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Titre:

Usability testing of JIActiv, a Social Media-Based Program Promoting Engagement in Physical Activity among Young People Living with Juvenile Idiopathic Arthritis

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Résumé

L'arthrite juvénile idiopathique (AJI) est une maladie chronique infantile d'origine inconnue caractérisée par de la douleur chronique, des enflures articulaires et de la fatigue. Malgré les effets positifs de l'activité physique (AP) sur les symptômes reliés à l'arthrite et la santé générale, les jeunes atteints d'AJI adoptent souvent un mode de vie sédentaire. Par conséquent, ils sont plus à risque de développer d'autres maladies chroniques telles les maladies cardio-vasculaires. Cela nécessite l'accès à un programme efficace pour inciter ces personnes à faire de l'AP. En réponse à ceci, notre équipe a développé le programme ActiJI livré sur Instagram promouvant l'engagement à l'AP auprès des jeunes personnes vivant avec l'AJI. La présente étude évalue l'utilisabilité d'ActiJI en ciblant la satisfaction et la performance d'utilisation parmi les jeunes atteints d'AJI. Une étude qualitative descriptive a été utilisée. Des adolescents (âgés de 13 à 17 ans) et des jeunes adultes (âgés de 18 à 25 ans) atteints d'AJI ont été recrutés via des associations patients, des centres hospitaliers et de réadaptation. Au total, 28 participants (âge moyen = 18,69 ans) ont complété des entretiens semi-dirigés sur deux cycles itératifs via Zoom (Enterprise Version 5.0.2). Les verbatims ont été transcrits, puis triés, organisés et codés avec MAXQDA 11 selon les recommandations de Huberman et al.. Le processus de codage s'est appuyé sur six thèmes ancrés dans les principes théoriques de l'utilisabilité et définis par les équipes de recherche, ceux-ci comprenaient la confidentialité et la sécurité, l'esthétique du design, les fonctionnalités, l'organisation, la connexion sociale et le contenu de la page. Nos résultats démontrent que le programme ActiJI est vu comme étant sécuritaire, convivial, et est apprécié pour ses activités de groupe et les interactions entre pairs. En particulier, le soutien éventuel offert par les professionnels de santé et les pairs motiveraient les jeunes atteints d'AJI à s'engager davantage dans l'AP. Les participants rapportent que le programme ActiJI est facilement utilisable, et que la page Instagram peut être naviguée efficacement. Les recommandations des participants ont été intégrées au programme ActiJI. Une prochaine étude visera à évaluer la faisabilité d'ActiJI.

Mots-clés : Arthrite juvénile idiopathique, maladies chroniques, activité physique, exercice, médias sociaux, e-santé

Abstract

Juvenile idiopathic arthritis (JIA) is the most common childhood chronic rheumatic condition of unknown origin and is characterized by chronic pain, joint inflammation and fatigue. Despite the benefits of physical activity (PA) in mitigating arthritis symptoms and for general health, young people with JIA have a greater tendency to adopt a sedentary lifestyle rather than engage in PA. Consequently, these young people are at greater risk for other chronic health conditions such as cardiovascular disease. Access to innovative and attractive means of promoting PA among these young people is sorely needed. In response to this need, our team developed JIActiv an Instagram-based program promoting physical activity among young people living with JIA. The current study aimed to assess the usability of the JIActiv program in terms of user performance and the level of satisfaction among adolescents and young adults living with JIA. We used a descriptive qualitative study design. Adolescents (ages 13 to 17 years) and young adults (aged 18 to 25 years) living with JIA were recruited from rheumatology clinics in rehabilitation and hospital centers, as well as through patient organizations. A total of 28 young people (mean age = 18.69, SD=± 2.28 years) completed semi-structured interviews over two iterative cycles using Zoom (Enterprise Version 5.0.2). The audio recordings of the interviews were transcribed word by word, then sorted, organized, and coded using MAXQDA 11 software following recommendations by Huberman et al.. The coding process was based on six themes anchored within the theoretical principals of usability testing and were specified by the research teams, which included privacy and safety, design aesthetics, functionalities, organization, social connection, and content of the page . Our findings have shown that the JIActiv program is viewed as secure and user-friendly. Participants appreciated the group activities and peer interactions. Notably, the potential support offered by healthcare professionals and peers may motivate those living with JIA to engage more in PA. Study participants reported that the JIActiv program was easy to use, and they navigated the Instagram page effectively. Participant recommendations were integrated within the JIActiv program. A subsequent study will assess the feasibility of JIActiv.

Keywords: Juvenile idiopathic arthritis, chronic diseases, physical activity, exercise, social media, e-Health

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List of abbreviations

JIA: Juvenile idiopathic arthritis

PA: Physical activity

QoL : Quality of life

CVD: Cardiovascular disease

SB: Sedentary behaviour

WHO: The World Health Organization

MVPA: Moderate to vigorous physical activity

EBCPGs: Evidence-based clinical practical guidelines

ERA: Enthesitis-related arthritis

ROM: Range of motion

HRQoL: Health-related quality of life

ILAR: The International League of Associations for Rheumatology

RF: Rheumatoid factor

NSAIDs : Nonsteroidal anti-inflammatory drugs

IAC : Intra-articular corticosteroid

DMARDs : Disease-modifying anti-rheumatic drugs

ICF: The International Classification of Functioning

PL: Physical literacy

METs: Equivalent metabolic units

ICTs: Information and Communication Technologies

ICI : Information and Communication Infrastructure

IT: Information Technology

m-Health: mobile Health

IPAQ: The International Physical Activity Questionnaire

PDPAR: Previous Day Physical Activity Recall

DLW: Doubly labelled water

PAD: People with a Disability

SCT: Social Cognitive Theory

TTM: The Transtheoretical Model

ORBIT: Obesity-Related Behavioral Intervention Trials

BCW model: The behavior change wheel model

COM-B model: The Capability-Opportunity-Motivation Behavior model

The APEASE criteria: Affordability, Practicality, Effectiveness, Acceptability, Side-effects/safety, and Equity

SCI: Spinal cord injury

ISO: International Standards Organization

PACMAD : People At the Center of Mobile Application Development

SUS : System Usability Scale

QUIS : Questionnaire for User Interaction Satisfaction

PSSUQ : Post-Study System Usability Questionnaire

CSUQ : Computer-System-Usability Questionnaire

AAC : Arthritis Alliance of Canada

CAPA : Canadian Arthritis Patient Alliance

PR-COIN: Pediatric Rheumatology Care and Outcomes Improvement Network

IURDPM: Institut universitaire sur la réadaptation en déficience physique de Montréal

RCT: Randomized Control Trial

AI: Artificial intelligence

OTs: Occupational Therapists

To my parents and my husband, for their unwavering belief in me,
and steadfast support throughout every phase of this journey.

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"Without curiosity, exploration remains dormant. Without courage, discoveries remain hidden."
Albert Einstein

Chapter 1- [Introduction]

Juvenile idiopathic arthritis (JIA) is the most prevalent chronic arthritis of unknown etiology among children and teenagers under the age of 16 which involves the joints, and it lasts for at least six weeks (1, 2). The characteristics of Juvenile idiopathic arthritis are sleep disturbances, joint stiffness, chronic pain, fatigue, joint swelling and activity limitations (3-7). Some studies reported that children with JIA are more likely than their healthy peers to experience psychological issues, such as anxiety, aggressive behaviours, and depression, which can result in a lower quality of life (QoL)(8, 9). Despite the benefits of engaging in regular physical activity (PA) during childhood and adolescence on maintaining healthy muscles and joints, reducing the risk of chronic diseases such as cardiovascular disease (CVD), and enhancing motor and cognitive development, quality of life, and self-esteem, individuals with JIA are less physically active compared to their healthy peers. They tend to choose sedentary behaviour (SB) (10-19). Sedentary behaviour can elevate the risk of developing other health problems such as obesity, depression, and cancer (colorectal, breast, endometrial, and prostate) (20-25). Engaging in regular PA may help limit the risks of other chronic illnesses and mitigate the effects of these diseases (20-25).

Physical activity is defined as "involving people moving, acting and performing within culturally specific spaces and contexts, and influenced by a unique array of interests, emotions, ideas, instructions and relationships."(26) (p.1). Based on the World Health Organization (WHO), individuals between 5 and 17 years of age should engage in at least 60 minutes of daily moderate to vigorous physical activity (MVPA), and adults (18–64 years) should participate per week in a minimum of 150 minutes of moderate-intensity or at least 75 minutes of vigorous-intensity, or an equivalent combination of MVPA to reap the benefits of PA (27). Young people with JIA receive rehabilitation interventions that comprise various services including physical and occupational therapy treatments, and psychological and orthopedic services. Although the beneficial effects of PA-based interventions, such as water-based exercises, core stabilization exercises, Pilates exercises, aerobic exercise, and stretching exercises have been reported among youth living with JIA, regular PA is not integrated within a comprehensive clinical treatment plan (28-31). Limited

human resources and narrow rehabilitation care mandates within hospitals and rehabilitation centers may partly explain this. Adequate community-based PA services may also be difficult to implement and/or adhere to because of barriers, such as time constraints regarding children and adolescents with JIA, unfavourable weather, low social support (e.g., peers), transportation challenges, limited knowledge about the PA (belief of harm by doing PA), the experienced discomfort during PA including, fatigue and pain, lack of motivation regarding doing PA, and high treatment costs (32, 33). Mobile health (m-health) and electronic health (e-health) alternatives needed to overcome the obstacles of current clinical-based in-person intervention programs in JIA are sorely lacking.

The use of the internet and related digital platforms (e.g., websites, smartphone applications) has increased progressively in the last decades and has become important for maintaining and creating new social interactions; education; and engaging in healthy behaviours such as regular PA (34-39). Adolescents and young adults everywhere are among those using social media the most (34-39). Therefore, e-Health can be an ideal solution to promote PA by delivering relevant information and practical solutions to the needs of a specific audience (40). Targeted health promotion solutions are essential in the promotion of healthy behaviour change, as this process is complex and varies from one individual to another (46). Studies suggest that the use of e-Health and social networks as a means of featuring health behavior change interventions can be cost-effective, as it addresses many of the logistical challenges posed by traditional in-person exercise-based therapies (35, 40-43). In 2019, one of the most popular social media platforms, Instagram, allowed users to express themselves and connect with others by sharing images, and status updates; recent studies have shown the potential for using digital treatments and social media like Instagram to encourage PA (44, 45). Social media-based solutions may support behaviour change in JIA (46). To promote healthy behaviour change and enhance PA participation in young people with JIA, more appealing and easily accessible methods of disseminating information, and programs focused on PA are required; these techniques should be based on current evidence-based clinical practical guidelines (EBCPGs) (46, 47). Hence, there is a need for developing and implementing novel approaches utilising social network sites to facilitate and maintain behaviour change among young people living with JIA.

To our knowledge, there are currently no social network-based interventions offering a comprehensive and illness-specific intervention delivering evidence-based information and behaviour change techniques to promote PA to young people living with JIA. In response to this unmet need, our team developed JIActiv, an educational and interactive program, delivered through Instagram. We adopted a sequential research phased approach which includes (i) knowledge syntheses (completed), needs assessments (completed); (ii) design, development and acceptability (completed); (iii) usability testing (current masters' thesis); and (iv) feasibility testing and preliminary outcome evaluation (in progress). The current master's project incorporates preliminary data from this larger study and reports on the usability testing phase of the JIActiv program.

Objectives

This study aims to assess the usability of JIActiv, an educational and interactive program promoting PA, in terms of user performance and level of satisfaction among adolescents and young adults living with JIA.

Structure of the master's project

This master's thesis is comprised of 6 chapters. Following the introduction in chapter 1, chapter 2 provides a literature review that summarizes the literature reporting on key topics related to our study. In chapter 3, we explain the methodology of this study. Chapter 4 contains a description of the findings of the present study through the presentation of a scientific article. Chapter 5 focuses on key insights drawn from the results of the preceding chapters and their implications. The final chapter, chapter 6, offers conclusions for the entire master's thesis. The appendices include information on data collection tools and knowledge transfer activities conducted during the research project.

Chapter 2 – [Literature Review]

We will delve into the epidemiology of JIA, the treatments used for this chronic illness, and the role of social media.

2.1 Juvenile Idiopathic Arthritis

2.1.1 Epidemiology of juvenile idiopathic arthritis

The reported prevalence of JIA in the world is between 0.07 and 4.01 per 1000 children (48). These results may vary due to differences in access to rheumatologists, differing quality of diagnostic methods, data collection and reporting methodologies (49). There are different types of JIA, the International League of Associations for Rheumatology (ILAR) stratifies subtypes of autoimmune inflammatory disorders based on the number of afflicted joints, systemic symptoms, and the presence of rheumatoid factor (RF). Based on the ILAR classification, JIA is divided into the following seven sub-types, each with different genetic susceptibility and disease severity: oligoarticular (permanent or prolonged), polyarthritis RF-positive, polyarthritis RF-negative, systemic Arthritis (sJIA), psoriatic arthritis, enthesitis-related arthritis (ERA) and undifferentiated arthritis (2). The ratio of females to males affected by JIA is typically greater, except for ERA which is more prevalent amongst males (50-52).

The physical presentations of JIA are painful, inflamed, and swollen joints, which are often accompanied by limitations in the normal range of motion (ROM) (53). Active arthritis can be present in the lower extremity joints (hip, knee, ankle) and the upper extremity joints (fingers, wrist, elbows), as well as the mandibular joint and vertebrae (54-57). Disease activity may also impact intraocular pressure by increasing it, leading to the development of uveitis (58, 59). The presence of pain and restriction of ROM in the lower extremities and back in children with JIA may alter their gait pattern and consequently affect their mobility. This may potentially delay the development of their gross motor skills (Figure 1)(57).

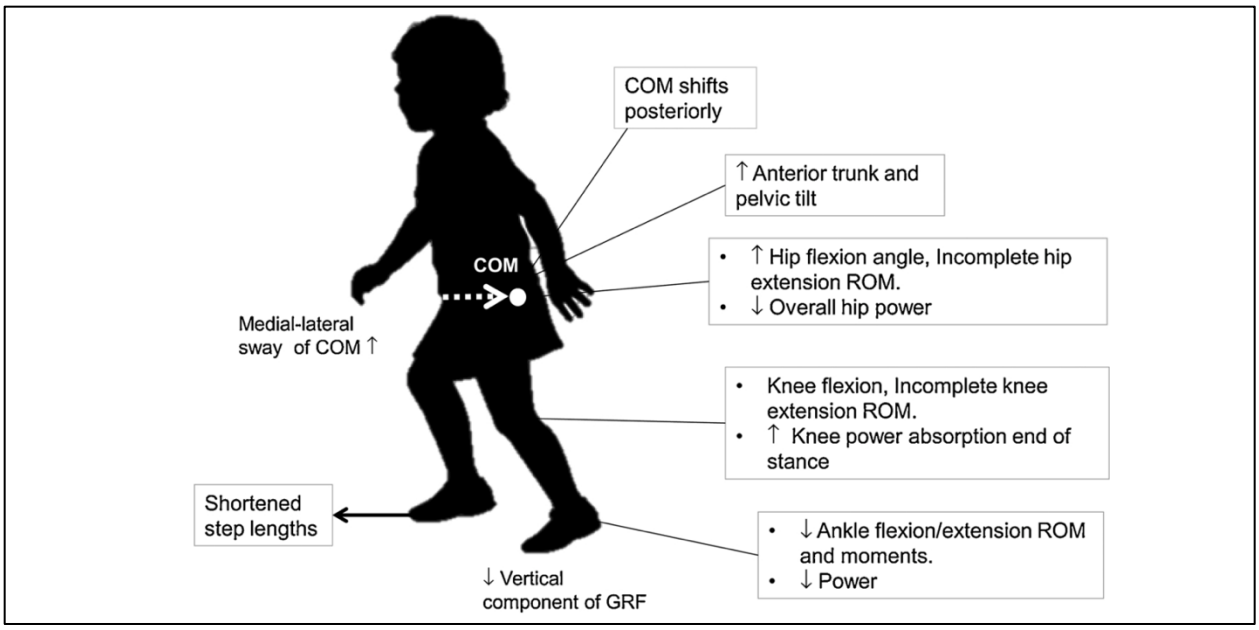

Figure 1 - Key features of gait in children with JIA compared to healthy counterparts (57)(p.52)

COM: center of mass, ROM: range of motion, GRF: ground reaction forces

The symptoms of active disease in JIA typically result in discomfort, limitations in performing daily activities and engaging in social interactions, as well as decreased overall well-being and health-related quality of life (HRQoL). Studies have also shown that children living with JIA are at greater risk of experiencing difficulties in academic performance and school absenteeism compared to healthy ones (60-62).

2.1.2 Treatment and Management of JIA

The clinical management of JIA includes a multi-disciplinary approach involving a pediatric rheumatologist, physiotherapist, occupational therapist, ophthalmologist, and psychologist, as both pharmacological and non-pharmacological treatments are used (53, 63).

2.1.2.1 Pharmacological interventions

The pharmacological treatment of JIA involves using various drugs based on the type of JIA and the patient's response. The initial choice for treatment is typically nonsteroidal anti-inflammatory drugs (NSAIDs), which do not alter disease progression but can help to reduce pain, inflammation and swelling (53, 63-65). In the case of more severe JIA, a systemic corticosteroid such as prednisone or prednisolone may be prescribed (53, 63, 65, 66). Some biologic medicines such as monoclonal antibodies, receptor antagonists, and soluble cytokine receptors have led to better

effects in the treatment of JIA, as per recent research; these types of drugs are administered when disease-modifying anti-rheumatic drugs (DMARDs) prove inefficient in managing JIA, as well, interleukin-1 and interleukin-6 targeted medicines are specifically used to mitigate sJIA (53, 66, 67).

2.1.2.2 Non-pharmacological interventions

Several non-pharmacological interventions are used by clinicians to manage JIA. Typically, such interventions are put into place by rehabilitation professionals, such as occupational therapists (OTs) and physical therapists (PTs). In fact, OTs and PTs play an essential role in improving and maintaining physical function (e.g. bone strength, joint range of motion, muscle endurance and strength) and optimising independence in daily tasks (e.g. self-care tasks) hence favoring participation in significant social roles (e.g. going to school, playing with friends, participating in leisure physical activities) (68, 69). Physiotherapists may focus on prescribing a regimen of isometric, passive joint mobilizations, gait training, aquatic, resistance and respiratory exercises (69). Whereas, occupational therapists may work with clients to develop new skills, adapt activities, modify the environment and provide education on the use of adaptive equipment, as well as fabricate orthotics to relieve arthritis related symptoms such as pain and joint stiffness (69). Moreover, consultation with a psychologist or other mental health professionals may be helpful to manage depression and anxiety thus reducing the feeling of isolation often felt by those living with a chronic condition such as JIA (63).

Therefore, client-centered rehabilitation services are needed to promote participation by considering factors related to the health condition, the person, activities (occupation) and the environment (68, 69).

2.2 Definition of key terms

In the following chapter, key terms are defined to ensure that the reader has a thorough understanding of the concepts and the methods applied in this master's research project, as well as to grasp the impact of subsequent findings.

