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People who live with Multiple Sclerosis tend to be less physically active (PA) than age matched peers. Physical activity promotion programs that target physical inactivity, build self-efficacy for PA, and educate on how to be physically active are needed for this population. Content experts and people with Multiple Sclerosis (pwMS) were invited to complete surveys to review *At the Core*. Survey respondents who were also pwMS were then invited to participate in a focus group. People with MS were also recruited to participate in 2 weeks of the *At the Core* program, which was preceded by pre-testing and followed by post-testing. Survey participants included 17 pwMS and 12 content experts. The focus group from survey participants consisted of 2 pwMS. Two pwMS participated in the small-scale study implementation and following focus group. Likert ratings from the survey and participant step counts from the implementation study were analyzed descriptively. Responses from open-ended survey questions and both focus groups were analyzed using Atlas.ti. Field notes were also taken during the implementation study. Trustworthiness was established through data triangulation of the survey, open ended, focus group data and field notes. Three main themes were identified as positive program attributes, suggested changes, and physical activity behavior. Overall, based on feedback from both surveys and focus groups, the program was found to be feasible with the need for minor modifications.

A PROCESS-FOCUSED FEASIBILITY STUDY OF AT THE CORE: A PHYSICAL  
ACTIVITY PROMOTION PROGRAM FOR  
PEOPLE WITH MULTIPLE SCLEROSIS

by

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Approved by

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Committee Chair

## DEDICATION

*I would like to dedicate this work first to my husband and daughter. They are my constant support, and I am eternally grateful for them both. I would also like to dedicate this to the clients I have had the privilege of serving during my years as a physical therapist. Had they not shared their journey with me, I would have not been inspired to complete this project. Finally, to my parents, both who passed away unexpectedly during my time in the program. Thank you, mom, for showing me how to be unapologetically gritty. Thank you, dad, for your unwavering belief in my potential.*

APPROVAL PAGE

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## CHAPTER I: PROJECT OVERVIEW

Physical inactivity and other modifiable health behaviors (e.g., poor nutrition and sleep) negatively impact the health and well-being of people with Multiple Sclerosis (pwMS) (Agland et al., 2018; Aldughmi et al., 2016; Mousavi-Shirazi-Fard et al., 2020). People with MS who are insufficiently physically active are at increased risk for functional decline (Block, Bove, et al., 2019). Poor nutrition, sleep deprivation, and high stress exacerbate functional loss. Consequently, it is sensible to address these contributing factors while promoting physical activity (PA). In pwMS, it is possible that lifestyle PA is more important than moderate to high intensity PA alone. The purpose of this study is to evaluate the feasibility of a lifestyle PA program, *At The Core*. This program addresses the specific needs of pwMS through the provision of evidence-based education, physical activity promotion, and yoga intervention.

### **Background Literature**

The following literature review begins with background information on MS. Next, PA promotion for pwMS is discussed, followed by an introduction to modifiable health behaviors that support a physically active lifestyle. Lastly, the *At the Core* program is described, and research aims and the purpose statement are presented.

### **Multiple Sclerosis.**

Multiple sclerosis (MS) is a chronic, incurable, neurodegenerative disease that affects approximately 1 million people in the United States (MS Prevalence, n.d.). Multiple Sclerosis is diagnosed most frequently in women, between 20-50 years of age. (Who Gets MS? | National Multiple Sclerosis Society, n.d.). The focus of healthcare for pwMS is disease management and preservation of function and quality of life.

Multiple sclerosis causes nerve damage throughout the central nervous system. Because the nerve damage occurs in different locations in everyone, the signs and symptoms experienced by pwMS vary widely. Signs and symptoms frequently include increased fatigue, accompanied by some combination of the following: muscle weakness, sensory loss, cognitive deficits, loss of bladder control, impaired fine motor control, imbalance, and abnormal and limited gait.

Historically, pwMS have been prescribed medication to treat their disease, and were told to avoid increased physical activity as it was believed to worsen their condition (Dalgas et al., 2019). Recent evidence indicates that PA benefits pwMS and may attenuate the degenerative disease process (Dalgas et al., 2019). Specifically, PA is effective in ameliorating symptoms associated with MS, such as fatigue and muscle weakness. (Dalgas et al., 2019; Kerling et al., 2015; Latimer-Cheung et al., 2013). Currently, experts recommend that pwMS should strive to achieve 150 minutes of PA weekly (Kalb et al., 2020).

Despite these recommendations, only 27% of pwMS report sufficient PA levels (Motl et al., 2015). Both internal obstacles (e.g. fear, fatigue, and muscle weakness) and muscle weakness, along with external environmental barriers contribute to decreased PA levels in pwMS (Learmonth & Motl, 2016). Holistic approaches to PA are needed to help pwMS overcome these obstacles so they may obtain PA-related health benefits.

### **Physical Activity Promotion in People with Multiple Sclerosis**

Although, PA promotion for pwMS is challenging, research points toward the use of Social Cognitive Theory (SCT) and Self-Determination Theory (SDT) to maximize PA participation (Fasczewski & Gill, 2018; Motl & Snook, 2008). Social Cognitive Theory focuses on the development of self-efficacy, or an individual's belief that they can perform an activity and achieve the desired outcome (Bandura, 2004). Self-efficacy may be improved by goal

accomplishment (mastery experience) or by witnessing another individual like oneself achieve a desired outcome (vicarious experience), verbal persuasion and emotional arousal (Bandura, 1977, 2004). Social Cognitive Theory posits that motivation, or the desire to continue with a behavior, is improved through cognitive means that include goal setting and obstacle navigation (Bandura, 2004; Bandura, 1977).

Self Determination Theory proposes that one's ability to self-regulate a behavior occurs on a continuum (Ryan & Deci, 2000). When an individual has no control over a behavior, they are in a state of amotivation, meaning the behavior is unregulated. As the ability to self-regulate behavior increases, individuals require less external motivation. For example, behaviors that are less self-regulated require external motivation, such as rewards or punishments. As self-regulation increases, a person may choose to engage in PA because of known benefits, termed identified regulation. Eventually, the individual perceives the activity as part of their identity (integrated regulation). Finally, a person demonstrates intrinsic motivation when the behavior is performed based on enjoyment. According to SDT, an individual will be self-motivated towards meaningful behavior that fosters well-being when their psychological needs for autonomy, competence, and relatedness are met. (Ryan & Deci, 2000). Intrinsic motivation is enhanced when individuals have (1) autonomy over their decision, (2) the tools and support needed to engage in a behavior, and (3) a sense of connection and value within a community.

Best practices for PA promotion in pwMS incorporate both SCT and SDT into applied PA promotion programs. Poor self-efficacy is considered a modifiable risk factor for decreased PA in pwMS (Motl & Snook, 2008). Self-efficacy and competence can be developed in PA promotion programs through the inclusion of vicarious experience (group activities) as well as goal setting. Identified regulation predicts quality of life and PA participation in this population

(Fasczewski & Gill, 2018). This finding implies that key components of PA promotion program for pwMS should include education on (1) how to successfully engage in PA, and (2) how PA helps sustain function.

### **Lifestyle Approach to Physical Activity in Multiple Sclerosis**

Numerous lifestyle behaviors impact how “well” pwMS live. Such behaviors include PA, dietary choices/nutrition, and sleep. The following section explains how each of these behaviors supports PA engagement in pwMS.

Physical activity, defined as activity performed throughout one’s normal day, may aid in the prevention of worsened symptoms and functional decline in pwMS (Block, Bove, et al., 2019; Dalgas et al., 2019). Exercise, or planned PA, also shows benefits in pwMS. Various types of exercise programs, including those focused on balance, core strength (Carling et al., 2017; Kalron et al., 2017), high intensity training (Orban et al., 2019; TollÁr et al., 2020) and walk-to-run (Feys et al., 2019), have demonstrated the potential to improve strength and balance in pwMS. Programs focused on core stability, such as Pilates (Kalron et al., 2017), and core stability plus dual tasking (Carling et al., 2017) resulted in improvements in balance, walking ability, and a decrease in self-reported falling. Interestingly, while high intensity treadmill or cycling compared to a stretching and a non-exercising control resulted in improved cognitive processing speed, cardiovascular fitness, and body composition did not result in increased function (Orban et al., 2019). These studies along with the work of Block (2019) indicate that exercise intensity in pwMS might be less important than total activity.

Yoga has also demonstrated the potential to benefit pwMS (Cohen et al., 2017; Fasczewski, et al., 2020; Garner et al., 2020). A 5 week medical therapeutic yoga program yielded improvements in reactive balance, dual-task performance Garner et al., 2020) and

increased self-efficacy for PA and quality of life in pwMS (Fasczewski et al., 2020). An 8-week yoga intervention developed for pwMS improved balance, walking, and fine motor control (Cohen et al., 2017). Mindful approaches to PA, such as yoga, often include self-inquiry and meditation and may support the development of other positive health behaviors that encourage increased PA levels in pwMS.

An overall healthy lifestyle focused on healthy eating Vitamin D supplementation, and sleep hygiene education are also important for pwMS. A healthy diet, such as a diet high in plant based foods and lean meats, low in saturated fats and processed foods, and with adequate levels of Vitamin D supplementation, aids in controlling the inflammatory process associated with MS (Jakimovski et al., 2019; Mousavi-Shirazi-Fard et al., 2020; Pierrot-Deseilligny & Souberbielle, 2017). Between 44-67% of pwMS report problems with sleep which is associated with decreased motivation (Bøe Lunde et al., 2012; Vitkova et al., 2014). Individuals who perform 32 minutes of moderate intensity PA per day indicate improved sleep compared to those who don't meet this milestone (Aburub et al., 2017). Poor sleep quality in pwMS may contribute to physical fatiguability (Aldughmi et al., 2016) and disability level (Vitkova et al., 2018). Education on Vitamin D supplementation, plant-based diet, sleep hygiene, and the positive impact PA has on sleep quality are important considerations of an educational program to target wellness in pwMS.

### **At the Core: A Physical Activity Promotion Program for People with Multiple Sclerosis**

*At the Core* is a PA promotion program designed specifically for pwMS by a licensed physical therapist (PT) with previous experience developing a Medical Therapeutic Yoga (MTY) program for pwMS. *At the Core* provides pwMS with an inclusive educational environment where they can safely and successfully develop a physically active lifestyle. The *At the Core* program consists of 8 weeks of disease-specific education to promote PA and other positive

health behaviors that support PA engagement. *At the Core* applies the tenets of SCT and SDT through education, group interaction, and individualized goal setting to foster competence and autonomy. Each synchronous session contains interactive exercise and meditation based on MTY, a therapeutic yoga methodology that focuses on core strength as well as flexibility and balance (Fasczewski et al., 2020; G. Garner, 2016; L. M. Garner et al., 2020). Medical Therapeutic Yoga incorporates introspection, goal setting, meditation, relaxation, and physical activity. It can easily be adapted to a virtual environment. Each week, *At the Core* participants are emailed links to educational materials and a video that details the exercise performed in class. The goals of *At the Core* are to: 1. Educate pwMS how to be physically active through disease specific behavioral modification within a lifestyle approach. 2. Increase or maintain step counts as monitored with the FitBit Inspire to >4800 steps per day (average weekly). 3. Increase self-efficacy and motivation for physical activity. 4. Promote lifelong PA while living with MS. See Appendix A for a full description of *At the Core*.

### **Purpose Statement and Aims**

The purpose of this study was to evaluate the feasibility of the *At the Core* program based on expert and stakeholder feedback. The aims of this study were to: Aim #1: Evaluate overall program organization, procedures, and outcome measures; Aim #2: Evaluate program content (educational materials and video exercise program); Aim #3: Evaluate a small-scale pilot of the program based on participant feedback.

