# MEDICATION ADHERENCE IN DISEASES REQUIRING SPECIALTY MEDICATIONS: A PHARMACIST'S PERSPECTIVE ON THE IMPACT OF THE WORLD HEALTH ORGANIZATION'S CATEGORIZATIONS, ALONG WITH TECHNOLOGY AND PHARMACEUTICAL INDUSTRY-INITIATED FINANCIAL ASSISTANCE

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by

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## **Abstract**

Challenges to adherence surrounding instructions for taking prescription medications have been around for centuries. Within chronic diseases, 'medication adherence' has unlimited complexities and contributes to poorer health outcomes of intended treatments. Unfortunately, medication nonadherence is very difficult to change due to a multitude of factors. Furthermore, interventions intended to help have been mostly unsuccessful over time. Significant research has been conducted with the aim of understanding medication adherence's complexity and importance. Consistently, it is argued that 'simple' approaches for improvement are difficult to achieve. Researchers agree that potential solutions are more complicated than would be ideal.

In recent decades, the advancement of various forms of interventions has opened up new opportunities to improve upon medication adherence. Progress has been slow and many gaps still exist. Utilizing frontline practitioners, retail pharmacists, who spend significant time engaged in providing specialty medications, this action research (AR) assessed opinions aligned with the accepted categorizations put forth by the World Health Organization (WHO). Additionally, the research sought to garner further knowledge within the use of technology and pharmaceutical industry-initiated financial assistance. The research desired to provide recommendations to help guide practical actions in an attempt to improve adherence rates which may optimally lead to better health outcomes. Further research and follow-up are recommended as the incremental upside of even the smallest improvements in medication adherence is significant.

Guidance was provided to the participants in order to assess or convey gaps in the existing knowledge. A total of seven concentrated categories were pursued for the mixed methods research thesis. A survey component of the study meant to garner a small convenience sample had 115 respondents while focus groups sessions had a total of 12 participants. To support analysis of the data collected, an integrated design was used as an assessment tool for synthesis assimilation. In total, a subset of 40 themes were assessed between the mixed methodologies. Seven themes emerged as dominant and included the cost of medications, reimbursement, the use of technology (prescription refill monitoring), third party financial assistance, drug navigation seeking funding, and two 'timing' concepts. Interestingly, four of the seven dominant

themes relate directly to the cost of the medication or how to fund it. The dominant themes provided a foundation for a set of recommendations.

The findings throughout this AR suggest that retail pharmacists in Atlantic Canada believe that medication adherence is a significant issue in the delivery of healthcare. However, improving adherence rates in diseases which require specialty medications will be challenging. It is agreed that taking a multifactorial approach will be fundamental. However, as this fact is already well known, to help improve upon the significant global issue and to potentially generate actionable knowledge that may avail change, this thesis puts forth two smart recommendations. It is hoped that these recommendations will be both accepted and pursued by both academics and practitioners in the field.

Two recommendations align directly with the advances in the use of technology and pharmaceutical industry-initiated financial assistance. Firstly, increase the timeliness, emphasis, and support for a national standardized approach of medication reviews as it directly relates to content, funding, training, and implementation. And secondly, establish a centralized repository of information regarding access and availability of Patient Assistance Programs (PAP). Furthermore, the effort must not stop there as both these recommendations will have limitations on whom designs, supports, and funds such coordination. Attention, action, and evolvement of the recommendations must be at the forefront of scholarly and practical stakeholders moving forward.

Future research leading to enhanced practical solutions is recommended and will need to be focused, consistent, and evolving in order to improve upon medication adherence rates and the lives of patients.

Key Words: medication adherence, action research, chronic disease, technology, financial assistance, and pharmacy.

# **Acknowledgements and Declaration of own Work**

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This action research was given general support by each of the four Atlantic Canada pharmacy associations during the data collection phase. These associations represent four of the Canadian provinces and include Newfoundland, Nova Scotia, New Brunswick, and Prince Edward Island. The content presented within this thesis and underlying action research data is solely the responsibility of myself, as the researcher, and does not necessarily reflect the opinion, policy, or position of any of the mentioned provincial pharmacy associations. I would like to thank each of the associations for their support.

During the research, I confirm that there were no discussions regarding individual patients or that which provided personal identifiers of unique patients but rather broad-based communication and professional discussion on the concepts of medication adherence which led to a set of smart recommendations.

# **Table of Contents**

	Abstract					
	Acknowledgements and Declaration of own Work					
	Table	Table of Contents				
	List	List of Appendices				
	List	List of Figures				
	List	List of Tables				
	Gloss	Glossary: Abbreviations and Acronyms				
		Terms and Definitions	1			
1.0	Introduction					
	1.1	1.1 Background				
	1.2	Research Aims				
	1.3	Research Question				
	1.4	Rationale				
	1.5	History of Nonadherence and Recognition	,			
	1.6	Significance of the Problem	,			
	1.7	Research Gaps and Opportunities for Improvement	,			
	1.8	Thesis Overview	,			
2.0	Review of the Literature					
	2.1	Search Methodology	2			
	2.2	Introduction				
	2.3	Definition				
	2.4	Prevalence				
	2.5	Categorizations, Patterns, Sub-classifications				
	2.6	Human and Societal Impact				
	2.7	Factors that affect medication adherence	,			
		2.7.1 Patient	4			
		2.7.2 Condition	4			

		2.7.3 Therapy	42
		2.7.4 Socioeconomics	43
		2.7.5 Health System	45
		2.7.6 Technology	47
		2.7.7 Financial Assistance Provided by the Pharmaceutical Industry	63
	2.8	Potential Research Gaps, Barriers, and Inadequacies	65
	2.9	Literature Review Summary	68
3.0	Meth	nodology	70
	3.1	Action Research Framework	76
	3.2	Ethical Considerations	82
	3.3	Action Cycle 1: Quantitative Survey	83
	3.4	Action Cycle 2: Qualitative Focus Group	85
	3.5	Action Cycle 3: Qualitative Focus Group	87
4.0	Story	y of Cycles of Action, Reflection	88
	4.1	Action Research Cycle 1: Online Survey	95
	4.2	Action Research Cycle 2: Focus Group Session 1	97
	4.3	Action Research Cycle 3: Focus Group Session 2	98
	4.4	Methodology Discussion	99
5.0	Eval	uation of Outcomes	100
	5.1	Overview and Analysis	100
	5.2	Action Cycle 1: Quantitative Survey	101
		5.2.1 Discussion of Quantitative Results	102
		5.2.2 Online Survey Themes	127
	5.3	Action Cycle 2: Qualitative Focus Group	128
	5.4	Action Cycle 3: Qualitative Focus Group	144
	5.5	Preparation of the Findings	153
	5.6	Field Methods	154
	5 7	Sense-making: Findings	155

	5.8	Mixed Methods Matrix			
		5.8.1 Convergent Themes	159		
		5.8.2 Other Themes of Importance	160		
		5.8.3 Surprise Themes which did not Converge across Methodologies	161		
6.0	Conc	lusions, Reflections, and Implications	161		
	6.1	Moments of Inquiry	161		
		6.1.1 Mapping the Terrain	162		
		6.1.2 Testing Plausibility	163		
		6.1.3 Evaluating Action	163		
	6.2	Recommendations	164		
	6.3	Discussion	170		
	6.4	Future Requirements in Research and Practice	172		
	Limitations of this Action Research	174			
	6.6	Reflection on the Action Research Process			
	6.7	Conclusion	179		
7.0	References				
	<b>Appendices</b>				

# **List of Appendices**

Appendix A Consent Form

Appendix B Participation Form Sheet

Appendix C Focus Group Invitation example

Appendix D Survey Invite

Appendix E Survey Action Research Questions Cycle 1 (Online)

Appendix F Power Point Presentation Action Research Cycle 2 (Focus Group Session)

Appendix G Power Point Presentation Action Research Cycle 3 (Focus Group Session)

# **List of Figures**

Figure #1: Atlantic Canada – Geographical Location of Research Participants Figure #2: WHO Categorization of Factors relating to Medication Adherence Figure #3: Rich Picture Experience of the Author and Participants Figure #4: Action Research Process as a Conceptual Model Figure #5: Type of Retail Pharmacy Participants were employed Figure #6: Pharmacy of Participant's Employment location Figure #7: Urban or Rural Pharmacy Location Participant's Educational Level Figure #8: Figure #9: Participant's Age Figure #10: Participant's Gender Figure #11: Participant's Job Function Figure #12: Years Participants have been in Job Function Figure #13: Participant Hours spent with Patients per Week Figure #14: Number Patients Participants see per Day Figure #15: Rankings of Importance, Socioeconomic Factors Figure #16: Rankings of Importance, Healthcare system Factors Figure #17: Rankings of Importance, Disease Related Factors Figure #18: Rankings of Importance, Therapy Related Factors

Figure #19: Rankings of Importance, Patient Related Factors

Figure #20: Rankings of Importance, Collective WHO Related Factors

Figure #21: Rankings of Importance, Technological Interventions

Figure #22: Rankings of Greatest Potential, Technological Interventions

Figure #23: Rankings of Greatest Potential Uptake, Technological Interventions

Figure #24: Rankings of Importance, Financial Interventions

Figure #25: Rankings of Greatest Potential Uptake, Financial Interventions

Figure #26: Interest in Participation in future Focus Groups

Figure #27: Designs for Mixed Methods Synthesis Studies

# **List of Tables**

Table #1: Literature Review

Table #2: Prominent Research Examples

Table #3: Demographic Profiles of the Participants

Table #4: Overall Findings, Mixed Methods Matrix

# Glossary

# Abbreviations and Acronyms

AR Action Research

EM Electronic Monitors

MPR Medication Possession Ratio

OOP Out of Pocket (costs)

PAP Pharmacy Assistance Program

WHO World Health Organization

#### Terms and Definitions

Biosimilars: a biologic medication that is 'similar' in chemical makeup to that of an original brand medication. Sometimes known as a subsequent entry biologic.

Brand Name Medication: a medication that has legal patent protection in a given geographical jurisdiction. The medication would have been discovered, clinically developed, and provided to the marketplace as a single source without risk of competitors copying, manufacturing, and marketing the same chemical. Manufacturers who wish to copy brand name medications for commercial purpose are known as generics. In Canada, generics are not legally allowed to be manufactured and sold legally within a geographical jurisdiction if a medication is within the limits of their patent protection.

Copay: "a fixed cost that a beneficiary may be required to pay per prescription (e.g., \$3.00 per prescription), or a system in which a beneficiary pays a percentage of the cost required to fill a prescription (e.g., 20 percent per prescription)" (Sutherland, Greg, and Thy, 2017). Both take place after deductible limits assigned to an individual drug or a benefit plan have been reached. Many Canadian drug or benefit plans, either public or private, require a co-pay amount by the patient. Copay requirements vary widely depending on the plan itself.

Chronic Diseases: "Diseases which have one or more of the following characteristics: they are permanent, leave a residual disability, are caused by nonreversible pathological alteration, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision, observation or care" (Dictionary of health services management, 2<sup>nd</sup> ed., 1982).

Drug Navigation: A subset of health navigation, drug navigation provides methods of assisting the patient in accessing medication (drug) relating to the overall health care they require. In general, the approach utilizes services or individuals that understand and work with each patient uniquely given the patient's own circumstances including factors such as the personal health coverage, income level, or geographical location. This service often includes the service provider

directly reaching out to external resources to 'navigate' through processes, exception guidelines, and perceived barriers to accessing medication. Overall, the objective of the navigation service is to assess the patient medication requirements provided by the healthcare provider, determine the resources that are already provided by the individual's drug or benefit plans, and engage external offerings as to fill in the gaps of care. Drug navigation is meant to seek out optimal medication coverage relative to the individual's personal circumstances regardless of one's broader status within the healthcare system.

Drug or Benefit Plan: Publicly (funded by the tax base) offered within Canada by the provincial or territorial Public Drug Benefit Programs. Each provincial and territorial government offers a drug benefit plan for eligible groups (Health Canada, 2017). Private plans are paid for by the individual either through their employer as part of an overall compensation package or by the person themselves. Individuals may have both a Public and Private plan.

Electronic Payment Cards: In the context of this AR, a payment system provided by the pharmaceutical industry for financial assistance toward the purchase of medications by the patient. The payment system would issue a payment to the processor and dispenser of the medication, the retail pharmacy. The electronic payment card is processed or adjudicated using pharmacy software systems. In general, the financial assistance provided by this means is intended to assist in the partial or whole payment provision of a patient's medical prescription, similar to an individual's public or private drug plan card.

Equivalence: Generic, multiple manufacturers of the same medication. Medication may be considered equivalent and not identical.

Exception Request: Funding request as an exception within a drug or benefit plan for a medication which is not listed as a predetermined benefit on the plan.

Generic Medication: a medication manufactured within a predetermined set of standards and assumed to be the same as a brand name medication as it relates to quality, dosage, safety, and

administration. In Canada, generic medications of the same chemical are approved under bioequivalence parameters and a considered interchangeable with the brand medication.

Healthcare Professional (HCP): known as one who is able to provide professional healthcare services or care for the patient, individually or as part of an integrated team. Within this action research, the healthcare professional was specific to the trained pharmacist working directly within the retail pharmacy setting.

HIV: Acquired Immunodeficiency Syndrome (AIDS) caused by the Human Immunodeficiency Virus (HIV).

IVR: Voice response technology

Me Toos: medications that are marketed and meant to emulate another medication of similar attributes which has already been deemed to have shown success.

Medication Adherence: "refers to whether patients take their medications as prescribed" (Ho et al, 2009). This would include taking the medications as instructed, including, for example, the number of times required daily or continuation over time.

Medication Compliance: "defined as the degree or extent to which a patient follows or completes a prescribed, diagnostic, treatment, or preventive procedure" (Capgemini Consulting, 2011). This perspective is from the health care provider as if the patient chooses to comply to the instructions. Generally, the terminology is used interchangeably with medication adherence.

Medication Review: One-on-one consultation with patients that elicits essential information for a medication assessment. During this time, which is generally separately assigned outside of the initial prescription dispensation, pharmacists and patients are able to reflect on a systematic approach for identifying medication and therapy problems while determining components of an adequate care plan and follow-up steps. Pharmacists provide a comprehensive assessment of a patient's medications and inform them on their appropriate use, safety and effectiveness. In

Canada, sessions generally last approximately 20 – 30 minutes whereby a patient goes through the two-way communication process and is provided a formal written document at the end, which they may use to provide to other healthcare professionals in their respective scope of care. Essentially, this acts as a personal medication summary and is intended to assist in providing better health outcomes due to the patient's engagement and understanding of how to properly take their medications, both prescription and non-prescription. The review also helps prevent medication wastage and misuse. Most provinces in Canada reimburse pharmacies for the services provided during a medication review (Canadian Pharmacist Association, 2018).

Pharmacists in different provinces across Canada are reimbursed for a medication review, medication assessment and care plan professional services. The Canadian Pharmacist Association (2018) notes that these services provide:

Essential information to elicit for a Medication Assessment.

Reflect on a systematic approach for identifying drug-therapy problems.

Identify and describe components of an adequate care plan and follow up.

Often, develop a written care plan for a patient scenario including solutions, suggestions, monitoring, and follow up.

Use criteria to self-assess the completeness and effectiveness of a care plan.

Reflect on how a patient care plan can be implemented in the community pharmacy practice setting.

Reflect on elements of successful communication and collaboration with other health care professionals as it pertains to Medication Review/Medication Assessment.

Utilize criteria to self-assess the effectiveness of a documentation note.

Payer of Last Resort: Within the context of processing of a prescription claim, the payer of last resort is sequenced last while seeking funding or payment from drug or benefit plans.

Payers: Public or private insurance plans which, on behalf of patients, pay for services such as medical treatments, prescriptions, etc. In the public context, within Canada, these are generally funded by the tax payer base at the federal level but administered at the provincial level. From a

private perspective, these are generally funded by employers as part of an employee's overall compensation plan or paid for directly by the individual.

Prescription: a written instruction provided by a medical professional, generally a prescribing physician, that authorizes the provider of medications, the dispensing pharmacist, to issue medications or treatment to an individual patient. In Canada, prescriptions are regulated by independent pharmacy regulatory bodies at both the national and provincial level.

Primary and Secondary payer: Within the context of processing of a prescription claim, the payer whom is sequenced first during the funding or payment is considered primary. Thereafter, the payer sequenced second is considered secondary, and so on.

Specialty Medications: a relatively new concept within the delivery of medications relating to high cost, frequent touch points, and complex disease management. Examples of diseases requiring specialty medications include cancer, rheumatoid arthritis, HIV, and multiple sclerosis.

Survey Monkey: software designed specifically for the facilitation of online surveys.

## 1.0 Introduction

This thesis engaged retail pharmacist to critically assess medication adherence as it directly relates to the interactions with patients on the front lines of healthcare. These interactions form the locus of action throughout this study. The aim was to develop a set of recommendations that may help improve medication adherence success rates and enhance the lives of patients.

My personal background includes 30 years in the pharmaceutical industry known to invent and manufacture medications. This background has availed exposure to the retail pharmacy professionals who are responsible for dispensation of the medications as part of the supply chain. Approximately 18 years ago, I was a co-founder of a Canadian organization known by retail pharmacists to have invented innovative processes to assist patients in accessing brand name medications in circumstances where they may not otherwise have been able to afford it. Although sitting as an outsider and free of commitment to the participant group, within the research I was not seen as a stranger. As such, I was quickly able to garner trust, credibility, acceptance, and cooperation. I was seen as a facilitator in pursuit of the research goals and as a competent, objective observer.

To commence with the research, it was important to establish a high-quality search methodology as to fully understand what medication adherence is by definition, prevalence, and how it is viewed or classified by those that have already spent so much time and effort attempting to understand it. In other words, what was the current state of knowledge in the field? The sensitivity to the answer of this question led to a critical view of the solutions currently provided. Not so much as lack of solutions, but rather the organization, formal coordination, and use of already existing knowledge. Furthermore, the search provided a view of the gaps and inadequacies thus setting the stage for potential actionable knowledge. The following introductory chapter attempts to shed light on how I approached these questions and ultimately, with the input of the participants, developed recommendations for the future.

#### 1.1 Background

Consistencies throughout this research suggest the importance of taking a multifactorial approach to improving medication adherence. Evidently, this was a complicated subject. Thus, I theorized that the complexities may likely be the root cause of stagnant medication adherence rates over recent decades. The current knowledge and paradigms of the participants required a baseline assessment. Thereafter, inquiry through discussions surrounding the everyday practical setting articulated themes leading to actionable solutions.

It is important to note that terminology used to describe medication adherence can vary depending on the communication. For example, the words 'compliance' or 'adherence', when referring to actions required to complete or act upon medication instructions, are generally known to be interchangeable. In the healthcare environment, when patients do not take their medications as required, it is an occurrence formally known as 'medication nonadherence' and the challenges are justified given the fact that the patient, being human, is solely responsible for the decision to adhere to the instructions given.

The term 'medication adherence' may be an unfamiliar topic to the general public. Arguably, the terminology used to introduce this concept would confuse most. Hence, society's lack of awareness of the enormous impact nonadherence has on the population as a whole. From a healthcare worker's perspective, specifically that of a retail pharmacist working in the practical setting, a greater understanding exists regarding both the individual and societal implications of medication nonadherence. Retail pharmacists may be the first to agree that, even though advancements have been proposed, there has been little impact on how adherence rates affect patients.

Nonadherence by patients to prescription medication regimens required as part of a treatment plan put forth by healthcare professionals is quite common, can be a complicated, and potentially an expensive societal issue (Dayer et al, 2013). Logically, it has a negative impact on treatment outcomes for the patient and consumes financial and non-financial resources, both directly and indirectly. Furthermore, accurate measurement of nonadherence and its impact is difficult.

Interventions and numerous ideas to improve upon troublesome medication adherence rates across chronic diseases have not been successful (Dayer et al., 2013).

Could times be changing? Arguably, technological advances, especially in the last couple of decades, provide opportunities for improvements. From this perspective, one can ask, "Does the intervention of technology or financial assistance provided to patients by the pharmaceutical industry have an impact on medication adherence?" Furthermore, what affect do these interventions have on adherence rates within diseases requiring specialty medications?

Fundamentally, what is medication adherence? Ho et al (2009) highlights that the term relates to how patients take their medications according to the instructions given by the healthcare provider. Or similarly, as Urquhart (1996) claims, how one's drug administration corelates to the recommended regimen. Cramer et al (2008) refers to the International Society for Pharmacoeconomics and Outcome Research and defines medication adherence as the level of which the patient acts in accordance to what the healthcare professional has set as the prescription interval, dose level and regimen.

The WHO emphasizes the importance of taking into consideration aspects not only related to medications, but also non-pharmaceutical variables such as health related actions (Sabate, 2003). Other contributing factors to an individual's health such as lifestyle, age, and taking an active role in one's health are important. Literature has demonstrated the importance of the relationship between the healthcare provider and the patient as being a critical factor of adherence (Sabate, 2003). This includes the initiation of effective treatment regimens, discussion, and planned follow-up. Numerous researchers have eloquently provided layman's wording on the meaning of medication adherence in an attempt to help all of society better understand and internalize its broader importance.

This research attempted to garner the status of current opinions relating to the five WHO categorizations of contributing factors to nonadherence while expanding upon the concepts of technology and pharmaceutical industry initiated financial assistance.

#### 1.2 Research Aims

- Seek to engage, inquire, and navigate relations (Ramsey, 2014) of the perceived barriers to
  medication adherence given the advancements of various forms of modern technology and
  financial assistance provided by the pharmaceutical industry.
- Pursue AR with retail pharmacists in order to determine the potential impact of each of these
  perspectives in the workplace. These may be considered nontraditional pathways to improve
  medication adherence in diseases requiring specialty medications.
- Acquire new levels of deliberate attention (Ramsey, 2014) from key informants; namely the retail pharmacist, a frontline healthcare practitioner, to improve medication adherence rates by consideration and development of a set of smart recommendations. The approach focuses on the input and opinion of participants within a defined geographical area, Atlantic Canada (*Figure #1*).



Figure #1: Atlantic Canada - Geographical location of Research Participants

#### 1.3 Research Question

Does the intervention of technology and financial assistance provided by the pharmaceutical industry to patients have an impact on medication adherence within diseases requiring specialty medications? If so, what are some smart recommendations that may be realistically implemented within the practical setting of the retail pharmacy?

#### 1.4 Rationale

The WHO reports rates of medication nonadherence for chronic conditions in developed countries at approximately 50% (Sabate, 2003). This has not improved over decades. Furthermore, according to the WHO, chronic disease prevalence is expected to rise to 57% of the world's population by 2020. For patients in Canada with chronic diseases, 90% will be utilizing one or more prescribed medicines (Mo et al, 2011 and Rotermann et al, 2014). These rates of nonadherence are deemed significant, given the pressures for advancements in research and the invention of new medications, considering that once those medications are available to the patient they are not taken properly about half the time.

The severity of the problem is enormous. In Canada, 5% of hospital admissions and 5% of physician visits were shown to be directly related to medication nonadherence (Sun Life, 2014). In 2019, Express Scripts Canada, utilizing prescription drug trending data ending 2018, reported quantitative statistics of medication nonadherence rates to at least one treatment of 44%, 58%, and 77% for patients (claimants) prescribed one, two or three, and more than four combined medications respectively. This data was measured across all diseases and is consistent with overall 50% nonadherence rates on average globally.

Critical judgement in a review of the five WHO categorized factors reveals that several gaps exist. The overall lack of improvements in medication adherence rates, along with the enormous modern-day societal reliance on electronic technology and pharmaceutical industry financial incentives to accept the use of newer medications, have opened up the possibility of finding solutions to improve upon previous shortcomings. Although the concepts of technology and

financial assistance provided by the pharmaceutical industry may be argued to fall into one of the formal WHO categories, these warrant further research and investigation given the rapid advancements of both in recent decades.

Although extensively researched, the aspect of medication adherence improvements has been challenging. Lack of adherence at approximately 50% (Sabate, 2003) is staggering given the current reliance on, and general acceptance of, medications to treat diseases and the constant pressure on providers (including the manufacturers and payers) to lower prices globally. Even with significant medication advancements for many serious diseases, significant nonadherence exists.

Understanding the concept of the 'human actor' is essential to evoking change, as not only is the patient human, so too are the providers of healthcare embedded in the Canadian system. This 'human' aspect brings potential variations of what can be deemed optimal care, as the interpretations of a single one-on-one engagement or communication regarding medications can be wide ranging. For example, patients are only able to recall about half of any given medical encounter (Schillinger et al, 2003). Given this single fact, one can easily understand the stagnant progress regarding medication adherence over time. Ultimately, a deeper understanding of the wide-ranging types of patients may uncover clues toward finding potential multifactorial approaches to tackling the problem of medication nonadherence.

## 1.5 History of Nonadherence and Recognition

The problem of medication nonadherence reaches a broad group of stakeholders including the patient, healthcare providers, and those that fund the medications. Arguably, it may be the largest healthcare problem in the world today, much of which is unavoidable. The WHO notes that improvements to medication adherence rates may have a larger effect on the overall health of patients than advancements of medications themselves (Brown & Bussell, 2011). Arguably, this holds validity as it highlights the reality that, at this point in time, although we have many great treatments available for the advancement of patient health, about half the time, patients simply don't use them properly.

For all the Canadian stakeholders that medication nonadherence affects, it is the 'patient' that is nestled within the core of any negative repercussions inclusive of increased morbidity and mortality. Common direct impact manifests itself in poorer health outcomes and lessened well-being such as faster disease progression and temporary disability. Indirect impact includes work related absenteeism and increased individual and societal costs (Sun Life, 2014).

The concept of medication adherence has been recognized for centuries. Sackett (1979) notes that even Hippocrates knew that patients often pretended to take their medicines. In more recent times, Dunbar-Jacob et al (1991) draw attention to medication adherence in the 1950s, highlighting a poor understanding and few improvements as recent as the 1970s and 80s. Certainly, advancements of new medications in the last century have brought huge attention to the importance of not only the invention, but also the necessity to use such inventions properly in order to achieve optimal outcomes.

Capgemini Consulting (2011) note the ever-growing importance of medication adherence in citing the WHO, the US National Institutes of Health, and the National Council on Patient Information and Education; each taking the position that poor adherence is a major public health issue and becoming more severe at a huge cost to the healthcare system.

From an epidemiological perspective, adherence rates remain consistent across chronic conditions irrespective of disease, complexity, or measurement (Iihara et al, 2004). Measurement continues to have its limitations in that most methods are proxy measures (Garfield et al, 2011) and include patient self-report, counting pills or refill rates, or biological or electronic monitoring. All of these measurement tactics have some form of flaw. Self-reporting relies heavily on memory and any of the possible inaccuracies that are associated with it, regardless of the disease or demographic (Weingart et al, 2008). The counting of pills by a patient's healthcare professional is also reliant on the patient and is subject to potential inaccuracies due to the risk of unreported actions such as destruction and/or dumping of pills or pill containers before counting (Osterberg et al, 2005). Biological monitoring seems impractical and requires specific timing and dose administration verification if it is to be relied upon (Dayer et al, 2013). With the exception

of microchips embedded directly within the medication, which is a relatively new technology, the various forms of electronic monitoring associated with packaging still have an inability to accurately determine if a patient has taken a pill, as they too rely on self-report or simply knowing if the pill bottle was opened.

The reasons for medication nonadherence are varied and extremely broad. In their basic form, researchers classify them as either intentional or unintentional (Dayer et al, 2013). In other words, did the patient consciously know that their actions led to nonadherence, or were they unaware of that as an outcome? Unfortunately, this broad or unspecific denotation of nonadherence may oversimplify the in-depth complexity of the concept (Garfield et al, 2011). Behavioral models of medication adherence largely focus on social cognition principles and rely upon individual beliefs and experiences influencing their behaviors (Dayer et al, 2013).

Numerous solutions have been put forth over decades highlighting the concept of multifactorial approaches. These include how to remind, counsel, and educate the patient, as well as, reinforce positive and negative actions and simplify the issue (Dayer et al, 2013). Often, many of these methodological approaches are pursued in combination with one another. There are numerous forms of improvement methods that are considered to be traditional approaches, including medication reminder systems such as containers that demonstrate the weekday and time of the action required, unit dose packaging, or packaged calendars. All of these systems are intended to be used by those whom unintentionally forget to take their medications. More modern approaches include technology such as the traditional landline telephone, pager, cell phone, or audiovisual devices (Dayer et al, 2013). Behavioral interventions such as counselling exist and take the form of patient education aimed to stimulate a patient's active participation.

Unfortunately, many gaps remain in terms of successful, long-standing, positive results.

#### 1.6 Significance of the Problem

Medication nonadherence rates are consistently at 50 percent regardless of numerous factors including the disease or patient (Iihara, et al, 2004). Even with these facts and retrospective views, rates remain constant. Globally, the problem is significant. The problem of medication

nonadherence has both direct and indirect implications which span across healthcare in relation to patients, healthcare providers (HCPs), and funders of medications such as private and public insurance payers (Brown & Bussell, 2011). The negative outcomes can be significant and impactful from both human and societal perspectives. It affects not only patients, but also those providers who may be either clinically or commercially focused. For patients, medication nonadherence leads to increased morbidity and mortality and manifests itself in higher rates of hospitalization and poorer health outcomes. Kleinsinger (2018) highlighted estimates of approximately 125,000 avoidable worldwide deaths annually directly linked to the problem.

For HCPs, including retail pharmacists on whom this research was the focus, the patient's misunderstanding of their medications and disease leads to increased burden on the system due to medication errors, additional hospital visits, and compromised patient health. For society as a whole, and those that pay for medications either through private employer plans or public funding, the financial burden is enormous. In the United States alone, medication nonadherence has been deemed the number one most avoidable cost (Clifton et al, 2018) at a direct impact of US\$105 billion annually (QuintilesIMS, 2016). Furthermore, overall

## 1.7 Research Gaps and Opportunities for Improvement

This action research was intended to encourage retail pharmacists to think critically about medication adherence and put forth practical recommendations to improve upon poor adherence rates. The large amount of previous scientific work noted throughout the literature search was not only largely empirical research, but revealed limited meaningful improvements in any of the five noted categories of medication adherence put forth by the WHO. Although numerous improvement methods have been studied and continue to be researched in an attempt to shed light on the patient journey, this research is distinct in that it takes an immersive approach to activities with practicing retail pharmacists in order to pursue engagement, inquiry, and navigation of relations (Ramsey, 2014). They are the point of direct contact with patients.

The emphasis is on 'action research'. Arguably, other than the patients themselves, retail pharmacists are at the closest 'touch point' in understanding the human concept related to the

consumption of medications. The research is seeking to find what are the important factors that drive medication adherence while encouraging discussions over and above the research participation to that of an everyday practical setting. It sought to elevate the cycling discussions to a generative level whereby the focus was meant to push the effort put forth by expert practitioners attempting to clearly explain what may not always be explicit or transferable given the human context. With this insight, and through the use of action cycling, it intended to articulate themes and put forth actionable recommendations given the continuous development over the last decade of various forms of technology to compliment disease treatments.

The research shows that advancements in medication adherence on a global scale appear to have stalled. Data published by the WHO suggest that medication adherence is a complex problem with outcomes influenced by the patient, as well as, health systems. Understanding the issues from a retail pharmacist's perspective during the AR cycles provided insight into opportunities to improve medication adherence through various technologies and pharmaceutical industry-supported financial assistance.

Research into the use of technology within medication adherence has been increasing in recent years as the problem evolves. Opportunities continue to arise and exist in furthering our abilities to understand the epidemiology of nonadherence, measure rates, categorization, denotation of any associated behavioral models, and identification of methods leading to improvement (Dayer et al, 2013). Past research suggests that the most favorable means to improving adherence may require a combination of technologies, albeit more complex for the patient, and multiple or multimodal strategies if adherence is going to be sustained (Haynes et al, 2008). Furthermore, it can be argued that a multifactorial approach tailoring communication to the individual, based on an analysis of their past adherence behaviors regardless of the technological combination, is the more likely pathway forward (Haynes et al, 2008).

Although further AR is suggested, including a variety of healthcare professions addressing different vantage points and perspectives, acceptance and use of the recommendations put forth by retail pharmacist in Atlantic Canada may provide some insight into new opportunities and help improve upon health outcomes. Even the smallest steps forward may be beneficial, given

that researchers suggest positive improvements may have a large effect on healthcare (Brown and Bussell, 2011).

#### 1.8 Thesis Overview

Medication nonadherence is prevalent, complicated, and costly. This action research was pursued in order to engage retail pharmacists to critically assess the problem with mindfulness and purpose in order to potentially arrive at practical solutions.

Previous research over decades noted throughout the literature availed limited improvements, especially in terms of improvement rates. This included over 200 subset variables (Vermeire et al, 2001) within these categories that have been isolated as contributing factors. Still, and although medication adherence has been well researched, gaps exist. Given advancements in technology and industry's financial assistance tactics, especially in the retail pharmacy setting, is it possible that, finally, these pathways may open up solutions to help improve upon nonadherence rates? This thesis attempts to partially fill that void.

In order to assess this question, this research pursued a mixed methods methodological approach utilizing both an online survey and focus groups in a cycling sequence to combine constructionist and positivist epistemological perspectives. All four Atlantic pharmacy associations supported the issuance of the survey using their own databases which preceded the focus group sessions. Total survey participants came in at 115 and provided a convenience sample to commence the AR cycling with a total of 12 individuals within the focus groups.

The purpose and objective of this thesis set out to identify themes of importance that might lead to potential organizational solutions. In total, forty themes emerged garnering narrowed discussions which led to the ability to isolate seven convergent themes of priority importance. Surprisingly, throughout the process, several other themes were given high importance during the first research cycle but faded out of importance thereafter. The research cycling availed the ability to provide those themes that were most significant and meaningful to retail pharmacists in their day to day workplace.

The roadmap for this thesis commenced with outlining the current status of medication nonadherence including its history, known understanding, and significance to patients and healthcare providers (Chapter one). Modern day advances in any of the numerous previously researched variables put forth provided the ability to open up gaps in the current knowledge while at the same time opening up possible opportunities for improvement.

The extensive literature search provided the background knowledge and baseline as to guide the first cycle (Chapter two). Not only did it provide the current baseline of knowledge and scientific work previously done, it provided the direction to set up the cycle 1 survey. For the research participants, this was fundamentally critical as to align on the definition, prevalence, factors, impact on society, and potential gaps given each individual came from varying backgrounds.

Methodologically, a mixed methods approach fit well in terms of the AR cycling (Chapter three). The quantitative approach during cycle 1 was meant to set the stage appropriately by opening up the broad variety of pathways that that needed to be considered regarding the subject matter. Thereafter, cycling through the focus groups was meant to create avenues to engage the retail pharmacists directly on what really mattered in day to day practical environment, convergent themes if you will, as to put forth recommendations.

Sequencing of the action cycles thereafter provided the ability to establish the baseline opinions of the participants and discuss in detail the important themes (Chapter four). Over time, a set of seven themes dominated the discussions.

The evaluation of the data availed throughout the action cycling required an integrated design (Chapter five). This type of design availed a transformative thinking process to understand or relate the quantitative and qualitative data (Sandelowski et al, 2006). A mixed methods matrix was developed and critical to the overall sensemaking of the overall findings. The effort assisted in comparing what is often viewed as incomparable as to reveal root causes. These themes, or "chunks" (Henning, 2011, p.3) aligned within the categorizations previously noted. Thereafter,

this extensive analysis and assimilation opened up the pathway for conclusions and the set of recommendations for practical application (Chapter six).

As this research was limited to that of three action cycles, further research to continue to understand and validate the ongoing important themes is recommended as to create a 'continuous improvement protocol' that would modify and enhance recommendations over time.

# 2.0 Literature Review

## 2.1 Search Methodology

Key words used for the search strategy included *medication adherence*, *action research*, *chronic disease*, *technology*, *financial assistance*, *and pharmacy*.

The literature review commenced with random searches throughout the library and ultimately narrowed to two main databases in that of Pubmed and Google Scholar as these provided the most pertinent responses. Consideration was also necessary of other relevant publications that are often not available through library resources including reputable industry sources such as the Center for Disease Control or industry associations. Content was identified, evaluated, and determined if useful over the entire thesis period and added periodically. As medication adherence is a global issue, much of the literature content was outside of the Canadian environment, but still highly relevant.

