

Are you ***HIRT?***  
(***Hemophilia Injury Recognition Tool***):  
Perceptions from young men with mild hemophilia in Canada on the use of  
the mobile app for injury self-management

A Thesis Submitted to the College of  
Graduate Studies and Research  
In Partial Fulfillment of the Requirements  
For the Degree of Master's of Health Science  
In the School of Physical Therapy  
College of Medicine  
University of Saskatchewan  
Saskatoon

By

JoAnn Kathryn Nilson

## PERMISSION TO USE

In presenting this thesis/dissertation in partial fulfillment of the requirements for a Postgraduate degree from the University of Saskatchewan, I agree that the Libraries of this University may make it freely available for inspection. I further agree that permission for copying of this thesis/dissertation in any manner, in whole or in part, for scholarly purposes may be granted by the professor or professors who supervised my thesis/dissertation work or, in their absence, by the Head of the Department or the Dean of the College in which my thesis work was done. It is understood that any copying or publication or use of this thesis/dissertation or parts thereof for financial gain shall not be allowed without my written permission. It is also understood that due recognition shall be given to me and to the University of Saskatchewan in any scholarly use which may be made of any material in my thesis/dissertation.

## DISCLAIMER

The mobile app, HIRT?, was created by a team of researchers prior to the initiation of this thesis, in which I was one of the team members. Although I am affiliated with the development of the app, I do not have any financial relationships or affiliations with any commercial entity related to this product as discussed in the thesis.

Requests for permission to copy or to make other uses of materials in this thesis/dissertation in whole or part should be addressed to:

Dr. Sarah Oosman and Dr. Cathy Arnold

Room 309 / 310,

St. Andrew's College, 1121 College Drive

School of Physiotherapy

College of Medicine

University of Saskatchewan

Saskatoon, Saskatchewan, S7N 0W3 Canada

OR

Dean

College of Graduate Studies and Research

University of Saskatchewan

107 Administration Place

Saskatoon, Saskatchewan, S7N 5A2 Canada

## ABSTRACT

**Introduction/ Objective:** Young men with mild hemophilia have a unique challenge with accessing relevant information to assist injury self-management. They do not bleed frequently. This limited experience may mean that they do not always identify musculoskeletal injuries requiring medical attention, potentially leading to significant health consequences. In response to this challenge, a team of clinicians, researchers and young men with mild hemophilia developed a self-assessment pathway which was converted into a mobile app to address the need for easier access to assessment resources. This study investigated the perceptions of young men with mild hemophilia in Canada on the use of the mobile app *HIRT?* (Hemophilia Injury Recognition Tool) for injury self-management. **Methods:** Key informant interviews were conducted with 12 young men with mild hemophilia, 18-35 years old. A mixed methods design was used. The qualitative method of interpretive description was used through in-depth recorded and transcribed interviews about access and usefulness of the mobile app. Qualitative data were analysed using inductive content analysis to identify themes and patterns. The quantitative data, gathered by a short self-report questionnaire, evaluated perceived injury self-management strategies and app utility. Perceived confidence levels for using and not using the app were also collected. Non-parametric McNemar chi-square test and Wilcoxon signed rank test were used to determine the association between self-management strategies and the confidence levels using the app versus not using the app, with a significance level set at  $p < .05$ . **Results:** From the qualitative analysis, themes included accessibility, credibility, the benefit of embedded alarms and overall usefulness. Quantitative analyses illustrated that perceived confidence levels significantly increased ( $p = 0.004$ ) with the use of the app compared to not using the app. However, perceived self-management strategies did not significantly differ when participants thought about not using the app and using the app. **Conclusions:** Technology is rapidly advancing and education needs to be accessible. This study gives evidence that there is a preference for a mobile app intervention and that perceived confidence in injury self-management significantly improved for young men with mild hemophilia in Canada with the use of *HIRT?*.

**Key Words:** Mild hemophilia, mobile app, injury self-management

## ACKNOWLEDGEMENTS

First of all I would like to acknowledge the young men with mild hemophilia living in Canada who were the inspiration for this study. Especially, I want to thank the young men with mild hemophilia that gave their time and experiences for this project.

Secondly, I would like to thank my supervisors, Dr. Sarah Oosman and Dr. Cathy Arnold. They have provided guidance and support, but also created an enlightening atmosphere which fostered and challenged new ideas. Next, I want to thank my committee members, Kathy Mulder, Dr. Candice Schachter and Dr. Kristy Wittmeier. I have appreciated their vast clinical experience, wisdom, enthusiasm, knowledge translation expertise and astute qualitative research insight. These attributes contributed greatly to this thesis.

I would like to acknowledge Dr. Richard Lomotey, the computer science expert and app developer. He began as a PhD candidate in the Computer Science Department at the University of Saskatchewan and now holds a position at Pennsylvania State University.

I would also like to thank Dr. Angela Busch for inspiring me to enter the Master's program and Dr. Lori Ebbesen for her encouraging words and assistance in grant writing. Thank you to Blanc Star for providing support and organization of committee meetings and to Dr. Steve Milosavljevic for chairing my committee meetings. I would also like to thank my external examiner, Dr. Nancy Gyurscik for her time and insight into this thesis.

Additionally, I want to thank the Canadian Physiotherapists in Hemophilia Care and the Canadian Hemophilia Society. Our annual meetings provided the venue to generate ideas and to support research. Our president, Karen Strike, became an active participant in recruiting young men with mild hemophilia for the study. The original committee members include Pam Hilliard, Marion Hahn, MaryJane Steele and Carolyn Jarock.

I would also like to acknowledge the Saskatchewan Bleeding Disorder Program team including, Michelle Sims, Rick Stene, Dr. Robert Card, Dr. Kelsey Brose, Dr. Roona Sinha, Nancy Hodgson, Heather Yuzik, Tara Schlosser, O'Lynda Lovas, Shannon Buckingham, Laurie Guenther, Diane Schaffel, Colleen Buehler, Jennifer King and Dylan Chipperfield who have been consistently encouraging. Thank you also to my supportive physiotherapy colleagues, especially Linda Mickalishen, Jacky McArthur, Janice Block, Andrea Willenborg and Nancy Glover.

I would like to acknowledge all the institutions involved; the Chronic Disease Management Program at Saskatoon Health Region, the School of Physiotherapy at the University of Saskatchewan, the University of Manitoba, the Winnipeg Health Region, and McMaster University in Hamilton.

Thank you also to the research grant funds which have been pivotal in completing this project; the Bayer Hemophilia Awards Program (BHAP) Caregiver's Award (2014) and the CHS-Baxalta Canada Bleeding Disorders Fellowship Program for Nurses and Allied Health Care Professionals (2014).

Finally, I would like to thank my family, my encouraging and supportive husband, James Lokken, also Nils, Olaf and Catherine (and unborn son), Torbjørn, Knut, Robin, Lauren, Oskar, Tulla and Sophia.

I am truly grateful for all the encouragement I have received from so many people through the process of completing this Master's thesis. I may have missed someone and if so, I do apologize as I have tried to create an inclusive list of acknowledgments.

# **DEDICATION**

To young men living with mild hemophilia in Canada

# TABLE OF CONTENTS

PERMISSION TO USE.....	i
ABSTRACT.....	iii
ACKNOWLEDGEMENTS.....	iv
DEDICATION.....	vi
TABLE OF CONTENTS.....	vii
LIST OF TABLES.....	xiv
LIST OF FIGURES.....	xv
LIST OF ABBREVIATIONS.....	xvi
Chapter 1: Introduction.....	1
1.1. Purpose.....	2
1.2. Objectives.....	2
1.3. Research Questions.....	2
1.4. Hypothesis.....	2
1.5. Relevance and Benefits.....	3
1.6 Summary.....	3
Chapter 2: Literature Review.....	4
2.1 Mild hemophilia.....	4
2.1.1. Definition.....	4



2.1.2. Prevalence .....	4
2.1.3. Diagnosis.....	5
2.1.4. Medical Management.....	5
2.1.5. Recommended Comprehensive Care .....	6
2.1.6. Life Expectancy .....	7
2.1.7. Quality of life.....	7
2.1.8. Young men with mild hemophilia .....	8
2.1.8.1. Background .....	8
2.1.8.2. The experience of living with mild hemophilia in Canada.....	9
2.2. Education resources for mild hemophilia .....	10
2.2.1. Recognizing the need for specifically tailored intervention for YMWMH....	11
2.3. Self-management .....	12
2.3.1. Definition of self-management .....	12
2.3.2 Self-management with a Chronic Disease .....	12
2.4. Self-management apps .....	15
2.4.1. Self-management apps for chronic conditions.....	15
2.4.2. Self-management app for young men with mild hemophilia.....	16
2.5. Summary .....	17
Chapter 3: Development of <i>HIRT?</i> (Hemophilia Injury Recognition Tool).....	17
3.1 Knowledge to Action Cycle.....	18

3.2 Knowledge to Action Cycle and Development of <i>HIRT?</i> .....	19
3.2.1 Knowledge Creation .....	19
3.2.2 Action Cycle: Identify Problem, Determine the Know/Do Gap, Select Knowledge .....	19
3.2.3 Action Cycle: Adapt Knowledge .....	19
3.2.4 Action Cycle: Tailor Knowledge .....	20
3.2.5 Action Cycle: Implementation .....	21
3.3 Master’s Research; Action Cycle: Monitor Knowledge Use .....	22
Chapter 4: Personal Statement of the Researcher .....	24
4.1 Personal Position .....	24
4.2. Discipline of Physiotherapy .....	25
4.3 Integration of theory to the researcher .....	27
4.4. Summary .....	27
Chapter 5: Methodology .....	28
5.1 Study Design: Convergent Parallel Mixed Methods .....	28
5.2. Step 1. Concurrent but separate data collection .....	29
5.2.1. Participants .....	29
5.2.2. Recruitment .....	30
5.2.3. Sample size .....	30
5.2.4. Ethical considerations .....	31

5.2.5. Procedure .....	31
5.2.6. Qualitative Data collection .....	32
5.2.7. Quantitative Data collection .....	33
5.2.7.1. Demographic frequencies and means of characteristics of participants ..	33
5.2.7.2 Number of app downloads .....	33
5.2.7.3 Self-report feedback Survey .....	34
5.2.7.4 Confidence levels.....	35
5.3. Step 2: Separate Data Qualitative and Quantitative analysis.....	35
5.3.1. Qualitative Analysis.....	35
5.3.2. Quantitative Analysis.....	36
5.3.2.1. Demographics .....	36
5.3.2.2. Number of <i>HIRT?</i> Downloads .....	36
5.3.2.3. Self-report feedback survey .....	36
5.3.2.4. Confidence levels.....	37
5.4. Step 3: Convergence of data with further analysis .....	37
5.5. Step 4: Interpretation.....	37
5.6. Rigor .....	38
5.6.1. Member validation .....	38
5.6.2. Expert validation.....	38
5.6.3 Triangulation (Converging the data).....	39

5.6.4. The researcher as an instrument in the research process .....	39
Chapter 6: Results .....	40
6.1 Demographics .....	40
6.2. Extent of app usage .....	40
6.3. Qualitative.....	41
6.3.1. Themes.....	41
6.3.1.1. Accessible: .....	42
6.3.1.2. Usefulness:.....	42
6.3.1.2.1. Useful to me.....	42
6.3.1.2.2. Not useful to me.....	43
6.3.1.2.3. Useful to others. ....	43
6.3.1.3. Alarms: .....	43
6.3.1.4. Credible:.....	44
6.3.1.5 Confidence: .....	45
6.3.2 Barriers to use .....	48
6.3.3. Facilitators or Improvement ideas .....	49
6.4. Quantitative.....	51
6.4.1. Self-report Feedback Survey.....	51
6.4.1.1. Accessible, reusable and manage an injury .....	51
6.4.1.2. Comparison of injury management with and without the app.....	53

6.4.2. Confidence levels.....	53
6.5. Convergence of Qualitative and Quantitative results .....	54
6.5.1. Integration of results .....	54
6.5.2. Summary .....	55
Chapter 7: Discussion .....	57
7.1 General Overview .....	57
7.2 The influence of <b>HIRT?</b> on Perceived Injury Self-management.....	58
7.3 Strengths and Limitations .....	65
7.3.1. Strengths .....	65
7.3.2. Limitations .....	66
7.4 Significance and Clinical Implications .....	68
7.5 Future Directions .....	70
7.6 End of Project Knowledge Translation.....	72
7.7 Conclusion .....	72
REFERENCES .....	74
APPENDIX A: Recruitment Material: Website Invitation.....	85
APPENDIX B: Ethics Renewal Certificate .....	87
APPENDIX C: Certificate of Approval.....	88
APPENDIX D: Saskatoon Health Region Operational Approval .....	89
APPENDIX E: Consent Form .....	90

APPENDIX F: Demographics Information and Interview guide .....	96
APPENDIX G: Google and Apple Downloads .....	103
APPENDIX H: Self-report Feedback Survey from the app .....	105

## LIST OF TABLES

3.1. Knowledge to Action and <i>HIRT?</i> Development .....	22
6.1. Demographics (Age / Age of diagnosis).....	40
6.2. Qualitative Themes .....	46
6.3. Barriers.....	48
6.4. Facilitators and Improvement Ideas.....	50
6.5. McNemar's Test Results .....	53
6.6. Joint Display of Qualitative and Quantitative data .....	55

## LIST OF FIGURES

3.1. Knowledge to Action Cycle.....	18
3.2. Screen shot of <i>HIRT?</i> .....	20
5.1. Convergent Parallel Mixed Methods Design.....	29
6.1. Qualitative Thematic Map .....	41
6.2. How easy was the app to access?.....	52
6.3. Ability to manage an injury .....	52
6.4. Would you use the app again? .....	52
6.5. Confidence levels with and without the use of <i>HIRT?</i> .....	54



## LIST OF ABBREVIATIONS

Abbreviation	page
1.1. YMWMH – Young Men with Mild Hemophilia	1
1.2. <i>HIRT?</i> – Hemophilia Injury Recognition Tool	1
1.3. CHS – Canadian Hemophilia Society	1
1.4. app – Application	2
1.5. HTC – Hemophilia Treatment Centers	2
2.1. WFH – World Federation of Hemophilia	4
2.2. CHARMS – Canadian Hemophilia Assessment and Resource Management Information System	4
2.3. IV – Intravenous	5
2.4. DDAVP – Desmopressin	6
2.5. MRI – Magnetic Resonance Imaging	8
2.6. CWTA – Canadian Wireless Technology Association	15
2.7. CDM – Chronic Disease Management	17
3.1. KTA – Knowledge to Action	18
3.2. CIHR – Canadian Institutes of Health Research	18
4.1. ID – Interpretive Description	24
4.2. CPHC – Canadian Physiotherapists in Hemophilia Care	26
5.1. REH – Research Ethics Board	31
5.2. SPSS – Predictive analytics software and solutions	36

## Chapter 1: Introduction

Mild hemophilia has been increasingly recognized as a “neglected diagnosis” (Schulman, 2012; Ekholm, Mattson, Astermark, Ljung, & Berntorp, 2010). Health care professionals have identified distinct and specific diagnostic and treatment challenges (Franchini, Favaloro, & Lippi, 2009; Goodyear, Lauf, Jenkins, McDonald, & Poon, 2012). Young men with mild hemophilia (YMWMH) do not bleed often (Gamba, Lodo, Trincherro, Montani, & Ghidelli, 2010), have limited experience and knowledge with bleeds compared to those with severe hemophilia (van Wanroij, Dielen, Amtari, Laros, & Novakova, 2010) and they do not attend the multidisciplinary hemophilia care clinics regularly (Lindvall, Colstrup, Loogna, Wollter, & Gronhaug, 2010). Therefore, it is difficult to connect with YMWMH to inform and educate them about how to recognize their infrequent bleeds. Specifically tailored self-management tools relevant to the severity of this diagnosis are urgently required (Schulman, 2012; Peerlinck, & Jacquemin, 2010). At this stage of life, young Canadian men aged 18-35 years with mild hemophilia are reluctant to acknowledge their hemophilia (Nilson, Schachter, Mulder, Hahn, Hilliard, Steele, & Jarock, 2012). Unrecognized musculoskeletal injuries can lead to significant medical consequences (Kumar, Stain, Hilliard, & Carcao, 2013).

In order to assist YMWMH to identify serious musculoskeletal injuries in need of health care management, a mobile application ***HIRT?*** (Hemophilia Injury Recognition Tool) was recently developed through collaborations with YMWMH, health care professionals and computer science experts (Lomotey, Mulder, Nilson, Schachter, Wittmeier, & Deters, 2014). It has been available for free download in both Apple and Google formats since December 2014.

Since releasing ***HIRT?***, there has been anecdotal evidence of the potential impact of this tool, as evidenced by a recent quote from an older man with mild hemophilia in the national newsletter for the Canadian Hemophilia Society (CHS). He stated “mild hemophilia is sneaky, it is slow to show itself, and if you don’t act in the right way and within the right time, you can be in big trouble” (Stephenson, Aug. 2015, *Hemophilia Today*, p. 25). The older man who has experienced the challenges of living with mild hemophilia (Stephenson, 2015), stated that he was

jubilant when he heard of *HIRT?*. He emailed his daughter and pointed out the relevance for his grandson who is also affected by mild hemophilia. He goes on to say how absolutely helpful it would have been for him when he was young.

### **1.1. Purpose**

The focus of this master's project was to formally explore whether YMWMH perceive their musculoskeletal injury self-management to be influenced by the use of the mobile application (app) *HIRT?*. This research study provided enhanced knowledge regarding mobile app technology for injury self-management, identified potential barriers and facilitators to the use of *HIRT?* and provided information to inform future app development.

### **1.2. Objectives**

1. To investigate the perceptions of YMWMH on the influence of *HIRT?* on their self-management skills when they sustain a musculoskeletal injury.
2. To identify any barriers or facilitators to use of the app as explained by YMWMH.
3. To direct future research and development of the app as an injury self-management tool for people with bleeding disorders.

### **1.3. Research Questions**

1. Does *HIRT?* influence the perceived musculoskeletal injury self-management practices among YMWMH in Canada?
2. Does *HIRT?* impact the perceived confidence of YMWMH in their injury self-management?
3. What barriers or facilitators are identified and explained by YMWMH to the use of *HIRT?*

### **1.4. Hypotheses**

It is hypothesized that the mobile app intervention, *HIRT?* which provides knowledge about bleed identification, first aid measures and the contacts for the Hemophilia Treatment Centers (HTC), will positively influence YMWMH to effectively access information to identify

an injury, improve perceived injury self-management confidence and provide assistance to contact the HTC.

### **1.5. Relevance and Benefits**

There has never been an intervention developed specifically addressing the needs of YMWMH. Therefore, this project is unique and relevant to YMWMH and health care practitioners working with them. It has been observed that there are significant personal and economic burdens to unrecognized bleeds in YMWMH (Price, Hawes, Bouchard, Vaughan, Jarock, & Kuhle, 2015). The personal losses of unrecognized bleeds include pain, social losses such as missing school and work, and financial and emotional stress. Economic burden is also reflected in the strain on the health care system; with increased demand on the health care professional's time, cost of hospital stays and increased replacement factor usage when bleeds are not identified and managed in a timely and appropriate fashion (Kumar et al, 2013). This intervention could have a substantial health benefit by assisting early injury recognition and contact with the HTC, leading to reduced hardship on these young men and the healthcare system. It could also help diminish the morbidity associated with mild hemophilia, such as long term muscle and joint damage (Ling, Heysen, Duncan, Rodgers, & Lloyd, 2011; Ashikaga, Nagae, Mori, Yamashita, & Taki, 2014). The first step toward these improved health outcomes is to provide a tool that can improve an individual's confidence and ability in the areas of injury recognition, assessment and management.

### **1.6 Summary**

This mobile app, ***HIRT?*** has been developed to provide a tailored injury self-management tool specific to the severity of the diagnosis of these young men. These young men do not bleed often, but when they do, it often goes unrecognized. ***HIRT?*** may help to fill the knowledge gap of bleed recognition and management and also address the need for health professional contact. This research study has assessed how YMWMH in Canada perceived the use of ***HIRT?*** to influence their injury self-management.

## Chapter 2: Literature Review

Young Canadian men with mild hemophilia are reluctant to acknowledge their condition or the associated risks, and they often engage in aggressive sports that cause many of their injuries (Nilson, Schachter, Mulder, Hahn, Hilliard, Steele, & Jarock, 2012). They are unsure of the signs of bleeding that require medical attention (Lipton, 2011; Kumar et al., 2013), and may delay treatment because they believe that their hemophilia is “*not that bad*” (Nilson et al., 2012, p. e122). There is growing recognition that mild hemophilia is a neglected diagnosis with distinct and specific diagnostic and treatment challenges (Peerlinck & Jacquemin, 2010; Goodyear et al., 2012). Self-management tools tailored to the severity of this diagnosis are urgently required (Francchini, Favaloro, & Lippi, 2009; Schulman, 2012; van Wanroij et al., 2010).

This chapter provides a review of the literature on mild hemophilia, educational materials available for mild hemophilia, self-management of chronic conditions and self-management apps developed for chronic conditions and YMWMH.

### 2.1 Mild hemophilia

#### 2.1.1. Definition

Hemophilia is a rare x-linked hereditary bleeding disorder. It is caused by a deficiency of a clotting factor protein in the blood. The most common deficiency is called hemophilia A which is the deficit of coagulation factor VIII (8), hemophilia B is the deficit of factor IX (9). The severity of hemophilia is based on plasma levels of factor activity. The normal level of factor protein activity in the blood is 50-100%. Severe hemophilia is defined by having less than 1% of normal levels of factor protein activity, while levels in moderate hemophilia is a range from 1 - 4% and in mild hemophilia 5 - 40%. (Blanchette et al., 2014).

#### 2.1.2. Prevalence

Hemophilia affects 1 in 5000 males globally (WFH - World Federation of Hemophilia guidelines, 2012). According to World Federation of Hemophilia’s Annual Global Survey (2004), the proportion of males diagnosed with hemophilia who have mild hemophilia was 34% (Stonebraker, Bolton-Maggs, Soucie, Walker, & Brooker, 2009). In Canada, the reported percentage of mild hemophilia is higher at 54% (CHARMS, 2014). This difference is likely due

to a good reporting system supported by our relatively strong economic status (Walker et al., 1995). As stated in the national registry, there are 1800 males in Canada with mild hemophilia; 25% are between the ages of 18-35 years.

### **2.1.3. Diagnosis**

A diagnosis of mild hemophilia can occur at birth through testing due to a family history or following bleeding episodes (Franchini, Favaloro, & Lippi, 2009). The bleeding episodes leading to diagnosis of mild hemophilia can include hematemesis, soft tissue or joint bleeding, or prolonged bleeding after surgery or dental procedures (Chambost, Gabouland, Coatmelec, Rafowicz, Schneider, & Calvez, 2002). The diagnosis is confirmed through a blood test, a factor assay which provides the percentage of circulating clotting factor in the blood. In one study performed in the United States (US) including 2 centers and 55 patients, it was noted that 64% were diagnosed at birth due to positive family history (Venkateswaran, Wilimas, Jones, & Nuss, 1998). Twenty-seven percent of their cohort was diagnosed following trauma or a bleeding episode with surgery. The average age of diagnosis was 5.3 years. It is not unusual to be diagnosed even at a later age after suffering a major hemorrhage due to complications from injury or surgery (Peerlinck & Jacquemin, 2010; Jones et al., 2013; Pappas, 1964; Beal et al., 1974; Tountas et al., 1992 and Allan et al., 2014). In an earlier study by our group, (Nilson et al., 2012), the average age of diagnosis of was 5.5 years, with an age range of 0-16 years.

Incidence in bleeding in mild hemophilia is usually in relation to trauma. Young men are actively involved in aggressive sports such as hockey, football and martial arts (Nilson et al., 2012). It was noted in the Venkateswaran study (1998) that trauma was responsible for 92% of the bleeding episodes. The bleeding was less often in the joint (32%) but more so in the soft tissue (53%). The Gamba (2010) study supports that bleeding patterns in mild hemophilia are mostly hematomas and cutaneous bleeding rather than hemarthroses.

### **2.1.4. Medical Management**

Medical management of hemophilia requires the replacement of the missing clotting factor, replacement factor VIII for hemophilia A and replacement factor XI for Hemophilia B. In severe hemophilia, where they have less than 1% of either factor VIII or XI, this requires a frequent replacement of the clotting factor (Schulman, 2012). The factor replacement is administered via intravenous (IV) access, which requires a direct venous puncture. Those with severe hemophilia

learn the skills of self-infusion of the replacement factors as they treat themselves regularly. This treatment is administered on a regular prophylactic basis to maintain factor levels so these individuals might reduce or avoid bleeding episodes.

In mild hemophilia there is low levels of available clotting factor in their blood (Groen et al., 2013), therefore administration of coagulation replacement therapies is only needed with significant trauma, dental or surgical procedures (Peerlinck & Jacquemin, 2010). When individuals have factor levels in the upper range of mild hemophilia (over 20% factor level), treatment with an antifibrinolytic, tranexamic acid may be sufficient (Schulman, 2012). This works by preventing blood clots from breaking down too quickly and is often used for any surgery involving mucosal membranes such as dental procedures. Another important treatment alternative to factor concentrates in mild hemophilia A is desmopressin (DDAVP). It is a synthetic derivative of the antidiuretic hormone. It was discovered that DDAVP elevates the FVIII level about three-fold over baseline (Mannucci, 2012). DDAVP can be administered by subcutaneous injection or nasally. These methods can be self-administered and used at home to prevent or treat minor bleeding episodes. Intravenous desmopressin is recommended before surgery or for treating a major bleed episode (Mannucci, 2012) in those individuals with mild hemophilia.

As a method of preventing injuries high impact activities are not recommended by many health care professionals and educational materials (All about Hemophilia, CHS 2010) for individuals with mild hemophilia. Consequently, when individuals participate in aggressive sports, the potential of unrecognized and unacknowledged injuries increases; it is these bleeding episodes which could lead to the extensive medical treatment and rehabilitation (Kumar et al., 2013).