### **Methods**

This mixed-methods study evaluated the feasibility of the *At the Core* program (See Appendix A). Evaluation of program content, organization, procedures, and outcome measures occurred using surveys (See Appendix C), focus groups (See Appendix D and G), and a small-

scale program implementation (See Appendix F for outline of implementation). See Appendix B for a schematic of the data collection procedures.

### **Participants**

Institutional Review Board approval was obtained through two state Universities prior to recruitment. Survey participants were recruited via email and snowball sampling from two groups: content experts (researchers and clinicians who work with pwMS) and pwMS. Survey participants (n=29) included 17 pwMS and 12 content experts. Survey respondents identified as female (n=25) and male (n=4). People with MS who completed the survey rated their functional level as normal using the Patient Determined Disease Steps Scale (n=3), mild disability (n=9), moderate disability (n=1), and early cane (n=4). Age ranges reported include: 25-34 years (n=2), 35-44 years (n=5), 45-54 years (n=9), 55-64 years (n=11), 64-74 years (n=2). Two survey participants identified as Black and Asian, while 25 identified as White/Caucasian. People with MS who participated in the survey were then recruited via email to participate in a focus group (n=2). Small scale implementation group participants (n=2) were recruited from a local pro-bono clinic that serves pwMS. People with MS who participated were required to rate themselves between 0 and 3 on the Patient Determined Disease Steps (PDDS).

### **Data Collection/Procedures**

After IRB approval, data were collected in the form of surveys, focus groups, and a small-scale implementation study. Recruitment emails were sent to potential survey participants. Individuals who responded that they would like to participate were then emailed a Qualtrics link to the survey. The survey questions were designed to assess if *At the Core* was feasible based on the accuracy and appropriateness of the pre and post testing, and educational and exercise materials. Finally, the survey sought to determine if pwMS would benefit from the program as



well as whether clinicians would refer pwMS to the program. Following survey completion, pwMS were invited to participate in a focus group. Additional pwMS were recruited from a local pro-bono clinic for pwMS to participate in a short version (e.g., 2 weeks instead of 8) of *At The Core* with an additional two weeks of pre and post testing. Following completion of the program, those who participated in a short version of *At the Core* were invited to participate in a focus group to discuss their experience. Field notes related to the intervention process as well as data collection procedures were collected by the therapist providing the intervention.

### **Survey with Focus Group**

Stakeholders and experts were emailed anonymous Qualtrics links and asked to provide demographic information, and then evaluate three program components: overall program flow and outcome measures, video home exercise program, and educational material links.

Participants rated the appropriateness of the overall program and outcome measures along with the accuracy and quality of the video and educational link content. Finally, participants rated how much the program would benefit pwMS and likelihood of referral to the program.

Following completion of the survey, pwMS were invited to participate in a focus group. One, one-hour long focus group was conducted via zoom with 2 pwMS who completed surveys. During the meeting, participants kept their cameras off and were asked not to use their names. The session was recorded and transcribed, checked for accuracy, and all personally identifiable information was removed. See Appendix C for focus group script.

### **Small Scale Program Implementation**

Program participants (n=2) were recruited from a local clinic for pwMS and had written medical clearance to participate from an appropriate medical provider (e.g., MD, PT, OT). Participants received a consent form to review prior to pre-testing. At pre-testing, informed

consent was completed, and the therapist reviewed educational materials with the participant followed by completion of pre-testing. Pre-testing included a) physical performance measures: Timed Up and Go (Podsiadlo & Richardson, 1991), the Cognitive Timed Up and Go (Shumway-Cook et al., 2000), the Five Times Sit to Stand (Whitney et al., 2005), The Two Minute Walk Test, (Butland et al., 1982); b) motivation and self-efficacy measures: The Task and Scheduling Self-Efficacy Self-Report Measure, (Rodgers et al., 2002), the Multiple Sclerosis Self-Efficacy Exam (MSSE; Schwartz et al., 1996), the Behavioral Regulation in Exercise Questionnaire – 3 (BREQ-3; Cid et al., 2018), Intrinsic Motivation Inventory (Deci et al., 1994); and c) physical activity measures: The Godin Leisure Time Exercise Questionnaire (Godin, 2011), step counts with FitBit Inspire 2 (Block, Zhao, et al., 2019); and d) one disease-specific measure: Patient Determined Disease Steps (Learmonth et al., 2013), and two other health-related measures: The Pittsburgh Sleep Quality Index (Buysse et al., 1989), and one researcher-developed question related to nutrition. Finally, participants were asked to wear a FitBit and email their step counts to the therapist daily via a secure Qualtrics link that was emailed to the participants daily by the PI. Please see Appendix D for a full description of the outcome measures.

## **Intervention**

Participants completed two weekly synchronous intervention sessions in a password protected Zoom meeting for which the link was emailed to participants weekly by the PI. Each session lasted approximately 1 hour and was led by a licensed PT. The first week the PT led the participants through the week 1 (Find Your Why) educational link. The second week the PT led the participants through week 2 (Navigating Obstacles) educational link. During each session, the PT led clients through the exercise protocol which consisted of breathing techniques to relax, breathing techniques to improve core stability, supine and quadruped core stability activities, and

standing balance and lower extremity flexibility exercises. An outline of each session can be found in Appendix F.

The week following the second intervention, participants were asked to return for an in person post-testing session using the same assessments (physical performance, motivation, PA and health-related) from pre-testing. Finally, participants were asked to participate in a focus group via Zoom with a second investigator (not the PI) to discuss their experience in the program. See Appendix G for focus group questions for this group.

### **Data Analysis**

Survey responses and step counts from the implementation study were analyzed descriptively (e.g., frequencies, mean, standard deviation) using SPSS v 28. Open-ended responses and focus group transcripts were coded using an inductive approach (Saldana, 2021) with the ATLAS.ti program. Once codes were developed and all documents were coded, second pass coding occurred to capture any re-named codes to ensure all codes were represented across all documents. After second pass coding occurred, codes were collapsed to create axial codes that combined similar codes and concepts. Themes were then developed from these axial codes. Trustworthiness was ensured by maintaining an audit trail during coding analysis and providing rich thick descriptions of themes and supporting data. Triangulation between surveys, focus groups, and implementation data was used to ensure data trustworthiness.

### **Results**

Six areas of focus were evaluated including: program acceptability, demand for program, likelihood of program implementation, program practicality, and limited-efficacy testing through a small scale study implementation (Bowen et al., 2009). Feasibility criteria were set a priori for each focus area. The focus areas of acceptability, demand, implementation, and practicality were

evaluated as feasible if 75% of survey respondents viewed the survey questions that asked about these areas favorably and the results from the focus groups support these data. Implementation was evaluated as feasible if a positive trajectory was found and if step counts rose or plateaued for at least 50% of participants, and if 75% of survey and focus group respondents agreed that the program can be implemented. The survey results are presented first, followed by the results for the focus group open-ended survey questions. Finally, small-scale implementation results are presented.

### **Survey**

Only 11 participants completed 100% of the survey, 16 completed 63% or more and two participants completed less than 63%. Thus, the number of responses differs with fewer responses to the items on the video and educational materials.

Overall, the program was rated highly with all 29 respondents reporting that they agreed or strongly agreed that the program goals were appropriate. All 29 agreed or strongly agreed that pwMS would benefit from this type of program and that the length of the program was sufficient to accomplish goals. One person felt that the program was not long enough. Eleven of 11 respondents agreed or strongly agreed that they would encourage pwMS to participate in the program and that the program is safe for people in the early stages of MS. See frequency tables in appendix H.

The outcome measures selected were also highly rated with 26 of 27 respondents agreeing or strongly agreeing on the measures appropriateness while one person did not know. Twenty-eight of 29 respondents strongly agreed or agreed that the PA measures (FitBit and Godin) were appropriate, while one participant disagreed. All 28 respondents strongly agreed or agreed that the physical performance measures (Timed up and Go (TUG), Cognitive (Cog) TUG,

Two Minute Walk Test (2MWT), and Five Times Sit to Stand (5xSTS)) were appropriate and 27 of 28 agreed that the outcome measures to assess items specific to pwMS were appropriate.

Regarding outcome measures that assess health related behaviors (diet and sleep) 26 responded that the measures were appropriate while two disagreed. Motivation and self-efficacy measures were deemed appropriate with 26 of 28 agreeing or strongly agreeing on appropriateness.

All 11 respondents strongly agreed or agreed that the video exercise program was engaging, enjoyable, easy to use, functioned well, and was appropriate, understandable, helpful, and safe for pwMS. All 11 also strongly agreed or agreed that the meditation component of the video was understandable, helpful, and safe. One person felt that the video was too long, but the other 10 agreed or strongly agreed that the video was an appropriate length.

All 15 respondents agreed or strongly agreed that the educational links were easy to use, and that the material presented was accurate, engaging, understandable, and usable by pwMS. Fourteen respondents agreed or strongly agreed that the educational links contained the right amount of information while one disagreed. Thirteen respondents agreed or strongly agreed that material in the links was appropriate with one person disagreeing. Finally, 13 respondents agreed or strongly agreed that the material in the educational links was helpful with one person disagreeing.

### **Open Ended Questions and Focus Group Results**

Three themes were identified: 1) positive program attributes, 2) suggested program changes, and 3) physical activity behavior.

#### **Positive Program Attributes**

Positive program attributes were primarily related to the overall program, educational links, exercise and meditation video, and some outcome measure selection. The overall program

was identified by survey participants as being “beneficial” (n=1), “comprehensive” (n=1), “easy to follow” (n=2), and “concise” (n=1). Survey participants appreciated that different exercise types were included; one participant commented that the “yoga and core breathings” were helpful while another mentioned the “muscles targeted” were a program strength. Post-survey focus group participants also appreciated the education on breathing, stating “I wouldn’t say learn, but reminded that breathing is important” and “I’m just learning how to breathe so that’s perfect for me.” Both post survey focus group participants liked the educational links with one stating the links were “really good” Both further reported that the educational material was a “good length” and “the length is just perfect.” One focus group participant also appreciated the journaling, stating “journaling . . .that’s an excellent thing to do to keep up with their goals.” and the “holistic nature of the thing. . .seems to help the whole person.” A survey participant also verbalized appreciation for goal setting, stating “I like setting goals.”

Survey and focus group respondents identified the video as one of the best components of the program. The video was mentioned as one of the best things about *At the Core* by 3 of the 11 survey respondents who completed the survey. Survey respondents liked that the video was available in an “on demand” video format, that the “video instruction to be used anytime” and that “step by step instructions” were given within the video.

While one post survey focus group participant didn’t remember the video, the other appreciated that “you showed like different levels” and expanded saying “so if you can’t do this level, and you want it easier, you showed what you can do”. One post survey focus group participant stated “I particularly enjoy the meditation part. I thought that was good at the end.” A survey participant also wrote “meditation is important.” Both post survey focus group

participants agreed that they “would love to participate in it” and “would definitely recommend it.”

### **Suggested Program Changes**

Areas for potential improvement suggested by participants focused on health literacy, the educational links, video length, progression of exercise, and outcome measures. One survey participant implied the health literacy of the target population needed checking by commenting that “this is a well-put together program. I am sure you have checked the health literacy level of our area clients.” Three other survey participants echoed the health literacy piece, stating “explain pelvic floor a little better”, “remove a lot of text from the website” and “concepts of SMART goals and motivation are mentioned but not adequately explained.” The third comment related to health literacy was to “condense some of the slides”. Two people commented on typos and grammatical errors in the educational links. One post-survey participant commented that “the times are usually what stops me from participating.”