To critically refine the analysis and arrive at a deeper level of discovery of the concepts and arguments which would eventually lead to a set of smart recommendations, it was important to focus on the subset constructs of medication adherence related technology and financial assistance. This narrowed the search significantly and aided in pursuing evidence-based material.

Hundreds of articles within the search results were systematically assessed as to ensure a complete, and in depth, coverage of the relevant material. The search databases availed many overlapping articles. Articles found not utilizing action research methodologies included a broad

range of quality resources, many of which were disease-specific or meta-analyses. Unfortunately, literature utilizing the critical search frame of action research AND medication adherence held significantly less results. Results showed a ten-fold higher quantity of non-action research versus that of action research articles. Furthermore, the criteria of sourcing articles by adding 'pharmacy', 'technology', or 'financial assistance' became even further limiting. This was not surprising and highlighted a gap in the use of action research in previous work within the subject area.

It was important to understand the context of duplicates within the literature search. Consensus has not been established on a simple method of how to identify duplicates as they are often variable across different databases and further improvement to methodologies in doing so is needed (Qi et al, 2013). As such, duplicates were manually pulled out throughout the screening phases.

Search Inclusion: Medications for Chronic Diseases

Academic Journal Articles: Both Independent and Meta-Analysis

Reputable Consulting Publications

Articles 2000 - 2019 with limited exceptions

Overall results of the literature review are seen in Table #1.

Table #1: Literature Review

			Literature	Search			
			Google Scholar	Pubmed	Other Reputable Articles	Studies included in this Review	
Identification	"Me	dication Adherence"	297,000	24,414			
		AND "Chronic Disease"	38,700	1,216			
		AND "Technology"	49,500	1,221			
Screenin	g	AND "Financial Assistance"	2,060	17			
		AND "Pharmacy"	53,200	4,103	1		
		AND "Action Research"	24,200	13			
Identification		Medication Adherence" <u>AND</u> "Action Research"	<u></u>	24,200	13		
		AND "Chronic Disease"	601	1	8	120	
Screenin	AND		807	1	8	138	
			60	0			
		AND "Pharmacy"	444	0			
Identification		dication Adherence"  AND Action Research"  AND "Pharmacy"	444	0			
		AND "Chronic Disease"	235	0			
Screenin	g	AND "Technology"	310	0			
		AND "Financial Assistance"	29	0			

## 2.2 Introduction

The concept of individuals not taking their medication as prescribed has arguably been around for as long as medicines have been available with a central component being the patient. Donovan & Blake (1992) argued that lack of progress regarding medication adherence could likely be attributed to the perspective of the patient. Unfortunately, nonadherence is a key reason for less than optimal clinical benefit (Rybacki, 2002). Vermeire et al (2001) concluded, during a comprehensive review of three decades of research on the subject matter that poor adherence is a major healthcare problem. Furthermore, the authors found that there was no measurement standardization (Vermeire et al, 2001). Krueger et al (2005), in yet another review, also reinforced the premise in that no standard criteria for measurement exists.

The theoretical framework of this research can be best described as 'transformational' (Clark & Wilson, 1991) in which the participants utilize their fundamental beliefs and understanding surrounding reasons for medication nonadherence, challenge norms or convictions on underlying themes, and transition to actionable recommendations that may be used in the practical setting. In this sense, the context was critical as the human actor, the patient, is unique and host varying backgrounds. As such, the theoretical frame entailed "critical reflection central to perspective transformation" (Clark & Wilson, 1991, p.75) which led to practical and actionable recommendations. The development of these potential solutions may arguably be 'relatively minor' when comparing to the broader context of the WHO five categorizations (Sabate, 2003) or even the 200 subset variables (Vermeire et al, 2001) that have been studied over the years. Nonetheless, as a scholarly practitioner, I suggest a similar argument in that the extensive knowledge (Ramsey, 2014) which already exists, and which we have been trained to rely upon, has provided little change or improvement in medication adherence rates over decades.

Furthermore, singular reliance or acceptance of such knowledge compromises progress. Gogovor et al (2019), for example, notes in a recent Canadian article that "non-adherence to prescribed therapies", in hope of a medication benefit plan funding all citizens, as a potential existential challenge. New perspectives and inquiry (Ramsey, 2014) are necessary to attempt to generate practical recommendations in the pursuit to achieve such important goals. The recommendations put forth as a result of the efforts by the participants, the retail pharmacists, are practical and actionable. Their discovery was a direct result of the three action cycles and emergent from the sequential, spontaneous, skeptical, and evaluative efforts (Ramsey, 2014) during each cycle.

#### 2.3 Definition

Ho et al (2009) describes medication adherence as whether patients comply to the medication instruction as prescribed. It is important to note that this reference, along with most others, take into consideration the use of medications only and excludes behaviors associated with other important factors that contribute to adherence and clinical outcomes such as diet, lifestyle, and non-medication related advice (Vermeire et al, 2001).

"In the 1970's, the term compliance came into use, and was defined as the degree or extent to which a patient follows or completes a prescribed, diagnostic, treatment, or preventive procedure" (Capgemini Consulting, 2011, p.4). Dunbar-Jacob et al (1991) note the term 'adherence' and 'compliance' may be regarded as interchangeable. Although this understanding had no effect on the research, it may be important to recognize in order to synthesize the various ways differing researchers address the concept. Further, medication adherence is often broken down into two concepts, adherence and persistence (Ho et al, 2009), whereby adherence refers to drug intensity and persistence refers to duration.

#### 2.4 Prevalence

The significance of medication nonadherence is far reaching; not only from the patient's clinical perspective but also economically, due to both direct and indirect costs. Challenges to adopt ways to promote adherence are faced by the healthcare providers in pursuit of the best outcomes (Spoelstra et al, 2014). The WHO advocates, for longer therapies, nonadherence is a world-wide problem (Ruppar et al, 2015) and further stated that it is a major public health issue due to half of patients being nonadherence.

Economically, the impact is difficult to determine although researchers agree upon significant direct and indirect financial costs, given that "medication nonadherence is considered responsible for 33 – 69% of medication-related hospital admissions, 23% of all nursing home admissions, increased use of expensive, specialized medical resources, unneeded medication changes, unexplained treatment failures, and repeat office visits" (Technologies for Optimizing Medication Use in Older Adults, 2011, p.13).

Gurwitz et al (2003) note that 90% of seniors use at least one prescription per week. Of this number, "a significant portion (12%) of patients will not take possession of dispensed medications" (Technologies for Optimizing Medication Use in Older Adults, 2011, p.13). For those that do fill their prescriptions, although it is difficult to generalize poor compliance rates, "30 – 50% of all patients, irrespective of disease, prognosis or setting" (Vermeire et al, 2001,

p.334) will non-comply with their medication regimen. This is also supported a WHO assessment noting, "approximately 50% of patients do not take their medications as prescribed" (Brown and Bussell, 2011, p.1). Ozok et al (2011) also found that rates among seniors for nonadherence were above 60% and likely lower due to the fact that their assessment was based on patients self-reporting, making it closely parallel to previous studies.

Overall, concerning the prevalence of medication nonadherence, research is consistent in that failure rates above 50% in any condition are common. Further compounding the problem, Ho et al (2009, p.3032) note, "because of the variety of data sources and adherence measures, it is often difficult to compare adherence rates across studies and conditions". Young (2008) also notes that medicines are often not used properly in terms of underuse, overuse, and misuse highlighting a multitude of issues given the consideration of the human factor associated with the subject matter.

#### 2.5 Categorizations, Macro and Micro Frames

Inherent in the WHO five formal categorizations as the root causes of medication nonadherence, inclusive of the health system, condition, patient, therapy, and socioeconomics (*Figure #2*), lies a numerous subset of factors that highlight the context of the larger problem, including an aging population, literacy levels, a patient's ability to pay for medicine, and the behavioral complexities of the patient, to name a few.

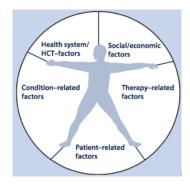


Figure #2: WHO Categorizations of Factors relating to Medication Adherence Adapted from Sabate (2003, p.27)

Within these five categorizations, a list of associated subsets of influential variables exists. Complicating the subject matter relative to these variables, and depending on the individual, medication adherence may be viewed as either unintentional or intentional (Stegemann et al, 2012), further clouding the path to any solution. Gurwitz et al (2003), for example, emphasize that medication nonadherence will likely grow due to an aging population who tend to take more medications over time. Furthermore, significant literature exists in associating the ability to pay for medications with rates of adherence as noted by Cutler and Everett (2010, p.1553) in that paying "out of pocket for medication clearly affects adherence; people use more drugs when the prices of the drugs are lower." The patient variables are numerous.

The rich picture (Figure #3) outlines the overall action research scope. In other words, the macro frame. Within this broader perspective, there are several micro considerations for the reader. Furthermore, each micro consideration is arguably, in its own right, quite complex, even for the professionals that operate directly within those environments. Within this research, at a minimum, the reader has to blend an understanding of at least six overlapping micro frames including:

- 1. Underlying concepts within medication adherence,
- 2. Chronic diseases,
- 3. the professional structure and stakeholder process of which the participant (retail pharmacist) operates within,
- 4. the action research process,
- 5. the context of the author's role within the research, and
- 6. the 'Locus of Action' in which the focus of the attention lies in order to potentially avail novel and workable solutions.

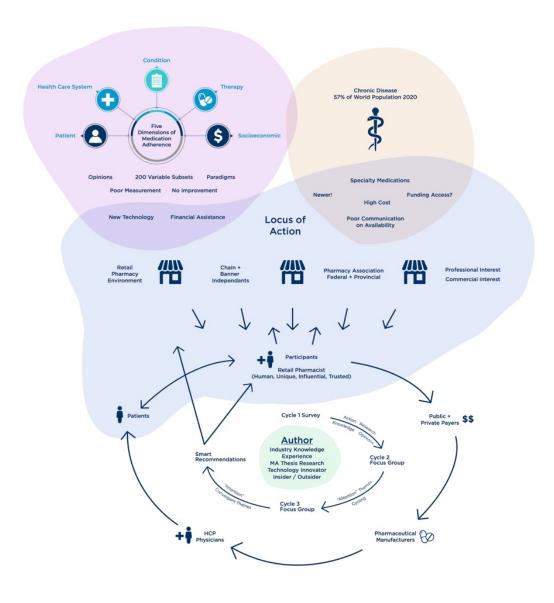


Figure # 3 Rich Picture Experience of the Author and Participants

The concepts within medication adherence are broad ranging. For the research, not only was the five WHO categorizations considered, but two other topics added that would normally be known as subsets within those categorizations. Within in this realm, although over 200 variables have been studied over the years, little has changed in terms of medication adherence improvement rates. Furthermore, measurement of such rates is varied, limited, and entails many gaps in quality. This has led to a broad range of a fairly rigid set of opinions and paradigms by stakeholders within healthcare.

Theoretically, medication adherence encompasses all diseases that require a medication prescription. Diseases may be further defined into those that are short term or acute, or those that are life-long or chronic. Notably, chronic diseases take up the vast majority of prescription volume globally. Furthermore, the WHO report that chronic diseases are prevalent within 57% of the world's population in 2020. Fortunately, the progress and evolution of medication treatment of many of these chronic diseases continues to improve by the advancements of specialty medications. These medications are known to be more complex, require higher levels of maintenance and patient touch points, and are increasingly more expensive.

Retail pharmacists are only one of several stakeholders in the healthcare structure and process that a patient enters when they require treatment that potentially leads to a medication prescription. Direct interaction with physicians and pharmacists is the known practical aspects of the engagement, but other stakeholders are involved including the innovators and manufacturers of medications along with those that may fund those medications such as private or public payers. Collectively, all stakeholders are integrated within the day to day process.

The research process, upon which this thesis is guided, is one of 'action'. Participants entered the process by way of a survey in order to determine a set of opinions and beliefs, 'knowledge' if you will. This garnered a convenience sample. This foundation set the stage for the subsequent cycles that moved from a foundational knowledge focus to that of 'attention' whereby, through the use of focus groups, the participants could engage ideas, inquire, and navigate relations (Ramsey, 2014).

As the author, I found myself in dual roles of an insider and an outsider. Although I had extensive industry knowledge and experience, while being known as an innovator for the pharmaceutical and pharmacy industries, it came with limitations. My role as an outsider in spearheading the project was limited to research design, methodology, setup of the action cycles, facilitation, and data collection. My direct opinions and input within the subject matter conversations where avoided and focused on an understanding of the data collection as to interpret the findings.

Within this thesis, at the heart of the locus of action, is the retail pharmacist. Their practical work setting is nestled within a micro frame that overlaps the others. For these professionals, they are employed by pharmacy organizations with both professional and commercial interests, while at the same time associated with pharmacy associations that have prioritized their individual interests as the core mandate. However, it is the direct contact with the patient that triggers that ability to potentially garner insight as to the important underlying factors that contribute to medication nonadherence. It is within that immediate human interaction that this trusted, influential stakeholder within the process is able to center on "deliberative attention rather than knowledge" (Ramsey, 2014, p.6). It was this form of scholarly research that has provided the setting to step aside of the day to day tasks, pose the questions, and create the conversations that enabled the epistemological practice for interactive and generative perspectives. This led to the smart recommendations.

### 2.6 Human and Societal Impact

Capgemini Consulting (2011, p.8) note the ever-growing importance of medication adherence, in referencing the World Health Organization, the US National Institutes of Health, and the National Council on Patient Information and Education, each of which took positions stating that poor adherence is a "significant public health issue" and becoming more severe at a huge cost to the healthcare system. Overall improvements in medication adherence may have a larger effect on healthcare than the advances of medications themselves (Brown and Bussell, 2011).

In a more recent comprehensive review Cutler, Fernandez-Llimos, Frommer, et al (2018) analyzed 79 studies adapting a formalized methodology, the Drummond checklist, across 14 diseases to provide an economic evaluation of the extent of the problem. There findings note the costs relating to "all causes" (Cutler, Fernandez-Llimos, Frommer, et al, 2018, p.1) of medication nonadherence had a range of \$5,271 - \$52,341 depending on the disease. And because approximately half of all adults globally have some form of a chronic condition (Center for Disease Control and Prevention, 2016), the societal costs are enormous citing annual amounts in the United States alone at US\$100 - US\$290 billion (New England Healthcare Institute, 2009).

Krueger et al (2005) along with Osterberg and Blaschke (2005) represent the majority of literature supporting the notion that medication nonadherence increases the chances of morbidity, mortality, and costs. Gurwitz et al (2003) emphasize that nonadherence will likely grow due to an aging population who tend to take more medications over time. Unfortunately, the use of interventions to help improve adherence are "rare in routine clinical practice" (Ho et al, 2009, p.3028). Given that the population's demographic is aging, the issue of medication nonadherence may become a greater problem due to a correlation between chronic disease and older human subjects. Kung et al (2008) report that 70% of deaths in the USA involve chronic conditions and highlight that over 25% of the same population manage multiple diseases.

Health outcomes and economic risks are high in that low adherence rates are a concern which undermines much of the benefit of medications that are readily available (Vermeire et al, 2001). Urquhart (1996) further notes that compliance provides a connection between process and outcome during care. Krueger et al (2005, p.320) note, "improving adherence can result in decreased consumption of medical resources" while referencing significant research in numerous diseases, and argue "it is clear that increasing adherence to medication regimens can improve clinical and economic outcomes for patients on long-term therapy."

Anticipated higher medication costs in future years suggest the need for improved levels of adherence in order to show a positive risk benefit and to lessen the financial impact. Economically, the impact to society can be considered significant. Although an agreed upon financial amount in the research has not been determined, all researchers conclude upon significant amounts. Osterberg & Blaschke (2005) estimated the societal economic impact to be \$100 billion annually. Other authors such as Donovan & Blake (1992) argue that the financial impact may be even higher and that this burdensome sum of \$100 billion is estimated to be imposed in the USA alone.

Rapoff (2010) quantified the cost of less than optimum adherence rates associated with increases of \$2 - 8000 per patient. DiMatteo (2004) notes increased odds of 2.9 times for quality outcomes for adherent patients versus those that are not.

#### 2.7 Factors that affect medication adherence

Significant amounts of literature exist relating to medication adherence and its broad range of underlying factors. Unfortunately, the perspective of action research on the subject matter was found to be less available and historically driven by academic interests utilizing non-action research approaches or commercial organizations who put forth reputable publications. The lack of volume within the subject matter area utilizing action research resulted in limited literature surrounding the locus of action. Specifically, that of action research of medication adherence with retail pharmacists relating to technology and financial assistance. The results sourced were limited to narrowed pathways relating to various cultures, minorities, patient variations, and much smaller study sizes. This limitation of articles found relating to action research created significant gaps in the understanding of medication adherence in the practical sense and opens up opportunities for future action research in the area.

There are many avenues of action research to pursue as the subsets of medication adherence variables are extensive, and arguably as complex as the human actor themselves. Consistent with the WHO's categorizations, many researchers assimilate the thinking to that of logical factors such as age, gender, race, language, residence proximity to one's healthcare provider, and disease (Roberts et al, 2014). The list of factors goes on and on hence, the rationale for past traditional research recommending a broad range of multifactorial approaches.

Table #2: Prominent Research examples:

Critical factors of Medication Adherence		
Factor	Research	Notes
Broad Categories	Sabate E (2003) Adherence to Long-Term Therapies: Evidence for Action. Geneva, Switzerland: World Health Organization. Citations: 3317  Ho et al (2009) Medication Adherence: It's Importance in Cardiovascular Outcomes. American Heart Association, Key Issues in Outcomes Research, P. 3028 – 3035. Citations: 1420	Although this article is dated, it is significantly referenced by other prominent researchers since publication. Report on measurement methods, prevalence, outcomes, reasons, and interventions.
Patient, Therapy, & Disease	Zullig et al (2014) A health literacy pilot intervention to improve medication adherence using Meducation technology, <i>Patient Education and Counseling</i> , 95, P. 288 – 291. Citations: 37  Calvert et al (2012). Patient-focused intervention to	Literacy and education approach.  Added counseling, attention,
	improve long-term adherence to evidence-based medications: A randomized trial, Outcomes, Health Policy, and Managed Care, <i>American Heart Journal</i> , Volume 163, Number 4, P. 657 – 665. Citations: 73	communication, ongoing assessment.
	Cutler et al (2018) Economic impact of medication non-adherence by disease groups: a systematic review. BMJ Open 2018: 8: e016982. Citations: 136	Assessment across several diseases.
Health System	Law et al (2018) The consequences of patient charges for prescription drugs in Canada: a cross-sectional survey. CMAJ Citations: 27	Canadian. Cost related nonadherence. Skip or delay prescription fills
	Gogovor et al (2019) Non-Adherence to Prescribed Therapies: Pharmacare's Existential Challenge. Special Focus on Healthcare in Canada. Healthcare Quarterly, Vol.22, No.2, P. 21 – 26. Citations: 1	Canadian. Evidence based Outcomes
Technology	Dayer et al (2013) Smartphone medication adherence apps: Potential benefits to patients and providers. Journal American Pharmacy Association, Vol. 53(2), PP 172 – 181. Citations: 391	Assessment and ranking of 160 adherence applications
	Granger & Hayden (2011) Medication Adherence: Emerging Use of Technology, <i>Current Opinion</i> <i>Cardiology</i> , 26(4), P. 279 -287. Citations: 128	Patients at risk, emerging technologies
	Linn et al (2013) 1 + 1 = 3? The systematic development of a theoretical and evidence-based tailored multimedia intervention to improve medication adherence, <i>Patient Education and Counseling</i> , 93, P. 381 – 338. Citations: 23	Technology: assessment, interpersonal, tailored
Financial Assistance	Roberts et al (2014) Patterns of Medication Adherence and Health Care Utilization Among Patients with Chronic Disease Who Were Enrolled in a Pharmacy Assistance Program. NCMJ, Vol. 75, No. 5, P. 310 - 318. Citations: 26	Approx. 50% of PAP participants nonadherent
	Zhu et al (2018) A Descriptive Study of Patients Receiving Foundational Financial Assistance Through	Copays, specialty medications

	Local Specialty Pharmacies, <i>The American Journal of Managed Care</i> , Vol. 24, No. 5, PP. S80. Citations: 2	
	Lee et al (2016) A retrospective study of direct cost to patients with the use of oncology medications for the treatment of multiple myeloma. <i>Journal of Medical Economics</i> , Vol. 19, No.4, P.397 – 402. Citations: 9	Correlation Rx abandonment related to cost
	Clifton et al (2018) Financial impact of patients enrolled in a medication adherence program at an independent community pharmacy. <i>Journal of the American Pharmacists Association</i> . Vol. 58, PP 109 - 113. Citations: 5	Pharmacy, revenue contribution
Measurement	Haynes et al (1980) Can simple clinical measurements detect patient noncompliance? American Heart Association. Hypertension 2: P. 757 – 764. Citations: 578	Very dated. The originating measure of MPR still used as a standard today of 80%.
	Stegemann et al (2012) Adherence measurement systems and technology for medications in older patient populations. <i>European Geriatric Medicine</i> , 3, P. 254 – 260. Citations: 35	Not one single measurement considered to be a gold standard.
	Vermeire et al (2001) Patient adherence to treatment: three decades of research. A comprehensive review, <i>Journal of Clinical Pharmacy and Therapeutics</i> , 26, P. 331 – 342. Citations: 2146	Comprehensive review. Consider the patient as a partner in their own care. No gold standard for measure.
	Brown & Bussell (2011) Medication Adherence: WHO Cares? <i>Mayo Clinic Proc.</i> April 86(4): P. 304 – 314. Citations: 1425	Incidence. (MPR). Practical strategies.
	Action Research	
Patient	Dowell et al (2002) Exploring medication use to see concordance with 'non-adherent' patients: a qualitative study, <i>British Journal of General Practice</i> , 52, P. 24 – 32. Citations: 96	Balint style - Discussion driven. Shared decision making.
Disease Outcomes	Ramli et al (2016) Effectiveness of the EMPOWER-PAR Outcomes of Type 2 Diabetes Mellitus in Primary Care: A Pragmatic Cluster Randomised Controlled Trial. BMC Family Practice. 17:157, P. 1 – 18. Citations 10	Large well design action research (PAR). Self- management and decision support.
Scholarly Practice	Ramsey C (2014) Management learning: A scholarship of practice centred on attention? <i>Management Learning</i> , Vol. 45 (1) P. 6-20. Citations: 56	Knowledge - Attention
	Reputable Consulting Publications	
Broad Categories	Capgemini Consulting (2011). Global Research Report. Patient Adherence: The Next Frontier in Patient Care, Vision & Reality, 9th Edition. Citations: 2	Factors, influencers, interventions.
Technology	Technologies for Optimizing Medication Use in Older Adults (2011). Center for Technology and Aging, Position Paper. Citations: 0	Optimization, adherence technologies, monitoring

#### **2.7.1 Patient**

Brown and Bussell (2011) cite several patient-related factors that have an impact on adherence to medications, including lack of understanding of their condition, lack of involvement in treatment plans, low literacy levels regarding medical topics, individual beliefs and attitudes toward health, motivation, medication costs, lack of transportation, and wait times to see a healthcare provider. Ho et al (2009, p.3031) add examples, stating "patient factors associated with medication adherence include younger age, nonwhite race, and depression". Common rationale for medication nonadherence is often patient related involving forgetfulness, being away from the primary residence, or simply occupied with other responsibilities (Reynolds et al, 2004) noting that reasons may be relatively basic. Agreeing, Brown and Bussell (2011, p.8) suggest that patients "recall as little as 50% of what is discussed during the typical medical encounter". It is understandable that rates of medication nonadherence are at such a high percentage.

Relating to a patient's knowledge and misunderstanding, Berkman et al (2011) & Gazmararian et al (2006) both found that low literacy of health knowledge contributed to nonadherence. Parker et al (2003) note that health and medication information is put forth to society at the grade ten reading level suggesting that literacy interventions could be a viable way to improve medication adherence. This may have some merit as Zullig et al (2014, p.288) found that "a health literacy intervention may be a feasible mechanism to improve cardiovascular related medication adherence and outcomes" during a trial in which patients self-reported their medication adherence at three months.

Vermeire et al (2001, p.335) highlight that "patients must believe that they are vulnerable or susceptible to the disease or its consequences, that they actually have it, and that the consequences of the disease on their well-being could be serious", although Donovan & Blake (1992) put forth that research relating to adherence has only just begun to take into consideration the patient view. This notes the slight shift in the difference between compliance and adherence depending on the vantage point.

Krueger et al (2005, p.336) provided evidence that certain patient backgrounds pertaining to "sex, ethnicity, and marital status" were thought to play a minor role on medication adherence, while those of "age, low literacy, lack of insurance coverage, and homelessness had most consistently reported negative impacts" (Krueger et al, 2005, p.336). Krueger et al (2005, p.336-337) further noted that a "patient's belief that a medication will work or is working is directly related to treatment adherence", as was "the level of English language proficiency or low health literacy".

The uniqueness of personalized methods to address nonadherence must take goals into consideration which should vary depending on the strategy and patient (Mrosek, Dehling, & Sunyaev, 2015). This again highlights the importance of a multifactorial approach to improving medication adherence.

#### 2.7.2 Condition

Ho et al (2009, p.3031) note "conditions that are asymptomatic and chronic in nature that require long-term therapy have also been associated with nonadherence". Morris & Schulz (1992) along with Griffith (1990) report an association between low compliance and chronic conditions.

Baily et al (2013) emphasize the importance of medication adherence in that management requires several phases such as understanding, organization, and monitoring. Because each medical condition may have its own nuances, it is important to take these cyclical phases into consideration. For example, Fenton (1994) notes a 3.7 times relapse risk on average of non-adherent patients versus adherent in schizophrenia. This enhanced risk may be different than that of other diseases such as cardiovascular disease or diabetes, and research with a broad range of conditions is lacking.

# 2.7.3 Therapy

Claxton et al (2001) note an "inverse relationship between number of daily doses and rate of compliance" while assessing adherence. In their systematic review of 76 studies they found that once-daily dosing was associated with higher adherence versus other more complex dosage regimens and concluded that compliance is better across varieties of medication classes, citing that inadequate compliance results in poor control in several disorders.

An association exists with low compliance and factors such as treatment duration and the number of medicines (Vermeire et al, 2001). Krueger et al (2005) also found that when the number of medications increases, adherence decreases, particularly with 4 or more medicines. With regard to therapy-related factors, Ho et al (2009, p.3029) note the "complexity of the regimen and the perceived or experienced side effects can impact adherence". Complex medication regimens and lack of communication are associated with nonadherence, especially for the elderly (Vermeire et al, 2001).

#### 2.7.4 Socioeconomics

From a medication adherence perspective, a patient's social status, economic situation, and environment may have an impact on their likeliness to adhere. Economically, Cutler and Everett (2010, p.1553) note that paying "out of pocket for medication clearly affects adherence; people use more drugs when the prices of the drugs are lower". Ho et al (2009, p.3031) suggest "research is needed to better understand the association between adherence and healthcare cost". Roberts et al (2014) note that high drug costs are a barrier to clinical improvements amongst low-income patients. In a study retrospectively reviewing 265 patients who utilized a pharmacy program offering financial assistance, they found that patients were approximately 50% adherent to their medications and suggested future research take a longer view of pharmacy assistance programs to enhance adherence (Roberts et al, 2014). The authors identified that although many of these programs are starting to be implemented, little is known about their impact on adherence.

Zullig et al (2013) supported that claim by reporting that during their research nearly half of the 164 participants mentioned cost as a reason for nonadherence. Unfortunately, patients were left to cope with the pressure of compensating high drug costs, doing so in many ways such as seeking out lower priced medications, borrowing funds, and reducing their usual spending on other necessities such as food (Zullig et al, 2013). Although it was noted that patients are likely to alter their day-to-day lifestyle in order to afford medication costs, surprisingly, during the multivariable analysis, confirmation of financial stress as a predictor of medication nonadherence wasn't clear, leaving it difficult to separate the subjective and objective factors (Zullig et al, 2013).

Krueger et al (2005, p.319) suggest "multifaceted interventions that target specific barriers to adherence are most effective, because they address the problems and reinforce positive behaviors". One variable outlined in their research affecting adherence is a patient's "inability to obtain and pay for medications". Hsu et al (2006) noted that patients with caps on their drug benefit plan showed higher nonadherence. Taira et al (2006) discusses a relationship grade between copayment and adherence. Consistent with these findings were Cole et al (2006) who recognized that with higher drug copayments came small decreases in medication possession ratios among patients. This suggests that patients will delay the purchase of their medication as it directly relates to out of pocket expenses. Ho et al (2009) note that due to the evidence associating nonadherence with medication costs, more studies are necessary in this area in order to improve upon and increase knowledge of any relationship between lowering costs and improving adherence.

Petry et al (2015), over a 12-week period, studied 29 patients utilizing self-recorded videos in which a financial reinforcement was used to earn rewards. Results suggested that cell phone technology, along with the positive reinforcement of a financial reward for compliance, might increase medication adherence. Furthermore, Cappemini Consulting (2011) proposes taking an interventional cost-related approach to combatting medication nonadherence by providing patients with discounts or vouchers.

During a focus on social status and environment, DiMatteo (2004) extensively reviewed the literature concerning the importance of social support relating to adherence with 122 studies dating from 1948 – 2001 and found a correlation between support and adherence and that patients in cohesive families are more adherent than those is situation of conflict. He further denoted the importance of categorizing social support into either structural support, such as marital and cohabitational, or functional support, referring to emotional or cohesive state.

Patients lacking practical support during treatment with medications show at least 65% nonadherence (DiMatteo, 2004). Vermeire et al (2001, p.335) further note "social factors, such as a positive attitude by others in the community improve compliance". Krueger et al (2005, p.336) highlight the importance of "family members, friends, or caregivers whom provide to help patients adhere to their medication regimens", having a positive impact relative to the size of the immediate group, and that that when too many people were involved adherence often suffered. Ho et al (2009, p.3031) note examples of "socioeconomic factors such as lower education and health literacy have been correlated with nonadherence".

#### 2.7.5 Health system

Ho et al (2009, p.3031) note, "nonadherence is not solely a patient problem but is impacted by both care providers and the healthcare system". Relationships and specific attributes such as trust and support were shown to have a positive affect within the healthcare system (Krueger et al, 2005). Ens et al (2014) highlighted that provider-patient relationships demonstration of quality communication and awareness improved adherence.

Concerning the situational complexity, Ho et al (2009) discuss examples of health system-related factors such as educational interaction and counselling during discharge, inpatient versus outpatient medication regimens, conflicting information, bureaucracy associated with drug plan insurance claims, and the physician-patient relationship each having a varying impact on medication adherence.

#### Pharmacist

Brown and Bussell (2011) highlight the contribution of high drug costs or copayments, lack of information technology or connectivity between healthcare providers, and a system that is overburdened in many countries with medication nonadherence. Pharmacists may be an important link to addressing some of these issues; although Svarstad et al (2003) reported mixed results and patient outcomes when studying the use of written communication between the pharmacist and patient. Overall, more interactivity or communication resulted in improved outcomes, but results varied greatly depending on the amount of time spent with the patient, workload, and type of pharmacy environment. This may be a field of research that requires more attention.

Xu, Chomutare, & Iyengar (2014) conducted a meta-analysis of 40 studies and found that the most common form of a persuasive attribute for medication adherence interventions were those of pharmacist counselling and reminders. These had moderate behavior change.

#### Physician

Anon (1997) notes that disease, process, setting, and therapy all influence adherence. Findings from that research highlight the doctor-patient relationship and its importance to compliance, although it is recognized as difficult to assess. Vermeire et al (2001, p.335) suggest that there seems to be a relationship between the "quality, duration, and frequency of interaction of the patient and doctor", although a consistent set of facts has yet to emerge. Krueger et al (2005) further supported this theory in that care providers effect adherence it in a positive way. Unfortunately, physician's insight to recognize nonadherence is lacking (Osterberg & Blaschke, 2005).

Sleath et al (2000) assessed the perspective of physician and patient interaction but were unable to associate adherence with specific patient demographics, although they did advocate the importance of the physician-patient principles of respecting the patient, providing proper rationale for treatment, discussing a plan, creating a nonthreatening environment, and ensuring

an emotionally significant and collaborative approach. These principles were meant to enhance the physician-patient relationship with the intent to improve adherence.

Brown and Bussell (2011) note several physician-patient related factors that may contribute to medication nonadherence, including issuing complex drug regimens, lack of explanation, poor communication, and the failure to connect information between healthcare settings such as the hospital and primary care environment.

Research-based findings emphasize the importance of strengthening the doctor-patient relationship as a means to improve compliance (Vermeire et al, 2001). King and Peck (1981) argue that in order to enhance patient compliance the care-giver should have three goals in mind: improving patient comprehension, patient recall and patient motivation. These goals imply strong communication practices between the doctor and the patient. Vermeire et al (2001) highlight a subset of actions to support this intent such as initiatives to enhance friendliness and approachability, to ameliorate presentation of information, types of medications prescribed, and advise on techniques to ensure the correct dosages are taken. Chesney (2000) also focuses on this argument in his research and adds that improvements require clarity in treatment and fitting to the patient's lifestyle. Further support comes from the notion that, from a present-day perspective and considering the ever-increasing use of technologies, it is likely that technology such as smartphone apps will eventually be prescribed as part of a patient's treatment regimen (Dayer et al, 2013). Hence, tailoring treatment to the patient's convenience and lifestyle.

#### 2.7.6 Technology

Capgemini Consulting (2011) highlights the substantial advancements within technology in recent years including mobile health (mHealth) smartphone applications, smart pills containing microchips, electronic pill bottles, remote patient monitoring, self-diagnostic tools and customer support call centers. Despite optimism toward technology, Granger & Hayden (2011) note that although many studies have been pursued to evaluate technology and interventions in helping improve upon adherence, most have shown only mixed results. Haynes et al (2008) note that most interventions require intense resources, lack specifics on delivery, and are impractical.

Krueger et al (2005) noted many initiatives directed at the Physician, Pharmacist, Patient, disease-specific groups, and other healthcare providers during a comprehensive assessment of the literature including various drug utilization reviews, point of care activities, computerized prescriber order entry activities, personal digital assistants, and actions involving electronic health records. The authors emphasized that there is no one approach to ensure adherence.

Various forms of medication adherence technologies exist and can be categorized into either single, multi, or advanced functioning along with others that integrate into alternative health management capabilities (Technologies for Optimizing Medication Use in Older Adults, 2011). Single-functioning technologies are generally associated with medication fills, reminders, and dispensation. These are the most commonly available. Multi-functioning technologies add a reporting capability to single functions, while some of the more advanced functioning technologies are associated with patient ingestion, metabolizing and adjustment of medications (Technologies for Optimizing Medication Use in Older Adults, 2011).

Yelena & Hommel (2014) emphasize the importance of recognizing the matching of various technology to particular problems. For example, Cappemini Consulting (2011) suggests that digitizing patient records will have a lasting impact on shaping the future of medication adherence, inclusive of electronic medical health records and trends that will help provide information leading to customized intervention designs.

In theory, reminder technologies such as pill calendars and unit-of-use packaging should help prevent nonadherence, particularly unintentional nonadherence (ie. the patient simply forgets to take their medication); however, as stated by Dayer et al (2013) these systems can be cumbersome for complex regimens and minimally involve the patient in the self-medication process. Most traditional reminder systems do not actively involve patients with the adherence reminder process or offer patients access to their own adherence data (Dayer et al, 2013). Technologies that engage the patient in their self-medication regime, such as Short Message Service (SMS) messaging and mHealth apps, appear to be much more affective.

With the wide variety of digital interventions available to aid medication adherence, it is important to consider both intentional and unintentional nonadherence. In an evaluation of the effectiveness of RTMM (real time medication monitoring) combined with SMS reminders, Vervloet et al (2011) note, a patient's increased awareness of a benefit will likely not lead to improved adherence if they unintentionally nonadhere. Furthermore, a reminder to patients to take medicines who have chosen intentionally not too may not be helpful. This statement supports the idea that a multi-faceted approach to the technologies is required in order to successfully improve upon medication adherence. The combination of education, data access, and reminders should work together to help patients' understanding and/or forgetfulness and assist in reducing nonadherence.

