are organizations out there to basically just make people aware of things and hopefully people will see they would rather listen to them. Right, they're not selling us. Right, they're not trying to get you to use Lipitor or anything else. (Group 2)

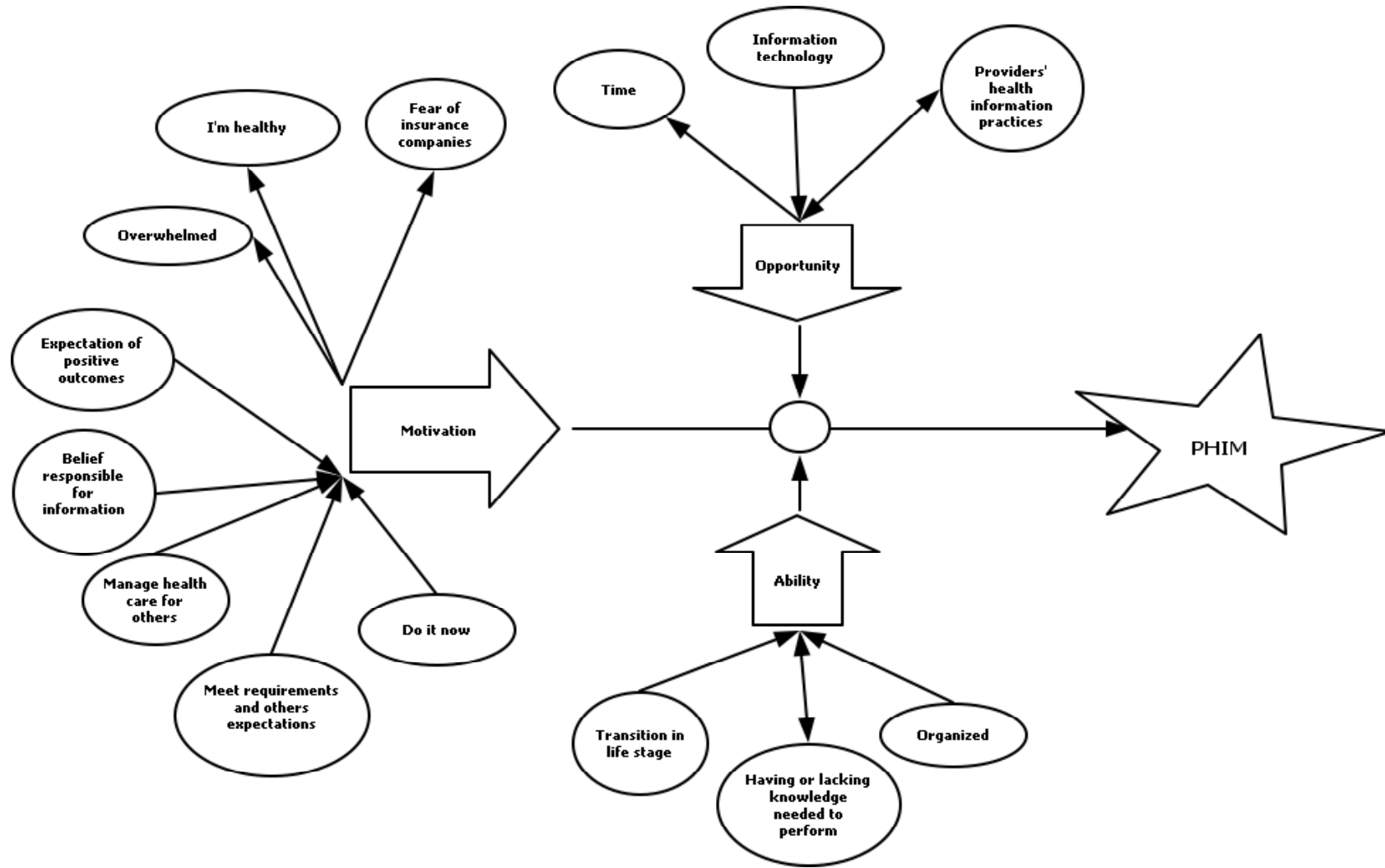
### Summary

The findings described in Chapter IV is the first step to discovering what may influence students at an academic medical center to adopt PHIM. A description of the research context and focus group participants sets the stage for understanding the research findings and developing a relevant social marketing strategy. This understanding begins with identifying the participants' perceptions of PHI and PHIM. To this group, PHI is their immunization records and information created by their health care providers. They described their experiences with PHIM as processes that made it difficult or facilitated their accessing their health information from their providers. Few spoke of activities outside of the realm of health care organizations as PHIM even though a large percent (84.8%) answered yes to the question, “Do you keep tract of health information for our yourself or anyone else?” on the intake form.

The findings are organized by the constructs of motivation, opportunity and ability as described in the MOA Model. Hughes (2007) diagrammed the relationship between the constructs, Figure 2.5, illustrating that motivation is needed to change

behavior and is influenced by both opportunity and ability. To begin an examination of the relationship between the research study's findings and the MOA constructs, I applied them to Hughes diagram in Figure 4.5. The directions of the arrows used to link this study's findings, indicated by circles, to the MOA constructs, indicated by block arrows, indicate if the finding is a facilitator or barrier. Arrows directed toward the construct are facilitators and arrows away from the construct are barrier. Arrowheads on both ends illustrate constructs that are both facilitators and barriers. For example, providers' health information procedures can facilitate PHIM by offering patients copies of records and place barriers by not being responsive to patients' requests for information. Figure 4.4 is a graphic representation of Table 4.3 and facilitates analysis and interpretation of the findings in Chapter V.

Figure 4.5 Relationship between MOA Model constructs to research findings and research questions





## CHAPTER V ANALYSIS AND INTERPRETATION OF RESEARCH FINDINGS

### Introduction

This research study is based on the premise that individuals' health and health care improve when individuals are actively involved. One way for individuals to be actively involved is for them to manage their personal health information (Committee on Quality of Health Care in America Institute of Medicine, 2001). Interest in this behavior has increased with the development of personal health records (PHR) and health record banking (HRB) as useful tools to manage personal health information. However, individuals have shown little interest in adopting the behaviors involved with utilizing PHRs and HRB ("Nearly two-thirds of Americans are not familiar with personal health records, a resource available to millions of consumers," 2007; Versel, 2007; Westin, 2008). To this end, this study was undertaken to discover what might influence a specified target group to adopt personal health information management (PHIM) behaviors to inform development of a social marketing strategy. As described in Chapter II Literature Review, social marketing techniques are used to influence individuals to adopt behaviors that result in benefiting society and the individual. Social marketing techniques are based on gathering information about characteristics of the target group and identifying their personally relevant goals regarding the behavior of interest. This information is key to developing an effective social marketing strategy.

The foundation for the analysis and interpretation was laid through development and exploration of models and matrixes as described in prior chapters. First, I compared the study's research findings to the benefits and barriers of PHIM empirical research explored in Chapter II. This overview of the comparison is shown in Table 5.1. The

categories of benefits and barriers to PHIM from the literature review are used to organize the findings. Shaded gray rows identify the sub-categories as used Tables 2.2 and 2.3. Empty cells indicate there were no comparable findings. I use this comparison throughout the analysis and interpretation of the research findings.

Next, I applied the Building Block Model (BBM) of Social Marketing introduced in Chapter II to the research findings. This application is accomplished in two steps. First, the bottom six blocks or the foundation of the BBM is applied to the research context and participants. Second, the seventh block, the marketing mix, is applied to the findings categorized by the Motivation, Opportunity, and Ability (MOA) Model as described in Chapter IV. This matrix composed of the marketing mix and the MOA Model form the conceptual framework. In this section, I discuss the findings under the categories of the marketing mix: product, price, place, and promotion, and apply the constructs of the MOA model. By comparing the findings to the categories and sub-categories of the PHIM empirical research, I interpret them in light of my experience and beliefs. The top block of the BBM of sustained behavior change is discussed in Chapter VI as part of the conclusion and recommendations from this research.

Table 5.1 Comparison of PHIM empirical research findings to dissertation research findings

<b>Categories from PHIM Empirical Research</b>	<b>Dissertation Research Findings</b>
<b>Benefits</b>	<b>Potential influencers to adopt PHIM</b>
Manage health information <ul style="list-style-type: none"> <li>• Provide convenient access to personal</li> </ul>	Feel responsible for health information and sharing information with health care

Categories from PHIM Empirical Research	Dissertation Research Findings
<p>health information</p> <ul style="list-style-type: none"> <li>• Control access</li> <li>• Share information with family and friends</li> <li>• Ensure accurate and complete information in providers' medical records</li> <li>• Organize data in useful ways, have one place for vital data</li> </ul>	<p>providers</p> <p>Avoid repeating the same information over and over</p> <p>Comfortable feeling organized and uncomfortable feeling disorganized</p>
	<p>Information technology systems that connect providers and patients</p> <p>Providers offering patients copies of records without being asked</p>
<p>Manage their health and health care</p> <ul style="list-style-type: none"> <li>• Use in autonomous decision making</li> <li>• Coordinate health care services, serve as own case manager</li> <li>• Track monitor and trend</li> <li>• Comply and adhere to instructions</li> </ul>	<p>Manage own or others' health and health care including prevention and health maintenance</p>

Categories from PHIM Empirical Research	Dissertation Research Findings
<p>and treatment</p> <ul style="list-style-type: none"> <li>• Support healthy behaviors and disease prevention</li> </ul>	
<p>Improve the effectiveness and safety of health care by providing health information to health care providers</p> <ul style="list-style-type: none"> <li>• Information available in emergencies</li> <li>• Share with other health providers</li> <li>• Jog memory to construct medical history</li> </ul>	<p>Improve effectiveness and safety of health care when complete information is available for example, when traveling or relocating</p> <p>Memory aid for completing forms for school</p>
<p>Improve knowledge and understanding about one's health and health care</p> <ul style="list-style-type: none"> <li>• Increase knowledge of health condition</li> <li>• Increase individuals' understanding, insight, clarification about their health and treatment</li> </ul>	

Categories from PHIM Empirical Research	Dissertation Research Findings
<p>Positively impact their relationships with physicians</p> <ul style="list-style-type: none"> <li>• Increase confidence and trust in doctors</li> <li>• Prepare for and improve physicians' office visits</li> <li>• Work together on health issues, change dynamic to formulate partnerships</li> <li>• Improve doctor patient communication</li> </ul>	
<p>Develop positive feelings about themselves and their health care providers</p> <ul style="list-style-type: none"> <li>• Feel empowered</li> <li>• Increase sense of control over their health and health care</li> <li>• Improve patient satisfaction</li> <li>• Feel secure and valued with ongoing</li> </ul>	

<b>Categories from PHIM Empirical Research</b>	<b>Dissertation Research Findings</b>
monitoring	
	<p>Save money</p> <p>Incentives</p> <p>Transition in life stage</p>
<b>Barriers and Concerns</b>	<b>Barriers to adopting PHIM</b>
<p>Privacy and security of health information</p> <ul style="list-style-type: none"> <li>• Concern for system security, including unauthorized access and backup</li> <li>• Did not prefer records stored on the Internet</li> </ul>	<p>Fear information used against you</p> <p>Feel lack of control over information</p>
<p>Difficulty understanding medical language and the medical record</p> <ul style="list-style-type: none"> <li>• Did not understand and difficult to use the medical record</li> <li>• Did not understand medical terms</li> </ul>	<p>Lack of knowledge on how to get copies, what information was important to keep, and rights to the information</p>
<p>Difficulty organizing and getting medical records from health care providers</p>	<p>Difficulty getting information from health care providers</p>

Categories from PHIM Empirical Research	Dissertation Research Findings
<ul style="list-style-type: none"> <li>• Frustrated getting copies from providers</li> <li>• Needed to integrate diverse types of information</li> </ul>	Multiple providers with different pieces of health information
<p>Avoidance of information about illness</p> <ul style="list-style-type: none"> <li>• Did not want to focus on their disease</li> <li>• Wanted to receive information directly from health care provider</li> <li>• Anticipated frightening health information</li> </ul>	
No need, interest, ability, and or do not want the responsibility for PHIM	I'm healthy and have not thought about it
	<p>Perceived small amount of discretionary time</p> <p>Reliance on others to do PHIM</p>

## Research Findings Applied to the Building Block Model of Social Marketing

### Part I

#### From Societal Goal to Exchange

As the bottom six blocks form the foundation of the BBM Model, they also serve as the base for the social marketing strategy. By examining the findings in relation to the societal goal, consumer orientation, theory/model, market segmentation, competition, and exchange as applied to this target audience and setting, I gained a clear understanding of the target group and identify points key to development of the social marketing strategy.