Improvements to the video focused on “reduce length of video, perhaps do multiple shorter videos” and “cut the distracting images in the glass wall on the right side of the video”. Another survey participant stated that it would be good to “include progression of core exercises over the weeks.” One post-survey focus group participant performed the video in the survey despite agreeing not to. They commented “my abs are really weak so when I do the breathing exercises, I couldn’t walk for a week or two, just because it was so sore and weak. Then I got used to it, and then I had no problem. I felt stronger.” They suggested “alternate the muscles you work each day.” Yet another participant suggested “add e-stim to strengthening exercises to speed up healing of the weak muscles”.

Recommendations of outcome measure changes included the addition of balance and endurance tests, self-care task analysis, and the removal of the nutrition question. One survey participant recommended the use of a balance test, while another suggested specific tests (Mini BESTest, Functional Gait Assessment, Berg Balance Test) and another suggested the 4-stage balance test. The endurance test recommended by two people was the 6-minute walk test rather than the 2-minute walk test. Finally, one participant recommended the use of the five time sit to stand test. One survey participant wrote “I don’t have a better solution, but I believe survey fatigue will be setting in with all of these surveys here and the sections previously. I suggest keep it simple.”, and another recommended “would not add more.” Other suggestions included adding disease specific and walking measures, specifically the Modified Fatigue Impact Scale (MFIS) and the Twelve Item MS Walking Scale (MSWS-12). Both post-survey focus group participants verbalized willingness to wear a FitBit, however, one reported an allergy to the plastic band.

### **Physical Activity Behavior**

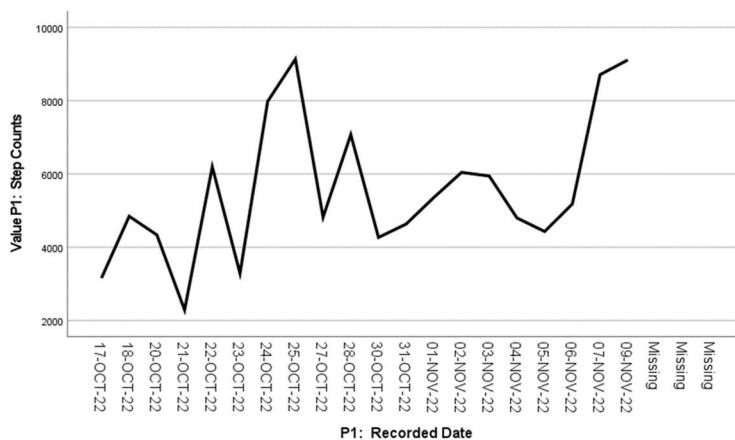
A theme related to motivation and physical activity behavior was observed. Survey and focus group participants consistently mentioned the importance of group activity, social interaction, seeing outcomes, and PA for pwMS. A survey participant also said “always more fun to be with others, maybe have a group lesson once” and another liked the “group setting”. Post-survey focus group participants also discussed the importance of exercise for pwMS stating “the activity is what keeps you from being in a wheelchair” and “if you don’t move it, you lose it.” One focus group participant expanded on this stating, “exercise gives you a natural high. . .and I think that MSers need all the natural highs they can get so it also improves mental health.”



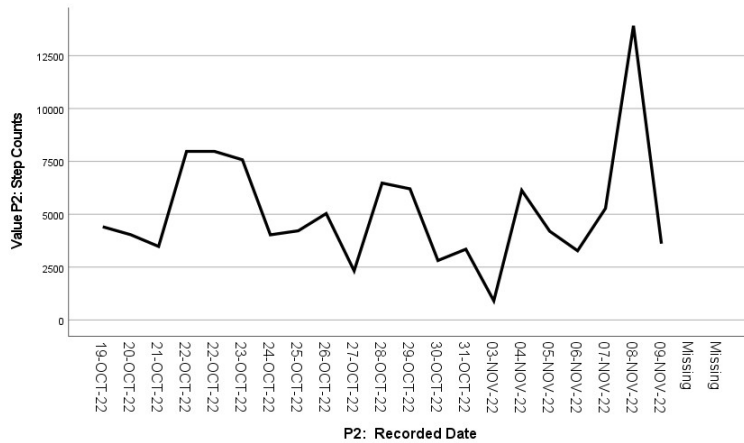
## Small-Scale Study Implementation

Small scale study participants (n=2) reported having Relapsing-Remitting Multiple Sclerosis (RRMS), each with differing capabilities. One participant rated themselves as a 2 (moderate disability) on the PDDS and the other a 3 (early cane). Both participants submitted step counts twice in the same day on at least one occasion calling into question the validity of the step count data points. Daily step count data for the two participants were plotted in graphs (see Fig. 1 and Fig. 2) and weekly counts are in Table 1. Both participants had a substantial step count standard deviation, indicating that there were days with substantially increased step counts and then days where step counts dramatically decreased.

**Figure 1: Participant 1 Daily Step Counts**



**Figure 2: Participant 2 Daily Step Counts**



**Table 1: Participant Step Counts**

Week	Participant 1 Mean (SD) n	Participant 2 Mean (SD) n
Week 1	4017.2 (1398.5) n=6	5909.0 (2144.0) n=6
Week 2	6179.9 (1885.6) n=7	4443.7 (1578.1) n=7
Week 3	5849.8 (1535.5) n=6	5295.6 (4149.9) n=7
Week 4	9110.0 (-) n=1	3610.0 (-) n=1

Pre and post physical performance test scores were captured on both participant 1 and 2 at weeks 0 and 4. Neither participant completed the CogTUG at pre testing due to errors with seated counting. Changes in the 2MWT were inconsequential for both participants. While there are no data available on a minimal detectable change (MDC) in TUG scores for pwMS, there are data for people with stroke (2.9 sec) (Flansbjerg et al., 2005) and Parkinson’s Disease (4.85 sec) (Dal Bello-Haas et al., 2011). Participant 1 did meet the MDC for people with stroke, but not for Parkinson’s Disease. Overall, it is difficult to know if meaningful change occurred for participant 1. Meaningful change did not occur in participant 2, likely due to participant 2 scoring within a

relatively normal range at -pre-testing. See Table 3 for pre and post test physical performance test scores. There are no data regarding a MDC for the five time sit stand test, however, participant 1 performed better at post testing while participant 2 performed worse.

**Table 2: Physical Performance Pre and Post Test Scores**

Performance Test	Participant 1 Pre	Participant 1 Post	Participant 2 Pre	Participant 2 Post
Time Up and Go (TUG)	17.61 seconds	14.67 seconds	9.30 seconds	9.91 seconds
Cognitive TUG	-	18.12 seconds	-	9.81 seconds
Five Time Sit to Stand	19.09 seconds	16.52 seconds	10.56 seconds	14 seconds
2 Minute Walk Test	257 feet	259 feet	443.6 feet	458 feet

Participant 1 completed only 2 out of 7 surveys while participant 2 completed all surveys at pre and post testing. Participant 1 showed a decline in motivation on the BREQ-3 while participant 2 showed substantial improvement with a shift away from introjected regulation to identified regulation. Participant 2 also demonstrated improved motivation on the Intrinsic Motivation Inventory. However, self-efficacy remained relatively unchanged according to the MSSE and Self-Efficacy Measure, but decreased on the Task Self-Efficacy Measure. See in Appendix I for a summary of pre and posttest survey scores as well as a breakdown of the self-regulation categories on the BREQ-3.

**Post-Implementation Focus Group**

Both implementation participants completed a focus group interview following completion of post testing. Both participants verbalized the same three themes noted in the surveys and post survey focus group. These included positive program attributes, suggested program changes, and physical activity behavior.

Implementation study participants found numerous positive program attributes. In regard to the educational links, one participant mentioned “I liked it because then that can give me information where I can move forward, and I tend to forget often.” One participant also mentioned “I love the video” and “the video, the exercise video that went on I think it’s very, very beneficial.” When asked about the most important thing they learned from the educational materials, participants replied “stick with it” and “keep trying.” Finally, when asked about a preferred program delivery method (e.g., asynchronous links sent weekly or synchronous sessions with or without educational links), participants responded that they preferred to have synchronous exercise sessions with educational links emailed.

Participants also verbalized suggestions for improvement. Overall, they wanted a longer program, stating “I would have liked it to be, you know, longer” and “I could have benefitted with more time to do it, because each time each week as I did it, I got better at something.” One participant also verbalized that some of the exercise was quite difficult by stating, “being on one hand and lift a leg that just kind of did not work for me. That my body didn’t work like that was exhausting.” One participant also wanted more instruction on how to use the FitBit App and stated, “I wish I had more instruction on using it, so that if it could have been more of benefit for me other than just recording steps.” One participant was also not happy with their progress and reported, “I was better. It wasn’t great. I wanted to be much better, but I was just better.” Both participants also agreed with the group facilitator when asked if wanted more time for socialization during the group.

They also discussed many program attributes that supported their engagement in PA. Both participants verbalized an appreciation for a guided program. This was supported by comments like, “. . . just having a pattern to follow was a benefit for me, so I knew what to do

and how to do it” and “. . .if you can stick with a program guided like in this way, it can show you the benefits that can come out of it.” Both participants really wanted to see outcomes. This concept was supported through comments like, “I would like to be held accountable for being able to see what the benefits are” and “see the outcome that comes out of it if you continue with it.” When asked about general thoughts about the program, one participant verbalized that “it was helpful for us to be able to move muscles. I noticed improvement in my muscles. I think that just having a pattern to follow was a benefit for me, so I knew what to do and how to do it correctly.”

Further, one person also said, “when I was diagnosed years ago, the first thing they said is you cannot exercise. Make sure you don’t exercise or do anything like that.” Later the same participant mentioned, “it’s so important to know that there is something we can do with MS.” Both participants also emphasized the benefits of social interaction was one of the best things about the live Zoom sessions stating, “the group work together was also important” and “. . .I’m more of a social person so doing something along with somebody else . . .I like that part the most”.

One implementation study participant discussed the benefit of education on average step counts “you want to try to hit that you know five thousand steps in a day. But it’s okay if you don’t hit it every day – that you could make up for the next day or you know that your overall goal is to try to get that in throughout whole week, and not just necessary have to push for it that day. Because there . . .are some days I just couldn’t get there.” Participants further explained that they liked being given ways to adapt exercises, explaining “. . .even though it was a certain exercise that we were supposed to do, we were always given the option to accommodate it to what would fit our mobility and best interests.”

The need for educational improvements was also noted within the field notes of the PI during small scale implementation. Expanded “information in educational link about how to use Zoom as well as instructions for FitBit app download” is needed. The instructor also thought that they “need to send participants an email prior to the first session that explains what is going to happen and how to set up their space to be successful during the first Zoom session.” The instructor also noted that “one participant required a tutorial on how to access the video” in the educational link. Finally, the instructor found that the exercise was “adequate” and “modifiable” but did think that the referral process should include participants being screened to ensure they can perform a floor transfer safely.

### **Discussion**

The goal of this study was to determine if *At the Core* was a feasible physical activity promotion for pwMS. The a priori criteria of at least 75% of participants viewing questions about program acceptability, demand, likelihood of implementation positively was met. Very few “disagree” responses were received on the survey, which indicates that the feasibility criteria were met. However, suggestions for improvement came from survey and focus group participants as well as a short-version implementation of the program. The following section discusses the identified program strengths and areas of the program that will be changed based on participant feedback. Finally, the need for incorporation of motivational strategies into PA promotion programs will be discussed.

One program strength was the video. While participants from all groups (survey, focus groups, and implementation) found the video helpful and easy to use, some people felt that it was too long. One simple change to be made is to include the full video, a shorter exercise-only video, and a meditation only video. To address the varied perceptions of program difficulty, one

solution is to divide the exercise program into two parts. Part one of the exercise program would consist of the first 4 weeks and contain basic exercises. Part two would then contain last 4 weeks of the program and could consist of the more difficult exercises. This modification also supports another survey participant suggestions to break the video down into shorter videos. Another recent feasibility study reported that exercise related fatigue was a barrier to exercise participation for pwMS (Louie et al., 2022). The experience of both the subjective experience and also the objective signs of fatigue (e.g., foot drop with walking far) may bolster the need for a more stepwise progression into any strength program. No suggestions for improvement were made for the meditation.

