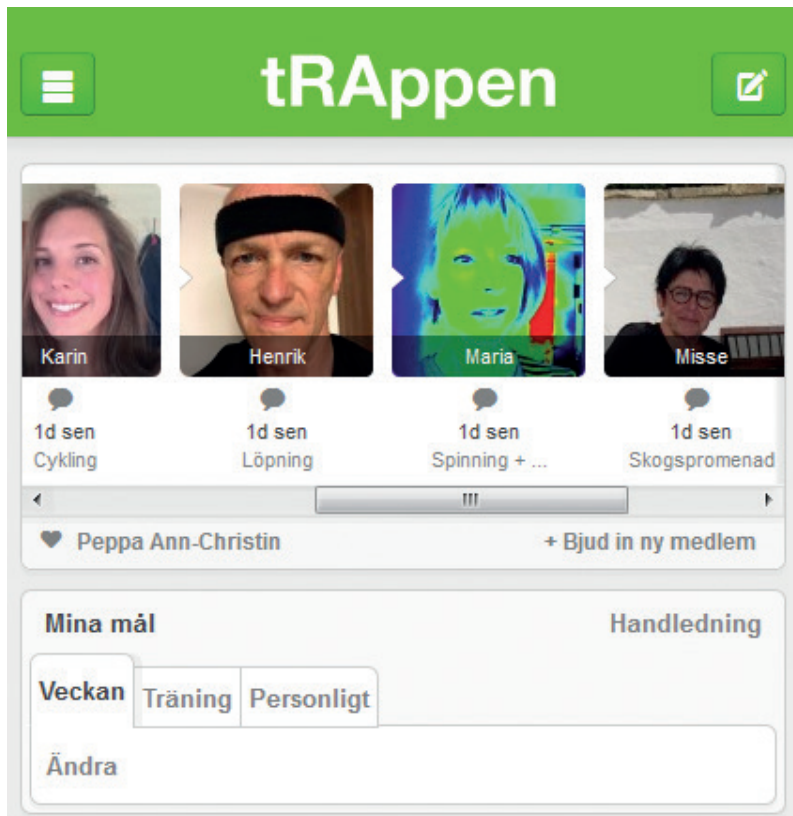


# Co-designing a mobile Internet service for self-management of physical activity in rheumatoid arthritis



Åsa Revenäs



**Karolinska  
Institutet**

A screen shot of the mHealth service tRAppen.

From THE DEPARTMENT OF NEUROBIOLOGY, CARE  
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# **CO-DESIGNING A MOBILE INTERNET SERVICE FOR SELF-MANAGEMENT OF PHYSICAL ACTIVITY IN RHEUMATOID ARTHRITIS**

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# CO-DESIGNING A MOBILE INTERNET SERVICE FOR SELF-MANAGEMENT OF PHYSICAL ACTIVITY IN RHEUMATOID ARTHRITIS

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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## ABSTRACT

**Aim:** The overall aim of the thesis was to describe and evaluate the content and outcome of co-designing a mobile Internet service for self-management of physical activity in rheumatoid arthritis (RA) with active lead user involvement, within the action research paradigm.

**Context:** Physical activity is known for its health benefits. However, maintaining a physically active lifestyle is a great challenge for most people, and maybe even more so for people living with RA. IT and mobile phones provide additional means to deliver health care services, i.e. mHealth, for physical activity self-management. Further, involvement of lead users in the development of services has been reported to improve their usability and effectiveness.

**Process:** In the first phase of the co-design process, six focus group interviews were performed with lead users (n=26) to explore their ideas on core features (Study I). In the next phase, four workshops were conducted, which included lead users, clinical and researcher physiotherapists, an eHealth strategist and an officer from the Swedish Rheumatism Association (n=10). The aim was to specify the system requirements of the future service (Study II and III). Video recordings, natural observations, prototypes of the future service and an online notice board were used to collect data on the requirements and challenges of co-design. In the third phase, the first test version of the service was produced and evaluated in terms of the participants' utilization of and experiences with the service (Study IV). Log-data were collected during the six week test period. Web questionnaires were sent out to and telephone interviews were performed with the participants after the test period.

**Content:** Four core aspects that are important to consider in the development of the mHealth service were identified: features, customized options, user interface, and access and implementation (result Study I). To produce the requirements specification, the participants had to merge their different perspectives, which was the core challenge of co-design (Study II). The merging resulted in "tRAppen", an mHealth service for maintenance of physical activity. tRAppen included two key components: 1) "My self-regulation features" and 2) "My peer support features" (result Study III). The first test version of tRAppen included 22 different behavior change techniques.

**Outcome:** Twenty-eight participants tested tRAppen (result Study IV). Most participants registered physical activity, sent likes and made an exercise plan. tRAppen was generally rated as easy and fun to use, and all participants would recommend it to other people. The results also described the experiences of using tRAppen as being influenced by physical and mental state and personal preferences.

**Conclusions:** The use of co-design in the development of the physical activity self-management service tRAppen was successful. The first test version of tRAppen was perceived as feasible and to have the potential to support a physically active lifestyle in people with RA. Co-design in collaborative workshops was an extensive decision-making process that put high demands on the participants' ability to find solutions, negotiate, come to agreements and reach final decisions.

## SVENSK SAMMANFATTNING

**Syftet:** Det övergripande syftet med denna avhandling var att beskriva och utvärdera resultatet av samskapandet av en mobilanpassad internetjänst för egenvård av fysisk aktivitet vid reumatoid artrit (RA), med aktiv användarmedverkan och aktionsforskning.

**Kontexten:** Att bibehålla en fysiskt aktiv livsstil är en utmaning för de flesta människor trots vetskapen om att fysisk aktivitet bidrar till bättre hälsa. Kanske är utmaningen ännu större om man lever med en kronisk sjukdom såsom RA. IT och mobiltelefoner ger nya möjligheter för hälso- och sjukvården att leverera så kallade egenvårdstjänster. Tidigare forskning har visat att involvering av de framtida användarna i utveckling av tjänster förbättrar tjänsternas användbarhet och effektivitet. I det aktuella projektet användes principer för erfarenhetsbaserat samskapande för att utveckla en mobilanpassad internetjänst, mHälsotjänst, för egenvård av fysisk aktivitet.

**Processen:** I den första fasen av utvecklingsprocessen genomfördes sex fokusgruppintervjuer med personer med RA (n=26). Syftet var att utforska deltagarnas idéer om viktiga funktioner i den framtida tjänsten (Studie I). I nästa fas genomfördes fyra workshoppar med personer med diagnosticerad RA tillsammans med forskare och kliniskt arbetande fysioterapeuter, en eHälsostrateg och en representant från Reumatikerförbundet (n=10), med syftet att kravspecificera tjänsten och att beskriva samskapandet (Studie II och III). Data samlades in med hjälp av videoinspelningar, observationer, prototyper av den framtida tjänsten och en online-anslagstavla. I den tredje fasen testades den första versionen av tjänsten (n=28) (Studie IV). Loggdata samlades in under testperioden. En webbenkät skickades ut och telefonintervjuer genomfördes efter den sex veckor långa testperioden.

**Innehållet:** Fyra aspekter som ansågs viktiga att ta hänsyn till under utvecklingen av tjänsten identifierades: funktioner, användarinställningar, användargränssnitt, och tillgång och spridning (Studie I). För att kunna kravspecificera tjänsten var workshopdeltagarna tvungna att föra samman och förena sina perspektiv samt att hitta lösningar och ta beslut. Att förena olika perspektiv var centralt och kännetecknande för samskapandet och en nödvändighet för att föra processen framåt (resultat Studie II). Resultatet blev "tRAppen", en mHälsotjänst för bibehållandet av fysisk aktivitet vid RA. tRAppen innehöll två huvudkomponenter: 1) "Mina självregleringsverktyg" och 2) "Min grupp" (resultat Studie III). Den första tesversionen av tRAppen innehöll 22 olika beteendeförändringstekniker.

**Utvärderingen:** Tjugoåtta personer med RA testade tRAppen. De flesta deltagare registrerade fysisk aktivitet, skickade "likes" och gjorde en aktivitetsplan. tRAppen upplevdes lätt och rolig att använda, och alla deltagare skulle rekommendera den till andra. Resultatet visade också att deltagarnas fysiska och psykiska hälsa och personliga preferenser påverkade upplevelsen av tRAppen (resultat Studie IV).

**Konklusioner:** Samskapande var en fungerande och konstruktiv metod för att utveckla en mHälsotjänst för bibehållande av fysisk aktivitet. tRAppen ansågs vara användbar och ha potential att underlätta en fysiskt aktiv livsstil hos personer med RA. Att samskapa i workshoppar, inkluderat olika experter, var en omfattande beslutsprocess som ställde stora krav på deltagarnas förmåga att förena och föra samman sina olika perspektiv.



## LIST OF SCIENTIFIC PAPERS

This thesis is based on the following original papers. Each paper will be referred to by its Roman numerals (Study I-IV):

- I. Revenäs Å, Opava C, Åsenlöf P. Lead users' ideas on core features to support physical activity in rheumatoid arthritis: a first step in the development of an Internet service using participatory design. *BMC Med Inform Decis Mak* 2014;14(21)
- II. Revenäs Å, Martin C, Opava H. C, Bruzewitz M, Keller C, Åsenlöf P. A Mobile Internet Service for Self-Management of Physical Activity in People with Rheumatoid Arthritis: Challenges in Advancing the Co-Design Process During the Requirements Specification Phase. *JMIR Res Protoc* 2015; 4(3):e111
- III. Revenäs Å, Opava H. C, Martin C, Demmelmaier I, Keller C, Åsenlöf P. Development of a Web-Based and Mobile App to Support Self-management of Physical Activity in Individuals with Rheumatoid Arthritis: Results From the Second Step of a Co-Design Process. *JMIR Res Protoc* 2015;4(1):e22
- IV. Revenäs Å, Opava H. C, Ahlén H, Bruzewitz M, Pettersson S, Åsenlöf P. A mobile Internet service for self-management of physical activity in people with rheumatoid arthritis. Evaluation of a test version. Submitted manuscript

All previously published papers are open access. As well as the above papers, the thesis includes additional results that have not previously been published.