#### *Societal Goal*

The societal goal for this project is to encourage individuals' active involvement in their health and health care through management of their personal health information. (Committee on Quality of Health Care in America Institute of Medicine, 2001) It is important to revisit the societal goal as I begin discussion of the analysis and interpretation of the research findings. Refocusing on the societal goal provides direction and serves as one criterion against which the usefulness of the finding to the social marketing strategy is judged. To frame the societal goal in manner relevant to the students, I needed to understand their perception of PHI and PHIM.

#### *Personal Health Information (PHI)*

##### *Immunization records.*

By asking each focus group what the term personal health information brings to mind, I learned that most students thought of their immunization/vaccination records. The students frequently referred immunization records not only in answer to this question but as a frame of reference throughout the focus group discussions. To be meaningful to



this target group, the social marketing strategy should focus on managing immunization records.

Two additional sources concur with the importance of immunization records to this target group. In the press release that announced the launch of the university's PHR, Dr. "Welby," the physician responsible for the project stated,

When our students move between training sites, their records remain in doctors' offices and hospitals. Using the personal health record approach, the medical information such as their vaccination records moves with them and the information is accessible when needed (O'Connor, 2007).

Popovich (2008) also identified the value of providing easy access to immunization records as a first step to encouraging PHIM. He said, "Access to immunization records presents an easy-win opportunity to significantly empower individuals with their own health information.... It will create a roadmap to support the inclusion of other medical information" (Section 2).

Access to immunization records is needed at specified points in time: application to college, verification of health status for clinical rotations, and employment. Students studying to become health professionals and scientists will most likely need access to their immunizations more than most people. Immunization records may be a good starting point for this target group. However, because the need for this information is sporadic, it will most likely not lead to a sustained behavior change to reach the societal goal.

*Health care providers' records.*

In addition to immunization records, students' discussion of PHI referred mainly to information created and maintained by health care providers such as growth charts, medical records, and x-rays. Most students did not equate PHI with records they kept for themselves. This point was driven home by comments of a fourth year medical student.

I keep track of my athletics; I mean, I keep track of my weights every morning and I could tell you what my resting heart rate is every morning. I also have them for the last like four years. It's not really health information, but it certainly affects the way I work out. (Group 3)

This point of view coupled with very few references to information not connected to health care providers is also informative in the description of PHI in social marketing strategy. I disagree with his opinion that workout information is not health information. However, for this target audience and their definition of PHI, influencing the students to track "wellness" information, such as exercise and diet, as PHIM behavior is contrary to the consumer orientation.

*Personal Health Information Management (PHIM)*

Students characterized PHIM as being organized and having their information in an accessible place. Many also thought that information technology would facilitate the process. On the intake form, 27 out of 33 (82%) answered yes to the question, Do you keep track of PHI for yourself or anyone else? However their discussion of PHIM focused on experiences that facilitated and or impeded obtaining copies of their PHI from health care providers. These findings are discussed later in this chapter under the

intersection of the category of place in the marketing mix and opportunity in the MOA Model.

### *Consumer Orientation*

Social marketing strategy is built on the foundational principle of consumer orientation. This principle encompasses the idea that the population is the best source of information on what may influence them to adopt the behavior of interest (Kotler, et al., 2002). Understanding the target audience includes not only the descriptive demographics but also information on their goals, wants, interests, needs, their use of discretionary time, and preferences for messages that may influence their behavior.

As described in Chapter IV, the focus groups participants were young adults (67% less than 25 years-old), female (85%), and single and not responsible for children (58%). Other key participant characteristics that relate to PHIM are the frequent reference to their “being healthy” and not having thought about PHIM before the focus group. As generally healthy individuals, they also have not had much contact with the health care system as patients themselves. The students compared themselves to those they saw in the clinical setting or of family members.

I think also if you feel healthy, then you don't really necessarily see a need why you need to keep track of it, but it is when you're sick..... (Group 1)

The fact that the participants in this study are students in demanding programs for health professions and graduate studies in medical sciences provides additional information about what may be important to this group. The students frequently referred to not having time to do PHIM. This is discussed later in the concept of competition and in the marketing mix.

Also as students, they are used to following directions to meet requirements. Several participants mentioned that if PHIM was required or if someone told them to keep track of their information, they would be more likely to do it. This is discussed more indepth in relation to opportunity aspects of the product.

The participants in the PHIM empirical research were very different than the participants in this study. The participants in 55% of the empirical PHIM studies had chronic diseases and were frequent users of health care services. Table 5.2 highlights the key differences between the two groups that may impact the PHIM social marketing strategy. By viewing the varied characteristics of the two groups, it is easy to see the importance of social marketing's consumer orientation. The social marketing strategy must appeal to the specific target audience to be effective. The contrasts between the two groups of participants are discussed throughout this chapter.

Table 5.2 Comparison of participants from dissertation research study to those in the PHIM empirical research

	<b>Focus group participants in dissertation research study</b>	<b>PHIM empirical research participants</b>
<b>Health status</b>	"I'm healthy"	Diagnosed with chronic illness
<b>User of health care services</b>	Infrequent	Frequent
<b>Perception of discretionary time</b>	Small amount	Not addressed
<b>Need for PHIM</b>	Fulfill school or work responsibilities	Continuation of health care services
<b>Useful in managing health and health care</b>	For others: children, spouses, and parents	Mostly for themselves
<b>Life stage</b>	Transition from dependent to independent	Independent
<b>Comfort with information technology</b>	Mostly comfortable	Somewhat uncomfortable

### *Theory or Model*

As described in Chapter II, the Motivation, Opportunity, and Ability (MOA) Model and the marketing mix form the conceptual framework upon which I based the analysis and interpretation of the data. By using a matrix to compare the study's research findings to the MOA Model and the 4 P's in the marketing mix, I am able to identify key points useful in developing a social marketing strategy. The application of the MOA Model and the marketing mix are described later in this chapter.

### *Market Segmentation*

The market segmentation block of the BBM involves identifying characteristics of members of the target audience who would be likely to adopt the behavior of interest. Identifying these subgroups within the target market also answers the first research question: What distinguishes individuals who have adopted or are ready to adopt personal health information management from those who are less interested in adopting the behavior? Individuals who are more likely to adopt PHIM are female, like to feel organized, believe that PHIM is meeting a requirement or someone else's expectations of them, realize that performing PHIM now will save time later, and are responsible for managing the health and health care of another. These characteristics are described more fully within the conceptual framework later in the chapter.

### *Competition*

PHIM's biggest competitor for this target audience is their perception of having a small amount of discretionary time and preference to use it for other activities. As students at an academic medical center, they spend hours each week in class, in laboratories, in clinical rotations, studying, and often working. Students' frequently

mentioned the issue of lack of time and desire for convenience. The issue of time is discussed within the context of place in the marketing mix.

### *Exchange*

The exchange building block recognizes that individuals are willing to accept the “costs” of performing the behavior in return for something they value. The exchange concept explains that individuals act primarily out of self-interest to obtain the greatest benefit in exchange for the least cost (Smith, 2006). Information gathered about the target groups’ goals, interests, wants, and needs assists the social marketer to identify the appealing aspects of the behavior of interest to the target audience. Because time is a precious commodity to these students, the social marketing strategy for PHIM must incorporate a valuable trade off for time needed to perform PHIM. The following comment is evidence of this thought.

I think it's very easy to get distracted from managing your own personal health care and managing your own records, but it's something that really does have a lot of benefit for the, time that you'll have to invest in it. (Group 2)

## Research Findings Applied to the Building Block Model of Social Marketing

### Part II

#### Application of the Conceptual Framework and Block 7 the Marketing Mix

##### *Overview*

This section focuses on the seventh block of the BBM, the marketing mix and the application of the conceptual framework. The conceptual framework, as first introduced in Chapter II and Table 2.8 and repeated below in Table 5.3, is composed of a matrix that allows for the intersection of the MOA model and the 4 P’s of the marketing mix;

product, price, place, and promotion. Using the relationships of the MOA Model to the marketing mix described by Chapman and Patel (2004) and the application of the MOA Model to the findings in Chapter IV, I integrated these research findings into the matrix. Unlike the PSI Researchers, I identified findings that fit the category of price. The completed conceptual framework, Table 5.4, serves as a useful basis for comparing the findings to the PHIM empirical research results. From the conceptual framework, comparison, and analysis, I derived the key points that will be most useful in developing the social marketing strategy and describe in Chapter VI.

Table 5.3 Conceptual framework: MOA model and marketing mix

	<b>MOA Model</b>		
<b>Marketing Mix</b>	<b>Motivation</b>	<b>Opportunity</b>	<b>Ability</b>
Product	X	X	X
Price			
Place		X	
Promotion	X		X

Table 5.4 Research findings integrated into the conceptual framework comparing the MOA Model to the marketing mix

<b>Marketing Mix</b>	<b>Motivation</b>	<b>Opportunity</b>	<b>Ability</b>
<p><b>Product</b></p> <p>The desired behavior and its associated benefits</p>	<p>Belief of “I’m healthy”</p> <p>Utility in managing own and others’ health and health care</p> <p>Replacing the need to repeat the same information</p> <p>Serve as memory aid</p>	<p>Meeting expectations of others and fulfilling requirements</p> <p>Reliance on others to do PHIM</p>	<p>Lack of knowledge on how to get information, what information to keep, and individuals’ rights to the information</p> <p>Not “computer savvy”</p> <p>Being organized</p>
<p><b>Price</b></p> <p>Monetary and non monetary loss from performing the behavior, may include time away from other activities, “psychic</p>	<p>Unmotivated</p> <p>Fear information used against you</p> <p>Feel lack of control over information</p>	<p>Perceived small amount of discretionary time</p> <p>Incentives</p> <p>Save money</p>	



<b>Marketing Mix</b>	<b>Motivation</b>	<b>Opportunity</b>	<b>Ability</b>
costs” of emotional loss, physical discomfort			
<b>Place</b> Location for the distribution of the product or service, might also be called distribution channel		Difficulty getting information from providers  Multiple providers with different pieces of information  Providers offering patients copies of records without being asked  Information technology system that connects providers and patients	
<b>Promotion</b> Incentives, events, publicity, advertising	Belief benefits of “do it now” outweigh “hassle” later (Desire for convenience)		Transition in life stage

<b>Marketing Mix</b>	<b>Motivation</b>	<b>Opportunity</b>	<b>Ability</b>
	<p>Belief individuals responsible for own information</p> <p>Improvement of effectiveness and safety of health care when complete information is available including when traveling or relocating</p>		

### *Product*

This section examines the findings that describe PHIM behavior or the social marketing product. The findings include the benefits that may lead the students to adopt PHIM or motivation, external influences or opportunity, and the students' skills and knowledge needed to perform PHIM or ability.

#### *Motivation.*

To influence adoption of PHIM behavior, individuals need to feel they gain something of value referred to as personally relevant goals (Rothschild, 1999). The findings identify beliefs that impact the personal relevance and include the belief of "I'm healthy," PHIM's utility in managing individuals' own and others' health and healthcare, replacing the need to repeat the same information over and over, and serving as a memory aid.

