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Conroy, S., Keldsen, L., Harcum, S., Washington, C., Nazi, K., Zhan, M., & Bever, C. (2018). A unique approach to upper extremity motor rehabilitation: VA secure messaging and translating post-stroke arm rehabilitation to a telerehabilitation format. *American Society of Neurorehabilitation*, *Neurorehabilitation and Neural Repair*, 32(3), 254-255. doi: 10.1177/1545968318772594

Nahm, E-S., Zhu, S., Bellantoni, M., Keldsen, L., Charters, K., Russomanno, V., ... Smith, L. (2018). Patient portal use among older adults: What is really happening nationwide? *Journal of Applied Gerontology*, 0(00), 1-7. doi: 10.1177/073346487 18776125

Nahm, E-S., Zhu, S., Bellantoni, M., Keldsen, L., Russomanno, V., Rietschel, M., ... Smith, L. (2018). The effects of a theory-based patient portal elearning program for older adults with chronic illnesses. *Telemedicine and e-Health*, 2(suppl_1), 731-742. doi: 10.1089.tmj.2018.0184

Conroy, S., Harcum, S., Keldsen, L., & Bever, C. (2020). Novel use of existing technology: A preliminary study of patient portal use for telerehabilitation. *J Telemedicine and Telecare*, (in press).

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**Abstract**

Title of Dissertation: Expanding Post-Stroke Telerehabilitation: A Qualitative Study of User Experience Piloting VA Secure Messaging Use in a Telerehabilitation Format

Linda M. Keldsen, Doctor of Philosophy, 2020

Dissertation Directed by Carla Storr, ScD, MPH, Co-Director, Center of Excellence in Health Outcomes Research, Professor, Family & Community Health

BACKGROUND: Stroke is the fourth leading cause of death and primary cause of long-term disability in the U.S. As many as 40% of stroke survivors are discharged home without any inpatient or outpatient comprehensive stroke rehabilitation leading to the need for continued care for basic activities of daily living (grooming, toileting and feeding). Barriers to post-discharge comprehensive stroke rehabilitation are distance to travel, lack of transportation and inadequate social support. Telerehabilitation has been suggested as a possible solution for the delivery of low cost, convenient, home-based rehabilitative care.

OBJECTIVE: To understand the experience of researchers and stroke survivors piloting the use of the My Health***e***Vet personal health record and secure messaging for stroke telerehabilitation.

METHODS: A retrospective qualitative study using semi-structured interviews with a convenience sample of five study participants from the intervention arm of VA funded stroke rehabilitation single-blinded randomized controlled trail was conducted in addition to a focus group of three of the research team members. A descriptive phenomenological approach was used to describe the study participants and selected research team members experience using the VA's My Health***e***Vet personal health record and secure messaging in telerehabilitation research.

RESULTS: Researchers and study participants reported benefits from using the My Health***e***Vet personal health record with secure messaging that included the ability to send and or respond to secure messages at a time and place of their choosing, flexibility in scheduling the time of their therapy, ability to use any internet-enable device to access their My Health***e***Vet account, and the ability to retrieve and reread or watch education provided by the therapist when needed. Barriers to use were outweighed by the increased flexibility in scheduling, feeling empowered and having caregiver support.

CONCLUSIONS: This small feasibility pilot suggests My Health***e***Vet with secure messaging may be an appropriate telecommunication tool for telerehabilitation. The

study researchers caution that this was a small pilot and consideration should be given to ensuring adequate resources to support a larger study panel if expanded.

KEY WORDS: My Health*e*Vet, secure messaging, telerehabilitation, stroke, personal health records

# Expanding Post-Stroke Telerehabilitation: A Qualitative Study of User Experience Piloting VA Secure Messaging Use in a Telerehabilitation Format

by
Linda M. Keldsen, 2020

Dissertation submitted to the Faculty of the Graduate School of the
University of Maryland, Baltimore in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
2020

## Dedication

To Mrs. Ruth Hahn, my third-grade teacher, who served as a guide and inspiration for a little girl whose mind was always questing for new information. She kindled the flame of a budding scientist by encouraging her to enter her first science fair. Mrs. Hahn's influence lives on although she has been gone for almost half a century. It is teachers like Mrs. Hahn who nourish young minds and see the potential that lives within them. That same dedication to finding the best in their students is emulated by my amazing professors at the University of Maryland School of Nursing, without whom I would not have believed this was even possible. I must devote most of the credit to getting me to where I am today to Dr. Eun-Shim Nahm, Dr. Carla Storr and Dr. Margaret 'Meg' Johantgen. To Dr. Nahm for kindling the idea of using the My Health***e***Vet patient portal and secure messaging as a research tool. Without her I may not have made the necessary leap of imagination that has culminated in this work. To Dr. Storr for stepping into the breach and taking on a student in a field totally outside of her usual area of work because she knew she could give that student the room she needed to make her vision happen, and last but not least Dr. Johantgen. One of the wisest women in education that I know who looked at this budding scientist and said 'what do you want to do' and when I told her what it was, she just said "do it." Without their faith in me and a bit of prodding along the way I might still be writing instead of doing. Lastly, I dedicate this to my family, and most especially my husband Don and daughter Amara who have walked this journey with me.

## Acknowledgements

I would like to acknowledge several individuals and groups who facilitated this research and my doctoral study through their support, encouragement, and guidance. I wish to acknowledge the men and women from the Office of Research & Development, Office of Connected Care and the My Health***e***Vet Program Office who were instrumental in working with the telerehabilitation research team to initiate new regulations, rules and procedures allowing the use of My Health***e***Vet and Secure Messaging as a tool for intervention research. I especially want to acknowledge Dr. Kim Nazi and Ms. Lisa Kendziora for their invaluable help and guidance as we were collaborating to create the first telerehabilitation secure messaging feasibility pilot.

I wish to thank my dissertation committee, who each contributed in a unique way to my learning and collectively provided the guidance and expertise essential to accomplishing this research. My committee chair, Carla Storr, ScD, MPH is the quintessential mentor. Her energy, accessibility, warmth, and absolute commitment to student learning are unparalleled. I will treasure the time and patience she has given me, her mentorship and support and the perseverance to do the best that I can. Debra Scrandis, PhD, CRNP-F, CRNP-PMH kindled my curiosity in qualitative research and taught me that the story is often as critical to understanding our patients' behavior and outcomes as what is going on at the cellular level. Charlotte Seckman, PhD, RN-BC, CNE, FAAN graciously gave of her expertise and ensured that clarity of thought reigned throughout this study. Christopher Bever, Jr., M.D., M.B.A. provided me with an incredible opportunity to participate in his research trial and Susan Conroy, DSc., PT welcomed me as part of the team while I merged my work experience with my research interest and was a gracious mentor throughout the entire experience. With Dr. Bever’s and Dr. Conroy’s consent I was able to complete my dissertation research by creating a qualitative study that enhances their parent study. I am profoundly grateful to my committee for sharing their expertise with me and for guiding and encouraging me throughout this journey.

I am also deeply grateful to the five stroke survivors who willingly told me their stories. Without their generous gift of time and openness in sharing their experiences with home-based telerehabilitation, this research would not be possible.

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## List of Abbreviations

| | |
|---|---|
| CSR | Comprehensive stroke telerehabilitation |
| DOD | Department of Defense |
| EHR | Electronic health record |
| HITECH | Health Information Technology for Economic and Clinical Health Act |
| ICT | Information communication technology |
| MHV | My Health***e***Vet |
| ONC | Office of the National Coordinator for Health Information Technology |
| OPM | Office of Personnel Management |
| PEoU | Perceived ease of use |
| PGHD | Patient generated health data |
| PHR | Personal Health Record |
| PP | Patient portal |
| PBC | Perceived behavioral control |
| PU | Perceived Usefulness |
| SCT | Social cognitive theory |
| SM | Secure message or securing messaging |
| TAM | Technology acceptance model |
| TR | Telerehabilitation/home-based telerehabilitation |
| TPB | Theory of planned behavior |
| VA | Veterans Administration |

## List of Abbreviations

| | |
|---|---|
| VHA | Veterans Health Administration |
| VR | Virtual reality |
| VRE | Virtual reality environment |
| VTC | Video teleconferencing |

# CHAPTER 1
# INTRODUCTION

## Background

Stroke is the fourth leading cause of death and primary cause of long-term disability in the U.S. affecting approximately 795,000 people annually, of whom greater than 15,000 are Veterans (Akbik et al., 2017; Centers for Disease Control and Prevention, 2015; Griffin & Hickey, 2013; Kurichi et al., 2014; National Institute of Neurological Disorders and Stroke, 2012). There are approximately seven million stroke survivors in the U.S. with treatment costs of $68.9 billion annually; expected to triple to $240.67 billion by 2030 (Wolf et al., 2015). Only 10% of stroke survivors recover completely (Wolf et al., 2015), while 80% have some degree of persistent hemiparesis and as many as 65% have upper limb deficits impacting their ability to perform activities of daily living, work and leisure (Connell, McMahon, & Adams, 2014; Kairy et al., 2016; Koh et al., 2015; Langan, DeLave, Phillips, Pangilinan, & Brown, 2013; Lutz, Chumbler, Lyles, Hoffman, & Kobb, 2009). Upper extremity motor impairments include changes in muscle tone, weakness or contracture, joint laxity and impaired muscle control giving rise to disabilities in reaching, grasping, gross and fine motor control (Hatem et al., 2016).

Recent reports demonstrate that as many as 40% of stroke survivors are discharged directly to home, after a median length of stay of four days, without any inpatient or outpatient stroke rehabilitation services (Bettger et al., 2015; Hall, Levant, & DeFrances, 2012; Lutz et al., 2017; MedPac, 2018; Winstein et al., 2016). For the approximately 24% who are treated in a post-acute inpatient stroke rehabilitation program the average length of stay is 15.4 days and comprehensive stroke rehabilitation (CSR) does not mediate the loss of mobility and functional independence experienced by the stroke survivor (MedPac, 2018; Tenforde, Hefner, Kodish-

Wachs, Iaccarino, & Paganoni, 2017). At discharge, the stroke survivor requires continued assistance with basic activities of daily living (grooming, toileting, and feeding) and are often unable to return to pre-stroke activities without continued specialized CSR services (Bakas, McCarthy, & Miller, 2017; Cherry et al., 2015; Lutz et al., 2017). Barriers to post-discharge CSR services include distance to travel from the stroke survivor's home, lack of reliable and/or affordable transportation, insufficient insurance coverage, and inadequate social support (Chen et al., 2015; Cherry et al., 2015; Chumbler et al., 2010, 2015; Tenforde et al., 2017; Wolf et al., 2015). Stroke survivors living in rural or geographically remote locales are at higher risk of living with permanent disability and loss of function due to lack of access to CSR services (Ricker et al., 2002). This may be especially true for veterans where approximately 30% live one-hour from the nearest VA medical center (Cherry et al., 2015).

Participation in a CSR program has the greatest impact on improving function, outcomes and health-related quality of life among those suffering a stroke (Chen et al., 2015; Henrique, Silva, Yano, Ananda, & Rego, 2015; Llorens, Noe, Colomer, & Alcaniz, 2015; NIH Medical Rehabilitation Coordinating Committee, 2017; Peretti, Amenta, Tayebati, Nittari, & Mahdi, 2017). The cost or distance to travel to CSR programs often prohibits veteran stroke survivors from receiving high quality, professional, supervised CSR, negatively impacting their recovery (Chen et al., 2015; Cherry et al., 2015; Chumbler et al., 2015; Chumbler et al., 2010). Home-based stroke rehabilitation has been proposed as an alternative to costly inpatient stroke rehabilitation, capitalizing on the advent of telerehabilitation technologies that increase access and convenience of services to the stroke patient (Kairy et al., 2016; Mayo, 2016; Marco Rogante, Grigioni, Cordella, & Giacomozzi, 2010; Schwamm et al., 2017). Telerehabilitation

(TR) is defined as the provision of *conventional* rehabilitation services (e.g., interview, physical assessment, diagnosis, intervention, maintenance activities, consultation, education and training) at a distance, using telecommunication technology as the service delivery medium (Brennan et al., 2010; Russell, 2009) thereby improving access to support independent living.

Providing rehabilitation services remotely advances the TR agenda by expanding services to medically underserved areas; enlarging the scope of rehabilitation using increasingly sophisticated communication technologies; improving health-related quality of life; reducing transportation costs by expanding access without increasing the number of providers; and reducing or eliminating travel time (Buzza et al., 2011; Laver et al., 2013; Linder et al., 2015; Marco Rogante et al., 2010; Washington, Bean-Mayberry, Riopelle, & Yano, 2011). TR has the capacity to be delivered across the breadth of points of service to include: clinics, homes, schools, healthcare centers and community-based worksites, as well as providing a broad scope of services (e.g., tele speech, tele occupational therapy, tele physical therapy, etc.) (Brennan et al., 2010; Lai, Woo, Hui, & Chan, 2004).

**Central Research Problem**

Current stroke telerehabilitation research has largely focused on technology used in an operative context (robotics or virtual reality) or the methodological or clinical aspects of rehabilitation (Marco Rogante et al., 2010). Stroke telerehabilitation has limited the focus of telehealth communication to telemonitoring, phone-based interactive voice-response systems, implantable devices transmitting hemodynamic data and electronic equipment that collects and transmits biometric information (Schwamm, 2014; Schwamm et al., 2017). There have been no published reports as to whether a home-based stroke telerehabilitation intervention can be successfully delivered by a remote therapist using an organizationally sponsored internet-based personal health record with secure messaging (SM) to communicate with the study participant.

**Purpose**

The purpose of this qualitative study was to examine the experience of VHA researchers and stroke survivors piloting the use of VHA's internet-based My Health***e***Vet secure messaging and to develop insights into the interaction of technology and the delivery of home-based telerehabilitation (TR). This qualitative study employed in-depth unstructured interviews and a focus group. A rigorous and systematic methodology for descriptive phenomenology was used to generate themes emerging from the analysis of the interview data. The study aimed to explore the experiences and perspectives of the researchers and patients in the use of four PHR features that could inform the design and implementation of future studies using information communication technology: electronic communication using secure messaging; patient health education resources; tools enabling the patient to track and self-report data; and the process for submission of self-reported data.

Creating a greater understanding of the stroke survivors' experience and perception of the usefulness of home-based TR will bring new insights into the dyadic communication relationship created by using an internet-based PHR with secure messaging as the service delivery medium for stroke rehabilitation. Successful implementation of the My Health***e***Vet PHR with secure messaging for telerehabilitation has the potential for creating new opportunities for the delivery of low-cost TR interventions alone, or in combination with other information communication technologies (ICT).

**Significance**

A recent study demonstrated as many as 40% of stroke survivors do not receive comprehensive stroke care in the post-acute period (Bettger et al., 2015). Stroke survivors living in rural or geographically remote locales are at higher risk of living with permanent disability and loss of function due to lack of access to CSR services (Ricker et al., 2002). As many as 50% of veterans travel 50 miles or more to seek treatment at a Department of Veterans Affairs (VA) medical facility (Schooley, Horan, Lee, & West, 2010). VHA has sought a solution to providing equitable, convenient, high quality telerehabilitation services to veterans. Home-based TR is an alternative to costly inpatient stroke rehabilitation, having the potential to increase access to medically underserved individuals with disabilities residing, bridging gaps in health services and providing an avenue to promote the safety and independent functioning of stroke survivors (Chen et al., 2015; Chumbler et al., 2010; Demiris, Shigaki, & Schopp, 2005; Kairy et al., 2016; Rogante et al., 2010; Tousignant, Boissy, Corriveau, Moffet, & Cabana, 2009). The stroke survivors' natural environment becomes the new locus of care. Easy to use home-based TR services whose design incorporates lessons learned from qualitative studies evaluating the stroke survivors' lived experience could fundamentally change routine care and the rehabilitation process (Chumbler, Haggstrom, & Saleem, 2011; Rogante, Silvestri, Bufano, Paone, & Macellari, 2006). The researchers' role in harnessing advanced ICT skills, multi-media education tools and new workflow processes must be fully explored to provide designers of home-based TR valuable data and information to create new models of TR care. The nursing informaticist is uniquely positioned to assist in the design and implementation of new modes of telerehabilitative care that captures meaningful data while ensuring the usability of the ICT system (Irizarry, De Vito Dabbs, Curran, DeVito Dabbs, & Curran, 2015).

**Research Questions**

The aim of this qualitative study was to explore the experiences and perspectives of researchers and patients piloting the use of an internet based PHR system with secure messaging (My Health***e***Vet). Question three has been refined to reflect the emerging findings and conclusions of the researchers and study participants.

**RQ1.** How have different kinds of health care professionals (physicians, physical therapists, exercise physiologist, etc.) within VHA experienced the use of the PHR patient portal, including 1) electronic communication via secure messaging; 2) attaching tools to support patient tracking of self-reported data; 3) attaching education to support patient performance of rehabilitation tasks; and 4) retrieving patient self-reported data?

1.1 What are the experiences of the health care professionals with patient use of PHR patient portal and the four features?

1.2 How do health care professionals report having engaged with patients in the use of the PHR patient portal and the four features?

1.3 How do the health care professionals experience their own use of the four features?

1.4 How do the health care professionals perceive the usefulness of the four features?

1.5 What is the health care professionals experience in incorporating the use of PHR into their work practices?

**RQ2.** How has the research patient experienced the use of the PHR patient portal, including 1) electronic communication via secure messaging; 2) attaching tools to report patient tracking of self-reported data; 3) retrieving education to support patient performance of rehabilitation tasks; and 4) retrieving tools to report patient self-reported data?

2.1 What are the experiences of the research patient with the use of the PHR patient portal and the four features?

2.2 How do research patients report having engaged with the researchers in the use of the PHR patient portal and the four features?

2.3 How do the research patients experience their own use of the four features?

2.4 How do the research patients perceive the usefulness of each of the four features?

2.5 What are the research patients' experiences incorporating the use of PHR into their daily life?

**RQ3.** Based on the reported experiences of health care professionals and study subjects was the PHR patient portal an effective method of communication?

3.1 Was the PHR patient portal viewed as easy to use?

3.2 Were there specific features that were viewed as helpful to either providers or study subjects?

3.3 Were there specific features that were viewed as cumbersome or unhelpful by either group?

**Organization of Dissertation Chapters**

The remainder of this dissertation is organized as follows: Chapter 2 provides a summary of the relevant literature to include a review of telerehabilitation technologies, electronic communication, and the use of secure messaging in research and telerehabilitation. The second part of the Chapter 2 provides an overview of two theoretical models used widely in technology acceptance research; Bandura's Social Cognitive Theory and Davis's Technology Acceptance Model (TAM) and a brief overview of conceptual frameworks to include the Social Cognitive Theory, Self-efficacy Theory, Theory of Planned Behavior, implementation science and their role in the spread and use of telerehabilitation. Chapter 3 details the central assumptions considered in the process of selecting the qualitative methodology used in this study. The design, setting, details the characteristics of the study participants and the data management plan are also laid out in this chapter. Chapter 4 describes the data collection and study findings focusing primarily on the participant's experience using the My Health***e***Vet secure messaging and the findings from the focus group, which largely entail the pre-work needed prior to study implementation. Chapter 5 provides an analysis, interpretation and synthesis of the findings as well as describing any limitations, future directions for further research and conclusions based on the study findings.

# CHAPTER 2
# REVIEW OF LITERATURE

## Introduction

The first part of this chapter provides a summary of the relevant literature exploring the development of telehealth and telerehabilitation in the Veterans Health Administration (VHA) and the use and impact of an organizationally supported personal health record with secure messaging (My Health***e***Vet) in VA healthcare. A summary of current evidence about the impact of telerehabilitation and internet-based personal health records with secure messaging in health care research will be presented. In the second part of this chapter relevant theoretical frameworks will be reviewed to include Bandura's social cognitive theory, self-efficacy, and Davis' technology acceptance model.

The Veterans Health Administration (VHA) is the largest integrated health system in the United States with over 1400 sites of care including 150 medical centers, 819 outpatient clinics, 300 vet centers, and 132 community living centers serving approximately 9 million veterans out of a total population of 21.9 million (National Center for Veterans Analysis and Statistics, 2014). The Veterans Administration Central Office (VACO) leads the organization and is headed by the Secretary of Veterans Affairs, Undersecretary for Health, and members of the senior executive leadership. All funding is through congressional appropriations (Department of Veterans Affairs, 2021).