### **2.1.5. Recommended Comprehensive Care**

In Canada the recommended management for hemophilia medical care is through a comprehensive care clinic setting. As recommended within the Canadian Comprehensive Care Standards for hemophilia ([CHS Comprehensive Care Standards](#)). The core medical care team includes a hematologist, nurse, social worker and physiotherapist. Intervals between the visits for people diagnosed with mild hemophilia are often longer than those with a more severe diagnosis, but usually a visit occurs every 2 -3 years. It is recommended in the standards document that at the clinic visit, a bleed history is recorded, a physical exam performed and laboratory tests completed (Schulman, 2012). Lifestyle recommendations and educational materials can be offered at these

appointments but due to the nature of many clinics, the people with mild hemophilia are not always seen by all the comprehensive care team members, such as physiotherapy. YMWMH may reject some of the advice given if they feel it is more appropriate for those with severe hemophilia (Ekholm et al., 2010, Nilson et al., 2012); and that the risk of injury was overstated by the health care professionals and their actual injuries were “*not that bad*” (Nilson et al., 2012, p. e122). As well, YMWMH are often poor attenders for their regular clinic care (Lindvall et al., 2010) and show up only for medical attention when they have a crisis (Kumar et al., 2013; Steele & Laudenbach, 2002).

#### **2.1.6. Life Expectancy**

The life expectancy of the mild hemophilia population is close to normal. As stated in the British study by Darby in 2007, the life expectancy for those with mild or moderate hemophilia is 75 years, compared with 78 years for the overall male population (Darby et al., 2007). Consequently, people with mild hemophilia suffer from co-morbidities related to their condition such as a high incidence of ankle arthropathy which was identified in the study by Ling et al. (2011). Therefore, if bleeds are recognized earlier and managed appropriately this situation could be minimized and potentially increasing their quality of life as they get older.

#### **2.1.7. Quality of life**

People living with mild hemophilia have reported a better health-related quality of life than those with people living with severe hemophilia (Miners, Sabin, Tolley, Jenkinson, Kinds, & Lee, 1999), but lower levels of quality of life compared to those without hemophilia (Walsh, MacGregor, Stuckless, Barrett, Kawaja, & Scully, 2008). An important indicator for this lower level of quality of life was directly related to their physical status and joint damage from previous bleeds (Walsh et al., 2008). A study completed in Japan (Ashikaga, Nagae, Mori, Yamashita, & Taki, 2014), with 53 cases of moderate and mild hemophilia stated the incidence of arthropathy was 8.7% in the teens, 18.1% in the twenties, 22% in the thirties and over 30% after 40 years of age. This is verified also by Ling et al. (2011) when the researchers identified a high incidence of ankle arthropathy in people with mild hemophilia. Chronic debilitating joint damage is occurring in this population, highlighting the importance of early bleed recognition and appropriate management.



## **2.1.8. Young men with mild hemophilia**

### ***2.1.8.1. Background***

Mild hemophilia in the more recent years has been considered a “neglected diagnosis” (Peerlink & Jacquemin, 2010; Schurman, 2012). Medical attention has not always been given to people with mild hemophilia to the same level as those with the more severe forms of the disease (Lipton, 2011).

People with mild hemophilia do not bleed often (Franchini, Favaloro, & Lippi, 2009). Some serious medical situations have resulted from unrecognized injuries (Kumar et al., 2013). One of the earliest reports on record is from 1964 (Pappas et al., 1964), when a situation is described about a young man aged 18 years who had a traumatic injury to his hip. His mild hemophilia was unrecognized, resulting in delayed medical attention leading to complications including hemarthrosis of the hip, an infection, osteomyelitis, sepsis and eventual leg amputation.

The complex situation presented by mild hemophilia is emphasized in a review from Larsson et al. (1983). The deaths of people with hemophilia from 1957-1980 in Sweden, showed a higher mortality rate in mild hemophilia compared to severe hemophilia with bleeding in the central nervous system (Larsson et al., 1983). Throughout the literature, there is further documentation of many acute bleeding episodes involving young men with mild hemophilia (Beal et al., 1974; Tountas et al., 1992; Terao et al., 2012; Kumar et al., 2013; Jones et al., 2013 and Allan et al., 2014). A multiple case report from the Hospital for Sick Children in Toronto, Kumar et al. (2013) describes two situations, both involving sports injuries to muscles in teenagers with mild hemophilia. The first situation was a 14 year old boy; he sustained a contusion to the right thigh playing basketball. He did not report to a local medical clinic until 9 days after the injury. He was given DDAVP, an alternative to factor concentrates and activity restriction. He was not compliant with the given recommendations and was improving slowly but at 5 weeks post injury he sustained another blow to the same site. He was then reviewed at the HTC, ultrasound revealed three large loculated hematomas in the vastus intermedius muscle. He was then treated with coagulation factor replacement, given a graduated physiotherapy program. Three months later an MRI (Magnetic Resonance Imaging) scan diagnosed a heterogenous mass with partial encapsulation and associated with new-bone formation along the femur consistent with a pseudotumor. Replacement factor was given consistently for a lengthy period of 20

months as the lesion slowly resolved. In the second case; another 14 year old boy diagnosed with mild hemophilia sought medical attention one week after his basketball contusion injury to the thigh. The initial ultrasound showed a large hematoma in the vastus intermedius muscle and he was treated with replacement factor. One month later on follow-up ultrasound there was heterotrophic calcifications within the hematoma consistent with myositis ossificans. These documented cases of medical complications due to the unrecognized severity of a bleed in mild hemophilia further emphasize that young men with mild hemophilia are an at risk population.

#### ***2.1.8.2. The experience of living with mild hemophilia in Canada***

A recent qualitative study completed by Nilson et al. (2012) interviewing 18 YMWMH about their lived experience of having mild hemophilia confirmed that YMWMH were reluctant to acknowledge their hemophilia and many expressed that it is “*not that bad*” (Nilson et al., 2012 p. e122). This resistance can affect their approach to injury management as stated by this young man, “*I extended it (treatment) to two weeks sometimes because I don’t like to admit that I’m a hemophiliac*” (Nilson et al., 2012, p. e123). This was also observed by hemophilia care centers in the United States (Lipton, 2011) and Sweden (Ekholm et al., 2010). In a case report by Lipton a young man, 19 years old, delayed medical attention for a basketball hamstring bleed. The research study from Sweden reviewed patient records (n=106) as well as utilized questionnaires and interviews to demonstrate the needs of people with mild hemophilia. The researchers discussed the importance of providing additional knowledge about mild hemophilia to the young men and encouraging more regular contact with the HTC.

Most participants in the Nilson study (2012) took a “wait and see what happens” approach to injury management. It was stated that pain at the injury site was the most common indicator of the severity of the injury. Participants who had previous experience with injuries from sport activities felt they just knew, as stated by this young man “*I just seem to have a good gauge of what’s going to be bad*” (Nilson et al., 2012, p.e124). Comparison to previously experienced injuries was the most common way that the participants decided if an injury was going to be severe. The young men in the study who were less experienced with injuries were less likely to think that an injury needed attention. Some of the men spoke about postponing medical attention for reasons such as not wanting to acknowledge their hemophilia, wanting to appear normal in front of their peers, fear of needles or the inconvenience of going to the get medical attention.

The attitudes and behaviours identified in this group of YMWMH left them less likely to have a system in place to access medical intervention for an injury. Consequently, they may delay seeking treatment until the pain and disability become significant from an injury.

Participants in the study (Nilson et al., 2012), also felt that the education and recommendations regarding activity restrictions and injury management provided by the health care team did not apply to them because their bleeds were so infrequent. Many stated that they did not take the recommendations from the health professionals seriously, relying instead on their own previous experience or that of their affected siblings or relatives. Some of these young men felt they were being treated like they had severe hemophilia, therefore resisted the advice given by the health care workers. One participant illustrated this by saying “*But telling me this might happen to me (bleeding injury) when that ain’t going to happen to me. That’s going to happen to someone with a severe case, that’s not factual. That’s made up*” (Nilson et al., 2012, p. e123). If their diagnosis was made at a later age their reaction to information given from the medical team could result in negative behaviour, such as this boy states “*they basically took all the wind out of my sails, I quit all sports and I was just basically drinking and doing drugs all the time*” (Nilson et al., 2012, p. e123).

The YMWMH in this study felt that it would be more effective for the health care team to work with them individually on bleeding episodes. Therefore, they could attempt to understand why some injuries become problematic and why others resolve without requiring treatment.

This qualitative research by Nilson et al. identified the knowledge gap and challenges facing YMWMH leading to the creation of the mobile app **HIRT?** (Lomotey, Mulder, Nilson, Schachter, Wittmeier, & Deters, 2014). It has been developed specifically for and with the input of YMWMH to try and overcome some of these attitudes and behaviours. A complete outline of the development of **HIRT?** is covered in chapter three.

## **2.2. Education resources for mild hemophilia**

Education regarding self-management of bleeding is an essential part of hemophilia care (Canadian Comprehensive Care Standards for Hemophilia and other Inherited Bleeding Disorders, Canadian Hemophilia Society, 2007). This reflects the principles of chronic disease management, which emphasizes the importance of disease specific education and self-management (Lorig et al.,

2001). Most hemophilia patient education materials have been developed primarily for individuals with severe hemophilia and make only passing reference to mild hemophilia with very little specific information for those with mild hemophilia (All about Hemophilia: A Guide for Families, chap.9, p.2-4, Canadian Hemophilia Society, 2010).

Some written educational materials have been developed for individuals with mild hemophilia. However, only one study identified in this literature review described the delayed-onset symptoms that would indicate to a person with mild hemophilia that he is having a serious bleed (Mild Hemophilia, 1998, Haemophilia Foundation of Australia). Most educational materials offer only general information such as “bleeds occur after significant trauma, dental extraction or surgery” (Information Booklet on Mild Hemophilia, Canadian Association of Nurses in Hemophilia Care, 2007). It is particularly important because most hemophilia education emphasizes “If in doubt, treat” or “Factor first” (All about Hemophilia: A Guide for Families. Second edition, Canadian Hemophilia Society. 2010). This advice is not always relevant to YMWMH because they have some circulating clotting factor and some injuries do resolve on their own without medical attention (Groen et al., 2013). There is a paucity of materials to support these men to recognize and self-manage a musculoskeletal injury.

### **2.2.1. Recognizing the need for specifically tailored intervention for YMWMH**

Healthcare professionals encounter clinical situations in which YMWMH seek attention only several days after known trauma (Kumar et al., 2013; Steele & Laudenbach, 2004; Lipton, 2011; Ekholm et al., 2010; Gamba et al., 2010; van Wanroij et al., 2010), suggesting that these YMWMH do not recognize an injury requiring medical attention when it occurs. As a result of a delay in seeking treatment, such injuries may require a lengthy period of rehabilitation and utilize large amounts of clotting factor concentrates, increasing the economic burden on our health care system (Kumar et al., 2013). There is also a significant decrease in quality of life for YMWMH due to the social and emotional burdens of missing school and/or work associated with a significant bleed (Walsh et al., 2008; Price et al., 2015). Evidence and clinical experiences suggest that negative consequences of delays could be avoided if bleeds were recognized earlier and treatment initiated sooner (Kumar et al., 2013; Jansen, Roosendaal, & Lafeber, 2008). Reports from many developed countries (Ekholm et al., 2010; Querol, Aznar, Haya, & Cid, 2002; van Wanroij et al.,

2010) suggest that YMWMH are a particularly high-risk group for unrecognized and unacknowledged bleeds with delayed health care contact.

Medical health professionals frequently express frustration about their capacity to influence patient behavior, especially when they see the negative impact of that behavior on their patients' health outcomes (Keller & White, 1997). This has also been expressed in hemophilia care (Goodyear et al., 2012; Laudenbach & Steele, 2002). Clinicians recognize that patients' behaviors and adherence to treatment plans are essential to producing positive health outcomes. This is reflected in the situation of YMWMH, who have been known not to attend clinic regularly (Lindvall et al., 2010) and resist acknowledgement of their hemophilia (Nilson et al., 2012) and often neglect to contact the HTC when they sustain a significant injury (Kumar et al., 2013). These facts emphasize the need for an intervention for injury self-management specifically tailored for YMWMH. There has been no similar type of resource available before the mobile app, *HIRT?* It has been developed with input from the young men with mild hemophilia and the health care professionals in Canada (Lomotey et al., 2014).

## **2.3. Self-management**

### **2.3.1. Definition of self-management**

Self-management refers to the measures that a person can take to manage and prevent the symptoms of his chronic disease in collaboration with the health care team (Johnson et al., 2008). Self-management has been a health education term used for a long time (Creer, 1976). Creer described the term self-management as the patient taking an active role in his treatment. A person's self-management consists of learning a certain set of skills and behaviors that create confidence in dealing with the medical, physical and emotional symptoms of his chronic disease (Lorig & Holman, 2003).

### **2.3.2 Self-management with a Chronic Disease**

There is evidence that supporting people to self-manage their chronic condition can improve their motivation, improve their health status and reduce utilization of health services (Newbronner et al., 2013). The self-management approach fosters development of an empowered patient with the skills and confidence to better manage chronic diseases and interact with the primary health care system (Lorig et al., 2001).

Chronic care models make a shift from reactive to proactive health care as seen in several models such as the Chronic Disease Self-Management Program described by Lorig (2001) and the Live well with Chronic Conditions model used in Saskatchewan (Chronic Disease Management, Saskatoon Health Region). These programs provide a 6-week face-to-face group for education and support.

Self-management programs seek to enhance the individual's ability to cope with his diagnosis and live better quality lives with fewer restrictions from their illness. This is done by developing self-efficacy, which is the level of confidence that an individual has in his ability to succeed in dealing with their own chronic disease (Johnston et al., 2008). The health care team provides self-management support to the individual to perform a certain set of tasks to enhance his confidence in dealing with the emotional, physical, and physiological symptoms related to their chronic disease (Stanford self-management program, 2008).

There are five core self-management skills as described by Lorig and Holman (2003): 1) problem-solving, 2) decision making, 3) how to find and utilize resources, 4) form a partnership with the health care providers and 5) taking action. Each skill will be briefly reviewed. **Problem solving skills** include a basic definition of the problem and seeking a solution, as in soliciting advice from friends, family or the health care providers. **Decision making** is part of problem solving but it involves the knowledge needed to make decisions around a change in one's condition. The skill of **how to find and utilize resources** is an important part of the education of self-management. The individual needs to know how to contact their healthcare provider but also where and how to get other appropriate resources. The self-management skill of assisting people to **form partnerships with their health care providers** is a skill emphasized because in the past people only sought the health care profession for acute illness. Now with the identified presence of chronic diseases, such as diabetes, asthma and bleeding disorders, the health profession becomes that of a teacher and partner in the management of the chronic condition.

**Taking action** is the final skill of self-management. Self-efficacy can be defined as the belief in one's capacity to succeed at tasks (Johnston et al., 2008). "Self-efficacy is measured by asking people how confident they are or how sure they are that they can under specific conditions achieve certain behaviours" (Lorig & Holman, 2003, p. 4). Taking action can be thought of as similar to the skill mastery in the self-efficacy model (Bandura, 1977). This skill is associated with

learning how to change a behaviour. The chronic disease self-management program, Live Well with Chronic Conditions ([LWWCC](#)), use this skill to initiate short term action plans. When a person makes the action plan around a change in behaviour, he must identify how confident he is that he will accomplish this plan. The confidence is measured on a scale from 0 (totally unconfident) to 10 (totally confident). If the confidence level is 7 or higher, then it is a good chance that the action will be completed. The individual is encouraged to change his action plan if his confidence level is less than 7. The individual must decide on a more accomplishable action plan. The new action plan should have a confidence level of equal or higher than 7 to avoid failure (Lorig, 2007).

The Choices and Changes model (Keller & White, 1997) is a simple method to assess confidence levels. It uses a numerical measurement of conviction and confidence levels towards certain health behaviours. As described by Keller and White, the person must be ready or believe that a change could enhance their well-being, which is the dimension of conviction. The second dimension of this model which is confidence is when the person believes he can make a change. These components of behaviour are measured by asking the patient his level of both conviction and confidence. They are graded on a 0 -10 scale. This model was developed for the clinicians to assess their patients and begin to understand the obstacles to health behavioural change, therefore assist in providing appropriate interventions (Keller & White, 1997).

All of the five core skills of self-management as described by Lorig and Holman (2003) should be present in self-management interventions if they are to be effective. Self-management support focuses on the individual, and his family but, does not replace a health care team. It encourages a reciprocal relationship between the individual and the health care team (Johnson et al., 2008). In a case study on the perceptions of self-care support for children and young people with chronic conditions (Kirk, Beatty, Callery, Milnes, & Pryjmachuk, 2012) effectiveness was discussed. These programs were all face-to-face groups, with one online support group. The study revealed the effectiveness of self-care support especially in the areas of confidence and independence, as well as developing knowledge and skills. In a systematic review of self-management interventions (N=78) for young people with chronic conditions (Sattoe, Bai, Roelofs, Bal, Miedema, & Staa, 2015) most of the programs were solely aimed at medical management. The researchers emphasized that the healthcare professionals were challenged to pay more

attention to the individual's emotions and self-management skills that go along with the chronic disease. Mild hemophilia is a chronic condition. There are no specific studies related to the efficacy of medical management or self-management for mild hemophilia. Therefore, these examples are provided to highlight that an intervention to be effective requires medical management as well as self-management supports.

## **2.4. Self-management apps**

### **2.4.1. Self-management apps for chronic conditions**

Technology is rapidly evolving. More than 24 million Canadians have mobile devices, with 4 out of 5 of those being smart phones. Most people access their mobile devices daily (Canadian Wireless Technology Association, CWTA, 2015 Facts and Figures). Thirty-six percent of those smart phones are used by the 18-34 year old age group, and over 80% of digital time is spent on apps (Future in Focus Digital Canada, 2015). Application technology for self-managing chronic illnesses, such as diabetes and asthma (Wood, Robson, Thompson, & Johnson, 2013; Padman, Jaladi, Kim et al., 2013; Marcano Belisario, Huckvale, Greenfield, Car, & Gunn, 2013), are being developed and offered for smart phone devices.

In one study, Dicianno et al., 2015 created an app for individuals with spina bifida. This app was developed to improve health outcomes for this complex chronic condition. It assisted to help people manage skin integrity, neurogenic bladder and general health issues. It was connected to a web-based program and provided reminders for checking skin for pressure sores and taking medications. If a problem was encountered then the individual could connect with a health care professional and information was dispersed via the web portal. Individuals living with spina bifida, along with clinicians and care givers who trialed the app, participated in a focus group discussion. The overall response of the focus group was positive to adopt the system for both professional and personal use. In the final evaluation of the group of interventions called mHealth technologies, which included the app for spina bifida, the researchers stated that these technologies have changed the way care is delivered and the way individuals in the community manage their own health. The study goes on to state that technology, including apps have shown promise in improving patient satisfaction, participation in self-management of their conditions and behaviour modification.



Many asthma self-management interventions have been developed into mobile apps. One study (Huckvale et al., 2015) evaluated 191 of the 764 apps offered for asthma. The authors found that rather than focusing on known gaps in self-management, many of the apps only offered basic information about asthma, and only one fifth of them addressed action plans. Some of the apps had a feature, such as reminders that could improve self-management, but none of the apps reviewed offered a method for connecting to a health care provider. The researchers stated future work needs to explore the validity of app ratings for quality and to continue to develop evidence-based specifically designed apps for asthma self-management.

In a systematic review by Krishna, Boren and Balas (2009), 25 studies were reviewed. The results showed that with information delivered through mobile technology, improvements were seen in self-management of chronic conditions, such as diabetes and asthma. The researchers suggested that this technology could deliver successful health improvement interventions to more hard to reach populations, where traditional interventions have not been successful.

The strengths and limitations of the evidence cited in this literature review emphasize the importance of further research investigating the use of mobile apps for self-management of chronic conditions. It shows that apps have shown promise to increase patient participation in their self-management (Krishna et al., 2009) and could deliver health improvement interventions for hard to reach populations (Wayne & Ritvo, 2014). It also revealed the importance of including disease specific self-management features into apps which recognize the differing needs of individuals (Huckvale et al., 2015). Therefore, in this study we have explored the perceived use of *HIRT?*, a mobile app, developed specifically for the hard to reach population of YMWMH in Canada.

#### **2.4.2. Self-management app for young men with mild hemophilia**

The mobile app, *HIRT?*, was developed specifically for YMWMH, with their involvement and feedback (Lomotey et al., 2014). *HIRT?* the injury self-management mobile application allows some latitude in management strategies, different from the treatment expectations developed for severe hemophilia. It recognizes delayed onset of symptoms, so users are reminded to recheck the injury at 1 hour, 24 hours and 2 days after first accessing the app. If the symptoms of injury worsen users are provided with contacts to their local HTC (Chapter 3, Figure 3.2: screen shots from the mobile app). *HIRT?* promotes the 5 core self-management skills. Chapter 3 outlines the development and implementation of *HIRT?*.

## 2.5. Summary

Mild hemophilia has been considered a neglected diagnosis (Lipton, 2011; Schulman, 2012). YMWMH are a challenge to the Canadian HTC's as they are reluctant to acknowledge their condition (Goodyear et al., 2012; Nilson et al., 2012), do not often recognize severe injuries (Kumar et al., 2013) and bleed infrequently (Peerlinck & Jacquemin, 2010). Therefore, it is difficult to provide this hard to reach population with an intervention that could be useful for them. *HIRT?* which is available for smart phones could improve health outcomes for YMWMH in Canada, by providing specific guidelines for assessment, care that is more appropriate for the milder form of the condition, as well as provide and facilitate the HTC contact.

As stated in Chronic Disease Management (CDM) literature, "A major part of becoming a self-manager of your chronic condition is knowing when you need help and how to find help" (Lorig et al., 2007, p. 31) This intervention, the mobile app, *HIRT?* was investigated in this research study on how it may or may not influence perceived self-management practices in YMWMH in Canada. If we can identify the potential benefits, facilitators and barriers to use of this app, these results could help direct future clinical practice strategies. The potential impact of *HIRT?* could be felt first and foremost by the YMWMH, not having to suffer the pain and consequences of an unrecognized injury. Subsequently, the health care system could also benefit with less demand on resources, including expensive coagulation factors, health professional's time and hospital stays. The app could also assist in better relationships between the young men and the health care team. Ultimately, it is our hope that *HIRT?* contributes to enhancing the quality of life of YMWMH in Canada.

## **Chapter 3: Development of *HIRT?* (Hemophilia Injury Recognition Tool)**

This chapter describes the several phases in the development of the mobile app *HIRT?* and how it followed the Knowledge to Action framework, developed by Graham et al. (2006).

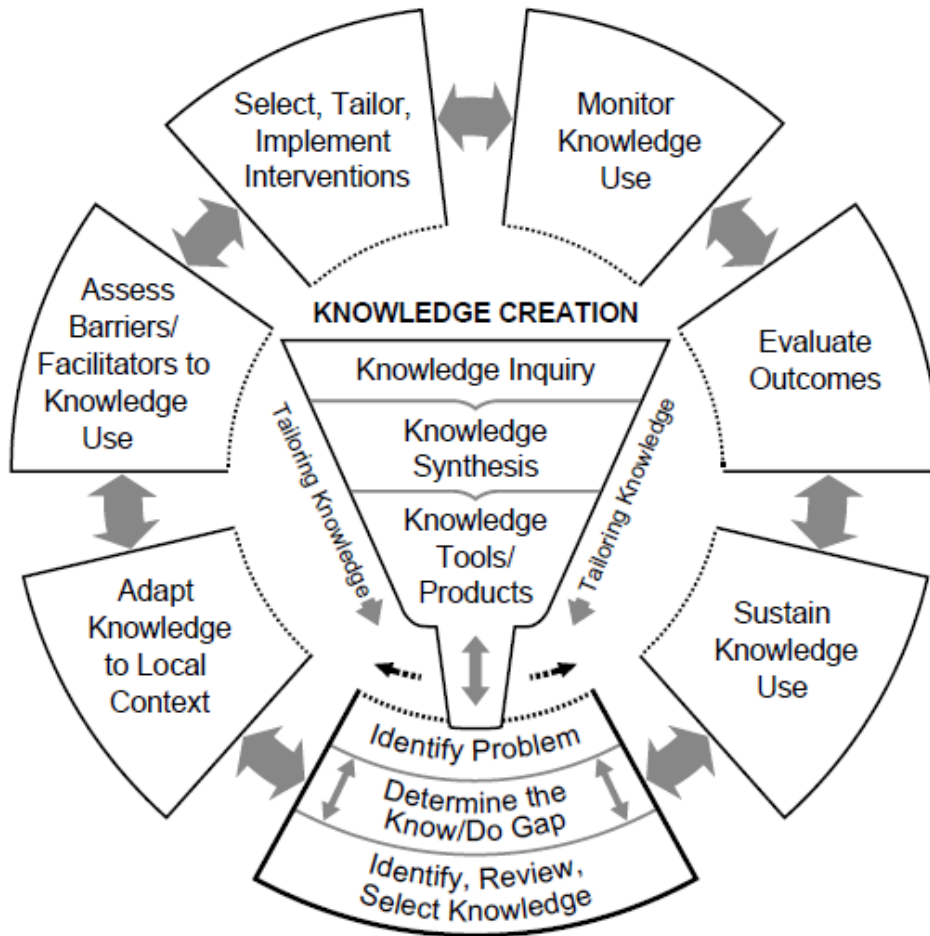


Figure 3.1: Knowledge to Action Cycle (License Number 3755550503726)

### 3.1 Knowledge to Action Cycle

The Knowledge to Action (KTA) cycle is a conceptual framework which is complex and allows for the process of creating and applying knowledge. The KTA cycle (Figure 3.1) has been adopted by the Canadian Institutes of Health Research ([CIHR](#)) as the accepted model for promoting the application of research and a framework for the process of knowledge translation. The KTA model is part of the field of implementation science, which is defined as “the scientific study of methods to promote the systematic uptake of clinical research findings and other evidence-based practises into routine practise and, hence, to improve the quality and effectiveness of health care” (Straus, Tetroe, & Graham, 2013. p. 17).