Mixed reviews were reported on the educational links with participant concerns related to health literacy and the amount of information in the links. While the health literacy concerns are valid, a recent study found that pwMS had improved health literacy, but not self-efficacy, following completion of an fully online educational program for pwMS (Bessing et al., 2022). Other authors have also found that peer support and even peer led intervention can be helpful at improving health literacy in pwMS (Dehghani, 2021). As presently designed, *At the Core*, offers participants both an emailed version of the links following a synchronous Zoom session in which the links are fully reviewed with participants. Both implementation participants preferred to have both live instruction as well as the educational links emailed to them following the class. Both the literature and implementation participants' preferences indicate that minimal changes to the educational links need to be made at this time. Further, the addition of peer support through the synchronous classes within *At the Core* may help build self-efficacy and health literacy simultaneously, however, this warrants further investigation.

Outcome measures also received mixed reviews. Based on participant feedback, it is important to continue with step count monitoring. However, increased education on how to use the FitBit, particularly the phone application, needs to be included in session 0. Session 0 also needs to contain education on how to set up their space at home for the synchronous exercise sessions.

There were many suggestions about the various physical performance tests. Participants recommended changing from the 2-minute walk test to the 6-minute walk test and adding a balance measure. In this study, the PI would assert that the 2-minute walk test was likely best for one participant and 6 minute for the other due to observed muscle fatigability during gait. This author would recommend giving an option to continue for the full 6-minute walk test if the client is not showing gait deviations that decrease safety after 2 minutes of walking. A postural control test, such as the Mini BESTest, Berg Balance Test, or Functional Gait Assessment will also be included in future pre and post test batteries with this population.

Several self-report outcome measures can also be deleted to minimize the potential for survey fatigue. Based on feedback, the nutrition question will be deleted. Also, due to the time taken to score the PSQI, this author recommends not performing this test in the future pilot of the program. However, the MSSE, which was used in this study, includes fatigue related task efficacy questions, and will likely be kept so that other self-efficacy measures that are less specific to pwMS can be deleted from the test battery. This author would choose to keep the MSSE and the BREQ-3 for a future pilot outcomes-based study. The BREQ-3 provided good information about stages of self-regulation and levels of motivation for one participant while the MSSE gives a good overall picture of self-efficacy for pwMS as they complete activities of daily living as well as activity in general. Clinicians working with pwMS may also consider both



outcome measures when promoting PA to pwMS. If the clinician wishes to determine information related to participant self-efficacy, the MSSE would be best to choose. Alternatively, if the clinician wishes to know more about motivation for PA, then the BREQ-3 might be best to choose. From the perspective of this author, the MSSE, is easier to score and may also provide clinicians with more meaningful information than the BREQ-3.

Support for the motivational and behavioral strategies incorporated within the program was also evident. The first was the need for education on pacing. Both implementation study participants demonstrated substantial standard deviations in their step counts, indicating the need to include a relative day of rest after a more active day. Based on these findings as well as previous literature that reports fatigue is a barrier to exercise in pwMS, future programs for pwMS should include education on exercise pacing (Louie et al., 2022). Based on the present study, this researcher recommends educating pwMS on the importance of rest days and average daily exertion goals versus specific daily prescribed exercise. For example, people in this study found it beneficial to focus on average weekly daily step counts versus being told to walk at least 5000 steps per day. While the goal is 5000 steps per day, the way the education is provided, seems to be important from a motivation perspective.

Overall, survey completers deemed the program safe for pwMS who are in the early stages of the disease process. However, it is important to ensure participant safety in any program, and to especially consider the specific needs for pwMS. To maximize participant safety, it is recommended that participants be screened by an appropriate healthcare provider to ensure they can safely get up and down off the floor prior to acceptance into the program.

*At the Core* was designed to focus primarily on the development of self-efficacy and self-determined motivation through goal setting, lifestyle PA (step count monitoring), and accessible

home-based exercise in a group format. Throughout the study participants commented about the importance of social support within a group environment. The use of group sessions for pwMS may be helpful to improve self-efficacy and again warrants further study.

This study had several limitations. First, the sample sizes are small, and the program was only partially implemented. Because the intervention was 2 weeks long, instead of 8, the participants did not have adequate time to experience substantial changes in physical performance related to the program. Also, both participants in the small-scale study implementation were known to the PI, which may have contributed to bias. Although an alternate researcher led the focus group for the implementation study, the previous relationship may have impacted participants' willingness to comment honestly. Despite these limitations, overall, the findings indicate that the program is feasible and can be implemented with a larger pilot and more targeted outcome measures.

## CHAPTER II: DISSEMINATION

The dissemination of this project will first occur in the form of a PowerPoint presentation to the clinicians who staff a free community-based clinic for pwMS - MSFit. Physicians, people with MS, local clinicians, and other stakeholders will also be invited to the presentation which will occur live in person and via Zoom. The 30-minute presentation will focus on my dissertation findings related to *At The Core* followed by a discussion about the best ways to begin implementation in the local area. I hope to be able to offer CEUs to clinicians to increase attendance.

**Slide 1: Presentation Title:** Hello my name is LaVerene Garner and I'm a faculty member at Winston-Salem State University in the Dept of Physical Therapy. I recently completed an EdD in Kinesiology at the University of North Carolina-Greensboro and am here to present my findings. I'm excited to introduce you all to *At The Core: A Physical Activity Promotion program for people who live with Multiple Sclerosis* and to begin identifying ways we can implement this program within our community.

**Slide 2: Objectives:** Today we will spend time talking about why physical activity is so important for people who live with Multiple Sclerosis, the findings from my dissertation project that investigated the feasibility of *At The Core*, and will also identify ways to begin implementing the program here in the local community.

**Slide 3: Background Information:** Let's talk now about background information related to MS – specifically what it is, who gets it, and typical interventions.

**Slide 4: MS and Physical Activity:** On average, people who live with MS tend to be much less physically active than people their same age who don't live with MS. In fact, only about 27% of pwMS meet the current physical activity recommendations, which advise 30

minutes of moderate PA, five times a week. An easy way to increase physical activity is just through increasing step counts. For pwMS, one study that investigated step counts found that those pwMS who walk at least 4766 average weekly steps per day are less likely to experience a decline in function. This means that PA that helps people with MS does not require equipment.

How might we get people with MS to move more? We need to educate them about specific benefits of PA, such as the study I just discussed. Finally, we need to help improve their self-efficacy for PA by assisting them in achievable goal setting and education. Group activities can also improve self-efficacy.

**Slide 5: The problem and the gap:** Unfortunately, there are few physical activity promotion programs available to people who live with MS and even fewer that use a hybrid environment – meaning someone does testing prior to and after the program in person but the program itself happens via Zoom.

**Slide 6: At The Core – V1:** The original At the Core program consisted of a week of pre-testing, 8 weeks of synchronous programming, followed by a week of post-testing. Pre-and post-testing weeks included instruction on FitBit use, dual task walking, timed sit to stand and walking tests, and self-efficacy/motivation questionnaires as well as a questionnaire about sleep.

**Slide 7: Dissertation: Purpose and Aims:** The purpose of my dissertation was to evaluate the feasibility of the At The Core program based on expert/stakeholder feedback. Three programmatic aims were targeted: 1. Overall program organization, procedures, and outcome measures. 2. Program content (video and educational materials). 3. Participant feedback based on a small-scale pilot.

**Slide 8: Methods:** Twenty-nine people in total (17 pwMS and 12 content experts) completed the survey, although only 11 finished the entire survey which means with survey data

alone there was less information received about the video and educational links than about the outcome measures and program overall. Two people with MS participated in the post survey focus group and 2 additional people participated in the small-scale study implementation. The majority of survey respondents felt that the program was appropriate, safe, and would benefit pwMS who are in the early stages of the disease progress.

**Slide 9: Main Themes:** There were three focused areas found within the study. The first was program strengths. The second was areas of growth. The third involved the importance of intentionally including strategies that build self-efficacy and support motivation for PA.

**Slide 10: Program Strengths:** The primary strengths of the program noted were the video, educational links, the use of FitBit step count monitoring, and the group environment. The exercise component of the video was found to be helpful due to the exercise variations demonstrated. Implementation study participants liked exercising in a group and liked having live sessions with links sent after the meeting that reviewed the educational material and provided a video home program. Survey participants liked the “core breathing and yoga” and the overall “holistic nature of the thing.” The meditation was also positively received with one participant stating, “I particularly enjoyed the meditation.”. The educational links were noted to be comprehensive and user friendly. Particularly the education on a variety of topics as well as pacing. In *At The Core*, we talk about a study completed with pwMS that recommends getting an average of 4766 daily average steps per day. One participant verbalized “you want to try to hit that you know five thousand steps in a day. But it’s okay if you don’t hit it every day – that you could make up for the next day or you know that your overall goal is to try to get that in throughout whole week, and not just necessary have to push for it that day. Because there are

some days I just couldn't get there." So this idea of being able to pace yourself and still meet the goal while accepting bad days, seemed important.

**Slide 11: Areas for Growth:** In this slide I will review the three areas for growth and the individual bullet points mentioned in the PowerPoint. The three areas for growth include the video, educational links, and outcome measures. For the video, a short-term goal is to divide the video into two parts – the exercise and the meditation to make the length more doable for those with time constraints. Long term, it may be prudent to make a program that consists of 4 weeks of lower level activity or 4 weeks of more advanced activity. In the educational links, improvements in education on how to use the FitBit app as well as more education on preparedness for Zoom sessions needs to occur. Further, typos need corrected and health literacy assessed. Finally, I will be changing some outcome measures by removing the nutrition question, increasing the 2 MWT to the 6MWT or basing which test is chosen based on functional level. A postural control measure will be added and the number of motivation and self-efficacy measures will be decreased to decrease survey burden.

**Slide 12: Self-Efficacy and Motivation:** It is important for those who work with pwMS to remember the history of the relationship of exercise to pwMS. Historically pwMS were told not to exercise by medical professionals. At the time there was sound reason for this because pwMS often show temporary worsening of symptoms with PA, especially when there is heat involved. A participant brought this up in the focus groups by stating "when I was diagnosed years ago, the first thing they said is you cannot exercise. Make sure you don't exercise or do anything like that" and later "it's so important to know that there is something we can do with MS." A lack of safety implies a lack of competence which could be a contributing factor to the overall physical inactivity in this group. This may also be why slow increases of weekly step

counts was positively received. Particularly when it occurred with education about how walking a weekly average of >4766 steps/day is associated with avoiding functional decline. Finally, the positive social implications of group exercise was emphasized across the board by participants. Participants also liked to see outcomes, again helping to foster a sense of competence which begets motivation to continue.

**Slide 13: Key Take Aways:** In summary, I think there are four main areas of key take aways. Those include education, outcomes, patience with the PA promotion process, and the use of group exercise.

**Slide 14: Education:** For pwMS, specific education related to how PA can help control disease symptoms is key to increase motivation. As a clinician or exercise professional, educate yourself about how to work with pwMS or find a mentor who does and educate your clients how to be active with MS. Currently the recommendations are for pwMS to engage in 30 minutes of moderate intensity PA, five times a week. However, if you are working with people who are not currently physically active, step counts may be a great place to start. Further, it is important that pwMS are educated on how PA or exercise can help them live better with MS. While education is important, it is also important that they experience success when adding PA to their lives.