## Reengineering VA Care

The Department of Veterans Affairs (VA) has been on the cutting edge of telehealth from as early as 1959, when it first delivered telemental health services between the University of Nebraska Medical School and the Omaha VA Medical Center (Darkins, 2014). VHA's early efforts to expand telehealth began with demonstration projects at individual VA medical centers, funded by local and federal grants. The success of those projects led to a nationally driven systems approach to telehealth care. VHA's telehealth expansion envisioned a 'multimedia health record' and communication platform that allowed the sharing the Veteran's electronic health record across all 150 medical centers and increasing numbers of community-based outpatient clinics, creating a seamless health care delivery system (Darkins, 2014). The expansion required the development of wide area networks (WANs) and telecommunication connectivity via integrated services digital network (ISDN) circuits with a video bridge and operator assistance allowing for local and national consultations to occur between VA clinicians, regardless of time or distance. As part of this innovative re-engineering, the VA sequentially implemented care coordination home telehealth (CCHT), clinical video teleconferencing (CVT) and store forward telehealth (SFT) (Darkins, 2014). This led to the VA piloting a range of telehealth services that included digital radiology, teledermatology, telemental health and telerehabilitation care among others (Table 1)

Table 1. Veterans Health Administration Telehealth Programs

| Program Name | |
|---|---|
| Teleaddiction Services | TeleAmputation Care |
| TeleAudiology | TeleBipoloar Disorder |
| TeleCardiology | TeleDental Care |
| TeleDermatology | TeleCardiology |
| TeleChaplian | TeleDentistry |
| Teleepilepsy | TeleGastrointestinal/Hepatitis Cae |
| TeleIntensive Care | TeleKinesiology |
| TeleMental Health | TeleMOVE! Weight Management |
| TeleNephrology | TeleNeurologoy |
| TeleNutrition | TeleRetinal Imaging |
| TeleRetinal Imaging | TeleOccupational Therapy |
| TelePain Management | TelePathology |
| TelePodiatry | TelePolytrauma Care |
| TelePrimary Care | TelePulmonology |
| TeleRehabilitation | TeleSchizophrenia |

(Darkins, 2014). Working in tandem, the leadership of VACO directed VHA's Office of Rural Health, Office of Policy and Office of Research and Development to work cooperatively to conduct, coordinate, promote and disseminate research into areas affecting veterans living in underserved areas of the United States (Department of Veterans Affairs, 2021; Department of Veterans Affairs, 2013). The U.S. Department of Veterans Affairs (VA) actively pursued an agenda to make the veterans' home and local community the preferred site of care through the provision of a broad array of telehealth services since 1994 (Darkins, 2014). VA actively pursued its agenda to make the

Veterans' home and local community the preferred site of care by capitalizing on the use of ICT to deliver care and treatment to the right patient at the right time and place when it was most needed (Chumbler et al., 2011; Darkins, 2014). The VA's aim was to

eliminate or reduce the veterans' travel burden while ensuring they received high quality care without diminution of services (Darkins, 2014). By the end of 2017, approximately 2.2 million telehealth episodes of care were completed with forty-five percent of the treated veterans living in rural areas (U.S. Department of Veterans Affairs & VHA Office of Connected Care, 2015; Department of Veterans Affairs, 2013).

Telerehabilitation (TR) also has a distinct advantage over facility based rehabilitation programs as it allows for the delivery of conventional rehabilitation therapy in the patient's home environment, which is associated with improved outcomes (Akbik et al., 2017; Gregory, Alexander, & Satinsky, 2011a; McCue, Fairman, & Pramuka, 2010) while providing services spanning the lifespan of patients and the continuum of care (Brennan et al., 2010). New research findings suggest that stroke survivors can benefit from rehabilitative services long after the initial neurological insult (Park, Kim, Winstein, Gordon, & Schweighofer, 2016; Wu, Guarino, Lo, Peduzzi, & Wininger, 2016) and the provision of continued supportive home-based TR therapy may promote functional improvement following discharge from CSR programs (Schneider, Lannin, Ada & Schmidt, 2016; Winstein et al., 2016; Winters, 2002). Kwakkel, et al., (2004) noted improvement in performance of activities of daily living with additional skills practice and

Veerbeek, et al., (2011) noted improved walking ability in individuals who received extra limb rehabilitation within 6 months of stroke. English and Veerbeek (2015) suggested caution when reviewing reports, suggesting that more rehabilitation services or ‘time’ devoted to additional practice must be dedicated to a task-specific practice to achieve improved functional outcome.

The success of telehealth has led to innovations in diverse areas of health care to include rehabilitation and telerehabilitation. Telerehabilitation has emerged as a growing branch of telehealth to deliver the components of traditional rehabilitation (e.g., interview, physical assessment, diagnosis, intervention, maintenance activities, consultation, education and training) (Brennan et al., 2010; Russell, 2009) using a broad range of ICTs. Developing rapport, engaging family and other caregivers in the process helps to frame the goals of TR by addressing the expectations of the patient and their support system (Pramuka & van Roosmalen, 2009). Conversely, TR also creates challenges in establishing a therapeutic relationship with the patient impacting the use of touch and demonstrating a shared commitment to assisting the patient to reach goals (Pramuka & van Roosmalen, 2009). Therapists and support staff must be sensitized to the need to modify materials, communication methods and education techniques to accommodate to the needs of the stroke survivor who may have speech or cognitive deficits requiring simplified demonstration of what is expected rather than a course-based instruction (Brennan & Barker, 2008). This premise is most easily illustrated when teaching to a task. Watching a video that demonstrates how to pick up an object and place it in the right container may be much easier than asking the patient to read a description of what you would like them to do. As the patient progresses, home-based TR may be effective in maintaining or improving functional status to a point where more complex levels of rehabilitation therapy can be introduced, especially in patients with chronic stroke (Hughes et al., 2014; Mawson & Mountain, 2011; Tenforde et al., 2017). Optimizing home-based TR strategies may provide a mechanism for increasing the dose and frequency of therapy without an increase in face-to-face supervision of the disabled individual (Laver et al., 2013; Winters, 2002). Randomized control trials demonstrate stroke survivors engaged in higher doses of intensive repetitive exercises have better outcomes than those who do not in the post-acute period (Chen et al., 2018; Lin, Finklestein & Cramer, 2018; Chumbler et al., 2012; Hassett et al., 2016; Redzuan, Engkasan, Mazlan, & Abdullah, 2012).

Telerehabilitation (TR) has widely embraced clinical video teleconferencing (CVT) systems as it allows for real-time interaction between the clinician and client (Finkelstein et al., 2012.; Gregory, Alexander, & Satinsky, 2011b; Piron et al., 2008). Piron, et al. (2009), reported in a randomized controlled trial of stroke patients with upper extremity deficits that use of CVT, in combination with virtual reality training, resulted in significantly improved outcome scores and motor performance. While TR via CVT may address barriers created by distance between specialized urban health centers and rural communities there are also detractors. Lack of access to affordable high-speed internet often means the individuals who would benefit the most from TR via CVT are the least likely to receive it. Motion assessments commonly performed during TR for gait, fine motor and gross motor skills can be severely degraded when assessed by a videorecording system operated at lower bandwidths versus higher bandwidths (Tan, Narayanan, Koh, Kyaw, & Hoenig, 2014). As of 2019, approximately two-thirds (63%) of rural Americans had access to broadband internet as compared to 79% of suburban households and rural

Americans are still less likely to own smartphones, tablets or desktop computers than their non-rural counterparts (Perrin, 2019.).

Newer and more complex telecommunication technologies include mobile health applications, wearable sensors (e.g., actigraphy, accelerometers, sleep sensing and gyroscopes, etc.), virtual reality (gait analysis, exercise, and balance monitoring), remote monitoring of biometric parameters (e.g., weight, blood pressure, heart rate, and pulse oximetry), and nanotechnology (Dobkin, 2017; Patel, Park, Bonato, Chan, & Rodgers, 2012; Russell, 2009; Tousignant et al., 2014; Winstein et al., 2016). Recently, store forward telehealth (SFT) technology has been used in TR as it allows for the asynchronous capture and review of data and images thus providing the therapist the opportunity to compare new findings with previous results (Chumbler et al., 2012; Hageman, 2016; Iacono, Stagg, Pearce, & Hulme Chambers, 2016). Virtual reality, wearable sensors, mobile applications, robotic assistive devices and text messaging are also being integrated into the design of telerehabilitation programs (Cuesta-Vargas & Roldán-Jiménez, 2016; Dobkin, 2017; Kairy et al., 2016; Linder et al., 2013; Llorens, Noe, Colomer, & Alcaniz, 2015). A variety of internet enabled devices (e.g., smart phones, iPads, tablets, desktop computers, laptops and gaming systems) can be used to provide distance support, data collection and information exchange (Free et al., 2013; Kvedar, Coye, & Everett, 2014; Pandor et al., 2013; Patel et al., 2012). Examples of common ICTs employed for TR communication include live interactive video conferencing (Dixon, 2010; Koh et al., 2015; Sutcliffe et al., 2011), video conferencing using a videophone or teleconferencing using a standard voice line or personal smart phone (Sutcliffe et al., 2011). While overall access to home-based TR has expanded due to innovations in sensor, image and virtual environment technology there is also evidence that all technology may not be appropriate for use with all disabled persons (Russell, 2009; Tan et al., 2014).

The use of gaming consoles in stroke telerehabilitation has reached prominence and requires a combination of devices and applications such as Microsoft Kinect, which is described as a motion input sensing device (Llorens, Noe, Colomer, Alcaniz, et al., 2015; Putrino, 2014). In addition to Microsoft Kinect the stroke survivor (SS) must also have access to a computer or laptop and a television to display the virtual environment he/she will be working in (Llorens, Noe, Colomer, Alcaniz, et al., 2015). Other gaming consoles that have been successfully used in stroke rehabilitation include Leap Motion or Wii (Carregosa et al., 2018; McNulty et al., 2015; Putrino, 2014). One area that ***has not*** been widely explored for use in home-based TR is internet-based personal health records with secure messaging.

**MyHealth*e*Vet**

Telerehabilitation and web-based patient portals with (PHR) and secure messaging (SM) have the potential to be integrated and serve as an asynchronous and interactive depository for the collection and sharing of remote data directly from the user. The Department of Veterans Affairs (VA) introduced the internet-based My Health***e***Vet (MHV) patient portal in 2003 (Nazi et al., 2010). The VA aggressively promoted this new tool as a complement to traditional face-to-face services; a mechanism to engage patients and families to play a more active role in the veteran's health and to promote patient-provider communication (Haun et al., 2014; Shimada et al., 2013; Zhou, Kanter, & Wang, 2010). As of December 2019, the VA reported more than 5.2 million MHV registered users out of a total estimated veteran pool of 20.4 million U.S. Veterans

(Bialik, 2017) and during the period July 2019 – Dec 2019 there were an average of 7.25 million visits per month to the MHV patient portal.

The My Health***e***Vet patient portal is the repository of an extensive Veterans Health Library that contains vetted digital, print and video material that is accessible to anyone with an internet connection (Nazi, 2013). An online account to the My Health***e***Vet patient portal is not required to access these materials. The materials are further enhanced with individual URL links that can be embedded in SMs and sent to a patient for easy access and use. Research literature is replete with comments about the need to provide education to the end users of patient portals (Nahm et al., 2018). Older adults are a particularly vulnerable population due to the number and complexity of chronic health conditions they may receive treatment for and the variety and number of health care providers they receive care from. Each provider may have their own patient portal with PHR and SM, thus requiring the patient to remember numerous URL addresses and usernames/password combinations. Additionally, patients often comment that there is no uniformity in the design of PHR thus making navigation more difficulty because usability and usefulness may be compromised by poor design (Nahm et al., 2018). The My Health***e***Vet patient portal has recently undergone a major redesign due to complaints about ease of use and navigability. The users' experience with navigating the patient portal, personal health record features and SM will inform future research into the usability and ease of use of MHV and SM. Prior experience with PHRs may be reflected in the users' perceived self-efficacy in their ability to successfully use the technology.

**Internet-based Portals**

Personal Health Records (PHRs), as defined by the Markle Foundation, are "an electronic application through which individuals can access, manage, and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment" (Markle Foundation, 2003). Integrated PHRs promote active, ongoing patient collaboration in care delivery and decision making (Klein, 2007; Ralston et al., 2009). PHRs may be tethered to a single provider or organization's electronic health record (EHR) enabling information from the EHR to populate the PHR or as a standalone product such as Google Health or Microsoft HealthVault (Avancha, Baxi, & Kotz, 2012; Tang, Ash, Bates, Overhage, & Sands, 2006). PHRs are largely designed to promote active engagement of patients and their families in the management of their own health information, care coordination and for communication with their providers using secure messaging without reference to time of day, distance or location, as long as an internet enabled device is available (Detmer, Bloomrosen, Raymond, & Tang, 2008; Mandl, Kohane, & Brandt, 1998; Pagliari, Detmer, & Singleton, 2007; Tang et al., 2006; Ford, Hesse, & Huerta, 2016; Ahern, Woods, Lightowler, Finley, & Houston, 2011; Byrne, Elliott, & Firek, 2009; Dixon, 2010; Haun et al., 2014; North et al., 2014; Otte-Trojel et al., 2015). Secure messaging is a dedicated ICT system that requires unique identifiers and log-in procedures to maintain the confidentiality and security of the communication between patient and provider and unlike e-mail that may be hosted on any internet-based platform (e.g., Gmail.com, AOL.com, etc.) (McGeady, Kujala, & Ilvonen, 2008; Wakefield et al., 2010; Byrne, Elliott, & Firek, 2009). Secure messaging (SM) is defined as "any electronic communication between a provider and patient that ensures only those parties can access the communication. The electronic message could be e-mail or the electronic messaging function of a personal health record, online patient portal, or any other electronic means" (Centers for Medicare & Medicaid Services, 2014). Tethered PHRs often include access to patient education materials, medication lists, appointment reminders, and the ability to view, download and transmit data from their provider managed EHR (Ford et al., 2016). While approximately 70 million people in the United States have access to a patient portal with PHR, the nationwide adoption rates vary across health care organizations and have been reported as low as 26.8%; with the VA reporting MHV registration rates over 51% (Agarwal et al., 2013; Bialik, 2017; Ford et al., 2016; Nahm et al., 2018; Tenforde et al., 2011). While approximately 7% of the American population have used a patient portal with PHR one time (Agarwal et al., 2013). In a study of a group practice with 175,909 enrollees, 29% (51,500) registered for the web-based patient portal with SM, whereas only 14% (25,075) exchanged at least one SM thread with their health care provider (Ralston et al., 2009). Ralston et al. also noted that patients were more likely to use SM if their providers had higher levels of SM use. In December 2019 alone 283,000 (25%) veterans sent a secure message to their provider and 556,000 (50%) requested prescription refills. Since its inception in June 2008 over 91 million secure messages have been initiated by VA patients and their health care teams using the MHV secure messaging feature (Bialik, 2017).

Some studies have noted that actual patient use of PHR and SM with their health care providers is only 2-9% (Olson, O'Brien, Rogers, & Charness, 2011; Porter & Donthu, 2006). In a Norwegian study of 6 providers and 200 patients there was a significant drop in face-to-face visits with the introduction and use of secure messaging (Bergmo, Kummervold, Gammon, & Dahl, 2005). In a study employing Kaiser Permanente HealthConnect there was an approximately 10% drop in patient visits with the implementation of secure messaging among 3000 patient users (Zhou et al., 2007) whereas another Kaiser study showed a significant increase of 0.7 visits per year after implementation of secure messaging (Palen, Ross, Powers, & Stanley, 2012). North, et al., (2014) found a statistically insignificant change in face-to-face visits in a study of 2,357 patients after the implementation of secure messaging and e-visits. Reid et al. (2009) demonstrated higher use of secure messaging within a medical home demonstration project in a Group Health Cooperative resulted in fewer emergency department visits. Wade-Vuturo, Mayberry and Osborn (2013) demonstrated that higher self-reported use of secure messaging in medical appointment management was associated with improved glycemic control ($\rho = -0.29$, $p = 0.04$) (Ralston et al., 2009). Using Healthcare Effectiveness Data and Information Set (HEDIS), Kaiser was able to demonstrate the effectiveness of the use of secure patient-physician e-mail on the screening and control of glycemia (HbA1c), cholesterol, and blood pressure in a large research trial with 35,423 enrollees (Zhou et al., 2010).

Other PHR research has primarily focused on patient satisfaction with specific features. Geisinger Health System surveyed 4,282 registered patients about ease of use and whether medical record information was accurate (Hassol et al., 2004). In a Group Health Cooperative study users of their PHR reported the highest satisfaction with medication refills (96%), secure-messaging (93%) and test results (86%) (Ralston, Carrell, & Reid, 2007). In a study of 272 older adults, 71.3% were using one or more patient portals with PHRs and secure messaging. When ranking the features of the patient portal, 21.1% selected communicating with their health care provider as the most frequently used feature ( Nahm et al., 2018). A recent study demonstrated that the lack of education how to access and use a PHR with SM can hamper usage (Nahm et al., 2018).

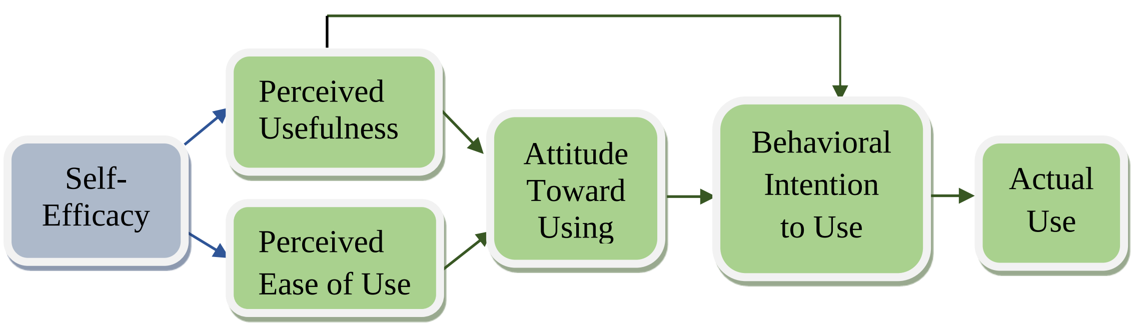
Researchers have examined whether SM can replace patient-provider face-to-face encounters that typify outpatient primary care with limited success (Ammenwerth, Schnell-Inderst, & Hoerbst, 2012; Goldzweig et al., 2013; Kruse, Bolton, & Freriks, 2015). Some studies have demonstrated that the number of phone calls received by the provider may decrease when SM is introduced while at the same time demonstrating no change in the number and frequency of face-to-face visits (Wallwiener, Wallwiener, Kansy, Seeger, & Rajab, 2009; Zhou, Garrido, Chin, Wiesenthal, & Liang, 2007). Research has also demonstrated desirable outcomes in the management of chronic diseases, patient satisfaction and patient empowerment with the use of patient portals, PHRs, access to internet-based patient education and SM (Bylund & Makoul, 2002; Cronin et al., 2015; Haun et al., 2014; Tsai & Rosenheck, n.d.). Ford et al. (2016) notes patients are the primary driver in the use of internet-based technologies, and it was predicted that by 2020, 75% of adults would use PHRs. This suggests the patient's experience using internet-based technologies is an important factor to consider in the development, testing, and implementation of new technology or newly defined uses for pre-existing technology. The use of a well-designed patient portal (PP) capable of facilitating a web-based stroke protocol to collect data, deliver education content and provide secure e-mail communication between study participants and researchers has not been addressed.

**Theoretical Framework**

Two theoretical models have been widely used in technology acceptance research; Bandura's Social Cognitive Theory and Davis's Technology Acceptance Model (TAM)

(Kukafka, Johnson, Linfante, & Allegrante, 2003). Bandura's Social Cognitive Theory identifies self-efficacy as the belief in one's ability to perform a given behavior while Davis' Technology Acceptance Model demonstrates that behavior or intention to use arises from the independent constructs of perceived ease of use and perceived usefulness. A modified Technology Acceptance Model incorporating self-efficacy (see Figure 3) will be used to inform this qualitative research study capturing the end users' experience with home-based telerehabilitation: 1) using My Health***e***Vet PHR and electronic communication via secure messaging; 2) attaching tools to report patient tracking of self-reported data; 3) retrieving education to support patient performance of rehabilitation tasks; and 4) retrieving tools to report patient self-reported data.

Figure 1. Modified Technology Acceptance Model with Self-Efficacy




Bandura's Social Cognitive Theory (SCT) considers the social environment in which individuals acquire, maintain, and perform specific behavior. The influence of the internal and external social environment is a critical component of social influence and is one driver of human behavior. Individuals set personal goals and measure their success and satisfaction with their performance as a mechanism for self-motivation, self-regulation, and self-reflection (Bandura, 1994). Bandura (1995) theorized that self-efficacy beliefs are central to motivation and behavior and influence an individual’s actions. Individuals are more likely to engage in activities that they have been successful at previously. Self-efficacy serves as a self-fulfilling prophecy, where individuals with high self-efficacy are more likely to achieve their goal, whereas individuals with low self-efficacy may not attempt to participate due to low expectations of success (Gecas, 2004).

The Technology Acceptance Model is rooted in three critical theories examining user acceptance of technology: Theory of Reasoned Action, Theory of Planned Behavior and Bandura’s Self-Efficacy Theory (Davis, 1989). Prior to the development of these theories implementation science drove technology adoption and failed to consider or use behavioral science in information technology adoption (Davis, Bagozzi, & Warshaw, 1989; Robey, 1979). The Theory of Reasoned Action (TRA) postulated individuals choose their course of action based upon rational intention after performing a cost-benefit analysis; and generated significant theoretical research into its limitations to predicting behavioral intention to use (Burton-Jones & Hubona, 2006; Davis et al., 1989; Ketikidis, Dimitrovski, Lazuras, & Bath, 2012). In an extension of the TRA, the Theory of Planned Behavior (TPB) proposed the concept of perceived behavioral control (PBC) on the assumption that attitudes, behaviors and motivations are controlled by the individual (Pai & Huang, 2011). TPB’s primary contribution to behavioral psychology has been the effect of contingencies (e.g., age, gender, and ethnicity) on behavioral intention (Venkatesh, Davis, & Morris, 2007). Davis (1989) noted in his seminal technology acceptance research that individuals were often “unwilling to accept and use” technology systems that offered the promise of improved performance. Behavioral intention is driven by an individual's attitudes and beliefs. Davis (1989) proposed two determinants of user behavior: perceived ease of use (PEoU) and perceived usefulness (PU).