2.2.1 Participation

The International Classification of Functioning (ICF) defines participation as: "involvement in a life situation" (70)(p.12), such as taking part in school activities, contributing to household chores, and being involved in enjoyable PA. A list of features central to the concept of participation was identified by individuals living with disabilities (immune system disorders, arthritis, cerebral palsy and other central nervous system conditions) (71) (Figure 2). Specifically, participants highlighted the importance of engaging fully in meaningful activities; having control over one's actions and having the freedom to choose; and having access and opportunity to take on desired social roles. Interestingly, responsibility to oneself was discussed as necessary in maintaining health and engaging in rehabilitation treatment, favored by positive thinking, improved self-esteem, and proactivity. Equitable opportunities and resources to support one's participation as a productive and valued member of society were emphasized. Furthermore, participants highlighted the importance of social interactions with peers and within the broader community (71). Another factor associated with the level of participation in many activities is engagement (72).

2.2.2 Engagement

Engagement is defined by Triparna de Vreede et al., as a phenomenon which includes emotional, behavioural, and cognitive aspects of engagement. First, the authors describe emotional engagement as the degree of positive psychological reaction experienced by the person while taking part in an activity or situation. Second, behavioural engagement refers to how a person actively participates and shows persistence in completing a task or an activity. Thirdly, cognitive engagement is regarded as being fully immersed in a task without succumbing to potential distractions (73). Active and meaningful engagement (being a part of) may differ according to each person's interests, needs, preferences, available opportunities and social network (71). Furthermore, feeling safe and secure was reported by persons living with disabilities as predictive of their level of engagement when taking part in novel and unfamiliar activities (71). Notably, engagement can be considered as a key element to ensure that individuals take part in regular physical activity.

Figure 2 - Qualitative theme areas epitomizing participation as described by participants (71) (p.1450)

2.2.3 Physical activity

Piggin (2020) proposes the following definition of PA: "Physical activity involves people moving, acting and performing within culturally specific spaces and contexts, and influenced by a unique array of interests, emotions, ideas, instructions and relationships" (26)(p.5). Physical activity has also been defined as "any bodily movement produced by the skeletal muscles, that results in energy expenditure" (74) (p.126). Therefore, the broader understanding of PA can be grouped into the following activity types: 1. Occupational and school; 2. Leisure (e.g., dancing); 3. Household, domestic, and self-care; 4. Transport (75). Our study will target these areas of PA, focusing on purposeful movement and meaningful active physical activities completed during the day. As depicted in figure 3., increased energy expenditure leads to improvement in health-related outcomes such as physical fitness health-related physical fitness, including cardiorespiratory fitness, musculoskeletal fitness (which pertains to muscular strength and endurance), flexibility, balance and coordination, and body composition (76).

Therefore, the behaviours (actions) of a person can directly impact the physical and physiological aspects of that person. Active and sedentary behaviour are two types of human behaviours influenced by physiological, psychological, social, and environmental factors (76).

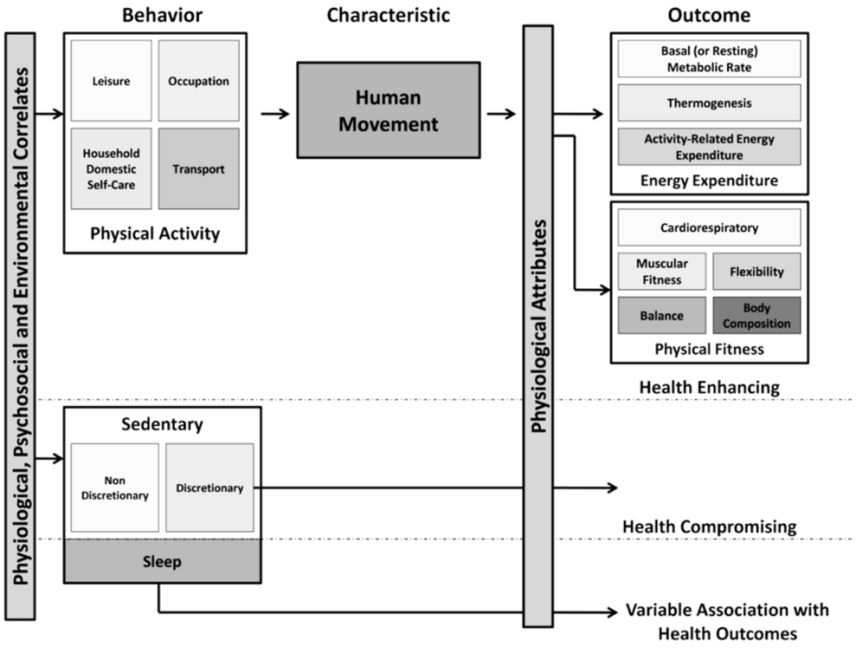

Figure 3 - A conceptual framework for physical activity as a complex and multidimensional behaviour (76) (p.S14)

2.2.4 Physical Literacy

Physical literacy is a key concept needed to maintain active and healthy behaviours. It " […] involves a continuum of learning in enabling individuals to achieve their goals, to develop their knowledge and potential, and to participate fully [in physical activity] within their community and wider society" (77)(p.26). Better physical literacy among primary school children has been associated with a lower body fat percentage, higher engagement in moderate to vigorous physical activity (MVPA), greater health-related quality of life (HRQoL), and improvements in systolic blood pressure among primary school children (78). Understanding the benefits of PA on health, as well as having the motivation and confidence to engage in PA throughout the lifespan may lead to improved function and general health.

2.2.5 Sedentary behaviour

Activities such "watching television, sleeping, sitting, talking, lying down, and electronic activities" are all examples of sedentary behaviour (79)(p.174) are can be described as "awake" activities resulting in energy expenditure of less than 1.5 equivalent metabolic units (METs). Sedentary behaviour is present in many aspects of our daily lives, such during productive occupations (e.g. at work or at school), during social gatherings, when traveling by motorized

vehicle (e.g. taking public transportation) and when taking part in passive leisure activities (e.g. reading, listening to music). The most prevalent sedentary behaviours among youth and adults involve extended periods of time spent sitting while watching television, using a computer, and engaging in social interactions (79-81). Considering, the popularity of such activities It may be relevant to counteract sedentary behaviour by incorporating digital devices and social connections to promote active physical activity.

2.2.6 Social media

Social media networks are online platforms that help users communicate and share information; the ability to share thoughts, ideas, and experiences with a larger audience has completely changed how people engage and connect (82, 83). Social media is known for its simplicity of use, speedy responses, and real-time interactions. With the help of these technologies, people may connect with friends and family, participate in internet-based communities, and remain up to date on news and popular issues. These technologies have grown in popularity and are now a standard part of many people's everyday lives (82, 83). Caleb T. et al. (83) propose the following definition of social media: “Social media are Internet-based channels that allow users to opportunistically interact and selectively self-present, either in real-time or asynchronously, with both broad and narrow audiences who derive value from user-generated content and the perception of interaction with others” (p.50). Findings from a study conducted among young people indicated that most participants use social media almost every day, including Facebook, Instagram, Twitter, and Snapchat (84). Results from a national survey, revealed that an overwhelming 97% of American adolescents utilize the Internet daily (85). Over the past few years, using social media to deliver pertinent information to promote healthier behaviour and contribute to improving health outcomes among young adults has increased (86).

2.2.7 Information and communication technology in healthcare

Information and Communication Technologies (ICTs) are a diverse set of technological tools and resources utilized for communicating as well as for generating, distributing, gathering and managing information (87). ICTs have two components: 1. Information and Communication Infrastructure (ICI), including broadcast and satellite, along with services such as the Internet, mail, and television; 2. Information Technology (IT) : hardware and software for information

processing and presentation (87). Electronic health (e-health) and mobile health (m-Health) are regarded as two types of ICT in healthcare (88).

Based on Eysenbach G.'s definition: E-health is an emerging field in the intersection of medical informatics, public health, and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state of mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology. (89) (p.1)

There are different types of e-Health services including; electronic health record, computerized physician order entry, clinical decision support system, telehealth, consumer health informatics, e-prescribing, and m-Health (90) .

Concerning m-Health, the utilization of portable devices such as smartphones, and tablets for enhancing health care and health outcomes is defined as m-Health (91-94). Mobile health options can serve as tools to enhance medication adherence in children, adolescents and young adults with acute lymphoblastic leukemia, as evidenced in the study by Heneghan et al.(92) . Pediatric participants and their parents expressed belief in the efficacy of m-health apps in promoting medication adherence by employing behaviour-changing techniques provided by the app in the study. This application offers the opportunity for children, teenagers, young adults, and their parents to receive assistance in attending all scheduled appointments, easy access to their profiles, communication with others sharing the same condition and their families, access to comprehensive information about medication and its side effects, and timely reminders for medication intake. The application employs various techniques, including problem-solving, biofeedback, social support, instructions on behaviour, and information about health consequences (92).

Electronic health options are rapidly gaining popularity in delivering public health initiatives due to its numerous advantages. It fills the gaps in service delivery, particularly in areas with limited access to rehabilitation services due to staff shortages, resources, and other challenges. Its user-friendly approach makes it particularly well-suited for engaging younger generations familiar with the technology, and it can used as a beneficial method of intervention to improve the level of PA

among younger generations (95, 96). The use of e-health resources may help improve quality of life (97), increase the level of PA (98), and contribute to smoking cessation (99).

2.3 Benefits of participation in physical activity

Physical activity positively impacts people's health, with benefits for adolescent well-being (100). Engaging in PA can also be a beneficial intervention for teenagers dealing with chronic diseases and enhancing their agility, health-related fitness, and muscle strength as well, PA has an impact on reducing body fat in this demographic (101).

2.3.1 General benefits of physical activity

According to studies, regular PA can reduce the risk of obesity, positively impact bone mineral density, alleviate symptoms of depression, and help to regulate cholesterol, and systolic blood pressure in children and adolescents living with chronic illness and disability (e.g. high blood pressure, obesity, low bone density, depression) (102). Physical activity also increases and maintains muscle mass and strength, maintains bone mass and increases bone strength, as well as physical function (103, 104). In addition, PA enhances children's cognitive function (105).

2.3.2 Disease-specific benefits of physical activity

Along with enhancing the lengthening of life expectancy, quality of life and well-being of those with chronic disorders and impairments, PA assists in mitigating the impact of disease symptoms (106). Physical activity strengthens the immune system, allowing the body to better defend against infections and lowering the risk of illness. This immune response improves lymphatic function and reduces inflammation (107). Participation in physical activity reduces the likelihood of developing conditions such as rheumatoid arthritis, CVD, type 2 diabetes, and certain cancers like breast, colon, and prostate cancer (106-108). Moreover, some kinds of PA, such as core stability exercises along with physical therapy in JIA, are linked with increasing bone health status and functional capacity (29).In addition, strengthening exercises impact aerobic fitness, muscle strength, self-efficacy, energy level, and quality of life while decreasing disease activity, pain and the need for medical treatment (109). The benefits of PA are not just limited to the physical domain, it also extends to mental health, PA can influence mental health by alleviating symptoms of depression and anxiety among children and teenagers (100, 110).

Despite the numerous benefits of taking part in PA, the intensity and frequency of PA can vary from one person to the next (111-113). Patterns of PA must therefore be measured before implementing activity-based care plans to identify the best intervention options for a given person.

2.4 Methods and measurement tools of PA

Physical activity can be measured using objective and subjective, observational, and patient-reported measurement tools. The following sections outline the techniques for assessing the level of involvement in PA among young individuals.

2.4.1 Physical Activity among adolescents and young adults

The measurement of PA in young people is essential for studying physical activity habits, determining the impact of physical activity programs, and understanding factors influencing physical activity behaviour (114, 115). This information is needed to assess the PA frequency, identify the necessary volume and intensity to impact health and evaluate the effectiveness of interventions to promote regular PA (115-117). The methods for measuring PA among young people can be grouped into the following five categories. The first relates to self-report measures of physical activity where participants report their activity, by either keeping track of it using a diary or remembering it over a specific period. However. the accuracy of self-reported data may be weakened as their reliability and validity depend on the individual's ability to recall past activities (115, 118). Self-reported measurements used for young people are the International Physical Activity Questionnaire (IPAQ), Physical Activity Diary (PAD), and Previous Day Physical Activity Recall (PDPAR). The second category involves using portable devices to track movement such as accelerometers and pedometers both commonly available to healthcare professionals and general public. The third category includes the measurement of biological indicators through the use of wearable devices such as heart monitors or specific biological tests such as doubly labelled water (DLW) (115). The doubly labelled water test is applied for measuring the energy expenditure to specify the level of PA which is evaluated through blood, saliva or urine samples (119) . The fourth category highlights the assessment of PA in real-life settings through direct clinical observation for example; at home, work or school settings. The fifth and final category identified proposes a combination of the aforementioned measures (115). The

following sections discuss PA among young people in good health and those with chronic illnesses and impairments, particularly those with JIA.

2.5 Participation in Physical activity among adolescents and young adults

2.5.1 Participation in Physical activity among healthy adolescent and young adults

Approximately 25 percent of the global population comprises individuals between the ages of 10 and 24 (120); hence allocating resources to promote their well-being could be an appropriate action. However, studies show that most adolescents and young adults do not meet the international guidelines for PA, and as they grow older, they tend to become less physically active (121, 122). Moreover, based on the Canadian 24-Hour Movement Guidelines for Children and Youth in 2022, merely 28% of kids and teens aged 5 to 17 engage in sufficient PA and meet the recommended level of PA (123). Hence, a big part of this population is engaging in a sedentary lifestyle and the proportion of inactive young individuals may increase in the upcoming years due to increased use of screen-based activities and social media (124, 125).

2.5.2 Participation in physical activity among adolescents and young adults with chronic conditions

Although exercise interventions should be part of a comprehensive treatment plan to help manage disease-related symptoms among those living with chronic disease, studies indicate that young adults living with chronic disease (e.g., cancer, Inflammatory Bowel Disease) are significantly less active, and do not meet the WHO recommendations (126, 127). In 2012, Bélanger et al. (128) conducted a study on the preferences of young adults who have successfully battled cancer regarding PA programming and guidance. The results showed that 86% of the participants surveyed were keen on participating in a structured PA program to boost their PA level. This group's most preferred types of PA were walking, biking, and skiing. Understanding this population's preferences for PA can help promote and encourage this population's level of physical activity. Also, knowing about barriers to PA among people with chronic conditions could help manage them and promote PA participation in this population. Studies revealed that different barriers reduce PA participation among children and young people with chronic diseases, including physical disability and related symptoms (fatigue, pain), lack of knowledge about PA and how they can do it without risking injury, time limitations and lack of enthusiasm for participation in PA (129). In 2016, Shields et al. (130) undertook a study to identify the perceived obstacles and

facilitators that influence the participation of children with disabilities in PA, parents of these children believed that PA programs designed for children with impairments are insufficient, and these groups of the population have to be in the waitlist for receiving the appropriate PA programs. In addition, the cost of health services such as occupational therapy, and speech therapy in countries where insurance does not cover the prices can be considered as an obstacle. Furthermore, families of these children suffer from another additional cost, because the parents may have to reduce their work engagement, resulting in a decrease in income; hence this places additional financial pressure on them (130).

2.5.3 Participation in physical activity among adolescent and young adults with juvenile idiopathic arthritis

The findings reveal a considerable difference in the average amount and level of PA between children and youths with JIA and their healthy counterparts (131). This difference may indicate a trend towards reduced PA in children with JIA, leading to increased sedentary behaviour, exacerbating pain and inflammation, and disrupting daily life activities. Nonetheless, some studies have demonstrated that physical activities like balance and strength exercises and yoga can enhance flexibility, and muscle strength, alleviate pain, and improve daily activity participation (132-134). Identifying and understanding barriers and facilitators of participation in PA is necessary to ensure that rehabilitation treatment plans target modifiable outcomes to facilitate regular engagement in sports and PA.

2.6 Facilitators and barriers influencing physical activity in adolescent and young adults

Many elements associated with the youth, family, and surroundings are being studied as possible hindrances or enhancers to participating in PA among young people and adolescents with and without chronic health problems. These elements are grouped into two categories; 1. personal factors, and 2. environmental factors (135).

2.6.1 Personal factors

Personal factors refer to internal aspects that have an impact on an individual, and support participation in PA and are organized into several categories, including their lifestyle, and physical and motor abilities. The facilitators to PA regarding personal factors could be a positive mindset

towards PA, coping strategies, knowledge and understanding, motivation, perceived competence and self-efficacy, and the obstacles to PA among adolescents and young people are fatigue or lack of sleep, lack of interest, insufficient knowledge or skills, low self-efficacy, lack of self-confidence and low self-worth, stress, limited time, and physical discomfort or illnesses (135-142). Hence, it is imperative to tailor interventions to adolescents' unique characteristics, interests, and circumstances to promote physical activity effectively. Incorporating the perspectives of the adolescents regarding barriers and facilitators to PA, better interventions will be designed for this target population, and it can enhance the overall effectiveness of PA initiatives (137).

2.6.2 Environmental factors

"Environmental factors include the physical, social and attitudinal environments in which a person lives and interacts" (135)(p.1090).

The environment significantly impacts whether young people engage in PA. Studies indicate that environmental factors, including safety concerns, inadequate settings/programs, access difficulties, expenses, disrespectful behaviour, heavy traffic, and adverse weather conditions, particularly during winter, present significant barriers to PA among adolescents and young people (136, 140, 143, 144). Additionally, the overuse of technology, such as the Internet, and limited access to facilities are considered barriers to PA for this population (136). For facilitating the environmental factors in school-aged individuals, creating secure settings has been proposed, for example, by utilizing school facilities outside of regular school hours, increasing access to sports supplies and introducing structured activities during lunch and after-school hours (144).

One hindrance to PA among young adults is the absence of social support, specifically from family and friends. Young people are less likely to engage in PA when their families are not supportive or involved in such activities. The key factor regarding the lack of parental support is that they value educational achievement more (136). Furthermore, parents' attitudes towards their child's physical appearance play a significant role in determining the level of PA they participate in. Parents often place more importance on providing sports equipment for boys and encouraging them to do PA than girls (136, 145).

2.6.3 Facilitators and barriers influencing physical activity in adolescent and young adults with chronic illness

Studies have revealed barriers to physical activity participation among adolescents and young adults suffering from chronic illnesses. These barriers encompass demographic factors such as age and gender and disease-related symptoms such as chronic pain and fatigue. Other factors include fear of injury, insufficient knowledge of local physical activity options, lack of knowledge about PA, transportation difficulties to sports facilities, conflicting schedules, and financial constraints (146-151). On the other hand, factors that encourage PA include having a positive attitude towards it in adolescents and their families and comprehending the health benefits of exercise, availability of attractive and non-boring facilities, for example; the existence of a wide range of PA to this population, and financial resources (149-151).

2.6.4 Studies on physical activity in JIA

A significant amount of research has been conducted on the level of PA in individuals with JIA; however, there is still limited information on the individual, social, and environmental factors that facilitate or hinder PA in this population. A systematic review that was done by Cavallo et al. (152), observed that various factors such as age, gender, type of JIA, pain, lower levels of well-being, stiffness, and fatigue can significantly impact an individual's ability to engage in physical activities. These factors need to be considered when trying to understand and address the challenges individuals with JIA face when engaging in physical activities.

Physical activity participation is influenced by various factors, making it difficult to understand and assess fully. However, conceptual frameworks can provide a structured approach to examining and evaluating these factors. In the following sections, we will explore the different conceptual frameworks that can be applied when examining the factors related to physical activity participation. These frameworks can provide a comprehensive overview of the relationships between participation and the various factors, giving us a deeper understanding of the complexities involved. By employing these frameworks, we can better understand the factors influencing physical activity participation and how they interact and develop interventions targeting factors inclined to change and integrated evidence-based strategies.