**Slide 15: Outcomes:** Outcomes are important – remember that outcomes and how they are presented to pwMS help them build a sense of competence. Set achievable goals and maybe focus on step counts versus minutes of exercise. Focusing on average daily step counts is backed by the literature and gives people permission to rest when needed. They can shift from “I feel guilty and ashamed” to “I am enough and I can do this.” Also, consider using the Multiple Sclerosis Self-Efficacy Scale – it does a great job of assessing how confident pwMS are at managing their MS related symptoms in relationship to performing various functional tasks.

**Slide 16: Group Activity:** Find a way to work with pwMS in groups. There is power in social support and vicarious expert. It's supported by theories and by many of the people who participated in this study.

**Slide 17: Patience:** Be patient with your clients and if you are a pwMS then be patient with yourself. Remember the history and that exercise has not always been seen as a friend to pwMS. The unwinding of beliefs takes time, artful goal setting, and consistent successful outcomes led by an educated professional who is a skilled educator and PA promoter.



## CHAPTER III: ACTION PLAN

This research will be presented as a continuing education class through a medium sized University in North Carolina. The presentation will discuss why physical activity promotion is needed for pwMS, the findings of the research, and a discussion on how the program can be implemented through partnerships with local entities.

### **Immediate Plans**

Immediately, I hope to revise the program based on the findings and then submit a new IRB through my employer (WSSU) so that I perform a larger outcome-focused pilot study. I am required to perform research and lead students through Capstone projects as one aspect of my job so this will allow me to teach students how to promote PA for pwMS while also performing research that supports a community-based need. I also plan to present this research to the clinicians at the local MSFit clinic as well and potentially through the National MS Society.

### **Long Term Plans**

Within a year, I hope to develop a program that trains healthcare professionals, researchers, and fitness professionals, how to implement the program in their communities within the next year. I hope then that the program can be piloted nationwide within the next 2-3 years and even potentially at some global locations with fidelity within 5-10 years. Finally, I hope to use the information gained in these endeavors to publish manuscripts and present at local (state APTA conferences) and national conferences, such as APTA Combined Section Meeting or The International Symposium on Gait and Balance in MS

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## APPENDIX A: ORIGINAL AT THE CORE PROGRAM

This is an 8-week prospective cohort-based intervention designed to promote increased physical activity in people with Multiple Sclerosis (pwMS). All participants will provide informed consent and participate in a week of pre-testing and a week of post-testing. Therefore, the program will last a total of 10 weeks with 8 weeks of intervention.

### **Participants**

Participants diagnosed with Clinically Isolated Syndrome (CIS), primary progressive (PPMS) or relapsing remitting MS (RRMS) who reside in North Carolina and rate themselves in the early to mid stages of the disease process (score of 0-3) on the Patient Determined Disease Steps Scale (PDDS). Individuals who have undergone a recent surgery for which they continue to have surgical precautions or are undergoing active treatment related to cancer will be excluded. Further, individuals with uncontrolled hypertension will be excluded from the study or program unless a referral granting clearance is made by their primary care physician. Individuals must have an email account and access to a cell phone or computer to participate in this study.

### **Measures**

Step counts and hours active during the day will be recorded using the FitBit Inspire 2 continuous activity monitor. The [FitBit Inspire 2](#) is a commercially available device that is waterproof which means that participants don't need to remove the device during swimming or showering making valid data collection more feasible. While the FitBit Flex 2 has demonstrated validity in measuring step counts in pwMS, however, it is no longer available from FitBit (Block, 2019).

[The Godin Leisure Time Exercise Questionnaire](#) is a self-report measure asks individuals to rate their engagement in low, moderate, and high intensity exercise across 7 days (Godin & Shephard, 1985).

[The Timed Up and Go \(TUG\)](#) asks individuals to stand up from a standard height chair with or without the use of their arms, walk 10 feet (with or without an assistive device) and return to sit in the chair from which they started (Podsiadlo & Richardson, 1991).

The Cognitive Timed Up and Go (CogTUG) asks individuals to count backwards by 3's from a number between 20 and 100 while performing the TUG above. The starting number is randomly chosen by another party, such as a researcher or clinician. The individual being tested performs the counting activity while seated prior to performing the counting activity in a dual task situation. This test has shown the ability to predict falls in community dwelling older adults (Shumway-Cook et al., 2000) but not people with MS (Quinn et al., 2019).

The five times sit to stand test (FTSTS) asks individuals to stand up and sit down five times in a row as quickly as possible with the arms crossed across the chest (Whitney et al., 2005).

The Two Minute Walk Test (2MWT) asks individuals to walk at a self-selected speed back and forth between two points that are spaced 50 ft apart (Butland et al., 1982).

[The Task and Scheduling Self-Efficacy](#) self-report measure asks individuals to rate how confident they are that can engage in physical activity/exercise (Rodgers et al., 2002).

[The Multiple Sclerosis Self-Efficacy Exam \(MSSE\)](#) is an 18 item questionnaire designed to assess confidence in one's ability to perform various functional tasks as well to control the

symptoms related to the disease process of MS. The test has demonstrated good convergent and divergent validity and test-re-test reliability (Schwartz et al., 1996).

[Pittsburgh Sleep Quality Index \(PSQI\)](#) is a self-administered questionnaire that investigates sleep quality and quantity (Buysse et al., 1989).

[The Behavioral Regulation in Exercise Questionnaire – 3 \(BREQ-3\)](#) is a 24 item self-report measure that quantifies an individual's self-determined motivation related to physical activity (Cid et al., 2018).

[The Intrinsic Motivation Inventory \(IMI\)](#) is a self-report measure that assesses self-determined motivation (Deci et al., 1994).

[Patient Determined Disease Steps \(PDDS\)](#) is a self-report measure that asks participants to classify their level of function on a scale of 0 (normal function) through 6 (wheelchair bound) (Learmonth et al., 2013).

Diet: This 1-item measure asks participants to describe their diet in the last 30 days. Which of the following categories best describes your diet in the last 30 days: 1. Primarily plant based. 2. Primarily lean meat. 3. Primarily fatty meat. 4. Mainly fast food or processed food

#### **Procedures:**

Individuals will provide informed consent with a Qualtrics consent form. See attachment {} for informed consent. After receiving informed consent, individuals will be screened for inclusion criteria by completing the PDDS through Qualtrics and certifying that their blood pressure is controlled by medications or otherwise normal and that they do not presently have restrictions from a physician due to a recent injury or surgery and are not under the care of a physician for cancer related care (ie active chemo or radiation). If inclusion criteria are met, participants will continue to complete the Task and Scheduling Self-Efficacy questionnaire, PSQI, BREQ-3, and MSSE via Qualtrics. Participants will then be contacted by the research team to schedule for an in person pre-testing session in which they will complete the TUG, CogTUG, FTSTS, 2MWT and receive their FitBit device.

Following pre-testing individuals will be scheduled for Session 0 in which they will receive further education on the At the Core program. Additionally, participants will receive instructions on how to wear their FitBit, download step counts and set SMART goals (See Addendum). Participants will be emailed an link to a webpage that contains the physical activity program and also selected educational materials for the week. Individuals will also meet with a researcher who is a licensed PT weekly for a synchronous session over zoom to review the materials issued via email and to perform the physical activity program together (See outline below). Each week participants will be asked to download data from their FitBits to a database (or plan B send in their step counts via a google form).

Program Title: At The Core: A Physical Activity Promotion Program for People Living

with MS

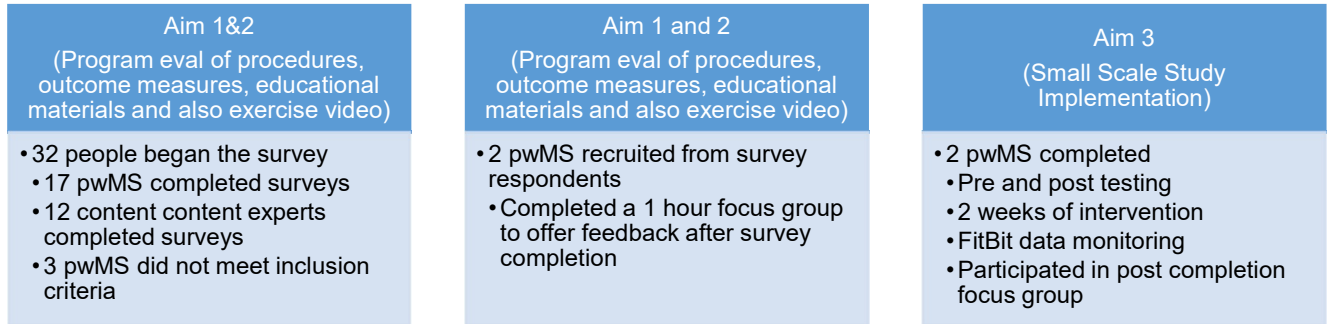
- A. [At The Core – Session 0: Intro and Pre-testing](#)
- B. [At The Core – Week 1: Find your Why?](#)
- C. [At The Core – Week 2: Navigating Obstacles](#)
- D. [At The Core – Week 3: Finding Support](#)
- E. [At The Core – Week 4: Learning to Juggle](#)
- F. [At The Core – Week 5: Physical Activity for Life](#)
- G. [At The Core – Week 6: Healthy Sleep](#)

- H. [At The Core – Week 7: Physical Activity or Exercise Check in](#)
- I. [At The Core – Week 8: Looking Back](#)
- J. At The Core – Week 9 Post testing and wrap up

**Post-Test Procedures**

Following completion of the 8 week program, participants will complete the Self-efficacy for task and scheduling, BREQ-3, MSSE, IMI, and PSQI via Qualtrics, download their final step counts and other requested data from the FitBit and complete in person post-testing that will consist of the FTSTS, CogTUG, and TUG.

## APPENDIX B: FEASIBILITY STUDY DESIGN SCHEMATIC



## APPENDIX C: SURVEY

### Section 1:

#### Background info:

##### What is your background?

- I am a person who lives with MS
- I am a researcher/professional/clinician who works with people with MS
- I am both a person with lives with MS and a researcher/professional who works with people with MS.

**Q2 and 3: Displayed only if I am a person who lives with MS is checked.** Please rate your level of function on the following scale:

[https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/10-2-3-28-Disease\\_Steps\\_Form.pdf](https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/10-2-3-28-Disease_Steps_Form.pdf)

*If person scores between 0-3 then continue with survey; If scores 4 or above, then: Thank you for your interest in this survey but at this time you do not qualify for the study.*

**Q3: Displayed only if I am a person who lives with MS is checked.** Have you had any recent surgeries for which you have surgical precautions? *If yes. Thank you for your interest in this survey but at this time you do not qualify for the study. If no, continue.*

In the next block of questions, you will be asked questions about yourself.

**Q4: Check the box that best corresponds with your professional or life experience (you may choose more than one).**

- Researcher (open box to describe)
- Clinician (open box to describe)
- Person with MS (open box for type and date of onset)

**Q3. What is your gender identity:** (male, female, non-binary, other, prefer not to say)

**Q4. What is your race/ethnicity?** (select all that apply) Hispanic/Latinx, white, black or AA, American Indian or Alaska Native, Afro-Caribbean, Asian, Native Hawaiian or Pacific Islander, Other – please specify).

**Q5. What is your age?** (Age ranges starting at 18 will be given)

**Q14: Which of the following best describes your physical activity level?** (High – I exercise 4-5 days at a week at a level that makes me breathe hard; Moderate – I exercise or walk several days a week at a level where my heart rate is up but I can still have a conversation; Low – I engage in minimal physical activity; prefer not to answer.)

All participants complete all components of the survey after this point.

#### II. Program Background and Procedures

Please review the program overview, goals, and participant requirements to answer the following questions.

##### Program overview

*At the Core* is an 8-week prospective cohort-based intervention study designed to promote increased physical activity in people with Multiple Sclerosis (pwMS). All participants will provide informed consent and participate in a week of pre-testing and a week of post-testing. Therefore, the program will last a total of 10 weeks with 8 weeks of intervention.