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## LIST OF ABBREVIATIONS

ASMP	Arthritis Self-Management Program
IT	Information Technology
RA	Rheumatoid Arthritis
SCT	Social Cognitive Theory
SRA	Swedish Rheumatism Association
TTM	The Transtheoretical Constructs of Stages and Process of Change
WHO	World Health Organization

# 1 PREFACE

When I in my early twenties chose university education, I had the choice between graduate engineer and physiotherapy. I decided on physiotherapy. I wanted to work with people and I remember visualizing myself helping people to recover from injuries and illnesses. I have not regretted that choice.

As a clinical physiotherapist, you work together with others. You meet a lot of people, you listen to their stories and experiences, try to understand what causes the problems, and guide them to recovery. Physiotherapy also has a clear connection between theory and practice, which for me is an important part of learning.

I am also the kind of person that gets bored if life is too much the same. I need challenges and changes in life now and then, and I have challenged myself in different ways through life both in my academic and private life, and mentally as well as physically.

Physical activity is an important part of my life. It improves my physical and mental wellbeing. I believe that everyday physical activity is of major importance to improve public health. Working within this area is interesting, and feels important and meaningful.

Another important part of my life is my family. My family gives me love, joy, happiness, inspiration, activity, safety, and also many challenges. They give me a sense of belonging and coherence, which is an essential part of life.

This project has provided me with many of these things: collaboration, a great challenge, theory and practice, and coherence. I have enjoyed working with all of you that in different ways have been involved in this project. I hope the project will contribute to a better understanding of mHealth services as support for physical activity maintenance and hence, to improved health in people with RA.



## 2 INTRODUCTION AND RATIONALE

It is not always easy to be physically active in modern society. Our way of living has removed most everyday physical activities. Consequently, most people are not physically active enough even though knowledge about the benefits of physical activity is well established [1 ,2]. If you are living with a chronic disease such as rheumatoid arthritis (RA), the challenge may be even greater since the disease itself leads to additional barriers to engagement in physical activity.

Rheumatology care has changed dramatically over the last few decades: more effective pharmacological treatments have improved the health of many people with RA [3] and the evidence for the benefits and safety of physical activity is today well documented [4]. Additionally, the rapid expansion of IT has made information available for people in the community. Thus, rheumatology care would benefit from developing treatment strategies that fit modern society and the RA population.

IT, including the Internet and mobile phones, provides additional means to deliver self-management services into peoples' everyday lives [5 ,6]. Self-management also provides the opportunity for community members to be actively involved in their own health care, which is an important goal for Swedish health care [7]. To the best of my knowledge, there is no RA-specific self-management mHealth service that focuses on the maintenance of physical activity.

This thesis embraces a bio-psycho-social perspective on human beings and human behavior. The assumption is that human behavior is complex and is determined by physiological, psychological, and environmental factors [8-10]. This perspective acknowledges a person's autonomy and ability to change or maintain a behavior and emphasizes the importance of considering and understanding a person's individual needs, experiences and preferences in providing optimal care. By involving people who live with RA, i.e. lead users, as co-designers of an mHealth service, it is possible to incorporate their preferences and experiential knowledge into the service and, hence, optimize the services.

This thesis described and evaluated the content and outcome of co-designing a mobile Internet service for self-management of physical activity in people with RA. To describe and evaluate the process the Pettigrew and Whipps' model of managing organizational change was used [11]. The model also provides a structure for this thesis. According to the model three elements are essential for the outcome: context, process and content. Context answers the question *why* it is important for people with RA to self-manage physical activity. The context also describes the potential of the IT and mobile phones and the value of lead user involvement in developing health care services. Finally, the need is described for different research paradigms and designs to study the development process. Process answers the question *how* the co-design process was performed and provides a description of the procedures and research methods used. Content is defined as the answer to the question *what* service was developed and provides a description of the service and how it evolved during the process (result Study I and III). Content also provides a description of the challenges of co-designing (result Study II). Outcome presents the results from the first

evaluation of the mobile Internet service in terms of its feasibility and support for physical activity (result Study IV). Finally, a section with general discussions and conclusions is provided.



### **3 AIMS**

The overall aim of the thesis was to describe and evaluate the content and outcome of co-designing a mobile Internet service for self-management of physical activity in RA with active lead user involvement, within the action research paradigm.

Specific aims of the thesis were:

1. To describe the challenges deemed important for advancing the co-design process during the requirements specification of the mobile Internet service (content).
3. To describe the features included in the mobile Internet service as they evolved during the process (content).
4. To describe the results from the evaluation of the test version of the mobile Internet service in terms of the participants' utilization of and experiences with the service (outcome).



## 4 CONTEXT

### 4.1 PHYSICAL ACTIVITY – A PUBLIC HEALTH CHALLENGE

Physical activity is known for its health benefits. It reduces the risk for cardiovascular disease, hypertension, diabetes and certain forms of cancer, and has a positive effect on mental health [1 ,2]. Physical activity also has an important role in the management of certain chronic diseases, such as rheumatoid arthritis (RA) [12].

Despite these apparent benefits there is a worldwide trend towards a less physically active lifestyle in sub-groups of the population [2]. Recent EU statistics indicate that more than half of the population over the age of 15 years never or seldom engage in physical activity such as cycling, dancing or gardening [2]. Further, people with disabilities report a more sedentary lifestyle than the general population and have an elevated risk for health problems associated with physical inactivity [1 ,2]. Consequently, increasing the level of everyday physical activity is a leading strategy to improve health in these sub-groups.

The World Health Organization (WHO) has formulated a strategy for the WHO European region with the aim of inspiring governments to work towards increasing the level of physical activity [2]. The importance of adapting physical activity interventions to the specific needs of different sub-groups is emphasized. Substantial suffering, poor health, medical costs and health care utilization may be avoided with a physically active lifestyle. However, maintaining a physically active lifestyle is a challenge for most people, and maybe even more so for people living with a chronic condition such as RA.

### 4.2 DEFINITIONS OF AND RECOMMENDATIONS FOR PHYSICAL ACTIVITY

Physical activity is defined as “any bodily movement produced by skeletal muscles resulting in energy expenditure” [13]. The concept of physical activity can be categorized into occupational, sports, household, or other activities. Exercise is a subset of physical activity that is planned, structured, and repetitive and that aims to improve or maintain physical fitness. Physical fitness is attributes that a person has or achieves, e.g. cardiorespiratory endurance, muscular strength and flexibility.

There are several recommendations available regarding physical activity for health or fitness. The recommendations used in this thesis are published by the American College of Sports Medicine and American Heart Association [14].

To maintain or improve health, adults are recommended to perform:

- Moderate-intensity aerobic (endurance) physical activity for a minimum of 30 minutes on at least five days each week OR vigorous-intensity aerobic physical activity for a minimum of 20 minutes on at least three days each week. The 30 minutes of moderate-intensity aerobic physical activity could be accumulated in several bouts of a minimum of 10 minutes each. Moderate-intensity aerobic activity causes noticeable acceleration of the heart rate, and can be achieved through, for

example, a brisk walk. Vigorous-intensity activity is, for example, jogging, causing rapid breathing and a substantial increase in heart rate.

AND

- Muscle strength exercises at least two days a week to maintain or increase muscular strength. Eight to ten exercises is recommended with 8-12 repetitions of each exercise. To maximize strength development, a resistance/weight should be used. Other muscle-strengthening activities include progressive weight-training programs, stair climbing, and similar resistance exercises that use the major muscle groups.

For older adults (>65 years), and for people with chronic conditions and/or functional limitation, the importance of the following is also emphasized [15]:

- The individual's aerobic fitness level should be taken into account in recommended aerobic intensity
- Mobility exercises that maintain or improve flexibility
- Balance exercises to maintain or improve balance for people with risk of falls
- An activity plan for achieving the intended physical activities

### **4.3 RHEUMATOID ARTHRITIS**

RA is a chronic, systemic autoimmune and progressive inflammatory disease mainly affecting the joints. The global prevalence of RA is 0.24% [16]. The estimated prevalence of the disease in Sweden is 0.77% [17]. The disease affects women more than men and is more common in older age groups [17,18]. The cause of RA is still unknown but is probably multifactorial due to genetic background, lifestyle and environmental factors [19].

RA affects both external and internal organs and is presented by many different symptoms. The major symptoms are polyarticular pain, swelling, and morning stiffness. Fatigue, malaise, low-grade fever and depression are also common symptoms [19]. People with RA have lower aerobic capacity and energy expenditure compared to the general population [20], and reduced muscular strength, which contributes to functional disability [21]. Increased risk of comorbidity, such as cardiovascular, respiratory and infectious diseases, with premature death, is also a consequence of the disease [22-24]. Consequently, RA puts a great burden on both physically and mental health-related quality of life [25].

The prognosis for RA is predicted by non-modifiable and modifiable factors. Non-modifiable factors include age, gender, genetic factors, and disease-specific factors such as autoantibody status [23]. Modifiable factors include pharmacological treatment, and behavioral factors such as smoking and physical activity [23].

#### **4.3.1 Secondary prevention**

Rheumatology care aims to support people with RA to manage the consequences of the disease and to prevent the development of co-morbidities. The optimal treatment is recommended to include a combination of pharmacological and non-pharmacological treatments [3,26].

Since the turn of the century, the pharmacological treatment of RA has changed dramatically [3]. New treatment strategies and drugs have been developed. The recommendations are early treatment, i.e. within twelve months after onset of symptoms, with a combination of disease-modifying anti-rheumatic drugs (DMARDs), including biological agents if indicated [3 ,27]. The drugs reduce joint swelling and pain, limit progressive joint damage, and improve physical functioning in many people [3]. However, despite low levels of inflammation, many people still report high levels of pain, fatigue, sleep disturbance [28], and low quality of life compared to the general population [29], and most people do not reach full remission [30]. Further, the drugs may cause minor and more serious adverse risks, e.g. infectious diseases, cancer and lymphoma [19]. Non-pharmacological treatments is therefore an important part of the treatment [4].

The aim of non-pharmacological treatment is to improve physical functioning and health, to remove barriers in the environment so as to improve active participation in everyday life and in society, and to provide people with self-management strategies to encourage a healthy lifestyle [31 ,32]. Interventions to enhance self-management have strong scientific support, as have physical activity and exercise programs [33].

#### **4.3.2 Physical activity**

Physical activity is an important component in the management of RA. Physical activity and exercise improve pain, cardiorespiratory fitness, muscle strength, and physical functioning [4 ,12 ,34-36]. Physical activity is also safe and does not have a detrimental effect on disease activity or radiological damage of the joints [4 ,36 ,37].