2.7 Conceptual frameworks for evaluating health behaviours including participation in physical activity

This section presents an overview of the widely used theoretical frameworks that explain the behaviour related to participation in physical activity. These frameworks examine intrinsic and extrinsic factors that may impact an individual's level of involvement in PA. Intrinsic factors refer to the internal drivers of behaviour, such as personal enjoyment or fulfillment, while extrinsic factors refer to external motivators, such as rewards or social pressure. Considering intrinsic and extrinsic factors, these theoretical frameworks offer an in-depth understanding of the determinants that may encourage or discourage an individual's participation in PA. This can provide valuable insight into the motivators for this population to engage in PA and help develop strategies to increase participation. In the following section, various theoretical frameworks will be explained, including the International Classification of Functioning (ICF), Disability and Health, The Physical Activity for People with a Disability (PAD) model, the conceptual model of Health through Sport for children and adolescents, Social Cognitive Theory, The Behavior Change Wheel (BCW) model, and The Transtheoretical Model (TTM). Furthermore, when pertinent their application in the present study will also be highlighted.

2.7.1 Measuring participation according to the International Classification of Functioning, Disability and Health (ICF)

A chronic health condition can profoundly impact one's involvement in various activities, especially PA. To fully comprehend these conditions' impact on participation in PA, it is essential to consider a range of factors. These include the biological impact of the disease, the individual's traits and experiences, the family context, and the community and school environment. By considering these different components and the potential ways in which they may interact, we can understand the relationship between chronic health conditions and disabilities and participation in PA. The ICF is part of the World Health Organization's global classifications. It serves as a structure for depicting the circumstances faced by an individual with a health issue (153, 154). "The ICF is comprised of three essential components (Figure 4): body functions and structures, activity, and participation. Body functions and structures refer to the body's physiological functions and physical structures, and impairments are deviations from normal. Activity refers to the individual's ability to perform tasks, and activity limitations are difficulties they may face.

Participation deals with the individual's engagement in their life context, and participation restrictions are difficulties they may encounter" (155).

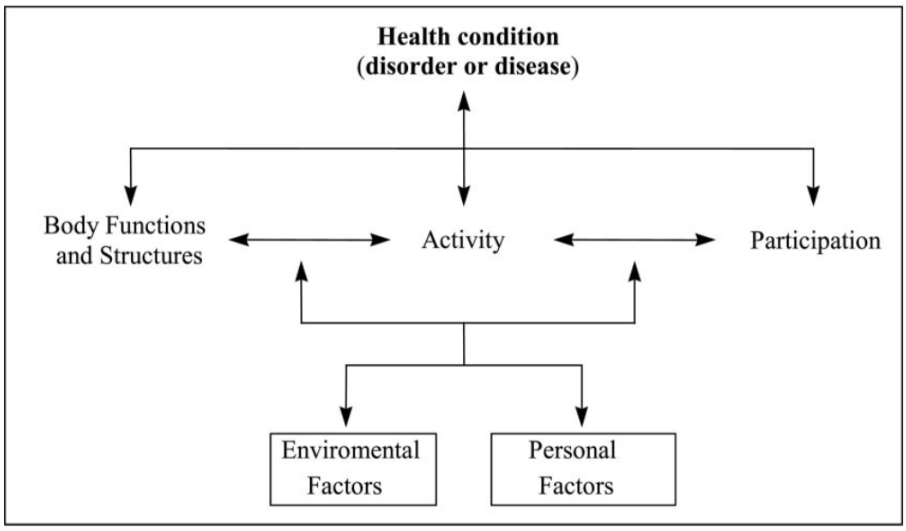

Figure 4 - International Classification of Functioning, Disability and Health (ICF)(155)(p.735)

In 2004 Hidde P. et al. (156), the authors proposed, after a thorough review of the literature, The Physical Activity for people with a Disability (PAD) model, "which is an integrated model of the relationship between physical activity behaviour, functioning and disability" (p.645) (Figure 5). The PAD adds to the existing ICF framework by offering a more focused and in-depth view of the interactions between contextual factors (personal and environmental) and the health condition. In particular, it highlights the impact of social influence (environmental factor), as well as self-efficacy, intention and attitude (personal factors) on the level of participation in various levels of PA functioning (156).

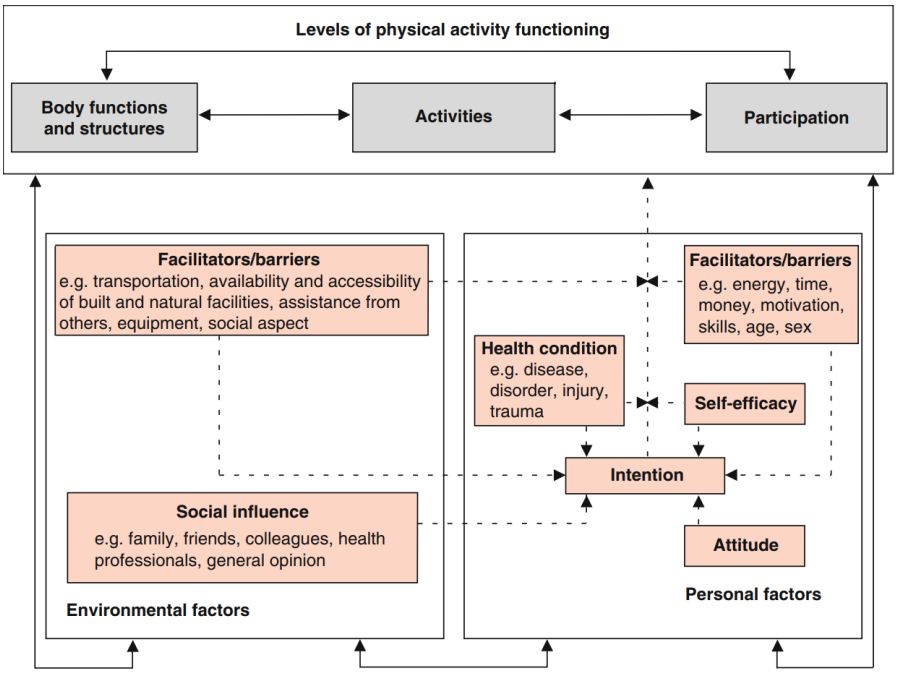

Figure 5 - The Physical Activity for People with a Disability (PAD)(156) (p.645)

2.7.2 Conceptual model for promoting physical activity

The conceptual model of Health through Sport for children and adolescents, illustrates the correlation between the factors influencing sports participation, and this indicates that the different aspects of human health, including physical, psychological and social well-being are impacted by engaging in different types of sports activities (Figure 6) (157). The overall approach to promoting health through sports can be applied by individuals of all ages, including children, teenagers, and adults (157).

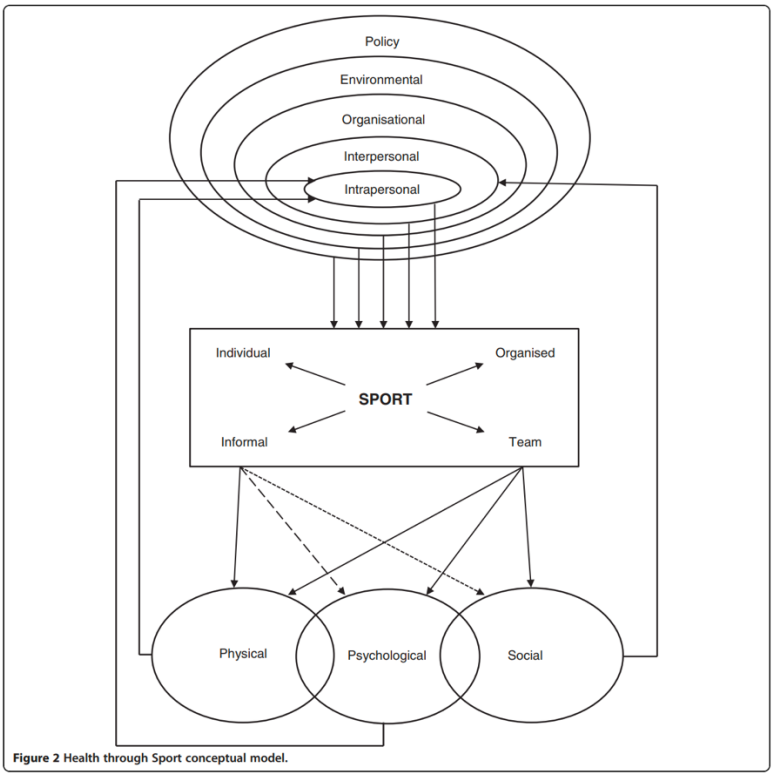

Figure 6 – Health through Sport conceptual model for Sport(157) (p.12)

2.7.3 Social-cognitive models of health and exercise behaviour

According to the Social Cognitive Theory (SCT), a combination of individual factors, actions, and surroundings shape a person's behaviour (158). The SCT has four main elements: self-efficacy, perceived outcomes, objectives, and facilitators or obstacles focused on promoting health and preventing disease (159) (Figure 7). Self-efficacy indirectly influences behaviour through goal setting and perceived advantages of PA, shaping an individual's outlook on PA outcomes (158, 160). Outcome expectations express an individual's belief that a specific conduct will deliver a particular outcome (159). Goals are additional guides and self-motivators for carrying out actions (159). The fourth primary component of the SCT mode is the socio-structural factor: this includes obstacles and facilitators referring to social and personal factors, as well as environmental aspects (e.g., access to resources) and policy considerations (including guidelines associated with PA in schools) (160).

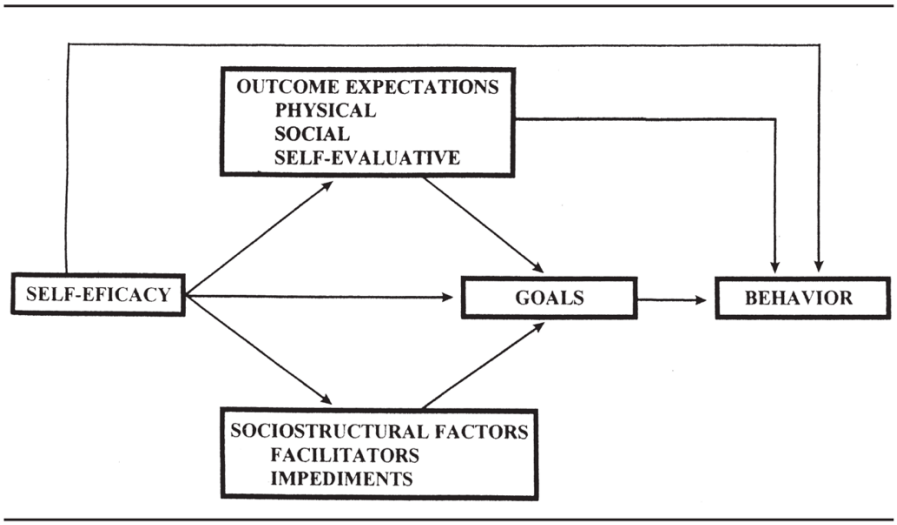

Figure 7 - Social Cognitive Theory(159) (p.146)

2.7.4 The behaviour change wheel (BCW) model to increase physical activity

The behaviour change wheel (BCW) model is useful for analyzing interventions. It aids in identifying the mechanisms behind intervention outcomes and can diagnose the causes of intervention failure (161). The BCW comprises of three layers (Figure 8): The internal layer, which is at the center of the wheel, focuses on achieving productive goals by uncovering the determinants of behaviour, this layer is divided into three components: capability, opportunity, and motivation. The second layer represents the different intervention functions applied to resolve the shortcomings of the three components of the first layer, and the last layer compromise of seven forms of policy including guidelines, environmental or social planning, communication or marketing, legislation, service provision, regulation and fiscal measures, these can be applied to undertake the intervention functions (161).

A three-stage method is available to assist intervention designers in utilizing the BCW effectively (Figure 9). This step-by-step approach guides the construction of interventions to alter the behaviour. Stage 1: Understand the behaviour: Understand and define the behaviour in specific terms, this includes identifying the subjects, as well as the behaviour involved. The target behaviour is then selected based on criteria such as impact, the feasibility of change, system and user-friendly measurement. Once the target behaviour is chosen, clear details are needed, comprising “who needs to perform the behaviour” (161)(p.46), what needs to change, when and where it should occur, how often, and with whom. Stage 2: Identify intervention options: this stage

focuses on finding the potential interventions within the Behavior Change Wheel framework. The APEASE criteria (Affordability, Practicality, Effectiveness, Acceptability, Side-effects/safety, and Equity) help guide the selection and adaptation of interventions to the specific context. Stage 3 involves selecting appropriate behaviour change techniques and delivery methods according to the local context and considering the APEASE criteria (161). The effectiveness of the BCW model is outlined in a study involving adults with spinal cord injury (SCI) who had a sedentary lifestyle. The study used a mobile fitness application called *Accessercise*, aligned with BCW, and it discovered that these interventions can have a significant impact on enhancing PA among individuals with SCI (162).

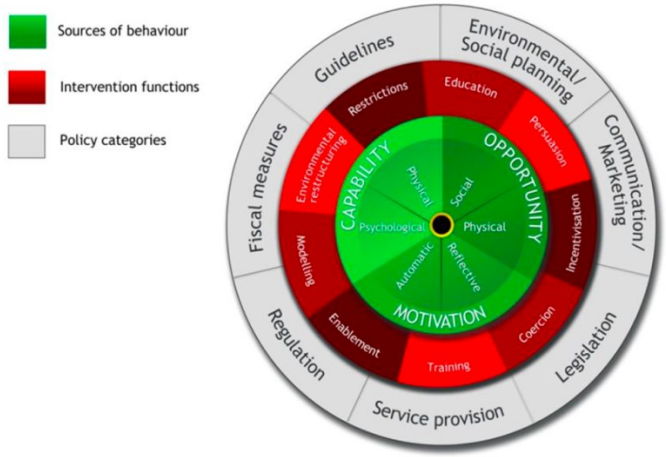

Figure 8 - The Behaviour Change Wheel (161) (p.44)

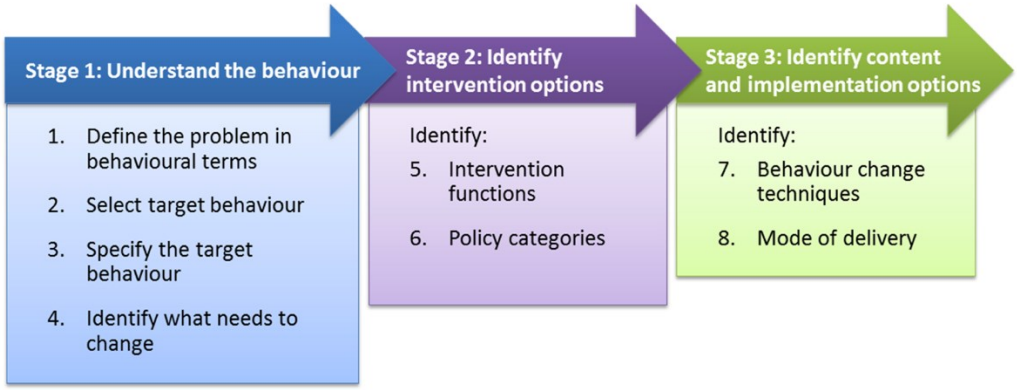

Figure 9 - Step-by-Step Method for Designing Behaviour Change Interventions (161) (p.45)

2.7.5 Transtheoretical model

The Transtheoretical Model (TTM) proposes strategies to support one's behaviour change, and considers the pros and cons (decision balance) and self-efficacy (confidence in being able to change (and maintain) one's behaviour) as integral to the process (163). In this model, individuals move progressively through five stages of behaviour change (pre-contemplation, contemplation, preparation, action, maintenance). The TTM highlights the importance of understanding these stages and incorporating corresponding strategies for successful adoption and long-term maintenance of physically active behaviours (163).

The first prototype of the JIActiv program was developed during earlier phases of the study and was not the focus of the current masters' thesis work. However, improvements to the initial prototype were informed by the findings of the current research. The final version of the JIActiv program and its themes are described below.

2.7.5.1 JIActiv program and TTM

The development of our proposed social media-based program (JIActiv) incorporated a variety of evidence-based content and methods recommended to promote PA among young people with JIA over the course of 12 weeks.

Specifically, in the first week of the JIActiv program the stages of pre-contemplation (for example, a person who may be physically inactive, and who has no intention to exercise within the next 6 months), and contemplation (for example, a person who is currently physically inactive but who intends to start exercising within 6 months) are addressed. The proposed activities aim to make sure that participants acquire enough knowledge regarding the benefits and the drawbacks of PA, in this stage we monitor their intention to change their behaviour within the next 6 months.

During weeks 2 to 5, participants are moving through the preparation phase towards the action phase (for example, a person may be more active but is still not engaging regularly in PA). To support this transition, lessons learned focus on symptom management (for example, pain; fatigue), they are given tools to create and discover new opportunities to be physically active and spending less time engaging in sedentary behaviour. They acquire knowledge about the benefits of PA in their daily life. They created their own SMART (Specific, Measurable, Attainable,

Realistic, Time-based) goals for engaging in PA and incorporate specific times for PA into their schedule.

Weeks 6 through 12 focus on working engaging regularly in PA. That is that participants are moving into the action stage (for example, they are engaging in regular PA but for less than 6 months). During this time the program addresses motivational factors to maintain an active lifestyle (for example, the importance of social support) and strategies to acquiring the needed support. They are also asked to identify the factors that may hinder their participation in PA and to explore solutions to overcoming these. Additionally, we request they share their PA schedules and find inspiration from others. During the last 4 weeks of the JIActiv program, they are encouraged to put all strategies learnt into practice. Regular messages of encouragement and requests for updates are sent to each participant. The knowledge acquired throughout the program contributes to reaching the final stage of the behaviour change process, the maintenance stage (for example, sustaining engagement in regular PA for more than 6 months) (164, 165). To favour adherence to the proposed behaviour-change program a user-centered and sequential phased approach was necessary for its development.

2.8 Methods and constructs applied when developing behavioural change interventions

The following will focus on illustrating the methods proposed to successfully develop and assess novel behavior-based interventions. Furthermore, the constructs of acceptability, usability, and feasibility, as well as supporting theoretical principles will be illustrated in the following paragraphs.

2.8.1 Obesity-Related Behavioral Intervention Trials (ORBIT) for developing behavioural treatments

The ORBIT framework consisting of four phases focuses on developing interventions in the early stages to guarantee that they are practical and appropriate for clinical trials (Figure 10) (166, 167). Based on studies, each phase of this model has its own goal; phase I: Design, aims to develop the critical aspects of a behavioural intervention or customize an existing intervention to address a novel problem; phase II: Preliminary Testing, determining if a fixed treatment approach can reduce a behavioural risk factor in a clinically meaningful way; phase III: Efficacy trial, the objective is

to assess an intervention's effectiveness while minimizing the impact of extraneous variables that could influence the outcome.; and the phase IV: Effectiveness, assesses whether the outcomes of efficacy trials can be reproduced in less regulated environments, such as particular clinical groups or healthcare settings (166, 167). Within this framework are also incorporated the concepts relating to acceptability, usability and feasibility.