Although technological innovations are exciting and promising, it is important to remember the human aspect of medication adherence, and not put the technology ahead of the patient relationship. Riekert and Rand (2002) may put it best in saying technology will not replace a relationship, listening, and understanding. This notion is supported by Park et al (2014), who argue that medication adherence monitoring will be successful if patients and caregivers work together and communicate effectively in the clinical setting. Consistently, researchers agreed that no matter the technology, a healthy patient-healthcare provider relationship is key to maintaining a relationship conducive to proper medication management.

SMS (Short Message Service) / Text

Yelena & Hommel (2014) note the potential of using text messaging as a means to improve medication adherence as there is significant increase in usage and costs are sustainable over time. Early research looks promising in this approach. Park et al (2014) implemented a systematic review of phone interventions and assessed 29 research publications and found that 18 of the studies identified improvement in adherence using text messages. Negative results were usually associated with basic and repetitious content while positive results were associated with a variety of educational and motivational content tailored to the individual patient. Vervloet et al (2012) found, over a six-month trial with 104 patients using real time medication monitoring (RTMM), that adherence improved with SMS reminders.

A study by Huang et al (2013) examined the effectiveness of SMS reminders as a digital intervention to determine whether they increased medication adherence. The objective of this study was primarily to analyze the impact of medication reminders on delayed and missed doses, and secondarily to determine patient satisfaction and demand for text message intervention. Huang et al (2013) assert that SMS messaging is simple and cost-effective and a method for reminding patients to take their medication. In the study, 83.1% of participants in the intervention group reported that SMS reminders were helpful for preventing missed or delayed doses, and 73.7% of participants in the intervention group considered SMS intervention to be of value for disease management.

Huang et al (2013) findings determined that SMS medication reminders could be an easy and effective way to improve medication adherence; particularly in short-term medication regimens, as the study followed patients for only one week, and long-term adherence may be more difficult to maintain. Similarly, Vervloet et al (2011) suggest that SMS text messaging improves medication adherence and can be effective in measuring adherence in the short term. Both researchers believe that more research is required to determine long-term success.

The simplicity of SMS text messaging sets it apart from other more complex digital interventions such as mobile health applications due to its compatibility with different types of telecommunication and, according to Thakkar et al (2016), ease of administration and automation using a computerized program. Unlike smartphones, SMS messaging is relatively old technology that can be used by mobile phones of all kinds, and is common across all demographics, cultures, and socioeconomic groups. SMS medication reminders can include personalized content such as motivational messages, educational and medication-specific information, humour, etc. which can encourage patient engagement (Thakkar et al, 2016).

In 16 studies examined by Thakkar et al (2016), the majority of patients reported moderate to high satisfaction with SMS messaging as an aid to medication adherence. When asked, the majority of patients would have liked to continue receiving text messages. Overall, it was

determined that SMS interventions may have the potential to improve adherence within chronic diseases.

The meta-analyses by Thakkar et al (2016) found that most participant dissatisfaction surrounded lack of privacy and confidentiality due to loud notifications, and inconvenient SMS timing. Huang et al (2013) found that participants who took several medications were inconvenienced by receiving multiple notifications, and that most patients preferred to receive reminders 30 minutes before the prescribed dosage was to be consumed. A potential solution to these challenges is to offer patients customization of notifications, giving them the option to choose timing, content, and alert style.

# SmartPhone Applications

In recent years, there has been a groundswell of smartphone applications in the pursuit to improve medication adherence, essentially attempting to tailor to the lifestyle of the patient and the common everyday use of the smartphone device. This is especially so in developed countries. Generally, for patients, these devices are inexpensive, scalable, and accessible (Dayer et al, 2013). However, Yelena & Hommel (2014) note, their overall effectiveness has yet to be proven and suggest the importance of more research in this area as to assess interventions such as networking and gaming. Furlow (2012) highlighted this lack of research, stating that regardless of the growth of mobile applications, most have not been tested. Further research is required to garner knowledge in how smartphone applications may have a positive impact on improving medication adherence rates in both acute and chronic diseases (Dayer et al, 2013).

Miller and Himelhoch (2013) describe the influence of new technologies on adherence in recent years as showing promising results within several conditions. Their study assessed 100 patients using a survey to evaluate willingness to use smart phones for the promotion of medication adherence. Over one quarter of subjects indicated they would use the mobile phone to help improve their adherence.

Using smartphone applications (apps) for the management of adherence to prescribed medication regimens could give patients a one-stop shop for tailored interventions. Apps offer a technological interface which consolidates multiple features such as reminders, medication information, activity logs, and connectivity with digital monitoring hardware. Smartphone accessibility adds efficiency and convenience to each mode of intervention, while engaging the patient and offering greater ease of access to valuable medical information. Further empirical analyses of the use of smartphone apps to aid in adherence is required (Dayer et al, 2013).

According to Dayer et al (2013), one key inclusion for a successful smartphone application is an educational component. This education has traditionally been part of the professional-patient interaction and relationship. To improve efficiency, the application may consolidate a patient's user information and streamline the educational process (Dayer et al, 2013).

A recent qualitative study carried out by Morrissey et al (2018) examines the patient's perspective while using MiBP (a Smartphone application consisting of medication reminders and home blood pressure monitoring via Bluetooth connection). Patients expressed feelings of empowerment when visiting doctors for follow-up appointments due to new knowledge surrounding their health and condition. Personal access to blood pressure data was easily retrievable in the form of graphs outputted by the app in accordance with BP monitor readings, which motivated patients to better understand the technology and its functions. This access to information could also make an asymptomatic condition more easily understood (Morrissey et al, 2018); however, some asymptomatic and more stable patients reported having less use for the apps (Hallberg, Ranerup & Kjellgren, 2015).

Negative findings from Morrissey et al (2018) include patient reports of anxiety driven by a lack of understanding of the technologies, and concerns surrounding the privacy and safety of data. These issues increased patient anxiety when using the MiBP app for self-monitoring and it was determined that more information would be needed to explain app compliance to privacy standards. Providing reassurance for some of these concerns could be as easy as a conversation between doctors and patients explaining data interpretation and recourse (Fletcher & Jensen,

2015); a conversation made easier by the availability of home-monitoring BP data and mHealth app databases.

It should be noted that the median age in Morrissey's study is 65, and that technological competency for this demographic may be lower than that of the average adult smartphone user. In a study on the effects of SMS reminders for outpatients who were prescribed more than 7 days of medication, Huang et al (2013) found that patients ages 65 years or older were less likely to experience an increase in timely doses compared with those aged 20 - 34 years, suggesting that older patients may resist change. Further investigation is required to determine MiBP's influence on overall medication adherence; however, this particular study demonstrates the potential for patient engagement and involvement in their own condition.

# Electronic Monitors of Adherence

Electronic monitoring (EM) of medication adherence comes in many forms including, but not limited to, electronic health records, medication events monitoring systems (MEMS) such as microchips in pill bottles and blister packages, wirelessly observed therapy (WOT) with ingestible sensors, mechanisms for metered dose inhalers (MDI), audiovisual reminder functions (AVRF), condition-specific monitors, and various combinations of multimedia and mobile phone utilities. (Park et al 2014). EM is considered to be a high-quality form of adherence measurement due to its accuracy and is preferred over less reliable methods such as patient self-reporting (Linn et al, 2011).

Electronic Monitors "record the date and time that medications were removed from the device or the medication was administered" (Yelena & Hommel, 2014, p.923) and have shown to increase usage in order to capture prospective and objective longitudinal data. These innovations may help by assessing the methods patients take medications. However, EMs are often expensive to purchase and, from a situational perspective and depending on the relative price of the medication, may not be practical (Cramer & Mattson, 1991). There may also be questions as to who pays for the EM and what payer scenario might be most cost beneficial. This data is often

used to compare against medication adherence in patient self-reports as well as prescription refills in pharmacy (Yelena & Hommel, 2014).

In a randomized controlled trial, patients of various socioeconomic backgrounds participated in six months of blood pressure self-monitoring using a telemonitoring service. Findings indicated that home telemonitoring does cost significantly more in services charges, patient training, and supplementary professional consultation; however, these costs could even out over time as a result of overall health condition improvement (Stoddart et al, 2013). According to Stoddart et al (2013), telemonitoring in primary care showed higher effectiveness during the six months after start and could be recuperated over the longer run as a direct result of prevention.

In corticosteroid therapy for Asthma patients, MDI paired with AVRF were deemed to increase medication adherence by 18%. However, it should be noted that adherence rates are typically lower in clinical practice than in a research environment (Charles et al, 2007). Although further study is required, Charles et al (2007) report that the MDI monitoring system, when paired with dynamic audiovisual reminders, does have opportunities to address nonadherence within chronic diseases.

Regarding EM methods of assessing adherence, Hansen et al (2011) found that, statistically, data records regarding prescription refills using electronic pill bottles were higher as compared to patient self-reports, prescription refill records, and pill counter lids which all provided similar outcomes. Furthermore, Demonceau et al (2013) found that EM interventions are potentially effective methods to improve adherence noting the dosing information is an important contributor.

As stated by Park et al (2014), electronic devices have the ability to time stamp certain data, offering caregivers and pharmacists/physicians the opportunity to recognize nonadherence patterns such as the 'white coat effect', which occurs when a patient takes proper dosages and/or over-compensates for nonadherence only in the short timespan leading up to appointments with their provider. Unfortunately, like most forms of electronic equipment, electronic devices are not

immune to malfunction. Hardware failures and damage due to accidental or intentional misuse have been reported (Park et al, 2014).

One disadvantage of EM is that, despite time and date signatures, there is no way to determine whether or not the medication was actually ingested, or if pill dumping (disposing of multiple pills in order to fake adherence) had occurred (Park et al, 2014). Additionally, the most commonly studied EM capabilities are limited to pill container technologies and are not applicable to liquid medications and/or injectables (Riekert & Rand, 2002). This field of EM requires further research in order to determine long-term results.

Although these dynamic technologies are exciting and offer many ways to monitor and improve upon adherence, it is difficult to determine their effectiveness. Longitudinal studies are required to assess patient satisfaction and the potential impact of these methods of digital intervention (Park et al, 2014).

# Microchip

Cressey notes that the microchip technology has recently been introduced for predefined therapeutic regimens whereby, upon ingestion, a telemonitoring communication is issued to record medication intake (Stegemann, 2012). Research has yet to show the significance of this technological advancement, though according to Avery and Liu (2011), smart pills show promise to safely revolutionize medication treatment. Avery and Liu (2011), however, raise the point that pharmaceutical companies may shy away from the research and development of such ingestible sensors due to regulations and high-cost technological requirements.

Compared to other forms of EM, ingestible biosensors are unique in their ability to detect near-exact time of consumption of medication (Chai et al, 2015). Sensors may detect adherence gaps and issue interventions. This data is valuable to the long-term pursuance of patient adherence, as interventions occurring at the exact time of nonadherence may be more effective than those occurring pre or post missed dose. Giving patients access to their own precise adherence data from ingestible biosensors could provide them with the insight needed to invoke positive

changes in attitude and behaviour surrounding their medication regimen, ultimately resulting in better adherence (Chai et al, 2015).

Eisenberger et al (2013) studied the Ingestible Sensor System (ISS), with its combination of ingestible event markers (IEM) and an adhesive personal monitor (APM) used to measure medication intake by ingestion-activated micro sensor which transmits data to the APM, then to a mobile phone via Bluetooth. The ISS was determined to be highly accurate in detecting time, type, dose, and number of medications a patient took. However, reports of skin irritability from the APM were one downfall, along with connectivity problems between the monitor and mobile device (Eisenberger et al, 2013).

# Illness-Specific Medical Devices

In recent years, several sophisticated devices with features to promote medication adherence and management of the disease have appeared on the commercial market (Yelena & Hommel, 2014). These include electronic devices such as blood glucose monitoring and blood pressure measurement systems. Limited research has been done on the utility of home monitoring systems.

Research in hypertension management has shown potential for success in patient-centered, multifaceted programs including self-monitoring, reminder systems, and presentation of educational information, with the combined use of Smartphone applications and wireless BP monitors. Timely data output gives patients a better understanding of their own hypertension activity, demonstrating the effects of lifestyle practices on hypertension and better preparing them to participate in discussions at the doctor's office (Morrissey et al, 2018).

According to Hallberg et al, (2015) the patient's ability to see immediate effects of lifestyle changes on blood pressure by viewing BP monitor reading outputs on an mHealth app, was reported as an eye-opener. Patients noted it taught them a lesson relating to the amount of forgetfulness. Other patients reported gaining a greater understanding of activities and lifestyle choices affecting their condition after interpreting BP monitor outputs, offering them more

control over their health. Immediate and visible results from patient's own bodies served as much more motivation than receiving suggestions from magazines or websites, particularly advocating for exercise. This awareness may encourage patients to better adhere to their medication regimen (Hallberg et al, 2015).

Conversely, Morrissey et al (2018) found some reluctance from participants to engage with the home BP monitor. Lack of know-how to interpret high readings was said to have caused unnecessary anxiety and could potentially lead to needless doctor visits. With regards to this technology, prior to self-monitoring, it is essential that the patient fully understand the technology's operation, function and capabilities before attempting at-home use. The patient must also understand monitor outputs as to lessen anxiety around readings.

#### Multimedia

The internet and electronic reminders offer optimal technology for putting forth customized interventions as it may assess barriers (Linn et al, 2013). The authors assessed medication intake behavior using an online preparatory assessment, along with tailored text communication, and found that 65.6% of patients viewed this type of intervention as positive.

Sajatovic (2015) conducted a study utilizing sensor automation in a pill cap and monitored remotely with an incentive component. Some of the challenges for patients included managing multiple types of adherence techniques simultaneously, hence recognizing a downside to more complex adherence interventions.

Laffer and Feldman (2014) evaluated the use of 17 medical videos to determine which forms of technologies help patients best adhere to certain regimens and found that patients rely more on reminder systems such as utilizing cell phones and calendars rather than medical videos. Although photo and video of medication ingestion can lower personnel costs for healthcare professionals, they require frequent communication with patients which can be considered time consuming (Park et al, 2014).

Linn et al (2011), in a systematic literature review, determined that adherence may be improved using individualized internet interventions. The customizability of web-based platforms is beneficial to patients, while the opportunity to collect data and monitor patient adherence is valuable to healthcare providers (Lin et al, 2011). Tailored internet interventions can be used in coordination with current treatment and/or adherence practices, offering insight which can improve the outcome of the patient's entire regimen (Lin et al, 2011).

In a review of multimedia interventions for over-the-counter medications, Ciciriello et al (2013) found that, despite low quality of evidence, multimedia interventions were effective in educating patients on their medication. By means of written word, diagram, photos, audio, animation or video, consumers can access detailed information more easily than traditional methods, and that multimedia education was more effective than usual care (Ciciriello et al, 2013).

# Self-Directed Technology

Self-Directed technologies include electronic monitoring, video, telephone calls, and mobile phones used as a direct intervention to improve adherence. These digital interventions (DI) generally require more participation from the patient and promote self-management of a medication regimen. Patients using these technologies to aid adherence may require more assistance from their healthcare provider (Morton et al, 2016), and may rely more heavily on athome support systems or caregivers.

As noted by Morrissey et al (2018) in regard to self-monitoring combined with a novel Smartphone application it helped form part of the doctor-patient relationship which confirmed the patient's need for physician support during self-management. This need is viewed by some as a potential burden, as self-management sometimes demands more time and assistance from healthcare providers (Morton et al, 2016).

Walker et al (2014) found, in a study of 33 patients with heart failure, that self-directed technology in the form of MyMedSchedule.com did not significantly improve adherence to medications. Barriers attributing to lack of improvement included age, medication cost, complex

medicine regimens, motivation, and social environment (Walker et al, 2014). Technologies like photo and video logging of medication ingestion require a greater level of patient engagement and more frequent communication between patients and their healthcare providers (Park et al, 2014). These methods, when properly executed, can confirm timely medication intake but further research is required to determine long-term results.

One benefit of self-directed digital intervention is the potential for positive reinforcement and encouragement due to increased involvement in the patient's own health care. In Hallberg et al (2015) study of at-home blood pressure monitoring for patients with hypertension, they determined that a self-management effort provided perceived benefits leading to awareness and influenced blood pressure. Similarly, Morton et al (2016) concluded, after a meta-ethnography review of published studies, that patients reported higher satisfaction with care received and felt more connected with healthcare providers after using various methods of self-directed device integration to manage their condition. This review determined that patients who were self-managing were more likely to engage in lifestyle change behaviours (Morton et al, 2016).

#### Prescription Refill Monitoring

Granger & Hayden (2011) note that pharmaceutical databases within the retail pharmacy setting offer insight into patient-level refill patterns. In general, this resource has been associated with analysis using medication possession ratios (MPR) and linking the information to that of reminder interventions thereafter. Interventional programs that have been pursued include database triggers, telephone reminders, picture cards to address low literacy, and physician alerts. Unfortunately, most of these programs have shown limited success or significant benefit (Granger & Hayden, 2011) in improving long-term adherence rates. A known limitation of this type of technological method is that it cannot confirm that a patient who filled their prescription at pharmacy and has possession of the medication has, in fact, used the medication (Sabate, 2003).

Arguably, pharmacists are properly positioned to engage with patients at optimal intervals relative to other healthcare providers (Calvert et al, 2012), as they have front-line access to

prescription refill information on patients. Unfortunately, the health system lacks a cohesiveness regarding patient information as pharmacists do not have the same level of insight into patient's medical history as physicians would. Pharmacists do not normally engage the prescribing physician to assist in resolving adherence problems (Calvert et al, 2012).

Refill monitoring, in contrast with EM alternatives, is fairly inexpensive. It is beneficial as an indirect method of adherence measurement because it can be done without informing the patient, which may increase the accuracy of results (Balkrishnan, 2005). Prescription data is easily attainable by the pharmacist, but patients who frequent more than one pharmacy may limit traceability of prescription refills; therefore, a unified pharmacy system is crucial to successful refill monitoring (Balkrishnan, 2005).

#### Techniques for Measuring Adherence

The various techniques considered in the pursuit to quantify adherence rates can be categorized as either direct or non-direct measurements. Vermeire et al (2001) makes this distinction in that direct measurements are often used to detect chemical markers in the body fluid". Non-direct measurements are used more frequently in the relevant literature and include activities such as self-report interviews, diaries, and pill counting (Vermeire et al, 2001). Each categorization has been noted to have their own drawbacks as either deterioration or improvement in patient health outcomes can be attributed to other non-medication related factors beyond the scope of measurement.

The ability to measure medication adherence rates is challenging (Brown and Bussell, 2011). The prediction of adherence has no stable factors (Sabate, 2003); however, an accurate measure is considered of the utmost importance if a change in the patient's regimen is required to ensure an optimal outcome (Sabate, 2003).

Brown and Bussell (2011) further highlight three different approaches: subjective, objective, and biochemical. Subjective approaches include actions such as simple asking the patient, family, or caregiver questions about the medications a patient is taking. This can be considered a self-

report. Unfortunately, accuracy in subjective measures has been problematic. Healthcare providers tend to overestimate the success rates (Dimatteo & DiNicola, 1982), while patients vary in whether they follow or deny treatment advice (Spector et al, 1986).

Objective measures include means of measuring adherence which involve counting pills or assessing pharmacy refill data. Objective measures might seem to be a preferred method over subjective measures, but they have their own drawbacks such as counting or timing inaccuracies (Matsui, 1994). A common method of measuring and quantifying medication adherence in recent years has been the use of electronic prescription data using pharmacy processing systems (Ho et al, 2009). Brown and Bussell (2011) also recognized the potential of electronic medical records and electronic prescribing to improve adherence. Two perspectives are often considered. Firstly, medication possession ratio (MPR) and secondly, proportion of days covered (PDC). Essentially, the ability to measure prescription refills and frequency can be correlated with health outcomes (Ho et al, 2009). The intention of MPR is to identify delayed filling on initial prescriptions and the refilling of future prescriptions (Brown and Bussell, 2011).

An early limitation to MPR is that, in order to capture all medications and refills patients are prescribed, they are required to obtain medications in a closed pharmacy network (Ho et al, 2009). This hinderance has improved in recent years, as many retail pharmacies have become linked and the closed pharmacy system has broadened. A further limitation to the tracking of electronic prescription data is that it only measures when the patient fills the physician order but is unable to track when the patient actually takes the medication in terms of time of dose (Ho et al, 2009). The concept of medication reconciliation (Brown and Bussell, 2011) seeks to create an accurate and collective list of all medications a patient is on and their respective uses.

Biochemical measures require blood and urine tests to detect medication levels (Brown and Bussell, 2011) by adding non-toxic biological markers to the medication. Unfortunately, this method of measurement also has its drawbacks, considering other influential factors such as a patient's diet, individual absorption rates, and excretion (Vitolins, 2000).

Using the medication possession ratio (MPR) measurement perspective viewing at prescription refill data at pharmacy adherence is generally considered at 80% (Ho et al, 2009), but it is also agreed upon that the MPR depends largely on the medication, formulation, and state of disease. Osterberg & Blaschke (2005) emphasize that no consistent standard exists that constitutes appropriate adherence referring to some trials that require greater than 80% acceptance and others that require greater than 95% depending on the disease condition and severity.

Medication Possession Ratio is defined as:

MPR = (# of pills Dispensed in Time X / # of pills Prescribed for Time X) times 100. (Brown and Bussell, 2011).

Another important subset of MPR is the duration of interval episodes between refills. Ho et al (2009) suggests that pharmacy records should also assess refill frequency and date of last dispensation. This may facilitate a method to recognize medication nonadherence.

Achieving accurate measurements of adherence is merely the beginning of solutions needed to help improve medication adherence. Granger & Hayden (2011) find that technological interventions without active human insight are ineffective regarding rate improvements of adherence. Granger & Hayden (2011) also note that in-person interaction complimented by automation of a reminder have the most effectiveness.

Krueger et al (2005), during a comprehensive review, was able to categorize several intervention tactics aimed at helping to improve adherence to medications, including theory-based methods which target knowledge and information, disease-based methods which target knowledge on the disease, dosage simplification, reminders, hospital discharge programs, one time discussions, and self-care initiatives.

It has been determined that interventions addressing adherence have shown modest results (Ho et al, 2009). Haynes et al (2008) noted singular interventions have been seen to be less effective than a multi-tiered approach, recognizing the multifactorial set of reasons for nonadherence. Deber (1994) suggests, as a means to improve adherence to medication regimens, that individual

patient autonomy is critical and participation in the process mandatory. Given the increase in a patient's ability to retrieve information on their own health diagnosis, and possible solutions through various advancements in technology and the Internet, Deber (2014) does maintain a strong argument.

Overall, the ability to measure medication adherence rates can be deemed an estimate at best. Many of the tools used to promote adherence are not available in all countries. Furthermore, no individual measurement strategy has been proven to demonstrate optimal and consistent results. Hence, a multi-method approach (Sabate, 2003) that combines many of the strategies and tools highlighted may seem the best avenue to pursue from a broad population perspective.

# 2.7.7 Financial Assistance provided by the Pharmaceutical Industry

Many medications that have been developed in recent years for diseases such as cancer, multiple sclerosis, rheumatoid arthritis, and HIV are generally more expensive for the healthcare system. Most of these medications are considered 'specialty medications' and the higher costs associated with them can present barriers to medication access, leading to patients non-adhering to the medicine regimes (Zhu et al, 2018).

Studies consistently show that the higher cost of medications leads to lower adherence rates due to the patient often having to pay more for their portion of the prescription, therefore delaying or avoiding taking their medicine as prescribed (Zhu et al, 2018). The patient payment requirement is known as the copay or coinsurance portion, and has been rising in recent years. In fact, in the United States during 2015, specialty medications accounted for 75% of all the new growth related to spending and of 36% of the total cost (IMS Institute for Healthcare Informatics, 2016). This is expected to continue for the foreseeable future and is viewed as a great burden to the payers within the healthcare system, most notably, when it comes to indirect costs such as poorer clinical outcomes leading to patients not being able to work or lower productivity outputs.

It is believed that financial assistance provided to patients with higher medication costs to compliment or assist in the payment of their copay portion may help to lower the direct and

indirect impact on the healthcare's fiscal burden. Pharmaceutical companies which develop, manufacture, and sell these specialty medications, along with retail pharmacy stores, have commercial incentives to provide financial assistance in this capacity in order to ensure that the patients have access to the medications they provide. Studies suggest a connection between the patient's out-of-pocket (OOP) costs for specialty medications and the outright abandonment of the medicine regimen, resulting in intentional medication nonadherence (Streeter et al, 2011 and Gleason et al, 2009). Further evidence put forth by Dusetzina et al (2014) demonstrates a connection between higher copay costs for patients and nonadherence or discontinuation of use.

Although financial assistance programs do exist, research continues to show medication adherence rates at approximately 50% within chronic diseases for patients who had used such programs. Roberts et al (2014) concluded, after following 866 patients with a chronic disease who participated in a Pharmacy Assistance Program, that although inpatient or emergency room resource requirements were lower, actual adherence to their medication regimens remained at 50%. In this study, the benchmark for a patient to be deemed adherent was 80%; a consistent level of adherence across much of the research. This may suggest that the basic availability of the PAP, leading to financial assistance for the patient in obtaining the medication, may not only be the determining factor in influencing the patient to adhere to the medication regimen.

Patients who have the ability to enroll in variations of financial assistance programs are able to lessen the cost burden generally associated with specialty medications (Garner, 2010). Unfortunately, there remains a gap in terms of clinicians providing information regarding such available programs leading only a small portion of the patient base in actually gaining access to the funding (Piette et al, 2004). Although, Zhu et al (2018) research suggest further research in the area of medication adherence and financial assistance, the coordination of information leading to matching those organizations whom provide fundamental financial assistance to the patients who need it most given the current high cost and trending newer of medications may be the critical link to patients not only accessing the medications but in turn adhering the regimens prescribed by the healthcare professional.

# 2.8 Potential Research Gaps, Barriers, and Inadequacies

Research gaps continue to exist regarding the understanding of how to manage, coordinate, and assign interventional medication adherence approaches given the multitude of factors involved. Noting the complexities and variations of medication nonadherence, Brown and Bussell (2011) suggest, opportunities for improvement must be multifactorial. During this research, retail pharmacists determined and agreed that engaging the human actor, from either the patient or the healthcare provider's perspective, presented many barriers and inadequacies. We are all humanly different and act in a variety of ways depending on the situation as it relates to either the delivery or acceptance of care.

Kumarasamy et al (2005) note that perceived barriers to patient's medication adherence may be classified into 'themes' such as cost and social support. Surprisingly, given a patient's action to seek out medical help, the research also denoted a rarely seen concept of the benefits of not adhering to the medication regime, claiming that some patients are concerned with broader aspects inclusive of side effects. In other words, some patients intentionally associated medication nonadherence with a benefit to themselves. This again highlights the web of complexity dependent on the patient.

Cost as a barrier to medication adherence was noted as one most frequently discussed factors and included several subset themes such as financial hardship due to life's other necessities, self-driven drug 'holidays' or intervals without taking the medication to help avoid financial hardship, and worry regarding future ability to buy medications (Kumarasamy et al, 2005).

Kumarasamy et al (2005) further highlight the importance of social support outside of the healthcare system. Depending on the disease state, there may be varying levels of support with respect to a patient's family, friends, and the community around them. This often impacted the medication adherence rates as the social support network could not only remind the patient, but sometimes directly assist in the administration of the medication, or even offer financial help in the purchase of the same.

Measurement methods of medication adherence are generally classified as self-reports put forth by the patient, counting the number of pills, prescription refill frequency, biological monitoring, and various forms of electronic monitoring. Each of these categories has its limitations (Garfield et al, 2011, Cramer et al, 1989 & Claxton et al, 2001). Self-reporting by the patient relies on accurate memory and recall of the action taken. Counting the number of pills in a bottle or package may be unreliable due to miscounts or lost pills. Monitoring prescription refills simply recognizes when the prescription has been filled and medication has been dispensed at the pharmacy and is not representative of when a patient actually takes the medicine. Biological monitoring is often deemed impractical or invasive, while electronic monitoring is only effective in recognizing when the patient opens the medication container.

Validation of reporting systems may not always be an accurate measure for recognizing medication nonadherence. Self-reporting methods such as pill counting, electronic monitoring, and the testing of blood levels all have an element of patient reliance, emphasizing the importance of awareness that the information is only as good as the accuracy of data put into the system.

Ho et al (2009) reference several studies that demonstrated improved adherence rates, focusing on interactive voice technology, pharmacist-led interventions, education, reminders, and follow-up with the healthcare provider. Unfortunately, management personnel are needed to oversee coordination. This increases cost of implementation (Ho et al, 2009), in turn, presenting challenges given the numerous barriers involved. Though a daunting task to pursue, research gaps exist regarding the complexities of how to manage, coordinate, and assign interventional medication adherence approaches given the multitude of factors involved.

Research suggests no one solution improves adherence versus any other (Vermeire et al, 2001). Various aspects of medication adherence have been researched including those not only related to patients, but also clinicians such as physicians and pharmacists, leading to a wide body of potential solutions inclusive of not assigning blame, less frequent dosing regimens, recognizing the importance of health literacy and attentiveness (Brown and Bussell, 2011). Zygmunt et al (2002) note that concrete problem solving and methods to motivate patients were prevalent

features of good programs, while targeted programs were more effective than broad-based programs. This area of identifying the correct intervention after a thorough assessment of the patient's situation may warrant further investigation.

Electronic technological advancements in the past decade, along with the shear pace of innovation, require further research on their interventional impact on clinical and practical application. Several advancements have been noted in this literature review, each with its own potential for more comprehensive offerings as they continue to develop and improve yearly. For example, a research gap exists regarding the use of electronic data within retail pharmacy and tracking patient's refill rates over time. Historically, this data has been compared to patient self-reports only. Moving forward, this same refill data may act as a control arm in studies with a comparison to many of the other means of medication adherence noted in this review. Little or no research exists in this area.

From a similar perspective, Kronish and Ye (2013) note that, although researchers and clinicians often use an 80% medication possession ratio to determine satisfactory adherence to medications, the reference can be traced back to a small trial of scant research which has been done to identify whether an 80% threshold as a marker for categorizing adherence was sufficient for all diseases. They suggest that this lack of a specific measure might cause a void in knowledge, although most researchers take for granted the 80% cutoff point. As such, the same pharmacy data may be used to pursue new knowledge regarding medication adherence and various diseases.

Brown and Bussell (2011) note that because influences on adherence are often complex and varied, methods of improvement must be multifactorial. Arguably, research gaps concerning medication adherence are numerous given the multifaceted background and human actor component. Vermeire et al (2001) argue that inadequacies of compliance research have been a result of assuming the patient should be a passive participant without active involvement in the instructions. With the abundance of medical information in today's society and the availability of certain technological advances, this assumption may be challenged in the pursuit of solutions to

improve adherence and compliance. Furthermore, Vermeire et al (2001) proposes that, going forward, adherence research should focus on the rational motivations of behavior.

Traditional methods of assisting patients to adhere to medication regimes include the basic non-technological strategies such as physically having the medications in one's possession, storing them in a convenient place as to cause notice, and depending on family and friends to remind patients. In these cases, the perceived consequences of not adhering to the medication regime are noted as disease progression, side effects, and quality of life (Kumarasamy et al, 2005).

Technological advancements in the past decade such as the use of the internet to connect directly with the patient using email and SMS text messaging, as basic examples, requires further research efforts in order to determine their impact during practical application. This thesis pursued action research in an effort to generate new knowledge gathered from those on the front lines of healthcare, and has produced a set of smart recommendations towards improvements.

Given the shear pace of innovation, and beyond the scope of these recommendations, there is the potential to explore how technology, financial assistance, and diseases requiring specialty medications are intertwined in how patients adhere to taking their medications.

# 2.9 Literature Review Summary

Within the review of existing literature regarding medication adherence, many conclusions may be drawn. Perhaps most dominant is the 'urgency' of improving medication adherence. The WHO's statement that adherence improvements may be more effective than specific medical treatment advances (Brown and Bussell, 2011) certainly highlights the importance. Canada is not immune given 37 percent of the population has some form of chronic illness (9000 Points of Care, 2013). Furthermore, one of the largest health insurance organizations in Canada report that 5 percent of hospital admissions and 5 percent of physician visits are directly related to medication nonadherence (Sun Life, 2014). Although this is true, the ability to notably increase adherence rates is a difficult task given the various diseases it affects and the multifactorial approaches required.

This literature review highlights several aspects of medication adherence, including the nuances of various terminologies in order to enable the synthesizing of available literature, the prevalence of the issue as a whole, various categorizations of related factors, and the overall societal impact. Furthermore, it has focused on the many factors that have an effect on medication adherence, ways to measure and improve it such as recent advances in technology, along with potential gaps in knowledge that exist.

A common theme in the research recognizes that medication adherence is a multifactorial concept. Krueger et al (2005) may be representative of most researchers who determined that no single approach to improving patient compliance is enough to ensure or guarantee a positive result, and suggested that any attempt involve the patient in the process. Today, patients are seen as partners during the interaction. Noteworthy conclusions of Krueger et al (2005)'s comprehensive review included the importance of patient-centric initiatives such as proper education, an understanding of what to expect, clarity of possible barriers and how to navigate them, patient-specific regimens, close supervision, follow-up and rewards, mutual agreement on treatment goals, good social support, less complex treatment regimens, and individual counseling.

This vast array of solutions for improving upon medication adherence seems like a daunting task to assess. Still, alternate ways of thought and specific approaches relating to adherence are needed (Krueger et al, 2005). The implications for practice and managerial professionals within retail pharmacy may be far reaching. If implemented for the long run, and embedded within the day to day process flow for the healthcare professional, it may be possible to improve upon medication adherence rates. This remains to be discovered and beyond the scope of this study future research is recommended to determine firstly, the extent of practical change that has happened in terms of recommendation adoption and secondly, are there improvement in the rates of adherence.

If the answers to both these questions are positive, the next step would be to formally expand upon the scope of the practice geographically and continue to develop improvement processes to

the recommendations themselves. Furthermore, the implications from a theoretical and research point of view will require continued assessment. As technology along with the use of alternative methods to financially assist the patient to pay for medications continue to innovate, these advances will need to be tested as to determine how best to utilize them in the pursuit to improve upon medication adherence rates.

In order to generate new knowledge, action research requires "an intent to change the organization" (Easterby-Smith, Thorpe, Jackson, 2012, p. 155), in this case an entire Canadian industry from both the patient and professional perspectives. This is a massive undertaking given the unlimited variables involved in medication adherence. The possibilities go beyond that of just patient and retail pharmacists and may be envisaged to other aspects of healthcare. Comparably, the recommendations put forth as part of this study may be as clear as those put forth by the WHO as to better utilize the medications already developed in order to improve upon health outcomes. In other words, in Canada, we already have great tools to treat diseases requiring specialty medications. Better utilization is required with respect to adherence and instructions. Without argument, enhanced utilization of what currently exists would fit with local norms, values, and practical application.

That said, the recommendations put forth by retail pharmacists in Atlantic Canada calls for a level of new knowledge by asserting the information which already exists within the toolbox of the profession. In doing so, the new knowledge and contribution to the practice of pharmacy may not be a giant leap in the advancement of medication adherence rates but a small and important step embedded and used within the front-line settings.

# 3.0 Methodology

This chapter outlines the action research framework along with ethical considerations that were necessary to design a study that would capture enough data to garner deep considerations by the participants of what would enable a set of practical recommendations. The research sought to create a new level of understanding through an attempt to change the situation being investigated (Easterby-Smith, Thorpe, Jackson, 2012).

This action research project takes a mixed-methods approach whereby the data collection process pursues a "partnership design" (Easterby-Smith et al, 2012, p.62), combining both constructionist and positivist epistemological approaches through the use of an online survey and two focus group sessions respectively. Attention to 'importance of themes' set the direction for the cognitive activity as to connect established opinions, practice, and contextual implications of the data findings (Ramsey, 2014). The data collected was isolated during each cycle and evaluated separately before moving onto the next cycle in the sequence. Preliminary findings during each cycle were presented at the commencement of each subsequent cycle in the sequence.