## 3.2 Knowledge to Action Cycle and Development of *HIRT?*

The development of *HIRT?* has followed the KTA cycle and continues to be framed by the KTA model (Table 3.1: Development of *HIRT?* with the KTA Cycle).

### 3.2.1 Knowledge Creation

The **knowledge creation component** consists of knowledge synthesis, tools and products. This component of the KTA cycle includes all the education materials which have been developed and available for all individuals with hemophilia. The education materials and resources have been developed primary for those with severe hemophilia.

### 3.2.2 Action Cycle: Identify Problem, Determine the Know/Do Gap and Select Knowledge

The KTA model **action cycle** starts with **identify problem**. The clinical experience of hemophilia health care professionals indicated there was a problem with YMWMH not attending clinics (Lindvall et al., 2010) and coming in for delayed treatment following injuries (Kumar et al., 2013). Therefore, the existing tools were not being used or were not effective for YMWMH. To determine the **Know/ Do Gap**; 18 young men with mild hemophilia discussed their experiences of living with mild hemophilia through grounded theory qualitative inquiry (Nilson et al., 2012). The qualitative research highlighted that YMWMH in Canada are reluctant to acknowledge their hemophilia and often use the strategy of “watch and wait” to self-management an injury. “They were less likely to have a system in place to access medical care in a timely manner and may delay seeking medical intervention until their pain and disability are significant” (Nilson et al., 2012, p.e124). Therefore, the **select knowledge** of injury self-management for YMWMH was identified as significant through this qualitative research (Nilson et al., 2012).

### 3.2.3 Action Cycle: Adapt Knowledge

Knowledge was **adapted** to create an injury self-assessment pathway in the form of a flow chart to assist YMWMH to identify musculoskeletal bleeds (Nilson et al., 2012b). The self-assessment pathway was based on current clinical practice guidelines (WFH Guidelines for the Management of Hemophilia, 2<sup>nd</sup> edition, 2012), and was reviewed by hemophilia care professionals across Canada (Mulder, 2011). It was designed specifically for YMWMH to assist

them with bleed recognition and injury self-management. The utility of the self-management pathway was evaluated by 14 YMWMH through key informant interviews (Nilson et al., 2012b). The young men perceived this pathway as useful, and collectively recommended that the pathway would be most useful if made available as a mobile app for their smart phones. Therefore, the mobile app became a facilitator to knowledge use.

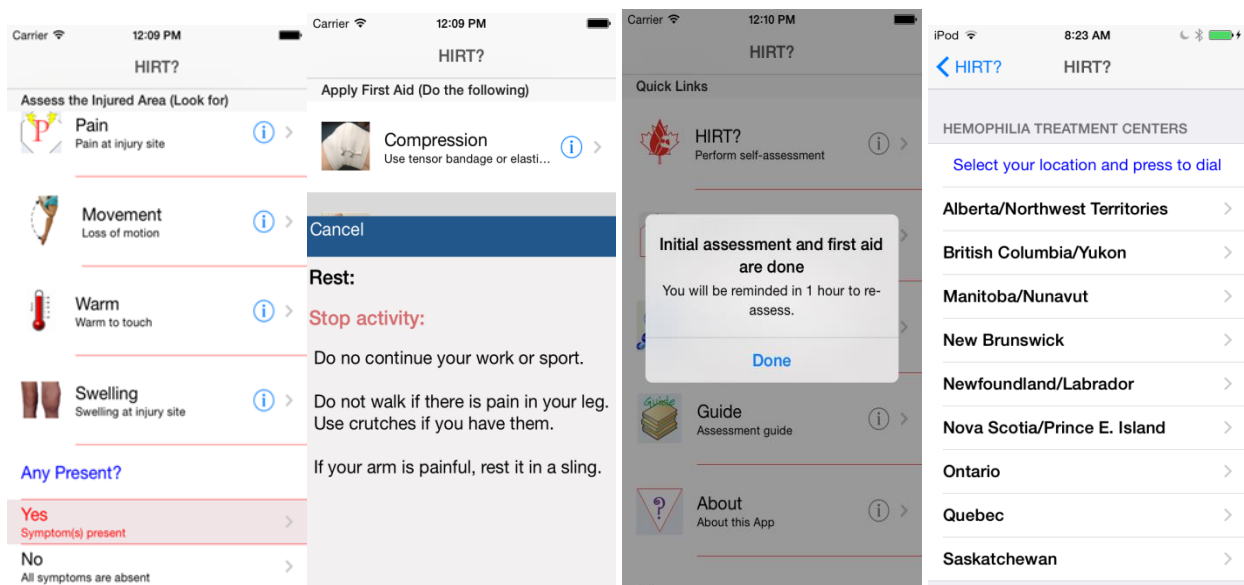


Figure 3.2: Screen shot of *HIRT?*

### 3.2.4 Action Cycle: Tailor Knowledge

**Tailoring** the knowledge was done through consultation and collaboration with the department of computer science. The self-assessment pathway was applied to inform the creation of a mobile app for injury self-management for YMWMH (Lomotey et al., 2014). The mobile app, *HIRT?*, was developed specifically for YMWMH, with their involvement and feedback (Nilson et al., 2012b). Accordingly, the self-assessment mobile application allows some latitude in management strategies, different from the treatment expectations developed for severe hemophilia. Self-management skills described by Lorig and Holman (2003) align with *HIRT?* The skills include problem solving, decision making, how to find and utilize resources, forming partnerships with healthcare providers and taking action. The skill of problem solving is addressed as YMWMH are often faced with the problem of identifying if an injury is going to become severe or not. It was indicated in former research (Nilson et al., 2012) that they mostly use the parameter of pain to determine the seriousness of an injury. The mobile app, *HIRT?* provides them with four

parameters to identify an injury: loss of movement, swelling, warmth, as well as pain. The app also provides information about treatment options of first aid, including rest, compression, elevation and the use of ice. Furthermore, the app recognizes delayed onset of symptoms, so users are reminded to recheck the injury at 1 hour, 24 hours and 2 days after first accessing the app. If the symptoms of injury worsen users are prompted to make a decision and are provided with contacts to their local Hemophilia Treatment Center (HTC) (Figure 3.2: screen shots of *HIRT?*). The self-management skill of how to find and utilize resources is covered by all the information that is available within their smart phones. A detailed assessment guide (Identifying Common Joint and Muscle Bleeds, CPHC, 2014) is present within the app to provide an additional resource. The skill of forming partnerships with the health care providers is enhanced by the ability for young men to have a quick option to connect with the HTC. The HTC contacts numbers, including phone numbers and after-hours pager numbers are available with a direct dial option through the app. Therefore, *HIRT?* could provide the guidance that could help YMWMH take action, the final skill of self-management.

Creation of the mobile app was done in partnership with researchers and clinicians from Saskatchewan and Manitoba bleeding disorders programs, School of Physical Therapy, University of Saskatchewan, Knowledge Translation Platform, Manitoba Centre for Healthcare Innovation and the Department of Computer Science, University of Saskatchewan (Lomotey et al., 2014).

### **3.2.5 Action Cycle: Implementation**

*HIRT?* was made available free of charge in both IOS and android formats through both Apple and Google stores. *HIRT?* has both French and English versions. All the instructions for download were made available on the Canadian Hemophilia Society website ([CHS](#)). Official **implementation** of *HIRT?* was December 2014 with a joint media release between Winnipeg, Manitoba and Saskatoon, Saskatchewan. (Media Releases: Self-management App for Mild Hemophilia World's First. Manitoba Health Region, December 4, 2014; App launched to help those with mild hemophilia, The Region Reporter, News from Saskatoon Health Region, December 9, 2014). The announcement of *HIRT?* created a significant interest throughout the bleeding disorders community. Coverage of the event included television, radio, newspaper and social media which greatly assisted with the dissemination of *HIRT?*. *HIRT?* subsequently

received the Connected to the Community Award, March, 2015, through the Canadian Wireless Telecommunications Association in both Saskatchewan and Manitoba ([Twitter](#), March, 2015).

### 3.3 Master’s Research; Action Cycle: Monitor Knowledge Use

This master’s research study addressed the “**Monitor Knowledge Use**” phase within the action cycle (Figure 3.1: KTA Cycle; Table 3.1: Development of *HIRT?* with the KTA Cycle). Knowledge use was defined specifically as conceptual use of knowledge, which implies changes in knowledge, understanding or attitudes (Strauset al., 2013). Within this phase it has also been necessary to determine how and to what extent the knowledge has diffused to the target population.

The process of the KTA cycle is complex and dynamic; therefore the boundaries between phases can be fluid and permeable (Graham et al., 2006; Straus et al., 2013). Other elements of the KTA cycle were also explored through participants’ responses in the interviews. I have spanned several phases of the KTA framework (Table 3.1; Knowledge to Action Framework and *HIRT?* Development), as I have attempted to discover the perceived barriers and improvement ideas, as well as monitor the extent of the use of this intervention.

Table 3.1: Knowledge to Action and *HIRT?* Development

Key to KTA Framework		Knowledge to Action Framework	Method
----------------------	--	-------------------------------	--------

<b>COMPLETED WORK</b>	2007-2008	Identify problem Determine Know/Do Gap	Qualitative research with YMWMH(Nilson et al., 2012)  Qualitative analysis: grounded theory
	2009-2010	Select Knowledge	Knowledge Integration with clinical practise guidelines  Self-care injury assessment pathway created to address the gap of unrecognized bleeds in YMWMH Health care professionals reviewed and agreed (Mulder, 2011)
	2011-2012	Adapt Knowledge	14 YMWMH interviewed. Concurrent data analysis used to indicate the utility and preference for a mobile app (Nilson, Mulder, and Schachter, 2012)
	2013	Tailor Knowledge	3 young men reviewed the app, modifications were completed, the young men named the app (Lomotey et al., 2014)
	2014	Implementation	<b>HIRT?</b> (Hemophilia Injury Recognition Tool) was implemented: Dec. 2014
	<b>MASTER'S RESEARCH STUDY</b>	<b>2015</b>	<b>Monitor Knowledge use</b>  <b>Assess Barriers/Facilitators</b>
<b>FUTURE RESEARCH</b>		Evaluate outcomes	Future Research
		Sustain Knowledge use	Future Research



## **Chapter 4: Personal Statement of the Researcher**

This chapter will cover the inspiration behind this research and my personal statement as the researcher.

A personal foreclosure is an important aspect of qualitative research. Thorne (2008) talks about the scaffolding of a research project, the two essential parts are the literature review (Chapter 2) and aligning the researcher with the project (Chapter 4). The theoretical forestructure is an element of interpretive description (ID) and was the qualitative method chosen for this research study (Thorne, 2008). This element recognizes and locates the researcher within the research field and the surrounding theoretical world (Thorne, 2008). It is recognized in ID that the researcher is an instrument of the study and will play a meaningful role in shaping the outcome of the inquiry (Thorne, 2008, p. 64).

“Bracketing” as described by Richard and Morse (2013) means putting your personal knowledge, as well as the knowledge one has gained from the literature aside so once can see the research setting and question with a clearer view and work inductively to understand the new information. Bracketing will be satisfied by the article by Nilson et al. (2012) which includes the evidence created about the attitudes, behaviour and knowledge of YMWMH in Canada.

Therefore, in this chapter, I will clarify my personal position, my discipline and define how the theoretical framework was integrated and aligned to the researcher.

### **4.1 Personal Position**

My personal background is identified in this section so you can gain an understanding of my point of view that may be reflected throughout this research study.

I am from western Canada. I grew up in a family where I was taught to respect all individuals equally. This provided the caring background which led me to pursue a career as a physiotherapist. I always wanted to have an impact on improving the quality of life of others. Throughout my career, I have had the opportunity to work and live in a variety of cultures; Canada, United States, Norway and Nigeria. This opportunity has provided me with an understanding of the wide spectrum in the level of healthcare available in each different community. Likewise, I have had experience in hemophilia care on a global perspective; being actively involved or

attending workshops and conferences in Mongolia, Spain, Argentina, USA and France. This has also given me a broad understanding of the many cultural diversities in hemophilia communities and the level of local health care services available to them. This understanding has made this project more exciting in many ways, as I have been approached from medical professionals from other countries who have also experienced the similar dilemma with their YMWMH.

I am married and have been fortunate to have 4 children. These four boys have given me the personal experience of how young men think and behave. They are presently between the ages of 18 to 28 years. This has given me an increased capacity to understand the attitudes and behaviours of the YMWMH who have given of their personal experiences to this study.

#### **4.2. Discipline of Physiotherapy**

My discipline is a physiotherapist, so this study will be conducted through that lens. I have had many years of clinical practise with the last 15 years in hemophilia care. This is a highly specialized area of physiotherapy. I have had the advantage to work within a provincial multidisciplinary team. This core medical team consists of a social worker, nurse, hematologist and myself, a physiotherapist. ([Saskatchewan Bleeding Disorders Program](#)). I also have had significant support and advanced professional education through the Canadian Physiotherapists in Hemophilia Care ([CPHC](#)). This group meets annually and is affiliated with the Canadian Hemophilia Society. I am presently the vice-president of this Canadian professional group.

Hemophilia is a hematologic condition with orthopedic manifestations. Bleeding complications primarily affect the musculoskeletal system (Lobet, Hermans, & Lambert, 2014). Therefore, physiotherapists are actively involved in the comprehensive rehabilitation care for YMWMH following their major musculoskeletal injuries. During the time I have practised physiotherapy in hemophilia care, I have had the experience of being involved in the extensive management of 6 YMWMH who sustained significant injuries. Those injuries were not initially recognized, and unfortunately turned into a cascade of serious medical consequences that may have been prevented if the injury was reported to the HTC earlier. I have the personal experience of witnessing how these traumatic events caused emotional, social and financial stress to those individuals and their families. The financial burden was also felt significantly by our health system for the expensive coagulation factor replacement products, hospital stays, and healthcare

professionals' time. These types of situations have been seen and described by my colleagues in many HTC across Canada (Steele & Laudenbach, 2004; Kumar et al., 2013; Sinha, 2014).

The Canadian Physiotherapists in Hemophilia Care (CPHC) were asked to supply some educational material to this group of young men who would show up with unrecognized bleeds in the emergency room in a medical crisis. Many Canadian hemophilia health care professionals perceived the need for an intervention for YMWMH through similar experiences. The CPHC group felt we did not know what specific information to provide or how to provide this information, so we began our research journey by asking these young men how it is to live with mild hemophilia. I became the principal investigator of the project, the precursor to this Master's of Science thesis. Basic theory about young men with mild hemophilia living in Canada was developed through the use of grounded theory qualitative inquiry (Nilson et al., 2012). In this study, 18 YMWMH, 17-31 years old (mean age 25.2 years) were interviewed from 6 different provinces. Half of the young men did not know their factor levels, only seven had received replacement clotting factor in the previous year, the majority missed no more than 2 days of work due to bleeding episodes and most of the participants' bleeds were musculoskeletal. Only one man denied sports participation, the others were involved in aggressive sports such as martial arts, hockey, snowboarding and football. The major common attitudes and perceived behaviours identified through this qualitative inquiry included reluctance to acknowledge having hemophilia, the importance of experiential learning, the negative reception of advice from the HCT and the wait and watch strategy for managing bleeds. The gap of knowledge we acted on with this study was their wait and see approach to manage injuries. This attitude along with their reluctance to acknowledge their hemophilia can make these men less likely to have a plan in place to access medical care in a timely manner. Consequently, YMWMH often leave injuries too long by not identifying an injury needing medical attention. Out of this knowledge gap the mobile app, *HIRT?*, was born. Throughout the app development process we have consistently consulted with these young men. We shared our ideas on what guidelines for bleed identification and management could look like for YMWMH, and they provided input. Their feedback demonstrated that their preference in how to receive / use the information was definitely in the form of an app.

### **4.3 Integration of theory to the researcher**

I have been extensively involved in this research project with YMWMH. The project has followed the structure of the KTA cycle (Ch. 3, Figure 3.1). This theoretical framework has guided our research from the beginning initially using grounded theory to understand the attitudes and behaviours of YMWMH, then to identify the evidenced-based gap in knowledge of these young men. We proceeded to develop a care pathway which morphed into an app at the recommendation of the YMWMH (Table 3.1: Knowledge to Action Framework and *HIRT?* Development). Compassion for the plight of these young men provided the driving force behind the years of research it has taken to get to this point. Continuing to move along the KTA cycle this Master's thesis addresses the monitor knowledge use phase, as well as continue to look for any barriers or facilitators to the interventions use. This project has been a team collaboration from the inception, it could not have proceeded to this extent if not for all the hard work of each individual involved. I have embarked on my Master's thesis project to investigate the perceived use of *HIRT?* as a tool for self-management for YMWMH.

### **4.4. Summary**

This chapter has included how the researcher has been involved with this project from the beginning. Through providing a personal perspective, I have aligned myself, the researcher with the project (Thorne, 2008) and put my personal knowledge aside (Richard & Morse, 2013) so I had the ability to work inductively to understand the new information. Even though, I have had a long involved history and extensive knowledge of this project involving YMWMH in Canada; I feel confident through this honest reflection that I have been true to the purpose of this research study.

## Chapter 5: Methodology

### 5.1 Study Design: Convergent Parallel Mixed Methods

Convergent parallel mixed methods design (Creswell & Clark, 2007) was used in this implementation research study. Qualitative investigation was informed by ID method as it was best suited to answer the research question that came from a clinical concern (Thorne, 2008). It also allowed the development of knowledge to enhance clinical practice. A self-report feedback survey provided the quantitative data on injury self-management directly from the mobile app. The two methods were used concurrently (Andrew & Halcomb, 2009) and both focused on the use of *HIRT?*. Combining the results occurred with a technique called weaving. This technique was used to align and verify the converged data. Narrative integration has enriched the interpretation and discussion (Fetters, Curry, & Creswell, 2013). Hence, this mixed method design combined the results of each method to create a better understanding of the overall perceived influence *HIRT?* has on YMWMH and their injury self-management.

Convergent parallel mixed methods design consists of 4 steps: 1) Concurrent, but separate collection of the qualitative and quantitative data; 2) Separate analysis of the qualitative and quantitative data; 3) Converging the two datasets with additional analyses; and 4) Interpretation of the integrated results formed the discussion (Creswell & Clark, 2007). In this study the process of converging the data was a short process. The final step was amalgamated with and informed the discussion by aligning the qualitative and quantitative results. See Figure 5.1.

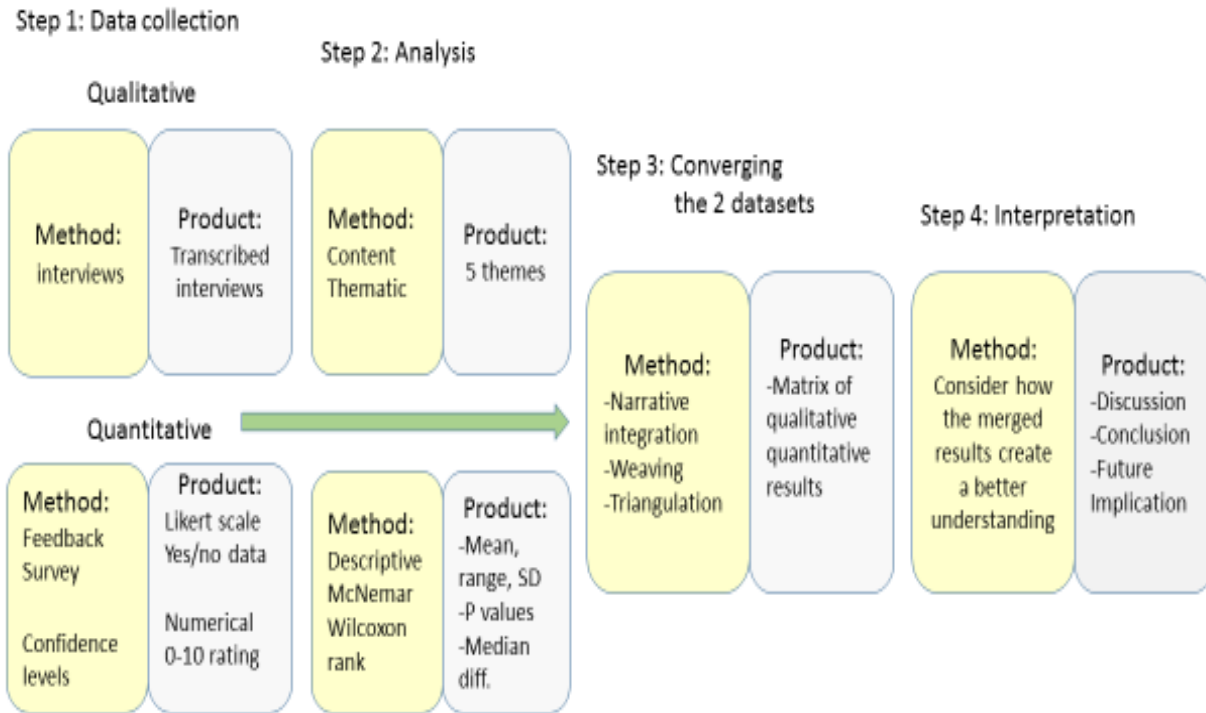


Figure 5.1: Convergent Parallel Mixed Methods Design

## 5.2. Step 1. Concurrent but separate data collection

### 5.2.1. Participants

Young men (18-35 years) diagnosed with mild hemophilia, fluent in French or English, and living in Canada were invited to participate. The sampling techniques used were purposeful and convenience (Richard & Morse, 2013). The sampling techniques were used to include those individuals who were good informants and were willing and able to reflect on the use of *HIRT?* on their perceived injury self-management, but also included those individuals who were involved in the prior research who expressed interest to continue their participation.

### **5.2.2. Recruitment**

Invitations to participate were delivered via: (1) an invitation located within the mobile app where users could have forwarded their contact information directly to the investigator, (2) an informative invitation posted on the national Canadian Hemophilia Society (CHS) webpage, (3) written information and wallet sized cards containing the app download information available at all the Canadian Hemophilia Treatment Centers (HTC), (4) newsletter invitations posted in all provincial hemophilia chapters of Canada and the national organization newsletter, (5) invitations sent to YMWMH who were participants in the previous studies for the development of *HIRT?* and agreed to be contacted for further research, and (6) regular (every three months) reminders were provided to all Canadian HTCs about *HIRT?* All these methods were used to ensure that *HIRT?* was being introduced to the YMWMH as they were reviewed at the HTC throughout this evaluation. The CHS webpage announcement, which is a sample of the recruitment material, is included in Appendix A. Recruitment lasted throughout the duration of the study ending at completion of the interviews, July 30, 2015.

YMWMH are difficult to recruit. This has been noted in a previous study by Nilson et al., 2012 who sent invitations to 151 potential participants and only 13 participants volunteered. Likewise, in the present study, only 12 participants resulted from the varying recruitment methods. The participants included; two participants from the Nilson et al. 2012 study; one volunteered via the app (Eight people sent their contact information via the app. However, only three individuals satisfied study inclusion criteria, and then only one responded and agreed to become a participant.); one contacted the investigator via information on the CHS webpage; two contacted the investigator through a national conference; two responded to written invitations and four were approached in person at their clinic visit. An addition one person consented, but then declined the interview.

### **5.2.3. Sample size**

The purposeful and convenience sampling technique provided 12 key YMWMH informants who participated in the study. Even though I may not be capturing all of the variation of experiences of a YMWMH and their injury self-management in Canada, this sample size is supported by previous literature. Charmaz (2006) discusses “theoretical completeness”, which is when the researcher can claim and demonstrate that the data collected are sufficient when no new themes or information are being gained. These 12 study participants provided ample information

to create our 5 major qualitative themes. In a study, *How many interviews are enough? An experiment with data saturation and variability* (Guest, Arwen, & Johnson, 2006, p.76), it states “if the goal is to describe a shared perception, belief, or behavior among a relatively homogeneous group, then a sample of twelve will likely be sufficient”. This sample of 12 individuals reflected similar characteristics of other study populations of mild hemophilia in relation to average age of diagnosis, types of bleeds, time since last treatment and knowledge of factor levels.

#### **5.2.4. Ethical considerations**

Re-approval from the Behavioural Research Ethics Board (REB) was received and renewed on Oct 1, 2015 (Appendix B). The original study was approved in 2011 (Appendix C). The original self-care pathway on paper was converted into an app. This process has taken many years. Annual renewals have been received, the Behavioural Research Ethics Board did not feel the project needed a full new application as the self-care pathway was created in a new form of a mobile app *HIRT?*. Organizational approval was also received from the Saskatoon Health Region (Appendix D). The study participants completed signed consent (Appendix E - Consent form). All research procedures were completed in accordance with the REB guidelines.

#### **5.2.5. Procedure**

Interested participants contacted the PI in-person, via the app, by phone or email. Informed consent was obtained, either in-person or via faxed or scanned documents (see Appendix E for the consent form). The YMWMH who consented to participate were contacted and selected an interview time and date of their choice. The interviews were conducted either in person (2 study participants) or over the telephone (10 study participants). The opportunity to complete two in-person interviews became available; one at a national hemophilia conference and one following a hemophilia clinic visit. Otherwise, the additional ten participants completed telephone interviews, as geographically this was the most convenient method. The interviews varied in length from 35 to 65 minutes. The interviews were audio-recorded with participant consent. The self-report feedback survey included in the app as a method for users to submit feedback was completed by the participants and submitted directly to the researchers computer via a web-server at the time of the interview. After completion of the interview, a monetary token of appreciation was mailed to each participant. The individual transcripts were sent via email to each study participant for their validation before analysis commenced.