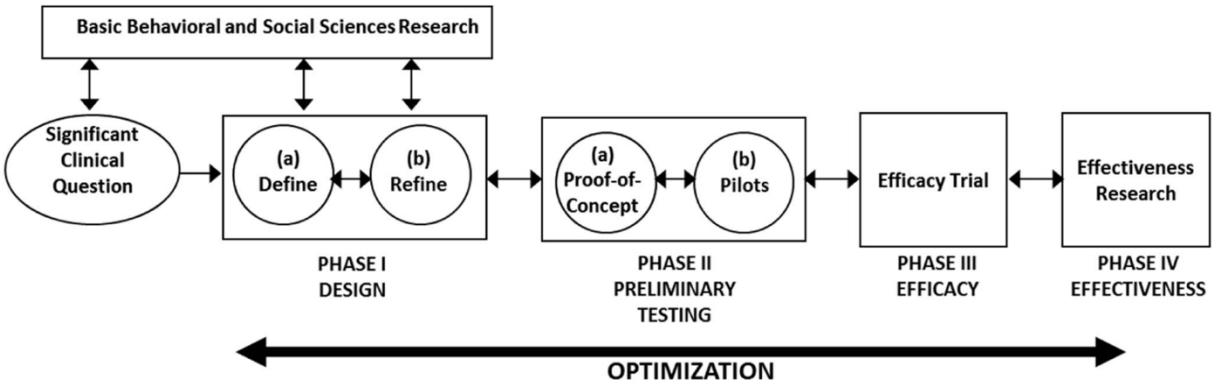

Figure 10 - The ORBIT model for behavioural treatment development field(166) (p.973)

2.8.2 Acceptability

Acceptability is a complex concept composed of seven parts: "affective attitude, burden, perceived effectiveness, ethicality, intervention coherence, opportunity costs, and self-efficacy" that will influence how helpful they find a given intervention. This concept and its elements are depicted in Figure 11 (168) (p.8). If users accept content and delivery of a particular intervention, and recognise its helpfulness in improving health outcomes, researchers will move to assess whether the proposed intervention can actually be used by the targeted population.

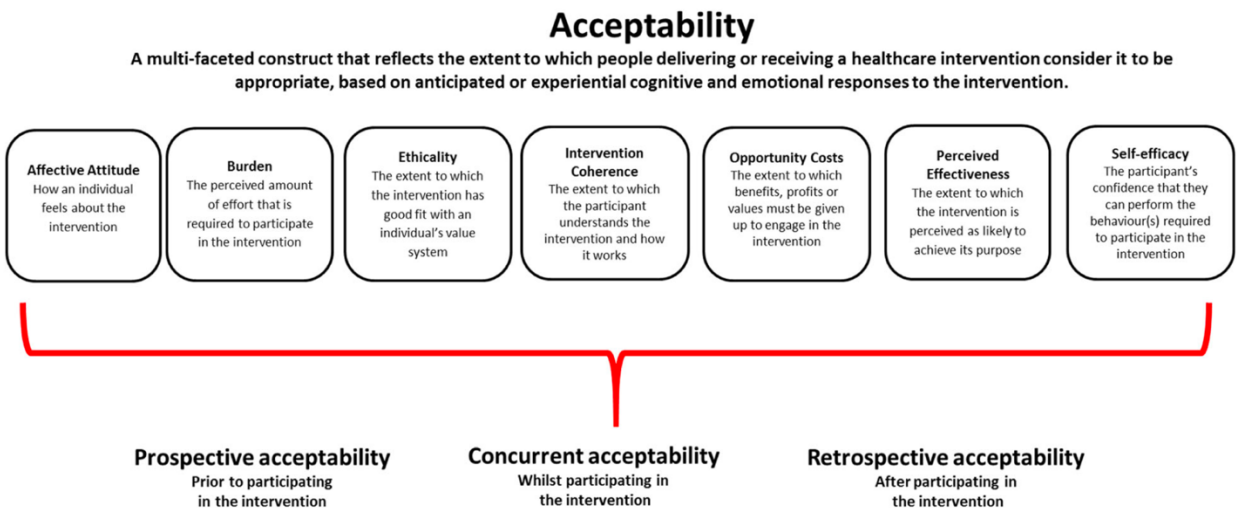

Figure 11 - Theoretical framework of acceptability (168) (p.8)

2.8.3 Usability

"Usability is a concept of execution time, performance, user satisfaction, and ease of learning, taken together "(169) (p.326). Usability is the ability of a product to be used easily and effectively under given circumstances by a specified group of users; however, neither researchers nor organizations that promote standardization have agreed on a standard definition of usability (169, 170). Some studies mentioned that a key method of assessment of suitability for website design and content is usability testing, which allows developers to identify problems with the system as well as gain more information about how users experience it (171, 172). According to Nielsen (173), a software usability expert, usability comprises five attributes. Firstly, efficiency: users should be able to operate the system quickly and easily. Secondly, errors: A system with minimal error frequency allows users to make minimal mistakes. Thirdly, learnability is an easy-to-learn system, so users can start using it without delay. Fourthly, memorability refers to a rememberable system which provides the opportunity for the users to resume without re-learning following a period of inactivity. Lastly, satisfaction: accessing an enjoyable system resulting in user satisfaction (173). The International Organization for Standardization (ISO) defines usability's 3 - attributes: effectiveness, efficiency, and satisfaction. However, the People At the Center of Mobile Application Development (PACMAD) usability model consists of 7 factors that indicate the usability of an application: Efficiency, Effectiveness, Learnability, Memorability, Errors, Cognitive load, and Satisfaction. Figure 12 shows these three models of usability (174)(p.3).

In a systematic review done by Sousa et al., (175) four questionnaires are considered the most robust questionnaires currently available when considering their ability to cover attributes, provide generalizability and measure quality, including the System Usability Scale(SUS), Questionnaire for User Interaction Satisfaction (QUIS), Post-Study System Usability Questionnaire(PSSUQ), and Computer-System-Usability Questionnaire (CSUQ) (175). Among these four types of questionnaires, the SUS is the most extensively used, and has been administered to young people living with arthritis (176). However, it is important to note that none of these questionnaires cover all usability attributes reported in the above-mentioned theories. As such, a qualitative study design approach is needed to collect data on all pertinent usability principles and provide a more in-depth analysis of individual users' experience and satisfaction regarding the novel digital intervention.

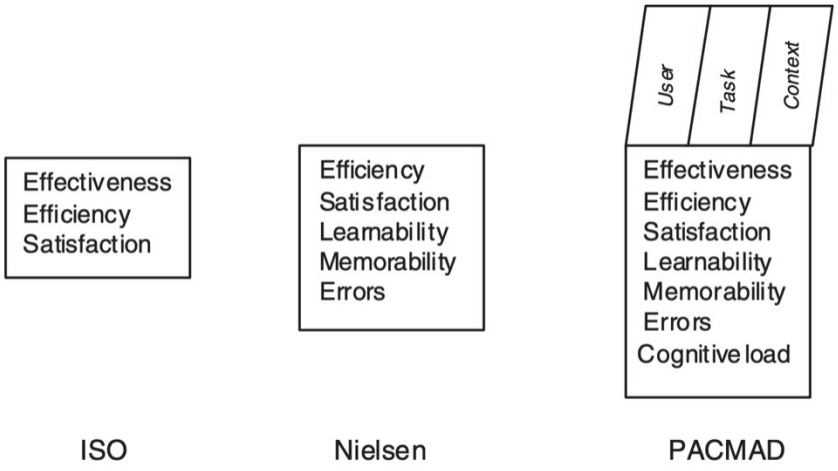

Figure 12-Comparison of usability models (174)(p.3)

2.8.4 Feasibility

Feasibility as a crucial initial stage when assessing the practicality of a new intervention is debated; in fact, the goals of feasibility studies are to answer some questions, including whether the upcoming research is feasible and, if yes, how it should be done, feasibility as well assess the unsuccessful execution, as well as offer a preliminary look into the potential effect of the proposed intervention (177-180). Conducting feasibility studies is important because they increase the quality and rigour of future large-scale studies such as randomized controlled trials, assessing the effectiveness of the intervention (178, 181).

Chapter 3 – [Method]

3.1 Study design

We conducted a descriptive qualitative study involving young people living with JIA.

3.2 Study population

A total of 54 participants were approached to participate in the usability phase of our study. These participants included adolescents aged 13 to 17 years with JIA (n=8) and young adults aged 18 to 25 with years with JIA (n=20). Participants were eligible to participate if they: 1. Were between the ages of 13 and 25 years; 2. have been diagnosed with JIA by a pediatric rheumatologist; 3. have a good understanding and knowledge of either English or French and be able to introduce themselves in one of these two languages; 4. have an email address or be willing to create a new one to participate in the study; and 5. have access to electronic devices such as computers, smartphone and/or tablets. Participants presenting with major comorbid illnesses or cognitive impairments that could affect their ability to use and understand the web-based program were excluded. Only those who fulfilled the requirements were invited to participate.

3.3 Recruitment procedure

Adolescents and young adults (13 to 25 years of age) with JIA were recruited from Canadian clinical care centers in Montreal, Quebec (*Centre de réadaptation Constance-Lethbridge du CIUSSS Centre-ouest de l'île de Montréal*) and in Ottawa, Ontario (Children's Hospital of Eastern Ontario; Ottawa community-based clinics). A rheumatologist reviewed the inclusion and exclusion criteria. If young people seen in clinic were eligible, they were contacted in person during their clinic visit or over the phone by the clinical coordinator to inquire whether they would agree to be contacted by a member of research team. If participants agreed, a member of the research team (graduate student, research assistant) contacted potential participants via phone or email to provide further information on the study. The research team recruited people with juvenile arthritis the Facebook pages and groups of arthritis-related organizations and associations across Canada (e.g., Arthritis Society, Arthritis Alliance of Canada (AAC), Canadian Arthritis Patient

Alliance (CAPA); Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN), Cassie and Friends). If interested in taking part in the study young people with JIA were asked to review information and consent form accessible online via an individual REDCap link sent to their email. Once participants consented (adolescents assented and we obtained parental consent), they were invited, using the same link, to answer, online questions pertaining to their age, gender, language preference, and JIA diagnosis (sub-type). They were then contacted by telephone or by email to set up a time for an individual semi-structured interview.

3.4 Data collection methods

Usability data were collected primarily through individually conducted semi-structured interviews with each participant. The development of the interview guide (Appendix 2) was done by incorporating key elements identified in two literature reviews previously completed by our research team about the program elements to be included in PA interventions and digital care approaches among young people with JIA, as well modeled after interview guides used by other team members for similar usability studies (182, 183) anchored in usability theory principles (174).

The research team created an anonymous Instagram account for each participant, which they were encouraged to use to explore the content of the JIActiv program and navigate the Instagram page over the course of two weeks. Throughout this time participants navigated the Instagram page posts and completed targeted activities. Participants could choose the French or English version of the JIActiv program based on their language preference. The option to choose between both languages was given to favour participants understanding of the program's content and facilitate communication when writing group message chats.

After this initial exposure to the JIActiv program participants were invited to take part in an individual online session (lasting 60 to 75 minutes) which included both usability task testing and a semi-structured interview over Zoom [Enterprise Version 5.0.2 secure platform (24030.0508)]. Reminders were sent one week and three days prior to the meeting to answer participants inquiries regarding the study, the Instagram page and connection to the Zoom platform (for example, being able to download the Zoom application onto their electronic device of choice). They were invited to use their electronic device of choice: computer, smartphone and/or tablet. During the online meeting, participants were instructed by the interviewer (graduate student, research assistant) to

navigate the Instagram page and complete specific tasks and activities included in the JIActiv program (watching short informational videos, completing quizzes, sending a chat message to the page administrator) (Appendix 1). Participants were invited to offer feedback on the usability of the JIActiv program and made recommendations on how to improve it. Specifically, information regarding safety and privacy, design aesthetics, functionalities, content, language display, and the program organization was collected.

In addition, quantitative data was collected modeling the Usability Test Task (184) recommended by Ohkubo et al. (2013) to further assess the ease of use and user performance. When participants completed 6 specific tasks, as instructed by the interviewer, navigation errors and interface issues were noted by the interviewer when participants completed a given task. The time required to complete each task was recorded in seconds. Time needed to complete the task and the user's ease in completing said task were rated on an ordinal scale (0 = not completed, 1 = completed with difficulty, 2 = easily completed).

3.4.1 Description of the JIActiv Program

The JIActiv program is featured on a private Instagram page, it includes 8 themed modules delivered over 8 weeks educating young people on various subjects related to their arthritis and PA, as well as applying new tools and methods to becoming more active. Week 1: Theme 1 provides participants with the necessary knowledge to comprehend the significance of physical activity for disease management, as well as the potential detriments of a sedentary lifestyle. During this week, participants completed quizzes to assess their understanding of the information imparted, ensuring their comprehension of PA and JIA. Week 2: Theme 2 emphasizes the exploration of daily opportunities for PA, enabling participants to engage in regular PA. Week 3: Theme 3 is centered around identifying individual expectations regarding PA. Week 4: Theme 4 involves teaching participants how to set self-directed SMART (Specific, Measurable, Achievable, Relevant, Time-bound) goals for PA. Week 5: Theme 5 focuses on learning and assessing self-efficacy and the perceived effects of PA. Week 6: Theme 6 revolves around recognizing the social support, including peers, family, and friends, that may be helpful in encouraging PA. Week 7: Theme 7 is dedicated to identifying strategies to overcome or cope with barriers to PA. Week 8: Theme 8 concentrates on teaching participants how to maintain a physically active lifestyle throughout their lives. Additionally, 4 weeks of maintenance are included between weeks 9 and

12 of the program, which affords participants the chance to apply what they learnt and act independently to achieve their personal PA goals. Participants are asked to self-monitor their progress in PA engagement (using a pedometer and a short self-reported questionnaire). The JIActiv program administrators send weekly tips, along with messages of encouragement and rewards to participants to favour adherence and commitment to reach personal PA goals. Furthermore, the JIActiv program administrators would be available to answer participants' questions as needed.

3.5 Data analysis

We saved the Zoom teleconferences as an audio-visual recording. To ensure confidentiality and security for all individuals involved, the recordings were stored and protected by a password on a secure server belonging to the *Institut universitaire sur la réadaptation en déficience physique de Montréal* (IURDPM). Audiotaped recordings were transcribed verbatim, sorted, organized, and coded using MAXQDA11 software.

Data Analysis

Descriptive statistics (means and standard deviations; percent) were used to present sociodemographic (age, gender, preferred language) and illness-related (JIA subtypes) data.

Qualitative data was analyzed using thematic descriptive analysis with a primarily inductive approach. It has been revealed that thematic analysis offers a flexible and valuable research method with the potential to provide an in-depth and complex understanding of the data (185). Audiotaped recordings were transcribed. The resulting transcripts were supplemented with notes taken during the interviews. Emerging themes were directly related to those informing and structuring the semi-structured interview guide, as such were categorized according to elements central to usability testing featured in the PACMAD model (174), these included satisfaction regarding privacy and safety, design aesthetics, functionality, program organization, social connections and page content. Resulting themes were subdivided and included in a code book generated by team members (FB and ZA) (Table 1). For each code, a clear and comprehensive definition was proposed. The codes were then applied to the interview transcripts to identify corresponding participant quotes. To ensure the rigour of the analysis, clarity and pertinence of the generated codes, 13 of the 28 transcripts were co-coded by two research team members (ZA and FB). Additional emerging codes

not included in the pre-existing list of codes were added when appropriate (deductive analysis). The recommendations from Huberman and Miles (1994) were applied for categorizing, coding, interpreting and organizing data (186). Table 1 represents the codes (and associated themes) applied to qualitative data from both cycles of semi-structured interviews.

Table 1 – Coding applied to qualitative data obtain from iterative usability testing cycles

Themes	Codes	Definition
Privacy and Safety	**Confidentiality** **Privacy** **Cyberbullying** **Safety**	Refers to the level of user comfort and satisfaction when using the JIActiv program online, as it pertains to safety and privacy: (i) Confidentiality of information shared during group discussions or with the JIActiv Page administrator (ii) Privacy of the JIActiv Page from non-members. (iii) Cyberbullying when using the JIActiv Page
Design and Aesthetics	**1. Ease of navigating** **2. Visual appeal**	Refers to the level of user appreciation of the JIActiv page design and aesthetics: (i) Efficiency when navigating through the Instagram page (for example, when moving from one themed module to the next or from one activity to the next) (ii) Satisfaction with the appearance of the Instagram page and all visual content
Functionalities	**1. Presentation and delivery of content (for example, highlights, videos)** **2. Interactive group tasks and activities (for example, group chat)** **3. Interactive individual tasks and activities (for example, individual quiz)**	Refers to the user satisfaction when level This theme relates the users' satisfaction with the functionalities of the system
Organization	**Weekly time requirement Length of posts** **Length of program** **Frequency of posts**	Refers to the level of user satisfaction with the amount and the order (sequence) of content presented in the JIActiv program**.**
Social connections	**Resource person** **Mentorship** **Private messages** **Video calls**	Refers to the level of user satisfaction with support options: (i) Access to a resource person (ii) Mentorship (iii) Exchanging with other JIActiv Page members (iv) Receiving and sending private messages (v) Using video calls.
Content of page	**Clarity of information** **Quality of information** **Credibility of information** **Relevance and pertinence of information**	Refers to the level of user satisfaction, as it relates to the adequacy of the information presented in the program.

Chapter 4 – [Results]

Findings pertaining to perceived needs and acceptability.

It is important to preface this section, by explaining the extensive work having gone into the development of the JIActiv program. The objective of this master's thesis is not to present detailed findings from previous phases of development (knowledge synthesis, needs assessment, design, development, acceptability) prior to the current usability testing phase. However, we found it pertinent to offer the following details. First, an extensive review of the literature (1 scoping review and 2 systematic reviews) were completed investigating the current PA needs and care options available to young people living with JIA. We presented our findings, as well as a proposal of social media-based PA program to a team of experts (focus group) in pediatric rheumatology (nurse, rheumatologist), of physical activity (kinesiologist), and of pediatric rehabilitation (OT, PT), as well as young people with JIA and their parents. Participants provided valuable information on the perceived needs of young people living with JIA in terms of engaging in PA, as well as on the acceptability of a program delivered over social media to promote PA (Featured on Facebook). Although, the proposal was well received by experts' suggestions highlighted the need to improve visual appeal and to explore other social media to favour adherence by users.

Further data was collected on acceptability through semi-structured interviews with young people living with JIA. Once again findings demonstrated good acceptability for the proposed program. The most major recommendation supported by most respondents (13/15) was to use Instagram to feature the JIActiv program. Participants explained that Instagram had greater visual appeal, was user-friendly, and was more popular among adolescents and young adults. One participant believed that the youth targeted by the program did not use Facebook as much anymore. The two participants who preferred Facebook were in the 18-25-year-old age group. One participant explained this was because Instagram required a photo for each post, while Facebook allowed for text-only posts. The other participant felt that Facebook groups were more personal, which helped with motivation, while Instagram pages were more general.

The following manuscript presents our findings following two iterative cycles of usability testing.

Manuscript

Usability testing of JIActiv, a Social Media-Based Program Promoting Engagement in Physical Activity among Young People Living with Juvenile Idiopathic Arthritis

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4.1 Abstract

Background: Despite the benefits of physical activity in mitigating arthritis symptoms and general health, young individuals with juvenile idiopathic arthritis (JIA) have a greater tendency to adopt a sedentary lifestyle rather than engage in physical activity when compared to their healthy peers. Consequently, these young people are at greater risk for cardiovascular disease, obesity, type 2 diabetes and other related conditions. Innovative and attractive means of promoting physical activity among these young people were sorely missing. In response to this need, our team developed JIActiv program, an Instagram-based program promoting physical activity among young people living with JIA. The current study aimed to assess the usability of the JIActiv program in terms of user performance and the level of satisfaction among adolescents and young adults living with JIA.