Despite these apparent benefits, most people with RA report low levels of physical activity and do not meet the recommendations for physical activity [21 ,38-40]. However, the results should be interpreted with caution, since the measurement tools, definitions and recommendations used vary among studies [38-40]. One of the studies investigated current and maintained physical activity in a Swedish sample of approximately 3100 people with RA [40]. The results demonstrated that 69% of the respondent were currently (last week) physically active according to the recommendations [14] measured by the International physical activity questionnaire [41], whereas only 11% reported maintaining (> 6 months) aerobic and strength training according to the recommendations [14] assessed by a modified version of the Exercise stage assessment instrument [40]. This result may indicate that it is important for health care to not only focus on the adoption of physical activity but also to support the maintenance of physical activity.

There are many factors associated with physical activity. Some are similar to the factors for the general population, whereas some are more specific for people with RA [42 ,43]. Physical, psychological, social, and environmental correlates of physical activity have been described [43-46]. The results are diverse but some factors are similar between studies, for instance prior physical activity, self-efficacy, and disease symptoms such as pain and restricted joint mobility.

To maintain a physically active lifestyle is a challenge for most people, but maybe even more for people with RA. Different kinds of support are needed depending on a person's view and perceptions of physical activity maintenance [47 ,48]. Therefore, health care needs to develop and provide different support for different peoples' needs, such as self-management interventions.

### **4.3.3 Self-management interventions**

Self-management interventions are considered a key component in rheumatology care [49]. There is no golden standard definition of the concept [50]. One definition refers to self-management as a person's ability to "*manage the symptoms, treatment, physical and psychological consequences and life-style changes inherent in living with a chronic disease*" [50]. Hence, self-management interventions aim to empower and support a person to self-regulate the behavior in every-day life.

Self-management implies an active and engaged person. It requires health care providers that coach rather than provide expert knowledge [51 ,52]. It involves collaborative care where the person and health care provider make health care decisions together. Self-regulation skills are taught, including goal setting, planning and problem solving, to enhance the person's every-day life [51 ,52]. Self-management considers personal, behavioral and environmental factors to provide individualized support. This is described in health behavior theories and models [8 ,9].

Self-management interventions have been demonstrated as being more effective if they use cognitive behavior approaches and approaches derived from the self-regulation theory than interventions that do not [33]. A review of self-management interventions for people with rheumatic diseases found that most interventions were based on Social Cognitive Theory (SCT) [49]. Some of the interventions reported positive outcomes in pain and physical functioning in a short-term perspective, i.e. 12 months or less. Another review concluded that the inclusion of more self-regulation techniques increased physical activity levels and reduced pain, anxiety and depressive symptoms [53]. The most evaluated program is the Arthritis Self-management Program (ASMP) [54 ,55]. This program has been shown to have long-term benefits in reducing pain and health care utilization, examined four years after participation in the program [55]. Self-management interventions with duration of at least 6 weeks, the explicit use of cognitive behavioral approaches and individualized weekly action plans with progress review, provided by the same trained leaders have been recommended for effective interventions [33].

Self-management interventions for arthritis are often multi-component in nature. These components often address knowledge, use of medication, management of disease symptoms, and psychosocial consequences, social support and lifestyle changes, including physical activity [50]. Hence, most existing self-management interventions focus on the management of the disease in general and not maintenance of physical activity.

## **4.4 THEORIES AND MODELS OF HEALTH BEHAVIOR**

Health behavior theories seek to explain why, when and how a behavior does or does not occur. They describe mechanisms of how behaviors are maintained and principles for the understanding of what it takes to make behavior modifications [56]. Physical activity is an example of a health behavior. It includes overt (that can be observed, for example cycling, walking, talking) and covert (that cannot be observed, for example thoughts, feelings) behaviors undertaken by a person to prevent, manage or relieve symptoms of illness and enhance health [57]. Many different theories exist which try to describe the determinants of health behavior.

### **4.4.1 Respondent and operant learning**

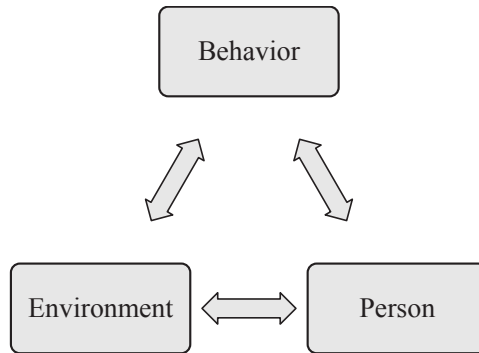
Behavior can be learnt by association (respondent learning) and by consequences (operant learning) [58 ,59].

Respondent learning posits how inborn reflexes become associated with new stimuli [58 ,59]. This learning occurs when a neutral stimulus (running or gym exercising) is closely associated with an inborn reflex (e.g. experience of strong pain that elicits fear). In future, the neutral stimulus may be conditioned to fear. For example, a person experiences strong pain when exercising, which elicits fear. The next time the person goes to the gym and exercises, or encounters a similar situation, the feeling of fear is elicited as a conditioned response even if the person does not experience pain. Hence, the person has learnt to associate exercise with fear.

Operant learning describes how behavior is shaped through its relationship with antecedent cues and following consequences [58 ,59]. In basic terms, a consequence can be reward or punishment. For example, if a person experiences pain after running or gym exercising, the pain may act as a punishment and will probably cause a decrease in gym exercising. If the gym exercising is followed by attention from others, for instance likes sent from my peer group in my exercise app, the attention from others may act as a reward and will probably increase the likelihood for the gym exercising to occur again. A reminder for planned exercise sent by email or as a pop-up message on the mobile phone from the exercise app may act as an antecedent cue for exercise.

### **4.4.2 Social Cognitive Theory**

SCT embraces the basic learning theories, such as respondent and operant learning, and adds the dynamic interaction between personal characteristics, the behavior and environment in shaping a behavior (Figure 1) [9 ,10]. SCT emphasizes a person's individual capability to make things happen by one's actions [8]. This enables a person to play an active part in their own self-development.



**Figure 1.** Reciprocal determinism. The environment influences a person and groups, but the person and groups can also influence their environment and regulate their own behavior [9].

*The person* includes personal characteristics as well as feelings and thoughts. An important element is self-efficacy, one’s confidence in one’s ability to perform a certain behavior during certain circumstances, for example physical activities. A person’s short and long term positive and negative expectations of performing the behavior are also important [9]. A person’s ability to control behavior through self-regulation, e.g. self-monitoring, goal setting, and feedback, is also important. *Environmental factors* include social support from family, friends, and exercise peers, as well as the influence of the physical environment, place and time. SCT also includes the concept of observational learning, e.g. observation and imitation of models similar to oneself.

Since SCT includes the above theories and emphasizes a bio-psycho-social perspective on behavior, SCT is a good base for the studies in the present thesis. SCT has been recommended as a framework for interventions in rheumatology [49]. SCT also emphasizes the importance of self-regulation, which has been demonstrated as essential for physical activity maintenance in adults [60] and in people with RA [61].

#### 4.4.3 Transtheoretical Constructs of Stages and Process of Change

The Transtheoretical Constructs of Stages and Process of Change (TTM) has been applied to a broad range of health behaviors [62]. TTM describes how a person moves through different stages of change in their effort to change a behavior, e.g. follow the recommendations for physical activity. In the first stage, the pre-contemplation stage, there is no intention to be physically active within the next six months. In the contemplation phase, there is an intention to be physically active according to the recommendations within six months. In the preparation phase there is an intention to be physically active within one month, and in the action phase the person has been physically active less than six months. In the last stage, the maintenance phase, physical activity has been sustained for at least six months [62 ,63]. TTM can be used to describe a person’s readiness for and engagement in physical activity [40].



#### **4.4.4 Behavior change techniques**

A behavior change technique is defined as the active component, or feature, of a behavioral intervention that alters or redirects the target behavior [64]. Behavior change techniques are universal and occur in more than one health behavior theory. Behavior change techniques may serve as a link between the theories and intervention features.

A comprehensive, consensually agreed taxonomy describing behavior change techniques has recently been published [65]. It consists of 93 labeled and defined behavior change techniques hierarchically clustered into 16 groups. The aim of the taxonomy is to improve reports on the content of intervention, facilitate comparison of results between studies, and help identify effective intervention features. Hence, using the behavior change technique taxonomy to describe intervention features may be of significant value.

The use of taxonomies has resulted in the identification of effective intervention features. Self-monitoring seems to be important to increase physical activity and/or monitor diet [66-68]. In addition, self-monitoring in combination with other self-regulation techniques, such as goal setting, feedback on performance and review of behavioral goals, has been suggested as further improving the efficacy of the interventions [66]. However, the results are diverse in terms of which and how many behavior change techniques produce the most effects on physical activity [69]. This may indicate that different behavior change techniques are more or less important depending on the population studied. In people with RA, self-regulation techniques have been demonstrated as important [53].

### **4.5 THE INTERNET AND MOBILE PHONES FOR HEALTH INFORMATION AND HEALTH SERVICES**

In 2015 the Swedish population between the ages of 16 and 85 years reported access to Internet at home at a rate of 89% [70]. Internet access was highest in the age group 16 to 54 years (96–98%) and lowest in the age group 75 to 85 years (40%). Mobile phones were used by 69% of the population to connect up with the Internet outside the home, but the use varied depending on age: 76–89% of persons in the age group 16–54 years and only 9% of persons in the age group 75–85 years [70].

The use of the Internet and mobile phones to access health information is growing. A recent population based study in the USA (n=approx. 35000) found that a little less than 50% used the Internet for health information [71]. Demographic characteristics such as higher education [72 ,73] and younger age have been reported as increasing Internet use [72], whereas functional disability due to arthritis did not influence use [71 ,73]. Somewhat contradictory, another study found that people with more illnesses are less likely to use the Internet to search for health information [72]. In the future it is likely that more people than today will use the Internet to access health information and health services.

#### **4.5.1 Definitions of eHealth and mHealth**

The use of the Internet and mobile phones for health information and health services has resulted in two new concepts: eHealth and mHealth.