The appropriate methodological choice for this research was important as the objective was to not only highlight the story of a very complex global problem, but narrow the purpose into a deep exploration and understanding of retail pharmacists' opinions regarding medication nonadherence in an attempt to put forth recommendations that had the ability to evolve. The journey of a mixed-methods approach was pursued as the intent was firstly, to establish a baseline of existing ideas, context, and opinions by the utilization of a survey. This was the existing knowledge component of the research. And secondly, move to an activity of scholarly practice through the use of focus groups whereby "attention is the key cognitive" (Ramsey, 2014, p.7). The methodological choice established the baseline norm and then let the participants drive the attention to active practice.

This research method of choice is defended in that the methodology required the ability to garner provisional insight or knowledge (hence the survey), reflective moments, a test environment, logic input, evaluation, and ongoing improvement throughout subsequent action cycles. In advance of the decision, it was important to fully understand the objectives of the overall research. Firstly, how would I establish the provisional insight? A survey was sequenced to commence the research utilizing the five WHO categorizations while adding two additional broad topics to inquire about the existing paradigms of the frontline practitioners. This was by no means the only methodology that may have been pursed at the start of the field research, but did

serve its purpose in informing a framework basis to proceed with general knowledge that the participants could understand.

Ramsey (2014, p.16) discusses the importance of "a practice of inquiry" as one of three subset domains of attention within managerial research and the action it involves as a formalized method to determine and test ideas towards arriving to a place of emergent sense making instead of being purely analytical. This scholarly practice research was focused on engagement, inquiry, and navigation of the themes or ideas of interest and was reflected in the methodological choice.

The situational 'context' was not only critical to the choice of research methodology, especially during the action cycles as a foundation for reflection, but also to mapping the terrain. In order to map the terrain in a scholarly fashion, it was critical to engage the intellectual imagination of the retail pharmacists within a "robust, intentional, and evaluative inquiry" (Ramsey, 2014, p.15). The depth of the participant's contextual competence aided in the ability to highlight the issues. Arguably, this level of insight, was only recognizable by practicing front-line professionals as to what the discoveries, or limitations, might be.

Enormous amounts of knowledge relating to medication adherence is available and well established. Adherence rates, lack of change, and similar solutions are common language across the academic literature. Significant reference and acceptance are given to the existing knowledge base relating to findings established by reputable researchers and authoritative bodies such as the WHO. Arguably, what is lacking is scholarly, rigorous practice that attempts to pursue "ongoing, skeptical and evaluative testing of actions" (Ramsey, 2014, p.18). In other words, what is the challenge to this knowledge?

Mapping of the terrain set out to identify themes of importance and attempted to interpret what resonated in detailed communications with patients. The forty themes isolated by the participants provided the robustness within the rigorous inquiry while the action cycling allowed for the "intentional and evaluative" (Ramsey, 2014, p.15-16) insight to narrow the importance of rankings. It was scholarly practice in motion.

## **Testing Plausibility**

The considerations and reflexive critique by retail pharmacists formed at a level of interaction through "knowing in action" (Ramsey, 2014, p.8) assisted in determining the two specific recommendations put forth as an output of this thesis. Varying levels of 'importance' of each of the forty different themes generated by the research helped isolate those that were a priority in order to assert lasting change of medication adherence rates. In doing so, the retail pharmacists brought concentrated attention to integrating ideas into practice. The recommendations would be intentional and purposeful.

As a result of connecting theory to practice, the patient's ability to fund their medications, monitoring of prescription refills, and the timing of discussions with the patient surrounding their medications were the central concepts once the bridging of ideas, inquiry, and navigating the relations had taken place.

Upon the formulation of the two recommendations during the final action cycle with retail pharmacists in Atlantic Canada, I had the opportunity to test plausibility on a broader scale in order to assess the potential for practical application on the front lines of healthcare. Separate meetings took place with the Canadian Pharmacists Association, which represents 60,000 membership pharmacists, and the Neighborhood Pharmacy Association, which represents the chain drug stores which account for approximately 75% of the Canadian prescription volume. Although none of the specific underlying findings in this study were disclosed so as not to impact the integrity of the research, the topic of medication nonadherence as major problem was discussed. The smart recommendations were put forth as a potential positive and practical offering and each organization supported this action moving forward. This subtle market test was an indicator of acceptance by those that are attentive to the profession, and a measure of plausibility of the recommendations.

Table #3: Demographic Profiles of Participants

Overview - Demographic Profiles of Participants			
	Cycle 1 Survey	Cycle 2 Focus Group	Cycle 3 Focus Group
Quantity	115 (3.7% of Atlantic Total)	10	11
Geo Breakdown: NS / PEI / NL / NB	12 / 23 / 28 / 36 (%)	2/5/0/3	4/4/0/3
% with a University Degree	93	100	100
% Experience > 10 years	50	90	91
% Work > 30 hours per week	53	100	100
% See > 45 Patients per day	42	90	91
% Employed in Chain or Banner vs Other	74 / 26	50 /50	64 /36
% Urban vs Rural	63 / 37	100 / 0	100 /0
% Above and Below Age 40	47 /53	90 / 10	91 / 9
% Gender M / F	28 / 72	60 / 40	55 / 45
% Front Line worker	67	90	91

The research sought to develop practical solutions for those on the front lines of healthcare directly working with patients every day. With the ability to pursue continuous cycling, forward thinking, and rigor towards the same, change may happen. This was the objective in this action research as it took in the perspective of practicality in a 'how to' (Elliott, 1991) approach, centered around the opinions of retail pharmacists.

Choosing to implement a mixed methods methodology fit the techniques required to garner a baseline of current believes and knowledge regarding medication non-adherence and the ability to use that baseline to lead into the deeper conversation and evolvement of new knowledge. The baseline of current opinions put forth by the participants taking on a positivist paradigm meant that as the observer I was independent, and given concepts of the WHO predetermined for basic units of analysis during measurability generalization could occur. The online survey fit these requirements. The transition into the cycling of focus groups thereafter would be able to utilize the survey outcome data whereby the philosophical perspective would then border on a move to the epistemology of relativism, in order to compare and generate opinions and new insights, to that of nominalism that enabled invention, participatory critique, engagement, shared experiences, sense-making, and the possibility of new knowledge and actionable recommendations (Easterby-Smith, Thorpe, Jackson, 2012).

The 'sequence' and starting point regarding the methodological design was critical as to put forth study aims, optimally utilize the data, and analyze or interpret the findings before a set of recommendations could be determined. However, dominance of both perspectives was given equal weighting and became critically important within the 'integrated' data analysis utilizing the Mixed Methods Matrix (Overall Findings, Table #4).

The ontological perspective was also an important consideration. Given that the patient is at the root cause of the concept of medication non-adherence which is socially defined, viewed, and experienced differently by different people a relativist paradigm was required. Also, a relativist paradigm across the whole research project was a must "if ontologies are very different there will be no way of resolving the confusion" and "if they are close enough then resolution may be possible" (Easterby-Smith, Thorpe, Jackson, 2012, p.64). This was also a good choice from the pharmacist vantage point as their views were assumed to be different from one professional to the next depending on backgrounds, status and practical pharmacist-patient experiences. Furthermore, as pragmatism "argues that knowledge and understanding should be derived from direct experience" (Easterby-Smith, Thorpe, Jackson, 2012, p.344) and noting that the objective of the study was to put for recommendations it would be important to take a pragmatic approach to commence without inhibiting creative ideas and discussions thereafter.

Data assimilation posed challenges as integration of both methodologies is 'difficult' at best (O'Cathain et al, 2010). Heading into the study, I realized that this may have led to a limitation in garnering new knowledge as to put forth future recommendations. It may have presented barriers in this synthesis (Voils et al, 2008). Fortunately, some researchers argue that there are methods, when adopted adequately, which provide pathways to synthesizing the data. I chose an integrated design put forth by Sandelowski *et al* (2006, figure #27) in an attempt to answer the research question regarding medication adherence.

Although the collective analysis was integrated, the data collection design was segregated and sequenced as:

The participants did not have input into the design of the three cycles. Furthermore, the research was considered participatory action research as it sought to make change as a result of collaboration and reflection in settings outside the practical work place as to focus on the deep consideration of the factors and possible solutions of medication non-adherence. The inquiry was based on practical experiences of the participants.

The concept of cycles during the action research highlights the continuous process to plan, act, observe, and reflect (Kuhne & Quigley, 1997) in the formal context. The individual epistemological approaches support the methodology design choice and requirements during specific times during the study. The terms cycles and either the online survey or focus group sessions may be used interchangeably depending on the context of the writing and the AR sequence above. Beyond the broader explanation of the framework, the chapter provides an indepth explanation of the action cycles 1, 2, and 3.

#### 3.1 Action Research Framework

Based on a preliminary assessment, the five WHO's categorizations of Patient, Therapy, Disease, Socioeconomics, and Health Related Systems relating to reasons for medication non-adherence would be the 'core' of the AR Framework. For the purpose of this research, the current available knowledge within these WHO categorizations was best suited to the research goals. Furthermore, this core would be further enhanced by breaking out two subset groupings that existed within the five formal categorizations to that of their own. The two groupings of 'technology' and 'financial assistance provided to patients' warranted further review in order to assert their role within the medication adherence construct, specifically relating to diseases that required specialty medicines.

As the researcher, I decided that these seven categorizations would optimize setting up a structured approach, without bias, to determine the current views and opinions of retail pharmacists in Atlantic Canada. An online survey during cycle 1 to commence the study, was an appropriate means to outline a solid baseline. This design highlights the importance of the survey results serving the requirements of focus group sessions thereafter. Hence, cycles 2 and 3 were qualitatively driven as to "demonstrate generalizability, and to provide deeper insights that explain why things take place" (Easterby-Smith, Thorpe, Jackson, 2012, p.63).

The choice of a mixed methods approach and subsequent framework was not meant to highlight any of the "long-standing tension" (Easterby-Smith, Thorpe, Jackson, 2012, p.1) of either method but complement each other during the scope of the project. This is consistent with the notion that for many important questions within management research that there are times when both methods would be not only acceptable, but optimal (Easterby-Smith, Thorpe, Jackson, 2012). Furthermore, although there is debate on the use of mixed methods approaches, for the requirements of this study, I sided with those that argue in favour in order to "increase validity and generalizability of results" (Easterby-Smith, Thorpe, Jackson, 2012, p.61).

The online survey structure was set up to align with the seven chosen categories. The instruments used in the research included a survey via SurveyMonkey (SurveyMonkey.com), an online software tool. Thereafter, small private focus groups to create discussion and an open dialogue were pursued. For data capture during the cycling of meetings throughout the focus groups, field notes, journaling, and audio recordings were used to assist in collection. This not only enhanced the quality of data during post-meeting assessments and early analysis, but also served as preparation for future meetings as part of the cycling process.

The intent of the action research framework was to create an environment whereby retail pharmacists in Atlantic Canada were able to focus their attention away from routine professional tasks and guide the discussion and thought process directly towards medication adherence. The

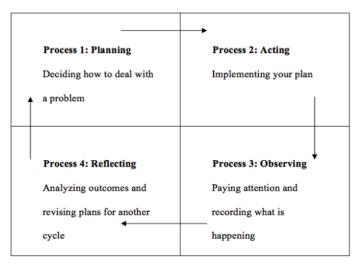
desire was that the participants would gain a comfortable and relaxed feeling with their own professional colleagues in order to create a forum for them to express their views. The opinions formed through engagement in research project were intended to provide enough data to enable the formal drafting of recommendations. If appropriate, these recommendations would be given to pharmacist colleagues along with other healthcare providers to assess and potentially implement in the practical setting thereafter. Furthermore, it could be possible that any of the smart recommendations may set the stage for third-party interest, commercial or otherwise, to pursue those actions that bring into reality the day-to-day set of professional tasks required to help improve medication adherence rates in the practical setting.

The goal was that the formalized smart recommendations, put forth by the practicing pharmacists, would become entrenched in the approach relating to matters of medication adherence at the point of care within retail pharmacies. It would need to become part of the protocol rather than an afterthought or an unachievable task on a list of competing priorities during a busy day in the retail pharmacy setting. As outlined in *Figure #3*, the action research process suggests to plan, act, observe, and reflect (Kuhne & Quigley, 1997), so too does the day-to-day operational aspect of long-term progress of medication adherence.

#### Overarching guidelines of the Research

- 1. Create an approach with the participants that keeps them comfortable to communicate but also challenges them to engage colleagues on the topic.
- 2. As participation was voluntary, ensure to provide an environment that promotes emotion and passion in order to engage them and encourage them to speak freely on the subject matter.
- 3. Encourage collaboration within the profession for the good of the patient, even though most participants will be employed with competitive organizations.
- 4. Celebrate the ability to be self-critical of conversation in order to build commitment to progressing towards a set of smart recommendations.
- 5. Explore direct examples of failures and successes.

- 6. Implement short cycles with small groups in order to slow the speed of progression. This will keep the subject matter at the forefront of the minds of participants. The research is not expected to find a set of complete solutions to medication nonadherence. Progress is the key and any set of smart recommendations should be able to be improved upon after the action research.
- 7. Keep the cycles moving. Ultimately, there should be no end point in the pursuit of improvement to medication adherence rates.



Action Research Process as a Conceptual Model (Kuhne & Quigley, 1997)

Figure #4: Action Research Process as a Conceptual Model

Each of the cycles built upon its antecedent by informing the participants of the preliminary input and results put forth by themselves and regional colleagues. This not only provided the ongoing feedback required to move through the cycles but continued to demonstrate themes necessary to investigate further and open up new discovery. This process was meant not to lead, but rather to open up the thought process and enable a deeper dive into the unknown given the comfort the participants felt in expressing their views and opinions (Easterby-Smith, 2012). These data collection techniques were used to ensure quality and accuracy.

Polyangulation, or by viewing the realities in multiple layers and dimensions (Raul AM, 2014) to compliment multiple realities (as in triangulation) assisted in the interpretation and comprehension of the data collected by the end of the third action cycle. This approach made

sense in relation to the recommendations and in terms of practical implementation. This consideration was taken given the social realities and potential shifts in the interpretation of discussions from one cycle to the next. Medication adherence is complex, given the human actor and psychological aspects, and requires a multilevel analysis, interpretation, and approach.

## Sample Characteristics

The online survey, cycle 1, ran from September  $6^{th}$  – October  $9^{th}$ , 2017. Preliminary survey data analysis took place from October  $10^{th}$  –  $30^{th}$ , 2017. Thereafter, cycle 2 (focus groups) took place from November  $1^{st}$  –  $22^{nd}$  and cycle 3 between November  $28^{th}$  –  $30^{th}$ , 2017 respectively. Ongoing data analysis took place during the week between both focus group sessions. It is important to note that the mid-cycling analysis took place not only to view data upon collection but to use that data to reflect and plan as part of the action research process. Data from cycles was discussed and reviewed as part of the opening of the ongoing sequenced cycles.

A total of 115 participants engaged in whole or part of the survey from across the four targeted provinces. This number of participants represented 3.7% of the 3108 total licensed pharmacists in Atlantic Canada (NAPRA, 2019). The survey garnered a convenience respondent sample which was the optimal outcome as to evaluate the current general opinions of retail pharmacists and set the stage for discussions. This convenience sample was a non-probability sampling method which did not aim to get specific with correlation or probability of any of the sample elements. The sample was meant to be convenient, as the provinces are located in reasonable geographical vicinity to where I live, and simply evaluate the current opinions of retail pharmacists in Atlantic Canada without providing probability statements or detailed statistics. Its value to the study was to enable the baseline opinions within the categories chosen relating to what is currently known in medication adherence without limiting the ability of future cycles to create their own pathways or categorizations of new discovery.

Data from the focus groups were coded manually rather than automated using any form of a software tool. This traditional approach involved myself, as the researcher, to assign a manual value of perceived importance relative to the discussion item (see Mixed Methods Matrix, Table

#4).

## My role as the researcher

My role as the researcher, considering both the important topic and interest within it, came with some advantages in that, although I wasn't a pharmacist participant and assumed without bias in terms of facilitation, I was seen as part of the collective group discussion. Furthermore, I was seen as objective in my role during the setup of the research meetings, discussion facilitation, and journaling. As well, my background related to their industry allowed me, to understand much of the sensitive information and discussion without having to stop and ask for clarification. There was a level of knowledge relating to their profession, albeit assumed, leading into the discussions.

Unfortunately, many of the attributes I brought as the researcher, may have created bias towards any of the interpretation during the conversation. It may be possible that some of the content leading to findings would have been inaccurate as a result of misinterpretation. Furthermore, as novice researcher, I may have focused on the larger discussions rather than those that may have been a deeper one-off which could have led to new knowledge. In other words, the routine conversations may have been overlooked especially given the limited amount of cycles during this research. This limitation may as well not have provided the time necessary to establish optimum levels of trust. This is an unknown.

As an insider, I was comfortable with the duality of roles as I took on the perspective of a researcher, although knowledgeable in the subject matter, limiting my discussion and opinion other than facilitation and clarification of the participant's communication. Furthermore, there were no notable conflicts of interest. Any perceived commercial or political stances assumed during the early introductory phases of the sessions, based on varying employers, where quickly dismissed at commencement thus supporting the professional aspects of their profession and value of practical opinion and experience.

#### 3.2 Ethical Considerations

Participants in either of the quantitative or qualitative methods of the study had minimal potential for any personal or professional risk. The importance of privacy and confidentiality played a critical role in the consideration of methodological choice (Brownlow & O'Dell, 2002), meeting settings, presentation structure and research flow. No personal data was needed within the enrolment for the online survey and as such informed consent was appropriate. Given that individual data requires reasonable protection from risk of loss, access, the ability to change, or viewing (Elgesem, 1999) this note leading into the online survey was bolded and implied consent was assumed based on the participant proceeding to fill out the survey thereafter:

Please respond to these questions openly and truthfully. All results will remain confidential and will only be reported in aggregate form. No individual personal identifiers will be reported in order to protect your confidentiality and privacy. The data will only be available to the researcher.

The survey invitation and survey questions are presented in Appendices D and E respectively. Data collected during the survey were stored in the SurveyMonkey system:

SurveyMonkey Website privacy policy: surveys are stored in a SAS 70 Type II certified Sungard data center protected with biometric access controls, a firewall that restricts access to all outgoing ports (except 80 and 443 as is customary), QualysGuard network scans run weekly, McAfee HackerSafe scans run daily, and data backups run hourly.

In keeping with the important ethical principles (Easterby-Smith, Thorpe, & Jackson, 2012) for focus groups, great care was taken to determine the venue, setting, and discussion flow. Independent focus group meetings were conducted in closed settings in order to ensure privacy and confidentiality. All participants were provided participation information sheets in advance of the sessions and formal written consent was discussed and obtained prior to focus group session commencement.

Limited personal data was required. Questions were asked regarding the professional background individually and presented in the collective context. For Consent forms and Participation Information Sheets refer to Appendices A and B respectively. An example of the copy of the Focus Group invitation is presented in Appendix C. Presentations during both focus groups are available in Appendices F and G respectively.

As with any type of collected or stored electronic data, even given significant safeguards for protection, it is reasonably possible for any form of information exchange through electronic communication to be hacked or accessed by external parties, the participants were made aware of this risk. If this were to happen, minimum or no harm would occur as a result as all data collection omitted any individual or personal identifiers including that of the participant or patient. These types of identifiers were unnecessary for the purpose of the study.

All data collected during this action research was be kept on a secure, encrypted flash drive. This will be done for up to a five-year period. The flash drive is password protected and will be accessible in the researcher's private office and residence. This office is locked at all times when not being used. Upon five years of storage the secured flash drive will be destroyed.

#### 3.3 Action Research Cycle 1: Online Survey

Survey Design: Utilizing the WHO categorizations relating to Medication Adherence

The WHO has identified five broad domains that are categorized in relation to medication adherence including Health System, Socioeconomic, Patient, Disease, and Therapy. Not only does the WHO refer to these domains from their perspective, research generally falls within one of these five areas, or at the very least, a subset list of associated variables which would fall within any one of said areas. For the purposes of this study, these domains are considered to be reasonable given the WHO's status and reputation. Furthermore, there was no challenge on the baseline list of these categorizations as the qualitative component during the focus group sessions would provide the avenue to discover other themes. The challenge or pursuit of new knowledge was devoted to uncovering practical applications to improve upon medication

adherence put forth by frontline retail pharmacists.

A survey of 24 questions provided a non-probability convenience sample from 115 retail pharmacists across Atlantic Canada. The survey captured the demographic profiles of the participants within the first ten questions and, for the remaining questions, focused on the 'level of importance' of subset factors categorized within the seven broader dimensions outlined within the title of the thesis. Importance of factors was determined by rankings of the participants whereby a software survey tool, SurveyMonkey, was used to implement a design with a 5-Point Likert Scale. Importance of themes were ranked whereby 1 stood for "Not Important", 2 "Somewhat Important", 3 "Important", 4 "Very Important", and 5 "Extremely Important". Thereafter, responses were grouped into three categories: 1) "Not Important/Somewhat Important", 2) "Important", and 3) "Very Important/Extremely Important" to facilitate analysis.

Participants were invited to participate in an online survey through each of their provincial associations membership databases. An email request including the survey introduction, my personal background, research purpose, and link to the survey were included. Reminders were sent out periodically to ask members of the association to engage with the survey.

Respondents were well educated with almost all having a university undergraduate degree at minimum. Most had a large amount of experience working in a pharmacy setting with a third working in their current job function for 10 years or more. The vast majority spent considerable time dealing with their patients, with almost half spending more than 30 hours with patients on an average week and almost half seeing at least 45 patients on an average day. Nearly half of the participants worked for a Chain retail pharmacy while almost two-thirds of respondents worked in an urban environment. The age range was split down the middle with just over half under 40 years and the other half over 40. Female respondents far outweighed the survey with almost three-quarters.

To summarize, the participant demographics suggest that those responding to the survey should have considerable and reliable insight into the patient populations they serve on a daily basis. Increasingly, many of these patients entering the pharmacy have diseases requiring specialty

medicines given the growth of these types of medicines within recent years.

## 3.4 Action Research Cycle 2: Focus Group Session 1

Three separate sessions were required for this focus group based on geographical considerations as participants were spread over three of the four provinces. Each session pursued a two-hour interactive discussion and was journaled and audiotaped. Each session garnered several pages of hand-written notes used to capture verbatim quotes, statements, and interactive subtle cues. The journaling by use of field notes was relied upon extensively for analysis post-focus group sessions. The audiotaping was used to confirm what was written and used only as a secondary backup for clarification if necessary.

Notably, the non-verbal communication was important as it provided a level or helpful measure of importance during that conversation or subtopic. Although observation of the non-verbal communication was not scientifically driven, it did take into consideration such things as body movements, posture, tone, and facial expressions to assert a level of importance of the noted discussion points. The observation of non-verbal aspects was considered casual and not formally documented other than imbedding in the importance level. The informality of the non-verbal observation was based on casual perception and understood to be a limitation given the insider's perspective.

Furthermore, many subtopics were given ample time in order to dig deeper on the underlying issue. The liberty to flow into various themes provided the understanding and breadth of possibility to put forth suggested changes leading to the set of smart recommendations.

Themes were assessed based on ranking of importance (high, med, low) by way of manual coding which is often used in qualitative research. This provided a means of "quantitising" (O'Cathain et al, 2010, p.6) the findings of the focus groups.

The total participants for the first of two focus groups across all four Atlantic provincial regions were 10. This included 5 from Prince Edward Island, 3 from New Brunswick, 0 from Newfoundland and 2 from Nova Scotia.

Although Newfoundland participants showed interest during the online survey portion of the research, little interested was shown to be involved during the focus group sessions thereafter. The survey data from Newfoundland respondents came from a vast amount of geographical locations and the focus group session was to be set up within the largest urban setting. Although it is unclear why no participants came forward, it is possible that the distance to travel may have been a limitation. As a result, action cycle meetings were not set up in Newfoundland. For the collective focus group session exclusive of Newfoundland, three separate meetings had to be set up based on the geographical locations of the participants. This created a significant amount of effort in the planning and execution of each individual meetings and data collected from each were grouped together.

Participants from the three provinces came from a variety of workplace backgrounds including chain pharmacy, banner pharmacy, niche or specialized pharmacy which focuses almost exclusively on patients with diseases requiring specialty medicines, and pharmacy independently owned or with a hospital background. With the exception of one participant who had over ten years of experience, all participants had a minimum of 20 or more years practical work experience on the front lines, directly with patients.

Written notes during each focus group session captured both verbatim comments and opinions throughout the groups. Though difficult to capture, nonverbal body language was attempted to be recorded during the discussions as to assist in validating the true meaning of the groups' communication. For example, was 'groupthink' a part of the broader meaning or was there true consensus? The sessions were also audiotaped in order to verify the intent and translation of the discussion points.

Regarding the interview and facilitation skills of myself as the researcher, there was no formal background training in the aspect of qualitative research interviewing. However, I had been

previously trained in the field of behavioral event interviewing for employment purposes and had spent decades in people management which often included formal interviews, facilitation, and presentations. Although not trained in the profession of pharmacy, I had over 25 years of direct experience interacting with pharmacists as my customer within the pharmaceutical industry. As such, I did not encounter any difficulties during the sessions. Furthermore, the focus groups were conducted in the English language and attention during discussions could focus on both verbal and nonverbal points of discussion.

### 3.5 Action Research Cycle 3: Focus Group Session 2

Participants who had been involved in the first action cycle were given priority to participate in the second focus group or action cycle 3. As with action cycle 2, a total of three independent meetings were set up based on geography in closed settings as to ensure privacy and confidentiality. Furthermore, two new participants joined the group and were provided participation information sheets upfront and formal written consent was discussed and obtained prior to the session commencement.

The implementation of this focus group was consistent with that of Cycle 2. Again, themes were assessed based on ranking of importance (high, med, low) by way of manual coding.

Collectively, the data was formally assessed by an 'integrated' analysis utilizing the Mixed Methods Matrix (Overall Findings, Table #4) to arrive at the overall findings. Within the analysis, treatment of data throughout each cycle focused on important themes. As mentioned, Cycle 1 utilized a quantifiable approach with a Survey and '5-Point Likert Scale'. Cycles 2 and 3 level of importance rankings were determined with 'manual coding' by myself as the researcher and based on observation. The final seven themes of most importance, or those that garnered deliberate attention (Ramsey, 2014), required a consistent level of 'high' ranking throughout the cycles in order to be considered generative as they directly laid out the foundation for smart recommendations.

The total number of participants across all provincial regions for action cycle 3 was eleven as

one participant dropped off in Nova Scotia. As such, this session included four from Prince Edward Island, three from New Brunswick, zero from Newfoundland and four from Nova Scotia. The two new participants from Nova Scotia were easily able to engage in the discussion as there was a brief overview of the first focus group session results and agreement was gained on the themes and issues that were arising. This slight change from one focus group to the next had no effect on the findings. Again, although Newfoundland participants showed interest during the online survey portion of the research, little interested was shown in being involved during the action cycles thereafter. As a result, a session was not set up in that province.

Consistent with the cycle 2 focus group, participants were noted to have come from a variety of workplace backgrounds including chain, banner, specialty and independent pharmacies. Of the total participants in the third action cycle (focus group), 9 had participated in the second action cycle (focus group). The other 2 were new participants but engaged quickly and agreed with the themes developed from the survey and prior focus groups.

Overall, this chapter binds together the action research framework regarding epistemological and ontological perspectives, ethical considerations, my role as an insider, and methodological approaches during each cycle. The choice of a mixed methods approach seemed justified for this study. Arguably, from either of the philological stances, there will be advantages and disadvantages along with varying receptivity of the study direction by participants. The most significant issue evolved around how to evaluate the data. Based on a review of different approaches, an integrated analysis often used in health research was chosen.

The following chapter takes a deeper dive into each of the action cycles data analysis methodology and reflection before leading into the complete evaluation of outcomes.

# 4.0 Story of Cycles of Action, Reflection

The recommendations put forth as an output of the key findings, consistent with actionable knowledge as a DBA requirement, determine that action is needed now although confidence levels will be lower in the pursuit of practical change. Reasonable judgement has prevailed

throughout the three action cycles in order to submit that further long-term cycling is required as to embed the processes of natural day-to-day work flow and evaluation directly into the practical settings or industry context.

This chapter provides an overview on how the action cycles were designed, processed, and implemented. Reflection between each action cycle provided space to commence with the preliminary analysis and sensemaking as well as develop the status content for the opening of future cycles. Cycle 3 also led to the evolvement of actionable recommendations given the important themes and new knowledge that was developed.

As noted by the Rich Picture Experience of the Author and Participants (Figure #3), participants in the action research, retail pharmacists at the forefront of interactive patient care, were within the locus of action. Their position within the environment is not only unique, but demanding given their place within the healthcare system structure and process, at the forefront of medication discussions and instructional adherence communication with patients.

The Participant

Working Environment - Structure

Prior to entry into the profession, pharmacists are trained in the profession of medication dispensation with an underlying set of standards around a broad range of clinical, ethical, and practical domains. This not only outlines their role within the clinical process inclusive of other stakeholders, but considers important aspects of the environment such as the significant number of patients with a chronic disease and how medication adherence is a dominant factor.

Participants did note that although other aspects of the retail pharmacy environment were highlighted and acknowledged during education and training, the conflict of the 'professional' and 'commercial' expectations were less of an emphasis and were assumed to be understood. Participants felt that this conflict impacted the concept of 'time' available within a busy retail setting. Furthermore, participants acknowledged the lack of training around the importance of

communication directed towards medication adherence behavior modification aside from formalized medication instruction and counselling.

#### Role and Integration - Process

Retail pharmacists bridge their background of professional training in the commercial setting with integration into a generalized process cycle which involves other stakeholders including the patient, physicians, pharmaceutical manufacturers, public and private payers, and a variety of other healthcare practitioners. Their interaction within this process involves multiple levels of knowledge and skillsets. Two-way communication can be noted at any stage of the process, but becomes fundamental when it involves the patient and the importance of adhering to medication instructions.

#### Reflection

During the action research cycles, the participants were asked to consider the retail environment and work flow processes they operate within and move from a set of opinions and beliefs, founded upon existing "knowledge" (Ramsey, 2014, p.6), to that of practice inquiry. During the transition from Cycle 1, driven by a survey, to that of the subsequent cycles 2 and 3 focus group sessions, the participants moved from the knowledge paradigm to a focus on deliberate attention (Ramsey, 2014).

Observationally, the stories of action noted the conversations as purposeful and generative whereby participants moved from a position of guardedness, given their framed positions within the structure and being employed by various and competing organizations, to that of understanding the research methodology and intent directed towards workable solutions. As an insider, I sensed the barriers of their differences breaking down very early in the process as understanding of the action research intentions increased, along with the realization of the importance of the effort. They engaged in the topic individually, rarely guarded, with passion for generative discovery that might lead to improvements of patient lives. Over time, the focus group sessions became more relaxed, friendly, with consideration of a common purpose through shared

experiences. The effort manifested itself in evolving themes known to be 'important' within the practical setting.

#### As the Author

My experience within the action research focused on setting up and executing the cycles in a structured and formalized approach. This included detailed attention to facilitation, clarification, and interpretation. Given that this was my first research project, I leaned heavily on the educational training and understanding I developed throughout the DBA degree. Fortunately, my industry experience and knowledge significantly help guide my actions during the preparation and facilitation of each cycle.

Given my personal background, and that of the research methodology, I took on a pragmatic mindset, not committed to a singular philosophy or reality. My intent was to facilitate a quality research project while, at the same time, not leaning on the academic structures I was generally accustomed to. Rather, I let the conversations focus on the attention to detail that led to small, progressive steps forward. Conversations were generative in nature. The intent was to "change the organization" (Easterby-Smith, Thorpe, Jackson, 2012, p.155) by utilizing the resources of those on the front lines of a practical setting.

My stories of action are reflective of my insider and outsider roles within the research. The cycle 1 survey overwhelmingly put me in the position of an outsider. Independent decisions relating to the quantitative approach, within the mixed methodology, were mine alone. These included the survey content questions and structure, implementation with the assistance of the provincial pharmacy associations, and analysis. The experience within the focus groups was much different as I felt the dual roles were prevalent. As an outsider, the sessions entailed detailing pages of hand-written notes in order to capture important conversation, quotes, and subtle cues to their meaning. My role as a facilitator often consciously kept me in check so as not to cross the line into the capacity as a participant. My observational skills were critical to compliment my interpretation of the discussions.

The insider role was notably important to the interpretation of non-verbal communication. It was within this role that the intimate understanding of the conversations took place and required consideration of the observational techniques assessing body movements, posture, tone, and facial expressions. As such, the observation of non-verbal aspects was considered casual and not formally documented other than imbedding in the importance level. The informality of the non-verbal observation was based on casual perception. Furthermore, many subtopics were given ample time in order to dig deeper on the underlying issue. The autonomy to flow into various themes provided the understanding and breadth of possibility to put forth suggested changes leading to the set of smart recommendations.

My experience as an insider was constantly top of mind. I was comfortable in the role and actively conscious and mindful of my position within the research setting. I took on the perspective as a researcher, an observer, and a facilitator. As I was knowledgeable in the subject matter, during the conversations, I limited any participation of my personal opinion or input. Actively, my outsider actions were focused on interactions to that of organizing, session setup, facilitation, and details clarification.

Assertions made as a direct result of the action cycling from a starting point of 'existing knowledge' garnered during the survey (cycle 1) to that of 'attention' provided by practical inquiry during the focus groups (cycles 2 and 3) led to a set of themes that were the foundation of two recommendations. The assertions that were dominant throughout each of the cycles were discussed with the participants at the commencement of each cycle in order to ensure any assumptions or perceptions by the author were correct. This action not only validated the dominant assertions but provided a critical linkage to the recommendations as an output of the thesis and practical inquiry.

During the survey, 32 predetermined themes were provided. Each of these themes were considered significant variables by the author in terms of medication adherence leading into the survey. Based on rankings of importance, five themes emerged as dominant that were directly related to (assertions) the future recommendations. These themes continued their important rankings throughout future cycles.

Cost and how to access funding for medications (four themes) and prescription refill monitoring (one theme) were highlighted as assertions or necessary considerations that supported the recommendation:

Establish a Centralized Repository of Information regarding access and availability of Patient Assistance Programs.

Numerous quotes by the participants provided the foundation for assertions leading to the recommendation. All direct quotes are not listed below. Those listed below are representative of the assertions made that supported the recommendation.

"We need knowledge and insight to be the patient assistance program advocate."

"The individual pharmaceutical manufacturers don't advertise the programs broadly. It would help if they all went on."

"Pharmacists feel stretched in terms of time allocation on finding what programs are available and in terms of navigating the system."

"Programs vary. Offerings are different. Forms are different. It is very time consuming to do this."

"With respect to medication adherence, we need to take the financial burden away."

"How do we navigate the system with the huge cost to these meds?"

"Some patients access the programs. Some don't, based on not knowing how. This is creating a two-tiered system."

Eight other themes were added during the focus groups and contributed to the breadth of discussion and brought the total thesis themes to 40. Interestingly, two additional themes ranking of high importance were highlighted during the focus group sessions. Although not considered as part of the dominant themes based on the requirements of importance ranking across the whole research project, the assertions were the foundation for the consideration of one of the two recommendations.

Those additional themes revolved around the importance of 'time' necessary to discuss medication adherence with patients and the 'timing' of those conversations. Those assertions supported the recommendation:

Increase the emphasis and support for a national standardized approach of medication reviews as it directly relates to timeliness, content, funding, training, and implementation.

All direct quotes are not listed below. Those listed are representative of the assertions made that supported the recommendation.

"Pharmacists have little time for medication adherence discussions and should be compensated for more than just counting pills."

"Unfortunately, the majority of education at pharmacy is when a person is sick. They have to absorb all the information at once. They are terrified, sick, and wanting to go home. How does that improve medication adherence?"

"Medication reviews need to take place when the patient is not sick or stressed in order to create the human connection."

"A personal connection... medication reviews are critical to this. Making it a basic principle should be paramount."

"An increase in adherence would mean an increase in revenue for pharmacy."

"IDR software can identify when patients need a refill and would improve medication adherence."

"Often, when a patient asks one question it creates others and a patient opens up."