### **Program goals**

1. Educate people with MS how to be physically active through disease specific behavioral modification within a lifestyle approach.
2. Increase or maintain step counts as monitored with the FitBit Inspire to > 4800 steps per day (average weekly).
3. Increase self-efficacy and motivation for physical activity.
4. Promote lifelong physical activity while living with MS.

### **Participants**

*Program participants will be individuals diagnosed with Clinically Isolated Syndrome (CIS), primary progressive (PPMS) or relapsing remitting MS (RRMS) who rate themselves in the early to mid stages of the disease process (score of 0-3) on the Patient Determined Disease Steps Scale (PDDS).*

#### **Questions:**

1. The program goals are appropriate for people with MS. (Strongly agree, agree, disagree, strongly disagree, open text)
2. People with MS would benefit from this type of program. (Strongly agree, agree, disagree, strongly disagree, open text)
3. The length of the program (8 weeks of intervention) is sufficient to accomplish program goals.  
(Strongly agree, agree, disagree, strongly disagree, open text)

### **Measures**

The next several blocks of questions will ask you to review various outcome measures, such as overall physical activity (step counts), physical performance (5 time sit to stand; Timed Up and Go), motivation/self-efficacy, Multiple Sclerosis specific measures, and some other health related measures.

For the first set of questions, please review the physical activity outcome measures listed below.

#### ***Physical Activity Measures***

**Step counts** and hours active during the day will be recorded using the FitBit Inspire 2 continuous active monitor.

**The Godin Leisure Time Exercise Questionnaire** is a self-report measure that asks individuals how often they engage in low, moderate, and high intensity exercise across 7 days (Godin & Shephard, 1985).

#### **Questions:**

1. The physical activity measures are appropriate to assess level of physical activity in people with MS.
2. Please list any physical activity measures you think should be added.
3. Please list any physical activity measures you think should be deleted.

For the next set of questions, please review the following physical performance measures.

#### ***Physical Performance Measures***



**The Timed Up and Go (TUG)** asks individuals to stand up from a standard height chair with or without the use of their arms, walk 10 feet (with or without an assistive device) and return to sit in the chair from which they started (Podsiadlo & Richardson, 1991).

**The Cognitive Timed Up and Go (CogTUG)** asks individuals to count backwards by 3's from a number between 20 and 100 while performing the TUG above (Shumway-Cook et al., 2000).

**The five times sit to stand test (FTSTS)** asks individuals to stand up and sit down five times in a row as quickly as possible with the arms crossed across the chest (Whitney et al., 2005).

**The Two Minute Walk Test (2MWT)** asks individuals to walk at a self-selected speed back and forth between two points that are spaced 50 ft apart (Butland et al., 1982).

### **Questions:**

1. The outcome measures that assess physical performance (ie TUG, COGTUG, 2 MIN WALK, 5xSTS) are appropriate to examine changes in physical function.
2. Please list any physical performance measures that you think should be added
3. Please list any physical performance measure you think should be deleted

For the following set of questions, please review the following Multiple Sclerosis Specific Measures

### ***MS Specific Measures***

**The Multiple Sclerosis Self-Efficacy Exam** is an 18 item questionnaire designed to assess confidence in one's ability to perform various functional tasks as well to control the symptoms related to the disease process of MS (Schwartz et al., 1996).

**Patient Determined Disease Steps (PDDS)** is a self-report measure that asks participants to classify their level of function on a scale of 0 (normal function) through 6 (wheelchair bound) (Learmonth et al., 2013).

### **Questions:**

1. The outcome measures that assess MS Specific Disease items are appropriate to examine the impact MS has on physical function from the perspective of a person living with MS. (Strongly agree, agree, disagree, strongly disagree)
2. Please list any MS specific outcome measures that you think should be added
3. Please list any MS specific outcome measures that you think should be deleted

For the following set of questions, please review the other health related measures list below:

### ***Other Health Related Measures***

**Pittsburgh Sleep Quality Index (PSQI)** is a self-administered questionnaire that assesses sleep quality and quantity (Buysse et al., 1989).

**Diet question (developed for study) One researcher developed question will also be asked.** Which of the following best describes your diet in the last 30 days. 1. Primarily plant based (fresh or frozen fruits or vegetables) with minimal meat or dairy consumption. 2. Primarily lean meat (turkey, chicken, lean ground beef, fish/seafood) with moderate (3-4 servings per day) of fruits/vegetables. 3. Primarily meats such as bacon, sausage, beef, pork, or

fried foods with minimal (1-2 servings) of fruits or vegetables. 4. Mainly fast food or processed foods, such as frozen pizza and/or burritos.

### **Questions**

1. The outcome measures that assess other health related behaviors (sleep, diet) are appropriate. (Strongly agree, agree, disagree, strongly disagree)
2. Please list any additional outcome measures that assess other health related behaviors that you think should be included.
3. Please list any outcome measures that assess other health related behaviors that you think should be deleted.

For the following set of questions, please evaluate the outcome measures that assess motivation and self-efficacy, or situation specific self-confidence, related measures.

### ***Motivation and Self-Efficacy Measures***

**The Behavioral Regulation in Exercise Questionnaire – 3 (BREQ-3)** is a 24 item self-report measure that quantifies an individual's self-determined motivation related to physical activity (Cid et al., 2018).

**The Intrinsic Motivation Inventory (IMI)** is a self-report measure that asks individuals to rate their agreement or disagreement (1 = not true; 7 = very true) with various constructs related to self-determined motivation (Deci et al., 1994).

**The Task and Scheduling Self-Efficacy** self-report measure asks individuals to rate how confident they are that can perform various task oriented and schedule-oriented items (Rodgers et al., 2002).

### **Questions:**

1. The outcome measures that assess motivation and self-efficacy are appropriate. (Strongly agree, agree, disagree, strongly disagree)
2. Please list any additional outcome measures that assess motivation and self-efficacy measures that you think should be included.
3. Please list any outcome measures that assess motivation and self-efficacy that you think should be deleted.

### **Questions:**

1. Overall, the outcome measures are appropriate for assessing program goals. (Strongly agree, agree, disagree, strongly disagree)
2. Assuming that a licensed healthcare provider refers to this program who should perform the in person pre and post measures?
  - a. Fitness professional (open answer box)
  - b. Licensed healthcare provider (open answer box)
  - c. Researcher
  - d. Other (open answer box)
3. Assuming that a licensed healthcare provider refers to this program who should monitor step count data?
  - a. Fitness professional (open answer box)
  - b. Licensed healthcare provider (open answer box)

c. Other (open answer box)

### III. Educational Material Evaluation – Section 2

THIS IS A GOOD PLACE TO TAKE A BREAK IF NEEDED. YOU CAN EXIT THE SURVEY TO TAKE A BREAK AND RETURN BY CLICKING THE LINK IN THE EMAIL SENT. IT IS ESTIMATED THAT THE NEXT SECTION WILL TAKE APPROXIMATELY 1 HOUR TO COMPLETE.

The following educational materials will be emailed to At The Core participants on a weekly basis as a component of the program. The links also contain the overall flow of each synchronous Zoom session. Please note that each link contains a video. Please do not review the video in this section. Please review the EDUCATIONAL materials, NOT THE VIDEO by clicking the links and provide feedback below.

[At The Core – Session 0: Intro and Pre-testing](#)

[At The Core – Week 1: Find your Why?](#)

[At The Core – Week 2: Navigating Obstacles](#)

[At The Core – Week 3: Finding Support](#)

[At The Core – Week 4: Learning to Juggle](#)

[At The Core – Week 5: Physical Activity for Life](#)

[At The Core – Week 6: Healthy Sleep](#)

[At The Core – Week 7: Physical Activity or Exercise Check in](#)

[At The Core – Week 8: Looking Back](#)

I understand that I am being asked to review the educational materials only in this survey. I also understand that I am not being asked to watch, review, or perform the video in this survey. (I understand or I do not understand). If I do not understand is checked – participants are taken to the end of the survey.

For the following set of questions, please refer to these links:

[At The Core – Session 0: Intro and Pre-testing](#)

[At The Core – Week 1: Find your Why?](#)

[At The Core – Week 2: Navigating Obstacles](#)

[At The Core – Week 3: Finding Support](#)

[At The Core – Week 4: Learning to Juggle](#)

[At The Core – Week 5: Physical Activity for Life](#)

[At The Core – Week 6: Healthy Sleep](#)

[At The Core – Week 7: Physical Activity or Exercise Check in](#)

[At The Core – Week 8: Looking Back](#)

#### Questions:

To what extent do you agree with the following statements (Strongly agree, somewhat agree, somewhat disagree, strongly disagree):

First set:

The educational links provided were easy to use.  
The educational links contain the right amount of information.

**Next set:**

**Content Evaluation: This set of questions relates to on the educational component of these links Please only respond based on the EDUCATIONAL materials presented in the links.**

[At The Core – Session 0: Intro and Pre-testing](#)

[At The Core – Week 1: Find your Why?](#)

[At The Core – Week 2: Navigating Obstacles](#)

[At The Core – Week 3: Finding Support](#)

[At The Core – Week 4: Learning to Juggle](#)

[At The Core – Week 5: Physical Activity for Life](#)

[At The Core – Week 6: Healthy Sleep](#)

[At The Core – Week 7: Physical Activity or Exercise Check in](#)

[At The Core – Week 8: Looking Back](#)

The material presented in the educational links is APPROPRIATE.

The material presented in the educational links is ACCURATE.

The material presented in the educational links is ENGAGING.

The material presented in the educational links is UNDERSTANDABLE.

The material presented in the educational links is HELPFUL.

People with MS would be able to USE the information in the educational links.

What did you LIKE most about the educational links.

What did you DISLIKE about the educational links.

#### IV: Video evaluation – Section three

**For the final part of the evaluation of At The Core, you will be asked to review a video. Prior to continuing, please read and agree with the following statement.**

**I understand that I am being asked to WATCH this video. I am NOT being asked to PERFORM this video.**

**Please watch this video (in this [link](#)) and then answer the following three sets of questions.**

**To what extent do you agree with the following statements (Strongly agree, somewhat agree, somewhat disagree, strongly disagree):**

**First set:**

The video was easy to use.

People with MS would want to use this video.

The video is an appropriate length.

The video functioned well.

The video is APPROPRIATE for people with MS.

The video is ENGAGING.

People with MS would enjoy performing this video.

For the final part of the evaluation of At The Core, you will be asked to review a video. Prior to continuing, please read and agree with the following statement.

I understand that I am being asked to WATCH this video. I am NOT being asked to PERFORM this video.

I understand I do not understand Participants who check I do not understand will be taken to the end of the survey.

**Next set: This set of questions relates to the EXERCISE component of the video. You will be asked about the meditation component of the video later. Please only respond based on the EXERCISE component of the video for this set.**

The exercise in the video is UNDERSTANDABLE.

The exercise presented in the video is HELPFUL.

The exercise presented in the video is SAFE for people with MS.

**Next set: This set of questions relates to the MEDITATION component of the video. Please only respond based on the MEDITATION component of the video for this set of questions..**

The meditation in the video is UNDERSTANDABLE.

The meditation presented in the video is HELPFUL.

The meditation presented in the video is SAFE for people with MS.

What did you like MOST about the exercise/meditation video?

What would you change, add, or remove from the exercise/meditation video?

#### **V. Closing questions**

The following questions ask you to comment on the whole program. Please consider the entire program (program structure, outcome measures, video, educational materials) when responding to the following questions.