### 5.2.6. Qualitative Data Collection

The qualitative methodological approach for this study used ID (Thorne, 2008). It was best suited to address a clinical concern and inform the research questions: (1) Does *HIRT?* influence the perceived musculoskeletal injury self-management practices among YMWMH in Canada?; (2) Does *HIRT?* impact the perceived confidence of YMWMH in their injury self-management? and (3) What barriers or facilitators are identified and explained by these young men to the use of *HIRT?*

ID was also the most appropriate method to guide the qualitative portion of this study. ID aims to describe a shared circumstance and the experiential knowledge of the participants. This was important because in our initial study (Nilson et al, 2012) found that YMWMH often relied on their own experiences and past bleeding episodes to guide their injury management, rather than the advice given by the health care team. The experience of YMWMH with bleed management was explored in the interviews. ID also recognizes that the researcher and the research are inseparable. This aspect is very true in this research project as I am the personal physiotherapist for 6 of the 12 young men. I see them every couple of years for their clinical review. Therefore due to this relationship, we could influence one another. ID reflects that issues are not bound by time and context; YMWMH do not bleed often. Consequently, in the interviews we inquired and helped the participants to re-play former injuries and how they managed them. Injury scenarios were covered in every interview. The scenarios provided the ability to discuss the use of the app as some participants had not used the app for an injury situation (Appendix F; interview guide). ID also aims to acknowledge the value of individual perspectives and represent the realities of multiple individuals (Thorne, 2008). In this study, each individual's perspective was identified. Then, the 12 interviews were compared as the analysis identified patterns and themes. Open-ended, semi-structured questions were used to encourage the participant to give thorough answers (Appendix F, Interview guide,).

Participants were asked to rate their perceived confidence levels of injury self-management skills without and with the use of the app. The rating scale was modified from a model for influencing patient health behaviour as described by Keller and White (1997). A similar rating scale is used also in self-management programs to define a person's ability to complete an action (Lorig & Holman, 2003). The perceived confidence levels were given a

numerical value during the interview and that became part of the quantitative data. The rating scale consisted of a value of 0 -10, zero for no confidence and 10 for very confident.

Interviews were conducted and completed by the researcher from April to July 2015. The interviews were transcribed verbatim by the researcher to allow increased familiarity with the collected information. In qualitative inquiry it is important to immerse yourself in the data. I had the opportunity to receive training in qualitative data and analysis at the social science research laboratories (SSRL; <http://ssrl.usask.ca/>) at the University of Saskatchewan. The training emphasized the importance of becoming familiar with the data. One method of achieving familiarity is through taking the time to know the interviews in detail, which occurs during the transcription process. I completed this time consuming task, which provided an extremely detailed knowledge of the interviews. The individual interviews were checked by each participant for their validation and for them to make any additions, deletions or further comments. All participants responded positively with only one suggesting a minor change. The interviews were then entered into the computer program, NVivo, version 10 (QRS International; [NVivo for windows](#)) to assist in the organization of the interviews in preparation for creating the data.

## **5.2.7. Quantitative Data Collection**

### ***5.2.7.1. Demographic frequencies and means of characteristics of participants***

This information was collected at the beginning of the interview and included in the interview guideline (Appendix F).

### ***5.2.7.2 Number of app downloads***

An understanding of the interest in and distribution of *HIRT?* in Canada was provided by the number of downloads from Google play and Apple Store. The number of downloads was collected from December 2014 to September 2015 (10 months). Graham (2006) and Straus et al., (2013) describes that in the KTA cycle, it is necessary to determine the extent to which an implemented intervention has reached the intended user group. These numbers determined the uptake of *HIRT?* These numbers have been represented in a graphical form as well as a total count. (Appendix G; A and B)

### 5.2.7.3 Self-report Feedback Survey

The quantitative data (12 feedback surveys) were collected at the time of the interviews through a self-report feedback survey (see Appendix H). The survey was submitted directly from the mobile app to the researchers secure password locked computer via a web based data program called the Apache Couch DB Futon Browse database ([Couch Database](#)) The feedback survey provided information to answer the research questions: Does *HIRT?* influence the perceived musculoskeletal injury self-management practices among YMWMH in Canada? The survey also assisted in confirming the data obtained through the qualitative methods.

The self-report feedback survey (Appendix H) was developed by the research team. This survey has face validity as it measures the constructs of interest. The feedback survey was developed, reviewed and revised by the research team of experts for grammar, organization and appropriateness (De Von et al., 2007). It included the primary variables of interest, which are bleed identification (Blanchette et al., 2014), use of first aid (Lobet, Hermans, & Lambert, 2014) and seeking medical attention (Kumar et al., 2013). There has never been a similar intervention developed, therefore, there was no standardized outcome measure available suitable to capture the app usage.

In the survey, the YMWMH reported what they perceived they did when they used *HIRT?* to manage an injury. They also reported what they perceived they may have done if they did not have *HIRT?*. If participants had not had a bleed, they were asked to report what they perceived they would have done with and without the app. The seven dichotomous variables (yes/no) of self-report injury self-management include assessing the injury, ignoring the injury, use of elevation, use of compression, use of ice, use of rest and contacting the hemophilia treatment center. The participant repeated each question, identifying what he perceived he did with the use of the app and what he perceived he would have done without the use of the app.

Also within the feed-back survey the variables of overall utility were represented in questions about app accessibility, re-usability and the ability for the app to assist in managing an injury. These variables add further data to answer research question one and were represented using Likert sliding scales from 1-5. The scales included accessibility (not at all easy, somewhat difficult, okay, quite simple, easy), re-usability (no, maybe, probably, most likely, definitely) and

the ability for the app to manage an injury (worse, not helpful, same as I would have, better, much better).

#### ***5.2.7.4 Perceived Confidence levels***

The choices and changes model for influencing patient health behaviour as described by Keller and White (1997) was used as a tool to measure perceived change in confidence for self management with and without the use of the app . It is a simple model to assess if a person's confidence has changed for performing an action. This scale is used in chronic disease management programs (Lorig, 2007) and family physicians care (Wasson & Coleman, 2014) to assess engagement of a desired health outcomes. The scale was chosen for this study as it could be conveniently incorporated into the interview. It is a simple scale which asks the participant to rate their perceived confidence levels on a scale of 0 to 10. Zero for no confidence to ten for the best possible confidence rating.

Given that this was not a prospective design, I measured perceived changes in confidence levels, envisioning potential behaviour change with and without the use of the app. Perceived confidence levels were collected verbally in the interviews. Participants rated perceived confidence twice, first, how confident they perceived they may be in injury self-management given a scenario where they had the app available to use verses a second confidence rating given a scenario where they would not have the app.

### **5.3. Step 2: Separate Data Qualitative and Quantitative analysis**

#### **5.3.1. Qualitative Analysis**

The 12 qualitative interviews were analysed using inductive content analysis (Thorne, 2008). This method identified specific observations about the influence of *HIRT?* then developed similar patterns within the group of participants. Thematic analysis (Braun & Clarke, 2008) was also used to assist with identifying, reviewing and reporting patterns that became apparent in the data. This is an extensive process. The interview guide was followed (Appendix F) so similar areas of interest were covered with each participant.

Themes were developed through the process of inductive content analysis. The interviews were reread several times before first coding of nodes was performed with the assistance of the Nvivo computer program. The next phase included grouping the nodes into categories, which

allowed for the search of the themes. Initial themes were developed. Themes were revised several times before a summary was created. Through thematic analysis (Braun & Clarke, 2008) the final themes were established and a visual map was created (see Figure 6.1).

### **5.3.2. Quantitative Analysis**

#### ***5.3.2.1. Demographics***

Descriptive statistics were used for frequencies and means of the characteristics of the individuals. Basic medical and activity status were also included (see Appendix F, Interview guide).

#### ***5.3.2.2. Number of HIRT? Downloads***

Download numbers were collected from the Apple and Google developer websites. It was tabulated from Dec 2014 to September 2015 (See Appendix G).

#### ***5.3.2.3. Self-report feedback survey***

SPSS ([SPSS version 23](#)) was used to analyze the self-report questionnaires from the app. A p-value of < .05 was used for all statistical analysis.

Descriptive data were generated for the overall utility of the app, represented in the Likert scales of 1-5, used for accessibility (not at all easy, somewhat difficult, okay, quite simple, easy), re-usability (no, maybe, probably, most likely, definitely) and the ability for the app to manage an injury (worse, not helpful, same as I would have, better, much better). Medians, ranges, means, and SD are reported.

For the self-report variables with answers of yes/no (dichotomous variables), the statistical test used was the McNemar test (Dawson & Trapp, 2003, Ch.5). A non-parametric test was chosen to answer the research question: "Does **HIRT?** influence the perceived musculoskeletal injury self-management practices among YMWMH in Canada?" due to the small sample size and marginal homogeneity of the data. The McNemar test is a form of the chi-square test that is useful for analyzing within-subjects data. The seven dichotomous variables include assessing the injury, ignoring the injury, use of elevation, use of compression, use of ice, use of rest and contacting the HTC. The McNemar test was used to assess if there was a reported

difference in the 7 injury self-management parameters with or without the use of the app. Each variable was analysed individually. The null hypothesis stated that the distribution of different values across the variables is equally likely. The alternate hypothesis stated that the different values across the variables are not equally likely.

#### ***5.3.2.4. Perceived Confidence levels***

The perceived confidence ratings in injury self-management with and without the use of the app were analyzed using SPSS, version 23. The Wilcoxon signed rank test, a non-parametric statistical test was used to assess the median differences between the confidence levels of injury self-management with the app compared to the confidence levels without the use of the app. This test was appropriate due to the small sample size (Dawson & Trapped, 2003, Ch. 5). The null hypothesis was: the median differences between the perceived confidence levels with and without the use of the app for injury self-management are equal to zero. The alternate hypothesis was the median differences are not equal, or one is greater than the other.

#### **5.4. Step 3: Convergence of data with further analysis**

Triangulation occurred with the integration of the two types of data, which confirmed the results. Narrative integration with the technique of weaving (Fetters, Curry, & Creswell, 2013) was used to verify and enhance the interpretation of the results of both the qualitative and quantitative data (Andrew & Halcomb, 2009). The themes developed in the qualitative data directly related to the quantitative data collected in the self-report survey. Therefore, the data collected in this study were conducive to the weaving technique as similar concepts were explored in each method.

#### **5.5. Step 4: Interpretation**

Interpretation of the converged results provides the discussion for this study. This mixed methods approach has increased the insights and challenged the data so it has given an expanded perspective of how YMWMH could perceive to be influenced in their injury self-management by an intervention such as a mobile app like *HIRT?* This will facilitate the conclusion of this research and provide discussion about the clinical implications.

## **5.6. Rigor**

When performing qualitative research it is important to build methods into the design to ensure rigor. Lincoln and Guba (1985) described trustworthy elements of credibility, transferability, dependability and confirmability. Thorne (2008) discusses how various researchers align these elements with techniques to ensure the study is trustworthy. In this study I have used the technique of member checking to address confirmability. Expert validation was used to ensure dependability and converging of the data or triangulation for credibility. Qualitative research, especially ID, recognizes that the researcher is an instrument and they are integrally involved in the project and honest reflection is required to ensure the research stays true to the purpose (Thorne, 2008). Therefore, I have included chapter 4 as a personal reflection to clarify the integrity of this study, in order to consider my potential bias and influence in the interpretation of the data.

### **5.6.1. Member validation**

Confirmability was strengthened by member checking (Andrew & Halcomb, 2009), a strategy when participants were given an opportunity to review their own transcripts to ensure that the information was accurate. The individual interviews were emailed to each participant for their review. They were asked to comment add or delete any content. Following the analysis, a thematic summary was then sent to the 12 study participants to get the second member validation. This further verified the authenticity of the created data.

### **5.6.2. Expert validation**

The strategy expert critique (Andrew & Halcomb, 2009) was used to ensure the dependability of the created data. Expert validation occurred when experts from the my master's committee, other than the lead investigator (M.Sc. student), coded the interviews to confirm the information was coded in the same way. Expert validation occurred in three ways. Initially two transcribed interviews were reviewed by two experts, validating the techniques used to begin initially coding of nodes. Then five experts gave their opinions on the emerging themes covering four additional interviews. Finally, all 12 interviews were reviewed by two expert members to develop the thematic summary. This expert validation additionally enhances the rigor of the study (Thorne, 2008).

### **5.6.3 Triangulation (Converging the data)**

This mixed methods study was performed for the purpose of confirming the results of both the qualitative and quantitative data. In this design the qualitative and quantitative data were collected and analysed separately, then the results were converged. Triangulation enhanced the credibility of the final interpretation by bringing the two sets of data together for confirmation.

### **5.6.4. The researcher as an instrument in the research process**

This section has been covered in chapter 4. It includes the personal point of view of the researcher, her professional background, and her interaction with the theory used in this study.



## Chapter 6: Results

### 6.1 Demographics

Twelve YMWMH consented to participate in this study. Nine had the diagnosis of Hemophilia A and three with Hemophilia B. Six participants had factor levels between 11-20%, two over 20% and four of the participants did not know their factor level. Four participants received factor replacement treatment in the last 12 months, five in the last 2-4 years and three participants had not received factor replacement treatment for over 5 years. Participants came from six different provinces (SK=6, ON=2, MB=1, QC=1, NFLD=1, NS=1). Seven received their treatments in the emergency department, two at the HTC, one at a health center and two self-infused. Education levels were three with grade 12, three with technical training, two with university degrees and four with a Masters or PhD. See Table 6.1 for further demographic information.

Table 6.1: Demographics (Age / Age of diagnosis)

N = 12	Median	Range	Mean	SD
Age in years	27.0	17 - 34	26.7	5.2
Age of Diagnosis in years	6.5	0 - 19	7.3	6.1

### 6.2. Extent of app usage

Sixty-one documented Google Play downloads for *HIRT?* occurred in Canada within the time period of December 2014 to September 2015, as well as 183 downloads from Apple for a total of 244 downloads (Appendix G). It is impossible to know whether all the downloads were by YMWMH as it was free for anyone to use and we know anecdotally that HTC team members were downloading it so they were familiar with it when they recommended it to their patients. It was downloaded by individuals in many other countries, with a total distribution of 700 downloads. See Appendix G for further details.

## 6.3. Qualitative

### 6.3.1. Themes

This section gives a thematic summary of the data created. Member validation occurred on each individual interview before analysis commenced. Minor changes were made to only one document. Otherwise all participants were completely comfortable in the accuracy of their interviews. A thematic summary was then validated by the participants. Five participants responded positively with comments, not replying was assumed agreement with the summary.

There were five themes: Accessible, Useful, Alarms, Credible and Confidence. Figure 6.1 gives a visual view in the form of a thematic map (Braun & Clarke, 2008). Table 6.2: Qualitative Themes gives some examples of quotes. Italics used in this section signify the direct words from the study participants.

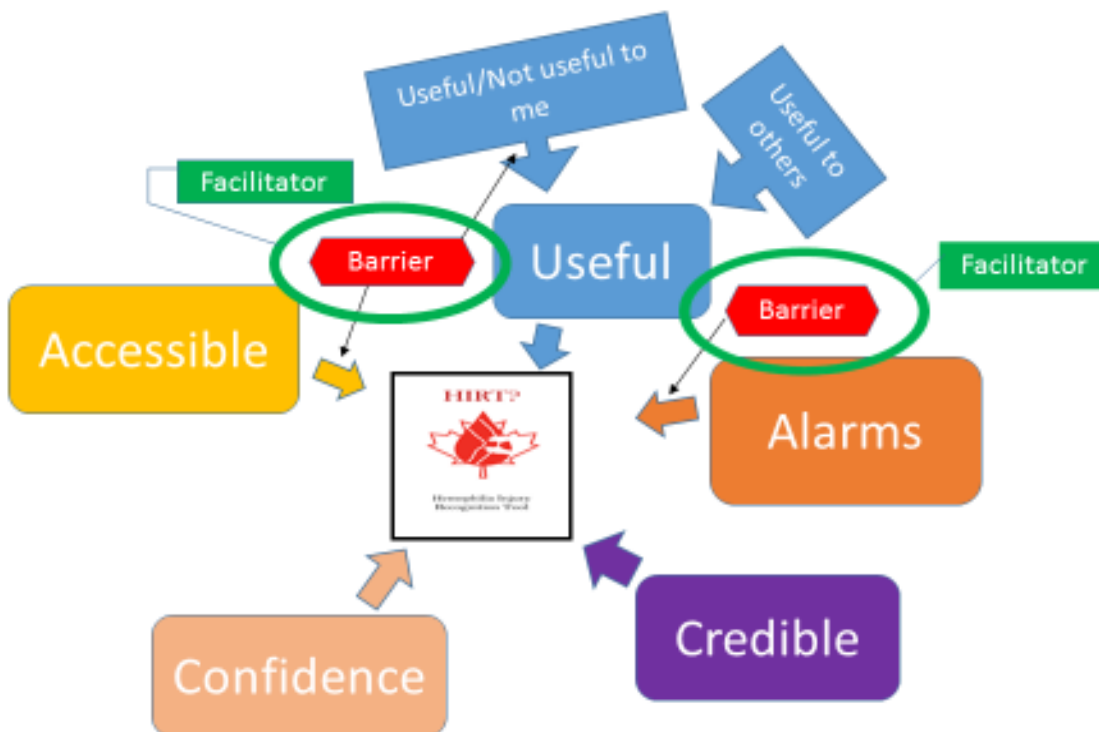


Figure 6.1: Qualitative Thematic Map

### **6.3.1.1. Accessible: “I always have my phone handy”**

The theme of accessibility was evident throughout all the interviews. All of the participants agreed that having information in a smart phone app was preferable to a booklet or pamphlet. Many of the young men had received paper resources, but they were unaware of where the booklet or pamphlet may be, were difficult to find in order to locate contact numbers, or had been recycled. This theme was unanimously positive for the format of the mobile app as evident in these quotes:

*“everyone always has a phone on them”, “at your fingertips and dials right away”, “obviously, that is the new generation now, so that is the way it should be. People have their phones on them all the time anyway” and “you don’t need to bust out the text books to figure out how to treat it.”*

### **6.3.1.2. Usefulness: “but if you have it on your phone, you could sort of do an assessment from the crime scene really, where ever you get injured “**

The participants discussed how the mobile app was either useful, not useful for them, or how they thought it would be useful to others. Hence, the theme of usefulness is divided into 3 sub-themes, useful to me, not useful to me and useful for others.

#### **6.3.1.2.1. Useful to me.**

Participants found **HIRT?** extremely useful for its ability to directly dial and contact the Hemophilia Treatment Centers in Canada. As stated here: *“the thing I like the best is all the phone numbers I just have to tap on it and it just calls it”*.

The assessment guide was also considered to be a “useful” feature and was a desired portion of the information provided by the app by all of the participants. The bleed recognition assessment guide enhanced the perceived skills of the participants who were experienced with an injury assessment and first aid, and gave them that additional guidance to fine tune their assessment skills. *“this is the specific information for higher level stuff that I do find helpful”* and *“This is awesome. It looks really in depth, so that is perfect”*.

The assessment parameters of pain, swelling, heat and loss of motion were discussed by many young men as a useful guide. It gave them a checklist, reminders of things to look for and reassurance that they had not missed anything. These excerpts describe these attitudes: *“I don’t*

*have to rely on my memory”, and “As it can show me if I have missed something or cross check with the app”.*

The first aid section, which recommended the use of compression, elevation, rest and ice, was thought beneficial by some participants. They indicated that they were introduced to different injury management options and it emphasized the strategy of rest, which may not have been considered otherwise. As stated here, *“I would never have done those things or thought of those things on my own”.*

#### *6.3.1.2.2. Not useful to me.*

The participants who had a lot of experience with injuries knew their assessment and treatment skills without reminders. These participants expressed that **HIRT?** would not be useful for their injury self-management. They felt the assessment and first aid sections were not useful as they have *“figured it out already”, “it wouldn’t really help, because I pretty much know the parameters”, “Knowing that anyway, I probably, would have already done most of it to begin with”, “well personally in terms of severity for me, what I look for is my own signs”, “so I don’t use it for that because I have simply memorized it” and “I do all this stuff out of instinct”.*

#### *6.3.1.2.3. Useful to others.*

The young men who described having developed self-management skills through their own injuries and experiences felt that the app would be most useful for those with less injury experiences. They described how **HIRT?** could be useful to younger people, those living in remote areas and parents of children with mild hemophilia. These statements demonstrate this theme: *“the biggest use of this app is for people who are just naturally unsure of themselves or inexperienced”, “new parents who don’t really know the signs naturally yet”, “it would be best for someone is new to hemophilia, they would not know what’s going on” and “And for men who are in more remote areas, who don’t have an easy access to treatment centers”.*

#### ***6.3.1.3. Alarms: “ Yes, I think it is important to gauge over time how your body is re-acting to the injury to see how the bleed is progressing or if it is healing at all”***

The alarm system to re-assess the injury is unique to the mobile app, **HIRT?**. The alarms to re-assess are set for 1 hour, 24 hours and 2 days. The alarms encourage re-evaluation of the

injury. If the injury is worsening, a prompt is given to contact the Hemophilia Treatment Center. This aspect of the intervention was not fully explored as only 3 of the 12 participants used the app in an injury situation in the period they downloaded the app to their interview . Even though it was not fully utilized, most participants felt this was an essential feature of this tool. Also the interviews explored the use of the notifications by presenting scenarios of injuries in the interview guide. These scenarios were discussed with each participant. These quotes indicate the importance of this theme:

- *“you just rub off the pain and go back to work”*,
- *“The fact that it reminds you to reassess even after you use the first aid and ice because it doesn’t always dawn on you to reassess everything after short periods of time or even long periods of time”*,
- *“Instead of sitting there and even if I get better, I am like well...what if I get worse, but the app, it is kind of like having your buddy to talk to, and kind of a guide.”*,
- *“cause if I am worried about the injury, I can stop because the app will remind in 1 hour to check.”*,
- *“So I am not going to make a decision about my state until that hour has passed. So now I am doing better in an hour but then I don’t worry because I am not going to worry if I am getting better until the app reminds me in 24 hours.”*,
- *“I think it is still there so having that reminder and having to click through it again and then realize that this is probably something that I needed to get treated for.”*,
- *“re-assessment of those injuries that are on the line of whether to seek treatment or not”*,
- *“because you get busy and forget to look at it”*.

#### **6.3.1.4. Credible: “I think it is methodology everyone knows”**

This credibility theme shows that the participants felt the information in the app was trustworthy. The information presented was similar to what they have been taught. Therefore, the consistent messaging gave the app credibility according to the participants. The quotes to indicate this were: *“like it is all the stuff I know”*, *“I have noticed that her questions are often*

*similar, just like yours are, does it hurt, is there pain, is it warm, have you lost motion.”, and “I would say they are pretty much the same thing.”*

**6.3.1.5 Confidence: “it is like having someone reaffirm what you already know”**

Perceived confidence levels were discussed with all of the participants in relationship to their injury self-management skills. Confidence in perceived injury self-management was enhanced by the mobile app *HIRT?* in all but 2 participants who indicated that their confidence levels stayed at the same level. As stated by one of them, *“I am used to this kind of stuff, ya my confidence would stay at a 9”*.

Perceived confidence was felt to be bolstered in many aspects of the injury self-management process. The app reinforced the confidence in the injury assessment, *“you get an injury and you sometimes overstate it or understate it so this reinforces the assessment”* and *“It’s like a second person, assessing the injury, with more information about what you may do”*.

The first aid section for some participants provided suggestions of treatment options they were not used to incorporating or trying for injury management. Such as in this situation, *“Often times though I may be injured but I don’t want to take time to rest and elevate the joint or whatever have you and it is good to make sure you do that”*.

The most important noted increase in perceived confidence was the encouragement and ease through which the app assisted with contacting the HTC. The participants felt at ease to know the numbers of the HTCs were in their phones and that they had easy access to them. *“I don’t have the number handy. That is really where the app helps me out”*.

Some also felt that they could discuss their injuries knowledgeably with the health care professional when they called because, *“I think it allows you to have done your homework and I think that is important. Because you are not just bugging them for no reason”*.

Many participants stated that they did not want to be a bother to the health care professionals. The app helped encourage the connection, *“it guides you and helps you contact as sometimes you feel like you are just bothering them”*.

Still with others the app verified their doubts about the injury not getting better, therefore they acted with increased confidence and contacted the HTC, *“I feel like when we have*

*doubt....., I'm very keen on discounting them, there is something telling me "you know your doubts may be right" and you are more likely to do something about it".*

Confidence was a theme which covered every aspect of the self-management of an injury, the use of the app appears to have positively enhanced the perceived confidence of these YMWMH in their injury self-management skills.