There is no consensus definition of the concept of eHealth [74]. The WHO defines eHealth as the use of electronic means to transfer health resources and health care. It includes the delivery and sharing of health information, education of health care providers and distribution of health service to improve public health [75]. mHealth, or mobile Health, is a subgroup of eHealth, and is defined by WHO as mobile or wireless devices, such as mobile phones and activity monitoring devices, used to support medical and health practices [76]. In the present thesis physical activity mobile phone applications found online are included in this concept. mHealth services are tested in different areas, for instance to improve access to emergency medical services, general health services and information and treatment adherence (e.g. scheduling a doctor's appointment, patients' records, 1177 disease management, enhancing clinical diagnosis). Hence, the concepts of eHealth and mHealth include administrative information sharing services as well as services to deliver interventions to improve health.

#### **4.5.2 eHealth and mHealth self-management services**

The Internet has the potential to bring self-management support into a person's everyday life, has broad population reach, is cost effective and is accessible 24 hours a day [77,78]. eHealth services have the potential to achieve behavior change in adult populations [5,6]. However, the effects are small and unsustainable [5]. Disease specific self-management services are available, for instance for people with cancer [79], diabetes [80], adolescents with juvenile idiopathic arthritis [81], obstructive pulmonary diseases [82], depression [83], and spina bifida [84] and more are coming. Evaluated self-management eHealth services targeting the arthritis population mainly target medication and disease management [85] and have been classified as educational, including information about the disease and medication [86]. A few of these include tracking of physical activity where the most evaluated is the Internet based ASMP, which provides an exercise log and individualized exercise programs [87,88].

eHealth services targeting physical activity in adults have the potential to improve physical activity behavior [89-91]. The huge amount of commercial mHealth services available in online application stores mostly targets the adult population [92-94], and are neither evaluated nor evidence based [95,96]. Disease specific eHealth and mHealth services are also available, for instance for people with knee injuries [97], osteoarthritis [98], and people with pulmonary disease and diabetes in primary care [99]. To the best of my knowledge, there is no self-management mHealth service available targeting maintenance of physical activity in RA.

To improve the effects of eHealth and mHealth services, the services should be adapted to the specific needs of the users. By involving people with RA, i.e. the lead users [100], in the development of an mHealth service their experiential knowledge and preferences can be incorporate into the service.

#### **4.6 PARTICIPATORY DESIGN**

Participatory design is about lead user involvement in the design of services. It focuses on developing new technology that is usable and effective from the perspective of the lead

users [101 ,102]. Participator design is also characterized by the use of different techniques to stimulate the participants' creativity, such as the use of different types of prototypes [103 ,104].

Participatory design was first introduced in workplaces in Scandinavia in the 1960s and 1970s, with employees, employers, researchers and the system developer collaborating on developing computer systems [104]. Participatory design has been suggested to offer a method for development of eHealth services [103]. It has been used in the development of services for people with juvenile idiopathic arthritis, adolescents with diabetes, family carers of frail older people, and people with cancer, pulmonary and cardiac diseases [79-81 ,105-108]. Participatory design improves the usability, viability and effectiveness of services [101 ,102 ,109]. Barriers to participatory design are the time and resource consuming process, and difficulties in finding the 'right' participants [109].

The importance of involving lead users in health care improvements has been recognized in Sweden. The National Board of Health and Welfare has developed guidelines on how to involve patients in health care improvements [110].

Participatory design share similarities with action research as both involve collaboration with the lead users, patients or community members to solve real life problems [103].

## **4.7 ACTION RESEARCH**

Action research has been described as a style of research rather than a specific method. It varies from experimental and research lead research to initiatives coming from community members where the researcher has the role of facilitator rather than responsible for the research [111]. Action research originates from the work done by Lewin, who was a social scientist concerned about minority groups in the United States in the 1940s [111]. Since then, action research has developed and is now more concerned about empowerment and with finding ways for the researchers and practitioners, patients, lead users or community members to collaborate.

Action research increases in use in health care settings. It is suitable for identifying clinical problems and helping to find solutions to improve practice and bring about change [112]. It has been applied in the areas of AIDS/HIV education, in nursing homes to improve care, in hospitals supporting community based health initiatives, and in school education mainly in Great Britain and the USA [111 ,113].

### **4.7.1 Participatory action research**

Participatory action research is a typology of action research that originates from organizational development in American industries in the 1940s [111].

Participatory action research includes three elements: action (activities, i.e. focus group interviews and workshops), research (i.e. data collection and analysis) and participation (i.e. involvement of lead users and other expertise in the activities and research). It is about doing research *with* and *for the* people rather than on people. It aims to empower people

and to bring about a change in practice. It includes a cyclical process of planning, action, analyzing and thinking, and feedback. It draws on multiple research methods, but qualitative methods are often used since people's experiences, needs and values are important for new knowledge to be created [111 ,112 ,114].

#### **4.7.2 Experience based co-design**

Experience based co-design is a participatory action research approach that use principles from participatory design [115]. In experience based co-design the patients are at the "heart" of the process and collaborate with health care providers to co-design health care services. Experience based co-design is inspired by design science, i.e. product and computer design and architecture [100 ,103] and focuses on designing experiences, not services or processes. Good service is not only about performance (functionality or how well it does its job) and engineering (how safe and reliable it is) but also about aesthetics (usability or how the interaction with the service is experienced, or "feels"). A service that is usable is more likely to lead to fewer errors and better performance [100]. Hence, aesthetics are strongly linked to both engineering and performance and should be considered in the development of health care services.

Experience based co-design has been used in organizational health care service improvements, for instance in the improvement of services for people with head and neck problems and people with breast and lung cancer in England and in Australia, and is expanding in use [107 ,116].

The present project used the principles of experience based co-design in the development of an mHealth service for self-management of physical activity in RA. Co-design, as defined in the present thesis, implied the active involvement of people with RA, i.e. the lead users [100], throughout the development process and *collaboration* with other experts. The lead users were involved in the decision-making process and were seen as equals to the other experts and their ideas and *experiences* important to consider in the development of the mHealth service.

### **4.8 DESCRIBING AND UNDERSTANDING LEAD USER INVOLVEMENT**

The methods for lead user involvement differ a lot between projects with regard to whether the lead users are seen as passive objects of study or active participants in the process [101]. There are different models or classification systems available which may help us to describe and understand the many variations of lead user involvement.

According to Arnstein's ladder of participation [117], the involvement is described in eight rungs. The two first rungs represent Non-participation and steps three to five represent Degrees of tokenism, i.e. the powerholder makes all the decisions. In rungs six to eight, the involvement in the decision-making process is increasing. In rung six, Partnership, the lead users and other experts negotiate. In the two last rungs, Delegated power and Citizen control, the lead users have the majority or full decision-making power. Another model proposed by Munford [118] describes the involvement in the field of participatory design.

In this model, three types of user involvement are described: Consultative, Representative and Consensus, the latter representing the highest level of lead user involvement including decision-making and responsibility for the implementation of the new system. Both the above typologies are very rough and do not tell us about the methods used and when in the process the lead users were involved.

Arnstein's ladder has been criticized since it focuses on the degree of power and does not consider the complexities of involving lead users (or patients/community members) [119]. When describing lead user involvement, one should acknowledge the value of the process and the complementary knowledge and experience of the participants involved. Further, different methods and time for involvement should be considered during the course of the project. The role and degree of involvement may vary depending on the phase in the process [119].

A more complex model describing lead user involvement is provided in the classification system of action research developed by Hart and Bond [111]. Four basic types of action research are described: Experimental, Organizational, Professionalizing and Empowering. Each type is described with seven different criteria. The action research types are not distinct; they overlap and a project may move between the different types during the course of a project. It is therefore difficult to classify a specific project into one single type. It has instead been recommended to use the classification system and the criteria to describe and think about how the lead users or other experts were involved in a specific project [114].

## **4.9 PHILOSOPHY OF SCIENCE**

A research paradigm is a worldview, a way of thinking and understanding the complex world [120 ,121]. It tells us what is important, legitimate and reasonable. Further, it tells us what constitutes credible and valuable knowledge. What research paradigm, and hence the methods used, should primarily be guided by the research question and phenomenon studied [120 ,122]. In the present project, different research paradigms and designs were required during the different phases of the project.

The two main paradigms in medical, behavioral and social science are the qualitative and the quantitative. In addition, the mixed methods paradigm, sometimes referred to as the third paradigm or the radical middle [120], was used in the present project.

### **4.9.1 The qualitative paradigm**

The qualitative paradigm deals with human nature as complex and influenced by bio-psycho-social factors. The most common worldview within this paradigm is constructivism, or naturalism [123]. Constructivists believe that researchers and participants within the research construct the meaning of the phenomenon under investigation. They believe reality is multiple and subjective, and that researchers' subjective values are inevitable and desirable in understanding the world.

Qualitative methods are often used to explore, describe or obtain an understanding of a phenomenon often studied from the participants' perspective and in real life settings [122

,123]. Ethnography, case studies and phenomenology are examples of designs. Qualitative methods generate detailed descriptions, classifications, typologies, patterns of associations and/or explanations [122 ,123]. The data collection and analysis are flexible, which makes it possible to explore emerging issues and adjust the procedure along the way. Studies including qualitative methods do not aim to generalize the findings but rather enable the results to be transferred to similar contexts, settings or groups [123 ,124].

#### **4.9.2 The quantitative paradigm**

The quantitative paradigm originates from a positivistic or postpositivistic worldview [120 ,122]. A positivist believes that research is objective and value-free. The researchers' values do not affect how they conduct or interpret their findings.

Quantitative methods are used when there is an existing body of knowledge about the phenomenon for which measurements are available. Experimental designs are often used, or surveys. It is a deductive process where the context is being, as much as possible, controlled and the aim is to generalize the findings [120 ,122]. The methods deal with research hypothesis in which the researchers explain and make predictions about a phenomenon before the research is conducted. The numerical data are analyzed using statistical methods. Conclusions about effects, relationships or differences between groups can be drawn [122 ,125].