4. I would encourage a person living with MS to participate in this program.  
(Strongly agree, agree, disagree, strongly disagree)
  5. This program is safe for people early in the MS disease process.  
(Strongly agree, agree, disagree, strongly disagree, unable to comment)
  6. The *At the Core* program is designed in a hybrid format. This means that pre and post-testing will occur in person and the intervention sessions will occur via Zoom. The weekly intervention sessions include:
    - Health related educational and behavioral coaching based on the educational links previously reviewed.
    - Physical activity routine included in the video previously reviewed
- Assuming that a licensed healthcare provider refers to this program, who should LEAD At The Core zoom coaching and PA sessions?
- a. Fitness professional(Open answer box)
  - b. Licensed healthcare provider (open answer box)
  - c. Researcher (open answer box)
  - d. Other (open answer box)
6. What are the best things about At The Core (list up to 3)?
  7. How could At The Core be improved (list up to 3)?
  8. Please add any other comments about the At The Core program.

Thank you for completing this survey. If you are a person with MS and are interested in participating in focus groups to discuss your feedback on At the Core in more depth, please click “here” to provide your name and email address to be contacted later.

## APPENDIX D: FOCUS GROUP SCRIPT FOR SURVEY PARTICIPANTS

Click [Here](#) to view demographic survey that will follow the focus group consent.

Demographic questions include race/ethnicity, gender identification, age, type of MS, and years of living with MS.

### **Focus Group Questions (post survey for pwMS)**

Good (morning, afternoon, evening), my name is LaVerene Garner and I'll be facilitating this group. I am a licensed physical therapist and I currently work as an assistant professor in the dept of physical therapy at WSSU. At WSSU, we have a clinic for people who live with MS so I have grown to really enjoy working with people with MS and wanted to develop a program to serve that group. So, here we are. I also want to thank you all for your willingness to participate in this focus group. The purpose of these groups is to gain more in depth feedback about At The Core than I could from the survey alone. I hope to use the feedback you all share to make At The Core better. In the session, you will be asked questions about At The Core. I will generally let a person respond first and then go around to each participant to make sure everyone gets a chance to share. I want to respect your time and keep this to one hour so let's get started.

### **Questions:**

- Let's start with each person discussing why you think a physical activity promotion program would benefit people with MS? Maybe you can also share a type of physical activity that you enjoy. Please remember not to say your name.
- Let's move on to discussing the At The Core program specifically. Please share your initial or general thoughts about the program.
  - Follow up questions: How would people living with MS benefit or not benefit from a program like At The Core. How is length of the program (too long, too short, etc)?
- Next I'd like to talk about using the FitBit. Do you think you would be willing to wear a FitBit so that a healthcare provider or researcher could monitor your step counts?
- One component of the program is the educational links you reviewed. What are your thoughts about the education links (Show week 1 and 2 links)? [At The Core – Week 1: Find your Why?](#) [At The Core – Week 2: Navigating Obstacles](#)
  - Follow up questions: What did you like best about these links? What did you like least? Were they easy to read and understand? What was the most important thing you learned?
- Now let's talk about the exercise and meditation video. There were breathing and core exercises, standing exercises, exercises on your hands and knees, and exercises on your back. There was also a meditation component. Please share your thoughts about the video.
  - Follow up questions: There were a couple of components of the video, such as the meditation and exercise. Did you like both? Did you try both? Or did you prefer one over the other?
- Would you participate or encourage others with MS to participate At The Core or participate in it yourself? Please explain why or why not?

- Is there anything else you'd like to add about the program that maybe we didn't have time to discuss previously?



## APPENDIX E: OUTCOME MEASURES

### *Physical Activity Measures*

**Step counts** and hours active during the day will be recorded using the FitBit Inspire 2 continuous active monitor.

**The Godin Leisure Time Exercise Questionnaire** is a self-report measure that asks individuals how often they engage in low, moderate, and high intensity exercise across 7 days (Godin & Shephard, 1985).

### *Physical Performance Measures*

**The Timed Up and Go (TUG)** asks individuals to stand up from a standard height chair with or without the use of their arms, walk 10 feet (with or without an assistive device) and return to sit in the chair from which they started (Podsiadlo & Richardson, 1991).

**The Cognitive Timed Up and Go (CogTUG)** asks individuals to count backwards by 3's from a number between 20 and 100 while performing the TUG above (Shumway-Cook et al., 2000).

**The five times sit to stand test (FTSTS)** asks individuals to stand up and sit down five times in a row as quickly as possible with the arms crossed across the chest (Whitney et al., 2005).

**The Two Minute Walk Test (2MWT)** asks individuals to walk at a self-selected speed back and forth between two points that are spaced 50 ft apart (Butland et al., 1982).

### *MS Specific Measures*

**The Multiple Sclerosis Self-Efficacy Exam** is an 18 item questionnaire designed to assess confidence in one's ability to perform various functional tasks as well to control the symptoms related to the disease process of MS (Schwartz et al., 1996).

**Patient Determined Disease Steps (PDDS)** is a self-report measure that asks participants to classify their level of function on a scale of 0 (normal function) through 6 (wheelchair bound) (Learmonth et al., 2013).

### *Other Health Related Measures*

**Pittsburgh Sleep Quality Index (PSQI)** is a self-administered questionnaire that assesses sleep quality and quantity (Buysse et al., 1989).

**Diet question (developed for study) One researcher developed question will also be asked.** Which of the following best describes your diet in the last 30 days. 1. Primarily plant based (fresh or frozen fruits or vegetables) with minimal meat or dairy consumption. 2. Primarily lean meat (turkey, chicken, lean ground beef, fish/seafood) with moderate (3-4 servings per day) of fruits/vegetables. 3. Primarily meats such as bacon, sausage, beef, pork, or fried foods with minimal (1-2 servings) of fruits or vegetables. 4. Mainly fast food or processed foods, such as frozen pizza and/or burritos.

### *Motivation and Self-Efficacy Measures*

**The Behavioral Regulation in Exercise Questionnaire – 3 (BREQ-3)** is a 24 item self-report measure that quantifies an individual's self-determined motivation related to physical activity (Cid et al., 2018).

**The Intrinsic Motivation Inventory (IMI)** is a self-report measure that asks individuals to rate their agreement or disagreement (1 = not true; 7 = very true) with various constructs related to self-determined motivation (Deci et al., 1994).

**The Task and Scheduling Self-Efficacy** self-report measure asks individuals to rate how confident they are that can perform various task oriented and schedule-oriented items (Rodgers et al., 2002).

## APPENDIX F: EXERCISE INTERVENTION PROGRAM OUTLINE

### I. Session 0

- a. Informed consent will be completed via a signed paper form.
- b. Participants will complete all surveys listed below in the form of a Qualtrics link.
  - i. Godin Leisure Time Exercise Questionnaire
  - ii. Multiple Sclerosis Self-efficacy Exam
  - iii. Patient Determined Disease Steps
  - iv. Pittsburgh Sleep Quality Index
  - v. Nutrition Question: Please indicate which of the following best describes your diet in the last 30 days. 1. Primarily plant based (fresh or frozen fruits or vegetables) with minimal meat or dairy consumption. 2. Primarily lean meat (turkey, chicken, lean ground beef, fish/seafood) with moderate (3-4 servings per day) of fruits/vegetables. 3. Primarily meats such as bacon, sausage, beef, pork, or fried foods with minimal (1-2 servings) of fruits or vegetables. 4. Mainly fast food or processed foods, such as frozen pizza and/or burritos.
  - vi. Behavioral Regulation in Exercise Questionnaire – 3 (BREQ-3)
  - vii. Intrinsic Motivation Inventory
  - viii. Task and Scheduling Self-Efficacy
- c. This [data collection form](#) will be completed the physical therapist/primary investigator at pre-post testing. The data collection linked above includes the pre-post physical performance outcome measures to be completed.
- d. Session 0 educational link will be reviewed with participants and emailed to participants following completion of pre-testing.
- e. Participants will be given a charged FitBit Inspire and instructed in its use. The researcher will review this [link](#) that participants will complete to report step counts and other physical activity related measures nightly. This link will be emailed to participants each night so that they can report their step counts.

### II. Session 1

- a. Participants will be emailed a link to a password protected Zoom meeting.
- b. Participants will log in to participate in the group with their cameras on
- c. PI will have the participant's physical address accessible via the name/address form collected previously so that if an emergency arises, the therapist can call EMS and have them dispatched to the participant's home.
- d. Participants will be lead through the [Find Your Why](#) session educational link. This link will be emailed to all participants following the session. Participants will also complete a virtual exercise session lead by the PI. The format for the session and the exercises included are in this video [link](#). Below is an outline of each of the exercise sessions as well.
  - i. [The Core Breath](#)
  - ii. Supine exercises
    1. Supine marching with core breath

- 2. Lower trunk rotations with core breath
    - 3. Bent knee fall outs with core breath
  - iii. Prone/Quadruped Exercises
    - 1. Quadruped Alt UE/LE
    - 2. Down dog prep
    - 3. Elbow plank
    - 4. Swimming
  - iv. Standing Exercises (Participants will be cued to use the back of chair, a kitchen counter, or a wall for safety during these activities. Please see the video linked previously for examples.
    - 1. Chair
    - 2. Warrior I
    - 3. Tree
    - 4. Warrior III
  - v. **The Core Driver Meditation**
- e. Principles of Progression
  - i. All exercises
    - 1. Weeks 1 and 2: 3-5 reps or until objective fatigue (poor technique, pain, increased spasticity)
- f. Participants will continue to be emailed Qualtrics [link](#) nightly to report step counts.

### III. **Session 2**

- a. Participants will be emailed a link to a password protected Zoom meeting.
- b. Participants will log in to participate in the group with their cameras on
- c. PI will have the participant's physical address accessible via the name/address form collected previously so that if an emergency arises, the therapist can call EMS and have them dispatched to the participant's home.
- d. Participants will be lead through the [Navigating Obstacles](#) session educational link. This link will be emailed to all participants following the session. Participants will also complete a virtual exercise session lead by the PI. The format for the session and the exercises included are in this video [link](#). Below is an outline of each of the exercise sessions as well.
  - i. **The Core Breath**
  - ii. Supine exercises
    - 1. Supine marching with core breath
    - 2. Lower trunk rotations with core breath
    - 3. Bent knee fall outs with core breath
  - iii. Prone/Quadruped Exercises
    - 1. Quadruped Alt UE/LE
    - 2. Down dog prep
    - 3. Elbow plank
    - 4. Swimming

- iv. Standing Exercises (Participants will be cued to use the back of chair, a kitchen counter, or a wall for safety during these activities. Please see the video linked previously for examples.
  - 1. Chair
  - 2. Warrior I
  - 3. Tree
  - 4. Warrior III
- v. **The Core Driver Meditation**
- e. Principles of Progression
  - i. All exercises
    - 1. Weeks 1 and 2: 3-5 reps or until objective fatigue (poor technique, pain, increased spasticity)
- f. Participants will continue to be emailed Qualtrics [link](#) nightly to report step counts.

#### **IV. Post-Testing**

- a. Participants will complete all surveys listed below in the form of a Qualtrics link.
  - i. Godin Leisure Time Exercise Questionnaire
  - ii. Multiple Sclerosis Self-efficacy Exam
  - iii. Patient Determined Disease Steps
  - iv. Pittsburgh Sleep Quality Index
  - v. Nutrition Question: Please indicate which of the following best describes your diet in the last 30 days. 1. Primarily plant based (fresh or frozen fruits or vegetables) with minimal meat or dairy consumption. 2. Primarily lean meat (turkey, chicken, lean ground beef, fish/seafood) with moderate (3-4 servings per day) of fruits/vegetables. 3. Primarily meats such as bacon, sausage, beef, pork, or fried foods with minimal (1-2 servings) of fruits or vegetables. 4. Mainly fast food or processed foods, such as frozen pizza and/or burritos.
  - vi. Behavioral Regulation in Exercise Questionnaire – 3 (BREQ-3)
  - vii. Intrinsic Motivation Inventory
  - viii. Task and Scheduling Self-Efficacy
- b. This [data collection form](#) will be completed the physical therapist/primary investigator at pre-post testing. The data collection linked above includes the pre-post outcome measures, demographic information, and vital signs that will be collected.
- c. Participants will continue to be emailed Qualtrics [link](#) nightly to report step counts.