Table 6.2: Qualitative Themes

THEMES	Representative Quotes
<b>Accessible</b>	<ol style="list-style-type: none"> <li>1. You can just pop it out</li> <li>2. In our hands that is available all the time</li> <li>3. All that information on your phone</li> <li>4. It is portable and you can access it on your phone</li> <li>5. More accessible a lot harder to lose, or misplace</li> <li>6. Especially to have this at your fingertips</li> <li>7. A whole lot more convenient than having books</li> </ol>
<b>Useful</b> - Useful to me	<ol style="list-style-type: none"> <li>1. A check point to make sure I didn't miss anything</li> <li>2. Gave pointers on what to do next</li> <li>3. You could identify it and get a hold of someone right away</li> <li>4. For you so to determine if you need to go in or just self do it.</li> <li>5. It will tell you to rest, ice compression and stuff</li> <li>6. I really like the guide you have in there</li> <li>7. I have the contacts for the all the Canadian Hemophilia treatment centers with me when I travel.</li> <li>8. Really we need to assess these injuries in an appropriate manner</li> <li>9. Useful for those injuries which are on the edge of knowing whether to get treatment or not</li> <li>10. I may be injured but I don't want to take time to rest and elevate</li> </ol>
- Not Useful to me	<ol style="list-style-type: none"> <li>1. Self-assessment becomes second nature and kind of easily recallable for someone over time</li> <li>2. I think the self-assessment tool is what I find the least useful</li> <li>3. I have been doing this for a while. I am no stranger to bleeding at all,</li> <li>4. It is really just routine for me at this point.</li> <li>5. I wouldn't need that to remind me</li> </ol>
- Useful to others	<ol style="list-style-type: none"> <li>1. It is like when my cousin, who also has hemophilia , he often sprains his ankle he'll ask me</li> <li>2. For younger folks where it is there first kick at the can, that for sure might be helpful</li> </ol>

	<ol style="list-style-type: none"> <li>3. A teen who didn't want to get help and wanted to figure it out on my own.</li> <li>4. Like some of my relatives who don't know how to treat it they just keep going</li> <li>5. If I was a man with hemophilia out in a more rural area the app would be extremely helpful</li> <li>6. Absolutely great tool for a young person that is new to the disease</li> <li>7. Even people from other countries might be interested. For the self-assessment or the self-assessment guide.</li> </ol>
<b>Alarms</b>	<ol style="list-style-type: none"> <li>1. He would have known in the 24 hours that something was going on</li> <li>2. Just encouraging him to go earlier or to monitor it more seriously</li> <li>3. To check regularly, and tell me is it okay or is it getting worse or is it getting better</li> <li>4. The 24 hours is good because this is a reasonable time or window, to re-remind me to see if I am still doing better.</li> <li>5. Especially after the 1 hour if you are still in quite a bit of pain, it is probably important that you seek something else.</li> <li>6. It reminded me this morning to re-check. That was great cause I woke up and I forgot I did it right</li> </ol>
<b>Credible</b>	<ol style="list-style-type: none"> <li>1. Including patients in the research design and making health information in a way people will use it. It is really exciting and this is just one good example</li> <li>2. I am familiar with the RICE formula, it is preached in the running community quite a bit</li> <li>3. They (the parameters of assessment) are very similar, almost identical.</li> </ol>
<b>Confidence</b>	<ol style="list-style-type: none"> <li>1. It is right up at 10 with the app. As it can show me if I have missed something or cross check with the app. I have something to reference off of.</li> <li>2. I would use that as a tool for next time. Having this tell me okay you right now are getting better, it gives me confirmation yes, I shouldn't call or I'm doing worse, I should probably call.</li> <li>3. An extra set of eyes or an extra opinion and all the information, which gives suggestions to try this or that</li> <li>4. I think it is a useful tool which allows me to build up my confidence in my own assessment, so I assess the injury and it wasn't severe enough for me to call or go in, it provided me with a tool to address it myself. So by doing that it would build up my confidence in my assessing myself.</li> </ol>



### 6.3.2 Barriers to use

The elements identified as most significant barriers to use of the app are features affecting the accessibility and the alarm system. More comments about barriers are shown in Table 6.3. The barriers affecting the accessibility of the mobile app were concerns related to the technical operation of the phone versus the utility of the app. Battery life of the phone was cited by many as a potential problem. Also losing or misplacing the phone could affect accessibility. It was also noted that if one were in a location with no cellular coverage relative to the internet, then this could be a barrier to the use of the app. As stated in this quote; “*Somewhere that doesn’t have internet connections, such as camping*”. Usefulness was impaired if the persons themselves were not capable of using the phone, such as trauma to the fingers, or more serious trauma, such as being unconscious.

The alarms and reminders were mentioned numerous times as having glitches or going off at inappropriate times. Some of the participants were frustrated because they needed to perform the assessment before they could access the rest of the information in the app. This was a feature of the app that was purposefully incorporated so an injury assessment would be completed. Others thought that not having an option to skip the assessment and go directly to the assessment booklet or call the HTC was a barrier to usage. It was also noted that if one had the app installed on an ipad, which was not with the individual, then one would miss the alarms and would not perform the interval of re-assessments. A few participants expressed the fact that if the app is not used it would not be helpful. Thus, a barrier to the use was if the young men were not made aware of *HIRT?*

Table 6.3: Barriers

Barriers:	Representative Quotes
Accessible	<ol style="list-style-type: none"> <li>1. If I hurt my thumbs and fingers. I guess it would be difficult to use</li> <li>2. realistically phone batteries don’t last that long, and lots die within 2 hours of usage</li> <li>3. Like I am injured in a place where I don’t have access to a phone</li> <li>4. Yes that is the nature of today’s smart phones they have, no battery life.</li> <li>5. It would be inconvenient when you don’t have it with you</li> <li>6. If you had a head bleed and were unconscious,</li> <li>7. Like phones are not life proof I guess if the battery dies or if you are in an area with no service.</li> <li>8. If you loose your fine motor skills in your hands if you were in shock or something like that so.</li> </ol>

	9. Always the battery dying, no service, and stuff like that.
Usefulness - to me - not useful	<ol style="list-style-type: none"> <li>1. It doesn't say directly put it on right? Like compression it doesn't say you shouldn't if it doesn't feel right.</li> <li>2. But like I said it kind of needs more information on what to do</li> <li>3. If anything my only criticism for me it is too simple. I would love to see it more difficult.</li> </ol>
Alarms	<ol style="list-style-type: none"> <li>1. Because it is on my Ipad not on my smart phone, the notification went off and I didn't hear the reminder so I didn't go back and do the self-assessment again.</li> <li>2. The reminders are great but if the timers to give you those reminders don't work.</li> <li>3. My app is always never getting to the 2 day mark it is always at the 1 hour alarm, I mean the 1 day, and it comes every single day here.</li> <li>4. Like I mentioned it before my notifications aren't working right,</li> <li>5. The only issues I have had with the app is trying to close out on it, when I am done.</li> </ol>

**6.3.3. Facilitators or Improvement Ideas**

Many participants stated they did not have any ideas to make the mobile app better. The following is a list of improvements recommended by participants who expressed suggestions. Refer to Table 6.4, Facilitator and Improvement Ideas.

- A menu button was suggested on the first screens so you could access the HTC numbers and assessment booklet without having to do the assessment and first aid.
- A preference for your language choice which would be remembered by the app, so each time you entered the app that language would be selected for you.
- Improvement in the alarms; firstly, so the glitches in timing are corrected, but also that you get notification in a method of your choice, either a ringtone, beep or just the alert on the phone screen.
- Participants who did not find the app as useful indicated that they needed more resources within the app. Some suggested information on pain management, or long term consequences of neglected injuries.
- Several participants wanted a more individualized assessment. One person suggested the possibility of grading your assessment parameters of pain, swelling, heat, and loss of motion. With each re-assessment he could then know if the injury was getting worse.

This group of YMWMH were engaged and enthusiastic about an intervention created just for them. They gave freely of their ideas and truly want to improve this tool so others like themselves could benefit.

Table 6.4: Facilitators and Improvement Ideas

Facilitators or Improvement ideas	Representative quotes
Accessible	<ol style="list-style-type: none"> <li>1. There is a lot of people that don't use the website. And a lot of people who don't know about the app. And they need to be convinced that they might have some use for it and try it first and I think the HTC's are very influential in that way. Especially to teach these people.</li> </ol>
Useful	<ol style="list-style-type: none"> <li>1. It would be nice to have an option to look at the information without having to assess yourself.</li> <li>2. If there was a way to bypass, without having to assess to get to the main menu</li> <li>3. If you have an injury you know you just want to get a hold of the HTC,</li> <li>4. If you had a news feed about hemophilia, recent papers that had been published or findings or if there is any talks being given at the hospital, it would be nice to have a link to that stuff, so we know it is out there, it would almost become a starting point for people with hemophilia, with mild hemophilia.</li> <li>5. In the best scenario, it would actually allow you to choose which symptoms I'm having, then from those symptoms, obviously it can't diagnose me but direct me to more appropriate treatment</li> <li>6. Just so it allows me to, feel like I am tending to my own injury, or to my own situation so the app is helping me look after what is happening to me, not just like an umbrella.</li> <li>7. If you could set your preferred hemophilia treatment center, even have it as a shortcut on the home page.</li> <li>8. Like if I could go and had a little human being and like if my knee hurts and I could touch the knee and it tells me you have this and this and this and it is probably a bleed.</li> <li>9. There could be some pain management stuff in here</li> <li>10. I don't know whether it prompts you like to go to Google maps or something.</li> <li>11. Yes the 1-10 for the pain, warmth and swelling, and if I checked the app in 2 -3 hours and the app would summarized, look your scores are getting worse not better, then I better getting away from the yes/ no, and oh my gosh whether I want to admit it or not I am ranking my pain higher. You know what I mean?</li> <li>12. Like if it is getting worse with time not better, is that more indicative of the story of hemophilia, that if the app said " because you have endorsed that your symptoms are worse, you should call your hemophilia treatment center" I would have!!</li> </ol>

	<p>13. But the other thing I found helpful is the factor first card, and I don't know if this is stretching things for you but incorporating that into the information or whatever into the app.</p> <p>14. I don't think my employer would have known what hemophilia was. Having something that they could say I have a health condition, I can't stay here. Me staying here is damaging to my health</p> <p>15. It would be nice if it saved your language preference. To speed things up a little bit.</p> <p>16. There is the red bar that says cancel, you must click actually on the word cancel, it would be nice if you just had to click on the whole red bar.</p> <p>17. Even I travel to the States it would be useful to have the hemophilia treatment center contacts available in the app for the US. Then you could choose Canada, or the US or whatever and have the subdivisions of areas.</p> <p>18. The other thing I was interested in was being able to put my own information in the app just in case something did happen</p>
Alarms	<p>1. The prompts themselves need to be improved. They need to run off a timer that doesn't reset when the phone turns off, then turns back on, and for the notifications themselves it needs to have volume settings,</p> <p>2. When you do get the prompt to reassess you don't recognize it as a message from the person you are trying to avoid, you don't miss it interiorly because your phone is on silence or something.</p> <p>3. That's where the options settings comes in, where you can change the alarm to your own preferences.</p> <p>4. So maybe if you are driving so you have it set on vibrate, but other than that you could set it on a blaring horn to let you know it is time to re-assess.</p> <p>5. The notifications need to be loud enough, and they need to be noticeable enough to get my attention back to the injury.</p>
Other	<p>1. Like aesthetically the graphics are pretty basic so if you could invest more in it , it would be nice to have a more modern look to it.</p>

**6.4. Quantitative**

**6.4.1. Self-report Feedback Survey**

***6.4.1.1. Accessible, reusable and manage an injury***

The descriptives and frequency for each of the questions on the feedback survey (Appendix H) are summarized in Figures 6.2, 6.3, and 6.4. The overall utility of the app was rated mostly positive across all 3 of these parameters, with 7-8 participants responding with the highest rating category, 58.3- 66.7 % of the responses. See Figures 6.2, 6.3 and 6.4.

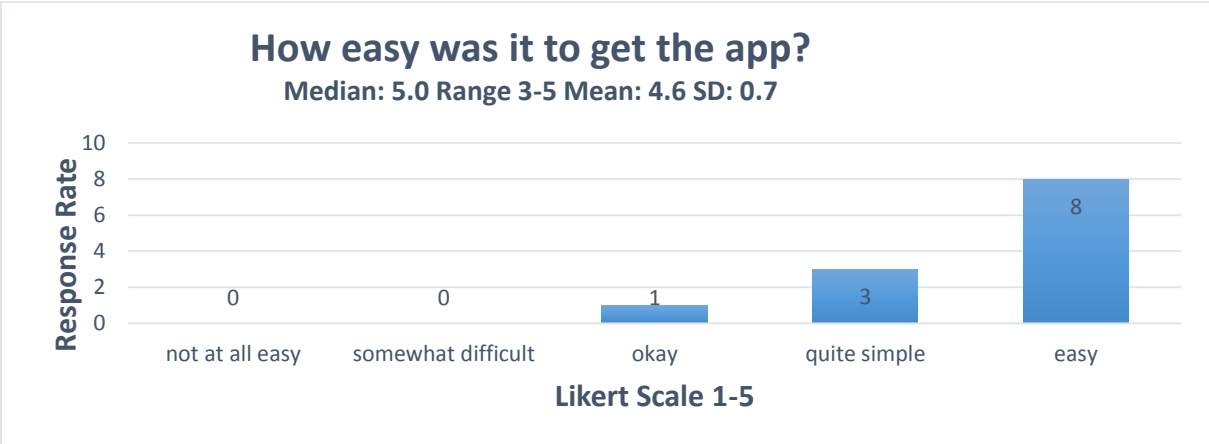


Figure 6.2: How easy was it to get the app?

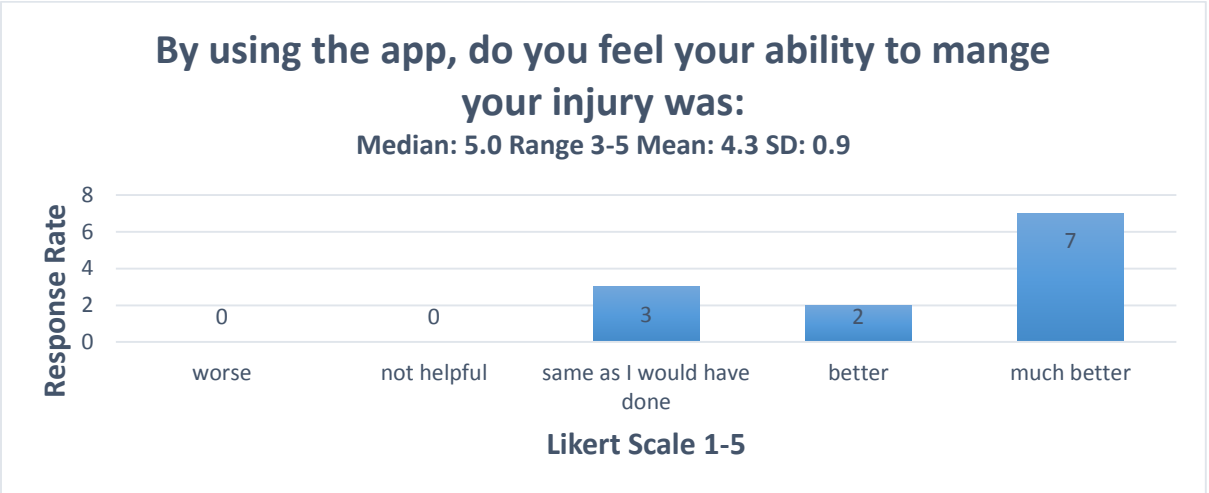


Figure 6.3: Ability to manage an injury

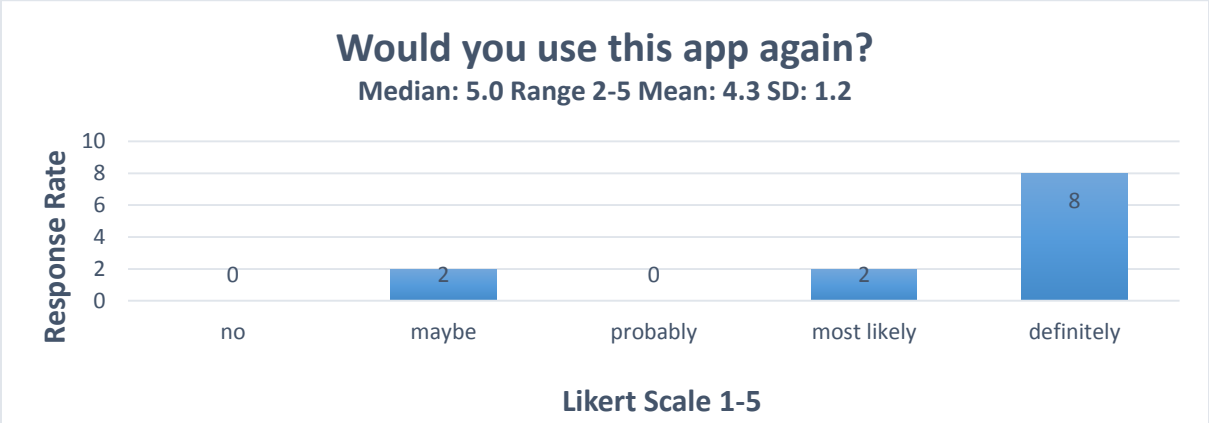


Figure 6.4: Would you use the app again?

**6.4.1.2. Comparison of perceived injury management with and without use of the app**

The results of the McNemar test comparing the use of the app versus no use of the app for each of the seven self-management variables are shown in Table 6.5. There were no significant differences; therefore the null hypothesis is retained.

Table 6.5 : McNemar's Test, self-management with and without the app

<b>Intervention</b>	<b>P value</b>
Assess the injury	0.250
Ignore the injury	1.000
Use of elevation	1.000
Use of compression	0.125
Use of Ice	1.000
Use of Rest	1.000
Contact the HTC	1.000

**6.4.2. Perceived confidence levels**

Figure 6.5 provides the distribution of self-rated perceived confidence levels of 0 -10 reported with and without the use of *HIRT?* The Wilcoxon signed rank test found a significant result when comparing perceived confidence ratings with and without the use of the app ( $p = 0.004$ ). The null hypothesis is rejected indicating a significant improvement in confidence ratings. Therefore, YMWMH perceive their confidence to improve in injury self-management when using *HIRT?*

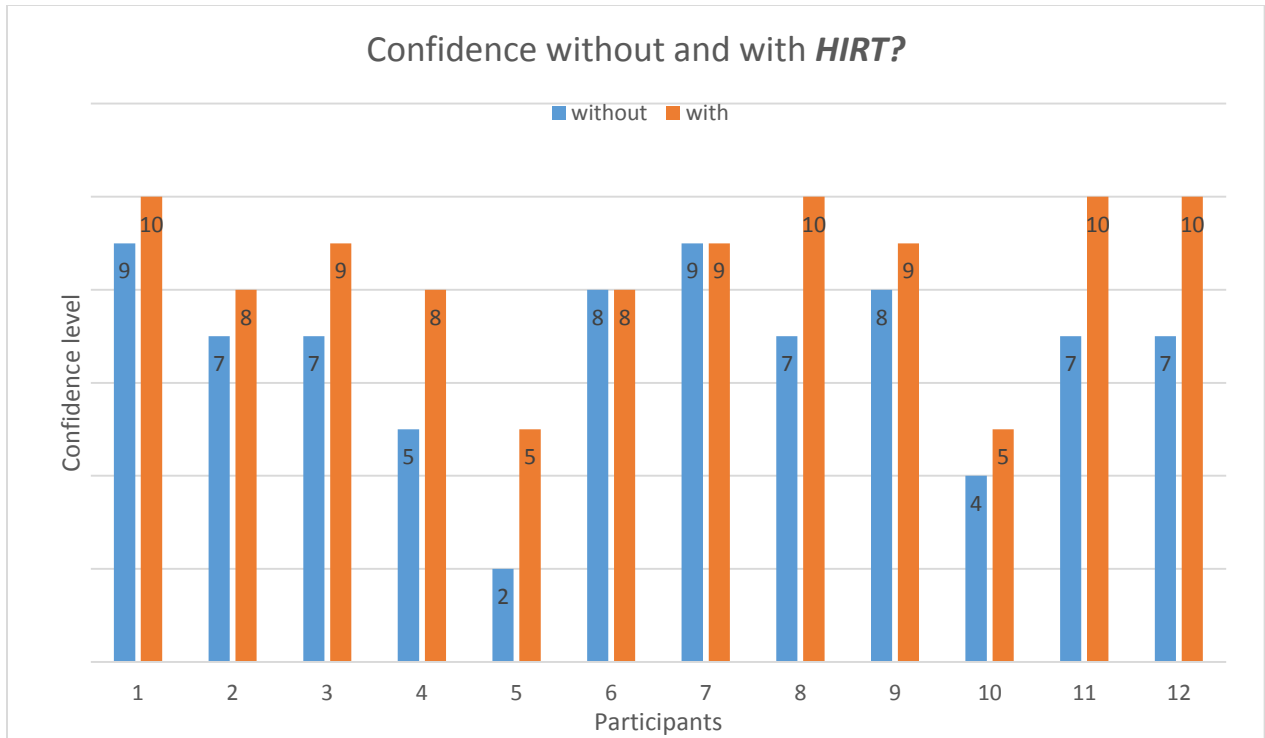


Figure 6.5: Perceived confidence levels with and without the use of *HIRT?*

## 6.5. Convergence of Qualitative and Quantitative results

### 6.5.1. Integration of results

Qualitative and quantitative data were integrated at this step. Merging and comparing the qualitative textual themes from the interviews and the quantitative data from the self-report survey were done with an approach called weaving (Creswell, 2013). This specific type of narrative integration was used because it allowed the connection of relevant themes in each dataset. See Table 6.6: Joint display (Fetters, Curry, & Creswell, 2013).

Table 6.6: Joint Display of Qualitative and Quantitative data

QUALITATIVE	Research questions	QUANTITATIVE
<b>Accessible</b>	<p>Does <i>HIRT?</i> influence the perceived musculoskeletal injury self-management practices among YMWMH in Canada?</p> <p>Does <i>HIRT?</i> impact self-management perceived confidence?</p> <p>What barriers and facilitators are identified by the YMWMH?</p>	<b>Accessible:</b> Median 5.0; Range 3-5 Mean 4.6/5 SD=0.7
<b>Usefulness</b>		<b>Re-usable:</b> Median 5.0; Range 2-5 Mean 4.3/5 SD=1.6
<ul style="list-style-type: none"> <li>• Useful to me</li> <li>• Not useful to me</li> <li>• Useful for others</li> </ul>		<b>Managing an injury:</b> Median 5.0; Range 3-5 Mean 4.3/5 SD=0.9
<b>Alarms</b>		<b>Self-report change</b>
<b>Credible</b>		<ul style="list-style-type: none"> <li>• Assessing an injury</li> <li>• Ignoring an injury</li> <li>• Use of elevation</li> <li>• Use of compression</li> <li>• Use of ice</li> <li>• Use of rest</li> <li>• Contacting the HTC</li> </ul> <p><b>No significant change</b></p>
<b>Confidence</b>	<b>Confidence difference:</b> pre and post use p = 0.004	

### 6.5.2. Summary

A brief overview shows that:

- Qualitative themes; Accessible, Usefulness (To me and for others), Alarms, Credible and perceived Confidence were all enhanced when aligned with the quantitative results.
- Not useful to me and the self-report pre and post use of the app results suggested that as the YMWMH become more experienced in assessing injuries they may not find the injury assessment or first aid sections useful.
- Reported perceived confidence levels for injury self-management were significantly improved with the use of the app.



- Barriers to use consisted mostly of phone and device related issues, or glitches with the alarms systems in the phones.
- Facilitators suggested trying to provide a more individualized method of assessment.

The increased understanding achieved by this step provided further comprehension about the possible use of *HIRT?* for perceived injury self-management for YMWMH in Canada. The discussion will be guided and enhanced with the integrated results of the qualitative and quantitative datasets. The interpretation, which is the last step of the study methods, is included in the last chapter.

## Chapter 7: Discussion

### 7.1 General Overview

The purpose of this master's project was to explore whether YMWMH perceive their musculoskeletal injury self-management to be influenced by the use of the mobile app *HIRT?*. The hypotheses were partially supported. The converged qualitative and quantitative data generally supported the format, unique alarm system, credibility and the ease of access of the mobile app. There was a significant improvement in the perception of confidence comparing self management without the use of the app to with the use of the app. The usefulness was explained by many as excellent, especially for the assessment guide and the contacts for the HTC. Some participants who were more experienced in bleeds did not find the assessment or first aid portions helpful, but suggested assessment and first aid information would be useful to others new to hemophilia or less experienced in bleed management. This result was reflected by the McNemar test which did not show a significant difference for the injury self-management strategies as reported by the participants with and without the use of the app. This research study also provided enhanced knowledge regarding mobile app technology for injury self-management, identified potential barriers and facilitators to the use of *HIRT?* and provided considerations for future app development.

Technology is prevalent in our society with tools such as smart phones becoming integrated more and more into everyday life (CWTA, Facts and Figures 2015). Mobile health technology, or mHealth (Dicianno et al., 2015), offers an interesting opportunity when working with diverse groups of individuals who have challenges with accessing appropriate and timely health care services (Free et al., 2013). YMWMH are such a group (Nilson et al., 2012). They are also part of an age group that spends significant digital time on mobile apps (Future in Focus, Digital Canada, 2015). Apps on smart phones provide an avenue to be easily accessible (Payne, Lister, West & Bernhardt, 2015), contain information useful for managing a chronic disorder and provide connections to the health care provider (Wayne & Ritvo, 2014). Therefore, smart phone apps have the potential to more actively engage young individuals in self-directing their care. This advancement in technology is beginning to change the way health care is delivered to people living with chronic conditions (Dicianno et al., 2015). Mobile app technology, for example, has been used with people mobilizing in wheelchairs who have a history of edema and

skin breakdown. The wheelchairs are equipped with the virtual seating coach, which is an important application to improve self-management in rehabilitation by providing feedback to adjust chair position at a designated time (Dicianno et al., 2015).

Mobile app technology has also been applied in other ways to supporting individuals living with chronic conditions (Leijdekkers & Gay, 2013; Parmanto et al., 2013). The Leijdekkers and Gay study (2013), described an app called myFitness Companion, which offered exercise tracking while monitoring blood pressure, blood glucose, temperature, respiration and heart rate. These are important measurements in monitoring conditions, such as diabetes, asthma, obesity and hypertension. Parmanto et al. (2013) describes how mobile app technology assisted those living with spina bifida in complex self-care tasks, such as skin care, bowel care and adherence to medications.

Similarly, among young men living with mild hemophilia, their resistance to acknowledge their condition (Nilson et al., 2012), inability to recognize an injury needing medical attention (Kumar et al., 2013) and hesitation to contact the HTC (Ekholm et al., 2010) have the potential to be targeted with this type of technology. Participants in this study verified that *HIRT?* was accessible, similar to other health apps for chronic disease management (Cummings et al., 2011). This accessible method of receiving information demonstrates why *HIRT?* shows promise to reach YMWMH. Wood et al., (2013) discuss the importance of targeting the intended end-users with the appropriate technology that reflects their expectations and behaviours. *HIRT?* was also created with the assistance and input of YMWMH, therefore has targeted the end-users.

## **7.2 The influence of *HIRT?* on Perceived Injury Self-management**

Technology, in the form of a smart phone app such as *HIRT?*, offers unique characteristics that supports the accessibility of information on bleed recognition and management, easy reminders to re-assessment an injury and connections with the health providers (Lomotey et al., 2014). Study findings provide support of these features for perceived injury self-management for YMWMH in Canada.