#### *Belief of "I'm healthy."*

One of the most common statements by participants in all three focus groups was that PHIM was not personally relevant because the participants saw themselves as healthy. The following statement exemplifies the beliefs of many of the students.

Like we were saying, you know, if you are young and healthy, you kind of don't pay attention, but you know if you're in and out of the hospital, it's something that's a lot more relevant to your day to day life. (Group 1)

Research participants were college students in only one study in the PHIM empirical research. The researcher's goal was to investigate preferred functionalities for PHIM and did not address motivation. Participants in an unpublished study were undergraduate students in health professional programs. The students expressed similar

disinterest in PHIM. Sixty-seven percent of the nursing students in this study referred to having “little to no need” for PHIM because of their relatively healthy status (College of Saint Scholastica, 2004). Respondents to surveys I conducted as part of various PHR presentations stated that they had no need to yet because they’re healthy. The respondents were college professors and health care professionals (Jacobs, 2005). The challenge is to design a product personally relevant to a healthy population.

*PHIM’s utility in managing individuals own and others’ health care.*

A few participants recognized the need for PHIM to manage their own health as discussed in Chapter IV. However, more participants spoke about the utility of PHIM when they are responsible for someone else. The following comments reflect this belief:

And, and for parents too, would be good to manage your kids' [information] because a lot of parents, you know especially with newborns, if it's their first baby, they wouldn't know necessarily when to go in as the best time for their first round of shots or whatever. (Group 2)

I'm sure I'll be the one who is in charge of my parents because the other two are not organized, and I would not have even the first clue of where to start just because, I don't know, they have a lot of health care in a lot of different places. (Group 3)

The findings in this study matched a major category of benefits of PHIM in the empirical research. PHIM helps individuals manage their health and health care. However, the difference between the two groups is that participants in this study saw their need for PHIM was mostly to take care of others, and the respondents in the PHIM

empirical studies saw the need for PHIM was to manage their own health care. The divergence in findings again emphasizes the effect of the consumer orientation on the social marketing strategy.

The data from the intake form, Appendix L, show that the majority of the students are not responsible for the health and health care of another (88%). Only four students indicated that they were responsible for children. In expressing this need for PHIM to take care of others, I think the students most likely were projecting into the future when they had children and their parents were elderly with chronic illnesses.

*Replacing the need to repeat the same information and serve as a memory aid.*

The next two findings that may make PHIM personally relevant to these students are (a) replacing the need to repeat the same information and (b) serving as a memory aid. A common complaint among users of health care services is the request to repeat the same information in each new department and for each new provider. One student said,

One thing that is frustrating in general is that with each provider, you have to fill out the same set of paper work over and over. You go to the dentist, you know what allergies do you have, what medical conditions; same thing for your primary care physician and maybe at your pharmacy. It would be nice if there wasn't so much repetition. (Group 3)

These specific findings did not replicate results found in the PHIM empirical research. However, most of us have experienced the need to repeat our health history. This need for repetition of information within the same organization decreases with the implementation of electronic medical records. Many hurdles need to be overcome before the request to repeat information to every new provider is eliminated. However sharing

information between unaffiliated health care providers is a work in progress (Dieker, 2008).

Participants in this study felt that having their own information helped to recall health events when completing forms for school and other things.

I think especially if you don't have a primary care physician..... So, knowing which doctor you went to for certain things, and of course you have different doctors for different things, and especially when you have to put all that on a form for your, you know, your school records and such, it could be complicated remembering where you know you got this shot or where this happened. (Group 3)

A finding from the PHIM empirical research was that PHIM jogged the respondents' memory to construct medical histories (Fischbach, et al., 1980; Fowles, et al., 2004). This contrasts with the students' need to remember information is not for health care but for use in a school or other settings where students are required to "fill out forms". Again this emphasizes the students' need for PHIM is relevant to other uses than health and health care.

### *Opportunity*

The opportunity aspect of the product includes items that are external to the individual and influences individuals' interest in performing PHIM. The students' comments addressed two issues external to themselves, meet requirements and expectations of others and reliance on others to do PHIM.

*Meet requirements and expectations of others.*

Students' common frame of reference to PHIM was the need to produce their immunization records to meet school and employment requirements. Some students felt that requiring PHIM or being accountable to someone else would influence them to adopt the behavior. One participant said,

Almost like if you're responsible to another person for it. If it's just me and it kind of benefits me by keeping track of it, well then it doesn't really matter if I don't do so great at it. But, if somebody else is counting on me to keep track of my health records, then that is definitely a big motivator. (Group 2)

To me this behavior flows from effective student behaviors of meeting requirements specified by someone else. Students' roles are to fulfill the expectations of others in class, in clinical performance, and on important tests that determine whether they will be allowed to practice their chosen profession. The PHIM empirical literature did not address this finding. However, I did not find it surprising myself, as a student and teacher.

*Reliance on others to do PHIM.*

Another finding that fits into the category of opportunity and affects the product is the participants' reliance on others for PHIM. They relied on their mother, their employer, or their primary care physician to maintain their records in one place. For these students, this reliance worked well. One student described the process as the following:

I got into the habit of every time I went to any doctor, I just had them fax it immediately to my primary care physician and so, you know, I've been to a dozen

different doctors between colleges and med school, and you'd never see the same person if you go to clinics. So, at least one person has all of my records in the same place, so I don't have to keep them. (Group 3)

In this scenario, the primary care physician's office is serving as the record custodian. The physician is a trusted resource and provides a valuable service. The student controls what information is shared with the primary care doctor and determines what information is disclosed. The student's behavior of requesting information be sent to his physician and all records being in one place could be described as PHIM. The respondents in the PHIM empirical research also preferred to rely on their health care providers to maintain their information. They did not want to responsibility for their records (Munir & Boaden, 2001 p. 664; Ward & Innes, 2003).

However, relying on another to maintain PHI will not readily meet the societal goal of involving individuals in their own health and health care resulting in improved health and health status. In the current paper format, access to PHI is not easy or timely. As we move toward increased availability of PHI to individuals through electronic information sharing, reliance on health care providers to maintain PHI will move closer to the societal goal.

### *Ability*

Skills and knowledge needed to perform the behavior, ability, can be incorporated into the design of the product and description of the behavior. When individuals feel competent to perform a task they are more likely to try it (Case, Andrews, Johnson, & Allard, 2005).



*Knowledge needed to perform PHIM.*

In order to perform PHIM, the participants thought they needed to know the process to access their providers' PHI, the type of information to be maintained, and their rights to access and to have copies of their information. The following comments reflect these perceptions.

I guess for me the most important thing is knowing what to keep and why you're keeping it. Like other people said, you don't need to know that you had a sinus infection, but if I kept track of all that then I've got a whole stack of papers this big and it's going to take me years to go through them when I need to find information. So, I guess just knowing what to keep and why I'm keeping it, is probably the most important message. (Group 1)

Some might expect that students at an academic medical center would know what information is important and how to go about getting it. Students in all three groups repeated this need for information about PHIM. The participants in the PHIM empirical literature echoed the concern over the difficulty of reading medical records and understanding medical language.

The concurrence of this study's findings with the findings of the PHIM empirical research emphasizes the importance of considering the user in the design of the system. Medical records are designed to be used by health care professionals who understand the language and format. Giving patients access to providers' medical records is analogous to the horseless carriages that placed an engine in the carriage. Patients need a tool that is useful to them and will help them be more involved in their care.

One student mentioned a concern more commonly expressed by the participants in the PHIM empirical research regarding ability to use information technology.

I wish I was more technologically savvy so that I could start working on that, because I think that the entire Internet or database idea is incredibly intriguing to me. (Group 2)

She was the only one to voice discomfort in using information technology. Considering the differences in ages and skills between the two participant groups, the dissimilarity in the number of participants concerned about using information technology is understood. Even though most expect young people to be “computer savvy,” I have personally experienced students wishing guidance on use of technology when the stakes were high as in meeting with college course requirements.

Gruen (2005) in describing the ability concept of the MOA Model differentiated between processes used and content knowledge needed to perform the behavior. In this context, process aspect of ability includes information technology skills and knowledge of the procedures to access to PHI. The knowledge of what information is important to keep and individuals’ rights to the information are content issues. This distinction is important in understanding the “ability” perspective of the product.

*Organizational ability.*

Being organized was a skill valued by participants. They saw that PHIM was a way of being organized. Some expressed discomfort when they were not organized. In response to what was the most meaningful thing said during the focus group, a few students referred to organization.

I agree with “Susie” that organization, I don't like to feel disorganized and I didn't realize that I was disorganized before this, and now I'm aware of it. So, thanks.

(laughing) (Group 2)

The participants in the all female Group 2 most frequently discussed a desire to be organized and discomfort when they felt disorganized. This increased prevalence in comments by females about organization in reference to health care may relate to the role many women take as the caretakers of not only their own health but those of their families (Fox & Rainie, 2000). Appealing to females' need to be organized may be useful in developing the social marketing strategy. The traditionally female role of family caretaker may also indicate that women are more likely to adopt PHIM. Being organized was also seen as a benefit of PHIM in the empirical research and included in the benefit sub-category of helping individuals manage their own health information. The organizational benefits of PHIM may be especially appealing to women.

#### *Price*

The price aspect of the marketing mix arises from the exchange principle when something of value is received from performing the behavior. In commercial exchanges, the price is monetary and given in return for a product or service. In social marketing, the price can be difficult to recognize. In fact, Chapman and Patel's (2004) application of the MOA Model to the marketing mix did not include price. However, other social marketers recognized that price should be included even if no money changes hands. They cautioned not to over look the costs of time, and difficulty in performing the new behavior (Maibach, et al., 2002).

### *Motivation*

Three findings in the motivation category speak to the cost of performing the behavior. They encompass the neutral and negative positions on the motivation continuum in Figure 4.4. In the neutral position, one student expressed that she was just “not motivated” to track a particular lab result needed to adjust her medication. She had a personally relevant goal but was not motivated. On the negative end of the motivation continuum are other potential costs from participating in the behavior. Specifically, one student expressed fear of insurance companies using information she provided against her sometime in the future. Another student felt a lack of control over her health information.

I’ve included these three “prices” in the findings and analysis even though many students did not express the same concerns. The lack of concurrence by participants in the focus groups does not mean they did not agree and could mean they felt no need to repeat what had already been said. Because qualitative research aims at discovering the range of attitudes, beliefs, and values and not at finding beliefs representative of and generalizable to a defined population, I felt these students’ ideas were important to include (Morgan, 1997).

Similarly only two students in Group 3 mentioned the fear of insurance companies using information against someone. This fear would be incorporated into the concern for privacy and security found in the PHIM empirical research (Civan, et al., 2006) and in opinion surveys. Privacy expert, Alan Westin’s 2008 survey for the Markle Foundation found that among the 54 percent of respondents not interested in a PHR, 56.8 percent cited worries about privacy and confidentiality as a reason for their reluctance. Westin described the traits of people with privacy concerns greater than the general

public as those with \$100,000 or greater annual income, who are married, 30-44 years in age, female, completing some college, having a major disability, or are in very good health, and provide care for a child (Westin, 2008). The participants in this research study differ significantly, except for gender, than those in Westin's study.

In health care industry journals, fear of loss of privacy is one of the most common reasons proposed for the low usage of PHRs (Kaelber, Jha, Johnston, Middleton, & Bates, 2008; Sarasohn-Kahn, 2001; Westin, 2008; Workgroup for Electronic Data Interchange, 2007). Concern about loss of privacy was rarely mentioned in informal surveys I conducted as part of PHR presentations. The respondents to my surveys were college professors and health care professionals. The difference may be that I posed an open-ended question while surveys used forced-choice questions that specify loss of privacy as a concern.

Similarly in an October 2008 presentation to college students who are studying to become health professionals, I found that they were not at all concerned about the privacy of their health information on the Internet. I probed and prodded them in my disbelief. But thinking over their frequent use of the Internet to communicate through social networking Internet sites, I found their lack of concern for privacy somewhat understandable. However, students choose to post information on the social networking Web sites. They control what information is disclosed and even who has access by making the page public or private available only to "friends."