## 4.1 Action Research Cycle 1: Online Survey (Sept. 6 – Oct. 9, 2017)

Participant invitations for the online survey were directed at retail pharmacists in Atlantic Canada, which includes the four provinces of Newfoundland, Prince Edward Island, Nova Scotia, and New Brunswick. These participants had some experience working on the frontlines of pharmacy with patients with diseases requiring specialty medicines. These pharmacists were generally members of local provincial associations that act on their behalf to support the professional development and economic interests of its members to advance the practice of pharmacy in their designated geographical area. Through upfront telephone discussions and formal written requests to each of the Directors of the provincial pharmacy associations in Atlantic Canada, approval of the online survey issuance to their membership was acquired. The survey was issued by the pharmacy associations using their own membership databases.

The formal request provided the thesis title, the researcher's personal background, intent of the research, a SurveyMonkey (survey software) web link, a privacy statement, and an invitation to voluntarily enroll into action cycle focus groups thereafter. Formal approval and endorsement were received through acceptance by the pharmacy association Directors of each province to email their membership requesting participation in the survey, and to complete the survey. Refer to Appendices D and E respectively for the survey invitation and questionnaire.

Pharmacists membership in each of the four provinces included:

Prince Edward Island	195	
Newfoundland	726	
New Brunswick	879	
Nova Scotia	<u>1308</u>	
Total Atlantic Provinces	3108	(3.7% of the total membership)

Phase I of the thesis research commenced September 6<sup>th</sup>, 2017 with dispersion of the online survey. This component of the research which represented action cycle 1, and the quantitative aspect, was placed first in sequence, followed by action cycles 2 and 3 representing the focus groups scheduled for November, 2017. Action cycle 1 was intended to provide a convenience sample. Reminders to the pharmacy association's membership went out after two weeks in order to encourage the participants to engage in the survey and increase the overall number of respondents. The survey closed October 9<sup>th</sup>, 2017. Although the respondent numbers counted 115 participants for the survey's duration, which did not provide a statistically significant representation of the broader group, the survey was considered a success.

With 115 respondents, the online survey provided a convenience sample intended to garner primary information which determined presentation content for the introduction to focus group action cycles 2 and 3. The respondents represented a cross section of participants from the profession including a background mix of age, gender, tenure in the industry, and associated employers. The inference of the data collected is assumed to be representative of the broader retail pharmacist population within the geographical area. As statistical significance of the data was not required an analysis of this was not pursued. The design methodology of the questionnaire and data analysis was meant to provide a foundation for discussion purposes of the subsequent cycles in an attempt to align with answering the research question and creating actionable knowledge.

## 4.2 Action Research Cycle 2: Focus Group Session 1 (Nov. 1 – 22, 2017)

Participants were determined using two methods; firstly, if they indicated on the final question of the online survey, which was sequenced prior to the focus group action cycles, that they had interest in further involvement in the action research, and secondly, if they responded to the formal invitation issued through their provincial pharmacy association. Priority was given to those who responded first who had working experience directly related to daily engagement with patients with diseases requiring specialty medicines. For action cycle 2, based on geographical considerations, three separate sessions where required. The same was also necessary for action cycle 3 discussed in the next section.

Action research cycle 2, the first of two focus group sessions, opened with a presentation to provide an overview of the online survey results. As previously noted, the survey was sent to all pharmacists in each of the Atlantic Canadian Pharmacy Association memberships prior to the session. This survey not only provided high-level results including opinions of professional pharmacists relative to the five WHO categorizations, but also addressed technology and the provision of financial assistance provided by the pharmaceutical industry through the use of electronic cards. This was intended to set the stage for formalized thought pathways that could be pursued during the focus group meetings.

Presentation of the research objectives, researcher's background and role, process and action research cycles, and high preliminary results of the online survey was implemented. This was provided not only to formalize the design and methodology of the research but to provoke themes and discussions around medication nonadherence in the participant's own practical work settings. Furthermore, it also provided a loose structure or "steered conversations" (Easterby-Smith, Thorpe, Jackson, 2012 p.133) to direct conversational engagement. Throughout the discussions, open probes following the organized format of a "topic guide" (Easterby-Smith, Thorpe, Jackson, 2012 p.133) were used to engage the audience and create opportunities for indepth conversation surrounding practical situations relating to each of the seven categorizations.

As all participants had common backgrounds, though mostly working for different organizations, participants seemed comfortable in expressing opinions. This allowed for the emergence of both generally known but also unforeseen areas of discussion. Common themes were recognized and pursued in order to dig deeper into the root causes of medication nonadherence. These themes were important in the manual coding as to assign discussion points accordingly. Overall, the settings and forum provided an environment for the participants to which they may not have otherwise been exposed, given the busy pace within the practical setting and limited time to discuss the issues surrounding medication nonadherence outside of the workplace. Assumingly, they felt relaxed and were able to put forth their experiences, views and opinions without threat (Easterby-Smith, Thorpe, & Jackson, 2012).

Given the action research cycle process, participants were instructed that it was necessary not to jump to conclusions, definitively attempt to match theories for medication nonadherence to solutions, or put forth final recommendations at that point, but rather openly pursue broad concepts or themes in order to bring out multiple thoughts and ideas. It was highlighted that the first action cycle focus group session was set up with the intent to explore a deeper understanding of the root causes of medication nonadherence from their own practical setting.

Thereafter, data collection across the common themes was assimilated across the broader set of sessions before going into the second set of formal focus group discussions.

# 4.3 Action Research Cycle 3: Focus Group Session 2 (Nov. 28 – 30, 2017)

Themes which began forming during the previous two cycles were assessed based on a manual coding, often used in qualitative research, using the measure of importance with that of low, medium, or high based on my informal perception. This was implemented as to avail the ability to compare data across the whole study in an integrated fashion. The observational data collected grouped the themes into 1. Either of the seven themes that originated within the survey, or 2. Other themes. Other themes of importance were captured only during the qualitative sessions and included surprise themes, two of which were consistently rated 'high' across both focus group

discussions and eventually played a critical part in the development of the smart recommendations.

To commence this session, a brief overview of the original presentation was provided which included the research objectives, researcher's background and role, and process. Furthermore, action cycle 3 began with the provision of an in-depth summary of the common themes discussed during action cycle 2, the previous focus group session, in order to create an environment in which to dig deeper on the root causes of medication nonadherence. These themes were given priority during action cycle 3. One further objective of this action cycle was to attempt to coordinate development of a set of smart recommendations to be put forth by the participants based on the themes generated during the action research.

#### 4.4 Methodology Discussion

Surprisingly, action research focused on deliberative attention by retail pharmacists to generate intentional and purposeful outputs surrounding medication adherence is, essentially, very limited. Researchers have consistently used empirical methods for decades while those involved in the day to day delivery of healthcare to patients have generally accepted, not only the process, but also the results. This highlights a significant gap in the overall research focus and the reliance on traditional methods. Argyris (1996) argues that interventions are unable to be pursued when 'operational' definitions are unknown that utilize underlying tacit and explicit knowledge to discover the intervention. I strongly agree.

Who best to engage, inquire, and navigate through the underlying considerations of medication nonadherence other than those practitioners that are one on one, face to face, within the center of gravity, with the PATIENT? It is based on this strong foundation, that I defend the reliability of the participants, their commitment, and involvement in this research. As the author, I ask, "Why hasn't significant effort within action research been afforded such an important topic already proven to lead to enormous financial, human, and societal deficits?"

This is a 'real problem' in a system that requires ongoing planning, assessment, adjustment, and evolvement. The basic concept of what numerous academic researchers suggest as solutions focused on a 'multifactorial approach' requires a constant ongoing set of cycles on many different narrowed pathways within medication adherence. The participants in this research, retail pharmacists, need to be congratulated on their energy and attention to detail on pursing workable solutions or a formalized set of smart recommendations. For those individuals, entering the action research was not mandatory. It was the pursuit of a better understanding that led them to this point by asking the tough questions and digging deeper on the emergent thoughts. It was about challenging the status quo, knowing full well that, although efforts may avail improvements, the road ahead within the practical setting will always require unique attention given the patient, a human actor, is each unique to their individual needs.

#### 5.0 Evaluation of Outcomes

## 5.1 Overview and Analysis

The required sequence of the partnership design and action cycles directed that the online survey was to be implemented first and the two sets of focus group sessions to follow thereafter. The online survey was issued simultaneously across each of the four Atlantic Canadian provinces through the provincial retail pharmacist's industry body known as pharmacy associations. Each provincial pharmacy association issued a communication invite to their respective membership utilizing their own individual databases.

Research Sequence Action Cycle 1: Online Survey

Action Cycle 2: Focus Group Session One (three groups)

Action Cycle 3: Focus Group Session Two (three groups)

The dominance of both methods used in the research was equal in regards to their individual importance for the overall data collection, although the focus group sessions did require more time and resource. Both the first and second focus group sessions required multiple meetings due

to geographical locations of the participants. The first focus group, as well as the second focus group, had participants in the respective provinces of New Brunswick, Nova Scotia, and Prince Edward Island. This element of the data collection and design required significant amounts of travel between the provinces, along with an enhanced level of coordination relating to the meeting settings and scheduling.

## 5.2 Action Cycle 1: Online Survey

The online survey constituted a convenience respondent sample in order to capture the current general opinions of retail pharmacists in Atlantic Canada. Consistent with the thesis objective, the online survey was utilized to garner a perspective on the impact of the current WHO five core categorizations of medication adherence factors, while simultaneously adding the constructs of both 1. technology and 2. pharmaceutical industry-initiated financial assistance. Altogether, this uncovered seven underlying pathways or themes which contributed to a set of data that would be presented to the focus group participants at the commencement of action cycle 2 and continue throughout the second and third action cycles.

Overall, the online survey appears to have captured input from a diverse group of 115 retail pharmacists in Atlantic Canada. In general, the four targeted provinces, as the geographical base of all survey participants, appear to have a fairly homogenous population within Canada with respect to socioeconomic and health-related factors. Furthermore, it is not unusual to see the four Atlantic provinces grouped together in national or collective reporting of many types such as health, employment, education and immigration issues, given that the population represents roughly nine percent (Statistics Canada, 2017) of the national total.

Upon completion, there was a slight under-representation of Nova Scotia within the survey respondents relative to the population. This under-representation of Nova Scotia should not be a negative factor, as a random-representative sample with statistical significance was not an objective of the study's design. Rather, a convenience respondent sample was the optimal outcome of the online survey as to evaluate the current general opinions of retail pharmacists and set the stage for conversation, along with early feedback elements, for the focus group sessions

in the second and third action cycles.

The target participants for the action research using the mixed methods approach are front-line retail pharmacists. This group represents two-thirds of respondents of the online survey. The other third of respondents are middle and senior management, formally educated and trained pharmacists, and presumably would have some previous experience on the front-line of retail pharmacy in Canada. Respondents are also well educated with almost all (93%) having a university undergraduate degree at minimum.

The respondent sample also had a large amount of experience working in a pharmacy setting with approximately half in their current job function for 10 years or more. Furthermore, they also spent considerable time dealing with their patients, with almost half spending more than 30 hours with patients on an average week and almost half (42%) seeing at least 45 patients on an average day.

#### 5.2.1 Discussion of Quantitative Results

The following dataset of questions 1 through 10 represents results of the characteristics of the convenience sample taken.

## Q1. What type of retail pharmacy do you currently work in?

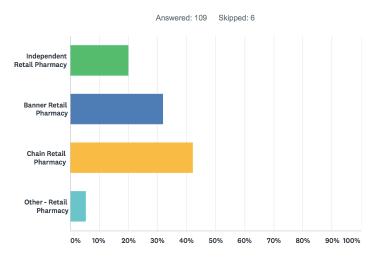


Figure #5: Type of Retail Pharmacy Participants were employed

As noted in *Figure #5*, among those pharmacists who responded to the online survey, most worked for a Chain Retail Pharmacy (n=46; or 42.2% of the respondents), followed by Banner Retail Pharmacy (n=35; 32.1%), and Independent Retail Pharmacy (n=22; 20.2%). The remaining 5.5% (n=6) worked in other types of retail pharmacies. Chain retail pharmacy in Canada represents the corporately owned entities which comprise the largest volume of stores within the commercial pharmacy environment. The majority of these large 'box' stores are owned by publicly traded companies. 'Banner' retail pharmacies represent a group of stores with the same published name for the purposes of promotion and group buying, but are independently owned and operated. Independent retail pharmacies are, in general, individually named, owned, and operated. These are privately owned.

## Q2. In which province in Atlantic Canada is the Pharmacy located?

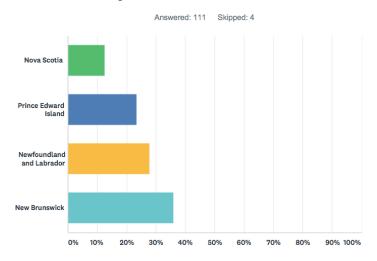


Figure #6: Pharmacy of Participant's Employment location

As noted in *Figure #6*, the survey responses proved interesting with strong representation from New Brunswick, Newfoundland and Labrador, and Prince Edward Island (PEI) with approximately 36%, 28%, and 23% respectively. Unfortunately, Nova Scotia, which represents the largest population in Atlantic Canada, faired lower with just over 12% of the total survey respondents. Having the largest population in the region, one would have expected to see the greatest participation among Nova Scotian pharmacists. This does not affect the overall desired

intent of the convenience sample. Relatively, the population in 2017 came in at approximately 40% for Nova Scotia, 6.7% for PEI, 23% for Newfoundland and Labrador, followed by New Brunswick with 32% (Statistics Canada, 2017). Consequently, one may have expected a much higher result in responses from Nova Scotia. Nonetheless, the overall capture of 115 respondents from Atlantic Canada was sufficient in providing a convenience sample with ample quantitative data to articulate the opinions of retail pharmacists. This data would serve as the leading information into the second action research cycle in that of the focus groups.

## Q3. Is the Pharmacy located in an urban or rural setting?

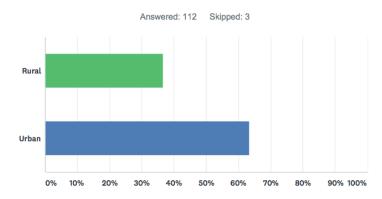


Figure #7: Urban or Rural Pharmacy Location

As noted in *Figure* #7, almost two-thirds of respondents (n=71; 63.4%) worked in an urban environment, with the remainder working in a rural setting. This was considered adequate in terms of data collection from respondents as essentially all of the major services provided within the provinces for diseases requiring specialty medicines are found within larger urban areas. A good example of this would be 'infusion clinics' whereby patients would be provided their specialty medicine under the care of a controlled clinic staffed by several types of healthcare professionals. Thereafter, even for patients living outside the urban setting, it is assumed that many of those patients would fill their prescription at a retail pharmacy within the urban setting.

## Q4. What is the highest level of education you have completed?

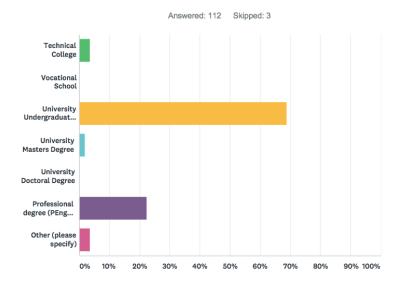


Figure #8: Participant's Educational Level

Since the early 1980s, the minimum requirement to practice the profession of pharmacy in Canada required an undergraduate degree in Pharmacy from one of ten accredited universities along with the completion of a national board examination. Prior to the 1980s, some provinces accepted the completion of programs from technical, college, or trade schools. As noted in *Figure #8*, the survey results are consistent with this educational requirement with the vast number of respondents in that of approximately 72% originating from a person with either an undergraduate degree or technical school. The remaining 28% represented other pharmacists with both undergraduate and advanced masters or professional degrees.

## Q5. What is your age?

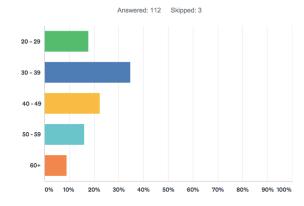


Figure #9: Participant's Age

As noted in *Figure #9*, a slight majority of respondents were aged under 40 years (n=59; 52.7%) with the balance of approximately 47% over the age of 40. This respondent rate was important because it generally reflects the level of experience within the profession. The majority of diseases requiring specialty medicines are deemed chronic and associated with an older demographic. With this in mind, it was important that the respondent have a considerable amount of experience as to assess the rationale for medication nonadherence within their own practical setting.

### Q6. Are you male or female?

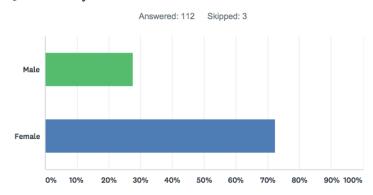


Figure #10: Participant's Gender

As noted in *Figure #10*, the survey yielded almost three-quarters of female respondents (n=81; 72.3%). This was not surprising as the ratio of female to male pharmacists has been increasing in Canada. In 2011, female pharmacists represented approximately 60% of the total pool and were growing. During that year, female pharmacists in Atlantic Canada represented 71% for Nova Scotia, 66% for PEI, 54% for Newfoundland and Labrador, and 67% for New Brunswick, respectively (Pharmacists in Canada, 2011).

## Q7. What best describes your current job function within the Pharmacy?

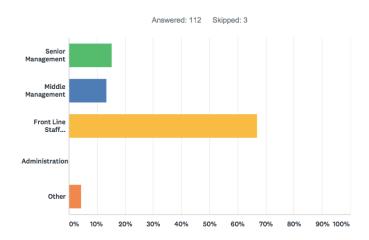


Figure #11: Participant's Job Function

As noted in *Figure #11*, the vast majority, two-thirds in fact, were Front-Line Staff Pharmacists (n=75; 67.0%), whereas 15 (13.4%) were Middle Management, and 17 (15.2%) were Senior Management. This was very important as the research required the vast majority of participants to have significant experience in dispensing specialty medicines to patients.

# Q8. How many years have you been within the current level of job function?

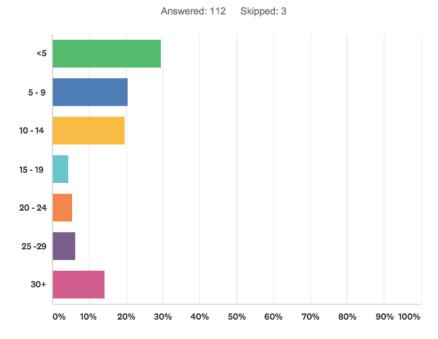


Figure #12: Years Participants have been in Job Function

As noted in *Figure #12*, the largest proportion of respondents have been in their current job for less than 5 years (n=33; 29.5%), followed by those between 5 to 9 years (n=23; 20.5%), 10 to 14 years (n=22; 19.6%), and 30+ years (n=16; 14.3%). Corresponding to the availability of the majority of specialty medicines within the last ten years, this is a relatively new and important factor in health care with approximately half of the survey respondents having less than ten years of experience. In other words, it would be assumed that for pharmacists that entered the field of pharmacy over the last ten years, their day-to-day experience regarding the provision and counselling needs for patients with specialty medicines would seem normal. Twenty years ago, pharmacists would have had fewer options.

## Q9. How many hours do you spend with Patients during an average work week?

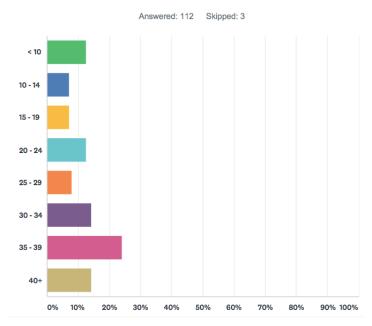


Figure #13: Participant Hours spent with Patients per Week

As noted in *Figure #13*, over half of respondents spent more than 30 hours with patients on an average week (n=59; 52.7%). This is considered significant in the scope of the average Canadian 40-hour work week.

# Q10. On average, how many patients do you interact with each day regarding their medications?

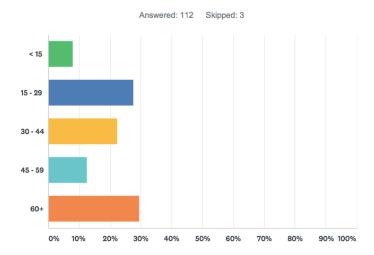


Figure #14: Number Patients Participants see per Day

As noted in *Figure #14*, the largest group of respondents interacted with 60 or more patients (n=33; 29.5%) on an average day, followed by those averaging between 30 and 44 patients (n=25; 22.3%) and those averaging between 45 and 59 patients (n=14). This reflects a fairly steady pace throughout a normal work week of five days, averaging twelve per day, which would mean pharmacists would have many interactions with patients not adhering to their medication regimens.

## Q. 11 Socioeconomic Related Factors

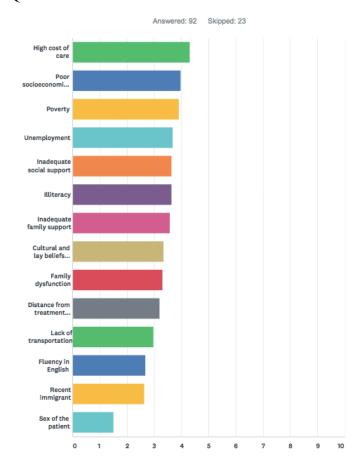


Figure #15: Rankings of Importance, Socioeconomic Factors

As noted in *Figure #15*, of the fourteen Socioeconomic factors identified by the WHO, a majority of respondents felt that eight were either 'very important' or 'extremely important' in the populations they serve. The high cost of care was considered to be most important (87%), followed by poor socioeconomic status (72%), poverty (72%), inadequate social support (60%), unemployment (59%), literacy (58%), inadequate family support (53%), and cultural and lay beliefs about illness and treatment (53%). Interestingly, sex of the patient, was not thought to play a significant role with 2% of respondents reporting it to be important or only somewhat important.

Notably, the highest-ranking socioeconomic factor(s) directly associated with medication nonadherence were related to the cost of the medication or the patient's ability to pay.

# Q. 12 Healthcare System Related Factors

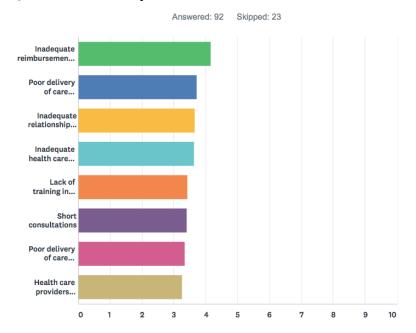


Figure #16: Rankings of Importance, Healthcare system Factors

As noted in *Figure #16*, The WHO lists eight healthcare system factors as predictors of medication adherence rates. Only 5 were perceived to be either 'very important' or 'extremely important' by a majority of respondents in the context of medication adherence within the population they serve. Inadequate reimbursement by health insurance plans was reported to be the most important (82%), followed by poor delivery of care education to the patient (60%), inadequate relationship between health care provider and patient (57%), inadequate health care providers (57%), and lack of training in changing the behavior of non-adherent patients (50%). Interestingly, but not surprisingly, the importance of reimbursement provided by health insurance plans ranked number one given the known high cost of newer specialty medications.

Many private and public health insurance plans struggle to determine how to reimburse patients for such high-priced medications, regardless of their medical advancement, as it puts upward pressure on the plan's financial cost. It is surprising that the other top-ranked factors relating to the healthcare system were focused on care delivery and included provider education, relationship, inadequacy, and training, suggesting the importance of the secondary human participant in the interaction; the healthcare provider. This demonstrates that communication

regarding the direction and importance of medication adherence is a 'two-way' street in that not only is the patient a human participant, so too is the healthcare provider.

Notably, the highest-ranking health system related factor directly associated with medication nonadherence was related to the inadequate reimbursement by health insurance plans.

#### O. 13 Disease or Condition Related Factors

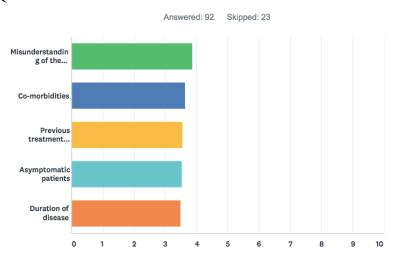


Figure #17: Rankings of Importance, Disease Related Factors

As noted in *Figure #17*, five elements make up the WHOs list of Disease or Condition related factors. Of these, a majority of participants responded that four were either 'very important' or 'extremely important' in the populations they serve. Misunderstanding of the diseases was considered to be most important (66%), followed by co-morbidities (58%), previous treatment failures (54%), and then asymptomatic patients (56%) in ranking. Duration of the disease (49%) came in with slightly less than a majority, but was still viewed as a relatively important factor.

Notably, with respect to disease or condition related variables directly associated with medication nonadherence, there was no dominant factor. A broader perspective arose implying lack of knowledge relating to understanding, treatment, symptoms, or duration.

# Q. 14 Therapy Related Factors

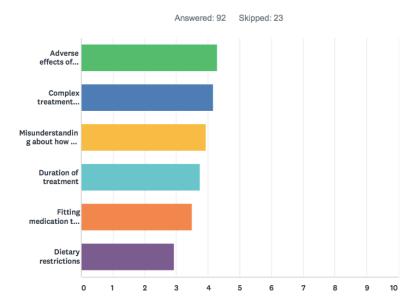


Figure #18: Rankings of Importance, Therapy Related Factors

As noted in *Figure #18*, six factors make up the WHO's list of therapy-related factors connected to medication adherence. Of these, a majority of respondents found that four were either 'very important' or 'extremely important' in the populations they serve. The adverse effects of treatment were considered to be the most important (84%), followed by complex treatment regimens (82%), misunderstanding about how to take the medications (70%), and duration of treatment (59%). Only 29% of respondents thought that dietary restrictions played a very or extremely important role.

Notably, with respect to therapy related variables directly associated with medication nonadherence, adverse effects of the medication were considered to be of utmost importance. This leads one to believe that perhaps many patients intentionally avoid taking their medications as prescribed in order to minimize or prevent adverse effects.

#### Q. 15 Patient Related Factors

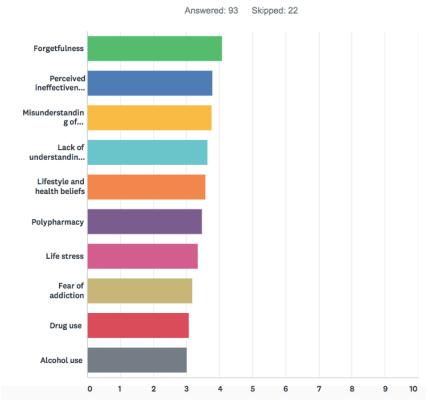


Figure #19: Rankings of Importance, Patient Related Factors

As noted in *Figure #19*, the WHO's list of patient-related factors concerning medication adherence is comprised of ten items. Of these, a majority of respondents reported that half (5) were either 'very important' or 'extremely important' in the population populations they serve. Forgetfulness was reported to be the most important (76%), followed by perceived ineffectiveness of the medication (61%), lack of understanding about vulnerability to illness (58%), misunderstanding of instructions for medications (57%), and lifestyle and health beliefs (53%). Only roughly a third of respondents believed that fear of addiction, alcohol use or drug use played a very or extremely important role. It is interesting to note the concept of 'non-intentional' medication nonadherence in that forgetfulness was ranked most important as opposed to the other perceived 'intentional' variables. This suggests the importance of both intentional and unintentional contributors to the broader issue when considering medication adherence support, prior to recommendations of action-oriented smart recommendations.

Notably, the highest-ranking patient related factor directly associated with medication nonadherence was forgetfulness.

Collective: WHO Factors associated with medication adherence

Q. 16 Based on your personal experience in the pharmacy where you work, what do you think are the <u>FIVE most important</u> sub-factors driving medication nonadherence? Responses to this question were limited to the answers of five subfactors.

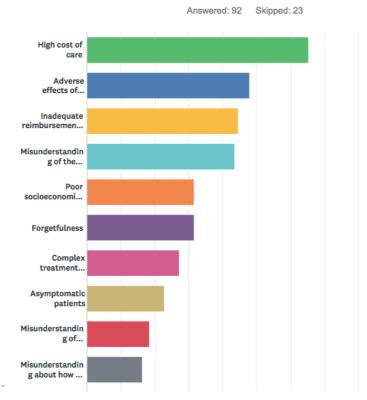


Figure #20: Rankings of Importance, Collective WHO Related Factors

Respondents were asked to determine the five <u>most important</u> factors influencing medication adherence in the patient populations they serve. As noted in *Figure #20*, there was a total of 92 participants who answered this question. The average score for each potential factor was computed and the top ten presented.

The top ten most important factors in order of importance were:

- 1. High cost of care
- 2. Adverse Effects of the Treatment
- 3. Inadequate reimbursement
- 4. Misunderstanding about how to take medications
- 5. Poor socioeconomic status
- 6. Forgetfulness
- 7. Complex treatment regimens
- 8. Asymptomatic patients
- 9. Misunderstanding of instructions
- 10. Misunderstanding of how to take medication

# Summary of importance and responsiveness of 10 most important WHO factors

Q.17 Of the five sub-factors you identified, please <u>rank</u> each in terms of their relative importance where 1 is the most important in driving medication nonadherence, 2 is the second most important, 3 is the third most important, and so on.

The 10 most <u>important</u> factors influencing medication adherence among the patients served by survey respondents came from all five domains, with the Disease and Therapy related categorizations the most prominent. Several themes appear, the most important related to misunderstandings about the disease itself or the medications used to treat the conditions. The costs of medication are also important, whether they be direct costs, the ability to pay, or those costs offset by insurance plans or other forms of reimbursement. Also playing a role within complex treatments were patient factors, such as forgetfulness and fear of the drugs' adverse effects, which were thought to heavily influence medication adherence.

There was no clear suggestive correlation between the factors ranked most <u>important</u> in influencing medication adherence and those considered most <u>responsive</u> to targeted interventions. For example, while high cost of care ranked first in importance, it was ranked

fourth in responsiveness. Interventions aimed at correcting misunderstandings were considered to have the greatest potential for success, followed loosely by interventions aimed at reducing financial burdens of patients. Understandably, outreach efforts to educate patients or minimize costs would appear to have more promise than trying to alleviate forgetfulness, identify asymptomatic patients or change a person's socioeconomic status.

# Responsiveness of 10 most important WHO factors to targeted interventions

Q.18 Again, based on your own personal experience, of the five sub-factors you selected, which do you think would be the <u>most responsive</u> to change from targeted interventions designed to improve medication adherence, where 1 would be the most responsive, 2 would be the second most responsive, 3 would be the third most responsive, and so on?

The factors reported to be most <u>responsive</u> to targeted interventions are listed in order:

- 1. Misunderstanding about how to take medications
- 2. Misunderstanding of instructions
- 3. Misunderstanding of the disease
- 4. High cost of care
- 5. Complex treatment regimens
- 6. Inadequate reimbursement
- 7. Adverse effects of treatment
- 8. Forgetfulness
- 9. Asymptomatic patients
- 10. Poor socioeconomic status

## Interventions aimed at improving medication adherence

# **Technology**

Q.19 Many forms of technology have been used in recent years in an attempt to improve

medication adherence. Some of these technological interventions are listed below. Please indicate whether or not you are familiar with the various interventions from a medication adherence perspective. Yes = green bar. No = blue bar.

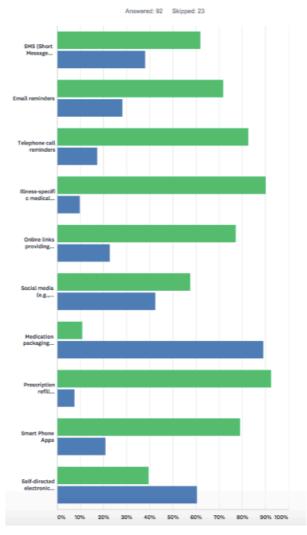


Figure #21: Rankings of Importance, Technological Interventions

As noted in *Figure #21*, there were 92 respondents to this question. Ten technological interventions where presented that have been used to promote improvements in medication adherence. The interventions varied in terms of sophistication and the length of time they have been trialed. For example, telephone call reminders versus medication packaging microchips.

The percentage of awareness was computed and the interventions were ranked from most to least familiar:

- 1. Prescription refill monitoring using pharmacy software systems (92%)
- 2. Illness-specific medical devices (e.g., blood glucose monitors) (90%)
- 3. Telephone call reminders (83%)
- 4. Smart Phone apps (79%)
- 5. Online links providing education (77%)
- 6. Email reminders (72%)
- 7. SMS (Short Message Text) reminders (62%)
- 8. Social Media (e.g., Facebook) (58%)
- 9. Self-directed electronic monitors of adherence (40%)
- 10. Medication packaging microchips (11%)

# Technological Interventions with the greatest impact on improving medication adherence

Q. 20 Based on your personal experience in the pharmacy where you work, what do you think are the FIVE technological interventions that would have the <u>greatest impact</u> on medication nonadherence? Again, it is very important that you limit your responses to five technological interventions.

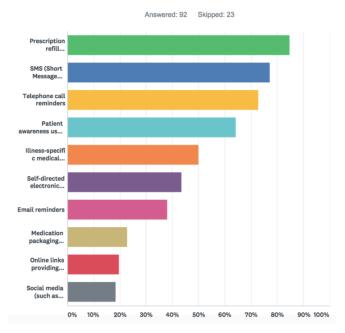


Figure #22: Rankings of Greatest Potential, Technological Interventions

As noted in *Figure #22*, there were 92 respondents to this question. Frequency of mentions was used to rank the technological interventions which were ranked from the greatest to least potential:

- 1. Prescription refill monitoring using pharmacy software systems 85% (78 mentions)
- 2. SMS (Short Message Text) reminders 77% (71 mentions)
- 3. Telephone call reminders 73% (67 mentions)
- 4. Smart Phone apps 64% (59 mentions)
- 5. Illness-specific medical devices (e.g., blood glucose monitors) 50% (46 mentions)
- 6. Self-directed electronic monitors of adherence (40 mentions)
- 7. Email reminders (35 mentions)
- 8. Medication packaging microchips (21 mentions)
- 9. Online links providing education (18 mentions)
- 10. Social Media (e.g., Facebook) (17 mentions)

# Technological Interventions with the greatest potential for uptake

Q. 21 Again, based on your experience working with the patients you serve in the retail pharmacy where you work, please rank the technological interventions you identified in terms of their <u>potential uptake</u>, where 1 represents the intervention with the greatest potential uptake, 2 is the second greatest, 3 is the third greatest, and so on.

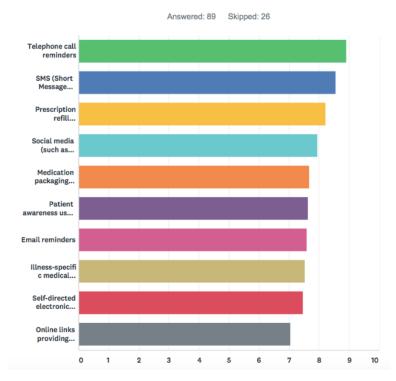


Figure #23: Rankings of Greatest Potential Uptake, Technological Interventions

As noted to *Figure #23*, there were 89 respondents to this question. An average score was used to rank the technological interventions from the greatest. The interventions were ranked from the greatest to least potential:

- 1. Telephone call reminders
- 2. SMS (Short Message Text) reminders
- 3. Prescription refill monitoring using pharmacy software systems
- 4. Social Media (e.g., Facebook)
- 5. Medication packaging microchips
- 6. Smart Phone apps
- 7. Email reminders
- 8. Illness-specific medical devices (e.g., blood glucose monitors)
- 9. Self-directed electronic monitors of adherence
- 10. Online links providing education

# Summary of Technological Interventions awareness and impact

Of the 10 technological interventions, respondents were most familiar with prescription refill monitoring pharmacy software solutions and illness-specific medical devices, likely because these systems and products are ubiquitous in retail pharmacies. All pharmacies including chain, banner, and independents require electronic pharmacy software in Canada in order to process prescription claims, so this finding is logical in terms of proactively determining when patients are should refill a prescription.

Familiarity of the remaining interventions, or lack thereof, appears to be related to the novelty of the intervention and level of sophistication. The technological interventions considered to have the greatest potential impact on improving adherence appear to be those that can be quickly directed towards the patient and are triggered by someone or something other than the patient. Pharmacy software systems immediately identify those who require prescription refills and may then issue SMS text reminders, telephone calls, and Smart Phone application notifications, all of which have the potential to prompt the patient at the appropriate time.