YMWMH are an interesting but a challenging group to research (Nilson et al., 2012). They are young men, active in their daily lives. Some may demonstrate resistance to

acknowledge their diagnosis and may even deny that they have mild hemophilia (Nilson et al., 2012). They are known for not attending their multidisciplinary hemophilia clinic appointments (Lingvall et al., 2010) and do not perceive their hemophilia as that serious, as compared to those with severe hemophilia (Nilson et al., 2012). Many YMWMH lack the skills of differentiating between serious and benign bleed severity (Steele & Laudenbach, 2004; Tagliaferri et al., 2012) and have hesitation to contact the HTC (Nilson et al., 2012; Lindvall et al., 2010). Some of these characteristics could cause them not to respond to an injury and end up in a medical crisis days after an unrecognized bleed (Kumar et al., 2013).

Injury self-management is an effort for YMWMH because their mild hemophilia only presents itself when they have a significant injury, which is infrequent. The infrequency of bleeds has been recognized for YMWMH throughout the literature (Steele & Laudenbach, 2004; Franchini et al., 2009; Lindvall et al., 2010; Peerlick & Jacquemin, 2010; Tagliaferri et al., 2012; Schulman, 2012). Less frequent bleeds may lead to less experience identifying injuries needing medical attention . This quote explains the dilemma of not recognizing bleeds from the perspective of the young man *“for myself when I am on the line about whether to go in or not, a lot of times I am a little stubborn and I don’t want to go to the hospital. Or not want to call the hemophilia treatment center so I think it is useful for that.”*

The challenge for YMWMH to recognize a bleed and their hesitation to call the HTC has been observed throughout Canada and globally (Kumar et al., 2013; Ekholm et al., 2010; van Wanroij et al., 2010). Consequently, a recognized need exists for providing information and appropriate injury self-management skills to YMWMH (Ekholm et al., 2010; van Wanroij et al., 2010; Schulman, 2012; Tagliaferri et al., 2012). ***HIRT?*** is a promising avenue that has provided many components necessary to self-manage an injury. Self-management, as described by Lorig and Holman (2003), has five core components: **problem solving, decision making, how to find and utilize resources, forming a partnership with the health care provider and taking action.** These components will be explored in this section and evidence from this study will assist to demonstrate how the use of ***HIRT?*** has been perceived by YMWMH to assist injury self-management. Self-management for chronic conditions has been noted to be feasible with mobile health technology (Payne et al., 2015). The technical evolution of this type of intervention has provided the venue to provide information for self-care (Dicianno et al., 2015),

encourage a positive health behaviour (Cummings et al., 2011), and provide a contact to the health care provider (Wayne & Ritvo, 2014). **HIRT?** contains all of these features. Smart phones are an excellent source to provide self-management as they are easily accessible (Free et al., 2013), provide the information when needed (van Velsen et al., 2015), provide specific individualized information (Gray et al., 2013) and have the interactive quality of connecting individuals to a health care provider (Wayne & Ritvo, 2014). These features of smart phones allow the “anytime anywhere” assessments (Boulos, Wheeler, Tavares, & Jones, 2011) that are so relevant for the YMWMH. As many of the study participants had a diagnosis of mild hemophilia later in life and bleed infrequently, they had less experience in recognizing bleeds and having a plan for addressing those injuries. When an injury occurred for these young men, having technology “*at your fingertips*” could assist with their **problem solving**, the first component of self-management. Some of the participants less experienced with injuries appreciated this section to help identify a bleed. Our data supported that **HIRT?** assisted some of them with their problem of bleed recognition and they stated the app helped them make an accurate assessment, not forget any steps and guide them in those injuries that were on the edge of needing attention.

The “useful for others” or “not useful” themes suggested that the **HIRT?** app would be most useful to those less experienced in bleeds or new to hemophilia. Those respondents more experienced in recognizing the signs and symptoms of an injury found the assessment section not useful. This was reflected through the self-report data that did not show any significant difference in bleed assessment or first aid use with or without the use of the app. Another type 1 diabetes study found no significant changes in any of the self-management dimensions with use of an app (Cafazzo et al., 2012). Further, in a systematic review, Payne et al., (2015) reviewed 24 studies evaluating apps with behavioural components for physical activity, weight loss, diabetes and depression. Findings support that many of the apps did not demonstrate a significant behavioural change promoted by the app. The researchers concluded that the studies were primarily pilot studies justifying feasibility, but more research needed to be done to study the efficacy and impact on health behaviour on a much larger scale with more rigorous designs.

The qualitative data in this study indicate that **HIRT?** provided easily accessible injury self-management strategies for participants. The first aid strategies were perceived as beneficial,

regardless of the non-significant finding from the survey data. The most commonly used form of first aid for YMWMH for an injury was ice (Nilson et al., 2012). *HIRT?* also offers suggestions of compression, elevation and rest. The first aid section was valued by many participants. The app provided suggestions on what and how to use the first aid, which was valued by this young man who said “*compression and ice I have never actually done that. And I would have never thought of it otherwise*”. This was not the case for all of the participants as the majority knew already what first aid strategies to use for an injury. Additionally, only 3 participants used the app in an actual injury situation, which could impact the responses. There still needs to be further exploration of the app with future prospective studies to fully understand utility.

Smart phone technology offers interesting attributes that support easy reminders, such as the alarms that are a unique feature of *HIRT?* The opportunity of a reminder is essential for young men as they need to be prompted to re-check an injury as they often forget or feel their injuries are not that bad (Nilson et al., 2012). The alarms to remind the YMWMH to re-assess an injury also assist in the **decision making** process of injury self-management, such as stated here, “*If I am worried about the injury, I can stop because the app will remind in 1 hour to check*”. The YMWMH believed that they may be more inclined to call the HTC when an injury was worsening because of the built-in reminders. Many of the participants stated they would forget about the injury, just like what occurred in the injury scenarios. The young man in the scenario received an injury on the soccer field (Appendix F), but he forgot about it until he asked his brother. His brother reminded him he had actually played soccer a few days earlier. That is when he remembered the thigh injury. The participants reflected that the scenarios were very true to life. They agreed that if they had the app, they may have avoided some unrecognized bleeds they had experienced in the past. For example, with their bleeds being so infrequent they tended to forget they had mild hemophilia, “*because you can sometimes forget, any time you get complacent about it*”. The alarms re-enforcing the rechecking of an injury was perceived by the young men participants as a great feature of the app.

Persuasive technology has been defined by Fogg (2003) as any computing technology system or device designed to change a person’s attitude or behaviour in a predetermined way. This technique is used in business marketing, education and health care (Chatterjee & Price, 2009). Free et al., (2008) conducted a randomized control trial with an intervention for smoking

cessation support. The mobile app provided a text “crave” function that sent immediate encouraging messages when the person experienced cravings. A system of daily texts also provided messages counting down from the quit day. The mobile app had a continual maintenance package for 3 text messages a week for 26 weeks. The trial showed a doubling in self-reported quitting in the short term (4 weeks). Therefore, findings suggest that mobile phones are a promising means of delivering smoking cessation support. However, the long-term effect of such support needs to be established. In *HIRT?*, alarms were used for re-assessment as the persuasive technique to lead the young men through the process to re-assess an injury, then motivate them to call the HTC if needed. The results from this study suggest that most participants perceived the alarms to be an asset in managing their bleeds, however, further research is required to fully elucidate impact on behaviour change. Likewise, in the Free et al. study the persuasive technique is demonstrated to be beneficial for assisting in smoke cessation.

Mobile app technology offers an appealing way to assist injury self-management, especially in **how to find and utilize resources**. The participants in this study exhibited their excitement in receiving information suited to their needs, with comments like this is “*awesome*”, “*great information*” and “*I even put it on my parent’s phone*”. Accessibility was notably acknowledged as “*easy*”. The YMWMH interviewed in this study unanimously agreed that the format of *HIRT?* was preferential to paper-based educational information on injury self-management. The emphasis of “*handy*” and “*at your fingertips*” was observed. This finding is supported by a systematic review by Payne et al. (2015) where self-management apps were identified as acceptable and easily accessible.

Study findings supported credibility of the messages provided in the mobile app. Most participants verified that the information provided in *HIRT?* was consistent with the advice that they received from the health care team.

Communication has been used in other apps to support self-management decisions. In a study by Wayne and Ritvo (2014), an app enabled a health coach intervention for people with diabetes. This allowed for two-way secure messaging between the participant and health coach. The researchers emphasized how the mobile app provided support at pivotal times of client decision making. This demonstrates how app technology has improved connections with people and the health care providers to assist in self-management skills. In *HIRT?*, smart phone

technology allowed a quick connection to the HTC. This was valued and considered a highlight by all participants. Many stated they would need to hunt for the HTC number if they decided to call, so this ease of access was deemed extremely useful.

This attribute of the app could help the YMWMH **form a partnership with the health care provider**, assisting to overcome their resistance to call the HTC. The easy access provided by *HIRT?* facilitates connection and partnership formation with the health care team. Many young men have felt their condition was “*not that bad*” (Nilson et al., 2012, p. e122), especially as compared to those with severe hemophilia. One of the study participants stated, “*I know when I was younger we tended to get a lot of lectures from health care professionals so this might be a nice alternative to that*”. This statement describes lectures received from the HTC following his many unreported injuries from activities. He indicated that if *HIRT?* could help avoid that situation by providing a connection to the HTC, then that would be beneficial. Some participants felt unsure of their ability to assess and know the signs of a bleed, as stated here, “*I think it allows you to have done your homework and I think that is important.*” Another expression suggestive of hesitation was by a participant who indicated that he did not want to bother the health care professionals, “*Because you are not just bugging them for no reason*”. Another participant decided to go to another clinic and not to see the HTC. He stated that with the app he may not have done so “*I could have skipped all of that if I had gone, it took 24-48 hours I wasted if I had just gone to the right place in the first place*”. The access for the app has been deemed easy. The app also has prompted and reminded participants of the next steps for injury self-management, which could ultimately provide a quick link to contact the HTC. This connection with the HTC could be the starting point of an improved partnership between YMWMH and their health care providers.

Technologies helped contribute to the convenience and potential for enhanced efficiency of future health care delivery in Canada. A news report (Canada NewsWire, 2013) states Canadians are ready for using mobile health for “convenient access to a physician, ability to obtain information, and greater control over one's health”. Mobile apps have the characteristic of being available as many people have their phones with them most of the time (CWTA Canada 2015). The YMWMH in our study support the accessibility of *HIRT?* Therefore, having the app



convenient could provide the information they need in real time (Boulos et al., 2011), when they injury themselves.

Confidence is a key component to self-management and is used in chronic disease management programs (Lorig, 2007). A confidence level of over 7/10, indicates that the chance that the person will act on a certain behaviour are high (Lorig, 2007). In one randomized control trial for the self-management of cystic fibrosis by Cummings et al. (2011), similar results to this study were found where the feasibility of mobile apps and improved confidence for self-monitoring was supported. In our study, respondents reported significantly higher levels of perceived confidence in injury self-management with the use of the app. This would suggest that **HIRT?** has the potential to assist YMWMH to **take action** when they sustain an injury, which is the final step in self-management.

Respondents recognized how YMWMH sometimes do not recognize an injury when the soccer injury scenarios were discussed (Appendix F). The participants understood that by not acknowledging his injury, the unaddressed bleed turned into a bad situation. One participant stated, *“Like mild’s can deny their hemophilia, and if the app could help me not deny it, it would be really effective.”* Many responded that they felt the app could possibly nudge the young man to act, therefore this would be helpful to him. This perception of the YMWMH helps define how **HIRT?** may assist them in an injury situation making them remember their hemophilia. The app could provide an additional assist in helping young men to acknowledge their mild hemophilia.

Health care technology in the form of a smart phone app has become ubiquitous (Huckvale et al., 2015). Despite the benefits and evolution of the technology, the current systems can still present shortcomings (Touati & Tabish, 2013). Touati discusses the designer challenges for developing various systems and the technology needs associated with advances. Parmanto et al. (2013) discusses how they had a glitch in a picture taking function on one app for monitoring skin care. The picture taking glitch was not a serious malfunction but it needed to be regularly upgraded to a faster operating system for more advanced phone systems. The mobile app was part of the iMHere and mHealth systems, a novel architecture of mobile health including smart phone apps to support complex self-care tasks for individuals living with chronic conditions.

In **HIRT?**, the reminders to re-assess were perceived as useful, yet they were also criticized for malfunctioning, alarming them repeatedly or at inappropriate times and could be an

annoyance . The study participants used terms like glitches and these were commonly considered important for an improvement idea for the app. When providing any self-management technology, a process to evaluate and discuss “glitches” and problems with the users is imperative so the glitches can be corrected. Technology advances demand that it is essential to develop a process of continually upgrading the interventions to maintain functionality (Touati & Tabish, 2013). Woods et al. (2013) describes selecting the best type of mobile application for chronic disease self-management. The researchers stated that developers must always consider the ease of creating and the updating of the apps. Touati (2013) also discussed how technology is advancing to create extended battery life for smart phones. Short battery life was an area that our participants indicated could be a barrier to the use of *HIRT?*

### **7.3 Strengths and Limitations**

#### **7.3.1. Strengths**

The mixed methods convergent parallel research design provided strength to this study. The design was efficient as the both qualitative and quantitative data could be collected at the same time, the data reflected on similar areas, the data converged and integrated to more broadly explore the findings. Comparing or triangulating these results validated the data and increased the understanding of the use of *HIRT?* as perceived by YMWMH.

Another study strength was taking the opportunity to solicit improvement ideas for *HIRT?*. The innovative ideas that were presented by this group of young men will be utilized to advance this intervention to greater usefulness. They appreciated having this resource on their phone but they could see it become even better. They suggested including a short informative piece about their mild hemophilia for their employers if needed. This idea came from the scenario where the young man who was injured was hesitant to leave work as his employer would not understand. They also made suggestions about downloading further personal information, such as their FactorFirst cards, which include their personal prescription for the specific factor product they would use in the event of a significant injury. Some additionally expressed the need for a more individualized approach to the injury assessment with one suggesting a method of grading pain, swelling and other assessment parameters so users could actually see a difference on the re-assessment time periods. This would let them know if they were getting worse, making the assessment section useful even for those young men more

experienced with bleeds. These suggestions for improvement added depth and value to this study. The improvement ideas are facilitators to knowledge use, a phase within the action cycle of the KTA model (Figure 3.1). The noted improvements will be considered in future developments of *HIRT?*.

The close connections to the national hemophilia health care network was a strength. Hemophilia is an extremely rare condition yet it has tremendous impact on those individuals who live with this genetic condition. This research study would not have been possible without the collaboration of physiotherapists, other health care professionals on the hemophilia care teams and the patient organization the Canadian Hemophilia Society. Therefore, through this strong supportive network recruitment was facilitated. The study sample size exceeded our target of 6-10 participants. Therefore, sufficient data for the qualitative analysis were collected. The hemophilia community also provides an avenue that the results will be disseminated.

*HIRT?* has created extensive interest in the hemophilia community both nationally and globally amongst health professionals and YMWMH. *HIRT?* has been available through the Apple and Google stores free of charge. Initially there was many downloads of the app (Appendix G) and then the downloads tapered off throughout the 10 month period. There was 244 downloads of *HIRT?* in Canada. We have not reached every YMWMH in our target population (approximately 500). Many downloads of *HIRT?* were by others such as parents, health workers and those with a more severe form of the disease or other factor deficiencies. The development of *HIRT?* appears to have fulfilled an unmet need. Other health providers are eager for information for this unique population of YMWMH. Health care professionals have stated that they appreciate having the assessment guide with them in the clinical setting. The *HIRT?* app has reached a global audience, with a total of 700 downloads from every continent (Appendix G). This study could be a preliminary exploration prior to adapting this intervention for specific use elsewhere in the world.

### **7.3.2. Limitations**

Recruitment was a challenge during this study and has also been for previous research in this population (Nilson et al., 2012). YMWMH are hard to reach individuals. It was difficult to get the information to them about *HIRT?* even though I exhausted many avenues of recruitment. Only 500 young men within our target population are registered in Canada (CHARMS, 2014),

and we reached 2.4 % of this group. The sample of 12 individuals who participated in this study did have similar characteristics for the general population of YMWMH in Canada such as their age of diagnosis, type of bleed situations and active lifestyle, reflected in other studies (Nilson et al., 2012; Tagliaferri et al., 2012). The quantitative data numbers were considered to be small for analysis.

Another limitation of this study could include the characteristics of the study participants who agreed to participate. The participants who became aware of *HIRT?* had some connection to the hemophilia community or their health care team. The study participants were key informants who provided rich information, but there may have been some gaps in perspectives not captured in this study. Some of the young men had experience with bleeds. Most of the participants perceived confidence in managing injuries was high even before use of the app. Many of them were already proactive and engaged in their self-care for dealing with injuries in a way many of those hard to reach YMWMH may not be; therefore this could bias the data.

Differences in interview administration could be another possible limitation, only 2 interviews were performed in person, and the rest were completed over the telephone. The quality of interaction can be reduced without being able to engage in mannerisms and facial expressions. In a study by Price et al. (2012) comparing telephone, video, and in-person encounters, the interpreters viewed the telephone interpretation as satisfactory for information exchange, but less satisfactory for the interpersonal aspects of communication. Subsequently, two telephone interviews were also conducted with the participant using a hand-free device for their telephones while driving. Although, these methods of collecting data may be perceived as limitations, they reflect that these young men are a difficult to reach population with busy active lives. Therefore, it was important to accommodate them, and I was very appreciative that they were willing and interested to be involved in the research process.

There is the possibility that some participants could have felt it was difficult to fully disclose information, especially since I am the physiotherapist who interacts with them at their HTC. This was noted in a study involving pharmacists and the disclosure of the use of complementary medicine (Necyk et al., 2013), a patient did not report the use of these products feeling that the health care provider would disapprove. There could also be a potential bias in the

confidence rating scale. As the participants could possibly want to please the researcher and respond that their perceived confidence had positively improved.

Another challenge of studying this population of young men is that they do not bleed often (Kumar et al., 2013; Lindvall et al., 2010; Peerlinck & Jacquemin, 2010; Ekholm et al., 2010). Thus, to capture a situation when they bleed and use the app could extend this study over many years. Therefore, even though only 3 of the 12 used the app in a bleed situation, the provided injury scenarios (Interview guide, Appendix F) allowed the participants to explore the app as if they themselves were managing an injury. There was a mixed response to the injury scenarios that occurred on the soccer field. Some reported the app should be used at the site of the injury, others still held the view of a “wait and see” attitude (Nilson et al., 2012) which could related to the privacy of not wanting to reveal their condition, or the inconvenience of getting out their phones. With this variety of attitudes as to when and how **HIRT?** should be used in the injury situation, they all felt the app would have been beneficial in getting the young man to act sooner with his injury. If he had called the HTC he may have avoided the severely painful prolonged bleed.

As seen in the previous study (Nilson et al., 2012), YMWMH react mostly to pain in evaluating the severity of an injury, **HIRT?** gives further parameters to evaluate an injury. **HIRT?** could definitely provide the information and resources needed in this situation. One young man understood the infrequency of bleeds and stated, “*every time that you need it, it is useful, it is just you rarely need it.*” The understanding of infrequent bleeds is essential, so that the YMWMH can be prepared in the event that he sustains an injury. Kumar et al. (2013) described 2 teenagers who bleed infrequently during their sports participation, showing up only when their injuries were extensive and requiring longer recovery times **HIRT?** may have the potential to assist these young men to identify, treat and follow-up on an injury, therefore YMWMH could possibly avoid these situations.

#### **7.4 Significance and Clinical Implications**

The clinical relevance is that **HIRT?** could provide an improvement in bleed management for the population of YMWMH in Canada. The app gives the health care professionals a way to begin educating these young men about injury self-management and potentially provide a means of communicating with them when they sustain an injury.

Health care professionals are challenged to meet the needs of YMWMH. YMWMH are reluctant to acknowledge their condition (Nilson et al., 2012), they do not bleed often (Franchini et al., 2009) and they infrequently attend clinic appointments (Lindvall et al., 2010). There has been an urgency reported by the health care professionals around the world for an intervention for these young men (Schulman, 2012; Ekholm et al., 2010; Steele & Laudenbach, 2004; Lindvall, 2010; van Wanroij, 2010). If YMWMH contact the HTC sooner with an injury needing medical attention, then many of the negative effects associated with an unrecognized injury could be avoided. The negative effects to the health system include the excessive use of expensive factor replacement, the hospital stays and the health care workers' time (Kumar et al., 2013, Lipton, 2011). The impact of this situation is also felt by the young men with pain and disability associated with the injury as well as the emotional, financial and physical burdens (Price et al., 2015; Jones et al., 2013). The unrecognized bleeds may lead to the long term consequences of reduced quality of life due to permanent disabilities (Ling et al., 2011; Ekholm et al., 2010). This study highlights the potential clinical relevance of *HIRT?* The mobile app is accessible, it provides credible information and the perceived confidence of YMWMH is enhanced in their injury self-management. This study provides preliminary evidence for the utility of a new intervention which the health care professional can promote and offer to all the YMWMH they interact with. With these positive results on the utility of *HIRT?*, knowledge translation will be fortified within the HTC's. Consequently, this could result in increased awareness and hopefully utilization of *HIRT?* within Canada by YMWMH.

This mobile app *HIRT?* is the first intervention to be offered to YMWMH that sought and utilized their input in the development. It allows the young man to use the 'wait and see' approach. However, through the timed reminders to re-assess, the young man is persuaded to decide if the injury is worsening. Perceived confidence levels among the participants significantly improved, therefore this intervention may reduce the hesitation of the YMWMH to contact the HTC. Early contact with the HTC following an injury could have a huge impact on the quality of lives of YMWMH. They would not have to endure the traumatic medical crisis associated with an unrecognized injury. *HIRT?* could also potentially lessen the impact of the economic burden on the health care system.

YMWMH are individually unique. Some did not find the assessment and first aid portions of the app useful. However, these individuals had injury management knowledge from previous bleed experiences or from involvement in their professions, first aid instruction received in aquatic classes or other physical activities.. The variations in knowledge and skills of each participant emphasizes the importance of understanding the individual to whom one is providing the intervention. *HIRT?* could provide the necessary knowledge and skills that YMWMH may need, especially for those newly diagnosed. Those experienced with bleeds appreciated the assessment guide and HTC contacts, other less experienced acknowledged the benefit of the assessment and first aid portions. The alarms added value to the app in assisting with prompting the re-assessment for those who may forget about an injury.

Communication with the health care team is extremely important in self-management, if *HIRT?* could enhance this relationship then this could lead to YMWMH being closer to partnering in their health care. Vincent Dumez (2015), a plenary speaker for the World Federation of Hemophilia Conference in July 2016 ([WFH Congress 2016](#)), specializes in patient partnership. He stated in one of his articles that self-care is a technique and it must be based on the knowledge held by the individual but also his knowledge needs. He explains that patient engagement has become a cornerstone for quality of care improvement (Pomey, Hihat, Khalifa, Lebel, Neron, & Dumez, 2015). With the evidence provided in this study, *HIRT?* could potentially begin to engage these young men in their injury self-management. Involving YMWMH in their injury self-management could possibly lead to improved quality of care and quality of life with reduced negative impacts of their conditions.

## **7.5 Future Directions**

The future focus for the CHS ([CHS, Strategic Plan 2016-2018 and beyond](#)) states they support “creative, focused and carefully targeted” interventions. *HIRT?* fits this focus and has been the first app developed for the challenging population of YMWMH. The strategic focus goes on to state that the CHS needs to “embrace new technologies and making information available to people in a multitude of ways”. The study evidence indicates the feasibility, utility and the perceived confidence for injury self-management with use of the mobile app, *HIRT?* for YMWMH in Canada. Hence, with the support of the national organization, my research team’s

future focus will be to disseminate this knowledge to as many of these young men as possible in Canada.

Initially, a short-term future direction will be an update of the present intervention addressing some of the barriers, and identified enhancements, impacting use of the app. These updates will include correcting the glitches with the alarms systems and upgrading the app to make it sustainable for the constantly progressing standards set by the Google and Apple developers.

Improvement ideas will be acted upon, especially in light of the fact that some of the YMWMH did not find the assessment and first aid portions helpful. All the participants liked the detailed assessment guide so the option to navigate straight to this assessment booklet and the HTC contacts will be implemented. This allows the young men to avoid assessing their injuries, but it does make the app more useful as a resource of information and not just a tool to insist an injury needs to be monitored. To avoid the chance that YMWMH would miss an injury, we will make an alert page to ensure they address a certain section of the app to initiate the reminder system. We will act on the suggestion from several participants to include a more individualized approach to assessment. We will develop a new design that will give parameters of measurement to pain, swelling, warmth and reduced motion which are indicators of an injury. These measurements would allow a visual cue to see that an injury is worsening on follow-up assessment. Addressing improvement ideas moves into the next phases of the KTA cycle to help sustain the knowledge use.

The next phase in the KTA cycle is evaluate outcomes. The information gained from this study could assist in developing further research studies to determine the efficacy of *HIRT?*. A prospective research design could determine the impact of *HIRT?* on injury self-management behaviours in YMWMH. A longitudinal, randomized trial design, could evaluate injury self-management with and without the use of the app intervention.

The use of *HIRT?* for larger age ranges within the mild hemophilia population has been discussed. This is possible but would require some needs-based investigation and further research to evaluate the utility and impact of the mobile app with other individuals. Suggestions also include developing *HIRT?* for a broader audience. The potential use in persons with severe hemophilia is a unique possibility. These individuals through their regular preventative



prophylactic treatment, have factor levels similar to those people with mild hemophilia. With good bleed management, their bleeds are infrequent (Hilliard et al., 2013). Therefore they could be in a position of not recognizing injuries needing attention very similar to the YMWMH. Therefore, it could be possible that *HIRT?* could be a useful tool for them.

There has been many suggestions for use and adaptations for *HIRT?*, all of which will be worth exploring. This would require further studies and research to fully investigate the benefits of *HIRT?* on each specific population and how it would require adaptations. *HIRT?* has provided a positive intervention for YMWMH. The use of this type of technology for injury self-management provides endless opportunities within the bleeding disorder community and could provide information for app usage in other chronic conditions.