**Self-Efficacy, Perceived Ease of Use, Perceived Usefulness**

This qualitative study used open ended questions to elicit items, things, or events that impacted the adoption of the My Health***e***Vet PHR and SM and selected tools for this study; using information developed from a conceptual analysis of perceived ease of use, perceived usefulness and self-efficacy as determinants of user behavior in technology acceptance. *Bandura (1997) defined self-efficacy* as the "belief in one's own capabilities to organize and execute the courses of action required to manage prospective situations."

Self-efficacy is a measure of 'I can' and not 'I will.' 'I can' is a clear expression of the individual's conviction and belief in their ability to accomplish the task, exercise, or goal in front of them. 'I will' is an estimation that their action will result or lead to a specific outcome (Bandura, 1978, 1997). There are four major influences on creating a strong sense of self-efficacy: personal mastery, social modeling, social persuasion, and somatic/emotional response. Self-efficacy can be developed through self-motivation, by taking control over difficult situations and purposive action in meeting pre-established goals. The individual builds personal mastery by taking on increasingly more complex tasks or pursuits and overcoming obstacles. Success results from continued trial and error and with success comes an increased sense of self-efficacy, or the ability to succeed (Bandura, 2012). Social modeling is the process of learning from the vicarious experiences of others. Watching someone else of a similar nature succeed at a difficult task can lead to the belief that the observer can obtain the same level of capability with a sustained effort. Social persuasion may occur alone or in combination with self-motivation, and social modeling.

Verbal encouragement from another individual can result in a higher level of function. Somatic and emotional complaints can interfere with an individual's judgment of their personal self-efficacy. Increased physical complaints and poor mood can lead to feelings of low self-efficacy while enhanced physical performance and positive mood is linked to high perceived self-efficacy (Bandura, 1994).

The effect that personal mastery, social modeling, social persuasion, and somatic/emotional response have on self-efficacy are best examined in relation to cognitive, motivational, affective, and selective activated processes. Bandura (2005) has argued that 'one size does not fit all' nor does it have any relevance without context. A classic example is driving self-efficacy. Bandura differentiates between the component skills needed for successful driving (steering, signaling and braking) and the special behaviors one can obtain (driving on the freeway, a twisting mountain road, in snow and ice) (Higgins, 2015). Motor or cognitive disabilities may require a reappraisal of self-efficacy for previously performed activities due to its association with meeting psychological, social, and functional recovery milestones.

Davis' concept perceived ease of use was extensively supported by Bandura's research on self-efficacy. Davis defined perceived ease of use as the "degree to which a person believes that using a particular system would be free of effort." Davis postulated that his second concept predicting user behavior, perceived usefulness, defined as the degree to which a particular system would enhance performance, is also closely aligned with Bandura's concept of self-efficacy (Davis, 1989). Individuals with high self-efficacy are more likely to expend effort if a behavior or action has perceived usefulness whereas individuals with low self-efficacy may not due to their belief that they do not have the ability to execute the behavior (Schwarzer & Luszczynska, 2005).

Self-efficacy (Bandura, 1978; 1997) has been conceptualized as a general and specific construct, creating a schism of thought in the research community. Bandura addressed this schism by writing that self-efficacy is a conditional expression and response to a given situation encountered in everyday life (Bandura, 2012). Bandura's (1994) Social Cognitive Theory provides a theoretical framework for examining the stroke survivor's self-efficacy and capability to produce specific levels of performance through cognitive, affective, and motivational processes (Bandura, 2012). Prior experience is often the best predictor of future performance, and while careful attention must be paid to the changes in neuromotor abilities resulting from a stroke, high self-efficacy in previous use of computers, e-mail and PHR may translate into actual use post stroke. A behavioral approach to technology acceptance allows the researcher to frame the participant's experience with telerehabilitation and the use of the My Health***e***Vet PHR and SM in the context of their self-belief in their ability to use the technology, the perceived usefulness, ease of use and actual use.

The modified theoretical framework informed the development of the research questions used for this study. Drawing upon Bandura's theory of self-efficacy it was postulated that self-mastery experiences provide the most genuine evidence of having what it takes to succeed (Bandura, 1997). Bandura (1997) assumed that previous success fostered self-efficacy beliefs, as it represented desired outcomes and thereby enhanced the likelihood of a certain behavior. Whereas, Davis' technology acceptance model's concept of perceived ease of use and perceived usefulness closely aligned with Bandura's concept of self-efficacy and if an individual believed the system would be effortless it would translate to enhanced performance (Bandura, 1997; Davis, 1989). The research questions were designed to elicit the study participant's and researcher's use of the My Health***e***Vet secure messaging (SM) and their perspectives and experiences engaging in and completing tasks (e.g., electronic communication with secure messaging;, attaching tools to support patient tracking of self-reported data; attaching education to support patient performance of rehabilitation tasks; and retrieving patient self-reported data). The theoretical model guided the development of the questions to seek the study participant's and researcher's perspectives and experience on the perceived ease of use and usefulness of the My Health***e***Vet PHR with SM and how they incorporated it into their activities of daily life (Davis, 1989).

**Summary**

This chapter provided a review of the relevant literature exploring the development of telehealth and telerehabilitation in the Veterans Health Administration (VHA), to include the current evidence about the use of information communication technologies employed in the delivery of home-based telerehabilitation and the use and impact of an organizationally supported personal health record with secure messaging (My Health***e***Vet) in VA healthcare. In the second part of this chapter relevant theoretical frameworks were reviewed to include Bandura's social cognitive theory, self-efficacy, and Davis' technology acceptance model and how they impacted the development of the research questions for this qualitative feasibility pilot. The next chapter will detail the methodology used in this study.

# CHAPTER 3
# METHODOLOGY

## Introduction

The qualitative approach to research provides the necessary tools to study the abundant landscape of human experience to interpret and clarify participants' stories (Creswell, 2013). The investigator focuses their intellect, senses, and awareness on the participant's experience of the phenomenon of interest to reveal its presence and accentuate its meaning. The objective of this qualitative study was to see with curious eyes; fresh and open to discover meaning rather than verifying truth or attempting to predict an outcome based upon preconceived notions or prior experiences (Finlay, 2014; Groenewald, 2004).

The purpose of the My Health***e***Vet Secure Messaging Pilot and Qualitative Study was to explore the experiences and perspectives of researchers and patients participating in a feasibility pilot exploring the use of the Veterans Health Administrations' (VHA) My Health***e***vet SM to deliver a stroke TR program to home-based stroke survivors with chronic upper extremity disability. Given the lack of research available on the use of My Health***e***Vet secure messaging in TR this qualitative research study employed Moustakas' rigorous and systematic methodology for descriptive phenomenology. The student researcher employed: 1) the attitude of 'epoche' to put aside or bracket prior experience and knowledge in order to understand the essence or 'is-ness' of the phenomenon; 2) intuited the phenomenon under investigation through immersion; and 3) extracted the meaning through an analysis and description of the phenomenon under investigation (Finlay, 2008; Moustakas, 1994a). The final step is not akin to data analysis; rather it is intended to gain an understanding of the meaning and essence of the experience felt by the participant(s) (Creswell, 2013; Moustakas, 1994a). It is only when we see and relate to others in their natural world that we can begin to perceive the phenomenon with naiveté and a self-meditative process that we can see the phenomenon in its essence (Giorgi, 1985). Plumbing the depths of the study participants' and researcher's lived experience, while gathering their unique perspectives within the context of stroke TR, will provide currently unknown insight into the benefits or limitations of PHRs and SMs for use in home-based TR now or in the future.

In-depth interviews were conducted with study participants who participated in the home-based TR group to understand their experience and perspective interacting with the My Health***e***Vet PHR and SM. In-depth interviews are a qualitative research technique moving from an overarching perspective of a phenomena to the emergence of categories, which provide focus for a deeper exploration of the phenomena to elicit rich information (Englander, 2012; Wimpenny et al., 2000). Interviews typically use open-ended or semi-structured questions to elicit responses rather than drawing from a defined list of responses. The interviewer can elaborate or refine on what is being asked based upon the interviewees' responses, gathering potentially valuable information that might be otherwise lost without the benefit of the qualitative method (Groenewald, 2004). The research method is guided by the research question (Al-Busaidi, 2008) and qualitative method is deemed the most appropriate to explore the lived experienced of the study participants' and researchers' use of the My Health***e***Vet PHR and SM in stroke TR (Cherry et al., 2017). Prior research examining telehealth has often focused on patient satisfaction and been found lacking due to the use of instruments that have not been assessed for validity or reliability and a failure to understand the patients' needs while participating in health research (Cherry et al., 2015; Lutz et al., 2009; Pang, Chang, Verspoor, & Clavisi, 2018). Human behavior and its interaction with key staff, organizational factors, relevant policies procedures are critical elements that define the contextual reference points needed for a qualitative study (Bloomberg & Volpe, 2016).

**Evolution of My Health*e*Vet**

While the VA was growing their telehealth systems of care they were simultaneously developing the My Health***e***Vet personal health record (PHR) for use by Veterans and other individuals as a secure personal health journal and source of health and wellness information. The primary goal was consumer empowerment rather than clinical utility or as an alternative to face-to-face episodes of care (Thompson & Brailer, 2004). The My Health***e***Vet PHR is in the public domain and is not limited for use by Veterans and can be used by anyone with an internet connection. Full benefit to all of the features of the My Health***e***Vet site are only realized by Veterans of the U.S. military services who have completed all of the enrollment requirements (Nazi, 2013). The tool was initially launched in 2003 and a revision with secure messaging (SM) was released in 2008. As of 2010, SM was mandated as the preferred provider-patient communication tool outside of face-to-face visits (Nazi, 2013). Research was limited to VA providers' and Veterans' use and experience with secure messaging in the outpatient environment with no provision for other sites of care (e.g., inpatient, same day surgery, emergency care, etc.) (Haun et al., 2014; Shimada et al., 2014; Turvey et al., 2012; Wakefield et al., 2008; Weddle et al., 2011). The limitation to outpatient use has been a critical factor in the evolution and growth of the My Health***e***Vet PHR and SM. The majority of research studies addressing SM adoption have involved non-federal providers and addressed lack of provider reimbursement as a primary barrier to SM adoption (Byrne, Elliott, & Firek, 2009; Car & Sheikh, 2004; Kittler et al., 2004; Liederman & Morefield, 2003). Until the approval of this feasibility pilot there have been no previous studies using the My Health*e*Vet PHR and SM for intervention research and more specifically it required the writing of new VA regulations and guidelines before authority to do so was granted. The selection of a qualitative methodology was one of the key influencers for the VA Office of Research and Development (ORD) granting this trial as there was concern that the operationalized use of secure messaging in research might be considered too intrusive by Veterans and VA providers. My Health*e*Vet is a patient facing technology and unlike electronic health records (EHR) the PHR contains patient generated health information and is not considered a part of the VA EHR and is not accessible by VA providers (Chumbler, Haggstrom, & Saleem, 2011; Hassol et al., 2004; Thielst, 2007). The VA has emphasized the 'personal' aspect of My Health*e*Vet due to the oft expressed concerns by Veterans regarding the security of the information that they may record in their personal health record (Haun et al., 2014).

**Design**

This retrospective qualitative study used a descriptive phenomenological approach to describe the stroke survivors' and selected research team members experiences using the Veterans Health Administrations' (VHA) My Health*e*Vet PHR and SM in telerehabilitation research. The study participants were drawn from a convenience sample of participants randomized to the intervention arm of a Veterans Administration (VA) funded stroke rehabilitation single-blinded randomized controlled trial titled "Translating Intensive Arm Rehabilitation to a Telerehabilitation Format" (HP-60526) and research team members who were instrumental in the development of the telerehabilitation arm of this feasibility pilot study. The parent trial consisted of 6-weeks of one-hour upper extremity rehabilitation using the table mounted Tailwind™, Encore Path, Inc. exercise equipment, 3 times per week for a total of 18 training sessions; an additional 3 weeks were allowed in the event of illness or scheduling issues. The research team members were the individuals who were directly involved in the development of the telerehabilitation framework used to communicate the intervention prescription; attach education materials and transmit same to the study participants; send and receive asynchronous communication between study participants and research team members; and receive patient generated data.

**Setting**

This study was conducted at the VA Maryland Health Care System's Baltimore VA Medical Center, a dynamic and progressive health care organization dedicated to providing quality, compassionate and accessible care, and service to Maryland's veterans. The Baltimore VA Medical Center is a 137-bed tertiary health care center co-located on the University of Maryland Medical System campus providing primary and tertiary regional care to veterans from across the mid-Atlantic region. The VA Maryland Health Care System is one of the over 1600 care sites of the largest integrated health care systems in the nation overseen by the Veterans Health Administration (VHA) (Asch, McGlynn, Hogan, Hayward, & Shekelle, 2004; Nazi, 2013).

**Participants**

A convenience sample of five study participants randomized to the intervention group agreed to participate and are described in Table 2. Most participants were women (60%) and African American (80%) and ranged in age from 50-69 years (80%). A semi-structured interview guide provided direction to ensure that core information was gathered from

Table 2. Demographic Characteristics Study Participants

| | N 5 (%) | |
|---|---|---|
| Sex | | |
| Male | 2 (40%) | |
| Female | 3 (60%) | |
| Total | 5 | |
| | | |
| Age in years | Males | Females |
| 50-69 | 1 (20%) | 3 (60%) |
| 70-84 | 1 (20%) | |
| Total | 2 | 3 |
| | | |
| Race | Males | Females |
| White Non-Hispanic | | 1 (20%) |
| African American | 2 (40%) | 2 (40%) |
| Total | 2 | 3 |
| | | |
| Age | Males | Females |
| Median Age in Years | 68 | 55 |
| Range | (56-79) | (52-58) |
| | | |
| Caregiver | Males | Females |
| Yes | 2 (40%) | 2 (40%) |
| No | | 1 (20%) |
| Total | 2 | 3 |
| | | |
| Median Time Since Stroke | Males | Females |
| In Months | 168 | 34 |
| Range | (56-280) | (26-42) |
| | | |
| Computer User Pre Stroke | Males | Females |
| Yes | 1 | 2 |
| No | 1 | 1 |
| | | |
| Email User Pre Stroke | Males | Females |
| Yes | 1 | 1 |
| No | 1 | 2 |

each stroke survivor participant (Appendix F). Additionally, three members of the research team participated in a focus group to share their experiences using My Health***e***Vet and Secure Messaging in an intervention research trial.

**Inclusion Criteria**

To be eligible for this qualitative study, participants must have met all inclusion criteria established for the parent study (Table 3) or have been members of the research team. In addition, the study participants must have consented to participation in the My Health***e***Vet Secure Messaging Pilot and Qualitative Study and randomization to the telerehabilitation or delayed entry arms of the study (see Appendix C). The study participants must have also consented to either be contacted about participation in future IRB-approved research projects for persons who have had a stroke or consented to participate in the Qualitative Study of Four Features (Table 4) of the My Health***e***Vet Secure Messaging Pilot. The research triage team members who participated in the development of the telerehabilitation component of the research trial using the My Health***e***Vet personal health record with secure messaging and tools must have consented to participation in the Qualitative Study of Four Features of the My Health***e***Vet Secure Messaging Pilot in order to participate in the focus group. No attempts were made to stratify by race.

Table 3. Parent Study Inclusion and Exclusion Criteria for Participation in the Intensive Arm Rehabilitation in Stroke to a Telerehabilitation Format

*Inclusion*

- Age 18 years or older.
- Have a clinically defined unilateral hemiparetic stroke with radiologic exclusion of other diagnosis.
- Stroke onset ≥ 6 months prior to enrollment.
- Moderate to severe upper extremity impairment based on a Fugl-Meyer score ranging from 19-50 out of 66.
- No previous experience using the BATRAC.
- Ability to use and interact with the tele-rehabilitation platform according to study protocol.
- Have an identified individual/caregiver to perform the TTT exercises if randomized to the home telerehabilitation group.

*Exclusion*

- Musculoskeletal diagnosis or significant arm pain that would interfere with positioning and use of the intervention (BATRAC) devices.
- Cognitive impairment such that the participant is unable to understand the study requirements to answer the Evaluation to Sign Consent Form tool accurately.
- Absence of a working telephone line or cell phone for telerehabilitation set-up if randomized to this group.
- Enrollment in a concurrent rehabilitation study or actively receiving therapy for their stroke affected arm.
- Having received botulinum toxin injection in their stroke affected (study) arm within 3 months of enrollment

Table 4. Four Features of My Health***e***Vet Using Secure Messaging

| My Health***e***Vet Feature | Key Components of the Feature | Use by Study Participant/Caregiver | Use by Researcher |
|---|---|---|---|
| 1. Electronic communication with secure messaging | 1. Communicate with research team.<br>2. Upload documents.<br>3. Schedule appointment.<br>4. Ask questions.<br>5. Report symptoms. | For example, study participant sends a message to the research physical therapist reporting soreness after last session and asking for advice. | 1. Researcher 1sends a secure message with exercise prescription.<br>2. Researcher gives encouragement for a job well done. |
| 2. Attaching tool to support patient tracking of self reported data | 1. Data form is pre-loaded on the iPad at beginning of study.<br>2. Pdf form can be filled out using the tablet after each rehab session. | 1. Study participants retrieves data tool from the Adobe Reader App and completes fields, renames, uploads, saves it to the "on my iPAD" Adobe Acrobat App files, & then attaches it to a SM and sends to research team; or a backup process to save to iCloud.<br>2. iPad pre-set with an accessibility button to allow for single press of a virtual button to take a screenshot of pdf form. Pdf screenshot automatically saved to photo album & can be directly linked to SM to send to research team. | 1. Research Coord could view pdf on TeleBATRAC iCloud not accessible to or from MHV (backup storage)<br>2. Research team member retrieves attachment from SM.<br>3. Research team member opens the pdf training record attached to SM and saves to the TeleBACTRAC iCloud as a backup. |
| 3. Attaching education to support patient performance of rehabilitation tasks | 1. YouTube videos<br>2. Veterans' Health Library resources | 1. Study participant watches YouTube video before and after doing training to check skills 2. Reviews library resources provided | 1. Witten handout provided at study initiation on how to log-n and use MHV to send a SM.<br>2. Researcher sends YouTube video showing correct way to perform exercises.<br>3. Hosts video chat to answer questions. |
| 4. Retrieving tools to report patient self-reported data | Data tools accessible through Adobe Reader App. | Study participant retrieves data tool from the Adobe Reader App and completes fields. | Attaches pdf or jpeg of completed training to SM depending on which process used to save form to iPad |

## Exclusion Criteria

To be eligible for this qualitative study the exclusion criteria of the parent study applied to all study participants (Table 3). In addition, study participants were excluded if they met the following exclusion criteria: 1) did not consent or withdrew consent to participate in the My Health***e***Vet Secure Messaging Pilot and Qualitative Study; 2) were not randomized to the telerehabilitation or delayed entry arms of the My Health***e***Vet Secure Messaging Pilot and Qualitative Study; 3) did not consent or withdrew consent to be contacted about participation in future IRB-approved research projects for persons with stroke; 4) did not consent or withdrew consent to participate in the Qualitative Study of Four Features of the My Health***e***Vet Secure Messaging Pilot. Research team members identified for participation in the focus group were subject to the following exclusion criteria: 1) were not members of the research team and 2) did not consent or withdrew consent to participate in the Qualitative Study of Four Features of the My Health***e***Vet Secure Messaging Pilot. This pilot study was approved by the VA Research and Development Committee and University of Maryland Institutional Review Board. All procedures were in accordance with the ethical standards of the Declaration of Helsinki and Good Clinical Practice.

## Procedure

All study participant interviews were conducted by the student researcher, audio recorded and supplemented with extensive handwritten field notes. The interviewees were interviewed by the student researcher in a private office located at the Baltimore Annex, a satellite building of the Baltimore VA Medical Center. This location was familiar to all study participants as it was also the location of the exercise lab for the parent study. Interviews were scheduled to minimize disruption to the interviewee's schedule. Interviews were conducted in person and to ensure the privacy and anonymity of the study participants, appointments were scheduled so that there was no possibility of overlap of date and time of the interview. The focus group was conducted as a conference call as all research members were not available to travel to a centrally located site to conduct the group in person. All group responses were recorded by hand as it was not possible to create an audio recording.

The study participant interviews were conducted using the semi-structured interview guide (see Appendix F). Particular attention was made to questions addressing the use of the My Health***e***Vet PHR and SM for: 1) electronic communication via secure messaging; 2) attaching tools to support patient tracking of self-reported data; 3) attaching education to support patient performance of rehabilitation tasks; and 4) retrieving patient self-reported data to gain an understanding of the study participants' lived experience of the phenomenon of home-based telerehabilitation. and the researcher's and MHV Coordinator's lived experience implementing home-based telerehabilitation using the My Health***e***Vet PHR and tools. Additional lines of inquiry were incorporated in the semi-structured interview guide as an outcome of the iterative nature of interviewing.

## Data Management and Analysis

### Framework for Analysis

The framework for data analysis was Moustakas' rigorous and systematic methodology employing the elements of epoche, intuiting, analyzing and describing in the phenomenological inquiry of normal experiences (Moustakas, 1994a). Moustakas' methodology requires the researcher to suspend their preconceptions and biases about the phenomenon under exploration. The student researcher's extensive experience with PHRs and SM, required an examination and tabling of prior experience with attitudes and beliefs surrounding the use of PHRs by health care providers and patients, allowing for an objective analysis of participant's experience.

The lived experience of each study participant was collected during a face-to-face interview using a semi-structured interview guide. All interviews, except for the focus group, which was recorded by notetaking, were recorded using Dragon Speech after an initial period of testing to allow for the software to recognize the speech of the study participants. Dragon Speech generates an editable typewritten record in addition to an audio recording of the speaker's responses to questions thereby allowing simultaneous viewing and correction of the record in real-time. In addition, handwritten notes were made by the student researcher.