Method: We used a descriptive qualitative study with semi-structured interviews. A purposive sample of adolescents (13 to 17 years) and young adults (18 to 25 years) with JIA (n=28, mean age= 18.69, SD=± 2.28) was recruited from rheumatology clinics in rehabilitation and hospital centers, as well as through patient organizations to participate in two cycles of semi-structured interviews. We conducted the online interviews via the Zoom Enterprise Version 5.0.2 platform. The audio recordings of the interviews were transcribed word by word and then sorted, organized, and coded using MAXQDA 11 software following recommendations by Huberman et al.. Qualitative data were analyzed using thematic descriptive analysis.

Results: Most participants did not express concerns about security issues like cyberbullying. Participants provided positive feedback regarding the program's user-friendly navigation and appealing visual design. They appreciated the structure of the intervention program. Participants valued engaging in group-based activities as it allowed them to interact with peers and learn from one another. Peer interactions and the opportunity to communicate with healthcare providers were identified as potentially motivating factors.

Conclusion: The study found that the JIActiv program demonstrated good usability. Participants were able to navigate Instagram and make use of its interactive features effectively. We incorporated participant feedback into the program, and the next phase will focus on evaluating

the program's feasibility based on the feedback from young people with JIA to ensure it meets their needs.

Keywords: Juvenile idiopathic arthritis, chronic diseases, physical activity, exercise, social media, e-Health

List of acronyms and abbreviations

JIA: Juvenile idiopathic arthritis

PA: Physical activity

HRQoL: Health-related quality of life

ROM: Range of motion

e-Health: Electronic health

ORBI: Obesity-Related Behavioral Intervention Trials

TTM: Transtheoretical model

CHEO: Children's Hospital of Eastern Ontario

AAC: Arthritis Alliance of Canada

CAPA: Canadian Arthritis Patient Alliance

PR-COIN: Pediatric Rheumatology Care and Outcomes Improvement Network

CRIR: Center for Interdisciplinary Research in Rehabilitation in Greater Montreal

C1: Cycle 1

C2: Cycle 2

UTT: Usability Test Task

4.2 Introduction

Juvenile Idiopathic Arthritis (JIA) is the most prevalent chronic rheumatic disease of unclear etiology that affects children (2). It appears before the age of 16 years and lasts at least six weeks or longer (2) and it is usually more prevalent among girls (187). Clinical presentations of JIA can include lower bone density and increased risk of fractures (188), lower quality of life, chronic pain, joint stiffness and swelling, chronic fatigue, physical disability, and visual impairment from uveitis (inflammation of the eye), these factors can limit participation in daily school and social activities (189-191). Pharmacological treatment options are prescribed to help mitigate disease-related symptoms; however, these treatments may often cause side effects such as pain, and nausea which may restrict participation in day-to-day activities (192, 193).

Although studies recognized the effectiveness of different types of physical activity (PA) on cardiorespiratory fitness, health-related quality of life (HRQoL) and pain management among children and adolescents with JIA (194-196), there is a significant difference, in both in average PA and in the level of PA, between children and adolescents with JIA and healthy peers (197, 198). A study by Lelieveld et al. (199) revealed that adolescents with JIA have significantly lower PA levels than their healthy peers. Only 23% of adolescents with JIA met the public health recommendations of engaging in 60 minutes of moderate to vigorous PA per day of moderate to vigorous PA, in contrast to 66% of healthy control group participants. Furthermore, the study found that adolescents with JIA spend more time on sedentary behaviour, such as lying down compared to their counterparts in the healthy comparison group.

Piggin (2020) defines physical activity as: “Physical activity involves people moving, acting and performing within culturally specific spaces and contexts, and [is] influenced by a unique array of interests, emotions, ideas, instructions” (26)(p.5). Physical activity can increase muscle strength, hand function, functional ability, and range of motion (ROM), and reduce pain and fatigue in people with JIA (132, 200). Thus, encouraging young people with JIA to participate in PA can be recommended to reap its benefits. However, children and young people living with chronic diseases (JIA, and Down syndrome) encounter several barriers to engaging in regular and meaningful PA; these may include the lack of knowledge about PA, lack of family support, lack of sufficient time (to commute), out-of-pocket cost of registering and travelling for community-

based activities, the lack of healthcare professionals with the necessary training to support young people in PA and limited access to PA adapted to their needs (32, 201, 202).

Due to technological advancement, most people can access to many interactive platforms and stay in touch with others (family members, friends, and healthcare professionals) with little to no difficulty. Nowadays, electronic health has been common. Electronic health (e-Health) can improve communication and information sharing among healthcare providers and between patients and healthcare providers (203-205). Eysenbach defines e-Health as: "an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies, in a broader sense, the term characterizes not only a technical development but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology" (89) (p.1).

E-health interventions are potentially effective options for the delivery of self-management and behaviour-change strategies to healthy children and adolescents, as well as young people living with chronic diseases such as asthma. Findings have shown that Internet-based interventions resulted in an improved ability to manage one's disease, decreased number of illness-related emergencies, favored participation in school activities, increased engagement in PA and consequently decreased time spent in sedentary behaviors (206, 207). However, to our knowledge, social networking sites have yet to be used to deliver a comprehensive intervention aimed at promoting PA in young people living with JIA through the delivery of evidence-based information and effective strategies for behaviour change.

We developed an Instagram-based educational and interactive program as a self-management tool to promote engagement in PA promotion among young people with JIA named JIActiv. Before testing the feasibility and exploring the potential efficacy of the JIActiv program, we will assess its usability. The objective of the current research study was to test the usability of JIActiv in terms of user performance and satisfaction from the perspectives of adolescents and young adults living with JIA.

4.3 Methodology

4.3.1 JIActiv Program Development

This Instagram-based program aims to promote engagement in PA among young people living with JIA. It was developed by applying the iterative process proposed by the Obesity-Related Behavioral Intervention Trials (ORBIT) for creating behaviour-based interventions (166). Following an extensive needs assessment, including systematic literature reviews and expert consensus meetings, the first JIActiv prototype was proposed. Preliminary findings suggested that key informants (researchers, clinicians, adolescents and young adults with JIA, and their parents) were supportive of the delivery platform, however recommended improvements to the user-interface, and the intervention content specifically as it pertains to behaviour change to improve PA. The structure and content of the JIActiv program are anchored within Prochaska's Transtheoretical model (TTM) of behavioural change (208). Whereby the young person with JIA is guided through different stages of behaviour change (precontemplation, contemplation, preparation, action, maintenance) to acquire the necessary knowledge and tools, to favor improved engagement in PA (208). The JIActiv program delivers educational content on the benefits of PA and how best to engage in regular PA, as well as offers interactive activities to be completed with peers living with JIA as a means of offering social support. The program includes eight themes and features one theme per week: benefits of PA and exploring opportunities for engagement, recognizing individual expectations and confidence, establishing SMART goals, understanding self-efficacy and perceived effects, investigating motivational techniques, and overcoming barriers (Table 2). We translated all the program's content from French into English and met a reading level of 6 to 7 grade.

Table 2 - JIActiv Program Themes

Week 1	Defining PA in JIA and its benefits on **disease management**
Week 2	Exploring **daily opportunities** for PA
Week 3	Identifying individual **expectations** for PA
Week 4	How to set self-directed **SMART goals** for PA
Week 5	Learning and assessing **self-efficacy** and perceived effect of PA
Week 6	Recognizing **social support** (peers, family, friends) to encourage PA
Week 7	Identifying how to **overcome** or **cope** with **barriers** to PA.
Week 8	**Maintaining** a physically active lifestyle throughout life
Weeks 9-12	**Action phase :** Participants are encouraged **to put into practice** lessons learned

4.3.2 Study design

The study used a descriptive qualitative design with two iterative cycles.

4.3.3 Participants

We recruited a purposive sample of adolescents and young adults living with JIA from Canadian rheumatology clinics, including one at a children's hospital, one at an external community-based clinic, and one at a rehabilitation center. Additionally, participants were sourced through various patient and partner organizations. Adolescents and young adults living with JIA (male and female) with varying levels of disease and JIA subtype were invited to participate if they met the following criteria: 1) were between 13 and 25 years of age, 2) had been diagnosed with JIA by a rheumatologist, 3) understood and were able to express themselves in English or French.

Once participants agreed to take part in the study, an individual REDCap survey link was sent via email to each person to obtain consent (assent for adolescents with parental consent). Participants

(adolescents and young adults with JIA) used the same link to complete a brief sociodemographic inquiring on personal data such as age, gender, preferred language, as well as JIA subtype.

We conducted the usability testing through semi-structured interviews, to assess the user interface's usability (ease of use, efficiency, errors, and user satisfaction), intervention content, and program functionalities (182). In total, two iterative cycles of semi-structured interviews each including adolescents (13 to 17 years) and young adults (18 to 25 years) were completed (209). According to Wichansky et al., (210) two to three cycles are sufficient to properly evaluate the usability of an online program. Semi-structured interview cycles were completed sequentially where findings and users' recommendations were applied to the JIActiv prototype before completing the following cycle. A sample size of 5 participants per cycle is said to be sufficient to identify 85% of platform usability problems (211). In the current study, we included 3 to 5 young people from each age group per iterative cycle to ensure maximum variation and diversity in terms of age. This conscious effort to recruit participants from both the younger and older age groups to best assess the needs across developmental stages resulting in larger sample sizes per semi-structured interview cycles.

We created anonymous Instagram accounts for each participant, and all had access to the JIActiv's private Instagram page. Our research team featured three new posts each week. Participants had full access to the program's content. They were asked to view informational videos, complete a quiz pertaining the weekly theme and participate in the featured interactive activities (e.g., group chats, and sharing pictures of their PA experience). A graduate student led participants in completing 60-90-minute-long semi-structured interviews over Zoom which included usability task testing. After navigating and using the JIActiv program, participants provided feedback on security concerns, design aesthetics, content, functionality, language display, program organization, and suggestions for improvement of the JIActiv program. The interviewer also noted difficulties encountered by participants, system errors and time to completing specified tasks.

4.3.3 Data analysis

Descriptive statistics (mean, standard deviation; percent) were used to analyse sociodemographic and illness-related information including age, gender, preferred language and the distribution of JIA subtypes.

Ethics approval was obtained from the Center for Interdisciplinary Research in Rehabilitation in Greater Montreal (CRIR) and from the Children's Hospital of Eastern Ontario (CHEO) Research Ethics Boards.

4.4 Results

4.4.1 Sample Selection and Participant Characteristics for both Cycle

In total, 54 eligible young people were approached for both cycles. Of the 28 eligible youth with JIA contacted, 15 (60%) agreed to participate in the first usability cycle. Additionally, of the 26 eligible youth contacted, 13 (50%) agreed to participate in the second cycle. Reasons for not taking part in the study as reported by participants were not enough time or no longer interested. Two iterative cycles of qualitative interviews were completed. Fifteen participants took part in cycle 1(C1), while 13 participated in cycle 2 (C2). The group included 8 teenagers aged 13 to 17 and 20 young adults aged 18 to 25, with an average age of 18.69 years (±2.28 standard deviation). Most participants (87%) were female. Polyarticular JIA was the most prevalent type of JIA among the participants, accounting for 25% of the cases. Table 3 provides further details on the sociodemographic and disease characteristics of the adolescents and young adults who participated in the study.

Table 3 - Participants' sociodemographic characteristics and JIA subtype

Characteristics	Participants (n=28)
Age mean ± SD years	18.69 ± 2.28
Sex	
Female, n (%)	22(78%)
Male, n (%)	5(18%)
Unspecified, n (%)	1(4%)
Preferred Language	
English, n (%)	13(46%)
French, n (%)	13(46%)
English and French, n (%)	2(8%)
Subtype of JIA	
Enthesitis related, n (%)	1(4%)
Oligoarthritis, n (%)	3(11%)
Chronic Recurrent Multifocal Osteomyelitis, n (%)	1(4%)

Polyarthritis (RF negative), n (%)	2(7%)
Polyarthritis (RF positive), n (%)	7(25%)
Psoriatic, n (%)	3(11%)
Uncertain, n (%)	10(36%)
Other, n (%)	1(4%)

4.4.3 Usability

We evaluated the JIActiv Instagram program's usability according to the following themes: 1. Privacy and Safety; 2. functionalities; 3. aesthetics; 4. social connectivity; and 5. program structure. Summary of participants' satisfaction with the usability of the JIActiv program interface is represented in table 4.

4.4.3.1 Privacy and Safety

The JIActiv team set up an anonymous Instagram account for all participants. A proportion of them (38%) preferred using the anonymous account as it provided them with a sense of privacy while engaging with the JIActiv page. Conversely, one participant (8%) would have preferred to access the JIActiv interface without switching between Instagram accounts using her personal account. Additionally, most participants (77%) did not appear to be worried about the possibility of cyberbullying.

4.4.3.2 Aesthetics

The term aesthetics pertains to the selection of colours and graphics used in the social media platform and the two video formats employed in the program, namely PowerPoint and Whiteboard. Overall, 89% of participants (n=25) expressed that the visuals were appealing, well-structured, and user-friendly. Consistency of the choice of colours throughout the posts came up several times in the participants' suggestions. However, 20% (n=3) of participants in C1 found that the program's aesthetics could be improved by choosing a colour palette for all postings on the social media platform and the videos. In contrast, after applying the modifications, all participants (C2=13) appreciated the choice of colour; 21-N*19 said: “I liked that there's a whole bunch of colours. It's more like eye-catching”.

4.4.3.3 Functionalities

Functionalities were measured in terms of presentation functionalities (highlights, videos) and interactive functionalities (reminders, encouragements, and quizzes). Among the participants, 19 found the highlights easy to understand and helpful in organizing and finding relevant information.

All 28 participants appreciated the conciseness of the information featured in the short videos. Additionally, all 15 participants in C1 appreciated reminders and encouragement. One adolescent participant suggested strategically placing daily reminders for better visibility.

4.4.3.3 Intervention program's structure/organisation

The chronological progression and the group format of participants determined the structure of the 12-week program. All the young participants who were interviewed (C1) chose the four weeks of action, and several (33%) noted that posting encouraging messages was essential to maintaining their commitment until the end of the program.

4.4.3.3.1 Chronology

This category includes weekly time requirements, length, frequency of posts, and activity order.

Weekly time requirement - The term "time frame" pertains to how activities are allocated throughout the 12-week program. Participants were asked about the frequency and duration of each activity and the program's overall length, 86% of participants (C1, C2) felt that the proposed length of the program and the number of activities and posts per week were appropriate.

Activity order - The "order of activities" pertains to arranging a regular week and aims to integrate the knowledge gained for each theme into different activities. In C1, we asked participants about the sequencing of activities scheduled for Monday, Wednesday, and Friday. All participants were content with the organization of a regular week. The order of activities offered a logical coherence of learning, which was appreciated by all.

4.4.3.3.2 Group format

The group format was discussed in three aspects, including 1. language, 2. group age range, and 3. group size.

Language - Given that the study participants consisted of young people who spoke either French or English, it was necessary to determine the language of communication for the social media posts

and exchanges between them. Most participants were comfortable with the program being conducted in French and English, given that they were bilingual. Moreover, one adolescent participant indicated that many individuals may not be well-versed in scientific or medical terminology in either French or English and recommended publishing the material in both languages, with one post for each language. In C2, five participants were asked about language display; three preferred having two posts in English and French separately; however, two preferred to merge the English and French posts and have one post in both languages instead of two. One participant thought that both versions could be interesting. Three of the four participants asked about their "willingness to follow the program" expressed their interest.

Group age range and size - Nine out of the 15 participants (C1) expressed acceptance of the program's targeted age range (13-25 years), and 80% of the participants were comfortable with the group size (5-10 person).

4.4.3.4 Social connectivity

This category had four subcategories: 1. Resource person, 2. Mentorship, 3. Private messages, and 4. Video calls. When asked about having a resource person and mentorship, all fifteen participants (C1) would appreciate having a healthcare professional as a resource, and 87% of them believed that a mentor should possess positive qualities such as being open-minded, friendly, and available for participants. In terms of messaging, most participants (23 out of 28) enjoyed group-based activities like messaging, with 8 of them stating that messaging promotes social interaction and enhances their sense of belonging and motivation to be active. Among the 15 participants (C1) who were asked about video calls, some (27%) mentioned feeling uncomfortable about participating in video calls with others at the beginning of the program, and 20% (n=3) claimed scheduling difficulties due to differences in everyone's schedules made it challenging to plan for video calls.

4.4.3.5 Content and information

Nearly all participants (27 out of 28) appreciated the quality and applicability of the educational content offered by the program. One adolescent in C1 claimed that knowledge about physical activity could encourage him to be more active. All young participants in C1 found it essential to talk about self-esteem, self-love and how to formulate a goal through the themes, and some of

them suggested additional themes. In addition, in C2, 6 participants talked about the relevance of activities and information, and all were satisfied.

Recommendations provided by participants were applied to improve the JIActiv prototype. Among them, one recommended gathering individuals' feedback on the Instagram page. At the same time, another presented managing the languages separately to prevent confusion. In addition, some mentioned considering titles for all videos and posts. When asked about their willingness to participate in the JIActiv program just over 60% of respondents indicated that they would use it.

Table 4 - – Summary of users' comments on the usability of JIActiv according to emerging themes

Themes	Codes	Examples of participants' comments
Privacy and Safety:	**Confidentiality** **Privacy** **Cyberbullying** **Safety**	C2:"Nobody knows that it's me. And it's not, it's a private account too, I'm not posting anything, so it's fine"(24-F16).
Design and Aesthetics	**1. Ease of navigating** **2. Visual appeal**	C1:"Uh, well that was good. But maybe, let's say the whiteboards, you can always add colour because it's more eye-catching."[Freely translated from French] (1-F14).
Functionalities	**1. Presentation and delivery of content (for example, highlights, videos)** **2. Interactive group tasks and activities (for example, group chat)** **3. Interactive individual tasks and activities (for example, individual quiz)**	C1: "I like the idea of quizzes and stuff like that, just for me personally I like something like that, it kind of motivates me to pay more attention to stuff." 3-F13) C2: "The amount (of information) was good. In a 5 minute video, there was a lot of information".(25-M16)
Organization	**Weekly time requirement** **Length of posts** **Length of program** **Frequency of posts**	C1: "I think it's good to have the voice because sometimes you just skim, like just read quickly or skim through, so having the voice is good because you'll actually listen " (6-F25) . C2: "I think the program is like long enough. I don't think it's too short or too long too" (27-M16).
Social connectivity	**Resource person** **Mentorship** **Private messages** **Video calls**	C1: "There are shy people, who don't write too much, maybe, it can be difficult for them. Some people are more like me personally, I prefer to watch, but I don't like to write too much" [Freely translated from French] (7-M18). C2: "Totally when you have someone who shares you see where they've been and then you're in the same conditions, so it's sure that it motivates you. And it gives you an idea of where you're headed as well excellent."(17-F19). [Freely translated from French]
Content of page	**Clarity of information** **Quality of information** **Credibility of information** **Relevance and pertinence of information**	C1: "I think it's all like, how to overcome barriers and the importance of exercise and physical activity, setting your SMART goals, strategies we explore to get more motivation, how to overcome all obstacles. It's all good information to have, and it's a good overview" (5-F21). C2: "I think the presentation of the information was good. It was easy for me to understand and to like follow along. It's also good that there was like a description on each post to kind of summarize it, but also give more ideas towards what the posts were. I felt it was pretty trustworthy"(21-N*19).