## **7.6 End of Project Knowledge Translation**

Health care professionals have expressed the need for an intervention for YMWMH (Ekholm et al., 2010; van Wanroij et al., 2010; Schulman, 2012; Tagliaferri et al., 2012). The HTC in Canada have been made aware of this intervention, but now the knowledge gained from this study needs to be disseminated to all the clinics in Canada. Action will be taken to present the findings at national and global hemophilia conferences. Newsletter and professional articles will be submitted for publication. Feedback needs to be solicited from the health care professionals on their perception of how an intervention like *HIRT?* could be most effectively dispersed among this hard to reach population. This leads to the need for further investigation into the impacts of this intervention on better communication with the HTC. Therefore, this intervention could become significant for the health care professionals as it could augment their interactions with the YMWMH.

## **7.7 Conclusion**

*HIRT?* the mobile app, has been perceived by YMWMH in Canada to be accessible, credible and useful. This study supports that *HIRT?* shows promise among participants to positively influence perceived self-management skills particularly when they are younger and first diagnosed with this bleeding disorder. *HIRT?* can assist the young men by increased perceived confidence to identify and manage bleeds. Therefore the mobile app could impact the

number of unrecognized bleeds in this population. The next challenge is to increase the uptake of knowledge by getting *HIRT?* into the hands of those who need it the most, the YMWMH.

## REFERENCES

- Allan J., Freidman K., & DeSancho M. (2014). Life-threatening bleeding in a patient with mild hemophilia A and heterozygosity for von Willebrand disease Type 2N. *International Journal of Hematology*, 100(6), 602-06.
- Andrew, S., & Halcomb, E.J. (2009). *Mixed Methods Research for Nursing and Health Sciences*, Blackwell Publishing Ltd.
- Apache CouchDB Futon Browse Database. Retrieved Dec. 15, 2015. <http://couchdb.apache.org/>
- Ashikaga, A., Mori, M., Yamashita, A., & Taki, M. (2014). The incidence of arthropathy in patients with mild and moderate hemophilia. *Haemophilia*, 20 (suppl.3), 56.
- Baxter, P., & Jack, S. (2008). Qualitative study methodology: Study design and implementation for novice researchers. *The Qualitative Report*. 13 (4); 544-559.
- Beall, C.L., O'Leary, D.S., & Pierce, LE. (1974). Delay in diagnosis of mild hemophilia A. *JAMA*, 229 (11), 1469-70.
- Blanchette, V.S., Key, N.S., Ljung, L.R., Manco-Johnson, M.J., Van der Berg, H.M., & Srivastava, A. (2014). Definitions in hemophilia: communication from the SSC of the ISTH. *Journal of Thrombosis and Haemostasis*, 12: 1935-1939.
- Boulos, M.N.K., Wheeler, S., Tavares, C., & Jones, R. (2011). How smartphones are changing the face of mobile and participatory healthcare: an overview, with example from eCAALYX. *Biomedical Engineering OnLine*, 10:24.  
<http://www.biomedical-engineering-online.com/content/10/1/24>
- Bowen, S. (2012). Canadian Institute of health research: A guide to evaluation in Health Research, Retrieved November 12, 2014, from <http://www.cihr-irsc.gc.ca/e/45336.html#a1.4>
- Bowen, G. A. (2008). Naturalistic inquiry and the saturation concept: A research note. *Qualitative Research*, 8(1), 137-152. doi: 10.1177/1468794107085301
- Braun, V., & Clarke, V. (2006) Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3:2, 77-101.
- Cafazzo, J.A., Casselman, M., Hamming, N., Katzman, D.K., & Palmert, M.R. (2012). Design of an mHealth app for the self-management of adolescent type 1 diabetes: a pilot study. *J Med Internet Res.*, 14(3):e70. doi:10.2196/jmir.2058.

- Canadian Hemophilia Society. (2010). *All about Hemophilia: A Guide for Families*, Second Edition. Retrieved from <http://www.hemophilia.ca/en/educational-material/printed-documents/hemophilia/>
- Canadian Hemophilia Assessment and Resource Management Information System (CHARMS). Report date 15 April 2014. Retrieved from <http://www.ahcdc.ca/index.php/charms>
- Canadian Hemophilia Society, Canadian Hemophilia Standards Group. (2007). Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders. [http://www.ahcdc.ca/documents.CanadianHemophiliaStandardsFirstEdition070612\\_1.pdf](http://www.ahcdc.ca/documents.CanadianHemophiliaStandardsFirstEdition070612_1.pdf) 11 June 2014.
- Canadian Hemophilia Society. (2015). *Strategic Plan 2016-2018*, Retrieved from <http://www.hemophilia.ca/files/CHS%20Strategic%20Plan%202016-2020%20draft%2001-12-2015.pdf>
- Canadian Hemophilia Society. (2014). *Identifying Common Joint and Muscle Bleeds*. Retrieved Dec 1, 2015 from <http://www.hemophilia.ca/files/Identifying%20bleeds.pdf>
- Canadian Hemophilia Society, Canadian Association of Nurses in Hemophilia Care. (2007). *Information Booklet on Mild Hemophilia*. Retrieved from <http://www.hemophilia.ca/files/MildHemophilia.pdf>
- Canada NewsWire. Health apps, virtual visits and remote monitoring - Canadians looking to manage their health one click at a time: *PwC report*. (2013, Jun 04). Retrieved from <http://search.proquest.com/docview/1362376873?accountid=14739>
- Canadian Wireless Technology Association, CWTA, Facts and Figures, 2015. <http://www.cwta.ca/facts-figures/> accessed Oct. 17, 2015.
- Charmaz K. *Constructing Grounded Theory: a Practical Guide through Qualitative Analysis*. Sage Publications Ltd: London; 2006.
- Chambost, H., Gaboulaud, V., Coatmelec, B., Rafowicz, A., Schneider, P., & Calvez, T. (2002). What factors influence the age at diagnosis of hemophilia? Results of the French hemophilia cohort. *J Pediatr.*, 141, 548-52.
- Chatterjee, S, & Price, A. (2009) Healthy Living with Persuasive Technologies: Framework, Issues and Challenges. *J Am Med Inform Assoc.* 16(2): 171-178. doi: 10.119/jamia.M2859.
- Creer, T, Renne, C, & Christian, W. (1976). Behavioral contributions to rehabilitation and childhood asthma. *Rehabilitation Literature*, 37:226–232, 247.

- Cresswell JW. (2013). Steps in conducting a Scholarly Mixed Methods Study. Digitalcommons@university of Nebraska- Lincoln. Retrieved from <http://digitalcommons.unl.edu/cgi/viewcontent.cgi?article=1047&context=dberspeakers>
- Creswell JW, & Plano Clark VL. (2011). Designing and conducting mixed methods research. 2nd ed. Thousand Oaks, CA: Sage.
- Cummings E, Hauser J, Cameron-Tucker H, Fitzpatrick P, Jessup M, Walters EH, Reid D, & Turner P. (2011). Enhancing Self-Efficacy for Self-Management in People with Cystic Fibrosis. European Federation for Medical Informatics. doi: 10.3233/978-1-60750-806-9-33.
- Canadian Wireless Technology Awards: CWTA awards, March 2015. <https://twitter.com/cwtawireless/status/578322445771345920>
- Darby, S.C. et al. (2007). Mortality rates, life expectancy, and causes of death in people with hemophilia A or B in the United Kingdom who were not infected with HIV. *Blood* 1 (110), 815-25. <http://www.jwatch.org/oh200708140000003/2007/08/14/lifespan-people-with-hemophilia#sthash.6qWGfhOh.dpuf>.
- Dawson, B., & Tarpped, R. (2004). Basic and Clinical Biostatistics. (ch.5). McGraw-Hill Companies.
- Des Jarlais, D. C., Lyles, C., Crepaz, N., & the TREND Group. (2004). Improving the reporting quality of nonrandomized evaluations of behavioural and public health interventions: the TREND statement. *American Journal of Public Health*, 94(3), 361-366.
- De Von, H. A., Block, M.E., Moyle-Wright, P., Ernest, D.M., Hatden, S.J., Lazzara, D.J., Savoy, S.M., & Kostas-Polston E. (2007). A Psychometric Toolbox for testing Validity and Reliability. *Journal of Nursing Scholarship*, Second quarter: 155-164.
- Dicianno, B.E., Parmanto, B., Fairman, A.D., Crytzer, T.M., Yu, D.X., Pramana, G., Coughenour, D., & Petrazzi, A.A. (2015) Perspectives on the evolution of Mobile (mHealth) Technologies and Application to Rehabilitation. *Physical Therapy*, 95(3); 397-405.
- Ekholm, C., Mattson, E., Astermark, J., Ljung, R., & Berntorp, E. (2010). Mild haemophilia in Sweden. *Haemophilia*, 16 (suppl 4): 90.
- Fetters, M. D., Curry, L. A., & Creswell, J. W. (2013). Achieving Integration in Mixed Methods

- Designs- Principles and Practices (pg. 2134-215) *HSR: Health Services Research* 48:6, Part II (December) doi: 10.1111/1475-6773.12117
- Franchini, M., Favaloro, E. J., & Lippi, G. (2009). Mild Hemophilia A. *Journal of Thrombosis and Haemostasis*, 8:421-432. doi:10.1111/j.1538-7836.2009.03717.x
- Free, C., Whittaker, R., Knight, R., Abramsky, T., Rodgers, A., & Roberts, I.G. (2009). Txt2stop: a pilot randomised controlled trial of mobile phone-based smoking cessation support. *Tobacco Control* 18(2):88-91. doi: 10.1136/tc.2008.026146
- Free, C., Philips, G., Galli, L., Watson, L., Lambert, F., Edwards, P., Patel, V., & Haines A. (2013). The effectiveness of Mobile-Health Technology-Based health Behaviour Change or Disease management Interventions for health Care consumers: A Systematic Review. *PLoS Med.* 10(1): e1001362. doi:10.1371/journal.pmed.1001362
- Fogg, B.J. (2003). *Persuasive Technology: Using computers to change What We Think and Do.* San Franiso: Morgan Kauffman Publishing.
- Future in Focus Digital Canada. (2015). Retrieved from <http://www.cwta.ca/wp-content/uploads/2015/06/Digital-Future-in-Focus-2015-CANADA.pdf>
- Gamba, G., Lodo, F., Trincherio, A., Montani, N., & Ghidelli. (2010). Patterns of bleeding, age at first bleeding episode and at diagnosis in severe and mild/moderate haemophilia. *Haemophilia*; 16 (suppl.4), 91.
- Geraghty S, Dunkley T, Harrington C, Lindvall K, Maahs J, Sek J. (2006). Practice patterns in haemophilia A therapy – global progress toward optimal care. *Haemophilia*; 12: 75-81.
- Goodyear, D., Lauf, A., Jenkins, D., McDonald, J., & Poon, M. (2012). Caring for mild haemophilia: A challenge to comprehensive haemophilia treatment centres. *Haemophilia*, 18, (s3), 106. doi/10.1111/j.1365-2516.2012.02820.x
- Graham, I.D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: Time for a map? *JCHEP*, 26, 13-24. doi:10.1002/chp.47
- Gray, C.S., Miller, D., Kuluski, K., & Cott, C. (2014). Tying eHealth tolls to patient needs: Exploring the use of eHealth for community-dwelling patients with complex chronic disease and disability. *JMIR Research Protocols*, 3(4), e67. doi:10.2196/resprot.3500

- Groen, W.G., Den Uijl, I.E.M., Van der Net, J., Grobbee, D.E., De Groot, P.H.G., & Fisher K. (2013). Protected by nature? Effects of strenuous physical exercise on FVIII activity in moderate and mild haemophilia A patients: a pilot study. *Haemophilia*, *19*: 519-523. doi:10.1111/hae.12111
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*. *18*(1), 59-82. doi: 10.1177/1525822X05279903
- Haemophilia Foundation of Australia. (1998). Mild Hemophilia. (2013 Dec 1) retrieved from: <http://www.haemophilia.org.au/documents/item/33>.
- Hilliard, P., Zourikian, N., Blanchette, V., Chan, V., Elliot, B., Isreal, S. J., Nilson, J., Poon, M.C., Laferriere, N., Van Neste, C., Jarock, C., Wu J., McLimont, M., & Feldman, B. (2013). Musculoskeletal health of subjects with hemophilia A treated with tailored prophylaxis: Canadian Hemophilia Primary Prophylaxis (CHPS) Study. *Journal of Thrombosis and Haemostasis* (*11*), *3*, 460-466. doi: 10.1111/jth.12113.
- Huckvale, K., Morrison, C., Ouyang, J., Ghaghda, A., & Car, J. (2015). The evolution of mobile Apps for asthma: an updated systematic assessment of content and tools. *BMC Medicine* *13*:58. doi: 10.1186/s12916-015-0303-x
- IBM; SPSS software. (3 March 2015) Retrieved from <http://www-01.ibm.com/software/analytics/spss/downloads.html>.
- Jansen, N.W.D., Roosendaal, G., & Lafeber, F.P.J.G. (2008). Understanding haemophilic arthropathy: an exploration of current open issues. *Br J Haematol.*; *143*: 632-640.
- Johnston, S., Liddy, C., Ives S. M., & Soto, E. (2008). Literature Review on Chronic Disease Self-Management, 1–26. Retrieved from <http://www.ontla.on.ca/library/repository/mon/24006/302504.pdf>
- Jones, G., Thompson, K., & Johnson, M. (2013). Acute compartment syndrome after minor trauma in a patient with undiagnosed mild haemophilia B. *Lancet (London, England)* *16*; *382*(9905), 1678.
- Karazivan, P., Dumez, V., Flora, L., Pomey, M.P., Del Grande, C., Ghadiri, D.P., Fernandez, N., Jouet, E., Las Vergnas, O., & Lebel, P. (2015). The Patient-as-Partner Approach in Health Care: A Conceptual Framework for a Necessary Transition. *Academic Medicine*, *90* (4): 437-441. doi:10.1097/ACM.0000000000000603

- Keller, V.F., & White, M.K. (1997). Choices and Changes: A new model for influencing Patient Behaviour. *Journal of Clinical Outcomes Management*, 4 (6): 33-36.
- Kirk, S., Beatty, S., Callery, P., Milnes, L., & Pryjmachuk, S. (2012). Perceptions of effective self-care support for children and young people with long-term conditions. *Journal of Clinical Nursing*. 21, 1974-1987. doi: 10.1111/j.1365-2702.2011.04027.x
- Kumar, R., Stain, A.M., Hilliard, P., & Carcao, M. (2013). Consequences of delayed therapy for sports-related bleeds in patients with mild-to-moderate haemophilia and type3 von Willebrand's disease not on prophylaxis. *Haemophilia*.19, e256-e269.  
doi:10.1111/hae.12162
- Larsson, S.A., & Wiechel, B. (1983). Deaths in Swedish hemophiliacs, 1957-1980. *Acta Med Scand* 214:199-206.
- Leijdekkers, P., & Gay, V. (2013). Mobile apps for chronic disease management: lessons learned from myFitnessCompanion. *Health Technol*. 3:111-118. Doi: 10.1007/s12553-013-0044-9.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic Inquiry*. Sage Publications, Newbury Park, CA.
- Lindvall K, Colstrup L, Loogna K, Wollter IM, Gronhaug S. (2010). Knowledge of disease and adherence in adult patients with hemophilia. *Haemophilia*; 16, 592-596.
- Ling, M., Heysen, J.P.H., Duncan, E.M., Rodgers, S.E., & Lloyd, J.V. (2011). High incidence of ankle arthropathy in mild and moderate haemophilia A. *Thromb Haemost*; 105:261-268.
- Lipton, R.A. (2011). I need to pay more attention to mild haemophilia patients. *Haemophilia*, 17(4)704. doi: 10.1111/j.1365-2516.2010.02484.x.
- Livewell Chronic Disease Management Program, Chronic Disease Management, Saskatoon Health Region. Retrieved from <https://www.saskatoonhealthregion.ca/livewell>
- Lomotey, R. K., Mulder, K., Nilson, J., Schachter, C., Wittmeier, K., Deters, R. (2014). Mobile self-management guide for young men with mild hemophilia in cases of minor injuries. *International Journal of Network Modeling Analysis in Health Informatics and Bioinformatics*, 3, (1), 1-12. doi: 10.1007/s13721-014-0064-z
- Lorig, K.R., & Holman, H.R. (2003). Self-management Education: History, Definition, Outcomes and Mechanisms. *Annals of Behaviour Medicine*; 26 (1), 1-7.
- Lorig, K., Holman, H., Sobel, D., Laurent, D., Gonzalez, V., & Minor, M. (2007). *Living a Healthy Life with Chronic Conditions*. Bull Publishing Company.



- Lorig, K.R., Ritter, P., Stewart, A.L., Sobel, D.S., Brown, B.W., Bandura, A., González, V.M., Laurent, D.D., & Holman, H.R. (2001). Chronic Disease Self-Management Program: 2-Year Health Status and Health Care Utilization Outcomes. *Medical Care*, 39(11), 1217-1223.
- Mannucci, P.M., Ruggeri, Z.M., & Pareti, F.I. et al. (1977). 1-Deamino-8-d-arginine vasopressin: a new pharmacological approach to the management of haemophilia and von Willibrands' diseases. *Lancet* 1:869-872.
- Mannucci, P.M. (2012). Desmopressin (DDAVP) in the treatment of bleeding disorders. No. 11, Treatment of Hemophilia, World Federation of Hemophilia. Retrieved from <http://www1.wfh.org/publication/files/pdf-1131.pdf>
- Marcano Belisario, J.S., Huckvale, K., Greenfield, G., Car, J., & Gunn, L.H. (2013). Smartphone and tablet self-management apps for asthma. *The Cochrane database of systematic reviews*, 11: Cd010013.
- Miners, A., Sabin, C., Tolley, K., Jenkinson, C., Kind, P., & Lee, C. (1999). Assessing health-related quality of life in individuals with haemophilia. *Haemophilia*, 5:378-85.
- Mitacs Inspiring Innovation in Canada, retrieved 2013 Dec 6 from: <http://www.mitacs.ca>
- Mulder, K. (2011). The Mild Hemophilia Project: questionnaire results from Calgary. *Hemophilia Today*. 46:3, 29. Retrieved from <http://www.hemophilia.ca/files/HT%20November%20-%20FINAL%20for%20Web.pdf>. 24 Feb 2015.
- Necyk, C., Barnes, J., Tsuyuki, R.T., Boon, H., & Vohra S. (2013). How well do pharmacists know their patients? A case report highlighting natural health product disclosure. *CPR/PC 146*, 4. doi: 10.1177/1715163513493387.
- Newbronner, L., Chamberlain, R., Barthwick, R., Baxter, M., & Sanderson, D. (2013). Sustaining and spreading self-management support, the health Foundation Inspiring Improvement. *Firefly illuminating research*. Retrieved from 6 Nov 2015. <http://www.health.org.uk/sites/default/files/SustainingAndSpreadingSelfManagementSupport.pdf>
- Nilson, J., Schachter, C., Mulder, K., Hahn, M., Hilliard, P., Steele, M., & Jarock, C. (2012). A qualitative study identifying the knowledge, attitudes and behaviours of young men with mild haemophilia. *Haemophilia*, 18, e120-e125. doi:10.1111/j.1365-2516.2011.02714.x

- Nilson, J., Mulder, K., & Schachter, C. (2012). A new self-assessment pathway tool for young men with mild hemophilia A and B who experience musculoskeletal bleeds. *Haemophilia*, 18(3):106. doi/10.1111/j.1365-2516.2012.02820.x
- Padman, R., Jaladi, S., Kim, S., Kumar, S., Orbeta, P., Rudolph, K., & Tran, T. (2013). An Evaluation Framework and A Pilot Study of a Mobile Platform for Diabetes Self-Management: Insights from Pediatric Users. *Studies in Health Technology & Informatics*, 192: 333-7.
- Pappas, A.M., Barr, J.S., Salzman, E.W., Britten, A., & Riseborough, E. J. (1964). The Problem of Unrecognized “Mild Hemophilia”. Survival of a Patient after Disarticulation of the Hip. *JAMA* 187:772-774.
- Parmanto, B., Pramana, G., Yu, D.X., Fairman, A.D., Dicianno, B.E., & McCue, M.P. (2013). iMHere: A Novel mHealth system for supporting Self-Care in Management of Complex and Chronic Conditions. *JMIR Mhealth Uhealth*. 1(2): e10. doi: 10.2196/mhealth.2391.
- Patton, M. (2002). *Qualitative Research & Evaluation Methods*, 3<sup>rd</sup> Edition, Sage publications, Inc.
- Payne, H., Lister, C., West, J., & Bernhardt, J.M. (2015). Behavioural Functionality of mobile apps in health Interventions: A systematic Review of the Literature. *JMIR Mhealth Uhealth* 3(1):e20. doi: 10.2196/mhealth.3335.
- Peerlinck, K., & Jacquemin, M. (2010). Mild Haemophilia: a disease with many faces and many pitfalls. *Haemophilia*. 16(suppl 5): 100-106.
- Pomey, M.P., Hihar, H., Khalifa, M., Lebel, P., Neron, A., & Dumez, V. (2015). Patient partnership in quality improvement of healthcare services: Patients’ input and challenged faced. *Patient Experience Journal*, 2(1): 29-42.
- Price, E.L., Perez-Stable, E.J., Nickleach, D., Lopez, M., & Karliner, L. (2012). Interpreter perspectives of in-person, telephonic, and videoconferencing medical interpretation in clinical encounters. *Patient Education and Counselling* 87, 226-232. doi: 10.1016/j.pec.2011.08.006.
- Price, V.E., Hawes, S.A., Bouchard, A., Vaughan, A., Jarock, C., & Kuhle, S. (2015). Unmeasured costs of haemophilia: the economic burden on families with children with haemophilia. *Haemophilia*, 21, e294-e299.
- Publications Manual of the American Psychological Association, 6<sup>th</sup> Edition, 2012.

- QRS International; NVivo for windows. Retrieved 3 Mar 2015 from [http://www.qsrinternational.com/products\\_nvivo.aspx](http://www.qsrinternational.com/products_nvivo.aspx) .
- Querol, F., Aznar, J.A., Haya, S., & Cid, A. (2002). Musculoskeletal injuries in patients with haemophilia. *Haemophilia*, 8: 478.
- Revel-Vilk, S., Blanchette, V.S., Sparling, C, Stain, M. A., & Carcao, M.D. (2002). DDAVP challenge test in boys with mild/moderate haemophilia A. *Br J Haematol*.117:947-951.
- Richard, L., & Morse, J.M. (2013). Readme First for a user's guide to Qualitative Methods. 3<sup>rd</sup> ed. Sage Publications Inc.
- Sattoe, J.N.T., Bal, M.I., Roelofs, P.D.D.M., Bal, R., Miedema, H.S., van & Staa, A. (2015). Self-management interventions for young people with chronic conditions: A systematic overview. *Patient education and counseling*, 98: 704-715.
- Schulman, S. (2012). Mild Hemophilia. *Treatment of Hemophilia*, No. 41. World Federation of Hemophilia, Retrieved from <http://www1.wfh.org/publication/files/pdf-1192.pdf>
- Steele, M.J., & Laudenbach, L. (2004). Delay in treatment and increased morbidity in mild hemophilia. *Haemophilia*, 10(suppl 3): 86.
- Stephenson, G. (2015) A bit of personal history amid current events. *Hemophilia Today*, 50, No 2. [http://www.hemophilia.ca/files/HT%20AUGUST%202015%20FINAL%20\(2\).pdf](http://www.hemophilia.ca/files/HT%20AUGUST%202015%20FINAL%20(2).pdf)
- Stonebraker, J.S., Bolton-Maggs, P.H., Michael, C., Soucie, J., Walker, I., Brooker, M. (2009). A study of the variations in the reported haemophilia A prevalence around the world. *Haemophilia* 18 (3); e91-e94. doi: 10.1111/j.1365-2516.2011.02588.x.
- Straus, S.E., Tetroe, J., & Graham, I.D. (2013). *Knowledge Translation in Health Care: Moving Evidence to Practise*. 2nd ed. Somerset, NJ, USA: John Wiley & Sons.
- Tagliaferri, A., Di Perna, C., Riccardi, F., Pattacini, C., & Rivolta, G.F. (2012). The natural history of mild haemophilia: a 30-year single centre experience. *Haemophilia*, 18, 166-174. doi: 10.1111/j.1365-2516.2011.02617.x.
- Terao, Y., Akiyama, M., Yokoi, K., Yamaoka, M., Shimizu, M., Kato, Y., Tanaka, K., Baba, Y., Kuwashima, N., Ashizuka, S., Yoshizawa, J., Motoki, T., Saito, Y., & Ida, H. (2012). Diagnosis of mild haemophilia A made by massive intraabdominal bleeding in a 13-year-old boy. *The Japanese Journal of clinical hematology*. 53(8), 765-9.
- Thebane, L., & Akhtar-Danesh, N. (2008). Guidelines for reporting descriptive statistics in

- health research. *Nurse Researcher*, 15(2), 72-81. Retrieved from <http://search.proquest.com/docview/200819961?accountid=14739>
- Thorne, S. (2008). *Interpretive Description*. Walnut creek, CA: Left Coast Press.
- Thorne, S., Reimer Kirkham, S., & O’Fleen-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, 3(1): 1-21.
- Thorne, S. (2000). Data analysis in qualitative research. *Evid Based Nurs*. 3(3): 68-70. doi:10.1136/ebn.3.3.68. retrieved 24 Feb 2015 from <http://ebn.bmj.com/>.
- Touati, F., & Tabish, R. (2013). U-Health System: State-of-the-Art Review and Challenges. *J Med Syst* 37:9949. doi: 10.1007/s109116-013-9949-0.
- Tountas, C.P., Ferris, F.O., & Cobb S.W. (1992). Exertional compartment syndrome in covert mild hemophilia. A case report. *Minnisota medicine*, 75(7), 27-9.
- Venkateswaran, L., Wilimas, J.A., Jones, D.J., & Nuss, M.D. (1998). Mild hemophilia in children: prevalence, complications, and treatment. *J Pediatr Hematol Oncol* 20:32-35.
- Walker, I., Pai, M., Akabutu, J., Rithie, B., Growe, G., Poon, M.C., Card, R., Ali, K., Isreals, S., & Teitel, J. (1995). The Canadian Hemophilia Registry as the basis for a national system for monitoring the use of factor concentrates. *Transfusion* 35: 548-51.
- Van Velsen, L., Beaujean, D., Wentzel, J., Van Steenbergen, J.E., & van Germert-Pijnen, J. (2015). Developing requiremnts for a mobile app to support citizens in dealing with ticks and tick bites via an end-user profiling. *Health Informatics Journal* 21(1) 24-35. doi:10.1177/1460458213496419.
- van Wanroij, H., Dielen, I., Amtari, M., Laros, B., & Novakova, I. (2010). Mild Hemophilia and Trauma. *Haemophilia*, 16 (suppl. 4), 91.
- Walsh, M., Macgregor, D., Stuckless, S., Barrett, B., Kawaja, M., & Scully, M. F. (2008) Health-related quality of life in a cohort of adult patients with mild hemophilia A. *J Thromb Haemost.* 6:755-761.
- Wasson, J., & Coleman, E.A. (2014). Health confidence: a simple, essential measure for patient engagement and better practise. *Fam Pract Manag* 21(5):8-12. Retrieved from <http://www.aafp.org/fpm/2014/0900/p8.html>
- Wayne, N., & Ritvo, P. (2014). Smartphone-Enabled Health Coach Intervention for people with Diabetes from a Modest Socioeconomic Strata Community: Single Arm Longitudinal Feasibility study. *J Med Internet Res.* 16(6): e149. doi: 10.2196/jmir.3180.