Even though the target group did not express many concerns about privacy and security of their PHI, the social marketing strategy must incorporate references to protection of individuals' privacy and provide individuals with the means to control the

content and access to their information. As described in Chapter II, control by the record subject is seen as one way to address privacy concerns of PHIM. Individuals' roles as gatekeepers to their health information will provide them with a "greater-than-customary" control and require new knowledge and behaviors that most are not ready to accept (Project HealthDesign, 2007). Given the potential for harm caused by privacy breeches, the social marketing strategy needs to address information privacy and access control whether or not the target audience feels it important.

### *Opportunity*

#### *Time.*

Time needed to perform PHIM is the biggest concern and therefore the largest cost for this group. The target audience needs to think that benefits gained from PHIM compensate for the time used to perform PHIM. Students studying to be health professionals and scientists perceive they have a small amount of discretionary time. The reference to time or lack of it was expressed in a variety of ways throughout the discussion. The following quotes demonstrate this concern.

Yeah. But, if I, if I, I guess if someone told me how it would be useful, you know they said how they saved time or helped diagnose something that needed to be taken care of, I would find it useful for myself. (Group 3)

I think it's kind of a convenience thing for me, too, because my time is so important to me since I don't have very much of it that knowing if I have everything organized, then I know what I've had done and I know where my records are, it will save me time and it will save me money. (Group 3)

I think our, I least I feel kind of overwhelmed by it. Uh kind of from a time issue, um, like I, I know for example, the students here have that personal health information, I don't know what it's called-thing, available to us and I saw it, but just like, I felt like I don't have the time, I wouldn't know where to start...it just seemed kind of overwhelming and, sort of, I don't know, like doing your taxes or something. You know, it seems like this big daunting thing, but maybe once you jump in, it's not as frightening as it seems. (Group 3)

Participants in the PHIM empirical research did not express concern over the amount of time to do PHIM. However in my own surveys, common answers to the question, What has kept you from keeping your own health records? were “I didn’t have time.”

Social marketing literature refers to time as an example of a non-monetary cost.

In a resource guide on social marketing, price is defined as:

The value applied to a marketing exchange. For goods or services, pricing generally implies monetary cost. In terms of social marketing, “time” might also be considered in terms of price (how much time will be exchanged for engaging in the desired behavior.) (Social Marketing National Excellence Collaborative, , p. 76).

The PHIM social marketing strategy must address the balance between benefits gained and time lost to appeal to students. Requesting students to use their discretionary time to perform a task that is not personally relevant is asking a lot. The key point is only to facilitate PHIM behavior to take a minimum amount of time.

*Incentives.*

Often incentives are used to influence behavior. Thirty-three students responded to the incentives of pizza and \$40 to participate in the focus groups. The focus group was a one-time event contrasting from sustained behavior change. Incentives that remain personally relevant over time are needed to reinforce sustained behavior change. The PHIM empirical research did not address incentives.

Several participants in Group 2 discussed the issue of incentives offered to hospital employees for participating in its wellness program. Participants earn points for completing their PHR, their health risk assessment questionnaire, and individual action strategy (Jacobs, 2005).

Participant 1: I don't really participate in the point system just because it is just too time consuming and you have to get it approved and...stuff like that.

Participant 2: Are all the incentives like a cash incentive? Are there others?

Participant 1: Um, you accumulate paid time off.

Participant 2: That would motivate me.

Participant 1: Yeah, you have to get your activities pre-approved and things like that. So. It is very good, but I just don't have the time to do it. I know it motivates a lot of people at the hospital and they're really; you know, I think it motivates maybe more the older age group. Being young, we're so busy with sleep, because we have school and work, and all these other things going on. That, and we're usually pretty active to begin with, so, so it's not a real huge incentive. (Group 2)



From this student's comment, I am unable to determine if the incentive was not personally relevant or the method for earning them was too time consuming. To be effective, the PHIM social marketing strategy must offer personally relevant incentives that are sustainable over time. The methods to earn the incentives must be easy to do as well as achieve the societal goal.

*Save money.*

PHR proponents in the health care industry frequently refer to the benefit of "saving money" by reducing the number of duplicate tests by having needed information in the individual's PHR (Leonard, et al., 2008; Leonard & Wiljer, 2007). The students' comments supported this view.

It may actually help to save money under some circumstances, you may not have to pay to have repeat tests done or have an additional vaccine that you've already received. So, a financial benefit such as having a titer done because you can't remember when you've had the vaccine, so you could save money. (Group 3)

However, the Center for Information Technology Leadership at Partners Healthcare System (2008) reported in the study on costs and benefits of increasing the adoption of PHRs that, "Unfortunately, there have been no studies to date that examine the impact of PHRs on the reduction in redundant tests" (Kaelber, Shah, et al., 2008, p. 29). This unconfirmed benefit along with the focus group participants being healthy and infrequent users of health care questions the use of "saving money" as a personally relevant benefit for this target group. If asked, most people would agree that they would like to avoid the inconvenience and cost of repeating tests because the results were not available when needed. However, the potentiality of this occurrence is in the future and

not likely to influence behavior change today. Determination of the importance of this benefit to the target audience confirms the need to learn what is personally relevant goals directly from the target group themselves.

### *Place*

Place is the channel through which the product/service reaches the consumer (Weinreich, 2006). Place has price implications. The product or service must be easy to access decreasing cost by removing barriers (Lefebvre & Flora, 1988). For social marketing, place can be translated into making the behavior easy to perform. For example when the university medical center first offered the PHR to students, I suggested placing a link to the PHR Web site on the students' learning management system Web page. This link provided a familiar and convenient location to access the PHR. Even though access was convenient, the number of students using PHR utilization is small.

### *Opportunity*

Place and opportunity logically converge because both address external facilitators and barriers to performing the behavior. Place and opportunity aspects of the social marketing strategy address the practices in the health care organizations that affect the ease of PHIM performance. The participants described situations they experienced when seeking their PHI from health care provider practices. A few recently were offered copies of their PHI. They were surprised because they did not know they had the right to this information.

I just had an experience with that and she [the doctor] actually had 'em [copies of medical records] out, and she was like 'Oh, do you want to take these with you?' and I was like 'yeah.' I want to look all of these up, (laughing). (Group 1)

One participant compared his veterinarian's handling of his dog's medical records to his own physician's procedures. The veterinarian routinely provides copies of his dog's records while the student has not had the same experience with his own doctor.

When I've gone, when I've taken my dog to the vet, like, they have given me a folder and put all that information in it and it wasn't even something I had to ask for. They gave it to you. So, in contrast, when I go to the doctor's office and get an annual physical or it is not something that is just given to me. It's, you know, with humans, you have to ask for it or you have to seek it out a little. (Group 1)

Echoing my own experiences, a participant said, "Sometimes it's a hassle if you do ask. Sometimes it's a hassle to get your hands on it." (Group 1)

The participants described frustrating experiences with health care providers' processes and procedures used to obtain copies of their PHI. The irritations experienced by the focus group participants are very similar to those recalled by participants in PHIM empirical research studies that were not based in specific health care provider settings (Civan, et al., 2006; Pratt, et al., 2006). The focus group participants said:

So, but yeah, it's kind of a hassle, cause you do have to go there yourself sometimes to pick them up. Not everyone has a fax machine. You're asking your mom at work to do stuff for you. (Group 3)

And, I've had things get lost in the shuffle when you're faxing consents to have your records also and it took a call from a doctor's office. I never was able to get my health records. It took the doctors office calling to actually get the records transferred to them. (Group 1)

My doctor's office tells me that I have to pick up my records in person if I want to take them to another doctor. They won't mail them. So, that was crazy. (laugh)

(Group 1)

Two lines of thought may explain these frustrating situations in getting records.

First from personal experience in consulting and giving presentations to the administrative staff of physicians' practices, I learned that many misunderstand the legal rights of individuals to access and obtain copies of their own medical records. One audience member said, "Her physicians would not allow patients to have copies of their own records." This practice violates the HIPAA Privacy Rule (Office of Civil Rights & US Department of Health and Human Services, 2002). In addition to misunderstanding the privacy laws, health care professionals may not understand the rationale for the procedures or if they do understand the rationales, they do not take the time to explain them to patients. This lack of explanation leaves the patients feeling frustrated. These practices are not intended to inconvenience patients but to protect their privacy and ensure that their PHI does not get into the possession of unauthorized parties (Abdelhak, et al., 2007).

Participants also realized that the barriers to access PHI experienced with one provider are multiplied because their PHI was housed in multiple health care provider organizations. This realization was expressed in all three focus groups.

If you could have it all in one spot, rather than like she was talking about, having it dispersed over so many providers, then when you had to provide the

information to say to meet the requirement for your schools, then it would be a much faster process for you. (Group 2)

And with that, goes, you know, there, different health providers might have different records of what you have when you visited them. So, you might discover an allergy later that they wouldn't have on file. So, it's hard to keep track of who knows what. (Group 3)

The focus group participants saw that use of information technology may facilitate PHIM in the future. This reference to use of information technology was one of the participants' most frequent comments in response to the summary question of, what is the most meaningful thing about personal health information management that was said here today? One participant's account is similar to the health record banking concept.

It would be so nice if, if there was a record somewhere that anybody could access that was almost like bank accounts where we can't see each other's but you sign in and you can see your own and then maybe it could be an open data base for physicians that you sign off so they can all see it if they need to. And that way, if you are like me, you would call one person up, you would call your latest practitioner or you could access it yourself and it would be a lot easier than try to pick and prod from everybody. (Group 2)

You don't have to rely on someone else's antiquated technology system like fax machines and phone calls, and red tape. It should be much simpler. It should be

an automatic, it's in the system and you know about it. It just puts a lot of responsibility on you ...to transfer of information to your providers. (Group 3)

Reference to benefits of information technology was not addressed in the PHIM empirical research. However, the purpose of several of the research studies was to determine patients' response to having access to electronic medical records (Honeyman, et al., 2005; Leonard, 2004; Winkelman & Leonard, 2004).

### *Promotion*

Promotion is the last of the 4 P's of the marketing mix. Discussing promotion last is appropriate due to its reliance on information identified in the prior three aspects. Promotion provides direction to the social marketing strategy on methods and messages used encourage the target audience to adopt new behavior (Andreasen, 1995; French & Blair-Stevens, 2008; Grier & Bryant, 2005; Kotler, et al., 2002). In addition to application of the MOA model, the discussion of promotion also includes the participants' comments on the mechanisms and messages used to promote PHIM.

### *Motivation.*

At the intersection of promotion and motivation are three beliefs: (a) "do it now" to avoid "hassle" later, (b) individuals are responsible for their own information and for sharing that information with their health care providers, and (c) effectiveness and safety of health care is improved with when complete information is available.

*"Do it now!"*

Some students who are motivated by convenience saw that getting their information now would save time later. One participant said,

It's important to have your own copy of things, especially if you're planning on moving or something and it's difficult to get things from different physicians and gather it all together. So, it's good to just do it as you go along so that when you need it immediately, it's not a pain. It's not hard to gather information. (Group 1)

The desire for convenience now suggests a time concern. Also the frustrating experiences they have had in obtaining past information may have resulted in the impetus to obtain the information instead of trying to get it later. The participants in the PHIM empirical literature did not express the same issue.

*Belief Individuals are responsible for their own information.*

Several students, mostly in Group 2, explained that they felt responsible for their own information and for sharing it with their health care providers. This feeling of responsibility appears to derive from different motivations. One student related it to her future health care professional role. Another described it in relation to taking care of her children and the third is as a backup in case information was lost. The following comments show this belief in action.