All field notes and observations during the interview were appended to the semi-structured interview guide at the end of the interview. The Dragon audio recording, written record and the student researcher's written notes were transcribed, reviewed, and analyzed by the student researcher. The audio recording of the interview was listened to in its entirety and the transcribed interview was reviewed word by word. It was during this process of intuiting that the student researcher immersed in the phenomenon under investigation, as expressed by each individual participant, in order to understand their views, perspective, beliefs, and the essence of their lived experience (Moustakas, 1994a). Data collection and analysis was performed simultaneously and often unconsciously while listening to the participants' description of the phenomenon of interest and highlighted the necessity to immediately record any pre/post observations to clarify, expand or explicate the interview content and carefully attend to the student researcher's preconceived biases (Moustakas, 1994b).

The student researcher preliminarily coded all interview transcripts to describe, classify, analyze, and report on the qualitative interview data. A line by line review of each interview transcript was completed, and each word, phrase or sentence highlighting the textural or structural description (horizonalization) of the participant's view of the phenomenon was aggregated into categories for analysis of the essence of the experience or clusters of meaning (Moustakas, 1994a). Clusters or themes were compared across all participants for further analysis and grouped to identify the commonalties of the lived experience. The material was reviewed by the principle investigator (PI) who was fully familiar with the study participants. The PI's insight from long experience with the study participants gave additional confirmation to the analysis performed by the student researcher in capturing the essence of their individual experiences and emerging themes. The student researcher transcribed the written notes from the focus group and re-read the transcript multiple times prior to performing preliminary coding. Using Moustaka's framework for analysis the focus group transcript was highlighted for the textural or structural description of the participants' view of the phenomenon which was compared and contrasted with that of the study participants (Moustakas, 1994a)

**Methodological Rigor**

Methodological rigor was achieved using a multi-focal strategy to ensure the integrity of the qualitative research process (Creswell, 2013; Ryan-Nicholls & Will, 2009). The semi-structured interview guide was reviewed by the qualitative member of the researcher's dissertation committee, a senior faculty member highly experienced in qualitative research, and the institutional review board consultant and committee prior to approval of this study to assess for semantic clarity. The student researcher reviewed the codes and themes from participant's transcript with the PI prior to completion of the coding process to validate the accuracy of data capture, interpretation and coalescence of the essence of the participant's lived experience with PHRs and SM (Creswell, 2013; Moustakas, 1994a). The student researcher's finalized coded findings were peer reviewed by a qualitative expert to confirm the accuracy of the analysis of the transcript, conveyed meaning, and depiction of the interviewee's actual lived experience with the phenomenon of interest. The student researcher and peer reviewer discussed all comments and reconciled any differences in interpretation and any revisions, omissions or additions to the data that would be incorporated and specifically noted as an outcome of the session.

**Ethics, Privacy and Confidentiality**

The ethical principles of respect for persons, beneficence and justice were employed in all aspects of this study (Gostin, 2007). Prospective participants were given a complete outline of the purpose of the research, aims of the study, the potential benefits, and risks of participation in the study (See Appendix C). The potential benefits of the study were the identification of common factors that will lead to the development of tools and processes to facilitate ease of use of PHRs and SM for researchers and their patients. The loss of identifiable information was a potential, but highly unlikely risk of the study due to methodological rigor, de-identification of participant data and the security protocols associated with the use of the secure messaging platform. All data remained secure throughout the study period. All data was de-identified and reported in the aggregate. Participation in the research study was voluntary and the participant's involvement remains confidential, and all data was safeguarded to ensure anonymity and privacy. Participants provided written informed consent at the time of the initial random selection and at each stage of the research data collection process (e.g., data collection by interview, consent for recording, etc.). The participant could withdraw from the study at any point in time, and all participants received a copy of the fully executed consent form (See Appendix C). The participant will receive a notice of destruction when audio or video recordings are destroyed and will be advised of the procedures for ensuring the confidentiality of the transcripts of the recordings (e.g. random number assignment unassociated with participant's name). Institutional Review Board approval was obtained prior to initiation of recruitment of participants and data collection. In the event that recruitment involved patients enrolled in care delivered through a community-based outpatient clinic(s) (CBOC), the leadership team (lead physician, nurse manager and facility administrator) was apprised of the research protocol, intended period for data collection and number of participants involved in research.

**Study Quality and Validity**

Several analytic techniques were used to improve the validity and reliability of the study.  A peer review panel consisting of researchers with experience in qualitative research reviewed sample study memos, codes, and themes at key time points in the project. Member checking was performed with a sample of study participants to review themes at the end of the project to check for authenticity of the investigator's interpretations (Lincoln & Guba, 1985). Members of the student investigator's dissertation committee performed external auditing throughout the study. Each of these techniques contributed to the quality of the study (Cohen & Crabtree, 2008).

**Summary**

This chapter described the evolution of the My Health***e***Vet (MHV) personal health record and secure messaging (SM) and its designation as the preferred mode of communication outside of face-to-face visits between providers and patients. The VA's goals for the use of MHV and SM for consumer empowerment and a possible alternative to face-to-face visits was briefly explored along with its limitations to outpatient care. Previous research has focused on VA providers' and Veterans' experience in the outpatient arena. Most SM research has focused on adoption rates and barriers to its use. Provider reimbursement has been identified as one of the principle barriers to adoption.

The remainder of the chapter provided a description of the methodology to be used for this feasibility pilot study. The study design, setting, participants, procedures, and data management and analysis plan were described in detail. The next chapter will address the feasibility of using My Health***e***Vet secure messaging for telerehabilitation; the results of implementing the study and the identification of any steps initiated by the researchers or study participants that contributed to the outcomes and the experiences of the researchers and study participants.

# CHAPTER 4
# RESULTS

## Introduction

The aim of this qualitative study was to explore the experiences and perspectives of researchers and study participants use of four features of My Health***e***Vet (MHV) patient portal and secure messaging (SM) that could inform the design and implementation of future studies using similar information communication technology: 1) electronic communication using secure messaging; 2) patient health education resources; 3) tools enabling the patient to track and self-report data; and 4) the process for submission of self-reported data. A secondary aim was to evaluate whether MHV SM or a similar organizationally sponsored patient portal with secure e-mail could be used as an effective information communication technology platform for the delivery of telerehabilitation. The first part of this chapter will discuss the rollout of MHV SM for use in this feasibility study. The second part of this chapter will examine the study's findings related to the researchers' and study participants' lived experience interacting with MHV SM and the four features listed above.

The information related to the rollout of this feasibility study was garnered from responses collected during the focus group interview with three research team members. The inclusion of these findings is considered important to future researchers who may be considering using MHV SM or a similar organizationally sponsored internet based personal health record with SM or e-messaging as this is the first research trial of its kind approved within the VA and elsewhere to the researcher's knowledge.

The researchers' and study participants' prior experience with MHV and its four features were obtained from background questionnaires and responses given by research team members participating in a focus group and study participants' responses to semi-structured interview questions. Key findings are presented as a composite summary and are linked to the research questions. Three overarching themes were identified as positive benefits from home-based telerehabilitation using MHV SM: caregiver support, increased mobility, and empowerment. Sub-themes classified as benefits or barriers will be highlighted and discussed in relation to the overarching themes and include flexibility, increased control over timing and scheduling of therapy, increased independence, autonomy, unfamiliarity with the use of computer technology, and inability to effectively use the iPad to communicate the results of stroke rehabilitation training. Representative quotes are provided when appropriate. Barriers and benefits to use of the MHV SM for telerehabilitation identified during the focus group and semi-structured interviews are discussed in detail.

**Background Questionnaire**

Research team members and study participants were asked to complete a pre-interview background questionnaire (Appendices D and E) to gather baseline knowledge about their individual experience with patient portals, personal health records and secure messaging to partially satisfy research questions one and two. Research team members were also asked basic questions about their roles in the research trial, work location, type of work and experience using the MHV patient portal and SM. Apart from one research team member no other members had knowledge of MHV SM or the four features under investigation prior to being introduced to it for the telerehabilitative portion of the research trial (Table 5). As shown in Table 5, research team members' and

Table 5. Reported Experience with the My Health*e*Vet Secure Messaging and Online Features

| | Study Participant N=5 | Research Team Member N=3 | All Participants N=8 |
|---|---|---|---|
| Used MHV Prior to Research Study | | | |
| Yes | | 1 | 1 |
| No | 5 | 2 | 7 |
| Prior Use of Secure Messaging | | | |
| Yes | | 1 | 1 |
| No | 5 | 2 | 7 |
| Used Patient Health Education Resources | | | |
| Very Frequently | | | |
| Frequently | | | |
| Occasionally | | | |
| Rarely | | | |
| Never | 5 | 3 | 8 |
| Used Patient Tracking Self-Reporting Data Tools | | | |
| Very Frequently | | | |
| Frequently | | | |
| Occasionally | | | |
| Rarely | | | |
| Never | 5 | 3 | 8 |
| Prior Computer Use | | | |
| Yes | 3 | 3 | 6 |
| No | 2 | | 2 |
| Use Computer or PHR in future Research Study | | | |
| Yes | 3 | 3 | 6 |
| No | 1 | | 1 |
| Maybe | 1 | | 1 |

study participants’ responses varied from ‘never’ to ‘no’. One study participant reported being enrolled in a private health plan known for having a robust personal health record (PHR) (Kaiser Permanente), and denied knowledge of the PHR or use of same. The single research team member with prior knowledge was broadly familiar with the MHV patient portal and had in-depth knowledge of SM, although not personally familiar with many of its features to include education resources and tracking of self-reported data (see Table 6).

Table 6. *Selected Features Available to Users* of *My HealtheVet Personal Health Records*

| Key: V=all site visitors R=registered users A=authenticated users | **V** | **R** | **A** |
|---|---|---|---|
| *Research Health:* Browse and search collections of evidence-based health information including Healthy Living Centers, Condition Centers, and medical databases. Access health screening tools, mental health resources, and articles. | x | x | x |
| *Personal Information:* Document and maintain contact information including emergency contacts. Manage account profile, preferences, and options. | | x | x |
| *Get Care:* Store and maintain information pertaining to caregivers and providers, treatment facilities and locations, and health insurance coverage. | | x | x |
| *Health Information Card*: Print selected personal and medical information on a pre-formatted wallet card for a convenient reference. | | x | x |
| *Personal Health History:* Record important health history information and events. | | x | x |
| *Family Health History:* Record family member's health history and events that may affect health. | | x | x |
| *Personal Health Summary:* Select information to print out as a personal health summary report to share with providers. | | x | x |
| *Health eLogs:* Track and graph common health measures (blood pressure, blood sugar, cholesterol, body temperature, weight, heart rate, pain, pulse oximetry, INR). | | x | x |
| *Allergies:* Record allergies by date, severity, reaction, diagnosis, and add comments. | | x | x |
| *Immunizations:* Record the immunization, date, method used, and any reactions. | | x | x |
| *Medical Events:* Keep track of illnesses, accidents, or other events by logging the date, treatment prescribed, and any comments regarding the event. | | x | x |
| *Food and Activity Journals:* Record food intake to monitor diet or control weight and keep track of exercise routines. Print journal worksheets for easy tracking. | | x | x |
| *Medications, Over-the-counter Drugs, Herbals and Supplements:* Record the name, starting and ending date, prescription number, and dosage. | | x | x |
| *My Complete Medications:* View and print a complete summary of both VA and self-entered medications to support medication reconciliation. | | | x |
| *Secure Messaging:* Exchange secure electronic messages with your healthcare team for non-urgent needs. | | | x |
| Key: V=all site visitors R=registered users A=authenticated users | V | R | A |

Adapted from: "Embracing a Health Services Research Perspective on Personal Health Records: Lessons Learned from the VA My Health***e***Vet System," by K. M. Nazi, T. P. Hogan, T. H. Wagner, K. McInnes, B. M. Smith, D. Haggstrom, . . . F. M. Weaver., 2010, Journal of General Internal Medicine, 25, Suppl. 1, p. S64.

## Focus Group Key Findings

### Implementation

An aim of the researchers was to determine whether the MHV SM could be used effectively for telerehabilitation. The VA Office of Connected Care, My Health***e***Vet Program Office and the Office of Research and Development had been seeking a small research trial that could be used to test whether My Health***e***Vet secure messaging could be operationalized for an intervention research telehealth study. Due to the broad interest and potential impact on the larger research community, this feasibility study was fast tracked for approval. The benefits, and barriers to its use in research are of interest to the wider research community. Findings are summarized and illustrated with representative quotes when appropriate.

Due to the nature of this feasibility pilot a team was assembled at the national level with membership from the Office of Connected Care, Office of Research and Development and the Program Office for My Health***e***Vet to work with principle investigator, student researcher, other research team members and facility stakeholders to address policy, procedure and resource issues that might arise during proposal development and implementation. The research team was often unsure about who to go to for answers and would rely on the national team to provide direction. However, it often felt like decisions were made very quickly at the national level and the researchers did not always know the reason why.

> *"…it would have been more helpful if they remoted in and looked at what we were trying to do.*

In particular, the confusion about how to establish secure messaging clinics extended to the local facility as well. It was routine to set up primary care provider clinics with the additional stop code for provider/patient secure messaging. The research teams' attempts to setup a clinic solely for the purpose of sending and receiving secure messages was not an established business practice. Policy changes had to be made at the national level to overcome current business rules that were prohibiting the formation of the secure messaging clinic needed for the pilot study.

> *"There were no guidelines to do what we were trying to do."*
>
> *"… This wouldn't have happened without national impact."*
>
> *"In a research realm where you may only have 2 years and x amount of time to use dollars and cents, this was lightning speed to accomplish this."*

Uniformly, the researchers reported their experience with the setup of the My Health***e***Vet Secure Messaging Clinic to be one of the most frustrating events of this research trial. The research team noted it was more complicated than originally expected and there were multiple steps in the process that hampered implementation of the feasibility trial. Much of this arose from the researchers being non-users of VA clinics in their normal daily practice and a lack of familiarity with the language, terminology, and steps needed to accomplish required tasks. There was no single source of information that could be used by the research team detailing the necessary steps to take for successful clinic setup and management.

> *"Part of being a new initiative meant that we didn't always know language, terminology, or the steps to take."*
>
> *"I learned a lot about secure messaging, stop codes and workload credit."*

The research team also noted setting up the clinic for enrolling all study participants was more complicated than originally expected and there were multiple steps in the process that hampered its usefulness.

*"Getting the clinic setup to be recognized and naming it. ... We had to get the name of the clinic first then request setup of clinic by the Clinic Profile Group."*

*"You needed to have a clinic name, so patients could be associated manually.*

When asked whether there were any concerns about using MHV SM for larger research projects there was immediate concern that the My Health***e***Vet coordinator could be overwhelmed by the demand. The research staff immediately pointed to large cooperative studies that could involve multiple sites and enroll upwards of 30,000 study participants. This would create a significant barrier to use of the MHV SM if a large majority of the participants were being newly enrolled in the MHV patient portal and SM program.

*"A regional person would need to be dedicated to support the research teams."*

*"You would also need to consider the size of the influx and time spent. Would need to consider the troubleshooting time needed."*

It was noted the current study represented a small feasibility pilot where the researchers were able to assist the study participants with the mechanics of enrolling in the MHV patient portal and SM. In a large clinical trial this might not be possible and additional consideration would have to be given to ensure the communication workflow would continue without interruption.

> “*You would need a train the trainer program or develop ad hoc MHV clinical champions and determine the number of clinical champions needed to help with set-up, registration and authentication.”*

The researchers opined that careful consideration would need to be given to the research design and clear parameters would have to be developed before committing to the use of MHV SM in large research trials. The commitment of time and resources could outstrip many research budgets without careful planning upfront.

> *“You would also need to consider the size of the influx and time spent. Would need to consider the troubleshooting time needed.”*

**Training**

The research focus group members reported engaging with study participants in their use of the MHV SM using screenshots printed out in booklet format. This method was often insufficient for guiding study participants how to create their accounts due to the number of steps involved.  The research focus group members noted that having a MHV dummy or test patient account would have facilitated training new users how to setup their accounts and to navigate the various features of the MHV website. The complexities of establishing a MHV account to have all necessary bells and whistles requires the study participant’s account to mimic a Veteran’s account setup in order for it to successfully associate with the ‘research clinic’ secure messaging stop code. Unless a researcher is already enrolled in MHV and willing to potentially use his/her account for illustration purposes and potentially share personally identifiable information the only real solution is a dummy or test patient account to work with for training purposes.

Unfortunately, the research team was never able to get permission to establish a test account for this research trial and relied on a paper-training booklet.

Another area that posed difficulty was ensuring the study participant correctly coded themselves when enrolling in the My Health***e***Vet program. Most study participants were non-Veterans but had to classify themselves as Veterans and VA patients to get the appropriate level of account to participate in the study trial.

> "*There were three steps: patient registration, patient authentication and patients manually associated."*

The researchers noted they were able to authenticate and manually associate study participants who were in the intervention arm of the study without difficulty.

At some point after the study trial began the MHV website underwent a redesign that was meant to simplify usability of the site. The goal was to put the most popular features of MHV on the splash page of the web site (see Figure 2). The new look was less cluttered, but it did not have the desired effect of reducing the number of clicks to navigate to the actual features (e.g., secure messaging, medication refills, etc.).

> *"One of the hardest things was clicking through the secure messaging pages"*
>
> *"It was hard to help walk the patients through the problems they were having."*
>
> *"Had to go to the people's homes to help them. Orientation was difficult."*
>
> *"The patients had to come into the VA for extra visits so we could teach them."*

Figure 2. My HealtheVet Webpage Before Redesign


Figure 2. My HealtheVet Home Page 2013 (color figure available from My HealtheVet Program Office archives)

Figure 3. My HealtheVet Webpage


Figure 2. Image of the My HealtheVet redesigned webpage displaying the four most popular features of the My HealtheVet Personal Health Record: access to Pharmacy prescription history and status of current medications, tracking appointments, secure messages, and access to VA health records. https://www.myhealth.va.gov/mhv-portal-web/home

The redesign also necessitated the training materials to be updated to reflect the changes made to the MHV website so that everything aligned as new study participants were randomized to the intervention group.

**Use Monitoring**

One of the barriers to SM is the restriction on the type of notes that can be saved to the study participant's electronic medical record, known as the VA's computerized patient recordkeeping system (CPRS). Unless a secure message contained clinically pertinent data (e.g., lab result, CT finding, etc.) it could not be incorporated into the study participant's medical record. The researchers felt this severely limited their ability to capture and evaluate note content.

> *"We were also instructed not to put notes in CPRS. Not putting in notes minimized the effectiveness of using the system."*

This is an important feature for clinicians who may be discussing clinical care with their patients. On the other hand, there was a concern that research notes might be misinterpreted or acted upon by the study participant's physician provider; thus, inadvertently affecting the study results or the patient's outcomes. It is for this reason that research study notes are rarely included in the patient's electronic health record unless there is a clear reason to do so.

> *"A lot of back and forth conversations with DSS[1] resulted in it becoming clear that no note[2] in CPRS meant that we couldn't capture data. When we tried to*

[1] DSS is Decision Support Services, the office responsible for establishing clinics and establishing the business rules under which they operate.
[2] In this context the term 'note' was synonymous with a 'secure message.'

*print … a note would print with lots of blank pages as it wasn't designed for printout and even if we saved it as a pdf it would still have blank pages."*

The only way for the team to extract key data points was to review each individual secure message and maintain a log of the data in a spreadsheet. This practice created inefficiencies. There was also an issue with who responded to escalations if a message was not reviewed within three business days.

*"If one person or a second person responded the time might not be captured and logged by the system."*

*"It left room for a lot of error."*

*"You could still count encounters, time spent on messaging."*

**Benefits to Use**

The researchers' experience with the study participants' use of MHV SM to operationalize their stroke rehabilitation was positive. Study participants were able to proceed through the research protocol remotely.

*"Allowed people to … receive the treatment intervention."*

"*Patient can review the videos at their own pace and patient can opt to do training at their convenience."*

In one instance where a study participant's repetitions decreased significantly the researcher used a video call to intervene with the affected study participant who commented:

*"…she told me how to adjust my machine. It was really easy, and my repetitions improved."*

Links to other sources of information were not used, although an overview of the resources and functionality of the Veterans Health Library was provided.

> *"I gave them an overview of the library and functionality. Only one patient expressed an interest and used other features."*

One of the researchers noted that there was a mixed response by study participants with some being extremely comfortable using SM, whereas others required prompting and on occasion had to be followed up telephonically. It was suggested that it would be great if you tell if they read their messages and the researchers were surprised to learn that was a feature 'read receipt' that could be activated. This might have been a barrier although it could more accurately be described as a lack of training for the researchers. Nonetheless, there was high satisfaction with the use of SM by the researchers evidenced by the following statements:

> "*When you had the exchange through secure messaging there was a true connection*."
>
> *" Felt like you were able to create a strong patient/provider relationship."*
>
> *"From a staff perspective gives flexibility of when to respond and there is no imperative to provide an immediate response."*

Whereas another focus group member stated:

> *"Personally, I felt the format was dated. Would be a good fit if could also go out as a text message. Simply getting patient to respond I had to sometimes call them to respond."*

While this focus group member opined the need for a My HealtheVet app, what was not known was that one was in development with a launch date planned within the next year, although no one would be able to predict how this study participant group would respond to the use of an ‘app.’