World Federation of Hemophilia. (2012). Guidelines for the Management of Hemophilia, 2<sup>nd</sup> edition, Retrieved 11 June 2014 from <http://www.wfh.org/en/resources/wfh-treatment-guidelines>

Wood, F.G., Robson, M.P., Thompson, M.K., & Johnson, R.L. (2013). Selecting the best type of mobile application for chronic disease self-management. *Computers, informatics, nursing: CIN*. 31(5): 208-11.  
<http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&AN=00024665-201305000-00002&D=ovft&PDF=y>.

## APPENDIX A: Recruitment Material: Website Invitation

***HIRT?***



### Announcing **HIRT?**

#### (Hemophilia Injury Recognition Tool)

This is an innovative INJURY self-management App developed specifically for young men with mild hemophilia.

This App will assist the young men with mild hemophilia in injury self-management by:

- Helping to identify signs and symptoms of a bleed
- Encouraging the use of first aid
- Reminding them to re-assess the injury (1 hour, 24 hours and 2 days) until the risk of re-bleed has passed
- Providing Hemophilia center telephone contact information in case the injury worsens and they require medical attention
- The booklet “Identifying Common Joint & Muscle Bleeds” is available within the App to assist with assessment.

#### DOWNLOADING THE APP

***HIRT?***



**Apple (iOS) Users have three options:**

- 1. Go to Apple Store and type “*HIRT?*” in the search bar.**
- 2. Go to iTunes and type “*HIRT?*” in the search bar.**
- 3. Follow this link: <https://itunes.apple.com/ca/app/hirt/id920165132> .**

**Google (Android) Users: Go to Play Store and search “*HIRT?*”**

We will be evaluating the App over the next year. If you are a young man with mild hemophilia, please try the App and contact me if you wish to provide feedback. If you have any questions or would be willing to participate in the evaluation don't hesitate to contact me at: [joann.nilson@saskatoonhealthregion.ca](mailto:joann.nilson@saskatoonhealthregion.ca)

The developers of ***HIRT?***: JoAnn Nilson, Kathy Mulder, Kristy Wittmeier, Candice Schachter, Richard Lomotey, Sarah Oosman and Cathy Arnold

## APPENDIX B: Ethics Renewal Certificate



UNIVERSITY OF  
SASKATCHEWAN

Behavioural Research Ethics Board (Beh-REB)

### Certificate of Re-Approval

PRINCIPAL INVESTIGATOR	DEPARTMENT	Beh #
Joann Nilson	Off-campus	11-300
INSTITUTION (S) WHERE RESEARCH WILL BE CARRIED OUT		
University of Saskatchewan Saskatoon SK		
SUB-INVESTIGATOR(S)		
Kathy Mulder, Sarah Oosman, Kristy Wittmeier, Candice L. Schachter, Cathy Arnold, Karen Strike		
FUNDER(S)		
BAYER HEMOPHILIA AWARDS PROGRAM		
TITLE:		
Development and Evaluation of a New Self-Assessment Pathway for Young Men with Mild Hemophilia A and B		
RE-APPROVED ON	EXPIRY DATE	
01-Oct-2015	30-Sep-2016	

Full Board Meeting

Delegated Review

#### CERTIFICATION

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

#### ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: [http://www.usask.ca/research/ethics\\_review/](http://www.usask.ca/research/ethics_review/)

Vivian Ramsden, Chair  
University of Saskatchewan  
Behavioural Research Ethics Board

Please send all correspondence to:

Research Ethics Office  
University of Saskatchewan  
Box 5000 RPO University, 1607 – 110 Gymnasium Place  
Saskatoon, SK S7N 4J8  
Phone: (306) 966-2975 Fax: (306) 966-2069



## APPENDIX C: Certificate of Approval



UNIVERSITY OF  
SASKATCHEWAN

Behavioural Research Ethics Board (Beh-REB)

### *Certificate of Approval*

PRINCIPAL INVESTIGATOR  
Joann Nilson

DEPARTMENT  
Off-campus

BEH#  
11-300

INSTITUTION(S) WHERE RESEARCH WILL BE CONDUCTED  
University of Saskatchewan

SUB-INVESTIGATOR(S)  
Kathy Mulder

FUNDER(S)  
BAYER HEMOPHILIA AWARDS PROGRAM

TITLE  
Development and Evaluation of a New Self-Assessment Pathway for Young Men with Mild Hemophilia A and B

ORIGINAL REVIEW DATE  
31-Oct-2011

APPROVAL ON  
03-Jan-2012

APPROVAL OF:  
Ethics Application  
Consent Protocol

EXPIRY DATE  
02-Jan-2013

Full Board Meeting

Date of Full Board Meeting:

Delegated Review

#### **CERTIFICATION**

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

#### **ONGOING REVIEW REQUIREMENTS**

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: [http://www.usask.ca/research/ethics\\_review/](http://www.usask.ca/research/ethics_review/)

John Rigby, Chair  
University of Saskatchewan  
Behavioural Research Ethics Board

Please send all correspondence to:

Research Ethics Office  
University of Saskatchewan  
Box 5000 RPO University, 1602-110 Gymnasium Place  
Saskatoon SK S7N 4J8  
Telephone: (306) 966-2975 Fax: (306) 966-2069

## APPENDIX D: Saskatoon Health Region Operational Approval



UNIVERSITY OF  
SASKATCHEWAN

Associate Vice-President Research – Health  
(University of Saskatchewan)  
Vice-President Research and Innovation  
(Saskatoon Health Region)  
Room A102, Health Sciences Building  
107 Wiggins Road, University of Saskatchewan  
Saskatoon, SK S7N 5E5  
Phone: (306) 966-8745

**DATE:** April 2, 2014

**TO:** JoAnn Nilson  
Saskatchewan Bleeding Disorders Program  
Royal University Hospital

**FROM:** Martha E. (Beth) Horsburgh  
Associate Vice-President Research – Health (University of Saskatchewan)/  
Vice-President Research & Innovation (Saskatoon Health Region)

**RE:** **RESEARCH ETHICS BOARD (REB) #: BEH-11-300**  
**PROJECT NAME: Development and Evaluation of a New Self-Assessment Pathway**  
**for Young Men with Mild Hemophilia A and B**  
**PROTOCOL #: N/A**

---

Saskatoon Health Region is pleased to provide you with amended operational approval of the above-mentioned research project to include changes to the study protocol as received on April 1, 2014 and approved by the Behavioural Research Ethics Board on March 26, 2014.

Kindly inform us when the data collection phase of the research project is completed. We would also appreciate receiving a copy of any publications related to this research. As well, any publications or presentations that result from this research should include a statement acknowledging the assistance of Saskatoon Health Region.

We wish you every success with your project. If you have any questions, please feel welcome to contact Shawna Weeks at 655-1442 or email [shawna.weeks@saskatoonhealthregion.ca](mailto:shawna.weeks@saskatoonhealthregion.ca)

Yours truly,

Martha E. (Beth) Horsburgh, RN, Ph.D  
Associate Vice-President Research – Health (University of Saskatchewan)/  
Vice-President Research & Innovation (Saskatoon Health Region)

cc: Rick Stene, Manager, SK Bleeding Disorders Program, CDM

*Catalyzing Health Research and Innovation Together*

## APPENDIX E: Consent Form



### CONSENT FORM:

---

You are invited to participate in a research project entitled Effectiveness of HIRT? (Hemophilia Injury Recognition Tool), an injury self-management App developed specifically for young men with mild hemophilia. Please read this form carefully, and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family or (if applicable) your doctor before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

#### **Researcher(s):**

JoAnn Nilson

Physiotherapist and MSc Student

Saskatchewan Bleeding Disorders Program

University of Saskatchewan

306-655-6628 or 306-655-2431

Dr. Sarah Oosman

Assistant Professor (Ph.D., M.Sc., B.Sc.PT)

College of Medicine

University of Saskatchewan

306-966-8260

Kathy Mulder

Physiotherapist

Manitoba Bleeding Disorders Program

Winnipeg Health Science Center

Winnipeg, Manitoba

204-787-2641

Dr. Kristy Wittmeier  
Physiotherapy Innovations & Best Practice Coordinator  
Physiotherapy Department, Health Sciences Centre,  
Winnipeg, Manitoba  
204- 787-8531

Dr. Candice Schachter  
Adjunct Professor  
School of Physiotherapy  
University of Saskatchewan

**Purpose and Procedure:** Young men with mild hemophilia often delay getting medical treatment because they cannot always determine the difference between ‘mild’ injuries and significant bleeds. Not recognizing a bleed can result in these young men suffering from major medical complications, missing school and /or work and experiencing significant physical pain with decreased mobility. The prolonged recovery results in higher use of expensive replacement clotting factor, and increases demands of health care during the rehabilitation period. “HIRT?” (Hemophilia Injury Recognition Tool) is an electronic application for smart phones that assists in the assessment of a muscle or joint injury to see if it needs medical attention. The App describes symptoms of bleeding, encourages the initial use of first aid and, if the symptoms worsen, assists the user to contact the Hemophilia Treatment Center. It was developed for and with the input of young men age 18-35 with mild hemophilia. This study will evaluate the App over one year. The use of the App will be tracked and about 6-10 of the young men who have used the App across the country will be asked about the effectiveness of this App. This research is the first to seek evidence about the usefulness of this new App self-management tool. It may contribute to earlier

treatment decisions by these young men with mild hemophilia, better quality of life for these young men and enrich the practice of health care professionals.

Approximately 6-10 young men with hemophilia will participate in telephone interviews in this study. If you participate in this study, you will be contacted to arrange a telephone interview at a time that is convenient for you. The telephone interview will take about 60-90 minutes. At the end of the interview, the interviewer will summarize your main comments. You can then add to or change anything that you said. The interview will be audio recorded to help the interviewer accurately summarize the information. A summary which includes any direct quotations that might be used will be sent to you for your review. You will be asked to approve this summary before the information is used. Up to one month after the interview, you can contact the interviewer if you would like to add to or change anything that you said during the interview.

Information from the interviews will be used to evaluate the utility of the app in assisting men with hemophilia make a decision about their injuries. Direct quotations may be used with permission in articles or at conferences to explain the effectiveness of the electronic application and it's usefulness. No identifying information will be used in direct quotations.

**Potential Benefits:** While we cannot guarantee any direct benefit from participating in this study, you will have the opportunity to help evaluate the utility and effectiveness of this self-assessment guide that may be beneficial to you or others with mild hemophilia in the future.

**Potential Risks:** There are no known risks to participation in this study.

**Storage of Data:** Any data with identifying information will be kept secured in a locked cabinet only accessible to the researchers. The data (including audio recordings) will be stored for 5 years, at which point it will be appropriately destroyed. Personal information (name, contact information) will be kept separately from interview records.

**Confidentiality:** No identifying information will be provided in any publications that may result from this work. If direct quotes are used from the interview, comments and information that may identify an individual will not be included. Consent forms and contact information will be kept separately from interview records.

**Right to Withdraw:** Your participation is voluntary, and you can answer only those questions that you are comfortable with. There is no guarantee that you will personally benefit from your involvement. The information that is shared will be held in strict confidence and discussed only with the research team. You may withdraw from the research project for any reason, at any time, without penalty of any sort and your decision to withdraw will not affect your medical care, access to services or payment. Your right to withdraw from the study will apply until we evaluate and pool the data for evaluation. After this it is possible that some form of research dissemination will have already occurred and it may not be possible to withdraw your data.

**Payment:** You will receive a \$50 honorarium for your participation in this study. A cheque will be mailed to you after completion of the telephone interview. You will not be compensated for the study if you do not complete the interview.

**Questions:** If you have any questions concerning the research project, please feel free to ask at any point; you are also free to contact the researchers at the numbers provided if you have other questions. This research project has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on Oct. 23, 2014. Any questions regarding your rights as a participant may be addressed to that committee through the University of Saskatchewan Ethics Office (306-966-2084, out of town participants may call collect). Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

## **Consent to Participate:**

### Written Consent

I have read and understood the description provided; I have had an opportunity to ask questions of JoAnn Nilson or the study staff, and my/our questions have been answered in a language I understand. I consent to participate in the research project, understanding that I may withdraw my consent at any time. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. A copy of this Consent Form has been given to me for my records.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Saskatchewan for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

I agree to be contacted for future follow-up in relation to this study,

Yes  No

or

### Oral Consent

I read and explained this Consent Form to the participant before receiving the participant's consent, and the participant had knowledge of its contents and appeared to understand it.

---

(Name of Participant)

---

(Date)

---

(Signature of Participant)

---

(Signature of Researcher)

The participant has agreed to be contacted for future follow-up in relation to this study.

Yes\_\_\_\_\_ No\_\_\_\_\_



## APPENDIX F: Demographics Information and Interview guide

### Section 1.

#### Demographic and Medical and Physical Activity Information

Participant Number: \_\_\_\_\_

Date: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

Completed education:

Present Occupation: (full time/part time)

How long have you known that you've had hemophilia?

What is your factor level? What type of hemophilia do you have (*expected answer A or B, OR F VIII or IX*)

Current sports / leisure activities (in the past year):

Do you participate regularly? How frequently?

Sports/leisure activities over the past 5 years

What kind of treatment do you usually use for bleeds? (DDAVP, Factor 8 or Factor 9).

*If use DDAVP:*

You say that you usually use DDAVP. Have you ever received F 8 or 9 products?

*(Interviewer notes: May have to prompt them "by Intravenous" and give them some possible brand names)*

Where do you usually receive these treatments (*both DDAVP and factor infusion*)

At home? At a local hospital clinic? At the Hemophilia center.

How many times have you seen the hemophilia care team in the past 5 years for clinic? For possible injuries?

What was the last (musculoskeletal) injury that you can remember that required your attention (including basic first aid or change of activity).

Date, injury, mechanism of injury:

What did you do for this injury? What actions did you take? (prompts: Assess? First aid?, stop activity? Treatment? Contact HTC?)

If you did NOT get DDAVP or factor for that injury, when is the last time that you remember receiving such treatment? Most recent infusion date:

Have you had to miss any days of work / school due to hemophilia over past year:

## **Section 2: Interview on App usage**

### **Participant Use of HIRT?**

What type of smart phone/device do you have?

Initial open ended questions:

Have many times have you used the app over the last 6 months? What do you think of it?

Thinking of your most recent injury, did you use the app? If so, how? can you describe your use of the app?

(Prompts: was your device with you?, did you think of using it?)

How are you in identifying a bleed or being able to differentiate a bleed from a bump/scrape/bruise? Did the app help to determine if the bleed was going to be serious? (i.e. what do you look for? Did you use information in the app or “gut feeling” whether it is bad).

Did you access the assessment document to provide more details about assessing the injury?

Describe how you used the first aid section.

Tell me how you responded to the alarms to re-assess? (Prompts at 1 hour, next day or 2 days?)

Did you contact the HTC through the app? If yes, was this because the app provided the info or would you have done so anyways?

Were there any injuries in which you used the app, which resolved without need of contact with the hemophilia treatment center? If so, can you tell me about it.

Are the steps in this App mostly similar to or mostly different than what you have been previously told to do if injured? If different, how? If similar, how? Could you comment on the format (mobile app) compared to receiving a pamphlet or booklet with the same information.

Now that a mobile app is available, comment on if you are convinced to use it.

Could you rate your level of confidence in managing an injury or bleed now with the use of HIRT?. Could you rate your confidence level before you had the mobile app? Has it changed? (1 being very little confidence and 10 being very confident in managing an injury)

Could you rate your level of confidence on the scale from 1-10 on using the app in the future for your injuries?

What is the most essential feature about the app? Do you think it would be helpful to others with mild hemophilia? Why or why not?

Describe a situation it would be difficult to use the app.

What would make it better? Easier to use?

How did you hear about the App?

**Use of Case Scenarios:**

*Interviewer to read scenario and following the reading allow the participant to choose what they may do with the assistance of HIRT?*

*Goal of this part is to allow the participant to interact with HIRT? and discuss how it would assist in bleed identification and be of possible assistance in these situations.*

**Scenario 1:**

A 20 y.o. soccer player who plays in a weekend men's league suffers a knee to the right thigh injury (near the end of the second half. This was a significantly greater blow than normal with pain at the time of injury, but he was able to walk off the field under his own steam. He was able to walk it off after a few minutes and resume play until the end of the game.

After the game, his leg felt tight and a bit stiff, but all the guys headed out for a post game get together and he joined in. The leg felt a bit stiffer by the end of the evening but

decided to just head home. He noticed a twinge in the thigh when he applied the brakes as he drove home.

The next morning there was some mild stiffness when he moved his knee but he told himself that it wasn't a big deal and he really didn't want to miss work. (*Interviewer Note: Sedentary Job*).

By the end of the day his leg felt OK. He drove home and spent a quiet evening. The next morning (2 days after the injury) he still felt ok. He went out for a walk at lunch time. By the end of the afternoon, his thigh was starting to feel tight again, but he could walk OK and bend his knee without too much pain. He went to watch his nephew play hockey. As he climbed the stairs to his seat at the arena, his thigh was quite sore. He stayed until the end of the game. When he got home, he put some ice on his leg for a while before he went to bed.

By third- day after the initial injury, he was unable to bend his knee without having pain. He couldn't get his jeans on because his thigh was swollen. He called his brother to see what he should do. He had forgotten about the collision at soccer but as his brother began asking him what he had been doing, he remembered the injury. His brother advised him to call the hemophilia care team.

The nurse told him to come to the hospital right away. He said he would have to go in to work for a while, he would come at lunch. By lunch, he was in lots of pain and could hardly walk. None of the guys in his department know that he has hemophilia. He calls his brother to pick him up and take him to the hospital.

*(Discussion prompt: How would **HIRT?** have been useful in this situation?)*

## **Scenario 2:**

A 20 y.o. soccer player who plays in a weekend men's league suffers a knee to the right thigh injury (during the first half). It stung, but he kept playing. At half time he put some ice on it and wrapped it with a tensor. He finished the game. His leg felt OK, so he joined the guys for a postgame get together. By the end of the evening, his leg felt a bit stiff and he noticed a twinge in the thigh each time he applied the brakes.

The next morning there was some mild stiffness when he moved his knee. He told himself that it wasn't a big deal and he really didn't want to miss work at the restaurant. As the day went on, he noticed that his leg was getting more painful and he was having trouble going up and down the stairs. After work, he put some ice on his leg before he went home. When he got home, he used his DDAVP like the hemophilia nurse had shown him. By the time he went to bed, his leg was feeling OK again, although it still looked a bit swollen.

The next day, he went to work as usual. After the lunch service was over, his thigh was throbbing and he could hardly bend his knee. He asked his boss if he could leave, but 2 of the afternoon waiters had called in sick so he had to stay. By 6 p.m. the pain was severe and he was sweating. He couldn't concentrate and started getting orders wrong. Finally his boss allowed him to leave.

He knew he should call the hemophilia nurse, but there was a sports clinic just down the street that was more convenient. He arrived there and had to wait to be seen by the doctor. The doctor gave him a prescription for Ibuprofen and told him to use crutches for a few days.

The next day he was too sore to go to work. He called the hemophilia nurse who yelled at him for not calling sooner.....

*(The interviewer will try to identify if the app gives enough information and prompts to assist in this situation for better injury management.)*

**Final Questions:**

Is there anything else that you would like to add? Anything that I didn't ask about that you think is important? , any final thoughts to share?

Is there anything you would like to ask me?

Would it be okay to contact you to clarify any of the points in our discussion?

If you think of anything after our conversation that you would like to add or clarify please feel free to contact me.

Would you like to receive a summary of findings of this study? Would you prefer Email?

Post?

Email address: \_\_\_\_\_

Mailing address: \_\_\_\_\_

**Section 3: The feedback form in the app.**

Each interviewed participant at this point in the interview will be asked to complete and submit the feedback form.

# APPENDIX G: Google and Apple Downloads

## A. Google Downloads

ALL APPLICATIONS							<a href="#">+ Add new application</a>
APP NAME	PRICE	CURRENT/TOTAL INSTALLS	AVG. RATING / TOTAL NO.	CRASHES & ANRS	LAST UPDATE	STATUS	
HIRT? 1.0	Free	42 / 114	★ 4.00 / 3	1	23 Mar 2015	Published	

Page 1 of 1

TOTAL INSTALLS BY USER ON 18 SEP 2015

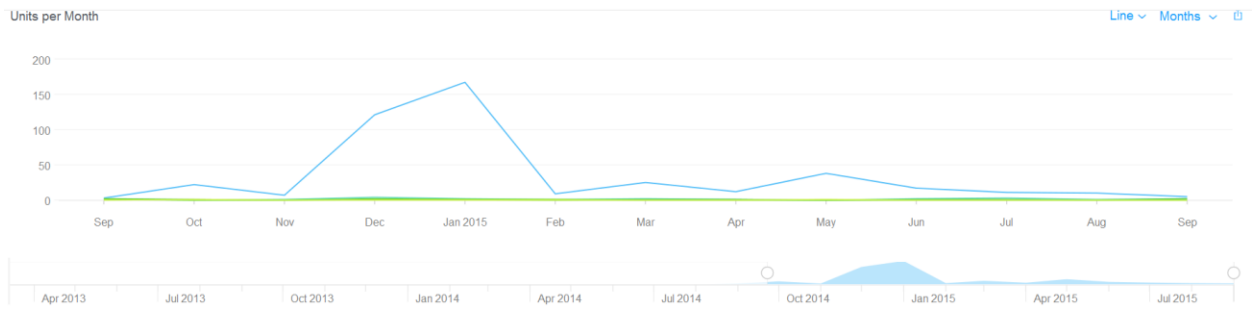


	YOUR APP	ALL APPS IN HEALTH & FITNESS	TOP 10 COUNTRIES FOR HEALTH & FITNESS
<input checked="" type="checkbox"/> Canada	61 53.51%	1.32%	United States 16.97%
<input checked="" type="checkbox"/> United States	16 14.04%	16.97%	South Korea 4.66%
<input checked="" type="checkbox"/> India	13 11.40%	3.48%	Germany 4.28%
<input checked="" type="checkbox"/> France	3 2.63%	2.30%	Brazil 3.84%
<input checked="" type="checkbox"/> Netherlands	3 2.63%	1.13%	India 3.48%
<input checked="" type="checkbox"/> Italy	2 1.75%	2.22%	Russia 3.41%
<input type="checkbox"/> Japan	2 1.75%	3.26%	Japan 3.26%
<input type="checkbox"/> Russia	2 1.75%	3.41%	United Kingdom 2.89%
<input type="checkbox"/> Bangladesh	1 0.88%	0.19%	Spain 2.44%
<input type="checkbox"/> Denmark	1 0.88%	0.26%	France 2.30%
<input type="checkbox"/> Others	10 8.77%		



## B. Apple Downloads

Territory	Units	Previous 365 Days
1 ● United States	264	0 n/a
2 ● Canada	183	0 n/a



Territory	Units	Previous 365 Days
1 ● USA and Canada	447	0 n/a
2 ● Europe	21	0 n/a
3 ● Asia Pacific	12	0 n/a
4 ● Africa, The Middle East, and India	4	0 n/a
5 ● Latin America and The Caribbean	2	0 n/a

## APPENDIX H: Self-report Feedback Survey from the app

Any information received will be confidential and will only be included in a group summary.

Please check one: person with mild hemophilia, a family member or a health care professional

1. How easy was it to get the app? 5-0 scale with “easy”-“Not at all easy”
2. Using this app, DID you: Y/N
  - a. Assess the injury
  - b. Apply first aid
    - i. Compression
    - ii. Rest
    - iii. Elevation
    - iv. Ice
  - c. Contact the treatment center
  - d. Ignore the injury
3. If you had never seen this app, indicate what you **would** have done with this injury Y/N
  - a. Assess the injury
  - b. Apply first aid
    - i. Compression
    - ii. Rest
    - iii. Elevation
    - iv. Ice
  - c. Contact the treatment center
  - d. Ignore the injury
4. By using this app, do you feel your ability to manage your injury was : scale “much better , same as I would have done , worse” Use a scale 5-0
5. Would you use this app again? “Definitely” –“no”, scale 5-0
6. Any comments: **(Put comment box)**  
If you wish to have a response to your comment or question, please include a method of contact, either email or phone.

Thanks for your participation!