Um, I think just the importance of asking, as a future health care provider, not only asking patients but also when I go in [as a patient], I would be, well, by the way can I take this? Is that going to be a problem with this medication? (Group 2)

For us, the children all had chicken pox last year, and so I made it a big point at every visit that we had, you know, especially for the younger two who are due to have their vaccinations for it, to make sure to tell them they've already had the live virus, I don't want them to have the shot. And, that way, it's in their record

and that way they don't have to get vaccinated. And, that's important for them, because they don't like getting shots anyway. (Group 2)

I think, even though health professionals do their best to keep track of everything, it's just like when you have a computer, you make multiple copies of things that you want to keep track of because you never know when something is going to get lost in, you know, some kind of disaster or something; I don't know. So, I think it is just good to be aware that, you know, where your extra copy is of your health care. You should keep that kind of stuff. (Group 1)

This study's findings in regard to participants "feeling responsible" for their information were similar to the results PHIM empirical research. Both groups described the belief in relation to interacting with health care providers and recognizing that they were a valued information source. In addition, the participants in the empirical PHIM research discussed the feelings that resulted from PHIM as being more in control and a part of the health care team (Liaw, et al., 1998; Ross, et al., 2005; Ward & Innes, 2003; Williams, et al., 2001).

*Effectiveness and safety of health care is improved when complete information is available.*

As identified in the PHIM empirical literature and illustrated in the PHIM Benefit Model, Figure 2.1, the students recognized that effective and safe health care is dependent on having complete and accurate information available for example while traveling or when relocating. Simply put, one participant said, "I believe that having that information will help them treat me better." (Group 1) The participants in the PHIM



empirical research thought that inaccurate and unavailable information could result in errors, even death (Agarwal & Angst, 2006). Accurate and complete information facilitated individuals receiving health services according to their needs (Rassin, et al., 2006). The importance of having pertinent health information available at the point of care is also promoted in various other health industry documents. Anecdotes and stories abound about patients and their loved ones going to great lengths to ensure that complete information is available (Commission on Systemic Interoperability, 2005; Goedert, 2002). Leaders in the health care industry agree that fragmentation of health information is a problem and impact the effectiveness and safety of health care. However, health care providers have been slow to implement systems that address this issue for a multitude of reasons. Until health systems are connected and information transparently flows between providers, individuals need to step up and take an active role in managing their own information (Waagemann, 2005). Even though the focus group participants recognized the importance of PHIM on the effectiveness and safety of health care, the potential benefit is in the future because of their healthy status and infrequent use of health care services.

*Ability – transition in life stage.*

Many of the focus group participants recognized that they have experienced a transition from being dependent on their parents to being responsible for themselves. This change occurred when they started college, medical school, or graduate school. They connected this shift to independence to PHIM and felt capable of managing PHI themselves. They said,

Yeah, and at the same time, before you make those big transitions, when I was in undergrad, I only knew that that one time when I was you know starting school and I just would call my mom, because my mom has always kept track of my shots and everything. But, when I moved to attend graduate school, I realized I really need to start keeping track of those for myself, because, I'm an adult now and....I had to find my own doctors here and everything, so. It is important to realize that even though you're healthy, you probably just have like a yearly check-up; it's good to start keeping track. (Group 1)

I was just thinking, when I was mentioning going to college and for me, that's when it changed, because before you know, my parents just took care of it and I didn't worry about it. But, then, when I started college and like whenever I go to student health or something like that, or getting health care too, I was getting all this information sent directly to me and said, well, I better keep track of this you know. (Group 2)

Considering the difference in age groups of the students and the participants in the PHIM empirical literature, no similar finding was found in the PHIM empirical research. This transition from dependent to independence is relevant to college students and may be useful in promoting PHIM

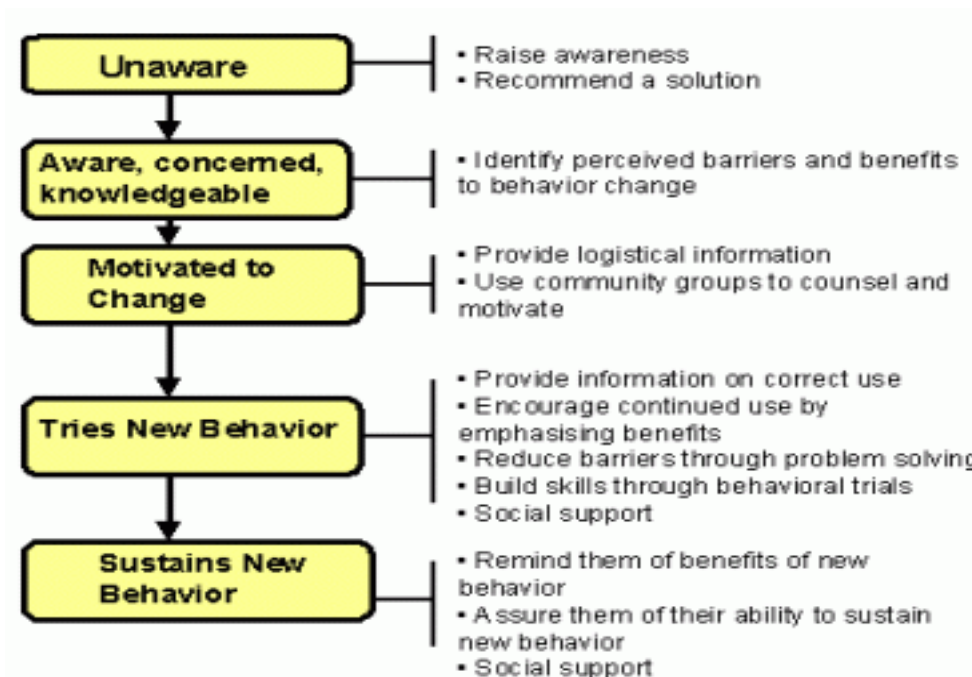
*Promotional messages.*

The students' recommendations regarding messages are useful in examining the promotional aspect of the social marketing strategy. Some of their suggestions follow the stages of behavioral change shown previously in Figure 2.3 and again in Figure 5.1.

Andreasen (1995) recommends using the stages of behavior change to segment the target

group and plan the appropriate message based on their readiness to change. Awareness messages are effective for those first learning about the behavior.

Figure 5.1  
Stages of Behavior Change



Communication for Behavior Change - The World Bank, 1996, by Cecilia Cabanero-Verzosa p 4 Figure 2

<http://www.comminit.com/en/node/27036/36> on 8/27/08

Several participants thought that messages aimed at increasing awareness to the importance of PHIM was a good place to start. Along with the reference to information technology, reference to awareness was the most common comment in responses to the concluding question of what was the most meaningful thing said about PHIM during the focus group.

Um, well, I think the best thing about this, is maybe I should think about my medical records and how I manage them because I really, even before this meeting I didn't really think about them. But, I mean, now I kind of have an idea that it's really important. I don't know how much, unless I have something like

another baby, that I will try to keep track of them. But, at least I'm thinking about it now. (Group 2)

Participants in Group 2 favored “scary stories” delivered through mass media involving celebrities as the most “attention grabbing” influential types of messages. The students seemed to focus on the scary stories due to the recent death of young actor from a fatal drug interaction. They felt if the doctor had only known what other medications the actor was on, the actor’s death would have been prevented.

Participant 1: Like (actor) drug over dose accident, just because of drug interactions he didn't know about and nobody had warned him of. Just little things like that are kind of for me, it's huge red flag, you know, mental note in the future, I'm going to read up on every medication I'm given (laugh) because that's so scary. You know he had absolutely no idea and took two pills and that's it.

Participant 2: It kind of goes back to your doctors giving you things, he was prescribed this sleep medicine and this anxiety, and this...and if your doctors all had like maybe access to your [PHI] in one place and help coordinate and things like that. (Group 2)

News items such as the young actor’s death can offer potentially “teachable moments” to increase awareness of the importance of PHIM.

Other students favored step-by-step instruction delivered in a one-on-one setting. The need for “how to” instructions was emphasized by one student’s response to the question, “Is there anything that we should have discussed but didn't?” She said,

Yeah, I think that maybe it would be wise to talk about how we can better manage it [PHI] ourselves instead of just like why don't we, and what we do do, ... what's worked. (Group 2)

### *Metaphors*

Metaphors are often used in marketing to relate an existing behavior to a new behavior. The students used several metaphors in their discussion. PHIM's similarity to managing financial information was the most frequent one mentioned.

But, similarly, I don't know anything about finances and so I'm going to have to. I'll hire a financial person to tell me what I need to do so I guess as health professionals, we need to take into account that our patients don't know these things and we take that for granted. (Group 1)

### *Placement and timing of promotion.*

Placement and timing of promotional aspects are important pieces of the social marketing strategy (Weinreich, 2006). Identification of places where students spend their time and where they are not likely to pay attention to the message is key to the degree of the messages' influence. Information learned about the students' use of their free time provides some interesting insights that will be helpful in planning promotion of PHIM. Many students spend their free time on physical activities and with friends and family. The PHIM empirical literature did not address messages that may influence behavior change. Because the goal of this research study is to inform a social marketing strategy to promote PHIM, the information is very useful.

## Summary

The purpose of this study is to learn directly from the target audience what may influence them to adopt personal health information management behaviors. Applying the research findings to the foundational bottom six blocks of the Building Block Model of Social Marketing sets the stage for identifying the key points to inform development of the social marketing strategy. From this analysis, I learned the students' perception of PHIM is behavior that results in having immunization and health care providers' information in an organized and easily accessible location. Students view themselves as "healthy" and are not frequent users of health care services. The biggest competitor to PHIM is using their small amount of discretionary time.

Examining the differences in relation to PHIM between the participants in the focus group and those in the PHIM empirical research highlights the importance of consumer orientation. The key to developing an effective social marketing strategy is to identify the target group's personally relevant goals. Through use of the conceptual framework that compares the marketing mix to the MOA model, I can discover potential personally relevant goals that may influence students to adopt PHIM, recommendations for health care providers to remove barriers and facilitate PHIM, and promotional ideas. Selection of the findings to include in the social marketing strategy is based on the criteria of being potentially personally relevant goals for the target group, leading to achievement of the societal goal of improving health by involving individual in their health and health care, and the "hierarchy of credibility" the variables experienced by the participants themselves instead of ones they observed.

## CHAPTER VI CONCLUSIONS AND RECOMMENDATIONS

### Conclusions and Contributions

#### *Personal Health Information Management Conclusions*

Sustained behavior change, the top block of the Building Block Model (BBM), is the goal of social marketing. Sustained behavior change is defined as specific observable behaviors that lead to the societal goal including means of measuring the behavior change. For this social marketing strategy the sustained behavior change would be the continuous practice of personal health information management (PHIM). As I learned through the focus groups, the students perceived health information as mainly immunization records and PHIM as means of obtaining records from health care providers and keeping them in an organized accessible manner preferably with the use of information technology. This behavior would be difficult to measure and will most likely not achieve the societal goal of increased involvement in health and health care leading to improved health status. As described in Chapter V, for this target group of students, immunization records are good starting points and may lead to students adopting PHIM for other types of information.