#### **V. Focus group to collect pt experiences on the program**

## APPENDIX G: POST PROGRAM IMPLEMENTATION FOCUS GROUP QUESTIONS

Good (morning, afternoon, evening), my name is Dr \_\_\_\_\_ and I'll be facilitating this group. I am a physical therapist and faculty member in the dept of physical therapy at WSSU. As a clinician I volunteer in the MSFit program at Winston-Salem State University. I want to start by thanking you all for your willingness to participate in this focus group. The purpose of these groups is to gain more in depth feedback about At The Core than I could from the survey alone. I hope to use the feedback you all share to make At The Core better. In the session, you will be asked numerous questions about At The Core. I will generally let a person respond first and then go around to each participant to make sure everyone gets a chance to share. I want to respect your time and keep this to one hour so let's get started.

### **Questions:**

- Let's start with each person introducing themselves and discussing why you might think a physical activity promotion program would benefit people with MS?
- Let's move on to discussing the At The Core program specifically. Please share your initial or general thoughts about the program.
  - Follow up questions: How would people living with MS benefit or not benefit from a program like At The Core. How is length of the program (too long, too short, etc)?
- Let's discuss the outcome measures next. What did you think about the outcome measures that you performed pre and post-testing? How did you like the Fit-Bit? Were the outcome measures too tiring? Were there too many? Did you find any of the outcome measures particularly beneficial or unbeneficial?
- Next, let's talk about the live sessions that happened via Zoom. Each session contained education, coaching or goal setting, exercise, and meditation. What did you like the most about the sessions? What did you like least?
  - Follow up questions: What did you like best about these links? What did you like least? Were they easy to read and understand? What was the most important thing you learned? How did you like using Zoom for the live sessions?
- Each week you received a link that contained information about the education and an exercise video that provided of review of what we did during the in person Zoom sessions. What are your thoughts about these resources?

Follow up questions: What did you like best about these links?

What did you like least? Were they easy to read and understand?

What was the most important thing you learned? Would you have preferred to just receive the weekly links instead of participating in the live sessions?

- Would you be willing to refer your friends with MS to At The Core or participate in it yourself? Please explain why or why not?
- Is there anything else you'd like to add about the program that maybe we didn't have time to discuss previously?

APPENDIX H: FREQUENCY TABLES

**Frequency Table: Overall Program**

	SA	A	D	SD	Mean	Standard Deviation
The program goals are appropriate for pwMS <b>G1</b>	22	7	0	0	1.24	0.435
People with MS would benefit from this type of program <b>G2</b>	22	7	0	0	1.24	0.435
The length of the program (8 weeks of intervention) is sufficient to accomplish program goals. <b>G3</b>	8	20	1	0	1.76	0.511
I would encourage a pwMS to participate in this program. <b>Q9</b>	8	3	0	0	1.27	0.467
This program is safe for people in the early MS disease process <b>Q10</b>	10	1	0	0	1.09	0.302

SA=Strongly Agree; A=Agree; D=Disagree; SD=Strongly Disagree

**Frequency Table: Outcome Measures**

	SA	A	D	SD	IDK	Mean	Standard Deviation
The PA measures (FitBit; Godin) selected are appropriate to assess level of PA in pwMS. <b>PA</b>	13	15	1	0	0	1.59	0.568
The outcome measures that assess physical performance (e.g. TUG, CogTUG, 2 MIN WALK, and 5xSTS) are appropriate to examine changes in physical function. <b>PE</b>	14	14	0	0	0	1.50	0.509
The outcome measures (MSSE; PDDS) that assess items specific to MS are appropriate to examine the impact MS has on physical function from the perspective of a pwMS. <b>MS</b>	11	16	0	0	1	1.71	0.810
The outcome measures (PSQI and Diet) that assess other health related behaviors are appropriate. <b>HE</b>	9	17	2	0	0	1.75	0.585
The outcome measures that assess motivation and self-efficacy are appropriate. <b>MO</b>	13	13	1	0	1	1.68	0.863



Overall, the outcome measures are appropriate for assessing program goals. Q36	12	14	0	0	1	1.67	0.832
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SA=Strongly Agree; A=Agree; D=Disagree; SD=Strongly Disagree; IDK=I don't know

### Frequency Table: Video (with meditation)

	SA	A	D	SD	Mean	Standard Deviation
The video was easy to use. Q31A	9	2	0	0	1.18	0.405
People with MS would want to use this video. Q32A	7	4	0	0	1.36	0.505
The video is an appropriate length. Q33A	5	5	1	0	1.64	0.674
The video functioned well. Q34A	7	4	0	0	1.36	0.505
The video is appropriate for pwMS. Q35A	9	2	0	0	1.18	0.405
The video is engaging. Q36A	6	5	0	0	1.45	0.522
People with MS would enjoy performing this video. Q37A	7	4	0	0	1.36	0.505
The exercise in the video is understandable. Q41	9	2	0	0	1.18	0.405
The exercise presented in the video is helpful. Q42	8	3	0	0	1.27	0.467
The exercise presented in the video is safe for pwMS. Q43	10	1	0	0	1.09	0.302
The meditation in the video is understandable. Q51	9	2	0	0	1.18	0.405
The meditation in the video is helpful. Q52	9	2	0	0	1.18	0.405
The meditation presented in the video is safe for pwMS. Q53	10	1	0	0	1.09	0.302

SA=Strongly Agree; A=Agree; D=Disagree; SD=Strongly Disagree

### Frequency Table: Educational links

	SA	A	D	SD	Mean	Standard Deviation
The educational links provided were easy to use. Q6-1	10	5	0	0	1.33	0.488
The educational links contain the right amount of information. Q6-2	7	7	1	0	1.60	0.632
The material presented in the educational links is appropriate. Q7-1	10	3	1	0	1.36	0.633
The material presented in the educational links is accurate. Q7-2	10	4	0	0	1.29	0.469
The material presented in the educational links is engaging. Q7-3	8	6	0	0	1.43	0.514

The material presented in the educational links is understandable. Q7-4	8	6	0	0	1.43	0.514
The material presented in the educational links is helpful. Q7-5	10	3	1	0	1.36	0.633
People with MS would be able to use the information in these links. Q7-6	10	4	0	0	1.29	0.469

SA=Strongly Agree; A=Agree; D=Disagree; SD=Strongly Disagree

APPENDIX I: SURVEY OUTCOME MEASURE PRE AND POST TEST TABLE

Summary of Pre and Post Test Surveys

Survey	Participant 1 Pre	Participant 1 Post	Participant 2 Pre	Participant 2 Post
PSQI	6	8	13	9
MSSE	-	-	92.78%	92.22%
IMI	-	-	48	71
Self-Efficacy Measure	-	-	76.7%	76.7%
Task Self Efficacy Measure	-	-	49.2%	16.4%
GLTEQ	-	-	15	12

Stages of Regulation Scores for BREQ-3

Motivational Stage	Participant 1 Pre	Participant 1 Post	Participant 2 Pre	Participant 2 Post
Amotivation	2	0	0	0
External Regulation	2	1	3	1
Introjected Regulation	9	12	12	5
Identified Regulation	7	5	13	13
Integrated Regulation	3	0	5	6
Intrinsic	6	4	7	9
Relative Autonomy Index	12	-2	26	45

# APPENDIX J: DISSEMINATION POWERPOINT

1/16/2023

A PROCESS FOCUSED FEASIBILITY STUDY  
OF AT THE CORE: A PHYSICAL ACTIVITY  
PROMOTION PROGRAM FOR PEOPLE  
WITH MULTIPLE SCLEROSIS

LAVIENE GARNIER, PT, DPT, EDD  
ABPTS NEUROLOGIC CLINICAL SPECIALIST

1

OBJECTIVES

- FOLLOWING THIS PRESENTATION, PARTICIPANTS WILL BE ABLE TO:
  - EXPLAIN THE IMPORTANCE OF PHYSICAL ACTIVITY FOR PEOPLE WHO LIVE WITH MS
  - RUSH THEMSELVES OR OTHERS TO PARTICIPATE IN THE AT THE CORE PROGRAM

2

BACKGROUND



WHAT IS MS? WHO GETS MS? INTERVENTIONS

3

MS and Physical Activity

- Only about 27% of pwMS meet PA recommendations (Mott, et al., 2015)
- No one method of PA necessarily better than another BUT... 4766 average weekly steps/day (Block, et al., 2019)
- Education on PA benefits help internalize motivation in pwMS (Fasczewski & Gill, 2018)
- Poor self-efficacy = modifiable risk factor for decreased PA (Mott & Snook, 2006)

4

THE PROBLEM AND THE GAP

- FEW PROGRAMS EXIST THAT PROMOTE PA IN PWMS
- EVEN FEWER THAT PROMOTE PA IN A HYBRID ENVIRONMENT

5

AT THE CORE – V1

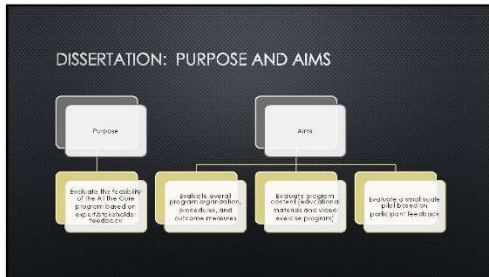


8 weeks of synchronous programming  
Education on how to live a life with MS  
Goal setting  
Physical Activity based on Medical Therapist's Report for pwMS

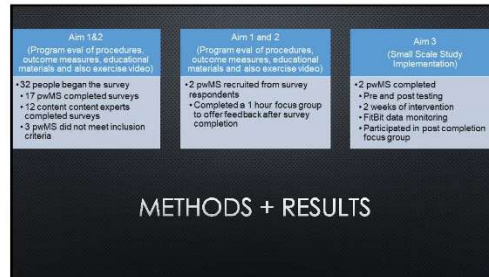


Pre-pod testing at week 0 and week 8  
Step Count  
Dual task walking  
Timed sit to stand and walk  
Self-efficacy and motivation measures  
Education on FIBEL app

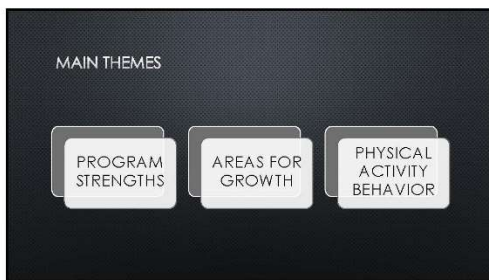
6



7



8



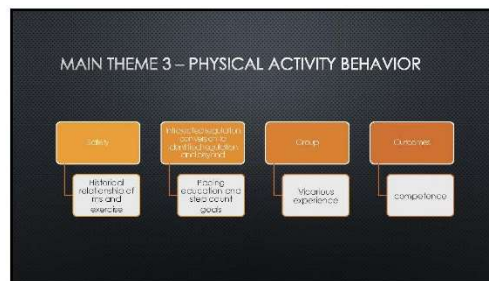
9



10



11



12

KEY TAKEAWAYS



EDUCATION    OUTCOMES    PATIENCE    GROUPS

13

EDUCATION



Obstacles    Pacing

14

OUTCOMES



REALISTIC GOALS    STEP COUNT MONITORING


15

GROUP ACTIVITY



- SOCIAL CONNECTION IS IMPORTANT
- CONSIDER PAIN GROUPS

16



BE PATIENT

HISTORICAL CONTEXT IS IMPORTANT

17

THAT'S ALL FOLKS

ANY QUESTIONS?

18

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