**Barriers to Use**

As shown in Table 5, the researchers and study participants were largely naïve users of the MHV patient portal and SM. One researcher noted a study participant used her personal email address instead of SM to contact her. This required further education to ensure MHV SM was used for all communication, except for phone contacts. Another researcher noted that much of their time was spent in follow up and playing phone tag, as illustrated by:

*“Simply getting the patient to respond…had to call them to get them to respond”*

*“Tracking them down after the fact and an inability to close the loop”*

Part of the difficulty for many of the study participants was the number of clicks it took to reach the SM page. Despite the redesign of the MHV patient portal, clicking on the message button still did not take you to a blank message form and depending on how the study participant’s secure messaging was set up might require several clicks to access his/her inbox. However, from the researcher’s perspective most study participants became comfortable logging into MHV and responding to SM from research team members after the initial orientation period.

*“For people who were able to do it, they were able to do it well.”*

The most notable barrier to use had to do with sending in the pdf form on the study participant’s training. The original method required uploading and saving the pdf form to the Cloud as an attachment. While this method saved the pdf in a manner that allowed it to be linked from the iPad to the SM as an attachment it took multiple steps and resulted in confusion for the study participants and research coordinator as the forms were not identifiable by study participant. The research coordinator had the ability to access and review the pdf forms in the Cloud in case they were not attached correctly to the SM. This problem prone process took approximately one year to resolve and only after the introduction of fresh eyes in the research coordinator role. The iPad was pre-set with an accessibility button that allowed the study participant to press a virtual button to take a screenshot of their training record pdf form. The photo was automatically saved to the photo album and could be linked to the SM and sent to research team members. While there were still occasional issues, this process was superior to the iCloud method.

## Study Participant Key Findings

### Caregiver Support

Caregiver support was one of the inclusion criteria for participation in the intervention arm of this study. Three of five study participants actively identified caregivers during their interviews, while only two acknowledged their participation in their care. Of the two, one demonstrated strong internal motivation throughout the research trial and made tremendous personal strides. When asked about the equipment setup at home this study participant noted:

> *"Everything set up fine. Xx set it up to be sure it was secure. … At first I had a concern about space and moved it from original placement to look out the window…"*

As the study progressed the same participant noted:

> *"I think it's hard for my partner now that he doesn't have to help me so much after doing so for so long."*

The study participant had no difficulties with any aspect of the research trial and if anything, was more likely to be an over achiever.

> *"Had equipment there, why not use it. Also, if you tell me 3 times a week, I'll do it. If you tell me I can do as much as I want, I will."*

For the remaining two participants who identified caregivers, the primary barrier affecting their full engagement in the telerehabilitation feasibility trial was their unfamiliarity with the use of an iPad and their inability to navigate the necessary steps to communicate with the research team members. The second study participant did not enlist the help of the caregiver when he/she had trouble with accessing the SM program, downloading, or uploading the data form or needed a response to a question.

> *"Wasn't easy to use at first. Switching back and forth, downloading the form, putting info on the from, then uploading and sending the messaging… Multiple steps."*

The study participant seemed to focus on being in control and ensuring the safety of the reported information as evidenced by the study participant's comment

> *"It made me feel safe. My information was secure."*

Whereas the third study participant totally relied on the caregiver for the submission of the study participant's data, reporting:

> *"I never did get comfortable cause my neighbor, she came over and she knew what to do. … If she had problems she overcame and didn't try to call for help, she figured it out."*

This study participant credited the communication with the research team to the study participant's neighbor if the study participant did not call the team directly. The study participant reported the neighbor helped or the research team came out to the house or the study participant would call the team to see if study staff would need to talk to the neighbor.

> *"... call to find out if she (neighbor) has to talk to the staff for help when she (neighbor) had problems with the iPad.*

The caregiver's support was an essential component in the continued participation of the third study participant's ability to remain in the study. For the remaining two individuals the role of the caregiver was less important, although it might be argued that the research team members played a strong supporting caregiver-like role for the second study participant. This study participant chose to rely on the research team member for assistance with submission of his study data rather than allowing his caregiver to participate in that process.

Most participants indicated that getting used to the tablet was not easy due to its small size, and difficulty navigating the screen to get to secure messaging because of the number of clicks. Navigation difficulties affected several processes. The original study design required clearing out the data collection form after each use and entering the new data to attach it to a secure message. This process did not work for many study participants and was changed. Study participants commented that the iPad would freeze when trying to transmit their training results and display a 'not communicating' message. The remaining study participants did not comment on the role of their caregivers during these breakdowns in communication. Instead they would call the research team members for assistance that was always available. The difficulty with the iPad was a recurring event that ultimately resulted in the research team changing the process for the submission of the exercise data to attaching a photo of the completed data entry form to the secure message approximately two weeks into the study. Once the process change was made there were no longer any transmission issues.

**Increased Mobility**

Anecdotally, every study participant reported improvement in their physical abilities because of their experience in this telerehabilitation feasibility trial. All study participants indicated they had greater control over the amount of time spent on rehabilitation and scheduling. While most preferred in-hospital rehabilitation for the companionship and encouragement provided by a trainer they also indicated they all made significant improvements in their physical abilities they had not made during their prior rehabilitation training. When asked if there was a difference in the level of physical improvement due to home or hospital rehabilitation the responses were all uniformly in favor of the home telerehabilitation.

*"…do more rehabilitation being at home cause you uh can uh fit to your schedule."*

> *"Yes, I can use my arm more: sweeping, washing dishes, dressing, shoes, clothes are all easier."*

> *"Picking up small objects, moving apparatus from one place to another."*

One study participant became very emotional when relating the degree of increased independence in activities of daily living experienced because of this telerehabilitation trial. The study participant's own words best describe the gains made due to the flexibility to engage in therapy at a time of their choosing.

*"I can give 2 arm hugs instead of just 1 arm hugs. ...I can finger walk up a wall where I couldn't do that before. I can open and close a door, get silverware. I'm able to cut food with my right hand and use a big knife. ... can pull my pants up two-handed. I can almost pull my shift (sic) over my head by myself. I can brush my teeth and rotate my toothbrush ... and can almost feed myself with my right hand."*

A second participant reported that while she still cannot carry anything in her affected hand there is so much more that she can do because of telerehabilitation.

*"...I can load the dishwasher. ... I still cannot carry with my left hand, but I can reach with it and lift it higher. I can move my arm now and I couldn't before. I can turn the light switch off and on and open and close the refrigerator door and raise my arm. This is all new."*

**Empowerment**

Increased independence and autonomy were often cited benefits to the use of My Health***e***Vet with SM for home telerehabilitation. Study participants noted they had the flexibility to decide when an activity was going to happen, or when to send or respond to a secure message.

*"I had a lot more options at home. …There are definitely benefits. The first is travel time it would take me to get to the therapist to do um my therapy."*

*"I liked being able to send texts to my therapist whenever I wanted too."*

*"I could send a secure message whenever I needed to and change up my appointments and it would be done."*

One study participant reported that in a prior trial there were a number of missed appointments and that was not going to be the case in this study because of the flexibility afforded by having the equipment at home and not having to travel for appointments.

> *"I had the flexibility to decide when I was going to do my therapy. It was in my home, so I worked it in for 10-11 and if that didn't work then 3 o'clock."*

All study participants indicated they had greater control over the amount of time spent on rehabilitation and scheduling and did not feel the need for supervised rehabilitation noting:

> *"She set me up for success." She said you need to do these exercises and I had them. I wasn't limited…"*

> *"I'm very self-motivated, I didn't need that. I encourage myself."*

One study participant reported that the YouTube videos provided by the research team members to instruct them in how to perform certain exercises felt like they were in the room with them. When asked if there were any problems retrieving the YouTube videos from the SM's the study participant stated:

> *"The videos were so easy. Just click on the link and boom you're connected."*

> *"If you can view advertisements to buy a board or do email or play games you can do this."*

When an individual was asked if he/she could ask questions about using secure messaging?

> *"Yes, you can.  Absolutely, absolutely, all my questions were answered. I would like to tell you they were wonderful from my first interview."*

Most study participants reported that the inability to effectively use the iPad was a barrier to communicating results of their training on the exercise equipment. One participant stated:

*"I never did get comfortable… I never learned how to use it."*

When asked how the study participant would report their exercise activity, the response was:

*"I just called the staff when I need to report information, or my neighbor helped, or they came to the house."*

Despite the initial barriers to uploading data and navigating the MHV website, only one participant stated they would not be in another study if computers were used. As one participant who became a convert stated:

*"Before this study I was a non-user. They said at first it would be hard, but it became easier over time…The tablet is so useful…I know I can use it for more than just secure messaging…I'm absolutely considering getting a tablet to communicate with family and friends and to be able to shop online or play games or watch a movie."*

**Summary**

The chapter described the experiences of the researchers' and study participants' use and interaction with the My HealtheVet patient portal and secure messaging during a qualitative stroke telerehabilitation feasibility trial. Key findings were presented addressing the two aims of the feasibility trial: 1) explore the experiences and perspectives of researchers and study participants use of four features of My Health***e***Vet (MHV) patient portal and secure messaging (SM) that could inform the design and implementation of future studies using similar information communication technology, and 2) evaluate whether MHV SM or a similar organizationally sponsored patient portal with secure e-mail could be used as an effective information communication technology platform for the delivery of telerehabilitation.

Key findings from background questionnaires, focus group and semi-structured interview responses were presented. The background questionnaires revealed that most of the researchers and study participants were naïve users of My Health***e***Vet and secure messaging and only two study participants had previously used a computer with any regular use prior to their stroke (Table 5). There was a general lack of use of patient portals and the tools associated with patient portals.

The second section of this chapter describes the researchers' lived experiences and perspectives using a descriptive phenomenological qualitative analysis of the focus review transcript. The researchers' experiences and perspectives were grouped into three categories identified as implementation, training and use monitoring. The presented categories are not intended to represent a thematic analysis, they are more akin to the stages of initiating a new process and relate to the descriptions attributed by the research participants. The researchers' experiences represent lessons learned and denote the benefits and barriers to taking morphing an established technology into a new use.

The last section of this chapter described the study participants' lived experiences and perspectives interacting with My Health***e***Vet secure messaging and the four features using a descriptive phenomenological qualitative analysis of the semi-structured interview transcripts. Key findings were presented as a composite summary and three overarching themes were identified as positive benefits from home-based telerehabilitation using My Health*e*Vet SM: caregiver support, increased mobility, and empowerment. Sub-themes classified as benefits or barriers were also highlighted and discussed in relation to the overarching themes and included flexibility, increased control over timing and scheduling of therapy, increased independence, autonomy, unfamiliarity with the use of computer technology, and inability to effectively use the iPad to communicate the results of stroke rehabilitation training. Representative quotes were provided when appropriate.

The final chapter will present a discussion of study findings identifying key factors that influence the use and adoption of information communication technology by researchers and study participants. The chapter will conclude with implications, study limitations and directions for future research.

# CHAPTER 5
# DISCUSSION

## Introduction

This retrospective qualitative feasibility pilot study was part of a larger VA funded single-blinded randomized controlled trial (HP-60526). The qualitative feasibility pilot sought to determine whether the My Health***e***Vet patient portal and SM could be an effective telehealth platform for the delivery of accessible, cost-effective, comprehensive home-based telerehabilitation care to stroke survivors with upper extremity deficits. The aims of this qualitative study were to explore the researchers' and stroke survivors' experiences and perspectives piloting the use of the internet based MHV patient portal with SM for stroke telerehabilitation. To achieve these aims researchers and study participants completed a background questionnaire and semi-structured interviews of a convenience sample of five study participants and a focus group of three research team members were conducted to elicit their experiences using MHV SM and four features. The four features evaluated were 1) use of electronic communication via secure messaging; 2) attaching tools to support patient tracking of self-reported data; 3) attaching education to support patient performance of rehabilitation tasks; and 4) retrieving patient self-reported data.

## Summary of Findings

Study participants and researchers completed a background questionnaire eliciting baseline information about prior computer use and experience with the four features under investigation. The results revealed most researchers and study participants were naïve users Table 5) of internet-based patient portals, My Health***e***Vet (MHV) and secure messaging (SM). The lived experiences and perspectives of the researchers on the rollout and use of MHV SM for telerehabilitation were elicited during a focus group. The researchers identified benefits and barriers to implementation, training, and on-going monitoring of use of MHV SM, yet also reported the pilot was successful as a delivery medium for communicating with the study participants and delivering their exercise prescription (Aim 1). Using a descriptive phenomenological approach, this feasibility study identified three overarching themes from the semi-structured interviews of the study participants: caregiver support, mobility, and empowerment. Contributing to these findings were sub-themes classified as benefits that included flexibility, increased control over timing and scheduling of therapy, increased independence, and autonomy; and barriers such as unfamiliarity with the use of computer technology, and inability to effectively use the iPad to communicate the results of stroke rehabilitation training. Overall, the study participants found the use of MHV SM an effective means of receiving stroke telerehabilitation (Aim 2) that will be discussed in greater detail below.

**Electronic Communication via Secure Messaging (RQ1.1 and RQ2.1)**

The researchers and study participants were largely naïve users of the MHV patient portal and SM. There was a mixed response among the study participants with some embracing the new technology and quickly becoming comfortable with logging into the MHV patient portal and navigating to SM, whereas others reported difficulty. A barrier to use was the design of the patient portal and the number of clicks necessary to get to the secure messaging feature to either compose or read a secure message. The recognition of design barriers in patient portals is not a new finding; and it is not relegated to the number of clicks it takes to complete an action (Barnard, Bradley, Hodgson, & Lloyd, 2013; Czaja et al., 2015). Other factors can impact a user's ability to successfully interact with any internet-based tool, starting with the device used to connect with the patient portal. As in this case, the biggest barrier to use was unfamiliarity with the iPad device issued to each study participant randomized to the intervention arm of the study.

In technology acceptance research ease of use and perceived usefulness (Davis, 1989) are important concepts as are the classical attributes of usability: easy to learn, efficient to use, easy to remember, error free and subjectively pleasing (Nielsen, 1993). The small size of the iPad tablet, number of icons on the screen, connectivity issues and unfamiliarity with using this device created some initial difficulty for study participants. While each study participant was required to have a certain level of cognitive and motor functioning for participation in this study there was no consideration given to what would have been the best device for their use during this feasibility study. Device selection was a complex issue addressed at a national level to meet accessibility, regulatory, security and privacy requirements. The selection of the iPad was one of convenience as it met the national level requirements and was available for use with the assistance of the Office of Connected Care.

Prior knowledge of computers did not automatically confer the ability to perform satisfactorily with an iPad, somewhat in contravention of Bandura's (2012) self-efficacy concept, which would have promoted the belief that prior successful computer use would be predictive of continued success. One study participant noted: "It is really different after a stroke; you aren't the same and have to learn all over again." Another study participant found it easier to access the internet and the patient portal using her smartphone stating: "I would log on using my phone to see a message. It was really convenient." The third participant simply refused to learn how to use the device and left the handling of the iPad and all communications to his caregiver. The final two study participants initially struggled to become proficient with one of them moving from a non-user to a somewhat enthusiastic user. Subjectively, the iPad device may not have been the best device choice from the study participants perspective as it did not meet ease of use, usability for use, and perceived usefulness criteria for the majority of study participants (Davis, 1989; Nielsen, 1993).

The experiences and perspectives of the study participants point to a critical element in technology acceptance research, that of understanding the end user of the device. Usability testing using the think aloud method as study participants and/or their caregivers navigate the use of the iPad device to access the MHV patient portal and SM might have garnered valuable information to improve performance and enhance overall adoption (Amirabdollahian et al., 2014; Czaja et al., 2015; Yen et al., 2018). Since no consideration was given to using this method during the rollout of the parent study this represents an area of future research where a nurse informaticist can generate valuable insight into device selection, use and the design of training prior to implementation of the research trial.

**Attaching Tools to Track Self-Reported Patient Data (RQ1.2 and RQ2.2)**

Attaching patient generated self-reported data was the most problem prone area of this feasibility study. Most study participants had initial difficulty with this process due to the selected telecommunication device. Study participants commented that the iPad would freeze when trying to transmit their training results and display a 'not communicating' message. The remaining study participants did not comment on the role of their caregivers during these breakdowns in communication. Instead they would call the research team members for assistance that was always available. The connectivity/communication issues were not easily surmounted by the study participants or research team members as they were most frequently associated with automatic updates conducted by the iPad software settings and the timing was unpredictable. Usability testing might have helped to address issues related to the attachment of self-reported patient data (Barnard et al., 2013; Yen et al., 2018). Face-to-face training was insufficient to improve the level of success for some study participants. One study participant chose to phone in their results on a weekly basis rather than to attempt to attach them to a secure message. Another study participant seemed to focus on being in control and ensuring the safety of the reported data. The security and acceptance of electronic technologies and internet based patient portals has been a reported concern in previous studies (Amante et al., 2014; Peek et al., 2014). After successfully transmitting his data using MHV SM the study participant commented: “It made me feel safe. My information was secure.”

Tools to support patient tracking of self-reported data were initially unsuccessful. Most study participants reported that the inability to effectively use the iPad was a barrier to communicating results of their training on the exercise equipment. The research team employed a user centered design technique to resolve the issue; assessing the problem with attaching the self-reported patient data iteratively until a solution was generated. The ultimate redesign of the process resulted in study participants taking a screenshot of the training report, saving it to the photo album and sending it to the therapist as a SM attachment after each session (Dabbs et al., 2009). The redesign of the attachment process for self-reported patient generated data addressed research questions 1.2 and 2.2. and 3.3. Study participants and researchers voiced satisfaction with the redesigned process. Screenshot images/photos of the exercise data were sent to the research staff without incident.

**Attaching Education to Support Patient Performance (RQ1.3 and RQ2.3)**

Study participants reporting increased mobility and physical activity due to the convenience of having the exercise device in their homes and receiving their education via SM rather than having to go to a research laboratory (Cherry et al., 2017). Accessing the YouTube education videos was performed with ease and addressed research questions 1.3, 2.3 and 3.2. One study participant reported that it felt like the therapists were in the room with them looking over their shoulder. When asked if there were any problems retrieving the YouTube videos from the SM's the study participant stated: "The videos were so easy. Just click on the link and boom you are connected. If you can view advertisements to buy a boat or do email or play games, you can do this." The ease of using the YouTube videos translated into actual performance (Davis, 1989).

Study participants commented on the advantage of being able to look back and review the YouTube video content if there were questions on how to perform an exercise, or the number of repetitions to do. Most appreciated the ability to perform at their own pace. All study participants indicated they had greater control over the amount of time spent on rehabilitation and scheduling and most did not feel the need for supervised rehabilitation noting: "She set me up for success." She said you need to do these exercises and I had them. I wasn't limited…" Anecdotally, each of the study participants shared their stories of the significant improvements they felt they made because of this feasibility study (Aim 2). One study participant spoke about being able to give two arm hugs now, whereas another was so proud that she could move her affected arm enough to turn a light off and on and load the dishwasher, while a third could uncurl and flatten his hand and another was able to lift a lid off of a pan. While these may seem like small accomplishments, to a stroke survivor, every improvement is power. The last study participant said it best: “Don’t give up, don’t get a chair and don’t stop trying.”

**Retrieving Tools to Track Self-Reported Patient Data (RQ1.4 and RQ2.4)**

The self-reporting patient data form was pre-loaded on the iPad distributed to each study participant at the start of the feasibility trial. A training protocol, with appropriate education, for how to use the device for accessing MHV patient portal with SM and the data reporting form were created by the staff and student investigator. The iPad devices were individually signed out to study participants. The form had to be cleared of old data before new data could be entered and this posed difficulty for some of the study participants. One solution was the use of paper data forms. The paper data forms were either distributed during home visits by a research team member or the study participant would come to the laboratory for a face-to-face training session and pick up additional paper forms as backups. While these temporizing measures worked during the redesign of the templated form and the process for attaching the self-reported data to the SM, it did not address the more fundamental issue of the tracking tool. Usability heuristics could have been employed by creating a clear action button or clear text button for use each time the tool was being sourced which might have simplified its use for novice users (Rogers, Sockolow, Bowles, Hand, & George, 2013; Yen et al., 2018).

Despite the initial barriers to uploading data, navigating the MHV website, and retrieving data, only one participant stated they would not be in another research study if computers were used. As one participant who became a convert stated: “Before this study I was a non-user. They said at first it would be hard, but it became easier over time.” Improving the process for uploading self-reported patient data was important in two aspects as it: 1) ensured data fidelity and secure reporting and 2) allowed for self-retrieval of data by the study participant through the review of sent SMs addressing research questions 1.4 and 2.4. One of the less discussed features of the MHV patient portal is the ability to archive sent and received messages in the user’s in box. One study participant commented on this feature, noting that if they had a question they would go back and read what the therapist had written in the SM.

**Ease of Use, Barriers and Benefits of MHV SM (RQ1.5, RQ2.5, RQ3.1, 3.2, 3.3)**

The reported experiences and perspectives of the researchers and study participants in this qualitative feasibility study suggest the MHV patient portal and SM was an effective method for delivering telerehabilitation (Aim 2). Applying Nielson’s classical definition of usability the secure messaging aspect of this study encompassed four of the five elements of usability: easy to learn, efficient, easily remembered, and error free (Nielsen, 1993) addressing research question 3.1. There was insufficient information derived from the focus group or semi-structured interviews to be able to determine if it was subjectively pleasing to the researchers or study participants although there were comments about flexibility and convenience which may translate to pleasing for some users.

Research providers were able to integrate the use of MHV patient portal with SM for home-based telerehabilitation for effective workflow communication, and flow of information between the study participants/caregivers and research team members without constraints based upon time, location, or the type of device (e.g., iPad, smartphone, laptop, etc.) used for communication (Nazi, 2013). Research staff noted it gave them the flexibility to send and respond to SM at a time that was convenient to them, allowing for greater control over their schedules addressing research question 1.5 and Aim 2. Researchers felt they were able to establish a strong patient/provider relationship through secure messaging.