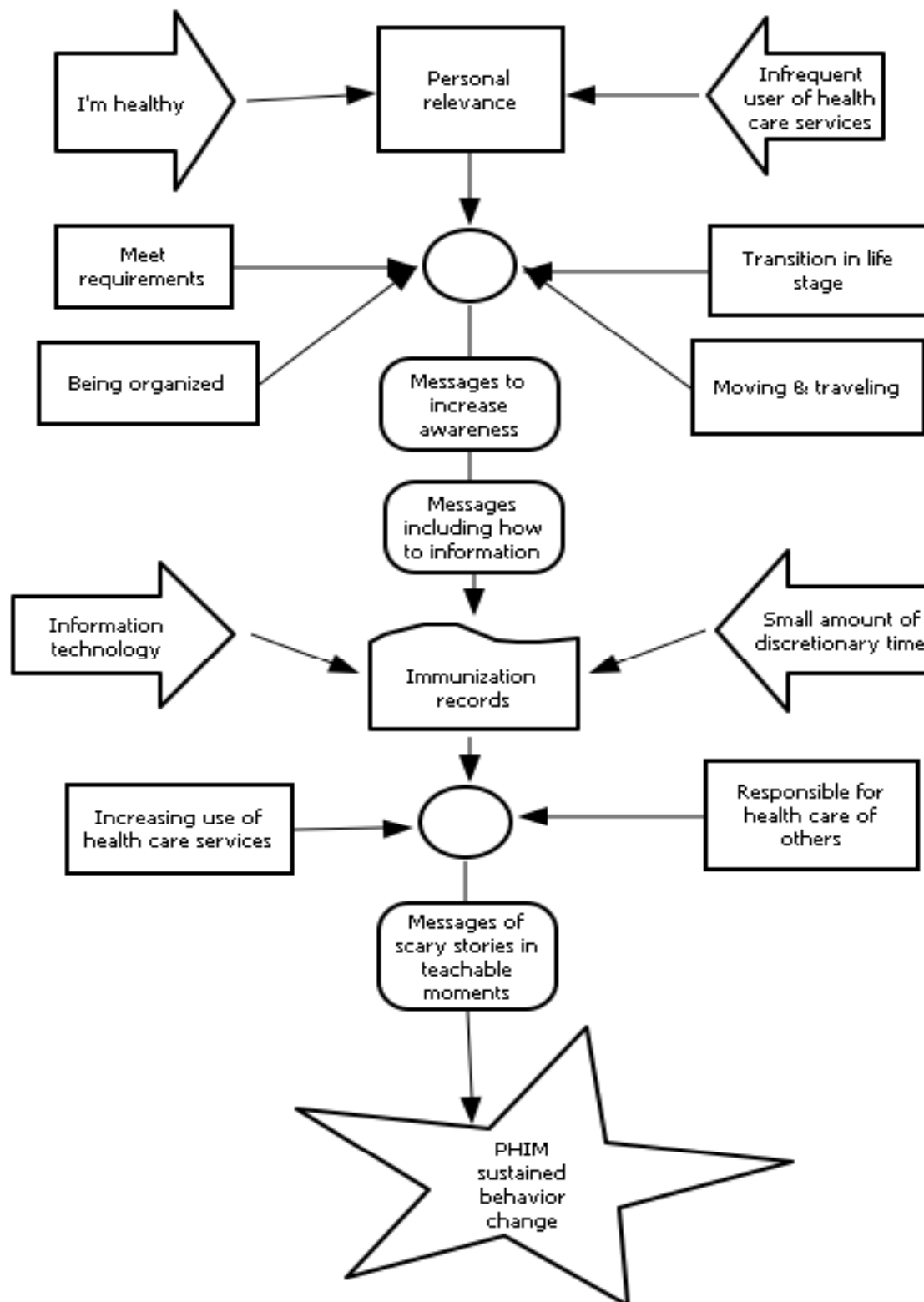
Desiring to go beyond a starting point, I used several analysis methods to derive additional conclusions of the study. Comparison of the participants in this dissertation study to the majority of participants in the PHIM empirical research was especially useful to recognize personally relevant factors. Short-term personal relevance became the standard against which the variables were evaluated for recommendation for inclusion in the social marketing strategy. For example, the students commented on the potential of saving money from not having to repeat tests or services due to unavailable information.

Because the students are mostly healthy and are infrequent users of health care services, I classified saving money as not immediately personally relevant and do not recommend including it in the social marketing strategy. The personally relevant findings and their relationship to each other are illustrated in Figure 6.1 and described in the following sections.

The shapes used in Figure 6.1 are used to reflect various types of concepts. Rectangles reflect current and future personally relevant goals. Block arrows show influences on the personally relevant goals. Rounded rectangles represent promotional messages. The document image is used for immunization records. Arrows illustrate the flow of the influence. Small circles are connectors for the personally relevant goals to the flow to sustained behavior change shown as a start.



Figure 6.1 Identification of personally relevant issues influencing adoption of PHIM



Students' perception of "I'm healthy" and their infrequent use of health care services influence their identification of short-term personally relevant goals. To influence the target audience to change behavior, the social marketing strategy needs to meet the population where they are and not create a need for them if one does not exist. The students' current needs for PHIM are to fulfill requirements and expectations of others, to be organized, to transition from being dependent on their parents to being independent, and to access to their personal health information (PHI) when traveling and relocating. In describing the content of the promotional messages, several participants said they were unaware of PHIM before the focus group and felt that promotional messages should first increase awareness about the importance of PHIM. Star power increases awareness. Governed by their perception of having small amounts of discretionary time, the students generally agreed that their immunization records were most important to them now. The students recommended the use of information technology to manage their immunization records.

Because immunization records are accessed sporadically, this will most likely not have a large impact on reaching the societal goal of increasing individuals' involvement in their own health. The students spoke of current (for a few) and future (for more) needs for PHIM. These needs include being responsible for the health care of others such as children, spouses, and elderly parents and increased use of the health care services as patients. To achieve sustained behavior change, PHIM will need periodic reinforcement. These future needs are illustrated on the bottom half of 6.1

To expand on the use of information technology for PHIM, the students wholeheartedly supported health information exchange between providers and patients.

One student's vision closely resembled the health record bank concept. The use of information technology for PHI raises the concerns for privacy and security discussed by only two students. Even though privacy and security were infrequently mentioned, the social marketing strategy must allay any potential fears about abuse of personal health information.

### *Conclusions for Health Information Management*

Even though this research focused on individuals' perceptions of PHIM, I could not help addressing the providers' health information management procedures that affect individuals' ability to perform PHIM. I was not surprised that the participants discussed difficulty obtaining their medical records from their health care providers. This finding highlights the need for providers to implement "patient friendly" practices to provide individuals with their PHI. Most desirable would be to send/give patients information without them asking. Next in desirability is to train staff to respond to the patient requests for PHI in a timely manner and to explain the reasons for the procedures such as signing authorization forms and providing proof of identification. Ultimately when patients have easy electronic access to their PHI, sustained PHIM will be possible.

By comparing PHIM to recycling, I realized the important roles played by several groups that all had to change for the recycling program to work. The manufacturers of plastic containers place the recycling number on the bottom of the container. The city engages a waste management company to pick up the recyclables and promotes recycling through promotional newsletters. Lastly, individuals dispose of recyclables through the city program. Describing PHIM as process with the impact and role of various stakeholders would be useful and advance the process of PHIM adoption. This research

investigated the individuals' role, but providers, information systems vendors, and health care professional educators all have a responsibility if PHIM is to achieve the societal goal of increasing individuals' participation in their health.

### *Contributions to Social Marketing*

In addition to adding to the PHIM knowledge base, this dissertation research contributes to the use of social marketing in health care. Through the use of social marketing, the attention was focused on influencing behavior change instead of utilization of particular tools such as the personal health record (PHR). I felt that focusing on the behavior instead of the tool was key to understanding the reasons why individuals do or do not use PHRs.

Throughout the study, I created new models and used existing models in new ways. Representing the major social marketing concepts with the Building Block Model of Social Marketing provided a structure for understanding the major concepts and their relationship to each other. Discovering the Motivation, Opportunity, and Ability Model and integrating it with the marketing mix into a conceptual framework proved useful to identify personally relevant goals to this target group. For me professionally and personally, I learned and appreciated the importance of discovering directly from the target audience their personally relevant goals that would influence behavior change.

### Recommendations

The recommendations derived from this study include the next steps for development of the social marketing strategy and suggestions for additional research.

### *Social Marketing Strategy: Next Steps*

Gaining information from the target audience through qualitative methods such as focus groups is the first step in developing a social marketing strategy. The next steps are:

1. Develop and implement a survey to confirm the focus group findings. A representative sample of students at the academic medical center should complete the survey.
2. Develop social marketing strategy using the results from the focus groups and the survey
3. Test the social marketing strategy with focus groups and make adjustments
4. Pilot test the social marketing strategy with a representative sample of the target audience and monitor its effectiveness
5. Revise the social marketing strategy based on feedback from the pilot
6. Launch the social marketing strategy to the whole target market, monitor its effectiveness in changing behavior, and revise as needed  
(Weinreich, 2006)

### ***Practical Suggestions to Encourage Use of University's PHR***

Several ideas to encourage use of the university's personal health record occurred to me during the course of the research. These suggestions could be implemented before or without the development of a social marketing strategy.

The staff of the Student Health Clinic at the academic medical center could be encouraged to assist students with PHIM. This clinic is responsible for ensuring

students' immunizations are current. Because students identified management of immunization records as a primary need, the clinic staff could facilitate PHIM by providing students with copies of immunization records as well as other records. They could also reinforce the need for keeping the records in an accessible place because of specified future needs. When beginning at the medical center, students might not be aware that they will be asked to produce proof of their immunizations at future times.

To assist students learning the processes and content for PHIM, the staff of the student health clinic and other points of access for students could refer students to myPHR.com. On-line information about PHIM could also include a link to myPHR.com. MyPHR.com is a "treasure trove" of information on the importance of keeping track of PHI, procedures and forms to obtain copies of PHI, and suggestions for the types of information to keep. Referral to this Web site would fulfill the students need for "how to" information.

During the students' tenure at the university, several "teachable moments" routinely occur that could be used to increase students' awareness of the importance of PHIM. These opportunities include: students' acceptance to the university, notification of requirements to produce immunization records, and proof of health insurance; the annual flu shots; and the notification of acceptance at a clinical rotation and the requirements to produce proof of immunizations.

#### *Future Research*

Many possibilities for research exist because personal health information management is a relatively unexplored area. Most of the studies found in the literature focus on various iterations of personal health records and patient access to providers'

records and not on behaviors that impact the utilization of the tools. Further exploration may include replicating this study with target groups at different life stages such as expectant parents. By moving to a stage later in life than students, a continuum of personally relevant goals could be identified and used to influence sustained adoption of PHIM.

This study highlighted the differences in personal relevant goals between healthy young students and individuals who are chronically ill and frequent users of health care services. Leonard (2007, 2008) enthusiastically supports the use of patient accessible health information for a group referred to as the 3C, consumers with chronic conditions. He argues that benefits to the individual as well as society are derived from the 3C use of PHI. Through longitudinal studies that follow the two populations and their use of PHIM, the long-term benefits for the varying populations could then be compared. Do young people who learn the behavior early continue to perform it? Does their use of PHIM influence their future families and peers? How does PHIM affect the 3Cs? Does it save money and improve health? No longitudinal studies have been performed on PHIM.

I think that the concept of health record banking (HRB), introduced in the introduction and described by one student, offers great potential for individuals to manage their own health information and overcome some of the obstacles of health information exchange between providers. HRB is being piloted in three communities in state of Washington, in Louisville, KY, and throughout Oregon ([www.nhinwatch.com](http://www.nhinwatch.com)). These pilot projects will provide rich resources for future research. Examination and comparison of the marketing plans used would also help inform future social marketing efforts.

The one student's opinion that his workout records were not health information surprised and disappointed me. A study, somewhat unrelated to this research but may have great future impact, is to discover students perceptions of health. A mixed method research design starting with focus groups and followed by a survey could be used to gain understanding of this groups' view of health. The research results could be used to develop a social marketing strategy for healthy life styles to the students. Future health care professionals need to practice well care and not just sick care.



Appendix A  
E-Mail to Student Organization Leader

Hello, I am requesting your advice as President of the (student organization) on the best way to seek students' participation in a focus group. The focus groups will be the basis for my doctoral dissertation and are to gain information on students' perceptions on managing their own health information. This health information is separate from and different than that maintained by physicians and hospitals. I'm seeking their perceptions as individuals and not as future health care professionals. Students will be compensated for their time and meals will be provided for the groups held during meal times and must be at least 19 years old.

Would you be willing to present the information in the attached flier, Appendix E, at a (student organization) meeting? I hope to hold the focus groups during the last two weeks in February. Would the (student organization) meet before then? I would provide you with copies of the fliers for distribution and pick up the completed ones when though.