#### **4.9.3 The mixed methods paradigm**

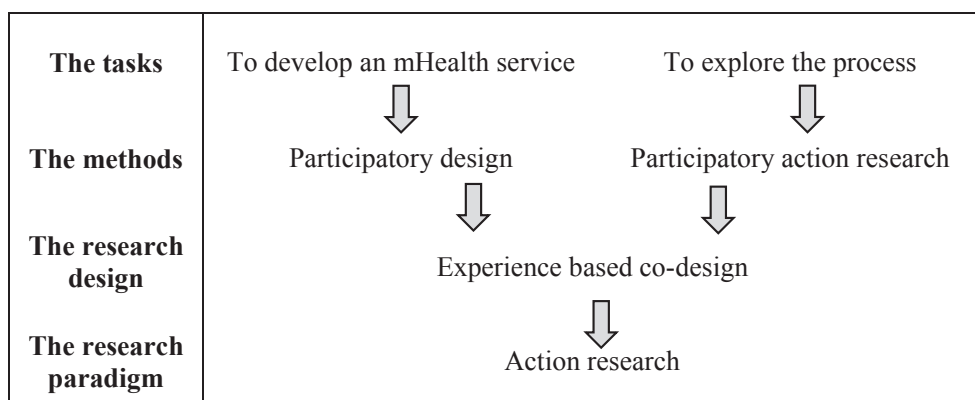
A mixed methodologist rejects the either/or in choosing quantitative or qualitative methods. The mixed methods paradigm is most often associated with pragmatism [120 ,125]. The pragmatist believes that a richer analysis can be achieved by combining quantitative and qualitative methods, and advocates the use of mixed methods to answer the research question. The design can be sequential (data collected in steps), concurrent (all data collected at the same time) or transformative (a theory are used as an overarching perspective). It involves the integration of statistical and thematic data analysis techniques [122]. Mixed methods have been advocated for use in the development of effective interventions since they can provide data on users' utilization and effects of interventions as well as provide a deeper understanding of why people do not adhere to or use features in an intervention [126].

## 5 PROCESS

### 5.1 OVERVIEW

The aim of the present project was twofold: to develop an mHealth service and to scientifically explore the process (Figure 2).

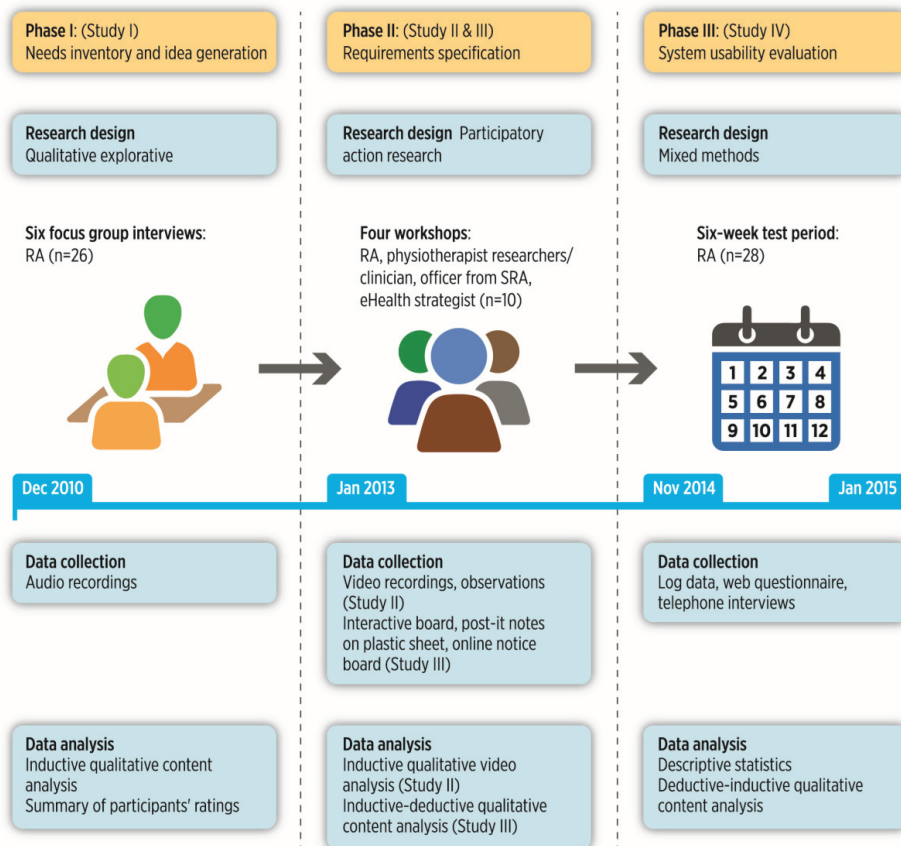
Different designs and methods were used in the different phases of the co-design process. Qualitative methods were used in all four studies included in the co-design process given the explorative nature of the investigation: to provide a detailed description of the participants' needs and ideas on features (Study I), verbal and nonverbal actions describing challenges of co-design (Study II) and the agreed requirements specification (Study III). In Study IV, the qualitative data were complemented with quantitative data, i.e. a sequential mixed methods design, to evaluate the first test version of the mHealth service in terms of participants' utilization of and experience with the service.



**Figure 2.** A description of and relation between the tasks, methods, research design and research paradigm in the present project.

The qualitative data in Studies I, III and IV were analyzed with manifest content analysis where texts were sorted into themes or categories [127, 128]. The analyses were inductive or a combination of induction-deduction, or deduction-induction [127]. Study I also consisted of a summary presentation of participants' ratings of core features and Study IV consisted of descriptive statistics to analyze the numerical data. In Study II a qualitative video analysis was performed where video sequences were identified and sorted into categories and themes [129].

An overview and description of the process is presented in Figure 3.



**Figure 3.** Overview of the three phases of the process of co-designing an mHealth service for self-management of physical activity in rheumatoid arthritis (RA), with a description of the different research designs, and data collection and data analysis methods used in the four studies included in thesis. SRA=Swedish Rheumatism Association.

## 5.2 PARTICIPANTS

An overview of the participants involved in the different phases of the co-design process is presented in Table 1.

In Study I the participants were purposively selected to represent various ages, genders, years with diagnosed RA, physical activity behavior, and Internet experiences in order to capture variations in experiences and ideas. The participants were recruited from three rheumatology clinics in central Sweden and from the membership register at the Swedish Rheumatism Association (SRA). In Studies II and III the participants were selected to create a sensibly sized co-design group and to include participants with knowledge of physical activity in RA, behavior learning theories, experiential knowledge in living with RA, and eHealth and mHealth service development. Participants were identified through



our research and clinical networks to ensure they had the required knowledge. In Study IV participants that had not participated in the previous studies and were ready to self-manage physical activity were recruited by health care providers at three rheumatology clinics and one primary care clinic in central Sweden to form three peer support groups.

**Table 1.** The characteristics of the participants involved in the co-design process.

	<b>Phase I: Study I</b> Needs inventory and idea generation	<b>Phase II: Studies II &amp; III</b> Requirements specification	<b>Phase III: Study IV</b> System usability evaluation
<b>Participants, n</b>	26	10	28 <sup>1</sup>
<b>Gender, Male/Female, n</b>	5/26	3/7	3/24
<b>Age, years, md (min-max)</b>	60 (31-71)	55 (34-73)	52(37-71)
<b>Diagnosed with RA, n</b>	26/26	6/10	27/27
<b>Years since diagnosis, n</b>			
< 1 year	0		3
1-5 years	6		8
6-10 years	4	5	4
> 10 years	16	1	12
<b>Perspective representatives, n</b>			
- Persons with RA	26	6 <sup>2</sup>	27
- Clinical/ researcher physiotherapist		3	
- Officer from SRA		1	
- eHealth strategist		1	
<b>Occupational status, n</b>			
Full or part time work	11	7	19
Old age or disability pension	13	3	4
Full time sick-leave	2		4
<b>Education, n</b>			
University	9	9	20
High school	13	1	4
Public school	4		3
<b>Meet the recommendations of physical activity <math>\geq 30</math> min <math>\geq 5</math> days/week<sup>3</sup> since <math>\geq 6</math> months, n</b>	NA	5	1
<b>Meet the recommendations for strength training <math>\geq 2</math> days/week<sup>3</sup> since <math>\geq 6</math> months, n</b>	NA	4	2
<b>Used to Internet, yes/no, n</b>	14/12	10/0	27/0

<sup>1</sup> One participant did not fill in the questionnaire. <sup>2</sup> One of the researchers had RA. SRA= Swedish Rheumatism Association, NA=data were not collected

In addition to the above participants, a project group was formed during Phase II to plan the workshops. The group consisted of three researchers, who also collected data during the workshops, one eHealth system developer (the workshop moderator, with expertise in the development and programming of eHealth services and experience of group moderation), one eHealth strategist and one patient research partner from the SRA. The latter two were also participants in the workshops.

Likewise, a test-group was formed during Phase III to test the mHealth service to ensure the features were feasible before the study started. The group consisted of the researchers, the patient research partner, the eHealth strategist and physiotherapy lecturers at the Physiotherapy program at Uppsala University. The eHealth strategist was also involved in the planning and performance of the study.

Throughout the co-design process, the researchers planned and performed the data collection and analysis.

### **5.3 PROCEDURE, DATA COLLECTION AND ANALYSIS**

In Phase I, six focus group interviews [130] were held at the three rheumatology clinics or at the central office of the SRA. Focus group interviews were chosen to explore the topic and to facilitate for the participants to collectively come up with ideas and to share experiences related to physical activity and web support [131]. In the sixth focus group interview no new ideas emerged, i.e. reasonable ‘saturation’ seemed to have been reached. The interviews were transcribed verbatim between each interview. A list with a comprehensive summary of the highest ranked ideas from each focus group interview was mailed to all participants with a request for their votes on three core features that they believed were important to include in the future mHealth service. An inductive qualitative content analysis [132] was performed, focusing on the manifest content, to describe the entire range of ideas on features in the future mHealth service. A quantitative analysis of the participants’ prioritization of core features was performed by summarizing participants’ ratings of core features.

In Phase II, four workshops were held, with 1-4 weeks between the workshops, in lecture rooms at Uppsala University and each lasted between 3½ and 5½ hours. Four workshops were considered enough to provide data for a requirements specification and to recruit participants that had the possibility to participate all four workshops. The workshops enabled the participants to share experiences and for the researcher to collect data during the process. The first workshop started by presenting the results from the Needs inventory and idea generation phase. In general, the discussions were outlined as follows: Each participant was provided with three post-it notes to write down their own ideas or suggestions. Each post-it note was then discussed in the group. Post-it notes that it was agreed contained similar opinions were clustered and compiled on an online notice board, or outlined on an interactive board or arranged on plastic sheets as prototypes of the future service. Post-it notes with ideas or suggestions that the participants were not in agreement on were saved and discussed again later. The following workshops then started with one of the researchers presenting a brief summary of what had been discussed last time, what

decisions had been made and what the goal was of the present workshop. Twice during the process the moderator programmed the prototypes as mHealth services. These were displayed on a screen and presented in the following workshop.