Similarly, study participants enjoyed the freedom of asynchronous SM communication and the ability to alter their schedule to a time that was more convenient for them. MHV SM gave study participants the flexibility to perform activities at their own pace and at a time convenient to them. Study participants were able to successfully receive SMs that contained their treatment intervention as well as the videos demonstrating the activities they were to perform, addressing research question 2.5 and Aim 2. Links to other sources of information were not used, although an overview of the resources and functionality of the Veterans Health Library was provided.

Researchers and study participants all agreed that the use of MHV SM allowed the study participants to progress through the research protocol remotely. The study participants reported being able to review the videos at their own pace or opting to do training at a time of their convenience. The study findings suggest the exercise equipment in the home and access to their exercise prescription and video instructions via SM promoted increased physical activity, improved mobility, increased independence, and a sense of empowerment, which generated the themes of increased mobility and empowerment addressing research questions 3.1, 3.2 and Aim 2. A qualitative telerehabilitation study using a robotic device in the home demonstrated similar findings with study participants reporting increased mobility and physical activity due to the convenience of having the device in their homes rather than having to go to a research laboratory (Cherry et al., 2017). Increased independence and autonomy were oft cited benefits to the use of MHV with SM for home telerehabilitation.

Anecdotally, every study participant reported improvement in their physical abilities because of their experience in this telerehabilitation feasibility trial. All study participants indicated they had greater control over the amount of time spent on rehabilitation and scheduling. While most preferred in-hospital rehabilitation for the companionship and encouragement provided by a trainer they also indicated they all made significant improvements in their physical abilities they had not made during their prior rehabilitation training. When asked if there was a difference in the level of physical improvement due to home or hospital rehabilitation the responses were all uniformly in favor of the home telerehabilitation addressing research question 3.2. One study participant became very emotional when relating the degree of increased independence in activities of daily living experienced because of this telerehabilitation trial. The study participant's own words best describe the gains made due to the flexibility to engage in therapy at a time of their choosing: "I can finger walk up a wall where I could not do that before; can pull my pants up two-handed; can almost feed myself with my right hand." A second participant reported that while she still cannot carry anything in her affected hand there is so much more that she can do because of telerehabilitation. "I can reach with it and lift it higher. I can turn the light switch off and on and open and close the refrigerator door and raise my arm. This is all new." To the non-disabled they may seem like such small accomplishments but to the stroke survivor they can represent conquering a mountain or a least a small hill.

There were several features that garnered praise from study participants: 1) notification via personal email that a secure message was waiting to be read, 2) asynchronous communication, 3) ability to use any internet-enabled device to access their My Health***e***Vet account, 4) ability to send from anywhere in the world where an internet connection was available, 5) ability to replay the training videos or review exercise instructions, on demand, by simply returning to the secure message whenever they wanted. The perceived ease of use and perceived usefulness of the secure messaging feature of the MHV patient portal was valued by all study participants/caregivers and overweighed any inconvenience caused by additional clicks to get to the appropriate page (Bandura, 2012; Davis, 1989). Study participants reported increased mobility, greater control over the amount of time spent on rehabilitation and the scheduling of their activities as positive benefits from home telerehabilitation. There were also two participants whose stated preference was for face-to-face rehabilitation. These same two study participants verbalized that having an opportunity to talk with other participants in the telerehabilitation study would enhance the experience. Whereas other study participants were interested in the chat room idea but did not feel they needed an external motivator to succeed. As one stated: "… my improvement is my record. I can see it."

The most notable barrier was the receipt of patient generated study data. The initial process required the patient to complete an online form received in a SM and to upload and send the document back to the research team via SM. This process proved too cumbersome and it took approximately one-year into the study to resolve the issue. Study participants were directed to take a picture of the completed form and send it as an attachment to the secure message. After this change in process there were no further issues in the transmittal of patient generated data (addressing research question 3.3).

**Implications for Researchers and the Organization**

Telehealth and telerehabilitation are rapidly expanding areas of study. Technology is developing at a rapid pace and equipment funding should be available throughout the entire length of the research trial for the replacement of defective, worn, or outdated equipment (Chumbler et al., 2010). In large studies it is recommended that a dedicated research coordinator with telehealth or informatics experience be identified who can work with the relevant regulations required to implement a telehealth study. Additionally, it is also recommended that the research team partner with all relevant services at a local, regional, and national level to prepare for regulatory, licensing, or reimbursement guidelines that may affect the implementation of the telehealth study. In large cooperative studies it is suggested that a research coordinator is necessary for each site. If future research studies are interested in using the My Health***e***Vet patient portal with secure messaging, early consultation with the Office of Connected Care and the facility Telehealth Coordinator and/or My Health***e***Vet Coordinator is highly recommended. One of the major barriers for the researchers in this study was the inability to establish a dummy or test account. Early discussions with the facility or Veterans Integrated Service Network (VISN) telehealth coordinator might enable the researcher to access the test account used for testing or the building of an account in preparation for the research study.

**Study Limitations**

This study has several limitations. First it is a qualitative research design which is not quantifiable or generalizable to the population as whole. Second, the principal findings are based on the experiences of a small convenience sample drawn from a larger parent study and three members of the research team. An aim of this study was to understand the experiences with four features of the My Health***e***Vet patient portal and Secure Messaging. This was somewhat limited as not all participants fully engaged in its use although a great deal of information was elicited about the benefits and barriers to use. Lastly, a potential for bias exists as the student investigator has experience with the My Health***e***Vet patient portal and secure messaging. To address this potential source of bias, the student investigator made careful field notes and submitted all transcripts, summary, and thematic analysis to the principal investigator for validation.

**Areas for Future Research**

Findings from this study suggest that internet-enabled patient portals and personal health records with secure messaging, such as, My Health***e***Vet may fill a gap in telehealth and telerehabilitation that have been previously unexplored. Areas for future research include examining telecommunication/telehealth applications designed for individuals with cognitive and or communication disabilities arising from stroke or other neurological conditions. Another suggestion for enhancement in telerehabilitation is the combination of an anonymous chat room for study participants in addition to the exchange of secure messaging between the study participant and researcher. While this suggestion would require close analysis to determine whether it should be monitored or unmonitored and used under what circumstances it provides an avenue for discussion not previously addressed. The recent pandemic has elevated the profile of My Health***e***Vet and secure messaging in the inpatient environment of VA hospitals nationwide. Efforts have been underway to equip inpatient's with iPads so that providers can use secure messaging to communicate with patients in quarantine. While the iPads are also being used for video communication the asynchronous nature of secure messaging allows the veteran inpatient to communicate with staff whenever they have a need to do so and the provider will be notified via their VA email that a secure message is waiting for them. Research into the success and or consequences of the use of My Health***e***Vet during this national emergency has the potential to deliver valuable data about integration of MHV and SM into inpatient workflow, patient/provider communication, and mapping it to health care activities across care processes. The informatics nurse can play a critical role in driving research efforts into patient portal use through usability testing, think aloud protocols and the development of specific plan of care tools to be used in conjunction with newly defined initiatives using patient portals for inpatient, outpatient and telerehabilitation care.

**Conclusions**

This retrospective qualitative feasibility pilot sought to determine whether the My Health***e***Vet patient portal and SM could be an effective telehealth platform for the delivery of accessible, cost-effective, comprehensive home-based telerehabilitation care to stroke survivors with upper extremity deficits. The aims of this qualitative study were to explore the researchers' and stroke survivors' experiences and perspectives piloting the use of the internet based MHV patient portal with SM for stroke telerehabilitation and to elicit their experiences using MHV SM and four features. The study results are promising, indicating MHV SM can be used to deliver home-based stroke telerehabilitation communication to include the exercise regimen and video instructions. Researchers and study participants reported MHV SM to be a convenient, asynchronous communication tool that empowered the study participants to have greater control over scheduling of rehabilitation, increased mobility, and enhanced caregiver support. Study participants and caregivers appreciated that secure messaging allowed for communication on their schedule regardless of time or location. Device barriers were identified during the feasibility trial due to the size of the device and the requirement to upload data. All participants felt the benefits of using MHV with SM outweighed the device barriers experienced during the feasibility trial.

APPENDIX A

RECRUITMENT SCRIPT

**My HealtheVet Secure Messaging Pilot and Qualitative Study**

Thank you for the opportunity to tell you about an important My Health***e***Vet research study and to invite your participation in the study to help us to better understand the experiences and perspectives of VA research professionals implementing the use of the My Health***e***Vet Patient Portal and Secure Messaging in research.

The national My Health***e***Vet Personal Health Record at www.myhealth.va.gov was launched in November 2003 and is available to all Veterans, VA staff, and non-veterans. There are approximately 3.18 million registered users (U.S. Department of Veterans Affairs, 2017). The My Health***e***Vet portal includes a medical library with patient education resources, a personal health record (PHR) that enables patients to track their personal health information, and electronic services such as online prescription refill and secure messaging (SM). Veteran patients with premium accounts may also view extracts from their VA Electronic Health Record, such as their VA prescription history, laboratory reports, provider notes and Wellness Reminders.

We use a variety of methods to elicit feedback from Veterans about My Health***e***Vet. Understanding the patient perspective is important. Patient PHR use also has broad implications for health care professionals. This study is focused on exploring the experiences and perspectives of VA researchers using the My Health***e***Vet patient portal and tools for the first time in research.

I will be conducting interviews and/or a focus group with VA researchers and My Health***e***Vet Coordinators to learn about their experiences with implementation and use of the My Health***e***Vet patient portal, secure messaging, education tools, and exchange of patient managed health data; to understand their lived experience about its impact on their interactions with study participants, existing work practices, and information flow.

The study will focus on four My Health*e*Vet patient portal features:

1) electronic communication with secure messaging.
2) attaching tools to support patient tracking of self-reported data.
3) attaching education to support patient performance of rehabilitation tasks; and
4) retrieving patient self-reported data in home-based telerehabilitation.

There are three requirements for participation in the study. Participants must:

- ✓ be a VHA researcher involved in the 'Telebactrac' parent study to this qualitative research trial
- ✓ have had experience with study participant use of one or more of these My Health*e*Vet features

- ✓ be able to participate in one 45-60-minute interview either in person or by telephone.

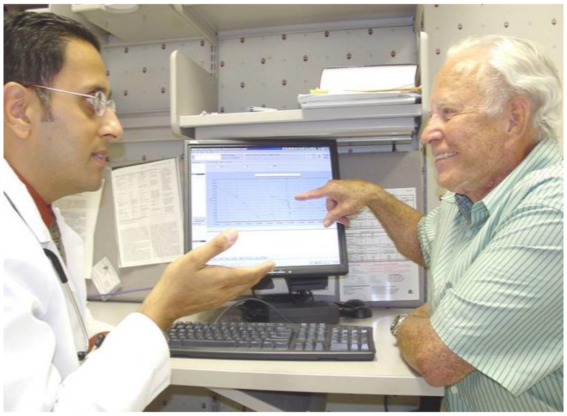
Participation in the study is voluntary and all information offered by participants will be kept confidential.

If you think you might be interested in participating in this study, or would like to learn more about it, please contact me by email (Linda Keldsen: Linda.Keldsen@va.gov) or by telephone (410) 605-7178. Please also share information about the study with other VA research professionals whom you think fit the requirements and who may be interested in participating.

Thank you.

-----------------------------------------------End of Script----------------------------------------

APPENDIX B
RECRUITMENT FLYER



Courtesy of VA Multimedia Stock Photo

**My Health*e*Vet Secure Messaging Pilot and Qualitative Study**

Linda Keldsen
VA Maryland Health Care System
University at Maryland, School of Nursing
Baltimore, MD

Study Participants in the VA Funded Telebactrac Home-based Stroke Rehabilitation Study using the My Health***e***Vet Patient Portal and Secure Messaging are invited to participate in an important research study to share their experiences and perspectives on Veteran and non-veteran use of the VA My Health***e***Vet patient portal found at www.myhealth.va.gov.

We will be conducting interviews and/or a focus group with study participants in the 'Telebactrac' home-based stroke telerehabilitation study to learn about their experiences with use of the My Health***e***Vet patient portal and to understand their perspectives about its impact on their interactions with the research team and the goals of their stroke rehabilitation.

The study will focus on four My Health***e***Vet PHR features:

1) electronic communication with secure messaging.
2) attaching tools to support patient tracking of self-reported data.
3) retrieving patient education to support patient performance of rehabilitation tasks; and
4) submitting patient self-reported data in home-based telerehabilitation.

We invite your participation in this study if you:

- ✓ are enrolled in the My Health***e***Vet portion of the 'Telebactrac' home-based stroke telerehabilitation study
- ✓ have had experience with the use of one or more of these My Health***e***Vet features
- ✓ can participate in one 45-60-minute interview either in person or by telephone.

Why participate?

Patient Portals and secure messaging are designed as consumer-oriented tools to empower patients and improve health care. Despite significant interest and the anticipated benefits, little is known about the usefulness of patient portals and secure messaging in research. Understanding the consumer's experience with these important tools is critical to our understanding of how these tools can be used to successfully support consumers. Patient portal and secure messaging use has broad implications for health care institutions, health professionals and researchers. **Help us to understand how Veterans and Non-Veterans use of the My Health*e*Vet Patient Portal and Secure Messaging has impacted your stroke recovery!** Participation is voluntary, and your input will be kept confidential.

**If you are interested in participating in the study, or would like to learn more about it, please contact Linda Keldsen by email (Linda.Keldsen@va.gov) or telephone (410-605-7178).**

-------------------------------------------------------Thank you--------------------------------------

APPENDIX C
INFORMED CONSENT FORM

**Department of Veterans Affairs** **Research Consent Form**

Participant Name: ________________________________ Date:______________

Title of Study: ***Translating Intensive Arm Rehabilitation in Stroke to a Telerehabilitation Format***

Principal Investigator: ***Susan Conroy, PT, DSc.PT 410-637-3213***
VA Facility: ***Baltimore (512)***

**STUDY No: HP-00060526: PATIENT CONSENT FORM**

**SPONSOR: VA Rehabilitation Research and Development**

You are invited to participate in a research study. This study, called TeleBATRAC, is investigating a home arm exercise program using the Internet. If you are eligible and wish to participate, please note that you are a volunteer and may ask questions at any time. The research will take place at the VA Maryland Health Care System (VAMHCS), conducted by VAMHCS researchers and staff at the Baltimore VA Annex located on 209 West Fayette Street, Baltimore, MD 21201, and at VA-leased space at the University of Maryland Allied Health Building, 100 Penn Street, Baltimore, MD 21201.

**PURPOSE OF STUDY:**

Stroke rehabilitation studies investigating recovery of arm use with a specific portable repetitive exercise device called the Bilateral Arm Training with Rhythmic Auditory Cueing (BATRAC) have shown to benefit people several months after stroke. The purpose of this study is to determine if a home program using the BATRAC can be successfully combined with traditional exercise and the VA's MyHealth*e*Vet website for remote "telerehabilitation" of arm weakness after stroke. The MyHealth*e*Vet website will allow for exercise video access and secure messaging to a therapist. We will compare this home-based telerehabilitation exercise program to the same exercise provided here at the VA and to a group that does not exercise for the first 6 weeks of the study. The BATRAC is available in the marketplace as an FDA-approved exercise device called the "Tailwind." It was developed and studied with patients with stroke at the University of Maryland and is NOT an investigational device.

You may qualify for this study if you had a stroke at least 6 months ago and continue to have weakness in your arm. You also have an identified person (caregiver) that will assist with your exercise program, if needed. The VAMHCS will be the primary location for this study, and you will be one of 98 participants asked to take part.

| Department of Veterans Affairs | Research Consent Form |
|---|---|

Participant Name: ______________________________ Date:______________

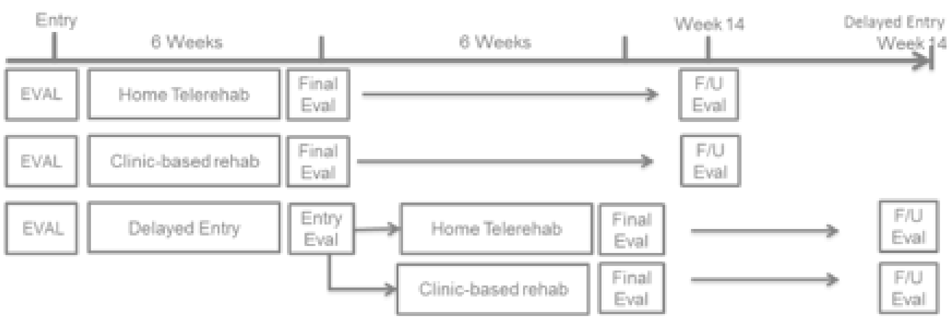
Title of Study: ***Translating Intensive Arm Rehabilitation in Stroke to a Telerehabilitation Format***

Principal Investigator: ***Susan Conroy, PT, DSc.PT 410-637-3213***
VA Facility: ***Baltimore (512)***

PROCEDURES:

**This is a single blind randomized controlled trial. This means our study evaluator will not know, and will be "blinded," to your exercise group assignment and cannot be told which treatment you are getting**. However, you, the therapist, and the study doctor will know. Please be aware that this study requires a large amount of time and effort. If you agree to participate, you may be asked to make about 24 visits to the VA. This entire study will take about 5–7 months.

**There are three exercise groups assigned at random. This means the group you get will be chosen by chance, like flipping a coin. Neither you nor the study team will choose what treatment you get.** There are three exercise groups you can be randomly assigned to: (1) a home-based telerehabilitation group, (2) a clinic-based rehabilitation group, or (3) a delayed-entry group. The first two groups will start training immediately after the consent and baseline process. The delayed-entry group will wait 6 weeks before starting their randomly assigned exercise training. The figure below shows how the study will be conducted.




If you agree to participate in this study, you will receive baseline evaluations for the first month (4 weeks), followed by <u>either</u> 6 weeks of your randomized exercise <u>or</u> 6 weeks of weekly phone calls if you are initially assigned to the delay group. Home-based telerehabilitation and clinic-based rehabilitation will include exercise sessions 3 times /week for a total of 18 training sessions. This training will be spread over a maximum of 9 weeks, to allow for missed visits due to transportation/weather or minor illness. You will be asked to return for a follow-up after 8 weeks of no training. Please note that if you are initially randomized to the delayed entry group, you will have a slightly longer maximum study commitment: 4 weeks of baseline + 6 weeks of delay + max. 9 weeks of intervention + 8 weeks of retention = 27 weeks.

The research related procedures performed include:

- General Medical Evaluation: A general neurological evaluation will be conducted at baseline by a neurologist to confirm clinical diagnosis of stroke and review medical records related to your stroke. A depression survey called the Center for Epidemiologic Studies Depression Scale, and a cognitive screening called the Montreal Cognitive Assessment will also be conducted at this time. The doctor will promptly notify you and refer you to a specialist if your depression or cognitive test indicate need for concern. This evaluation should take approximately 30–40 minutes.

- Robotic Evaluation of Arm Function: The KinArm robot is an arm robot specifically designed to test motor skill and coordination of both your arms at the same time. It will be used to evaluate your arm function. This evaluation will occur once at the start of the study, and once at the end of the study by a trained study staff member. This VA-owned robot is located at VA-leased space at the University of Maryland Allied Health Building.

- Non-robotic Evaluations of Arm Function and Use: **These will be performed at the VA by an evaluator that is not supposed to know your treatment assignment.** Each evaluation visit will take approximately 90 minutes to complete. You will need to attend three baseline visits with him/her approximately one week apart in the first month. You will also need to be seen by this evaluator at a final evaluation visit (on Week 6–9), and after an 8-week time period of no training (at a visit called the retention evaluation visit).

- Questionnaires and surveys about your activity, arm use, self-efficacy, satisfaction, and learning.

The specific non-robotic research evaluations are as follows:

- Wolf Motor Function Test: This includes 15 timed arm/hand tasks and two strength activities designed to measure the capabilities of your stroke-affected arm. Time to administer this test is approximately 25 minutes.

- Fugl-Meyer Upper Extremity Motor Performance: This is an examination of your ability to move your arm and hand for specific tests including reflexes, sensation, and movement quality. Time to administer this test is approximately 25 minutes.

- The Action Research Arm Test is an evaluation of your ability to handle objects and complete gross and fine-motor tasks with your left or right hand. Time to administer is 7–10 minutes.

- Stroke Impact Scale (Questionnaire): This is a structured interview consisting of 50 questions about your physical activity, activities of daily living, mobility, and hand function after your stroke. Time to administer is approximately 10 minutes.

- Motor Activity Log-28 (Questionnaire): This is a structured interview about the quality and amount of arm movement you have throughout your day. It includes activities ranging from eating to dressing to housework. This interview will be conducted with you and with your designated caregiver. Time to administer is approximately 15 minutes.

- Strength: Strength grip will be tested using a force-measuring device called a dynamometer, and manual muscle testing of the upper extremity. Time to administer is approximately 10 minutes.

Questionnaires and surveys include:

- Telerehabilitation Satisfaction Survey (for the home-based telerehabilitation group, and the clinic-based group): This is a 12- to 17-question survey of participant satisfaction with the intervention. It includes questions related to ease of use, and general satisfaction. Time to administer is approximately 5–10 minutes.

- Self-efficacy questionnaires about your exercise expectations and barriers to exercise: Time to administer the two questionnaires is approximately 10 minutes.

- Home Activity Questionnaire (for the delayed-entry group only): This is a 10-question survey of activities completed in the past week using your stroke-affected arm, also to record general household activities and community outings. Time to administer is approximately 5 minutes.