Would you be willing to send e-mail messages to members of (student organization)? Also attached as Appendix C.

Where would you recommend I post posters that would attract students' attention? Is there a student lounge or bulletin board where students frequent? A sample flier is attached. However, the one that is posted must have the IRB stamp on it.

I hope to hold the focus groups during the weeks of Feb. 18 and 25, 2008. During those weeks what might be the best time of day and day of the week for the students to attend the focus groups? Lunchtime? Early afternoon? Is there a conference room near where most of their classes are held?

Thank you for any help you can provide me. I so appreciate your taking the time to respond to my questions.

Ellen

Appendix B  
E-mail to Academic Program Directors

Hello, I am requesting your advice as Program Director on the best way to seek (program name) students' participation in a focus group. The focus groups will be the basis for my doctoral dissertation and are to gain information on students' perceptions on managing their own health information. This health information is separate from and different than that maintained by physicians and hospitals. I'm seeking their perceptions as individuals and not as future health care professionals. Students will be compensated for their time and meals will be provided for the groups held during meal times and must be at least 19 years old.

Do the students meet where I could ask one (or I could come myself) to present the information in the attached flier, Appendix E? I hope to hold the focus groups during the last two weeks in February. I would provide copies of the fliers for distribution and pick up the completed ones when though.

Where would you recommend I post posters that would attract the students' attention? Is there a student lounge or bulletin board where students frequent? A sample flier is attached. However, the one that is posted must have the IRB stamp on it.

I hope to hold the focus groups during the weeks of Feb. 18 and 25, 2008. During those weeks what might be the best time of day and day of the week for the students to attend the focus groups? Lunchtime? Early afternoon? Is there a conference room near where most of their classes are held or labs where they work?

Thank you for any help you can provide me. I so appreciate your taking the time to respond to my questions.

Ellen

Appendix C  
E-Mail to Students

Dear Fellow Student:

I am recruiting students who are at least 19 years old to participate in focus group research. The purpose of the focus groups is to learn your views on individuals' roles in collecting, entering and maintaining your own health information. This health information maintained is for your own use and is separate and different from the doctors' and hospitals' medical records. It can include everything from appointment reminders, exercise logs, food diaries, lists of immunizations and drug allergies. We need your opinions as consumers of health care not as future health care professionals. Are you willing to participate in this research? Participation means attending one focus group of 6 to 10 students and sharing your opinions about personal health information management. No personal health information will be collected during this study. Each focus group will meet once, take up to two hours of your time, and be held on campus during the weeks of February 18 and 25, 2008. The conversations of the focus groups will be audio recorded.

Participants will be compensated for their time and provided a meal for groups that meet during mealtime.

On the attached interest form, you will find additional information about the research (Appendix E). Please contact me at [ejacobs@xx.edu](mailto:ejacobs@xx.edu) or xxx-xxx-xxxx to discuss your questions and interest in participating in the focus groups.

Your opinion matters! Please respond by February 7th, 2008.

Thank you so much for giving this your consideration,

Ellen B. Jacobs, M.Ed, RHIA



**Appendix E**  
**Interest Form (E-Mail)**  
**In Search of a Message to Promote Personal Health Information Management**  
**IRB 429-07-EP**

Thank you for expressing interest in becoming a focus group participant. The purpose of the focus groups is to learn of your views on individuals' role in collecting, entering and maintaining their own health information. This health information maintained is for your own use and is separate and different from the doctors' and hospitals' medical records. It can include everything from appointment reminders, exercise logs, food diaries, lists of immunizations and drug allergies. We need your opinions as consumers of health care not as future health care professionals.

I am looking for (name of academic medical center) students who are at least 19 years old and are willing to participate in this research. Participation means attending a focus group of 6 to 10 students and sharing your opinions about personal health information management. No personal health information will be collected during this study.

The university Institutional Review Board has approved this study. Your participation is voluntary. If at anytime during the focus group you feel uncomfortable, you may choose not to answer questions, to ask questions of the researchers, or to leave the room.

Focus groups will meet once for up to two hours on campus. You will be compensated for your time for participating in the focus groups. A light meal will be provided during the focus group.

The results will be confidential, and individual responses will not be connected to your identity in any report or publication. We will not retain identification information in the data that are used to prepare reports or papers from this research. I will take precautions to be sure that references to particular comments do not use information that could reveal your identity.

The focus groups will be the primary data collection method for my doctoral dissertation and is supported by a grant from the Foundation of Research and Education (FORE) of the American Health Information Management Association (AHIMA).

. If you are interested in participating, please supply the following information and return it as an attachment to email [ejacobs@xxx.edu](mailto:ejacobs@xxx.edu). Encourage your friends to participate and have them complete the attached form as well.

I will send you information confirming the date, time and place for the focus group meeting. Thank you for considering participating. Please return this form by XXXXXXXX. Focus groups will be held during the weeks of XXXXXXXX and XXXXXXXX.

Ellen B. Jacobs  
Candidate for Doctor of Philosophy Degree

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*Name (please print first and last name)*

---

*E-mail  
number*

---

*phone*

What is your program of study?

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(Specify for example: nursing, medicine, physical therapy, public health, etc.)

Gender:  Male  Female

Do you keep some type of health information about yourself and/or others:  Yes   
No

(This could include appointment reminders, immunization records, medication records,  
and copies of lab results.)

**Appendix F**  
**Confirmation Letter To Participants**

**In Search Of A Message To Promote  
Personal Health Information Management  
IRB #429-07-EP**

Date

Dear (Name):

Thank you for accepting the invitation to talk about health information ownership. We want to learn directly from UNMC students how they feel about being responsible for their own health information. It doesn't matter if you already keep some form of health information or not. We're interested in the ideas of all UNMC students. We have kept the group size small to allow participants an opportunity to share their ideas.

You are scheduled for a focus group that will meet

**On:** (Day of Week), (month, day, year) from (start time) to (finish time)

**At:** (room) of (building) at (address).

To prepare for the focus group, please review the enclosed Consent Form and Rights of Research Subjects. Please contact me with any questions or concerns regarding the research topic or focus groups. I am happy to answer any questions you may have.

You will be compensated for your time for participating in the focus group. . A light meal will also be provided.

Please let me know as soon as possible if are unable to attend the focus group at this scheduled time by e-mail at [ejacobs@xxx.edu](mailto:ejacobs@xxx.edu) or phone at xxx-xxx-xxxx. Please include your name and the scheduled date of your focus group in your message.

Thank you,

Ellen B. Jacobs, M.Ed, RHIA  
Candidate for Doctor of Philosophy Degree  
University of XXX



## **Appendix G Informed Consent**

**IRB #429-07-EP**

### **Title of this Research Study**

#### **RESEARCH: IN SEARCH OF A MESSAGE TO PROMOTE PERSONAL HEALTH INFORMATION MANAGEMENT**

#### **Invitation**

You are invited to take part in this research study. The information in this form is meant to help you decide whether or not to take part. If you have any questions, please ask.

#### **Why are you being asked to be in this research study?**

You are being asked to be in this study because you are a student at the University of Nebraska Medical Center.

#### **What is the reason for doing this research study?**

This research is designed to gain an understanding of students' perceptions about individual responsibility for completing and maintaining their own health information. This information is separate and distinct from medical records kept by physicians and hospitals. Individuals' responsibility for their health and health care is increasing. Keeping track of personal health information assists in being an informed participant in one's health and health care.

#### **What will be done during this research study?**

Should you agree to participate, it will take up to two hours of your time for focus group discussion. The discussion group will be made up of 6 to 12 UNMC students.

At the beginning the focus group meeting, those who consent to participate in the study will indicate they understand the purpose of the study and sign this consent form.

During the group discussion, as a consumer of health care services, you will be asked to discuss your perceptions about uses of and barriers to managing your own (or that of another) personal health information.

A researcher from the University of Nebraska Medical Center will guide the discussion and make sure that all participants are polite and respectful of each other.



All participants will be asked not to discuss who was present at the discussion or the specific details of any participants' statements outside of the group setting.

The group discussions will be tape-recorded to ensure that researchers have an accurate record of the discussion. By signing this consent form, you are also agreeing to be tape-recorded during the discussion. The audiotapes will be maintained in locked cabinets available to the research team and will be destroyed upon completion and acceptance of the doctoral dissertation.

**What are the possible risks of being in this research study?**

Possible risks and discomforts you could experience during this study include:

There is a possible risk that your identity and/or comments may be shared with others after the focus groups session is completed. This outcome could embarrass you.

**What are the possible benefits to you?**

Potential benefits to you are increased awareness of personal health information management.

**What are the possible benefits to other people?**

Information gleaned from this research may be used to gain an understanding of individuals' perceptions of responsibility for their own health information. This understanding may help develop a marketing strategy to promote individuals' responsibility for their personal health information that may result in improved health.

**What are the alternatives to being in this research study?**

Instead of being in this research study, you can choose not to participate.

**What will being in this research study cost you?**

There is no cost to you to be in this research study other than your time needed to participate in the focus groups.

**Will you be paid for being in this research study?**

If you participate in this study, you will receive a light meal during the discussion and \$40 at the end of the discussion group to compensate you for your time and effort.

**What should you do if you have a problem during this research study?**

Your welfare is the major concern of every member of the research team. If you have a problem as a direct result of being in this study, you should immediately contact one of the people listed at the end of this consent form.

**How will information about you be protected?**

Reasonable steps will be taken to protect your privacy and the confidentiality of your study data. The contact information you provided will be kept in a locked cabinet accessible only by the study team to ensure confidentiality and

anonymity. The audio recordings of focus group discussions will be kept in a locked file cabinet accessible only by the principal investigator and the participating personnel. All audiotapes of the focus group discussions will be destroyed upon completion and acceptance of the doctoral dissertation. The electronic transcripts and coding analysis will be permanently stored in the computer network owned and controlled by the UNMC and maintained for use in future research.

The only persons who will have access to your research records are the study personnel, the Institutional Review Board (IRB), and any other person or agency required by law. The information from this study may be published in scientific journals or presented at scientific meetings but your identity will be kept strictly confidential.

### **What are your rights as a research subject?**

You have rights as a research subject. These rights have been explained in this consent form and in The Rights of Research Subjects that are included in this information packet. If you have any questions concerning your rights or complaints about the research, talk to the investigator or contact the Institutional Review Board (IRB) by:

- Telephone (402) 559-6463.
- Email: [IRBORA@unmc.edu](mailto:IRBORA@unmc.edu)
- Mail: UNMC Institutional Review Board, 987830 Nebraska Medical Center, Omaha, NE 68198-7830

### **What will happen if you decide not to be in this research study or decide to stop participating once you start?**

You can decide not to be in this research study, or you can stop being in this research study (“withdraw”) at any time before, during, or after the research begins. Deciding not to be in this research study or deciding to withdraw will not affect your relationship with the investigator, or with the University of Nebraska Medical Center or The Nebraska Medical Center Hospital.

You will not lose any benefits to which you are entitled.

If the research team gets any new information during this research study that may affect whether you would want to continue being in the study, you will be informed promptly.

### **Documentation of informed consent**

You are freely making a decision whether to be in this research study. Signing this form means that (1) you have read and understood this consent form, (2) you have had the consent form explained to you, (3) you have had your questions answered and (4) you have decided to be in the research study.

If you have any questions during the study, you should talk to one of the investigators listed below. You will be given a copy of this consent form to keep.

---

Signature of Subject	Date	Time
----------------------	------	------

My signature certifies that all the elements of informed consent described on this consent form have been explained fully to the subject. In my judgment, the participant possesses the legal capacity to give informed consent to participate in this research and is voluntarily and knowingly giving informed consent to participate.