Aside from pharmacy software solutions and medication packaging microchips, the technological interventions with the greatest potential for uptake are those that can be tailored to and launched on a smart phone, which most patients typically have on their person. From a proximity perspective, this may be the closest to the patient a solution can get for the time being. Presumably, telephone call reminders lead the way because the vast majority of Atlantic Canadians presumably have either a land line or a cellular phone.

#### Financial Assistance

Financial assistance may be provided to patients within Canada in various ways. It may be in the basic method of simply issuing the appropriate funds directly to the patient as reimbursement for prior payments made toward one's healthcare services, in this case medications. Alternatively, financial assistance may be issued directly to the service provider upon proof of the service by way of electronic funds transfer, credit card, or cheque. In recent years, the latter has been

enhanced by the provision of electronic payment cards provided by a third party, generally known to have commercial interest, such as pharmaceutical manufacturers, in which case the patient is able to access financial assistance similar to a public or private drug benefit plan. These electronic payment cards are predominantly given to assist in the funding of one medication whereas a public or private drug benefit plan would cover hundreds or even thousands of medications and/or services. Electronic payment cards for individual medication coverage are only able to be processed electronically through pharmacy software systems available in Canada.

Q. 22 Based on your personal experiences or perceptions from the patients that you serve at the retail pharmacy where you work, please rate each of the factors in terms of their <u>potential impact</u> on improving medication adherence.

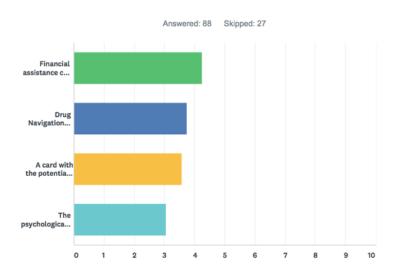


Figure #24: Rankings of Importance, Financial Interventions

As noted in *Figure #24*, respondents were presented with 4 electronic card types that either offset the direct costs of drug coverage or enable the patient to accumulate non-financial rewards such as devices to help manage the patient's disease or non-disease related freebies such as gift cards. Respondents were asked to rate cards in terms of their potential to positively impact medication adherence among the patient populations they serve using a 5-point Likert scale, where 1 stood for "Not at All", 2 "Very Little", 3 "Somewhat", 4 "Quite a Bit" and 5 "A Great Deal". Responses were grouped into three categories: 1) "Not at All/Very Little"; 2) "Somewhat"; and 3) "Quite a bit/A great deal" to facilitate analysis. The latter grouping was considered to be most

relevant. There were 88 respondents to this question.

Financial Assistance (electronic payment cards) thought most impactful, in order of importance were:

- 1. Financial assistance cards to help in the partial or full payment of a remaining balance of medication costs after coordination with the patient's own private or public health insurance plan (78%);
- 2. Drug Navigation service funded by the providers of financial assistance through the use of electronic cards to help access drug coverage from any source, i.e., disease societies (56%);
- 3. An electronic card with the potential for other services of non-financial assistance relating to a specific disease (e.g., non-medication offerings such as a free blood pressure monitor (51%);
- 4. The psychological aspect of using a card to access a 'freebie' similar to a gift card offering or a points schemes (regardless if the patient ever uses the freebie or whether points may be accumulated or not (32%).

## Financial assistance using electronic payment cards with the greatest potential for uptake

Q. 23 Again, based on your retail pharmacy experience, please rank the electronic cards described in terms of their <u>potential uptake</u> among the patient population that you serve, where 1 represents the intervention with the greatest potential uptake, 2 is the second greatest, 3 is the third greatest, and so on.

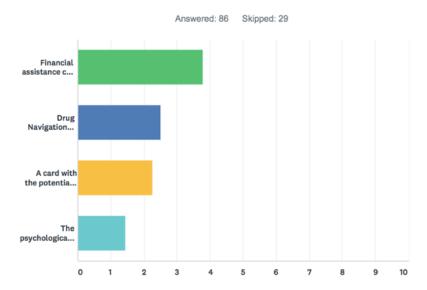


Figure #25: Rankings of Greatest Potential Uptake, Financial Assistance

As noted in Figure #25, there were 86 respondents to this question and the average score was used to rank the potential of these interventions. Financial assistance (electronic payment cards) thought to have the greatest potential for uptake, in order of importance were:

- 1. Financial assistance cards to help in the partial or full payment of a remaining balance of medication costs after co-ordination with the patient's own private or public health insurance plan (average=1.2);
- 2. Drug Navigation service funded by the providers of financial assistance through the use of electronic to help access drug coverage from any source, i.e., disease societies (average=2.5);
- 3. A card with the potential for other services of non-financial assistance relating to a specific disease (e.g., non-medication offerings such as a free blood pressure monitor) (average=2.8);
- 4. The psychological aspect of using a card to access a 'freebie' similar to a gift card offering or a point scheme regardless if the patient ever uses the freebie or whether points may be accumulated or not (average=3.6).

## Summary: Financial Assistance

Respondents thought that 3 of the 4 factors would benefit patients in some way through a medium of electronic payment cards. Most respondents viewed these factors as having the potential to improve medication adherence quite a bit or a great deal, including financial assistance to help in the partial or full payment of a remaining balance of medication costs after coordination with the patient's own private or public health insurance plan. Interestingly, a drug navigation service, a means to assist patients in accessing financial assistance for medications from any source, also stood out has having a very clear majority with three-quarters of respondents (78%) in agreement.

The ranking of potential uptake for electronic payment cards was consistent with the perceived impact on medication adherence. Financial assistance to compensate for partial or full payment of a remaining balance of medication costs was thought to have the greatest potential uptake, with an average score that was followed distantly by the other value using an electronic card.

# Q. 24 Would you be interested in participating in the focus group phase of this research?

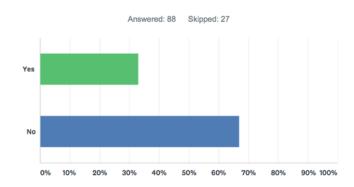


Figure #26: Interest in Participation in future Focus Groups

There were 88 respondents to this question. Interestingly, as noted in *Figure #26*, 59 respondents (67%) expressed no interest in further participation in the qualitative component or focus group sessions of the research. This did not impact the overall results as, again, the online survey was intended to avail a convenience respondent sample. The remaining 29 respondents that did show interest in the focus groups or future action cycles established the foundation for a contact list

and were the first potential participants solicited once the meeting settings and dates were determined.

# **5.2.2** Action Cycle 1 Online Survey Themes

Medication nonadherence has been recognized for decades, even centuries. Throughout the previous findings in the literature search, it has been noted that there have been a vast array of underlying variables leading to formal categorizations put forth by organizations such the WHO. During this research, there were a multitude of rationalizations or themes regarding medication nonadherence discussed during each of the action cycles whereby participants were able to isolate general topics and provide further insight into their own practical environment.

The online survey questions were determined prior to their issuance to the participants and disseminated through their provincial professional association's membership databases. One of the downsides to such research using surveys is that, although at first glance an objective set of data may be perceived to provide optimal clarity into the underlying issues, potential data leading to new knowledge outside of the realm of survey questions may be omitted. The standalone research of an online survey may not allow for data to arise that is outside of the methodological scope and questionnaire, in this case, the five categorizations of the WHO along with the addition of technology and financial assistance. This was taken into consideration as the online survey representing action research cycle 1 was meant to capture the baseline opinions of retail pharmacists regarding medication adherence at a point in time.

During this first action cycle it was clear that the overwhelming factors put forth by the retail pharmacists directly associated with medication nonadherence were that of the cost of the medication and funding along with the ability to connect with the patient regarding their disease and treatment. The findings were consistent across regions. These factors dominated the ratings on 'importance' and provided the first insight into seven themes that would be established over the course of the cycles.

# 5.3 Action Cycle 2 Focus Group Session One

The qualitative approach using focus groups provided an excellent complement to the online survey. Several themes were discovered during the action cycle 2; the first of two focus group sessions. Interestingly, two of the seven themes were outside of the selected factors chosen to align within the survey questions. The seven themes included:

- I. Time constraints of the retail pharmacist
- II. Timing of the medication adherence consultation with the patient
- III. Cost of the medication and who provides the funding
- IV. Navigation to assist the healthcare provider and patient in optimizing available programs
- V. Optimal methods of engaging the patient
- VI. Uses of technology
- VII. Financial assistance provided by the pharmaceutical industry

# I. Time constraints of the Retail Pharmacist

Effective time management required by retail pharmacists in Atlantic Canada in order to complete daily professional tasks is becoming increasingly challenging to achieve. Within the retail pharmacy setting, the pharmacist has a multitude of responsibilities. The fundamental set of priorities would surround the interaction with patients during the processing, filling, and dispensation of their prescriptions. Although the pharmacist is formally trained in the professional capacity of healthcare delivery, their ability to fulfill the commercial responsibilities of a pharmacist in the practical retail setting are of the utmost importance. In the vast majority of cases, the employer of the retail pharmacist has a commercial interest in ensuring the ability to process as many prescriptions as are available in supply. The professional responsibilities of the pharmacists essentially converge with the business requirements, and though rarely discussed, it can be argued that a conflict is enacted. However, in general, the professional and commercial pharmaceutical interests are part of a symbiotic relationship.

From a medication adherence perspective, it is the professional responsibility aspect that it would fall under. As such, any reduction in the professional tasks as to provide the commercial interest within the retail pharmacy environment would be at the detriment of increased time necessary for communication to patients regarding medication adherence. The blend of professional and commercial time constraints during quotidian operations of retail pharmacies put increasingly more pressure on the pharmacists to implement other services such as a periodic and holistic medication reviews, which include medication adherence discussions, at later dates. In other words, it may mean that these important discussions will occur further into the future, if at all. Medication adherence discussions are often a key aspect of an overall medication review. Unfortunately, lack of such reviews supplemental to medication dispensation means less time spent discussing the importance of adherence.

Compounding the problem of missed or delayed medication adherence discussions for patients with diseases requiring specialty medications is the fact that those diseases are known to be more complex, expensive, and requiring of increased resources from a care and maintenance perspective. There is an elevated need for follow-up and/or comprehensive medication adherence discussions with patients who have diseases requiring specialty medications, and this extra communication is deemed optimal in order to reinforce the instruction and improvement of care.

Retail pharmacists during the focus group session continued to reflect on the importance and reinforcement of communication on medication adherence if optimal care is to be achieved. Often, instructions given during the initial medication dispensation and communication period may not be internalized or fully understood by patients. From an information provision point of view, the patient is likely dealing with emotional stresses due to the disease diagnosis. Information reception and retention capabilities of the patient may be lowered at this critical point in time. Even with this knowledge in mind, it was consistently agreed upon by the research participants, that there is limited time allocated for supplemental services such as medication reviews or deeper follow-up conversations surrounding medication adherence.

Although participating pharmacists in the action research believe medication adherence discussions should be paramount in the services they provide, many pharmacies may not have a

standardized process, formalized timelines, or methods with which to do so. Furthermore, participants highlighted that there may be competing interests in terms of who should fund such a service. Should it be public and private insurance plans or, alternately, a third party such as the manufacturers of medications. Again, although the concept of time spent enhancing discussions regarding medication adherence is generally one perceived to be fundamental in a professional context, the practice of devoting time to it would require funding. Evidently, time has a monetary value; and, if the service were performed it would require compensation for the service.

Currently, from the public payer perspective, individual provincial government bodies in Canada outline different criteria for broader services in which medication adherence discussions are provided. Payment allowances vary by province, suggesting that the services available to each patient, even if there was a consistent delivery mechanism put forth by the pharmacy providers, would differ across provinces. Participants' opinions suggest that perhaps independent patient advocate groups are required to put pressure on the pharmacy profession to align and assign more time for counselling on medication adherence, regardless of who provides funding for the service.

Overall, time required to complete the day to day professional aspects within the retail pharmacy are not only becoming more challenging but have to compete for commercial consideration when determining how to enhance the requirement of medication adherence discussions with patients utilizing specialty medications.

# II. Timing of Medication Adherence Consultations with Patients

Research participants noted that, unfortunately, much of the in-pharmacy education and discussion regarding proper medication adherence with patients occurs shortly after the time of disease diagnosis. This is at a time when the initial prescription for the diagnosed disease is dispensed. Although this is required and an important timing of a discussion on how best to adhere to one's medication, pharmacists recognize that this may be happening at a time when the patient is generally sickest and least attentive, impeding their ability to interpret and process new information.

Often, relating to the need for specialty medications, patients have just been diagnosed with a life-threatening or altering disease and are sick, scared, and simply want to go home to be comfortable. Pharmacists agree that this decreases the patient's receptivity to information being exchanged on the importance of taking the medications properly. Furthermore, it is the same time at which a significant amount of information on the treatment and overall care is transferred using both verbal and paper methods to accompany the prescription. From the patient's perspective, this period of emotional stress and/or trauma may be overwhelming and potentially impairing to their comprehension of the means necessary for optimal care and adequate medication adherence.

During this action research, the question arose by the participants on what the true impact of this timing of communication really is at this most important time in the illness of the patient. Research participants agreed that the timing of a medication adherence conversation varies greatly from patient to patient and depends largely on a vast array of individual variables that are known subsets of the five WHO categorizations. For example, if a person has low health literacy, is their attentiveness affected by the timing of a conversation relating to their medication regimen?

Timing of medication adherence communication is critical in order to provide the most optimal care required. Depending on the individual patient, and given the right timing, other questions may arise due to a more relaxed individual and/or environment. Research participants agreed that several things may come out in latter medication adherence conversations that may not have been discovered when the patient initially arrived at the pharmacy with their first prescription in hand, and that the patient is more opt to be stressed at that time. Factors such as the patronizing of multiple pharmacies for other medications prior to the present diagnosis, other known diseases or conditions, funding towards the medication, and the patient's social status need to be considered. The more information a pharmacist has regarding the patient, the more it may correlate with the delivery of care benefiting by both the pharmacist and patient thereafter.

The timing factor, or when best to interact with the patient at various stages of the disease, was emphasized by participants to be of critical importance to the overall success of patient communication. The attentiveness and mental receptiveness of the patient was also noted to be crucial to success. Pharmacists recognize that formal assistance and communication relating to medication adherence is only as good as the ability of the patient to receive, process, and understand it.

# III. Cost of the Medication and who provides the Funding

The cost of specialty medications for diseases such as cancer, HIV, multiple sclerosis, and rheumatoid arthritis, to name a few, are known to be significantly higher than the average medication (IMS Institute for Healthcare Informatics, 2016). As the overall direct and indirect costs associated with healthcare are rising, including that of newer medications, it begs the question of how to fund these medications. Furthermore, if funding is provided by a public or private plan other than the patient, how much funding is provided? The concept of the growing availability of specialty medications over the last decade has generated new hope for many patients, but obtaining these medications is not a simple feat for most. This may have a substantial impact on medication adherence and the ability to improve upon rates.

## Availability of specialty medications:

Newer medications, specifically those referred to as specialty medications, generally tend to be expensive. In 2015, these medications accounted for 75% of all the new growth in spending and 36% of the total cost in the United States (IMS Institute for Healthcare Informatics, 2016). The research, development, and availability of these medications has become prevalent over the last decade and in the United States alone, the direct impact of which accounts for \$105 billion annually (QuintilesIMS, 2016).

The significant increase in cost of specialty medications and debate over who provides the necessary funding are major issues in the overall care of patients diagnosed with diseases such as

MS, cancer, rheumatoid arthritis, HIV, and many others. Inherently, this leads healthcare providers and patients to search for alternate ways to either access the specific specialty medications they are prescribed or seek out solutions that may provide a similarly desired outcome relating to their disease.

Due to the high cost of specialty medications, healthcare providers such as retail pharmacists may look for ways to substitute these newer medications with older therapies which may be provided in the generic form, a biosimilar, or one which has similar clinical outcomes. The advantage is that most often these alternative medications have lower costs than the newer specialty medications. This is largely due, in part, to the many alternative medications that have lost their patent protection in Canada and may be produced by several manufacturers as long as those producers are able to provide the older medications in a bioequivalent form. Similar regulatory processes and pricing laws exist in developed countries around the world. Furthermore, many have been priced lower in any given market for competitive reasons. There are potential disadvantages of this phenomenon. Of note, when a healthcare provider makes a substitution for a medication within the same therapeutic class or with a generic equivalent of the same chemical, it is possible that the original & replacement medications may not be deemed to be comprised of identical molecules and may have slightly different effects from one patient to the next.

Newer medications are often not considered as the first line of treatment if it is believed that an older, more traditional approach would suffice. Validation that the older medications are not optimal or should not be considered is a rarity given the paradigms that exist in healthcare. The decision to switch medications is left with the practicing physician who has the responsibility of caring for the patient. Over the years, healthcare providers have been educated and taught to be professionally wary of 'me toos' (generics and biosimilars) put to market by the manufacturers of pharmaceutical treatments.

Often, the cost of a medication to the patient becomes a barrier to having the ability to prescribe certain kinds of medications, in this case specialty medications. This burden is negatively impactful. Not only from the patient's perspective and who funds it but also from the prescribing

physician. If a medication is dispensed at a higher price point and the patient is unable to fund the full or partial amount they are responsible for, the physician may be forced to prescribe a lower-priced medication. Further complicating this variable in the decision-making process is the fact that prescribing physicians often do not know the specific prices of medications, although they may know if it is deemed expensive or not.

Brand name medications from a single source within the given market are generally known to be more expensive during the period of their market exclusivity given patent rights versus that are non-brand medications. There is no formal system within the physician's office for them to assess this key component of the prescribing thought process. Employees working in retail pharmacy in Canada have the ability to look up specific prices either manually or, most times, electronically. Unfortunately, by the time the retail pharmacist is required to do so, the prescription has already been issued by the physician and any substitution for an alternative medication requires the pharmacist to contact the physician to obtain approval for that change.

# How the funding for Specialty Medications is broken down:

Many patients are unable to pay out-of-pocket for the full price of the more expensive specialty medications in Canada. Furthermore, the average household income in Atlantic Canada is relatively low compared to the average Canadian household income (Statistics Canada). For many patients, specialty medications may not be prescribed unless the patient has some form of a third-party drug benefit plan. Even then, the vast majority of patients do not have the ability to pay the patient co-pay portion of the prescription cost of most specialty medications due to their high prices. For example, if the patient portion or co-pay in Canada are 20% of the amount of the total prescription including costs of the medicine, applicable wholesale and retail markups, and the fee for processing or dispensing the medication, it may be inaccessible for the patient. One research participant quoted, "some people don't have an extra \$20,000 per year to pay for their medications". The consensus provided from the broader research group was that these monetary challenges present great cause for concern.

Regarding specialty medications not covered by a third-party drug benefit plan in Canada, either public or private, often there may be the ability to file an 'exception request' to the plan provider for an individual patient assessment if the medicine should be funded based on unique circumstances. Unfortunately, these exception requests require a significant amount of forms to be filed out by the patient or healthcare provider including information on whether a lower priced medicine has been previously tried with unsuccessful results. This process may be viewed as a barrier to the provision of the specialty medicine due to the inherent creation of delays in amount of time the prescription will be written while waiting for a rejection or acceptance of the request.

During the review and acceptance process of who funds the medication for the patient, the third-party drug plan payers often formalize policies on the primary and secondary payer sequence if a patient has multiple plans. These policies are known as 'payer of last resort'. For example, public plans provided by federal or provincial governments mandate the acceptance of their funding sequenced secondarily to that of a patient's private plan. Similarly, when patients have access to multiple private plans, as is the case if a patient has their own plan but is also covered by their spouse or significant other's plan, these plans implement informal policies in order to minimize their own funding outlay. Theoretically, this forces the premiums a patient has to pay for the private plan itself.

Example for the payment flow of a prescription for which a patient utilizes both public and private plans for funding:

Primary Payer = 80%, Secondary Payer = 20%, Third Payer = 0%. If a patient has both public and private drug plans, the first or 'primary' payer (in this example the private plan), pays a significantly higher portion than the second payer (the public plan). If a patient only has public plan coverage than the public plan funding would increase accordingly as they would hold the burden of the primary payer.

IV. Navigation to assist the Healthcare Provider and Patient in Optimizing
Reimbursement

Given that the newer specialty medications are generally priced relatively high, the question becomes not only who funds these medications but also, what resources are available to help those involved in patient care to navigate through the healthcare system and access the funding. The amount of time spent assisting the patient in attaining funding that is not readily available may be perceived to be significant, especially if that time spent lacks compensation for the service. For the busy retail pharmacist, allocating time to seeking such access to funding may be difficult as they are already at full capacity filling prescriptions for other patients and tending to the quotidian business of the pharmacy. A general consensus was made by the research participants that most commercial pharmacy operations have cut back on pharmacist personnel and those on the front lines are expected to do more with less. As the discussion regarding medication adherence commences with the first visit to pharmacy based on the initial prescription, it often is the case that the optimal communication necessary to ensure the patient is best equipped to fully adhere does not take place.

Should funds be allocated to incentivize both the pharmacists and the patient to improve medication adherence? Participants in this research agree that if incentives were implemented, guidance and regulations would need to be drafted. Furthermore, barriers exist for the retail pharmacist in implementing such a service if there are no centralized repository systems or formal pathways to access the information necessary to provide the service.

Navigation through the healthcare system to access services can be a major problem. Caregivers and healthcare providers often feel they lack knowledge and insight into how to be the patient's advocate in many situations.

Example 1: 'Where a patient lives' relative to a core set of services for patients with diseases requiring specialty medications, such as MS and Cancer, is a major issue in healthcare delivery. If the patient lives in a small town 300 kilometers from the nearest available radiation treatment center, there is an assumed incremental cost for the patient and accompanying family member(s) such as travel costs, lost productivity, etc.

Example 2: 'Delays in approval for medications' to be funded may impact patient care. For many of the specialty medications, these approvals require exceptional status forms to be completed and submitted. During the extra time required to process the exception request, a patient may have to seek other types of reimbursement avenues including private or commercial interest groups or, depending on the urgency, switch to other medications.

The examples are numerous. Overall, the amount of energy and resources necessary to navigate the system, at a time when the patient is burdened with health limitations and stress, can be daunting.

V. Patient Engagement and Optimal Methods

#### Communication

Varying diseases require different methods and frequency of communication regarding medication adherence. Each patient is different. Each healthcare provider, although assumedly trained in similar care delivery methods, act and communicate differently. Often, the human interaction partly depends upon the audience, regardless of the communication. Several services are provided at the various healthcare touchpoints inclusive of the family physician, the specialist, the disease clinic, and the retail pharmacy. Patients have many healthcare providers discussing various aspects of their disease. Different diseases required different approaches.

For example, depending on the disease and the patient a stigma may be associated with going to any or all of the healthcare services provided. Nonetheless, it is critical to have a consistent message to the patient regarding their disease and treatment from all aspects of the healthcare system and the providers. If not, the patient potentially may become confused about which actions to take.

# Conflicting roles of the pharmacist

Although pharmacists in the professional context pursue making a positive difference in the patient's care, it is also a profession, amongst very few, associated with a commercial entity driven to make a profit. Often, a pharmacist may be caught up in commercial productivity requirements of the business and time spent with individual patients is shortened in order to move on to the next patient.

# **Pharmacy Operations and Training**

Formal pharmacist training on the optimal timing and methods used for facilitating an effective discussion regarding medication adherence does exist; however, this training assumes the pharmacist is practicing in an ideal environment. Unfortunately, it may have never been properly established on what a perfect environment is or what is the day to day reality. Furthermore, multiple sessions may be required to create an optimal situation whereby the patient has full understanding of the communication on medication adherence.

In recent years, some pharmacies have attempted to redesign the operational flow of the patient experience when requiring a prescription in order to improve information retention and understanding. For example, there are separate areas for prescription drop-off, patient counselling, and prescription pick-up. The thought is that each of these services requires a slightly different type of patient engagement and, when tailored, can enhance the patient experience. Research participants agreed that there was a direct relationship with the level of personal connection the pharmacist has with the patient that assists in the understanding and importance of the aspects of medication adherence. Emotionally, it is a method of incenting the patient to better adhere to their medications. Pharmacists agree that patients are often comfortable even if a proactive call is made to them at their home regarding their pharmacy services.

#### Inpatient versus outpatient process flows

Oral medications require lower amounts of patient interaction as opposed to injectable or infusion medications. Furthermore, oral medications are not monitored as closely as injection or intravenous products as they are not administered within the inpatient setting. With respect to inpatient services for injection or intravenous medications, when a patient has a disease requiring specialty medications there is an assumed increase in direct monitoring and care for the specific time at which a patient receives these medications. Inherent in this standard approach to inpatient care is the discussion of how a patient is to receive their medications as there are more healthcare professionals involved at the time of care. Much of the aspect of medication adherence is left to the healthcare professional. On an out-patient basis, for those patients receiving oral medications, there is generally less time allotted for the discussion on medication adherence as it is considered part of the normal upfront counselling when a medication is dispensed. From the research participants' perspective, the question arises, "shouldn't we advise all patients the same when it comes to the medication adherence discussion"?

#### **Candid Discussions**

It is unfortunate but necessary that one of the first questions generally posed to the patients while interacting with the retail pharmacist tends to be, "Do you have drug coverage?" Does this create a two-tiered system of those who have medication funding versus those that do not? Candid discussions with patients need to be pursued in order to help avoid financial hardship and take away subsequent burdens such as disease relapse, loss of work, or a multitude of other negative repercussions directly relating to medication nonadherence.

## VI. Uses of Technology

New forms of technology that could assist healthcare providers, including pharmacists, in improving patient experience would be beneficial to all and could potentially increase the interaction and revenue for the pharmacy profession.

#### Software

Pharmacy software in Canada currently facilitates prescription refill monitoring in order to indicate when a patient requires their next prescription. This information provides a trigger point at which to contact the patient as a reminder to pick up their medications. Inherent in this functionality is an indicator of medication nonadherence by the patient in that they have neglected to pick up their medications. Proactively, these systems are able to either provide a real-time notification or communication through the software or, alternatively, run a report on command. Although these types of software systems are broadly available, pharmacies that are more involved in diseases requiring specialty medications are more opt to use such a system, given the higher individual monetary value of the patient.

Participants in the research noted that a centralized software system functionality is lacking that provides a convenient and productive method to isolate patients that should be provided a timely medication adherence discussion. This is left to the determination of the individual retail pharmacist and is added onto the long list of professional and commercial competing priorities in any given day. Certainly, software does exist that enables a notification to the user, the pharmacist, when actionable tasks are due. This functionality is only as useful as the 'user's' proactive input efforts to the action.

Research participants noted that formalized guidelines or algorithms may be of assistance regarding this often-neglected priority. Advanced functionality designed to assist in developing a formalized approach to scheduling medication reviews, including medication adherence as a significant subset, with the patient at a time when there is anticipated to be ample time and attention to review the patient's full medication profile. This will potentially improve the effort when complimented by an environment in which the patient is relaxed, in order to create an improved communication connection. Timing of this effort is critical in order to set the patient on the best pathway towards better adherence.

#### Advancements

In November 2017, the Food and Drug Administration in the United States approved the first medication that would include a digestible microchip to indicate that a pill has been swallowed. This form of technology, although potentially very useful, has yet to be proven in terms of patient acceptance.

Voice technology (IVR), an automated software used within numerous industries including healthcare, can assist when a patient needs their prescription refilled. When prompted, the technology sends an automated telephone call reminder to patients. This type of prescription refill monitoring functionality does come with some downsides; some patients may not want unsolicited communication in any form. As such, research participants agreed that this form of technology still requires human intervention in order to customize an approach that focuses on those that are open to participation. Pharmacists believe that, although IVR technology is a beneficial tool to assist in contacting patients when a prescription requires a refill, human contact is the most optimal method. Unfortunately, most retail pharmacy businesses in Canada do not have time to schedule an outgoing call due to an already time-constrained working environment. Research participants concluded the optimal approach using IVR technology would be a combination of automated and direct human telephone calls with an emphasis on the individual aspect in order to create a natural conversation.

#### **Payers**

It is possible that certain third-party providers, those generally with private and commercial interests, offering financial assistance through the use of electronic cards may put relief on the private and public payers if they have the ability to distinguish definitively who is providing that financial assistance. Although beneficial to the patient, the concept of being able to track these payments electronically is worrisome to the pharmacists as adding a third payer to the mix of eligibility may create a more rigid payer environment in the future in that each payer will continue to implement policies directing the pharmacists to sequence themselves as last payer or

'payer of last resort'. Pharmacists suggested that this type of technology has not yet reached its full potential for being monitored or tracked in Canada.

#### **Privacy and Security**

Provincial and federal privacy legislation in Canada protects patient's personal information; however, the implied consent of the patient allows for some level of internal sharing of information through technology in order to provide the service criteria during prescription processing. For example, during the processing of a prescription medication, it may be necessary to electronically submit a claim to public or private plan payers in order to determine if the medication will be funded by the patient's individual plan. The same technology limited to provincial or federal privacy regulations may be helpful in identifying those patients non-adherent to their medication regimens. This may then allow for the provision of various forms of assistance or intervention. Use of the same information by external parties may be a threat to privacy and security.

#### **Device Reminders**

Various forms of device reminders could be a unique solution in improving medication adherence. These types of notifications or device reminders are directly available on most smartphones and various tools specifically designed for this purpose. Good examples of these tools include automatic pill boxes or dispensers which are available in both the basic physical formats which provide a visual reminder, or more advanced forms with electronic functionality. Device reminders, as an added tool in assisting patients adhere to their medication regimens, are readily available within most retail pharmacies. These can be recommended by the pharmacists and are especially useful when a patient has multiple medications with different regimens. Furthermore, some pharmacies provide formalized services whereby the medications can be ordered online, packed, and delivered to the patient's home. Ordering online and then picking the medications up via a drive-thru scenario is becoming a more viable option for patients that are unable or prefer not to go directly into a pharmacy.

# **Demographics**

Of the 34 million Canadians, those who are eligible for either a public or private benefit plan that funds medications are by far in the majority (Sutherland, Greg and Thy, 2017). It is estimated that approximately 5.2 percent of the Canadian population is not eligible for a public plan or enrolled in a private plan (Sutherland, Greg and Thy, 2017). This suggests the gap requirement for some form of medication funding is relatively small. Given the low percentage of those not eligible, this is true. Unfortunately, the vast majority of public or private benefit plans do not cover the total cost of the medicine and require co-pays or some form of partial payment put forth by the patient. This puts a financial burden on the patient, especially those in lower income brackets (Sutherland, Greg and Thy, 2017). The amount of out-of-pocket spending to make up the co-pay difference for which the patient is responsible varies greatly, is increasing, and is largely dependent on the patient's plan design. Rationale for patients who self-reported not adhering to a prescribed medication cited expense of the medication or unaffordability as the main reason representing 7% of the medication non-adherent group overall (Sutherland, Greg and Thy, 2017).

#### **Pharmaceutical Manufacturers**

As the demographic age increases, those requiring funding for medications will likely increase. This will, in turn, put pressure on the healthcare system and both public and private benefit plans are predicted to be harder to access in the future. This pressure on the healthcare system may result in healthcare providers such as the retail pharmacists and patients seeking out other methods to fund medications such as third-party commercial interests. Unfortunately, when it comes to those programs that offer financial assistance to patients on specialty medications, many healthcare providers and most patients are not aware of such offerings. Pharmaceutical manufacturers do not always formally advertise these programs in a broad-based perspective. As such, wide-ranging knowledge of this service or resource does not exist across the public domain.

Research participants believe that the service of financial assistance to those patients requiring it should be universal. Unfortunately, the cost for a pharmaceutical manufacturer to do so may not be viable or sustainable. Furthermore, these types of programs may become more prevalent over the coming years as downward pressure increases on household income due to tightening of government provided pension plans and other income supplementing services. Population aging becomes a major problem on the government or public system when such a high percentage of the population enters their senior years at the same time, certainly a consideration of the 'baby boomers' generation.

Though popular for those that are fortunate enough to access such programs, financial assistance provided by pharmaceutical manufacturers may sometimes be problematic. The vast majority of the manufacturers that offer these programs are those that have a patent on the chemical molecule, hence programs designed to commercially promote the sale of the molecule during the patent exclusivity period. Once the patent expires, retail pharmacists understand that there is risk involved with such offerings as pharmaceutical manufacturers may discontinue the financial assistance programs as their return on investment may decline due to other competing organizations vying for the same business. In this scenario, the patient may be left without the assistance they depended upon to fund the medication and be required to pursue pathways to find other supplemental funding or switch or discontinue the medication regimen.

# 5.4 Action Cycle 3 Focus group Session Two

The collective set of seven themes established during the first and second action cycles represented the discussion pathways for the commencement of action cycle 3 (the second focus group session). The commentary that follows is either reinforcement of what was discovered in the first focus group or new information added for each of the themes.

# I. Time constraints of the Pharmacists or healthcare professional (HCP)

Retail pharmacists, during this research, agreed that varying levels of service are provided

regarding necessary communication on medication adherence. Aspects relating to the province of service, retail chain and individual pharmacist all affect the level and quality of attention to the communication. As medication adherence discussions are generally a component of a broader medication review, the question is posed "what is the expectation of a competent medication adherence discussion embedded in an overall review"? It was recommended that a discussion surrounding medication adherence, at a minimum, requires 10-15 minutes of time during a patient visit versus that of a broader medication management discussion which would require at least an hour and is believed to provide more of a 'teaching' scenario for a patient.

Various topics may need to be covered in a discussion to reasonably expect to have patients consider the importance of medication adherence. This has been highlighted by the concept of prior research, noting the importance of a multifactorial approach given the varying human aspects of different patients. Topics may include indirect medication adherence assessment criteria not directly focused on the specifics of adhering to one's medication regimen such as the cost of the medication, who provides funding for the medications, the quality of communication provided by the pharmacist, and timing of the conversation just to name a few.

Conflicting time constraints within retail pharmacy in Atlantic Canada exist. Not only do retail pharmacists provide the services of medication dispensation, and all the regulatory and legal responsibilities that surround it, they are often also engaged in activities involving the non-prescription service delivery of the store. In other words, activities that are non-prescription related and further away from the perspective of discussions relating to medication adherence on prescription medications. This again highlights the conflict that exist in retail pharmacies within Canada by addressing the balance of professional and commercial affairs. A simple example of the reinforcement of this mix is the basic physical layout of the vast majority of retail pharmacies. The dispensary area of prescriptions is at the rear end of the retail pharmacy. This calculated design forces the consumer, the patient, to pass through the front store area before being able to engage with the pharmacist. This further lends to the pressures of pharmacists to participate in the business aspects of retail pharmacy in that it is generally accepted that they are required to dispense a minimum number of prescriptions each day to maintain a profitable

commercial situation. Again, this highlights the connected responsibilities of both professional and commercial activities of the retail pharmacist in order to maintain a viable business.

## II. Timing of Medication Adherence consultation with the Patient

The concept of the timing of a medication adherence discussion with the patient often becomes 'generalized' as a subset of the broader medication review. This is blended if you will, or clouded into the other responsibilities in a wholistic medication review. This natural tendency seemed reasonable given the fact that formalized training and professional reference usually evolved around the broader review.

Participants in the research felt that though patient-specific medication reviews inclusive of a medication adherence discussion should be conducted at least every six months at a minimum to create optimum care and direction for the patient. Unfortunately, this timing recommendation put forth by the participants is not consistent with the providers of funding for a medication review. Overall, the most common funding for medication reviews, from the provincial government, is limited to once per year and, by in large part, sets the stage for if and when these reviews take place.

Funding for medication reviews varies from province to province. Provincial funding in Canada at the time of this research has different payment provisions depending on the Province. Most provincial funding is provided for a one-time annual review; however, participants recommended that once a patient is diagnosed, and the initial prescription filled, a medication review should automatically be scheduled within six months. This conflicts with the current funding provincial provisions if the patient is unable to fund the service themselves. Overall, it was agreed that this type of a formalized schedule should be driven by the individual patient and disease requirements, not by funding provisions. Unfortunately, this aspect was determined to be conflicting.

Other parameters were discussed. In what setting should medication reviews including the medication adherence discussion be completed? For example, should they be conducted in the

patient's home versus in a professional healthcare setting? Consistently, it was agreed that this may be also patient and disease specific.

Overall, research participants agreed that recommendations need to be put forth emphasizing the patient or disease requirements regarding medication adherence, a subset of the broader medication review. A multitude of questions arose relating to funding, where should the discussion take place, how should it differ from patient to patient, and if it would be preferable to take on a more formalized national scope. Ultimately, national guidelines supported by a central body may be the optimal outcome for such an important and impactful healthcare consideration.