4.4.4 Supplementary quantitative data pertaining to user performance when using JIActiv

Additional quantitative data was collected to further assess users' performance in completing the targeted JIActiv tasks featured on the Instagram page. Three main concepts were investigated: (i) ease of navigating the interface; (ii) their ability to learn to use its various functions; and (iii) the frequency of navigational errors observed during the Usability Test Task (UTT) (212). The participants reported ease of navigating the JIActiv interface (qualitative data) was corroborated by their performance in the UTT, as shown in Table 5. Specifically, at least 85% of the participants could complete four out of the six tasks with ease. However, 12 errors were observed when they attempted to complete all tasks. These errors were categorized into three main types: 1. presentation errors, 2. usability errors, and 3. programming errors.

Presentation errors were identified as instances where participants experienced difficulty or failed to locate a publication or feature on the JIActiv interface. For instance, in Task 3, 15% of participants selected the wrong publication, despite the presence of numbering. Additionally, 38% of participants encountered difficulties locating the featured item in week 4, likely due to their unfamiliarity with the terminology. Consequently, it has been decided to rename the featured items to "Featured Item - Week X" to address this issue.

Usability errors were characterized as instances where participants faced difficulty or encountered failure while attempting to use the various features of the JIActiv interface. For example, in Task 4, one participant struggled with copying and pasting the link in the publication's description to access the PA list. To address this issue, the link's location was changed, and it is now included within the featured item for Week 3, making it accessible with a single click. Only one participant demonstrated slight difficulty changing publications within the featured item and responding to a private message. However, this participant was able to complete both tasks without verbal assistance. Therefore, we deemed no necessary changes at this level.

Programming errors refer to difficulties or failures in utilizing a particular feature on the Instagram app that arise due to limitations. For instance, one such restriction is that a survey can only be taken on a featured item 24 hours after publication. Consequently, in Task 5, none of the participants could spontaneously respond to the survey since it had been published more than 24 hours before they accessed it. Moreover, 38% required verbal assistance to find an alternative

means of completing the survey. Despite these issues, we made no modifications since all youth involved in the real-time program will adhere to the activity schedule and complete the survey on the day of its release. Hence, this inconvenience should not recur.

Table 5 - Participant success and time (seconds) required to complete Usability Test Tasks

		Time to complete each task (seconds)					
		Task 1	**Task 2**	**Task 3**	**Task 4**	**Task 5**	**Task 6**
Success level	Easily, n (%)	13(100)	13(100)	11(85)	9(69)	7(54)	13(100)
	With difficulty, n (%)	0	0	2(15)	3(23)	6(46)	0
	Not completed, n(%)	0	0	0	1(8)	0	0
Average time, seconds (SD)		6,31 (± 5,44)	15,77 (± 7,97)	12,23 (± 6,72)	64,92 (± 57,66)	58,00 (± 31,19)	17,15 (± 7,29)

4.5 Discussion

The study aimed to investigate specific objectives, including assessing the JIActiv program's acceptance level by users, its alignment with their needs, and their satisfaction with program content, user interface, and program functionalities.

The findings led to a better comprehension of what young people living with JIA prefer to see included in the proposed educational and interactive program. Additionally, the study identified motivational factors that influenced the participants' level of physical activity. Our findings demonstrated that the JIActiv program was positively received by young people living with JIA. Suggestions made by study participants were applied, when possible, to improve platform usability, encourage greater youth engagement to participate in the given activities and promote participation in regular physical activity.

Most participants reported being active less than 60 minutes a day, which is below the recommended Canadian 24-Hour Movement Guidelines (213). Despite lower than desired levels of daily physical activity their appreciation of the JIActiv program did not appear to be influenced. The literature has often shown that those with JIA are less physically active than their peers due in large part to their arthritis-linked symptoms (214, 215). Our experiences show that energy conservation strategies, in addition to knowledge regarding using online-based physical activity programs, can greatly improve increased levels of physical activity. Participants in our study reported that the proposed strategies would be helpful and motivational to increase and maintain their engagement in new and regular physical activities. It is worth noting that those living with chronic diseases need to work within their pain and fatigue threshold and not go beyond their tolerance (216, 217). Unfortunately, incorporating an all-or-nothing approach can lead to physical and mental fatigue (217), which may result in disengagement and decreased motivation among young people. In line with the JIActiv's central components, findings from Fiona C et al. (218) support the development of endurance, adjustable intensity levels based on comfort, and engaging in varying types of preferred physical activities.

4.5.1 Content of page

Content of the page includes the information quality and credibility, as well as relevance of information and activities. Accessible and evidence-based information can help individuals to incorporate into a health promotion program. Young people with JIA have reported that they do not know enough about the benefits of physical activity, which leads to lower levels of engagement in the PA and is seen as a barrier (199, 219).

Physical literacy is one of the significant elements of improving PA through increasing individuals' commitments to the PA (220-222). "Physical literacy can be described as a disposition to capitalize on our human embodied capability, wherein the individual has: the motivation, confidence, physical competence, knowledge and understanding to value and take responsibility for maintaining purposeful physical pursuits/activities throughout the life course" (77)(p.28). Studies demonstrate the limited physical literacy among children and young people with chronic diseases which can result in reducing PA levels and increasing sedentary behaviour and deprive them of the benefits of PA (223). To counter this lack of knowledge and understanding of physical activity

the JIActiv program included relevant evidence-based information and strategies in easy-to-read text, which all participants highly appreciated it.

4.5.2 Functionalities

Functionalities consist of presentation functionalities like highlights and videos, as well interactive functionalities such as group-based messaging and individual-based quizzes. The interactive aspects of a behaviour change program such as JIActiv make it more appealing to participants. The JIActiv program provided a variety of activities and functionalities including reminders, encouragements, quizzes, highlights, and videos, which were appreciated and valuable by participants to engage them more in the PA.

This study investigated the impact of social interaction on physical activity, and it has been shown that peers played a crucial role as external motivational factors. These findings align with previous research indicating that engaging in social interaction with peers can be beneficial for encouraging them to engage more in physical activity (224). In addition, in a study conducted by Gillian et al. (225), one of the important factors regarding social media was providing peer interaction, which allows participants to share their lived experiences. Another study done by Christa et al. (226) among individuals with spinal cord injury revealed the significance of having access to peers with the same condition. Participants believed that such access provided them a chance to acquire knowledge about improving PA through discussion with their peers. Moreover, our results showed that participants were inclined to participate in group-based activities, such as messaging and found it crucial to boost their social connections.

Undoubtedly, people have specific preferences when selecting social media platforms. In our study, what we found was that the majority of participants favoured Instagram. Participants showed proficiency in navigating the JIActiv program modules and interface and utilizing Instagram's various features. This proficiency could be attributed to the fact that all participants were already regular users of Instagram before the study. This high level of usage was expected, given that more than 90% of Canadians between the ages of 15 to 34 spend time on social media regularly according to Schimmel et al.'s report (227). Furthermore, the proficiency exhibited by participants in effectively navigating the JIActiv program, coupled with minimal difficulties or errors in performance, further supports this observation.

4.5.3 Design Aesthetics (1. Ease of navigation, 2. Visual appeal)

"Aesthetics is a branch of philosophy and is often associated with art" (228)(p.3). Aesthetics depicts the qualities seen in something like an object; when something has good aesthetics it can attract more people's attention. However, the interpretation of esthetics is different for anyone because of the differences in cultural and social norms (228). The significance of the JIActiv program's aesthetics was also emphasized. Hence this program is perceived as well-structured, vibrant, and visually appealing, based on the feedback from the participants. This parallels the study of David et al. (229) and Stinson et al. (182) revealed that incorporating interactive features and enhancing visual appeal can significantly increase motivation among participants to engage in the program's platform. Moreover, aesthetic design has a significant effect on user's perception regarding the quality of the appearance of the main page which can impact the level of satisfaction among end users (230).

4.6 Clinical Implications for the JIActiv Program

In the short term, our findings have highlighted changes that need to be implemented in the JIActiv program based on feedback from young people with JIA, which will enhance both the program itself and the Instagram functionalities to be integrated with the preparation for the feasibility study of JIActiv in a clinical setting. Active involvement from young people with JIA throughout the iterative testing and improvement process of JIActiv's usability is crucial, as Wichansky et al. (211) highlighted this as well. This involvement ensures that the program content and interface meet the actual needs of the target population, maximizing the likelihood of its uptake after its official rollout.

JIActiv is set to significantly impact both care providers and young people living with JIA. By supplementing traditional interventions, this online program could maximize its effectiveness and reduce the costs of promoting the benefits of physical activity to young people with JIA. The education provided by JIActiv would enrich existing clinical care, providing healthcare professionals with recommendations and education about physical activity for young people with JIA. Additionally, young people who may not feel comfortable discussing their condition with an adult might be able to privately seek evidence-based advice from the JIActiv team or even a peer mentor.

To our knowledge, JIActiv is the only program available on Instagram that promotes engagement in physical activity for young people with JIA. Once officially launched, JIActiv has the potential to serve as a template for other programs promoting physical activity or symptom self-management for various chronic conditions.

4.7 Limitations

This qualitative study has limitations that need to be discussed. Initially, the sample recruited for the program did not include representation from all eligible age groups. In the first cycle, there was a lack of diversity in terms of ages, with only 2 participants in the 13-17 years old group and 13 participants in the 18-25 years group. However, despite the limited representation, we observed that the responses were quite similar between the age groups. It is important to note that this lack of representation was not observed in the second cycle, where we had a more balanced distribution of participants between adolescents and young adults. The study primarily involved participants from two centers in Canada, with one participant from the United States and another participant who was a Canadian resident but currently residing in South Africa. As a result, there was limited diversity in terms of the location of care, which may restrict the transferability of the results. Nevertheless, we have provided detailed information to facilitate extrapolation and determine if the findings apply to different contexts.

The research team implemented the recommended changes, and they deemed only a few changes unfeasible due to time constraints or limitations within the Instagram platform settings. However, this study has offered valuable insight into participants' impressions and experiences with the JIActiv program which will further inform its development.

4.8. Conclusion

This study aimed to assess and enhance the usability of the JIActiv program. In summary, the JIActiv program was well received in format and content during the 12-week program, with good usability reported. Our findings support the selection of social networking sites, as the participants could navigate Instagram and utilize its interactive functionalities. Furthermore, most participants expressed satisfaction with the privacy, aesthetics, content, and opportunities for interaction the program offers. We incorporated any feedback from participants regarding minor changes to

aesthetics and content into the program. The next phase of the study, which evaluates JIActiv's feasibility, will be initiated, still based on the feedback of young people with JIA to ensure that the interface meets their needs.

4.9 Acknowledgements

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Chapter 5 – [Discussion]

This section summarizes and discusses our main results, and as compared to other published works. Finally, we described the clinical implications of the proposed Instagram-based intervention, as well as highlighted strategies to optimize its use and clinical integration.

The main objective of this master's project was to investigate the usability of JIActiv an Instagram-based educational and interactive program promoting PA among young people living with JIA. Specifically, we explored user performance and satisfaction among participants living with JIA when navigating the JIActiv Instagram page and completing the program's tasks. Usability is an essential phase in the development of an intervention, as in our study, this helped gather participants' insights regarding the practicality and functionality of the JIActiv program. This process has allowed us to modify the JIActiv program's content and features to meet participants' needs and preferences. Our study is the first to assess the usability of the JIActiv program as featured on Instagram. Our findings demonstrated that most participants were satisfied with the latest version of the JIActiv program and reported that it could help favor their engagement in physical activity. In fact, study participants highlighted several factors that could help motivate them to take part in physical activity.

Findings on motivational factors were analyzed according to two categories. Internal motivation originating from an individual's internal factors, such as biological, emotional, and spiritual aspects; when someone is internally motivated to pursue an activity, they do so for self-pleasure and satisfaction (231). Whereas, external motivation refers to "any stimulus that comes from outside of [the] learner, and which drives the learner in the learning process" (231) (p.550).

As per our findings, sources of external motivation such as support from healthcare providers, parents, peers, and Instagram page administrators (i.e., research team personnel and graduate student) were considered important and helpful by participants.

Studies have revealed the use of social media by patients and healthcare professionals (232). Our analysis starts with the nature of social media use and its motivations. Upon reviewing articles, it becomes clear that patients utilize social media not to bypass healthcare professionals but to have access to a supplementary tool to complement healthcare professional services to meet their needs beyond the scope of professional care (232).In addition, patients use social media because they tend to address the gap between traditional health information and their everyday life conditions (233).

The existence of healthcare through social media can positively impact patient involvement in PA. In our study, participants mentioned that having healthcare professionals on social media could be helpful and would motivate them to be more engaged in physical activity, this aligns with findings from Marie A. et al.'s (234), which identified healthcare professionals as motivators for increased physical activity among children and adolescents (234).

Studies indicate that children appreciated the support from family members (5), children aged between 10-12 are more motivated to engage in physical activity when their parents, especially their mothers, participate in various activities such as cycling, walking, and sports (235). Another study conducted among adolescents (11-15 years old) emphasized four types of parental support that enhance adolescent involvement in physical activity. These include parental encouragement, active participation by parents in physical activities, parents observing adolescents during physical activity, and discussing physical activity (236). Hence, parental support is helpful during early development up until the age of 15. However, it seems that older teenagers and young adults, such as those participating in our study, may not rely on parental support as much, if at all, to promote engagement in physical activity.

The findings of our study highlighted the importance of peer support, following previous studies that recognized friends and peers act as motivators to increase PA engagement among children and adolescents as well; peer support provides the situation to be in the supportive societies (225, 234). In addition, studies completed among children with JIA underscore the value of the support of peers with the same condition who had similar experiences and they mentioned that they had a sense of belonging to a community (5). Moreover, peer support groups through social media provide solutions based on shared lived experiences and offer valuable emotional support (232).

Participants appreciated the group-based functionality of our program and the participants' feedback is parallel with the result of the study by Gentry et al. (237) which participants preferred group activities and declared that they have a good sense of being supported by others.

In addition to seeking support from individuals in their immediate environment, such as home, and school young people may also look to connect with peers over social media sites. However, as in the study of Elliott et al. (238) clinicians mentioned, challenges may exist for those living in remote geographical locations, as these individuals may be at risk of not having access to the internet. Young individuals with chronic kidney disease expressed a desire for peer support; however; they faced limitations in engagement due to the cultural and ethnic diversity with the peer support. Additionally, some individuals with chronic kidney disease may have a lower level of acceptance of their condition and readiness to participate in peer support (238). Although the use of social media has many benefits, concerns surrounding privacy and safety may still exist for some.

5.1 Privacy and Safety

Based on the definition of Johannes Heurix et al.(239) (p.1). "Privacy is a complex and multidimensional concept and has been perceived as a legal, philosophical, or even technical term". Privacy relates to the protection of the personal identities of participants (239) and one of the important success factors in internet-based health services is participants' privacy preservation (240). In the context of e-Health, providing a secure environment guarantees the patients' records (241). We successfully managed this element in our study, participants had an anonymous account and most of them saw the program as a safe and secure one as well and they did not have any concerns regarding cyberbullying. We used a password-protected secure server to safeguard participant privacy and confidentiality and one of the members of the research team encrypted all private information. In our study, based on the participants' reports, the majority did not share any concerns regarding their safety and privacy while using the JIActiv Instagram page.

There are recommendations and guidelines concerning the use of social media in healthcare systems. The findings Basevi et al.'s review (242) emphasized the significance of privacy and confidentiality breaches, to address this issue, any online postings must be made with care and caution. In 2020, Rivera-Romero et al. (243) did a study to recognize ethical considerations regarding engagement in health participation through social media and health, IT professionals

underlined the ethical issues regarding data collection and the importance of transparency. Participants mentioned that “Ethical issues might arise due to lack of consideration of users’ cultures (of participatory health technologies) since they are reflected both in user interfaces and in the algorithms used ”(243)(p.73).

When discussing e-Health privacy, it is crucial to address a significant threat known as a masquerade attack which occurs when an attacker uses a counterfeit identity for unauthorized access to the e-Health system and can have unlimited access to the patients’ information and delete or change the information causing dangerous consequences and may threaten the patient’s health (241). One of the recent techniques for enhancing privacy and security in e-Health is blockchain, based on the definition of Tagde et al. (244) (p.52811) “The blockchain is a distributed database using state machine replication, with atomic changes to the database referred to as transactions grouped into blocks, with the integrity and tamper-resistance of the transaction log assured via hash links among blocks”. Blockchain technology can be utilized to transform healthcare through patient-focused care, and it enables a secure private and public network for data exchange. However, its adoption in e-Health needs clear evidence (244, 245). In 2022 Akram Hossain et al. (246) introduced a system design in telemedicine service that provides consultants easy access to patients' data. It makes the transaction transparent and enhances data privacy protection using its three modules: 1. The client agent: a client agent is software designed to manage data input and output. It enables doctors to input new data and grants patients access to their information. To ensure secure communication, it utilizes an encrypted channel with shared key pairs issued by the system, and sessions are launched through private key and signature verification for access control, 2. Data Storage: consists of clusters that keep binary files, such as photos, videos, and reports, and are responsible for encrypting and decrypting the files, and 3. Smart contract (Blockchain): The proposed system utilizes blockchain for secure data management. Blockchain stores session data as transactions in linked blocks, ensuring data stability. This decentralized approach grants control to all users and ensures a permanent, permission-controlled data recording (246). In future studies, our goal is to utilize this model as a secure and State-of-the-art strategy.

5.2 Design aesthetic

The significance of beauty or aesthetics in day-to-day living has been known for years and it has changed and developed over time with various interpretations. Beauty refers to the things that seem captivating and accompanied by a sense of enjoyment (247). Based on Persada et al.'s definition "Aesthetics is a branch of science that discusses the beauty and harmony among design elements" (248)(p.1). The role of design aesthetics is crucial in capturing the user's attention, and interest, and it can impact emotions and feelings (228, 249). In addition, studies reveal that the more appealing the aesthetics, the higher the user-reported usability and level of satisfaction, as these elements have been shown to influence one another (250). This aligns with our study, where the general appearance of the Instagram posts and page of the JIActiv program was perceived as well-structured, colourful, and attractive. Participants considered these aesthetic qualities important for their engagement and found the program highly satisfying and user-friendly. Denison-Day suggests incorporating four aspects as described by the Visual Aesthetics Website Inventory (VisAWI) by Moshagen et Thielsch in the development of the website aesthetics (251) . These facets are colourfulness (includes elements related to the selection and combination of colour), craftsmanship (when it comes to craftsmanship in the domain of a site or website, it means using the latest technology skillfully), simplicity (it represents elements such as clarity, order, and balance, which contribute to making the perception of a layout easier), and diversity (indicating visual dynamics, creativity and modernity) (252). Our JIActiv program incorporates these four elements. In the JIActiv program, there are highlights and videos designed to captivate and engage users visually. These visual aids enhance the program's content delivery, enabling users to absorb better and comprehend the information presented on social media or websites.