MyHealth*e*Vet (for the home-based telerehabilitation group only):

For the home-based telerehabilitation group, secure messages are exchanged as part of the study over the VA's MyHealth*e*Vet website to communicate treatment activities and recommendations between you and the study team. You will receive training and education in how to register and use the system by the study team if randomized to this group. This will take approximately 15 minutes.

If you are randomized to the home-based telerehabilitation group, you also will have the **option** to videoconference with the study team via the VA's "VA Video Connect" app. VA Video Connect uses encryption to ensure a secure and private session, and it allows quick and easy health care access from any mobile or web-based device. You can learn more about VA Video Connect at https://mobile.va.gov/app/va-video-connect. If you choose to use this app, you will receive training and education on how to use it. This training will take approximately 5 to 10 minutes.

Please check the box below indicating whether or not you choose to communicate with the study team via VA Video Connect.

_____ Yes, I agree to communicate with the study team via the VA's "VA Video Connect" app—in addition to the VA's MyHealth*e*Vet website—if I am randomized to the home-based telerehabilitation group. I understand this is an **optional** part of the study, and using this app has no bearing on my enrollment or randomization in this study. I also understand that I may withdraw consent to participate in this aspect of the study at any time.

_____ No, I am not interested in communicating with the study team via the VA's "VA Video Connect" app if I am randomized to the home-based telerehabilitation group. I understand that refusing this option has no bearing on my enrollment or randomization in this study.

Subject Initials __________ Date___________

Home Activity Monitoring with Accelerometers:

Accelerometers are portable sensors that can be worn on your wrist to record your arm activity. We will ask you to wear these watch band-type devices for approximately 4 days at the start of the study, and then again at the end of the study. This information will complement the questionnaires and further add to the understanding of the level of your arm activity after a stroke.

**FUTURE RESEARCH:**

After completing this study, you may be eligible to participate in future IRB-approved research projects for persons who have had a stroke. Please check the box below indicating whether or not you agree to be contacted for future research studies. Even if you agree to be re-contacted now, you may still change your mind about this in the future.

_____ Yes, I may be re-contacted to learn about future research studies.

_____ No, I may not be re-contacted to receive this information

Subject Initials __________ Date___________

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**[OPTIONAL] MyHealth*e*Vet SECURE MESSAGING PILOT AND QUALITATIVE STUDY:**

The VA Maryland Health Care System (VAMHCS) would like to gather information about the use of MyHealth*e*Vet (MHV) secure messaging for research communication in the TeleBATRAC main study. Secure messaging is used clinically at the VA for patient and provider communication, but it has not been fully evaluated for research communication.

You have the **option** of participating in the MyHealth*e*Vet Secure Messaging Pilot and Qualitative Study. If you are interested in participating, and if you are randomized to the home telerehabilitation group or the delayed entry group in the primary study, you will be asked to complete additional questionnaires at the beginning and end of the study. These questionnaires will add an additional 30 minutes to your pre- and post-study assessments and include the eHealth Literacy Scale, Web-Based Learning Self-Efficacy Scale, and Montreal Cognitive Assessment, as well as a brief MyHealth*e*Vet interview. At the end of the study, you will be asked to complete a brief background questionnaire about your previous experience with the MyHealth*e*Vet patient portal and a one-hour face-to-face interview. **This data collection is <u>optional</u>, and you can opt to participate or refuse. Your participation in this pilot study does not affect your participation in the primary study.**

Questionnaires and interviews for the MyHealth*e*Vet Secure Messaging Pilot and Qualitative Study are as follows:

1. eHealth Literacy Scale (eHeals): This is an 8-item questionnaire that measures your perceived ability and comfort using information technology for health. It will be used to gain an understanding of your electronic health literacy at the beginning and again at the end of the study. It should take approximately 5 minutes to complete.

2. Web-Based Learning Self-Efficacy Scale (WBLSES): This is an 8- to 12-item questionnaire used to rate your confidence using electronic tools for web-based online learning. Questions ask you to rate your opinion the MyHealth*e*Vet instructions used, availability of assistance, amount of time available to complete the items, encouragement, physical conditions, and computer navigation methods. It will be given at the onset of the study and again at the end of the study. It should take approximately 5 minutes to complete.

3. Background Questionnaire: This is an 8- to 12- item questionnaire used to gather your prior experience with the MyHealth*e*Vet patient portal and its tools prior to participating in this pilot study. It should take approximately 5 minutes to complete.

4. Interview: The MyHealth*e*Vet interview will be completed after you receive instruction in using the MHV website for access to the secure messaging portal and mail group. This interview will be completed after your initial instruction and at any follow-up training. Questions will focus on your experience with the training and confidence using the site. An additional one-hour interview at the end of the study will focus on your overall experiences and perspectives on MyHealth*e*Vet use.

**RISKS:**

- The MyHealtheVet Secure Messaging Pilot and Qualitative Study has a risk of frustration and/or irritation with completing the questionnaires and interviews. You can skip any question that you find uncomfortable.
- There is a minimal risk that a breach of confidentiality could occur. Loss of confidentiality will be minimized by storing data in a secure location, such as a locked office and locked cabinet, and electronic and voice-recorded data will be password-protected and secured behind a firewall in a database within a VA server.

Please check the box below indicating whether or not you agree to participate in these additional activities for the MyHealtheVet Secure Messaging Pilot and Qualitative Study.

_____ Yes, I agree to participate in the MyHealtheVet Secure Messaging Pilot and Qualitative Study. I understand this is an **optional** part of the study and enrolling has no bearing on enrollment or randomization. I agree to complete additional questionnaires and an interview. I also understand that the study team will make every effort to coordinate the MyHealtheVet Secure Messaging Pilot and Qualitative Study appointments with the primary study appointments to avoid undue travel. I also understand that I may withdraw consent to participate in this aspect of the study at any time.

_____ No, I am not interested in participating in the MyHealtheVet Secure Messaging Pilot and Qualitative Study. I understand that refusing this option has no bearing on enrollment or randomization in the primary study.

Subject Initials _____________ Date:_________________

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**[OPTIONAL] RETURNING STUDY PARTICIPANTS—QUALITATIVE STUDY OF FOUR FEATURES OF THE MyHealtheVet SECURE MESSAGING PILOT:**

You have indicated a willingness to be notified about additional research studies. The VA Maryland Health Care System (VAMHCS) would like to gather information about your experience and perspective using four features of the MyHealtheVet personal health record during your previous participation in the MyHealth*e*Vet secure messaging pilot. Your experience and perspective could have important ramifications on the design and implementation of future studies using this communication technology for home-based telerehabilitation. This area of research has not been previously addressed, and your experience will provide valuable insight into the use of information communication technology in telerehabilitation research.

You have the **option** of participating in the Qualitative Study of Four Features of the MyHealth*e*Vet Secure Messaging Pilot. To participate in this Qualitative Study of Four Features of the MyHealth*e*Vet Secure Messaging Pilot, you must have (1) been randomized to either (A) the home-based telerehabilitation group or (B) the delayed entry group, and (2) agreed to be contacted about participation in other research studies following your participation in the primary study. If you are interested in participating, you will be asked to complete an 8- to 12-item questionnaire, and to participate in a one-hour face-to-face interview. **This data collection is optional, and you can opt to participate or refuse. Your participation in this pilot study does not affect your participation in the primary study.**

**RISKS:**

- The Qualitative Study of Four Features of the MyHealth*e*Vet Secure Messaging Pilot has a risk of frustration and/or irritation with completing the questionnaires and interviews. You can skip any question that you find uncomfortable.
- There is a minimal risk that a breach of confidentiality could occur. Loss of confidentiality will be minimized by storing data in a secure location, such as a locked office and locked cabinet, and electronic and voice-recorded data will be password-protected and secured behind a firewall in a database within a VA server.

Please check the box below indicating whether or not you agree to participate in these additional activities for the Qualitative Study of Four Features of the MyHealth*e*Vet Secure Messaging Pilot.

_____ Yes, I agree to participate in the Qualitative Study of Four Features of the MyHealth*e*Vet Secure Messaging Pilot. I agree to complete a questionnaire and a one-hour face-to-face interview. I also understand that the study team will make every effort to coordinate the Qualitative Study of Four Features of the MyHealth*e*Vet Secure Messaging Pilot appointments with regularly-scheduled VA appointments or at a time convenient for me to avoid undue travel.

Department of Veterans Affairs

**Research Consent Form**

Participant Name: ______________________________ Date:____________

Title of Study: ***Translating Intensive Arm Rehabilitation in Stroke to a Telerehabilitation Format***

Principal Investigator: ***Susan Conroy, PT, DSc.PT 410-637-3213***
VA Facility: ***Baltimore (512)***

I also understand that I may withdraw consent to participate in this aspect of the study at any time.

_____ No, I am not interested in participating in the Qualitative Study of Four Features of the MyHealtheVet Secure Messaging Pilot. I understand that refusing this option has no bearing on my prior participation in the parent study.

_____ N/A, I am not a returning study participant, so this section about the Qualitative Study of Four Features of the MyHealtheVet Secure Messaging Pilot does not apply to me.

Subject Initials ______________ Date: ________________

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**[OPTIONAL] MyHealtheVet TRIAGE TEAM MEMBERS—QUALITATIVE STUDY OF FOUR FEATURES OF THE MyHealtheVet SECURE MESSAGING PILOT:**

The VA Maryland Health Care System (VAMHCS) would like to gather information about your experience and perspective using four features of the My HealtheVet personal health record in the MyHealtheVet Secure Messaging Pilot. Your experience and perspective could have important ramifications on the design and implementation of future studies using this communication technology for home-based telerehabilitation. This area of research has not been previously addressed, and your experience will provide valuable insight into the use of information communication technology in telerehabilitation research.

If you are interested in participating, you will be asked to complete an 8- to 12-item background questionnaire about your prior use of the MyHealtheVet patient portal, and to participate in a one-hour face-to-face interview. **This data collection is optional, and if you are an employee or student, your employment status or academic standing at the VA Maryland Health Care System or University of Maryland will not be affected by your participation or non-participation in the study**.

Participant Name: ________________________________ Date:______________

Title of Study: ***Translating Intensive Arm Rehabilitation in Stroke to a Telerehabilitation Format***

Principal Investigator: ***Susan Conroy, PT, DSc.PT 410-637-3213***
VA Facility: ***Baltimore (512)***

**RISKS:**

- The Qualitative Study of Four Features of the MyHealth*e*Vet Secure Messaging Pilot has a risk of frustration and/or irritation with completing the questionnaires and interviews. You can skip any question that you find uncomfortable.
- There is a minimal risk that a breach of confidentiality could occur. Loss of confidentiality will be minimized by storing data in a secure location, such as a locked office and locked cabinet, and electronic and voice-recorded data will be password-protected and secured behind a firewall in a database within a VA server.

Please check the box below indicating whether or not you agree to participate in these activities for the Qualitative Study of Four Features of the MyHealth*e*Vet Secure Messaging Pilot.

_____ Yes, I agree to participate in the Qualitative Study of Four Features of the MyHealth*e*Vet Secure Messaging Pilot. I agree to complete a questionnaire and a one-hour face-to-face interview. I understand that I may withdraw consent to participate in this study at any time.

_____ No, I am not interested in participating in the Qualitative Study of Four Features of the MyHealth*e*Vet Secure Messaging Pilot.

_____ N/A, I am not a MyHealth*e*Vet triage team member, so this section about the Qualitative Study of Four Features of the MyHealth*e*Vet Secure Messaging Pilot does not apply to me.

Subject Initials: _____________ Date:_________________

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**[OPTIONAL] MyHealth*e*Vet TRIAGE TEAM MEMBERS—FOCUS GROUP:**

If you are interested in participating, you will be asked to complete an 8- to 12-item background questionnaire about your prior use of the MyHealth*e*Vet patient portal (unless already completed), and to participate in a one-hour focus group to elicit observations and experiences that may only come to light as a result of the sharing of experiences in an open forum. **This data collection is optional, and if you are an employee or student, your employment status or academic standing at the VA Maryland Health Care System or University of Maryland will not be affected by your participation or non-participation in the study**.

**RISKS:**

- The Optional Focus Group Qualitative Study of Four Features of the MyHealth*e*Vet Secure Messaging Pilot has a risk of frustration and/or irritation with completing a focus group, and you may only participate to the degree that you feel comfortable. There is also a risk of inconvenience and interruption to your schedule.
- There is a minimal risk that a breach of confidentiality could occur. Loss of confidentiality will be minimized by storing data in a secure location, such as a locked office and locked cabinet, and electronic and voice-recorded data will be password-protected and secured behind a firewall in a database within a VA server.
- Anonymity cannot be assured if all MyHealth*e*Vet triage team members elect to participate in a focus group. The members will be aware of the statements attributed to each other. Use of any statements made in the group will be deidentified if later used as part of a publication for research, and, if possible, will be used in such a way that comments represent a conclusion rather than direct attributions.

Please check the box below indicating whether or not you agree to participate in these activities for the Optional Focus Group Qualitative Study of Four Features of the MyHealth*e*Vet Secure Messaging Pilot.

_____ Yes, I agree to participate in the Optional Focus Group Qualitative Study of Four Features of the MyHealth*e*Vet Secure Messaging Pilot. I understand that I may withdraw consent to participate in this aspect of the study at any time.

_____ No, I am not interested in participating in the Optional Focus Group Qualitative Study of Four Features of the MyHealth*e*Vet Secure Messaging Pilot.

_____ N/A, I am not a MyHealth*e*Vet triage team member, so this section about the Optional Focus Group Qualitative Study of Four Features of the MyHealth*e*Vet Secure Messaging Pilot does not apply to me.

Subject Initials _____________ Date:_________________

**WHAT ARE MY RESPONSIBILITIES IF I TAKE PART IN THIS RESEARCH?**
If you take part in this research, you will be responsible to:

- Keep study appointments and notify the study team if you need to reschedule.
- Discontinue any current arm exercise programs you are participating in to avoid any potential interference of your activities with the study results.
- Notify us of any emergent medical problems that will affect continuing with the training or overall study.
- Notify us if you become pregnant over the course of the study.

**POTENTIAL RISKS/DISCOMFORTS:**
There are no major risks or discomforts that you are likely to experience as a participant in this research. Additionally, pregnancy will not affect the ability to use the device, increase risk, or affect the scientific design. Below are some potential minor risks or discomforts that may occur:

1. There is a small risk of muscle strain or pull in the assessment of strength and coordination. You will be instructed to perform within your level of comfort.

2. There is a risk of injury by the robot. The possible injuries from this malfunctioning robot include bumps, bruises, fingers jammed, pinching, or lacerations. The risk of injury is minimized by continuous oversight by a qualified staff member trained in the use of the robot during all evaluations. The robot design is specific to evaluations of neurologically impaired people and includes an emergency stop to immediately terminate all robot forces if there is any potential for injury.

3. There is a risk of frustration and/or irritation with completing the questionnaires. You will be informed that you can skip any question that is uncomfortable.

4. Training involves repetitive arm motions which may cause muscle soreness, and joint irritation to your shoulder and elbow. This is a relatively rare occurrence and is more likely in the early stages of training when you are unused to the exercise. The risk is reduced by providing regular opportunities to rest within the training protocol. You will be asked about joint and muscular pain after each session and told to rest the affected area and report back if pain persists. Therapy sessions will be suspended if pain worsens, and you will be asked to seek a medical evaluation before resuming research activities.

5. There is a small risk that your privacy/confidentiality may be compromised. There is a potential risk to your confidentiality related to the use of MyHealtheVet secure messaging. Secure messages are electronically stamped by the VA system and include your name, date of birth, and last four digits of your Social Security Number. These messages are stored securely in the VA system and may be reviewed by study staff. They may also be counted by the VA as part of VHA Support Service Center (VSSC) reports. The information retrieved for the VSSC reports will not include your identifiable information. Several procedures are in place to minimize this risk. All research activities will be conducted in a private setting. The PI and research team will keep identifiers linking names to research codes in a secure file locked in a cabinet in the locked research space or the PI's office. Only the PI and research team will have access to this information on an as-needed basis. Only these research codes will be used for data collection and training records. Electronic data, including digital video and secure messages, will be password-protected and kept within the VA firewall in approved computers and servers. There are no foreseeable psychological, social, or legal risks for this study.

6. There may be risks in this study which are not yet known.

**POTENTIAL BENEFITS:**

- You may or may not benefit from taking part in this study. There is no guarantee that you will receive direct benefit from your participation in this study.
- A potential benefit oy your participation is the development of a new home telerehabilitation program for survivors of stroke.
- There is a potential benefit in defining those who can successfully use this new telerehabilitation approach after stroke.

**ALTERNATIVES TO PARTICIPATION:**

This is not a treatment study. Your alternative is to not take part. If you choose not to take part, your healthcare at the VA Maryland Health Care System (VAMHCS) will not be affected.

**COSTS TO PARTICIPANTS:**

It will not cost you anything to take part in this study. You will not be charged for any treatments or procedures that are performed for research purposes in this study. If you usually pay co-payments for VA care and medications, you will still pay these co-payments for VA care and medications that are not part of this study.

**PAYMENT TO PARTICIPANTS:**
You will be reimbursed $10 for each study visit completed at the VA. In the event you do not complete the study, you will receive $10 per session attended to be paid on the last day of your participation. You will receive a voucher from the study team at the Baltimore VA Annex to be redeemed at the Baltimore VA Medical Center cashier's office at 10 North Greene Street, Baltimore, MD 21201 as follows:

- BASELINE: At the completion of the entire baseline testing phase, a voucher for your consent and baseline evaluation visits 1–4 and robot evaluation visit 5 will be distributed in the amount of $50.

- TRAINING:
  A) If you are randomized to the clinic-based rehabilitation group, you will receive additional vouchers for travel to/from the VA for intervention visits 1–18. This voucher will be issued at the final training evaluation visit in the amount of $180 if all appointments are kept.
  B) If you are randomized to the home-based telerehabilitation group, you will NOT NEED TO TRAVEL to the VA for your exercise visits, so you will NOT be reimbursed for sessions 1–18.

- EVALUATION: At the retention visit, a voucher for the final arm and robot evaluation visits, and for the retention arm evaluation visits will be given in the amount of $30.

In summary, if you are immediately enrolled in the clinic-based group and keep all your appointments, you will receive $260. If you are immediately enrolled in the home-based group and keep all your evaluation visits, you will receive $80. If you are in the delayed intervention group, you will receive payment for the intervention described above after the delay, and one additional evaluation reimbursement of $10 for your delayed retention evaluation.

**MEDICAL TREATMENT AND COMPENSATION FOR INJURY:**

Every reasonable safety measure will be used to protect your well-being. If you are injured as a result of taking part in this study, the VA Maryland Health Care System (VAMHCS) will provide necessary medical treatment at no cost to you unless the injury was due to your not following the study procedures. This care may be limited by local or federal law.

If you should have a medical concern or get hurt or sick as a result of taking part in this study, call:

DURING THE DAY OR AFTER HOURS:
Dr. Christopher Bever, Jr. at 202-443-5734

The VA does not normally provide any other form of compensation for injury. However, by signing this form, you have not waived any legal rights or released the VAMHCS or its agents from liability for negligence.

**CONFIDENTIALITY AND ACCESS TO RECORDS:**

- The study will involve use of confidential information. Study personnel will have access to the information, and it will be coded to protect your identity. The investigators will use the codes with all research data in electronic format (including any digital video), and all other files with confidential information will be stored in locked file cabinets within locked office or lab space at the VA Annex. Your research records and/or identifiers will be retained in accordance with the VA records control schedule. The "records control schedule" is a set of rules set by the federal government that states when federal agencies are allowed to dispose of records. The VA and VHA must follow these rules.
- The data from the study may be published. However, you will not be identified by name. People designated from the institutions where the study is being conducted and people from the sponsor will be allowed to inspect sections of your medical and research records related to the study. Everyone using study information at the VAMHCS will work to keep your personal information confidential. Your personal information will not be given out unless required by law or authorized by you in the VAMHCS "HIPAA Authorization to Obtain, Use and Disclose Protected Health Information for Research." However, if your information is disclosed to other entities, the VAMHCS no longer has

control of that information. Please see the HIPAA Authorization for this study for further details.

- Efforts will be made to limit your personal information, including research study and medical records, to people who have a need to review this information. The Veterans Health Administration (VHA) and its Offices may inspect your research records. Your research records will be stored in a locked file cabinet at the VA Maryland Health Care System (VAMHCS) Annex.
- We cannot promise complete secrecy. Organizations that may inspect and copy your information include the IRB, the VAMHCS Office of Research Compliance and other representatives of this organization including the VA Office of Research & Development (ORD), VA Office of Research Oversight (ORO), VA Office of Inspector General (OIG), and Office of Human Research Protections (OHRP).
- Study monitors, auditors, and the IRB will be granted direct access to your medical records for verification of the research procedures and date. By signing this document, you are authorizing this access.

If you are a patient in the VAMHCS, the results of your medical tests for this study may be included in your medical record. Your medical and research records will be kept strictly confidential to the fullest extent permitted by law.

**RIGHT TO WITHDRAW:**
Your participation in this study is voluntary. You do not have to take part in this research. You are free to withdraw your consent at any time. Refusal to take part or to stop taking part in the study will involve no penalty or loss of benefits to which you are otherwise entitled. Your participation will not affect the way you now pay for medical care at the VAMHCS.

If you decide to stop taking part, if you have questions, concerns, or complaints, or if you need to report a medical injury related to the research, please contact the investigator, **Susan Conroy, PT, DSc.PT at 410-637-3213.**

- There are no adverse consequences (physical, social, economic, legal, or psychological) of your decision to withdraw from the research.