#### III. Cost of the Medication and who Reimburses

Unfortunately, physicians do not have a competent level of knowledge regarding the price of medications and this sometimes creates a problem once a medicine is prescribed. For newer medications, physicians may have a general knowledge that because they are new and have molecule exclusivity relating to a patent, they are therefore more expensive.

Patients are often not given a choice of which medications are prescribed due to the amount funded by their drug plans. Choice provisions generally come with limitations relative to funding. Some plans may pay 100% of the total cost of the medication and other plans may only pay 50%. This creates a situation whereby the prescriber, the physician, may be pressured to prescribe the medication based on what can be afforded given that the patient, in most cases, will bear the burden of a partial funding of the total cost.

As physicians generally don't know what medications are funded by any individual public or private benefit plan, they sometimes will issue two alternate medication prescriptions. Once the patient is at the pharmacy seeking a medication dispensation, the pharmacist can often identify which one is funded by using the pharmacy software system. This method notably lacks efficiencies for the healthcare system. The intent by the physician is that only one medication prescription is dispensed. Clearly, this may impact optimal care given that the physician may

have a preferred clinical choice of a medication for the betterment of the patient, but prescribing actions are impacted by funding.

IV. Navigation to assist the Healthcare Provider and Patient in Optimizing Available Programs

### **Accessing Information**

Retail pharmacies providing services for patients with diseases requiring specialty medications are assumed by the research participants to have more informational resources in place to provide direction or navigation on accessing medication funding over and above one's individual public or private benefits plan. Unfortunately, this information is not readily available for the broader range of healthcare providers.

## Navigation through the current process

The design of forms and eligibility requirements vary greatly from one financial assistance program to the next. Many forms are provided in the manual format only while others are available electronically. For those formats only available manually, simple ability to cut and paste information if medication funding is denied for use on another application is not an option. For those formats available electronically, the action may be cumbersome. Notably, by the research participants, accessing third party medication funding that lacks a streamlined process may be a daunting task. Although some help for financial assistance navigation does exist for diseases that are deemed more serious and life-threatening such as cancer and HIV, lack of centralize pathways affects productivity in the pursuit of such services. This begs the question, should other stakeholders such as healthcare associations or federal and provincial payers be seen as leading the action steps to provide a centralized drug navigation system? If so, do they even wish to be involved? Certainly, for the time being, these questions remain. Optimistically, moving forward, improved navigation may be enabled by modern day pathways such as the use of websites or technological applications to streamline the process of access.

## V. Patient Engagement and Optimal Methods

## **Training and Education**

Retail pharmacists are required to continue training and educational activities in order to hold their professional status and designation. This is often accomplished by pursuing professional credits through various training and educational offerings put forth by the federal or provincial pharmacy associations or conferences. Research participants noted that, in general, especially relating to pharmacy associations, these conferences do not include medication adherence discussions, but are more focused on 'what's trending' in the industry at that time. In the practicality and productivity sense, this is inconsistent with the opinion and advice of the WHO whom highlight medication nonadherence as one of the most significant threats to healthcare today.

Minimal formal training exists regarding medication adherence in the educational curriculum of university pharmacy programs. Furthermore, minimal ongoing accreditation requirements for ongoing formal pharmacist training exist relating to medication adherence and the behavioral psychology surrounding it given the suggested pathway of a multifactorial approach. We need to remember as well, the retail pharmacist, as another human actor in the communication with the patient. Training, education, and effective methods of communication by the pharmacist are critical to the ability to create adequate levels of medication adherence moving forward. Patient engagement needs to be personal. Often, it requires a connection to personal interest. In many scenarios, cultural and language barriers may exist. Many considerations need to be taken into account during the development of any formal training programs.

## **Proximity to Healthcare Services**

Atlantic Canada is a large geographical area. The vast majority of services for diseases that require specialty medications such as cancer, MS, and HIV are located in urban areas. For those patients that live in remote or rural areas, it often creates an added disadvantage due to travel times, coordination, and associated costs. Arguably, distance from major healthcare centers in

the urban setting often leads to less than optimal care for many patients outside the immediate areas. Theoretically, where a patient lives may affect the quality of care they receive.

Generally, research participants noted that, in Canada, we create less than optimal methods of care in that we are more opt to 'fix' problems rather than provide proactive methods or reward good behaviour such as adherence to medication. Clearly, this approach is costly and lacks productivity. Consistency and control of the message to the patient regarding medication adherence requires rigidity from all points of care, including that of the physician, pharmacist, and other healthcare providers.

## VI. Uses of Technology

#### Software

Pharmacy software continues to evolve. The advancements and evolution of Information Technology systems such as alert notifications and prompts for pharmacists when a patient has not returned to the pharmacy to pick up their follow-up prescriptions have improved over time. This is one indicator that given the concept of time and a specified dosage regimen for a medication, the patient is assumed to return to the pharmacy for sequential prescription medications on a calendar date. Using this indictor, known as prescription refill monitoring, the retail pharmacist is able to monitor prescriptions and reach out to the patient in advance to inform them that the prescription is ready for pick up. This assumes that the patient has not died or gone to an alternate retail pharmacy for those future oriented services.

Unfortunately, for retail pharmacists and ultimately patients, these advancements in prescription refill monitoring are only as effective as the user's desire to use them. If the user has other competing priorities at the time of use, the alert notification may be simply bypassed or overridden. Although automation may free up time for other services, any advancement in the ability to implement an improvement to medication adherence discussion is left to the decision of the practicing pharmacist.

#### **Privacy and Security**

Privacy laws vary slightly from the federal and provincial governmental levels. Furthermore, these laws differ greatly from province to province. How, then, does this play into the use of technology and provision of services, especially if a standardized approach to medication adherence is desired? These considerations are necessary given the concept of notifications to patients who haven't provided formal consent to be contacted. Research participants agreed that careful attention to this issue is necessary if a more proactive engagement is pursued with patients regarding their adherence to medications once they have left the retail pharmacy after the initial prescription dispensation.

#### **Device Reminders**

Not only is there a requirement by healthcare professionals to have more tools such as device reminders readily available, but advancements of the technological capabilities or attributes within those device reminders are also desired. This not only demonstrates progress in the movement to improve upon the ability to provide new services in medication adherence, but also creates a question of how to match the 'individual' patient, the central human actor in the mix, with the optimal device reminder. Certainly, not all patients have the ability to use technology at a competent level, let alone the desire. Hence, the need for a multifactorial approach to matching new technologies of device reminders to patients.

#### Web and mobile applications

With the advancements of technological offerings separate from healthcare requirements, more and more retail pharmacy organizations are opening up to use those technologies to provide their own unique and complimentary services such as web and mobile applications to create competitive advantage. This advances the services provided by the pharmacists but not without effort, as these such applications require professional and technological support of their own over and above the busy work environment which already exists. Questions remain, as each patient is

unique in their desire and competency to use such offerings, regarding who provides the time and follow-up support once a patient has accepted the offering.

VII. Financial Assistance provided by the Pharmaceutical industry / Electronic Cards

## **Demographics / Patient Variability**

Retail pharmacists agree that adherence to medication regimens will generally be affected when a patient needs to take a conscious action regarding their medications. For diseases that are chronic in nature, notably those that require specialty medications, the concept of the individuality of the patient will constantly be a present factor. Within the broader perspective, a patient may be deemed to adhere despite missing or delaying a medication dosage from time to time. For most patients, these infrequent or minor deviations from the prescription regimen may not have clinical consequences. Research participants agreed that the true impact will vary from patient to patient depending on the disease and medication, amongst many other variables.

#### Repository of Information on Available Programs

Unfortunately, no central formalized scenario or repository of information exists to inform the pharmacist on what financial assistance and patient support programs are available, nor how to access them. Pharmaceutical manufacturers have commercial intentions relating to the provision of such programs of availing financial assistance when a patient's primary or secondary drug benefit plan does not fund the entirety of the medication. Availability and communication of the same are largely driven by the brand's objectives, marketing strategy, and intention of the pharmaceutical manufacturer themselves. Furthermore, competitive aspects from one manufacturer to the next are important considerations.

## Financial Assistance: Electronic Cards as a Promotional Tool

Given the significant lack information or a centralized repository, inconsistencies regarding the use, how to access, or availability of electronic cards exist. Several risks are also perceived by

retail pharmacist in enrolling patients into such programs. It is possible that since the organizations that fund these financial assistance programs have limited exclusivity on the timeframe of a particular brand patent that a program may end at any time. What are the implications of these stoppages for the patient and what repercussions will this cause? Research participants, though knowing that such programs will have a start and eventual end date, agreed that these factors are likely to create distrust and decreased confidence which undermines the overall offering itself. At the very least, adequate communication relating to program limitations including an expiration date written into the program agreement should be explicit.

Overall consistency in the methodology and user experience of varying forms of financial assistance programs is limited. Separate from the use of an electronic card to facilitate payment to the retail pharmacy processing the prescription claim, some pharmaceutical manufacturers provide a reimbursement to the pharmacy using replacement inventory of the same medication or alternatively, through the use of credit cards. For those using electronic payment cards specifically designed for use in pharmacy software processing systems, the vast majority have program scope that would differ slightly from one to another including the application process, eligibility, payment levels, and duration. Research participants overwhelmingly agreed that the extensive limitations on program availability along with the different offerings create extra effort on the part of the retail pharmacists that most do not have time for, given their competing priorities.

## 5.5 Preparation of the Research Findings

Action research was conducted using a mixed methods approach. The objective was to determine an integrated design analysis utilizing both quantitative and qualitative data collection methods that could relate to each other (Sandelowski et al, 2006) with the intent of assimilating the findings, rather than a configuration. The approach commenced with the actioning of an online survey and, thereafter, sequencing a qualitative method utilizing focus groups. The aim was to enable a set of smart recommendations put forth directly by retail pharmacy practitioners. The recommendations, or practical solutions, are intended to assist in the improvement of medication adherence rates for patients with diseases requiring specialty medications. This practical research

effort desires to create new knowledge usable directly within the retail pharmacy setting in the future. The recommendations could be continuously enhanced and potentially utilized by other healthcare practitioners over time. Ongoing action research cycling of these efforts for the longer term would be beneficial.

#### 5.6 Field Methods

Overwhelmingly, studies from both methodological approaches agree that integration of quantitative and qualitative views is 'difficult' at best (O'Cathain et al, 2010). This leads to a limitation or barrier in achieving enhancements of knowledge in the field of health. In order to implement a complete synthesis of both quantitative and qualitative methodologies during an analysis of field research, it is important to focus on both commonalities and differences. The difference in the methodologies, however, can be a significant obstacle in this synthesis (Voils et al, 2008). Not surprisingly, the ability to synthesize mixed methods research has been arguably unsatisfactory in the opinion of experts in both of the methodological domains. The ability to come to a single common, precise and detailed measure of qualitative findings equal to that of the numerical, narrowed dimensionality of quantitative findings (Buchanan, 1992) has been continuously debated.

As seen in *Figure #27*, the synthesis summarization of the action cycles during this research was determined by an assimilation of the findings, including that of the online survey and focus group cycles. Through an integrated design (Sandelowski et al, 2006), understanding of the findings were combined for synthesis assimilation, rather than specific methodological approach, in an attempt to answer the research question or address similar phenomenon aspects of medication adherence.

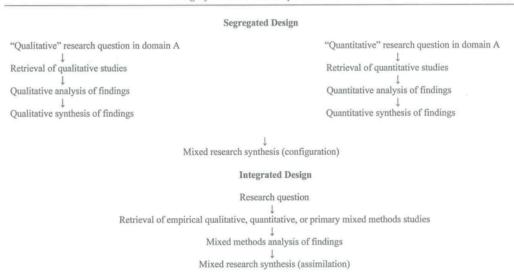


Figure #27: Designs for Mixed Methods Synthesis Studies (Adapted from Sandelowski et al, 2006)

This research led to an interpretive assessment or attempt to make sense of the overall findings. The integrated design was pursued, versus that of either segregated or contingent designs, as an assessment tool supporting the 'analysis' of the overall findings. This effort assisted in comparing what is often seen as incomparable or combine the non-combinable (Sandelowski et al, 2006).

## 5.7 Sense-making: Research Findings

Significant amounts of empirical academic research exist surrounding medication adherence. A view from this vantage point has been highlighted throughout the extensive literature search during this thesis preparation. The aim of this thesis was to explore the opinions and recommendations put forth from the practical viewpoint of frontline practitioners; that of retail pharmacists. Field work of the research was completed in Atlantic Canada. The WHO five categorizations of Patient, Therapy, Disease, Socioeconomics, and Health Related Systems along with two additional constructs, Technology, and Financial Assistance provided to patients set up adequately the aligning of broader themes in the research.

The findings from the online survey set the stage for opening up discussion during both focus group sessions. Significant effort was put forth to approach the data analysis from a holistic or aggregative perspective. Integration of both the quantitative and qualitative analysis was necessary to yield knowledge that collectively provides a greater summation of both methods versus that of analyzing either independently (O'Cathain et al, 2010). The technique used in this study was that of a 'Mixed Methods Matrix' outlined by O'Cathain et al (2010) as one of three techniques often used by health researchers to create new knowledge.

Many ideas were discussed at length in order to reveal root causes of medication nonadherence. These created the pooled sub-topics, themes, or "*chunks*" (Henning, 2011). Considered findings, individual chunks aligned within the seven categorizations noted in the opening to this section. All qualitative data gathered during each of the focus group sessions was assigned or grouped to ensure imperative consideration of all data, regardless of how minor its perception.

## Coding

Coding during the survey utilized a Likert scale with 'importance' as the core determinant for analysis whereby 'very important or extremely important' measures were considered a High rating. The traditional method of Manual coding was used for the focus group sessions, aligning with the themes, utilizing High, Medium, and Low for consistency across the study and for the "quantitising" (O'Cathain et al, 2010, p.6) of qualitative findings. Manual coding was based on my perception as the researcher. Across the meta-themes, the focus was to identify the most important themes ranked high throughout both methodologies. Five themes stood out. It was also important to note 'other' themes that ranked high in either methodology as to help understand any discrepancies throughout the analysis. Furthermore, outside of the themes aligned to the seven categorizations or 'chunks', there were any other surprise themes that ranked high and brought into the discussions by the participants themselves. These themes were only possible during the focus groups sessions as a natural progression of the discussions around workflow the practical setting.

The approach to data integration is not meant to imply that it was unproblematic but rather to take a stance to have consistency in its evaluation. During the analysis portion it took on a "subtle realist" (O'Cathain et al, 2010, p.6) ontological position meant to aid the understanding without losing the appreciation of the importance of both methodologies. Although an insider, and while knowing so during the research, I accepted the facts as put forth by the participants as true and to 'perceive' their meaning to the best of my ability.

#### 5.8 Mixed Methods Matrix

The assimilation (Mixed Methods Matrix, Table #4) provides a synthesis of the findings collected throughout each action cycle. The integrated design (Sandelowski et al, 2006) provides a systematic method to logically understand both divergent and convergent themes based on importance over the course of the study.

Table #4: Overall Findings, Mixed Methods Matrix

Categorization (WHO)					AP Cycle 2 (E	,	1			Doforonco
Categorization (WHO)		Actio	Action Research Cycle 1 (Online Survey)	→ (Nanach)	את כעכוב ב נה	AR Cycle 2 (Focus Group)	<b>^</b>	AR Cycle 3 (Focus Group)	cus Group)	Keleielice
	Factors Very / Extremely Important	% of Resp Agreed	Top 5 Important Factors Top 5 Responsive Factors	op 5 Responsive Factors	Discussion Theme	e Importance		Discussion Theme	Importance	
Socio-Economic Related Factors	High Cost of Care	87	•			High			High	e
	Poor S/E Status	72								
	Poverty	72								
	Inadequate Social Support	09								
	Unemployment	59								
	Literacy	22 23								
	Cultural & Lay Beliefs	53. 53								
Health System Related Factors	Inadequate Reimbursement	82	•			High			High	q
	Poor deliver of Care / Education	09								
	Relationship Caregiver & Patient	57								
	Inadequate Healthcare Providers	57								
	Lack of Training Patient Behaviour	20				Med			Med	
Disease Related Factors	Misunderstanding of Disease	99								
	Comorbidities	58								
	Previous Treatment Failures	54								
	Asymptomatic Patients	20 20								
Therapy Related Factors	Adverse Effects of Treatment	84	•	•						
	Missinderstanding Treatment	28								
	Direction of Treatment	0/								
Patient Related Factors	Forgetfulness	92								
	Percieved Medication Effectiveness	61								
	Lack of Understanding Vulnerbility	288								
	Misunderstanding of Instructions	57		•						
	Lifestyle and Beliefs	53								
Technology	Ry Refill Monitorine	985		3		Ţ,			High	
50	Text Reminders	77		2						,
	Telepone Call Reminders	73		1		Med				
Financial Assist / Electronic Payment	_	78		1		High			High	ъ
	Drug Navigation seeking coverage	26		2	•	High			High	a
	Non Financial services w/ Elec Card	51	•	3						
Other Themes brought up at AR 2 & 3	Time Constraints of Pharmacist					High			Hiph	
0						Hg.H			High	. 64
	Micro Chip within Medication					Low				
	Burden of Demographics on System					Med				
	Residency Proximity to HC Services								Med	
	Medical Device Reminders								Med	
	Importance of Web & Mobile Applications								Med	
	Repository of Information on Programs								Med	
Manual Coding for Integration Analysis										
AR Cycle 1 Findings denote only those	AR Cycle I Findings denote only those rankings that were deemed 'very important' or 'extremely important'	extremely important								
AR Cycles 2 and 3 Coded for Importano	e: Researcher's perception using High / Medium	/ low								
Colour Coding	ConvergentThemes ranked Important									
	Other Themes ranked Important									

A total subset of 40 themes or factors relating to medication adherence were assessed between both methodologies throughout the action research. Upon reflection, but not surprisingly, it is important to note that the cycling evolved the themes which rose above the others as deemed important. There themes ranked important during the survey but fell off during the focus groups. Furthermore, other themes ranked important were not included in the survey were quickly brought to light during the first focus group discussion. This provided some validation that the concept of using both methodologies was a good choice and the perspective of cycling is an important tool in working towards solutions in a practical environment.

The survey utilized a Likert scale to assess the quantitative findings. Furthermore, qualitative findings were coded for importance. With respect to the qualitative findings, a manual coding rating system was utilized based on the researcher's perception using a scale of importance of High / Medium / Low. The method of attempting to quantify the qualitative findings is a technique sometimes used in health research (Sandelowski, 2000). The technique is meant to assist in the integration through a formalized approach. It is not meant to imply that integration is unproblematic, but rather to take a positivism stance to the analysis versus that of assessing philosophical beliefs which would also provide an understanding of the findings (Sandelowski, 2000).

#### **Convergent Themes**

This action research sought to provide a set of smart recommendations put forth by the retail pharmacists. The recommendations are intended to contribute to the improvement of medication adherence rates regarding patients with diseases requiring specialty medications. As such, a convergence (O'Cathain et al, 2010) relating themes across the methodologies ranking high in either overall 'importance' or of perceived 'responsiveness' of the patient were considered. Seven themes emerged as dominant in relation to medication adherence. These include:

- a) High cost of Care (medications)
- b) Inadequate Reimbursement

- c) The use of Technology for Prescription Refill Monitoring
- d) Financial Assistance provided by a third party
- e) Drug Navigation seeking funding or coverage of a Medication
- f) Time constraints of Pharmacist
- g) Timing of Medication Adherence discussion

Interestingly, four of the seven dominant themes relate directly to the cost of the medication or how to identify the ability to fund the medication. This, overwhelming, highlights the importance and concern retail pharmacists view patients have in accessing their medications relating directly to the financial aspect of the medication purchase. Cost, funding, and means of finding help or information on how to access the medications are factors which are top of mind for most patients. The ability to utilize pharmacy software as a means to identify when a patient is required to refill a future prescription in order to issue notifications to the patient in advance along with concepts of timing were dominant themes considered non-financial.

#### Other Themes of Importance

Notably, time constraints of the pharmacist (f) along with the timing of the medication adherence discussion (g) were ranked of high importance during the qualitative component of the mixed methods research. Unfortunately, these themes were brought up during the focus group sessions in action cycles 2 and 3. They were not included during the questionnaire design of the online survey. This was one of the limitations of creating the survey questionnaire and of the quantitative approach, as the content is left to the best judgement of the researcher and may often omit critical topics that the participants consider important. Although not considered convergent themes across the methodologies, based on the criteria of being pursued, the notation regarding these themes is warranted as they were brought up by the participants as top of mind when rationalizing medication nonadherence by patients. Both themes considered 'time' as relating the importance of quantity and quality (timing) of the medication adherence discussion with patients.

#### Surprise Themes which did not Converge across Methodologies

Five themes were rated highly in either overall 'importance' or perceived patient 'responsiveness' during the online survey portion of the research, but surprisingly did not come up as an important discussion topic during the focus groups. Misunderstanding of the disease, adverse effects of treatment, complex treatment regimens, misunderstanding of treatment, along with misunderstanding of instructions were all themes, though reported to be important during the setup of the focus groups, that did not capture any discussion time during those sessions. This is seemingly unfortunate as all of these five factors highlight the importance of patient engagement and knowledge of how to help themselves to better understand and manage their disease. Nonetheless, although not considered as part of this integrated analysis, these themes were considered to be important and were therefore brought forth by the participants. These themes may potentially resurface during future cycling of this action research as a means to continue upon the improvements necessary in medication adherence.

# 6.0 Conclusions, Reflections, and Implications

#### 6.1 Moments of Inquiry

This thesis pursed actionable knowledge as to put forth a set of recommendations that not only made sense by looking at the existing knowledge, current views, and possible solutions regarding medication adherence but also that which had practical application within the retail pharmacy setting. In other words, the actionable knowledge garnered from the research inquiry and insight had to enable 'achievable' actions and move from theory to the real world.

This chapter provides a view into the early thoughts of what already existed regarding the subject matter and how the cycles were means to put forth an attempt for improvements where little have improved over decades. The alignment of important themes paved the way for the participants to come forth with possible ideas or practical solutions and what barriers may be in the way to realization. Two recommendations were subtly tested with their membership associations as to their plausibility or realistic ability to succeed. In order to identify success, the actions will

require a long-term perspective in the practical setting. Furthermore, ongoing cycling will be needed beyond the scope of this study but more likely directly within the profession and organizations that they operate. Evaluation and further improvements will be ongoing. The details of the smart recommendations along with a subset of secondary requirements are presented and aligned to each of the five 'important' themes.

## 6.1.1 Mapping the Terrain

It is very possible that industry or government will take on either or both of these recommendations. It is important to note that the two recommendations are uniquely different and will require different implementation plans.

Recommendation number one (medication reviews) will require significantly more effort, coordination, and acceptance than recommendation number two (centralized repositories). The evolvement of medication reviews beyond those that are currently available to patients and funded by governments will require a national plan, but would be approved and implemented at the provincial level. As highlighted in the limitations of this research, federal and provincial associations may disagree on the required content, balance relating to medication adherence, and compensation. Furthermore, determination of who will be the owner and acceptant of its continued evolvement is also required. This recommendation was put forth by retail pharmacists as a result of this research and is top of mind as a necessity as it relates to timing of medication adherence discussions.

The recommendation of establishing a centralized repository of information regarding access and availability of Patient Assistance Programs in Canada will have a high likelihood of acceptance within pharmacy practice. It is a direct response to addressing the correlation between patient out-of-pocket expenses and prescription abandonment or non-adherence for specialty medications (Lee et al, 2016). At this time, the information exists, but lacks centralization and is ad-hoc. This research uncovers the need for such a centralized resource which is easily accessible by patients and clinicians while updated in a timely fashion. This recommendation does not require the coordination levels and approvals as the previous one. As such, it requires

the assimilation of the information and the communication of the availability of the central resources. To enhance even these requirements, the action will commence with one disease, Multiple Sclerosis, and add other diseases over time.

## **6.1.2** Testing Plausibility

A national pilot in coordination with the Canadian Pharmacist's Association is scheduled to launch September 1, 2020. The pilot will focus on one recommendation at this point in time. The pilot will focus on providing an online platform whereby patients may engage in activities to better understand their disease, treatments, and access to medicines. The recommendation of establishing a centralized repository of information regarding access and availability of Patient Assistance Programs in Canada, as an output of this research, will be imbedded in the content within the platforms so as to avail easy access for both patients and clinicians.

The platform will commence within Multiple Sclerosis and the sixteen Disease Modifying Therapies (DMTs) that are available to Canadian patients affected with the disease. Actions in parallel with the pilot will align with the coordination and centralization of content repositories of other diseases such as cancer and autoimmune disorders and implemented when timing is appropriate.

#### **6.1.3** Evaluating Action

The actionable knowledge garnered during this study is the critical link to the recommendations put forth. This knowledge was generated directly from the participants throughout the focus groups assessing the totality of the information put forth during the action cycles. The spirit of the study was that of a 'working group' better known within the commercial sector rather than an academic study. This supported the concept of finding new knowledge and aligning practical application in that the proposed actions are directly usable by those that put them forth. They are actionable intentions that with coordination and support may be implemented effectively within the profession.

Evaluation of the two recommendations will commence once both have been fully established. The recommendations will also require a continuous improvement process as to enact ongoing practical cycling. These actions are beyond the timeline of this thesis. Furthermore, the actions should have a long-term view as to embed in the practical pharmacy setting. To this end, the process of taking action on the recommendations, continuous evaluation, and evolvement thereafter has commenced with a formal agreement by each of the noted associations, if needed, to sit on an advisory board. The advisory board will be spearheaded by Blue Charm Adherence Inc. Although unintended, this company has been established by myself, the researcher, in order to enact these and other future recommendations put forth and handling the complexities of such innovation including coordination, limitation, measurement, and continuous improvement. This connects the ideas put forth by retail pharmacist as part of this action research into a practical work context.

#### 6.2 Recommendations

Increase the emphasis and support for a national standardized approach of medication reviews as it directly relates to timeliness, content, funding, training, and implementation.

#### Content

✓ <u>Increase the frequency</u> of mini medication reviews as opposed to the current comprehensive model normally implemented on an annual basis. The annualized medication review is largely driven by the funding available. Medication adherence discussions, as a subset of this, would naturally increase.

Alignment with Themes: F, G

✓ Given that pharmacists are in a unique position and have the ability to interact with a patient multiple times during a year, <u>devote more formalized attention</u> as a focus on medication adherence than that during a broader medication review, generally done annually, if at all. This may avail an opportunity for optimal communication that establishes a connection during a time when the receptivity of important medication adherence information is needed.

Alignment with Themes: E, F, G

✓ Offer the ability to facilitate medication reviews within <u>alternative settings</u> such as the

patient's home as an option. This may create an environment for increased comfort and

information receptivity.

Alignment with Themes: F

**Funding** 

✓ Standardize a <u>national fee for service</u> for medication reviews. Funding of the service, which

is consistent throughout the practice of pharmacy nationally, is currently the responsibility of

the individual provinces.

Alignment with Themes: B, D

✓ Consider other funding alternatives such as those in the private sector.

Alignment with Themes: B, D, E

✓ Set funding models to incentivize the retail pharmacists, who are in the 'for profit' scenario,

at an acceptable level which is high enough to generate adequate levels of supply relative to

demand.

✓ Compensation models may need to be developed that provide the incentive for pharmacists

to spend a greater amount of time discussing medication adherence with the patient, with or

without a full medication review.

Alignment with Themes: B, D, E

Training

(Although not aligned with important themes, a training component is suggested as to support

the ongoing reinforcement of the recommendations. This is based on my own personal

165

experience and meant to support the generation of current and future actionable knowledge).

✓ Expand the <u>agenda topics during national and provincial pharmacy conferences</u> to include medication adherence. Participants suggested that little presentation or formal training exists as part of the agendas during pharmacy conferences. Pharmacy conferences are not only a means whereby pharmacists are able to obtain up-to-date information regarding the current topics in pharmacy practice, but are also often an avenue of acquiring 'credits' necessary to maintain their professional license to practice.

Alignment with Themes: N/A.

✓ Within the current acceptable context that pharmacists are able acquire training, list 'behavioral training' as a core offering. Such content may increase the communication skills required to approach medication adherence as a multifactorial perspective. Alignment with Themes: N/A.

*Implementation* 

✓ <u>Utilize the pharmacy technician</u> for the first upfront conversation on medication adherence in order to engage the patient's interest and triage the patient towards the appropriate direction of optimum care thereafter. The profession of a pharmacy technician has developed significantly over recent years whereby higher levels of accreditation, education, and certification are required.

The technician is of critical importance and assistance in the workflow within pharmacy today, arguably more than ever before. Essentially, the pharmacy technician works closely with the pharmacist to free up time for the pharmacist. Any increase in available time for the pharmacist may provide them with the ability to pursue medication adherence discussions with patients. Coordinating roles of both the pharmacy technician and the pharmacist may be determined based on a variety of criteria including disease, type of medication, and individual patient requirements. Furthermore, the operational process may be set up similarly to that of the entry into a hospital setting and formal triage whereas patients are directed and

cared for based on a formalized set of criteria such as urgency and other mitigating factors. Alignment with Themes: F, G

#### Limitations

- ✓ Federal and provincial pharmacy associations may disagree on the required content and balance of the medication review.
- ✓ What would the national compensation model for the service be? How would this be chosen? Challenges may occur within the pharmacy profession in agreeing upon the current funding models as provided by public and private payers. Those at the higher end of the compensation model may feel compromised relative to a risk in a decrease in fee for other services.
- ✓ If further training on the concept of medication reviews were to pursue a formalization pathway, who would fund and implement the training?
- ✓ What are the legal and monitoring limitations required for the pharmacy technician's role expansion within the practice of pharmacy?

Establish a Centralized Repository of Information regarding access and availability of Patient Assistance Programs

#### Program offerings

✓ Centralize one standardized system for healthcare providers to access information relating to the access for patients of Patient Support Programs (PAP) for any given disease.

Unfortunately, manufacturers of the medications used in diseases requiring specialty medications often view the ability to provide a patient with financial assistance an important sales and marketing tactic.

Given the wide-spread demand for this type of financial support to supplement one's own drug benefit plan, it is perceived by the research participants that manufacturers sometimes

limit the amount of available information on the programs and only direct the offerings to a select few customers. The centralized repository of program information could be coordinated in partnership with the federal or provincial pharmacy associations as any pharmacy that would process the prescription on behalf of the patient would be affiliated with these formalized pharmacy bodies. This specific recommendation is an area that 'technology' may optimize the availability and accessibility of the information needed to be centralized.

✓ Mandate, with the support of the federal and provincial pharmacy associations, that all PAPs provide a communication during the implementation of any programs availed to the patient by the use of an electronic drug card, explaining to the patient that there is a possibility of discontinuation of the program. This should be communicated clearly within any central repository of program information. Suggest the explicit print of an expiration date on the electronic drug card. This may help mitigate any negative impact to the patient who may need to find alternate funding for the medication, and could increase trust due to transparency.

Alignment with Themes: A, B, D, E

✓ Require all PAP providing any form of financial assistance to follow a <u>specified design</u> <u>pathway for accessing the offering</u>. This should include not only the central repository of possible PAPs available but also a standardized model of the application process, including similar forms, the submission process, and the ability to transfer information from one program to the next in the event of a requirement to switch a medication. This specific recommendation is an area that 'financial assistance may be optimized by the availability of the offerings as all pharmacies within Canada are able to process these payment cards. Alignment with Themes: A, B, D, E

#### Limitations

Although there is little variation regarding the context of the findings related to political, economic, or technological factors for the pharmacy profession across Canada and beyond the

geographical boundaries of the study there may be slight variations in the socio-cultural perspective. The actionable knowledge put forth by this study is not suggested that it may be required for all patients but rather a limited number that potentially will non-adhere due to the important themes generated. The concept of a multifactorial number of variables that impact patients may be slightly different depending on the socio or cultural background of the different regions within such a large geographical area. Implementing practical solutions as an output of the new knowledge garnered throughout this study for all patients in such a broad scope was not the intention. Rather, the recommendations put forth are meant to assist a minor segment of the overall population but be novel enough to have improvement potential.

- ✓ Patient Support Programs may be limited to a maximum number of patients given the perceived demand as a result of return on investment (ROI) requirements of the individual manufacturer and brand. If manufacturers were forced to provide a centralized repository of information for all programs, the demand may far outweigh the supply. Unfortunately, this could potentially pressure the manufacturers to either provide it for all patients or discontinue the programs altogether.
- ✓ With the consideration of any centralized repository of information regarding PAPs, the question will be posed as to who coordinates, maintains, and funds the effort. Assumingly, the repository would require not only human resources but also IT hardware and software resources.
- ✓ Lack of desire by the manufacturers and current funders of PAPs to participate within the concept of a centralized repository may arise. The manufacturers of the medications available under such programs have a vested interest in maintaining their individual uniqueness of marketing and sales efforts. Any efforts to centralize information and standardize access may be seen as limiting or neutralizing to these efforts.

Overall, although there are two recommendations put forth by the participants the potential to have a major impact on improving medication adherence rates are significant. However, the

actions will require time, effort, coordination, and financial resources. Unfortunately, up until this point in time in Canada, these resources have not been established.

Both recommendations put forth as a result of this research constitute the collective output of efforts by practicing retail pharmacists in Atlantic Canada through a set of three action cycles. The key deliverables of this research for the major stakeholders involved are:

- 1. Design and implementation of a Pilot whereby patients are able to engage in activities to better understand their disease, treatments, and access to medicines. This deliverable will be in coordination with the Canadian Pharmacist's Association as the major stakeholder involved and which represents the frontline retail pharmacists' membership in Canada. The fulfillment of the recommendation of establishing a centralized repository of information regarding access and availability of Patient Assistance Programs in Canada will be embedded within this action.
- 2. Regular communication to the Canadian Pharmacist's Association and the MS Society of Canada, which represents a patient centric association, on the progress of each recommendation.

#### 6.3 Discussion

Medication adherence continues to pose a problem to healthcare providers, as well as researchers, in the push to improve patient care. It is critical for all healthcare practitioners along the continuum of patient care to consider the importance of medication adherence as it directly relates to health outcomes. Although significant knowledge, effort, and formalized protocols exist to prescribe the most appropriate medication and counsel accordingly, the patient's responsibility to take certain actions and adhere to a specific regimen is paramount. Even considering modern-day technologies and financial assistance provided by third party interest groups, along with advances in the categorizations put forth by the WHO, medication nonadherence rates across chronic diseases remain around 50%. As a result, there continues to be a negative impact on direct and indirect factors affecting patient care, including cost, quality of life, and overall clinical outcomes. Although it is already generally well-understood, this action research further supported the concept of medication costs and the ability to fund them as being

of paramount importance to improving medication adherence rates. Furthermore, the patient motivation, coordination, and engagement aspects must be considered. These perspectives where highlighted and contributed to the development of practical smart recommendations.

The findings throughout this action research suggest that retail pharmacists in Atlantic Canada believe that medication adherence is a significant issue in the delivery of healthcare. Ideas and innovations seeking to improve medication adherence rates outlined in the literature have shown limited success. Interventional strategies and tactics have rarely shown promise. It is overwhelmingly agreed that taking a 'multifactorial' approach to the challenge of non-adherence is fundamental to complement any consideration of improving upon medication adherence rates. Furthermore, the same participants believe that there are feasible avenues for improvements in that they themselves could be directly involved with regarding the important themes they discussed. Specifically, although there is much communication and information exchange that currently takes place during early counselling and follow-up with a patient, there seems to be an agreement amongst the research participants that longer term and continuous follow-through are lacking, given the immediacy of the day-to-day business responsibilities of most retail pharmacists.

Could it be possible that the paradigms of research up to this point in time have largely missed the logical considerations of using more appropriately what we already know in a coordinated fashion by simply filling in the blanks or information that is readily available? This may be a practical issue to consider as the profession has significant knowledge, processes, healthcare infrastructure, and technology. Yet, overall improvements are evasive. Yes, it is critical of the current status quo but upon reflection of the baseline knowledge the participants put forth and how the cycling using a practical scope may be a missing link. Furthermore, it could be argued that lack of research using an action research focus relating to cycling may be a determent to the overall pursuit of solutions using predominantly academic one-off studies. Arguably, it may be less about the breath of extant research and more about the depth of the research. Specific research on individual factors and the multitude of issues may need to be pursued with increasingly narrowed pathways.