Data collection included video recordings, naturalistic observations, the prototypes, and the online notice board. Between each workshop, the data were compiled and analyzed briefly by one of the researchers. The researchers collecting data, the moderator and the eHealth strategist planned the following workshop. The data analysis comprised an inductive qualitative video analysis [129] on the challenges (Study II). The data consisted of approximately 16 hours of video recordings along with the observation protocols. Numerous text documents on suggested features (i.e. postings on the online notice board, prototypes on the interactive board, plastic sheet and programmed mobile phone services) were also analyzed with a manifest inductive qualitative content analysis [132] that was followed by a deductive analysis to link the requirements specification to theoretically derived behavior change techniques [133] (Study III). An overview of the data used in the analysis is presented in Table 3.

**Table 3.** The type of data used for main analysis (X) and for clarification and validation (O) in Phase II.

Type of data	Challenges (Study II)	Features (Study III)
Postings on the online notice board		X
The First prototype outlined on the interactive board (pdf)		X
The Second prototype outlined on a plastic sheet		X
Video sequences	X	O
Observation protocols	O	O
The programmed prototypes displayed on a mobile phone		O

In Phase III, a review of existing mHealth services was conducted to find out if there was any existing platform that corresponded to the requirements specification produced during the workshops. A company providing a physical activity mHealth service to companies in Sweden was willing to let us use and modify their platform to fit our needs. The test-group tested the modified platform during autumn 2014 to ensure the features were feasible. Before the study started, the participants were invited to a meeting to get an introduction to the mHealth service and to meet their peers. The participants were instructed to interact with their peers, share physical activity experiences, set goals, plans and register physical activity performances. Data collection included log data collected during the six-week test period, and a web questionnaire and semi-structured telephone interviews after the test period. The interviews were transcribed verbatim. The data analysis consisted of descriptive statistics presented as frequencies (n, %) or medians (md) with ranges (min-max), of the

log-data and web questionnaire. The transcribed telephone interviews were analyzed by a directed content analysis [128], a combination of a deductive and inductive manifest qualitative content analysis.

#### **5.4 ETHICAL CONSIDERATIONS**

All the participants in the three phases of the co-design process (Study I-IV) received verbal and written information about the aim, methods and procedure. They were informed about what and how the data would be collected and handled, and that their participation was voluntary. The participants gave their final consent by attending the focus group interviews (Study I) and workshops (Studies II-III). Written consent was obtained from each participant in Study IV. The Regional Ethics Review Board of Stockholm approved the studies (D.nr. 2010/1101-31/5, Study I-III, and D.nr. 2014/1522-31/2, Study IV).

Participatory action research has some specific ethical dilemmas to consider [134]. This concerns, for instance, anonymity, confidentiality and power inequality between the participants. Protection of participants' anonymity may not be possible since recognition of individual views is likely due to the small number of participants [114 ,134]. Confidentiality was discussed with the participants at the beginning of the first workshop. They agreed not to talk to other people about what the other participants had said. We considered letting the participants read the manuscript for Study II before publication but decided this might only put an extra burden on them. We also decided to only describe the participants on a group level.

Privacy protection, third party access and safe storage of data need to be considered in research that includes eHealth and mHealth [135]. An agreement was signed by the company that owned the platform to ensure safe data storage and to regulate use of the data.

## **6 CONTENT**

### **6.1 PHASE I: NEEDS INVENTORY AND IDEA GENERATION**

The first phase of the co-design process resulted in the identification of four aspects important to consider in the development of the future mHealth service (Study I): features, customized options, user interface, and access and implementation.

#### **6.1.1 Features**

The features aspect describes the focus group participants' ideas on important features that should form part of the future service. Self-regulation features should be included to assist in the planning and performance of physical activity and features for social interaction with peers to inspire and encourage. Up-to-date and evidence-based information and instructions were also considered essential.

#### **6.1.2 Customized options**

The participants expressed the need for the mHealth service to include individualized set-ups to provide flexible use. Being able to choose the level of engagement, i.e. to only read information or to interact with peers, was suggested. Connection to other programs was desired, as was a mobile application.

#### **6.1.3 User interface**

Another important and crucial aspect for success, according to the participants, was an appealing and attractive user interface and a service that was fun to use. They underlined the significance of avoiding pointers and boring paragraphs.

#### **6.1.4 Access and implementation**

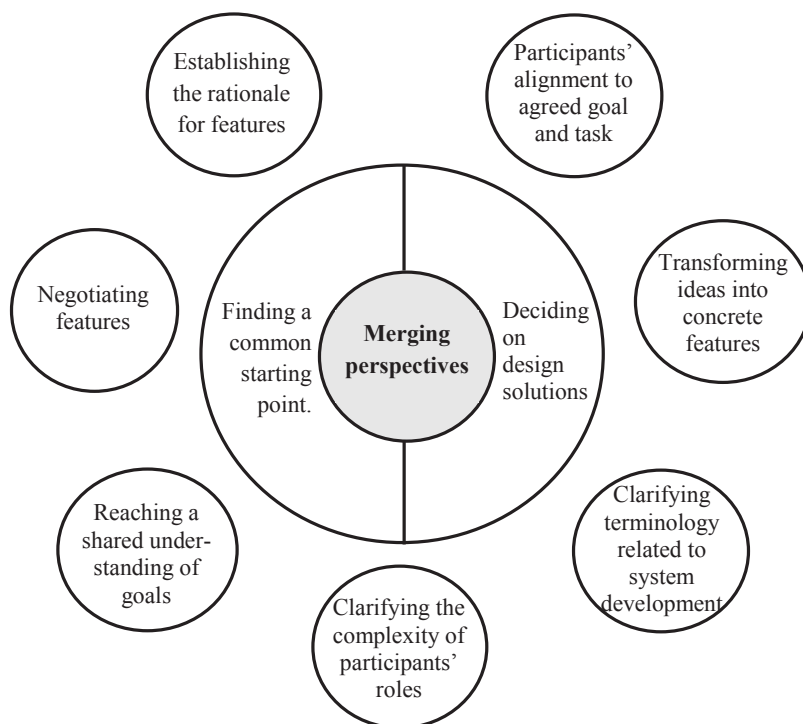
Ideas on how to inform and reach the RA population about the existence of the mHealth service were considered. The need for a personal introduction to get started, and where and who should deliver that introduction, was one of the concerns discussed. The participants believed the future mHealth service would be most appropriate for maintaining physical activity, since adopting physical activity was considered difficult for some people without personal face-to-face coaching.

### **6.2 PHASE II: SYSTEM REQUIREMENTS SPECIFICATION**

During this phase a specification of the system requirements of the mHealth service was produced during the four workshops. Co-designing in collaborative workshops including lead users and other experts was a challenging process-

### 6.2.1 Challenges of co-design

The core challenge of co-design was the merging of participants' different perspectives (Study II). This merging of perspectives influenced all discussions during the workshops: to find a common starting point for the process, and to decide on feature design solutions. The participants shared, argued, and considered their different viewpoints, and integrated and counterbalanced these differences. They had to find solutions, negotiate and reach a final decision (Figure 4).



**Figure 4.** Overview of the challenges of co-designing the requirements specification of an mHealth service for self-management of physical activity in rheumatoid arthritis (RA). A central theme, merging perspectives, surrounded by two subthemes reflecting different areas of merging, emerged during the analysis. The peripheral seven categories illustrate the challenges deemed important for advancing the co-design process toward the goal.

### 6.2.2 The requirements specification

The merging of participants' perspectives resulted in the agreement on the mHealth service being named 'tRAppen' in order to reflect RA, App and stair (Swedish: *trappa*) to represent physical activity (Study III). tRAppen should include two key components: (1) "My self-regulation": including a calendar feature for planning, goal setting, and registering physical activity and progress, and (2) "My peer support": including features to provide a small community with peers for positive feedback and support. tRAppen should be a service for

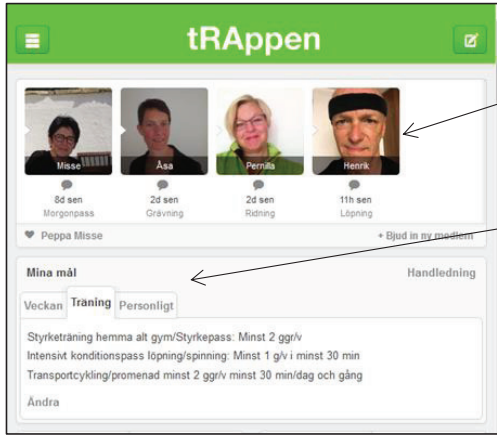
maintenance of physical activity. It was furthermore proposed that it should be a lifelong companion that would encourage physical activity during good and bad periods of the disease.

### **6.3 PHASE III: SYSTEM USABILITY EVALUATION**

The first test version of tRAppen was based on the two key components: 1) “My self-regulation”, and 2) “My peer support”. In addition, a guide with evidence based information and instructions were included. tRAppen was an mHealth service and could be used on a computer, mobile phone or tablet with Internet access.

#### **6.3.1 Overview of features and behavior change techniques in tRAppen**

tRAppen included a total of 22 different behavior change techniques. The techniques belonged to 10 of the 16 groups included in Michie’s taxonomy [65]: Goals and planning (7 different codes), Feedback and monitoring (3 different codes), Social support (3 different codes), Shaping knowledge (1 code), Natural consequences (2 different codes), Comparison of behavior (1 code), Associations (1 code), Comparison of outcome (1 code), Reward and threat (2 different codes), and Identity (1 code). Screen shots of tRAppen with a few examples of features and behavior change techniques included are presented in Figure 5.



Pictures of peers in order since last physical activity performed  
*BCT: Social comparison*

Tabs to set and display physical activity behavior and outcome goal, and weekly physical activity plan  
*BCTs: Goal setting behavior, goal setting outcome and action planning*



Thumb-up icon to send likes  
*BCT: Social reward*

Peers' postings of performances  
*BCT: Prompts/cues*

Field for comments as free text  
*BCT: Social support*



Example of monthly rewards  
*BCT: Non-specific incentive*

**Figure 5.** Screen shots of the mHealth service tRappen with examples of features and behavior change techniques (BCT) in italics [65].



## 7 OUTCOME

The outcome of the co-design process is presented as the result from the evaluation of the first test version of tRAppen which was performed in the System usability evaluation phase. The outcome is presented as description of the participants' utilization of and positive and less satisfactory experiences with tRAppen (Study IV).