- If you withdraw from this study, already collected data may not be removed from the study database. You will be asked whether the investigator can collect data from your routine medical care. If you agree, this data will be handled the same as research data.
- You will be told of any significant new findings which develop during the study which may affect your willingness to participate in the study.

**CAN I BE REMOVED FROM THE RESEARCH?**

The person in charge of the research study or the sponsor can remove you from the research study without your approval. Possible reasons for removal include failure to follow instructions of the research staff, or if the principal investigator decides that the research study is no longer in your best interest. The sponsor can also end the research study early. The study doctor will tell you about this and you will have the chance to ask questions if this were to happen.

**The VA Maryland Health Care System (VAMHCS) has designated the University of Maryland Baltimore (UMB) Institutional Review Board (IRB) to review this research study.**

If you wish to confirm that this study is, in fact, IRB-approved and is being conducted at the VAMHCS, you may contact Susan Conroy, PT, DSc.PT at 410-637-3213 or the study recruitment line at 443-206-3304. Additional information can be found at the ClinicalTrials.gov website (www.clinicaltrials.gov).

The University of Maryland, Baltimore (UMB) is committed to providing participants in its research all rights due them under State and federal law. You give up none of your legal rights by signing this consent form or by participating in the research project. This research has been reviewed and approved by the Institutional Review Board (IRB). Please call the Institutional Review Board (IRB) if you have questions about your rights as a research participant.

The research described in this consent form has been classified as minimal risk by the IRB of the University of Maryland Baltimore. The IRB is a group of scientists, physicians, experts, and other persons. The IRB's membership includes persons who are not affiliated with UMB and persons who do not conduct research projects. The IRB's decision that the research is minimal risk does not mean that the research is risk-free. You are assuming risks of injury as a result of research participation, as discussed in the consent form.

If you are harmed as a result of the negligence of a researcher, you can make a claim for compensation. If you have questions, concerns, complaints, or believe you have been harmed through participation in this research study as a result of researcher negligence, you can contact members of the IRB or the staff of the UMB Human Research Protections Office (HRPO) to ask questions, discuss problems or concerns, obtain information, or offer input about your rights as a research participant. The contact information for the IRB and the HRPO is:

University of Maryland Baltimore
Office of Academic Affairs Regulatory Compliance
Human Research Protections Office
620 West Lexington Street, Second Floor
Baltimore, MD 21201
410-706-5037

You may also contact the VAMHCS Human and Animal Research Protections Officer (HARPO). The contact information for the HARPO is:

VAMHCS Human and Animal Research Protections Officer
Baltimore VA Medical Center
10 North Greene Street, Mail Stop 151
Baltimore, MD 21201
410-605-7000, extension 56582
Room 3D-158

The VAMHCS Human and Animal Research Protections Officer may contact you in the future to ask you about your experiences with this research study.

Department of Veterans Affairs **Research Consent Form**

Participant Name: ______________________________ Date:______________

Title of Study: ***Translating Intensive Arm Rehabilitation in Stroke to a Telerehabilitation Format***

Principal Investigator: ***Susan Conroy, PT, DSc.PT 410-637-3213***
VA Facility: ***Baltimore (512)***

Signing this consent form indicates that you have read this consent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.

If you agree to participate in this study, please sign your name below.

______________________________
Participant's Signature

Date:______________________________

______________________________
Investigator or Designee Obtaining Consent Signature

Date:______________________________



-----------------------------------------------End of Consent Form----------------------------------

APPENDIX D

RESEARCH PROVIDER

BACKGROUND QUESTIONNAIRE

**My Health*e*Vet Secure Messaging Pilot and Qualitative Study**

Dear VA Health Care Professional,

The purpose of this brief questionnaire is to enable me to learn more about you and the kinds of experiences you've had with the My Health***e***Vet patient portal (www.myhealth.va.gov) to help me prepare for our interview discussion. Your response to these questions will help me to maximize our time together during the interview. All information will be kept confidential. Please complete the questionnaire and return to me at your earliest convenience, either by email (Linda.Keldsen@va.gov) or FAX (410) 605-7917.

**About You:**

Name: ______________________________________

Title: ______________________________________

VA Facility: ______________________________________

VISN #: ________

What is your current role at VA?

- ☐ Physician
- ☐ Physical Therapist
- ☐ Exercise Physiologist
- ☐ Occupational Therapist
- ☐ Registered Nurse (RN)
- ☐ Biostatistician
- ☐ Other Please specify: ___________________________

1. In which of the following clinical settings do you currently work?
   - ☐ Research
   - ☐ Specialty Care
   - ☐ Other

   Please specify: ___________________________

2. Please estimate the percentage of your time that you spend doing the following:

Direct Research: _____%
Administrative work: _____%
Other: _____%

3. Did you use the My Health*e*Vet Patient Portal prior to the parent research study? ☐ Yes ☐ No

4. How frequently did you use the My Health*e*Vet Patient Portal during your normal work week?
   ☐ Daily
   ☐ Weekly
   ☐ Other
   Please specify: ___________________________

5. In what context did you use the My Health*e*Vet Patient Portal?
   ☐ Provider
   ☐ Member of a Secure Messaging Triage Team
   ☐ Other
   Please specify: ___________________________

**About Your Experiences with Veteran Use of Four My Health*e*Vet Features:**
**Questions 7 thru 10** Apply to experience with these features **prior** to this research study.

6. **Patient health education resources:** My Health*e*Vet provides site visitors with access to health education resources, including Healthy Living Centers, Condition Centers, Medical Libraries (MedLinePlus®, HealthWise®, and Veterans Health Initiative) and online education courses. To what degree have you experienced study participant use of any of these resources?
   ☐ Very frequently

   ☐ Frequently

   ☐ Occasionally

   ☐ Rarely

   ☐ Never

7. **Tools that enable patient tracking and self-reporting of data:** My Health*e*Vet contains journals and logs in which registered users can self-enter information including vitals, labs and tests, medical events, allergies, immunizations, etc. Registered users can also document health history. To what degree have you experienced Veteran use of any of these tools?
   ☐ Very frequently

   ☐ Frequently

☐ Occasionally

☐ Rarely

☐ Never

8. **Electronic communication via Secure Messaging:** Secure Messaging is a My Health***e***Vet service that enables VA patients to communicate electronically with their VA Health Care Team. Patients can send appointment requests, prescription renewal requests, or ask questions. The VA Health Care Team can triage and respond to these messages and initiate new messages to VA patients associated with their team. Secure Messaging is currently available at 8 sites. Were you a member of a Secure Messaging Health Care Team prior to this research study?
   ☐ Yes

   ☐ No

9. How would you prefer to be contacted to schedule your individual interview?
   ☐ Telephone: ____________________________________________

   ☐ Email: ________________________________________________
   ☐ Contact Person: ________________________________________

---------------------------------------------------End---------------------------------------------

APPENDIX E

RESEARCH STUDY PARTICIPANT

BACKGROUND QUESTIONNAIRE

**My HealtheVet Secure Messaging Pilot and Qualitative Study**

Dear VA Research Participant,

The purpose of this brief questionnaire is to enable me to learn more about you and the kinds of experiences you've had with the My Health***e***Vet patient portal (www.myhealth.va.gov) to help me prepare for our interview discussion. Your response to these questions will help me to maximize our time together during the interview. All information will be kept confidential. Please complete the questionnaire and return to me at your earliest convenience, either by email (Linda.Keldsen@va.gov) or FAX (410) 605-7917.

**About You:**

Name: ______________________________

a. Do you currently receive your health care at a VA Facility? ☐ Yes ☐ No

b. What VA facility do you receive most of your care at? ____________________

c. If you responded No to question 1, who is your primary care physician? ________________________

d. When did you first enroll in My HealtheVet?
   - ☐ Already enrolled before entering research study
   - ☐ Enrolled when I agreed to participate in the research study

e. If you were already enrolled in My HealtheVet prior to entering the research study, how frequently did you use the secure messaging feature.
   - ☐ One time per week
   - ☐ More than one time per week
   - ☐ At least once per month
   - ☐ More than one time per month but less than every week
   - ☐ Other Please specify: _________________________

f. If you are new to My HealtheVet did you use another Personal Health Record with email provided by your health plan or health provider?
   - ☐ Yes
   - ☐ No

g. If you answered Yes to Question 6, please provide the name of the other Personal Health Record with email you have used previously (e.g., My Chart, My Portfolio, etc.) If more than one, please list as many as you can remember.

______________________________________________________________________

______________________________________________________________________

**About Your Experiences with Veteran Use of Four My Health*e*Vet Features:**

**Questions 8 thru 10** Apply to experience with these features **<u>prior</u>** to this research study.

h. **Patient health education resources:** My Health*e*Vet provides site visitors with access to health education resources, including Healthy Living Centers, Condition Centers, Medical Libraries (MedLinePlus®, HealthWise®, and Veterans Health Initiative) and online education courses. To what degree have you used of any of these resources?

☐ Very frequently

☐ Frequently

☐ Occasionally

☐ Rarely

☐ Never

i. **Tools that enable patient tracking and self-reporting of data:** My Health***e***Vet contains journals and logs in which registered users can self-enter information including vitals, labs and tests, medical events, allergies, immunizations, etc. Registered users can also document health history. To what degree have you experienced Veteran use of any of these tools?

☐ Very frequently

☐ Frequently

☐ Occasionally

☐ Rarely

☐ Never

j. **Electronic communication via Secure Messaging:** Secure Messaging is a My Health***e***Vet service that enables VA patients to communicate electronically with their VA Health Care Team. Patients can send appointment requests, prescription renewal requests, or ask questions. The VA Health Care Team can triage and respond to these messages and initiate new messages to VA patients associated with their team. Secure Messaging is currently available at 8 sites. Were you a member of a Secure Messaging Health Care

Team prior to this research study?

☐ Yes

☐ No

k. How would you prefer to be contacted to schedule your individual interview?

☐ Telephone: ____________________________________________

☐ Email: ________________________________________________

☐ Contact Person: _________________________________________

------------------------------------------------------End-------------------------------------------------

## APPENDIX F

## SEMI-STRUCTURED INTERVIEW QUESTIONNAIRE

## STUDY PARTICIPANTS

This semi-structured interview questionnaire is not meant to be used in its entirety for any participant consented for this qualitative inquiry. Core questions will be asked of all participants and additional questions may be asked based upon the lived experience of the interviewee in order to capture the essence of their experience with telerehabilitation and the use of a patient portal with secure messaging. Each participant will be encouraged to speak freely and openly about whatever they think is relevant to the study, and to their experience, etc.

**Research Question:** What are the research patients' experience in incorporating the use of PHR into their daily life practices?

- What are the experiences of the research patient with the use of the My Health***e***Vet PHR patient portal and these specific features?
    - How do research patients report having engaged with the researchers in the use of the PHR patient portal and these features?
    - How do the research patients experience their own use of these features?
    - How do the research patients perceive the usefulness of each of these features?

CQ1. Tell me about your experience with stroke rehabilitation. How were you recruited for telerehabilitation care?

Q2. Description of the first day assigned to telerehabilitation. Can you tell me about your experience of home-based telerehabilitation? How did this experience compare to other therapy you may have received?

Q3. Experienced benefits or damages from environment. Can you tell me about your experience performing therapy at home? What was your experience of the time it took to do the therapy on your own and how your progressed? Tell me more about your experience at home and how it affected your day to day activities during treatment?

CQ4. Experiences from contact with research team members/study participants (ease of use). Could you tell me about your experience communicating with secure messaging? Additional comments/reflection.

CQ5a. Experiences with using equipment (ease of use, perceived usefulness). Tell me about your experience using the iPad to access My Health***e***Vet?

CQ5b. Experience using computers and internet enabled programs (self-efficacy). Can you tell me about your experience using computers and the internet before your stroke? What is your experience now? Did your prior experience affect your ability to use My Health***e***Vet and Secure Messaging?  Tell me more.

CQ5c. How is your experience different from before your stroke if you used an iPad or computer to access My Health***e***Vet and Secure Messaging?

CQ5d. Can you tell me about your experience completing the reports on your exercise progress?  Tell me about how you made those reports to the research team? Were there any difficulties attaching documents to your secure messages?

Q6. Before your stroke, how active were you (self-efficacy exercising)? Tell me about your experience with exercise before your stroke. What sorts of things did you do? How did you feel about exercising in this way? Is there anything you did not enjoy? Why was that? Tell me more.

Q7. Continuation of rehabilitation beyond stroke trial (intention to use, actual use). Is there anything from your experience of Telebactrac that affects your life now? Why is that? Do you have plans to continue exercising now that the research trial is over? Tell me more.

----------------------------------------------------Thank You---------------------------------------

# APPENDIX G

## SEMI-STRUCTURED INTERVIEW QUESTIONNAIRE

## RESEARCHERS

This semi-structured interview questionnaire is not meant to be used in its entirety for any participant consented for this qualitative inquiry. Core questions will be asked of all participants and additional questions may be asked based upon the lived experience of the interviewee in order to capture the essence of their experience with telerehabilitation and the use of a patient portal with secure messaging. Each participant will be encouraged to speak freely and openly about whatever they think is relevant to the study, and to their experience, etc.

**RESEARCH QUESTION:** What is the health care professionals experience in incorporating the use of My Health*e*Vet PHR into their work practices?

- What are the experiences of the health care professionals with patient use of the PHR patient portal and these specific features?
- How do health care professionals report having engaged with patients in the use of the PHR patient portal and these features?
- How do the health care professionals experience their own use of these features?
- How do the health care professionals perceive the usefulness of each of these features?

CQ1. Tell me about your experience using computers and information communication technology?

CQ2. Tell me about your experience navigating the different features of the My Health*e*Vet portal? Have any of the features stood out as being particularly easy to use or useful?

CQ3. Tell me about your experience with My Health*e*Vet as a rehabilitation researcher? Has it influenced you to think about stroke telerehabilitation differently?

CQ4. What has been your experience using secure messaging to communicate with research participants?

CQ5. What has been your experience been in the quality and quantity of communications with research participants? Have your experienced barriers? Tell me more?

CQ6. What has your experience been using the My Health*e*Vet patient portal tools to meet the aims of the parent study (e.g., exchange health education materials, data collection tools, self-reported patient data)?

CQ7. Tell me about your experience as a researcher using a patient portal with access to patient tools and secure messaging?  Has this experience influenced you as a researcher? Tell me more.

**Focus Group Question**: Tell me about your experience with designing, building, and implementing the components needed to use My HealtheVet SM in research for the first time? Are there any experiences that particularly stand out?

---------------------------------------------------Thank You--------------------------------------

## APPENDIX H

## THANK YOU NOTE TO VA RESEARCHER

Dear VA Researcher,

Thank you for your recent participation in the study about use of the My Health***e***Vet Personal Health Record and Secure Messaging. Your input is critical and will enable the development of important insights that will directly inform further development of the My Health***e***Vet Program. More broadly, this research will be an integral step toward better understanding the social and organizational context and impact of patient portal and secure messaging use in clinical practice settings.

If you have any additional comments or insights to share with me or if I can provide you with any additional information, please do not hesitate to contact me.

Sincerely,

Linda Keldsen

# APPENDIX I

## THANK YOU NOTE TO PARTICIPANTS

Dear VA Study Participant,

Thank you for your recent participation in the study about use of the My Health***e***Vet Patient Portal and Secure Messaging. Your input is critical and will enable the development of important insights that will directly inform further development of the My Health***e***Vet Program for research. More broadly, this research will be an integral step toward better understanding the impact of patient portal and secure messaging use in clinical and research practice settings.

If you have any additional comments or insights to share with me or if I can provide you with any additional information, please do not hesitate to contact me.

Sincerely,

Linda Keldsen

# GLOSSARY

**Assistive Technology** – is an umbrella term used for any device or system that allows an individual to perform a task they would otherwise be incapable of doing or increases the safety and ease by which the task can be performed (Magnusson, Hanson, & Borg, 2004).

**Comprehensive stroke rehabilitation –** highly integrated inpatient rehabilitation programs where patients typically receive a minimum of three hours of therapy per day with a primary goal of functional restoration (Bates et al., 2015)**.**

**Consultative stroke rehabilitation –** therapy ranges in intensity and frequency from two to several visits from Physical Medicine & Rehabilitation (PM&R) professionals for patients admitted to general care beds, where functional restoration is not the primary goal (Bates et al., 2015).

**Gerontechnology** – describes the content and breadth of assistive technologies for older people (Magnusson et al., 2004).

**Haptic –** describes the use of technology stimulating the senses of touch and motion while gathering kinesthetic information that includes proprioception, motion and force (Sugarman, Dayan, Weisel-Eichler, & Tiran, 2006).

**Health Information Technology for Economic a Clinical Health (HITECH) Act -** is part of the American Recovery and Reinvestment Act of 2009 (ARRA). ARRA contains incentives related to health care information technology in general (e.g. creation of a national health care infrastructure) and contains specific incentives designed to accelerate the adoption of electronic health record (EHR) systems among providers. This legislation anticipates a massive expansion in the exchange of electronic protected health information (ePHI), the HITECH Act also widens the scope of privacy and security protections available under HIPAA; it increases the potential legal liability for non-compliance; and it provides for more enforcement (Blumental, 2010).

**Health Literacy -** “degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” (Ratzan & Parker, 2000)

**Home-based telerehabilitation -** the provision of conventional rehabilitation services (e.g., interview, physical assessment, diagnosis, intervention, maintenance activities, consultation, education and training) at a distance using telecommunication for the exchange of data (written, audio, visual, or haptic) to provide distance support and information exchange between disabled persons living at home and their providers (Chumbler et al., 2010; Chen et al., 2015; Laver et al., 2013; Ricker et al., 2002; Russell, 2009; Tenforde et al., 2017).

**Information Communication Technology (ICT)** – enables individuals and/or groups to communicate, gather information, and interact speedily and easily with distant services without limits to time and space; may be applied to communication, information, paid and/or voluntary employment, electronic commerce, independent living, inter-generational relationships, distance learning, cost reduction in the delivery of services and strengthening the community (Magnusson et al., 2004).

**Office of the National Coordinator for Health Information Technology –** established by President Bush in April 2004 to develop a strategic plan to guide the nationwide implementation of health information technology in the public and private sectors within 90 days of taking office. The ONC identified four goals: 1) Inform clinical practice by incentivizing EHR adoption, reducing the risk of EHR investment and promote EHR diffusion in rural and underserved areas; 2) Interconnect clinicians by fostering regional collaboration, developing a national health information network and coordinating federal health information systems (e.g., DOD, VA, OPM); 3) Personalize care by encouraging the use of PHRs, enhancing consumer choice and promoting the use of telehealth systems; and 4) Improve population health by unifying public health surveillance architectures, streamline quality and health status monitoring and accelerate research and dissemination of evidence (Thompson & Brailer, 2004).

**Patient-Generated Health Data –** are health-related data created, recorded or gathered by and from patients, their family members and/or caregivers to health address a health concern. The gathering of PGHD supplements existing clinical data, filling in gaps in information and providing a more comprehensive picture of how patients are doing between medical visits; provides information for use in shared decision-making and offers potential health care cost savings and improvements in quality, care coordination and patient safety (Office of the National Coordinator for Health Information Technology & U.S. Department of Health and Human Services, 2018)

**Patient Portal** – a secure online website that provides patients and their authorized representatives with 24-hour access to view, download, and transmit personal health information from anywhere with an internet connection through a secure channel that ensures all content is encrypted and integrity is protected in accordance with the standard for encryption and hashing algorithms specified by § 170.204(f). (Centers for Medicare & Medicaid Services, 2014; Federal Advisory Committees, 2015)

**Perceived Ease of Use** – is defined as "the degree to which a person believes that using a particular system would be free of effort." (Davis, 1989)

**Perceived Usefulness** – is defined as "the degree to which a person believes that using a particular system would enhance his or her job performance." (Davis, 1989)

**Personal Health Records -** an internet-based set of tools, maintained in a secure and private environment that conforms to nationally recognized interoperability standards, that allow people to access and coordinate their lifelong health information and make appropriate parts available to those who need it (National Alliance for Health Information Technology, n.d.; J. M. Schneider, 2010; Thompson & Brailer, 2004).

**Secure messaging** – "any electronic communication between a provider and patient that ensures only those parties can access the communication. This electronic message could be email or the electronic messaging function of a personal health record, an online patient portal, or any other electronic means." (Centers for Medicare & Medicaid Services, 2014)

**Self-efficacy** – "refers to beliefs in one's capabilities to organize and execute the courses of action required to manage prospective situations" (Bandura, 1995) or "what an individual believes he or she can accomplish using his or her skills under certain circumstances." (Snyder & Lopez, 2007)

**Telecommunication Technology** - "communication over a distance by cable, telegraph, telephone or broadcasting, or the branch of technology concerned with telecommunication" (*Webster's Encyclopedic Unabridged Dictionary of the English Language*, 1989).

**Telehealth** - "use of electronic information and telecommunications technologies to support long-distance clinical healthcare, patient and professional health-related education, public health, and health administration" (US Department of Health and Human Services, 2001).

**Telerehabilitation** - "Telerehabilitation is the application of telecommunication technology that provides distance support, assessment and intervention to individuals with disabilities" (Ricker et al., 2002) by improving access to support independent living.

**Telematics** – refers to the use of computers alongside telecommunications systems and ranges from dial-up services through the internet to broadband applications to include full service networks (Magnusson et al., 2004).

**Telemedicine** – involves the use of telehealth technologies to support the exchange of health information between health care professionals for remote consultation, diagnosis, care planning, and treatment across distance and institutions (Magnusson et al., 2004).

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