Given the feedback from this research with retail pharmacists in a practical setting, the possibilities of improving upon medication adherence rates seem a reality. Certainly, in the opinions of the participants, who often provided practical examples of medication nonadherence, while simultaneously suggesting possible solutions, it seems achievable. Furthermore, to strengthen the argument that improvement is possible, similar important themes emerged throughout the action cycles. Narrowed perspectives arose even in light of each independent focus group not being privy to the discussions of their counterparts in other provinces. This design approach was pursed so as not to bias the participants but to avail clear pathways for new ideas or themes. Assimilated information was not provided to the broader group until the commencement of the next action cycle in the sequence. The important themes considered of high importance were top of mind with retail pharmacists. This is encouraging, given the history of medication nonadherence and the healthcare system's inability to make significant improvements to adherence rates, even with the enormous amount of research and understanding that currently exist.

The broader findings of this research emphasizes that there is no one unified approach to medication adherence. The concept is complex, as are the potential solutions. Efforts to improve upon medication adherence rates need to involve both the patient and the healthcare providers in the individualized patient process. Patients need to be seen as participants in their care and accept or 'adhere' to the regimen instructions rather than a healthcare provider's push to 'comply'. Patients need not only to be properly educated about their medications and the importance of adhering to instructions, but a consistency across healthcare providers such as the retail pharmacists, doctors, and nurses is a must. Furthermore, resources are needed to assist healthcare workers and patients by setting up the right environment with the right tools for success. Smart recommendations put forth by the retail pharmacists within this research should be acted upon in order to create opportunities for improvement.

## 6.4 Future Requirements in Research and Practice

The findings of this research, though small relative to the massive amounts of available information on medication adherence, may have implications for healthcare practitioners and

new knowledge in the field if implemented correctly. This would not only require action on the set of smart recommendations which itself would require a coordinated effort, but also longevity in order to instill the recommendations as part of the overall process in the provision of patient care. "Medication nonadherence is a growing concern to clinicians, healthcare systems, and other stakeholders (payers of medication drug plans) because of mounting evidence that it is prevalent and associated with adverse outcomes and higher costs of care" (Ho et al, 2009). Given the demographics of an aging population and the growing strain on the healthcare system's ability to provide optimal care to the general population, contributions put forth by practitioners in the field such as the retail pharmacists are important to implement in order to assess their ability to enact positive changes.

Future action research with a variety of participants from different practical healthcare backgrounds is recommended in order to not only assess these smart recommendations but to put forth others. Both recommendations are important but the ability to formalize a central repository of information that aligns the provision of healthcare services funded by the public domain to that of commercial industry may be useful to other healthcare professions outside of pharmacy. The actionable knowledge put forth through this study is critical of the knowledge transfer across domains that provide patient care. The good news is that solutions are within reach utilizing existing knowledge. Given that many of the healthcare systems within the developed world are similar and information readily available it is possible that these same recommendations may be easily transferrable across borders. Further research into the healthcare systems in other countries, beyond the scope of this study, is desired and assessed by professions in those areas. Arguably, if implemented, various countries would have different success rates leading to the ability to critically assess what actions are put forth in terms of the coordination of information, as well as, implementation within the practical setting with measurable variables such as program quality, funding, and longevity. Actions should be implemented with considerations of all chronic diseases including those that require specialty medications.

#### 6.5 Limitations of this Action Research

#### Representation of the broader perspective of Retail pharmacists:

Medication nonadherence is a global problem throughout all diseases. This research was limited to a select group of retail pharmacists in Atlantic Canada. The online survey was meant to provide a convenience sample with which to lead into the focus group sessions and action cycles. Given the findings within this study, broader research including more action cycles with pharmacists throughout various regions is warranted.

#### Research directly related to diseases requiring Specialty Medications:

Most of the current empirical research surrounding medication adherence revolves around the broader aspect of chronic diseases. Lack of improvement in medication adherence rates is consistent across all chronic diseases inclusive of those requiring specialty medications. The literature search did review many diseases associated with specialty medications and the adherence rates were consistent with those of chronic diseases. Given the advancements of specialty medications within the past decade, it is recommended that further research be pursed specific to that area as a subset of chronic medications.

# Financial assistance from other sources beyond that facilitated by the pharmaceutical industry:

Financial assistance may come from various pathways. In this action research, it was assessed by the participants in the context of funding provided by pharmaceutical manufacturers as a means to commercially promote their specialty medications and access new patients who need assistance. Other forms of financial assistance may exist. Some with commercial intent and others without it.

#### A broader assessment of ~200 variables already studied regarding medication adherence:

Previous empirical research is generally categorized within five WHO fields. Within these five areas, as many as 200 individual factors directly related to medication adherence have been studied. This action research was designed to pursue three action cycles given the time limitations. Further action research is necessary to pursue a continuous pathway of action cycles in order to avail deeper conversation and insight into a wider range of variables.

#### **Continuous evolution of these Smart Recommendations:**

The smart recommendations put forth during this action research are a genuine set of opinions put forth from those practitioners on the front lines with patients. These recommendations have yet to be implemented. Limitations exist on the desire to move beyond the current day to day activities of pharmacists, the business of pharmacy, and the associations that are meant to represent their interests. This is a known difficulty from at least three perspectives. Firstly, change is difficult and going against the status quo is always a risk. Secondly, who will support the effort? And thirdly, will there be momentum to ensure that over time it has enough foundation to be measured?

Assuming that the smart recommendations do get past this stage and are implemented within some areas within Canada, they would be expected to evolve over time and act as their own sequence of cycling outside that of research. In other words, the recommendations would take on a commercial application whereby those involved and participating in the evolution are rewarded for their efforts in some way, either professionally or commercially. There are positive implications for patients, the pharmacy profession, and other healthcare professionals including, most importantly, an increase in medication adherence rates. Another benefit may be the notion of utilizing such approaches as action research to be more embedded into other practical problems within the healthcare settings.

## 6.6 Reflection, Reflexivity, and Learnings on the Action Research Process

## Reflection

As a first-time action researcher, the process provided a very insightful pathway to understanding the approach and linking the participant's own norms, understandings, and opinions on how to improve medication nonadherence. It makes logistical sense to engage those directly practicing in the field of a given subject matter, most of those who would rarely participate in the formal research. This action research was able to involve the pharmacy associations that represent the membership of those in Atlantic Canada along with individual pharmacists, some of whom had the best interest of their pharmacy employers up front and center during the research commencement. It seemed as if the patient was secondary in the thought process. Interestingly, the formal association or commercial responsibilities that may have been promoted early in the action cycles were quickly dissolved once the concept and importance of medication adherence were posed to the group.

Reflection leads me to believe that although the participants did have employer and commercial interests to protect, given the desire and intent to improve upon medication adherence rates for the betterment of patients and health outcomes, superior motives and energy to engage in order to put forth a viable set of smart recommendations took precedent. The participant's professional attributes, rather than their commercial or political interests, took over. As an observer, this was very rewarding.

Given this is my first time as a researcher, I would likely not change anything about this first study. I would however engage more cycles in further studies as I think this is where new knowledge lies and considering action research separates it from past approaches.

Commercialization of a business relating to medication adherence may provide that opportunity.

#### Reflexivity

Reflecting upon the process, and coming from the perspective of a scholarly practitioner, the concept of action research, especially the approach of cycling along with cause and effect, made logical sense to me. Similar to work environments, the participatory point of view and equal voice in moving towards improvements created a bidirectional relationship. Comparatively, I did not sense this during the review of the extant literature in that there was little examination or future action based on learnings. Other research, without the practical perspective, seemed too rigid. Especially, in this field of research in which little improvement has changed as a result.

The ability to be an insider discussing in detail the finer points or human perspectives on medication adherence brought out the socially responsive nature of each participant. As such, I did not find any difficulty in implementing the action research. The process of moving through the cycles including the smaller details of working with the pharmacy associations, invitations, setting choice and setup along with meeting execution was not only informative, but exciting. Activities required during the meetings including audio requirements, journaling, and facilitation were tedious to navigate, but necessary. Ultimately, little of the audio requirements were used as the extensive journaling worked well. This accuracy of the notes was partly reflective of, although a non-participant insider, understanding what the pharmacists were communicating during facilitation and not having to intervene much during discussions.

The recommendations were an accumulation of the knowledge put forth during the cycles, especially relating to the taken-for-granted and underlying tacit knowledge that already exists within the profession. This brought a sense of accomplishment or liberation even if the recommendations have yet to be implemented. It was a sense of 'we have something here that may finally be actionable with results'. I would use this type of practical research again, not only from an academic perspective, but certainly in formalized process within organizations. For other future action researchers, I would suggest that this form of research will open up your mind to what is possible but recommend commencing with the cycles early as to avail the possibility of additional ones as needed given the process is continuous. The more cycles, the better as it is an evolution of the knowledge.

#### Learnings

I have acquired many skills over the years in the pursuit of scholarly practice. In doing so, I have realized the need for an understanding of the structure and proper context of the environment or subject matter in order to have an influence upon it (Aram & Salipante Jr., 2003). Arguably, knowledge and attention are only relevant in context. The closer I may get to the locus of action, or the physical, the better the practice centric learning becomes.

In the broader sense, I have an enhanced understanding of the importance of scholarly practice. This not only includes the movement through the cycles in a formalized approach by acting, planning, observing and reflecting but diving deeper into a lessened 'knowledge' focused paradigm to that of an 'attention' based mindfulness. For most, including myself, a lifetime of learning with the focus on 'knowledge' has created and embedded a paradigm or rigidity of habits. My professional development within this DBA program has taught me to push forward by challenging "the unchallenged supremacy of knowledge as the goal of management higher education" (Ramsey, 2014, p.7) and utilize an attention focus within the scholarly process. I do admit that the consistency required to create this new habit will not be easy. New habits will need to be formed during the implementation of future research projects.

Professionally, I am able to deploy a formalized process of engagement, inquiry, and navigation (Ramsey, 2014, p.7). Furthermore, I understand that a mindful, deliberate, generative, and conscious top of mind approach is critical to the scholarly practice while at the same time, realizing each practitioner will put forth a different individual profile. Easterby-Smith, Thorpe, Jackson (2012) highlight the importance of mindfulness of my own identity within the research and its significance in the structure and process.

Scholarly practice skills developed from concepts in the practical setting were an output of this research. Along the way, I personally was able to apply different methodologies in this context. In terms of a mixed methods approach, there are arguments for and against using it let alone using it in a first research attempt. Although arguably more difficult to implement, the combined methodologies layered into the study enabled me not only to end up with practical applications

for the healthcare profession, but commenced the training necessary to understand its value, especially in the organizational setting.

Easterby-Smith, Thorpe, & Jackson (2012) note that a mixed methods approach may increase the explanation of credibility, generalization, and availing deeper insights. In this study, I would agree with this argument. I did not struggle with the duality of roles, likely because of my aligned background within the pharmacy setting for many years along with my Executive Masters in Business Administration which, as well as, had a practical scope to it. The concept of cycling was new to me although I have participated in various continuous improvement processes within organizations over the years. This skill will be very applicable within my professional life. Medication adherence was not new to me as I have had an interested in it for some time but lacked formal background knowledge on the subject matter. Any preunderstanding was limited similar to that of others known basic opinion of root causes and basic solutions.

#### 6.7 Conclusion

Considering the novel findings and contribution of this action research, it is important to reflect on the overall objective. It wasn't only to assess the current opinions of retail pharmacists in Atlantic Canada, but also engage those participants to put forth a set of smart recommendations. Although four of the top five prioritized themes discussed during the research evolved around the cost of medications and its funding other themes critical to improving upon medication adherence arose including the amount of time required to implement adequate discussions and when to do so. Furthermore, the amount of misunderstanding regarding both the disease and treatment were also noted. Although the top nonadherence themes emerged, unfortunately, pharmacist's time and misunderstandings seemed to get lost in the consideration of prioritizing those important themes which led to the set of smart recommendations. For patients with diseases requiring specialty medicines such as multiple sclerosis, cancer, and HIV to name a few, these practical recommendations are hoped to contribute to improved health outcomes.

At this point in time, it is difficult to argue the extent of how novel the findings may be. I submit that many great findings over history may have not been impressively novel but rather slightly novel and highly logical, especially in hindsight. Although the potential for societal contributions are possible and incremental upside is great, limitations of the findings are significant. Considering the lack of improvement of medication adherence rates over time it is important to be cautious as to the potential of these smart recommendations chance for long term success. The broad-based complexities inherent in any of the WHO categorizations along with technological advancements and the availability of financial assistance programs will undoubtedly all play a critical role in health outcomes and individual wellness.

Rates of medication nonadherence across chronic diseases which require specialty medicines will be challenging to improve upon given the human actor perspective. The recommendations put forth within this study address only a very limited number of the multifactorial variables known to cause nonadherence. Whether intentional or not, patients will find all kinds of creative ways to avoid and alter their treatment regimens. The practical reality is that, for many patients, this will mean direct and indirect implications associated with their adherence. The 'working' patient, for example, may experience required time off from their work. The elderly, in particular, may also encounter secondary negative consequences such as falling and injuring themselves. Ultimately, the web of connected problems is concerning if improvements to rates of medication adherence aren't pursued.

As demographics continue to change with the aging of populations throughout the world there will be increased pressure on healthcare budgets and those who fund it will be challenged to find new ways to ensure the best return on investment. From a business perspective, how do societies get the most out of the spending allocated towards healthcare? In order to best manage the resources available, a heightened level of attention from the human or patient perspective will be needed. Furthermore, the factors that are not patient-driven, including the advancements in medicinal and technological offerings, may then be more effectively utilized when patients engage in their own care. It will be important to maximize available resources. Patients will become empowered, and potentially pressured, to utilize these resources to their full worth in order to optimize health outcomes and manage their personal illnesses. As part of treatment

regimes, medications will be expected to be taken as prescribed. Unfortunately, that will not always be the case. There is no doubt that medication adherence will factor greatly into all aspects of society's ability for healthcare resources to be optimized to their fullest.

Academically, over the years both researchers and advocates suggest multifactorial approaches, which can potentially be just as complex as the reasons for medication nonadherence. Long term practical approaches will need to compliment academic findings and perspectives. Most patients attempt to follow the treatment plans put forth by their healthcare provider and generally give the indication or impression that at the time of the communication the plan is understood, accepted, and ready to implement. In other words, the patient intends to follow the healthcare practitioner's advice. Unfortunately, studies have shown that what happens thereafter is far from what is desired. Nonetheless, as researchers, practitioners, and patients, we all need to continue to focus on the possibilities of improvement. This action research project has attempted to contribute to that though academic assessment by way of a mixed methods approach and the suggestion of practical applications thereafter.

The ability to engage in longer term action research cycling may be critical to success. The research participants came from a variety of backgrounds regarding age, gender, work experience, and so on. Furthermore, they came from various retail pharmacy organizations, each with their own set of commercial priorities. It is recommended that future activities evolve implementation of the smart recommendations utilizing the provincial pharmacy associations in Canada to partner with available resources to bring them to life. Thereafter, those same associations should engage formally around the ongoing steps for continuous improvements. Incentive to do so may be both professional, in terms of the pharmacy profession, but also financial to avail a 'return on investment' and align with the commercial needs of the organizations. Retail pharmacists, in the day to day practice settings, need not view medication adherence discussions as unrewarding, or a diversion from other responsibilities, but as a compliment to the overall health and well-being of the patient. And, they should be compensated accordingly.

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# **Appendices**

## Appendix A Consent Form

#### PARTICIPANT CONSENT FORM

#### Title of Research Project:

Medication Adherence in Specialty Diseases: A Pharmacist's Perspective on the Interventional Impact of Technology and Pharmaceutical Industry initiated financial assistance through the medium of electronic Payment Cards

Researcher: Greg Patey, 902 4898954, greg.patey@online.liverpool.ac.uk

Consent	Initial Box
I confirm that I have read and have understood the information sheet dated [DATE] for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected. In addition, should I not wish to answer any particular question or questions, I am free to decline.	
I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide and I can also request the destruction of that information if I wish.	
lagree to take part in the above study.	
The information you have submitted will be published as a report; please indicate whether you would like to receive a copy.	
I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications.	
I agree for the data collected from me to be used in future research and understand that any such use of identifiable data would be reviewed and approved by a research ethics committee.	
I understand and agree that my participation will be audio recorded recorded and I am aware of and consent to your use of these recordings for the following purposes: subsequent review of Focus Group's notes for clarity and understanding.	
I agree for the data collected from me to be used in relevant future research.	
I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymized responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.	
I understand and agree that once I submit my data it will become anonymized and I will therefore no longer be able to withdraw my data.	

November 1, 2017 Participant Name

Signature

## Appendix B Participation Information Sheet

#### **Participant Information Sheet**

Medication Adherence in Specialty Diseases: A Pharmacist's Perspective on the Interventional Impact of Technology and Pharmaceutical Industry initiated financial assistance through the medium of electronic Payment Cards

#### 2. Version Number and Date

Version 2, May, 2017

#### 3. Invitation

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. Please feel free to discuss this with your friends, relatives and Greg Patey (Student Researcher) if you wish. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to. If you choose to participate the research will take approximately 90 minutes per session involving two sessions at a minimum.

#### 4. What is the purpose of the study?

The purpose of this study to to help answer the question, "From a retail pharmacist's perspective in the practical setting, does the intervention of financial assistance by the pharmaceutical industry provided to patients through the use of electronic payment cards and / or technology have an impact on medication adherence within specialty diseases?" Answers to this question are arguably very complex. A common theme in the literature search recognized that medication adherence is a multifactorial concept. In order to potentially enact new knowledge on the topic, this research will focus on 5 broad categories of medication nonadherence put forth by the World Health Organization along with considering the impact of layering in the use of technology and financial incentive provided by the pharmaceutical industry utilizing the medium of electronic card based programs. This research is separate and distinct from the Researcher's professional role.

#### 5. Why have I been chosen to take part?

The research will focus on the input of retail pharmacists in Atlantic Canada and selected through a qualification criteria of either experience in processing, or been witness to the processing, of an electronic payment card that has provided financial assistance to a patient. These participants will be identified by having worked in a setting in which have dispensation of prescriptions associated with specialty diseases. The research is seeking to garner new knowledge from the retail pharmacist's perspective in how to improve medication adherence rates within Specialty diseases. As a retail pharmacist, you have been selected to participate to share your experience, expertise, and opinion.

#### 6. Do I have to take part?

Participation is voluntary and participants are free to withdraw at anytime without explanation and without incurring a disadvantage.

#### 7. What will happen if I take part?

The research will utilize two forms of research methods. Firstly, an anonymous survey and secondly, Focus Groups. The research will be conducted solely by Greg Patey (Student Researcher). The survey will be conducted online and the Focus Groups will be done in person. All findings may be shared at either the discretion of the participant or through the provincial pharmacy association. With respect to the Focus Groups, all questions, interviews, and interaction with participants will be carried out using observational techniques in both verbal and written perspectives. Participants will be asked to interact on more than one occasion. The research we be conducted at varying dates and times throughout 2017. All information provided at the time of any research interaction will be displayed in an appropriate format for the participant involved in the research to fully understand the context of why a question is asked or discussion to take place. If any part of the research will involve audio or visual recording the participant will be informed. Focus Group session will take approximately 90 minutes all inclusive.

#### 8. Expenses and / or payments

Participation within the online survey will be without compensation. Participants within the Focus Groups will be compensated in return for their time a sum of \$25.00 (Canadian) for each discussion session.

#### 9. Are there any risks in taking part?

There should be no aspect of the research that will disadvantage the participant with any interaction. If at any time there is any discomfort or perceived disadvantage on the part of the participant it should be made known to the researcher immediately.

#### 10. Are there any benefits in taking part?

The purpose of the study is to help garner the practical knowledge of the Retail Pharmacist with respect to improving adherence rates within Specialty diseases. Your participation in the study will potentially contribute new knowledge towards this objective.

The implications of this research for practitioners, academia and professional knowledge may be significant. Medication non adherence is a growing concern to clinicians, healthcare systems, and other stakeholders (payers of medication drug plans) because of mounting evidence that it is prevalent and associated with adverse outcomes and higher costs of care. Given the potential impact on medication nonadherence, even a small positive contribution may warrant the effort.

#### 11. What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting Greg Patey (Student Researcher) at (902) 489 8954. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the Research Governance Officer at ethics@liv.ac.uk. When contacting the Research Governance Officer, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

#### 12. Will my participation be kept confidential?

There is minimal risk potential for any of the participants regarding confidentiality. The concept of privacy and confidentiality play an important role in consideration of a methodological choice. Very limited personal data will be required and personal data should be reasonably guarded against risks such as loss, unauthorized access, modification and disclosure. In this context, it is important to note what is a reasonable mode of electronic communication always has the possibility to be accessed by those desiring the information as often seen by security breaches within large scale commercial enterprises. Survey data will be collected online using either SurveyMonkey or Google Forms website and stored according to their storage and privacy policy. Focus Groups data will be collected either at the retail pharmacy (work setting) or a neutral site, conducted at various times of the day, audio taped, and journaled to provided clarity and reference to assimilate the findings. The data will be stored as to maintained privacy and downloaded to an encrypted flash drive having business-grade security that safeguards 100 per cent of confidential data. The drive will also enforce complex password protection. Data will be stored for five years and disposed of thereafter utilizing a professional services qualified to do so.

#### 13. What will happen to the results of the study?

The results of the research will be made available to the participants upon request or through the provincial pharmacy associations. If published, the research results will be accessible by both the participants and the general public at large. It is important to note that if the research results are published to the general public the participants will not be identifiable from the results.

#### 14. What will happen if I want to stop taking part?

As a participant, I may withdraw from the research at anytime, without explanation. Your input up to the period of withdrawal may be used unless otherwise requested to be destroyed at which point no further use will made of it. If your input into the research is anonymized, the results may only be withdrawn prior to anonymization.

#### 15. Who can I contact if I have further questions?

Greg Patey 295 Basinview Drive Bedford, NS Canada B4A 3X8

(902) 489 8954 greg.patey@online.liverpool.ac.uk

## Appendix C Focus Group Invitation example

#### RESEARCH PROJECT

Focus Group #1 Discussion / Action Cycle

#### Medication Adherence in Diseases Requiring Specialty Medicines:

A Pharmacist's Perspective on the Interventional Impact of Technology and Pharmaceutical Industry initiated financial assistance through the medium of electronic Payment Cards

#### Hosted by:

Greg Patey Student, University of Liverpool Doctorate of Business in Administration (Candidate)

#### The thesis research is intended to:

- Assess the opinions Atlantic Canadian pharmacists around Medication Adherence directly related to the formal categorizations of the World Health Organization (WHO).
- Put forth a set of Smart Recommendations that would be an output of Focus Groups with Atlantic Canadian pharmacists. These would be shared with the provincial associations.

Date: November 9th, 2017

Venue: Gusto Italian Grill and Bar

(private meeting room downstairs) 130 Westmorland St, Moncton, NB

Agenda: 6:30 - 6:45pm Arrival / Meet and Greet

6:45 - 7:00pm Dinner Order

7:00 - 7:30pm Research Project Overview

Medication Adherence Survey Results

7:30 - 8:30pm Focus Group discussion 8:30pm Next Steps / End

RVSP: Greg Patey

greg.patey@online.liverpool.ac.uk

IMPORTANT NOTE: As this is a Focus Group session, the enrollment will be limited to 10 Participants in order to allow for an in-depth discussion given the intent and scope of the meeting. Preferably, this would be of most interest to Pharmacists with a strong background in dispensation of specialty medications for diseases such as Cancer, Multiple Sclerosis, and Rheumatoid Arthritis. The first 10 respondents who meet the eligibility criteria will be accepted into this Focus Group research session. Thank you.

## Appendix D Survey Invite

#### Dear Pharmacist,

My name is Greg Patey and I am a student with the University of Liverpool, England conducting research on 'Medication Adherence'. I was hoping you could help me. I am a resident of Nova Scotia and this research is part of my Doctorate of Business thesis. A short online survey (see link below) is meant to gain a small convenience sample from Atlantic Canadian pharmacists. It should take approximately 10-15 minutes to complete.

#### My background:

Student within the Doctorate of Business Administration (DBA), University of Liverpool, England Retired from the pharmaceutical industry.

#### Thesis Title:

Medication Adherence in Specialty Diseases: A Pharmacist's Perspective on the Interventional Impact of Technology and Pharmaceutical Industry initiated financial assistance through the medium of electronic Payment Cards

#### The thesis research is intended to:

Firstly, assess what opinions Atlantic Canadian pharmacists have around Medication Adherence directly related to the formal categorizations of the World Health Organization (WHO). The survey is meant to assess the current opinions upfront before leading into small focus groups in the fall (October – November).

Secondly, put forth a set of Smart Recommendations that would be an output of Focus Groups with Atlantic Canadian pharmacists thereafter. These would be shared with the provincial associations.

Please see the following link in order to complete the brief Survey.

#### NOTE

The second part of this research will pursue action research though small Focus Groups in an attempt to garner new knowledge to assist in improving medication adherence rates within Specialty diseases such as cancer, rheumatoid arthritis, and multiple sclerosis. These sessions will be conducted throughout October and November of 2017. It is hoped that a set of 'Smart Recommendations' will be the outcome of these sessions.

#### Survey Action Research Questions Cycle 1 (Online) Appendix E

#### Introduction

Medication adherence is a term used to summarize whether a medication is being used in the manner in which it was prescribed. This research being conducted by Greg Patey as a student through the University of Liverpool, seeks to understand the traditional and accepted beliefs surrounding medication adherence, especially as it relates to the work of the World Health Organization. The information from the survey will be used to further pursue action research with retail pharmacists to understand the potential impact of various solutions to improve medication adherence rates in specialty diseases such as cancer or multiple sclerosis.

Please respond to these questions openly and truthfully. All results will remain confidential and will only be reported in aggregate form. No individual personal identifiers will be reported in order to protect your confidentiality and privacy. The data will only be available to the researcher.		
Background Information		
Please note that this background information will only be used to aggregate the data and describe the demographics of the survey sample.		
What type of retail pharmacy do you currently work in?		
● ☐ Independent Retail Pharmacy		
● □ Banner Retail Pharmacy		
● ☐ Chain Retail Pharmacy		
● □ Other - Retail Pharmacy		
In which province in Atlantic Canada is the Pharmacy located?		
● □ Newfoundland		
● □ New Brunswick		
● □ Nova Scotia		
● □ Prince Edward Island		
Is the Pharmacy located in an urban or rural setting?		
• Urban		
● □ Rural		
What is the highest level of education you have completed?		
● □ Technical College		
● □ Vocational School		
● □ University undergraduate Degree		
● □ University Masters Degree		
● □ University Doctoral Degree		
● □ Professional degree (PEng, etc)		
• Other, specify		
What is your age?		
□ 20–29 □ 30–39 □ 40–49 □ 50–59 □ 60+		
Are you male or female?		

☐ Senior Management

What best describes your current job function within the Pharmacy?

☐ Male ☐ Female

Management
ine Staff Pharmacist
stration
ou been within the current level of job function?
15 □ 16 − 20 □ 21 − 25 □ 26 − 30 □ 31+
spend with patients during an average work week?
ou interact with each day regarding their medications?
5 🗆 46–60 🗀 61+
Medication Adherence
anization has identified five factors that influence medication adherence, including: social and economic factors, the health care team/health tics of the disease, disease-related therapies and patient-related factors. Understanding the extent to which these factors are universal and whe nedication adherence is to be improved.
IO factors, please describe the extent to which you believe each influences medication adherence among the patients that you serve at your macy using a scale of 1 to 5, where 1 is Not Important and 5 is Extremely Important. Please note that within each subcategory, there is an option two additional responses that you feel are important contributors to medication adherence.
on should reflect your individual opinion and categorized as follows:
actors
cost of care aployment socioeconomic status tty acy f the patient English speaking ti immigrants quate social support quate family support of transportation distance from treatment setting filly dysfunction ral and lay beliefs about illness and treatment t, specify t, specify

### Health Care Team/Health System Factors

- Q2a Health care providers inadequate understanding of the disease
- Q2b Inadequate reimbursement by health insurance plans
- Q2c Inadequate relationship between health care provider and patient Q2d Inadequate health care providers 3. 4.
- 5. Q2e Poor delivery of care education to the patient
- Q2f Poor delivery of care education to family and caregivers
- Q2g Short consultations
- Q2h Lack of training in changing the behaviour of non-adherent patients
- Q2i Other, specify Q2j Other, specify

#### Disease or Condition

- Q3a Poor understanding of the disease and its symptoms
- Q3b Co-morbidities
- 3. Q3c Asymptomatic patients
- O3d Previous treatment failures 4.
- Q3e Duration of disease 5.
- 6. Q3f Other, specify
- Q3g Other, specify

#### **Disease-Related Therapy Factors**

- Q4a Complex treatment regimen
- Q4b Long duration of treatment
- Q4c Adverse effects of treatment
- Q4d Misunderstanding about how to take the medication
- 5 Q4e Dietary restrictions
- Q4f Fitting medication to patient's lifestyle 6.
- Q4g Other, specify
- Q4h Other, specify

#### Patient-Related Factors

- Q5a Forgetfulness
- Q5b Lifestyle and health beliefs
- Q5c Polypharmacy
- Q5d Misunderstanding of instructions about medications
- Q5e Lack of understanding about vulnerability to illness O5f Perceived ineffectiveness of the medication 5
- 6.
- Q5g Fear of addiction
- Q5h Life stress
- Q5i Alcohol use
- 10. Q5j Drug use
- 11. Q5k Other, specify
- Q51 Other, specify

### **Most Important Factors**

Q. Based on your own personal experience, what do you think are the five most important sub-factors (including those you may have provided) contributing to medication nonadherence overall, in order of importance where 1 is the most important, 2 is the second most important, etc.? Have a drop down list

#### Most Responsive to Uptake

Q. Again, based on your own personal experience, what do you think are the five sub-factors most open or responsive to change, where 1 is the most open, 2 is the second most open, etc.?

Have a drop down list

#### **Greatest Impact on Medication Adherence**

Q. Of the five sub-factors most responsive to change, which do you believe have the greatest potential to impact medication adherence, in order of impact where 1 has the greatest impact, 2 has the second most impact, etc., in order of impact where 1 has the greatest impact, 2 has the second most impact, etc.

Have a drop down list

#### **Technological Interventions**

Many forms of technology have been used in recent years in an attempt to help improve medication adherence. Some of these technological interventions are listed below. Again, there is an opportunity for you to include an additional two interventions that you feel are important to medication adherence.

1. Not at All 2. Very Little 3. Somewhat 4. Quite a Bit 5. A Great Deal

- Q6a SMS (Short Message Service) / Text Reminders
- Q6b Email Reminders
- Q6c Telephone Call Reminders
- 4
- Q6d Patient awareness using SmartPhone Apps Q6e Self-Directed Electronic Monitors of Adherence
- Q6f Illness-Specific Medical Devices (such as tracking on Blood Glucose monitors
- Q6g Online Links providing education
- Q6h Social Media (such as Facebook)
- Q6i Medication packaging Microchips (used to report when the package is open)
- 10. Q6j Prescription Refill Monitoring using Pharmacy Software systems
- Q6k Other, specify
- 12. Q61 Other, specify

#### Most Responsive to Uptake

Q. Based on your own personal experience or perceptions, what do you think are the five technological interventions (including those you may have provided) that would be most open or responsive to uptake, where 1 is the most responsive, 2 is the second most responsive, etc.?

Have a drop down list

#### **Greatest Impact on Medication Adherence**

Q. Of the five technological interventions, which do you believe have the greatest potential to impact medication adherence, in order of impact where 1 has the greatest impact, 2 has the second most impact, etc.

Have a drop down list

#### Financial Assistance using Electronic Payment Cards

Electronic cards have been used for many years to entice loyalty (i.e., AirMiles, Optimum, Aeroplan, etc.). These same type of cards have also been used by Pharmaceutical companies to off-set the payment of medication at the retail pharmacy level either in full or partial payment of the prescription medication.

Below are different potential electronic card benefits that could be used to help individuals access the medications they require (note: there is an option to include up to two of your own ideas in Q7e and Q7f).

#### Again, please rate as follows in terms of the importance:

- 1. Not at All 2. Very Little 3. Somewhat 4. Quite a Bit 5. A Great Deal
- Q7a Financial assistance to help in the partial or full payment of a remaining balance of medication costs after coordination with the Patient's own private or public plan. Q7b Potential for third party assistance other than through the Physician Clinic or Pharmacy in accessing medication coverage with the Patient's private or public plan. (This is termed a Drug Navigation service and is generally funded by the providers of the financial assistance through the use of electronic cards. In general, this is offered by a Pharmaceutical company using a third party organization trained in providing this unique service).
- Q7c Potential for other services of non-financial assistance relating to a specific disease (ie, non-medication offerings such as free devices. An example would be a free blood pressure monitor).
- Q7d The psychological aspect of using a card to access a 'freebie' similar to gift card offering or points schemes (regardless if the patient ever uses the freebie or points that may be accumulated or not).

5.	Q7e Other, specify
6	O7f Other specify

#### Most Responsive to Uptake

Q8. Based on your own personal experience or perceptions, which electronic card types (including those you may have provided) do you think would be most open or responsive to uptake, where 1 is the most responsive, 2 is the second most responsive, etc.?

Have a drop down list

#### **Greatest Impact on Medication Adherence**

Q. Of the electronic card types you mentioned, which do you believe have the greatest potential to impact medication adherence, in order of impact where 1 has the greatest impact, 2 has the second most impact, etc.

Have a drop down list

#### SPECIAL NOTE

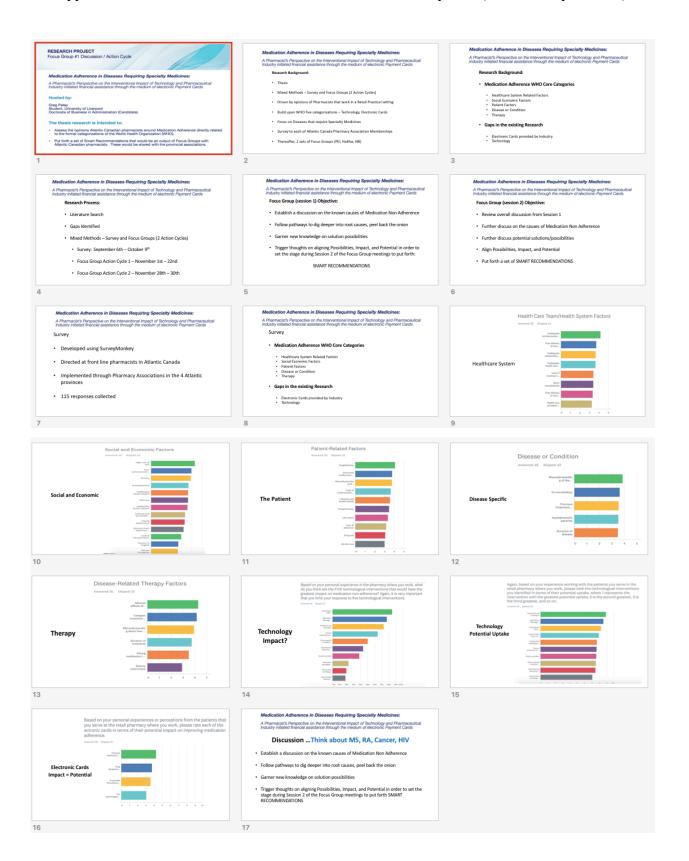
The second part of this research will pursue action research though small Focus Groups in an attempt to garner new knowledge to help assist in improving medication adherence rates within Specialty diseases such as cancer, rheumatoid arthritis, and multiple sclerosis. These sessions will be conducted throughout September, October, and November of 2017 and a nominal participation fee will be provided. It is hoped that a set of 'Smart Recommendations' will be the outcome of these sessions.

If you are interested in participating in a Focus Group please indicate by providing your contact information below: Name:

Address:
Email contact: Telephone contact:

Thank you,
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Appendix F Power Point Presentation Action Research Cycle 2 (Focus Group Session)



## Appendix G Power Point Presentation Action Research Cycle 3 (Focus Group Session)