When discussing the aesthetics of a website or a similar topic, the colours used play a significant role. Colours have a notable impact on the visual appeal of websites (250). In 2011, Bonnardel et al. (253) conducted a study to determine the favourite colours from the perspective of website users, and they found that blue and orange were the most appealing colours. In a qualitative study conducted by Jacqueline M. et al. (254) on the development of a multimedia website, the findings indicated that colour significantly influenced the engagement of both children and adolescents in joining clinical trials through multimedia websites. Children showed a preference for the colour orange, while young people favored teal. Therefore, overall, both generations exhibited a

preference for bright colours. In the JIActiv program, a combination of colours was used which was appreciated by participants.

5.3 Program content

5.3.1 Information quality

The organization of the JIActiv program plays a crucial role in making the program effective and enhancing users' engagement. In the current study, this theme involved the amount of content and the frequency of the posts. Young people taking part in the JIActiv program are presented with comprehensive explanations about their JIA, the impact of PA on disease management, evidence-based strategies to help manage their JIA symptoms, have access to a visual schedule and receive reminders for upcoming posts and activities to engage in. As a result, the program's content and the frequency of the posts were appreciated by participants. Additionally, we took great care to simplify and break down the information, making it easily understandable for all participants, regardless of their background or prior knowledge. Moan et al. (255) identified five dimensions of perceived information quality on health-related websites: 1. Completeness emphasizes comprehensive information on the site, eliminating the need for external searches. 2. Consistency ensures uniformity in language, symbols, and information format, facilitating straightforward interpretation. 3. Understandability involves clear language and accessible information. 4. Accuracy prioritizes error-free content, free from grammatical, spelling, and typographical errors. 5. Relevance highlights providing information directly related to the subject, avoiding unnecessary diversions.

5.3.2 Information delivery

To facilitate easy access to information delivered by websites or social media, certain criteria can be important. This includes using different languages (256) as provided by our program, and we utilized both French and English languages. Additionally, in the JIActive program, participants received text messaging reminders. Studies revealed that text messaging reminders positively impacted medication adherence in the cohort group compared to the control group (211).

It is noteworthy to add that the information provided by the JIActiv program was not only based on current evidence and relevant practices but was also easily accessible. Having easy access to relevant and evidence-based information ensured that participants could quickly obtain

information and comprehend the content. Brett et al. (257) emphasized the significance of easy access to information, in this study women with breast cancer noted that having convenient access to the necessary information on the e-Health app can be considered as a crucial aspect on the e-Health app .

5.4 Limitations

Each study has its limitations that should be acknowledged for future studies and research. Our study is not exempt from this. The following paragraphs address the limitations of this study that we discussed. Firstly, although we used purposive sampling it was dependent on the availability and interest of the potential participants, which may elevate the risk of selection bias in the participant recruitment (258, 259), there is a possibility that individuals with severe JIA, in terms of the number of affected joints and disease duration, may choose not to participate in the JIActiv program. Secondly, in our study, the transferability of the findings may be limited because we recruited the majority of participants from two Canadian provinces, with only one participant from the United States and another who was a Canadian resident currently living in South Africa, hence, this could weaken the external validity of the study. In addition, we did not include the clinicians in this phase; meanwhile, acceptability, usability and implementability of the JIActiv program are currently being assessed among clinicians in a separate phase of the larger study.

5.5 Upcoming research phases

Based on the limitations encountered in the current study, we propose some recommendations. It would be beneficial to recruit individuals from various provinces and even different countries, encompassing diverse cultures and ethnicities. Additionally, involving parents could be advantageous as family support and knowledge about JIA might alleviate the burden of the disease and encourage greater participation in physical activities among the participants.

5.6 Clinical implications

In this study, we discovered that an Instagram-based program like the JIActiv program could be attractive to both young adults and teenagers. These users can access credible, evidence-based resources to enhance their understanding of JIA and its implications, as well as how individuals in this demographic can effectively manage symptoms such as fatigue and pain. The active

involvement of young people with JIA throughout the iterative process of evaluating and improving the usability of the JIActiv program is crucial. The JIActiv program could have a significant impact both for treatment teams and for young people affected by JIA. The educational component of the JIActiv program would supplement current clinical care services, providing additional assistance to healthcare providers in advising physical activity for adolescents with JIA. Furthermore, when considering the implementation of such a program in clinical settings, it is imperative to evaluate the feasibility of integration and ensure that healthcare professionals are well-informed about its existence.

5.7 Future directions: Metaverse; Virtual world; Virtual community; Virtual reality

A further avenue to explore is the utilization of artificial intelligence (AI), particularly within the metaverse context, which could have a potential impact on the well-being of young individuals with JIA and other chronic conditions. The primary focus could be behaviour change and promoting the level of PA in this population. Based on Weinberger's definition, "The Metaverse is an interconnected web of ubiquitous virtual worlds partly overlapping with and enhancing the physical world. These virtual worlds enable users who are represented by avatars to connect and interact with each other and to experience and consume user-generated content in an immersive, scalable, synchronous, and persistent environment" (260)(p.13). Avatars have diverse applications in healthcare, including patient education and simulating medical procedures. They improve understanding of medical conditions and treatment options and allow telemedicine, offering personalized care, and potentially improving patient outcomes (261). The metaverse can be applied in the management of chronic pain and is a safe intervention (262). Studies have shown that AI can be effective in the health domain and can detect chronic diseases (263). Anan et al. (264) conducted a study investigating the impact of an AI-Assisted Health Program on chronic pain. The program assisted the workers in pain management, and to facilitate the interactions they utilized a chatbot. The findings revealed that this program had a significant effect, resulting in a reduction in the level of pain experienced by workers compared to the control group, with 92% (44/48) adhering to the program. (264). Given that chronic pain is one of the main symptoms of JIA, it may be beneficial to include such programs in future studies within the JIActiv program.

5.8 Further / concurrent steps

Another parallel phase is being completed among clinicians to assess the acceptability, usability and implementability of the JIActiv program in their clinical practice. Feasibility testing is currently underway among young people with JIA. We will evaluate the potential efficacy of the program on outcomes such as knowledge acquisition, and actual use. Following the feasibility phase, the next study will be a Randomized Control Trial (RCT) that will involve participants from various regions, cultures, and age groups.

Chapter 6 – [Conclusion]

The objective of this master's thesis was to assess the usability of an Instagram-based program designed to encourage engagement in physical activity among young individuals with Juvenile Idiopathic Arthritis. We conducted a two-cycle evaluation of the program's usability. The majority of participants reported that the program was highly usable and that it would be helpful to engage them in physical activity.

Our findings revealed that employing these social media-based initiatives enhances participants' understanding of their condition and related symptoms and guides them in choosing suitable types of PA to alleviate these symptoms. Additionally, these programs foster connections among peers facing similar conditions, contributing to a sense of community and ultimately motivating greater participation in PA. Participants' feedback further emphasized the program's merit. Most participants perceived the program as secure and felt confident that their privacy was ensured. They appreciated the program's visually appealing and engaging design, coupled with informative content that motivated their usage. Furthermore, participants expressed satisfaction with the quality and relevance of information presented in the posts, deeming them reliable. Consequently, many participants expressed their willingness to continue following the program and recommended it to others also dealing with JIA. The upcoming phase of the research focuses on assessing the feasibility of the JIActiv program and relies on feedback from young individuals with JIA to ensure that the interface caters to their needs.

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Appendices

Appendix 1

Description of the 6 tasks performed during the Usability Test Task

Task 1: Please show me how you would go from your Instagram feed to the JIActiv Instagram page.

Task 2: Show me how you would go from JIActiv Instagram page to the first French video of week 3.

Task 3: Please show me how you would go from this video to the third post in French of week 3.

Task 4: Please read the post description and show me how you will view the physical activity list for your age group.

Task 5: Please see the week 3 featured items and answer the question.

Task 6: Please send a private message containing your favorite sport to the JIA team.

Appendix 2

Interview guide - Usability study (JIActiv) (English version)

Introduction

Hello (insert participant's name)! How are you doing today?

First off, thank you for agreeing to meet with me. My name is ..... and I will be guiding you through the JIActiv Program. To put you into context, JIActiv is a program created on Instagram. The goal of the program is to motivate teens and young adults with Juvenile Idiopathic Arthritis to become more physically active.

Our goal is to get teens and young adults with JIA to want to use this program. Seeing as you are a (insert "teen" or "young adult") with JIA, we would like to use your expert's point of view to improve the JIActiv Program.

To do so, our meeting will take around 90 minutes. It will be separated in two parts. First off, I'll have you navigate through the Instagram platform and would like to get your opinion on whether or not it is easy to use and why. Afterwards, I'll ask you what you liked and disliked about the program. Is that ok with you?

This is a judgement free zone. So, through this whole process:

- Don't' hesitate to tell me if you have any ideas on how to improve the program.
- Don't hesitate to ask me questions at any time if there are things that aren't clear to you.

Before we start the first activity, I would like to ask you a few questions regarding your current social media use.

1. Do you usually use social media plateforms?
    a. If so, what platforms do you usually use (Facebook, Instagram, Twitter, Tiktok, Snapchat, etc.)?

b. How often do you check your social media (a couple of time an hour, every few hours, a couple of times a day, only when you get notifications, etc.)?
c. On average, how much time do you spend on social media per day?

2. What electronic devices do you use to go on social media platforms (tablet, laptop, cell phone)?

Activity 1 – Navigating through Instagram

Task 1: From Instagram's feed to JIActiv's Instagram page

Please show me how you would go from your Instagram feed to JIActiv's Instagram page.

Pathway(s)	**Time to Completion**	**Success**	**Notes/Observations** (Why was the user successful or not)
USING A PHONE 1. Tap the magnifying glass 2. Tap the search bar 3. Write JIActiv 4. Tap the actiji-jiactiv icon	Time started: Time completed Total time to completion:	0 Not completed 1 Completed with difficulty or help 2 Easily completed	

USING A COMPUTER 1. Click the Search bar 2. Write JIActiv 3. Tap the actiji-jiactiv icon			

Task 2: Video

Please show me how you would go from JIActiv's Instagram page to the first english video of Week #3.

Pathway(s)	**Time to Completion**	**Success**	**Notes/Observations** (Why was the user successful or not)
USING A PHONE OR A COMPUTER 1. Scroll down to Week 3 2. Tap on the video titled *Physical Activity Opportunities*	Time started: Time completed Total time to completion:	0 Not completed 1 Completed with difficulty or help 2 Easily completed	

Task 3: Picture

Please show me how you would go from this video to the third English post of Week #3.

Pathway(s)	**Time to Completion**	**Success**	**Notes/Observations** (Why was the user successful or not)
USING A PHONE OR A COMPUTER 1. Scroll up 2. Tap on the picture titled *What physical activity would you like to try?* *USING A COMPUTER ONLY* 1. Click on the left arrow 4 times **Or** 1. Scroll up 2. Tap on the picture titled *What physical activity would you like to try?*	Time started: Time completed Total time to completion:	0 Not completed 1 Completed with difficulty or help 2 Easily completed	

Task 4: Physical Activity List

Please read the post description and show me how you would consult the physical activity list for your age group.

Note: the links to consult the PA list are in the highlights of the 3rd week (not in the post anymore)

Pathway(s)	**Time to Completion**	**Success**	**Notes/Observations** (Why was the user successful or not)
USING A PHONE 1. Copy the link. 2. Open an Internet application (safari, google chrome, firefox) 3. Paste the link into the search bar 4. Tap Seach USING A COMPUTER 1. Copy the link. 2. Open a new Internet tab	Time started: Time completed Total time to completion:	0 Not completed 1 Completed with difficulty or help 2 Easily completed	

3. Paste the link into the search bar 4. Press enter			

*Ask them to come back to the Instagram post before proceeding to Task #5.

Task 5: Highlights

Please go to the Week 3 Highlights and answer the question.

Pathway(s)	**Time to Completion**	**Success**	**Notes/Observations** (Why was the user successful or not)
USING A PHONE OR A COMPUTER 1. Scroll up 2. Tap on the Week 3 highlights 3. Tap on the first image 4. Tap the *Type something* icon 5. Type in answer	Time started: Time completed Total time to completion:	0 Not completed 1 Completed with difficulty or help 2 Easily completed	

6. Press the arrow on the bottom right corner to send the answer.			

Task 6: Private message

Please send a private message containing your favorite sport to the JIActiv Team.

Pathway(s)	**Time to Completion**	**Success**	**Notes/Observations** (Why was the user successful or not)
USING A PHONE OR A COMPUTER 1. Tap the *Message* button 2. Tap the Message bar 3. Type in answer 4. Tap the send button or enter button USING A PHONE	Time started: Time completed Total time to completion:	0 Not completed 1 Completed with difficulty or help 2 Easily completed	

1. Tap the house icon on the bottom left corner 2. Tap the arrow on the top right corner 3. Tap the Search bar 4. Type in JIActiv 5. Tap the actiji-jiactiv icon 6. Tap the Message bar 7. Type in answer 8. Tap the send button USING A COMPUTER 1. Click the arrow on the top right corner 2. Click the Search bar			

3. Type in JIActiv 4. Click the actiji-jiactiv icon 5. Click the Message bar 6. Click in answer 7. Click the send button or click enter			

<u>Activity 2 - Semi-structured interview</u>

For the second part of our meeting, I would like to ask you questions regarding the Instagram platform as well as the program's content. Would that be ok with you?

This is a judgment free zone so please answer as honestly as you can. Are you ready?

Privacy and safety

1. Do you have privacy concerns related to using or posting on the Instagram platform?

Probes: *Would you be concerned about your privacy when creating an Instagram acount in to participate to the JIActiv program? Would you be concerned about your privacy when posting pictures or videos of yourself on your personnal or on JIActiv's Instagram page?*

2. Do you have safety concerns related to the use of the Instagram platform features?

Probes: *Are you concerned about cyber bullying when posting comments on the JIActiv programs' posts? Are you concerned about cyber bullying when using the group messaging feature of the JIActiv program?*

Usability

1. Can you tell me what you liked best about JIActiv's Instagram page?

Probes: *For example, the layout, the aesthetics (colors, graphics), the variety of features (posts, stories/highlights, private and group messages)? Why did you like this aspect?*

2. Can you tell me what you liked the least about JIActiv's Instagram page?

Probes: *For example, the layout, the aesthetics (colors, graphics), the variety of features (posts, stories/highlights, private and group messages)? Why did you not like this aspect?*

3. Can you tell me about what you thought of the overall look of JIActiv's Instagram page and posts?

Probes: *For example, the design, colors and images used for the publications? Do you think the overall look of the Instagram page is visually appealing? What could make it more appealing?*****

4. Can you tell me how easy it was to find your way around JIActiv's Instagram page?

Probes: *What were the challenges of navigating through the site? What would make it easier to navigate through the site? Keep*

5. Can you tell me how easy it was to use the different features (posts, stories, highlights, group and private messages) of the Instagram page?

Probes: *What were the hardest features to use? What were the challenges of using these features? What would make it easier to use these features? Keep*

6. Can you tell me what you thought about how the information lay out on the JIActiv Instagram page?

How do you find the presentation of the information (Do you think the order of presentation of the themes is adequate?), the frequency of the posts and how do you find the duration of each post AND the program duration 8 weeks of information and 4 weeks only

How do you feel about the time required to complete one week? --> Are you satisfied with the time it takes to complete one week?

Probes: *Was the information on the private Instagram page clearly presented? Was it easy to read and understand? Keep*

7. If you could make any changes to JIActiv's Instagram page, what changes would you make?

Probes: *Can you tell me more about that? Keep*

1. Can you tell me what you thought about the quality of the information provided by the JIActiv program?

Probes: *How do you feel about the accuracy of the information? How do you feel about the trustworthiness of the information provided? What do you think about the amount of information that was provided? Was there any information that you thought should be on the site but was not there? Was the information provided helpful? Do you think this information would help you become active?*

2. Can you tell me what you thought about the different activities provided by the JIActiv program?

Probes: *For example, the informational videos and PowerPoints, the quizzes, the creation of your weekly schedule, the Pass the ball challenge, etc. Why did you like or dislike these activities?*

3. Can you tell me what you thought about the private and group messages used throughout the program? *In a hypothetical case, if you had to use it how would you have felt AND Would you use it?*

Probes: *Can you tell me more about that? Would you use the group message to interact with other participants? Why or why not?*

4. Would the JIActiv program motivate you to become more active daily?

Probes: *What part(s) of the program would motivate you to become active? What part(s) of the program would motivate you the least to become active?*

Future use of the JIActiv Program

1. If you were introduced to the JIActiv program, would you follow it in order to become more active?

Probes: *Why or why not? What would motivate you or demotivate you to follow it? Do you think the JIActiv program could help you to become more active?*

2. If your health care professional recommended you follow of the JIActiv program, would you follow it?

Probes: *Why or why not? What would motivate you or demotivate you to follow it? Do you think the JIActiv program could help you to become more active?*

3. Can you tell me about whether you think other teens or young adults with JIA would be interested in following the JIActiv program to learn how to become more physically active?

Probes: *Would you recommend the JIActiv program to a friend with JIA? Do you think the JIActiv program could help other teens or young adults become more active? Do you think they would follow this 12-week program?*

Other

Is there anything else you would like to tell us about the JIActiv program and it's Instagram page?

Probes: *Do you have any modification recommendations for the program's content or Instagram page? Can you tell me more about that?*

Appendix 3

Guide d'entrevue – Étude d'utilisabilité (ActiJI) (French version)

Introduction

Salut (insérer le prénom du participant)! Comment vas-tu?

Premièrement, merci d'avoir accepté de me rencontrer aujourd'hui. Je m'appelle (insérer le nom de l'évaluateur). Pour te mettre en contexte, ActiJI est un programme créé sur la plateforme Instagram. Son but est de motiver les adolescents et jeunes adultes atteints d'arthrite juvénile idiopathique à devenir plus actifs au quotidien.

Notre but est d'amener les jeunes atteints d'AJI à utiliser ce programme. Puisque tu es un (insérer «adolescent» ou «jeune adulte») atteint d'AJI, nous aimerions avoir ton point de vue d'expert pour améliorer le programme ActiJI.

Pour ce faire, notre rencontre va durer environ 60-90 minutes et sera divisée en deux parties. Premièrement, je vais t'inviter à naviguer sur Instagram afin d'avoir ton opinion sur la facilité d'utilisation de la plateforme. Ensuite, je vais te poser des questions afin de comprendre ce que tu as aimé et moins aimé du programme. Est-ce que ce déroulement te convient?

Saches que nous sommes dans un environnement sans jugement. Donc, au cours de notre rencontre :

- N'hésite pas à me dire si tu as des idées sur comment améliorer le programme.
- N'hésite pas à me demander des questions à tout moment si quelque chose n'est pas clair pour toi.

Avant de commencer la première activité, j'aimerais te poser quelques questions en lien avec ton utilisation quotidienne des réseaux sociaux.

1. Utilises-tu des réseaux sociaux?
    a. Si oui, lesquels utilises-tu (Facebook, Instagram, Tiktok, Snapchat, etc.)?
    b. À quelle fréquence utilises-tu tes réseaux sociaux (quelques fois par heure, toutes les quelques heures, quelques fois par jour, seulement quand tu reçois des notifications, etc.)
    c. En moyenne, combien de temps passes-tu sur les réseaux sociaux par jour?

2. Quel(s) appareil(s) électronique utilises-tu pour aller sur tes réseaux sociaux (tablette, ordinateur portable, cellulaire)?