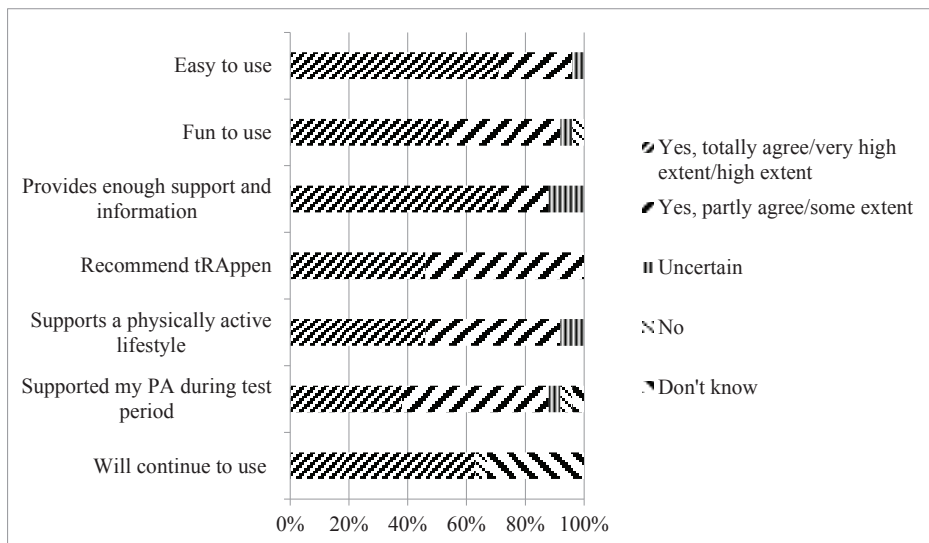
### 7.1.1 Frequency of use

Twenty-five of the 28 participants used tRAppen. A majority of participants registered performed physical activities, sent likes, posted comments, set goals and made exercise plans. Six participants changed their goals once or twice during the test period. On average the participants registered 22 physical activities, sent 36 likes and posted 2 comments during the six-week test period.

### 7.1.2 General experience

tRAppen was generally rated as easy and fun to use, and as providing enough physical activity support (Figure 6). tRAppen was also supposed to be a great tool for people with recently diagnosed RA. One participant expressed her experiences:

*"I think tRAppen is fantastic! It is such fun. I like the monitoring of physical activity and the motivation I get from the group. I think this helps me a lot to be physically active."*  
(3:96)



**Figure 6.** Participants' (n=24) rating of tRAppen in general. PA=physical activity

Less satisfactory areas included log-in difficulties and the lay-out not being entirely suitable for a mobile phone screen. Other participants found tRAppen to be a burden and not to enhance physical activity. One participant expressed her view:

*“I get the feeling that tRAppen doesn’t provide me with anything new that makes me exercise more or in another way.” (2:22)*

### **7.1.3 Feasibility of features**

The features were generally rated as easy to understand and use. The participants reported that the features were easy to find and with clear instructions. The statistics shown on tRAppen were said to provide a clear overview of performance. Others had difficulties in understanding the statistics. Further difficulties were related to formulating goals and plans. The instructions and labeling of the tabs was perceived to be unclear. Planning when and how to exercise in the coming week was problematic due to the disease and variations in the state of physical and mental health. Furthermore, the “rules” for what counts as physical activity were reported to be unclear.

### **7.1.4 Features as support for physical activity**

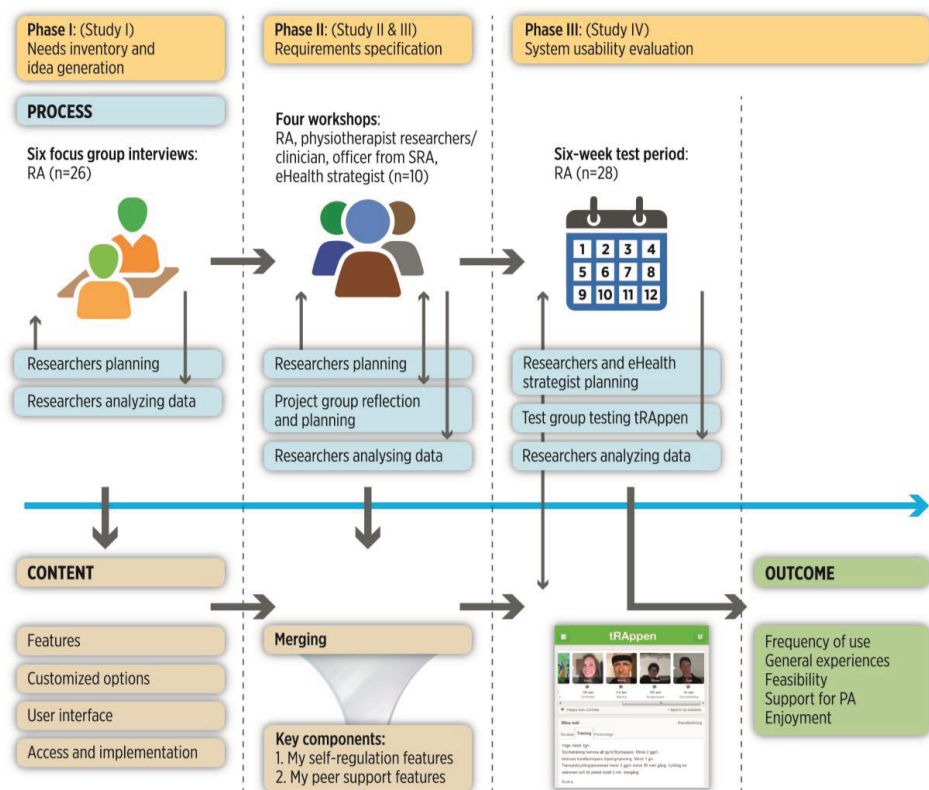
The ratings of features as support for physical activity varied more than the ratings of feature feasibility. The highest ranked support feature was planning and registration of physical activity. This was described by participants as encouraging. Being able to share and read about peers’ physical activity performances was reported as being an important support for physical activity, but sometimes not. The peer support improved self-efficacy and was reported as providing encouragement, inspiration, and motivation. But some participants said the opposite. The participants’ experiences of whether the feedback provided (statistics, the weekly email on goal achievement and updates, rewards) actually enhanced physical activity also varied a lot.

### **7.1.5 Enjoyment**

The users’ unfolded emotional feelings and reactions when using the different features in tRAppen. The users expressed feelings of joy, happiness, satisfaction and the feeling of belonging to the peer group during physically active and healthy periods, whereas feelings of sadness, stress, discontent, and disloyalty were felt during periods of illness when less physical activity was performed. Changing the goals during these periods was perceived as conceding defeat and this feature was little used.

## 8 SUMMARY OF PROCESS, CONTENT AND OUTCOME OF THE CO-DESIGN OF TRAPPEN

A summary of the co-design process of tRAppen with a description of the process, content and outcome of the three phases is presented in Figure 7. Process describes the procedures and research methods used. Content describes the iterative process of deciding on features to include. Phase I resulted in four aspects important to consider in the development of the service: features, customized options, user interface, and access and implementation; In Phase II, the participants' perspectives were merged and the features were specified. Two key components were agreed on: 1) "My self-regulation", and 2) "My peer support". In Phase III the first test version of tRAppen was produced. Outcome presents the results from the evaluation of the first test version of tRAppen, which were descriptions of frequency of use, general experiences, feasibility, support for physical activity and enjoyment.



**Figure 7.** A summary of the process, content and outcome of the co-design of the physical activity self-management service tRAppen. RA=rheumatoid arthritis, SRA=Swedish Rheumatism Association, PA=physical activity.



## 9 GENERAL DISCUSSION

The co-design process, which was characterized by the merging of participants' different perspectives, resulted in the first test version of the mHealth service tRAppen. tRAppen included two key components: 1) "My self-regulation", including features for goal setting, activity planning and physical activity registration, and 2) "My peer support", including features enabling communication with peers. In addition, a guide with evidence based information on physical activity in RA was included. The first evaluation of tRAppen found it feasible and supportive of physical activity performance. Further, the results pointed to the importance of being able to individualize tRAppen according to physical and mental health status and personal preferences.

### 9.1 WHAT IS UNIQUE AND RA-SPECIFIC IN TRAPPEN?

A defining characteristic of tRAppen is that it is a self-management service for people with RA that is not delivered directly by the health care system. Rather, the service emphasizes the role of peers by providing features for peer support, advice and inspiration.

Another defining characteristic is that tRAppen is an mHealth service for the maintenance of physical activity behavior. Most available commercial mHealth services are educational and focus on information transfer or demonstrations of physical activities and exercises [93 ,94]. In contrast, tRAppen provides self-regulation features and social support. The provision of a peer support group for people with RA is available in the ASMP eHealth service [88], but has not been found in any other existing mHealth service even though the provision of features enabling communication with peers is common [93]. In addition, tRAppen includes evidence based recommendations on physical activity in general and in RA, which are not included in commercial services directed at the general population [96 ,136].

The RA-specificity is also generated by the users themselves, since the comments, for instance on how to handle problematic situations and provision of advice, and the posted physical activities are RA-specific. Easy access and encouragement to review goals and plans are also distinctive features that might be of major importance for people with RA.

tRAppen includes more behavior change techniques than most commercial mHealth services [93-95]. The main reason for this may be that tRAppen is based on the evidence of behavior learning theories, while most commercial mHealth services are not [95 ,96]. The inclusion of many behavior change techniques might be preferable since physical activity is determined by personal and environmental factors [8 ,9]. Hence, an mHealth service that includes behavior change techniques related to these factors might be more effective. However, previous research has been inconclusive. It is not clear whether more behavior change techniques result in more effective services [66 ,137].

In addition to the above, the most unique characteristic of tRAppen was how it was developed. tRAppen was co-designed, i.e. developed *with*, not only for people with RA in collaboration with physiotherapy researchers and clinicians, and system developers.

## 9.2 THE PERFORMANCE OF CO-DESIGN

The present co-design project is distinct from other projects that involve lead users in the development of eHealth services in at least three ways.

First, the lead users, i.e. people with RA, were involved in *all* phases of the co-design process including the requirements specification of the future service. It is more common to involve lead users in the needs inventory and/or evaluation phase, i.e. to ask them about their needs and let them evaluate the service in hindsight [80 ,81 ,105 ,138].