---

Signature of Person Obtaining Consent	Date
---------------------------------------	------

### **Authorized Study Personnel**

Principal Investigator	Daytime Phone
------------------------	---------------

Ellen B. Jacobs, M.Ed., RHIA	402-932-5696
------------------------------	--------------

Secondary Investigator	Daytime Phone
------------------------	---------------

Keith Mueller, Ph.D.	402-559-4318
----------------------	--------------

Participating Personnel	Daytime Phone
-------------------------	---------------

Michelle Mason, MA	402-559-8406
--------------------	--------------

Sara Roberts, MPA	402-559-7485
-------------------	--------------

Kathy Minikus	402-559- 8619
---------------	---------------

Sue Nardie	402-559- 3889
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**Appendix H  
Research: In Search of a Message to Promote Personal Health Information  
Management  
IRB 429-07-EP**

**THE RIGHTS OF RESEARCH SUBJECTS**

**AS A RESEARCH SUBJECT AT THE NEBRASKA MEDICAL CENTER  
YOU HAVE THE RIGHT ...**

**... to be told everything you need to know about the research before you are asked to decide whether or not to take part in the research study.** The research will be explained to you in a way that assures you understand enough to decide whether or not to take part.

**... to freely decide whether or not to take part in the research.**

**... to decide not to be in the research, or to stop participating in the research at any time.** This will not affect your medical care or your relationship with the investigator or the Nebraska Medical Center. Your doctor will still take care of you.

**... to ask questions about the research at any time.** The investigator will answer your questions honestly and completely.

**... to know that your safety and welfare will always come first.** The investigator will display the highest possible degree of skill and care throughout this research. Any risks or discomforts will be minimized as much as possible.

**... to privacy and confidentiality.** The investigator will treat information about you carefully, and will respect your privacy.

**... to keep all the legal rights you have now.** You are not giving up any of your legal rights by taking part in this research study.

**... to be treated with dignity and respect at all times**

**The Institutional Review Board is responsible for assuring that your rights and welfare are protected. If you have any questions about your rights, contact the Institutional Review Board at (402) 559-6463.**

**Appendix I**  
**In Search of Message to Promote Personal Health Information Management**  
**Focus Group Participant Information**  
**IRB #429-07-EP**

Name as used in the focus group (Please print):

---

1. Age: \_\_\_\_\_
2. Gender:  Male  Female
3. Program of study:  
 \_\_\_\_\_  
 (For example: Nursing, Medicine, Pharmacy, Graduate Studies, Physician Assistant)
4. Life stage (Circle the one closest to your current living situation);  
 Single no children  
 Single living with children  
 In a committed relationship not responsible for children  
 In a committed relationship and responsible for children  
 Other: please explain \_\_\_\_\_
5. I am responsible for managing the **health and health care** of another such as children, parents, spouse, other?  Yes  No
6. Do you keep track of **personal health information** for yourself or anyone else?  Yes  No
7. What resources have you used for finding health information related to your own or another's health and or personal interest (not related to your studies)? Check all that apply.  
 I have searched on the Internet for health information.  
 I have purchased a book or magazine on health or health related issue.  
 I have subscribed and/or received a health magazine or newsletter.  
 I have used other health or medical resource.  
 Other:  
 \_\_\_\_\_  
 I have not used/looked for health information.
8. Did you know that UNMC has offered students a web based personal health record (PHR) available on your Blackboard Home Page?  Yes  No
9. Please check all that apply in regards to the UNMC PHR.  
 I have looked at the demo for the PHR.

- I have signed up for the PHR.
- I have entered personal health information on the PHR.
- I have referred to my PHR as a source for information about me or my family.
- I have printed a copy to take to my health care provider.
- I have not looked at the UNMC web based PHR.
- Other: \_\_\_\_\_

Appendix J  
**FOCUS GROUP AGENDA**  
**In Search of a Message to Promote Personal Health Information Management**

Date

Noon to 1 pm

1. Introductions of researchers
2. Informed consent
3. Intake form
4. Ground rules for discussion
  - a. Everyone's participation is important.
  - b. There are no right or wrong answers. We can agree to disagree.
  - c. Questions and approximated time for each are on the flip charts.
  - d. Avoid using actual health care details; use generalizations instead.
  - e. What is discussed here, stays here.
  - f. Take turns talking and please no side conversations
5. Self-introduction of participants
6. Thoughts before discussion begins
  - a. Respond as health care consumers, not future health care professionals or scientists.
  - b. Consider personal health information is for your own use and under your control. It does not replace the health care providers' medical records.
7. Participant discussion questions
8. Wrap up
9. Compensation

Appendix K  
**Moderator Script and Focus Group Questions**  
**In Search Of A Message To Promote Personal Health Information Management**  
 IRB 429-07-EP

**I. Informed consent and Ground Rules (7 minutes)**

**Moderator Introduction**

Welcome, my name is Ellen Jacobs and I want to thank you for taking the time to talk with us about your thoughts and ideas about individuals' responsibility for completing and maintaining their own health information. What you have to say today is important and will not only serve at the basis for my dissertation but also help to develop a message to promote personal health information management. The research is supported by a grant from the Foundation of Research and Education (FORE) of the American Health Information Management Association (AHIMA).

I will let other members of the research team from the UNMC introduce themselves.

Please go ahead and get your meal. While you are eating, we will explain what you can expect during the next hour.

**Informed consent process, explanation of audio recording, and intake form**

- First, we want to be sure that everyone is comfortable with the discussion topics. You received a copy of the consent form as an attachment to an e-mail. If you brought the consent form with you please look at it now. If you need a copy, please let us know.
- The purpose of this discussion is to obtain your thoughts and ideas about personal health information management. We understand that talking about health care may be a bit upsetting to discuss with others. (Pause). You are free to leave the group at any time.
- Three other discussions like this will take place on campus. Because it is important that we remember the points brought up by each group, we will tape-record our discussion. The only people who will use the tapes are the UNMC researchers. All audiotapes of the focus group discussions will be destroyed upon completion and acceptance of my doctoral dissertation. The electronic transcripts and coding analyses will be permanently stored on the UNMC network accessible by the research team and maintained indefinitely for future research.
- Since your privacy is important, your comments will not be connected with your name at any time. Any reports about this discussion will not refer to you by name.
- During the discussion, you can use a different name than your own. Please write the name you would like to use on the nametag and the same name on the Intake Form.
- You will receive \$40 in cash at the end of today's discussion.
- Does anyone have a question about the purpose of the study? Are there any questions about participating in the discussion?
- (After answering questions) Please sign your initials in the blanks at the bottom of each page of the consent form to show that you understand the information on that page and your full signature on the last page.
- Next, please fill out the **Intake Form on yellow paper**. We will use this information to help us understand the results of the discussion groups. Remember



to use the name you choose to use during the discussion on the form. We will only connect you with the specific discussion with the use of this pseudonym. After completing both forms, raise your hand and one of the researchers will sign the last page of the consent form and collect both forms.

### **Ground Rules**

Here are some rules for us to keep in mind so that our discussion goes smoothly.

- Everyone's participation is important. Feel free to say what you think...there are no right or wrong answers. We can agree to disagree if we need to so that all points of view are heard.
- It is important that we hear everyone's honest opinion so I may ask each of you to give a short (a minute or less) response to the question. However, I may interrupt you to move the discussion along so we can hear from everyone and discuss all of the questions. We have indicated the time each question should take on the flip chart. Our time keeper, (name), may remind us if we are spending too much time on a topic.
- Since privacy is important, two cautionary notes:
  - When discussing a situation you or someone you know might have had regarding health information, please do not include any details of the individual's health or condition. For example, you could say you needed to get copies of x-rays or records and not include the reason you needed them or what type of condition was being treated.
  - Please don't talk specifically about what someone else said outside of this group. If you are asked about what you did in this group, just say you talked about individuals' managing their own health information.
- Remember to take turns talking, to not have any side conversations, and tell us what you think about personal health information management.

### **II. Introductions (5 minutes)**

**So we can all get to know each other, please share something about yourself. Please introduce yourself by the name you have chosen to go by today and share with us one of your favorite activities. How do you like to spend your free time?**

### **III. Discussion Questions**

**As we move into discussion of the research topic, please remember we want to know what you think as individuals not as future health care professionals or scientists. We want to learn what you think and feel about managing your own (or others) health information. This health information is for your own use and under your control. It does not replace the health care providers' medical records. For example, personal health information could mean that a person tracks their weight and exercise routine to see if their exercise plans has any affect on their weight.**

#### **Key Questions:**

1. (4 minutes) (Goal: Moving into the topic)

**What types of information does the term "personal health information" bring to mind?**

Probe: What are some examples?

Probe: Do you keep track of any information for your own use that you did not get from a health care provider?

2. (6 minutes) (Goal determine behaviors that should be encouraged/discouraged leading to adoption of personal health information management behavior)

**What are your experiences with managing personal health information?**

Probe: What works well and what doesn't work?

3. (6 minutes) (Goal: benefits or beliefs and values)

**What benefits are gained from managing personal health information?**

Probe: What makes it worthwhile

**OR**

**What beliefs and attitudes would motivate you to manage your personal health information?**

4. (6 minutes) (Goal: barriers)

**What are some reasons people don't take an active role in managing their own personal health information?"**

Probe: How might this barrier be addressed?

5. (6 minutes) (Goal: Context where the behavior change might be most likely)

**What are some situations that cause individuals to manage their health information?**

6. (6 minutes) (Goal: Learn the types of messages that resonate with the Target Audience)

**What type of messages or stories might motivate individuals such as yourselves to take a more active role in PHIM?"**

Probes: Where and when would be the most effective methods to reach individuals similar to you with this message?

Probe: Who (in terms of characteristics) would be most effective in delivering these messages?

**Ending questions: I'd like to go around the table and have each of you give an answer to the last questions. (10 minutes)**

- What is the most meaningful thing about personal health information management that was said here today?
- Is there anything we should have discussed but didn't?
- Do you have any suggestions for how we can improve this process?

Thank you all for coming and sharing your thoughts and feelings about personal health information management. You have significantly contributed to methods that we hope will make the United States a healthier nation.

Hand out payments.

## Appendix L

## Summary Of Responses To Intake Form Questions

	<b>Group 1</b>	<b>Group 2</b>	<b>Group 3</b>	<b>Total</b>	<b>Percentage of Total</b>
<b>No of Participants</b>	9	13	11	33	100
<b>Age</b>					
19-24	5	12	5	22	66.67
25-30	4	0	6	10	30.30
31-34	0	1	0	1	3.03
<b>Gender</b>					
Male	1	0	4	5	15.15
Female	8	13	7	28	84.85
<b>Program of Study</b>					
Graduate Studies	3	0	2	5	15.15
Medicine	3	1	8	12	36.36
Nursing	3	9	0	12	36.36
Pharmacy	0	0	1	1	3.03
Physician Assist	0	3	0	3	9.09
<b>Life Stage</b>					
Single no kids	4	11	4	19	57.58
Single living with kids				0	0.00
Committed relationship not responsible for children	5	1	5	11	33.33
Committed relationship and responsible for children		1	2	3	9.09
<b>Responsible for managing health and health care of another</b>					
Yes	0	1	3	4	12.12
No	9	12	8	29	87.88
<b>Resources searched for health information</b>					
Internet	9	13	11	33	100.00
Book or magazine	4	4	5	13	39.39
Subscribed to health magazine or	2	5	2	9	27.27

	<b>Group 1</b>	<b>Group 2</b>	<b>Group 3</b>	<b>Total</b>	<b>Percentage of Total</b>
newsletter					
Used other health or medical resource	5	6	5	16	48.48
Other	Asked experts 1		Micromedex 1	2	6.06
<b>Keep track of PHI for yourself or anyone else</b>					
Yes	8	10	9	27	81.82
No	1	3	2	6	18.18
<b>Know about university PHR</b>					
Yes	5	4	4	13	39.39
No	4	9	7	20	60.61
<b>University PHR</b>					
Looked at the demo					
Signed up					
Entered PHI on the PHR					
Referred to my PHR as a source for information					
Printed a copy to take to my health provider					
Not looked at it	9	13	11	33	100.00
Other					

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