Activité 1 – Naviguer sur Instagram

Tâche 1: Du flux Instagram à la page Instgram de JIActiv

Veuillez me montrer comment vous passeriez de votre flux Instagram à la page Instagram de JIActiv.

Chemin(s)	**Temps requis pour compléter la tâche**	**Niveau de succès**	**Notes et observations** (Pourquoi l'utilisateur a-t-il réussi ou non?)
USAGE D'UN TÉLÉPHONE 1. Appuyer sur la loupe 2. Appuyer sur la barre de recherche.	Heure de début de la tâche: Heure à laquelle la tâche est terminée :	0 Non complétée 1 Complétée avec difficulté ou avec aide 2	

3. Écrire JIActiv 4. Appuyer sur l'icône actiji-jiactiv. USAGE D'UN ORDINATEUR 1. Cliquer sur la barre de recherche. 2. Écrire JIActiv 3. Appuyer sur l'icône actiji-jiactiv.	Temps total requis pour compléter la tâche:	Aisément complété	

Tâche 2 : Vidéo

Montrez-moi comment vous passeriez de la page Instagram de JIActiv à la première vidéo en français de la semaine 3.

Chemin(s)	**Temps requis pour compléter la tâche**	**Niveau de succès**	**Notes et observations** (Pourquoi l'utilisateur a-t-il réussi ou non?)
À L'AIDE D'UN TÉLÉPHONE OU	Heure de début de la tâche:	0 Non complétée	

D'UN ORDINATEUR 1. Défiler jusqu'à la semaine 3 2. Appuyer sur la vidéo intitulée *Les opportunités d'activité physique*	Heure à laquelle la tâche est terminée : Temps total requis pour compléter la tâche:	1 Complétée avec difficulté ou avec aide 2 Aisément complété	

Tâche 3 : Image

Veuillez me montrer comment vous passeriez de cette vidéo au troisième article en français de la semaine 3.

Chemin(s)	**Temps requis pour compléter la tâche**	**Niveau de succès**	**Notes et observations** (Pourquoi l'utilisateur a-t-il réussi ou non?)
À L'AIDE D'UN TÉLÉPHONE OU D'UN ORDINATEUR 1. Défiler vers le haut 2. Appuyer sur l'image intitulée *Quelle activités*	Heure de début de la tâche: Heure à laquelle la tâche est terminée : Temps total requis pour compléter la tâche:	0 Non complétée 1 Complétée avec difficulté ou avec aide 2 Aisément complété	

physique aimerais-tu essayer? USAGE DE L'ORDINATEUR SEULEMENT 1. Cliquer 4 fois sur la flèche gauche **Ou** 1. Défiler vers le haut 2. Appuyer sur l'image intitulée *Quelle activités physique aimerais-tu essayer?*			

Tâche 4: Liste d'Activité Physique

Veuillez lire la description de l'article et me montrer comment vous consulteriez la liste d'activité physique pour votre groupe d'âge.

Note: les liens ont été ajoutés en story et ne sont plus sur le post

Chemin(s)	**Temps requis pour compléter la tâche**	**Niveau de succès**	**Notes et observations** (Pourquoi l'utilisateur a-t-il réussi ou non?)

USAGE D'UN TÉLÉPHONE 1. Copier le lien. 2. Ouvrer une application Internet (safari, google chrome, firefox) 3. Coller le lien dans la barre de recherche. 4. Appuyer sur Recherche. USAGE D'UN ORDINATEUR 1. Copier le lien. 2. Ouvrir un nouvel onglet Internet 3. Collez le lien dans la barre de recherche. 4. Appuyer sur Entrée.	Heure de début de la tâche: Heure à laquelle la tâche est terminée : Temps total requis pour compléter la tâche:	0 Non complétée 1 Complétée avec difficulté ou avec aide 2 Aisément complété	

* Demandez au participant de revenir à la publication sur Instagram avant de passer à la tâche 5..

Tâche 5: « Highlights »/ Élément en vedette

Veuillez consulter les « highlights »/ élément en vedette de la semaine 3 et répondre à la question.

Chemin(s)	**Temps requis pour compléter la tâche**	**Niveau de succès**	**Notes et observations** (Pourquoi l'utilisateur a-t-il réussi ou non?)
USING A PHONE OR A COMPUTER 1. Défiler vers le haut 2. Appuyer sur les éléments en vedette de la semaine 3 3. Appuyer sur la première image 4. Appuyez sur l'icône Envoyez un message… . 5. Entrer la réponse. 6. Appuyer sur la flèche dans le coin inférieur droit pour envoyer la réponse.	Heure de début de la tâche: Heure à laquelle la tâche est terminée : Temps total requis pour compléter la tâche:	0 Non complétée 1 Complétée avec difficulté ou avec aide 2 Aisément complété	

Task 6: Message privé

Veuillez envoyer un message privé contenant votre sport préféré à l'équipe JIActiv.

Chemin(s)	**Temps requis pour compléter la tâche**	**Niveau de succès**	**Notes et observations** (Pourquoi l'utilisateur a-t-il réussi ou non?)
USAGE D'UN TÉLÉPHONE 1. Appuyer sur l'icône de la maison dans le coin inférieur gauche. 2. Appuyer sur la flèche dans le coin supérieur droit. 3. Appuyer sur la barre de recherche 4. Saisir JIActiv 5. Appuyer sur l'icône actiji-jiactiv. 6. Appuyer sur la barre de messages. 7. Entrer la réponse.	Heure de début de la tâche: Heure à laquelle la tâche est terminée : Temps total requis pour compléter la tâche:	0 Non complétée 1 Complétée avec difficulté ou avec aide 2 Aisément complété	

8. Appuyer sur le bouton Envoyer. USAGE D'UN ORDINATEUR 1. Cliquer sur la flèche dans le coin supérieur droit. 2. Cliquer sur la barre de recherche 3. Saisir JIActiv 4. Cliquer sur l'icône actiji-jiactiv 5. Cliquer sur la barre de messages. 6. Entrer la réponse 7. Cliquer sur le bouton Envoyer ou cliquez sur Entrée.			

Activité 2 – Entrevue semi-structurée

Pour la deuxième partie de la rencontre, j'aimerais te poser des questions en lien avec la plateforme Instagram ainsi que le contenu du programme.

Comme j'ai dit au début, nous sommes dans un environnement sans jugement alors réponds de la manière la plus honnête possible. Es-tu prêt?

Confidentialité

1. As-tu des préoccupations de confidentialité liés à l'utilisation de la plateforme Instagram?

Sondes : *Serais-tu préoccupé par la confidentialité de tes informations personnelle si tu devais te créer un compte Instagram pour participer au programme ActiJI? Serais-tu préoccupé par la confidentialité de tes informations personnelle si tu devais publier des photos ou des vidéos de toi sur ta page personnelle ou sur la page du programme ActiJI?*

2. As-tu des préoccupations de confidentialité liés à l'utilisation de diverses fonctionnalités de la plateforme Instagram?

Sondes : *Serais-tu préoccupé par le risque de cyber intimidation si tu devais publier des commentaires sur des publications dans le cadre du programme ActiJI? Serais-tu préoccupé par le risque de cyber intimidation si tu devais utiliser la fonction de messagerie de groupe dans le cadre du programme ActiJI?*

Utilisabilité

1. Peux-tu me décrire les aspects de la page Instagram d'ActiJI que tu as préféré?

Sondes : *Par exemple, la mise en page, l'esthétique (couleurs, graphismes), la variété des fonctionnalités (publications, stories/highlights, messagerie privée et de groupe)? Pourquoi as-tu aimé ces aspects?*

2. Peux-tu de décrire les aspects de la page Instagram d'ActiJI que tu as moins aimé?

Sondes : *Par exemple, la mise en page, l'esthétique (couleurs, graphismes), la variété des fonctionnalités (publications, stories/highlights, messagerie privée et de groupe)? Pourquoi n'as-tu pas aimé ces aspects?*

3. Peux-tu me décrire ce que tu as pensé de l'apparence générale des publications et de la page Instagram d'ActiJI?

Sondes : *Par exemple, le design, les couleurs et les images des publications? Penses-tu que l'apparence générale de la page Instagram est attrayante? Qu'est-ce qui pourrait la rendre plus attrayante?*

4. Peux-tu me décrire à quel point il a été facile ou difficile de se repérer sur la page Instagram d'ActiJI?

Sondes : *Quels ont été tes plus grands défis lorsque tu naviguais sur la page Instagram d'ActiJI? Qu'est-ce qui faciliterait la navigation sur la page Instagram d'ActiJI?*

5. Peux-tu me décrire à quel point il était facile ou difficile d'utiliser les différentes fonctionnalités de la page Instagram?

Sondes : Par exemple, *publications, stories/highlights, messagerie privée et de groupe? Qu'elles ont été les fonctionnalités les plus difficiles à utiliser? Quels ont été les défis liés à l'utilisation de ces fonctionnalités? Qu'est-ce qui faciliterait l'utilisation de ces fonctionnalités?*

6. Peux-tu me décrire ce que tu as pensé de la présentation des informations sur la page Instagram du programme ActiJI?

Comment vous trouvez la présentation des informations (L'ordre de présentation des thèmes trouvez-vous ça adéquat?), la fréquence des posts et comment trouvez-vous la durée de chaque post ET la durée programme 8 semaines d'information et 4 semaines seule

Que pensez-vous du temps nécessaire pour terminer une semaine? --> Êtes-vous satisfait du temps qu'il faut pour terminer une semaine?

Sonde : *Les informations sur la page Instagram étaient-elles clairement présentées? Les informations étaient-elles faciles à lire et à comprendre?*

7. Si vous pouviez apporter des modifications à la page Instagram d'ActiJI, quelles seraient-elles?

Sondes : *Pourriez-vous m'en dire plus à ce sujet?*

1. Peux-tu me décrire ce que tu as pensé de la qualité des informations fournies par le programme ActiJI?

Sondes : *Que penses-tu de l'exactitude de l'information? Que penses-tu de la fiabilité de l'information? Que penses-tu de la quantité de l'information fournie? Y avait-il des informations que vous pensiez retrouver dans le programme mais qui n'y étaient pas? Les informations fournies ont-elles été utiles? Penses-tu que cette information t'aiderait à devenir plus actif?*

2. Peux-tu me décrire ce que tu as pensé des activités proposées par le programme ActiJI?

Sondes : *Par exemple, les vidéos et Powerpoint informatifs, les quizz, la création d'emploi du temps, le défi Passe la balle, etc. Pourquoi as-tu apprécié ou non ces activités?*

3. Peux-tu me décrire ce que tu as pensé des messages privés et de groupe utilisé tout au long du programme? *Dans un cas hypothétique, si tu avais à l'utiliser comment te serais-tu senti ET l'utiliserais-tu ?*

Sondes : *Peux-tu m'en dire plus à ce sujet? Utiliserais-tu la messagerie de groupe pour interagir avec d'autres participants? Pourquoi?*

4. Est-ce que le programme ActiJI te motiverais à devenir plus actif au quotidien?

Sondes : *Quelle(s) partie(s) du programme t'inciteraient à devenir plus actif? Quelle(s) partie(s) du programme te motiveraient le moins à être plus actif? Pourquoi?*

Utilisation future du programme

1. Si on te présentait le programme ActiJI, le suivrais-tu afin de devenir plus actif?

Sondes : *Pourquoi? Qu'est-ce qui te motiverais ou démotiverais à le compléter? Penses-tu que le programme t'aiderait à devenir plus actif au quotidien?*

2. Si un professionnel de la santé te recommandait de suivre le programme ActiJI, est-ce que tu le compléterait?

Sondes : *Pourquoi? Qu'est-ce qui te motiverais ou démotiverais à le compléter? Penses-tu que le programme t'aiderait à devenir plus actif au quotidien?*

3. Penses-tu que d'autres jeunes atteints d'AJI seraient intéressés à suivre le programme ActiJI pour apprendre à devenir plus actifs de manière sécuritaire?

Sondes : *Recommanderais-tu le programme ActiJI à un ami atteint d'AJI? Penses-tu que le programme ActiJI pourrait aider d'autres jeunes atteints d'AJI à devenir plus actifs? Penses-tu qu'ils suivraient ce programme de 12 semaines?*

Autres

Y a-t-il autre chose que tu aimerais me dire à propos du programme ActiJI et s page Instagram?

Sonde : *As-tu des recommandations de modifications à apporter au programme ou à la page Instagram? Peux-tu m'en dire plus à ce sujet?*

Appendix 4

Introduction email (English and French version)

Introduction email – Usability study (JIActiv)

Hi (insert participant's name),

Thank you very much for your interest in participating to our research project titled "Promoting engagement in physical activity among young people with juvenile idiopathic arthritis: Development of a social network-based intervention".

As mentioned, JIActiv is an Instagram-based intervention aimed at promoting physical activity among young people living with JIA. We would like to hear your thoughts on the programs Instagram page and content. Your opinion will help us improve the program in order to better promote physical activity amongst young people living with JIA.

Study participation includes:

- A review of the content included in themes 2 and 4 of the JIActiv Program. It is encouraged that you go through as many themes as possible before completing the questionnaire and the interview.
- One 15-minute questionnaire to complete at home.
- One 60 to 90-minute interview on the Zoom platform.

If you participate, you will receive compensation in the form of a gift certificate.

A consent form is attached to this email. Please take the time to read it and do not hesitate to contact me if you have any questions.

If you agree to participate in this research project, please return the signed consent form to this email address along with your availabilities for the next X weeks. That way, we can schedule our meeting.

Thank you very much and have a great day,

Signature

Courriel d'introduction - Étude d'utilisabilité (ActiJI)

Bonjour (insérer le nom du participant),

Merci beaucoup pour votre intérêt à participer à notre projet de recherche intitulé « Promouvoir l'engagement dans l'activité physique chez les jeunes atteints d'arthrite juvénile idiopathique : développement d'une intervention sur les réseaux sociaux ».

Comme nous l'avons mentionné, ActiJI est un programme basé sur Instagram visant à promouvoir la pratique d'activité physique chez les jeunes atteints d'AJI. Nous aimerions entendre votre opinion sur la page Instagram ainsi que le contenu du programme. Votre participation nous aidera à bonifier le programme afin d'améliorer la promotion de l'activité physique chez les jeunes atteints d'AJI.

La participation à ce projet de recherche comprend :

- Un examen du contenu des thèmes 2 et 4 du programme ActiJI. Nous vous encourageons à passer en revue autant de thèmes que possible avant de remplir le questionnaire et l'entrevue.
- Un questionnaire d'environ 15 minutes à compléter à la maison.
- Une entrevue d'environ 60 à 90 minutes sur la plateforme Zoom.

Si vous participez, vous recevrez une indemnité sous forme d'un certificat cadeau.

Nous avons joint le formulaire de consentement à ce courriel. Prenez le temps de le lire et n'hésitez pas à nous contacter si vous avez des questions.

Si vous acceptez de participer, S.V.P renvoyer le formulaire signé à cette adresse courriel ainsi que vos disponibilités au cours des X prochaines semaines afin que nous puissions planifier l'entrevue.

Merci et bonne journée,

Signature

Appendix 5

The Sociodemographic Questionnaire(English and French version)

Initials: _____ **Date**: _____

Socio-demographic and Medical Information Questionnaire

This questionnaire will take approximately 5 minutes to fill out. Feel free to ask your parent or caregiver for help.

Socio-demographic Information

1. **What is your date of birth (dd/mm/yyyy)?**

2. **What gender do you identify as?**
   a. Female
   b. Male
   c. Other, please specify:

3. **What city and province do you currently live in?**

4. **What are the first 3 characters of your postal code?**

Medical Information

1. **How old were you when you got diagnosed with juvenile idiopathic arthritis?**

2. **What type of juvenile idiopathic arthritis are you currently diagnosed with?**
    a. Oligoarthritis
    b. Polyarthritis Rheumatoid Factor positive arthritis (RF)+
    c. Polyarthritis Rheumatoid Factor negative arthritis (RF) –
    d. Psoriatic juvenile arthritis
    e. Systemic juvenile arthritis
    f. Enthesitis-related arthritis
    g. Another type of arthritis or joint problem.
    h. Please specify:_____
    h. Unsure

3. **Do you have active inflammation in at least one joint?**
    a. Yes
    b. No

If so, how many of your joints are inflamed? _____

4. **Where are you followed for your juvenile idiopathic arthritis (Name and type of institution)?** *For example, Sainte-Justine's Hospital, Montréal, Québec*

5. **Are you currently followed by a rheumatologist?**
    a. Yes
    b. No

If so, how often do you have appointments with your rheumatologist:
    a. Once a month
    b. Once every 3 months
    c. Two times a year
    d. Once a year

6. **Are you followed by other health care professionals (nurse, psychologist, occupational therapist, physiotherapist, etc.)?**
    a. Yes
    b. No

7. **What is the name of the medication(s) you are taking?**
    a. Methotrexate
    b. Non-steroidal anti-inflammatory drug
    c. Sulfasalazine
    d. Intra-articular injections
    e. Biological agents

8. **What other medication(s) are you currently taking?**

Initiales: _____ **Date**: _____

Questionnaire sociodémographique et d'information médicales

Ce questionnaire vous prendra environ 5 minutes à compléter. N'hésitez pas à demander l'aide de votre parent ou proche aidant.

Information sociodémographique

1. **Quelle est votre date de naissance (jj/mm/aaaa)?**

2. **A quel genre vous identifiez vous?**
   a. Femme
   b. Homme
   c. Autre, veuillez spécifier:

3. **Dans quelle ville et province vivez-vous?**

4. **Quel(s) sont les trois premiers caractères de votre code postal?**

Information médicale

1. **A quel âge avez-vous reçu votre diagnostic d'arthrite juvénile idiopathique**?

2. **Quel type d'arthrite juvénile idiopathique avez-vous présentement?**
   a. Forme oligoarticulaire
   b. Forme polyarticulaire facteur rhumatoïde positif (FR+)
   c. Forme polyarticulaire facteur rhumatoïde négatif (FR-)
   d. Forme psoriasique
   e. Forme systémique
   f. Enthésite avec arthrite
   g. Autre type d'arthrite ou problème articulaire. Veuillez spécifier:_____
   h. Incertain.e

3. **Est-ce que vous avez de l'inflammation dans au moins une de vos articulations?**
   a. Oui
   b. Non

Si oui, combien de vos articulations sont enflammées? _____

4. **À quel endroit est-ce que vous êtes suivis pour votre arthrite juvénile idiopathique (Nom et type d'institution)?** *Par exemple: Hôpital Sainte-Justine, Montréal, Québec*

5. **Êtes-vous suivi par un rhumatologue?**
   a. Oui
   b. Non

Si oui, à quelle fréquence êtes-vous suivis par votre rhumatologue?
   a. 1 fois par mois
   b. 1 fois aux 3 mois

c. 2 fois par année
d. 1 fois par année

6. **Êtes-vous suivi par un ou plusieurs autres professionnels de la santé (infirmière, psychologue, ergothérapeute, physiothérapeute, etc.)?**
   a. Oui
   b. Non

7. **Quel(s) médicament(s) vous a été prescris?**
   a. Méthotrexate
   b. Anti-inflammatoire non-stéroide
   c. Sulfasalazine
   d. Injection intra-articulaire
   e. Agents biologiques

8. **Quel(s) autre(s) médicament(s) prenez-vous présentement?**

Appendix 6

The screenshots of the Instagram-based JIActiv program

Group messages

Private messages