Second, during the Requirements specification phase of tRAppen, the lead users *collaborated* in workshops with researchers, clinicians, and an officer from the SRA and system developers. This phase is more commonly performed by researchers and/or system developers only [80 ,81 ,105 ,138] or with lead users and researchers or clinicians in separate groups [84 ,99 ,108 ,139].

A third distinctive feature was that Phase I (Study I) aimed not only to ask the participants about their needs but also about their ideas for features. A possible criticism levelled at this is that it might be difficult for lead users to know what they want or need if they do not know what they can get. This was also the case for some of the participants in our study. However, we did not ask them about concrete features but rather for their ideas on support for physical activity, which may have facilitated the discussion.

Our assumption was that the involvement of participants with different perspectives in collaborative workshops would lead to a more usable, appealing and effective service. The merging of participants' different perspectives would lead to further refinement and clarification of features. Furthermore, it might also reduce the communication errors between the system developer and other participants [140], since any ambiguities concerning needs and suggestions for features could be clarified directly. This way of co-designing puts great demands on the participants' ability to find solutions, negotiate, come to agreement and reach necessary decisions, as was demonstrated in Study II. There might also be a risk that not all perspectives were voiced. The power relationships that existed might have influenced participants' suggestions and ideas. The researchers might be seen as being in a position of power because of the knowledge base they possessed, which could cause the other participants to feel repressed [134]. However, we did not experience any such problems. On the contrary, the researchers were too silent and had to be told to speak up. The reasons for this may have been that the researchers were afraid of being too dominant and that they respected the lead users' perspective.

An alternative approach that might have reduced some of the risks described above would have been to include the Idea generation phase as part of the workshop series. The lead users and the other experts could have been separated into two groups during the first and maybe second workshop. Thereafter the participants could have shared their ideas and perspectives. This would have shortened the co-design process significantly. It might also have reduced the concern about power and the risk of not all voices being heard. However, this would have led to less lead user involvement. The comprehensive result from Study I was and will be important in the future development of tRAppen.

### 9.3 UNDERSTANDING CO-DESIGN FROM A THEORETICAL PERSPECTIVE

According to Arnstein's ladder of participation, the co-design process in the present project may be interpreted as Partnership, the 6th rung of participation [117], which indicates that the lead users were involved in the decision making. In Munford's model the corresponding type would be Consensus, the highest level of lead user involvement [118].

The classification of action research by Hart and Bond [111 ,114] provides a more detailed description of the role and involvement of the lead users. According to their classification, the present project fulfils criteria for different types of action research i.e. "Experimental", "Organizational", "Professionalizing" and "Empowering".

The present project could be classified as Experimental action research, since the researchers were the ones who initiated the project. They acknowledged the need for an mHealth self-management service to support physical activity in RA. The project was also time limited and task focused. The aim of the project was overall predetermined, which is a criterion for Organizational action research. But the aim was not specified in terms of what kind of service and what features to include, which is a criterion for the Empowering type. The problem, i.e. maintenance of physical activity in people with RA, was/is of interest not only to the lead users, Empowering action research, but also to health care providers, Organizational action research. Finally, maintenance of physical activity in RA was explored during the process to improve our knowledge and understanding of this phenomenon, which is a criterion for Empowering action research.

The examples above describe the complexity of action research and the difficulty to classify a project into one single type. The lead users in the present project had different roles and were involved in different ways during the different phases of the co-design process. In all, the present project might be interpreted as Empowering since the overall aim was to empower people with RA to take an active part in their own health and wellbeing by providing them with a self-management service for physical activity maintenance.

### 9.4 RESEARCH METHODOLOGICAL CONSIDERATIONS

In participatory action research the boundaries between researchers and participants are vague. Participatory action research implies research *with*, and not *on* or *for*, the participants in a collaborative work process [111 ,114]. In the present project two of the participants in the workshops were part of the project group. Additionally, one of the participating researchers was one of the main investigators throughout the project. The project group fed back their reflections to the participants at the beginning of each workshop, which was the starting point for the discussions. Hence, the researchers influenced the process and the data collected. This is one characteristic of participatory action research. It is not objective and controlled, but rather subjective and influenced by the researchers' interpretations [112].

To ensure trustworthiness we used different methods [141 ,142]. Methods and researcher triangulation was used to ensure credibility. Researchers with different skills and expertise were involved to complement and provide divergent perspectives on the analysis, which

reduced the risk for biased and idiosyncratic analysis. Member checking was also used; by showing the participants the programmed prototypes they had the opportunity to confirm, reject or clarify what had been discussed and agreed on the previous workshop. The video recordings provided authentic data on the workshops and enabled review of the data several times. Even if these different methods were used to improve credibility and dependability, there is still a risk that the researchers have missed some important aspects.

To enhance the reader's evaluation of the results the studies comprised thorough descriptions of the settings, participants' characteristics (except for Study II), and the procedure for data collection and analysis [141 ,143]. All four studies provided tables to describe the link between codes, categories/themes. Citations and video excerpts provided the reader with authentic data. The descriptions enable the reader to assess the transferability of the results to similar settings and groups.

The results may be transferred to similar co-design processes and populations. The description of the co-design process may serve as a model for co-design of mHealth services where lead users and other experts collaborate. However, this project reports from one co-design process only. Further research is needed that describes similar processes. Most of the participants with RA were well-educated, had had the disease for more than 6 years, and had a median age of around 55 years. In Phase III (Study IV) the participants also had high functional capability, worked and most had been physically active before disease onset. The result might therefor reflect this subgroup of RA. The result might also be transferred to similar sub populations but with other chronic conditions, for instance other rheumatic diseases. In the next step of the development process inclusion of younger and less well-educated participants should be considered, since this group might be part of the target users of tRAppen.

## **9.5 POTENTIAL FOR PHYSICAL ACTIVITY SUPPORT AND FUTURE IMPROVEMENTS**

tRAppen offers a service based on evidence of physical activity in RA, behavior learning theories, and lead users' ideas and preferences. tRAppen can be used in everyday life and provides the opportunity for active involvement in one's own health and wellbeing.

The first evaluation of tRAppen was promising and indicated that it has the potential to support maintenance of physical activity in certain subgroups of RA. However, we cannot truly evaluate the outcome until tRAppen has been implemented in a wider population and when its effects on physical activity and health have been studied [119]. The new era of mHealth has been suggested as improving health outcomes since it can provide anyone who has a mobile phone with health care expertise and knowledge [144]. Further, eHealth offers a good possibility for supporting people to self-manage autonomously in everyday life [144]. To achieve sustainable growth of eHealth and mHealth services, collaborative strategies are vital for developing services that meet different lead users' needs and preferences [145].

The evaluation of the first test version of tRAppen highlighted some issues important to consider in the future development:



In the population of RA, where physical and mental health status varies a lot, the possibility of individualizing the service accordingly is important. Previous research has reported similar results in people with obstructive pulmonary disease [146]. In addition, it has been suggested that individualized services responsive to change in physical activity level will improve ease of use, engagement and viability of the service [147].

The self-regulation features of tRAppen already provide such opportunities through personal goal setting, activity planning and feedback on goal achievement. This urges the user to reflect on what is realistic and possible to achieve depending on their physical and mental health status. It has been suggested that features for goal setting should be simplified to make these features more accessible to a broader population [146]. The highest rated mHealth services have also been demonstrated as including easy input of information [148]. However, the solution might not only be to simplify these features. Another approach is to develop features for goal setting and activity planning that is feasible and appealing for the users. This individualization is an important part of successful self-regulation [53 ,66].

Another concern discussed by the participants in the present project was whether mHealth self-management can replace face-to-face meetings and contact with health care. The fear of losing face-to-face meetings in favor of online meetings was obvious. This is in line with previous research that reported that people with cancer wished to use the eHealth service in adjunction to traditional health care [79]. Access to a health care provider might also improve the effectiveness of the service [137]. tRAppen might be used as a complement to traditional health care and serve as a link between health care and public wellness centers. If additional coaching and contact with health care is needed, it should be further explored. Further, it should be explored whether the coaching should be delivered face-to-face or by other means for best effect. Nevertheless, tRAppen offers the opportunity for people who are ready and capable of self-managing to receive support from peers, which will make health care recourses available for those who really need face-to-face meetings.

## 9.6 CONCLUSIONS

- The co-design of the physical activity self-management service “tRAppen” was feasible and successful. The use of IT and mobile phones, active lead user involvement, and principles of experience based co-design in the development of health care services might be valuable since the first test version of tRAppen was produced and was perceived to have the potential to support a physically active lifestyle in people with RA.
- Co-design in collaborative workshops, including lead users, researchers, clinician and system developer, was an extensive decision-making process which placed high demands on the participants’ ability to find solutions, negotiate, come to agreement and reach final decisions.
- The co-design process resulted in the first mHealth self-management service for maintenance of physical activity developed *with* not only *for* people with RA. It is

based on evidence of physical activity in RA and behavior learning theories. Further, it includes established self-regulation techniques, peer group support and recommendations for physical activity in RA.

- Areas for improvement of relevance for tRAppen version 1.0 are to further individualize the service to support physical activity during periods with both good and bad health.

## **9.7 THE FUTURE OF TRAPPEN AND FURTHER RESEARCH**

mHealth services such as tRAppen have the potential to empower people by supporting a person's autonomy and the ability to take responsibility for their own health. This is important for physical activity behavior maintenance. Further, mHealth services have a wide reach and can be used in people's everyday life. In the future, tRAppen could quite easily be modified to suit people with other chronic conditions. Hence, it could be used by a broad population and hopefully contribute to improved health for many people.

- Further studies should be performed with the lead users to improve the feasibility of tRAppen. How the features for goals and plans should be designed and how the peer support groups should be composed are some areas that deserve to be studied.
- Studies that describe the participants' experiences of co-design would be valuable, in order to improve our understanding of the process.
- The present project does not provide any evidence for the effect of tRAppen on physical activity maintenance. A randomized register controlled trial should be performed within the Swedish Rheumatology quality register.
- Future studies should also identify which features are most effective in maintaining physical activity in the population of RA and identify for whom tRAppen is best suited.
- Studies that provide comprehensive descriptions of co-design processes and reviews that report on different methods and time for involvement of lead users and other experts in the development of eHealth services are scarce and would be useful for others in the planning and performance of co-design.

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